Improving Inclusion in Research: working with people with a learning disability

# Overview

“NIHR has launched a new requirement that all applicants demonstrate how their research will address existing inequalities in health and social care as a condition of funding. The requirement will ensure that research is intentionally designed, conducted and communicated inclusively, and researchers will be held to account for delivering on their plans.”

<https://www.nihr.ac.uk/news/inclusion-now-key-condition-nihr-funding>

We hope that the following resources will help you with this.

# Organisations

* NIHR: [Homepage | NIHR](https://www.nihr.ac.uk/)
* Regional Research Delivery Networks: [Homepage | NIHR RDN](https://rdn.nihr.ac.uk/)
* Mencap: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics>
* Down’s Syndrome Association: <https://www.downs-syndrome.org.uk/our-work/services-projects/research-support/>
* Down’s Syndrome Research Foundation: <https://www.dsrf-uk.org/>
* Autistica: <https://www.autistica.org.uk/>

# Groups

* [Yellow Tulip Group | (tuffrey-wijne.com)](https://www.tuffrey-wijne.com/?page_id=1004)
  + [Learning Disabilities (LD) - Research - Kingston University London](https://www.kingston.ac.uk/faculties/faculty-of-health-social-care-education/research/cahscr/learning-disabilities/)

The Learning Disability Research Group at Kingston University. *“We are a group of people working and studying at Kingston University in London. We meet every month to talk about research. Our research in about health and social care. Irene and Richard chair the meetings. They are researchers at the university. Irene is a professor. Richard is a researcher with learning disabilities.”*

# Resources for researchers

* [Inclusion now a key condition for NIHR funding](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nihr.ac.uk%2Fnews%2Finclusion-now-key-condition-nihr-funding&data=05%7C02%7Csusie.beresford%40nhs.net%7C3b2ae83dd57a494b32d108dd121abf19%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638686628257967333%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=0Yb6g8K%2BPEg66C8k5vnYUrfHxcJ0CFzoHgIoy0odZ1A%3D&reserved=0)
* [OUR NAME ON THE DOOR: Kingston University employs researchers with a learning disability (youtube.com)](https://www.youtube.com/watch?v=siZzuFODzuA)
* [Research Support Service | NIHR](https://www.nihr.ac.uk/support-and-services/research-support-service)
* [Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR](https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research)
* [Inclusive research design to become an NIHR condition of funding | NIHR](https://www.nihr.ac.uk/inclusive-research-design-become-nihr-condition-funding)
* [NIHR Research Design Service Equality, Diversity and Inclusion Toolkit](https://www.rssleicesterresources.org.uk/edi-toolkit?tags=EDI)
* [NIHR Disability Framework](https://www.nihr.ac.uk/nihr-disability-framework)
* [Inclusive research design to become an NIHR condition of funding](https://www.nihr.ac.uk/documents/inclusive-research-design-to-become-an-nihr-condition-of-funding/36278)
* [Improving inclusion of under-served groups in clinical research: Guidance from the NIHR-INCLUDE project](https://www.nihr.ac.uk/documents/improving-inclusionof-under-served-groups-in-clinical-research-guidancefrom-include-project/25435)
* [INCLUDE: better healthcare through more inclusive research](https://sites.google.com/nihr.ac.uk/include/home).
* [A practical guide to being inclusive in public involvement in health research: Lessons learnt from the Reaching Out programme](https://arc-nenc.nihr.ac.uk/wp-content/uploads/2021/04/NIHR-Reaching-Out_-A-practical-guide-to-being-inclusive-in-public-involvement-in-health-research-Lessons-learnt-from-the-Reaching-Out-programme-April-2021.pdf)
* [Being Inclusive in Public Involvement in Health Research](https://www.nihr.ac.uk/documents/being-inclusive-in-public-involvement-in-health-and-care-research/27365)
* [Supporting equity and tackling inequality: how can NIHR promote inclusion in public partnerships?](https://www.learningforinvolvement.org.uk/content/resource/supporting-equity-and-tackling-inequality-how-can-nihr-promote-inclusion-in-public-partnerships/)
* [Briefing notes for researchers - public involvement in NHS, health and social care research](https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371)
* [Guidance on co-producing a research project](https://www.learningforinvolvement.org.uk/content/resource/nihr-guidance-on-co-producing-a-research-project/)
* [Taking Stock – NIHR public involvement and engagement](https://www.nihr.ac.uk/taking-stock-nihr-public-involvement-and-engagement)
* [How to involve the public in knowledge mobilisation](https://evidence.nihr.ac.uk/collection/how-to-involve-the-public-in-knowledge-mobilisation/)
* [Going the extra mile: Improving the nation’s health and wellbeing through public involvement in research](https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf)
* [Equality Impact Assessment (EqIA) Toolkit | ARC EM 2024 (nihr.ac.uk)](https://arc-em.nihr.ac.uk/arc-store-resources/equality-impact-assessment-eqia-toolkit)
* [EDI Toolkit (rssleicesterresources.org.uk)](https://www.rssleicesterresources.org.uk/edi-toolkit)
* [COALITION Project - Legal Capacity Research](https://legalcapacity.org.uk/coalition-project/), which includes:
  + [Accessible Research Toolkit - Legal Capacity Research](https://legalcapacity.org.uk/accessible-research-toolkit/)
* [NIHR-INCLUDE Project](https://sites.google.com/nihr.ac.uk/include/home)
  + [INCLUDE Impaired Capacity to Consent Framework - Capacity consent research](https://www.capacityconsentresearch.com/include-impaired-capacity-to-consent-framework.html)
* [Listen Include Respect UK - Down's Syndrome Association (youtube.com)](https://www.youtube.com/watch?v=7DY9Xo5ji5I) (contact [Julian.hallett@downs-syndrome.org.uk](mailto:Julian.hallett@downs-syndrome.org.uk) for information on this training)
* [The Leeds Approach to Engaging with Communities for Research - Leeds Biomedical Research Centre](https://leedsbrc.nihr.ac.uk/ppie-strategy/engaging-with-communities/)
* [Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups](https://www.england.nhs.uk/aac/wp-content/uploads/sites/50/2023/02/B1905-increasing-diversity-in-research-participation-v2.pdf.pdf)

# Consent

* <https://legalcapacity.org.uk/accessible-research-toolkit/>
* <https://www.rssleicesterresources.org.uk/edi-toolkit>
* <https://www.capacityconsentresearch.com/include-impaired-capacity-to-consent-framework.html>

# Resources for people with a learning disability

* [Clinical Trials: an easy-read guide - Suffolk Ordinary Lives](https://suffolkordinarylives.co.uk/resources/clinical-trials-an-easy-read-guide/)
* [Yellow-Tulip-Group-easy-read-info-2023.pdf (tuffrey-wijne.com)](https://www.tuffrey-wijne.com/wp-content/uploads/2021/08/Yellow-Tulip-Group-easy-read-info-2023.pdf)

# Equality, Diversity and Inclusion Publications

Anderson AM, Brading L, Swaithes L, et al. [Building trust and inclusion with under-served groups: a public involvement project employing a knowledge mobilisation approach](https://eprints.whiterose.ac.uk/218323/). Res Involve Engagem. In press. DOI: 10.1186/s40900-024-00647-2.

Bailie J, Fortune N, Plunkett K, Gordon J, Llewellyn G. [A call to action for more disability-inclusive health policy and systems research](https://gh.bmj.com/content/8/3/e011561). BMJ Glob Health. 2023;8(3).

Bodicoat DH, Routen AC, Willis A, Ekezie W, Gillies C, Lawson C, et al. [Promoting inclusion in clinical trials—a rapid review of the literature and recommendations for action](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-021-05849-7). Trials. 2021;22(1):880.

DeCormier Plosky W, Pluviose-Philip MJ, Bierer BE. [Accessibility by Design in Clinical Research Toolkit](https://mrctcenter.org/diversity-in-clinical-research/tools/abd_toolkit/). Version 1.0. Cambridge and Boston, MA: Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard (MRCT Center). 2023.

Greenwood M, Fakih B, Steff M, Bechange S, Mwifadhi M. [Hear my voice: a community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania](https://www.km4djournal.org/index.php/km4dj/article/view/308). Knowledge Management for Development Journal. 2016;11(2):63-78.

Jameson C, Haq Z, Musse S, et al. [Inclusive approaches to involvement of community groups in health research: the co-produced CHICO guidance](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-023-00492-9). Res Involve Engagem. 2023;9(1):76.

Kuper H, Hameed S, Reichenberger V, Scherer N, Wilbur J, Zuurmond M, et al. [Participatory Research in Disability in Low- and Middle-Income Countries: What have we Learnt and what Should we Do?](https://sjdr.se/articles/10.16993/sjdr.814) Scandinavian Journal of Disability Research. 2021;23(1):328–337.

National Institute for Health and Care Research (NIHR), Chief Scientist Office (CS), Health and Care Research Wales, Public Health Agency Northern Ireland. [UK Standards for Public Involvement](https://sites.google.com/nihr.ac.uk/pi-standards/standards). 2019.

RE4ALL. [Welcome to RE4ALL! Accessible Research Ethics Education for Community Research Partners](https://re4all.org/). 2024.

Rios D, Magasi S, Novak C, Harniss M. [Conducting Accessible Research: Including People With Disabilities in Public Health, Epidemiological, and Outcomes Studies](https://ajph.aphapublications.org/doi/10.2105/AJPH.2016.303448). Am J Public Health. 2016;106(12):2137-44.

Shepherd V, Joyce K, Lewis A, et al. [Improving the inclusion of an under-served group in trials: development and implementation of the INCLUDE Impaired Capacity to Consent Framework](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-024-07944-x). Trials. 2024;25(1):83.

Swenor B, Deal JA. [Disability Inclusion as a Key Component of Research Study Diversity](https://www.nejm.org/doi/10.1056/NEJMp2115475). N Engl J Med. 2022;386(3):205-7.

Witham MD, Anderson E, Carroll C, et al. [Developing a roadmap to improve trial delivery for under-served groups: results from a UK multi-stakeholder process](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-04613-7). Trials. 2020;21(1):694.

World Health Organization (WHO). [Global report on health equity for persons with disabilities](https://www.who.int/publications/i/item/9789240063600.). 2022.

Wylde V, Brennan S, Johnson E, et al. [Recommendations for developing accessible patient information leaflets for clinical trials to address English language literacy as a barrier to research participation](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-024-08471-5). Trials. 2024 Sep 27;25(1):624.

# Learning Disability Publications

Agbonmwandolor JO, Croot L, Finlayson J, et al. [Approaches to support meaningful research participation for adults with a learning disability – a scoping review of grey and peer-reviewed literature protocol](https://osf.io/42bz7/). Centre for Open Science. 2023.

Berrou I, Roberts R, Parfitt L, et al. [Making clinical consultations inclusive for people with learning disabilities](https://doi.org/10.12968/jprp.2024.6.5.202). Journal of Prescribing Practice. 2024;6(5).

Bishop R, Laugharne R, Shaw N, et al. [The inclusion of adults with intellectual disabilities in health research - challenges, barriers and opportunities: a mixed-method study among stakeholders in England](https://onlinelibrary.wiley.com/doi/full/10.1111/jir.13097). J Intellect Disabil Res. 2024;68(2):140-149.

Frankena TK, Naaldenberg J, Cardol M, et al. [A consensus statement on how to conduct inclusive health research](https://onlinelibrary.wiley.com/doi/10.1111/jir.12486). J Intellect Disabil Res. 2019;63(1):1-11.

Hewitt O, Langdon PE, Tapp K, et al. [A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences?](https://onlinelibrary.wiley.com/doi/full/10.1111/jar.13100) J Appl Res Intellect Disabil. 2023;36(4):681-701.

Kahonde CK. [A call to give a voice to people with intellectual disabilities in Africa through inclusive research](https://ajod.org/index.php/ajod/article/view/1127). Afr J Disability; 2023;12(1127).

Learning Disability England. [‘No research about us without us’](https://www.learningdisabilityengland.org.uk/no-research-about-us-without-us/). 2024. Accessed 08 Nov 2024.

Legal Capacity Research. [COALITION: Co-Producing Accessible Legal Information](https://legalcapacity.org.uk/coalition-project/). 2024. Accessed 08 Nov 2024.

Leishman, E., Quilgars, D., Abbott, D. et al. [Working collaboratively with an online advisory group of people with learning disabilities in covid-times: carrier pigeons, cats and drones](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-023-00494-7). Res Involv Engagem. 2023;9;9(1):79.

Mikulak M, Ryan S, Bebbington P, et al. [‘'Ethno…graphy?!? I can't even say it”: Co-designing training for ethnographic research for people with learning disabilities and carers](https://onlinelibrary.wiley.com/doi/10.1111/bld.12424). Br J Learn Disabil. 2022;50:52–60.

Purple Patch Arts. [The Purple Research Group](https://purplepatcharts.org/research/). 2024. Accessed 08 Nov 2024.

Purple Patch Arts. [The Purple Patch: A Research Comic](https://thepurplepatchcomic.wixsite.com/research). 2023. Accessed 08 Nov 2024.

Spaul SW, Hudson R, Harvey C, et al. [Exclusion criterion: learning disability.](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30051-9/fulltext) Lancet. 2020;395(10223):e29.

The British Diabetic Association. [Improving care for people with diabetes and a learning disability](https://www.diabetes.org.uk/for-professionals/improving-care/good-practice/for-people-with-learning-disability). 2024. Accessed 08 Nov 2024.

Tuffrey-Wijne I, Lam CKK, Marsden D, et al. [Developing a training course to teach research skills to people with learning disabilities: “It gives us a voice. We CAN be researchers!”](https://onlinelibrary.wiley.com/doi/10.1111/bld.12331). Br J Learn Disabil. 2020;48:301–314.

University of Leeds. [Capacity, Consent & Autonomy](https://capacityconsent.leeds.ac.uk/). 2024. Accessed 08 Nov 2024.

UK Research and Innovation (UKRI). [Changing the pace of change: Disability inclusion in development responses to sexual violence for women with disabilities through arts & humanities](https://gtr.ukri.org/projects?ref=AH%2FX009505%2F1#/). 2024. Accessed 08 Nov 2024.

Wanjagua RW, van Heumen L, Parker Harris S. “[Will I Be Celebrated at the End of This Training?” Inclusive Research in Kenya](https://www.mdpi.com/2076-0760/13/2/95). Soc Sci; 2024;13(12):95.

# Projects in progress

* [No research about us, without us! Removing research barriers for people with learning disabilities | NIHR](https://www.nihr.ac.uk/no-research-about-us-without-us-removing-research-barriers-people-learning-disabilities)
* [OU partners with University of Oxford on learning disability research | Faculty of Wellbeing, Education and Language Studies (open.ac.uk)](https://wels.open.ac.uk/news/ou-partners-university-oxford-learning-disability-research)