IRISH HEALTH RESEARCH *forum*

HRCI Health Research Charities Ireland

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

Is Ireland missing out on vital health research?

Irish Health Research Forum Recommendations and Event Report

14th May 2026

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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 interest holders 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 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 ***https://hrci.ie/irish-health-research-forum/***

About Health Research Charities Ireland (HRCI)

HRCI is the national umbrella organisation of over 40 charities engaged in health, medical and social care research, collectively representing over 2 million people in Ireland. We champion our members' interests and work 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 Shared Learning Group for our members. ***www.hrci.ie***

Irish Health Research Forum Recommendations

	WHAT	WHY	ORGANISATIONS WITH A KEY ROLE
1	**Embed research across the health and social care system.**	The health service needs to be a meaningful research partner. National and regional research leadership should enable research wherever care is delivered, including primary, community and social care.	Department of Health; HSE; HRB
2	**Enable the health and social care workforce to lead and participate in research.**	Research should not depend on academic affiliation or unpaid effort. Protected time, resources and career recognition can democratise who gets to lead and participate in research across professions and care settings.	HSE; Department of Health; healthcare employers, education bodies and professional regulators
3	**Create a consistent and risk proportionate research environment.**	Variation in ethics, governance, contracting and data access creates delay and waste. Greater consistency and a proportionate approach to risk would make high-quality research easier to deliver.	HSE; Department of Health; relevant national ethics and data structures
4	**Sustain shared research support and expertise.**	Successful research needs accessible methodological, statistical, data and health-economic expertise, alongside shared infrastructure and networks, including Clinical Trial Networks.	HRB; HSE; universities; Clinical Trial Networks and other research infrastructures

5	**Invest in long-term PPI and co-production.**	Meaningful involvement improves research relevance and impact and helps democratise research, but trusted relationships need support between projects as well as within individual grants.	Research funders; HSE; PPI Ignite Network; research-performing organisations
6	**Demonstrate and communicate the value of research.**	Health, service, societal and economic value should be considered from the outset, supported by greater health-economic capability and better evidence and stories showing how research improves care, outcomes and use of resources.	HRCI; Department of Health; HSE; HRB; Research Ireland and wider research community
7	**Develop a shared language and identity for this research.**	Research outside the commercial and regulated clinical research space is described using multiple, imperfect terms, making its scale, contribution and needs less visible. A shared, accessible language would build recognition among the public, professionals and decision-makers.	HRCI; HSE; HRB; research funders and wider research community

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 like to thank the HRCI Board and staff for their continued management and support of the Forum, and Salesforce who kindly provided the venue and site support for the event.

This meeting has been sponsored by Roche Products (Ireland) Limited. Roche Products (Ireland) Limited has had no control over the educational content of this activity.

This report was compiled by Dr Sarah Delaney, HRCI Research Support Manager and Dr Avril Kennan, HRCI CEO.

Abbreviations used:

CTAC: Clinical Trials Advisory Council

HDAB: Health Data Access Body

HRB: The Health Research Board

HRB-TMRN: The HRB Trials Methodology Research Network

HRCI: Health Research Charities Ireland

HSE: Health Service Executive

IEP: Integrated Exercise Practitioner for Mental Health

ILP: Investigator-Led Projects

IP: Intellectual Property

MD: Doctor of Medicine

NCCP: National Cancer Control Programme

NCTOG: National Clinical Trials Oversight Group

PCOS: Polycystic Ovary Syndrome

PMOS: Polyendocrine Metabolic Ovarian Syndrome

PPI: Patient and Public Involvement in Research

RECs: Research Ethics Committees

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Welcome address

Prof Mark White
Chair, Irish Health Research Forum and Executive Dean of the Faculty of Nursing and Midwifery, RCSI University of Medicine and Health Sciences

Prof Mark White started by welcoming the attendees to the event. He welcomed the group and introduced the topic of the day: patient/public-facing, non-commercial research embedded in health and social care (investigator-led research). Sometimes overshadowed but fundamentally important, this type of research often provides the foundation for meaningful and sustained improvement in the health service, and research capacity building in the workforce. It is the source of innovation and often is the spark for larger scale research.

Mark emphasised that these small-scale research projects often play a critical role in addressing real-world challenges at the point of care, facilitating managers, clinicians, and educators to investigate frontline, immediate issues, and in doing so, improving care for patients. This means that they punch above their weight in terms of impact, and many practices that we now consider to be standard have their roots in small, focused research projects that tested an idea, generated evidence, and were subsequently scaled.

He pointed out that these studies build research capability and competence across the research and health system workforce, fostering a culture of inquiry and continuous improvement, and multidisciplinary collaboration. Small studies often generate a lot of the preliminary data that underpins much larger studies, grant applications and national programmes of work. Mark pointed out that as our health system evolves and moves towards integrated care with more complexity, the ability to rapidly generate, test and apply evidence locally will be essential. He argued that supporting non-commercial research is not a peripheral add-on activity but a fundamentally important part of the research ecosystem.

Mark finished by outlining the agenda for the day and inviting HRCI's Chair, Brian Lynch, to the podium.

> ***Supporting small scale research projects is not a peripheral activity. They're practical, they're cost effective, and they're one way to drive quality improvement, strengthen staff research competence and capability, and create the pipeline for larger follow-on studies that ultimately improve healthcare outcomes.***

HRCI welcome

Brian Lynch,
Chairperson, HRCI Board and Operations Manager & Deputy Head of School – Partnerships, School of Population Health, RCSI University of Medicine and Health Sciences

Brian Lynch welcomed the attendees to the event on behalf of HRCI and described how the title of the event is designed to provoke and prompt a consideration of a wide range of questions and issues inherent in this question. He emphasised how this event, and all Irish Health Research Forum events, are valuable opportunities to air issues and consider a variety of perspectives. Additionally, the outputs arising from Forum events help to progress not just the discussion around these issues, but ultimately health research itself, and Forum outputs have been found to be of considerable value.

Brian pointed out that HRCI's independence and patient focus meant that it is ideally placed to bring together the diverse group of interested parties to this Forum event. In turn, the themes and outputs of the Forum are guided by an exceptional Steering Group. The aim is to connect research with people's everyday lives and to build trust. Brian said that health is part of the national conversation, but too often the visibility of health research is missing. The Irish Health Research Forum aims to address that. Brian finished by thanking the Irish Health Research Forum steering group, chaired by Professor Mark White, the HRCI team, and the generosity of Salesforce who provided the venue for the event.

> ***Now in its twelfth year, the Irish Health Research Forum has explored national and international concerns in health research, engaging with issues which impact population health, patient outcomes, the health service, the development of new treatments and interventions, research careers, and many others.***

Setting the scene: research at the coalface of care

Oonagh Ward;
Head of Research and Innovation Infrastructures, Health Research Board

Oonagh Ward spoke about research conducted at the coalface of the healthcare system, describing studies that assign individuals or groups to health-related interventions to evaluate their impact on outcomes. Unlike commercial research, which typically focuses on new drugs or medical devices, this work is largely led by clinicians and plays a vital role in building the evidence base needed to improve healthcare systems.

She highlighted international evidence showing that participants benefit by gaining a better understanding of their health and the healthcare system, experiencing improved outcomes, and becoming more involved in decision-making. Health and social care systems also benefit through enhanced quality of care, increased innovation, faster implementation of change, and improved staff recruitment and retention due to expanded research opportunities.

Oonagh noted the complex terminology used in this field, including non-commercial research, investigator-led studies, and effectiveness trials, and stressed the need for clearer, more accessible language. She used the term "investigator-led studies" throughout, emphasising their importance in addressing urgent, practice-driven questions often overlooked by commercial entities. These studies are typically developed by clinicians and include patient input in their design, but they are complex and require both sufficient funding and an enabling environment.

The Health Research Board supports this work through its Investigator-led Clinical Trial Programme (ILCT, formerly known as DIFA), established in 2017. The scheme funds intervention studies of various designs, including randomised controlled trials, and includes a feasibility stream to assess the acceptability of proposed interventions. Awards can reach up to €1.3 million depending on scale, and there are currently 52 studies with over €40 million invested. Examples include a study examining the use of older blood stocks in critically ill patients and a feasibility study using virtual reality to raise awareness of testicular disease, both demonstrating clear impact.

Oonagh emphasised that these studies require strong support systems to ensure high-quality design, conduct, and analysis. Many necessary skills lie outside individual research teams, making access to shared resources and infrastructure essential. Ireland, she noted, is well positioned, with strong national and European networks providing support.

Key elements of an enabling environment include clinical trial networks that bring together expertise and support patient and public involvement, investment in methodological support such as the Trials Methodology Research Network (HRB-TMRN), and sustained funding from national and EU sources. While connections with European infrastructures provide additional support, further investment is needed.

She outlined several challenges for clinician-researchers, including funding eligibility constraints and complex regulatory and approval processes involving ethics, data protection, and contracting. Multi-site studies can face delays due to multiple ethics approvals. Emerging trends such as decentralised trials will require new delivery models, particularly in community settings, alongside strong data management and transparency.

Additional challenges include the need to report both positive and negative findings and to communicate results clearly to participants and contributors. Looking ahead, priorities include embedding trials into routine care, strengthening patient engagement, streamlining governance processes, and enhancing support for study design and emerging methodologies.

Oonagh concluded by highlighting Ireland's strengths, including strong connectivity, HRB support on funding mechanisms for national and multinational trials, and alignment with national policy developments, such as the Programme for Government, the HRB strategy, the forthcoming Clinical Trials Advisory Council (CTAC), the potential European BioTech Act, and the imminent Health Data Access Body (HDAB). She emphasised the importance of sharing impactful case studies to demonstrate value and build momentum for investigator-led studies.

> ***International evidence has shown that people who take part in these studies really benefit. They can learn a lot more about their health, the health system, they have an active role in their decision making, and they can have better health outcomes. And the health and social care settings that conduct these studies also benefit.***

Lightning talks: research changing practice

Martin Sweeney;
Cancer Patient Advocate and Researcher

Martin Sweeney introduced himself as a cancer patient and advocate who is co-investigating a research project supported by Cancer Trials Ireland and the HRB, titled PRO-ACT. The project examines how prostate cancer treatment impacts patients and their partners and has been presented at the European Association of Urology conference in March 2026. This developed through Martin's work as an advocate with Cancer Trials Ireland, leading to his invitation to co-lead PRO-ACT alongside oncologist Dr Paul Kelly. Martin described how this project expanded the concept of PPI beyond developing the research idea or contributing to protocol development, to patients designing the research, establishing the steering committee, presenting the research, disseminating the findings, and using the results to campaign for change.

Martin reflected that there is a risk that health research is currently missing the expertise that patients and their partners can bring to the development of research, particularly in shaping the research question and identifying what truly matters. This is especially important as cancer research increasingly focuses on survivorship, quality of life, best practice in treatment delivery, and the impact of serious illness on communities. He outlined the potential of PRO-ACT to drive change in clinical guidelines.

Martin stated that patients need the trust of the research community, along with adequate funding of approximately €500,000 per year ring-fenced for patient-led research. He emphasised that patients and their partners are the experts in this area of research. Researchers contribute scientific expertise, but this is not as directly grounded as the lived experience of patients and partners. He urged the research community to enable patients and their partners to design and define what the project will address, so that the final results are better for all.

> ***Let us take charge, let us design and determine what the project is going to be about and what the end result can be for the better of everybody.***

Prof Rachel Crowley;
Consultant Endocrinologist, St Vincent's University Hospital, and Clinical Professor, UCD

Professor Rachel Crowley spoke about a project she undertook when she was a registrar in Endocrinology. This was sparked by a meeting with a woman with craniopharyngioma and her husband. Craniopharyngioma is a very rare condition. It is a benign growth in the hypothalamus and pituitary regions of the brain, and it infiltrates surrounding tissue. It is typically managed surgically, and the surgeon is faced with a difficult decision: either to excise the tumour along with a significant amount of surrounding tissue to ensure complete removal (which can cause considerable damage), or to perform a more limited excision while accepting the risk of recurrence. For many years, the focus of treatment was on managing the consequences of surgery, radiotherapy, and pituitary hormone replacement. However, Rachel was struck by her conversation with the woman and her husband, who were living daily with the effects of surgery including markedly increased appetite, obesity, impaired temperature regulation, absence of thirst, and sleep disturbances. She was inspired by this encounter, and by her supervisor, to think more broadly and creatively, which led to a research project exploring the wider consequences of treatment for craniopharyngioma.

Rachel described this as a life-changing experience, originating from the lived experience of a patient and her husband. The research project had significant impact, both in terms of academic outputs such as obtaining a Doctor of Medicine qualification (MD) and producing publications, and in presenting findings that supported a more holistic approach to care for patients with craniopharyngioma. This has been reflected in changes to care approaches within the Irish hospital treating these patients, including interventions addressing obesity and sleep disturbances.

Rachel also emphasised how her current role as a leader in rare disease research in Ireland, funded by the HRB and working closely with HRCI, began with a patient encounter and a supervisor who had access to funding to support research that was not part of a PhD and did not have a prior defined topic. She stressed that such opportunities would be much more difficult to pursue today, and that there is a need for an enabling environment that fosters creativity and innovation. Rachel noted that this experience helped her develop skills in caring for rare disease patients that have extended beyond the clinic and her specialty, and beyond Ireland, through sharing PPI expertise with European and international collaborators.

> ***It started with one patient and with a supervisor who was in an environment where he had what we would now call soft money to support me doing a project that wasn't a PhD, that didn't have a developed idea up front. And that was a great opportunity. We need to think about how we foster creativity and innovation.***

Dr Evan Matthews;
Lecturer and Researcher in Health and Mental Health Promotion, South East Technological University

Dr Evan Matthews set the context for his research by highlighting a stark inequality: individuals with significant mental health challenges who engage with specialist services experience a life expectancy gap of approximately 15 years compared to those who do not. This disparity is largely driven by preventable physical and cardiometabolic health conditions. Despite strong evidence demonstrating that physical activity improves mood, reduces anxiety symptoms, and enhances cognitive function—particularly among those with mental health challenges—such interventions are frequently overlooked in mental health settings.

Evan presented his research findings at a 2019 public seminar at South East Technological University in Waterford, where he demonstrated that physical activity levels among service users were low, while sedentary behaviours were high. These findings prompted local mental health services to engage his research team in developing a solution to address this gap. This collaboration led to the creation of a new role: the Integrated Exercise Practitioner for Mental Health (IEP).

Initial pilot funding of €49,000 was secured through Sláintecare, enabling the development and evaluation of the role. Following a successful pilot, the IEP position was formally established within Wexford Mental Health Services. The model reflects strong cross-sector collaboration: while the roles are funded by the HSE, practitioners are employed by Mental Health Ireland, a national mental health charity. Oversight is provided by a Steering Committee chaired by Evan, which has established operating procedures, confidentiality agreements, and referral pathways to support the integration of IEPs within multidisciplinary teams.

Evan outlined several key enablers of successful implementation. Broad stakeholder engagement is essential, both internal and external, including partnerships with local sports organisations, Mental Health Ireland, the HSE, and academic institutions. Collaborative governance - particularly involving service users - is also critical, alongside the exploration of diverse funding streams. Additional facilitators include alignment with service priorities, investment in internal capacity, and fostering cultural change within services.

He concluded by emphasising the impact of the initiative: shifting perceptions of exercise within mental healthcare, increasing physical activity levels, and enhancing connection and engagement among service users. He referred to a powerful testament from a service user on the steering committee who said the project is saving his life.

> ***Through our work, I believe we have changed perspectives on exercise – it's a tool in the toolkit for services, we have increased physical activity levels, we have improved connection and engagement, and as one service user who works on our steering committee commented, it is saving his life.***

Prof Michael O'Reilly
Consultant Endocrinologist at Beaumont Hospital and Honorary Clinical Professor at RCSI University of Medicine and Health Sciences

Professor Michael O'Reilly's clinical and research focus is on androgens, a group of hormones that includes testosterone. His work centres on the condition formerly known as Polycystic Ovary Syndrome (PCOS), now understood as a complex metabolic disorder affecting reproductive-aged women. He describes his research as a journey that has progressed from exploratory beginnings to meaningful clinical impact.

This journey began during his PhD in Birmingham, where an unfunded, opportunistic study arose from an idea floated at a lab meeting. Using archived samples collected a decade earlier, his team conducted an observational study comparing androgen levels in approximately 120 women with PCOS and 60 control participants. The study yielded important findings, demonstrating that androgens other than testosterone may serve as more effective biomarkers in PCOS. In particular, androstenedione—present in higher circulating concentrations than testosterone—was found to be strongly associated with insulin resistance. These findings were later reflected in the first international PCOS consensus guidelines published in 2018, which recommended measuring androstenedione in specific clinical scenarios, particularly when testosterone levels appear normal.

Upon returning to Ireland in 2019, Professor O'Reilly secured support from the HRB through an Emerging Clinician Scientist Award. This funding enabled him to focus on a specific subgroup of androgens known as 11-oxygenated androgens. In collaboration with UK-based researchers, his work has shown that these are the predominant circulating androgens in individuals with PCOS and are closely linked to insulin resistance and broader metabolic dysfunction.

These biomarkers may help stratify patient risk for conditions such as type 2 diabetes and fatty liver disease. The broader impact of this work is reflected in his involvement in an international consensus group representing Ireland and the UK, which, alongside patient representatives, endorsed renaming PCOS to Polyendocrine Metabolic Ovarian Syndrome (PMOS). This change acknowledges the condition's metabolic basis and evolving scientific understanding.

> ***The name of PCOS changed this week. I was fortunate, through work funded by the HRB and my own background over the years, to be part of the consensus group representing Ireland and the UK that commissioned and approved with service users this name change. So, the new name for PCOS is Polyendocrine Metabolic Ovarian Syndrome (PMOS).***

Discussion groups

Attendees at the event were asked to consider 4 themes through discussion groups of 8-10 people (two groups per theme) with an assigned facilitator. Discussion groups were asked to focus on solutions and ideas for what an enabling environment for investigator-led research would look like in 2032. The main findings of each theme, as reported in feedback at the event by facilitators, are outlined below.

1 Telling the impact story

Feedback was provided by group facilitators Dr Nikki Dunne, Research Manager, Family Carers Ireland, and Dr Sarah Delaney, Research Support Manager, HRCI.

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

- Ireland needs a stronger research culture in which PPI and co-production are valued and integral to the impact story. A co-production approach to impact stories could include testimonials from patients, families and clinicians illustrating the difference research has made in real terms, using a range of creative methods. Funding for PPI and co-production needs to be provided before and between discrete grant schemes, with a focus on rapid translation into treatment and care standards.
- In order to truly embed a research culture in the healthcare system, we need clear pathways to refer patients into research.
- A wider public education campaign could show people that they have a voice in research, and that research can bring value to patients, services, and the country as a whole. This could be delivered via a national media campaign, driven by government.
- Impactful research relies on having the right infrastructure in place, including funding, time, co-ordination roles that support embedding research into healthcare, ethical guidance for sharing patient stories, and ways of translating research findings into treatment and care.
- One way of maximising the impact story from research is to bring together key interest holders (clinicians, academics, patients, and policy makers) to submit a joint application for funding (national and international) to form a community of practice on communications and impact. This should include work on developing an agreed language and terminology to describe this type of research.

2 Demonstrating economic value

Feedback was provided by group facilitators Dr Lesley O'Hara, CEO, St John of God Research Foundation, and Dr Cassandra Dinius, PPI Liaison, Rare Disease Clinical Trial Network and HRCI.

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

- Capacity-building and training of the workforce is necessary to enable them to assess and determine the economic value of investigator-led research. Training for researchers and clinicians should include health economics. This will support investigators to develop the skills to assess economic value.
- Identifying common metrics that can be used across projects allows reporting to be standardised according to consistent outcomes. This would be supported by better sharing of data and signposting to publicly available datasets that can be used to identify metrics.
- There needs to be better communication between key interest holders (researchers, policy makers and funders) about their respective interests. Policy makers should share their expectations of what kind of cost-effectiveness data they are looking for, and researchers should share what is actually demonstrable within the terms of their research.
- Researchers should build in measuring and capturing data on at least one economic metric from the outset of a study that can be reported on at the end of the project.
- A central support service should be established to provide clinicians and researchers with resources and support on research design, biostatistics, PPI and methodology.
- The current processes involved in doing investigator-led research need to be streamlined, to save time and reduce research waste. This would encompass research ethics, regulatory processes, data sharing agreements and so on.
- PPI is essential in considerations of the economic value of investigator-led research. PPI contributors initiate ideas and ensure the relevance of a piece of research to the relevant population, which facilitates acceptability and translation of research findings.

3 Mobilising patients and the public

Feedback was provided by group facilitators Dr Mary Vasseghi, Patient Advocate, Rare Disease Clinical Trial Network, and Dylan Keegan, Research Subject Advocate, UCD Clinical Research Centre.

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

- Change takes time and we need to take a long-term approach. Long-term investment in PPI infrastructure is needed to enable a culture shift and improved environment for change, and to embed co-production, recognition, and reimbursement for PPI.
- Leadership needs to come from both the top down and the bottom up. This includes government, the HSE, and other key organisations, clinicians and researchers, and the patients who need to be involved and embedded at all levels, with the aim of normalising involvement in research.
- We need to build public trust in research, employing inclusive methods to break down barriers.
- Education and awareness-raising is key in PPI. While PPI contributors might be able to access education, not all clinicians and researchers have been familiar with PPI from its inception. More broadly, there is a lack of awareness about what PPI is and the value it brings. We need to build awareness of the fundamentals of health research in Ireland. One way to achieve this is via a national education programme that follows a top-down approach, with embedded PPI, and it should be included in healthcare curricula.
- PPI should be underpinned by legislation, to make it the norm, an essential part of doing research, on a par with ethics. This would provide a standardised, structured process that facilitates PPI, with legal accountability.

4 Bringing about culture change

Feedback was provided by group facilitators Niamh Gavin, CEO, Adelaide Health Foundation; and Dr Gerry Hughes, Research Synergies Manager, HRB Clinical Research Facility at St James's Hospital.

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

- Clearly allocated protected resources, both in terms of time and funding, are needed to facilitate investigator-led research in the healthcare system.
- Communication and collaboration are key, with organisations and systems working together, including government departments and key organisations such as the HRB, Research Ireland, and HRCI.
- We need to develop a greater risk appetite and reduce fears around data breaches, taking a proportionate approach to risk, to enable innovation and growth.
- Clear career pathways for clinicians are required, supported by targeted education to address the research literacy gap, and with research recognised as an optional aspect of healthcare workforce roles.
- National leadership is needed to drive reform and position research as a core part of healthcare in Ireland, with a focus on the economic outcomes and benefits of good health research to support a shared understanding.
- Fragmented research systems, processes, and frameworks should be aligned and streamlined, including legislation, data protection, and research ethics, alongside developing a shared language to reduce jargon and barriers to research.

Panel discussion and audience Q&A: what can the system do to help?

Chair – Simone Walsh;
Chair, Irish Research Nurses and Midwives

Simone introduced the panel discussion by reiterating that the importance of communication in this area had been raised repeatedly throughout the event. She also highlighted how important it is for investigator-led research to be a priority, in order for progress to be realised.

She stressed that greater attention needs to be given to measuring and demonstrating the economic impact of research outside of commercial regulated clinical trials. Economic evidence is a key factor in informing government investment decisions, yet the contribution of investigator-led research is not consistently captured or articulated within the Irish system.

Simone also said that many of the issues that face investigator-led research are the same as those facing clinical trials in general. She felt it is important that the investigator-led research community should not ringfence itself or become isolated from the broader health research system. Deciding to belong to a wider community can facilitate real change.

She finished by introducing the members of the panel: Dr Ana Terrés, HSE Assistant National Director, Research and Evidence; and Laura O'Connor, Network Manager, HRB Primary Care Clinical Trials Network.

> ***Too often, the economic impact of investigator-led research is not consistently measured, reported or recognised, despite economic impact being a key consideration in government investment decisions.***

Dr Ana Terrés;
HSE Assistant National Director, Research and Evidence

Dr Ana Terrés identified a key gap in the healthcare system: the lack of an enabling environment for research. While there are centres of excellence, especially in the major academic teaching hospitals or in specific professions that have joint clinical/academic career pathways, overall, the system is fragmented. Ana would like to see the democratisation of research and the opening up of research opportunities in the healthcare system as a whole, including research in community and primary care, and involving health and social care professionals beyond medical staff.

However, there has been progress. The work done by the HSE National Research and Development Office to advocate for and create an enabling environment for research is slowly bearing fruit. Ana gave the example of the reform of research ethics committees (RECs) which is progressing, albeit slowly. She attributed the slow pace of change to the existing constraints within the healthcare system, such as recruitment bans which can delay things by 1 or 2 years. Notwithstanding this, she said that there has been progress in establishing research leadership at regional level, with the appointment of regional directors of research. Their role is to provide leadership for the proposals for national reform made by the National Office. Having interested parties on the ground at local level who can take ownership of the agenda and lobby for change could bring momentum for reform.

At the top, Ana identified two levels of leadership of the overall health system – the Department of Health and the HSE. While economic impact is of key importance to the Department of Health, the HSE tends to be more concerned with the improvement of quality of care and managing risk. She advocated for awareness-raising among the senior leadership in both organisations that an enabling environment for research in the healthcare system is necessary to optimise the impact of investment in research. She wants to demonstrate to leadership the potential impact of having a prime environment within the healthcare system to adopt innovation, to participate in research and to have healthcare professionals involved in collaborations and partnerships. At the moment, she feels that an understanding of the health service as a partner in the overall system of health research is not present among senior leaders.

Ana finished by stressing that we do have research excellence in Ireland, and we are punching above our weight, supported by enabling national and European legislation. But the health system is currently only tangential to this success. She argued that we are not going to continue to make progress with research excellence if the health service itself is not a meaningful partner which deserves the necessary development and support to enable research.

> ***If the health service itself is not considered as something that needs to be developed to finish the equation, we're not going anywhere. So, somebody needs to join the dots and understand that there is a missing dot that needs to be addressed.***

Laura O'Connor;
Network Manager, HRB Primary Care Clinical Trials Network

Laura O'Connor echoed Ana in saying that there is a tendency to see research as existing only in universities and among those healthcare professionals that are closely linked to universities. This view neglects research done in community settings. However, she pointed to PPI as being instrumental in creating a shift towards viewing research as something that everyone can be involved in. From the Primary Care Clinical Trials Network perspective, excellent research is being done in primary care settings, and she would like to see the wider health system catch up. Laura argued that ultimately a lot of research is paid for by tax, which means that every citizen is investing in research, and it should be something that benefits citizens in the long run. She stated that research done in primary and community care settings provides us with a great opportunity to achieve this. Laura also felt that we have moved past the idea of goodwill being the main currency of investigator-led research, either from PPI contributors giving up their time without recognition or reward, or academics and researchers working beyond their contracts to do research.

There is more recognition of the value of the time that people put into research. In terms of the growth of PPI in research, Laura praised the increased visibility given to PPI, either formally via the PPI Ignite Network or through individual PPI contributors spreading the word. She said that legislation to underpin PPI is an interesting consideration, given the success of initiatives such as citizens' assemblies providing a model for public involvement in decision-making. She said that the key to success is showing the impacts that can happen when PPI is done right and getting buy-in from senior leadership at the Department level. One example of this is the new HRB strategy with its focus on PPI.

Supporting investigator-led research in primary and community care settings requires flexibility and collaboration, according to Laura. The unique nature of this kind of research calls for innovative and creative approaches to research timeframes and funding. It may take a little longer to get primary and community healthcare providers on board for recruitment of patients to a trial than would be the case in traditional hospital settings. The structure of existing funding schemes may not allow for GPs to cost the time that it would take them to facilitate research in their practice. Working with those on the ground with firsthand experience when designing research studies, and the schemes that fund them, would help cut through this complexity. Laura advocated looking at the system more broadly to allow for the ripple effects of doing research. Laura finished by highlighting the potential of digital health records to allow for the collection of non-sensitive data, such as the system used by most GPs in Ireland. However, this should not be done without proper engagement with patients and the public. Done right, this could be an excellent way of demonstrating to the public how seemingly mundane data can help realise significant changes in service delivery.

> ***We are a little bit stuck in our ways of seeing research as something that exists within universities and we don't do a great job of looking into the community. PPI has been a huge way of creating a mind shift for people to see research as something that everybody should be getting involved in.***

Panel questions and answers session

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

- University overheads are particularly high on research commissioned by charities, the HSE, and other external organisations because it is regarded as a service. As the commissioner, the charity or organisation will own the results and intellectual property (IP). This means that universities have little to gain on these contracts other than financial benefit. However, the HSE places great importance on commissioned research because it is a quicker way of addressing an evidence gap to inform service delivery. HSE Research and Development is exploring alternative ways of funding research that may have lower overheads, but this is still in progress.

- HSE Research and Development is working closely with the Patient and Service User Engagement Unit to include research as part of their agenda and to link with the Regional Health Forums. Both units are informing each other's strategies. These structures are important to progress the embedding of research in the healthcare system.

- Some of the main barriers to enabling research in the healthcare system include the necessity of obtaining multiple ethical approvals and undertaking time-consuming regulatory and governance processes such as data sharing and contracting. With the exception of academic teaching hospitals, HSE services do not have the human or financial resources to support them in doing research in these circumstances. The system is also fragmented, so doing research in the HSE South West is different to doing it in HSE West and North West and there is no standardised approach. Full-time clinical staff are not enabled to do research, and research is not valued as part of career progression. A culture needs to be developed within the HSE that recognises that research can improve quality of care.

- The strongest PPI work is built on longstanding relationships – facilitated by someone who brings people together and creates the right environment for reciprocity and trust. However, the current funding structures for research make it difficult to maintain these relationships, because when the grant runs out, often researchers have to move on to other roles. There is too much emphasis on how researchers should leverage current activities for the next piece of work. More time needs to be spent on PPI relationships, taking a risk, and embracing some uncertainty, to invest in these relationships over time.

- We are currently in a phase of significant transformation in healthcare, aiming to progress integrated care, with a focus on mental health, disability, older people, and community care. HSE leadership in charge of these national divisions need to lead on partnerships with the relevant patient cohorts. Leadership in driving action on PPI and partnership activities is essential to progress.

Closing Words

Prof Mark White;
Chair, Irish Health Research Forum and Executive Dean of the Faculty of Nursing and Midwifery, RCSI University of Medicine and Health Sciences

Professor Mark White summarised the key points that arose throughout the morning's proceedings. He praised Oonagh Ward from the HRB for setting out the landscape for investigator-led research funding, providing a funding avenue for both early career and more established researchers. He summarised the lightning talks as demonstrating the strong impact investigator-led research can have, as demonstrated by Martin Sweeney's story of coproduced research; Professor Rachel Crowley's journey in her research career – starting from just one patient, one idea, and one supportive supervisor; Dr Evan Matthews' demonstration of how a small pot of funding led to significant change in the approach to physical activity in mental health services; and finally to Professor Michael O'Reilly's retrospective study reusing 10-year-old samples taken for another purpose which ultimately led to reshaping the classification of PCOS to PMOS. Mark went on to praise Dr Ana Terrés and Laura O'Connor for their honesty in describing the healthcare system constraints which slow the embedding of research in healthcare, touching on leadership, collaboration, research excellence, and partnerships between PPI contributors, the health system, and researchers.

Mark finished by thanking Brian Lynch, Chair of HRCI, Avril Kennan, Linda McGrath, and the HRCI team, the eight discussion group facilitators, the photographer and the audiovisual support, Salesforce for offering the venue and the Salesforce volunteers for providing valuable assistance throughout the event.

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/***

IRISH HEALTH RESEARCH *forum*

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