Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Statement of Outcomes

Report on the outcome of the public consultation on the Draft National Standard Demographic Dataset and Guidance for use in all health and social care settings in Ireland

December 2013

Safer Better Care

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive continuous improvement in Ireland's health and personal social care services, monitor the safety and quality of these services and promote person-centred care for the benefit of the public.

The Authority's mandate to date extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, the Health Information and Quality Authority has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for those health and social care services in Ireland that by law are required to be regulated by the Authority.

- **Social Services Inspectorate** – Registering and inspecting residential centres for dependent people and inspecting children detention schools, foster care services and child protection services.

- **Monitoring Healthcare Quality and Safety** – Monitoring the quality and safety of health and personal social care services and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health Technology Assessment** – Ensuring the best outcome for people who use our health services and best use of resources by evaluating the clinical and cost effectiveness of drugs, equipment, diagnostic techniques and health promotion activities.

- **Health Information** – Advising on the efficient and secure collection and sharing of health information, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

Overview of Health Information function

Health is information-intensive, generating huge volumes of data every day. Health and Social Care workers spend a significant amount of their time handling information, collecting it, looking for it and storing it. It is therefore imperative that information is managed in the most effective way possible in order to ensure a high quality, safe service.

Safe, reliable, health and social care depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a service user a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right service user and that the service user is not allergic to it. Similarly, lack of up-to-date information can lead to the unnecessary duplication of tests – if critical diagnostic results are missing or overlooked, tests have to be repeated unnecessarily and appropriate treatment may be delayed or not given. In a children's residential centre, family access arrangements need to be communicated and recorded to inform a child's care plan.

In addition, health information has a key role to play in health and social care planning decisions – such as where to locate a new service, or whether or not to introduce a new national screening programme and decisions on best value for money in health and social care provision.

Under section (8) (1) (k) of the Health Act, 2007 the Authority has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, the Authority is charged with evaluating the quality of the information available on health and social care (Section (8) (1) (i)) and making recommendations in relation to improving the quality and filling in gaps where information is needed but is not currently available (Section (8) (1) (j)).

Information and Communications Technology (ICT) has a critical role to play in ensuring that information to drive quality and safety in health and social care settings is available when and where it is required. For example, it can generate alerts in the event that a service user is prescribed medication to which they are allergic. It can support a much faster, more reliable and safer referral system between the GPs and hospitals. It can help identify trends in notifiable incidents in nursing homes.

Although there are a number of examples of good practice the current ICT infrastructure in health and social care is highly fragmented with major gaps and silos of information. This results in service users being asked to provide the same information on multiple occasions.

Information can be lost, documentation is poor, and there is an over-reliance on memory. Equally those responsible for planning services may experience great difficulty in bringing together information in order to make informed decisions. Variability in practice leads to variability in outcomes and cost of care. Furthermore, individuals are being encouraged to take more responsibility for their own health and well-being, yet it can be very difficult to find consistent, understandable and trustworthy information on which to base their decisions.

As a result of these deficiencies, there is a clear and pressing need to develop a coherent and integrated approach to health information, based on standards and international best practice. A robust health information environment will allow all stakeholders – the general public, patients and service users, health and social care professionals and policy makers – to make choices or decisions based on the best available information. This is a fundamental requirement for a highly reliable health and social care system.

Through its health information function, the Authority is addressing these issues and working to ensure that high quality health and social care information is available to support the delivery, planning and monitoring of services. A key requirement is the ability to accurately and consistently identify service users. Hence, one of the areas currently being addressed through this work programme is the development of a national standard demographic dataset and guidance for use in health and social care settings in Ireland.

Contents

1. Introduction and background to the National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland

Safe and reliable health and social care depends on access to, and use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. A demographic dataset is essential to provide core information about an individual. It comprises of identifying data elements about the subject of care, including, for example, the individual's date of birth, name and address as well as other items associated with an individual.

The purpose of the national standard demographic dataset for health and social care services in Ireland is to remove the duplication and variation within and between service providers when collecting patients' and service users' demographic data. It will also assist all service providers, including primary care centres, general practitioners, hospitals, allied health professionals, children's residential centres and residential centres for older people to collect standard core data about patients and service users.

The development of a national standard demographic dataset will help to standardise how demographic data is recorded and facilitate easier sharing of information within and between health and social care services. This will help reduce duplication in a number of areas, including, for example, fewer duplicate records, appointments, testing and prescribing, resulting in time, administration and cost savings. A national standard demographic dataset will also assist with more accurate tracking and trending of the demographic breakdown of those using health and social care services, enabling better planning of services and care provided.

The current absence of a standardised national demographic dataset in Ireland has resulted in health and social care providers developing their own rules for the data items they wish to collect on individuals. The consequence of this ad hoc approach is that there are several different ways to collect the same data item, for example, the name McCarthy can be collected as McCarthy, Mc Carthy or MacCarthy and so forth.

A demographic dataset standardises the core demographic information collected for each individual who uses health or social care services. It identifies an individual's first or given name, surname or family name, date of birth and contact details. Not only does the demographic dataset ensure that the same data items are collected on each individual it also ensures that the data items collected have the same format. For example, date of birth can be collected in several different ways, including mm/dd/yyyy, dd/mmm/yyyy. The demographic dataset sets out that date of birth should be collected as dd/mm/yyyy, removing potential for confusion and potential error. The guidance explains what each data item is and provides suggestions on how to collect each data item.

2. Overview of consultation submissions

The consultation was made up of eight questions, the aim of which was to ascertain the public's opinion on the proposed draft national standard demographic dataset. This statement provides an overview of the submissions received for each question.

In total there were 80 responses, 74% responded on behalf of their organisation, 22% of responses were from individuals, 3% of the responses were on behalf of both, and 1% did not indicate whether the response was individual or on behalf of an organisation. Appendix 1 outlines the organisations that made a submission to the public consultation.

For ease of use and in order to facilitate the widest participation from all possible stakeholders, the consultation responses could be returned by availing of several different media. The choices were to respond online with 'Polldaddy', via email or by post. Of the 80 responses, 51% (n=41) responded via Polldaddy, 46% (n=37) emailed their responses and the remaining 3% (n=2) of the responses were sent by post.

3. Methodology

The draft standards(1) were developed by conducting a review of national practice through examining the demographic data being collected by a number of national agencies both within and outside of health and social care. Relevant international standards were reviewed and detailed discussions were conducted with a number of key stakeholders. Throughout the development of the demographic dataset, the Authority consulted with members of the General Practice Information Technology Group (GPIT) and the Department of Social Protection, Client Identity Services (DSP/CIS).

An eight-week public consultation on the *Draft National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland* took place from 18 February, 2013 to 12 April, 2013. In order to engage as many people as possible, personalised emails were sent to over 380 stakeholders, including the Health Service Executive (HSE), Department of Health, patient groups, interest groups and professional bodies, inviting them to participate in the consultation.

To facilitate the collection of feedback on the draft standards a consultation feedback form was developed (see Appendix 2) which contained eight questions requesting comments on aspects of the *Draft National Standard Demographic Dataset.* This form was made available on the Authority's website in MS Word and PDF formats. In addition the facility to respond online via Polldaddy was provided.

Each submission received was read in its entirety, analysed, and action points decided on. An overview of the submissions is in the next section.

All submissions to the consultation informed the development of the final national standard demographic dataset and guidance. The Authority welcomed all submissions and would like to thank all those who contributed.

4. Feedback from public consultation

The consultation form was divided into eight questions that sought feedback on the draft national standard demographic dataset. The feedback provided suggestions on whether and why to include or remove the proposed data items, in addition to ideas and suggestions on how to improve upon the demographic dataset and guidance. This section provides an overview of the responses for each question.

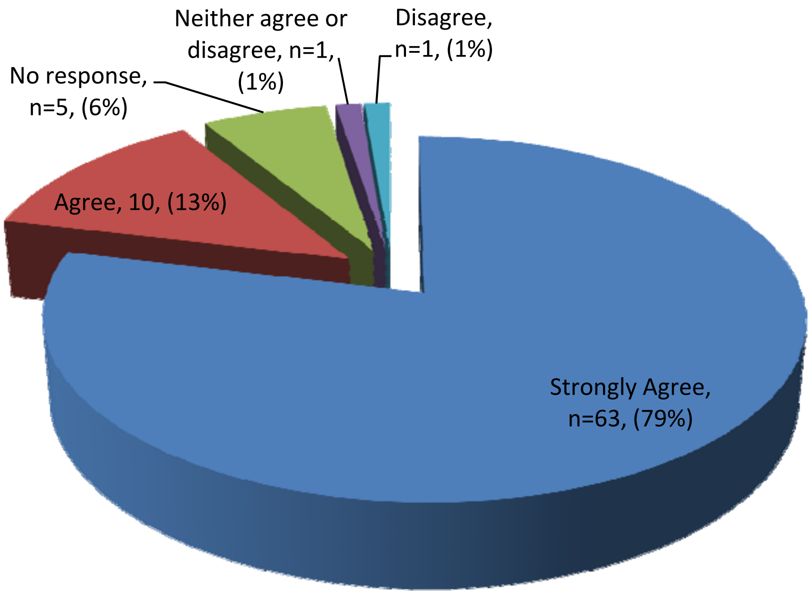
Overall, the feedback was extremely positive, highlighting the requirement for a national standard demographic dataset in the health and social care sector.

4.1 Question 1: Benefit of demographic dataset

Question 1: Do you agree or disagree that there is a benefit to having a national standard demographic dataset?

Question 1 asked if the respondent agreed that there is a benefit to having a national standard demographic dataset? As depicted in Figure 1 on the following page, the majority of respondents, 79%, 'strongly agreed' that there is a need for a standard demographic dataset versus just 1% believing that there is no need for a demographic dataset.

Figure 1. Responses to consultation question one



What the respondents said:

"Great step forward, agree it would reduce duplication of work."

"We support the standardisation of patient data and consider this to be a very good dataset which will assist delivery of healthcare."

"Disagree - feel we get this data already from patients notes –better to audit current practice, heighten awareness of good practice, improve our current documentation practices."

"…I am heartened at the proposal to introduce a national dataset."

"…good to have data set standard - well done."

"It seems complete and workable."

4.2 Question 2: Data items to include

Question 2: Have all the appropriate data items been included in the demographic dataset? Are there additional data items that you think should be included?

Question 2 asked if all of the appropriate data items had been included. There was a significant proportion of the responses requesting the inclusion of ethnicity, changes to gender and accommodation for the proposed new postcode.

Nineteen percent of respondents requested the inclusion of ethnicity. It was felt that it is essential for policy development, planning and research purposes.

The options under gender also generated a broad discussion with 15% of the respondents requesting changes to the options for gender, in the main to incorporate more gender options to help ensure that optimum clinical care is provided.

The potential new postcode was the third area that was of particular interest with 12% of respondents requesting that the dataset include a data item that will accommodate the new postal code, to ensure that the dataset is future proofed.

What the respondents said:

"Yes, all the appropriate data items have been included."

"I think at a high level all are included - much debate recently about whether ethnicity should be included in demographic datasets for health."

"I work in ID and find that lack of reliable data presents duplication of all sorts in terms of service delivery. What I hope is that the proposed data set will enable service providers to plan more strategically based on national data."

"Yes, I think it would be very beneficial if you included an Ethnic Identifier question and specifically the EI question that is now included in the Census."

"Consideration re Nationality and Ethnicity. Need to have some system in place which monitors and ensures equal access for all members of society."

"In relation to the gender classification there should be an option for transgender."

"Is the Gender option "intersex" or "indeterminate" really necessary when "inadequately described" is also an option? As it is a coded text option and although sensitivity is recommended, the risk exists of these terms being used for people undergoing transgender therapy or cross-dressers and may cause hurt. It may be more suitable to keep it within the newborn setting or to ensure the coding includes reference to paediatric or newborn setting."

"…there should be capacity to include the new postal code system, as in the UK, this allows you to input postcode and the address is automatically populated."

"A standard such as proposed here will need to be future proofed. I think some mention should be made of national postcode project? "

4.3 Question 3: Removal of data items

Question 3: Have all the appropriate data items been included in the demographic dataset? Would you *remove* any of the data items listed?

Fifty nine percent (n=47) of respondents had suggestions of data items that they would thought should be removed, religion caused the greatest concern. Twenty five percent (n=20) of the respondents thought that all of the appropriate data items were included, 12% (n=10) did not respond to this question and 4% (n=3) did not think that the appropriate data items were included.

What the respondents said:

"There are no data items that we would suggest to be removed."

"No I think all data items listed are necessary."

"Not sure of the relevance of religion."

"…Religion – is this necessary? I also wondered about including the type of residence a person lives in – is this necessary? While it may be deemed helpful to have certain pieces of information in the dataset, the more information included, the greater the margin for

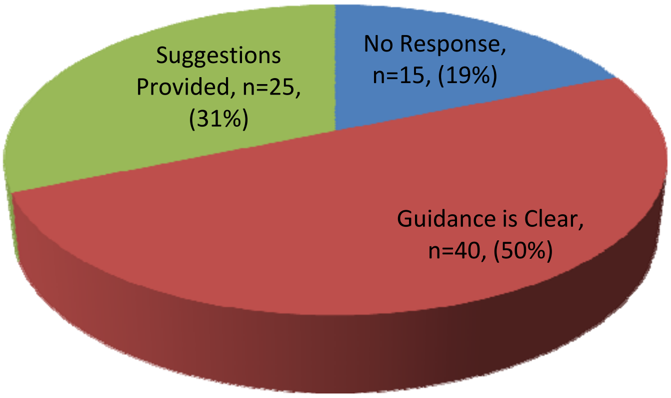
error and the length of time needed to collect the data. I would include only essential information and I would not feel that the type of residence a person lives in or their religion as essential information…"

4.4 Question 4: Is the guidance clear and easy to understand?

Question 4: In your opinion is the guidance that follows each of the tables clear and easy to understand?

Half of the respondents expressed their satisfaction with the guidance for the draft national standard demographic dataset. A number of questions and suggestions were offered, in particular around the recording of names.

Figure 2. Responses to consultation question four



What the respondents said:

"..Guidance is clear.."

"The guidance on the recording of names (use of spaces, apostrophes etc) can be difficult to follow and may not be consistently implemented."

"No, the section in relation to surnames could cause confusion. It is unclear what benefit is to be gained by keeping 'unknown', rather than overwriting, as a surname where the correct one is known. Given that a patient will have a unique identifier this information would appear redundant. "

"In relation to 'Surname', the use of the term 'Family Name' as the primary identification for this data item is preferable. 'Surname' suggests a name other than 'First Name' – for some communities in Ireland their routine naming convention may be 'Family Name' followed by Given Name'."

"..Yes the guidance is clear and easy to understand..."

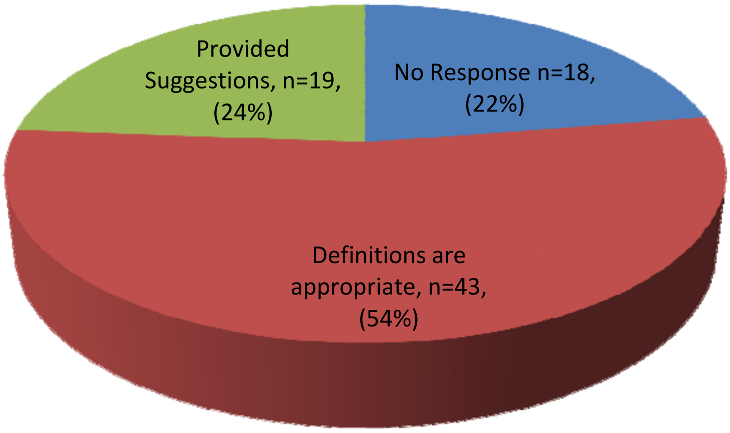
"..Yes guidance is good. No suggestions to make..."

4.5 Question 5: Appropriate definitions

Question 5: Do the definitions provided throughout the document clearly explain each of the data items?

As depicted in Figure 3 a large number of the respondents found that the definitions provide clear explanations for the data items, however, approximately 24% did provide suggestions on how to improve upon the definitions.

Figure 3. Responses to question consultation question five



What the respondents said:

“Yes, the explanations provided are clear.”

“Yes and drawn from international standards as stated so this provides additional weight.”

“…the Given name is not well defined: the name by which the subject of care is uniquely identified.”

“The guidance is fairly good but needs to be ‘irishised’ more. Names - rather than Daniel Lyons II, I think in Ireland we don't use that form as much as the OG, such as Cork hurlers Donal Og Cusack. Sean Og O'Hailpin.”

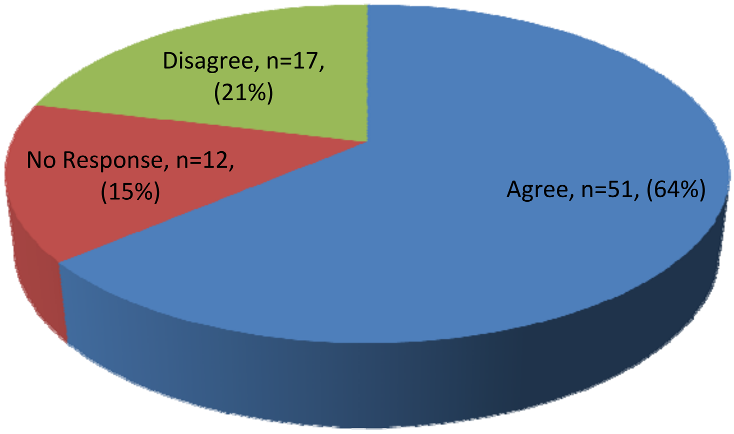
“‘Surname’ – this is identified in the document as the second part of the subject of care’s name – this is not necessarily correct for communities who use their ‘Family Name’ first.”

4.6 Question 6: Optionality for each data item

Question 6: Do you agree with the proposed optionality for each data item?

Sixty four percent of the respondents agreed with the proposed optionality for each data item. Of the 21% that did not agree with the optionality, the main concern was the usefulness of the 'optional' data items. It was queried if they are just optional, will they be completed, or should they be removed?

Figure 4. Responses to consultation question six



What the respondents said:

"…*The guidelines help to provide clarity ON the use of the optionality.*"

"…Too many items are optional and many of them are important items… I would question why are important items such as building or apartment number/ floor level number not mandatory items?.."

"…all optional items could be removed…."

4.7 Question 7: Order of sections

Question 7: Is the order of the sections appropriate or inappropriate?

Seventy four percent (n=59) of the respondents thought that the order of the sections is appropriate, 18% (n=14) did not respond to the question, and 9% (n=7) of the respondents did not think the order was appropriate.

What the respondents said:

"Consider preceding 'address details' with 'communication details.'
Not all subjects of care will necessarily have a geographical or physical address but all should have some form of contact channel for e.g. via a virtual address, mobile telephone number or e-mail address."

"No the order of the sections is not appropriate.
Proposed Order:
-ID
-Bio Id
-Name
-Additional Demographic Details
-Address
-Communication Details."

4.8 Question 8: General Comments

Question 8: Are there any general comments you wish to make in relation to the demographic dataset or guidance?

The responses to this question ranged from the positive and complimentary, to the provision of suggestions on how to improve the dataset.

What the respondents said:

"Delighted that the work is progressing on a national standard demographic dataset."

"Are there training implications and, if so, how will these be catered for?"

"Correct patient/provider identification and common coding approaches underpin the evolution of the E Chart which will enable the provision and ongoing assurance of quality care. In addition, such concepts are essential foundation stones for epidemiology and research."

5. Conclusions and next steps

Once revised, the National Standard Demographic Dataset and Guidance will go through an internal review before the standard is submitted to the Authority's Board for appoval. It will then be submitted to the Minister for Health for mandating and will be published on the Authority's website http://www.hiqa.ie

The level of engagement and interest of all stakeholders including the HSE, health information resources, professional representative bodies, service user representatives and other regulators in the Draft National Standard Demographic Dataset and Guidance was very encouraging. The Authority welcomed all contributions and would like to thank all those who contributed to the public consultation on the Draft National Standard Demographic Dataset.

6. Glossary of terms and abbreviations

Term	**Definition**
Subject of care	Any person who uses or is a potential user of a health or social care service, for example a patient, service user or resident.
Individual Health Identifier (IHI)	An IHI is a unique, non-transferable lifetime number assigned to all individuals accessing health and social care in Ireland. Its purpose is to accurately identify the individual, enabling health and social care to be delivered to the right patient, in the right place and at the right time.(2)
Optionality	Refers to having options. In this case it indicates whether the data element is required or optional. *Required* means that it is mandatory and must be completed; *Optional* means that it needs to be completed when appropriate.

7. References*

(1) Health Information and Quality Authority. *National Standard Demographic Dataset and Guidance*. 2013. Available online from: http://www.hiqa.ie/publications/draft-national-standard-demographic-dataset-and-guidance-use-health-and-social-care-set.

(2) Directive 95/46/EC of the European Parliament and of the Council.1995. Available online from: PrFont34Bin0BinSub0Frac0Def1Margin0Margin0Jc1Indent1440Lim0Lim1Council Directive 95/46.

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[*] Online references were accessed at the time of preparation of this statement of outcomes report.

Appendix 1: Organisations that made submissions to the Public Consultation

The list details the names of the organisations that made submissions to the public consultation in an organisational capacity.

Association of Optometrists Ireland

Barringtons Hospital

Central Remedial Clinic

Children's Rights Alliance

Citizens Information Board

CompleteGP Ltd.

Cork University Hospital

Daughters of Charity

Emergency Medicine Programme

Graduate Entry Medical School, Faculty of Education and Health Sciences, University of Limerick

GS1 Ireland

Health Intelligence, Health Services Executive

Health Information Society of Ireland Nurses and Midwives Group

Health Protection Surveillance Centre

Health Research Board

Health Service Executive, Estates and Procurement, Children and Family Services

Health Service Executive - ICT Directorate

Health Service Executive, Learning and Disability Services, Sligo

Health Service Executive, National Asthma Programme

Health Service Executive, National Contract Office

Health Service Executive, National Dental Office

Health Service Executive, National Immunisation Office

Health Service Executive, Office of the CEO and Quality and Patient Safety Directorate

Health Service Executive, Primary Care Reimbursement Service

Health Service Executive, Sligo/Leitrim/West Cavan PCCC services

Irish College of General Practitioners, IT

Independent Hospitals Association of Ireland

Institute of Community Health Nursing

Institute of Public Health in Ireland

Irish College of General Practitioners

Irish Hospitals Consultant Association

Irish Medicines Board

Irish Nurses and Midwives Organisation

Irish Pharmaceutical Healthcare Association

Irish Pharmacy Union

Irish Society of Chartered Physiotherapists

Mater Misericordiae University Hospital

Mental Health Commission

Mount Carmel Private Hospital

National Acute Medicine Programme

National Cancer Control Programme

National Cancer Registry

National Clinical Programme in Anaesthesia

National General Practice Information Technology Group (GPIT)

National Healthlink Project

National Treatment Purchase Fund

Nursing and Midwifery Board of Ireland

Nursing and Midwifery Planning and Development Unit HSE West/Mid West

Our Lady’s Children’s Hospital, Crumlin

Pre-Hospital Emergency Care Council

Quality Initiatives, Clinical Audit and Accreditation (QCA)

Royal College of Surgeons in Ireland, Faculty of Radiology

Saint John of God Hospital Limited

St James's Hospital Medical Board

St. Joseph's Private Hospital, Sligo

St. Lukes Hospital, Kilkenny, on behalf of Medical Consultants

Súil Eile Management Consultancy

The College of Psychiatrists of Ireland

The Irish Longitudinal Study on Ageing (TILDA)

Appendix 2: Consultation Questions

Q1: Do you agree or disagree that there is a benefit to having a national standard demographic dataset?

Q2: Have all the appropriate data items been included in the demographic dataset?

Are there additional data items that you think should be included?

Q3: Have all the appropriate data items been included in the demographic dataset? Would you remove any of the data items listed? Please explain.

Q4: In your opinion is the guidance that follows each of the tables clear and easy to understand? Please suggest any changes here.

Q 5: Do the definitions provided throughout document clearly explain each of the data items? If not, please suggest improvements.

Q6: Do you agree with the proposed optionality for each data item?

Yes ☐

No ☐

If you disagree with the proposed optionality for certain data items, please explain.

Q7: The demographic dataset is broken down into five main sections:

health identifiers, name details, address details, communication details and other details.

Is the order of the sections appropriate or inappropriate:

Yes, the order of the sections is appropriate : ☐

No, the order of the sections is not appropriate: ☐

If the order is not appropriate, please help us understand why you selected this answer.

Q 8: Are there any general comments you wish to make in relation to the demographic dataset or guidance?

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