Logistics

British Sign Language (BSL) interpreting: Our BSL interpreters are spotlighted.

Real-time captions: Can be accessed by clicking the ‘CC’ button at the bottom of your screen or via the live captions link in the chat.

Slides, recording and transcript: To be posted on the Disability Inclusion in Research Collaboration (DIRECT) webpage.

Technical difficulties: If you have technical difficulties, please email PPIBRC@Leeds.ac.uk.

Questions

Join at:
vevox.app

ID:
179-519-560

NIHR | National Institute for Health and Care Research

DIRECT

A global call to action for disability inclusion in health research

Disability Inclusion in Research Collaboration (DIRECT); NIHR Biomedical Research Centre: Leeds; and NIHR HealthTech Research Centre: Accelerated Surgical Care.

08/06/2026

20 Years

Agenda

- Introduction
- Using data to advance disability-inclusive research
- Research cycle
- Research and advisory workforce
- Take-home messages
- Questions

Introduction

Dr Anna Anderson, University of Leeds

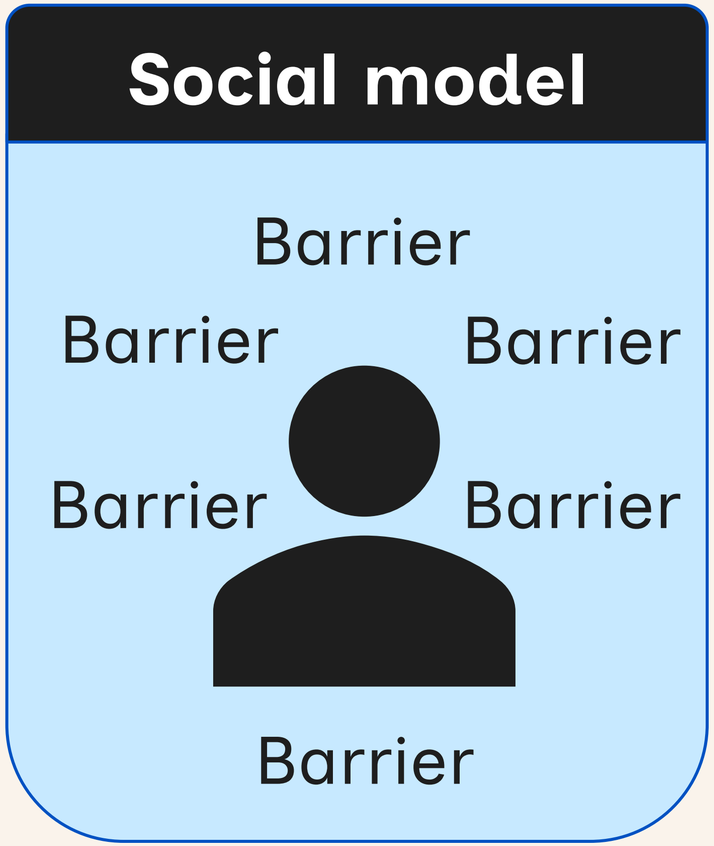
Some questions….

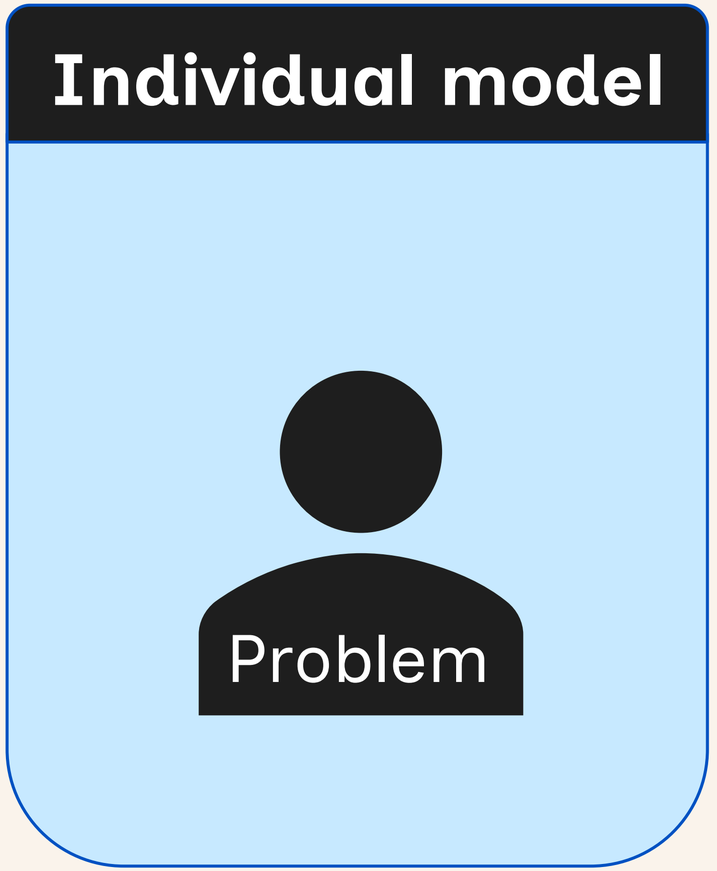
- How would you define disability?
- In studies you're familiar with:
  - What disability data have been collected?
  - What steps have helped or hindered inclusion of disabled people?
- What proportion of the research workforce do you think declare they are disabled or have a disability?

Who do we mean by ‘disabled people’?

Options to consider:

- **Legal definitions**, such as the Equality Act (2010) definition
- **Conceptual approaches**, such as the social model (Oliver, 1990)





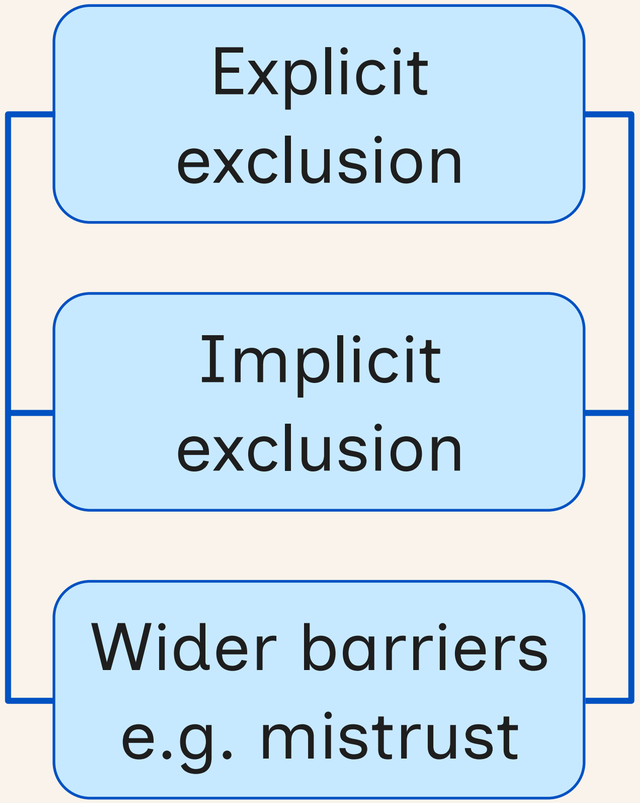
Language choices

- Disability language preferences vary.
- **‘Disabled people’** aligns with the social model.
- People who meet a specific definition of disability may not identify as disabled.
- People who identify as disabled may not have a formal diagnosis.

In practice, the choice of language should be **determined by the people with lived experience** being engaged.

Current context

- Around 1 in 6 people worldwide experience disability (WHO, 2022).
- Disabled people have valuable insights and skills to bring to health research but are often unjustly excluded.



Why is action needed?

‘[…] evidence-based changes in healthcare may not be safe, effective, acceptable or accessible for disabled people, and so risk increasing health inequities.’

Anderson et al. (2025)

Reasons to improve inclusion:

- Moral and ethical
- Legal and human rights
- Scientific
- Health equity
- Economic
- Research funding

Global call to action

- Comment published in Nature Medicine (Anderson et al., 2025).
- Calls for multi-level actions to improve disability inclusion in health research.
- Developed by the Disability Inclusion in Research Collaboration (DIRECT).
- Underpinned by the social and human rights models.

Key challenge areas

Anderson et al. (2025)

Introduction: references

Anderson AM, Martin RA, DeCormier Plosky W, Ned L, Swenor BK, Bailie J, Mathias K, Maggo JK, Omino MA, Russell AM, Lawson AMM, Brown AE, Bierer BE, Shariq S, Mwifadhi M, Deane KHO, Philip S, Shepherd V, Walsh NE, McHugh GA. A global call to action for disability inclusion in health research. Nat Med. 2025;31(5):1399-1403. https://doi.org/10.1038/s41591-025-03587-w.

Equality Act, 2010, c.15.

Oliver, M. 1990. Disability Definitions: The Politics of Meaning. In: The Politics of Disablement. London: Palgrave Macmillan, pp.1-11.

World Health Organization (WHO). Global report on health equity for persons with disabilities. 2022.

Using Data to Advance Disability-Inclusive Research

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disabilityhealth.jhu.edu

Bonnielin Swenor, PhD, MPH
Director | Johns Hopkins Disability Health Research Center
Endowed Professor of Disability Health and Justice
Johns Hopkins School of Nursing, Johns Hopkins Bloomberg School of Public Health, and Johns Hopkins School of Medicine

Data is power.

Who counts depends on who is counted.

Johns Hopkins University | Disability Health Research Center

Limited data on disabled academics & researchers

- Academic literature is limited - few studies focus on disabled researchers.
- Disabled people are underrepresented in research fields.
- There are challenges to ‘measuring’ disability

Country or Region	% Academics with disabilities
US	9% academic workforce
UK	8% academic staff
Canada	7% of academics
Australia	0% of senior leaders
Japan	Limited data
South Africa	Limited data
India	Limited data
Latin America	Limited data

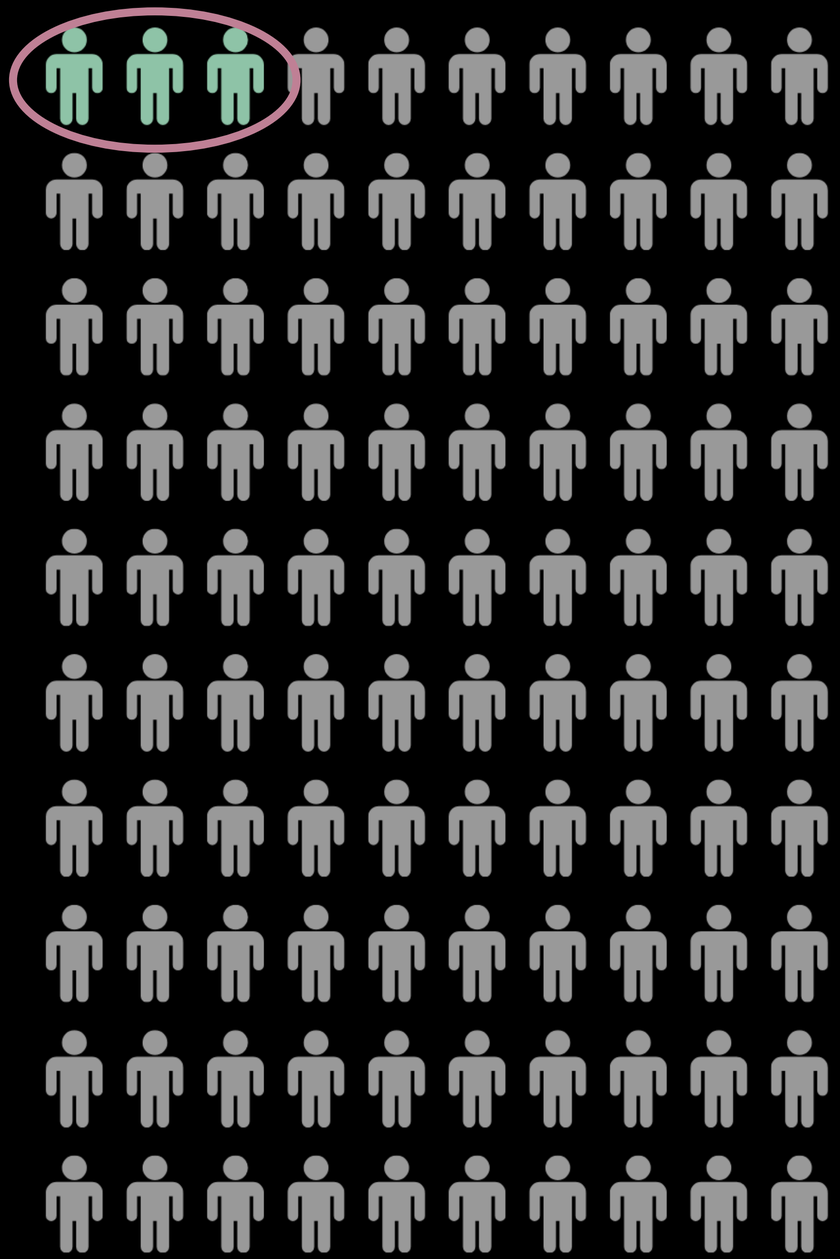
Limited representation in academia & research

US NSF. NCSES. 2021.
UK HESA. 2026.
Statistics Canada. 2019.
Australia: ADCET. 2022

Johns Hopkins University | Disability Health Research Center

Using data to drive change:
An example from the U.S.

JOHNS HOPKINS UNIVERSITY
Disability Health Research Center

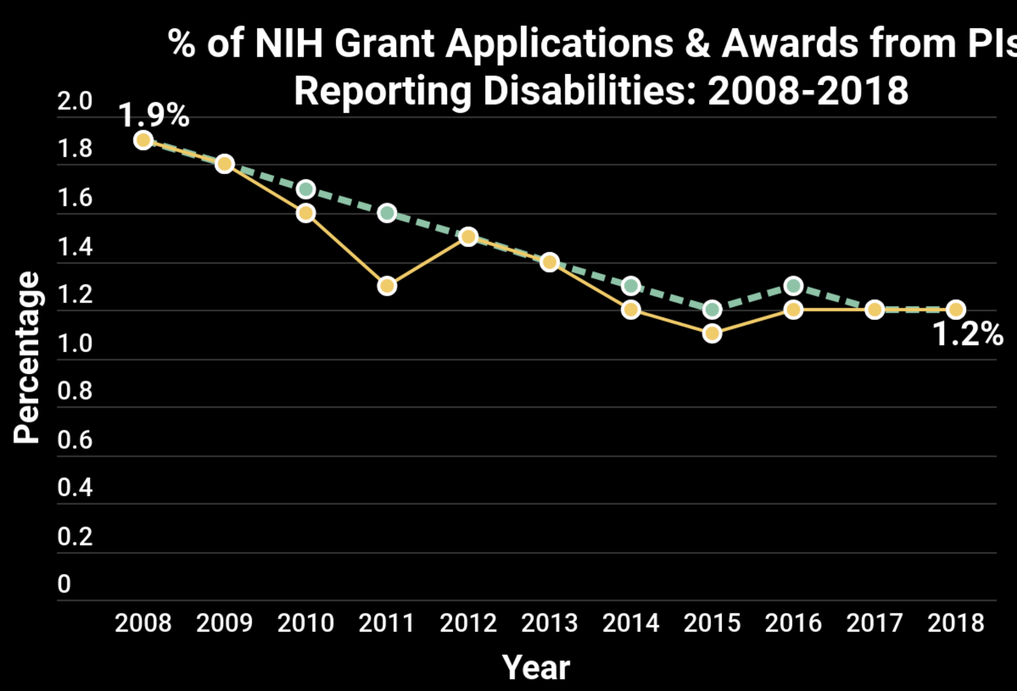


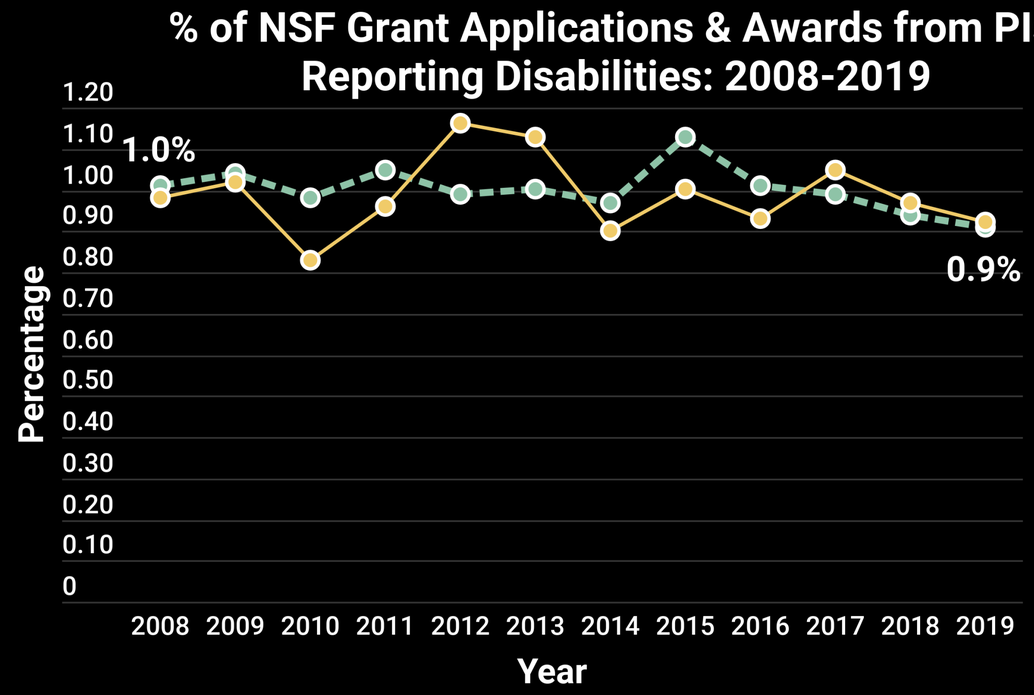
NSF. NCSES. 2021.

<3% of the U.S. STEM workforce report having a disability:

The only group without improved representation over the past 10 years.

<2% of research U.S. investigators report having a disability





Swenor et al. Plos One. 2020.
NSF Merit Review Process Report. 2019

Johns Hopkins University | Disability Health Research Center

Disabled scientists earn less

$10,580

Disabled people with STEM doctorate degrees earn less per year than their colleagues without disabilities

$14,360

The pay gap for academics in STEM fields with early disabilities (before age 25) is even greater

Castro et al. Nature Hum Behav. 2023.

Johns Hopkins University | Disability Health Research Center

Qualitative Data: Barriers to research careers

“I’ve never had a mentor with a disability…”

”Sometimes I think there’s a perception that researchers/academics with disabilities, especially those that disclose their disabilities, are only ‘advocates’…”

“It’s ridiculous that I’m regularly the only disabled person in a room, group, etc. focused on the study of people with disabilities.”

“The pandemic gave me the accommodations the institution wouldn’t…”

”The whole problem with academia is it presumes that you’re able to put in a 60-hour week.”

Castro et al. Plos One. 2024.

NEWS RELEASES

Tuesday, September 26, 2023

NIH designates people with disabilities as a population with health disparities

Designation, new research program and update to NIH mission are actions to ensure inclusion of people with disabilities.

Disability groups win fight to be included in health equity research

The designation of disabled people as a ‘health disparity population’ allows for more funding and research into the health equity barriers disabled people face

By Amanda Morris

September 26, 2023 at 11:00 a.m. EDT

The Washington Post

Global Progress

DIRECT

DOCS WITH DISABILITIES INITIATIVE

DHERN
Disability Health Equity Research Network

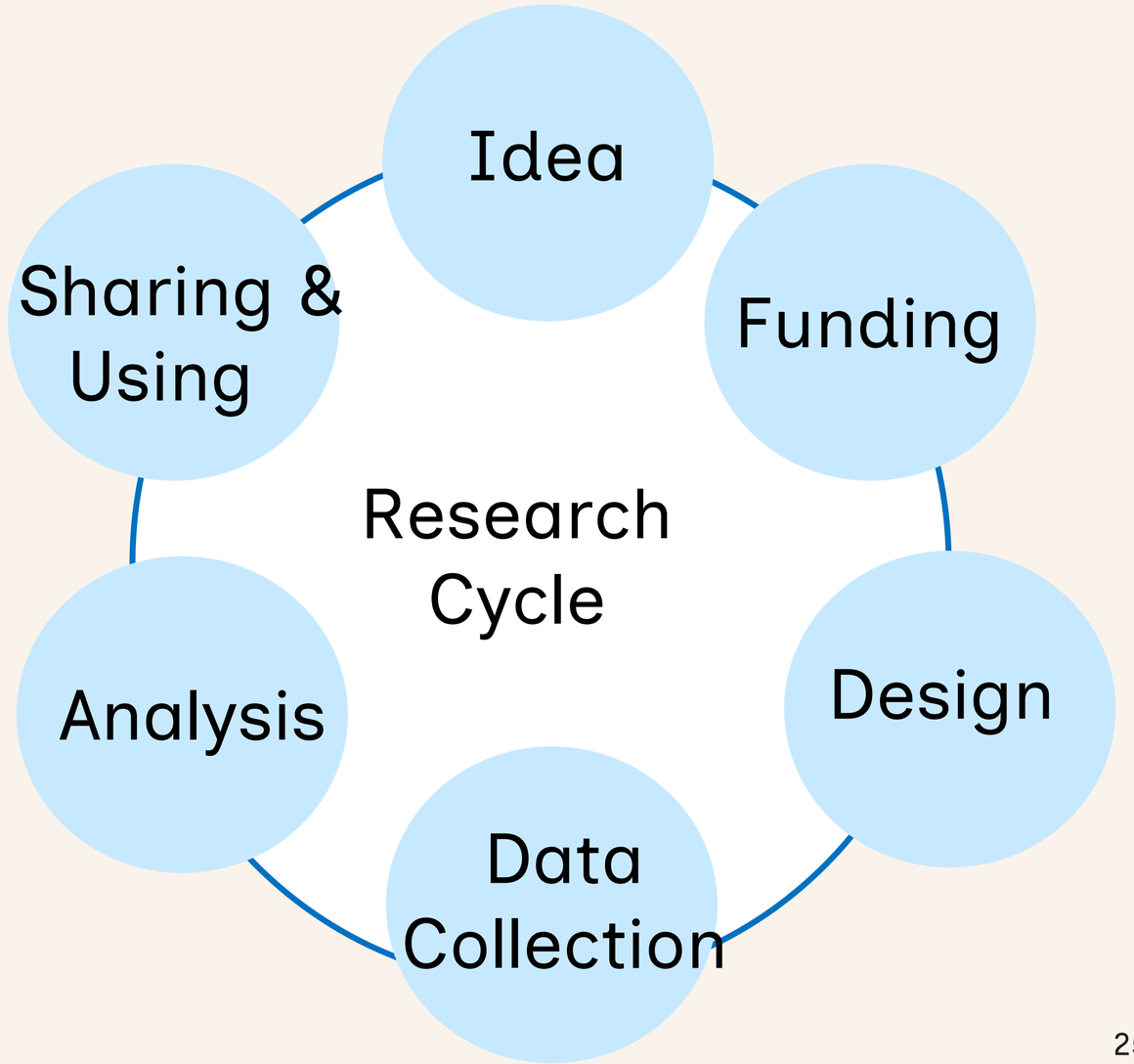
JOHNS HOPKINS UNIVERSITY | Disability Health Research Center

Research cycle

Jasjot Maggo, University of Otago, New Zealand

Stages of the Research Cycle

The research cycle consists of a series of stages used to develop new knowledge.



Key Challenge

People with disabilities are often seen as research subjects rather than active partners in the research process.

Research **on** people with disabilities

Research **with** people with disabilities

Barries to Inclusion

- **Attitudinal and Societal:** prejudice, perception, ableism, stigma.
- **Physical:** inaccessible infrastructure, lack of resources.
- **Communication:** lack of accommodations.
- **Institutional:** lack of inclusive policies, strategies and structures.
- **Research-specific:** rigid protocols, study designs, and deadlines.

Guiding principles

- Build trusting respectful relationships.
- Involve disabled people at all stages.
- Adopt a strengths-based approach.
- Take steps to address power imbalances.
- Offer a range of involvement roles.
- Maximise accessibility.
- Develop mutually agreed ways of working.
- Make sure everyone benefits.
- Be transparent.

Impact of Meaningful Involvement

- **Design and data collection:** Accessible, inclusive of diverse needs, and informed by people with lived experience to address historical mistrust.
- **Analysis:** Flexible, person-centred, and meaningful to disabled people.
- **Sharing and using:** Findings are interpreted through a multi-level context, utilising inclusive language and diverse, accessible dissemination strategies to reach both academic and community partners.

Working with people with learning disabilities

Dr Amy M Russell,
Associate Professor,
University of Leeds, UK

Routine Exclusion

In 2013 Fieldman *et al* found **90%** of research studies excluded people with learning disabilities.

In 2023 Bishop *et al* found **78%** of studies in NIHR portfolio excluded people with a learning disability.

Challenges identified:

- Recruitment
- Inclusion and Exclusion criteria
- Capacity assessments
- Ethical review not allowing it
- Insufficient funding
- Lacking communication skills

Nothing About Us, Without Us 1

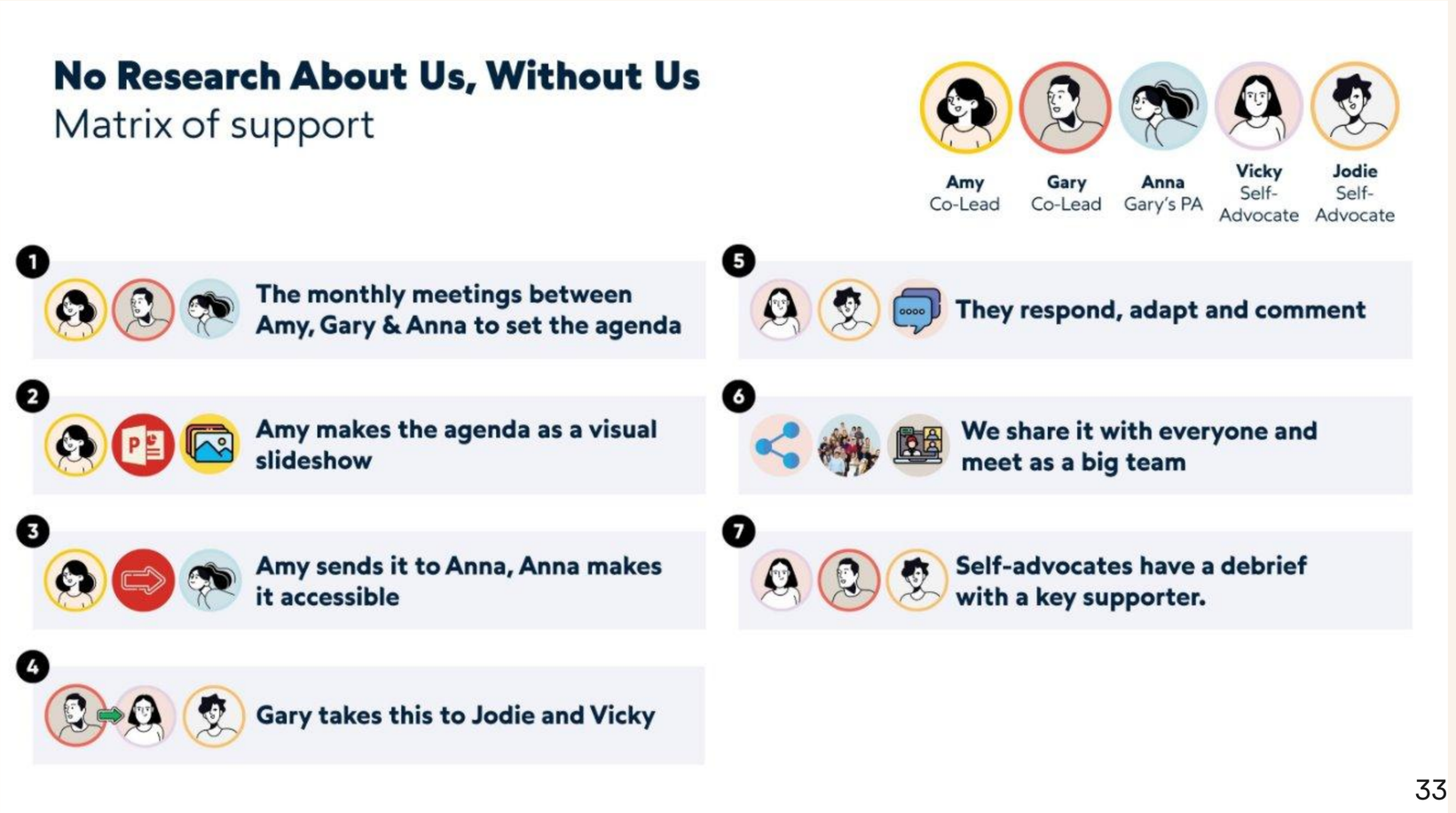
Tools we created to support your research

- If you want to make your research inclusive co-produce it
- Advice on building trust and relationships including planning and pace

Nothing About Us, Without Us 2

Tools we created to support your research

- Matrix of Support: 7 steps for inclusive support in project work



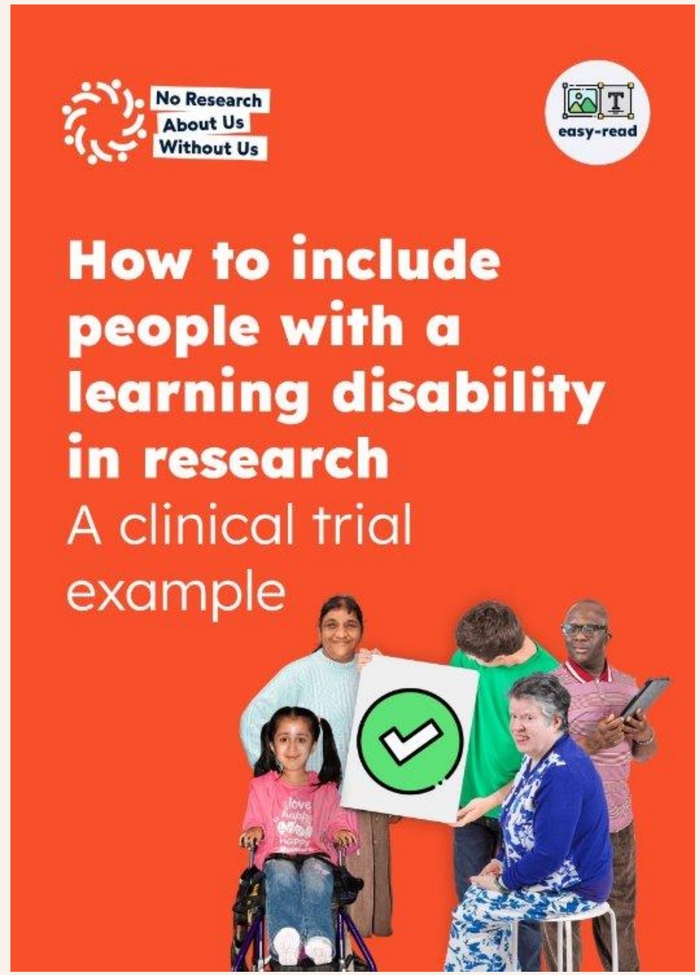
Nothing About Us, Without Us 3

Tools we created to support your research

- Accessible information throughout: see our examples

QR code: Project summary on Learning Disability England website

SCAN ME



Nothing About Us, Without Us 4

Tools we created to support your research

- Video explainers

Nothing About Us, Without Us 5

Tools we created to support your research

- Visual Branding and reminders

Nothing About Us, Without Us 6

Tools we created to support your research

- Creative and arts-based evaluation

- Project summary on Learning Disability England website

Yes? An Audio story about research consent

- Observations of ethics committees
- Co-production workshops
- Created a script that illustrates some of the challenges to giving research consent
- Shared with third sector groups and ethics committees
- Autonomy versus protection and the importance of the right kind of support

QR code: Audio story

Creative Inclusion

With Melissa Kirby and Purple Patch Arts we have co-created a toolkit of arts-based activities that explain research concepts in an accessible and imaginative way.

- Research
- Consent
- Anonymity
- Withdrawal

QR code: Creative Inclusion

Working with people with learning disabilities: references

Bishop, R., Laugharne, R., Shaw, N., Russell, A. M., Goodley, D., Banerjee, S., Clack, E., SpeakUp, CHAMPS, and Shankar, R. (2024) The inclusion of adults with intellectual disabilities in health research – challenges, barriers and opportunities: a mixed-method study among stakeholders in England. Journal of Intellectual Disability Research, 68: 140–149. **https://doi.org/10.1111/jir.13097**.

Feldman MA, Bosett J, Collet C, Burnham-Riosa P. Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. J Intellect Disabil Res. 2014 Sep;58(9):800-9. doi: 10.1111/jir.12091. Epub 2013 Sep 3. PMID: 24001184.

Russell, A.M. , Bourlet, G., Clark, M. et al. (16 more authors) (2025) *The Matrix of Support: How to Build a Structure of Support for Meaningful Participation and Leadership in a Research Project*. Report. White Rose Libraries. https://eprints.whiterose.ac.uk/id/eprint/234831/

Research with people with impaired capacity to consent

Dr Victoria Shepherd, Cardiff University, UK

Research and impaired capacity to consent

- Over 2 million people in the UK have significantly impaired decision-making due to illness, injury or disability
- People with impaired decision-making should be provided with appropriate support when making decisions about research
- May be unable to provide consent even with support; other consent arrangements may be needed such as alternative decision-maker
- This can raise ethical, legal and practical challenges, which leads to this group often being excluded from research

Cognitive impairment as an exclusion

- A review of 2710 trials found 958 had explicit exclusion criteria related to disability, with exclusion due to ‘cognitive impairment’ present in almost half of those (Camanni et al 2024)
- Example study: ‘Effect of probiotic supplementation on endothelial function’ which involved people with heart disease taking a probiotic supplement
- Exclusion criteria: ‘known history of cognitive impairment’
- Researchers did not report why this group were excluded, or what support was provided

Challenges across the research cycle

6. Ongoing consent

1. Research design

5. Alternative decision-maker

2. Ethical frameworks

4. Determining capacity

3. Seeking consent

(Shepherd et al 2022)

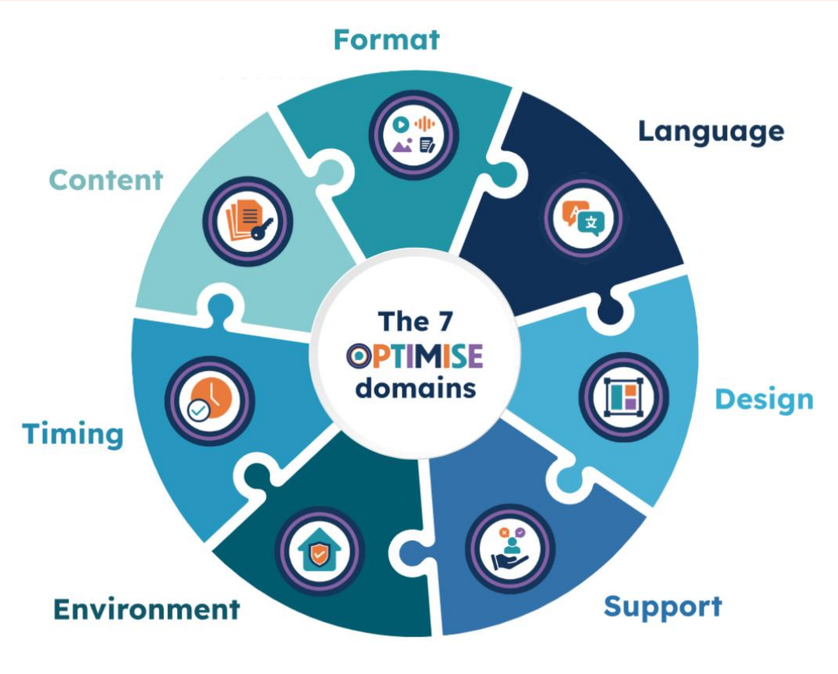
Researchers' views about barriers

Complexity of ethical and legal frameworks	Inadequate support and resources	Lack of knowledge affects confidence
"It feels like an insurmountable black box of horrendousness. If you get this wrong, you will be illegal and the ethics police will come for you!"	"I've been stabbing in the dark 'where should I look for reliable information'? A lot of potluck Googling."	"We need better support and guidance, to give people more confidence to set up a study of this kind."

Ensuring consent is accessible by design

If provided with more accessible information and the right support, people with impaired decision-making will be better able to make decisions about research participation.

OPTIMISE recommendations help to design more inclusive consent, highlighting seven domains across which accessibility can be improved.



> The key message is that even small, achievable adaptations can meaningfully improve accessibility.

Identifying and addressing barriers

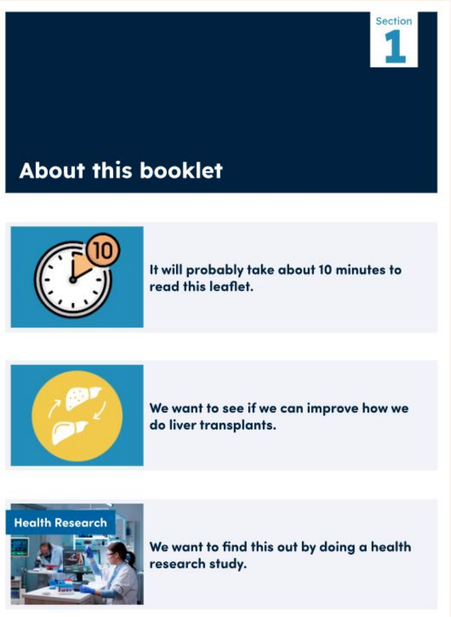
INCLUDE Impaired Capacity to Consent Framework helps researchers to identify ethical and practical issues that may arise, and minimise barriers to inclusion.

It includes four key questions for researchers to consider, and worksheets to help address them such as the resources that may be needed.

> How might the study design, such as eligibility criteria, consent process, or data collection methods, make it harder for some groups to take part?

Practical tips to improve inclusion

- Provide accessible information in range of formats
- Focus on inclusivity throughout the study design
- Carefully consider eligibility criteria
- Review the legal and ethical frameworks
- Ensure sufficient time, support and resources



Visit CONSULT website (capacityconsentresearch.com)

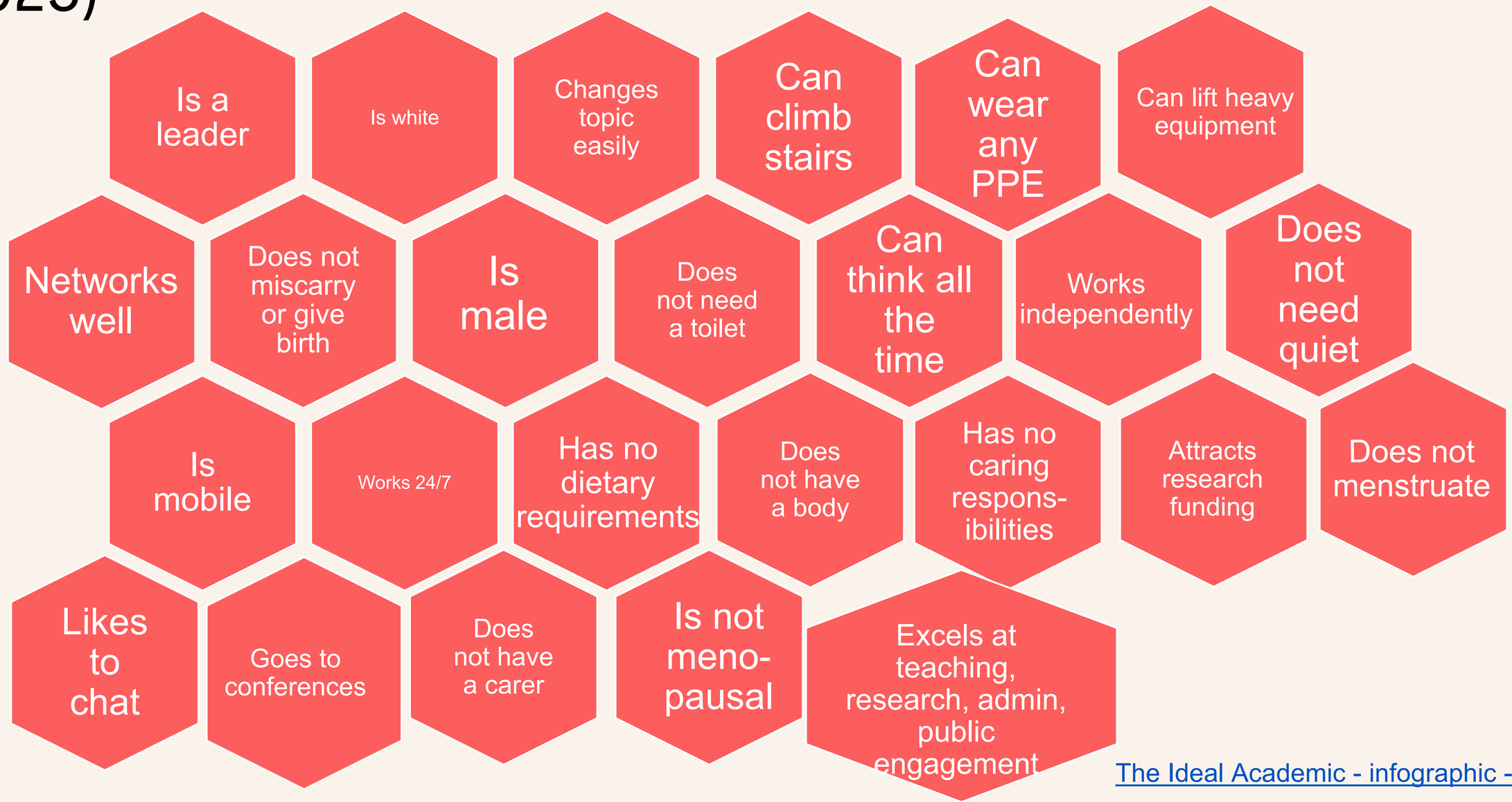
Consent example: references

- Camanni G, et al. ‘Being disabled’ as an exclusion criterion for clinical trials: a scoping review. BMJ Glob Health (2023);8:e013473. https://doi.org/10.1136/bmjgh-2023-013473
- Shepherd, V, et al. Unpacking the ‘black box of horrendousness’: a qualitative exploration of the barriers and facilitators to conducting trials involving adults lacking capacity to consent. Trials (2022) 23, 471. https://doi.org/10.1186/s13063-022-06422-6
- CONSULT website https://www.capacityconsentresearch.com

Research and advisory workforce

Associate Professor Katherine Deane, University of East Anglia, UK

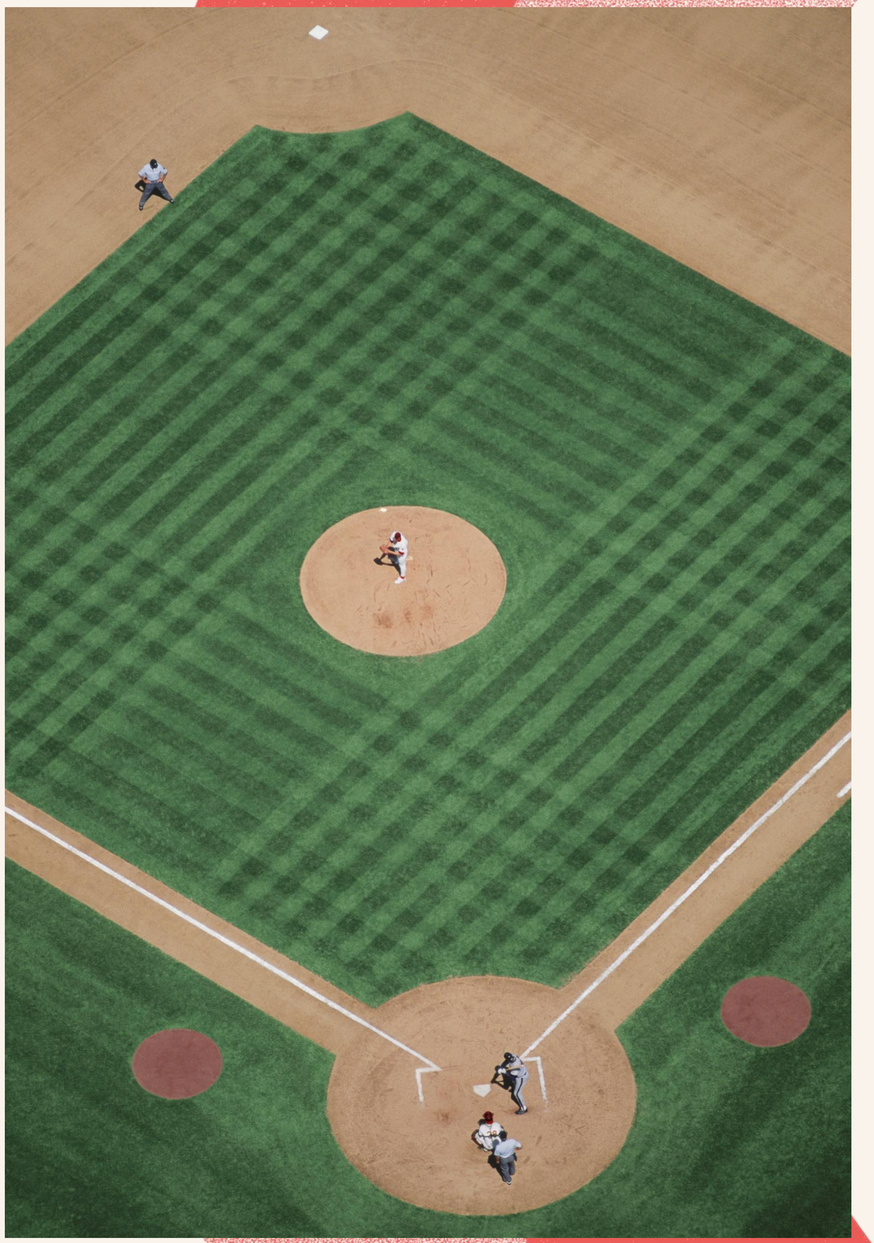
The Ideal Academic (Kate Sang, EDICa, 2017, 2025)



[The Ideal Academic - infographic - EDICa]

If you build it they will come...

- Expect, welcome, and value diversity
- Need time, space, flexibility
- Prioritise actions
  - With feedback
  - With research / sharing
- Expect push back

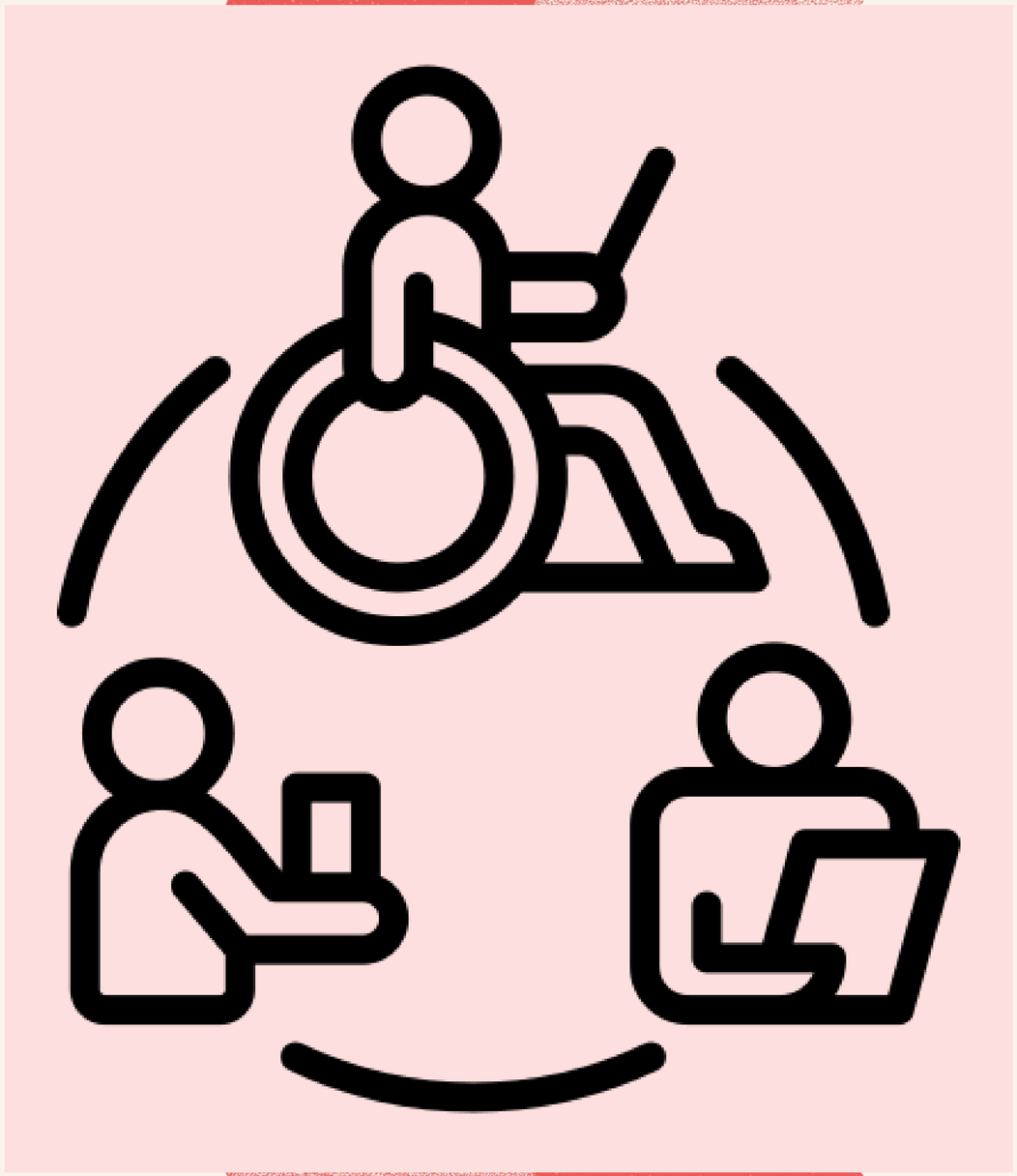


Accessible systems of employment

- Recruitment processes
- Flexible and hybrid working
- Access welcome pack – including hotels, taxis, restaurants
- Know how to access additional funds – travel, care, etc
- Reasonable accommodations – within 1 month of starting
- Enable access to relevant support
  - Unions, charities, mental wellbeing, admin support to complete forms, training
- Require accountability
- Reward actions

Patient involvement as a tool for inclusion

- Explicitly welcome under-served communities
- Expect disabled participants
- Value diversity of viewpoints
- Make research design more practical and achievable
- Use of language
- Provision of assistance, technology



Training to ensure inclusion

- **For staff and advisers**
- Focus on behaviour change not legal compliance
  - COM-B model
  - Lund University Values Work
- Ensure relevance for audience

Examples

- Inclusive research design
- Committee skills
- Cultural competency
- Bystander interventions
- Reciprocal mentoring

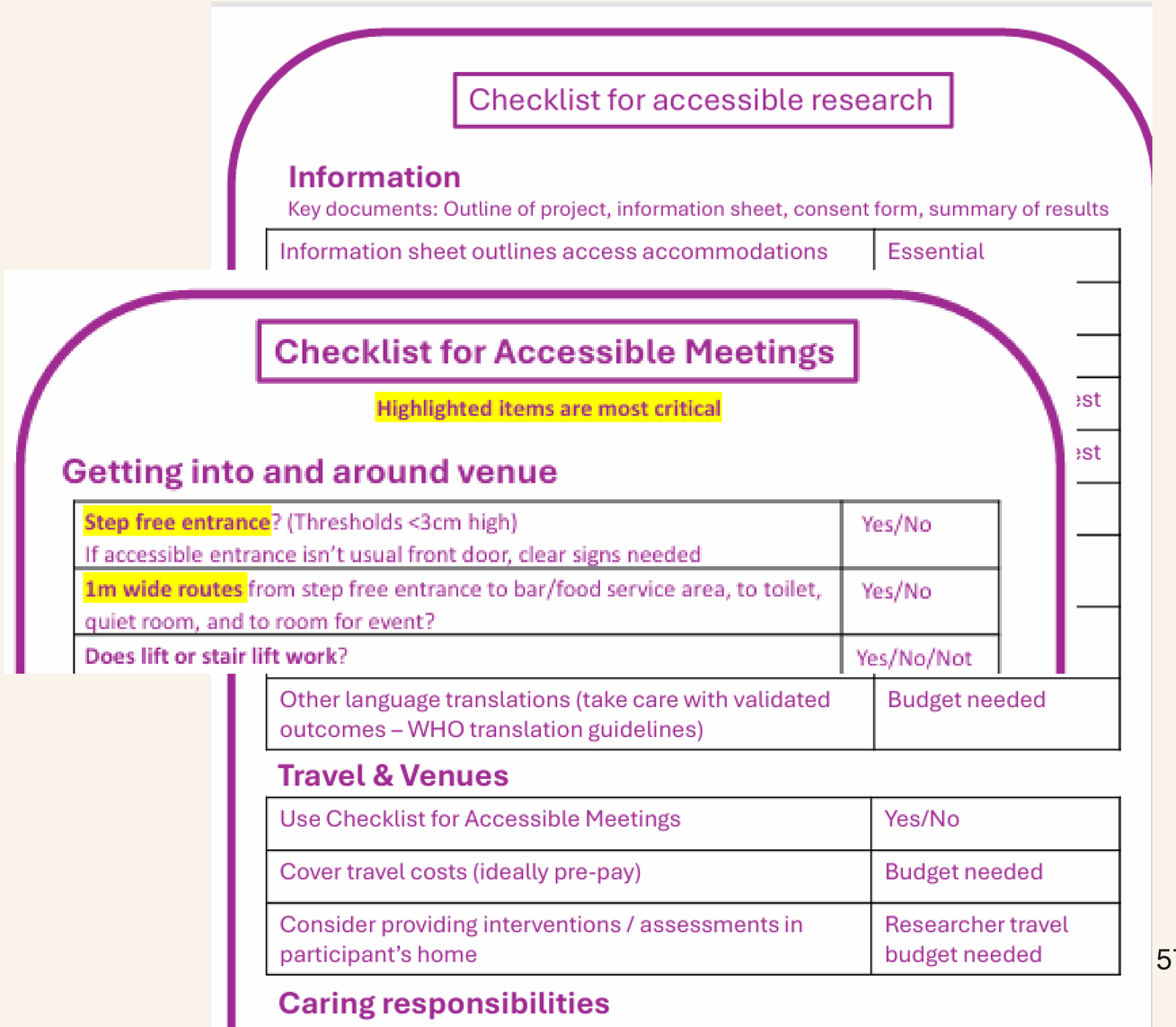
How is this research accessible for you?

- Information formats
  - Word/ pdf
  - Large print/ Easy read
  - Videos (with sign language)
- Accessible venues
  - Step free / Toilets / Parking / Public transport
  - Refreshments
  - Childcare / Elder care
  - Patient’s homes

©Jenny Mespel

Inclusive dissemination

- Hard copy documents
- Videos (with sign language)
- Websites (WCAG compliant)
- Conferences
  - Organisation, timing, refreshments…
  - Venues, quiet rooms, toilets…
  - Interpreters, captions etc



Checklist for accessible research

Information

Key documents: Outline of project, information sheet, consent form, summary of results

Information sheet outlines access accommodations	Essential

Checklist for Accessible Meetings

Highlighted items are most critical

Getting into and around venue

Step free entrance? (Thresholds <3cm high) If accessible entrance isn't usual front door, clear signs needed	Yes/No
1m wide routes from step free entrance to bar/food service area, to toilet, quiet room, and to room for event?	Yes/No
Does lift or stair lift work?	Yes/No/Not

Other language translations (take care with validated outcomes – WHO translation guidelines)	Budget needed

Travel & Venues

Use Checklist for Accessible Meetings	Yes/No
Cover travel costs (ideally pre-pay)	Budget needed
Consider providing interventions / assessments in participant's home	Researcher travel budget needed

Caring responsibilities

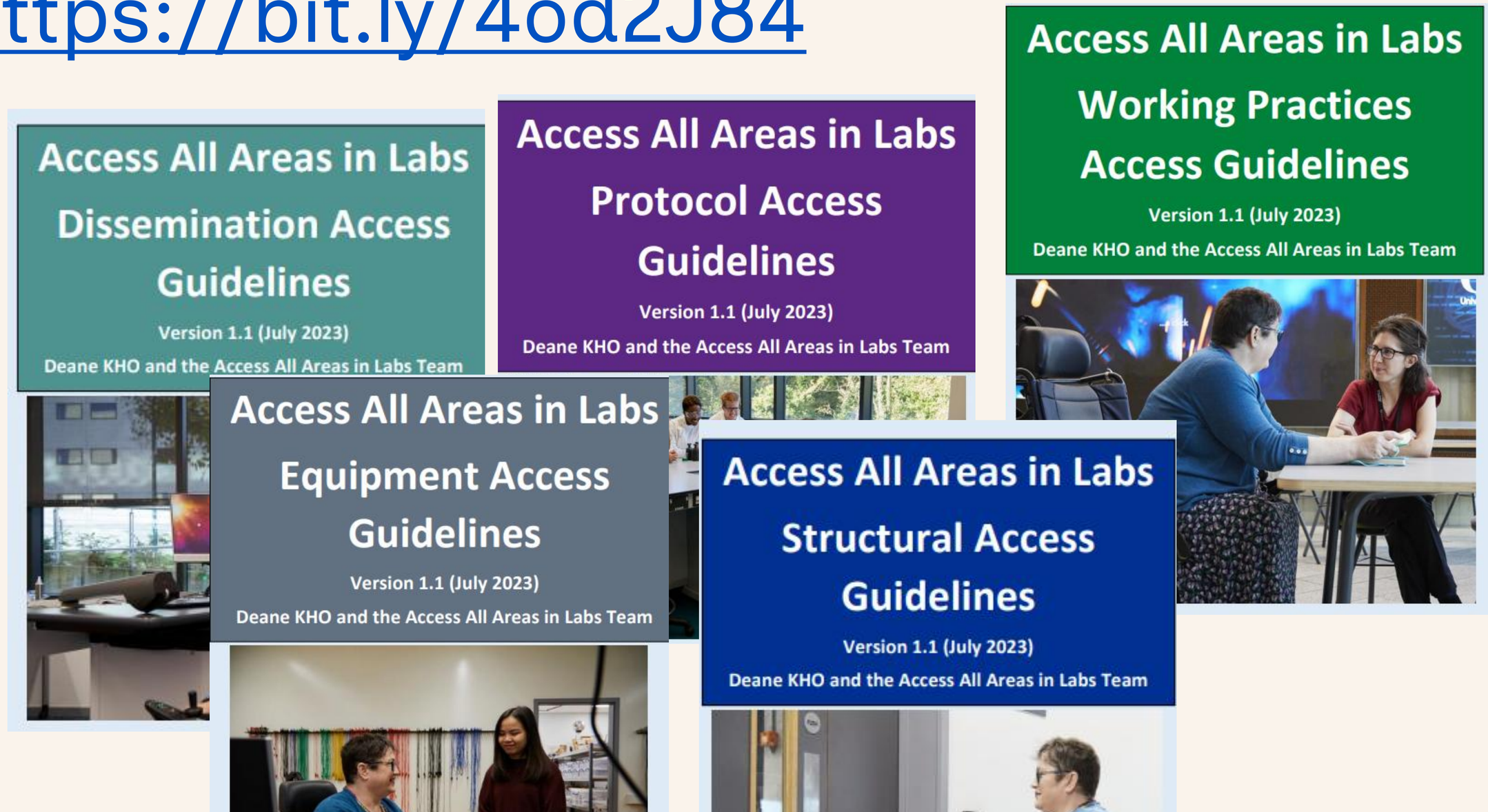
Lab access guidelines

Associate Professor Katherine Deane, University of East Anglia, UK

Getting the basics wrong

- Ergonomics
  - 46% ergonomic adjustable seating
  - >90% benches & equipment not height adjustable
- Toilets
  - 68% labs in building with accessible toilet
- Safety
  - 80% did not have a PEEP
- Poor access = poor safety, unlawful practices, poor recruitment, poor retention
- Suite of access guidelines

Access Guidelines: https://bit.ly/4od2J84



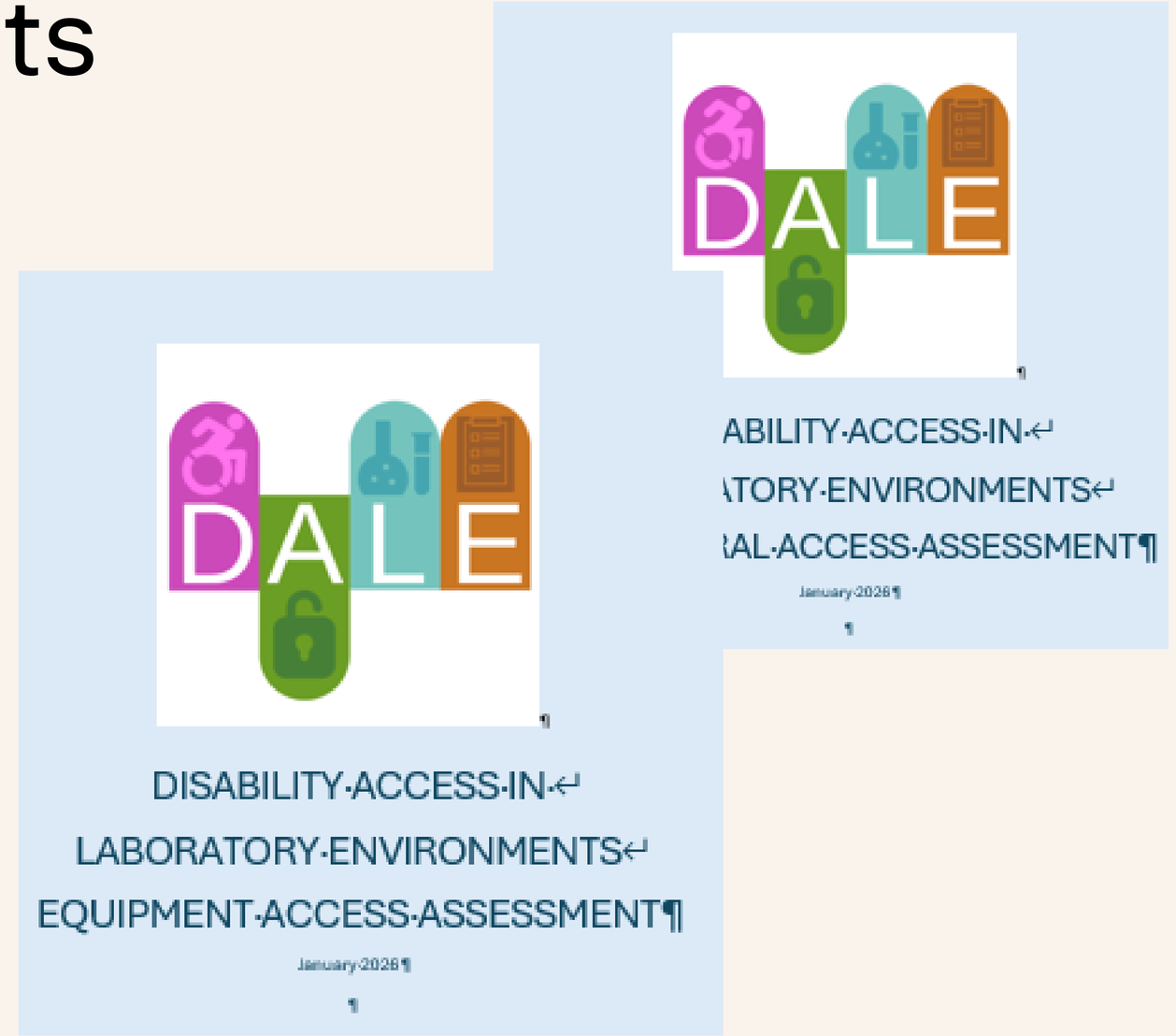
Nice – but do they work?

- New Science
  - New build
  - Labs for biology, chemistry, physics, electronics
  - 6 years use
- Productivity East
  - Refurbishment
  - Engineering workshops
  - 5 years use

- Design is safe, durable, effective
- Works well for everyone
- Amendments generally of the “Yes, but more” kind

Access Assessments

- Derived from guidelines plus expert advice
- Tested across 4 institutions and multiple lab types
- Working on sharable electronic version
- Pragmatic assessment of disability access
- Provide info that can be shared on web pages
- Allow creation of list of future improvements



Assessment as an intervention

- Raised awareness and increased priority
- Challenged and changed thinking about disability access
- Highlighted deficits in current practice
  - PEEPs for temporary impairments due to injury (need to ask)
- Highlighted need for access consideration in
  - Maintenance
  - Equipment purchases (discussions with manufacturers)
  - Refurbishments and new builds
- Created a “long list” of access barriers
  - Quick wins and long-term considerations

Accessibility as a system

- Small things can lead to large impacts – positive and negative
- Limited training – commonly staff pay out of pocket
- Advocates unsupported – risk burn out, worry about acting outside scope of expertise
- Information fed into university but doesn't feed back to staff in labs
  - PEEPs, requests for reasonable accommodations, accident and near miss reports
  - Limited sharing of knowledge – reinventing wheels
- Challenge of assessing the less tangible aspects of disability access – attitudes, behaviours etc

Accessible environment driving culture change

- *“It does actually embolden people. It feels like it is literal, inclusive practise in action. And I think we are increasingly seeing students who are happier to talk about their additional needs. And as a cohort I think they are very supportive of each other in terms of people that might not look like them”*

k.deane@uea.ac.uk

- DALE Accessible meeting checklist: https://bit.ly/4wmYtHE
- DALE Accessible research checklist: https://bit.ly/4demNUN
- DALE Access assessment (coming soon): https://bit.ly/4wxJefa
- Access All Areas Access guidelines): https://bit.ly/4od2J84
- Deane K, Burrill B. Step up and be an ally – accessible labs benefit everyone. *Biochem (Lond)* 2024; bio_2024_138. https://doi.org/10.1042/bio_2024_138
- Deane K et al. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. 2019 *BMJ Innovations*. https://bit.ly/4wtaETm
- The home of the COM-B model The COM-B Website
- Brage T, et al. (2016). Core values work in academia: – with experiences from Lund University. Lund University https://bit.ly/4tyQGnp
- DeCormier Plosky, W. et al. Accessibility by Design in Clinical Research Toolkit. Version 1.3, 2024; https://bit.ly/4dLpY6p

Take-home messages

Dr Anna Anderson, University of Leeds, UK

Key points

- Disabled people are an under-served group in health research.
- We all have a part to play in improving inclusion.
- Even small steps can make a big difference.

‘By taking responsibility and working in partnership with disabled people, we can all play our part in advancing disability inclusion to help achieve high-quality, impactful and equitable research.’

Anderson et al. (2025)

Key actions

- Advocate for disability inclusion.
- Use people’s preferred language.
- Collect and report disability data.
- Meaningfully involve disabled people across the research cycle.
- Maximise accessibility and inclusion.
- Promote inclusion in workplaces and teams.
- Build your knowledge and skills in disability inclusion.

Thank you!

Many thanks for joining and to all the people and organisations who have supported this webinar.

This webinar is supported by the Disability Inclusion in Research Collaboration (DIRECT), the National Institute for Health and Care Research (NIHR) Biomedical Research Centre Leeds and the NIHR HealthTech Research Centre in Accelerated Surgical Care. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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Questions

Join at: vevox.app

ID: 179-519-560

20 Years

nihr.ac.uk