CIB Responses to HIQA Consultation on ICT Enablement of Older Peoples Services

Recommendations 1-3

Recommendation 1

An overarching strategy should be developed, at national level, for the full engagement of the public and private sector in the ICT enablement of health service delivery, in line with national policy and the Sláintecare vision. This strategy should describe how current undertakings, including the 'ICT Spine', align with longer term priorities under Sláintecare — that is, with the national eHealth solutions, including the National Shared Care Record, as those programmes evolve.

Recommendation 2

The appropriate overall governance structure(s) should be identified, to develop this strategy and oversee its implementation, across the full public and private sector, aligned to the wider transformation of health service delivery and Sláintecare. This will support the ICT enablement of health service delivery at national level, for all cohorts and populations, including older persons.

Recommendation 3

The Integrated Care Programme for Older Persons (ICPOP) seeks to provide a national service model for older persons, with appropriate ICT enablement, and stakeholders are currently determining the scope of a formal evaluation of the ICPOP programme. The findings of the formal evaluation should inform the overarching strategy for the ICT enablement of older persons services.

Response to Recommendations 1-3 Strategy and Governance

The proposed system will require an overall integrated National Strategy with clearly stated high level goals for the establishment of an integrated information system as an essential component of the implementation of Sláintecare. The Strategy needs to include clearly stated goals in respect of the following:

- Management of the significant changes required within and across health and social care agencies;

- Integration and rationalisation of the various initiatives that have been put in place or proposed in recent years, e.g. e-health, the InterRAI assessment system, Individual Health Identifier;

- Addressing the deficits identified in the national health information system by clearly identifying the remediation measures required;

- Development of a better fit between community-based and residential care in order to have a meaningful and realistic continuum of long-term care and provision for those who need it;

- Provision of clear protocols for ensuring that a person-centric approach is reflected in all health and social care interventions;

- Ensuring that ICT enablement and capacity-building occurs across all health and social care settings;

- Identification of the resource implications of the system taking into account the fact that health and social care providers (hospitals, community care and residential care) will require a change management process and appropriately trained personnel to oversee its implementation;

- The specific governance structures required at both national and regional levels and how these are to be developed;

- A clear statement about the health and social care providers that will be included in the new system;

- How to involve end-users of the system, including, in particular, the 'data subjects' (users of health and social care services)

Recommendations 4-10 Vision and roadmap

Recommendation 4

A full stakeholder mapping should be undertaken, across the public and private sectors, and an appropriate plan for the engagement of stakeholders — particularly core end-user groups in the public and private sectors — should be developed. The governance body should be responsible for ensuring this plan is implemented, to ensure that ICT enablement meets the needs of stakeholders, particularly core end users.

Recommendation 5

As part of the overall strategy, a clear vision for the overall ICT enablement of older persons services should also be developed, for the short, medium and long term. This vision should be developed in collaboration with all stakeholders and provide a common understanding (especially for core user groups) across all the settings outlined, and how it will align with their work practices, across the full sector, public and private.

Recommendation 6

In common with all other cohorts and populations receiving primary or community care, older persons' information should be stored and shared through the 'ICT Spine' initially, and then through national eHealth solutions, such as the National Shared Care Record, as they are developed.

Recommendation 7

An overall roadmap for the ICT enablement of older persons services should also be developed, outlining the realisation of that vision over the short, medium and long term. Again, this should take account of the dependencies on the HSE 'ICT Spine', especially on the following Community ICT solutions:

- ☐ The Integrated Community Case Management System
- ☐ The Residential Care Management System
- ☐ The Home Care Management System
- The InterRAI Assessment System (replacing the Single Assessment Tool).

It should also identify all dependencies on national eHealth priorities, including the national shared care record, and align to their delivery schedules, and on any other core enablers.

Recommendation 8

The overall roadmap should ensure that an audit of all existing hardware, electronic systems and datasets is undertaken in the short to medium term.

This recommendation is not specific to older persons as a population, but will also benefit all other cohorts and populations whose care is managed using the same systems.

Recommendation 9

The roadmap should also align with the criteria, guidelines, and procedures for the HSE programme of technology refreshment for ICT hardware and software. This will ensure that systems and solutions are replaced and upgraded appropriately. Again, this recommendation is not specific to older persons as a population, but will also benefit all other cohorts and populations whose care is managed using the same systems.

Recommendation 10

National health identifiers, such as the Individual Health Identifier, are used in conjunction with other identifying criteria to enable a high degree of safe identification of those presenting for use of a health service. The roadmap should ensure that every system to be used for the delivery of older persons services uses national health identifiers. This requirement is not specific to older persons as a population, but will also benefit all other cohorts and populations whose care is managed using the same systems.

Response to Recommendations 4-10: Vision and Roadmap

A Roadmap should be developed which sets out how the Information System is to be developed incrementally taking into account the need for a standardised and standards-based approach to sharing health and social care information relating to patient identification, medical history, medication, referrals, discharges and assessed health and social care needs.

The roadmap will need to set out mechanisms for enabling all health and social care providers delivering services to older persons to use a national standardised electronic information system.

The Roadmap will need to identify how the significant funding, specialised skillsets and training are to be provided and how the resource implications will be addressed.

The Roadmap will need to take into account the challenges posed by the current health and social care delivery model – the significant (and increasing) role of the private sector in the provision of both residential care and community-based care; the inherent bias towards nursing home care in the

funding structures for long-term care and support; and GP services operating outside the HSE community care services system.

The Roadmap will need to make provision for the full implementation of the Integrated Care Programme for Older Persons (ICPOP) based on the InterRAI assessment as the national standard for care needs assessment. (This process has been somewhat piecemeal to date with the InterRAI Single Assessment Tool being first piloted in 2016).

The Roadmap will need to fully acknowledge that a full roll-out of the InterRAI Assessment information system will be a major change and challenge for GPs and public health nurses, in that it represents a move from current well-established practices at local level to a new model of assessment of an older persons' home care needs, as well as a move from a paper based to digitally-based system.

It is critical that the Roadmap learns from the experience to date of implementing the Single Assessment Tool model taking into account the fact that the mainstreaming of the project has been slow and that it is still not being widely used in situations where older people are seeking access to Home Support Services and to the Nursing Home Support Scheme. It would appear that the Common Summary Assessment Report (CSAR) (a paper-based process) continues to be the main mechanism used to assess people's need for access to the Nursing Home Support Scheme ('Fair Deal') and that this does not always assess or identify the supports that could enable a person to live in the community.

Recommendations 11-14: Standardised sharing of information

Recommendation 11

A comprehensive suite of national standards for interoperability should be developed, in collaboration with core user groups and led by the appropriate national Standards function. This includes ☐ mapping the data used in systems across health and social care settings.

- ☐ definition of standardised minimum data sets required
- ☐ use of standardised assessments, including InterRAI
- ☐ use of approved national standard terminologies, including SNOMED CT
- ☐ development of key performance indicators, as national standards, for appropriate reporting.

The goal is to create a framework of national standards (particularly HL7 FHIR and APIs) to ensure (near) real-time sourcing of data and thereby support the effective sharing of health information, underpinned by national eHealth solutions such as national shared care record and national health identifiers.

Recommendation 12

Healthcare professionals have identified the following transitions as among the most challenging and important:

- ☐ admission to acute care from nursing home
- ☐ admission to acute care from older person's home
- ☐ discharge from acute care to nursing home
- ☐ discharge from acute care to older person's home
- ☐ transfer between or within settings.

HIQA should undertake an analysis of the actual information needs of healthcare practitioners, in collaboration with the HSE and other stakeholders, to inform development of national standards for information requirements for core user groups involved in these transitions of care. Work undertaken to date by the HSE on requirements for these core user groups should also inform the national standards.

Recommendation 13

Sharing of information between GP practice management systems, nursing homes, and acute hospitals is a high priority. This may require the definition of national standards for the point-to-point transfer of information above. However, consideration should also be given to how the necessary information could be made available to any healthcare profession or facility responsible for continuity of care of that patient. Findings from the full mapping of existing datasets should inform this analysis.

Recommendation 14

In the longer term, formal review assessing compliance against the interoperability standards outlined in Recommendations 11 and 12 should be undertaken.

Response to Recommendations 11-14: Standardised sharing of information

The sharing and transfer of knowledge and information between different stakeholders - for example, acute hospitals, nursing homes, GPs, consultants, and public health nurses - is an important consideration and central to achieving best practice in an integrated information system. This evidently requires inbuilt inter-operability and a shared digital platform.

There are a number of factors that need to be acknowledged in setting up an integrated digital information platform:

- The obvious value of having an Integrated IT Information System must be balanced by the need to ensure privacy and confidentiality in accordance with both data protection legislation and each individual's basic right to privacy as recognised by the European Convention on Human Rights.

- While most users of health and social care services will be aware that information about them needs to be shared among the healthcare professionals delivering care, they should be informed that they have a right to ask for certain information to be withheld or kept confidential.

- There is evidence that personal information regarding older service users of both health and social care services have in the past been made available to 'next-of-kin' and other family members without the knowledge or express permission of the person concerned. The proposed transformation of the system will need to ensure and make clear that such data sharing is not acceptable or possible.

- It will be necessary to ensure that access to people's medical history and records remains strictly limited to those entitled to legitimately and professionally access such information. This is likely to raise particular difficulties in settings which primarily provide social care (as

distinct from medical care), in settings involving less-well trained staff, and settings managed by private contractors. It may also present difficulties in cases where a person has communication difficulties or lacks decision-making capacity (e.g., as in the case of some people with an intellectual disability, with dementia, or some people experiencing mental health difficulties). Access to records needs to be cognisant of provisions made under the Assisted Decision Making (Capacity) legislation.

- National standards, protocols and regulations for interoperability across older persons' services will need to be developed and operationalised.

Recommendations 15-18 User Engagement

Recommendation 15

The appropriate overall governance structure(s) should ensure that core user groups, in both public and private sectors, are sufficiently engaged during the planning, design and implementation of systems used for these transitions of care, as well as on an ongoing basis post implementation.

Recommendation 16

The appropriate overall governance structure(s) should ensure that mechanisms are in place to ensure that all systems conform to basic principles of user centred design. It should also ensure that gateway reviews in the roadmap include review of user satisfaction with the systems implemented and with the overall implementation process.

Recommendation 17

The appropriate overall governance structure(s) should also ensure that comprehensive, self-paced training is made available for all users of all systems and ideally, that users are supported in this training until they feel comfortable and confident using the applications and systems required in their role.

Recommendation 18

The appropriate overall governance structure(s) should consider national initiatives for the 'uplift' of digital skills for healthcare professionals and all those providing care to older persons, and to other cohorts and populations. Best practice also emphasises the role of accredited continuing professional education, and of particular support for the professional development of clinician informatician sphere, again benefitting all cohorts and populations (including older persons) whose care is managed using the same systems.

Response to Recommendations 15-18: User Engagement

It is essential that all users of the new electronic information system are fully aware of the dedicated time and effort that will be needed not only during the system implementation phases, but also during the planning and design phases. There will clearly need to be common understanding among all users on the scale of this undertaking and what is required to make it successful. As a minimum, this will require a full commitment to the cessation of paper-based systems as distinct from maintaining duplicate electronic systems and paper-based systems.

However, this will also require a major emphasis on security in order to avoid the potentially significant fallout if the system was to be subjected to a cyber-attack.

The proposed system change will, of necessity, involve sharing of information between state agencies - such as the HSE - and others in the private and the voluntary sectors. The shortcomings in

the regulatory arrangements regarding the extent to which certain non-HSE funded services are legally obliged to comply with regulatory standards will need to be addressed, at least in the context of data sharing.

There is a need to fully recognise that a significant proportion of staff, especially in the home care and nursing home sectors are – at present – poorly trained and equally poorly remunerated. Many do not enjoy or have access to the supports and conditions that are more prevalent in the HSE and state sectors. The development of a new system will, therefore, need to realistically assess and plan for how these important workers can participate in the development and implementation of the new arrangements.

While the recommendations regarding User Engagement as set out in the *Draft for Consultation* are to be welcomed, it would appear that the term 'User' is presented as meaning staff and agencies who will access the proposed system and not the 'data subjects' of the system, i.e. the older members of the public whose information will be entered, stored and accessed from the system. It will continue to be crucial that present and future beneficiaries of the health and social care services are consulted and engaged with in the development and implementation of the new system. This can be achieved through a multitude of methods, either directly or through advocacy and representative organisations.

General Comments

CIB suggests that an Integrated IT Health and Social Care Information System for Older Persons could be enhanced by the following provisions:

- A clear statement that this System is an essential step in developing a seamless health and social service for older persons;

- Clarity about the purpose and the limitations of the Integrated IT System and about which health and social care staff (and under what conditions) will have access to the information held on the system;

- Clear information about the electronic nature of the System and its advantages and potential risks;

- Individuals being fully informed that any information that they provide in one health or social care setting will be available to other health and social care agencies and their staff;

CIB identifies a number of factors that need to be taken into account in the ICT enablement of older persons' services.

Protecting confidentiality
The particular difficulties related to ensuring that confidentiality is protected in an electronic data system need to be openly acknowledged, particularly where information provided in one setting (e.g., hospital) is to be transferred to another setting, e.g., a private nursing home or a private home care provider. Information provided to a health professional on the basis of confidentiality, e.g., to a GP, may be different from the type of information that the individual may wish to provide in another setting, e.g., to a home care provider.

Stringent safeguards will be required to protect the personal health information of every individual and to ensure that the data stored digitally can only be used for the purposes for which it is intended.

Standardised data collection
There is a clear need to foster a strong ethos of standardised data collection throughout the whole of the health and social care system (public and private).

Retrieval of information
Capacity to retrieve the information must be an integral part of the system.

Resource implications
There will be significant resource implications in developing and maintaining the proposed ICT enablement system for all health and social care services. Care is thus required in order to ensure that service to individuals is not lessened because of IT system requirements.

Mandatory or Optional?
A question to be addressed is whether participation in the system should be mandatory for all health and social care providers.

Ensuring participation by all relevant agencies and practitioners
Unless there is full support for the ICT enablement of older persons services by the population in general, by health and social care practitioners and relevant health and social care agencies, the benefits of the system will not be realised. Furthermore, the system would be at risk of becoming dysfunctional in terms of its main purpose.

Descriptors and Terminology
The Consultation Document includes reference to and a description of a range of current relevant initiatives. However, because of the similarities between some initiatives, it is sometimes not at all clear where each fits in the overall system. This is a matter which will need to be addressed if potential users of the system are to be facilitated in coming on board fully and in understanding what is required at the various levels.

Questions relating to implementing ICT enablement of health service delivery
CIB identifies the following as key questions to be addressed in progressing the ICT enablement of older persons services:

1) Who will have primary responsibility for developing, operating and monitoring the system?

2) Who can access the information and under what conditions?

3) Will people be able to access their own medical records on-line and how will this be provided for?

4) How will the obvious training implications be provided for?

5) Who will decide which health /social care professionals will have access to an individual's record?

6) Who will be responsible for putting in place the required IT systems and interfaces and other security protocols?

7) Who will be responsible for ensuring that the information is up to date?

8) What costs are associated with setting up and maintaining the system and how will these be met?

9) What protocols will be put in place to ensure that the information on the system cannot be linked inappropriately with other datasets?

10) What will be the processes for reviewing the system?

CIB agrees that the ICT enablement of older persons' services proposed is a significant stepping-stone in a move towards a more integrated and accessible health and social care records system and centrally relevant to the implementation of Sláintecare.

The introduction of the digitally-based system must, however, be managed incrementally in a manner that ensures that each phase of the process is consolidated before moving on to the next phase. Engaging all stakeholders (agencies and practitioners) at each stage of the process and getting inputs at each stage of development from potential users of the system will be essential.

There is a need for clarity about the respective roles of the different agencies – HIQA, the HSE and the Department of Health – in developing the new system with particular reference to which agency has overall strategic responsibility. There is also a need for clarity about which parts of the system will be managed nationally and which will require management at regional/local level.

While the ICT enablement of older persons' services will be an important step forward in the delivery of integrated health and social care, it will not and can never be a substitute for ensuring that older persons have access to the full range of supports required for their health, well-being and safety. The ICT enablement of older persons' services will not on its own deal with the fragmentation and inequality in the current older persons' health and social care infrastructure.