IRISH HEALTH RESEARCH *forum*

HRCI Health Research Charities Ireland

Public Trust in Health Research: Are We Doing Enough?

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

Recommendations and Event Report

14th November 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

Public trust is essential for the health of the nation. Without it, people will reject, misunderstand or under-use the health research which can save and enhance their lives.

The practical and achievable recommendations below aim to build and maintain public trust in health research into the future. They are drawn from fruitful and insightful discussions at the event, enhanced by the input of the Forum Steering Group. Overarching recommendations which apply to all stakeholders are followed by those targeted to particular groups.

Overarching Recommendations

1. Make sure research is open, honest and high-quality

All stakeholders should **champion the highest possible standards of research quality and integrity** by promoting open practices, transparency and inclusive decision-making.

2. Help the public understand and talk about research

Stakeholders should **prioritise accessible and inclusive communication about health research** through developing the necessary skills, partnerships and infrastructure.

Recommendations for research institutions:

- **Integrate public trust-building activities,** such as open research, transparency around conflicts of interest, and proactive public engagement into researcher recruitment and career progression assessment criteria.
- **Embed training in public engagement and science communication** into researcher development programmes at all levels, formally recognising these skills in career development frameworks and promotion criteria.
- **Ensure that researchers are actively encouraged and feel safe to engage with the media** by instituting protection and support measures for when their research becomes publicly relevant.

Recommendations for researchers:

- **Practise full transparency** by openly discussing how research works, including its challenges, uncertainties and non-linear progress, and with clear disclosure of all conflicts of interest.
- **Broaden the scope of PPI to actively include the general public** as well as patients, with an emphasis on equality, diversity, and inclusion.
- **Build trust among groups which are currently underrepresented in health research** by forging culturally appropriate connections with trusted community leaders.

Recommendations for research funders:

- Incorporate measures such as open research practices, transparency about conflicts of interest, and PPI into the **funding assessment process for researchers**.
- **Institutionalise transparency mechanisms** across all funding processes by embedding public involvement in decision-making panels and agency governance structures, and inviting key stakeholders to be observers at panel meetings.
- Facilitate rapid, evidence-based responses to emerging health stories by strengthening partnerships between research institutions and the media and supporting **sustained investment in the pilot Science Media Centre Ireland.**

Recommendations for charities and PPI contributors:

- **Take a proactive role as interpreter between researchers and the public**, helping to translate complex science for general audiences.
- Actively **challenge misinformation and disinformation** when they arise and advocate for high research standards.

Recommendation for the Department of Health:

- Develop a **joined-up national approach to building trust in health research**, in line with the Programme for Government 2025 commitments on disinformation, by bringing together key stakeholders to create a shared plan.

Recommendation for the media:

- In the public interest, **upgrade specialist science reporting** and build ongoing relationships with researchers, institutions, and trusted intermediaries, through using the resources of Science Media Centre Ireland.

Key themes which emerged at the event

Some high-level challenges to and opportunities for progressing biobanking in Ireland emerged from the in-depth discussions at this event.

Challenges

There has been a sociocultural shift in attitudes to science and the nature of truth. This can lead to poor research practices which erode public trust.

Mis and disinformation are increasingly in evidence at societal level.

Researchers are under increasing pressure on a number of fronts: sometimes expected to comply with expectations that they write their research in a certain light; and under pressure to publish in high impact journals.

Researchers can face barriers to becoming effective communicators yet they are asked to do more engagement work without an increase in resources.

It is difficult to target research communications to audiences who have historically been excluded. This can lead to a lack of diverse perspectives which can undermine the validity and relevance of research findings.

The government faces a challenge in talking about complex health research endeavours in a way that is relevant to the public, and making sure that this is sustained over the long term.

Researchers are often at the forefront of discussions about science. Those who wish to talk about their work in the public domain face the risk of negative backlash.

Many researchers start their careers in an atmosphere of distrust, from doctoral level onwards. This can create tension when they are later expected to communicate openly with the public.

Opportunities

Prioritising integrity and inclusivity enables the research community to maintain core values of knowledge creation, innovation and creativity.

The work done by key stakeholders in media and communications, such as the Science Media Centre Ireland pilot, press officers in organisations, and health and science correspondents in the media can be strong allies in combatting mis- and disinformation.

Meaningful involvement of the public, patients, and families throughout the funding and research lifecycle lays a strong foundation for building public trust.

Training and initiatives for PhD students and early career researchers give them opportunities to communicate their work to the public clearly and accessibly.

Initiatives that seek to involve people from diverse communities mark the beginning of a broader movement that will develop and grow, and build relationships with researchers based on trust.

The new Research Policy and Innovation Unit in the Department of Health has the potential to contribute to creating a unified understanding of what health research is, and how it can contribute to policy at governmental level.

Civil society organisations are ideally placed to make research accessible and understandable to the public, and encouraging them to get involved in research.

Integrating public trust throughout the values, principles and work of funding agencies offers the opportunity to strengthen the relationship between the public, funders, and researchers.

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:

CPD – Continuing Professional Development

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

EDI – Equality, Diversity and Inclusion

EHDS – European Health Data Space

EViR – Ensuring Value in Research Funders Forum

HRB – Health Research Board

HRCI – Health Research Charities Ireland

HSE – Health Service Executive

IPPOSI – Irish Platform for Patients Organisations, Science and Industry

PPI – Patient and Public Involvement in research

PVCR – Patient Voice in Cancer Research

SFI – Science Foundation Ireland (recently renamed Research Ireland)

TMRN – Trials Methodology Research Network

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The digital copy can be found on the ***HRCI website*** and in our Lenus collection: ***Health Research Charities Ireland (HRCI) (lenus.ie)***

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 welcomed the group and emphasised the importance of the focus of the day: public trust in health research. He pointed out that trust is the bedrock of research. It underpins health research reliability, credibility and societal impact. Mark described how important the relationships between researchers, institutions and the public are, and how they hinge on the integrity and transparency of research. He stressed that without trust, evidence-based advancements in health risk losing their legitimacy, thus eroding the public's confidence in health care, treatments, and service delivery.

Mark set out the key factors that influence trust in health research. The first is the credibility and acceptance of research findings. As research informs policy and practice and technological innovation, any public perception that the research is biased will undermine implementation and effectiveness of innovation. Secondly, advancements in the knowledge produced by research are founded on collaboration and data sharing, and a culture of open communication and mutual respect between researchers leads to an open ecosystem of robust peer review.

In terms of ethics, Mark said that trust is inextricably linked to adherence to the ethical guidelines for research. Mark also pointed out how modern society has shifted in terms of trust and what it means for research, with more examples of false claims, bending of rules, and using statistical analysis to suit the data rather than using the methods that are required to validly answer the research question. Transparency and openness in research methods, funding sources, and conflicts of interest play a vital role in fostering trust. He said that researchers are sometimes under pressure from funding conflicts of interest, expected to write evaluations and research reports in a certain light.

Communication is key to establishing public trust, and Mark stressed how miscommunication has an impact on trust in research. Sometimes the oversimplification of complex findings can lead to misinterpretation and mistrust by the public. Other challenges he identified were the inability to replicate many published studies that raise questions about the reliability of research findings, and the pressure to publish – often in a high impact journal – that can incentivise questionable research practices. However, despite these challenges, Mark said that by prioritising integrity and inclusivity, the research community can maintain its core values of knowledge creation, innovation and creativity. Mark finished by encouraging attendees to bring their thoughts and perspectives on the solutions to the challenges that face the research community when building and maintaining public trust.

> ***Trust forms the bedrock of research. It underpins the reliability, the credibility and the impact of all health sciences endeavours. In the pursuit of knowledge, the relationship between health researchers, institutions and the public hinges on the integrity and transparency of the work that we do.***

HRCI welcome

Dr Avril Kennan
CEO, Health Research Charities Ireland

Dr Avril Kennan welcomed the attendees to the event on behalf of the HRCI team, and thanked the team, HRCI's Chair and Board of Directors, and Roche for sponsoring the event. She went on to explore the complex concept of trust, which has come to the fore consistently in previous Irish Health Research Forum events. She stressed that we don't necessarily all have the same understanding of what trust is. While the health research community is already doing a lot to build and maintain trust, it hasn't historically looked at research endeavours through a truth and trust lens. Avril also pointed to significant societal change which brings with it fear and uncertainty. Some people react to this by accepting the positives and working to fix the challenges we face, others deal with fear by going back to old certainties such as religion or clearly differentiated gender roles. So, for Avril, trust is very much about doing everything we can to make people feel safe, and she presented this as one of the many ideas that could be discussed during the event.

> ***We are living through a time of incredible change. And it is scary in many ways. For me, trust is very much about doing everything so that people feel safe.***

Scene setting conversation

Dr Sandra Galvin
National Programme Manager HRB – Trials Methodology Research Network (TMRN)

Dr Sandra Galvin welcomed the two contributors to the scene-setting conversation: Fiona Lethbridge of the Science Media Centre, and Michael Bowdery, of Health and Care Research Wales and the Ensuring Value in Research (EViR) Funders Forum. She was struck by the parallels between the topic of the day and work of the TMRN in building public trust in health research by doing clinical trials better, and by supporting research into improving trial methodology. The TMRN strives to support research that makes clinical trials easier to participate in, thus improving trials' accessibility and trustworthiness.

Sandra said that she could see the Science Media Centre and EViR as bookends of the research ecosystem: EViR at the early stages of planning and funding research; and the Science Media Centre at the later stages of dissemination and communication. She said that there is greater recognition of the importance of training for early career researchers in communications and media, with initiatives such as Threesis and Soap Box Science supporting PhD students to communicate their findings to the public clearly and accessibly.

Sandra stressed the importance of having a baseline of trust to underpin research which can enable timely responses to crises such as the Covid-19 pandemic. She referred to the mis- and disinformation that was prevalent during Covid, and emphasised that we need to learn from that and focus our efforts on building public trust. In the Irish context, she recognised how the HRB has been a significant driver of patient and public involvement in research (PPI), in its funding schemes and its funding of the PPI Ignite Network. She said that research that includes PPI is perceived as more meaningful, because people were involved in discussing and conceptualising the research.

> ***It's so important to have that baseline platform of trust so that when we're faced with a crisis, you can really hit the ground running. We all remember the level of misinformation and disinformation that was circulating during Covid. We need to learn from that time, and have a better building of public trust.***

Fiona Lethbridge
Senior Press Manager,
Science Media Centre UK

Fiona Lethbridge pointed out that the national news media is a key source of information for the public about science. Scientists and researchers therefore need to engage with the media when their topics hit the headlines, no matter how controversial it is, to ensure high quality reporting and public access to accurate information. Otherwise, the gap will be filled with non-experts who either have insufficient knowledge about the topic, or are campaigners with agendas of their own.

Fiona described the work of the Science Media Centre – an independent press office for science, that aims to increase the accuracy, quality and evidence-base of science media coverage. The Centre undertakes three main activities: rapid reactions to breaking news stories that have a scientific aspect; round ups - written comments from scientists critiquing and assessing the quality of research before it is published; and press briefings, media conferences and press conferences – where scientists describe new research to journalists with detailed and nuanced discussion and questions and answers. She also drew attention to the new Science Media Centre pilot in Ireland, which is testing whether rapid reactions and round ups are useful in the Irish science media landscape.

Scientists need to be open and honest about uncertainties, caveats, and limitations inherent in research. Fiona also stressed the unique and specific role of scientists in the media landscape. Scientists are not politicians or campaigners, and should rather judge each piece of science on merit and be guided by the evidence. She was heartened that many scientists now see communications and engagement with the media as part of their job. However, she would like to see barriers to this being addressed, such as government interference and control, obstructive levels of administration and sign-off within organisations, and organisations being risk-averse at senior levels. She identified some important ways of addressing these barriers, such as the work done by the Science Media Centres, the work of highly skilled press officers at the research institutions, science correspondents in the news media who have high standards when reporting research and and who can be an ally in the fight against misinformation.

> ***We need scientists to be something more – bringing to bear the evidence, not just their opinion, but talking about research, talking about data.***

Michael Bowdery
Head of Programmes, Health and Care Research Wales, and EViR Steering Group Chair

Michael pointed out that most funders have committed to meaningful public and involvement and have built in a commitment to funding research that benefits the public, patients and carers in their mission statements. Public involvement is essential if we are to identify the right questions and unmet needs, and to ensure the relevance, feasibility and acceptability of funded research. He used the example of how research delivered solutions to a global emergency such as the Covid-19 pandemic, which relied on public trust so that people would take part in trials and then take up the resulting vaccine. He also referred to the growth of misinformation on social media, which constitutes a significant challenge that needs to be combatted.

Michael described his contribution to building public trust through his two roles. First, as Head of Programmes in Health and Social Care Research Wales, he oversees all their research funding schemes. The most important work he does in this context to build public trust is to meaningfully involve the public in all aspects of the funding schemes and throughout the whole research cycle. Secondly, as Chair of EViR – a community of research funders committed to maximising the value of funded research through improving practice – he works to promote partnership across funders, the public, research institutions, health services and the media. Internationally, from a research funder's perspective, public trust is at the heart of what funders do and the improvements they're trying to make. He cited the example of the development of EViR's guiding principles, which include transparency, open science, meaningful involvement, dissemination and knowledge mobilisation, and inclusion. He said that public trust is a common strand throughout all of these.

Michael pointed out that the issue of public trust is not new, it's been a question throughout the growth of big data and large biobanking initiatives that rely on people to come forward and donate samples and information and to consent to the use and storage of samples and data. He cited Simon Denegri (Executive Director of the Academy of Medical Sciences (AMS) in the UK) who said if you can demystify the process, and if people can understand what you're doing and why you're doing it, then they usually say yes. Finally, Michael urged attendees at the event to reflect on their own role and what they can do to make things better in order to ensure that the whole is greater than the sum of the parts.

> *I would put the emphasis on partnership, all of us have a part to play in engaging with the public and building trust. We need to see the development and maintenance of public trust in a holistic way and as a shared enterprise.*

Discussion groups

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 solutions and ideas that would strengthen public trust in health research. The main findings of each theme, as reported in feedback at the event by the facilitators, are outlined below.

The role of researchers, research organisations and industry

Feedback was provided by table facilitators Suzanne McCormack, Network Manager, Rare Disease Clinical Trial Network and Dr Sarah Delaney, Research Support Manager, HRCI.

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

- We need to understand the context in which researchers are working, such as the constant pressure to publish in high impact journals, being asked to do more engagement work with no increase in resources, and working in an atmosphere where the role of experts is being eroded by distrust.
- We need to consider how we identify and label misinformation. Sometimes scientists who hold outlier views not supported by evidence can gain momentum, and they may not be aware that what they are contributing is misinformation.
- Training and upskilling of researchers is important to help them become effective communicators, and to understand social media and other communications channels. This should take a multi-stakeholder approach and be given formal recognition through CPD or other types of certification.
- PPI must be a central focus in consideration of public trust in health research, involving training and awareness for researchers and patients. PPI should focus on the public as well as patients, building on efforts to improve research literacy, dissemination beyond traditional academic channels, and founded on principles of equality, diversity and inclusion (EDI).
- Adopting radical transparency will help build trust, by talking about how research actually works, the ups and downs of doing research, and how it is not a simple linear progression. As part of this, we need to foster a culture of open research.

The role of funding and oversight bodies

Feedback was provided by table facilitators Dr Catherine Bates, Research Engagement Lead, Technological University Dublin, and Dr Robert O'Connor, Director, HRB National Clinical Trials Office

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

- Funders and oversight agencies need to be aware of the evolving landscape in health research and adapt to changing needs.
- Increasing transparency of the process for assessment and communicating its rigour is very important to build public trust in funding decisions. This can be achieved through inviting key stakeholders including patients on to funders' boards or by inviting observers from universities, charities and the public.
- Early career researchers need to be funded and supported to connect with and involve those with lived experience. This could involve arranging for funding for PPI in advance of main grant funding – at the proposal design stage. Funders could also support platforms where PPI contributors can be identified and recruited, and this should be available to all universities.
- Government needs to invest in capacity-building for communication and dissemination throughout the research process. This should involve reaching out to participants and PPI contributors and working with them to disseminate evidence to policy makers.
- Activities that build public trust, such as open research, broader career metrics and KPIs need to be incentivised and supported by funders.
- It is very important that funders manage the public's expectations of how health research works by articulating the complexity of health research and not overpromising on the outcomes and timeframes of research
- Funders should look to their own internal processes, such as Board appointments and public engagement, to foster public engagement, co-development and trust within their organisations.

The role of civil society representatives

Feedback was provided by table facilitators Emma Murtagh, Director of Development and Member Services at the Wheel, and Denise Dunne, Operations Manager, Cystinosis Ireland.

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

- Civil society has an important role in ensuring that people are at the heart of research, not just clinical research, but psychosocial research too. This will help build public trust by ensuring that people see the tangible impacts of research in their community.
- Sometimes research can seem inaccessible. Storytelling is a useful way to contextualise research and bring it home for people. Civil society representatives can take on the role of encouraging people to get involved in research, and ensuring that people understand what research is and make informed choices about getting involved. Telling the story of research impact is also very important for building public trust.
- Civil society has a responsibility to be brave: pointing out instances where research is not impact-focused, or where there is bad practice. Civil society needs to take its share of responsibility for advocating for high standards in research, and calling out mis- and disinformation, acting as interpreters between researchers and the public.
- While civil society organisations play a vital role in PPI as a way of bolstering public trust, there are PPI contributors who choose not engage with patient organisations. It is important to engage with PPI more broadly beyond the scope of such organisations.
- At the same time, patient organisations need to be resourced to support PPI and engagement. Staff responsible for PPI need to be resourced sufficiently and given the necessary time to do it well. Training is essential but can be time consuming and difficult to access, so this needs to be facilitated.
- Communication about the process of PPI in research needs to be clear and in Plain English. Universities should train their students in clear communication by learning from best practice or by co-writing materials with PPI contributors.

The role of research communicators

Feedback was provided by table facilitators Adam Murphy, Pilot Science Media Centre for Ireland; and Lorna Jennings, Managing Director, Hanover Communications.

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

- We need to consider who the audience is that we're targeting our communications about research to, including those who have been historically excluded. We need to think about how to engage with them, by reaching out to find out what their priorities and needs are.
- Building responsibility and respect at all levels and across stakeholders is key. If each group of stakeholders (such as universities, press officers, and the public) takes responsibility and respects other groups, this builds communication and accountability and ultimately provides the environment for accurate and transparent communication to support public trust.
- We need to establish a culture of open communication, offering training to students and early career researchers from undergraduate to post-doctoral levels, so that they feel safe and supported to be brave and open about how they communicate their research.
- Preparation and capacity building for engagement with the public can be facilitated by building in requirements for engagement and dissemination to patient-centred research. This involves planning what should be done to facilitate training and engagement at the outset.
- Research communicators need to think about their audiences and how they can target those who are less engaged with the conversation. This is particularly important in the context of the increase in mis- and disinformation about health internationally. One way of achieving this is thinking carefully about what channels are used to communicate health research, not just online, but at community level, possibly through the HSE health regions.

Panel discussion and audience Q&A

Chair – Dr Lesley O'Hara
CEO, St John of God Research Foundation

Lesley O'Hara opened the panel discussion by sharing how encouraged she was by the discussions so far that focused on inclusion, engaging with partners and communities, accessibility in research communications, and reaching the most marginalised groups in our society. She pointed out that exclusionary practices in research lead to a lack of diverse perspectives which can compromise the validity and applicability of research findings. Citing the example of intellectual disability which is a central focus of the work of the St John of God Research Foundation, she said that it is very important to put our effort into advocating for national pathways to participation in health research, along with appropriate consent procedures. She then invited the members of the panel to speak.

> ***Trust is the bedrock of research and exclusion from research leads to a lack of diverse perspectives which can compromise the validity and applicability of research findings. So it's really important that we emphasise all our efforts in terms of national pathways to participation and appropriate consent procedures.***

Joe Murphy
PPI reviewer of research submissions

Joe Murphy opened by exploring the role of hope in research, and how hope is at the core of why we do health research. Over his years of reviewing research proposals he has been struck by the potential of research to offer hope to patients, whether that's solving a problem, improving treatment or quality of life. Sometimes this key message of hope can be lost, but he stressed how important it is to communicate the message as well as involving the public and patients in research from beginning to end. This, he said, will build trust.

Joe has seen a significant improvement in the quality of PPI in research since he started as a PPI representative in 2017. Principal investigators are now including PPI in their proposals. However, he said that increasing attention is paid now to how genuine the PPI plans are in proposals. He praised research that has charity involvement because it promotes patient-centred research that has been vetted by charities or patient organisations.

Joe pointed out that certain types of research, such as scientific research and research on rare diseases, have a clearer route to impact; whereas this can be harder to demonstrate for health services or mental health research. At the same time, these types of research can be of central importance to patients and carers and need the same opportunities for funding as clinical research. He finished by arguing that when it comes to PPI, we don't need to change anything, we just need to live the process of PPI throughout the research lifecycle. He said that the nearer research is to the patient, the better positioned it is to gain trust.

> ***Communication is so important from a PPI perspective, that people are involved from the beginning to the end. And if you're involved from beginning to end, I think that trust will build. Trust can be lost in a second, you need to keep working on that.***

Prof Amanda McCann
Chair, Patient Voice in Cancer Research (PVCR)

Prof Amanda McCann began by recalling the early days of PVCR, and how at the first meeting the researchers knew each other but the patients did not know the researchers or each other. She noted that it took some time before the researchers knew the professional backgrounds of the patients. She stressed the importance of time: investing time to build and sustain good relationships with patients. She also pointed to the role of transparency, honesty and openness in building relationships, and need for researchers to avoid being prescriptive about involving patients and the public in research. She referred to the PVCR, where most of the patients who initially joined are still members, borne of trustworthy relationships. However, she would like to see provision in grant schemes for sufficient funding for patients who are giving their time and expertise to PPI.

Amanda talked about the importance of involving people from diverse ethnic communities, and described a project funded by an SFI Discover grant, which has resulted in engaging with 200 diverse voices from around Ireland. She said she hoped that with initiatives like this aiming to engage with these communities, we are now at the beginning of a broader movement that will develop and grow. Amanda highlighted the need to engage with community leaders and other stakeholders who are respected by the community, in order to form long-term, sustainable relationships. Community leaders have the trust of the people they represent, and they are able to assure them of the trustworthiness of researchers who are reaching out. In this way, they can act as a conduit for research relationships built on trust.

> ***Trust takes time and that's the only way you're going to be able to sustain those really good relationships. Transparency gives a lot of confidence to the group, knowing the researchers are really being honest with us.***

Dr John O'Neill
Head of Research Policy and Innovation, Department of Health

Dr John O'Neill introduced himself and his role as head of the new Research Policy and Innovation Unit in the Department of Health. John's unit works closely with the HRB and the HSE, but also with wider government, collaborating with Department of Further and Higher Education, Research, Innovation and Science through IMPACT 2030, and within this context public trust is a key consideration for his team in working across the health research agenda.

Some of the main topics the Research Policy and Innovation unit are looking at are clinical trials, genomics, and biobanking, all of which are quite complex. At the heart of these is the need to understand what we mean by health research, and how that is communicated both to the research system and to the wider public. John said that it is important to understand what health research means at government level and how that informs research activities. John said that there is a substantial amount of work to be done in raising awareness of health research among the public: thinking about how we talk about complex topics such as genomics and clinical trials in a way that is relevant to people, and how that conversation can be sustained over the long-term.

John noted that tackling complex topics means dealing with not only patients and the public, but also with the research community who have their own understanding of what we're trying to achieve in these areas. He also raised the importance of communicating the Department's intentions regarding health research across wider government: what it wants to achieve in the areas of clinical trials and genomics; what that means for people who haven't yet engaged with the system; why it's important for Ireland to look at this from a long-term perspective; why such concerns are so important; and what does it mean for patients and families.

John referred to previous examples of where topics like genomics or biobanking have previously been the subject of bad press in the media and stressed the importance of working collaboratively to ensure that trust is built in these areas and that there is clear communication about what the Department, and the State is trying to achieve in this regard. He finished by highlighting the tension between open data and transparency on the one hand, and research security on the other, and the need to balance these issues and manage the tension between them.

> ***Dealing with really complex topics, such as clinical trials or genomics, I think there is some work that we need to do in terms of communicating what the intention is in terms of having a positive impact on health outcomes. How do we actually talk about the complexity of genomics? How do we talk about what happens with clinical trials, and how do we sustain that conversation?***

Panel questions and answers session

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

- It is important to minimise situations where people are recruited to pilots or clinical trials that do not go on to result in a change to treatment (such as a new drug). In order to build public trust, communication is key in telling people the results of a clinical trial, even if it didn't result in positive outcomes. If PPI is done correctly in research, this should be anticipated and planned for, with clear and timely communication of anticipated and realised impacts in Plain English.
- Building public trust takes place in the context of the forthcoming European Health Data Space (EHDS), which brings with it the complexity of dealing with large volumes of data. While the changes associated with the EHDS are still three or four years away, it is important to examine what needs to be done, for example regarding secondary use of data and informed consent, in the intervening period. Regarding public trust, part of this is to develop a shared understanding of consent across key stakeholders. Clear communication about the implications of the EHDS not only regarding collecting and use of data, but also how patients can access their data, is essential to ensure public trust.
- The Irish health research community has key expertise in communicating complex areas of research such as genomics, biobanking and clinical trials. Examples include the IPPOSI citizens' jury on genomics and the FutureNeuro deliberative dialogue on genomics. If the Department of Health is to succeed in gaining the trust of the public in health research, engagement needs to happen early in the research cycle and be sufficiently funded. Investment is needed in research communications and in universities to support researchers to engage in implementation of research findings, creative planning and dissemination.
- Raising the profile of research across all stakeholders would help to build trust, and this is a challenge for government, especially at the highest levels. It is important that all stakeholders are united and speaking with one voice on health research, and how research findings can be translated into treatment, practice and service delivery.
- Transparent communication is a good way for industry to break down barriers of distrust on the part of the public. Being careful about how language is used by industry and being prepared to highlight industry successes is important.

- Using art to communicate science is an excellent way to reach out to minority communities, because it helps build strong relationships. However, this requires investment of time and resources to provide communities to engage with researchers and talk about what is important to them.
- Research institutions are centres of discussion about science and research, and researchers are at the forefront of many of these. Researchers need to feel supported and protected to speak out about their work, in case they are faced with negative backlash. Institutions should not just foster academic debate, but work actively to protect it.

Mentimeter poll

After the panel discussion, attendees at the event were asked to answer two questions using a Mentimeter poll.

The first question was: what is the most important action YOU can take to help build and maintain public trust in health research?

81 people answered this question and attendees overwhelmingly said they would focus on communication and engagement. **Communication** in particular was mentioned 39 times and covered a range of sub-themes such as clarity and accessibility of communications (including use of Plain English), managing expectations, reaching all stakeholders and using all available channels, reaching out and building relationships with those who are less engaged or harder to reach, embedding communication in research culture, developing communication plans, training in communication, funding experts in research communications, developing media and dissemination plans, connecting with reporters and including negative results. **PPI and engaged research** were mentioned 16 times and also covered many sub-themes such as research planning, clinical research, managing expectations, co-developing communications and dissemination, providing training in PPI and engaged research, engaging with hard-to-reach stakeholders, and positioning the public at the heart of research. Closely related to both communications and engagement was **transparency**, mentioned 12 times. This theme focused on transparent communication, clearly establishing trustworthiness, transparency throughout the research lifecycle, and fair funding decisions.

The second question was: If we hold another Forum event on public trust in health research, what specific topic would you like us to focus on?

80 people answered this question and, similarly to question 1, **communications** and **engagement** were the top two topics identified by attendees. This was followed by **collaboration and networking** and **government and policy**. The word cloud presented in Figure 1 below shows the key topics identified by attendees.

Figure 1: Word cloud representing the specific topics attendees would like to focus on at a future Irish Health Research Forum event on public trust.

Closing Words

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

Professor Mark White summarised the key points that arose throughout the morning's proceedings, starting with the scene-setting conversation that covered issues related to public trust and the media, engagement by researchers with the media, engaging with the public and PPI, and the need for openness and a clear and coherent message. He highlighted how PPI had emerged as an important concept throughout the group discussions, as well as the need for researchers to tend to their efforts to build trust and enhance research communication, all while taking account of the broader societal context. Mark went on to identify the main themes arising from the panel discussion: the need for training in communications for researchers, how to ensure that our efforts encourage diversity and inclusion when engaging with the public on research, and the encouraging trend towards improved PPI in grant applications. He said that the panel discussion also emphasised the need for researchers to be honest about successes and failures. He also praised the evidence of strong government intent in raising awareness of the importance of health research and the need to communicate this in order to build public trust. He discussed some of the questions and comments from the audience, pointing to the need to mitigate the harms from mis- and disinformation and for researchers to feel protected when stepping up to communicate their research in this context.

Mark said that the conversation about the complex and broad topic of public trust in health research had only just started, and that it could be explored further in a future Irish Health Research Forum event. He noted that many researchers start their careers in an atmosphere of distrust. As they initiate their doctoral studies, they are told not to share their work, and this distrust follows them through their careers. At the same time, they are expected to be open and honest with the public, and these contradictory expectations cause significant tension for researchers. This disparity is mirrored by how researchers are perceived by the public, and how they deal with the public.

Mark concluded that further work needs to be done to understand the complexities inherent in building public trust and how to move forward. He concluded by thanking the attendees for bringing their time, attention and energy to the event, and thanking the HRCI team for their work in organising the event.

> ***A lot more needs to be discussed. I think we have only just started the conversation, and I'm taking away that there is so much to this, so many elements to it that need to be highlighted in this space.***

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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