

Considering Trauma Informed Principles When Partnering with Lived Experience Advisors Across The Research Cycle

This table is written in plain language for potential lived experience advisors, consumers, lay people, health professionals and researchers.

Steps of the Research Journey	How Lived Experience Advisors (LEAs) can be involved?	PAUSE, REFLECT & CONSIDER! Considerations when applying Trauma Informed Principles
<p>1. Concept and Research Question:</p> <p>Considering the clinical problem/concept and formulating a research question is the starting point of research. Consider who? (population), what now? (intervention), what currently happens? (control) and what we want to achieve (outcome)?</p>	<p>LEAs can be involved in:</p> <ul style="list-style-type: none"> • Advising what aspects of this topic or condition or care is important to them • Advising what would make a difference in living with this condition • Helping to determine research priorities • Helping to refine the research question 	<p>When thinking about the concept and research questions:</p> <ul style="list-style-type: none"> • What is the lead researcher's own experience and understanding of the problem? • How does this problem affect patients and families? • What do we need to know to improve things and how would this knowledge improve patient outcomes and lived experience? • When inviting LEAs to be part of this study, how can we ensure that we can support them throughout the research journey when they would be required to revisit, remember, re-experience and then share to strangers about their experiences. • How do we codesign communication processes with LEAs so that they feel a sense of control and can signal their desire to engage, pause, retreat or withdraw at any time throughout the research process according to their capacity?



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<p>2. Forming the Team:</p> <p>Good research teams bring together people with a diversity of perspectives, experiences, skills and interests to address a problem. These may include researchers, health professionals, patients, family members, etc.</p>	<p>LEAs can advise of:</p> <ul style="list-style-type: none"> • Key professionals they interacted with who may join the team • Other parents/families with this condition who might be good on the team 	<ul style="list-style-type: none"> • During the formation meeting, introduce all team members, their experiences with the issue, their roles on the team, and how they can contribute. • Consider how the PI & the whole team will work together to intentionally embed the six principles of trauma informed care: “Safety, Trust, Choice, Collaboration, Empowerment, & Respect” into team processes, meeting processes, communication and interactions throughout the research journey? • How can we support LEAs and all team members to develop trust to be able to share experiences, be vulnerable, regroup, feel respected and heard, feel safe to share and supported, feel that contributions are valued? • How can we ensure and signal that team diversity is valued and respected (e.g. physical, cultural, race, gender, orientation, profession etc)?
<p>3. Designing the research:</p> <p>Team members select a research design that is most appropriate to answer the research questions within the given constraints (type of questions, budget, timeframe, resources, etc).</p>	<p>LEAs can:</p> <ul style="list-style-type: none"> • Inform the research design • Advise whether methods are appropriate, acceptable, cost-prohibitive and feasible for children and families • Review tools/ Questionnaires/PICFs for readability and understanding 	<ul style="list-style-type: none"> • Respecting LEAs contributions when advising on how much of an impact the research design or questionnaires will have on patients' time/ finances, or whether they are meaningful. • Reflect and respect how LEAs may feel when they see a potential intervention that they or their child/loved one did not have access to as part of their own experience.



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<p>4. Seeking funding:</p> <p>Research often requires specific funding to adequately resource the project and provide extra funded time to conduct activities to produce high quality research. Embedding an LEA component often persuades funders about the importance and relevance of the research.</p>	<p>LEAs can:</p> <ul style="list-style-type: none"> • Review funding applications • Provide lay descriptions and impact statements to funding applications • Advise on costs to families • Be part of presentations to funding bodies or community groups to talk about the research. 	<ul style="list-style-type: none"> • Articulate how the LEAs contributions about their experiences have influenced and improved the funding applications and communicate the research to lay people. • Reflect on how presenting to funding bodies, panels and community groups may cause LEAs to revisit painful experiences whilst telling their story. Discuss together how this may affect them. Plan together how you can support them if things become difficult. • Ensure the LEA always feels that they have a choice to be part of, or to withdraw from presenting at any time.
<p>5. Ethics approval:</p> <p>Research that collects new data from people has to be approved by an ethics committee before they commence. The ethics committee will review the study to ensure participant (patients, children, families) rights and voices are upheld, and that the study is ethically acceptable.</p>	<p>LEAs can:</p> <ul style="list-style-type: none"> • Ensure research is ethical from a patient perspective • Help review/refine outcome measures (e.g. Patient reported outcome measures) • Review lay summary • Consider costs to patients • Reviewing grant applications from a patient perspective • Be part of ethics committees or advisory groups 	<ul style="list-style-type: none"> • Ensure LEAs have had ample opportunity to review and contribute to the ethics protocol, selection of outcome measures, development of lay summaries and impact statements, resources, PICFs and fact sheets as they are able • Ensure their feedback is heard, respected, considered, valued and integrated wherever possible. • If some suggestions are not integrated, respectfully discuss the decision why suggested changes were not included; and reassure LEAs feel empowered to continue to contribute their thoughts and ideas to the team.



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<p>6. Collecting the data:</p> <p>This stage collects data from the participants. This might include reviewing data from clinical charts, conducting assessments on children/families, interviewing people to understand their viewpoints, and providing interventions and treatments.</p>	<p>LEAs may:</p> <ul style="list-style-type: none"> • Be part of a steering or advisory committee for the life of the project • Be an 'Expert patient' to advise participants if they have questions • Assist in recruitment (e.g. through their community or patient advocacy group) • Promote the research through community networks. 	<ul style="list-style-type: none"> • Ensure that advisory committee meetings incorporate a format and processes where all members and their contributions are heard, respected, and encouraged. • If LEAs contribute as 'expert patients' to assist, advise and/or support research participants, consider again how sharing their story or hearing the story of others with similar experiences might trigger emotions and responses. Plan together what support will be offered for the LEA and the research participant at the time from the PI or team or other support network. • Consider how to support the LEA if their experience was worse than other participants in the research: how do they manage their own feelings, sense of loss, possible resentment towards others, professionalism not to influence others or talk about health professionals that they encountered, separate their role as a team member versus their identity as a person with lived experience when interacting with others.
<p>7. Analysing the data:</p> <p>Once data has been collected, the information is analysed in order to answer the research question. A variety of methods (such as quantitative or qualitative) may be used to analyse data depending upon the design of the study, data collected and original question.</p>	<ul style="list-style-type: none"> • LEAs may be involved in analysing data with researchers such as coding qualitative interview data. 	<ul style="list-style-type: none"> • Providing choices to be part of the data analysis process. • If LEAs are potentially reviewing qualitative interview data about a condition, consider and discuss how reading about the experiences of others may be triggering for them. • Review together that the LEA can withdraw from this activity if things become too overwhelming or triggering & the PI has a backup plan if they chose to withdraw from this activity (don't feel pressured to keep doing this for fear of letting others down).



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<p>8. Interpreting results and drawing conclusions:</p> <p>Results are interpreted considering the original question to explain what the results mean, how a range of factors influenced each other, and how they extend our knowledge beyond what we knew about the problem before we started.</p>	<p>LEAs may:</p> <ul style="list-style-type: none"> Assist the team in developing themes from qualitative data Be consulted to see if they understand the data or interpret the findings in the same way as research or clinical team members Consider findings in light of their own experience – what might be the reason (explanation) for the findings and what insights can they offer. 	<ul style="list-style-type: none"> Contribute to safety by recognising the potential emotional risk that may come from reviewing findings for LEAs and ensure supports are available as planned together earlier in the process Listening to LEAs in interpreting the findings contributes to a sense of trustworthiness and strengthens results, providing actionable recommendations from the conclusions
<p>9. Telling people about the findings:</p> <p>It's important to tell all stakeholders about our research findings in order to improve outcomes for patients and providing the best care, our health service staff, and our institutions. We can tell people through giving talks, writing journal articles, plain language summaries, tv and media interviews, providing professional and consumer training, and posting on websites and social media.</p>	<p>LEA can be part of, or responsible for:</p> <ul style="list-style-type: none"> Developing lay communications (e.g. patient summaries) to communicate the research results through patient & community networks Joint presentations to scientific meetings and community groups Media: Posts for social media and being part of all medical communications (podcasts, television & radio interviews, etc) Talking to charities and funding bodies and government 	<ul style="list-style-type: none"> Maintain trust by ensuring that LEAs are included in authorship for any guidelines, manuscripts or presentations Invite LEAs to participate in presentations. Empower and support their participation by offering training as needed, providing options on how they can contribute to dissemination and be respectful if they do not want to disclose their own experience when sharing study findings.



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<p>10. Changing practice:</p> <p>It is important that research findings are embedded into new routines, new/updated clinical assessment and treatment guidelines, treatments are able to be offered by services and claimed through health fund providers as soon as possible.</p>	<ul style="list-style-type: none"> • LEAs can contribute to development of clinical guidelines and be committee members to inform/develop new health care services 	<ul style="list-style-type: none"> • Empower LEAs to contribute to the development of guidelines and participate in working groups • Contribute to trust and safety by ensuring that the voices of LEAs are heard by clinicians and staff as well as researchers
<p>11. Re-evaluate and the Next Steps:</p> <p>Answering one question often leads to more questions or answering the same question on a much larger scale across multiple health services. This can lead to more research and the cycle begins again. It's also important to reflect on the research itself and the team dynamics and journey to continuously learn together: what went well, what would change or improve, how can we do better next time, what or who else would we need to help us?</p>	<p>LEAs can:</p> <ul style="list-style-type: none"> • Collaborate with the team to evaluate the research process or CCI impact • Reflect on their role & learnings in the team and how the team could better partner together • Continue involvement with study team to develop new research projects arising from the research • Be part of representations to government or lobby groups 	<ul style="list-style-type: none"> • Reflect on the experience with LEAs and take what is learned to strengthen the process of family engagement in research in a genuine and meaningful way • Continue to work collaboratively with LEAs, taking every opportunity to empower them and support their development as members of the research team for future projects



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