IRISH HEALTH RESEARCH *forum*

HRCI Health Research Charities Ireland

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

**Irish Health Research Forum Recommendations and Event Report**

# Biobanking in Ireland: Moving Forward

16th November 2023

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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 and the public being at the heart of all activities.

As an independent organisation, representing 45+ 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)

Health Research Charities Ireland (HRCI) is the national umbrella organisation of charities active 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***

# Irish Health Research Forum recommendations on biobanking in Ireland

Biobanks serve as a critical backbone in the advancement of medicine through scientific discovery. They enable research on human tissue samples, including blood, skin, tumours, DNA etc., along with the associated patient information, thereby enhancing our understanding and treatment of medical conditions. However, managing biobanks in Ireland presents significant challenges, including limited information on existing biobanks and inadequate support for their optimal operation, which hinders their potential impact for patients and the public nationwide.

To realise the full potential of national biobanking, comprehensive support from the Irish Government is essential, with a focus on long-term objectives. The achievable steps to success include these 7 recommendations, with a particular emphasis on recommendation 1, from which many of the others will follow.

## Recommendations

To build on current successes in biobanking, support a thriving health research environment, attract more industry investment, and reduce research waste on behalf of patients, researchers, and research funders, the Government must:

1. **Establish a National Biobank Office:** This office would coordinate, oversee, and provide expert support for biobanking activities, drawing from the experiences of the Covid-19 Biobank and supporting the following recommendations.
2. **Enact Primary Biobanking Legislation:** Legislation should underpin the National Biobank Office; provide a standardised definition of biobanking; and address gaps in the regulatory framework, ensuring clarity on ethical, legal, and operational aspects.
3. **Conduct Comprehensive Mapping:** Mapping the biobanking landscape in Ireland will identify existing biobanks, the samples they hold, and how they are being utilised.
4. **Provide Long-Term Financial Support:** Sustained support for the establishment, staffing and maintenance of biobanks will ensure their continuity, quality, and effectiveness over time.
5. **Establish Education and Training Programs:** Programs tailored to varied biobanking competency requirements, supported through involvement with international biobanking consortia, will enhance expertise and skills in the field.
6. **Focus on Inclusion and Trust:** Meaningful and diverse patient and public involvement (PPI) across the biobanking lifecycle, accessible informed consent procedures, transparent information, and ongoing communication with participants and the public will help to build widespread support for biobanking.
7. **Adopt Individual Health Identifiers:** The adoption of Individual Health Identifiers, aligned with national and EU health data legislation, will ensure that biobanks maintain an ongoing connection between samples and patient data and allow them to operate according to the FAIR (Findable, Accessible, Interoperable, and Reusable) data principles.

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 progressing biobanking in Ireland emerged from the in-depth discussions at this event.

## Challenges

- The biobanking landscape in Ireland remains unmapped and the number and scope of biobanks is unknown.
- There is no standard definition of biobanking in Ireland and the distinction from research projects is not always understood.
- An absence of primary biobanking legislation contributes to delays and confusion.
- Health data associated with bio-samples lacks standardisation, hindering interoperability and utilisation.
- The absence of long-term, sustainable funding poses a risk of losing valuable samples and data.
- Retaining and supporting high-calibre staff with all the requisite competencies is a challenge.
- Biobanks are not always inclusive of all sectors of society and patients are often not aware if and how their samples are being used.

## Opportunities

- Ireland boasts a number of excellent biobanks.
- Patients are very supportive of the value of biobanks to their health and to future healthcare.
- Increasing levels of PPI (patient & public involvement) will help to improve biobanks, highlight their value and improve the public's trust in them.
- Existing biobanking networks, such as the National Biobank Working Group, facilitate the sharing of knowledge and resources between biobank experts.
- The infrastructure developed for the National Irish Covid-19 Biobank lays a foundation for future advancements in the field.
- International biobanking consortia could support capacity in Ireland through training and best-practice approaches if we join.
- The Health Information Bill and the European Health Data Space will create an ecosystem favourable to data sharing and collaborative research.

# 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 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:

**BBMRI-ERIC:** Biobanking and Biomolecular Resources Research Infrastructure – European Research Infrastructure Consortium

**CTRNet:** Canadian Tumor Network Repository

**ESBB:** European, Middle Eastern and African Society for Bio-preservation and Biobanking

**FAIR:** Findable, Accessible, Interoperable, and Reusable

**GDPR:** General Data Protection Regulation

**GDP:** Gross Domestic Product

**HRB:** Health Research Board

**HRCI:** Health Research Charities Ireland

**IPPOSI:** Irish Platform for Patient Organisations, Science and Industry

**ISBER:** International Society for Biological and Environmental Repositories

**NICB:** National Irish Covid-19 Biobank

**NREC:** National Office of Research Ethics Committees

**PPI:** Patient and public involvement in research

**PPSN:** Personal Public Service Number

**RECs:** Research Ethics Committees

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# Welcome address


**Dr Conor O'Carroll**
Acting Chair, Irish Health Research Forum/ Founder and Director, SciPol Services & Independent Consultant on Research and Higher Education Policy

Conor welcomed the group, especially attendees participating for the first time in a Forum event. He outlined the purpose of the day: to gather all stakeholders to discuss the key issues in biobanking in Ireland. He said that this was an opportunity for a mix of people who do not often come together to bring their expertise to the table, share knowledge with others, and hopefully answer the most important questions in Biobanking. Conor then introduced the scene setting conversation, welcoming Emma Snapes and Prof Clíona Ní Cheallaigh in conversation with Dr Avril Kennan.

> ***This is an opportunity for you to work together, to bring experts in the field together, from all perspectives: professionals, non-professionals, patients; to get that mix of people who are so important, who often don't sit together in the same room to discuss these issues***

# Scene setting

**Dr Avril Kennan**
CEO, Health Research Charities Ireland

Avril introduced the scene setting conversation by emphasising that patients are at the core of the biobanking arena, and the samples collected by biobanks provide the fundamental underpinning for research about, and ultimately for, patients. She said that biobanking is all about the connection of the patient to their sample, and the connection between that sample and other samples, to the extent that biobanking is a lens through which we can look at the broader ecosystem we work in. The purpose of this scene-setting conversation was to provide information and context for the subsequent discussion groups, comments, and questions. Avril went on to introduce Emma Snapes as someone with extensive experience in biobanking in both the Irish and international contexts, developing international guidance on the topic; and Professor Clíona Ní Cheallaigh as a clinician-researcher with central involvement in the National Covid-19 Biobank. Avril then kicked off the conversation by asking Emma Snapes what she thought we are doing right in terms of biobanking in Ireland at the moment.

> ***Patients with serious conditions want to survive and equally they want to thrive. Bio-samples are a critical underpinning for the research that can make a difference for them.***

**Emma Snapes**
Founder, BioConsulting

Emma first praised the opportunity provided by the Irish Health Research Forum to bring the key stakeholders in Irish biobanking together. She also highlighted the commitment of the attendees to progressing and strengthening biobanking in Ireland. She said that the grassroots organisations in the arena generate new ideas and approaches, harnessing their collective expertise to guide policy and Government investment. She stressed that this work also feeds into international activities and standards.

However, she did identify some important challenges facing biobanking in Ireland. As biobanks are not revenue-producing bodies, it is impossible to put a value on them and this means that it is difficult, if not impossible to determine their true value within translational research. She underscored the necessity of supporting biobanks, quantifying their value, and identifying strategies to ensure they underpin fit-for-purpose research.

Emma stressed the need to ensure that biobanking staff are supported and have the necessary competencies to run a biobank from planning stages to initiation, execution, and the end of the lifespan of a collection. Staff are often fire-fighting, due to severe under-resourcing and a holistic approach is needed to support biobanks encompassing human resources and competencies, infrastructure, and facilities.

She recommended Ireland's involvement in international biobanking organisations, such as BBMRI-ERIC, ISBER or ESBB. She emphasised the role that many of these play in providing training, citing the example of CTRNet (the Canadian Tumor Network Repository), and called for the fiscal and other supports necessary for Irish biobanking to participate in and benefit from the experiences of international peers.

Emma wrapped up by highlighting a key concern: the current lack of knowledge of the biobanking landscape in Ireland could be hiding trends, opportunities and concerns that exist for key stakeholders. She cited practices that need to be checked for, including a disconnect between specimens and data due to underfunding for hosting data to maintain the link to the specimen, and the phenomenon of "biohoarding", where samples are collected but are not accessible for research use. Recommending the undertaking of a landscape assessment, Emma argued that this would give a comprehensive view of the Irish situation which could guide the formulation of national policies to target the main areas of need in Irish biobanking.

> ***We need to know what biobanks we already have in Ireland, where they are with specimens, and do they have annotated data associated with them, or is there a divorce between the data and the specimens***

**Prof Clíona Ní Cheallaigh**
Associate Professor, Department of Clinical Medicine, Trinity College Dublin & Consultant Physician, Inclusion Health Service, St James's Hospital

Avril invited Clíona to talk about her experience of the National Irish Covid-19 Biobank and its importance. Clíona set the context for the establishment of the Biobank by explaining how, when Covid hit in 2020, there was no evidence to guide treatment or to predict who was going to develop serious illness. This necessitated rapid collaboration between researchers across institutions to collect samples. However, it soon became apparent that it was very inefficient to have separate collections of samples in different hospitals, and so stakeholders from key research institutions and hospitals came together to build the National Irish Covid-19 Biobank.

Clíona emphasised the importance of people volunteering their time to work on the Biobank, stressing that most involved were not funded to do this work. They recognised that this was an opportunity to develop a national solution to the challenges raised by Covid. Establishing a National Research Ethics Committee (NREC) for the Biobank was a crucial first step. When the NREC was set up, it eliminated the need to apply to multiple local research ethics committees (RECs) which helped the work of the Biobank significantly. Clíona said she hopes that the National Irish Covid-19 Biobank NREC provides a model that will continue to facilitate the founding of other NRECs.

She described some of the challenges facing the Biobank. Underfunding and resource constraints were key difficulties affecting the personnel directly involved and the universities supporting the Biobank. This has made it difficult to ask already overstretched research offices and data protection offices to put the time and effort into building new structures. Public and Patient Involvement (PPI), a crucial element to the success of the Biobank, also requires expertise, time, and resources, which are in short supply.

Clíona also focused on the importance of including populations that are often overlooked in health research, such as people who are homeless, members of the traveller community, people with experience of drug addiction, people with low literacy levels, and so on. She pointed out that we don't have the evidence to understand why these groups of people have lower life expectancy, or why Covid deaths predominantly affected people who were socially excluded. She argued that there is an ethical issue with leaving people out of research because they're perceived to be vulnerable, as it impoverishes the evidence base that should underpin effective treatment and service delivery. She stressed how proud she is of the Biobank because of its representation of often-unrepresented populations in its repository.

Finally, Clíona cited the example of Finland, a country with an excellent data repository with a unique patient identifier. The opt-out rate for this repository is extremely low, and she said that this reflected the fact that Finnish citizens felt informed and involved.

> ***There are people who would often be perceived as vulnerable populations, who are more likely to die in their 40s or 50s, and who are often not included in clinical trials. But there is an ethical element to leaving people out of research because they're perceived to be vulnerable. And one thing that I'm really proud of in the National Irish Covid-19 Biobank is that we have representation for these populations.***


**Dr Conor O'Carroll**
Acting Chair, Irish Health Research Forum/Founder and Director, SciPol Services & Independent Consultant on Research and Higher Education Policy

Conor wrapped up the scene-setting conversation by picking up on three main points in the discussion. The first point centred on access to data according to the FAIR principles: Findable, Accessible, Interoperable, and Reusable. He pointed out that this is a very topical issue across Europe with some major European projects supporting those who wish to make their data available according to the FAIR principles. Secondly, Conor highlighted the need to identify who is responsible for gathering the information needed by biobanks, as this takes time, effort, and specific expertise. Finally, he called for caution when using the term "biohoarding", as this carries negative connotations when in fact it could be that people collecting samples for health research studies do not have the capacity or knowledge about how to communicate the existence of these samples and how to allow access to them.

> ***Access to data is a very topical issue right across Europe, the need for open access data in a FAIR manner, where you keep your data as open as possible, and only as closed as necessary. There are a various number of European projects who are happy to take on groups who want to configure their data to fit into the FAIR standards across Europe.***

# 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. The main recommendations to address each theme, as reported in feedback at the event by the facilitators, are outlined below.**

## 1 Patient and public perspectives on biobanking

***Feedback was provided by table facilitators Dr Claire Kilty, Head of Research, Irish Cancer Society, and Orla Dolan, Chief Executive, Breakthrough Cancer Research.***

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

- Taking a lifecycle approach to mapping biobanking would help pinpoint exactly where PPI could play a role in each of the steps. This would make it very clear to PPI contributors what role they play in biobanking. PPI contributors can contribute from the beginning of the process, all the way to the end.
- Building trust is fundamental in biobanking. The more trust we have, the more likely patients are to donate their samples and consent to their data being used. It will also facilitate effective and meaningful PPI.
- One way to build trust is to develop robust, structured, and well-funded biobanking systems. This is a really important opportunity to embed PPI in a systems approach from the very start.
- Related to the above points, informed consent needs to be clearer and more accessible for diverse patients. Sometimes it's what's not said on a form that is more telling. Patients prefer when researchers are honest and truthful about some of the difficult aspects of biobanking on information leaflets and consent forms.
- Training is essential for all people involved in biobanking and should be mandatory for biobanking staff who meet with patients. A repository for training resources targeting biobanking staff and PPI contributors should be set up.
- We should not make prior assumptions about what people would or wouldn't consent to in biobanking. It is important to ask people what they understand about biobanking and what are their concerns, and then develop a positive public narrative around biobanking.

## 2 The biobanking landscape in Ireland

*Feedback was provided by table facilitators Dr Abaigeal Jackson, Medical Affairs Scientist, Pfizer Healthcare Ireland, and Niamh Clarke, Data Protection Lead Officer, TILDA, Trinity College Dublin.*

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

- There is an urgent need for a clear definition of biobanking. Currently, definitions vary locally within Ireland, as well as internationally. This is especially important in the context of national legislation such as the Human Tissue Bill and forthcoming European legislation.
- A National Biobank Office should be established to co-ordinate biobanking across the country. This would support awareness-raising, developing a positive public narrative, as well as enabling effective PPI. It would bring key expertise together on the commercial, legal, and ethical aspects of biobanking, facilitating the development of a community of practice in the field. The National Covid-19 Biobank could be a good exemplar to build on.
- The development of a national strategy for biobanking is necessary and provides an opportunity to integrate what we have learned from establishing the National Covid-19 biobank
- We need to undertake national mapping and stock-taking of biobanking in Ireland. We need a better understanding of who is doing biobanking and where it is taking place.
- Sustainability is key in biobanking. We cannot operate in a landscape where biobanks are funded for a limited time, while the samples and their associated data still need to be curated beyond this time. In order to achieve this, dedicated funding needs to be provided and the question of who will provide this funding needs to be answered.
- There should be communication and information sharing between different strategies and policies that include biobanking activities, such as with the National Strategy for Genetics and Genomics in Ireland..

## 3 Collecting samples and data effectively and ethically

*Feedback was provided by table facilitators Evelyn Fox, Research Data Protection Officer, Trinity College Dublin, and Dr Tomás Carroll, Alpha-1 Foundation Ireland.*

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

- There is a need for primary biobanking legislation in addition to other relevant legislation. The lack of it causes delays and confusion relating to the use of bio-samples in research in Ireland.

- It is also important to introduce legislation to align consent in research with consent to medical care and data protection legislation.
- An overarching government body/National Office should be set up to oversee Irish biobanking, with meaningful PPI involvement.
- Related to this, the question of sustainability must be addressed, highlighting the need for long-term funding to maintain biobanks over time.
- It was recommended that a model of broad consent should be implemented to facilitate the collection, storage, and secondary analysis of samples in biobanks. This would be dependent on transparency and constant engagement with people who have given their consent to take part in research, so that they are aware of and can consent to further use of their samples in future research. One way of doing this is to have an opt-in model for people using health care services. Research Ethics Committees and Data Protection Officers need to view this type of consent more favourably.

## 4 Competencies and operations in running a biobank

***Feedback was provided by table facilitators Dr Patrick Buckley, Chief Scientific Officer, Genseq Group, and Dr Blánaid Mee, STTAR Covid-19 Co-ordinator, NICB Facilitator, and R&I Clinical Scientist, St James's Hospital Dublin..***

The main recommendations from two multi-stakeholder discussion groups who addressed this theme echoed many of those made in the previous three themes and include:

- There is a need for a clear definition of biobanking that distinguishes it from research projects.
- We need specific legislation for biobanking and a clear rationale for the use of unique identifiers (as opposed to the PPS number) in the Health Information Bill.
- Biobank IT systems need to be standardised and made interoperable so that they can communicate with each other.
- We need to build national biobanking infrastructure, which applies across different grants and institutions. This would allow for the recruitment of high quality personnel independent of specific funding streams, facilitating staff recruitment and retention. It would also enhance the quality of samples and data collected for biobanks.
- Related to this, sustainable funding should be provided for a National Biobank in Ireland to include funding for infrastructure such as freezers, monitoring, software, training, and staff.
- Competency-based education and training specific to the requirements of biobanking is required. Existing expertise could be leveraged to train and upskill current staff, and future options include a post graduate diploma in biobanking or adapting existing courses such as those provided by ISBER. These could be made available via HSeLanD, either on an opt-in basis or as a requirement before being granted ethical approval.

# Panel discussion and audience Q&A

**Chair – Dr Laura Brady**
Digital Health Innovation Lead, Future Neuro SFI Research Centre, RCSI University of Medicine and Health Sciences

Dr Laura Brady introduced the panel discussion by remarking on the diversity of people attending the meeting and noting how biobanks exist within an ecosystem of a multitude of stakeholders: the people who have generously donated their samples to biobanks in the hope that this will benefit people in the future; clinicians and researchers; patient representative organisations; and those involved in the day-to-day running of a biobank.

Laura recognised the important role of biobanks in advancing clinical research, especially in this era of precision medicine and large-scale, data-driven research. She said that there are unique opportunities to progress biobanking in Ireland, with our increasing focus on PPI and our rich health research landscape. But there are also challenges such as sustainability, infrastructure, consent documentation, and ethics review. She urged attendees to collectively explore how we move forward, and how to create an optimal, sustainable, impactful, and collaborative biobanking environment in Ireland. Laura then introduced the panel members and invited each to speak before opening it up to the floor.

> ***There are unique opportunities here in Ireland. We're very passionate about genuine PPI and we have a very rich health research landscape. Collectively, let's try and explore how we move forward.***

**Siobhán Gaynor**
Patient Advocate

Siobhán Gaynor started by stating her first wish: for researchers to consider the patient as more than a passive contributor to research. She highlighted the significant number of expert patient advocates emerging thanks to national and international initiatives such as the IPPOSI Patient Education Programme. She said she feels very impressed by the expertise of the patient advocates she encounters. She wanted biobanking stakeholders to be aware of the capacity of patients to quickly take on board a significant amount of information and develop the skills for PPI, regardless of background or level of education, even when they have been given a difficult diagnosis. Siobhán stressed the need to include patients traditionally considered vulnerable and excluded from research. She recommended that researchers should understand that many patients recognise that research should be a part of clinical care standards.

Siobhán went on to make the point that governance, transparency and building trust are key principles for biobanking. She emphasised the need to avoid making assumptions when dealing with patients who are in general very supportive of research and biobanking. Every patient is different, with different opinions and experiences. Finally, Siobhán reminded us of the motto of the rare disease community: "Nothing about us, without us."

> ***Trust is critical, it takes a long time to build but it takes a second to lose it. Trust, governance, and transparency have to be key principles for biobanks.***

**Prof Des Tobin**
Full Professor of Dermatological Science & Director, The Charles Institute of Dermatology, UCD School of Medicine

Professor Des Tobin gave his perspective as a researcher mentoring the next generation of researchers, and as someone who had recently returned to Ireland after 30 years away working as a researcher in the USA and UK. This has allowed him to question some of the approaches in the field that have been generally accepted over the last 10 or 20 years. He said there is a need to break down some of these static paradigms to ensure that we map our own systems (including political systems) to make sure that biobanking is fit for purpose in today's complex world.

Des recommended that when looking for international examples of best practice in biobanking to support developments in Ireland, we should look at countries with broadly similar populations, GDP, regulatory environments etc. to develop soundly checked and analysed bespoke solutions suitable and workable in the Irish context. He also said it is important not to simply add new processes to legacy systems that are not suitable for the current context, but to start nearly from scratch.

His second point was that much of what we call 'human health research' is often in fact 'non-human research', as so much of it is derived from mouse, zebra fish or other non-human animal models. Arguing that most of the big medical advances in human health have been made as a result of serendipity or re-purposing, Des urged funders to examine where their investment is really going, and its return rate. This is particularly important when tax-payer patients struggle to understand why it takes so long for large scale research projects to translate into meaningful impacts for our nation's health and social care provision. It is therefore important that the patient voice is not excluded in provisions around biobanking.

Finally, Des made the point that human research is essentially interactive, and team based. In order to build capacity around biobanking, we must recognise the reality of PhD studentship and post-doctoral timeframes, which constrain the time that supervisors have to undertake research projects. This can limit our ability to grow capacity and career opportunities for (especially home-grown) researchers. He said that this needs to be addressed in order to make it attractive for researchers to get involved in human health research, given the increased hurdles/bureaucracy of human research compared to much more 'convenient' but much less-translatable animal model-based research.

> ***We're at a point now where we have to break down some of the static paradigms that have been in place over the past 10 or 20 years, to ensure that we plot our own systems that are fit for purpose in today's complex world.***

**Dr Sharon O'Toole**
Co-Chair of Trinity St James's Biobank Network & National Biobank Working Group

Dr Sharon O'Toole spoke from her experience of being at the coalface of biobanking over the last number of years. She pointed out that a lot of biobanks originally started life as research projects, not intending to become biobanks. This means that the necessary structures and sustainability weren't really considered initially. However, she did feel that the introduction of GDPR has the benefit of bringing the biobanking community together resulting in excellent networks such as the National Biobank Working Group, and the Trinity St James's Biobank Network. These networks have facilitated the sharing of resources which has been very beneficial in the absence of a national approach.

Sharon went on to highlight the influential role that PPI contributors have played in changing how stakeholders look at biobanking, and she stressed the need for professionals involved in biobanking to explain what they're doing and communicate that to patients. She said it was important to leverage the expertise of the many patients who are willing to get involved to build momentum in the biobanking space.

Sharon stressed that funding and sustainability are major issues facing all biobanks. However, the infrastructure that is being built with the establishment of the National Irish Covid-19 Biobank has the potential to underpin ongoing and future developments in Ireland. Sharon praised the idea of a National Biobank Office and a registry of all biobanks, so long as this is dovetailed with sufficiently resourced research ethics and data protection approaches.

> ***GDPR really brought the biobanking community together and we have some great networks, and the sharing of resources that we can do with those networks have been very beneficial***

# Panel questions and answers session

**Several questions were put to the panel, and the following points were made:**

- In the UK the introduction of the Human Tissue Authority Act 2004 resulted in a complete overview of what tissues were housed in hospitals and universities, creating a starting position for how a single country could develop a model for the use of tissue in health research.
- Staffing remains a problem in biobanking, with research assistants on short-term contracts reliant on ongoing funding to secure their posts. Lack of funding for renewing these posts can result in losing staff who received extensive training and who have developed significant biobanking expertise
- This problem is compounded by the fact that many biobanks started out life as research projects and their staffing and funding model reflects this. There is an over-reliance on the good will of PhD students and research assistants agreeing to help. Proper infrastructure and career progression for biobanking staff is a very important requirement.
- Patients have bought in to biobanking, but building and maintaining trust is essential to maintain this. It is important not to make prior assumptions about what patients are willing to do.
- PPI is moving towards a more sophisticated model and there are increasing numbers of skilled, experienced patient advocates. It is important to reflect this in approaches to PPI in biobanking across different activities, and to carefully think about the opportunities for PPI contributors to deliver maximum impact. Their role in the multidisciplinary team needs to be clearly defined and supported.
- People working in biobanking will need to adhere to the defined rules and regulations set by their institution. Given that many biobanks were originally conceived of as research projects and the legacy of historical collections of human samples, some period of time will have to be provided to allow for behavioural change at the individual PI level.
- We need to move away from the idea that the investigators own the samples, and towards a position that the patient's own the samples (noting that ownership of samples is a complex topic).

4 *https://hrbopenresearch.org/articles/4-96*

# Conference close


**Dr Conor O'Carroll**
Acting Chair, Irish Health Research Forum / Founder and Director, SciPol Services & Independent Consultant on Research and Higher Education Policy

Dr O'Carroll thanked the speakers and the HRCI team and emphasised that the report of the event will be extremely important in acting as a basis for progressing biobanking in Ireland. He praised the event for hosting a really productive discussion, which identified the key issues facing the biobanking community. He hoped that this event brought many people together and provided an opportunity to create networks to drive forward progress 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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