The collection and integration of data on migrants in health information systems: evidence from Ireland

International Journal for Equity in Health

RESEARCH Open Access

The collection and integration of data on migrants in health information systems: evidence from Ireland

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Abstract

Background Addressing disparities and promoting health for migrants requires policies and practices that are grounded in comprehensive and accurate health data. Health Information Systems (HIS) play a crucial role in this process. However, data on migrants is often incomplete and of poor quality in European HIS. A recent scoping review identified a gap in research on strengthening HIS for data on the health of migrants in Ireland, a country where one in five of the population has been born abroad. This study aims to address this gap.

Methods Using WHO European Region technical guidance on the collection and integration of data on the health of refugees and migrants, we mapped national data repositories ($N = 128$ repositories) including administrative sources, censuses, surveys and patient registries. We identified repositories collecting migration-related variables, such as country of birth, citizenship, and language spoken. For relevant repositories, information was extracted on the variables collected, the use of inclusive data collection strategies such as multilingual surveys, whether there was a procedure to access the data for secondary data analysis, the potential for data linkage and how the data had been used.

Results Of the 128 data repositories, 28 (22%) recorded migration-related variables. The majority of these repositories (18/28) recorded country of birth, followed by nationality (6/28). Four repositories recorded language(s) spoken and only two national surveys translated the survey instrument into different languages. No examples were identified of migration-related variables being used or analysed in national or regional disease registries and there was limited use of data linkage.

Conclusions The collection and integration of data on the health of migrants in HIS in Ireland is fragmented. Enhancing data collection practices, for example by using multilingual surveys and inclusive sampling strategies with participatory approaches, could improve the representation of migrant populations and the quality of data collected. Adapting policy considerations from WHO at a country level provides an opportunity to standardise data collection and establish a robust evidence base to inform equitable health policies and practices for migrants.

Keywords Migrant, Refugee, Health information system, Data, Health policy

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Introduction

Migration is a longstanding, global phenomenon and people move for many reasons including employment, education, family, or to escape conflict, persecution or the impact of climate change. There is no universally accepted definition of a migrant and capturing the complex relationship between the drivers of migration in categories of migrants is challenging [1, 2]. Using the United Nations definition (see Table 1), there were 304 million international migrants globally in 2024, representing 3.7% of the world's population [3]. The number of forcibly displaced people, which includes refugees and asylum seekers (see Table 1 for definitions), reached a record 123 million by the end of 2024 [4]. Differences in health needs and outcomes between migrants and host populations can depend on length of stay, country of origin and reason for migration [5]. Some studies have reported a 'healthy migrant effect' with better health status for some migrant groups compared to the host population [6]. Refugees, however, can have poorer health outcomes due to the physical and psychological toll of forced displacement [7].

Promoting health and addressing any disparities for migrants requires policies and practices that are grounded in comprehensive and accurate health data. Health Information Systems (HIS) play a crucial role in this process by collecting, analysing, and disseminating health data, which helps inform decision-making and enables targeted interventions [8]. The COVID-19 pandemic underscored the vital role of HIS in identifying vulnerabilities and ensuring equitable resource allocation, particularly for migrants [9]. It also highlighted the persistent structural barriers to the full integration of migrants within health systems and revealed the need for more inclusive and data-informed approaches to health planning [10].

The integration of data on the health of migrants into national HIS often remains fragmented or invisible because migration-related variables are not routinely collected [11]. A review of the evidence on the availability and integration of refugee and migrant health data in HIS in the WHO European Region found that data was only available in 25 of the 53 member states [12]. This lack of comprehensive data limits the ability to address the health needs of migrants and poses significant challenges to developing cohesive policies and strategies essential for improving health outcomes [11]. Research has emphasized how digital health technologies can promote equity but also risk deepening exclusion if not implemented with attention to migrants [13]. To address the lack of comprehensive data, the WHO European Region has developed policy considerations in advocating for the integration of refugee and migrant health data into national HIS [14]. This approach avoids the risks associated with creating separate systems for migrants that can be resource intensive and unsustainable for countries to maintain. It also increases the availability of data and supports comparisons with the host population [14].

One in eight people in the WHO European Region is a migrant [7]. Ireland, a member of this region, has a higher proportion, with the most recent Census in 2022 reporting that one in five residents was born abroad [15]. Alongside this, as of 2024, over 109,566 people from Ukraine had registered in Ireland as Beneficiaries of Temporary Protection [16] and 18,561 people arrived in Ireland in 2024 seeking international protection [17]. Despite the growing diversity of its population, Ireland lacks comprehensive studies on the capacity of its HIS to support migrant health. Recent scoping reviews of migrant health research in Ireland revealed no focus on strengthening HIS for this purpose [18, 19]. The aim of this study is to help address this gap by mapping and evaluating the capacity of national HIS in Ireland to inform migrant health research, policy and practice. Informed by the WHO technical guidance, the objectives are to (a) identify where and how migration-related data are collected in the national HIS, (b) the potential for

Table 1 Definitions[1]

International migrant	"any person who has changed his or her country of residence. This includes all migrants, regardless of their legal status, or the nature, or motive of their movement." (United Nations) [3]
Refugee	**Refugees** include individuals recognized under the 1951 Convention relating to the Status of Refugees, its 1967 Protocol, the 1969 Organization of African Unity (OAU) Convention Governing the Specific Aspects of Refugee Problems in Africa, the refugee definition contained in the 1984 Cartagena Declaration on Refugees as incorporated into national laws, those recognized in accordance with the UNHCR Statute, individuals granted complementary forms of protection, and those enjoying temporary protection. The refugee population also includes people in refugee-like situations. **People in refugee-like situation** refers to a category which is descriptive in nature and includes groups of people who are outside their country or territory of origin and who face protection risks similar to those of refugees, but for whom refugee status has, for practical or other reasons, not been ascertained. (UNHCR) [38]
Asylum-seekers	**Asylum-seekers** are individuals who have sought international protection and whose claims for refugee status have not yet been determined. (UNHCR) [38]
Forced displacement	People forcibly displaced as a result of persecution, conflict, violence, human rights violations and events seriously disturbing public order. (UNHCR) [4]

[1] Organisations such as WHO and United Nations use the terminology 'refugees and migrants'

data linkage and secondary data analysis, and (c) how the data have been used.

Methods

National catalogue of health and social care repositories

We used a catalogue of national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries, to map the capacity of HIS in Ireland to inform migrant health policy and practice. The catalogue is publicly available from the Health Information and Quality Authority (HIQA) website [20]. HIQA is an independent statutory authority whose responsibilities include advising on the efficient and secure collection and sharing of health information, setting standards, and evaluating information resources. HIQA published the fourth edition of the catalogue in 2022, which includes 128 data repositories (84 national data repositories, 11 national surveys, 10 national performance and activity reports, 7 data repositories with regional coverage, 9 national and 4 international collated sources of health information, and 3 national censuses). We also included five new data repositories established since 2022 that were noted in the catalogue as being under development. This ensured that all relevant data repositories, whether pre-existing or newly established, were considered in our analysis.

The metadata template in the catalogue includes information such as the coverage of the data repository (geographical and temporal), whether a data dictionary is available, whether national-level identifier variables are included, data collection methodology and how the data can be accessed. Equity stratifiers were included as a new field in the catalogue in 2022. These are specific variables selected to reflect a (perceived) inequality, for example, place of residence, gender, religion and ethnic group [21]. They are used to measure and monitor inequalities through comparing aggregate data on groups of people. Ninety-four data repositories (65%) collected data on one or more equity stratifiers.

Core and recommended migration-related variables

We used recently developed guidance from WHO European region [14] that provides practical policy considerations for the collection and integration of data on refugee and migrant health. This guidance outlines current evidence, knowledge and best practice relating to the integration of migration health data into national HIS including the core variables to be collected: country of birth, country of citizenship, year and month of arrival and country of birth of both parents. A set of recommended variables includes reasons for migration, legal status, knowledge of the official language(s) of the host country, and whether citizens have ever resided abroad for at least 12 months.

We electronically searched the online version of the catalogue of 128 data repositories as well as the 5 data repositories listed as under development, searched data dictionaries (where available) and emailed contacts provided in the catalogue to identify data repositories which included core and recommended variables related to migration. Additionally, we documented where ethnicity was recorded in the data repositories. Although the WHO's technical guidance does not include ethnicity, it is included as an equity stratifier in HIQA's catalogue and its collection is a strategic goal of national intercultural health strategy in Ireland [22]. Previous research identified that ethnicity is most commonly operationalised in terms of the ethnic categories in the Census of Population, and that it is self-identified rather than assigned [23].

Data linkage and secondary data analysis

Given potential sensitivities around data collection, the technical guidance recommends linkage between datasets to enhance the availability and completeness of migration health data [14]. We assessed the potential for data linkage of the data repositories including the use of an individual health identifier (IHI). An IHI includes a number that uniquely identifies each person and its use is currently being rolled out in health and social care services in Ireland. We also noted other identifiers such as name, address, date of birth and personal public services number (PPSN) with potential for data linkage across data repositories.

The WHO technical guidance also recommends the use of data collection strategies such as multilingual surveys, purposive sampling, and the involvement of cultural mediators, to increase the response of migrants and their trust in the process. We documented whether the data stored in the repositories were collected using these methods and also if the repositories had a formal procedure for requesting data for secondary data analysis.

We searched two recent scoping reviews of migrant health research in Ireland [18, 19] for peer-reviewed research that used these data repositories and searched for grey literature using Google Scholar with the repository name as the search term. We also searched the websites of these repositories and emailed contacts provided for them in the catalogue.

Results

Where and how migration-related variables are collected

A total of 28/128 (22%) data repositories recorded at least one of the core or recommended migration-related variables (see Table 2), most commonly country of birth (18/128, 14%). Eight data repositories (6%) included more than one core migration-related variable, and six (5%) included all four recommended migration-related

Table 2 Data repositories with core and recommended migration-related variables

Type of data repository	Name of repository	Core migration variables	Recommended migration variables	Population covered	Data availability on request	Data linkage variables
Reporting system	Computerised Infectious Disease Reporting system	Country of birth		All cases of 80 notifiable infectious diseases in the population	Yes	Name, address, date of birth
	National Psychiatric Inpatient Reporting System	Country of birth		Inpatients in psychiatric services	Yes	**IHI**[1]
	National Perinatal Reporting System	Nationality (Place of birth) of mother and father		All births in Ireland	Yes	Date of birth
	National Drug Treatment Reporting System	Country of birth	Language spoken at home	Treated cases of problem drug and alcohol use	Yes	**IHI**[1]
Disease registry	Irish Prostate Cancer Outcomes Research registry	Nationality		Men with prostate cancer in 16 hospitals across Ireland	Yes	Name, address, date of birth
	Cystic Fibrosis Registry of Ireland	Country of birth		Patients with cystic fibrosis attending recognised centres	Yes	Name, address, date of birth
	Irish Childhood Diabetes National Register	Country of birth Date of arrival to Ireland (if born abroad)		Young people under the age of 15 years developing type 1 diabetes (19 centres nationally)	Yes	Date of Birth
	Irish Epidermolysis Bullosa Registry	Country of birth		Epidermolysis Bullosa patient population in Ireland	Yes	Not available
	Irish Thoracic Society Interstitial Lung Disease Registry	Country of birth		Patients with Interstitial Lung Disease in Ireland	Yes	Not available
	Cork and Kerry Congenital Anomaly Register JRC EUROCAT Registry 49	Migrant status		All births where mothers are resident in Cork and Kerry	Yes	Date of birth
	Southeast Ireland EUROCAT Registry of Congenital Anomalies (HSE EUROCAT Registry South-East)	Migrant status		All births where the mother is resident in Carlow, Kilkenny, Wexford, Waterford and South Tipperary	Yes	Date of birth

Table 2 (continued)

Type of data repository	Name of repository	Core migration variables	Recommended migration variables	Population covered	Data availability on request	Data linkage variables
Survey	European Social Survey	Country of birth, citizenship, country of birth of both parents	Language	Adults aged 15+	Yes	Not available
	Growing Up in Ireland – National Longitudinal Study of Children in Ireland	Citizenship, Country of birth, length of time since arrival in Ireland if born abroad	Language spoken at home	9 year old children and an infant cohort aged nine months old	Yes	Name, address, date of birth
	Health Behaviour in School Aged Children	Migrant status, place of birth (self and parents)		Children in schools with pupils from 3rd-6th class (primary school) and pre-leaving certificate year (post-primary school)	Yes	Not available
	Healthy Ireland Survey	Country of birth		People aged 15 years and over	Yes	Address
	Irish Health Survey (European Health Interview Survey)	Nationality		People aged 15 years and over	Yes	Not available
	TILDA – The Irish Longitudinal Study on Ageing	Country of birth, what age first moved to Ireland if born abroad, Nationality	Ever lived abroad for more than 6 months	Individuals aged 50 and over and their spouses or partners of any age, resident in Ireland.	Yes	Name, address, month and year of birth, medical card number
	SILC- Survey on Income and Living Conditions	Country of birth, country of birth of both parents and country of main citizenship		All private households residing in the state at the time of data collection, excluding offshore island communities.	Yes	Name, date of birth, PPSN
Vital statistics	Vital Statistics — Live Births Registration	Country of birth and nationality of mother and father		All live births in Ireland	Yes	Date of birth
Census	Census of Population	Place of birth (country if born abroad), country of citizenship	Language spoken at home, ever lived abroad for a year or more	De facto population	Yes	Name, address, date of birth
	Irish Psychiatric Units and Hospitals Census	Country of birth		Inpatients in approved psychiatric units, hospitals and centres	Yes	**IHI**[1]
Collated data source	State of the Nation's Children	Immigrant status		Children aged 0–17 years resident in Ireland. A small number of indicators include young adults 18–24 years.	Yes	Not available

Table 2 (continued)

Type of data repository	Name of repository	Core migration variables	Recommended migration variables	Population covered	Data availability on request	Data linkage variables
Other data repositories	Hospital In-Patient Enquiry system		Legal status (Temporary protection – Ukraine)	Inpatients in all acute public hospitals	Yes	Date of birth
	National Drug-Related Deaths Index	Country of birth		People who use drugs and alcohol dependent persons	Yes	**IHI**[1]
	COVAX: National Covid-19 Immunisation System	Nationality		All residents of the State who have registered for COVID-19 vaccination	Yes	IHI, PPSN
	National Register of Individual Health Identifiers	Country of birth, Nationality		Everyone engaging with publically provided health and social care services	Yes	IHI, Name, address, date of birth, PPSN, medical card number
	Irish National Intensive Care Unit Audit	Country of birth		All patients admitted to intensive care or high dependency units in public and private hospitals	Yes	**IHI**[1]
	Work Related Fatal and Non-Fatal Incident Database	Nationality (country of citizenship)		All employees	Summary reports can be downloaded	Name, Eircode
New data repositories						
Disease registry	The Irish Atopic Eczema Systemic Therapy Register	Country of birth		Children and adults with atopic eczema	Yes	Date of Birth
	Global Registry of Alopecia Areata Disease Severity and Treatment Safety- GRASS Ireland	Country of birth		People with Alopecia Areata Disease	Yes	Not available

[1] A field available for IHI but not currently recorded/complete

variables. Six data repositories (5%) recorded nationality and four (3%) recorded citizenship. Definitions of these terms varied, for example one repository defined nationality as place of birth and another as country of citizenship. Only four data repositories (3%) recorded data on language(s) spoken. Of the 28 data repositories capturing migration-related data, half ($N=14$) also recorded ethnicity. Additionally, there were 16 data repositories that did not gather core or recommended migration-related variables but included information on ethnicity or cultural background, giving a total of 30 data repositories (23%) recording ethnicity (see Table 3).

National surveys were more likely to include migrant-related variables (7/11, 64%). All seven of these surveys collected information on core migration-related variables, with three also capturing data on recommended variables. Country of birth was the most commonly collected core variable (six of the seven surveys). Although these surveys have recorded migration-related variables, none of them used inclusive sampling for migrants and only two translated the survey instruments into different languages.

Five national disease registries recorded at least one core migration-related variable (see Table 2). Four of these registries recorded country of birth and one recorded nationality. In addition to the national registries, two regional registries also recorded migration-related information, as part of a European network of congenital anomaly registers. Four national reporting systems (for drug and alcohol treatment, admissions and discharges from psychiatric hospitals, surveillance of infectious diseases, and perinatal events) recorded at least one core migration-related variable.

Two national censuses (Census of Population and Irish Psychiatric Units and Hospitals Census) recorded migration-related variables. The most recent Census of Population in 2022 recorded country of citizenship (with an option for dual citizenship) and country of birth. Previous censuses recorded nationality, but this was changed to fulfil a legal requirement under EU regulations to produce Census data on country of citizenship rather than nationality. Since 2005, being born in Ireland does not automatically confer citizenship, which can depend on parents' country of birth and citizenship. A vital statistics data repository for live births registration in Ireland

Table 3 Data repositories with ethnicity information

Type of data repository	Name of repository	Core/recommended migration variables	Variable related to ethnicity	Population covered	Data availability on request	Data linkage variables
Reporting system	Computerised Infectious Disease Reporting system	Country of birth	Ethnicity	All cases of 80 notifiable infectious diseases in the population	Yes	Name, address, date of birth
	National Psychiatric Inpatient Reporting System	Country of birth	Ethnicity	Inpatients in psychiatric services	Yes	**IHI**[1]
	National Drug Treatment Reporting System	Country of birth/ Language spoken at home	Ethnicity	Treated cases of problem drug and alcohol use	Yes	**IHI**[1]
Disease registry	Cystic Fibrosis Registry of Ireland	Country of birth	Ethnicity	Patients with cystic fibrosis attending recognised centres	Yes	Name, address, date of birth
	Irish Childhood Diabetes National Register	Country of birth, Date of arrival to Ireland (if born abroad)	Ethnic group/origin	Young people under the age of 15 years developing type 1 diabetes (19 centres nationally)	Yes	Date of birth
	Irish Epidermolysis Bullosa Registry	Country of birth	Ethnicity	Epidermolysis Bullosa patient population in Ireland	Yes	Not available
	Irish Thoracic Society Interstitial Lung Disease Registry	Country of birth	Ethnicity	Patient with Interstitial Lung Disease in Ireland	Yes	Not available
	Alpha One Foundation Registry		Ethnicity	All Alpha-1 patients attending National Alpha-1 Outpatient Clinic in Beaumont Hospital	Yes	Not available
	Cleft Database		Ethnicity	Children or adults who present with cleft lip and/or palate in Ireland	Yes	PPSN, Name, Address
	Irish National Rare Kidney Disease Registry		Ethnicity	Irish patients with primary systemic vasculitis	Yes	Name, address
	National Haemophilia System		Race	People with haemophilia and other related bleeding disorders in Ireland	Yes	Name, address, date of birth
Survey	Growing Up in Ireland– National Longitudinal Study of Children in Ireland	Citizenship, Country of birth, length of time since arrival in Ireland if born abroad /Language spoken at home	Race	9 year old children and an infant cohort aged 9 months old	Yes	Name, address, date of birth
	Healthy Ireland Survey	Country of birth	Ethnic background/Race	People aged 15 years and over	Yes	Address
	2019-20 Irish National Drug and Alcohol Survey		Ethnicity	Irish population aged 15 years and older and living in private households	Yes	Not available
	National Inpatient Experience Survey		Ethnicity	Patients aged 16 years or older, who spent at least 24 h in a public acute hospital and were discharged from hospital.	Yes	Name, address, date of birth
	National Maternity Experience Survey		Ethnicity	Women who have recently given birth	Yes	Name, address, date of birth

Table 3 (continued)

Type of data repository	Name of repository	Core/recommended migration variables	Variable related to ethnicity	Population covered	Data availability on request	Data linkage variables
Census	Census of Population	Place of birth (country if born abroad), country of citizenship/ Language spoken at home, ever lived abroad for a year or more	Ethnicity	De facto population	Yes	Name, address, date of birth
	Irish Psychiatric Units and Hospitals Census	Country of birth	Ethnicity	Inpatients in approved psychiatric units, hospitals and centres	Yes	**IHI**[1]
Other data repositories	Irish National Intensive Care Unit Audit	Country of birth	Ethnicity	All patients admitted to intensive care or high dependency units in public and private hospitals	Yes	**IHI**[1]
	National Audit of Severe Maternal Morbidity		Ethnicity	Women experiencing specific severe maternal morbidities and /or who require a higher level of care	Yes	Not available
	Perinatal Mortality National Clinical Audit		Ethnicity	Data on fetal and maternal characteristics recorded in the clinical record from 19 maternity units in Ireland	Yes	Not available
	Planned Home Births in Ireland Audit		Ethnicity	All planned births with the HSE home birth service	Yes	Not available
	Neonatal Therapeutic Hypothermia Audit		Ethnicity	Infants who underwent Therapeutic Hypothermia in Ireland	Yes	Name, time of birth, current age in hours
	Irish Paediatric Critical Care Audit		Ethnicity	All admissions of children to paediatric critical care units and children aged 16 years and over admitted to adult intensive care unit in Ireland	Yes	Date of birth
	Surveillance of severe acute respiratory infections		Ethnicity	Severe acute respiratory infections cases aged 14 years and older	Yes	IHI, Address
	COVAX: National Covid-19 Immunisation System	Nationality	Ethnicity	All residents of the State who have registered for COVID-19 vaccination	Yes	IHI, PPSN
	Acute Flaccid Paralysis surveillance		Ethnicity	Children aged less than 15 years from all regions of the Ireland	Yes	Name, address, date of birth
	National Drug-Related Deaths Index	Country of birth	Ethnicity	People who use drugs and alcohol dependent persons	Yes	**IHI**[1]
	Very Low Birth Weight Infants in the Republic of Ireland		Ethnicity	Infants born alive with weight between 401 and 1500 g or whose gestational age is between 22 weeks 0 days and 29 weeks 6 days	Yes	Not available
	National Ability Supports System		Ethnic/cultural background	People who use or require health service executive funded disability services	Yes	**IHI**[1]
New collections						

Table 3 (continued)

Type of data repository	Name of repository	Core/recommended migration variables	Variable related to ethnicity	Population covered	Data availability on request	Data linkage variables
Surveys	National End of Life Survey		Ethnicity	People who registered the death of a family member or friend	Yes	Not available
	National Maternity Bereavement Experience Survey		Ethnicity	Women and their partners who experienced a second trimester miscarriage, a stillbirth or the early neonatal death of a baby	Yes	Not available
	National Nursing Home Experience Survey		Ethnicity	Nursing home residents and their relatives or friends	Yes	Not available
Disease registry	The Irish Atopic Eczema Systemic Therapy Register	Country of birth	Ethnicity	Children and adults with atopic eczema	Yes	Date of birth

[1] A field available for IHI but not currently recorded/complete

records country of birth and nationality of mother and father.

The Hospital In-Patient Enquiry (HIPE) system records information on all discharges from, and deaths in, acute public hospitals in Ireland. In 2022, an administrative variable was added to HIPE to identify those seeking care under the Temporary Protection Directive for people fleeing the war in Ukraine. This was the only example of a legal status variable found in the data repositories.

Other data repositories that recorded at least one-migration related variable included an epidemiological database on drug-related deaths, a national audit on intensive care units, a national database on fatal and non-fatal work-related incidents, a register of IHIs, a national COVID-19 immunisation system dataset and a collated source of information on children (see Table 2).

Across all repositories that recorded at least one of the core or recommended migration-related variables, the populations covered were diverse, ranging from the general population to specific subgroups; however, none of the repositories focused solely on migrant populations (see Table 2). Seven repositories (7/28, 25%) captured information on the general population, including adults and all residents, such as in the Census of Population. Another seven (7/28, 25%) focused specifically on children or perinatal populations, including birth registries, congenital anomaly registers, and surveys of school-age children. Only one repository (1/28, 4%) focused exclusively on older adults (50 years and older). The largest proportion of repositories (13/28, 46%) focused on people with specific health conditions, those receiving health services, or defined population groups, including psychiatric inpatients, men with prostate cancer, people receiving drug or alcohol treatment, or patients with chronic or rare diseases.

Potential for data linkage and secondary data analysis

All 28 data repositories had procedures for requesting access to data. Anonymised datasets for five of the seven national surveys were available through a national data archive (Irish Social Science Data Archive). Other data repositories provided an email contact for data requests, often with management or steering committee oversight on approvals for data access.

The majority of data repositories (22/28, 79%) recorded at least one variable that could facilitate data linkage, most commonly date of birth. A key data repository for facilitating data linkage is the National Register of IHIs. This register includes the unique identifier number for individuals, along with migration-related variables such as place of birth (or country of birth for those born outside Ireland) and nationality. Seven data repositories with migration-related variables had a field for IHI number. Seven other data repositories in the catalogue did not include any migration-related variables but included a field for IHI number, providing an opportunity for linking them with the National Register of IHIs.

How the data have been used

We found multiple examples of peer-reviewed journal articles using data from national surveys for migrant health research, for example Cotter et al. investigated the relationship between migration, psychopathology and stressful events in children using Growing up in Ireland survey data [24]. Barlow et al. used data from the Healthy Ireland survey to compare healthcare utilisation of migrant adults relative to the host population [25]. We also found journal articles using data from national reporting systems. For example, data from an infectious disease reporting system was used to explore the epidemiology of paediatric tuberculosis over time in Ireland and compared trends in Irish-born and foreign-born children [26].

The national perinatal reporting system and vital statistics on births routinely reported the nationality of the mother [27, 28]. The national COVID-19 immunisation system compared the nationality of people who had received a booster with that of those who had not [29]. We found no examples, however, of migration-related variables being used or analysed in national or regional disease registries.

There were few examples of data linkage. One example reported on mortality inequalities in Ireland, matching vital statistics on mortality with the Census of Population to facilitate an analysis by country of birth and nationality. The matching was conducted by the Central Statistics Office with an 80% match rate between the two sources and was governed by national legislation and a data protocol [30].

New data repositories

Five new data repositories were identified that were noted in the catalogue as being in development. These include three surveys and two national registries. Both registries recorded country of birth and one recorded both country of birth and ethnicity. All three surveys recorded ethnicity only. Only one survey (National Maternity Bereavement Experience Survey) translated its instruments into multiple languages. However, another survey (National End of Life Survey) listed one of the reasons for opting out as "The survey is not available in my first language."

Discussion

Main findings

This study offers a detailed examination of Ireland's HIS and highlights the current landscape and gaps in its capacity to inform migrant health policy and practice. Despite the increasing diversity of Ireland's population, with one in five residents born abroad [15], there is limited integration of migration-related variables into national data repositories. These findings are similar to those of Bozorgmehr et al. (2019) which found that even in the countries that recorded this information in HIS in the WHO European Region, integration into national HIS was limited [12].Our analysis identified 22% of data repositories in Ireland that included at least one migration-related variable, with country of birth being most commonly recorded. However, only eight of these repositories captured more than one core variable, and only six incorporated recommended migration variables such as language spoken. National surveys were more likely to include migration-related variables, but lack of inclusive sampling methods or multilingual survey instruments limits their accessibility and representativeness for migrant populations. There is ongoing research for one national survey (National Inpatient Experience Survey) to improve information gathering about experiences of inequality in hospital care and increase the number of people from marginalised communities who take part in the survey [31]. This research may inform the future collection of variables to compare the care experienced by different communities (including migrants) in a range of care settings. Participatory approaches with migrants can also guide the collection of sensitive data in these settings [11].

The WHO technical guidance does not include ethnicity as a migration-related variable and Bozorgmehr et al. highlighted concerns that use of ethnicity as a sole indicator for migration can lead to "othering" and racialization of some ethnic groups [11]. However, our study found slightly more existing data repositories collecting ethnicity than collecting migration-related variables and more new data repositories collecting ethnicity only. This may reflect goals of the national intercultural health strategy in Ireland and the advocacy of a non-government organisation, representing an indigenous ethnic minority, for the collection of ethnicity data [23]. Ethnicity was the sole indicator collected in 16 existing data repositories, which suggests a need for a more standardized, policy-based approach to capturing data to better address intersectional health disparities. Similarly, standardisation on the definition and use of citizenship rather than nationality (given the recent change by the Census of Population) would enhance comparability across data repositories and internationally.

In our mapping, we found just one example where legal status was recorded and that was in the context of identifying people under the Temporary Protection Directive for those fleeing the war in Ukraine. There are important reasons for not collecting legal status. Health services must meet strict data protection requirements, meaning that sensitive data such as legal status can only be collected when necessary and proportionate [32]. Recording legal status may also discourage people from seeking health care because of fears of stigma or immigration enforcement [33], particularly for undocumented migrants. Legal status can also change over time, making it difficult to capture in a meaningful or consistent way [34]. As a result, most systems focus on broader indicators such as country of birth [34]. However, the absence of data can limit understanding of health needs of some groups such as undocumented migrants, even though they may face barriers to care and higher risk of poor health [35]. Partnership with non-governmental organisations which often have strong relationships and trust with undocumented migrants and using participatory approaches can provide opportunities to generate complementary data and insights.

The study identifies limited use but substantial opportunities for data linkage, particularly with the rollout of the IHI and the inclusion of country of birth and nationality in it. Given the fragmented HIS in Ireland, leveraging the potential for data linkage could enhance the utility of existing datasets, allowing for more nuanced analyses of health disparities and targeted policy development. Privacy-preserving record linkage has been identified as a way of connecting data from different sources without revealing personal information, but there are still ethical concerns about consent and potential misuse of data [11]. Recent regulation on the European Health Data Space (EHDS) addresses responsible and secure secondary use of health data including data governance and protection, an opt-out option, and prohibited uses of health data that could negatively impact individuals or groups [36]. Under the EHDS, each European Union Member State will be required to establish a Health Data Access Body to facilitate access to linked datasets and Ireland is currently developing the infrastructure to implement this. This new infrastructure has the potential to play an important role in migrant health research and policymaking.

Limitations

Our focus was on national health and social care data repositories. We supplemented publicly available information on these repositories by emailing contacts provided for them, but not all contacts responded. There may also be other sources of data relevant for migrant health, for example from non-governmental organisations, and further research should explore the potential of data from these organisations for policy and practice [37].

Conclusion

The findings highlight the need for a coordinated approach to standardising definitions and integrating migration-related data into Ireland's HIS, informed by the WHO's technical guidance. Enhancing data collection practices such as multilingual surveys and inclusive sampling strategies with participatory approaches, could improve the representation of migrant populations and the quality of data collected. By adopting coordinated approaches guided by international best practice and leveraging opportunities for data linkage, Ireland can establish a robust evidence base to inform equitable health policies and practices. This approach also provides an example for other countries to adapt health information systems for increasingly diverse populations.

Abbreviations

HIS	Health Information System
HIQA	Health Information and Quality Authority
IHI	Individual Health Identifiers
WHO	World Health Organization

Acknowledgements
None.

Author contributions
AH, AB, JW, POD, RA, SP and AMacF contributed to the proposal for funding. DV searched the catalogue. DV and AH conducted the analysis. DV prepared the first draft of the manuscript. All authors critically reviewed the manuscript and approved the final version.

Funding
This work is being supported by the Health Research Board (SDAP-2023-003). The funding body had no role in the design of the study, the collection, analysis, and interpretation of data, or in writing the manuscript.

Data availability
The catalogue of national data repositories is publicly available at Catalogue of National Data Collections | HIQA.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Received: 1 August 2025 / Accepted: 10 November 2025
Published online: 22 November 2025

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