



REsearch with **L**ived **E**xperience **E**xperts:
A **P**lanning, **O**nboarding, and **P**articipation Guide for Researchers

Researchers + Lived Experience Experts in equal partnership = Best results from research.

Consumer involvement in healthcare research occurs when principles of co-design are used to create an authentic and equal partnership between Lived Experience Experts (LEEs) and researchers. The shared goal is one of undertaking research to improve real-world outcomes for patients, healthcare consumers, and their families.

What is RELEE-POP?

RELEE-POP is a supportive guide for researchers wanting to engage with LEEs in their work. What does RELEE-POP cover?

- Information on involving LEEs in your work, links to educational materials, and self-reflective questions.
- Ensures researchers can thoroughly prepare to support LEEs throughout the lifespan of the research work.

So, you're a researcher? Here's how to use this guide:

1. Follow the POP steps to start your journey of consumer involvement.
2. Click on the inline links or reference materials to find more detail on each step.
3. Complete the RELEE-POP Checklist at the end and submit with your HREC application.
4. That's everything!



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1. P for Plan: Lived Experience Expert Involvement

Design

1.1.1. Partners or participants?

How will you ensure that lived experience experts are partners in this research rather than participants?

Consider:

- Partners should be allowed to make suggestions, ask questions, challenge the researchers' ideas, and share decision-making at all stages.
- See the Power Dynamics and Education sections below for other ways to ensure equitable partnerships.

How will you ensure the LEEs are representative of the group/s of people, patients, survivors, or families that should most benefit from the research project?

Consider:

- Breadth of diversity - do you have people with a range of ages, cultures, genders, perspectives, experiences etc.?

1.1.2. Feasible and flexible commitment?

Will LEEs be able to choose their role and level of commitment?

- Consider a brief outline of the different roles available, expectations for each level of commitment, e.g. time required, work tasks, or if meetings will be in person or online.
- Provide enough detail to allow LEEs to make informed decisions about their involvement.
- Discuss with LEEs that their level of commitment can be flexible and can change over time, or according to life circumstances, if they need it to.



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Please review these resources for more detailed guidance and examples of different roles:

A [Consumer Involvement Model](#) developed by Cancer Australia.

A [systematic review](#) on frameworks for supporting patient and public involvement in research.

1.1.3. Lived Experience Experts' advocate

Who will coordinate LEEs, and advocate for them to the research group, if needed?

- How will these processes work?
- Who will mentor the LEEs throughout the project?

Consider a Buddy System where researchers are matched to LEEs.

- The mentor and mentee might, for example, meet/touch base before meetings to prepare, and after meetings or deadlines to debrief, review content, or plan next steps for the LEE.

1.1.4. Study design

What are the research questions you want to address with co-design?

- Consider a Priority Setting Partnership approach with your LEEs to guide selection of topics or questions to answer (here are a few examples).

Is the study design feasible for participants?

- LEEs can share their expertise and experiences on the impact/s of research participation, e.g. to their time and stress levels. This knowledge can directly guide the study development.

What outcomes are important to measure, and when?

- Ensure they are seen as important and relevant to the LEEs.



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Consider project evaluation at this stage (how will you know if your partnership with LEEs has been successful?).

See the ['P for Participation'](#) section for more on this.

Collaboration

1.1.5. Roles and responsibilities

What responsibilities might LEEs have? Have you considered if they might be:

- Sharing their experience as content experts?
- Suggesting and prioritising research questions?
- Designing documents and surveys for participants?
- Collecting data, e.g. interviewing participants?
- Analysing data - who will teach them? Do they bring data analysis skills from their other role/s in life?
- Disseminating results - who will support them to do this? Or, what experiences can they bring to this?

LEEs should be invited to share their knowledge and skills base so they can be supported to take on appropriate roles.

Roles & Responsibilities should be co-produced early and be clearly documented in the Terms of Reference.

You may want to review some exemplar responsibilities for each stage of the research process, as outlined in this [Planning Guide](#) from Gabison and Skorska (2019).



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1.1.6. Communication preferences and methods:

All communications should be mutually respectful, transparent and take the experience of LEEs into account.

Consider allocating a research observer to monitor the culture of communications.

- How will you ensure that communications with LEEs meet their needs?
- Will communications be written or verbal? Via email? Video?
- Can you allocate team members (researchers and LEEs) to develop plain language summaries of all relevant documents?
- Can you be inclusive of Culturally and Linguistically Diverse LEEs?
- Timelines for sending out comms and deadlines for receiving input should be included in the Terms of Reference.

You can find more information on this topic in [Table 4](#) of the Consumer Involvement page on the NHMRC website.

1.1.7. Regular reviews?

Will roles and responsibilities for LEEs be reviewed regularly to ensure they are feeling supported not overburdened?

- Terms of Reference and levels of commitment can be adapted during the project, as required.

Procedural

1.1.8. Funding

It is considered [best practice](#) to compensate LEEs for their time and expertise. You can review detailed guidance, considerations, and case examples in [this](#) NHMRC publication.



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Some elements for you to consider:

- To calculate a budget, consider the number of hours you think your LEEs will need to contribute to the work.
- Include calculations for tasks such as pre-reading, meeting attendance, data analysis, and manuscript review.
- You might even seek funds to support LEEs to present the research findings at conferences.

Costs may also be incurred for recruiting, onboarding, training and supporting LEEs through the life of the project. Have you considered applying for funding to cover these expenses?

- You could use the RELEE-POP Checklist to support your application!

You may want to consider the following resources:

A [*qualitative study*](#) on the barriers of consumer involvement in research.

Some examples of other online past research training events from the CHILD-BRIGHT Network, a pan-Canadian patient-oriented research network <https://www.child-bright.ca/events>

1.1.9. Terms of reference

Terms of reference should be co-produced with your LEEs so that expectations can be outlined and agreed on before the research begins.

The terms of reference may include details on the background to the research and the main aims and objectives.

Practical items to consider include:

- Governance Structure:
 - How big the team will be? How many researchers and LEEs are required?
- Roles and responsibilities, including reporting structure



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- Meeting format, duration and frequency
- Compensation
- Dispute resolution framework

[This](#) terms of reference template produced by Metro North Health (Queensland Government) provides an excellent place to start.

1.1.10. Conflict resolution steps

How will minor disagreements or barriers be overcome?

How will any larger disputes within the team be resolved?

Will researchers and LEEs have equal power to vote for or against proposals?

How will you ensure that LEEs feel empowered and safe to speak up if they disagree with the researchers in the team?

Consider an independent LEE advocate for this purpose, e.g. a LEE with experience in research co-design who has previously had a senior role in a Consumer Organisation or a research project.

1.1.11. Risk assessment

Have you assessed risk for the team in this research project?

Have you considered any harms that may come to the LEEs by being involved in this work?

- Do you have a plan to mitigate the risks?
- Have these been developed and discussed with LEEs?

See the [section on Sensitivities](#) for more information and considerations for applying a trauma-informed lens.

P for Plan: Empowerment

Power dynamics

1.1.12. Power structures in the team

What are the [power dynamics](#) within your team that may need to be addressed?

- Consider the possible gaps in technical and research expertise and psychosocial inequities that might impact power.
- Providing education in plain language will help overcome gaps in expertise.
- Assuring LEEs that their experiential expertise is of equal value to the technical expertise of the research team will assist with managing perceived power imbalances.

1.1.13. Group make-up

Have you considered the balance between LEEs and researchers in your group?

E.g. Are there at least two LEEs in the team?

How is the 'fit', or the combination of people (researchers and LEEs)?

- Are there people willing to listen?
- Are there people willing to learn?
- Are there people willing to share?

1.1.14. Strategies for welcoming:

How will you welcome LEEs to the team? A warm welcome can help team members to feel safe and inspired to share their experiences and reflections.

Tips for creating a welcoming and caring team:

- Introduce each LEE by talking about the essential skills, experiences, and insights that they are bringing to the team.



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- Consider holding meetings in a neutral space. Allow time in early sessions forgetting to know one another. E.g. researchers and LEEs could introduce themselves using a story rather than a job title or condition name.
- Check in with each other at the start of meetings - how is everyone feeling? This will help to create a caring environment.
- And remember...providing refreshments at the start of meetings can help people to relax and have informal chats!

Sensitivities

1.1.15. Considerations for the population

How are you being sensitive to the population you're working with?

E.g. what specific considerations are you making for the group that you're engaging with, given their health condition/s or 'typical' shared experiences?

- Do you need to address accessibility barriers for LEEs or researchers with disabilities, such as visual or hearing impairment, or use of a wheelchair for mobility?
- Do recruitment materials need to be translated into other languages?
- Do you need additional supports for young adults who want to be involved as LEEs?

See the section on [Mentors](#) for further suggestions.

1.1.16. Trauma-informed models

Are you using a [trauma-informed model](#)?

- Which elements are you specifically integrating? How?
- A module on trauma-informed communication should be included in the educational materials for the researchers.

O for Onboard

Recruitment

1.1.17. Identification, expressions of interest, & screening

How will you identify LEEs appropriate to your area of research?

- Consider accessing Consumer Registries within your organisation or through external stakeholder groups, clinics, online support forums, condition-specific support groups, local or statewide consumer councils, internet, and social media advertising.
- Previously engaged LEEs can provide key links to their communities; they will be trusted and once you establish initial connections it will be easier to involve others in co-design projects.
- They can also co-develop advertising material and provide input on modes of advertising, e.g. social media, and appropriate language to use to connect with their communities.

The CP-Achieve Centre for Research Excellence website [here](#) provides an example of listing research opportunities for lived experience experts.

How will LEEs be able to express an interest in joining the research team?

- Consider offering different options for LEEs to contact the research team to register their interest, e.g. hyperlink in advertisement, phone call, email, or QR code scan.
- Which research team member will respond to the expressions of interest (EOIs), how, and in what timeframe?

Here there is an example of an [EOI](#) used by the CP-Achieve research team.



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How will prospective LEEs be screened for suitability?

- Consider a matrix to sensitively assess skills and expertise against role requirements.
- The EOI proforma could ask some simple questions about why they are interested in being involved, what they feel they can bring to the work and what they would like to get out of it.

Will there be an interview process?

- If so, who will manage this? What will the process be?

1.1.18. Induction package:

Have you developed an Induction package specific to LEEs?

- Consider Working with Children and Police Checks if required.
- How will these costs be covered?

Do you need to ask for and store contact and bank details (for payment)?

- If so, how will this be managed securely?

Who will provide an orientation to the environment for on-site activities?

- How will this be recorded, and will it satisfy workplace safety requirements?

Will LEE team members need names badges/security passes?

- If so, who will be responsible for organising these?

Does your institution require LEEs to undertake any mandatory training?

- If so, how will they access this?
- How will training be logged?

1.1.19. Mentors

Have you considered the use of mentors for any LEE on your team?



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- A mentor may be useful for example if LEEs are young adults with a childhood-onset disability, who may be affected by cognitive or language difficulties.

What will the scope of a mentor be? What will their responsibilities be?

- Examples of roles for a mentor may include supporting consumers to prepare for, or debrief from meetings, and to review documents.

It is good practice to recruit and onboard mentors at the same time as LEEs, so mentors can support participation in activities and build relationships early.

The CP-Achieve Centre for Research Excellence are a research group who pair LEEs with mentors. [This](#) page describes how a mentor and LEE collaborative relationship may work.

Education

1.1.20. Principles for education

Researchers can be educated on the many benefits that come with authentic co-design with LEEs.

- These include higher participant recruitment rates, higher impact of results, increased feasibility of knowledge translation and many more positive outcomes.

LEE's can be taught about research methodology in accessible and easy to absorb ways.

Providing opportunities to upskill for both groups will assist with breaking down barriers, such as power imbalances.

1.1.21. Research processes

How will you train and provide education to LEEs about:

- The basics of research methodology



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- Human Research Ethics Committees and funding processes
- Research governance, including data protection
- Appropriate and timely dissemination of results
- Software application training, e.g. Teams, Zoom, Google docs, databases
- Graded assertiveness skills to ensure their voice is heard and acted upon

The LEEs on your team will come with different experiences and skill sets. Some may be new to research and the processes, so it is important that you consider their experience and role in your project.

Courses specific to LEEs and their involvement in research include the [Consumer and Community Involvement](#) (Monash Partners) and the [Family Engagement in Research](#) course (CanChild, McMaster University).

If they have previous experience, the [Good Clinical Practice](#) course may be appropriate for them.

Please note: these resources can be costly to access, and these costs should be considered during your planning phase (see previous section).

1.1.22. Accessible information

Have you developed plain language versions of relevant research documents, e.g. HREC forms, to share with your LEEs?

Have you created a glossary of key definitions or scientific terms relevant to your study area?

- This [plain language glossary](#) is a great place to start (Talyor, Knutson and McCrossin, 2019).

Can you make the research materials available in multiple languages or provide an interpreter service to increase diversity?

Resources

What resources will be required so that LEEs can do their work?

- Have you included these resources in the terms of reference or developed a plan to provide these resources if needed?

Note: Oftentimes, the main resource required is time. LEEs may need to take time off work to participate as some activities may be undertaken during business hours.

1.1.23. Letters of support

Are you able to provide a letter of support to their employer for sign-off or can meetings times be dictated by the LEEs?

1.1.24. Environment, Technology, & Travel

Can you provide LEEs a physical space to work with you if they require one?

Will LEEs in your project require any specific technology to enable them to participate? Some examples may include:

- Laptop
- Webcam
- Data card / internet connection
- Wireless headphones

Are there local systems or organisational processes that LEEs may need access to? For example, must all team members use a specific software program to communicate via, or share information through?

- If so, how will this be managed?
- Will LEEs need an introduction to these systems, or training, in order to participate fully?



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Note: This may differ for different LEEs at different stages of the research process.

- How will you determine what is needed?
- How will you enable or facilitate this training?

Would LEEs need to be provided reimbursements or resources for transportation to complete their research activities? Some examples may include:

- Rideshare or taxi vouchers
- Myki top ups
- Parking vouchers

1.1.25. Knowledge and template bank:

For LEE partners who are co-designing research materials, it would be helpful to provide them with access to document templates, e.g. consent forms.

You can view resources about the use of plain language in research through the [RCH website](#).



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P for Participate

Note: Some of these ideas have been covered in previous sections. They are included here again to ensure that they are not missed if researchers are only reviewing the Participation section of this guide during the research project.

Work plans:

Have you co-designed a realistic project [roadmap](#) so the LEEs can plan their involvement over the course of the study?

How will the group (researchers and LEEs) meet for the duration of the study, e.g. in person, online, hybrid?

How will communications be managed, e.g. email, cloud documents, paper?

What are the time expectations for meetings, review work, etc.?

Is there a plan for flexibility to allow LEEs to manage the project work alongside their usual duties in life, e.g. can deadlines be extended?

How will the team address occasions where “life happens” and the LEE needs to step back to a different level of engagement?

Tasks:

What sorts of work might LEEs undertake during the study? Some examples include:

- Suggesting and prioritising research questions
- Creating plain language summaries and surveys for research participants
- Test prototypes/protocols



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- Data collection/entry/analysis
- Interpretation of results, including translation
- Dissemination of results, e.g. authorship on papers, conference presentations

Safety for LEEs and researchers:

What are the standards and structures in place to welcome LEEs and support positive working relationships between LEEs and researchers?

Have LEEs been introduced to the established processes for reporting risks or complaints to research project leaders or stakeholders?

How will you prevent harm related to engaging in this research for LEEs? Have you considered a trauma-informed approach?

- This resource may support you as you plan to work with LEEs (link to resource from FER group)

Has the safety of researchers within this team been considered?

- How?
- Which specific elements of researcher safety are relevant to your work?

You may want to read further about the existing National Standards that support best practice when involving consumers in research.

National Safety and Quality Health Service (NSQHS) Standards for: [Partnering with consumers in organisational design and governance.](#)

National Clinical Trials Governance Framework Governance Framework Component 5: [Partnering with consumers.](#)



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The National Health and Medical Research Council [Statement on Consumer and Community Involvement in Health and Medical Research 2016](#)

The Medical Research Future Fund's [Principles for Consumer Involvement in Research](#).

The Consumer Involvement Vision developed by the [Australian Health Research Alliance in 2018 Australia-wide audit](#)

Reporting:

1.1.26. Outcomes and dissemination

How will you acknowledge the expertise and contributions LEEs have made to the research project?

- It may be appropriate to include LEEs as authors - you can review authorship guidelines [here](#).

How will you share with LEEs what you have learnt from them, and how their input has shaped the research?

1.1.27. Compensation

It is good practice to estimate and then budget for the time required for each task LEEs may undertake.

In addition to e.g. time spent in meetings, is there budget for the time that LEEs might spend reviewing documents, preparing for meetings, or debriefing from events?

Has a pay scale for LEEs been selected (e.g. [VCCC recommendations](#))?



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What sorts of payment methods for LEEs are available through your workplace? E.g. GiftPay may avoid potential impact on support payments (Refer to [Appendix 1 - Examples of payment models](#))

Might LEEs be able to select their preferred method?

Evaluation

Evaluation of the partnership between LEEs and researchers is key ([Evaluation Design by AIFS, 2021](#)). How do you plan to evaluate the success of the collaboration with LEEs in the research project?

- How will you evaluate what worked, what didn't?

An example evaluation form for LEEs can be found [here](#), and another, for researchers, [here](#).

Elements to consider:

- What are your measures of success?
- What did you learn from working together?
- How do you think the partnership impacted the study outcomes?
- What worked really well?
- What would you do differently next time?

Some helpful resources might be [this](#) series of templates and this evaluation [toolkit](#).



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References and resources

Key publications

Australian Commission on Safety and Quality in Health Care, 2022. The National Clinical Trials Governance Framework and user guide for health service organisations conducting clinical trials. Australian Government, Department of Health.

The Australian Commission on Safety and Quality in Healthcare, 2023. Partnering with consumers in organisational design and governance [WWW Document]. URL <https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/partnering-consumers-organisational-design-and-governance> (accessed 12.10.23).

Australian Health Research Alliance, 2018. Consumer and Community Involvement in Health and Medical Research: An Australia wide audit. https://ahra.org.au/wp-content/uploads/2021/02/AHRA_CCI_Final_Report.pdf

Greenhalgh, T, Hinton, L, Finlay, T, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expect*. 2019; 22: 785-801. <https://doi.org/10.1111/hex.12888>

National Health and Medical Research Council, Australian Research Council, and Universities Australia. (2019). Payment of participants in research: Information for researchers, HRECs, and other ethics review bodies. Commonwealth of Australia, Canberra.

National Health and Medical Research Council, 2016. Statement on consumer and community involvement in health and medical research. <https://www.nhmrc.gov.au/about->



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us/publications/statement-consumer-and-community-involvement-health-and-medical-research

McKenzie A., Bulsara C., Haines H., Hanley B., Alpers K. (2016) Barriers to community involvement in health and medical research - Researchers perspectives on consumer and community involvement in research: a qualitative study. The University of Western Australia School of Population Health, Telethon Kids Institute and The University of Notre Dame.

Resources from websites

Anderson, N., 2023. Your Research Project Roadmap: Essential Steps for Ensuring for a... [WWW Document]. dscout.com. URL <https://dscout.com/people-nerds/research-project-roadmap>.

Cancer Australia. (2023). Consumer Involvement Model. Retrieved from <https://consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/consumer-involvement-model>

National Health and Medical Research Council. (2018). Consumer involvement. Retrieved from <https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>

VCCC Alliance. (2023). Consumer remuneration. Retrieved from <https://vccalliance.org.au/our-work/consumer-engagement/resources/pages/consumer-remuneration/>

The National Lottery Community Fund. (2021). Trauma-informed Social Research: A Practical Guide. Retrieved from <https://www.tnlcommunityfund.org.uk/media/insights/documents/Trauma-informed-social-research-A-practical-guide-2021.pdf>



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Specific training on co-design with LEEs

Monash Partners. Consumer and Community Involvement. [Online training module]. Available at: <https://monashpartners.org.au/education-training-and-events/cci/>

CanChild. Family Engagement in Research Course. [Online course]. Available at: <https://www.canchild.ca/en/research-in-practice/family-engagement-program/fer-course>

Online Training

Monash Partners. Module 4: Managing Power Dynamics and Imbalances. [Online training module]. Available at: <https://monashpartners.org.au/education-training-and-events/cci/module-4-managing-power-dynamics-and-imbbalances/>

Murdoch Children's Research Institute. Core Workshops: Practical Skills in Research. MCRI. Available at: <https://www.mcri.edu.au/research/researcher-training-resources/clinical-research-development-office/core-workshops-practical-skills-in-research>

ACTEC. Online Courses. MyOpenLMS. Available at: <https://actec.myopenlms.net/course/index.php?categoryid=3>

Templates or resources from other websites

Terms of reference

Metro North Hospital and Health Service. (2022). Roles and Accountabilities - Co-Design Team. Retrieved from <https://metronorth.health.qld.gov.au/get-involved/co-design/team/roles-and-accountabilities>



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Recording of past events

Child-BRIGHT. (2019). Events. Retrieved from <https://www.child-bright.ca/events>

Research opportunities for LEEs

CP Achieve. (2020). Current Opportunities for Consumer Involvement. Retrieved from <https://www.cp-achieve.org.au/consumer-involvement/current-opportunities-for-consumer-involvement/>

Resources for evaluation

Centre of Excellence on Partnership with Patients and the Public, n.d. Evaluation Toolkit
Available at: <https://ceppp.ca/en/evaluation-toolkit/> (accessed 12.10.23).

Johnson, S., 2021. Evaluation design: Families and children expert panel project. Medical Research Future Fund, 2023. Principles for consumer involvement in research funded by the Medical Research Future Fund.

Expression of interest for LEEs

ACU (2023). CP-Achieve Advisory Group [Form]. Qualtrics.
https://acu.qualtrics.com/jfe/form/SV_bJmbObhDUI7Pa4K

Mentorship for LEES

CP Achieve. (2020). Mentors for Adolescents with Cerebral Palsy. CP Achieve. Available at: <https://www.cp-achieve.org.au/consumer-involvement/consumer-advisory-groups/mentors-for-adolescents-with-cerebral-palsy/>

Plain language resources

Royal Children's Hospital Melbourne. Plain Language Resources. Informed Consent and Plain Language. Available at: [https://www.rch.org.au/ethics/informed_consent_and_plain_language/Plain Language Resources/](https://www.rch.org.au/ethics/informed_consent_and_plain_language/Plain_Language_Resources/)



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Family Engagement in Research KT tools

The following online resources were developed as part of previous knowledge translation tools in the Family Engagement in Research Certificate of Completion Program run by McMaster University, and Kids Brain Health Network.

Produced by: Gabison and Skorska, March 2019

Link:

https://canchild.ca/system/tenon/assets/attachments/000/002/733/original/FERcoursePlanningGuideSharonMalvinaApr2019_final.pdf

Produced by: Taylor, Knutson and McCrossin, March 2019

Link:

https://canchild.ca/system/tenon/assets/attachments/000/003/539/original/FER_Glossary.pdf