# Reflections in accessibility and inclusion in PPIE

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#### Why focus on inclusion in research?

* Diversity of team’s expertise = creative problem solving
* Increases data quality
  + generalisability and social relevance of findings
  + through inclusion of under-served groups.
* Meets ethical standards e.g. Declaration of Helsinki amended 2024
* Addresses funder requirements:
  + NIHR inclusive research requirement - inclusion fully integrated and costed
  + EPSRC EDI plans for infrastructure grants, and colleges of doctoral training

#### Adopt social model of disability

* Shifts responsibility for change from the disabled person to their society
* Apply to all social biases
* Researchers need to do the work to ensure inclusion
* Everyone’s responsibility to take action
  + Informed by disadvantaged people
  + BUT not solely enacted by them
* Activism / advocacy necessary to overturn societal norms

#### PPIE as a tool for inclusion

* Explicitly welcome under-served communities
* Value diversity of viewpoints
* Make research design more practical and achievable
* Use of language
* Provision of assistance

#### Potential barriers

|  |  |
| --- | --- |
| * Cultural aspects * Language * Financial costs * Caring responsibilities * Travel * Time * Energy * Understanding * Relevancy | * Vision * Hearing * Mobility * Speech * Understanding information * Mental wellbeing * Energy limitations * Dietary restrictions * Toileting needs |

#### Does your web page look like me?

|  |  |
| --- | --- |
| Representation is essential  Consider diversity of   * Disability * Gender * Sexuality * Skin colour * Faith markers * Ages | Consider what people are doing   * Groups * Activities * Aspirations |

Ask your advisers for photos (Permissions)

#### How we have made this project accessible for you?

|  |  |
| --- | --- |
| Information formats   * Word/ pdf * Large print * Easy read * Videos | Accessible venues   * Step free / Toilets / Parking * Refreshments * Childcare * Near public transport * Patient’s homes |

#### More inclusion considerations

|  |  |  |
| --- | --- | --- |
| Language   * British sign language * Easy read * Translations (with caution) * Videos | Travel   * Routes (videos) * Pre-payment | Meeting costs   * Write into grant applications * IDEA project (in UEA FMH)   + K.deane@uea.ac.uk |

#### Measure diversity

* Use detailed demographics
  + DAISY
* Tracking inclusion
* Unknown factors
* Re-use of anonymised datasets

#### References: Why bother?

* Inclusive research design to become an NIHR condition of funding <https://www.nihr.ac.uk/inclusive-research-design-become-nihr-condition-funding>
* ‘Being disabled’ as an exclusion criterion for clinical trials: a scoping review. Camanni, G. et al. *BMJ Glob Health*. **8**, e013473 (2023). <https://gh.bmj.com/content/bmjgh/8/11/e013473.full.pdf>
* 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>

#### Where to find advisers?

* UEA Citizen’s Academy <https://www.uea.ac.uk/about/faculties-and-schools/faculty-of-medicine-and-health-sciences/citizens-academy>
* PPIRes - <https://nspccro.nihr.ac.uk/working-with-us/public-patient-and-carer-voice-in-research>
* Parkinson’s UK Research Support Network <https://www.parkinsons.org.uk/research/research-blog/our-research/parkinsons-uk-research-support-network>
* MIND <https://www.mrn.org/>
* Alzheimers UK <https://www.alzheimers.org.uk/research/get-involved/our-research-network-volunteers>
* MS Society <https://www.mssociety.org.uk/research/take-part-in-ms-research/research-network>
* Stroke Association <https://www.stroke.org.uk/research/get-involved-research/take-part-research>

#### Best practice and guidelines

* Deane K, et al. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative 2019 BMJ Innovations. 13. DOI: 10.1136/bmjinnov-2018-000317 <https://innovations.bmj.com/content/5/1/43.info> (Just Table 3)
* Access All Areas in Labs Dissemination Access Guideline <https://bit.ly/3ZjsgCB>
* Patients focussed medicines development [https://patientfocusedmedicine.org/#](https://patientfocusedmedicine.org/)
* INVOLVE <https://www.invo.org.uk/>
* Synapse <https://synapse.pfmd.org/resources>
* Improving inclusion of under served communities <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435>
* DeCormier Plosky, W. et al. Accessibility by Design in Clinical Research Toolkit. Version 1.3; <https://mrctcenter.org/diversity-in-clinical-research/tools/abd_toolkit/> (Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard (MRCT Center) 2024).
* iHEAR Peers for Equity; <https://www.sangath.in/projects/ihear-peers-for-equity> (Sangath, accessed 12 September 2024)
* DAISY DIVERSITY AND INCLUSION SURVEY (DAISY) QUESTION GUIDANCE - WORKING DRAFT (V2) <https://edisgroup.org/wp-content/uploads/2022/05/DAISY-guidance-current-upated-May-2022-V2.pdf>

#### Thank you

* Guideline link – Dissemination Access
* <https://www.uea.ac.uk/web/groups-and-centres/projects/access-all-areas-in-labs>
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