HSE National Policy for Consent in Health & Social Care Research

Webinar Launch, 14:30-16:00, Thursday 09th February 2023

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#HSEResearchPlan #ResearchConsent #InformedConsent

Speaker Biographies & What Consent in Research Means to them/ their Areas of Work

Dr Philip Crowley

Dr Philip Crowley is the **National Director for Strategy and Research** in the Health Services Executive (the national organisation that delivers public health services in Ireland). In his previous national health service roles over the last 10 years he was National Lead for Quality and Patient Safety and National Lead for Quality Improvement. He leads on strategic planning, research, population health and wellbeing, global health, human rights and performance reporting to the HSE Board. He is a graduate of the Advanced Training Programme in Healthcare Delivery Improvement, Intermountain Healthcare Salt Lake City Utah. He is a doctor who works part-time as a General Practitioner. He worked for five years in Nicaragua, trained in public health in Newcastle Upon Tyne and worked for 6 years as Deputy Chief Medical Officer in the Department of Health.

@crowley_philip

https://www.linkedin.com/in/dr-philip-crowley-321ba441/

What does research consent in the HSE mean to me and my area of work?

"*Health and social care research is a dynamic, interactive process and it has to be based on trust, respect with the mutual aims of improving health, wellbeing and patient outcomes. The policy, a milestone for the HSE, aims to ensure that impactful research can be conducted safely, ethically, and in compliance with legal requirements, while maintaining the confidence of the participants and keeping them at the centre of the research process*."

Dr Ana Terrès

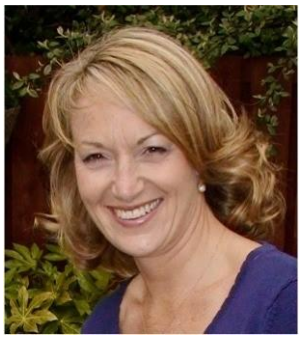
Dr Ana Terrés is the Assistant National Director, **Head of Research and Evidence**, HSE Strategy and Research since 2018. Ana has over twenty five years of experience in research, research administration, support, management, governance and strategic development of research. Before moving to the HSE she was Director of Research at Dublin City University, where she played a key role in the development and implementation of the university research strategy and the restructuring of research support services. Ana received a BSc, MSc and a PhD from the University Complutense of Madrid (Spain) and moved to Ireland as a Marie Curie fellow. She worked in biomedical research at Trinity College Dublin (Department of Clinical Medicine, St. James Hospital) for seven year and she co-founded Innovadis, a TCD biotechnology start-up.

@AnaMTerres @HSEResearch

https://www.linkedin.com/in/ana-terres-b27855a/

What does research consent in the HSE mean to me and my area of work?
"*International evidence has shown that health services where research is formally integrated as part of the organisational structure deliver better care. Research supports best practice and optimal healthcare outcomes. The new HSE National Policy for Consent in Health and Social Care Research will guide high-quality health research in the context of the HSE National Framework for Governance, Management, and Support of Health Research*".

Ms Ann Cullen



Ms Ann Cullen is a member of the **HSE National Research and Development Patient and Public Involvement (PPI) Reference Panel**. She has over 20 years' experience in the provision of research support to Principal Investigators and researchers in the areas of life and biomedical sciences in UCD. She is a graduate of the Irish Platform for Patients' Organisations, Science & Industry (IPPOSI) Patient Education Programme and a member of the Department of Health Cancer Patient Advisory Committee, established under the National Cancer Strategy 2017 -2026. Ann is also a peer support volunteer and patient advocate for the Irish Cancer Society and a facilitator for the National Cancer Control Programme (NCCP), Self-Management in Chronic Disease: 'Cancer, Thrive and Survive' programme. She is passionate about PPI and committed to the principles of advocacy, with the adoption of a PPI-centred approach within health care and health research to empower and give a voice to all research participants in an equal, diverse, inclusive, multicultural Ireland.

linkedin.com/in/ann-cullen-40b36165

What does research consent in the HSE mean to me and my area of work?
"The new HSE National Policy for Consent in Health and Social Care Research, is a progressive and welcome document, which, through its development, placed PPI at the centre of a dynamic policy development process. In doing so, it reinforces the position of the participant at the very centre of the research consent process. It provides guidance for researchers in health and social care, to consent research participants in quality research, which is carried out within a legal and ethical framework and conducted in a consistent way".

Dr Barry Lyons

Dr Barry Lyons graduated in medicine from University College Dublin in 1989, has a BA in philosophy & history (2007), and a PhD in Bioethics & Medical Jurisprudence (University of Manchester, 2011). He practices as a **Consultant in the Department of Anaesthesia and Critical Care Medicine at Children's Health Ireland, Crumlin**, Associate Professor of Medical Ethics and Law at TCD, and **Chair of the CHI Research Ethics Committee**. He is also Director of Patient Safety at the College of Anaesthesiologists of Ireland. He is involved in a number of advisory groups examining consent in clinical and research practice and is a member the HSE Research Ethics Committee Reform Working Group. His research interests relate to the role of negative emotions in medicine and, more generally, the interface between law and medicine.

@BarryLyons66 @COAIrl @CHI_Ireland

What does research consent in the HSE mean to me and my area of work?
"*The paediatric section of the HSE National Policy for Consent in Health and Social Care Research starts with the rights of children. Thus, while parental/ legal guardian consent to healthcare research relating to the child is an essential legal and bureaucratic requirement, researchers must be conscious of their obligation to attend to the rights of the child prior to their involvement in a study. Article 12 of the UN Convention on the Rights of the Child (UNCRC) is of particular importance in this context, as it holds that the views of the child must be taken into account in all matters affecting them. Assuming parental consent, the child's assent (where possible), or refusal to assent, is determinative. The Policy makes it clear that effective information provision, participant understanding, and non-coercion are principles that are as important in respect of children as they are for adults. In essence, researchers should engage with children as active partners in the research process. For researchers interested in children's health and wellbeing, such engagement is likely to have significant benefits. For the child it can bring a sense of increased control, fear reduction, feeling valued, the opportunity to express feelings, and to develop confidence and competence. For the researcher, a child's enhanced sense of solidarity carries an increased likelihood of assent, acceptance of interventions, and improved provision of clinical and social information*".

Prof Peter Doran

Professor Peter Doran is Established Professor of Clinical Trials and **Director** of the newly created **Clinical Trials Institute** at the **University of Galway**. Prof Doran has extensive experience in leading clinical research programmes and was the founding director of the UCD clinical Research Centre. He has also served as Vice-Principal for Research at the UCD College of Health and Agricultural Sciences and Director of the Ireland East Hospital Group Research Network.

https://www.linkedin.com/in/peter-doran-31a21323/

What does research consent in the HSE mean to me and my area of work?
"*The launch of the HSE National Policy for consent in Health Research will have a tremendous impact of health research throughout Ireland. It provides a framework for all investigators to ensure their studies are carried out in a consistent way, with the interests of the patients being priorities. Importantly, this policy also signals to the wider community that research within Irish healthcare is conducted to the highest standards, where the best science sits within a quality framework. This consent policy will ensure we can continue to innovate in healthcare to ensure best outcomes for our patients*"

Prof Gianpiero Cavalleri

Prof Gianpiero Cavalleri is a professor of human genetics at RCSI and **Deputy Director of the SFI FutureNeuro Research Centre of Excellence**. His research team focus on the role of human genetic variation in the development and treatment of disease.

@Futureneuro_ie @RCSI_Research @RCSI_Irl
https://ie.linkedin.com/in/gianpiero-cavalleri-622322137

What does research consent in the HSE mean to me and my area of work?
"*This policy provides important and much needed guidance on current standards for consent in research and how to correctly obtain consent, whilst complying with data protection legislation and ethical values. The information is of fundamental importance to all researchers, from students to experienced principal investigators*."

Dr Jean Saunders

Dr Jean Saunders is a **Consultant Statistician** and the **Director of Claddagh Statistical Consultancy Services Ltd** which provides statistical support and research methodology advice to researchers, pharmaceutical companies and academia together with Health Services in Ireland. She was formerly Director of Centre for Support Training Analysis Research at the University of Limerick (CSTAR@UL) which was funded by the HRB. Jean holds a Degree in Mathematics and Statistics (Hons) from the University of London, a BA in Computing, Technology and Statistics (Hons) from the Open University, a MSc. in Applied Statistics from the Sheffield Hallam University and a PhD in Medical Statistics from the University of Bradford. She is also a Chartered Statistician and Fellow of the Royal Statistical Society UK. She is Vice Chair of the University Hospitals Limerick and HSE Mid-western Area REC and is also Deputy Chair of the National Research Ethics Committee (NREC) Clinical Trials of Investigational Medicinal Products (CT) B Committee (known as NREC-CT B) as well as advising the HSE on the roll-out of the new HSE Reference RECS and contributing to the working group for the HSE National Consent Policy.

What does research consent in the HSE mean to me and my area of work?
"*As a member and Vice-Chair of various health research RECs within Ireland for over 20 years I feel that a clear policy document on (informed) consent is very important particularly after various changes in this area over the years e.g., EU directives, GDPR and national legislation etc. Every health researcher needs to keep themselves fully informed of the current regulations governing the taking and processing of consent. RECs also need to keep up-to-date on appropriate consent processes in order to be able to review research ethics applications and advise researchers as needed*".

Dr Emily Vereker

Dr Emily Vereker is the **Head of National Office for Research Ethics Committees** in Ireland and has oversight of a high performing professional team that supports the national system for research ethics review, now an integral component of the Irish infrastructure for health research. Prior to taking up this interim role, Emily joined the Health Research Board (HRB) in January 2019 as Programme Manager of the Secretariat to the Health Research Consent Declaration Committee (HRCDC), a statutory body appointed by the Minister for Health under the Health Research Regulations. Prior to her career in health research regulation, Emily was the Senior Patents & Licensing Manager in Trinity College Dublin, with specific case management role in life sciences. She gained over 10 years of experience in intellectual property portfolio management, technology commercialisation and collaborative academic-Industry agreements. Prior to working in technology transfer, Emily spent over 5 years as a Postdoctoral researcher at the Montreal Neurological Institute, McGill, Canada. She is a graduate of National University of Ireland, Maynooth and received her doctorate from Trinity College Dublin.

@NREC_Office @HRCDC_Ireland

What does research consent in the HSE mean to me and my area of work?
"*The policy is an important and comprehensive document that is reflective of the evolving regulated research environment in Ireland. The essential safeguards and best practice to obtaining consent and assent for research described in the policy, will support a consistent, ethical and participant-centred approach, inclusive of all individuals of society that may benefit from health and social care research carried out in Ireland*."

Dr Clare Farrell

Dr Clare Farrell has worked in the **Research and Evaluation Unit of the Department of Children, Equality, Disability, Integration and Youth** since 2015, and leads on strategic research and maximising the policy use of data from the Growing Up in Ireland (GUI) study. Clare has been with DCEDIY since 2015 and worked previously in research at the National Council for Special Education, and at the Combat Poverty Agency. Clare is also a member of the Adoption Authority Research Ethics Committee. She has a Masters (Sociology) and a PhD from UCD (2009). Her PhD research focused on health inequalities and the social determinants of health, and was completed with the support of an IRC Government of Ireland scholarship.

@dcediy

What does research consent in the HSE mean to me and my area of work?
"This new HSE policy on consent for research, will be enormously helpful to researchers, particularly those working with children or persons with capacity difficulties. It provides important and valuable guidance on the process of gaining informed parental consent and assent from children. It also offers guidance to researchers on obtaining informed consent for persons who may have capacity difficulties, in-line with the Assisted Decision-Making (Capacity) Act 2015, as amended, which is expected to commence early this year. This Act has been expanded to include participation in health and social care research and provides individuals with the opportunity and support to participate in and benefit from research, in line with their will and preference".

Dr Edel Tierney

Dr Edel Tierney is a **National Research Officer with Tusla Child and Family Agency**. The National Research Office is part of Tusla's Quality and Regulation Directorate. Edel was a member of the HSE National Policy for Consent in Health Research Steering Group. With her colleagues in Tusla she gave particular input on Section 5: Research involving children and young people aged under 18 years. Edel's current research focus lies in finding ways to embed the voice of children and young people in the research activities of Tusla and how this can inform practice and policy. She is interested in the questions of how can research inform and improve our responses to children. How can research make a difference in the day-to-day lives of children and families? And how can the voice of children and families be embedded in this process?

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instagram.com/tuslaireland

What does research consent in the HSE mean to me and my area of work?
"*In the National Research Office, Tusla aims to endeavour to keep child and youth voices at the core of their work programme, and believe that understanding consent for children and young people in the research process is central to this. We plan to endorse this policy as a Tusla policy for research*".

Dr Laura Méchineau-Phelan

Laura Méchineau-Phelan is the **Senior Manager Contracts and Data Governance**, National Research and Development, HSE Strategy and Research. Laura has over 17 years of expertise and experience in research governance, data protection, corporate and research agreements, the interpretation and application of the regulatory framework governing research in Ireland and Europe, the development and implementation of institutional research policies, research commissioning, and international capacity building *(incl. Zambia, Malawi, Tanzania*). She is an active member of the Health Research Data Protection Network (HRDPN). Prior to taking this role, Laura was the Research Manager for the Division of Population Health Sciences of the Royal College of Surgeons in Ireland. She has an excellent track record in pre- and post-award legal and financial management of over 130 National, European and International multi-disciplinary and multi-sites research awards. She has extensive experience in negotiation with a wide range of funders and stakeholders. Her academic qualifications in Sciences, Law and Data Protection provide her with an excellent background in complementary disciplines. She authored two academic theses including in the area of data protection, data management and consent in research involving human participants. The HSE National Research and Development Legal Team were finalist in the Public Sector Lawyer of the year awards 2022.

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What does research consent in the HSE mean to me and my area of work?
"The concept of consent can be complex and daunting to approach and apply for health and social care researchers. Multidimensional and co-existing forms of consent must be addressed to conduct health research that is legally and ethically compliant, meets international best practice standards, and protects the fundamental rights and best interests of research participants. The ***HSE National Policy for Consent in Health and Social Care Research*** *is a comprehensive document that will support health and social care researchers to navigate the various forms and dimensions of consent."*