Partnerships in Trials Methodology - working together for stronger science

Register: https://www.hrb-tmrn.ie/training-education/upcoming-events/

20th October 2023 – Galway Bay Hotel

| Time | Title / Topic | Speaker | |
|-------|--|--|--|
| 09:00 | Welcome Tea / Coffee | | |
| 09:15 | Welcome address | Dr Teresa Maguire Health Research Board | |
| 09:25 | Technology innovation, as a way of building site partnerships | Dr Ronan Fox ICON plc | |
| 09:45 | Co-designing ID trials to make them more inclusive and representative | Stephen O'Hare HIV Ireland | |
| 10:05 | From idea to completion, the role of partners in ensuring reporting guidelines are useful | Dr David Moher Ottawa Hospital Research Institute, Canada | |
| 10:25 | Q&A Panel | | |
| 11:00 | Tea / Coffee | | |
| 11:20 | Investigating the communication of retention strategies in clinical trials | Ellen Murphy University College Cork | |
| 11:25 | Recruiting for an online children's and parents' advisory group internationally - challenges and facilitators | Simone Lepage University of Galway | |
| 11:30 | Developing a model for conducting public and patient involvement in activities in maternal and neonatal trials | Kathleen Hannon Trinity College Dublin | |
| 11:35 | Integrating digital technology into clinical trials | Emer Gunne University College Dublin | |

A total of 4.5 CPD credits have been assigned to this event





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| 11:40 | Opportunities and pitfalls for decentralised clinical trials | Dr Paul Wicks Wicks Digital Health | |
| 12:00 | Trials methodologies priorities | Dr Sinead Holden University College Dublin | |
| 12:20 | Q&A Panel | | |
| 12:55 | Lunch & networking | | |
| 14:15 | The James Lind Alliance: working in partnership with patients and clinicians to set priorities for research | Beccy Maeso James Lind Alliance | |
| 14:35 | When is the stepped-wedge cluster randomised trials a good design choice? | Prof Karla Hemming University of Birmingham | |
| 14:55 | CTU partnerships to improve the conduct of trials through knowledge exchange and innovation projects | Prof Kerry Hood Cardiff University | |
| 15:15 | Madness, magic or mystery - a patient and trials methodology | Roger Wilson Patient Advocate | |
| 15:35 | Q&A Panel | | |
| 16:05 | Awards | | |
| 16:15 | Closing Address | | |
| 16:30 | Close | | |

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Ronan Fox is Senior Vice President in IT R&D at ICON with over 25 years' experience in the application of technology to solve key problems in Health Care and Life Sciences. He has significant experience in leading the delivery of innovative, impactful technology solutions for the industry across multiple domains from bench to bedside. With a PhD in Informatics, one of Ronan's focus areas is the use of technology and data to enable and engage sites, patient, and sponsors to accelerate clinical trials and reduce the burden on our stakeholders.



Emer Gunne is a Health Research Board funded PhD scholar with UCD Clinical Research Centre. Emer completed Graduate Medicine UCD in 2017 and an MSc in Clinical and Translational Research in 2019. She worked as a Research Associate with Children's Health Ireland receiving the award for Research Paper of the year 2022 for her latest publication "An Estimate of the Cumulative Paediatric Prevalence of Rare Diseases in Ireland and Comment on the Literature". Emer is studying under the supervision of Prof Peter Doran (University of Galway School of Medicine) and Prof Michael Keane (UCD School of Medicine), her project is on the use of Digital Technologies in Clinical Trials.



Kathleen Hannon is a HRB-TMRN PhD candidate, based in the School of Nursing and Midwifery, Trinity College Dublin. Her doctoral research aims to develop a model for conducting Patient and Public Involvement activities in clinical trials in maternal and neonatal health. The research will explore stakeholders' perspectives and experiences of PPI in maternal and neonatal clinical trials, including perspectives on recruitment of PPI contributors, facilitating contributors' involvement in trial design and decision-making, and how PPI experience and trial impact is evaluated.



Prof. Karla Hemming is a Professor of Biostatistics at the Institute of Applied Health Research, University of Birmingham, UK. Karla's research interests include how to design cluster and stepped-wedge trials so as to maximise their statistical efficiency and minimise their risk of bias; how to model time and treatment effect heterogeneity in longitudinal cluster trials; and the ethical issues surrounding these pragmatic trial designs, such as ethical oversight and consent. Karla has recently led the CONSORT extension for the stepped-wedge cluster randomised trial; and she is currently leading the extension for the reporting of statistical analysis plans to cluster randomised trials.

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Dr Sinéad Holden is an Assistant Professor in the School of Public Health, Physiotherapy and Sports Science, UCD. She has a special interest in research methodology, transparency and enhancing reporting of research for the benefit of end-users. She has over 65 peer reviewed publications, and a H-index of 26. Sinéad's current methodological research focuses on how we can best integrate technology into clinical trials to enhance their quality and efficiency, and how to increase sustainability of clinical trials. She is currently leading a priority setting exercise to establish future priorities for clinical trial methodological research, together with collaborators from the HRB-TMRN and TMRP.



Prof. Kerry Hood is a Professor of Trials and Director of the Centre for Trial Research which is a UKCRC Registered CTU at Cardiff University. Kerry has over 26 years' experience of applied research in health and social care with a focus on trials, infections and underserved populations. From a governance perspective, Kerry sits on Cardiff University's Open Research Integrity & Ethics Committee and it's subgroups for Clinical Trial Governance and Open Research and is the main methodological assessor for decisions on University sponsorship. Kerry has sat on numerous trial governance committees and has chaired over 12 Data Monitoring Committees for trials in other universities. This includes engaging with funders around continuation of trials which are experiencing challenges and representing a UK funder on a non-UK TSC to represent UK interests.



Simone Lepage holds first class honours degrees in the following: a BSc in biology from the University of South Florida an MSc in biology from Texas A&M University, a BSN from Columbia University in New York and a higher diploma in Midwifery from the National University of Ireland, Galway. Before starting her PhD she was an Evidence Synthesis Ireland fellow for a Cochrane Systematic Review update. Simone's clinical experience is in high dependency and intensive care nursing and pre-, intra-, and post- natal care. Simone's research interests include improving clinical trial methodology and its implementation in healthcare. Her project, The Kid's Trial, will focus on co-creating an online, randomised trial with kids to teach them what randomised controlled trials are, why they matter, and how we conduct them.

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Beccy Maeso is the Executive Lead for the James Lind Alliance (JLA) and an Assistant Director at the National Institute for Health and Care Research, University of Southampton. The JLA initiative was established in 2004 to bring patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 questions that they would like to see answered by research. JLA PSPs provide an important opportunity for the users of research to help shape and inform the research agenda. Beccy has been involved with the JLA for 10 years, overseeing the coordination of all JLA activity, working with a team of JLA Advisers to develop the priority setting method as set out in the JLA Guidebook, and providing guidance to the many PSPs that take place in the UK and across the world.



Dr. David Moher is a senior scientist, Clinical Epidemiology Program, Ottawa Hospital Research Institute, where he directs the Centre for Journalology. Dr. Moher is also a full Professor, at the School of Epidemiology and Public Health, Faculty of Medicine, University of Ottawa. Dr. Moher received an MSc in epidemiology and PhD in clinical epidemiology and biostatistics. Dr. Moher is a fellow of the Royal Society of Canada, and Canadian Academy of Health Sciences. Dr. Moher works in knowledge synthesis; predatory journals; reporting guidelines; and open science.



Ellen Murphy is a PhD student with the HRB-TMRN based at the HRB Clinical Research Facility at University College Cork. Ellen has an undergraduate degree in Public Health and is now doing a PhD in the field of trial communication focusing on the communication of retention strategies in clinical trials. Ellen's work is looking at how retention strategies are communicated in trial protocols, patient information leaflets, investigating trial teams' and trial participants' views and opinions on retention strategies and their communication in clinical trials.



Stephen O'Hare is Executive Director of HIV Ireland, a nationally focused, non-profit, community organisation working to end new HIV transmissions and advance the rights of people living with HIV. He is also Chair of the PPI Community Advisory Board for the Infectious Diseases - Clinical Trials Network Ireland (ID-CTNI). Prior to joining HIV Ireland, Stephen was Executive Director of Transgender Equality Network Ireland (TENI) and, before that, Senior Policy Programme Manager and Director of European Projects at the Irish Council for Civil Liberties (ICCL). Stephen is a qualified barrister and social researcher who has worked extensively on human rights and health-related policy, strategy and campaigns.

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Paul Wicks, Ph.D., is an independent consultant who helps digital health companies generate evidence, revenue, and awareness. Prior to consulting, for 13 years he led innovation at PatientsLikeMe, an online community for over 850,000 people living with medical conditions. Paul has over 185 peer-reviewed publications including multiple decentralized clinical trials, patient-reported outcomes, applications of medical AI, and a dose-response curve for friendship. He sits on the editorial boards of the BMJ, BMC Medicine, JMIR, Digital Biomarkers and The Patient. His Ph.D. at the Institute of Psychiatry (King's College London) explored cognition and neuroimaging in ALS, with a postdoc in psychological consequences of Parkinson's disease. His work has been profiled by the BBC, NPR, CNN, the Wall Street Journal, and the New York Times. In 2011 he was awarded MIT Technology Review's TR35 "Humanitarian of the Year" award, recognized as a TED Fellow in 2012, and joined the inaugural FLIER Program at the Academy of Medical Sciences in 2019.



Roger Wilson was diagnosed with a sarcoma in 1999 and has had six recurrences since. Treatment has involved surgery, including an amoutation, chemotherapy (on an EORTC study) and radiotherapy. His latest surgery in 2013 was bilateral thoracic metastectomy. He has been an active patient advocate since 2002 working within the UK's cancer research community, with a focus on sarcoma. In 2003 he founded and ran Sarcoma UK until it moved to London in 2011 and he was one of the co-founders of Sarcoma Patients Euronet in 2009. He has co-authored many papers on sarcoma, quality-of-life issues and patient involvement. He has been active in the UK and Europe working on professional educational programmes and developing patient involvement in research. Until recently he chaired the EORTC's Patient Panel. He is an Hon President of Sarcoma Patients Advocacy Global Network (SPAGN). He has a particular interest in methodology issues including statistics, study design, PROs, quality of life appraisal and regulatory matters. He does not claim to be a statistician or a methodologist, just an enquiring mind. With PROs (patient reported outcomes), he has been working with the UK's NCRI, the University of Birmingham Centre for PRO Research (CPROR) and with EORTC's Quality of Life Group. He was appointed CBE in the 2011 New Year Honours and holds honorary degrees from the Universities of Sheffield and Lancaster. He has three daughters and five grandsons. By background he was a journalist and TV producer.



