IRISH HEALTH RESEARCH forum

Irish Health Research Forum Meeting

A single voice *to improve health*

More than publications: maximising societal benefit from health research

10th November 2022

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About the Irish Health Research Forum

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 over 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/irish-health-research-forum/**

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

Irish Health Research Forum Recommendations on maximising societal benefit from health research

The topic of research impact, or more specifically in the context of this event, societal benefit from research, has had limited focus in Ireland to date.
This event was very useful in facilitating the diverse audience to find a shared language and to collectively consider what changes would lead to improvements in realising impact from research.
Guided by the discussions and nuanced by input from our expert Steering Group, the Irish Health Research Forum offers the following recommendations.

1. Those designing research should plan a **pathway to impact**, from the inception of a project to beyond its completion.
2. Researchers should **co-create projects with PPI contributors and key potential end users** of the research.
3. To help the uptake of research outputs, research teams should **tailor communications** about them for all relevant audiences.
4. To facilitate better tracking, measurement, realisation and description of research impact, the health system should introduce effective mechanisms for the **collection and use of health and social care data**.
5. To ensure the vital contribution to research of charities and other societal partners, funders and researchers should ensure that their **inclusion costs are covered adequately**.
6. Policy makers should develop mechanisms to articulate the evidence they need to inform policy and should explicitly **attribute research used to underpin policy.**
7. All groups involved in the design and use of research should **establish communities of practice**, focused onenabling a culture of research impact.

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

Key themes which emerged at the event

Some high-level challenges to and opportunities for maximising societal benefit from health research emerged from the in-depth discussions at this event.

Challenges

- There is a **lack of a culture** of considering and capturing research impact, beyond traditional academic metrics.
- **Defining** what we mean by research impact is challenging and it can mean different things to different people.
- Current approaches to **health data collection** are poor, leading to a failure to realise and track impact.
- **Charities and community organisations**, who are well-placed to facilitate research impact, are often not resourced for their work.
- Our current ability to achieve societal impact from health research is constrained by the **short-term nature of research funding schemes**.

Opportunities

- An increasing focus on **PPI and engaged research** throughout the research lifecycle makes impact more likely.
- **Funding schemes supporting partnerships** between researchers and knowledge users facilitate pathways to impact.
- The **planned transformation of the Irish health service** will lead to more data collection in hospitals, primary care, and community settings.
- Ireland's strong sector of **health and social care charities** will act as catalysts for collaboration and knowledge translation.
- **A growing range of resources** relating to research impact and knowledge translation will support the necessary actions for improvement.

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 staff and Board 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 Officer and Dr Avril Kennan, HRCI CEO.

Abbreviations used:

DORA: Declaration on Research Assessment

HRB: Health Research Board

HSE: Health Service Executive

NGOs: Non-Governmental Organisations

PPI: Patient and public involvement in research

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Welcome address

Dr Mark White;
Vice President of Research, Innovation and Graduate Studies, South East Technological University (SETU) & Chair, Irish Health Research Forum

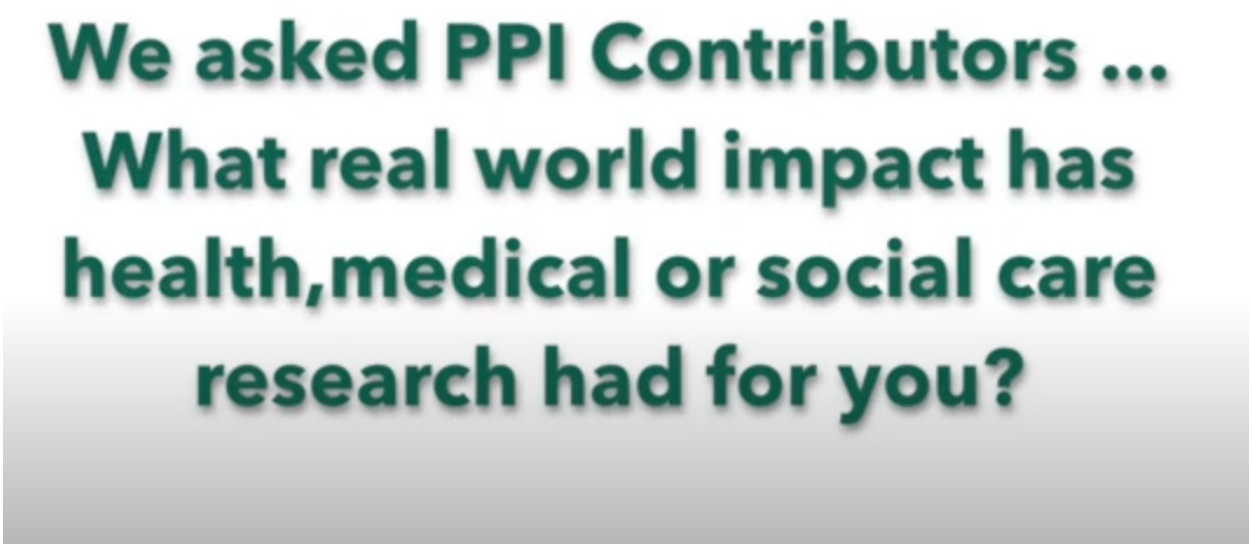
Mark welcomed the group and thanked HRCI for their work in preparing for the event. He noted that the theme of the event, focusing on research impact, or more specifically in the context of this audience, achieving societal benefit from research, is a timely and important one. He also acknowledged that it can be a challenging topic to get your head around but said that ultimately it comes down to thinking about and understanding the 'so what?' of research.

Contributions from patients and members of the public on research impact

HRCI, which runs the Irish Health Research Forum, wanted to ensure that patient and public voices were very well represented through both in person attendance at the Forum event and via invited contributions. A short video was created to highlight the benefit of health, medical and social care research for patients and was used to set the scene for later discussions on how research can have better, more tangible outcomes for patients, families, carers and members of the public. You can find the video here:
https://bit.ly/ResearchImpactPatients

Many thanks to the participants for giving us their time and sharing their experiences:

- Siobhan Freeney - Founder of Being Dense & Patient Representative, Irish Health Research Forum Steering Group
- Maureen Gilbert - Human rights-based disability and equality consultant / Public Representative, Irish Health Research Forum Steering Group
- Derek Stewart OBE - Patient Advocate and Honorary Professor, NUI Galway
- Nikolett Warner – Patient Contributor
- Kevin Quaid - Irish Dementia Working Group / Vice Chair, European Working Group of People with Dementia and co-founder of Lewy Body Ireland
- Marie Downes – Patient Contributor



Conversation – Are we embracing the need for societal benefit from research?

Sarah Bowman; Director of Strategic Engagement & Impact Assessment, Office of the Dean of Research, Trinity College Dublin

In conversation, Sarah Bowman and Dr Austin Warters acknowledged that thinking about research impact can give rise to mixed feelings. An audience response to a question posed by Sarah indicated that while, for some people, thinking about research impact is exciting, it fills many people with dread. This is especially the case in considering how to define and identify impact. Sarah emphasised that, while it can be a tricky concept, ultimately, in the context of this audience, we are thinking about a beneficiary model – who benefits, how do they benefit and your role in delivering those benefits?

Sarah and Austin stressed the need to embed a culture that embraces and values impact in health research and the health system. An element of this means valuing curiosity as an important trait and making sometimes small or incremental changes to integrate impact more fully across a research life cycle.

Improving collaboration and building relationships are key to maximising research impact, according to Sarah and Austin. A successful pathway to impact often requires the involvement of a number of diverse stakeholders and it's important to seek out opportunities to connect with relevant people and to seed new collaborations. The HRB's Applied Partnership Awards was highlighted as a useful scheme to engage with the appropriate stakeholders and to take a targeted approach to achieving societal benefit from research.

They also discussed what methods should be used to measure and describe research impact. This generally involves using a mix of quantitative and qualitative methods.

Dr Austin Warters; Manager of Services for Older People, HSE

Targeted data collection is key to enabling accurate measurement of impact and clever approaches are needed e.g., through using assessment tools that can be repeated and offer data on how a health or social care service is performing over time, for example. Often it is necessary to look at progress indicators rather than final outcomes but always asking 'What's different' and 'Who is it different for?'

Austin emphasised that we are in a process of change in the health service and there is an opportunity to embed research, not just in hospital settings but also in community settings. There are a lot of data currently being gathered in these settings that has the potential to be leveraged for assessing the societal impact of health research but is not yet used for that purpose. Sarah emphasised that when we are more intentional about both planning for impact and impact assessment, we can better position research teams and leverage investments already made.

The overarching message from this conversation related to the need to be more intentional about achieving impact from research, from before a project starts to long after it ends.

> ***"How many of you have "curiosity" as a core competency in interviews and performance assessments?" (Dr Austin Warters)***

Discussion groups

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

1 Planning for Societal impact

Feedback was provided by table facilitators Sinéad Hickey, Research Manager at DEBRA Ireland, and Finnian Hanrahan, Scientific Programme Manager at Science Foundation Ireland.

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

- **Identifying the right stakeholders** when planning for societal impact is key - we need to identify not only what matters, but who matters. We should not focus on a small group of stakeholders but expand the net to include end users, families, communities, clinical settings, and, importantly, key decision makers. This will ensure the outputs can be translated to outcomes and impact.
- Planning for societal impact necessitates **communicating with the right audience at the right time**. Key messages should be adapted according to the audience: decision makers, end users, the extended community of care, and so on.
- It is essential to **plan for societal impact right throughout the research lifecycle** to the very end, to avoid failing at the last hurdle. Research planning should include planning for translation of outputs into outcomes to allow for impact on policy and service provision.
- **A Patient Advisory Council should be set up** linked to the Department of Health to advocate for the translation of research outputs into societal impact. If this is not possible then investment at community and decision-making levels is needed.

2 Achieving societal impact

Feedback was provided by table facilitators Roberta Horgan, Vice-Chair at Lynch Syndrome Ireland, and Michael Foley, Programme Manager at Trinity PPI Ignite.

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

- It is important to be **aspirational about societal impact**, and to see the end goal before research begins. Co-creation with key stakeholders and PPI is key to this process.
- We need to **improve how we use research data and how we collect data** in order to cut down on research waste. This requires collaboration across stakeholders. NGOs and patient registries are important catalysts for collaboration. They are the 'connective tissue' that brings academics, the public sector, clinicians, patients and others together.
- The **public sector needs to encourage curiosity, experimentation, learning, agility and flexibility,** in order to facilitate a culture of research impact.
- The **public sector also needs a forum in which they can articulate their policy needs clearly** to researchers, NGOs, and PPI contributors.
- **NGOs need to be supported to get involved in research**. While funding schemes that involve NGOs are very important, these often require co-funding, which is beyond the scope of smaller NGOs. In-kind co-funding is one way to address this.

3 Measuring and reporting societal impact

Feedback was provided by table facilitators Louise Hopper, Assistant Professor in Psychology at Dublin City University, and Michelle Flood, RCSI PPI Ignite Site Lead/ Senior Lecturer at RCSI University of Medicine and Health Sciences.

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

- In order to effectively measure and report societal impact from health research, it is important to **involve a broad base of key stakeholders early in the research lifecycle.** The nature of the desired impact and the methods by which it will be measured should be defined early.
- Measuring societal impact from health research, which may only be realised in the medium-to-long term, is hampered by the short-term nature of research funding and high staff turnover. Funding terms should be extended to **include impact and knowledge translation in the research lifecycle.**
- It is important to **identify who is responsible for realising the impact of health research**, especially when considering longer-term impact that may extend past the funding period of a specific grant.
- An **inclusive and strategic approach to measuring and reporting societal impact** from health research is essential. Data needs to be collected intentionally (in other words, we should plan the collection of data that directly maps to measuring and reporting impact). Realistic and proportionate goals should be set for impact, rather than undefined expectations of "changing the world".
- **PPI** is vital if we are to **set impact goals that are meaningful and relevant to patients and the public.** PPI has the potential to keep our curiosity alive, because PPI contributors encourage us to think about impact in new and different ways.

4 Valuing and encouraging societal impact

Feedback was provided by table facilitators Emma Dorris, Programme Manager at UCD PPI Ignite, and Sarah Delaney, Research Support Co-ordinator at HRCI.

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

- If we are to truly value and encourage societal impact from health research, **dedicated funding and human capital resources need to be provided** so that relevant data on impact can be captured. These structural resources give value to impact, which will not be prioritised otherwise. Investing in research on research (meta research) is also important for realising impact.
- In order to understand the societal impact of health research, we need **collaborative collection of the evidence for impact.** Investment is needed to support charities and community groups to articulate and communicate their research needs and to build strong and enduring relationships with the research community.
- PPI needs additional **investment, in the form of training and to support engagement activities, in order to ensure that research is connected with the needs of communities.**
- The **research that underpins policy needs to be properly recognised** and explicitly attributed, to facilitate tracking of impact.
- **A culture of impact needs to be embedded** across sectors: research, policy and service planning. The progress that has been made to date should be recognised, but time should be taken to raise awareness among stakeholders of the value of data-informed policy and service planning.
- When planning a pathway to impact, it is important to **think about impact early, in advance of initiating research projects.** Planning for impact also requires us to understand and incorporate the different ways that impact is conceptualised across key stakeholders: communities and patients, researchers, policy makers and service planners.

Creating our Future update

Ruth Kelly; Strategy Lead, Science Foundation Ireland

Ruth Kelly gave an update on Creating Our Future, a Government of Ireland campaign to stimulate a national conversation that generates ideas from the public to inform the direction of research in Ireland. The public were asked to make submissions in response to the question, *"Tell us your idea for what researchers in Ireland should explore to create a better future."* 18,062 valid submissions were included in the analysis. An Expert Committee (more than 70 experts) led the analysis and interpretation of the submissions and shaped findings that reflected the public's voice.

Sixteen themes were identified from the analysis of the submissions. Some key findings with regard to health included submissions on specific areas of concern and of public importance such as cancer, dementia and other neurological conditions, women's heath, chronic disease, and infectious disease. Health related findings also centred on research and implementation within the health and social care system, PPI, patient-centred health care, and mental health and well-being.

Ruth described how these findings informed a series of "Calls to Action" for health research, including:

- The integration of research within the health and social care system, with the public playing a central role in health research.
- Enhanced communication with the public, on health research in Ireland.
- Research focused on better screening, diagnosis, treatment, prevention, and interventions to improve quality of life.
- Research on infectious diseases and immunology.
- Research on mental health.
- Increased research on non-pregnancy-related women's health.

Ruth stated that the outputs of Creating Our Future have been noted at Cabinet and are reflected in the new national Research and Innovation Strategy, Impact 2030. Twenty campaign recommendations were produced to ensure the findings and Expert Committee recommendations are taken forward by Government and others.

> ***"The uniqueness of this report lies in the light it shines on the public's understanding of the capacity of research to help address the complex challenges we face and to create a better future."***

Panel – Reflections and looking to the future

Dr Graham Love; Partner, Mazars

Dr Graham Love welcomed the panellists to this discussion. Referring to his own perspective on research impact, he emphasized the need to shift academic recruitment and reward systems towards more holistic frameworks such as the Declaration on Research Assessment (DORA). He asked the panel to reflect on how to start scaling impact, and how to bring the producers and users of research closer together, to maximise the societal benefit of research.

Dr Virginia Minogue;
Research Management Consultant, Advisor, Coach and Mentor, HSE Research and Development

Dr Virginia Minogue started by restating the need to embed a culture that supports research impact in health systems and health research. She urged us to think about what an impact-enabling culture might look like, and how to define research impact. Virginia pointed out that there is a wide range of data users – from services and service planners to patients and patient groups – and we need to understand the different perspectives and needs in terms of realising research impact. She highlighted that just as health research is "everybody's business", so too is research impact. She described a "virtuous cycle" of enabling research impact: where the findings of health research are transferred to practice, practice-based evidence is generated, which provides data for further research and service planning.

Enabling a culture of research impact involves creating communities of practice that align the needs of academics, healthcare practitioners, and policy makers with those of patients and the public. Virginia said that we need to focus on increasing the value of health research: asking the right questions, using existing data where possible, ensuring research knowledge gets to the right knowledge users at the right time and engaging with PPI contributors early in the process. She also stressed the need for reaching and engaging with people who are seldom heard within this process.

Virginia concluded by stressing the need to interweave research impact throughout the research lifecycle. It is essential to consider who is going to benefit from the research, who needs to be involved and at what stage. This should happen from the start of a project: from deciding on the research question through to dissemination and knowledge translation. She emphasised that impact is not a one-off phenomenon, it takes place throughout a research project. Virginia also referred to the HSE's process for dissemination and knowledge translation, and the range of resources, planning tools and training modules they have developed to assist people.

> ***"The process of knowledge translation is key...we need to plan from the outset who needs to be engaged and involved at each stage."***

Dr Maura Hiney; Head of International Cooperation, Evaluation and Targeted Programmes, Health Research Board*

Dr Maura Hiney cautioned us to think carefully about what we mean when we talk about research impact. Often, we are actually talking about research outputs and outcomes. Maura questioned the concept of talking about societal impact, which is broader and very difficult to measure. She sees the more important questions as how evidence has been used (for example, to effect changes in policy or practice) and what that has resulted in (for example, better health outcomes or better access to health care). If we focus on these aspects, it follows that we need to get better at attributing evidence sources in policy so that we can trace the evidence through to its translation.

Maura introduced the concept of 'Impact by Design', which refers to clarity from the outset about the aim of the research activity. We should know what we want to come out of the activity in the short, medium, and long term, and how we can best design our research to achieve those aims. Once we know this, it is easier to agree what is worth measuring and how we might go about measuring it. As examples, Maura described how the HRB is working to improve the translation of its funded research through integration of researchers and health care practitioners and policy makers (for example, through the Applied Partnership Awards and the Research Collaborative in Quality and Patient Safety awards). This encourages multi-, trans-, and cross-disciplinary capacity-building and research. The HRB is particularly interested in the implementation of health services research and in understanding the needs and challenges of the populations that are the focus of research.

> ***"Researchers need to think about potential impact of research from the beginning. Who might take up evidence generated and what evidence is needed to make a change?"***

Maura emphasised the role that developing collaborative structures play in facilitating knowledge translation, for example, through co-creating; using convenors (or knowledge brokers); using existing fora such as the Irish Health Research Forum or developing new ones; improved engagement with charities; and co-funding of research (cash and in-kind).

Maura also stressed that Public, Patient and Carer Involvement (PPI) is an essential part of enhancing translation, if it is incorporated into the research life cycle through conception, design, conduct, analysis and dissemination (and, by implication, in the assessment of the outcomes of research).

Finally, Maura mentioned frameworks for evaluating and measuring outputs and outcomes of health research for example the Payback Framework of Buxton and Hanney, and for improving the assessment of research ideas, for example DORA. Globally, funders are changing how they assess applications for funding. The Transforming Research Assessment agenda, driven by Science Europe and the European University Association and supported by the European Commission through the Coalition for Advancing Research Assessment, will have a significant influence on the types of metrics we will collect in the future, with increased focus on quality over quantity, and broader outputs and outcomes.

*** Dr Maura Hiney is now Adjunct Professor, Institute for Discovery, University College Dublin**

Dr Avril Kennan; CEO, Health Research Charities Ireland (HRCI)

Dr Avril Kennan spoke of the significant differences in needs and expectations between NGOs and researchers in terms of what they hope for from research. Many charities fund or otherwise support research and, while they understand the importance of peer-reviewed publications (the primary goal for many researchers), their hope is for research to positively change lives.

Nonetheless, she highlighted the many positive changes in the wider system that have more closely aligned the needs of charities and researchers. She emphasised that charities and other community organisations can be a 'friend' to researchers in maximising societal benefit from research because of their access to extensive networks of key stakeholders; their skills in advocacy and communications and their PPI expertise. Avril gave an example of patient organisation forming a network of clinicians, researchers and people living with a condition in order to draw on the evidence from research to develop clinical practice guidelines that directly influence clinical care. She pointed out that 'Impact by Design' is crucial, as is PPI, in order to translate research into practice, and that health charities are crucial cogs in this wheel. Avril argued that we are still speaking at a largely theoretical level about societal impact from research, but that through PPI (which is inextricably linked with impact), and through collaboration, we can make real progress.

> ***"There can be a chasm between the needs of researchers & patients/patient groups...[but] health research charities are a friend to researchers, not least because of their networks."***

Closing remarks

Dr Mark White; Vice President of Research, Innovation and Graduate Studies, South East Technological University (SETU) & Chair, Irish Health Research Forum

Bringing the event to a close, Dr White thanked the speakers and welcomed their insight on the way forward for maximising the societal benefit of health research in Ireland.

Further information

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

www.hrci.ie/irish-health-research-forum/

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HRCI Health Research Charities Ireland

pobal government supporting communities

Rialtas na hÉireann Government of Ireland