

HIQA consultation on the draft recommendations on the Implementation of a National Electronic Patient Summary in Ireland.

IPPOSI response

September 2020

Recommendation 2

We welcome the decision to invite patient representatives onto the National Summary Care Record Project Board. We ask that:

- these representatives are identified via an open and transparent selection process which invites expressions of interest from a broad cross-section of the patient community.
- at least two patient representatives are included in the Project Board composition to ensure the responsibility does not rest on a single individual.
- alternates be appointed as patient representatives are frequently unable to attend due to illness or other medical commitments.
- patient representatives be remunerated for their expenses and for their expertise. In August 2019, former Minister for Health Simon Harris shared a government commitment to properly remunerate patients for their work. There is currently no national guidance around the remuneration of patients in Ireland, but we can look to models within the UK and elsewhere ([IPPOSI policy paper](#)).

Recommendation 3

Public and patient perceptions of the national summary care record are listed as key determinants in the successful implementation of the summary care record. We passionately agree, and we call on HIQA to:

- publish in full the findings from the national public engagement survey on the consent model, planned for later in 2020.
- design the survey to identify whether different perceptions may exist within different sections of our society based on ethnicity, gender etc.
- use findings from the survey to develop a public communications campaign to address identified 'negative' perceptions, including specific resources for breaking down perceptions within certain communities.
- include patient representatives in designing the survey questions, and in developing any corresponding communication campaign strategy or materials.

We note the absence of a specific strategy around addressing clinician perceptions of the proposed summary care record. Training alone (recommendation 5.3) is unlikely to sufficiently address entrenched practices of repeatedly collecting information directly from the patient at each interaction. Recommendation 3.2 mentions clinical champions, but perhaps a survey/research into the perceptions of clinicians would be useful to ensure that these champions concentrate on breaking down the most prevalent perceptions.

Recommendation 4

We recommend that more patient data be integrated into the summary care record. The experience of the COVID-19 tracking and tracing project has proven that this can be done.

To support the standardisation of data across these datasets, we recommend that the roll-out of the National Data Dictionary be

accelerated and we suggest that its use be mandatory for all new datasets and that existing datasets should be migrated over.

Recommendation 5

We firmly agree that in identifying the essential criteria for inclusion of information from potential sources, the National Summary Care Record must seek to “lift all boats”. The summary care record should push existing information sources to collect more standardised, better quality data, rather than require the summary care record to accept whatever data is accessible and available. The summary care record should encourage these systems to review, and if found wanting, improve upon some of their own standardisation and quality challenges. Performance indicators, reported upon annually, should ideally be put in place by HIQA to add momentum to this process.

We ask that patient perspectives around the creation, maintenance and use of the summary care record be included in any training for end-users (point 5.3). Patient representatives, either from the Project Board or other should be included in the creation of training material to ensure that this perspective is sufficiently and accurately captured.

Recommendation 6

Patient representatives should be heavily involved in the process of identifying learnings from the National Summary Care Record project, as these will inform future digital health projects within the State.

While we understand that the summary care record may be rolled out in phases and that different information may be collected during different phases, we underline that at the end of the project one central summary care record must be available for use in every site. Centralising the summary care record forces questions of integration and interoperability to be

addressed and it helps to manage how the information is owned/governed going forward.

To encourage uptake, we ask that patients be able to formally request that their GP complete a National Patient Summary Care Record for them. This should organically push GP practices to on-board the summary care record for more of their users.

General comments

We believe that a glossary along the lines of IPPOSI's terminology explained document is important for clearer public and patient understanding in this area. The language used often falls outside that of terms which we use on a daily basis, and a brief lay-man explanation is needed.

We propose that the health condition information requirements recommend that GPs use the most accurate disease classification code including ICD, SNOMED and orphacodes.

We understand that HIQA is developing recommendations on a consent model for the collection, use and sharing of personal health information in Ireland. These will be important recommendations for patients. Patients should be extensively and actively involved in the preparation of these recommendations from the earliest possible stage. Patients and the public should be consulted on the draft recommendations. A public information campaign should be initiated to help people make informed choices about consent and the models on offer.

We are not clear where the governance of the summary care record is addressed – who is the central owner of the summary care record, where does the information sit?