

Empower, Innovate, Transform: Driving the Future of Health Research

10th Anniversary of the Irish Health
Research Forum



A single
voice **to**
improve
health
research

Recommendations and Event Report

16th May 2024

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About the Irish Health Research Forum

The Irish Health Research Forum, which is run by Health Research Charities Ireland (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, service users, carers and the public being at the heart of all activities.

As an independent organisation, representing 45+ charities and with a strong patient/public 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 <https://hrci.ie/irish-health-research-forum/>

About Health Research Charities Ireland (HRCI)

HRCI is the national umbrella organisation of over 45 charities engaged in health, medical and social care research, collectively representing over 2 million people in Ireland. We champion our members' interests, to enhance the environment for health research in Ireland. We empower them to realise our shared vision of improving lives through impactful research.

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 are also a national leader in patient and public involvement (PPI) and run a PPI Shared Learning Group for our members. www.hrci.ie

Introduction

This landmark event for the Irish Health Research Forum offered an opportunity to reflect on the key issues addressed by past Forum events and, in particular, to identify the recurring themes that have emerged from the recommendations generated from each event. To mark this occasion, a report titled *Celebrating 10 Years of the Irish Health Research Forum*, was prepared, highlighting the eight themes that have most strongly and consistently emerged over the past five years. These themes provided the framework for discussions at the event.

Building on these insights and the dialogues that took place, the *Irish Health Research Forum Steering Group* has developed a consensus statement, capturing our shared vision and the collective agreement that has evolved over time.

Steering Group Consensus Statement

For the past 10 years, the Irish Health Research Forum has been at the forefront of driving change to improve lives through health research. Through numerous deliberations, and the participation of hundreds of diverse delegates, we build consensus and deliver impactful recommendations that have informed the landscape of health research. From this shared dialogue, two imperatives have emerged: the critical need for increased funding for health research and the necessity to embed research in the health service.

As we mark the 10th anniversary of the Forum, we call on the Government to act on these high-level priorities by:

1. Ring-fencing a portion of the health service budget to support and advance research, including fully resourcing the HSE Action Plan for Health Research 2019-2029, which will put the building blocks in place to ensure that the health service is enabled to embrace research.
2. Establishing a cross-governmental health research group to provide strategic coordination, promote a unified vision, and drive sustainable investment in research.

Elevating health research as a national priority is a strategic imperative for a healthier and more secure future. By acting on these priorities, the Government can improve the health and well-being of every person in Ireland.

Recommendations for the Irish Health Research Forum

This 10th anniversary event also provided an opportunity to reflect on the achievements of the Irish Health Research Forum and consider its future direction. Based on the suggestions and discussions at the event, and with input from the Steering Group, we have developed five key recommendations to guide the Forum over the next five years.

The Irish Health Research Forum is not a single organisation, but an initiative led by Health Research Charities Ireland, supported by a multidisciplinary steering group and involving hundreds of diverse health research stakeholders. We invite everyone involved to consider how they can contribute to implementing these recommendations to further strengthen health research in Ireland.

- 1** Take an inclusive approach to the definition of health research, to encompass all disciplines and research methodologies relevant to health and social care.
- 2** Strengthen engagement with political stakeholders across all relevant government departments and key decision-makers in health research, to progress the implementation of the recommendations that have emerged from Forum events.
- 3** Broaden participation in Forum events to include diverse and under-represented groups, ensuring that all perspectives are heard and considered.
- 4** Consistently highlight the value of health research in improving societal well-being and contributing to economic growth.
- 5** Ensure that the Forum's activities and recommendations remain centred on the needs and experiences of patients, service users, and caregivers.

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

Key themes which emerged at the event

This celebration event offered a rare chance to reflect on the positive progress made, in addition to discussing the challenges ahead. Key themes included the advancements in health research over the past decade and the core strengths of the Irish Health Research Forum, which are outlined briefly below.

Progress in health research

- Significant strides have been made to embed research within Ireland's health service. The HSE Strategy and Research Team has developed a foundational framework, while the Department of Health has recognised research as a key enabler in Sláintecare reform.
- Since the Forum's first event on PPI, it has become integral to health research, with noticeable improvements in both quality and inclusivity. There is also increasing public involvement in shaping legislation and regulation.
- Additionally, the harmonisation and standardisation of research ethics has advanced, notably with the establishment of National Research Ethics Committees (NRECs) and reforms to HSE research ethics processes.

Strengths of the Forum

- A key strength of the Forum is its ability to bring together individuals from different backgrounds to collaboratively address the challenges and opportunities in health research in Ireland. It provides a unique space for open discussion and creative problem-solving across sectors.
- The Forum has built a strong sense of community, and a network dedicated to driving change and fostering innovation in health research.
- Patients and the public have always been at the core of the Forum's work agenda since its inception.
- The Forum has influenced policy development in areas such as PPI, genomics, research ethics, and health research infrastructure.

Acknowledgements

Thank you to the chairs, speakers, panellists, facilitators, 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 Board and staff for their continued management and support of the Forum. Finally, we would like to thank Roche Products (Ireland) Limited who part-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 Manager and Dr Avril Kennan, HRCI CEO.

Abbreviations used:

CRCI: Clinical Research Coordination Ireland

DCU: Dublin City University

DFHERIS: Department of Further and Higher Education, Research, Innovation and Science

EU: European Union

GDPR: General Data Protection Regulation

HRB: Health Research Board

HRCDC: Health Research Consent Declaration Committee

HRCI: Health Research Charities Ireland

HSE: Health Service Executive

IPPOSI: Irish Platform for Patient Organisations, Science and Industry

IRC: Irish Research Council

NRECs: National Research Ethics Committees

OECD: Organisation for Economic Co-operation and Development

PPI: Patient and public involvement in research

RECs: Research Ethics Committees

SFI: Science Foundation Ireland

TREs: Trusted Research Environments

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Welcome address: 10 years of the Irish Health Research Forum



Dr Avril Kennan
CEO, Health Research Charities Ireland

Dr Avril Kennan welcomed the attendees to this 10th anniversary of the Irish Health Research Forum. She considered the Forum's key achievements, the main themes that have emerged, and future priorities. She gave a summary of the history of the Forum, which started in 2014 with a landscape assessment of health research in Ireland commissioned by HRCI (then the Medical Research Charities Group) and delivered by Professor Bernie Hannigan. A key recommendation arising from this report was to establish a health research forum in Ireland to bring together all the stakeholders. At the time there was no place to come together and talk about the challenges and solutions to doing health research in Ireland. HRCI kickstarted the Irish Health Research Forum by setting up an initial steering group with representatives from many different stakeholder organisations, which has grown and developed over time. It was envisaged that HRCI, being a very small organisation, would pass responsibility for running the Forum to a larger agency, but the value of continuing to do so was quickly recognised. HRCI's independence allows it to make strong recommendations, utilise its networks of member charities and stakeholders, and keep a focus on patients, service users and the public at the heart of the Forum.

Avril emphasised the important role of community in the Irish Health Research Forum, bringing people together to make connections, share expertise and create change and innovation. In addition to having excellent expert speakers at events, the discussion groups are integral to hearing all the voices in the room and feeding into the recommendations arising out of each event.

She went on to describe the top eight themes that have come through the collective Forum events and that are presented in a **10-year anniversary report** prepared for this event. These are:

1. PPI – with the first Forum event held on this topic.
2. Research impact – conceptualised as benefit for patients and the public through health research.
3. Investment in health research – in the components that support research projects and programmes.
4. Education and training for researchers, PPI contributors, data protection officers and policy makers.
5. Legislation and policy – supportive legislative frameworks, strategies and guidelines.
6. Research Ethics Committees (RECs) and governance – towards national and local harmonisation.
7. Embedding research in the health service through fostering a culture of research.
8. Using health data effectively – taking cognisance of the forthcoming Health Information Bill.

Avril finished with a call to action for all attendees at the event: to clearly and repeatedly articulate and advocate for health research to benefit the patients and the public of Ireland. She then introduced the next session of the event which focused on the perspectives of Steering Group members on the Forum.

My bigger call to action is to clearly and repeatedly articulate the societal and economic value of health research. We are not doing that enough. It's not on politician's minds. It is not on the minds of leaders that are not here in this room.

Reflection and projection: Forum Steering Group perspectives



Finnian Hanrahan
Scientific Programme Manager,
Science Foundation Ireland

Dr Finnian Hanrahan opened this session by saying how honoured he is to sit on the Irish Health Research Forum Steering Group, recognising its value and impact. His membership of the Steering Group has kept him informed about the conversations ongoing in the health research space, and the key issues and challenges facing stakeholders. He also emphasised the value of the Forum in bringing individuals from different backgrounds together, which is unique in the Irish landscape.

Finnian referred to the amalgamation between Science Foundation Ireland (SFI) and the Irish Research Council (IRC) to form a new funding agency, Research Ireland (Taighde Éireann), stating that this was built on a recognition of the value of engaging with different groups and looking holistically at the challenges and opportunities facing research in Ireland. He views the Forum as an excellent example of such engagement, especially when it comes to PPI, with Ireland being one of the leading countries in Europe. He referred to international senior researchers reviewing SFI Research Centres who note that Ireland is far exceeding their own countries' activities in public and patient engagement. Leading on from this, he emphasised that decision makers and policymakers do hear the collective voice of the Irish Health Research Forum, and this informs policy making, innovation and change. He stressed the vital importance of engaging with politicians, funders and policymakers. However, he acknowledged that these groups do not always tell advocates when decisions are at least partially influenced by events such as this. Importantly, Finnian highlighted the need for the Forum to ask who is not in the room, and which voices are underrepresented, because this offers a vital path for growth in the future.

I really want to emphasise that you are heard, that people – decision makers and funders – want to be part of this discussion, to receive your reports, and it does have an impact.



Dr Fionnuala Keane

Director of Operations, Clinical Research Centre, RCSI Education and Research Centre

Dr Fionnuala Keane described how reading Professor Hannigan’s landscape assessment of health research in Ireland when she was Development Lead for HRB Clinical Research Coordination Ireland (CRCI), led to tangible benefits when building a business case for HRB CRCI. She also described how, when attending the first Irish Health Research Forum event on PPI, she was struck by how many people were in the room, many of whom she had not met before. The event revealed how many people were trying to deal with the same issues, but independently of each other. For Fionnuala, the Forum was the first opportunity to bring together all the different stakeholders across the broad spectrum of health and clinical research. The first Forum’s focus on PPI, along with the work of IPPOSI and the HRB, progressed the PPI agenda at the time and in the years since.

Fionnuala described the work of the Forum’s Steering Group including discussing and agreeing topics for future events and praised HRCI’s willingness to take on difficult topics. The key questions raised by the Steering Group when planning events include: what are the biggest issues at the moment? What do we need to discuss about these issues? Who do we need to have in the room to make sure there is a fair balance of opinions? How and where can the Forum make an impact?

She presented her top five topics covered by Forum events: PPI, investing in research and the people who undertake it, genetics and genomics, improving research ethics and biobanking. Topics she would like to see covered in future events are the sustained and adequate funding of clinical research infrastructure, development of more permanent research roles for clear career structures, embedding clinical research further into the Irish healthcare system, improving study start-up timelines, and further exploration of biobanking and patient registries infrastructure. Fionnuala wrapped up by highlighting the importance of the Forum in facilitating the engagement of stakeholders across the health research ecosystem in Ireland.



Bringing together the relevant stakeholders is vital and is enabled by the Irish Health Research Forum. I’ve seen the importance of engaging with others nationally and outside our own local environments.





Dr Conor O'Carroll

Independent consultant on research and higher education policy and funding

Dr Conor O'Carroll placed Professor Hannigan's landscape assessment of health research in Ireland at the core of his perspective on the Irish Health Research Forum. He presented the issues facing the researchers who took part in the study, key among of which was a lack of access to funding – either because they didn't have the economic focus insisted upon at that time, or due to underfunding of research on patient health. This was compounded by national research priorities not focusing sufficiently on health. Researchers also faced issues to do with patient registries, research ethics, and the lack of career structure for researchers who wished to move from post-doctoral positions to the next stage towards becoming a research leader. Participants in the study identified the lack of a research culture in health services, particularly hospitals, with associated lack of protected time for research, poor employment opportunities, short-term contracts, and lack of research leadership in the HSE. Conor pointed out that many of these issues persist today. However there has been progress in a number of areas – research is increasingly embedded in the HSE thanks to the work of Dr Ana Terres and her team; there is greater public awareness of the value of health research especially since Covid; and there are better career transition opportunities thanks to the opportunities provided by the HRB (such as the Emerging Clinician Award and the Emerging Investigator Award) and by the Irish Universities Association's Research Career Framework.

Conor moved on to examine the newer challenges facing health researchers in Ireland. While welcoming the growth of open science, it has brought its own challenges, including the protection of patient data and the rapid growth of poor quality and poorly reviewed publications, and falsification of data. He considered the future for researchers, highlighting the potential benefits brought by the new European Charter for Researchers which focuses on greater integrity of research, greater focus on open science, reduction in the reliance on fixed-term contracts for early career researchers, and a reformed approach to research assessment which has already been implemented by the HRB.

Finally, Conor considered whether the Irish Health Research Forum has been a success. He has found each Forum event engaging, interesting and stimulating. It has been successful in providing an open environment for free discussion and innovation and has allowed people to listen to each other and hear perspectives from very different backgrounds in an open and collaborative space. That is why it has persisted and grown to date.



Has the Forum been a success? Well, I personally think it has. In terms of every Forum I've come to, I've found it engaging, interesting and stimulating. What it has provided is this open environment where nobody is being pressured to do something, where people can listen to each other in that open collaborative manner.



Discussion groups



The discussion groups were guided by **Maureen Gilbert**, Irish Health Research Forum Steering Group member

Attendees at the event were asked to consider four themes through discussion groups of 8-10 people (two groups per theme), with an assigned facilitator. Discussion groups were asked to focus on progress over the last 10 years and things that would strengthen health research over the next 10 years. The main findings of each theme, as reported in feedback at the event by the facilitators, are outlined below.

1 Patient and public involvement and research impact

Feedback was provided by table facilitators Deirdre Mac Loughlin, PPI Contributor and Dr Lucy Whiston, Programme Manager, PPI Ignite Network @ DCU.

The main points made by two multi-stakeholder discussion groups who addressed this theme are:

- There has been an improvement in understanding and awareness of PPI. PPI is becoming widely accepted and expected in health research, and research has become more focused on patient needs and solutions. This has been paralleled by higher quality PPI.
- Increasing democratisation of research in order to engage the public and value the lived experience of patients and the public is key to strengthening health research.
- More education and training resources need to be developed to increase the understanding of good practice in PPI. This should initially target health researchers, but later expand to include people working within service delivery and policy making.
- PPI contributors need to be involved early in the research life cycle, from grant application stage onwards. This will require capacity-building for PPI in all sections of society
- PPI contributors should be treated as equal partners in health research, and a key way of doing this is to clarify arrangements for paying them. Their contribution is vital and must be valued and maintained. This would help to break down barriers between PPI contributors and researchers.

2 Investment in and support for research

Feedback was provided by table facilitators Dr Helen Burke, Senior Research Officer, DCU Research, Dublin City University, and Dr Nicola Mountford, Associate Professor in Management, School of Business, Maynooth University.

The main points made by two multi-stakeholder discussion groups who addressed this theme are:

- We need to review what was achievable in health research during Covid and examine how to apply this to research going forward. This could include fast-tracking ethics reviews, enhancing collaboration and increasing the agility and flexibility of funding.
- Research capacity and support, like that available in universities, should be made available to other sectors such as hospitals and charities. This would enable hospitals and/or charities to lead applications, receive funding and overheads and would support equity across sectors.
- More investment is needed in research and management systems, to include a single point of entry for all applicants to reduce administrative burden. This would allow a national view of what research is being funded.
- Long-term sustainable funding for research is recommended. While the ingredients for a productive health research ecosystem do exist, permanent rather than programmatic funding for these is needed to enable long term planning and sustainability.
- The PPI Ignite Network has developed capacity and enhanced recognition of the value of PPI in health research. However, the sustainability of PPI in the system needs to be improved through long-term funding, standardisation of funder expectations and the removal of barriers to PPI payments.
- Accountability for health research needs to be clearly established at the highest levels of the system. This should be based on ringfenced funding, decision making power, and the provision of clear direction on health research. This should be completely embedded across the system with targeted metrics.

3 Research legislation, policy and governance

Feedback was provided by table facilitators Pat O'Mahony, Chief Executive of Clinical Research Development Ireland, and Dr Anne Cody, Head of Investigator-Led Grants, Research Careers and Enablers, Health Research Board.

The main points made by two multi-stakeholder discussion groups who addressed this theme are:

- There has been good progress in harmonising and standardising research ethics processes, particularly with the establishment of national research ethics committees (NRECs) and the forthcoming changes to the HSE research ethics system.
- Greater inclusion of the public has been evident particularly in the development of legislation, regulation, and the research ethics system.
- The Irish Health Research Forum's contribution to developments in research ethics, the Health Research Consent Declarations Committee (HRCDC), and the National Genetics and Genomics Strategy should be recognised.
- The health research community needs to be prepared for forthcoming changes such as the European Health Data Space. It is important to consider the implications of this and any resourcing requirements in advance.
- There are gaps in current legislation for biobanking, genetics and genomics, and patient registries. There is a need to progress legislation more rapidly than has been the case up to now.
- It was suggested that one way of strengthening health research over the next 10 years would be to ringfence a minimum percentage of health budgets allocated to research.
- The Irish Health Research Forum should strengthen its work on advocacy – influencing policy and the Programme for Government.
- Research governance should be strengthened: one suggested approach is to integrate leadership responsibility across hospitals and universities, and another is to harmonise research governance across the six new HSE health regions planned under Sláintecare.

4 Research in the health service and health data

Feedback was provided by table facilitators Simone Walsh, Programme Manager, Irish Research Nurses and Midwives and Study Feasibility and Activation Manager, RCSI Clinical Research Centre; and Prof Seán Dinneen, PPI Ignite Network Lead and Senior Lecturer, University of Galway.

The main points made by two multi-stakeholder discussion groups who addressed this theme are:

- Harmonisation, standardisation and linkage of data is necessary to enable health research. This would be facilitated by the introduction of a unique health identifier, building on what was done during Covid. Data standardisation and linkage could also support the growth of predictive analytics, where data are used to generate ideas for research. An additional consideration is that we will depend on data standardisation if we are to have adequate governance in the context of the European Data Space. In the future, researchers will be required to collect variables that are standardised across all research environments in order to be able to match data.
- Related to this, education of the key staff involved in managing data will be necessary in order that everyone working on the data is approaching it in the same way.
- The Health Information Bill needs to be enacted, and the key structures and systems need to be in place to enable the health service to respond to the Bill when it is enacted.
- We need to enable a culture of research within the health service and the key organisations working in the health space. This should not just be restricted to providing protected time for clinicians, but also recognising the critical role of administrators and PPI contributors.
- Electronic consent to research should be progressed, allowing patients control of and access to their consent and their data.

5 Additional discussion group: progress to date and strengthening health research over the next 10 years

Feedback was provided by table facilitator Michael Foley, Civic Engagement and Social Innovation Manager, Provost's Office, Trinity College Dublin.

The main points made by this multi-stakeholder discussion group are:

- Progress has been made in the development of health research infrastructure, including patient identifiers, outcome measures, and Trusted Research Environments (TREs). It is now time to move into an implementation phase, to figure out how to capture the data that such infrastructure has the potential to generate and how to use these data to change how infrastructure is created and managed, how to treat people and ultimately improve their quality of life.
- There is a danger that 'health research' becomes increasingly equated with 'clinical research'. The Irish Health Research Forum should highlight the need for a broader conceptualisation of health research: what it includes, wider health research needs and activities.
- Research, science and facts are all under threat in the public discourse. The Forum needs to develop links with a wider network of trustworthy organisations to support a conversation championing research, involving local stakeholders who are passionate about health research and the difference it can make in people's lives.

Panel discussion and audience Q&A



Chair – Eibhlín Mulroe
CEO, Cancer Trials Ireland

Eibhlín Mulroe opened with valuable background and context to the panel discussion by describing how the initiative to set up the Irish Health Research Forum had a focus on patients at its core. This meant that from its inception through to today, the Forum has always kept this focus on patients, as its remit has grown to embrace the gamut of health and social care research. Eibhlín pointed to the increasing involvement of health researchers in patient advocacy. Health researchers are listening to patients' needs and concerns and using this as the basis for the development of new research studies.

She went on to name the two key factors that drive success for people living with illness: people working together and sufficient funding. Noting the presence of key funders and policy makers on the panel such as the HRB, the HSE, and the Department of Health, she said that this is a testament to the leadership of HRCI and the Forum Steering Group.

Eibhlín shared her experience of a recent illness and how this has given her insight into what it means to be a patient, and why advocacy for people living with illness matters so much when they are too ill to advocate for themselves. The Forum's emphasis on the centrality of the patient is especially important in this regard. She finished by asking the Forum to keep listening to patients and using that to guide its work, and went on to invite the panel to speak.

There's two things that, in my experience in 10 years of clinical trials, drive success for people who are sick. And that's when people work together and when it's funded.



Muiris O'Connor

Head of Research and Development and Health Analytics, Assistant Secretary, Department of Health

Muiris O'Connor began by applauding the work done by HRCI and the Irish Health Research Forum. He stressed the critical role played by the community and voluntary sector in the Irish health and social care system, and complimenting HRCI's ability to bring together disparate groups. This is particularly important for people living with rare diseases who can otherwise feel very isolated.

Muiris argued that the insights and priorities identified by the Forum are issues that are still live today, and that they are higher profile than they would have been without the drive provided by the Forum. Examples include the championing of PPI, research ethics, biobanking, genetics and genomics, and innovation in health data. The support for policy development has been extremely valuable, and the contributions of the Forum add a counterbalance to those who are less trusted. He cited the example of GDPR, which in Ireland has been interpreted too cautiously. This has been detrimental to the linking of health care records, in comparison to other EU member states who have been able to deliver summary care records in the same regulatory environment. The Department of Health has taken care to spell out specifically the expectation and duty to share health information in the Health Information Bill.

When considering positive developments over the past 10 years, Muiris pointed to the growth in the impact and the budget of the HRB, and the work being done by Ana Terres and her team to embed research in the HSE. He was encouraged by increasing evidence of national approaches being taken to dealing with complex issues, praising the work of the many volunteers who have supported the Department of Health in developing these national approaches to doing research at scale. He finished by referencing the exponential growth in EU and international co-operation and ambition for health research.



I think that the connections across groups that have been available through this Forum are really useful to the people involved. It's hugely valuable to policy makers as well, because when these groups come together, they have identified challenges and opportunities of common interest. And when something is of common interest across diseases, it's a policy matter.





Dr Ana Terres
Head of HSE Research and Evidence

Ana Terres described her experience of membership of the Irish Health Research Forum Steering Group as really positive. She has felt welcomed and among friends. The work of the Forum has also been hugely for her and her team to understand the key issues in health research in Ireland and what needs to be addressed. She said that her team in the HSE take these issues and look at them from a health system perspective and try to address them in that context.

Ana reflected on the progress made by the HSE Strategy and Research Team since it was set up, highlighting how innovative it was to have a team with a dedicated focus on research. She said that when they reviewed the extent of research activities in the HSE, they realized that there was a lot of activity, however, the necessary governance and support structures were absent. Gaps were identified in terms of governance, management capability, ethics, and infrastructure. To address these, the HSE Action Plan for Health Research was published in 2019 with the objective of embedding research in the delivery of care so that it is part and parcel of what health professionals do, rather than being an add-on. Ana recognised that significant strides have been made since 2019 despite multiple challenges, and firmly believes that embedding the organisational architecture for research in the health care service should be a key element of the Sláintecare reform, as research is essential for continued improvement. She referenced the HSE National Framework for the Governance, Management and Support of Research published in 2021, which aims to address the challenges that health and social care professionals face when doing research in the health service. She stressed that the cohesive implementation of this framework is essential, as it is the foundation for embedding research in the health system. It focuses on building organisational capacity, addressing governance issues, alleviating bottlenecks and standardising protocols and processes for research, ultimately fostering a culture of innovation and improvement in healthcare.

In 2023, Ana and her team were successful in obtaining some resources to commence the establishment of research leadership in the HSE health regions. This should assist in making sure research is built into the fabric of the development of the new regions and implementation of Sláintecare. Ana praised the partnerships with the Department of Health and the HRB, which she felt will be very beneficial to their future work.

In this Forum I've always felt like I was among friends. And the work that the Forum does has been hugely informative for us to understand what the issues are and what needs to be address. So, we look at those issues from the healthcare system perspective and try to address them.



Dr Teresa Maguire
Director of Research Strategy and Funding,
Health Research Board

Dr Teresa Maguire started by commending HRCI as a driving force behind the Irish Health Research Forum, acting as an honest broker and providing strong leadership in bringing diverse stakeholders together. She said it was good to see the progress that has been made in discussion about the relevance and impact of health research, reducing research waste and duplication, and making research findable. She also commended the work done by Muiris O'Connor and his team at the Department of Health to ensure that research, data and evidence are included as key enablers in Sláintecare. Teresa detailed the changes she has seen in her involvement in research in Ireland over 20 years. She highlighted the importance of having a diverse group of stakeholders (including patient representative organisations) publish reports and make recommendations for progress. This informs and expedites legislation and policy making and often reduces the need for further pre-legislative scrutiny.

She went on to look forward to the next 10 years and reflected on how we can maximise the value of the funding for health research in Ireland, in the context of developments since 2014 on multiple fronts including the establishment of the Department of Further and Higher Education, Research, Innovation and Science (DFHERIS), the forthcoming Health Information Bill, the launch of Research Ireland, the founding of the Technological Universities, and Impact 2030 (Ireland's Research and Innovation Strategy).

However, investment in research remains low, with the HRB budget only returning to 2008 levels in 2023. She pointed out that we are still below the EU and OECD averages when it comes to government expenditure on research at 0.9%.

In the context of all these recent developments, Teresa said that now is a good time for policy makers and decision makers to discuss how to effectively invest in health research. She felt that this is a pressing need, given the financial constraints impacting health researchers.

Teresa echoed Dr Ana Terres in advocating for research to be built in as an integral aspect of Sláintecare implementation and the setting up of the health regions. This could reduce institutional complexity and streamline research processes throughout the system. She also made the point that there is no longer a boundary where health research is separate to health care, given the move to personalised medicine and genomics. According to Teresa, we need to broaden our conceptualisation of health research beyond clinical research and schools of medicine to include primary and social care. Finally, she advocated for a cross-governmental task force (involving the Department of Health, the Department of Further and Higher Education, Research, Innovation and Science, and the Department of Enterprise, Trade and Employment at a minimum) to develop and oversee the implementation of a strategy to ensure that health-related research and innovation is expanded and integrated by design in the new regions. This would help to address many of the current issues we face in terms of support for researchers, infrastructure, accessing EU funding, data sharing and the variances in interpretation of GDPR in the context of Irish research.

I commend everybody that has been involved in HRCI, who really are a driving force behind this and really act as honest brokers and provide huge leadership in bringing us all together over the years. Great to see the progress that has been made in the discussion around relevance and impact of the research that was done, reducing waste, reducing duplication, and making research findable.

Panel questions and answers session

A number of questions was put to the panel, and the following points were made:

- People working in health research are not valued enough. They are on short-term contracts with little provision for support if they become ill or need to take parental leave. This raises the larger question of whether health research as a whole is really valued in Ireland.
- Collective advocacy for research to be made a priority in the new HSE health regions is important. Research is not a priority within the HSE, and this is reflected in the HSE leadership who are not really familiar with health research and its importance. Education of HSE senior management and encouraging them to come on board and work with the Irish Health Research Forum could be ways of addressing this.
- In the past, protected time for research in consultants' contracts was eroded due to the demands on their time for clinical care and service delivery. It is important that the protected time in the Sláintecare consultants' contracts for research is truly protected. Research also needs to be made attractive for clinicians: they need to see the value of doing research as part of their role. This can be served by incorporating a commitment to research and evidence-based approaches into service delivery and service development.
- There is a willingness to take the points raised at this Forum back to feed into the deep engagement taking place in the HSE as the new health regions are in a transition and consultation phase.
- There should be a recognised duty to have high-quality, supported research and innovation activity within the health system. Data, research, and evidence should be embedded in a strategic and purposeful way, and this should be mirrored by dedicated leadership and support posts. Holding the leadership team to account for research ensures that it is part of the conversation at that level.
- Health system reform will facilitate a frame of reference to allow for better understanding of health care interventions in terms of their impact on people's health outcomes. The European Health Data Space will complement this with linkages to evidence for care and service delivery across 27 member states.
- This could inform local management and clinical teams when they come together to develop services at community level. Across the regions, there is a desire to improve the understanding of evidence-based best practice within the HSE.

Closing Words



Brian Lynch

Chair, HRCI & Operations Manager and Deputy Head of School, Partnerships, School of Population Health, RCSI

Brian Lynch referred back to the landscape assessment of health research in Ireland by Professor Hannigan and how it spoke about creating a space for open and constructive discussion. He said that this had been achieved not only at this event but over the past 10 years. He praised the Forum for bringing together people from different backgrounds in the health research space such as clinicians, academics and patient and community representatives to share experiences and progress the agenda of the Forum. Professor Hannigan's report also said that the Forum should be a robust mechanism to realise a set of strategic actions, and Brian said that even if these actions are still a work in progress, we are seeing progress nonetheless and we are ambitious in trying to push for robust actions and change in the future. He recommended that we think about what we can do to progress and implement the discussions and recommendations that are produced arising from Forum events.

Brian stressed the importance of the value placed on the expertise and knowledge of attendees at Forum events, in the current societal context of increasing misinformation. He also praised the Forum's focus on the patient and how extraordinary it is to take the personal experience of being a patient and bring it to the Forum. This is especially important given that the definition of "patient" is more challenging in the context of the rise of multi-morbidities and the likelihood that we will all be patients at some point in our lives. He felt that there is a need to pivot to become more population-health-oriented in the Forum's focus in the future.

What the Forum managed to do is bring together a whole intersection of different people from clinical space, from academia, patient groups, to be able to share experiences and to be able to inform and articulate and progress the agenda.

Brian thanked the previous Chairs of the Irish Health Research Forum and the members of the Steering Group over the years who have contributed their personal time and expertise to making the Forum a success.

He also commended the work of the HRCI staff for their vision and commitment to the Forum and thanked the speakers at this event for contributing so generously. He finished by quoting from Professor Hannigan's report on the health landscape in Ireland: "because research provides hope". He said that throughout everything we've come through in the last 10 years, the audacity of hope is a scarce commodity and urged us to refer back to that message as we go forward.



For further information

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

<https://hrci.ie/irish-health-research-forum/>

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