Equitable practice in lived experience storytelling

Challenges, Learning and Practical Ideas

People's Voice Media
Connecting Communities

NCRM NATIONAL CENTRE FOR RESEARCH METHODS

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This report is based on the insights and ideas from the 6th Annual Community Reporting Conference (May 2024). We would like to acknowledge the varied expertise that has enabled us to run deliver this event and produce this reporting & accompanying video.

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Conference Attendees

We are extremely grateful of the varied expertise – lived, living and learnt – that our conference attendees contributed to the event and this report. Without your generosity in sharing knowledge and curiosity to co-create with other people at the event, this report would not have been possible. Our heartfelt gratitude is yours.

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Introduction

People's stories help us to make sense of our world. They help us to see things from different perspectives and to understand society. Recently, there has been an increased interest in working with lived experience stories as data, and an openness to co-production techniques.

Stories can help to bring different voices into research and decision-making arenas. They can enable people with lived experience to influence research agendas and findings, and shift power dynamics. However, we shouldn't think of this as a perfect solution.

While such work can help to address power imbalances and enable different perspectives to be heard, it can also exacerbate divides and problems. For example, when not approached with care, storytelling can reinforce systemic issues, further marginalise voices, and re-traumatise people. It is therefore crucial to think carefully and be ready to question and improve these methods.
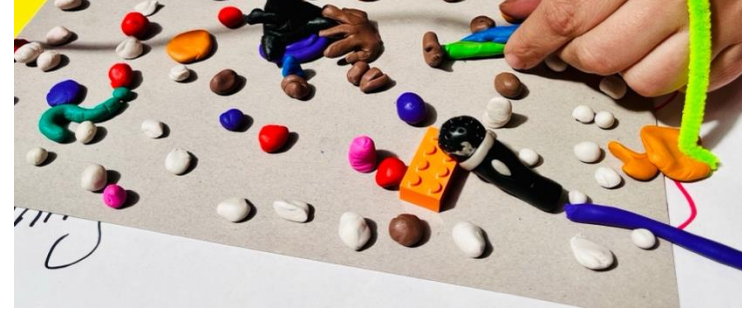
With this in mind, in May 2024, People's Voice Media convened their 6th Annual Community Reporter Conference. With support from the National Centre for Research Methods (NCRM), the conference was run as hackathon. A hackathon is an event where people come together to collaborate intensively on solving problems, creating innovative solutions, or developing new ideas. They foster creativity, experimentation, and rapid development of ideas. At the event, a group of 56 experts working with lived experience expertise in research from the academia, policy and practice came together at the People's History Museum in Salford to tackle the central questions. These experts included people with lived experience, researchers, creative practitioners and storytellers, public engagement professionals, evaluators, and third and public sector workers.

The event explored the central question of:

How can we make lived experience storytelling practice more accessible and inclusive?

It focused specifically on how storytelling could be accessible for people who do not use spoken word, inclusive for people who are neurodivergent and actively anti-racist. The event began with a range of 'welcomes' that decentered whiteness, platformed diversity and set the tone for a day of curiosity, creativity, and learning.

The hackathon was underpinned by a 'design-thinking' approach. Design thinking is a human-centered, iterative process used to solve complex problems by prioritizing empathy, creativity, and collaboration. It involves five key stages: empathize, define, ideate, prototype, and test, encouraging continuous feedback and refinement to develop innovative solutions (Brown, 2009). This approach can support us to emphasise understanding people's experiences and encourage cross-disciplinary teamwork, often leading to more sustainable outcomes.

The hackathon also used future-thinking methods to help attendees think beyond the present day. Such approaches help to "unblock decision-making and action on contentious, long-term challenges" (Ramos et al, 2019: 7). Activities in the hackathon included sharing of experiences, problem analysis, serious play and vision building, and storyboarding of future scenarios.

This report synthesises the results of the hackathon and is structured to highlight key challenges, learnings, and practical ideas for equitable practice in lived experience storytelling.

A summary video of the event can be [viewed here](#) or by scanning the QR code.

Storytelling beyond the spoken word

Key Insights

Barriers to storytelling

The hackathon identified several key challenges in making storytelling accessible for people who communicate in ways beyond spoken word. A significant issue is the overreliance on traditional spoken-word methods and interviewing techniques, which limits participation for individuals who communicate in different ways. This is compounded by a lack of knowledge and skills in easy-read and visual communication methods, preventing facilitators from offering accessible alternatives.

Additionally, hierarchies of disability further create barriers to equitable access. Attendees spoke about

Image 1: Gatekeeping of opportunities

Image 2: Making decisions for people

how in their lived and practice-based experience, they've seen individuals with certain types of disabilities given more consideration than others when it comes to the design of storytelling practices. These challenges align with existing research that critiques the privileging of verbal over non-verbal forms of communication in storytelling.

More so, when people communicate without spoken words, this can mean that people who are in support roles make decisions for them. This can limit people's choices and opportunities, as well as preventing them from taking part in activities that they may want to.

Removing the barriers

To remove barriers, we should use different methods and mediums in storytelling activities that extend beyond speech. This could include the use of visuals and crafts, of the use of auto-photography. This is an ethnographic research method that enables the researcher to see the world through the participants eyes by asking people to express their ideas through photos they create themselves. These multimodal approaches and the development of communication tools (e.g., visual aids, easy-read guides) can foster more inclusive storytelling environments.

Image 3: Use different methods and mediums to share stories

Image 4: Balance power when supporting people to communicate their ideas

It is important to understand that communication goes beyond words – spoken or otherwise (Hall et al, 2018). Taking the time to get to know people and understand body language and reactions is critical in understanding people's experiences and should be integrated into storytelling practice. Furthermore, co-produced and inclusive training is crucial, reflecting the "nothing about us without us" principle found in disability activism (Charlton, 1998). This approach ensures that participants with disabilities are actively involved in shaping storytelling processes. This should also extend into how people's stories are curated and used.

Inclusivity and neurodivergence

Key Insights

Non-inclusive storytelling practice

Rigid structures and inflexible timeframes often hinder neurodivergent individuals. This can limit the space for neurodivergent participants to express themselves in ways that suit their needs. Neurodivergent individuals can benefit from flexible, adaptive approaches. The lack of flexibility in how stories can be shared restricts opportunities for neurodivergent individuals to communicate in ways that align with their preferences such as non-verbal, visual, or alternative modes of storytelling. A focus on feelings can also make storytelling inaccessible for some people.
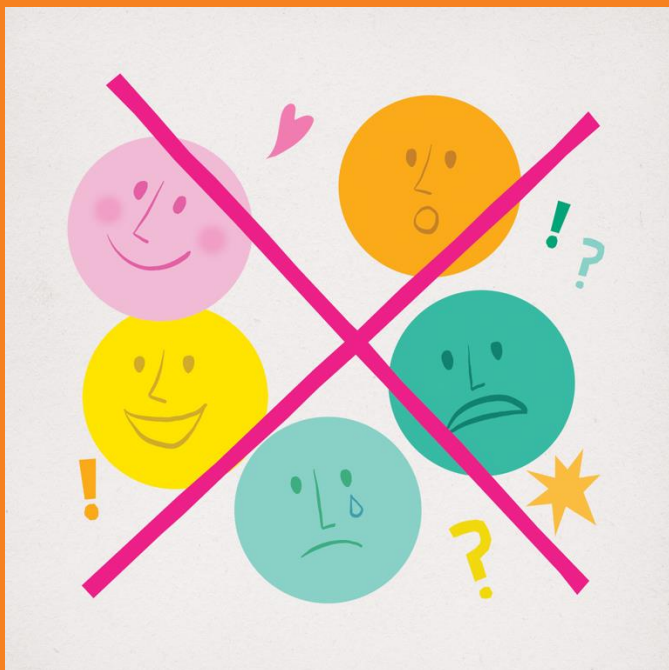

Image 6: Sensory overload can hinder people's ability to participate

Image 5: Focusing on feelings rather than events can be difficult

Sensory overload, resulting from overwhelming environments (i.e., lots of sounds, clapping, visual stimulations etc.), was also identified as a major barrier. This highlights the importance of sensory-friendly spaces for neurodivergent participation. Also, the repetition of storytelling – often framed as a requirement for deeper understanding - can feel draining and invasive. This highlights how repeated demands for personal narrative can cause emotional fatigue.

Flexible approaches that enable involvement

We learned that planning must remain adaptable and responsive to the varying needs of participants. Based on ideas from the hackathon, we suggest that storytelling practices should prioritise flexibility. Additionally, stories are frequently unheard because the methods employed don't align with the preferences or communication styles of neurodivergent individuals. Creating sensory-friendly environments is key - neurodivergent people benefit from calm, low-stimulation spaces that support their ability to participate.

Image 8: Working with people as individuals to plan the best way for them to share their story

Image 7: Finding ways to reduce sensory overload in storytelling environments

Paying attention to actions in storytelling, rather than solely emotions, can enhance engagement and understanding. Finally, neurodivergence covers a wide range of accessibility topics and thus there isn't a one size fits all approach. Speaking to the person who wants to share their story to find the best way for them to participate, and adapting workshops and activities accordingly is what we'd recommend.

Being actively anti-racist

Key Insights

Othering and Silos

The hackathon highlighted ways storytelling methods often centre whiteness, inadvertently creating "others" and reinforcing exclusionary narratives. This aligns with critiques of how dominant narratives, shaped by white perspectives, frame marginalised groups as outsiders. The lack of trust and co-creation in storytelling processes further marginalises underrepresented voices. Storytelling without genuine co-creation results in exclusion and the reinforcement of existing power structures. Such work should be restorative and healing – not just surface level.

Image 10: There is a need to break down echo chambers and work across silos for racial justice

Image 9: Anti-racist work should be healing, it shouldn't be a sticking plaster

It was also felt that marginalised voices, particularly those from global majority communities, are often given less weight in storytelling, reflecting systemic inequities that privilege certain narratives over others. Additionally, financial constraints and structural biases restrict the creation of truly inclusive storytelling spaces. Limited resources and institutional barriers perpetuate unequal representation. Finally, conversations about racial justice are happening in silos and we need to break out of our echo chambers to make real change.

Anti-racism in practice

A key insight from the event is the value of synergy between knowledge types. Lived experience, academic research, cultural insights, and practice know-how can all enrich storytelling and decision-making processes. This resonates with the notion of "epistemic pluralism", where diverse ways of knowing create more nuanced understanding. Food, music, and cultural practices can serve as powerful tools to bridge differences. Storytelling is more than words; it is a multisensory, cultural act.

Image 12: The seat of power mustn't be hard and angular with one guarded entrance. It should be like a circle with many doors that we come through and meet in the middle

Image 11: We should recognise and value different expertise and contributions

Building trust and fostering co-creation were found to be foundational for equitable storytelling. We advocate for relationships based on mutual respect and shared authority in storytelling. We should prioritise healing and long-term engagement over short-term "sticking plaster" solutions. Finally, breaking down echo chambers requires the creation of psychological safety and an openness to learning from diverse perspectives. To do this we can build bridges by decentralising power and creating open spaces for participation.

Working equitably

Recommendations and Core Practice

Recommendations

Based on the results of the hackathon, we are putting forward the following recommendations as a call to action for all those seeking to work with lived experience expertise and stories in equitable ways.

1. **Co-Production & Ethical Curation:** Ensure that all storytelling efforts are co-produced with participants and that their voices are ethically represented in the results of the storytelling activity. This could involve 'sense-making' (i.e., co-analysis of stories) with participants so that findings from a set of stories accurately represent the perspectives of the storytelling. It could also mean working with storytellers to determine how and where their stories are presented. Key to this is embodying the principle of "nothing about us without us" in your work. It is essential to ensure people who face barriers to inclusion and whose voices are often overlooked, are actively involved in shaping storytelling processes – including how the stories are used in the future.

2. **Flexibility & Inclusion:** Create flexible, multisensory storytelling environments that cater to individual needs and remove rigid structures that marginalise groups. This could include the use of visuals, image descriptions, sensory aids, flashcards, speech support devices, taking the time to get to know people's body language indicators and such, helping to overcome the overreliance on traditional spoken-word methods. More so, create sensory-friendly environments to reduce sensory overload, and consider delivering storytelling activities in smaller, trusted peer groups to empower participants to share more freely and meaningfully.

3. **Cultural Recognition & Anti-Racism:** Actively decenter whiteness by incorporating diverse knowledge systems and storytelling methods. Engage in practices that build trust and psychological safety, ensuring that stories reflect the richness of all cultures. Be careful that when recognising and celebrating different cultures – for example, adopting non-Western centric approaches – that this doesn't lead to cultural appropriation. Cultural appropriation is the adoption or use of elements from one culture by members of another, typically more dominant, culture in ways that exploit, disrespect, or misrepresent the original culture. Working with (and remunerating accordingly) practitioners from different cultures to deliver storytelling activities with diverse cultural influences is recommended.

Core Practice

These recommendations – and the learning presented in this report – should enable us to centre the voices of people who are often marginalised or excluded in lived experience storytelling practices and activities. To support people to implement them, we are proposing that people adopt the below core components of the practice that underpins taking these actions forward.
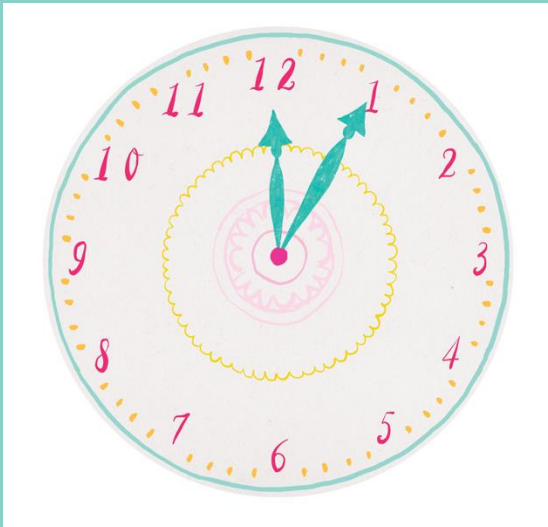
Don't Go Too Fast
Slow down the pace, be mindful of other people's schedules, develop, long-term relationships, act now for the future

Listen, Really Listen
Create spaces to listen and really hear what people are saying, be curious, seek to understand, and be open to new ideas

Work Together
Be supportive, create platforms, amplify voices, share resource, get alongside one another, move aside when needed

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