



The United Kingdom

**Population**

67,026,000

Area

242,751 km²

Capital

London

3 largest cities

London (9,050,000)

Birmingham

(1,160,000)

Glasgow (630,000)

Neighboring countries

Ireland

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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

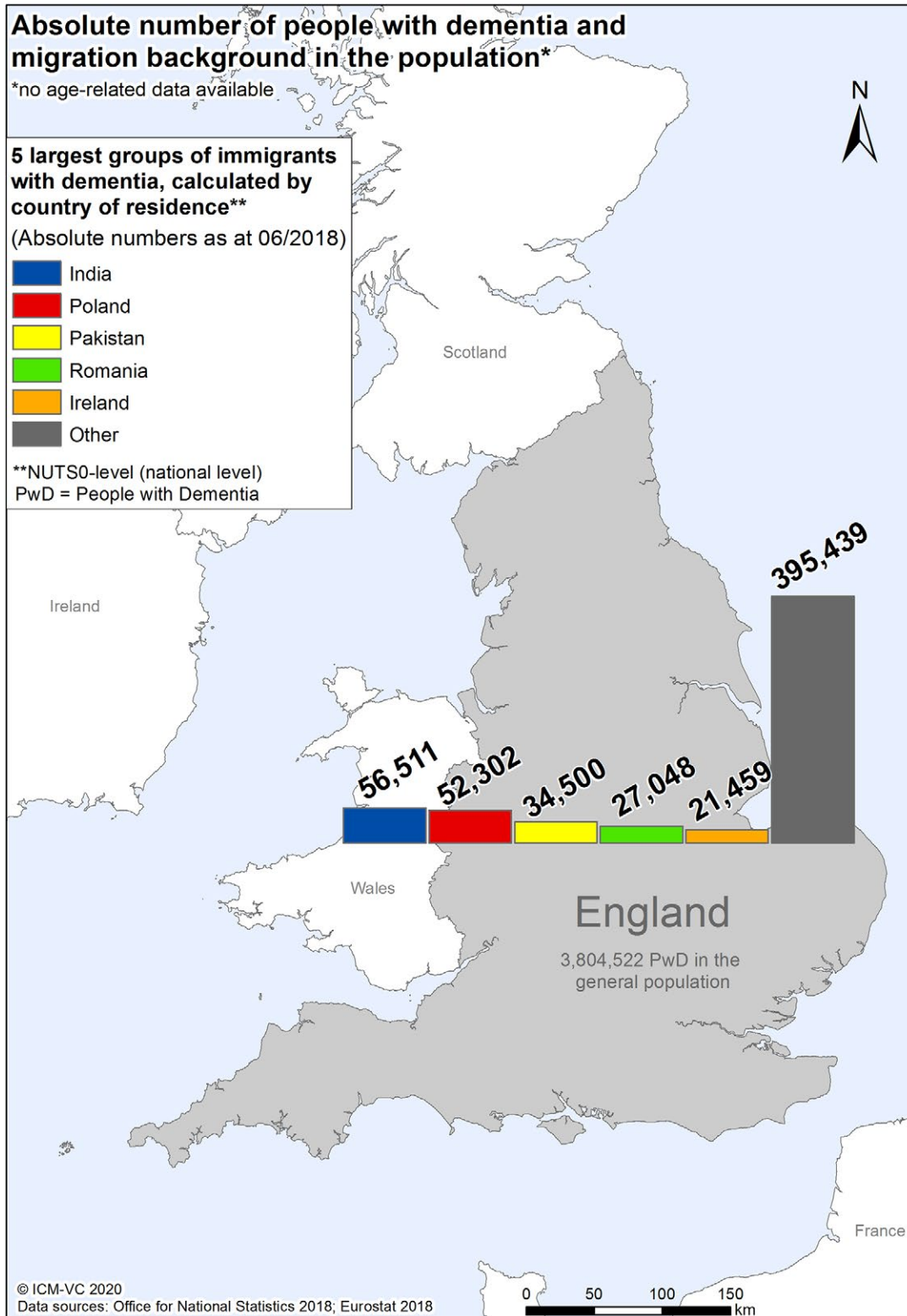


Fig. 3.7.32.1: Absolute number of PwM with dementia (England – Nation)



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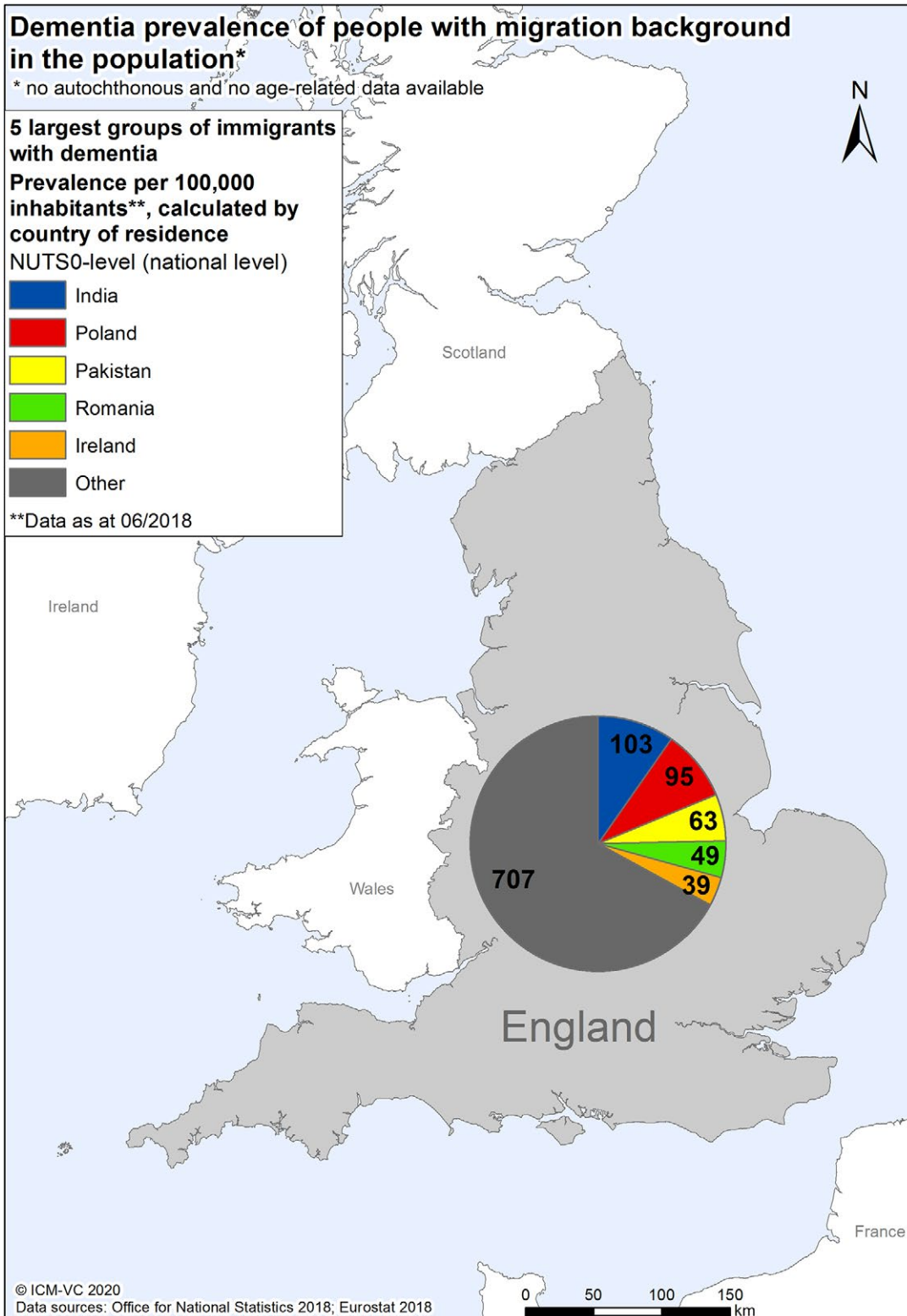


Fig. 3.7.32.2: Prevalence of PwM with dementia among the population (England – Nation)



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).



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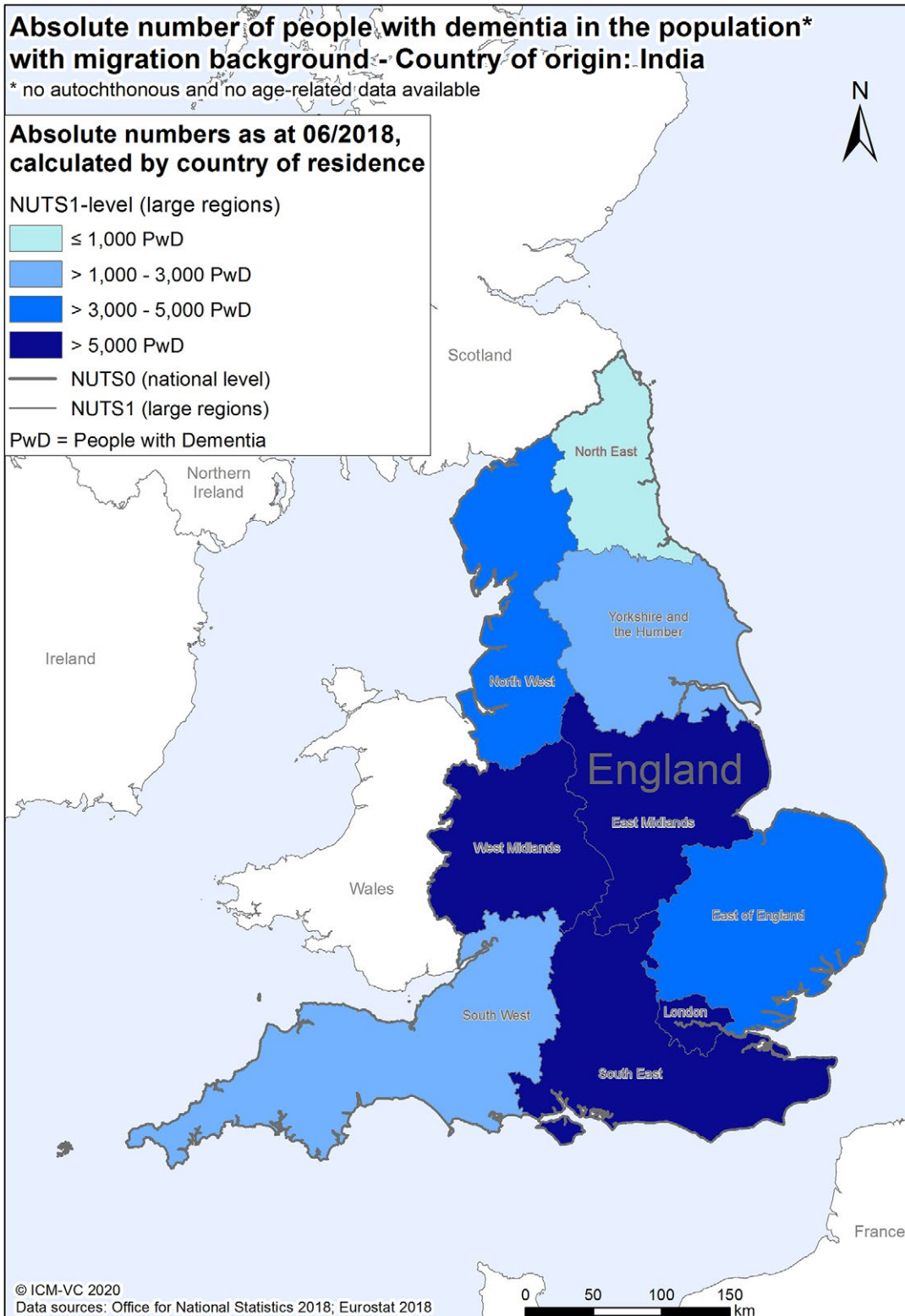


Fig. 3.7.32.3: Absolute number of PwM with dementia.
Country of origin: India (England – NUTS1)

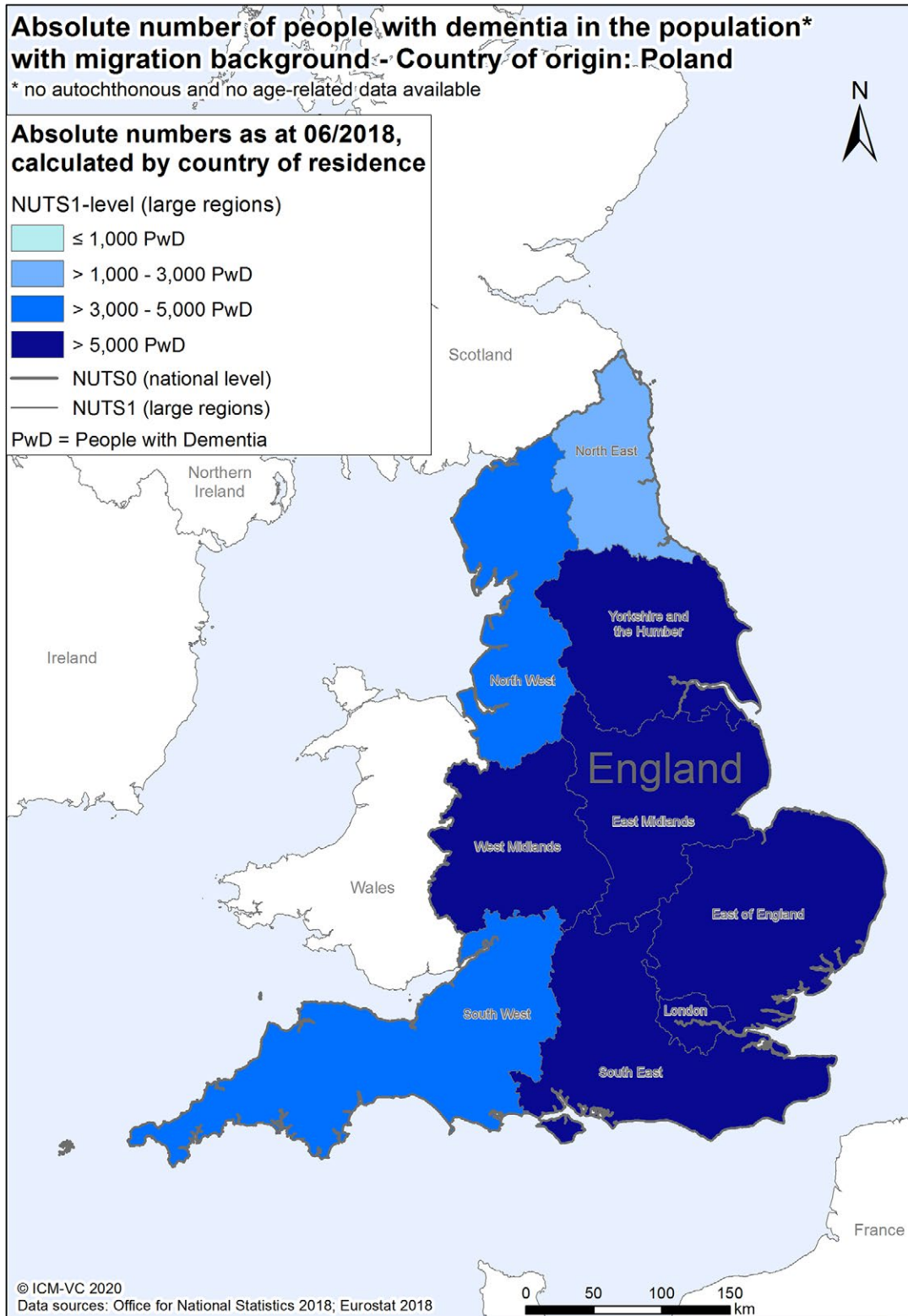


Fig. 3.7.32.4: Absolute number of PwM with dementia. Country of origin: Poland (England – NUTS1)



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Fig. 3.7.32.5: Absolute number of PwM with dementia.
Country of origin: Pakistan (England – NUTS1)

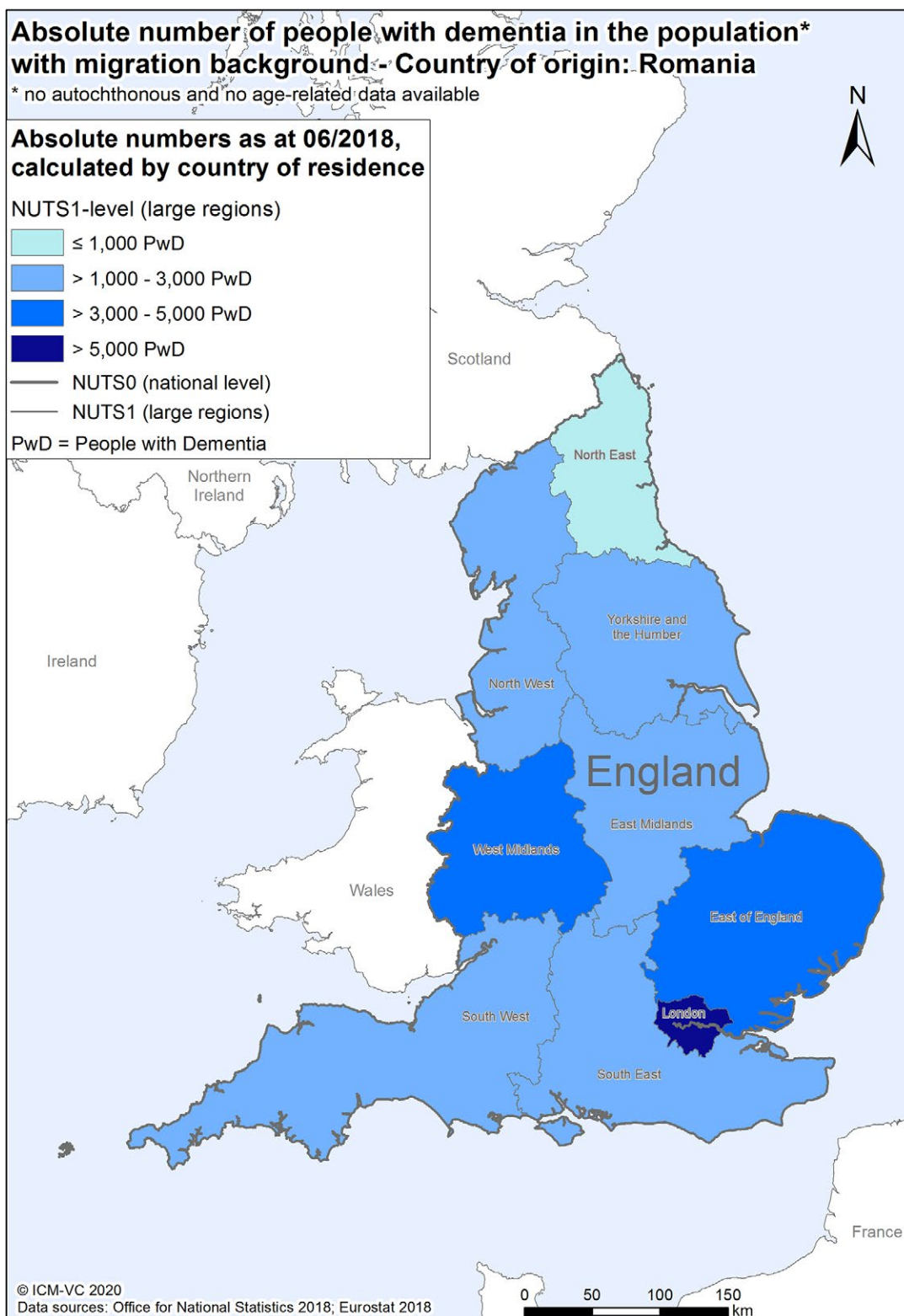


Fig. 3.7.32.6: Absolute number of PwM with dementia.
 Country of origin: Romania (England – NUTS1)



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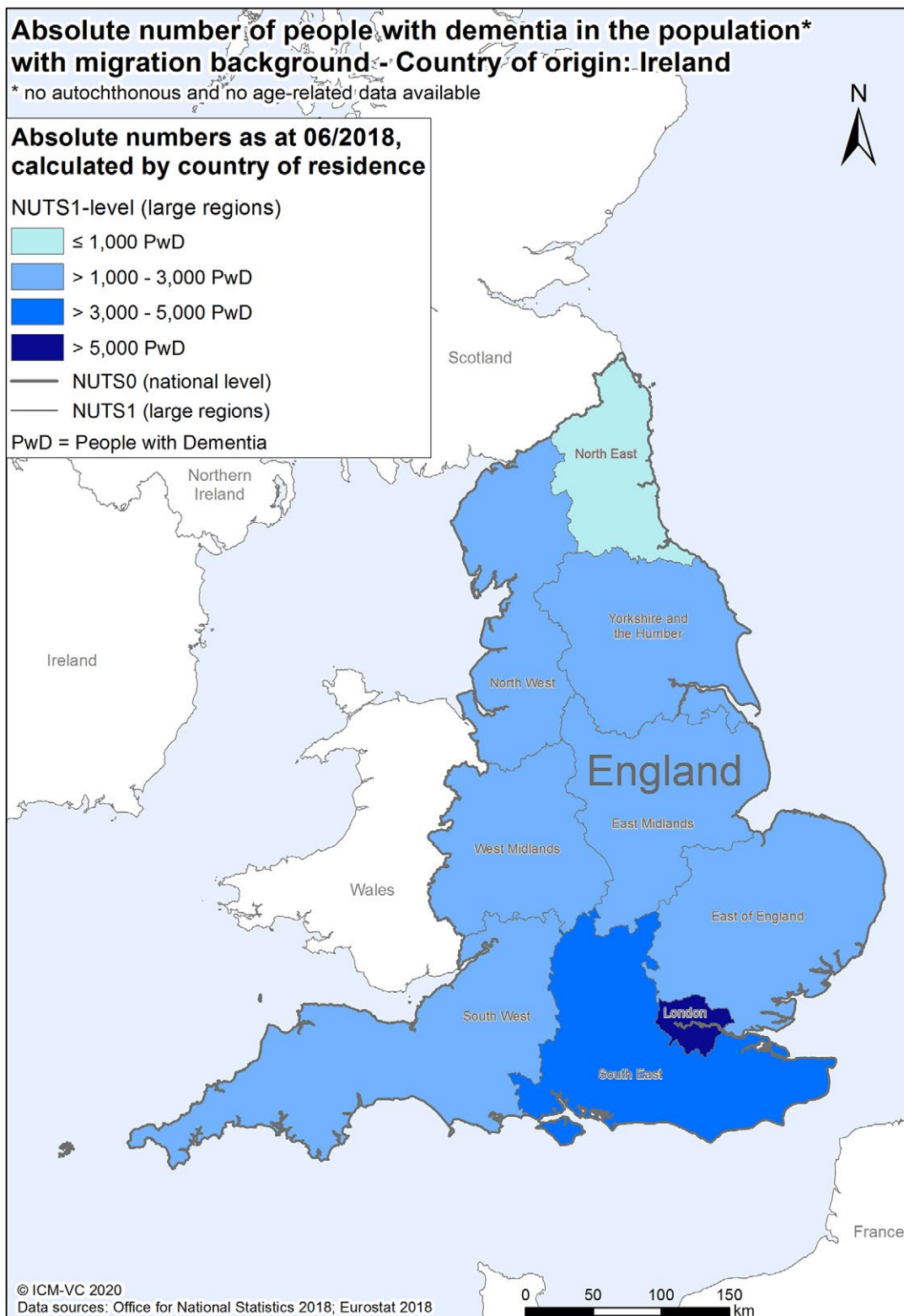


Fig. 3.7.32.7: Absolute number of PwM with dementia.
Country of origin: Ireland (England – NUTS1)

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].

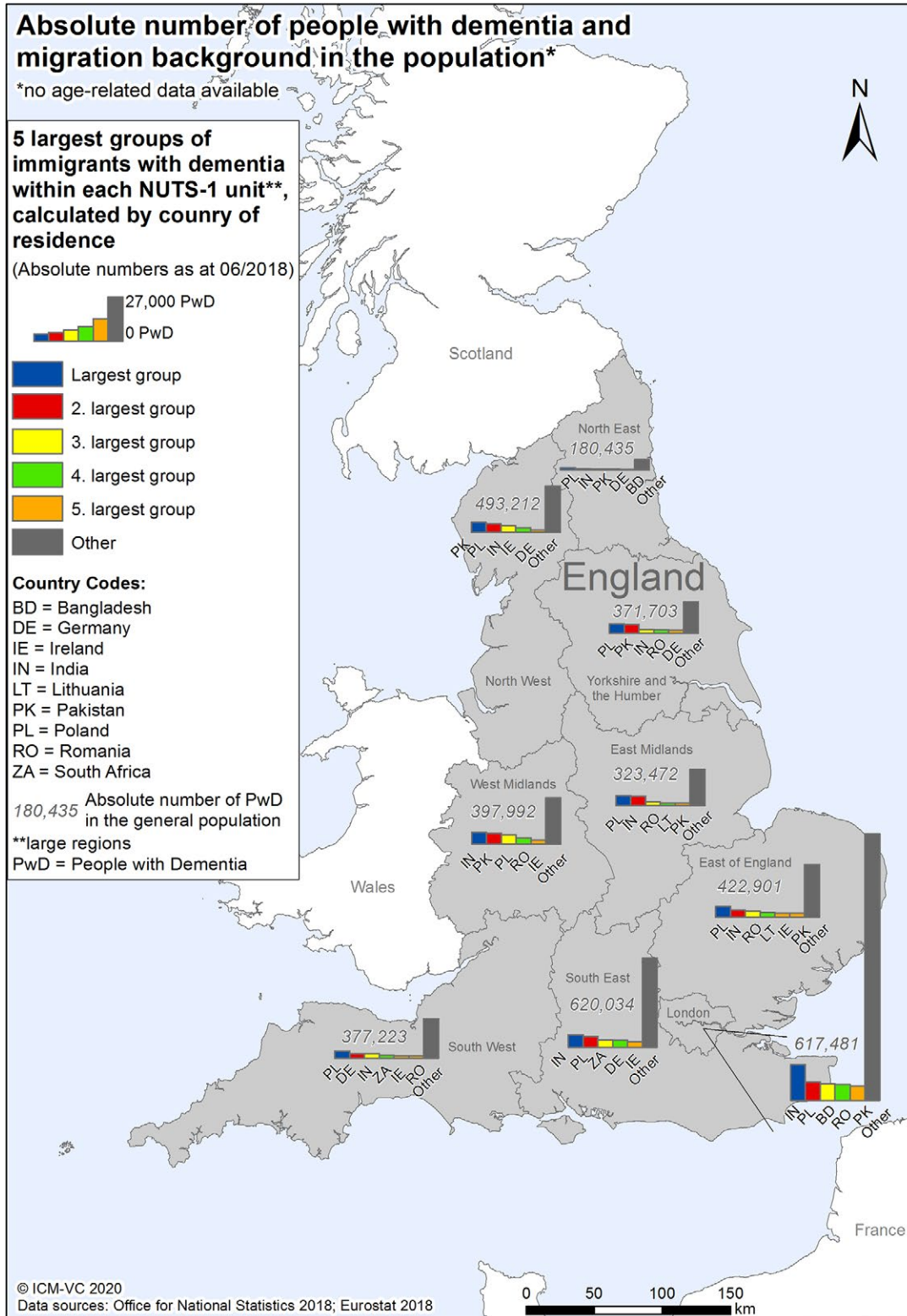


Fig. 3.7.32.8: Absolute number of PwM with dementia (England – NUTS1)



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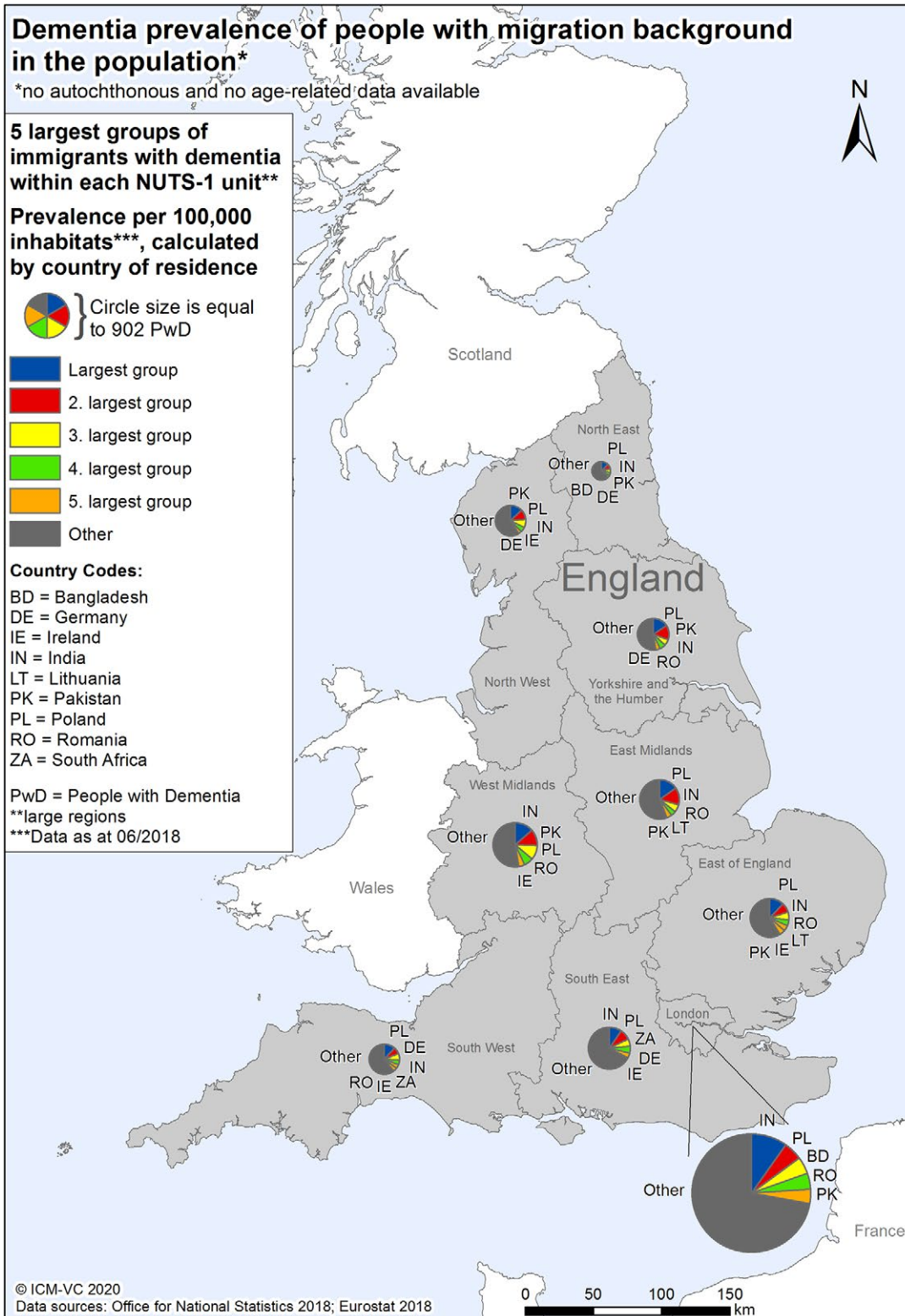


Fig. 3.7.32.9: Prevalence of PwM with dementia among the population (England – NUTS1)



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

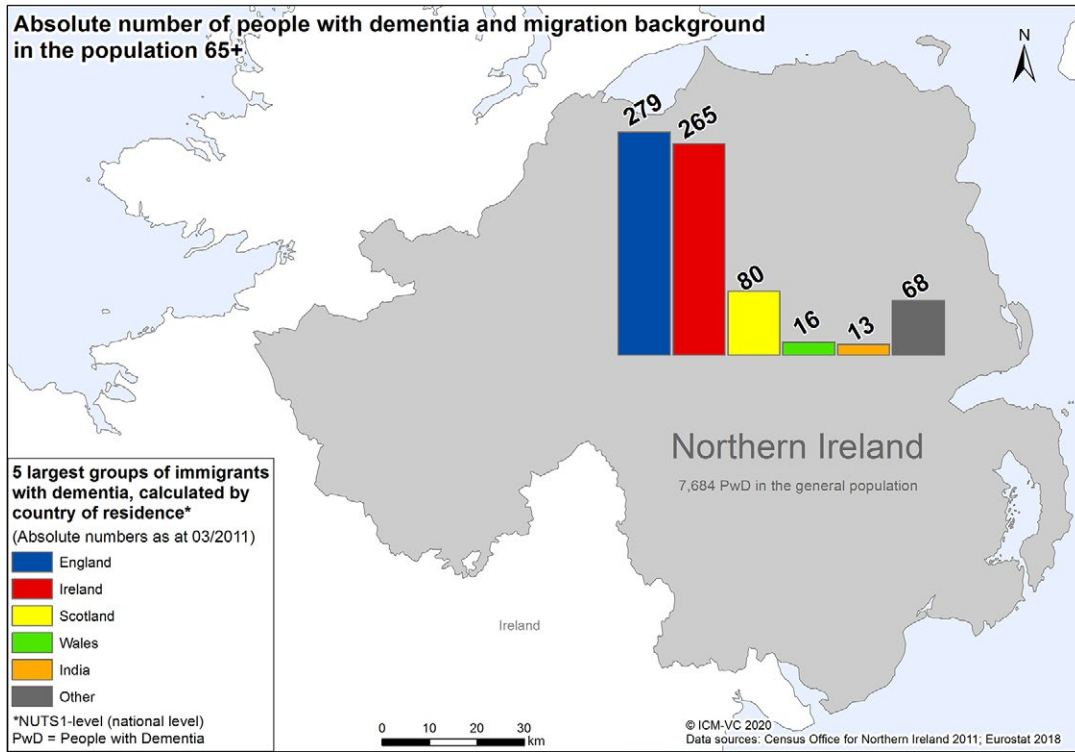


Fig. 3.7.32.10: Absolute number of PwM with dementia aged 65+ (Northern Ireland – Nation)

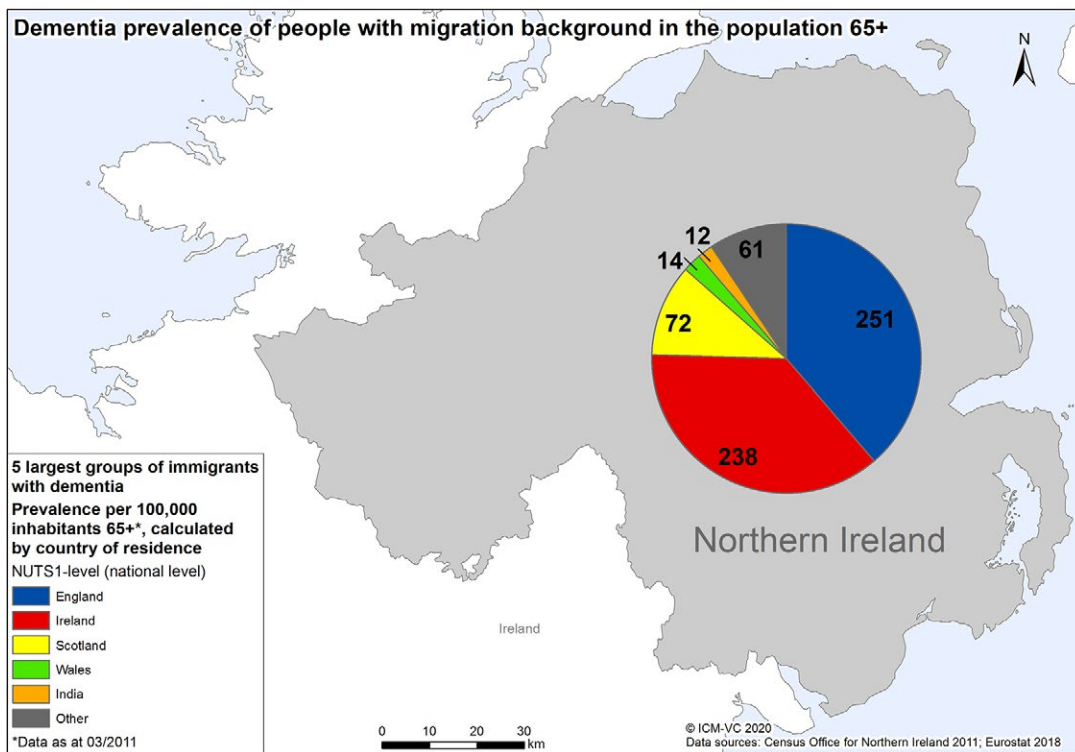


Fig. 3.7.32.11: Prevalence of PwM with dementia among the population aged 65+ (Northern Ireland – Nation)



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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

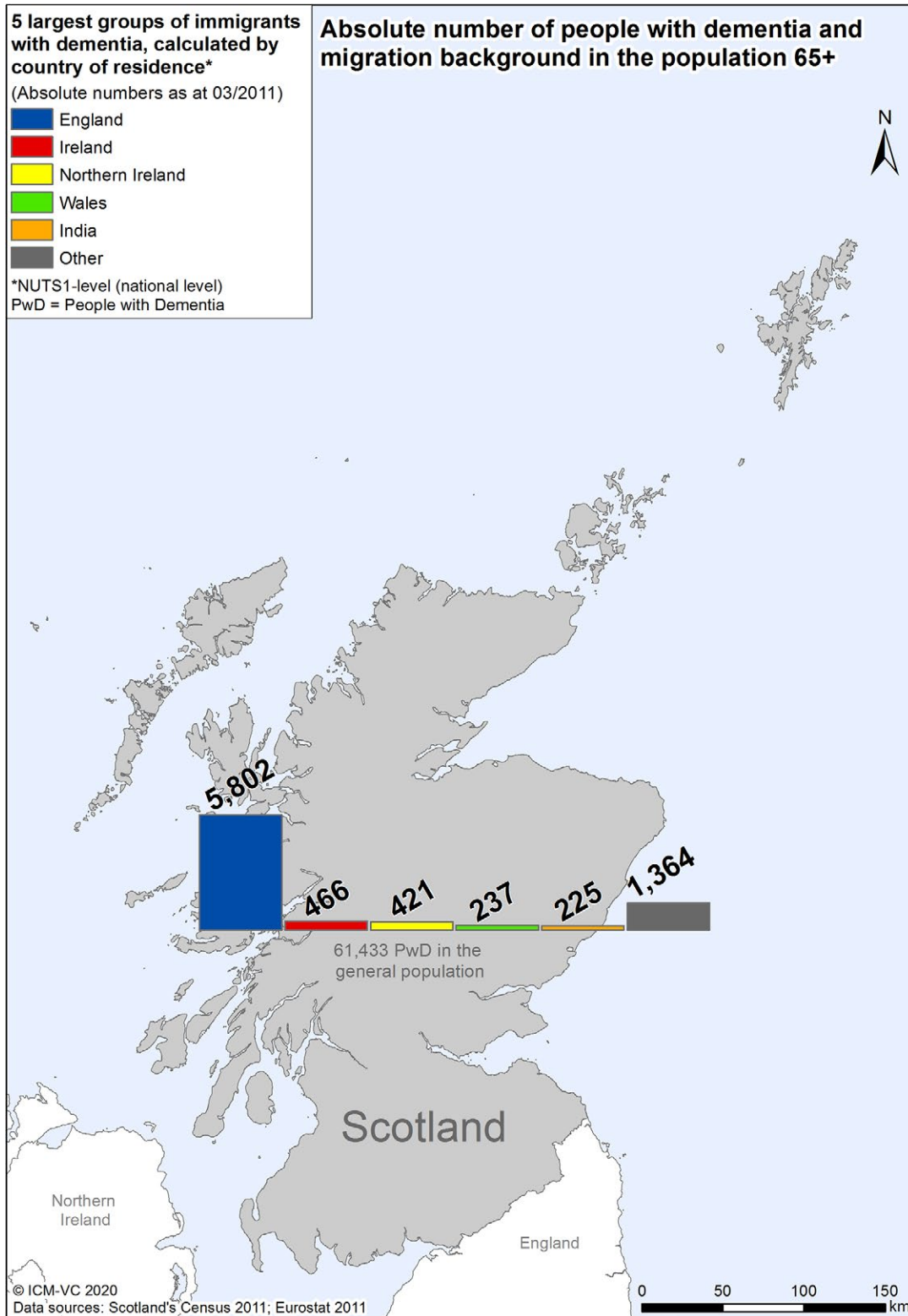


Fig. 3.7.32.12: Absolute number of PwM with dementia aged 65+ (Scotland – Nation)



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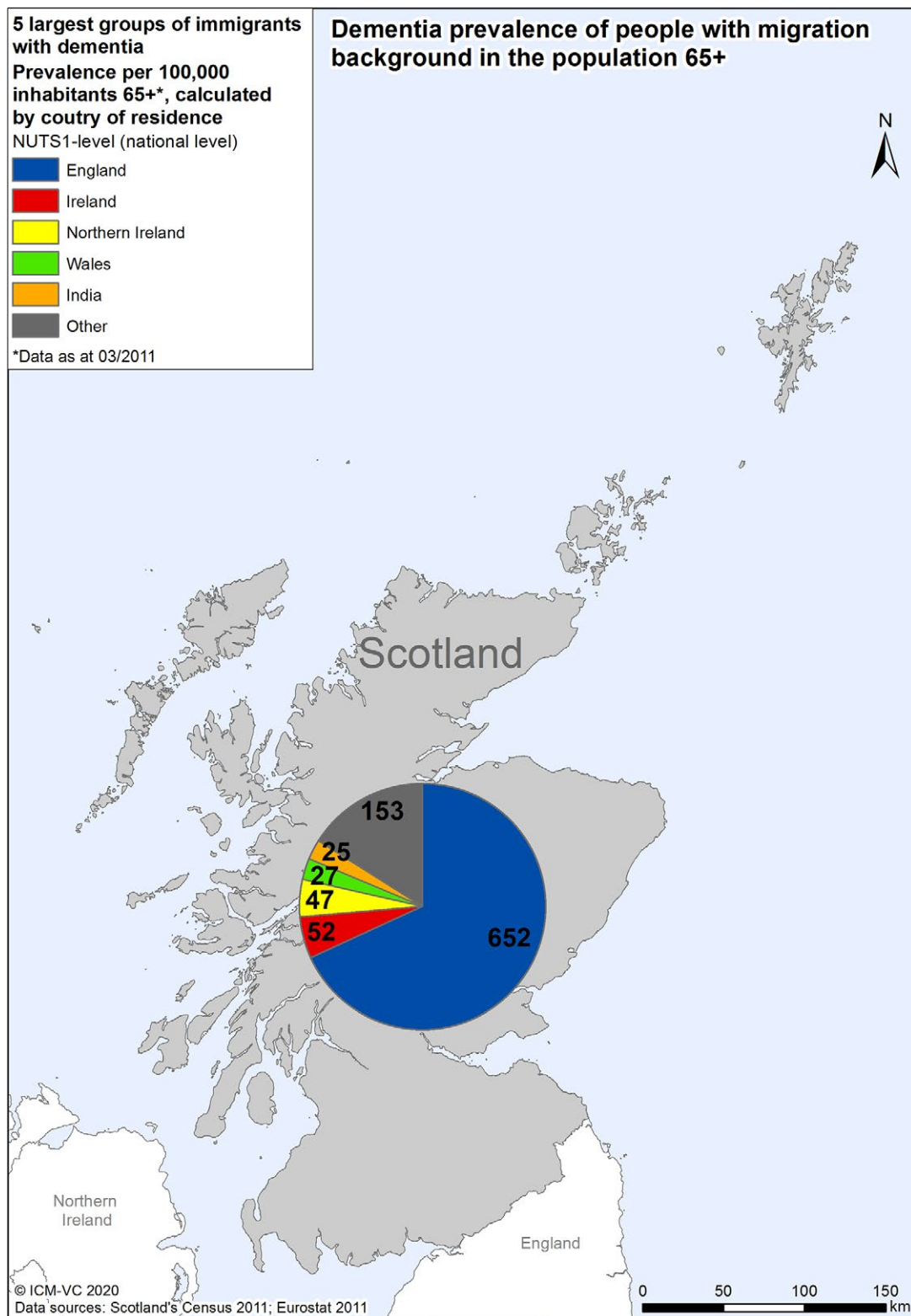


Fig. 3.7.32.13: Prevalence of PwM with dementia among the population aged 65+ (Scotland – Nation)



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).



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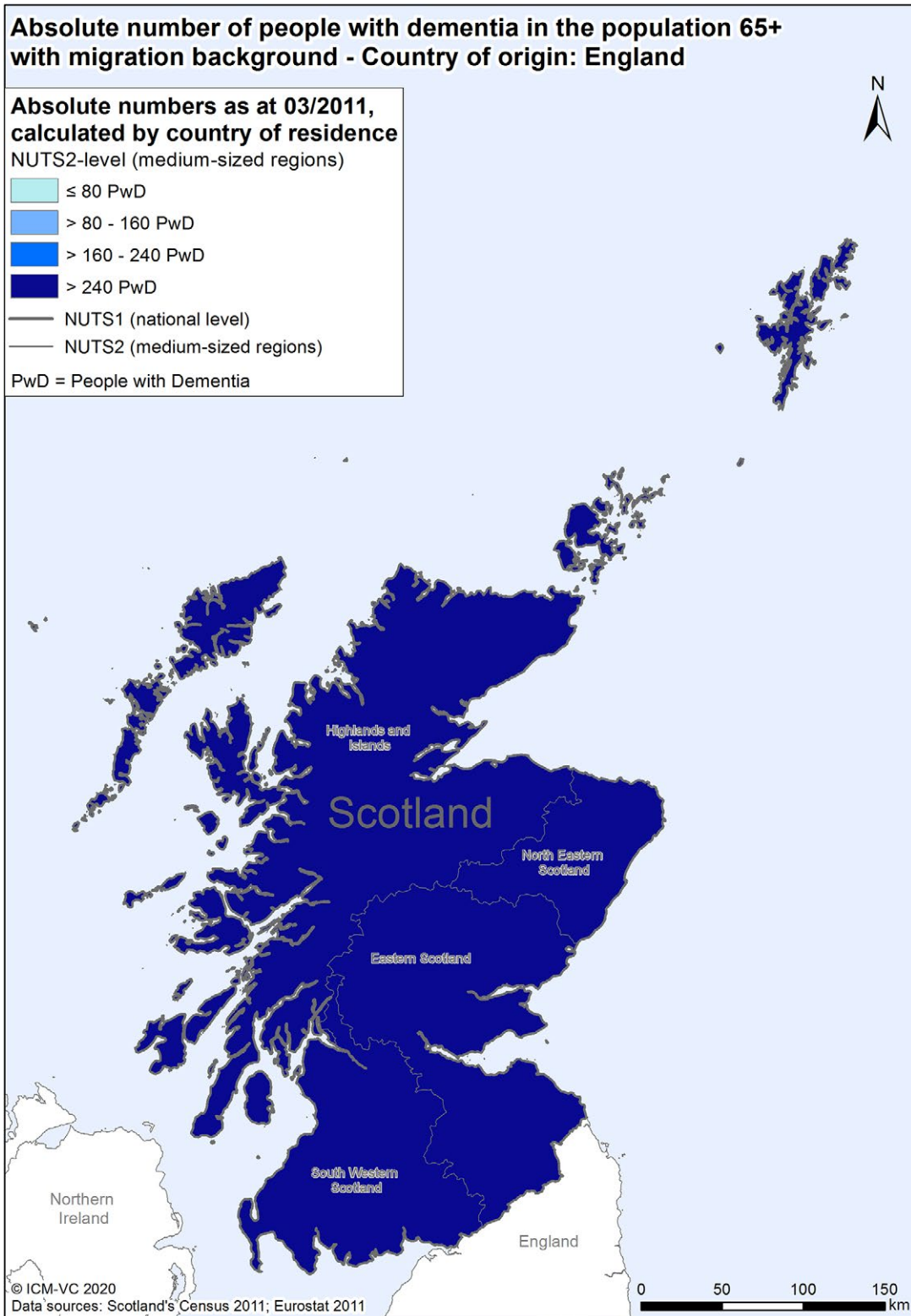


Fig. 3.7.32.14: Absolute number of PwM with dementia aged 65+. Country of origin: England (Scotland – NUTS2)



Fig. 3.7.32.15: Absolute number of PwM with dementia aged 65+. Country of origin: Ireland (Scotland – NUTS2)



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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].

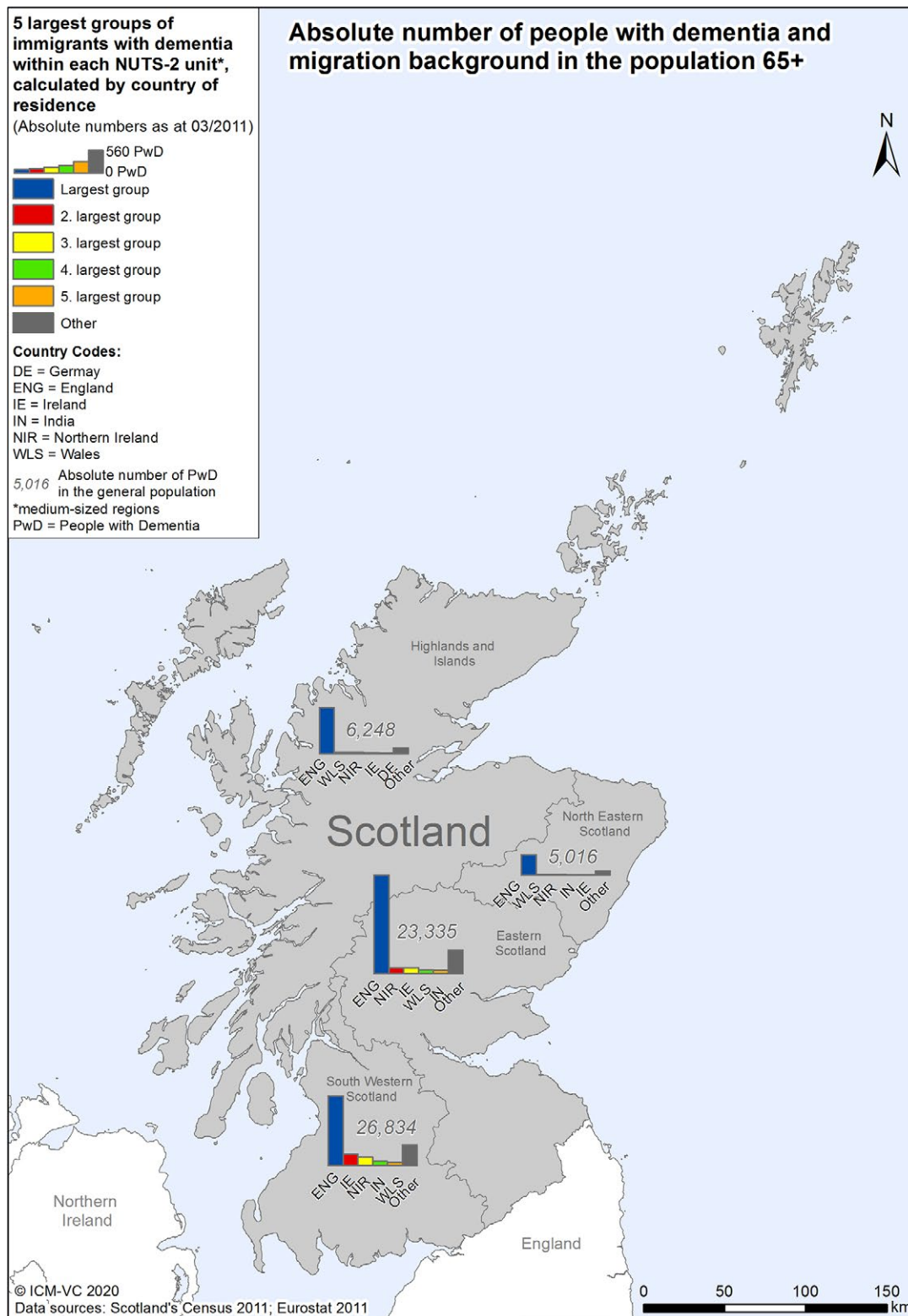


Fig. 3.7.32.20: Absolute number of PwM with dementia aged 65+ (Scotland – NUTS2)

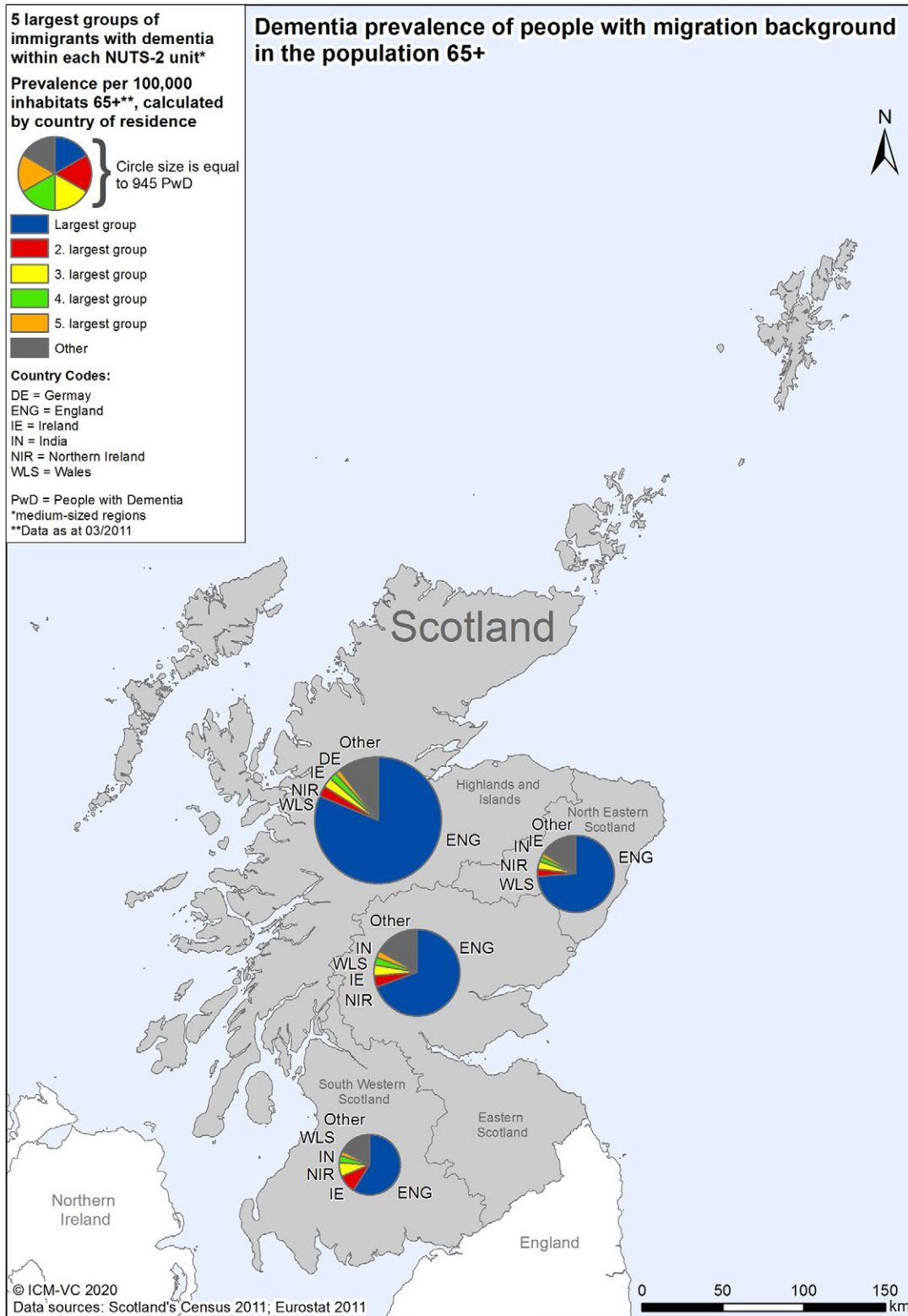


Fig. 3.7.32.21: Prevalence of PwM with dementia among the population aged 65+ (Scotland – NUTS2)



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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

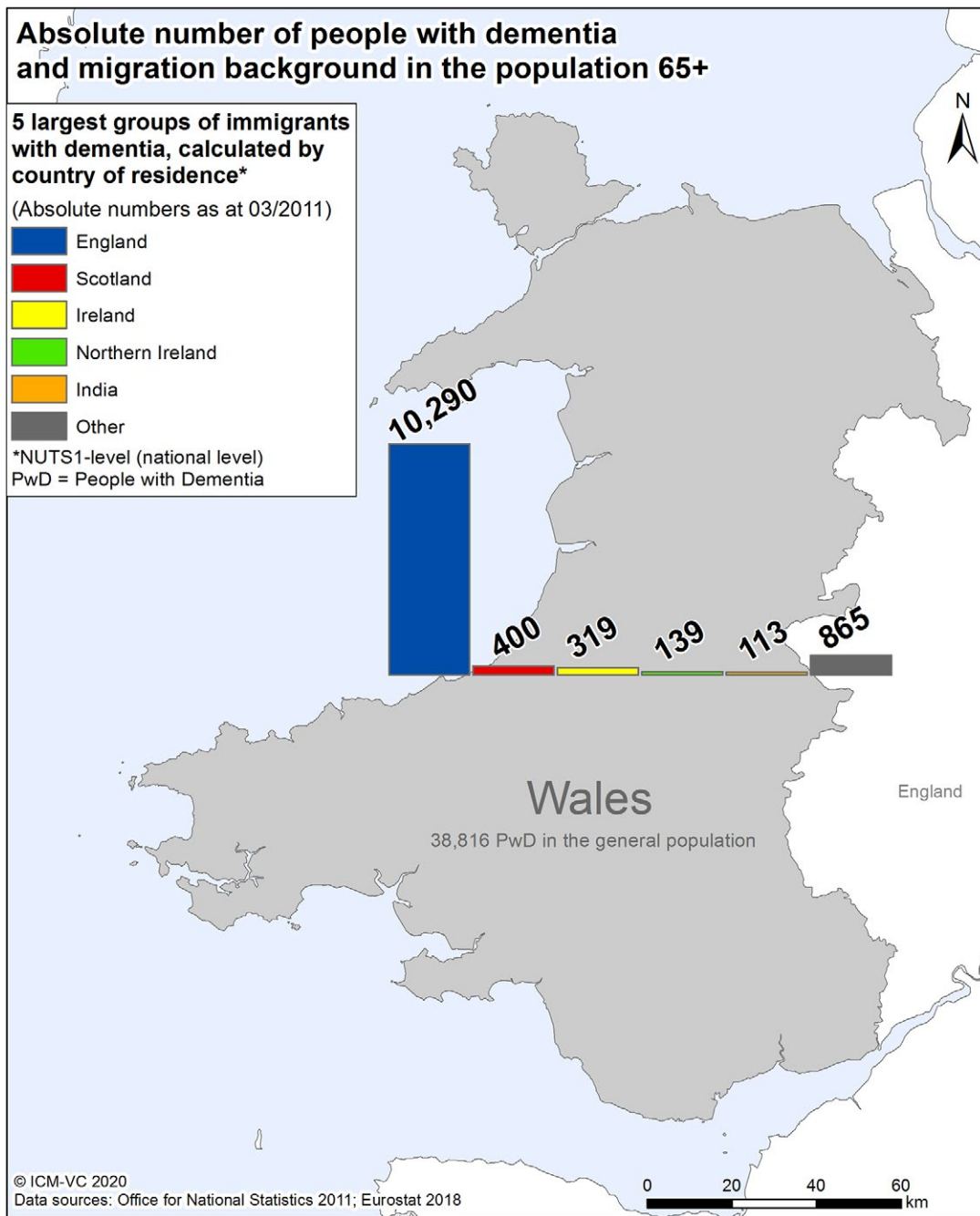


Fig. 3.7.32.22: Absolute number of PwM with dementia aged 65+ (Wales – Nation)

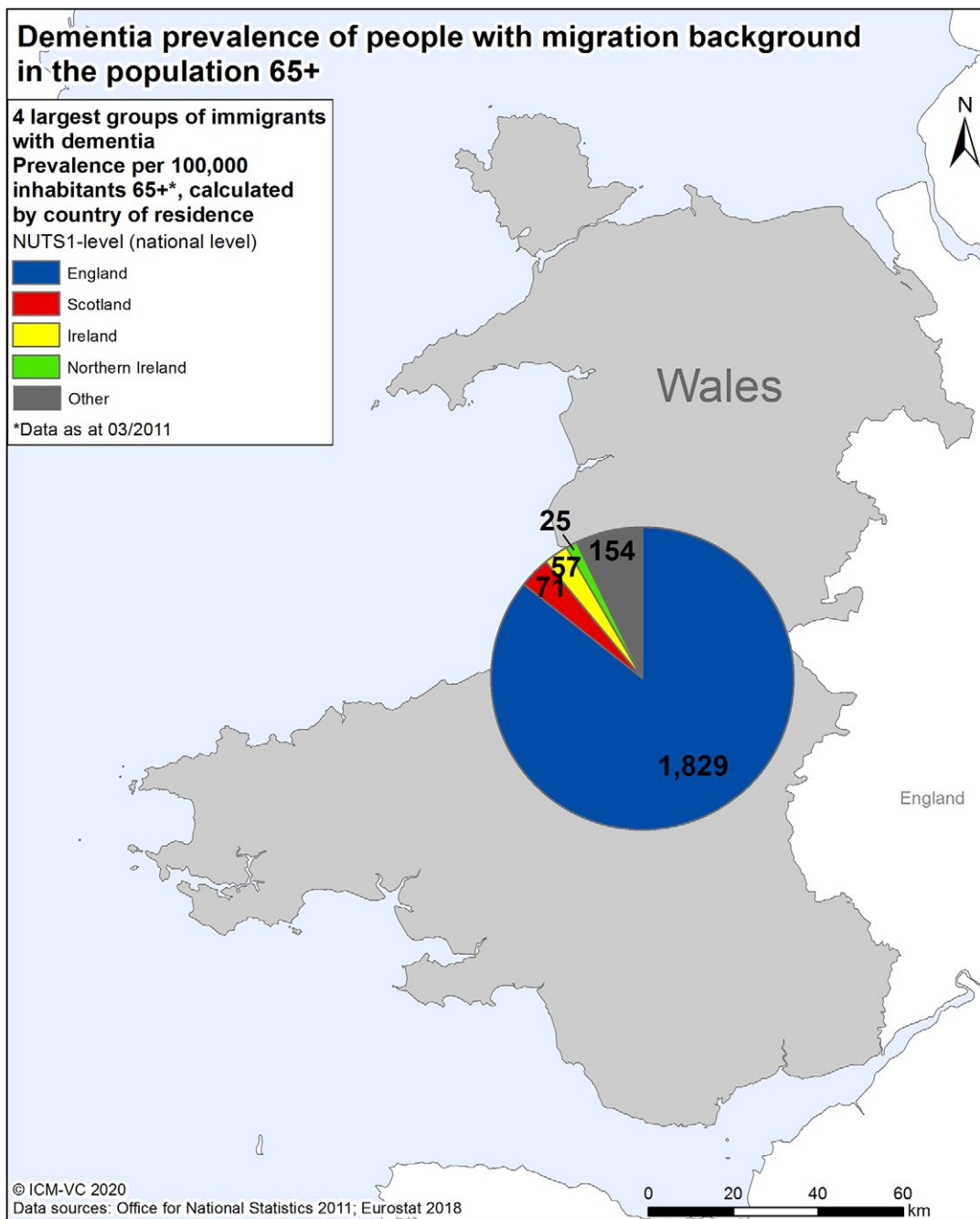


Fig. 3.7.32.23: Prevalence of PwM with dementia among the population 65+ (Wales – Nation)



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).

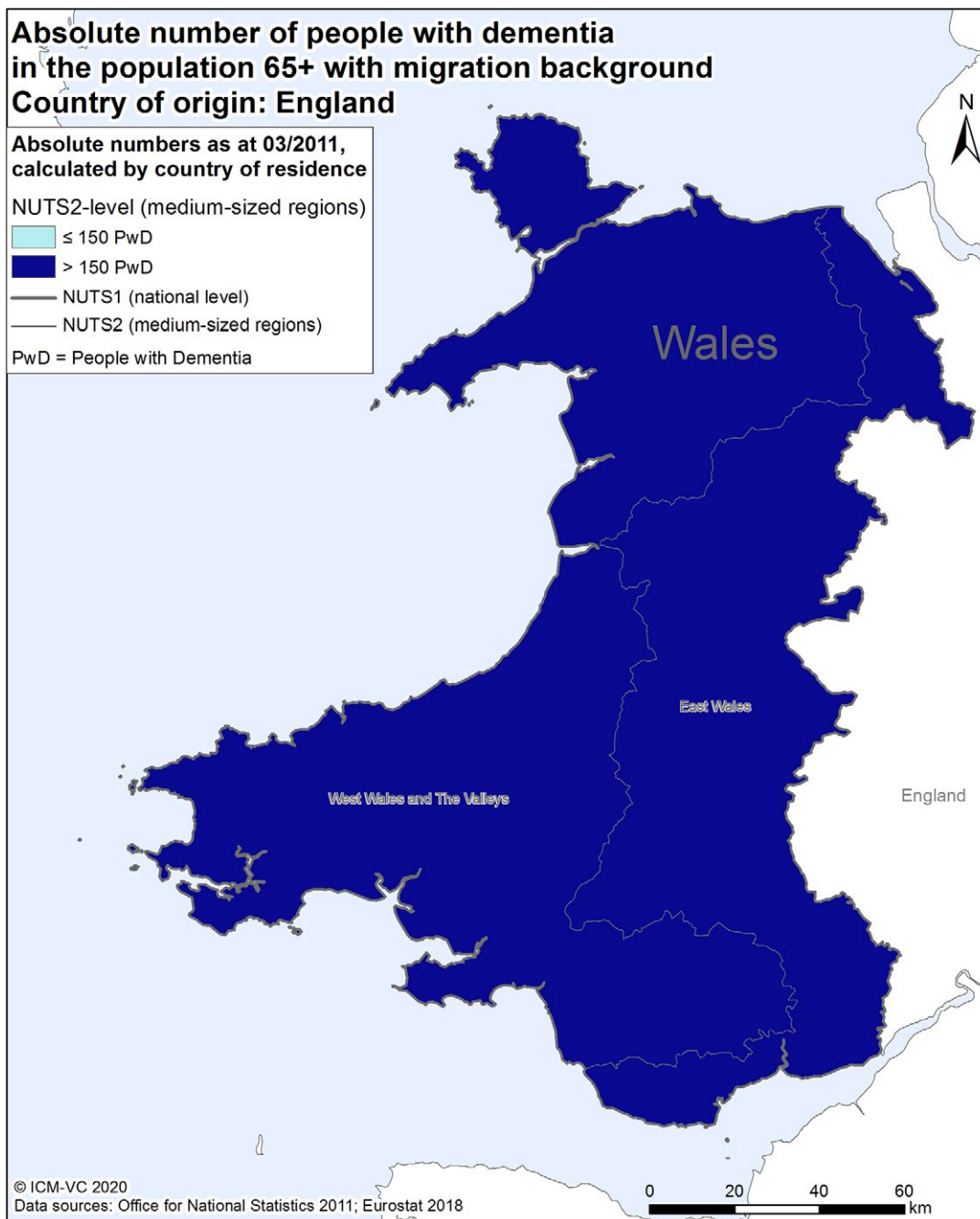


Fig. 3.7.32.24: Absolute number of PwM with dementia aged 65+. Country of origin: England (Wales – NUTS2)

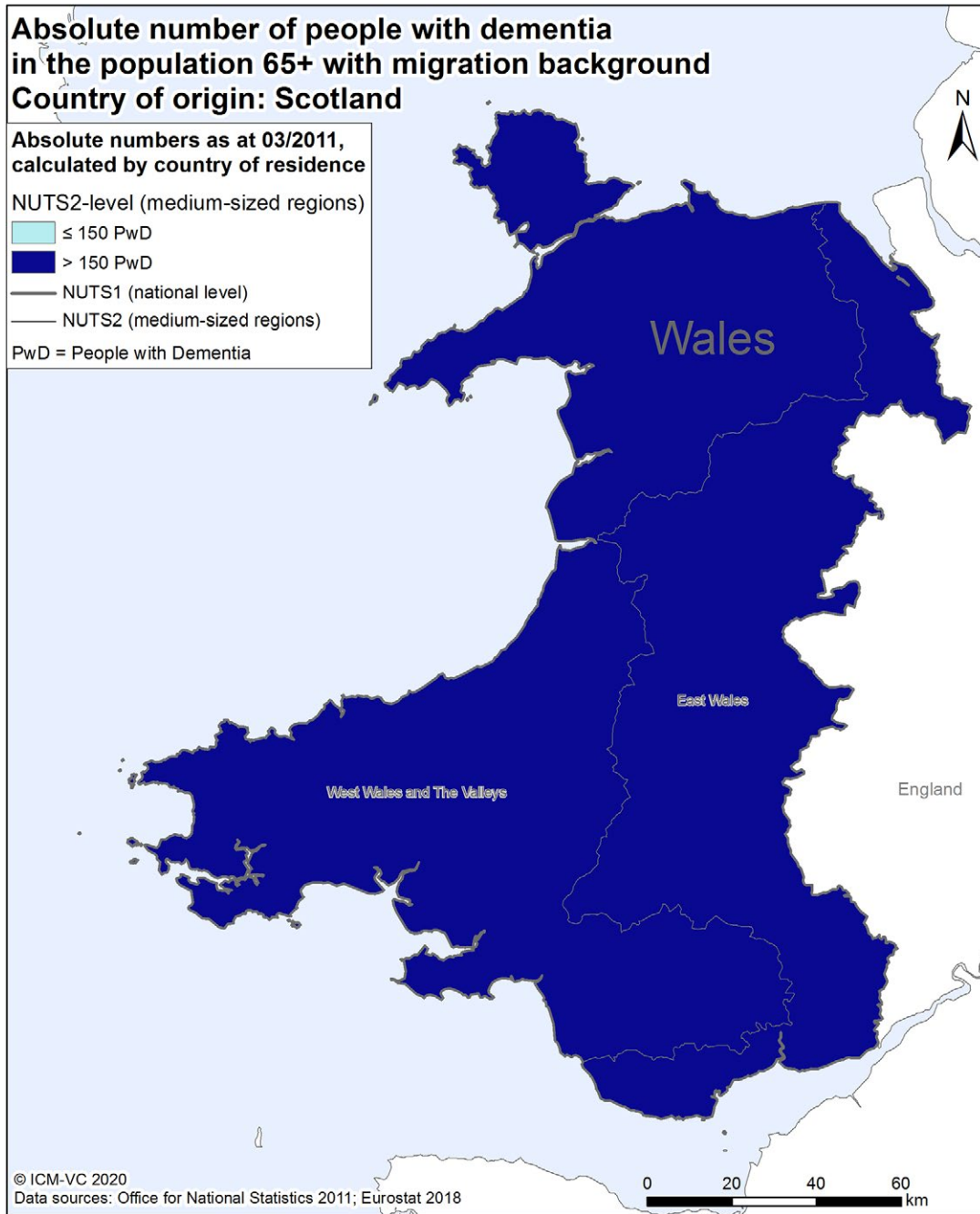


Fig. 3.7.32.25: Absolute number of PwM with dementia aged 65+. Country of origin: Scotland (Wales – NUTS2)

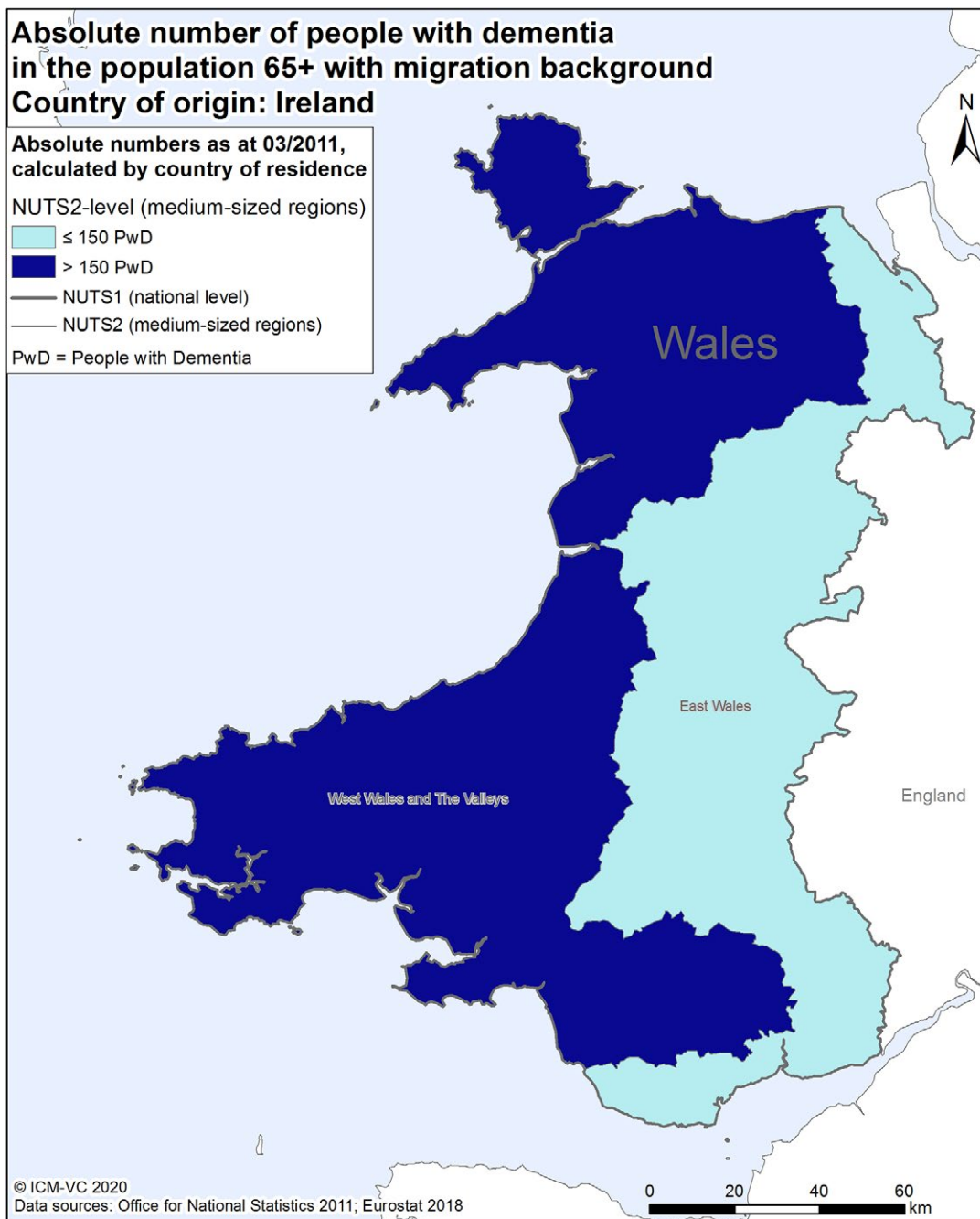


Fig. 3.7.32.26: Absolute number of PwM with dementia aged 65+. Country of origin: Ireland (Wales – NUTS2)

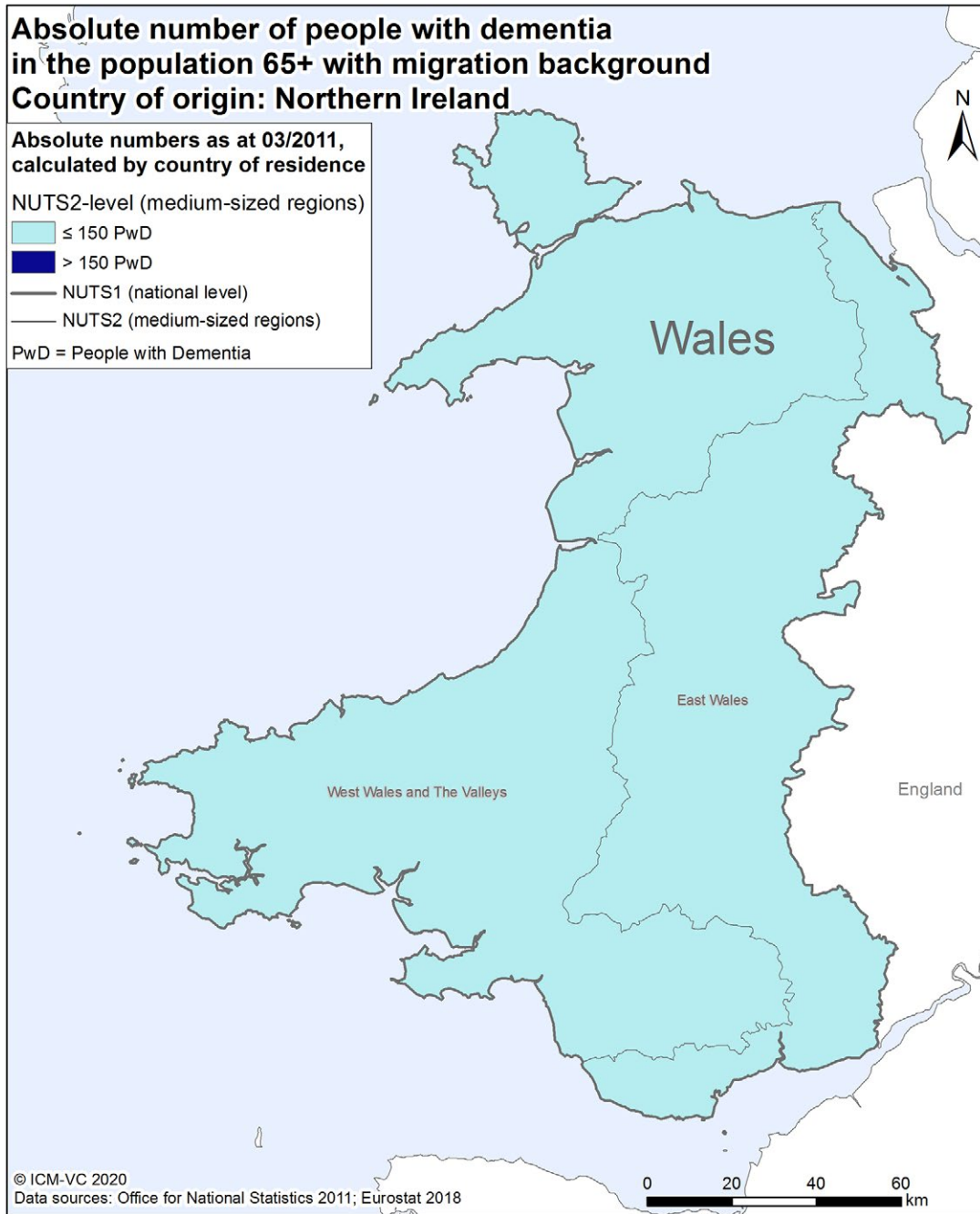


Fig. 3.7.32.27: Absolute number of PwM with dementia aged 65+.
 Country of origin: Northern Ireland (Wales – NUTS2)

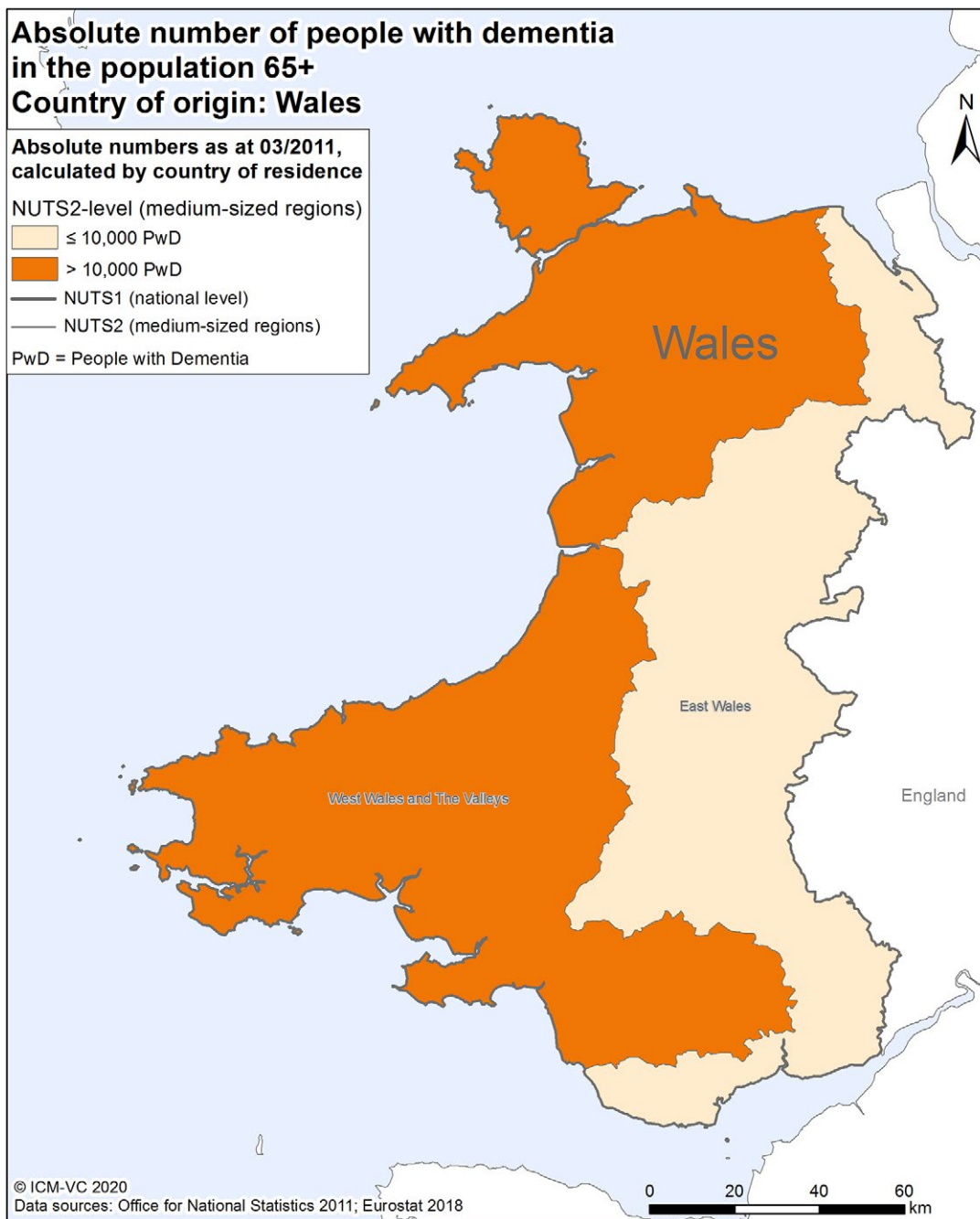


Fig. 3.7.32.28: Absolute number of people with dementia aged 65+. Country of origin: Wales (Wales – NUTS2)



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].

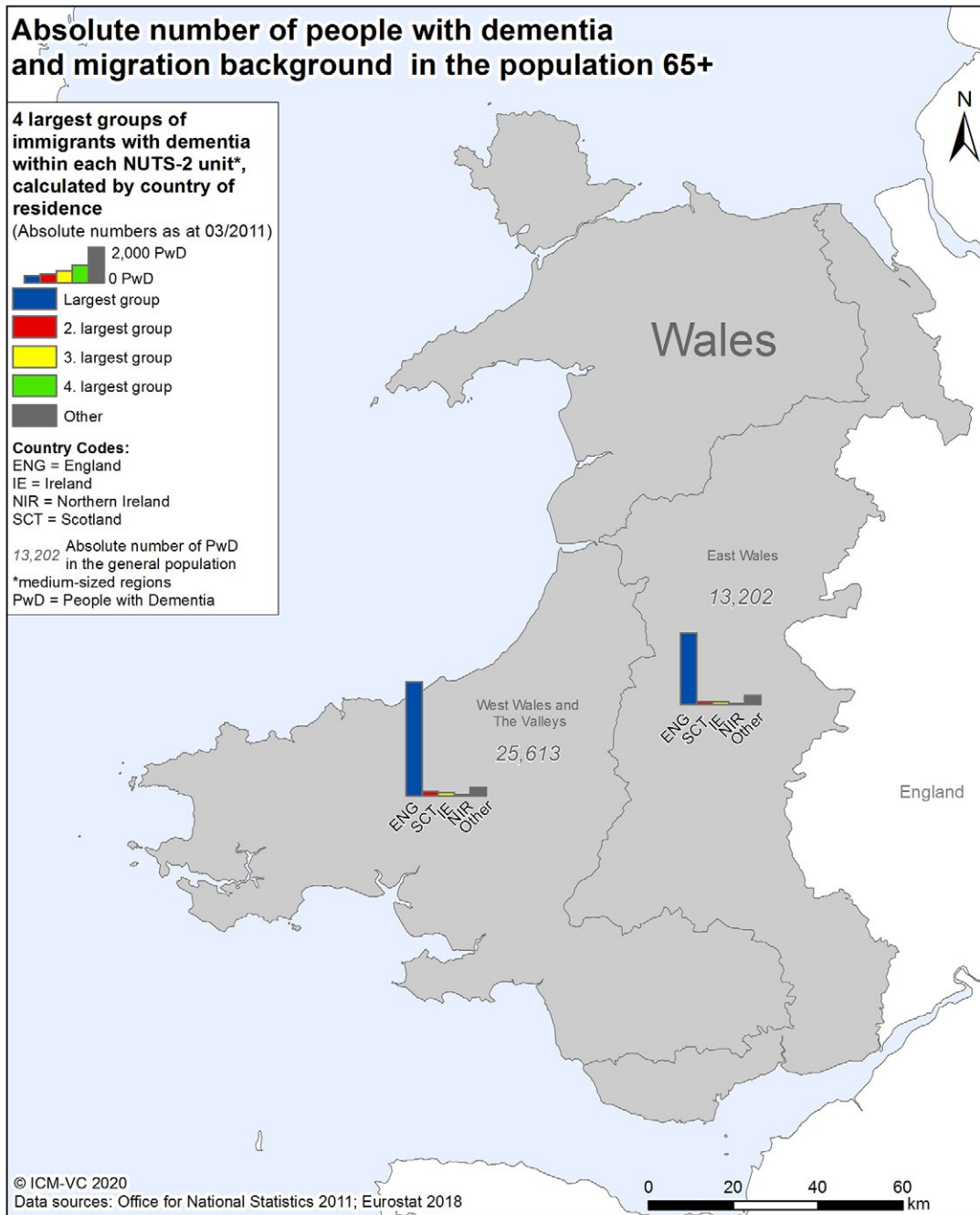


Fig. 3.7.32.29: Absolute number of PwM with dementia aged 65+ (Wales – NUTS2)

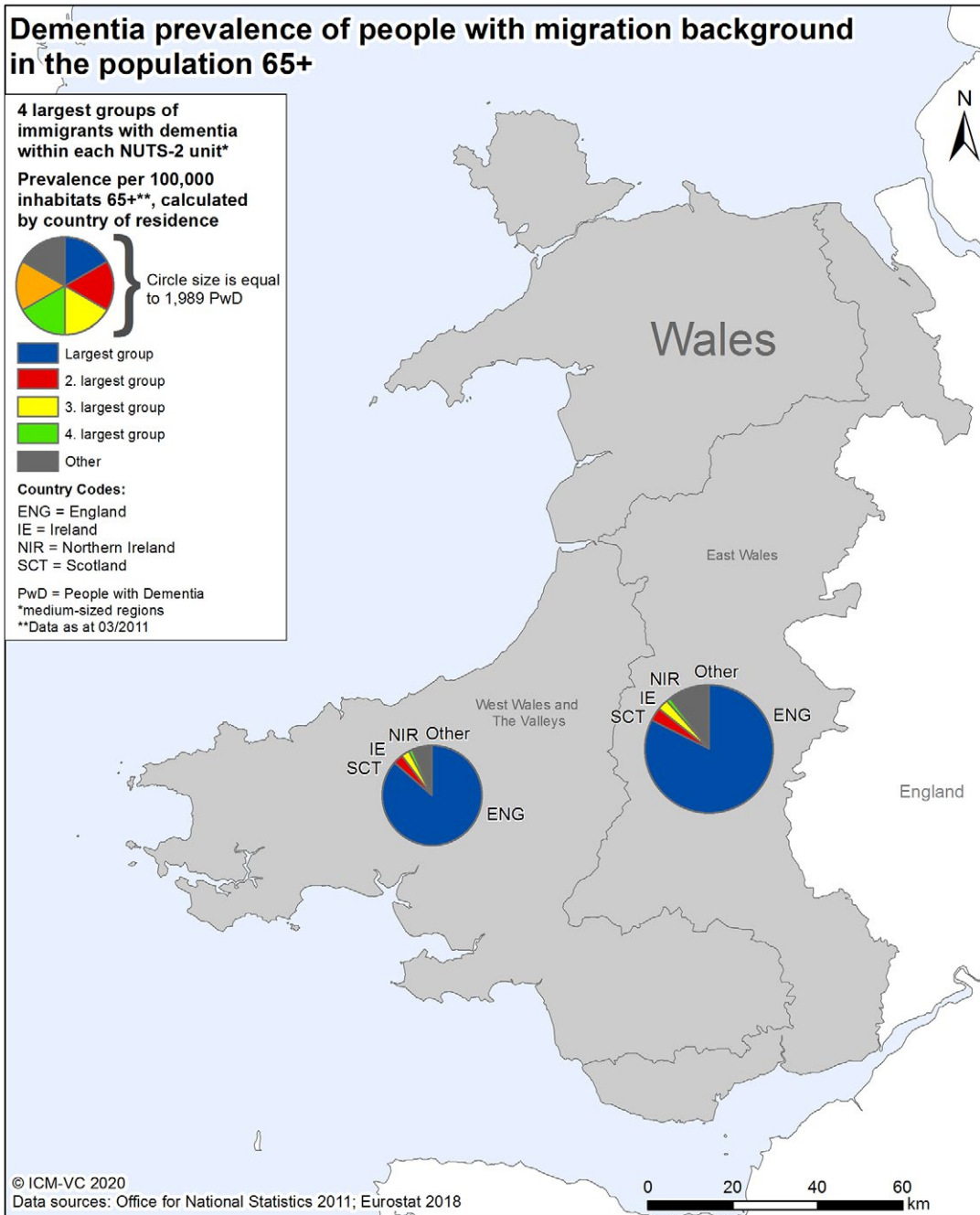


Fig. 3.7.32.30: Prevalence of PwM with dementia among the population aged 65+ (Wales – NUTS2)



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



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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

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].

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