

# EU-Atlas

## Dementia & Migration

Estimated number, care situation, and policies regarding people with a migration background with dementia in the EU, EFTA, and UK.



funded by



**Robert Bosch  
Stiftung**





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We would like to thank every expert who participated in the interviews for their valuable contribution to our work.

## Authors

Dear readers,

thank you for your interest in the topic of dementia and migration! You are about to read the result of an intensive work effort lasting 2 ½ years, which have been quite an exciting journey for all of us involved. In 2018 we, a small team of researchers from Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), site Rostock/Greifswald, were chosen by the Robert Bosch Stiftung to undertake this important project. In April 2019, our team was officially set up and started working in close cooperation with the Institute for Community medicine on this interesting and under-researched topic. Looking back, we would say we started our work with basic knowledge about dementia and migration, but with curiosity, a thirst for accumulating knowledge, enthusiasm, and the wish to shine a light on a topic that does not get the attention it deserves and needs. Throughout these 2 ½ years, we were sometimes overwhelmed about the complexity of the topic, the heterogeneity of views and learned to know what a unique and multi-faceted phenomenon we were describing.

Fairly quick we developed a plan and already in October 2019, we were able to conduct a workshop to present and discuss our project, procedures, and first preliminary results to experts in the topic of dementia and migration at the 29th Alzheimer Europe Conference in The Hague. The excellent feedback was used to adjust our work and strategy to make it more appropriate for this research field. We were anticipating to dive into more detail in all countries by researching literature, calculating statistics, but also visiting and interviewing experts throughout Europe in 2020. However, the COVID19 pandemic emerged and put an end to the personal encounters planned. We had to adjust and changed to conducting more and more videoconferences. These interviews gave us the opportunity to have fascinating talks with knowledgeable people, who were all immensely helpful and gave us intriguing insights in the care situations of different European countries!

Gathering all the data and information however was just one milestone and for us as researchers the dissemination of this work introduced us to an exciting topic: designing the layout of this atlas, creating a website, and planning events to make the atlas publicly known to stakeholders, politicians, service providers, and people affected. During this time, we collaborated with various dedicated and competent professionals in the fields of science communication, webdesign and programming, layout and graphic creation, as well as printing, which has been a lot of fun and resulted in a high learning effect.

In the end, we created something we are proud of and we cherished the opportunity to expend our knowledge on a topic as compelling as this. We would like to thank the Robert Bosch Stiftung for funding this special project, all the experts who supported our work by giving us advice and/or participating in the interviews and the professionals who helped in creating this atlas! And last but not least, we hope that our work is beneficial to all people affected by dementia and migration in a personal and/or professional way!



Jessica Monsees, Tim Schmachtenberg and Dr. Jochen René Thyrian  
On behalf of all authors

### Robert Bosch Stiftung

In our demographically changing societies, dementia poses particular challenges due to the large number of people affected, the loss of memory as a key feature of the disease, and the lack of cure options to date.

According to estimates, the number of people with dementia in Europe will increase significantly in the coming years: While in 2010 almost 10 million people were living with dementia in European countries, an increase of about 40 percent to approximately 14 million is expected for 2030. Due to internal mobility in Europe and immigration from outside the Union, the issue of dementia is also becoming increasingly important for older people with a migration background and their families. Particularly because there are additional challenges for these people. For example, in the course of the disease, the language learned in the country of destination might be forgotten. Or biographical work, which is successful in the case of dementia, is made more difficult because characteristics and customs from the country of origin are not known. Finally, access to medical information and the fit between medical and nursing care may not be completely satisfactory due to language barriers and cultural differences.

Effective remedies begin with better knowledge of the situation. However, the database on the prevalence and the health and care situation of people with a migration background and dementia in Europe is difficult to access. Analysis-related evaluations of individual European countries are only rudimentary and do not allow reliable statements on the care situation of those affected.

The present EU-Atlas of Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), site Rostock/Greifswald closes important knowledge gaps. With the funding of the 'EU Atlas: Dementia & Migration', we hope to support transnational exchange, networking, and cooperation between stakeholders from politics, science, practice, and professional areas for the benefit of those affected and their families.



Professor Dr. Joachim Rogall  
President and CEO  
Board of Management  
Robert Bosch Stiftung GmbH

### Alzheimer Europe

As our societies are ageing, the number of people with dementia is increasing. Many people who migrated to Europe in the 1960s are now reaching an age at which their likelihood of developing dementia and needing care is significantly higher. As a result, the number of people with dementia from minority ethnic groups in Europe is similarly predicted to rise in the coming decades.

Despite this, a recent Alzheimer Europe report found that there was a general lack of appropriate intercultural care and support for both people with dementia and their informal carers from minority ethnic groups. In this report, we made a number of recommendations on how to improve the awareness and understanding of dementia, encourage help seeking for people affected, develop culturally sensitive diagnosis and assessment methods and promote culturally appropriate care and support.

This European Atlas on Dementia and Migration provides much needed additional information on the numbers of people with dementia and carers with a migration background or from minority ethnic groups. All European countries will be confronted with growing numbers and healthcare systems should identify ways to support better and culturally appropriate diagnosis, care and treatment.

Despite these population trends, this excellent publication highlights that few dementia strategies and few diagnostic and treatment guidelines take into account their specific needs and experiences. By carrying out an in-depth literature review and an analysis of national dementia strategies and care and treatment guidelines, the authors identify shortcomings as well as good practices which will hopefully provide guidance and advice for countries interested in further developing intercultural care and support.

I wanted to congratulate the authors on their thorough analysis, the instructive country profiles of 32 European countries and the important conclusions and recommendations they make. I hope that this report is widely read by policy makers, healthcare providers and national Alzheimer's associations and be seen as a call to action to better take into account the needs of the growing numbers of people with dementia from minority ethnic groups.



Jean Georges  
Executive Director of Alzheimer Europe

### Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE)

Globalization as result of economic pressure and migrations forced by underdevelopment, war and famines have been reshaping our societies over the past decades. Migrations are not a new phenomenon in Europe and blending different ethnicities has created challenges. Different cultures, life styles, nutrition and hygienic habits have resulted in new complex interactions between genetic backgrounds and acquired environmental influences. In modern societies this is exemplified by acquisition by migrant populations of typical patterns of disease risk factors common in our societies.

The challenge posed by the diversity of genetic and epigenetic factors in autochthone and migrant populations is complex. It goes from the understanding of genetic diversity to measures aimed to improve selective healthcare protocols.

Nutrition and lifestyle do play important roles. However, good healthcare and disease prevention, while increasing longevity in migrant populations have also increased their risk for age-related chronic diseases such as diabetes, cardiovascular disease, some forms of cancer and neurodegenerative diseases, including dementia.

The Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE) is a national research organization founded by the Federal and State Governments in Germany with the mission to understand, prevent and cure neurodegenerative diseases. Since its inception in 2009, the DZNE has aimed to carry out high-quality research on dementia, including research to foster better healthcare. Under the leadership of Prof. Rene Thyrian, and his colleagues, DZNE uses quantitative methods to estimate the dementia prevalence in people with migration background, qualitative discourse analyses of dementia plans and care guidelines as well as qualitative (guideline-based) interviews with country-specific experts to obtain information on the available care services for people with a migration background with dementia. People with a migration background who develop dementia are a particularly vulnerable group and require special care. The goal is to suggest first measures to meet the dementia-related needs of migrant individuals and their families and carers.

The EU-Atlas on Dementia and Migration funded by the Robert Bosch Stiftung aims to consolidate and analyse information of migration in Europe and the resulting implications for our healthcare systems. It estimates the number of people with a migration background who might have dementia and takes into consideration whether or not national dementia plans as well as national dementia care and treatment guidelines of European countries pay sufficient attention to migration background. It examines the care situation of people with a migration background and dementia and available healthcare services for this group in Europe and focus on possible recommendations for a culturally sensitive care.

DZNE welcomes the initiative of the Robert Bosch Stiftung to support this work and looks forward to contribute to the publication of the EU-Atlas on Dementia and Migration.

Kind regards,



Prof. Pierluigi Nicotera, MD PhD  
Scientific Director and Chairman of  
the Executive Board

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## 1. Introduction

Migration on a global scale occurred as early as in the 15th century, when Europe's cultural, economic, and political-territorial expansion started. At first, Europeans would mostly migrate within Europe, but from the early 19th to the early 20th century this changed and Europeans have been migrating to other parts of the world ever since [1]. Emigration and immigration in Europe from the 19th century onwards can be divided into different waves, with Europe initially being a continent of emigration and gradually turning into an immigration destination. These waves are characterised by wars, labour migration, collapsing systems, and economic crises. By mid-2020, the total number of international migrants amounted to 280.6 million globally according to the Migration Data Portal. This data portal provides statistics and information about global migration data and is part of the International Organization for Migration (IOM). Of the 280.6 million migrants, 86.7 million live in Europe, out of which 16.2% are 65 years or older (approx. 14 million) [2]. This group is at risk for the development of age-associated diseases, an important disease being dementia. There is an increased risk of developing this disease with growing age, for example, the dementia prevalence in Europe is estimated to be 1.5 for the age range 65 – 69 and 24.9 for the age range 85 – 89. There is an increased risk of developing this disease with growing age, for example, the dementia prevalence in Europe is estimated to be 1.5 for the age range 65 – 69 and 24.9 for the age range 85 – 89 [3]. Dementia affects cognitive functioning and is often associated with problems in motivation, emotional control, or social behaviour. Memory, language, orientation, learning capacity, or thinking are only a few functions that worsen over the course of this chronic, progressive syndrome. The impact is not limited to the person affected since dementia has ramifications

for the families and the caregivers as well. In addition to persons living with dementia and their families, dementia has a considerable social and economic impact [4].

According to Barbarino et al. (2020), over 50 million people were affected by dementia worldwide in 2020. This number is expected to increase to 152 million by 2050 [5]. According to 'Dementia in Europe Yearbook 2019' by Alzheimer Europe, the number of people with dementia in Europe was 9.78 million in 2018 and is expected to be 18.85 million in 2050 [3]. Research has highlighted that people with a migration background (PwM) often have a higher risk of dementia than the population without a migration background. For example, black people from the Caribbean in the United Kingdom (UK) display higher prevalence of dementia than white UKborn people [6] and in the Netherlands, dementia and mild cognitive impairment have been shown to be more prevalent in non-western immigrants than in the autochthonous population [7]. An analysis from 2019 estimates the number of PwM with dementia in the European Union (EU) and European Free Trade Association (EFTA) member states to be about 475,000 [8].

It is not just that PwM are at higher risk for dementia, but the health outcomes are worse. For example: the Alzheimer Europe Report 'The Development of Intercultural Care and Support for People With Dementia from Minority Ethnic Groups' from 2018 points out in great detail the various problems PwM face when trying to get help for dementia from healthcare systems. It further highlights that action can be taken to tailor services and information to the needs of this population and to educate people working in healthcare about PwM with dementia. On the PwM's side, there is often a lack of knowledge about dementia, the healthcare system and its services, and how to obtain support. Additionally, the health-

# 1. Introduction

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care system is often not equipped to take care of this population and does not have services appropriate for their needs. Furthermore, healthcare professionals and service providers may have misconceptions about PwM, for example, they may think that certain PwM groups with familism-based cultures prefer to take care of sick family members at home and therefore do not require specialised support from the state. These are only just a few existing challenges and problems that this report highlights. A more detailed and recent overview of this topic is provided by Alzheimer Europe (2018) [9].

The challenges mentioned above and the expected increase in the number of PwM with dementia in the coming years pose a challenge of an unknown magnitude for healthcare systems in Europe and the world. To face this challenge and to provide the people affected with the best support and information possible, healthcare systems, healthcare professionals, politicians, and stakeholders need more information on this vulnerable population and its situation. Evidence is needed on the number of PwM with dementia, how they are included in the healthcare systems at the moment, and where room for improvement exists. Such insights can not only guide people and organisations working with people on a daily basis, but also and equally important can be of significance in strategically developing healthcare systems and its services on a political level in laws, policies, strategies, and action plans. This atlas is especially intended to be used for the latter.

Data on the number of PwM with dementia in Europe exist, however they are scarce, and data for all EU and EFTA countries and the UK broken down by individual countries of birth are missing. Within different countries, there are more and more strategies, plans, and guidelines raising awareness on dementia and discussing improvement of treatment

and care for people with dementia and their families. However, to the best of the author's knowledge no data has been produced that gives an overview of the prevalence of dementia and national documents on dementia across Europe with a focus on PwM.

Having identified this gap of information, the aim was to create an atlas that provides: (1) prevalence data and graphical presentation for the 27 EU and 4 EFTA member states as well as the UK; (2) analyses of national dementia plans (NDPs) and guidelines on diagnosis, treatment, and care; and, (3) analyses of healthcare systems in terms of the services and support they provide for the people affected. This atlas focuses on dementia in PwM. It is a supplement to the vast literature and knowledge about dementia, and a valuable resource due to its sharp focus on the care situation of PwM with dementia.

Since 'migration' is a widely used term with many facets and implications, labelling a group of people with having a migration background creates definitional problems on many levels [9]. Migration background is associated, for example, with ethnicity, culture, socialisation, and certain stereotypes. Referring to PwM as one group might disregard the heterogeneity of this group and one has to be very cautious when drawing conclusions. The group is heterogeneous and while looking at it from a national or even a European perspective the challenge is to define who talked about, whose situation is described and what conclusions can be drawn. This goes hand in hand with limitations in comparability and perhaps oversimplification of the situation. The authors are aware of this challenge, but to make analyses possible a definition is needed and limitations have to be taken into account. The primary focus of the atlas is on measures to improve the care situation of people who have immigrated to the European country they currently live in. To illustrate some fields of discussion: in this

atlas the authors do not refer specifically to 'minority ethnic groups' as it is used in many international studies and reports. The specific challenges of PwM discussed in this atlas differ from the challenges faced by people from minority ethnic groups who might already be living in the respective country for generations. While there are many similarities and intersections between these groups, not every member of a minority ethnic group is a migrant [9]. In some European countries, certain minority

ethnic groups have specific rights (for example, concerning linguistic and culturally sensitive information) that PwM currently do not have in most countries [10]. Along these lines the authors also do not refer to groups with certain cultural background, shared ethnicity, and the like in the analyses. This is acknowledged in the limitations sections and the authors believe that there is a clear benefit of the analyses to advance the field and healthcare for this vulnerable group.

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## 2. Method

To fulfil the aim of this project the work was divided in different work packages. The migration history was illustrated, the number of PwM with assumed dementia was estimated, the NDPs and guidelines on treatment, care, and diagnosis were analysed as well as interviews with experts on the actual state of healthcare were conducted for the EU and EFTA member states and the UK.

### 2.1 Definitions

#### 2.1.1 People with a migration background

A central challenge for comparative studies is the fact that there is no common definition of PwM at the European level currently. The individual EU, EFTA, and UK countries use different terms in official national documents for this population. For example, these are the terms they used in national dementia care guidelines: immigrant, people with minority backgrounds (Norway); people from minority ethnic groups (UK); people from different cultural or religious groups (Spain); and people with different cultural or linguistic backgrounds, people born abroad (Sweden). Furthermore, the definition of the frequently used term 'migrant' also varies [1]. For instance, in the UK a migrant can be a person whose country of birth is different from the country of residence, whose nationality is different from the country of residence, or who changes the country of usual residence for a period of at least a year [2]. In Germany, the concept of migration background is based on an individual's own and parents' citizenship; that is, those who are not born with German citizenship or have at least one parent who was not born with German citizenship are considered PwM. [3].

To be able to compare data (number of PwM with dementia, results of expert interviews) at the European level, uniform use of terms and a clear definition of the term used was needed.

In this study, the United Nations definition is used as it is the basis for most international migration-specific databases and data sets (for example, the Migration Data Portal of the IOM) and is also used by most national statistical offices of the EU, EFTA, and UK countries. Therefore, in the authors' view, it is the most suitable definition for comparing data on dementia and migration at the European level. Besides, the definition is also clear and has a well-defined inclusion and exclusion criterion. The United Nations defines PwM as people who are residing in a country other than that in which they were born [4]. Consequently, in this study, all people who are residing in the country in which they were born, including the offspring of foreign-born immigrants, are excluded.

This study includes all older people (65 years or older) who reside in an EU, EFTA, or UK country and were born abroad.

#### 2.1.2 Individual/local/regional/national level

*Individual level:* Represents individuals such as one or several caregivers or doctors. It is in contrast to the organisational level, which includes one or several organisations such as nursing homes, nursing services or hospitals, and the systemic level, which includes, for example, the healthcare system with all organisations, professionals, and care planners.

*Local level:* Level of individual cities, municipalities, or communities.

*Regional level:* Includes several cities, municipalities, or communities located in a certain geographically contiguous territory.

*National level:* Level of the nation-states. When referring to measures at the national level, this includes measures taken by the respective national government and its representatives, ministries or institutions, or by other national organisations that have a nationwide relevance or whose functions concern the whole country.

*Healthcare services at the national level:* Defined as all services involving healthcare, such as information, support, advice, diagnosis, or treatment plans, which are not limited to specific regions, companies, or institutions and are referred to in official national documents by country representatives (e.g., representatives of health ministries, other members of government, or representatives of national professional societies).

### 2.1.3 Policies, guidelines, recommendations

*Policies:* Instructions for action published by legally legitimate institutions that must be followed in a binding manner and that reflect the state of knowledge of medical science at a certain point in time [5-7].

*Guidelines:* Systematically developed and scientifically based, legally non-binding decision-making assistance on the appropriate procedures for specific health problems [8, 9].

*Recommendations:* Suggestions, advice, hints, or consensual solution strategies for selected questions. They are based on relatively weaker scientific evidence and have a lower normative character than guidelines [5, 7].

### 2.1.4 Inpatient and outpatient care

The authors understand inpatient care as the permanent accommodation, care, and treatment of a person in need of care in a nursing facility. Examples include nursing homes, hospices, and rehabilitation facilities [10].

Outpatient care comprises support for persons in need of care and their relatives through the provision of medical or non-medical care in their residence. A home care provider offers day-to-day support to the patient and the family, which enables family caregivers to better organize care, and other obligations, such as work or childcare, and to provide the highest possible level of care to the individual living

with the disease [11].

### 2.1.5 Healthcare and healthcare services

#### ***Integrative, segregative, and hybrid care model***

The authors have defined the integrative care model as a model where PwM are provided with mainstream services together with non-migrants (people without a migration background).

In a segregative care model, PwM or individual migrant groups are offered specialised services that are tailored for them (based on Kaiser 2009 [12]).

A hybrid care model comprises both integrative and segregative elements. This model exists, for example, when the healthcare system has areas where PwM with dementia are offered the same services as the autochthonous population, as well as areas where specialised care services are provided for this population or certain groups from this population.

#### ***Inclusion of people with a migration background with dementia in healthcare***

Generally, inclusion is defined as the social involvement of people or their participation in the life of society [13]. With regard to the social subsystem of healthcare and the population in focus in this study, inclusion is the involvement of PwM with dementia in the healthcare system.

Concretely, the inclusion of PwM with dementia in the healthcare system means that: 1. Providers of healthcare services (e.g. general practitioners, specialists, nursing homes, and home care providers) are sensitised to the unique (e.g. cultural or linguistic) needs that PwM or people from certain migrant groups with dementia may have. 2. Service providers offer PwM care, treatment, and support services adapted not only to the cultural and linguistic, but also their individual needs. 3. PwM with dementia receive these services. 4. PwM are aware that the services are tailored to their needs.

## 2. Method

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To include PwM with dementia, the services offered to this group must be validated and evaluated by them. Only if PwM with dementia have a sense of participation in the healthcare system and its services, and feel that the professionals working in the system are responsive to their individual needs, inclusion could be considered successful.

### ***Participation in the development of healthcare services***

One key element of inclusion is the participation of PwM with dementia as well as their family members, especially the family caregivers, in the development and implementation of specialised PwM-oriented care structures and services. The participatory approach means that PwM-specific care services would not only be developed for, but also *by* or at least *with* the PwM. Full participation means that their views are taken into account throughout the development process. One way of implementing such an approach is integrating them into the respective project teams. Another possibility is to systematically ask them before the beginning of the development phase about their core needs and what kind of care services would they find helpful. Moreover, they should have the opportunity to assess the implementation of the specialised services in the development as well as post-finalisation stages. In both cases, the designed care services must be systematically validated in the care practice by PwM with dementia and/or their family caregivers.

### ***Culturally sensitive care***

Culturally sensitive care is the orientation of care practices and treatments to the specific culture the person in need of care belongs to [14]. Such care is characterised by an intercultural orientation (an attitude that is in harmony with the cultural, ideological, and religious identity [15] of the individual professional car-

egivers), an intercultural opening (a strategy that lays emphasis on equality of access to and quality of services for people with different cultural backgrounds) of care facilities, and intercultural competence (ability to derive concrete forms of action and interaction from these positions [16]) of the professional caregivers and facilities [14]. For nursing staff, culturally sensitive care means consciously, consistently, and continuously considering cultural and migration-related dimensions in the care relationship. In other words, they would be expected to accept and respect the lifestyles, traditions, values, and beliefs of the people in need of care [17].

The central goal of culturally sensitive care is to recognise and fulfil the specific needs of PwM and enable equal access to care. Through knowledge and appreciation of cultural differences both on the part of nursing staff and on the part of the persons in need of care, the care relationship should be improved and the intercultural competence of the respective care facility should be further developed [18].

To be able to provide culturally sensitive care, healthcare staff must perform their duties, such as detailed documentation of life history and anamnesis, in a way that takes into account the cultural background of patients and how it may affect their healthcare needs. In addition, care standards and, particularly, a standardised procedure for informing nursing staff must be defined [18].

### ***Intercultural care***

By intercultural care, it is meant that a professional caregiver looks after a person in need of care who has a different cultural background and the care practice is based on the mutual understanding of the respective cultures (based on Yakar und Alpar 2018 [19]).



### ***Vulnerability of people with a migration background with dementia***

In the context of PwM with dementia, a group is described as vulnerable in this study if their members either have a higher risk of developing dementia, the disease occurs on average earlier in their lives, the course of the disease is worse (e.g. faster degeneration of cognitive abilities, poorer health outcomes), the negative effects of the disease are greater (e.g. loss of knowledge of the language of the host country, loss of employment, previous need of care), the care situation is worse, or they are affected by inequalities such as underdiagnosis or underprovision.

## **2.2 Expert workshop at the 29th Alzheimer Europe Conference**

An essential step in this project was the recruitment of experts. The experts were recruited by an official call via European Foundations' Initiative on Dementia (EFID), Alzheimer Europe, The network on 'Early detection and timely INTERvention in DEMentia' (INTERDEM), the European Network of Intercultural Elderly Care (ENIEC), and the Alzheimer Societies of the EU and EFTA countries and the UK. In this call, a brief project description was given along with an invitation to support this project, attend an expert workshop at the 29th Alzheimer Europe Conference in The Hague in October 2019, and take part in an interview. The organisations were sent the call, which they then forwarded to their partners in their mailing lists. Interested potential experts contacted the project team and were invited to participate in the expert workshop. At this workshop, the project was presented along with the interview guide to get feedback, discuss the planned approach with the experts, and adjust the work packages.

## **2.3 Migration history**

A literature analysis was conducted to determine the history of migration. For this purpose, the search engines Google and Google Scholar were searched for scientific literature (including documents by historians, political scientists, and other migration experts). In addition, political documents, European and national migration reports, data from national statistical offices, and international databases such as the Migration Data Portal as well as articles from migration-specific websites such as those of the Migration Policy Institute or the IOM were studied. The search was limited to documents published in English and German. The date of screening of the search engines and websites was 1 July 2019. For each country and for the history of migration on a European level, different documents, reports, and data were evaluated and a consensus was formed from the results of this evaluation. For the analysis of the history of migration at the European level, the period from the beginning of the 19th century to the present was taken into account. This period was chosen as it provides a useful background to present-day migration, historically established and currently relevant migration flows, the composition of the European migrant population, and the historical and current significance of migration in Europe. The selection of this period, and especially the inclusion of the 19th century, allows, inter alia, to illustrate the changes in Europe in terms of the direction of migration. In presenting the migration history of the individual countries, no uniform period was chosen, as the developments in the individual countries vary considerably. There are countries with a long migration history where developments or occurrences from past centuries have a major influence on current migration patterns or at least contribute to the understanding of recent developments, and there are countries where the topic of migration has only played

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a relevant role for a few decades. In addition, the terms used to describe the respective population (e.g. migrant, immigrant, emigrant, refugee, guest worker) were taken from the original documents when describing the migration history of the individual countries.

### 2.4 Number of people with a migration background with dementia

#### 2.4.1 NUTS level

The system 'Nomenclature des Unités territoriales statistiques' (NUTS) is a geographical classification system that subdivides EU and UK countries in hierarchical levels: NUTS0, NUTS1, NUTS2, and NUTS3. There is also a NUTS coding system for countries outside of the EU. These are the EFTA countries, countries joining the EU, and potential EU countries. NUTS0 corresponds to the member state. The NUTS1 regions (large regions) house 3 to 7 million people. NUTS2 regions (medium-sized regions) are inhabited by approx. 800,000 to 3 million people while the NUTS3 regions (small regions) have 150,000 to 800,000 residents. The intention of this subdividing is '...the collection, development and harmonisation of EU regional statistics; socioeconomic analyses of the regions; (...); framing EU regional policies;...' [20, 21].

For the following sections, the intended procedures will be explained first. Since these were not applicable for every country, the section 'Exceptions' will describe the changed approaches that were done for these cases.

#### 2.4.2 Data and dementia prevalence rates

To determine the number of PwM with dementia, the statistical offices of the EU and EFTA countries and the UK were contacted to obtain data divided by different ethnicities on PwM who are 65 years and older living in the respective countries. These data were sought for the

NUTS3 regions. The statistical offices either provided data or a link to a statistical data portal where data could be obtained. Due to data protection reasons only a few countries—Finland, Greece, Hungary, Ireland, Romania, Slovenia, and the UK—could hand out the required data on NUTS3 regions. Because only a few countries could provide NUTS3 data, it was then decided to display NUTS2 data instead of NUTS3. Some countries, such as Bulgaria or Romania, do not show data below a certain value out of data protection reasons. The data will be presented as absolute numbers of PwM with dementia aged 65 or older for the whole country (NUTS1 or NUTS0) and NUTS2. Data will also be showcased as PwM with dementia aged 65 or older in relation to the whole population aged 65 or older of the respective country (per 100,000) and in relation to the population aged 65 or older with a migration background (per 10,000). These two will be shown for the whole country and the NUTS2 level, if available. Values below 5 will not be shown because of confidentiality reasons. Absolute numbers below five will not be displayed due to data protection reasons.

The prevalence rates for dementia used for the calculations were taken from the 'World Alzheimer Report 2015' by Alzheimer's Disease International (ADI). In this report, ADI depicts the prevalence rates of dementia for different parts of the world (e.g. North Africa, Central Europe, the Caribbean, South Asia, and Oceania) as well as for the world as a whole. These prevalence rates refer to people aged 60 or older [22]. It was decided to use the dementia prevalence rate of the country the people are living in. The data in this atlas refer mostly to people at the age of 65 or older—except for Bulgaria, Lithuania, Malta, and Poland whose data refer to people aged 60 or older—which points to the risk that the numbers of PwM with dementia are underestimated.

### 2.4.3 Calculations

To determine the absolute number of PwM with dementia aged 65 or older the dementia prevalence rate of a country was applied to every ethnic group living in that country and the single NUTS2 regions. These absolute numbers were taken and put into relation to:

a) the whole population aged 65 or older of that country or the NUTS2 regions (per 100,000 inhabitants aged 65+) with the formula

$$\frac{\text{PwM with dementia} * 100,000}{\text{Population 65+}}$$

b) the population with a migration background aged 65 or older of that country or the NUTS2 region (per 10,000 inhabitants with a migration background aged 65+) with the formula

$$\frac{\text{PwM with dementia} * 10,000}{\text{Population with migration background 65+}}$$

### 2.4.4 Maps

The maps were created based on the estimated data on PwM with dementia. The program that was used is ESRI®ArcGIS® 10.7.1 Esri Inc., Redlands/California (USA). The statistical offices that provided data either refer to the NUTS-system 2016 or 2010 which were used for the creation of the maps. To depict non-European countries and waters 'World Countries' or 'World Ocean Background' by Esri were used [23, 24].

In total, there are five different maps designed to display the data. For the whole country there is one map with a bar chart displaying the absolute numbers of PwM with dementia aged 65 or older and one map with a pie chart showing the number of PwM with dementia per 100,000 people aged 65 or older in that country. These data were always shown for the population (with and without a migration background) as a whole and for the five

countries most PwM with dementia originated from. The other countries of origin were summarised in the category 'other'. Furthermore, choropleth maps were created. A choropleth map shows how many people with dementia of a particular ethnicity are living in the different NUTS2 regions of the respective country. These were prepared for the population without a migration background and the top five countries of origin. The categorisation within the choropleth maps follows the median of the autochthonous population for the population without a migration background. For the different ethnicities it is the median of all PwM from these five ethnic groups combined.

On the NUTS2 level are two maps for each country. One map shows the absolute numbers of PwM with dementia aged 65 or older in a bar chart and the other map depicts the number of PwM with dementia per 100,000 people aged 65 or older in that country in a pie chart.

Furthermore, two choropleth maps for Europe are included. One map shows the absolute number of PwM with dementia in the EU and EFTA states and the UK. The other shows the number of PwM with dementia per 100,000 inhabitants aged 65+. For these maps the categories were created using the Jenks Natural breaks algorithm. This algorithm summarizes cases with similar value into one category. That way the within difference (or variance) in the categories is small while the between differences between the categories is as large as possible [25].

In the maps as well as in the tables codes are used for the countries. The country codes can be found in the list of abbreviations (chapter 8).

### 2.4.5 Tables

To elaborate on every relevant figure depicted in the maps, tables are provided: one table for the country as a whole and one table for the NUTS2 regions. Both tables show the absolute number of PwM with dementia (Absolute num-

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bers), PwM with dementia per 10,000 PwM aged 65 or older (Prevalence/10,000 inhabitants with a migration background aged 65+) in the country or the respective NUTS2 region, and PwM with dementia per 100,000 people aged 65 or older (Prevalence/100,000 inhabitants aged 65+) in the country or the NUTS2 region. This is shown for the population (with and without a migration background) as a whole and the top five countries of origin of PwM with dementia. Remaining countries of origin are summarised in the category 'other' which is calculated by subtracting the population without migration with dementia and the PwM with dementia from the top five countries of origin from the total number of people with dementia living in the country or the NUTS2 region respectively. For the section 'Prevalence/10,000 inhabitants with a migration background aged 65+' no figures are shown for the population without a migration background. To calculate this value, only PwM were included in the computation, making the population without migration not relevant for this section.

### 2.4.6 Exceptions

#### ***Countries with only one NUTS level***

A number of countries are not differentiated by NUTS1, NUTS2, and NUTS3 regions because the allocation by NUTS region is not applied equally to all countries. Some countries are not that large and use only one NUTS-level as a whole while others are just divided into NUTS1 and NUTS3 regions. Hence, in this atlas, for some countries, only data for the whole country are shown. This pertains to Cyprus, Estonia, Iceland, Liechtenstein, Luxembourg, Latvia, Malta, and Northern Ireland.

#### ***Countries with data only for the whole country despite having NUTS2 regions***

Some countries did not have the kind of data that were needed on NUTS2 level. These

countries were Croatia, France, Italy, Lithuania, and Sweden. For Croatia and Lithuania, only NUTS1 data could be obtained, while the data for France was for people aged 55 years or older. Italy did not have country-of-origin data as they had only recorded larger regions, rather than single countries, as places of origin of PwM. Sweden only provided data for the country as a whole. In these cases, data for the entire country were used.

#### ***Countries with data on NUTS1 level instead of NUTS2 level***

For Germany and England, it was decided to present the data on NUTS1 instead of NUTS2 level because the number of NUTS2 regions was so big that it was not possible to portray all the data on the maps in a legible way.

#### ***Data obtained from Eurostat instead of the statistical offices***

For three countries, the data on PwM being 65 or older available from the statistical offices did not meet the requirements of this atlas. These countries were France, Italy, and Luxembourg. Luxembourg did not provide a huge selection of different countries of origin, while the data for France were for people aged 55 years or older. The data for Italy either referred to places of previous residence or the region of the continent a person was born in but not the individual countries. Therefore, the European Statistical System (Eurostat) was consulted to acquire the required data.

#### ***Countries with missing choropleth maps***

England and Wales only have four choropleth maps each. For England, no data are available for the population without a migration background, just a category 'UK' was used where all UK countries were summarised in. Therefore, there is no choropleth map for the autochthonous population of England. For Wales, a choropleth map for India was supposed to be

shown, but Wales does not provide data on PwM originating from India on the NUTS2 level, so this choropleth map is also missing.

### ***Changes in calculations***

For England, the 'other' category is computed by adding up PwM from all countries of origin besides the five most relevant. This was done because there are no data available for the population without a migration background.

## **2.5 National dementia plans**

The NDPs were subjected to a qualitative discourse analysis based on the model of Reiner Keller (2011). This approach adopts the open research logic of qualitative social research. The proposed methods help in structuring the analysis process but do not represent regulations for the research process. The discourse analysis focused on the analysis of natural communication processes in different contexts. In the case of this study, discursive practices in the form of national documents were used. This knowledge-sociological approach aims to identify the processes and practices of knowledge production at the level of institutional fields. This method can be used to reconstruct whether and to what extent discourses establish or organize relations between phenomena [26]. Thus, this model is a suitable approach for revealing to what extent attention is paid at the national level to the relation between dementia and migration and what knowledge is available or imparted about PwM with dementia. With this method, an overview can be given of the institutionally stabilised knowledge resources regarding the care situation of PwM with dementia.

### **2.5.1 Data sources**

The information sources for the identification of NDPs were: the online platform of Alzheimer Europe [27], the 'Dementia in Europe Year-

book 2018' [28], the ADI's overview of dementia plans from 2018 [29], and the report 'From Plan to Impact III - Maintaining Dementia as a Priority in Unprecedented Times' from 2020 [30]. The online platform of Alzheimer Europe and the search engines Google and Google Scholar served as a database for the documents. These data sources were selected because they best meet the criterion of wide public accessibility. They should serve as a central source of information on dementia for relatives of people with dementia, care providers, and policymakers. The databases were screened on two dates: 1 June 2019 and 4 January 2021. As a result of the first search on 1 June 2019, the data corpus for the analysis of the NDPs of EU, EFTA, and UK countries included 30 documents from 23 countries. In addition to 18 NDPs from 16 EU countries, 4 NDPs from 3 EFTA countries, and 6 NDPs from 4 UK countries, one more national document from England and Northern Ireland valid at the time of the search was taken into account (as the NDPs of these two countries were no longer valid in 2019). In Belgium, the dementia plan of the northern region Flanders was considered, as Belgium is a federal state, and dementia is only treated at the level of the Flemish (official language: Dutch) or French-speaking community (Wallonia, parts of Brussels) [31]. Consequently, there is no dementia plan for the whole of Belgium. The other two regions, Brussels-Capital and Wallonia, do not have a dementia plan. The data corpus was then extended to include NDPs that were found during the second search on 4 January 2021 (8 NDPs from 6 EU and 2 EFTA countries). Furthermore, 9 additional national documents on dementia from 5 EU countries and England were found in the search for NDPs, which were also screened for a migration reference and considered in the individual country profiles. The corpus for the comparative analysis of the NDPs, the findings of which are

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presented in chapter 3.3, comprises 38 documents. (30 documents from the first search and 8 from the second search). The corpus for country-specific analyses, whose results are included in chapter 3.7, comprises 47 documents. All the documents utilized in the comparative analysis and country-specific analyses were published in the period 2008-2020.

### 2.5.2 Procedures

These documents were systematically screened for their relevance to migration. The first step was to examine whether the documents included separate chapters on migration. Then, the NDPs were screened for these key terms: minorities, minority, migration, culture, ethnic, background, migrant, sensitive, cultural, diverse, diversity, and language. If the migration topic was found, a content analysis of the section in which it was located was carried out. For this purpose, the contents were paraphrased, memos and comments were added, and the text passages were coded using the strategy of open coding. The categories were derived from the contents of the documents. First, the content was roughly structured according to the categories' problem description and actions and then fine-tuned according to the categories presented in table 2 in section 3.3.1. These categories were selected because they describe the content of the sections related to migration in the best way and include the central elements of the research question. Then, the contents of the statements were reconstructed in an interpretative-analytical way. Afterward, the results were interpreted and assessed [26]. The data were first interpreted individually for each country, then short country profiles were produced, and, in the end, the findings were compared.

### 2.5.3 Language of national dementia plans

In the search for NDPs, primarily English and German terms were used. If no documents

could be found in this way, a search was conducted using terms translated into the respective national language. A total of 47 documents were examined out of which 23 were available in English and 8 were in German, the native language of the authors. These 8 documents in German were from: Austria (2), Germany (4), Liechtenstein (1), and Switzerland (1). Nine of the remaining 16 documents (from France, Italy, Luxembourg, the Netherlands (2), Poland, Portugal (2), and Spain) were translated using the translation program DeepL. The remaining 7 documents from Cyprus, The Czech Republic, Hungary, Iceland, Norway, Slovenia, and Sweden were found (on Google Search) and screened by translating the keywords into the respective national languages using Google Translate.

## 2.6 National dementia care and treatment guidelines

The national guidelines of the EU, EFTA, and UK countries for the care and treatment of dementia patients were also systematically analysed using the qualitative discourse analysis method of Keller (2011). Basically, the same analysis steps were carried out as in the study of the NDPs. The documents were obtained with the help of national non-governmental organisations (NGOs), ministries, and professional societies. The organisations were contacted (by e-mail) in the period: 2 May–11 July 2019.

### 2.6.1 Data sources

The following organisations were contacted for information about the existence of national guidelines, policies, and recommendations: national Alzheimer societies (n=28), national health or social ministries (n=32), and national professional societies for geriatrics, gerontology, or neurology (n=27) of 27 EU, 4 EFTA and 4 UK countries. The Alzheimer societies were



contacted first (on 2 and 3 May 2019), the health ministries second (on 20 and 21 May 2019), and the professional societies third (on 10 and 11 July 2019). These organisations were asked whether care or treatment guidelines for people with dementia exist at the national level and how these documents could be accessed. The response rate was just over 39% (33 of 87 organisations responded). It was particularly high in the national health or social ministries (almost 72%, i.e. 23 of 32), but significantly lower in the national Alzheimer societies (about 21%, i.e. 6 of 28), and the national professional societies for geriatrics, gerontology, or neurology (almost 15%, i.e. 4 of 27). The ministries and professional societies were identified by a Google search, while the Alzheimer Europe website served as the basis for the contact data of the Alzheimer societies [30]. To substitute for the organisations that did not respond, a Google search was carried out to find research institutions, university faculties, medical facilities, clinics, or NGOs, and a PubMed search was conducted to find researchers dealing with the topic of dementia in the individual countries, who were then written to. In two cases (Slovakia and Poland), the respective embassies in Germany and the German embassies in the respective capitals were also contacted. Finally, responses were received from 47 organisations of 35 countries and thus it was possible to create a profile for each EU, EFTA, and UK country. The list of responding organisations is attached in the appendix (table 4). To integrate documents from as many countries as possible, no definitions or restrictions were made. All documents offered by these organisations were included in this study. The organisations either sent the documents themselves or pointed to online platforms where they were accessible. Accordingly, the websites of the national Alzheimer societies, the health ministries, and various professional societies (geriatrics, neu-

rology, psychology), and associations (medical association) served as sources of data. Besides, a Google search was conducted. The corpus of documents for this analysis was 45 documents from 29 countries (36 documents from 21 EU countries, 6 documents from 4 EFTA countries, and 3 documents from 4 UK countries). In the comparative analysis of the national treatment and care guidelines (chapter 3.4.1), the two documents from Croatia and Liechtenstein, which were taken into account in the respective country profiles, were excluded, as they are not national documents (Croatia and Liechtenstein) and do not contain recommendations, guidelines, or directives on dementia care (Liechtenstein). Therefore, the corpus comprises 43 documents.

### 2.6.2 Procedures

The documents were heterogeneous and contained different document types with different definitions of policies, guidelines, and recommendations. To structure this corpus, the documents were assigned to standardised categories (for an overview and definition of these categories see the section definitions below in this chapter). Subsequently, the content of the documents was described. First, the tables of contents were examined for an existing migration chapter. Then, the continuous text was screened for the following key terms: minorities, minority, migration, culture, ethnic, background, migrant, sensitive, cultural, diverse, diversity, language, origin, non-western, characteristic, communities, religious, native, and guest. If a migration reference could be identified, the content of the respective section was subjected to detailed analysis.

The data were analysed according to the following scheme: 1. The relevant text passages were read repeatedly. 2. The contents were paraphrased. 3. The individual text passages were assigned memos and comments. 4. The text passages were coded. 5. The statement

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contents were recorded and reconstructed in an interpretative-analytical way. 6. The empirical results were interpreted and assessed. 7. The results were presented in tabular and text form. In the comments, it was noted which criteria were used to formulate the respective codes and assign them to a text passage, and in the memos, it was documented what further considerations, ideas, and hypotheses arose regarding the specific text passage. For the coding of the text passages, the strategy of open coding was used [26]. Table 3 in chapter 3.4.1 shows the categories derived from the documents that were analysed. As in the analysis of the NDPs, the data were first interpreted individually for each country, then short country profiles were produced, and finally, the findings were compared.

### 2.6.3 Language of national dementia care guidelines

During the data collection, the languages English and German were primarily used. Country-specific institutions and experts were contacted in English and the German-speaking countries (Germany, Austria, Switzerland, Liechtenstein, and Luxembourg) in German. In some (mainly Eastern European) countries, after a certain period without response, follow-up contact was made in the respective national language. For this purpose, the translation program DeepL, Google Translate, and the support of a native speaker from the environment of the authors were used. The 45 documents sent in by the institutions and experts were mostly (29) written in the respective national languages. Eight documents (1 each from England, Wales, Scotland, Ireland, Malta, Flanders, Spain, and the Netherlands) were available in English, and eight documents (3 from Switzerland; 2 from Austria; 1 each from Germany, Liechtenstein, and Luxembourg) in German. Of the 28 documents published exclusively in the respective mother

tongues, 9 (4 by France, 3 by Belgium/Flanders, 1 each by the Netherlands and Portugal) were translated with the help of DeepL. The remaining 20 documents were searched for keywords in the respective national languages with the help of Google Search, Google Translate, and a native speaker (Polish/expertise in some related Eastern European languages). The documents were translated using the Pro version of the translation service DeepL and the Google Translator. The results of the analyses of the NDPs and care guidelines as well as the further preliminary project results were discussed, with a focus on dementia and migration, with various experts from different EU, EFTA, and UK countries (Belgium/Flanders, Bulgaria, Denmark, England, the Netherlands, Norway, Portugal, and Romania) at a workshop in The Hague (the Netherlands) in 2019 and a project session during the virtual Alzheimer Europe conference 2020.

### 2.7 Expert interviews

In addition to the document analyses, it was decided to conduct interviews with experts on dementia and migration. This was done to obtain further views on this topic and receive in-depth responses on how the care situation looks like in practice. This way it was also possible to verify whether the NDPs and guidelines reflect the actual care situation of the PwM with dementia and their family members or if they are disconnected from what is happening in the healthcare landscape.

The experts who participated in the expert workshop were invited to take part in the interviews. Since experts were not found for every country in that initial recruiting process, researchers and care providers were contacted during events or presentations on the topic of dementia and migration. Furthermore, databases such as PubMed were searched for articles on dementia and migration, and the relevant authors were



contacted. Google searches for healthcare providers who focus on this topic were conducted and editors or authors of NDPs, national health ministries, professional societies, and Alzheimer societies were written to.

The first interview was done in person while the rest were conducted via the videoconference platform Zoom over the course of 12 months. Overall, 25 experts were interviewed from 17 countries: Austria, Belgium, Bulgaria, Denmark, Finland, Germany, Greece, Ireland, Italy, Liechtenstein, Luxembourg, the Netherlands, Norway, Portugal, Romania, Sweden, and England. For almost all countries oral interviews were conducted. The only exception was the expert from Sweden who provided written statements. Almost all interviews were conducted in English with the exception of Germany, Liechtenstein, and Luxembourg, which were held in German. The experts were researchers, care planners, care providers, and representatives of dementia associations or Alzheimer societies. Thus, this study includes representatives of people with dementia, but primarily representatives of the scientific and healthcare systems. The participants were not always experts in the field of dementia and migration, as dementia in immigrants is not an important topic of study in some countries. Therefore, in such cases, health and migration experts or dementia experts were interviewed or a round table was organised in which both dementia experts and migration experts participated. For a few countries, such as the Baltic States, no researchers or care providers working on this topic could be found. In some cases, the topic of immigration does not play a major role and the topic of dementia is rarely addressed. Overall, the recruitment of experts was a challenge that was intensified by the COVID-19 pandemic. Since the outbreak of the pandemic, for example, no response from some countries were received for a certain amount of time.

### 2.7.1 Interview guide

The questions for the interviews were derived from scientific articles, national and international reports, and the analysis of NDPs. The primary source was the Alzheimer Europe report 'The Development of Intercultural Care and Support for People With Dementia from Minority Ethnic Groups' from 2018. Topics of the interview were: general questions, care, inclusion, and information of PwM (with dementia), professional care, and support for family caregivers. The experts were sent the interview guide together with a document containing definitions of key terms and the research proposal of this project before the interview. Besides, the experts were offered a fee of 400€ for their participation in the interview. The interview guide and the document with the key terms can be found in the appendix in English and German.

### 2.7.2 Data evaluation

The interviews, which lasted 90 minutes on average, were recorded and then transcribed. Thereby, the transcription rules of Kuckartz's qualitative content analysis (2010) were applied and a verbatim transcription was conducted. The evaluation of the interviews was based on the method of qualitative content analysis of Mayring (2014). To structure the content, a combination of deductive and inductive categorisation was used. First, three categories were deductively derived from the categories for the interview agenda—1. services and information for PwM with dementia, 2. professional qualification and PwM in healthcare, 3. support for family caregivers. The text sections directly relating to one of these three topics were assigned to the categories and extracted. The other sections were not included as they do not provide direct answers regarding the main aims of the interviews and the atlas. Afterward, the extracted material was sorted and the content was summarised into

individual categories. Then subcategories were inductively derived from the data. Sub-topics were formed for the three main topics and generic terms were derived for the respective phenomenon described. In the end, a final category system was created and the material was sorted, summarised, and integrated into the country profiles for the atlas.

For a few countries (8), interviews were conducted with several experts. In the country profiles, the central statements of all experts were mentioned and divergent statements of different experts from one country were marked accordingly. In chapter 3.6 'Care situation of people with a migration background and dementia and available healthcare services for this group in Europe', where the results are first presented quantitatively, and in figures, only one answer per country was taken into account. In most cases, especially among the experts who were interviewed together, their central statements were in agreement. However, in two cases there were discrepancies in central statements—once for the two experts from Bulgaria and once for the two experts from Liechtenstein. In both cases, the answer of the expert who, according to a self-assessment conducted at the beginning of the interview, had the higher expertise in this field and who substantiated the given answer was given weightage.

### 2.7.3 Changes due to the COVID-19 pandemic

The global COVID-19 pandemic necessitated changes to the planned procedures. The original plan for the interviews was to visit the experts in their respective countries and do the interviews face-to-face. However, due to the heightened health risks and travel bans, the format changed to interviews via videoconference. Also, the circumstances resulting from COVID-19 and the need for modifications to the approach led to the extension of the project duration by six months.

## 2.8 Important elements for the provision of culturally sensitive care to people with a migration background with dementia

To provide a brief overview of key elements of culturally sensitive care that considers the specific needs of PwM with dementia according to the current state of scientific knowledge, a systematic analysis of articles from peer-reviewed scientific journals, scientifically oriented oral statements from conference presentations, governmental dementia plans and international reports, as well as medical-oriented guidelines on the care of PwM with dementia was performed. Thereby, three methodical models were combined (triangulation) as follows. For the collection of statements from scientific articles, the systematic literature analysis by Becker (2018) was used; for the analysis of the data, the discourse analysis by Keller (2011) was implemented; and for the coding, qualitative content analysis by Mayring (2014) was applied.

### 2.8.1 Data collection

1. To identify relevant articles in scientific journals, the databases PsycARTICLES, Psychology and Behavioral Sciences Collection, and PsycINFO on the platform EBSCOhost and the PubMed database were screened. Thereby, the key terms—care, Versorgung, dementia, Demenz, migration, and Migration—were used. In this analysis, only articles in German and English were considered as these represent the mother tongue and second language, respectively, of the authors. The study covers the period from 1 January 2009 to 1 November 2019. This period is based on the validity of recommendations for action from guidelines and NDPs of various European countries. In most EU, EFTA, and UK countries, the validity of guidelines and dementia plans is five years. Since the recommendations for action in two successive documents often differ only

slightly and since clear discrepancies only occur after a gap of more than 10 years, this period was used as a basis for this analysis. The database search was limited to abstracts and titles because the study was supposed to only consider articles that focus on the care of PwM with dementia.

The formal search criteria were as follows. Language: German and English, publication date: 1 January 2009–1 November 2019, publication type: Open Access, and search date: 1 November 2019. The search terms and results were as follows: PubMed: (((Versorgung [Title/Abstract] OR care [Title/Abstract])) AND (Demenz [Title/Abstract] OR dementia [Title/Abstract])) AND (Migration [Title/Abstract] OR migration [Title/Abstract]): 17 hits; EBSCOhost: database: PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycINFO: (((Versorgung or care [Abstract])) AND (Demenz or dementia [Abstract])) AND (Migration or migration [Abstract]): 21 hits. Thus, the total number of articles after excluding duplicates was 25.

After excluding four articles due to the date of publication and four articles due to the implementation of material quality criteria requiring inclusion of elements/measures on the topic of care of PwM with dementia, the corpus comprised n=17 articles.

2. Afterwards, the following documents were integrated into the corpus:

- NDPs of the EU, EFTA, and UK countries, which were available via the website of Alzheimer Europe or the search engine Google on 1 November 2019
- dementia care guidelines received until 1 November 2019 from the national Alzheimer societies, health ministries, and professional societies for geriatrics, gerontology, and neurology of the EU, EFTA, and UK countries. These guidelines were provided

in response to mail requests that were sent out between 2 May and 11 July 2019.

- articles referenced in the systematically derived articles
- international reports, books, databases, and websites available online on 1 November 2019 in which elements or measures regarding the care of PwM with dementia were present. These were found through a Google search using several keywords such as: report/book/database/website and dementia and migration, dementia care, or migrants and health.

3. Finally, oral statements were derived from conference presentations, workshops, and discussion panels in EU countries on the topic of dementia and migration. Only contributions from events attended by the authors were considered. The authors evaluated the programs of various events organised at the EU level and attended those that highlighted topics the authors deemed relevant in the context of caring for PwM with dementia. Additionally, an event of the German Alzheimer Society in which scientists, practitioners, and family caregivers gave their inputs on the topic of dementia and migration was considered.

### 2.8.2 Basis of the data

The search resulted in the following hits: n=113 documents, books, databases, and websites and n=4 events. After screening the content of these texts and events, the following discourse fragments remained: n=64 documents, books, databases, and websites and n=4 events. Their breakdown is as follows: 28 scientific articles; 15 national guidelines; 11 NDPs; 6 international reports on dementia, health, and migration; 2 books on dementia and migration; 1 database with initiatives on intercultural care; 1 website on health and migration; the North Sea Dementia Group Meeting 2019; the Alzheimer Europe Conference 2019;

## 2. Method

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the European Public Health Conference 2019; and the Symposium on Dementia and Migration of the German Alzheimer Society 2019. These texts, publications, and events represent the database for the results of this study.

### 2.8.3 Data evaluation

The relevant text sections and oral contributions were paraphrased; memos and comments were added; and the text was coded [26]. A combination of deductive and inductive categorisation was used. First, categories were derived from other guidelines on de-

mentia care [33-37]. These categories were assigned to the individual text sections. From data material that could not be coded in this way, content categories were aggregated. Then, the category set was structured by formulating main categories. Afterward, a rough structure was generated from the main categories, and the content was ordered [38]. A consensus was built, central statements were derived, and deviating or singular statements were excluded [39]. Subsequently, the central statements were summarised into a catalogue of measures and finally structured.

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### 3. Results

#### 3.1 Europe's migration history

Migration in Europe is not a modern or recent phenomenon. Since the beginning of human history, migration has been a central element of social change. Global migration on a larger scale began in the 15th century, when Europe began to expand worldwide politically-territorially, economically, and culturally. Until the early 19th century, the emigration of Europeans to other regions of the world was still moderate [1].

##### 3.1.1 Waves of European migration history since the beginning of the 19th century

Recent migration history can be divided into six waves:

**1st wave: Early 19th century–early 20th century:** Europe was a continent of emigration and more than 60 million Europeans left the continent for North and South America (most of them for the USA), Australia, and New Zealand.

**2nd wave: Beginning of the First World War–end of the 1940s:** The two world wars led to large internal and intercontinental flight movements. During the wars, soldiers from Asia, Africa, and the Caribbean were also recruited by the colonial powers, with several thousand remaining in Europe at the end of the war. After the Second World War, massive migratory movements occurred due to the displacement of entire ethnic groups (for example in the former German eastern territories).

**3rd wave: 1950 to mid-1970s:** Mass immigration into Europe began. Large groups of migrants immigrated from former European colonies and developing countries to France, United Kingdom, Belgium, Portugal, and the Netherlands. In the 1950s and 1960s, the industrial core countries (Western) Germany, northern Italy, Switzerland, Austria, France, Belgium, the Netherlands, Luxembourg, Unit-

ed Kingdom(England), Denmark, and Sweden also recruited labour migrants from the less developed countries such as Spain, Italy, Yugoslavia, Greece, Ireland (to United Kingdom), and Finland (to Sweden). From the 1960s onwards, German, Belgian, Dutch, French, and Scandinavian employers began to recruit workers from Turkey, Morocco, Algeria, and Tunisia, as well as from certain former colonies such as Senegal or Mali (former French colonies), and the Caribbean (for British colony). As a result of positive migration balances, the population in Europe increased by about 10 million.

**4th wave: Mid-1970s–early 1990s:** The halt in the recruitment of labour migrants by most Northern and Western European countries during the economic recession of the mid-1970s resulted in a large number of migrants settling permanently in the host nations and relocating their families in order to live with them. Family reunification from the Maghreb states, Turkey, and other countries of origin characterised the European migration process. Moreover, the recruitment halts caused a shift in labour migration towards the southern European peripheral states, which successively developed from countries of emigration to countries of immigration. After economic growth resumed from the mid-1980s and a structural economic transformation towards a service-oriented economy occurred, the demand for low- as well as highly-skilled labour migrants in the industrial core countries grew again.

**5th wave: Early 1990s–2007:** After the collapse of the communist systems, the end of the Cold War, and the Yugoslavian wars, the Central and Eastern European countries (Poland, Ukraine, Albania, Romania, Bulgaria, and the Baltic states) developed into major countries of origin of migrants moving to Western and Southern Europe, and partly into independent



transit and immigration countries. In addition, the southern and western peripheries (Ireland, Italy, Spain) were established as destination countries. Furthermore, immigration from Africa has increased since the mid-1990s. At the beginning of the 21st century, immigration from East, South, and Southeast Asia, as well as from Latin America, also increased significantly. Overall, there has been a diversification of countries of origin and migration motives (e.g. nurses and doctors from the Philippines; refugees and asylum seekers from Africa, the Middle East, Asia, the Balkans, and the former Soviet Union; students from China).

**6th wave: 2008–Present:** The world economic crisis of 2008 was the starting point for the current phase of the stabilisation of intra-European migration and the increasing immigration of non-EU citizens. The crisis initially

led to a decrease in migration within and towards the EU and stimulated emigration from particularly crisis-ridden countries such as Greece, Spain, Portugal, and Ireland to Northern Europe. From 2012 onwards, immigration from non-EU countries increased, partly due to the Syrian and Ukrainian conflicts. Besides, some countries such as Germany, Sweden, Denmark, and the UK have initiated programs to recruit international students and highly qualified migrants, and the EU has established an EU-wide residence and work program for non-EU immigrants (Blue Card system). In 2015, intra-EU migration was 1.4 million, and legal migration from non-EU countries 2.4 million. While Romania and Poland are the main countries of origin for intra-EU migration, Syria and Ukraine have become the main countries of origin for external migration [2-5].

### 3.1.2 Current situation in the EU, EFTA, and UK countries

Tab. 1: Overview of migration data of EU/EFTA/UK countries

Country	Number of migrants*1 in 2019	Migrant share in the total population in 2019	Migrant population trends between 1990 and 2019	Net migration-number*2 (rate*3) 2020	Total number of new migrants in 2013	Migrant stock: Top 3 countries of origin 2013
Austria	1.8 million	19.9 %	226.93 %	325,000 (7.4)	101,900	Germany (199,935) Serbia (174,437) Turkey (165,206)
Belgium	2 million	17.2 %	153.85 %	240,000 (4.2)	118,300	Italy (189,367) France (155,879) Netherlands (148,440)
Bulgaria	168,500	2.4 %	783.72 %	- 24,000 (- 0,7)	18,600	Russian federation (19,733) Romania (6,371) Ukraine (6,193)
Croatia	518,100	12.5 %	108,98 %	- 40,000 (- 1,9)	10,400	Bosnia and Herzegovina (499,059) Serbia (118,071) Slovenia (47,768)

Country	Number of migrants*1 in 2019	Migrant share in the total population in 2019	Migrant population trends between 1990 and 2019	Net migration-number*2 (rate*3) 2020	Total number of new migrants in 2013	Migrant stock: Top 3 countries of origin 2013
Cyprus	191,900	16 %	438.13 %	25,000 (4.2)	13,100	UK (42,854) Greece (27,912) Georgia (17,994)
Czech Republic	512,700	4.8 %	464.40 %	110,100 (2.1)	30,100	Ukraine (127,239) Slovakia (73,437) Viet Nam (61,744)
Denmark	722,900	12.5 %	307.36 %	76,000 (2.6)	60,300	Germany (35,316) Turkey (32,829) Poland (30,931)
Estonia	190,200	14.4 %	49.79 %	19,600 (3.0)	4,100	Russian Federation (159,036) Ukraine (21,014) Belarus (12,419)
Finland	383,100	6.9 %	605.21 %	70,000 (2.5)	31,900	Russian Federation (68,434) Sweden (36,117) Estonia (34,013)
France	8.3 million	12.8 %	140.68 %	182,600 (0.6)	332,600	Algeria (1,406,845) Morocco (911,046) Portugal (629,118)
Germany	13.1 million	15.7 %	222.03 %	2.7 million (6.6)	692,700	Turkey (1,543,787) Poland (1,146,754) Russian Federation (1,007,536)
Greece	1.2 million	11.6 %	194.14 %	- 80,000 (- 1.5)	57,900	Albania (574,840) Bulgaria (55,988) Romania (38,597)
Hungary	512,000	5.3 %	147.34 %	30,000 (0.6)	39,000	Romania (232,793) Germany (33,896) Ukraine (31,632)
Iceland	52,400	15.5 %	545.83 %	1,900 (1.1)	6,400	Poland (9,357) Denmark (3,066) Sweden (1,876)
Ireland	833,600	17.1 %	365.61 %	118,000 (4.9)	59,300	UK (253,605) Poland (124,566) Lithuania (37,823)
Italy	6.3 million	10.4 %	450.00 %	744,700 (2.5)	307,500	Romania (1,008,169) Albania (448,657) Morocco (425,188)



Country	Number of migrants*1 in 2019	Migrant share in the total population in 2019	Migrant population trends between 1990 and 2019	Net migration-number*2 (rate*3) 2020	Total number of new migrants in 2013	Migrant stock: Top 3 countries of origin 2013
Latvia	237,300	12,4 %	36.73 %	- 74,200 (- 7,6)	8,300	Russian Federation (146,628) Belarus (49,235) Ukraine (36,106)
Liechtenstein	25,500	67 %	233.95 %	No data	696	2013: No data 2016: Switzerland (3,612) Austria (2,203) Italy (1,572)*4
Lithuania	117,200	4.2 %	33.55 %	- 163,900 (- 11,6)	22,000	Russian Federation (62,143) Belarus (35,708) Ukraine (13,322)
Luxembourg	291,700	47.4 %	256.33 %	48,700 (16.3)	21,100	Portugal (85,716) France (32,752) Italy (18,667)
Malta	84,900	19,3 %	562.25 %	4,500 (2.1)	8,400	UK (11,429) Australia (5,463) Canada (2,136)
Netherlands	2.3 million	13,4 %	191.67 %	80,000 (0.9)	129,400	Turkey (303,483) Suriname (191,182) Morocco (173,489)
Norway	867,800	16.1 %	450.57 %	140,000 (5.3)	68,300	Poland (76,184) Sweden (53,082) Germany (30,819)
Poland	656,000	1.7 %	59.64 %	- 147,000 (- 0.8)	220,300	Ukraine (221,307) Germany (81,779) Belarus (81,363)
Portugal	888,200	8.7 %	203.81 %	- 30,000 (- 0.6)	17,600	Angola (161,395) Brazil (138,664) France (93,781)
Romania	462,600	%	%	- 370,000 (- 3.8)	153,600	Moldova (49,785) Italy (27,462) Bulgaria (18,271)
Slovak Republic	188,000	3.4 %	455.21 %	7,400 (0.3)	5,100	Czech Republik (83,050) Hungary (15,895) Ukraine (9,398)

## Results

Country	Number of migrants*1 in 2019	Migrant share in the total population in 2019	Migrant population trends between 1990 and 2019	Net migration-number*2 (rate*3) 2020	Total number of new migrants in 2013	Migrant stock: Top 3 countries of origin 2013
Slovenia	253,100	12.2 %	142.11 %	10,000 (1)	13,900	Bosnia nad Herzegovina (98,501) Croatia (49,475) Serbia (36,719)
Spain	6.1 million	13,1 %	742.45 %	200,000 (0.9)	280,800	Romania (797,603) Morocco (745,674) Ecuador (451,184)
Sweden	2 million	20 %	253.55 %	200,000 (4)	115,800	Finland (167,185) Iraq (130,449) Poland (76,848)
Switzerland	2.6 million	29.9 %	185,71 %	260,000 (6.1)	160,200	Germany (356,974) Italy (260,746) Portugal (202,745)
United Kingdom	9.6 million	14.1 %	259.46 %	1.3 million (3.9)	526,000	India (756,471) Poland (661,482) Pakistan (476.144)
<b>EU/EFTA/UK</b>	<b>61,657,700</b>				<b>3,635,596</b>	

\*1 Born abroad, \*2 immigrants minus emigrants (in the last 5 years), \*3 immigrants minus emigrants per 1,000 inhabitants (in the last 5 years), sources: Columns 2-6: IOM (International Organization for Migration) 2019: Migration Data Portal, Column 7: United Nations, Department of Economic and Social Affairs 2013: Population Division. Trends in International Migrant Stock: The 2013 Revision, \*4 Column 7 Liechtenstein: Office of Statistics (Principality of Liechtenstein) 2017: Liechtenstein in Figures 2018, in bold: Highest figure per column

Table 1 presents the key data on migration in the individual EU and EFTA countries and the UK. The migrant population (born abroad) of all EU and EFTA states and the UK comprises almost 61.7 million people. Approximately 70% of all migrants of the EU, EFTA, and UK states live in Germany (13.1 million), the UK (9.6 million), France (8.3 million), Italy (6.3 million), and Spain (6.1 million). In terms of the proportion of immigrants in the total population, it is highest in Liechtenstein, Luxembourg, Switzerland, Sweden, and Austria. In Liechtenstein, about two-thirds of the population was born abroad; in Luxembourg, it is just under half; in Switzerland almost one third; and in Sweden and Austria about one fifth. However, there are fundamental differences between the countries with the highest proportion of migrants and the countries with the largest number of migrants in terms of the dominant regions of origin. In Liechtenstein and Luxembourg, the largest migrant groups come from other EU, EFTA, and UK states and neighbouring countries with the same national language, for example, from Switzerland and Austria to Liechtenstein, and from Portugal and France to Luxembourg. In contrast, in Germany (from Turkey, Russia) and United Kingdom (from India, Pakistan) several non-EU states are among the main countries of origin of migrants. In 23 of 31 EU and EFTA states and the UK, migrants represent more than 10% of the total population. In Finland, Hungary, the Czech Republic, Lithuania, Slovakia, Romania, Bulgaria, and Poland the migrant population and especially the proportion of migrants in the total population is rather small (below 7%). Portugal has a slightly larger migrant population than these countries (888,200), but the proportion of migrants there is also below 10% (8.7%). Since 1990, the migrant population has

increased almost eightfold in Bulgaria (the highest figure of all EU/EFTA/UK states), nearly sixfold in Finland, and almost fivefold in Slovakia and the Czech Republic. Besides, in the last five years before 2020, the Czech Republic had a positive net migration of 110,100; Finland of 70,000; Hungary of 30,000; and Slovakia of 7,400. This shows that even in some of the countries where the migrant population is currently relatively, the number of immigrants and the proportion of the migrant population is growing. In these countries, migrants come almost exclusively from the neighbouring regions and mainly from the immediate neighbouring countries. Lithuania and Poland are the only two countries with a migrant proportion of less than 10% (4.2 and 1.7%), a clearly negative net migration (-163,900, -147,000), and a declining migrant population compared to 1990 (down to about one-third, almost halved). In all EU, EFTA, and UK countries except Estonia, Latvia, Lithuania, and Poland, the migrant population has increased since 1990 and in 20 of the 32 countries, it has more than doubled. Net migration has been positive in 23 countries (in the last five years before 2020). In absolute terms, it was highest in Germany (2.7 million), and in terms of population size, it was highest in Luxembourg (net migration rate<sup>1</sup>: 16.3). In 2013, there were over 3.6 million new international migrants in all EU, EFTA, and UK countries, most of them in Germany (692,700). Almost 65% of the new migrants lived in Germany, the UK (526,000), France (332,600), Italy (307,500), Spain (280,800), and Poland (220,300). The example of Poland shows that the immigration of international migrants is of central importance even (and especially) in traditional emigration countries. Overall, migration and especially the immigration of international migrants represents

1 The net migration rate is the total number of immigrants less the annual number of emigrants during the period (in the last 5 years prior to 2020) per 1,000 persons of the population of the respective country.

a central element of the social change in Europe, which is characterised by globalisation and digitalisation. In recent decades, most EU, EFTA, and UK states have developed into immigration countries whose migrant populations have grown significantly and will probably grow at a fast rate in the future [6].

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## 3.1.3 References

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## 3.2 Estimated number of people with a migration background with dementia in Europe

As described in the migration history of Europe as a whole and the individual countries, Europe is a continent of emigration and immigration. However, the number and proportion of PwM varies significantly across these countries. Countries such as Germany, France, Spain, and Italy are typical immigration countries. Therefore, they have higher numbers of PwM living there as opposed to other countries in Europe that might not be attractive destination countries, or might be just transit countries, or people stay there temporarily for work and go someplace else after that.

When looking at the population of PwM that is at least 65 years old, it is apparent that these migrant groups are mostly originating from another European country. Of course, there are exceptions. For example, in France: People from Algeria and Morocco are two of the biggest migrant groups and people originating from Indonesia and Suriname are two of the largest migrant groups in the Netherlands. The European countries that host the most PwM aged 65 or older are Germany (1,990,000), France (1,440,400), the UK (919,400), Poland (437,200), and Romania (405,900). Naturally, in countries with a high number of PwM aged 65 or older there is a higher occurrence of PwM with dementia in absolute numbers. Therefore, the European countries with the highest number of estimated PwM with dementia aged 65 years and above are: Germany (137,300), France (99,400), the UK (63,600), Switzerland (25,400), and Spain (24,900) (see figure 3.2.1).

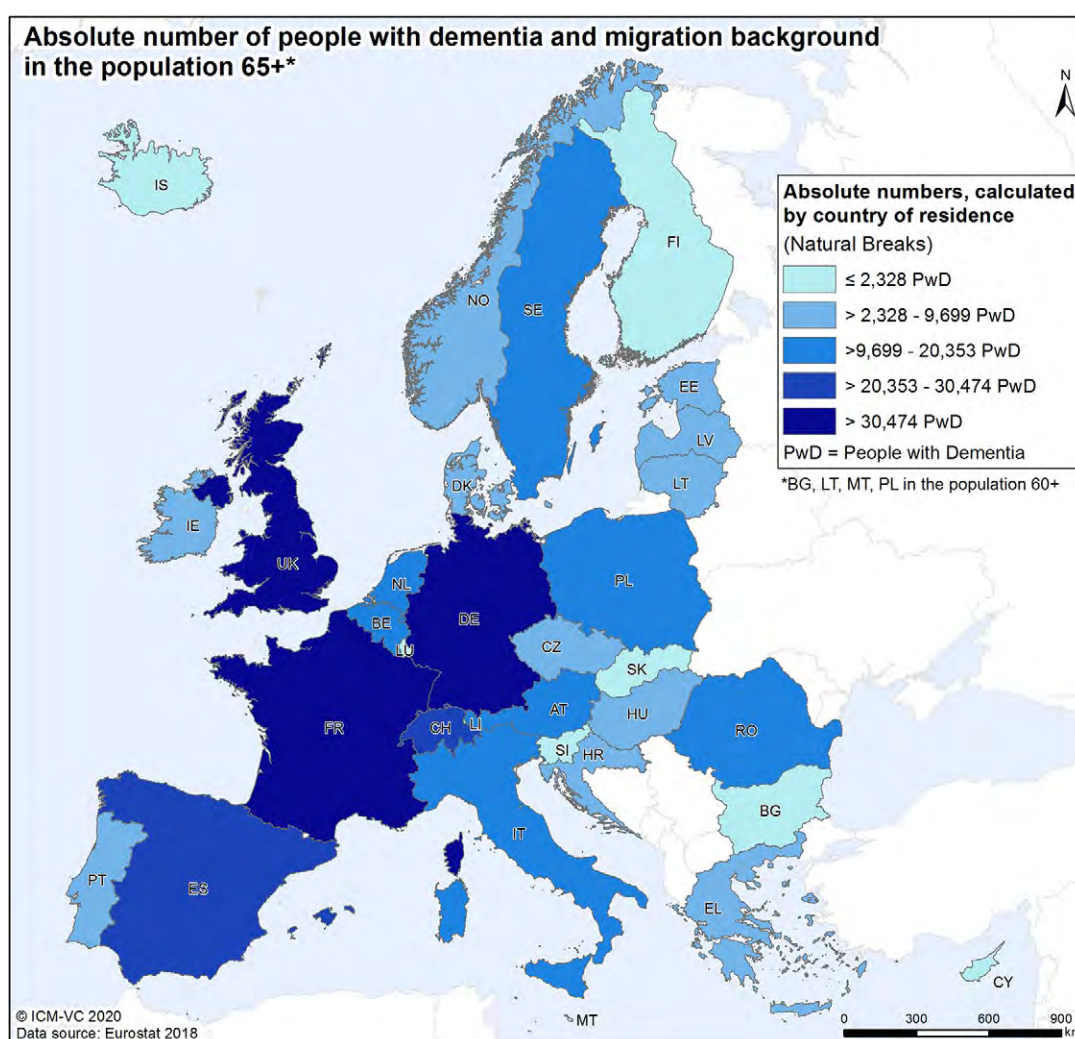


Fig. 3.2.1: Absolute number of PwM with dementia aged 65+ in Europe

In total, there are approx. 531,400 PwM with dementia living in the EU and EFTA member states and the UK. This total number of PwM with probable dementia is to be taken carefully since the literature suggests there is a high number of unknown cases amongst PwM due to lack of diagnosis. Therefore, the estimated numbers in this atlas are to be interpreted with caution keeping this fact in mind.

The distribution of the highest numbers of estimated PwM with dementia changes across the European countries regarding relative instead of absolute data. This is the case when

putting the absolute numbers of PwM with probable dementia in relation to the whole population aged 65 or older of the respective country (combining the population with a migration background and the autochthonous population). Taking this ratio into account, the countries with the most PwM with assumed dementia per 100,000 inhabitants are Liechtenstein (3,500), Luxembourg (1,900), Switzerland (1,800), Latvia (1,400), and Estonia (1,400) (see figure 3.2.2).



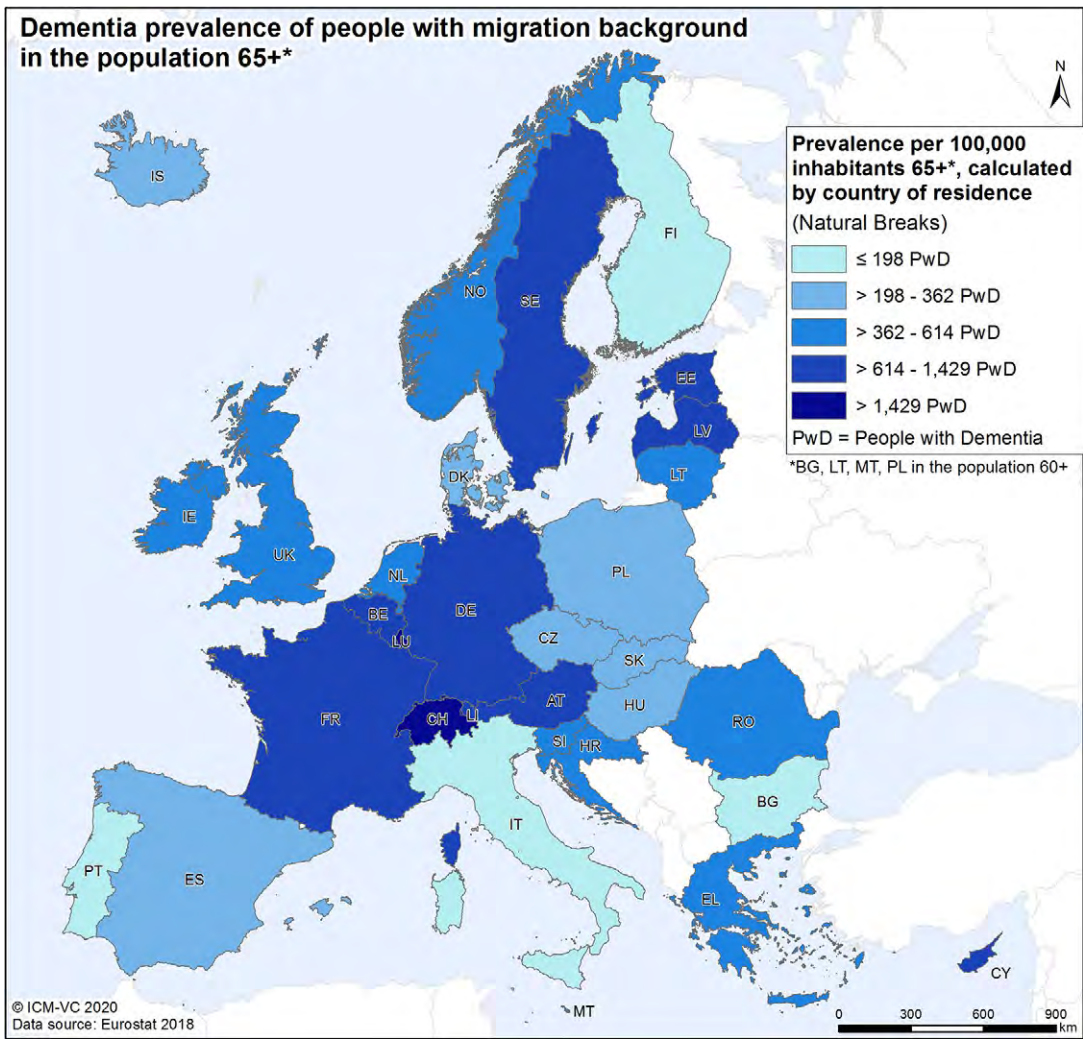


Fig. 3.2.2: Prevalence of PwM with dementia among the population aged 65+ in Europe

All over Europe, the migrant groups estimated to be mostly affected by dementia in absolute numbers originate from Italy (30,300), Alge-

ria (27,300), the Russian Federation (24,400), Germany (22,800), and Poland (22,200).

### 3.3 National dementia plans and strategies: Focus on migration

This chapter summarizes the results of the systematic analysis of the NDPs and strategies of the EU, EFTA, and UK countries. Sub-chapter 3.3.1 presents the findings of the first analysis, which covers all documents published until 1 June 2019. In the next section (3.3.2) the results of the comparison of the NDPs that were found during the second search on 4 January 2021 are reported. In the concluding section 3.3.3, the principal results of both searches are merged. The detailed results for the documents of the individual countries are presented in chapter 3.7.

#### 3.3.1 Results from the first search on 1 June 2019

The analysis of NDPs and strategies published until 01 June 2019 showed that 16 of the 27 EU countries (59%), 3 of the 4 EFTA countries, and all 4 UK countries have issued NDPs. More than half (13) of the countries with NDPs do not refer to migration. Ten countries discuss migration in their documents (Austria, Belgium/Flanders, Cyprus, England, Northern Ireland, Norway, Scotland, Switzerland, the Netherlands, and Wales). These 10 countries published a total of 14 NDPs or similar documents with migration references. This means that more than half (53%) of the 30 documents identified in the first search did not include migration issues at all. Besides, only one state (Austria) has an NDP with a chapter on migration (table 2).

The NDPs with migration references differ considerably in terms of the scope of the reference, the range of topics, and the focus and depth of the content [1]. The 'Austrian Dementia Report 2014', for example, devotes four full pages in detail to PwM with dementia [2]. Other NDPs, such as those in Scotland, Switzerland, or Cyprus, minimally touch upon this topic, with only a few sentences addressing varying aspects of the issue (Scotland: early diagnosis and care, Switzerland: migrant needs and diagnostic challenges, Cyprus: dementia risk and care) [3-5]. Eight of the ten NDPs with migration references identify specific needs of PwM in dementia care. Nine countries are planning migrant-related actions. However, only Norway, Northern Ireland, and the Netherlands currently provide specialized healthcare services for PwM at the national level (table 2). Norway is improving the skills of staff members working with language minorities and developing a post-diagnostic follow-up program for people with dementia with different cultural backgrounds and their relatives [6]. Northern Ireland has developed a self-assessment tool for service providers that contains a whole questionnaire with items around the topic of migration [7]. In the Netherlands, special attention has been paid to PwM in the early detection and prevention of dementia [8]. Such concepts, communicated at the national level by representatives of the state, can help to raise awareness on the topic of migration among providers of dementia-specific care services and can serve as models of good practice for other countries.

**Tab. 2: Migration reference in NDPs of EU/EFTA/UK countries**

Countries	Dementia plans and migration reference			Sub-themes related to migration		
	Dementia plan available	Reference to migration	Chapter on migration	Prevalence	Needs	Dementia diagnosis
Austria	X	X	X	X	X	X
Switzerland	X	X	—	—	X	X
Netherlands	X	X	—	X	X	X
Belgium / Flanders	X	X	—	X	X	—
England	X	X	—	X	X	—
Scotland	X	X	—	—	—	X
Wales	X	X	—	—	X	X
Northern Ireland	X	X	—	—	X	—
Norway	X	X	—	—	X	X
Cyprus	X	X	—	—	—	—
Denmark	X	—	—	—	—	—
Finland	X	—	—	—	—	—
Ireland	X	—	—	—	—	—
Czech Republic	X	—	—	—	—	—
Slovenia	X	—	—	—	—	—
Liechtenstein	X	—	—	—	—	—
Luxembourg	X	—	—	—	—	—
France	X	—	—	—	—	—
Greece	X	—	—	—	—	—
Italy	X	—	—	—	—	—
Spain	X	—	—	—	—	—
Portugal	X	—	—	—	—	—
Malta	X	—	—	—	—	—
Sweden	—	—	—	—	—	—
Iceland	—	—	—	—	—	—
Estonia	—	—	—	—	—	—
Latvia	—	—	—	—	—	—
Lithuania	—	—	—	—	—	—
Germany	—	—	—	—	—	—
Poland	—	—	—	—	—	—
Bulgaria	—	—	—	—	—	—
Romania	—	—	—	—	—	—
Slovakia	—	—	—	—	—	—
Hungary	—	—	—	—	—	—
Croatia	—	—	—	—	—	—



		Migrant-related needs and services			Countries
Care	Utilization of formal services	Identification of special needs	Specific services available	Specific actions planned	
X	X	X	—	X	Austria
—	—	X	—	X	Switzerland
X	—	X	X	X	Netherlands
X	—	X	—	X	Belgium / Flanders
—	—	X	—	X	England
X	—	—	—	X	Scotland
X	X	X	—	X	Wales
X	—	X	X	X	Northern Ireland
X	X	X	X	X	Norway
X	—	—	—	—	Cyprus
—	—	—	—	—	Denmark
—	—	—	—	—	Finland
—	—	—	—	—	Ireland
—	—	—	—	—	Czech Republic
—	—	—	—	—	Slovenia
—	—	—	—	—	Liechtenstein
—	—	—	—	—	Luxembourg
—	—	—	—	—	France
—	—	—	—	—	Greece
—	—	—	—	—	Italy
—	—	—	—	—	Spain
—	—	—	—	—	Portugal
—	—	—	—	—	Malta
—	—	—	—	—	Sweden
—	—	—	—	—	Iceland
—	—	—	—	—	Estonia
—	—	—	—	—	Latvia
—	—	—	—	—	Lithuania
—	—	—	—	—	Germany
—	—	—	—	—	Poland
—	—	—	—	—	Bulgaria
—	—	—	—	—	Romania
—	—	—	—	—	Slovakia
—	—	—	—	—	Hungary
—	—	—	—	—	Croatia

The countries are sorted according to the scope and thematic range of their migration references. The more of the selected categories were considered in the document of the respective country, the higher the country is listed in the table.

In most NDPs, the focus is on the problem description. The most frequently addressed problems are: cultural and language barriers, late diagnosis, and lower utilisation of care services. Language barriers, cultural factors, inappropriate diagnostic instruments, and a lack of migrant-specific services were named as obstacles to receiving care. While in some countries such as the Netherlands or Belgium/Flanders, PwM are identified as a risk group for dementia, and in almost all countries as a risk group for underdiagnosis and a lower level of care, England seems not to perceive PwM as a vulnerable group. The planned actions are that attention will be paid to the conception of tailored information materials; training of caregivers; training medical and nursing professionals or staff to operate migrant counselling centres; and the development of language and culturally appropriate diagnostic tools. Additionally, several countries would like to take greater account of cultural aspects in prevention or early detection and the needs of PwM regarding living spaces. Thus, it was found that at present the topic of migration in the context of dementia plays a subordinate role at the national level in most European countries, and there are hardly any specific care plans for PwM [1].

### 3.3.2 Results from the update of the data on 4 January 2021

In the second search on 4 January 2021, 17 national documents from EU, EFTA, or UK countries on dementia were found, of which 12 (71%) take migration into account. Eight of these 17 documents are NDPs or dementia strategies (Austria, Germany, Hungary, Iceland, Italy, the Netherlands, Norway, and Spain). With the exception of the dementia plan of Iceland, all NDPs include the topic of migration. Compared to the first search, where only half of the NDPs found (43%) mentioned or discussed migration, the proportion of NDPs

with a migration reference doubled in the second search (88%). However, the first search included almost three times more NDPs (23). Among the NDPs found in the second search, only the German dementia strategy has a chapter or several chapter sections on issues related to migration.

Regarding the extent of the migration reference, there are clear differences between the individual NDPs, just like in the first search. While several NDPs (Austria, Hungary, Italy) only refer to migration in a single sentence in one passage, the NDPs of Norway and Germany each address this topic in 14 sections with in different chapters and several separate paragraphs. A few documents, such as that of the Netherlands, do not have separate sections on this topic but refer to it in different chapters with several sentences.

In terms of content, there are some differences but also many parallels between the migration-related sections of the different NDPs. While in the NDPs of Austria, Italy, and Germany the framework for action predominates, in the documents of the Netherlands and Spain almost only descriptions of the care situation are given. The Norwegian NDPs contain both a relatively detailed description of the situation and the problems in dementia care as well as a comprehensive framework for action. Several documents state that the number of older PwM with dementia is increasing [9, 10]. Furthermore, it is identified that the investigation and diagnosis of dementia as well as dementia counselling are challenging due to cultural and language barriers and inappropriate diagnostic procedures. The NDPs of Germany and Norway also state that PwM with dementia do not use healthcare services to the same extent as other people with dementia. In addition to linguistic, cultural-religious, and institutional barriers, insufficient culturally sensitive services and lack of access to the healthcare system are cited as causes of not using care services

[9, 11]. Overall, four (Germany, the Netherlands, Norway, and Spain) of the seven NDPs with a migration reference identify specific needs (in terms of communication, language, culture, and religion) of PwM with dementia that need to be given special consideration in care. Several NDPs with a migration focus have set themselves the goal of taking greater account of linguistic and cultural diversity in the population of older people when developing diagnostic, information, counselling, care, and treatment services for people with dementia and tailoring services to the specific needs of PwM. Three countries (Austria, Germany, and Norway) refer in their NDPs to concrete measures they plan to take or recommend to achieve this goal. These measures include adapting cognitive assessment tools to people with different cultural and linguistic backgrounds; developing culturally and religiously sensitive support, counselling, and advice for family caregivers; training staff in healthcare facilities in language skills and cultural understanding; as well as training staff in migrant associations on dementia [9-11]. Currently, only the NDPs of Germany and Norway refer to existing services. Norway's dementia plan cites a project completed in 2020 that adapted test procedures for assessing cognitive abilities and dementia symptoms to foreign languages [9]. The German dementia strategy refers to various counselling services tailored to PwM with dementia and their relatives [11]. Almost all the NDPs analysed after the second search address the topic of migration. In the Norwegian and German documents, older PwM are identified as being vulnerable to problems such as late diagnosis of dementia and insufficient access to post-diagnostic care, and in the Dutch document older migrants with non-Western background are identified as a risk group for the development of dementia [10]. However, considering the length of the documents, migration appears to be a minor

topic in most of the NDPs examined and only singular or few aspects of this complex topic are highlighted.

### 3.3.3 Summary of the results

According to this analysis, a total of 18 of 27 EU countries (67%) as well as all 4 EFTA countries, and all 4 UK countries have NDPs or a dementia strategy. Of these 26 countries with NDPs, 14 countries (54%) address migration in their documents. The proportion of NDPs with migration reference in the second search was twice as high as that in the first search. A separate chapter or sub-chapter on dementia care for PwM is only included in the 'Austrian Dementia Report 2014' and the German dementia strategy. The majority of the other NDPs with a migration reference, address the topic only briefly. While in the NDPs of the first search the focus was primarily on the description of the issues related to the care of PwM with dementia, the relationship between the problem description and the framework for action is relatively balanced in the documents of the second search. Ten countries refer in their NDPs to planned measures or provide recommendations for action for care planners and care providers (first and second search). However, only the documents of Germany, the Netherlands, Northern Ireland, and Norway refer to measures already taken to improve the care situation of PwM with dementia or available services for this population (figure 3.3.3.1). The causes for these country-specific differences in terms of migration reference and focus may be the different years of publication and length of the documents as well as social and political reasons and the varying relevance of the topic of migration in the individual European countries. An analysis conducted within the framework of this project indicates that immigration countries with a high proportion of migrants are more likely to address the topic of migration in their NDPs than

## Results

emigration countries with a low proportion of migrants [1].

Overall, this study shows that the topic of migration plays a subordinate role in most NDPs

of European countries and is not addressed in almost half of the documents from the EU, EFTA, and UK countries.

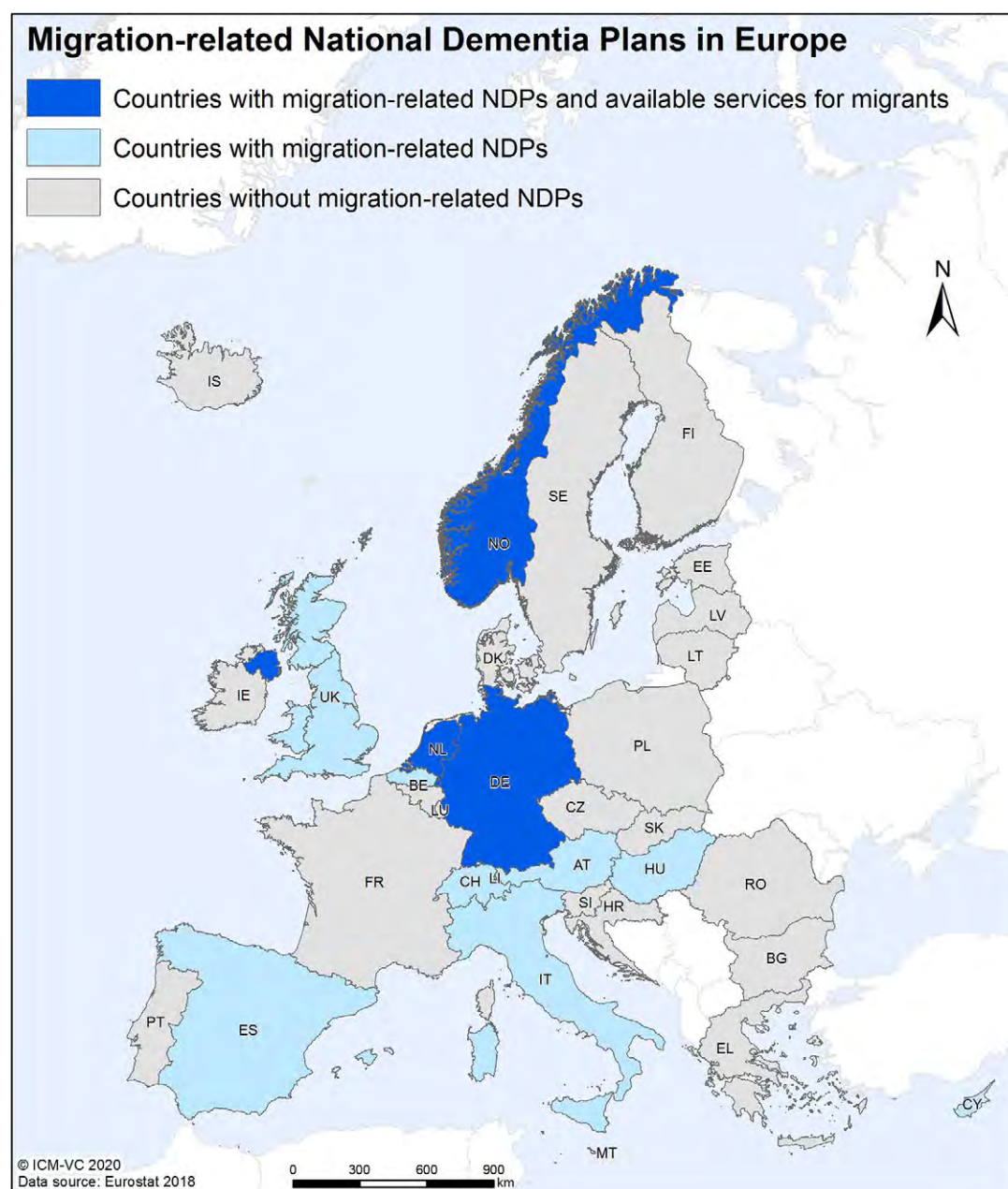


Fig. 3.3.3.1: EU/EFTA/UK countries with migration-related NDPs and available healthcare services (as of 04 January 2021)

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### 3.4 National dementia care and treatment guidelines: Focus on migration

In this chapter, the results of the national care and treatment guidelines analysis of the EU, EFTA, and UK countries are presented (status: July 2019). The results are summarised here for Europe. The detailed results concerning guidelines of individual countries are presented in chapter 3.7.

#### 3.4.1 Results

There are documents at the national level with recommendations, guidelines, or policies for the care of people with dementia in 20 of 27 EU countries (74 %), 3 of 4 EFTA countries, and all four UK countries. Those 27 EU, EFTA, and UK countries provided a total of 43 documents. Most of these are guidelines (n = 30). Only three countries (Scotland, Norway, and Switzerland) have policies. In addition, 7 recommendations for action and 3 reports/strategies were taken into account. Eight countries (Greece, Italy, Croatia, Liechtenstein, Lithuania, Cyprus, Slovakia, and Poland) have no such documents. Fifteen documents from seven EU countries (Belgium/Flanders, Denmark, Germany, Ireland, Austria, Sweden, and Spain), four UK countries (England, Northern Ireland, Scotland, and Wales), and the EFTA country Norway touch upon or discuss the topic of migration. Twenty-eight documents from 13 EU and 2 EFTA countries do not refer to migration at all. Norway and Sweden have a chapter on migration (table 3). Northern Ireland also addresses this topic in detail in its guidelines. Most other countries refer only briefly with single sentences or short sections to specific aspects of this topic. In addition to country-specific differences, there are document type-specific differences. While none of the 3 reports/strategies refers to migration, 2 of 7 recommendations, 11 of 30 guidelines, and 2 of 3 policies do have a reference [1].

**Tab. 3: Migration reference in national dementia care guidelines of the EU/EFTA/UK countries**

Countries	Migration reference of national guidelines		Subthemes related to migration				
	Reference to migration	Chapter on migration	Needs	Dementia diagnosis	Care	Care-inequalities	Service access
Norway	X	X	X	X	X	X	X
Sweden	X	X	X	X	X	X	X
Northern Ireland	X	—	X	X	X	X	X
Spain	X	—	X	X	X	X	—
Scotland	X	—	X	X	X	X	X
Belgium (Flanders)	X	—	X	—	X	X	X
England, Wales	X	—	—	X	X	X	X
Denmark	X	—	X	X	—	—	—
Germany	X	—	—	X	—	—	—
Austria	X	—	—	X	—	—	—
Ireland	X	—	—	X	—	—	—
Bulgaria	—	—	—	—	—	—	—
Estonia	—	—	—	—	—	—	—
Finland	—	—	—	—	—	—	—
France	—	—	—	—	—	—	—
Iceland	—	—	—	—	—	—	—
Latvia	—	—	—	—	—	—	—
Luxembourg	—	—	—	—	—	—	—
Malta	—	—	—	—	—	—	—
Netherlands	—	—	—	—	—	—	—
Portugal	—	—	—	—	—	—	—
Romania	—	—	—	—	—	—	—
Switzerland	—	—	—	—	—	—	—
Slovenia	—	—	—	—	—	—	—
Czech Republic	—	—	—	—	—	—	—
Hungary	—	—	—	—	—	—	—

			Migrant-related needs, services, and recommendations for action			Countries
Utilization of formal services	Care barriers	Suitability screening tests	Identification of special needs	Specific services available	Recommendations for action	
X	X	X	X	X	X	Norway
X	X	X	X	X	X	Sweden
X	X	X	X	—	X	Northern Ireland
X	X	X	X	—	X	Spain
—	X	—	X	—	X	Scotland
—	X	—	X	—	X	Belgium (Flanders)
—	—	X	—	—	X	England, Wales
—	—	X	X	X	—	Denmark
—	X	—	—	—	X	Germany
—	—	X	—	—	—	Austria
—	—	X	—	—	—	Ireland
—	—	—	—	—	—	Bulgaria
—	—	—	—	—	—	Estonia
—	—	—	—	—	—	Finland
—	—	—	—	—	—	France
—	—	—	—	—	—	Iceland
—	—	—	—	—	—	Latvia
—	—	—	—	—	—	Luxembourg
—	—	—	—	—	—	Malta
—	—	—	—	—	—	Netherlands
—	—	—	—	—	—	Portugal
—	—	—	—	—	—	Romania
—	—	—	—	—	—	Switzerland
—	—	—	—	—	—	Slovenia
—	—	—	—	—	—	Czech Republic
—	—	—	—	—	—	Hungary

The countries are sorted according to the scope and thematic range of their migration references. The more of the selected categories were considered in the document of the respective country, the higher the country is listed in the table.



The focus of the national documents of the EU, EFTA, and UK countries on the care of PwM with dementia is on early detection and diagnosis. Only Belgium (Flanders) does not take this topic into account. The main problem identified is that the cultural background and acquired language skills of PwM can influence the results of dementia diagnostic tests. Consequently, the focus in most countries (9 out of 12) is on the suitability of cognitive screening tools for minority groups. Norway, Northern Ireland, England, Wales, and Spain report that standardised cognitive tests such as the Mini-Mental State Examination (MMSE) or the clock test are not suitable for people with a different linguistic or cultural background. Ireland and Austria refer to cognitive screening tests such as the Memory Impairment Screen (MIS) and the Mini-Cog as a 'Screening for Cognitive Impairment in Older Adults', which are less prone to linguistic and cultural influences. Norway, Sweden, and Denmark point to the validity of Rowland Universal Dementia Assessment Scale (RUDAS) for people with a different linguistic or cultural background.

The second central topic is the existence of care inequalities between ethnic minorities and the majority population (in 8 of 12 countries). Norway and Sweden note that PwM use fewer formal healthcare services (primary healthcare services, community support services, inpatient care services). In documents of 7 countries, the access of PwM with dementia to healthcare services is discussed. Some countries report that PwM or ethnic minorities have less access to healthcare services, and they have lower chances of early detection and appropriate drug treatment. Six countries point to care barriers such as stereotyping or linguistic, cultural, and ethnic barriers. As a result, PwM are mentioned by several countries as a risk group for underdiagnosis and lower use of care. Seven countries identify the specific needs of PwM. They refer to a different

perspective on dementia, different preferences for care, and other ideals, ideas, and desires regarding information and self-determination. Nine countries provide recommendations for the care of PwM with dementia. Norway, Sweden, Germany, England, and Wales recommend that the linguistic and cultural background of people should be taken into account when selecting diagnostic test procedures. Norway, Sweden, Northern Ireland, and Spain recommend that care providers offer specialised support and tailored information to PwM dementia and their ethnic minority relatives, regarding their cultural, religious, and linguistic needs. Norway, Northern Ireland, and Spain note that information in the preferred language and an independent interpreter should be offered to PwM with dementia and their caregivers in case of language barriers [19]. Currently, only Norway, Sweden, and Denmark have specialised healthcare services at the national level for PwM with dementia (figure 3.4.1.1). Norway has published informational material on dementia in four different languages (Norwegian, English, Polish, and Urdu) and a brochure with information on rights, requirements, and guidelines concerning the provision and use of professional interpretation services [2]. Sweden has adapted RUDAS to people with different linguistic and cultural backgrounds and developed a training program for health professionals regarding the application of this tool [3]. Denmark has validated RUDAS for PwM [4]. Sweden, Denmark, England, Wales, and Belgium (Flanders) follow an integrative care model. They adapt the mainstream services of the healthcare system to people with different linguistic or cultural backgrounds. Northern Ireland recommends that healthcare providers develop specialised services for ethnic minorities [5]. The Norwegian Directive pursues a segregative care strategy with specialised services for cognitive assessment, dementia diagnosis, and follow-up, while



subsequent treatment and care are provided as part of general medical care [2]. Another central finding of this analysis is the different naming of the people considered as PwM, which is as follows: Norway: immigrant, people with minority backgrounds [2]; UK: people from minority ethnic groups [5, 6]; Belgium/Flanders: people with a migrant background [7, 8]; Spain: people from different cultural or religious groups [9]; Sweden: people with different cultural or linguistic backgrounds [10],

people born abroad [3]. Heterogeneity in the use of terms regarding migrants and the different definitions of such terms across Europe are likely to impact the attributed importance of migration concerning dementia. Similar to the study of the NDPs, this analysis shows that migration plays a subordinate role in national documents on dementia care. In some countries, models of good practice exist, but in Europe, as a whole, there is a significant gap in care services for PwM with dementia.

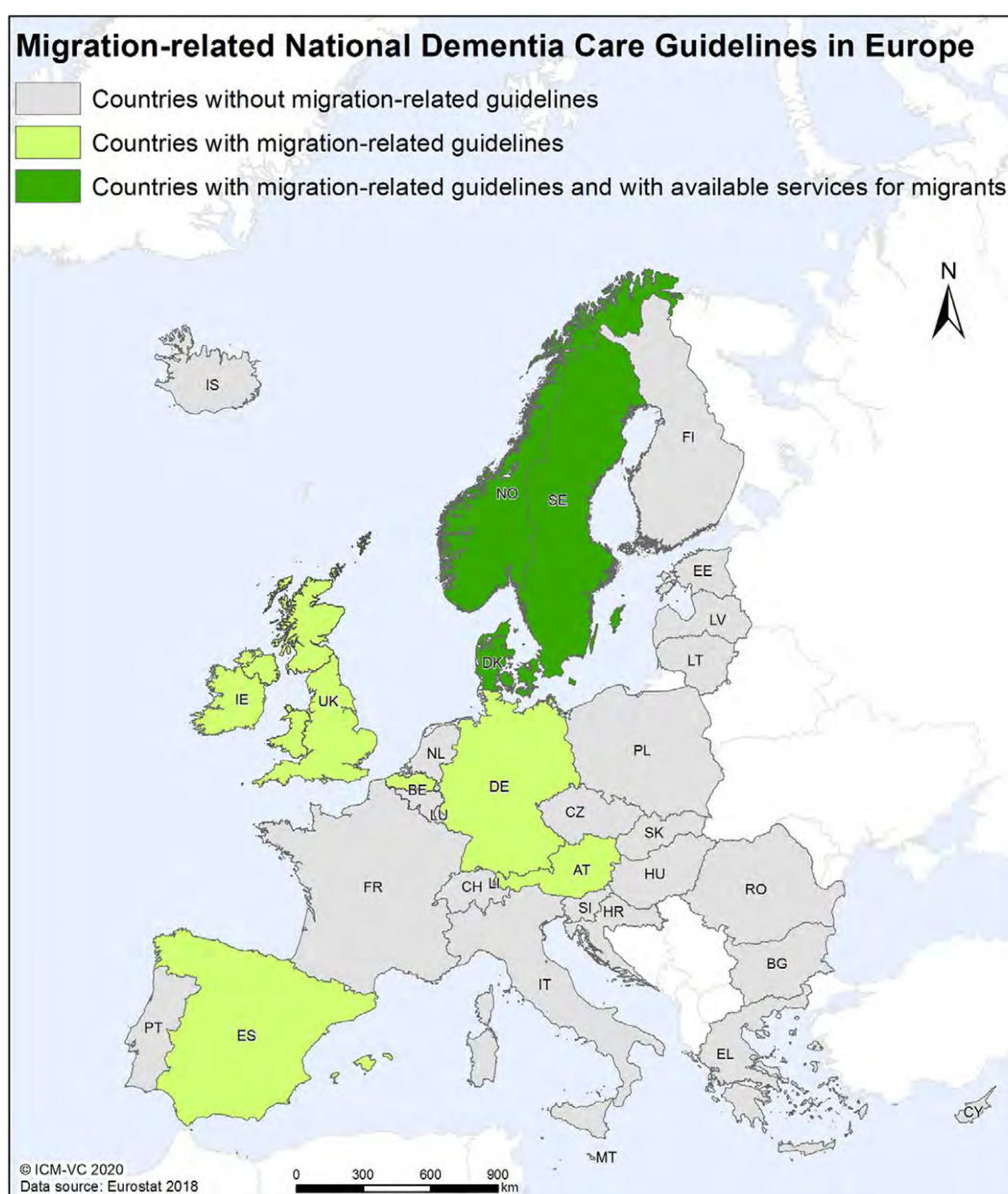


Fig. 3.4.1.1: EU/EFTA/UK countries with migration-related national dementia care guidelines and available healthcare services (as of 11.07.2019)

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## 3.5 Conclusions on national dementia documents: Focus on migration

Thirty-one of the 35 EU, EFTA, and UK countries have NDPs, national treatment guidelines, national care guidelines, or national documents with recommendations for the care of people with dementia. Only Croatia, Lithuania, Poland, and Slovakia have not published such a document (NDPs: as of January 2021, guidelines: July 2019). Twenty-one European countries (60%) have both NDPs and national documents with guidelines, policies, or recommendations on dementia care. Seventeen of 31 countries (55%) refer to the topic of migration in their dementia plans or national care guidelines. Four of these 31 countries (Austria, Germany, Norway, and Sweden) have a separate chapter or subchapter on dementia care for PwM. Thirteen countries refer in their documents to planned measures or make recommendations for care providers to improve the care situation of PwM with dementia. Already implemented measures or currently available services for this population group are referred to in documents from 6 different countries (Denmark, Germany, Northern Ireland, Norway, Sweden, and the Netherlands). Nine of the 35 EU, EFTA, and UK countries (26%) have NDPs and documents with national policies, guidelines, or recommendations addressing migration. Norway is the only country that refers to already implemented measures and/or currently available healthcare services for PwM with dementia in both its NDP and its national professional guidelines on dementia.

Overall, 90 documents on the care of people with dementia were considered in this analysis, of which 38 contain migration references (42%). Although the proportion of NDPs has increased slightly due to the integration of documents published in 2019 and 2020 into the corpus of this study, migration is still a minor topic in the national plans, strategies, and

guidelines for the care of people with dementia in most European countries.

### 3.6 Care situation of people with a migration background with dementia and available healthcare services

Conducting interviews with experts is a good way of obtaining relevant first-hand practical insights about a field, making the interviews a valuable source of information for this atlas. The experts spoke about how the healthcare situation for PwM with dementia in different countries actually looks like. Interviews and discussions could be conducted with 25 experts for a total of 17 countries. These countries were: Austria, Belgium, Bulgaria, Denmark, Finland, Germany, Greece, Ireland, Italy, Liechtenstein, Luxembourg, the Netherlands, Norway, Portugal, Romania, Sweden, and England. In these interviews, different aspects of dementia in PwM were discussed such as dementia and migration, inclusion in the healthcare system, dissemination of and access to information, professional care, and support for family caregivers.

While naturally, all parts of the interviews were

relevant, important, and interesting, the following paragraphs highlight some of the most noteworthy points.

#### 3.6.1 General aspects on people with a migration background with dementia

First, the interviewed experts were asked some general questions about dementia and migration to be able to classify the societal importance and healthcare policy relevance of the topic in the respective country and to determine the priority it has in the national healthcare systems as well as among regional care planners and service providers. Furthermore, the authors of this atlas wanted to find out to what extent PwM as a whole or individual migrant groups are identified by the healthcare system as vulnerable groups in terms of healthcare and whether PwM with dementia are treated as a group with specific healthcare needs. These questions were of fundamental importance to the authors, as the identification of specific needs of a group or population is the basis for the development of specialized services.



Fig. 3.6.1.1: Importance of dementia and migration

Figure 3.6.1.1 shows that, according to the expert interviews, only one country (Austria) considers dementia and migration as a serious concern at the national level, with other coun-

tries giving no importance to the topic. Half of the remaining answers are divided between the categories 'partly important' and 'rather unimportant/not important'. While the coun-

try-specific experts stated that the topic is not seen as important by the healthcare system in Belgium and Greece, it is perceived as rather

unimportant in Finland, Ireland, Liechtenstein, Luxembourg, Norway, and Romania.

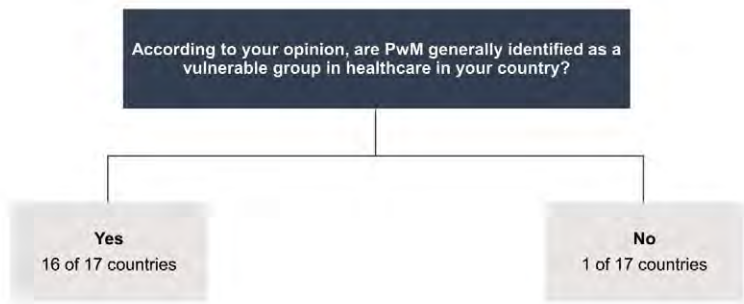


Fig. 3.6.1.2: PwM as a vulnerable group in healthcare

Simultaneously, according to the statements of the experts, PwM (regardless of dementia) are identified as a vulnerable group in health-care in all countries except Greece (figure

3.6.1.2). That is because Greece does not define people as vulnerable based on place of birth, but rather on their age and whether they have special needs.



Fig. 3.6.1.3: PwM with dementia as a group with specific needs in healthcare

Concerning PwM with dementia, the picture is different again (figure 3.6.1.3). Based on the expert interviews, there are twice as many countries whose health systems never (Belgium, Ireland, Italy, Romania) or rarely (Greece, UK) treat PwM with dementia and their family members as a group with specific needs than countries whose health systems always (no country) or mostly (Austria, Bulgaria, Finland) do so. Almost half of the countries have a

health system that partly treats PwM with dementia as a group with special needs.

3.6.2 Care

The questions about care of PwM with dementia focused primarily on the availability and suitability of formal care services. Regarding the question about the distribution of care services, a distinction was made between out-patient and inpatient care.

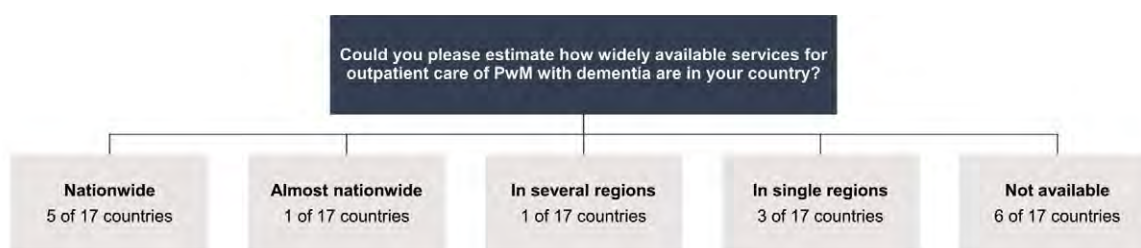


Fig. 3.6.2.1: Availability of outpatient care services for PwM

As seen in figure 3.6.2.1, the expert interviews revealed that just over a third ( $n=6$ ) of the countries have nationwide (Finland, Liechtenstein, Luxembourg, Norway, UK) or almost nationwide (Bulgaria) coverage of specialised services in outpatient care for PwM with dementia. In contrast, more than one-third of the

countries, which include Belgium, Greece, Ireland, Italy, Portugal, and Romania, do not offer such services. In Netherlands, such services can be found in several regions, while in Austria, Denmark, and Germany, they are available in one region only.

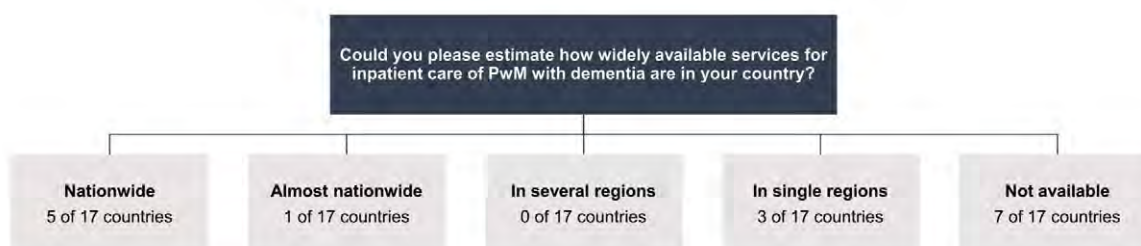


Fig. 3.6.2.2: Availability of inpatient care services for PwM

With regard to inpatient care, the situation is the same as for outpatient care, with two exceptions (see figure 3.6.2.2): 1. In the Netherlands, specialised services in inpatient care for PwM with dementia are only available in a few regions. 2. Denmark, does not offer specialised services in inpatient care for this population. Thus, in terms of inpatient care, the expert interviews show that in 10 of 17 countries, specialised services for PwM with dementia are either only available in individual regions ( $n=3$ ) or not available at all. As in

the case of outpatient care, the experts from Finland, Liechtenstein, Luxembourg, Norway, and the UK also refer to a nationwide availability of inpatient care services for PwM with dementia. The expert from Sweden pointed out for both outpatient and inpatient care, that everyone in Sweden has the same rights to care and support. However, linguistic, cultural, and educational differences, combined with a lack of adaptation of healthcare, result in fewer opportunities for PwM to use existing care structures.



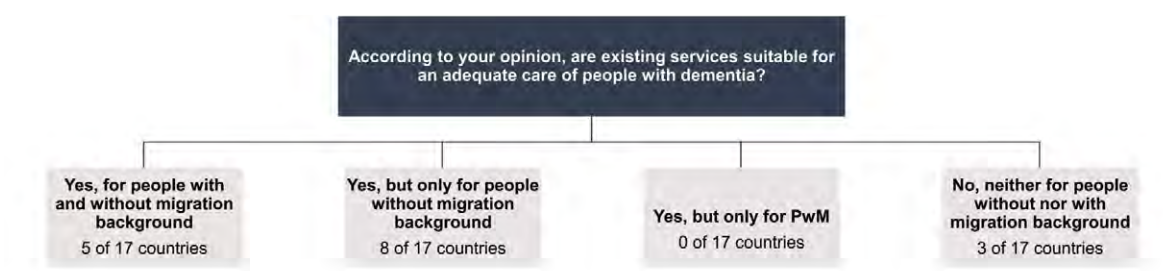


Fig. 3.6.2.3: Suitability of existing services for adequate care of people with dementia

The evaluation of the expert interviews showed that in less than a third of the countries, the existing care services are adequate for people with dementia with and without a migration background. According to the experts interviewed, this is only the case in Austria, Bulgaria, Liechtenstein, Luxembourg, and the Netherlands, with the expert from the Netherlands adding that the existing dementia-specific services are more suitable for non-migrants. Still, the expert from Austria pointed out that the available care services are far from sufficient to meet the current demand. Based on the experts' view, in almost half of the countries (n=8) the existing dementia-specific care services are only suitable for non-migrants, and in three countries (Germany, Ireland, the UK) they are neither adequate for PwM nor for non-mi-

grants. The experts from Portugal mentioned some adequately effective services do exist but not everyone can easily access them.

3.6.3 Inclusion and provision of information to people with a migration background (with dementia)

In this category, the experts were asked about the degree of inclusion of people with dementia, PwM, and PwM with dementia in healthcare. This is the case for instance when these groups participate in the current care structures and services or when they are also actively involved, for example, in the development, evaluation, and enhancement of care services.



Fig. 3.6.3.1: Inclusion of PwM with dementia in healthcare

Figure 3.6.3.1 shows that in the opinion of the experts, in no country PwM with dementia are completely or almost completely included in the healthcare system. In almost two-thirds (n=11) of the countries, this population is either

only slightly (Bulgaria, Italy, Liechtenstein, Norway, Portugal) or not at all (Austria, Belgium, Germany, Greece, Ireland, Romania) included in the healthcare system. In Denmark, Luxembourg, the Netherlands, Sweden, and the UK,

the experts rated the level of inclusion of PwM with dementia as partial. The information about this aspect was not available for Finland.

### 3.6.4 Professional care

In the section, the experts were asked, among

other issues, to assess the proportion of professional caregivers with a migration background in outpatient and inpatient care and whether the need for culturally sensitive care for PwM with dementia is met by sufficiently qualified professionals.

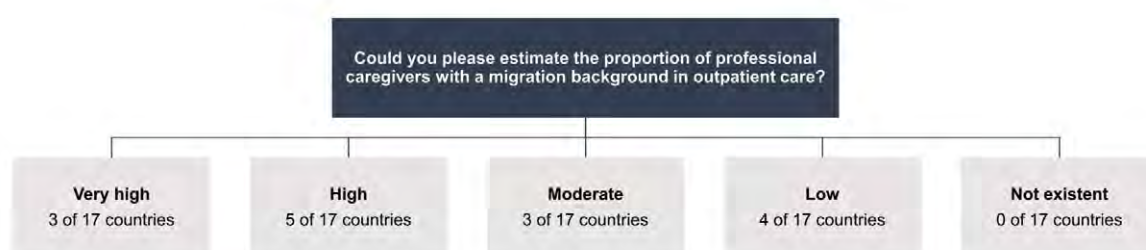


Fig. 3.6.4.1: Proportion of PwM in outpatient care (as healthcare workers)

In terms outpatient care (figure 3.6.4.1), the experts from almost half of the countries (n=8) estimated the proportion of professional caregivers with a migration background as very high (Italy, Liechtenstein, Ireland) or high (Austria, Denmark, Greece, Norway, Sweden). The expert from Italy even described the proportion of migrants in this field as extremely high and estimated that the majority of Italian people with dementia have a professional caregiver with a migration background. Less than a quarter of

the countries (Bulgaria, Luxembourg, Portugal, Romania) have a low proportion of professional caregivers with a migration background in outpatient care, based on the evaluation of the interviews. The experts from Belgium and the UK did not give an answer that could be assigned to one of these categories. These experts reported that the proportion of migrants among care professionals is high in larger cities (e.g. in London and Birmingham) and much lower in rural areas.



Fig. 3.6.4.2: Need for culturally sensitive care in outpatient care

According to the expert interviews, the need for culturally sensitive outpatient care for PwM with dementia is not met by sufficiently quali-

fied professionals, except the Netherlands (figure 3.6.4.2).

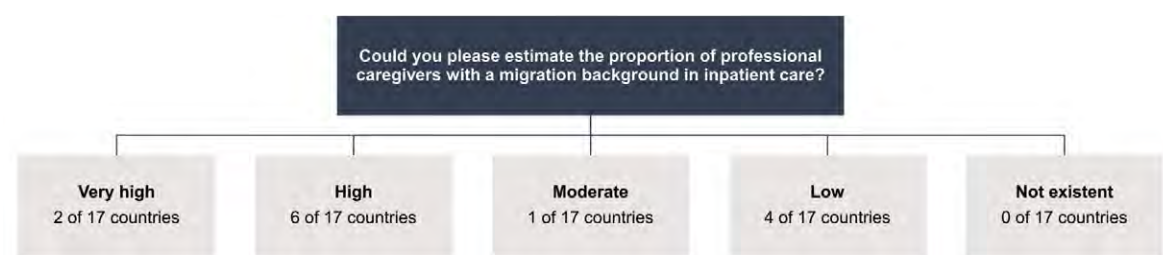


Fig. 3.6.4.3: Proportion of PwM in inpatient care (as healthcare workers)

In terms of inpatient care (figure 3.6.4.3), in almost half (n=8) of the countries considered the proportion of professional caregivers with a migration background is also estimated by the experts to be very high (Ireland and Liechtenstein) or high (Austria, Denmark, Germany, Italy, Norway, Sweden), and low in the same four countries (Bulgaria, Luxembourg, Portugal, Romania) that were mentioned in outpatient care. At the level of the individual countries, however, there are a few minor differences compared to outpatient care. The

expert from Italy, for example, estimates the proportion of migrants in inpatient care not as extremely high, but as high. The situation is reversed in Germany, where the proportion of professional caregivers with a migration background is higher in inpatient care than in outpatient care (moderate). Moreover, the experts from Finland and Greece could not answer this question. The answers of the experts from Belgium and the UK could not be assigned to any of the categories listed, just as in the case of outpatient care.

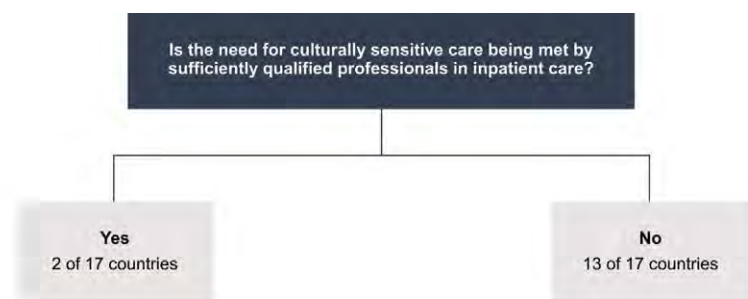


Fig. 3.6.4.4: Need for culturally sensitive care in inpatient care

Based on the interviews, it is observed that, as in outpatient care, there is a lack of sufficiently qualified professionals to provide culturally sensitive inpatient care to PwM with dementia with the Netherlands again being an exception along with Liechtenstein (figure 3.6.4.4). It must be noted that Liechtenstein was lacking in this respect in terms of outpatient care, but was evaluated positively for inpatient care. The experts from Finland and Greece did not answer this question.

3.6.5 Support for family caregivers

The last section of the interviews focused on the important issue of support for family caregivers of PwM with dementia. The experts were asked about the need for specific information and formal support services for family caregivers of PwM with dementia and the current differences in the provision of information and support services for family caregivers of people with dementia with and without a migration background.



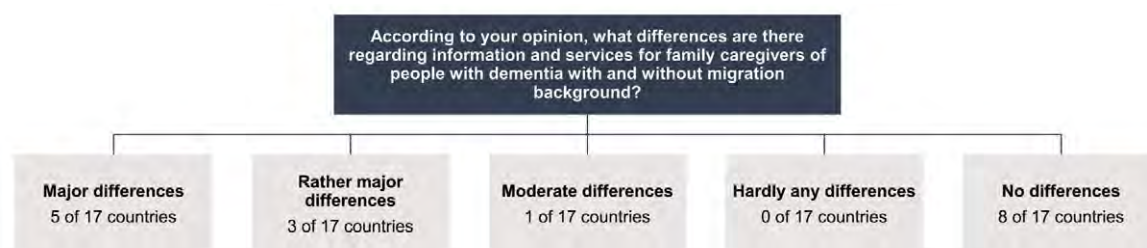


Fig. 3.6.5.1: Differences in information and services for family caregivers

The evaluation of the interviews indicated that in eight countries there are either major (Germany, Greece, Italy, the Netherlands, Portugal) or rather major differences (Norway, Sweden, UK) and in eight of the other nine countries there are no differences in the provision of information and services to family caregivers of people with dementia with and without a migration background. Only for Liechtenstein the differences were estimated as moderate (figure 3.6.5.1). This large variance can be explained primarily by the experts' different interpretations of the question. The experts who stated that there are no differences in their country explained their answer by referring to the existing equal rights to care (Bulgaria) or the equal offer of information or support services (Austria, Denmark, Finland, Ireland,

Luxembourg). The experts from Belgium explicitly pointed out that no differences exist because there are no specialised services for PwM with dementia and their relatives. With the same argumentation, the experts from Greece and Portugal, for example, substantiated their answer that the differences in their country are large. In addition to the lack of specialised services for family caregivers of PwM with dementia, the experts from Norway and Germany also stated that often no culturally sensitive instruments and media channels are used to communicate the multilingual information that is already available in some cases. Overall, almost all experts stated that there are clear differences between PwM and non-migrants in the utilisation of information and support services by family caregivers.

## 3.6.6 Conclusions

The evaluation of the interviews indicated that there is a great lack of attention in society, care policy, and science regarding dementia and migration. According to the experts interviewed, this topic is not declared as important in the healthcare systems of the countries included in this study. As a result, in most countries, the experts identified that either there are no specialised services for PwM with dementia or these services exist only in individual regions. Based on the experts' assessments, in approximately two-thirds of the countries, the currently existing dementia-specific care services are not adequate for the care of PwM with dementia. Furthermore, the existing need for culturally sensitive care is not met by sufficiently qualified professionals in almost all countries. Additionally, the experts stated that family caregivers of PwM with dementia use formal support much

less frequently. Most experts believe that this is due to the absence of specialised services providing support and information to them. This lack of services is particularly problematic as in 14 of the 17 countries there is either a very high need (n=10) or a high need (n=4) for such specialised services, according to the experts. Only the expert from Romania and one of the two experts from Bulgaria estimated the need as low. In addition to these large care gaps, a few examples of good care practice could be identified in this study. In the Netherlands, for example, there are models for culturally sensitive care and inclusion of PwM with dementia in various regions or cities. Besides some challenges, the relatively high proportion of migrants among professionals in outpatient and inpatient care in many European countries offers also great potential concerning the future care of PwM with dementia.

# 3.7

## Country Profiles







# Austria

**Population**

8,901,000

**Area**

83,882 km<sup>2</sup>

**Capital**

Vienna

**3 largest cities**

Vienna (1,897,000)

Graz (289,000)

Linz (206,000)

**Neighboring countries**

The Czech Republic,  
Germany, Hungary,  
Italy, Liechtenstein,  
Slovakia, Slovenia,  
Switzerland

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References

## 1. Migration history

Austria has a long history of migration, characterised by waves of emigration of smaller population groups, but mainly by immigration and transit migration [1]. For example, more than half of the increase in Vienna's population between the end of the 18th century and 1916 (from 235,000 to 2,239,000) was due to international migration [2]. From 1919 to 1937, more than 80,000 people from Austria emigrated overseas and many more to Palestine, Germany, and the Soviet Union. As a result of Nazi annexation, 128,000 Jews had to leave Austria between 1938 and 1941, and 64,500 Jews had been murdered by 1945 [1]. During the Second World War, about one million slave labourers (1944) worked on Austrian territory [3]. Immediately after the war, about 1.4 million foreigners were living in Austria. These included more than half a million so-called 'displaced persons' (war refugees, former concentration camp prisoners, forced labourers, prisoners of war) and more than 300,000 German-speaking expellees, so-called "Volksdeutsche" (ethnic Germans) from Central and Eastern Europe. Most of them left the country in the following years [2]. After the Second World War, Austria became one of the most important transit countries for refugees from Eastern Europe. Between 1945 and 1990 about 650,000 people (mainly from Hungary, Czechoslovakia, and Poland) migrated to the West via Austria [2, 3]. At the same time, about 20,000 people from Hungary (1956/1957), 12,000 from the Czech Republic and Slovakia (1968), and a few thousand from Poland (1981/1982) settled permanently in Austria. As a result of bilateral labour recruitment agreements, about 265,000 guest

workers immigrated to Austria between 1961 and 1974, most of them from Yugoslavia and Turkey (in 1973, 78.5% of guest workers were from Yugoslavia and 11.8% were from Turkey). In 1974, the Austrian government decided to stop the recruitment of guest workers and to adopt a restrictive policy. This led to a 40% decline in the number of foreign workers between 1974 and 1984. At the same time, many guest workers extended their stay and family reunification compensated the decline in labour migration. The coup d'état in Romania at the turn of the year 1989/1990 and the armed conflicts in Croatia, Bosnia-Herzegovina, and Kosovo between 1991 and 1999 resulted in larger flows of refugees to Austria. After the accession of Bulgaria and Romania to the EU in 2007, the number of immigrants from these countries increased [2]. Immigration to Austria reached its peak with approximately 110,000 people during the wave of large-scale migration of refugees in 2015 [3]. The biggest migrant groups in Austria according to the country of birth are people from Germany (232,200), Bosnia and Herzegovina (168,500), Turkey (159,700), Serbia (143,200), and Romania (121,100) (as of 01.01.2019) [4]. The migrant population (born abroad, 793,200 to 1.8 million) and its proportion in the total population (10.3 to 19.9%) roughly doubled between 1990 and 2019 [5]. Austria has also had a positive net migration rate (the difference between the number of persons immigrating and emigrating per year, per 1,000 persons) for decades and an increasing annual rate for some years (2020: 7.4) [6]

## 2. Estimated number of people with a migration background with dementia

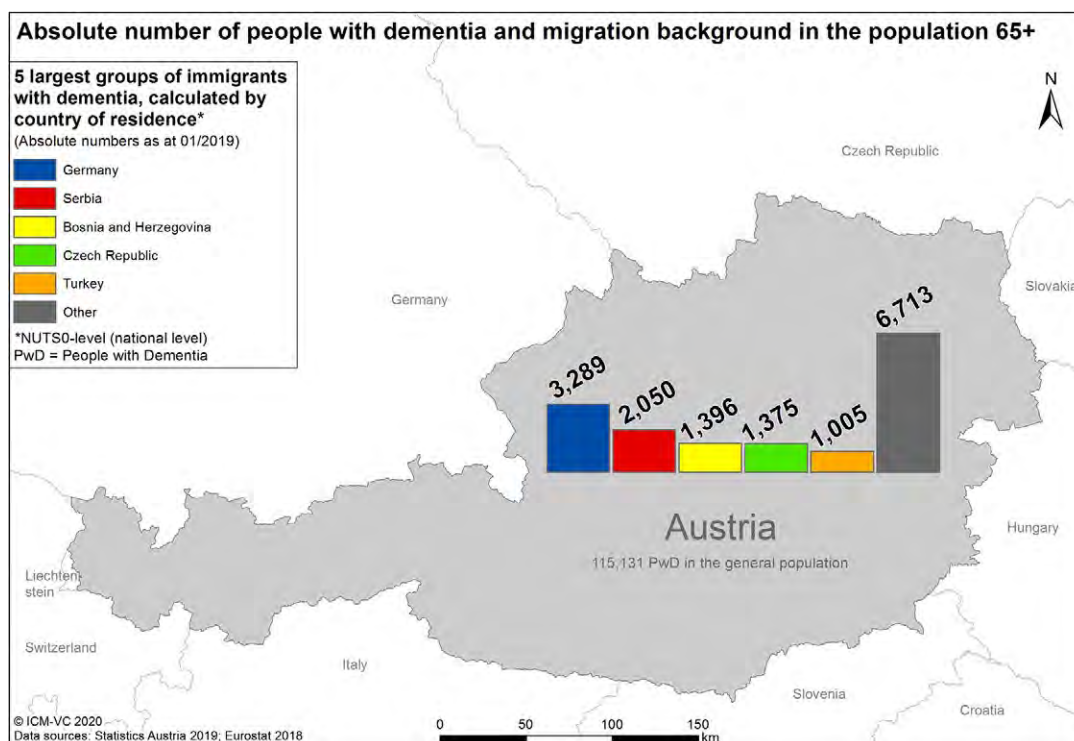


Fig. 3.7.1.1: Absolute number of PwM with dementia aged 65+ (Austria – Nation)

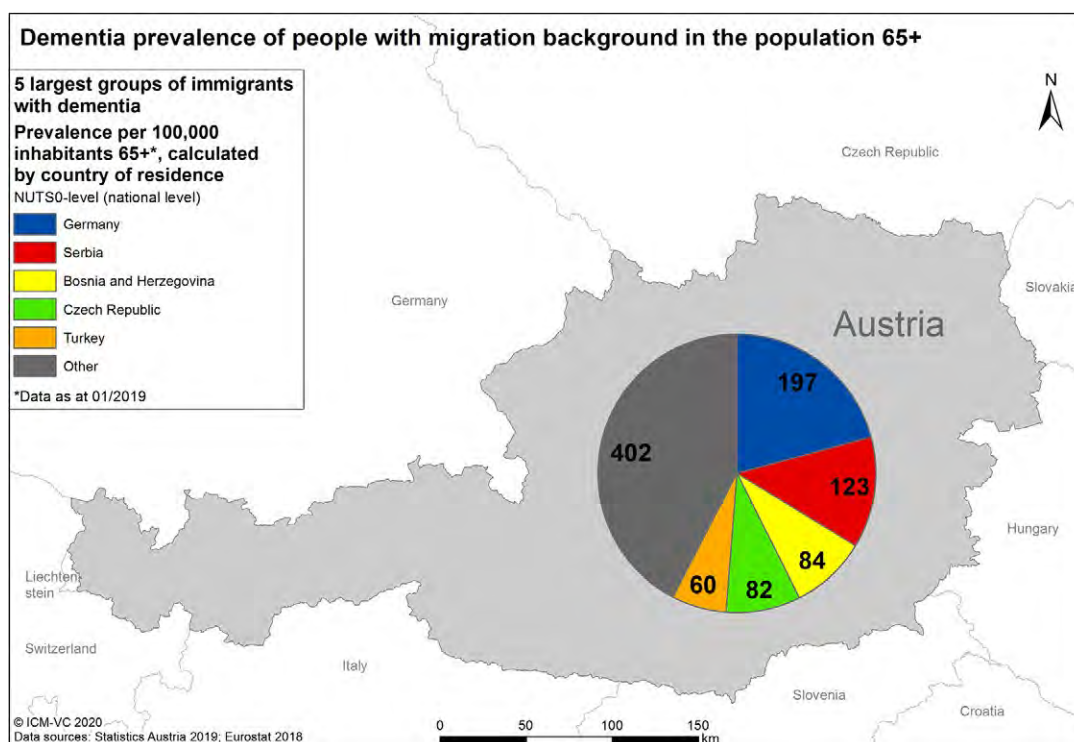


Fig. 3.7.1.2: Prevalence of PwM with dementia among the population aged 65+ (Austria – Nation)

**Tab. 5: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Austria – Nation)**

NUTS	Total	AT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Austria	115,131	99,302	DE 3,288	XS 2,050	BA 1,396	CZ 1,374	TR 1,005	6,713
Prevalence/10,000 inhabitants with migration background 65+								
Austria	5,019	-	DE 143	XS 89	BA 61	CZ 60	TR 44	293
Prevalence/100,000 inhabitants 65+								
Austria	6,900	5,951	DE 197	XS 123	BA 84	CZ 82	TR 60	402

Data source: Statistics Austria (2019)

There are 229,400 PwM aged 65 or older. Of those, approx. 15,800 are estimated to exhibit some form of dementia. Figure 3.7.1.1 shows the most affected migrant groups presumably originate from Germany (approx. 3,300), Serbia (approx. 2,100), Bosnia and Herzegovina (approx. 1,400), the Czech Republic (approx. 1,400) and Turkey (approx. 1,000). The second graph highlights the number of PwM with de-

mentia in Austria per 100,000 inhabitants aged 65 or older (figure 3.7.1.2). Table 5 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Germany, Serbia, Bosnia and Herzegovina, the Czech Republic, and Turkey throughout the country in the NUTS2 regions (figures 3.7.1.3 – 3.7.1.7.8).



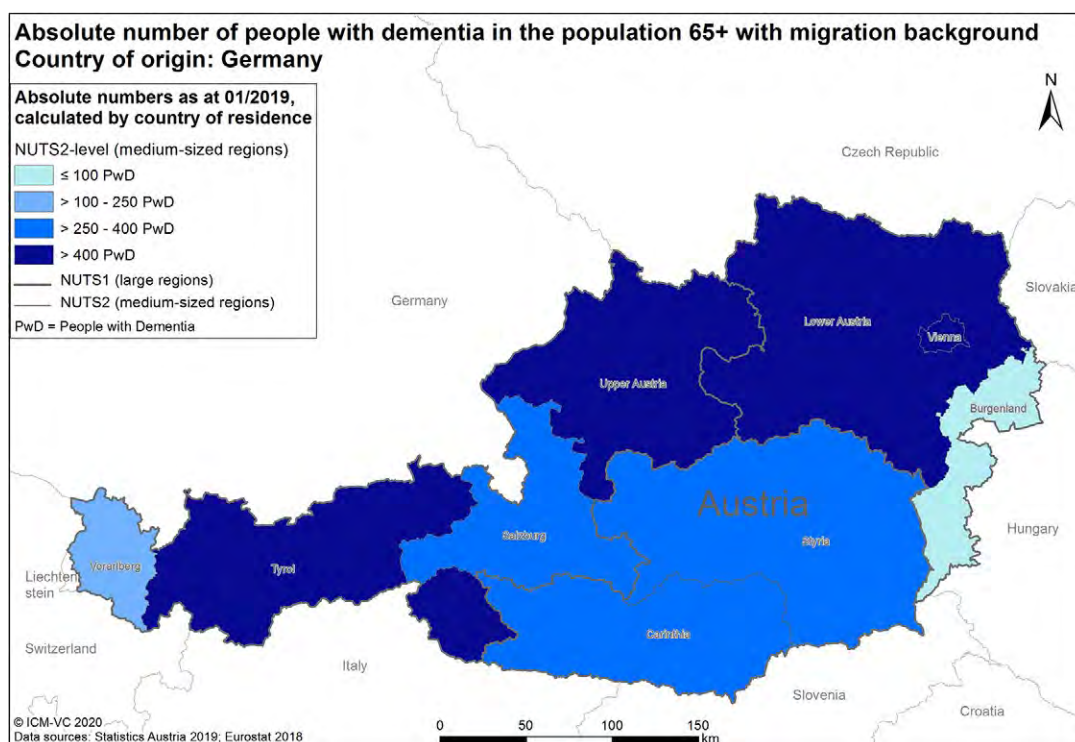


Fig. 3.7.1.3: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Germany (Austria – NUTS2)

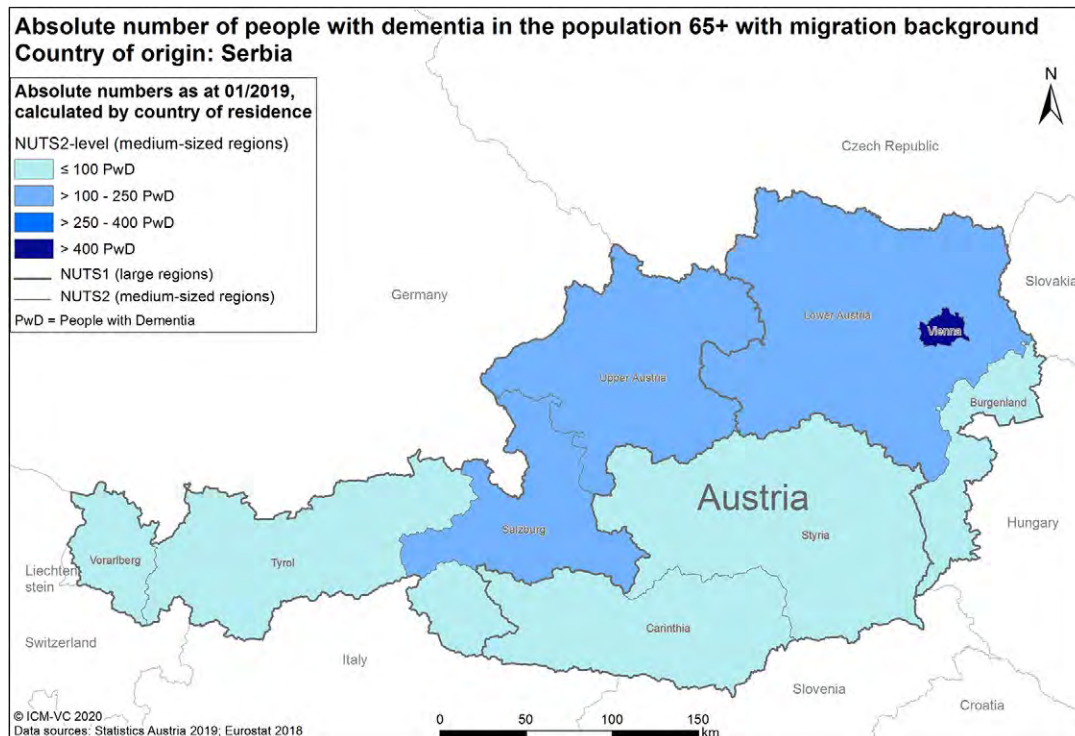


Fig. 3.7.1.4: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Serbia (Austria – NUTS2)

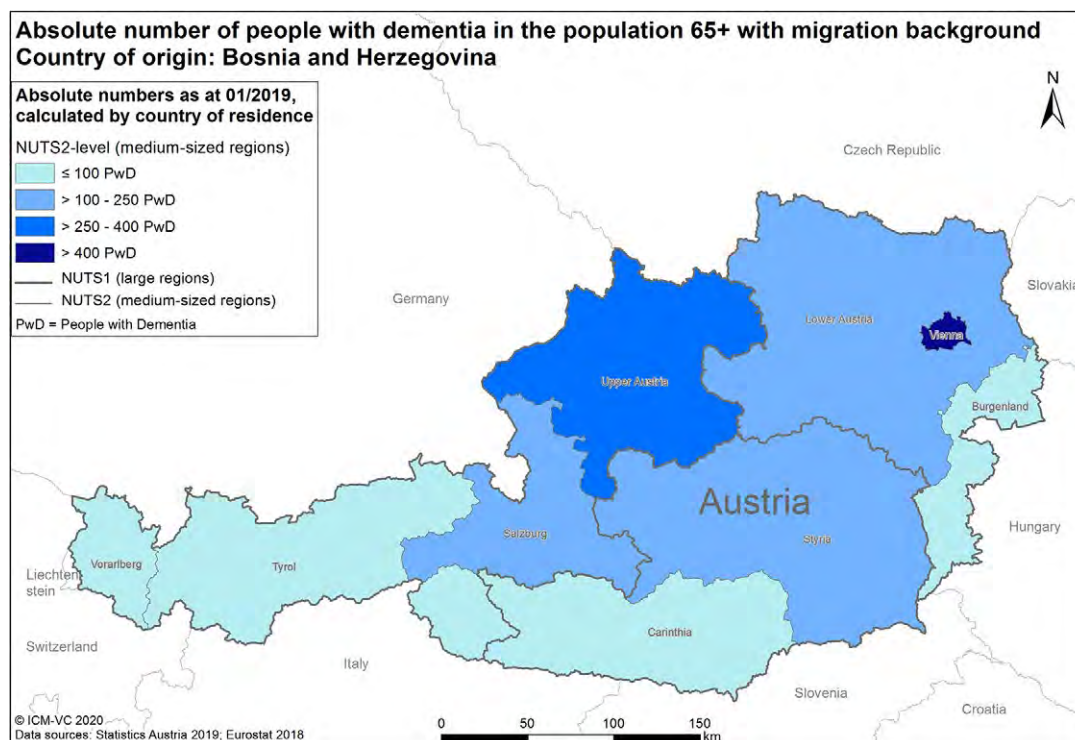


Fig. 3.7.1.5: Absolute number of PwM with dementia aged 65+. Country of origin: Bosnia and Herzegovina (Austria – NUTS2)

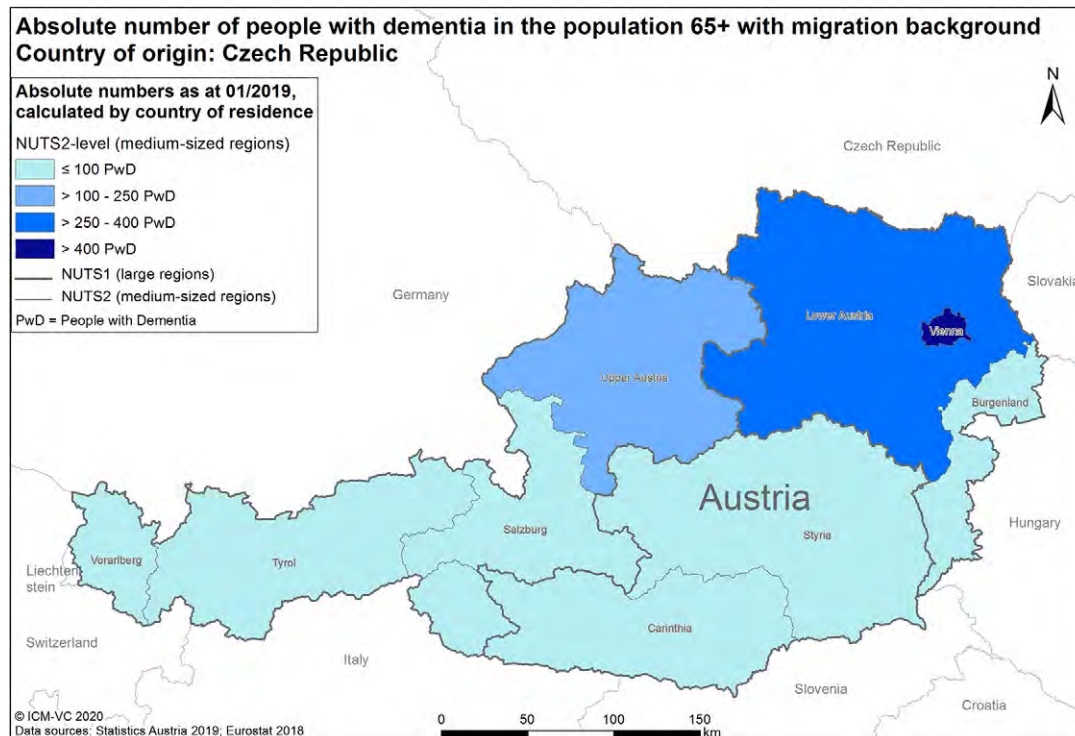


Fig. 3.7.1.6: Absolute number of PwM with dementia aged 65+. Country of origin: The Czech Republic (Austria – NUTS2)

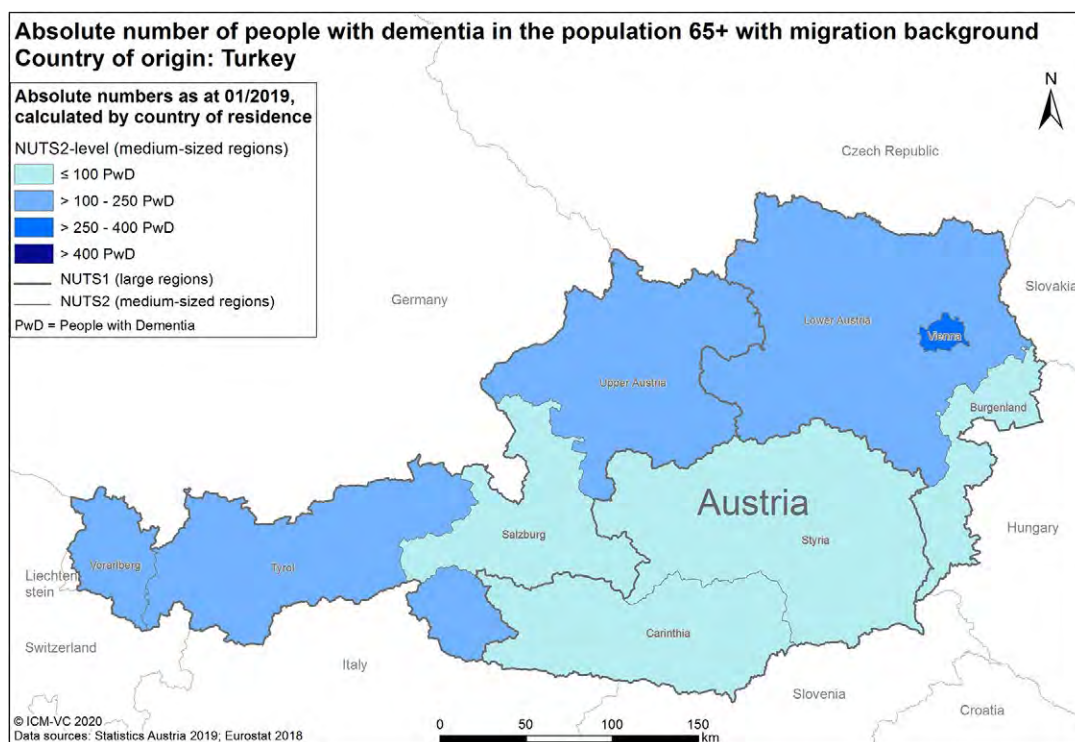


Fig. 3.7.1.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Turkey (Austria – NUTS2)

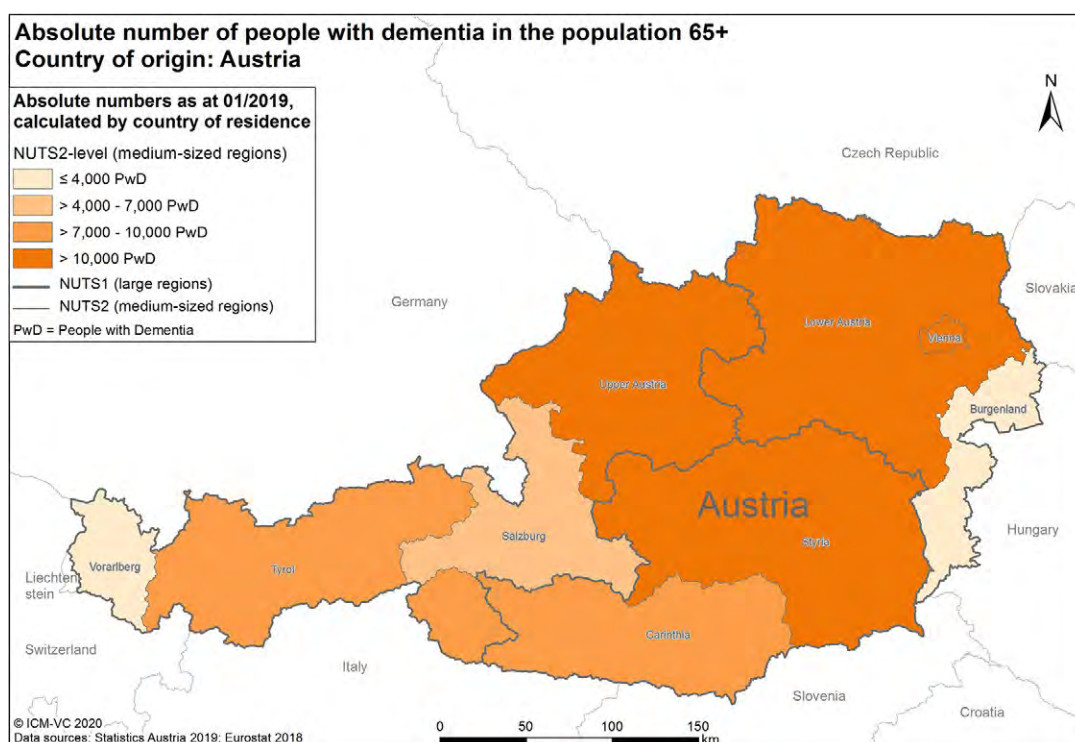


Fig. 3.7.1.8: Absolute number of people with dementia aged 65+.  
Country of origin: Austria (Austria – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.1.9). The sec-

ond graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions. (figure 3.7.1.10). The values from the NUTS2 level can be found in table 6 [7, 8].

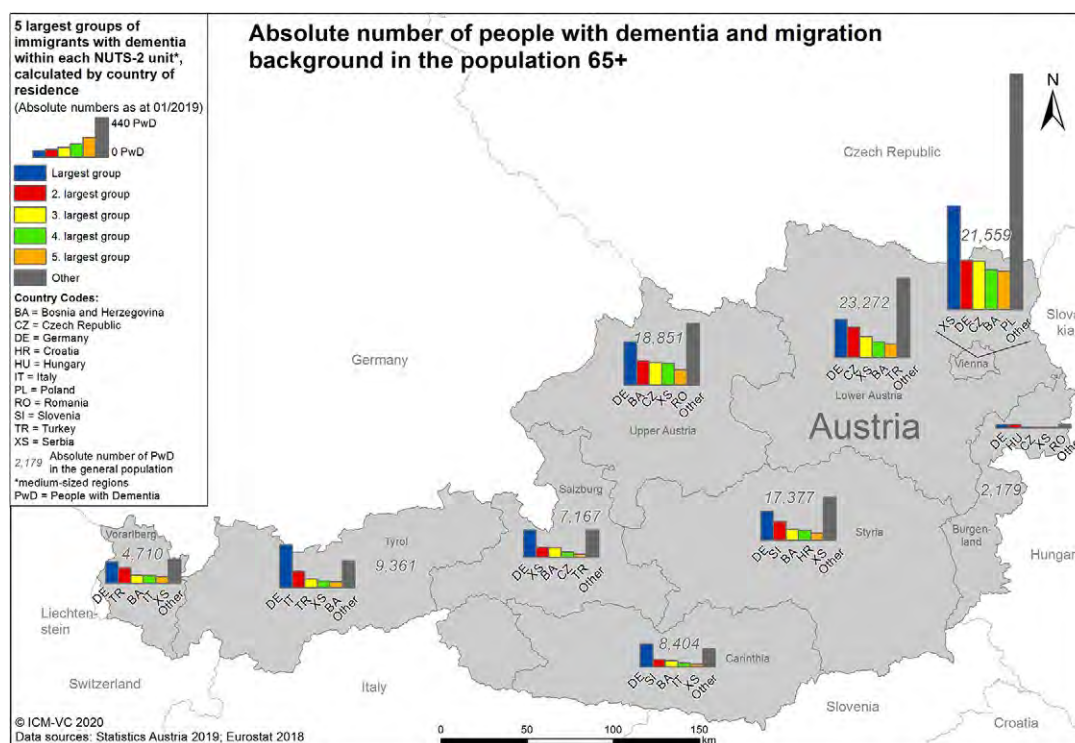


Fig. 3.7.1.9: Absolute number of PwM with dementia aged 65+ (Austria – NUTS2)

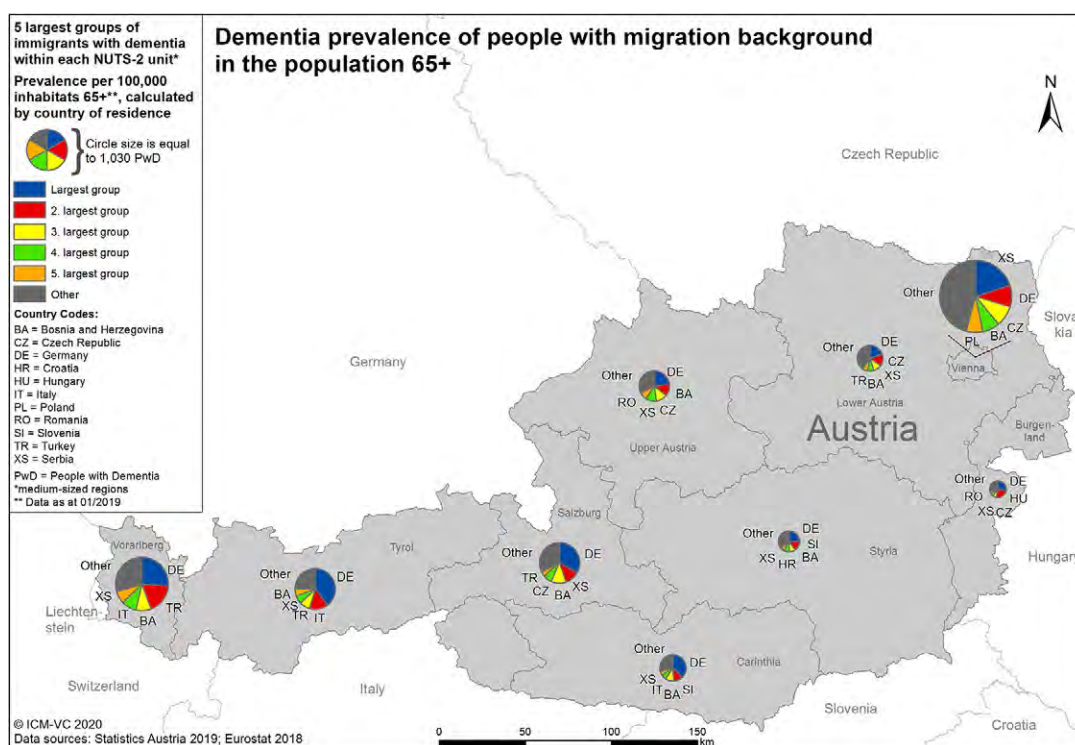


Fig. 3.7.1.10: Prevalence of PwM with dementia among the population aged 65+ (Austria – NUTS2)

**Tab. 6: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Austria – NUTS 2)**

NUTS	Total	AT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Burgenland	2,179	2,042	DE 38	HU 35	CZ 10	XS 8	RO 7	39
Lower Austria	23,272	21,085	DE 420	CZ 334	XS 233	BA 172	TR 151	877
Vienna	21,559	15,832	XS 1,150	DE 547	CZ 538	BA 443	PL 426	2,623
Carinthia	8,404	7,593	DE 302	SI 96	BA 84	IT 54	XS 38	237
Styria	17,377	16,040	DE 329	SI 210	BA 121	HR 115	XS 78	484
Upper Austria	18,851	16,771	DE 477	BA 268	CZ 249	XS 242	RO 169	675
Salzburg	7,167	6,101	DE 351	XS 127	BA 126	CZ 71	TR 42	349
Tyrol	9,361	7,964	DE 551	IT 212	TR 117	XS 92	BA 81	344

NUTS	Total	AT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Vorarlberg	4,710	3,807	DE 233	TR 166	BA 85	IT 82	XS 70	267
Prevalence/10,000 inhabitants with migration background 65+								
Burgenland	10,903	-	DE 189	HU 175	CZ 52	XS 41	RO 33	200
Lower Austria	7,342	-	DE 133	CZ 105	XS 74	BA 54	TR 48	276
Vienna	2,597	-	XS 138	DE 66	CZ 65	BA 53	PL 51	317
Carinthia	7,155	-	DE 257	SI 82	BA 71	IT 46	XS 32	202
Styria	8,968	-	DE 170	SI 108	BA 62	HR 59	XS 40	251
Upper Austria	6,253	-	DE 158	BA 89	CZ 83	XS 80	RO 56	224
Salzburg	4,639	-	DE 272	XS 82	BA 81	CZ 46	TR 27	182
Tyrol	4,622	-	DE 272	IT 105	TR 58	XS 46	BA 40	169
Vorarlberg	3,600	-	DE 178	TR 127	BA 65	IT 63	XS 54	203
Prevalence/100,000 inhabitants 65+								
Burgenland	6,900	6,463	DE 120	HU 111	CZ 33	XS 26	RO 21	126
Lower Austria	6,900	6,252	DE 125	CZ 99	XS 69	BA 51	TR 45	259
Vienna	6,900	5,067	XS 368	DE 175	CZ 172	BA 142	PL 136	840
Carinthia	6,900	6,235	DE 248	SI 79	BA 69	IT 44	XS 31	194
Styria	6,900	6,369	DE 131	SI 83	BA 48	HR 46	XS 31	192
Upper Austria	6,900	6,139	DE 174	BA 98	CZ 91	XS 88	RO 62	248
Salzburg	6,900	5,874	DE 338	XS 122	BA 121	CZ 69	TR 40	336
Tyrol	6,900	5,870	DE 406	IT 156	TR 86	XS 68	BA 60	254
Vorarlberg	6,900	5,577	DE 341	TR 244	BA 124	IT 121	XS 103	390

Data source: Statistics Austria (2019)



### 3. National dementia plan

For Austria, two national documents that support care planners and care providers in developing strategies and action plans to improve the living and care situation of people with dementia and their relatives were found. The first document of this type, the 'Austrian Dementia Report 2014', was published in January 2015. This document has a separate chapter on migrants with dementia. It comprises four pages and points to the problems of late diagnosis and the lower utilisation of care services, especially by migrants from Turkey. In this chapter, reference is made to various international studies on the situation of dementia patients with a migration background and, in a separate section, to a national study on the care of migrants with dementia from Turkey (Barkhordarian 2013). The report points to major gaps in information on dementia and migration. For example, it says that no definitive statements can be made about the number of PwM with dementia and on their care situation in Austria. Moreover, it also discusses the evident lack of migrant-specific healthcare services, especially with regard to dementia prevention. In general, there seem to be both qualified dementia experts and qualified migration experts, but there is a lack of cooperation, exchange, and networking between these two groups. Dementia experts seem to know little about the needs of migrants suffering from dementia and their family carers, and conversely, migration experts and family carers seem to lack information on suitable prevention or healthcare services. The gaps in information and knowledge and the lack of migrant-specific prevention services, together with the use of dementia diagnostic tools that are not suitable for migrants, and language barriers are cited as reasons why migrants with dementia are often diagnosed later than non-migrants. Results of the national study on the care of migrants from Turkey with de-

mentia mentioned above indicate that PwM with dementia from Turkey rarely make use of formal care services and that their family caregivers hardly use any support services. Cultural and religious factors are mentioned as central causes for this tendency. Healthcare providers are encouraged in this report to pay special attention to the needs of PwM with dementia. Specific needs may arise inter alia from taboo and fear of stigmatisation within the community, as well as previous traumatic experiences associated with migration history, which can again become a problem in the case of dementia. To better address the needs of migrants, native speakers with intercultural experience should be employed, caregivers trained, and staff in migrant counselling centres made aware of available services. For the families of PwM with dementia, information and support structures tailored to their needs must be created. In the context of the problem of standardised dementia diagnostic procedures that are inappropriate for migrants, the 'Austrian Dementia Report 2014' also refers to the screening instrument Transkulturelles Assessment mentaler Leistungen (=Transcultural Assessment of Mental Performance) (TRAKULA) developed at the University of Cologne for the detection of cognitive disorders in PwM, which has been in the testing process since 2008 (status: 2015) [9].

The second document was also published in 2015 and is entitled 'Dementia Strategy – Living Well With Dementia'. This Austrian dementia strategy contains seven impact goals and 21 recommendations for action. However, none of these goals and recommendations directly relate to migration. The document only refers to migration in two passages using different terms. First, in the section on the 'Principles for the development of impact goals and recommendations for action' at the beginning of the dementia strategy, it is stated



that in the context of identifying the needs of people with dementia and their relatives, the inequalities regarding the access of minorities and PwM to support services must be taken into account. Second, an indirect reference to migration is made within the framework of the recommendation for action for low-threshold information services, that suggests conduct-

ing multilingual information dissemination events. Overall, migration is treated as a very minor topic 'Dementia Strategy – Living Well With dementia', in contrast to the 'Austrian Dementia Report 2014'. The two recommended actions that may be relevant for PwM are set in brackets and therefore appear optional [10].

## 4. National dementia care and treatment guidelines

The 'Medical Guidelines for the Integrated Care of Dementia Patients' from 2011 only refers in two sentences within one chapter to a subject area that is relevant for migration. The topic of migration is briefly touched upon without explicitly addressing it. It is pointed out that neuropsychological tests for the differential diagnostic clarification of questionable or mild dementia must consider the socio-cultural background and language skills of a person. In addition, reference is made to the Mini-Cog screening test as a simple test procedure for the early detection of dementia, whose validity is not affected by linguistic and cultural differences. However, it is not pointed out that a migration background or another cultural or linguistic background can be a factor for an uncertain diagnosis and that standardised screening tests or common neuropsychological test procedures may not be suitable for these groups. Screening tests such as the

MMSE or clock test are listed, without referring to problems of use with cultural or linguistic minorities. In subsequent chapters, no reference is made to problems related to dementia diagnosis or care for migrants/ethnic minorities [11]. On behalf of the Federal Ministry of Health, the scientific report 'Non-Drug Prevention and Therapy for Mild and Moderate Alzheimer's Dementia and Mixed Dementia' was published in 2015. However, this 241-page report does not refer to the topic of migration at any point [12].

The following parts on services and information for PwM with dementia, professional care, and support for family caregivers are based on an interview with an expert and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy with results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

Although the topic of dementia and migration is considered very important by healthcare professionals and health experts, there currently seems to be no significant care structure. However, sufficient multilingual information material on dementia (for example in inpatient facilities) is available. In addition, there are insti-

tutions such as the Vienna-based joint venture Terra, which provides multilingual counselling, support, and mediation services for migrants in areas such as health and social welfare [13]. According to the expert, there are only a few specialised services for PwM with dementia in Austria. With regard to both inpatient and out-



patient care, models of good practice seem to exist only in individual regions, such as the transcultural outpatient clinic at the AKH (General Hospital) in Vienna. Concerning specialised services for PwM with dementia, the expert could not name such models of good practice. Since the demand is higher than the supply, the expert mentioned insufficient provision as a problem. Moreover, according to the expert, Austria has nationwide standards for inpatient care regarding the consideration of religion-based food needs (e.g. preparing dishes without pork), culture-specific needs during family visits (e.g. setting up visitor rooms for extended families), and language needs (e.g. initiating a video interpreting service at the federal level and incorporating language-support provisions such as professional interpreters and multi-lingual brochures into inpatient facilities). In terms of care for PwM with dementia,

there is apparently no uniform strategy at the political or national level. How a person from this population is cared for depends on the individual care provider in the respective region. These care providers probably have different care models. One approach that is widely used and that is also part of the education of healthcare professionals is the model of validation. This means that people with dementia are being heard, accepted, and respected. In doing that healthcare professionals then might try to accommodate the persons and their needs. In the opinion of the expert, PwM with dementia are not receiving adequate care not only due to a lack of services, but also because they rarely (or never) proactively utilise the existing services. In Styria, for example, there is a gerontological psychiatric service that offers state-sponsored home visits, but is not used by PwM.

## 6. Professional qualification and people with a migration background in healthcare

Although there are dedicated courses on culturally sensitive care for doctors and nursing staff, culturally sensitive care does not exist as a compulsory module within a traditional medical study or nursing education according to the expert. At the level of medical and nursing academies, there are professional training and further education opportunities in intercultural care, but these are also optional courses that are offered mostly in urban areas. In rural areas, there are only a few such training courses. An interesting characteristic of the Austrian healthcare system is the relatively high proportion of PwM among the labour force in this sector. According to the expert, the proportion of migrants (in both inpatient and outpatient care) among caregivers is at least 14 to 15%. The expert pointed out that in the sector of 24-hour care, only PwM are employed. On the

basis of a change in the law introduced in the years 2006 to 2008, PwM can come to Austria as so-called free self-employed persons for a 4-week period and care for a patient at home in 24-hour care. These people are mainly women from Romania, Bulgaria, and Croatia. In general, many caregivers with a migration background originate from former Yugoslavia (for example Croatia) and border regions such as Hungary and Slovakia. The healthcare system and care providers try to use this diversity potential to meet the needs resulting from the diversity of patients and to overcome the existing language barriers between people from certain migrant groups and healthcare providers. There are currently no nationwide interpreting services in Austria, but most hospitals have language lists in which professional caregivers with different mother tongues are listed.

They are contacted and hired as needed, but there are currently no set rules or training requirements imposed on these interpreting services, which leads to various problems. Overall, the expert states that the need for cul-

turally sensitive care is not met by sufficiently qualified professionals and cites the lack of a systematic approach and the absence of a nationwide emphasis on diversity management education as the central cause.

## 7. Support for family caregivers

According to the expert, family caregivers of PwM with dementia receive the same information material (in the respective mother tongue) as non-migrant family caregivers without a migration background. There is also no significant difference in the provision of other support services. However, a huge difference can be identified in the utilisation of these services as PwM tend to use the services scarcely. For instance, structurally it is possible to be insured as a caring relative in Austria. This provides the legal opportunity to be a professional family caregiver. Recognised family caregivers receive a salary and are entitled to vacation and paid rehabilitation. In principle, this structure is available to regular migrants who are part of the welfare state. Multilingual information material about it is also available. However, this opportunity is also much less used by PwM. A central and huge barrier is the bureaucratic apparatus. To receive such support services,

various forms must be filled out. PwM are very often afraid of the bureaucracy and such forms. They are afraid that they will not receive assistance or will receive it very late if they fill in a form incorrectly. As a result, a large part of the services provided by organisations such as Terra to support migrants consists of filling in forms to help them apply for care allowance or support.

While the utilisation of support services by family caregivers of PwM with dementia is very low, partly due to bureaucratic and language barriers, the expert estimated the need for specialised services and information for this population as very high and very diverse. Apart from having to cope with the responsibility of being a family caregiver, which is extremely demanding even for a person without a migration background, there are specific problems, burdens, and care barriers that family caregivers of PwM with dementia are exposed to.

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# Belgium

**Population**

11,550,000

**Area**

30,528 km<sup>2</sup>

**Capital**

Brussel

**3 largest cities**

Antwerp (529,000)

Ghent (264,000)

Charleroi (203,000)

**Neighboring countries**

France, Germany,  
Luxembourg,  
the Netherlands

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Belgium was an emigration country in the past. Between 1830 and 1914, a large part of the population emigrated due to poor working conditions and economic circumstances. During the two world wars, about two million people fled the country. The history of immigration began during the First World War when people from neighbouring countries, Eastern Europe, and Italy searched for work in Belgium. In the interwar years, migration increased significantly as a result of government recruitment campaigns for the prospering coal industry. In 1930, the Belgian mining industry employed approximately 30,000 foreign workers. After an agreement with Italy, 110,000 workers arrived between 1946 and 1956 from Italy. Subsequently, Belgium concluded bilateral recruitment agreements with countries such as Spain (1956), Morocco (1964), and Turkey (1964). In the late 1960s and early 1970s, Belgium then attempted to limit immigration

through strict guidelines. However, this led to the situation wherein people who had already immigrated from non-European countries stayed permanently. In addition, refugees from conflict areas, foreign students, and migrants from the new EU member states took the place of migrant workers. Overall, immigration figures continued to rise until 2011. After a brief decline in migration as a result of a more restrictive immigration policy towards non-EU foreigners, the figures increased again from 2015 onwards. In 2017, migrants from Morocco were the largest migrant group with 215,000 people, followed by France (185,000), the Netherlands (130,000), and Turkey (98,000) [1]. Between 1990 and 2019, the migrant population (born abroad) increased from 1.3 to 2 million people and the migrant proportion in the total population rose from 12.8 to 17.2% [2]. The net migration rate has always been positive and as of 2020 amounts to 4.2 [3].



## 2. Estimated number of people with a migration background with dementia

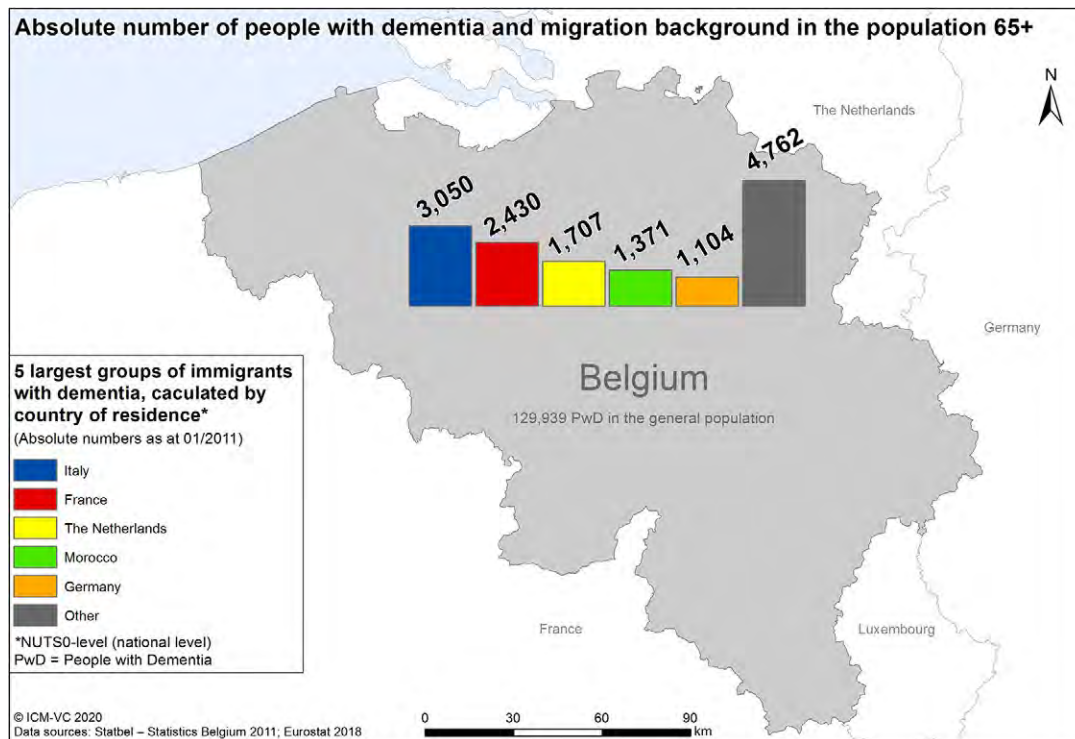


Fig. 3.7.2.1: Absolute number of PwM with dementia aged 65+ (Belgium – Nation)

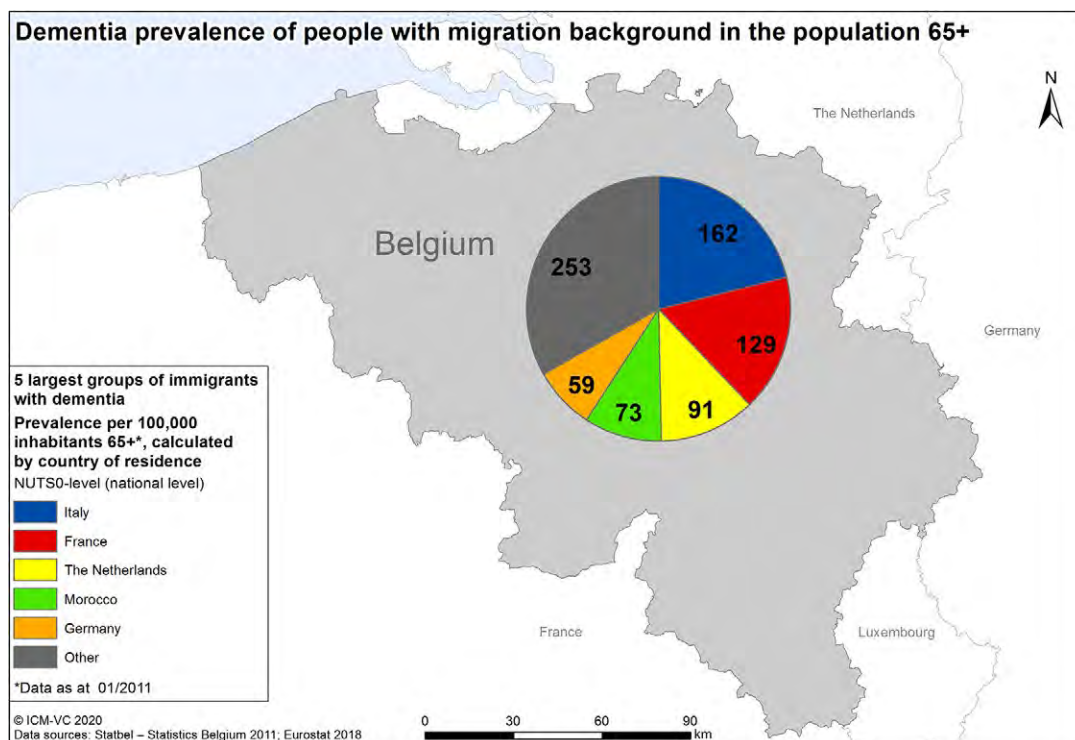


Fig. 3.7.2.2: Prevalence of PwM with dementia among the population aged 65+ (Belgium – Nation)



**Tab. 7: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Belgium – Nation)**

NUTS	Total	AT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Belgium	129,939	115,517	IT 3,050	FR 2,430	NL 1,707	MA 1,371	DE 1,104	4,762
Prevalence/10,000 inhabitants with migration background 65+								
Belgium	6,217	-	IT 146	FR 116	NL 82	MA 66	DE 53	227
Prevalence/100,000 inhabitants 65+								
Belgium	6,900	6,134	IT 162	FR 129	NL 91	MA 73	DE 59	253

Data Source: Statistics Belgium (2011)

There are 209,000 PwM aged 65 or older. Of those, approx. 14,400 are estimated to exhibit some form of dementia. Figure 3.7.2.1 shows the most affected migrant groups presumably originate from Italy (approx. 3,100), France (approx. 2,400), the Netherlands (approx. 1,700), Morocco (approx. 1,400), and Germany (approx. 1,100) (Fig. 3.7.2.1). The second graph highlights the number of PwM with dementia

in Belgium per 100,000 inhabitants aged 65 or older (figure 3.7.2.2). Table 7 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants and PwM with dementia from Italy, France, the Netherlands, Morocco, and Germany throughout the country in the NUTS2 regions (figures 3.7.2.3 – 3.7.2.8).

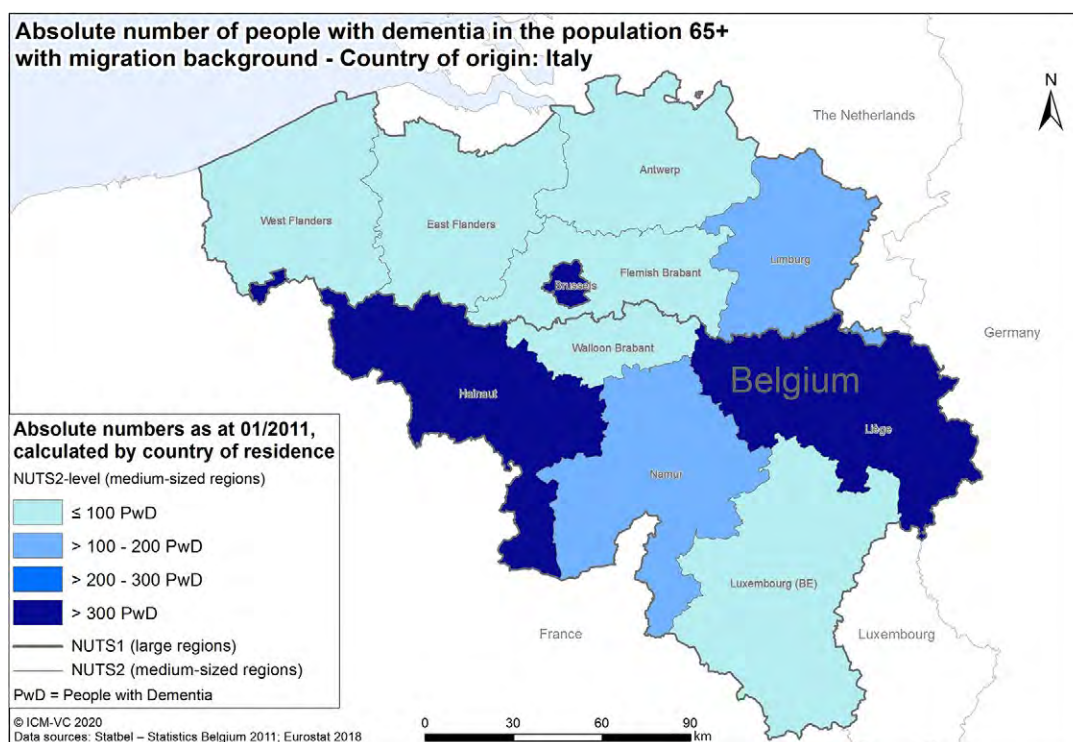


Fig. 3.7.2.3: Absolute number of PwM with dementia aged 65+. Country of origin: Italy (Belgium – NUTS2)

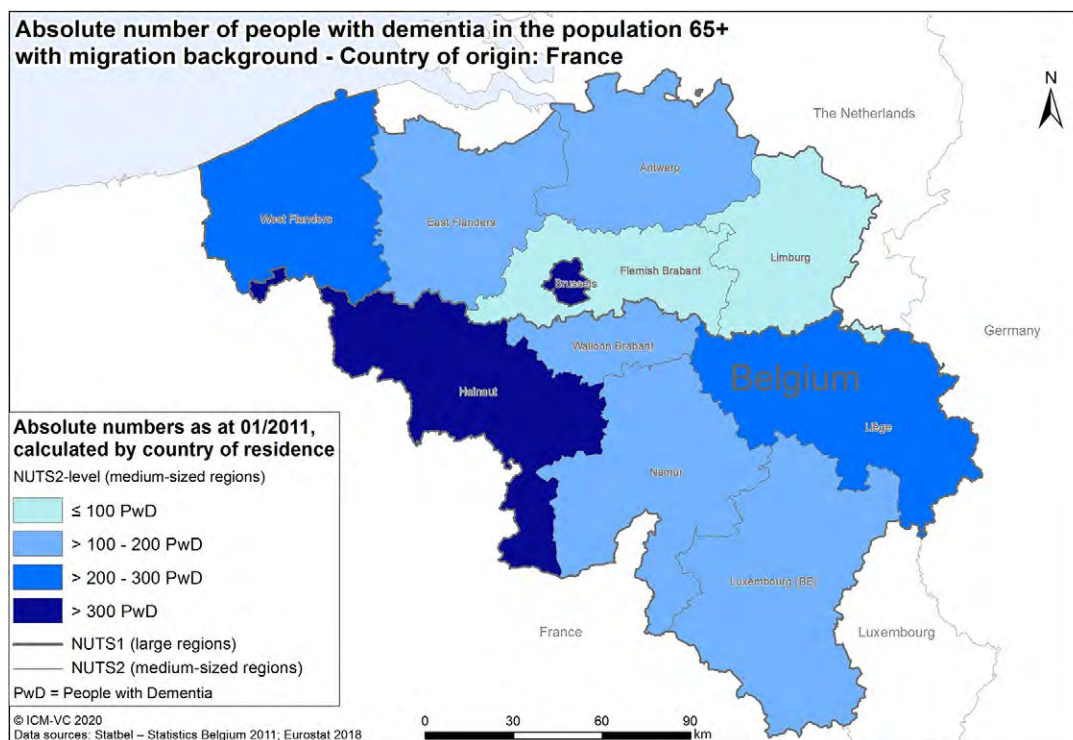


Fig. 3.7.2.4: Absolute number of PwM with dementia aged 65+. Country of origin: France (Belgium – NUTS 2)

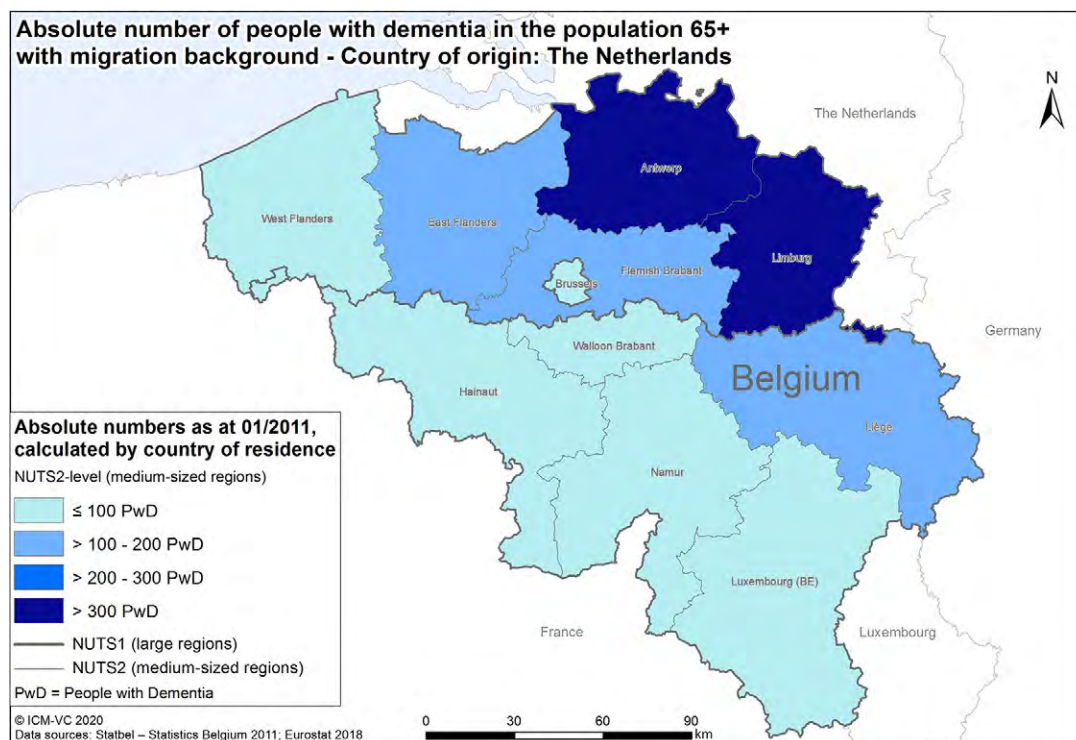


Fig. 3.7.2.5: Absolute number of PwM with dementia aged 65+. Country of origin: The Netherlands (Belgium – NUTS2)

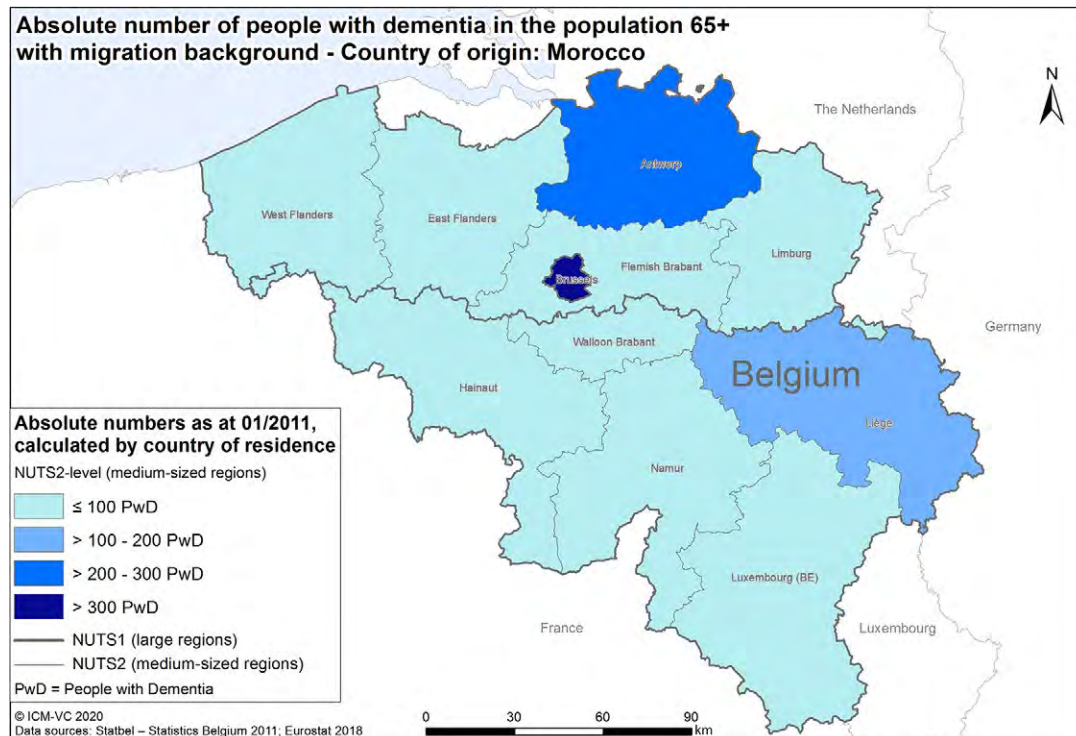


Fig. 3.7.2.6: Absolute number of PwM with dementia aged 65+. Country of origin: Morocco (Belgium – NUTS2)



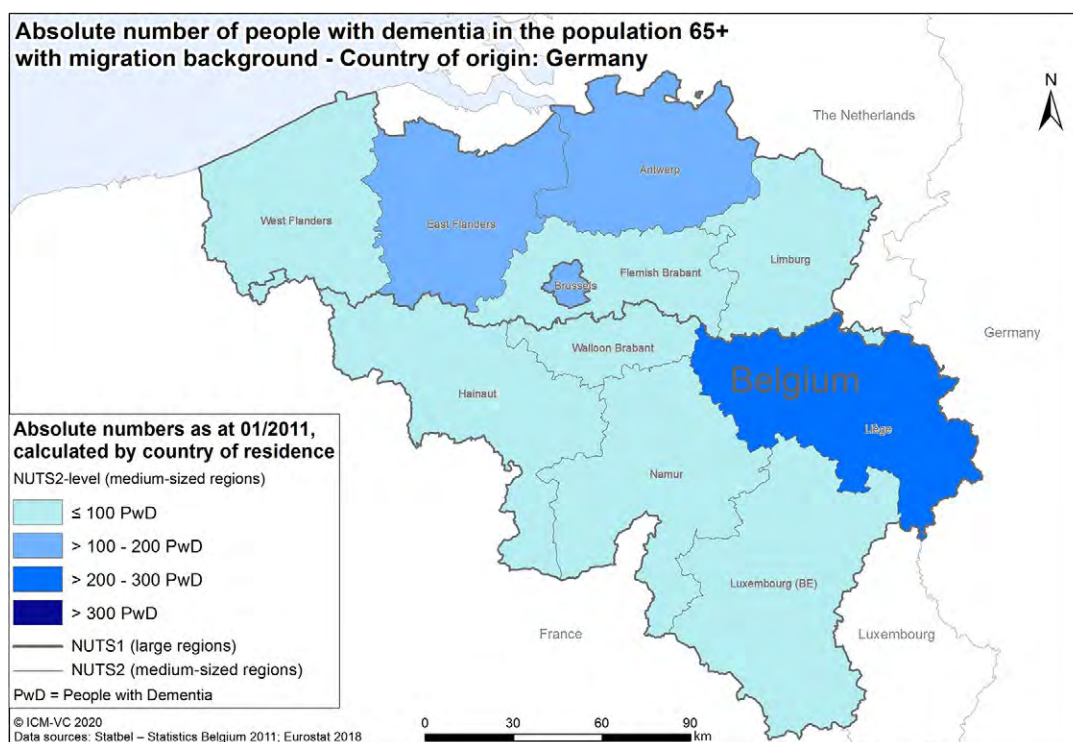


Fig. 3.7.2.7: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Belgium – NUTS2)

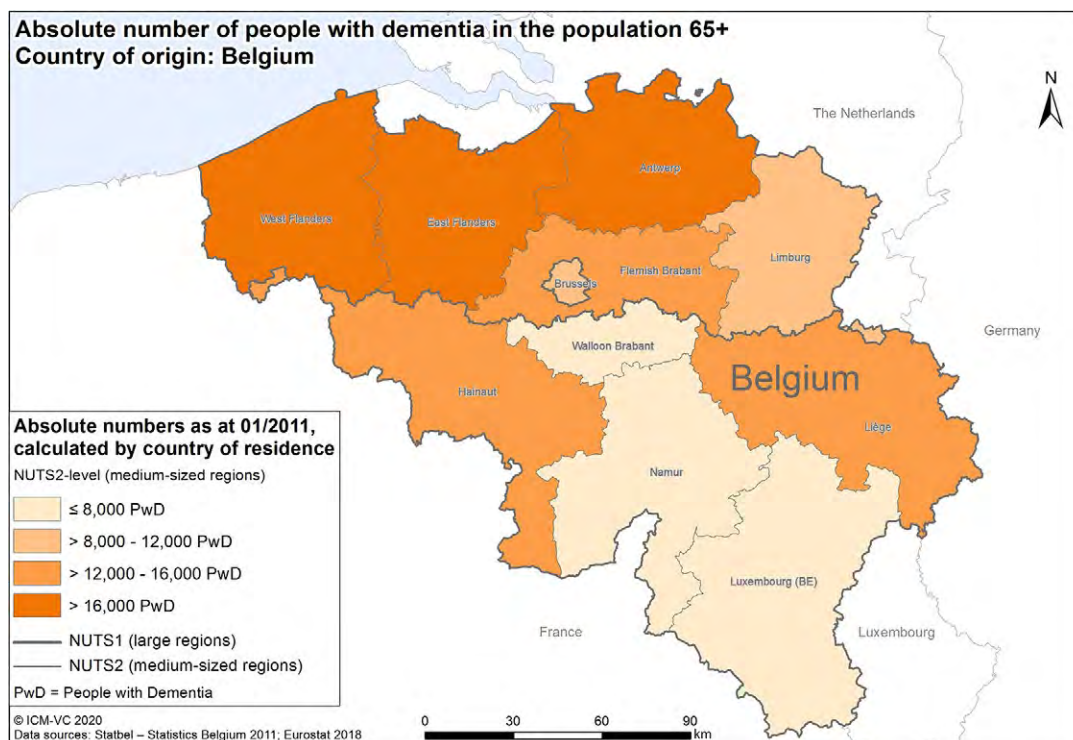


Fig. 3.7.2.8: Absolute number of people with dementia aged 65+. Country of origin: Belgium (Belgium – NUTS 2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map displays the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.2.9). The sec-

ond graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.2.10). The values from the NUTS2 level can be found in table 8 [4-6].

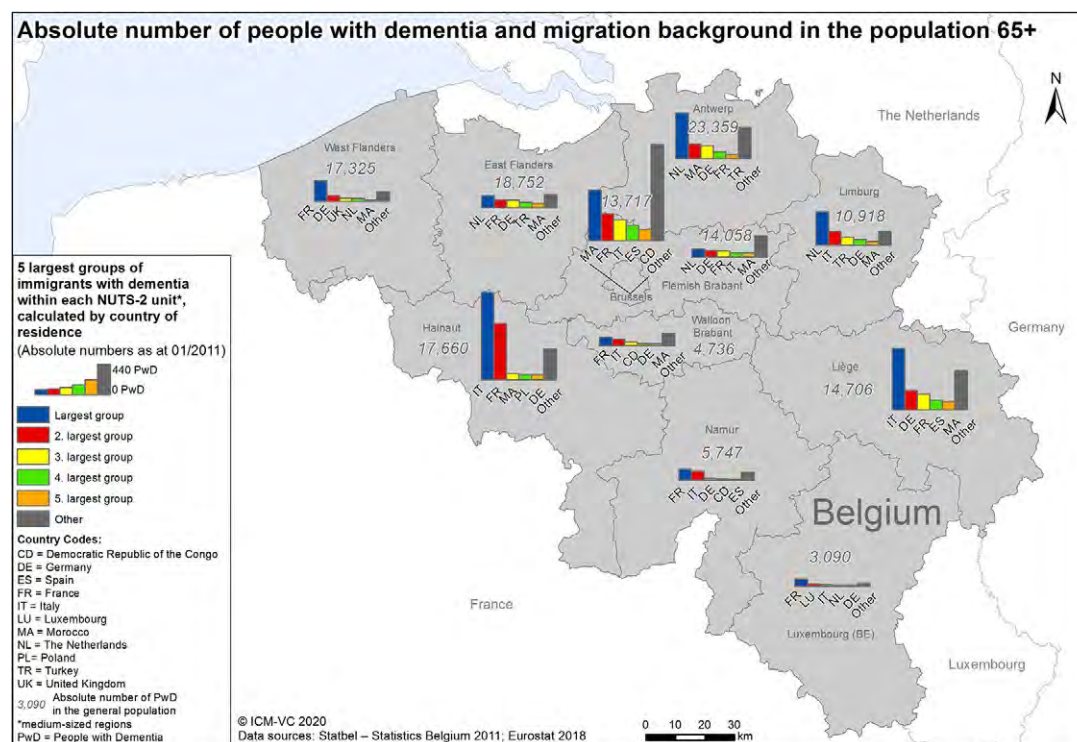


Fig. 3.7.2.9: Absolute number of PwM with dementia in the total population aged 65+ (Belgium – NUTS2)

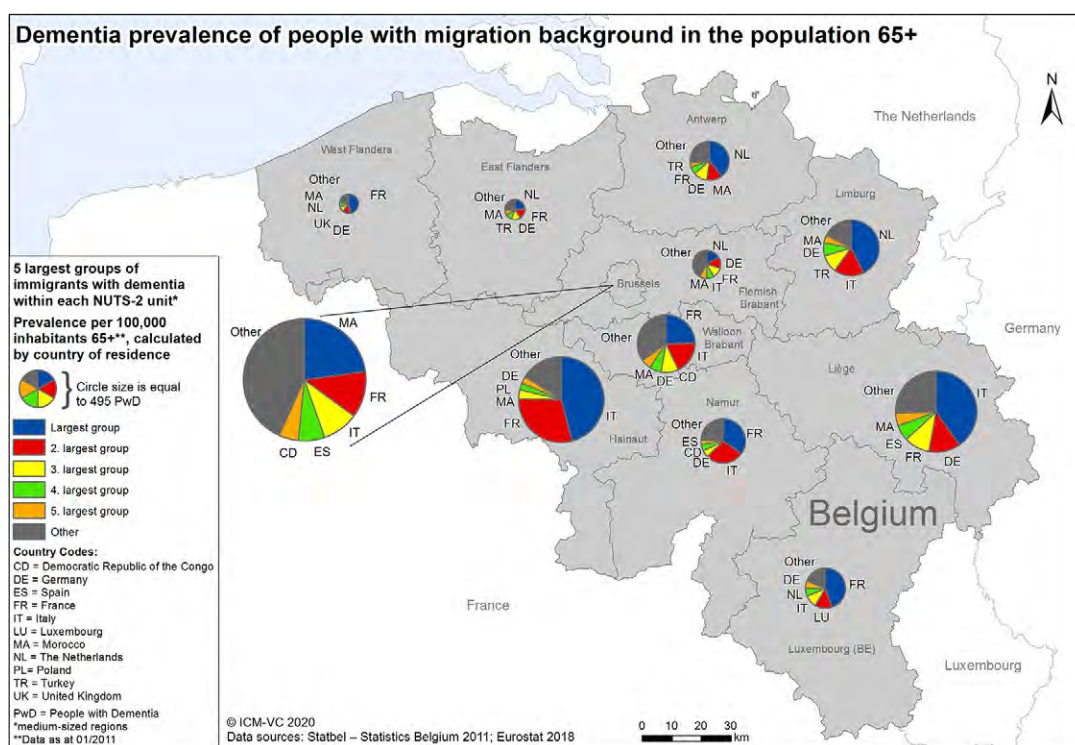


Fig. 3.7.2.10: Prevalence of PwM with dementia among the population aged 65+ (Belgium – NUTS2)

**Tab. 8: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Belgium – NUTS 2)**

NUTS	Total	BE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Brussels	13,717	10,534	MA 723	FR 388	IT 305	ES 223	CD 167	1,377
Antwerp	23,359	21,684	NL 662	MA 211	DE 189	FR 103	TR 60	450
Limburg	10,918	9,813	NL 470	IT 193	TR 115	DE 83	MA 51	193
East Flanders	18,752	18,060	NL 167	FR 112	DE 104	TR 72	MA 56	181
Flemish Brabant	14,058	13,327	NL 118	DE 95	FR 89	IT 62	MA 59	308
West Flanders	17,325	16,707	FR 292	DE 81	UK 50	NL 41	MA 18	136
Walloon Brabant	4,736	4,228	FR 124	IT 93	CD 50	DE 33	MA 28	180
Hainaut	17,660	14,899	IT 1,266	FR 813	MA 93	PL 74	DE 72	443





NUTS	Total	BE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Liège	14,706	12,518	IT 881	DE 277	FR 223	ES 136	MA 114	557
Luxembourg (BE)	3,090	2,861	FR 102	LU 32	IT 23	NL 15	DE 14	43
Namur	5,747	5,277	FR 163	IT 131	DE 24	CD 22	ES 15	115
Prevalence/10,000 inhabitants with migration background 65+								
Brussels	2,974	-	MA 157	FR 84	IT 66	ES 48	CD 36	299
Antwerp	9,624	-	NL 273	MA 87	DE 78	FR 43	TR 25	184
Limburg	6,814	-	NL 297	IT 122	TR 73	DE 53	MA 32	36
East Flanders	18,697	-	NL 166	FR 112	DE 103	TR 72	MA 56	181
Flemish Brabant	13,260	-	NL 111	DE 89	FR 84	IT 58	MA 49	299
West Flanders	19,353	-	FR 326	DE 90	UK 56	NL 46	MA 20	152
Walloon Brabant	6,431	-	FR 168	IT 126	CD 68	DE 45	MA 39	244
Hainaut	4,413	-	IT 316	FR 203	MA 23	PL 19	DE 18	111
Liège	4,637	-	IT 278	DE 87	FR 70	ES 43	MA 36	176
Luxembourg (BE)	9,329	-	FR 307	LU 96	IT 69	NL 44	DE 42	132
Namur	8,445	-	FR 239	IT 193	DE 35	CD 33	ES 22	168
Prevalence/100,000 inhabitants 65+								
Brussels	6,900	5,299	MA 364	FR 195	IT 153	ES 112	CD 84	693
Antwerp	6,900	6,405	NL 195	MA 62	DE 56	FR 31	TR 18	133
Limburg	6,900	6,201	NL 297	IT 122	TR 73	DE 53	MA 32	122
East Flanders	6,900	6,645	NL 61	FR 41	DE 38	TR 27	MA 21	67
Flemish Brabant	6,900	6,541	NL 58	DE 46	FR 44	IT 30	MA 29	152
West Flanders	6,900	6,654	FR 116	DE 32	UK 20	NL 16	MA 7	55



NUTS	Total	BE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Walloon Brabant	6,900	6,160	FR 181	IT 135	CD 73	DE 49	MA 42	260
Hainaut	6,900	5,821	IT 495	FR 318	MA 36	PL 29	DE 28	173
Liège	6,900	5,873	IT 413	DE 130	FR 105	ES 64	MA 53	262
Luxembourg (BE)	6,900	6,390	FR 227	LU 71	IT 51	NL 33	DE 31	97
Namur	6,900	6,336	FR 196	IT 157	DE 28	CD 27	ES 18	138

Data source: Statistics Belgium (2011)

### 3. National dementia plan

Belgium's health system is organised at a regional level. Therefore, it does not have a dementia plan that applies to the whole country. For the southern region Wallonia, no plan could be identified [7]. The northern region Flanders published 'Dementia Plan for Flanders 2016–2019' in 2016, but it has no separate chapter on migration. However, in two paragraphs of the chapter on the prevalence of dementia and in three sections of the chapter on objectives and measures, brief references are made to migration. In these chapters, PwM are identified as a risk group for dementia. The proportion of PwM in the Flemish population has increased in recent years, especially in the 65+ age group, and a further increase is expected. PwM suffering from dementia are considered as a group that should be given special attention in scientific research and the development of care strategies. It is pointed out that

they have specific care needs that must be taken into account when developing dementia strategies. Flanders aims to offer necessary care and support to PwM with dementia and increase the knowledge about dementia among immigrant communities. Simultaneously, it also intends to raise public awareness regarding the importance of cultural diversity in dementia care. The dementia plan of Flanders aims to ensure that PwM have access to dementia-specific care and that culturally sensitive care services are made available. Currently, there still seems to be a lack of culturally sensitive healthcare services for PwM with dementia in Flanders. The specific situation of this vulnerable group had not been given special attention in the past. According to the 'Dementia Plan for Flanders 2016–2019', this is set to change in the future [8].



### 4. National dementia care and treatment guidelines

According to a representative of the Agence pour une Vie de Qualité (=Walloon Agency for Quality of Life) (AVIQ), Wallonia does not have any publicly accessible documents that contain dementia-specific treatment or care guidelines [9]. For Flanders, four such documents could be found. While the 'Transit Plan Dementiekundige Basiszorg in het Natuurlijk Thuisomgeving' from 2014 does not take migration into account [10], the other three guidelines refer to it to different extents. The document 'You and Me, Together We are Human: A Reference Framework for Quality of Life, Housing and Care for People With Dementia' from 2018 refers to migration in a section with two large and one small paragraph. The focus is on the problem description. At first, it is discussed that increasing diversity in western societies poses challenges for carers. Then, a few differences in the perception of dementia and in the needs and care practices between PwM and non-migrants are mentioned. It is pointed out that some cultures perceive dementia as a pathology of the brain, while other cultures see it as a part of normal aging, a psychiatric problem, a religious or mystical experience, or punishment for bad behaviour. In some of these cultures, dementia is strongly taboo. As a result, such people need to be better informed and their awareness of dementia needs to be raised. The reference framework concludes that current healthcare services for migrants are insufficient. The care institutions are directly invited to consider the culture-specific needs of people without falling into stereotyping and over-culturalization. In the future, Flanders wants to focus in particular on culturally sensitive healthcare for PwM

with dementia. However, there are no plans to develop specialised for this group [11]. In the 'Memorandum' of 2014 published in 2013 by the 'Expertisecentrum Dementie Vlaanderen' and the 'Vlaamse Alzheimer Liga', it is mentioned that the number of older people from Italy, Morocco, or Turkey is increasing, which is one reason for the growing pressure on informal care and the rising importance of diversity of care [12]. The 'Memorandum' of 2019 from 2018 describes the situation with the same wording. This indicates that the situation has not changed in recent years—the number of older migrants continues to rise, the pressure on informal care continues to increase, and diversity of care is still being neglected. This could be the reason why at the end of the memorandum the recommendation is made that in the future greater attention should be paid to PwM with dementia [13].

The analysis of the Flemish documents has shown that the topic of dementia and migration is becoming more important in Flanders and is also increasingly taken into account while writing documents on dementia care. PwM with dementia are identified as a vulnerable group with specific needs to whom culturally sensitive care should be offered in the future. Currently, there seem to be major gaps in this regard.

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.



## 5. Services and information for people with a migration background with dementia

There are large gaps in care for PwM with dementia since dementia and migration is a new topic in society, politics, science, and the healthcare system, and is currently not being given any structural attention within these systems. The two experts interviewed are part of the sole research project running on the topic. Until now, the Belgian healthcare system, policymakers, and care organisations have not identified PwM with dementia as a group with special needs. As a result, no national or regional programs, guidelines, or official documents (published by the government) that raise awareness of dementia and migration among healthcare providers can be identified. According to the interviewees, PwM are not included in the healthcare system in Belgium at all. Thus, there is already a lack of focus on health and migration, which is reflected in the absence of public policies and best practice examples addressing the subject. In the current situation, the provision of culturally sensitive services to PwM with dementia is dependent on initiatives taken on an individual level, with no involvement of the state. The experts state that there are currently no specialised healthcare services for PwM with dementia in Belgium and the government, the healthcare system, and the healthcare organisations are also not taking any measures to ensure future

intercultural care or support for people with dementia. At the individual level, there are a small number of healthcare providers and caregivers who are sensitised to the specific needs of PwM with dementia and offer culturally sensitive care based on their own profile (e.g. own migration background) and experience of working with PwM. The experts mentioned the following two examples. First, a day care centre for PwM with dementia was set up in Brussels in 2017 by a group of nurses; the day care has looked after about ten people since it was launched (estimation of one expert). The second example was the culturally sensitive dementia café in Mons. There are also individual nursing homes with a high proportion of migrants, such as a nursing home in Brussels with many migrants from Italy, which have been sensitised to the topic. According to the experts, with the exception of these examples, there is no specific attention on ensuring adequate care for PwM with dementia in Belgium. No standard of care, no policy, and no systematic consideration of the needs of this specific group of individuals seem to exist. Due to understaffing in the field of elderly care, there is a general lack of sensitivity to personal needs for dementia patients; this applies in particular to PwM.



## 6. Professional qualification and people with a migration background in healthcare

According to the interviewed experts, intercultural or culturally sensitive care is not an integral part of the professional training of health or nursing staff. Although there are courses on intercultural care, they are not a mandatory module, are not offered nationwide to all students, and are not considered as an important basic component for care provision. Moreover, these courses are often only attended by those who are already sensitised to the topic. The large majority of trainees/students do not attend courses on intercultural care.

Regarding cultural diversity and the proportion of healthcare professionals with a migration background, region (rural or urban) and professional qualification play a key role. In cities and for low qualification jobs, the proportion of professionals with a migration background is much higher than in rural areas and jobs requiring advance qualifications. In residential care in Brussels, for example, it is very high. In addition, the proportion of migrants among doctors is much lower compared to nurses. Likewise, the proportion of cleaning staff with a migrant background is probably 80 to 90% (estimation by one expert). This may indicate that jobs with lower qualifications are generally those undertaken by migrants. With regard to regions and countries of origin, the group of professional caregivers with a migration background in residential care in cities is very heterogeneous (from all parts of the world, e.g. Eastern Europe, America, Pakistan). In most hospitals (except those in Brussels), the pro-

portion of migrants and cultural diversity is much lower. Overall, the diversity among staff in inpatient care is lower than in outpatient care. The two experts pointed out that there are currently some structural and social conditions in Belgium that represent a barrier to the inclusion of PwM in the entire spectrum of healthcare professions. PwM are often seen as one group in policy, which leads to the false expectation that caregivers with a migration background generally offer culturally sensitive care, because of their migration background, and thus have the skills and knowledge to manage care among these populations. Overall, the experts state that higher expectations are set for healthcare providers with a migration background than for healthcare providers without a migration background. In terms of regular healthcare tasks and duties, both are expected to have the same level of expertise. At the same time, both are expected to be prepared to provide translation services when necessary and offer culturally sensitive care. A high level of ethnic diversity among the staff provides great potential but does not automatically lead to culturally sensitive care. The diversity needs to be utilised fruitfully with the help of elements such as good leadership, communication, and supportive non-stereotypical policy. According to the experts, another central problem is the structurally caused lack of inclusion of PwM in high-skill jobs in the health system, in which they are underrepresented.

## 7. Support for family caregivers

The experts explained that the family network plays a key role in supporting caregivers of PwM with dementia. However, generally, families and other potential support networks such

as religious communities and migrant organisations are largely unfamiliar with dementia care, and therefore, they must first be sensitised and informed about it. In contrast to fam-



ilies, religious communities and migrant organisations currently do not play an important role in providing dementia-specific support to family caregivers. According to the experts, this is not due to an absence of willingness, but due to lack of awareness and knowledge related to dementia. However, there are also differences between the individual migrant organisations. Some countries of origin are better organised and other countries are not represented in migrant organisations at all. Thus, the extent to which family caregivers receive support from these organisations depends on the country of origin. Migrants from Italy, for example, have a social service that supports them in terms of access to care, while people from Morocco do not have such an organisation. Currently, the closest family caregivers support the person with dementia most of the time. They are also the ones who educate their social circle about dementia, which in turn increases the burden of care.

According to the experts, there is a general problem of support and information for family caregivers of people with dementia in Belgium. This problem is even greater and more complex with regard to the relatives of PwM with dementia. There are no specialised information resources (such as books, films) enabling them to discuss the topic of dementia with their family in their mother tongue. In addition, the information available on dementia is not culturally sensitive or culturally adapted in terms of individual elements (e.g. people or situations depicted in pictures, illustrations, or videos). For the relatives of PwM with dementia, it is important that they can recognize themselves in the (virtual) information. Overall, there is a great need for specialised services providing support and information to this population. It is necessary to develop linguistically and culturally sensitive information bearing in mind that this information must be accessible and lead to accessible care services.

## 8. References

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# Bulgaria

**Population**

6,951,000

**Area**

110,372 km<sup>2</sup>

**Capital**

Sofia

**3 largest cities**

Sofia (1,243,000)

Plovdiv (348,000)

Varna (336,000)

**Neighboring countries**

Greece, North

Macedonia, Romania,

Serbia, Turkey

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Between 1880 and 1988, 808,600 people immigrated to Bulgaria and about 1,283,000 people emigrated from Bulgaria. The people who came to Bulgaria during this period were mainly ethnic Bulgarians from neighbouring countries [1]. The first immigrants were refugees from Armenia (1915–1917) who fled the Armenian genocide in the Ottoman Empire. The next wave of immigration occurred during the socialist period (1944–1989) when large groups of students came from the Third World. To meet labour demand, immigrants from Vietnam were admitted in the late 1970s. From 1989, immigration increased and large groups from China and Arab-speaking countries came to Bulgaria. After Bulgaria joined the EU in 2007, the number of immigrants from the former Soviet Union and former Yugoslavia increased. New large immigrant groups were formed (people from the Russian Federation, Ukraine, Arab-speaking countries, Albania, Armenia, Serbia, Turkey, etc.). Bulgaria's accession to the EU, its geographical location on the south-eastern external border of the

EU and the Syrian War have transformed Bulgaria from a traditional net emigration country to a transit country [2] with a reduced net emigration [3]. Especially from June 2013, the number of migrants who arrived in Bulgaria in search of international protection increased significantly. These migrants were mainly from Iraq, Afghanistan, Syria, Pakistan, and Iran and most of them migrated undocumented to Northern and Western Europe. In 2016, people from Afghanistan represented 40% of the new asylum seekers [4]. In 2013, the largest migrant groups were from the Russian Federation (19,700), Romania (6,400), Ukraine (6,200), Greek (5,200), and Turkey (4,200) [5]. Between 1990 and 2019, the migrant population (born abroad) has increased almost eightfold (21,500 to 168,500) and the proportion of migrants in the total population has increased twelvefold (0.2 to 2.4%) [6]. Overall, Bulgaria's migrant population is smaller and its migration history is shorter than most other EU countries [2]. As of 2020, the net migration rate is -0.7 [7].

## 2. Estimated number of people with a migration background with dementia

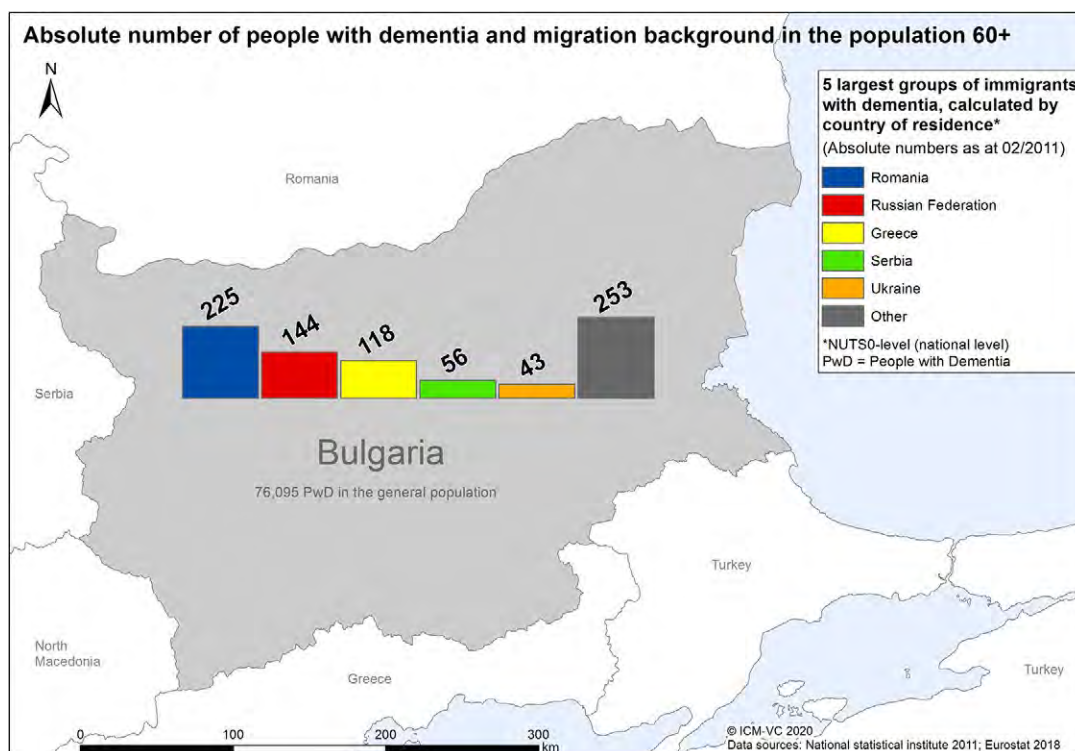


Fig. 3.7.3.1: Absolute number of PwM with dementia aged 60+ (Bulgaria – Nation)

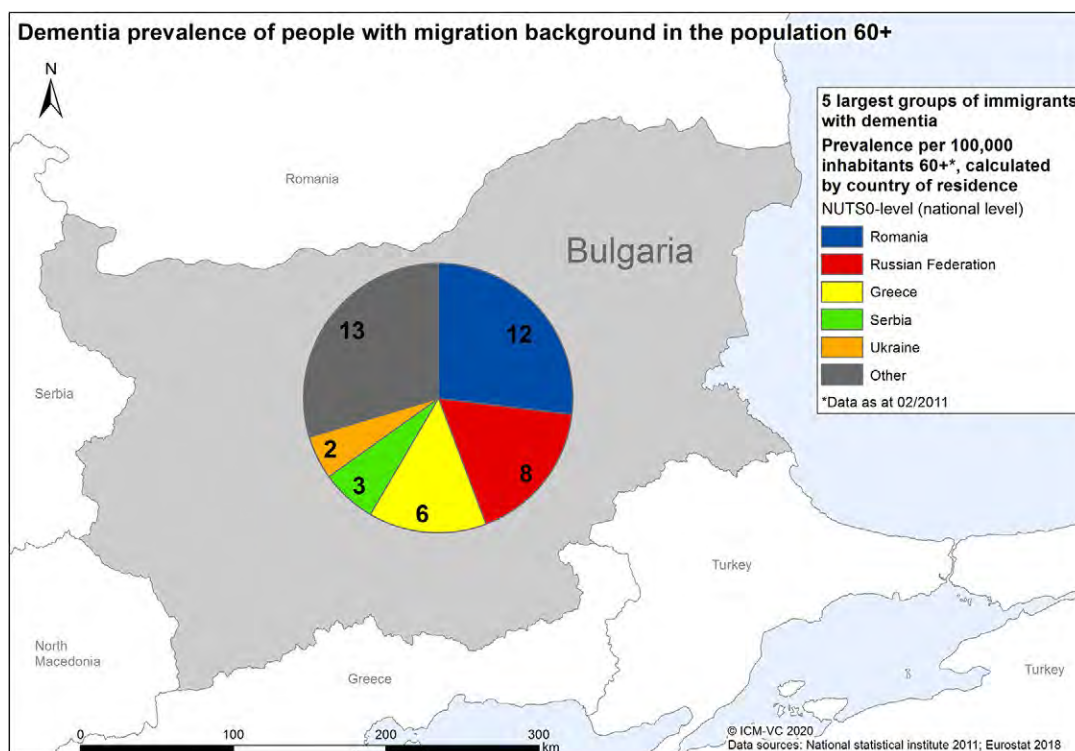


Fig. 3.7.3.2: Prevalence of PwM with dementia among the population aged 60+ (Bulgaria – Nation)

**Tab. 9: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Bulgaria – Nation)**

NUTS	Total	BG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Bulgaria	76,095	75,256	RO 225	RU 144	GR 118	XS 56	UA 43	253
Prevalence/10,000 inhabitants with migration background 60+								
Bulgaria	36,282	-	RO 107	RU 69	GR 56	XS 27	UA 21	120
Prevalence/100,000 inhabitants 60+								
Bulgaria	4,000	3,956	RO 12	RU 8	GR 6	XS 3	UA 2	13

Data source: National statistical institute (2011)

There are 21,000 PwM aged 60 or older. Of those, approx. 800 are estimated to exhibit some form of dementia. Figure 3.7.3.1 shows the most affected migrant groups presumably originate from Romania (approx. 200), the Russian Federation (approx. 100), Greece (approx. 100), Serbia (approx. 60), and Ukraine (approx. 40). The second graph highlights the number of PwM with dementia in Bulgaria per

100,000 inhabitants aged 60 or older (figure 3.7.3.2). Table 9 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Romania, the Russian Federation, Greece, Serbia, and Ukraine throughout the country in the NUTS 2 regions (figures. 3.7.3.3 – 3.7.3.8).

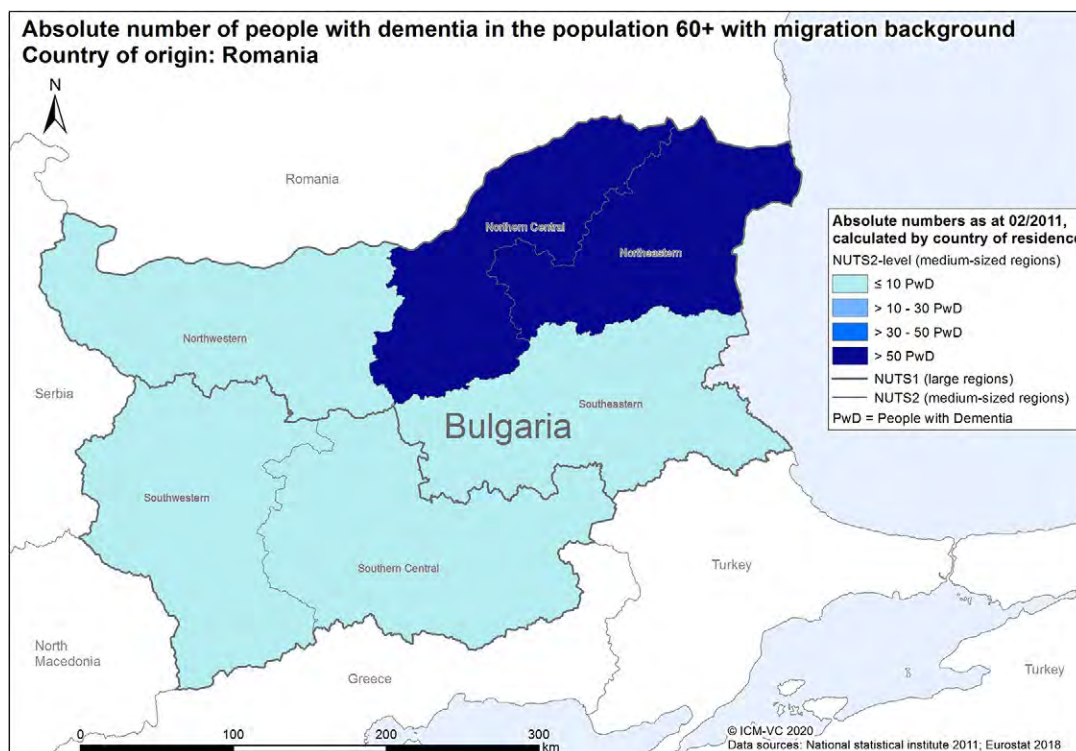


Fig. 3.7.3.3: Absolute number of PwM with dementia aged 60+.  
Country of origin: Romania (Bulgaria – NUTS 2)

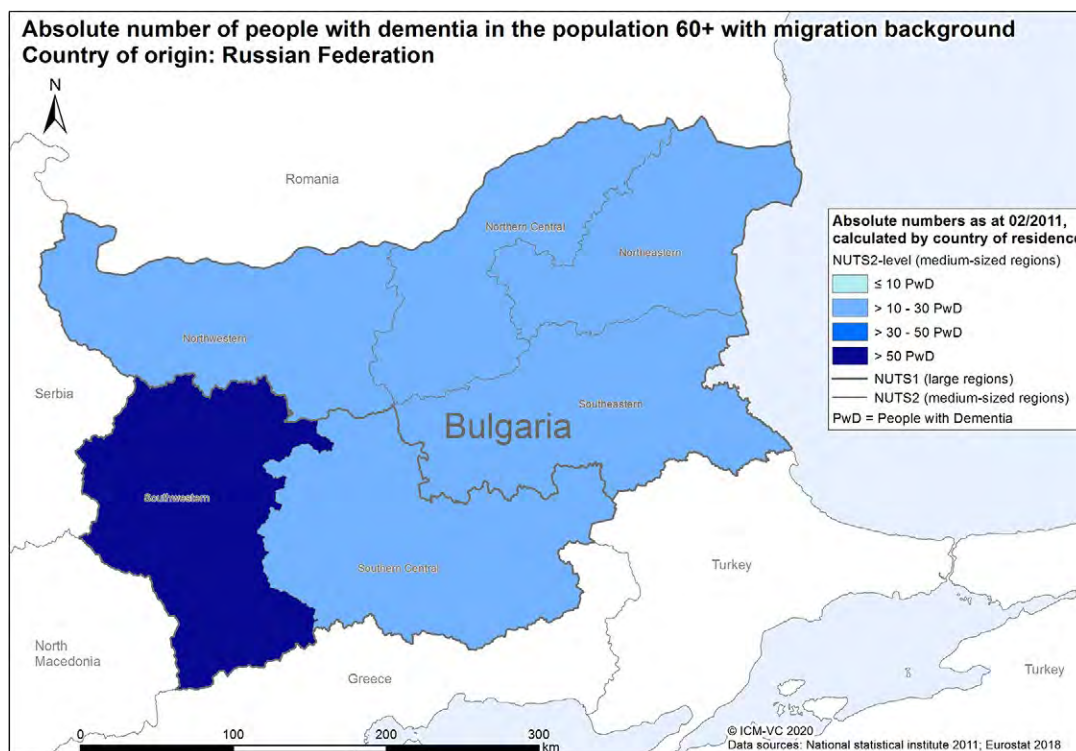


Fig. 3.7.3.4: Absolute number of PwM with dementia aged 60+.  
Country of origin: The Russian Federation (Bulgaria – NUTS 2)



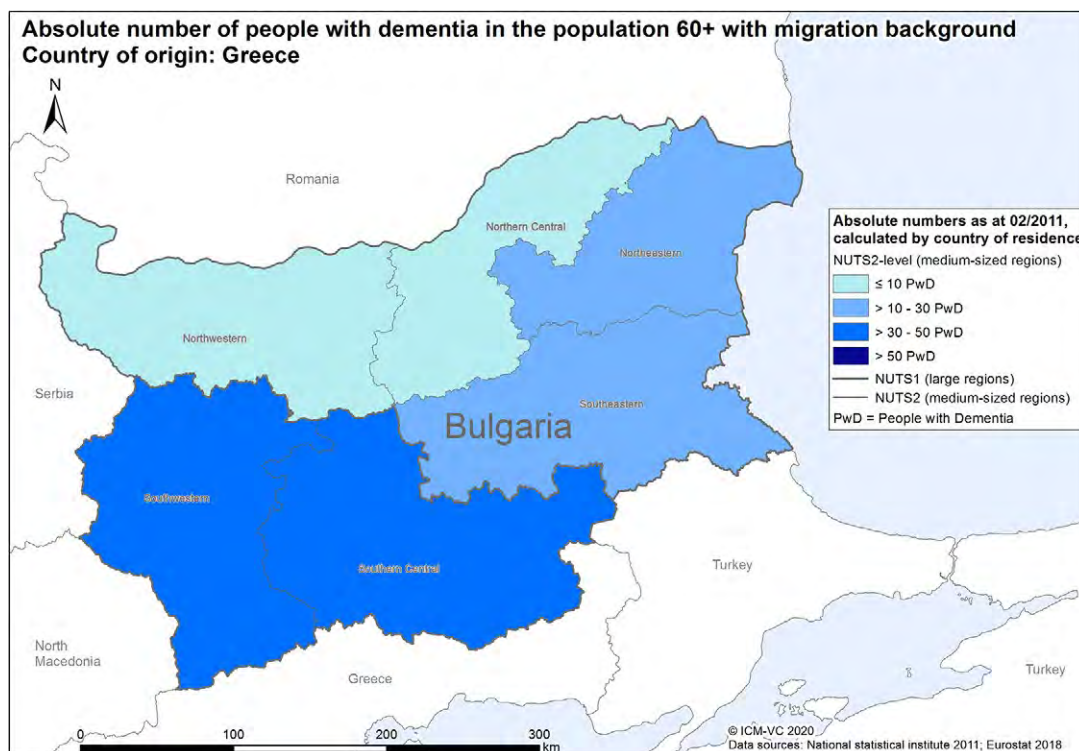


Fig. 3.7.3.5: Absolute number of PwM with dementia aged 60+.  
Country of origin: Greece (Bulgaria – NUTS 2)

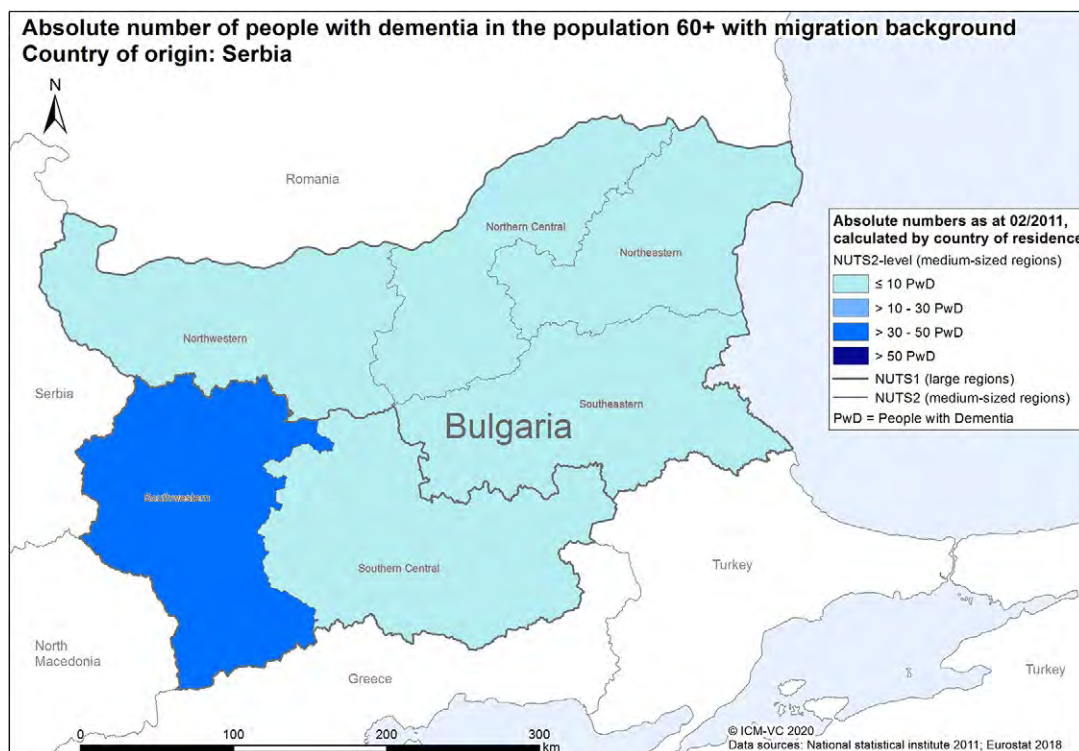


Fig. 3.7.3.6: Absolute number of PwM with dementia aged 60+.  
Country of origin: Serbia (Bulgaria – NUTS 2)

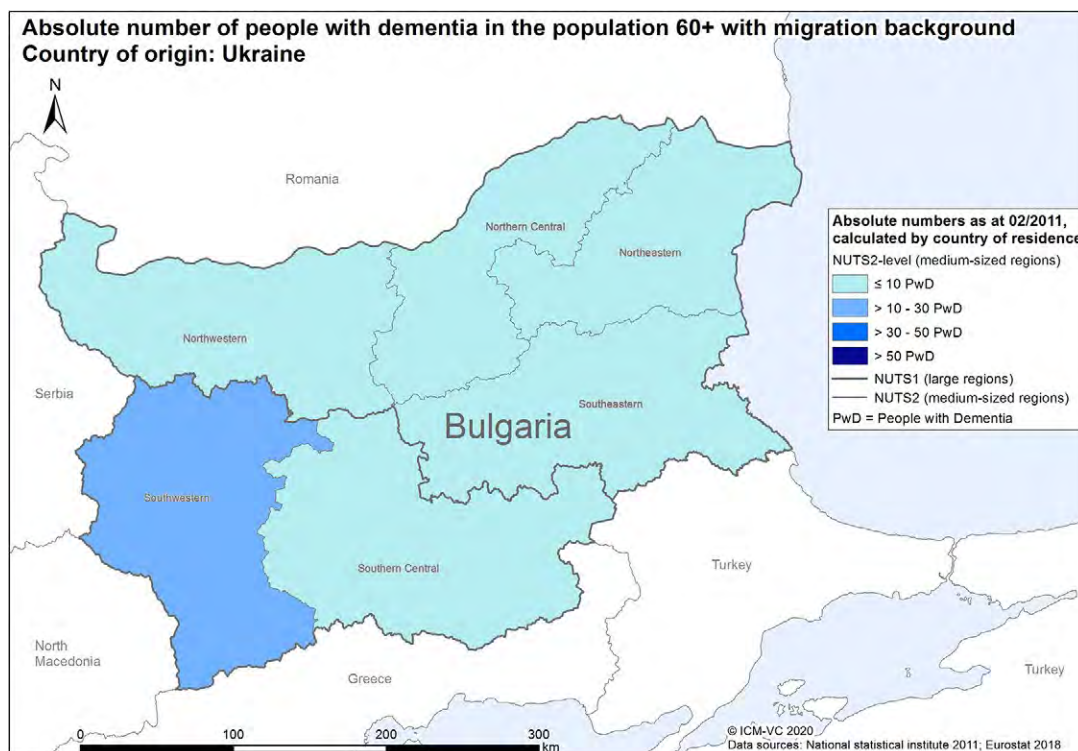


Fig. 3.7.3.7: Absolute number of PwM with dementia aged 60+.  
Country of origin: Ukraine (Bulgaria – NUTS 2)

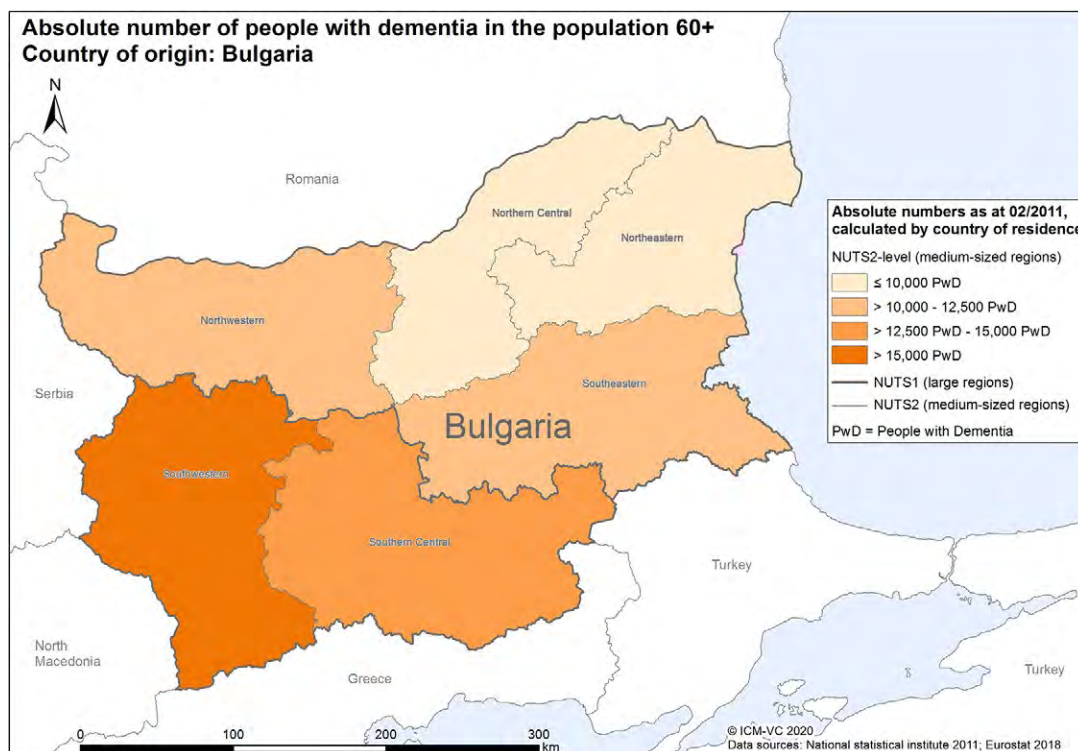
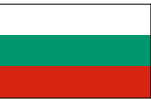


Fig. 3.7.3.8: Absolute number of PwM with dementia aged 60+.  
Country of origin: Bulgaria (Bulgaria – NUTS 2)





The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS 2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS 2 regions (figure 3.7.3.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 60 or older in the NUTS 2 regions (figure 3.7.3.10). The vales from the NUTS 2 level can be found in table 10. [8-10].

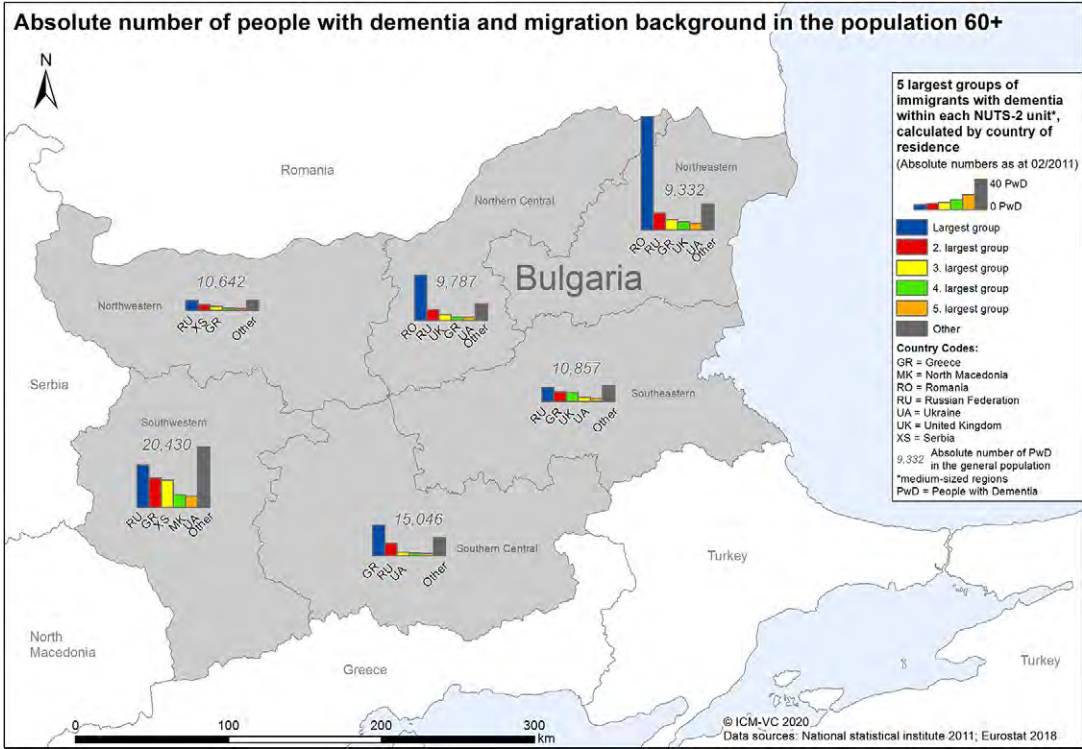


Fig. 3.7.3.9: Absolute number of PwM with dementia aged 60+ (Bulgaria – NUTS 2)

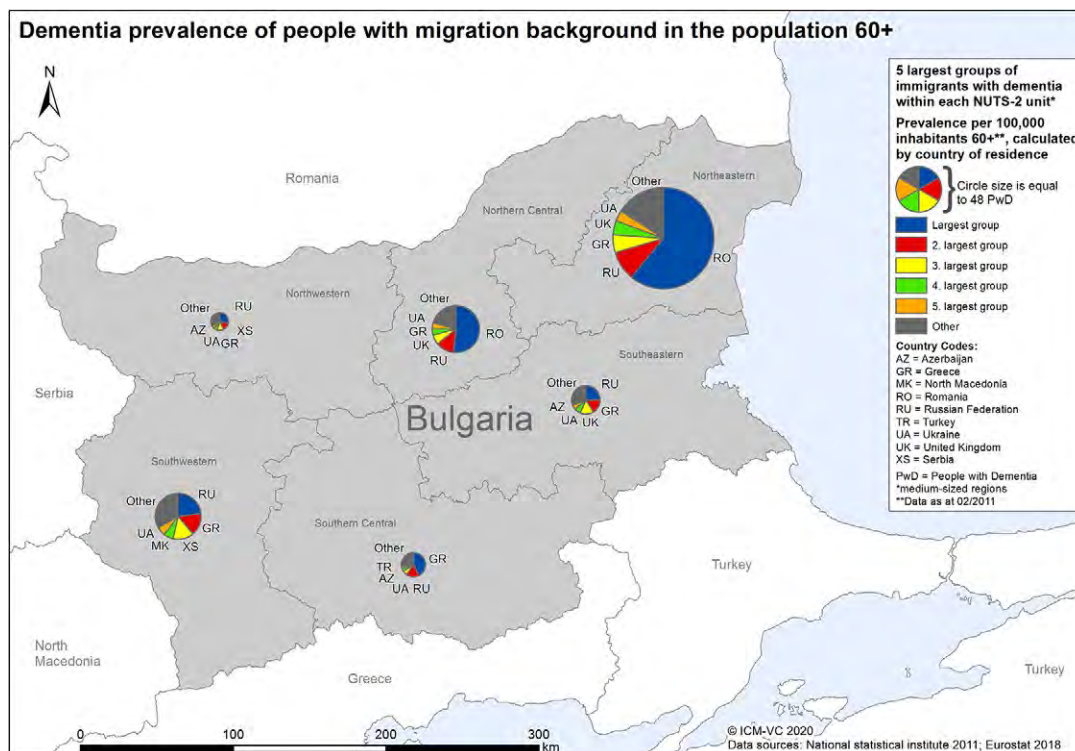


Fig. 3.7.3.10: Prevalence of PwM with dementia among the population aged 60+ (Bulgaria – NUTS 2)

**Tab. 10: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Bulgaria – NUTS 2)**

NUTS	Total	BG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Northwestern	10,642	10,593	RU 13	XS 8	GR 6	<5	<5	16
Northern Central	9,787	9,668	RO 62	RU 15	UK 8	GR 5	UA 5	24
Northeastern	9,332	9,085	RO 152	RU 23	GR 14	UK 11	UA 9	38
Southeastern	10,857	10,777	RU 19	GR 13	UK 12	UA 6	<5	26
Southwestern	20,430	20,185	RU 56	GR 39	XS 36	MK 17	UA 15	82
Southern Central	15,046	14,948	GR 41	RU 17	UA 5	<5	<5	28
Prevalence/10,000 inhabitants with migration background 60+								
Northwestern	87,015	-	RU 109	XS 62	GR 47	UA 26	AZ 20	136



## Bulgaria

NUTS	Total	BG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Northern Central	32,668	-	RO 205	RU 49	UK 26	GR 17	UA 17	86
Northeastern	15,089	-	RO 245	RU 38	GR 23	UK 18	UA 14	62
Southeastern	54,585	-	RU 98	GR 65	UK 60	UA 29	AZ 19	129
Southwestern	33,334	-	RU 92	GR 64	XS 59	MK 27	UA 25	133
Southern Central	61,388	-	GR 168	RU 70	UA 22	AZ 16	TR 13	111
Prevalence/100,000 inhabitants 60+								
Northwestern	4,000	3,982	RU 5	XS 3	GR 2	UA 1	AZ 1	6
Northern Central	4,000	3,951	RO 25	RU 6	UK 3	GR 2	UA 2	11
Northeastern	4,000	3,894	RO 65	RU 10	GR 6	UK 5	UA 4	16
Southeastern	4,000	3,971	RU 7	GR 5	UK 4	UA 2	AZ 1	10
Southwestern	4,000	3,952	RU 11	GR 8	XS 7	MK 3	UA 3	16
Southern Central	4,000	3,974	GR 11	RU 5	UA 1	AZ 1	TR 1	7

Note: Absolute numbers < 5 are not given for data protection reasons.

Data source: National statistical institute 2011



### 3. National dementia plan

Currently, no publicly available NDP could be identified for Bulgaria. In February 2015, Alzheimer Bulgaria published a report on national policies and practices in Bulgaria. This report has a volume of three pages and contains information about dementia diagnosis,

treatment, and care services concerning the main barriers for adequate care of people with dementia. There is also a one-page draft with basic goals for a national dementia strategy. Both documents do not refer to migration [11].

### 4. National dementia care and treatment guidelines

The 'National Consensus on Early Diagnosis and Treatment of Alzheimer's Disease and Other Forms of Dementia' from 2015 is 32 pages long and includes the topics of socio-medical significance of dementia, principles of the dementia diagnostic algorithm (criteria for dementia), concretisation of the activity (diagnostic activity in outpatient conditions, diagnostic activity in hospital conditions), and medicines used for the treatment of dementia.

This consensus document also makes no reference to migration at any point [12].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on two conducted interviews and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.

### 5. Services and information for people with a migration background with dementia

Both experts state that the healthcare strategy for inpatient and outpatient care in Bulgaria is an integrative one, but PwM with dementia are only partly included in it. Information on dementia is available almost nationwide and therefore technically available to PwM. However, there is neither information with a special focus on the needs of PwM with dementia nor any state supported services providing information on dementia in other languages, according to the first expert interviewed. In the 'Foundation Compassion Alzheimer' (a non-governmental organization to help and support older people with Alzheimer's disease and dementia and their families as well as their friends) there are team members who speak other languages than Bulgarian and if asked they are able to provide information in

English, French or Italian. The second expert said that, in general, services and information are more readily available in bigger cities than in other regions. Services for inpatient and outpatient care for people with dementia have almost nationwide availability for PwM—that is, if they have documents and are entitled to social security and healthcare benefits—since they are entitled to the same healthcare and social rights as non-migrants in Bulgaria. There are eight dementia expert centres for diagnosis, detection, and referral in different cities in Bulgaria, where people from small towns and settlements are being referred to as well. The experts agree that existing services are suitable for people with and without a migration background. As long as individuals can afford these services, they will be taken

care of, regardless of migration background. Health laws prohibit discrimination based on age, sex, origin, language, nationality, ethnicity, political affiliation, education, beliefs, cultural background, sexual orientation, personal/social/material status, disability, and type and cause of the disease. According to the experts, there is currently no intercultural care available for PwM with dementia and there are no measures implemented or in development to provide such care. Although there are

no options for intercultural care for PwM with dementia and no other specialised services for this population there is the 'Health mediator project' aimed at facilitating access to social and health services for people from the Roma community. PwM with dementia and their families are also rarely consulted when it comes to designing information material or healthcare services for PwM with dementia according to the second expert.

## 6. Professional qualification and people with a migration background in healthcare

The experts assume that administrative staff and professional care providers might not be qualified on culturally sensitive care. Additionally, there seems to be no training in intercultural care available. However, there are trained social workers, cultural mediators, and Roma mediators providing support for intercultural

needs. They facilitate Roma community and refugees' access to social services and healthcare. Another concern reported by the experts is that, personnel in centres for refugees who directly work with PwM and refugees lack knowledge about different groups of ethnicities.

## 7. Support for family caregivers

According to both experts, service providers play an important role in supporting family caregivers. The first expert rated the importance of family, religious communities, and migrant organisations to be moderate while the second expert rated it high.

The second expert assumed no differences in information and services for family caregivers of people with dementia with and without a migration background since PwM are entitled to the same rights as the non-migrant population. Migrants and some ethnic communities may experience language barriers; nevertheless, social mediators exist to facilitate their

access to information. It seems that neither on a national nor a municipal level are training opportunities for family caregivers provided. Organisations like the 'Foundation Compassion Alzheimer' provide information and guidance on dementia to family caregivers. However, the second expert assumed a very high need for specialised information and services for family caregivers, particularly in terms of how to deal with the health and social system, disease information, care and management of the disease, support opportunities available, and prospects on how to live well within the community.



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# Croatia

**Population**

4,058,000

**Area**

88,073 km<sup>2</sup>

**Capital**

Zagreb

**3 largest cities**

Zagreb (806,000)

Split (170,000)

Rijeka (117,000)

**Neighboring countries**

Bosnia Herzegovina,  
Hungary, Montenegro,  
Serbia, Slovenia

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

Due to their affiliation to the former Austro-Hungarian Monarchy, a large number of people from other parts of the monarchy (Austria, Bosnia and Herzegovina, Hungary, the Czech Republic, Slovakia, Slovenia, Italy, Ukraine, and Poland) came to Croatia between the 19th and the beginning of the 20th century. Today, the descendants of these immigrants represent the core of the ethnic minority population. Between 1918 and 1941, immigration from economically disadvantaged regions of Bosnia-Herzegovina increased. Overall, Croatia's migration until the 1970s was characterised by immigration from economically disadvantaged parts of Yugoslavia [1]. In the second half of the 20th century, there was a trend of immigration from the Middle East. After the violent dissolution of Yugoslavia in 1991, many people from other parts of the former Yugoslavia immigrated to Croatia. EU accession in 2013 has led to an increase in the number of immigrants in recent years [2]. Historically, Croatia has been a country of emigration. The history of mass emigration began as a result of the wars between the Ottomans and the Habsburgs during the 15th and 18th centuries. Between 1890 and 1914, approximately 350,000 to 450,000 people emigrated, most of

them to Germany, Belgium, or France. After the Second World War around 250,000 people left Croatia, many of them overseas (Canada, Australia, New Zealand). During the socialist period, there were two waves of emigration. The first wave, in 1946–1963, was mainly characterised by illegal emigration to Italy and Austria. The second wave, 1964–early 1970s, was characterised by the state-supported mass emigration of workers to Western European countries (mainly Germany). The dissolution of Yugoslavia and the war between 1991 and 1995 were followed by the last major wave of emigration [1]. In the past, Croatia was characterised by larger waves of emigration, but also by immigration flows from neighbouring countries. In 2013, the largest migrant groups were from Bosnia Herzegovina (499,100), Serbia (118,100), Slovenia (47,800), Montenegro (39,357), and North Macedonia (20,677) [3]. The migrant population (born abroad, 674,100 to 518,000) and the proportion of migrants in the total population (14.6 to 12.5%) decreased slightly between 1995 and 2019 [4]. The net migration rate has been negative since the 1990s, and as of 2020 is -1.9 [5]. This shows that Croatia is still a country of emigration.

## 2. Estimated number of people with a migration background with dementia

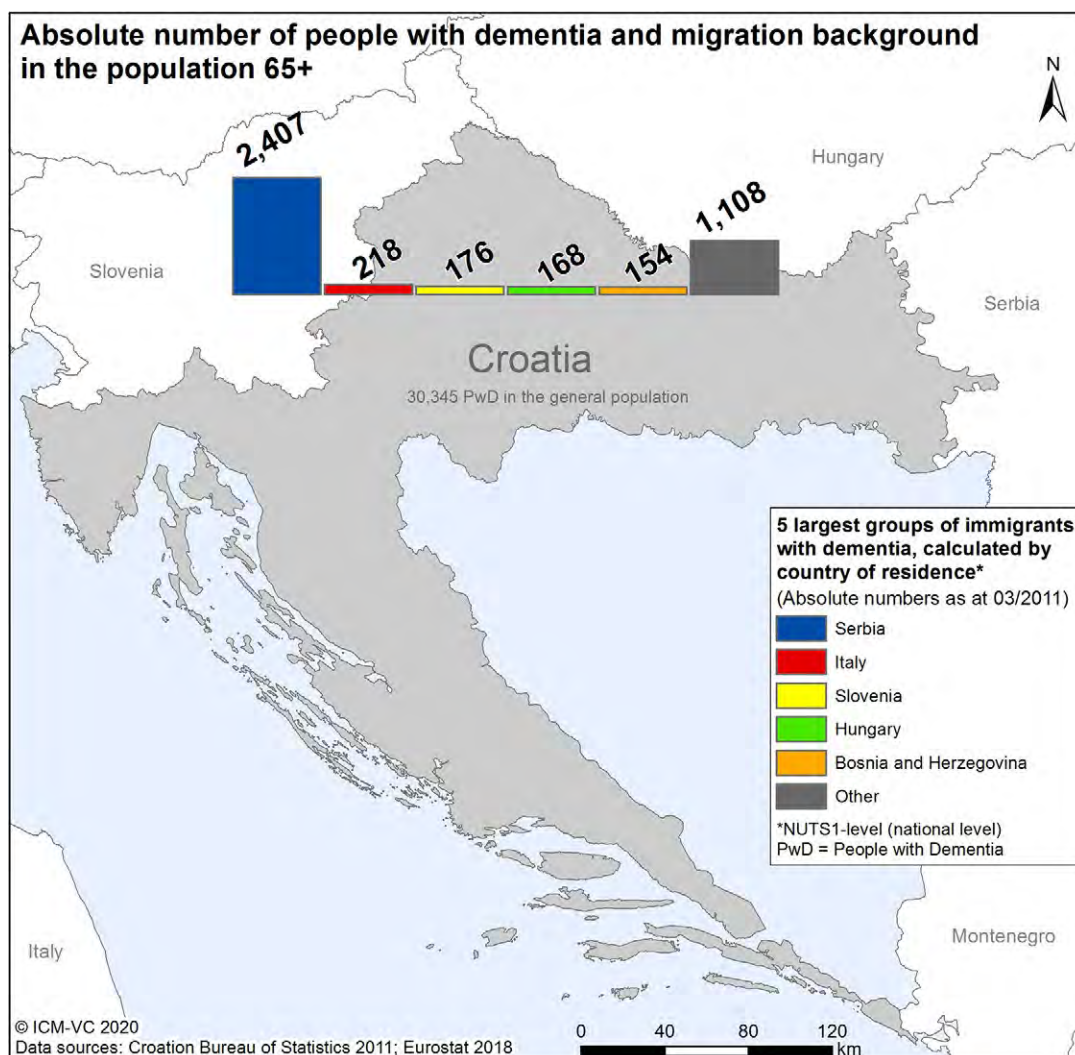


Fig. 3.7.4.1: Absolute number of PwM with dementia aged 65+ (Croatia – Nation)

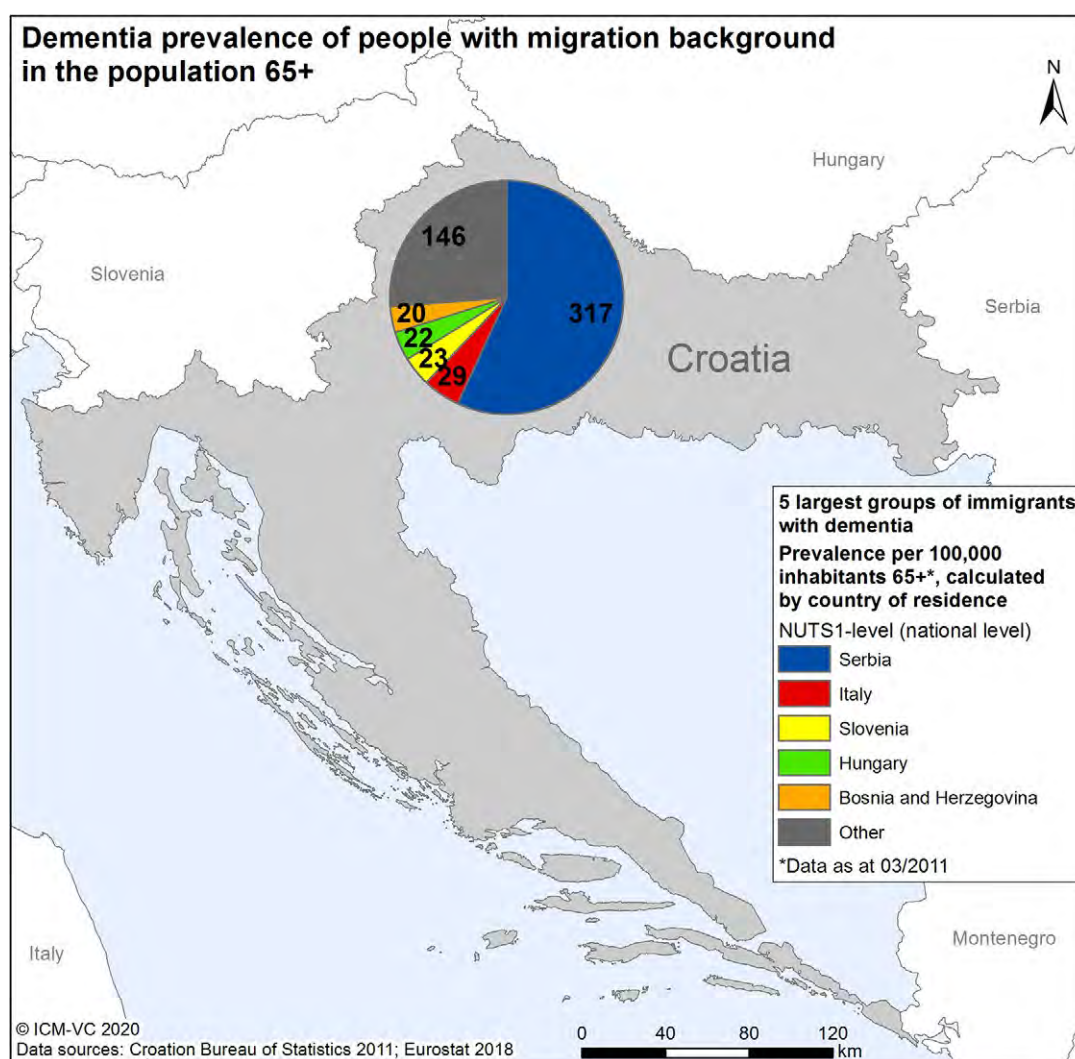


Fig. 3.7.4.2: Prevalence of PwM with dementia among the population aged 65+ (Croatia – Nation)

**Tab. 11: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Croatia – Nation)**

NUTS	Total	HR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Croatia	30,345	26,113	XS 2,407	IT 218	SI 176	HU 168	BA 154	1,110
Prevalence/10,000 inhabitants with migration background 65+								
Croatia	2,868	-	XS 228	IT 21	SI 17	HU 16	BA 15	103
Prevalence/100,000 inhabitants 65+								
Croatia	4,000	3,442	XS 317	IT 29	SI 23	HU 22	BA 20	145

Data source: Croatian Bureau of Statistics (2011)

There are 105,800 PwM aged 65 or older. Of those, approx. 4,200 are estimated to exhibit some form of dementia. Figure 3.7.4.1 shows the most affected migrant groups presumably originate from Serbia (approx. 2,400), Italy (approx. 200), Slovenia (approx. 200), Hunga-

ry (approx. 200), and Bosnia and Herzegovina (approx. 200). The second graph highlights the number of PwM with dementia in Croatia per 100,000 inhabitants aged 65 or older (figure 3.7.4.2). Table 11 displays the values depicted in the maps on the national level [6-8].

### 3. National dementia plan

For Croatia no NDP could be identified [9].

## 4. National dementia care and treatment guidelines

According to the Ministry of Health, no specific national guidelines exist for the care of people with dementia in Croatia [10]. However, there are clinical guidelines for the pharmacological treatment of dementia from 2015 developed by the Croatian Alzheimer's Alliance and various scientists. This document has a volume of seven pages and deals with the starting point for the development of the strategy (epidemiology of Alzheimer's disease, obligations of the Republic of Croatia [arising from EU and WHO documents], mission of the Croatian Association for Alzheimer's Disease), the strategic framework (purpose, main goals, principles of the strategy), and the strategic areas in

the fight against Alzheimer's disease. The strategic areas include early diagnosis of Alzheimer's disease, availability of treatment such as anti-dementia drugs and other psychopharmaceuticals, support for research work in the area of Alzheimer's disease, access to social benefits and services, development of systematic support for patients with Alzheimer's disease and their families/informal carers, balanced regional development of diagnostic centres and treatment of Alzheimer's disease, development of palliative care for people with dementia, and destigmatization. The guidelines do not refer to migration [11].

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# Cyprus

**Population**

888,000

**Area**9,251 km<sup>2</sup>**Capital**

Nicosia

**3 largest cities**

Nicosia (342,000)

Limassol (245,000)

Larnaca (147,000)

**Neighboring countries**

None

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References





### 1. Migration history

Cyprus has a long history of migration. Already in the 12th century B.C., Achaean Greeks came to Cyprus to colonize the island. Between the 9th century AD and the Middle Ages, larger groups of people from Syria and Lebanon immigrated. In the 14th century, the first Roma settlements were established, and in 1521 larger groups from Turkey came to the country (during the conquest of the island by the Ottomans) [1]. In recent history, there have been two waves of large-scale emigration: 1. the early 20th century when many people emigrated to find jobs and improve their living standards, 2. during 1960–1975 when large groups fled due to the violent clashes between Greek and Turkish Cypriots. Destination countries were United Kingdom, the US, and Australia [1, 2]. Between 1974 and 1989, migration took various forms. In the north, Turkish communities settled in several phases. In the south, many Greek Cypriot refugees emigrated to the Middle East (Saudi Arabia), North Africa (Libya), the UK, the US, or Australia. With the collapse of the Soviet Union in 1989, migration patterns changed and Cyprus became an immigration country. After the restrictive

policies of the 1970s and 1980s, the policy of an open labour market (for migrants) was implemented [1, 3]. From the 1990s onwards, many people immigrated from countries like Sri Lanka, the Philippines, Bulgaria, Romania, Greece, the UK, and the Russian Federation [2]. EU accession in 2004 and the real estate boom at the end of the first decade of the new millennium, acted as additional pull factors for immigration [1]. The financial crisis then led to a decrease in immigration and an increase in emigration around 2013 [1, 4]. In recent years, immigration numbers have been rising again. During the summer of 2018, the number of refugees arriving in boats increased significantly [1]. In 2013, the largest migrant groups were from United Kingdom and Northern Ireland (42,900), Greece (27,900), Georgia (18,000), the Russian Federation (15,300), and Sri Lanka (11,600) [5]. Between 1990 and 2019, the migrant population (born abroad) more than quadrupled (43,800 to 191,900) and the migrant proportion of the total population almost tripled (5.7 to 16%) [6]. As of 2020, the net migration rate is 4.2 [7].

## 2. Estimated number of people with a migration background with dementia

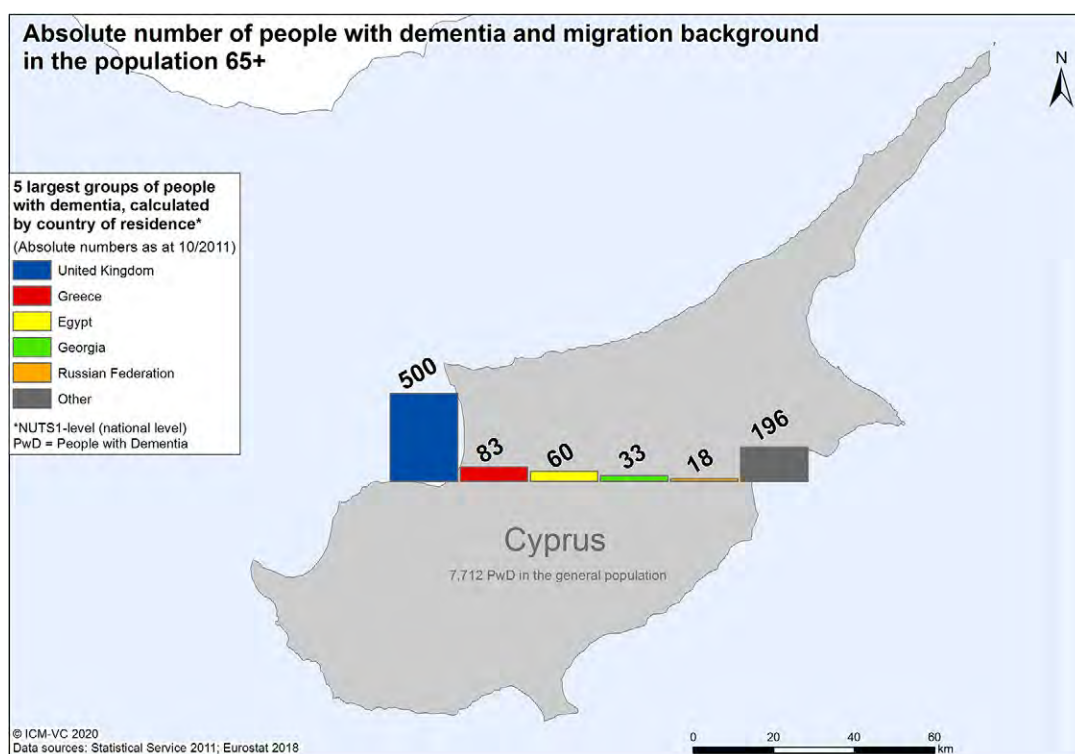


Fig. 3.7.5.1: Absolute number of PwM with dementia aged 65+ (Cyprus – Nation)

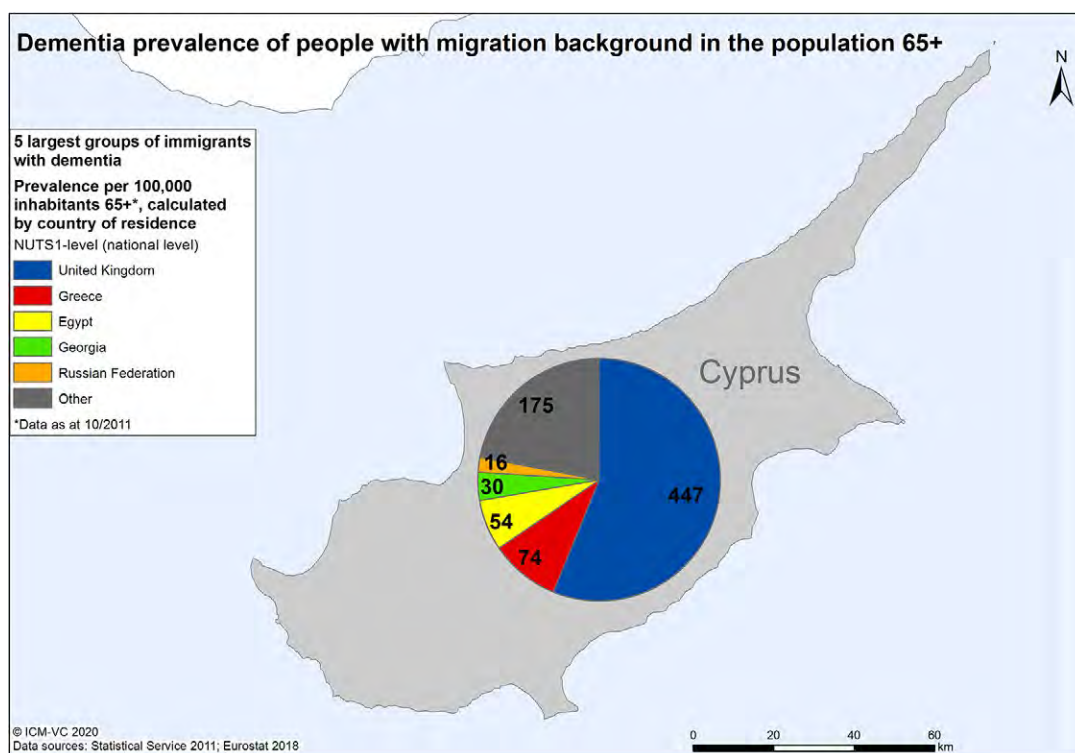


Fig. 3.7.5.2: Prevalence of PwM with dementia among the population aged 65+ (Cyprus – Nation)

**Tab. 12: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Cyprus – Nation)**

NUTS	Total	CY	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Cyprus	7,712	6,823	UK 499	GR 83	EG 60	GE 33	RU 18	171
Prevalence/10,000 inhabitants with migration background 65+								
Cyprus	5,984	-	UK 388	GR 64	EG 47	GE 26	RU 14	151
Prevalence/100,000 inhabitants 65+								
Cyprus	6,900	6,104	UK 447	GR 74	EG 54	GE 30	RU 16	150

Data source: Statistical Service (2011)

There are 12,900 PwM aged 65 or older. Of those, approx. 900 are estimated to exhibit some form of dementia. Figure 3.7.5.1 shows the most affected migrant groups presumably originate from United Kingdom (approx. 500), Greece (approx. 80), Egypt (approx. 60), Geor-

gia (approx. 30), and the Russian Federation (approx. 20). The second graph highlights the number of PwM with dementia in Cyprus per 100,000 inhabitants aged 65 or older (figure 3.7.5.2). Table 12 displays the values depicted in the maps on the national level [8-10].

## 3. National dementia plan

The 'National Action Plan for the Treatment of Dementia in Cyprus 2012–2017' from 2012 has no separate chapter on migration but refers briefly to this topic with three sentences in two sections. First, it is pointed out that ethnicity is a risk factor for dementia, as well as age and gender. Why and to what extent ethnicity is a risk factor is not explained. In addition, the national strategy commits to the values of equal access to diagnostic tests, treatments, medicines, and care without discrimination on

the basis of gender, age, ethnicity, and origin. How they intend to ensure this equal access or fight against discrimination based on ethnicity or origin is not stated (no strategies/measures). Other issues such as prevalence, needs, or diagnosis are not addressed. Overall, the topic of migration plays a marginal role in the national action plan for the treatment of dementia, although inequalities in dementia risk and access to dementia care associated with ethnicity and origin are acknowledged [11].



## 4. National dementia care and treatment guidelines

According to the National Ministry of Health, Cyprus does not have a document with national treatment guidelines for dementia [12]. Regarding the organisation of healthcare, it can be noted that Cyprus is a (small) country with a highly centralised public administration, whose public health services are provided through a network of hospitals, health centres,

sub-centres, and dispensaries. Most of the organisational, administrative, and regulatory functions of the healthcare system are carried out at the state level, and the lower levels of the administration also cooperate with the central administration, especially in the implementation of public health and health promotion initiatives [13].

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# The Czech Republic

**Population**

10,694,000

**Area**

78,871 km<sup>2</sup>

**Capital**

Prague

**3 largest cities**

Prague (1,324,000)

Brno (381,000)

Ostrava (288,000)

**Neighboring countries**

Austria, Germany,

Poland, Slovakia

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References



## 1. Migration history

Migration has had a great influence on Czech society for centuries. The first large influx of migrants (from Germany) occurred during the 13th and 14th centuries. German immigration played a central role until the 1940s. Between 1850 and 1914 (note that from 1867 the Czech Republic was part of the Austro-Hungarian Empire), about 1.5 million people emigrated first to the US and later to Argentina, Austria, Brazil, Hungary, the Russian Federation, and Yugoslavia [1]. At the beginning of the 20th century and during the First World War, there were two waves of large-scale immigration of Ukrainians [2]. In the 1920s and 30s, many people from the newly founded Czechoslovakia emigrated to the US, Germany, and France. Despite 40,000 people from the Czech Republic returning from the US and about 100,000 from Austria, emigration was the predominant phenomenon of the interwar years. During the occupation of Czech territory by Nazi Germany, about 80,000 Jews died in concentration camps. Of the remaining 13,000 Jews, approximately half emigrated to Israel by 1950. Between 1945 and 1946 about 2.8 million people from Germany were expelled [1]. However, about 200,000 people from Czechoslovakia returned in the post-war period [3]. During the communist era (1948–89) approximately 500,000 people from Czechoslovakia left the country (mainly to Germany, Canada, Australia, and the US). From the 1950s onwards,

temporary workers immigrated from Angola, Cuba, Mongolia, Poland, and especially Vietnam, and there were migration movements from Slovakia [1-3]. Since regaining independence in 1989 and secession from the Slovak Republic in 1993, the Czech Republic has developed from an emigration country to a country of transit migration and increasing immigration. Especially the accession to the EU in 2004 led to a considerable influx of foreign workers. After stagnating in the wake of the financial crisis in 2008, the immigration of foreign workers increased again from 2013 onwards. The system upheaval in 1990 and EU accession in 2004 also led to the emigration of smaller groups of citizens (especially Czech students) [1]. Currently, two parallel trends can be observed: 1. a significant increase in the immigration of labour migrants (from Ukraine, Slovakia, Romania, Bulgaria, Mongolia, and other Asian countries) 2. a stagnating and comparatively low number of asylum seekers with falling acceptance rates [4]. In 2013, the largest migrant groups were from Ukraine (127,200), Slovakia (73,400), Vietnam (61,700), the Russian Federation (33,000), and Poland (19,000) [5]. Between 1990 and 2019, the migrant population (born abroad) almost quintupled (110,400 to 512,700) and the proportion of migrants in the total population more than quadrupled (1.1 to 4.8%) [6]. As of 2020, the net migration rate is 2.1 [7].



## 2. Estimated number of people with a migration background with dementia

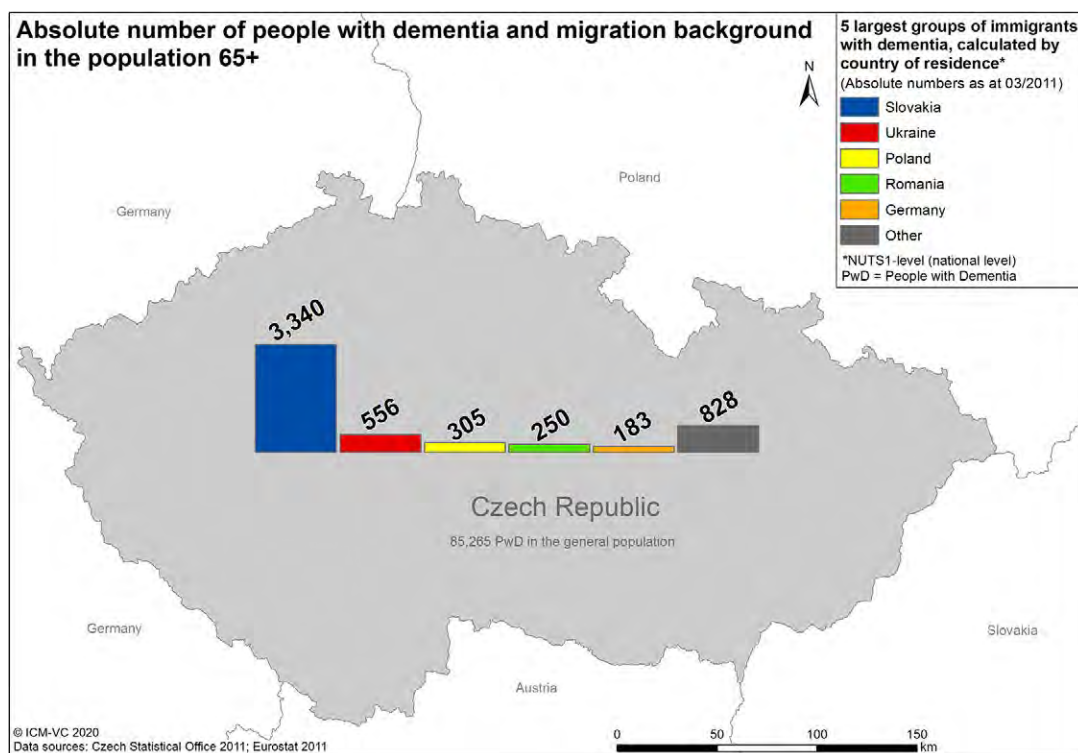


Fig. 3.7.6.1: Absolute number of PwM with dementia in the population 65+ (The Czech Republic – Nation)

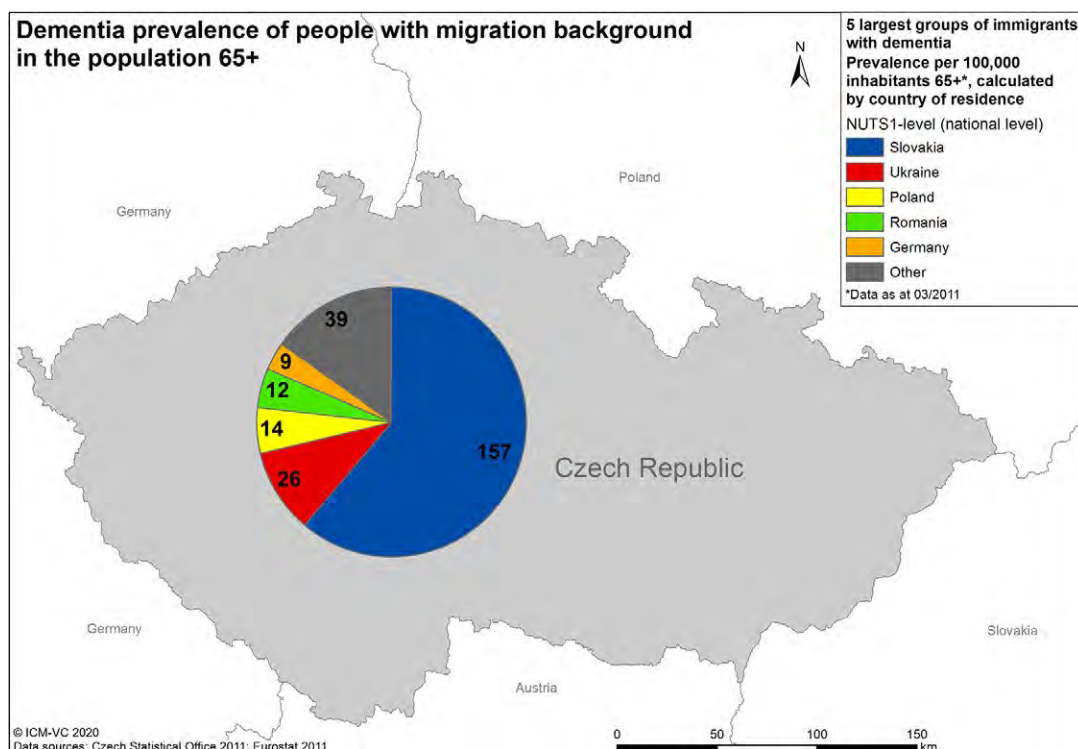


Fig. 3.7.6.2: Dementia prevalence of PwM in the population 65+ (The Czech Republic – Nation)



**Tab. 13: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Czech Republic – NUTS-2)**

NUTS	Total	CZ	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
The Czech Republic	85,265	79,805	SK 3,340	UA 555	PL 304	RO 250	DE 183	828
Prevalence/10,000 inhabitants with migration background 65+								
The Czech Republic	6,246	-	SK 245	UA 41	PL 22	RO 18	DE 13	61
Prevalence/100,000 inhabitants 65+								
The Czech Republic	4,000	3,744	SK 157	UA 26	PL 14	RO 12	DE 9	32

Data source: Czech Statistical Office (2011)

There are 136,500 PwM aged 65 or older. Of those, approx. 5,500 are estimated to exhibit some form of dementia. Figure 3.7.6.1 shows the most affected migrant groups presumably originate from Slovakia (approx. 3,300), Ukraine (approx. 600), Poland (approx. 300), Romania (approx. 300), and Germany (approx. 200). The second graph highlights the number of PwM with dementia in the Czech

Republic per 100,000 inhabitants aged 65 or older (figure 3.7.6.2). Table 13 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Slovakia, Ukraine, Poland, Romania, and Germany throughout the country in NUTS2 regions (figures 3.7.6.3 – 3.7.6.8).

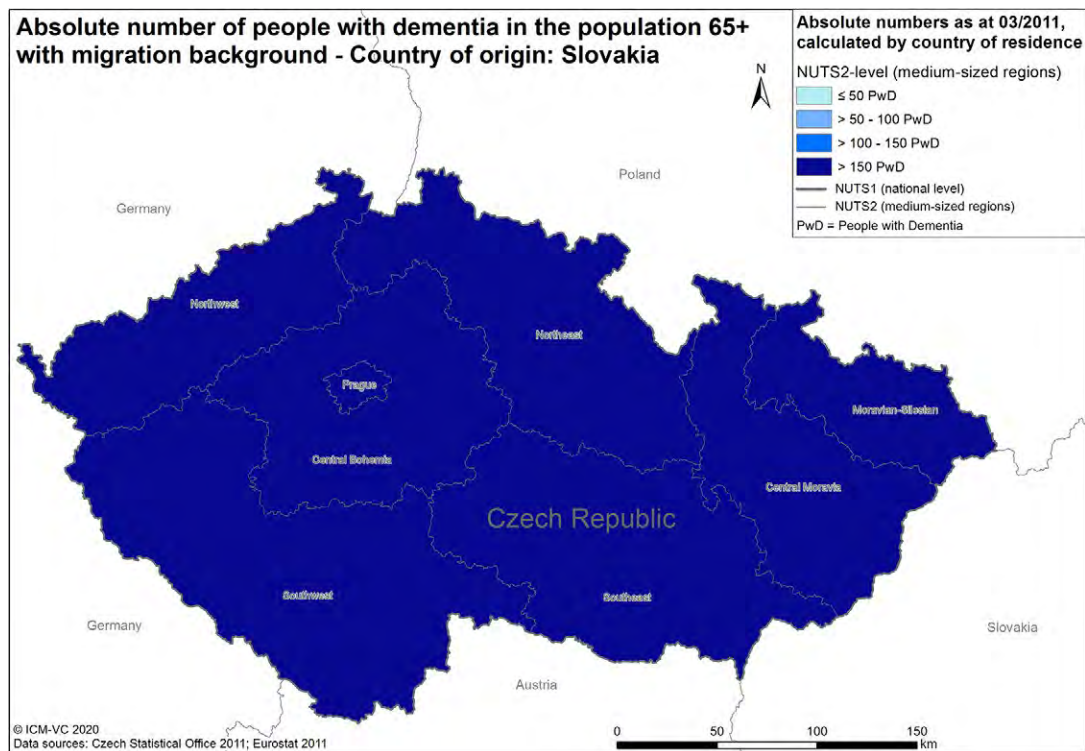


Fig. 3.7.6.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Slovakia (The Czech Republic – NUTS2)

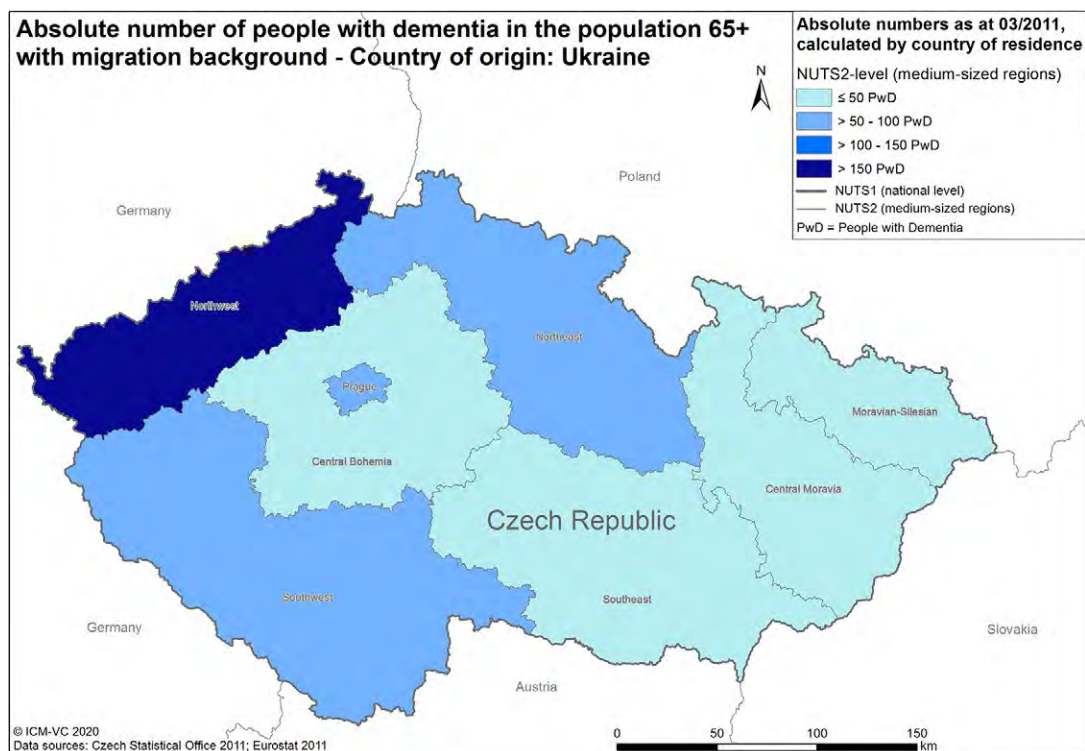


Fig. 3.7.6.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Ukraine (The Czech Republic – NUTS2)

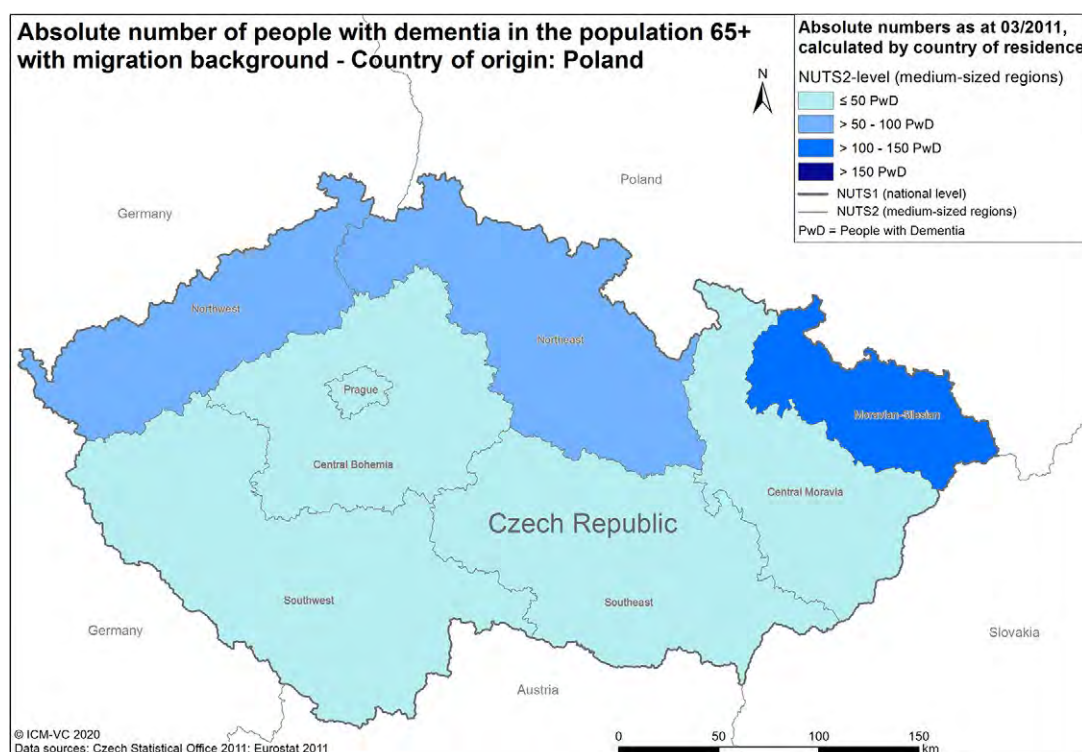


Fig. 3.7.6.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Poland (The Czech Republic – NUTS2)

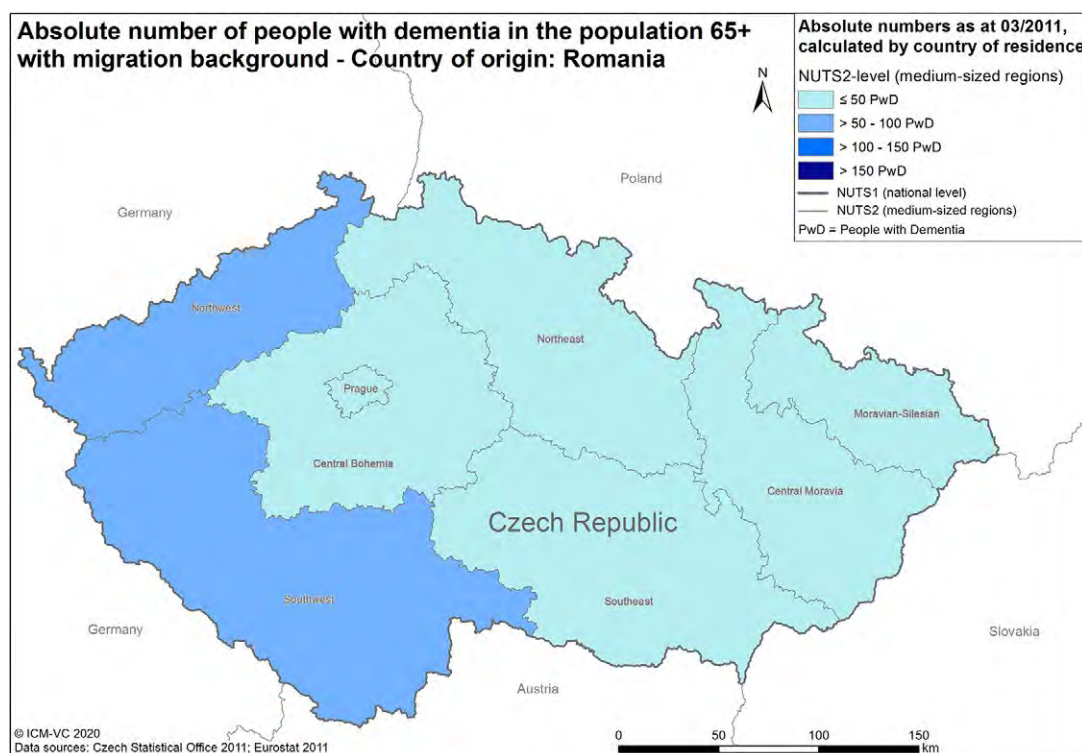


Fig. 3.7.6.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Romania (The Czech Republic – NUTS2)



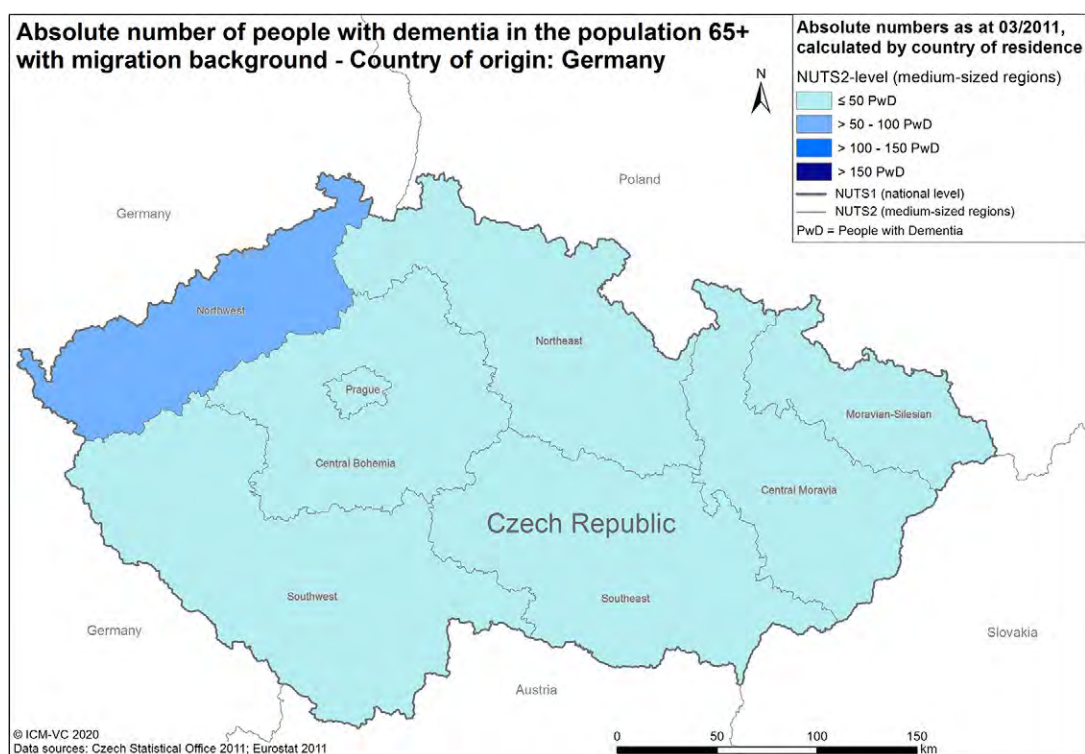


Fig. 3.7.6.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (The Czech Republic – NUTS2)

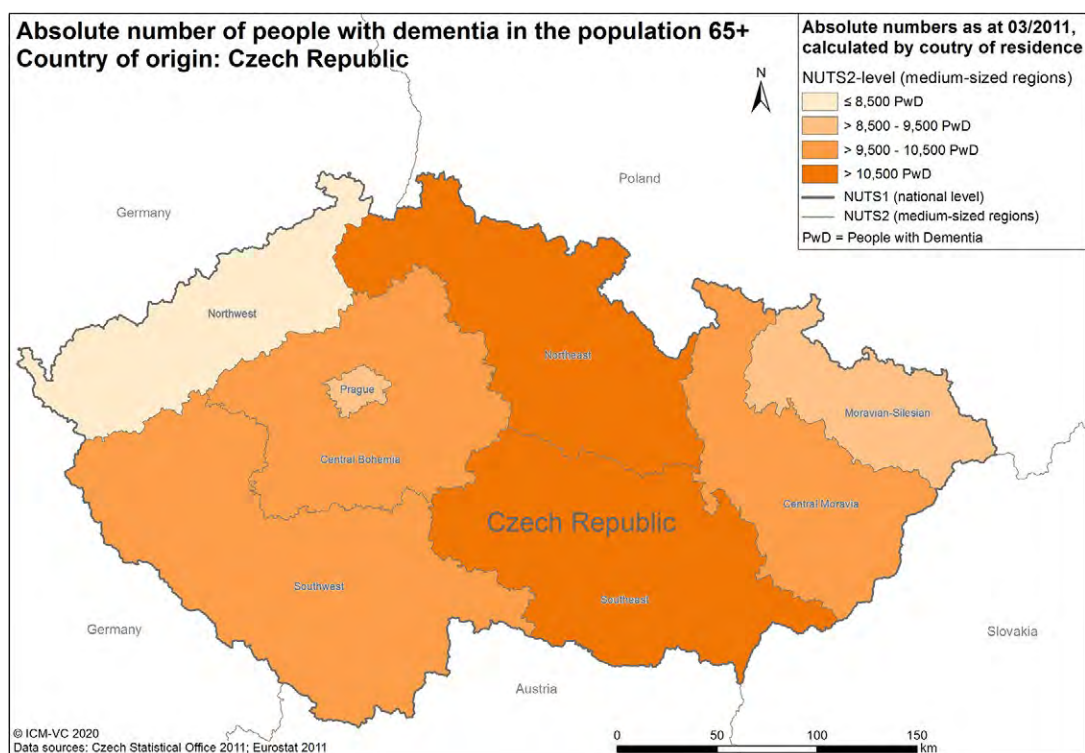


Fig. 3.7.6.8: Absolute number of PwM with dementia aged 65+.  
Country of origin: The Czech Republic (The Czech Republic – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.6.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.6.10). The values from the NUTS2 level can be found in table 14 [8, 9].

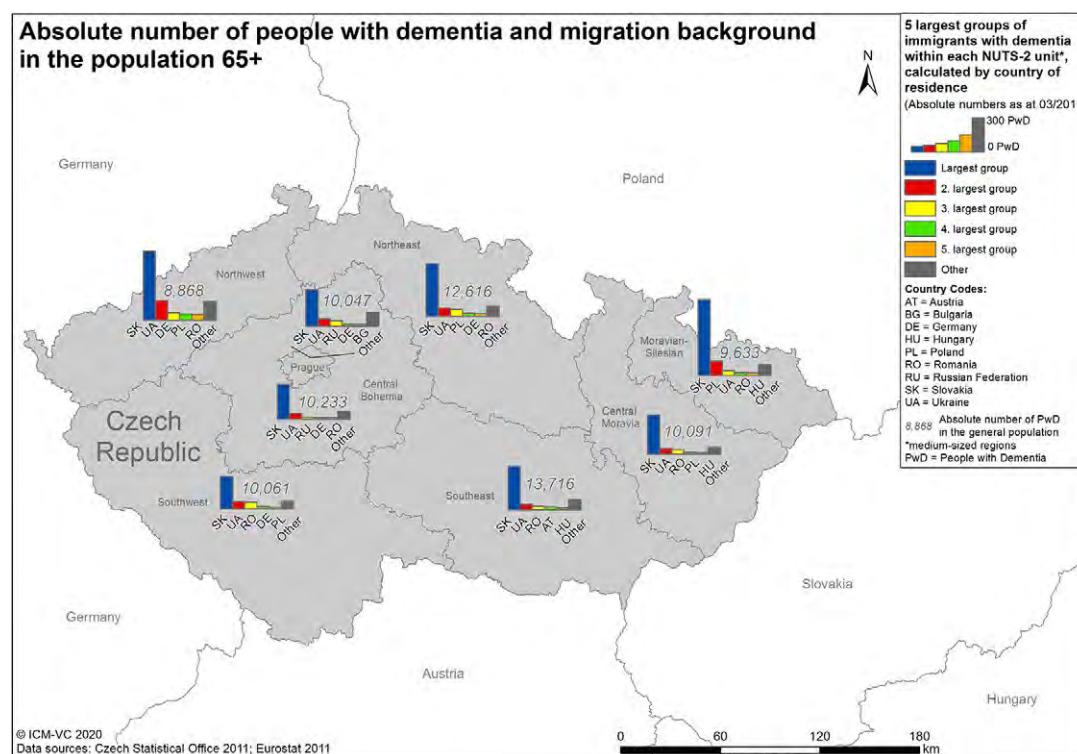


Fig. 3.7.6.9: Absolute number of PwM with dementia in the population 65+ (The Czech Republic – NUTS2)

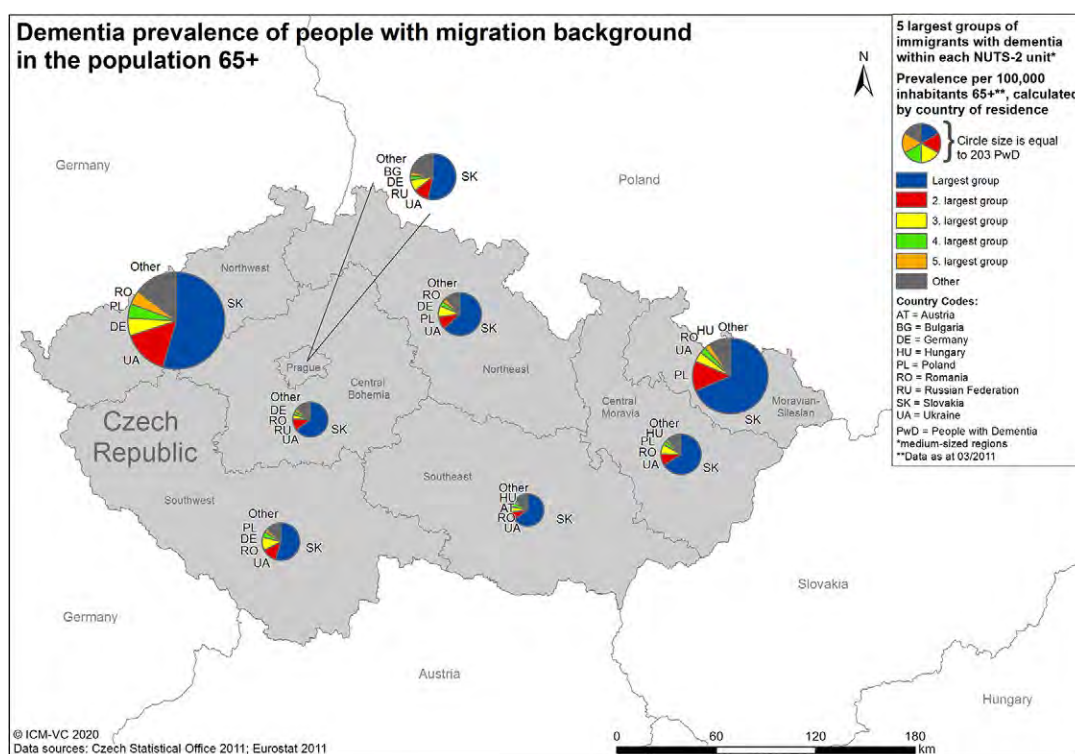


Fig. 3.7.6.10: Dementia prevalence of PwM in the population 65+ (The Czech Republic – NUTS2)

Tab. 14: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Czech Republic – NUTS 2)

NUTS	Total	CZ	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Prague	10,047	9,451	SK 321	UA 65	RU 47	DE 18	BG 15	130
Central Bohemia	10,233	9,779	SK 294	UA 50	RU 17	RO 13	DE 13	67
Southwest	10,061	9,550	SK 280	UA 65	RO 60	DE 22	PL 16	68
Northwest	8,868	7,754	SK 609	UA 171	DE 65	PL 53	RO 52	164
Northeast	12,616	11,904	SK 450	UA 68	PL 58	DE 26	RO 22	88
Southeast	13,716	13,124	SK 384	UA 48	RO 30	AT 25	HU 15	90
Central Moravia	10,091	9,573	SK 343	UA 48	RO 40	PL 17	HU 10	60
Moravian-Silesian	9,633	8,669	SK 660	PL 124	UA 41	RO 25	HU 22	92





# The Czech Republic

NUTS	Total	CZ	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/10,000 inhabitants with migration background 65+								
Prague	6,743	-	SK 215	UA 43	RU 32	DE 12	BG 10	88
Central Bohemia	9,025	-	SK 259	UA 44	RU 15	RO 12	DE 11	59
Southwest	7,872	-	SK 219	UA 51	RO 47	DE 18	PL 12	53
Northwest	3,183	-	SK 218	UA 61	DE 23	PL 19	RO 19	60
Northeast	7,090	-	SK 253	UA 38	PL 33	DE 15	RO 12	49
Southeast	9,268	-	SK 260	UA 33	RO 20	AT 17	HU 10	60
Central Moravia	7,797	-	SK 265	UA 37	RO 31	PL 13	HU 7	47
Moravian- Silesian	3,998	-	SK 274	PL 52	UA 17	RO 11	HU 9	37
Prevalence/100,000 inhabitants 65+								
Prague	4,000	3,763	SK 128	UA 26	RU 19	DE 7	BG 6	42
Central Bohemia	4,000	3,823	SK 115	UA 19	RU 7	RO 5	DE 5	20
Southwest	4,000	3,797	SK 111	UA 26	RO 24	DE 9	PL 6	23
Northwest	4,000	3,497	SK 275	UA 77	DE 29	PL 24	RO 24	68
Northeast	4,000	3,774	SK 143	UA 22	PL 18	DE 8	RO 7	23
Southeast	4,000	3,827	SK 112	UA 14	RO 9	AT 7	HU 4	22
Central Moravia	4,000	3,795	SK 136	UA 19	RO 16	PL 7	HU 4	19
Moravian- Silesian	4,000	3,600	SK 274	PL 52	UA 17	RO 11	HU 9	33

Data source: Czech Statistical Office (2011)



### 3. National dementia plan

The 'National Action Plan for Alzheimer's Disease and Other Similar Diseases for 2016–2019' from 2016 is 23 pages long and covers the following topics: 1. Problem definition: dementia, its symptoms and causes, number of people living with dementia, care for people with dementia, and economic impacts of dementia; 2. Tasks: improving access to diagnosis and ensuring timely and correct diagnosis of dementia, improving access to appropriate care (ensuring appropriate care and its coordination), increasing support for

carers, ensuring the education of informal carers, development of educational programs for professional caregivers, preventive measures in health and social services, raising dementia awareness among the general public, coordinated research efforts (including the use of already available results), organisation of epidemiological monitoring, and involvement of the Czech Republic in European cooperation. None of these topics contain any reference to migration [10].

### 4. National dementia care and treatment guidelines

At the national level, three guidelines or recommendations for the diagnosis of dementia and the treatment of people with dementia (from 2007 [11], 2008 [12], and 2018 [13]) were identified for the Czech Republic. These documents are 6 [11], 8 [12], and 16 pages [13] long and comprise the following topics: 1. pharmacological treatment and non-pharmacological interventions for various forms of dementia such as Alzheimer's disease and vascular de-

mentia [11]; 2. information on the diagnosis of dementia, imaging methods and their use in the diagnosis of dementia, evaluation of clinical diagnosis, evaluation of behavioural and psychiatric symptoms, and evaluation of daily life activities [12]; 3. types of dementia and etiology, diagnostic procedure, and therapeutic procedure [13]. None of the three documents discuss migration [11-13].



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# Denmark

**Population**

5,840,000

**Area**

42,938 km<sup>2</sup>

**Capital**

Copenhagen

**3 largest cities**

Copenhagen (632,000)

Aarhus (350,000)

Aalborg (217,000)

**Neighboring countries**

Germany, Sweden

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Denmark has a history of continuous immigration in recent centuries, beginning from the immigration of Dutch farmers in the early 16th century who were followed by Jewish migrants from various European countries in the 17th century; people from Germany between the mid-17th and 19th centuries; and unskilled workers from Poland, Germany, and Sweden between mid-19th century and World War One. Migration history in the 20th century is characterised by several waves of large-scale refugee immigration. As a result of the two world wars, many people from Eastern Europe and Germany as well as Jews came to Denmark. In the late 1960s and early 1970s, there was a short wave in which guest workers from Turkey, Pakistan, Yugoslavia, and Morocco migrated to Denmark. In addition, Denmark was the destination of about 1,000 refugees every year from Chile and Vietnam in the 1970s. The Cold War, the collapse of Yugoslavia and the Soviet Union, and the Middle Eastern conflicts in the 1990s resulted in the formation of new migrant groups (people from the Russian Federation, Hungary, Bosnia and Herzegovina, Iran, Iraq, and Lebanon). After an increasing number of refugees came from developing countries, a shift towards a restrictive policy took place in the mid-1990s. As a result, the number of refugees declined significantly [1]. Despite factors such as a stringent refugee policy, the implementation of the 1996 Schengen

Agreement from 2001 [2], and the increase in the number of workers from the Baltic States and Poland, after those countries joined the EU in 2004, non-Western immigrants still outnumber Western-origin immigrants in Denmark today. Although citizens from Western countries, especially from Scandinavian countries, the EU, and North America also arrive, they usually stay in Denmark for only a limited period to work or study. Most of the immigrants arriving in Denmark are asylum seekers and persons from non-Western countries who enter as family members of immigrant workers in accordance with the laws regulating family reunification [1, 3]. In 2017, the number of non-Western-origin immigrants living in Denmark was almost twice as high as that of Western-origin immigrants. While the net migration of Western-origin immigrants has languished since 2007, the net migration of non-Western-origin immigrants continues to increase [3]. Between 1990 and 2019, the migrant population (born abroad) more than tripled (235,200 to 722,900) and the proportion of this group in the total population more than doubled (4.6 to 12.5%) [4]. The net migration rate has always been positive and currently amounts to 2.6 [5]. In 2017, people from Turkey (62,700), Poland (44,900), Syria (33,600), and Germany (29,600) represented the largest migrant groups [3].

## 2. Estimated number of people with a migration background with dementia

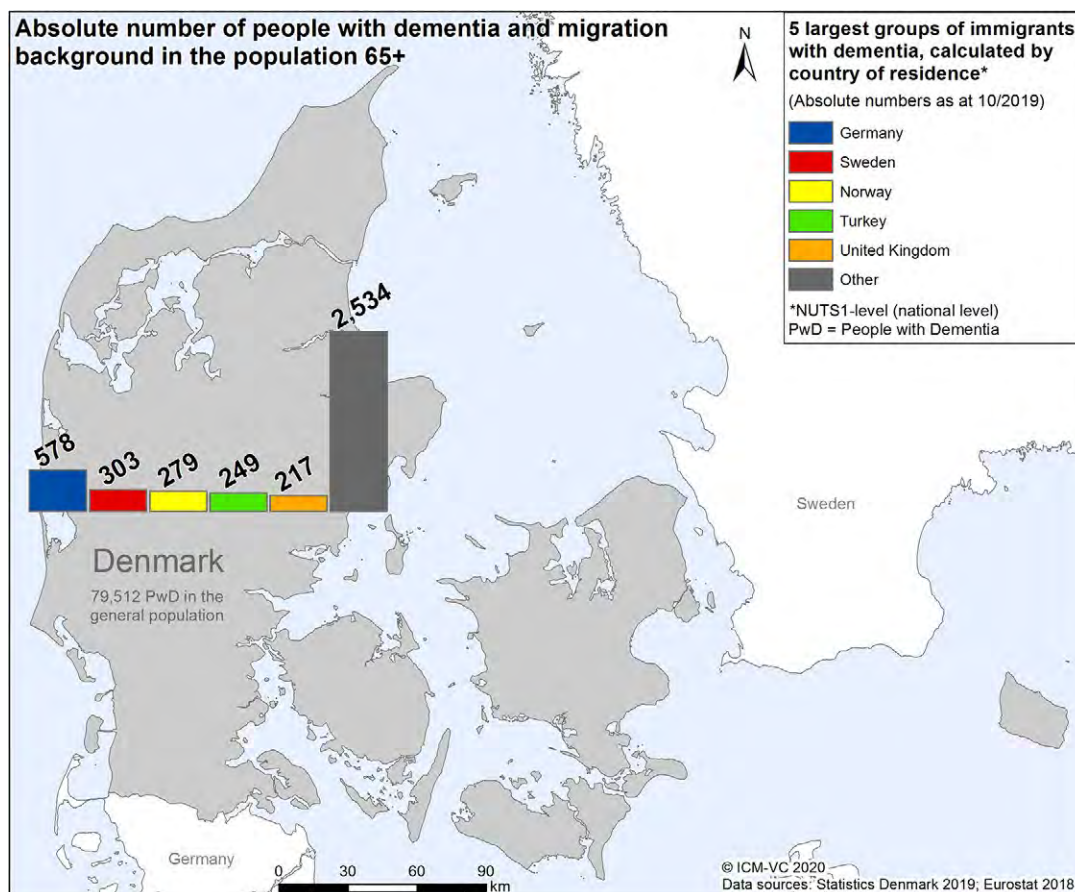


Fig. 3.7.7.1: Absolute number of PwM with dementia aged 65+ (Denmark – Nation)



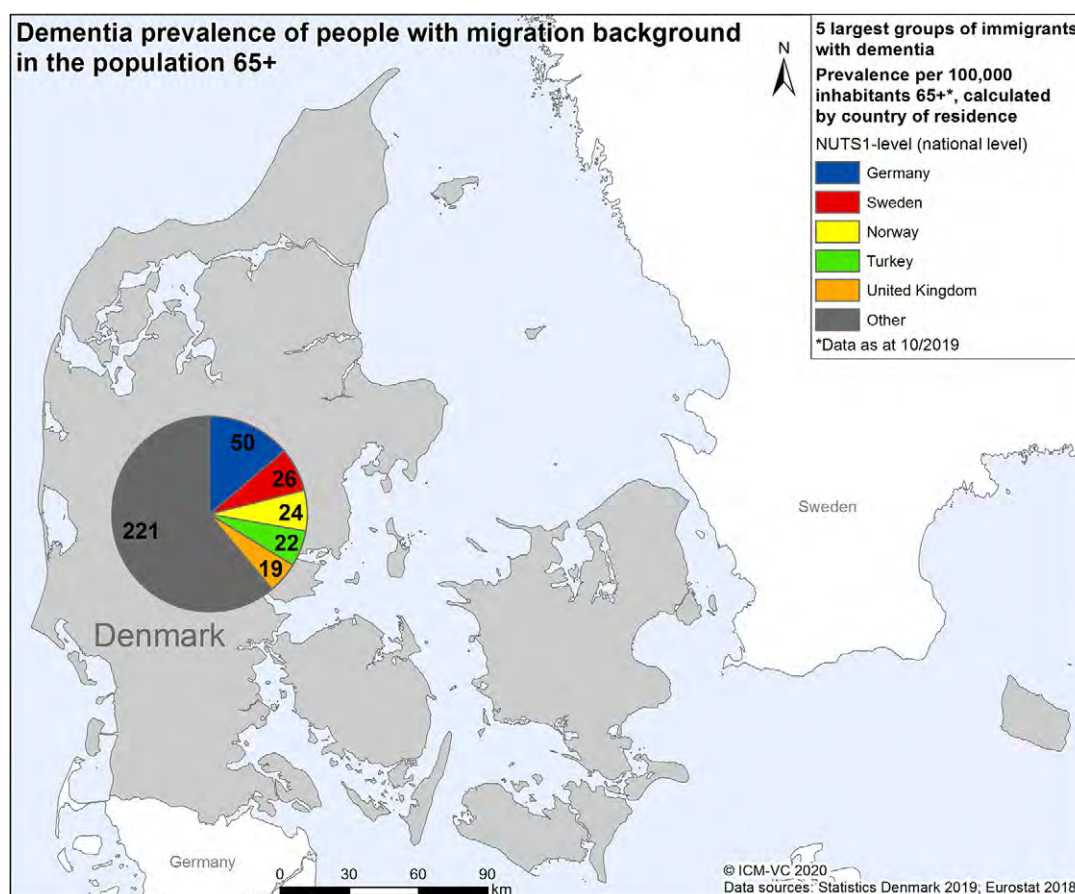


Fig. 3.7.7.2: Dementia prevalence of PwM in the population 65+ (Denmark – Nation)

**Tab. 15: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Denmark – Nation)**

NUTS	Total	DK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Denmark	79,512	75,343	DE 577	SE 303	NO 279	TR 249	UK 217	2,544
Prevalence/10,000 inhabitants with migration background 65+								
Denmark	13,161	-	DE 96	SE 50	NO 46	TR 41	UK 36	421
Prevalence/100,000 inhabitants 65+								
Denmark	6,900	6,538	DE 50	SE 26	NO 24	TR 22	UK 19	209

Data source: Statistics Denmark (2019)

There are 60,400 PwM aged 65 or older. Of those, approx. 4,200 are estimated to exhibit some form of dementia. Figure 3.7.7.1 shows the most affected migrant groups presumably originate from Germany (approx. 600), Sweden (approx. 300), Norway (approx. 300), Turkey (approx. 300), and United Kingdom (approx. 200). The second graph highlights the number of PwM with dementia in Denmark per

100,000 inhabitants aged 65 or older (figure 3.7.7.2). Table 15 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Germany, Sweden, Norway, Turkey, and the UK throughout the country in the NUTS2 regions (figures 3.7.7.3 – 3.7.7.8).

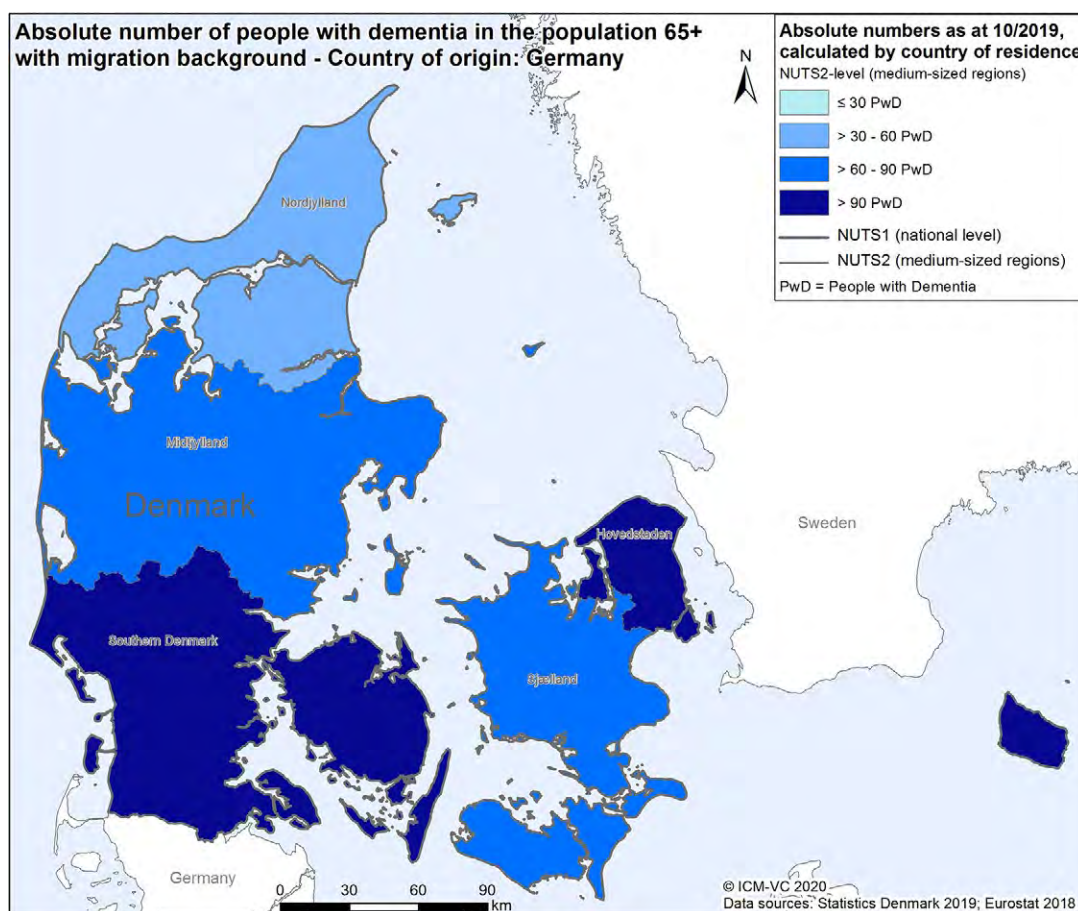
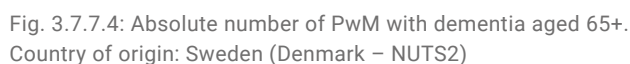


Fig. 3.7.7.3: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Denmark – NUTS2)



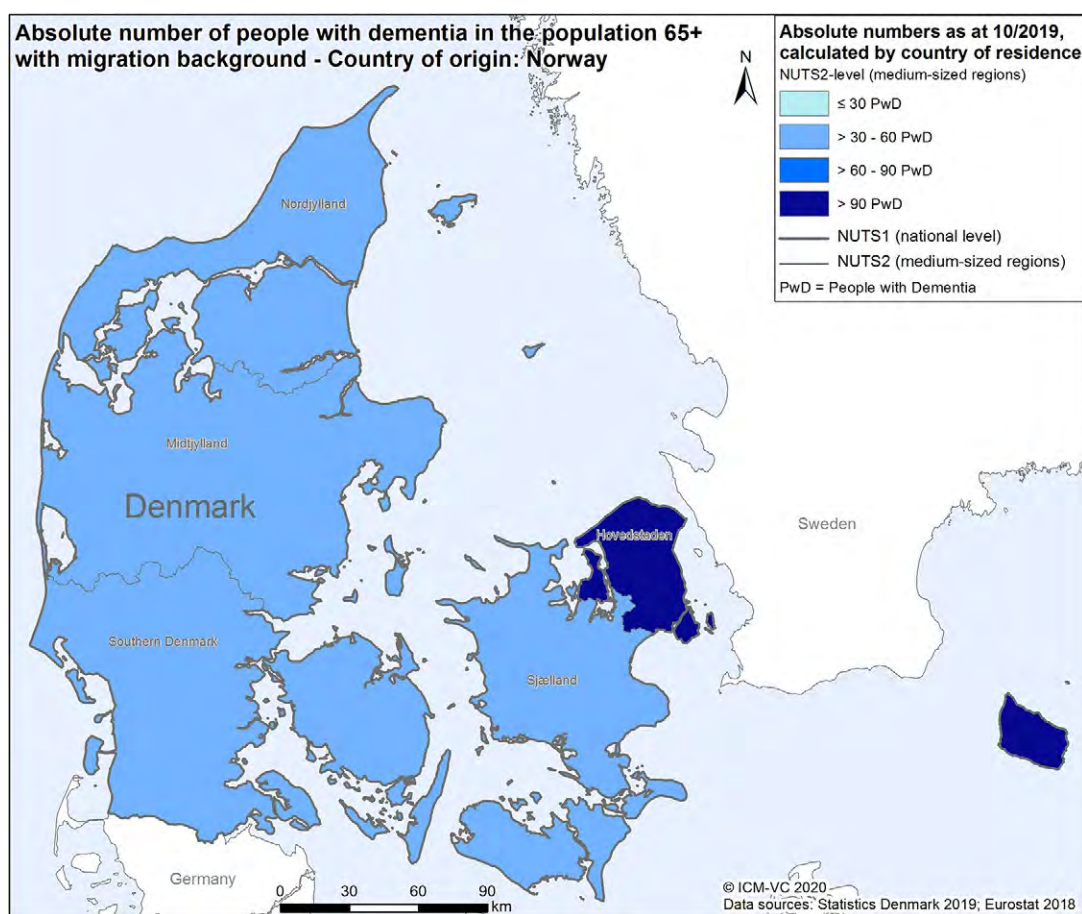


Fig. 3.7.7.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Norway (Denmark – NUTS2)



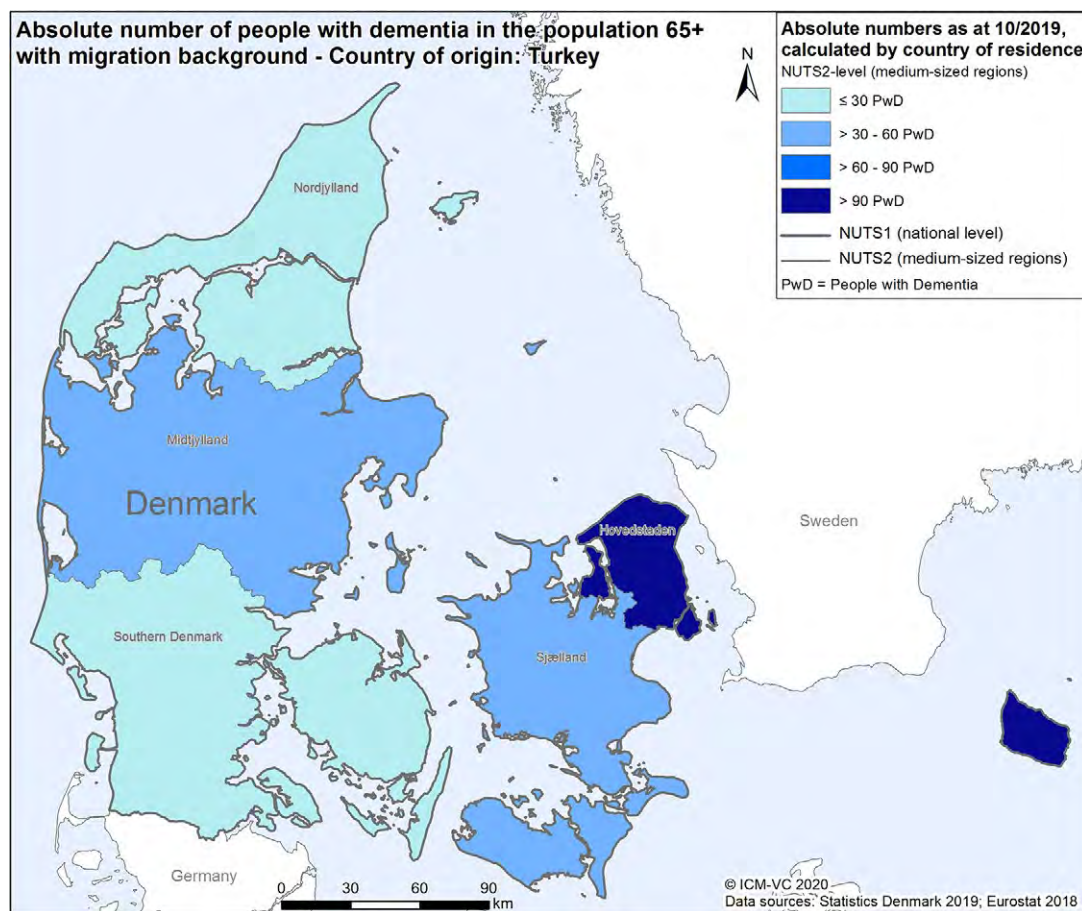


Fig. 3.7.7.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Turkey (Denmark – NUTS2)

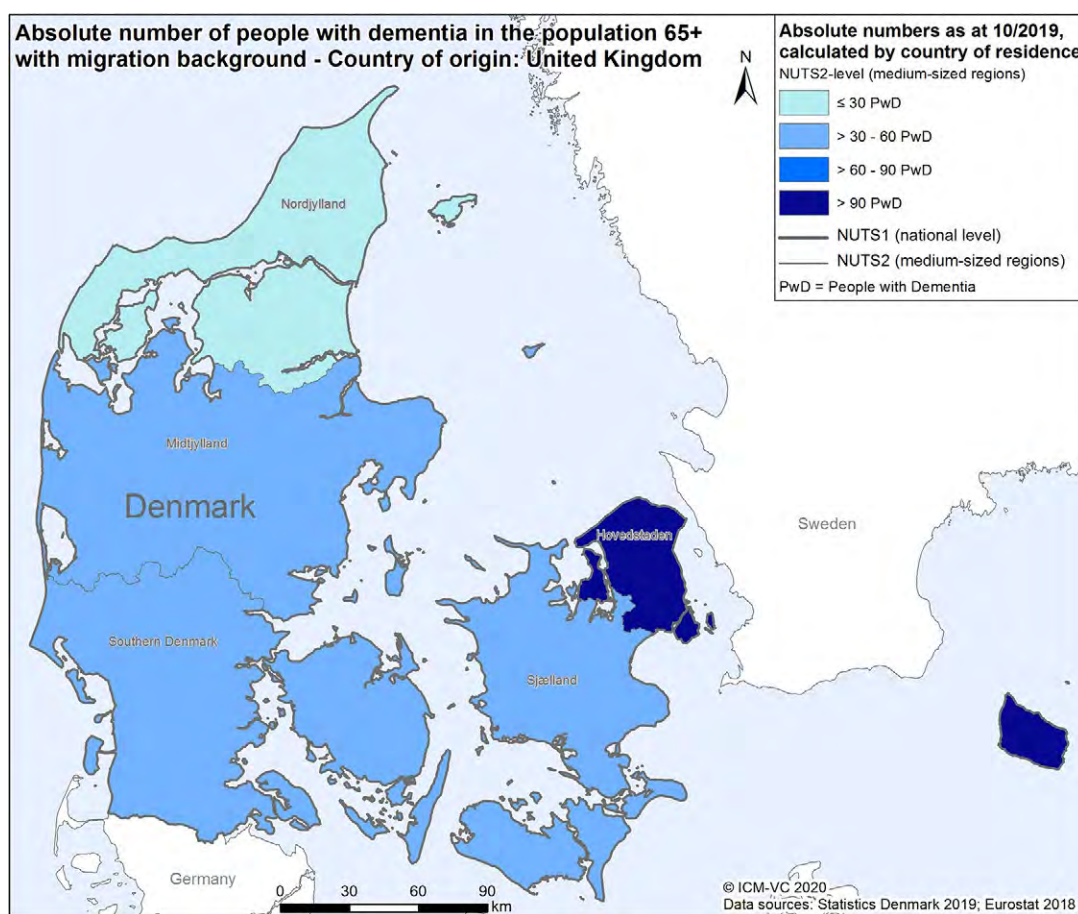


Fig. 3.7.7.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: United Kingdom (Denmark – NUTS2)

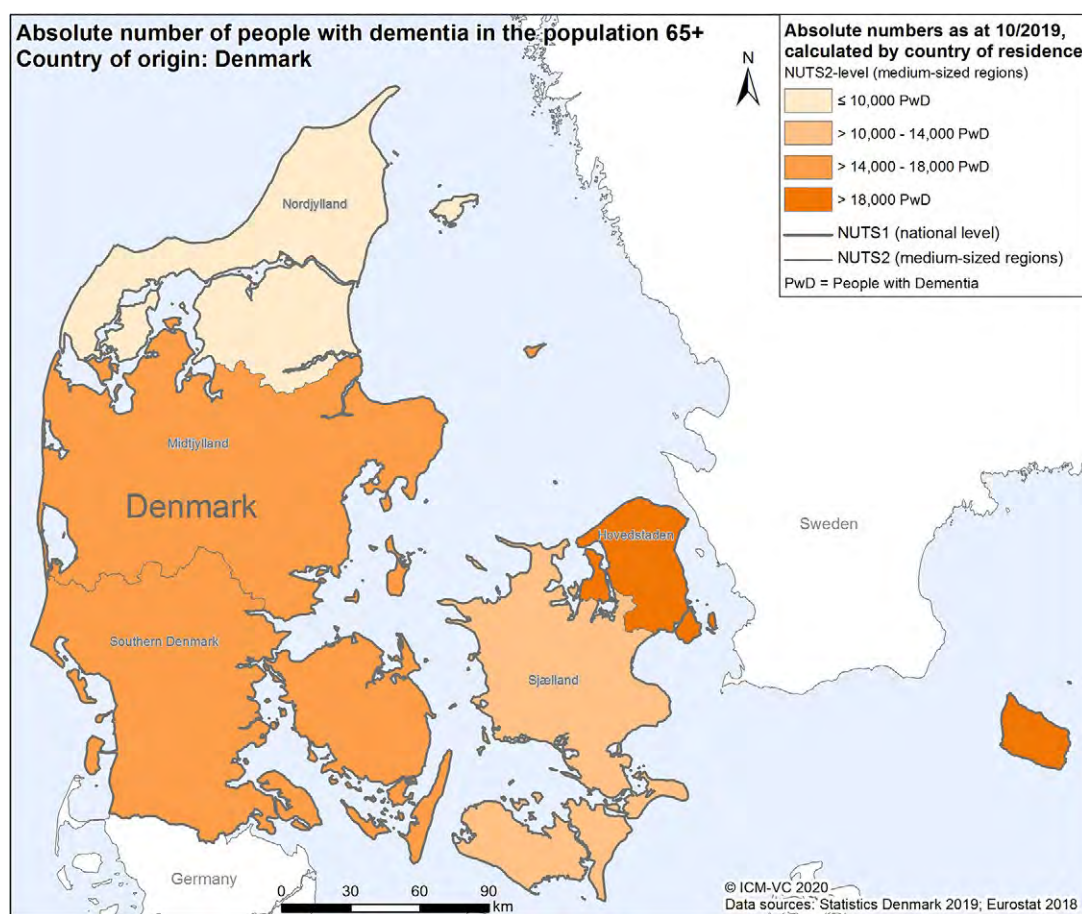


Fig. 3.7.7.8: Absolute number of PwM with dementia aged 65+.  
Country of origin: Denmark (Denmark – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.7.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.7.10). The values from the NUTS2 level can be found in table 16 [6-8].

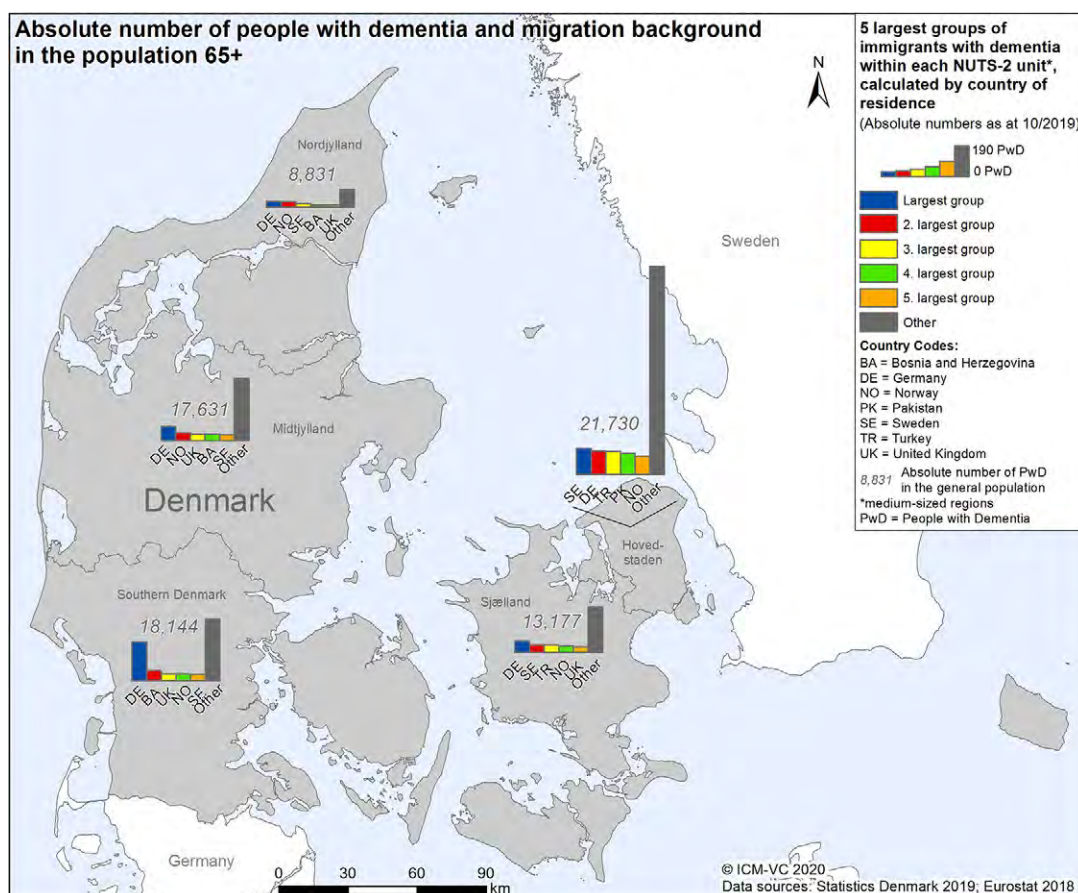


Fig. 3.7.7.9: Absolute number of PwM with dementia aged 65+ (Denmark – NUTS2)

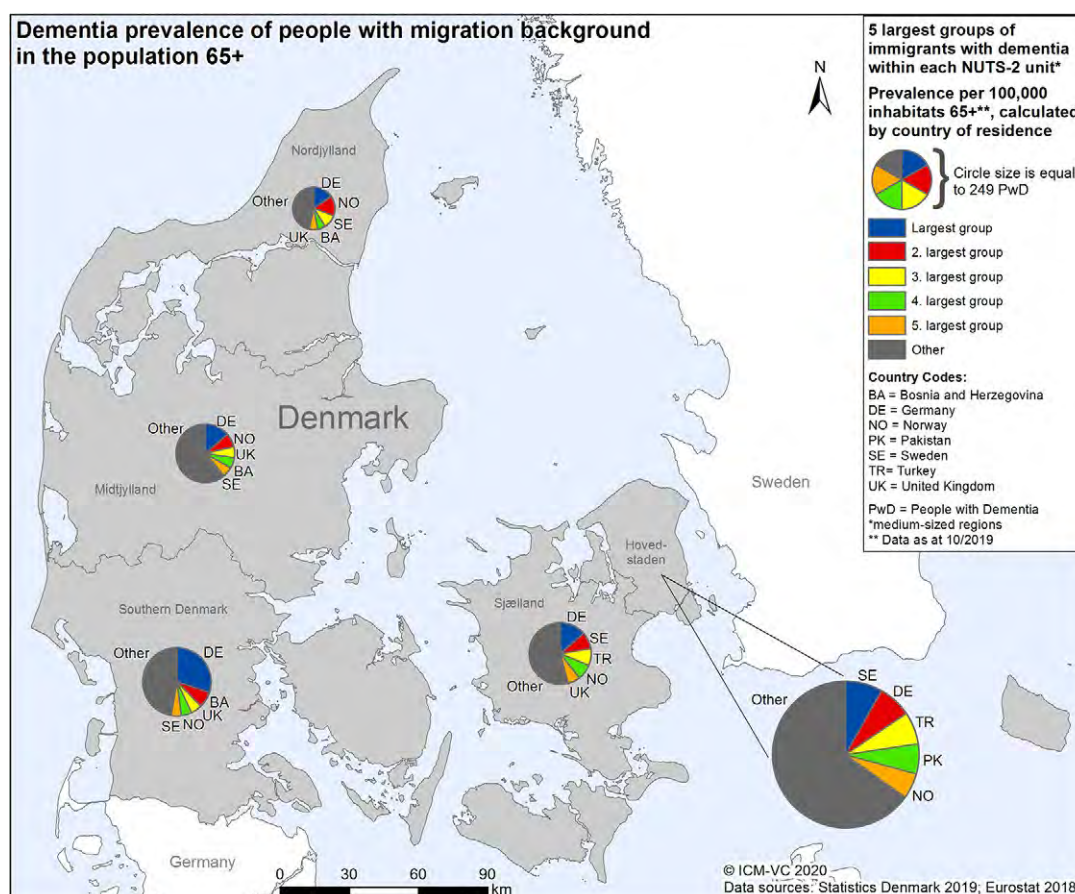


Fig. 3.7.7.10: Prevalence of PwM with dementia among the population aged 65+ (Denmark – NUTS2)

**Tab. 16: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Denmark – NUTS 2)**

NUTS	Total	DK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Hovedstaden	21,730	19,726	SE 162	DE 149	TR 143	PK 132	NO 115	1,303
Sjælland	13,177	12,670	DE 69	SE 44	TR 44	NO 41	UK 33	276
Syddanmark	18,144	17,360	DE 234	BA 62	UK 40	NO 39	SE 37	372
Midtjylland	17,631	16,995	DE 88	NO 48	UK 38	BA 38	SE 35	389
Nordjylland	8,831	8,592	DE 37	NO 36	SE 24	BA 15	UK 15	112



NUTS	Total	DK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/10,000 inhabitants with migration background 65+								
Hovedstaden	7,484	-	SE 56	DE 51	TR 49	PK 45	NO 40	449
Sjælland	17,932	-	DE 94	SE 60	TR 60	NO 56	UK 45	375
Syddanmark	15,970	-	DE 206	BA 54	UK 35	NO 35	SE 33	327
Midtjylland	19,149	-	DE 96	NO 52	UK 42	BA 41	PL 38	421
Nordjylland	25,487	-	DE 107	NO 104	SE 69	BA 44	UK 43	323
Prevalence/100,000 inhabitants 65+								
Hovedstaden	6,900	6,264	SE 51	DE 47	TR 45	PK 42	NO 36	403
Sjælland	6,900	6,635	DE 36	SE 23	TR 23	NO 21	UK 17	132
Syddanmark	6,900	6,602	DE 89	BA 23	UK 15	NO 15	SE 14	128
Midtjylland	6,900	6,651	DE 35	NO 19	UK 15	BA 15	PL 14	137
Nordjylland	6,900	6,731	DE 29	NO 28	SE 19	BA 12	UK 12	75

Data source: Statistics Denmark (2019)

### 3. National dementia plan

There is a Danish 'National Action Plan on Dementia 2025' from 2017. It consists of 14 pages and focuses on five objectives: 1. Early detection and better quality of examination and treatment, 2. improved quality of care, nursing, and rehabilitation, 3. support and guidance for the relatives of people with dementia, 4. dementia-friendly communities and housing, and 5. increasing knowledge and professional skills. Across different sections, 23 initiatives are mentioned; for example, the section on objective 4 presents Initiative 15, which concerns establishing 98 dementia-friendly municipalities. However, neither the five objectives nor the 23 initiatives refer to PwM [9]. In addition

to the NDP, Denmark has published a white paper 'Denmark - a Dementia-Friendly Society' in 2018. This document is 36 pages long and addresses several distinct topics: early detection of dementia, high quality diagnosis, evaluation and treatment, dementia-friendly hospitals, quality of care and rehabilitation, support of person-centred care through digital care planning, support for family caregivers, support of people with dementia and their families through technological tools, improvement of the safety of people with dementia, increasing knowledge and professional skills, and interactive technology-based staff training. The white paper also has no reference to migration or PwM [10].



### 4. National dementia care and treatment guidelines

For Denmark, four clinical guidelines for dementia at the national level were identified: one for dementia and medicine, one for diagnosing mild cognitive impairment and dementia, one for examining and treating dementia, and one for preventing and treating behavioral and psychological symptoms in people with dementia. The 'National Clinical Guideline on Dementia and Medicine' from 2018 and the 'National Clinical guideline for the Prevention and Treatment of Behavioral and Mental Symptoms in People with Dementia' from 2019 do not refer to the topic of migration [11, 12]. The 'National Clinical Guideline for the Diagnosis of Mild Cognitive Impairment and Dementia' from 2018 makes a brief reference to migration and points out that in Denmark a validation of the Rowland Universal Dementia Assessment Scale (RUDAS) exists, a dementia screening tool developed in Australia as an interculturally appropriate measurement. This validation is based on tests of 137 patients, including 34 PwM [13]. The 'National Clinical Guideline for the Examination and Treatment of Dementia' from 2013 has a short section with two paragraphs on ethnic minorities. It points out that the number of immigrants older than 65 years (approximately 16,000 in 2013) will increase in the next decades. Fur-

thermore, the group of people from non-Western countries is highlighted as a vulnerable group with regard to the diagnosis of dementia. The heterogeneity of this group in terms of cultural background, language skills, and educational level may make it difficult to examine and assess cognitive functions. If educational and language skills are not taken into account, there is a significant risk of overdiagnosis of cognitive impairment. According to a study from 2010, there are almost 1,000 immigrants from non-Western countries living in Denmark who are over 65 years old and have dementia. Moreover, it is pointed out that the cognitive function test MMSE (Mini Mental Status Examination) is sensitive to the influence of language skills. The guideline concludes that there may be particular difficulties in the assessment of dementia in immigrants from non-Western countries [14].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

### 5. Services and information for people with a migration background with dementia

According to the expert, PwM are in principle identified as a vulnerable group in Denmark. PwM mostly originate from Turkey, Pakistan, Arab speaking countries, and Yugoslavia. While there is a general awareness of this issue, it is not a focus area and, is only seen as partly important. It is clear that dementia in PwM is treated as important only in the major cities like Copenhagen, rather than in other

parts of Denmark where fewer PwM live. Challenges related to PwM concern cognitive assessments, the use of professional interpreters, adherence to clinical recommendations and treatment plans, and how dementia care should be organised for this population. The main issues identified by the expert are an increased risk for development and progression of dementia, under-diagnosis, and lack of ac-



cess to formal healthcare services.

The expert stated that in general Denmark follows an integrative healthcare strategy in which the mainstream services accommodate the special needs of people with dementia. Information material and fact sheets about dementia, Alzheimer's disease, and vascular dementia are published in ten different languages (Danish, English, Turkish, Urdu, Farsi, Croatian, Bosnian, Serbian, Polish, Somali) and have been verified by people from the different language or ethnic communities. There are no specialised services for PwM with dementia as well as no specialised services for any specific minorities according to the expert. However, there are two specialised immigrant clinics, located in Copenhagen and Aarhus, which treat patients with complicated medical histories. They take into account the economic situation, immigration issues, medical and psychiatric illness etc. of patients. There is also an ethnic resource team in Copenhagen that organizes home care. Their personnel have different ethnic and language backgrounds and they are matched with care receivers who wish to have professional caregivers of the same ethnicity and language as their own. A nursing home in Copenhagen specializes in multicultural care

and caters to the dietary needs and different religious backgrounds of the people.

As stated by the expert, existing services for dementia are suitable for the care of non-migrants but not for people from ethnic minority groups. There is a high need for specific information and services because the needs often differ from what is provided in mainstream services. Without any specialized information or services many caregivers cannot really access those services.

Furthermore, the expert pointed out that in order to improve the situation of PwM with dementia different projects were or are being executed. A current project is focusing on spreading awareness and knowledge about dementia in minority groups by reaching out to them at places where they socialize or congregate with others from their community, such as cultural centres, and also at private homes. Different projects are concentrating on intercultural care and trying to map the care needs of older PwM. There is another project investigating the needs of people and families from minority groups by directly talking to them so that services can be based on real needs rather than assumptions.

## 6. Professional qualification and people with a migration background in healthcare

The expert interview showed that options for continuing education in cross-cultural encounters and communication exist but it is mainly provided in the major cities. Furthermore, culturally sensitive care is part of the curriculum in most programs for healthcare professionals but it is not a mandatory part of any curriculum or continuing education.

The high proportion of professionals with a migration background working in healthcare is another point that was of special interest in

the interview. Professional caregivers in Denmark mostly originate from Turkey, Pakistan, or Arab speaking countries. The cultural differences between care givers and receivers leads to various cultural challenges in healthcare. Discrimination and racism towards the care personnel can arise. Sometimes such care personnel are not familiar with the culture-based needs of the care receiver and also might not be able to communicate effectively in Danish. Also, opinions on 'good care' can





differ. 'Good care' in Denmark refers to rehabilitation and focuses on helping older people to manage on their own. But many of the young women with a migration background are perceived to come from family-oriented cultures

where one cherishes older people, meaning that good care is doing everything for them. That is counterproductive to rehabilitation. At the moment, the need for culturally sensitive care for PwM is rated as not being met.

## 7. Support for family caregivers

The expert highlighted that the main support for the family caregivers and the people living with dementia comes from the immediate family – and in many cases only the family – and service providers, healthcare professionals or social workers. The ethnic and religious communities as well as the migrant organisations are not seen to play a role in dementia care.

Additionally, the expert pointed out that there are major differences in terms of accessibility of services and information between family caregivers with and without a migration background. In the absence of specialised support and guidance, PwM are unable to access the available services. Therefore, they are in high need of specialised services.

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12. Sundhedsstyrelsen: National klinisk retningslinje for forebyggelse og behandling af adfærdsmæssige og psykiske symptomer hos personer med demens; 2019.
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# Estonia

**Population**

1,329,000

**Area**

45,228 km<sup>2</sup>

**Capital**

Tallinn

**3 largest cities**

Tallinn (438,000)

Tartu (93,000)

Narva (54,000)

**Neighboring countries**

Latvia, the Russian  
Federation

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

Over the last one and a half centuries, the population and ethnic structure in Estonia has been majorly impacted by migration. There were two waves of extensive emigration. First was in the second half of the 19th century (to the Russian Federation) and the second wave was in 1944 (to the West). During the Second World War, mainly ethnic minorities left the country (from Germany, Sweden, Jewish communities). Only the Russian community was not destroyed. After the Second World War, Estonia transformed from an emigration country to an immigration country. Most immigrants came from the Russian Federation. Immediately after the Second World War, net migration was 10,000 people per year. The second wave of large-scale immigration took place in the 1960s. The restoration of independence then led to a renewed change in the direction of migration. Between 1989 and 1994, more than 80,000 people left Estonia. Many people returned to the Russian Federation, but some also emigrated to the West.

Between 1989 and 2000, the total population declined by more than 12% and ethnic minorities shrank by more than a quarter. Since the turn of the millennium, both emigration and immigration have increased. The majority of immigrants came from Finland (33%) and the Russian Federation (22%). Almost half of them are returnees. The most frequent destination countries for emigrants were Finland (two thirds), the Russian Federation (7%), and the UK (6%) [1]. In 2019, people from Russia (118,100), Ukraine (24,000), Belarus (10,400), Latvia (6,000), and Finland (5,900) represented the largest migrant groups [2]. Thus, Russian-speaking minorities who came to Estonia during the Soviet era make up the largest migrant group [1]. Between 1990 and 2019, the migrant population (born abroad) halved (382,000 to 190,200) and the proportion of migrants in the total population fell from 24.4 to 14.4% [3]. As of 2020, the net migration rate is 3; it is positive for the first time since 1990 [4].

## 2. Estimated number of people with a migration background with dementia

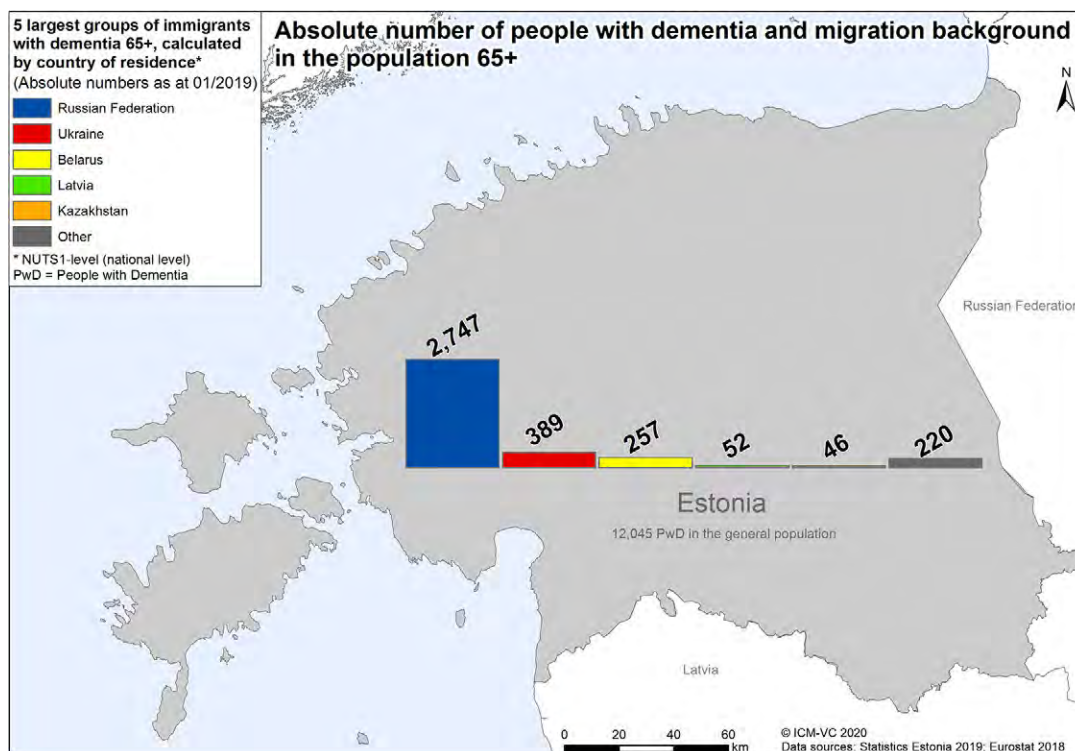


Fig. 3.7.8.1: Absolute number of PwM with dementia aged 65+ (Estonia – Nation)

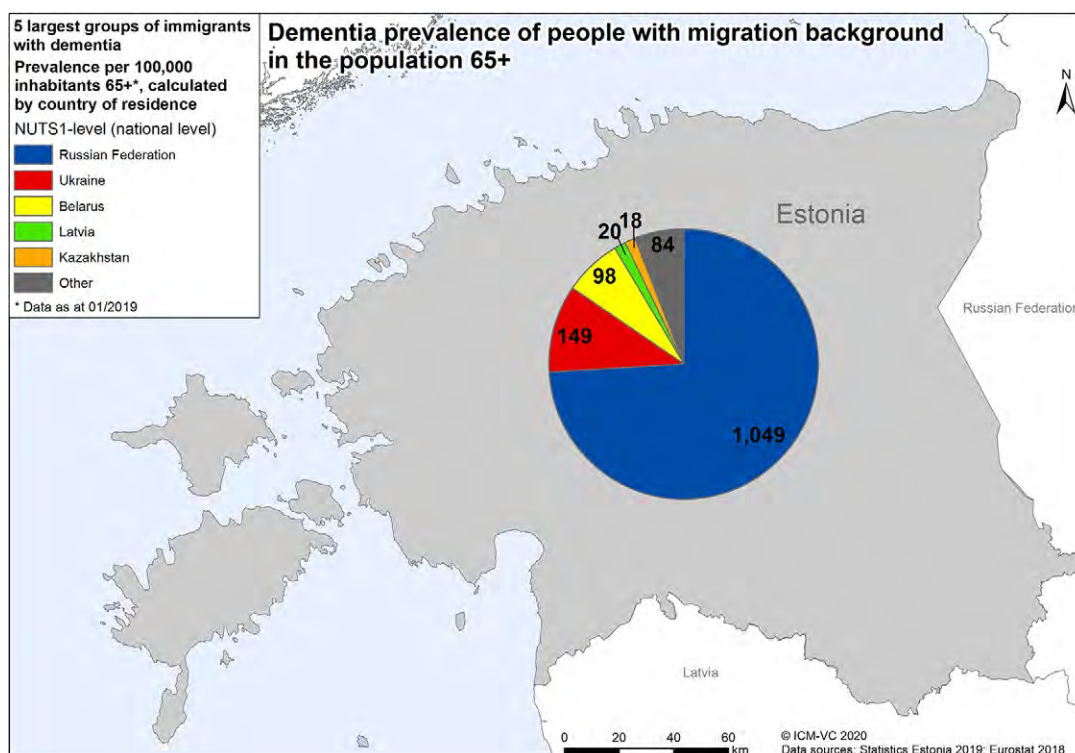


Fig. 3.7.8.2: Prevalence of PwM with dementia among the population aged 65+ (Estonia – Nation)

**Tab. 17: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Estonia – Nation)**

NUTS	Total	EE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Estonia	12,045	8,335	RU 2,747	UA 389	BY 257	LV 52	KZ 46	219
Prevalence/10,000 inhabitants with migration background 65+								
Estonia	1,493	-	RU 341	UA 48	BY 32	LV 6	KZ 6	27
Prevalence/100,000 inhabitants 65+								
Estonia	4,600	3,183	RU 1,049	UA 148	BY 98	LV 20	KZ 18	84

Data source: Statistics Estonia (2019)

There are 80,700 PwM aged 65 or older. Of those, approx. 3,700 are estimated to exhibit some form of dementia. Figure 3.7.8.1 shows the most affected migrant groups presumably originate from the Russian Federation (approx. 2,800), Ukraine (approx. 400), Belarus (approx.

300), Latvia (approx. 50), and Kazakhstan (approx. 50). The second graph highlights the number of PwM with dementia in Estonia per 100,000 inhabitants aged 65 or older (figure 3.7.8.2). Table 17 displays the values depicted in the maps on the national level [5-7].

### 3. National dementia plan

No NDP could be identified for Estonia [8].

### 4. National dementia care and treatment guidelines

The 'Estonian Guideline for Treatment and Diagnosis of Dementia' from 2006 is 43 pages long and includes the topics epidemiology, prevention, screening, diagnosis of dementia (definition and symptoms of dementia, neuropsychological diagnosis, radiological examinations),

dementia and driving, treatment of dementia (treatment of cognitive disorders, treatment of behavioural and psychological disorders), and stages of dementia. There is no reference to migration in any of these topics [9].



## 5. References

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# Finland

**Population**

5,525,000

**Area**

338,452 km<sup>2</sup>

**Capital**

Helsinki

**3 largest cities**

Helsinki (654,000)

Espoo (290,000)

Vantaa (234,000)

**Neighboring countries**

Norway, the Russian

Federation, Sweden

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Finland does not have a long tradition of international migration. Before the 1990s, the history of migration was mainly characterised by economically motivated emigration [1]. Between 1860 and 1999 more than one million people emigrated from Finland, almost 500,000 before the Second World War and over 730,000 thereafter. Before the Second World War, the majority of emigrants left the country for North America, and afterward, 75% of them emigrated to Sweden. About half of the emigrants returned to Finland. Finland was a part of the Russian Federation between 1809 and 1917, tens of thousands of people from the Russian Federation lived in Finland during this period. They remained there even after the country's independence, establishing a small community of approximately 15,000 people in the 1930s. The admission of the earliest international migrants dates back to 1973 when about a hundred refugees came from Chile.

Since 1986, Finland has accepted annual immigration of about 500–1,000 refugees. In 1990, the first asylum seekers reached Finland [2]. From that time Finland developed into an immigration country with migrants from the Russian Federation, Estonia, Somalia, Syria, Afghanistan, and Iraq [1]. In 2017, people from the former Soviet Union (56,700) represented the largest migrant group, followed by Estonia (46,000), Sweden (32,400), and Iraq (16,300) [3]. Compared to other European and Scandinavian countries, the migrant population in Finland is relatively small. However, between 1990 and 2019 this population (people born abroad) has grown many times over (from 63,300 to 383,100). During the same period, the proportion of migrants in the total population has also increased significantly (from 1.3 to 6.9%) [4]. As of 2020, the net migration rate is 2.5 [5].

## 2. Estimated number of people with a migration background with dementia

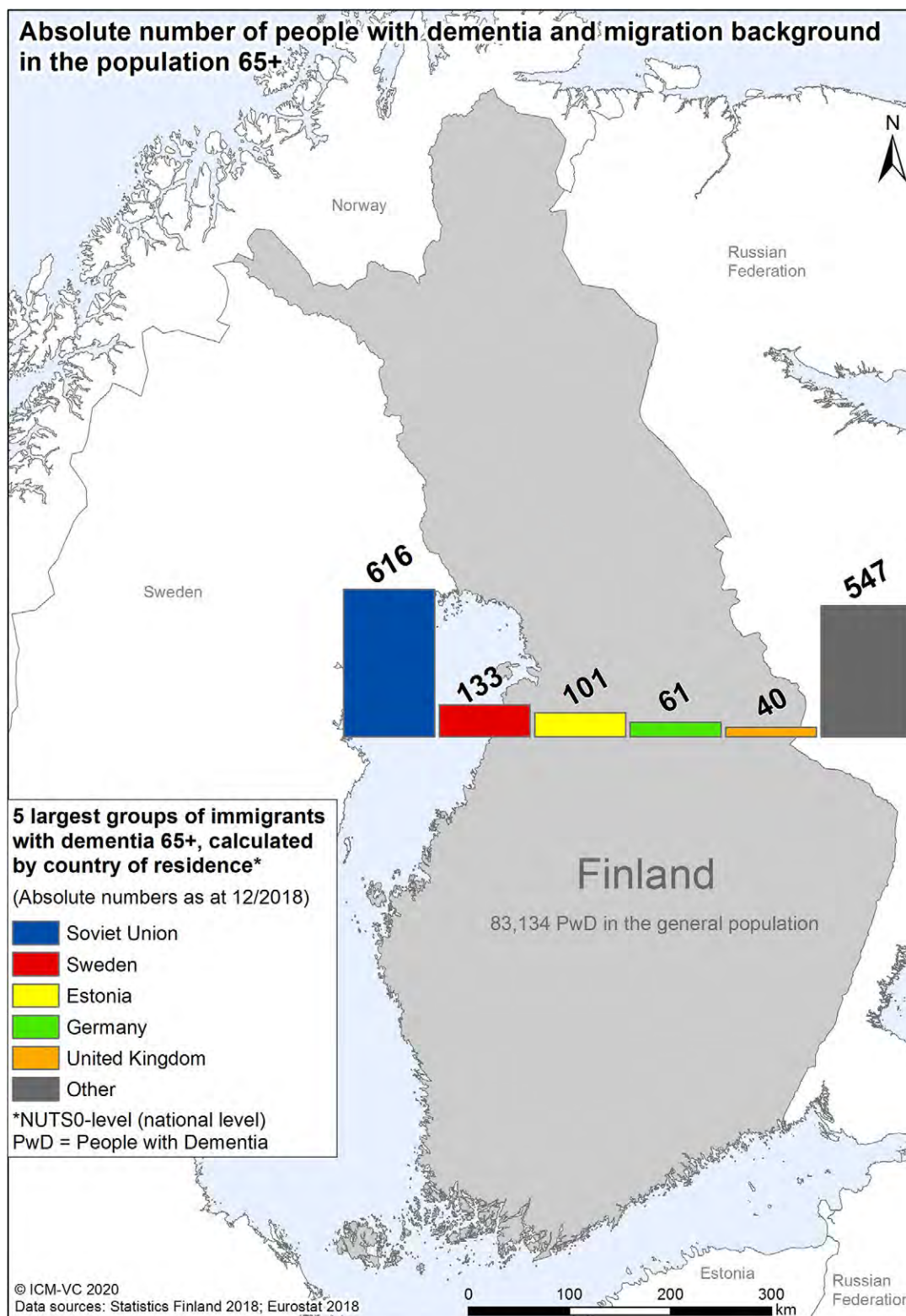


Fig. 3.7.9.1: Absolute number of PwM with dementia aged 65+ (Finland – Nation)

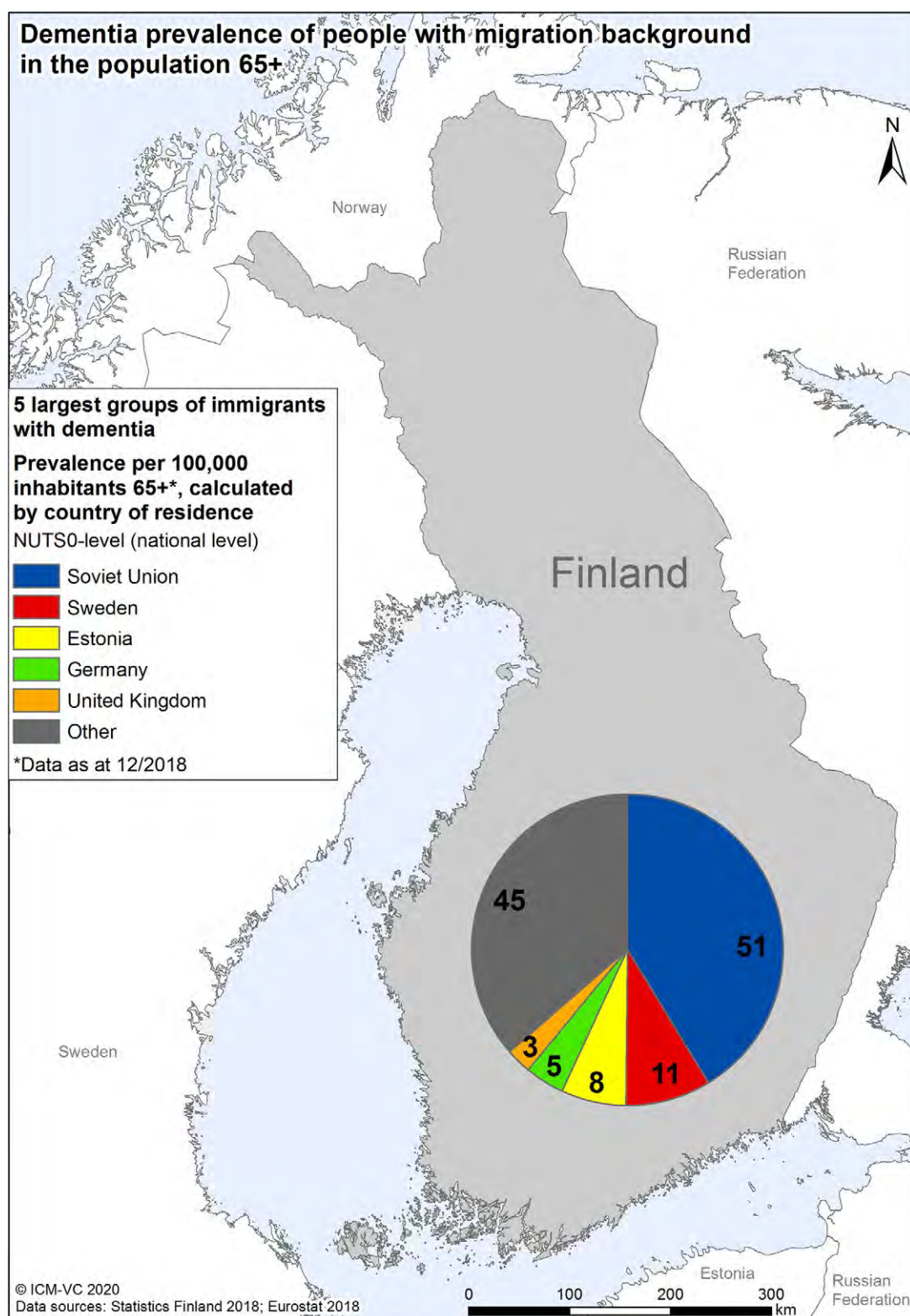


Fig. 3.7.9.2: Prevalence of PwM with dementia among the population 65+ (Finland – Nation)

**Tab. 18: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Finland – Nation)**

NUTS	Total	FI	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Finland	83,134	81,637	SU 616	SE 132	EE 101	DE 61	UK 40	547
Prevalence/10,000 inhabitants with migration background 65+								
Finland	38,332	-	SU 284	SE 61	EE 46	DE 28	UK 18	253
Prevalence/100,000 inhabitants 65+								
Finland	6,900	6,776	SU 51	SE 11	EE 8	DE 5	UK 3	99

Data source: Statistics Finland (2018)

There are 21,700 PwM aged 65 or older. Of those, approx. 1,500 are estimated to exhibit some form of dementia. Figure 3.7.9.1 shows the most affected migrant groups presumably originate from the Soviet Union (approx. 600), Sweden (approx. 100), Estonia (approx. 100), Germany (approx. 60), and United Kingdom (approx. 40). The second graph highlights the number of PwM with dementia in Fin-

land per 100,000 inhabitants aged 65 or older (figure 3.7.9.2). Table 18 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Sweden, Estonia, Germany, United Kingdom and the Russian Federation throughout the country in the NUTS2 regions (figures 3.7.9.3 – 3.7.9.8).



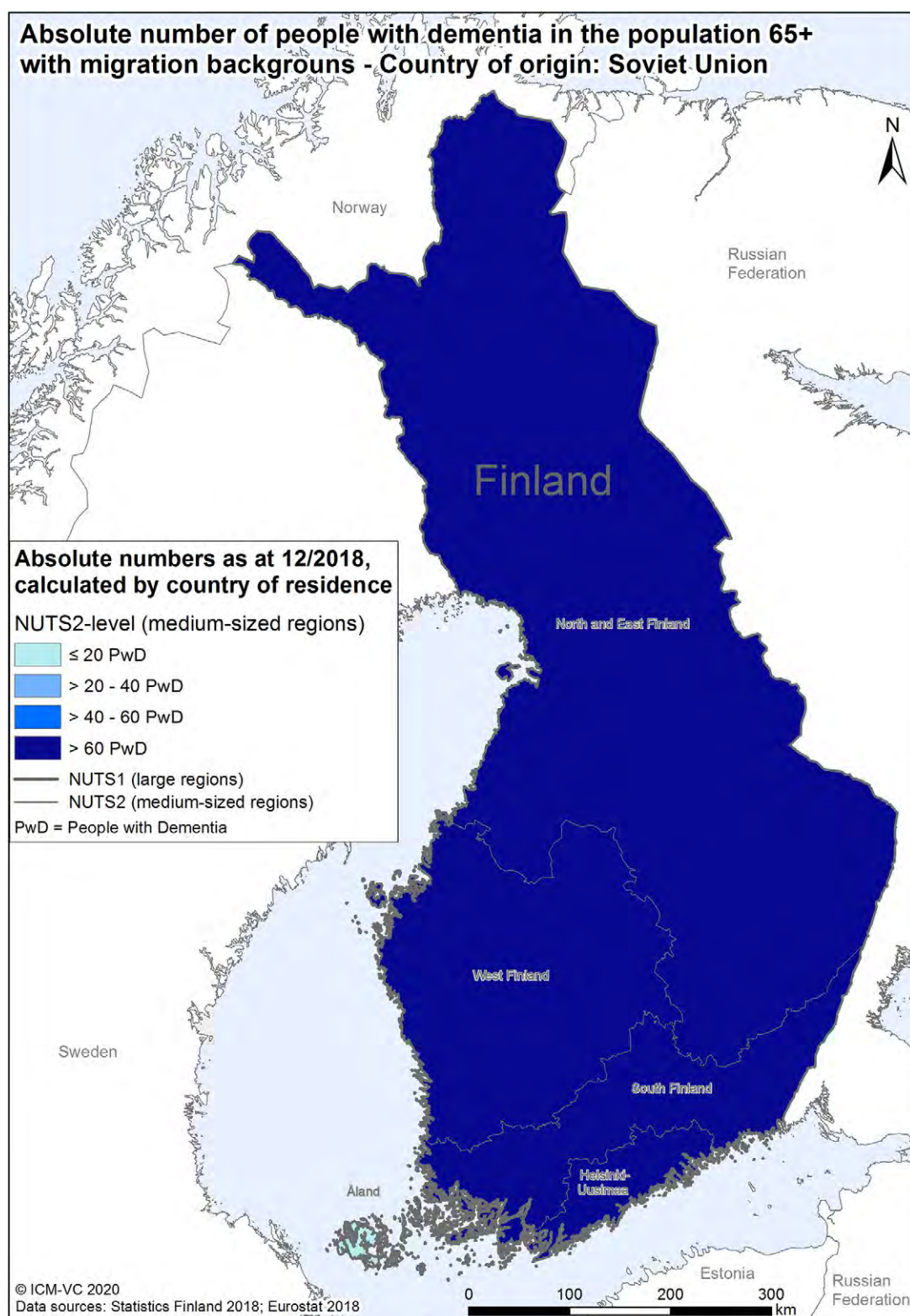


Fig. 3.7.9.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Soviet Union (Finland – NUTS2)



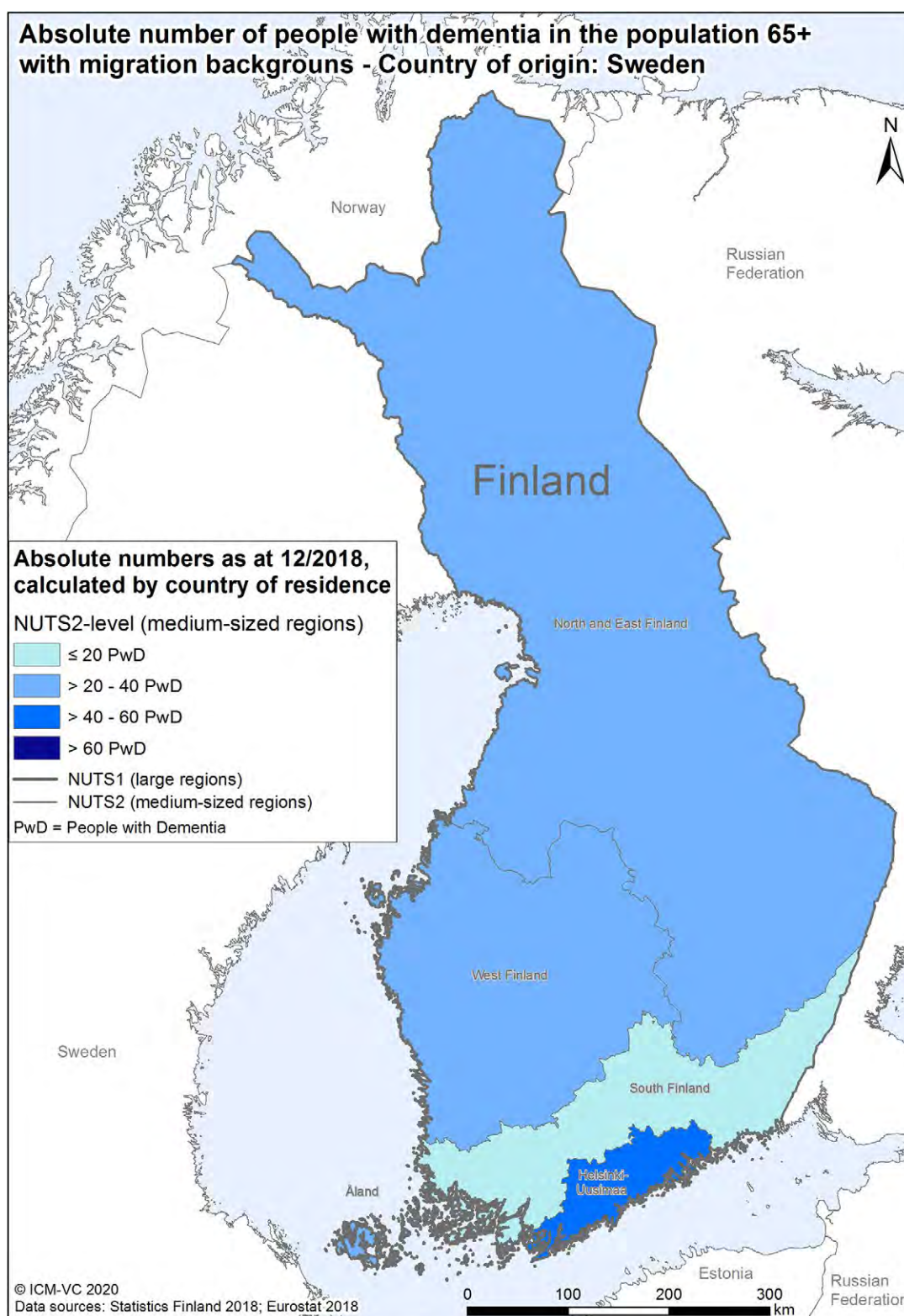


Fig. 3.7.9.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Sweden (Finland – NUTS2)

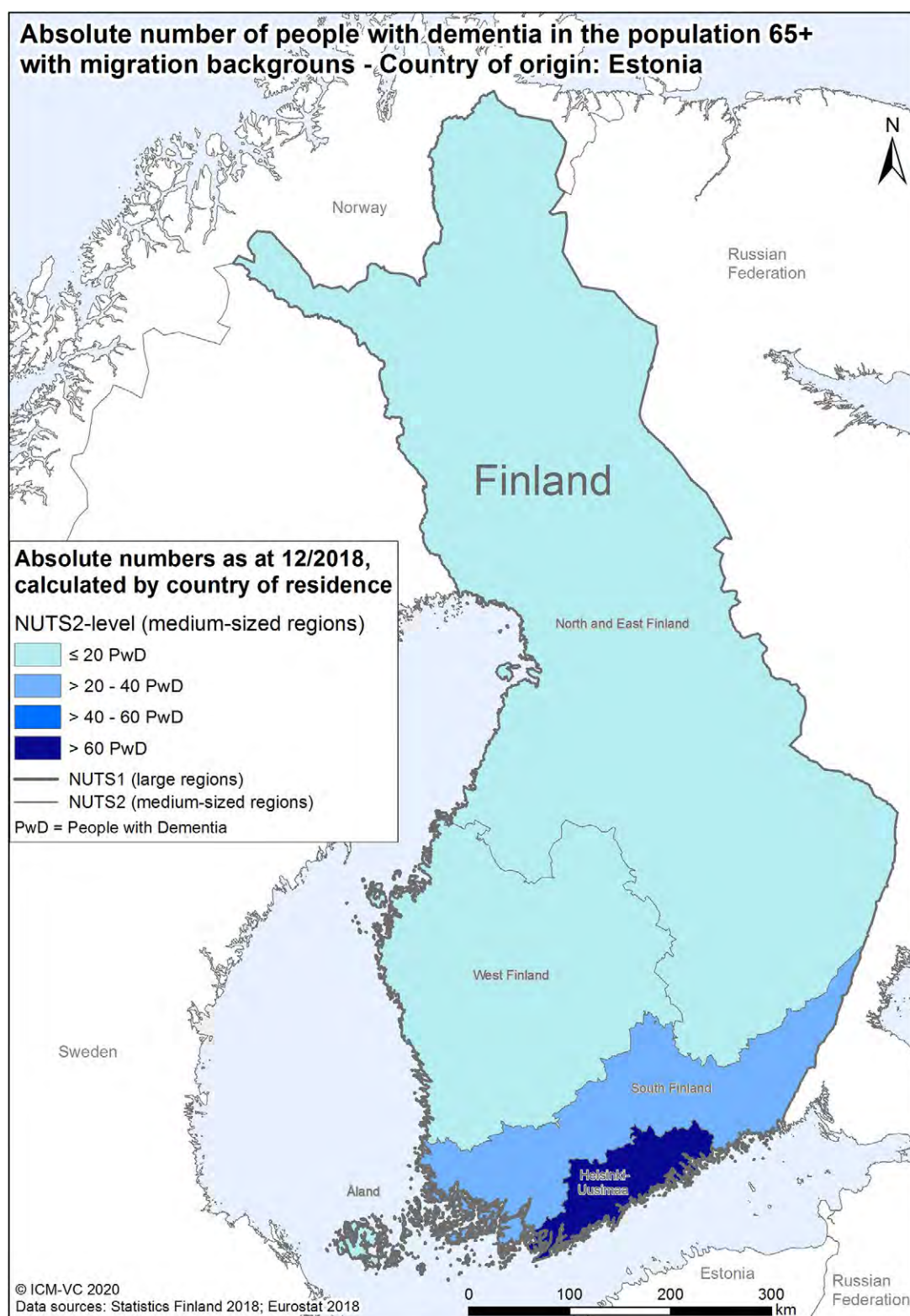


Fig. 3.7.9.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Estonia (Finland – NUTS2)

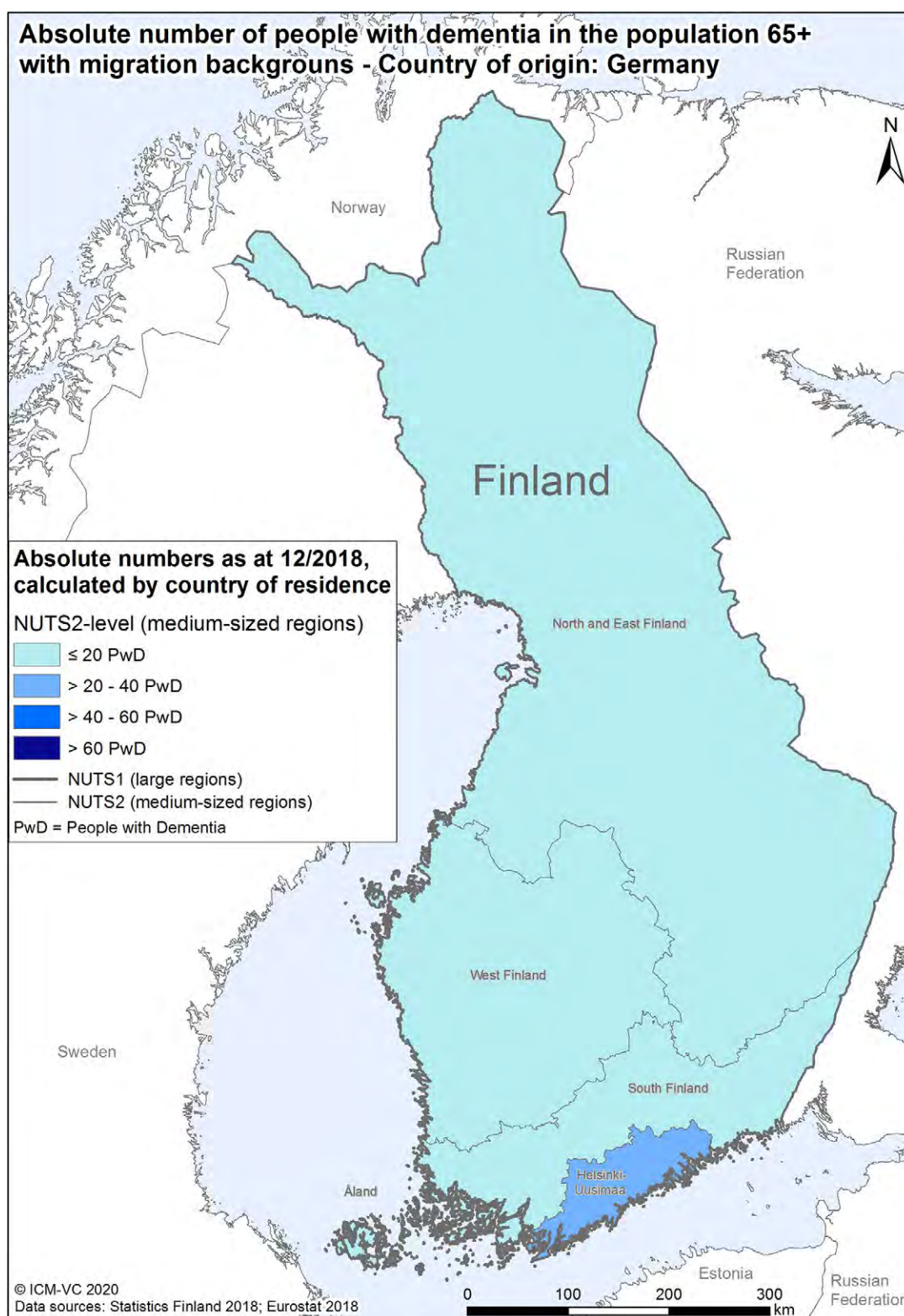


Fig. 3.7.9.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (Finland – NUTS2)



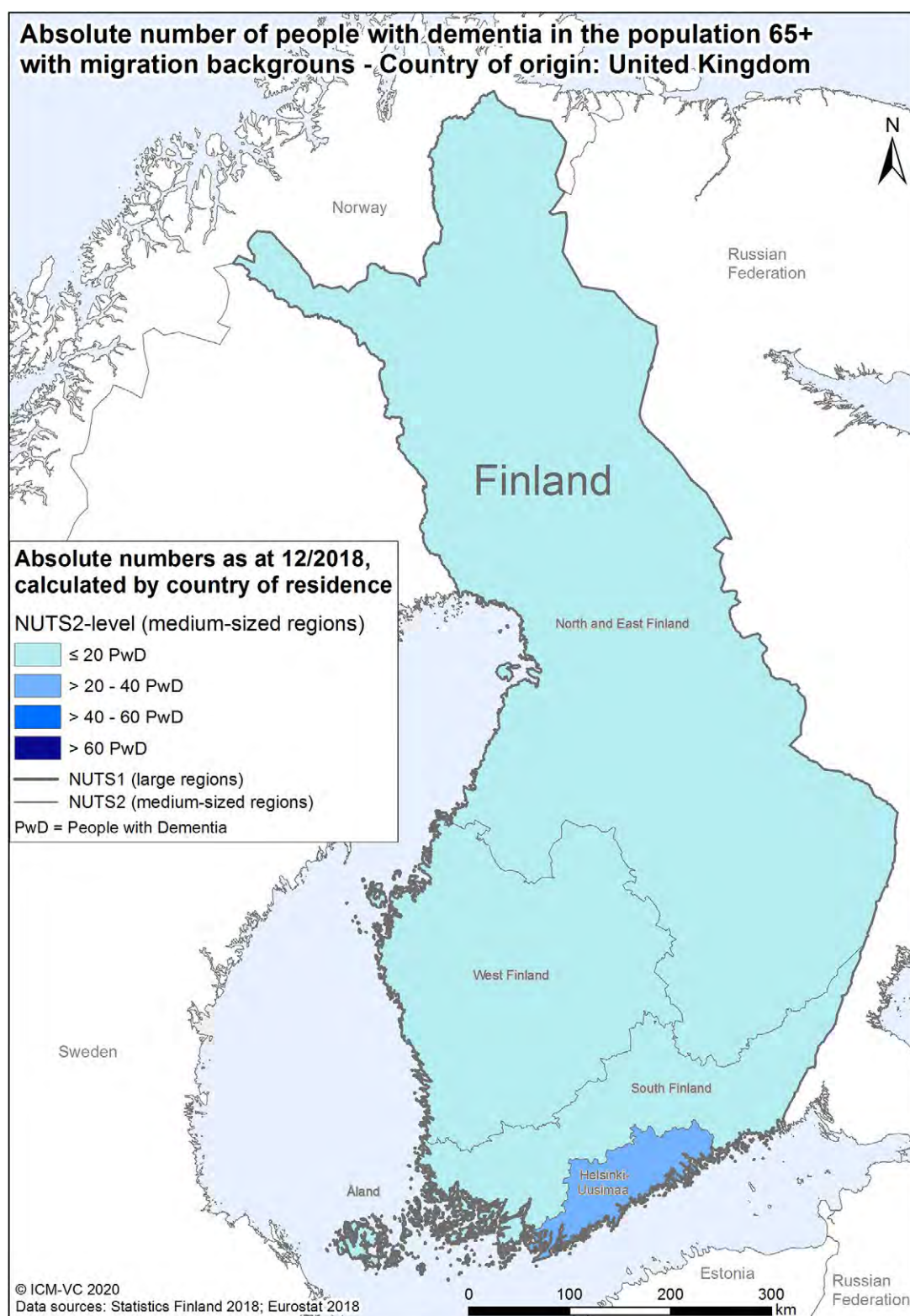


Fig. 3.7.9.7: Absolute number of PwM with dementia aged 65+. Country of origin: United Kingdom (Finland – NUTS2)

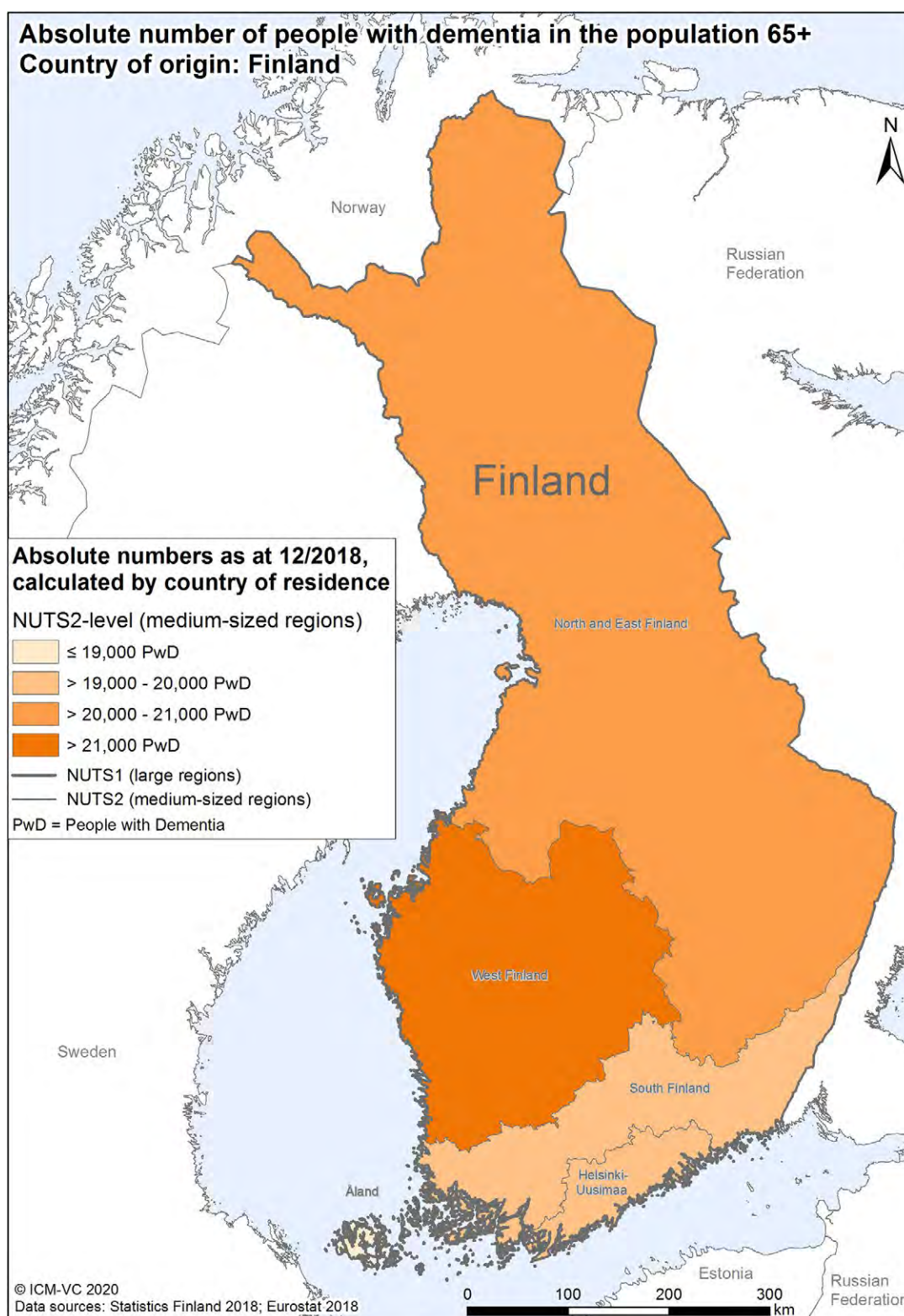


Fig. 3.7.9.8: Absolute number of people with dementia aged 65+.  
Country of origin: Finland (Finland – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.9.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (Fig. 3.7.9.10). The values from the NUTS2 level can be found in table 19 [6-8].

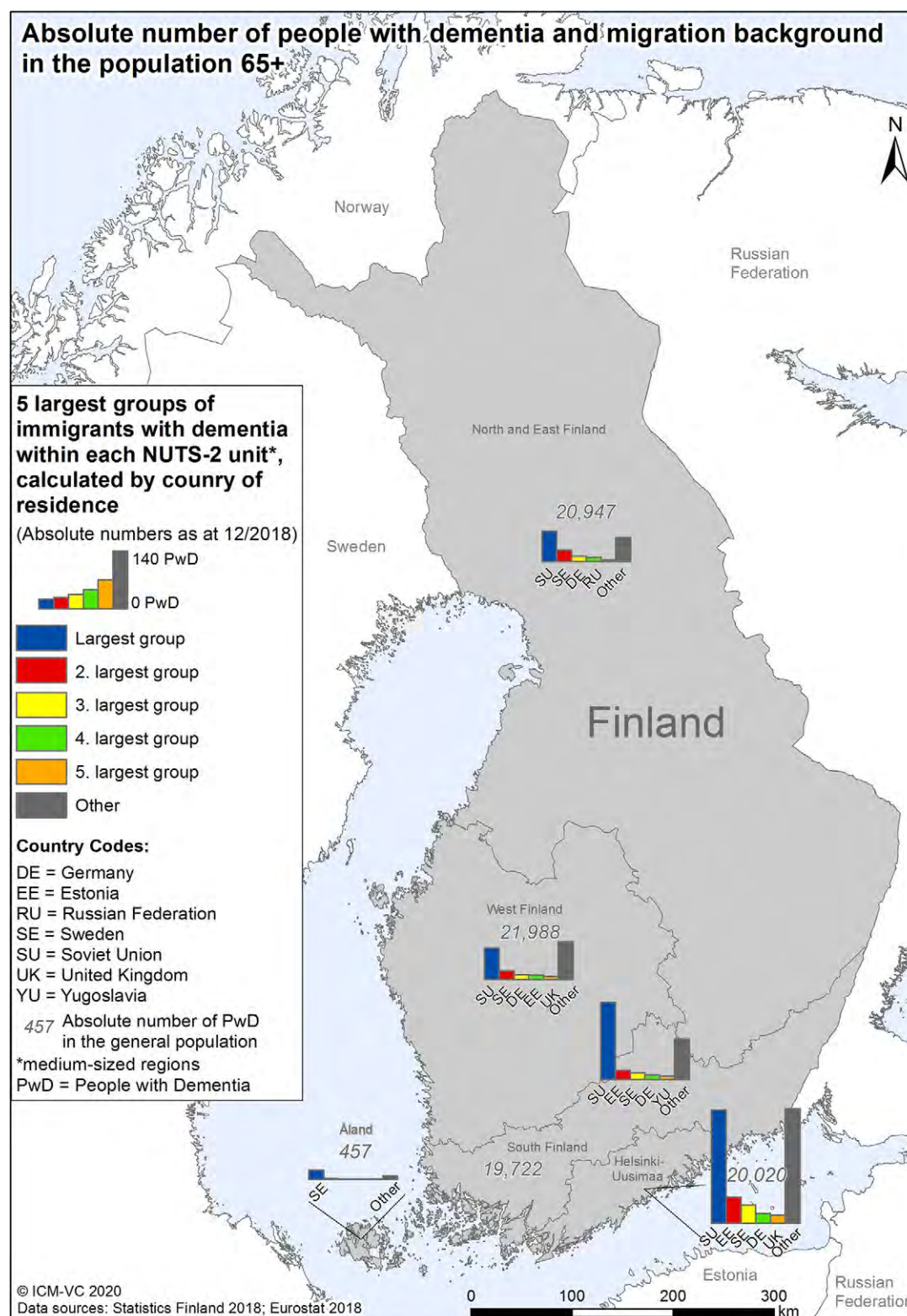


Fig. 3.7.9.9: Absolute number of PwM with dementia in the population 65+ (Finland – NUTS2)



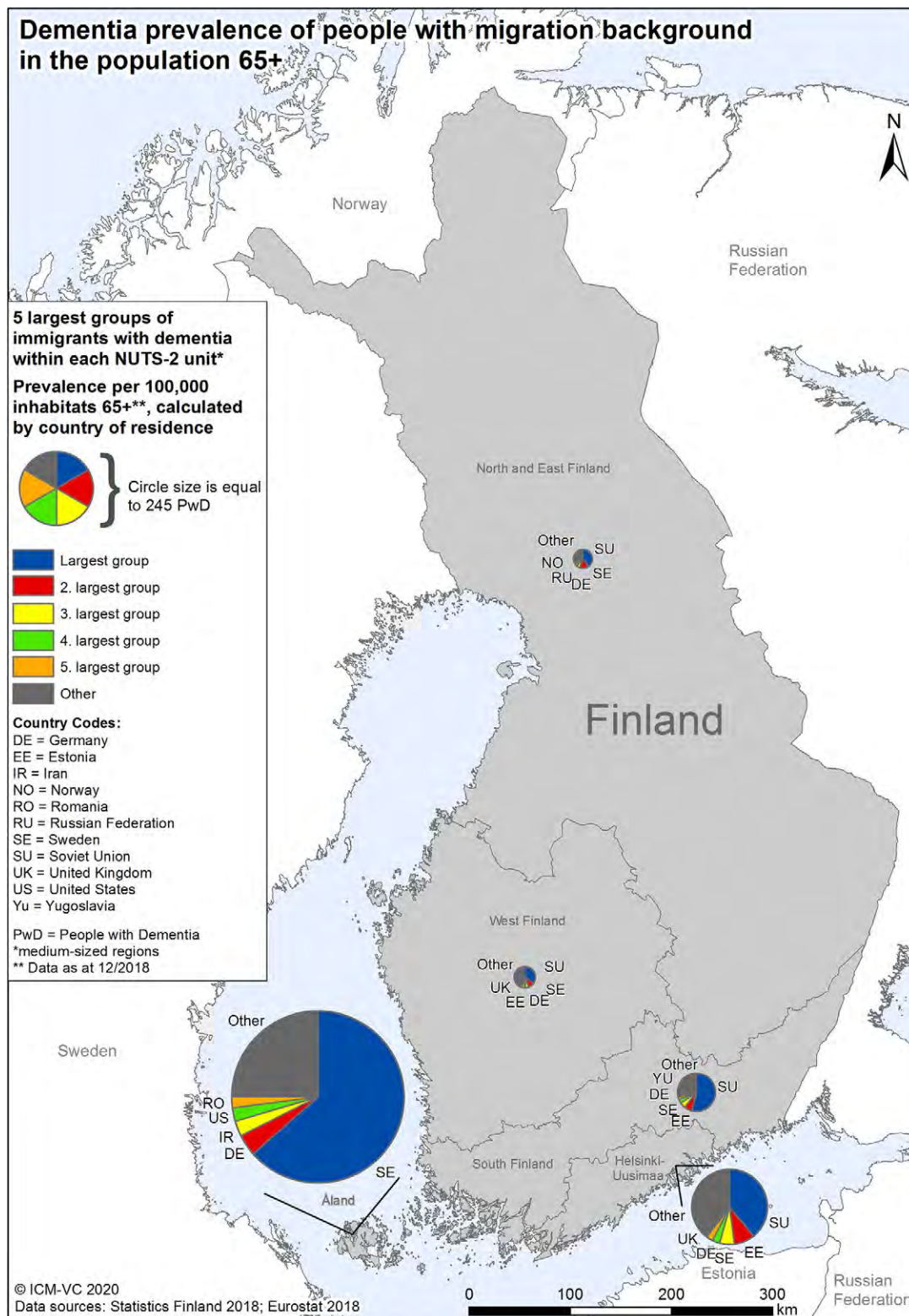


Fig. 3.7.9.10: Dementia prevalence of PwM in the population 65+ (Finland – NUTS2)



**Tab. 19: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Finland – NUTS 2)**

NUTS	Total	FI	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
West Finland	21,988	21,770	SU 76	SE 21	DE 12	EE 10	UK 8	91
Helsinki-Uusimaa	20,020	19,309	SU 278	EE 64	SE 44	DE 24	UK 20	281
South Finland	19,722	19,376	SU 188	EE 23	SE 16	DE 12	YU 8	99
North and East Finland	20,947	20,761	SU 74	SE 28	DE 12	RU 9	<5	59
Åland	457	421	SE 23	<5	<5	<5	<5	9
Prevalence/10,000 inhabitants with migration background 65+								
West Finland	69,539	-	SU 240	SE 67	DE 37	EE 32	UK 25	289
Helsinki-Uusimaa	19,422	-	SU 270	EE 62	SE 43	DE 23	UK 20	272
South Finland	39,326	-	SU 375	EE 46	SE 32	DE 23	YU 16	198
North and East Finland	78,072	-	SU 275	SE 104	DE 46	RU 35	NO 15	215
Åland	8,784	-	SE 438	DE 28	IR 20	US 17	RO 15	172
Prevalence/100,000 inhabitants 65+								
West Finland	6,900	6,832	SU 24	SE 7	DE 4	EE 3	UK 2	54
Helsinki-Uusimaa	6,900	6,655	SU 96	EE 22	SE 15	DE 8	UK 7	198
South Finland	6,900	6,779	SU 66	EE 8	SE 6	DE 4	YU 3	103
North and East Finland	6,900	6,839	SU 24	SE 9	DE 4	RU 3	NO 1	45
Åland	6,900	6,358	SE 344	DE 22	IR 16	US 14	RO 11	138

Note: Absolute numbers < 5 are not given for data protection reasons.

Data source: Statistics Finland 2018



### 3. National dementia plan

The 'National Memory Programme 2012 – 2020: Creating a Memory-friendly Finland' from 2013 is 21 pages long. The document explains why a National Memory Program is needed and what is the program objective. The main part is divided into the following four chapters: 1. 'Brain Health Is a Lifelong Concern'. 2. 'Memory Disorders Affect Us All

- Time for an Attitude Check. 3. 'Proper Treatment and Care Are Worthwhile Investments'. 4. 'More Research and Education Is Still Needed'. Finally, some information regarding the planned implementation of the program is provided. No reference to migration is made at any point [9].

### 4. National dementia care and treatment guidelines

In 2017, Finland published treatment guidelines for 'memory disorders'. The 41 pages long document featured the following topics pertaining to memory disorders: symptoms, incidence, risk factors, opportunities for prevention, causes, diagnosis and evaluation of symptoms, typical clinical conditions, medication, treatment of behavioural symptoms, the totality of care for a memory patient, memory outpatient clinics, and care teams.

Again, the topic of migration was absent [10].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

### 5. Services and information for people with a migration background with dementia

The expert estimated that in Finland the health-care strategy is an integrative one where inpatient as well as outpatient services for people with dementia are available nationwide to PwM. Dementia and migration is still a fairly new topic in Finland so there is currently a lack of culturally sensitivity in care services and no specialised healthcare services for PwM with dementia are available. One service that is provided nationwide is information material about dementia in different languages. Also, there are NGOs focused on health promotion, such as

ETNIMU, which also address PwM. The ETNIMU project focuses on Somali, Estonian, and Russian speakers, and older Roma and their family members and offers customer-oriented group-based activities [11]. Additionally, they work together with migrant organisations and educate them about memory diseases which the migrant organisations will then relay to PwM. Regarding the existing mainstream services for dementia, the expert opined that they are only suitable for non-migrants.



### 6. Professional qualification and people with a migration background in healthcare

According to the expert, the ability to provide culturally sensitive care is given limited importance in the professional qualification of healthcare workers in Finland. Training for intercultural care is available nationwide but not mandatory anywhere.

As stated by the expert the proportion of PWM working as professionals in outpatient care is moderate. These caregivers work in home care as well as institutional care and mostly originate from the Russian Federation, North Africa, and the Baltic countries.

### 7. Support for family caregivers

According to the expert, the extended Family, migrant organisations, religious communities, and service providers play a significant role in supporting family caregivers. Furthermore,

there is a high need for specialised services providing support and information to family caregivers of PWM with dementia in Finland.

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# France

**Population**

67,099,000

**Area**

643,801 km<sup>2</sup>

**Capital**

Paris

**3 largest cities**

Paris (2,190,000)

Marseille (860,000)

Lyon (520,000)

**Neighboring countries**

Andorra, Belgium,

Germany, Italy,

Luxembourg, Monaco,

Spain, Switzerland

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References



## 1. Migration history

France has a long immigration history. To this day, the immigration situation is strongly influenced by the colonialism of the past centuries and the long tradition of recruiting foreign workers [1]. Overall, immigration has risen continuously since the mid-19th century [2]. Already in the 18th century, France admitted immigrants as a result of a labour shortage. After the two wars of 1870–71 and 1914–1918, France concluded agreements with Italy, Belgium, Poland, and Czechoslovakia for the recruitment of workers. In the 1930s, France was the second most important immigration country in the world (after the US). At that time, about 2.7 million immigrants lived in France (6.6% of the population). In the 1950s and 1960s, France again recruited large numbers of workers from Italy, Portugal, Spain, Belgium, Germany, and the Russian Federation. At the same time, immigration from the former colonies increased. After the Algerian war (1954–62), a large number of people from Algeria came to France.

In 1974, the government stopped the recruitment of foreign workers. From then on, family reunification became the dominant reason for immigration. In parallel, the composition of the migrant population has also changed. Between 1962 and 2005, the proportion of European immigrants fell from 79 to 40%. In 2005, for the first time, more migrants from Africa lived in France than from the European Union [1]. Despite the political shift from an open to a restrictive immigration policy towards refugees from Africa at the end of the 20th century [2], the migrant population (born abroad) has risen from 5.9 million to 8.3 million, with their proportion in the total population growing from 10.4 to 12.8% between 1990 and 2019 [3]. In 2015, the largest migrant groups (born abroad) in France were from Algeria (790,700), Morocco (741,200), Portugal (621,800), Italy (286,300), and Tunisia (269,900) (born abroad) [4]. As of 2020, the net migration rate is 0.6 [5].



## 2. Estimated number of people with a migration background with dementia

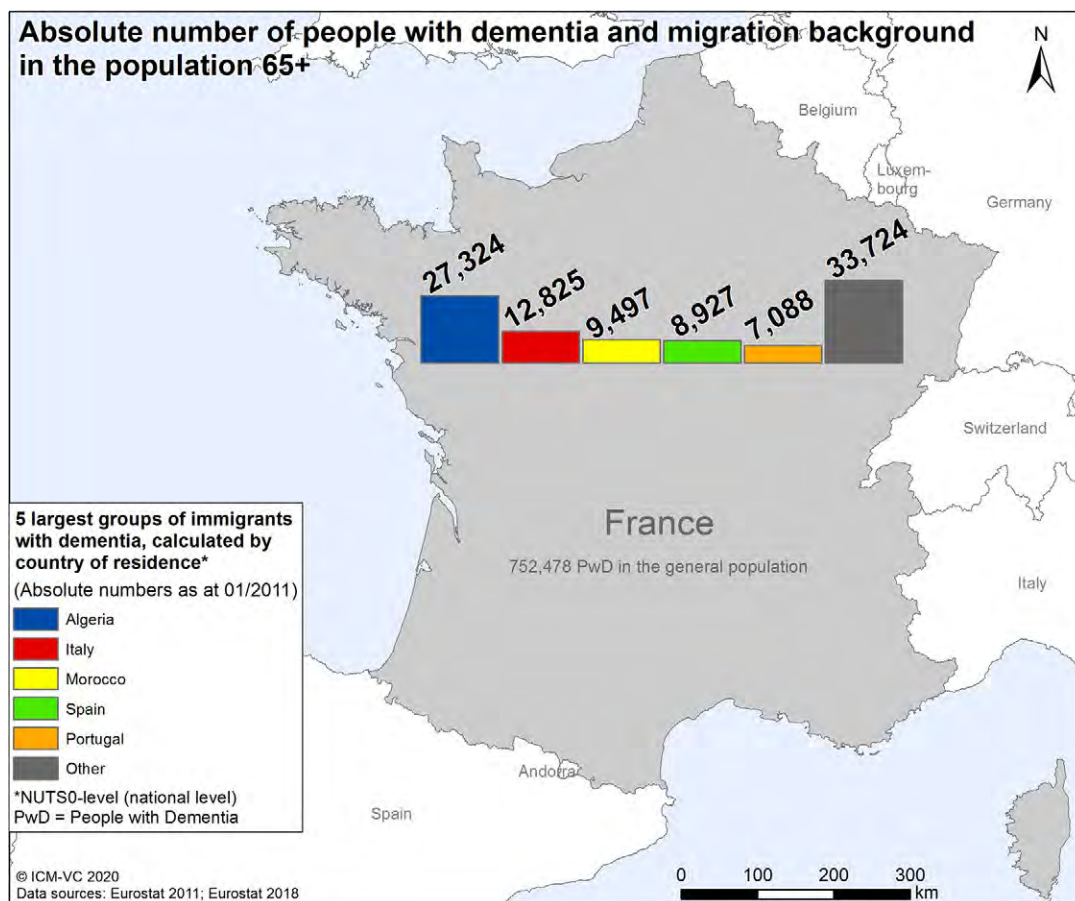


Fig. 3.7.10.1: Absolute number of PwM with dementia aged 65+ (France – Nation)

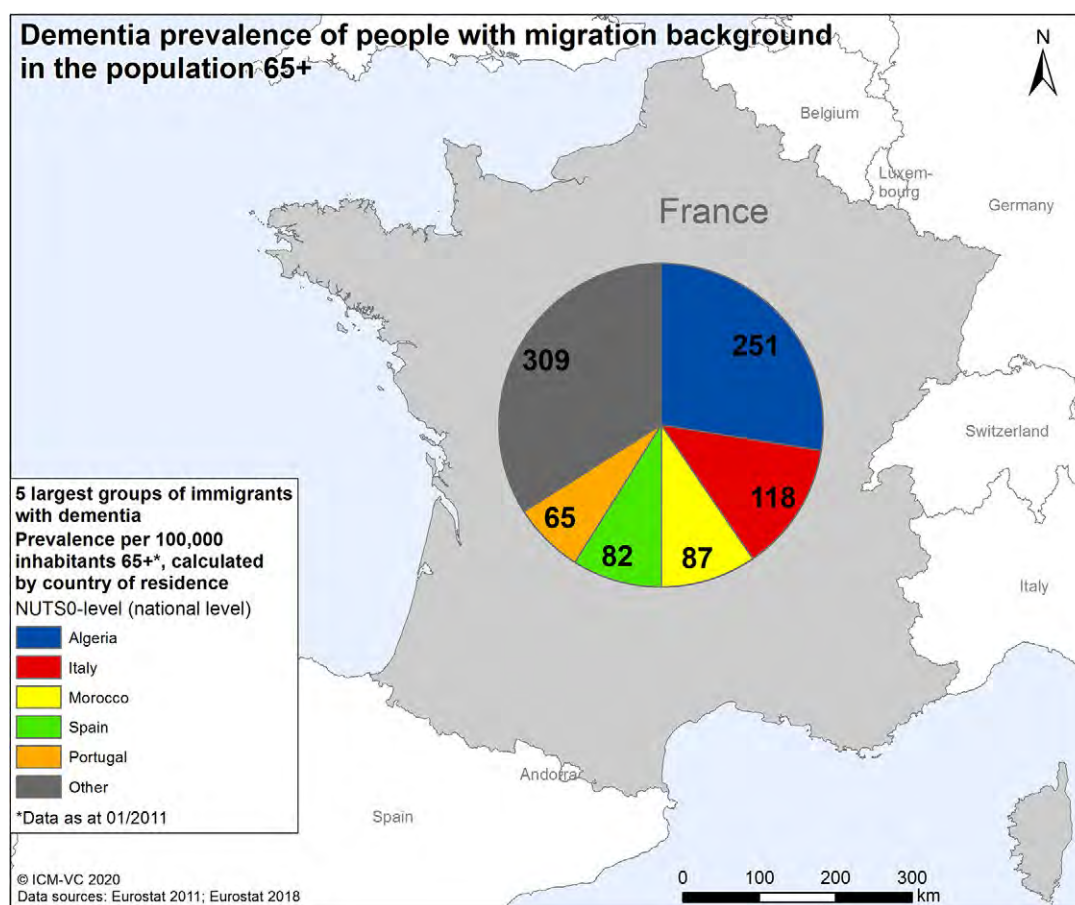


Fig. 3.7.10.2: Prevalence of PwM with dementia among the population aged 65+ (France – Nation)

**Tab. 20: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (France – Nation)**

NUTS	Total	FR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
France	752,478	658,094	DZ 27,324	IT 12,824	MA 9,497	ES 8,927	PT 7,088	33,724
Prevalence/10,000 inhabitants with migration background 65+								
France	5,224	-	DZ 190	IT 89	MA 66	ES 62	PT 49	234
Prevalence/100,000 inhabitants 65+								
France	6,900	5,989	DZ 251	IT 118	MA 87	ES 82	PT 65	308

Data source: Eurostat (2011)



There are 1,440,400 PwM aged 65 or older. Of those, approx. 99,400 are estimated to exhibit some form of dementia. Figure 3.7.10.1 shows the most affected migrant groups presumably originate from Algeria (approx. 27,300), Italy (approx. 12,800), Morocco (approx. 9,500),

Spain (approx. 8,900), and Portugal (approx. 7,100). The second graph highlights the number of PwM with dementia in France per 100,000 inhabitants aged 65 or older (figure 3.7.10.2). Table 20 displays the values depicted in the maps on the national level [6-8].

### 3. National dementia plan

The 'National Plan for "Alzheimer and Related Diseases" 2008-2012' from 2008 comprises 84 pages, with the content arranged into 3 large sections. The first section entitled 'Improving Quality of Life for Patients and Carers' declares multiple objectives, some of which are: increasing support for carers, enabling patients and their families to choose support at home, improving access to diagnosis and care pathways, developing and diversifying respite structures, improving health monitoring for family carers, and implementing a system for giving diagnosis and providing counseling. The second section entitled 'Knowledge for Action' discussed various objectives and measures concerning the generation of knowledge and the creation of a scientific basis for future action. It declared many objectives such as making unprecedented efforts in research and, organising epidemiological surveillance and follow up. It discussed measures such as creating a foundation for scientific cooperation to stimulate and coordinate scientific research, conducting further clinical

research on Alzheimer's disease, and improving evaluation of non-drug therapies. The third section entitled 'Mobilising Around a Social Issue' declared the objectives of disseminating information for general public awareness and, making Alzheimer's disease care a European priority [9]. In addition, the 'Plan Maladies Neurodégénératives 2014 – 2019' was published in 2014. This document has 124 pages and includes, inter alia, the following topics: promoting quality diagnosis, promoting a general and shared assessment of the situation, access to quality care throughout life with the disease, adapting the training of professionals to improve the quality of response to sick people, making it easier to live with the disease in a respectful and inclusive society, supporting caregivers (including family caregivers), mitigating the economic consequences of the disease and helping young patients to maintain their careers as well as strengthening and better coordinating research [10]. In none of the two documents is the topic of migration addressed at any point.

## 4. National dementia care and treatment guidelines

For France, four documents containing guidelines or recommendations at the national level could be identified: 1. 'Synthèse du guide parcours de soin de la maladie d'alzheimer ou d'une maladie apparentée' from 2018 (the guide comprises four pages), 2. 'Adapter la mise en oeuvre du projet d'établissement à l'accompagnement des personnes âgées atteintes d'une maladie neuro-dégénérative en ehpad' from 2018 (18 pages), 3. 'L'accueil et l'accompagnement des personnes atteintes d'une maladie neuro-dégénérative en pôle d'activités et de soins adaptés' from 2017 (eight pages), and 4. 'L'accueil et l'accompagnement des personnes atteintes d'une maladie neuro-dégénérative en unité d'hébergement en unité d'hébergement renforcés' from 2017 (eight pages). The 'Guide for Care for Alzheimer's disease or a related condition' (first document) provides recommendations for accompanying a patient to specialist counselling, preserving the patient's environment, supporting the caregiver, dealing with sudden deterioration in cognitive abilities or mental status, managing chronic behavioural disorders, and providing care until the end of life [11]. The second document (Adaptation of the implementation of the founding project for the support of elderly people with a neurodegenerative disease in Établissements d'Hébergement pour Personnes Âgées Dépendantes [=Residential

Facilities for Dependent Elderly Persons] [EHPAD] has three main priorities: 1. improving diagnosis and patient care, 2. Ensuring the quality of life of patients and residents, and 3. developing and coordinating research [12]. In the third document (The inclusion and support of people with neurodegenerative diseases in an appropriate activity and care centre), EHPAD managers who have established or want to establish an activity and care centre are given recommendations regarding the implementation of a Pôle d'Activité et de Soins Adaptés (=Activity and Adapted Care Center) (PASA) project, the organisation of cooperation between EHPAD and PASA, the inclusion and support of people in PASA, activities related to the therapeutic concept of unaccompanied persons, and a specific internal professional organisation [13]. The fourth document (Reception and support of people with neurodegenerative diseases in reinforced housing) is divided into three chapters. The first chapter deals with the implementation of the reinforced housing project, the second chapter with the organisation of the arrival of the residents, and the third chapter with the reception and support of residents accommodated in reinforced housing [14]. However, none of the chapters of the four guideline/recommendation documents refer to migration.



## 5. References

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# Germany

**Population**

83,167,000

**Area**

357,581 km<sup>2</sup>

**Capital**

Berlin

**3 largest cities**

Berlin (3,669,000)

Hamburg (1,847,000)

Munich (1,484,000)

**Neighboring countries**

Austria, Belgium,  
the Czech Republic,  
Denmark, France,  
Luxembourg,  
the Netherlands,  
Poland, Switzerland

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



### 1. Migration history

In the migration history of Germany in the 19th, 20th, and the early 21st century, several fundamental processes can be identified. From the early 19th century until about 1890, the transatlantic emigration flows of people from Germany dominated [1]. Between 1820 and 1920 about six million people emigrated from Germany due to wars and famines (especially to North America) [2, 3]. The economic success of the German Empire after 1890 led to more people immigrating than emigrating [2]. Most foreigners came from Austria, the BENELUX states (Belgium, the Netherlands, and Luxembourg), the Russian Federation, and Italy. The two world wars of the 20th century and their political consequences led to an enormous increase in forced migration [1]. During National Socialism, many foreigners were expelled, executed in concentration camps, and employed in forced labour [2]. Overall, Germany was a centre of forced migration in Europe during and after both world wars [1]. Especially after the Second World War, there was a large group of expellees and refugees [2]. From the middle of the 20th century, a new migration policy was established in the legal and welfare state. Between 1955 and 1973, foreign workers were recruited with the support of intergovernmental agreements, and the residence status of these workers was gradually consolidated as the length of their stay increased [1]. As a result of the recruitment agreements and the

economic upswing, between 1959 and 1964 about one million of these so-called guest workers came to Germany. The countries of origin of these migrants were Italy, Greece, Spain, Turkey, Morocco, Portugal, Tunisia, and Yugoslavia. After the decline in immigration in the 1980s, developments such as the collapse of the Soviet Union led to a sharp rise in immigration rates in the 1990s [2]. East-west migration, which had been severely restricted during the Cold War, became much more important [1]. Actions like the introduction of dual citizenship in 2000 and the 2005 Immigration Act, and developments such as high youth unemployment in southern Europe and the Syrian conflict, led to further growth in the migrant population [2]. In 2005, the proportion of migrants in the total population was 17.9% [4]. By 2017, this number increased to 23.6 percent, equivalent to 19.3 million people [5]. The largest migrant groups are people from Turkey (2.8 million), Poland (2.1 million), the Russian Federation (1.4 million) and, Kazakhstan (1.2 million) [6]. Between 1990 and 2019, the migrant population (born abroad) and their proportion in the total population more than doubled (5.9 million [7.5 percent] to 13.1 million [15.7 percent]) [7]. As of 2020, the net migration rate is 6.6 [8]. Overall, Germany has developed from an emigration country to an immigration country.

## 2. Estimated number of people with a migration background with dementia

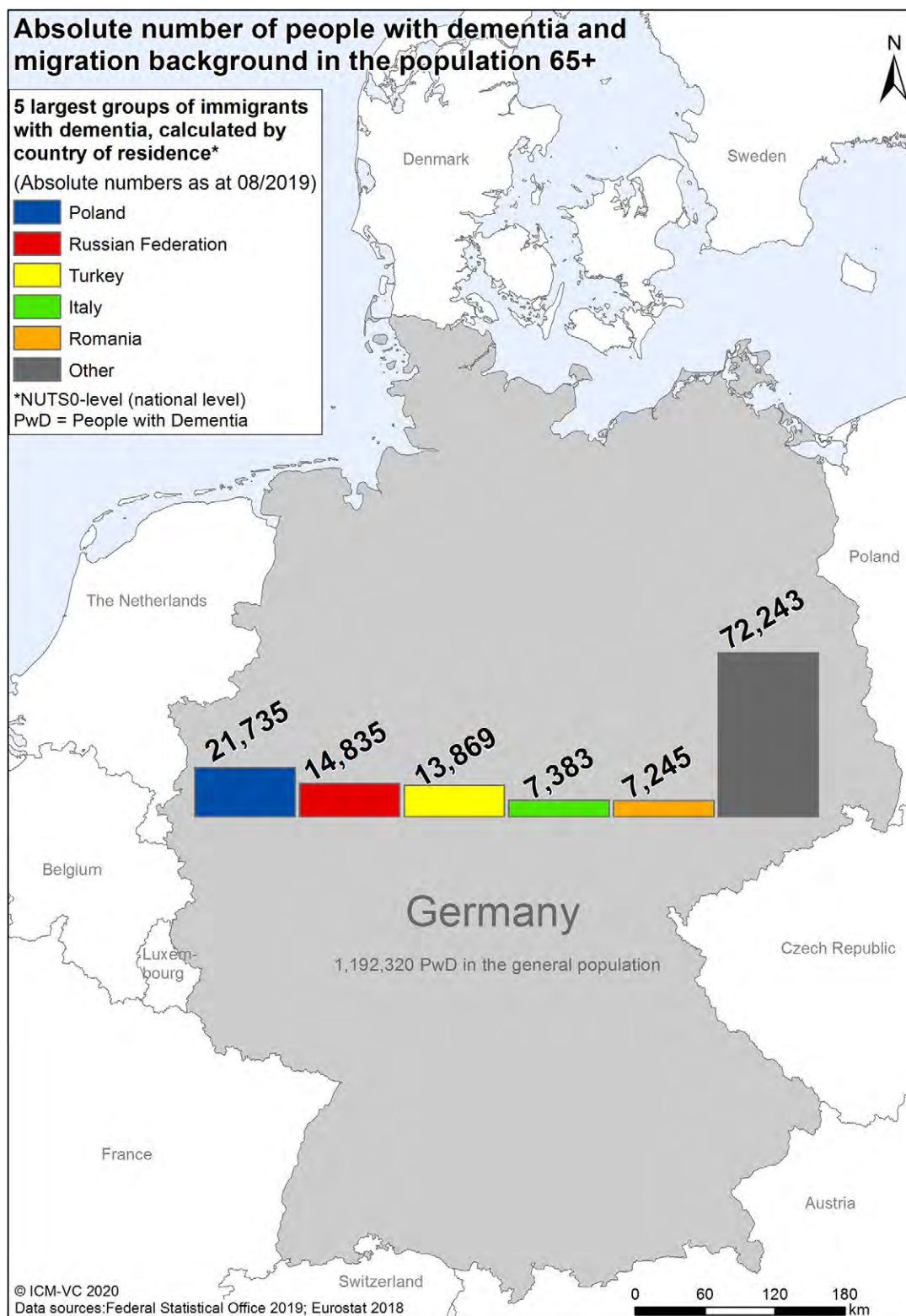


Fig. 3.7.11.1: Absolute number of PwM with dementia aged 65+ (Germany – Nation)

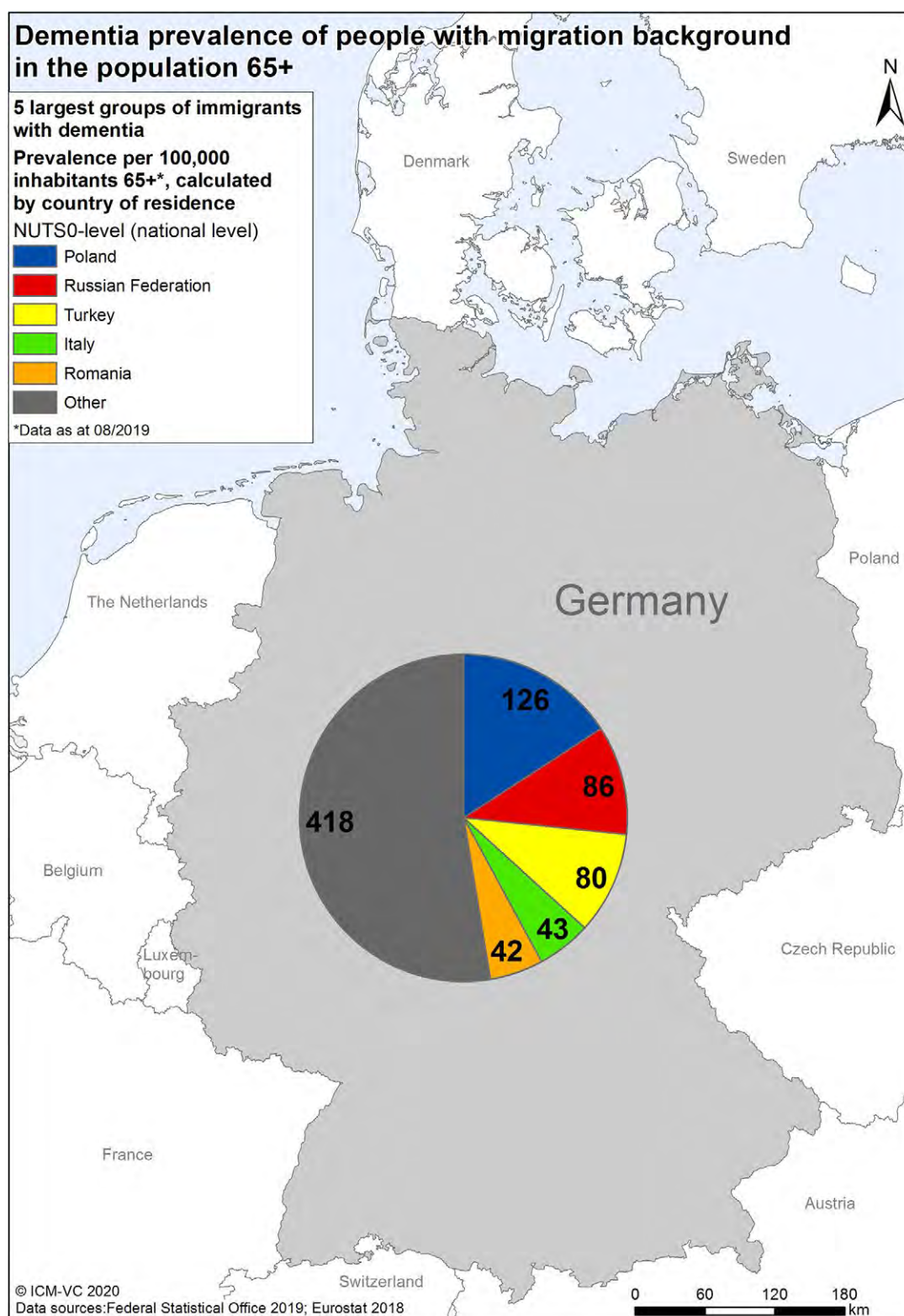


Fig. 3.7.11.2: Prevalence of PwM with dementia among the population aged 65+ (Germany – Nation)



**Tab. 21: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Germany – Nation)**

NUTS	Total	DE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Germany	1,192,320	1,055,010	PL 21,735	RU 14,835	TR 13,869	IT 7,383	RO 7,245	72,243
Prevalence/10,000 inhabitants with migration background 65+								
Germany	5,992	-	PL 109	RU 75	TR 70	IT 37	RO 36	363
Prevalence/100,000 inhabitants 65+								
Germany	6,900	6,105	PL 126	RU 86	TR 80	IT 43	RO 42	418

Data source: Federal Statistical Office (2019)

There are 1,990,000 PwM aged 65 or older. Of those, approx. 137,300 are estimated to exhibit some form of dementia. Figure 3.7.11.1 shows the most affected migrant groups presumably originate from Poland (approx. 21,700), the Russian Federation (approx. 14,800), Turkey (approx. 13,900), Italy (approx. 7,400), and Romania (approx. 7,300). The second graph highlights the number of PwM with

dementia in Germany per 100,000 inhabitants aged 65 or older (figure 3.7.11.2). Table 21 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Poland, the Russian Federation, Turkey, Italy, and Romania throughout the country in the NUTS1 regions (figures 3.7.11.3 – 3.7.11.8).



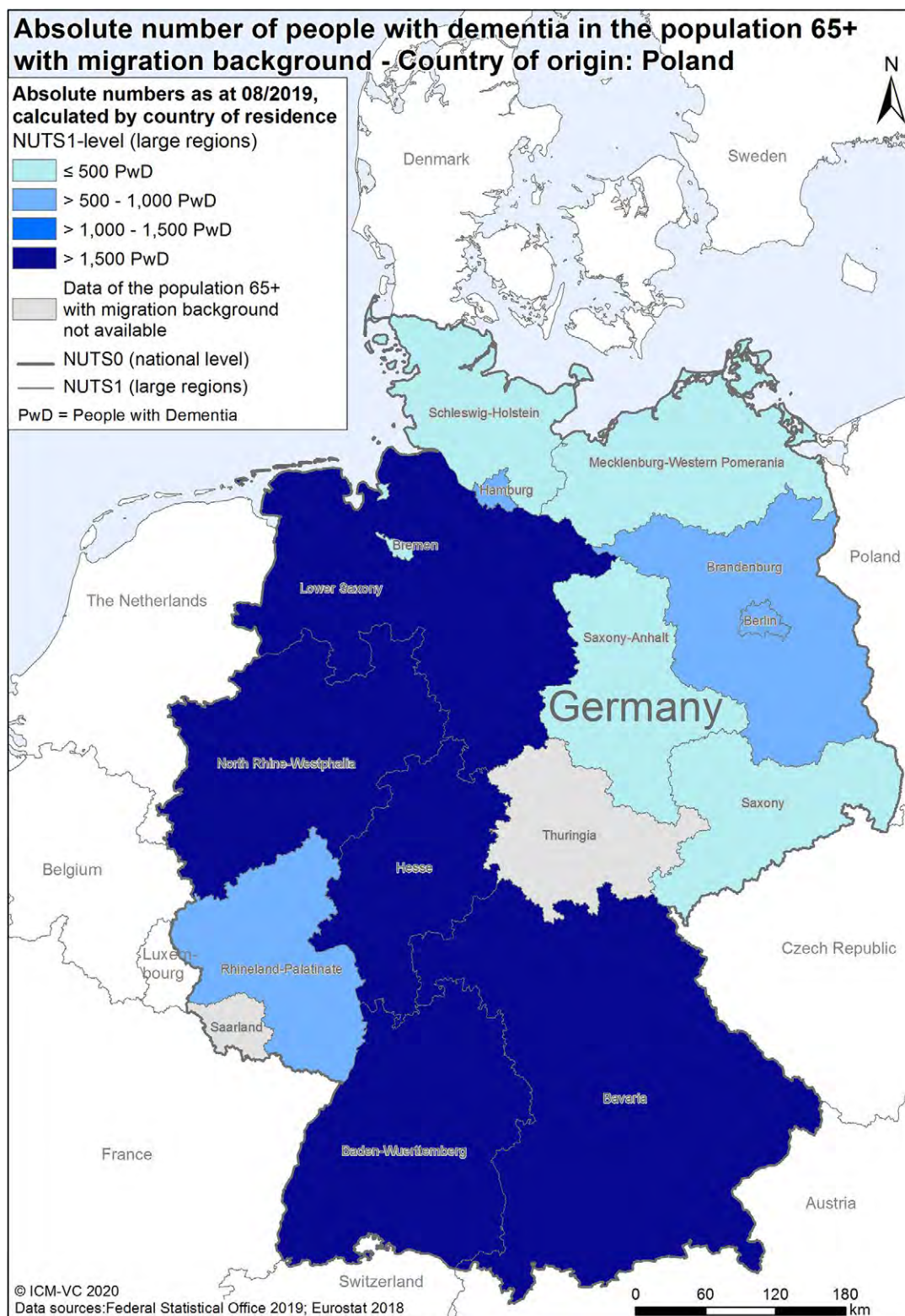


Fig. 3.7.11.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Poland (Germany – NUTS1)



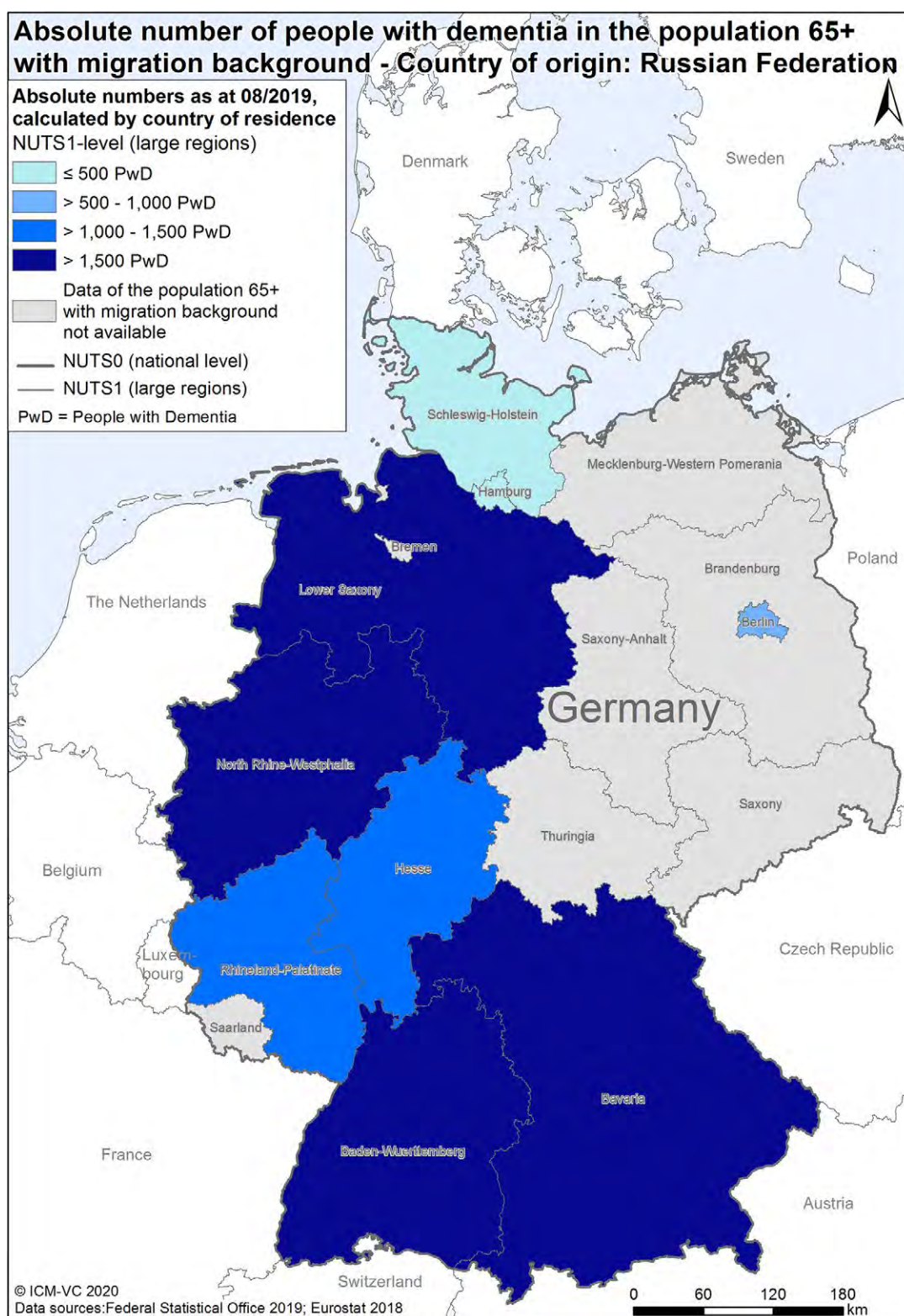


Fig. 3.7.11.4: Absolute number of PwM with dementia aged 65+. Country of origin: The Russian Federation (Germany – NUTS1)

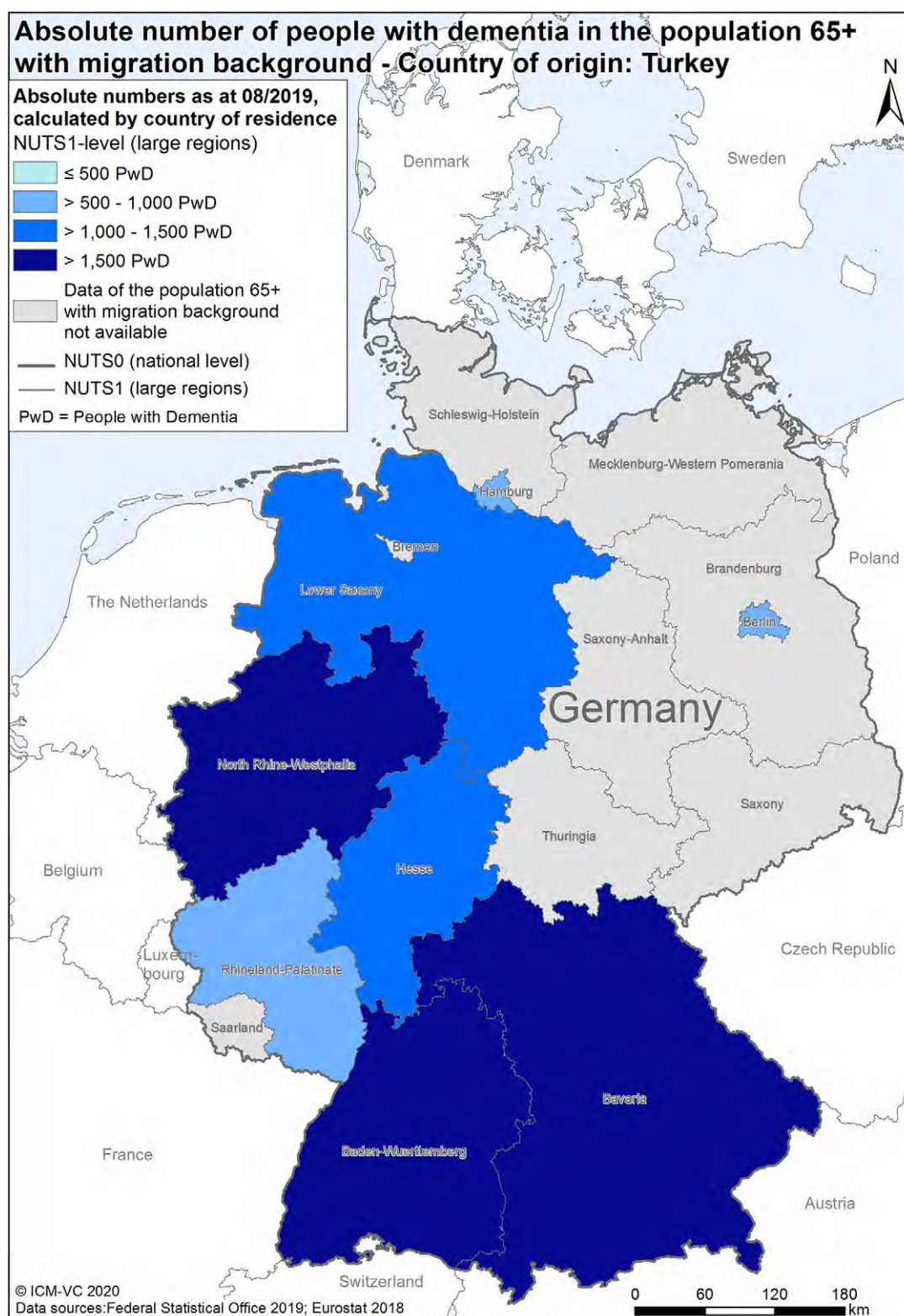


Fig. 3.7.11.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Turkey (Germany – NUTS1)



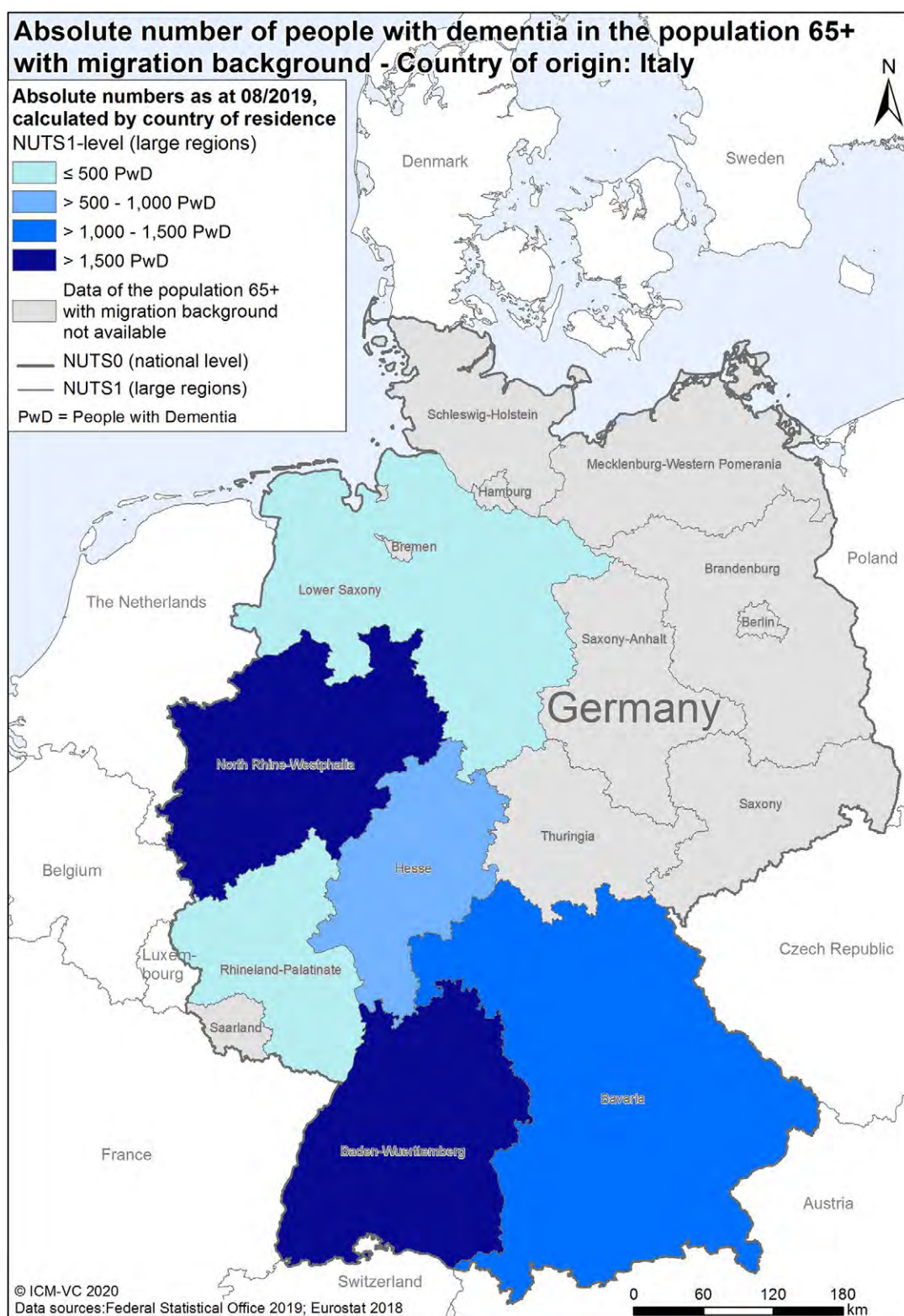


Fig. 3.7.11.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Italy (Germany – NUTS1)



Fig. 3.7.11.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Romania (Germany – NUTS1)





Fig. 3.7.11.8: Absolute number of people with dementia aged 65+.  
Country of origin: Germany (Germany – NUTS1)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS1 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS1 regions (figure 3.7.11.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS-1 regions (figure 3.7.11.10). The values from the NUTS1 level can be found in Table 22 [9-11].

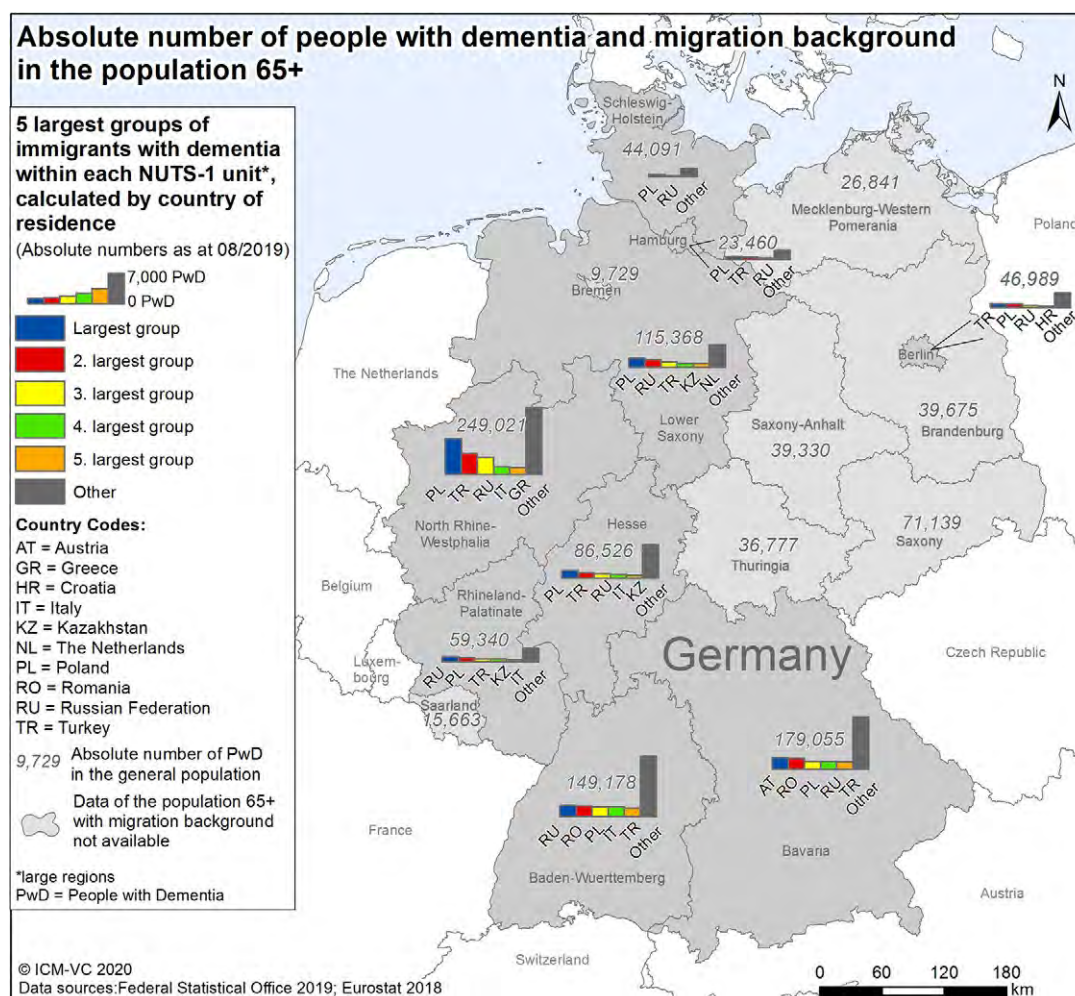


Fig. 3.7.11.9: Absolute number of PwM with dementia aged 65+ (Germany – NUTS1)



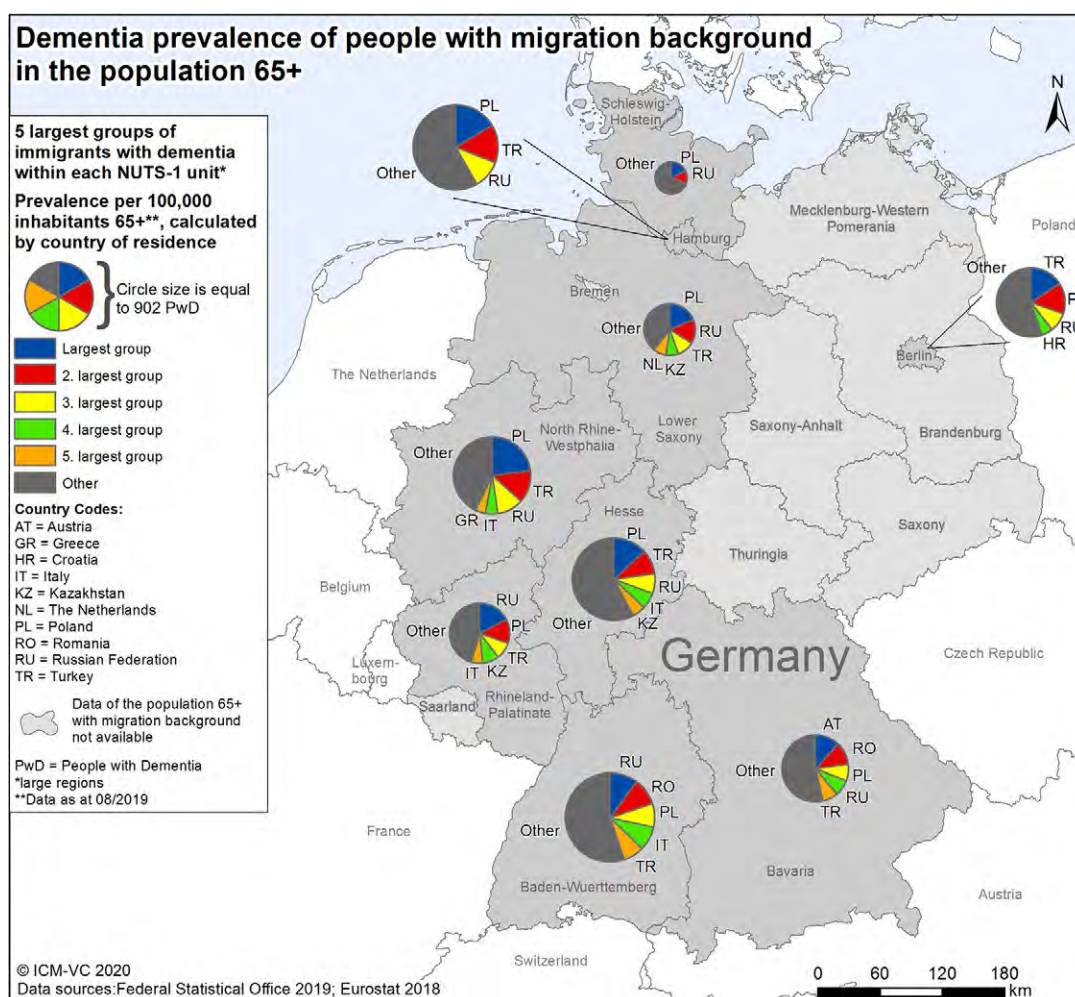


Fig. 3.7.11.10: Prevalence of PwM with dementia among the population aged 65+ (Germany – NUTS1)

Tab. 22: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Germany – NUTS 1)

NUTS	Total	DE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Baden-Wuerttemberg	149,178	123,786	RU 2,553	RO 2,484	PL 2,208	IT 2,208	TR 1,932	14,007
Bavaria	179,055	156,285	AT 2,691	RO 2,553	PL 1,794	RU 1,794	TR 1,725	12,213
Berlin	46,989	40,848	TR 966	PL 897	RU 552	HR 345	N/A	3,381
Brandenburg*	39,675	38,295	PL 552	N/A	N/A	N/A	N/A	828
Bremen*	9,729	8,487	PL 414	N/A	N/A	N/A	N/A	828



## Germany

NUTS	Total	DE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Hamburg	23,460	19,665	PL 621	TR 552	RU 414	N/A	N/A	2,208
Hesse	86,526	72,933	PL 1,794	TR 1,311	RU 1,035	IT 897	KZ 690	7,866
Mecklenburg- Western Pomerania*	26,841	26,151	PL 345	N/A	N/A	N/A	N/A	345
Lower Saxony	115,368	104,190	PL 2,070	RU 1,725	TR 1,173	KZ 897	NL 897	4,416
North Rhine- Westphalia	249,021	212,451	PL 8,418	TR 4,968	RU 4,071	IT 1,863	GR 1,587	15,663
Rhineland- Palatinate	59,340	52,509	RU 1,173	PL 897	TR 621	KZ 621	IT 414	3,105
Saarland	15,663	14,145	N/A	N/A	N/A	N/A	N/A	1,518
Saxony*	71,139	69,483	PL 414	N/A	N/A	N/A	N/A	1,242
Saxony-Anhalt*	39,330	38,364	PL 414	N/A	N/A	N/A	N/A	552
Schleswig- Holstein	44,091	41,400	PL 483	RU 345	N/A	N/A	N/A	1,863
Thuringia	36,777	36,087	N/A	N/A	N/A	N/A	N/A	690
Prevalence/10,000 inhabitants with migration background 65+								
Baden- Wuerttemberg	4,054	-	RU 69	RO 68	PL 60	IT 60	TR 53	381
Bavaria	5,426	-	AT 82	RO 77	PL 54	RU 54	TR 52	370
Berlin	5,280	-	TR 109	PL 101	RU 62	HR 39	N/A	380
Brandenburg*	18,893	-	PL 263	N/A	N/A	N/A	N/A	394
Bremen*	5,121	-	PL 218	N/A	N/A	N/A	N/A	436
Hamburg	4,344	-	PL 115	TR 102	RU 77	N/A	N/A	408
Hesse	4,392	-	PL 91	TR 67	RU 53	IT 46	KZ 35	399
Mecklenburg- Western Pomerania*	26,841	-	PL 345	N/A	N/A	N/A	N/A	345
Lower Saxony	7,121	-	PL 128	RU 106	TR 72	KZ 55	NL 55	273



NUTS	Total	DE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
North Rhine-Westphalia	4,699	-	PL 159	TR 94	RU 77	IT 35	GR 30	296
Rhineland-Palatinate	5,994	-	RU 118	PL 91	TR 63	KZ 63	IT 42	314
Saarland	7,120	-	N/A	N/A	N/A	N/A	N/A	690
Saxony*	29,641	-	PL 173	N/A	N/A	N/A	N/A	518
Saxony-Anhalt*	2,6220	-	PL 276	N/A	N/A	N/A	N/A	368
Schleswig-Holstein	11,305	-	PL 124	RU 88	N/A	N/A	N/A	478
Thuringia	36,777	-	N/A	N/A	N/A	N/A	N/A	690
Prevalence/100,000 inhabitants 65+								
Baden-Wuerttemberg	6,900	5,726	RU 118	RO 115	PL 102	IT 102	TR 89	647
Bavaria	6,900	6,023	AT 104	RO 98	PL 69	RU 69	TR 66	470
Berlin	6,900	5,998	TR 142	PL 132	RU 81	HR 51	N/A	497
Brandenburg*	6,900	6,660	PL 96	N/A	N/A	N/A	N/A	144
Bremen*	6,900	6,019	PL 294	N/A	N/A	N/A	N/A	587
Hamburg	6,900	5,784	PL 183	TR 162	RU 122	N/A	N/A	649
Hesse	6,900	5,816	PL 143	TR 105	RU 83	IT 72	KZ 55	627
Mecklenburg-Western Pomerania*	6,900	6,723	PL 89	N/A	N/A	N/A	N/A	88
Lower Saxony	6,900	6,231	PL 124	RU 103	TR 70	KZ 54	NL 54	265
North Rhine-Westphalia	6,900	5,887	PL 233	TR 138	RU 113	IT 52	GR 44	434
Rhineland-Palatinate	6,900	6,106	RU 136	PL 104	TR 72	KZ 72	IT 48	361
Saarland	6,900	6,231	N/A	N/A	N/A	N/A	N/A	669
Saxony*	6,900	6,739	PL 40	N/A	N/A	N/A	N/A	121
Saxony-Anhalt*	6,900	6,731	PL 73	N/A	N/A	N/A	N/A	96



NUTS	Total	DE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Schleswig-Holstein	6,900	6,479	PL 76	RU 54	N/A	N/A	N/A	291
Thuringia	6,900	6,771	N/A	N/A	N/A	N/A	N/A	129

Note: N/A = not available

Data source: Federal Statistical Office (2019)

## 3. National dementia plan

At the time of the first search, 1 June 2019, no NDP could be identified for Germany [12]. However, four German federal states (Saarland, Bavaria, Schleswig-Holstein, and Rhineland-Palatinate) have developed their own dementia strategies [13]. Saarland, Bavaria, and Schleswig-Holstein have a dementia plan, which is accessible online. All three dementia plans refer to the topic of migration. The 'Bavarian Dementia Strategy' from 2013 indicates in a separate chapter that the employment of foreign caregivers and domestic help can be a measure to ensure that people with dementia remain in their home environment. It points out several labour law options for the employment of foreign care assistants in private households and presents a strategy which consists of using information material and advisory services to educate affected persons and relatives about the risks and opportunities of using such care assistants. Simultaneously, the problem of lack of data regarding legal and illegal employment relationships is also discussed. In another chapter, it is emphasised that Bavaria would like to develop tailored advertising and information materials to integrate PwM into the elderly care profession. Reference is also made to the project 'Intercultural Network Dementia', which investigates how existing networks of mutual support in the migrant community can be strengthened and access to elderly care improved [14].

In the slightly shorter 'First Dementia Plan of the Saarland' from 2015 there is no chapter on migration. It only refers to the topic in one paragraph and recommends that counselling of dementia patients and their relatives must take into account social differentiation factors such as migration background [15]. The 'Dementia Plan for Schleswig-Holstein' from 2015 refers to migration in more detail. Although it does not contain a separate chapter, it has a section with three paragraphs on the topic of PwM with dementia. There it is discussed that the topic of dementia and migration background is gaining relevance nationwide as well as in Schleswig-Holstein due to the significant increase in the number of older migrants. Besides, the importance of the family in providing care is emphasised and it is explained that external support services are rarely or not at all accepted by PwM. Afterward, it is pointed out that there are hardly any specialised services for this population in Schleswig-Holstein. The third paragraph outlines a possible care strategy. First, a comprehensive installation of special services for this population is rejected due to the low proportion of migrants. Instead, it is recommended to integrate culturally sensitive care into nursing education to a greater extent, to offer more training on this topic, to use trained multipliers to inform the migrant community about support services and to carry out intercultural projects. According to this



document, the strategy should focus on the training of professionals and the education of the migrant community [16]. Overall, the analysis of the dementia plans has shown that official documents on dementia care in individual federal states (3 of 16) deal with some aspects of dementia and migration to varying extents. The focus is on problem identification and description. Specialized healthcare services were not mentioned. However, the 'Dementia Plan for Schleswig-Holstein' explicitly refers to a lack of specialized services for PwM with dementia.

On 1 July 2020, Germany published its first national dementia strategy ('Nationale Demenzstrategie'). This strategy refers to migration. In relation to the length of the document (152 pages), the topic does not play a key role, but it is dealt with to varying extents in a total of 14 chapters or sub-chapters. The dementia strategy contains a separate chapter with three sub-chapters on migration and three further sub-chapters on different thematic areas related to migration; also seven other sections refer to this topic (twice in one paragraph and five times briefly with individual sentences or words scattered across the seven sections). First, several challenges and problems regarding the current care situation of PwM with dementia and their families are described. It is identified that diagnosis and counselling for PwM is a particular challenge due to cultural and language barriers and unsuitable diagnostic procedures. In addition, care insurance benefits are often not fully utilised. Language, cultural-religious or institutional barriers, and inadequate culturally sensitive services are cited as causes. Furthermore, the national dementia strategy highlights the current focal points in dementia research and shows that the topic of migration only plays a marginal role there. Only in healthcare research are several aspects related to this topic examined (situation of foreign assistance and care staff, so-

cial inequality in support services experienced by relatives of PwM with dementia). Overall, the migration-related sections of the German dementia strategy have a strong action framework. Thereby, the focus is on the sensitizing of healthcare providers, and the development of needs-oriented low-threshold support and counselling services for PwM with dementia as well as their relatives. For this purpose, multipliers for PwM and stakeholders in the healthcare system will be trained in the development of such services and care centres will build up intercultural competencies. Besides, reference is made to the ongoing projects 'Intercultural Bridge Builders in Care', where people from different countries of origin are trained on relevant care-related topics, 'Dementia and Migration', which offers multilingual information on dementia, and 'DeMigranz', which aims to improve access to support and counselling services for PwM and dementia. In several passages, the general aim of expanding and developing culturally sensitive counselling services for people with dementia and their relatives is expressed. Specifically, it is stated by the end of 2024, culturally and religiously sensitive support and counselling services for family caregivers should be available, and all care support and counselling centres should have a range of services tailored to their needs. By the end of 2022, barrier-free information services containing information on multilingual counselling services should already be available in all federal states, and the nationwide database on existing culturally sensitive counselling centres and networking services on the website [www.demenz-und-migration.de](http://www.demenz-und-migration.de) should be expanded. Also, by the end of 2022, the medical associations Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e.V. (=German Society for Gerontopsychiatry and Psychotherapy) (DGGPP) and Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Ner-

venheilkunde e.V. (=German Society for Psychiatry and Psychotherapy, Psychosomatics, and Neurology) (DGPPN) intend to develop recommendations for the use of multilingual, culturally sensitive assessment instruments for dementia diagnosis. The national dementia strategy thus formulates several objectives with annual figures that aim to develop linguistically and culturally sensitive support, in-

formation, and counselling services as well as multilingual and culturally sensitive diagnostic tools for PwM. However, most of these objectives are formulated in very general terms and therefore allow much leeway for varying interpretations. In addition, there is a lack of clarity on how the objectives can be achieved and who would develop the care services or to what extent PwM would be involved [17].

## 4. National dementia care and treatment guidelines

In the 'S3 Guideline Dementias' from 2016 no direct reference to migration is made at any point. However, one passage addresses the topic indirectly in the form of a discussion about the connection between sociocultural background/language skills and dementia diagnosis. It is shown that socio-cultural background and language skills influence the cognitive performance of people with dementia and can thus also influence the results of dementia diagnostic tests. This leads to the recommendation that detailed neuropsychological tests for differential diagnosis of ques-

tionable or mild dementia should take the socio-cultural background or language skills into account. Overall, the topic of migration does not play a significant role in the German guidelines for dementia [18].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, there are large regional differences in Germany regarding the attribution of importance to the topic of dementia and migration. In some regions and municipalities, the topic already receives more attention, while in other regions it is still completely neglected. As examples of these regional disparities, the expert mentioned the federal state of North Rhine-Westphalia, where the topic is given much importance, and the Free State of Saxony, where it is completely ignored, especially politically. Overall, the issue of dementia and migration only plays a partial role at the national and political level. According to the

expert, the issue has been noticed in the German health system for just under ten years, and attention has already declined again in the last two to three years. On the side of the care providers and professionals, the sensitivity regarding dementia and migration is also very different. While many experts recognize that PwM with dementia need special treatment, some feel that people who have been living in the country for decades should begin to adapt. Special needs are identified by service providers and professionals related to different religions and language difficulties. The expert stated that problems arising in the con-





text of care for PwM with dementia are often hastily justified by a person's religion, culture, or origin, which is an obstacle to a differentiated examination of the respective situation. The healthcare system constructs refugees, so-called guest workers, and ethnic German re-settlers as groups with specific problems in the context of healthcare. In the case of refugees, the healthcare providers perceive the biggest problems in language mediation. Besides the expectation of doctors that refugees bring their interpreters, the expert points out, that a central problem is that the decision regarding the necessity of medical treatment for people who do not have an electronic health card is the responsibility of the social services. In the case of guest workers, the existence of a family, that provides part of the care and translation services, is often assumed. Stressful employment biographies and the resulting higher need for care are identified as central problems. Overall, PwM with dementia are identified as a group with specific needs in the context of the diagnosis of dementia (under-diagnosis) and the utilisation of care services. According to the expert, central differences between PwM and non-migrants regarding dementia care consists in the knowledge concerning the entitlement to and application for care services, the access to information on applying for care services, barriers to utilisation of care services, and a different understanding of dementia. Furthermore, PwM are often unfamiliar with the tasks of a professional caregiver in the context of outpatient care, which may cause them irritation.

Moreover, the expert states that care of PwM with dementia is based on a hybrid model with segregative elements (especially for people of from Turkey) and integrative services (for people outside of Turkey). Overall, PwM with dementia are currently not integrated into the healthcare system. According to the expert, little knowledge is available in Germany about

the utilisation of care services and the care situation of PwM with dementia. However, it is assumed that this population uses considerably fewer care services than the autochthonous population (only in the case of care allowance [financial support from the state] there are no major differences). In terms of information and counselling for PwM with dementia and their relatives, the expert states the central problem, the expert states, is that the existing counseling structures and information services often focus either on dementia or on the migration background, and a combination of these characteristics or other aspects are rarely or never taken into account. Only in three to four regions are single counselling centres offering specific mother-tongue counselling for PwM with dementia (for example through the Alzheimer Society in Gelsenkirchen and Berlin as well as within the framework of the initiative DeMigranz in Stuttgart). Specialised services for outpatient and inpatient care of PwM with dementia currently are available in individual regions. As examples of existing care services, the expert mentioned the outpatient care service 'Alicare' in Berlin, which provides care in shared flats where people from Turkey and Poland are accommodated. A reference was also made to the inpatient daycare facility 'Veringeck' in Hamburg. Furthermore, some cities such as Berlin, Cologne, or Bielefeld have self-help offices with specific self-help services. Although such services are increasing in numbers, they are currently more the exception than the norm. The expert argues that the existing dementia-specific care services are neither suitable for PwM nor for non-migrants. There are some examples of high-quality care, but overall, the existing care structures are not sensitive to the individual needs of people with dementia. Especially the aspect of intersectionality is completely missing. The existing services are not focused on diversity characteristics of a person and if they take into ac-

count a diversity characteristic such as migration background, they assume a relatively homogeneous group. Consequently, even the few specialised services that already exist are rarely geared towards a heterogeneous population with a migration background. According to the expert, this is a central reason why PwM with dementia hardly use the existing care services. However, measures for intercultural care or support for people with dementia are locally widespread and locally in development. In the expert's opinion, PwM with dementia and their family members rarely participate in the development of care services. If participation occurs, it is only because the managers or

staff of the care service organisations have a migration background themselves.

The expert commented that currently culturally sensitive care focuses almost exclusively on religion, country of origin, and food, but in order to encourage more PwM to use dementia-specific care services additional diversity characteristics besides migration background, such as sexual orientation and gender identity, as well as aspects such as traumatisation and loss of the second language, must be taken into account. To ensure person-centred care for PwM with dementia, the expert recommended diversity-sensitive care from an intersectional perspective.

## 6. Professional qualification and people with a migration background in healthcare

According to the consulted expert, the topic of culturally sensitive care plays a rather subordinate role, at least in the education of professional caregivers. When the expert analysed the curricula for nursing education in different federal states a few years ago, some federal states included the topic, even though it was mostly not explicitly termed so. However, cultural sensitivity was only addressed very selectively, for example, by giving knowledge about different religions. Only a few federal states have allocated a fixed number of hours to the topic of culturally sensitive care in education or studies; North Rhine-Westphalia was the state with the highest number of hours. According to the expert, the topic of culturally sensitive care is underrepresented in the education of professional caregivers. A similar situation can be observed in the further training of healthcare professionals. Although there are further training opportunities for professionals in intercultural care, these are not mandatory and are therefore primarily used by those who are already dealing with the issue at their workplace. The professionals who

have the biggest need for further training, for example, because they are less open-minded towards PwM, seem to not attend such courses. Moreover, the expert stated that a single training on the topic of interculturality is not sufficient, as the development of a culturally sensitive or diversity-friendly attitude is a long-term process. According to the expert's knowledge, necessary measures such as the establishment of platforms for a continuous exchange on these topics or the initiation of team supervision have not been implemented so far.

The expert stated that based on a study of more than 1,500 caregivers, the proportion of professional caregivers with a migration background is just over 10% in outpatient care and just over 14% in inpatient care. More than half of the professional caregivers with a migration background are originally from the Russian Federation, Poland, Kazakhstan, or another Eastern European country, just under 18% are from Western Europe (including the former Yugoslavia), and just under 7% are from non-European countries (including Turkey).



The expert pointed out that this relatively high heterogeneity among professionals is very positive for the provision of care, but it also poses challenges. As an example, it was mentioned that it can strengthen existing language barriers on the side of people in need of care with a migration background if a care professional speaks a dialect (German or non-German). Moreover, this dialect can trigger a traumatized person in a certain way, which can have a negative effect on the situation of this person. According to the expert, these problems can be countered, if the care providers and professionals are sensitised to them. Simultaneously, the high cultural and linguistic diversity in care also has many benefits. For example, the expert argued that people in need of care with a migration background and their relatives, who do not have perfect German lan-

guage skills, might have less language-related inhibitions and fear of discrimination if they speak to a professional caregiver who does not speak perfect German herself. In the expert's opinion, the topic of diversity sensitivity in care should be much more present because the diversity of people in need of care as well as the diversity of professional caregivers play a major role. The expert adds that caregivers with a migration background also have a high need for sensitisation. Just because a person has immigrated from a certain country or region does not automatically make them culturally sensitive.

Finally, the expert concluded that the current level of awareness of diversity and cultural differences among healthcare professionals is not sufficient to meet the need for person-centred care.

## 7. Support for family caregivers

According to the expert, the social network of the family plays a very big role in supporting family caregivers of PwM with dementia. Providers of medical healthcare services are also very important as they are the ones who diagnose and inform about dementia. However, in many cases, they fall short in fulfilling their functions as they do not advise or guide PwM in seeking further dementia-specific care. Therefore, PwM often lack access to outpatient and inpatient care, which means that the formal care and support sector plays a much less active role than it should in the care. Religious communities and migrant organisations generally make low to moderate contributions in providing dementia-specific support for family caregivers, although the support potential of both networks is very large. Currently, the religious communities are willing to provide support, for example, in recruiting participants for studies on the topic of dementia and migration, but they do not have

their own stance on this topic, which would be necessary to sensitize the members of the respective communities about dementia.

The need for specialised services providing support and information to family caregivers of PwM with dementia is estimated by the expert to be very high. Currently, there is a huge lack of information about the healthcare system, the nature of dementia, and the prevalence of the disease. Multilingual information resources do exist, but they are hardly used, presumably due to wrong communication mediums. The expert pointed out that research has shown that flyers and other such literature are less effective information transfer mediums for PwM than other mediums such as lectures or films.

Accordingly, it is not only important to provide specialized information adapted to the needs of PwM but also to choose the right medium for information transfer.



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# Greece

**Population**

10,710,000

**Area**

132,049 km<sup>2</sup>

**Capital**

Athens

**3 largest cities**

Athens (664,000)

Thessaloniki (325,000)

Patra (214,000)

**Neighboring countries**

Albania, Bulgaria, North  
Macedonia, Turkey

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



### 1. Migration history

From the 1830s to the end of the 20th century, Greece was characterised by the emigration of large parts of the population. Between the late 19th and early 20th centuries and after the Second World War, two waves of large-scale immigration occurred. From 1890 to 1914 approximately one-sixth of the Greek population left the country. Between 1950 and 1974 another million people emigrated. In the years 1974 to 1985 about half of the emigrants of the post-war period returned [1]. During the 1980s, Greece developed into a transit country for people from Eastern Europe, the Middle East, and Africa [2]. The collapse of the Central and Eastern European political systems in 1989 led to a significant increase in immigration. Between 1990 and 2005, Greece evolved from an emigration country to an immigration country. In the early 1990s, mainly people from Albania came to Greece. After 1995, many immigrants arrived from other Balkan states, the former Soviet Union, Pakistan, and India. In 2001, the foreign population already comprised of 762,200 people. Almost two-thirds of the people in this population came from Albania, Bulgaria, and Romania (more than

half from Albania) [1]. From 2007 onwards, the number of irregular migrants and asylum seekers (from Pakistan, Bangladesh, Iraq, Afghanistan, etc.) entering Greece via the Aegean Sea and the land route has also increased significantly [2]. Since the Syrian conflict in 2011, transit migration to Greece has increased significantly. In 2015 alone, around 860,000 people from North Africa or via Turkey reached Greece, most of them by sea. In 2019 (until 20 October), more than 53,000 people arrived in Greece by land or sea. The largest groups of people came from Afghanistan (13,800) and Syria (9,100). Most of them subsequently migrated to Western or Northern Europe [3]. In 2013, people from Albania (574,800), Bulgaria (56,000), Romania (38,600), Georgia (37,900), and Pakistan (24,500) represented the largest migrant groups [4]. Between 2010 and 2019, the migrant population (born abroad) declined from 1.3 to 1.2 million and its proportion in the total population fell from 12.1 to 11.6%. Previously, it had doubled compared to 1990 (618,100/6%) [5]. Since 2010, the net migration rate has been negative. Currently, the rate is -1.5 [6].



## 2. Estimated number of people with a migration background with dementia

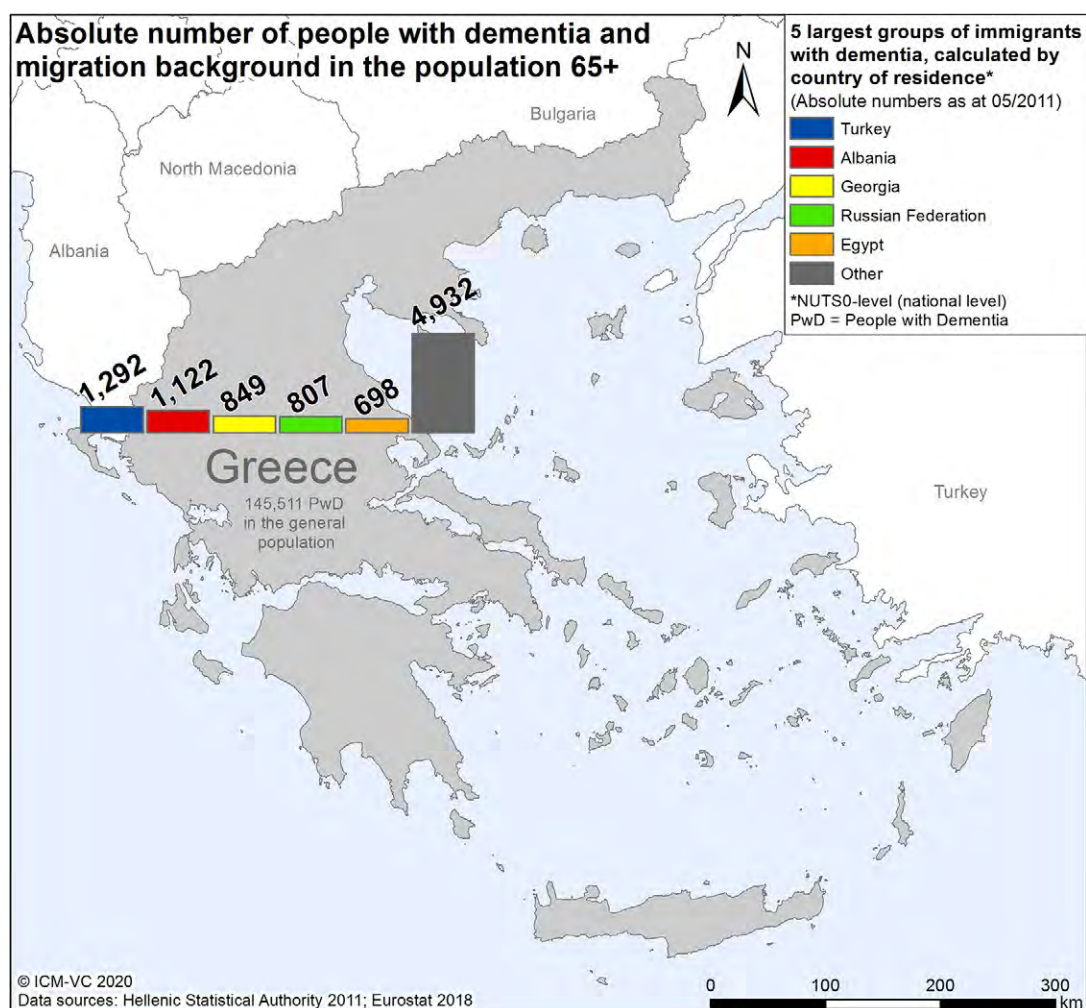


Fig. 3.7.12.1: Absolute number of PwM with dementia aged 65+ (Greece – Nation)

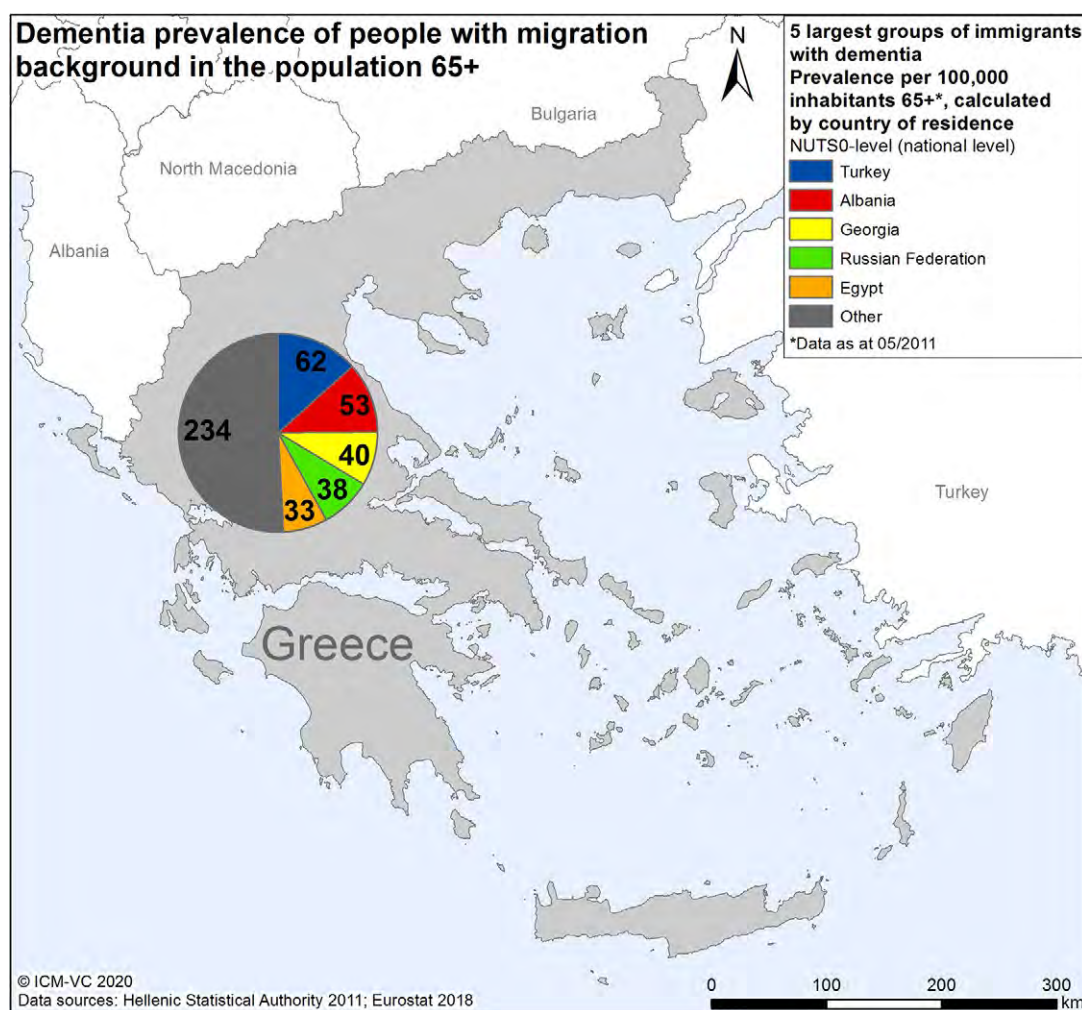


Fig. 3.7.12.2: Prevalence of PwM with dementia among the population aged 65+ (Greece – Nation)

**Tab. 23: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Greece – Nation)**

NUTS	Total	GR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Greece	145,511	135,812	TR 1,292	AL 1,122	GE 849	RU 807	EG 698	4,931
Prevalence/10,000 inhabitants with migration background 65+								
Greece	10,352	-	TR 92	AL 80	GE 60	RU 57	EG 50	351
Prevalence/100,000 inhabitants 65+								
Greece	6,900	6,440	TR 61	AL 53	GE 40	RU 38	EG 33	83

Data source: Hellenic Statistical Authority (2011)

There are 140,600 PwM aged 65 or older. Of those, approx. 9,700 are estimated to exhibit some form of dementia. Figure 3.7.12.1 shows the most affected migrant groups presumably originate from Turkey (approx. 1,300), Albania (approx. 1,100), Georgia (approx. 900), the Russian Federation (approx. 800), and Egypt (approx. 700). The second graph highlights the number of PwM with dementia in Greece

per 100,000 inhabitants aged 65 or older (figure 3.7.12.2). Table 23 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Turkey, Albania, Georgia, the Russian Federation, and Egypt throughout the country in the NUTS2 regions (figures 3.7.12.3 – 3.7.12.8).

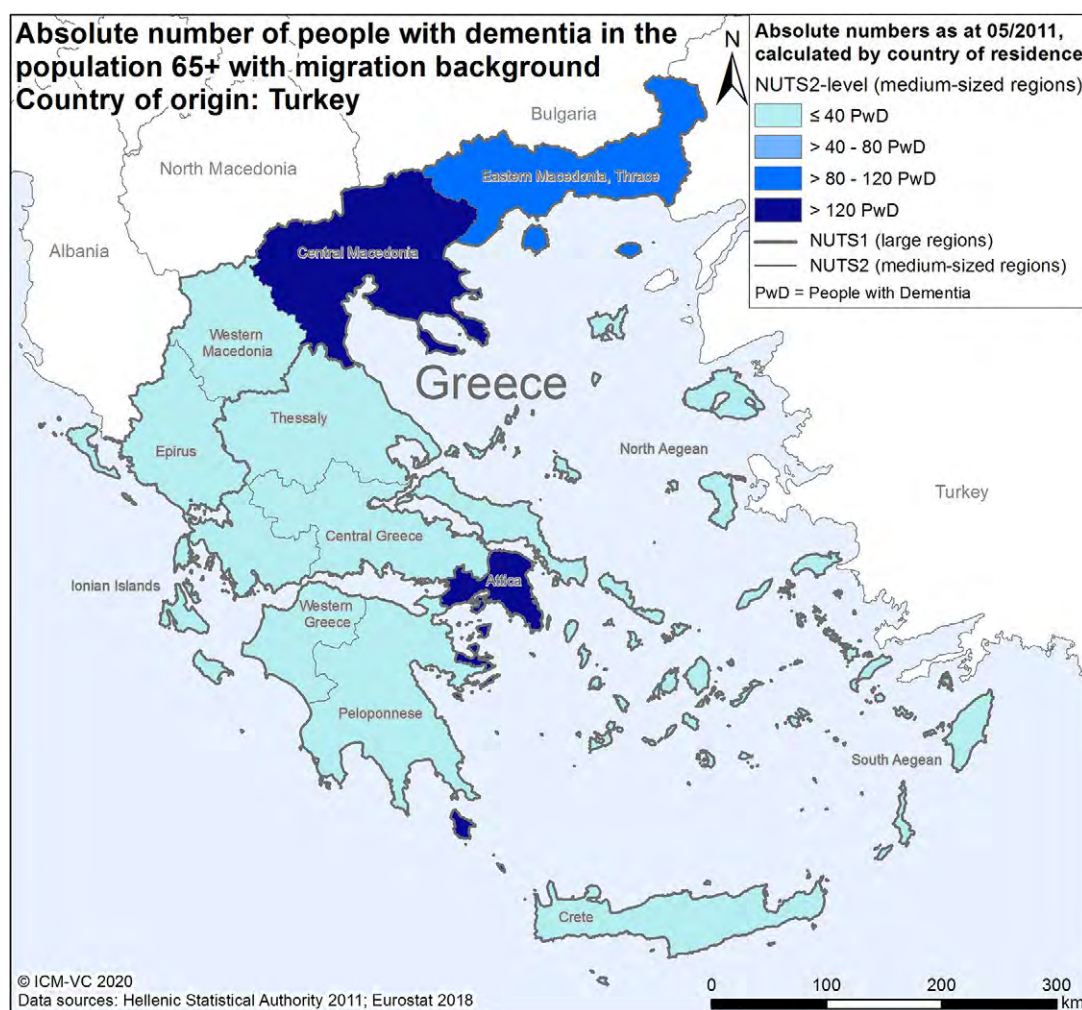


Fig. 3.7.12.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Turkey (Greece – NUTS2)



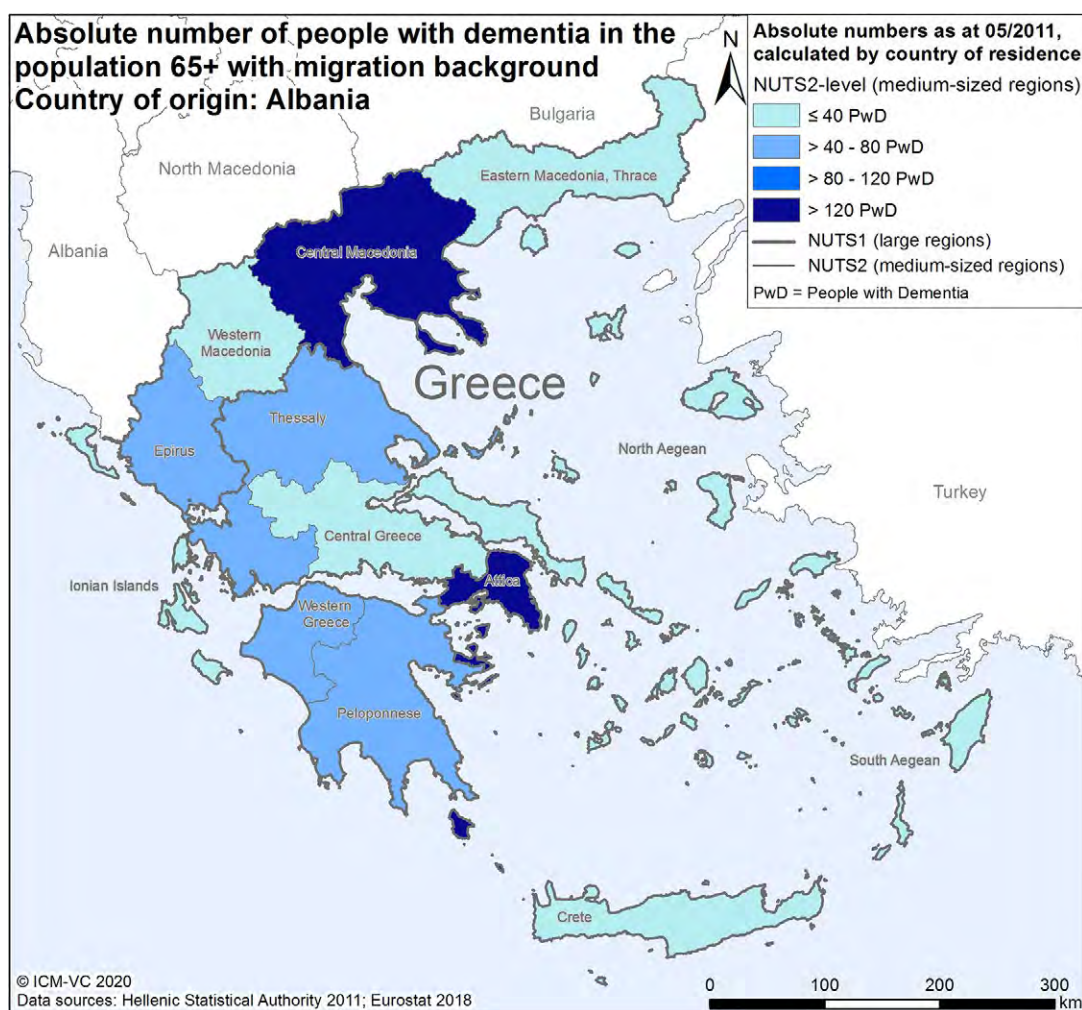


Fig. 3.7.12.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Albania (Greece – NUTS2)

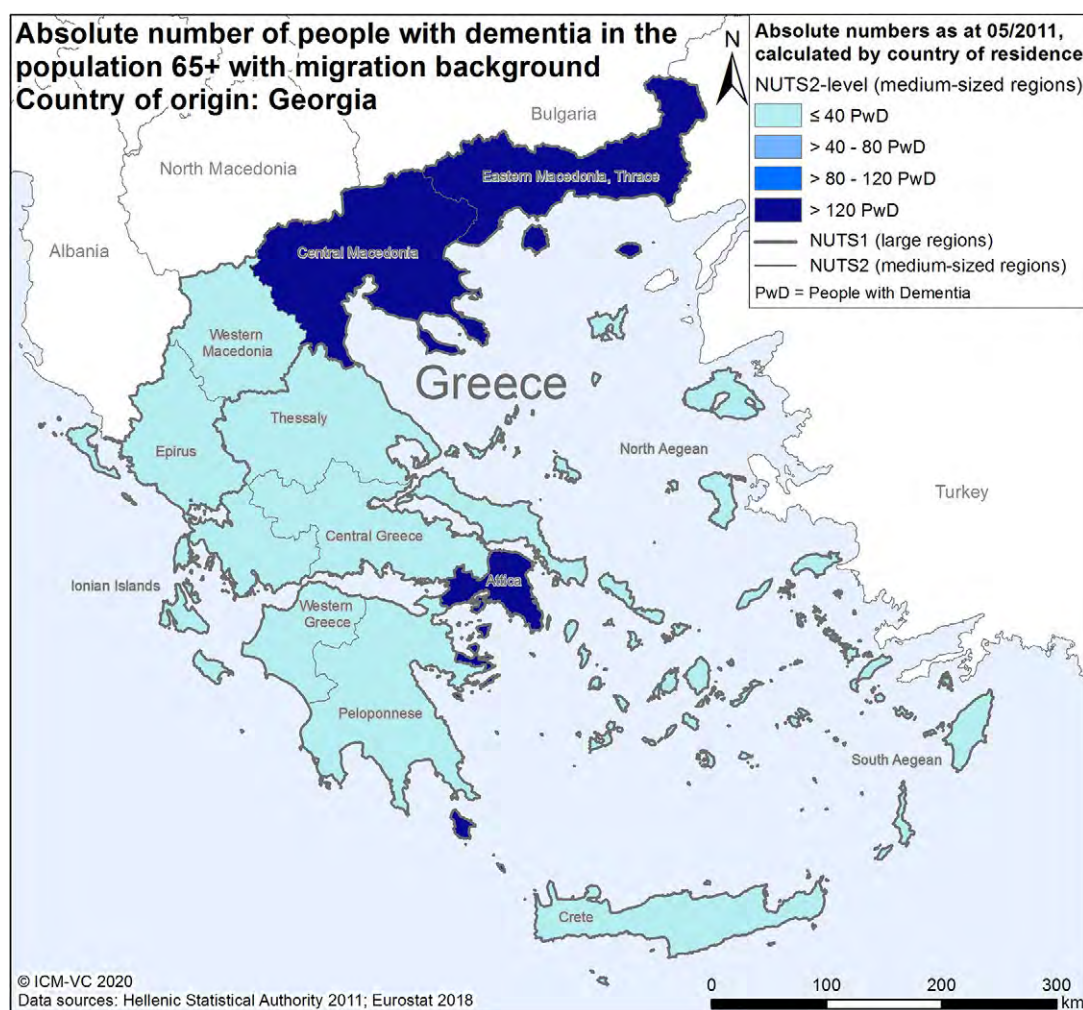


Fig. 3.7.12.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Georgia (Greece – NUTS2)



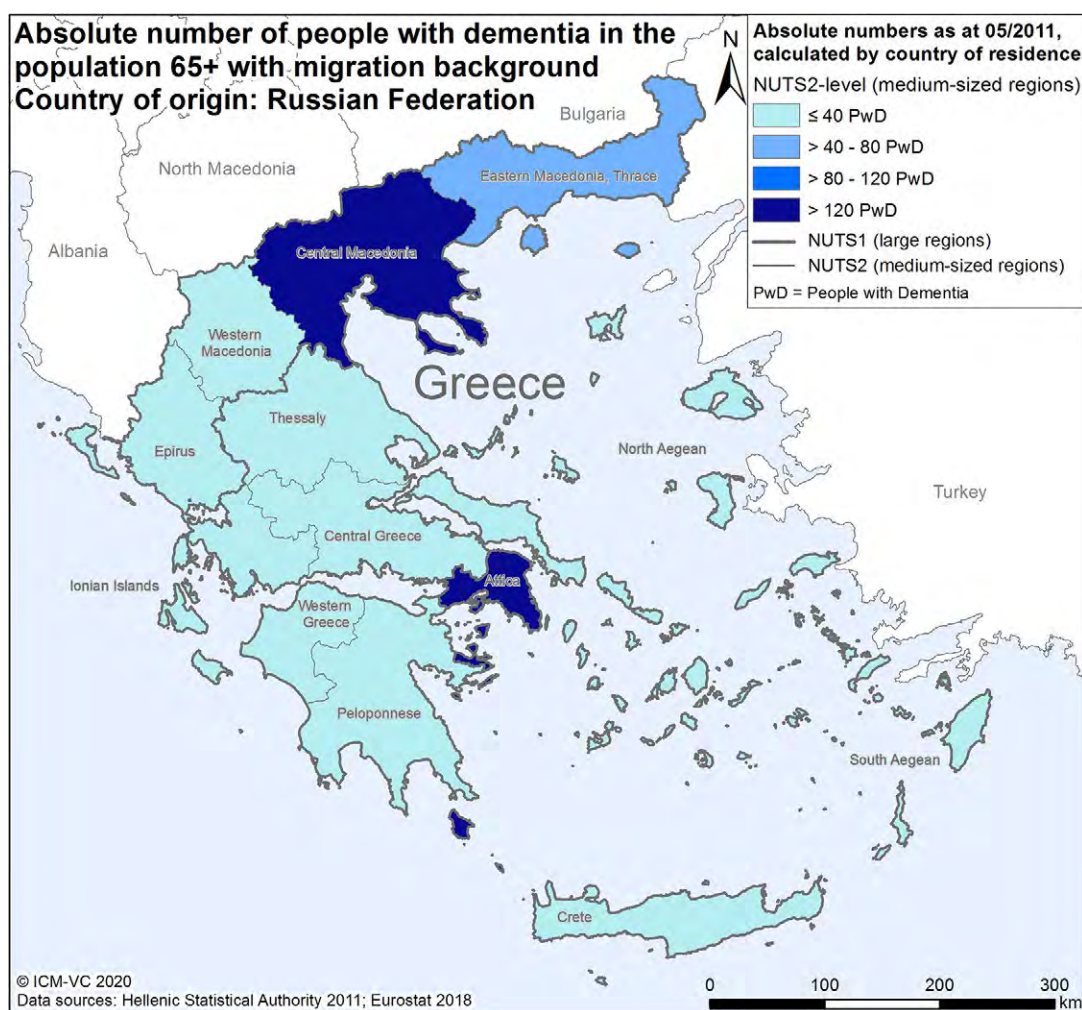


Fig. 3.7.12.6: Absolute number of PwM with dementia aged 65+.  
 Country of origin: The Russian Federation (Greece – NUTS2)

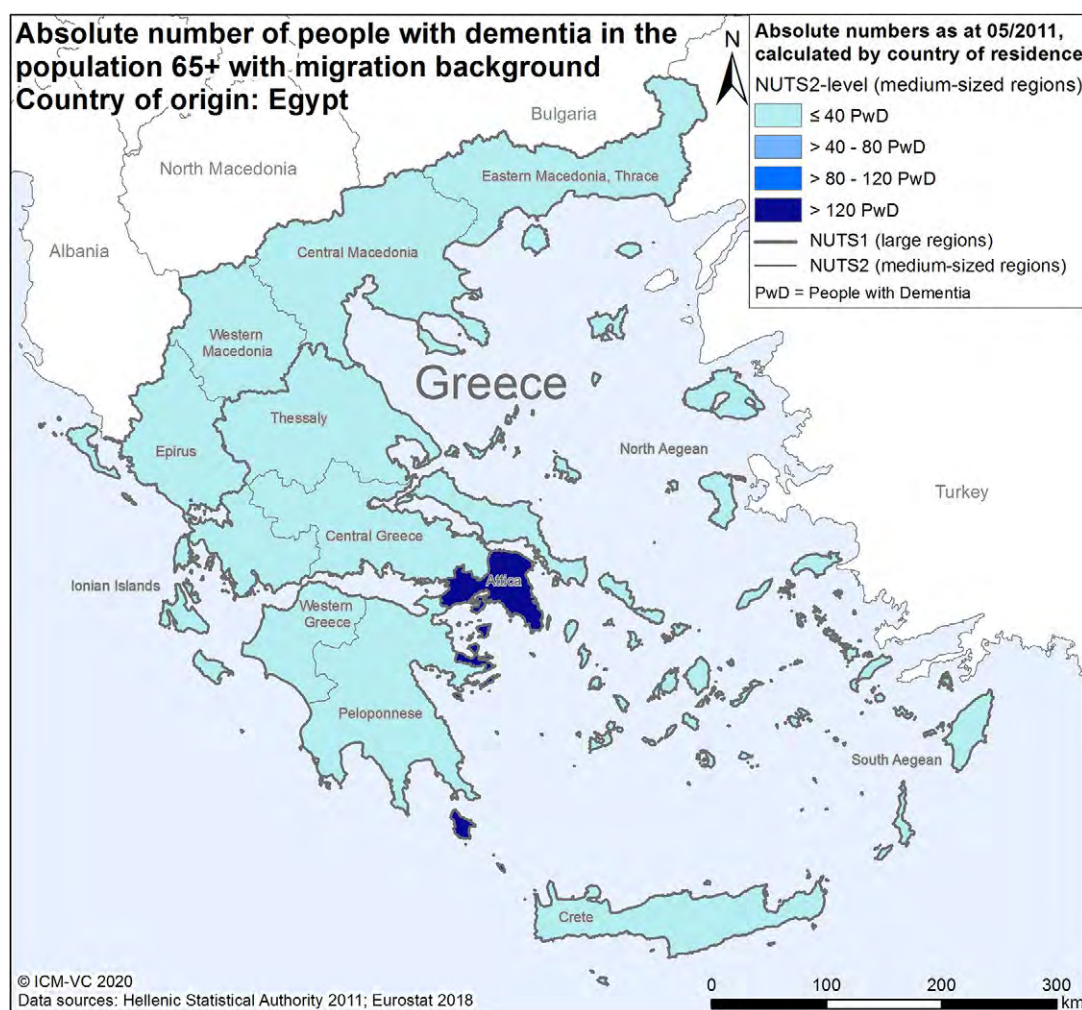


Fig. 3.7.12.7: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Egypt (Greece – NUTS2)

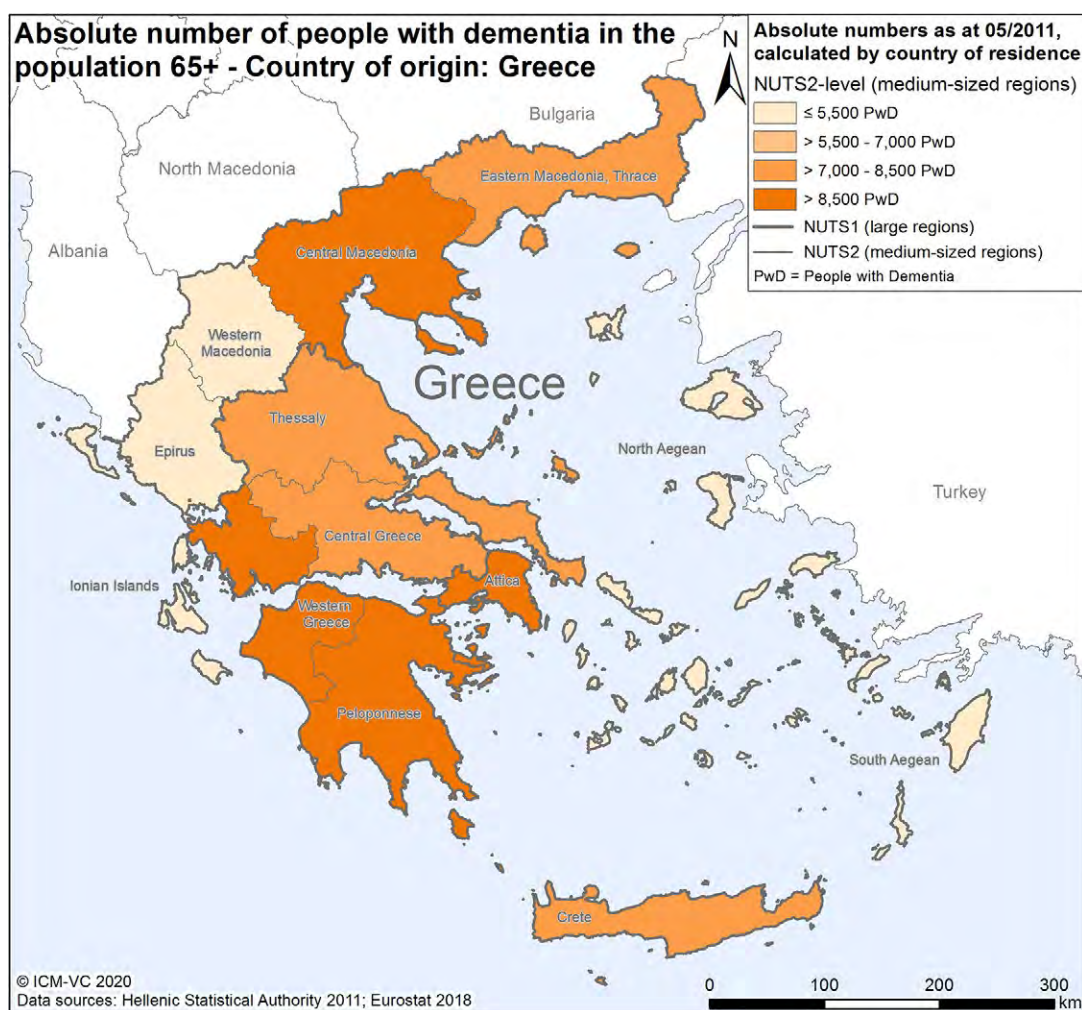


Fig. 3.7.12.8: Absolute number of people with dementia aged 65+.  
Country of origin: Greece (Greece – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.12.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.12.10). The values from the NUTS2 level can be found in table 24 [7-9].

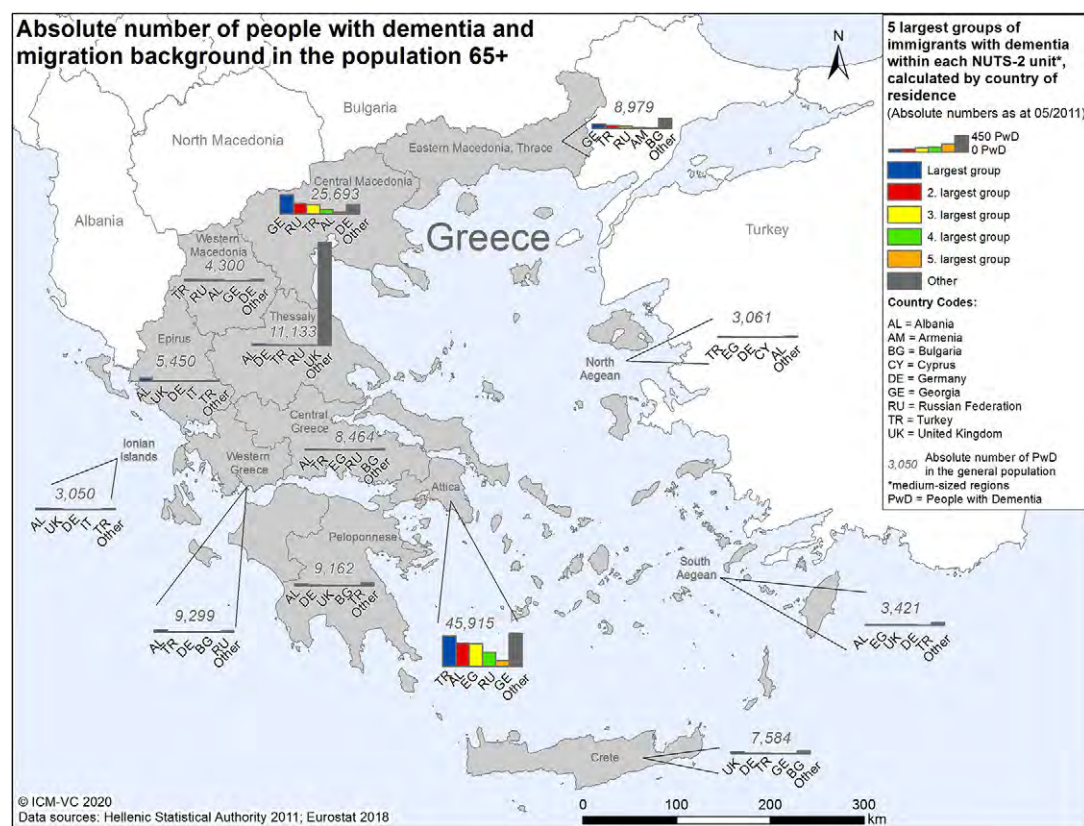


Fig. 3.7.12.9: Absolute number of PwM with dementia aged 65+ (Greece – NUTS2)

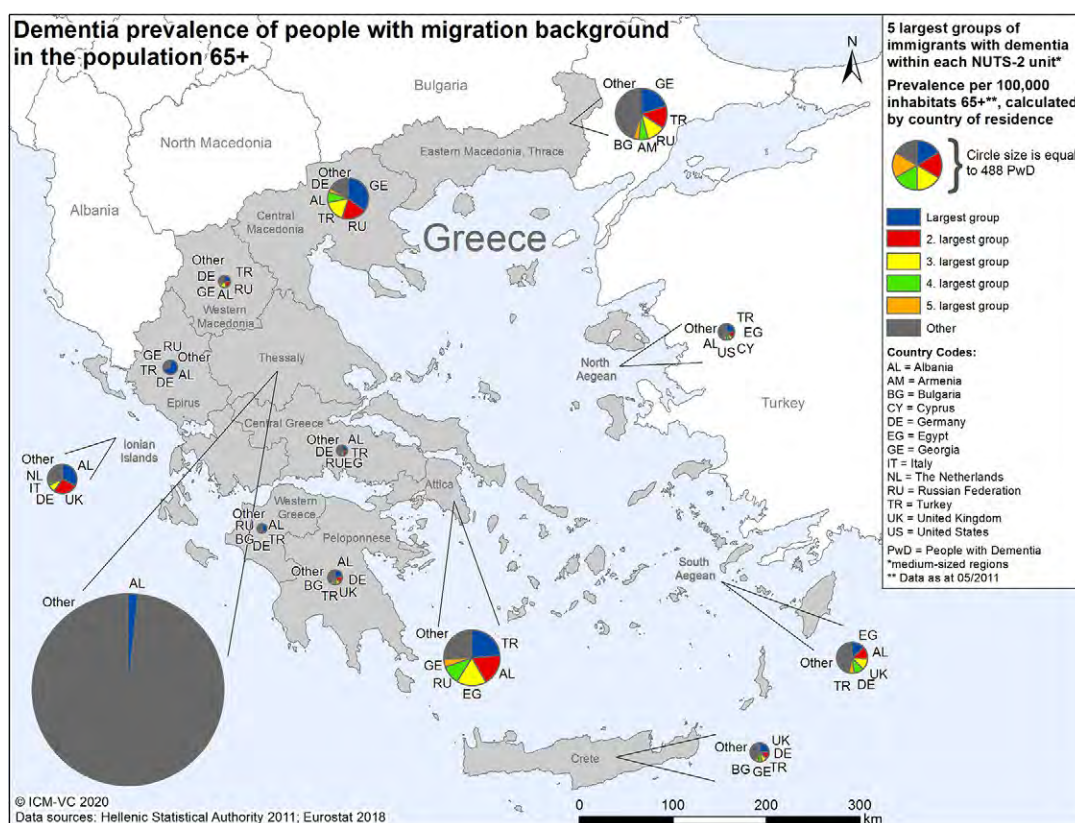


Fig. 3.7.12.10: Prevalence of PwM with dementia aged 65+ (Greece – NUTS2)

Tab. 24: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Greece – NUTS 2)

NUTS	Total	GR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Attica	45,915	42,392	TR 828	AL 637	EG 611	RU 383	GE 166	898
North Aegean	3,061	2,991	TR 18	EG 8	CY 5	US 5	AL 5	29
South Aegean	3,421	3,274	EG 19	AL 19	UK 18	DE 16	TR 8	67
Crete	7,584	7,383	UK 49	DE 25	TR 17	GE 15	BG 10	85
Eastern Macedonia, Thrace	8,979	8,344	GE 126	TR 91	RU 74	AM 35	BG 24	285
Central Macedonia	25,693	24,211	GE 522	RU 291	TR 248	AL 125	DE 48	248
Western Macedonia	4,300	4,228	TR 17	RU 15	AL 14	GE 6	<5	16



## Greece

NUTS	Total	GR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Epirus	5,450	5,342	AL 77	DE 7	<5	<5	<5	16
Thessaly	11,133	8,237	AL 48	DE 17	TR 14	RU 12	UK 10	2,795
Ionian Islands	3,050	2,927	AL 40	UK 33	DE 10	<5	<5	34
Western Greece	9,299	9,173	AL 57	TR 11	DE 9	BG 6	RU 6	37
Central Greece	8,464	8,337	AL 34	TR 21	EG 12	RU 9	DE 8	43
Peloponnese	9,162	8,972	AL 45	DE 28	UK 17	TR 12	BG 12	76
Prevalence/10,000 inhabitants with migration background 65+								
Attica	8,992	-	TR 162	AL 125	EG 120	RU 75	GE 32	176
North Aegean	29,985	-	TR 172	EG 82	CY 49	US 47	AL 46	4,294
South Aegean	16,003	-	EG 89	AL 88	UK 83	DE 73	TR 39	318
Crete	26,054	-	UK 168	DE 87	TR 59	GE 50	BG 36	290
Eastern Macedonia, Thrace	9,765	-	GE 137	TR 99	RU 81	AM 38	BG 26	309
Central Macedonia	11,967	-	GE 243	RU 136	TR 116	AL 58	DE 22	115
Western Macedonia	41,035	-	TR 164	RU 144	AL 130	GE 54	DE 36	162
Epirus	34,867	-	AL 492	DE 44	TR 22	GE 19	RU 15	98
Thessaly	2,653	-	AL 11	DE 4	TR 3	RU 3	UK 2	667
Ionian Islands	17,163	-	AL 226	UK 186	DE 57	IT 19	NL 17	185
Western Greece	51,010	-	AL 312	TR 61	DE 51	BG 34	RU 33	199
Central Greece	46,023	-	AL 183	TR 112	EG 65	RU 47	DE 44	239
Peloponnese	33,257	-	AL 163	DE 102	UK 63	TR 44	BG 42	276



NUTS	Total	GR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/100,000 inhabitants 65+								
Attica	6,900	6,371	TR 124	AL 96	EG 92	RU 58	GE 25	122
North Aegean	6,900	6,741	TR 40	EG 19	CY 11	US 11	AL 11	57
South Aegean	6,900	6,602	EG 39	AL 38	UK 36	DE 31	TR 17	126
Crete	6,900	6,717	UK 45	DE 23	TR 16	GE 13	BG 10	57
Eastern Macedonia, Thrace	6,900	6,412	GE 97	TR 70	RU 57	AM 27	BG 18	51
Central Macedonia	6,900	6,502	GE 140	RU 78	TR 67	AL 34	DE 13	58
Western Macedonia	6,900	6,784	TR 28	RU 24	AL 22	GE 9	DE 6	23
Epirus	6,900	6,763	AL 97	DE 9	TR 4	GE 4	RU 3	14
Thessaly	6,900	5,105	AL 30	DE 10	TR 9	RU 7	UK 6	23
Ionian Islands	6,900	6,623	AL 91	UK 75	DE 23	IT 8	NL 7	63
Western Greece	6,900	6,807	AL 42	TR 8	DE 7	BG 5	RU 4	21
Central Greece	6,900	6,797	AL 27	TR 17	EG 10	RU 7	DE 7	28
Peloponnese	6,900	6,757	AL 34	DE 21	UK 13	TR 9	BG 9	49

Note: Absolute numbers < 5 are not given for data protection reasons.

Data source: Hellenic Statistical Authority (2011)

### 3. National dementia plan

The 'National Action Plan for Dementia - Alzheimer's Disease' from 2017 has a scope of 93 pages and contains four general chapters: 1. 'Dementia World-wide (topics: epidemiology and risk factors of dementia, types of dementia, international policy for treating dementia, and rights of people with dementia), 2. 'Dementia in Greece' (research and education, economic dimensions, and health and so-

cial care), 3. 'Strategic Planning' (vision, principles, and aims of the national action plan), and 4. 'Axes and Actions of the National Plan (registration and classification of people with dementia in Greece, prevention, support of caregivers of people with dementia, and treatment of dementia). In none of these chapters a reference is made to the topic of migration [10].

## 4. National dementia care and treatment guidelines

According to an expert from the School of Psychology at the Aristotle University of Thessaloniki, Greece currently has no national treatment guidelines. This expert stated that clinicians treat dementia primarily with medication, with a few centres (Hellenic Alzheimer's Association, Athens Alzheimer's Association) and individual practitioners providing

cognitive enhancement/rehabilitation [11].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, migrants are not seen as a vulnerable group solely by virtue of being migrants. The Greek healthcare system sees people as vulnerable based on their individual characteristics such as age or physical disability, rather than only ethno-cultural background. Dementia and migration is not an important topic in Greece on a state level. No specialised services available for PwM with dementia are provided by the government either on a national or regional level. This is not surprising as a) also other topics regarding migration are not a focal point either, e.g. health and migration or education and migration and b) the earliest services for dementia were implemented at the beginning of the millennium and there are just not a lot of dementia services. Only in the latest years, there was a mental health reform where units for dementia multiplied. In addition, there was an effort to connect ambulatory memory services with day-care centres for the elderly to detect early symptoms of dementia. In practice, the healthcare professionals try to use the MMSE, but there are no culturally adapted diagnostic tools for people with a different cultural background. The expert reported that generally speaking, 'there is no specific provision for a culturally sensitive or a migrant-friendly healthcare

here in Greece'. The expert also stated that there are no current or planned measures to provide care and support for PwM with dementia. If a migrant person regardless of dementia, goes to a clinic or any other service there will not even be specialised interpreters as they are expected to provide translation by themselves. The expert noted that if there is some support offered to PwM or to refugees in general, then it is by individual initiatives or NGOs, e.g. Caritas tried to set up a service for refugees with dementia. However, since there was no demand from this group, as refugees are a younger population, this service folded. There seems to be a low demand for such services. The expert assumed that people from countries that do not offer dementia-specific services do not ask for these services since they are not familiar with their existence. In addition, if one does not speak Greek or at least English, it will be a further hindrance in getting help. Also, if organisations that work with migrants come across PwM who might possibly have dementia, they have to rely on their own resources to find solutions and provide help. Another interesting point the expert mentioned is that the private sector offers healthcare services, and if someone is able to pay for them, one will be taken care of no matter the ethnic background.



## 6. Professional qualification and people with a migration background in healthcare

It seems that culturally sensitive care is not part of the professional qualifications, and there are no professional training possibilities in intercultural care available as per the expert. So, there is a significant need for awareness and training regarding culturally sensitive care. The expert assumed there is a high proportion of (professional) caregivers in outpatient care. There are females with a migration background, employed by certain agencies, who work in the private sector as caretakers of people with dementia. Usually, these wom-

en originate from Ukraine, Georgia or African countries, and they live in the house of the person with dementia as domestic staff. Mostly they are not professionally trained and work in Greece irregularly. Since they work the whole day and only have a couple of hours off on Sundays, the impact of this work on their mental health is very serious. Regarding inpatient care the expert mentioned that there seem to be suggestions about training people with a refugee background to work in inpatient care.

## 7. Support for family caregivers

It was noted by the expert that since absolutely no specialised services are provided by the state, the family, religious communities, and migrant organisations play a crucial role in support. These networks can, to some extent, fill the gap between needs and services for PwM with dementia.

The expert stated that existing services and in

formation resources are not adequately helpful for family caregivers of PwM since their unique needs are not addressed by them. Furthermore, information is not even available in different languages. So, the expert pointed out a very high need for specialised services providing support and information to family caregivers.

## 8. References

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# Hungary

**Population**

9,770,000

**Area**

93,022 km<sup>2</sup>

**Capital**

Budapest

**3 largest cities**

Budapest (1,752,000)

Debrecen (201,000)

Szegedin (161,000)

**Neighboring countries**

Austria, Croatia,  
Romania, Serbia,  
Slovakia, Slovenia,  
Ukraine

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

Migration has played a key role in Hungary since the foundation of the state in the 10th century. There have been large migratory movements during the Habsburg Empire from the 16th century onwards and during the Austro-Hungarian Monarchy. Until the 1880s, Hungary was mainly characterised by immigration flows. Between the 1880s and the First World War, about two million people emigrated. The two world wars led to the next major migratory flows. From 1919 to 1923, about 200,000 ethnic Hungarians resettled in Hungary. After the Second World War, about 200,000 ethnic people of Germany were expelled from Hungary and over 100,000 people emigrated (including 73,000 Slovaks). At the same time, about 308,500 ethnic Hungarians resettled in Hungary [1]. The next wave of large-scale migration occurred in 1956 when 176,000 people from Hungary left the country for the US, Canada, Austria, and other Western European countries. Overall, migration flows were severely restricted under the socialist state. The number of legal immigrants (excluding returning Hungarian citizens) was only 52,000 in 1987. The collapse of the communist systems (1989/1990) led to a significant increase in immigration and emigration. In the mid-1990s, emigration decreased again and many former emigrants returned to Hungary. After the beginning of the Yugoslav wars (1991), non-ethnic Hungarian ex-Yugoslav citizens (from Bosnia and Herzegovina, Serbia, and Albania) applied for asylum. In the mid/late 1990s, Hungary developed from a sending country to a destination country for migrants. Around two-

thirds of the immigrants of the 1990s came from neighbouring countries (from Romania, Ukraine, the successor states of the former Yugoslavia, and Slovakia). EU accession in 2004 subsequently led to more waves of large-scale emigration and immigration. In 2008, immigration increased again (35,000). Most of the immigrants were from Romania, Serbia, Ukraine, and Germany [2]. From 2009 to 2012, immigration figures declined due to the economic downturn [2, 3]. Between 2013 and 2015, there was a wave of extensive transmigration from Africa and the Middle East and the number of asylum applications (especially from Syria and Afghanistan) increased [4]. After 2015, the number of asylum applications and illegal border crossings, which had peaked at 441,515 in 2015, declined again. Currently, the immigration of labour migrants from neighbouring countries (especially from Ukraine) represents the central characteristic of migration. For some years, emigration figures have also been increasing again (29,400 in 2016) [5]. In 2013, people from Romania (232,800) represented the largest migrant group, followed by Germany (33,900), Ukraine (31,600), Serbia (26,800), and Slovakia (24,000) [6]. Between 1990 and 2019, the migrant population (born abroad), increased from 347,500 to 512,000, and the proportion of migrants in the total population grew from 3.3 to 5.3% [7]. As of 2020, the net migration rate is 0.6 [8]. Hungary is a country of sending, transit, and destination of migrants [1]. However, the migrant population is much smaller than in many other EU and EFTA countries.



## 2. Estimated number of people with a migration background with dementia

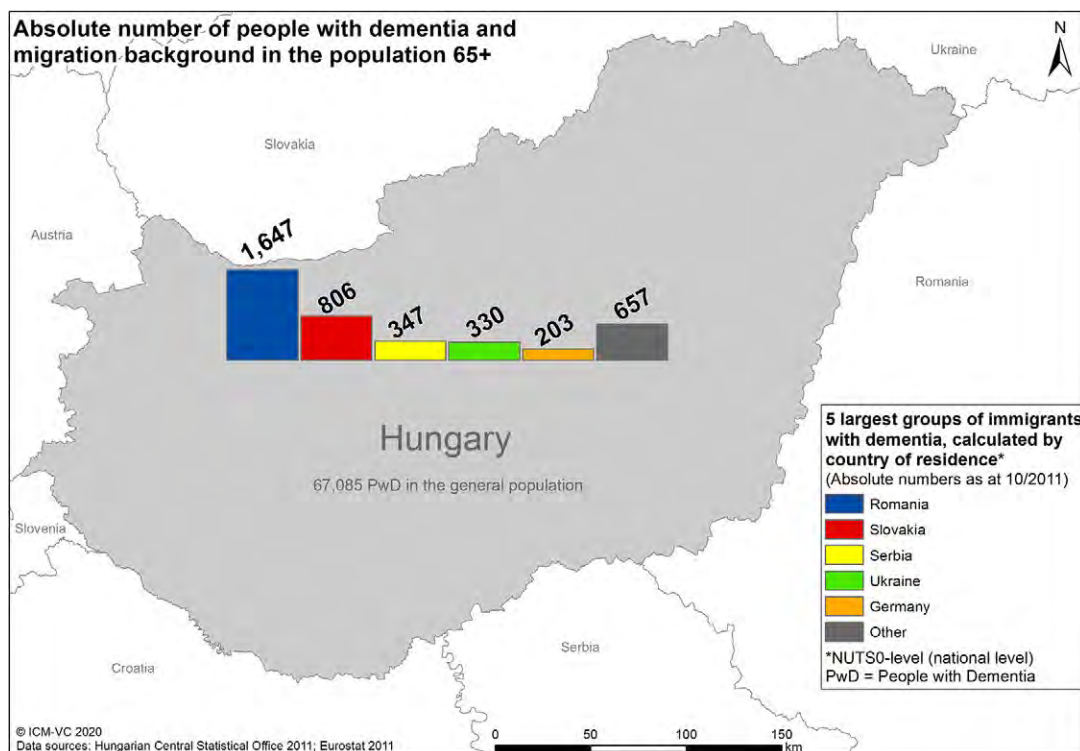


Fig. 3.7.13.1: Absolute number of PwM with dementia aged 65+ (Hungary – Nation)

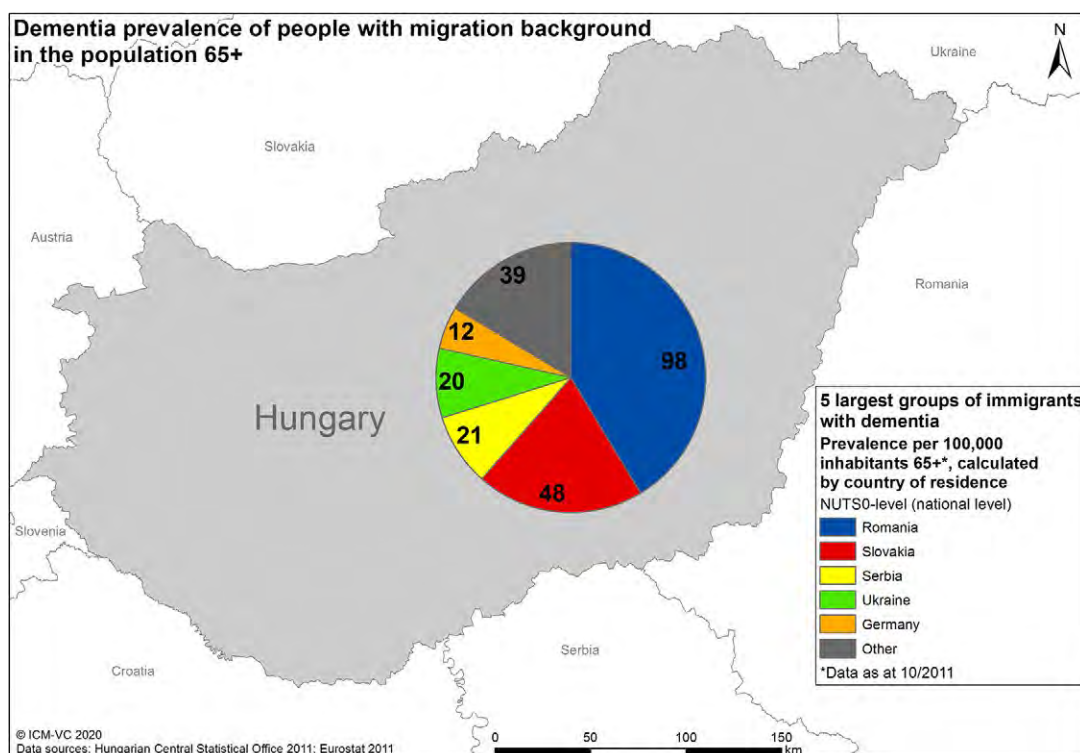


Fig. 3.7.13.2: Prevalence of PwM with dementia among the population aged 65+ (Hungary – Nation)



**Tab. 25: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Hungary – Nation)**

NUTS	Total	HU	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Hungary	67,085	63,096	RO 1,647	SK 806	XS 347	UA 330	DE 203	656
Prevalence/10,000 inhabitants with migration background 65+								
Hungary	6,727	-	RO 165	SK 81	XS 35	UA 33	DE 20	66
Prevalence/100,000 inhabitants 65+								
Hungary	4,000	3,762	RO 98	SK 48	XS 21	UA 20	DE 12	39

Data source: Hungarian Central Statistical Office (2011)

There are 99,700 PwM aged 65 or older. Of those, approx. 4,000 are estimated to exhibit some form of dementia. Figure 3.7.13.1 shows the most affected migrant groups presumably originate from Romania (approx. 1,700), Slovakia (approx. 800), Serbia (approx. 400), Ukraine (approx. 300), and Germany (approx. 200). The second graph highlights the number of PwM with dementia in Hungary per 100,000 inhab-

itants aged 65 or older (figure 3.7.13.2). Table 25 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Romania, Slovakia, Serbia, Ukraine, and Germany throughout the country in the NUTS2 regions (figures 3.7.13.3 – 3.7.13.8).

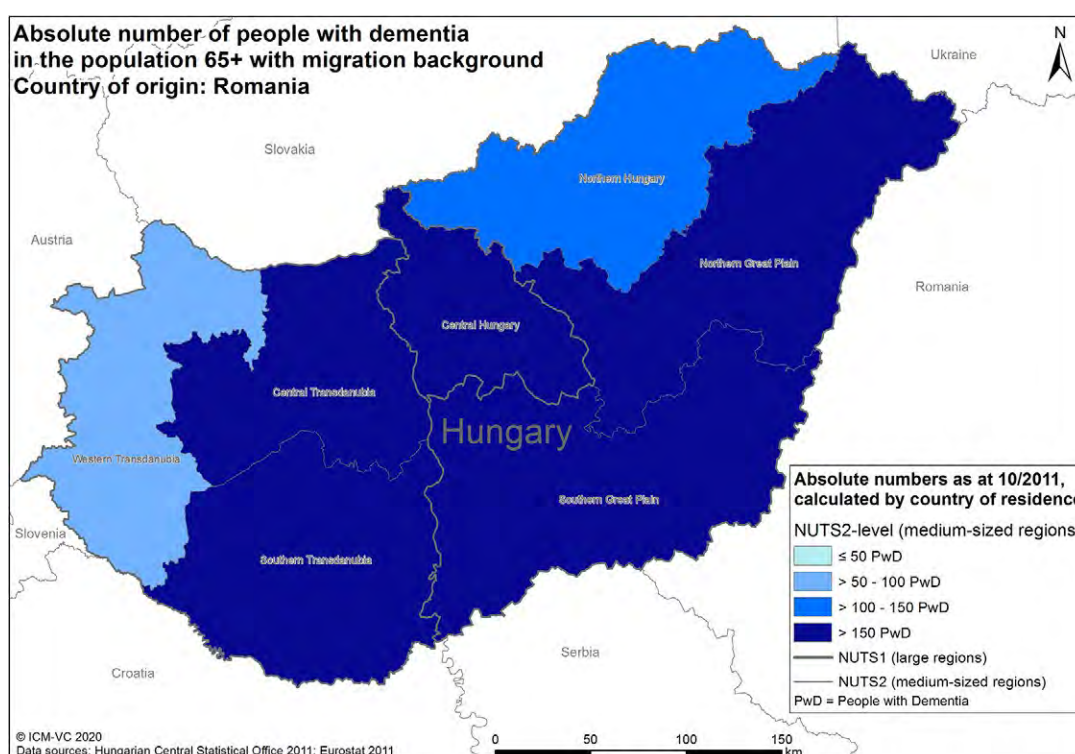


Fig. 3.7.13.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Romania (Hungary – NUTS2)

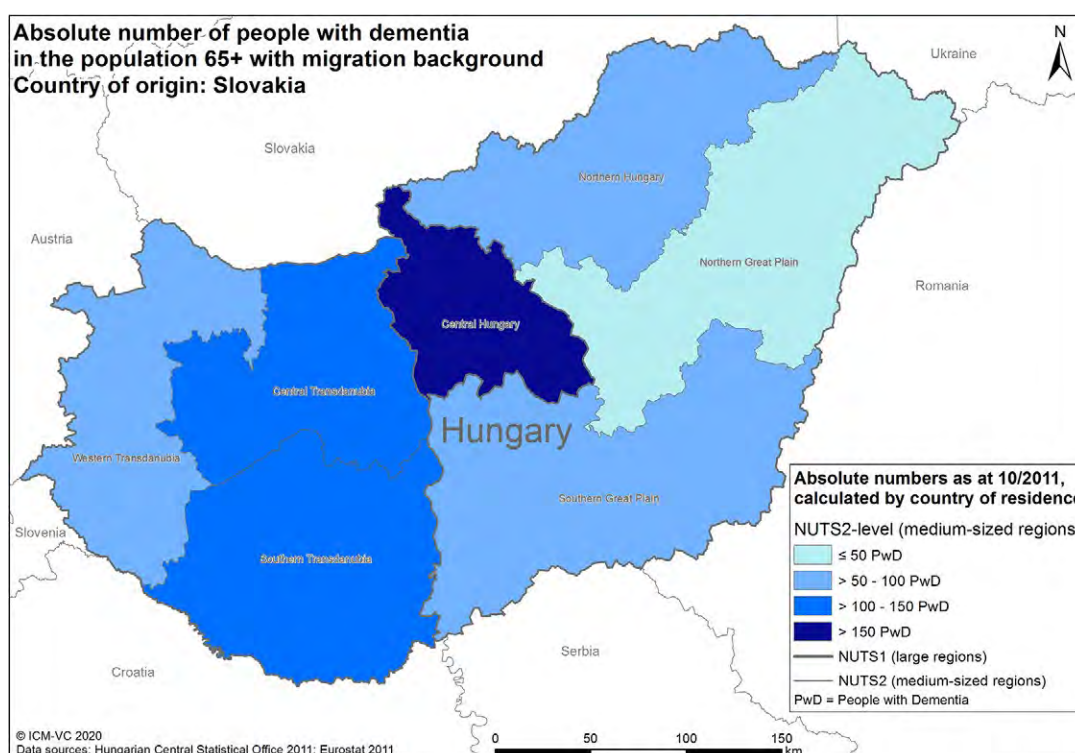


Fig. 3.7.13.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Slovakia (Hungary – NUTS2)

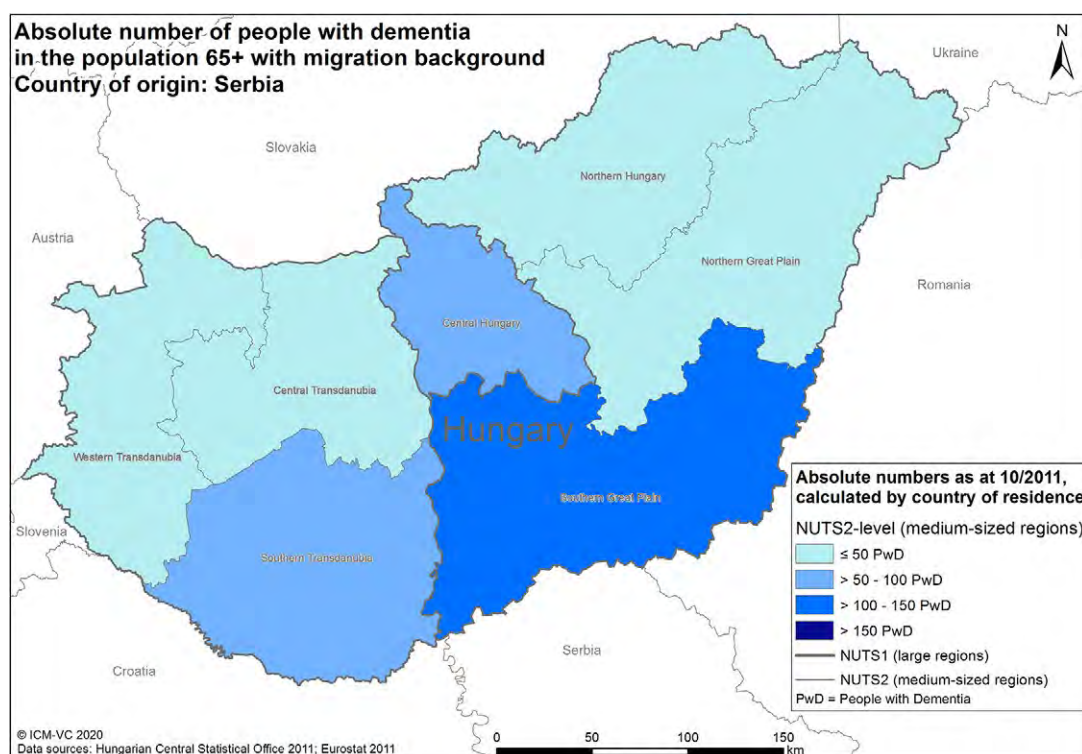


Fig. 3.7.13.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Serbia (Hungary – NUTS2)

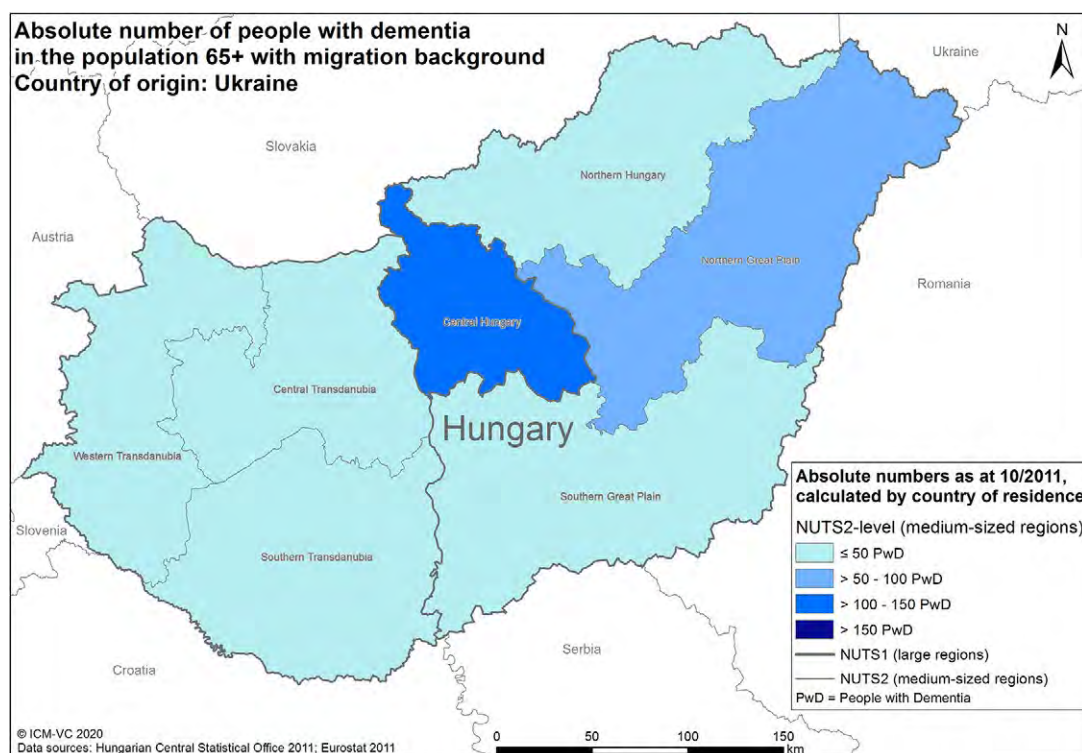


Fig. 3.7.13.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Ukraine (Hungary – NUTS2)



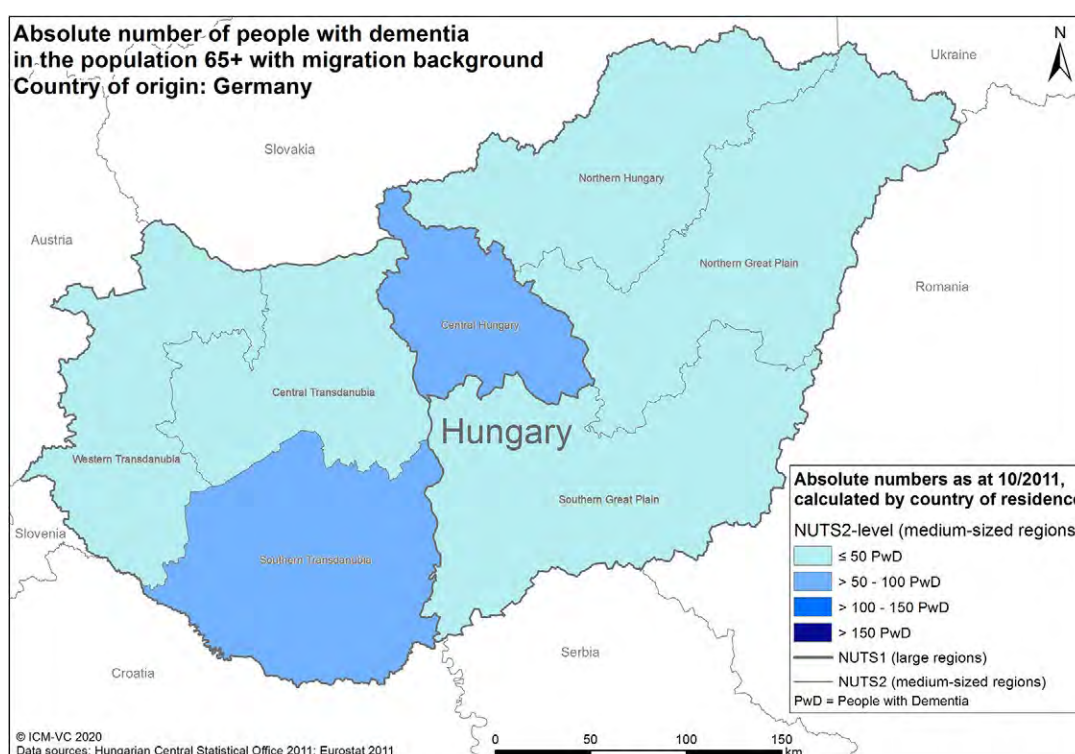


Fig. 3.7.13.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (Hungary – NUTS2)

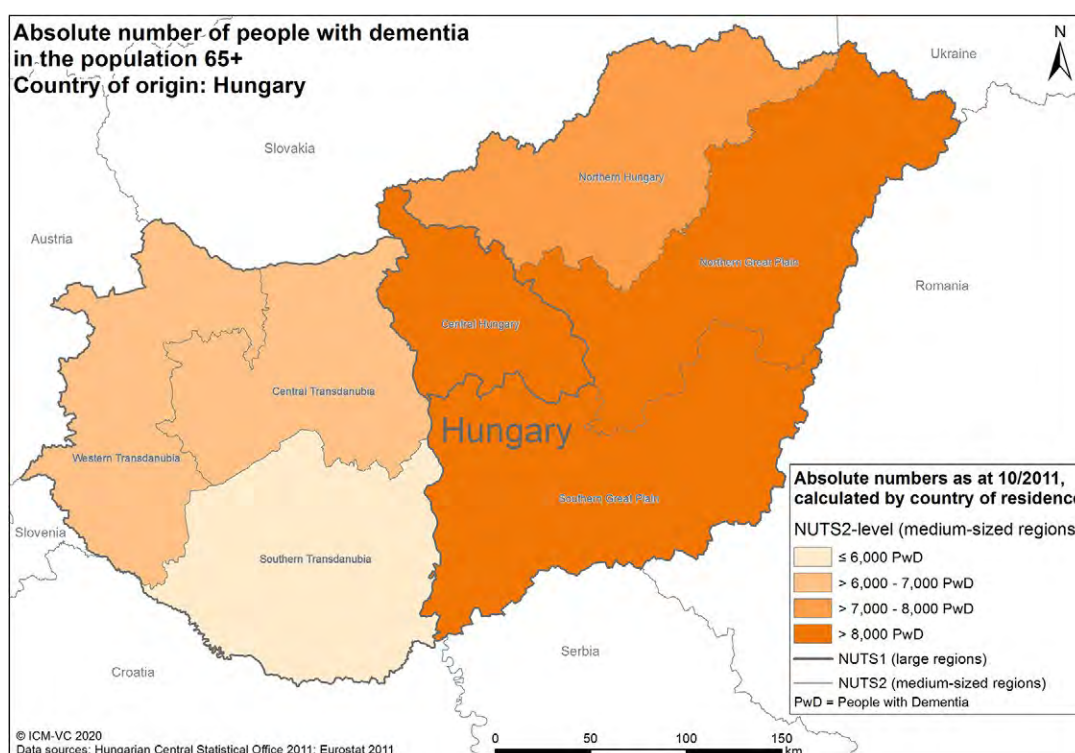


Fig. 3.7.13.8: Absolute number of people with dementia aged 65+.  
Country of origin: Hungary (Hungary – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.13.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (Fig. 3.7.13.10). The values from the NUTS2 level can be found in table 26. [9, 10].

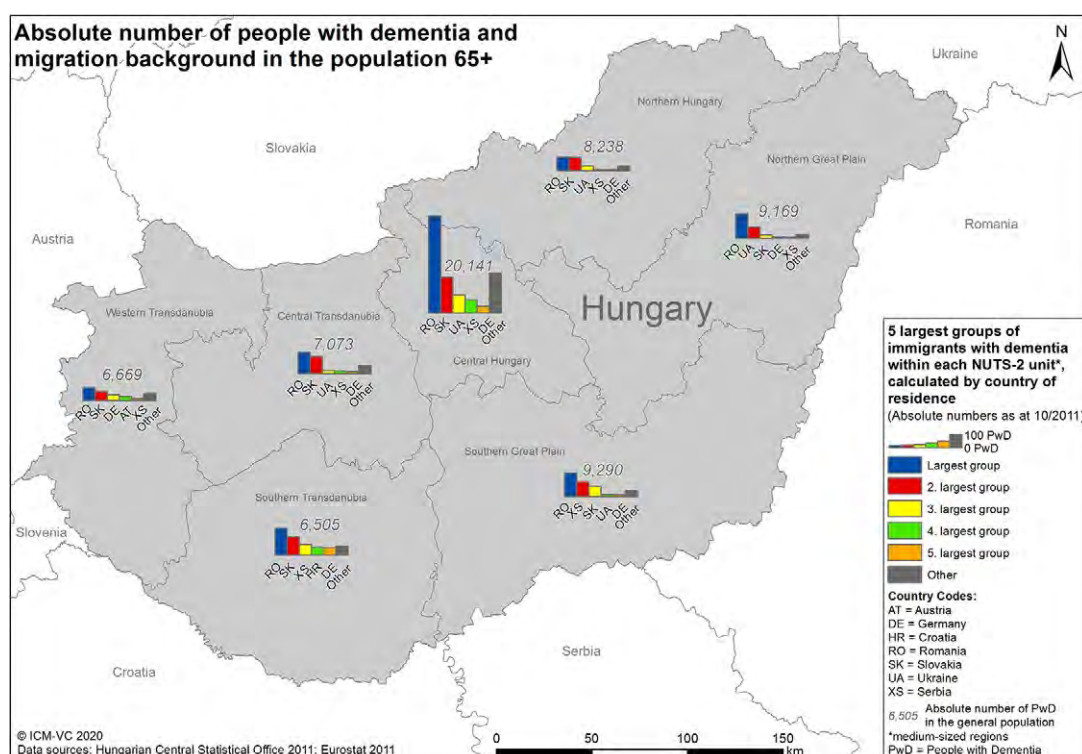


Fig. 3.7.13.9: Absolute number of PwM with dementia in the population 65+ (Hungary – NUTS2)



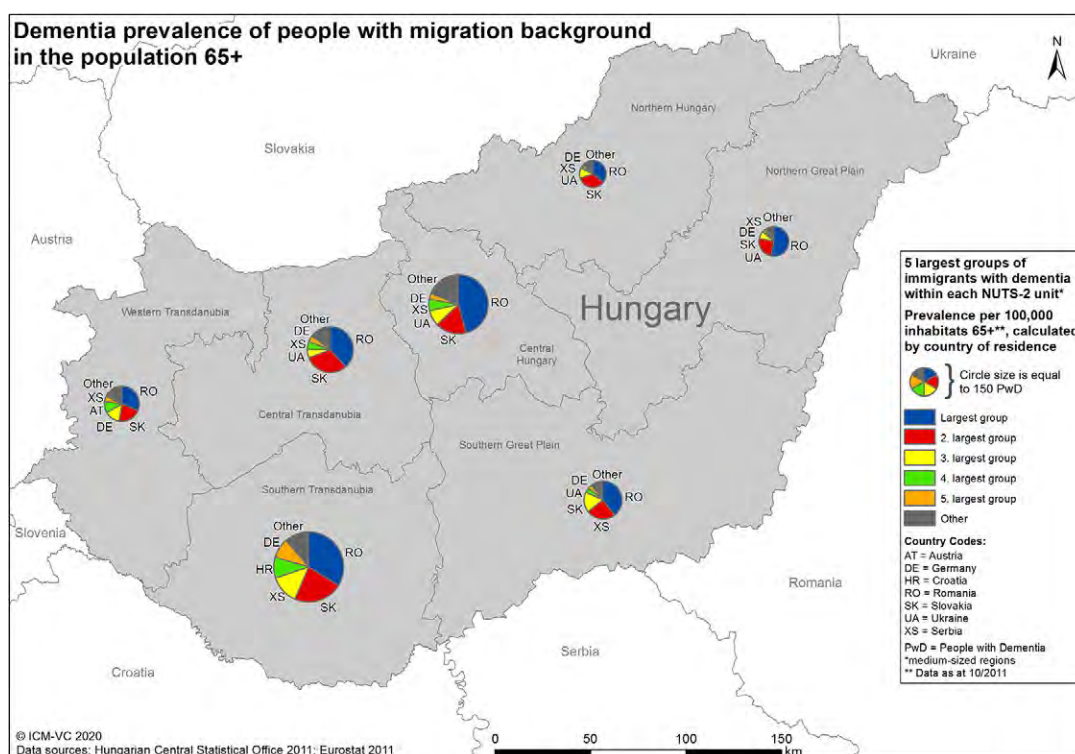


Fig. 3.7.13.10: Prevalence of PwM with dementia among the population aged 65+ (Hungary – NUTS2)

Tab. 26: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Hungary – NUTS 2)

NUTS	Total	HU	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Central Hungary	20,141	18,553	RO 729	SK 270	UA 136	XS 100	DE 52	301
Central Transdanubia	7,073	6,658	RO 159	SK 128	UA 25	XS 23	DE 18	62
Western Transdanubia	6,669	6,359	RO 96	SK 67	DE 44	AT 32	XS 15	56
Southern Transdanubia	6,505	5,905	RO 203	SK 137	XS 80	HR 58	DE 54	68
Northern Hungary	8,238	7,951	RO 101	SK 98	UA 35	XS 8	DE 8	37
Northern Great Plain	9,169	8,825	RO 183	UA 86	SK 28	DE 9	XS 8	30
Southern Great Plain	9,290	8,845	RO 177	XS 112	SK 78	UA 18	DE 16	44



NUTS	Total	HU	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/10,000 inhabitants with migration background 65+								
Central Hungary	5,073	-	RO 184	SK 68	UA 34	XS 25	DE 13	76
Central Transdanubia	6,811	-	RO 153	SK 123	UA 24	XS 22	DE 18	60
Western Transdanubia	8,608	-	RO 124	SK 87	DE 57	AT 42	XS 20	70
Southern Transdanubia	4,340	-	RO 135	SK 91	XS 54	HR 38	DE 36	46
Northern Hungary	11,508	-	RO 141	SK 137	UA 50	XS 11	DE 11	50
Northern Great Plain	10,645	-	RO 212	UA 100	SK 32	DE 10	XS 10	36
Southern Great Plain	8,348	-	RO 159	XS 100	SK 70	UA 16	DE 15	40
Prevalence/100,000 inhabitants 65+								
Central Hungary	4,000	3,685	RO 145	SK 54	UA 27	XS 20	DE 10	59
Central Transdanubia	4,000	3,765	RO 90	SK 72	UA 14	XS 13	DE 10	36
Western Transdanubia	4,000	3,814	RO 58	SK 40	DE 27	AT 19	XS 9	33
Southern Transdanubia	4,000	3,631	RO 125	SK 84	XS 49	HR 35	DE 34	42
Northern Hungary	4,000	3,861	RO 49	SK 48	UA 17	XS 4	DE 4	17
Northern Great Plain	4,000	3,850	RO 80	UA 38	SK 12	DE 4	XS 4	12
Southern Great Plain	4,000	3,808	RO 76	XS 48	SK 34	UA 8	DE 7	18

Data source: Hungarian Central Statistical Office (2011)

## 3. National dementia plan

While no Hungarian dementia plan could be found at the time of the first search in June 2019 [11], a document entitled 'Living with Dementia: National Dementia Strategy' was publicly available in January 2021. The 23-page document addresses the topics: 'What is dementia?', 'What causes dementia?', 'provision

of adequate information', 'early diagnosis', and 'development of services'. However, the topic of migration does not play a significant role. There is only one passage in which it is emphasized that dementia can affect anyone, regardless of ethnicity [12].



## 4. National dementia care and treatment guidelines

The Hungarian dementia care guidelines 'Professional Protocol for Diagnosis, Treatment, and Care of Dementia' published in 2008 expired on 31 December 2013 and have not been renewed since then. Thus, national treatment guidelines had been published in Hungary, but they are no longer valid. This document is 46

pages long and contains chapters on the diagnosis of dementia (topics: physical examinations, mandatory diagnostic tests, additional diagnostic tests, differential diagnosis) and on therapy (non-pharmacological treatment, drug treatment, rehabilitation). The topic of migration is not addressed [13].

## 5. References

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# Iceland

**Population**

364,000

**Area**103,000 km<sup>2</sup>**Capital**

Reykjavík

**3 largest cities**

Reykjavík (131,000)

Kópavogur (38,000)

Hafnarfjörður (30,000)

**Neighboring countries**

None

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References



## 1. Migration history

As a result of its geographical location, Iceland does not have a long history of migration. Until a few years ago, the population remained relatively isolated and homogeneous. In the past, Iceland has been more characterised by the emigration of citizens and return migration. Between 1960 and 1996, Iceland had a net emigration of about 9,300 people. Strong economic growth and a booming tourism sector have led to a larger number of immigrants without Icelandic background coming into the country at the end of the 1990s and beginning of the new millennium. Between 1997 and 2008, Iceland had net immigration of 20,300 people. As a result of the banking crisis in 2008, the number of emigrants exceeded the number of immigrants between 2009 and 2012. In 2013, net migration was positive again and in 2016, it exceeded the 10,000 mark. While the population balance of non-Icelandic citizens is clearly positive, the number of Icelandic citizens has declined slightly. This has led to a historic increase in the number and proportion of foreign citizens on the island

[1]. In the period 1990–2019, the migrant population (born abroad) increased from 9,600 to 52,400 and the proportion of migrants in the total population from 3.8 to 15.5% [2]. In recent decades, there has also been a change in the immigrant's countries of origin. In 1986, 70% of non-Icelandic immigrants came from Denmark, the US, United Kingdom, Sweden, and Norway. In 2016, citizens from non-Nordic EU countries made up the largest group [1]. With the exception of 2004 (Portugal), since 1995 Poland is the main country of origin for immigrants (2016: 2,800 or 36%) [1, 3]. But people also immigrated from Lithuania (700), the US (300), Germany (300), and other countries (3,800) (as of 2016) [1]. In 2013, people from Poland (9,400), Denmark (3,100), Sweden (1,900), US (1,900), and Germany (1,600) represented the largest migrant groups [4]. Iceland has developed into an immigration country especially for migrants from Poland and some other EU member states. As of 2020, the net migration rate is 1.1 [5].



## 2. Estimated number of people with a migration background with dementia

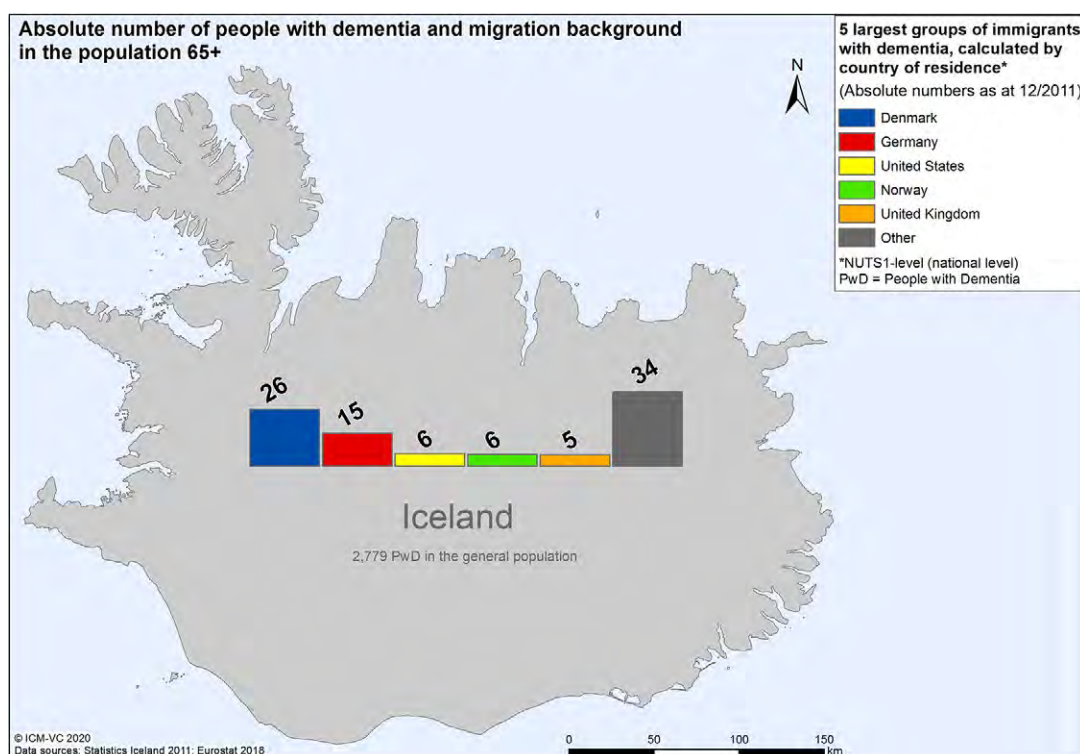


Fig. 3.7.14.1: Absolute number of PwM with dementia aged 65+ (Iceland – Nation)

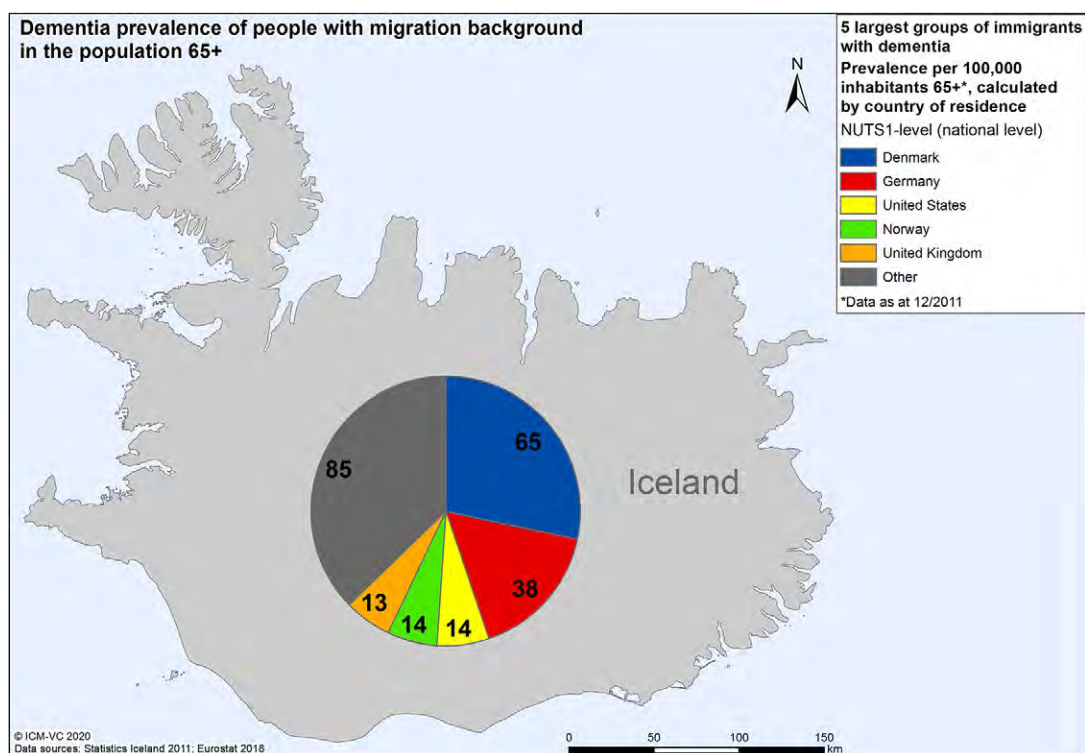


Fig. 3.7.14.2: Prevalence of PwM with dementia among the population aged 65+ (Iceland – Nation)



**Tab. 27: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Iceland – Nation)**

NUTS	Total	IS	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Iceland	2,779	2,687	DK 26	DE 15	US 6	NO 6	UK 5	34
Prevalence/10,000 inhabitants with migration background 65+								
Iceland	20,851	-	DK 196	DE 113	US 43	NO 41	UK 39	258
Prevalence/100,000 inhabitants 65+								
Iceland	6,900	6,672	DK 65	DE 38	US 14	NO 14	UK 13	76

Data source: Statistics Iceland (2011)

There are 1,300 PwM aged 65 or older. Of those, approx. 90 are estimated to exhibit some form of dementia. Figure 3.7.14.1 shows the most affected migrant groups presumably originate from Denmark (approx. 30), Germany (approx. 20), the US (approx. 10), Norway (approx. 10),

and United Kingdom (approx. 10). The second graph highlights the number of PwM with dementia in Iceland per 100,000 inhabitants 65 or older (figure 3.7.14.2). Table 27 displays the values depicted in the maps on the national level [6-8].

### 3. National dementia plan

At the time of the first search, 1 June 2019, no NDP could be identified for Iceland [9]. However, in April 2020, the government published a NDP: The 'Action Plan for Services for People with Dementia'. This dementia plan is 27 pages long and covers 5 topics: 1. right of self-determination, patient involvement, and legal framework, 2. pre-

vention, timely diagnosis in the right place, and post-diagnostic follow-up, 3. activity, self-help, and support, 4. appropriate care based on the stage of dementia, and 5. research, knowledge, and skills. The document does not refer to the topic of migration [10].

### 4. National dementia care and treatment guidelines

Iceland has a treatment guideline entitled 'Clinical Guideline 2007: Dementia Diagnosis and Treatment' from 2007 of 10 Pages which refers to the topics analysis (anamnesis and differential diagnosis, initial assessment of cognitive abilities, search for other and accompanying diseases, image analysis, etc.),

non-drug treatment (stimulation of cognitive abilities, sensory stimulation, physical activity and rehabilitation, environmental design, etc.), drug treatment, and information for patients and relatives. The topic of migration is not considered in this document also [11].



## 5. References

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# Ireland

**Population**

4,964,000

**Area**

70,273 km<sup>2</sup>

**Capital**

Dublin

**3 largest cities**

Dublin (553,000)

Cork (126,000)

Galway (80,000)

**Neighboring countries**

Northern Ireland

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Ireland is traditionally a country of emigration. Since 1800 about ten million people have left the country [1]. As a result of famine, the Irish population declined from 6.5 million in 1841 to 2.8 million in 1961 [2]. Between 1961 and 1981, the population increased by 22% as a result of the return of a large number of Irish emigrants [2, 3]. The recession in the early 1980s led to a new wave of emigration [1]. In the 1990s, Ireland developed into a country of immigration. The economic growth led to the return of many Irish emigrants from the mid-1990s to the early 2000s [3]. At the same time, the number of asylum seekers increased significantly. Until 1999, most asylum seekers came from Africa, more than half from Nigeria, Congo, and Algeria. Since 1999, people from Romania and Nigeria have been the largest groups of asylum seekers. In the period 1995-2004, 486,300 people moved to Ireland, while 263,800 people left [2]. Between 2002 and 2004, people mainly immigrated from non-EU countries. After the EU enlargement in 2004,

a large number of people came from the ten new member states. Between 2005 and 2008, people from Romania and Bulgaria represented almost half of the immigrants [3]. As a result of the Irish banking system collapse, net immigration declined from 2008 and was negative again in 2015 (for the first time since 1995) [4]. Between 2008 and 2012, the number of Irish emigrants tripled. From April 2014 to April 2015, 81,000 people left Ireland. The majority of them were Irish citizens [1]. After 2015, emigration figures declined and Ireland had positive net immigration again [4]. In 2013, people from United Kingdom and Northern Ireland (253,600), Poland (124,600), Lithuania (37,800), the United States of America (24,900), and Latvia (21,800) represented the largest migrant groups [5]. The migrant population (born abroad) has grown from 228,000 to 833,600 between 1990 and 2019. In the same period, the proportion of migrants in the total population rose from 6.5 to 17.1% [6]. As of 2020, the net migration rate is 4.9 [4].





## 2. Estimated number of people with a migration background with dementia

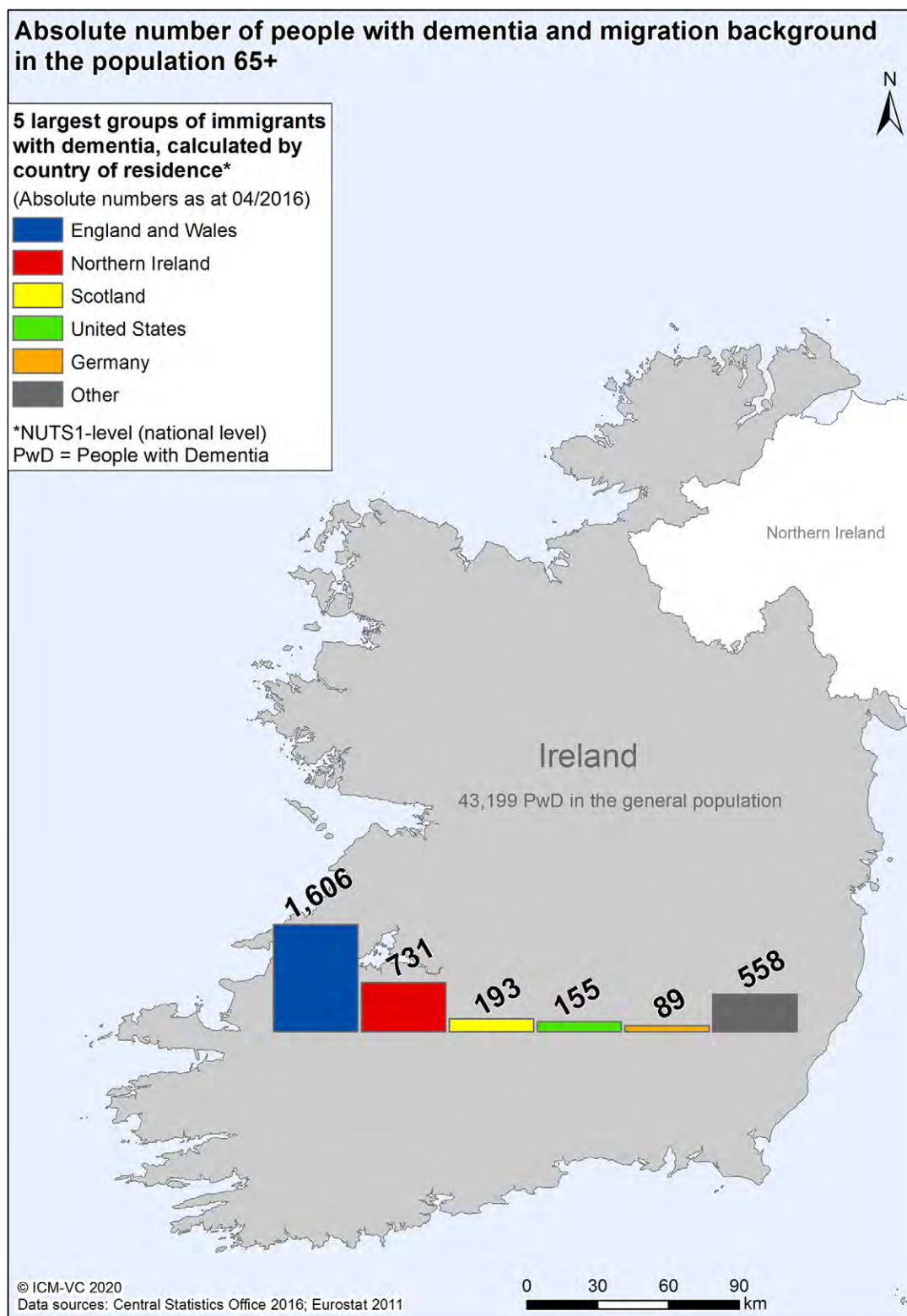


Fig. 3.7.15.1: Absolute number of PwM with dementia aged 65+ (Ireland – Nation)

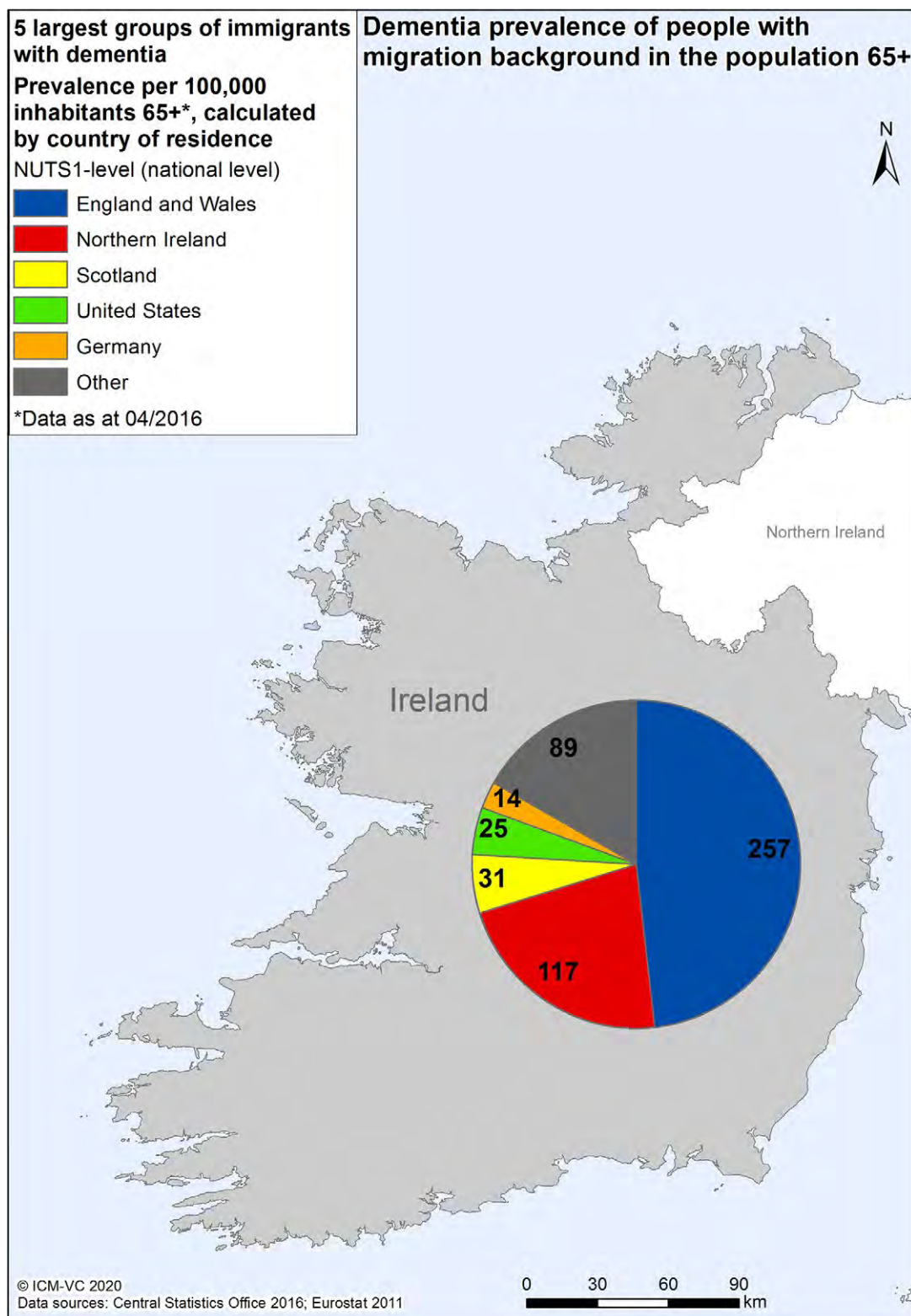


Fig. 3.7.15.2: Prevalence of PwM with dementia among the population 65+ (Ireland – Nation)



**Tab. 28: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Ireland – Nation)**

NUTS	Total	IE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Ireland	43,199	39,867	EAW 1,606	NIR 731	SCT 193	US 155	DE 89	558
Prevalence/10,000 inhabitants with migration background 65+								
Ireland	8,946	-	EAW 333	NIR 151	SCT 40	US 32	DE 18	116
Prevalence/100,000 inhabitants 65+								
Ireland	6,900	6,368	EAW 257	NIR 117	SCT 31	US 25	DE 14	89

Data source: Central Statistics Office (2016)

There are 48,300 PwM aged 65 years or older. Of those, approx. 3,300 are estimated to exhibit some form of dementia. Figure 3.7.15.1 shows the most affected migrant groups presumably originate from England and Wales (approx. 1,600), Northern Ireland (approx. 700), Scotland (approx. 200), the US (approx. 200), and Germany (approx. 90). The second graph highlights the number of PwM with

dementia in Ireland per 100,000 inhabitants aged 65 or older (figure 3.7.15.2). Table 28 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from England and Wales, Northern Ireland, Scotland, the US and Germany throughout the country in the NUTS2 regions (figures 3.7.15.3 – 3.7.15.8).

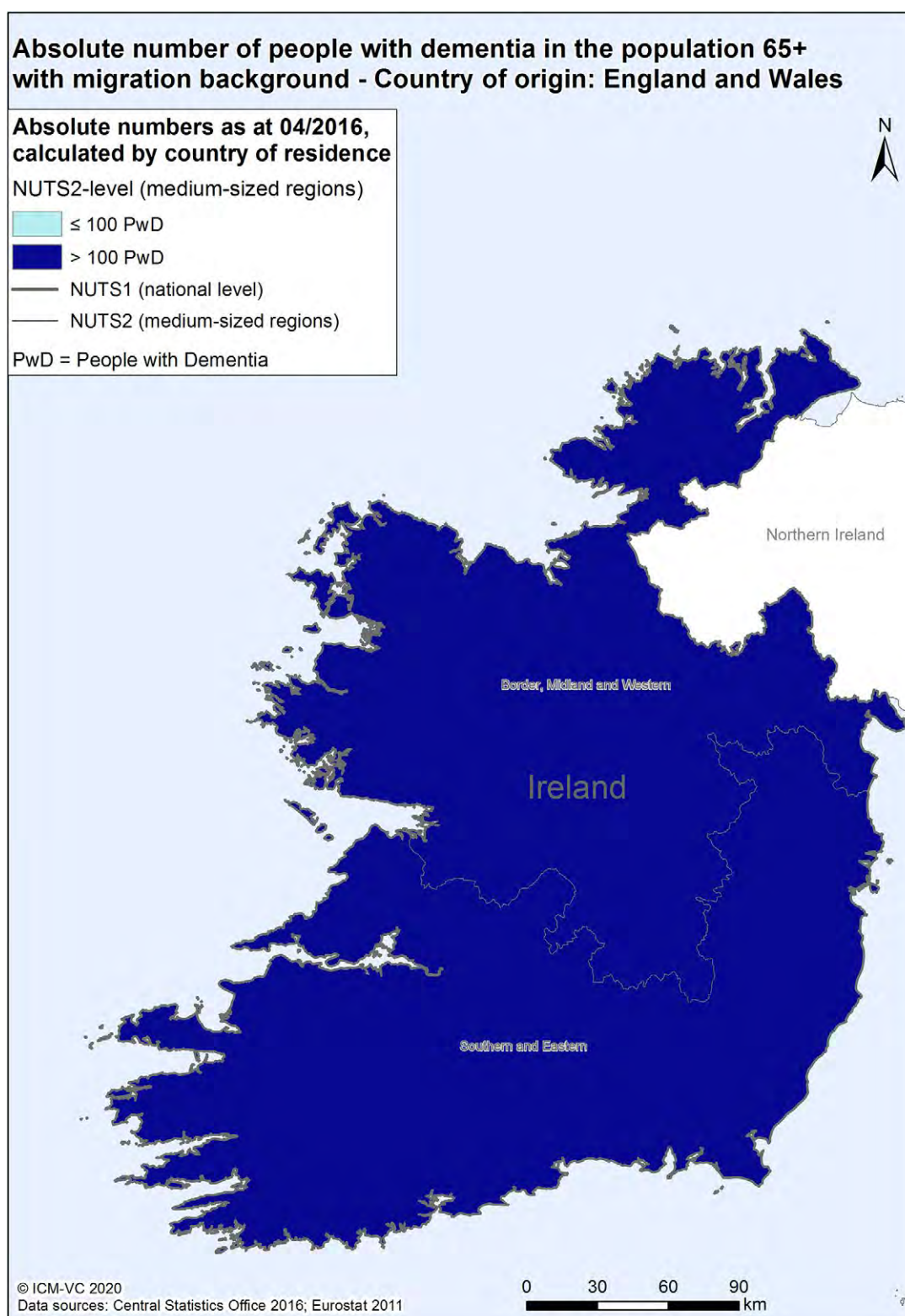


Fig. 3.7.15.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: England and Wales (Ireland – NUTS2)



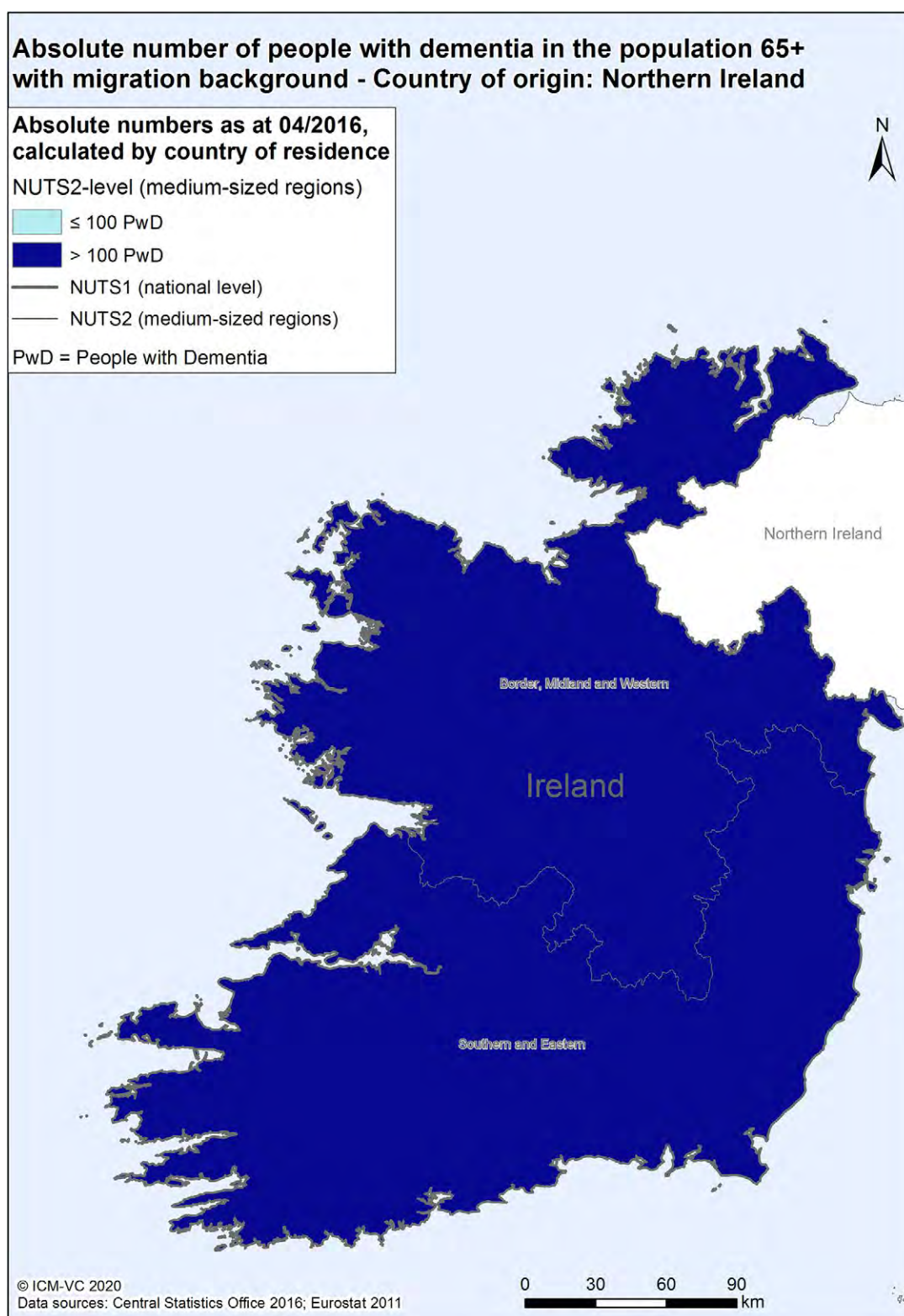


Fig. 3.7.15.4: Absolute number of PwM with dementia aged 65+. Country of origin: Northern Ireland (Ireland – NUTS2)

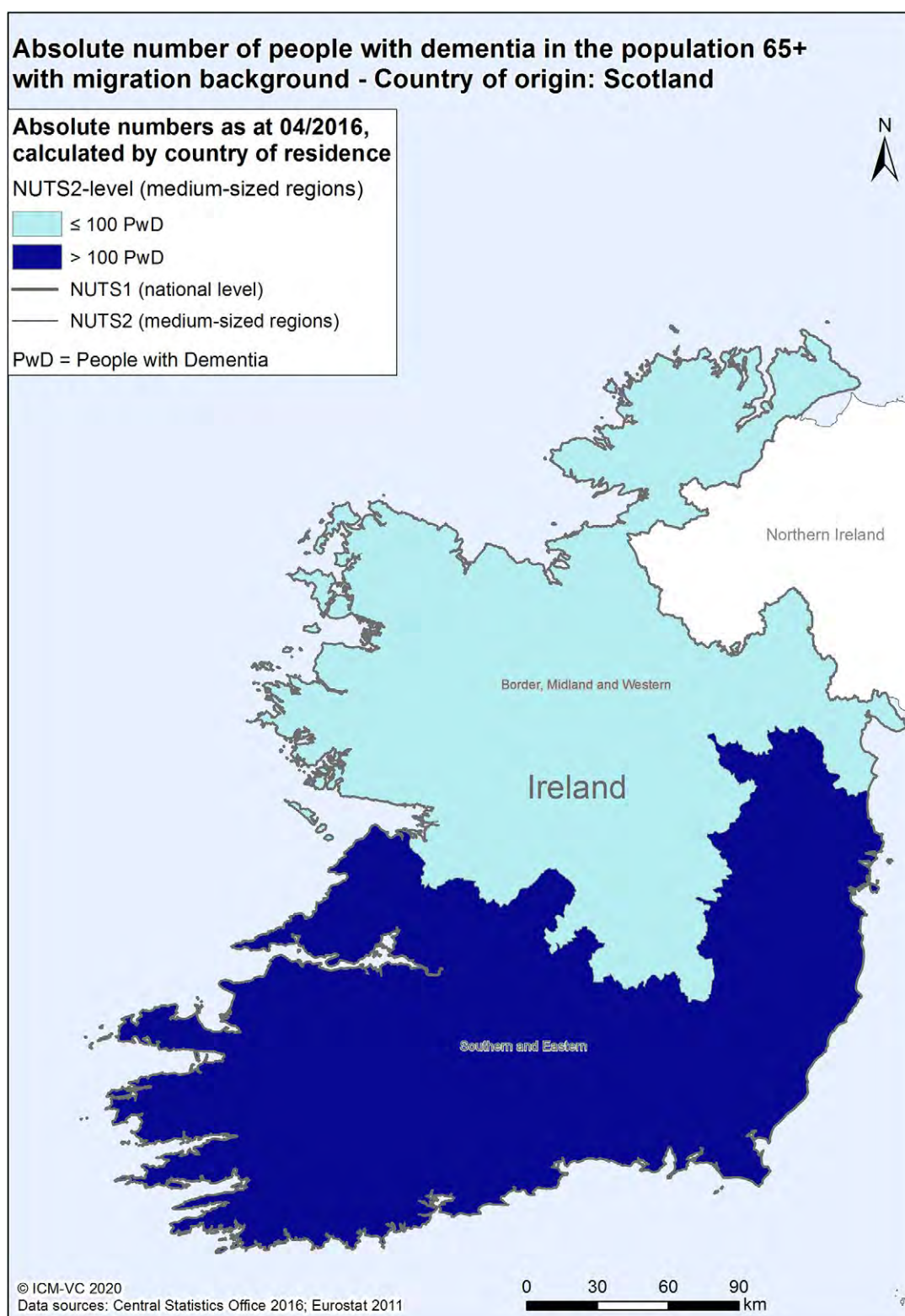


Fig. 3.7.15.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Scotland (Ireland – NUTS2)



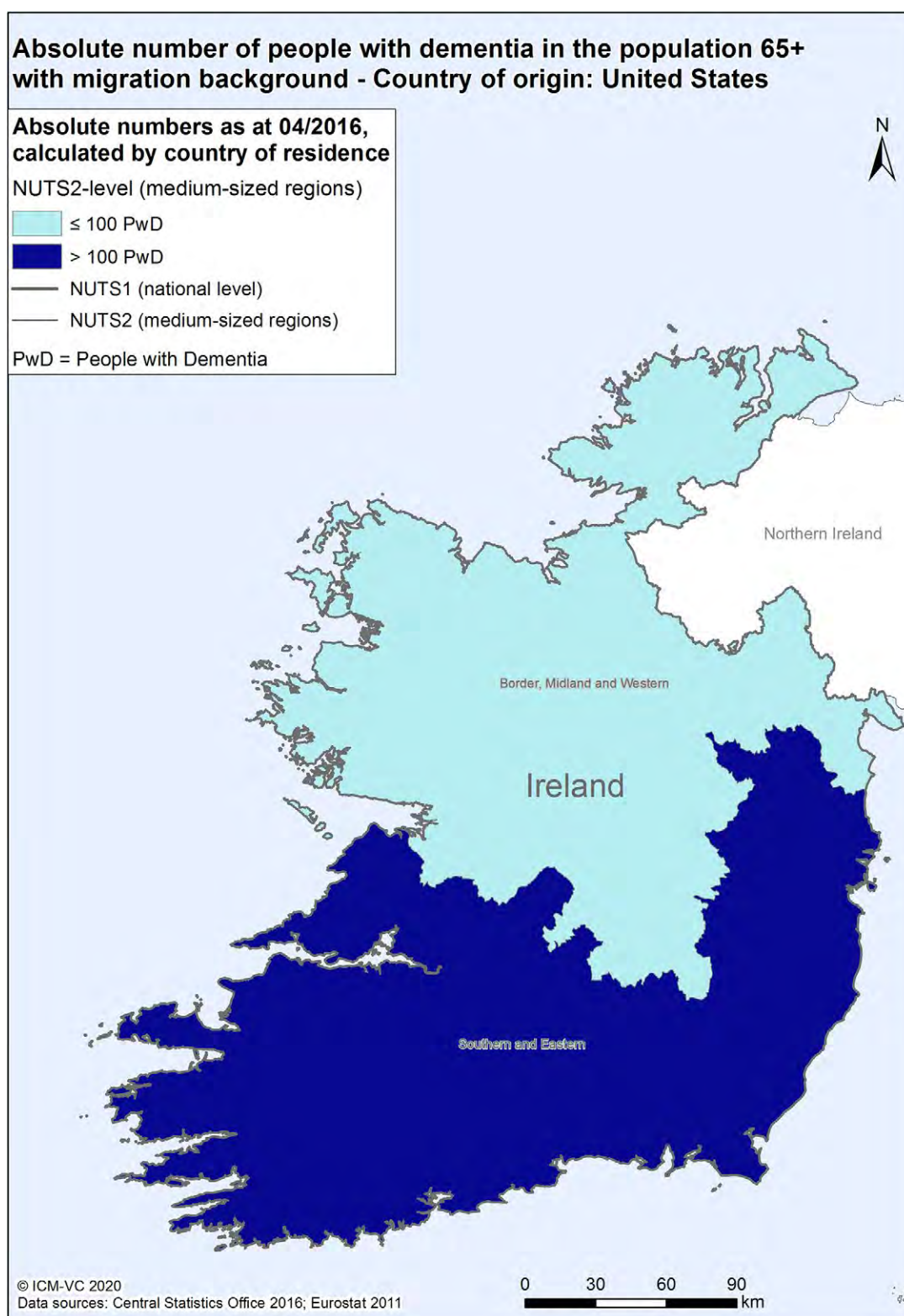


Fig. 3.7.15.6: Absolute number of PwM with dementia aged 65+. Country of origin: The US (Ireland – NUTS2)

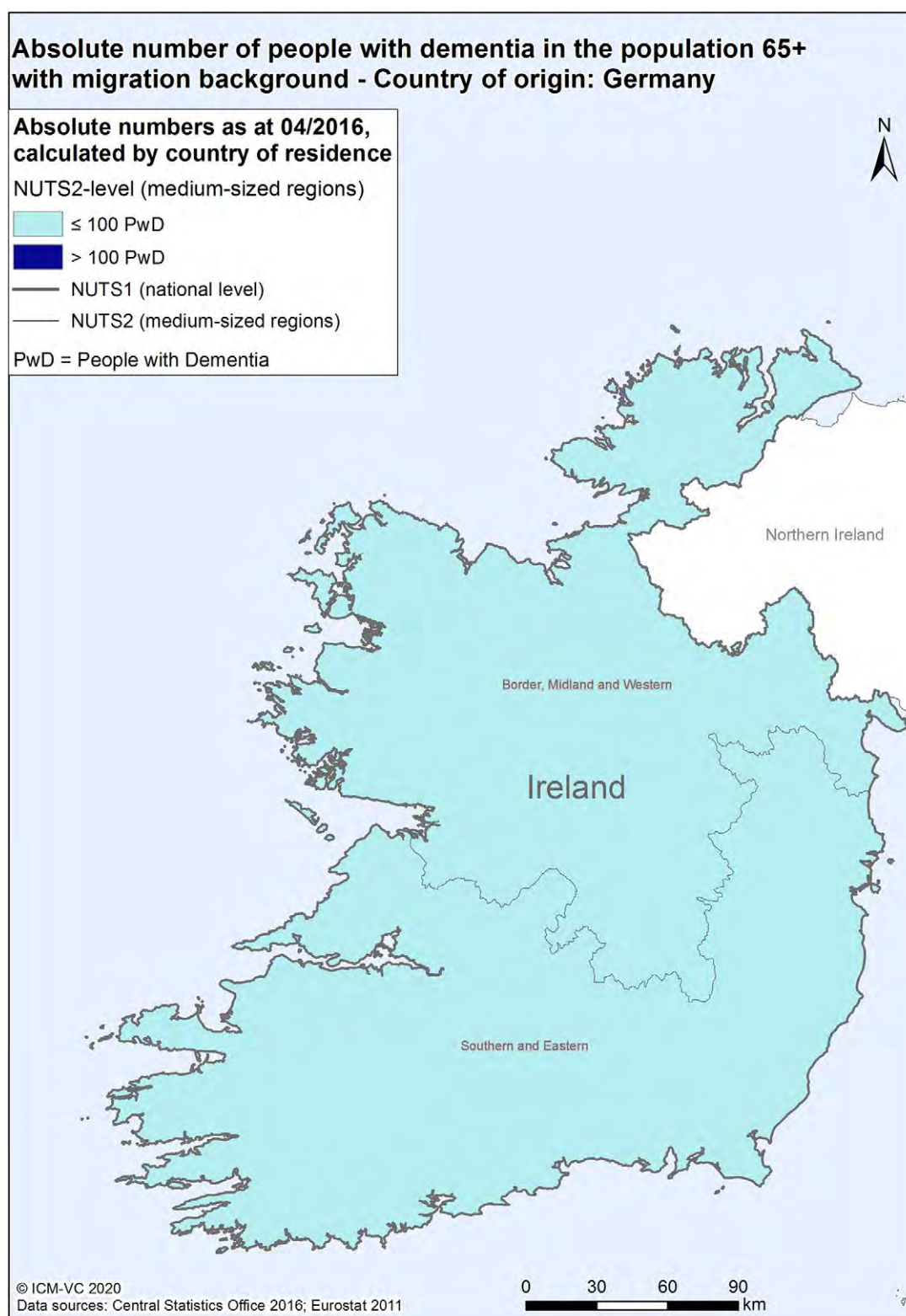


Fig. 3.7.15.7: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Ireland – NUTS2)

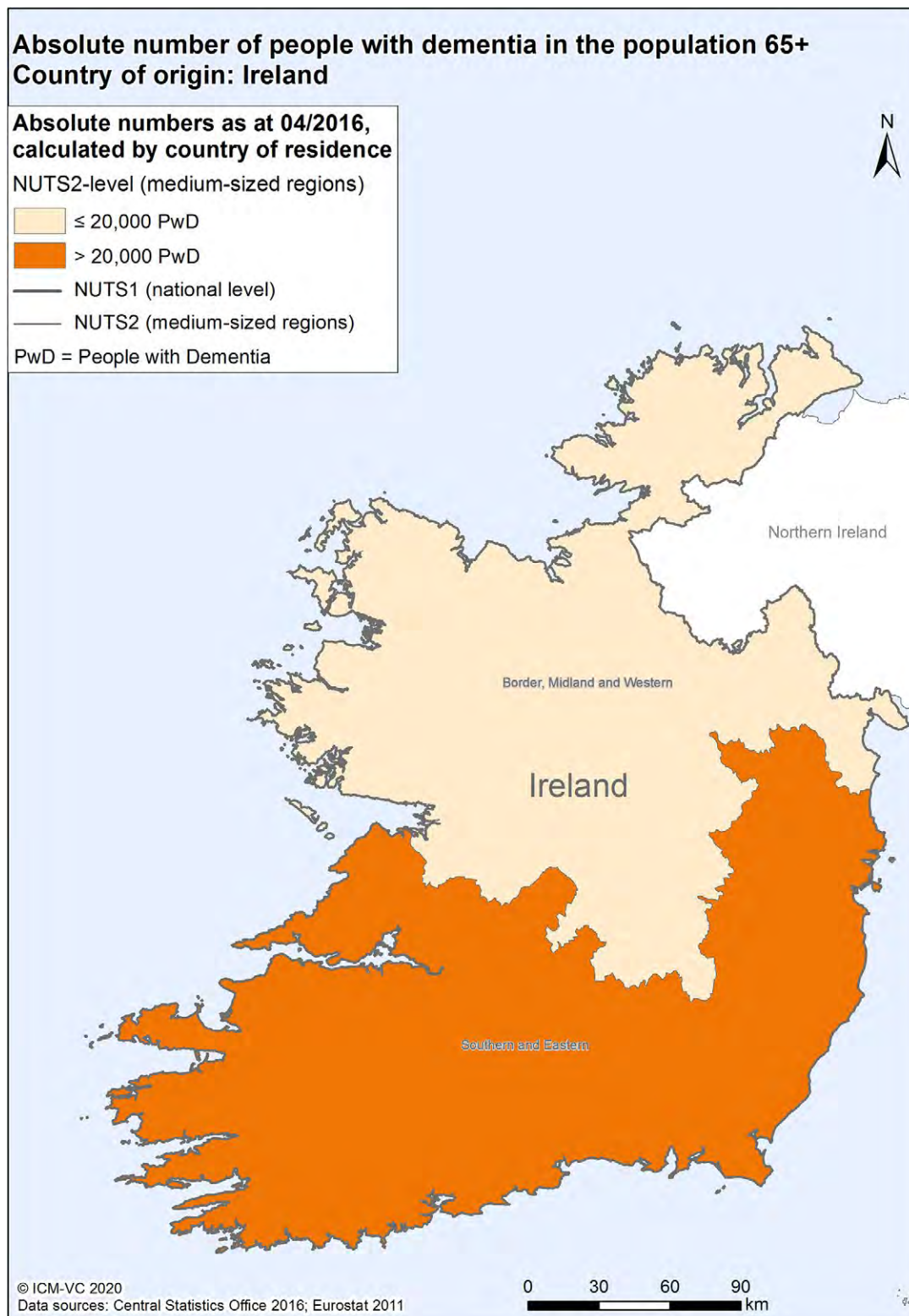


Fig. 3.7.15.8: Absolute number of people with dementia aged 65+.  
Country of origin: Ireland (Ireland – NUTS2)





The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.15.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (Fig. 3.7.15.10). The values from the NUTS2 level can be found in table 29 [7-9].

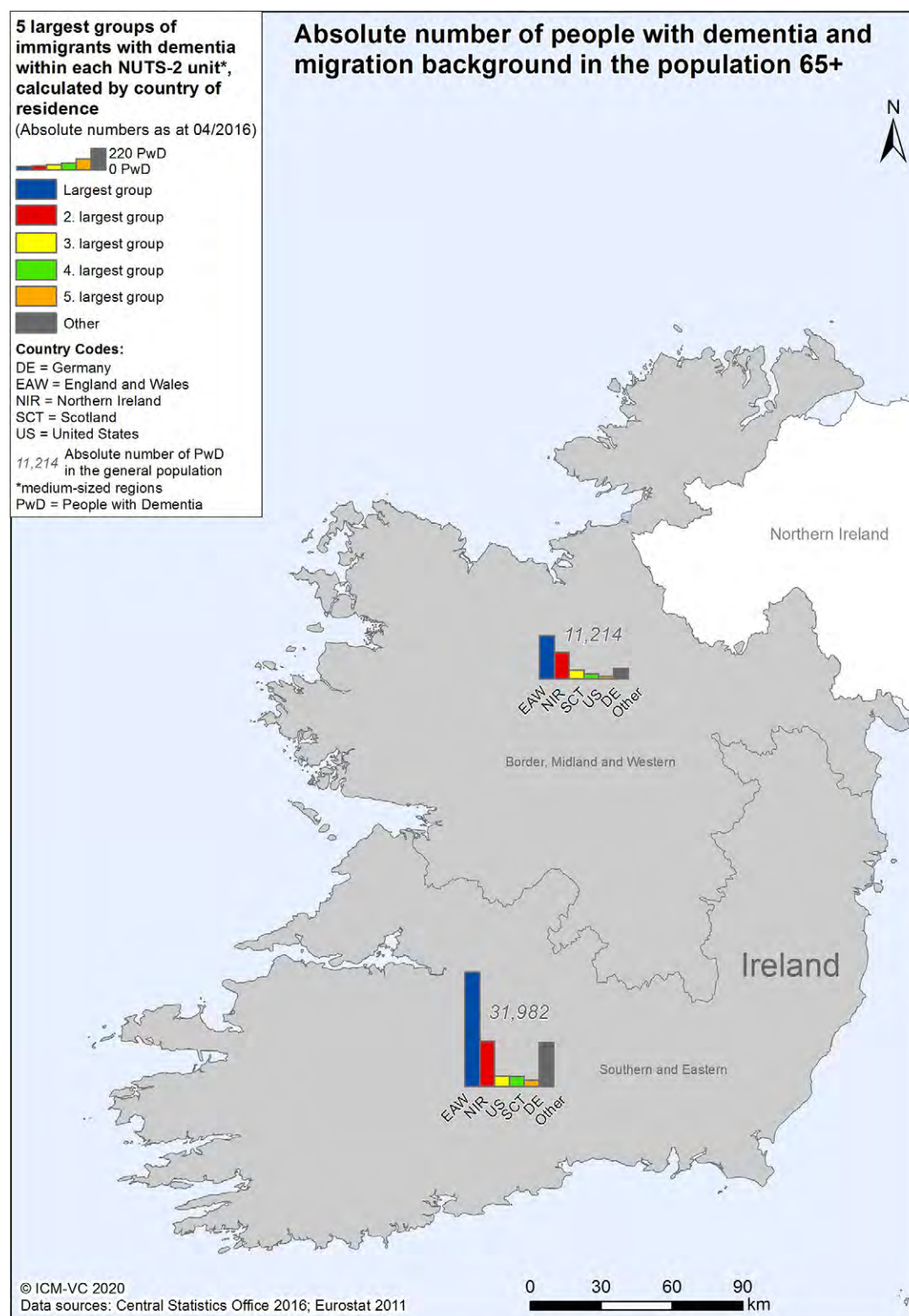


Fig. 3.7.15.9: Absolute number of PwM with dementia aged 65+ (Ireland – NUTS2)

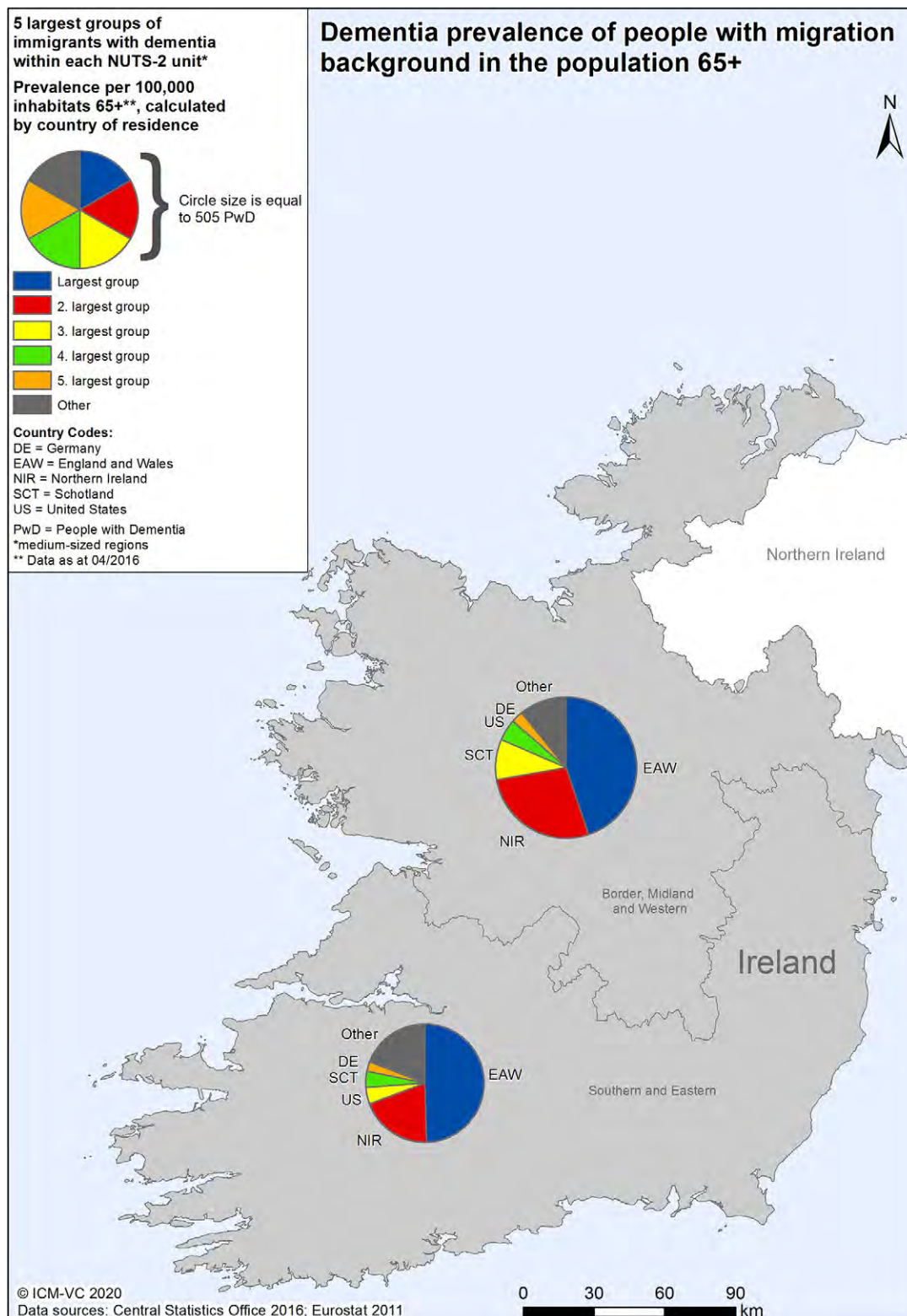


Fig. 3.7.15.10: Prevalence of PwM with dementia among the population 65+ (Ireland – NUTS2)



**Tab. 29: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Ireland – NUTS 2)**

NUTS	Total	IE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Border Midland and Western	11,214	10,227	EAW 442	NIR 270	SCT 91	US 49	DE 27	107
Southern and Western	31,982	29,640	EAW 1,164	NIR 461	US 106	SCT 102	DE 62	448
Prevalence/10,000 inhabitants with migration background 65+								
Border Midland and Western	78,844	-	EAW 310	NIR 189	SCT 64	US 34	DE 19	75
Southern and Western	9,422	-	EAW 343	NIR 136	US 31	SCT 30	DE 18	132
Prevalence/100,000 inhabitants 65+								
Border Midland and Western	6,900	6,293	EAW 272	NIR 166	SCT 56	US 30	DE 17	66
Southern and Western	6,900	6,395	EAW 251	NIR 99	US 23	SCT 22	DE 13	97

Data source: Central Statistics Office (2016)

### 3. National dementia plan

The 'Irish National Dementia Strategy' of 2014 has 40 pages and addresses the issues of awareness and understanding of dementia, timely diagnosis and treatment, integrated services, support and care for people with dementia and their carers, primary care, mental

health and community-based care, acute care, long-term care, palliative care for people with dementia, education and training, as well as research and information systems. None of these issues include the topic of migration [10].

### 4. National dementia care and treatment guidelines

Currently, no published guidelines for the treatment of dementia could be identified for Ireland comparable to the guidelines by the National Institute for Health and Care Excellence (NICE). As part of the National Dementia Strategy implementation, the National Dementia Office is working on dementia diagnostic and post-diagnostic framework to guide holistic assessment, diagnosis, disclosure, and immediate post-diagnostic support. In addition,

clinical guidelines on the appropriate prescription of antipsychotic and psychotropic medications for people with dementia are planned to be published [11]. A guide on 'Dementia: Diagnosis & Management in General Practice' (from 2019) already exists in primary care. This document does not have a separate chapter on migration but briefly references this topic at three points in a subchapter. First, it identifies the problem that a person's





cultural background may influence their performance in cognitive impairment screening tools. Then the suitability of existing screening tools for cognitive impairment among ethnic minorities is examined. The MIS and the Mini-Cog Screening Test are two tools that are particularly suitable for ethnic minorities. The Mini-Cog Test has been validated for a multi-ethnic, multilingual population. This situation is described, but no recommendations for action or measures are derived from it. Other topics related to dementia and migration are

not examined [12]. Ireland appears to consider ethnic minorities as a group that requires special attention in dementia diagnosis in general practice.

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, the healthcare system does not treat PwM with dementia as a vulnerable group. In addition, the topic of dementia and migration is relatively unimportant in Ireland. A possible reason could be that dementia has only been prioritised in the last few years and diversity in the nation only developed in the late 90s. Hence, the combination of dementia and migration is a new topic that Ireland is not yet prepared to face.

In general, the expert assumed that the traditionally nomadic communities and the Roma community would be acknowledged as particularly disadvantaged groups. Gaining access to the healthcare system is difficult because of language barriers, absence of support, and low literacy. In addition, the expert stated that the lack of interpretation services adds to the problem.

Based on the observation that PwM use formal healthcare services to a lesser extent and dementia is underdiagnosed, the expert suggested that possibly older migrants are cared for at home by the family or that the nomadic communities does not even acknowledge de-

mentia. Also, the coverage of memory clinics in the whole country is limited; thus, the expert affirmed that the specialised clinics do not have a nationwide presence. Thus, the location of residence also influences access to support.

Ireland follows an integrative healthcare strategy according to the expert. Still, no information on dementia is available in other languages. There are no specialised services for PwM with dementia. Existing services are open for everyone, and if a person accesses a service, they will be looked after. The expert declared that existing dementia services are not suitable for people with and without a migration background. The reason for that would be that there are no specialised care homes or nursing homes for dementia and no particular care package for home care for people with dementia. In addition, the expert noted that there is no consistency in the general home care packages meaning different people would be delivering the care, leading to a large issue of continuity of care.



### 6. Professional qualification and people with a migration background in healthcare

According to the expert training on culturally sensitive care does not seem to be offered as part of healthcare provider education. However, sometimes in courses related to the end of life, topics such as being mindful of somebody's religion are covered, although this is not widely done. The expert assumed that the proportion of PwM among professional caregivers working in outpatient and inpatient care is very high. Many of them originate from African countries and there is a significant number of nurses from the Philippines working in Dublin.

The impact that a high proportion of professional caregivers with a migrant background can have on care is mediated by language, according to the expert. If no common language is spoken, it can generate certain difficulties between caregivers and care recipients. The expert stated that a majority of the caregivers are 'fabulous, warm, caring people' but if a person is only doing the job because they cannot find anything else, they might be resentful because that job is not what they want to do.

### 7. Support for family caregivers

The expert rated the importance of family, religious communities, migrant organisations, and service providers of outpatient and inpatient care as source of support for family caregivers as high to very high. Particularly, the expert stressed the importance of supporting families through information and education, so that people with dementia can receive the necessary support and medical help. Similarly, the expert alluded to the importance of religious communities, as they can serve as a tool to bring comfort and peace for family

caregivers and persons with dementia. Therefore, it may be relevant to consider and respect the different religious beliefs they may have. Finally, the expert opined that outpatient and inpatient care services are crucial of the support system of family caregivers, as they provide support as well as guidance based on objective information and clinical experience, which substantially contributes to the mental, psychological and emotional health of family caregivers.



## 8. References

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# Italy

**Population**

60,245,000

**Area**

302,068 km<sup>2</sup>

**Capital**

Rome

**3 largest cities**

Rome (2,840,000)

Milan (1,400,000)

Naples (960,000)

**Neighboring countries**

Austria, France,

San Marino, Slovenia,

Switzerland,

Vatican City

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

In recent decades Italy has developed from an emigration country to an immigration country. Between 1876 and 1976 almost 24 million people emigrated from Italy (mainly to America before the Second World War, and then to Northern Europe). Before the 1970s, immigration to Italy was mainly characterised by the arrival of small groups of people from the former colonies in East Africa (e.g. Eritrea) and Catholic countries in Latin America and Asia. In the 1960s, seasonal workers from Tunisia migrated to Sicily. In addition, some political refugees from Vietnam and Chile, and students from Iran and Greece were admitted. However, Italy first had positive net immigration in 1973. Since then, the foreign population has increased strongly and Italy has evolved into an immigration country. The reason for the change in the 1970s was the restrictive immigration policy of many Northern European countries after the oil crisis and Italy's lack of immigration policy. The first large immigration wave occurred between 1984 and 1989 when

700,000-800,000 people arrived in Italy. Most migrants came from Tunisia, Morocco, Senegal, and the Philippines. Many migrants came from Eastern Europe in the 1990s (Albania, Yugoslavia, Poland) and early 2000s (Romania, Ukraine, Moldova). In 2013, people from Romania were the largest migrant group with 832,100 people, followed by Albania (451,400) and Morocco (407,100) [1]. Between 2014 and 2017, a large number of migrants and refugees came to Italy by sea (624,700) [2]. In recent decades, the lack of immigration policy has resulted in an extremely heterogeneous composition of the migrant population in Italy (192 different countries of origin) and a large number of undocumented immigrants [1]. Overall, between 1990 and 2019, the migrant population (born abroad) more than quadrupled (1.4 to 6.3 million). The same happened for the proportion of migrants in the total population in the same period (2.5 to 10.4%). The net migration rate has been continuously positive since 2000 (2020: 2.5%) [3].



## 2. Estimated number of people with a migration background with dementia

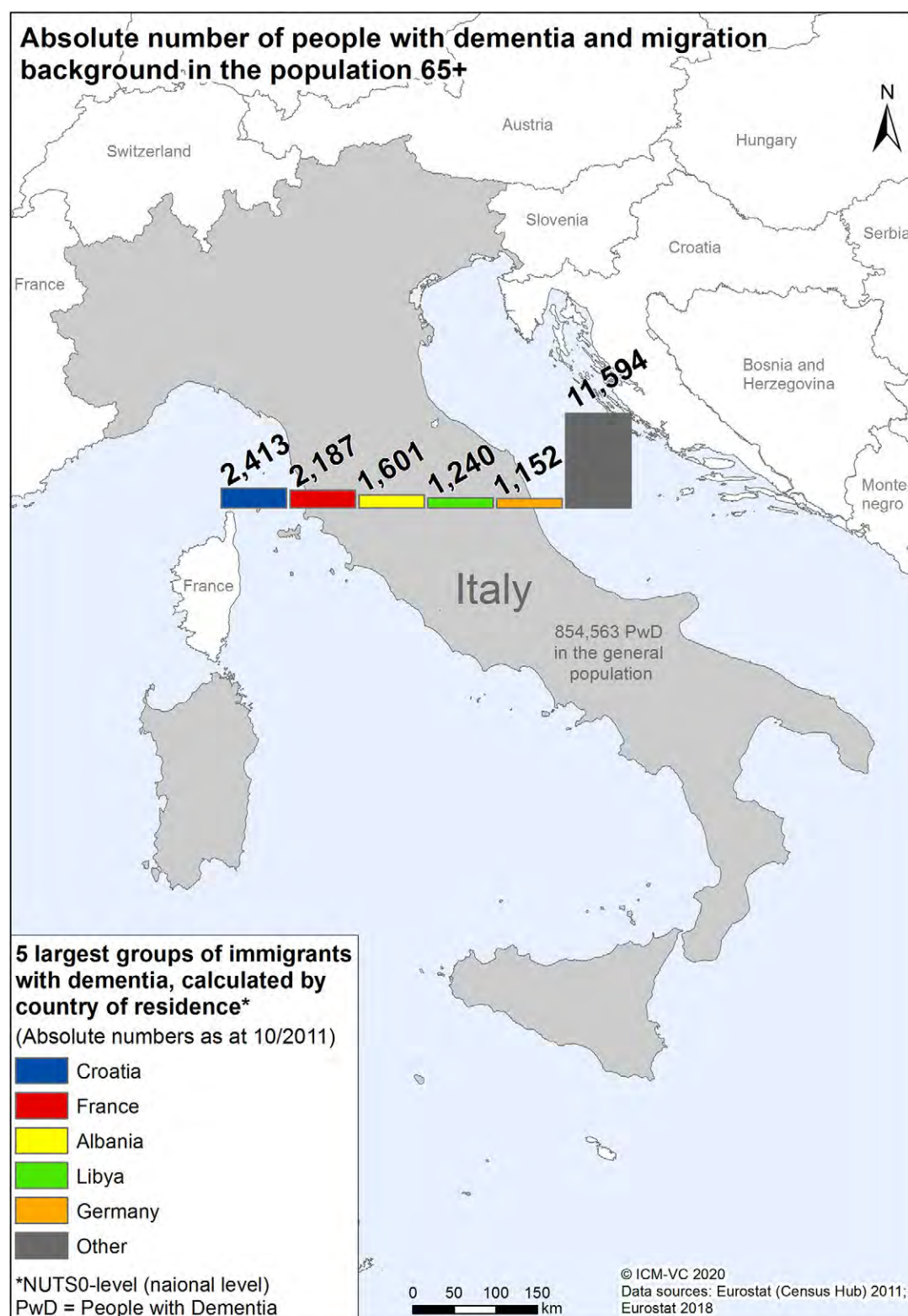


Fig. 3.7.16.1: Absolute number of PwM with dementia aged 65+ (Italy – Nation)

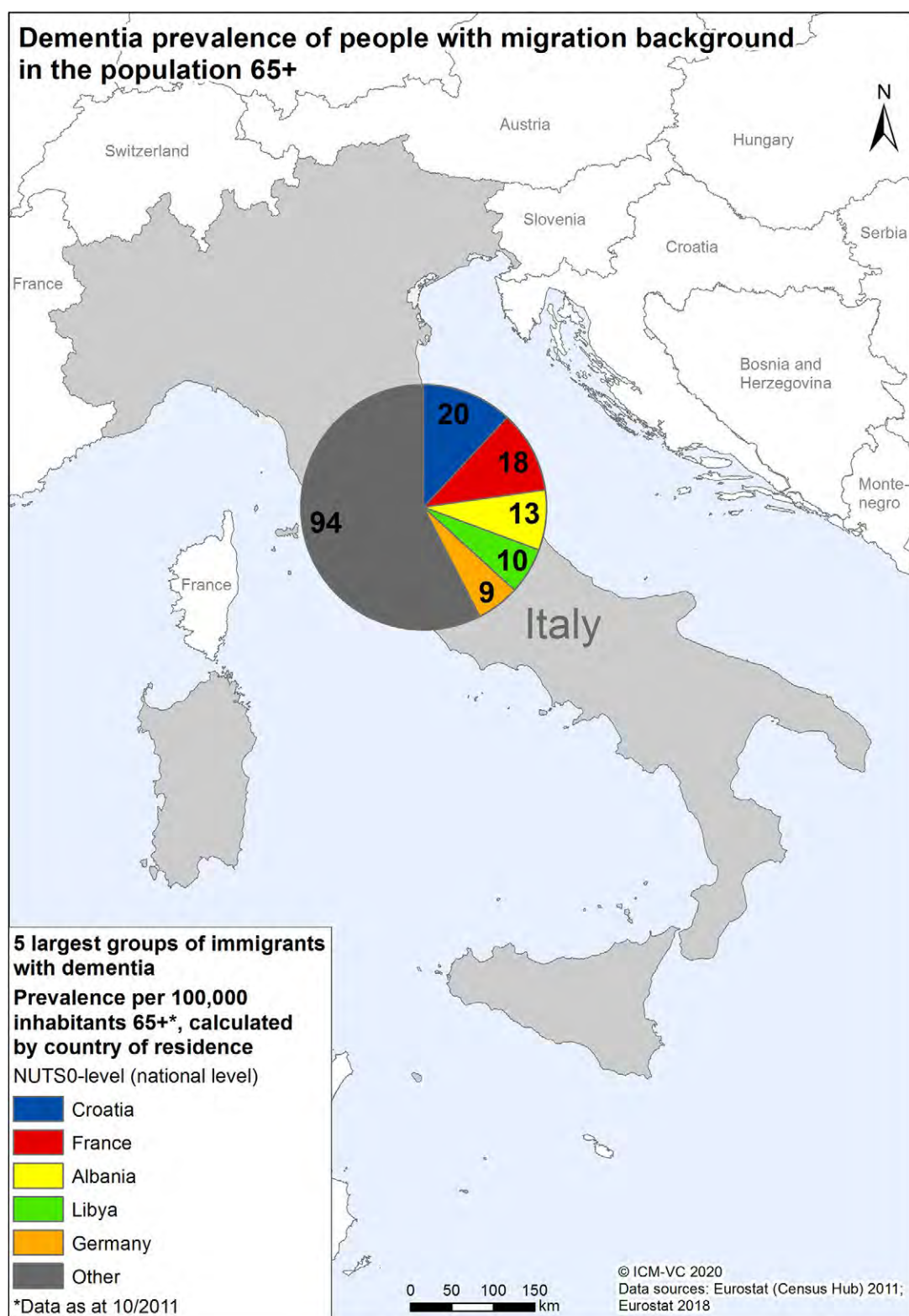


Fig. 3.7.16.2: Prevalence of PwM with dementia among the population aged 65+ (Italy – Nation)



**Tab. 30: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Italy – Nation)**

NUTS	Total	IT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Italy	854,563	834,377	HR 2,413	FR 2,187	AL 1,601	LY 1,240	DE 1,152	11,593
Prevalence/10,000 inhabitants with migration background 65+								
Italy	29,210	-	HR 82	FR 75	AL 55	LY 42	DE 39	397
Prevalence/100,000 inhabitants 65+								
Italy	6,900	6,737	HR 19	FR 18	AL 13	LY 10	DE 9	94

Data source: Eurostat (2011)

There are 292,600 PwM aged 65 or older. Of those, approx. 20,200 are estimated to exhibit some form of dementia. Figure 3.7.16.1 shows the most affected migrant groups presumably originate from Croatia (approx. 2,400), France (approx. 2,200), Albania (approx. 1,600), Libya

(approx. 1,200), and Germany (approx. 1,200). The second graph highlights the number of PwM with dementia in Italy per 100,000 inhabitants aged 65 or older (figure 3.7.16.2). Table 30 displays the values depicted in the maps on the national level [4-6].

### 3. National dementia plan

For Italy, two documents could be identified entitled 'The new Italian National Strategy' from 2014 and 'National Dementia Plan – The State of the Art' from 2019.

'The New Italian National Strategy' on dementia from 2014 is 13 pages long. It consists of the topics: Italy and dementia (population size of older people and people with dementia in Italy, the estimated number of family caregivers), health services for dementia in Italy, the national plan on dementia (addressed areas: prevention, the network of services, integrated care, research, ethics and empowerment of patients/caregivers, fight against stigma), objectives of the plan, actions, and future developments. In none of these topics, a reference is made to migration [7].

The document 'National Dementia Plan – The

State of the Art' from 2019 is 25 pages long and focuses on the topics definition and causes of dementia, the influence of the environment, cognitive impairment and frailty, demographic change and Italian incidence, health and socio-medical policy interventions and actions, implementation of strategies and interventions in care, supportive activities, physical activity and rehabilitation, technological innovations, raising awareness and reducing stigma, increasing quality of life, research, dementia observatory, Italian guidelines, and existing international tools. In this document, the project 'Dementia in immigrants and ethnic minorities living in Italy: clinical-epidemiological aspects and public health services' (ImmiDem) is cited, which is the first Italian project to address the prevalence of dementia in the immigrant pop-



ulation and among ethnic minorities. However, no further reference is made to the topic of de-

mentia and migration [8].

## 4. National dementia care and treatment guidelines

According to a representative of the Italian Society for Gerontology and Geriatrics, no Italian guidelines for the treatment of dementia exist. There is only a version of the English guidelines translated into Italian by the Gruppo Italiano per la Medicina Basata (=Italian Group for Evidence-Based Medicine) (GIMBE) [9].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, PwM are generally considered as a vulnerable population consisting of people from Romania, Ukraine, Peru and North African countries such as Morocco, Tunisia, Algeria and Libya. The healthcare system recognizes them and their needs. But while the topic of health and migration is considered a very important one, dementia and migration is still such a new concept that has generated low interest and attention so far, according to the expert. As of today, only one national initiative focuses on dementia and migration – the ImmiDem project. The expert noted that PwM are a vulnerable group in terms of diagnosis and access to formal healthcare services. Dementia is under-diagnosed in this population, which also makes their needs under-recognised. Moreover, PwM do not use healthcare services much. If they display some cognitive problem they might go to their general practitioner or their community but usually do not seek further medical help or specialised services.

Italy tries to follow an integrative healthcare strategy, in which PwM with dementia utilize existing healthcare services. However, the expert pointed out that in reality the services are

not suitable for patients with dementia from different backgrounds and cultures since it is such a recent topic in Italy. There are many barriers, such as language barriers, health illiteracy, as well as unknown barriers that the healthcare system and healthcare providers are possibly not aware of, that lead to PwM with dementia not using the services. So, PwM with dementia are only slightly included in the healthcare system. From experience, the expert noted that mostly fitter, wealthier, and more integrated migrants access specialized services. Information on dementia in different languages for PwM is only available in a few regions. The ImmiDem project aims to set up a website where PwM can find out about centres where their language is spoken and where they can find the address and contact details to improve and increase access to services. The expert stated that currently there are no specialised services for PwM with dementia in inpatient and outpatient care in Italy. From the 600 memory clinics in Italy, only a few deliver culturally sensitive care. In some centres in some regions, cross-cultural cognitive tools and information material in languages other than Italian are available and used, for



example in Milan or Trento. A few individual centres or services are working with general practitioners to facilitate access to memory clinics and disseminate information. Some are developing or using measures, tools or information material for PwM such as the RUDAS as a cognitive screening instrument, but this happens only on a local basis. So, there is no uniform, culturally sensitive approach to diagnostics to also support and involve families in the process. Usually, most centres use the same diagnostic procedures for PwM that they use for non-migrants, meaning they use the MMSE and other tests that are strongly influenced by cultural aspects. Thus, the expert estimated that existing services are only suitable

for non-migrants with dementia.

The expert stated that overall, it is crucial to develop a culturally competent approach to dementia in general, and there is a responsibility to improve the provision of care. This is not just a matter of meeting the current needs of PwM. Right now, dementia and migration is a peripheral concern, but it is going to grow more important gradually, so it is important to anticipate a great need for such services in the future. Additionally, it is imperative to forge collaborations amongst general practitioners, other healthcare professionals, specialised services, religious communities and other organisations to raise awareness on the topic.

## 6. Professional qualification and people with a migration background in healthcare

According to the expert, culturally sensitive care is not part of the professional qualification, and professional training possibilities in intercultural care exist only as a few isolated initiatives.

The proportion of professional caregivers with a migration background in outpatient care is exceptionally high, as stated by the expert. They mostly originate from East European countries like Romania and Ukraine as well as Peru and the Philippines. Depending on the cultural background, the care they deliver varies. For example, professional caregivers

from Peru are extremely gentle and kind with patients with dementia. The situation is very similar in inpatient care. The proportion of professional caregivers with a migration background is high. They mostly originate from East European countries like the Russian Federation, Ukraine, Romania, Sri Lanka, Bangladesh, and other South Asian countries as well as from South America. But the need for culturally sensitive care is not being met by sufficiently qualified professionals in inpatient and outpatient care.

## 7. Support for family caregivers

The expert stated that the family as well as migrant organisations, religious communities and service providers are significant in supporting family caregivers. However, there may be some variations in their importance due to the heterogeneity of PwM. For example, for some PwM, the religious communities might

be a more important source of support than for other PwM. But overall, the importance of all these networks is very high.

There are major differences in the suitability and utilisation of existing services between PwM and non-migrants because the healthcare system currently not equipped to serve



PwM effectively, as stated above. Therefore, a very high need for specialised services for PwM was recognized. The expert noted that it is essential to develop a better system to

provide information and support to family caregivers of people with dementia in Italy, irrespective of the migration background.

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# Latvia

**Population**

1,908,000

**Area**

63,290 km<sup>2</sup>

**Capital**

Riga

**3 largest cities**

Riga (627,000)

Daugavpils (82,000)

Liepaja (69,000)

**Neighboring countries**

Belarus, Estonia,  
Lithuania, the Russian  
Federation

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

Latvia's migration history is characterised by waves of large-scale immigration and emigration (especially to and from the Russian Federation). The first larger groups of people from the Russian Federation came to Latvia in the 18th century. By the end of the 19th century, the population from the Russian Federation had increased to 200,000 [1]. During the First World War, about 400,000 people fled to the Russian Federation [2]. After the peace treaty with the Russian Federation was signed in 1918, almost 300,000 people returned from the Russian Federation [3]. During the Second World War, 200,000 people fled towards the West and Germany. Parallel to this, a large influx of people from the Russian Federation began in 1940. Between 1945 and 1959 about 400,000 people from the Russian Federation and 100,000 people of other ethnic minorities immigrated to Latvia (at the same time at least 60,500 people born in Latvia were expelled) [2]. Immigration from the Russian Federation remained high until the 1980s. In 1989, the proportion of ethnic minorities in the total population was 48%. As a result of the dec-

laration of independence on 4 May 1990 and the collapse of the Soviet Union in 1990/1991, Latvia took over half a million immigrants (including entire families) from the Soviet Union. After that, the number of immigrants and emigrants declined significantly. At the same time, Latvia has developed from a country with positive net migration (until 1990) to negative net migration (from 1991) [3]. Between 1990 and 2019, the migrant population (born abroad) decreased from 646,000 to 237,300, and the proportion of migrants in the total population fell from 24.2 to 12.4% [4]. Latvia has developed from an immigration country to an emigration country. Especially after EU accession in 2004, emigration has accelerated [3]. As of 2020, the net migration rate is -7.6 [5]. However, a large number of people originating in the Russian Federation still live in Latvia and make up about a quarter of the population (as of 2016) [1]. There are also small populations of people from Belarus, Ukraine, Poland, and Lithuania. In total, one-third of the population speaks Russian [6].

## 2. Estimated number of people with a migration background with dementia

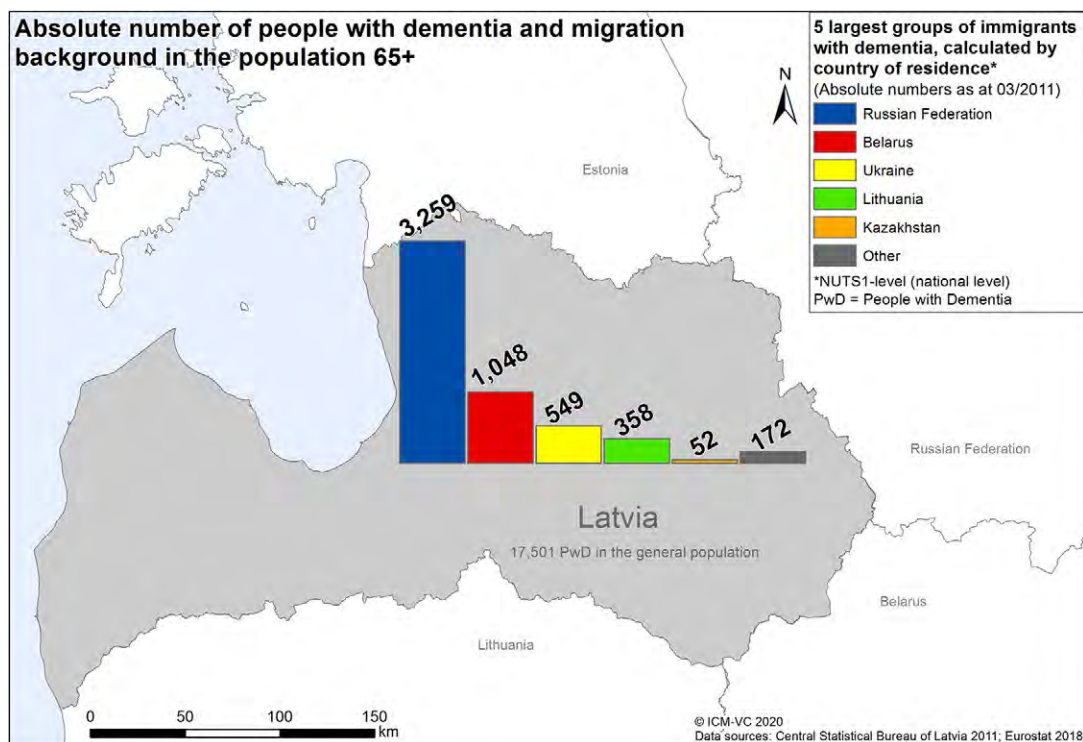


Fig. 3.7.17.1: Absolute number of PwM with dementia aged 65+ (Latvia – Nation)

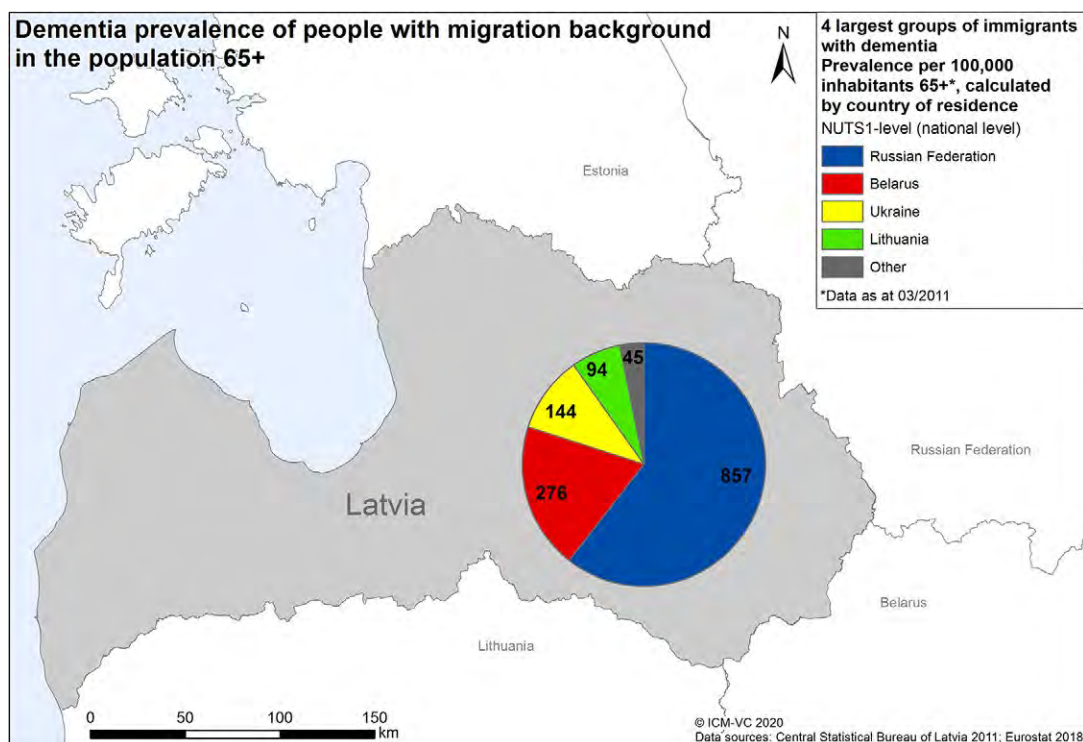


Fig. 3.7.17.2: Prevalence of PwM with dementia among the population aged 65+ (Latvia – Nation)

**Tab. 31: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Latvia – Nation)**

NUTS	Total	LV	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Latvia	17,501	12,064	RU 3,259	BY 1,048	UA 549	LT 358	KZ 52	172
Prevalence/10,000 inhabitants with migration background 65+								
Latvia	1,481	-	RU 276	BY 89	UA 46	LT 30	KZ 4	15
Prevalence/100,000 inhabitants 65+								
Latvia	4,600	3,171	RU 857	BY 275	UA 144	LT 94	KZ 14	45

Data source: Central Statistical Bureau of Latvia (2011)

There are 118,200 PwM aged 65 or older. Of those, approx. 5,400 are estimated to exhibit some form of dementia. Figure 3.7.17.1 shows the most affected migrant groups presumably originate from the Russian Federation (approx. 3,300), Belarus (approx. 1,100), Ukraine (approx. 600), Lithuania (approx. 400),

and Kazakhstan (approx. 50). The second graph highlights the number of PwM with dementia in Latvia per 100,000 inhabitants aged 65 or older (figure 3.7.17.2). Table 31 displays the values depicted in the maps on the national level [7-9].

### 3. National dementia plan

For Latvia, no NDP could be identified [10].

### 4. National dementia care and treatment guidelines

In Latvia, one document with treatment guidelines was published: the 'Clinical Guideline for Alzheimer's Disease, Vascular Dementia, Lewy-Body Dementia, and Frontotemporal Dementia' in 2017. This document has 162 pages. It deals with two main topics: 1. the most common forms of dementia, and 2. characteristics and effects of drugs for the treatment of neurodegenerative dementias. With regard to

the first topic, the etiology, risk factors, prognosis, clinical picture, diagnostic criteria, diagnosis, prevention, and treatment of each form of dementia is discussed. With regard to the second topic, the focus is on the treatment of memory disorders, neuropsychiatric diseases, Parkinson's syndrome, and sleep disorders. In none of these topics is a migration-related issue addressed [11].



## 5. References

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# Liechtenstein

**Population**

39,000

**Area**

160 km<sup>2</sup>

**Capital**

Vaduz

**3 largest cities**

Schaan (6,000)

Vaduz (6,000)

Triesen (5,000)

**Neighboring countries**

Austria, Switzerland

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Within a few years, Liechtenstein has developed from an emigration country to an immigration country. In the 19th century, there were several waves of emigration in which parts of the population emigrated to America because of poverty and lack of prospects. The emigration continued until the 1920s. In the 1930s, mainly citizens from Germany were naturalised. Thereafter, industrialisation led to gradual immigration from Switzerland in the second half of the 19th century [1]. After the Second World War, Liechtenstein became an immigration country due to the economic boom [2]. The increasing need for skilled workers was largely met by immigration from German-speaking countries. For less qualified jobs, people were recruited from southern European countries such as Italy, Spain, or Portugal. After 1963, the predominantly seasonal workers from Italy were increasingly replaced by guest workers from Yugoslavia, whose number more than tripled between 1973 and 1980. The political, social, territorial, and economic changes in Europe have led to an increased influx of foreigners from Eastern and Southeastern Europe, including Turkey since 1980 [1]. Between 1990

and 2019, the migrant population (born abroad) more than doubled (10,900 to 25,500). At the same time, the proportion of migrants in the total population has risen from 37.9 to 67 %. This is the highest growth among all EU, EFTA, and UK countries and the fifth-highest worldwide [3]. According to the population statistics of the Office for Statistics of the Principality of Liechtenstein, the proportion of foreigners with non-Liechtenstein citizenship in the total permanent population of Liechtenstein was 34.2% in 2019. The largest migrant groups are from Switzerland (3,700), Austria (2,300), Germany (1,700), Italy (1,200), Portugal (700), and Turkey (600) [4]. The great importance of migration in Liechtenstein is due to the economic position of the country, the globally operating companies, the high number of employees (especially migrants) the fluctuations in the composition of the population (immigration, emigration, and naturalisation of foreigners, high mobility of persons between states), and the multinational identities of many citizens. In quantitative terms, family reunification of migrants and marriage migration plays the most important role in immigration [2].

## 2. Estimated number of people with a migration background with dementia

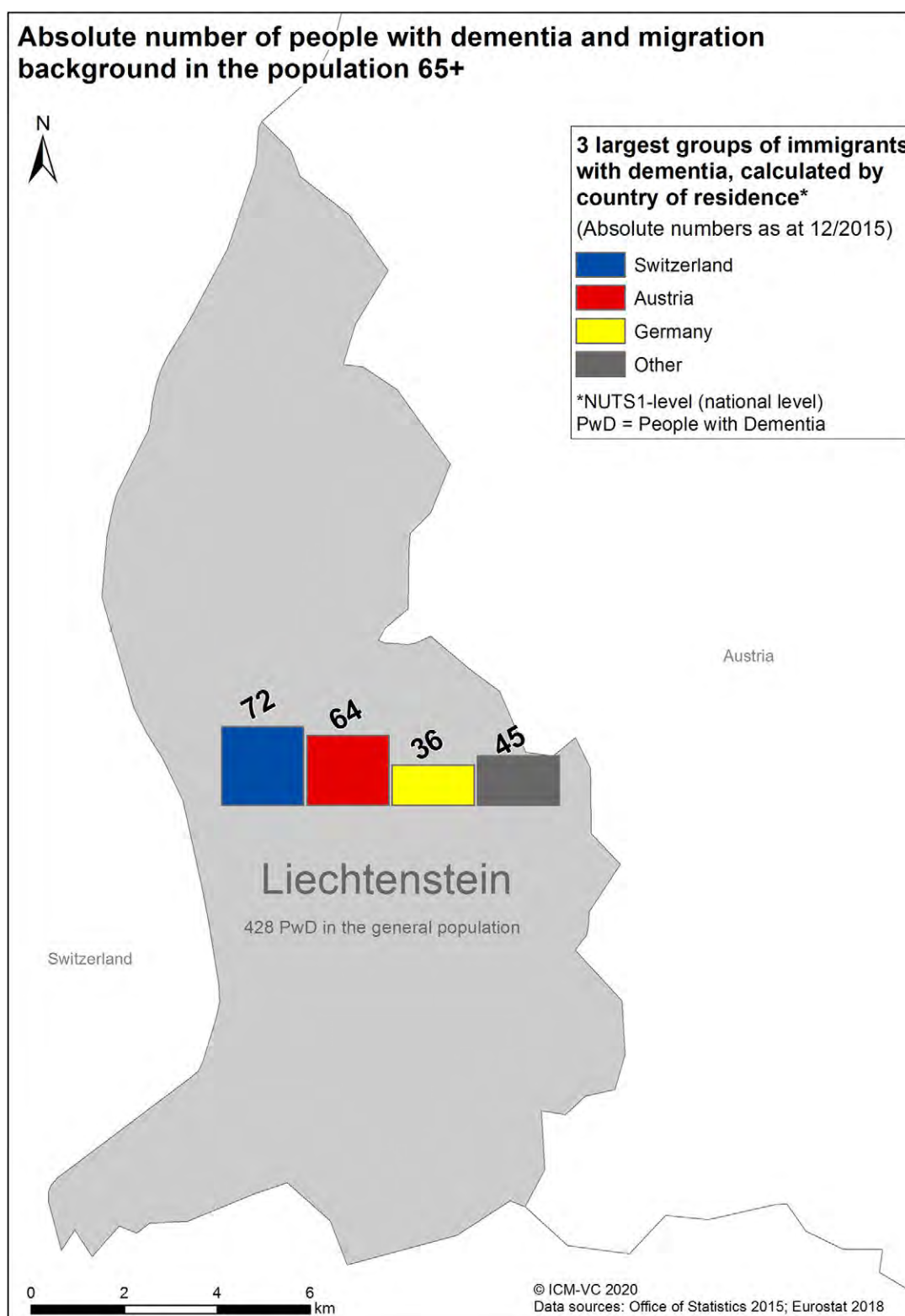


Fig. 3.7.18.1: Absolute number of PwM with dementia aged 65+ (Liechtenstein – Nation)

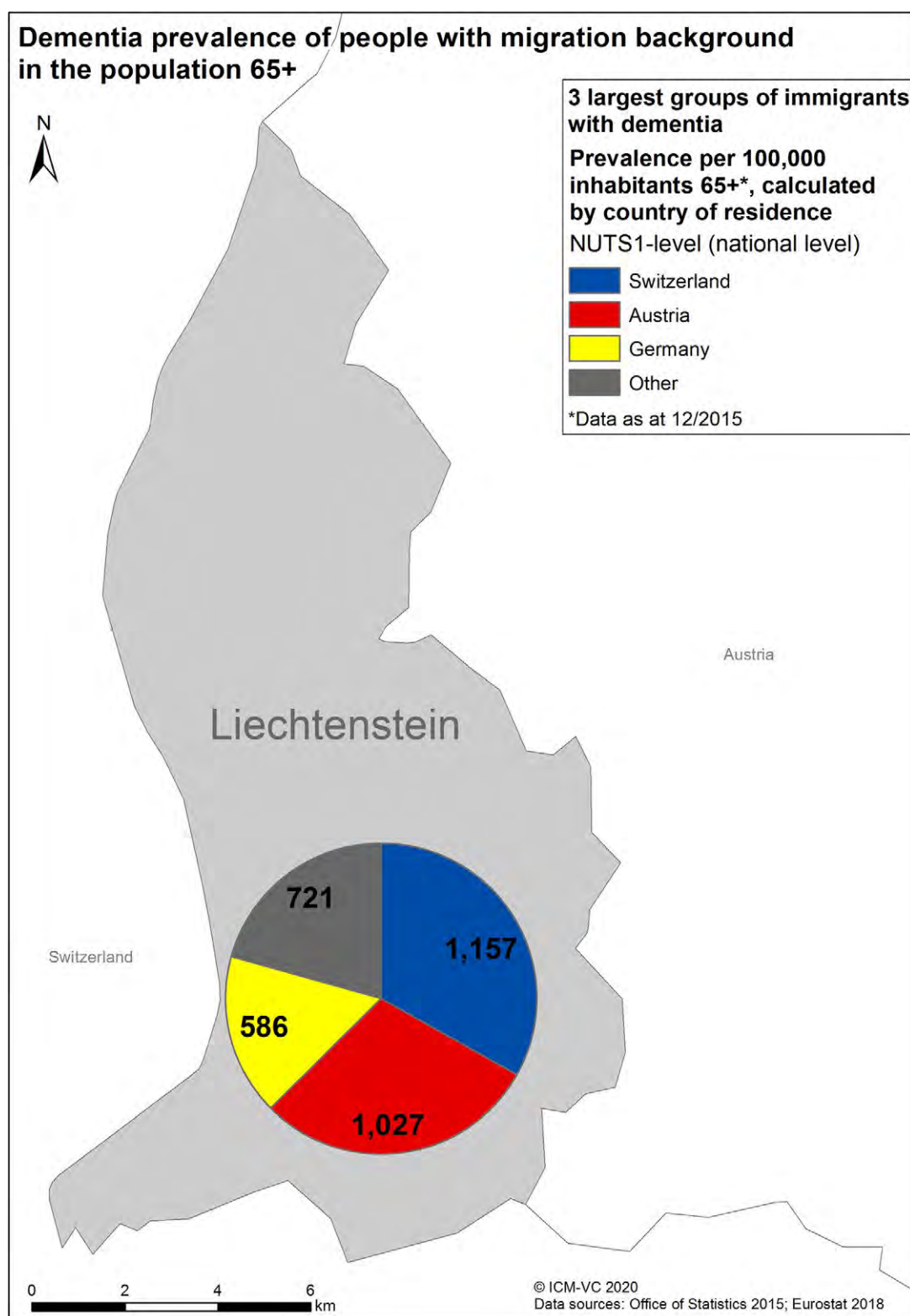


Fig. 3.7.18.2: Prevalence of PwM with dementia among population aged 65+ (Liechtenstein – Nation)

**Tab. 32: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Liechtenstein – Nation)**

NUTS	Total	LI	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Liechtenstein	428	211	CH 72	AT 64	DE 36	N/A	N/A	45
Prevalence/10,000 inhabitants with migration background 65+								
Liechtenstein	1,364	-	CH 229	AT 203	DE 116	N/A	N/A	143
Prevalence/100,000 inhabitants 65+								
Liechtenstein	6,900	3,409	CH 1,156	AT 1,027	DE 585	N/A	N/A	721

Note: N/A = not available.

Data source: Office of Statistics (2015)

There are 3,100 PwM aged 65 or older. Of those, approx. 200 exhibit some form of dementia. Figure 3.7.18.1 shows the most affected migrant groups presumably originate from Switzerland (approx. 70), Austria (approx. 60), and Germany (approx. 40). The second graph

highlights the number of PwM with dementia in Liechtenstein per 100,000 inhabitants aged 65 or older (figure 3.7.18.2). Table 32 displays the values depicted in the maps on the national level [5, 6].

### 3. National dementia plan

The 'Dementia Strategy for the Principality of Liechtenstein' from 2012 has a length of 36 pages. This document is divided into four chapters: 1. 'Dementia: An Overview', 2. 'Health and Social Policy Significance of Dementia', 3. 'Dementia in Liechtenstein: Current Situation', 4. 'Goals of the Dementia Strategy 2020'. It deals, inter alia, with the topics: What is dementia? Forms of dementia, diagnosis, requirements in the case of dementia, treatment

gap, costs of dementia, future challenges, current care structure in Liechtenstein, the situation of family caregivers, quality standards, the six fields of action of the dementia strategy (1. sensitisation, 2. Early detection, 3. education and training, 4. services, 5. cooperation and networking, 6. family caregivers) as well as the implementation and financing of the dementia strategy. None of the above-mentioned topics is set in a migration context [7].

## 4. National dementia care and treatment guidelines

According to the expert, there are no treatment or care guidelines for dementia at the national level. While two funding agencies have been commissioned to provide care for older inpatients, the 'Association for People with Dementia in Liechtenstein' has an implicit mandate from the State to provide care for people with dementia living at home [8]. The statutes of this association (from 2016) do not consider

the topic of migration [9].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and written statements and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

The expert stated that the topic of migration in the context of old-age and dementia care does not play a major role in Liechtenstein. Although there is a high proportion of migrants, the majority of them come from German-speaking countries. The population of non-German-speaking PwM who are at an age that is relevant for dementia care is extremely small. In Liechtenstein, their cases are treated as individual cases. For example, the expert often works in nursing homes and does not know of any Turkish speaking residents and only knows around a handful of residents from Italy.

Regarding the care of PwM with dementia, an integrative model is used. Due to the small total population (approximately 38,400 in 2020 [10]), there is a relatively high level of social control in Liechtenstein, and as a result of extensive educational work (e.g. by the Association for People with Dementia in Liechtenstein), a high level of sensitivity to the topic of dementia. Dementia-specific information and healthcare services are available nationwide. For example, all households are provided with dementia-specific information flyers. According to the expert, this national availability of services in principle also applies to PwM. However, there are no care services specifically tailored to the needs of PwM with dementia

and the information is only available in German (in the health context, there is no multilingual website and there are no foreign-language information brochures on the topic of dementia). Due to a relatively high proportion of migrants in the nursing profession and a high diversity with regard to the countries of origin of the nursing staff (according to the expert's estimate approximately ten different nationalities), linguistic and cultural competences are basically available, but they are currently not systematically applied or used for the development of specialised care services for PwM.

The expert mentioned a non-dementia-specific general model of good practice. It is characterised by the fact that care providers in Liechtenstein have the time and financial resources to deal intensively with the respective patient and to identify his or her individual needs. These resources are used, for example, to determine the language needs of PwM and to consult competent translators if necessary. In addition, female migrants have access to the Information and Counselling Centre for Women 'Infra', which offers information events on topics such as work, marriage law, finance, and health as part of the state-supported project 'Integra'. If required, translations into Spanish, Portuguese, English, Tibetan, and Turkish are organised [11]. Fur-





thermore, free individual counselling is provided in the respective mother tongue [12] and a read-write service is offered to help foreign-language women understand, read or write official letters or fill in forms [13].

According to a second expert, the existing care services in Liechtenstein are suitable for

non-migrants as well as PwM with dementia. Although cultural knowledge is not always present, person-centred care is practiced in nursing homes, where the nursing staff deals with the respective cultural and biographical backgrounds of the individual persons.

## 6. Professional qualification and people with a migration background in healthcare

According to the first expert, there is a lack of professional training opportunities for healthcare professionals in culturally sensitive or intercultural care (the expert interviewed was only involved in one intercultural training event in his 30-year career). The second expert, however, stated that culturally sensitive issues are part of the education and training of caregivers. In Liechtenstein, there is a high proportion of migrants among professional caregivers. According to the second expert, the proportion of professional caregivers with a migration background in inpatient care is approximately 60%. The majority of these caregivers are from German-speaking countries (Germany, Switzerland, and Austria). The in-

terviewed expert estimated the proportion of caregivers with a migration background from non-German-speaking countries in inpatient care at 5 to 10%. In outpatient care, in his experience, the diversity in terms of countries of origin is slightly higher. There, the proportion of caregivers with a migration background from non-German-speaking countries is approximately 10 to 15%. The main countries of origin are Italy, Portugal, and Spain. A number of (female) caregivers in outpatient care also originate from South America (Brazil, Ecuador, Costa Rica), Thailand, and the Philippines. The need for culturally sensitive care is not met (either in outpatient or in inpatient care) by sufficiently qualified professionals.

## 7. Support for family caregivers

According to the expert, various networks in Liechtenstein play a role in supporting family caregivers of PwM with dementia. The expert considered the importance of families in this context to be very high and the importance of care providers and migrant organisations

to be high. The need for specialised services providing support and information to family caregivers of PwM with dementia was also identified as high. Currently, there is still a lack of tailored, native-language information resources for caregivers of PwM with dementia.

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# Lithuania

**Population**

2,794,000

**Area**

62,643 km<sup>2</sup>

**Capital**

Vilnius

**3 largest cities**

Vilnius (559,000)

Kaunas (293,000)

Klaipeda (149,000)

**Neighboring countries**

Belarus, Latvia, Poland,  
the Russian Federation  
(Oblast Kaliningrad)

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References



## 1. Migration history

Lithuania does not have a long migration history. The Balkan state has developed from a country with a positive migration balance (between the 1960s and 1980s) to an emigration country (since the 1990s). From 1940 to 1958, Lithuania lost about one million people through expulsions, acts of war, and the Holocaust. The end of the Second World War was characterised by the expulsion of the Baltic Germans and the resettlement of ethnic groups from the Soviet Union. Then, industrialisation led to an influx of workers from the Soviet Union. Until the end of the 1980s, Lithuania had a positive migration balance of 6,000 to 8,000 people per year. After 1991, migration patterns changed. Previously expelled people from Lithuania returned home and the newly settled ethnic groups left the country. After the opening of the state to the West, emigration of workers began. Since the restoration of independence in 1990, Lithuania has experienced a significant population decline. In the first years after the declaration of independence, mainly

members of ethnic minorities emigrated to the Russian Federation and Ukraine. In the second half of the 1990s, there was increased emigration to Western Europe and North America. With the EU accession in 2004, the number of people from Lithuania working or studying abroad increased significantly. Between 2004 and 2006, most people left the country to the UK, Sweden and, Ireland. Since 1990, Lithuania has experienced negative net migration [1]. In 2013, people from the Russian Federation (62,100), Belarus (35,700), Ukraine (13,300), Latvia (6,400), and Kazakhstan (5,400) represented the largest migrant groups [2]. Between 1990 and 2019, the migrant population (born abroad) decreased from just under 350,000 to 117,200. The proportion of migrants in the total population has declined from 9.4 to 4.2% [3]. As of 2020, the net migration rate is -11.6 [4]. These figures show, that Lithuania has a significantly smaller migrant population than the other Baltic states [1].

## 2. Estimated number of people with a migration background with dementia

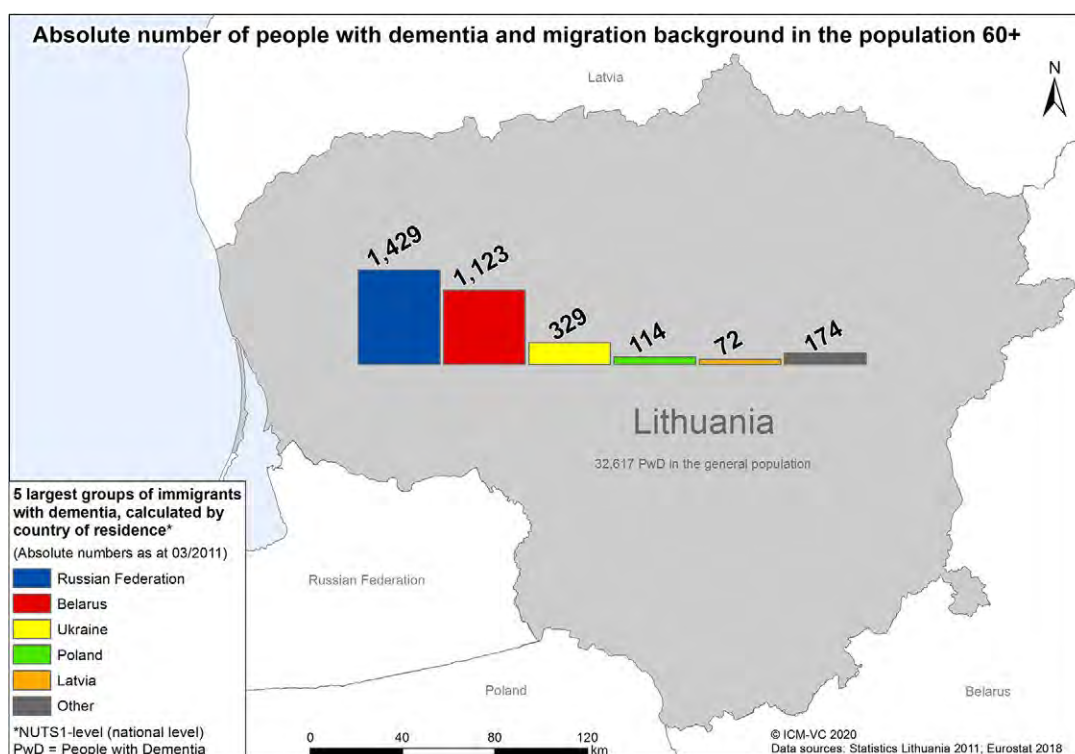


Fig. 3.7.19.1: Absolute number of PwM with dementia aged 60+ (Lithuania – Nation)

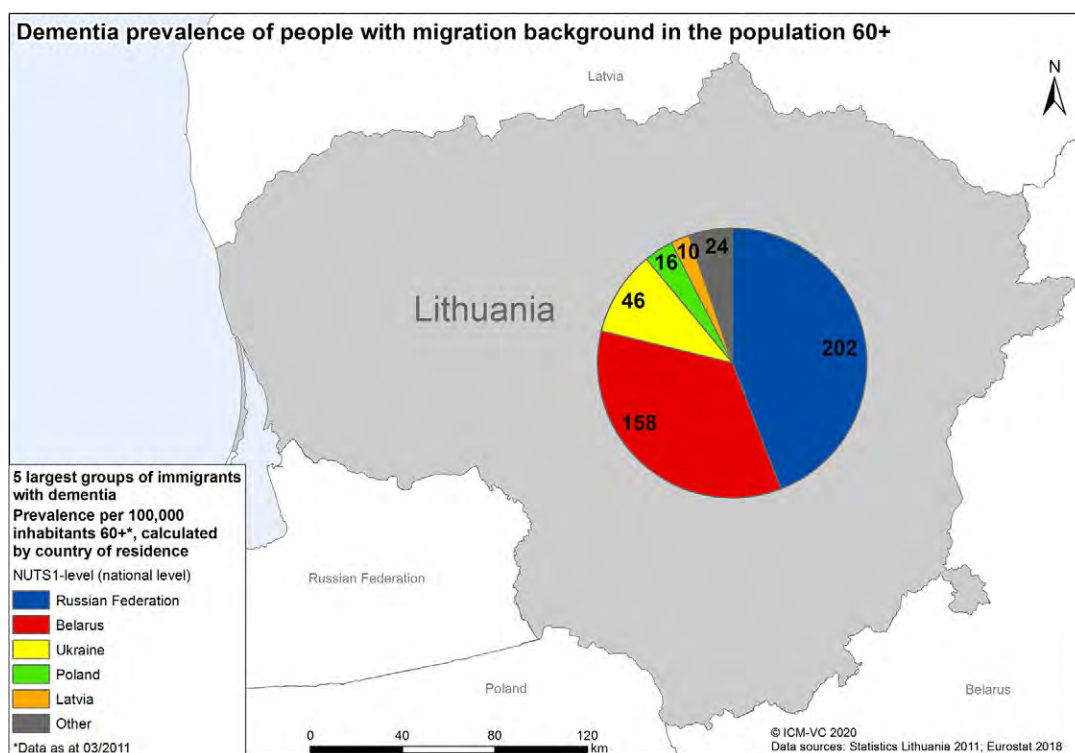


Fig. 3.7.19.2: Prevalence of PwM with dementia among the population aged 60+ (Lithuania – Nation)



**Tab. 33: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Lithuania – Nation)**

NUTS	Total	LT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Lithuania	32,617	29,376	RU 1,429	BY 1,123	UA 329	PL 114	LV 72	174
Prevalence/10,000 inhabitants with migration background 60+								
Lithuania	4,629	-	RU 203	BY 159	UA 47	PL 16	LV 10	25
Prevalence/100,000 inhabitants 60+								
Lithuania	4,600	4,143	RU 202	BY 158	UA 46	PL 16	LV 10	24

Data source: Statistics Lithuania (2011)

There are 70,500 PwM aged 60 or older. Of those, approx. 3,200 are estimated to exhibit some form of dementia. Figure 3.7.19.1 shows the most affected migrant groups presumably originate from the Russian Federation (approx. 1,400), Belarus (approx. 1,100), Ukraine

(approx. 300), Poland (approx. 100), and Latvia (approx. 70). The second graph highlights the number of PwM with dementia in Lithuania per 100,000 inhabitants aged 60 or older (figure 3.7.19.2). Table 33 displays the values depicted in the maps on the national level [5-7].

## 3. National dementia plan

For Lithuania, no NDP could be identified [8].

## 4. National dementia care and treatment guidelines

According to a representative of the ministry of health, there are no national treatment guidelines for dementia in Lithuania [9]. These findings suggest that the topic of dementia does not play a relevant role in public policy and medical discourse in Lithuania. Regarding the organisation of healthcare, it can be stated that Lithuania has a mixed healthcare system, financed mainly by the National Health Insurance Fund through a compulsory insurance system, supplemented by significant state contributions on behalf of the economically

inactive population. Most healthcare institutions in Lithuania are non-profit organisations. Administrative functions are the responsibility of the national Ministry of Health or local municipalities. The political agenda is set by the Parliament through legislative amendments as well as through state programs, strategies, and plans. The latest cuts in public health spending and high out-of-pocket payments (especially for medicines) could jeopardize the access of vulnerable groups to healthcare [10].





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# Luxembourg

**Population**

626,000

**Area**

2,586 km<sup>2</sup>

**Capital**

Luxembourg (city)

**3 largest cities**

Luxembourg (city)

(122,000)

Esch-sur-Alzette

(36,000)

Differdange (27,000)

**Neighboring countries**

Belgium, France,  
Germany

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



### 1. Migration history

Between 1840 and 1870 approximately 72,000 people emigrated from Luxembourg. After the discovery of iron mineral deposits at the end of the 19th century, a large number of foreign workers (mainly from Italy and Germany) came to the country. In the 20th century, this development continued and especially white, Catholic, and European immigrants (mainly from Italy and Portugal) were admitted. From the mid-1980s onwards, immigration to Luxembourg increased significantly [1]. At the beginning of the 1990s, Luxembourg accepted over 2,000 asylum seekers, most of them from Bosnia. During the Kosovo war (1998/1999), 5,300 asylum applications were filed in Luxembourg, of which only 4% were accepted. As a result of a campaign carried out by the Luxembourg government in 2001 to legalize asylum seekers, 2,850 people were accepted as legal immigrants. Most of them came from the former Yugoslavia [2]. In the period

after the Kosovo war, most of the immigrants came from other EU countries. In 2017, for example, people from France, Portugal, and Italy represented the largest immigrant groups [3]. Immigration to Luxembourg is historically and currently dominated by flows from other European countries. In 2015, the proportion of immigrants from European countries was approximately 85% [1]. By country of origin, people from Portugal are the largest migrant group (16% of all foreigners), followed by France (7.6%), Italy (3.6%), Belgium (3.4%), and Germany (2.1%) [3]. Luxembourg's migrant population (born abroad) more than doubled between 1990 and 2019 (113,800 to 291,700). At the same time, the proportion of migrants in the total population has also risen significantly (from 29.8 to 47.4%). As of 2020, the net migration rate is about 16.3 [4]. These figures show that Luxembourg is an immigration country.

## 2. Estimated number of people with a migration background with dementia

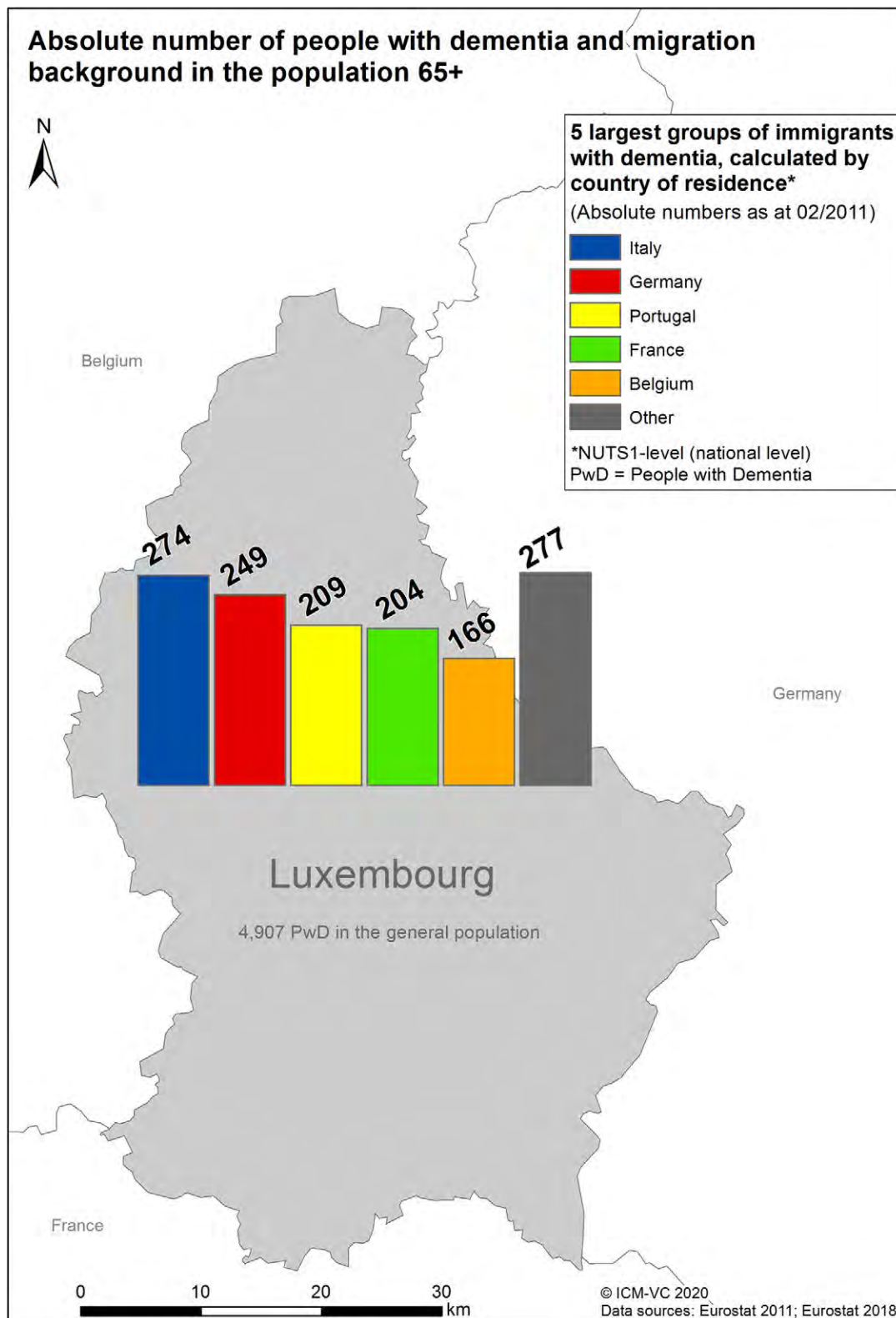


Fig. 3.7.20.1: Absolute number of PwM with dementia aged 65+ (Luxembourg – Nation)

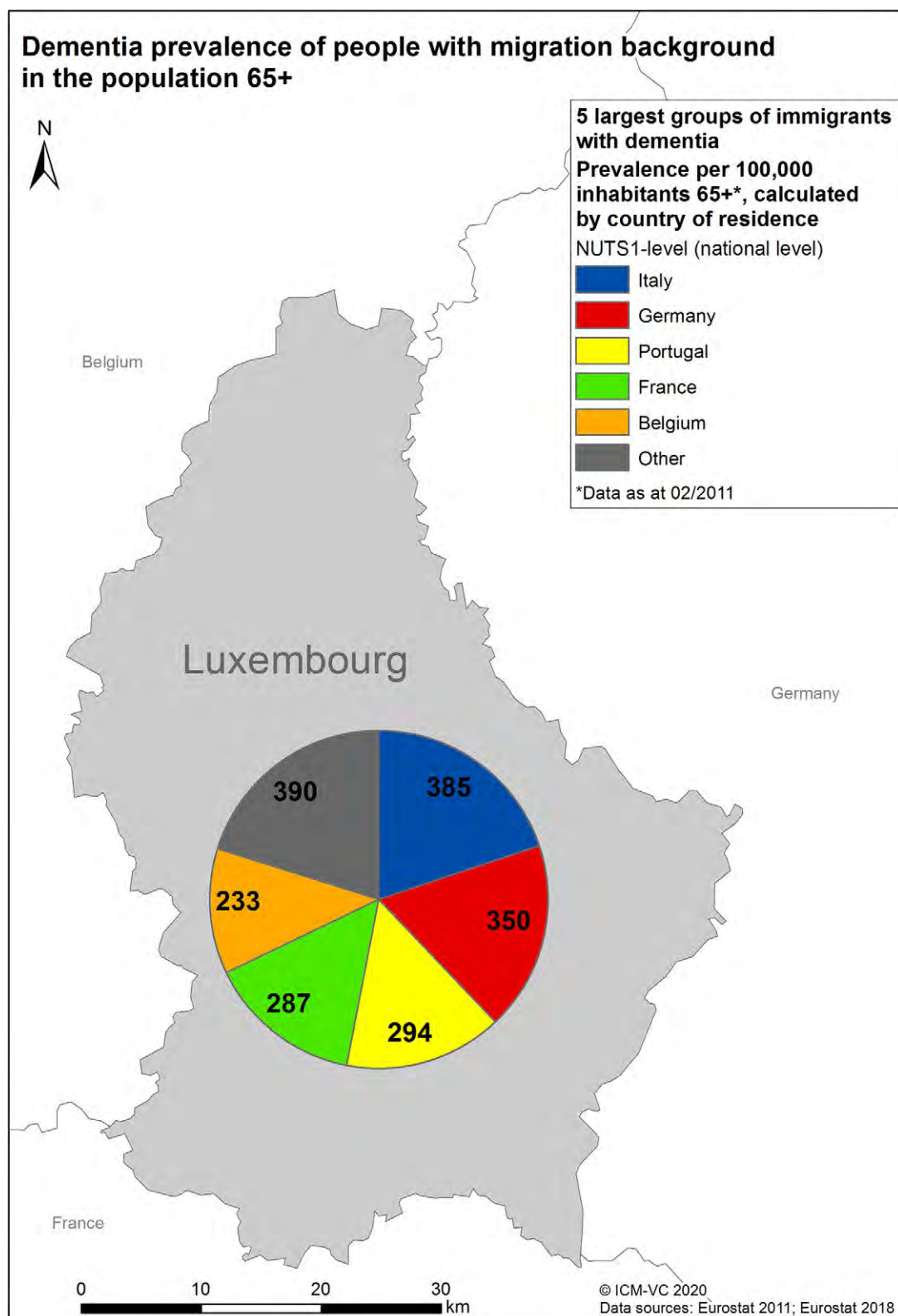


Fig. 3.7.20.2: Prevalence of PwM with dementia among the population aged 65+ (Luxembourg – Nation)





**Tab. 34: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Luxembourg – Nation)**

NUTS	Total	LU	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Luxembourg	4,907	3,529	IT 274	DE 249	PT 209	FR 204	BE 166	277
Prevalence/10,000 inhabitants with migration background 65+								
Luxembourg	2,458	-	IT 137	DE 125	PT 105	FR 102	BE 83	139
Prevalence/100,000 inhabitants 65+								
Luxembourg	6,900	4,963	IT 385	DE 350	PT 293	FR 287	BE 233	390

Data source: Eurostat (2011)

There are 20,000 PwM aged 65 or older. Of those, approx. 1,400 are estimated to exhibit some form of dementia. Figure 3.7.20.1 shows the most affected migrant groups presumably originate from Italy (approx. 300), Germany (approx. 300), Portugal (approx. 200), France

(approx. 200), and Belgium (approx. 200). The second graph highlights the number of PwM with dementia in Luxembourg per 100,000 inhabitants aged 65 or older (figures 3.7.20.2). Table 34 displays the values depicted in the maps on the national level [5, 6].

### 3. National dementia plan

Luxembourg has a national action plan on dementia published in 2013. This 130-page document addresses the issues of quality of life of affected people, prevention, mild cognitive impairment, dementia diagnosis, medical care, care needs of families, monitoring of the disease and management over time, the ac-

companiment of the affected person and their environment, home care, institutional support, ethical aspects, rights and protection of affected people, social exclusion, healthy aging, and dementia-friendly society. However, the NDP does not refer at any point to the topic of migration [7].

### 4. National dementia care and treatment guidelines

The guideline 'People With Dementia in Hospital' from 2018 consists of 40 pages and discusses the topics of admission to hospital or rehabilitation facility, accompaniment by relatives and/or healthcare professionals, hospital accommodation, technical and structural measures, volunteers, and specialised training

for all persons involved in the care. PwM or aspects related to migration do not receive special attention [8].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based



on a conducted interview and reflect the experience and opinion of the expert. A selection

bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

Based on the interview with the expert PwM in Luxembourg can be divided into two groups: The 'early' migrant groups from Spain, Italy, Portugal, and former Yugoslavia that settled in Luxembourg a long time ago and the 'newer' migrant groups from Afghanistan and Syria that arrived in the last 10 – 15 years.

The healthcare strategy in Luxembourg is an integrative one. The 'early' migrant groups are fully integrated in Luxembourg culture and also almost fully integrated into the healthcare system according to the expert. PwM with dementia are not included to this extent because Luxembourg has a problem with detecting dementia in general. The 'newer' migrant groups are not integrated into the healthcare system, which is shown in the low utilisation of available healthcare services. The expert assumed that one reason for this is the lack of awareness about dementia as a disease. But from his experience with other migrant groups, he assumes that utilisation will increase the longer the people live in Luxembourg. The healthcare services and service providers do not discriminate between people with and without a migration background. They try to include PwM and try to adapt to

the needs of this population. Information is also available to everyone. In Luxembourg, there is an 'Info-Zenter Demenz' (=information centre on dementia) that informs the public about dementia and supports them in utilizing help. This service is open to people with and without a migration background. Inpatient and outpatient care services are available for PwM with dementia. Furthermore, the expert stated that measures to ensure interculturally sensitive care are nationwide in development. Additionally, if there are problems with communication in healthcare and other services, providers can consult a translator to help with that. This translation service is financed by the government.

Regarding participation in designing information material and healthcare services, the expert noted that PwM with dementia from the newer migrant groups are very rarely included. That is because the government wants to focus on integration this group into Luxembourg culture, by helping them learn the local language and customs, rather than engaging them in creating specialised services that would segregate them from the mainstream.

## 6. Professional qualification and people with a migration background in healthcare

Intercultural care does not seem to be a part of the professional qualification of healthcare professionals on a national scale. There are training and learning opportunities about intercultural care for healthcare professionals but

they are provided on an individual basis, not as large-scale, group courses.

The expert assumed that the proportion of PwM who were born in another country than Luxembourg working in healthcare is low.



Those that are working in healthcare are originate from the former Yugoslavia. But there is

a rather large proportion of PwM from the second generation working in healthcare.

## 7. Support for family caregivers

According to the expert, families and religious communities play a crucial role in supporting family caregivers of PwM with dementia while migrant organisations play only a moderately important role. Healthcare service providers are important for the 'early' migrant groups but not so much for the 'newer' migrant groups.

The expert estimated the need for developing specialised services as low since adequate services already exist and they are always being adapted to the needs of migrants. However, the expert acknowledged that the utilisation of these services by PwM is still moderately low.

## 8. References

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# Malta

**Population**

515,000

**Area**

313 km<sup>2</sup>

**Capital**

Valletta

**3 largest cities**

Saint Paul's Bay  
(32,000)

Birkirkara (25,000)

Sliema (24,000)

**Neighboring countries**

None

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

The Maltese islands have a long migration history [1] due to their geographical location in the centre of the Mediterranean Sea and the British colonial rule, which lasted for 164 years until 1964. At the beginning of the 20th century, many people from Malta emigrated to Egypt, Libya, Algeria, and Tunisia. Between the mid-1950s and 1980s, Australia, United Kingdom, Canada, and the US were the destinations of many emigrants. At the same time, only a few migrants lived in Malta. There was a community from India of 300 people, a community of 3,000 people from Arab-speaking countries, and small communities from Nigeria and United Kingdom [2]. In the further course of the 20th century, Malta developed from an emigration country to an immigration country, whereby especially the British community grew strongly [1]. Simultaneously, with the arrival of Asians from Uganda in 1972, the island state began to develop into a country of humanitarian immigration. This development continued with two waves of immigration in 1991: Iraqi immigration during the Second Gulf War and a second wave after the collapse of Yugoslavia. During the negotiations for accession to

the EU between 1990 and 2004, thousands of migrants from sub-Saharan Africa came to Malta. This development intensified after accession on 1 May 2004 [2]. Between 2002 and 2008, 11,500 migrants arrived in Malta by sea. At the same time, Malta became one of the countries with the highest acceptance rate of asylum applications in Europe [3]. In recent years, mainly migrants from Syria and Libya have applied for asylum in Malta. Although an increasing number of migrants come from non-EU countries (in 2013, migrants from non-EU countries outnumbered migrants from EU countries), people from the EU represent the largest migrant group [1]. In 2013, United Kingdom and Northern Ireland (11,400), Australia (5,500), Canada (2,100), Italy (1,600), and the US (1,500) were the main countries of origin of the migrant population [4]. The migrant population of Malta (born abroad) more than quintupled between 1990 and 2019 (15,100 to 84,900). At the same time, the proportion of migrants in the total population has increased from 4.2 to 19.3% [5]. The net migration rate has been continuously positive since 1990 and currently is 2.1 (2020) [6].



## 2. Estimated number of people with a migration background with dementia

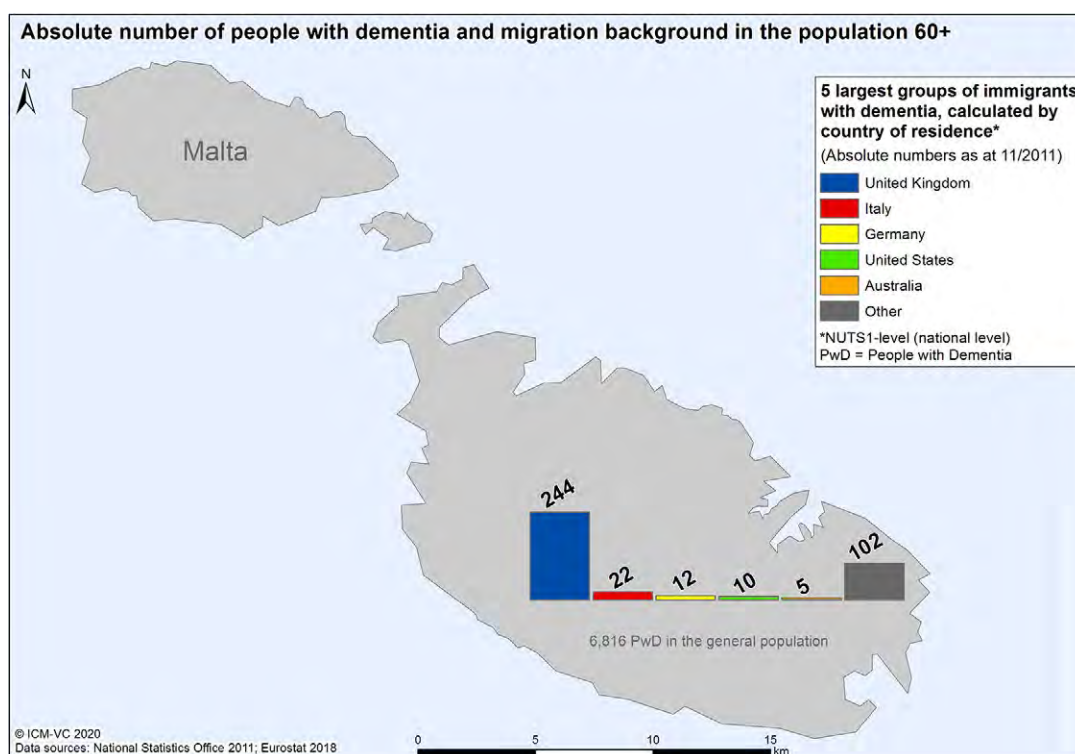


Fig. 3.7.21.1: Absolute number of PwM with dementia aged 60+ (Malta – Nation)

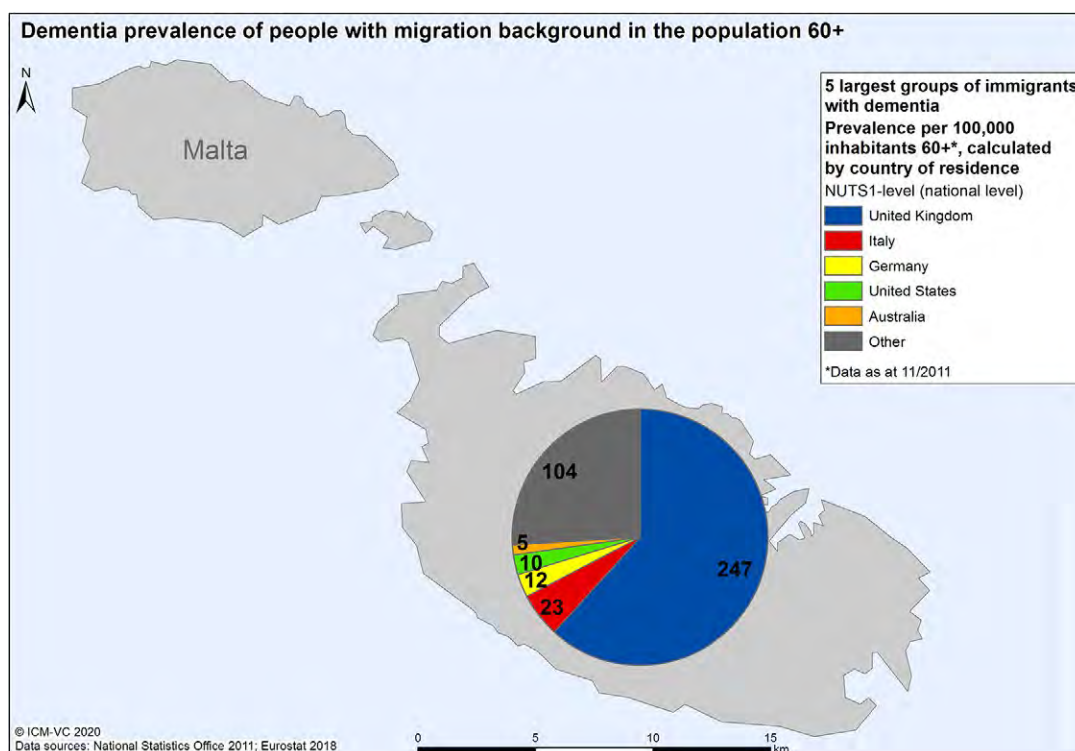


Fig. 3.7.21.2: Prevalence of PwM with dementia among the population aged 60+ (Malta – Nation)



**Tab. 35: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Malta – Nation)**

NUTS	Total	MT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Malta	6,816	6,421	UK 244	IT 22	DE 12	US 10	AU 5	102
Prevalence/10,000 inhabitants with migration background 60+								
Malta	11,889	-	UK 426	IT 39	DE 20	US 17	AU 9	179
Prevalence/100,000 inhabitants 60+								
Malta	6,900	6,500	UK 247	IT 23	DE 12	US 10	AU 5	104

Data source: National Statistics Office (2011)

There are 5,700 PwM aged 60 or older. Of those, approx. 400 are estimated to exhibit some form of dementia. Figure 3.7.21.1 shows the most affected migrant groups presumably originate from United Kingdom (approx. 200), Italy (approx. 20), Germany (approx. 10), the

US (approx. 10), and Australia (approx. 10). The second graph highlights the number of PwM with dementia in Malta per 100,000 inhabitants aged 60 or older (figure 3.7.21.2). Table 35 displays the values depicted in the maps on the national level [7-9].

## 3. National dementia plan

The 'National Strategy for Dementia in the Maltese Islands 2015–2023' from 2015 has 132 pages and addresses the topics of definition of dementia, types of dementia, dementia risk and protective factors, the burden of dementia, financial consequences of dementia, the perspective of people with dementia and

their caregivers, Dementia awareness, early diagnosis and intervention, drug and non-drug interventions, community-based care services, long-term and palliative care, ethical aspects related to dementia management and care, and research. The topic of migration is absent [10].

## 4. National dementia care and treatment guidelines

In addition, Malta published the three-page guideline 'Dementia Treatment' in 2012. This document deals exclusively with the drug

treatment of dementia using donepezil. No reference to migration is made in it [11].

## 5. References

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11. Azzopardi Muscat N: Dementia Treatment. In. Edited by Office of the Chief Medical Officer; 2012.





# The Netherlands

**Population**

17,408,000

**Area**

34,188 km<sup>2</sup>

**Capital**

Amsterdam

**3 largest cities**

Amsterdam (873,000)

Rotterdam (651,000)

The Hague (546,000)

**Neighboring countries**

Belgium, Germany

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Dutch migration history is characterised by large immigration and emigration flows. During the First World War thousands of Belgian refugees immigrated and between 1920 and 1940 many Jews and other Nazi persecuted groups fled to the Netherlands. After the German invasion of 1940, a large group of the autochthonous population emigrated to United Kingdom[1]. Between 1946 and 1969, almost half a million people left the country (mostly to Canada, Australia, the US, South Africa, and New Zealand) [2, 3]. At the same time, many people immigrated from former colonies and guest worker countries. As a result of Indonesia's independence in 1945, about 300,000 Dutch-Indonesian repatriates and 12,500 Malukans came to the country. After Suriname's independence in 1975, almost half of its population emigrated to the Netherlands. In the 1960s and 1970s, guest workers were recruited mainly from Turkey, Morocco, and Spain. After the recruitment stop in 1975,

family reunification was the main source of immigration. Since 2007, labour migration has shaped the migration patterns in the Netherlands [2]. A central characteristic of recent migration history is the continuous influx of immigrants from other EU states, especially from Germany [3]. In 2019, people from Turkey represented the largest migrant group (194,300), followed by Suriname (178,300), Morocco (170,500), Poland (145,200), Germany (120,600), and Indonesia (115,100) [4]. The migrant population (born abroad) almost doubled between 1990 and 2019 (1.2 to 2.3 million). At the same time, the proportion of migrants in the total population has also increased significantly (7.9 to 13.4%) [5]. As of 2020, the net migration rate is 0.9 [6]. While the Netherlands was an emigration country after the Second World War, it evolved into an immigration country between the 1960s and the millennium. For some years now, immigration and emigration figures have been converging.



## 2. Estimated number of people with a migration background with dementia

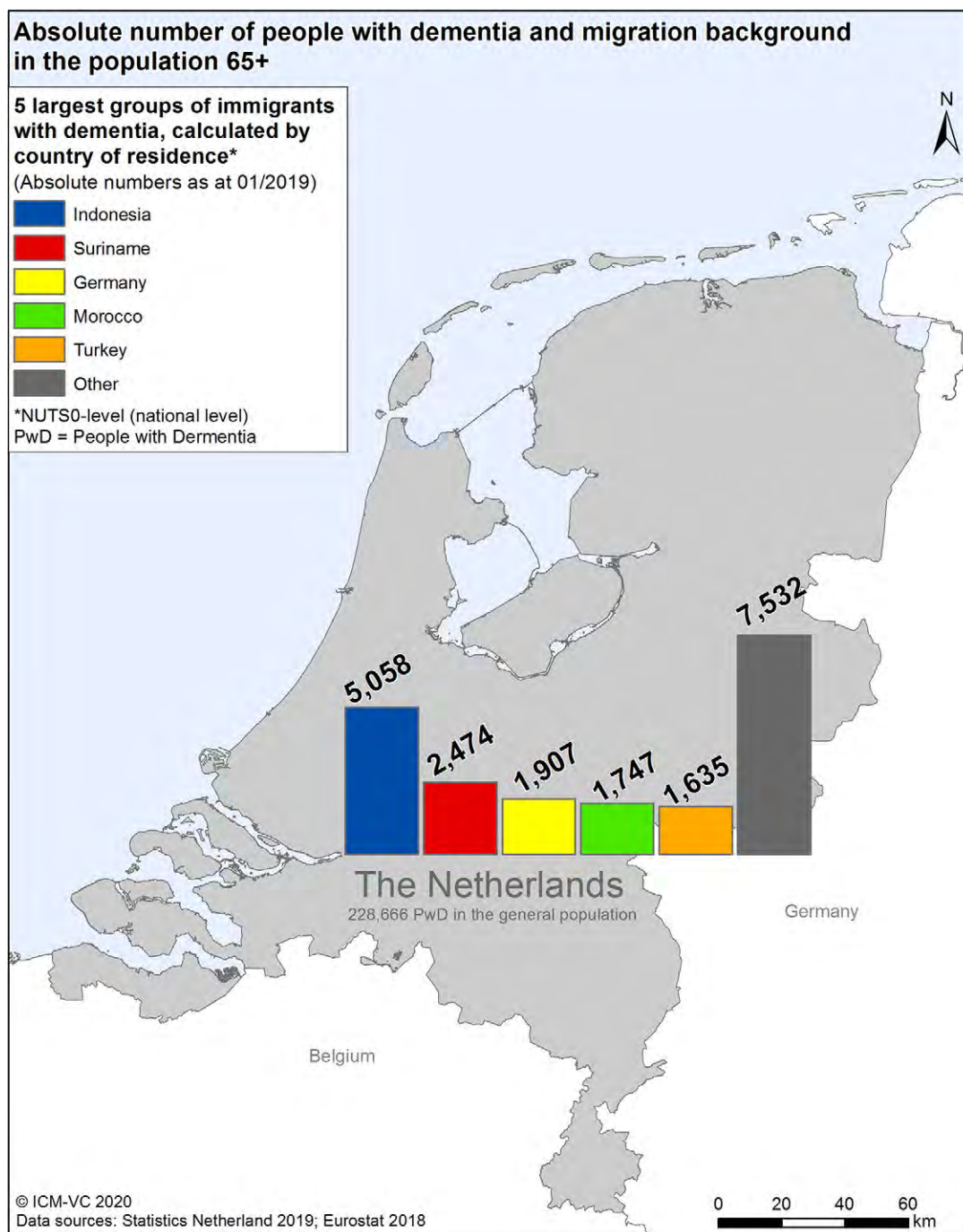


Fig. 3.7.22.1: Absolute number of PwM with dementia aged 65+ (The Netherlands – Nation)

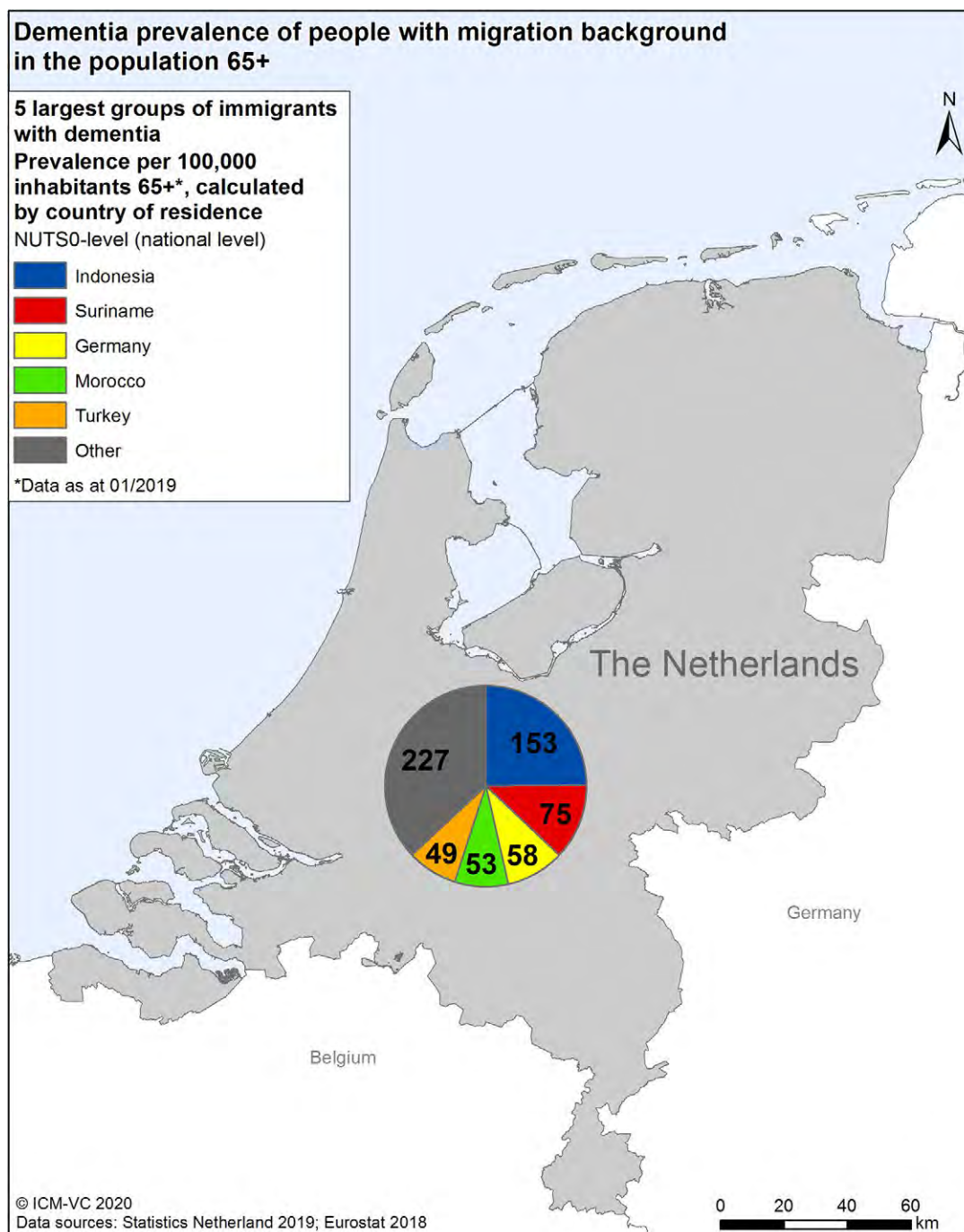


Fig. 3.7.22.2: Prevalence of PwM with dementia among the population aged 65+ (The Netherlands – Nation)



**Tab. 36: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Netherlands – Nation)**

NUTS	Total	NL	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
The Netherlands	228,666	208,313	ID 5,058	SR 2,474	DE 1,907	MA 1,747	TR 1,635	7,532
Prevalence/10,000 inhabitants with migration background 65+								
The Netherlands	7,752	-	ID 171	SR 84	DE 65	MA 59	TR 55	255
Prevalence/100,000 inhabitants 65+								
The Netherlands	6,900	6,286	ID 153	SR 75	DE 58	MA 53	TR 49	227

Data source: Statistics Netherlands (2019)

There are 295,000 PwM aged 65 or older. Of those, approx. 20,400 are estimated to exhibit some form of dementia. Figure 3.7.22.1 shows the most affected migrant groups presumably originate from Indonesia (approx. 5,100), Suriname (approx. 2,500), Germany (approx. 1,900), Morocco (approx. 1,800), and Turkey (approx. 1,600). The second graph highlights the number of PwM with dementia in the

Netherlands per 100,000 inhabitants aged 65 or older (figure 3.7.22.2). Table 36 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Indonesia, Suriname, Germany, Morocco, and Turkey throughout the country in the NUTS2 regions (figures 3.7.22.3 – 3.7.22.8).



Fig. 3.7.22.3: Absolute number of PwM with dementia aged 65+. Country of origin: Indonesia (The Netherlands – NUTS2)





Fig. 3.7.22.4: Absolute number of PwM with dementia aged 65+. Country of origin: Suriname (The Netherlands – NUTS2)



Fig. 3.7.22.5: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (The Netherlands – NUTS2)





Fig. 3.7.22.6: Absolute number of PwM with dementia aged 65+. Country of origin: Morocco (The Netherlands – NUTS2)



Fig. 3.7.22.7: Absolute number of PwM with dementia aged 65+. Country of origin: Turkey (The Netherlands – NUTS2)



Fig. 3.7.22.8: Absolute number of people with dementia aged 65+.  
Country of origin: The Netherlands (The Netherlands – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.22.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (Fig. 3.7.22.10). The values from the NUTS2 level can be found in table 37 [7-9].

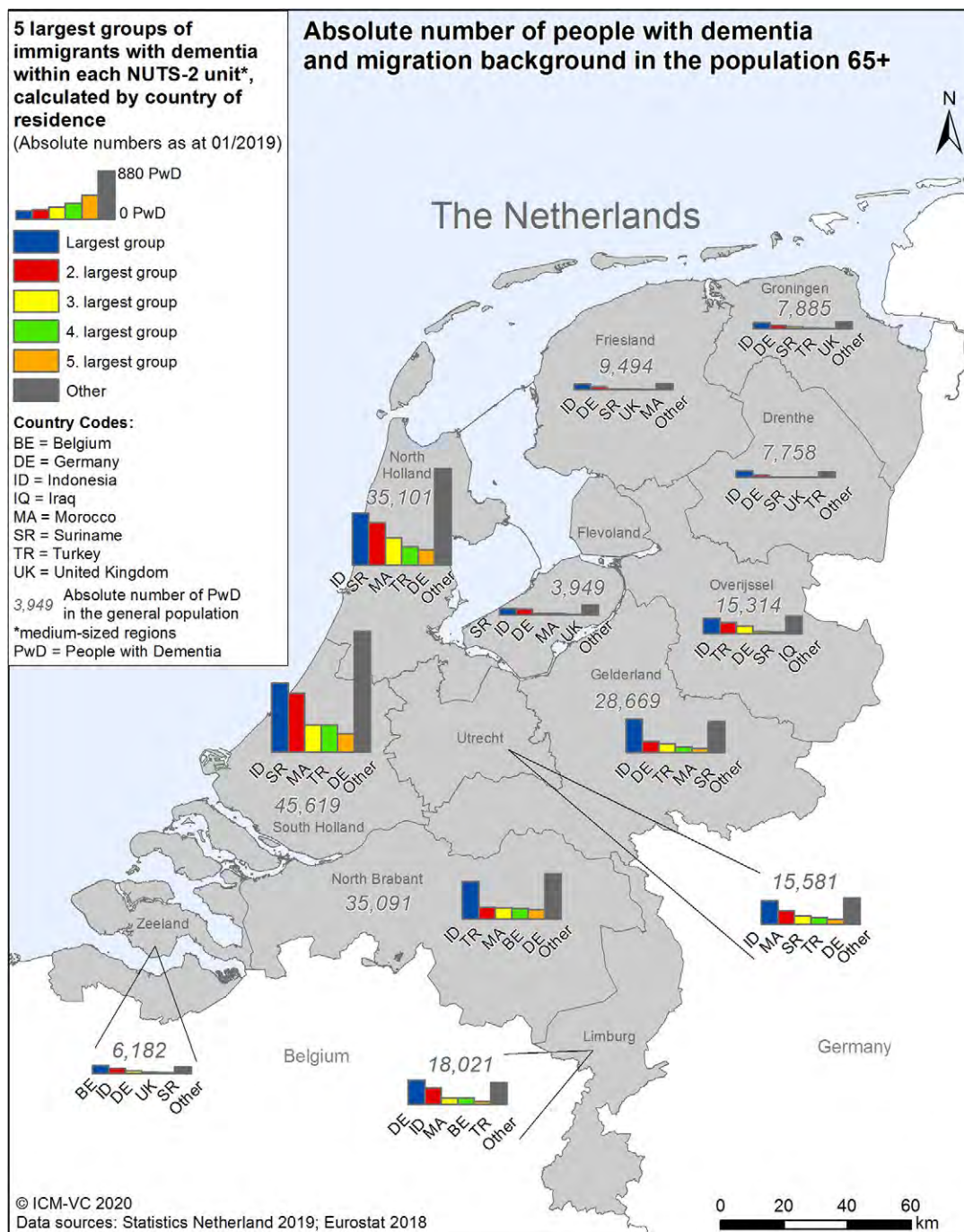


Fig. 3.7.22.9: Absolute number of PwM with dementia aged 65+ (The Netherlands – NUTS2)

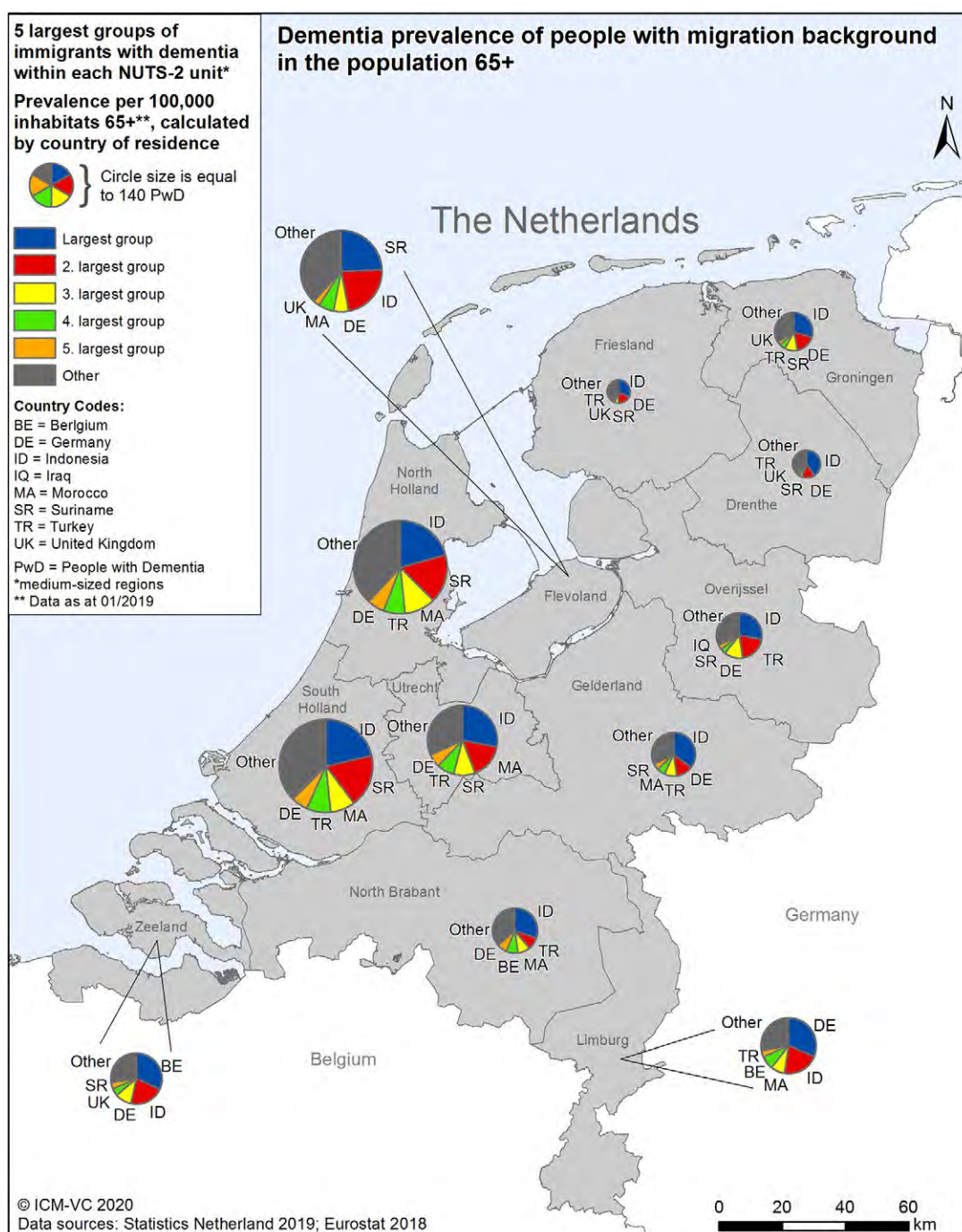


Fig. 3.7.22.10: Prevalence of PwM with dementia among the population aged 65+ (The Netherlands – NUTS2)



**Tab. 37: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Netherlands – NUTS 2)**

NUTS	Total	NL	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute numbers								
Groningen	7,885	7,473	ID 122	DE 72	SR 45	TR 20	UK 13	140
Friesland	9,494	9,187	ID 101	DE 53	SR 17	UK 14	MA 8	114
Drenthe	7,758	7,462	ID 120	DE 46	SR 10	UK 10	TR 8	103
Overijssel	15,314	14,335	ID 272	TR 195	DE 132	SR 35	IQ 34	310
Gelderland	28,660	26,893	ID 629	DE 214	TR 167	MA 104	SR 83	579
Flevoland	3,949	3,498	SR 111	ID 101	DE 27	MA 27	UK 12	172
Utrecht	15,581	14,064	ID 424	MA 243	SR 152	TR 123	DE 89	485
Noord-Holland	35,101	30,501	ID 948	SR 777	MA 500	TR 341	DE 279	1,755
Zuid-Holland	45,619	39,707	ID 1,270	SR 1,086	MA 502	TR 500	DE 339	2,216
Zeeland	6,182	5,743	BE 140	ID 95	DE 47	UK 19	SR 17	122
Noord-Brabant	35,091	32,841	ID 677	TR 202	MA 201	BE 190	DE 165	814
Limburg	18,021	16,609	DE 444	ID 298	MA 114	BE 112	TR 51	393
Prevalence/10,000 inhabitants with migration background 65+								
Groningen	13,195	-	ID 204	DE 120	SR 76	TR 33	UK 22	235
Friesland	21,316	-	ID 226	DE 119	SR 39	UK 31	MA 19	257
Drenthe	18,042	-	ID 279	DE 106	SR 24	UK 23	TR 18	239
Overijssel	10,796	-	ID 192	TR 138	DE 93	SR 25	IQ 24	218
Gelderland	11,136	-	ID 244	DE 83	TR 65	MA 49	SR 32	225
Flevoland	6,044	-	SR 169	ID 155	DE 42	MA 42	UK 18	264
Utrecht	7,087	-	ID 193	MA 111	SR 69	TR 56	DE 41	220





Noord-Holland	5,265	-	ID 142	SR 117	MA 75	TR 51	DE 42	263
Zuid-Holland	5,324	-	ID 148	SR 127	MA 59	TR 58	DE 40	259
Zeeland	9,705	-	BE 220	ID 149	DE 73	UK 30	SR 27	192
Noord-Brabant	10,763	-	ID 208	TR 62	MA 62	BE 58	DE 51	250
Limburg	8,803	-	DE 217	ID 146	MA 56	BE 55	TR 25	192
Prevalence/100,000 inhabitants 65+								
Groningen	6,900	6,539	ID 107	DE 63	SR 40	TR 17	UK 12	123
Friesland	6,900	6,677	ID 73	DE 38	SR 13	UK 10	MA 6	83
Drenthe	6,900	6,636	ID 107	DE 41	SR 9	UK 9	TR 7	92
Overijssel	6,900	6,459	ID 123	TR 88	DE 60	SR 16	IQ 15	140
Gelderland	6,900	6,472	ID 151	DE 52	TR 40	MA 25	SR 20	139
Flevoland	6,900	6,112	SR 193	ID 177	DE 48	MA 47	UK 21	301
Utrecht	6,900	6,228	ID 188	MA 108	SR 67	TR 54	DE 39	215
Noord-Holland	6,900	5,996	ID 186	SR 153	MA 98	TR 67	DE 55	345
Zuid-Holland	6,900	6,006	ID 192	SR 164	MA 76	TR 76	DE 51	335
Zeeland	6,900	6,409	BE 156	ID 106	DE 52	UK 21	SR 19	136
Noord-Brabant	6,900	6,458	ID 133	TR 40	MA 39	BE 37	DE 33	160
Limburg	6,900	6,359	DE 170	ID 114	MA 44	BE 43	TR 19	151

Data source: Statistics Netherlands (2019)

### 3. National dementia plan

Four NDPs, strategies, or standards were identified for the Netherlands. While the four-page 'Netherlands Deltaplan for Dementia' from 2017 and the 26-page 'Public Version Care Standard Dementia' from 2016 do not address migration [10, 11] the 'Care Standard Dementia'

for professional service providers from 2013 (82 pages) and the 'National Dementia Strategy 2021 – 2030' from 2020 (24 pages) refer to this topic [12, 13].

The 'Care Standard Dementia' for professional service providers does not have a separate

chapter on migration, but several passages of this document briefly address the topics of dementia prevalence, specific needs, dementia diagnosis, and care in relation to PwM with dementia. Thereby, it refers to the fact that dementia is increasingly common among people of non-Dutch origin (due to the aging population and a high prevalence of cardiovascular diseases and diabetes) and that this group has special needs in dementia diagnosis and care. It is argued that patients and their families with migrant backgrounds have different preferences in communication and decision-making regarding illness and treatment. The Netherlands pays particular attention to migrants in early detection and prevention. People affected by dementia and their relatives are offered activities (mental, physical, and learning activities) oriented to their cultural background. In the future, special attention will be given to migrants with dementia in the provision of housing. In addition, information on dementia will be adapted to the linguistic and cultural background of people of foreign origin. Thus, the version of 'Care Standard Dementia' from 2013 which is targeted at profes-

sional service providers points out that in the Netherlands specialised services are currently available for PwM with dementia and that further actions will be taken to improve the care situation of this population group [12]. The 'National Dementia Strategy 2021 – 2030' briefly refers to migration in three sub-chapters. In the section 'Facts and Figures', a short paragraph (5 lines) highlights that of the 178,000 people who have a formal dementia diagnosis and are on the radar of healthcare providers, 14% have a migration background. Furthermore, it is outlined that dementia figures among people with a non-Western migration background are rising faster than among people with a Dutch background and that dementia is three to four times more common in this population. In two subsequent sub-chapters, this document emphasizes that future care, and specifically the dementia care, networks must focus on cultural diversity among people in need of care. However, no strategy or specific measures are mentioned to achieve this. Overall, the topic of migration plays a subordinate role in the 'National Dementia Strategy 2021-2030' [13].

## 4. National dementia care and treatment guidelines

In the Netherlands, two documents with guidelines on dementia were identified: 1. 'The Guideline for Integrated Dementia Care' from 2009 and 2. the 'Dementia Treatment Policy' from 2012. The first document comprises 62 pages and deals with the topics such as: 1. diagnoses (sub-topics: criteria and recommendations for the diagnosis of different types of dementia, cognitive screening tools, neuropsychological tests); 2. treatment (drug treatment for dementia symptoms and neuropsychiatric symptoms, psychosocial and other non-drug interventions such as cognitive training and, physiotherapy); 3. support groups for caregivers of people with dementia; and 4. training of

caregivers [14]. The second document is 38 pages long and includes the topics: 1. people with dementia and their families (sub-topics: what is dementia and what does it do, People with dementia, their families and numbers [i.e. 'Number of people with dementia in the Netherlands]; people with dementia, their families, and their questions [identification of different problem areas]); 2. integrated dementia care and its important aspects (sub-topics: what is important for good dementia care in the region [i.e. what is good dementia care]; 3. what is important in terms of good quality integrated care (i.e. criteria for good management of integrated care), and 4. case managers as a



crucial link in the care chain (i.e. good examples of case management) [15]. Neither the first nor the second document refers to migration in any of the topics mentioned [14, 15].

The following parts on services and information for PwM with dementia, professional care

and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the two experts, the healthcare system identifies older PwM as a vulnerable group. For example, the Centre of Expertise on Differences in Health Access Pharos, which provides health education for patients and professionals, has a special focus on migrant groups. But overall, there are large regional differences in the relevance of the topic of dementia and migration in the Netherlands. For these experts, who work in a hospital in Amsterdam, and care providers from other larger cities in the west of the Netherlands, such as Rotterdam or The Hague, where many migrants live, the topic is very important. One expert stated that in a few years, a third of people living in Amsterdam who are 60 years or older will be non-western migrants. In provinces like Groningen or Drenthe, where only a few migrants live, the topic of dementia and migration is not seen as important. Older PwM are considered vulnerable in the areas of development and prevalence of dementia (which is higher in migrant groups), lack of care, underdiagnosis, and utilisation of healthcare services. Especially older migrants from Turkey and Morocco of the first generation are identified as vulnerable (due to language, cultural, and educational barriers).

According to one expert, a hybrid healthcare strategy with integrative and segregative elements is used in both outpatient and inpatient care for PwM with dementia. In inpatient care, however, the segregative model is somewhat

more widespread. This expert noted that there are slightly fewer migrant-specific care services in inpatient care than in outpatient care. The two experts still reported that there are adequately effective services for outpatient care of older migrants in several regions that meet their needs. For example, the intercultural dementia screening tool RUDAS is used in many memory clinics to assess dementia among migrants. In addition, some memory clinics offer a specialist day-care program with interpreters as well as training related to the topic of dementia and migration. As a basic model of good practice, one expert highlighted the combination of clinical practice and scientific research in the context of diagnostics in some centres and universities, such as the Amsterdam Department of Psychiatry and Medical Psychology and the Erasmus University Rotterdam. There are also many other centres that are learning from the two organisations, for example by using interpreting services, increasing their knowledge of educational and literacy barriers, and organizing symposia bringing together hospitals where diagnoses are made with general practitioners and care institutions which have many migrant patients. In follow-up care, the model of good practice is to have a strong care chain in which the actors know each other well and have knowledge about the relevant stakeholders. Although a growing number of cities such as Amsterdam, Rotterdam, or The



Hague are offering specialised services such as allocation of apartments in nursing homes for elderly migrants from Turkey and Morocco (with halal food, native-speaking staff, and religion-specific services), there are currently still many regions without such options.

One expert pointed out that the measures for intercultural care and support for dementia are spread nationwide. Most services are accessible via the Internet. For example, there are tools and videos that help people to recognize symptoms of dementia and talk about dementia. Furthermore, in many regions, there are training courses for key community members

on how to recognize dementia symptoms and set up care chains. The information is available online, allowing to provide such training in all regions.

According to the experts, the existing care services are adequate for people with dementia with and without a migration background. However, as they are usually designed by non-migrants, they are more suitable for non-migrants. PwM with dementia or their relatives are also less frequently involved in the development of such services, even though such participatory projects do exist in the Netherlands.

## 6. Professional qualification and people with a migration background in healthcare

In the education of healthcare professionals in universities and medical faculties, a special focus is set on the topic of culturally sensitive care as stated by the experts. In addition, the institution Pharos provides special courses on culturally sensitive care and other topics relevant to older migrants, such as dementia and palliative care. Pharos has also developed a special course on end-of-life care for first-generation migrants, an initiative in which the two experts were involved. While culturally sensitive care is mostly part of curricula for the education of professionals, there seem to be no official training opportunities for doctors or caregivers in intercultural care. However, the hospital in Amsterdam, where the two experts are employed, offers courses or lectures in which health professionals or students from

other regions also participate.

The proportion of professional caregivers with a migration background is increasing relatively strongly in both outpatient and inpatient care. According to the experts, it is currently still at a moderate level. The three main countries of origin of the caregivers with a migration background are Suriname, Turkey, and Morocco. An increasing proportion of professional caregivers from these countries has a very positive influence on patients who have also immigrated from these countries. However, some patients fear that they cannot trust a caregiver who has the same cultural background because they are afraid that they are gossiping about what they tell. This problem is also evident with official interpreters.



## 7. Support for family caregivers

According to the experts, the family is very important in supporting family caregivers of PwM with dementia. Religious communities, migrant organisations, and care providers are also relevant in this context. One expert argued that it is important for professional care providers to establish contact with religious communities and migrant organisations to provide PwM information on dementia.

Family caregivers of PwM with dementia often lack information about formal services and have a very high need for specialised services providing support and information. According to one expert, such specialised

services currently only exist in a few regions (in larger cities with a higher number of elderly migrants, such as Rotterdam, Amsterdam, and The Hague). The other expert noted that in the Netherlands there is generally a lot of information on dementia, but it is primarily available online. Especially for older migrants, different paths of access to information and support are needed. There is also a high need for awareness-raising and education about dementia, as dementia is often not seen as a disease in some migrant groups (e.g. by many people from Morocco and Turkey), which is an obstacle to the active utilisation of services.

## 8. References

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# Norway

**Population**

5,368,000

**Area**

309,158 km<sup>2</sup>

**Capital**

Oslo

**3 largest cities**

Oslo (693,000)

Bergen (284,000),

Trondheim (205,000)

**Neighboring countries**

Finland, the Russian

Federation, Sweden

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



### 1. Migration history

Norway, which declared its independence from Sweden in 1905, was an emigration country at first. Between 1825 and 1945, about 850,000 people left the country (mostly for the US), the second-largest emigration in Europe by population size (after Ireland). Until the 1970s, the population in Norway was relatively homogeneous. After creating a common labour market between Norway, Sweden, Finland, and Denmark in the 1950s (Iceland joined in 1982), many people migrated from neighbouring Scandinavian countries. In the late 1960s, some migrant workers came to Norway from Morocco, Yugoslavia, Turkey, and Pakistan. Labour migration and family reunification characterised immigration in Norway until the immigration ban in 1975. After that, refugee migration came to the fore for several years. While Norway accepted only 223 refugees between 1960 and 1970, there were 1,680 in 1978 and 1979, of whom more than 1,300 came by sea from Vietnam [1]. Between 1990 and 2017, labour migration and family reunification were again the central characteristics of non-Nordic foreign immigration [2]. The number of work permits for migrants increased by about 10,000 between 1999 and 2003, reach-

ing a peak of 33,000 in 2004. In 2004, 74% of all Norwegian work permits were issued to citizens of the new EU member states, most of them seasonal workers from Poland and Lithuania. From 2004 onwards, significant migratory flows came from Sweden, the Russian Federation, Denmark, and Poland [1]. In 2017, the number of immigrants was 58,200, 8,600 fewer than in the previous year, confirming the slightly declining immigration trend since 2008. By country of origin, most immigrants came from Syria (7,000), Poland (5,200), and Lithuania (2,750) [2]. In 2019, people from Poland (98,700), Lithuania (39,300), Sweden (35,600), Syria (30,800), and Somali (28,600) represented the largest groups of immigrants (foreign-born with two foreign-born parents) [3]. Except for 1989, Norway has had positive net migration every year since the late 1960s [2]. The migrant population (born abroad) more than quadrupled between 1990 and 2019 (192,600 to 867,800). At the same time, the proportion of migrants in the population has risen from 4.5 to 16.1% [4]. As of 2020, the net migration is 5.3 [5]. This indicates that Norway has developed into an immigration country.

## 2. Estimated number of people with a migration background with dementia

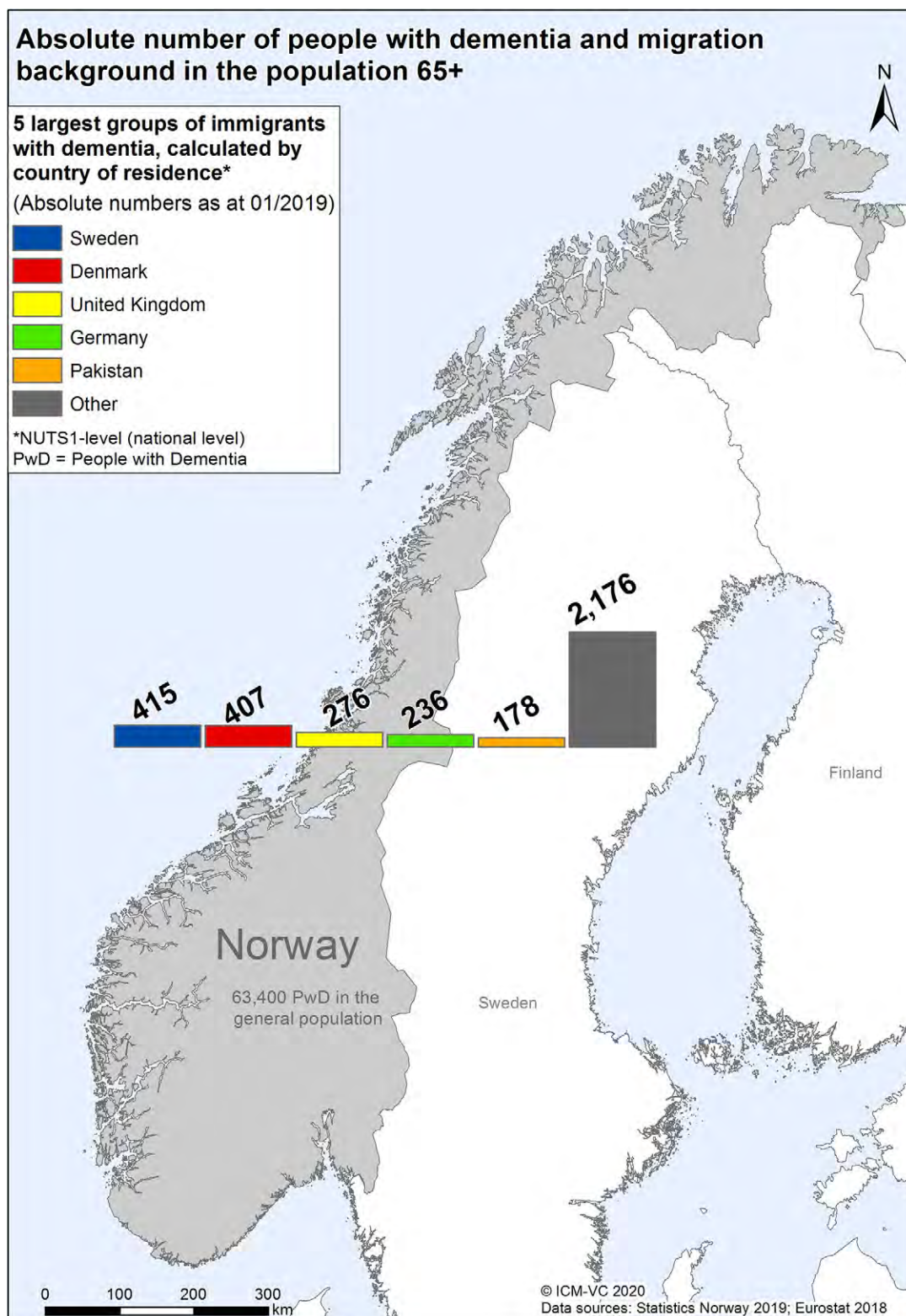


Fig. 3.7.23.1: Absolute number of PwM with dementia aged 65+ (Norway – Nation)

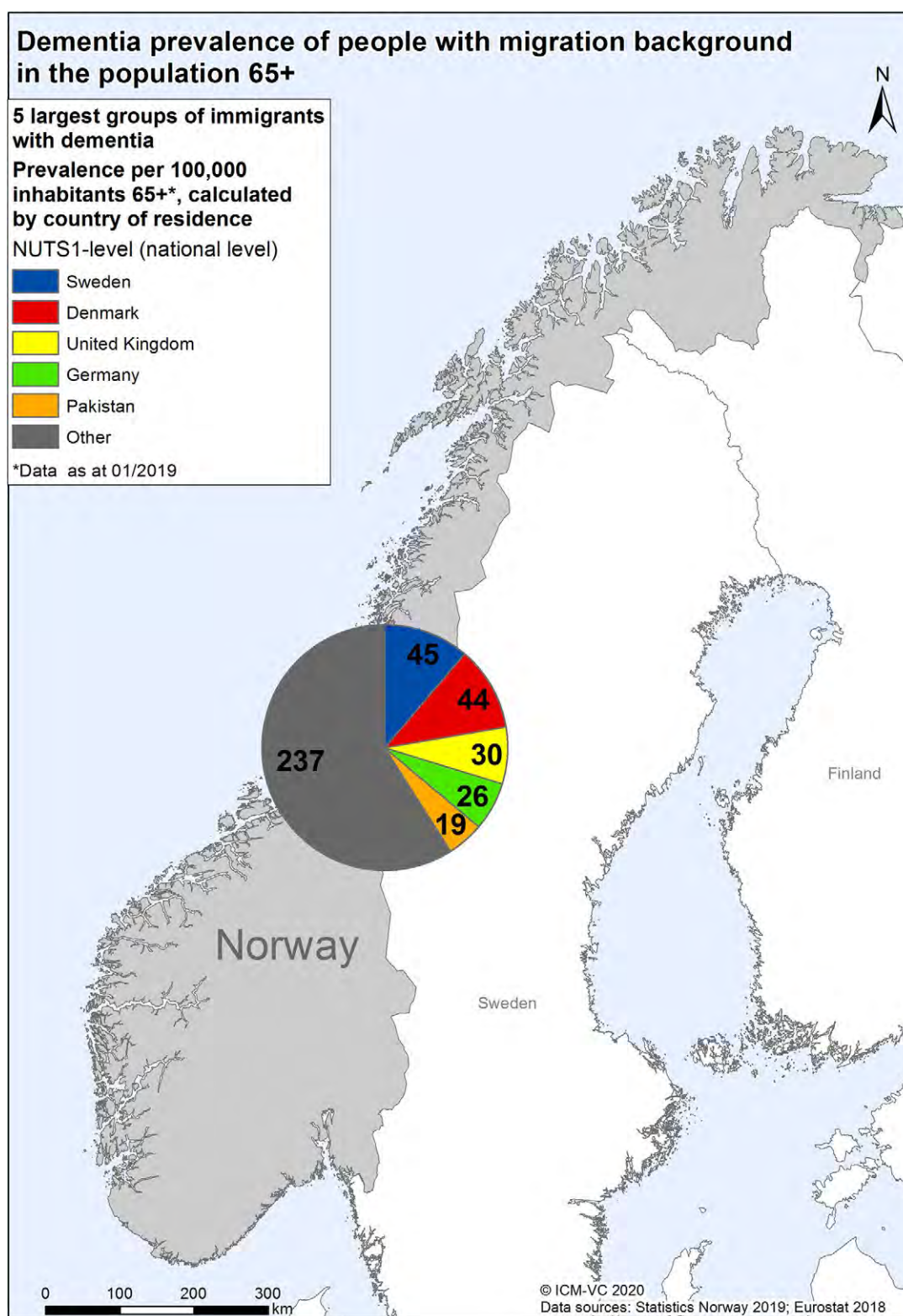


Fig. 3.7.23.2: Prevalence of PwM with dementia among the population aged 65+ (Norway – Nation)

**Tab. 38: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Norway – Nation)**

NUTS	Total	NO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Norway	63,400	59,711	SE 415	DK 407	UK 276	DE 236	PK 178	2,176
Prevalence/10,000 inhabitants with migration background 65+								
Norway	11,860	-	SE 78	DK 76	UK 52	DE 44	PK 33	407
Prevalence/100,000 inhabitants 65+								
Norway	6,900	6,499	SE 45	DK 44	UK 30	DE 26	PK 19	237

Data source: Statistics Norway (2019)

There are 53,500 PwM aged 65 or older. Of those, approx. 3,700 are estimated to exhibit some form of dementia. Figure 3.7.23.1 shows that the most affected migrant groups presumably originate from Sweden (approx. 400), Denmark (approx. 400), United Kingdom (approx. 300), Germany (approx. 200), and Pakistan (approx. 200). The second graph highlights the number of PwM with dementia in

Norway per 100,000 inhabitants aged 65 years or older (figure 3.7.23.2). Table 38 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Sweden, Denmark, United Kingdom, Germany, and Pakistan throughout the country in the NUTS2 regions (figures 3.7.23.3 – 3.7.23.8).



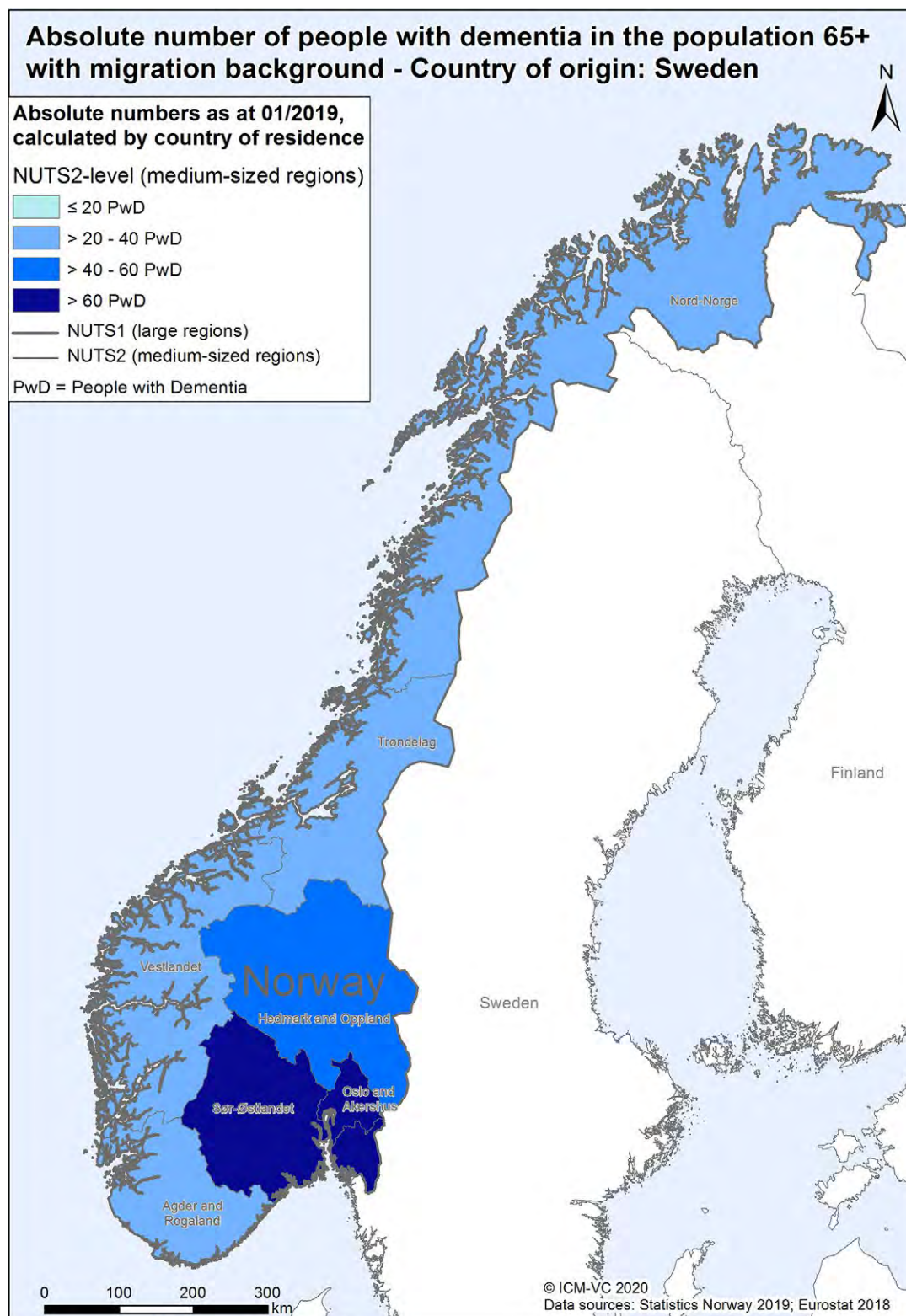


Fig. 3.7.23.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Sweden (Norway – NUTS2)



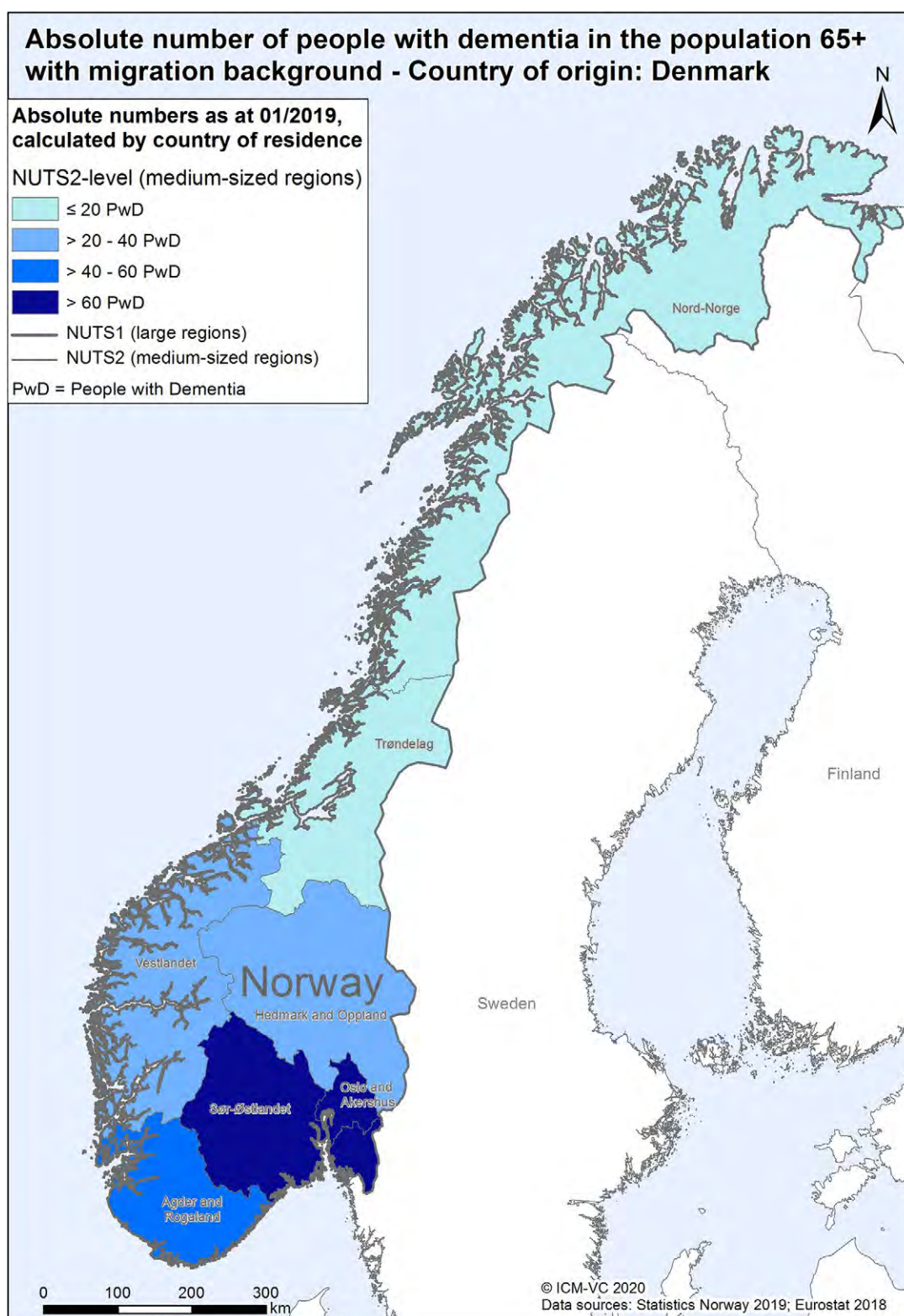


Fig. 3.7.23.4: Absolute number of PwM with dementia aged 65+. Country of origin: Denmark (Norway – NUTS2)



Fig. 3.7.23.5: Absolute number of PwM with dementia aged 65+. Country of origin: United Kingdom (Norway – NUTS2)



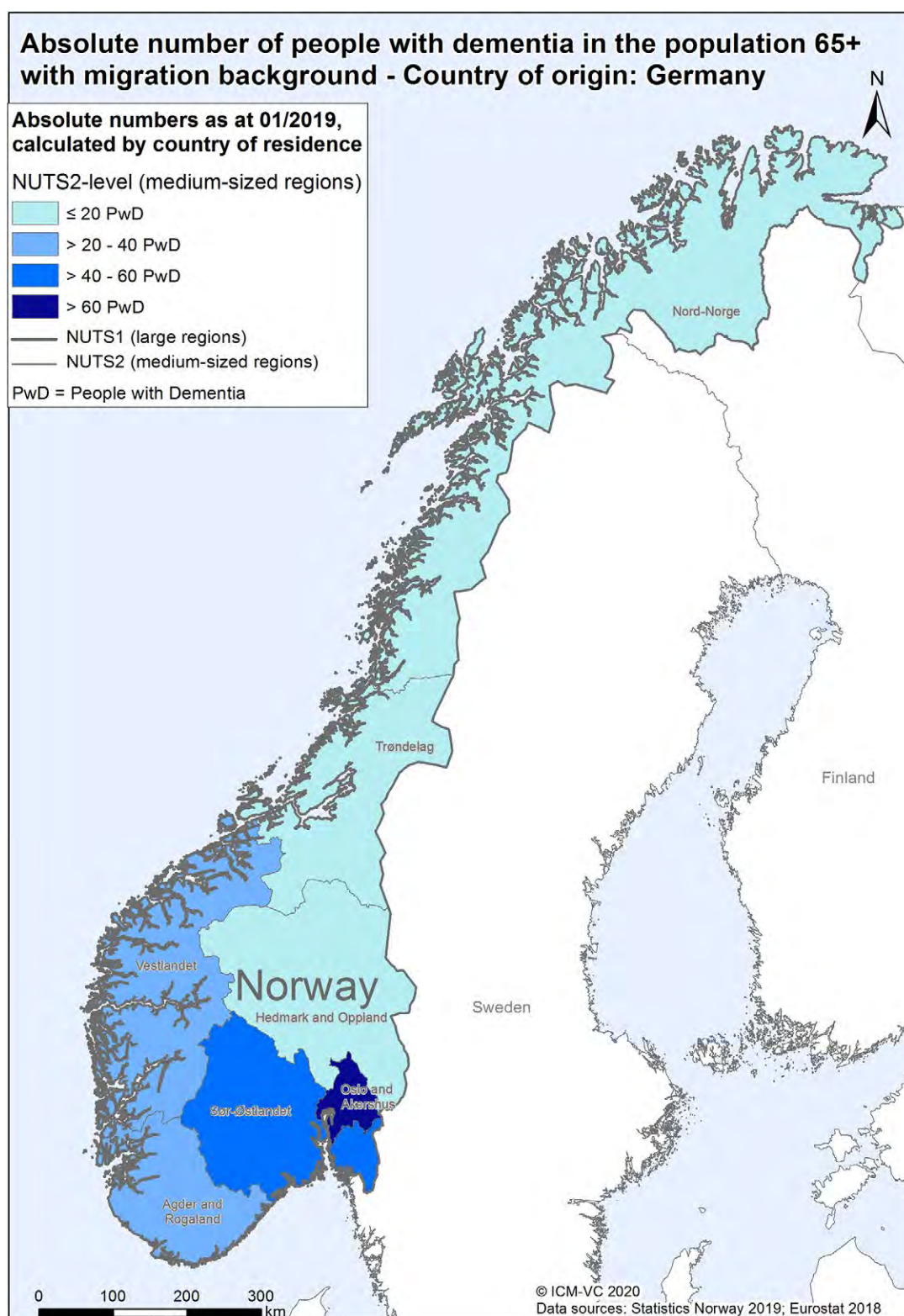


Fig. 3.7.23.6: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Norway – NUTS2)

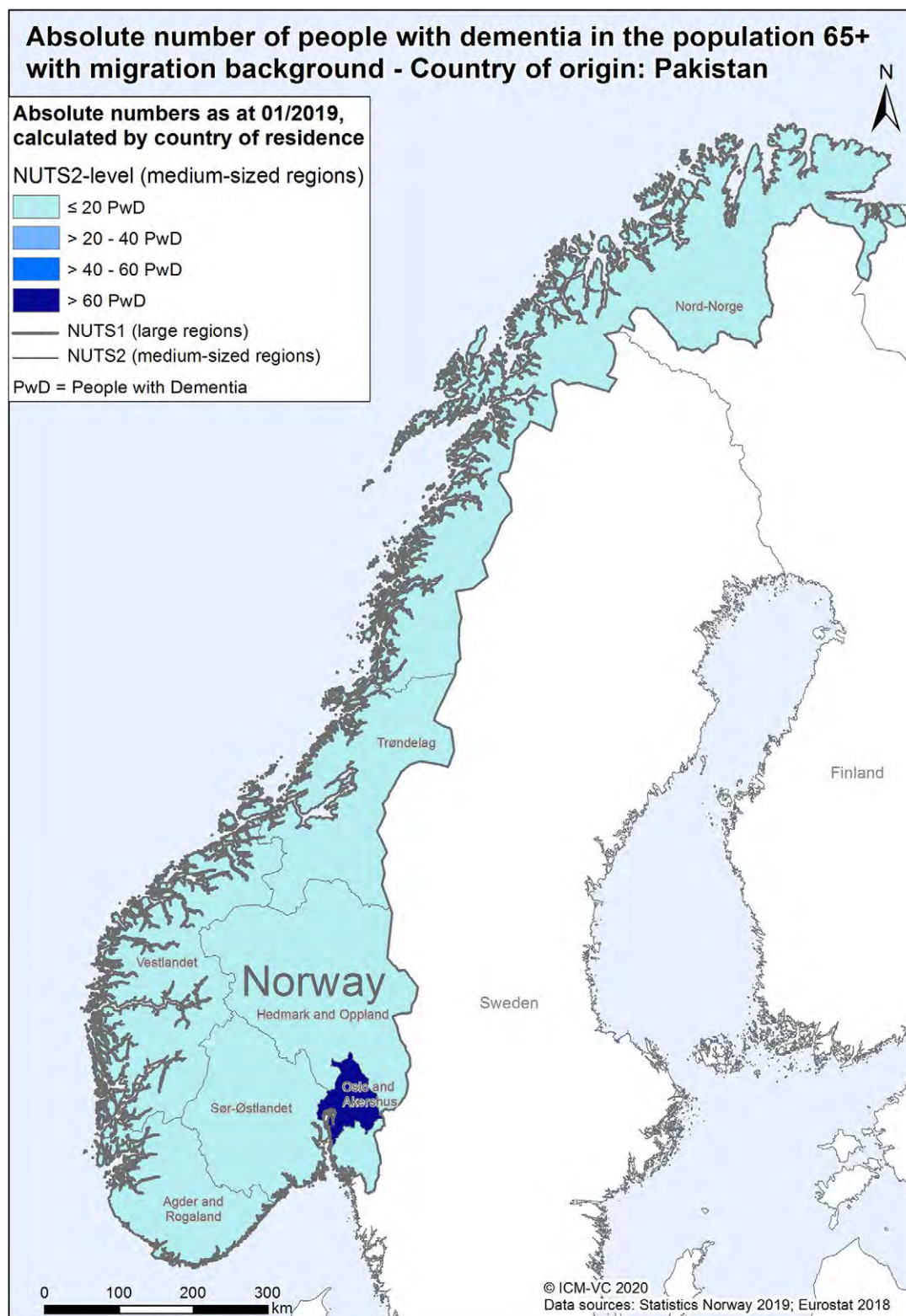


Fig. 3.7.23.7: Absolute number of PwM with dementia aged 65+. Country of origin: Pakistan (Norway – NUTS2)





Fig. 3.7.23.8: Absolute number of people with dementia aged 65+.  
Country of origin: Norway (Norway – NUTS2)



## Norway

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The graphics below highlight which immigrant groups are estimated to be most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figures 3.7.23.9). The sec-

ond graphic shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.23.10). The values from the NUTS2 level can be found in table 39 [6-8].



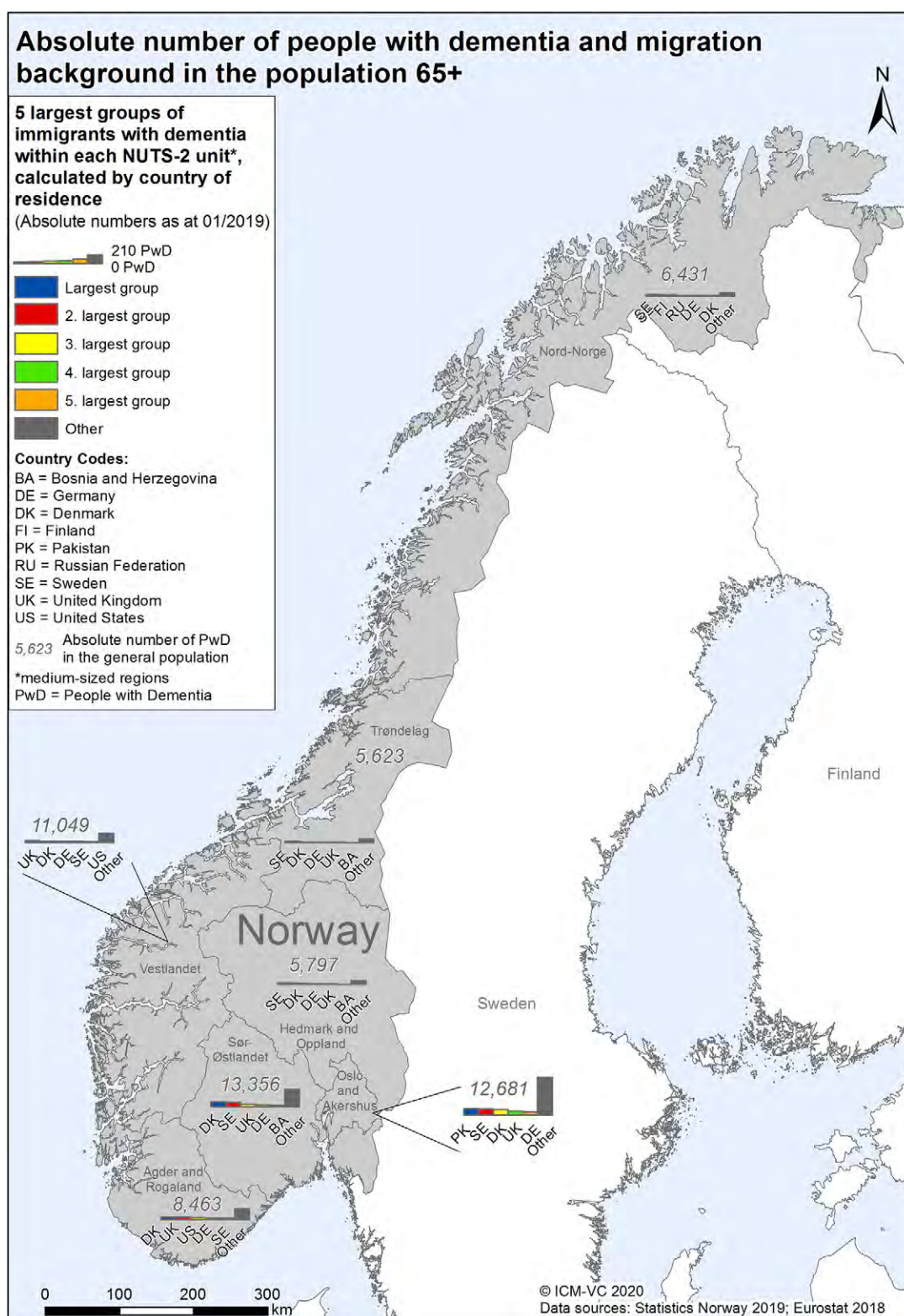


Fig. 3.7.23.9: Absolute number of PwM with dementia aged 65+ (Norway – NUTS2)

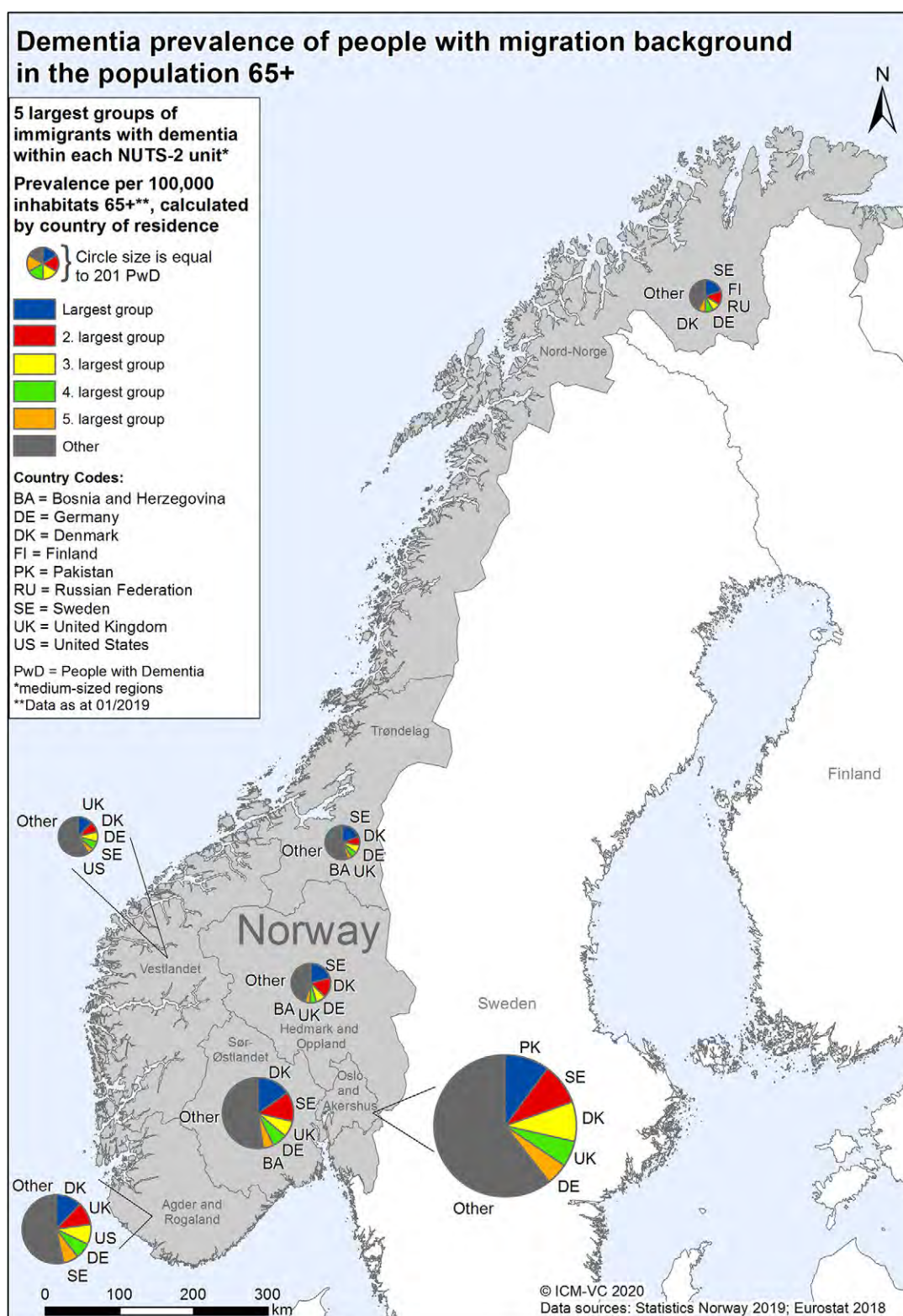


Fig. 3.7.23.10: Prevalence of PwM with dementia among the population aged 65+ (Norway – NUTS2)

**Tab. 39: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Norway – NUTS 2)**

NUTS	Total	NO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Oslo and Akershus	12,681	11,177	PK 151	SE 143	DK 135	UK 89	DE 75	911
Hedmark and Oppland	5,797	5,604	SE 40	DK 32	DE 15	UK 10	BA 8	87
Sør-Østlandet	13,356	12,558	DK 123	SE 107	UK 59	DE 53	BA 39	417
Agder and Rogaland	8,463	7,977	DK 58	UK 53	US 45	DE 36	SE 34	260
Vestlandet	11,049	10,677	UK 46	DK 33	DE 31	SE 25	US 18	220
Trøndelag	5,623	5,459	SE 32	DK 13	DE 12	UK 10	BA 7	90
Nord-Norge	6,431	6,260	SE 34	FI 23	RU 15	DE 14	DK 13	72
Prevalence/10,000 inhabitants with migration background 65+								
Oslo and Akershus	5,819	-	PK 69	SE 66	DK 62	UK 41	DE 34	418
Hedmark and Oppland	20,741	-	SE 144	DK 114	DE 55	UK 35	BA 30	312
Sør-Østlandet	11,547	-	DK 107	SE 92	UK 51	DE 46	BA 34	361
Agder and Rogaland	12,005	-	DK 83	UK 75	US 64	DE 51	SE 48	369
Vestlandet	20,491	-	UK 85	DK 61	DE 57	SE 46	US 34	407
Trøndelag	23,674	-	SE 134	DK 55	DE 51	UK 41	BA 30	379
Nord-Norge	3,210	-	SE 138	FI 94	RU 59	DE 57	DK 53	289
Prevalence/100,000 inhabitants 65+								
Oslo and Akershus	6,900	6,082	PK 82	SE 78	DK 73	UK 49	DE 41	469
Hedmark and Oppland	6,900	6,670	SE 48	DK 38	DE 18	UK 12	BA 10	104
Sør-Østlandet	6,900	6,488	DK 64	SE 55	UK 30	DE 27	BA 20	216
Agder and Rogaland	6,900	6,503	DK 47	UK 43	US 37	DE 29	SE 27	212



Vestlandet	6,900	6,668	UK 28	DK 20	DE 19	SE 16	US 12	137
Trøndelag	6,900	6,699	SE 39	DK 16	DE 15	UK 12	BA 9	110
Nord-Norge	6,900	6,716	SE 37	FI 25	RU 16	DE 15	DK 14	77

Data source: Statistics Norway (2019)

## 3. National dementia plan

For Norway three published NDPs were identified. The 'Dementia Plan 2015', the 'Dementia Plan 2020: A More Dementia-friendly Society', and the 'Dementia Plan 2025' all address the topic of migration or language/ethnic minorities. In the 'Dementia Plan 2015' from 2008 the topic of migration is briefly addressed. In one passage it is mentioned that the Directorate of Health and Social Affairs plans to carry out research projects to gain insights into the situation of persons with minority language backgrounds with dementia in the period 2006 to 2010. A short section on 'Persons with Minority Language Backgrounds Who Develop Dementia' highlights a three-year Nordic development program for this population. This program will focus on information, diagnosis, treatment, and assistance needs. The Nordic countries are expected to provide professional expertise and funding for this program. The first NDP shows that the Norwegian government is involved in initiating or planning projects on dementia in persons with a minority language background, although there is no further substantive discussion of this topic [9]. The 'Dementia Plan 2020: A More Dementia-friendly Society' from 2015 refers to migration in several sections. In dementia care, Norway has adopted a person-centred approach that considers the cultural background. Furthermore, the second Dementia Plan refers to particular needs of the Sámi people and people from linguistic minority groups and expresses the need for more knowledge about

these groups and a better awareness of cultural differences. It also discusses the need for healthcare professionals to receive training and counselling on the diagnosis of dementia in people with special needs. A fundamental problem identified is that elderly migrants with dementia often do not use healthcare services until the disease is at an advanced stage. In the absence of linguistically and culturally appropriate services, the family burden increases. Another key issue is the language barriers between professionals and patients, which endanger patient safety. To address this problem, it is recommended that care providers employ multilingual staff. Another recommendation relates to the construction or modernisation of nursing homes and assisted living facilities, where the unique needs of people from Sámi and minority language groups should be taken into account. One particular section on research, knowledge, and competence calls for healthcare and socio-educational curricula in universities and colleges to be more strongly focused on increasing knowledge about these groups. Within the chapter on measures for the planning period 2016–2020, reference is made to a published brochure on healthcare services for elderly Sámi, which aims to improve the competence of staff working with people with dementia from Sámi or minority language groups. It is stated that in the future people with dementia from different cultural groups and their families should be involved in developing a pilot project for post-diagnostic follow-up.





The 'Dementia Plan 2020: A More Dementia-friendly Society' considers people with dementia from Sámi or linguistic minority groups as a group with specific needs that have to be considered separately. It identifies some specific problems related to diagnosis and care of people from these groups and mentions some concrete measures to tackle them. However, it also reveals the current lack of awareness of cultural differences and knowledge about Sámi and language minority groups in the Norwegian healthcare system. Besides, no data on dementia prevalence within these groups are given [10].

The 'Dementia Plan 2025' from 2020 refers in detail to the topic of migration in a total of 14 sections in 7 chapters. In several chapters, there are separate sections or paragraphs on this topic. It is pointed out several times that the proportion of older people with an ethnic minority background is increasing, and consequently, so is the number of people with dementia from this population. In different parts of the document, it is emphasised how important an adaptation of information, counselling, treatment, and care services (e.g. community day activities) to the individual language and cultural background of people with dementia and their relatives is. At first, different challenges in the care of people with an ethnic minority background and specific needs of this population are described in various sections related to migration. In this context, it is repeatedly stated that language problems, cultural differences, different perceptions of dementia, and the lack of knowledge of many older people with a minority background about Norway's healthcare system, as well as the lack of diversity competence on parts of the healthcare providers, are barriers to effective healthcare. In particular, the investigation and diagnosis of dementia among ethnic minorities can be challenging due to communication problems. This NDP concludes that people from minority

backgrounds do not receive the same health-care services as other people with dementia even as the disease gets worse. According to the document, one problem could also be that many people from these groups do not seek professional help as they feel guilty or ashamed of not being able to care for their family members without help from the state.

The third Norwegian Dementia Plan also lists some actions that have already been taken by the government and care providers as well as measures that are yet to be taken by municipalities and service providers to meet the challenges of dementia care and to ensure that people with different ethnic backgrounds have access to equal services. It is stated that the government will continue to focus on information and dissemination of knowledge about the minority language population with dementia. Furthermore, it is noted that a national competence area for culture, health, and care has been created as part of the Dementia Plans 2015 and 2020. Besides, a separate box highlights the project on the assessment of cognitive abilities and dementia symptoms in people with other language and cultural needs, which started in 2019 and finished in 2020. This project has brought together a group of clinicians from Oslo University Hospital, St. Olav's University Hospital (Trondheim), and Vestfold Central Hospital (Tønsberg) to offer adapted cognitive tests to foreign-language patients. In addition to this program, reference is made to studies that have shown that communication in the patient's mother tongue is central to maintaining functional levels of cognition and that the use of high-quality interpretation services is beneficial. It is argued that people with dementia from minority backgrounds and their relatives prefer person-centred care services wherein the staff has the required language skills and cultural understanding. Furthermore, this dementia plan shows that there is an open need

for adapted (multilingual) instruments for basic dementia assessment. People with different cultural and linguistic backgrounds should be more involved in the process of adapting such instruments, and their feedback should be systematically surveyed. Besides, the national quality and research register of treated dementia patients developed for doctors as well as healthcare staff should be expanded to include English-language register sets.

Overall, the topic of migration plays an important role in the third and current Norwegian Dementia Plan. The growing group of people with an ethnic minority/migration background as well as dementia is identified as a vulnerable population with specific needs on which the government and care providers have already been focusing for some years, but which needs to be given more attention in the future, especially by municipalities and care providers. The existing problems and inequalities in care

for minorities and immigrants are described in detail, along with a significant framework for action. In the 'Dementia Plan 2025', reference is made to measures already taken and projects completed on the topic of dementia and migration, but recommendations for action for care planners and service providers are also given [11].

Compared to other European countries, the Norwegian dementia plans from 2015 and 2020 take the topic of migration or language/ethnic minorities into account in a comprehensive manner. The fact that the scope of the migration reference, the communicated scientific knowledge, and the framework of action regarding immigrants or language/ethnic minorities expands with each publication year of the dementia plans suggests that the topic of dementia and migration/minorities is being given increasing importance at the government level in Norway.

## 4. National dementia care and treatment guidelines

The 300-page 'National Professional Guidelines on Dementia' from 2017 refers in detail to the topic of migration. The chapter 'Groups That May Have Special Needs: Assessment and Follow-up in Dementia', has a separate section on 'People With Minority Backgrounds With Suspected Dementia' (1 ½ pages). The term 'People With Minority Backgrounds' includes PwM, but not all people with minority backgrounds have a migration background. The guidelines also refer to dementia among migrants and people with minority backgrounds in 9 of the 18 other chapters. Notably, a representative from the Nasjonal kompetanseenhet for migrasjoner – og minoritetshelse (=Norwegian Centre of Competence for Migration and Minority Health) (NAKMI) was in the task force that developed the guidelines. In 2015, the Norwegian Ministry of Health commissioned the NAKMI to research the care

situation of people with minority backgrounds and dementia. The thematically relevant sections of the document first describe the general challenges in caring for people with minority backgrounds and dementia. The focus is on the challenges associated with diagnosis. It is identified that people from minority groups are examined at a later stage of dementia. Their cultural and linguistic background may make the diagnosis difficult. Moreover, existing cognitive testing procedures are not suitable as assessment tools for migrants. Another phenomenon is the lower utilisation of formal healthcare services (primary healthcare services, prescription of medication, inpatient stays in nursing homes) by people with minority backgrounds and dementia. After the general problem description, the focus is on the identification of specific care barriers and needs. It is discussed that people who are not



familiar with the Norwegian healthcare system may need additional guidance and care. In addition, stereotyping of people with minority backgrounds can be a barrier to personalised care. Another topic discussed is the different perceptions of dementia symptoms within this group (e.g. the perception that dementia is simply a result of slight confusion, normal aging, psychological stress, family problems or migration experiences, spiritual factors (God's will), or fate). The Norwegian guidelines repeatedly identify people with minority backgrounds as a group with specific needs. They explain that people from other cultures have different ideals, ideas, and wishes regarding information and self-determination.

In addition, the guidelines give some specific recommendations for action, which are declared as strong recommendations. One recommendation addresses the medical service, which should examine whether the educational level, language, or cultural background of persons with minority backgrounds and suspected dementia represent a barrier to treatment. Besides, care providers are recommended to document a person's resources and vulnerability in terms of culture and spirituality in an individual action plan. The analysis of the recommendations, measures, and care services show that Norway is generally trying to provide integrative care for people with minority backgrounds. The aim is to integrate them into the general primary healthcare system. However, in areas where care barriers are significant, specialised services are also being developed. One area in which Norway seems to have chosen a segregative model is dementia diagnosis. As the standardised screening tests used by the majority population (e.g. MMSE) are very language and culture-specific,

the utilisation of the intercultural screening tool RUDAS is recommended for people without higher education and with other cultural and linguistic backgrounds. In general, standardised versions in the mother tongue should be used for oral tests. For people with minority backgrounds, a comprehensive assessment by the medical service is also recommended (including neuropsychological examination). This is especially important if language, educational level, or culture are a barrier to assessment. In the case of language barriers, an interpreter should be consulted. For extended cognitive assessment, there are currently no standardised tests suitable for people with minority backgrounds. Post-diagnostic care should be provided as part of general primary care. Further, efforts are underway to ensure effective healthcare to people with minority backgrounds through policy making, e.g., by enshrining in law the right to native language information on health/care and the right to have access to an interpreter. Furthermore, specialised services such as a brochure on healthcare interpreters, the information material on dementia in four languages (Norwegian, English, Polish, and Urdu), and the Norwegian version of RUDAS are provided.

Overall, the topic of migration or minority groups features prominently in the 'National Professional Guidelines on Dementia' [12].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and a discussion round and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert who was interviewed first, dementia and migration is relatively unimportant in Norway as a whole. Currently, there are not many older immigrants in Norway. However, the proportion of the population with an immigration background varies significantly between different regions and municipalities. In Oslo, for example, the issue is much more relevant than in other parts of the country. The second expert stated that the migrant population is very heterogeneous. Within this population, there are large differences in the regions of origin, the time of immigration, the reason or purpose of migration, and the individual's educational level. These differences affect the level of inclusion in the healthcare system. In Norway, the topic of dementia and migration was first addressed in a project in 2012. The background to the project, in which the two experts were involved, was the growing awareness among doctors and other healthcare professionals about the incidence of dementia in older migrants in Norway and their specific needs. However, the number of such projects is relatively low. According to the first expert, the existing developmental centres for nursing homes and home care services as well as the care research centres do not have a particular focus on this topic. It is through the individual projects carried out that Norway has research-based knowledge about underdiagnosis problems and lower utilisation of formal healthcare services by PwM. According to the first expert interviewed, Norway uses an integrated care model in which PwM have the same rights as the autochthonous population. In outpatient and inpatient care, formal services are generally available nationwide to PwM with dementia. However, PwM often have less access to care due to a lack of knowledge about the healthcare system and a lack of cultural and linguistic adaptation

of services. According to a third expert interviewed, the central structural problem is that people from the migrant groups, unlike individual minority groups originating from Norway, do not have a legal right to culturally sensitive mother-tongue information and care services. Currently, few services in Norway are tailored to the specific needs of PwM with dementia. The first expert cited the Memory Clinic at Oslo University as a model of good practice, which has special expertise in assessing dementia in patients with a migration background. According to the second expert, a few general practitioners and nursing homes in Norway have many employees with a migration background and try to adapt their services to the needs of PwM with dementia within the legal limits. As an example of a specialised inpatient care service, the first expert also mentioned the Jewish nursing home and the nursing home for people from Denmark in Oslo.

However, these are all private initiatives and not state initiatives. It seems that a national strategy is missing, and that current specialised care services for migrants with dementia are far from adequate in terms of meeting their needs. According to the experts, the existing specialised services are not sufficiently adapted to the individual, cultural, and linguistic needs of PwM with dementia. PwM are not provided the tailored information they need about various aspects of living with dementia and they are not invited to participate in the development of services meant for them. Considering that the society in Norway has a heterogeneous migrant community, according to experts, Norway needs to continue working on ensuring diverse, culturally sensitive healthcare services for migrants in the long term. This is especially important as the number of aged PwM will continue to grow in the coming years.



## 6. Professional qualification and people with a migration background in healthcare

The first expert pointed out that culturally sensitive care is partly included in the healthcare professional's qualifications. Professionals who were educated many years ago probably had less contact with this topic during their education. However, a change is currently in process. The topic of culturally sensitive care is becoming more and more part of the curriculum for nurses and doctors, and there is an increasing number of presentations on this topic at universities or in the context of nursing education. However, the modules are not compulsory, and the topic is rarely part of the examinations. Thus, one of the most crucial tasks in education for the future is to include migration and diversity in the curricula as a mainstream and transversal issue that permeates the different health topics taught within the curricula. The second expert stated that the need for action on dementia and migration is still much more significant in the training of healthcare professionals than in the area of care. According to the third expert, the main problem is that the education system for professionals is not being changed in line with the social change towards more diversity. Concerning the training of healthcare professionals, the first expert reported that there is now a nationwide availability of intercultural care courses. The Oslo Metropolitan University, for example, offers a training program on multicultural healthcare, and other universities such as Bergen University have similar programs. In nursing homes and care services, the 'Dementia ABC Educational Program' for unskilled workers is available, including a module on older immigrants and dementia.

In 2017, 17% (24,700) of regular employees

in municipal care services were immigrants. In 2009 the proportion was 11% (13,700) [13]. According to the first expert, the reason for this increase is the Norwegian policy to qualify immigrants for working in care services. However, there are large regional differences in the proportion of immigrants in the care sector. In Oslo, the proportion of employees with a migrant background is 44%, whereas, in Nord-Trøndelag (Central Norway), it is 8%. The leading country of origin of immigrants is by far the Philippines. Other frequent countries of origin are Poland, Eritrea, Somalia, Sweden, and Thailand. The staff in the municipal care services originate from a total of 160 different countries [13]. The second expert stated that PwM are also well represented among general practitioners (one of five) and specialists in Norway. According to the experts, this high cultural and linguistic diversity in the care sector offers a high potential, which, is currently not strategically used. The first expert noted that many people in Norway see the high proportion of migrants in care services as a challenge rather than a resource in terms of adapting services to people with a different linguistic or cultural background. For example, current projects focus more on overcoming communication barriers. According to the expert, there is no systematic work or project on how to use these staff's resources.

Despite this positive trend in the area of training for employees in the healthcare sector, the need for culturally sensitive care in Norway, in general, is currently not met by sufficiently qualified professionals as stated by the experts. Especially in the area of healthcare education, there is a great need for action.

## 7. Support for family caregivers

According to the first expert, family networks, migrant organisations, religious communities, and voluntary organisations are very important in supporting family caregivers of PwM with dementia. Providers of outpatient or inpatient care currently play a rather subordinate role. For the third expert, the foreigners clubs are especially important for PwM with dementia and their family caregivers due to the presence of people they can trust and talk to in their mother tongue. This is particularly important for the transfer of knowledge on the topic of dementia and care.

The first expert pointed out that there are currently significant differences between PwM and non-migrants in terms of the accessibility of information and utilisation of services. For the general population, there is plenty of information available about dementia. However, PwM do not use the same media channels as non-migrants, and they are less familiar with the Norwegian healthcare system, which results in higher barriers to information. A survey of family caregivers showed a high demand for tailored information

in the respective mother-tongues for PwM.

According to the first expert, training courses are available nationwide for caregivers of people with dementia. As no relatives with a migration background have attended these training courses, a project was initiated to develop tailored courses for people from Pakistan and Turkey and offer them in different cities. In addition, an e-learning course was developed in which other municipalities were given recommendations on how to set up a course for relatives with a migration background. The medical staff, as well as minority organisations, migrant organisations, and key persons from the respective communities, were involved in the development of these courses.

In Norway, according to the experts, there is currently still a great lack of tailored information and accessible support services offered by outpatient and inpatient care providers. However, there are first models of good practice in the training of family caregivers from some migrant groups.

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# Poland

**Population**

37,958,000

**Area**

309,158 km<sup>2</sup>

**Capital**

Warsaw

**3 largest cities**

Warsaw (1,791,000)

Krakow (779,000)

Lodz (680,000)

**Neighboring countries**

Belarus, the Czech

Republic, Germany,

Lithuania, the Russian

Federation (Oblast

Kaliningrad), Slovakia,

Ukraine

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Report on the situation of people with Alzheimer's disease
6. References

## 1. Migration history

The history of Poland's migration is characterised by emigration [1]. During the second half of the 18th century and throughout the 19th century, mainly political refugees left the country. Economic emigration began at the end of the 19th century. From 1871 to 1913, almost 3.5 million people emigrated (mainly to the US). During the two world wars, 2.1 million people left the country, most of them to France, Belgium, Germany, and America. Between 1944 and 1949, almost 1.5 million people returned [2]. After the Second World War, between six and eight million people left Poland, most of them emigrating to Germany [2, 3]. In the 1980s, 1.1 to 1.3 million citizens from Poland (partly as a result of the suppression of the Solidarność movement) and hundreds of thousands of German repatriates left the country, many of them to West Germany [1, 2]. After the collapse of communism in 1989, transit migration and immigration from neighbouring eastern countries (Ukraine, Belarus, the Russian Federation) increased. As a result of EU accession on 1 May 2004, emigration to other EU states, especially to United Kingdom and Ireland, has risen [1, 3]. Since the 1980s,

Poland's migration history has been strongly influenced by circular migration (people from Poland working in Germany and citizens of the former Soviet Union working in Poland). Poland has an ethnically relatively homogeneous society. As a result of the Holocaust and forced resettlement after the Second World War, the population of minorities has become considerably smaller (1931: one third, 2008: 2 to 3% of the population) [1]. In 2013, people from Ukraine were the largest migrant group (221,300), followed by Germany (81,800), Belarus (81,400), Lithuania (54,100), and the Russian Federation (40,900) [4]. For more than a century, Poland has been one of the largest sending countries of migrants in Central and Eastern Europe and serves many Western European and North American countries as a reservoir of labour (since EU accession in 2004, labour emigration is mainly to other EU member states) [3]. Between 1990 and 2019, the migrant population (born abroad) and its share in the total population has almost halved (1.1 million to 656,000; 3 to 1.7%) [5]. The net migration rate has always been negative in recent decades and as of 2020 it is -0.8 [6].



## 2. Estimated number of people with a migration background with dementia

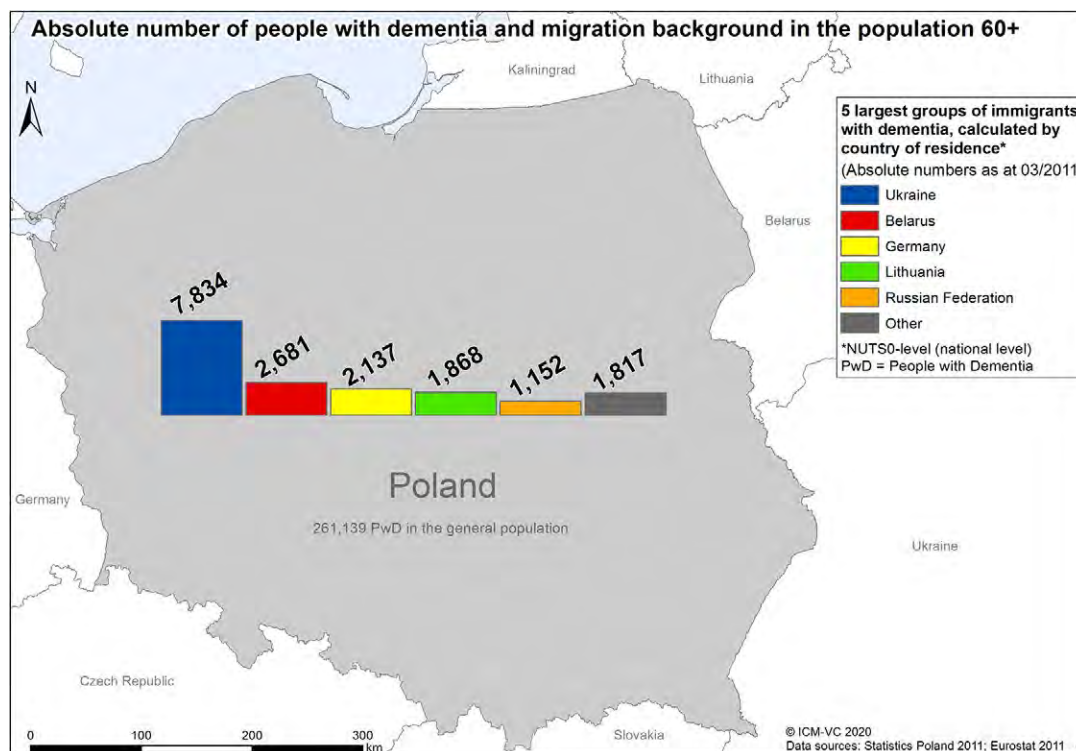


Fig. 3.7.24.1: Absolute number of PwM with dementia aged 60+ (Poland – Nation)

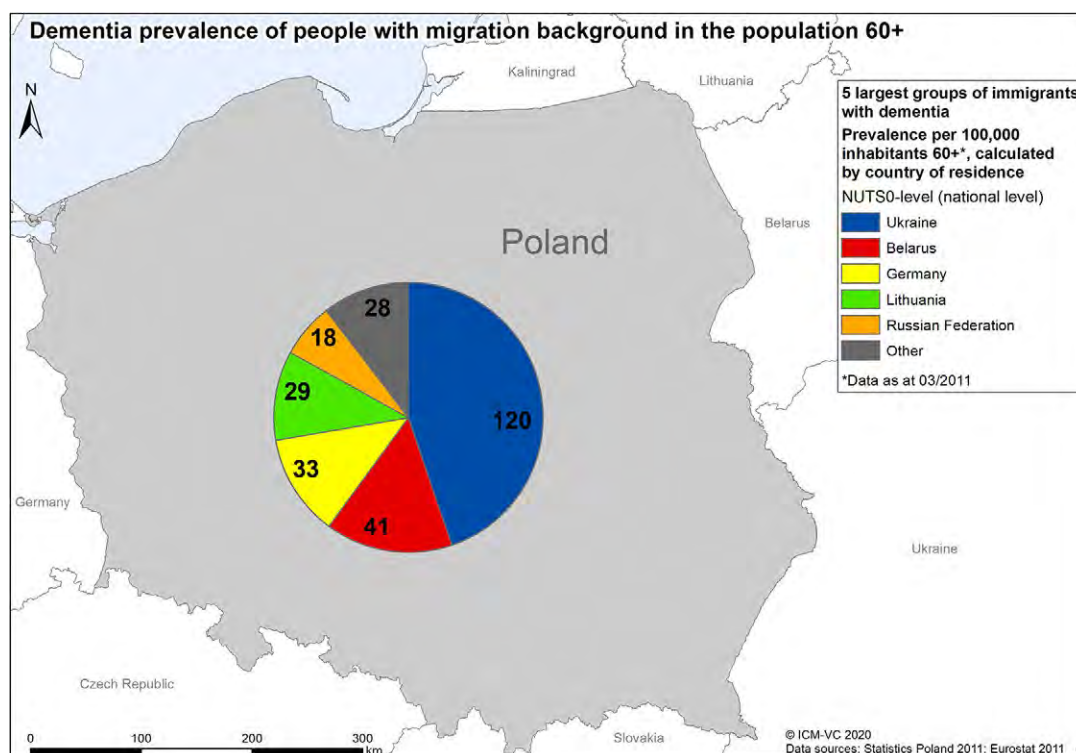


Fig. 3.7.24.2: Prevalence of PwM with dementia among the population aged 60+ (Poland – Nation)

**Tab. 40: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Poland – Nation)**

NUTS	Total	PL	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Poland	261,139	243,649	UA 7,834	BY 2,681	DE 2,137	LT 1,868	RU 1,152	1,817
Prevalence/10,000 inhabitants with migration background 60+								
Poland	5,972	-	UA 179	BY 61	DE 49	LT 43	RU 26	42
Prevalence/100,000 inhabitants 60+								
Poland	4,000	3,732	UA 120	BY 41	DE 33	LT 29	RU 18	28

Data source: Statistics Poland (2011)

There are 437,200 PwM aged 60 or older. Of those, approx. 17,300 are estimated to exhibit some form of dementia. Figure 3.7.24.1 shows that the most affected migrant groups presumably originate from Ukraine (approx. 7,800), Belarus (approx. 2,700), Germany (approx. 2,100), Italy (approx. 1,900), and the Russian Federation (approx. 1,200). The second graph highlights the number of PwM with de-

mentia in Poland per 100,000 inhabitants aged 60 or older (figure 3.7.24.2). Table 40 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Ukraine, Belarus, Germany, Italy, and the Russian Federation throughout the country in the NUTS2 regions (figures 3.7.24.3 – 3.7.24.8).

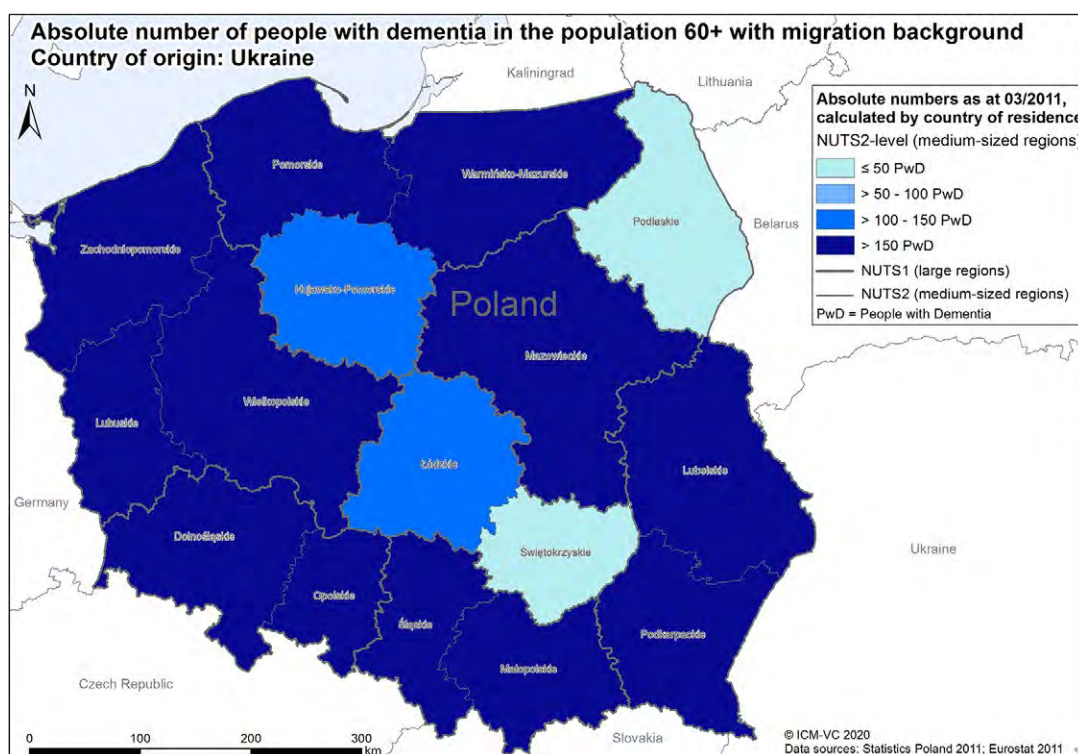


Fig. 3.7.24.3: Absolute number of PwM with dementia aged 60+.  
Country of origin: Ukraine (Poland – NUTS2)

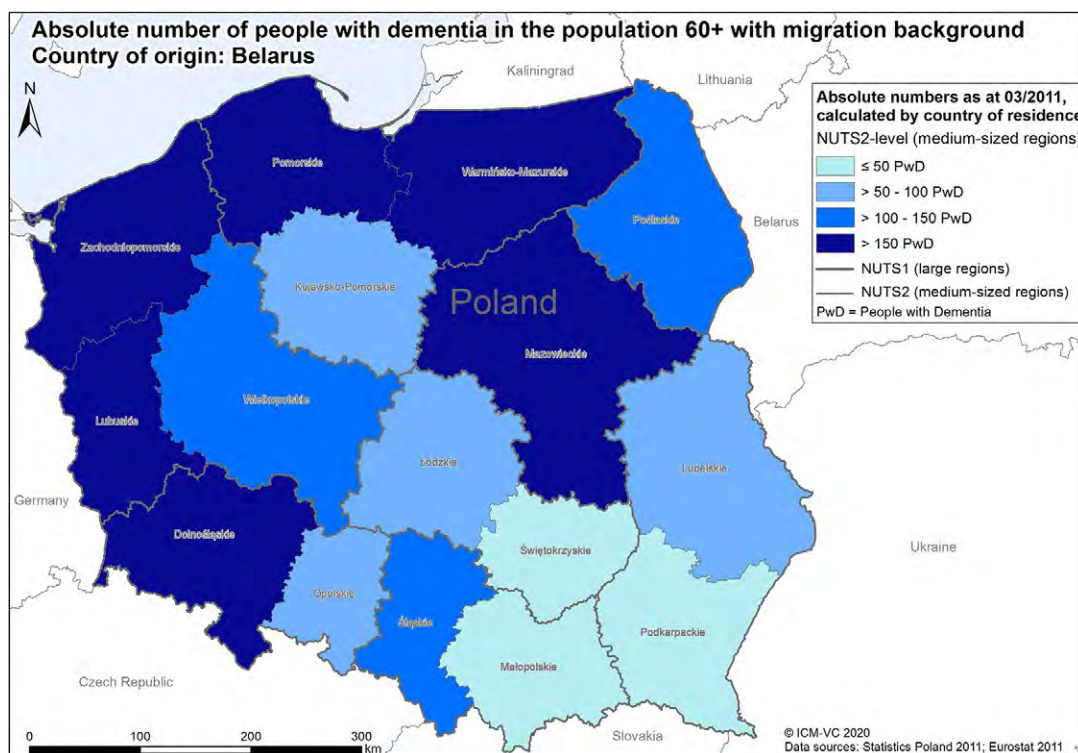


Fig. 3.7.24.4: Absolute number of PwM with dementia aged 60+.  
Country of origin: Belarus (Poland – NUTS2)



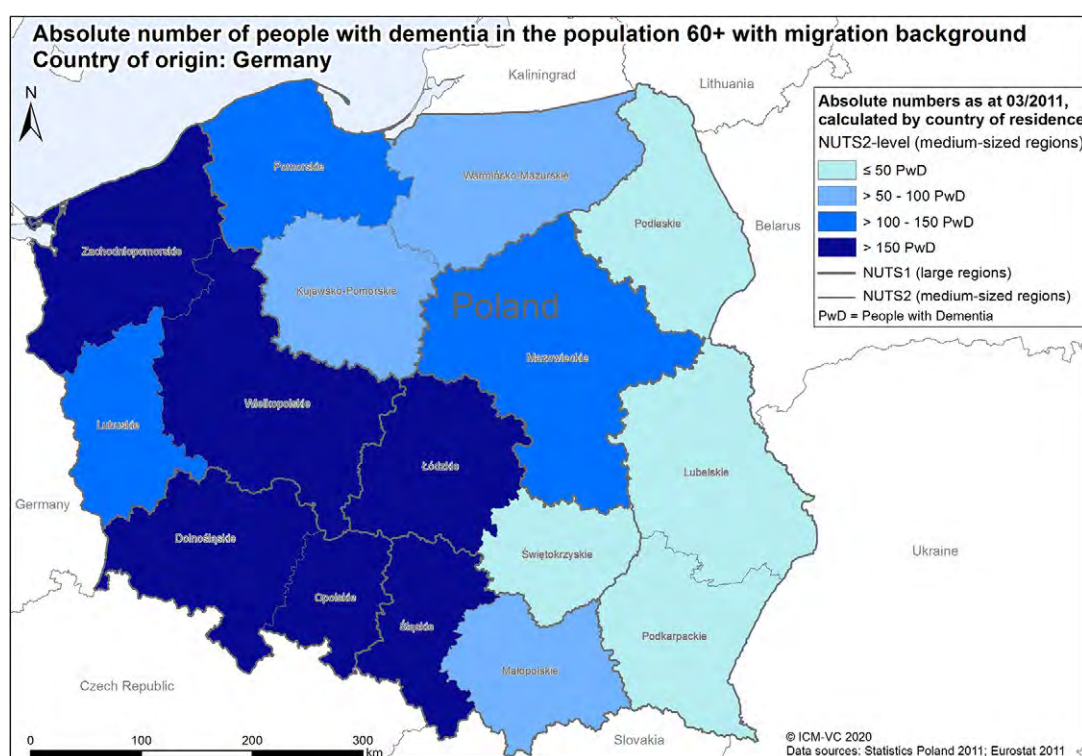


Fig. 3.7.24.5: Absolute number of PwM with dementia aged 60+.  
Country of origin: Germany (Poland – NUTS2)

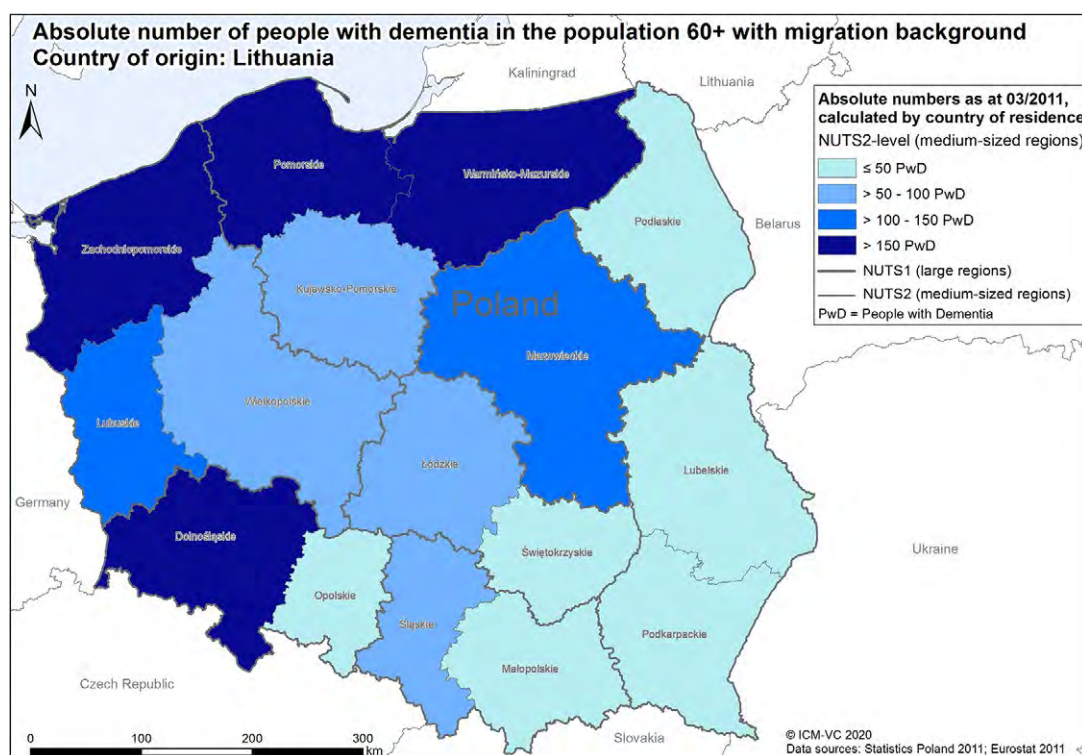


Fig. 3.7.24.6: Absolute number of PwM with dementia aged 60+.  
Country of origin: Lithuania (Poland – NUTS2)

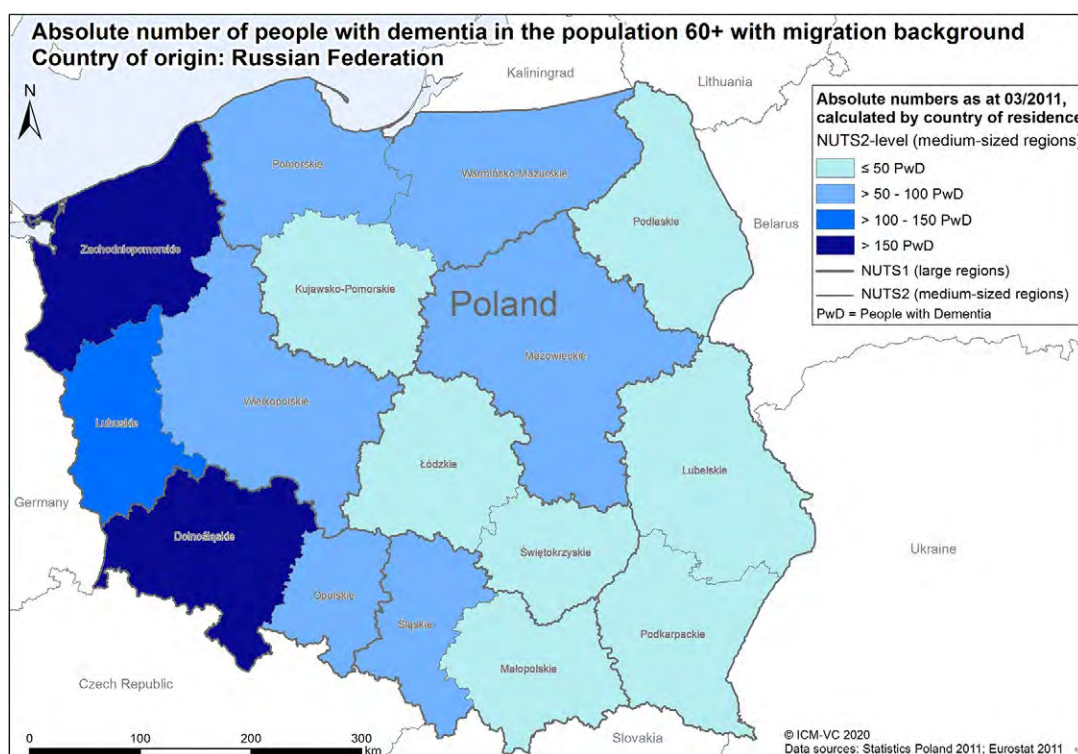


Fig. 3.7.24.7: Absolute number of PwM with dementia aged 60+.  
Country of origin: The Russian Federation (Poland – NUTS2)

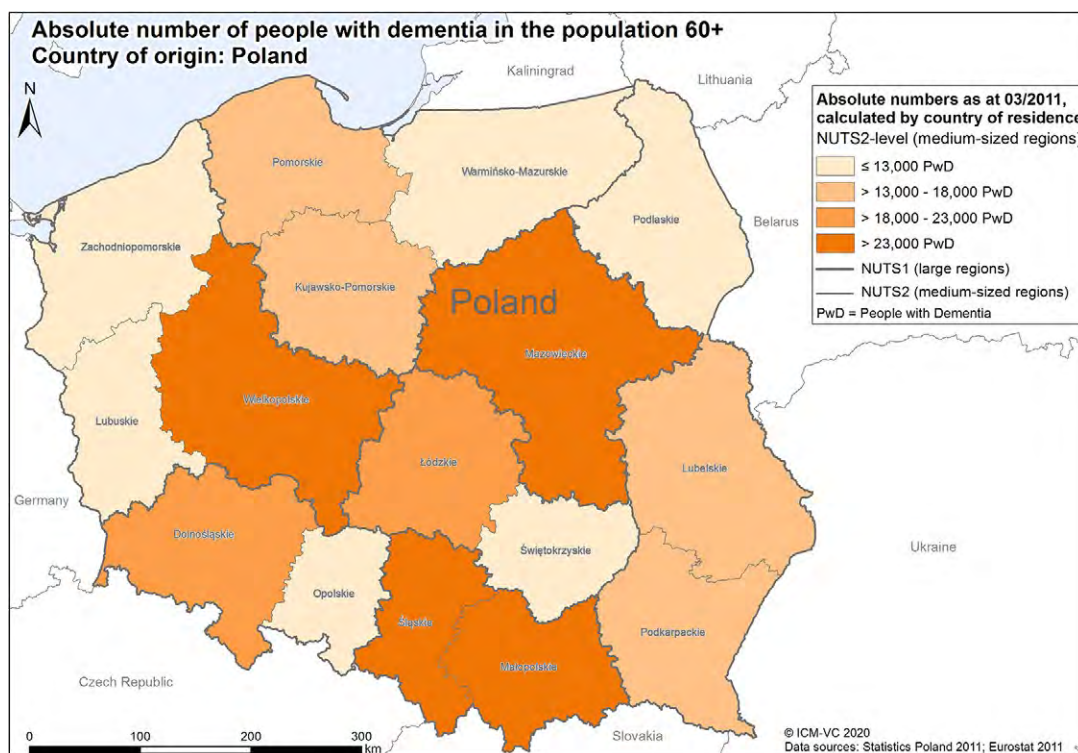


Fig. 3.7.24.8: Absolute number of people with dementia aged 60+.  
Country of origin: Poland (Poland – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.24.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 60 or older in the NUTS2 regions (Fig. 3.7.24.10). The values from the NUTS2 level can be found in Table 41 [7, 8].

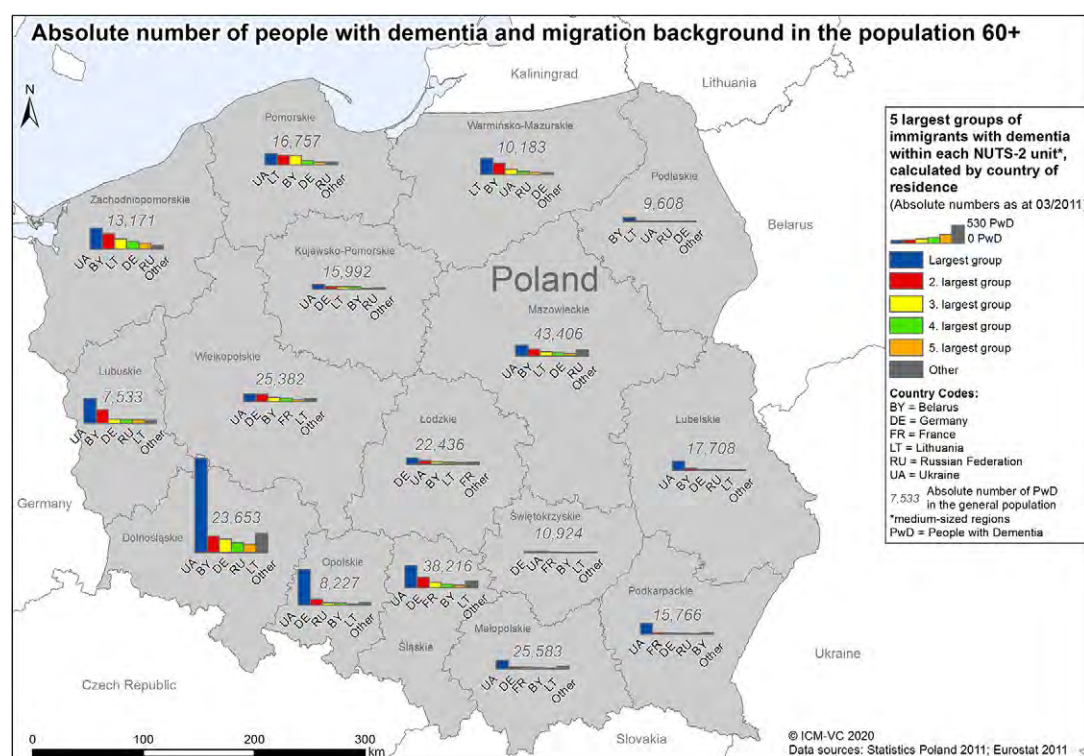


Fig. 3.7.24.9: Absolute number of PwM with dementia aged 60+ (Poland – NUTS2)



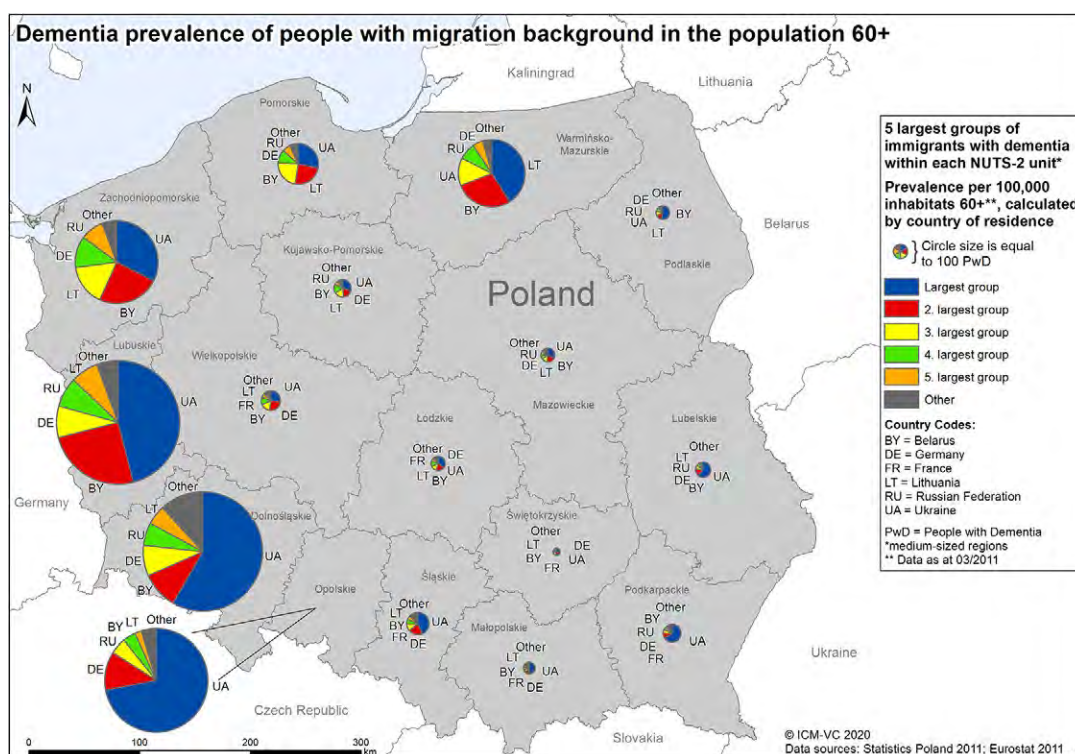


Fig. 3.7.24.10: Prevalence of PwM dementia among the population aged 60+ (Poland – NUTS2)

Tab. 41: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Poland – NUTS 2)

NUTS	Total	PL	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Łódzkie	22,436	21,873	DE 195	UA 110	BY 74	LT 67	FR 50	68
Mazowieckie	43,406	42,380	UA 322	BY 205	LT 135	DE 106	RU 81	177
Małopolskie	25,583	25,071	UA 258	DE 55	FR 44	BY 38	LT 32	85
Śląskie	38,216	36,692	UA 662	DE 312	FR 159	BY 105	LT 83	203
Lubelskie	17,708	17,237	UA 287	BY 68	DE 42	RU 32	LT 18	24
Podkarpackie	15,766	15,282	UA 319	FR 44	DE 35	RU 25	BY 14	46
Świętokrzyskie	10,924	10,791	DE 42	UA 33	FR 17	BY 13	LT 8	20
Podlaskie	9,608	9,378	BY 124	LT 31	UA 23	RU 22	DE 10	20

Wielkopolskie	25,382	24,530	UA 227	DE 221	BY 136	FR 106	LT 62	100
Zachodniopomorskie	13,171	11,262	UA 621	BY 462	LT 308	DE 233	RU 172	113
Lubuskie	7,533	5,905	UA 750	BY 408	DE 134	RU 125	LT 119	92
Dolnośląskie	23,653	18,778	UA 2,846	BY 492	DE 402	RU 304	LT 255	577
Opolskie	8,227	6,748	UA 1,065	DE 179	RU 77	BY 58	LT 31	69
Kujawsko-Pomorskie	15,992	15,515	UA 144	DE 90	LT 81	BY 81	RU 32	50
Warmińsko-Mazurskie	10,183	9,014	LT 479	BY 329	UA 157	RU 94	DE 60	51
Pomorskie	16,757	15,572	UA 334	LT 285	BY 279	DE 128	RU 80	79
Prevalence/10,000 inhabitants with migration background 60+								
Łódzkie	16,108	-	DE 140	UA 79	BY 53	LT 48	FR 36	49
Mazowieckie	17,370	-	UA 129	BY 82	LT 54	DE 42	RU 32	70
Małopolskie	20,355	-	UA 205	DE 44	FR 35	BY 30	LT 25	67
Śląskie	10,118	-	UA 175	DE 83	FR 42	BY 28	LT 22	53
Lubelskie	15,130	-	UA 245	BY 58	DE 36	RU 28	LT 16	20
Podkarpackie	13,211	-	UA 268	FR 37	DE 30	RU 21	BY 12	39
Świętokrzyskie	33,642	-	DE 128	UA 102	FR 52	BY 39	LT 25	61
Podlaskie	17,018	-	BY 219	LT 55	UA 40	RU 40	DE 17	36
Wielkopolskie	12,032	-	UA 108	DE 105	BY 64	FR 50	LT 29	47
Zachodniopomorskie	2,783	-	UA 131	BY 98	LT 65	DE 49	RU 36	24
Lubuskie	1,861	-	UA 185	BY 101	DE 33	RU 31	LT 29	22
Dolnośląskie	1,952	-	UA 235	BY 41	DE 33	RU 25	LT 21	47
Opolskie	2,240	-	UA 290	DE 49	RU 21	BY 16	LT 8	18
Kujawsko-Pomorskie	13,562	-	UA 122	DE 76	LT 68	BY 68	RU 27	43

Warmińsko-Mazurskie	3,524	-	LT 166	BY 114	UA 54	RU 32	DE 21	17
Pomorskie	5,721	-	UA 114	LT 97	BY 95	DE 44	RU 27	27
Prevalence/100,000 inhabitants 60+								
Łódzkie	4,000	3,900	DE 35	UA 20	BY 13	LT 12	FR 9	12
Mazowieckie	4,000	3,905	UA 30	BY 19	LT 12	DE 10	RU 7	16
Małopolskie	4,000	3,920	UA 40	DE 9	FR 7	BY 6	LT 5	13
Śląskie	4,000	3,841	UA 69	DE 33	FR 17	BY 11	LT 9	21
Lubelskie	4,000	3,894	UA 65	BY 15	DE 9	RU 7	LT 4	5
Podkarpackie	4,000	3,877	UA 81	FR 11	DE 9	RU 6	BY 4	12
Świętokrzyskie	4,000	3,952	DE 15	UA 12	FR 6	BY 5	LT 3	7
Podlaskie	4,000	3,904	BY 52	LT 13	UA 10	RU 9	DE 4	8
Wielkopolskie	4,000	3,866	UA 36	DE 35	BY 21	FR 17	LT 10	16
Zachodniopomorskie	4,000	3,420	UA 188	BY 140	LT 93	DE 71	RU 52	34
Lubuskie	4,000	3,136	UA 398	BY 217	DE 71	RU 66	LT 63	49
Dolnośląskie	4,000	3,175	UA 481	BY 83	DE 68	RU 51	LT 43	98
Opolskie	4,000	3,281	UA 518	DE 87	RU 37	BY 28	LT 15	34
Kujawsko-Pomorskie	4,000	3,881	UA 36	DE 22	LT 20	BY 20	RU 8	13
Warmińsko-Mazurskie	4,000	3,541	LT 188	BY 129	UA 62	RU 37	DE 23	20
Pomorskie	4,000	3,717	UA 80	LT 68	BY 67	DE 31	RU 19	19

Data source: Statistics Poland (2011)

### 3. National dementia plan

Poland does not have an NDP [9]. On request, the Polish Ministry of Health stated that they

intended to draw up a dementia plan by 2025 [10].

### 4. National dementia care and treatment guidelines

Currently, no publicly available and valid national guidelines on dementia care could be

identified for Poland [11].

### 5. Report on the situation of people with Alzheimer's disease

As no online accessible NDPs or care guidelines could be found at the time of the search, the 80-page report 'The Situation of People With Alzheimer's Disease in Poland' from 2016 that was identified in this search was screened for migration references. The individual chapters of this report contained sections titled: 'Can Poland Be a Dementia-Friendly Country?'; 'Aging of Society - Data, Demographic Prognoses, and Recommendations'; 'Epidemiology of

Alzheimer's Disease'; 'Disease Pattern'; 'Methods of Diagnosing Alzheimer's Disease and Other Dementias'; 'Organization of Care for Alzheimer's Patients in Poland'; 'Home Care'; 'Treatment Options for Alzheimer's Disease and Other Dementias'; and 'Role of Organisations Reuniting Families of Patients' did not give any indication of the situation of PWM with dementia in Poland [12].

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# Portugal

**Population**

10,296,000

**Area**

90,996 km<sup>2</sup>

**Capital**

Lisbon

**3 largest cities**

Lisbon (553,000)

Porto (238,000)

Vila Nova de Gaia  
(187,000)

**Neighboring countries**

Spain

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References

## 1. Migration history

Three major emigration periods occurred in Portugal. The first lasted the whole 19th century and continued into the 1960s. More than two million people left the country, mainly to Brazil, and the US [1-3]. During the second cycle between the 1950s and 1974, the same number of people emigrated, mainly to France and Germany. The third cycle started in 1985 and continues to the current day. With the EU accession in 1986, emigration was even more concentrated towards other European countries (especially Germany, Luxembourg, and Switzerland) [1, 2]. Since the 1970s, immigration to Portugal has also become more important. This was caused by the decolonisation processes in the PALOP states. PALOP stands for países africanos de língua oficial portuguesa and is an informal acronym that designates African countries in which Portuguese is the official language. In the mid-1970s more than half a million people came to Portugal from Cape Verde, Angola, Guinea-Bissau, and Mozambique. Between the mid-1980s and late 1990s, rising labour demand and EU accession led to the emergence of a new migration cycle. The main regions of origin of foreigners with legal residence in Portugal during and after this period (1981, 1991, 2001) were Africa, America (especially Brazil), and Western Europe. Since the end of the 1990s, immigration from Eastern Europe, especially Ukraine, the Russian Federation, Moldova, and Romania, has also increased. Portugal has

been a country of emigration for centuries, but in recent decades it has also developed into a country with increasing immigration. In this context, the close links to the Portuguese diaspora and the former colonies play an important role. Central characteristics of recent migration history are temporary emigration to other EU member states [3], seasonal immigration for agriculture or tourism, temporary immigration in the form of rising student migration, and long-term immigration due to labour migration and family reunification [1]. In 2013, Angola (161,400), Brazil (138,700), France (93,800), Mozambique (72,500), and Cape Verde (61,500) were the countries of origin of the largest migrant groups [4]. At present, Brazil, Cape Verde, Romania, and Ukraine are the most common countries of origin [5]. A specific ethnicity within the migrant population, which represents a relevant community in Portugal and is particularly affected by problems of disintegration, social exclusion, and discrimination, is the gypsy community [6]. Compared to 2017, the number of foreign residents increased by 13.9% in 2018. The largest increases occurred in the populations of people from European countries, Brazil, Angola, China, and Guinea Bissau [5]. Between 1990 and 2019, the population of the migrant population and its proportion in the total population roughly doubled (435,800 to 888,200; 4.4 to 8.7%) [7]. As of 2020, the net migration rate is -0.6 [8].



## 2. Estimated number of people with a migration background with dementia

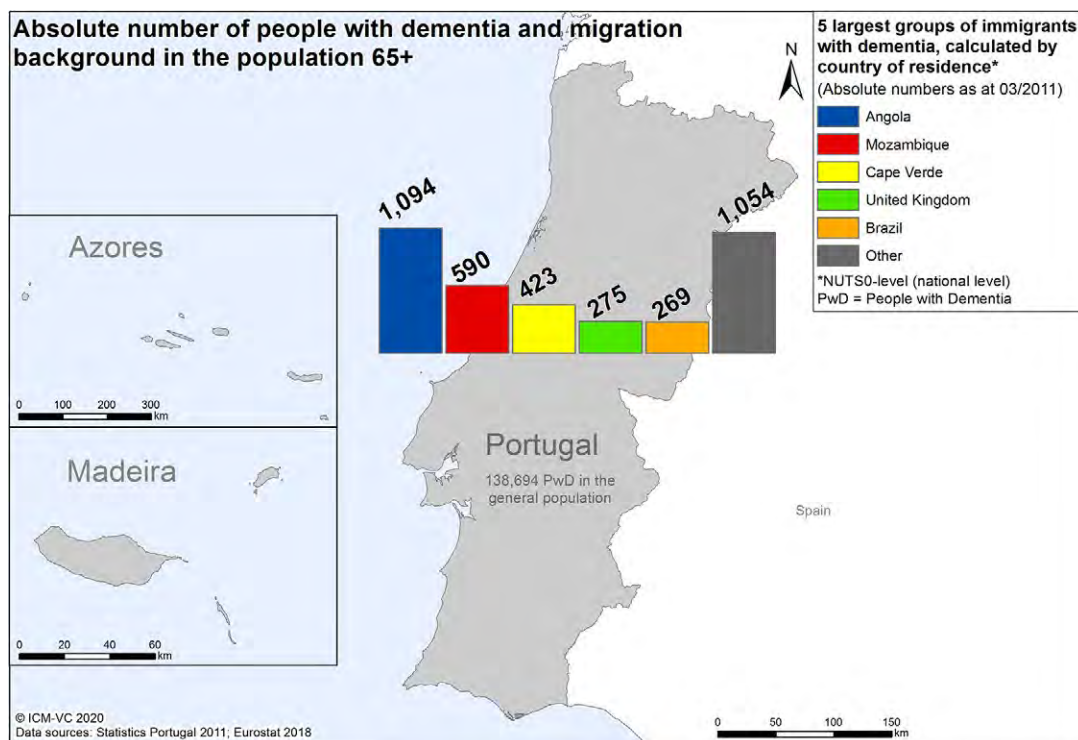


Fig. 3.7.25.1: Absolute number of PwM with dementia aged 65+ (Portugal – Nation)

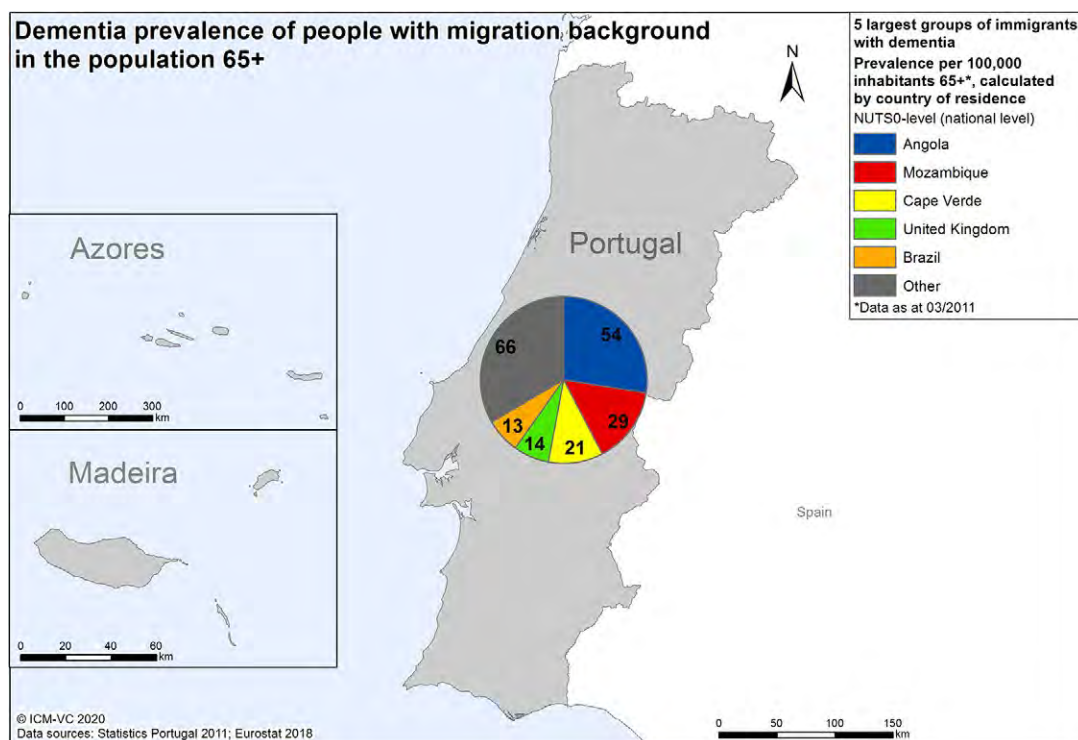


Fig. 3.7.25.2: Prevalence of PwM with dementia among the population aged 65+ (Portugal – Nation)

**Tab. 42: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Portugal – Nation)**

NUTS	Total	PT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Portugal	138,694	134,720	AO 1,094	MZ 590	CV 423	UK 275	BR 269	1,054
Prevalence/10,000 inhabitants with migration background 65+								
Portugal	24,076	-	AO 190	MZ 102	CV 73	UK 48	BR 47	230
Prevalence/100,000 inhabitants 65+								
Portugal	6,900	6,702	AO 54	MZ 29	CV 21	UK 14	BR 13	66

Data source: Statistics Portugal (2011)

There are 57,600 PwM aged 65 or older. Of those, approx. 4,000 are estimated to exhibit some form of dementia. Figure 3.7.25.1 shows the most affected migrant groups presumably originate from Angola (approx. 1,100), Mozambique (approx. 600), Cape Verde (approx. 400), United Kingdom (approx. 300), and Brazil (approx. 300). The second highlights shows the number of PwM with dementia in Portu-

gal per 100,000 inhabitants aged 65 or older (figure 3.7.25.2). Table 42 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Angola, Mozambique, Cape Verde, United Kingdom, and Brazil throughout the country in the NUTS2 regions (figures 3.7.25.3 – 3.7.25.8).

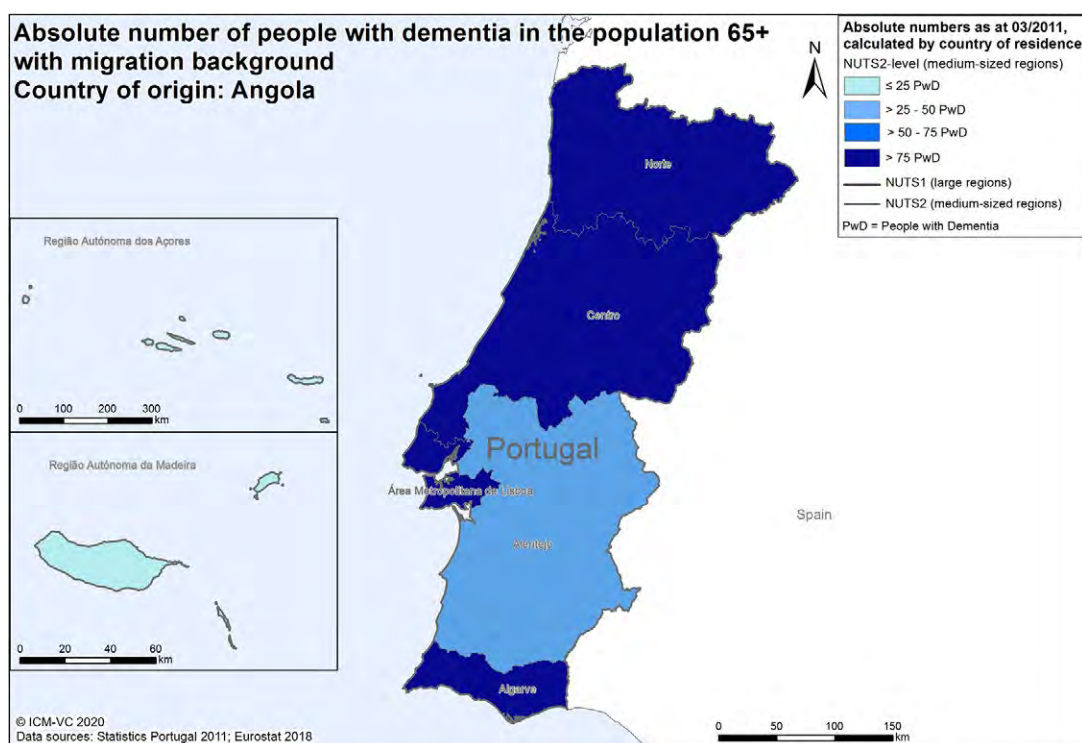


Fig. 3.7.25.3: Absolute number of PwM with dementia aged 65+. Country of origin: Angola (Portugal – NUTS2)

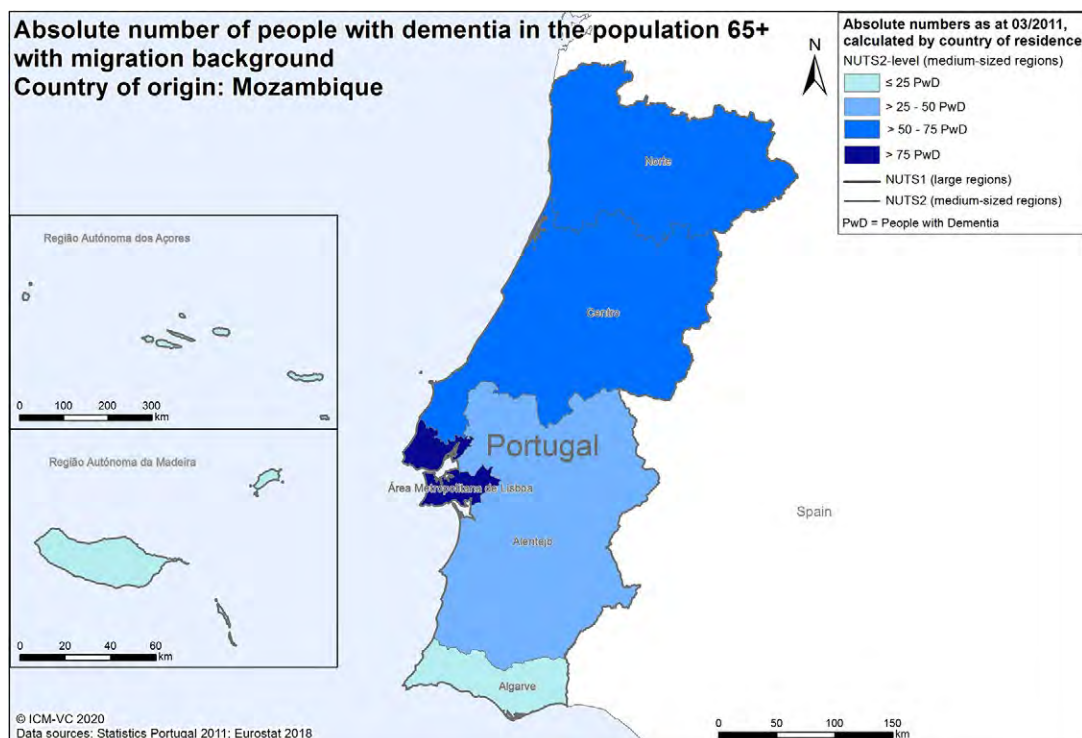


Fig. 3.7.25.4: Absolute number of PwM with dementia aged 65+. Country of origin: Mozambique (Portugal – NUTS2)

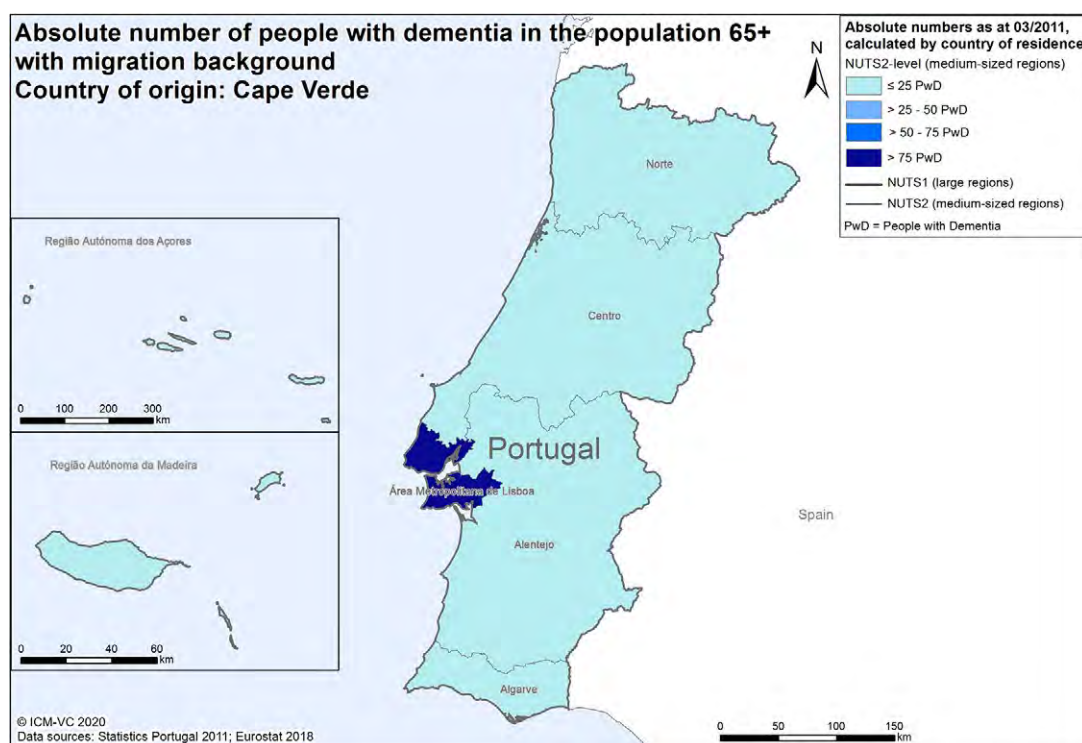


Fig. 3.7.25.5: Absolute number of PwM with dementia aged 65+. Country of origin: Cape Verde (Portugal – NUTS2)

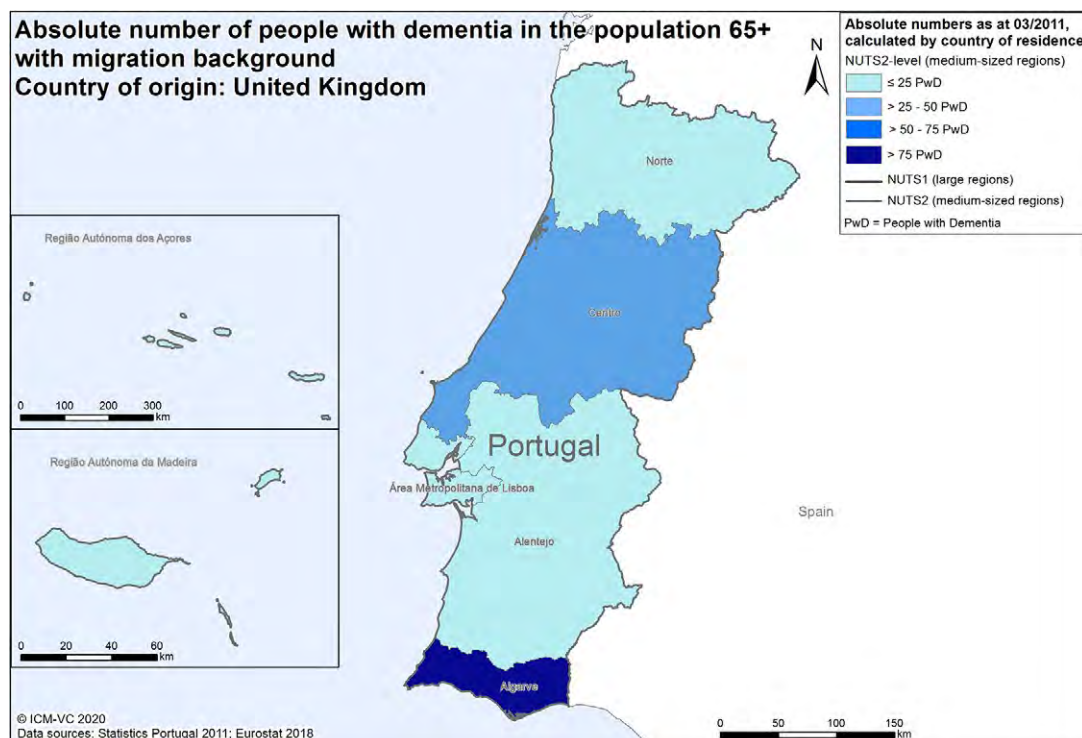


Fig. 3.7.25.6: Absolute number of PwM with dementia aged 65+. Country of origin: United Kingdom (Portugal – NUTS2)



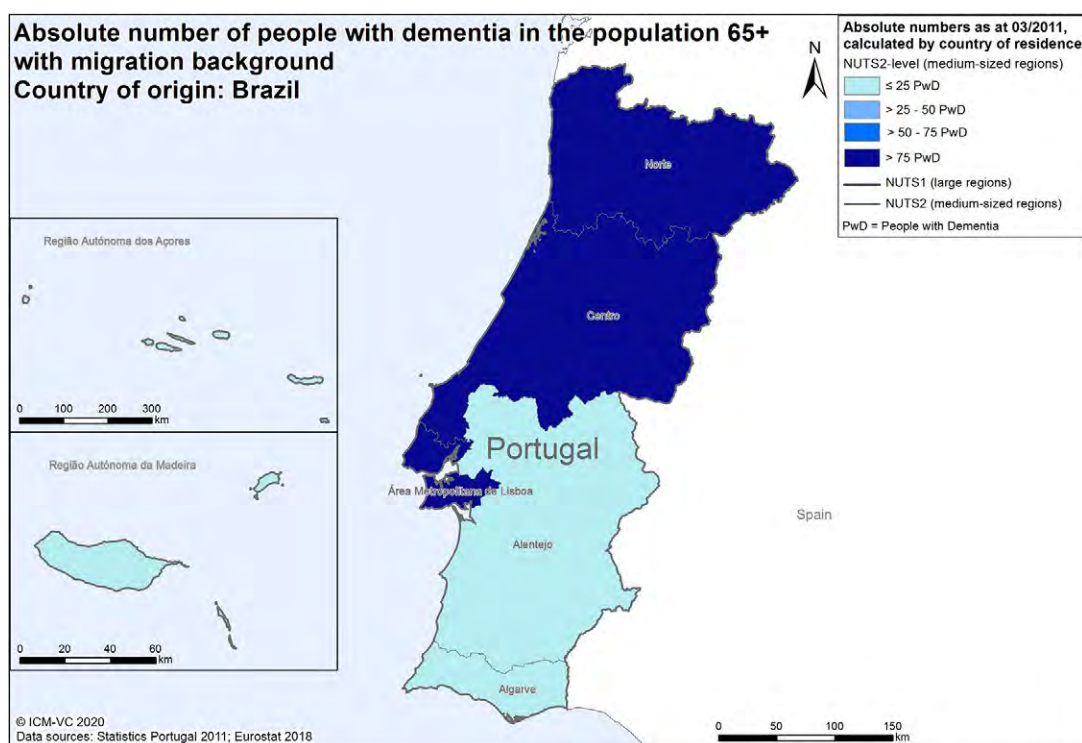


Fig. 3.7.25.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Brazil (Portugal – NUTS2)

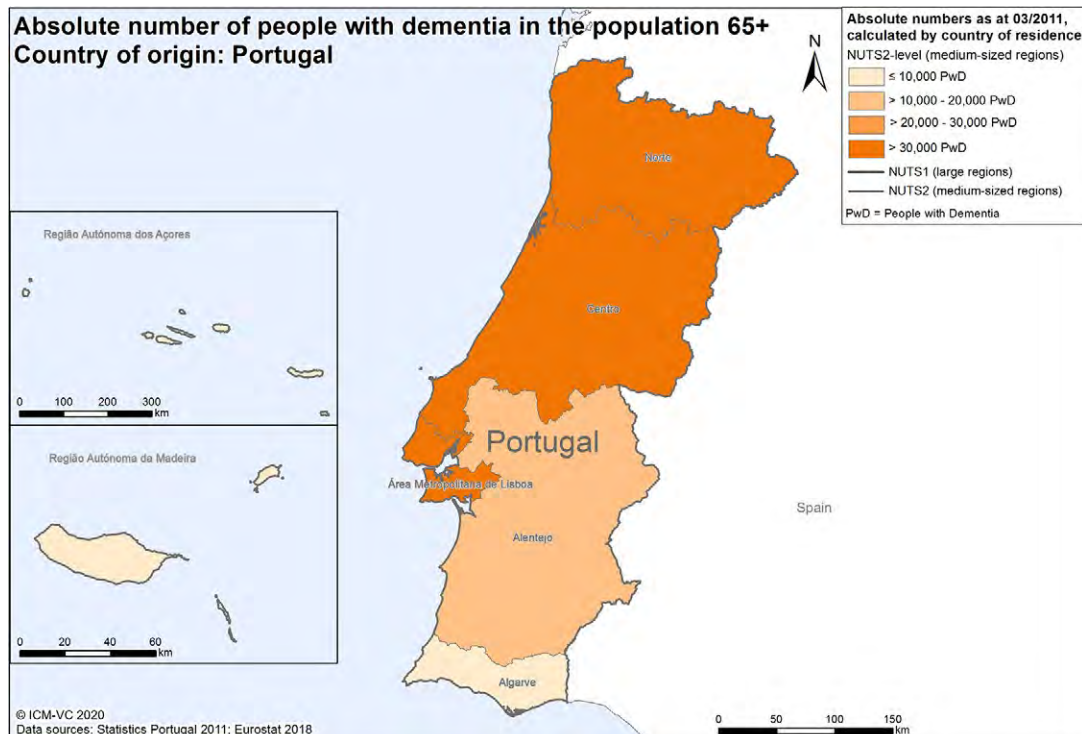


Fig. 3.7.25.8: Absolute number of people with dementia aged 65+.  
Country of origin: Portugal (Portugal – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.25.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figures 3.7.25.10). The values from the NUTS2 level can be found in table 43 [9-11].

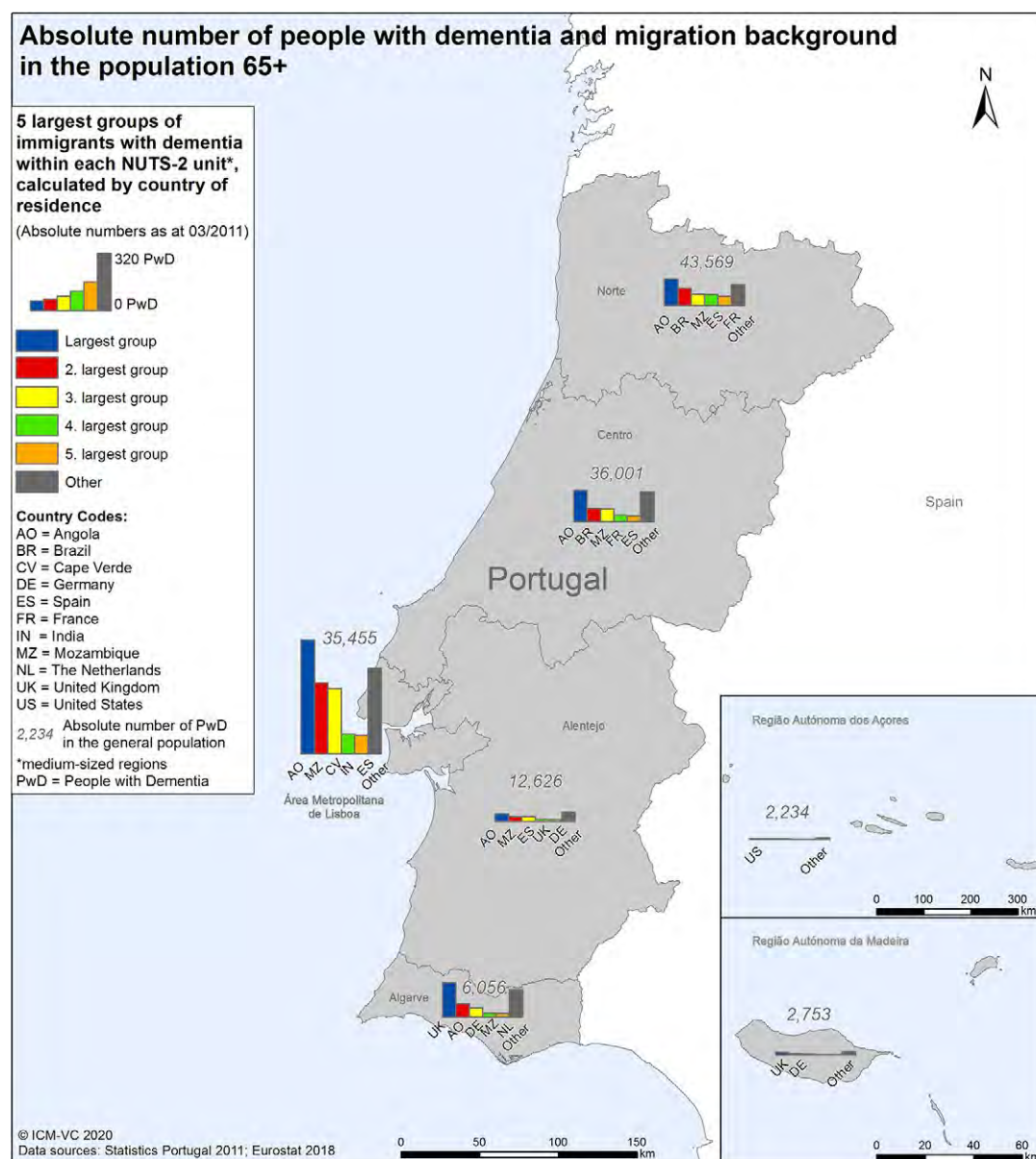


Fig. 3.7.25.9: Absolute number of PwM with dementia aged 65+ (Portugal – NUTS2)



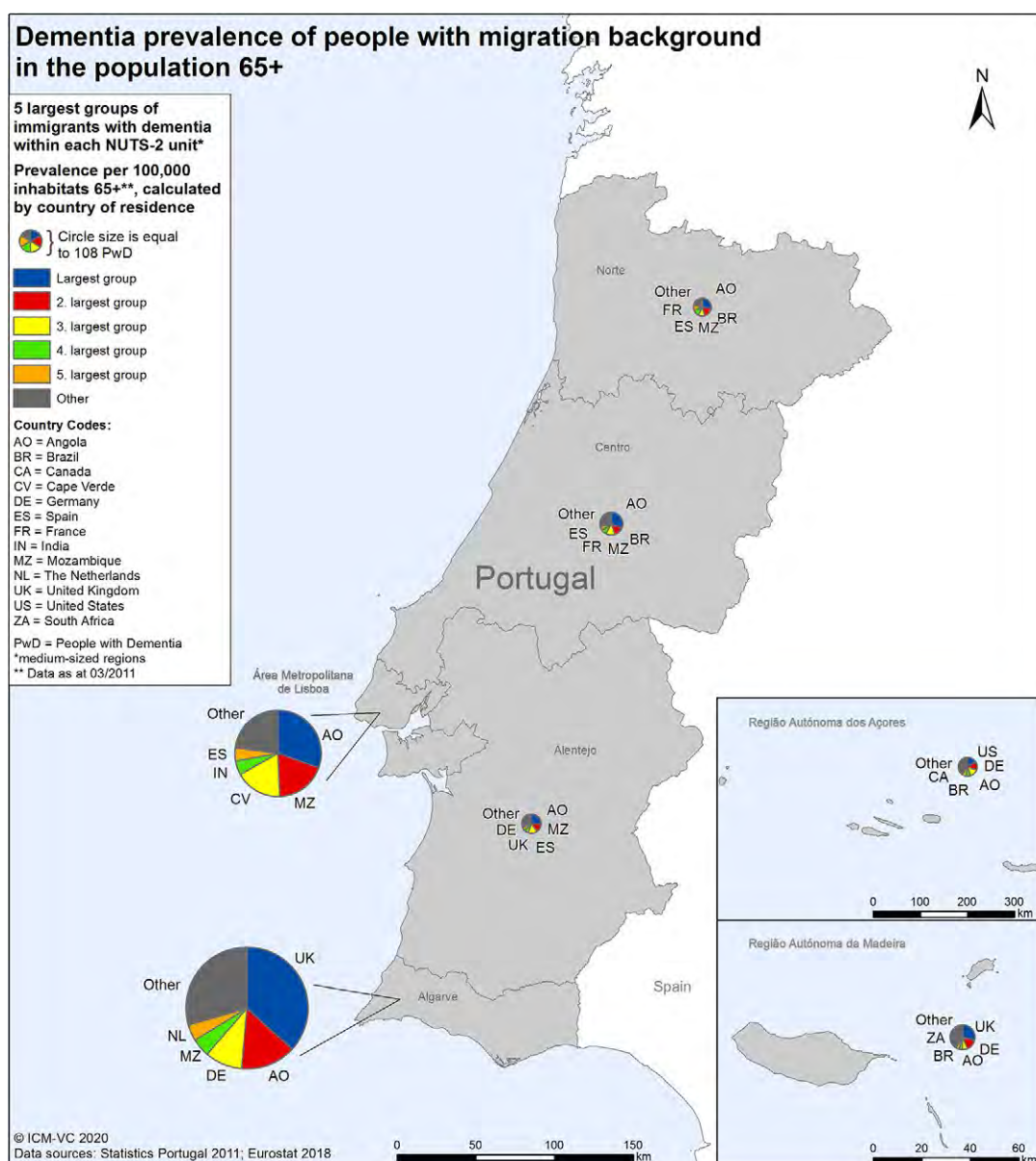


Fig. 3.7.25.10: Prevalence of PwM with dementia among the population aged 65+ (Portugal – NUTS2)

**Tab. 43: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Portugal – NUTS 2)**

NUTS	Total	PT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Norte	43,570	43,030	AO 149	BR 97	MZ 63	ES 62	FR 52	117
Algarve	6,060	5,550	UK 187	AO 75	DE 51	MZ 24	NL 22	150
Centro	36,000	35,440	AO 176	BR 76	MZ 73	FR 37	ES 33	168
Área Metropolitana de Lisboa	35,460	33,340	AO 644	MZ 403	CV 371	IN 112	ES 104	486
Alentejo	12,630	12,460	AO 42	MZ 25	ES 25	UK 12	DE 10	52
Região Autónoma dos Açores	2,230	2,210	US 5	<5	<5	<5	<5	11
Região Autónoma da Madeira	2,750	2,710	UK 14	DE 7	<5	<5	<5	20
Prevalence/10,000 inhabitants with migration background 65+								
Norte	55,644	-	AO 191	BR 123	MZ 81	ES 79	FR 67	149
Algarve	8,199	-	UK 254	AO 102	DE 68	MZ 33	NL 30	203
Centro	44,075	-	AO 216	BR 93	MZ 89	FR 45	ES 41	206
Área Metropolitana de Lisboa	11,545	-	AO 210	MZ 131	CV 121	IN 36	ES 34	158
Alentejo	52,391	-	AO 175	MZ 105	ES 103	UK 50	DE 40	217
Região Autónoma dos Açores	53,575	-	US 114	DE 101	AO 96	BR 56	CA 46	276
Região Autónoma da Madeira	40,189	-	UK 198	DE 103	AO 45	BR 29	ZA 28	286
Prevalence/100,000 inhabitants 65+								
Norte	6,900	6,814	AO 24	BR 15	MZ 10	ES 10	FR 8	19
Algarve	6,900	6,319	UK 213	AO 86	DE 58	MZ 28	NL 25	171



NUTS	Total	PT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Centro	6,900	6,792	AO 34	BR 15	MZ 14	FR 7	ES 6	32
Área Metropolitana de Lisboa	6,900	6,488	AO 125	MZ 78	CV 72	IN 22	ES 20	95
Alentejo	6,900	6,809	AO 23	MZ 14	ES 14	UK 7	DE 5	29
Região Autónoma dos Açores	6,900	6,811	US 15	DE 13	AO 12	BR 7	CA 6	36
Região Autónoma da Madeira	6,900	6,782	UK 34	DE 18	AO 8	BR 5	ZA 5	49

Note: Absolute numbers < 5 are not given for data protection reasons.

Data source: Statistics Portugal 2011

### 3. National dementia plan

For Portugal, a formal national dementia program and a policy-driven NDP could not be identified. In 2009, however, Alzheimer Portugal issued a 'National Alzheimer's Plan of Intervention' having 28 pages. It first provides general information on dementia, the prevalence of dementia, further relevant figures in Portugal, and the impact of Alzheimer's disease. Afterward, the importance of an NDP is discussed, the content of dementia plans from other European countries (i.e. France, England, and Norway) is described, and the European framework is highlighted. The middle part of the document focuses on principles and values as well as the vision and goal of the Alzheimer's plan before discussing the role of Alzheimer Portugal, various stakeholders, and policymakers in dementia care is addressed. Finally, the content of the Alzheimer's plan is presented. There, the focus is on the improvement of the quality of life of people with dementia and their caregivers through pharmacological and non-pharmacological interven-

tions; research on the causes of dementia; prevention and diagnosis of Alzheimer's disease; and the creation of a legal framework for, care, intervention, and research on people with Alzheimer's disease. In none of these topics, reference is made to PWM or the phenomenon of migration in general [12]. In addition, a general dementia strategy ('Despacho n.º 5988/2018', length: 8 pages) was published in 2018 as a result of a working group commissioned by the Ministry of Health. The strategy assigns primary care providers the tasks of: 1. early screening for cognitive impairment, 2. working with secondary care providers to enable integrated diagnosis and management of people with dementia, and 3. coordinating person-centred care for patients and families with health and social care community services. The topic of migration is not considered at any point [13]. In Portugal, civil society and political efforts are underway to develop dementia care strategies, but their implementation in national policy or an official NDP

is still pending. In contrast, no such efforts with regard to the topic of dementia and mi-

gration could be identified.

## 4. National dementia care and treatment guidelines

The Portuguese guideline document 'Therapeutic Approach to Cognitive Impairment' from 2011 is 21 pages long. First, it provides 18 recommendations with different degrees of evidence (A-C). Recommendations are given related to: the medical history as well as the physical and neurological examination of persons with suspected dementia, cognitive assessment, changes in behaviour and activities of daily living, identification of comorbidities, drug control, blood tests, clinical follow-up, the effectiveness and the advantages/disadvantages of different drugs, the treatment of underlying diseases (in vascular dementia) such as high blood pressure, diabetes and heart disease, and the control of psychological and behavioural changes. After the basic recommendations, detailed criteria are given for the diagnosis of dementia, the implementation of cognitive assessment, the evaluation of activities of daily living, the assessment of psychological and behavioural changes, the information and counselling of people with dementia and their families, cognitive rehabilitation, non-pharmacological/pharmaco-

logical approaches regarding psychological and behavioural changes in dementia and the support of caregivers. At the end of the document, two sections list measures to monitor and evaluate the implementation of the guidelines and provide information on scientific support for the development of the guidelines (i.e. which scientists and institutes were involved in the development). Accordingly, the Portuguese guideline from 2011 provides recommendations on the diagnosis of dementia, the assessment of the health and life situation of people with dementia, as well as the treatment of dementia and comorbidities. In none of these areas, recommendations are given for PwM with dementia or caregivers with a migration background [14].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the experts. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the experts, PwM are recognised as a vulnerable group by the healthcare system. Main vulnerable groups would be the Roma and the Gypsy communities. Still, the topic of dementia and migration is only partially seen as relevant at a regional and national level. However, if looking at dementia and migration separately, they are both considered as important. Normally, the topics are not men-

tioned in combination and there is no mention of PwM with dementia in official documents. In addition, the experts stated that research pays little attention to PwM with dementia. A possible reason for this could be that the idea of a relationship between mental health, aging and migration is quite new; usually the focus is on migration and infectious diseases. Whether PwM with dementia are treated as a group



with specific needs depends on the individual organisation or care professional. Healthcare providers and professionals do not make the distinction between PwM and non-migrants and PwM have access to mainstream healthcare services making the healthcare strategy in Portugal an integrative one. According to the experts' estimate, there are no specialised services for inpatient or outpatient care for PwM with dementia available. The experts noted

that some dementia-related services in Portugal provide adequately beneficial and effective care, regardless of the migration background of people, but these are only few and accessing them is problematic. Barriers to access are for example financial issues or transport as these services may only exist in the main centres. For migrants, language might be an additional barrier.

## 6. Professional qualification and people with a migration background in healthcare

Currently, in the field of medical education and in the social work field, culturally sensitive care is not part of the professional qualification as noted by the experts. However, there are some pilot projects aiming to incorporate intercultural care training into social work and healthcare education.

The experts stated that they do not have data on PwM working in inpatient and outpatient

care but based on perceptions their proportion would be low to moderate. They would mostly be originating from Africa and Eastern European countries. In the expert's estimation, such caregiver could be a great source for getting and staying in touch with migrant populations. Overall, the need for culturally sensitive care is only met partially, if at all.

## 7. Support for family caregivers

According to the experts, the family is a very important source of support. Religious institutions and small migrant associations play a very important role in support as well in terms of encouraging physical well-being, providing information, and facilitating access to social and healthcare services. Service providers have a moderate to high importance in supporting family caregivers.

The experts stated that there are differences regarding services and information for family caregivers of PwM and non-migrants with dementia. While there are some services that are helpful for non-migrants, PwM do not have any services that meet their needs. Therefore, there is a very high need for specialized services and tailored information for family caregivers of PwM with dementia.



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# Romania

**Population**

19,318,000

**Area**

234,270 km<sup>2</sup>

**Capital**

Bucharest

**3 largest cities**

Bucharest (1,883,000)

Cluj-Napoca (325,000)

Timișoara (319,000)

**Neighboring countries**

Bulgaria, Hungary,

Moldova, Serbia,

Ukraine

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Romania has been a country of emigration for more than a century [1]. The first wave of large-scale emigration to the US occurred in the late 19th and early 20th centuries [2, 3]. During the First and Second World War, Romania was affected by other large migration flows. In 1940, approximately 220,000 ethnic Romanians moved from Hungarian to Romanian territory and about 160,000 ethnic Hungarians from Romanian to Hungarian territory [3]. As a result of the Holocaust, the Jewish population in Romania (780,000) was halved. During the communist era (1947–1989), there were some more emigration waves (1957–1965, 1989). Ethnic minorities (Jews, people from Germany, people from Hungary) were overrepresented in the emigrant population; for example, most Jewish populations (300,000 to 350,000) emigrated to Israel or the US. The immigration of foreign migrants was minimal. However, from the 1970s onwards, a relatively large number of foreign students from the Middle East and African countries began immigrating [2, 3]. After the collapse of communism, about two million people emigrated [3]. More than 75% of them were peo-

ple that had come from Germany. Circular and temporary migration is the central characteristic of Romanian emigration. Labour migration proceeded in three waves: 1. 1990–1995: to Israel, Turkey, Italy, Hungary, and Germany; 2. 1996–2001: to Spain, the US, and Canada; 3. 2001–2006: to Italy, Spain, Israel, Germany, and Hungary [1]. The EU accession on 1 January 2007 further intensified emigration. In mid-2007, about 3.4 million people of Romania worked abroad, only 1.2 million of them legally [3]. In contrast, immigration to Romania is much smaller. Only because of EU accession, Romanian companies began to hire more foreign workers [1]. In the second half of the 1990s, immigration from Moldova increased. In 2013, people from Moldova (49,800), Italy (27,500), Bulgaria (18,300), Spain (14,500), and Ukraine (11,900) represented the largest migrant groups [4]. The migrant population (born abroad) more than tripled between 1990 and 2019 (135,800 to 462,600) and their proportion in the total population quadrupled (0.6 to 2.4%) [5]. However, the net migration rate remains negative (2020: -3.8) [6].

## 2. Estimated number of people with a migration background with dementia

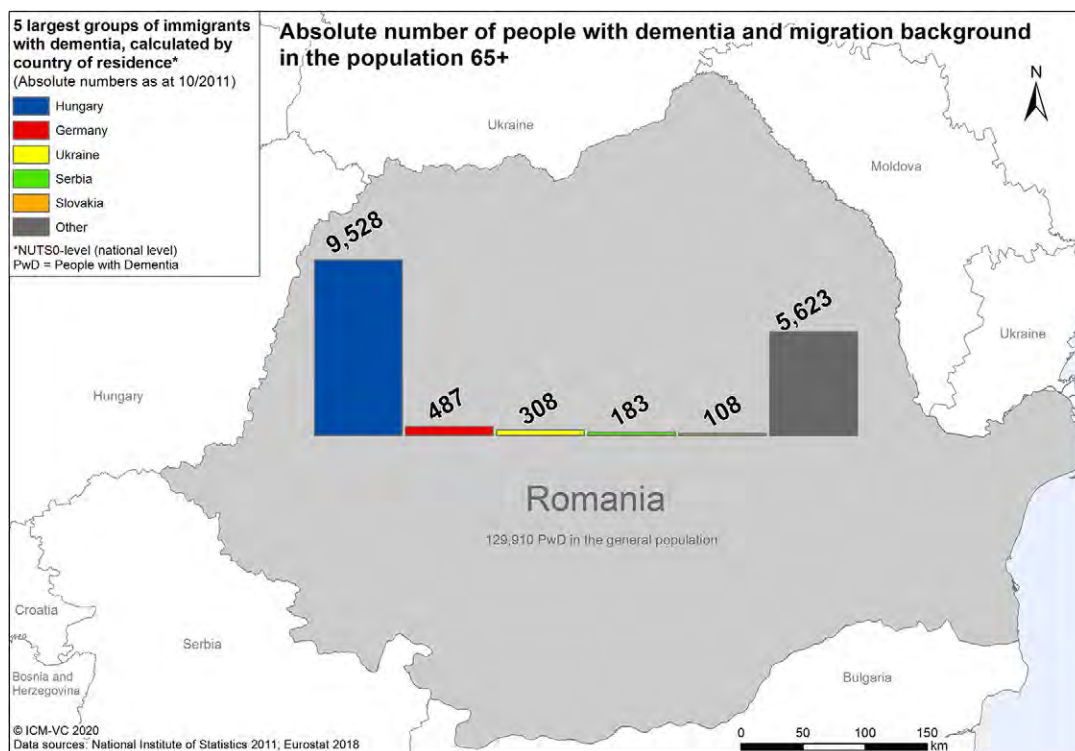


Fig. 3.7.26.1: Absolute number of PwM with dementia aged 65+ (Romania – Nation)

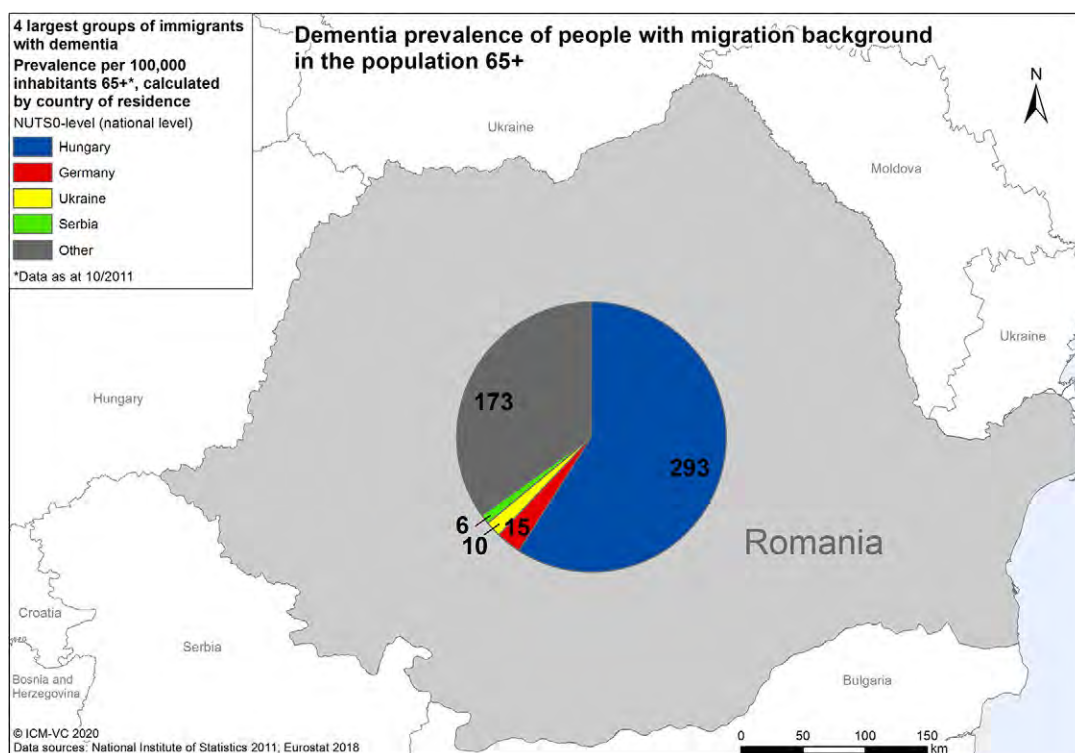


Fig. 3.7.26.2: Prevalence of PwM with dementia among the population aged 65+ (Romania – Nation)



**Tab. 44: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Romania – Nation)**

NUTS	Total	RO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Romania	129,910	113,674	HU 9,528	DE 487	UA 308	XS 183	SK 108	5,623
Prevalence/10,000 inhabitants with migration background 65+								
Romania	3,201	-	HU 235	DE 12	UA 8	XS 5	SK 3	139
Prevalence/100,000 inhabitants 65+								
Romania	4,000	3,500	HU 293	DE 15	UA 10	XS 6	SK 3	173

Data source: National Institute of Statistics (2011)

There are 405,900 PwM aged 65 or older. Of those, approx. 16,200 are estimated to exhibit some form of dementia. Figure 3.7.26.1 shows that the most affected migrant groups presumably originate from Hungary (approx. 9,500), Germany (approx. 500), Ukraine (approx. 300), Serbia (approx. 200), and Slovakia (approx. 100). The second graph highlights the number of PwM with dementia in Romania per

100,000 inhabitants aged 65 or older (figure 3.7.26.2). Table 44 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Hungary, Germany, Ukraine, Serbia, and Slovakia throughout the country in the NUTS2 regions (figures 3.7.26.3 – 3.7.26.8).

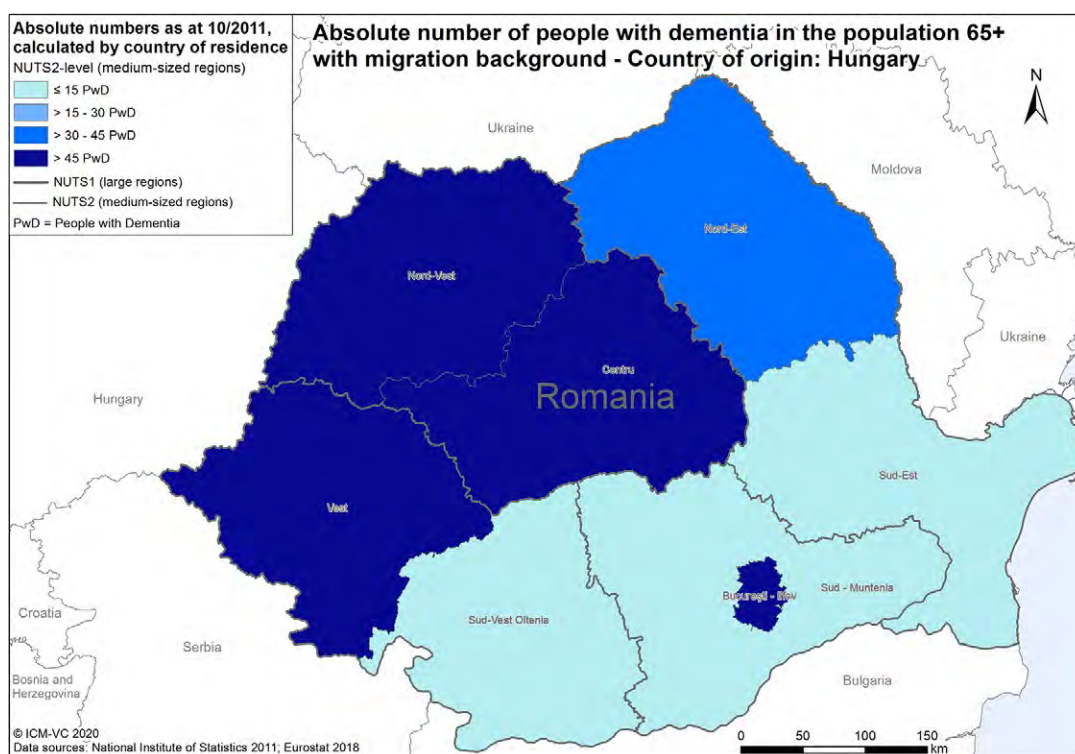


Fig. 3.7.26.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Hungary (Romania – NUTS2)

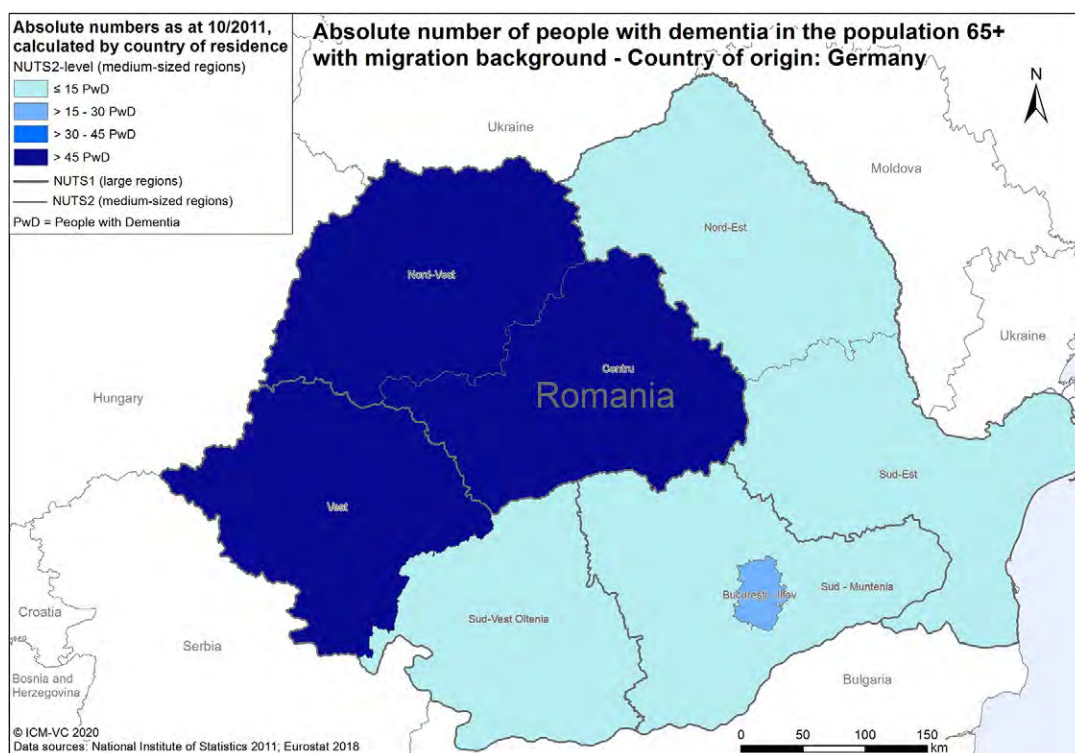


Fig. 3.7.26.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (Romania – NUTS2)



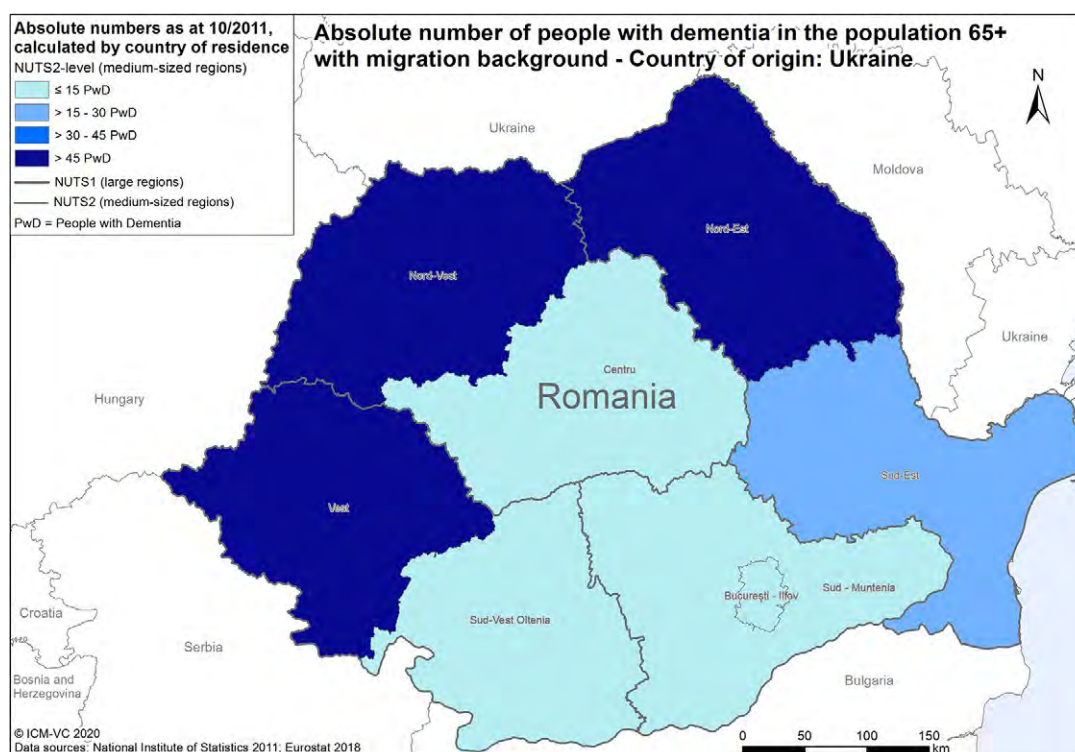


Fig. 3.7.26.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Ukraine (Romania – NUTS2)

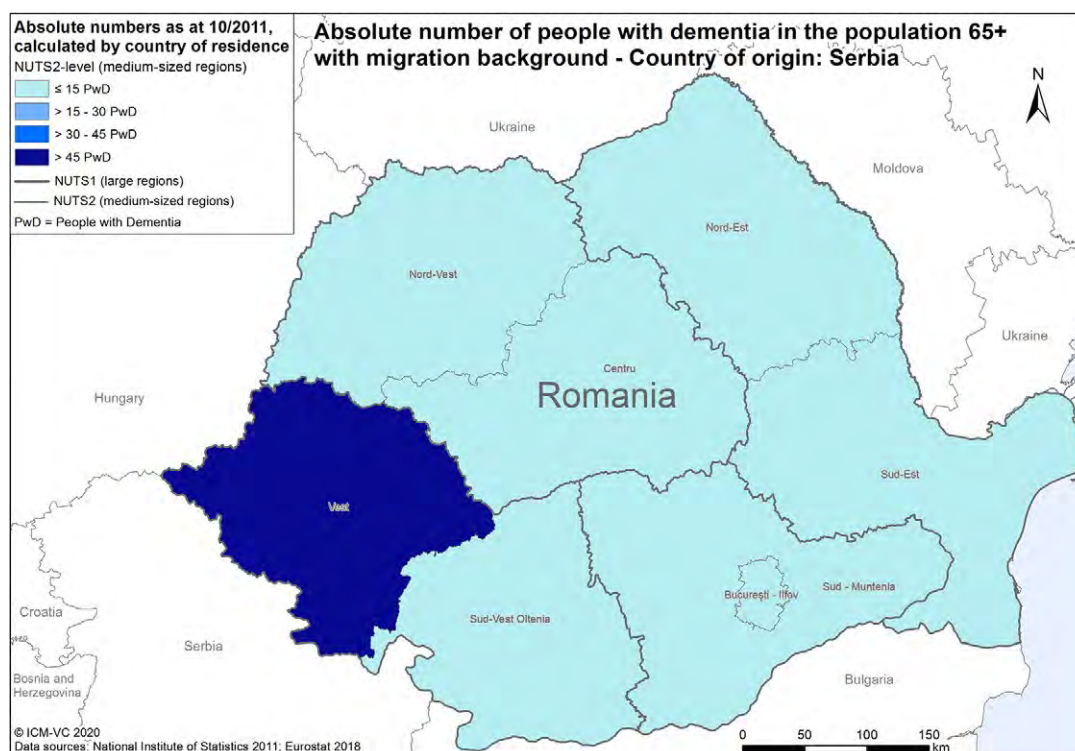


Fig. 3.7.26.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Serbia (Romania – NUTS2)



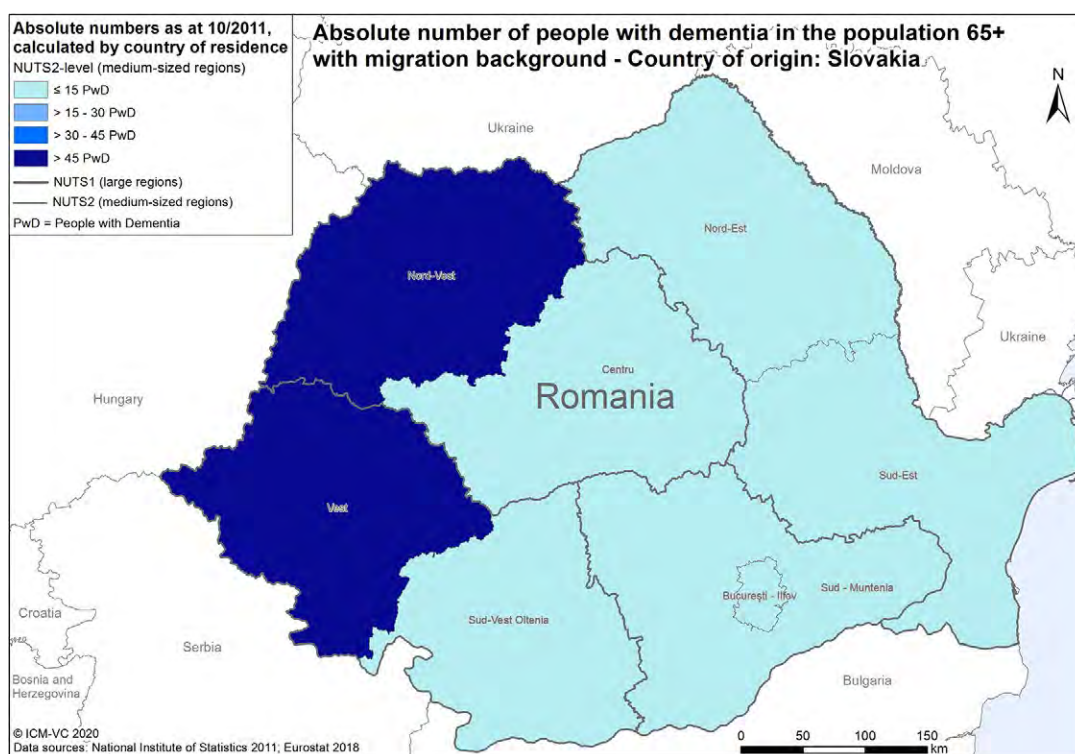


Fig. 3.7.26.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Slovakia (Romania – NUTS2)

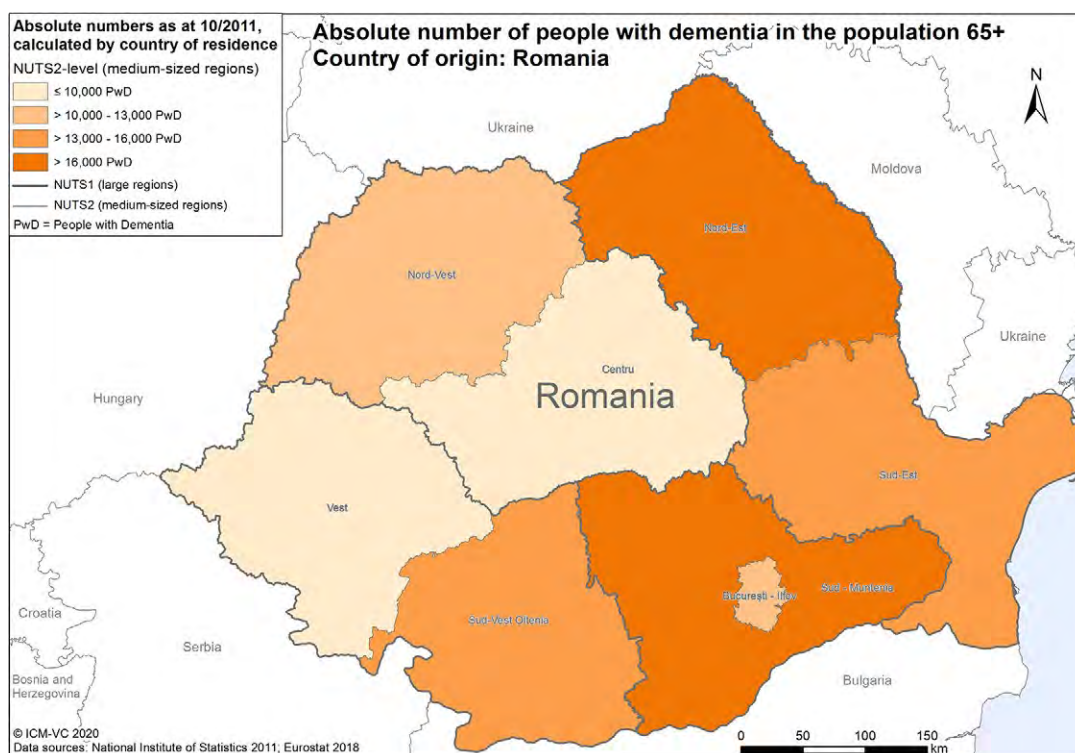


Fig. 3.7.26.8: Absolute number of people with dementia aged 65+.  
Country of origin: Romania (Romania – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.26.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.26.10). The values from the NUTS2 level can be found in table 45 [7-9].

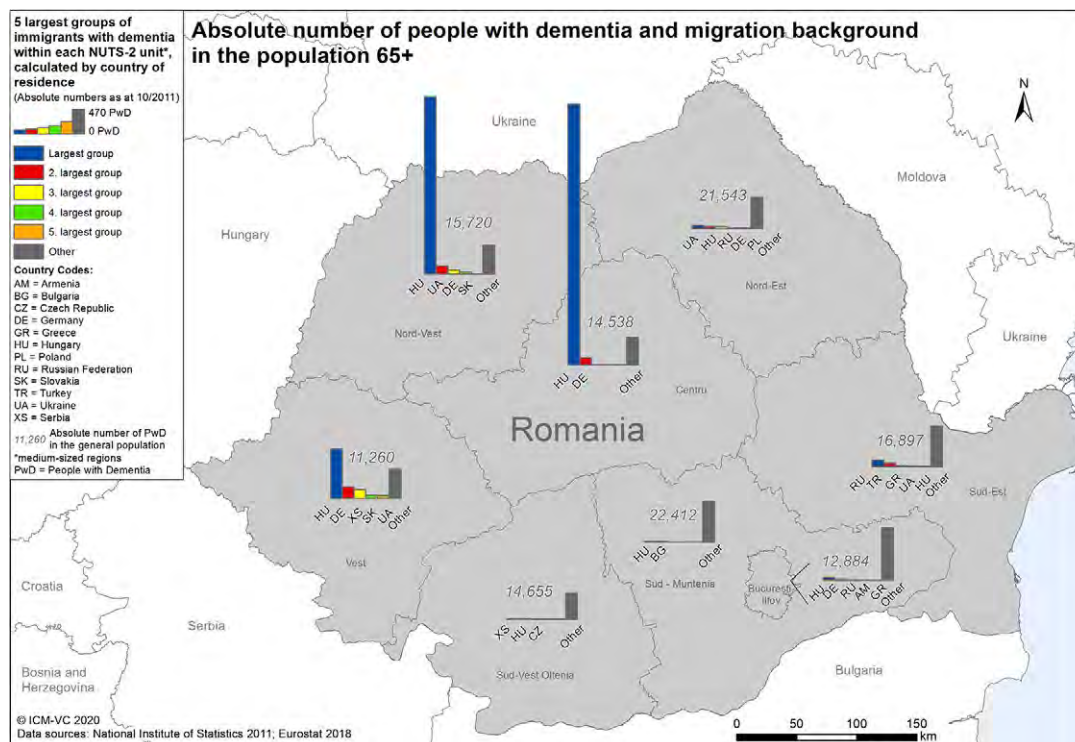


Fig. 3.7.26.9: Absolute number of PwM with dementia aged 65+ (Romania – NUTS2)

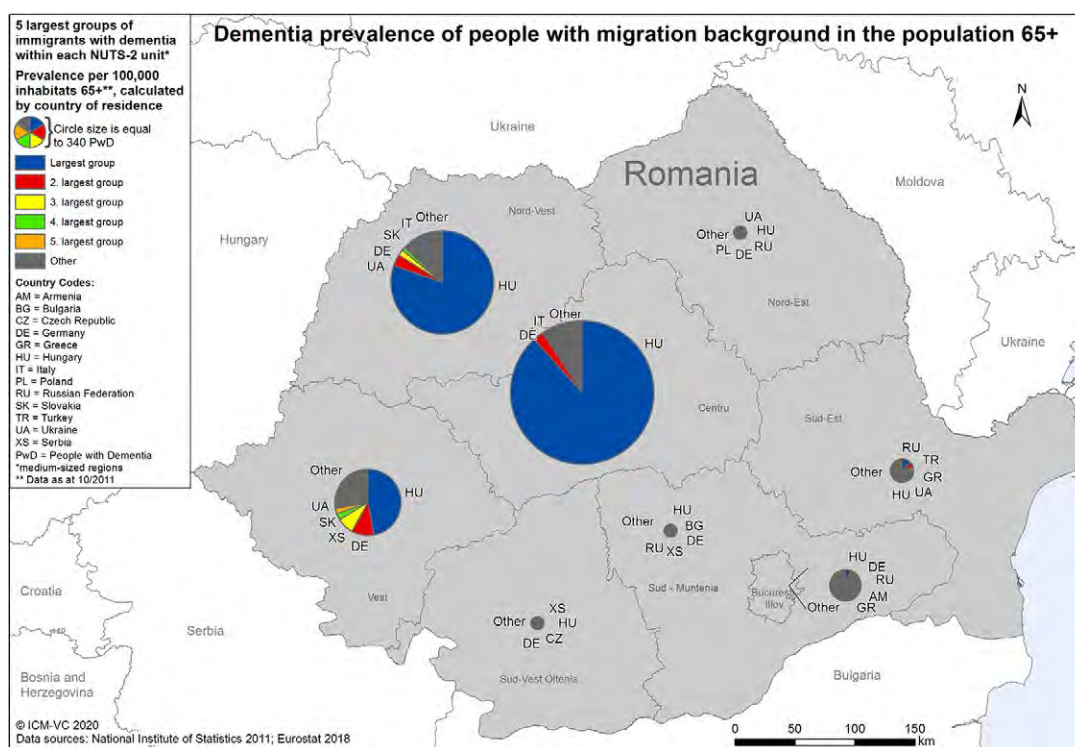


Fig. 3.7.26.10: Prevalence of PwM with dementia among the population aged 65+ (Romania – NUTS2)

Tab. 45: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Romania – NUTS 2)

NUTS	Total	RO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Nord-Vest	15,720	11,374	HU 3,484	UA 160	DE 83	SK 47	<5	570
Centru	14,538	8,902	HU 4,970	DE 137	<5	<5	<5	524
Nord-Est	21,543	20,770	UA 67	HU 40	RU 39	DE 14	PL 13	599
Sud-Est	16,897	15,852	RU 131	TR 73	GR 22	UA 18	HU 12	789
Sud-Muntenia	22,412	21,593	HU 13	BG 12	<5	<5	<5	783
București-Ilfov	12,884	11,789	HU 55	DE 19	RU 12	AM 8	GR 6	995
Sud-Vest Oltenia	14,655	14,137	XS 8	HU 8	CZ 5	<5	<5	491
Vest	11,260	9,256	HU 944	DE 219	XS 167	SK 59	UA 55	561



NUTS	Total	RO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/10,000 inhabitants with migration background 65+								
Nord-Vest	1,447	-	HU 321	UA 15	DE 8	SK 4	N/A	53
Centru	1,032	-	HU 353	DE 10	N/A	N/A	N/A	38
Nord-Est	11,147	-	UA 35	HU 21	RU 20	DE 7	PL 7	310
Sud-Est	6,466	-	RU 50	TR 28	GR 8	UA 7	HU 5	302
Sud-Muntenia	10,952	-	HU 6	BG 6	DE 2	XD 1	RU 1	383
București-Ilfov	4,705	-	HU 20	DE 7	RU 4	AM 3	GR 2	363
Sud-Vest Oltenia	11,322	-	XS 7	HU 6	CZ 4	DE 3	MK 1	379
Vest	2,248	-	HU 188	DE 44	XS 33	SK 12	UA 11	112
Prevalence/100,000 inhabitants 65+								
Nord-Vest	4,000	2,894	HU 887	UA 41	DE 21	SK 12	IT 1	145
Centru	4,000	2,449	HU 1,367	DE 38	IT 1	N/A	N/A	145
Nord-Est	4,000	3,856	UA 12	HU 8	RU 7	DE 3	PL 2	111
Sud-Est	4,000	3,753	RU 31	TR 17	GR 5	UA 4	HU 3	187
Sud-Muntenia	4,000	3,854	HU 2	BG 2	DE 1	XS 1	RU 1	140
București-Ilfov	4,000	3,660	HU 17	DE 6	RU 4	AM 2	GR 2	309
Sud-Vest Oltenia	4,000	3,859	XS 2	HU 2	CZ 1	DE 1	N/A	134
Vest	4,000	3,288	HU 335	DE 78	XS 59	SK 21	UA 19	199

Note: Absolute numbers < 5 are not given for data protection reasons. N/A = not available.

Data source: National Institute of Statistics 2011



### 3. National dementia plan

For Romania no NDP could be identified [10].

### 4. National dementia care and treatment guidelines

Romania has published a 'Diagnosis and Treatment Guide for Dementia' (from 2010). This document comprises 11 pages and covers various topics pertaining to dementia such as diagnosis, drug treatment, risk factors, assessment of psychiatric and behavioural symptoms, and non-drug treatment of psychiatric and behavioural symptoms. The issue of migration is not addressed [11].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

### 5. Services and information for people with a migration background with dementia

According to the expert, PwM are not identified as a vulnerable group in terms of dementia and healthcare. Although between 1992 and 2005 there was a significant population of older Russian- and Polish-speaking people with dementia, currently this type of immigrant population no longer exists. The expert is aware of a small group of people from Pakistan and Tunisia, but the majority of them are between 30 and 40 years old. Furthermore, the expert knows of some people from China, Africa, and business people from Germany, Iran, and Turkey. However, most of these are younger and have immigrated for professional reasons. The expert pointed out that those migrants who work in the economy have sufficient financial resources to afford private services, and economically weaker migrants do usually not pay attention to prevention and health in older age. Thus, the topic of dementia and migration is relatively unimportant in Romania due to the low proportion of migrants, the type of migration, and the structure of the migrant population. The healthcare system and care

providers do not treat PwM with dementia and their family members as a group with specific needs. According to the expert, Romania uses an integrative model in the care of PwM with dementia, in which the migrants are integrated into the healthcare of the country. If migrants enter the country legally, work at their jobs or businesses, and pay a health insurance contribution, they have the same healthcare rights as Romanian citizens. The expert could not identify any government-initiated specialised services PwM with dementia, neither in outpatient nor inpatient care. Furthermore, no measures seem to be taken to provide intercultural care in the future. In bigger cities in the western part of the country like Timișoara, there are single private care facilities for certain groups of migrants, such as people from Italy, Germany, or Hungary. However, these facilities were built by wealthier business people from these migrant groups for people like their parents and are not the result of a government initiative. According to the expert, these migrant groups are better cared for than





the Romanian population. The general population has access to very few dementia-specific care services, which are only offered in some nursing homes in individual regions, mainly in big cities. In hospitals and psychiatric departments, people with dementia are often treated together under the same conditions as younger people. Besides, many institutions, such as the 'Department of Emergency Psychiatry of the "Carol Davila" University of Medicine and Pharmacy' in Bucharest, which is headed by the expert, have a considerable lack of room

capacity and staff. In the department where the expert works, 4–5 caregivers are responsible for the care of 60 patients in a space that in developed western countries would have 16–20 beds. Dementia-specific care is not possible there. Many people from the general population have no access to information about dementia or healthcare services in rural areas. According to the expert, much more political support and an NDP are needed to address these care inequalities.

## 6. Professional qualification and people with a migration background in healthcare

According to the expert, the proportion of professional caregivers with a migration background is low in both outpatient and inpatient care in Romania. This is particularly the case for the care of older people. The recruitment of professional caregivers with a migration background can benefit PwM. For the provision of high-quality care, the caregivers must have adequate knowledge of the Romanian language. The expert stated that communication is a central problem among the majority of professionals with a migration background. As communication with patients is most important in outpatient care, and technical nursing skills, and knowledge of pathology are more

relevant in inpatient care, the field of inpatient care could be more suitable for professional caregivers with a migration background.

Currently, culturally sensitive care is not part of the training of healthcare professionals in Romania. Furthermore, there are no opportunities at the national level for the training of professionals in intercultural care. However, some non-governmental projects on such training exist.

According to the expert, currently, qualified professionals equipped with high cultural sensitivity are not available. However, the need for such professionals is not high either.

## 7. Support for family caregivers

The expert pointed out that there is no difference between information and support for family caregivers of PwM with dementia and non-migrants with dementia in Romania. However, the expert also stated that there is no need for developing specialised services

for family caregivers of PwM with dementia, as their numbers are extremely low. As a result, no specialised services are currently available for family caregivers from the migrant population.





## 8. References

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# Slovakia

**Population**

5,458,000

**Area**

48,702 km<sup>2</sup>

**Capital**

Bratislava

**3 largest cities**

Bratislava (438,000)

Kosice (239,000)

Prešov (88,000)

**Neighboring countries**

Austria,  
the Czech Republic,  
Hungary, Poland,  
Ukraine

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

In the last three centuries, Slovakia was a country of emigration [1]. The wave of most extensive emigration occurred between 1871 and 1914, when about 850,000 people emigrated, most of them to the US. Between the two world wars, 220,000 people left the country to France, Belgium, Canada, and Argentina. However, many emigrants returned [2]. After the Second World War, approximately 2.8 million people from Germany emigrated from Czechoslovakia. This emigration was only partially compensated by the re-immigration of citizens from the Czech Republic and Slovakia. Between 1948 and 1950, 250,000 people left the Slovakia. During the wave of emigration between 1968 and 1971, 200,000 people emigrated. From 1971 to 1990, only 100,000 people left the country. The main destinations of emigrants were West Germany, Austria, Australia, the US, and Canada [3, 4]. More people emigrated from the Czech Republic than from Slovakia [3]. From 1950 to 1989, there were large migratory movements between the present-day Czech Republic and Slovakia. Slovakia experienced a net migration loss of

230,000 inhabitants [2]. After the collapse of the communist regime in the late 1980s, the volume and diversity of migration flow increased [5]. Following the foundation of the Slovak Republic on 1 January 1993, there was a significant increase in migration towards the west and, for the first time, towards Slovakia [3]. Slovakia's accession to the EU (2004) and the Schengen area (2007) further increased migration in both directions. Since 2015, the employment of third-country nationals (mainly from Ukraine and Serbia) and EU nationals (Romania) has increased significantly [1]. In 2013, people from the Czech Republic were the largest migrant group (83,100), followed by Hungary (15,900), Ukraine (9,400), Romania (4,900), and Poland (4,400) [6]. Between 1990 and 2019, the migrant population (born abroad), and the proportion of migrants in the total population more than quadrupled (41,300 to 188,000; 0.8 to 3.4%) [7]. As of 2020, the net migration rate is 0.3 [8]. Currently, Slovakia is mainly a transit country for migrants from Eastern Europe [4].

## 2. Estimated number of people with a migration background with dementia

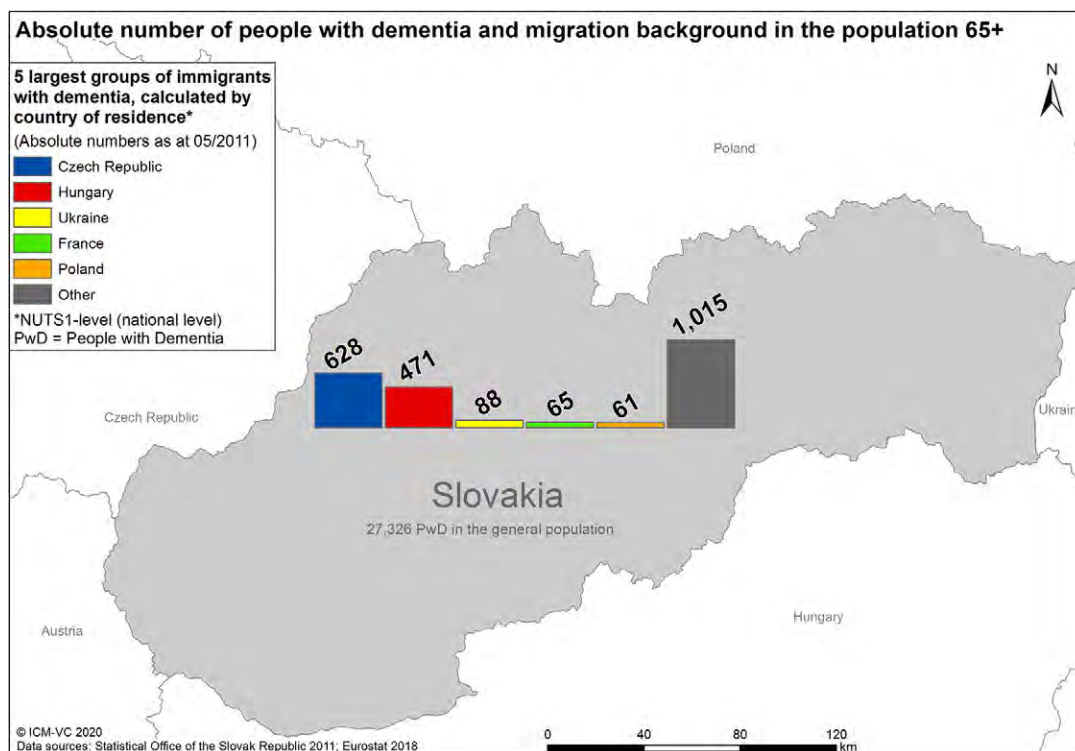


Fig. 3.7.27.1: Absolute number of PwM with dementia aged 65+ (Slovakia – Nation)

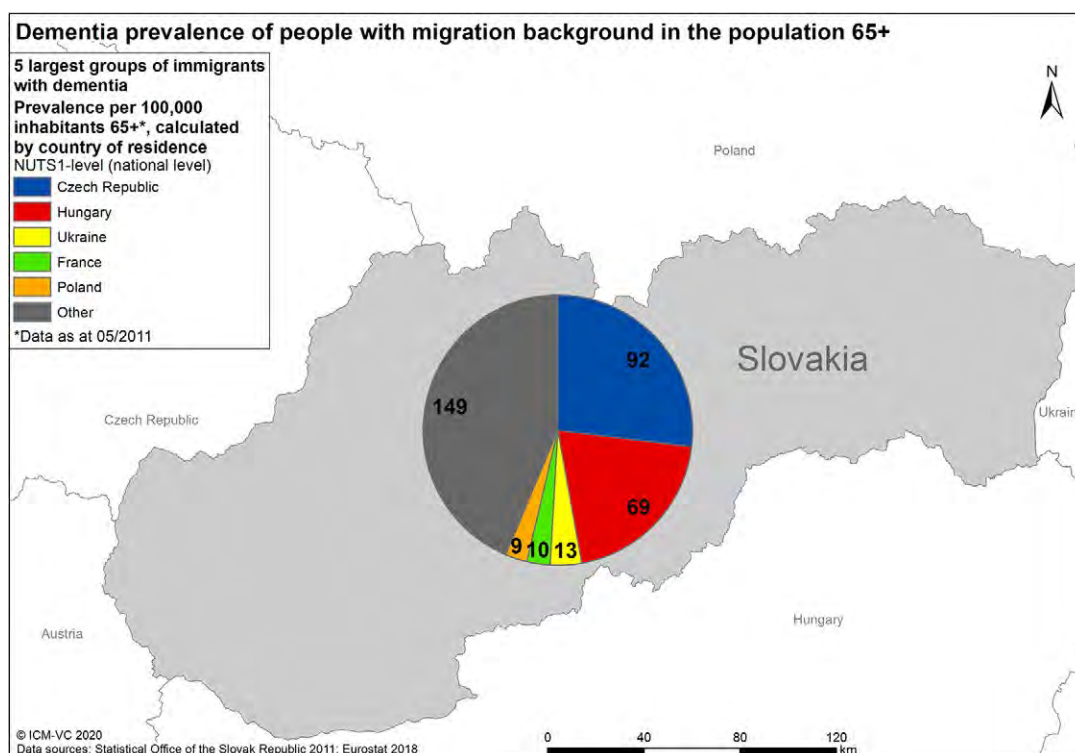


Fig. 3.7.27.2: Prevalence of PwM with dementia among the population aged 65+ (Slovakia – Nation)

**Tab. 46: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovakia – Nation)**

NUTS	Total	SK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Slovakia	27,326	24,998	CZ 628	HU 471	UA 88	FR 65	PL 61	1,015
Prevalence/10,000 inhabitants with migration background 65+								
Slovakia	7,151	-	CZ 164	HU 123	UA 23	FR 17	PL 16	265
Prevalence/100,000 inhabitants 65+								
Slovakia	4,000	3,659	CZ 92	HU 69	UA 13	FR 10	PL 9	149

Data source: Statistical Office of the Slovak Republic (2011)

There are 38,200 PwM aged 65 or older. Of those, approx. 1,500 are estimated to exhibit some form of dementia. Figure 3.7.27.1 shows the most affected migrant groups presumably originate from the Czech Republic (approx. 600), Hungary (approx. 500), Ukraine (approx. 90), France (approx. 70), and Poland (approx. 60). The second graph highlights the number of PwM with dementia in Slovakia per 100,000

inhabitants aged 65 or older (figure 3.7.27.2). Table 46 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from the Czech Republic, Hungary, Ukraine, France, and Poland throughout the country in the NUTS2 regions (figures 3.7.27.3 – 3.7.27.8).



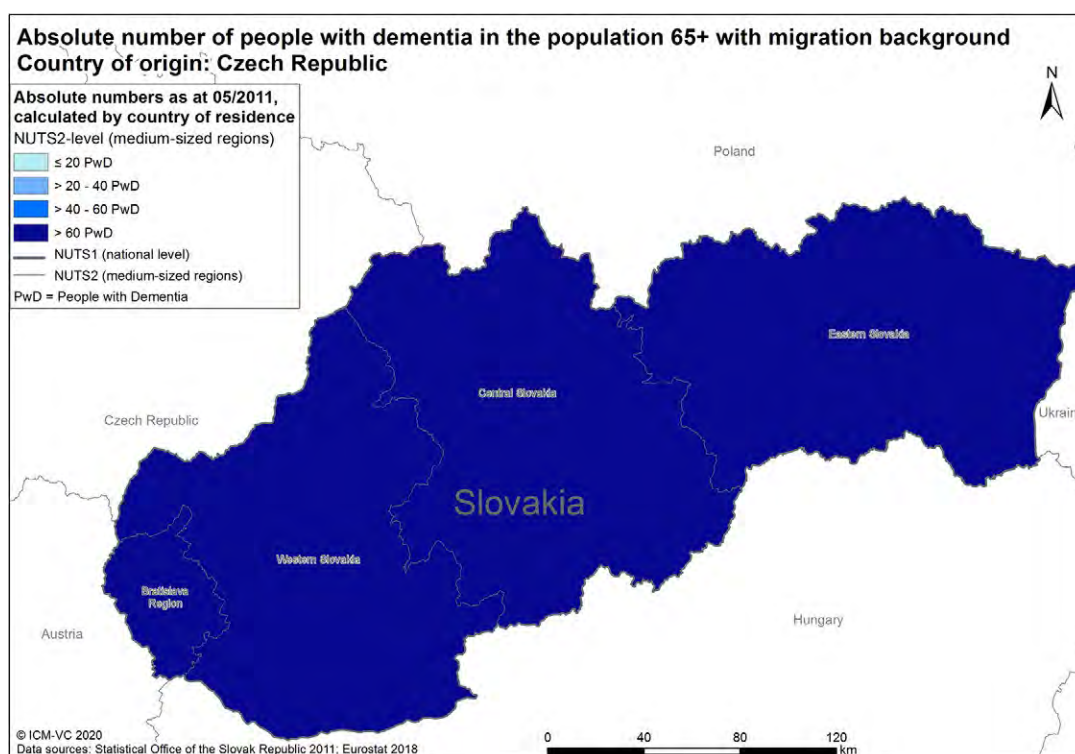


Fig. 3.7.27.3: Absolute number of PwM with dementia aged 65+.  
 Country of origin: The Czech Republic (Slovakia – NUTS2)

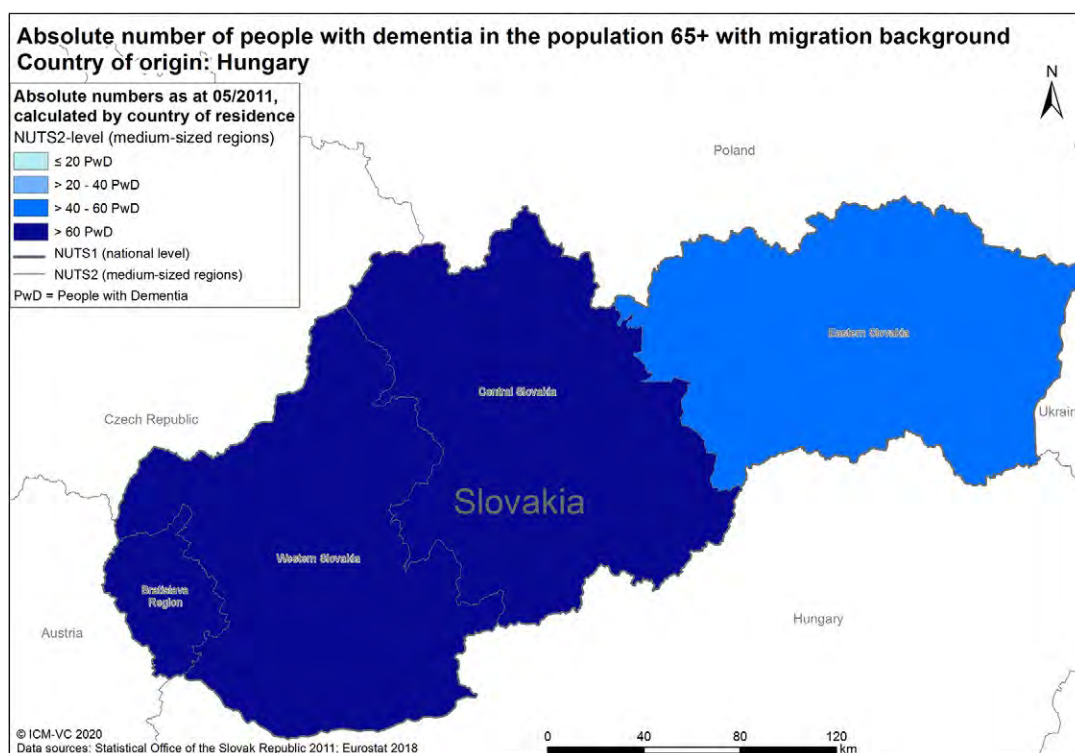


Fig. 3.7.27.4: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Hungary (Slovakia – NUTS2)

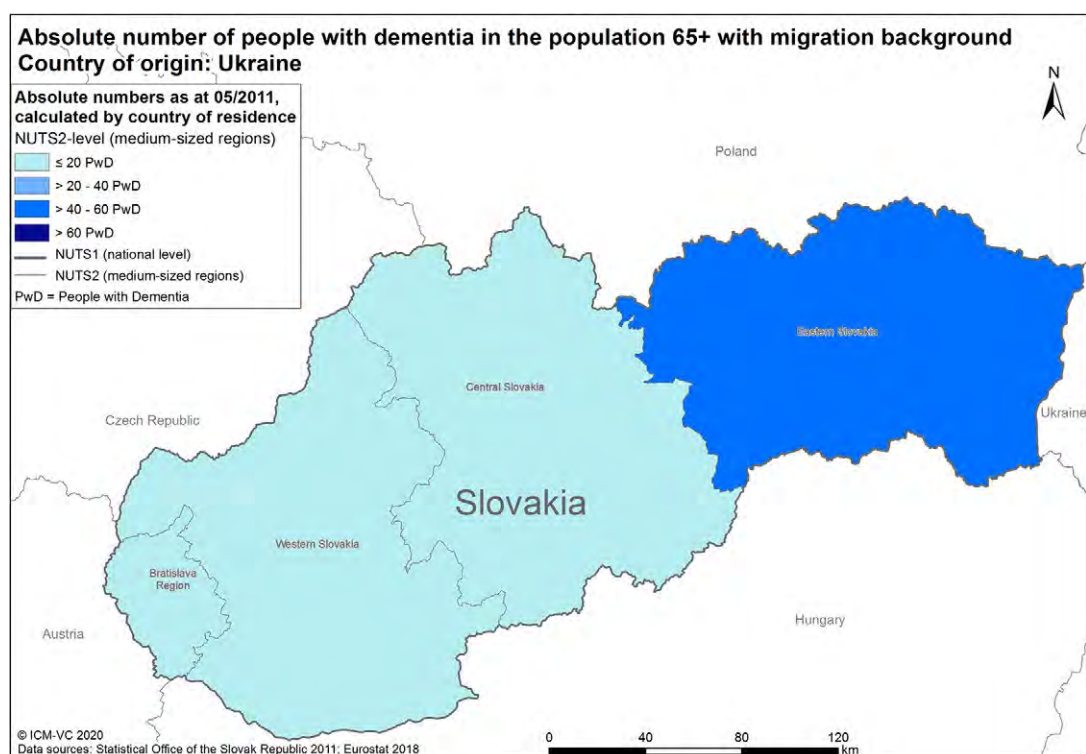


Fig. 3.7.27.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: Ukraine (Slovakia – NUTS2)

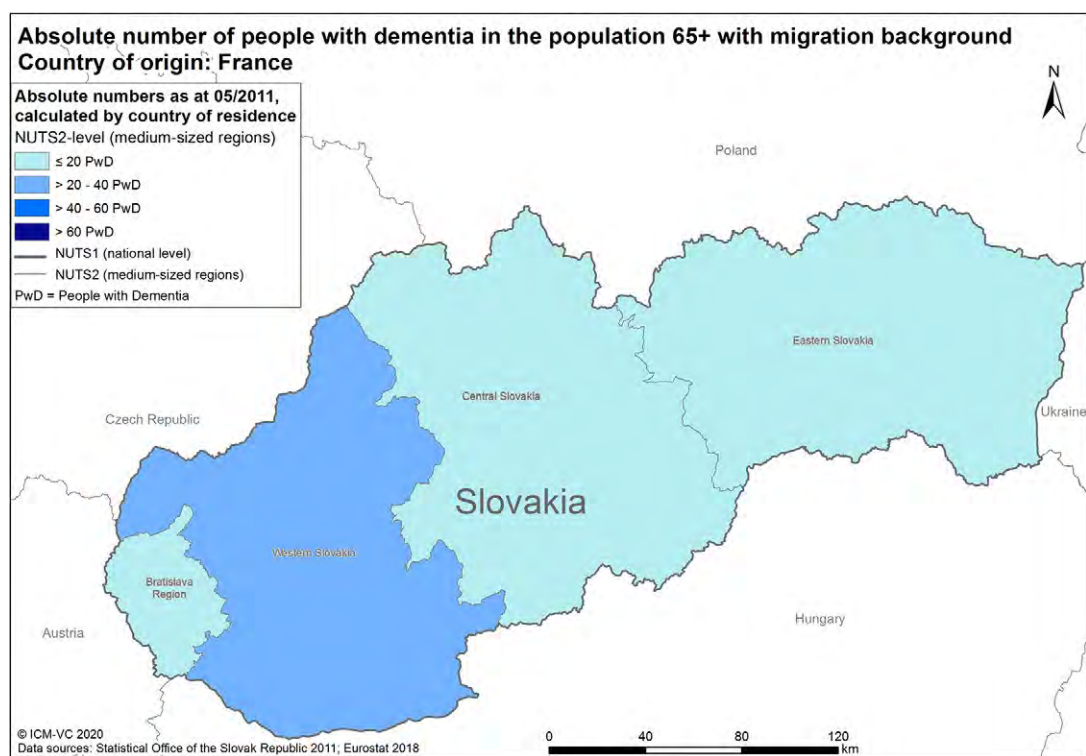


Fig. 3.7.27.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: France (Slovakia – NUTS2)

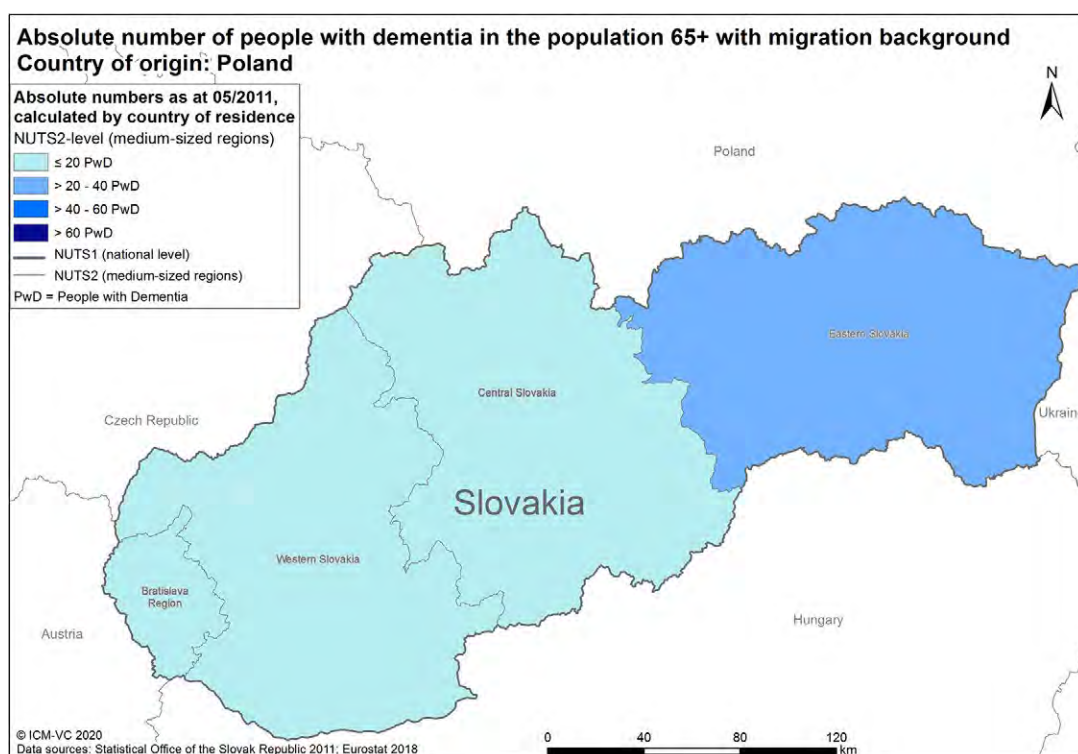


Fig. 3.7.27.7: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Poland (Slovakia – NUTS2)

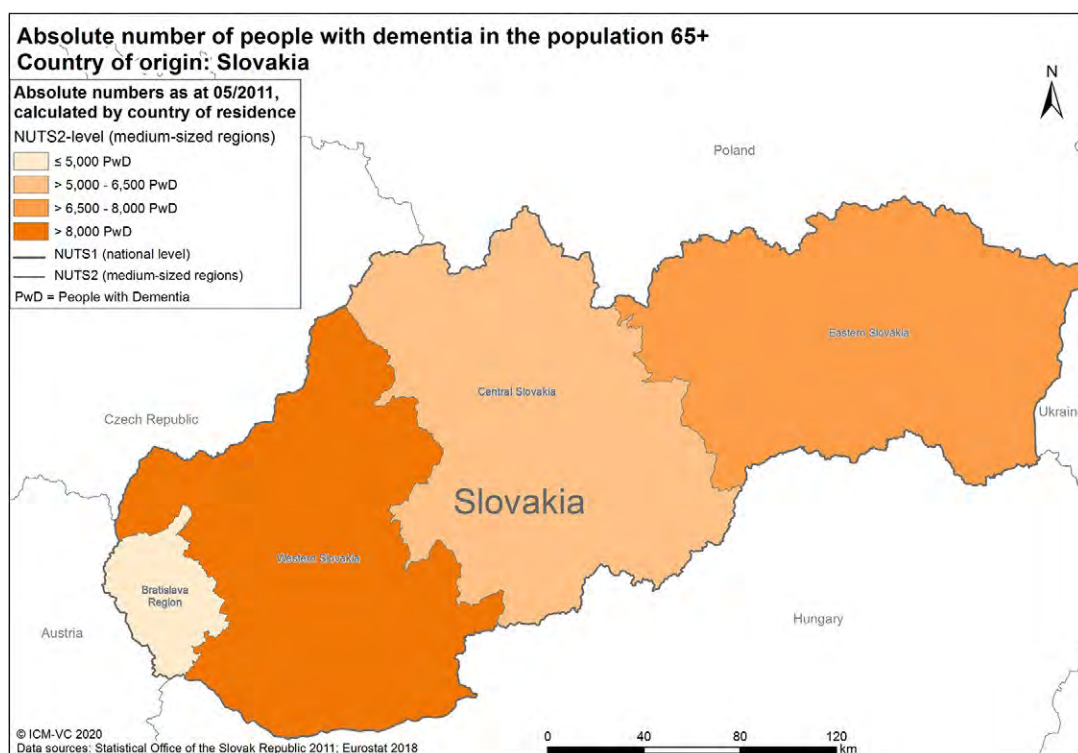


Fig. 3.7.27.8: Absolute number of people with dementia aged 65+.  
 Country of origin: Slovakia (Slovakia – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrate the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.27.9). The

second map shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.27.10). The values from the NUTS2 level can be found in table 47 [9, 10].

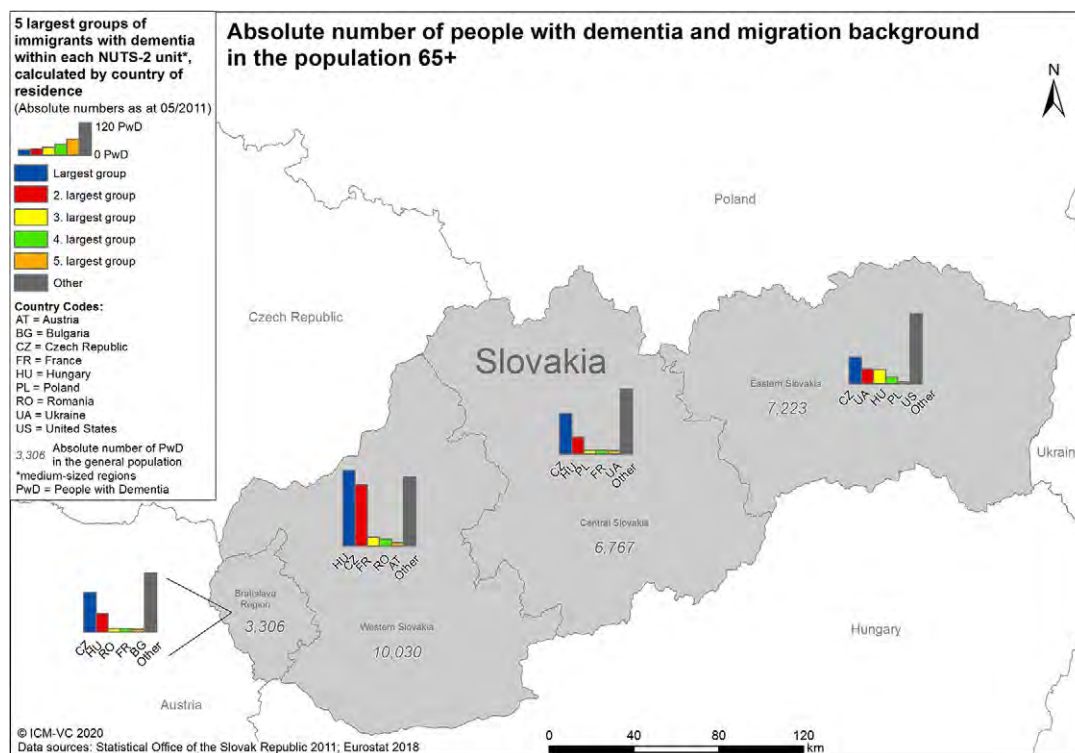


Fig. 3.7.27.9: Absolute number of PwM with dementia aged 65+ (Slovakia – NUTS2)



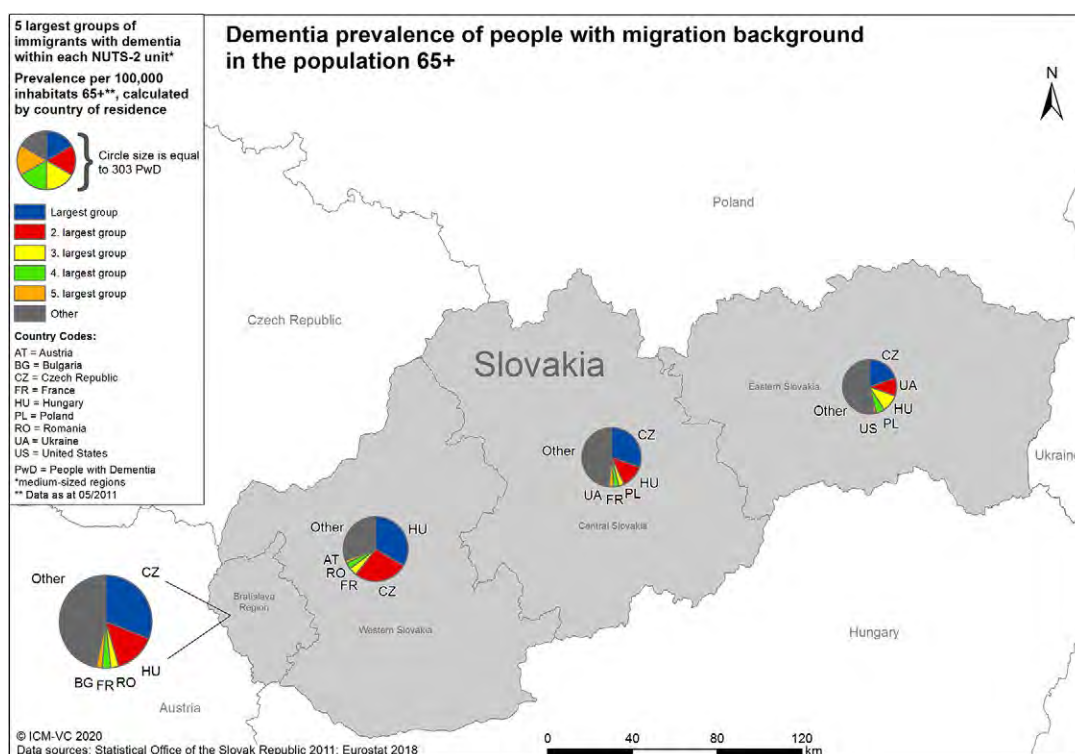


Fig. 3.7.27.10: Prevalence of PwM with dementia among the population aged 65+ (Slovakia – NUTS2)

**Tab. 47: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovakia – NUTS 2)**

NUTS	Total	SK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Bratislava Region	3,306	2,851	CZ 141	HU 66	RO 13	FR 13	BG 10	212
Western Slovakia	10,030	9,177	HU 286	CZ 232	FR 34	RO 26	AT 14	261
Central Slovakia	6,767	6,254	CZ 156	HU 65	PL 15	FR 15	UA 14	248
Eastern Slovakia	7,223	6,716	CZ 100	UA 55	HU 53	PL 26	US 7	266
Prevalence/10,000 inhabitants with migration background 65+								
Bratislava Region	4,431	-	CZ 189	HU 89	RO 17	FR 17	BG 14	284
Western Slovakia	6,127	-	HU 175	CZ 142	FR 21	RO 16	AT 9	159
Central Slovakia	8,894	-	CZ 205	HU 86	PL 20	FR 19	UA 18	326
Eastern Slovakia	10,666	-	CZ 147	UA 82	HU 78	PL 38	US 10	393

NUTS	Total	SK	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/100,000 inhabitants 65+								
Bratislava Region	4,000	3,449	CZ 170	HU 80	RO 16	FR 16	BG 12	257
Western Slovakia	4,000	3,660	HU 114	CZ 93	FR 14	RO 10	AT 6	104
Central Slovakia	4,000	3,697	CZ 92	HU 39	PL 9	FR 9	UA 8	147
Eastern Slovakia	4,000	3,719	CZ 55	UA 31	HU 29	PL 14	US 4	148

Data source: Statistical Office of the Slovak Republic (2011)

## 3. National dementia plan

For Slovakia no NDP could be identified [11].

## 4. National dementia care and treatment guidelines

Currently, no publicly accessible national guidelines for dementia care in Slovakia could be found. According to a high-ranking repre-

sentative of the Slovak healthcare system, a document on combating dementia ('Slovakia Against Dementia') is being prepared [12].

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- University Hospital Bratislava: National treatment guidelines for dementia. In., E-Mail conversation edn; 2019.





# Slovenia

**Population**

2,096,000

**Area**

20,145 km<sup>2</sup>

**Capital**

Ljubljana

**3 largest cities**

Ljubljana (289,000)

Maribor (110,000)

Kranj (43,000)

**Neighboring countries**

Austria, Croatia,  
Hungary, Italy

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

The migration history of Slovenia after the Second World War can be divided into three periods: 1. 1945 to 1954: Slovenia was a country of emigration and had a negative migration balance. 2. 1955 to 1990: Slovenia developed into an immigration country. Further characteristics of this period were the immigration from the other regions of the former Yugoslavia (mainly from Bosnia and Herzegovina, Croatia, and Serbia) and the temporary migration of people to Germany and Austria. 3. From 1991: The collapse of Yugoslavia, the Yugoslav wars, and Slovenia's declaration of independence from Yugoslavia (1991) led to the emergence of forced migration and temporary refugee migration from war zones in the former Yugoslavia [1]. At the beginning of September 1991, 2,500 refugees from Croatia were registered in Slovenia, a month later there were already 20,000, and in December 23,000 registered refugees. In 1992 and 1993, Slovenia accepted about 70,000 refugees from Bosnia and Herzegovina [2]. The temporary reception of refugees from Bosnia and Herzegovina extended into the 2000s. Between 1998 and 2000, an increase in irregular migration from

African and Asian countries occurred, most of them using Slovenia as a transit country to Western Europe. There was also an increase in the number of asylum seekers (from Iraq, Iran, Bangladesh, Afghanistan, Turkey, Serbia and Montenegro, Bosnia and Herzegovina, Macedonia, Sierra Leone, and Algeria) [1]. Between October 2015 and March 2016, 477,791 migrants reached Slovenia; most of them subsequently migrated to Austria and other Northern and Western European countries [2]. In 2018, Bosnia and Herzegovina (107,700), Croatia (45,000), Serbia (25,400), North Macedonia (17,100), and Kosovo (17,100) were the main countries of origin of the migrants in Slovenia (as of 19.12.2019) [3]. Between 1990 and 2019, the migrant population (born abroad) increased from 178,100 to 253,100 and the proportion of migrants in the total population grew from 8.9 to 12.2% [4]. As of 2020, currently, the net migration rate is 1 [5]. Slovenia has developed from a country of emigration to a destination country for immigrants especially from other Eastern European states and a transit country for refugees from Asia and Africa [6].

## 2. Estimated number of people with a migration background with dementia

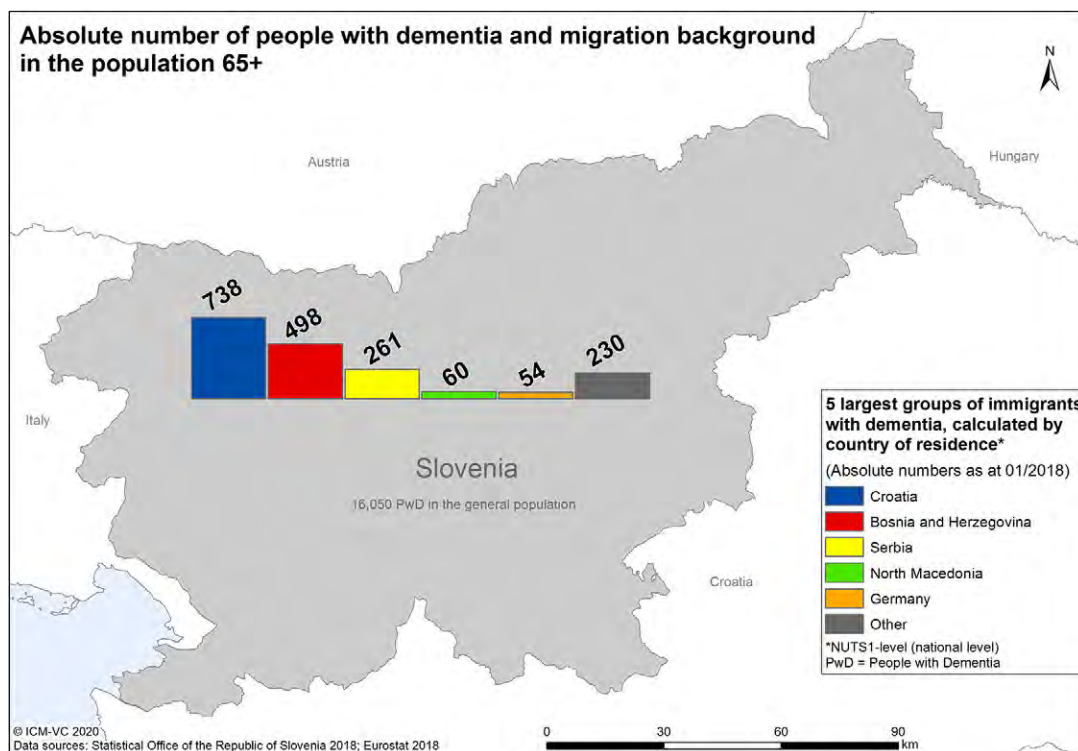


Fig. 3.7.28.1: Absolute number of PwM with dementia aged 65+ (Slovenia – Nation)

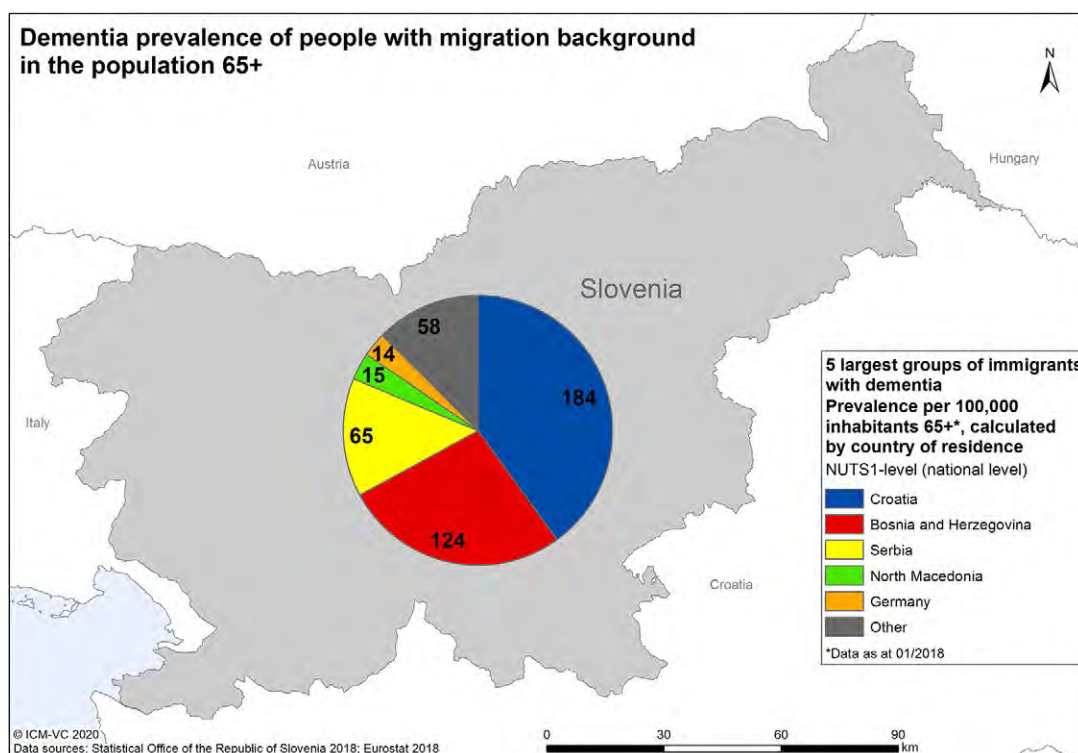


Fig. 3.7.28.2: Prevalence of PwM with dementia among the population aged 65+ (Slovenia – Nation)

**Tab. 48: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovenia – Nation)**

NUTS	Total	SI	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Slovenia	16,050	14,209	HR 738	BA 498	XS 261	MK 59	DE 54	230
Prevalence/10,000 inhabitants with migration background 65+								
Slovenia	3,486	-	HR 160	BA 108	XS 57	MK 13	DE 12	50
Prevalence/100,000 inhabitants 65+								
Slovenia	4,000	3,541	HR 184	BA 124	XS 65	MK 15	DE 13	459

Data source: Statistical Office of the Republic of Slovenia (2018)

There are 46,100 PwM aged 65 or older. Of those, approx. 1,800 are estimated to exhibit some form of dementia. Figure 3.7.28.1 shows the most affected migrant groups presumably originate from Croatia (approx. 700), Bosnia and Herzegovina (approx. 500), Serbia (approx. 300), North Macedonia (approx. 60), and Germany (approx. 50). The second graph highlights the number of PwM with dementia

in Slovenia per inhabitants aged 65 or older (figure 7.28.2). Table 48 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Croatia, Bosnia and Herzegovina, Serbia, North Macedonia, and Germany throughout the country in the NUTS2 regions (Figs. 3.7.28.3 – 3.7.28.8).

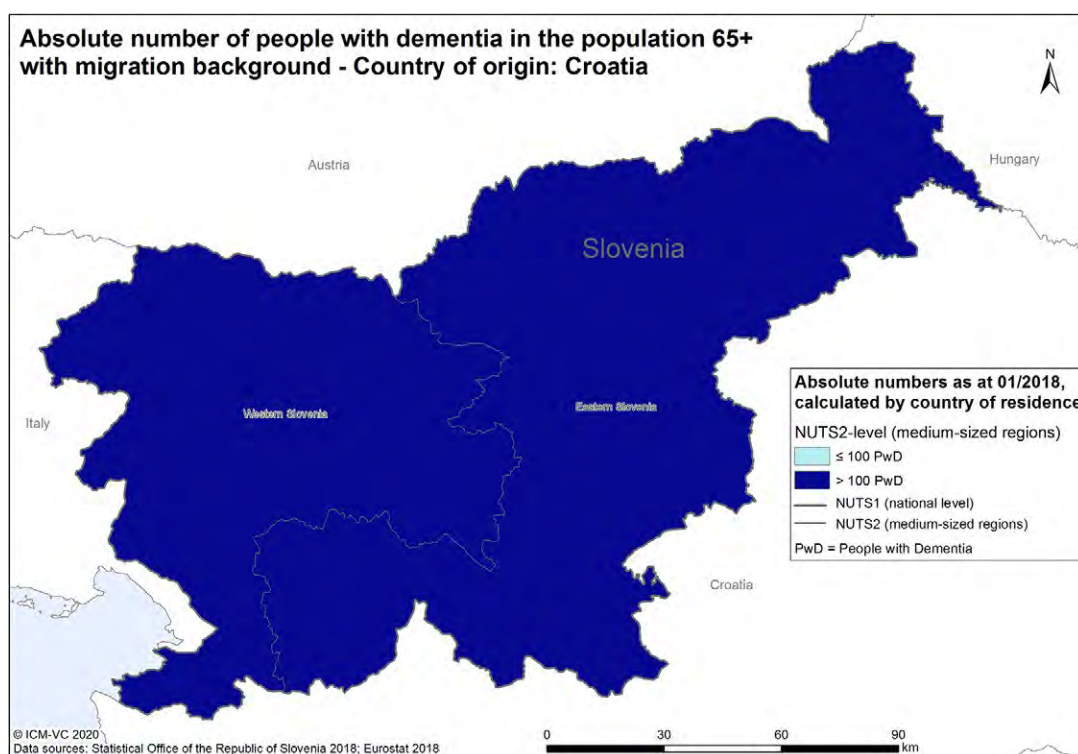


Fig. 3.7.28.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Croatia (Slovenia – NUTS2)

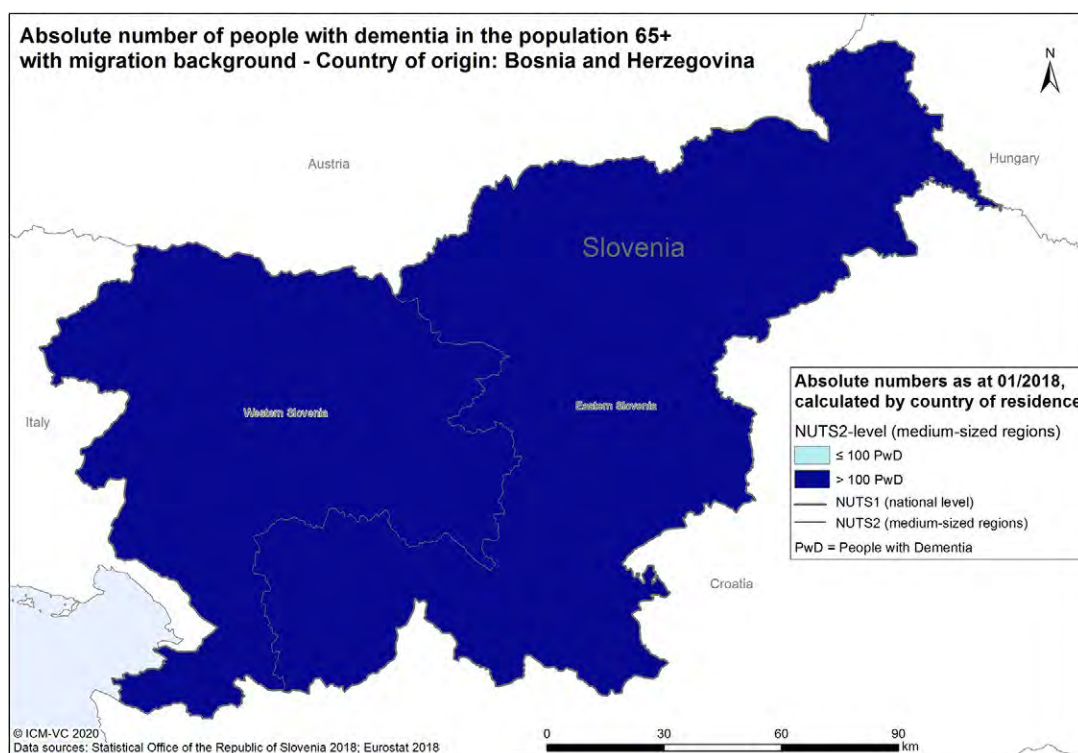


Fig. 3.7.28.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Bosnia and Herzegovina (Slovenia – NUTS2)



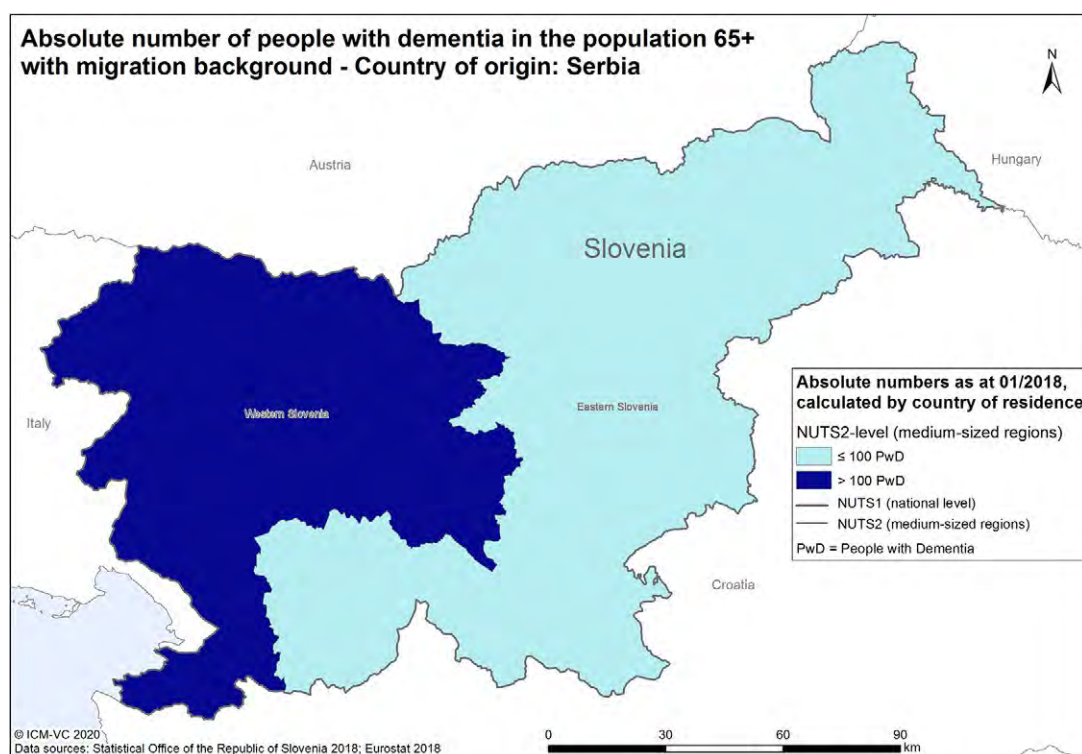


Fig. 3.7.28.5: Absolute number of PwM with dementia aged 65+. Country of origin: Serbia (Slovenia – NUTS2)

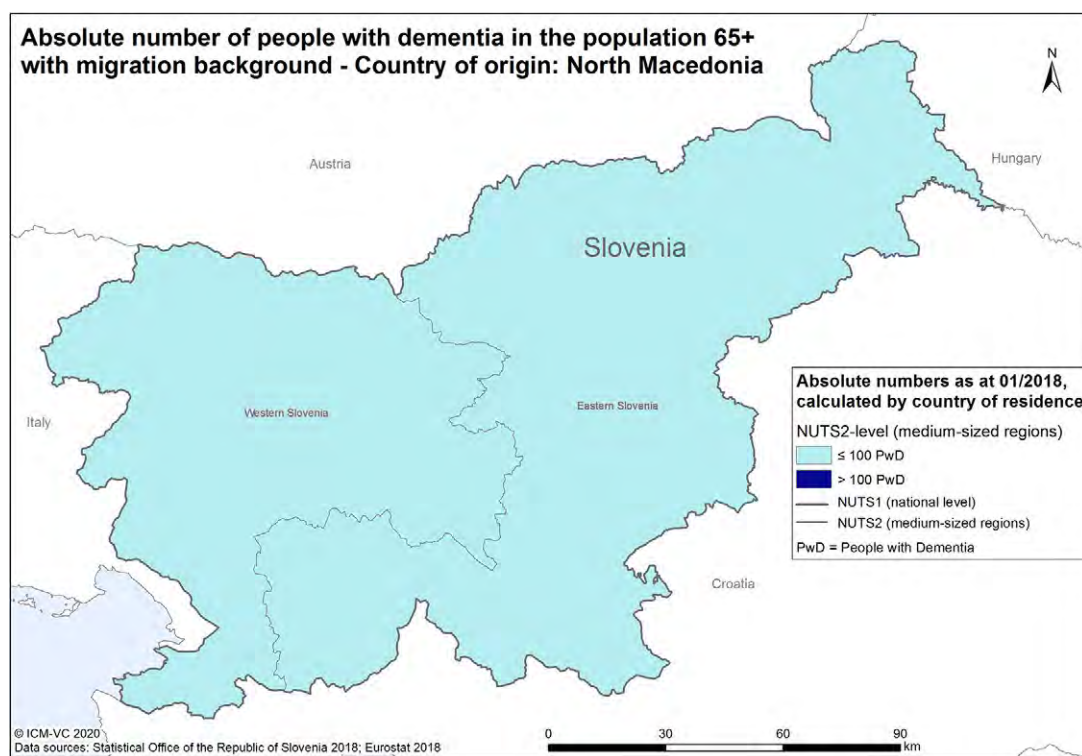


Fig. 3.7.28.6: Absolute number of PwM with dementia aged 65+. Country of origin: North Macedonia (Slovenia – NUTS2)



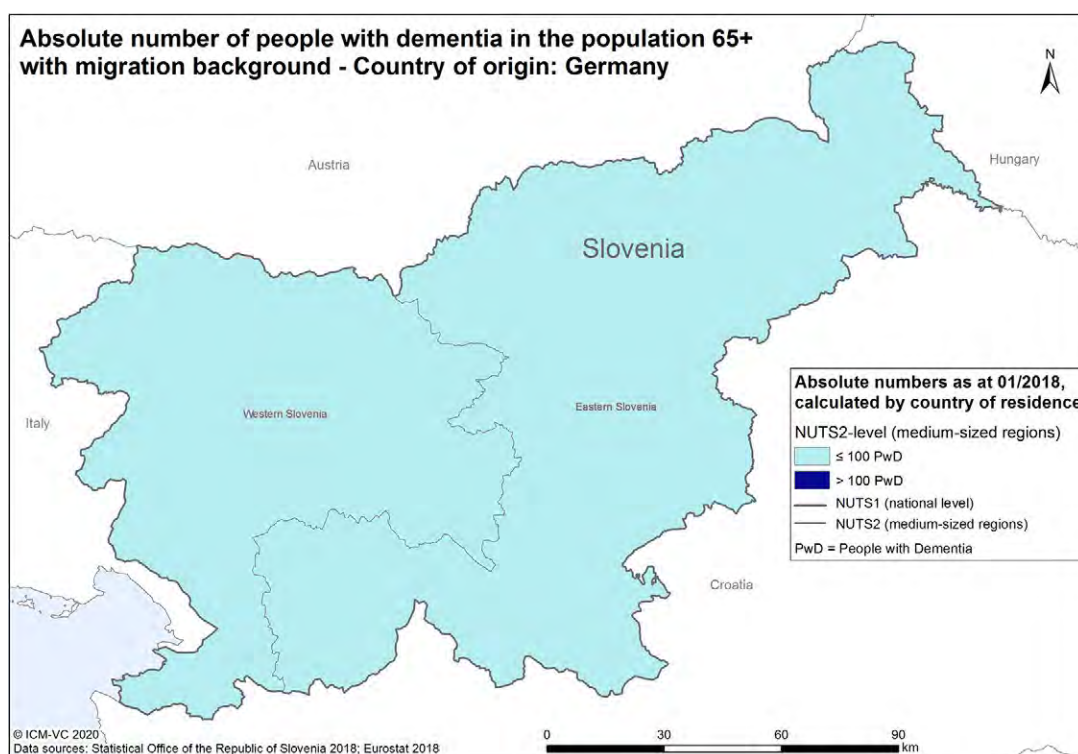


Fig. 3.7.28.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (Slovenia – NUTS2)

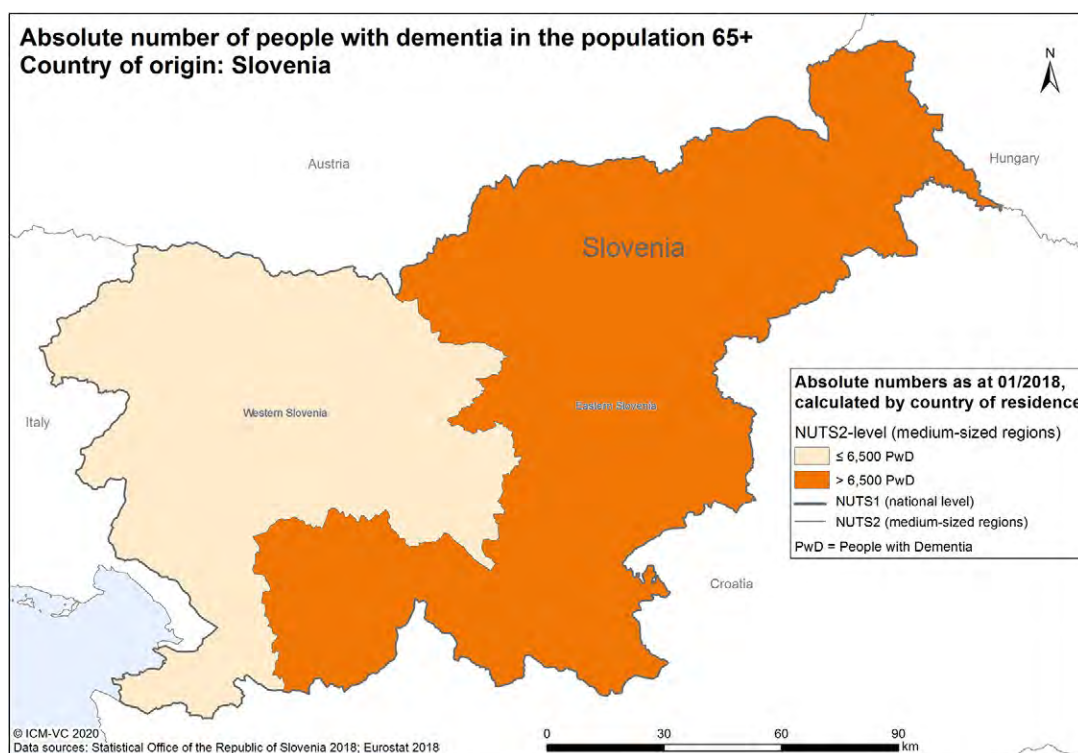


Fig. 3.7.28.8: Absolute number of people with dementia aged 65+.  
Country of origin: Slovenia (Slovenia – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.28.9). The

second map shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.28.10). The values from the NUTS2 level can be found in table 49 [7-9].

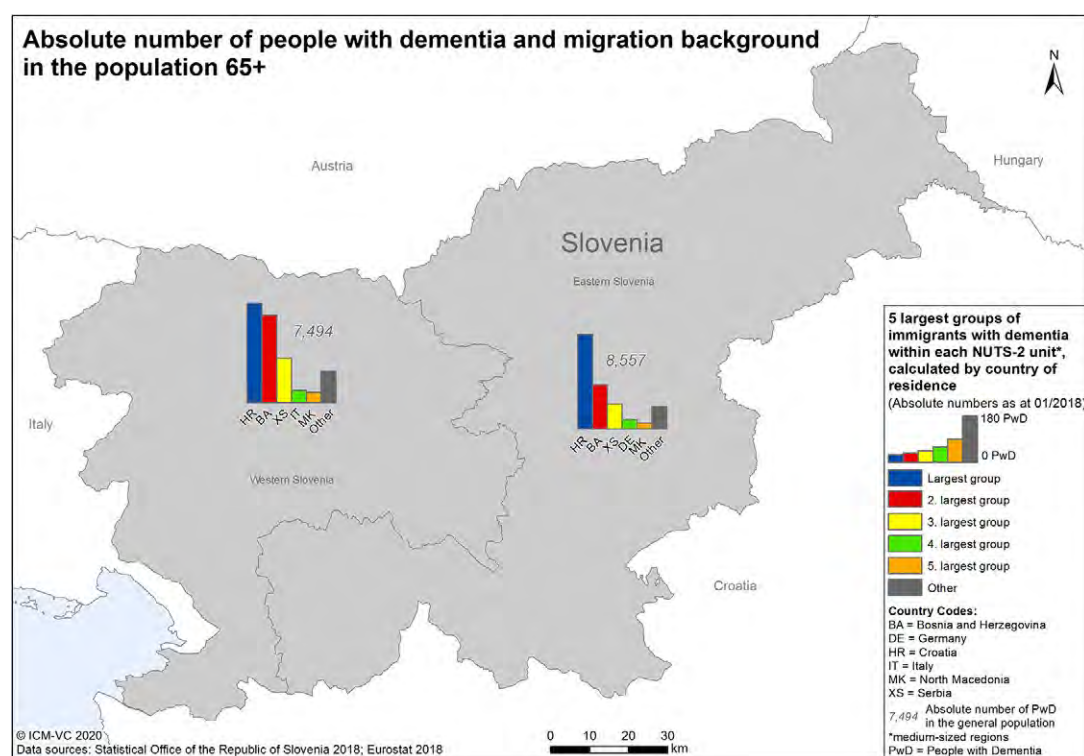


Fig. 3.7.28.9: Absolute number of PwM with dementia aged 65+ (Slovenia – NUTS2)

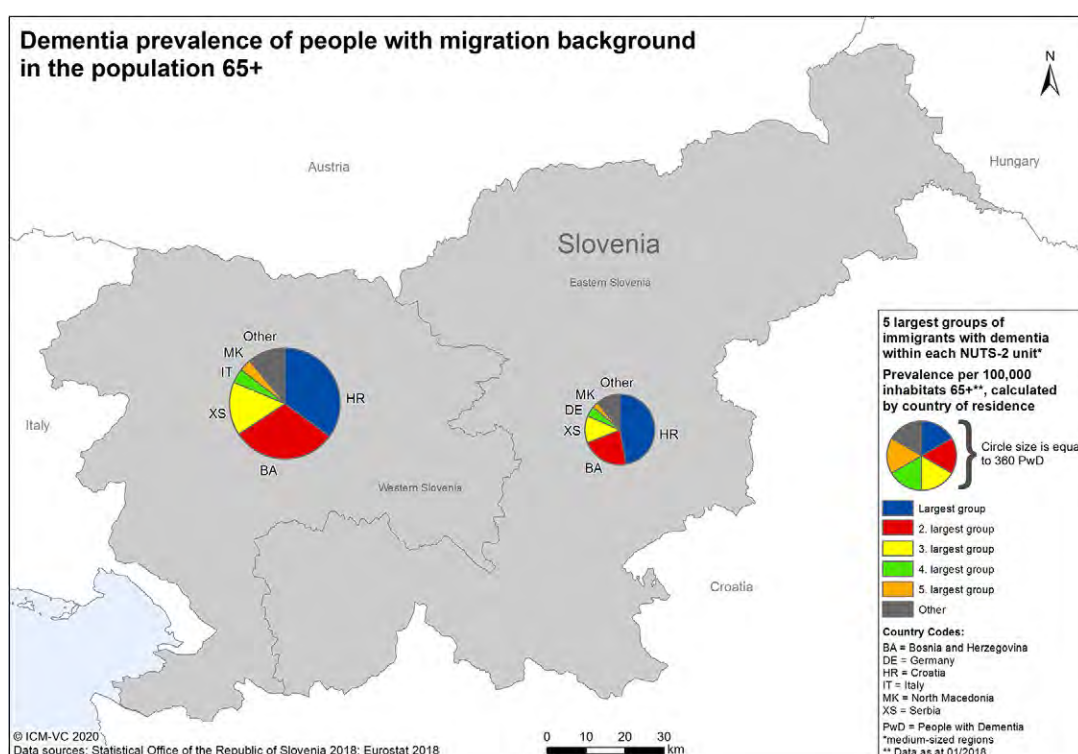


Fig. 3.7.28.10: Prevalence of PwM with dementia among the population aged 65+ (Slovenia – NUTS2)

Tab. 49: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovenia – NUTS 2)

NUTS	Total	SI	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Eastern Slovenia	8,557	7,787	HR 363	BA 169	XS 95	DE 36	MK 22	85
Western Slovenia	7,494	6,422	HR 375	BA 330	XS 166	IT 45	MK 38	118
Prevalence/10,000 inhabitants with migration background 65+								
Eastern Slovenia	4,444	-	HR 189	BA 88	XS 50	DE 19	MK 11	44
Western Slovenia	2,797	-	HR 140	BA 123	XS 62	IT 17	MK 14	44
Prevalence/100,000 inhabitants 65+								
Eastern Slovenia	4,000	3,640	HR 170	BA 79	XS 45	DE 17	MK 10	40
Western Slovenia	4,000	3,428	HR 200	BA 176	XS 89	IT 24	MK 20	63

Data source: Statistical Office of the Republic of Slovenia (2018)

### 3. National dementia plan

'Slovenia's Dementia Management Strategy 2020' from 2015 consists of 36 pages and addresses the topics of the epidemiology of dementia, early diagnosis, disease stigma, treatment of persons with dementia, multi-disciplinary treatment in the GP referral clinic, drug therapy with anti-dementia drugs, ac-

cess to social welfare services, palliative care, representation of persons with dementia, dementia research, epidemiological data, professional training, planning, as well as the role of stakeholders. However, none of these topics are related to migration [10].

### 4. National dementia care and treatment guidelines

The 'Guidelines for Treatment of Patients With Dementia' published in 2013 has 39 pages and covers the topics of the definition of mild cognitive decline and dementia, diagnosis of mild cognitive decline and dementia, treatment, behavioural and psychological symptoms of dementia, emergencies, delirium, medication, and psychosocial measures in dementia. The issue of migration is not mentioned at any point in the document [11]. In the 224-page document 'National Health Plan Resolution 2016-2025: Together for the Health Society'

from 2016, which has a section on dementia, migration is briefly mentioned, but not in the context of dementia. There it is generally stated that the high level of migration in the population of Slovenia is a challenge for the financial sustainability of the healthcare system. Furthermore, it is pointed out that poor access for certain population groups due to their ethnic origin and low socioeconomic status leads to growing health inequalities. Language and cultural differences are explicitly mentioned as barriers to healthcare access [12].

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# Spain

**Population**

47,330,000

**Area**

502,654 km<sup>2</sup>

**Capital**

Madrid

**3 largest cities**

Madrid (3,330,000)

Barcelona (1,660,000)

Valencia (800,000)

**Neighboring countries**

Andorra, France,

Portugal

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References

## 1. Migration history

Over the last 500 years, Spain's migration was characterised by emigration, especially to Latin America. It reached its peak between 1905 and 1913 when 1.5 million people left the country for Argentina, Uruguay, Brazil, and Venezuela. Between 1946 and 1958, further 624,000 people emigrated. Afterward, the number of emigrants to Latin America decreased (300,000 between 1958 and 1975) and emigration shifted towards other European countries. Between 1960 and 1975, about two million people emigrated to Germany, France, and Switzerland [1, 2]. Approximately 1.5 million of them returned to Spain. In the 1970s and 1980s, the immigration of people from Latin America, the Philippines, and the former colony of Equatorial Guinea, as well as pensioners from Northern and Western Europe increased. In the following years, migration trends shifted towards south-north migration from North Africa (especially Morocco) and east-west migration from Central and Eastern Europe. Spain became the second most popular destination for migrants from Romania. Between 1975 and 2000, the number of foreigners increased fivefold, and from 2000 to 2007, the number of holders of residence permits grew by 20% annually [1].

After the financial crisis in 2008, the number of immigrants decreased for several years. This trend was interrupted by the arrival of 457,700 migrants in 2011 [3]. Between 2016 and 2018, the number of refugees and migrants who arrived in Spain via the western Mediterranean route has increased again (from 14,600 to 65,400) [4]. Most migrants came from Morocco, Algeria, Guinea, the Côte d'Ivoire, Gambia, and Syria [4, 5]. Spain is a popular destination for pensioners from Northern and Western Europe, for foreign workers from Eastern Europe (especially Romania), Portugal, Latin America (Ecuador, Colombia, Bolivia) and North Africa (especially Morocco) and, for several years now, for migrants from Sub-Saharan Africa (Nigeria and Senegal) [1]. In 2013, the largest migrant groups were from Romania (797,600), Morocco (745,700), Ecuador (451,200), United Kingdom and Northern Ireland (381,000), and Colombia (359,200) [6]. Between 1990 and 2019, the migrant population (born abroad) grew more than sevenfold (821,600 to 6.1 million) and the proportion of migrants in the total population more than sixfold (2.1 to 13.1%) [7]. As of 2020, the net migration rate is 0.9 [8]. Overall, Spain has developed into an immigration country since 1990.



## 2. Estimated number of people with a migration background with dementia

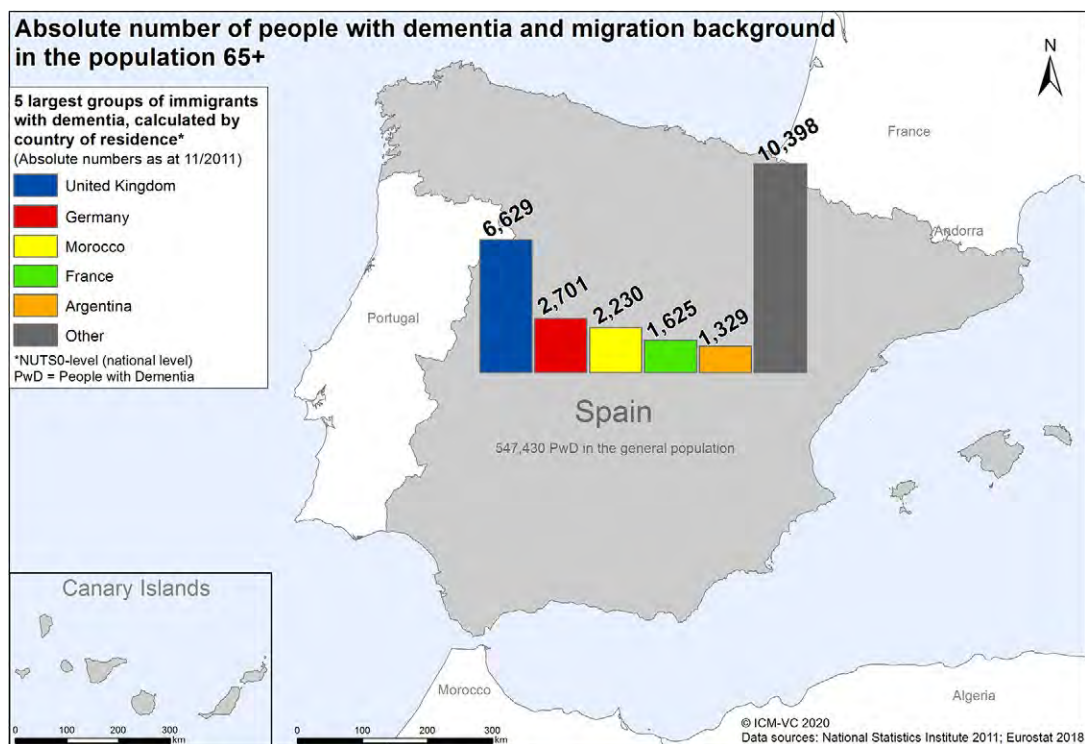


Fig. 3.7.29.1: Absolute number of PwM with dementia aged 65+ (Spain – Nation)

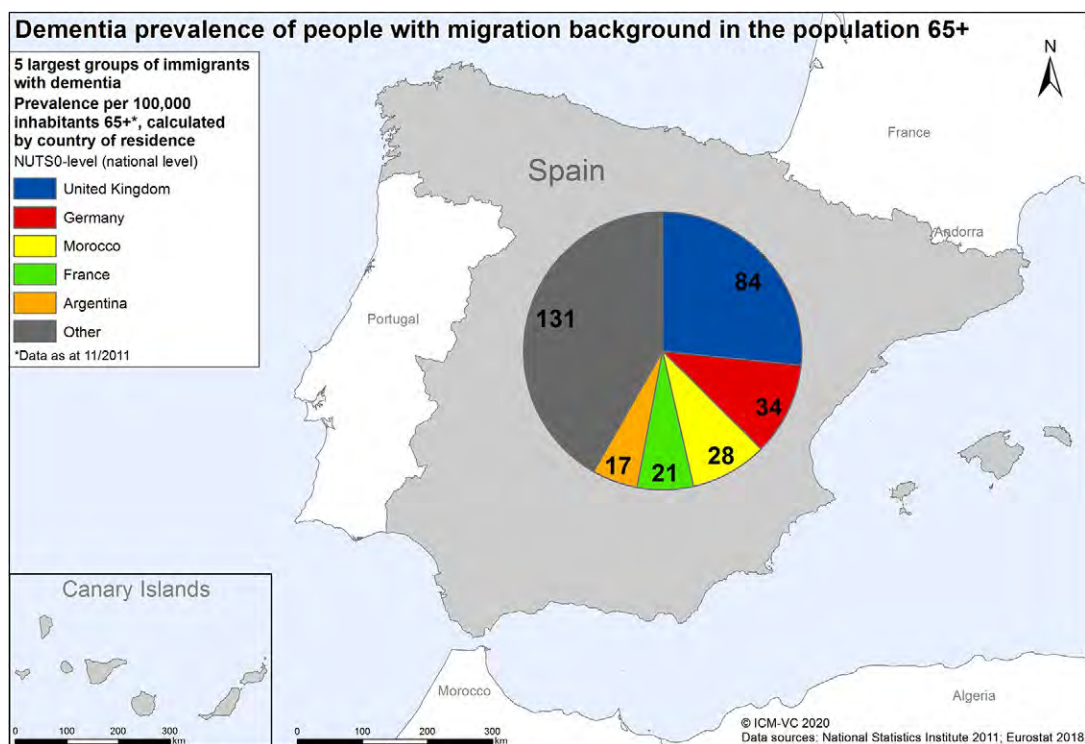


Fig. 3.7.29.2: Prevalence of PwM with dementia among the population aged 65+ (Spain – Nation)

**Tab. 50: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Spain – Nation)**

NUTS	Total	ES	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Spain	547,430	522,519	UK 6,629	DE 2,701	MA 2,230	FR 1,625	AR 1,329	10,398
Prevalence/10,000 inhabitants with migration background 65+								
Spain	15,162	-	UK 184	DE 75	MA 62	FR 45	AR 37	287
Prevalence/100,000 inhabitants 65+								
Spain	6,900	6,586	UK 84	DE 34	MA 28	FR 20	AR 17	131

Data source: National Statistics Institute (2011)

There are 361,000 PwM aged 65 or older. Of those, approx. 24,900 are estimated to exhibit some form of dementia. Figure 3.7.29.1 shows the most affected migrant groups presumably originate from United Kingdom (approx. 6,600), Germany (approx. 2,700), Morocco (approx. 2,200), France (approx. 1,600), and Argentina (approx. 1,300). The second graph highlights the number of PwM with dementia

in Spain per 100,000 inhabitants aged 65 or older (figure 3.7.29.2). Table 50 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from United Kingdom, Germany, Morocco, France, and Argentina throughout the country in the NUTS2 regions (figures 3.7.29.3 – 3.7.29.8).

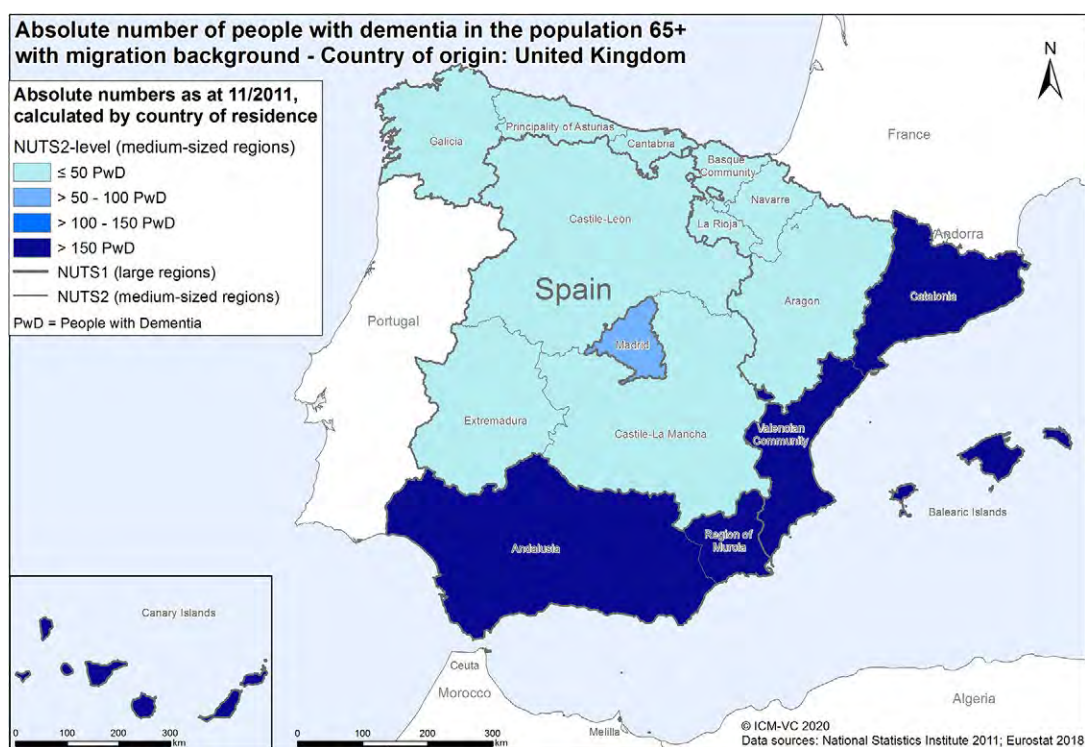


Fig. 3.7.29.3: Absolute number of PwM with dementia age 65+.  
Country of origin: United Kingdom (Spain – NUTS2)

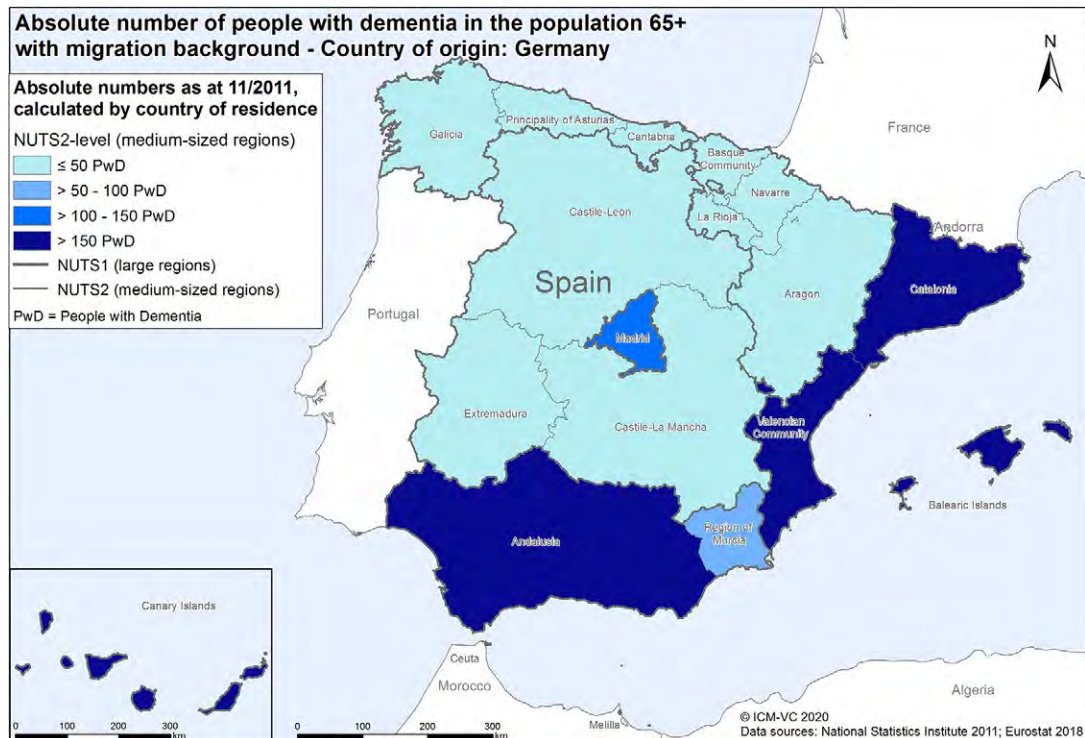


Fig. 3.7.29.4: Absolute number of PwM with dementia age 65+.  
Country of origin: Germany (Spain – NUTS2)



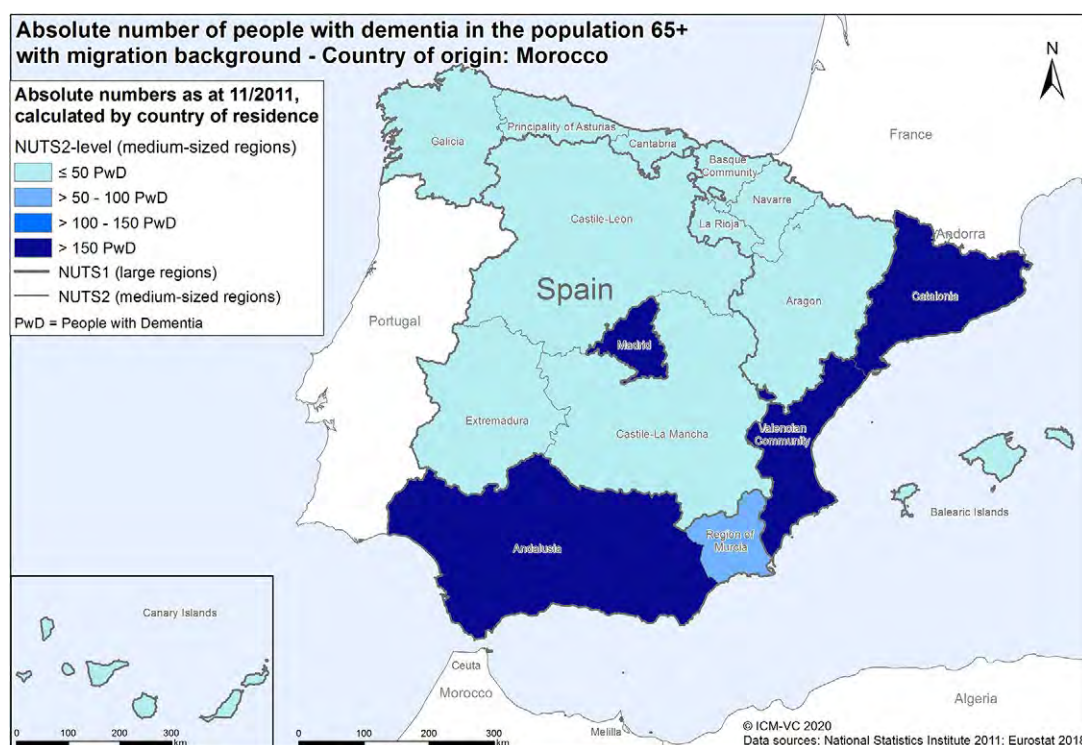


Fig. 3.7.29.5: Absolute number of PwM with dementia age 65+.  
Country of origin: Morocco (Spain – NUTS2)

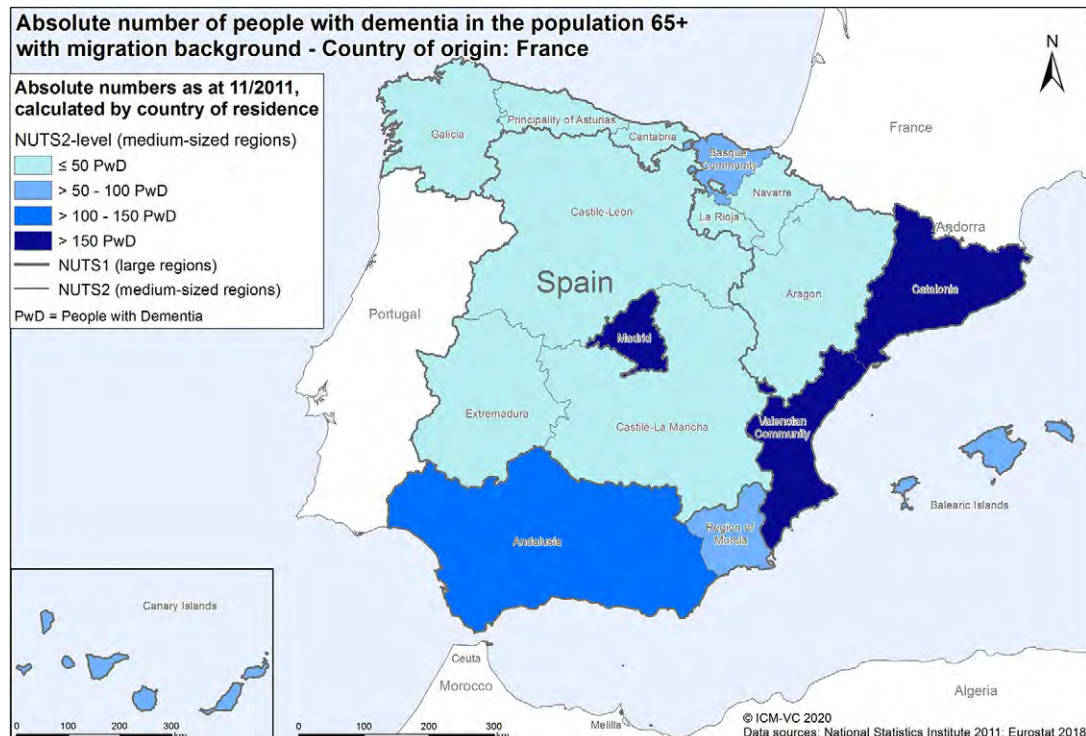


Fig. 3.7.29.6: Absolute number of PwM with dementia age 65+.  
Country of origin: France (Spain – NUTS2)

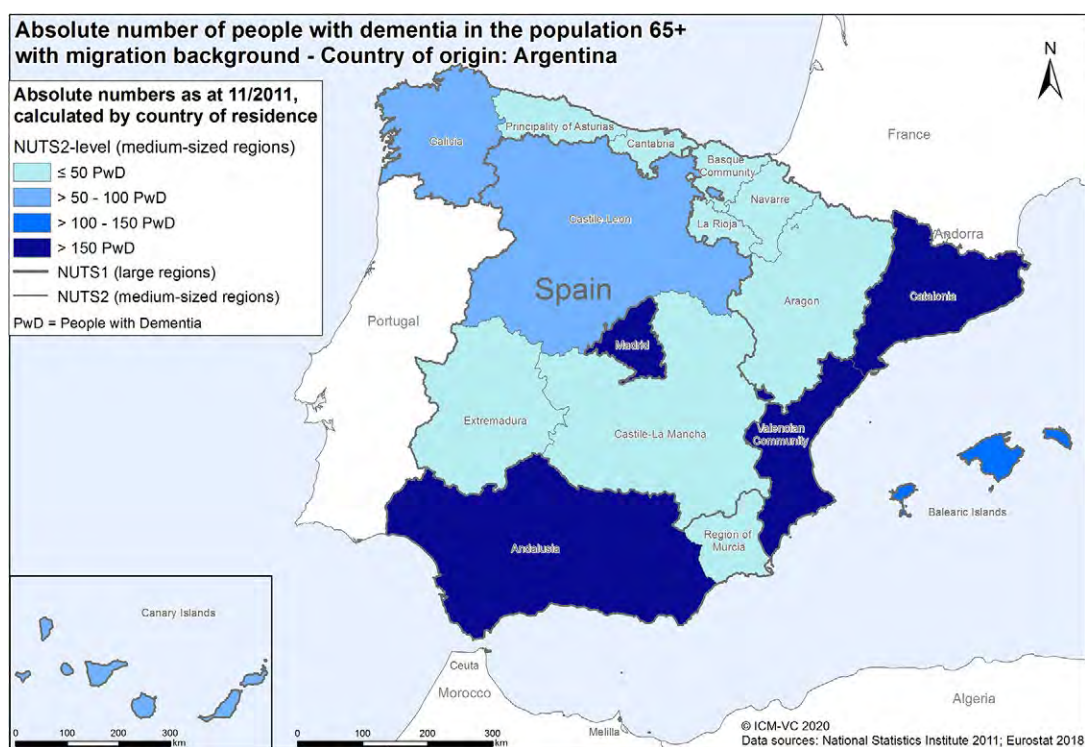


Fig. 3.7.29.7: Absolute number of PwM with dementia age 65+.  
Country of origin: Argentina (Spain – NUTS2)

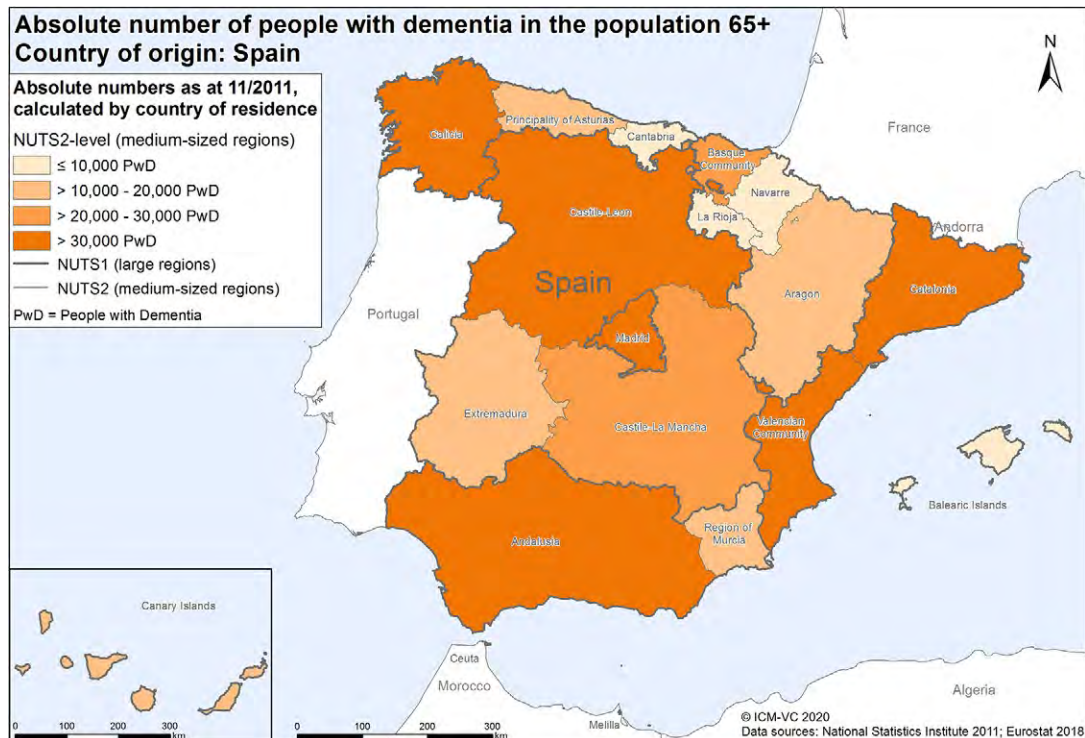


Fig. 3.7.29.8: Absolute number of people with dementia age 65+.  
Country of origin: Spain (Spain – NUTS2)

The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.29.9). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.29.10). The values from the NUTS2 level can be found in table 51 [9-12].

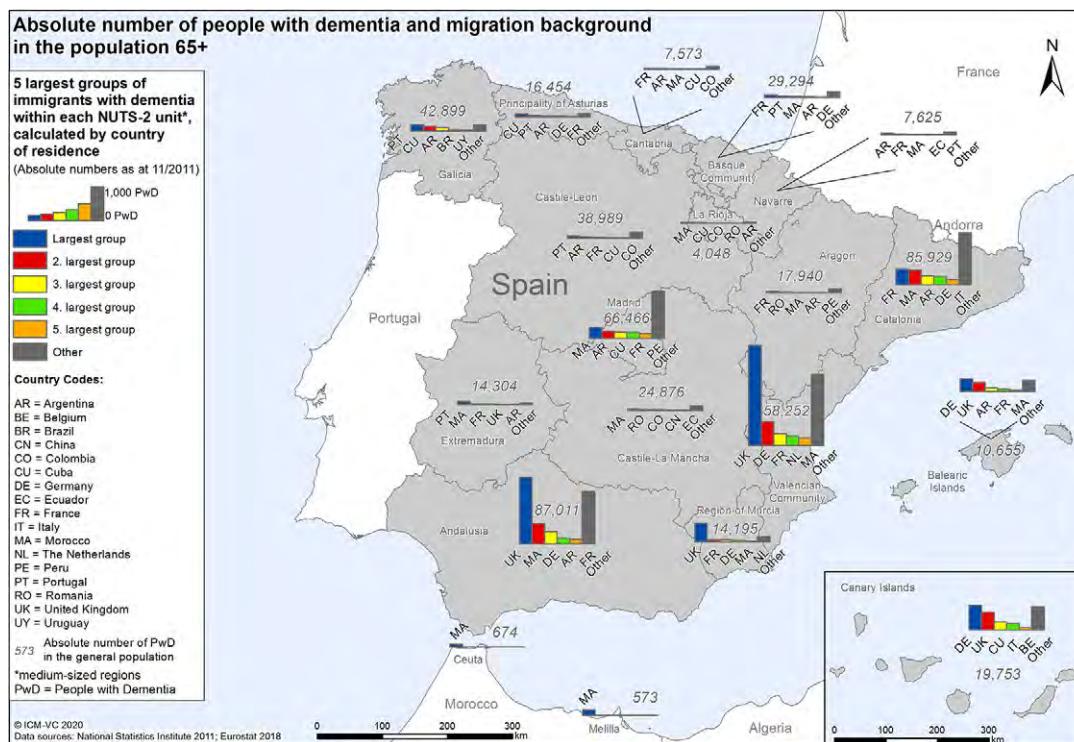


Fig. 3.7.29.9: Absolute number of PwM with dementia aged 65+ (Spain – NUTS2)



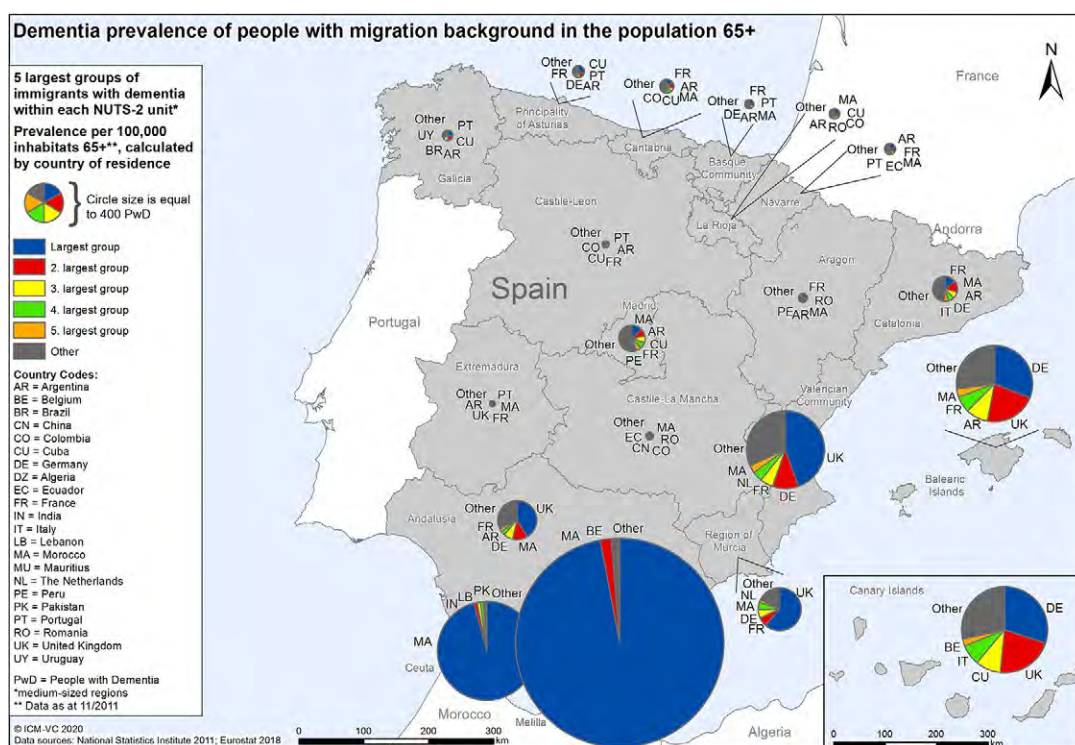


Fig. 3.7.29.10: Prevalence of PwM with dementia among the population aged 65+ (Spain – NUTS2)

Tab. 51: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Spain – NUTS 2)

NUTS	Total	ES	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Galicia	42,899	42,235	PT 188	CU 139	AR 95	BR 33	UY 30	179
Principality of Asturias	16,454	16,162	CU 85	PT 46	AR 24	DE 22	FR 19	97
Cantabria	7,573	7,415	FR 23	AR 22	MA 15	CU 14	CO 11	72
Basque Community	29,294	28,899	FR 81	PT 43	MA 40	AR 29	DE 21	180
Navarre	7,625	7,499	AR 31	FR 13	MA 10	EC 8	PT 7	57
La Rioja	4,048	3,985	MA 13	CU 9	CO 6	RO 6	AR 5	23
Aragon	17,940	17,703	FR 43	RO 22	MA 18	AR 16	PE 14	124
Madrid	66,466	63,946	MA 337	AR 227	CU 199	FR 183	PE 153	1,420

NUTS	Total	ES	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Castile-Leon	38,989	38,589	PT 73	AR 50	FR 47	CU 25	CO 23	183
Castila-La Mancha	24,876	24,594	MA 44	RO 28	CO 27	CN 20	EC 19	146
Extremadura	14,304	14,181	PT 60	MA 14	FR 12	UK 6	AR 5	27
Catalonia	85,929	82,753	FR 472	MA 449	AR 273	DE 243	IT 169	1,571
Valencian Community	58,252	51,660	UK 2,941	DE 711	FR 354	NL 275	MA 218	2,093
Balearic Islands	10,655	9,461	DE 370	UK 263	AR 111	FR 82	MA 43	323
Andalusia	87,011	81,965	UK 2,081	MA 635	DE 384	AR 175	FR 145	1,626
Region of Murcia	14,195	13,296	UK 551	FR 60	DE 59	MA 52	NL 20	157
Ceuta	674	576	MA 93	<5	<5	<5	<5	1
Melilla	573	393	MA 169	<5	<5	<5	<5	2
Canary Islands	19,753	17,268	DE 747	UK 535	CU 238	IT 190	BE 68	707
Prevalence/10,000 inhabitants with migration background 65+								
Galicia	44,570	-	PT 196	CU 144	AR 99	BR 34	UY 31	186
Principality of Asturias	38,762	-	CU 199	PT 108	AR 58	DE 52	FR 44	229
Cantabria	33,214	-	FR 103	AR 98	MA 65	CU 62	CO 47	315
Basque Community	51,168	-	FR 141	PT 76	MA 71	AR 51	DE 37	315
Navarre	41,778	-	AR 168	FR 74	MA 53	EC 42	PT 40	314
La Rioja	44,973	-	MA 146	CU 100	CO 69	RO 69	AR 54	253
Aragon	52,076	-	FR 126	RO 64	MA 53	AR 45	PE 42	360
Madrid	18,205	-	MA 92	AR 62	CU 55	FR 50	PE 42	389
Castile-Leon	67,108	-	PT 125	AR 87	FR 80	CU 43	CO 40	315
Castila-La Mancha	60,821	-	MA 107	RO 68	CO 65	CN 48	EC 46	356



NUTS	Total	ES	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Extremadura	80,135	-	PT 336	MA 77	FR 66	UK 33	AR 27	151
Catalonia	18,666	-	FR 103	MA 98	AR 59	DE 53	IT 37	341
Valencian Community	6,098	-	UK 308	DE 74	FR 37	NL 29	MA 23	219
Balearic Islands	6,161	-	DE 214	UK 152	AR 64	FR 48	MA 25	187
Andalusia	11,899	-	UK 285	MA 87	DE 52	AR 24	FR 20	222
Region of Murcia	10,894	-	UK 423	FR 46	DE 45	MA 40	NL 15	121
Ceuta	4,759	-	MA 655	IN 7	LB 7	PK 7	PT 6	7
Melilla	2,204	-	MA 652	BE 11	AR 6	MU 6	DZ 5	9
Canary Islands	5,484	-	DE 207	UK 148	CU 66	IT 53	BE 19	196
Prevalence/100,000 inhabitants 65+								
Galicia	6,900	6,793	PT 30	CU 22	AR 15	BR 5	UY 5	29
Principality of Asturias	6,900	6,777	CU 35	PT 19	AR 10	DE 9	FR 8	41
Cantabria	6,900	6,757	FR 21	AR 20	MA 14	CU 13	CO 10	65
Basque Community	6,900	6,807	FR 19	PT 10	MA 10	AR 7	DE 5	42
Navarre	6,900	6,786	AR 28	FR 12	MA 9	EC 7	PT 7	52
La Rioja	6,900	6,794	MA 22	CU 15	CO 11	RO 11	AR 8	39
Aragon	6,900	6,809	FR 17	RO 8	MA 7	AR 6	PE 6	48
Madrid	6,900	6,638	MA 35	AR 24	CU 21	FR 19	PE 16	147
Castile-Leon	6,900	6,829	PT 13	AR 9	FR 8	CU 4	CO 4	32
Castila-La Mancha	6,900	6,822	MA 12	RO 8	CO 7	CN 5	EC 5	40
Extremadura	6,900	6,841	PT 29	MA 7	FR 6	UK 3	AR 2	13
Catalonia	6,900	6,645	FR 38	MA 36	AR 22	DE 20	IT 14	126

NUTS	Total	ES	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Valencian Community	6,900	6,119	UK 348	DE 84	FR 42	NL 33	MA 26	248
Balearic Islands	6,900	6,127	DE 240	UK 170	AR 72	FR 53	MA 28	209
Andalusia	6,900	6,500	UK 165	MA 50	DE 30	AR 14	FR 11	129
Region of Murcia	6,900	6,463	UK 268	FR 29	DE 29	MA 25	NL 10	76
Ceuta	6,900	5,900	MA 950	IN 11	LB 11	PK 11	PT 9	10
Melilla	6,900	4,740	MA 2,042	BE 36	AR 19	MU 18	DZ 17	28
Canary Islands	6,900	6,032	DE 261	UK 187	CU 83	IT 67	BE 24	247

Note: Absolute numbers < 5 are not given for data protection reasons.

Data source: National Statistics Institute (2011)

## 3. National dementia plan

Spain has published a National Strategy for Neurodegenerative Diseases in 2016 and a National Alzheimer's Plan in 2019.

The 'Strategy for Neurodegenerative Diseases of the National Health System' from 2016 has 165 pages. It addresses different neurodegenerative diseases prevalent in Spain such as Alzheimer's disease and other dementias, Parkinson's disease, and multiple sclerosis. It discusses aspects such as prevention and early detection, support and care of patients, support for family caregivers, autonomy and rights of patients, education and training of professionals, and research and coordination of health and social care. However, the document does not refer to the topic of migration [13].

The 94-page 'Comprehensive Plan for Alzheimer's and Other Dementias (2019–2023)' from 2019, which covers the topics: scope and impact of Alzheimer's disease on society and health; policy context and legal framework; raising public awareness of

Alzheimer's disease; living environment of the person with Alzheimer's disease; prevention, diagnosis, and treatment; rights, ethics, and human dignity; as well as research, innovation, and knowledge, also does not refer directly to migration. However, in three passages of two chapters, this document briefly addresses a sub-theme related to dementia and migration, that is, the issue of culturally sensitive care. In these passages, the importance of developing awareness campaigns and care programs on Alzheimer's disease and that are appropriate to the cultural context and the specific needs of the respective communities is emphasised. With regard to the care of people with Alzheimer's disease, it is stated that the needs and preferences of these individuals should be considered by developing coordinated support systems and providing health and psychosocial care that is person-centred, culturally appropriate, and has a strong community base. The use of innovative social and health

technologies can be beneficial for people with Alzheimer's disease and their caregivers if age-, gender-, and culturally-specific needs are taken into account [14].

Within the context of several areas of care for people with Alzheimer's disease, the Spanish Alzheimer's plan highlights the importance

of considering the cultural background of the persons with Alzheimer's disease, but there is no specific focus on people with a different cultural background than the autochthonous population. Overall, the topic of migration does not play a relevant role in these national plans/strategies.

## 4. National dementia care and treatment guidelines

The 'Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias' from 2010 is no longer valid, but still publicly available. Furthermore, no newer dementia-specific guidelines could be identified. The document does not have a separate chapter on migration, but in several sections, it refers briefly to the topics of cultural differences in care and the proportion of immigrants among caregivers. First, the aim of culturally independent equal opportunities in health and social care is formulated. The implied statement that culture influences opportunities in health and social care is again made explicitly for the group of people suffering from dementia and their families. Thereby, the problem is identified that the cultural background of a person can influence the results of the cognitive tests used for the diagnosis of dementia. In the section on dementia treatment, it is pointed out that the information provided to patients and families must also consider their ethnicity, culture, and religion. The guideline repeats several times that in the case of language barriers an independent mediator must be consulted. It also mentions cultural influences as one reason for the low utilisation of the support services of the Asociación de Familiares de Enfermos de *Alzheimer* y Dementias (=Association of Families of Patients with Alzheimer's Disease) (AFA), which offers counselling for holistic care of people with dementia and represents the

interests of these persons and their families before other institutions. In another chapter, an assessment of the treatment of dementia patients is given. Here, it is described that the treatment of dementia patients by professional caregivers without dementia-specific education or training has increased significantly. It is pointed out that these carers are mainly young immigrants, the majority of whom come from Latin America. Thus, a specific need for training is identified in the group of young carers with a migration background and especially in the subgroup of immigrants from Latin America. Another topic discussed is the abuse of people with dementia. In this regard, the influence of cultural factors on the risk of abuse of people with dementia is discussed and the consideration of cultural differences in the investigation of cases of abuse is demanded. In the context of psycho-emotional and psycho-social needs of people with advanced dementia, it is identified that people from other cultural or religious groups may have different spiritual needs that should be considered. The 'Clinical Practice Guideline on the Comprehensive Care of People with Alzheimer's Disease and Other Dementias' describes various challenges regarding dementia in people with a different cultural background and gives some recommendations for improving the care situation of this group. However, no reference is made to currently available specialised healthcare services [15].

## 5. References

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# Sweden

**Population**

10,328,000

**Area**

407,000 km<sup>2</sup>

**Capital**

Stockholm

**3 largest cities**

Stockholm (1,759,000)

Gothenburg (651,000)

Malmö (322,000)

**Neighboring countries**

Denmark, Finland,

Norway

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

Sweden has a long history of migration. During the 15th and 17th century larger groups of Roma, Walloons, Jews, and people from Germany, France, and Italy came to Sweden. Between 1850 and the 1930s, 1.5 million people emigrated to America or Australia from Sweden [1]. In the early 20th century, there were also waves of emigration to Denmark and Norway [2]. Through the immigration of about 180,000 refugees from Finland, Norway, Estonia, Denmark, and Germany during the Second World War, Sweden developed into the immigration country it is today [1, 2]. In the 1960s and early 1970s, Sweden actively recruited labor migrants from the Netherlands, West Germany, Italy, Austria, Belgium, Greece, Yugoslavia, and Turkey. In addition, many migrants came from Finland [2]. After recruitment was stopped in 1972/73, many labour migrants (especially from Finland) returned to their home countries, resulting in a negative migration surplus in the early 1970s. In the 1980s and 1990s, refugee flows and family reunification increased significantly. Large groups of migrants came from Iran, Iraq, Lebanon, Syria, Turkey, Eritrea, Somalia, and Chile. During the war in Yugoslavia, about 100,000 Bosniaks were admitted. EU accession in 1995, accession to the Schengen Agreement in 2001, and

especially the EU enlargement rounds in 2004 and 2007 led to a significant increase in immigration from other EU states (especially Romania) [1, 2]. In recent years, immigration of asylum seekers, refugees, family members of existing migrants, and international students has increased. While less than 60,000 people immigrated in 2000, the number of annual immigrants has exceeded 100,000 annually since 2012 [1]. In 2014, 127,000 people moved to Sweden. Most of these immigrants were born in Syria (26,100), Eritrea (5,300), Poland (5,100), and Somalia (4,400). In addition, a large group of people born in Sweden returned from abroad (15,200). In terms of population size, Sweden was the main destination for asylum seekers in the EU in 2014 and 2015. In 2015, approximately 163,000 people applied for asylum [2]. People from Syria (191,500), Iraq (146,000), Finland (144,600), Poland (93,700), and Iran (80,100) were the largest migrant groups (born abroad) in 2019 [3]. Between 1990 and 2019, the migrant population (born abroad) and their proportion in the total population more than doubled (788,800 to 2 million; 9.2 to 20%) [4]. The net migration rate has always been positive in recent decades, and as of 2020 it is 4 [5].

## 2. Estimated number of people with a migration background with dementia

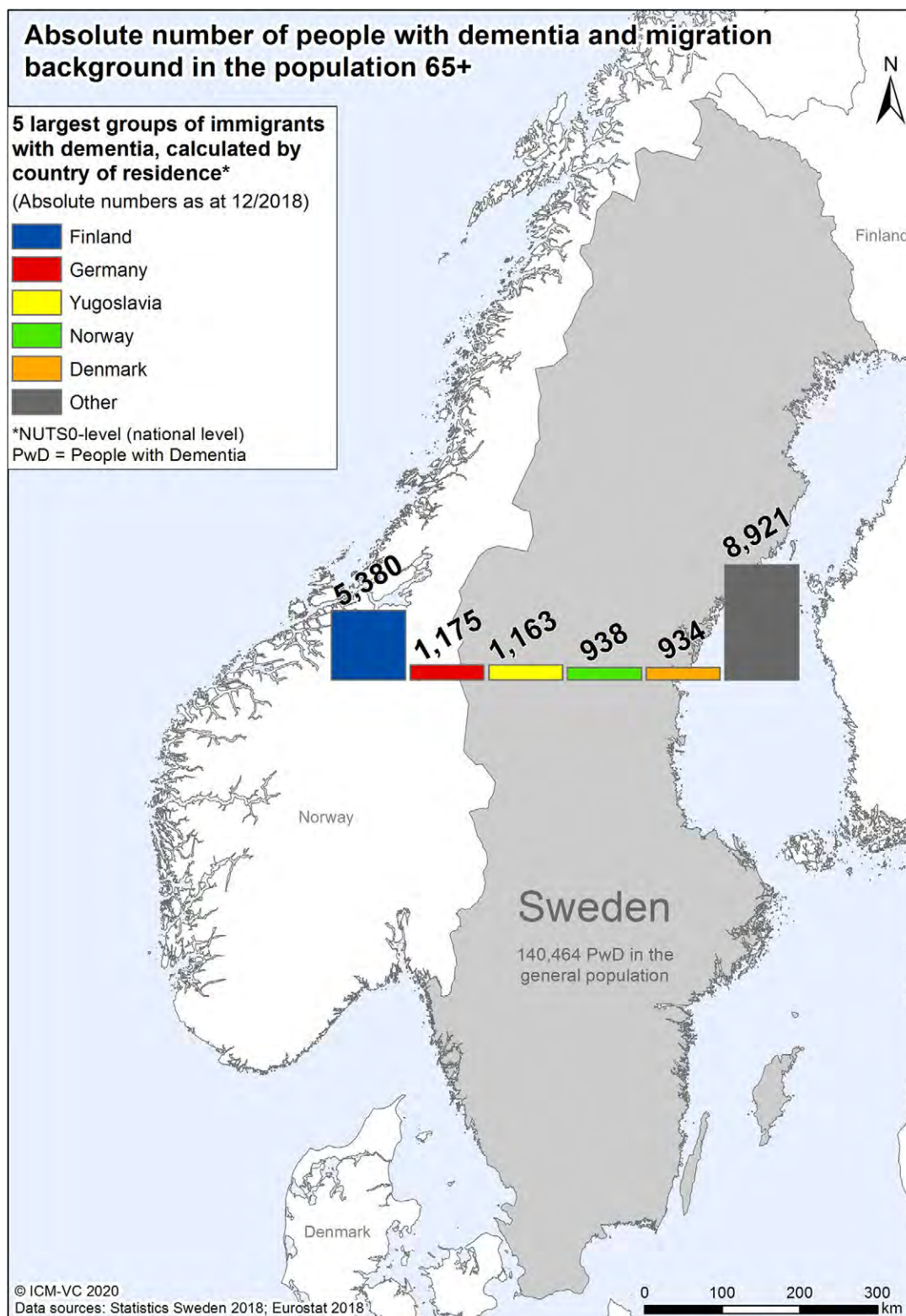


Fig. 3.7.30.1: Absolute number of PwM with dementia aged 65+ (Sweden – Nation)

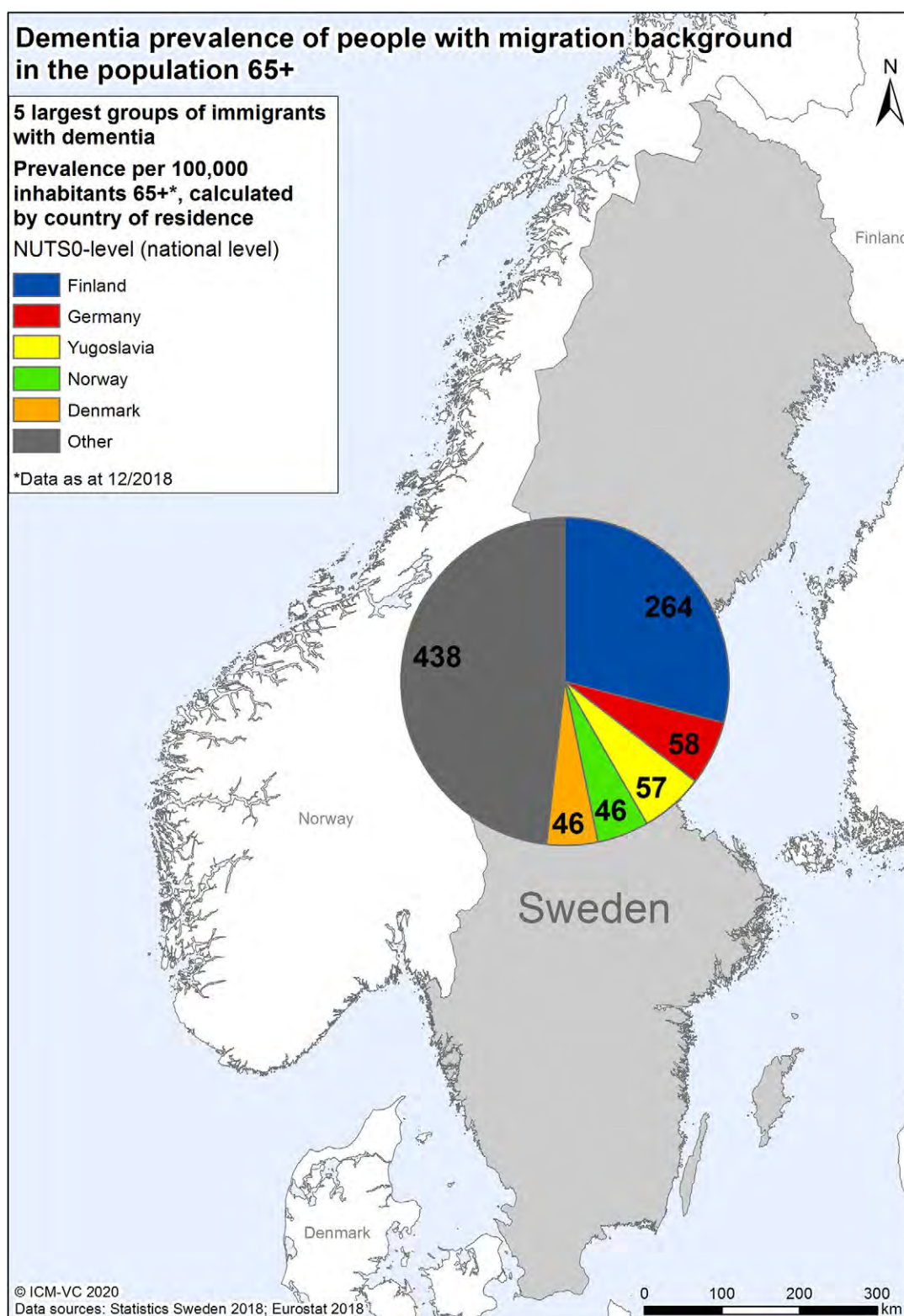


Fig. 3.7.30.2: Prevalence of PwM with dementia among the population aged 65+ (Sweden – Nation)

**Tab. 52: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Sweden – Nation)**

NUTS	Total	SE	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Sweden	140,464	121,953	FI 5,380	DE 1,175	YU 1,163	NO 938	DK 934	8,921
Prevalence/10,000 inhabitants with migration background 65+								
Sweden	5,236	-	FI 201	DE 44	YU 43	NO 35	DK 35	332
Prevalence/100,000 inhabitants 65+								
Sweden	6,900	5,991	FI 264	DE 58	YU 57	NO 46	DK 46	438

Data source: Statistics Sweden (2018)

There are 268,300 PwM aged 65 or older. Of those, approx. 18,500 are estimated to exhibit some form of dementia. Figure 3.7.30.1 shows the most affected migrant groups presumably originate from Finland (approx. 5,400), Germany (approx. 1,200), Yugoslavia (approx. 1,200),

Norway (approx. 900), and Denmark (approx. 900). The second graph highlights the number of PwM with dementia in Sweden per 100,000 inhabitants aged 65 or older (figure 3.7.30.2). Table 52 illustrate the values depicted in the maps on the national level [6-8].

### 3. National dementia plan

Currently, no NDP could be identified for Sweden. However, according to a parliamentary speech by Prime Minister Stefan Löfven on 12 September 2017, the publication of a dementia strategy is planned [9, 10]. Furthermore, the National Board of Health and Welfare (Socialstyrelsen) has published the document 'A National Strategy for Dementia: Documentation and Proposal for a Plan for Prioritized Initiatives by 2022' in June 2017.

This document discusses the topic of migration in great detail. In a separate 4 ½ page section ('Foreign-Born People With Dementia'), six main topics ('Working with People With Dementia and a Foreign Background', 'Working with an Interpreter', 'RUDAS', 'Migration School', 'Care for the Elderly in National Minority Languages', 'Translation into other

Languages') and in 16 further text passages in ten chapters/subchapters, various issues related to migration are discussed. In these sections, the increasing need to examine and care for people who speak a language other than Swedish and have dementia is emphasised several times. According to the document, approximately 20,000 of the 160,000 people with dementia living in Sweden were born in another country. By 2036, the number of foreign-born people with a cognitive disease is expected to double. A general problem pointed out in this dementia strategy is that district councils and municipalities have only a few initiatives for people with dementia with a mother tongue other than Swedish. There is a particular lack in the areas of diagnostics and care for people with dementia. Only three dis-



district councils (Stockholm, Skåne, and Örebro) have initiated specific activities in these areas targeting people with a mother tongue other than Swedish. However, it is also stated that the district councils and municipalities need support to increase the willingness to help people who do not speak Swedish. Other major issues, according to a study by the Migration School, Knowledge Centre for Dementia Skåne that is referred to in this document, are that foreign-born people perform worse on traditional cognitive assessment instruments (e.g. MMSE), they receive less dementia-specific medication, and they are prescribed more neuroleptics than domestic-born people. Furthermore, it is repeatedly mentioned that there is a lack of interpreters in Sweden. According to the research findings cited, the quality of interpretation is often unsatisfactory and the communication gaps caused by inaccurate interpretation can have a negative impact on the results of cognitive tests and the subsequent diagnosis. Lack of expertise on the side of interpreters and lack of knowledge regarding how to best use interpretation services are cited as main reasons for this issue. To address these problems, the National Board of Health and Welfare recommends an improvement of recruitment practices and the expansion of training for interpreters in dementia care.

After the description of the key problems related to the care of PwM with dementia, this document also mentions some efforts already made in this field. In this context, the Migration School, Dementia Knowledge Centre in the region of Skåne is mentioned several times. This organisation has been engaged in developing and implementing working methods to improve dementia care for people with a foreign background since 2011. In the dementia strategy, several services already implemented by the Migration School are highlighted, such as online accessible web-based training on dementia in different languages or interpreter

training for medical staff working with people with dementia. In the context of the topic of interpreter utilisation, reference is made to an ongoing study at the Memory Clinic in Malmö, which is researching how the examination of dementia is influenced by the presence of an interpreter. The aim of the study is to identify development opportunities and develop routines for optimised interpreter use in dementia examinations. A service that is already integrated into care is the screening instrument RUDAS, which has been used since 2014 in several memory clinics and health centres in the county of Skåne for cognitive tests of people with a low level of schooling and other language or cultural backgrounds. Another model of good care practice is the cooperation between municipal social services and regional healthcare to support people with dementia from a foreign background, which has been established in a district of Malmö since 2013. Within the framework of this cooperation, various methods have been developed that staff at outpatient care services or inpatient facilities in Malmö and the region of Skåne, which is also involved in the cooperation, use in the case of communication difficulties between the staff and people in need of care who have lost their knowledge of Swedish. One method that has already been implemented is the matching of care recipients to staff members with the same mother tongue during the identification of the contact person. If such a matching is not possible, the staff members are supposed to learn the most important terms for care in the patient's mother tongue. Furthermore, the contact person should also have knowledge of the culture and living conditions of the region in which the care receiver grew up. Another method that has already been used is the maintenance of an action and implementation plan by the staff, in which the individual needs and wishes of the care receiver are described. In addition to these regional models of good





care practice, this document also refers to a few nationally available information and counselling services for PwM. For example, the Swedish Dementia Centre offers multilingual information about dementia through print and online mediums, and Alzheimer Sweden has a hotline that also addresses people who do not speak Swedish.

The dementia strategy also includes a few basic guidelines as well as some detailed recommendations for action for care providers and professionals. First, there is an explanation that a person-centred approach includes special consideration of the needs of people with a different cultural or language background. The staff of health and social services need to consider the cultural and language background while providing guidance and information to persons in need of care and their relatives and use an interpreter if necessary. The use of interpreters can be particularly important in the examination and treatment of persons with a mother tongue other than Swedish. In this dementia strategy, reference is made to the im-

portance of having an external person present during interpreted patient interviews, who has knowledge about the care and the lingo used in care as well as the language of the patient. Regarding support for the patient's relatives, care planners and providers are encouraged to plan and implement interventions based on the individual's needs, ethnicity, and gender. At the end of the document, the measure is recommended to ensure that knowledge about the needs and conditions of foreign-born people with dementia is disseminated in the healthcare system by 2022 [11].

Thus, 'A National Strategy for Dementia: Documentation and Proposal for a Plan for Prioritised Initiatives by 2022' not only presents a detailed thematic introduction and description of the main problems related to dementia care for PwM, but also provides a comprehensive framework for action with recommendations for care planners and service providers as well as references to existing studies, projects, care structures, and care services.

## 4. National dementia care and treatment guidelines

Two documents with national guidelines for dementia care were identified: 1. 'Care and Support for Dementia Patients: Support for Guidance and Management' from 2017, 2. 'Care and Support for Dementia Patients: Summary with Potential for Improvement' the evaluation of the national guidelines from 2018. The first document does not have a separate chapter on migration but makes a brief reference to people with a different linguistic or cultural background in eight sections. These people are identified as a group with special needs in terms of dementia care. In the context of person-centred care, the person with dementia should be given the opportunity to practice their religion, eat culturally adapted food, preserve their cultural traditions and cus-

toms, and have access to staff who speak the same language. Overall, the guidelines seem to identify cognitive assessment and early detection in people with suspected dementia and different linguistic or cultural background as a key challenge. In four passages they recommend the use of the intercultural assessment scale RUDAS, which has already been adapted to this group. In terms of inpatient care, it is recommended that the physical environment should be designed considering the cultural and religious needs of people with dementia. In addition, the guidelines point to the right of linguistic minorities to receive individually tailored information on health status and available care services, and to the need for the adaptation of services to the linguistic background.



Sweden seems to be following an inclusive model of care, where existing healthcare services are adapted to the needs of people with different linguistic or cultural background [12].

The second document from 2018 has a separate chapter on migration ('Needs of People from Other Countries Need Attention'). In addition to this three-page chapter, the topic also plays a role in another separate section and a later chapter. Overall, the evaluated guidelines refer to migration in a much broader sense than the guidelines from the previous year. This indicates that the topic is becoming increasingly more important at the national level. The focus of the content is on raising awareness among providers of dementia care services, and especially among municipalities and districts, of the needs of people from other countries. Communication difficulties are mentioned as a particular challenge, as many people who have a different mother tongue lose their Swedish language skills due to dementia. Further, the problem of traumatic experiences and their effects on psychological symptoms and the validity of results in dementia diagnostic tests for people with a foreign background are addressed. The document assumes that the number of people with dementia born in another country will increase significantly in the coming years (doubling within the next twenty years). Of the current 20,000 people, most were born in Finland or another neighbouring Scandinavian country. Several passages mention the importance of considering the specific needs of people from different linguistic or cultural backgrounds in the provision of care and assistance. With almost the same wording as in the guidelines from 2017, several needs are cited and the implementation of concrete measures such as the use of RUDAS for people with suspected dementia and another mother tongue is recommended. The evaluated version adds that a training program for the use of RUDAS is available to healthcare professionals. The screening tool and the

training program have spread nationally in recent years. At present, half of the districts are already using RUDAS. In addition, two-thirds of the districts stated in a survey that they have developed routines for the use of interpreters. Simultaneously, the guidelines also reveal that there is a shortage of care and assistance for people from other countries. This shortage exists particularly in terms of early detection and screening for dementia, appropriate drug treatment, and specialised post-diagnostic care. Less than one in ten municipalities provides daycare, home care, or family care services adapted to the needs of linguistic minorities. Although the proportion of municipalities with residential facilities that focus on people with a different mother tongue has increased, it was still only 16% in 2017. The geographical distribution of services for linguistic minorities is highly concentrated in large cities. Furthermore, research has shown that people born outside Scandinavia are prescribed less dementia medication. There are large gaps in the knowledge of the needs of cultural and linguistic minorities and the appropriate measures to meet these needs. As a result, foreign-born persons make less use of municipal support services than persons originating from Sweden. The 2018 evaluated guidelines conclude that the districts and municipalities need to work more actively to diagnose dementia in people from other countries and to gain more knowledge about the investigation and treatment of dementia in this group. Prescription of dementia drugs needs to be reviewed and more municipalities need to develop specialised services for people with different mother tongues [13]. The analysis of the documents from 2017 and 2018 has shown that Sweden is paying close attention to the topic of dementia and migration at the national level. The national guidelines give general recommendations to municipal healthcare providers and show them concrete options for actions to address the cur-



rent knowledge and care gaps regarding people with foreign backgrounds and dementia.

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on

written statements and reflect the experience and opinion of the expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, PwM are identified as a vulnerable group in the healthcare system. This applies particularly to people born outside Europe, e.g. Asia, the Middle East, or Africa. Still, the topic of dementia and migration is only partly considered to be important at the national level in Sweden. For instance, no national budget for dementia and migration exists. However, some individual experts focus on this topic. In some regions, the topic is very important. The expert noted that PwM are considered vulnerable with regard to the development, process, and consequences of dementia as well as gaps in care, underdiagnosis, and utilisation of formal healthcare services. In general, care is adapted to people born and raised in Sweden. People having other linguistic and cultural backgrounds, and especially migrants with less education, remain deprived of the kind of care they need. In addition, the diagnosis of dementia is less reliable because the tests used are influenced by culture, language, and education and there is a lack of professional interpreters. In Sweden, the concept of person-centred dementia care is pursued. According to the expert, this concept does not work in practice for PwM. Basically, an integrative model of care is used, in which all people have the same right to seek care and support. However, the problem is that healthcare and society are not adapted to everyone. Differences in language, culture, and education, as well as a lack of knowledge about how healthcare works and what society offers in terms of resources, mean that migrants have

fewer opportunities to make use of available services. As an example, the expert cited the day care services for people with dementia that are basically available to everyone in Sweden, but which are not used by many PwM because they cannot interact well with staff or patients. For these reasons, the expert concluded that existing care services are more suitable and adequate for non-migrants with dementia. However, there are also groups of migrants for whom care is more appropriate (people from Finland or Denmark) because they are better integrated into society and there are fewer language and cultural problems. Furthermore, some ethnic groups with a long history of migration have access to healthcare staff who come from the same country or to homes for people with dementia with staff who speak the same language (e.g. the home for Jews, people from Finland, as well as Persian and Arabic speaking people in Stockholm). Measures for intercultural care are local and not nationally distributed or under development. In the county of Skåne in southern Sweden, some information films on dementia, the importance of seeking help at an early stage of the disease, and dementia investigation have been developed in different languages.

The expert identified a great need for improvement in the early diagnosis of dementia in PwM, the use of cognitive screening tools that are less influenced by language, culture, and education, and the use of interpreters during dementia assessment.

## 6. Professional qualification and people with a migration background in healthcare

The expert stated that culturally sensitive care is partly included in the education of healthcare professionals. Reflecting on one's own culture and the prejudices and beliefs about others, as well as its potential impact on treatment, is basically part of the person-centred approach. However, dedicated courses on culturally sensitive care are not available nationwide. In this respect, there are great differences between different universities and colleges. Moreover, the courses are mostly elective and it is not certain that all students attend such courses. The situation is similar for professional training opportunities in intercultural care. In southern Sweden, professional caregivers can attend courses organised by the Knowledge Center of Dementia. There are also small nationwide efforts in this area.

According to the expert, the proportion of PwM among professional caregivers is high in both outpatient and inpatient care, ranging

between 20 and 40%. The proportion is even higher in the elderly care sector. The professional caregivers with a migration background are from many different countries of origin (e.g. Iran, Iraq, Poland, Greece, Bosnia, North Macedonia). This high diversity among professional caregivers has different effects on care. On the one hand, these caregivers provide people in need of care access to language and intercultural care. On the other hand, many of these professionals have the feeling that they are often used as interpreters, which is not acceptable to them, as they do not have additional time or any compensation for these extra tasks. Furthermore, the absence (vacation, illness) of healthcare professionals with a migration background often results in waiting times for patients with the same mother tongue. Overall, the need for culturally sensitive care in Sweden is not being met by sufficiently qualified professionals.

## 7. Support for family caregivers

The expert highlighted that in Sweden, family and care provider networks are very important and migrant organisations have an important role in supporting family caregivers of PwM with dementia. Currently, there are major differences in the suitability of existing information resources and support services for family caregivers of PwM and non-migrants with dementia. The expert pointed out that family

caregivers of PwM with dementia are in great need of specialised services providing support and information. However, the expert could think of only one such specialised service that is currently available: telephone counselling provided by a non-profit association for persons with dementia and their family members in the Persian and Bosnian languages.



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# Switzerland

**Population**

8,606,000

**Area**

39,860 km<sup>2</sup>

**Capital**

Bern

**3 largest cities**

Zurich (420,000)

Geneva (204,000)

Basel (173,000)

**Neighboring countries**

Austria, France,

Germany, Italy,

Liechtenstein

1. Migration history
2. Estimated number of people with a migration background with dementia
3. National dementia plan
4. National dementia care and treatment guidelines
5. References



## 1. Migration history

Switzerland was an emigration country until 1888. From the 15th to the beginning of the 19th century, hundreds of thousands of military entrepreneurs and mercenaries emigrated to other European states [1, 2]. In the 19th century, about half a million people emigrated to North America. At the end of the 19th century, Switzerland developed into an immigration country. During this period, many people immigrated from neighbouring regions in southern Germany, northern Italy, western France, and Austria [2]. In the last third of the 19th century, many foreigners studied in Switzerland. The development into an immigration country was temporarily halted by the two world wars when immigration was severely restricted. In June 1948, an agreement on the recruitment of guest workers was concluded with Italy. During the Cold War, Switzerland also accepted refugees from communist systems [1]. Since the Second World War, the foreign population has increased continuously, with the exception of the oil crisis in the 1970s and the economic slump in 1983 [3]. Until the end of the 1970s, the majority of labour migrants came

from Italy and Spain. After the conflicts of the 1990s, an increasing number of people immigrated from countries such as Portugal and Yugoslavia [4]. However, between 1970 and 2000 approximately two million 'guest workers' returned to their home countries [3]. In recent years, tens of thousands of workers have immigrated from other EU member states [4]. In 2018, the largest migrant groups originated from Italy (322,100), Germany (307,900), and Portugal (265,500). Overall, approximately 68% of the foreign resident population comes from EU, EFTA, and UK states [5]. The migrant population (born abroad) increased tenfold between 1941 and 2019 (223,500 to 2.6 million) and almost doubled between 1990 and 2019 (1.4 million to 2.6 million) [3, 6]. The proportion of migrants in the total population also increased significantly (20.9 to 29%) between 1990 and 2019 [7]. Switzerland currently is one of the European countries with the highest proportion of foreigners [2]. The net migration rate has always been positive in recent decades, and as of 2020 it is 6.1 [8].

## 2. Estimated number of people with a migration background with dementia

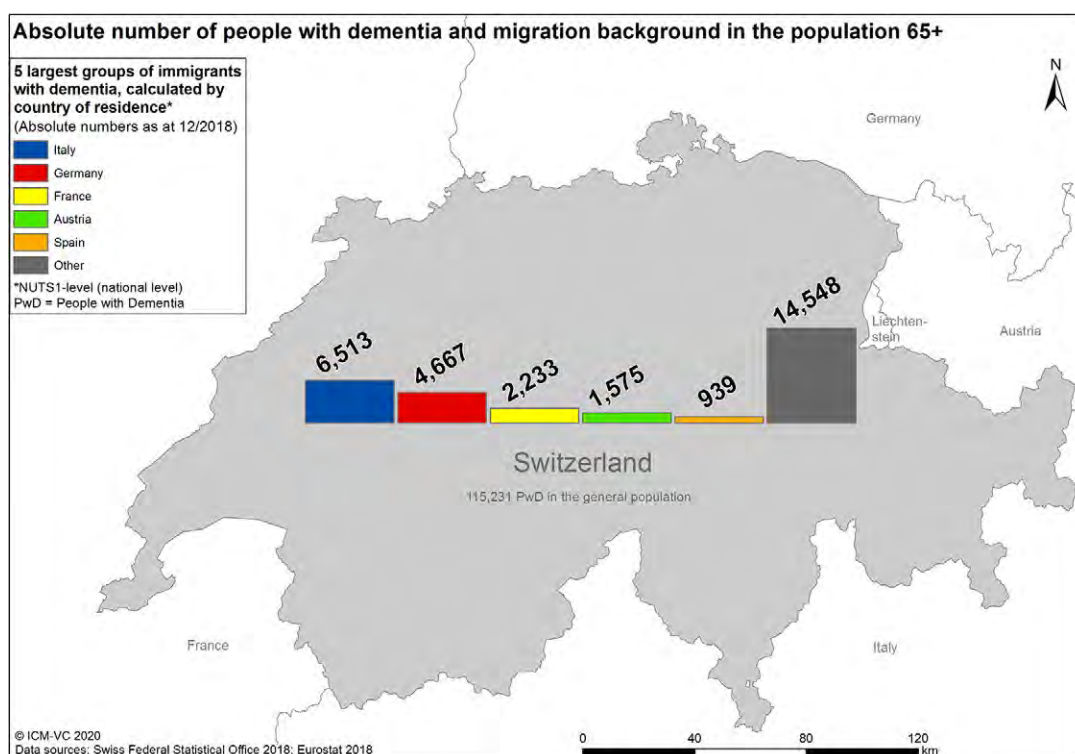


Fig. 3.7.31.1: Absolute number of PwM with dementia aged 65+ (Switzerland – Nation)

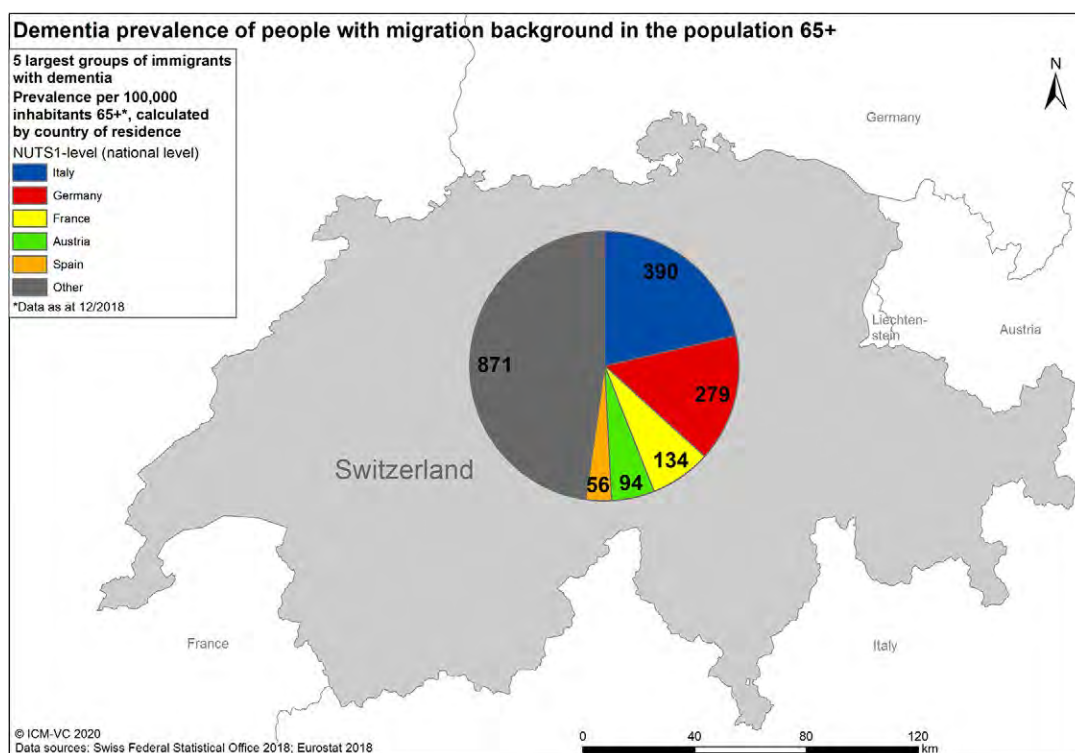


Fig. 3.7.31.2: Prevalence of PwM with dementia among the population aged 65+ (Switzerland – Nation)



**Tab. 53: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Switzerland – Nation)**

NUTS	Total	CH	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Switzerland	115,231	84,757	IT 6,513	DE 4,667	FR 2,232	AT 1,575	ES 939	14,548
Prevalence/10,000 inhabitants with migration background 65+								
Switzerland	2,609	-	IT 147	DE 106	FR 51	AT 36	ES 21	329
Prevalence/100,000 inhabitants 65+								
Switzerland	6,900	5,075	IT 390	DE 279	FR 134	AT 94	ES 56	593

Data source: Swiss Federal Statistical Office (2018)

There are 368,300 PwM aged 65 or older. Of those, approx. 25,400 are estimated to exhibit some form of dementia. Figure 3.7.31.1 show the most affected migrant groups presumably originate from Italy (approx. 6,500), Germany (approx. 4,700), France (approx. 2,200), Austria (approx. 1,600), and Spain (approx. 900). The second graph highlights the number of PwM with dementia in Switzerland per 100,000

inhabitants aged 65 years or older (figure 3.7.31.2). Table 53 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from Italy, Germany, France, Austria, and Spain throughout the country in the NUTS2 regions (figures 3.7.31.3 – 3.7.31.8).

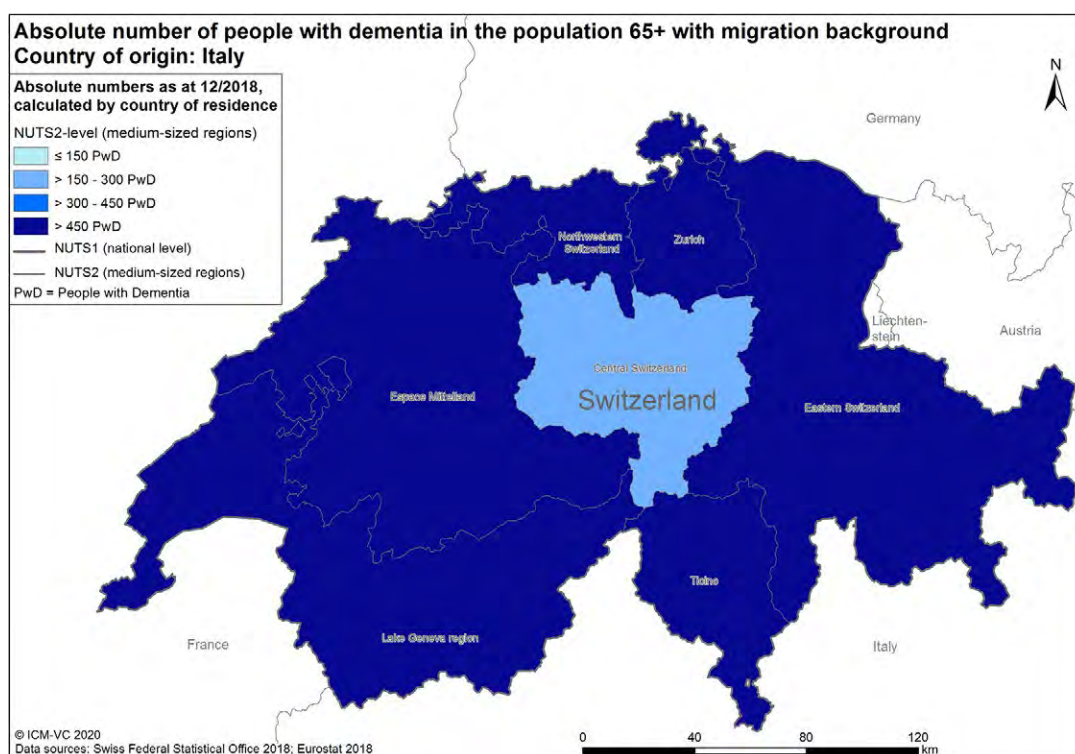


Fig. 3.7.31.3: Absolute number of PwM with dementia aged 65+.  
Country of origin: Italy (Switzerland – NUTS2)

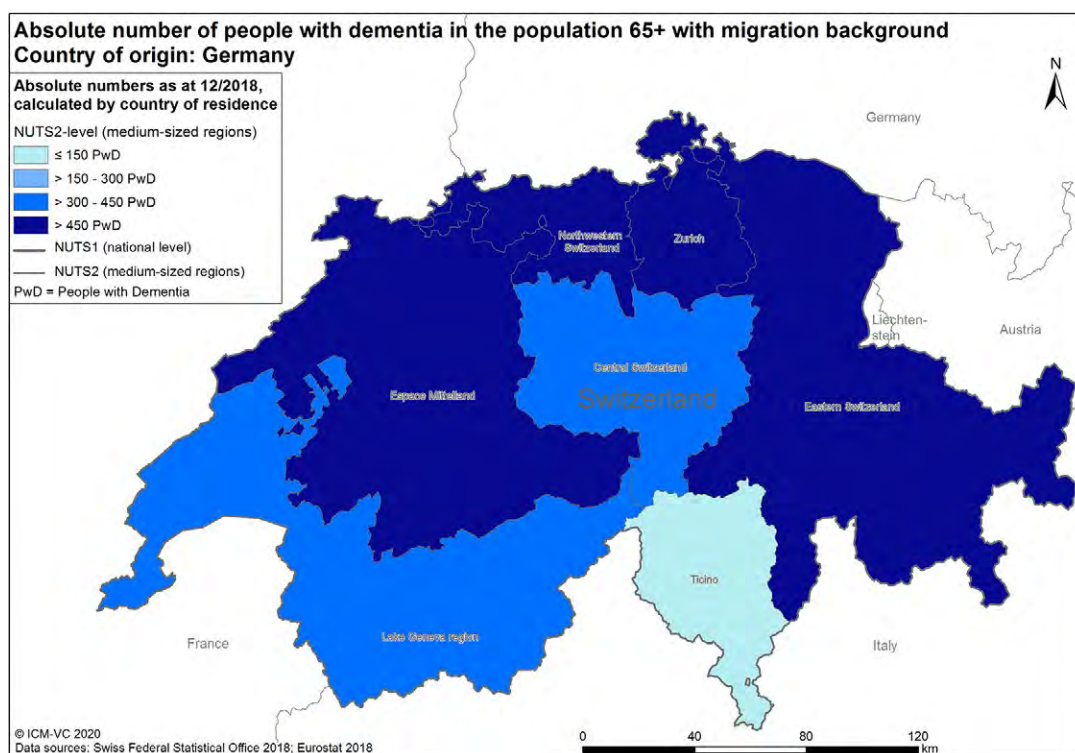


Fig. 3.7.31.4: Absolute number of PwM with dementia aged 65+.  
Country of origin: Germany (Switzerland – NUTS2)



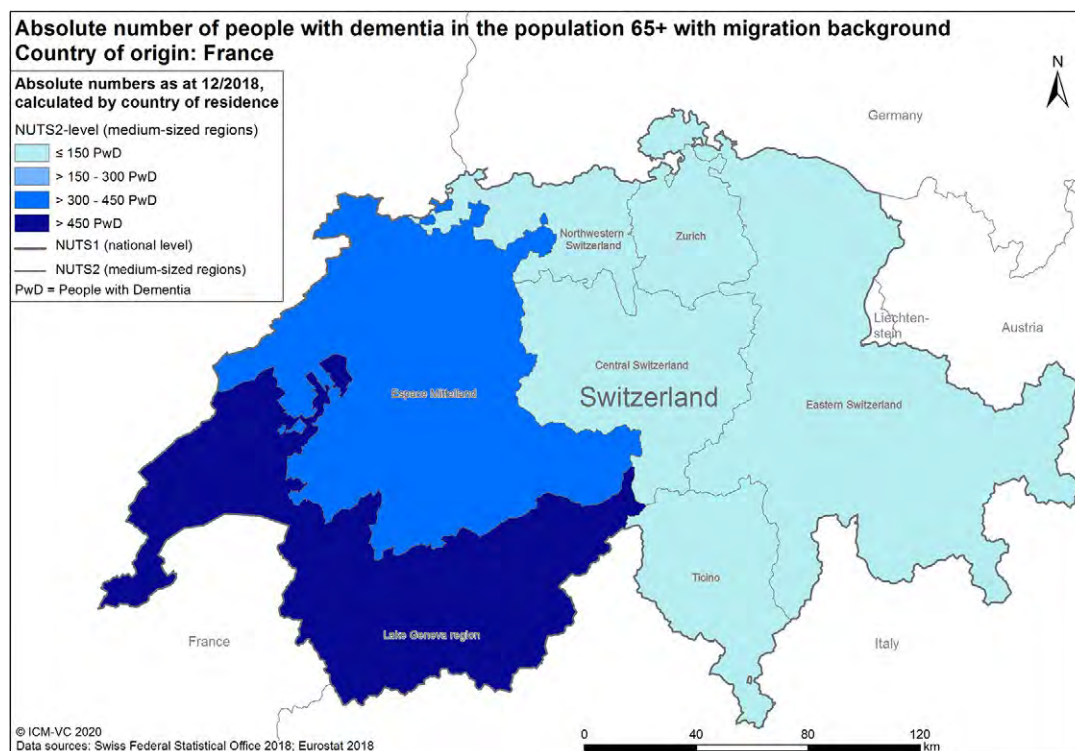


Fig. 3.7.31.5: Absolute number of PwM with dementia aged 65+.  
Country of origin: France (Switzerland – NUTS2)

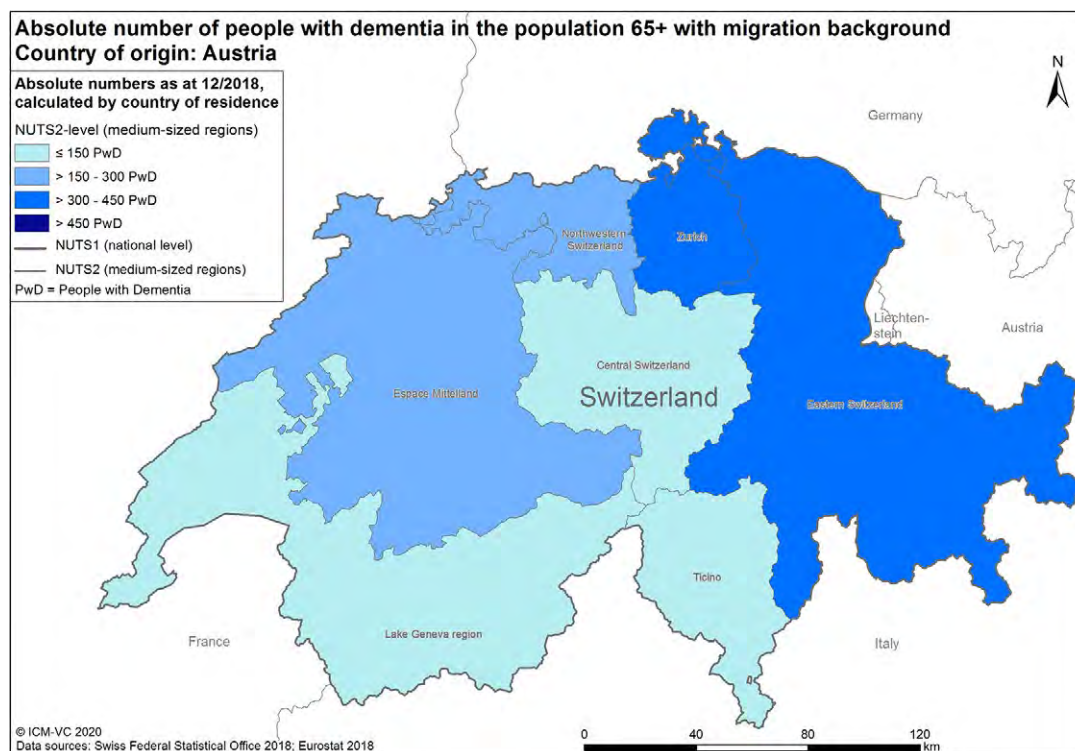


Fig. 3.7.31.6: Absolute number of PwM with dementia aged 65+.  
Country of origin: Austria (Switzerland – NUTS2)



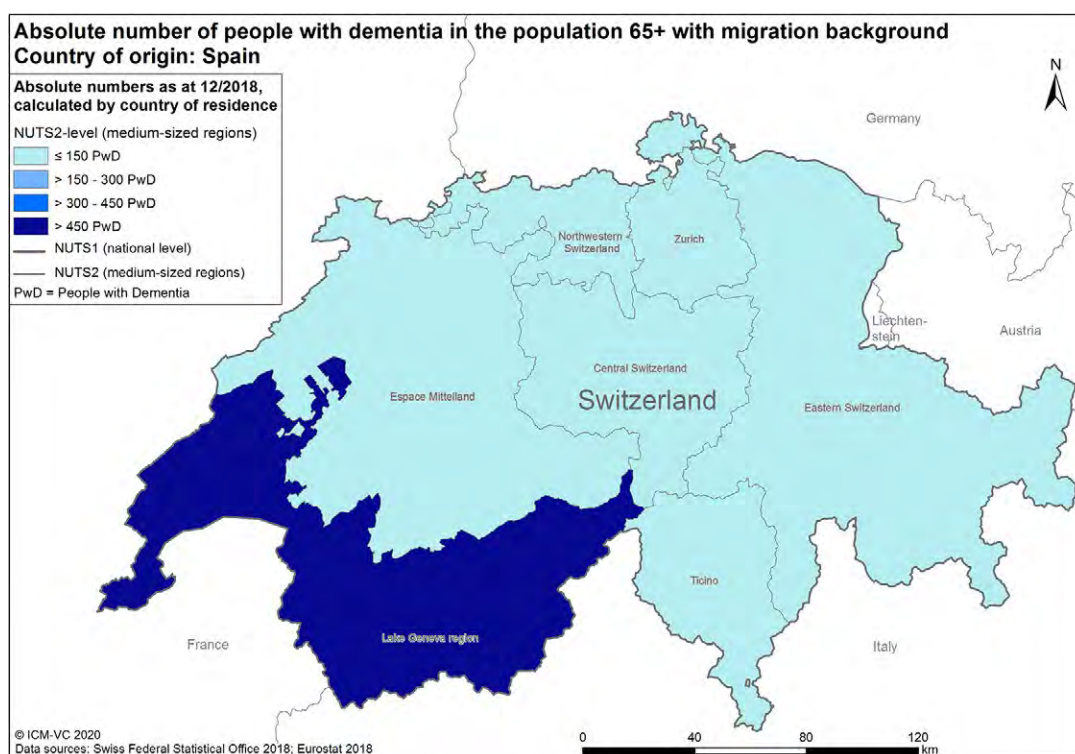


Fig. 3.7.31.7: Absolute number of PwM with dementia aged 65+.  
Country of origin: Spain (Switzerland – NUTS2)

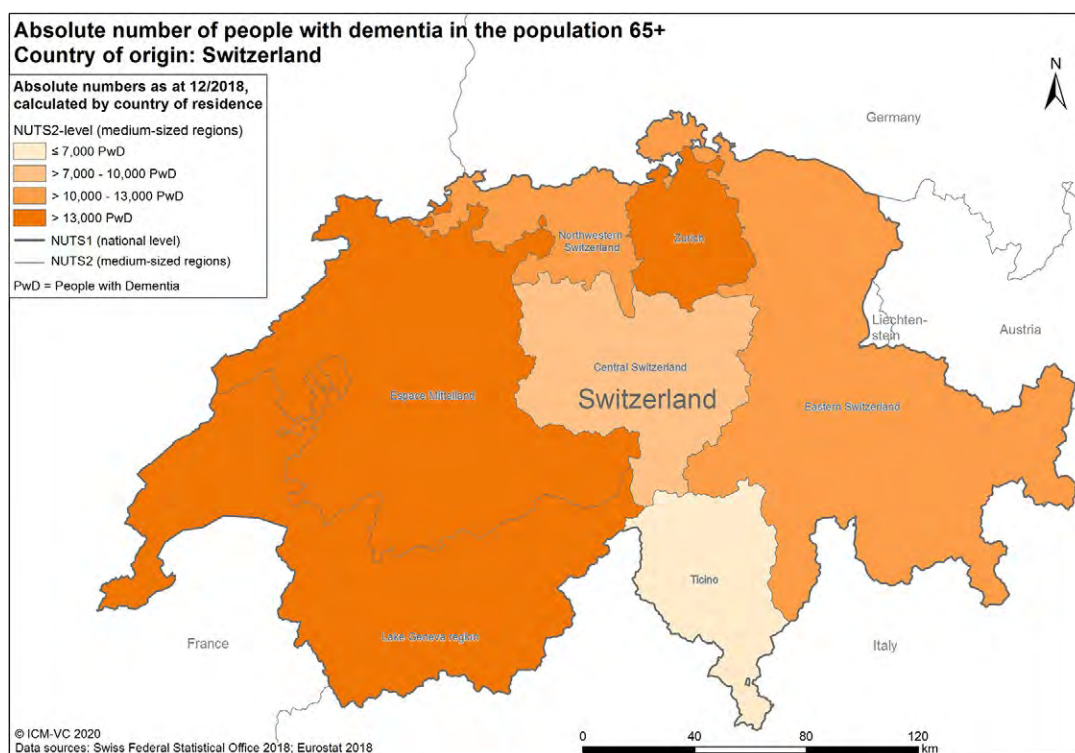


Fig. 3.7.31.8: Absolute number of people with dementia aged 65+.  
Country of origin: Switzerland (Switzerland – NUTS2)

The graphics below highlight which immigrant groups are estimated to be most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.31.9). The second

map shows the number of PwM with dementia per 100,000 inhabitants aged 65 years or older in the NUTS2 regions (figure 3.7.31.10). The values from the NUTS2 level can be found in table 54 [9, 10].

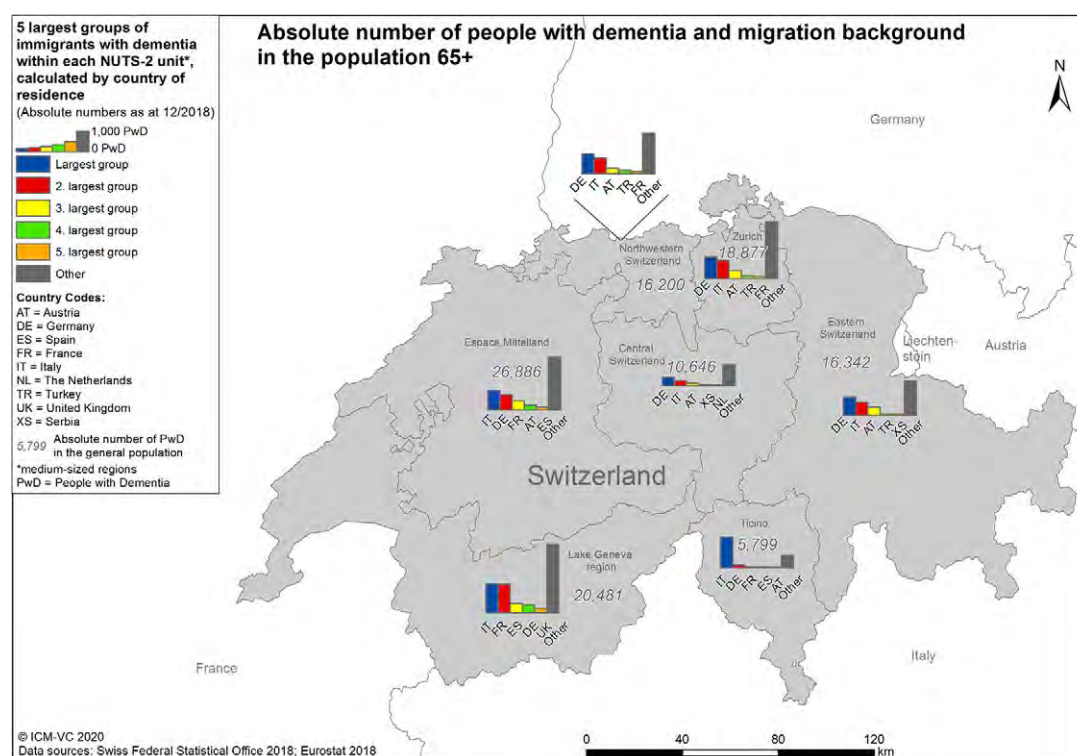


Fig. 3.7.31.9: Absolute number of PwM with dementia aged 65+ (Switzerland – NUTS2)

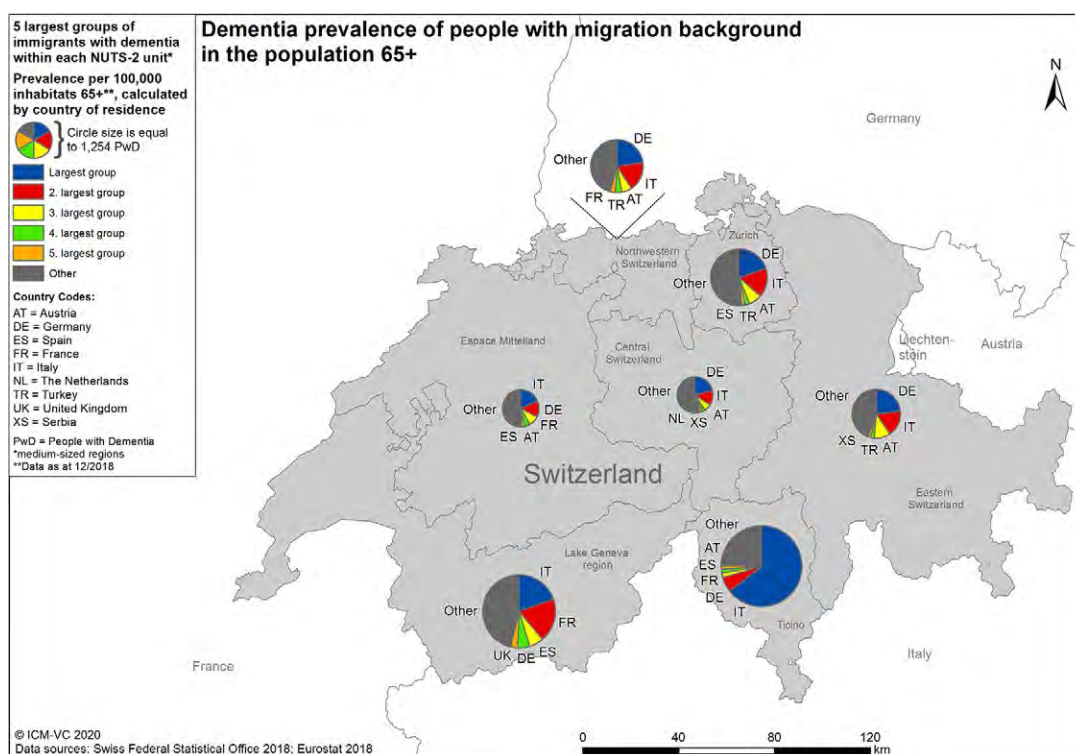


Fig. 3.7.31.10: Prevalence of PwM with dementia among the population aged 65+ (Switzerland – NUTS2)

Tab. 54: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Switzerland – NUTS 2)

NUTS	Total	CH	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Lake Geneva region	20,481	13,091	IT 1,452	FR 1,430	ES 464	DE 396	UK 227	3,421
Espace Mitelland	26,886	21,926	IT 913	DE 712	FR 440	AT 235	ES 133	2,527
Northwestern Switzerland	16,200	11,796	DE 998	IT 796	AT 274	TR 174	FR 138	2,024
Zurich	18,877	13,300	DE 1,112	IT 921	AT 413	TR 136	ES 116	2,879
Eastern Switzerland	16,342	12,491	DE 897	IT 662	AT 423	TR 81	XS 81	1,707
Central Switzerland	10,646	8,710	DE 409	IT 254	AT 125	XS 53	NL 47	1,047
Ticino	5,799	3,443	IT 1,515	DE 143	FR 45	ES 33	AT 28	592



NUTS	Total	CH	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/10,000 inhabitants with migration background 65+								
Lake Geneva region	1,912	-	IT 136	FR 134	ES 43	DE 37	UK 21	319
Espace Mittelland	3,741	-	IT 127	DE 99	FR 61	AT 33	ES 19	351
Northwestern Switzerland	2,538	-	DE 156	IT 125	AT 43	TR 27	FR 22	317
Zurich	2,336	-	DE 138	IT 114	AT 51	TR 17	ES 14	356
Eastern Switzerland	2,928	-	DE 161	IT 119	AT 76	TR 15	XS 14	305
Central Switzerland	3,795	-	DE 146	IT 91	AT 45	XS 19	NL 17	372
Ticino	1,698	-	IT 444	DE 42	FR 13	ES 10	AT 8	173
Prevalence/100,000 inhabitants 65+								
Lake Geneva region	6,900	4,410	IT 489	FR 482	ES 156	DE 133	UK 76	865
Espace Mittelland	6,900	5,627	IT 234	DE 183	FR 113	AT 60	ES 34	372
Northwestern Switzerland	6,900	5,024	DE 425	IT 339	AT 117	TR 74	FR 59	589
Zurich	6,900	4,862	DE 407	IT 337	AT 151	TR 50	ES 43	758
Eastern Switzerland	6,900	5,274	DE 379	IT 280	AT 178	TR 34	XS 34	453
Central Switzerland	6,900	5,646	DE 265	IT 165	AT 81	XS 34	NL 30	426
Ticino	6,900	4,097	IT 1,803	DE 170	FR 53	ES 40	AT 33	418

Data source: Swiss Federal Statistical (Office 2018)

### 3. National dementia plan

The 'National Dementia Strategy 2014 – 2019' from 2016 does not have a separate chapter on migration but refers briefly to it in three sub-chapters. It points out that the proportion of migrants in the total population is increasing, especially of the older age groups, which has an impact on the demand for and quality requirements of healthcare services. In addition, it is described that in case of PwM, the language barriers pose a particular challenge for dementia diagnosis, as common test procedures are unsuitable or require translation assistance. The document explicitly states

that the care and treatment of people with dementia should consider individual circumstances such as employment or migration background. Furthermore, in the future the existing federal program on migration and health will also include measures related to the topic of dementia. In Switzerland's national dementia strategy, the topic of migration plays a subordinate role and there is no reference to existing healthcare services for PwM with dementia. However, specific needs related to the diagnosis of dementia and a planned measure are highlighted [11].

### 4. National dementia care and treatment guidelines

At the national level, the following three documents with guidelines, policies, or recommendations were identified for Switzerland. 1. The 99-page 'Recommendations for the Diagnosis and Treatment of the Behavioral and Psychological Symptoms of Dementia (BPSD)' from 2014 discusses prevalence, incidence, and phenomenology of BPSD; the role of comorbidities in BPSD; the role of the environment; qualitative and quantitative assessment of BPSD; diagnostic recommendations for BPSD in care; therapies in BPSD; nursing interventions; person-centred care of people with dementia; pharmacological and non-pharmacological therapies in dementia; and drug treatment of BPSD in specific forms of dementia. 2. The 'Medical-Ethical Guidelines: Care and Treatment of People With Dementia' from 2013

has 37 pages and addresses the topics of respect for dignity and autonomy, quality of life and well-being, quality of care and treatment, communication with people with dementia, treatment planning and advance directives, information and consent, decision-making in the care and treatment team, dementia diagnosis, appropriate care and treatment, emotions and behaviour, end-of-life decisions, dealing with the wish for suicide, relatives, and research with people with dementia. 3. The expert recommendation 'Dementia: Diagnosis, Treatment and Care' from 2014 is 40 pages long and addresses dementia, assessment and diagnosis, drug and non-drug treatments, daily living arrangements, support and care, and medication. None of these three documents takes migration into account [12-14].



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# The United Kingdom

**Population**

67,026,000

**Area**242,751 km<sup>2</sup>**Capital**

London

**3 largest cities**

London (9,050,000)

Birmingham

(1,160,000)

Glasgow (630,000)

**Neighboring countries**

Ireland

1. Migration history
2. Estimated number of people with a migration background with dementia
  - 2.1 England
  - 2.2 Northern Ireland
  - 2.3 Scotland
  - 2.4 Wales
3. National dementia plan
  - 3.1 England
  - 3.2 Northern Ireland
  - 3.3 Scotland
  - 3.4 Wales
4. National dementia care and treatment guidelines
  - 4.1 England and Wales
  - 4.2 Northern Ireland
  - 4.3 Scotland
5. Services and information for people with a migration background with dementia
6. Professional qualification and people with a migration background in healthcare
7. Support for family caregivers
8. References



## 1. Migration history

The UK has a long history of migration. Already in the 19th century, large migrant groups came from Ireland and Italy. Around 1900, the largest immigrant community came from Germany. At the same time, many people emigrated to Canada and the US from United Kingdom[1]. After the beginning of British colonialism, (1858-1947) more than 100,000 migrants from United Kingdom and Ireland worked in India. In the further course of colonial rule, more and more Indian workers came to the UK [2]. Following Kristallnacht 1938, approximately 10,000 Jewish refugee children from Germany, Austria, and Czechoslovakia fled to the UK. After the Second World War, there were two waves of large-scale immigration: 1. immigration of soldiers from Poland and their families following the adoption of the Polish Resettlement Act 1947, 2. immigration of workers from the 'new' Commonwealth (the Caribbean, Africa, and India) after the adoption of the Nationality Act (full right of entry and citizenship to all Commonwealth citizens) 1948 [3]. In the 1950s, 500,000 Commonwealth migrants came to the UK [4, 5]. During the 1950s and early 1960s especially more and more from India and Pakistan arrived to work in the textile factories in northern England (later their families followed). Furthermore, the number of people from Ireland increased significantly from the 1950s onwards (in 1971 it was one million) [3]. From 1961 to 1971 a total of 600,000 people immigrated to the UK (from all countries of origin together) [4]. Between 1945 and 1982, 1.5 million people from United Kingdom emigrated to Australia and many others to Canada [6]. In the dec-

ade following the Maastricht Treaty of 1993, continuous large-scale immigration occurred. For the first time, more people came to the UK than left the country [3]. In the first decade of the 21st century, especially the immigration of people from India and Ireland increased [2, 3]. Between May 2004 and September 2007, the UK accepted approximately 715,000 workers from the EU states that joined in 2004 (66% from Poland, 10% each from Lithuania and Slovakia). Besides, the UK initiated the 'Highly Skilled Migrant Programme' (HSMP), through which mainly nationals from Indian and Pakistan came to the country [4]. In 2018, 602,000 people immigrated to the UK (54% were non-EU citizens, 33% were nationals of other EU countries, and 13% were citizens of United Kingdom). The migrant population of the UK is mostly concentrated in London (35%). While the proportion of migrants in the total population in England is 15.4%, it is 6.1% in Wales, 7.9% in Northern Ireland, and 8.8% in Scotland [7]. In 2017/2018, the largest migrant groups (born abroad) originated from Poland (889,000), India (862,000), Pakistan (529,000), Romania (410,000) and Ireland (380,000) [8]. Between 1990 and 2019, the migrant population (born abroad) and the proportion of migrants in the total population more than doubled (3.7 to 9.6 million; 6.4 to 14.1%) [9]. As of 2020, the net migration rate is 3.9 [10]. These figures illustrate that the UK has become one of the main immigration countries in Europe since the 1990s. The extent to which the EU withdrawal (31 January 2020) will have an impact on migration patterns will become apparent in the coming decades.

## 2. Estimated number of people with a migration background with dementia

### 2.1 England

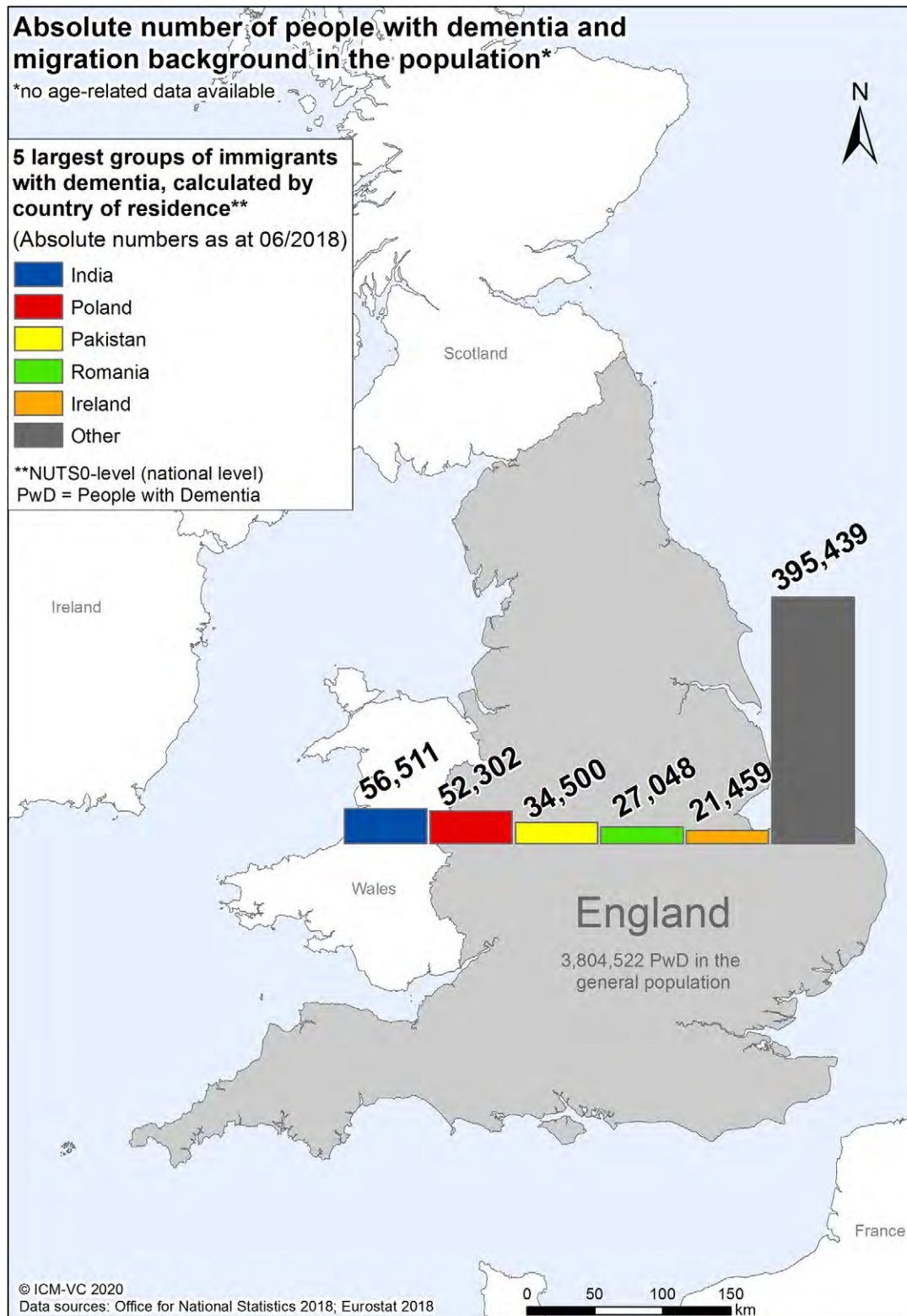


Fig. 3.7.32.1: Absolute number of PwM with dementia (England – Nation)

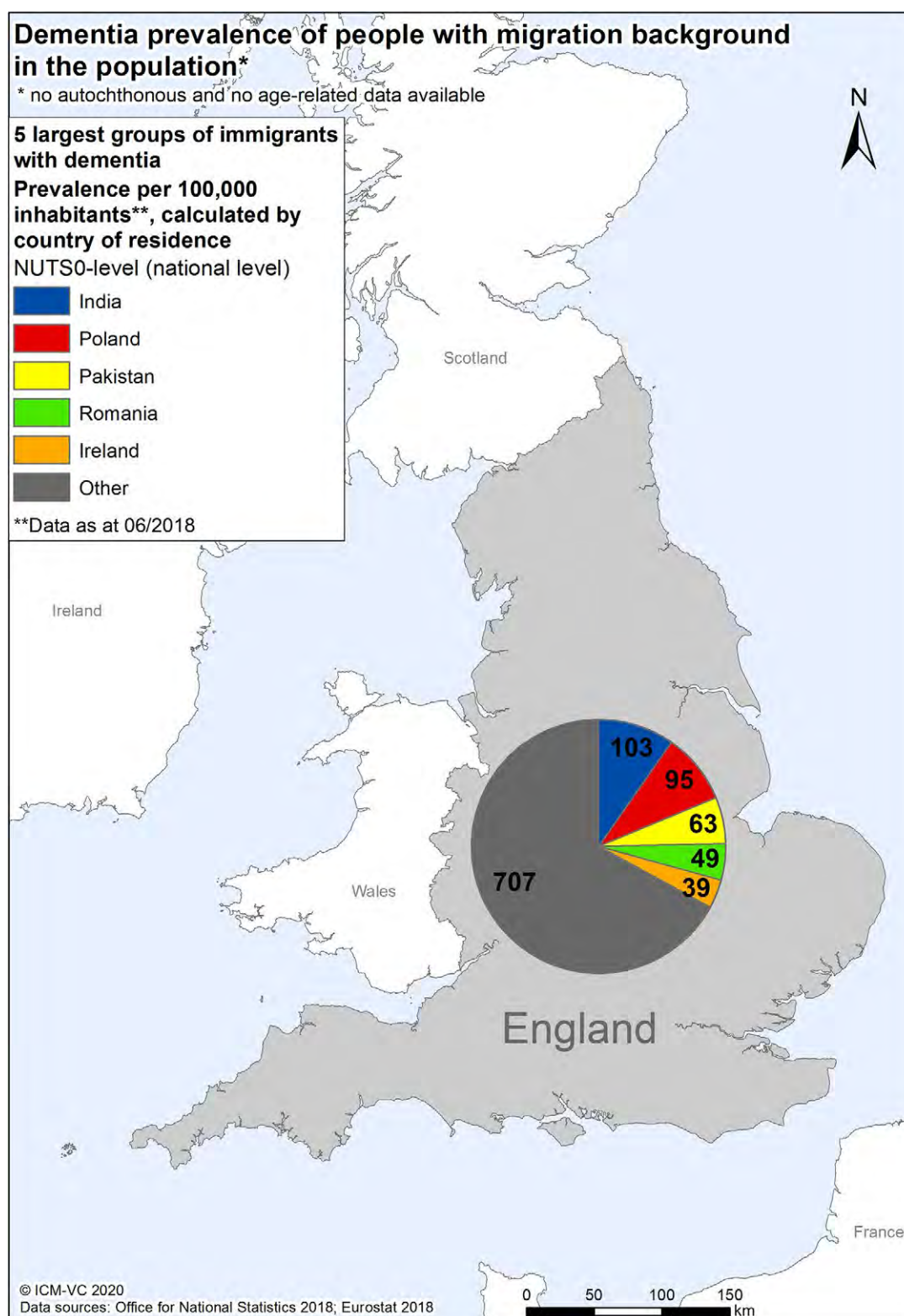


Fig. 3.7.32.2: Prevalence of PwM with dementia among the population (England – Nation)



**Tab. 55: PwM with dementia: Absolute numbers, prevalence among PwM, and prevalence among overall population (England – Nation)**

NUTS	Total	ENG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
England	3,804,522	3,211,260	IN 56,511	PL 52,302	PK 34,500	RO 27,048	IE 21,459	401,442
Prevalence/10,000 inhabitants with migration background 65+								
England	4,425	-	IN 66	PL 61	PK 40	RO 31	IE 25	467
Prevalence/100,000 inhabitants 65+								
England	6,900	5,824	IN 102	PL 95	PK 63	RO 49	IE 39	707

Data source: Office for National Statistics (2018)

There are 8,511,000 PwM. Of those, approx. 588,100 are estimated to exhibit some form of dementia. However, these data are not age-specific but for the whole population with a migration background, so these numbers are naturally higher and overestimated than if data for the age group 65+ were obtainable. Figure 3.7.32.1 shows the most affected migrant groups presumably originate from India (approx. 56,510), Poland (approx. 52,300), Pakistan (approx. 34,500), Romania (approx.

27,100), and Ireland (approx. 21,500). The second graph highlights the number of PwM with dementia in England per 100,000 inhabitants aged 65 or older (figure 3.7.32.2). Table 55 displays the values depicted in the maps on the national level. The following maps show the distribution of PwM with dementia from India, Poland, Pakistan, Romania, and Ireland throughout the country on NUTS1 level (figures 3.7.32.3 – 3.7.32.7).



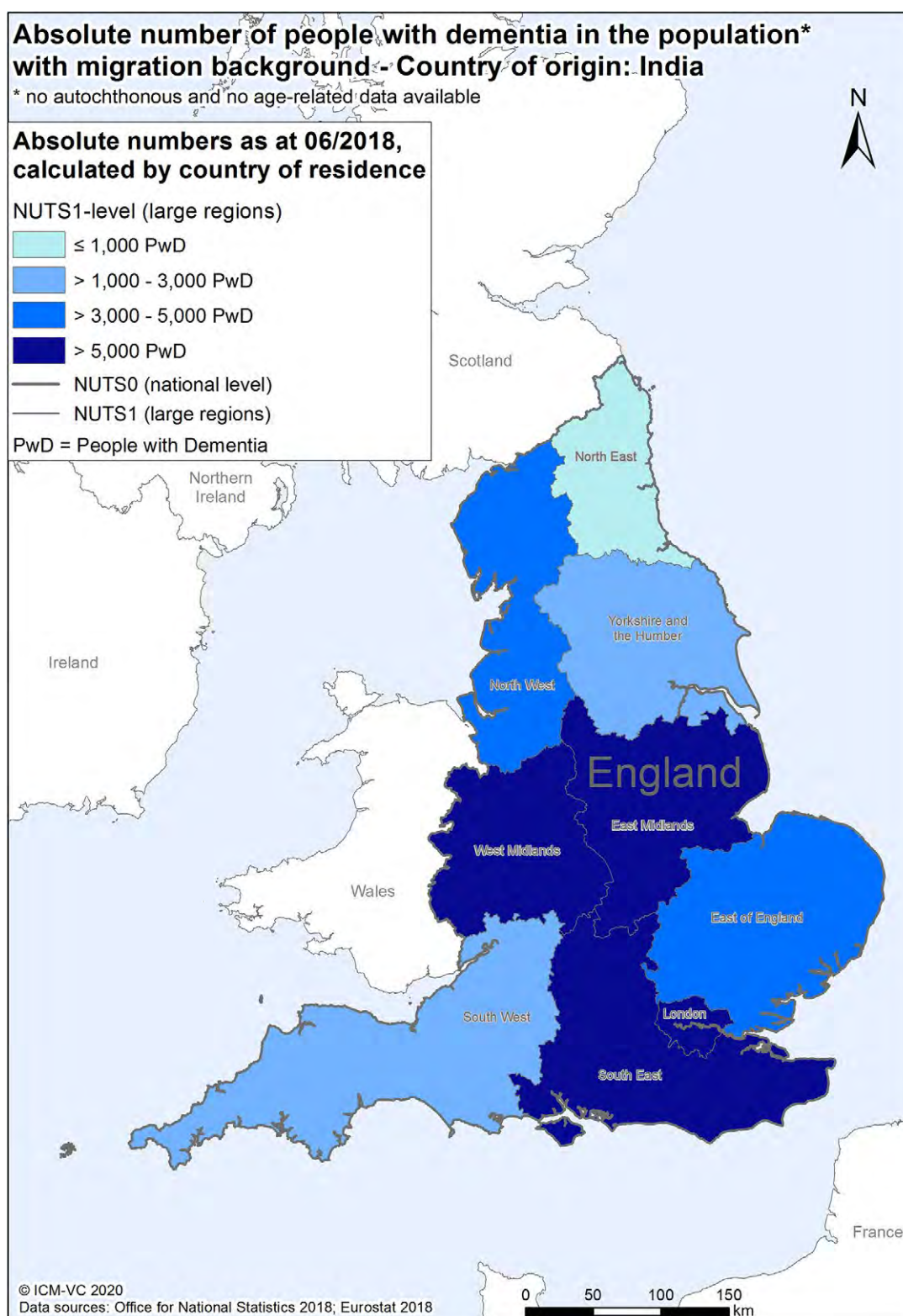


Fig. 3.7.32.3: Absolute number of PwM with dementia.  
 Country of origin: India (England – NUTS1)



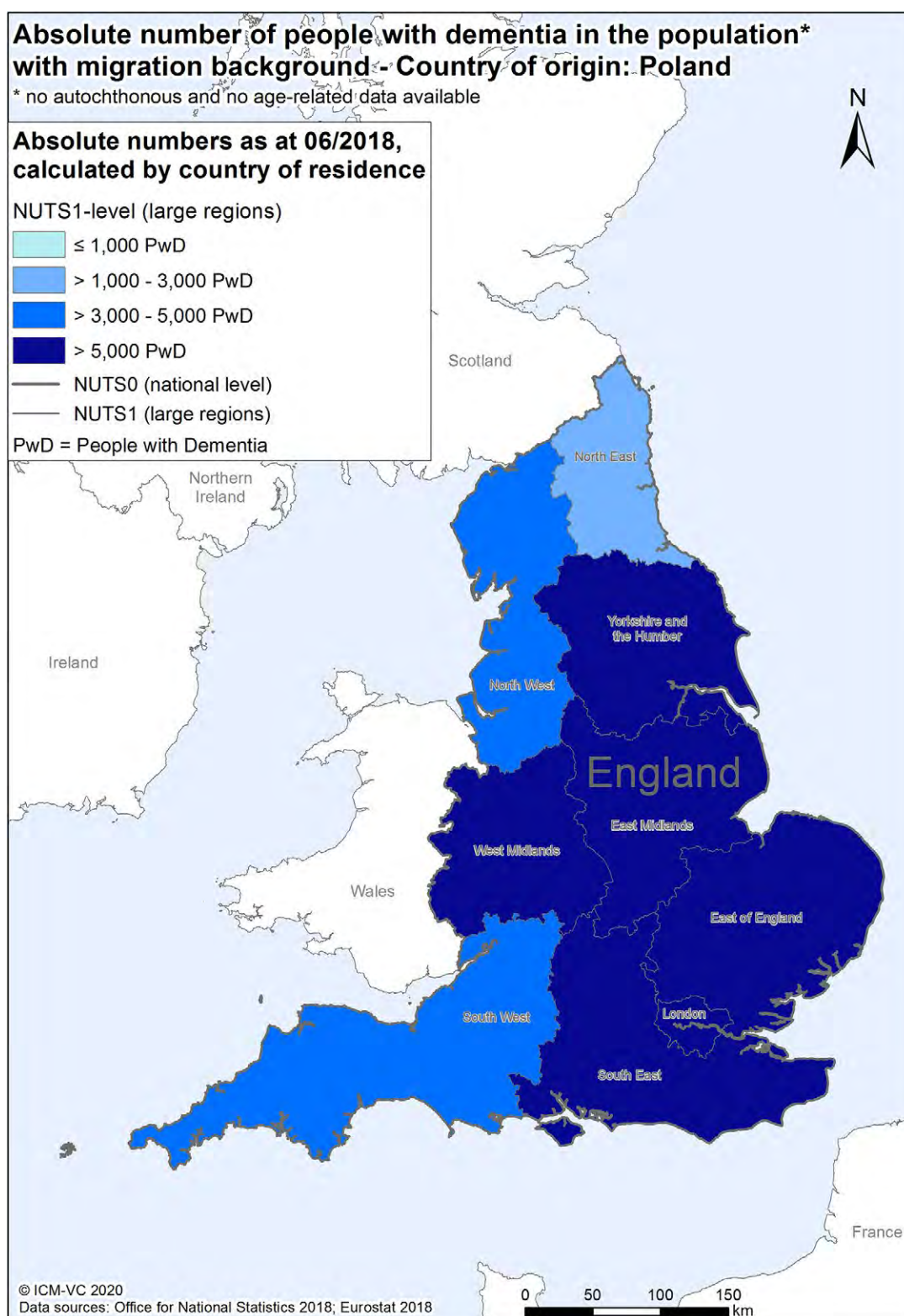


Fig. 3.7.32.4: Absolute number of PwM with dementia.  
 Country of origin: Poland (England – NUTS1)

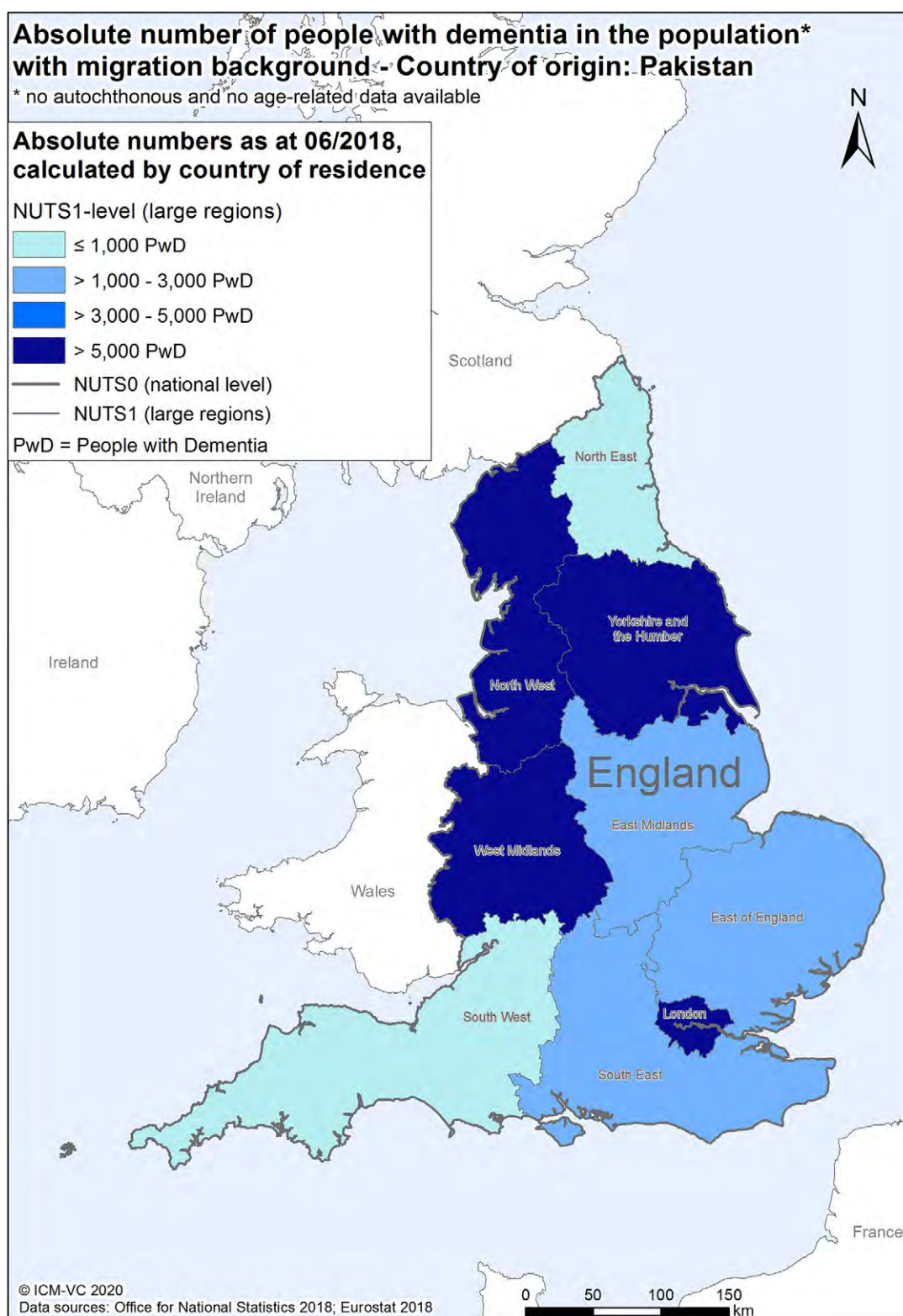


Fig. 3.7.32.5: Absolute number of PwM with dementia.  
 Country of origin: Pakistan (England – NUTS1)

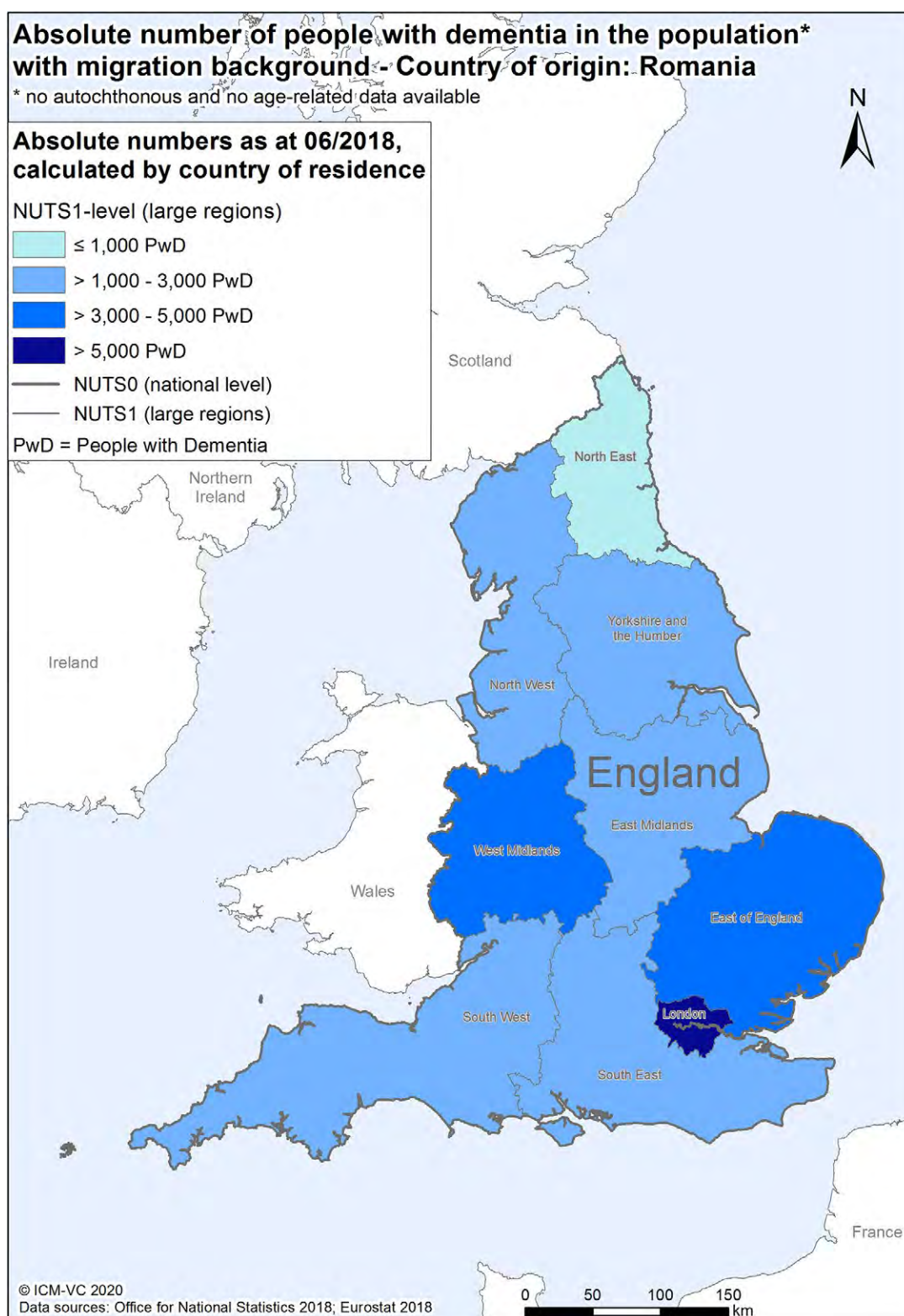


Fig. 3.7.32.6: Absolute number of PwM with dementia.  
 Country of origin: Romania (England – NUTS1)



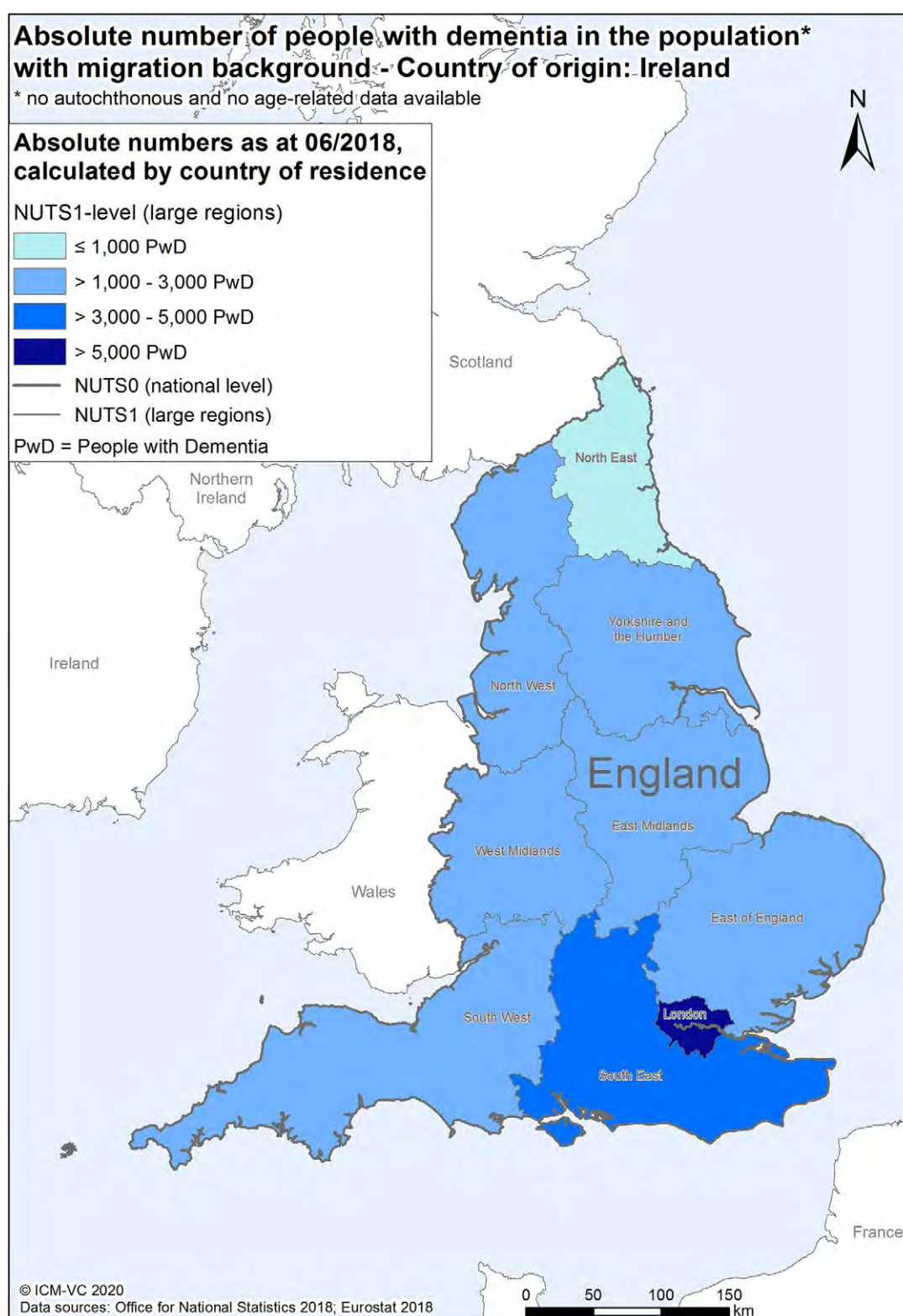


Fig. 3.7.32.7: Absolute number of PwM with dementia.  
 Country of origin: Ireland (England – NUTS1)

The graphics below highlights which immigrant groups are estimated to be the most

affected at the NUTS1 level. The first map illustrate the absolute numbers of PwM with de-



mentia in the NUTS1 regions (figure 3.7.32.8). The second map shows the number of PwM with dementia per 100,000 inhabitants in the

NUTS1 regions (figure 3.7.32.9). The values from the NUTS1 level can be found in table 56 [11-13].

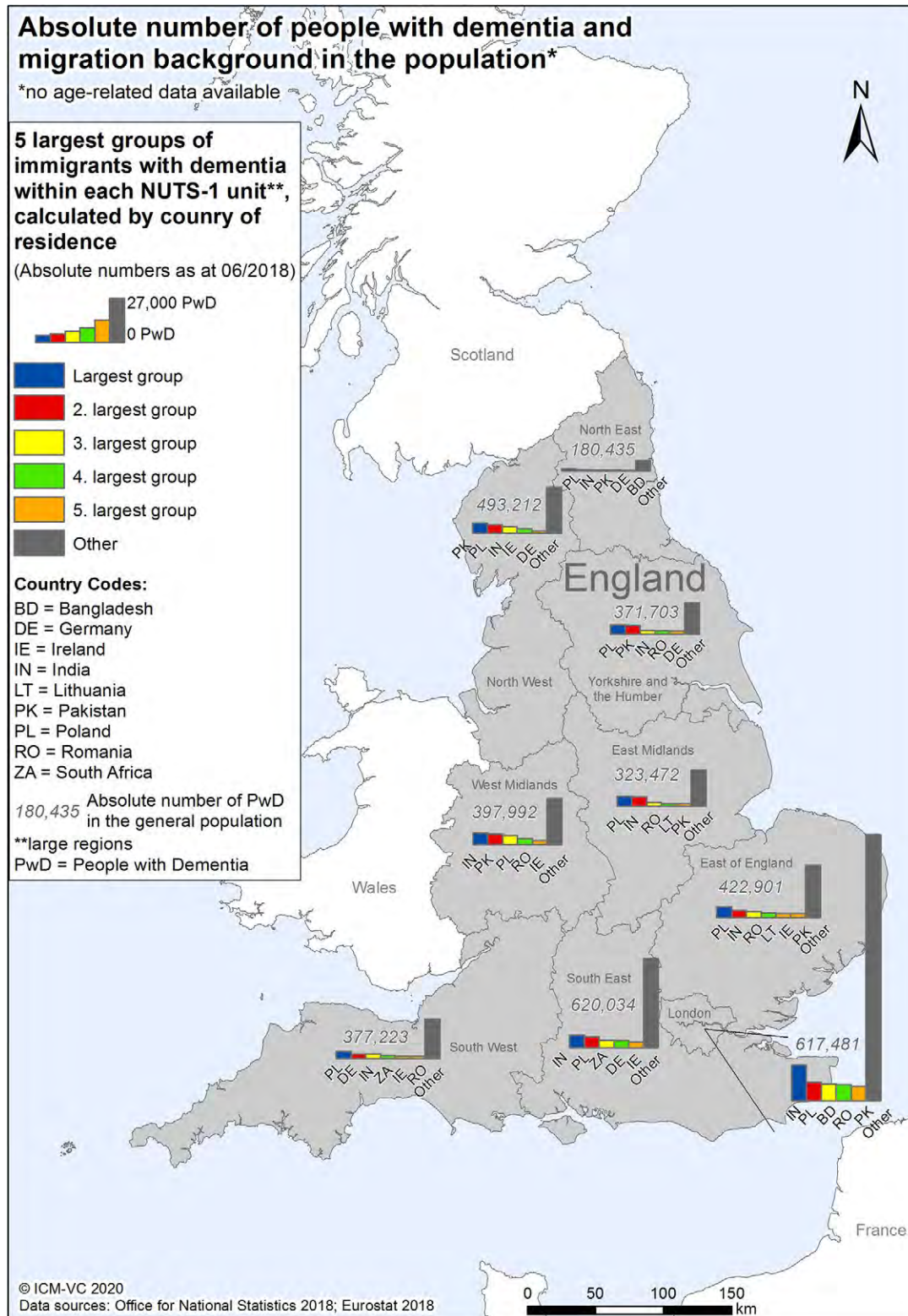


Fig. 3.7.32.8: Absolute number of PwM with dementia (England – NUTS1)



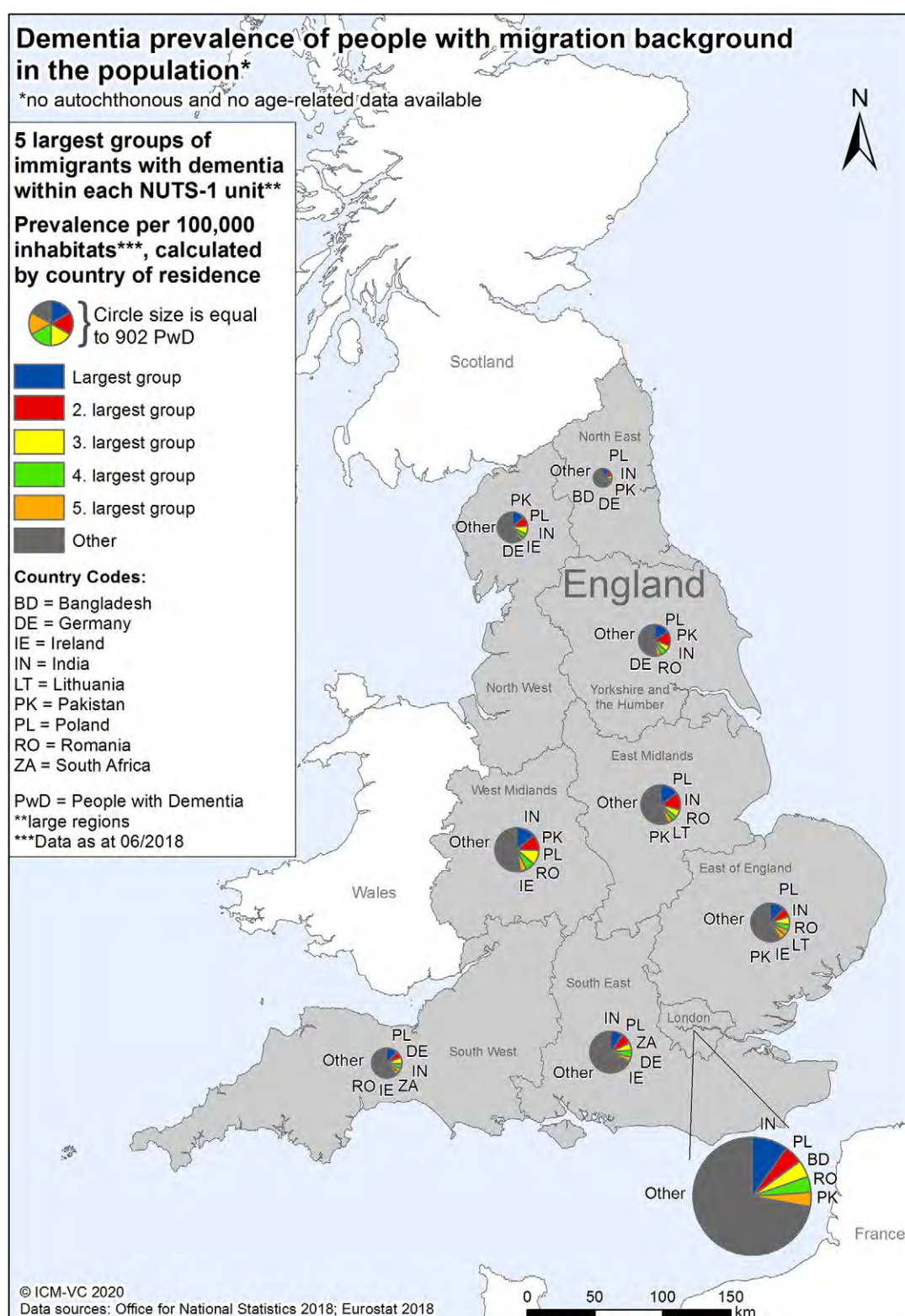


Fig. 3.7.32.9: Prevalence of PwM with dementia among the population (England – NUTS1)





**Tab. 56: PwM with dementia: Absolute numbers, prevalence among PwM, and prevalence among overall population (England – NUTS 1)**

NUTS	Total	ENG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
North East	180,435	169,257	PL 1,311	IN 897	PK 690	DE 621	BD 414	7,245
North West	493,212	445,947	PK 5,934	PL 4,968	IN 4,002	IE 2,415	DE 1,449	28,497
Yorkshire and the Humber	371,703	334,305	PL 5,727	PK 5,382	IN 2,277	RO 2,139	DE 1,725	20,148
East Midlands	323,472	282,486	PL 6,072	IN 5,727	RO 2,346	LT 1,725	PK 1,656	23,460
West Midlands	397,992	342,378	IN 7,383	PK 6,624	PL 5,796	RO 3,588	IE 2,484	29,739
East of England	422,901	370,323	PL 6,003	IN 4,071	RO 3,381	LT 2,622	IE & PK 2,346	34,155
London	617,481	388,332	IN 22,011	PL 11,592	BD 10,488	RO 9,867	PK 8,901	166,290
South East	620,034	537,096	IN 7,659	PL 6,762	ZA 4,554	DE 4,347	IE 3,312	56,304
South West	377,223	341,067	PL 4,140	DE 2,553	IN 2,484	ZA 1,794	IE & RO 1,449	23,736
Prevalence/10,000 inhabitants with migration background 65+								
North East	11,138	-	PL 81	IN 55	PK 43	DE 38	BD 26	447
North West	7,200	-	PK 87	PL 73	IN 58	IE 35	DE 21	416
Yorkshire and the Humber	6,858	-	PL 106	PK 99	IN 42	RO 39	DE 32	372
East Midlands	5,446	-	PL 102	IN 96	RO 39	LT 29	PK 28	396
West Midlands	4,938	-	IN 92	PK 82	PL 72	RO 45	IE 31	368
East of England	5,550	-	PL 79	IN 53	RO 44	LT 34	IE & PK 31	449
London	1,859	-	IN 66	PL 35	BD 32	RO 30	PK 27	500
South East	5,158	-	IN 64	PL 56	ZA 38	DE 36	IE 28	468
South West	7,199	-	PL 79	DE 49	IN 47	ZA 34	IE & RO 28	453



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NUTS	Total	ENG	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Prevalence/100,000 inhabitants 65+								
North East	6,900	6,473	PL 50	IN 34	PK 26	DE 24	BD 16	248
North West	6,900	6,239	PK 83	PL 70	IN 56	IE 34	DE 20	381
Yorkshire and the Humber	6,900	6,206	PL 106	PK 100	IN 42	RO 40	DE 32	351
East Midlands	6,900	6,026	PL 130	IN 122	RO 50	LT 37	PK 35	474
West Midlands	6,900	5,936	IN 128	PK 115	PL 100	RO 62	IE 43	499
East of England	6,900	6,042	PL 98	IN 66	RO 55	LT 43	IE & PK 38	526
London	6,900	4,339	IN 246	PL 130	BD 117	RO 110	PK 99	1,816
South East	6,900	5,977	IN 85	PL 75	ZA 51	DE 48	IE 37	606
South West	6,900	6,239	PL 76	DE 47	IN 45	ZA 33	IE & RO 27	420

Data source: Office for National Statistics (2018)



2.2 Northern Ireland

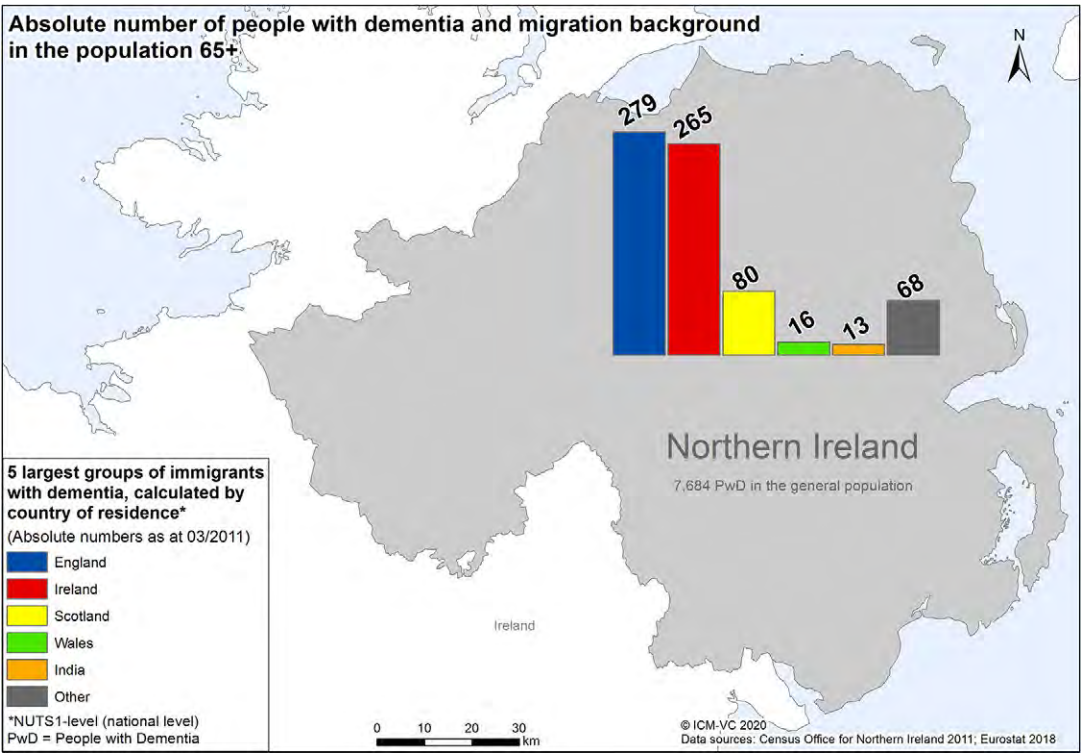


Fig. 3.7.32.10: Absolute number of PwM with dementia aged 65+ (Northern Ireland – Nation)

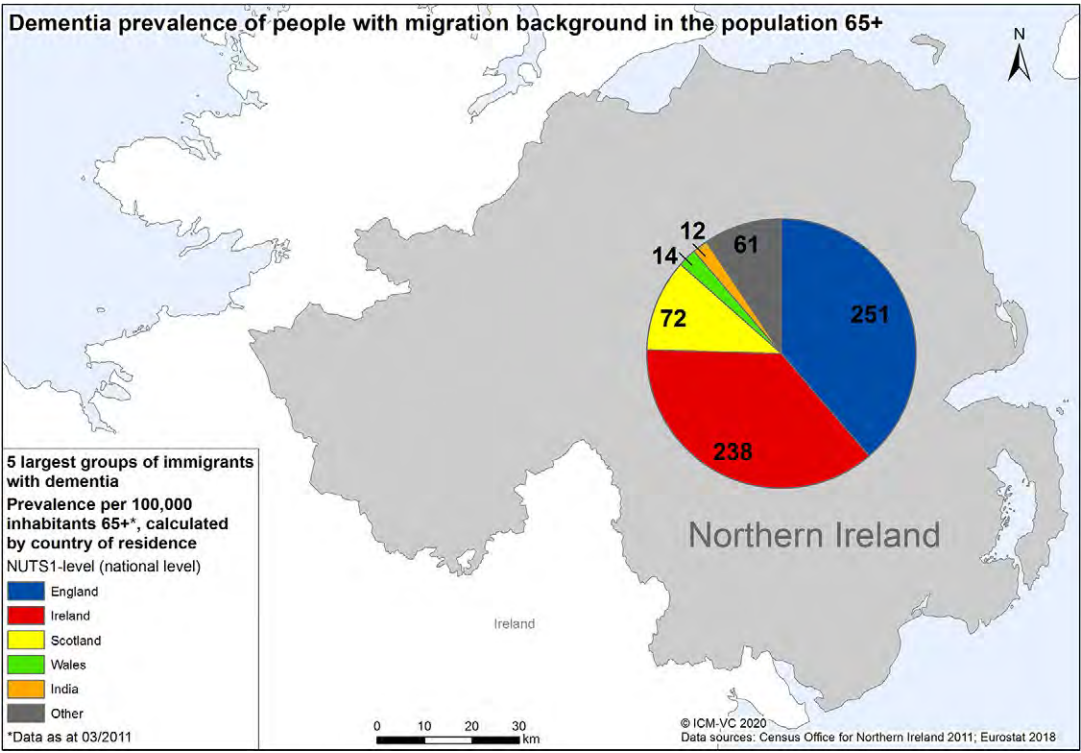


Fig. 3.7.32.11: Prevalence of PwM with dementia among the population aged 65+ (Northern Ireland – Nation)



**Tab. 57: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Northern Ireland – Nation)**

NUTS	Total	NIR	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Northern Ireland	7,684	6,963	ENG 279	IE 265	SCT 80	WLS 16	IN 13	68
Prevalence/10,000 inhabitants with migration background 65+								
Northern Ireland	7,351	-	ENG 267	IE 253	SCT 76	WLS 15	IN 13	65
Prevalence/100,000 inhabitants 65+								
Northern Ireland	6,900	6,252	ENG 251	IE 238	SCT 72	WLS 14	IN 12	61

Data source: Census Office for Northern Ireland (2011)

There are 10,500 PwM aged 65 or older. Of those, approx. 700 are estimated to exhibit some form of dementia. Figure 3.7.32.10 shows the most affected migrant groups presumably originate from England (approx. 300), Ireland (approx. 300), Scotland (approx. 100),

Wales (approx. 20), and India (approx. 10). The second graph highlights the number of PwM with dementia in Northern Ireland per 100,000 inhabitants aged 65 or older (figure 3.7.32.11). Table 57 displays the values depicted in the maps on the national level [11, 12, 14].



2.3 Scotland

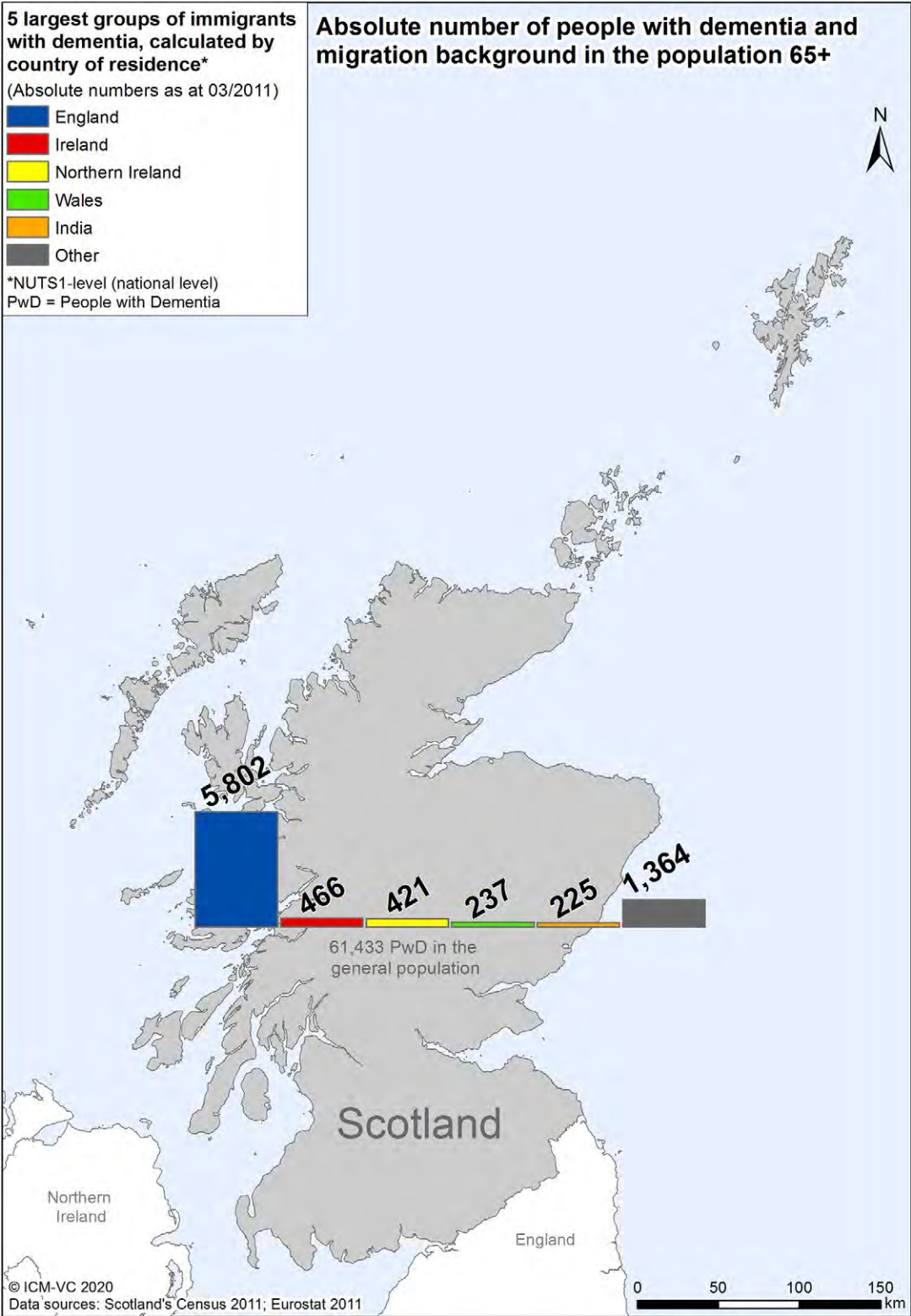


Fig. 3.7.32.12: Absolute number of PwM with dementia aged 65+ (Scotland – Nation)





# The United Kingdom

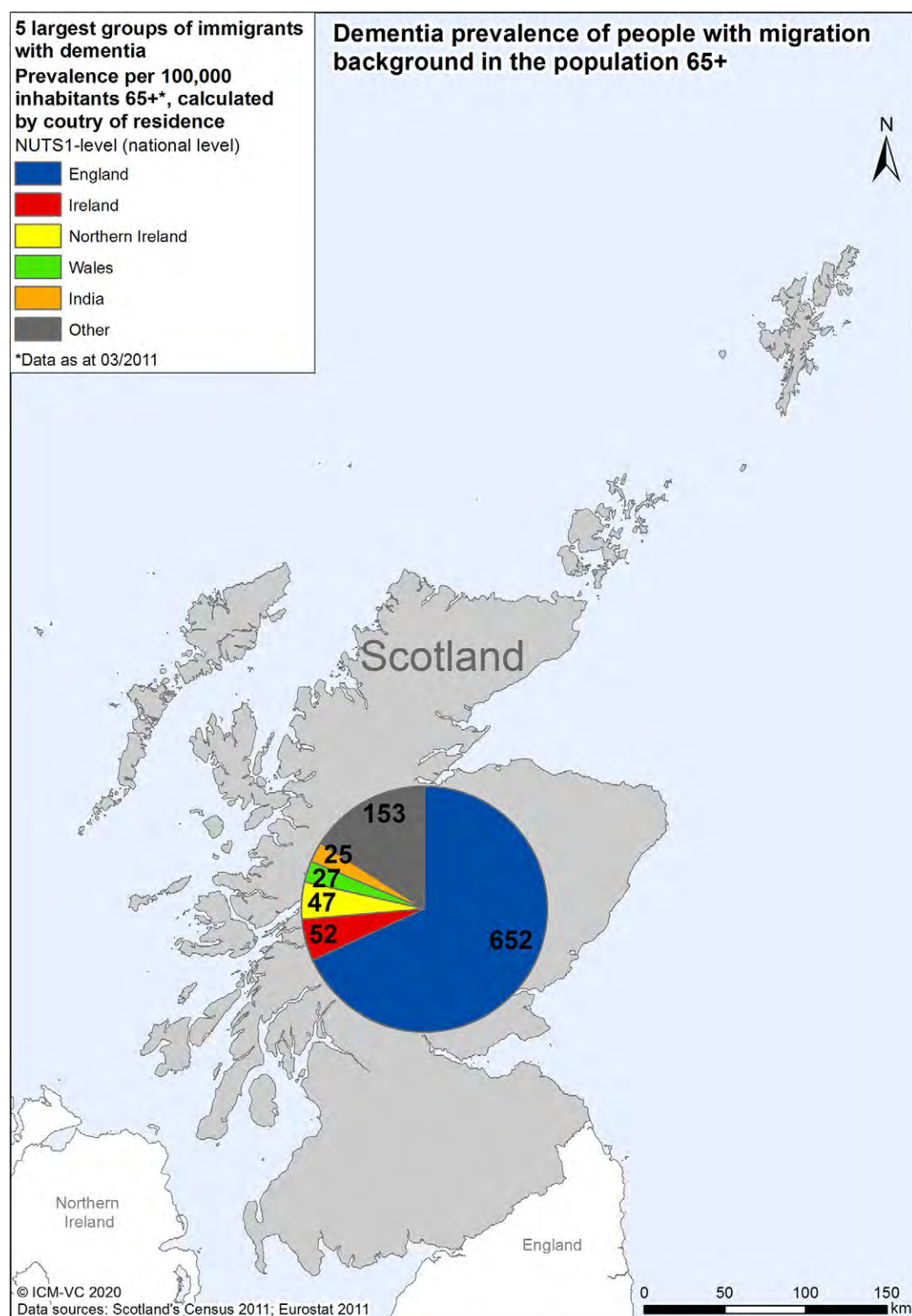


Fig. 3.7.32.13: Prevalence of PwM with dementia among the population aged 65+ (Scotland – Nation)





**Tab. 58: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Scotland – Nation)**

NUTS	Total	RO	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Scotland	61,433	52,919	ENG 5,802	IE 465	NIR 421	WLS 237	IN 225	1,362
Prevalence/10,000 inhabitants with migration background 65+								
Scotland	4,978	-	ENG 470	IE 38	NIR 34	WLS 19	IN 18	111
Prevalence/100,000 inhabitants 65+								
Scotland	6,900	5,944	ENG 652	IE 52	NIR 47	WLS 27	IN 25	153

Data source: Scotland's Census (2011)

There are 123,400 PwM aged 65 or older. Of those, approx. 8,500 are estimated to exhibit some form of dementia. Figure 3.7.32.12 shows the most affected migrant groups presumably originate from England (approx. 5,800), Ireland (approx. 500), Northern Ireland (approx. 400), Wales (approx. 200), and India (approx. 200). The second graph highlights the number of PwM with dementia in Scotland per

100,000 inhabitants aged 65 or older (figure 3.7.32.13). Table 58 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from England, Ireland, Northern Ireland, Wales, and India throughout the country in the NUTS2 regions (figures 3.7.32.14 – 3.7.32.15).

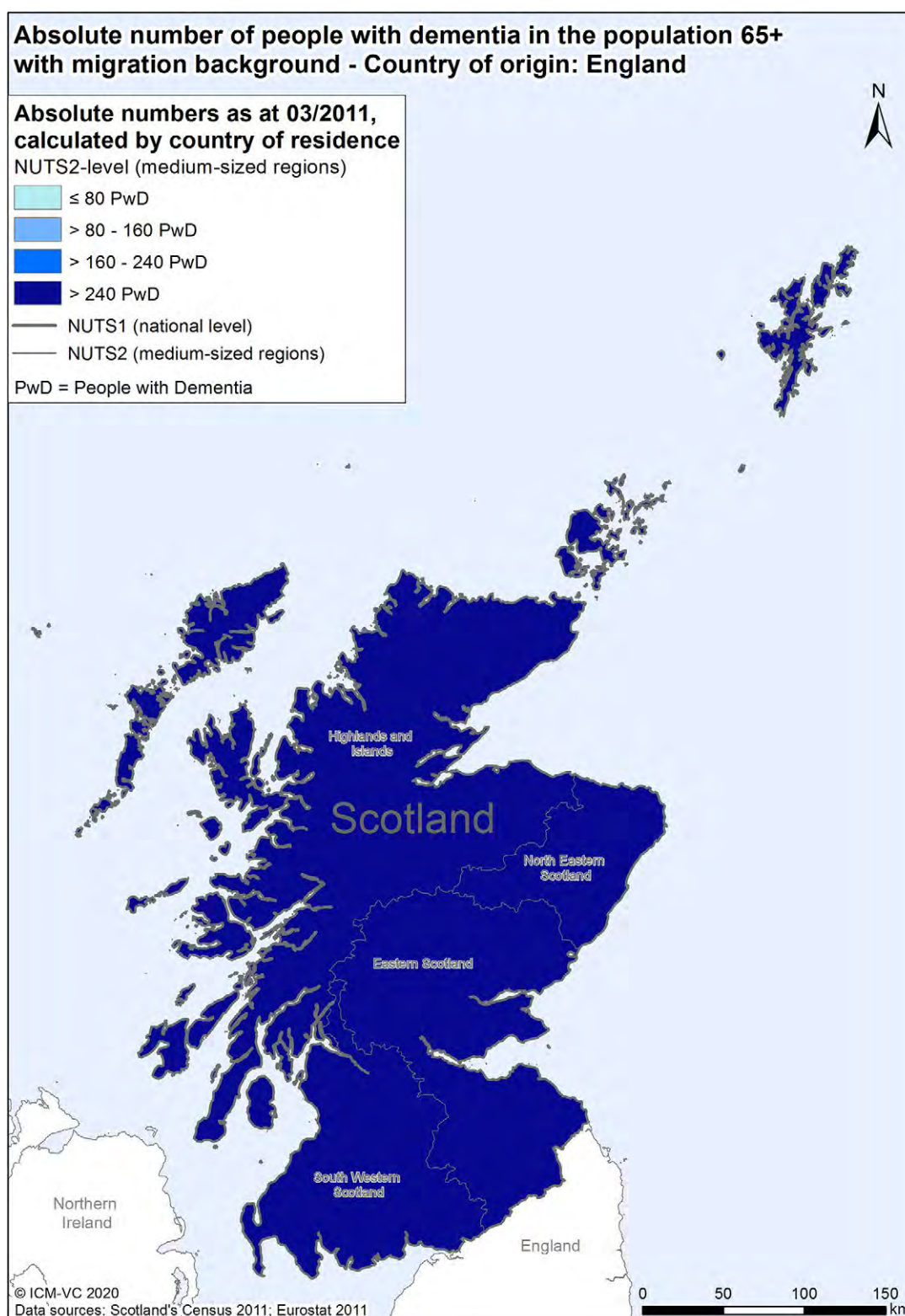


Fig. 3.7.32.14: Absolute number of PwM with dementia aged 65+.  
Country of origin: England (Scotland – NUTS2)

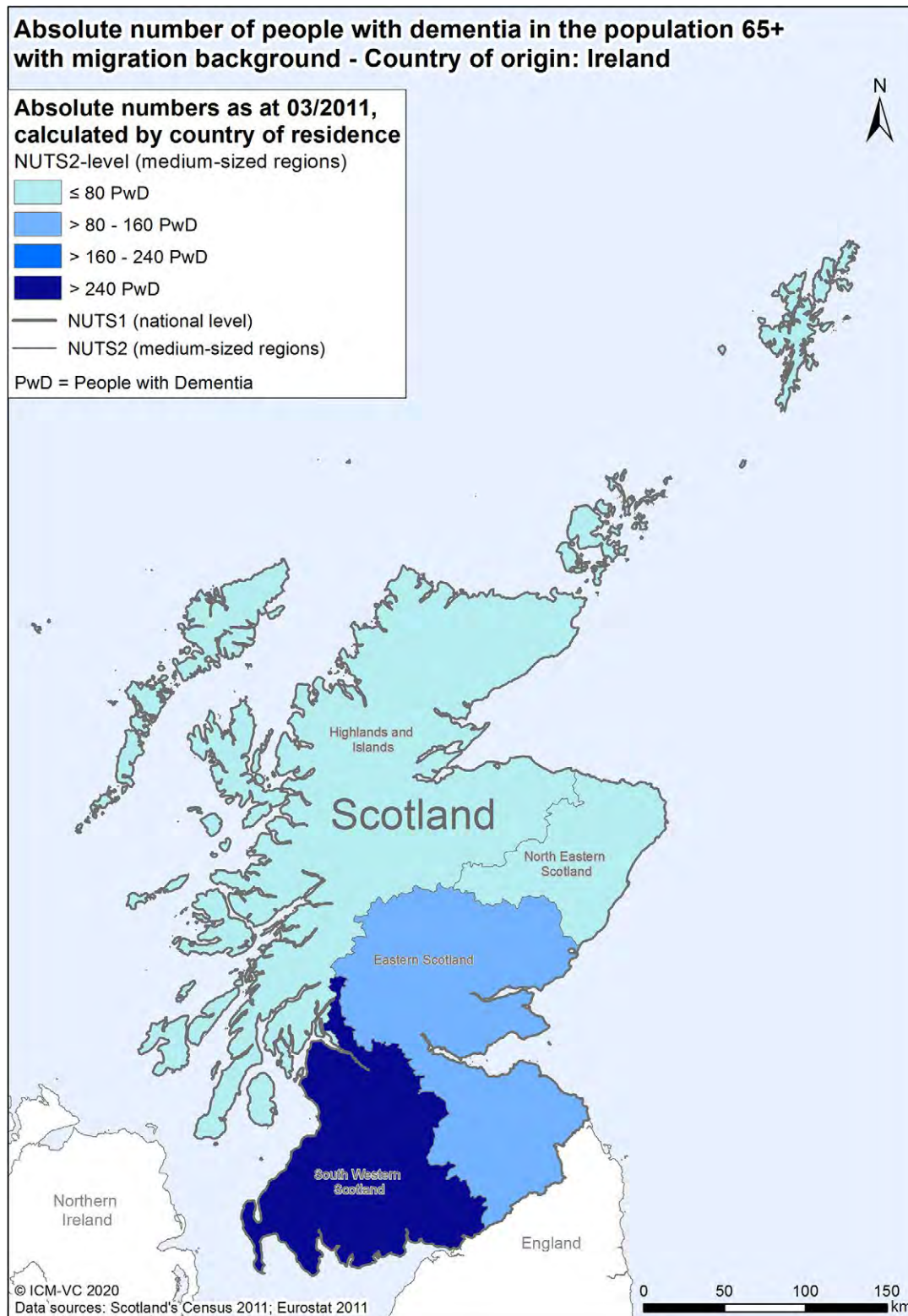


Fig. 3.7.32.15: Absolute number of PwM with dementia aged 65+. Country of origin: Ireland (Scotland – NUTS2)

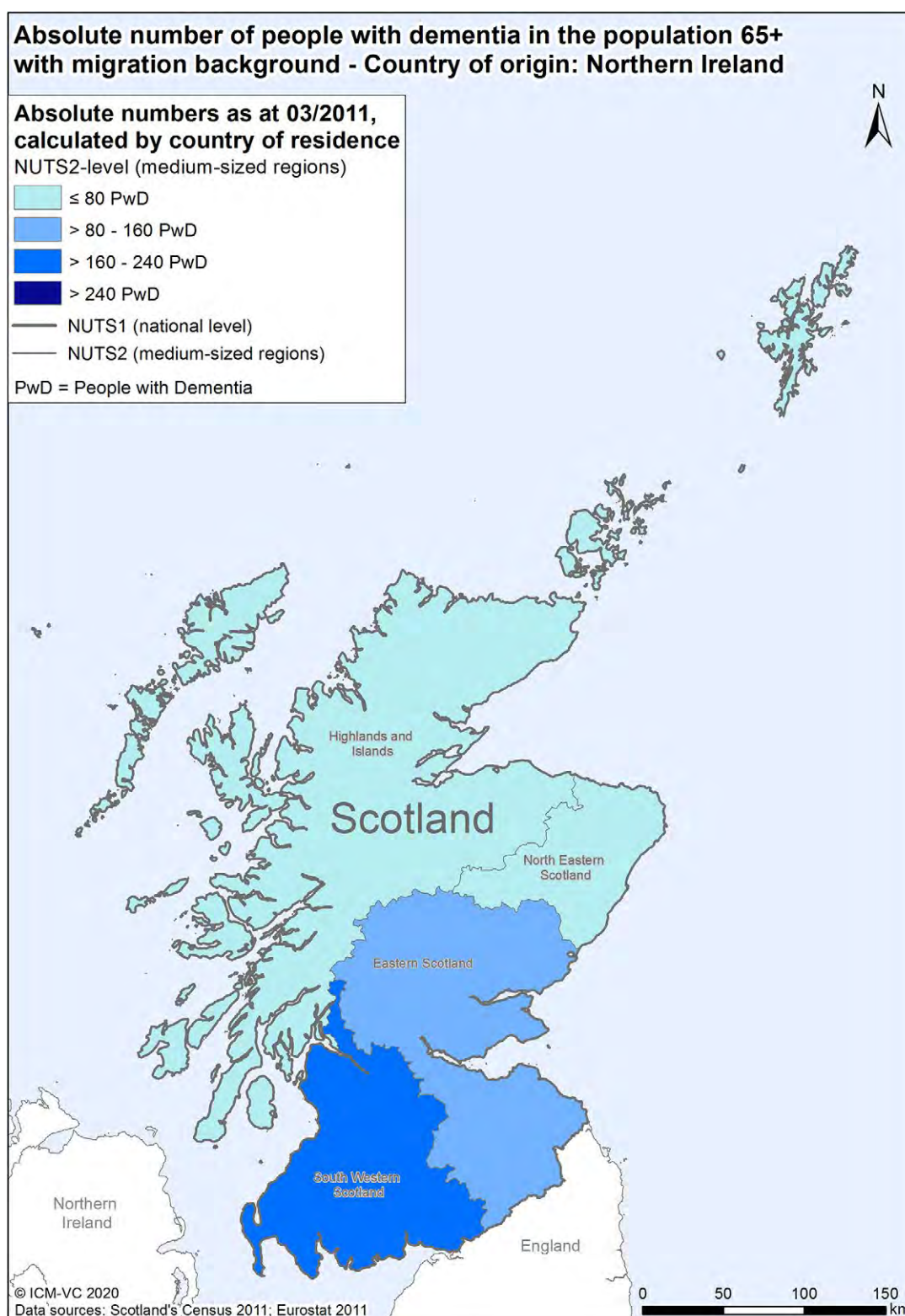


Fig. 3.7.32.16: Absolute number of PwM with dementia aged 65+.  
Country of origin: Northern Ireland (Scotland – NUTS2)



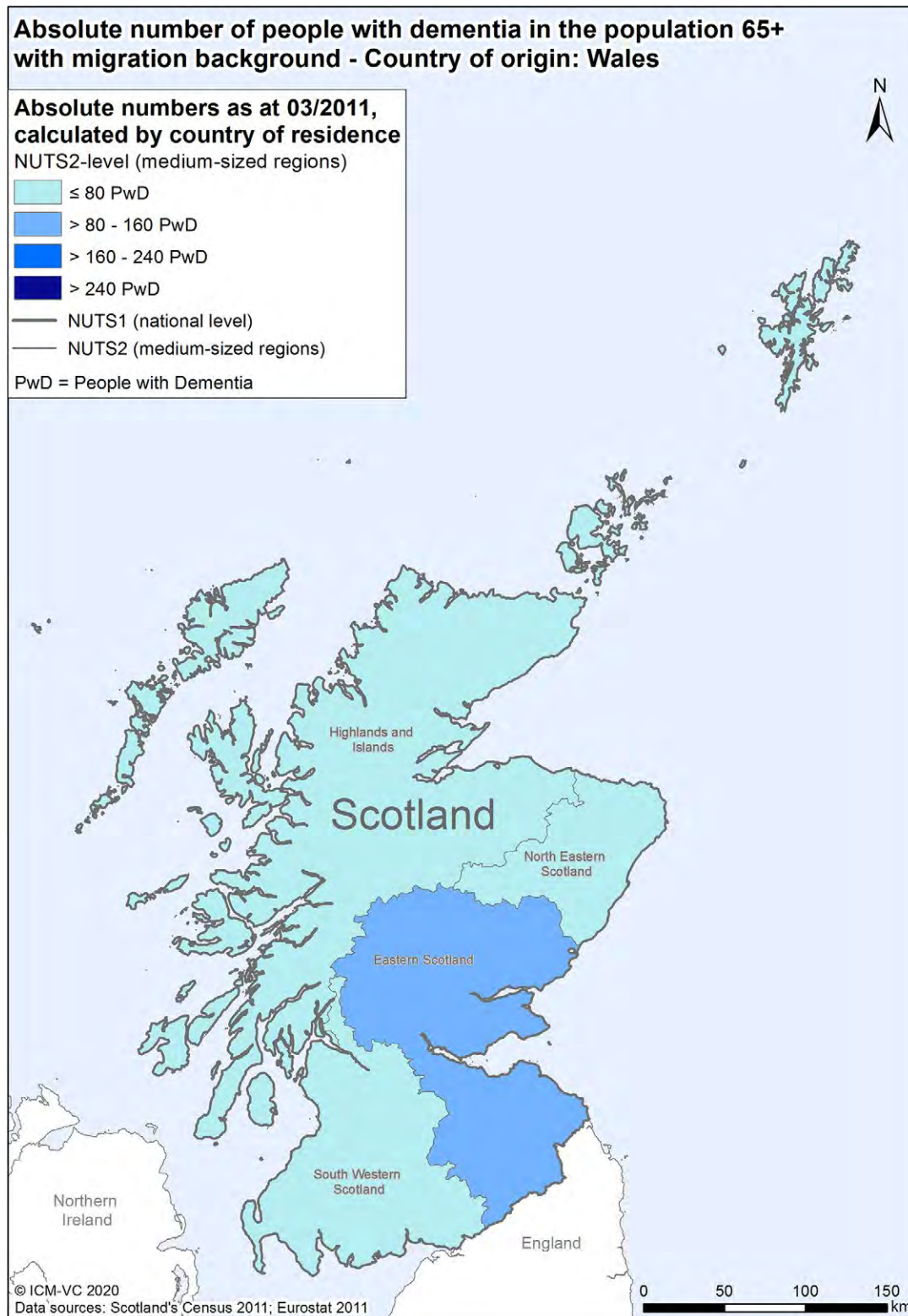


Fig. 3.7.32.17: Absolute number of PwM with dementia aged 65+.  
Country of origin: Wales (Scotland – NUTS2)

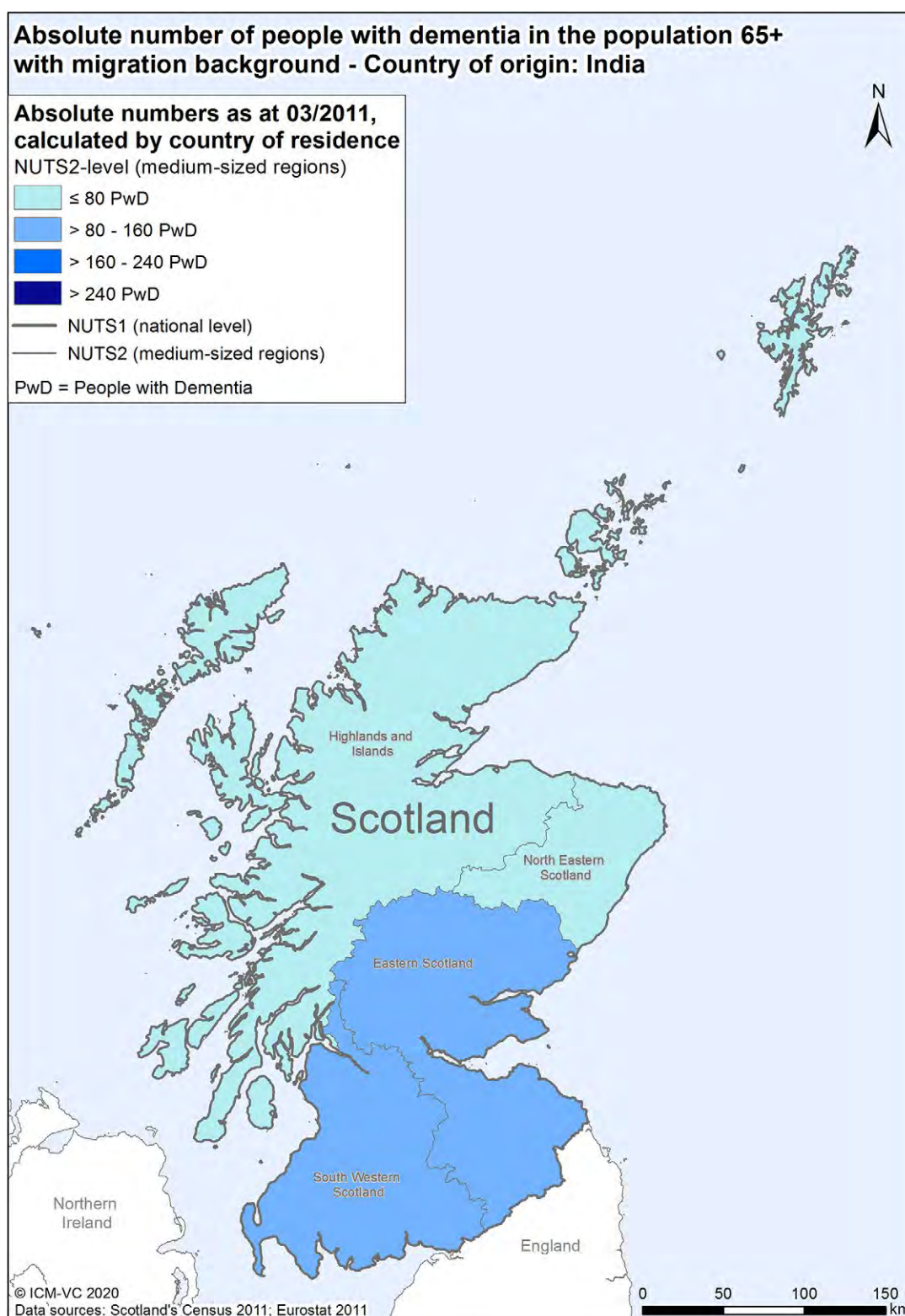


Fig. 3.7.32.18: Absolute number of PwM with dementia aged 65+. Country of origin: India (Scotland – NUTS2)



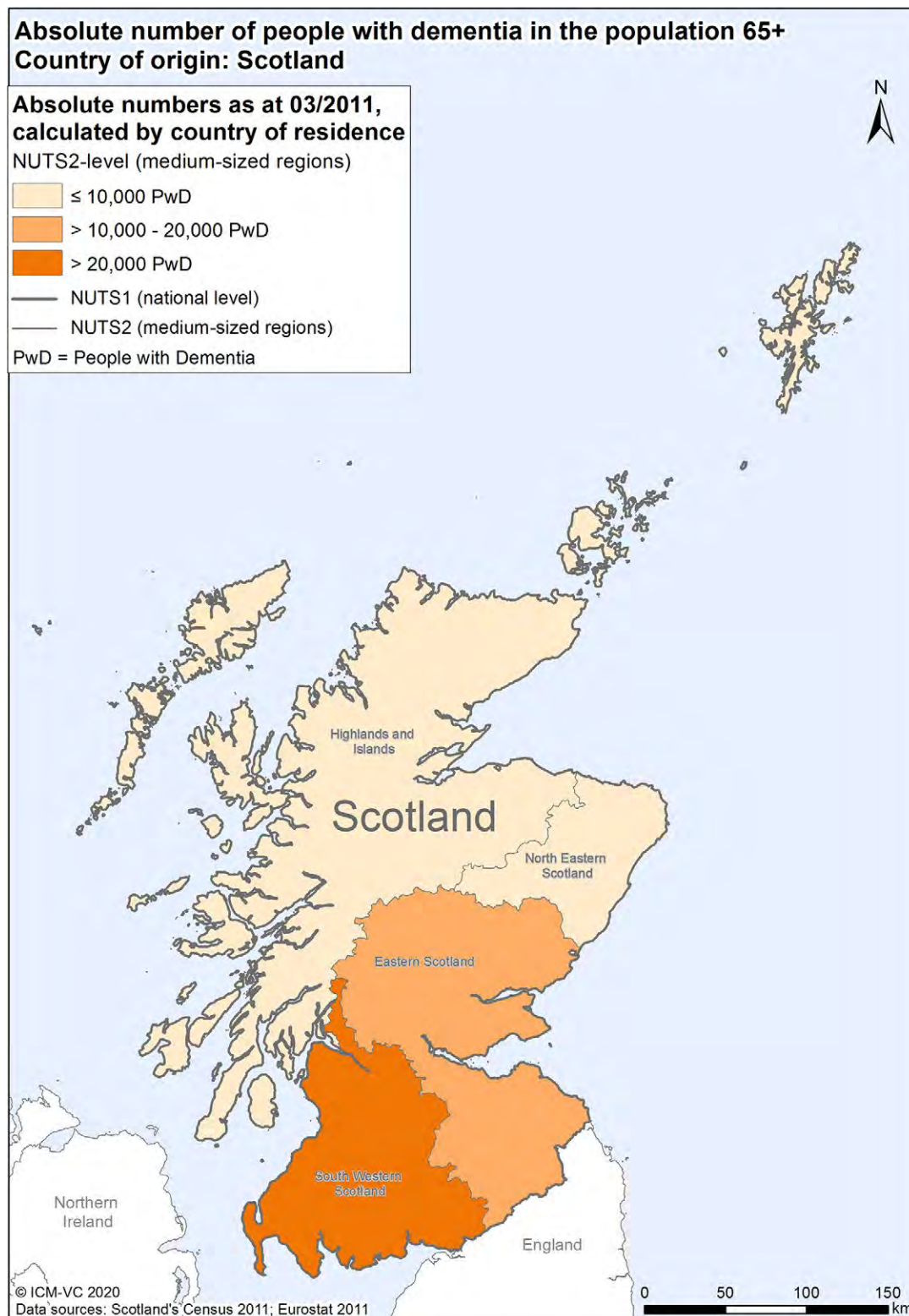


Fig. 3.7.32.19: Absolute number of people with dementia aged 65+.  
Country of origin: Scotland (Scotland – NUTS2)

The graphics below highlight which immigrant groups at the NUTS2 level. The first

map illustrate the absolute numbers of PwM with dementia in the NUTS2 regions (figure



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3.7.32.20). The second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions

(figure 3.7.32.21). The values from the NUTS2 level can be found in table 59 [11, 15, 16].

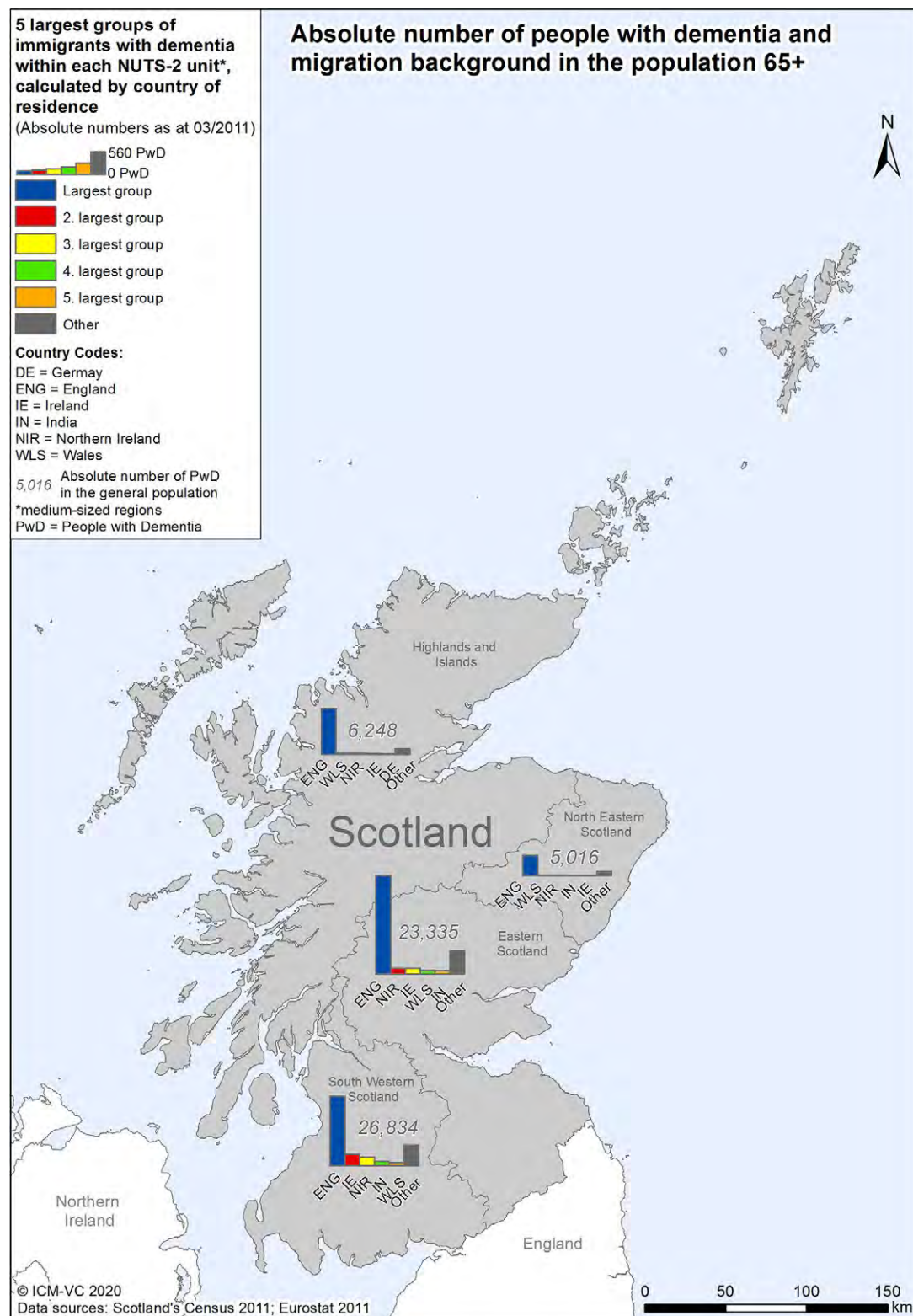


Fig. 3.7.32.20: Absolute number of PwM with dementia aged 65+ (Scotland – NUTS2)

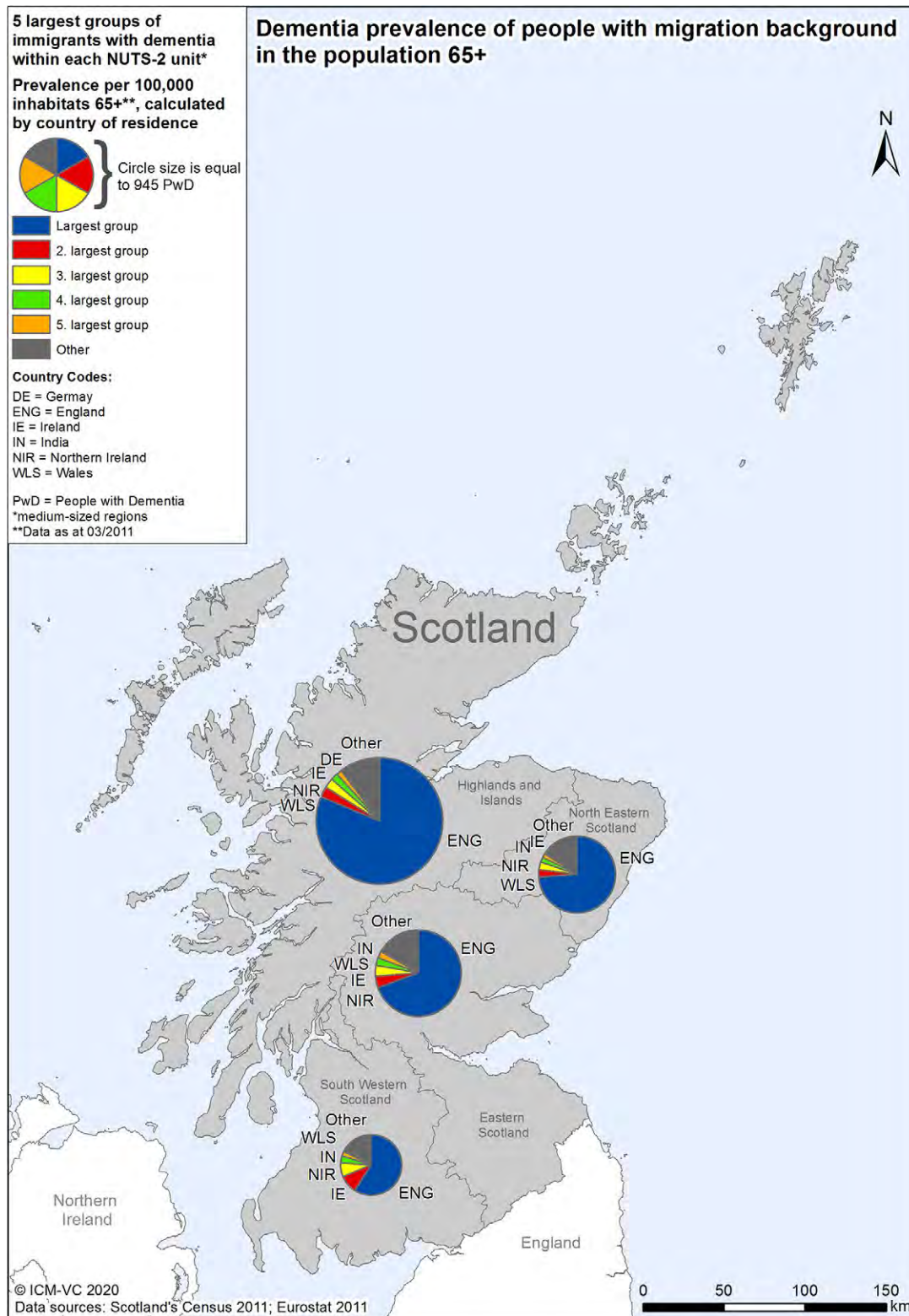


Fig. 3.7.32.21: Prevalence of PwM with dementia among the population aged 65+ (Scotland – NUTS2)



## The United Kingdom

**Tab. 59: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Scotland – NUTS 2)**

NUTS	Total	SCT	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Eastern Scotland	23,335	19,771	ENG 2,475	NIR 153	IE 147	WLS 103	IN 91	595
South Western Scotland	26,834	23,954	ENG 1,696	IE 280	NIR 212	IN 106	WLS 74	511
North Eastern Scotland	5,016	4,329	ENG 507	WLS 22	NIR 22	IN 14	IE 12	110
Highlands and Islands	6,248	4,865	ENG 1,123	WLS 38	NIR 34	IE 26	DE 18	144
Prevalence/10,000 inhabitants with migration background 65+								
Eastern Scotland	4,518	-	ENG 479	NIR 30	IE 29	WLS 20	IN 18	115
South Western Scotland	6,428	-	ENG 406	IE 67	NIR 51	IN 25	WLS 18	122
North Eastern Scotland	5,038	-	ENG 509	WLS 22	NIR 22	IN 14	IE 12	111
Highlands and Islands	3,117	-	ENG 561	WLS 19	NIR 17	IE 13	DE 9	72
Prevalence/100,000 inhabitants 65+								
Eastern Scotland	6,900	5,846	ENG 732	NIR 45	IE 44	WLS 30	IN 27	176
South Western Scotland	6,900	6,159	ENG 436	IE 72	NIR 55	IN 27	WLS 19	131
North Eastern Scotland	6,900	5,955	ENG 698	WLS 30	NIR 30	IN 19	IE 16	151
Highlands and Islands	6,900	5,373	ENG 1,241	WLS 41	NIR 38	IE 29	DE 29	159

Data source: Scotland's Census (2011)



## 2.4 Wales

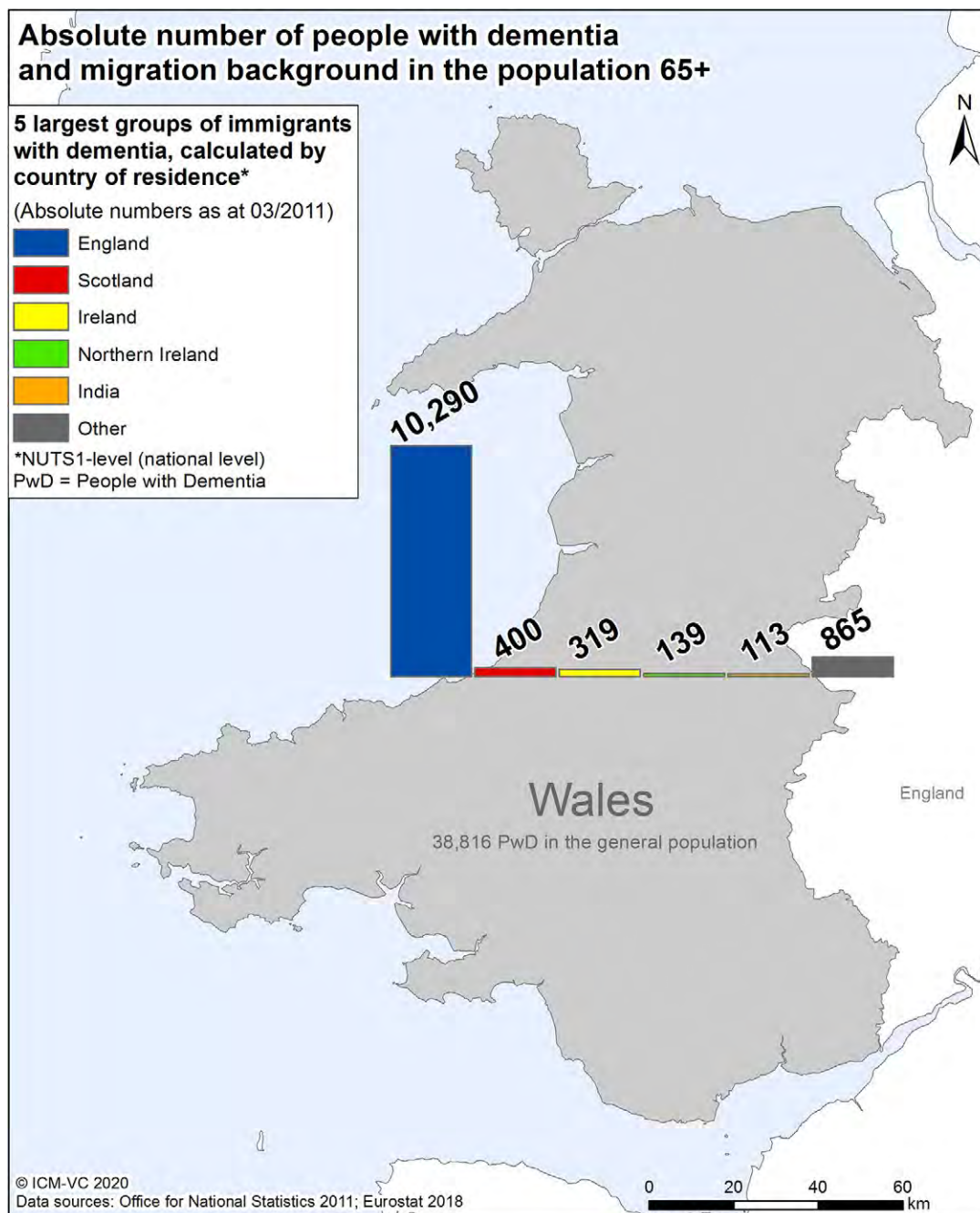


Fig. 3.7.32.22: Absolute number of PwM with dementia aged 65+ (Wales – Nation)



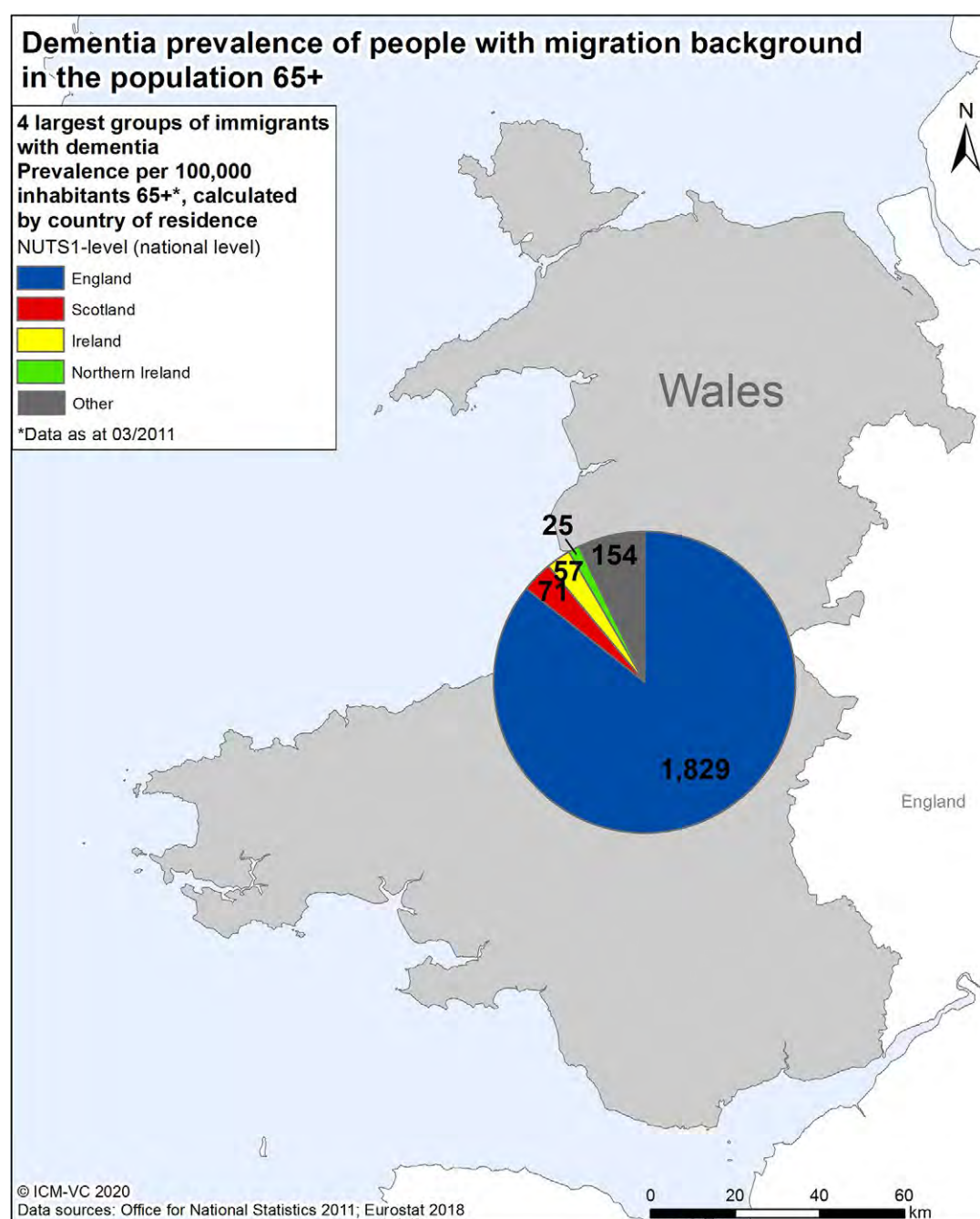


Fig. 3.7.32.23: Prevalence of PwM with dementia among the population 65+ (Wales – Nation)



**Tab. 60: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Wales – Nation)**

NUTS	Total	WLS	1. largest group	2. largest group	3. largest group	4. largest group	5. largest group	Other
Absolute Numbers								
Wales	38,816	26,690	ENG 10,290	SCT 400	IE 319	NIR 138	IN 112	867
Prevalence/10,000 inhabitants with migration background 65+								
Wales	2,209	-	ENG 586	SCT 23	IE 18	NIR 8	IN 6	49
Prevalence/100,000 inhabitants 65+								
Wales	6,900	4,745	ENG 1,829	SCT 71	IE 57	NIR 25	IN 20	153

Data source: Office for National Statistics (2011)

There are 175,700 PwM aged 65 or older. Of those, approx. 12,100 are estimated to exhibit some form of dementia. Figure 3.7.32.22 shows the most affected migrant groups presumably originate from England (approx. 10,300), Scotland (approx. 400), Ireland (approx. 300), Northern Ireland (approx. 100), and India (approx. 100). The second graph highlights the number of PwM with dementia in

Wales per 100,000 inhabitants aged 65 or older (figure 3.7.32.23). Table 60 displays the values depicted in the maps on the national level. The following maps show the distribution of non-migrants with dementia and PwM with dementia from England, Scotland, Ireland, and Northern Ireland throughout the country in the NUTS2 regions (figures 3.7.32.24 – 3.7.32.28).

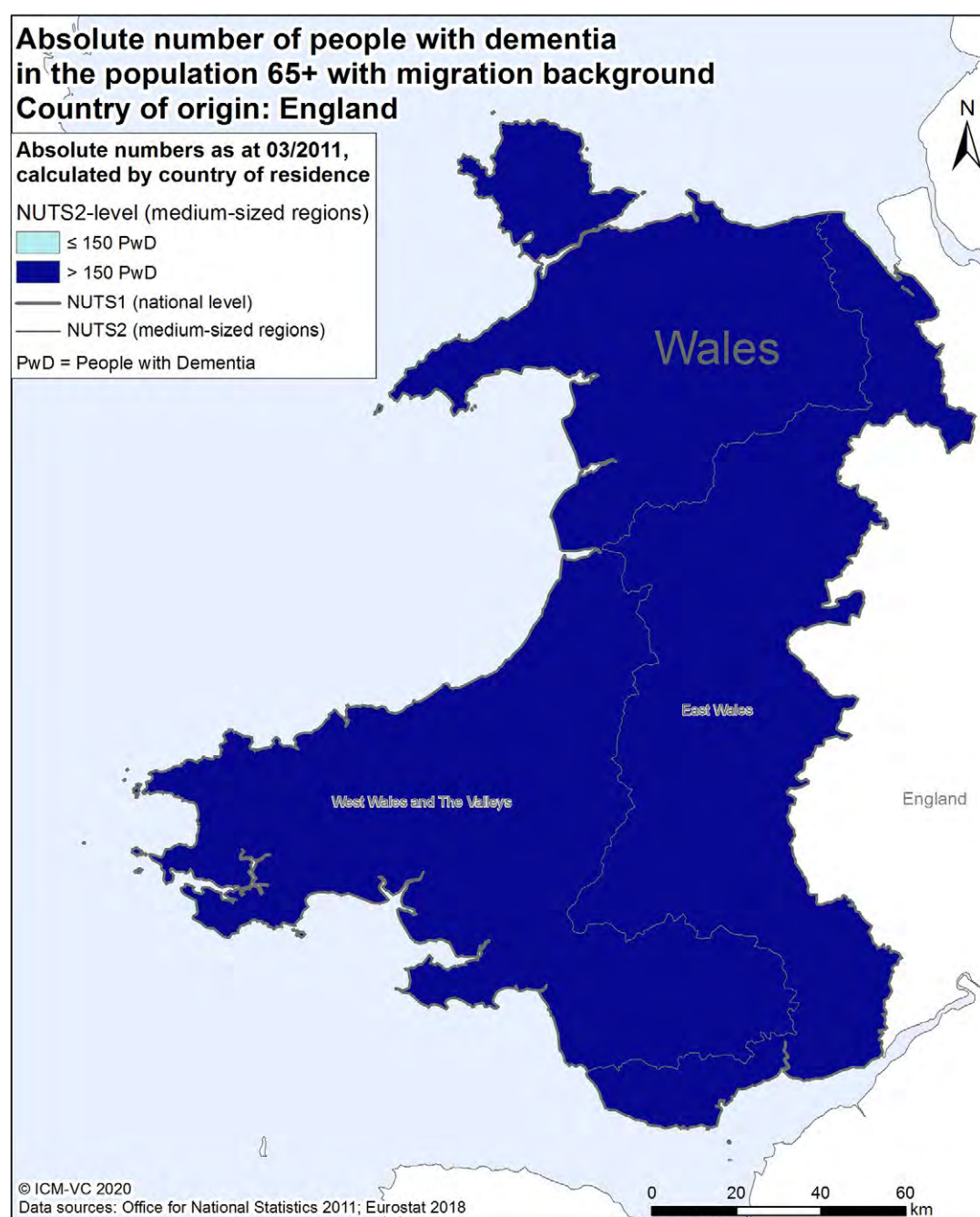


Fig. 3.7.32.24: Absolute number of PwM with dementia aged 65+. Country of origin: England (Wales – NUTS2)

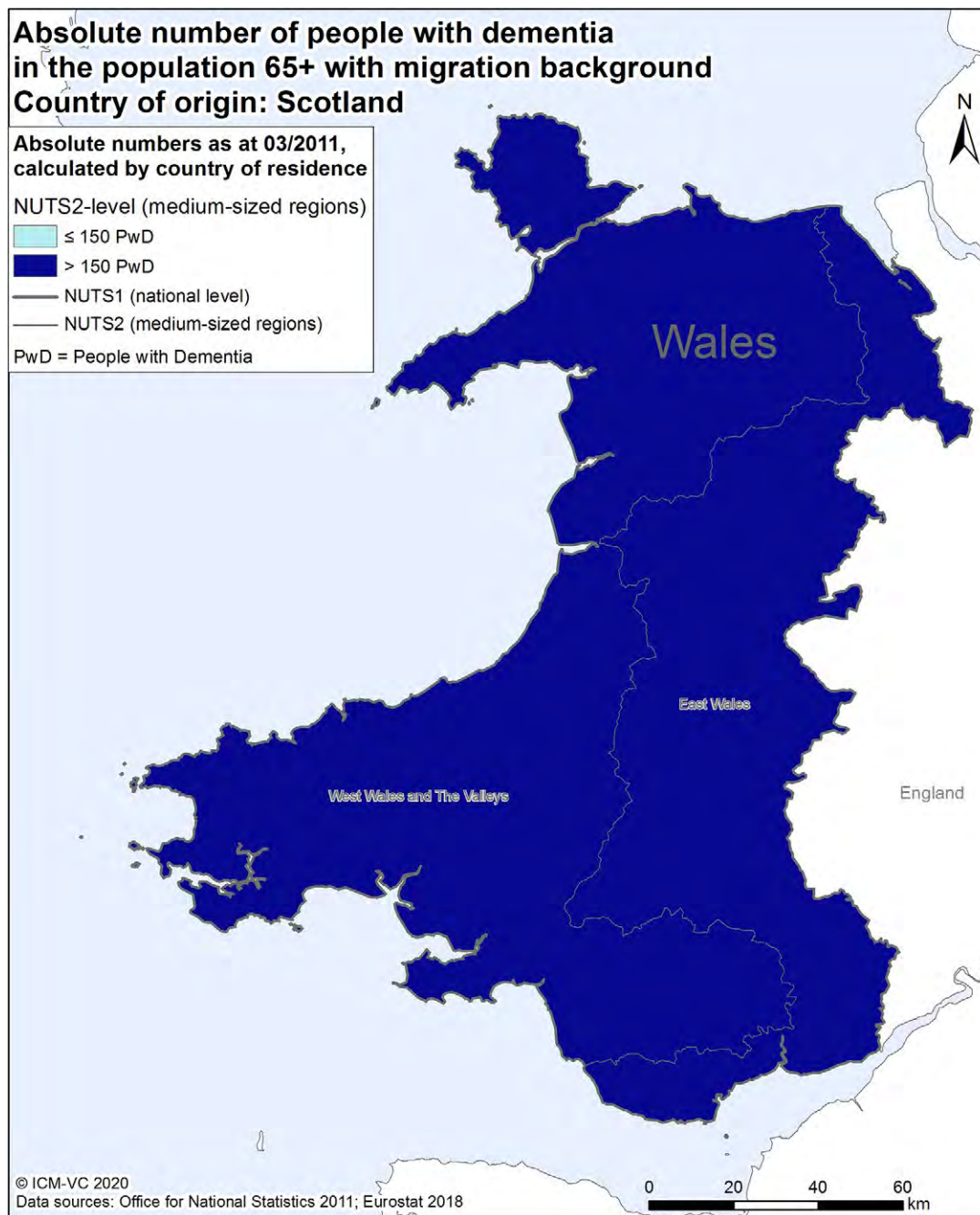


Fig. 3.7.32.25: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Scotland (Wales – NUTS2)



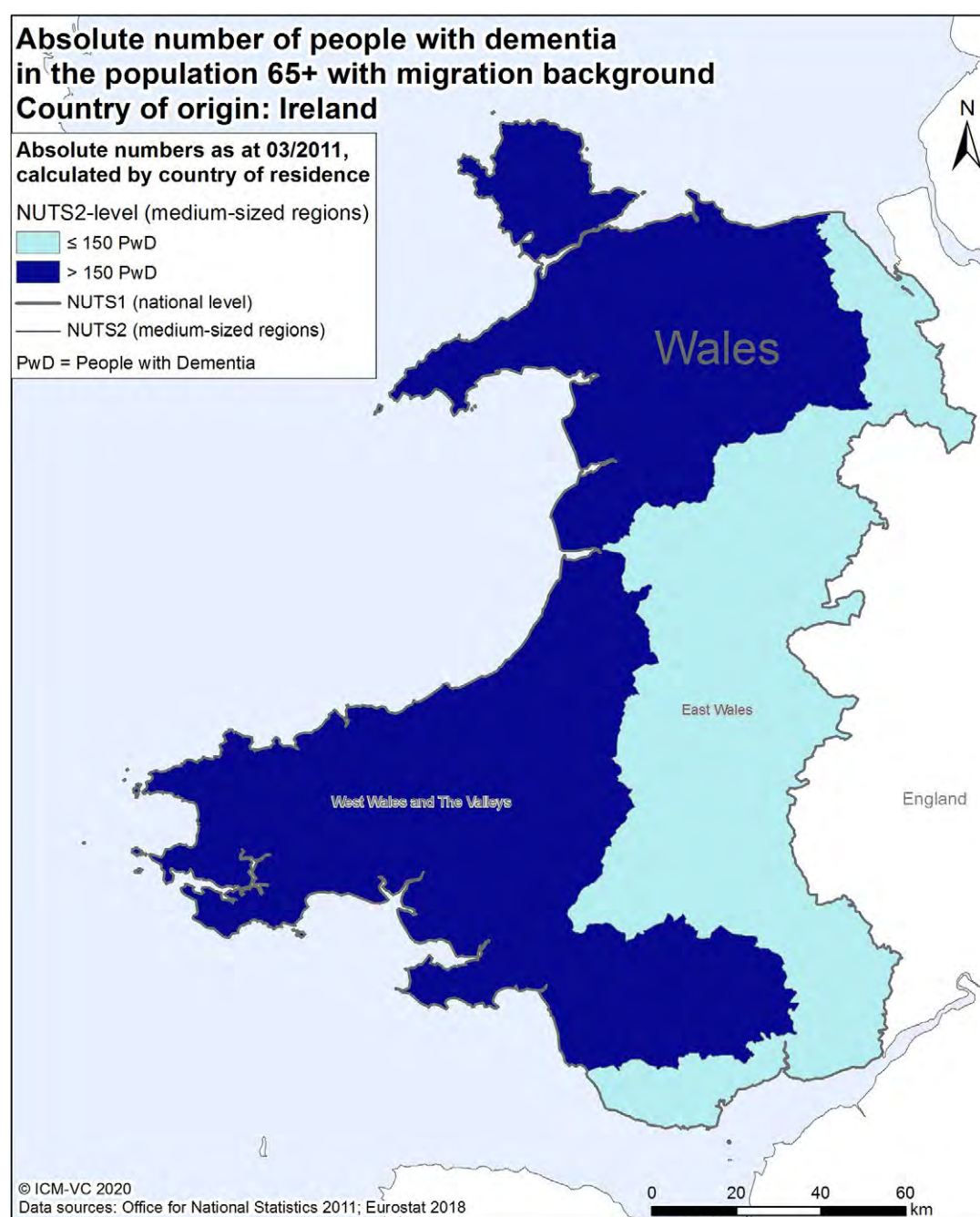


Fig. 3.7.32.26: Absolute number of PwM with dementia aged 65+. Country of origin: Ireland (Wales – NUTS2)



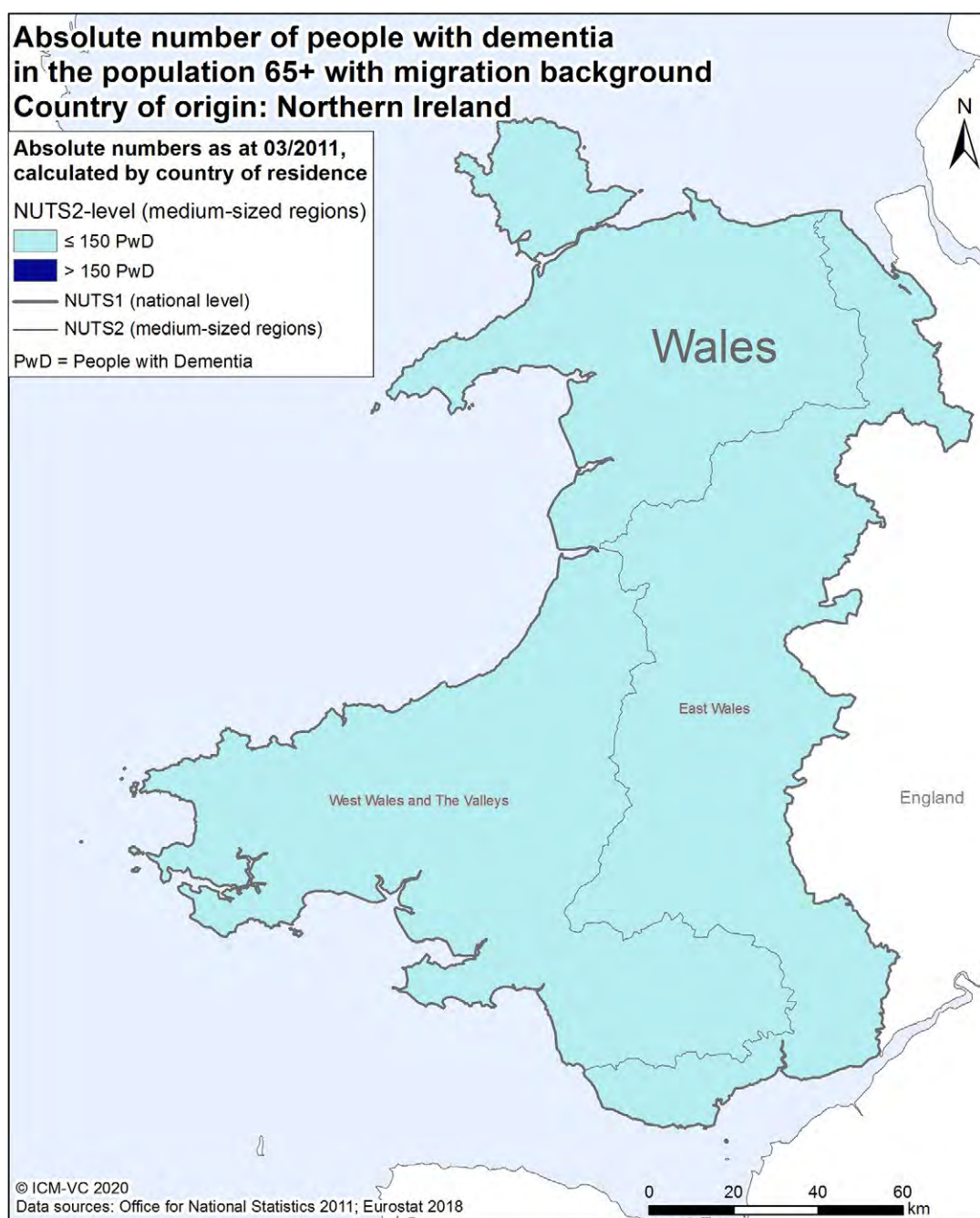


Fig. 3.7.32.27: Absolute number of PwM with dementia aged 65+.  
 Country of origin: Northern Ireland (Wales – NUTS2)

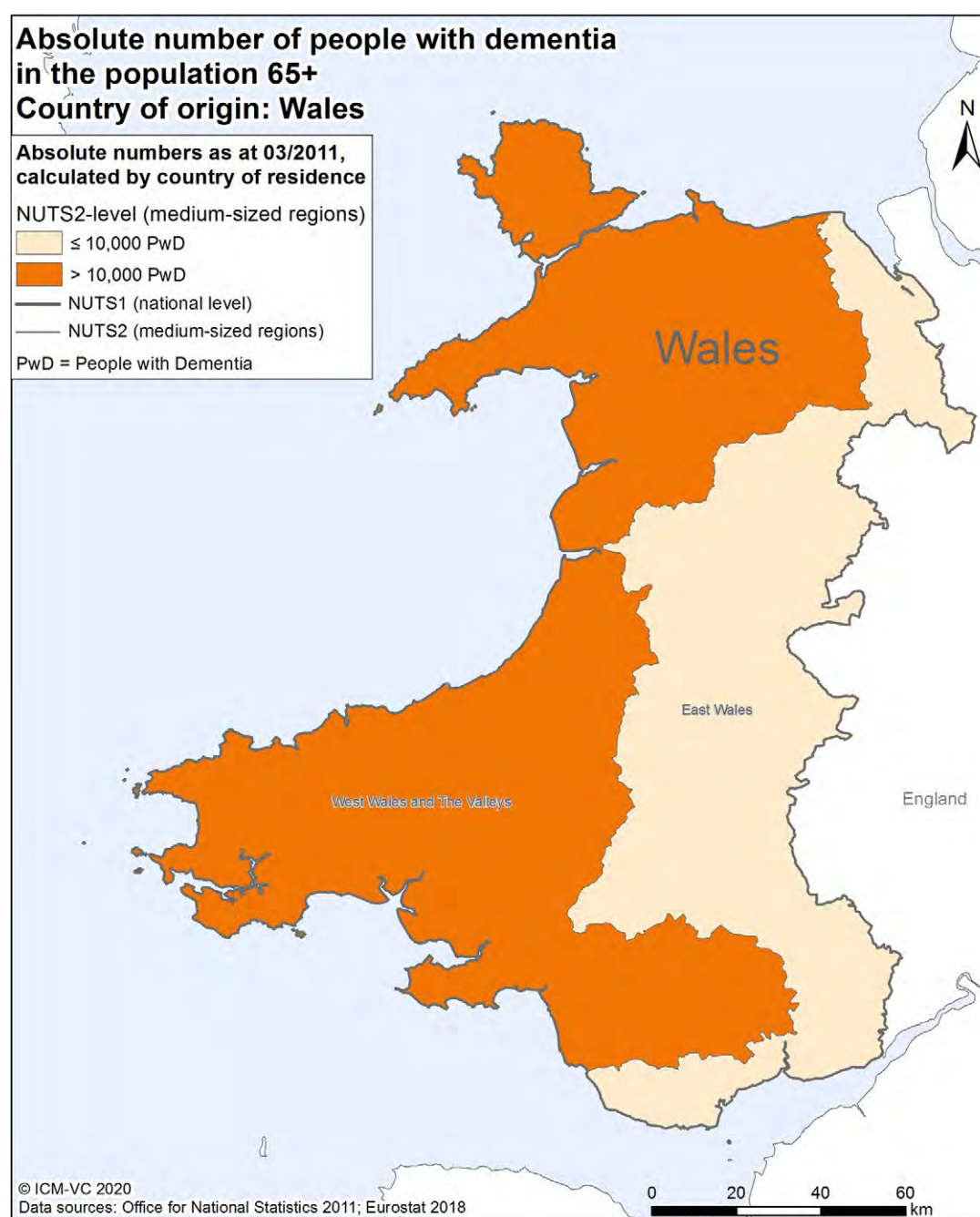


Fig. 3.7.32.28: Absolute number of people with dementia aged 65+. Country of origin: Wales (Wales – NUTS2)



The graphics below highlight which immigrant groups are estimated to be the most affected at the NUTS2 level. The first map illustrates the absolute numbers of PwM with dementia in the NUTS2 regions (figure 3.7.32.29). The

second graph shows the number of PwM with dementia per 100,000 inhabitants aged 65 or older in the NUTS2 regions (figure 3.7.32.30). The values from the NUTS2 level can be found in table 61 [11, 12, 17].

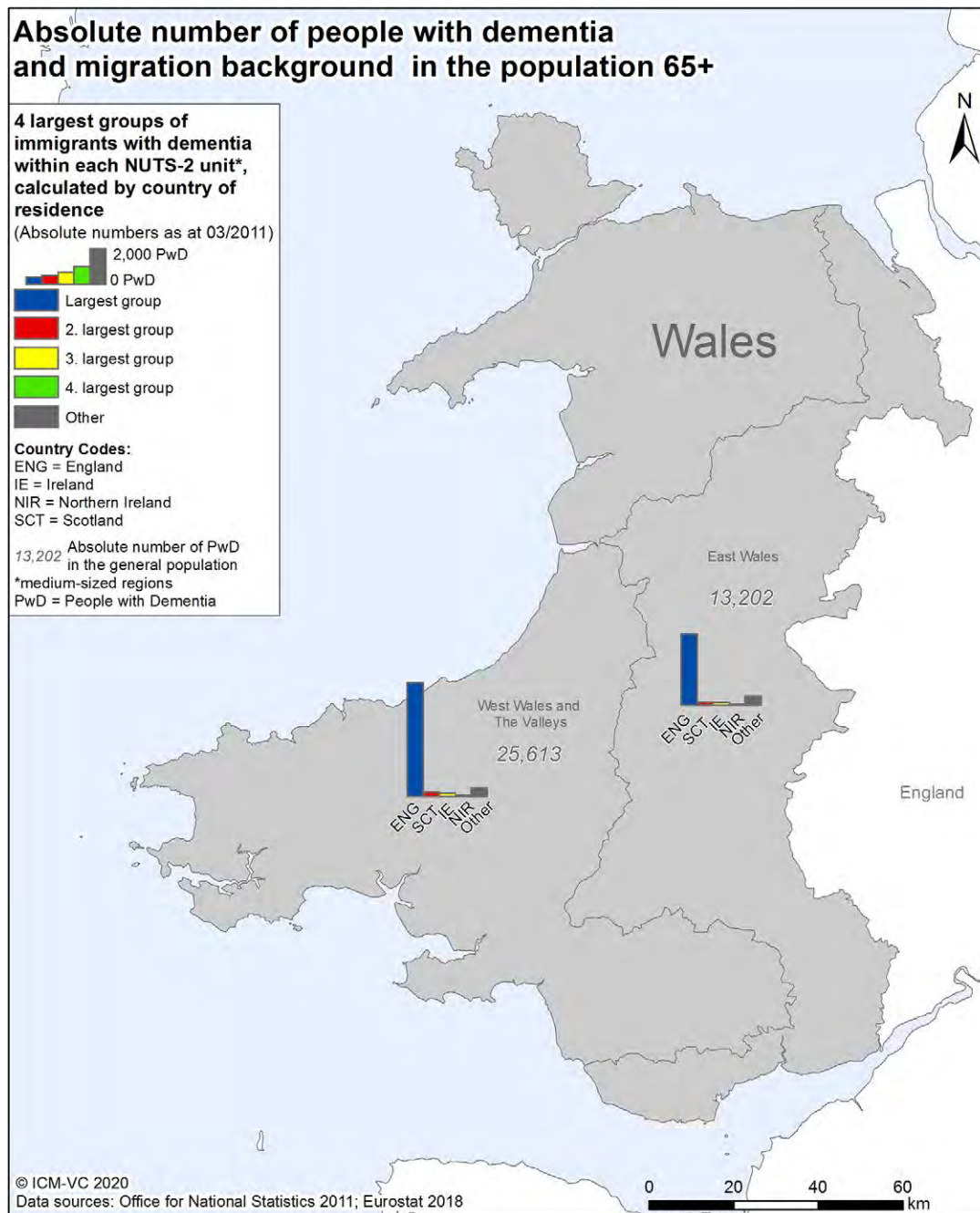


Fig. 3.7.32.29: Absolute number of PwM with dementia aged 65+ (Wales – NUTS2)



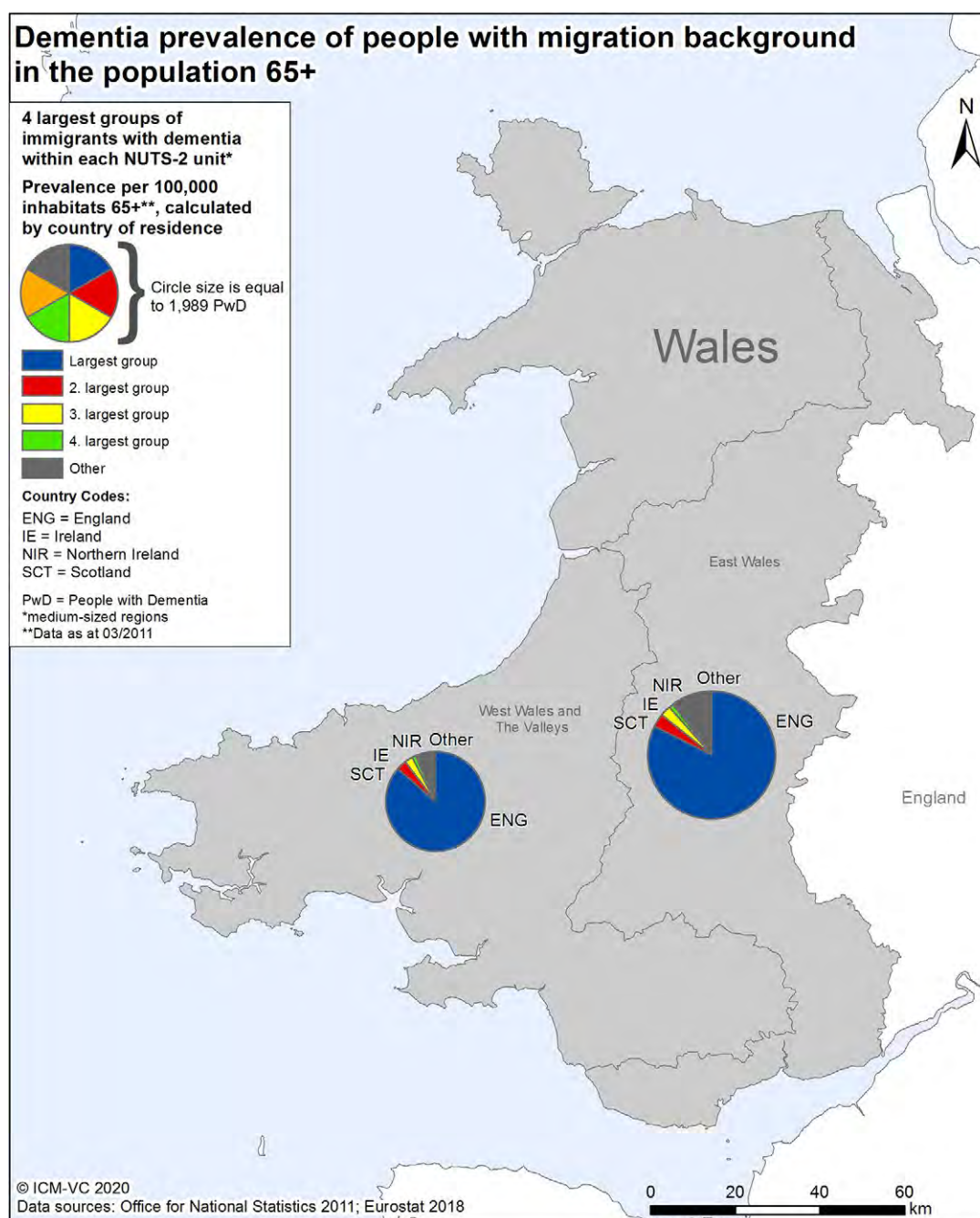


Fig. 3.7.32.30: Prevalence of PwM with dementia among the population aged 65+ (Wales – NUTS2)



**Tab. 61: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Wales – NUTS 2)**

NUTS	Total	WLS	1. largest group	2. largest group	3. largest group	4. largest group	Other
Absolute Numbers							
West Wales & The Valleys	25,613	18,229	ENG 6,382	SCT 242	IE 194	NIR 85	481
East Wales	13,202	8,461	ENG 3,908	SCT 158	IE 125	NIR 53	497
Prevalence/10,000 inhabitants with migration background 65+							
West Wales & The Valleys	2,393	-	ENG 596	SCT 23	IE 18	NIR 8	44
East Wales	1,922	-	ENG 569	SCT 23	IE 18	NIR 8	72
Prevalence/100,000 inhabitants 65+							
West Wales & The Valleys	6,900	4,911	ENG 1,719	SCT 65	IE 52	NIR 23	115
East Wales	6,900	4,422	ENG 2,042	SCT 83	IE 65	NIR 28	228

Data source: Office for National Statistics (2011)

### 3. National dementia plan

In the UK, a total of six NDPs were identified (three in Scotland and one each in England, Northern Ireland, and Wales). Three more national documents on dementia care were also considered in this research (two from England and one from Northern Ireland). Seven of these nine documents (three from England, two from Scotland, and one each from Northern Ireland and Wales) address the topic of migration to varying degrees. The following sections present the detailed results for the individual countries

#### 3.1 England

For England the three documents entitled 'Living Well with Dementia: A National Dementia Strategy' from 2009, 'Building on the National Dementia Strategy: Change, Progress, and Priorities' from 2014, and 'Prime Minister's

Challenge on Dementia 2020: Implementation Plan' from 2016 were found.

The national dementia strategy from 2009 does not have a separate chapter on migration, but individual chapters refer briefly to minority ethnic groups. In the sections containing references to these groups, it is noted that the views of people with dementia from minority ethnic groups have been taken into account in the development of the dementia strategy. These sections also provide information on the prevalence (approximately 15,000 people with dementia from minority ethnic groups), identify differences in needs between people from minority ethnic groups and the majority population, and recognize the need for specialised services for people with dementia and their caregivers from minority ethnic groups. Furthermore, it is pointed out that curricula for





the initial and advanced training of health and social care professionals should be designed in a way that promotes an understanding of diversity concerning dementia and takes into account the needs of people from minority ethnic groups. However, the document does not identify minority ethnic groups as a risk group for dementia and does not propose a specific strategy or set of measures for their benefit. The idea of developing specialised services for immigrants is a very minor topic in this document. No reference is made to currently available specialised services for people from minority ethnic groups [18].

The report from 2014, which is based on the national dementia strategy, also does not have a separate chapter and only briefly refers to ethnic minority communities in one chapter. Reference is made to the study 'Dementia Does Not Discriminate' from 2013, which states that people with dementia from black, Asian, or ethnic minority communities may be socially isolated. To address this problem, the use of so-called 'dementia leads' (people with special responsibility for ensuring quality care) is recommended. Such people can act as a linkage between local organisations and the contracted service providers and ensure that the needs of all people with dementia are met [19].

The 'Implementation Plan' from 2016 discusses migration in nine passages. First, the general goal is formulated to create a society in which all people with dementia, their families, and caregivers receive high-quality and culturally competent care, regardless of their origin and ethnicity, by 2020. Currently, according to the document, there are inequalities in care based on geography, age, and gender, as well as ethnicity. Several current (implemented) or planned measures to address these care inequalities are mentioned. These include the establishment of a working group that also advises on support for people with dementia from ethnic minorities. Furthermore, there are

plans to improve access to data on ethnicity and to work with the organisation 'Skills for Care' to develop a tool to support social workers who work with people with dementia from different cultures and backgrounds. A film focusing on the specific needs of the African-Caribbean community within the care process has already been commissioned and will be made available free of charge to health and social care providers. The document also highlights that materials raising awareness and understanding of dementia have already been developed for black and minority ethnic people. In terms of scope, the topic of migration plays a minor role in this Implementation Plan from 2016. However, it identifies inequalities in care for black and minority ethnic groups and refers to several measures to address them. The reference to considering the views of black and minority ethnic groups in the introduction also gives the issue a certain presence and importance [20].

### 3.2 Northern Ireland

For Northern Ireland the document 'Improving Dementia Services in Northern Ireland - a Regional Strategy' from 2011 and 'The Dementia Learning and Development Framework' from 2016 were identified. While the dementia strategy from 2011 does not bring up migration [21], the document from 2016 refers to this topic in four chapters. The chapter 'Equality, Cultural Diversity, and Inclusion in Dementia Care' focuses in some detail on ethnic and cultural minorities. First of all, it is emphasised that the equality of people with dementia with an ethnic minority background is of particular importance. Furthermore, this chapter contains a description of different experiences and skills that service providers need to have to support people with dementia from different cultural and ethnic backgrounds. This includes recognition of cultural differences and the fact that people from various cultures have



different approaches to living with dementia, as well as an awareness of the impact of cultural differences on people with dementia. The other sections dealing with migration have an action framework. In them, learning goals are formulated, recommendations are given, and reference is made to an existing instrument for sensitizing care providers to migration-specific issues. Palliative care providers are advised to support people with dementia in meeting their spiritual, religious, and cultural needs. The available self-assessment tool for service providers, which includes a four-level scale of assessment for different dementia-related issues and has a special focus on people from different cultural backgrounds, is an instrument at the national level to raise awareness among care providers of the needs of people with dementia, their families, and caregivers from other cultures. In this document, Northern Ireland has identified people from different cultural and ethnic backgrounds as a group with special needs concerning dementia care. To improve the provision of care for them, several concrete measures are mentioned and recommendations are given [22].

### 3.3 Scotland

For Scotland three national dementia strategies were identified (2010, 2013, and 2017). The version from 2010 ('Scotland's National Dementia Strategy') has no chapter on migration and makes no reference to this topic in the continuous text of the actual strategy. Only the preface refers to the necessity to ensure that the needs of people from ethnic minorities are not neglected [23]. In the version from 2013 ('Scotland's National Dementia Strategy: 2013 - 16') there is no chapter on migration, but a short section on black and ethnic minority communities. This section refers to a different relationship of these communities to health and social services, which is based on strong family structures. It is stated that the

family-based culture reduces the likelihood of them seeking diagnosis or becoming more involved in services after diagnosis. Following this problem description, the general goal of providing services in a way that this group is not disadvantaged is formulated. To this purpose, the intention to conduct an investigation that focuses on the care pathway (from diagnosis and support to treatment and care) for people with dementia in black and ethnic minority communities is stated. The necessity of taking the specific needs of family members and caregivers into account is mentioned. The main goal of this investigation is to identify further necessary measures and to adapt the areas of diagnosis, post-diagnostic support, and care coordination to the needs of this group. Thus, the National Dementia Strategy for the period 2013 - 2016 briefly refers to one aspect related to ethnic minority communities, but announces its intention to further investigate their needs and formulates the general goal of removing ethnic barriers to access to post-diagnostic support [24].

The latest version ('Scotland's National Dementia Strategy 2017 - 2020') makes no direct reference to migration. In the section on dementia and equality, it is generally stated that awareness and understanding of signs and symptoms across all different population groups in Scotland are fundamental to promoting early detection. Moreover, the need for further research to identify the most effective ways to improve the quality of life and to build understanding and awareness of dementia among different population groups is emphasised. In the same section, it is conveyed that care must consider cultural aspects and that people from protected characteristic groups with a diagnosis of dementia must have access to competent local services and post-diagnostic support services. The terms 'different population groups' and 'protected characteristic groups' are likely to be used



primarily to describe different minority ethnic groups and PwM. The section could refer to the population called black and minority ethnic communities in the Dementia Strategy from 2013. This term is not used at all in 'Scotland's National Dementia Strategy 2017 – 2020' [25].

### 3.4 Wales

The 'Dementia Action Plan for Wales 2018 – 2022' from 2018 does not have a separate chapter on migration, but the section 'Meeting the Needs of Specific Groups' contains three paragraphs on people with dementia from black, Asian and ethnic minority communities. These paragraphs identify the challenges of low utilisation of care and support services by some ethnic groups, the changing language needs of people with dementia during the

dementia progress, and the difficulties of diagnosis due to cultural and linguistic interpretations. The stigma associated with dementia and diagnosis in some cultures and services that do not meet cultural needs or religious requirements are mentioned as reasons for the lower use of services. Based on the challenges identified, three goals are formulated. In the future, easy access of ethnic minority groups to appropriate services needs to be ensured. Services should respond to language and communication needs and diagnostic tools must be available in a variety of languages and be culturally appropriate. However, the dementia plan does not describe how these goals are to be achieved. There is no indication of a comprehensive approach to culturally sensitive care services [26].

## 4. National dementia care and treatment guidelines

According to the contacted experts, three guidelines on care, treatment, and/or support for people with dementia are used in the UK (a common document for England and Wales, and one each for Northern Ireland and Scotland). All three guidelines refer to the topic of migration to varying degrees (two briefly, one in detail). The following three sub-chapters summarize the contents of the sections with a migration reference from these documents.

### 4.1 England and Wales

The NICE Guideline 97 'Dementia - Assessment, Management and Support for People Living With Dementia and Their Carers' from 2018, similar to all other NICE guidelines, serves both the English and Welsh health systems. The guideline has no separate chapter on migration, but briefly describes the relationship between membership of a minority ethnic group and access to dementia-specific care services in several sections. Accordingly, people from black, Asian, and other minority

ethnic groups generally have less access to health and social services. Concerning dementia, especially caregivers from Africa and the Caribbean do not have access to the support to which they are entitled. Furthermore, the problem is identified that some diagnostic tools are not appropriate due to cultural differences and language deficits and therefore lead to biased results in certain population groups. Based on this problem description, the guideline makes several recommendations for health and social service providers. First, care providers should design their services in a way that makes them accessible to people from black, Asian, and minority ethnic groups. When selecting diagnostic test procedures, they should consider if the respective tool is appropriate for cultural differences and language deficits. It is also pointed out that culturally appropriate approaches may be needed to support caregivers from minority ethnic groups. Concrete measures or a specific strategy for the care of people with dementia and



the support of caregivers from these groups are not mentioned. Compared to the scope of the guideline (419 pages), the topic of migration or minority ethnic groups plays a minor role [27].

## 4.2 Northern Ireland

Northern Ireland does not seem to have its own national document with dementia care guidelines. According to the Alzheimer's Society Northern Ireland, it follows the guidelines by NICE and the Social Care Institute for Excellence (SCIE) called 'NICE-SCIE Guideline on Supporting People With Dementia and Their Caregivers in Health and Social Care - National Clinical Practice Guideline Number 42' from 2007 [28]. However, the Northern Ireland Department of Health points out on its homepage that this guideline was developed for England and cannot be simply adopted [29]. The guideline refers in detail in almost all chapters and most subchapters to minority ethnic groups. Nearly all relevant subject areas are linked to this topic. The guideline not only describes the central problems in diagnosing and caring for people with dementia from minority ethnic groups at several points in the text, but also indicates possible measures for solving the specific problems and makes concrete recommendations for action. People from black and minority ethnic communities are identified as a group with specific language, cultural, religious, spiritual, and communication needs. Besides, the need for culturally sensitive training for caregivers from this group is pointed out. The guideline identifies black and minority ethnic communities as a vulnerable group. In particular, it highlights that non-native English speakers are vulnerable to the effects of dementia, as memory impairment exacerbates existing communication problems. People from minority ethnic communities are also identified as a risk group in terms of underdiagnosis of dementia and a lower level of dementia

care. Causes cited are communication difficulties, language barriers, culturally/linguistically inappropriate or less valid diagnostic tools and care services, stigmatisation within the communities, pressure to provide at-home family-based care rather than professional care, and lack of knowledge about care opportunities. Some ethnic groups are also identified as a risk group for developing dementia: The increased incidence of hypertension and diabetes in people from Africa, the Caribbean, and Asia leads to an increased risk of developing vascular dementia among older people. The guideline also concludes that the needs of ethnic minorities, especially non-native English speakers, had not been sufficiently recognised in the past. To address all these challenges mentioned above, it recommends that health and social care providers develop and offer specialized services for ethnic minorities. These services must be culturally sensitive and take into account the religious and spiritual needs of people with dementia and their caregivers from minority ethnic communities. According to the guideline, specialised services providing support, information, and culturally oriented training for caregivers are needed. Care providers are asked to consider the cultural identity and religious beliefs of people with dementia and their families when developing training programs for healthcare professionals. The professionals should identify the religious and ethnic-specific needs of people with dementia and their caregivers from minority ethnic communities and care plans should take these into account. In the case of language barriers in care, and especially regarding dementia screening tests for non-native speakers, independent interpreters should be consulted and information should be provided in the preferred language. Overall, Northern Ireland (according to the Alzheimer's Society Northern Ireland) is following a guideline that has identified and described some of the key issues related to dementia and migra-



tion and has created a framework for action to address these issues [30].

### 4.3 Scotland

The 'Standards of Care for Dementia in Scotland' from 2011 do not have a separate chapter on migration and this topic does not play a central role in this national document, although it is briefly referred to in several chapters. The document recognises the problem that language, cultural, and ethnic barriers are a challenge for communication in dementia care. Furthermore, it is suggested that black and minority ethnic groups do not receive attention in the diagnosis of dementia. Diagnostic tools seem to be based on the needs of the majority population. Therefore, it is announced that in the future, national health services will ensure that people with dementia from black and minority ethnic groups will also have timely access to services for assessing cognitive impairments. In addition, healthcare providers are asked to make themselves, their procedures and policies, as well as their staff aware of cultural, ethnic, and other barriers to good communication and to take measures to overcome these barriers. The national health services must ensure that communication and language support is available

when there are language, cultural, and knowledge barriers. Furthermore, the report cites a case study, which shows that language and cultural barriers can pose a particular challenge to formal care for PwM, but that these challenges can be overcome with appropriate awareness-raising and specific measures tailored to the individual, language, and cultural needs of migrants. In the Scottish dementia care standards document, the particular situation of PwM with dementia has been recognised, especially in the context of diagnosis and formal care, and some measures have been introduced to address it. While there are examples of culturally sensitive care for PwM at the local level and in relation to individual care institutions, there still seems to be a great lack of specialised services for this population at the national level [31].

The following parts on services and information for PwM with dementia, professional care and support for family caregivers are based on a conducted interview with an expert from England and reflect the experience and opinion of this expert. A selection bias in information and a discrepancy to results from the previous sections might ensue.

## 5. Services and information for people with a migration background with dementia

According to the expert, the healthcare strategy is an integrative one where there is an effort to make 'mainstream healthcare services' more acceptable and fitting for minority groups to promote their inclusion. Still, PwM with dementia are only partly integrated in the healthcare system in England with potential barriers to equitable care being for instance language barriers, lack of relevant information, transportation, family commitments, beliefs, and potential stigma. There are organisations

like the Alzheimer's Society that are providing culturally specific information on dementia and trying to raise awareness on the topic. But it is not something that is widely done within England. Services for inpatient and outpatient care for people with dementia are available nationwide for PwM, however, the expert estimated that PwM with dementia are probably rarely involved in designing information material or healthcare services for people with dementia. Making existing healthcare services





more fitting to minority groups is the preferred approach rather than setting up specialised services for specific groups. The latter also exist in some local area in England, generally in the form of day care centres catering to specific ethnic groups. Existing care services for people with dementia are not fitting for PwM according to the expert but this is a constantly fluid situation depending on various aspects such as funding and staff levels. Measures to

provide intercultural care are locally in development. These are local initiatives with different models, methods, and service provision that are being tried out to see what works. For example, in one area in London, there is a focus on raising awareness of dementia within ethnic communities by setting up cultural dementia cafés. There is also an effort to involve the community and religious leaders with links to the communities.

## 6. Professional qualification and people with a migration background in healthcare

The expert estimated that culturally sensitive care is part of the qualification of healthcare professionals nationwide. However, the quality and extent of it probably depend on the course providers. Culturally sensitive care as curricula of universities, colleges, and other institutions that train professionals is taught in nursing, health, and social care but it might just be a part of a module or course in single institutions. Therefore, the extent and context of training or teaching culturally sensitive care probably differ. There are organisations that provide short courses on topics such as intercultural care and communication. Also, there are published professional standards for nurses and care workers working in institutions such as care homes, nursing homes, or home care and they specify what competence cri-

teria are required for people to practice in dementia or old age care and they outline what is needed to provide a holistic, person-centred as well as culturally sensitive care.

The proportion of professional caregivers with a migration background in inpatient and outpatient care is high in big cities, more so than in the rest of the country according to the expert. They mostly originate from Africa, the Caribbean, Asia, and Eastern Europe. These professional caregivers often tend to have lower education or qualifications and lower pay, and language or cultural issues may arise that have an impact on the care provided. The expert felt that because of the low qualification and education cultural needs are not being met although this is difficult to assess.

## 7. Support for family caregivers

The expert stated that the family and religious communities, migrant organisations, as well as providers of inpatient and outpatient care, are very important in supporting family caregivers of PwM with dementia. According to the expert, there are major differ-

ences in the suitability and utilisation of existing services by family caregivers of PwM with dementia and non-migrant dementia patients. Accordingly, there is a very high need for specialised services providing support and information in England.



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### 4. Important elements for the provision of culturally sensitive care to people with a migration background with dementia

In the systematic analysis of written and oral expert contributions about the situation of PwM with dementia, several key topics and measures have been identified that should be considered in the context of building structures and developing services for culturally sensitive care of PwM with dementia. Since the analysis only refers to excerpts of certain medical-scientific and policy-related discourses, the following overview does not claim to be complete. Moreover, the measures listed must be adapted to the respective national and regional circumstances as well as the specific needs of PwM with dementia and their relatives and subsequently evaluated in practice. The inclusion of PwM with dementia and their relatives has to be the focus throughout the development and implementation process. The following elements should be included in strategies or guidelines for establishing cultural sensitivity in dementia-specific care:

#### Awareness-raising among migrant communities

Many migrant communities have a high need for information about living with dementia, symptoms of dementia, possible disease progression, diagnosis, and available care services. Conducting events, developing web portals, and publishing guides with the aim of disseminating information on a nationwide scale, in a culturally sensitive way that is accessible to people of different languages and cultures, would help meet this need [1-8].

#### Healthcare structures

Particularly important is the building of structures that promote the intercultural opening of healthcare, the inclusion of PwM in the healthcare system, and the participation of this pop-

ulation in providing care. A first step could be the establishment of national institutions for the health of PwM with a task force on dementia [9]. At the local level, the establishment of migrant health centres with dementia-specific trained medical staff and dementia-specific care services can be an opportunity to include PwM into healthcare [10-13].

#### Cooperation of key stakeholders in developing measures for PwM with dementia

There should also be a focus on developing care networks and promoting local, national, or international cooperation between government representatives, care providers, care recipients, initiatives, and researchers in the field of dementia and migration [11].

#### Diagnostics

As an exact diagnosis is essential for tailored care and PwM are a population with specific needs regarding dementia diagnosis and care, special attention should be paid to initiating measures that ensure an early and valid diagnosis of dementia in PwM [14] with linguistically and culturally sensitive diagnostics [2, 15]. Applying an intercultural dementia screening tool like RUDAS and consulting professional interpreters could help in the diagnostic process [16-18].

#### Support for family caregivers

To improve the care situation of people with dementia and reduce the burden on their relatives, family caregivers should be offered support oriented towards their individual, linguistic, and cultural needs [19, 20]. Emphasis should be laid on counselling services [21], help with household and nursing activities, as well as emotional and mental support [6, 22].

### Support for care providers

A key factor in providing culturally sensitive care is supporting providers of dementia care services in gaining awareness and knowledge about the importance of PwM-specific, cultural, and religious elements in dementia care [23]. Care and health professionals must be trained regarding cultural sensitivity, the needs and treatment of PwM with dementia, dealing with barriers, and using community resources [13, 14, 24-26].

### Communication between care providers and care recipients

Furthermore, measures need to be taken to overcome communication barriers between care providers and PwM with dementia [27]. Professionals who care for PwM with dementia should have access to special publications [18, 28] such as handbooks on linguistically and culturally sensitive patient conversations [10].

### Access to healthcare

PwM must have the same access to the health system and be offered the same level of care as non-migrants [29]. One way to ensure this is to provide health cards for all migrant groups [27]. Besides, it should be ensured that culturally sensitive care and support for dementia patients is generally accessible and multilingual information, as well as mother-tongue services, are comprehensively available [13, 14].

### Culturally sensitive care

Following diagnosis, it is crucial that PwM with dementia receive culturally sensitive support, care, and treatment, preferably from a person who speaks their mother tongue [9, 25]. A person-centred approach has proven to be appropriate in this context [6]. Key elements of culturally sensitive care could be: 1. an inclusive culture of care providers [30]; 2. a systematic identification of the individual, linguistic, cultural, spiritual, and religious needs of peo-

ple in need of care, as well as their priorities regarding illness, health, and care by service providers [14, 25, 27, 31]; 3. the integration of a cultural mediator in healthcare teams [10]; 4. the recruitment of multicultural staff with intercultural experiences [5, 21, 22, 32, 33]; 5. the inclusion of PwM (e.g. integration of family caregivers into formal care [23, 34, 35], inclusion of professional caregivers with a migration background in the health system [29]); 6. development of integrative services [19, 21, 22, 36] and segregative services for PwM [13, 21]; 7. design of innovative intercultural or culture-specific housing and care concepts [21, 32]; and 8. validation of cultural sensitivity of care services [11, 14].

### Research

More attention must be paid to the equal inclusion of PwM in studies when designing research projects on the care situation of people with dementia [14]. Furthermore, there need to be separate studies on the needs of PwM with dementia [22, 32]. Researchers with a migration background should be involved in the design and implementation of these studies [21].

### Conclusions

To systematically build structures and develop nationwide culturally sensitive dementia-specific care services, the above mentioned and other measures should be included in NDPs and care guidelines. The development of dedicated and extensive national or European guidelines on culturally sensitive care for PwM with dementia can also be useful in establishing care standards. In both cases, state/institutional funding and clear budgeting for the development and practical implementation of culturally sensitive services as well as systematic monitoring of the implementation of the specified action plans are of central importance [37].



## 4. Important elements

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### 5. Discussion

The analyses carried out within the framework of this project have shown that the topic of dementia and migration is not given special attention at the national level in most EU, EFTA, and UK countries, despite the fact that the number of PwM with dementia in Europe is expected to rise [1], mainly due to demographic change [2]. There are a few countries, such as Norway or the Netherlands, where projects for the care of PwM with dementia have been implemented for several years and where specialised services for PwM with dementia exist, at least in cities with a high proportion of older PwM, such as Oslo, Amsterdam, or Rotterdam. However, in most European countries such efforts do not exist or are only visible at the level of individual service providers or professionals. The interviews with experts conducted in this study confirmed the findings of the previous analyses of NDPs and national guidelines on dementia-specific treatment and care, that there is a great lack of culturally and linguistically appropriate healthcare services for PwM with dementia at the national level in EU and EFTA countries as well as in the UK [3, 4]. After the evaluation of the interviews, it had to be concluded that the gaps in care for this population are even larger in practice than the care strategies and guidelines suggested. The fact that, despite the increasing quantitative importance of the topic [5], no attention is paid to it in most European countries, in terms of developing the necessary policies and structures, can have several reasons [3, 4, 6]. These may include political factors (e.g. low voter potential within the migrant population, rejection of migrant-friendly policies by larger groups of voters, nationalist/right-wing populist developments), discriminatory structures, little inclusive (political/medical) discourse, under-representation of PwM or their representatives in relevant working groups, and/or xenophobic attitudes among policy-makers. Furthermore,

political decisions and healthcare strategies are generally oriented towards the majority population [7]. With regard to older migrants, there is also the issue that in many of the countries analysed, misconceptions of politics, administration, and economy (migrant population returns to their home country in old age, migrants are cared for by their relatives, etc.) have led to a neglect of this population [8]. In addition to the policy and healthcare system agenda, PwM are significantly under-represented in dementia-specific scientific studies [9], which is the reason why there is very little research on dementia and migration [10, 11]. When studies are conducted, this is usually done by researchers who have very little in common (culturally, socio-economically, in terms of origin) with the PwM being studied [12]. As a result, there are large gaps and biases in understanding migration and ethnicity in dementia-specific and gerontological research [13].

The lack of inclusion of PwM and the insufficient attention given to dementia in PwM on the level of policy-making and scientific research is supposed to be the central reason why PwM with dementia and their relatives currently fall through the information, medication, and treatment grids of the healthcare systems [14]. This, combined with other factors such as language problems, cultural perceptions of dementia and care, and lack of knowledge [9, 15-18], is also a cause of lower utilisation of care and support services by PwM with dementia and their family caregivers, a problem that was unanimously confirmed by the experts and various NDPs and dementia care guidelines and several studies [11, 19-23]. These inequalities in service utilisation can lead to poorer health-related and dementia-specific outcomes in PwM, a finding highlighted by a study on the black and minority ethnic groups in the UK, the USA, and Aus-

tralia [21]. Contrary to what is often assumed by care planners, providers, and experts, the need for linguistically and culturally sensitive support services and information for PwM with dementia and their relatives is high [10, 24-28]. This high need is reflected by the experts' opinions in the interviews conducted for this atlas. The prevalent misconception that PwM take care of their own is contradictory to this high need and the fact that PwM with dementia and their family members are willing to utilize formal help [24, 27, 29, 30].

A further key challenge identified in this project and in various studies related to PwM is the diagnosis of dementia. For example, a meta-analysis of 28 studies on dementia screening procedures showed that a dementia diagnosis could not be made with the same certainty in PwM as in non-migrants [31]. One major reason for this is that standardised cognitive testing procedures used in many European countries are not suitable for PwM. This is reported by individual experts, in many NDPs and guidelines, as well as in the Alzheimer Europe report 'The Development of Intercultural Care and Support for People With Dementia from Minority Ethnic Groups' (2018). Especially the MMSE, which is one of the most widely used cognitive screening tools in Europe, has a cultural, social, ethnic, and educational bias [1]. An issue that is also critical due to the increasing proportion of migrants in many European countries is the integration of healthcare professionals with a migration background into the healthcare systems. The experts interviewed in this project agreed that integration and especially the inclusion of healthcare professionals with a migration background can be part of the solution to the challenges related to the care of PwM with dementia. A study of healthcare providers' experiences in caring for patients with a migration background has shown that healthcare providers from ethnic minority groups are more aware of their own

culture and are therefore sensitive to cultural differences in patients [32]. However, the experts and reports also cite various challenges that can arise when healthcare professionals are from the same migrant group as the people with dementia [1]. Therefore, according to the experts and the authors of this atlas, the assumption that a higher proportion of migrants and a higher cultural and linguistic diversity among professionals in the health system is the solution to all problems related to dementia and migration is missing the point by far. For example, there is also a high demand for training on dementia-specific and culturally sensitive care among professionals with a migration background. Furthermore, the problem of the significant underrepresentation of PwM in higher-income groups, occupational groups with a higher level of education (e.g. doctors), and management positions in care institutions must also be addressed, among other issues. Concerning the search for solutions to the problems described in this and other studies in the context of dementia-specific care for PwM, the question of whether an integrative or segregative care model should be preferred, which was also discussed in the expert interviews, arises relatively quickly. This question is of double importance for PwM with dementia, since linguistic-cultural aspects must be taken into account in addition to dementia. The expert interviews show that in most European countries an integrative model of care is used. However, according to Kaiser (2009), following a consistent biography and milieu orientation, a target group-specific segregative care would be the better approach, at least with regard to housing and care concepts [10]. In a few countries (e.g. Germany) there is also a hybrid care model with integrative and segregative elements, which for example is recommended by one expert.

To be able to choose the appropriate care model, it is necessary to have a detailed dis-

cussion about the structure and specific needs of the migrant groups residing in the respective countries and regions. This also requires a fundamental discussion of the similarities and differences between PwM or individual migrant groups and non-migrants in terms of general and dementia-specific care needs. In terms of the symptomatology of dementia, the degenerative course of the disease, and individual coping, PwM initially face similar challenges as non-migrants [27, 30, 33]. The older people with dementia from the autochthonous population are also often affected by discrimination and stigmatisation due to age and the dementia disease, and comorbidities such as psychiatric diseases (e.g. depression) or delirium are also widespread in this population [34-37]. However, there are also several specific problems such as a socioeconomic status, cultural and social disruptions, or discrimination and stigmatisation due to migration background. The social problems of older migrants are expressed mainly in an on-average lower level of education and precarious income and housing conditions [38-41]. These factors are expected to have a considerable influence on the care situation and the requirements for care services. In the context of perceptions of dementia and attitudes towards care, there are also clear differences between many migrant groups and non-migrants. For example, in some migrant groups, the view that dementia is part of the normal aging process is much more common. Moreover, in some languages, there is no word for dementia [1]. In addition to the partly large differences between the organisation of the healthcare systems in the countries of origin and the countries of residence, the different expectations of the healthcare professionals are also relevant for formal care [15]. With regard to the selected forms of care, it is noticeable that home care is even more dominant in many migrant groups than in the autochthonous population [42]. The tra-

dition in some migrant groups that the family (mostly female family members [43] from whom it is oftentimes expected [24, 25, 44]) cares for the person with dementia [1, 45] represents a fundamental difference with the philosophy prevalent in many parts of Europe of promoting the independence of patients. Care arrangements based on familialism in which taking care of a sick family member is associated with a 'deep sense of pride and moral superiority' [44] can bring benefits if family structures are intact but can become problematic if they hinder timely access to the healthcare system in cases of severe illness [15]. In addition to the home care arrangements, the interviews in this project showed that informal networks are a source of support for the family caregivers. Other family members are an essential source of help as are, depending on the culture, religious communities and migrant organisations. Therefore, it is worthy to think about including those networks in the offering of formal help. This idea is reflected in the literature. For example, Regan (2014) suggests including religious leaders in the effort to promote services. Another major problem is that the psychological burden of family caregivers with a migration background is even higher than among non-migrants [47-49]. In some cultures, not only dementia but mental illnesses in general are much more tabooed than in many European countries and the fear of being stigmatised by one's own community is much more prevalent [25, 50]. This can lead to the social isolation of the people affected. Concerning the dementia disease itself, a major challenge lies in the fact that the disease is often accompanied by an early loss of learned foreign languages, which for PwM is frequently the language of the country in which they currently live [51].

Overall, PwM can be described as a vulnerable group in the context of dementia. On average, older migrants have a poorer state of health



than older non-migrants. Age-associated diseases such as dementia occur at a younger age among them, and they often have an earlier need for care [43]. Therefore, it is assumed that the incidence and prevalence of dementia in older migrants are higher than in the autochthonous older population [52]. Furthermore, the connection between dementia and prevention has a lower priority or is tabooed among many migrant groups [43]. Simultaneously, acculturation effects and intergenerational differences also ensure that the willingness of PwM to use professional services or even consider inpatient placement is growing. However, this growing need also results from the decreasing family support potential among PwM due to social modernisation processes, pluralistic tendencies, and economic necessities [10, 43, 53].

Besides some commonalities of PwM regarding aspects relevant to dementia care, there are also many differences between and within different migrant groups. The migrant population of most European countries is extremely heterogeneous in terms of cultural, ethnic, religious, and social origin [15], age, education level, socio-economic status, as well as social and residence status of individuals. As a result, for example, the health-relevant influencing factors and the accessibility of educational measures also vary strongly between and within the individual migrant groups [54]. Research has also shown that there are significant differences between individual migrant groups in terms of the barriers they experience in accessing health services [15]. Contrary to what is often assumed, it cannot automatically be expected that people who have immigrated from other cultures will have problems adapting to the healthcare system and have less knowledge about dementia. For example, the Japanese healthcare system is quite similar to some Western European healthcare systems, and knowledge and care services re-

garding dementia are more widespread there than in large parts of Europe. Most scientific studies and healthcare systems do not cover the heterogeneity within the migrant population due to a one-sided fixation on certain migrant groups [43]. Furthermore, there are also many PwM with dementia who have other diversity characteristics, apart from the migration background and the dementia disease. The interaction of these other characteristics with the dementia disease and the care situation should be addressed in more detail in future studies. In this context, the interviewed expert from Germany recommended focusing on an intersectional approach in which several diversity characteristics of a person, such as migration background, sexual orientation, gender identity, or a possible trauma experience, are considered together.

Another issue identified in this project as particularly relevant in the context of dementia and migration, which was also discussed in the expert workshop and the expert interviews, is the central terminology. In Europe, many different terms are used in the context of PwM, which are based on different concepts and definitions. For example, official documents and studies from some countries use the term ethnic minorities or minority ethnic groups (e.g. in Ireland [54]), while in other countries terms such as people from different cultural or religious groups (Spain [55]) or language minorities (Norway [56]) are common. In some reports and studies, the term PwM or migrants only includes people who were born abroad or do not have the respective citizenship, while in other studies the children of immigrants are also considered. The different use and understanding of terms related to PwM in various national and international studies or reports is a challenge for care planners, care providers, and researchers, as it creates confusion about the relevant target groups, the size of the target groups, and the care needs regard-

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ing these groups. Often terms such as PwM, migrants, or minority ethnic groups are used interchangeably or as synonyms for each other, although not all members of minority ethnic groups are migrants. The Alzheimer Europe report 'The Development of Intercultural Care and Support for People With Dementia from Minority Ethnic Groups' (2018) discusses various concepts and terms frequently used in scientific articles, international reports, and policy documents, such as 'ethnic minority group', 'migrant', or 'immigrant'. In this report, ethnic minority groups are defined as groups of people who share a common cultural identity and who differ in some way from the ethnic majority group in the respective country (e.g. in terms of language, culture, or religion). The concepts of 'migrant' and 'immigrant' are described as unclear, as there is no generally

accepted definition [1]. In this project, for pragmatic reasons (primarily for comparability of data from European countries), PwM are defined as all people who were born abroad.

Overall, this project confirms the findings of previous research on dementia and migration, according to which older PwM with dementia and their relatives do not participate in the current state of research and standard of care to the same extent as the autochthonous population due to individual and structural conditions and, as a result, are often exposed to precarious living situations (Kaiser 2009). These inequalities endanger the ideals of equal living conditions and equal care for all people living in Europe or the respective European country, to which the European institutions and most European states have committed themselves.

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## 5. Discussion

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## 6. Limitations

### Migration history

The content of Europe's and the individual European countries' migration history presented in this atlas is based exclusively on an online search via the platforms Google Search and Google Scholar as well as some international reports and online databases (for example the Migration Data Portal). These platforms and documents were searched using certain keywords. Documents or data that did not contain these keywords and were not accessible online on one of the mentioned databases or platforms were not considered. Furthermore, only documents in English and German were included. When presenting the data, exclusively major migration flows and general characteristics of the migration history as well as some figures regarding the current migrant population were mentioned to facilitate comparability of the profiles and for content-related purposes. Since the migration history is primarily intended to serve as background information for the readers and to give them the possibility of a better understanding of the current situation regarding PwM with dementia in the country, the discussion of detailed backgrounds, causes, and effects of the migration flows was omitted. An additional limitation regarding the comparability of the countries concerning their migration history is the fact that data (e.g. on the largest migrant groups by country of origin) from the same year or the same periods could not be identified for all countries. Additionally, the key terms used in the reports and databases, such as migrants, immigrants, refugees, or guest workers, some of which are based on different definitions, were adopted, which also makes comparability slightly more difficult. However, this approach allows for more specific insight into the situation or the communication of the situation of the individual countries.

### Estimated number of people with a migration background with dementia

With the exception of Bulgaria, Lithuania, Malta, and Poland the data on PwM refer to people aged 65 or older and the data for England is not age-specific. The prevalence rates that were used in this atlas refer to people aged 60 or older. Additionally, some countries did not disclose data below a certain value. Therefore, the number of PwM with dementia is slightly contorted. An important note is that the prevalence rates from the 'World Alzheimer Report 2015' that were used in this atlas are based on a meta-analysis of population-based studies on dementia prevalence from the different Global Burden of Disease World Regions. A few limitations come with this. For one, the world regions present an uneven number of available studies, e.g. East Asia (89 studies) or Western Europe (71 studies) provide a high number of studies while regions such as Central (5) and Eastern Europe (1) only have very limited data. There are also differences in the methodological approaches of the underlying studies, such as disparities in the process of diagnosing dementia, with only 34% of the studies performing a thorough assessment using different methods like disability assessment and multi-domain cognitive testing [1]. These factors indicate that the prevalence numbers might vary in quality and might be over- or underestimated which in turn has an influence on the calculations in this atlas to the effect that the estimated numbers might not show the actual situation.

If one wants to compare countries it should be kept in mind that the data on countries of origin from the different European countries differ in their degree of detail. Some countries provided an overview of a wide variety of countries of origin, such as Iceland or England, while others focused on the most rele-



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vant countries, like the Netherlands or Cyprus. Then some countries like Liechtenstein only provided information for a smaller collection of countries. Not all data was provided by the statistical offices of the countries, some were obtained from Eurostat's Census Hub. Furthermore, the data goes back to various years. For example, many countries provided data on PwM from the census that was carried out in 2011, like Croatia, Slovakia, or the Czech Republic, then there were countries where it was possible to obtain more current data from 2019, such as Norway or Estonia. These are all factors that complicate and make difficult the comparison between countries and therefore should be taken into account by the reader.

Another aspect to mention is the fact that for some countries people from countries of origin were identified as the most affected migrant groups, where it could be argued whether they truly are a group of concern to the healthcare system. For example, for Scotland, the most affected migrant groups originate from England, Ireland, and Northern Ireland. One could make the point that people from these countries are more adept in the Scottish healthcare system than people from countries outside of UK and do not need that much special attention from the healthcare system in regards of dementia and the healthcare system as other PwM. Other PwM might have more problems accessing and utilizing the healthcare system and them not being highlighted here poses the risk that they continue to be invisible to the healthcare system.

### Analysis of national dementia plans

The results of NDPs analysis are based exclusively on documents that could be identified through an online search (on Google Search). Countries that do not have such documents, that have not published their documents online, or whose documents did not contain the keywords that were searched for could not

be taken into account. Furthermore, some NDPs have been published several years earlier than others. The topic of dementia and migration should be more important in large parts of Europe today than it was a few years ago due to the increase in prevalence and the growing number of older PwM. Thus, the different dates of publication can be a cause for the country-specific differences concerning the reference to migration. Another reason is the different levels of importance given to migration in individual countries. This analysis shows that immigration countries with a large proportion of migrants are more likely to have migration-related NDPs than emigration countries with a low proportion of migrants. Another striking feature is the disparate terms used in the context of migration and the unequal definition of terms such as 'migrant'. Despite its limitations, this analysis provides an overview of the extent to which the topic of migration is taken into account in the NDPs of the European countries and which thematic emphases are set if the topic is considered [2].

### Analysis of national dementia care guidelines

Except for Belgium/Flanders, this analysis refers only to national policies, guidelines, and recommendations on dementia care published by national organisations or authorities such as the Alzheimer societies, professional societies, or ministries of health. Therefore, only those documents were considered that were sent on request by the respective organisations or ministries. It cannot be ruled out that organisations and documents exist that were not contacted or identified by the authors. However, the organisations involved in this study were asked to refer to appropriate information or informants, which were then included. Nevertheless, some organisations did not give any response. Accordingly, in the individual EU and EFTA countries and the UK,

there are other documents on the care of people with dementia (e.g., at the local level) that were not included in this study. However, this was not the aim of the analysis, and the inclusion of these documents would have compromised the standardisation of the procedure and would have reduced comparability [3].

### Interviews

Despite an extensive search for interview participants, it was unfortunately not possible to find experts from every country. Of course, there is always the chance that with the performed procedure potential candidates were not detected. Based on the experts' statements and self-ratings, not every person interviewed was an expert on dementia and migration. Some were experts on migration (e.g. Greece) while others were experts on dementia (e.g. Liechtenstein). That could be because in some countries the topic of dementia and migration is not a focal point or it is such a new topic that currently there is simply no one who can call themselves an expert on it. In these cases, the analyses might have shown other results and conclusions if experts on the combined topics dementia and migration were existent. Moreover, there was no definite and rigid criteria that an expert had to meet to qualify for an interview. This was done to not restrict the pool of potential interview candidates on this topic since this group is very small to begin with. Thus, due to the rarity of the topic, the group of experts consulted for this atlas might be a very selective one.

The interview guide for conducting the semi-structured interviews was prepared based on a literature search and an expert workshop by the authors of this atlas. This was done systematically, but it certainly did not establish representativeness in terms of literature and experts on the topic of dementia and migration. Therefore, the selection of categories and questions for the interview is

also influenced by the views and positions of the authors as well as the selectively chosen experts. A further limitation concerns the predefined answer categories, which improve the comparability of the data, but lead to the possibility that the documented views of the experts on the care situation in the respective country are biased, and complexities and heterogeneities in the individual countries are underestimated. To counteract this limitation, open questions were asked after almost every closed question with fixed answer categories. When analysing the data, the authors had to make selections of thematic blocks, categories, questions, and contents concerning the extensive interviews with often very detailed answers of the experts. Furthermore, interpretations were necessary for some answers to ensure the comparability of the data. For this purpose, certain methodological models and identical analysis steps were used. However, the results presented in this atlas do not represent a verbatim reproduction of the experts' statements but are summaries of the expert interviews by the authors.

### Literature analysis for the identification of important elements for the provision of culturally sensitive care to people with a migration background with dementia

The data basis for this analysis are scientific publications and therefore the recommendations for action are only derived theoretically. Furthermore, the measures described have a general, cross-national, and cross-group character. Consequently, they need to be adapted to the country-specific context, economic opportunities, structural conditions, and health-care systems of each country and tailored to the individual migrant groups. It is also necessary to evaluate these measures in practice. Additionally, the online search for written statements in articles and other documents was limited to the databases PsycARTICLES,

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Psychology and Behavioural Sciences Collection, PsycINFO, and PubMed, the search engine Google, and the Alzheimer Europe website, and the search for oral statements was limited to events attended by the authors. The screening of the databases was conducted exclusively based on the keywords: care, Versorgung, dementia, Demenz, migration, and Migration. The screening was confined to the abstracts and titles. When compiling the data corpus, only articles in German and English were selected, and the investigation was limited to the period from 1 November 2009 to 1 November 2019. Besides, a filtering procedure with the application of material quality criteria

was carried out for the selection of articles for the systematic literature analysis. Due to these limitations, this analysis represents a selection of the scientific, political, and medical discourses on care for PwM with dementia. Statements about elements or measures related to this topic: 1. were not accessible online, on the determined platforms, or via the attended events; 2. were included in articles not published during the defined investigation period, or 3. could not be identified by the selected keywords, were not considered. However, due to the systematic approach, this analysis gives an overview of central elements of culturally sensitive dementia care [4].

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## 7. Conclusion

Despite the aforementioned limitations that come with every study, this atlas accomplished what it set out to achieve. It provides detailed data on the number of PwM with dementia broken down by individual countries of birth; a thorough overview on how dementia and migration is considered in official documents; and an analysis of healthcare systems, its services, and the support for the people affected.

The findings of this project lead to several conclusions and implications. Concerning the estimated number of PwM with dementia, the calculations show that every country hosts a number of people affected. Of course, countries vary in the estimated numbers of PwM affected by dementia and it is debatable if the most affected migrant groups shown in this atlas are really the groups that the healthcare systems need to be concerned about. Still, it is not deniable that PwM with dementia and their families represent a significant group that is vulnerable and needs help and support in obtaining information and finding their way around in the healthcare system. When a migrant group that is shown here to be of significance does not ‘appear’ in the healthcare landscape of a country because they do not ask for help, it does not mean and it would be wrong to assume that they do not need support. Literature as well this study show that often times PwM are not informed enough to know that they are entitled to support and do not know how to seek help. It is essential to be aware about which migrant groups are present in a country and what their specific needs are. The heterogeneity of PwM—not just between different ethnicities but also within ethnicities—has to be an important factor when creating measures and services for this group and making decisions on measures for adequate care. It is not enough to make minimal changes with the hope that these fit for every person of a different cultural background and

expect that everything will be fine for all PwM with dementia and their family members. Different groups require different measures.

Another important aspect is the inclusion of informal networks in the provision of care. That means including not just the primary family caregiver but also other family members involved in the caretaking process. It also means working together with important people from that community, religious leaders, and migrant organisations to ‘normalize’ dementia as a disease, encourage the acceptance of professional help to manage it, and spread knowledge about dementia and healthcare. Migrant organisations, religious communities, as well as other facilities and clubs that represent meeting places for PwM, people from a specific migrant group, or people with different origins, need targeted state funding and institutional support to raise awareness on dementia. Generally, in Europe as a whole and in the individual European countries, there is a need for more awareness in society, politics, science, the healthcare system, and care providers on the topic of dementia and migration, as well as for the establishment of structures for the specialised care of PwM with dementia and their relatives. This was shown by the various literature searches and especially the analysis of national dementia plans, dementia strategies, and care and treatment guidelines of EU, EFTA, and UK countries, which were carried out within the framework of this project. Just over a third of the 90 analysed documents on dementia care address the topic of migration and most of the documents that do consider this issue refer to it only briefly and unsystematically. Exceptions were the recent dementia plans and care guidelines of Norway and the care guidelines of Sweden, which addressed the topic in more detail and referred to existing care services. The expert interviews confirmed the results of these anal-

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yses and showed that there is a great lack of social, care policy, and scientific attention regarding the topic of dementia and migration, at least in the European countries considered. Whether the situation is better in the EU, EFTA, and UK countries, for which no experts could be recruited and no documents on dementia care were identified during this project, despite repeated intensive searches or multiple inquiries, cannot be answered, but doubts are reasonable.

Overall, the literature analyses and the expert interviews indicate that there are no or very few specialised diagnostic, care, information, and support services for PwM with dementia and their relatives in most European countries. The few services that do exist are also, according to the interviewed experts, extremely unevenly distributed, especially geographically. This means that in many European countries, whether or not a PwM is offered a valid dementia diagnosis and specialised formal care depends on the place of residence. Furthermore, some interviews suggested that care provision is also extremely unevenly distributed socially and that a person's socioeconomic status is a determining factor for access to specialised care. The expert interviews show that in about two-thirds of the countries considered, the currently existing dementia-specific care services are not adequately helpful for PwM. The Netherlands is one of the few countries that, according to the interviewed experts, has models of good care practices for PwM with dementia, at least in individual regions and cities. The lack of adaptation of dementia-specific care services to the cultural, linguistic, and individual needs of PwM and the resulting lack of suitability of services in most of the EU, EFTA, and EU countries considered is probably one of the central reasons why PwM with dementia and their relatives use fewer care, information, and support services than non-migrants and are much more

affected by problems such as underdiagnosis and underprovision. The very high need for culturally sensitive care, tailored information, and specialised support for PwM with dementia and their relatives in most European countries is currently far from being met. This has been clearly demonstrated by the analyses carried out within this project.

Simultaneously, this project has also highlighted that there are many potential measures that could help reduce the existing care inequalities and improve the care situation of PwM with dementia in Europe. Besides, there are some models of good practice on the level of care policy and care practice, which can be used by other countries, regions, care planners, or service providers as a basis for developing their own care strategies and services or as a starting point for international cooperation. One example is the relatively high proportion of migrants among professional caregivers in outpatient and inpatient care in many European countries, and the resulting high cultural and linguistic diversity in healthcare systems in most countries, which was identified in the expert interviews. If this diversity is systematically used and structurally promoted (for example, through programs for dementia-specific and culturally sensitive education/further training of healthcare professionals with a migration background as well as measures for the inclusion of these professionals in higher-income/occupational groups), it could serve as a great resource for the provision of culturally sensitive mother-tongue care of PwM with dementia and their relatives, in addition to helping tackle some challenges that also need to be faced.

The authors believe that pursuing a top-down strategy can be helpful to systematically implement these and other measures recommended in this atlas in European countries, to reduce the existing considerable inequalities in care and to be able to establish a minimum



standard of care for PwM with dementia at the national or European level. National governments or European institutions, together with research institutions and care providers, should develop a joint strategy for the care of this vulnerable population and establish supranational, transnational, and intersectoral cooperation. The improvement of the legal situation (especially concerning healthcare, dementia-specific offers, and mother-tongue services) of PwM with dementia and their relatives must be centrally discussed. At the same time, research programs need to be set up that focus on dementia diagnostics, the situation of people directly affected by the disease, and the exact utilisation patterns of PwM with regard to formal dementia-specific care services. Based on this, participatory studies are necessary for the development and implementation of specialised care concepts and services for PwM with dementia and their relatives, in which PwM should be included both on the side of the research teams and on the side of the study participants throughout the whole study process. Besides national or European dementia plans, supplementary national or Eu-

ropean guidelines on culturally sensitive care for PwM with dementia could serve as a formal framework for the development of such programs. However, part of such a strategy should also be to systematically promote bottom-up elements and thus also offer individual care providers and professionals the opportunity to develop innovative care concepts at the regional level and to disseminate these nationally or internationally through better networking of care providers and potential care recipients. This atlas and the overview it contains of the distribution of PwM with dementia in the individual countries and regions as well as the recommendations for action presented for their care can serve as an orientation in this process. With this comprehensive work, it is furthermore able to support stakeholders, politicians, healthcare providers, and others in decision making, for example on a political level concerning policies or action plans. It can also help the healthcare system, its services, and service providers in developing their own strategies on how to provide care for PwM with dementia and their families.

### 8. Abbreviations

<b>ADI</b>	Alzheimer's Disease International
<b>AFA</b>	Asociación de Familiares de Enfermos de <i>Alzheimer</i> y Dementias
<b>AVIQ</b>	Agence pour une Vie de Qualité
<b>BPSD</b>	Behavioural and psychological symptoms of dementia
<b>DeMigranz</b>	Demenz und Migration
<b>DGGPP</b>	Deutsche Gesellschaft für Gerontopsychiatrie und –psychotherapie e. V.
<b>DGPPN</b>	Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde e. V.
<b>EFID</b>	European Foundations' Initiative on Dementia
<b>EFTA</b>	European Free Trade Association
<b>EHPAD</b>	Établissements d'Hébergement pour Personnes Âgées Dépendantes
<b>ENIEC</b>	European Network of Intercultural Elderly Care
<b>ETNIMU</b>	Improving the brain health of ethnic minority elderly
<b>EU</b>	European Union
<b>Eurostat</b>	European Statistical System
<b>GIMBE</b>	Gruppo Italiano per la Medicina Basata
<b>HSMP</b>	Highly Skilled Migrant Programme
<b>ImmiDem</b>	Dementia in immigrants and ethnic minorities living in Italy: clinical-epidemiological aspects and public health services
<b>INTERDEM</b>	Early detection and timely INTERvention in DEMentia
<b>IOM</b>	International Organization for Migration
<b>MIS</b>	Memory Impairment Screen
<b>MMSE</b>	Mini Mental State Examination
<b>NAKMI</b>	Nasjonal kompetanseenhet for migrasjons – og minoritetshelse
<b>NDP</b>	National Dementia Plan
<b>NGO</b>	Non-governmental organisation
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NUTS</b>	Nomenclature des Unités territoriales statistiques
<b>PALOP</b>	Países africanos de língua oficial portuguesa
<b>PASA</b>	Pôle d'Activité et de Soins Adaptés
<b>PwM</b>	People with a migration background
<b>RUDAS</b>	Rowland Universal Dementia Assessment Scale
<b>SCIE</b>	Social Care Institute for Excellence
<b>TRAKULA</b>	Transkulturelles Assessment mentaler Leistungen
<b>WHO</b>	World Health Organization

### Countries

<b>AL</b>	Albania	<b>ID</b>	Indonesia
<b>AM</b>	Armenia	<b>IE</b>	Ireland
<b>AO</b>	Angola	<b>IN</b>	India
<b>AR</b>	Argentina	<b>IQ</b>	Iraq
<b>AT</b>	Austria	<b>IR</b>	Iran
<b>AZ</b>	Azerbaijan	<b>IT</b>	Italy
<b>BA</b>	Bosnia and Herzegovina	<b>KZ</b>	Kazakhstan
<b>BD</b>	Bangladesh	<b>LB</b>	Lebanon
<b>BE</b>	Belgium	<b>LT</b>	Lithuania
<b>BENELUX</b>	Belgium, The Netherlands, Luxembourg	<b>LU</b>	Luxembourg
<b>BG</b>	Bulgaria	<b>MA</b>	Morocco
<b>BR</b>	Brazil	<b>MK</b>	North Macedonia
<b>BY</b>	Belarus	<b>MU</b>	Mauritius
<b>CA</b>	Canada	<b>MZ</b>	Mozambique
<b>CD</b>	Democratic Republic of the Congo	<b>NIR</b>	Northern Ireland
<b>CN</b>	China	<b>NL</b>	The Netherlands
<b>CO</b>	Colombia	<b>NO</b>	Norway
<b>CU</b>	Cuba	<b>PE</b>	Peru
<b>CV</b>	Cape Verde	<b>PK</b>	Pakistan
<b>CY</b>	Cyprus	<b>PL</b>	Poland
<b>CZ</b>	The Czech Republic	<b>PT</b>	Portugal
<b>DE</b>	Germany	<b>RO</b>	Romania
<b>DK</b>	Denmark	<b>RU</b>	The Russian Federation
<b>DZ</b>	Algeria	<b>SCT</b>	Scotland
<b>EAW</b>	England and Wales	<b>SE</b>	Sweden
<b>EC</b>	Ecuador	<b>SI</b>	Slovenia
<b>EE</b>	Estonia	<b>SK</b>	Slovakia
<b>EG</b>	Egypt	<b>SR</b>	Suriname
<b>ENG</b>	England	<b>SU</b>	Soviet Union
<b>ES</b>	Spain	<b>TR</b>	Turkey
<b>FI</b>	Finland	<b>UA</b>	Ukraine
<b>FR</b>	France	<b>UK</b>	United Kingdom
<b>GE</b>	Georgia	<b>US</b>	United States
<b>GR</b>	Greece	<b>UY</b>	Uruguay
<b>HR</b>	Croatia	<b>WLS</b>	Wales
<b>HU</b>	Hungary	<b>XS</b>	Serbia
		<b>YU</b>	Yugoslavia
		<b>ZA</b>	South Africa

### 9. Figures

#### 3.2 Estimated number of people with a migration background with dementia in Europe

Fig. 3.2.1: Absolute number of PwM with dementia aged 65+ in Europe

Fig. 3.2.2: Prevalence of PwM with dementia among the population aged 65+ in Europe

#### 3.3 National dementia plans and strategies: Focus on migration

Fig. 3.3.3.1: EU/EFTA/UK countries with migration-related NDPs and available healthcare services (as of 04 January 2021)

#### 3.4 National dementia care and treatment guidelines: Focus on migration

Fig. 3.4.1.1: EU/EFTA/UK countries with migration-related national dementia care guidelines and available healthcare services (as of 11.07.2019)

#### 3.6.1 General aspects on people with a migration background with dementia

Fig. 3.6.1.1: Importance of dementia and migration

Fig. 3.6.1.2: PwM as a vulnerable group in healthcare

Fig. 3.6.1.3: PwM with dementia as a group with specific needs in healthcare

#### 3.6.2 Care

Fig. 3.6.2.1: Availability of outpatient care services for PwM

Fig. 3.6.2.2: Availability of inpatient care services for PwM

Fig. 3.6.2.3: Suitability of existing services for adequate care of people with dementia

#### 3.6.3 Inclusion and provision of information to people with a migration background (with dementia)

Fig. 3.6.3.1: Inclusion of PwM with dementia in healthcare

#### 3.6.4 Professional Care

Fig. 3.6.4.1: Proportion of PwM in outpatient care (as healthcare workers)

Fig. 3.6.4.2: Need for culturally sensitive care in outpatient care

Fig. 3.6.4.3: Proportion of PwM in inpatient care (as healthcare workers)

Fig. 3.6.4.4: Need for culturally sensitive care in inpatient care

#### 3.6.5 Support for family caregivers

Fig. 3.6.5.1: Differences in information and services for family caregivers

#### 3.7.1 Austria

Fig. 3.7.1.1: Absolute number of PwM with dementia aged 65+ (Austria – Nation)

Fig. 3.7.1.2: Prevalence of PwM with dementia among the population aged 65+ (Austria – Nation)

Fig. 3.7.1.3: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Austria – NUTS2)

Fig. 3.7.1.4: Absolute number of PwM with dementia aged 65+. Country of origin: Serbia (Austria – NUTS2)

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Fig. 3.7.1.6: Absolute number of PwM with dementia aged 65+. Country of origin: The Czech Republic (Austria – NUTS2)

Fig. 3.7.1.7: Absolute number of PwM with dementia aged 65+. Country of origin: Turkey (Austria – NUTS2)

Fig. 3.7.1.8: Absolute number of people with dementia aged 65+. Country of origin: Austria (Austria – NUTS2)

Fig. 3.7.1.9: Absolute number of PwM with dementia aged 65+ (Austria – NUTS2)

Fig. 3.7.1.10: Prevalence of PwM with dementia among the population aged 65+ (Austria – NUTS2)

### 3.7.2 Belgium

Fig. 3.7.2.1: Absolute number of PwM with dementia aged 65+ (Belgium – Nation)

Fig. 3.7.2.2: Prevalence of PwM with dementia among the population aged 65+ (Belgium – Nation)

Fig. 3.7.2.3: Absolute number of PwM with dementia aged 65+. Country of origin: Italy (Belgium – NUTS2)

Fig. 3.7.2.4: Absolute number of PwM with dementia aged 65+. Country of origin: France (Belgium – NUTS2)

Fig. 3.7.2.5: Absolute number of PwM with dementia aged 65+. Country of origin: The Netherlands (Belgium – NUTS2)

Fig. 3.7.2.6: Absolute number of PwM with dementia aged 65+. Country of origin: Morocco (Belgium – NUTS2)

Fig. 3.7.2.7: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (Belgium – NUTS2)

Fig. 3.7.2.8: Absolute number of people with dementia aged 65+. Country of origin: Belgium (Belgium – NUTS2)

Fig. 3.7.2.9: Absolute number of PwM with dementia aged 65+ (Belgium – NUTS2)

Fig. 3.7.2.10: Prevalence of PwM with dementia among the population aged 65+ (Belgium – NUTS2)

### 3.7.3 Bulgaria

Fig. 3.7.3.1: Absolute number of PwM with dementia aged 60+ (Bulgaria – Nation)

Fig. 3.7.3.2: Prevalence of PwM with dementia among the population aged 60+ (Bulgaria – Nation)

Fig. 3.7.3.3: Absolute number of PwM with dementia aged 60+. Country of origin: Romania (Bulgaria – NUTS2)

Fig. 3.7.3.4: Absolute number of PwM with

dementia aged 60+. Country of origin: The Russian Federation (Bulgaria – NUTS2)

Fig. 3.7.3.5: Absolute number of PwM with dementia aged 60+. Country of origin: Greece (Bulgaria – NUTS2)

Fig. 3.7.3.6: Absolute number of PwM with dementia aged 60+. Country of origin: Serbia (Bulgaria – NUTS2)

Fig. 3.7.3.7: Absolute number of PwM with dementia aged 60+. Country of origin: Ukraine (Bulgaria – NUTS2)

Fig. 3.7.3.8: Absolute number of people with dementia aged 60+. Country of origin: Bulgaria (Bulgaria – NUTS2)

Fig. 3.7.3.9: Absolute number of PwM with dementia aged 60+ (Bulgaria – NUTS2)

Fig. 3.7.3.10: Prevalence of PwM with dementia among the population aged n 60+ (Bulgaria – NUTS2)

### 3.7.4 Croatia

Fig. 3.7.4.1: Absolute number of PwM with dementia aged 65+ (Croatia – Nation)

Fig. 3.7.4.2: Prevalence of PwM with dementia among the population aged 65+ (Croatia – Nation)

### 3.7.5 Cyprus

Fig. 3.7.5.1: Absolute number of PwM with dementia aged 65+ (Cyprus – Nation)

Fig. 3.7.5.2: Prevalence of PwM with dementia among the population aged 65+ (Cyprus – Nation)

### 3.7.6 The Czech Republic

Fig. 3.7.6.1: Absolute number of PwM with dementia aged 65+ (The Czech Republic – Nation)

Fig. 3.7.6.2: Prevalence of PwM with dementia among the population aged 65+ (The Czech Republic – Nation)

Fig. 3.7.6.3: Absolute number of PwM with dementia aged 65+. Country of origin: Slovakia (The Czech Republic – NUTS2)



Fig. 3.7.6.4: Absolute number of PwM with dementia aged 65+. Country of origin: Ukraine (The Czech Republic – NUTS2)

Fig. 3.7.6.5: Absolute number of PwM with dementia aged 65+. Country of origin: Poland (The Czech Republic – NUTS2)

Fig. 3.7.6.6: Absolute number of PwM with dementia aged 65+. Country of origin: Romania (The Czech Republic – NUTS2)

Fig. 3.7.6.7: Absolute number of PwM with dementia aged 65+. Country of origin: Germany (The Czech Republic – NUTS2)

Fig. 3.7.6.8: Absolute number of people with dementia aged 65+. Country of origin: The Czech Republic (The Czech Republic – NUTS2)

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Tab. 19: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Finland – NUTS2)

**3.7.10 France**

Tab. 20: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (France – Nation)

**3.7.11 Germany**

Tab. 21: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Germany – Nation)

Tab. 22: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Germany – NUTS1)

**3.7.12 Greece**

Tab. 23: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Greece – Nation)

Tab. 24: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Greece – NUTS2)

**3.7.13 Hungary**

Tab. 25: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Hungary – Nation)

Tab. 26: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population

aged 65+ (Hungary – NUTS2)

**3.7.14 Iceland**

Tab. 27: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Iceland – Nation)

**3.7.15 Ireland**

Tab. 28: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Ireland – Nation)

Tab. 29: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Ireland – NUTS2)

**3.7.16 Italy**

Tab. 30: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Italy – Nation)

**3.7.17 Latvia**

Tab. 31: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Latvia – Nation)

**3.7.18 Liechtenstein**

Tab. 32: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Liechtenstein – Nation)

**3.7.19 Lithuania**

Tab. 33: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Lithuania – Nation)

**3.7.20 Luxembourg**

Tab. 34: PwM with dementia: Absolute



numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Luxembourg – Nation)

### 3.7.21 Malta

Tab. 35: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Malta – Nation)

### 3.7.22 The Netherlands

Tab. 36: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Netherlands – Nation)

Tab. 37: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (The Netherlands – NUTS2)

### 3.7.23 Norway

Tab. 38: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Norway – Nation)

Tab. 39: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Norway – NUTS2)

### 3.7.24 Poland

Tab. 40: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Poland – Nation)

Tab. 41: PwM with dementia: Absolute numbers, prevalence among PwM aged 60+, and prevalence among overall population aged 60+ (Poland – NUTS2)

### 3.7.25 Portugal

Tab. 42: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population

aged 65+ (Portugal – Nation)

Tab. 43: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Portugal – NUTS2)

### 3.7.26 Romania

Tab. 44: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Romania – Nation)

Tab. 45: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Romania – NUTS2)

### 3.7.27 Slovakia

Tab. 46: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovakia – Nation)

Tab. 47: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovakia – NUTS2)

### 3.7.28 Slovenia

Tab. 48: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovenia – Nation)

Tab. 49: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Slovenia – NUTS2)

### 3.7.29 Spain

Tab. 50: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Spain – Nation)

Tab. 51: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population

aged 65+ (Spain – NUTS2)

(England – NUTS1)

### 3.7.30 Sweden

Tab. 52: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Sweden – Nation)

### 3.7.31 Switzerland

Tab. 53: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Switzerland – Nation)

Tab. 54: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Switzerland – NUTS2)

### 3.7.32 The United Kingdom

#### England

Tab. 55: PwM with dementia: Absolute numbers, prevalence among PwM, and prevalence among overall population (England – Nation)

Tab. 56: PwM with dementia: Absolute numbers, prevalence among PwM, and prevalence among overall population

### Northern Ireland

Tab. 57: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Northern Ireland – Nation)

### Scotland

Tab. 58: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Scotland – Nation)

Tab. 59: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Scotland – NUTS2)

### Wales

Tab. 60: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Wales – Nation)

Tab. 61: PwM with dementia: Absolute numbers, prevalence among PwM aged 65+, and prevalence among overall population aged 65+ (Wales – NUTS2)

## 11. Appendix

### 11.1 Responding organisations

**Tab. 4: List of responding organisations**

Country	Organisations responding to the e-mail request
Austria	Alzheimer Austria Federal Ministry of Social Affairs, Health, Care and Consumer Protection
Belgium	Vlaamse Regering Agence wallonne pour une vie de qualité (AViQ) Expertisecentrum Dementie Vlaanderen
Bulgaria	Foundation Compassion Alzheimer Bulgaria
Croatia	Alzheimer Croatia Klinika za psihijatriju Vrapče
Cyprus	Ministry of Health
Czech Republic	Ministry of Health of the Czech Republic
Denmark	Danish Ministry of Health Danish Health Authority
Germany	Federal Ministry of Health
England	Department of Health and Social Care
Estonia	Ministry of Social Affairs
Finland	Ministry of Social Affairs and Health
France	French Society of Geriatrics and Gerontology Institut national de la santé et de la recherche médicale (Inserm)
Greece	Hellenic Association of Geriatrics and Gerontology Aristotle University of Thessaloniki
Hungary	National Healthcare Service Center
Ireland	National Dementia Office Department of Health
Italy	Italian Society of Gerontology and Geriatrics
Latvia	Ministry of Health of the Republic of Latvia
Lithuania	Ministry of Health of The Republic of Lithuania
Luxembourg	Ministry of Health
Malta	Malta Dementia Society
Netherlands	Netherlands Centre of Expertise for Long-Term Care (Vilans)
Northern Ireland	Department of Health, Social Services and Public Safety
Poland	Ministry of Health of the Republic of Poland
Portugal	Chronic Diseases Research Center (CEDOC)
Romania	Alzheimer Society Romania
Scotland	Scottish Government
Sweden	Ministry of Health and Social Affairs Svenskt Demenszentrum

Country	Organisations responding to the e-mail request
Slovakia	German Embassy Bratislava Centrum Memory Bratislava
Slovenia	Slovenian Geriatric Medicine Society
Spain	Ministry of Health, Social Services and Equality
Wales	Department of Health and Social Services
Iceland	Ministry of Health
Liechtenstein	Ministry of Society/Department of Health Demenz Liechtenstein
Norway	Ministry of Health and Care Services
Switzerland	Association Alzheimer Suisse Federal Office of Public Health

## 11. Appendix

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The interview guide and definitions of key terms used in the interviews were sent to the experts before the interviews took place.

These documents were provided in English or German and are included in the following sections.

### 11.2 Interview guide

#### Start

- 1) Could you please rate your expertise in the field of **dementia** on a scale from 1 to 10 – 1 = 'no expertise' and 10 = 'very high expertise'.

1    2    3    4    5    6    7    8    9    10

- 2) Could you please rate your expertise in the field of **migration** in your country on a scale from 1 to 10 – 1 = 'no expertise' and 10 = 'very high expertise'.

1    2    3    4    5    6    7    8    9    10

- 3) Could you please rate your expertise in the field of **dementia and migration** in your country on a scale from 1 to 10 – 1 = 'no expertise' and 10 = 'very high expertise'.

1    2    3    4    5    6    7    8    9    10

- 4) Do you know any other experts in the field of dementia and migration in your country?

- 5) According to your opinion, how **important** is the topic dementia and migration regarded in your country?

- ☐ Very important  
☐ Important  
☐ Partly  
☐ Rather unimportant  
☐ Not important

a) Could you explain this in more detail?

- 6) According to your opinion, how important is the topic dementia and migration regarded in individual areas?

- ☐ Very important  
☐ Important  
☐ Partly  
☐ Rather unimportant  
☐ Not important

- a) Could you explain this in more detail?
- 7) According to your opinion, are people with a migration background generally identified as a vulnerable group in healthcare in your country?
- ☐ Yes
- ☐ No
- a) Are people from certain ethnicities identified as vulnerable groups in the healthcare system?
- ☐ Yes
- ☐ No
- ☐ Partly
- b) If so, which ethnicities are identified as vulnerable groups?
- 8) According to your opinion, does the **healthcare system** treat people with a migration background with dementia and their family members as a **group with specific needs** (because of their migration background)?
- ☐ Always
- ☐ Mostly
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- a) Which specific needs are primarily recognized?
- 9) According to your opinion, in which area are people with a migration background identified as a vulnerable group with specific needs in your country?
- ☐ Development of dementia
- ☐ Process/Progress of dementia
- ☐ Consequences of dementia
- ☐ Lack of care of dementia
- ☐ Under-diagnosis of dementia
- ☐ Utilisation of formal healthcare services
- ☐ In no area
- a) According to your opinion, what are the key differences in these areas between people with a migration background and people without a migration background regarding care?



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### Care

#### *People without a migration background*

- 1) Please estimate to what extent are services for outpatient care of people with dementia widespread in your country?
  - ☐ Nationwide
  - ☐ Almost nationwide
  - ☐ In several regions
  - ☐ In single regions
  - ☐ Not available
  - a) Could you explain this in more detail?
- 2) Please estimate how widely available services for inpatient care of people with dementia are in your country?
  - ☐ Nationwide
  - ☐ Almost nationwide
  - ☐ In several regions
  - ☐ In single regions
  - ☐ Not available
  - a) Could you explain this in more detail?

#### *People with a migration background*

- 3) Please estimate how widely available services for outpatient care of people with a migration background with dementia are in your country?
  - ☐ Nationwide
  - ☐ Almost nationwide
  - ☐ In several regions
  - ☐ In single regions
  - ☐ Not available
  - a) Could you explain this in more detail?
  - b) Are there any models of good practice?
- 4) Which healthcare strategy is used predominantly?
  - ☐ Integrative model
  - ☐ Segregative model
  - ☐ Hybrid model with integrative and segregative elements
  - a) Are there differences between ethnicities?

- b) Could you explain this in more detail?  
c) Are there any models of good practice?
- 5) Please estimate how widely available services for inpatient care of people with a migration background with dementia are in your country?
- ☐ Nationwide  
☐ Almost nationwide  
☐ In several regions  
☐ In single regions  
☐ Not available
- a) Could you explain this in more detail?  
b) Are there any models of good practice?
- 6) Which healthcare strategy is used predominantly?
- ☐ Integrative model  
☐ Segregative model  
☐ Hybrid model with integrative and segregative elements
- a) Are there differences between ethnicities?  
b) Could you explain this in more detail?  
c) Are there any models of good practice?
- 7) According to your opinion, are existing services suitable for an adequate care of **people with dementia**?
- ☐ Yes, for people with and without a migration background  
☐ Yes, but only for people without a migration background  
☐ Yes, but only for people with a migration background  
☐ No, neither for people without nor for people with a migration background
- a) Could you explain this in more detail?
- 8) Are measures distributed or in development to provide intercultural care of and/or support for dementia?
- ☐ Nationwide distributed  
☐ Nationwide in development  
☐ Locally distributed  
☐ Locally in development  
☐ Measures for development are planned  
☐ Neither distributed nor in development

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- a) Could you explain this in more detail?
  - b) Are there any models of good practice?
- 9) Which specific and/or specialized healthcare services are available for people with a migration background or for people from certain ethnicities in your country?
- a) Are there any models of good practice? Which ones? Where?

### Inclusion and information of people with a migration background

#### *People without a migration background*

- 1) Could you please estimate the level of inclusion of people with dementia into healthcare in your country?
- ☐ Completely
  - ☐ Almost completely
  - ☐ Partly
  - ☐ Slightly
  - ☐ Not at all
- a) Are there any models of good practice?
- 2) According to your opinion, how widely available are information services for people with dementia and their family members in your country?
- ☐ Nationwide
  - ☐ Almost nationwide
  - ☐ In several regions
  - ☐ In single regions
  - ☐ Not existent/available
- a) Could you explain this in more detail?
- 3) According to your opinion, are people with dementia and/or their family members participating in the development of healthcare services, the design of information material or the design of residential and care facilities?
- ☐ Always
  - ☐ Often
  - ☐ Sometimes
  - ☐ Rarely
  - ☐ Never
- a) Could you explain this in more detail?

### *People with a migration background*

- 1) Could you please estimate the level of inclusion of people with a migration background into healthcare in your country?

- ☐ Completely
- ☐ Almost completely
- ☐ Partly
- ☐ Slightly
- ☐ Not at all

a) Are there any models of good practice?

- 2) Could you please estimate the level of inclusion of people with a migration background with dementia into healthcare in your country?

- ☐ Completely
- ☐ Almost completely
- ☐ Partly
- ☐ Slightly
- ☐ Not at all

a) Are there any models of good practice?

- 3) According to your opinion, how widely available are information services for people with a migration background with dementia and their family members in your country?

- ☐ Nationwide
- ☐ Almost nationwide
- ☐ In several regions
- ☐ In single regions
- ☐ Not existent/available

a) Could you explain this in more detail?

- 4) According to your opinion, are people with a migration background with dementia and/or their family members participating in the development of healthcare services, the design of information material or the design of residential and care facilities?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

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- a) Could you explain this in more detail?
- b) Are there any models of good practice?

### Professional care

- 1) According to your opinion, is culturally sensitive care part of the professional qualification?

- ☐ Nationwide
- ☐ Mostly
- ☐ Partly
- ☐ Hardly
- ☐ No

- 2) Are there professional training possibilities in intercultural care available?

- ☐ Nationwide
- ☐ Mostly
- ☐ Partly
- ☐ Hardly
- ☐ No

- 3) Could you please estimate the proportion of professional caregiver with a migration background in outpatient care?

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

- a) Which countries or regions are the professional caregivers originating from?
- b) According to your opinion, what impact does that have on care?
- c) Is the need for culturally sensitive care being met by sufficiently qualified professionals?

- 4) Could you please estimate the proportion of professional caregivers with a migration background in inpatient care?

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

- a) Which countries or regions are the professional caregivers originating from?
- b) According to your opinion, what impact does that have on care?
- c) Is the need for culturally sensitive care being met by sufficiently qualified professionals?

### Support of family caregivers

- 1) According to your opinion, what differences are there regarding information and services for family caregivers of people with dementia **with and without a migration background**?

- ☐ Major differences
- ☐ Rather major differences
- ☐ Moderate differences
- ☐ Hardly any differences
- ☐ No differences

- 2) How high do you estimate the need for specific information and services for family caregivers of people with a migration background with dementia?

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

- 3) How high is, in your opinion, the importance of the following networks in supporting family caregivers of people with a migration background with dementia?

a) Family

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

b) Religious communities

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent



c) Migrant organizations

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

d) Service providers (outpatient/inpatient)

- ☐ Very high
- ☐ High
- ☐ Moderate
- ☐ Low
- ☐ Not existent

### 11.3 Interviewleitfaden

#### Start

- 1) Könnten Sie bitte Ihre Fachkenntnisse auf dem Gebiet der **Demenz** auf einer Skala von 1 bis 10 bewerten – 1=“keine Fachkenntnisse” und 10=“sehr hohe Fachkenntnisse”.

1    2    3    4    5    6    7    8    9    10

- 2) Könnten Sie bitte Ihre Fachkenntnisse auf dem Gebiet der **Migration** auf einer Skala von 1 bis 10 bewerten – 1=“keine Fachkenntnisse” und 10=“sehr hohe Fachkenntnisse”.

1    2    3    4    5    6    7    8    9    10

- 3) Könnten Sie bitte Ihre Fachkenntnisse auf dem Gebiet **Demenz und Migration** auf einer Skala von 1 bis 10 bewerten – 1=“keine Fachkenntnisse” und 10=“sehr hohe Fachkenntnisse”.

1    2    3    4    5    6    7    8    9    10

- 4) Kennen Sie weitere Experten auf dem Gebiet der Demenz und Migration in Ihrem Land?

- 5) Als wie wichtig wird das Thema **Demenz und Migration** in Ihrem Land Ihrer Meinung nach betrachtet?

- ☐ Sehr wichtig  
☐ Wichtig  
☐ Teilweise  
☐ Eher unwichtig  
☐ Nicht wichtig

a) Können Sie das näher erläutern?

- 6) Als wie wichtig wird Ihrer Meinung nach das Thema **Demenz und Migration** in einzelnen Regionen betrachtet?

- ☐ Sehr wichtig  
☐ Wichtig  
☐ Teilweise  
☐ Eher unwichtig  
☐ Nicht wichtig

a) Können Sie das näher erläutern?

- 7) Werden Ihrer Meinung nach Menschen mit Migrationshintergrund in der Gesundheitsversorgung in Ihrem Land als vulnerable Gruppe identifiziert?
- ☐ Ja  
☐ Nein
- a) Werden Menschen bestimmter Ethnien als eine vulnerable Gruppe vom Gesundheitssystem identifiziert?
- ☐ Ja  
☐ Nein  
☐ Teilweise
- b) Wenn ja, welche ethnischen Gruppen werden als vulnerable Gruppen identifiziert?
- 8) Behandelt das Gesundheitssystem Ihrer Meinung nach Menschen mit Migrationshintergrund mit Demenz und ihre Familienangehörigen als eine Gruppe mit spezifischen Bedürfnissen?
- ☐ Immer  
☐ Meistens  
☐ Manchmal  
☐ Selten  
☐ Nie
- a) Welche Bedürfnisse werden vorrangig identifiziert?
- 9) In welchem Bereich werden Ihrer Meinung nach Menschen mit Migrationshintergrund in Ihrem Land als vulnerable Gruppe mit spezifischen Bedürfnissen identifiziert?
- ☐ Entwicklung einer Demenz  
☐ Verlauf/Voranschreiten der Demenz  
☐ Folgen einer Demenz  
☐ Unterversorgung bei einer Demenz  
☐ Unterdiagnostizierung von Demenz  
☐ Inanspruchnahme von Versorgungsleistungen  
☐ In keinem Bereich
- a) Was sind Ihrer Meinung nach die wesentlichen Unterschiede zwischen Menschen mit Migrationshintergrund und Menschen ohne Migrationshintergrund hinsichtlich der Versorgung in diesen Bereichen?

### Versorgung

#### *Menschen ohne Migrationshintergrund*

- 1) Bitte schätzen Sie ein, in welchem Umfang Dienste für die ambulante Versorgung von Menschen mit Demenz in Ihrem Land verbreitet sind.

- ☐ Landesweit
- ☐ Nahezu landesweit
- ☐ In mehreren Regionen
- ☐ In einzelnen Regionen
- ☐ Nicht verfügbar

a) Können Sie das näher erläutern?

- 2) Bitte schätzen Sie ein, in welchem Umfang Dienste für die stationäre Versorgung von Menschen mit Demenz in Ihrem Land verbreitet sind.

- ☐ Landesweit
- ☐ Nahezu landesweit
- ☐ In mehreren Regionen
- ☐ In einzelnen Regionen
- ☐ Nicht verfügbar

a) Können Sie das näher erläutern?

#### *Menschen mit Migrationshintergrund*

- 1) Bitte schätzen Sie ein, in welchem Umfang Dienste für die ambulante Versorgung von Menschen mit Migrationshintergrund mit Demenz in Ihrem Land verbreitet sind.

- ☐ Landesweit
- ☐ Nahezu landesweit
- ☐ In mehreren Regionen
- ☐ In einzelnen Regionen
- ☐ Nicht verfügbar

a) Können Sie das näher erläutern?

b) Gibt es hierfür irgendwelche models of good practice?

- 2) Welche Versorgungsstrategie wird überwiegend angewendet?

- ☐ Integratives Modell
- ☐ Segregatives Modell
- ☐ Hybrides Modell mit integrativen and segregativen Elementen

a) Gibt es hierbei Unterschiede zwischen verschiedenen ethnischen Gruppen?

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- b) Können Sie das näher erläutern?  
c) Gibt es hierfür irgendwelche models of good practice?
- 3) Bitte schätzen Sie ein, in welchem Umfang Dienste für die stationäre Versorgung von Menschen mit Migrationshintergrund mit Demenz in Ihrem Land verbreitet sind.
- ☐ Landesweit  
☐ Nahezu landesweit  
☐ In mehreren Regionen  
☐ In einzelnen Regionen  
☐ Nicht verfügbar
- a) Können Sie das näher erläutern?  
b) Gibt es hierfür irgendwelche models of good practice?
- 4) Welche Versorgungsstrategie wird überwiegend angewendet?
- ☐ Integratives Modell  
☐ Segregatives Modell  
☐ Hybrides Modell mit integrativen and segregativen Elementen
- a) Gibt es hierbei Unterschiede zwischen verschiedenen ethnischen Gruppen?  
b) Können Sie das näher erläutern?  
c) Gibt es hierfür irgendwelche models of good practice?
- 5) Sind Ihrer Meinung nach die bestehenden Versorgungsangebote für eine angemessene Betreuung von **Menschen mit Demenz** geeignet?
- ☐ Ja, für Menschen mit und ohne Migrationshintergrund  
☐ Ja, aber nur für Menschen ohne Migrationshintergrund  
☐ Ja, aber nur für Menschen mit Migrationshintergrund  
☐ Nein, weder für Menschen mit noch für Menschen ohne Migrationshintergrund
- a) Können Sie das näher erläutern?
- 6) Sind Maßnahmen für eine interkulturelle Versorgung und/oder Unterstützung für Menschen mit Demenz verbreitet oder in Entwicklung?
- ☐ Landesweit verbreitet  
☐ Landesweit in Entwicklung  
☐ Lokal verbreitet  
☐ Lokal in Entwicklung  
☐ Maßnahmen zur Entwicklung sind geplant  
☐ Weder verbreitet noch in Entwicklung

- a) Können Sie das näher erläutern?
  - b) Existieren hierfür models of good practice?
- 7) Welche spezifischen und/oder spezialisierten Versorgungsangebote gibt es für Menschen mit Migrationshintergrund mit Demenz oder für Menschen bestimmter Ethnien mit Demenz in Ihrem Land?
- a) Gibt es models of good practice? Welche sind das? Wo gibt es welche?

### Inklusion und Aufklärung von Menschen mit Migrationshintergrund

#### *Menschen ohne Migrationshintergrund*

- 1) Könnten Sie bitte den Grad der Inklusion von Menschen mit Demenz in die Gesundheitsversorgung in Ihrem Land einschätzen?
- ☐ Vollständig
  - ☐ Nahezu vollständig
  - ☐ Teilweise
  - ☐ Kaum
  - ☐ Überhaupt nicht
- a) Gibt es hierfür models of good practice?
- 2) Wie weit sind Ihrer Meinung nach Informationsangebote für Menschen mit Demenz und ihre Familienangehörigen in Ihrem Land verfügbar?
- ☐ Landesweit
  - ☐ Nahezu landesweit
  - ☐ In mehreren Regionen
  - ☐ In einzelnen Regionen
  - ☐ Nicht vorhanden/verfügbar
- a) Können Sie das näher erläutern?
- 3) Sind Ihrer Meinung nach Menschen mit Demenz und/oder ihre Familienangehörigen an der Entwicklung von Versorgungsangeboten, an der Gestaltung von Informationsmaterial oder an der Gestaltung von Wohn- und Pflegeeinrichtungen beteiligt?
- ☐ Immer
  - ☐ Häufig
  - ☐ Manchmal
  - ☐ Selten
  - ☐ Niemals
- a) Können Sie das näher erläutern?



### *Menschen mit Migrationshintergrund*

- 1) Könnten Sie bitte den Grad der Inklusion von Menschen mit Migrationshintergrund in die Gesundheitsversorgung in Ihrem Land einschätzen?  
  - ☐ Vollständig
  - ☐ Nahezu vollständig
  - ☐ Teilweise
  - ☐ Kaum
  - ☐ Überhaupt nichta) Gibt es hierfür models of good practice?
  
- 2) Könnten Sie bitte den Grad der Inklusion von Menschen mit Migrationshintergrund mit Demenz in die Gesundheitsversorgung in Ihrem Land einschätzen?  
  - ☐ Vollständig
  - ☐ Nahezu vollständig
  - ☐ Teilweise
  - ☐ Kaum
  - ☐ Überhaupt nichta) Gibt es hierfür models of good practice?
  
- 3) Wie weit sind Ihrer Meinung nach Informationsangebote für Menschen mit Migrationshintergrund mit Demenz und ihre Familienangehörigen in Ihrem Land verfügbar?  
  - ☐ Landesweit
  - ☐ Nahezu landesweit
  - ☐ In mehreren Regionen
  - ☐ In einzelnen Regionen
  - ☐ Nicht vorhanden/verfügbara) Können Sie das näher erläutern?
  
- 4) Sind Ihrer Meinung nach Menschen mit Migrationshintergrund mit Demenz und/oder ihre Familienangehörigen an der Entwicklung von Versorgungsangeboten, der Gestaltung von Informationsmaterial oder der Gestaltung von Wohn- und Pflegeeinrichtungen beteiligt?  
  - ☐ Immer
  - ☐ Häufig
  - ☐ Manchmal
  - ☐ Selten
  - ☐ Niemalsa) Können Sie das näher erläutern?

b) Gibt es hierfür models of good practice?

### Professionelle Versorgung

1) Ist Ihrer Meinung nach kultursensible Versorgung Teil der beruflichen Qualifikation?

- ☐ Landesweit
- ☐ Meistens
- ☐ Teilweise
- ☐ Kaum
- ☐ Nein

2) Gibt es professionelle Ausbildungs- bzw. Weiterbildungsmöglichkeiten in interkultureller Versorgung?

- ☐ Landesweit
- ☐ Meistens
- ☐ Teilweise
- ☐ Kaum
- ☐ Nein

3) Könnten Sie bitte den Anteil der professionellen Pflegekräfte mit Migrationshintergrund in der ambulanten Versorgung schätzen?

- ☐ Sehr hoch
- ☐ Hoch
- ☐ Mäßig
- ☐ Niedrig
- ☐ Nicht vorhanden

a) Aus welchen Ländern oder Regionen stammen die professionellen Pflegekräfte?

b) Welche Auswirkungen hat dies Ihrer Meinung nach auf die Pflege?

c) Wird der Bedarf an kultursensibler Pflege durch ausreichend qualifizierte Fachkräfte gedeckt?

4) Könnten Sie bitten den Anteil der professionellen Pflegekräfte mit Migrationshintergrund in der stationären Versorgung schätzen?

- ☐ Sehr hoch
- ☐ Hoch
- ☐ Mäßig
- ☐ Niedrig
- ☐ Nicht vorhanden

a) Aus welchen Ländern oder Regionen stammen die professionellen Pflegekräfte?

- b) Welche Auswirkungen hat dies Ihrer Meinung nach auf die Pflege?
- c) Wird der Bedarf an kultursensibler Pflege durch ausreichend qualifizierte Fachkräfte gedeckt?

### Unterstützung der pflegenden Angehörige

- 1) Welche Unterschiede gibt es Ihrer Meinung nach in Bezug auf Informationen und Dienstleistungen für pflegende Angehörige von Menschen mit Demenz **mit und ohne Migrationshintergrund**?
  - ☐ Wesentliche Unterschiede
  - ☐ Ziemlich große Unterschiede
  - ☐ Moderate Unterschiede
  - ☐ Kaum Unterschiede
  - ☐ Keine Unterschiede
- 2) Wie hoch schätzen Sie den Bedarf an spezifischen Informationen und Dienstleistungen für pflegende Angehörige von Menschen mit Migrationshintergrund mit Demenz ein?
  - ☐ Sehr hoch
  - ☐ Hoch
  - ☐ Moderat
  - ☐ Niedrig
  - ☐ Nicht vorhanden
- 3) Wie hoch ist Ihrer Meinung nach die Bedeutung der folgenden Netzwerke für die Unterstützung von pflegenden Angehörigen von Menschen mit Migrationshintergrund mit Demenz?
  - a) Familie
    - ☐ Sehr hoch
    - ☐ Hoch
    - ☐ Moderat
    - ☐ Niedrig
    - ☐ Nicht vorhanden
  - b) Religiöse Gemeinschaften
    - ☐ Sehr hoch
    - ☐ Hoch
    - ☐ Moderat
    - ☐ Niedrig
    - ☐ Nicht vorhanden

c) Migrantenorganisationen

- ☐ Sehr hoch
- ☐ Hoch
- ☐ Moderat
- ☐ Niedrig
- ☐ Nicht vorhanden

d) Versorgungsanbieter (ambulant/stationär)

- ☐ Sehr hoch
- ☐ Hoch
- ☐ Moderat
- ☐ Niedrig
- ☐ Nicht vorhanden

## 11.4 Definition of key terms on the topic of dementia and migration

### 1. People with a migration background

A central challenge for comparative studies is the fact that there is currently no common definition of people with a migration background at the European level. The individual EU and EFTA countries use different terms in official national documents in the context of this population. The United Nations definition will be used as it is the basis for most international migration-specific databases and data sets (for example, the Migration Data Portal of the International Organization for Migration) and is also used by most national statistical offices of the EU and EFTA countries. The definition is also clearly and has a well-defined inclusion and exclusion criterion. The United Nations defines people with a migration background as people who are living in a country other than that in which they were born (United Nations 2019). Consequently, all people who are living in the country in which they were born are excluded. That also covers subsequent generations of foreign-born immigrants.

**This study includes all older people (65 years or older) who live in an EU or EFTA country and were born abroad.**

### 2. Inpatient and outpatient care

We understand inpatient care as the permanent accommodation, care, and treatment of a person in need of care in a nursing facility. Such facilities are for example nursing homes, hospices, and rehabilitation facilities.

Outpatient care comprises the support of persons in need of care and their relatives in provision of nursing and domestic care in their domesticity by service providers such as home care providers. The home care providers offer families support in everyday life, enabling family caregivers to better organize care, assistance and other obligations such as work or

childcare, and to provide the highest possible level of care for their relatives in need of care.

### 3. Integrative and segregative care model

We have defined the integrative care model as a model where people with a migration background are provided with mainstream services together with people without a migration background.

In a segregative care model, people with a migration background or individual migrant groups are offered specialized services that are developed only for these groups.

### 4. Inclusion in the context of people with a migration background with dementia and healthcare

Inclusion is the involvement of people with a migration background and dementia in healthcare practice. Concretely, inclusion of people with a migration background and dementia in the healthcare system means: 1. That providers of healthcare services (e.g. general practitioners, specialists, nursing homes, and home care providers) are sensitized to the specific (e.g. cultural or linguistic) needs that people with a migration background or people from certain migrant groups with dementia may have, 2. that the service providers offer these people care, treatment, and support services adapted to the cultural, and linguistic, but also their individual needs, 3. that people with a migration background and dementia use these services, and 4. that these people are under the impression that the services are tailored to their needs.

### 5. Culturally sensitive care

According to the authors' definition, culturally sensitive care is the orientation of care practice and treatments to the specific cultural context and individual cultural values of a person in need of care (Dömling, 2010-2012). The central goal of culturally sensitive care is to

make the specific needs of people with a migration background visible and to enable equal access to care.

#### 5.1 *Culturally sensitive care in the professional qualification*

Do curricula of universities, colleges or other institutions that train healthcare professionals consider a module or a course of culturally sensitive care? If the curricula have modules or courses for culturally sensitive care, are they compulsory and thus a requirement for graduation, an optional compulsory module, or a voluntary additional offer?

#### 5.2. *Intercultural care*

Intercultural care means that a professional caregiver looks after a person in need of care who has a different cultural background and the care practice is based on the mutual understanding of the respective culture.

### 6. Vulnerability in the context of people with a migration background and dementia

In the context of people with a migration background and dementia, a group is described as vulnerable if their members either have a higher risk of developing dementia, the disease occurs on average earlier in their lives, the course of the disease is worse (e.g. faster degeneration of cognitive abilities, poorer health outcomes), the negative effects of the disease (e.g. loss of knowledge of the language of the host country, loss of employment, previous need of care) are greater, the care situation is worse, or they are affected by inequalities such as underdiagnosis or underprovision.

## 11.5 Definition von Schlüsselbegriffen zum Thema Demenz und Migration

### 1. Menschen mit Migrationshintergrund

Eine zentrale Herausforderung für vergleichende Studien ist die Tatsache, dass es derzeit keine gemeinsame Definition von Menschen mit Migrationshintergrund auf europäischer Ebene gibt. Die einzelnen EU- und EFTA-Länder verwenden in offiziellen nationalen Dokumenten im Zusammenhang mit dieser Bevölkerung unterschiedliche Begriffe. Wir werden die Definition der Vereinten Nationen verwenden, da sie die Grundlage für die meisten internationalen migrationsspezifischen Datenbanken und Datensätze ist (z.B. das Migrationsdatenportal der Internationalen Organisation für Migration) und auch von den meisten nationalen statistischen Ämtern der EU- und EFTA-Länder verwendet wird. Die Definition ist ebenfalls klar und hat ein gut definiertes Ein- und Ausschlusskriterium. Die Vereinten Nationen definieren Menschen mit Migrationshintergrund als Personen, die in einem anderen Land leben als dem, in dem sie geboren wurden (United Nations 2019). Folglich sind alle Menschen, die in dem Land leben, in dem sie geboren wurden, ausgeschlossen. Das gilt auch für nachfolgende Generationen von im Ausland geborenen Einwanderern.

**Diese Studie umfasst demnach alle älteren Menschen (65 Jahre oder älter), die in einem EU- oder EFTA-Land leben und im Ausland geboren wurden.**

### 2. Stationäre und ambulante Versorgung

Unter stationärer Pflege verstehen wir die dauerhafte Unterbringung, Betreuung und Behandlung einer pflegebedürftigen Person in einer Pflegeeinrichtung. Solche Einrichtungen sind zum Beispiel Pflegeheime, Hospize und Rehabilitationseinrichtungen (VFR Verlag für Rechtsjournalismus).

Ambulante Pflege umfasst die Unterstützung pflegebedürftiger Personen und ihrer Ange-



hören bei der pflegerischen und häuslichen Versorgung in ihrer Häuslichkeit durch Leistungserbringer wie z.B. Homecare-Anbieter. Die Homecare-Anbieter bieten Familien Unterstützung im Alltag, damit die pflegenden Angehörigen Pflege, Betreuung und andere Verpflichtungen wie Arbeit oder Kinderbetreuung besser organisieren und ihre pflegebedürftigen Angehörigen auf höchstem Niveau versorgen können (Bundesministerium für Gesundheit, 2019).

### **3. Integratives und segregatives Versorgungsmodell**

Wir haben das Modell der integrativen Versorgung als ein Modell definiert, bei dem Menschen mit Migrationshintergrund gemeinsam mit Menschen ohne Migrationshintergrund in Versorgungsangeboten betreut werden.

In einem Modell der segregativen Versorgung werden Menschen mit Migrationshintergrund oder einzelnen Migrantengruppen spezialisierte Leistungen angeboten, die nur für diese Gruppen entwickelt werden (in Anlehnung an Kaiser 2009).

### **4. Inklusion von Menschen mit Migrationshintergrund und Demenz und Gesundheitsversorgung**

Inklusion ist die Einbeziehung von Menschen mit Migrationshintergrund und Demenz in die Gesundheitspraxis.

Konkret bedeutet die Einbeziehung von Menschen mit Migrationshintergrund und Demenz in das Gesundheitswesen: 1. dass die Anbieter von Gesundheitsleistungen (z. B. Allgemeinmediziner, Fachärzte, Pflegeheime und Homecare-Anbieter) für die spezifischen (z. B. kulturellen oder sprachlichen) Bedürfnisse sensibilisiert werden, die Menschen mit Migrationshintergrund oder Menschen aus bestimmten Migrantengruppen mit Demenz haben können, 2. dass die Leistungserbringer diesen Menschen Pflege-, Behandlungs- und Unter-

stützungsleistungen anbieten, die den kulturellen und sprachlichen, aber auch den individuellen Bedürfnissen angepasst sind, 3. dass Menschen mit Migrationshintergrund und Demenz diese Leistungen in Anspruch nehmen, und 4. dass diese Menschen den Eindruck haben, dass die Leistungen auf ihre Bedürfnisse zugeschnitten sind.

### **5. Kultursensible Versorgung**

Nach unserer Definition ist kultursensible Versorgung die Ausrichtung der Pflegepraxis und der Behandlungen auf den spezifischen kulturellen Kontext und die individuellen kulturellen Werte einer pflegebedürftigen Person (Dömling, 2010-2012). Zentrales Ziel einer kultursensiblen Versorgung ist es, die spezifischen Bedürfnisse von Menschen mit Migrationshintergrund sichtbar zu machen und einen gleichberechtigten Zugang zur Versorgung zu ermöglichen.

#### *5.1 Kultursensible Pflege in der beruflichen Qualifikation*

Sehen die Lehrpläne von Universitäten, Hochschulen oder anderen Institutionen, die Fachkräfte im Gesundheits- und Pflegebereich ausbilden, ein Modul oder einen Kurs für kultursensible Versorgung vor? Falls die Curricula Module oder Kurse für kultursensible Versorgung vorsehen, sind diese obligatorisch und damit Voraussetzung für einen Abschluss, ein optionales Pflichtmodul oder ein freiwilliges Zusatzangebot?

#### *5.2. Interkulturelle Versorgung*

Unter interkultureller Versorgung verstehen wir, dass eine professionelle Pflegeperson eine pflegebedürftige Person mit einem anderen kulturellen Hintergrund betreut und die Pflegepraxis auf dem gegenseitigen Verständnis der jeweiligen Kultur basiert (in Anlehnung an Yakar und Alpar 2018).

### **6. Vulnerabilität von Menschen mit Migrationshintergrund und Demenz**

Im Zusammenhang mit Menschen mit Migrationshintergrund und Demenz wird eine Gruppe als vulnerabel bezeichnet, wenn ihre Mitglieder entweder ein höheres Risiko haben, an einer Demenz zu erkranken, die Krankheit im Durchschnitt früher im Leben auftritt, der Krankheitsverlauf schlimmer ist

(z.B. schnellerer Abbau kognitiver Fähigkeiten, schlechtere gesundheitliche Ergebnisse), die negativen Auswirkungen der Krankheit (z. B. Verlust der Kenntnis der Sprache des Aufnahmelandes, Verlust des Arbeitsplatzes, frühere Pflegebedürftigkeit) größer sind, die Versorgungssituation schlechter ist oder sie von Ungleichheiten wie Unterdiagnostik oder Unterversorgung betroffen sind.

Both dementia and migration impact society and interact with each other, but very little is known about 'Dementia & Migration'. There is emerging evidence that a migration background is associated with underdiagnosis or lack of access to appropriate health-care. Thus, the care of people with a migration background (PwM) is a public health challenge. This atlas aims to contribute to the comprehensive analysis of the situation in Europe. It is a supplement to the existing knowledge about dementia and sees its value in focusing on PwM and their situation. It provides: (1) estimations of the number of PwM with dementia and graphical presentation for the EU and EFTA member states and the UK; (2) analyses of national dementia plans and care guidelines; (3) as well as analyses of healthcare systems. Based on statistical analyses, literature research, and expert interviews this work (a) provides information for people and organizations operating in the field and (b) can be a guide for stakeholders when strategically developing healthcare systems and services on a national or international level in laws, policies, strategies, and action plans. In the end, it is one of the very few, up-to-date comprehensive analyses to inform on dementia and migration across Europe.



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