



Equality, Diversity and Inclusive
Research Association

Conference 2025



The Book of Doers

Let's COCO:

Collaboration, Outreach, Co-creation, Outcomes



Friday, 7th November, 2025

11:30 – 23:00 GMT



**Edgbaston Park Hotel,
Birmingham**

Edited by

Dr Sondra Butterworth, CEO, RareQoL and EDIRA Co-Chair

Dr Andrew Mitchell, Associate Professor, University of Chester and EDIRA Co-Chair

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Introductions

The Book of Doers is a powerful collection of case studies carefully selected and brought together by EIDIRA Co-Chairs Dr Sondra Butterworth and Associate Professor Dr Andrew Mitchell, with the support of Costello Medical. The case studies were presented at the Equality, Diversity, and Inclusive Research Association (EDIRA) conference:



Dr Sondra Butterworth
Community Psychologist
CEO, RareQoL



Dr Andrew Mitchell
Associate Professor
University of Chester



Dr Sondra Butterworth is the **Founder of RareQoL**. She is a community psychologist, educator, mixed methods researcher, mentor and coach. Sondra brings expertise in inclusive research, leadership development and diversity training. [RareQoL](#)

Dr Mitchell is an **Associate Professor of Mental Health Research at the University of Chester, UK**. He is a registered Mental Health Professional and a Chartered Psychologist. He co-chairs the research association EDIRA and speaks for inclusiveness in research and research ethics.



DIVERSITY • DIALOGUE • DEVELOPMENT

Equality, Diversity and Inclusive Research: The EDIRA 2025 Conference

About RareQoL

RareQoL, a not-for-profit social enterprise providing **support for rare disease and ethnic minority communities**, was founded in July 2020 by a small team of advocates and professionals with lived experience and expertise in rare diseases and health inequalities. The organisation collaborates with academics and healthcare, pharmaceutical and public sector bodies to undertake community-based research, deliver consultancy, training, and coaching services, and offers volunteer opportunities and mentorship for students.

With their heritage rooted in the lived experience of a rare disease family navigating long-term health conditions and the realities of health inequality, RareQoL understand firsthand the barriers faced by those living with rare diseases. Through innovative research, advocacy and education, RareQoL empower individuals and organisations alike – their **inclusive networks and collaborative initiatives** ensure that everyone's voice is heard and valued on the journey toward better quality of life (QoL).

The Need for the EDIRA Conference

The lack of diversity in rare disease research, particularly in clinical trials, 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.^{1,2}

In 2021, the Department of Health and Social Care published the new UK Rare Diseases Framework.³ This document provided details about the government's commitment to improving the lives of the 3.5 million people living with rare conditions in the UK.^{3,4} The framework emphasised the need to listen to the patient voice and identified four key priority areas to bring about change:

1. Helping patients **get a final diagnosis faster**
2. **Increasing awareness** of rare diseases among healthcare professionals
3. Better **coordination of care**
4. **Improving access** to specialist care, treatments, and drugs

The framework also included underpinning themes. The “patient voice” was a core underpinning theme, recognising the vital role of lived experience in shaping effective policy and services.

Inspired by the new framework, RareQoL founded the Equality, Diversity and Inclusive Research Association (EDIRA) joined by Dr Andrew Mitchell as EDIRA Co-Chair. The campaign aimed to promote the inclusion of patient voices, particularly those from underserved and under-represented communities, in consultations about rare disease service provision.

EDIRA brings together a dynamic network of partners – including health professionals, researchers, patient advocates, pharmaceutical leaders and academic institutions – to collectively address barriers to inclusion in research. This collaborative community of practice fosters a safe environment for shared learning, capacity-building and the co-design of solutions that prioritise equality, diversity and

inclusion. By leveraging the expertise of EDIRA's partners, they advance participatory methodologies and champion inclusive practice across the rare disease landscape.

Inclusive research produces authentic knowledge that can be translated to diverse communities.⁵ Therefore, a specific aim of the EDIRA campaign in 2023 was to develop an inclusive research framework, which would provide practical guidance, obtained through collaboration with diverse rare disease communities, healthcare and research practitioners. At the heart of inclusive research is the idea that those who have often been regarded as only the objects of investigation instead become the agents of their own transformation.⁶ For this reason, the development of the inclusive framework was guided by the principle that patients should be involved in making decisions that impact the services they receive.

RareQoL hosted the first EDIRA Conference in May 2023. 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 experience from rare and diverse communities to meet and discuss with established researchers, policy influencers and more.

Through its Rare Community Network (RCNet), EDIRA further extends its reach to, and actively engages with, seldom-heard voices in rare disease and minority communities. Outreach activities include targeted engagement, culturally sensitive communications and community-led forums that empower individuals to share lived experiences and inform research priorities. This inclusive approach aligns with the INCLUDE guidance, the UK Rare Diseases Framework and NHS commitments to patient partnership and health equity.^{3, 7, 8}

The culmination of these efforts is the development and dissemination of good practice guidance and evidence-based publications.^{9, 10} These outputs provide actionable recommendations for building trust, improving inclusion, and raising the patient voice in research and healthcare delivery.

EDIRA 2025 Conference: Let's COCO

As challenges persist for those living with rare diseases, especially in marginalised and underserved groups, EDIRA's **Let's COCO** (Collaboration, Outreach, Co-creation, Outcomes) event shines a light on the transformative power of patient engagement and truly inclusive research. By elevating diverse voices and showcasing real-world solutions, EDIRA conferences help to build a more equitable future in health, education and research.

'**Let's COCO: Celebrating the Doers**' is an uplifting event from the Equality, Diversity and Inclusive Research Association (EDIRA).

COCO with EDIRA by:

- **COLLABORATING** with communities of practice
- Redefining **OUTREACH** strategies
- **CO-CREATING** using diverse approaches
- Seeing impactful **OUTCOMES**



This hybrid event brings together people from research, health, education and community sectors to recognise and celebrate those making a real difference in equality, diversity and inclusion – especially for rare disease and marginalised communities.

The EDIRA Partners have collaborated with innovative teams who have addressed issues of health equity and inclusion. They have made a significant impact on quality of life for diverse and underserved communities accessing health services, and for rare disease patients and families. Here, the aim is to celebrate them and those working to achieve the same goal, learning from their innovative work.

During this event, case study presentations from our EDIRA Partners, collaborators, and sponsors showcase real-world examples of:

1. **Equality, Diversity, and Inclusion (EDI):** Tackling barriers, building trust and promoting public participation and engagement for all communities.
2. **Rare Disease Advocacy:** Elevating the voices and lived experiences of rare disease patients, and advancing narrative-based, trauma-informed approaches.
3. **Health Education:** Raising awareness of cultural competence and rare disease issues, and supporting inclusive, accessible education for healthcare professionals and the public.
4. **Inclusive Research:** Promoting health literacy, patient-centricity and diversity in research and clinical trials through innovative, participatory methods.
5. **Service Innovation and Improvement:** Advancing practical solutions, digital health and co-designed services to improve quality of life and care for all.

This event aligns with the ambitions of the NHS' 10-year Plan, which places patient voice and health equity at the heart of healthcare transformation.¹¹ EDIRA supports the Plan's vision for a more equitable, responsive and patient-centred health system.

Special Thanks

We must give a special thanks to Rose Francis our RareQoL Project Manager whose support contributed to the success of this project.

Let's COCO and Celebrate the Doers!

EDIRA Case Study

Inclusive Research

Enhancing Equality, Equity, Diversity and Inclusion in Rare Disease Research

Contributors: Andrew Mitchell & Sondra Butterworth

Background: Inclusion of underrepresented rare-disease communities in research remains limited, threatening representativeness and equity.

Mission statement: Our mission is to foster trust with rare disease and underserved communities by bringing together researchers, charities, and advocates. We are dedicated to building meaningful relationships and promoting equitable participation and inclusion in access to support and interventions. We strive to enhance diversity in research, ensuring that the resulting data accurately reflects the community we serve.

Collaboration: This presents the findings of a study involving smaller charities and community advocates from the Rare Community Network (RCNet) and the Equality, Diversity, and Inclusive Research Association (EDIRA). Charities and community advocates play a vital role in the rare disease community. These partner organisations served as both gatekeepers and collaborators in the current study. The published paper can be found [HERE](#).

Outreach: The primary objective of this project and collaboration was to build trust among the rare disease community, researchers, charities, and advocates. Central to our mission is our dedication to developing effective outreach and engagement strategies. We aim to cultivate meaningful relationships, ensuring equitable participation and inclusion in access to support and interventions. Also to promote diversity in research to ensure that data accurately and authentically represent the needs and experiences of the community.

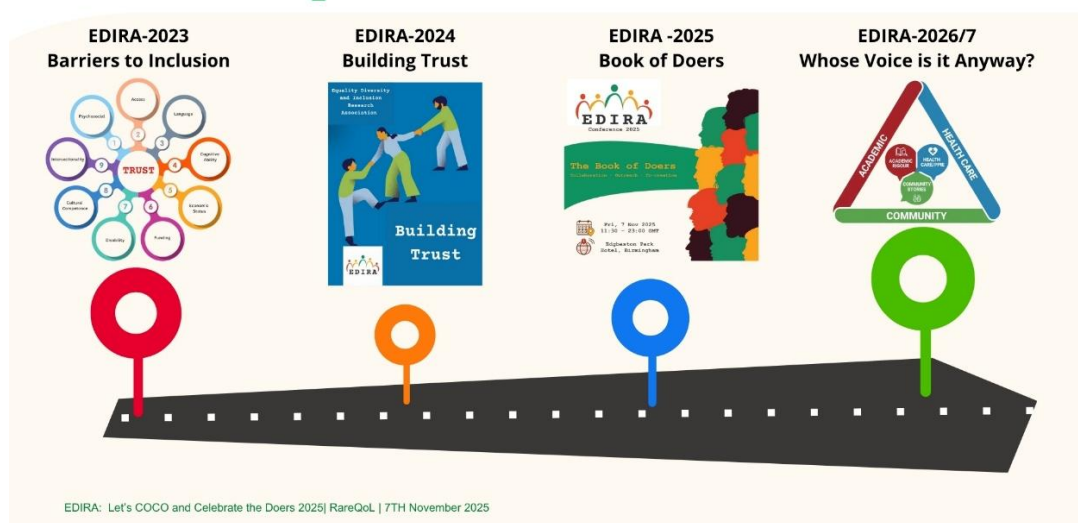
Co-creation: A mixed-method study was proposed to gain insights into the unique experiences, challenges, and needs of individuals living with rare diseases. During two consultation meetings organised by EDIRA, key issues and components were identified. The resulting questions informed the development of the research tool, accounting for various stakeholder categories. The aim is to build upon these findings in collaboration with the community as co-participants.

Outcomes: The findings from the present research highlight views and opinions from the rare disease community on equality, equity, diversity, and inclusion in research, and, importantly, the barriers to

participation in research. The present findings extend the scope of such research by focusing on participation in all types of research with the rare disease community. The study uncovers several complex issues around the low levels of diverse participation and inclusion in research: overcoming these barriers holds the potential to develop new treatments for the groups that are most in need and under-resourced, offering hope and optimism for the future; a list of actionable recommendations based on the findings regarding participation and inclusion in research includes fostering trust through transparent engagement and collaboration; providing research materials and communication in multiple languages to reach a broader audience; offer financial assistance or compensation for participation in research to alleviate economic barriers that may prevent involvement; establish cultural frameworks to address identified barriers to participation and ensure the protection of vulnerable populations, as well as guidance for including adults who may lack standard consent processes in research.

Look to the future: The EDIRA case study charts a journey from identifying Barriers to Inclusion (2023), Building Trust (2024) and celebrating action in the Book of Doers (2025). Next, EDIRA will launch the “Whose Voice Is It Anyway?” campaign and develop interconnected communities of practice across (1) community (2) academic and (3) healthcare settings, ensuring diverse voices shape future research, ethics and impactful outcomes. Future research should focus on equity by providing equal access to resources and opportunities to participate in research, ensuring that the process and ethical considerations, address barriers that inhibit those within rare disease and underserved communities from participation, by addressing well-known barriers. These may include knowledge around capacity to consent; understanding the patient need, language barriers, cognition, financial considerations and most importantly trust.

Our Roadmap to Success: What Next



The Book of Doers

This **Book of Doers** captures and celebrates the stories, strategies and practical wisdom of those leading the way in inclusive research and patient engagement. The book is more than a collection of case studies – it is a **living resource and practical toolkit** for anyone working to make health research, care and advocacy more inclusive, equitable and effective. It is organised around **five key areas of expertise and action**:

Area	Description
Equality, Diversity, and Inclusion (EDI)	Dismantling barriers to inclusion, building trust and fostering meaningful patient and public involvement and engagement (PPIE). Diverse perspectives shape every stage of research and service delivery.
Inclusive Research and Practice	Innovative methods to promote health literacy, patient-centricity and diversity in clinical trials. Participatory research and advocacy groups build trust and ensure research is accessible and relevant.
Medical and Healthcare Education	Raising awareness about cultural competence and rare disease inclusion in medical education. Diversifying curricula and equipping professionals to serve all populations with empathy and expertise.
Rare Disease Advocacy	Elevating the voices of those living with rare diseases. Narrative-based and trauma-informed approaches shape policy, improve support and drive the patient voice as a catalyst for change.
Service Improvement and Innovation	Practical solutions and positive change, drawing on frameworks such as the UK Rare Diseases Framework ³ and Anti-Racist Wales Action Plan . ¹² Applying behavioural science, digital health, service co-design and quality improvement for rare disease communities.

Case Studies

Rare Disease Advocacy

1. Childhood Dementia in Rare Disorders



Stakeholders: Amy and Friends Charity in collaboration with the **Childhood Dementia Initiative** and **Erasmus University**

Contributors: Jayne Hughes (Amy and Friends), Dr Arjan Theil (Erasmus University), Mark Hughes, Megan Simpson, Joshua Parry

Background: Cockayne Syndrome is a rare genetic disorder, characterised by small stature, microcephaly (smaller-than-normal head), developmental delay and premature ageing. Amy and Friends is a non-profit organisation supporting young people and their families or carers suffering from DNA repair disorders, such as Cockayne Syndrome, in childhood. With their network of dedicated staff, volunteers and expert medical professionals, they provide practical and emotional support, information and education whilst promoting and engaging with groundbreaking research in the UK and internationally.

Amy and Friends mission statement: 'We are committed to improving the lives of individuals affected by DNA repair disorders in childhood, with compassion and through a family-centred approach.'

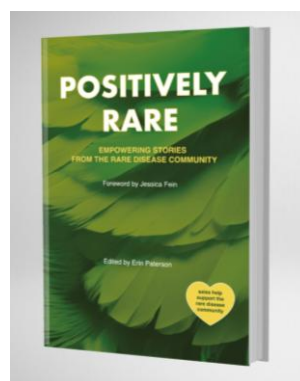
Collaboration: Amy and Friends have collaborated with Erasmus University in researching childhood dementia in Cockayne Syndrome. They have also formed bonds with Childhood Dementia Initiative, an organisation aiming to accelerate the development of treatments for children with dementia and improve accessibility and quality of care. A collaboration with Advanced Therapies Wales is also in development. Amy and Friends worked closely with families of children affected by dementia to produce case studies and Dr Arjan Theil from Erasmus University provided scientific research.

Outreach: Amy and Friends have a large collaborative network of clinicians and scientists worldwide and have worked closely on this project with families from North Wales, Texas and Ipswich.

Outcomes: This project details the progress of dementia in young people with Cockayne Syndrome and this has been scientifically researched in mouse models, showing tangling in neurons when dementia is apparent. The project has propelled forward one of the organisation's key goals – that childhood dementia eventually be added to the list of symptoms – bringing recognition to patients.

Look to the future: Amy and Friends hope to work more closely with NHS Wales and Advanced Therapies Wales and are confident that their growing knowledge base and ongoing research will act as a strategic blueprint for other organisations.

2. The 'Positively Rare' Book



Stakeholders: PTENUKI, Lemonade Press

Contributors: Erin Paterson (Lemonade Press), Kelly Kearley (PTENUKI), Adrienne Shirk, Andy Sinclair, Courtney Wells, Daniel DeFabio, Dunstan Nicol-Wilson, Erika Boulavsky, Halsey Blocher, Hannah Remillard, Heather Halsey Dye, Jen Cueva, Jenny Jones, Joanne Paquette, Jocelyn Wong, Joe Kammers, Kerri Mauer, Kimi Sorensen, Laura Will, Maddie Gillentine, Melissa Ryant, Tessa Koller

Background: Many people from the rare disease community have experienced medical gaslighting and toxic positivity, often leaving them feeling isolated, alone and misunderstood. Erin Paterson founded Lemonade Press because she wanted to create a space for people's voices to be heard and to empower patient communities. This publishing house gives these communities the opportunity to share not only the hardships they have been through, but the ways they have grown, the lessons they have learned and the good things about their lives. Erin wanted to give people the opportunity to experience the catharsis of storytelling.

Mission statement: 'Our stories are important. Lemonade Press gives people the opportunity to share them.'



Collaboration: Positively Rare amplifies the collective voice of the rare disease community and helps eliminate the stigma and fear of living with a rare disease. The stories in Positively Rare are written by people from the community in their own voices.

Outreach: The creators reached out to their rare disease community network to find authors and actively put together a team to represent a range of people affected by rare disease – patients, family members, carers and more. They continue to work tirelessly as a team to reach the rare community with the book, taking it to events, advertising it on social media and talking about it on podcasts.

Co-creation: Erin from Lemonade Press organised 20 authors to come together to share their rare disease stories; Kelly Kearley (with PTENUKI) sponsored the book and wrote one of the chapters, to highlight how living with a rare disease affects mental health.

Outcomes: Through their stories of triumph in the face of adversity, the authors spread the word that they are **‘so much more than our rare disease’**, bringing hope and help to all those affected by them and ensuring they are not alone in their journey. The book acts as a resource for medical professionals to better understand the impacts a disease has on families and improves patient health by empowering people to seek appropriate support and medical care.

“This book is not just about rare diseases; it’s about finding purpose, strength, and love in life’s most challenging moments. An inspiring and life-changing read that gives voice to the often unheard.”

– Rob Haselberg, Huntington’s disease gene carrier and rare disease advocate

Look to the future: 50% of the profits go towards Global Genes, an international charity that helps support all those affected by a rare disease, so the book continues to support the rare disease community in its sales. Upcoming projects highlight specific rare diseases in similar formats, aiming to give a voice to different disease communities by telling their stories in their own words.

Inclusive Research

3. Addressing Ethnic Inequalities in Cancer Diagnosis



University
of Exeter

Stakeholders: University of Exeter, The Redeemed Christian Church of God Exeter, FORCE Cancer Charity, Inclusive Exeter

Contributors: Dr Tanimola Martins (University of Exeter [UoE]), Lucy Kirkland (Exeter University co-PI), Joy Okumbor (Director Inclusive Exeter), Samuel Odewunmi (The Redeemed Christian Church of God Exeter)

Background: Previous research has revealed poorer outcomes and satisfaction with health services in Black and Asian groups, for both breast cancer and prostate cancer.¹³ Dr Tanimola Martins is a pioneer in the field of cancer diagnostics and has produced multiple publications on ethnic inequalities in diagnosis of cancer.¹³⁻¹⁵ Their work has demonstrated that Black and Asian patients are waiting up to a month longer than White patients for some cancer diagnoses, from the point at which they first seek medical help. Building on this existing work, the project team were awarded the University of Exeter Engagement Award for raising public awareness of cancer and sparking meaningful conversations around the topic.

Project mission statement: 'Join us in working towards reducing ethnic inequalities in cancer diagnosis in primary care together.'

Collaboration: UoE are building a relationship with the Redeemed Christian Church of God community and local hospitals in Exeter to acknowledge the ethnic disparities in cancer and Black African, Caribbean and Asian heritage communities' underrepresentation in cancer research.

Outreach: The central aim of this project is the development of trust between the local community, researchers and health and social care services in Exeter. At the heart of their efforts is a commitment to fostering meaningful relationships and promoting equity in access to healthcare, as well as encouraging diverse research participation. The UoE are delivering the Community Conversation – a project including a series of engagement activities designed to raise awareness about the early warning signs of cancer, support better understanding of how to navigate the NHS and local support systems and encourage greater inclusivity in health research. Through these conversations, they aim to

empower individuals – particularly those from underrepresented or marginalised groups – to participate more confidently in their health care and in research that shapes the future of services.

Co-creation: The community leaders were co-applicants in funding for the project. They are leading participant recruitment, helping to shape content and delivery of the agenda and co-facilitating conversations.

Outcomes: Based on this collaboration, the UoE have heard from individuals who, for the first time, responded to cervical screening invitations and others who sought help from their GP for previously ignored bodily changes. Additionally, there has been a noticeable increase in local interest and willingness to participate in health-related research initiatives.

4. SHE HEALS: the Supporting Health Equity through Holistic Empowerment, Art, and Lived Experience study



Stakeholders: Institute of Global Health Innovation (IGHI) - Imperial College London, Marylebone Project, Central London Healthcare (CLH), National Institute for Health and Care Research (NIHR)

Contributors: Jodie Chan (IGHI), Sarah Hancock (Marylebone Project), Dr Chatsuda Chierakul (CLH), Miriam Kennedy (Marylebone Project), Dr Phoebe Averill (IGHI), Dr David Sunkersing (IGHI), Anna Lawrence-Jones (IGHI)

Background: People experiencing homelessness have shorter life expectancies, poorer physical and mental health and less access to healthcare than the general population.¹⁶ For women experiencing homelessness, the average age of death is estimated at 43, which is 2 years younger than the estimation for men and nearly half the life expectancy of women in the general population.^{17, 18} Many

homeless women are survivors of abuse, and more research is needed to provide specialised support for this group in trauma-informed spaces.

However, current research practices can be harmful for the women who take part. Short-term projects where researchers ask participants to answer personal questions and recount traumatic events without taking the time to build trust and rapport do not offer a safe environment for women to authentically share their experiences.

Project mission statement: This project aims to create a psychologically informed environment for research which empowers women experiencing homelessness to safely and meaningfully share their experiences and priorities on their own terms to influence research, policy and practice.

Collaboration: Imperial's Institute of Global Health Innovation has partnered with the Marylebone Project (the UK's oldest and largest women's homelessness organisation) and Central London Healthcare (a federation of 33 general practices in Westminster) to understand how they can safely and meaningfully involve women experiencing homelessness in their research.

This project was funded through NIHR's Developing Innovative, Inclusive and Diverse Public Partnerships scheme (NIHR207101), which recognises that most funding applications remain researcher-generated despite a big push for public involvement. This project flips this narrative – it centres a problem raised by community partners and solutions developed by service users.

Outreach: The team spent the first two months holding Lunch and Learns at the Marylebone Project, where service users could meet the team and learn about the project in an informal setting. By focusing on relationships first, rather than deliverables, they built a sense of community that greatly improved future discussions.

Co-creation: For eight months, the project collaborators met with eight experts by experience on a fortnightly basis to explore the barriers to getting involved in research and identify how to remove those barriers through psychologically informed approaches. This has led to the co-production of a 'psychologically informed environment (PIE) for research'.¹⁹ They then worked with the experts by experience to co-produce a research study designed to test this PIE approach.

Outcomes: The co-produced SHE HEALS study aims to explore what holistic, trauma-informed healthcare looks like for women at risk of or experiencing homelessness through participatory arts-based approaches. Participants have used photography to represent their current experiences of healthcare and have created drawings and collages to visualise what they would like healthcare to look like in the future. Qualitative feedback shows that participants felt safe, supported, and able to authentically share their thoughts thanks to the PIE approaches implemented.

Look to the future: The team are currently exploring opportunities to share the art from this project with healthcare professionals to encourage a culture change around patient-centred care. They will also produce a guide on PIE research to support future research with inclusion health groups.

5. The REP-EQUITY Toolkit



Stakeholders: University of Birmingham, National Institute for Health and Care Research (NIHR) Applied Research Collaboration West Midlands, NIHR Birmingham Biomedical Research Centre

Contributors: Dr Ameeta Retzer, Bircan Ciytak, Foram Khatsuria, Juma El-awaisi, Isobel M. Harris, Philip N. Newsome, Melanie Calvert, Laura Chapman, Tony Kelly, Jenny Richards, Emily Lam

Background: Without representative participation, clinical trials cannot accurately reflect how medical interventions impact patients – introducing bias and affecting research quality. This can result in reluctance to offer treatments to specific groups, contributing to health inequality. Backed by NIHR Biomedical Research Centre (BRC) funding, researchers at the University of Birmingham have developed the REP-EQUITY toolkit to guide representative and equitable inclusion in clinical research.

Collaboration: Lead author and Associate Professor Dr. Ameeta Retzer of NIHR Birmingham Biomedical Research Centre – a mixed methods researcher with expertise in outcome methodology, applied health, health inequalities and public health, and research equity – was working as a researcher funded by the Birmingham BRC and the Applied Research Collaboration (ARC) West Midlands. Together with Professor Melanie Calvert, they secured a small amount of BRC funding, and both the BRC and ARC kindly supported the development of this initiative.

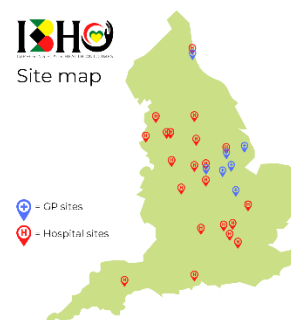
Outreach: Laura Chapman, lived experience manager at the Birmingham BRC, supported involvement of people with lived experience who had an interest in equality, diversity and inclusion in this project. This involved individuals from a range of backgrounds across England.

Co-creation: People with lived experience joined the research team and were involved in every stage of the project, providing their advice, and project plans were adapted based on their feedback. The final toolkit was developed in partnership with lived experience colleagues.

Outcomes: The toolkit describes seven key questions for investigators to consider when recruiting people to take part in their trials, guiding the inclusion of relevant underserved groups. This work has resulted in a peer-reviewed publication in Nature Medicine²⁰ but most importantly, it has been adopted as part of the [NIHR Research Inclusion Toolkit](#). Both toolkits guide representative and equitable inclusion in research and their use may promote trust between communities and research institutions and improve the applicability of research findings.

Look to the future: A system to track its use is in development, and the researchers are also working on new projects to test and implement the toolkit. One of these is funded by the Birmingham BRC, and the other is funded by the Stroke Association.

6. Embedding Improving Black Health Outcomes (IBHO) Recruitment in Community Organisations



Stakeholders: [NIHR BioResource](#), [BHA for Equality](#)

Contributors: Hannah Stark (NIHR BioResource), Donna Miller (BHA), Sandra Opping (BHA)

Background: People of African ancestry are known to have increased genetic diversity compared to other populations but are under-represented in large genome-wide association data sets. Such disparity limits the ability to draw conclusions from genomic data that can be applied to Black communities.²¹ This has implications for the understanding of prognosis and effective treatments for affected individuals.

The IBHO BioResource is a new research programme, led by the NIHR focused on improving the knowledge and understanding of health conditions and their unique impacts on UK Black communities. With the aim of addressing the under-representation of individuals of African ancestry in research, the IBHO BioResource will aid investigations into health questions of importance to UK Black communities.

Collaboration: BioResource has started a new collaboration with BHA for Equality to establish a programme of community engagement and outreach. They have also started a collaboration with Shape History to create a marketing campaign driven and delivered by people with lived experience.

Outreach: IBHO has already recruited over 4,000 participants and is open in primary care, secondary care, community and mental health hospitals. Three Research Delivery Networks are using their research buses to support community recruitment. BHA has received an NIHR grant to drive community engagement and participant recruitment to IBHO in Manchester. The grant will fund a Community Engagement Worker to support outreach in Black communities. BHA's potential reach is over 9,000 individuals in a year via engagement activities, events and community radio stations.

Co-creation: Working with several community groups and people with lived experience, BioResource are creating engagement materials that address key concerns from communities and use imagery that is reflective of the communities.

Outcomes: The impact of the partnership with BHA will be to develop a model of recruitment that can be adapted in other regions of England. Embedding recruitment in community organisations will make IBHO a research programme that has been developed and delivered with, and held to account by, the communities it aims to represent.

Look to the future: IBHO aims to recruit at least 5,000 people from across Black communities in the UK, continue collecting genetic and questionnaire data, and to link this to clinical, demographic and self-reported lifestyle data to better inform future research.

7. Understanding Surgical Outcomes in Poland Syndrome



Stakeholders: PIP-UK, Birmingham Children's Hospital, Birmingham Newman University

Contributors: Janelle Kolas (Birmingham Newman University), Sam Fillingham (PIPUK), Dr Kim Daybell (Barts Health NHS Trust), Dr Andrea Jester (Birmingham Children's Hospital), Professional Volunteers with Medical/Scientific Background (Focus Group Facilitation, Data Analysis), Volunteers with Lived Experience of Poland Syndrome (Co-researchers), PIP-UK Community Members (Participants)

Background: Poland Syndrome is a rare birth difference. This syndrome occurs during foetal development with no known cause, and the baby is born with physical differences, commonly an under-developed or missing chest muscle. There are many children born in the UK and across the world with Poland Syndrome – very few people are aware of this rare syndrome, and it is hard to find the right

people in the know in the medical community. PIP-UK, the centre for expertise for Poland Syndrome research, support and community connection, aim to change this and make sure people get access to the right disease information for them, at the right time.

Mission statement: ‘Advocate for earlier, consistent diagnosis and treatment paths for the Poland Syndrome community. Building awareness for Poland Syndrome and providing support to the community.’

Collaboration: This project brings together clinicians from Birmingham Children’s Hospital, professional volunteers with medical and scientific expertise and people with lived experience of Poland Syndrome to jointly explore surgical outcomes.

Outreach: Participants were recruited through PIP-UK’s community networks, social media and direct outreach to families and individuals affected by Poland Syndrome.

Co-creation: The Poland Syndrome community identified this research as their top priority over five years ago. It has taken significant time to bring together the right experts willing and able to carry out this work. Once engaged, clinicians, professional volunteers and those with lived experience worked collaboratively to design the study – developing the research questions, preparing the ethics submission and shaping the focus group process. PIP-UK’s community members then took part in the focus groups themselves, ensuring that the research is grounded in lived experience and addresses the needs they identified.

Outcomes: The study will identify key themes in decision making and satisfaction around chest wall surgery, informing the creation of a future community questionnaire and guiding patient care.

8. Healthy Starts Focus Group Recruitment



Stakeholders: Communeconnect, Public Health Wales, Emotional Logic

Contributors: Dr Kendra-Jean Wamadie (Communeconnect), Emeka Dibigbo (Communeconnect), Farah Ege (Community engagement intern, Communeconnect)

Background: Healthy Start is a UK-wide government scheme that helps women who are pregnant or have young children and are receiving benefits to buy nutritious food.

Communeconnect mission statement: ‘Bridge the gap. Increase your impact.’

Outreach and Collaboration: Emotional Logic, the research partner, enabled Communect, a community engagement agency specialising in connecting under-served groups with health researchers, to provide childcare for in-person Healthy Starts focus groups. Initial focus groups were affected by the challenges of having children present, but Communect were wary of introducing additional barriers of childcare by asking participants not to bring their children to the sessions. By interacting with and seeking guidance from groups of mums, Communect were able to arrange childcare for the focus groups at no cost to participants, allowing children to be looked after close by, in a separate room, making it easier for participants to take part and therefore boosting the success of the focus groups.

Co-creation: Data and feedback from the three focus groups were collected and fed back to the research partner.

Outcomes: The series of focus groups highlighted the need to, and means for, addressing the potential barrier of childcare to participation in this group. Providing on-site childcare at no cost to the participants was an effective way of tackling this barrier. The quality of the focus groups was greatly improved by this change, as there was less noise interference and distraction from the children.

9. RareCare



Stakeholders: Realise Advocacy, Consilium Scientific, Coventry University, RareQoL, Rare Revolution Magazine, Alström Syndrome UK, SWAN UK (Syndromes Without A Name UK), CamRARE (Cambridge Rare Disease Network), Medics for Rare Disease, MSUK (Metabolic Support UK), Beacon for Rare Diseases, Research Advisory Group (multi-stakeholder), Human Data Sciences

Contributors: Lindsay Birrell (RareCare PPIE strategy; CEO Realise Advocacy)

Background: Rare diseases affect an estimated 3.5 million people in the UK at some point in their lives.²² The RareCare project will determine if the UK Rare Disease Framework is benefiting people affected by rare diseases in England. The research is assessing how performance should be measured, identifying areas for improvement and generating practical outputs for patients, carers and service providers. Findings are informing decision-makers on how to enhance the way the NHS and related services support people living with rare diseases.

Collaboration: RareCare brings together individuals and families, clinicians, policy experts and academics to understand and strengthen the implementation of the UK Rare Disease Framework. The project is conducted in collaboration with the University of Cambridge, which is leading research on improving health and social care coordination for people with rare diseases.

Outreach: RareCare ensures that people living with rare diseases are involved in every stage of the project from concept design and methodology development to data collection, reviewing outputs, and disseminating findings. The project places a strong emphasis on inclusive engagement, ensuring participation from underserved and underrepresented groups. Other engagement activities include surveys and interviews with healthcare professionals, providing further insight into the challenges and opportunities in coordinating care for people living with rare diseases.

Co-creation: All aspects of RareCare have been developed through co-creation with people living with rare diseases. This includes the design of a peer research programme, where individuals living with rare disease and stakeholders collaboratively created and delivered training to enable peer researchers to collect qualitative data that helps contextualise the project's findings.

Expected outcomes:

- Recommendations for improving care coordination across the NHS and support services.
- Metrics that matter – outcomes that reflect the priorities and lived experiences of people with rare diseases.
- Actionable tools and evidence for the Department of Health and Social Care and other delivery partners to strengthen rare disease policy implementation.

Look to the future: The project is scheduled to conclude in June 2026, culminating in a final report to be shared with government departments, healthcare partners, and the rare disease community.

10. Exploring the Tapestry of Public Involvement in Health Research through an Intersectional Weave of Gender and Race



Stakeholders: Robert Gordon University (RGU), University of Aberdeen (UoA), NIHR-Aberdeen Health Determinants Research Collaboration (NIHR-HDRC Aberdeen)/Aberdeen City Council, NHS Grampian, Equity Lighthouse

Contributors: Leila Neshat Mokadem (RGU/Equity Lighthouse), RGU contributors: Dr Sherly Melianti, Gosia Singh, Equity Lighthouse contributors: Dr Clare Depasquale, Dr Betty Dube, and Global Ethnic Majority Women from Aberdeen: Jane Akadiri, Yasmin Mahdi, Olena Tsapenko, Hossa Skandary-McPherson. Acknowledgements: supervisory team – Dr William P Ball (RGU), Dr Kathryn Martin (UoA), Dr Bea Dawkins (NIHR-HDRC Aberdeen)

Background: Global Ethnic Majority (GEM) women are often missing across all stages of health research. Despite calls for more inclusive public engagement and involvement practices, the notion of ‘hard to reach’ persists. With changing demographics across Scotland, and the need for culturally responsive and representative civic engagement, Leila (doctoral researcher at RGU & CEO of Equity Lighthouse) brought together a panel of diverse women from Black, Asian, mixed, migrant, Traveller, refugee, and Minority Ethnic heritage and set up the ‘Global Ethnic Women for HER (Health Equity Research)’ group.

Collaboration: This project is a funded PhD which, in addition to the RGU’s diverse public co-researchers, is a collaboration across University of Aberdeen, NIHR-Aberdeen Health Determinants Research Collaboration, NHS Grampian and women with intersectional, racialised and gendered lived experience across Aberdeen, Scotland.

Outreach: Outreach included going into local community centres, on social media, at festivals and events for migrants and refugees, engaging with charities and the third sector, dissemination at public speaking events and through faith groups and religious leaders in mosques and churches.

Co-creation: The use of decolonial epistemologies and methodologies such as sharing circles underpin the project’s co-creation activities. Weaving as a conceptual framework acts as both metaphor and

method – to celebrate the shared kinship among the global heritage women who are graciously and boldly acting as co-researchers. The aim is to co-create a framework for inclusive public involvement with diverse members of the public, practitioners and academics acting as equal partners and co-researchers. The intended impact is to build community and researcher capacity for representative and inclusive research practices to ultimately reduce health inequalities.

Outcomes: Informed by policy, practice, global scholars, literature and Leila's pilot study, a research axiology (values-based approach) called TAPESTRY (foregrounded on anti-racist and restorative justice principles) has been co-created to guide the research from design to dissemination. A global scoping review is underway to map representation and involvement challenges, opportunities and decolonial methodologies to inform a participatory ethnographic study with, for, and by, global heritage women. As a result of the project so far, the first public partnership group of global heritage women across the Grampian region has been formed. Knowledge exchange, dissemination and training of practitioners in inclusive participatory research methods has taken place, as well as awareness raised, and day-to-day practices influenced at institutional higher education, public health, and local government levels.

Look to the future: The aim is to co-create a framework for inclusive public involvement in health research. The intended impact is to dispel the notion of 'hard to reach' and build community and researcher capacity for inclusive research practices to ultimately reduce ethnic health inequalities.

Health Education

11. The Patient Voice



Stakeholders: Bionical Emas

Contributors: Naomi Litchfield (Bionical Emas), Dr Sondra Butterworth (RareQoL)

Background: A patient-centred approach to early access programs puts patients, families and caregivers first. This ensures their needs, preferences and perspectives are at the heart of the process of bringing life-changing investigational medicines to current and future patients. For early access to be truly patient-centred, words need to be put into action.

Project mission statement: 'We must collectively recognise that patient-centricity cannot be achieved by just one approach or one voice.'

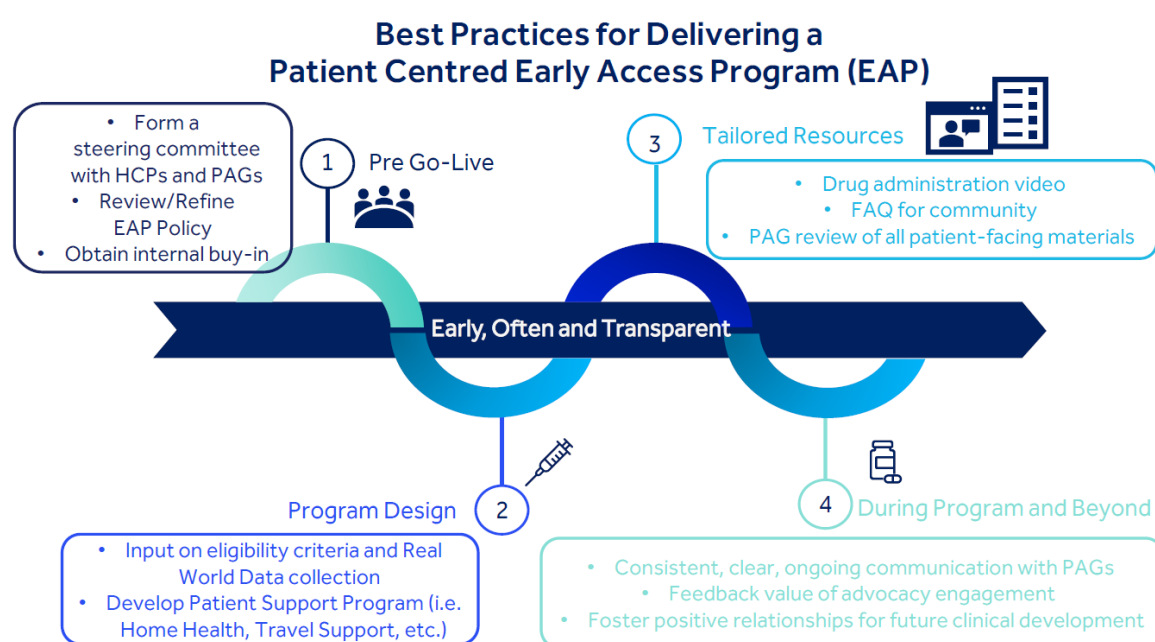
Collaboration: Hosted by Bionical Emas, 'The Patient Voice' brings together stakeholders from across the clinical development space – from industry experts, patient advocacy organisations and healthcare professionals to patients, families and caregivers – as they share their experiences and insights. Discussing barriers and challenges, solutions and strategies and their personal journeys, they explore how patient voices can be embedded in all stages of the ever-evolving clinical development process.

Outreach: Naomi Litchfield engages with patients and advocates, providing a platform for them to share their stories. This ensures their needs, preferences and perspectives are at the heart of the process of bringing life-changing investigational medicine to current and future patients.

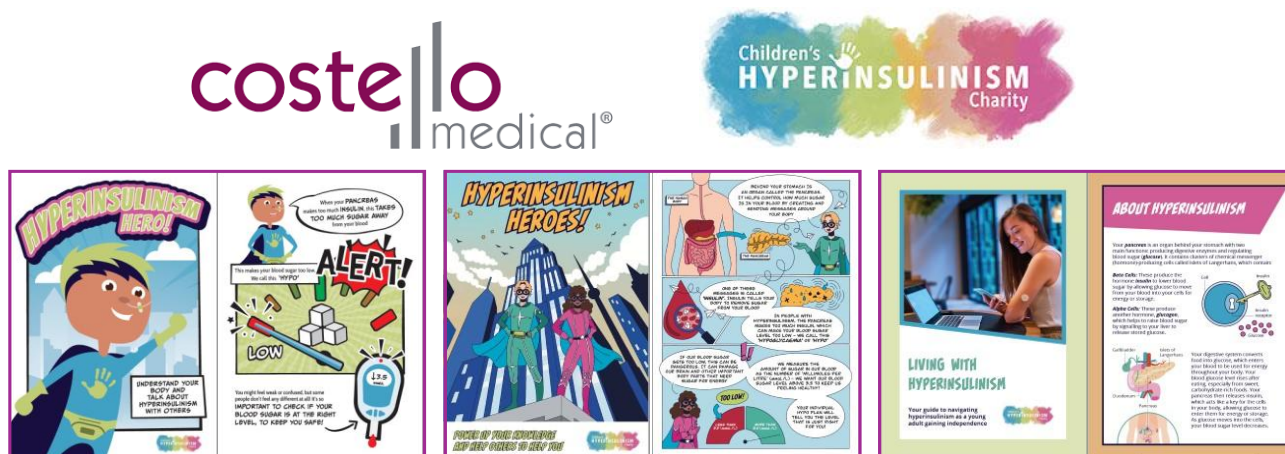
Co-creation: Bionical Emas believes co-creation with the patient community and a patient and family-focused collaboration between all stakeholders is vital to the drug development process. The podcasts are co-created with the interviewees to ensure that their stories are told authentically.

Abbreviations: HCP, healthcare practitioner, PAG, patient advocacy group.

Outcomes: A comprehensive podcast series that supports health education for the pharmaceutical industry and patient engagement specialists, and raises awareness of patients' lived experience, is available and widely accessible in the public domain. In [Episode 3 with Dr Sondra Butterworth](#), we hear from two people who have lived experiences in advocating for their ethnicity, race, gender and communities, both broadly and in the healthcare space. Another example of how the **patient voice** is incorporated into the design and delivery of Early Access Programs please see below-



12. Co-Creation of Self-Advocacy Comic Books for Children Living with Hyperinsulinism



Stakeholders: Costello Medical, The Children's Hyperinsulinism Charity

Contributors: Andrew Wilhelmsen, Melanie Howes, Peter Lang, Courtney Gray, Shereen Baban (all Costello Medical), the Children's Hyperinsulinism Charity team and trustees, children with hyperinsulinism and their families/guardians

Background: Costello Medical provides scientific support in the analysis, interpretation and communication of clinical and health economic data. Costello Medical are passionate about sharing their expertise to help improve health and healthcare globally. They therefore deliver projects free of charge, on a pro bono basis, to charities and non-profit organisations. Costello Medical supported The Children's Hyperinsulinism Charity with the development of three age-appropriate, educational booklets to promote self-advocacy in children living with the condition.

Costello Medical Mission statement: 'To be a community of the very best people building trusted partnerships across the healthcare sector by delivering an exceptional service.'

Collaboration: Costello Medical regularly met with trustees of the charity to identify exactly the type of content, intended purpose and audiences of the educational materials and to continue refining materials throughout the project. Within Costello Medical, colleagues from across their Pro Bono, Medical Communications and Creative Teams worked together to bring their respective expertise to the project. To ensure the booklets truly reflected the interests and voice of the target audiences, children and the families/caregivers of children living with hyperinsulinism were recruited to participate in their co-creation.

Outreach: The charity put calls out on their social media channels to ask for children and families/caregivers who would be interested in helping to shape and review the booklets. Costello Medical provided participant information sheets and consent/assent forms to ensure everyone was fully informed and happy to participate.

Co-creation: To support the creation of three booklets for children and young people of different ages (ranging from ~5 to 18 years), three groups of children and their families/caregivers were recruited. Online workshops were hosted to learn about what type of books/stories they enjoyed, the type of characters they would like to see, how their condition could be represented visually, the language to be used and the topics/challenges they face that matter most to them. Based on their input, draft booklets were developed which were then reviewed by participants and the charity and further refined.

Outcomes: Three booklets were developed and printed, with a consistent but age-appropriate theme/style running through them. Feedback received showed that the children/young people were extremely pleased with the final results; the characters were relatable, and the information was clear

and helpful. The Children's Hyperinsulinism Charity are featuring the booklets at the Cambridge Rare Summit 2025 and are using the booklets in school packs, at training days and community events, sharing them with healthcare professionals and families alike.

13. Medics for Rare Disease Genomics Education Programme



Stakeholders: Medics for Rare Disease, Genomics Education Programme (GEP – NHS England)

Contributors: Helen Maginnis (Medics for Rare Disease), Lucy McKay (Medics for Rare Disease), Alison Pope (GEP), Aine Kelly (GEP), Amelia McPherson (GEP)

Background: Genomics Education Programme (GEP) is NHS England's delivery partner for Priority Two of the UK Rare Diseases Framework (increasing healthcare professional awareness of rare diseases).³ Feedback to the Framework Forum suggested that stakeholders felt that GEP's platform would benefit from more resources aimed at generalist healthcare professionals about rare disease.

Mission statement: 'To shape a medical profession that can provide people living with rare conditions a timely diagnosis and excellent care, with a vision for equitable healthcare for all.'

Collaboration: GEP partnered with Medics for Rare Disease and our clinical and lived-experience Ambassadors to make its online educational resources on rare disease more accessible, patient-centred, and relevant to healthcare professionals in mainstream clinical practice.

Outreach: Medics for Rare Disease consulted extensively with people living with rare disease, carers, clinicians and advocacy groups through surveys, interviews and a Patient and Public Involvement webinar to ascertain the educational priorities of the community.

Co-creation: Medics for Rare Disease worked with GEP to produce a range of educational resources, informed by community insights and co-produced with our ambassador network based on priorities highlighted during the outreach. This ensured content was rooted in lived experience and community priorities, clinically robust and relevant to genomic and non-genomic rare disease.

Outcomes: The collaboration delivered patient-centred GeNotes content and bitesize website resources about priority topics highlighted in our outreach (e.g. Rare Disease and Mental Health and Working with Advocacy Groups). A streamlined Rare Disease Hub supports healthcare practitioners

(HCPs) to find support for both themselves and their patients. These community-inspired resources support timelier diagnoses, better communication and improved care for people with rare conditions.

14. Living Proof



Stakeholders: The Patient Project, Ideosound

Contributors: Michelle Warner (The Patient Project), Elizabeth Feller (The Patient Project)

Background: The Patient Project ensure medicines bring more value to those who need, provide and develop them by partnering with patients, healthcare experts and biopharma. One of The Patient Project's initiatives, The Listening Room, is a space where real stories and meaningful conversations come together to reveal the human side of healthcare. Here, patients share their journeys, challenges, and triumphs in podcasts and videos, while professionals reflect, respond, and learn together.

The Patient Project Mission statement: 'The Patient Project brings science and patients together as equal partners, sharing ambitious patient-focused goals.'

Collaboration: Engagement through patient organisations, directly through LinkedIn and the Patient Project network allows this organisation to find patients living with the same condition but differing in age, demographics, geographies or socioeconomic backgrounds. Collaboration is key through the 'chemistry meetings' they hold, hearing perspectives on discussion topics of greatest interest and importance.

Outreach: Stories will be shared through their [website](#), by the patients themselves and those that advocate for them. Pharmaceutical companies working in a given disease area are also approached, giving a more 'human' style to compliment data/AI-driven patient insight generation together with development of 'scientific narratives'.

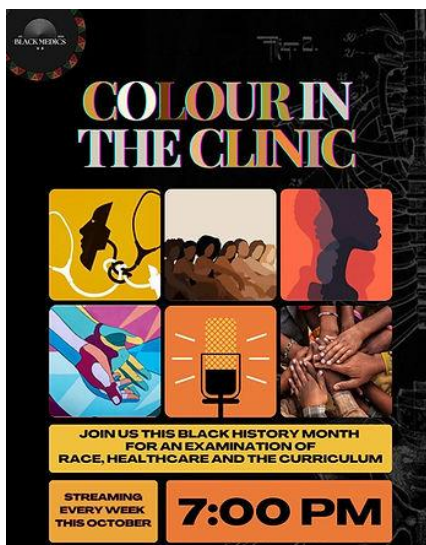
Co-creation: Recordings made of free-flowing conversations are shared with the patients and, together, they edit and co-create a podcast and short soundbites of often unexpected insights, together with pharmaceutical companies. Technical expertise is provided by Ideosound, ensuring professional production with sound that leaves a lasting impression.



Outcomes: Living Proof is a multi-purpose end product, consisting of authentic human dialogue for use as health and disease education. The hope is that healthcare professionals, patients, carers, pharmaceutical companies and patient organisations find the podcasts valuable and that this education drives a better understanding of patients' unmet needs, hopes, fears and expectations.

Equality, Diversity and Inclusion

15. Colour in the Clinic



Stakeholders: Black Medics UK (BMUK), University of Nottingham

Contributors: Osaruese Egharevba, Aisia Lea, Dr Kaylita Chantiluke, Natasha Noel Barker

Background: For too long, medical education has overlooked the nuances of diversity. Textbooks have historically centred on White, Eurocentric models, leading to gaps in how conditions present across different skin tones. Implicit biases, shaped by these educational materials, can impact clinical decision-making, often with real-world consequences for patient outcomes. BMUK are dedicated to empowering and amplifying the voices of Black medical students and trainees throughout the United Kingdom. Representation in medicine matters – not just in who enters the profession, but in how medicine is taught and practiced. For Black History Month 2025, BMUK hosted "Colour in the Clinic," a talk series exploring the crucial role of diversity and inclusivity in medical education and clinical practice. With over 220 registrations, the series sparked conversations on how the medical landscape is evolving to better serve diverse populations.

BMUK Mission statement: 'Breaking Barriers, Building Futures, Bridging the Gap. Change starts with awareness and action.'

Collaboration: Through this talk series, medical professionals and student leaders who are actively challenging these gaps were brought together in a partnership. This project was delivered by BMUK in collaboration with healthcare professionals and educators, bringing together clinical expertise, lived experience and educational insights to address ethnic disparities in research, curriculum design, and clinical practice. Each session explored a different aspect of representation in medicine, from anatomical education to implicit bias in clinical practice.

Outreach: The project engaged over 200 participants through targeted outreach to medical schools, student networks and healthcare organisations. Black Medics UK utilised social media, mailing lists and partnerships with academic institutions to ensure broad access, particularly among underrepresented groups in medicine and research.

Co-creation: Co-creation was central to the project, with speakers and attendees shaping content through interactive case studies, live Q&A and feedback loops. Black Medics UK collaborated with clinicians, educators and students to ensure sessions addressed real-world gaps in research, education and practice from diverse, community-informed perspectives.

Outcomes: The collaboration resulted in increased participant confidence, critical awareness and commitment to inclusive practice. Key outcomes include the development of an engaged network of students and professionals, improved understanding of ethnic disparities in healthcare and a scalable model for integrating diversity into medical research, education and clinical training. This series showed just how crucial these conversations are, as the overwhelming engagement and thought-provoking discussions reaffirmed the need for continued advocacy for a more inclusive and representative medical education system.

16. Tackling Local Racial and Ethnic Disparities in Rare Diseases: The HEAL-RD Study



Stakeholders: Queen Elizabeth Hospital (University Hospitals Birmingham [UHB] NHS Foundation Trust), Amicus Therapeutics, Society for Mucopolysaccharide (MPS) Diseases, Birmingham Community Healthcare

Contributors: Professor Rick Steeds (UHB NHS Foundation Trust), Dr Sophie Thompson (UHB NHS Foundation Trust), Natalie Tuzcuoglu (Amicus Therapeutics), Chris Wingrove (Amicus Therapeutics), Fiona Stewart (MPS Society UK), Claudia Church-Smith (UHB NHS Foundation Trust) and Farhana Darwich (BLACHIR)

Background: Fabry disease is a rare, inherited disease that is life-limiting and affects quality of life. The disease is pan-ethnic, so can affect people from any racial and ethnic background, yet through the collaborative HEAL-RD project, an underdiagnosis in non-White populations was discovered. Birmingham is one of the most diverse cities in the UK, yet the population diagnosed with Fabry disease

is over 90% White. This project aims to address the disparities in access to diagnosis and appropriate specialist care that can alter the course of Fabry disease, working with communities to understand and overcome barriers to diagnosis.

Collaboration: Industry, community groups, patient advocacy organisation (PAOs) and healthcare practitioners (HCPs) are working together under a united aim to improve the diagnostic odyssey for people living with rare diseases. They are working to understand community needs, identify opportunities to raise awareness of rare diseases with communities and create a simpler diagnostic pathway to overcome the challenges some people face in accessing care.

Outreach: The organisations involved have worked with community engagement experts to host a series of focus groups and roundtables, aiming to understand the barriers to a rare diagnosis. They have worked with some of the few diagnosed non-White patients in Birmingham to understand how they overcame barriers and assess how the service could be improved.

Co-creation: The HEAL-RD collaboration raised awareness and highlighted the importance of addressing health inequalities in rare diseases with a panel session and hackathon at NHS ConfedExpo, bringing together the health ecosystem to spark and share innovative ideas to address the challenge. The collaboration also hosted three successful focus groups with patients, PAOs and community leaders.

Outcomes: The first published data on health inequalities in Fabry disease as part of a Fabry Family Screening project²³ and the first images of the presentation of Fabry-related angiokeratoma in a South Asian patient have both been published for the first time thanks to this collaboration. There are plans to create a pilot programme for raising rare disease community awareness and to develop new pathways to help ensure equitable and fair access to care.

Look to the future: Further research into clinical manifestations of Fabry disease in diverse groups may help clarify the pathogenicity of variants, resulting in increased diagnoses in these groups whilst also increasing confidence in health services. Learning from new roles such as community engagement experts will be fundamental in engaging rare disease patients from underrepresented communities and supporting their journey to diagnosis.²³

Service Innovation and Improvement

17. The MAHI Project Series



Stakeholders: Mo'sho Adeosun Health Initiative (MAHI), Five Twenty One LLC, Lochi's Light House LLC, Rotaract Club, University College Hospital (UCH)

Contributors: Folusho Adeosun (MAHI), Omololu Paulson (Temitope Five Twenty One LLC), Emilia Adaobi Ndupu (Lochi's Light House LLC)

Background: The Mo'sho Adeosun Health Initiative (MAHI) is a grassroots-led health equity organization committed to transforming the sickle cell disease (SCD) experience in Africa and beyond. Founded by Mr Mo'sho Adeosun, MAHI is driven by a passion to reimagine SCD care through innovative tools, targeted outreach, and co-created community care models. Through its core programs, MAHI empowers SCD warriors, trains patient advocates, and strengthens access to quality healthcare across underserved communities.

MAHI's key components include:

1. **The MAHI Mobile App:** A digital platform for education, self-management, and real-time support.
2. **Hub-and-Spoke Hospital Network:** Designed to improve specialist access in rural and semi-urban areas.
3. **SCD Pods:** Community-based mini-centres offering screening, counselling, and ongoing care.
4. **Advocacy & Outreach Programs:** Focused on stigma reduction, genotype compatibility, and inclusion awareness.

MAHI Mission statement: 'Our long-term vision is to build a continent-wide support ecosystem – led by warriors, powered by technology and sustained by partnerships.'

Collaboration: In pursuit of this mission, MAHI partnered with Five Twenty One LLC, Lochi's Light House LLC, and the Rotaract Club, UCH to co-create educational resources, psychosocial support programs, and outreach strategies tailored for SCD warriors and caregivers. These collaborations

strengthened MAHI's holistic model, promoting mental wellness, youth engagement and community inclusion, while bridging care gaps across underserved regions.

Outreach and co-creation: Together, these partners executed MAHI's maiden outreach program, which reached multiple underserved SCD communities through a blend of digital engagement, educational materials and psychosocial interventions. The co-creation approach ensured that every intervention was warrior-informed, community-driven, and locally adaptable, reflecting MAHI's commitment to sustainable and inclusive design.

Outcomes: The strategic collaboration between MAHI and its partners resulted in measurable impact and visibility gains across several domains:

- **Digital Impact:** Co-developed the blueprint of the MAHI mobile app, integrating real-time warrior support, medication tracking, and genotype education tools
- **Health Infrastructure:** Advanced the design and implementation plan for the Hub-and-Spoke Hospital Network, with SCD Pods mapped across priority regions in Nigeria to decentralise and improve point-of-care delivery
- **Community Reach:** Educated up to 500 individuals (including students, parents and community leader) on genotype compatibility, SCD management and stigma reduction
- **Content & Creative Direction:** Improved digital storytelling, campaign branding and media documentation, resulting in a 40% increase in social engagement
- **Co-creation Culture:** Established a replicable, community-led design model ensuring that all tools, programs, and interventions remain warrior-informed and contextually relevant

By combining technology, advocacy and psychosocial care, MAHI and its partners have laid the foundation for a sustainable ecosystem of support – one that empowers warriors, engages caregivers and inspires global partnerships.

18. A Review of NHS Health Communications with (and for) Jewish Communities



Stakeholders: Intent Health, NHS Race and Health Observatory

Contributors: Jane Brearley, Jenny Carrington-Elson, Serena Rianjongdee (Intent Health)

Background: Intent Health believe that access to healthcare is a human right, whoever you are, wherever you live and whoever you love – they are the only consultancy with a unique business model designed to address health inequities through strategic communications and collaboration with expert partnerships. They have joined forces with the NHS Race and Health Observatory to support their mission to tackle race inequities in health and social care, enabling long-term transformational change. This year-long phased project began with a rapid evidence review, followed by stakeholder mapping, advisor engagement and an extensive period of informed community engagement.

Collaboration: Under commission from NHS Race and Health Observatory, Intent Health worked alongside various Jewish community groups and advisors to improve health communications for the community. Together, they researched, co-produced and delivered [national recommendations and resources](#) to improve NHS engagement, trust and culturally competent communications with Jewish communities across England.

Outreach: Co-creation with advisors from the Jewish communities was central to each stage; shaping research design, validating findings and producing culturally competent toolkits, assets and guidance.

Co-creation: Assets were created with stakeholder input into strategy, creation, validation and delivery to ensure representation and maximum impact within the Jewish community and their healthcare touchpoints. These resources support NHS staff and services nationwide to tailor communications, build trust and remove barriers in healthcare engagement with the diversity of Jewish communities.

Outcomes: This project constituted the first national, evidence-led review of NHS health communications with Jewish communities. It provides actionable guidance, systemic change recommendations and partnership models to address barriers, improve outcomes and embed culturally competent, community-led engagement across the NHS for the Jewish community.

19. Wales Digital Rare Care Centre



Stakeholders: Wales Rare Disease implementation Network (RDIN), Cardiff and Vale University Health Board and Carecircle Partnerships, Bevan Commission Exemplar project, NHS Wales performance and improvement: Quality, Safety and improvement (EPP) service

Contributors: Rhiannon Edwards (RDIN), Dr Jamie Duckers (Cardiff and Vale University Health Board, Public Health Wales), Laura MacDonald (Carecircle)

Background: The Wales Digital Rare Care Centre (RCC) project was developed out of a vision that all people impacted by Rare Diseases should have an equitable access to support and resources to enable them to live well with rare diseases. It is an example of a global rare disease network.

Collaboration: A subset of the global health community Carecircle has been created, where the collaboration is wide and across multi-sector partnerships, driven by an unsuccessful application to LifeArc.

Outreach: RDIN reached out to multiple patient advocacy organisations, rare disease clinical teams and academic colleagues to understand the needs for the centre. They enabled discussions and engagement opportunities on how collective participation can lead to prudent and effective use of resources and access to NHS and non-NHS support.

Co-creation: The LifeArc bid application focused on 5 research themes, the first working group focused on 'The Rare Care Centre – A central point for engagement with the patient community' and has been used for continued collaboration, alongside academic colleagues and clinical teams who are facilitating the co-creation of the centre to enable focus group and patient and public involvement and engagement conversations.

Outcomes: The RCC has been commissioned by three (Southeast Wales) health boards for evaluation. A logo competition was carried out to enable those with lived experience to work with graphic designers to create the badge for the centre (see above).



Look to the future: Five Rare Disease clinical teams have been recruited to pilot and develop the centre, focusing initially on transition care. This exciting health technology and NHS collaboration will work to transform the care of rare disease conditions.

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Collaborator Sponsors and Supporters

Collaborator



[Bionical Emes](#) is a global Early Access Programs (EPA) and Clinical Trial Supply (CTS) group bringing life-changing medicines to patients around the world.

In 2025 Bionical Emes announced that RareQoL had been selected as their (not-for-profit) Charity of the Year 2025. This collaboration has assisted RareQoL's ambition to advance inclusive research, health equity, and patient centric approaches for rare diseases and minority ethnic communities.

"This collaboration will also support the Equality Diversity and Inclusive Research Association (EDIRA) to drive forward inclusive research practices and foster a more equitable healthcare landscape. Their work closely aligns with our company's values and signals our commitment to patient advocacy and making a meaningful impact for underserved communities." Tom Watson, CEO, Bionical Emes.

Sponsors



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The [NIHR](#) funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth.

The NIHR BioResource national coordinating centre is located in Cambridge and is hosted by Cambridge University Hospitals NHS Foundation Trust in partnership with the University of Cambridge.



[Amicus Therapeutics](#) is a global, patient-dedicated biotechnology company focused on discovering, developing and delivering novel high-quality medicines for people living with rare diseases.

Sponsors



Astellas is a global life sciences company committed to turning innovative science into VALUE for patients. We provide transformative therapies in disease areas that include oncology, ophthalmology, urology, immunology and women's health. Through our research and development programs, we are pioneering new healthcare solutions for diseases with high unmet medical need. Learn more at www.astellas.com.



The Patient Project

We ensure medicines bring more value to those who need, provide and develop them by partnering with patients, healthcare experts and biopharma and associated industries such as Med comms/tech/ devices

Pro Bono Support

