Demographic dataset and guidance statement of outcomes

Report on the outcome of the public consultation on the revision of draft national standard demographic dataset and guidance for use in all health and social care settings in Ireland

January 2016

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent authority established to drive high-quality and safe care for people using our health and social care services in Ireland. HIQA's role is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

HIQA aims to safeguard people and improve the safety and quality of health and social care services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, HIQA has statutory responsibility for:

- **Setting Standards for Health and Social Services** — Developing person-centred standards, based on evidence and best international practice, for health and social care services in Ireland.

- **Regulation** — Registering and inspecting designated centres.

- **Monitoring Children's Services** — Monitoring and inspecting children's social services.

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

- **Health Technology Assessment** — Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.

- **Health Information** — Advising on the efficient and secure collection and sharing of health information, setting standards, 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 healthcare depends on access to, and the use of, information that is accurate, valid, reliable, timely, relevant, legible and complete. For example, when giving a patient a drug, a nurse needs to be sure that they are administering the appropriate dose of the correct drug to the right patient and that the patient 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, at best, appropriate treatment is delayed or at worst not given.

In addition, health information has a key role to play in healthcare planning decisions – where to locate a new service, 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 Health Information and Quality Authority (HIQA) has responsibility for setting standards for all aspects of health information and monitoring compliance with those standards. In addition, under section 8(1)(j), HIQA is charged with evaluating the quality of the information available on health and social care, making recommendations in relation to improving the quality, and filling in gaps where information is needed but is not currently available.

Information and communications technology (ICT) has a critical role to play in ensuring that information to promote 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 patient is prescribed medication to which they are allergic. Further to this, it can support a much faster, more reliable and safer referral system between the patient's general practitioner (GP) and hospitals.

Although there are a number of examples of good practice, the current ICT infrastructure in Ireland's health and social care sector is highly fragmented with major gaps and archives of information which prevent the safe and effective transfer 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 over-reliance on memory. Equally, those responsible for planning our services 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, we are all being encouraged to take more responsibility for our own health and wellbeing, yet it can be very difficult to find consistent, clear and trustworthy information on which to base our 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.

HIQA has a broad statutory remit, including both regulatory functions and functions aimed at planning and supporting sustainable improvements.

Through its health information function, HIQA 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.

In October 2013, HIQA released the first version of the *National Standard Demographic Dataset and Guidance for use in health and social care settings in Ireland*. As a result of feedback we received on the first version of the Standard, and with the expected introduction of a national healthcare identifier in Ireland, HIQA felt it was timely to review and revise the national standard demographic dataset and guidance for use in health and social care settings in Ireland.

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1. Introduction and background

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 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 (GPs), hospitals, primary care services, allied health professionals, children's residential centres and residential centres for older people or people with disabilities 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 approach for this purpose 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.

2. Overview of consultation submissions

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

In total there were 41 responses. Of these, 56% (n=23) responded on behalf of their organisation, 34% (n=14) of responses were from individuals, and 10% (n=4) 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 41 responses, 66% (n=27) responded via Polldaddy, 34% (n=14) emailed their responses and no responses was received by post.

3. Methodology

The original draft standards[1] published in 2013 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 informed and interested parties. Throughout the development of the demographic dataset, HIQA consulted with members of the General Practice Information Technology Group and the Department of Social Protection's Client Identity Services.

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. Following this, the standards were published in October 2013.

HIQA considered it important to review these standards following the publication of the Health Identifiers Act 2014. In order to develop this revision of the standards, the Authority revisited the 2013 standards and the dataset in the Health Identifiers Act 2014. During the development of this revised draft for consultation, HIQA undertook a targeted consultation with key stakeholders and consulted with a

broader group of stakeholders via a public consultation. The draft revision of the standard for consultation was published in October 2015 for a five week period which ran until 13 November 2015.

The consultation was available on our website and in order to engage as many people as possible, personalised emails were sent to almost 500 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). 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. HIQA welcomes all these submissions and would like to thank all those who contributed to the targeted and to the public consultation.

4. Feedback from public consultation

The consultation form was divided into seven 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 on 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, the majority of respondents, 68%, 'strongly agreed' that there is a need for a standard demographic dataset.

Figure 1. Responses to consultation Question 1

Is there a benefit to having a national standard demographic dataset?

- 15% (n=6)
- 17% (n+7)
- 68% (n=28)
- Strongly Agree
- Agree
- No response
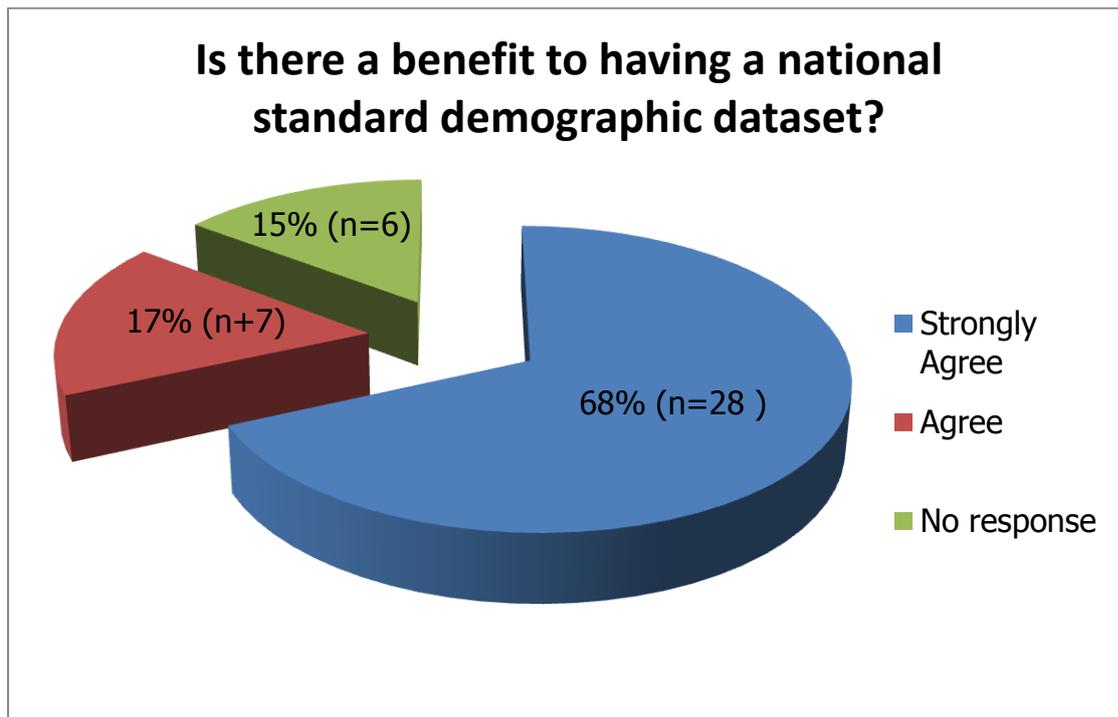
4.2   Question 2: Data items to include

Question 2: **Are there additional data items that you think should be** *included* **in the demographic dataset?**

Question 2 asked if all of the appropriate data items had been included. There was a significant proportion of the responses requesting changes to gender, the inclusion of ethnicity, capturing of language and communication needs.

Five 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, while respecting people's rights.

What the respondents said:

"No, it seems like a very comprehensive document."

"If patient's first language isn't English and they require an interpreter at hospital visits, this should be recorded."

"I believe the dataset should include the ethnicity of the person, not just nationality. Thus would enable health providers to address areas of health inequality experienced by minority ethnic groups in Ireland. In the case of the Traveller community this would highlight aspects of health that are a concern and would facilitate the targeting of supports to the community. An ethnic data collection system should have a human rights framework."

"Transgender people are often invisible in official records and therefore it is very difficult to address the needs of this population. This process is a unique opportunity to explore how transgender people could be more accurately represented within health and social care settings in Ireland."

"While not related to demographic data as such, this would be very useful for assisting health service providers to communicate with the subject of care and to identify if translation services are required for engaging with the individual. The facility to indicate the preferred language would also be very useful."

"Communication and support needs. Many people with an intellectual disability and or autism and people with a sensory disability have difficulty with traditional communication methods. They may require the assistance of sign language, other non-verbal communication methods, accessible written information, etc. A person may require an advocate or assistant decision maker."

4.3   Question 3: Removal of data items

> **Question 3: Would you *remove* any of the data items listed in the demographic dataset?**

Fifty four percent (n=22) of the respondents thought that all of the appropriate data items were included, 39% (n=16) did not respond to this question and 7% (n=3) did not think that the appropriate data items were included.

What the respondents said:

"Is there a necessity to collect many of the biometric markers identified? The collection a mass scale of finger prints, retinal scanning and DNA would be worrying to many individuals and civil society groupings."

"Current mandatory data items and optional data items requested appear to provide scope for service user and service provider preferences."

"Are all the address fields required now that the Eircode exists?"

4.4   Question 4: Appropriate definitions

> **Question 4: Do the definitions provided for the data set clearly explain each of the data items? If not, please suggest improvements.**

Just over 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 area of gender and date format.

Figure 2. Responses to consultation Question 4

Are the definitions provided for the data set clearly explained?

12% (n5)

37% (n=15)

- Suggestions provided
- No response
- Guidance is clear

51% (n= 21)
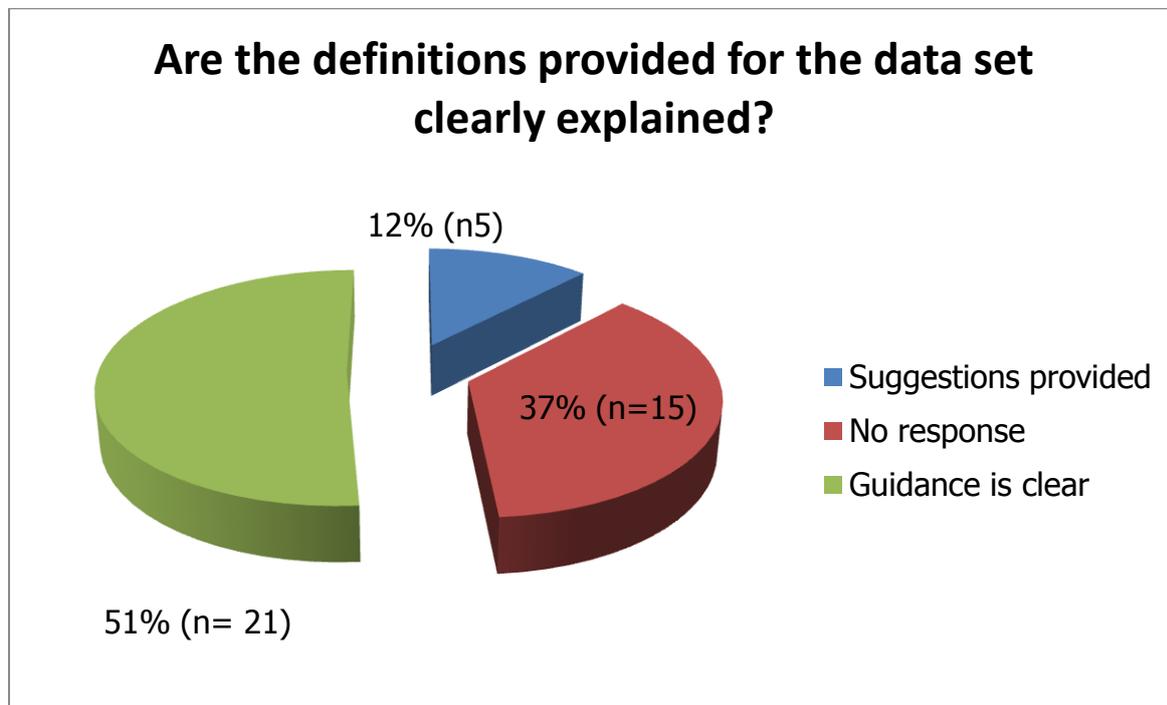
What the respondents said:

"Yes, the definitions provided for the data set explain each of the data items clearly."

"Further, in the introduction, the example of using a standardised date is given to explain the basis for looking to implement standards, however, it is difficult to derive from the document what the 'standard format' for dates should be – e.g. dd/mm/yyyy. While a guideline is given for date of birth, no similar guideline is given for date of death."

"Yes. Useful to have summary table in Section 8 with broad description and mandatory/optional status as well as usage."

"There may be some lack of clarity between 'Name usage classification' and 'Preferred name'."

"All are very clearly explained."

"… Are there other acceptable descriptions apart from male and female. What entry should a person, who is in the process of transitioning to a different gender, make?"

4.5   Question 5: Optionality for each data item

> **Question 5: Do you agree with the proposed optionality for each data item?**

As depicted in Figure 3, a large number of the respondents agreed with the optionality for the data items, or did not provide suggestions on how to improve upon the optionality. Suggestions relating to the mandatory capturing of county, place of birth, date of death and nationality were received.

Figure 3. Responses to question consultation Question 5
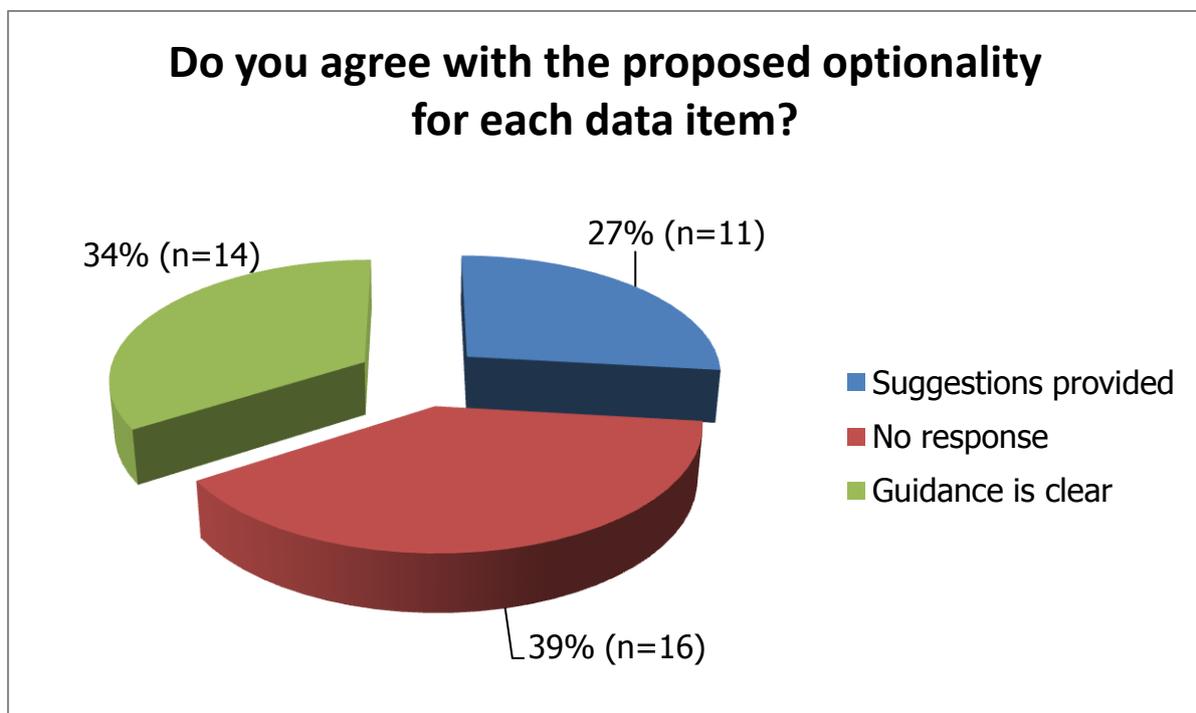
What the respondents said:

"Yes in general we agree with the proposed optionality for each data item. However… can you record a townland and town in this section? Many live in townlands outside of a town and record both on their address."

"Agree with optionality. A total of nine data items are mandatory (four of which have mandatory where applicable status) this serves as a useful comparable minimum data set across systems."

"I believe that the postcode (2.5) should be mandatory for residents of Ireland, the unique identifier element being invaluable."

"Nationality should also be made mandatory."

"I agree with the options."

"County should be mandatory - this is currently required for HIPE [Hospital In-Patient Enquiry] and is implemented on our patient administrative system."

4.6   Question 6: Is the guidance clear and easy to understand?

> **Question 6: In your opinion is the guidance provided clear and easy to understand?**

Twenty seven percent of the respondents provided suggestions to improve the clarity of the guidance. Similar themes relating to the name and preferred name classification and gender were noted. The remaining number of respondents were evenly split in agreeing the guidance was clear or providing no response.

Figure 4. Responses to consultation Question 6

Is the guidance provided clear and easy to understand?

33% (n=14) 31% (n=13) 36% (n=15)

- Suggestions provided
- No response
- Guidance is clear
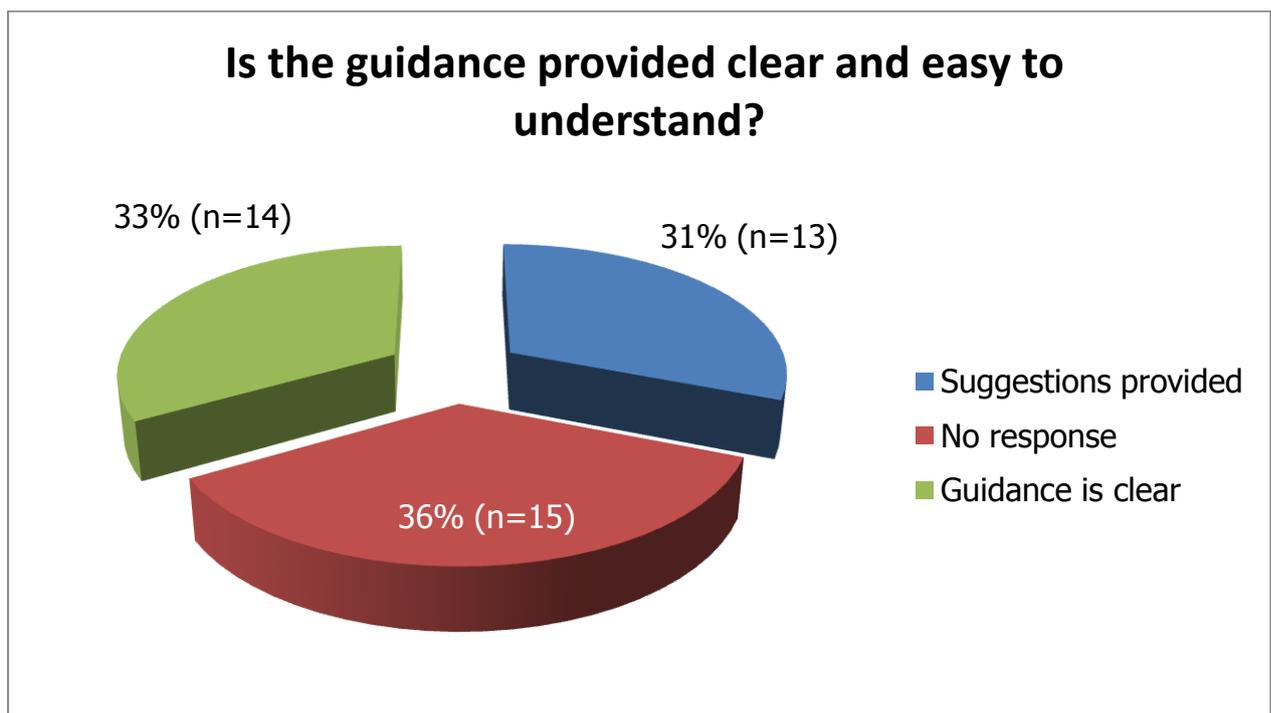
What the respondents said:

"Yes the document is very accessible and more streamlined that 2013 version."

"… Preferred Name and Name Classification. Perhaps an example would assist in clarifying this."

"… suggest that there is guidance in how to change information relating to a person's gender identity or name/title change."

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

4.7   Question 7: General comments

> **Question 7: 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 providing suggestions on how to improve the dataset.

What the respondents said:

"Good work. Roll out and implementation will be very important."

"Just to state the importance of including an ethnic identifier in the data system."

"I am delighted to see a recommendation document that strives for intra-operability using clinical documentation architecture."

"There are a number of babies born each year who have a medical condition that makes gender either / or. How does Gender work in cases of transsexuals either before or after gender reassignment surgery — is birth gender or current gender?"

"Individual patient identifier is an excellent initiative. Great thought put into this piece of work. It is a comprehensive document and will greatly assist the roll out across the system. Very well done to all who contributed."

5. Conclusions and next steps

Once amended, the revision of the draft 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 revision of 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 revision of the draft national standards.

6. Changes to guidance

Sections	Changes
Name details — Punctuation	Guidance amended to accommodate that some systems cannot capture some punctuation formats such as an Irish language fada.
Name details — Registering an unidentified service user.	Guidance amended to accommodate that some systems cannot capture an 'unknown' service user.
Name details — Registering unnamed newborn babies	Guidance on newborn babies was amended.
Name details — Name usage classification and preferred name	Overall sections of the guidance amended to make the distinction clearer.
Address — Suburb, town, townland or locality	The guidance was amended to allow 'Townland' and 'Town' to be recorded.
Additional demographic details — Date of birth and date of death format	The guidance was amended to give greater clarity.
Additional demographic details — Gender	The guidance has been amended to provide greater clarification to the purpose of capturing a service user's 'gender' as part of the demographic dataset.

7. 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.

8. References‡

Reference List

(1) Health Information and Quality Authority. *Draft National Standard Demographic Dataset*. 2013. Available online from: http://www.hiqa.ie/publications/draft-national-standard-demographic-dataset-and-guidance-use-health-and-social-care-set. Accessed on: 9 September 2013.

(2) Health Information and Quality Authority. *Recommendations for a Unique Health Identifier in Ireland for individuals*. 2009. Available online from: http://www.hiqa.ie/content/recommendations-unique-health-identifier-individuals-ireland.

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‡ Online references were accessed at the time of preparation of this 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 Occupational Therapists of Ireland

Citizens Information Board

Cork Traveller Women's Network

Dental Health Foundation

Health Protection Surveillance Centre

Health Research Board

Health Service Executive

Health Service Executive, Advocacy Unit

Health Service Executive, Head of Quality and Safety — Social Care Division

Healthlink

Inclusion Ireland

Irish Pharmacy Union

Mental Health Commission

National General Practice Information Technology (GPIT) Group

National Office for Suicide Prevention

Nursing and Midwifery Board of Ireland

Office Nursing and Midwifery Services Director, Clinical Strategy and Programmes, HSE

Pavee Point

Royal College of Surgeons in Ireland

Saolta University Healthcare Group

St Anthony's Park Community Development Initiative (Cork)

Transgender Equality Network Ireland (TENI)

Traveller Health Unit (Cork/Kerry a partnership structure between HSE and Traveller organisations)

Appendix 2 — Consultation questions

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

Q2:   Are there additional data items that you think should be included in the demographic dataset? Please comment.

Q3:   Would you *remove* any of the data items listed in the demographic dataset? Please explain.

Q4:   Do the definitions provided for the data set clearly explain each of the data items? If not, please suggest improvements.

Q 5:   Do you agree with the proposed optionality for each data item? If you disagree with the proposed optionality for certain data items, please explain:

Q6:   In your opinion is the guidance provided clear and easy to understand? Please suggest any changes here.

Q7:   Are there any general comments you wish to make in relation to the demographic dataset or guidance?