

# Renewal through health research

Health Research Charities Ireland

**Position Paper 2021**

**[hrci.ie](https://www.hrci.ie)**



**Covid has shown us that the most important things in life depend on the outcomes of research – our health and the health of our loved ones.**

*However, healthcare is only as good as the research that underpins it.*

*Research is not some luxury add-on but should be integral to healthcare.*

*Supporting health research is an investment, not a cost. It will ensure better health for Irish people and a stronger economy.*

*Investing in an improved research environment will positively impact everyone affected by ill health, in every county of Ireland.*

*Involving patients and their representatives in the shaping of research will make it more relevant, better quality and more impactful.*

## **Summary of recommendations**

- Recommendation 1** Increase support for clinical research
- Recommendation 2** Develop a national genomics strategy
- Recommendation 3** Integrate PPI into research strategy and policy

# About HRCI and its members

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active in health and medical research, together representing over 1 million Irish patients. Through support and advocacy, we represent the joint interests of our 40 members, working to improve health and prevent illness through research. We also fund and manage the Irish Health Research Forum, bringing together all stakeholders to improve health research in Ireland. It is our core belief that today's health research is tomorrow's healthcare.

## Our key activities include

### Ensuring impactful health research through PPI

Positioned at the interface of science and society, HRCI and our members have a very important role to play in patient and public involvement (PPI). We support our members in involving their patient communities in their research decision-making and in linking patient and carers with researchers.

### Facilitating research funding

HRCI operates a 'Joint Funding Scheme' in partnership with the Health Research Board (HRB) which, unlike any other scheme in Ireland, is open to all types of health research, for all conditions, including rare and neglected diseases. To date, 134 awards have been made, with approximately €13.5 million invested by the HRB and matched by charity funding.

### Supporting our members

We assist our member organisations to maximise the benefits from their research activities. We facilitate a vibrant and supportive community, keep them up to date on developments and are there for them through every step of their research activities.

### Improving the research landscape

By managing the [Irish Health Research Forum](#) (IHRF), a high-level collective of stakeholders working together to influence health research practice and policy in Ireland, we are actively helping to improve patient care through research.



# The context

## What Covid has taught us

Through the ongoing pandemic, health researchers have become our great hope and our heroes. The world held its breath waiting for these scientists to understand how SARS-CoV-2 impacts our bodies and minds, to develop treatments for Covid-19 and to find an effective vaccine. While nothing before has spurred such a concerted focus on the importance of health science, let's not forget that those same researchers, plus millions more, were already working on a myriad of aspects of human health and disease. If you consider, for a moment, your family and friends, you can probably list off numerous health conditions that affect their lives. With a little more thought, you can probably also point to many and various ways that their life has been improved or even saved by the outcomes of research.

## Health research charities shaping research

Health research charities are very familiar with the power of research and play an extremely valuable role in supporting it, shaping it and in ensuring it gets translated into benefits for patients and the wider public. Their most obvious role is that of funding health research and our members invested more than €14 million in health research in 2019 (for context, that is almost one third of the annual HRB budget). Beyond funding, they also ensure that research is relevant to the communities they represent, act as a lynchpin between patients, researchers, healthcare professionals and the public and effectively communicate the outcomes of research in ways that can be understood by all.

## Putting science at the heart of society

Irish people have a strong belief in science and understand its importance to their lives, especially their health. A 2020 survey of 1,000 people, commissioned by Science Foundation Ireland, showed that healthcare came out on top, at 82%, when respondents were asked how they would like to see science have a positive impact.<sup>1</sup>

As countries all around the world battle to restore the role of truth and fact in society, US President Joe Biden announced in January that he has elevated the position of the administration's top science advisor to a cabinet post for the first time. The appointee, Prof Eric Lander, is a geneticist who co-led the Human Genome Project. Ireland would do well to take such decisive steps to ensure that science and evidence are embedded at the heart of Government. Nowhere is this more important than in formulating policy relating to human health.

*In this broad context, we present key 2021 priorities for HRCI and our members. We are asking politicians, policy makers and everyone with influence in the health research space to prioritise them as they plan for the year ahead.*

---

<sup>1</sup> Covid-19 changing Irish people's expectations of science, study shows, 2020, Irish Times: <http://bit.ly/3qDSKdL>

# The recommendations

As we hold regular meetings with our highly informed member organisations, themes around health research emerge, reoccur and evolve. As a community, we continually refine our knowledge of patient needs, the potential of research and the barriers to progress.

## The recommendations below are based on:

- The views of our members as captured over many years
- A 2021 HRCI member survey
- The outcomes of Irish Health Research Forum events (run by HRCI)

The recommendations have been devised, not only on the basis of what is important, but also what is achievable, and we have focused on areas in which we have observed recent momentum. With political will and partnership among key stakeholders, implementing these recommendations has the potential to tangibly improve the health of the Irish public.

## Recommendation 1: Increase support for clinical research

As the Covid-19 pandemic has repeatedly driven home to us, research in the clinical setting should not be considered a hobby for those lucky enough to be able to carve out a little time for its undertaking. On the contrary, it should be an integral and central aspect to the delivery of care. Clinical centres that are research-active show better outcomes for patients and save lives.

Research brings many benefits, including:

- Healthcare that is built on and constantly improved by evidence.
- The delivery of better patient care in healthcare settings with a strong research culture. This relates to many factors such as improved clinical standards, increased efficiencies and increased staff retention.<sup>2,3</sup>
- The possibility of early access for Irish patients to innovative treatments, through clinical trials.
- An increase in Ireland's attractiveness for the life-sciences industry.

However, with the exception of some pockets of excellence, research is not yet appropriately prioritised within the Irish health service. A review by the HRB shows that there is significantly less clinical trial activity in Ireland compared to European countries such as Denmark, Norway and Finland.<sup>4</sup> Strong political will is needed to overcome the challenges created by chronic underinvestment in clinical research, a culture of viewing research as a dispensable add-on and a health service long caught in a fire-fighting cycle.

We strongly welcome some steps in the right direction. For many years, the HRB has invested in clinical research which has paid many dividends, including stronger clinical research infrastructures. A number of recent strategies and plans also promise improvements, including:

---

<sup>2</sup> Does the engagement of clinicians and organisations in research improve healthcare performance? A three-stage review, 2015, BMJ Open. <https://bmjopen.bmj.com/content/5/12/e009415>

<sup>3</sup> Organisational benefits of a strong research culture in a health service: a systematic review, 2017, Aust Health Rev. <https://www.ncbi.nlm.nih.gov/pubmed/27074113>

<sup>4</sup> Review of clinical research infrastructure in Ireland, 2019. Health Research Board. <https://bit.ly/3nXhIIM>

- The 2019 **Sláintecare Action Plan** which emphasises the importance of research to support improved healthcare.<sup>5</sup>
- The 2019 **HSE Action Plan for Health Research**, outlining practical and sensible steps towards improvement.<sup>6</sup>
- The ambitious 2020 **Children’s Health Ireland strategy for research**.<sup>7</sup>
- The 2019 Clinical Research Development Ireland (CRDI) **Future Investment in Clinical Research** report, developed with the involvement of a wide array of stakeholders.<sup>8</sup>

These plans and strategies provide a roadmap for how clinical research can be supported, in order to result in tangible changes for patients and healthcare professionals. However, strong action, focus and commitment will be required to ensure that they don’t just sit on shelves.

### **As highlighted in a 2020 IHRF report<sup>9</sup>, specific actions to increase support for clinical research include:**

- Introduce **research key performance indicators**, as part of the job descriptions and role metrics for all relevant health service staff, from the leadership down.
- Improve **research governance and support structures** within the health service.
- Increase the number of funded **academic–clinical posts**, across all healthcare professions.

## **Recommendation 2: Develop a national genomics strategy**

The genome refers to the 20,000 or so genes we each have. It is what makes us who we are. It is responsible in large part for our personalities and appearances. It is also responsible for genetic diseases and a significant contributing factor in illnesses that have multiple causes. Even the severity of Covid-19 has been shown to be impacted by a person’s genetic code.<sup>10</sup>

When you consider the combined genomes of the Irish population, together they offer an incredible wealth of data. Data is now sometimes referred to as the ‘new oil’ and nowhere is this more true than in the case of genomic data from a large population of relatively homogenous people. The most obvious use of this data is in its power to change healthcare.

Genomic research on all forms of human genetic disease, from cancer, to rare single-gene conditions like cystic fibrosis, to complex conditions with many causes like multiple sclerosis, is pointing the way to a better and more personal approach to medicine. Giving the right medicines to the right people, at the right time will make the health service more cost-effective. In 2018, a group of the UK’s leading medical scientists predicted that genomics was one of the key areas with the most potential to transform society and suggested that it will become a ‘first-line technology’ for healthcare within the next 30 years.<sup>11</sup>

<sup>5</sup> **Sláintecare Action Plan**, 2019. <https://health.gov.ie/blog/publications/slaintecare-action-plan-2019/>

<sup>6</sup> **HSE Action Plan for Health Research**, 2019-2029. <https://bit.ly/38VY9ad>

<sup>7</sup> **Children’s Health Ireland Strategy for Research**, 2021-2025. <http://bit.ly/3qzCv1g>

<sup>8</sup> **Future Investment in Clinical Research report**, 2019, Clinical Research Development Ireland. <https://crdi.ie/future-resourcing-of-clinical-research/>

<sup>9</sup> **IHRF report: Working Across Health Services & Academia – Challenges and Solutions for Health Research**, 2020. [http://bit.ly/IHRF\\_healthservices-academia](http://bit.ly/IHRF_healthservices-academia)

<sup>10</sup> **Genetic mechanisms of critical illness in Covid-19**, 2020, Nature. <https://www.nature.com/articles/s41586-020-03065-y>

<sup>11</sup> **Horizon Scanning – research and innovation to transform the health of society by 2048**, 2019, The Academy of Medical Sciences. <https://acmedsci.ac.uk/more/news/academy-horizon-scanning-report-published>

However, with the exception of some pockets of excellence, the Irish health service has been very slow to use the power of genomic data and research to inform its clinical decision-making. This contrasts with the UK where great advances are being made in genomic medicine and research through public funding.<sup>12</sup>

In a welcome step, a National Genetics and Genomics Medicine Network, was committed to in the 2020 Programme for Government<sup>13</sup>. Separately, it is a widely held belief among those working in the field that Ireland should invest in a public genome project. This is not an insurmountable goal. Speaking at a recent IHRF event<sup>14</sup>, Professor John Grealley, Director of the Centre for Epigenomics in Albert Einstein College of Medicine, New York, proposed that Ireland take a lead from the Finnish National Genome Project (FinnGen). This model could allow for public-private partnership but would protect genomic data for the benefit of the Irish public.

As an essential prelude to the above proposals, Ireland must develop a **national genomics strategy**. This should be undertaken with the involvement of all key stakeholders, including patient representatives. It has the potential to be among the greatest public health investments the state could make.

### **Actions required to position Ireland to take advantage of the genomics revolution:**

- Develop a **national genomics strategy**.
- Establish a **National Genetics and Genomics Medicine Network**.
- Invest in an **Irish public genome project**.

## **Recommendation 3: Integrate PPI into research strategy and policy**

For too long, health research was undertaken without the simple act of asking patients and the public what they wanted from it. However, patient and public involvement (PPI), is fast becoming the norm in health research and is transforming the way health research is undertaken. It refers to the involvement of patients, carers and the public, not just as research subjects but as decision makers in the research process. While it brings many challenges, when done in a meaningful way it can improve the research quality, relevance and impact for patients and wider society.<sup>15</sup>

While much progress is still required, there are now many, exciting examples of good PPI practice in Ireland. Health research charities are mobilising networks of patients and carers to get involved in research. A national PPI network has been planned, to include all Irish universities and ten national partners, building on five successful PPI Ignite initiatives<sup>16</sup>. Individual research teams are embracing

---

<sup>12</sup> **UK DNA project hits major milestones with 100,000 genomes sequenced**, 2018, New Scientist.

<https://www.newscientist.com/article/2187499-uk-dna-project-hits-major-milestone-with-100000-genomes-sequenced/>

<sup>13</sup> **Programme for Government: Our Shared Future**, 2020: <https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/>

<sup>14</sup> **IHRF event and discussion paper: Advancing genomics research in Ireland**, 2020. <https://hrci.ie/advancing-genomics-in-ireland-feature/>

<sup>15</sup> **Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis**, 2018, British Medical Journal. <https://www.bmj.com/content/363/bmj.k4738>

<sup>16</sup> **National PPI Network funding scheme**, 2020, HRB. <https://www.hrb.ie/funding/funding-schemes/all-funding-schemes/grant/national-ppi-network-1/>

PPI and upskilling to ensure that their PPI activities are inclusive and meaningful.

While we continue to support and encourage PPI in health research, it is equally important that PPI be included in structures relating to health research strategy, policy and oversight. Sometimes it is seen as too challenging and fraught to include people who wish to bring a patient or public perspective to committees, boards or other such structures. However, while it can create challenges and requires effort, there are now many positive examples to follow and resources to be guided by, including some HRCI guides<sup>17,18</sup>.

In a recent and welcome example of PPI within a State body, the National Office for Research Ethics Committees is actively recruiting patients and members of the public to sit on ethics committees and thereby demonstrating that experiential knowledge, as well as professional knowledge, is valued.<sup>19</sup> It and other examples demonstrate that PPI in such contexts is possible and show how it can be achieved. It is essential to include PPI in all committees/groups working at a national or local level making big decisions about health research, including any future committee to shape Ireland's strategy for genomics.

### **When integrating PPI into research strategy and policy, the following should be adhered to:**

- Undertake an **open recruitment process** whenever possible (rather than the hand-picking of known patient advocates).
- Build in an **inclusion and divers approach** to recruiting and supporting PPI contributors.
- **Appoint more than one PPI contributor** so that they can support each other and increase the diversity of views.
- **Support and enable** PPI contributors to undertake their role to the best of their ability.
- **Always cover PPI contributors' expenses** and **financially compensate** them for their time whenever possible.
- **Inform and/or train** all other members of the group about the role and value of PPI contributors.

## **Finally**

Thank you for taking the time to read this position paper. We are always open to engagement and questions so please don't hesitate to get in touch.

For other organisations undertaking advocacy in health research, we have a strong belief in the power of sharing so please feel free to use anything of value to you within this document.

---

<sup>17</sup> **Making a start: a toolkit for research charities to begin a PPI relationship**, 2020, HRCI. <https://bit.ly/HRCIPPItoolkit>

<sup>18</sup> **Developing a PPI Strategy: A Guide**, 2018, HRCI. <http://bit.ly/HRCIPPIguide>

<sup>19</sup> **National Office for Research Ethics Committees**, 2020. <https://www.nrecoffice.ie/become-a-member/>



**Health Research Charities Ireland (HRCI)**

**Digital Office Centre**

12 Camden Row  
D08R9CN  
Ireland

**T** 353 1 479 3234

**E** [avril@hrci.ie](mailto:avril@hrci.ie)

**[www.hrci.ie](http://www.hrci.ie)**

Registered charity number (RCN): 20052973

HRCI is an independent  
charity supported by



Rialtas na hÉireann  
Government of Ireland

