

Equality Diversity and Inclusive Research Association

Can a 'Community of Practice' approach be used as a method to widen participant and inclusion of diverse communities in research?

EDIRA
Conference 2023
12th May 2023 in Cardiff
19th May 2023 online



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EQUALITY Diversity Inclusive Research Association

Can a 'Community of Practice' approach be used, as a method to widen the participation and inclusion of diverse communities in research?



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Abstract



It is well documented that communities from diverse backgrounds do not widely participate in research or consultations that are designed to improve policy development and health and social care practice.

The National Library of Medicine published a paper 'Urgent actions and policies needed to address COVID-19 among UK ethnic minorities. The author writes '...what is strikingly clear from early data is the disproportionate effect of COVID-19 on elderly, socioeconomically deprived, and ethnic minority groups, both in the UK and globally. Chastain, D.B., Osae, S.P., Henao-Martinez, A.F., Franco-Paredes, C., Chastain, J.S., Young, H.N., (2020). *Racial disproportionality in Covid clinical trials. N Engl J Med. 383(9), pp. 1-11.*

The EDIRA™ project brings together a diverse group of people with lived experience and experts in the field of rare diseases, research ethics, intersectionality, and equality diversity and inclusive practice. The aim of the EDIRA project is to develop an inclusive research framework for diverse rare disease communities.

This poster presentation will provide an insight into the development of an inclusive research conference applied to principles underpinning the Communities of Practice approach.

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Communities of Practice



A Community of Practice has three characteristics:

DOMAIN: A shared domain brings the communities together. The EDIRA conference shared domain will be **RESEARCH**

COMMUNITY: What brings individuals together to form a community, can be a shared location, background, or experience. The EDIRA conference will include members of the **DIVERSE & RARE DISEASE COMMUNITY.**

PRACTICE: Practitioners from different fields of work including, health, social care, academia, research and pharma are invited to the conference, to focus on **INCLUSIVE PRACTICE.**

Lave, Etienne & Wenger (1991) "Introduction to communities of practice - A brief overview of the concept and its uses". Etienne and Beverly Wenger-Trayner. October 2013. Retrieved 13 June 2020.

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Inclusive Research



The concept of inclusive research was primarily used in the field of Learning Disabilities and was grounded in approaches that include the views of research participants.

Advocates of Inclusive Research propose that its central premise is that those who have in the past so often been the mere objects of investigation themselves become the agents of their own transformation through inclusion and participation.

(Holt, Jeffries, Hall, & Power, 2019).

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The Road to EDIRA



It is well documented that communities from ethnic backgrounds do not widely participate in research or consultations that are designed to improve policy development and health and social care practice.

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Where are you on the road?



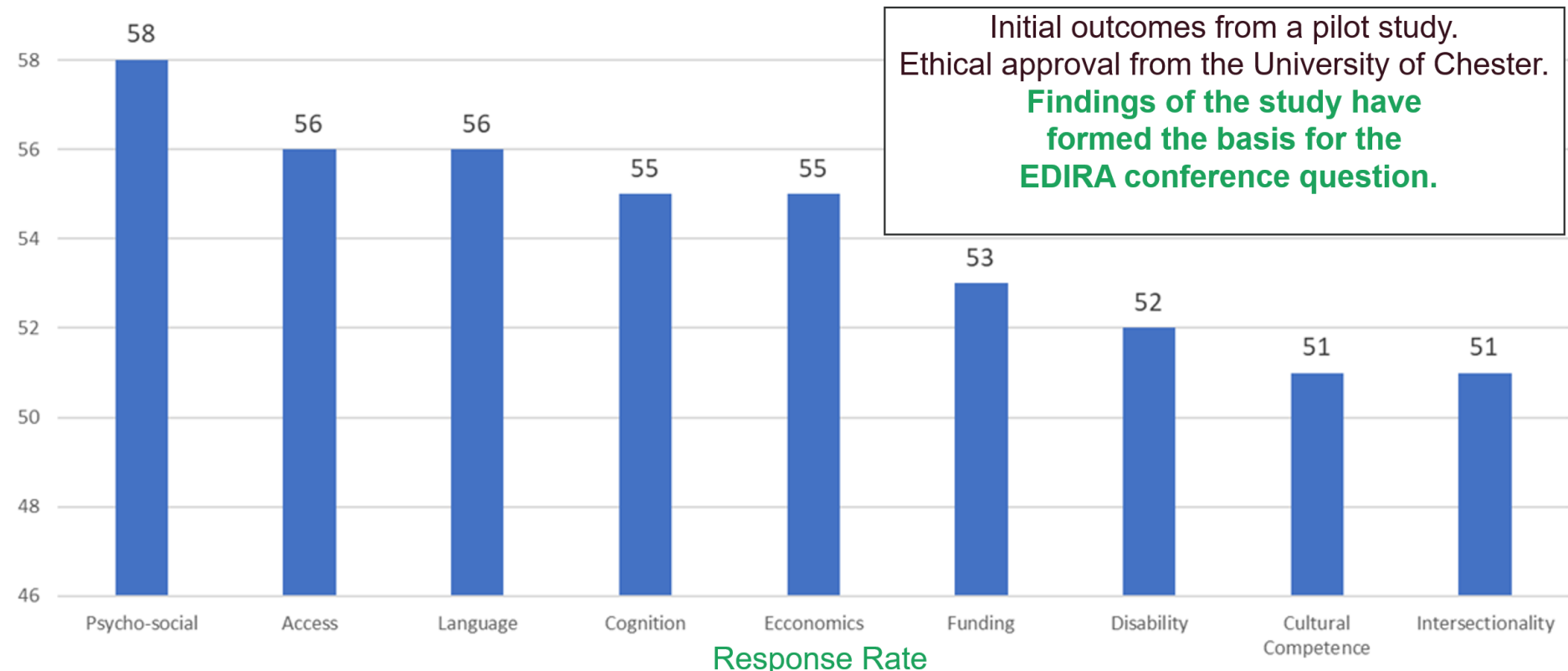
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Barriers to Inclusion



Initial outcomes from a pilot study. Ethical approval from the University of Chester. Findings of the study have formed the basis for the EDIRA conference question.



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Communities of Practice



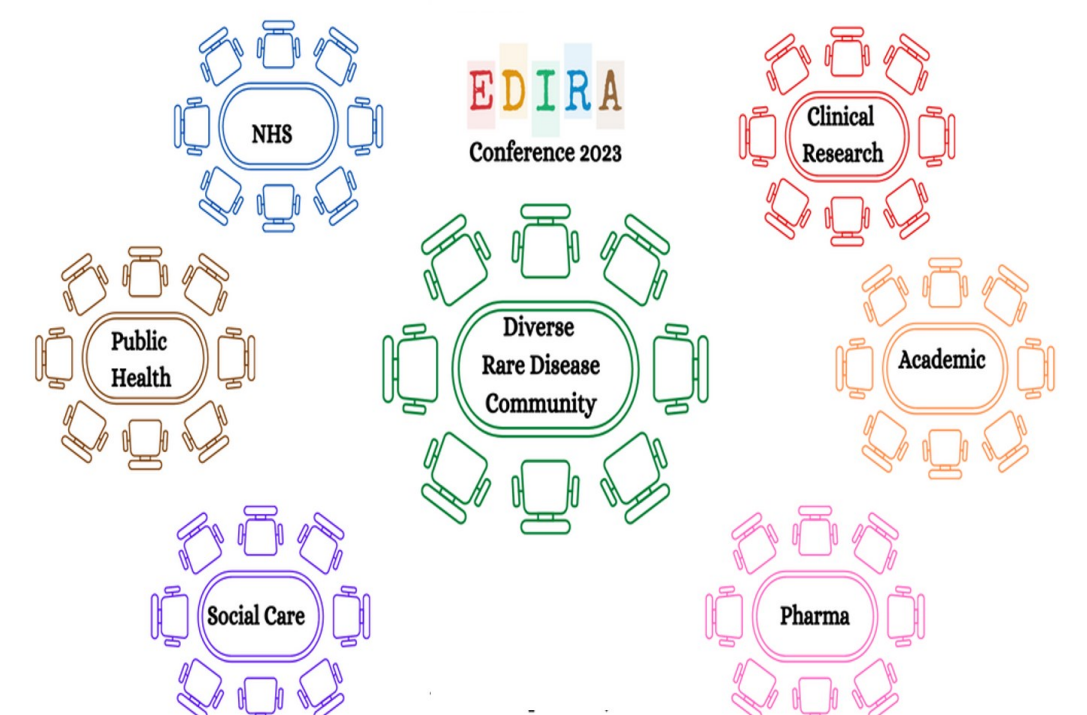
Dr Sondra Butterworth from RareQoL a Associate Professor Dr Andrew Mitchell will co-chair our EDIRA conference.

Each Community Group will address a conference question.

The community groups will include

1. Moderator
2. Facilitator
3. Advocate
4. Scribe

The outcomes of the conference will be written up into a conference paper.



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Raise your voice for inclusive research in rare disease communities!

EDIRA Conference
DIVERSITY · DIALOGUE · DEVELOPMENT

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19th May 2023 Virtual

Register your interest!

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