

# BMJ Open Ethnic Minority Health in Ireland – Co-creating knowledge (EMH-IC): a participatory health research protocol

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**To cite:** Hannigan A, Basogomba A, LeMaster J, *et al.* Ethnic Minority Health in Ireland—Co-creating knowledge (EMH-IC): a participatory health research protocol. *BMJ Open* 2018;**8**:e026335. doi:10.1136/bmjopen-2018-026335

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2018-026335>).

Received 30 August 2018  
Revised 13 September 2018  
Accepted 28 September 2018



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## ABSTRACT

**Introduction** International policy recommends continuous, cost-effective monitoring of health data to enable health services to identify and respond to health inequities as experienced by different ethnic groups. However, there is a lack of routinely collected ethnicity data, particularly in primary care, and very little implementation research internationally to understand how ethnic identifiers are introduced, embedded and used in healthcare settings. This paper describes a protocol for a novel participatory health research project with the objective of building the evidence base on ethnic minority health in Ireland. Findings on the participatory appraisal of ethnic identifiers as an intervention to generate useful data about minority and majority ethnic groups will have relevance in other settings and countries.

**Methods and analysis** This multidisciplinary project is designed as a participatory health research study where all stakeholders, including ethnic minority communities, participate in co-design of the research protocol, project governance, collaborative data interpretation and disseminating findings. A national catalogue of all routinely collected health data repositories will be electronically searched for any repositories that contain information on ethnicity. A secondary quantitative analysis of a population-representative cohort study, Growing Up in Ireland, will be carried out to compare the health of ethnic minority and majority groups. A qualitative case study informed by normalisation process theory will be carried out at three primary care sites to monitor the implementation of an ethnic identifier and identify barriers and levers to implementation.

**Ethics and dissemination** Ethical approval for the qualitative case study has been granted by the Irish Council for General Practitioners (06/09/17). Permission to access data from Growing Up in Ireland has been granted by the Director General of the Central Statistics Office. Dissemination will be carried out at community events and academic conferences, in peer-reviewed journal publications, and through academic and healthcare provider networks.

## INTRODUCTION

There is evidence that health, well-being and health service utilisation vary by ethnicity.<sup>1–4</sup> For example, some ethnic minority groups have been identified as having a higher

## Strengths and limitations of this study

- This is the first study to use a participatory health research approach to involve communities in examining the implementation of ethnic identifiers in primary care.
- It is a multidisciplinary project using both qualitative and quantitative methods to build the evidence base on ethnic minority health.
- The qualitative case study is informed by a theoretical framework, which focuses on the work that people do to operationalise complex interventions into their daily routine.
- The quantitative study is population-representative of families in Ireland but doesn't include adults without children.
- The project only has resources for three case study sites in one region, which are unlikely to represent the full range of primary care settings but will be chosen to maximise transferability of findings.

prevalence of diabetes, worse diabetes control and higher rates of complications than majority ethnic groups.<sup>5</sup> A fundamental step in identifying health inequities is through ethnic equality monitoring where 'information about the relevant aspects of people's ethnic origins is collected, recorded and used to establish patterns, which can be compared with other information about their relationship with society and need'.<sup>6</sup> Ethnic equality monitoring can enable health services to respond to health inequities as experienced by different social groups, to deliver culturally appropriate health services and to enable effective clinical management of patients.<sup>7</sup>

International policy recommends continuous, cost-effective monitoring of data related to equality and discrimination while acknowledging the sensitivity of data on ethnicity and the lack of an agreed definition.<sup>8,9</sup> Country-specific ethnic identifiers have been developed and adapted in several countries, eg, the USA, the UK, Australia, New Zealand and Canada. There are

examples of resources to promote the use of ethnic identifiers<sup>10</sup>; however, there is a pattern of poor uptake and a lack of routinely collected ethnicity data,<sup>4</sup> particularly in primary care.<sup>7</sup> Limited use of the data collected has also been reported.<sup>11</sup>

Despite the challenges in implementing ethnic identifiers, there is very little implementation research internationally to investigate how ethnic identifiers are introduced, embedded and used in healthcare settings. There is also growing interest in the use of theoretically informed implementation research<sup>12</sup> and a range of theories and conceptual frameworks are in use, each offering a particular perspective.<sup>13</sup> The value of implementation research in this context would be to demonstrate when and where barriers and levers to implementation occur and to elucidate how barriers impact on the nature, quality and use of the data being recorded. For example, concerns about classifications of ethnicity<sup>4</sup> and lack of use of the data could reduce 'buy-in' from health service providers and service users. Health service providers' reluctance to request data for fear of giving offence could lead to missing and incomplete data. Language barriers could limit service users' ability to understand the reasons for the data being collected.<sup>7</sup>

Given international recommendations to involve ethnic minority groups, and in line with broader imperatives to involve communities in health research,<sup>14 15</sup> any exploration of the implementation of ethnic identifiers should involve ethnic minorities. To our knowledge, however, there are as yet no examples of this in the literature. Because ethnicity is a multifaceted, fluid and subjective concept,<sup>16</sup> such involvement is essential to ensure that the complex interlinks between different dimensions of ethnicity (eg, skin colour, religion, language) are represented by both *insider* (emic) and *outsider* (etic) perspectives.

We have developed a participatory health research partnership with academic, community and health sector partners with the objective of building the evidence base on ethnic minority health in Ireland to address health inequities. Specifically, we aim to:

1. Identify all existing national data repositories with information about ethnicity and health.
2. Use one existing data repository to compare the health of minority and majority ethnic adults.
3. Conduct a theoretically informed qualitative case study to research the implementation and utility of an ethnic identifier in primary care.

This research will lay the foundation for strengthening the evidence base on ethnic minority health in Ireland but will also contribute to the international health policy agenda around ethnicity and migrant health. Given the lack of theoretically informed research on the implementation of ethnic identifiers, findings from this project will have relevance in other settings and countries.

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

What is your ethnic or cultural background?	(A) <i>White</i> Irish Irish Traveller Any other White background (B) <i>Black or Black Irish</i> African Any other Black background (C) <i>Asian or Asian Irish</i> Chinese Any other Asian background (D) <i>Other, including mixed background</i> Other, write in description
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Country of birth

Religion

Main language spoken

## METHODS AND ANALYSIS

### Setting and context

In the Irish context, the majority ethnic community refers broadly to Irish-born white people. The ethnic minority community refers to the indigenous community of Irish Travellers (0.7% of the population) and more recently arrived migrants. The Republic of Ireland is an increasingly diverse society, with the number of foreign-born living there representing 17% of the population in 2016, the fifth highest in the EU-28.<sup>17</sup>

In line with international policy, the Irish health service has proposed a system-level response to record data about ethnicity: an ethnic identifier (see [table 1](#)) embedded in existing health information systems. Ethnic equality monitoring is also supported by the national non-governmental organisation (NGO) that works to promote Traveller and Roma rights in Ireland.<sup>18</sup> However, in keeping with international experience, there is no routine collection of data about ethnicity across the Irish health service and no systematic mapping of where it occurs or how it is used. While there has been a considerable amount of qualitative research about ethnic minorities in Ireland, there is a lack of quantitative research comparing the health of majority and minority ethnic groups at a population level.<sup>19</sup>

### Patient and public involvement

Ethnic Minority Health in Ireland—Co-creating knowledge (EMH-IC) is a 3-year project (2017–2020). It is designed as a participatory research project where research is co-constructed between researchers, community members and decision makers who apply research findings.<sup>20</sup> Its design follows the four criteria for participatory health research set out by Jagosh *et al*<sup>20</sup>: participation of all stakeholders in the development of the research protocol, project governance, data interpretation and dissemination of findings. Academic project

leads in EMH-IC represent the disciplines of biostatistics, sociology, political science and public health, and have worked with a broader group of stakeholders from community organisations and the national health service in the co-construction of the research question. To facilitate collaborative decision making, a Steering Group composed of different stakeholders including community members will oversee the conduct of this research and will participate in data interpretation and dissemination.

We are mindful of the power differentials in mixed stakeholder groups and are aware that there can be real difficulties in creating an environment that allows all voices to be heard equally and in a meaningful way. In anticipation of this, we plan to support this collaborative decision-making process in Steering Group meetings using Participatory Learning and Action (PLA) techniques. PLA is an adaptive strategy that enables diverse groups and individuals to learn, work and act together in a co-operative manner, to share, enhance and analyse their knowledge and to plan together for positive action.<sup>21</sup> It has been used successfully to facilitate the meaningful engagement and contribution of ‘hard to reach’ migrant groups in primary healthcare research.<sup>22</sup>

Resources have also been allocated in the project for community development and liaison workers from ethnic minority communities to work alongside academic researchers and support recruitment and field work.

Within this participatory health research design, EMH-IC will involve both qualitative and quantitative research. The individual work packages are summarised in [table 2](#).

### Mapping existing data repositories

*Objective 1* is to create an inventory of all existing national data repositories that can be accessed to conduct secondary quantitative data analysis about ethnicity and health.

The Health Information and Quality Authority is an independent authority with responsibility for advising on the efficient and secure collection and sharing of health information, setting standards and evaluation of

information resources in the Republic of Ireland. It has produced a catalogue of all 120 national repositories of routinely collected health and social care data, including administrative collections, censuses, national routine surveys and patient registries.<sup>23</sup> This catalogue will be electronically searched for any data repositories that contain information on ethnicity. Data dictionaries for repositories will also be searched and key informants for repositories contacted.

The following information will be collected for each of the data repositories that collect information on ethnicity:

- ▶ The ethnic categories used and how this data is collected, for example, self-identified by the service user or assigned by service providers.
- ▶ Other measures related to ethnicity in the data set, for example, language spoken at home, country of birth, religion.
- ▶ Measures of health outcomes and/or healthcare utilisation recorded.
- ▶ Data controller for the data (defined as the individual or the legal person who controls and is responsible for the keeping and use of the data).
- ▶ Format of the data set (electronic, structured manual files).
- ▶ Availability, procedures for ethical approval and access to the anonymised data for research.
- ▶ Whether the data set has previously been analysed for differences in healthcare utilisation, access and/or health outcomes by ethnicity and any available reports of this analysis.

This information will be brought to Steering Group meetings and discussed to consider its relevance for the implementation of an ethnic identifier in primary care. For example, evidence about where existing information about ethnicity is stored and how it is shared may be relevant to fieldwork with service providers and service users. A guidance document for progressing secondary data analysis of existing data sets in Ireland about ethnic minority health will be produced to facilitate ethnic equality monitoring.

**Table 2** Work packages, objectives, design and analysis of EMH-IC

Work package	Objective	Study design	Sample size and participants	Data analysis
1	To identify where and how ethnicity is recorded in routinely collected health data.	Mapping and scoping exercise.	120 data repositories.	Descriptive analysis of data repositories with information on ethnicity and health.
2	To compare the health of ethnic minority and majority groups.	Secondary quantitative data analysis of <i>Growing Up in Ireland</i> .	11 134 mothers (16% from a minority ethnic group) and 8430 fathers (17% from a minority ethnic group).	Regression analysis of health outcomes over time by ethnic group, adjusting for confounders.
3	To explore the implementation of an ethnic identifier in primary care.	Qualitative case study.	Three primary care sites with interviews and focus groups of health service providers and service users.	Deductive data analysis informed using <i>Normalisation Process Theory</i> .

## Comparing the health of minority and majority ethnic groups at a population level

*Objective 2* is to conduct a secondary quantitative analysis of one existing data repository to compare the health of minority and majority ethnic groups.

We will use the Growing Up in Ireland (GUI) Infant Cohort Study, which is a government-funded national longitudinal study of over 11 000 Irish children aged 9 months at baseline in 2008/9 and followed up at age 3 and 5 years.<sup>24</sup> The aim of GUI is describe and understand all aspects of the development of the children, but detailed information is also available on their primary and secondary caregivers (parents), who are the primary focus of EMH-IC.

The rationale for using GUI is that:

- ▶ GUI is a population representative study that uses the same ethnic identifier as the national census. It also records nationality, citizenship, language spoken at home, religion and length of time spent living in Ireland for parents. It provides, therefore, an opportunity to compare data for ethnic minorities with other groups.
- ▶ The national census in 2011 reported that the majority of foreign-born are in the 22-year to 44-year age group and half of private households headed by foreign-born have children. Parents in GUI are younger than 50, so this study is more likely to represent the increasing ethnic diversity of the Irish population than older cohorts.
- ▶ GUI uses valid and reliable scales for measuring stress and depression, and also International Classification of Diseases coded, self-reported chronic health conditions, which will allow for comparison with international studies. Trained fieldworkers measured height and weight of parents in the home, providing objective measurements of obesity.
- ▶ GUI records detailed socio-demographic information on parents including highest level of education, employment status, income and eligibility for free healthcare, which will facilitate adjusting for potential confounders in comparative analysis.
- ▶ The time period covered by GUI (from 2008 to date) represents a time of significant social and economic challenges for Ireland and an opportunity to explore the impact of these on the health and well-being of ethnic minority groups over time.

### Data analysis

A descriptive analysis of health variables at each time point by ethnicity, language spoken at home and length of time spent living in Ireland will be carried out. Hypothesis tests will be used to test for significant differences/associations between health variables and ethnic groups at each time point. Minority ethnic groups will be matched to majority ethnic groups using propensity score matching across socio-demographic characteristics (eg, partner in the home, highest level of education, eligibility for free healthcare, employment status). A regression analysis of

health outcomes will be carried out at each time point, adjusting for socio-demographic confounders.

This proposed statistical analysis will provide findings about:

1. Self-reported health status, barriers to accessing healthcare, prevalence of chronic health conditions, objectively measured body mass index and well-being of parents by ethnic group with a subgroup analysis by language spoken at home and length of time spent living in Ireland.
2. Changes over time in the health and well-being of parents by ethnicity.

Findings will be presented to the Steering Group so that they can contribute to data interpretation and the development of recommendations.

### Implementing an ethnic identifier in primary care

*Objective 3* is to conduct a qualitative analysis of the implementation of an ethnic identifier in primary care services to generate knowledge about health differences between minority and majority ethnic groups, focusing on the utility of questions about ethnicity. This is designed as a theoretically informed case study,<sup>25</sup> drawing on an internationally recognised theory of implementation—Normalisation Process Theory (NPT).<sup>26</sup>

The rationale for using NPT in this study is that it differs from other theories because of its focus on the work that stakeholders in healthcare settings have to do individually and collectively to embed a new way of working in practice to the point of normalisation. NPT has four constructs (see [table 3](#)) which describe the work that stakeholders have to do to implement innovation in healthcare settings. In this study, we will use NPT as a heuristic device to generate specific questions about the implementation process and to monitor the implementation of the ethnic identifier in primary care.

### Case selection

We will sample contrasting primary care sites to generate comparative data about the implementation work required to introduce, embed and sustain the use of an ethnic identifier in daily practice. Participating sites will have a significant proportion of service users who are from ethnic minorities. The sites may differ in terms of the nature and strength of links to community, whether they are large or small scale, and whether they represent traditional general practices, recently developed primary care centres with co-located primary care professionals or services targeted at marginalised communities. The Steering Group will co-operate to develop criteria to select sites.

### Sampling and recruitment at selected sites

We will follow the principles of purposeful and network sampling and recruitment at the recruited sites.<sup>27</sup> Using a combination of letters, emails and meetings, we will recruit ethnic minorities attending the services as well as clinical and administrative staff involved in the

**Table 3** NPT constructs applied to the implementation of an ethnic identifier

NPT construct and explanation	NPT-informed questions
<i>Coherence:</i> What sense do stakeholders make of the ethnic identifier?	Is an ethnic identifier considered valuable and worthwhile to all stakeholders? Do they think the current situation (no use of an ethnic identifier) needs to be changed?
<i>Cognitive participation:</i> Do stakeholders buy into it and seek to drive it forward?	Do primary care staff think that it is part of their role to engage with the use of ethnic identifier? Will minority ethnic groups 'buy into' the idea of answering questions about their ethnicity or will concerns about for example, confidentiality impact on their engagement?
<i>Collective action:</i> What is required to enact the ethnic identifier in daily practice?	What are the time implications for service providers of asking questions about ethnicity? Are primary care information systems able to incorporate the data about ethnicity with other practice-level data? Are healthcare staff skilled to ask questions about ethnicity in an effective manner? How might questions about ethnicity impact on trust in service user–service provider relationships?
<i>Reflexive monitoring:</i> Can stakeholders appraise the impact of the ethnic identifier on their work?	Will the use of an ethnic identifier produce useful data to compare health between minority and majority ethnic groups? Does the current ethnic identifier need to be changed or reconfigured to make it more useful?

organisation and delivery of care. We will seek to identify a small inter-stakeholder implementation group at each site who will take on ownership of the implementation work and liaise with their clinical and administrative colleagues and service users in their setting.

### Data generation and analysis

Drawing on the four NPT constructs and relevant NPT-informed questions (see [table 3](#)), the focus of the fieldwork will be to:

- ▶ Introduce the ethnic identifier in the selected sites to the implementation group and explore their sense-making (*NPT coherence*) and engagement (*NPT cognitive participation*) work
- ▶ Monitor the progress of the implementation group to introduce and embed the ethnic identifier in their practice setting, exploring any arising levers and barriers to enactment work (*NPT collective action*). This will include the provision of training in ethnicity for clinical and administrative staff and exploring their experiences of asking questions about ethnicity in practice. It will also include exploration of service users' experiences of being asked questions about ethnicity. We will seek examples of what is working well, what is problematic and what solutions/alternatives may be relevant.
- ▶ Appraise the data about ethnicity that is produced in each practice setting and explore how it can be used in conjunction with other practice data to identify differences between ethnic majority and minority groups (*NPT-reflexive monitoring*). For example, we will compare data about practice consultation rates, utilisation of out-of-hours services, prescriptions and diagnostic test results by ethnicity. Appraisal also involves exploring what changes, if any, need to be made to the ethnic identifier to increase the likelihood that it will be sustained in routine practice.

Specific methods for data generation will be designed in consultation with the Steering Group, but we anticipate:

- ▶ Focus groups with the implementation group every 2–3 months to explore their experience of sense-making and driving the work forward
- ▶ One-to-one interviews with clinical and administrative staff about their experiences of sense-making and enactment at two time points (early and late in the implementation process)
- ▶ Focus groups with service users about their experiences of sense-making and enactment at two time points (early and late in the implementation process).

Outcomes from this qualitative fieldwork will include:

1. Knowledge about the success of the implementation of questions about ethnicity in three primary care sites
2. Identification of site-specific and more generic levers and barriers to implementation
3. Identification of site-specific and more generic solutions to identified barriers
4. Knowledge about the utility of an ethnic identifier to identify differences in health status and health service utilisation between ethnic groups.

### Ethics and dissemination

Work relating to *objective 1* involves the development of an inventory of existing national data repositories with no participant contact. Work relating to *objective 2* involves the secondary analysis of GUI with no participant contact. Approval to access the researcher microdata file for GUI has been granted by the Director General of the Central Statistics Office, with authors AH and NV appointed as Officers of Statistics under the Statistics Act, 1993.

Work relating to *objective 3* will involve fieldwork in three primary care sites. Given the focus on collection of data about ethnicity, we acknowledge that this is a sensitive area that may cause distress for some participants, particularly service users. To address this, recruitment at the

selected case study sites will draw on community networks and we will endeavour to make the purpose and importance of service users' voices in the research very clear, with information leaflets and consent forms translated into languages as appropriate and developed for low-literacy groups as required. Data generation encounters will be conducted by trained community researchers to address language and cultural needs. Information on the research findings will be made available to all participants and the wider community so that there is a clear 'feedback loop' between the research and the community. Presentations will be carried out at community events recommended by community partners in EMH-IC.

We also plan to engage researchers and policy-makers nationally and internationally with the results of the study through academic conference presentations, peer-reviewed journal publications, academic and healthcare provider networks and links with the WHO Public Health and Migration Regional Office for Europe.

## DISCUSSION

The relationship between ethnicity and health is complex and, as countries become more ethnically diverse, valid and reliable data is required to understand this relationship, inform healthcare policy and address inequities.<sup>28 29</sup> Given the sensitivity of the data, the challenges in generating meaningful, context-specific categories for ethnicity<sup>30</sup> and broader imperatives to involve communities in health research, deciding what data to collect and how to collect it should involve community members from different ethnic groups. This also allows some critical exploration of the utility of existing ethnic categories and the data they produce. As Salway recently argued, systematically considering when, why and how to employ or reject ethnic categories is important.<sup>31</sup> It can help us to unpack and navigate the complex relationships between ethnicity and health. In this paper, we describe a protocol for a participatory health research project to build the evidence base on ethnic minority health in Ireland, in partnership with academics, ethnic minority communities and healthcare providers.

A first step is to map what information is currently collected on ethnicity in existing national health information systems. Effective and efficient use of this information should avoid costly duplication of data collection and provide the opportunity for continuous monitoring of health outcomes.<sup>8</sup> We anticipate that this mapping exercise will inform EMH-IC but also be of use nationally to health researchers and policy-makers for conducting secondary data analysis and monitoring of policy implementation.

Through the analysis of a large-scale, population-representative cohort study, we aim to provide evidence on the nature of the association between multiple health outcomes and ethnicity in the Irish context over time, adjusting for socio-economic status. Given increasing evidence of the variability in the social determinants

of health, health behaviours and outcomes in different ethnic groups,<sup>32</sup> this analysis will add to the international literature by providing data on these patterns in another national context. Understanding the complex patterns between health outcomes, ethnicity and the social determinants of health can inform evidence-based, targeted and culturally appropriate interventions and potentially improve the health of the whole population.<sup>29</sup>

Despite the need for valid and reliable data on ethnicity, many challenges have been documented in the literature on the implementation of an ethnic identifier, including poor uptake and use of data.<sup>7</sup> The use of a theoretically informed case study in EMH-IC, providing the opportunity to understand the barriers and levers to implementation and the appraisal of an ethnic identifier as an intervention to generate useful data about minority and majority ethnic groups, will have international relevance, which we will explore. NPT is particularly useful in this context because, unlike other theories, it focuses on the work that people do to operationalise complex interventions and new technologies into their daily routine.<sup>33 34</sup> The use of this theoretical framework will allow us to provide a coherent explanatory account so that the depth of understanding from the examination of a specific case-study will allow us to draw conclusions that are transferable to other settings (*conceptual* generalisability). We anticipate that the use of NPT as a theoretical framework will thus enhance the generalisability of findings in EMH-IC across healthcare settings in other countries.

Taken together, the findings from EMH-IC will build the evidence base on the health of ethnic minorities in Ireland and will also contribute to the international health policy agenda around ethnicity and migrant health.

**Acknowledgements** Maura Adshead for contributing to the proposal for funding and membership of the Steering Group. Austin O'Carroll, James Whitney and Santino Severoni for contributing to the proposal for funding. Steering Group members from Shannon Family Resource Centre, Shannon, Co. Limerick who are partners in the conduct of EMH-IC: Colette Bradley, Adelle Aherne, Ashling Romer, Ana Papyan, Sharon McCarthy.

**Contributors** AH, AB, JLM, DN, FOR and AM co-constructed the research question and proposal for funding. AH, AB, JLM, DN, MR, NV and AM are members of the Steering Group. AH 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 (HRA-PHR-2015-1344).

**Competing interests** None declared.

**Patient consent** Not required.

**Ethics approval** Irish Council of General Practitioners Research Ethics Committee (06/09/17).

**Provenance and peer review** Not commissioned; peer reviewed for ethical and funding approval prior to submission.

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