

Making the invisible, visible: Using participatory photovoice and mapping methods to work with undergraduates with Multiple Sclerosis in HEIs across the UK

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How can participatory methods and the use of smart phone cameras, capture and map the intersectional experiences of students with MS in the spaces of UK Higher Education?

- This project uses a theoretical framework of Critical Disability Studies (CDS) and a conceptually coherent methodological approach in inclusive participatory methods.
- It unsettles the historic ableist divisions of the academy between the non-disabled researcher and the disabled subject (Dolmage 2017: 4), by uniting a disabled researcher with MS and HE students with MS in the co-production of knowledge.
- It uses research methods which evidence how disability is produced within the **Environments of Higher Education**.

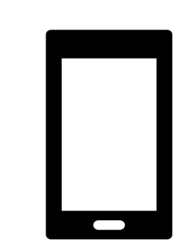
Theoretical Framework > Research Methods

- CDS is critical theory allied approach which favours ‘collaborative’ (Lather 2006:39), and transformative research methodologies. Therefore, participatory methods are in paradigmatic alignment with a CDS framework.
- Research using participatory methods capturing the specific experiences of undergraduates with one condition in HE.
- Grounded in a theoretical understanding of spatialised social power (Massey 1996:120), these methods work on visualising and mapping how students with invisible physical and cognitive impairments are enabled or disabled by environments of HE and urban transit.

Participants

- 7 Undergraduate students, 19-21 years old, living with MS across 6 UK universities. Participants are of diverse backgrounds and ethnicities.
- Recruited via MS community groups on social media & NHS MS Nurses.
- Participants compensated with vouchers for time committed to project.

Methods



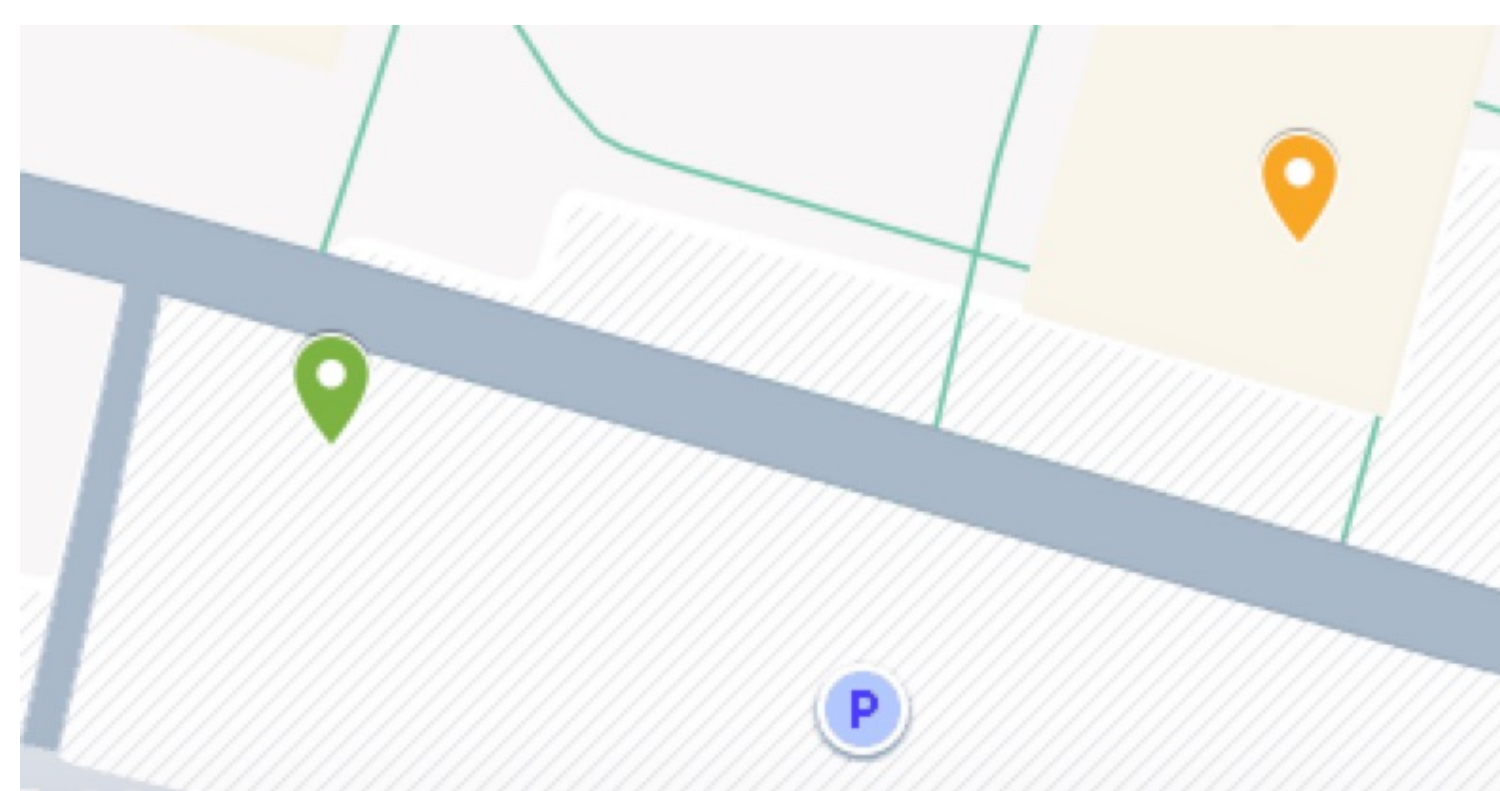
Smartphone Photovoice: Participants use phone cameras to capture journeys to, locations on campus and personal study spaces. Participants annotated photos with simple sentence on experience of place.



Digital Mapping: Photos plotted, with location pins on campus maps (inspired by Amie Hamraie’s Critical Access Mapping (2018)).



Workshops: Collaborative analysis of data begun, colour coding of pins and categorization of photos.



Example fragment of location pins on an example campus Google My Map

Designing *Inclusive* Research Methods

Smartphone Based

Minimising Perceptual Barriers

- Everyday tool for participants collecting data.

Minimising Access Barriers

- Participants and researcher comfortable with using adaptations on phone (ie dictation), if MS symptoms impacted on data gathering techniques.
- Ease of data capture for people with MS often living with imposing fatigue.

Visual Methods

- Capturing embodied experiences of HE spaces and the interaction with participants’ invisible and idiosyncratic symptoms, where there is often a ‘poverty of language’ around MS and illness (Woolf 1930: 6).
- Making visible *the disabling or enabling impact of HE spaces*: putting the focus on the space.

Methods inspired by Gen Z MS community on social media

- Many parts of MS community have a positive social media presence, especially Gen Z. Hence the annotated, personalised phone camera images are also inspired by the Instagram tools they use to connect and share their stories.

Digital Mapping

- Used private personalised interactive Google ‘My Maps’ platform- again a familiar tool.
- Inspired by Critical Access Mapping (Hamraie 2018), but this mapping process designed and undertaken independently by each participant on their different campuses.
- Making the invisible, marginalised experience visible: Locating the connections between spaces and intersectional feelings of belonging or exclusion.

Participatory Workshops

- Online- fostered a sense of openness amongst participants, speaking from comfortable home environment.
- Workshop activities included colour-coding location pins and categorising photos by participants, this began collaborative analysis.

Ethical Considerations

- Use of smart phones and tech platforms as tools and a site for data produced to sit, albeit as safely as possible (Kara 2015: 51).
- Staying cognizant of power imbalance between researcher and participants, despite many shared lived experiences, as well as the researcher’s continued ‘impact on the scene’ (Tracy 2010: 842).

Methodological Considerations/Impact

- Transformative ? : Despite reservations about how much participants would be interested in any sense of collective identity or shared endeavor in the project; participants voiced their belief in the importance of collective research and action against disabling practices and spaces in both the main and pilot study.
- All participants expressed the desire to connect with other undergraduate students with MS, people in their exact context and age demographic, and saw this to be a key benefit to their collaboration in the research.

Next Steps

- Initial collective analysis continues with participants.



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<<For all references
and more information

