Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Public Consultation Feedback Form

The Health Information and Quality Authority (HIQA) is an independent statutory body established to promote safety and quality in the provision of health and social care services. HIQA has a responsibility to develop standards, recommendations and guidance to support the Irish digital health and health information landscape to ensure safer, better care for people using health and social care services.

HIQA is now in the process of revising the National Standard for a Demographic Dataset for Health and Social Care (Version 2 published in 2016 available here). A National Standard for a Demographic Dataset for Health and Social Care defines the core set of data elements required to identify an individual uniquely, in order to provide safe, quality care and support. The standard applies to children and adults who are receiving care and treatment in a health and social care service that collects and records demographic details. Examples of demographic details include forename, surname and date of birth.

The public consultation gives people the opportunity to provide feedback on the draft standard and become involved in the development process by submitting their views to us.

HIQA will carefully assess all feedback received and use it, along with other available evidence, to revise the National Standard for a Demographic Dataset for Health and Social Care. Before you complete this consultation feedback form, please read the instructions for submitting feedback on the next page.

The closing date for the public consultation is 5pm on Friday 25 July 2025.

Instructions for submitting feedback

- If you are commenting on behalf of a service or organisation, please combine all feedback from your organisation into one submission form and include the details of the service or organisation.
- Please do not paste other tables into the boxes already provided — type directly into the box as the box expands.
- If you are handwriting responses, please feel free to use additional paper.
- Please spell out any abbreviations that you use.

Data Protection and Freedom of Information (FOI)

This consultation is being conducted in accordance with data protection law, including the GDPR and Data Protection Act 2018.

HIQA will only collect and store personal information during this consultation for the purposes of verifying your feedback, or where you have indicated that you would like to be contacted to participate in future focus groups.

For further information on how HIQA uses personal information, please see our Privacy Notice available here. If you have any concerns regarding your personal information, please contact HIQA's Data Protection Officer on dpo@hiqa.ie.

Following the consultation, we will publish a report summarising the responses received, which will include the names and types of organisations that submitted feedback to us. For that reason, it would be helpful if you could explain to us if you regard the information you have provided us as being confidential or commercially sensitive.

Please note that HIQA is subject to the Freedom of Information (FOI) Act and the statutory Code of Practice for Public Bodies in relation to FOI. We cannot give you an assurance that confidentiality can be maintained in all circumstances due to the requirements of the FOI Act.

By submitting your feedback, you are agreeing to participate in this consultation.

1. About you

1.1 Are you providing feedback as:

☐ an individual

(If you would like to be contacted to participate in future stakeholder engagement, please provide your name and contact number below. Otherwise please skip)

☒ on behalf of an organisation

(If you are responding on behalf of an organisation, please provide your organisation's name and contact details below for verification purposes)

Irish Medical Organisation

1.2 Are you commenting:

☐ In a professional capacity?

(please use the box below to specify your role in the organisation you currently work for)

? Consultant in Public Health medicine

☐ As a member of the public / user of health and social care services? *(If you would like to provide any additional details, please share in the box below)*

2. Feedback on the draft standard

In this section, we would like to find out what you think of the content of the demographic dataset and guidance. This section focuses on the data elements, their descriptions and associated conformance, cardinality and guidance. The questions in this section are not intended in any way to limit your feedback, and other comments relating to the draft standard are welcome.

2.1 Have all the appropriate data elements been included in the demographic dataset?

☐ Yes

☒ No – if no, please specify the additional data elements that you think should be included and state why.

Insert text here

There is a need for the inclusion of equity stratifiers as mandatory data elements in all health data collections. These are required so that groups can be stratified appropriately for the purposes of identifying and dealing with health inequalities. This is in keeping with the requirements of the Public Sector Equality and Human Rights Duty (section 42 of the Irish Human Rights and Equality Commission Act 2014). Under this legislation, all public bodies must assess relevant human rights and equality issues, develop policies and actions to address them, and report on their progress. So far this has not been implemented in the HSE.

It is also essential for Public health proactitioners who are Medical Officers of Health to properly be enabled to fulfil their obligations under the Duties of Officers legislation: **S.I. No. 128/1949 - Health (Duties of Officers) Order, 1949** which mandates that Medical Officer of health shall: "inform himself as respects all influences affecting or threatening to affect injuriously the public health in the county and as respects the causes, origin and distribution of diseases in the county"

2.2 Are there any data elements that you would remove from the demographic dataset?

☐ Yes – if yes, please specify the data elements that you would remove and state why. Please include the relevant data element number.

☒ No

Insert text here

2.3 Do the descriptions provided for each data element clearly explain the data elements?

☒ Yes

☐ No – if no, please suggest improvements. Please include the relevant data element number.

Insert text here

2.4 Do you agree with the conformance for each data element?

Conformance indicates whether the data element is mandatory, required or optional.

a) Mandatory: The information must be included.
b) Required: If it exists, the information should be included.
c) Optional: A local decision is made as to whether the information is included.

☐ Yes

☒ No – if no, state why. Please include the relevant data element number.

Insert text here

As already said, ethnicity, race, country of birth, and additional equity stratifiers not yet included should be mandatory

General Practitioners recognise the value of Electronic Patient Records and the vast majority have invested in GP practice management systems. Under the terms of the 2019 GP Agreement between the Department of Health, the HSE and the IMO (Hereafter 2019 GP Agreement), GPs agreed to co-operate with a number of eHealth initiatives including the roll out of the Individual Health Identifier
Appendix D of the 2019 GP Agreement lays out the information to be contained in the Summary Care Records which is designed to be auto -populated from GP practice systems at a point in time.
Any additional data elements will require both additional resources and agreement. Practice management systems must be able to auto-populate and update the data as required.

2.5 Do you agree with the cardinality for each data element?

Cardinality refers to how many entries can be made for a data element for example in some situations, some data elements may require a zero, one or many entries.

☐ Yes

☒ No – if no, state why. Please include the relevant data element number.

Insert text here

This is actually unintuitive and difficult to understand, and could be presented with more clarity.

2.6 Is the guidance provided throughout the document clear and easy to understand?

Guidance for each data element is provided at a high level in the dataset and in more detail in Chapter 3 of the document.

☐ Yes

☒ No – if no, please suggest improvements. Please include detail of the data element being referred to.

Insert text here
As mentioned above, the cardinality is presented in a way that is not intuitive, and is difficult to follow

3 General feedback

3.1 Do you think the language used in the draft standard is clear, easy to follow and easy to understand?

☐ Yes

☒ No – if no, please suggest improvements.

Insert text here

As above

3.2 Do you think the content and structure of the draft standard is clear, easy to follow and easy to understand?

☒ Yes

☒ No – if no, please suggest improvements.

Insert text here
As above

3.3 Are there any general comments you wish to make in relation to the draft standard?

Insert text here

There is a misinterpretation of the GDPR legislation when it comes to collecting data on ethnicity and race. This data is essential for the proper provision of care to those whose ethnicity and race may affect their putcomes. It should be mandatory in all health collections.

The document states:

Section 4.0

However, personal data revealing for example, racial or ethnic origin are categorised as special category data under the General Data Protection Regulation 2018, therefore explicit consent and strong legal justification are required to collect these data.

However, I believe that in the case of the health service, this is superceeded by the exclusion outlined in section 2 as highlighted in yellow below:

1. Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person’s sex life or sexual orientation shall be prohibited.

2. Paragraph 1 shall not apply if one of the following applies:

Article 9; 2 (i)

1. processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy;

This also applies to the collection of equity stratifiers. If these are not collected as a country we will continue to lag behind most other western countries in our ability to identify and mitigate against health inequalities.

4. Use of the standard in practice

4.1 What will help to support the implementation of this standard in the service that you use or work in? (For example additional guidance, tools or educational material)

Insert text here

No additional comments