ETHNICITY DATA COLLECTION IN HEALTH SYSTEMS IN IRELAND: HOW CAN WE IMPROVE THE COLLECTION AND USE OF DATA?

PROFESSOR ANNE MACFARLANE[1,2] AND PROFESSOR AILISH HANNIGAN[1,2]
[1]SCHOOL OF MEDICINE, UNIVERSITY OF LIMERICK. [2]HEALTH RESEARCH INSTITUTE, UNIVERSITY OF LIMERICK.

EXECUTIVE SUMMARY

In line with international and national drivers for equality monitoring in healthcare, the implementation of an ethnic identifier throughout the HSE, including in primary care, is a priority action in the Health Service Executive (HSE) Second National Intercultural Health Strategy (NIHS) 2018-2023.

This participatory research project involved a quantitative study to explore where ethnicity data is currently collected and how it is being used. It involved a qualitative study to identify levers and barriers to implementing the HSE ethnic identifier in general practice settings, where most of us access care. The analysis showed that ethnicity data collection in health and social care data collections in Ireland is underdeveloped, fragmented and has too much focus on high-risk populations. While the idea of ethnicity data collection in general practice broadly makes sense to community members and GPs, there are concerns about collecting these sensitive data in busy, under-resourced general practice settings and fears that data may be mis-used. The recommendations are *to develop multi-sectoral partnerships* and *initiatives to oversee data collection and use* and to *collect ethnicity and migration variables in an Individual Health Identifier record*.

CONTEXT

What is ethnicity and why collect ethnicity data?

Ethnicity is a term used to refer to a group of people who identify with each other because of a shared and distinctive culture, ancestry, language, religion, or nationality. It is considered to be a complex concept because it is subjective based on a *feeling of identity* and it can change over time. **Ethnic group should always be identified by the individual and should not be assigned to them by others.**

If we consider ethnicity in the context of health, **we are interested in collecting ethnicity data from everyone in the population so we can find out how many are in a particular group and then calculate the rate of disease, healthcare access and health outcomes in that group.** This allows us to make comparisons across groups to see where differences are occurring. This is particularly relevant for minority ethnic groups and migrants living in precarious social, legal or economic circumstances because they have poorer health status and outcomes than the majority population. This pattern of health inequity is illustrated most recently in relation to the COVID-19 global pandemic.

Monitoring ethnicity in the context of health is an **equality monitoring measure** and allows us to intervene where necessary to improve outcomes. In other words, if we don't collect ethnicity data, we don't know if there are differences between groups and if we don't know about any differences between groups, then we can't do anything about it.

The principle of 'leaving no-one behind' in the UN Sustainable Development Goals and the promotion of Universal Health Coverage underlines **the importance of having national health information systems that record and use data about health and determinants of health, including ethnicity and migration**. There are country-specific ethnic identifiers in healthcare settings in several countries, including the USA, the UK, Australia, New Zealand and Canada. There are also examples of linking ethnicity data from a Census of the population to health information e.g., the Scottish Health and Ethnicity Linkage Study. Ethnicity is difficult to measure, however, and almost half of European Union countries do not record it, often for historical or political reasons. The integration of data about migration status in health information systems is also limited.
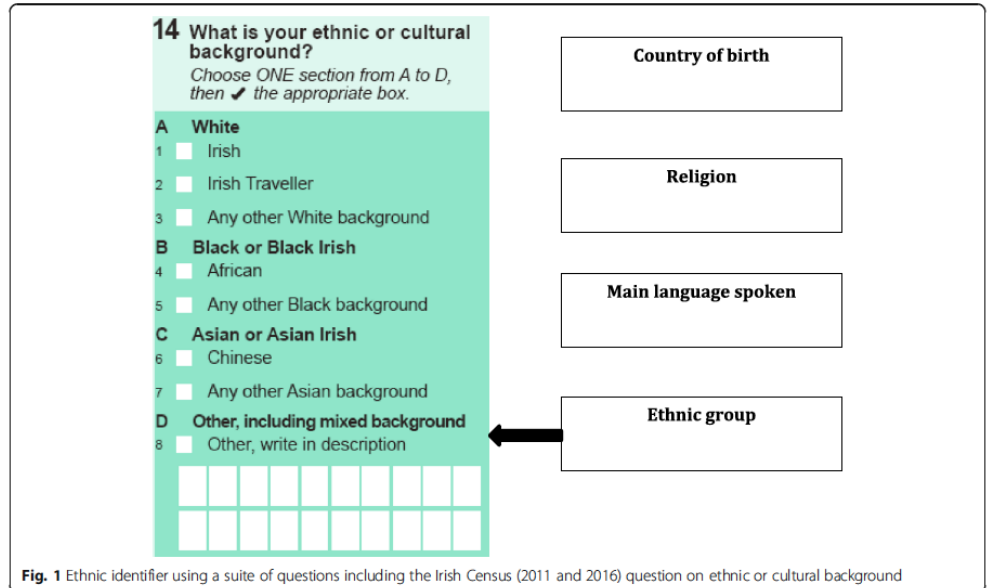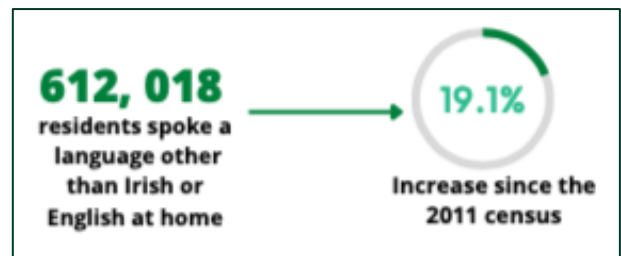

Fig. 1 Ethnic identifier using a suite of questions including the Irish Census (2011 and 2016) question on ethnic or cultural background

Ethnicity data collection in Ireland

In Ireland, ethnicity has been recorded since 2006 in the Census of the Population using a question about ethnic or cultural background. **In the 2016 census...**

Following a consultation exercise by the CSO, the question about ethnic or cultural background will change in the next Census in 2022 with new categories added.

Given the increasing cultural and linguistic diversity of Irish society**, it is essential that equality monitoring measures are in place and reviewed in this way.** Indeed, equality monitoring in the health services is a legal requirement under Section 42 of the Irish Human Rights Equality Commission Act (2014), referred to as the Public Sector Duty. The Health Service Executive has used the ethnicity question in the Census, combined with questions about country of birth, language and religion to develop a holistic view of ethnicity in an ethnic identifier.

In line with the broader policy context for migration and integration, **implementation of this ethnic identifier throughout the HSE, including in primary care, is a priority action in the Health Service Executive (HSE) Second National Intercultural Health Strategy (NIHS) 2018-2023**. This research was designed to support the implementation process.

ABOUT THE STUDY

What did we do and how?

This research was developed through the Partnership for Health Equity, which is a partnership between the HSE National Social Inclusion Office, North Dublin City GP training programme, Irish College of General Practitioners and the University of Limerick School of Medicine. **The research was participatory**, meaning that it was designed and conducted with community partners from the Intercultural and Diversity Education Centre, Ireland and Shannon Family Resource Centre, as well as with partners from the HSE National Social Inclusion Office.

We completed a <u>quantitative and qualitative study</u> shown in the following table:

STUDY TYPE	FOCUS	WHAT WE DID
QUANTITATIVE	**Where** data is currently collected and **how** it is being used?	• We conducted an **electronic search** of the Health Information and Quality Authority (HIQA) catalogue of national health and social care data collections (N = 97 data collections) to identify any collections which contained information on ethnicity. • For each of the data collections that collected information on ethnicity, **we extracted data on the ethnic categories used and how this data is collected**; the completeness of ethnicity recording; and other measures related to ethnicity in the data collection. • Relevant outputs for these data collections, related to ethnicity, were **identified through key informants and electronic searches** and examined to see how the data had been used.
QUALITATIVE	Identify **levers and barriers** to implementing the HSE ethnic identifier in general practice settings where most of us access care.	• We used **Normalisation Process Theory** to design fieldwork • We conducted **ten focus groups** with 62 community members comprised of Travellers and migrants. We conducted interviews and one focus group with 8 GPs. All 70 participants were living in the Mid-West of Ireland in either a city, town or rural area. • We asked all participants **does the idea of ethnicity data collection** *make sense* to you? Would you *engage* with and 'buy into' the data collection process?

WHAT DID WE FIND OUT?

FROM THE **QUANTITATIVE** STUDY:
- We found that of the 97 data collections in the HIQA catalogue, **only 14 (14%)** collected information on ethnic or cultural background.
- Country of birth was collected by **10 of these 14 data collections**.
- **Most used the ethnic categories in the Census** and recommended that ethnicity should be self-identified and not assigned. Reported rates of identification were generally high (≥90%) but lower for some infectious disease notifications.
- Data collections which recorded ethnicity tended to be **focused on potentially high-risk populations** e.g., for treatment for drug or alcohol problems, or with infectious diseases.
- There was no routine recording in primary care.

- Limiting data collection to high-risk populations **may stigmatize members of ethnic minorities and reinforce common myths** about being carriers of disease and a burden to the system.
- There are some examples of where ethnic equality monitoring had informed targeted interventions (e.g., vaccination awareness initiatives or cultural training for healthcare staff). Overall, however, **there was under-utilisation of existing data to inform policy and practice.**
- Data integrity of ethnicity, which measures accuracy and consistency of **data from multiple sources had not been audited**. This requires data linkage which is challenging in Ireland due to a fragmented information technology structure, lack of governance and, until recently, no unique health identifier.

FROM THE **QUALITATIVE** STUDY:
- **The link between ethnicity and health was often considered relevant by community members and GPs** because they grasped connections with genetic (skin colour, lactose intolerance), geographic (prevalence of disease, early years exposure), behavioural (culture, food) and social determinant (housing) factors. The link between health and religion was less clear for participants.
- **Most participants thought that the categories for measuring ethnicity were fine, but they were problematic for others**; for some there was too much of a focus on distinguishing between Irish and non-Irish, leading to 'othering' (e.g., being categorised as Black *or* Black Irish) and for others the categories did not capture the complexity of mixed ethnicities.
- There was some **scepticism** among community members about how the collection of data would benefit GP consultations and **concerns regarding confidentiality** and the actual uses of the data (e.g., risk of discrimination, social control).
- **GPs wanted to know, how would this fit into the existing workload in general practices?**
    - They emphasised **the difficulty in explaining a complex concept such as 'ethnicity'** in the limited time available in consultations.
    - They also asked **what added value would ethnicity data collection bring to their consultations and, was it was their role to collect this data?**
    - Their biggest concern was about **data protection issues** in light of the European Union General Data Protection Regulation (GDPR).
    - When consulted about this specific issue, the Irish College of General Practitioners Information Technology Group advised that **ethnicity is highly sensitive data** that would not be routinely collected in General Practice - it should be recorded on an "as required" basis where it is considered to be medically relevant. This means that the role of GPs collecting ethnicity data for ethnic monitoring purposes is not supported by a key stakeholder group. **This represents a barrier to the NIHS 2019-2023 actions to implement an ethnic identifier in primary care.**

CONCLUSION

Ethnicity data collection in health and social care data collections in Ireland is **underdeveloped, fragmented** and has too much focus on **high-risk populations**. While the idea of ethnicity data collection in general practices broadly makes sense to community members and GPs, **there is a lack of coherence between key policy and professional stakeholders about ethnicity data collection in this setting**. There is scepticism and concerns among GPs and community members about data use/misuse. There are concerns about the practicality of collecting ethnicity data effectively in general practice settings, which are under resourced. **Overall, this analysis shows that the barriers to implementing ethnicity data collection in general practice settings in Ireland outweigh the levers**. **Other options for ethnicity data collection should be pursued.**

RECOMMENDATIONS:

1. A **multi-sectoral partnership approach** between community organisations and advocates, academia, HSE and the government is needed if meaningful and comprehensive ethnicity data collection is to be achieved in Ireland. This partnership could have a role to inform decisions about what data is collected (ethnicity and migration variables), annually monitor if data collection is GDPR compliant and if effective use is being made of collected data.
2. **Initiatives are needed to reassure people** in ethnic minority and migrant communities that systems are in place to oversee the collection, security and use of their data.
3. Given the current fragmented approach and documented barriers to data collection, consideration should be given to **include ethnicity and migration variables in an Individual Health Identifier record**. The Individual Health Identifier needs to be implemented across the health service and data linkage infrastructure used to ensure comprehensive knowledge about the relationship between ethnicity and health.

ACKNOWLEDGEMENTS

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