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Designing an accessible and equitable conference and the evaluation of the barriers to research inclusion for rare disease communities

Diseñar una conferencia accesible y equitativa y la evaluación de las barreras a la inclusión de la investigación para las comunidades de enfermedades raras

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ABSTRACT

Introduction: the United Kingdom Rare Diseases Framework, published in 2021, addresses the lack of diversity in rare disease research, particularly in clinical trials, due to intersecting issues related to rare disease symptoms and health inequalities. The framework outlines the government's commitment to improving the lives of the 3,5 million people living with rare conditions in the United Kingdom.
Objective: the primary objective is to advance equality, diversity, and inclusion in research by developing innovative methods to engage with communities, establish trust, and enhance the participation and voices of underrepresented and underserved communities.
Methods: the conference was held in May 2023, bringing together voices with lived experiences from rare and diverse communities to meet and discuss with established researchers, policy influencers and advocates. The evaluation design was developed using the Program Logic Model and utilised a conference evaluation form on barriers to inclusion.
Results: the Rare Disease Community identifies disability as the primary obstacle to inclusion. Social Care and Public Health Communities and Clinical Research Communities identified a need for more cultural competency. The Diverse Community selected psychosocial issues, and the Academic Community identified funding as the most significant barrier.
Conclusions: the Community of Practice workshops showed the variety of lived experiences and potential barriers people confront for inclusion in research. Listening to individual viewpoints was crucial to creating or repairing community trust. The Academic Community felt that research funders and ethics review boards must adapt their institutional practices to include financial resources for outreach and participation in research design.

Keywords: Rare Diseases; Equality Diversity and Inclusion; Wellbeing; Diversity in Rare Disease Research; Inclusive Research; Quality of Life.

RESUMEN

Introducción: la Infraestructura de Enfermedades Raras del Reino Unido, se publicó en 2021, aborda el falto de diversidad en investigación de enfermedades raras, sobre todo en ensayos clínicos, debido a problemas interseccional relacionados con síntomas y desigualdades de salud de enfermedades raras. La infraestructura resume el compromiso del gobierno de mejorar las vidas de los 3,5 millones de personas que viven con condiciones raras en el Reino Unido.
Objetivo: el objetivo primario es avanzar en la igualdad, diversidad, e inclusión en investigación por desarrollar métodos innovadores para involucrarse en comunidades, establecer confianza, y aumentar la participación y las voces de las comunidades subrepresentadas y subreservidas.

Métodos: la conferencia se llevó a cabo en mayo 2023, juntó a voces con experiencias vividas de comunidades raras y diversidades para conocer y discutir con investigadores establecidos, influenciadoras políticas y defensores. El diseño de evaluación se desarrolló usando el Modelo Lógico del Programa y utilizó un formulario de evaluación de la conferencia sobre los obstáculos a la inclusión.

Resultados: la Comunidad de Enfermedad Rara identifica la discapacidad como el obstáculo primario a la inclusión. Las Comunidades de Cuidado Social y Salud Pública y de Investigación Clínica identifican una necesidad de más competencia cultural. La Comunidad Diverso selecciona problemas psicosociales, y la Comunidad Académica identifica el financiamiento como el obstáculo más significativo.

Conclusiones: la Comunidad de Práctica talleres muestran la variedad de experiencias vividas y obstáculos potenciales que la gente enfrenta de la inclusión en investigación. Escuchar a puntos de vista individuales fue crucial para crear o reparar la confianza de la comunidad. La Comunidad Académica siente que los financiadores de investigación y los comités de ética deben adaptar sus prácticas institucionales para incluir recursos financieros para el alcance y la participación en el diseño de investigación.

Palabras clave: Enfermedades Raras; Igualdad Diversidad e Inclusión; Bienestar; Diversidad en la Investigación de Enfermedades Raras; Investigación Inclusiva; Calidad de Vida.

INTRODUCTION

The lack of equality, diversity and inclusion in rare disease research, particularly in research, has been well documented.[1] Intersecting issues related to rare disease symptoms and health inequalities contribute to low rates of diverse participation, which is an obstacle to understanding the safety and effectiveness of new treatments.[2,3] In light of this, RareQoL, support for rare disease communities, was founded in July 2020 by a small team of advocates and professionals with lived experience and expertise in rare diseases.

In 2021, the Department of Health and Social Care published the new United Kingdom (UK) Rare Diseases Framework.[4] This document details the government's commitment to improving the lives of the 3,5 million people living with rare conditions in the UK.[5] The framework emphasised the need to listen to the patient's voice and identified four key priority areas to bring about change: helping patients get a final diagnosis faster, increasing awareness of rare diseases among healthcare professionals, better coordination of care and improving access to specialist care, treatments, and drugs.

The conference served as a call to action for, and a cornerstone to, the development of the inclusive research framework. This conference was the first of its kind, bringing together voices with lived experiences from rare and diverse communities to meet and discuss with established researchers, policy influencers and more. Inspired by the new framework, RareQoL founded the Equality, Diversity and Inclusive Research Association (EDIRA). The conference aims to encourage the participation of patient voices, especially those from underserved and under-represented communities, in consultations about rare disease service provision. Often, we hear the terms equality, diversity, and inclusion as the acronym EDI. The term equality encompasses the equitable distribution of resources and opportunities and the fostering of a sense of equity. Equality is a structural issue that prevents people from achieving their full potential. Diversity pertains to including and representing a broader spectrum of individuals and their backgrounds within communities or organisations, and inclusion relates to incorporating diverse social, cultural, and individual experiences and considering their needs.

Inclusion is about respecting people for who they are, supported in the publication "Creating Inclusive Research Practices: New Directions for Institutional Research,"[6] emphasising the importance of inclusive research practices in promoting social justice and transformation. The authors argue that involving the community in the research process is vital for building trust and understanding among community members.[6] Inclusive research produces authentic knowledge that can be translated into diverse communities.[7] At the heart of inclusive research is the idea that those often regarded as only the objects of investigation become the agents of their transformation.[8] For this reason, the development of the inclusive approach was guided by the principle that patients should be enabled to participate in decisions that impact the services they receive.

The aim of the conference, associated workstreams and projects is to improve the wellbeing and quality of life for underserved and under-represented communities by promoting equality, diversity and inclusion in research. Community engagement from the rare disease community is essential to building trust and understanding.[8] The conference activity and evaluation of the barriers to research inclusion are essential to the principle of community engagement to build trust and understanding of the rare disease community.[9] The conference evaluation of the top barriers to inclusion used the communities of practice approach.[10] Delegates were pre-assigned to the communities of practice: rare diseases, social care and public health, clinical research, academic and diverse community.

Various experts, not limited to professional expertise but also incorporating wisdom gained through lived experience, were invited to speak and facilitate aspects of the conference. The contacted experts included academics, consultants, patient advocates and others with wide-ranging backgrounds and experiences.

Objective is to identify the top barriers to inclusion from delegates within the communities of practice perspective: rare diseases, social care and public health, clinical research, academic and diverse community.

METHODS

The authors received full ethical approval from the Faculty Research Ethics Committee (FREC) for Health, Medicine and Society (RESC0423-1169) at the first authors' institution for a study exploring inclusive research practice and barriers to inclusion to publish the findings in a peer-reviewed journal. An anonymity pledge was made, with anonymous responses and voluntary participation. Five unique communities were organised by facilitators into interactive workshops using the Community of Practice framework.[10]

The Program Logic Model for evaluation design was used to develop the evaluation approach for the conference. Logic modelling can be utilised as a process and tool for evaluation. It supports the design, planning, communication, evaluation and learning from an event or activity. Logic models can be used as a graphic way to organise information and display thinking. Logic models can be referred to as 'chains of reasoning' or 'logical framework'.[11] The model allows for the connections to be organised between the resources needed to run a program, the actions and activities required to implement the program, and the changes or outcomes to be achieved.[11]

With the phases of the logic model in mind, the workshops asked: 'What are the top three possible barriers to inclusion in research or practice?' (table 1). From a list of nine types of potential barriers to inclusion, each community was asked to select the most critical barrier within their area of practice or experience. Each community group was chaired by a moderator, who was a subject expert and joined by facilitators who were familiar with the community. In order to promote interactive and fair conversation, the facilitator was responsible for encouraging discussion, while the moderator was responsible for ensuring that the discussions were impartial. At the end of the session, the moderators and facilitators reported back the discussions and conclusions to all conference participants.

Table 1. Conference activity
Barriers to inclusion
Access: Researchers and/or Practitioners are often unsure about how to access participants from diverse groups or underserved communities.
Cognition/Understanding: Researchers and/or Practitioners do not always demonstrate how to include participants who may lack capacity.
Cultural Competence: Researchers and/or Practitioners often don't understand that people from different cultures may have different perspectives which create a barrier to participation in research or consultations.
Disability: Researchers and/or Practitioners see mainly the physical aspects of disability and do not understand the social support required for inclusion.
Economic: Researchers and/or Practitioners do not understand that the lack of monetary resources to meet needs can be a barrier to participation in research or consultations
Funding: Researchers and/or Practitioners do not include the support costs associated with inclusive practice.
Intersectionality: Researchers and/or Practitioners do not understand what intersectionality is and what intersectionality does to reduce opportunities for inclusion.
Language: The use of complicated language or the lack of translation in the recruitment process is a barrier to research participation.
Psychosocial issues: Researchers and/or Practitioners do not fully understand that issues such as trust, anxiety and safety are barriers to inclusion.

Before and at the start of the in-person and virtual conference, participants were informed of the code of conduct, which was underpinned by the four ethical principles of the British Psychological Society: respect, competence, responsibility and integrity. This guidance ensured that the conference provided a safe space with equitable opportunities for all attendees to engage and be heard.

DEVELOPMENT
Commitment to Accessibility

The Equality Act 2010[12] was considered throughout the development and implementation of the conference. This meant considering the wants, needs, challenges and barriers experienced by people within each community of practice to ensure the conference was inclusive, diverse and accessible. The conference developed a branding concept and usage strategy organised to ensure consistency, featuring several key considerations applied to all

created materials.

A cohesive colour scheme was developed in the primary colour palette to maximise visual clarity and impact. Two clear, readable and accessible typefaces were used throughout (Courier Prime and Noto Sans). All written content used a large font size with a dark grey or purple tint on a white background. Materials published on social media featured alternative captions to support the use of screen readers.

Considerations of physical accessibility were also factored into the delivery of the conference. It was decided that the conference would be held in-person and virtually, with the virtual conference taking place one week after the in-person event. Stringent considerations were given to the in-person event venue to ensure it was as accessible as possible. Firstly, it was considered that the venue must be in an accessible region of the city centre, with good, reliable and affordable public transport connections, disabled access parking and road-side access for vehicle drop-offs and pick-ups.

Furthermore, the venue needed a conference room with accessible entrances, exits, bathroom facilities, and ample space to enable comfortable and confident movement. Additionally, high-quality audio equipment was utilised to ensure that all speakers could be heard as clearly as possible, with sound and lighting checks performed before the in-person conference.

The chosen venue was in Cardiff, which fulfilled the key suitability and accessibility requirements and had space available to provide a quiet space. As per all content developed for the conference, all signage and presented materials utilised clear, large text with strong colour contrasts to maximise readability. Before the in-person conference, participants were invited to share any access and dietary requirements so that suitable support, food and drinks could be provided.

A production company recorded in-person sessions and subsequently edited and uploaded them to the virtual conference platform SwapCard. This platform provided an accessible, interactive platform to host content and facilitate attendees' interaction. The virtual event combined the pre-recorded sessions with live hosting and interaction using video conferencing software.

Attracting Sponsorship

The successful delivery of the conference was only possible with the support of sponsors. To that effect, reaching out with targeted emails and social media engagement were undertaken to attract relevant sponsors. By sponsoring the conference, these organisations demonstrated their support for rare disease communities while highlighting their commitment to tackling health inequalities and issues of inclusivity in research.

Potential sponsors were invited to support the conference through one of several levels of sponsorship (table 2), all featuring invitations to attend post-conference seminars as part of their package. As a result of this targeted sponsorship campaign, a total of 14 partnering organisations supported the conference. Social media materials and posting guidance were provided to all sponsors to help them demonstrate their support for the conference and promote the event to a broader audience.

Table 2. Sponsorship levels
Levels
Bronze sponsorship offered attendance at both in-person and virtual conferences, with the organisation's logo and company profile featured on the registration site, pre-meeting materials and the conference booklet.
Silver sponsorship also allowed a sponsor's representative to function as a facilitator in the interactive communities of practice sessions.
Gold sponsorship enabled organisations to present a promotional/informative stand at the in-person event.
Platinum sponsorship additionally provided organisations to contribute to developing a publication on inclusive research and awarded the EDRIA Inclusive Research Campaign Partner status for 2023.

RESULTS

Communities of Practice

Each community of practice brought unique perspectives, reflecting their lived or professional experiences. The summary of learnings for each community, presented below, is based on the discussions held at in-person and virtual conferences; the number one barrier to inclusion selected by each community is based only on discussions from the in-person event.

Academic Community

The academic community, comprising individuals with professional experience in academic research, identified funding as the most significant barrier to inclusion. They felt that progress with inclusive research practice could be made efficiently with access to sufficient, appropriately allocated and protected funding. Furthermore, academics felt that greater flexibility was required by funding bodies to allow for subsequent

changes to be made to research practices, if required, to facilitate inclusion as and when new barriers are identified.

The academic community also emphasised the need for greater knowledge and support from relevant ethics committees, by whom research applications must first be approved, to ensure that considerations of equality, diversity and inclusivity (EDI) are built into the research proposal. They considered how, historically, the role of ethics committees has focused on research safety and participant wellbeing, but they identified a growing need also to consider the ethics of inclusion. Therefore, if ethics committees first scrutinised research proposals to ensure that they addressed these factors from the outset, these requirements would filter through to grant and funding applications.

In addition to funding and ethical review, they considered cultural competence and cognition issues, particularly regarding communication, trust and access, to all play a central role in positively engaging with potential research participants.

Clinical Research Community

The clinical research community, comprising individuals with a range of professional experiences in designing and delivering clinical research, considered cultural competence the most significant barrier to inclusion. Many practitioners felt that they faced challenges regarding access to diverse participants.

Trust and other psychosocial concerns were deemed crucial, with intersectionality felt to be embedded in all nine potential barriers. The community, however, felt that language such as 'hard to reach' was too often used to justify a need to explore new methods and approaches. Indeed, language was considered a common barrier, more broadly covering issues not only of cultural competence but also the challenging technical language that often presents a barrier to the general public. This highlighted the need, within clinical training, for greater education in cultural competence and the potential benefits of a more holistic approach to communication and engagement with diverse communities.

Diverse Community

Bringing a wide range of lived experiences of issues surrounding EDI within the rare disease and broader healthcare space, the diverse community felt that psychosocial barriers presented the most significant limitation to inclusion. Principally, this centred on trust issues stemming from historical mistrust within some communities.

The diverse community felt that other issues could be addressed only once trust was shared between participants and practitioners. Specifically, it was emphasised that vocabulary and practices only sometimes easily translate between languages and cultures. The community understood that researchers might experience a fear of 'getting things wrong' but felt that this should not be used as a justification for not trying to bring about change. Therefore, understanding cultural considerations and practices is required to support effective communication, to minimise unnecessary jargon and to reduce the risk of unconscious bias in the translation and interpretation of information.

Social Care and Public Health Community

In social care and public health, practitioners identified a lack of cultural competency as the most significant barrier to inclusion. The community felt that understanding cultural context could not be understated.

They highlighted the potential harms of making assumptions due to a lack of cultural awareness that assuming knowledge will inherently result in exclusive practices. Therefore, there is a need for greater understanding to prevent the need for assumptions. This lack of cultural competence was considered to tie in with psychosocial issues, such as deep-rooted historical mistrust in the pharmaceutical and healthcare bodies. It was considered vital, therefore, to focus on rebuilding trust within communities, which will require access to funds to enable the necessary outreach and engagement. The community felt that if practitioners could increase their cultural awareness and understanding, they would be better advocates for rare and diverse communities. This could help to improve engagement practices meaningfully.

Rare Disease Community

Within the rare disease community, comprising patients and caregivers, considerations regarding disability were perceived to be the top barrier to inclusion within research. It was discussed that this could be physical barriers, such as the absence of suitable lifts within a research setting. It also includes barriers of cognition and the consequences of past trauma. This highlighted the need for research practitioners better to understand the lived experiences of people with disabilities.

The impact of intersectionality was also considered very important since experiences of disability and isolation are often complex and occur in combination. For instance, an individual with a disability or who cares for someone with a disability could also experience chronic pain or fatigue, severely impacting their ability

to adhere to research protocols. This emphasised the potential benefit for research to be moved away from traditional academic or clinical institutions and to be taken out into the community. This fed into considerations of trust, the benefits of working with local advocates to improve it, and the importance of communication before, during and after the research process, using language appropriate for the community being served. Collectively, the rare disease community emphasised the importance of exercising involvement and engagement with humility and a willingness to listen and to learn, therefore valuing the patient for the expert that they are.

DISCUSSION

The first-ever conference in this format with the communities of practice approach provided an open, inclusive and safe space for listening to and learning from different voices within the rare disease space. Several key messages resonated throughout both the in-person and virtual conferences.

The main objective was to identify the top barriers to inclusion from delegates within the communities of practice. The findings were that the Rare Disease Community recognises disability as the main barrier to participation. Disabilities as a barrier to research inclusion have been recognised within the disability research literature as an obstacle to participatory research [13]. The Social Care and Public Health Communities and Clinical Research Communities recognised a need for enhanced cultural competence. The need for cultural competence in underserved communities is supported by previous research.[14,15]. The Diverse Community chose psychosocial difficulties, while the Academic Community named finance and funding as the primary obstacles. This study reinforces earlier findings highlighting the negative consequences of insufficient financial assistance to cover the expenses of those participating in clinical trials.[16,17]

Furthermore, the importance of collaboration and communication between communities was highlighted, for which the conference initiated and facilitated exchanges of ideas and experiences between people who might not otherwise have interacted.[9] Previous studies have primarily focused on removing obstacles to participation in clinical trials. These findings extend the scope of such research by highlighting the importance of community collaboration and communication.[18,19] Through considered, open discussion, participants had the opportunity to reflect on the perspectives of others to challenge their own beliefs and practices. These exchanges were not unidirectional, however. Research practitioners benefited from hearing the voices of the diverse and rare disease communities, and the communities, gained knowledge from practitioners.[7] These discussions revealed the range of lived experiences and potential barriers faced by different people, some common to many, others unique to individuals. Indeed, listening to individual voices was considered foundational in building or rebuilding community trust.[2,3] Alongside these psychosocial issues, the academic community felt that there is a need for institutional change from research funders and ethics review boards to ensure that the financial resources necessary to facilitate outreach and engagement are factored into research design. This included the need to incorporate the costs associated with holistically supporting accessibility to participation, including childcare, translation services and the use of community or home-based settings.

The conference demonstrated the importance for professionals involved in the research process to continually evaluate why research is being carried out, who it is being carried out for and how the process can be improved. These discussions highlighted the need for more inclusive research strategies, which must be based on the voices and experiences of the affected community.

Limitations

The conference evaluation used a convenience sample of key stakeholders and individuals with lived experiences. However, the self-report measures and convenience sampling may have resulted in response bias and socially desirable responses, which could limit the generalisability of the findings.

CONCLUSIONS

The success of the conference and workshops demonstrated the appetite and need for its recurrence. The next conference will focus on showcasing the knowledge gained and changes made, thanks to the involvement of all communities of practice. Following the conference and informed by its learnings, resources will report upon best practices for EDI within research, featuring voices from underserved communities, academics, patient groups and more. All conference attendees were invited to participate in creating these resources, hoping that it too would be a collaborative endeavour employing a patient-led, bottom-up approach.

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CONFLICT OF INTEREST

AM: Nothing to declare; SB: CEO of RareQol Ltd.

AUTHORSHIP CONTRIBUTION

AM contributed substantially to the conception, design, and interpretation, while SB contributed substantially to the conception, design, organisation, and data collection. AM and SB were involved in drafting or revising the article critically for important intellectual content. Finally, both AM and SB approved the final version of the article to be published.

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