Terms of Reference – HIQA advisory group - Revision of information management standards for national data collections

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1. Introduction:

In 2017, HIQA published Information management standards for national data collections. The primary purpose of these standards is to ensure that national health and social care information is of the highest possible quality, the availability of which will ultimately drive improvements in patient safety.

The Authority has now commenced work on the first revision of the information management standards. The standards are being revised and updated in order to reflect changes in the health information landscape since 2017, including the enactment of the General Data Protection Legislation (GDPR).

HIQA is convening an Advisory Group to assist in the process of revising these standards. The key focus of the group will be to review international evidence in this area and to advise the Authority on revising standards for national health and social care data collections in Ireland. Advisory Group members will be asked to provide support and collaboration on the revision of the information management standards to provide advice in their relevant areas expertise, and vision and insight on how to support the implementation of the standards in practice, and also to promote the concept and purpose of the standards at policy and service development level.

2. Terms of Reference

The role of the working group will be to:

2.1 To provide knowledge and expert advice in relation to the revision of the information management standards including aspects relating to the content and implementation of the standards.

2.2 To provide knowledge and expert advice in relation to the current systems in place (and those in development) in the Irish health and social care sector in relation to national health and social care data collections, as well as insight into advances in information management practices in the future.

2.3 To review international evidence in relation to national health and social care data collections.

2.4 Advise on further steps in relation to increasing understanding and raising awareness of the information management standards.

2.5 To inform HIQA of research, programmes, activities, policies or other developments that may be relevant to HIQA's work in the development of national standards, guidance and supporting material.

2.6 To provide vision and insight on the development and application of methods that measure and report the impact and reach of HIQA's work across the system.

3. Governance and process

3.1 Membership - the Advisory group will include nominees from various organisations, including:

- Department of Health
- Central Statistics Office
- HSE, including the Office of the Chief Information Officer
- Child and Family Agency (Tusla)
- Health Research Board
- Patients and patient representatives
- Representatives from national data collections
- Academics and researchers.

3.2 The Chair of the Advisory group will be the Director of Health Information and Standards in HIQA.

3.3 The Board of HIQA will approve the final set of standards in advance of submission to the Minister for Health.

3.4 A quorum of five members is necessary to hold a meeting.

3.5 While HIQA is ultimately responsible for the development of standards, all comments received from Advisory Group members will be collated and carefully considered to inform the final set of standards for the Minister.

3.6 Meeting frequency: members of the Group will be invited to attend two meetings per year. Additional meetings may be held as necessary.

3.7 Meeting location – meetings may take place online via Zoom online meeting platform or in HIQA's Dublin office.

3.8 Administrative arrangements – an agenda and documentation to be reviewed will be circulated one week in advance of each meeting. Meeting minutes will be circulated within three weeks following each meeting.