

Understanding and Implementing Lived Experience Research

Insights, Methodologies, and Applications

Lived Experience

Lived experience offers profound insights through first-hand accounts, emphasizing individuals' personal perceptions and emotions regarding their social, cultural, and historical contexts. Understanding the lived experience of place involves comprehending how individuals perceive, interact with, and are influenced by their physical and social environments and the consequent impacts on their physical and mental health and well-being.

It has been observed by the Community Empowerment Group that there is a risk of a “cluttered landscape” and a duplication of effort in the employment of lived experience methodologies across our communities. This paper is the combination of a mapping exercise undertaken by the CEG of lived experience methodologies being used and scoping research and literature review undertaken by the embedded researcher from HDRCA.

Lived Experience Approaches Identified by the Community Engagement Group

Seven approaches to lived experience were identified by the CEG: interview methods, focus groups, community media, regular meetings, youth forums, steering groups and co-design associates,.

- **Narrative Interviews** were conducted by Community Justice staff in collaboration with the University of Aberdeen and HDRCA which aimed to gather insights from vulnerable individuals who had been involved with the justice system. Community Justice staff were upskilled in qualitative interviews and data analysis from HDRCA and the University of Aberdeen.

The **benefits** include gathering detailed life experiences to support service improvement and upskilling staff for future engagement opportunities.

The **challenges** of recruitment from this population is recognised. Incentives were in the form of a £20 gift card were provided.

- **Focus Groups:** CFINE established a reference group on behalf of the Food Poverty Action Group to engage a diverse range of individuals with lived experience of poverty. The group meets at least once a month in CFINE's premises to discuss topics on agreed themes including public policy, local interventions and political engagement.

The **benefits** include raising awareness and informing public policy.

The **challenges** include recruitment and participation on a regular basis, although support including, lunch, travel expenses, and shopping vouchers helped with this.

- **Community Media:** involves communities creating or co-creating media such as films, podcasts, radio shows, or magazines. This approach allows individuals to share their personal lived experiences without participating in broader media production, and it can be done anonymously. Examples of community media include shmu's "Cost of Warmth" documentary, "Challenge Poverty" video, shmu Press magazine, and shmu In Focus podcasts.

The **benefits** of community media include a sense of ownership, development of creative and technical skills, and inclusivity for those with communication barriers.

The **challenges** are that this method is resource-heavy and time-consuming, often requiring training and support.

- **Regular Lived Experience Group Meetings:** have been established to share information and expertise to inform a project. These meetings help build bonds and trust among participants, providing a supportive environment where individuals can share their experiences and insights. For example, the group has engaged in film making to share information and experience of 'No recourse to public funds'.

The **benefits** of these meetings include fostering a sense of community, enhancing a project's relevance and effectiveness, and ensuring that the voices of those with lived experience are heard and valued.

The **challenges** are the need for long-term commitment from participants and proper budgeting to support the meetings.

- **Youth Forums:** 151 young people were involved in designing a resource to engage young people in issues that affect them. Developed with young people from Granite City Speaks, the youth forum with the Dennis Law Trust, and Aberdeen Foyer, the approach recognizes that there is no one-size-fits-all method for involving young people and provides suggestions for individuals and organizations to consider when engaging them. These include: where and when young people would be most open to answering questions; explaining clearly and using appropriate language; getting to know the young people; and valuing their time.

The **benefits** of this approach include obtaining honest opinions from young people and involving them in the development of resources.

The **challenges** are careful planning when engaging young people.

- **Steering Groups:** bring real-life perspectives to policy development, ensuring diversity and inclusion, and providing tailored support and skill development for participants. An example of an ongoing project is Aberdeen City Council's commission of the Scottish Women's Budget Group to explore the impact of poverty and gender inequality on women and their families and identify solutions. SWBG will develop a non-extractive community research project that takes an intersectional lens to gender inequality.

The **benefits** of these groups include creating policies that better reflect the real needs of people, ensuring diversity and inclusion, providing tailored support and skill development for participants, and giving policy and projects more credibility.

The **challenges** are that people with lived experience may find it difficult to commit to the role and may also find it emotionally taxing. The capacity of the organization to provide the support needed for people with lived experience to engage can result in tokenistic engagement .

- **Co-Design Associates:** are individuals with lived or living experience of the issue being addressed who work closely with the project team at every stage to ensure the work is meaningful. For example, The Changing Futures project is a joint initiative by the Ministry of Housing, Communities and Local Government and The National Lottery Community Fund aimed at organisations working in partnership to better support people who experience multiple disadvantage.

The **benefits** of involving co-design associates include meaningful inclusion of lived/living experience voices, ensuring that the work is centred on the issues that are most pressing for the affected population.

The **challenges** are that involvement of a co-design associate is often varied and requires a large time commitment and co-design associates may need additional support to ensure their continued involvement in the work, incentives are also often necessary.

Lived Experience Approaches Identified in the Research Literature

Visual Methods

Visual methods can enrich lived experience research by incorporating photographs taken by participants, researchers, or co-created images into in-depth interviews. This method, known as photo elicitation, has been utilized to explore the relationship between place and health. For example, Sebastião et al. (2016) used photo elicitation to better inform public health about physical activity and eating behaviours in underserved populations, while Padgett et al. (2013) employed it to understand the experiences of formerly homeless individuals. The Centre for Food Policy (2021) used photo elicitation to explore food environments.

Visual Methods References

- To better inform public health about physical activity and eating behaviour in underserved populations (Sebastião et al .2016):
<https://www.proquest.com/docview/1771106645/fulltextPDF/AAF49E131C4741A3PQ/1?accountid=8155&sourcetype=Scholarly%20Journals>

- Among formerly homeless individuals (Padgett et al. 2013): <https://acrobat.adobe.com/id/urn:aaid:sc:EU:666bba65-fffa-44d3-94c3-e78edc37d836>
- To explore food environments (Centre for Food Policy, 2021): <https://acrobat.adobe.com/id/urn:aaid:sc:EU:d0dd354b-663c-4d0e-a4dc-1f60e4a3a762>

Art-scaping encourages participants to use drawing, painting, theatre, video, or poetry to depict their lived experience of place. For instance, painting and drawing have been used to challenge perceptions of stigmatized neighbourhoods and facilitate access to nature among deprived communities. Drama has served as a tool to explore experiences of parenting in poverty.

The **benefits** of this approach are it captures complexity and nuances often missed by traditional methods. Participants feel more involved in the research process. It is not language-based, thus open to a broader audience. It encourages creative thinking and can lead to novel insights and solutions.

The **challenges** are that artistic data production and interpretation can be highly subjective thus analysis of outputs can be complex and time-consuming, potentially requiring specialized skills. It is resource-intensive, requiring materials, time, and expertise in both art and research.

Art-scaping References

- Painting and drawing used to challenges perceptions in and of stigmatised neighbourhoods (<https://journals.sagepub.com/doi/epub/10.1177/1468794120927683>)
- Facilitate access to nature among deprived communities (<https://www.sciencedirect.com/science/article/pii/S0272494423001202?via%3Dihub>)
- Drama as a tool to explore experiences of parenting in poverty https://www.tandfonline.com/doi/pdf/10.1080/13691457.2012.702311?casa_token=_mMDuoAACXsAAAAA:GBCKGylcmhBMJtrihxJ0phllpV_J2LU11DaQ0NdijLJMNnggfFog9HUs0meGA7wNsZIMXXkOtTP1BwA

Geospatial Methods

Geospatial methods involve participants capturing data about places that may not be covered during interviews, thus generating deep understandings of the relationships between people and places. Bell et al. (2014) conducted a study using personalized maps, participant trackers, GPS, and mobile 'go-along' qualitative interview approaches to explore people's relationships with green spaces. Thompson et al. (2013) used 'go-along' interviews during food shopping to examine environmental determinants of diet.

The **benefits** of these methods are that they position participants as experts in their environment, encouraging and empowering them to share information openly. They can provide deep insights into individuals' connections to places.

The **challenges** of these methods are that they require equipment and expertise that can be costly. There are also ethical considerations with tracking participants, particularly around data governance.

Geospatial References

A study seeking to understand the place of people's green space wellbeing practices in their daily lives <https://acrobat.adobe.com/id/urn:aaid:sc:EU:ab6163f3-fbb6-47eb-a187-ec0bd8ea90b5>

'go-along' interviews during participants' food shopping to explore the environmental determinants of diet <https://www.sciencedirect.com/science/article/pii/S1353829212001712?via%3Dihub>.

Other Methodologies

Co-design and systems mapping, and group model building emphasize participant involvement and prioritize their role in research design and execution. These methodologies propose contextually relevant, community-driven, and sustainable changes in policy. Examples of successful co-design include creating short films to identify and challenge mental health stigma from young people's perspectives; redesigning a helpline to support disabled people in the community; and using journey mapping and personas with refugee participants to gather food insecurity narratives.

The **benefits** of these methods are that it can be empowering for communities when policies reflect their lived experiences.

The **challenge** is they may be viewed as tokenistic if participant engagement is not meaningful or has little impact on policy/project.

Other Methodologies References

- Co-design approach to create short films to identify and challenge mental health stigma from the perspective of young people who have experienced it, <https://journals.sagepub.com/doi/pdf/10.1177/10497323231211454>
- Co-design to redesign a helpline to support disabled people in the community, <https://researchinvolvement.biomedcentral.com/counter/pdf/10.1186/s40900-024-00573-3.pdf>
- Journey mapping, personas used with refugee participants to design research to gather food insecurity narratives, <file:///C:/Users/CWoods-Brown/Downloads/r4a-3205-gingell.pdf>

Best Practice Statement for Lived Experience Projects

To ensure meaningful engagement and a positive impact in lived experience projects, adopting a participatory approach that respects and values all participants' contributions is crucial. Here are some best practices:

- **Authentic Engagement:** Foster an environment where participants feel heard, respected, and valued.
- **Transparency:** Clearly communicate the goals, processes, and potential outcomes of the project.
- **Collaboration:** Work collaboratively with participants at all stages of the project.
- **Capacity Building:** Provide training and support to enhance participants' skills and knowledge.
- **Feedback Mechanisms:** Establish regular feedback loops for participants to share their thoughts and experiences.
- **Sustainability:** Plan for the long-term sustainability of the project's outcomes.
- **Cultural Sensitivity:** Respect and accommodate participants' values, beliefs, and practices.
- **Evaluation:** Implement robust evaluation methods to assess the project's impact and effectiveness.