The role of Irish bioethics

(re)building trust and reasonable discourse in medicine, science and technology

Report from the Royal Irish Academy symposium held on 15 April 2021

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Acadamh Ríoga na hÉireann
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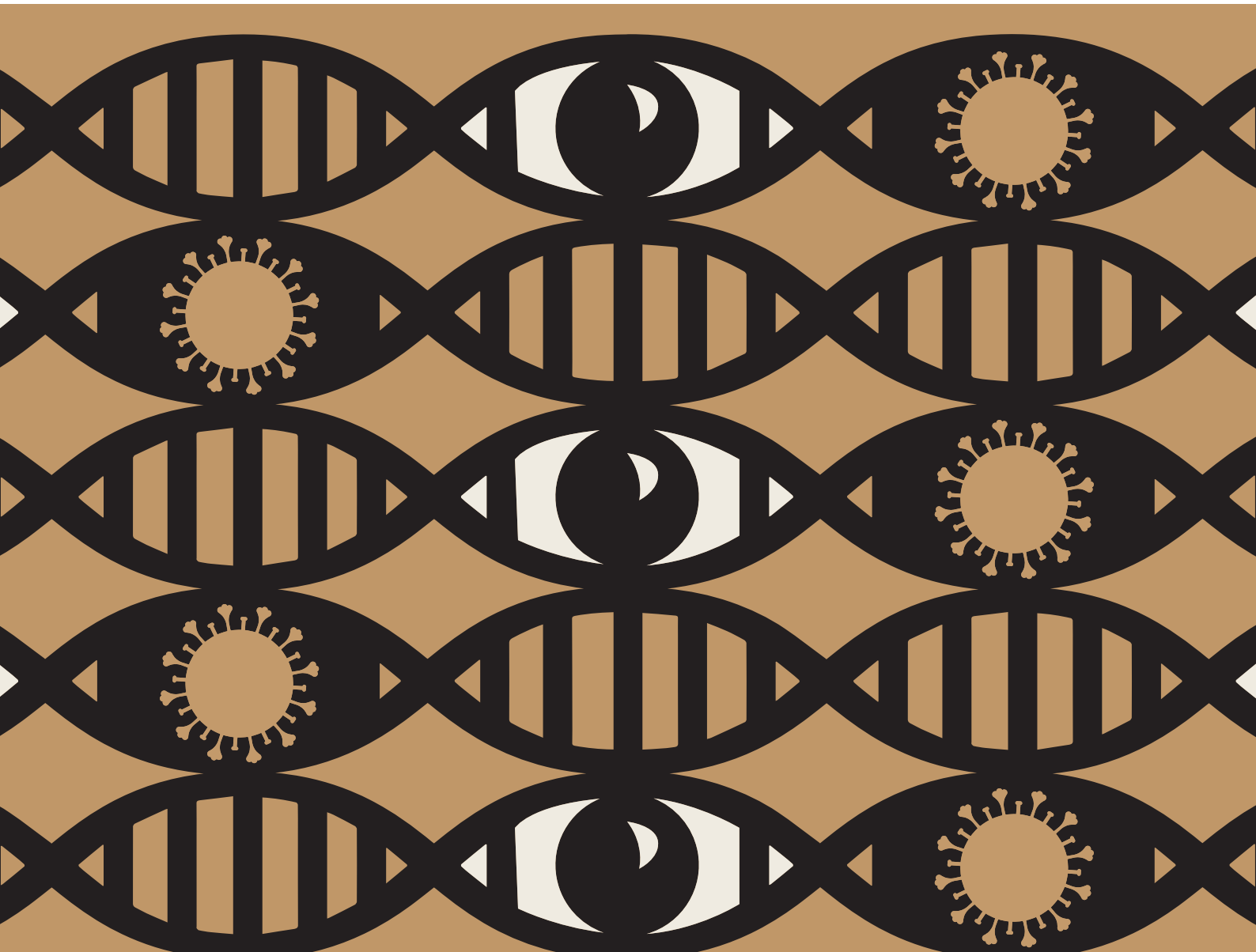

Introduction

The Covid-19 pandemic has potentially brought about a step-change in the public's engagement with scientific and medical research. As a result, bioethical dialogues have been at the forefront of our civic conversations as societies have grappled with questions of individual liberty, the public good and the issue of distrust in science. Such distrust is sometimes fuelled by (online) misinformation, or arises when legitimate concerns by ordinary citizens are not adequately, and respectfully, addressed.

Participants at the symposium from which this report emerges sought to fill a vacuum in Irish discourse on bioethics through robust discussion of pressing issues and by attending to the quality of bioethical discourse itself. Each panel of the symposium emphasised the need to engage in effective scientific communication coupled with ethical debate, guided by ideals of respect and understanding, as a pressing task for clinicians, policymakers and researchers. This is important to enhance public understanding and engagement with technology, science and medicine, and to enable researchers and clinicians to better understand those affected by their work. Conversations were shaped by the context of the pandemic, especially the issue of tackling vaccine hesitancy across Ireland's increasingly diverse populous. While Covid-19 created the backdrop to the event, the discussions and panels focused upon broader themes, covering trust in science and genomics in Ireland as well as issues directly related to responses to the pandemic itself.

Panel I engaged with the conceptual centrality of trust in the Irish and international experience of the Covid-19 pandemic, and the ways in which policy decisions need to be ethically justified. Responses from panellists and special guests emphasised how clarity of information, equity and representation are fundamental values that had been jeopardised due to a lack of robust discussion before the pandemic unfolded.

Panel II discussed how genomics is a field undergoing exponential growth, but one that is challenged by a lack of national leadership concerning best practice for clinicians and researchers. A note of optimism was struck regarding the significant number of opportunities open to Irish clinicians, their patients and researchers in genomics; this was tempered, however, by the recognition that many ethical, legal and societal issues still need to be adequately addressed (including by a long-awaited national strategy).

Panel III, which closed the symposium, explored broader considerations of trust, healthcare ethics and vaccines. Panellists stressed how the dissemination of mis- and dis-information erodes public trust in public healthcare systems, and they discussed possible solutions in the form of public education and the creation of an ethos of respectful engagement with those who hold positions contrary to our own.

All panels highlighted the peril of allowing public bioethical discourse to lag behind medical and scientific developments and emergent crises, emphasising the importance of attending to its quality alongside its immediate outcomes. They linked this to the need for not only clear, understandable scientific and medical communication, but also public dialogue, engagement and deliberation, rather than simply top-down dissemination.

Key themes emerged throughout the symposium, particularly those centring around engendering trust, as well as respectful discourse and the need to pay attention to all voices and perspectives—from the bioethicist to the clinician, from the patient to the policymaker, from the scientist to the citizen, the young to the old, the able-bodied to those with additional needs, and so on. Finally, a key theme that emerged over the course of the day, and that was reflected in the discussions by all the panels, was the fact that ethical considerations—values and principles and critical reflection—are not soundbites; nor are they superfluous or dispensable areas of attention to be discussed when the real work of science and medicine is over. Ethical decision-making has an impact on scientific and medical decision-making and on broader policy-making, with consequences for society and individuals.

Panel One

Ethics and public health—from infectious diseases to pandemics: the case of Covid-19

Panel I was chaired by Deirdre Madden MRIA (Professor of Law, UCC and Deputy Chair, Health Service Executive Board) and examined the handling of the pandemic by the Irish Health Service Executive (HSE), reviewing the shift in attitudes, policy and discourse as events unfolded. The panel discussed fundamental concepts such as privacy, freedom and resource-allocation; concepts that became core issues in the collective choices made during the Covid-19 pandemic.

1.

In the imposition of restrictions during the pandemic, how was the balance between personal freedoms and public health goals (ethically) justified? What are the counter-arguments to the use of restrictions, and were these sufficiently heard by the decision-making bodies?

Dr Gabriel Scally (President, Epidemiology and Public Health Section, Royal Society of Medicine) observed the difficulty of conducting discussions about the pandemic as events rapidly unfolded. He stated that this had led to problematic categorisations, such as 'those with underlying conditions', in the early stages. He also observed, however, the mobility of pandemic attitudes, drawing a comparison with the shift away from initial rejections of seatbelt legislation as an infringement of personal liberty.

Professor Francesco Della Corte (Director, Centre of Research and Education in Emergency and Disaster Medicine, Università del Piemonte Orientale) described the Italian pandemic response, highlighting the public's desire for information and reassurance. This rendered public messaging urging 'pulling together' important, especially during the first wave (from March to May 2020.) He noted a tangible shift in the latter stages of the pandemic, however, when messaging became conflicting.

Professor Siobhan O'Sullivan (Chief Bioethics Officer, Department of Health) stated that minimising harm, with the least restrictive measures and without discrimination, was the core priority of the Irish response. She highlighted the need for a more robust public dialogue in advance of crises emerging, pointing out that countries considered well-prepared, such as the UK and the US, were not necessarily the most successful in implementing pandemic response plans.

Jacqui Browne (disability equality activist and consultant) highlighted problematic language use in the pandemic's early stages, stating that the term 'vulnerability' and discussions of 'cocooning' constituted lost ground in disability activists' work to ensure 'nothing about us, without us'. She stated that the pandemic had exposed systemic vulnerabilities, rather than vulnerable individuals.

Professor O'Sullivan supported this, highlighting the situational character of vulnerability. Dr Scally noted that inclusion would gain renewed importance as society reopens, raising concern for those who are medically unable to avail of a COVID-19 vaccine should a vaccine-passport system be implemented.

Dr Louise Campbell (Lecturer in Medical Ethics, NUI Galway) returned to justifying the limitation of freedoms to protect public health. At an immediate level, she stressed the necessity of public understanding of the quality of scientific evidence underpinning public health measures, and she outlined the broader issue of governmental authority in implementing sweeping restrictions.

2(a).

What ethical and societal challenges arose from enacting emergency legislation?

Professor O'Sullivan noted that the speed of deliberations curtailed consultation and caused the drafting of legislation using a sub-optimal evidence base to meet colleagues' need for advice about their obligations.

Professor Della Corte stated that rapidly changing decrees rather than legislation in Italy generated public confusion and material for political debate. This created instability and

reduced clarity about priorities. Contrasting needs between the north and south of Italy were an issue within the first wave, and remained so in decisions concerning vaccine allocation.

Jacqui Browne stated that releasing an ethical framework in March 2020 that did not reference existing UN and EU frameworks for best practice broke the trust between those with disabilities and the system, raising concerns about situations in which choices might arise about the fair provision of life-saving measures between non-disabled and disabled people.

Dr Scally observed that emergency legislation tends to centralise powers and responsibilities, thereby exacerbating existing geographical inequalities. Although necessary, emergency legislation exposes the deficiencies in our decision-making capabilities at a national, EU and international level.

Professor Mary Horgan (Chair of the National Research Ethics Committee and President of the Royal College of Physicians of Ireland) highlighted the need, one year into the pandemic, for national reflection on the transparency of decision making, the use of evidence and the accommodation of new scientific developments.

Dr Campbell highlighted the need to analyse whether certain groups were disproportionately impacted by emergency legislation, and a need for reflection on inclusivity in decision-making processes.

Professor O'Sullivan highlighted the need for debate and transparency about values being fundamental in decisions surrounding vaccine allocation.

2(b).

What resource allocation issues and potential issues in rationing care arose, for example, in terms of who should get priority (such as challenges facing persons with disabilities, the elderly, rationing personal protective equipment (PPE))?

Professor Della Corte outlined the difficulty of resource allocation in relation to PPE and for ICU patients. The northern region of Italy was under-prepared. Many commentators only engaged superficially with initial guidelines, focussing disproportionately on age as a criterion for ICU admission, leading to an emotionally charged, unscientific discussion.

Dr Scally highlighted the difficulty of resource allocation, identifying how the under-representation of some groups in public discourse resulted from the power of lobbying by other groups. He pointed to examples such as the reopening of schools in the UK without

a ventilation assessment, and the discharging of older adults to care homes, which rapidly spread Covid-19.

Professor O'Sullivan identified how the pandemic had rendered the issues of critical care and access to vaccines urgent. She stated that non-discrimination must guide discussions about priorities, to prevent better-represented voices from dominating public discourse.

Jacqui Browne distinguished the first phase of the pandemic (March–May 2020) and the situation today. Initially, the redeployment of staff and the rapid disappearance of outpatient and day-care services isolated the families of those with additional needs. Now, severe regression—resulting from reduced supports, particularly for children—has become a pressing issue.

Professor Mary Horgan stated that a shift in resource-allocation discourse toward non-Covid-19 care was needed. She claimed Ireland needs to stop 'robbing Peter to pay Paul' and focus instead on long-term planning to bolster non-Covid care, such as cancer diagnostic care.

3.

Was the correct balance achieved between responding to Covid-19 and maintaining healthcare to non-Covid-19 patients? What about other service users such as children and adults with disabilities?

Dr Scally noted the negative impact of Covid-19 disruptions on screening services, stating that this evidenced the urgent need for a coherent strategy focused on reducing disruption and considering the eventuality of new variants and upsurges. The lack of Irish investment in local public health teams, however, may hamper curative and preventative care maintenance. The upsurge in South African variant cases that required mass-testing of all those over eleven years old in four London boroughs showed the kinds of local interventions that may be required in the coming year.

Professor Della Corte stated that Italy shares these concerns. Most patients attending Italian A&E departments during peak times were Covid-19 sufferers, resulting in severe delays in treating patients with myocardial infarctions, who avoided hospitals because of Covid fears. Suicide attempts increased, with peaks following announcements of high Covid deaths rates. The admission of large numbers of Covid-19 patients for intubation disrupted oncologic surgeries. Overall, Professor Della Corte felt that an excessive focus on Covid-19 had negatively affected other forms of care.

Jacqui Browne felt the pandemic represented an opportunity to intervene in the HSE IT

infrastructure. For example, a lack of unique health identification numbers causes issues for patients who receive care from multiple agencies.

Professor O'Sullivan suggested that many patients felt unsafe and have thus avoided engaging with health services. The pandemic is an opportunity to identify critical physical and infrastructural weaknesses to build the health system's future resilience and the resilience of public bioethical discourse.

Professor Mary Horgan stressed that the pandemic should become a catalyst for meaningful change, from unique identification numbers for patients to moving treatment into the community.

Questions and comments from attendees focussed first on the issue of vulnerabilities, and the associated language.

Jacqui Browne stated that a shift towards using 'those at greater risk' rather than 'vulnerable persons' or alternatives such as 'those with health issues' or 'underlying conditions' would be favourable.

Dr Scally stated that those with disabilities require an equal society, not just in terms of rights but also access. He noted that in the UK, the high death rate among BAME NHS staff and the case rate within local authorities in deprived areas has exposed gross social inequalities. The distribution of vaccination has mirrored these inequalities, which will cause recurrent problems in the future if left unaddressed.

Professor O'Sullivan spoke about the value of equity needed to displace previously dominant utilitarian approaches to tackling difficulties faced by minority groups. She stated that the collective effort of the Irish public and the pace of innovation within the health service has been impressive.

Attendees commented on the prescriptive approach to applying restrictions as being effective, but stressed the need for transparency to sustain compliance. Professor Madden invited panellists to critically appraise the management of public health messaging in their contexts.

Professor Della Corte outlined the importance of basing public health messaging on scientific messaging. Dr Scally reflected on his experience working with behavioural scientists within the UK's SAGE group and their stress on the need for clear and coherent messaging. He outlined the added difficulty for Ireland's coalition government in providing the same, suggesting a de-centralisation of decision-making as a potential solution.

Dr Campbell questioned whether the 'non-scientific' public was sufficiently resourced to disentangle facts and values within current public health dialogues and emphasised the need for clarity to allow the public to understand and to participate meaningfully in public discourse.

Professor Horgan stated that the task remained to empower communities to take ownership over the management of health issues and learn from Irish communities that successfully suppressed the disease, such as Cork.

Professor O'Sullivan endorsed the value of behavioural science in informing public health approaches, which the NPHET approach mirrored. The success of public policies hinges on them being both efficacious and engaging.

Professor Madden provided an overview of other issues raised by attendees, including the lack of investment in non- Covid care and its long-term impacts and calls for a group similar to NPHET to tackle this. The audience shared concerns about infrastructure development in IT and in physical buildings to increase the Irish system's future resilience.

Panel Two

New genomic opportunities and challenges in Ireland

Dr Derick Mitchell (Chief Executive, Irish Platform for Patient Organisations, Science and Industry) chaired this panel. Throughout, speakers and special guests highlighted genomic medicine as a rapidly advancing field that represents an opportunity for Irish healthcare providers and researchers to work collaboratively to improve patient outcomes. Grasping this opportunity requires effective science communication, having robust ethical and legal safeguards in place, and the urgent drafting of an Irish policy on genomic medicine and research.

1.

What is the status of genomic medicine in Ireland in terms of infrastructure and supports available, and where does Ireland fall short in comparison with other European countries? What challenges and opportunities are emerging in the Irish context in new developments in genetics and genomics?

Orla Hardiman MRIA (Head of the Academic Unit of Neurology, TCD and Consultant Neurologist at the National Neuroscience Centre of Ireland at Beaumont Hospital) stated that genomic medicine is a field of challenge and opportunity. She stated that although a lack of national genetics and genomics strategy, sub-optimal genetic testing infrastructure, and a dearth of policies concerning handling information and disclosures were challenging, this new landscape in therapeutics makes this an exciting time to be a clinician.

Dr Sarah McLoughlin (Research Scientist, School of Biology and Environmental Science, UCD) endorsed this account of the challenges facing genomic medicine, stating that there is also hope and excitement for patients. She suggested that being less progressed than other nations represents a learning opportunity for the Irish medical system. She added that there

are number of importantly different things discussed under the umbrella of genomics—for instance, contrasting genetic diagnosis in a clinical setting under existing treatments with more future-orientated genomics research on what we can learn about our genome—and therefore there is a need for clarity and precision in our discussions. Another issue of importance is how 'genomics' fits in with the overall Irish health service (for instance, referring to a recent report by the Irish Cancer Society, she stated that effective diagnosis, such as for the BRCA genes, needs to be followed by the provision of appropriate services, such as genetic councillors and healthcare options).

Dr Heidi Howard (Senior Researcher, Department of Medical Ethics, Lund University) urged caution regarding claims that Ireland lags, stating these are primarily based on comparisons with the UK, the US and the Netherlands. Sweden, for example, only recently established a national project in genome sequencing, despite the existence of aspirations to use sequencing to inform individuals' treatment. Existing policies reflect ethical, legal, and social issues (ELSI) indicative of the varying contexts in which genomic medicine projects are deployed. As projects, patients, and public discourse mature, policies must adapt to the challenge of relaying and returning results and secondary findings.

Professor Cathal Seoige (Professor of Bioinformatics, NUI Galway, and Scientific Director, SFI Centre for Research Training in Genomics Data Science) echoed the need for a national strategy and leadership from government. He stated that the UK/US evidence provides for the role of public–private partnerships, the establishment of which should be led and policed by the government. A national institute to lead the field and advocate for patients is one potential solution. Ireland can learn from other nations and capitalise on its small size to become 'nimble', quickly determining what can and should be done in a rapidly changing field. The danger of being 'ruled by fear', however, must be countermanded by meaningful public engagement, for instance through a citizens' assembly, to render the system proactive rather than reactive.

2.

How can Ireland build a national genomics capacity that is trustworthy to the public? Are there lessons from other countries' experiences with regard to developments in whole-genome sequencing (WGS) and population testing involving patients and the public?

Dr McLoughlin emphasised the fundamental nature of trustworthiness, adding that transparency, engagement and involvement are core criteria to ensure this is something that happens 'for and not to' people. Public engagement at every stage, beginning with policy, can ensure the emergence of positive outcomes.

Ms Lora Ruth Wogu (Chief Operations Officer, European Sickle Cell Federation and CEO/ Patient Representative, Sickle Cell and Thalassaemia Ireland) stated trust is reciprocal. Trust requires accurate and clear information provision and sensitivity to diverse cultural beliefs. Increased understanding of people's fears is fundamental to building participation and trust in what is offered. For example, in the African/Asian community, there is a lack of trust in research and what will happen to information provided to researchers. A deficit of understanding about what treatments or innovations in genomic research will do for Ireland's diverse population can be combatted by providing more straightforward information.

Professor Owen Smith (Professor of Paediatric and Adolescent Medicine, UCD, and Chief Academic Lead, UCD Children's Hospital Group) agreed that trust was central. Ireland's lack of a policy or white paper on genomics is a significant issue. In, for example, childhood cancer, genomic technologies have facilitated identifying genetic predispositions, but these advancements require building trust.

Professor Hardiman highlighted that this erosion of trust has extended beyond healthcare and that acknowledging this is fundamental for the HSE. Developing a national, public, integrated genomics institute—built through collaboration between clinicians and academics in educational institutions—that marries scientific breakthroughs to care and treatment systems can be instrumental in rebuilding trust. Patients' diverse and complex perspectives must be recognised and reflected in future choices and discussions.

Dr Howard suggested that utilising the word 'publics' reflects the plurality of stakeholders. She added that decision-makers are united by a wish to 'do good' for patients, but under this broad beneficence umbrella, different values are at play. Also, people's immediacy to a situation will bring about different priorities; for instance, being a parent of a child with a rare illness will create as focus of interest in treatment for a loved one, ahead of other, broader ethical considerations. In current empirical 'anglophone' research, there is a high level of trust in medical doctors, lower in researchers, lower again in private researchers, and the lowest of all in government.

Professor Smith endorsed this, providing the example of the Lindsay Tribunal, which acted as a catalyst in advancing Ireland's ability to provide comprehensive haemophilia care via the establishment of a National Haemophiliac Council; he suggested a similar council approach for genetics and genomics.

Dr McLoughlin stated the pandemic had highlighted the importance of science communication and the potential costs of impaired communication. She added that science communication concerns not merely information provision, but a deeper understanding of *to whom* information is communicated, and the valuable contribution lived experience can make to understanding a given disease.

Professor Seoige highlighted the connection between trust and public understanding, suggesting that a more robust dialogue between researchers and the public might assist in creating a richer account of what the public needs to know.

Dr Mitchell highlighted that several panellists mentioned 'uncertainty', querying how this should be tackled within genomics in Ireland.

Professor Hardiman stated that humans cope poorly with uncertainty, citing public dialogues around vaccine rollout as an example of what and whom the population trusts. Individuals may trust *their* doctor, but trust in the whole system is low. A lack of public trust in institutions makes uncertainty more challenging.

3.

What ethical principles should guide national regulatory processes regarding consent and data sharing in the context of genomic and clinical data? How robust and how effective are the procedures currently in place in Ireland for consent, feedback of results or incidental findings, counselling for genetic testing, data management and storage, and research?

Dr Howard identified three core principles. First beneficence, in terms of whose interests are being represented, and the need to be aware of possible conflicts of interest for clinicians and researchers who are part of commercial companies; second, transparency; and third, focus on honest engagement with 'publics' to explicitly explain uncertainty. These principles require time and financial investment; for example, citizen juries are time-consuming, yet they need to be included in pilot projects and research budgets to ensure meaningful community engagement.

Professor Hardiman confirmed the conceptual centrality of uncertainty, stating that it is increased by the diverse ways a disease progresses following a genetic diagnosis. This uncertainty renders the approach to genomic diagnosis and the required counselling as iterative processes, demanding sizeable public investment. This inflated uncertainty means there can be no 'one size fits all' approach to genetic counselling. In addition, due to the developing nature of genomics, counsellors can have counselling expertise but a deficit of knowledge around the newly developing variables.

Ms Wogu highlighted the need for simplicity in communication, since a lack of understanding can foster fear. For some, the barrier might be a misunderstanding of what a gene is and

how hereditary diseases operate. Better education is needed to dispel common urban myths, such as that certain diseases only belong to specific ethnic groups.

Professor Smith highlighted the unique character of genomics as an exponentially developing field that touches each medical sub-discipline. As such, he argued that changes in medical education are required to integrate genomics teaching across specialties.

4.

Should WGS of a population be a commercial and/or public venture? Who should have access to what information (Irish scientists, commercial companies)?

Professor Seoighe argued that although there is a role for public and private interests, leadership is required to ensure the benefits of technological advancements are unlocked for the whole Irish population and that a future 'scandal of inaction' is avoided. Integration between scientists, clinicians and the wider health service is vital for Ireland to benefit from the advances in planning and prediction made possible through these technologies. If commercial companies are to become productive partners in this area, national coordination is needed.

Dr Mitchell asked panellists where the responsibility for leadership lies? If the public's willingness is contingent on who maintains the data, what principles need to be embedded in future public–private partnerships?

Professor Hardiman contended that responsibility and benefit are connected. A vacuum in leadership has led to opacity in regard to some recent innovations. Linking the genome to the clinical presentation of an individual is where progress will be made, be this in the clinic or at the cellular level. This linkage requires investment in researchers and clinician education. Since all taxpayers are invested in this process, public benefits must be tangible and transparent. She stated that since commercial interest is predicated on a lack of availability, a definitive account of investment and outcome must be established at the beginning of any public–private partnership.

Professor Seoighe addressed data ownership, stating that data should belong to the person who provided it. Clear limits concerning the maintenance of data and its use must be established. For instance, in the UK, commercial partners only have access to data for a limited period; such an approach would be beneficial in the Irish context.

Dr McLoughlin stated that a straightforward conversation about what is and is not acceptable is needed, especially concerning benefits to the population and the contributing

individuals. Although an open science format might promote public benefits, there are questions about the potential harms to the individual when information becomes publicly available, such as the potential for increased health insurance costs based on genomic disclosures.

Dr Mitchell introduced the questions from attendees. First, can anybody recommend best-practice strategies elsewhere that can be implemented in Ireland? Could there be benefits to coordination at an EU level?

Dr Howard stated that the differences between nations regarding consent, secondary use of data, the plurality among health systems and the difference between registries and biobanks make EU coordination challenging. She added that minimum requirements at an EU level might be possible, however, and that best-practice strategies are under development by multi-national professional bodies as technologies develop.

Professor Smith claimed that Ireland needs to develop a best-practice strategy from within.

Dr Mitchell summarised comments concerning the need for a de-mystification of rare diseases and the reticence about public engagement by state agencies and others, connecting this to earlier comments from Professor Seoighe on the risk of being ruled by fear.

Professor Hardiman stated that recognising rare diseases is a recent phenomenon, arising because these are likely one of the first sites to deploy genomic treatments. Highlighting the value of investing in rare diseases, however, is challenging when health economics dominates the discourse. Establishing a closer relationship between research and clinical treatment is one method for investing in rare disease treatment that is relevant to accounts about the public good.

The audience asked about the lack of counselling service within the Irish system, querying what role genetic counselling might have in developing a national strategy?

Professor Smith reiterated the need for a white paper and coherent national strategy to move away from existing ad-hoc approaches.

Dr McLoughlin challenged the notion that various disciplines possess incommensurable differences, arguing that several services might be improved through findings concerning a rare disease group.

The audience asked whether there is room for Irish ethical companies in Ireland in data and data ownership?

Professor Seoighe suggested that there may be a role for new technologies such as blockchain in allowing data to yield benefits while protecting the best interests of the data provider.

Dr Howard emphasised that research participant understanding of the process is essential. For example, even when a patient withdraws from a research programme, in some studies their data remains as part of the research; withdrawal does not mean they will never be identified. Establishing how and to what extent patients understand these factors is fundamental to increasing public trust.

Panel 3

Healthcare ethics, vaccines and public trust

This panel, chaired by Bert Rima MRIA (Professor of Molecular Biology, Queen's University Belfast), examined vaccine hesitancy and public understanding of the role of science in society.

1.

What benefits and risks are presented by vaccines at the individual and public health/population level?

Kingston Mills MRIA (Professor of Experimental Immunology, School of Biochemistry and Immunology, TCD and Head, Centre for the Study of Immunology, Trinity Biomedical Sciences Institute) stated that after clean water, vaccines have had one of the most positive impacts on human health. While the success of vaccines is evident, risks are assessed by Phase III trials, and rarer side effects only become apparent through surveillance after roll-out, such as was the case with the clotting issues with the COVID-19 vaccine. Such risks are rare but real, and people have a right to the data and its assessment, with the help of expert advice and clear, unambiguous data. Trust in the information provided is a further issue, and such trust can be further eroded through mishandling and partial reporting by the media. Therefore, information needs to be qualified by experts.

Professor Sam McConkey (Associate Professor and Head, Department of International Health and Tropical Medicine, RCSI) connected conversations about these risks to a society that possesses multiple tools to enable better living. All technological interventions have risks and benefits that challenge people's self-perception, especially those that consider themselves risk-averse. Finding ways to help the risk-averse cope with the risks endemic to modern life is essential.

Professor Rima confirmed the public struggle with risk perception, a position confirmed by Dr Simon Mills (S.C., Barrister at Law, Irish Bar Council.) He added that members of the public struggle to inform themselves about areas in which they have a knowledge deficit. This situation gives rise to two obligations: clear communication regarding risks, and acknowledgement of the difficulty in understanding them.

Maria Baghramian MRIA (Professor of American Philosophy, UCD and member of the ALLEA Working Group on Trust and Expertise) problematised claims that people should be taught data analysis. Studies have exposed a human tendency to overlook probabilistic outcomes in emotive issues. Forcing rationality on others where rationality is rarely found may be unproductive.

Dr Nick Flynn (G.P., Senior partner at My Cork GP) stated that trust in vaccines is a first-world problem, since the developing world is still struggling to access widely available vaccines.

2.

How to distinguish trustworthy sources from unreliable or fake sources? Is distrust in established science and medicine on the rise? What are the threats and causes?

Professor Dónal O'Mathúna (Associate Professor, College of Nursing, Ohio State University and Founding Director, Center for Disaster and Humanitarian Ethics) stated that the public needs to be encouraged to interrogate media headlines and ask about their provenance. Critical-reading skills need to be introduced at all levels of education. Carefully compiled syntheses of trial information are helpful for busy clinicians, as is keeping up-to-date with the developments in their operative fields. Academics have a role in translating peer-reviewed data into accessible formats across various contexts, and providing links to the raw data provides a ready answer to those who publicly express cynicism.

Professor Rima questioned whether this was an excessively academic perspective on misinformation, and argued that the success of misinformation on Twitter indicates this problem. How can we teach people to identify misinformation?

Professor McConkey responded that we have a responsibility to educate people about the unregulated nature of social media sites and to point out that these are fora for entertainment rather than information.

Professor O'Mathúna stated that the apprehension that 'checking sources' is an academic pursuit indicates our contemporary moment. Reinstating the value of checking information

across domains of life and the unique role of professionals in explaining data is part of a long process of rehabilitating better approaches to knowledge acquisition.

Dr Flynn stated that patients would not spend time reading academic articles; therefore, we need to ensure that they access clear information. For example, a misleading broadsheet headline, 'Blue inhalers linked with death', fostered mistrust about these safety aids. While academic literature is important, we must accept that the general public lacks interest in these types of publications.

Dr Mills added that we need to consider the quality of our engagement with those who oppose our views, particularly in the context of COVID-19. A portfolio of untruths and reasonable conclusions often support these positions. Engaging reasonably through dialogue with opposing positions is vital.

Professor Rima endorsed this position, adding that such dialogues need to begin from a position of respect in order to engender change; he acknowledged that such a process is time-consuming.

Professor Mills identified two key groups who have a role in fostering recent interest in science, particularly in the pandemic. First, the journalists, particularly editors, who draft headlines. Second, medical professionals, who need to engage more openly with the public.

Professor Baghramian stated that imagining a move away from social media as a news outlet is wishful thinking. She cited the PERITIA project findings that younger people currently focus on social media as their primary news source. Combatting the spread of dis/misinformation through fact-checking methods can assist in rebuilding a 'climate of trust'; that includes having trustworthy experts connecting them with sources that correctly reflect their views. She added that there are means such as gameplaying fora in which young people can build their critical thinking skills, which is the primary task of those seeking to combat fake news and dis/misinformation.

Professor Rima shifted the discussion to a focus on the latter part of this question, namely, is distrust in established science and medicine on the rise? What are the threats and causes?

Professor McConkey agreed that there are high levels of public interest in science, noting that the openness endorsed by Professor Mills is on the rise, for example within the HIV community, where information has empowered patients, strengthening clinician–patient partnerships. Medicine's principle of respect for autonomy over beneficence entails respecting patients' right to make decisions their clinician might not endorse.

Professor Rima problematised the common claim that politicians are 'following the science' when scientists themselves hold conflicting priorities. The more important question is *how* we engage with vaccine hesitancy and the nested questions around this problem.

3.

How to engage vaccine-hesitant parents and citizens: by increasing information, communication, trust? What role do healthcare professionals, with their patient-facing experience, have to play?

Dr Mills claimed that the pandemic upended the prioritisation of patient autonomy, as was reflected in public health messaging about the importance of collective action. He predicted that this tension between the need for compliance and the value of autonomy would prove fundamental to vaccination progress.

Professor Rima cited the consideration given by the US Supreme Court to introducing compulsory vaccination as a means of disease control in 1914, raising the question of how far these conditions justify the limitation of personal freedom.

Professor O'Mathúna agreed that autonomy has possessed conceptual primacy in western medicine and added that productive engagement with the vaccine-hesitant must be led by questions that foster understanding of the source of the interlocutors' misgivings. In turn, this requires a step-change in science's answer-oriented tendencies.

Professor Baghramian added that, even in the west, autonomy is a post-Kantian development and that other ethical frameworks emphasise communitarian perspectives. Instead, she suggested that the principle of not doing harm or being harmed should have a greater prominence and should remain in a position of prominence beyond the pandemic.

Dr Mills warned against an overly simplistic definition of autonomy, favouring the reasoned autonomy advocated for by Onora O'Neill.

Professor McConkey endorsed this notion, adding that fairness, equity and justice are important values in pandemic discourse. The disproportionate pandemic effects on those at the fringes of society have exposed the disintegration of any inclusive social contract in Ireland.

Professor O'Mathúna stated that these values require a global extension to mitigate the potential harms inflicted by more prosperous nations' vaccine hoarding, which will short-circuit long-term recovery.

Professor Rima stated that the failure of the World Health Organization's COVAX scheme to distribute vaccines equitably at global level, for example. is an indictment of these deeply rooted behaviours .

Professor Baghramian suggested that appealing to self-interest by stressing that 'until everyone is vaccinated, no one is' could be more efficacious than arguments made on ethical grounds.

Dr Flynn stated that in negotiating vaccine hesitancy, the worst outcome is a person refusing a vaccine and having an impaired relationship with their physician as a result, since the vaccine is only one 'episode of care'. Choosing language carefully, understanding the power of personal stories and the alienation caused by excessively scientific language is fundamental in patient–clinician conversations.

4.

Should vaccines be mandatory or voluntary? Policy options—advantages and disadvantages?

Professor Mills argued that vaccines should be enabling rather than mandatory. A 'carrot and stick' approach with clear, unambiguous messaging is required to increase vaccine confidence.

Professor Rima invited the panel to consider the question of vaccine passports.

Professor Baghramian stated that making vaccines mandatory for travel is consistent with existing systems, and Professor Mills argued that vaccine/immunity certificates would encourage vaccination.

Dr Mills distinguished mandatory and strongly incentivised vaccination, stating that while cogent arguments for mandatory vaccination might be made for subsets of the population, the case for widespread mandatory vaccines is thin.

Professor McConkey stated that vaccine passports could not be effectively advocated for without further data on vaccine efficacy or re-infection rates.

Professor Rima opened audience questions, asking how best to combat vaccine nationalism, and inviting Professor Baghramian to comment on arguing effectively for global rather than national vaccination.

Professor Baghramian answered that she was less hopeful for the compulsion offered by moral arguments, stating that emphasising the emergent goods of community immunity might be more effective.

The audience also asked: is it ethical for a person in Ireland to accept the vaccine when healthcare workers in the developing world are unvaccinated?

Professor Baghramian stated that refusing a vaccine in Ireland will not mean a healthcare worker in the developing work will receive it, but she endorsed pressuring leaders to share vaccines rather than hoard them.

Professor Rima introduced the practice of the publication of 'pre-prints' on vaccine research to the discussion. Although this has become common in the pandemic, it might lead to problems connected to trust in scientific research. Professor Mills stated that although the practice of making research available via pre-prints was efficacious in helping others progress their research, it risked articles reaching the stage of public dissemination without the rigour of the peer-review process, which commonly counters excessive claims before publication of research findings.

Professor Rima added that although this development has been interesting, the media have handled early released data poorly.

Dr Flynn stated that as an 'end user' of scientific work, care needs to be taken in the ways findings are produced and communicated.

Professor O'Mathúna stated that research pre-prints could have a legitimate role, but the information they present must be used with caution.

Professor Baghramian pointed out that the communication of scientific disagreement by the media had undercut trust in science, stressing that reporting on disagreement is based on a misunderstanding of science as a field that *only* provides certainty. As science developed through disagreement and through highlighting falsification, reasonable disagreement is positive. Therefore, science communication must both remedy this fundamental misapprehension and disseminate complex findings carefully.

Professor McConkey suggested that the RIA could step into the space of journalist education and training to facilitate the proper appraisal of data before its publication in the mainstream media.

Professor O'Mathúna suggested the example of the partnership between the Cochrane organisation and Wikipedia as a success story that improved the quality of evidence-based information about health and medical issues available online.

Dr Mills suggested that it was unsurprising that half-truths and untruths have been disseminated, given the pandemic's rapid pace of change.

Professor McConkey reminded the panel that the findings for Covid-19 vaccines in real-world contexts had mirrored trial data.

Dr Flynn suggested that an ethics watchdog should regulate the media in the future.

Conclusions

Across all three panels, speakers and guests highlighted two critical tasks: (1) to attend to the type and transparency of information, as well as to (2) the quality of the dialogues within which this information is exchanged, discussed and (occasionally) disputed.

Good bioethical dialogues were characterised as those that strive to understand opposing viewpoints (Mills and O'Mathúna, Panel III), while attending carefully to the power of personal stories (Flynn, Panel III and Howard Panel II) and the power of language (Browne, Panel I) and of cultural differences (Wogu, Panel II) in building or eroding trust between diverse publics and researchers, clinicians and policymakers.

For some, this requires a redefinition of basic concepts such as science (Baghramian), away from the simplistic assumption of certainty through testing toward a more nuanced grasp of scientific development as a contested field.

As was highlighted, allowing bioethical discourse to lag behind current events and scientific innovations risks leaving society at large ill-prepared to participate meaningfully in new clinical developments, or to deliberate between incommensurable goods such as public health and personal freedom. Although it would be a time-consuming undertaking, all three panels made a case for increased, well-resourced, and diverse conversations on Irish bioethics into the future.

Given the inactivity of the National Advisory Committee on Bioethics and the disbandment of the Irish Council for Bioethics, this symposium was important in highlighting the need for a sustained bioethics forum in order to discuss properly the highly significant bioethical issues facing the Irish, European, and international contexts. By reflecting on the question 'What is ethical?' within the topics each explored, the panels also addressed the broader issue of 'How do we respectively, constructively and collaboratively discuss and manage both ethical agreement and disagreements?' This is a crucial step toward public deliberation, rather than heated polemical argument, on some of the key bioethical concerns arising in Ireland: ethics and public health, genomic developments, and public trust in science and medicine (as noted in the case of vaccines).

Symposium Organising Committee: Dr Oliver Feeney (University of Tübingen/NUIG), Professor Jane Farrar (TCD), Professor David Smith, (RCSI), Dr Derick Mitchell (The Irish Platform for Patient Organisations, Science and Industry), Dr Joe MacDonagh (Technological University Dublin, Tallaght), Professor Dónal O'Mathúna (Ohio State University; formerly DCU), Professor Deirdre Madden (UCC), and Mark Crowe MRIA (UCD), Chair of the RIA Life and Medical Sciences Committee.

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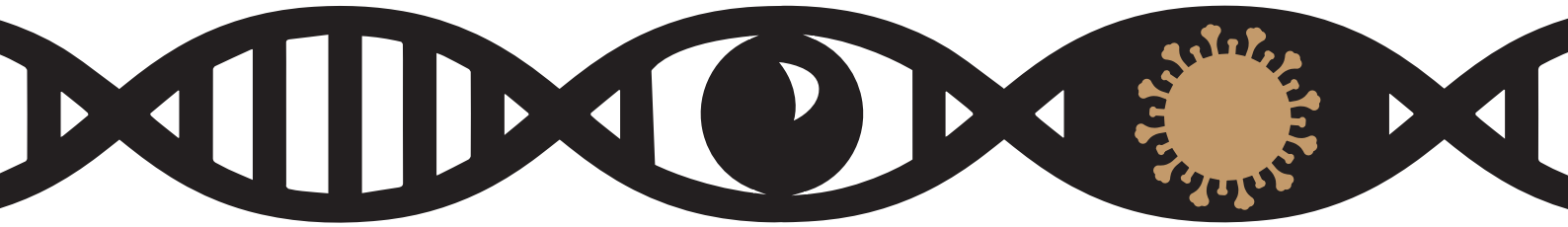

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