

Inclusion of Ethnic Minorities in health Research: Challenges & Opportunities

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Outline

- ⊕ Importance of promoting migrant & ethnic minorities health in European
- ⊕ Importance of including migrants & ethnic minorities in health research
- ⊕ Challenges of including migrants & ethnic minorities in health research
- ⊕ Progress & Opportunities
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Importance of promoting migrants & ethnic minority groups health in Europe

- Promoting migrants health & equitable access to care has several benefits:
 - Improves overall population health outcomes
 - Maximizes the benefits of mobility and diversity and helps countries to achieve the SDGs
 - Increase economic and health benefits - reduces the risk of late presentation of diseases, with greater associated personal and economic costs,
 - Plays a key role in improved public health outcomes



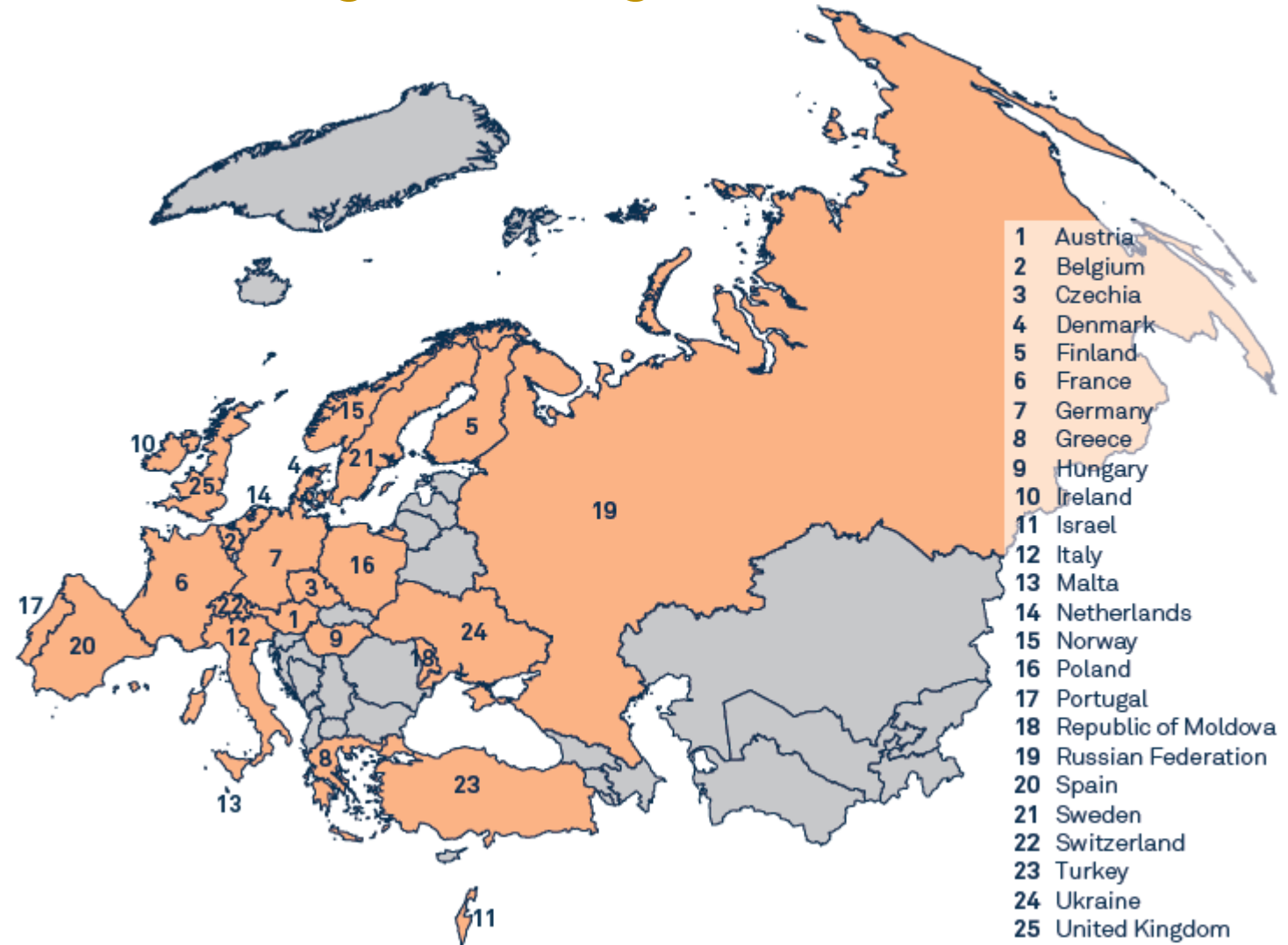
Importance of including migrants in health research

- **Progress towards promoting migrant health & access to care cannot be assessed without systematically collected reliable data on both health and health-related indicators for migrants. This means inclusion of migrants in health studies!**
- **High-quality data are important for:**
 - Assessing risk factors & health needs for migrants
 - Safeguarding & promoting migrant health status
 - Facilitating identification of vulnerabilities and gaps in care
 - Facilitate evidence-informed policy-making & implementation
- Migrants too often remain invisible, marginalized and excluded in health studies



MS of WHO-European Region with available refugee and migrant health data in 2019

Migration health data is collected in some form by 25 of the 53 Member States



Exclusion and Inclusion of Nonwhite Ethnic Minority Groups in 72 North American and European Cardiovascular Cohort Studies

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Competing Interests: RB served on the Biobank UK Science Committee (2003–July 2004) and is currently a member of the Scottish Regional Collaborating Centre of Biobank UK. The conception of this paper precedes these roles. The views expressed here are personal and do not represent those of Biobank UK.

Author Contributions: MR and RB designed the study and analyzed the data. MR and RB contributed to writing the paper.

Academic Editor: Paramjit Gill, University of Birmingham, United Kingdom

Citation: Ranganathan M, Bhopal R (2006) Exclusion and inclusion of nonwhite ethnic minority groups in 72 North American and European cardiovascular cohort studies. *PLoS Med* 3(3): e44.

Received: May 15, 2005

Accepted: November 4, 2005

Published: January 3, 2006

DOI:

10.1371/journal.pmed.0030044

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ABSTRACT

Background

Cohort studies are recommended for understanding ethnic disparities in cardiovascular disease. Our objective was to review the process for identifying, including, and excluding ethnic minority populations in published cardiovascular cohort studies in Europe and North America.

Methods and Findings

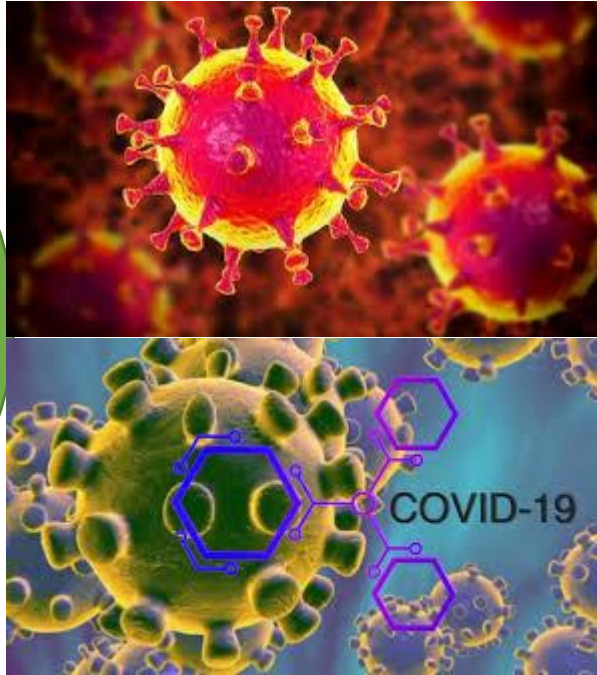
We found the literature using Medline (1966–2005), Embase (1980–2001), Cinahl, Web of Science, and citations from references; consultations with colleagues; Internet searches; and RB's personal files. A total of 72 studies were included, 39 starting after 1975. Decision-making on inclusion and exclusion of racial/ethnic groups, the conceptual basis of race/ethnicity, and methods of classification of racial/ethnic groups were rarely explicit. Few publications provided details on the racial/ethnic composition of the study setting or sample, and 39 gave no description. Several studies were located in small towns or in occupational settings, where ethnic minority populations are underrepresented. Studies on general populations usually had too few participants for analysis by race/ethnicity. Eight studies were explicitly on Caucasians/whites, and two excluded ethnic minority groups from the whole or part of the study on the basis of language or birthplace criteria. Ten studies were designed to compare white and nonwhite populations, while five studies focused on one nonwhite racial/ethnic group; all 15 of these were performed in the US.

Conclusions

There is a shortage of information from cardiovascular cohort studies on racial/ethnic minority populations, although this has recently changed in the US. There is, particularly in Europe, an inequity resulting from a lack of research data in nonwhite populations. Urgent action is now required in Europe to address this disparity.



Disaggregation of health data by migration status is vital to respond to the health needs of migrants including NCDs, infectious diseases & health inequities



Difficulties in collecting migration health data leads to problems in identifying specific groups at risk in time of national emergencies e.g. COVID-19 pandemic

The need for migration health data



- Countries with mandatory data collection by ethnicity were able to shed light on the extent of the ethnic inequalities very quickly
- These data were crucial for public health messages targeted to these populations



Challenges in collecting migrant health data: Administrative systems

- *Lack of routine systems to collect data & when collected, emphasis is often on infectious diseases*
- *Fragmentation of national health information systems (HIS)*
- *Comparability problems of collected data - limits data sharing & access across government entities*
- *Disaggregation of available health data by ethnic status are often impossible*
- *Existed migration status data often not linked with health data*
- *Available migration health data are not representative of all migrant populations*
- *Legal hurdles*



Challenges in collecting migrant health data: Socio-cultural issues

- *Heterogeneity of migrants with varying terminology for what constitutes a migrant*
- *Lack of trust in the authorities & health institutions that collect data & what their data will be used for*
 - *Historical abuses e.g. Tuskegee Syphilis Study*
- *Language barriers & difficulty accessing migrant subgroups*
- *Fear of stigmatization of unfavourable results*



helius



sabre



biobank^{uk}

Enabling scientific discoveries that improve human health



Sapharti
cohort



Progress & Opportunities

● Progress has been made

● Linkage techniques e.g.:

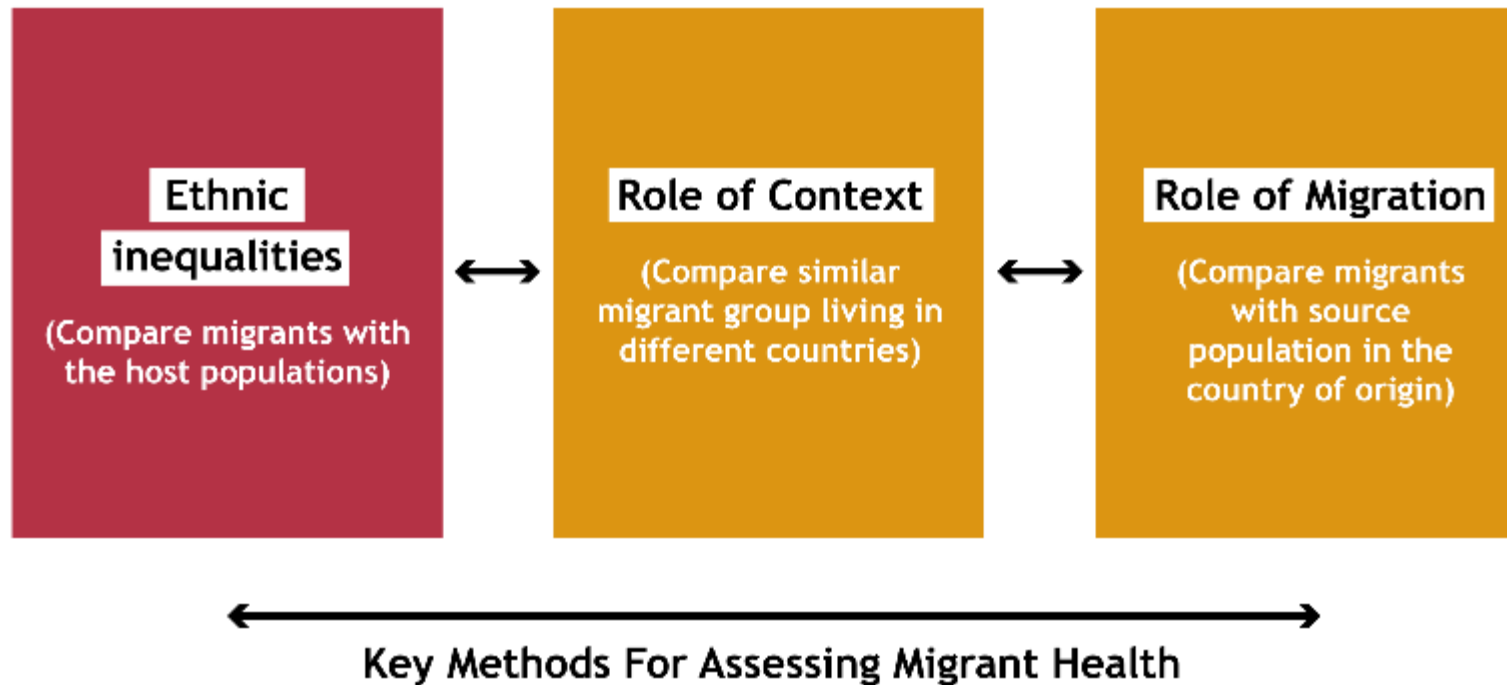
- *Danish Migrant Health Linkage Cohort*
- *Swedish Migrant Health Linkage Cohort*
- *Scottish Health and Ethnicity Linkage Study*
- *Netherlands Nationwide Registry Linkage Study on Migrants*

● Development of new cohort studies e.g.:

- *HELIUS study*
- *RODAM study*
- *Sapharti cohort*
- *ABCD study*
- *Generation R*
- *Southall And Brent REvisited Study (SABRE)*
- *UK Biobank study*
- *Born in Bradford cohort*

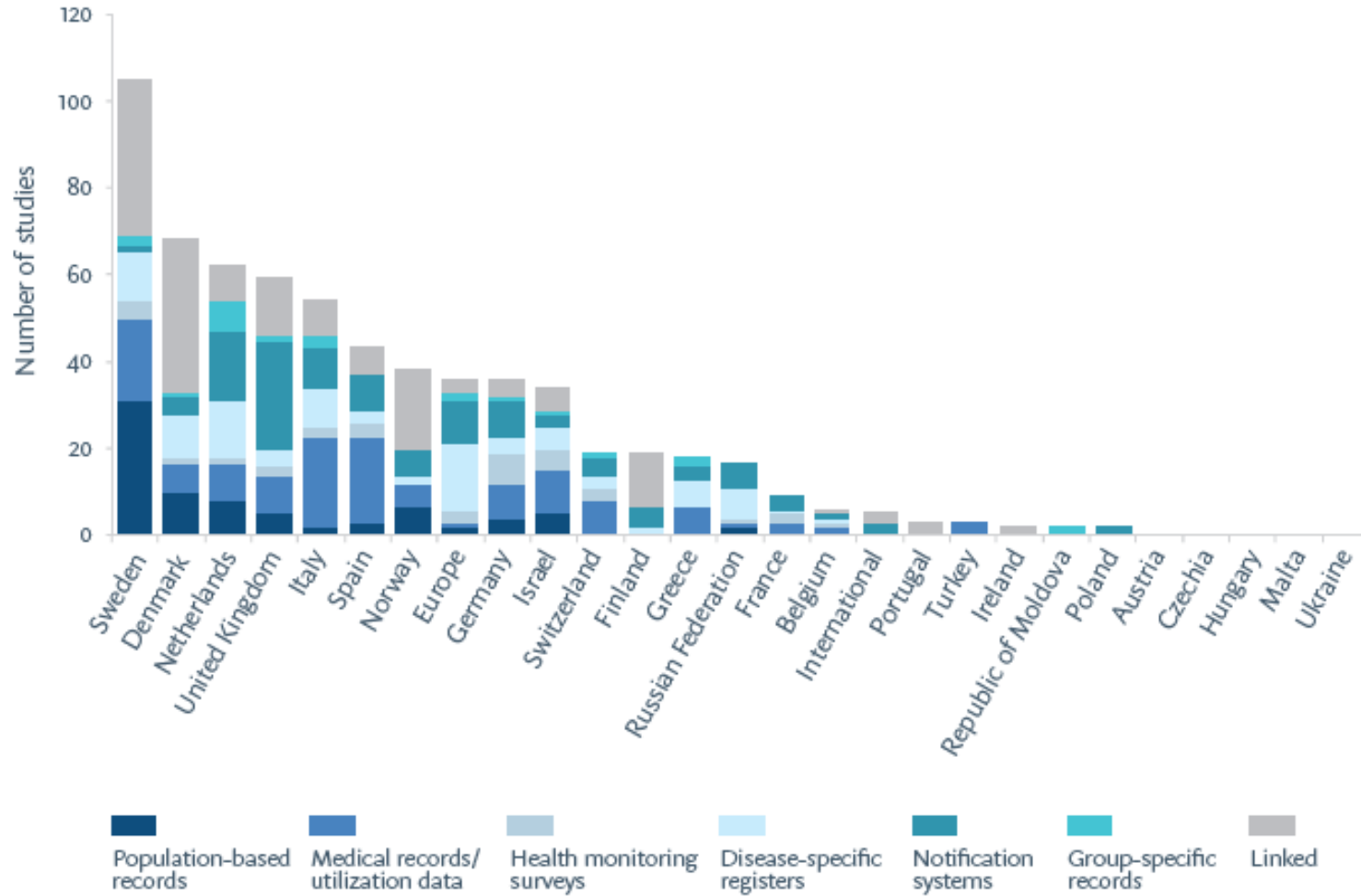


Current cohorts are yielding new knowledge through various methods





Number of studies by country and type of routine data source



Studies published between January 2000 to December 2018 in English, German or Russian)

Office of Minority Health in the national funding agencies is needed!!



Long-term funding government support



Commitment of the study participants



Institutional support



Sustainability of the current cohorts



Critical look at Six Components of Health Information Systems

HIS Resources

Personnel:
involve migrants ,
cultural
mediators

**Legislative,
Regulatory:**
Global compacts,
IHR, GDPR

Logistics support:
Translation

ICT: data linkage

Indicators

Variables:
Core, &
Recommended
Integrated into
National HIS

Data Sources

**Traditional
sources + data
linkage**

**Medical
Screenings**

**Qualitative data
sources**

Big data

Data Management

Data Collection:
oversampling,
electronic
sources,
multilingual
surveys

**Data Storage &
Flow:** central
data repository,
anonymization,
safeguard against
surveillance

**Data Processing
& Analysis:** data
linkage , data
quality
assessment

Information Products

**Data
transformed into
information :**
Joint monitoring
frameworks

**Basis for
evidence and
knowledge:**
access to data for
researchers

Dissemination and Use

**Info readily
accessible:**
publish data
regularly

**Incentives for
use of info:**
Policy forums,
websites/dashbo
ards, Evidence
Briefs for Policy,
workshops



National level Policy recommendations for migration health data

Create inventory of current data sources within the national HIS

Organize a Multi-stakeholder national working group

Develop a strategy for collection/integration of migration health data within national HIS

Integrate 'core variables' into **routine** data collection systems

Modify/clarify regulations to allow for collection and sharing of relevant data

Introduce measures to prevent unauthorized **access/use** of the data

Provide training for data collectors

Establish electronic data collection systems as best practice

Consider innovative sampling strategies

Use multilingual survey instruments, interpreters and cultural mediators

Use data linkage techniques

Collect qualitative migration health data as well

Make available **anonymized** data in an easily accessible and usable format

Analyze & publish available data at regular frequencies & facilitate public access



Regional level Policy recommendations for migration health data

Organizations should develop guidelines and resolutions to call upon MS to collect migration health data

International and intergovernmental organizations should act as liaising agents

Integrate core migration health variables into already existing reporting frameworks

A supra national body could initiate the creation of a regional dataset for migration health

Organizations should facilitate the processes necessary to develop consensus on the definition of 'migrant'



Inclusion of migrants and ethnic minority groups in health research is in the best interest of all and should be mandatory



Migrant health studies in European countries should be supported through structural funding mechanism & there should be Office of Minority Health in the national funding agencies in Europe

Conclusion statements