

Irish Health Research  
Forum Meeting

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A single  
voice **to**  
**improve**  
**health**

# Embedding research in the Irish health service

11th May 2022

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# About the Irish Health Research Forum (IHRF)

The Irish Health Research Forum, which is run by HRCI, brings together all stakeholders nationally to positively influence health research. The Forum considers key health research issues at two events every year and produces widely used reports and recommendations. The events are constructive and inclusive, with benefit to patients and the public being at the heart of all activities.

As an independent organisation, representing 40+ charities and with a strong patient-focus, HRCI is ideally placed to bring people together to tackle the big issues in health research and to bring about change. We are supported in all Irish Health Research Forum activities by an exceptional and diverse Steering Group of leaders. For more information, see [www.hrci.ie/ihrf](http://www.hrci.ie/ihrf)

# About Health Research Charities Ireland (HRCI)

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active in health, medical and social care research, together representing over 1 million people in Ireland. Through support and advocacy, we represent their joint interests, to achieve our vision of improved lives through a united community of health research charities.

In addition to running the Irish Health Research Forum, we offer our members the potential for matched research funding through the Joint Funding Scheme, run in partnership with the Health Research Board (HRB). We also a national leader in patient and public involvement (PPI) and run a PPI Shared Learning Group for our members. [www.hrci.ie](http://www.hrci.ie)

# Irish Health Research Forum recommendations on how to embed research in the Irish health service

Research is vital for achieving better outcomes for patients and the public who use health services in Ireland. Current frustrations, positive developments, new ideas and an unshakable belief in the possible, stimulated lively, challenging, engaged, multi-stakeholder discussions at the Forum event. Nuanced by input from our expert Steering Group, the Irish Health Research Forum offers the following crucial recommendations under two main headings: **Nurturing a culture where research is valued and integrated in the Irish health service** and Ensuring that patients and the public are valued and integrated at the heart of research.

## Nurturing a culture where research is valued and integrated in the Irish health service

This will require:

- 1 **health service leadership to embrace a research culture** and a move towards all relevant staff, including those in community settings, becoming research active.
- 2 **strengthening infrastructure and systems** to support research, building on the *HSE National Framework for the Governance, Management, and Support of Health Research*.
- 3 the development of **career tracks** for research staff, **joint appointments** with universities for all types of healthcare professionals and **protected research time**.
- 4 the provision of **education and training** in all aspects of health research, with a focus on co-learning across stakeholder groups.

## Ensuring that patients and the public are valued and integrated at the heart of research

This will require:

- 5 increasing the **diversity of PPI contributors and providing reimbursement for their time** to ensure that all research stakeholders come together on an equal footing.
- 6 a **focus on knowledge translation and societal impact from research**, in line with Impact 2030: Ireland's Research and Innovation Strategy.
- 7 **legislation to guide the use of health data for research**, developed in consultation with patients, members of the public and all stakeholders.
- 8 A **public information campaign** on the value of research, to build awareness and trust about research processes and health data use.

For more detail on the recommendations, and the debates which formed them, see the remainder of this report.

# Key themes which emerged at the event

From the in-depth discussions at this event there emerged some high-level challenges and opportunities for embedding research in the Irish health system.

## Challenges

- There is not yet a widespread culture of research in the health system and an attitude of competition rather than collaboration can hinder progress.
- Infrastructure, systems and legislation to support research in the health service are not yet well-developed, making the current system confusing and difficult to navigate.
- A health service in perpetual crises means that protected research time is not the norm for health and social care professionals.
- Current career pathways do not incentivise or reward research roles comparably to clinical roles.
- Patient and public involvement (PPI) is still far from integral to the entire research cycle.
- Research waste is a significant challenge, limiting potentially the impact from both researchers' and participants' time and effort.
- Research impact, beyond journal publications, is not considered enough.

## Opportunities

- There is enormous potential to improve patient outcomes, staff satisfaction and efficiencies through research evidence.
- The HSE National Framework for the Governance, Management, and Support of Health Research (September 2021) is a strong step towards streamlining and integrating the necessary governance structures, services and systems for research in the HSE.
- A move towards embracing PPI will help to increase research impact and reduce research waste.
- The current process of streamlining the research ethics approval system should reduce duplication and delays.
- Plans for more research offices and a national electronic research management system will help with the governance, management and support of research.
- The experiences of the HSE in communicating with the public about Covid public health measures and vaccines will aid in strong communications about research and health data.
- Exemplars in clinical-academic partnerships, such as the new Paediatric Academic Health Science Centre, will provide a model of excellence for similar initiatives.

# Acknowledgements

Thank you to the chairs, speakers, panellists and attendees at this event, who gave generously of their time and knowledge. We wish to acknowledge the support of the excellent Irish Health Research Forum Steering Group in shaping the agenda for the day and in developing the recommendations. We would also like to thank the HRCI staff and Board for their continued management and support of the Forum. Finally, we would like to thank Roche Products (Ireland) Limited who funded this Irish Health Research Forum event through an independent grant. Roche Products (Ireland) Limited have had no editorial influence over the content of the event or this report.

This report was compiled by Dr Sarah Delaney, HRCI Research Support Officer and Dr Avril Kennan, HRCI CEO and Claire O'Connell, Freelance Science Writer.

Audio recordings of the talks at this Irish Health Research Forum event can be found here:

<https://bit.ly/IHRFmay2022playlist>

## Abbreviations used:

**CHI:** Children's Health Ireland

**HSE:** Health Service Executive

**HRCI:** Health Research Charities Ireland

**PPI:** Patient and Public Involvement

**REC:** Research Ethics Committee

**SCC:** Sports Surgery Clinic

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The digital copy can be found on <https://hrci.ie/ihrf/>

## Opening remarks



**Dr Mark White;**  
Chair Irish Health Research Forum Steering Group & VP for Research, South East Technological University

Opening the event, Dr White focused on the diversity, opportunities and supporting needs for research in the Irish health services. Welcoming delegates to the first in-person Irish Health Research Forum in two years, he described it as a great opportunity to shine a light on the good things that are happening in health services research in Ireland as well as the challenges, and to have a discourse about what needs to happen to grow this research. Dr White noted the diversity and complexity of health services research, which is difficult to even define. He highlighted how health service research includes many different experts and disciplines such as epidemiology, medical anthropology, decision theory, biostatistics and clinical sciences to name but a few. He stressed the need for infrastructure and services to support research and the importance of keeping the patient at the centre of such research. This, as well as the variety of health care systems operating in Ireland, makes embedding research in health services both complex and context-specific. In addition, he noted, health services research needs a community of investigators of sufficient numbers, disciplinary mix and experience, underpinned by educational and employment structures through which people can pursue appropriate training and a relevant career path.

***This dynamic time of change in the Irish health service provides us with so much scope and material to research and examine the current clinical services, to look at new HSE structures and how they are dynamically changing, new delivery and finance models. The scope of research topics and the demand for data around these topics continues to grow and they are absolutely endless.***



# Health Research Charities Ireland (HRCI) welcome



**Suzanne McCormack;**  
Chair with HRCI and CEO with The Irish Thoracic Society

Suzanne McCormack welcomed everyone to the event. She noted that the Irish Health Research Forum had held productive and important virtual forums in the last two years, and that it was heartening to be back in the room together with a wealth of perspective, knowledge and ideas to share. She said that the topic of embedding research in the Irish health service goes to the heart of what patients deserve: access to evidence based care, access to innovative treatments, and the opportunity to shape and to improve the healthcare of the future. Ms McCormack described how research-active healthcare settings provide better outcomes for patients and more attractive workplaces for healthcare professionals. While such pockets of excellence exist in Ireland, she said that we need more time with the right culture, infrastructure and systems to support research-active healthcare settings more broadly in Ireland.



***Days like today really bring home to us in HRCI why we got involved in setting up and running the Irish Health Research Forum in the first place. That is because it is so critically important to bring all stakeholders together to discuss health research issues. It is also so important to do this in a way that puts the patient and charities at centre stage."***



# Supporting research within the HSE



**Dr Philip Crowley;**  
National Director for Research and  
Strategy, HSE

Dr Crowley's talk focused on the importance of research in the health services in Ireland. He described how the Forum was an important collaboration for the HSE, and how the partnerships in the room represented the engine that drives work and creates space and leverage to build research in the HSE. In terms of priorities for such research, Dr Crowley highlighted the need for research to support healthcare staff wellbeing, particularly in light of the 'great resignation' as a result of the pandemic, as well as research on preventative health and population wellness. He described systemic challenges in Irish healthcare, such as the attitude of competition rather than co-ordination and collaboration, and the focus on reacting in crisis mode rather than stepping back, taking stock and asking are we doing the right things well. Patching institutions and groups together is not the solution to silos, he added.

Dr Crowley highlighted issues in Irish health services such as inequity (particularly in referral to secondary care), the collapse of hierarchy seen during the pandemic, the need to respect expertise and resources, and the need to modernise infrastructure. Research and development needs to be a key business for the HSE, he said, and it will result in better performance, better quality patient care

and satisfaction, as well as better staff morale, recruitment and retention and a more positive and collaborative environment. Research needs to be a core business; it cannot continue to be the icing on the cake. However it will need resources and education and it will need time. Dr Crowley said it would be a long road, but he was optimistic that we will get there.

***Ultimately if we are serious about research and we invest in it, and we stick together and we work through our partnerships, we will develop a better health service."***



**Dr Ana Terres;**  
 Head of Research and Evidence,  
 Assistant National Director, HSE

Dr Ana Terres noted that the last time she spoke at the Irish Health Research Forum it was to describe the HSE Action Plan for Health Research. On this occasion she wanted to describe what has been happening since to create an environment that facilitates research becoming embedded in healthcare in Ireland. She acknowledged that the current system for doing research in the healthcare service in Ireland is confusing and difficult to navigate, and it is challenging to get multi-site projects off the ground. There are many stakeholders and agencies with important roles in deciding how things are done, including multiple governance structures at local and national levels, such as research ethics committees (RECs). What we are missing is a national set of policies, standard operating procedures and guidelines. Collaboration and consensus is the only way forward, she noted, and a step in the right direction is the HSE National Framework for the Governance, Management and Support of Health Research, which was launched in September 2021. Her office is also working to reform the REC system, moving from the need for multiple committees towards a single REC approval, improving efficiency. Dr Terres said that her office is advocating for Research Offices to co-ordinate the processes of research governance, including data protection, and they are about to tender for a national electronic research management system to bring the research approvals process into the 21st century. Capacity building is one of the biggest challenges, she said. In addition, an enabled system will need national policies, standards and legislation, knowledge translation and dissemination strategies and public and patient engagement and buy in. Guidance, training and support

will also be necessary for the research community as well as host organisations, managers, members of RECs and Data Protection Officers, added Dr Terres, who said that the HSE has developed some tools available through the HSE portal.



***Without the engagement of the public, patients, their carers and the people who use the healthcare services in supporting this effort, we probably won't get anywhere.***



# Research at the centre of children's care: Children at the centre of research



**Professor Paul McNally;**  
Director of Research and Innovation at  
Children's Health Ireland

Children's Health Ireland (CHI) has a unique opportunity to rethink academic health science and to put the focus on impact for patients and their families, according to Professor Paul McNally, who spoke about how CHI is realigning its overall approach to academic healthcare, including research. CHI currently has relationships with four universities, and has the strong support of the Children's Health Foundation, providing important research funding for CHI. Professor McNally described how the new Paediatric Academic Health Science Centre will strengthen and focus these relationships, and how hospital's dedicated Research and Innovation Office, Clinical Research Centre and the Children's Research and Innovation Centre will help to drive research forward on the campus. A wider Academic Health Science Network will bring researchers and clinicians together across all hospitals and universities in Ireland that look after children. A Chief Academic Officer (shared between the hospital and the academic partners) will head up the Academic Health Science Centre and oversee all children's research, innovation and education undertaken by the partners.

Professor McNally outlined the importance of a streamlined focus on research in CHI which will cover the spectrum from low complexity projects and non-academic (clinical) research staff to high complexity academic studies with a strong focus throughout on impact for children. To make it easier for people

in healthcare services to engage with research, CHI is developing seed funding through its Foundation to provide time and training in aspects such as project management, ethics, data, governance, methodology and biostatistics. CHI is also striving to forge strong links with PPI partners - to engage meaningfully with them and keep PPI at the centre of research activity across CHI.

***We know we have phenomenal people; it is about making research as accessible and streamlined as possible for clinical and academic staff so we can translate that potential into impacts for children."***

# Discussion groups

Attendees at the event were asked to consider four questions through discussion groups of 8-10 people (two groups per question), with an assigned facilitator. The main recommendations to address each question, as reported in feedback at the event by the facilitators, are outlined below.

## 1 How can we listen to patients/the public and meet their real-life needs through research?

*Feedback was provided by table facilitators Elaine Quinn (Institute Manager - Communications & Education; UCD Conway Institute) and Suzanne McCormack (CEO; Irish Thoracic Society & Chairperson; HRCI)*

The main recommendations from two multi-stakeholder discussion groups who addressed this theme are:

- **PPI needs to be integral throughout the research lifecycle**, from research priority setting to dissemination and research offices should support this and insist on it.
- **Ongoing training for both PPI contributors and researchers** should be provided, building on the efforts of the PPI Ignite National Network and others.
- **Researchers need to be given time to meaningfully engage** with patients and to undertake PPI.
- **PPI contributors should be reimbursed for their time**, in order to ensure they are equal to others in the research process.
- Resources are needed **to increase equality, diversity and inclusion in PPI**, for example, resources to overcome language barriers.
- More should be done to **capture and reward the impact of PPI** in research.

## 2 How can we move the dial on ensuring health data is used for research?

*Feedback was provided by table facilitators Bernadette Rock (Head of Research; Medical Council Ireland) and Lorna Kerin (RCSI Manager of Public Patient Involvement in Research; RCSI University of Medical and Health Sciences)*

The main recommendations from two multi-stakeholder discussion groups who addressed this theme are:

- The **confidence and trust of the public**, in how their health data is used and protected, needs to be built and maintained, through transparency and good practice.
- The public should have **access to their own health data**.
- A **national information campaign focused on the value and protection of health data** should be undertaken.
- **Legislation enabling and supporting the collection, use, sharing and protection of health information** for research, needs to be progressed, with the involvement of all stakeholders.
- We need to **build digital health literacy and to support PPI**, to ensure that patients are drivers of positive change in relation to the use of health data for research.
- **Informed consent processes** for the use of health data need to be layered and dynamic, and appropriate processes and systems are required to allow this.
- **Extreme interpretations of GDPR and the Health Research Regulations should be avoided** because they can further marginalise excluded groups in research, by making it too difficult to include their data.
- **Investment is required in infrastructure** to support a connected data environment and secondary data analysis.

### 3 How can we ensure that research impacts care in all health care settings?

*Feedback was provided by table facilitators Virginia Minogue (Research management consultant, adviser, coach and mentor; HSE Research and Development and Mike Walsh (Programme Manager for National Clinical Programme for People with Disability & National Clinical Programme for Dermatology; Clinical Design & Innovation, Office of the Chief Clinical Officer, HSE)*

The main recommendations from two multi-stakeholder discussion groups who addressed this theme are:

- Research impact needs to go **beyond journal publications** and requires consideration of who the impact is for and how it will be assessed. PPI should be a big part of this.
- Realising the impact of research on health and social care needs resourcing, incentivising, and **an impact plan** from the outset.
- We need to ensure **that research has an impact on care, not just in hospitals, but also more marginalised settings** such as disability, addiction, and social care services.
- **Focus on the importance of research and knowledge transfer should become part of the day-to-day** for all front-line practitioners and health service decision-makers e.g. through continuous professional development, professional bodies, networks of practice.
- **Co-learning between different stakeholders**, such as PPI contributors, health care professionals and academics, could help bridge disconnects in the research and knowledge transfer systems.
- The **grant approval system could be used to incentivise knowledge transfer** by rewarding research teams that have already demonstrated impact.

## 4 What can we do to support healthcare professionals to be research active?

*Feedback was provided by table facilitators Lesley O'Hara (General Manager; St John of God Research Foundation) and Rob O'Connor (Head of Research; Irish Cancer Society)*

The main recommendations from two multi-stakeholder discussion groups who addressed this theme are:

- **Protected time for research, for healthcare staff at all levels**, is required. Joint appointments (between clinical and academic settings) are an example of a successful model, but there are also other approaches to look to internationally.
- A stronger culture of research in the health services needs **senior management buy-in**.
- **Career tracks** that encourage, incentivise and reward research are needed e.g. research nurses and biostatisticians need the same salary and pension entitlements as their clinical peers.
- Better co-ordination and **stronger links between academic and clinical institutions are required**. Research nurses and midwives are well-positioned to achieve this.
- **Research Offices can provide practical support** in helping researchers move more quickly through research processes e.g. through support with completing forms, providing templates.
- **Frontline staff could be engaged in feasibility studies** to examine the practicalities of carrying out research and to determine the expertise needed for success.
- **A simplification of the research approval process**, such as that currently in progress with research ethics committees will be important e.g. overarching contracts and data processing agreements can reduce duplication.



# Panel Discussion



**Chair: Professor Rachel Crowley;**  
Consultant Endocrinologist, St. Vincent's  
University Hospital and Clinical Professor,  
University College Dublin

Professor Crowley started by outlining her 'Christmas wish list' for embedding research in health services in Ireland. This included include new structures, individual health identifiers and electronic patient records, as well as an environment that makes patients findable and makes data usable in collaboration with other researchers. Professor Crowley noted the importance of access to research and said that we need to think about service planning, including who replaces whom in research posts in academic and clinical care. She also stressed the importance of developing trust and partnerships with the public and patients. She wants to see expanded training and support for patients who want to be part of research and she highlighted that people in academic institutions need to recognise that research is a tide that raises all boats and improves care.

***It is completely unethical to exclude patients from either clinical care or research on the grounds of membership of a minority, a language barrier, a neurodiversity issue, or a mobility issue that means they can't come to the hospital.***



**Dr Sarah McLoughlin;**  
Patient Advocate

Dr McLoughlin is a molecular biologist by training who was diagnosed with cancer in 2016. She has brought her experience both as a patient and a researcher together to advocate for greater patient involvement in research and healthcare, which covers not only patients enrolling in and taking part in studies, but also involving patients directly in the research process from the start. Dr McLoughlin wants people who are impacted by research to be involved in decision making early in the design of research. She also noted that patients may be participants in research for many reasons, such as getting access to treatment for themselves. In some cases there may not be immediate benefit for themselves but they want to pay it forward for future patients. However, Dr McLoughlin pointed out there are risks involved in participation in research, including the use of their time, samples and data, and these need to be respected and explained clearly to patients. She also raised the important point that research that benefits patients may not be financially beneficial, and said we need to consider who decides what research gets funding. She welcomed that patient involvement is already a part of research in Ireland and pointed to enabling steps such as HRB funding requirements, but she would like to see even more training for healthcare providers, researchers and for patients in this area. The main thing, she stressed,

***[People] are giving their bodies and minds to research - and that can be a positive thing but it can also be a risk, people are putting themselves in quite a vulnerable position for the benefit for themselves or somebody else, but also for the benefit of research and the furthering of science. They are really entering into it and bringing themselves completely forward for it, and I think that is something that needs to be respected.***

is that patient involvement is impactful and that needs both structures and mutual understanding of expectations. Time is a big issue and it needs to be valued, added Dr McLoughlin, and embedding research into healthcare will need clinicians to have protected time and patients to be supported so that they have the time, space and trust to participate. Her overarching point was that patient involvement in all aspects of research could help to address issues around research impact and waste and lost opportunities due to poor research structures or governance, and such involvement could result in more patients availing of potentially beneficial treatments.



**Professor Philip Nolan;**  
 Director General, Science Foundation  
 Ireland (SFI)

Inspired by seeing the biodiverse lawn outside Trinity College Dublin the previous day, Professor Nolan started with a philosophical point: that thriving ecosystems can look messy to the uninitiated eye. Ecosystems look messy because they are complex, he said, and he is fascinated by and very supportive of the efforts being made in the HSE to embed research culture in the complex ecosystem of healthcare in Ireland. Bosses may not be sure about messes, but this is the nature of the ecosystem. Keeping with the analogy, he described how carefully cultivating an ecosystem can help to encourage it (in this case offices and structures etc) but that it is also about culture and seeding and fertilising the right aspects. Professor Nolan wants to see Ireland mobilise our resources more fully, including nursing, health and social care and administrative workforce and agencies, and to be respectful of and include disciplines. Aligning governance structures in the different parts of the healthcare ecosystem is an important step forward. Lessons from the pandemic have shown that data infrastructures and linked electronic health records are vital for research, he added, as would be unique citizen identifiers - we need to have a mature societal conversation to remove the fear of such things.

Professor Nolan believes that PPI should be the first thing we think about for research, asking the right questions and then implementing the professional practice of study design led by biostatisticians. Professor Nolan pointed to welcome initiatives such as the SFI Empower Centre for data governance and the HRB Sphere doctoral programme, but he is concerned that we do not have the capacity of economists, biostatisticians, etc. He warned that we do not carry out enough evidence synthesis and systematic review, which are what get leadership attention. He highlighted the problem of research waste: asking the wrong questions; poorly designing studies; failing to record data fully and openly; and failing to synthesise the results. Professor Nolan also talked about the importance of impact, which is the focus of the new national strategy on research and innovation, and said the research funding agencies - SFI, the HRB, and the Irish Research Council (IRC) - need to work more closely and create a more cohesive response.

*It is relatively easy to fund a project to say we will get a group of cancer biologists together and they will solve a known problem. It is much messier and more difficult to say we are finding it really difficult to design this service and that requires clinicians, it requires scientific thinkers, it requires social scientists. It needs to be embedded in an organisation with the clinicians and with the patients and with the public.*



**Dr Andy Franklyn Miller;**  
Director of Research and Rehabilitation with  
The Sports Surgery Clinic (SSC)

Dr Miller spoke about the journey at the SSC, a private organisation, to build a service that incorporates research with patients. He described convincing the Board to support the research, pointing out that it may not always show positive results. Patients were willing to pay a fee for biomechanics expertise in the research (it needed to be cost neutral for the SSC) and they have chalked up around 60 publications across 10 years with the involvement of thousands of patients. Some of the research showed positive effects - such as halving patients' return-to-play time following groin injury and a 10-fold reduction in anterior cruciate ligament (ACL) re-injury risk - while other research studies faltered due to study design (underestimating the numbers of patients that could be recruited) or found poor results for patients. As a private organisation, the SSC was able to move quickly in research, noted Dr Miller, as they did not need to go through the process of grant application and approval, and they have now set up patient-focused initiatives such as registries.

***What I have got to bring today is a tiny case study, in how I have taken a commercial organisation on a research journey based on a bit of a whim and taken our patients with us on trust. And it is incredibly valuable. We wouldn't have done that without the ability to work fast. We had the question, we have a great patient population, we needed a quick answer and it needed to be cost neutral.***

# Audience questions and answers

Key highlights from the audience question and answer session included:

- The system of ethics and data approval is too slow in Ireland and that can lead to research waste. We need to enable a culture where signing off on research is prioritised rather than being at the bottom of the pile, but there is a lack of capacity to achieve this.
- Ireland needs greater interoperability and commonality across governance entities, and a 'trusted trader' approach where sign-off by one governance entity is enough for everyone in the system.
- Our risk appetite needs to change from being intolerant of any exposure, towards accepting that mistakes may occur in research and then learning from mistakes.
- Biostatisticians are recognised as an important component of health services research, yet there is no career structure for these expertise in the HSE.
- Data protection and privacy is a fledgling industry and we lack human capital to support it. We need to push for investment in the public health system to develop the workforce and capital to speed things up.
- It is important to publish research that has negative results.
- Research waste is not just about researchers' time and effort, it is also about the people who participating with their time, their efforts, their bodies, and if that is for nothing then it can undermine trust in research.
- Economic impact has tended to be the focus when it comes to research outputs. We need to broaden that to include societal and ecological impact.
- Patients should be empowered to feel confident about asking questions about the track record of treatments and practitioners and to change practitioner if needed
- We need to ask patients about the problems, then clinicians can guide the research questions.

# Closing remarks



**Dr Mark White;**  
Chair, Irish Health Research Forum Steering  
Group & VP for Research, South East  
Technological University

Bringing the event to a close, Dr White thanked the speakers and welcomed their inputs on strategic directions, concrete examples, research waste and ways of supporting a more research-active health service. He particularly thanked the Forum participants for discussions on PPI and leadership and for sharing the trials and tribulations from their case studies of embedding research into health services in Ireland.

# For further information

For further information on the activities of the Irish Health Research Forum please see our website:

<https://hrci.ie/ihrf/>

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