

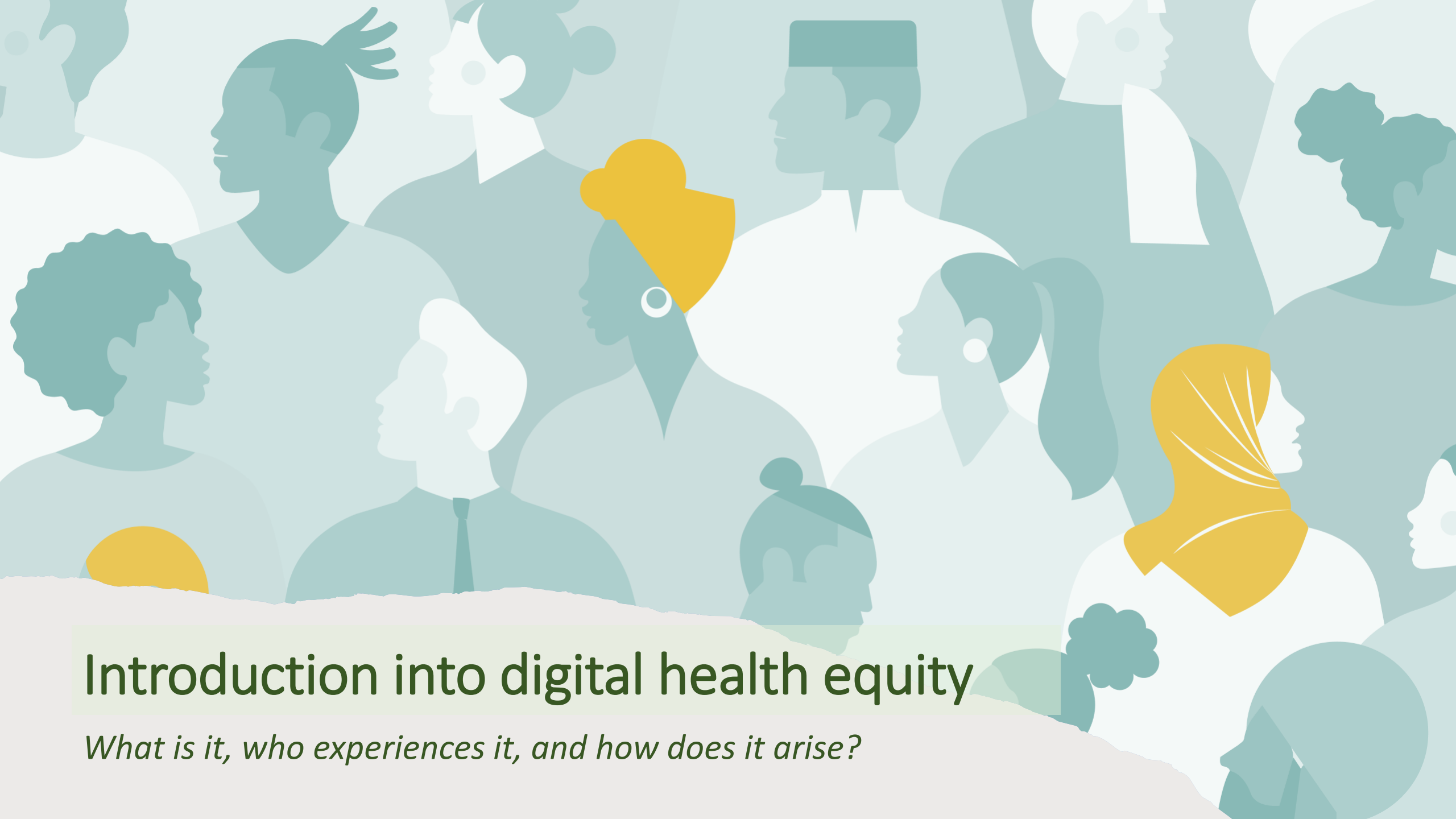
Considering health equity when using digital technology for research data collection

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University of Manchester

Health Research from Home webinar, November 2024

Webinar topics

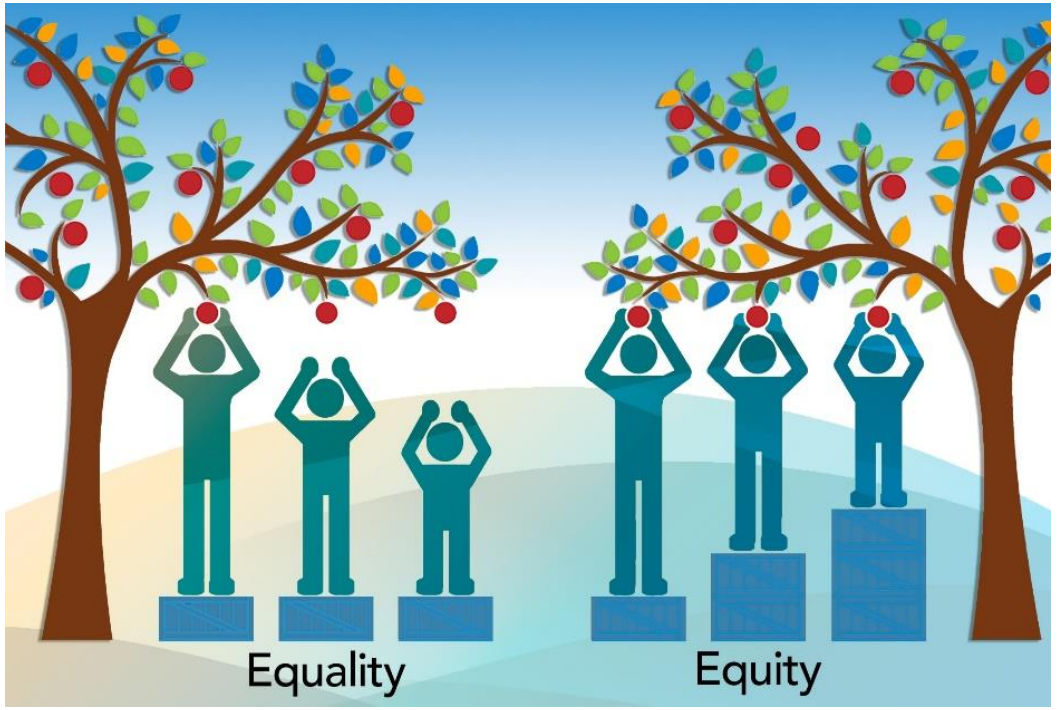
1. Introduction into digital health inequity
   - What is it? Who experiences it?
2. Managing health equity impacts of digital technology
   - Approaches and strategies, including cultural adaptation
3. Digital health equity for ethnic minority groups
   - How to widen participation among people from ethnic minority backgrounds in (digital) health research? What are specific considerations for ethnic digital health equity?



Introduction into digital health equity

What is it, who experiences it, and how does it arise?

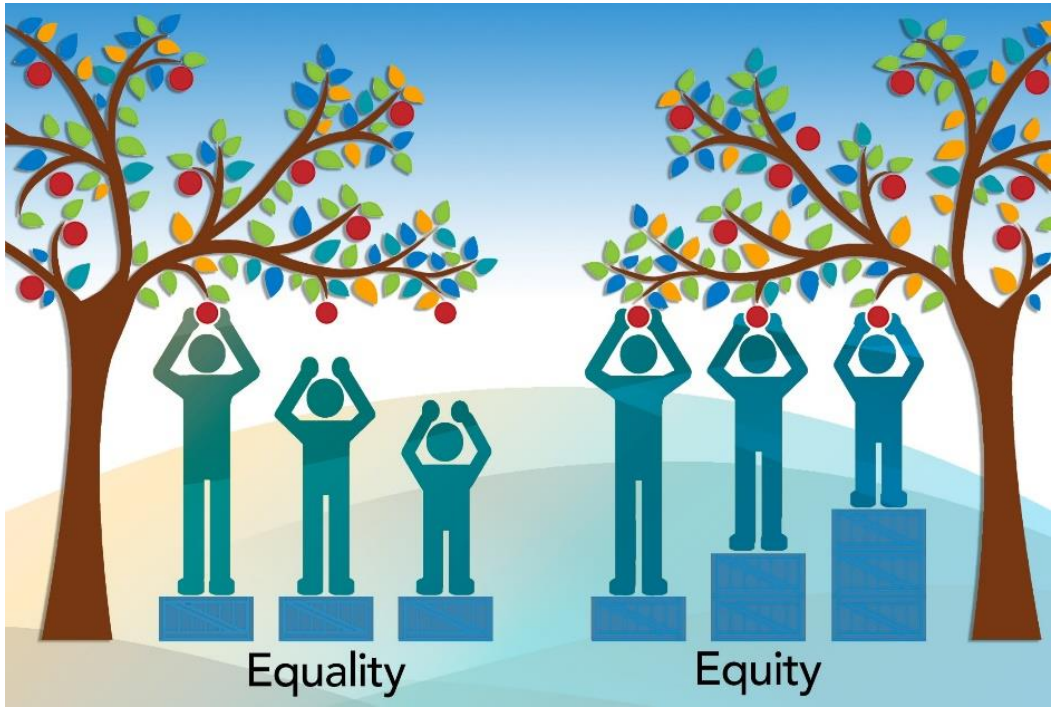
What is health equity?



Health equity (WHO)

The absence of *unfair* and *avoidable* or *remediable* differences in health among population groups defined socially, economically, demographically or geographically

What is digital health equity?



- Equity* in the design of digital health solutions
- Equitable access to digital healthcare
- Equitable uptake of digital healthcare
- Equitable outcomes from and experience with digital healthcare

* absence of *unfair* and *avoidable / remediable* differences

Richardson et al 2022 DOI: 10.1038/s41746-022-00663-0
Veinot et al 2018 DOI:10.1093/jamia/ocy052

Who are at risk of experiencing health inequities?

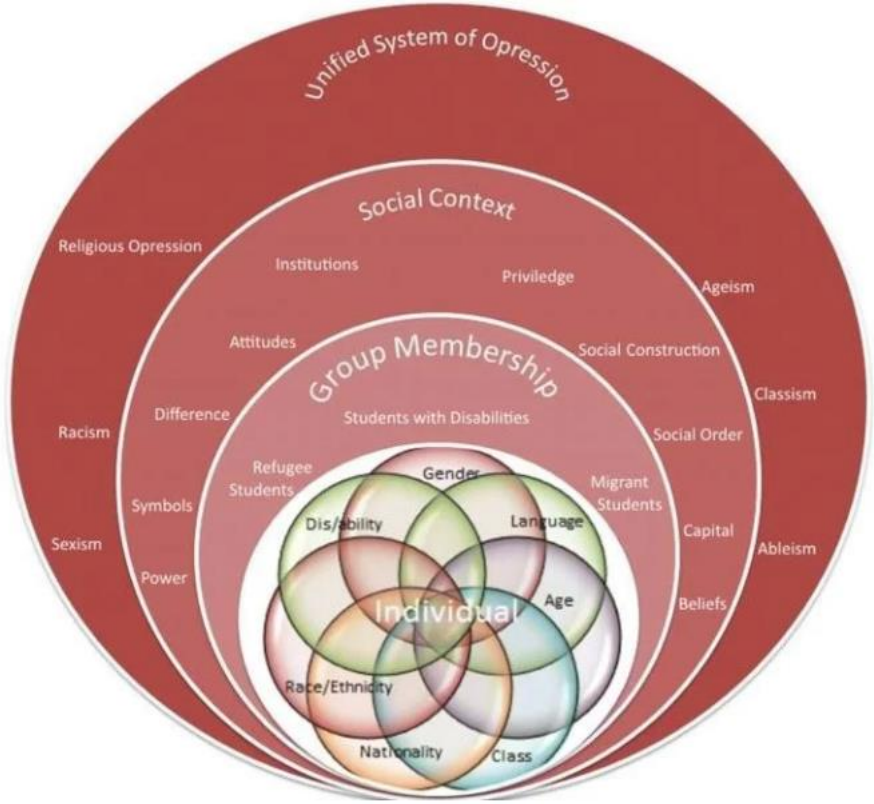
Social determinants of health

- **PROGRESS** refers to:
  -  Place of residence
  -  Race/ethnicity/culture/language
  -  Occupation
  -  Gender/sex
  -  Religion
  -  Education
  -  Socioeconomic status
  -  Social capital

-  **Plus** refers to:
  1) personal characteristics associated with discrimination (e.g. age, disability)
  2) features of relationships (e.g. smoking parents, excluded from school
  3) time-dependent relationships (e.g. leaving the hospital, respite care, other instances where a person may be temporarily at a disadvantage)

https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus

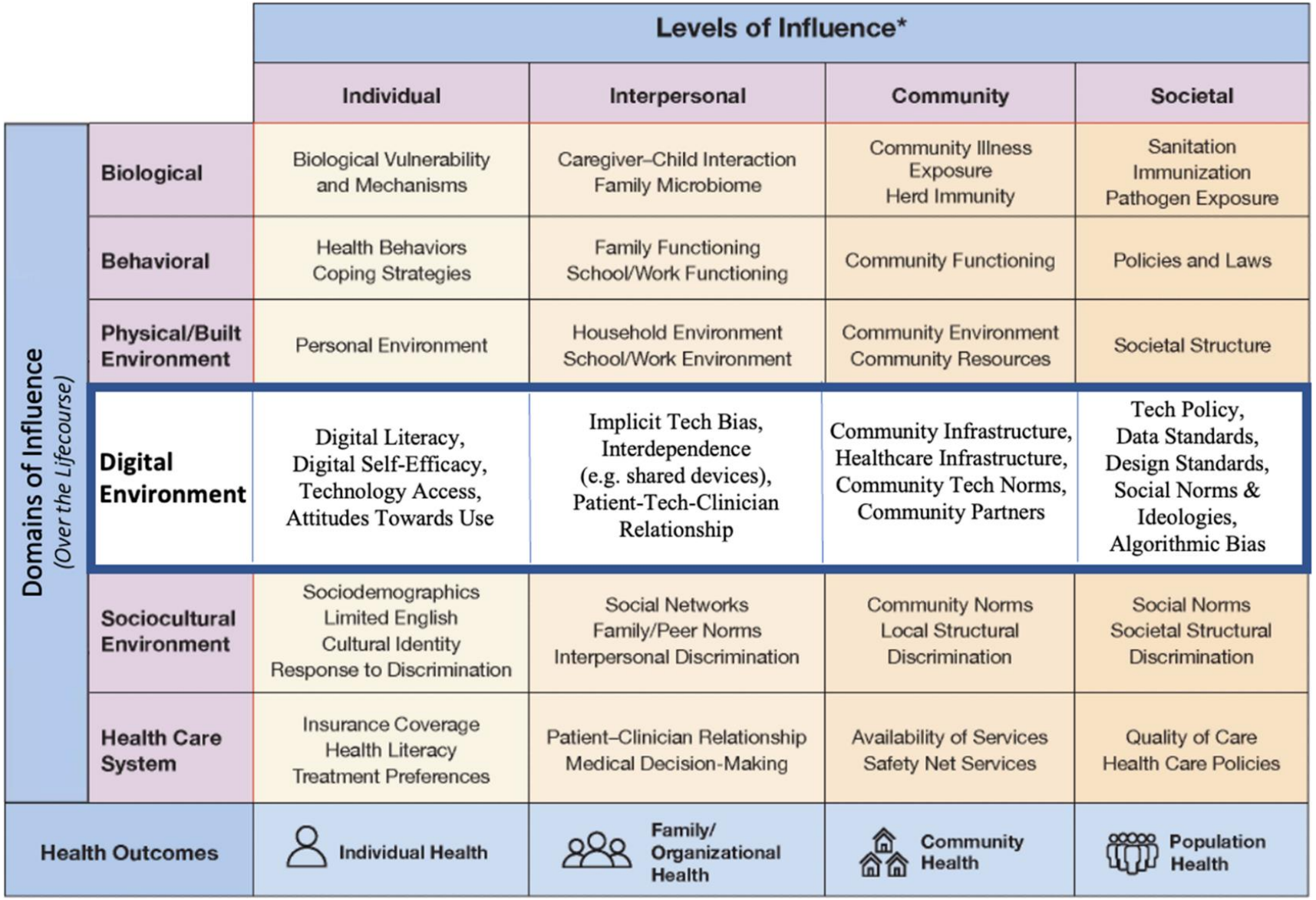
Intersectionality



A concept for understanding how aspects of a person's identities combine to create different and multiple discrimination and privilege

https://www.mitemainehealth.org/monthly-tips/positionality-intersectionality-and-privilege-in-health-professions-education-research/

Digital determinants of health



Domains of Influence (Over the Lifecourse)	Levels of Influence*			
	Individual	**Interpersonal**	**Community**	**Societal**
Biological	Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen Exposure
Behavioral	Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
Physical/Built Environment	Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
Digital Environment	Digital Literacy, Digital Self-Efficacy, Technology Access, Attitudes Towards Use	Implicit Tech Bias, Interdependence (e.g. shared devices), Patient-Tech-Clinician Relationship	Community Infrastructure, Healthcare Infrastructure, Community Tech Norms, Community Partners	Tech Policy, Data Standards, Design Standards, Social Norms & Ideologies, Algorithmic Bias
Sociocultural Environment	Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Social Norms Societal Structural Discrimination
Health Care System	Insurance Coverage Health Literacy Treatment Preferences	Patient–Clinician Relationship Medical Decision-Making	Availability of Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes	**Individual Health**	**Family/ Organizational Health**	**Community Health**	**Population Health**

Npj Digital Medicine (2022) 5: 119; https://doi.org/10.1038/s41746-022-00663-0

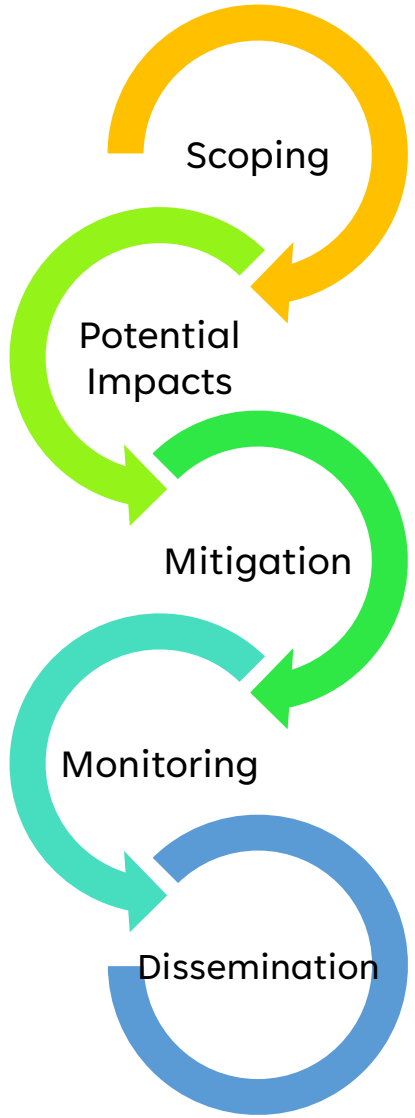


Managing health equity impacts of digital technology

Approaches and strategies

Assessing potential equity impacts

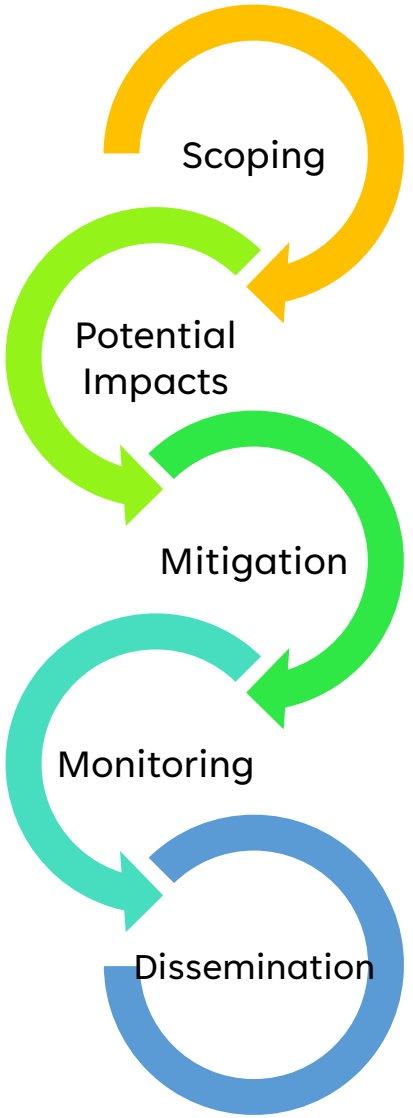
- Health Equity Impact Assessment – Digital Health Supplement (HEIA-DH)
- 5-step process for consulting stakeholders about unintended positive and negative digital health equity impacts, and strategies to manage these impacts
- Aims to prompt service providers and tech developers to consider health equity when designing, evaluating and implementing digital health technologies



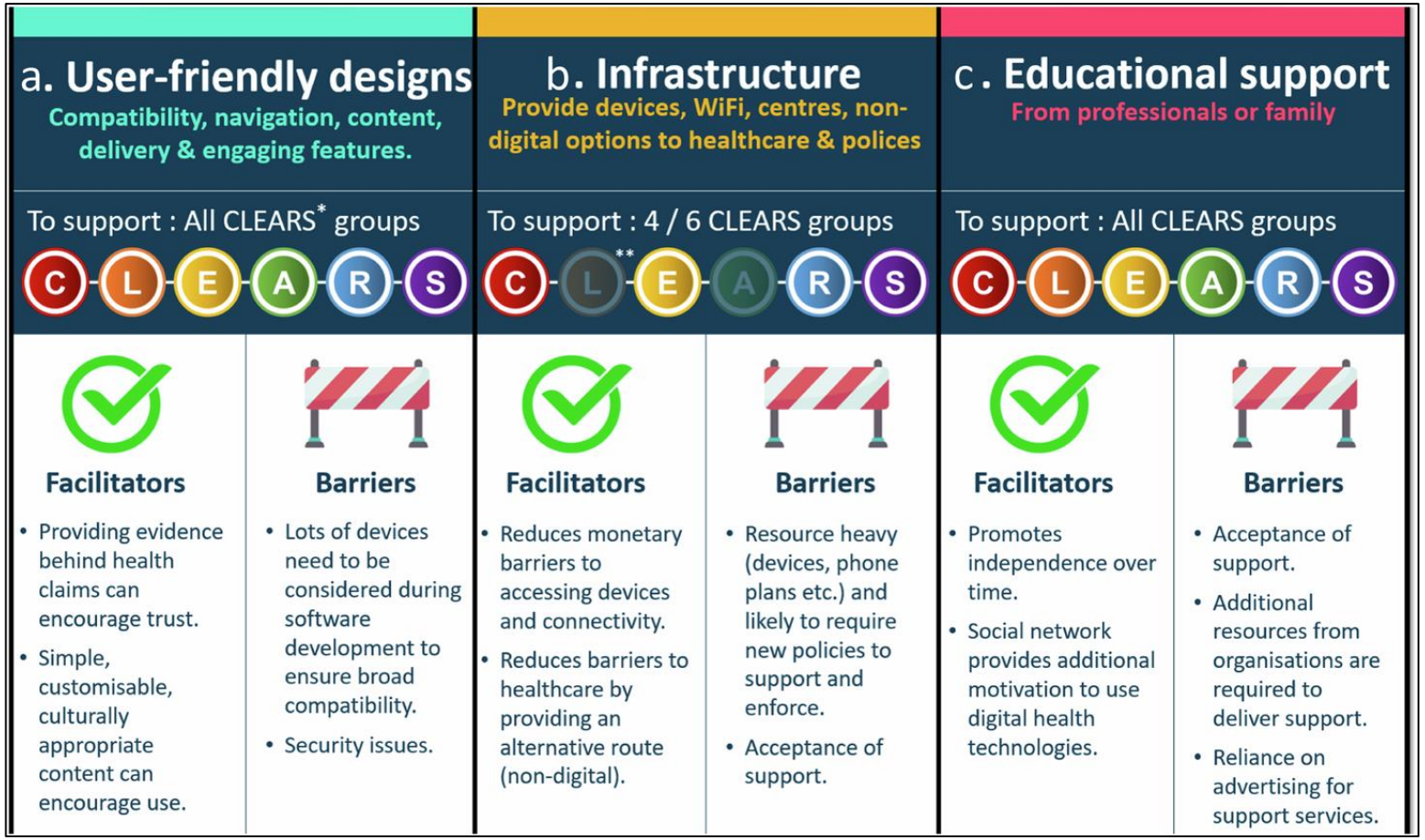
https://www.pankhurst.manchester.ac.uk/2023/09/06/improving-the-equity-of-digital-health-technology-by-using-the-health-equity-impact-assessment-digital-health-supplement-heia-dh/

HEIA-DH steps 1 and 2: example outcomes

Step 1. Scoping		Step 2. Potential Impacts		
a. population Use evidence to identify populations or groups that may experience significant unintended consequences of virtual care in you setting. Be aware of intersectional identities	b. determinants of health Identify social and digital determinants of health that should be considered	Unintended positive impacts	Unintended negative impacts	More information needed
First Nations, Inuit and Métis People living in remote communities	• Access to internet • Colonization and history of racism within healthcare	• Increased access to healthcare close to home • Decreased travel	• Services may not be experienced as culturally safe or meaningful • May not want to access avail services	• What are holistic models of care that have worked in healthcare and/ or virtual care?



Strategies to support digital health equity



Recommendations for strategy design and implementation

- Co-design technologies with end-users
- Collaborate with professionals to provide supportive infrastructure and educational services
- Raise awareness of available support for those at risk of inequities
- Raise awareness of accessibility/inclusivity standards among developers and researchers

* CLEAR groups: **C**ulture, **L**imiting conditions, **E**ducation, **A**ge, **R**esidence, **S**ocio-economic status

Wilson *et al* 2024 DOI: 10.1038/s41746-024-01177-7

Cultural adaptation of digital data collection methods

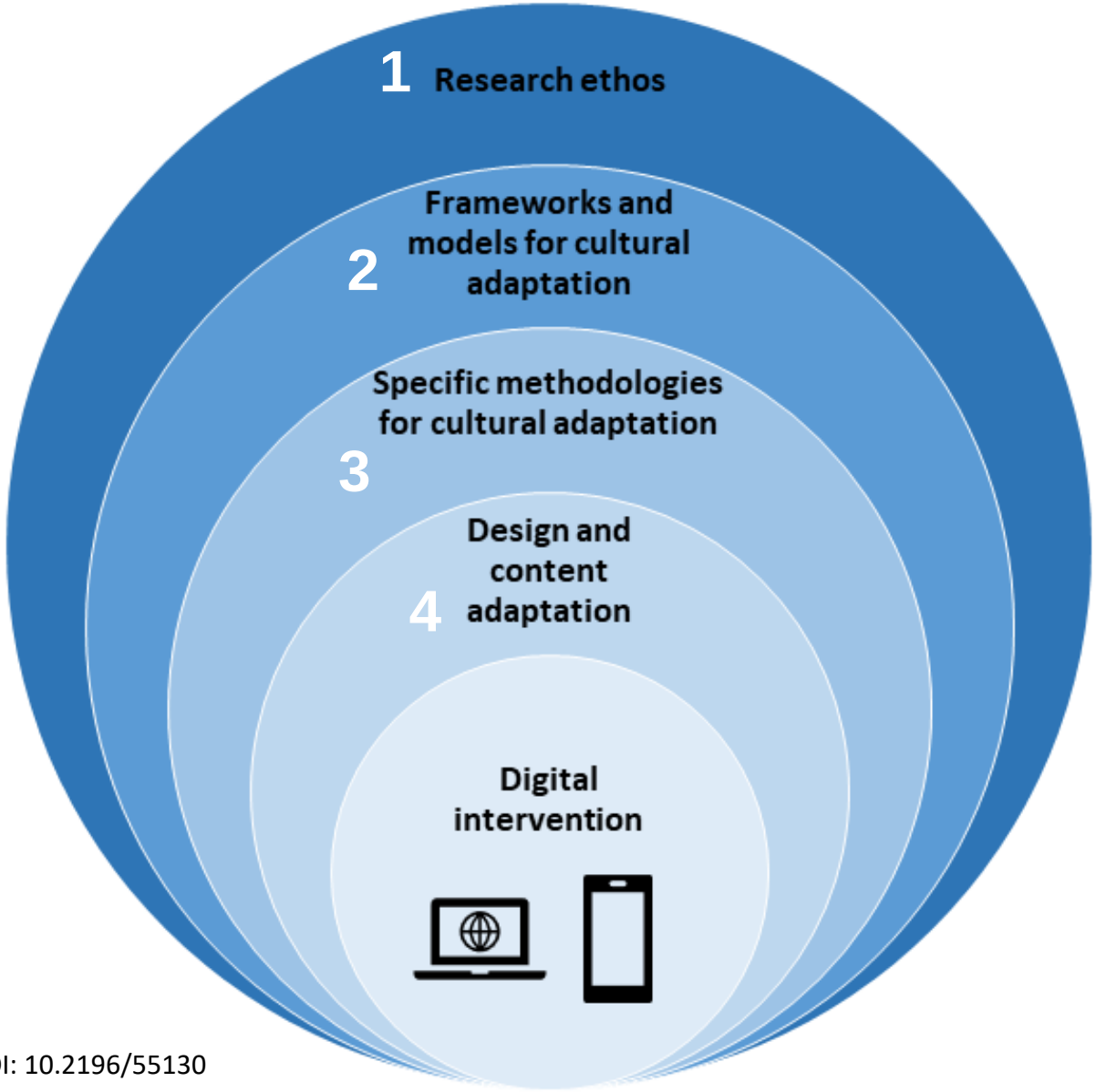
- Systematic process of isolating components of the data collection method identified as *cultural* and tailoring them to target populations without compromising their reliability and validity
- Includes but goes beyond cross-cultural validation of questionnaires
- Considers observable social and behavioural characteristics (surface level) and factors influencing behaviours (deep structure level)
- There are different layers of considerations and approaches to cultural adaptation of digital health tools (next slide)

Naderbagi *et al* 2024 DOI: 10.2196/55130

Layers of considerations for cultural adaptation

Examples within layer

1. Navigating cultural differences with research teams and partnerships
2. Ecological validity model, PEN-3 model
3. Community-based participatory research
4. Language, user interface design, format



Naderbagi et al 2024 DOI: 10.2196/55130



Digital health equity for ethnic minority groups

Methods and considerations to widen participation

Understanding & addressing the equity impact of ePGHD: case study

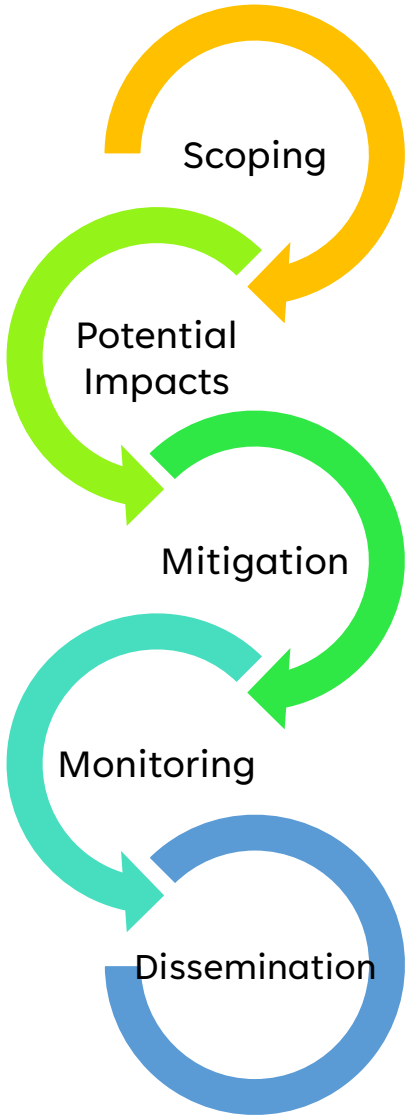


Manchester Digital Pain Manikin (MDPM)

https://www.pankhurst.manchester.ac.uk/2022/04/19/the-manchester-digital-pain-manikin/

Ethnic digital pain inequities in the UK

- Chronic pain is more prevalent among South Asians
- Prevalence is higher among older SAs
- Prevalence is higher among women
- SAs less likely to receive initial treatment with MTX or glucocorticoids (Adas et al., 2023)
- Delay in referring to a rheumatologist is 4X higher (22 weeks vs 6 weeks) (Stack et al. 2019)
- Existing digital pain manikins seldom offered personalisation features or culturally tailored aspects
- Ethnic minorities are less likely to engage with digital health tools



Whom we need to engage with?

PROGRESS-Plus

For managing health inequities

South Asians

Women

Older age

Socioeconomically deprived areas

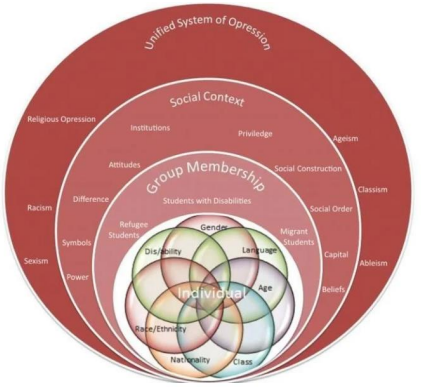
First generation immigrants

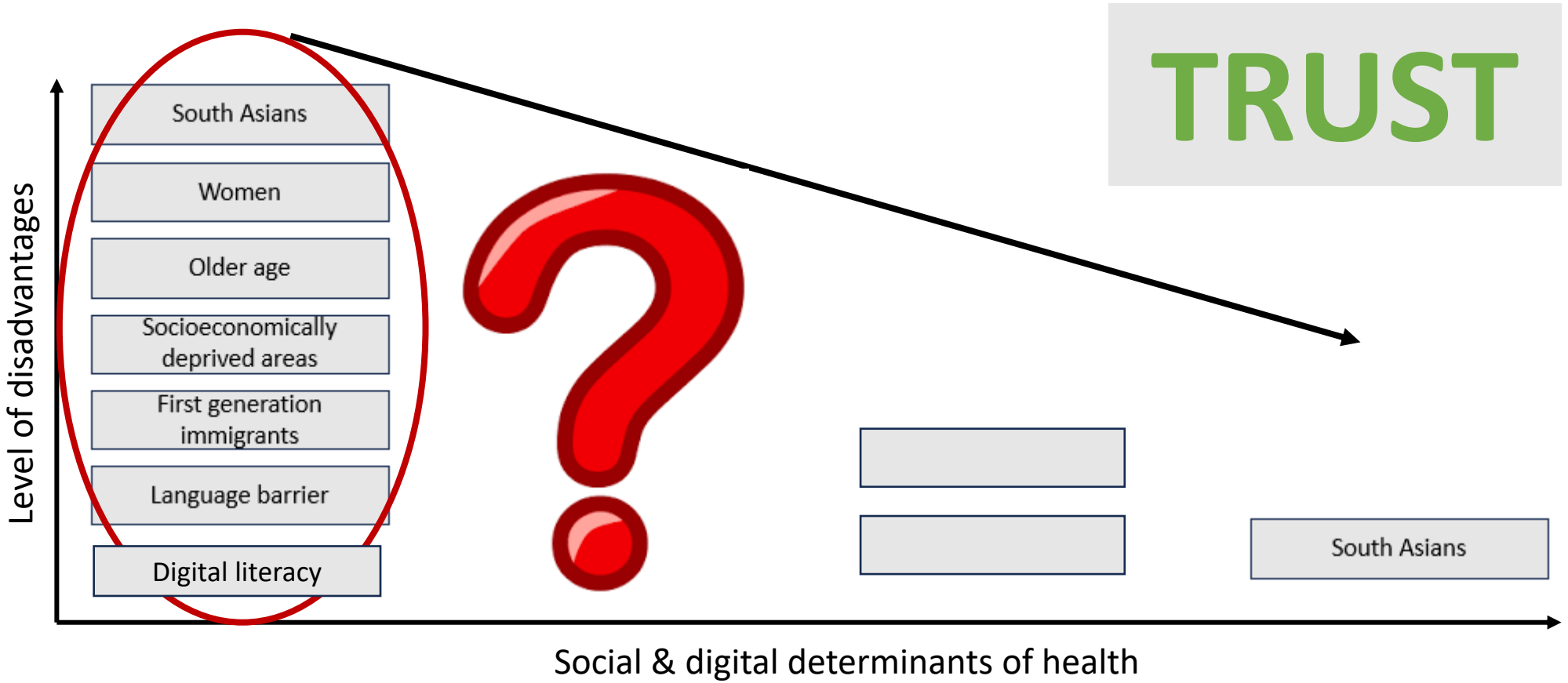
Language barriers

Digital literacy

Whom we need to engage with?

For managing health inequities

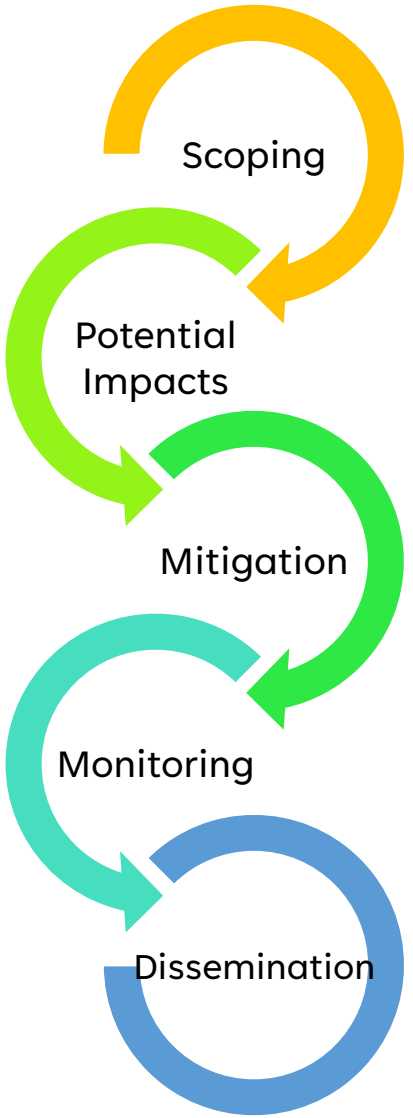




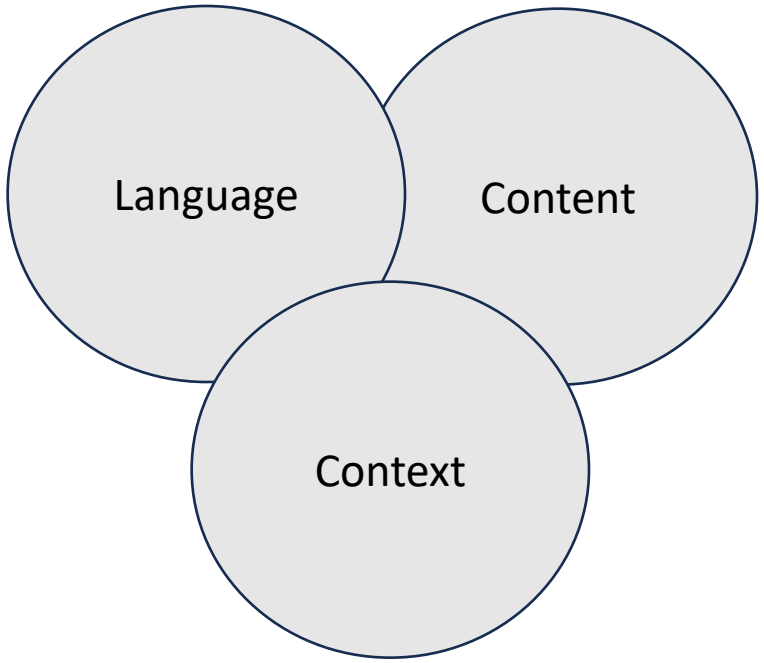
If we start considering them, would we be able to ensure their engagement and participation?

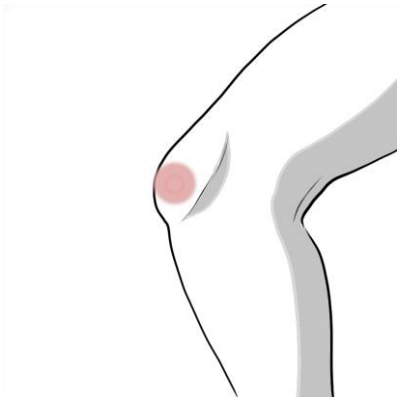
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South Asians – Pakistani	People with language barriers	Aiding patient-provider communication	Lack of knowledge of pain terminologies	

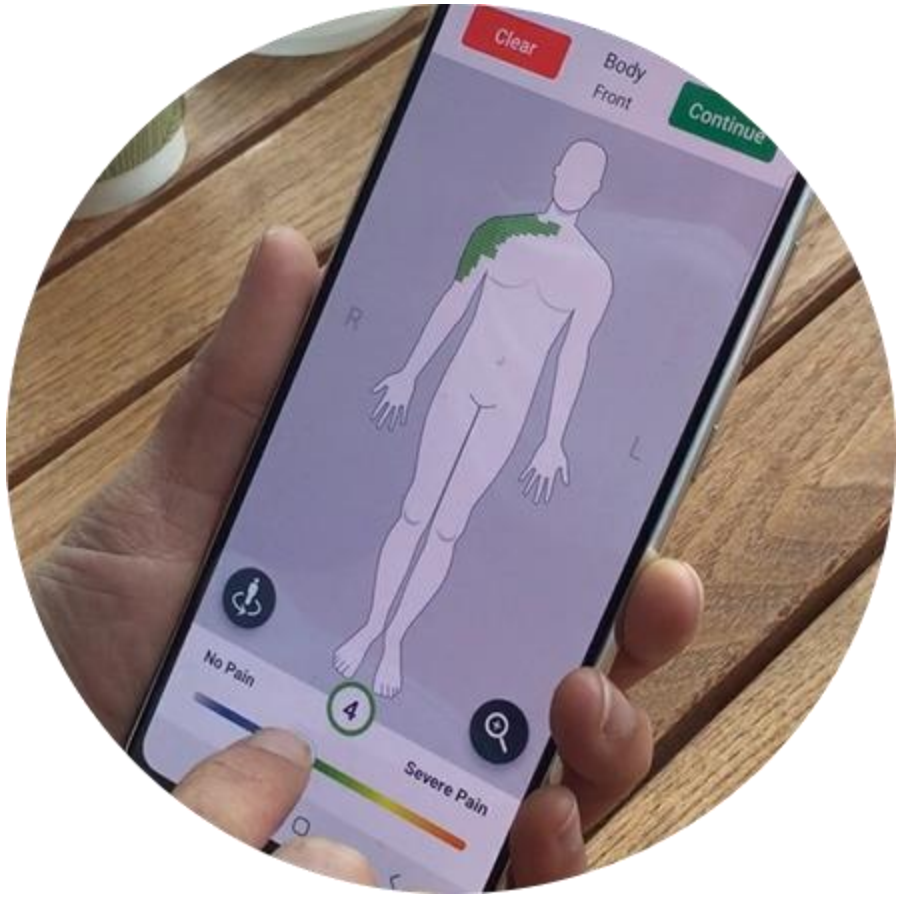


Mitigation strategies – cultural adaptation approaches





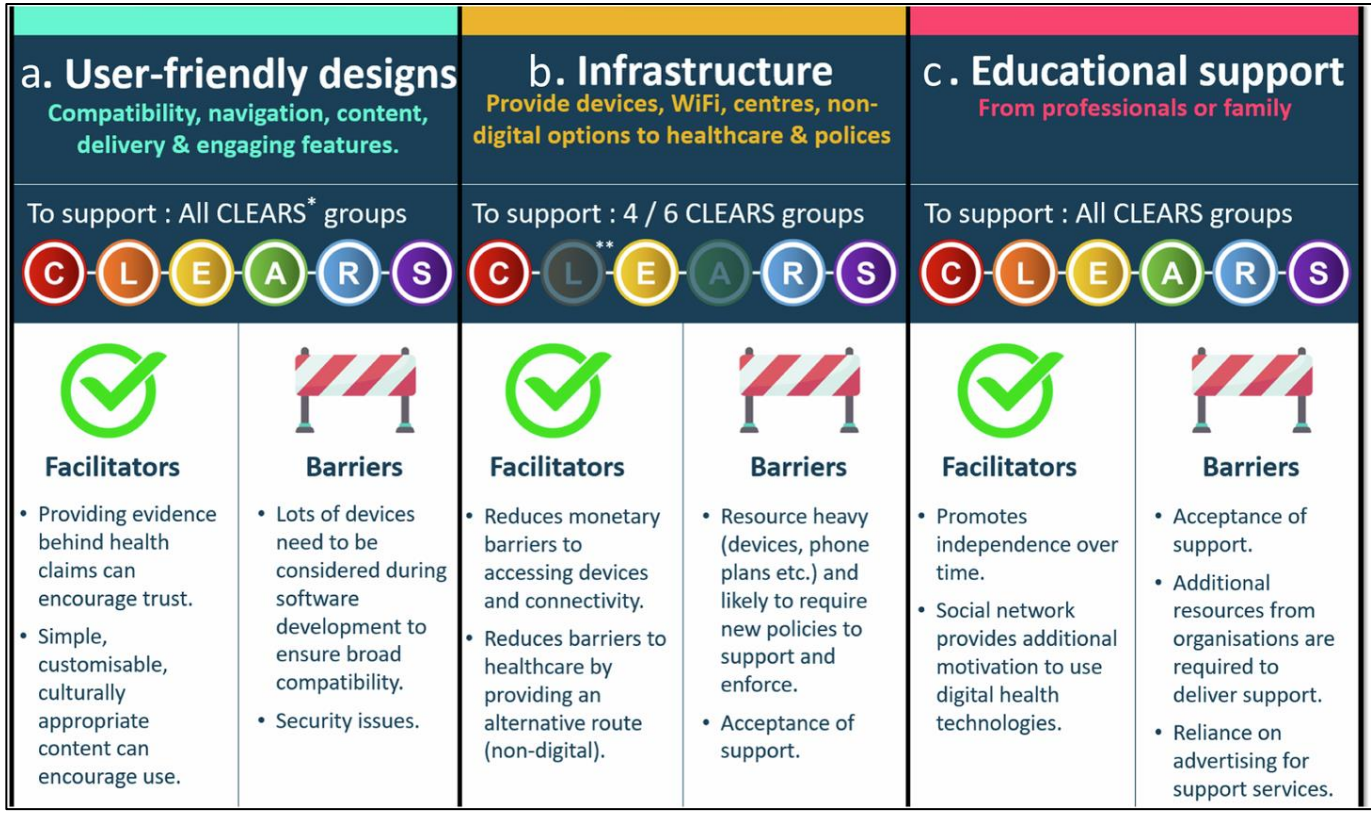
Pain terminologies
For example, pain quality descriptors



Accessibility of the tool

Inclusive research

- Trusted advocates
  - Imams & mosques
  - Charitable organisations
- Leveraging community resources (family values; cohesion)
  - Ownership of devices
  - Digital literacy
  - Health literacy



Take home messages

- Digital health inequities are unfair and avoidable differences between groups that happen when designing, accessing or using digital data collection methods
- They are associated with people's social and digital determinants of health
- There are a range of strategies you can consider for supporting digital health equity – effectively collaborating with stakeholders is key to all of them
- Proactively engage with the people who are at risk of digital health inequities to create positive research impact
- Long-term partnerships with community-based organisations can widen participation among ethnic minority groups and contribute to sustained digital health equity



Thank you

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