

TOOLKIT

Deepening Research & Practice: A Lived Experience Toolkit by Connecting Climate Minds



A Lived Experience Toolkit

by Connecting Climate Minds

Description

This toolkit offers a starting point for researchers and practitioners concerned with lived experience engagement in the context of climate change and mental health. It draws on lessons from international collaborations working to meaningfully integrate diverse lived realities and mental health challenges in the context of the climate crises. At its core, this toolkit serves as more than just a compendium of strategies; it's a testament to the power and necessity of lived experiences as a source of expertise and wisdom. Through insights gleaned from international partnerships and cross-disciplinary research collaborations, it offers pathways for engaging those directly impacted by climate change and its associated mental health ramifications. Drawing upon the collective wisdom of experts and individuals with firsthand experience, the toolkit offers practical guidance on navigating the complexities of lived experience engagement.

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Climate
Mental Health
Network

“Foreword

Dear Reader,

We are sending care to you today as you explore this toolkit. This document is an invitation to explore the important practice of centering lived experience as a legitimate form of expertise in research and action on climate change and mental health. We hope that you will come to see that listening to and learning from various individuals and communities that are directly affected by the interrelated challenges of climate change and mental health is not just important to create impactful research, but that it is fundamental to more inclusive research and action.

While it is not new to involve lived experiences as a form of knowledge in these fields, we have noticed some problematic trends. These trends include only involving people with lived experience tokenistically, forming partnerships that only focus on utility, treating people's experiences as something to exploit or extract, and not recognising the valuable wisdom that comes from lived experiences related to mental health and climate change. These practices can make certain groups feel excluded and replicate ways of working that prioritise victim-centred narratives over others.

Fortunately, there is a growing movement to change these practices and focus on fairness, justice, and the intentional involvement of diverse experiences in research and practice. These approaches strive to undo the harmful practices of the past, engage sensitively and respectfully, and ensure that everyone involved feels like they have a stake in the work being done. This work builds on the tireless labour of individuals and communities within both the climate and mental health spaces who have sought equal and just treatment for decades.

It is important to recognise that experiences related to climate change and mental health are complex and interconnected, influenced by environmental, political, cultural, social and historical factors. These factors have varying influences from the individual to the collective level and are deeply rooted in communities' experiences through time and space. Different cultures may have different understandings of what it means to be healthy or unwell. So, we encourage readers to think broadly about lived experiences and consider the cultural context and history behind them.

We believe that a new era of research and practice has arrived; one that not only necessitates lived experience involvement but recognises lived experience as ubiquitous and fundamental. It is up to researchers and practitioners to help usher in improved ways of working and relating. In doing so, research and practice will better reflect the communities it aims to serve and play its part in uplifting communities most impacted by compounding challenges.

The toolkit below provides learnings and reflections from coordinating an international group of researchers working to integrate lived experience practice into regional activities. It is meant for anyone interested in meaningfully engaging those often left out of mainstream research and practice efforts. It also serves as a testament to the profound insights and wisdom that come from people with lived experiences when they are meaningfully engaged. We hope you find value in the material shared and thank you for working to value and include those with lived experience in your work.

Sincerely,

CCM LE Working Group

(Ayo, Britt, Lekwa, Lian, Jennifer, Maria, Sarah, Svetlana, Sacha, Emma)



Starting: What, Why and Where

How To **Initiate** Lived Experience Work

WHAT:

Lived experience (LE) means the unique forms of person-centred and communal knowledge, insight, stories, and expertise that come from a range of experiences. The design of this toolkit stemmed from work focused on people who share lived experiences of mental health challenges in the context of climate change.

WHY:

LE leadership aims to bring wisdom and expertise from perspectives not traditionally valued or engaged in research efforts. Importantly, LE is not merely about sharing personal experiences but rather creating processes together and helping bring new and creative dimensions to the mental health and climate change field by ensuring those closest to these intersecting challenges are active collaborators across research, policy development, storytelling and practice activities.

Important considerations for exploring LE work

Meaningful LE engagement does not try to attribute individual experiences to entire populations and also asks people to speak for themselves rather than on behalf of entire communities.

It is important to examine how society actively produces privilege, racism, classism and other inequities that shape how people experience the range of determinants of mental health to guard against relaying those patterns in LE practice.

Collaboration moves at the pace of trust. In order to collaborate meaningfully, think about what it means to be trustworthy, and how to demonstrate trustworthiness. For instance, be upfront about not only the benefits of the engagement but also the costs. Benefits might include opportunities for networking, academic achievement, access to information and resources, early involvement, shaping knowledge and practice outcomes, financial compensation, and public outreach: co-authoring papers, speaking on panels, media spots, that bring visibility and reach to their LE stories and perspectives, etc. Costs might include: time and energy required to build relationships, efforts needed to come to common understanding across significant cultural differences, exposure to energy-intensive processes or overload of information, etc.

The way we use language can create barriers to understanding, and misunderstandings can easily arise and create unfortunate negative consequences for LE practice if the terminology is not unpacked and clarified, such as 'mental health' and 'mental illness'.

Just because an individual with LE is from a particular community, that does not mean they represent the whole community; often more enfranchised individuals quickly move to the forefront and may be more easily accessible for engagement regardless of if they are the most representative member of their community, which is an important dynamic to be aware of when building relationships for engagement.

Engagement with individuals with LE must always be conducted in a manner that is mindful of their need to benefit from the engagement - reciprocity is core to the work.

Engagement with LE should always be meaningful and substantive, never tokenizing or superficial so that power is shared and trust can be built throughout any interaction.

Pathways for LE Engagement in Climate Change and Mental Health

This section highlights the various ways people with lived experience can be involved in climate change and mental health research and action activities. Importantly, there are many ways to engage people with lived experiences and it is up to a project team to discern what works best for a given project. From our work over the last year, we identified the following ways people with lived experiences were able to contribute:



For these pathways to be realised, the following conditions must be in place:

- Engagement of the LE group must be voluntary; individuals expressing a desire not to participate should never be coerced or pressured to cooperate.
- Implementation of comprehensive plans involving LE.
- Adoption of flexible timelines to accommodate the needs of the project and participants.
- Commitment to proceeding at a pace dictated by the establishment of trust.
- Willingness to provide capacity building and mentoring support as needed.
- Adoption of diverse approaches for payment and distribution of funds, particularly in international settings.
- Provision of training on cultural sensitivity and trauma-informed engagement to foster trust and safety.
- Establishment of feedback mechanisms at both relational and institutional levels.
- Minimal use of research jargon and communicate in easily understandable language.
- Openness to various styles of communication and availability of different channels such as WhatsApp and voice notes.
- Availability of in-house language services or access to language support as necessary to ensure language justice.
- Implementation of appropriate safeguarding mechanisms, including considerations for mental health.
- Incorporation of accessibility considerations to accommodate the diverse needs of individuals and groups, including communication methods, consent procedures and technology access and use.

Experiential reflection: Creating multiple pathways for LE engagement in the CCM project

The expectations we asked of diverse community members who engaged as lived experience advisors for CCM included:

Share expertise and experiences in climate change and mental health from the perspective of lived experience. (This can include personal stories but does not necessarily mean sharing personal stories only. Rather it can include the wisdom and knowledge that comes from those experiences)

Inform dialogue processes with lived experience of the impacts of climate change on mental health and wellbeing.

Provide insights on intersectionality in the context of climate change and mental health, including considerations of how race, gender, class, disability, sexual orientation and other identities can affect lived experiences.

Identify cultural differences and power imbalances that may affect the development of research priorities and suggest ways to address them.

Collaborate with researchers, policymakers and other stakeholders at the global and regional levels to co-create dialogue approaches and priorities that reflect the needs of communities most affected by climate change and mental health.

Contribute to the dissemination of research findings and recommendations to relevant stakeholders, including policymakers, civil society and affected communities.



Relational approaches to LE engagement

People who have experienced mental health challenges due to climate hazards hold invaluable knowledge. Yet, their voices remain marginalised in research. To truly integrate their expertise, we need a relational approach that prioritises genuine connection, systemic change and mutual value. Here are some entry points for accomplishing this;



Conduct thorough background research to understand the experiences and challenges faced by individuals with LE regarding mental health challenges resulting from climate hazards and chronic impacts in their region.



Clearly communicate the research's purpose and provide detailed instructions, emphasising the importance of including personal stories, insights and experiences to ensure inclusivity and avoid extractivism.



Allow individuals with LE to express their needs and expectations for participation, ensuring equitable community-academic partnership.



Create a respectful space to integrate diverse LE wisdom, avoiding advice-giving and devaluing communal/individual care practices. Consider involving and training individuals with LE as co-designers, researchers, advisors and participants throughout the research process.



Demonstrate value for the insights and perspectives of those with LE by co-creating initiatives and incorporating findings and feedback into project outputs.



Fairly compensate and acknowledge the contributions of individuals with LE as participants, advisors, and researchers. This may include providing stipends for their time and ensuring appropriate recognition in project outputs. Investigate existing community guidelines on equitable pay and compensation to uphold principles of partnership and avoid historical exploitation by researchers.

Strategies for adapting project structures and work culture to meet the needs of those with lived experiences



Establish clear expectations, roles, and boundaries: Define engagement policies and procedures clearly. Where possible, incorporate input from individuals with lived experience into internal policies.



Promote accessible communication tools: Encourage the use of technology that is accessible to all. Address language barriers, provide accommodations for disabilities, and bridge the digital divide through low-tech options, translation services, and free internet access.



Address power imbalances: Acknowledge and respond to power dynamics that may affect engagement with lived experience. Recognise intersectionality and the compounding effects of trauma to ensure equitable participation.



Build flexibility into timelines: Allow adequate time for meaningful engagement by both individuals with LE and staff. Incorporate flexibility into project timelines to accommodate varying needs.



Provide ongoing training and support: Offer continuous training and support for collaboration and learning. This includes workshops on cultural sensitivity, creating safe spaces for dialogue, addressing decolonial perspectives and providing trauma-informed support.

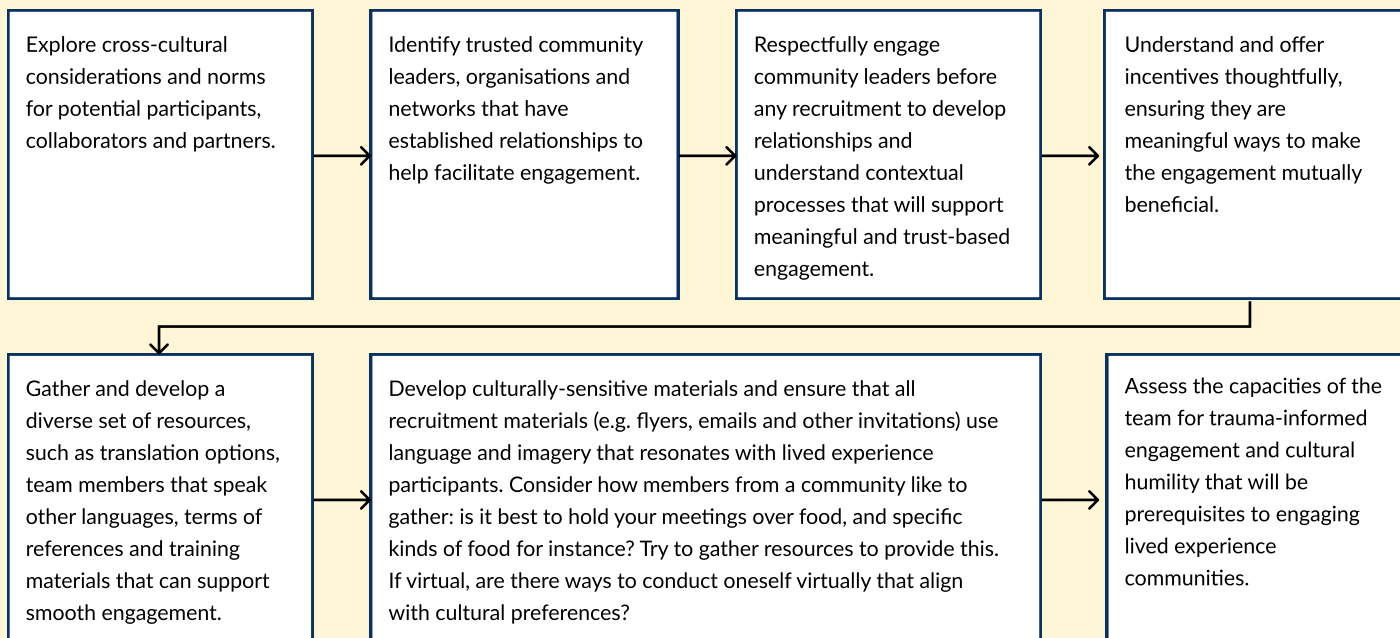


Use contextual language: Communicate using language that is clear and accessible, avoiding disciplinary jargon. Unpack and clarify terminology when interacting with individuals with LE. Offer multiple communication methods (written, verbal, visual) to ensure understanding.

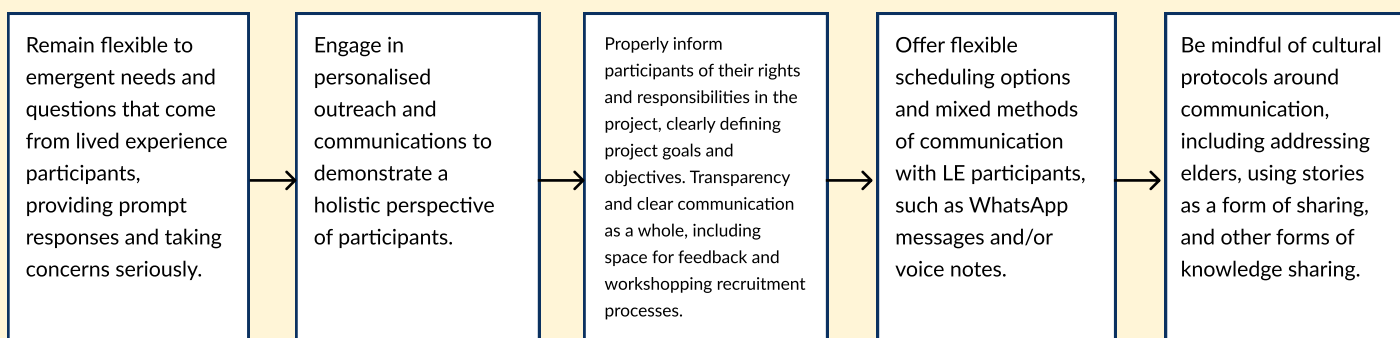
Recruitment of LE participants

To have a plan for recruiting participants and potential collaborators that is thoughtful and caring, we have to think about the lifecycle of engagement.

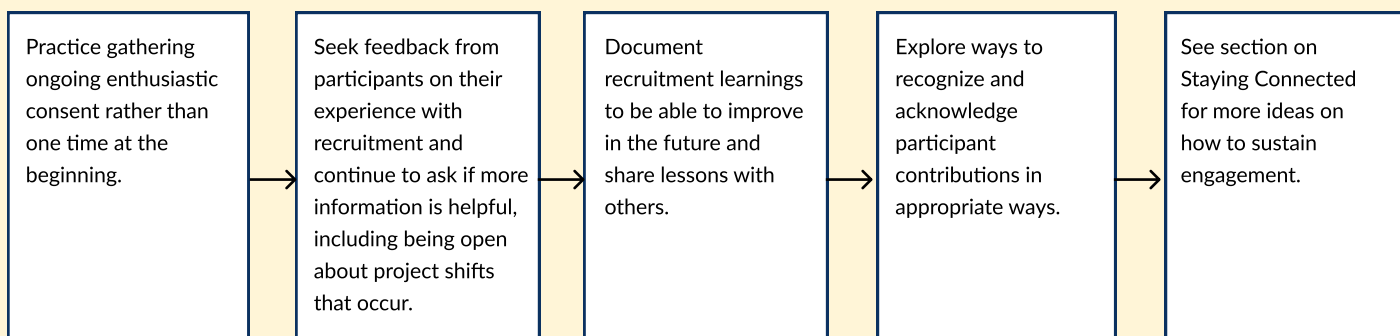
Before recruitment begins



During recruitment



After recruitment



Research processes friendly to diverse LE

Valuing LE as integral to the research process and fostering an inclusive environment where voices are not only heard but actively shape the agenda, requires ways of engagement that are not extractive or tokenistic. The ability to tend to process as part of the outcome and impact of projects is not only necessary but more possible within an environment of institutional flexibility and collective alignment.

Explore the following practices to create enabling environments rooted in care:

Make Space

- Value other frameworks and ways of knowing. This includes being open to changing initial frameworks and doing some donor education on the relevance of incorporating other worldviews and conceptualisations in the work. (Read on [Epistemic Justice](#))
- Be mindful of language accessibility, and ensure that communication is culturally sensitive, clear and accessible to the communities. (Read on [Language Justice](#))
- Making different formats and spaces available for exchange, supporting both intra- and inter-community exchange.
- Integrate lived experience expertise at all levels and stages of the project cycle. Avoid tokenisation and include diverse different lived experience expertise across all core teams.

Support

- Offer flexibility with deliverable deadlines and address any barriers to participation, including internet access, childcare needs, concerns about safety, etc.
- Establish a space of mutual benefit - ensure there are mechanisms for benefit sharing to ensure that the outcomes of the research contribute positively to the well-being of the communities involved. This involves contributing back to the community, beyond the immediate research objectives, for example through capacity-building, skill development or tangible benefits based on community priorities.
- Attention to accessibility at all stages.
- Recognise labour and contributions. In addition to monetary compensation, recognise intellectual contributors and list collaborators as co-authors in publications and outputs.
- Offer different ways to engage and participate in the work when recruiting people into the team and workspace (see possible Pathways for Engagement above).

Collaborate

- Engage in an iterative process of shared decision-making whereby different groups/collaborators can actively shape the design of the project.
- Take guidance from lived experience advisors along different identity groups, etc. providing training and resources to enable community members to participate actively in the research process, fostering self-determination.
- Decolonise research methodologies and open up to different formats of engagement. This includes embracing various communication styles, whether oral traditions, storytelling, artistic practices, photo-based or visual approaches, etc.

How to Collect LE Stories and Provide Adequate Safeguarding Guidance

Why stories are important and how to collect them thoughtfully

Lived experience stories hold significant importance for everyone as they provide invaluable firsthand accounts of people's encounters with issues that affect and resonate with them in a myriad of ways like climate change and mental health struggles, including mental health struggles that come from climate impacts. Unlike quantitative insights and datasets, these stories offer pathways to sensitise audiences (whether expert or lay) to the human impacts and experiences associated with climate change and mental health that themselves may lead to more granular and targeted solutions that match such experiences. By integrating these lived experience stories, researchers gain access to diverse perspectives and foster a deeper understanding of the nuanced impacts of the issues on people's lives. Moreover, these stories also empower individuals to share their voices and contribute to shaping research agendas and policy decisions.

How to collect lived experience stories thoughtfully:

1

Foster Trust and Rapport

Create safe spaces for sharing stories, respecting autonomy and confidentiality.

2

Follow Ethical Guidelines

Secure informed consent, explaining research purposes, usage of stories, and potential risks.

3

Embrace Participatory Approaches

Collaborate with participants in shaping research, from questions to dissemination.

4

Ensure Diversity and Inclusivity

Seek diverse voices and perspectives, mindful of power dynamics and privilege.

5

Practice Active Listening and Reflection

Listen without bias, reflect on personal biases, and consider their influence.

6

Uphold Respect and Reciprocity

Honor participants' agency and self-determination, offer feedback opportunities, and ensure mutual benefit.

Safeguarding and trauma-informed story-gathering guidance provided to international teams:

Any conversation or testimonial about the mental health impacts of climate change could potentially trigger distressing or traumatic responses in individuals who've experienced these challenges. Psychological First Aid is an evidence-based technique used in a wide variety of humanitarian, conflict and disaster settings to reduce stress responses in individuals and assist them in healthy recovery. Before gathering any stories from storytellers, ensure that you have done at least one of the following Psychological First Aid training below. In order to support storytellers who might experience distress while recording their own story, these training sessions will also assist you in listening and responding to their needs.

Please select, and complete at least ONE of the online training listed below (*they are all free to complete*)

- **Basic Psychosocial Skills:**
<https://open.uts.edu.au/COVID-19-responders-en.aspx>
- **Psychosocial support playlist, watch videos 1 to 7:**
https://www.youtube.com/playlist?list=PLqCHWV3Swuc9IdPc_mzWHJjrItqfH5Aly
- **Introduction to Psychological First Aid – Caring for Ourselves and Others**
- **English:**
<https://www.youtube.com/watch?v=9DvHSJ5Bsg8>
- **French:**
<https://www.youtube.com/watch?v=sjm3t5xNTOo>



The Process of Consent and Shared Ownership

Central to inclusive and equitable LE practice is engaging in accessible and reciprocal forms of consent and knowledge co-ownership that confront data colonialism¹ and extractive practices. With the fields of climate and mental health both having a history of harmful practices related to consent and co-ownership, considerations at this intersection for researchers and practitioners are paramount to being in right relations with those most impacted. We found this area of work to be central because it confronts many traditional research and practice norms that centre ownership outside of the communities in which knowledge is derived and held.

Experiential reflection

During the CCM project we had to make adjustments to the consent process to ensure right relations with communities historically harmed and devalued in global research efforts.

Some of the amendments we made in our work to be more inclusive include:

- Using fingerprints and verbal consent processes to support access for those that cannot read and write.
- Engaging in a two-step process for obtaining informed consent with certain groups, particularly Indigenous communities, involving collective consent from traditional authorities as well as individual consent from dialogue participants.

When working to create inclusive consent processes and data co-ownership approaches explore the following considerations:

- **Accessibility:** Consider how to make the consent forms as accessible as possible, using easy to understand language and having team members ready to walk participants through the implications of consenting.
- **Data ownership:** Consider institutional mandates and data storage rules that take ownership of knowledge out of communities in which it was derived and work to amend rules to favour ownership staying in communities and/or co-ownership practices, including Indigenous data sovereignty principles and practices.
- **Free, prior, and informed consent (FPIC)²:** Draw lessons from the FPIC movement, especially for work with Indigenous communities, to ensure the right to withhold, withdraw, or adjust consent is given to lived experience communities. This area of work also involves iterative consent that must be engaged throughout research and practice. While FPIC centres the rights of Indigenous people worldwide we found the lessons and guidance from this movement to be helpful in creating inclusive processes for diverse lived experience participants.
- **Institutional coaching:** Consider strategies, such as gathering existing evidence and workshopping, for coaching institutions that have not engaged in different consent and co-ownership processes before.

Staying Connected

Historically, people with LE have served as mere 'subjects' in research, expected to passively share their experiences without genuine collaboration. Meaningful engagement goes far beyond tokenism. It means empowering people with LE to become active co-creators throughout the research process. By directly engaging with these lived experts through experience, we unlock a crucial avenue for translating evidence into actionable, sustainable solutions. Importantly, these individuals intimately understand their own and their communities' needs for resilience and change.

Cultivating trust and maximising project impact hinges on staying connected. CCM has explored various strategies to ensure sustained engagement beyond the initial research phase. This ensures that lived experience experts retain ownership and their voices remain central to the work.

Why Stay Connected?

- **Sustained impact** - By staying connected, findings and solutions remain relevant and become living documents to address evolving needs. Allowing for further insights and contributions to the project.
- **Maintaining trust** - Staying connected informs participants of how contributions are used, ensuring ongoing consent. This can motivate sustained engagement for desired change.
- **Community building** - Building a global network of LE experts, researchers and policymakers strengthens and facilitates support, co-creation and solidarity.
- **Knowledge sharing** - Spaces to connect foster opportunities for learning, wisdom and insights.

How to Stay Connected

The Connecting Climate Minds project has established an online global hub designed as a central space for individuals interested in the intersection of climate change and mental health. This hub encompasses valuable resources such as regional and lived experience research and action agendas, toolkits, case studies, research guidelines and other project outputs. By presenting this information in different formats and languages, the hub ensures accessibility to a diverse global audience.

Various formats include:

- **Visuals:** Photographs, maps, and infographics
- **Text:** Comprehensive written resources
- **Video:** Case studies, stories and presentations
- **Audio:** Case studies and interviews



Additional Resources

The LE team on the CCM project learned from a range of perspectives resources, and practice areas to be able to deliver this work. Importantly, we believe in a community-oriented approach to lived experience engagement in which knowledge is shared openly and widely. While we could not share every resource we learned from, the following sources and links offer additional directions for learning and practice when it comes to LE engagement in research and practice at the intersection of climate and mental health.

Other Lived Experience Toolkits to Explore:

- Engaging Lived Experience Toolkit: <https://www.communitycommons.org/collections/Engaging-Lived-Experience-Toolkit>
- Fearless Futures: A Feminist Cartographer's Toolkit: <https://fearlesscollective.org/project/fearlessfutures/>
- National Survivor Network Toolkit: <https://nationalsurvivornetwork.org/wp-content/uploads/2023/01/2023-Meaningful-Engagement-of-People-With-Lived-Experience-Toolkit.pdf>
- Global Fund To End Modern Slavery Lived Experience Toolkit: <https://gfems.org/wp-content/uploads/2023/01/Meaningful-Engagement-of-People-with-Lived-Experience.pdf>
- Lived Experience Principles Checklist: <https://www.vmiac.org.au/wp-content/uploads/LE-Principles-Checklist.pdf>
- [How to Guide for Meaningful Youth Lived Experience.](#)

Other Resources:

- How to Build Language Justice: https://antenaantena.org/wp-content/uploads/2012/06/langjust_eng.pdf
- Land Body Ecologies: <https://www.landbodyecologies.com/>
- Principles of partnerships: <https://www.lachon.org/partnerships>



References

1 Tahu Kukutai ,Indigenous data sovereignty—A new take on an old theme. Science382, eadl4664(2023). DOI:10.1126/science.adl4664

2 https://rights.culturalsurvival.org/01-what-free-prior-and-informed-consent?gad_source=1&gclid=CjwKCAiA29auBhBxEiwAnKcSquJmOUvXEdQYvymwfabtAMiz85G7Gbqdu8dyfzg39uh2zU-Ft3D5fxoC9k4QAvD_BwE