

Large-scale epidemiological data on cardiovascular diseases and diabetes in migrant and ethnic minority groups in Europe

Snorri B. Rafnsson, Raj S. Bhopal

Background: Data on differences by ethnicity in cardiovascular diseases (CVDs) and diabetes, reflecting the influence of diverse cultural, social and religious factors, are important to providing clues to disease aetiology and directing public health interventions and health care resources. **Methods:** Through a network of European public health researchers and searches of bibliographic databases and internet sites, we determined the availability and characteristics of ethnically relevant data on mortality and morbidity from coronary heart disease (CHD), stroke and diabetes, in current European Union countries; data from the four countries comprising the UK were assessed separately. **Results:** In total, 25 countries had one or more relevant data sets (72 in total); however, two-thirds ($n=47$) of the data sources came from only eight Nordic and Western European countries. For several countries, no data could be identified. Ethnically relevant, national death registers were available in 24 countries. Country of birth was the most common indicator of ethnicity. Data on CHD, stroke and diabetes morbidity among migrant and ethnic minority populations are currently scarce; both between and within countries, there are important differences in how ethnicity as well as disease outcomes are defined and measured which limits data comparability. **Conclusion:** Reliable routine data are key to evidence-based public health policies at both national and EU level. EU countries have a relatively weak base for assessing needs and planning health care interventions for its migrant and ethnic minority populations. The lack of ethnically relevant data on CVD and diabetes across the EU needs to be addressed urgently.

Keywords: cardiovascular diseases, diabetes mellitus, data collection, ethnic groups, European Union.

Introduction

Chronic diseases, including cardiovascular diseases (CVDs) and diabetes, are currently the major causes of morbidity and mortality in Europe. In the EU Member States, almost 2 million deaths are attributed to CVD every year; ~50% are from coronary heart disease (CHD) and ~25% are from stroke.¹ Diabetes is a major risk factor for CVD which affects over 48 million adults in Europe¹ and is increasing in prevalence.

These burden of disease estimates are likely to mask important differences in mortality and morbidity between different population groups within regions and countries, including migrant and ethnic minority groups. Significant changes in the ethnic composition of Europe have already taken place following substantial emigration and immigration throughout the 20th century, undoubtedly affecting the epidemiology of chronic diseases and their determinants.^{2,3} In fact, the increasing burden of chronic diseases, especially CVD and diabetes, in migrant and ethnic minority populations, is a major public health challenge for European countries.² For example, epidemiological studies conducted in a few EU countries have shown that, depending on their country of origin and ethnic background, some groups experience greater risks of mortality or morbidity from CVD^{4–10} and diabetes^{11–15} compared with the European White populations in these countries.

Ethnicity has been used as a variable for describing differences in population characteristics and disease experiences.¹⁶ Differences by ethnicity in CVD and diabetes are likely to reflect complex influences of diverse cultural, social and religious exposures which in turn affect risk factors for disease, such as lifestyle, dietary and health practices.^{17–19} Given an appropriate understanding of variations by ethnicity in health behaviours and beliefs, data on ethnic differences in disease can provide aetiological clues and help direct public health interventions and health care resources.²⁰ However, comparable, routine health data for migrant and ethnic groups have not been collected systematically at a European level.^{21,22} Limitations of existing data include incompleteness and inconsistency in ethnic-group coding.²³ A major ongoing challenge for the European public health community is to fill in the current gap in the availability of comparable, ethnicity-specific data on the burden of CVD, diabetes and other major diseases.^{24–26}

The 'Monitoring the health status of migrants within Europe: development of indicators' (acronym MEHO i.e. Migrant and Ethnic Health Observatory) is a European collaborative project, funded by the European Commission, which started in 2007 (project website: www.meho.eu.com). Major objectives of the individual project Work Packages include the mapping of available data sources across EU Member States and the development of ethnicity-specific health indicators for five independent health areas, including CVD and diabetes. Specific Work Packages have the role of examining self-perceived health of ethnic groups in Europe and evaluating the variables and relevant criteria used for defining these in different EU countries. Here we present results from the Work Package on CVD and diabetes. Our aim was to identify ethnicity-specific data on mortality and morbidity from CHD, stroke and diabetes in the EU countries and appraise the information collected in different data sets, while focusing on the types of indicators used for determining ethnicity.

Public Health Sciences Section, The Centre for Population Health Sciences, University of Edinburgh, Edinburgh, Scotland, UK

Correspondence: Snorri B. Rafnsson, Public Health Sciences Section, The Centre for Population Health Sciences, University of Edinburgh, Teviot Place, Edinburgh EH8 9AG, Scotland, UK, tel: +44 (0) 131 650-3201, fax: +44 (0) 131 650-6904, e-mail: S.B.Rafnsson@ed.ac.uk

Methods

Search strategy

Network of collaborators

European researchers interested in the health of migrant and ethnic minority groups were recruited to a network (MEHO-CVD) to assist with identifying available data sources. Recruitment was based on: personal contacts; a call for collaboration published in the newsletter of the European Public Health Association; a call for collaboration to members of the European Heart Network; members in other related EU-funded health indicator projects; including delegates attending MEHO conference workshops. The members are listed in the Acknowledgements section.

Data inventory

A data collection form was sent to all network members asking about: the availability and types of data on CVD and diabetes mortality and morbidity; CVD and diabetes indicators in different data sets; ethnic groups included in existing data sets as well as the methods used for measuring ethnicity.

Bibliographic databases

We performed a bibliographic search of MEDLINE and EMBASE from inception to January 2008 using the following terms and their combinations: 'ethnicity', 'immigrants', 'migrants', 'minority', 'cardiovascular diseases', 'coronary heart disease', 'myocardial infarction', 'angina', 'stroke', 'diabetes' (EU country names were also included in the search with the four countries forming the UK i.e. England, Wales, Northern Ireland and Scotland considered individually).

Internet sources

The following EU-level databases were searched: WHO Mortality Database; WHO Health for All Database; EUROSTAT; OECD Health Data; WHO MONICA Study; International Diabetes Federation's Diabetes Atlas; British Heart Foundation Statistics. Websites of offices of national statistics and health departments were also examined as were the following resources: national health interview and examination surveys;²⁷ general practice surveillance networks;^{28,29} CVD cohort studies.²⁶ Finally, we performed a Google search using the following terms and their combinations for each country at a time: 'hospital discharge register', 'diabetes incidence', 'diabetes prevalence', 'myocardial infarction incidence', 'myocardial infarction prevalence', 'stroke incidence', 'stroke prevalence', 'sentinel general practice network', 'diabetes register', 'myocardial infarction register', 'stroke register'.

Data selection and extraction

No universally agreed operational definitions exist for categorising ethnic minority groups. The following definitions were adopted for the specific needs of the MEHO project which mainly focuses on socio-economically disadvantaged groups: a *migrant* is any person who migrated to the current EU countries from outside the EU-15 Member States (before the expansion of the EU in 2004), while further excluding North America and Australasia but including the post-World War II guest workers from the European periphery (e.g. Turkey) and re-settlers from the former countries of the Soviet

Union, *and* is staying in the destination country as a resident (not a visitor, asylum seeker, temporary worker or student). *Ethnic group*, which is the social group a person belongs to, and either identifies with or is identified with by others as a result of a mix of cultural and other factors including language, diet, religion, ancestry and physical features, was defined based on one or more of the following: self-identification; country of birth of one of the parents and/or the person; nationality or citizenship; last name/characteristic name; religion; language spoken. In the MEHO project, those groups that do not comprise the majority population of the country, or a sub-set of the majority, are considered to be ethnic minorities. Only data sets containing information on migrant and ethnic minority groups meeting the above definitions were included. Also, the data inclusion criteria were based on whether clear information was available on any disease outcomes and the population coverage of the data set.

We extracted the following information from all relevant sources: country; data type; area coverage; ethnic group; methods for measuring ethnicity; CVD and diabetes health status indicators; disease assessment method; availability of data on potential confounding factors. As only anonymized data sources have been examined in this study there were no ethical issues.

Results

Overview

Of the 30 countries assessed, 25 had data sets containing ethnicity-specific information on one or more CVD and diabetes mortality and morbidity indicators (Table 1). Ten Western European countries, seven Central and Eastern European countries, five Southern European countries and three Nordic countries, had one or more relevant data sets (72 in total). A total of 41 individual data sets were identified in Western Europe, 14 in the three Nordic EU member countries, 10 in Southern Europe and 7 in the Central and Eastern European region.

Mortality data

National mortality registers with ethnicity-specific data were identified in 24 countries (Table 2). This included data based on death certificates or those available through linking mortality data with population data. Considerable heterogeneity existed in the measures of ethnicity available in different countries. Country of birth was the most commonly reported indicator and was available in 15 countries. Nationality and/or citizenship were recorded in 15 countries. All countries collected additional data on sociodemographic factors although substantial differences existed between countries regarding the details of the available information. Apart from Greece, all countries used the 10th version of the ICD classification system, and collected data on CHD, stroke and diabetes, thus allowing comparable coding of cause-specific mortality across countries.

Population-based registers and hospital episode data

We located relevant data in six countries (Table 3). Apart from Sweden, England and Scotland, we identified one set of data in each of the other three countries. Disease-specific, population-based, registers were available in Germany, England, Scotland and Sweden. Also, both Denmark and Sweden had national, population-based, registers on the basis of linked routine data, such as population registers or censuses and national registers of hospital discharges and

Table 1 Summary of migrant and ethnic group-specific data on CVD and diabetes mortality and morbidity by country

Country	Number of data sources	Data type ^a	Ethnic minority group ^b	Ethnicity measurement proxy ^c	Cause of death ^d	Disease outcome ^e	Sociodemographic factors ^f
Austria	1	1	Not reported	2, 3	1, 2, 3	Not available	1, 2, 5, 6
Belgium	2	1, 4	Not reported	4	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
Bulgaria	0	Not available	Not available	Not available	Not available	Not available	Not available
Cyprus	1	1	Not reported	4	1, 2, 3	Not available	1, 2
Czech Republic	1	1	Not reported	5	1, 2, 3	Not available	1, 2, 4, 5
Denmark	5	1, 3, 4	1, 5, 6	2, 3, 5	1, 2, 3	1, 2, 3	1, 2, 3, 6
Estonia	1	1	6	1	1, 2, 3	Not available	1, 2, 4, 5, 6
Finland	1	1	Not reported	2, 4	1, 2, 3	Not available	1, 2, 5
France	5	1, 4	4	2, 4	1, 2, 3	1, 2, 3	1, 2, 3, 4, 6
Germany	3	1, 3, 4	6	2	1, 2, 3	1, 3	1, 2, 5, 6
Greece	1	1	Not reported	5, 7	1, 2, 3	Not available	1, 2, 5, 6
Hungary	1	1	Not reported	5	1, 2, 3	Not available	1, 2, 3, 5, 6
Ireland	0	Not available	Not available	Not available	Not available	Not available	Not available
Italy	3	1, 2, 4	Not reported	2, 5	1, 2, 3	1, 2, 3	1, 2, 4, 5, 6
Latvia	1	1	Not reported	5	1, 2, 3	Not available	1, 2, 5
Lithuania	0	Not available	Not available	Not available	Not available	Not available	Not available
Luxembourg	1	1	Not reported	4	1, 2, 3	Not available	1, 2, 5, 6
Malta	0	Not available	Not available	Not available	Not available	Not available	Not available
Netherlands	8	1, 4	3, 4, 5, 7	1, 2, 3	1, 2, 3	1, 2, 3	1, 2, 5, 6
Poland	0	Not available	Not available	Not available	Not available	Not available	Not available
Portugal	3	1, 4	3, 4	2, 3	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
Romania	1	1	6, 7	4	1, 2, 3	Not available	1, 2
Slovakia	1	4	7	Not reported	Not available	1, 2, 3	1, 2, 4, 6
Slovenia	1	1	Not reported	2, 5	1, 2, 3	Not available	1, 2, 4, 5
Spain	2	1, 4	3, 4, 7	2	1, 2, 3	3	1, 2, 3, 5
Sweden	8	1, 2, 3, 4	5, 7	2, 6	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
UK-England	13	1, 3, 4	1, 2, 4, 5, 7	1, 2, 3, 6, 7	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
UK-Wales	2	1, 4	1, 2, 3, 4, 7	1, 2	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
UK-N. Ireland	2	1, 4	1, 2, 3, 4, 7	1, 2	1, 2, 3	1, 2, 3	1, 2, 3, 4, 5, 6
UK-Scotland	4	1, 2, 3, 4	1, 2, 4, 5, 7	1, 2	1, 2, 3	1, 2, 3	1, 2, 3, 5, 6

a: 1 = Mortality records; 2 = hospital episode records; 3 = population-based register; 4 = surveys/ad hoc studies.

b: 1 = South Asian (Indian, Pakistani, Bangladeshi and Sri Lankan); 2 = other Asian; 3 = Latin American; 4 = African; 5 = Turkish/Middle Eastern; 6 = Eastern European/Baltic; 7 = other ethnic group.

c: 1 = Self-reported; 2 = country of birth; 3 = parents/grandparents country of birth; 4 = nationality; 5 = citizenship; 6 = name; 7 = religion; 8 = other.

d: 1 = CHD; 2 = stroke; 3 = diabetes.

e: 1 = CHD; 2 = stroke; 3 = diabetes.

f: 1 = Age; 2 = sex; 3 = SES; 4 = education; 5 = marital status; 6 = other.

Table 2 Countries with national-level migrant and ethnic group-specific death registers

Country	Record collection period	Ethnicity measurement proxy ^a	Sociodemographic factors ^b	Latest ICD version	MEHO-CVD relevant causes of death (ICD codes)
Austria	Before 1990—present	2, 4	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Belgium	Before 1990—present	4	1, 2	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Cyprus	From 2000—present	4	1, 2	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Czech Republic	Before 1990—present	5	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Denmark	Before 1990—present	2, 5	1, 2, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Estonia	Before 1990—present	1	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Finland	Before 1990—present	2, 4, 8	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
France	Before 1990—present	2	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Greece	Before 1990—present	5	1, 2, 3, 4	ICD-9	CHD (410–414); stroke (430–438); diabetes (250)
Germany	From 1990—present	2	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Hungary	Before 1990—present	5	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Italy	Before 1990—present	2, 5	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Latvia	From 1990—present	2, 5	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Luxembourg	Before 1990—present	4	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Netherlands	Before 1990—present	2	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Portugal	Before 1990—present	2, 5	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Romania	From 2000—present	4	1, 2	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Slovenia	From 2000—present	2, 5	1,2,3,4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Spain	From 2000—present	4	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
Sweden	Before 1990—present	2	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
UK-England	Before 1990—present	1, 2	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
UK-Wales	Before 1990—present	1, 2	1, 2, 3	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
UK-N.Ireland	Before 1990—present	1, 2	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)
UK-Scotland	Before 1990—present	2, 8	1, 2, 3, 4	ICD-10	CHD (I20–I25); stroke (I60–I69); diabetes (E10–E14)

a: 1 = Self-reported; 2 = country of birth; 3 = parents/grandparents country of birth; 4 = nationality; 5 = citizenship; 6 = name; 7 = religion; 8 = other.

b: 1 = Age; 2 = Sex; 3 = marital/family status; 4 = other.

death records. For five data sets we were unable to verify the type of ethnic group for which data were collected. We also observed important differences regarding the recording of ethnicity and disease outcomes between countries and registers. For example, self-reported ethnicity was available in two countries, country of birth also in two countries and parents/grandparents country of birth in one country. Data on CHD were collected in all countries, and data on stroke and diabetes in five countries. All registers in all countries collected additional information on age and sex, and commonly on other sociodemographic factors as well.

Four countries had hospital episode registers with national coverage (Table 3). In Italy, for example, the only ethnic group proxy measure available was citizenship. In Scotland, in contrast, coding of ethnic group on hospital discharge records is self-reported (although very incomplete) and based on the ethnicity categories used in the 2001 census. Data sets contained information on CHD, stroke and diabetes (Italy only) as well as various sociodemographic characteristics.

Health surveys and epidemiological studies

Nine countries had ethnicity-specific health survey data (Table 4). Nationally representative health examination surveys were available in England, France and Scotland. Each survey employed different measures of ethnicity. Also, whereas both the Health Survey for England and Scotland collected information on CHD, stroke and diabetes, the French Health Examination Survey 2006 examined only the prevalence of diabetes. Similarly, we located nationally representative, health interview surveys in Belgium, Denmark, England, France, Italy, Northern Ireland, Portugal and Wales. Most collected information on country of birth. The three UK-based surveys included information on self-reported ethnicity. Also, all surveys gathered self-reported information on CHD and/or diabetes; history of stroke was also recorded in the surveys from Belgium, France, Northern Ireland,

Portugal and Wales. Information on a wide range of socio-demographic factors was available in all the surveys.

Epidemiological studies were located in Germany, the Netherlands, Sweden and England and Wales (Table 4). Of these, only the Dutch National Survey on Morbidity Interventions in General Practice was nationally representative. In three out of the seven studies ethnicity was determined by self-report; five studies collected information on country of birth and/or the study subject's parents or grandparents. In total, six studies collected information on CHD, three on stroke and eight on diabetes. Considerable differences were observed between studies regarding disease diagnostic methods; clinical history/diagnosis was used in four studies whereas four studies applied specific criteria for assigning case status, including self-reported illness.

Discussion

There are large differences regarding the availability, type and quality of ethnicity-specific data on CVD and diabetes, both between and within EU countries. For example, of the 72 individual data sets that were identified, almost two-thirds (47 in total) came from only 8 Nordic and Western European countries. For several countries, we were unable to find any data, including some that recently have experienced considerable immigration (e.g. Ireland).

There have been long-standing concerns over the quality of available data sources. Data quality, including the completeness of case ascertainment and recording, is a major determinant of their usefulness for health research.^{23,30} Evaluations of the availability and quality of CHD data in the UK²² and of data sources on ethnicity and health in Scotland²⁴ have highlighted the following problems: incompleteness, variability in the use of ethnic coding, lack of training for staff on collecting data on ethnicity and lack of provision within information technology systems for information on ethnicity to be recorded and exchanged.

Table 3 Countries with migrant and ethnic group-specific disease register and secondary care data

Country	Data type	Area coverage	Ethnic minority group ^a	Ethnicity measurement proxy ^b	Disease outcome	Disease assessment method	Sociodemographic factors ^c
Denmark	Population-based register on the basis of linked routine data	Major city/region	1, 5, 6	2, 3	CHD, stroke, diabetes	Clinical diagnosis	1, 2, 3, 6
Germany	Disease-specific population-based register	Local area	Not reported	Not reported	CHD, diabetes	Clinical diagnosis, self-report	1, 2
Italy	Hospital episode records	National	Not reported	5	CHD, stroke, diabetes	Clinical diagnosis	1, 2, 5
Sweden	Population-based register on the basis of linked routine data	National	Not reported	2	CHD, stroke	Clinical diagnosis	1, 2, 3, 6
UK-England	Disease-specific population-based register	Major city/region	Not reported	2, 6	CHD	Clinical diagnosis	1, 2, 6
	Disease-specific population-based register	Major city/region	Not reported	2	Stroke	Clinical diagnosis	1, 2, 3, 5
	Disease-specific population-based register	Local area	1, 2, 4	1	Stroke	Clinical diagnosis	1, 2, 3
	Hospital episode records	National	1, 2, 3, 4, 7	1	CHD, stroke, diabetes	Clinical diagnosis	1, 2, 6
UK-Scotland	Hospital episode records	National	1, 2, 3, 4, 7	1	CHD, stroke	Clinical diagnosis	1, 2, 6
	Disease-specific population-based register	National	1, 2, 3, 4, 7	1	Diabetes	Clinical diagnosis	1, 2, 6

a: 1 = South Asian (Indian, Pakistani, Bangladeshi and Sri Lankan); 2 = other Asian; 3 = Latin American; 4 = African; 5 = Turkish/Middle Eastern; 6 = Eastern European/Baltic; 7 = other ethnic group.

b: 1 = Self-reported; 2 = country of birth; 3 = parents/grandparents country of birth; 4 = nationality; 5 = citizenship; 6 = name; 7 = religion; 8 = other.

c: 1 = Age; 2 = Sex; 3 = SES; 4 = education; 5 = marital status; 6 = other.

As already discussed, the concept of ethnicity implies shared origins or social background, distinctive culture and customs, and a common language or religious beliefs.¹⁶ Thus, ethnicity reflects cultural identification, which is fluid and may change over time.¹⁸ As ethnicity is not easily measured, we observed, perhaps not surprisingly, no consensus and vast differences between data sources and countries regarding the types of available proxy measures of ethnicity. Country of birth was the most commonly available indicator of ethnicity, followed by nationality and citizenship. Country of birth is a crude method of ethnic group classification which becomes more inaccurate with time since migration.^{31,32} Nationality or citizenship are problematic indicators of ethnicity as immigrants may share nationality and citizenship of the host country yet belong to ethnic groups that differ greatly with respect to religious, lifestyle and other cultural practices.¹⁶ In contrast, self-reported ethnicity, which is both context-specific and changeable over time, reflects the view that ethnicity is largely a matter of identity, self-perception and perception by others.^{16,19} It has been recommended that data on language, religion, country of origin and length of stay in country should be collected alongside self-reported ethnicity for determining the impact of cultural differences on health and disease.³³ We found that information on self-reported ethnicity was collected in only a very few health data sources. Despite the strong yet non-mandatory recommendation for its collection in Scotland, for example, information on self-reported ethnicity is missing for the vast majority of hospital discharge records.²⁴

The lack of consensus on ethnicity indicators in available data sources limits their usefulness for producing comparable estimates of the burden of CVD and diabetes across ethnic groups. The greatest consistency between countries was observed for national death registers which could provide information on cause-specific mortality by country of birth. Marked differences by country of birth in mortality, particularly from CHD and stroke, have already been reported in a few EU countries.^{4,8-10} Diabetes mortality is hugely underestimated in national death registers as a consequence of underreporting of diabetes on death certificates, necessitating the use of morbidity data for describing ethnic disparities in the burden of diabetes across Europe. This is, however, challenging in light of both the lack of ethnicity-specific morbidity data for many EU countries as well as differences in the types of information available in existing data sources. For example, in the Scottish Diabetes Register, currently ~60% of the records are ethnic group-coded. Such population-based registers provide important information on the outcome of disease as well as its prevalence and incidence (although successful registers are few in number partly because of the difficulties in maintaining up-to-date records).³⁴

When information on ethnicity is incomplete or missing in existing databases, record linkage can be used to enrich available data.^{5,6,23,35-37} In Scotland, for example, linkage based on probability matching has been used successfully to combine information on individual ethnic groups from the Scottish census with hospital discharge records and mortality data.⁵ Similarly, in Sweden, hospital discharge data and mortality data have been linked using unique, personal identification numbers, with the aim of identifying incident cases of myocardial infarction.³⁷

Information from health examination surveys on the prevalence of CVD and diabetes in different ethnic groups seems to be limited to a few countries. The high cost of implementing fieldwork may be one reason for the overall lack of health examination surveys in the EU.³⁸ The lower cost of national health interview studies probably explains their greater numbers. However, important differences, for example, in

Table 4 Countries with migrant and ethnic group-specific health survey and epidemiological data

Country	Data type	Area coverage	Ethnic minority group included ^a	Ethnicity measurement proxy ^b	Disease outcome	Disease assessment method	Sociodemographic factors ^c
Belgium	Health interview survey	National	Not reported	2, 4	CHD, stroke, diabetes	Self-report	1, 2, 3, 4, 5, 6
Denmark	Health interview survey	National	2, 5, 6	2, 3	CHD, diabetes	Self-report	1, 2, 3, 4, 5, 6
	Health interview survey	National	5, 6	2, 3	CHD, diabetes	Self-report	1, 2, 3, 6
	Health interview survey	National	Not reported	2, 3	CHD, diabetes	Self-report	1, 2, 3, 4, 5
France	Health interview survey	National	4	2, 4	Diabetes	Clinical diagnosis, self-report	1, 2, 3, 4, 6
	Health examination survey	National	Not reported	2, 8	Diabetes	Clinical diagnosis, self-report	1, 2, 3, 4, 6
	Health interview survey	National	Not reported	4	CHD, stroke, diabetes	Clinical diagnosis, self-report	1, 2, 3, 4, 6
Germany	Epidemiologic study	Local area	5	2	CHD, diabetes	Other	1, 2, 5, 6
Italy	Health interview survey	National	Not reported	2, 5	Not reported	Self-report	Not reported
Netherlands	Epidemiologic study	Major city/region	3	1, 2, 3	CHD, stroke, diabetes	Clinical diagnosis	Not reported
	Epidemiologic study	Major city/region	4, 5	1, 3	CHD, stroke, diabetes	Clinical diagnosis	Not reported
	Epidemiologic study	Local area	3, 4, 5, 7	2, 3	Diabetes	Other	1, 2
	Epidemiologic study	National	3, 4, 5	Not reported	CHD, diabetes	Clinical diagnosis	Not reported
Portugal	Health interview survey	National	Not reported	2	CHD, stroke, diabetes	Self-report	Not reported
	Epidemiologic study	Local	3, 4	2, 3	CHD, stroke, diabetes	Self-report	1, 2, 4, 5, 6
Sweden	Epidemiologic study	Local area	Not reported	2	CHD, diabetes	Other	1, 2, 3, 6
	Epidemiologic study	Not reported	7	2	CHD, diabetes	Clinical diagnosis	1, 2, 3, 4, 5, 6
UK—England	Epidemiologic study	Local area	1	1	CHD, diabetes	Other	1, 2, 3, 4, 6
	Health examination survey	National	1, 2, 4	Not reported	CHD, stroke, diabetes	Self-report	1, 2, 3, 6
	Health interview survey	Local area	1	1	Diabetes	Clinical diagnosis, other	1, 2, 6
UK—Wales	Health interview survey	National	1, 2, 3, 4, 7	1	CHD, stroke, diabetes	Self-report	1, 2, 3, 4, 5, 6
UK—N. Ireland	Health interview survey	National	1, 2, 3, 4, 7	1	CHD, stroke, diabetes	Self-report	1, 2, 3, 4, 5, 6
UK—Scotland	Health examination survey	National	Not reported	1	CHD, stroke, diabetes	Clinical diagnosis, other	1, 2, 3, 4, 6

a: 1 = South Asian (Indian, Pakistani, Bangladeshi and Sri Lankan); 2 = other Asian; 3 = Latin American; 4 = African; 5 = Turkish/Middle Eastern; 6 = Eastern European/Baltic; 7 = other ethnic group.

b: 1 = Self-reported; 2 = country of birth; 3 = parents/grandparents country of birth; 4 = nationality; 5 = citizenship; 6 = name; 7 = religion; 8 = other.

c: 1 = Age; 2 = sex; 3 = SES; 4 = education; 5 = marital status; 6 = other.

the choice of examination methods and measurements across different studies may significantly limit the comparability of existing national health survey data.

Comparable estimates of the burden of CVD and diabetes by ethnicity are difficult to obtain from existing epidemiological studies given the limited number of appropriately designed investigations. Also, most were set up to test specific risk factor-outcome associations rather than provide information on the disease burden in individual ethnic groups, and are therefore based on selected populations and settings. A recent review highlighted the unjustified exclusion of ethnic minority groups from European CVD cohort studies, one consequence of which is the significant lack of information on ethnic disparities in the incidence of CVD.²⁶

Potential limitations of our study need to be discussed. Although we used several different search methods, the possibility remains that we failed to identify some relevant data. For example, we found that hospital discharge data in Italy record citizenship. Other countries or institutions may collect similar data on a routine basis yet we might have failed to identify them. It is unlikely, however, that such data are particularly helpful for describing ethnic disparities in health. In contrast, if high quality data existed without our knowledge, it is unlikely that these have been used by researchers as we would have identified any relevant published studies using these data. However, in the unlikely event of this occurring, our work demonstrates the difficulty in collecting information on routine data sources across the EU. It highlights the need for continuing the search for data and for regular updates of our tables. In a few instances, and despite repeated attempts, we were unable to get information on particular variables (missing diagnostic codes or ethnic groups were therefore coded as missing or not reported in the tables). Updates or refinements of the information available for some of the data sources selected for inclusion in the present study will be necessary. As the search for data continues, we hope that readers will send us missing information or updates.

In conclusion, our results show that reliable and comparable data on CVD and diabetes in migrant and ethnic minority groups are scattered, incomplete or missing for most EU countries. The collection of health data, disaggregated by ethnicity, is essential for generating aetiological hypotheses and for supporting public health policies and planning. To meet the needs of migrant and ethnic minority populations in future EU health policies, we must increase the amount and quality of routine data, while finding methods for maximizing the value of what little is available. Phase two of this project will focus on this goal.

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Key points

- Routine health data are essential for informing public health policies and health care planning at both national and EU level.
- High-quality, comparable, routine data on the health status of migrant and ethnic minority populations are generally not available in Europe.
- Of the 72 data sets identified, 47 came from only 8 Nordic and Western European countries. For several EU Member States, no relevant data could be identified.
- There are vast differences in the number, type and quality of available data, both between and within individual EU countries, which are likely to reduce the comparability of existing data sources.
- To meet the needs of migrant and ethnic minority populations in future EU health policies, the significant lack of routine health data, disaggregated by ethnicity, must be addressed.

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