



Letter to the Editor

Establishing an Irish autism research network

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To the Editor,

We are writing to share with you and your readership, a community engagement event that we hosted on World Autism Awareness Day 2021 — ‘Autism Research Thesis In Three’. We wish to share the purpose of this event, the details of the day, and our intent to establish an autism research network in Ireland.

Since 2010, there has been a significant increase in international autism research that is reflected here in Ireland. This research has the potential to further our understanding of the underlying biological mechanisms of autism, to enhance the quality of care and to improve services. This potential can only be translated if the research conducted is relevant and of benefit to the autism community. However, current research has highlighted a disconnect between the research priorities of autism researchers and the autism community. This has been attributed to several factors, one of which is a lack of involvement of the autism community in research (Pellicano *et al.* 2014a, 2014b).

Public and patient involvement (PPI) provides a solution for bridging the disconnect between researchers working on autism projects and the autism community. PPI has been identified as a priority by researchers and the autism community alike, and recent studies highlight the benefits of PPI in terms of improving the quality and relevance of autism research (Fletcher-Watson *et al.* 2019). PPI refers to research carried out ‘with’ or ‘by’ members of the public rather than ‘to’ or ‘for’ them, which helps researchers and the autism community to align on all aspects of research, including setting research priorities, appropriate study design, and dissemination of results. In Supplementary Table 1, we provide a list of PPI resources that are useful guides for building PPI relationships and conducting PPI activities.

An essential component of conducting effective PPI is the development of strong working relationships between researchers and the autism community. Community engagement can be an effective way of establishing these relationships, building curiosity and interest in research, and highlighting PPI opportunities in upcoming projects.

Considering this, we hosted the ‘Autism Research Thesis In Three’ Event, on World Autism Awareness Day 2021, April 2nd, <https://www.tcd.ie/medicine/ThesisInThree>. This event was a collaboration between the Family Genomics Research Group in the Kathleen Lonsdale Institute for Human Health at Maynooth University and the Autism and Neurodevelopmental Research

Group in the Department of Psychiatry at Trinity College Dublin. An aim of this event was to showcase the impactful research ongoing in the Irish autism research community by inviting early-career autism researchers in institutions across Ireland to participate in a virtual ‘Thesis in Three’ competition.

We brought together 13 early-career researchers to present their research in three minutes using one static slide, hosted by Fiana Ní Ghrálaigh and facilitated by Dr Nadia Bolshakova. These researchers came from six Higher Education Institutions across Ireland: Institute of Technology Carlow, University of Limerick, Trinity College Dublin, National University of Ireland Galway, University College Cork, and Maynooth University. Three broad research themes emerged from the day: ‘Living with autism’, ‘Neurobiology of autism’ and ‘Genetics and genomics of autism’.

We also aimed to establish working relationships between researchers and the autism community, which are essential for progressing with PPI in future projects and events. We welcomed a diverse audience of 50–60 individuals (69 registrations) from the autism community in Ireland, from advocates to educators to healthcare workers and researchers and we recognise the benefit that comes with engaging these key stakeholders (Nicolaidis *et al.* 2011; Bottema-Beutel *et al.* 2021). Dr Lorna Lopez hosted an interactive session inviting feedback from the audience on their experience at the event and gathering suggestions for future events. Valuable audience feedback was given in this session on the language used during the event, in particular use of term ‘disorder’. We circulated a post-event feedback questionnaire asking two questions; ‘Do you have any feedback on the event that we could use to improve our future events?’ and ‘Are there any aspects of the event you would like to have in any future events?’. This survey had $n = 27$ respondents with the majority indicating an interest in the research presented and an ‘appetite to hear more’. Responses show demand for more ‘workshop/seminar’ and ‘symposium’ style formats in the future. Feedback highlighted the importance of ‘participation of autistic researchers’, ‘autistic-led research’ and ‘autistic involvement’. This echoes discussion within the autism advocacy community and points to the importance of the efforts that are ongoing to include autistic people in research. These responses will be incorporated into our future activities to ensure a mutually respectful environment and conversation space between researchers and the autism community.

Our final objective of the Thesis In Three event was to propose the establishment of an autism research network. This event highlighted the need, importance, and direction of such a network. We are currently aiming to bring together the autism community to highlight research priorities, provide opportunities for networking

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and build capacity in autism research in Ireland, such as AIMS-2-Trials (Supplementary Table 1). We are guided by the PPI principles and framework as listed in Supplementary Table 1. We invite the readership of the *Irish Journal of Psychological Medicine* to get in contact by emailing autism@tcd.ie to join us in establishing this network.

To conclude, effective engagement is important for establishing relationships between researchers and the autism community, which is a key step in the move towards conducting meaningful PPI. We hope that in sharing this event we highlight the value of research engagement between the autism research community and the broader autism community in Ireland. Our aim is to continue to build and maintain our relationships and partnerships within the community and to progress from engagement to involvement through the establishment of an autism research network. For those that are interested in further PPI resources or information on autism genomics in Ireland, please see Supplementary Table 1 and Supplementary Table 2. Finally, we would like to thank the participants for making this event a success, in particular the members of the autism community, funders, judging panel and presenting researchers.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/ipm.2022.39>

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Conflict of interest. None

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008.

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