



HOW CAN PERSONALISED HEALTHCARE BE ACHIEVED IN IRELAND?

A PERSONALISED APPROACH TO CARE

For many years now, healthcare has been moving away from the “one-size-fits-all” approach, to one that puts the patient firmly at the centre, offering the appropriate treatment tailored to their individual needs. Such an approach presents both challenges and opportunities; while some healthcare systems are at an advanced stage when it comes to delivering this type of care to patients, others lag behind. Elements necessary to enable the provision of personalised healthcare include a wider move to the utilisation of an individual’s health information to tailor their care, the prudent use of genomic data to inform treatment choice, and the adoption of new technologies, among others.

Personalised healthcare is far more than just a buzzword. It is an evolution of the healthcare system, making it more targeted and patient-centric, by providing the right intervention to the right patient at the right time. It seeks to provide not only what patients need, but what they want, in the most appropriate setting and at the best time. An individualised approach to care eschews bureaucracy, putting the patient first, and the system second. Advances in technology will enable such an approach. Personalised healthcare promises not only efficiencies for the patient but also the healthcare system as a whole, as resources are used in a more targeted and effective manner.



WHAT IS THE PERSONALISED HEALTH INDEX?

The Futureproofing Personalised Health Index, which is led by an independent panel of global health policy experts and supported by Roche, measures a country's performance based on four discrete but equally weighted Vital Signs, which evaluate fundamental components of personalised healthcare: Policy Context; Health Information; Personalised Technologies; and Health Services. Included within each Vital Sign are a range of measures, on which each country receives a score, based on the available data. The development of the Index was overseen by the expert panel and all the data within the Index comes from accredited publicly available sources.

The goal of the Index is to applaud successes and encourage best practices, while also identifying areas where improvement is needed. Ultimately, the findings should help to inspire collaboration and cooperation between those with the common interest of futureproofing healthcare.



Overall, Ireland ranked

19th out of
34 other
countries

in the **Personalised Health Index**

Overall, Ireland ranked 19th out of 34 countries¹, a distinctly average performance that puts us firmly in the middle of the pack. Ireland displayed significant scope for improvement across a wide range of measures within each Vital Sign.



**Mary Harney, Independent Director and Business Adviser,
Former Tánaiste and Minister for Health:**

“Personalised healthcare is about delivering the right treatment to the right person at the right time, and I would emphasise, in the right place. Every citizen's data is valuable, your data belongs to you, but once shared for science and health purposes it can be used to deliver better outcomes for you as a patient, and better treatments for others.”



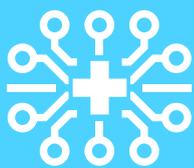
Ireland ranked
12th for
Policy Context

Policy Context

Measures within this Vital Sign included: Civic participation; Environmental/social determinants; Biobanks; Access to data (for research); and Scale-up funding.

Ireland scored 50 points out of a maximum of 100, giving it an overall rank of 12 for this Vital Sign, similar to the UK². While there were areas of strength for Ireland, such as relatively high scores for environmental and social determinants of health, there are also several weak spots. These included the paucity of available funding for the scale-up of initiatives and a lack of willingness to share data for medical research and care improvement. Poor access to data was a consistent hallmark: despite the presence of biobanks, Ireland does not appear in the BBMRI-ERIC European database of Biobanks due to the inability to access this data.





Ireland performed below average for Personalised Technologies

sharing rank **19** with Poland and Lithuania

Personalised Technologies

Measures within this Vital Sign included: Wearables; Treatment Availability; Decision Support Systems; and Access to CAR-T technologies.

This Vital Sign looked at Ireland’s adoption of the devices, applications, platforms, and reimbursement structures that will drive personalised healthcare based on the needs of stakeholders. At 38 points, Ireland’s score was well below the European average of 46 points and we shared 19th place with Poland, and Lithuania³. Despite a recent explosion in the area of mHealth, which is defined as medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices, Ireland had particularly low scores in Decision Support Systems in mHealth and also access to ground-breaking CAR-T therapies, with penetration for both abysmally low compared to most other countries.

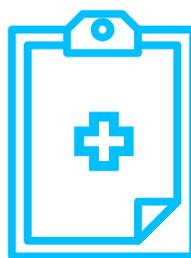


Ireland ranked
19th
for
Health Information

Health Information

This Vital Sign was evaluated using a variety of specific measures: Patient Data Control; Cross-border Data Cancer Registries; Use of EHRs; and Data Infrastructure

Ireland's score for this Vital Sign was 56 points, just above the average of 54 points, giving us a ranking of 19th⁴. Our registry quality (assessed by using cancer as a bellwether) was deemed excellent, we also received relatively high scores for legislation on Electronic Health Records. Yet use of EHRs across healthcare facilities was graded as poor and no data was available for Ireland in the 2018 SmartHealthSystems Bertelsmann Stiftung report, on the extent to which patient data can be transferred securely and automatically to transnational networks.



For Health Services
Ireland ranked below
the average at

22nd
out of
34 countries

Health Services

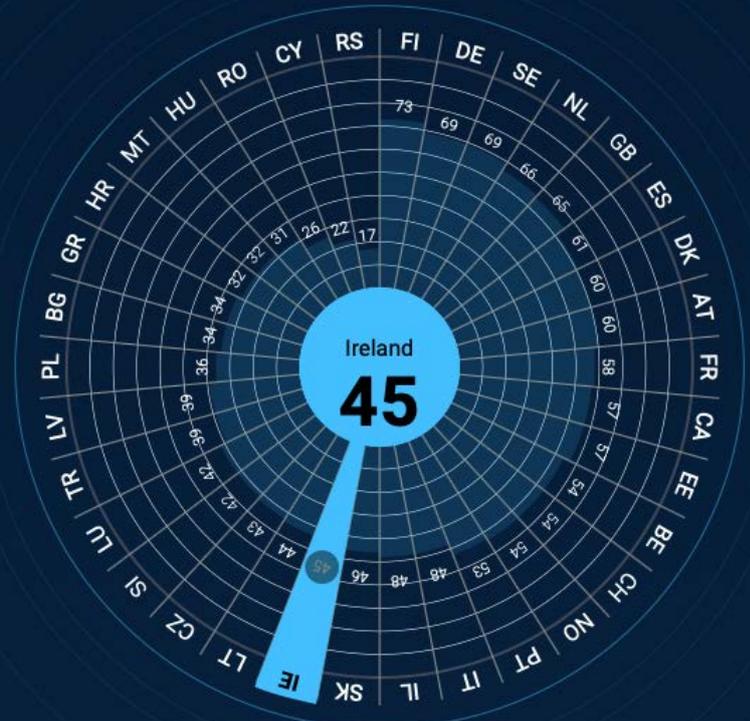
Measures of this Vital Sign assessed the planning, organisation, and delivery of services that will drive personalised healthcare: Equity; Healthcare R&D; Patient Portals; Telemedicine; Integrated Care; Genomic Testing.

At 37 points, Ireland's score was far below the average of 42 points for the countries involved, giving us a ranking of 22nd⁵. Although access to genomic testing (specifically for breast cancer) was ranked as high, this was based only on the availability of one genomic test in Ireland and does not necessarily reflect the national picture in terms of access to genomic testing for cancer patients. The adoption of telemedicine policies and strategies and Integrated Care Initiatives were evaluated as poor. Certain data was also lacking: the percentage of GDP spent on healthcare R&D was not included for Ireland in the Global Observatory on Health R&D, however, an assessment based on GDP figures alone would most likely be skewed due to high multinational exports.



HOW DOES IRELAND COMPARE INTERNATIONALLY?

The Personalised Health Index functions as an effective tool for highlighting best practice both within and between countries but it is worth noting that even those countries that scored highly showed room for improvement in specific areas. The delivery of personalised healthcare relies on a number of moving parts and while some countries may be at a more advanced stage when it comes to some elements of this approach, they may lag behind when it comes to others. For example, across a number of measures, some lower income countries outclassed Ireland when it came to the early adoption of new technologies or digital health. Top tier countries included Finland, Germany and Sweden, receiving the three highest scores, respectively. Strong performers included the UK, the Netherlands and Spain, while Ireland was ranked middle of the pack along with Norway, Slovakia, Italy and Lithuania. The Index highlighted multiple weaknesses for Romania, Cyprus and Serbia, who ranked in the bottom three of the 34 countries evaluated⁶.



IRELAND SCORED 45 POINTS IN THE PERSONALISED HEALTH INDEX



Finland, Germany and Sweden were the top three countries ranked in the Personalised Health Index



Netherlands, United Kingdom and Spain were rated as 'strong performers' ranking 4th, 5th and 6th on the Index



Romania, Cyprus and Serbia ranked in the bottom three of the 34 countries evaluated



Austria, Finland and Norway received top marks for access to data for research



The Netherlands and Sweden scored top marks for the civic participation measure



Norway, Finland, Estonia and Belgium are at an advanced stage of embedding national electronic health records in their health system



The Netherlands, Estonia and Sweden scored high marks for consistent and appropriate use of teleradiology, tele dermatology, telepathology, telepsychiatry, and/or remote patient monitoring.

EXPERT PANEL

A panel of experts from a broad range of disciplines was brought together by Roche Products (Ireland) Ltd. to review the Index and investigate Ireland's score against each vital sign and various measures. Two panel meetings were held to discuss the findings and identify areas of improvement, with recommendations on how to improve personalised healthcare in Ireland.

MEMBERS INCLUDED:



Dr Nina Byrnes, GP, Medical Director Generation Health Medical Clinics, Media Medical Expert



Mary Maguire, Personalised Healthcare Lead, Roche Products (Ireland) Ltd.



Liam Doran, Former General Secretary, Irish Nurses and Midwives Organisation (INMO)



Dr Derick Mitchell, CEO, The Irish Platform for Patient Organisations, Science and Industry (IPPOSI)



Professor Stephen Finn, Consultant Pathologist, St. James's Hospital



Tony O'Brien, NED, Strategy Consultant, Columnist and former HSE Director General



Mary Harney, Independent Director and Business Adviser, Former Tánaiste and Minister for Health



Dr Jennifer Westrup, Director of Oncology and Consultant Medical Oncologist, Beacon Hospital



Professor Bryan Hennessy, Consultant Medical Oncologist, Beaumont Hospital & Vice Clinical Lead, Cancer Trials Ireland



Dr Patrick Buckley, Vice President of Laboratory Operations, Genuity Sciences



Dr Avril Kennan, CEO, Health Research Charities Ireland

WHAT DOES THIS MEAN FOR IRELAND?

REALITY VS PERCEPTION

There was consensus among the group that the “reality” on the ground may not be reflected in the available data utilised in building the Index. Some aspects of care explored were too narrow in scope to clearly illustrate Ireland’s progress, or lack thereof, on certain measures. For example, while Ireland scored highly for its legislation allowing patients to access, control and amend data held

in Electronic Health Records, the measure did not allow for the failure to implement this legislation nor did it evaluate the extent of patient education on their rights. Similarly, while access to genomic testing was deemed excellent, this was based solely on its companion diagnostic role in breast cancer. In practice, the availability of genomic testing is patchy and remains under-resourced.



**Professor Stephen Finn, Consultant Pathologist,
St. James’s Hospital:**

“What personalised medicine does is to make every patient have a rare disease. The highly specific treatment of patients with rare diseases may be applied to every patient if you consider it in such a way. If you have genomics on everybody it makes every single disease in every single patient a rare, even unique, entity.”

LACK OF DATA

The panel agreed that Ireland suffers not only from a lack of data, but also the wrong kind of data, affecting our ability to compare like with like. Addressing this surfeit of poor-quality data – for example, that held in paper records and/or silos – will require significant investment. The Irish health service also fails to utilise the majority of the data it does collect – the panel noted that 97% of hospital data isn’t used.

While Ireland received top marks for its excellent cancer registry, according to the panellists, this is a noted anomaly; they highlighted a paucity of funding and practical resources for registries for many other diseases. And despite a high score for access to data, the truth is that patients have poor access to health records and no ability to edit them.



**Dr Derick Mitchell, CEO, The Irish Platform for
Patient Organisations, Science and Industry (IPPOSI):**

“The quality of the data in the system hasn’t come up to a certain minimum standard in order for it to be interoperable or shareable between systems. I think what increases trust in patient data sharing is the transparency of what the use is for and that has to be a key building block of any data sharing initiative.”



Dr Avril Kennan, CEO, Health Research Charities Ireland:

“While we do have a strong cancer registry, and some independently supported ones, unfortunately we’re really weak on patient registries overall. We have a public that doesn’t fully realise the benefits of research to themselves or to others. They don’t necessarily know that if they take part in a clinical study that their care is likely to be better or that they may get earlier access to innovative new medicine.”

IT DEFICIENCIES

Legacy IT infrastructure is stymying Ireland’s adoption of new technologies and the interoperability of varying systems across different healthcare settings. Outmoded and outdated IT systems are a hallmark of the Irish health service – a notable example is primary care which has invested heavily in recent years, while there are also pockets of good practice in secondary care, namely the private hospitals and St James’s Hospital. Healthlink, the primary care secure messaging service, has become

increasingly invaluable for GPs but it exposes the legacy IT issues and data collection issues within hospitals; often records are duplicated, with multiple files for the same patient. This further points to the need for a system-wide EHR. Indeed, an overall digitisation of the health service is required – the forthcoming National Children’s Hospital which will be “born digital” should serve as the impetus to get the rest of the health service in line and ensure true interoperability of data systems.



Dr Nina Byrnes, GP, Medical Director Generation Health Medical Clinics, Media Medical Expert:

“We have to start recognising that wearables are here to stay and they’re an asset in medicine and start encouraging patients to use them, encouraging feedback. And have our health record systems able to take that data and use it. One thing I’d love to see moving forward in an index like this is far more people using wearables because the data from them can be helpful.”





Tony O'Brien, NED, Strategy Consultant, Columnist and former HSE Director General:

“COVID is both an enabler, and to some extent an impediment, recognising the high level of resource that is having to be absorbed by COVID and how much priority is having to be given to developing systems that support the COVID response. But we live in hope that this will be a transient phase and that it will leave some extra building blocks that can be further built upon.”



IMPACT OF COVID

The COVID pandemic has left an indelible mark on the health service, and the panellists noted that it may already have made tangible and potentially long-lasting positive differences to the adoption of digital health technologies that had been in existence but not widely adopted, for a variety of reasons. For example, the use of telemedicine has skyrocketed out of necessity since the beginning of the public health crisis, while the introduction of electronic

prescriptions, long delayed despite obvious advantages, has finally happened in the intervening months to the relief of medical practitioners, pharmacists and patients alike. Healthlink has seen demand increase exponentially since March 2020, with a 500% increase in messaging. Panellists also agreed that the pandemic may have made the wider public more aware of the merits of clinical research and thus more willing to share their data.



Dr Patrick Buckley, Vice President of Laboratory Operations, Genuity:

“The whole future concept of e-consenting and dynamic consenting, where patients can opt in and out of studies as they wish.... puts the patient at the centre of the study to make informed studies themselves.”

LACK OF INVESTMENT

The constrained drug budget also serves to disallow personalised healthcare – Ireland’s patients wait, on average, up to 500 days for access to newly-approved therapies⁷. For patients with rare diseases, the wait can be up to 800 days⁸. The panellists, including the frontline clinicians, agreed that this lack of access to medicines is affecting the delivery of personalised healthcare. Investing in the required technologies e.g. genomic testing would allow more precise and targeted use of these therapies to the patients who will derive the most benefit. Ireland’s inability to monitor the real-world effectiveness of therapies, such as the German health system does, ultimately impacts the cost-effectiveness of drugs as payment mechanisms that are related to surveillance-based outcomes cannot be adopted.



Professor Bryan Hennessy, Consultant Medical Oncologist, Beaumont Hospital & Vice Clinical Lead, Cancer Trials Ireland:

“We’re now 500 days on average for new cancer therapeutics to get reimbursed in this country as opposed to 100 days or shorter in almost all of our European neighbours and it really is impacting on precision medicine, and personalised healthcare delivery.”

TRUST AND TRANSPARENCY

Recent data breaches, both nationally and internationally, have led to a general distrust and high index of suspicion when it comes to the sharing of personal health data. Despite this, people are happy to share relevant data when it comes to using certain smartphone apps, for example. Patients are keen to share their data as they understand

it may ultimately improve care and thus outcomes, but the wider public is less open to this idea. Educating the wider public on the value of their data in furthering medical research as well as emphasising its security and the protection provided by the consent process is key to increasing civic participation.



Liam Doran, Former General Secretary, Irish Nurses and Midwives Organisation (INMO):

“The trust issue cannot be overestimated in terms of the population. We have to convince people that the healthcare system is dynamic. For personalised healthcare to be achieved, we need to make the system less systematic in terms of its own needs and more aware of what the individual it serves needs are so that it shapes service delivery in that regard.”



INSIGHTS AND EXPERT RECOMMENDATIONS

The expert panel reached consensus in terms of their recommendations for how to address the deficiencies highlighted by the Personalised Health Index.



Panellists agreed that the electronic health record (EHR) is the building block for much of the delivery of personalised healthcare. It will allow patients and healthcare professionals to access their data in a variety of settings, allowing the seamless transfer of care. A secure patient portal allowing ease of access would be the ideal. The unique health identifier/individual health identifier already exists and is underpinned by legislation, but its widespread rollout has been delayed as the health service's IT infrastructure remains inadequate. Using the successful examples of EHR systems in St James's or the National Maternity Hospital as a proof point for other hospitals, would not only help to build trust but could also iron out any potential problems.



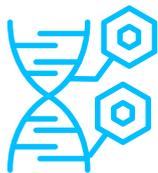
According to the panellists, Sláintecare, the cross-party plan for the future of healthcare, could serve as the "trigger" for the delivery of personalised care. The panellists agreed that Sláintecare cannot progress without an interoperable EHR; similarly, its rollout will require significant investment and this could provide the necessary funding for the upgrading of data and IT systems.



The panellists also suggested the development of an Interdepartmental strategy, aligning academia, medical schools, clinical research and primary/secondary/tertiary care towards the common goal of enabling personalised healthcare.



A coherent and extensive public awareness campaign is required to educate the broader public on the value of sharing data for the betterment of medical care and clinical research. For example, scepticism around participation in clinical trials for cancer therapies has been largely addressed by way of a successful public information campaign, while campaigns such as usemydata.org in the UK have also been successful. Appealing to people's altruistic instincts is key, as is communicating the concept of the EHR as a "locked safe".



As regards genomic testing, a formalised national policy is required, as well as an appropriately funded genome resource. This will maximise the benefits of pre-existing and forthcoming targeted therapies and enable the use of data in ground-breaking clinical research. With an overlap between genomics research and using genomics for clinical care, a public-private partnership may be the solution. Again, a significant public education piece will be required around this.



**Mary Maguire, Personalised Healthcare Lead,
Roche Products (Ireland) Ltd**

"We need to start having this conversation about citizen information rather than patient information. Everyone should know more about the benefits of sharing data for research and clinical purposes. We want to design better diagnostics and medicines but to do that we need more precise information to deliver truly personalised care."



CONCLUSION: A COHESIVE VISION IS REQUIRED

The Futureproofing Personalised Health Index served to paint a stark picture of Ireland's lack of preparedness to move towards a system of personalised healthcare. It was evident that there is a sharp disconnect between policy and implementation. While some elements are in place, e.g. legislation for an individual patient identifier, or the use of electronic health records in some areas of the health service, the implementation of these has been patchy. A cohesive vision and approach for personalised healthcare in Ireland is lacking.

Significant investment of both time and resources is required but equally as important is a coherent public awareness campaign, to assuage any concerns around the sharing of health data for research purposes and effectively "normalising" the sharing of health data. The roll out of a national EHR system is pivotal; it will enable an efficient healthcare delivery system and pave the way for digital health and thus must be viewed as a priority.

While the Index provided an indication of where Ireland lies in relation to our international counterparts, it's worth

noting that deficiencies exist across the board, with many other countries in a similar position to Ireland when it comes to the adoption and integration of digital health initiatives. Ireland should look towards countries of similar size who performed well in the Index, e.g. Finland, and take learnings from them.

With health budgets under increasing strain, even more so due to COVID, technology must be viewed as an enabler to more efficiency in effective care and a crucial component of a modern health system. The findings of the Index exposed this fundamental failing of the Irish healthcare system. Immediate steps to address this must be taken, otherwise Ireland – and Irish patients – will get left behind as healthcare inexorably moves towards a more personalised and tailored approach.

The Index serves to highlight a range of existing deficits and shortcomings that will need to be addressed if true personalised healthcare is to become a reality in Ireland.



Dr Jennifer Westrup, Director of Oncology and Consultant Medical Oncologist, Beacon Hospital

"Electronic Health Record should be able to collect patient generated data. The other data that we should be getting is the research data, the genomic data. Everything should flow. And then integrated care initiatives can happen. I think that's a pivotal point if we're going to futureproof our healthcare. Personalised Healthcare is the future and the benefits are enormous to patients."





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