Joint Committee on Health

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OPENING STATEMENT

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Cathaoirleach and members of the Committee,

Thank you for the opportunity to speak to you today about electronic records in healthcare and related issues. I am the CEO of Health Research Charities Ireland (HRCI), the national umbrella body for charities in Ireland who are improving lives through health, medical and social care research. I am accompanied today by our Chair, Suzanne McCormack, and the Chair of the Irish Health Research Forum, Dr Mark White.

The main message I want to impart to you today is that **electronic health records are essential, not just for healthcare, but also for research**. But I want to start by telling you a story. There's a woman who lives in the midlands, who is getting older but who is definitely not old. She is full of life, has a fabulous pixie cut, is planning on getting back to dancing after a Covid-enforced break and, once, despite no official training as a chef, won an award for running one of the best restaurants in the world! She's busy with her children and many grandchildren and she is also very busy having to manage her own health. She, like many, has a complicated medical history. She has severe allergies to many foods as well as most antibiotics, has a rare condition of the adrenal glands, and has some lung damage from a lifetime of asthma.

When she first meets a healthcare professional she has many, many things to explain. And explain she must because her health records are filed with her GP, on paper in different departments in two separate hospitals, more recently with an online doctor and also in her handbag. There is no centralised record of her complicated medical history that either she or her doctors and nurses can access. Her all too regular rushes to the Emergency Department result in repeated and long-winded explanations about her medical history and require her to be well enough to impart that information. During her most recent admission, she was not allowed to have anyone accompany her and so, being very weak at the time, she handed her phone to a nurse and asked them to read her own curated 'medical notes'. She has essentially created her own electronic health record. But it is nowhere except on her phone and so all that rich data about her rare and unusual symptoms is lost to medical research. Her rare condition could have been prevented through better medical management and yet, without capturing her health data digitally, what she has gone through can never be used to ensure future patients don't go through the same thing.

I tell you this story because I know you will relate, whether through your own experiences or those of your family or friends. I work with and represent over 40 charities who in turn represent, and work on behalf of, over 1 million patients in Ireland, all of whom have similar stories.

While many of our member organisations provide patient services, they come to us because they are also focused on improving lives through research. They fund research, support patient and public involvement in it, work to ensure that research is meaningful to the

people they represent and strive to ensure that its outcomes truly make a difference in people's lives. They understand **that research is the healthcare of tomorrow** and know that not enabling research in all aspects of healthcare is like doing the weekly shop but only buying enough food to last two days. They are an essential part of the health research ecosystem in Ireland.

To give you a sense of who the health research charities are, those that are represented on our Board (because HRCI is itself a charity) are the Alpha 1 Foundation, The Central Remedial Clinic, Cystic Fibrosis Ireland, DEBRA Ireland, The Irish Thoracic Society, The National Children's Research Centre, and Saint John of God's Research Foundation. Our other members represent people with rare diseases, cancer, dementia, heart conditions, mental health issues, many other chronic conditions and also carers. Together these charities provide a beautiful example of what research means to people and families and how its impact reaches every family in Ireland.

Today we launch the 2023 HRCI Position Paper, entitled **Embedding Research in Healthcare** which makes three recommendations to improve health research in Ireland. It is based on the outcomes of Irish Health Research Forum events (which HRCI founded and runs), our ongoing conversations with all stakeholders in the sector and surveys of our member charities. The top priority to strengthen health research in Ireland for our members, is the **implementation of a national electronic health record**. It is therefore the first recommendation in our Position Paper. The other two recommendations, which relate to the need to support genetics and genomics research and the importance of establishing research support functions within the HSE, are also heavily dependent on an electronic health record.

Our members recognise that, as a long-term digital record of a patient's medical history, across different health services, a national electronic health record would facilitate the use of valuable data to improve services and to support research. However, despite pockets of excellence, too many health services are still working in silos and too much valuable data is being lost.

We are not alone in calling for electronic health records and there is widespread recognition of their importance. There are strong eHealth commitments in the Programme for Government, Sláintecare plans and the eHealth Strategy for Ireland. A recent HIQA report makes a strong case for them and the 2022 OECD Economic Survey of Ireland points out Ireland's weakness in digital health and emphasises the need to link existing healthcare datasets. What is not always discussed however, is **the need for a national electronic health record to enable research from the very start**. To this end, the research community and must be involved in the planning at all stages. Patient involvement is also key, to consider issues around consent and to ensure public trust. Separately, the Health Information Bill,

currently under development must provide a strong legislative basis to support the so-called secondary use of data – the use of data in research studies and to improve services.

In an example of the power of electronic health records to provide data for research, the information coming out of the UK during the pandemic was critical in the world's efforts to save lives. For example, during the very early stages of Covid, researchers analysed 17 million NHS electronic health records. This enabled them to identify the most at-risk populations, ultimately leading to decisions around which groups to prioritise for Covid vaccines.

We're very aware of the enormous cost and challenges involved to implementing a national electronic health record. Media coverage over the last week indicates that the barriers may be very big indeed. Patient involvement is key in this process, to overcome resistance where it exists. Patients won't and shouldn't tolerate red tape, inertia or resistance to change that will improve their lives and they need to be involved in discussions at every stage and every level. And from the earliest discussions, the importance of enabling research needs to be considered.

There is no alternative to going digital in healthcare, so it is only a matter of when. It will require bravery and investment but if we are not taking charge of our own future healthcare then who is?

We and our members are working in a myriad of ways to create positive change for patients, their family and carers across Ireland, through research. We are asking you to work with us to this end. Stay connected with us. Do whatever is in your gift to implement a national electronic health record and, if I can leave you with one take-away, in every conversation you have about healthcare, ask the question, **'how is research being enabled?'**

Thank you for your presence and your attention today. My colleagues and I welcome any questions. This concludes my opening statement.