



REsearch with Lived Experience Experts:
A Planning, Onboarding, and Participation Guide for Researchers

The RELEE-POP checklist

Purpose of the checklist:

To help you co-design healthcare research through authentic involvement of lived experience experts (LEEs). The checklist will be of most benefit if it is completed before submission of research documentation to local Human Research Ethics Committees or funding bodies.

How to use it:

The items on the checklist reflect the content of the RELEE-POP website.

- Work through each point to ensure you have thoroughly considered all of the questions posed in the RELEE-POP tool and have read all relevant resources provided in text or via embedded links and additional resources.
- Use the 'Page number' column to record, where in your main document (e.g. protocol or grant proposal) you have discussed each element of RELEE-POP.
- Alternatively, you may want to use the checklist as a template in which you provide answers to each question and then incorporate the checklist into your main document to create a dedicated section that details how you will involve LEEs in your project.
- Some items may not be applicable to your plan of co-design and you may want to briefly explain why they have been omitted in the last section.

PROJECT TITLE	
Version number & date of protocol or grant proposal under review	

PRINCIPAL INVESTIGATOR (PI)	
Position Title	
Department / Group	
Institution	



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P for Plan: Lived Experience Expert Involvement

	CRITERIA: <i>Using the righthand columns, please indicate if each question has been addressed and where in your main document you have discussed it (if not incorporating the checklist with answers into the main document as a separate section).</i>	Yes/ No/ NA	Section, page
Design	1. How will you ensure that lived experience experts are partners in this research rather than participants?		
	2. How will you ensure the LEEs are representative of the group of patients, survivors or families that should most benefit from the research project?		
	3. Will LEEs be able to choose their role and level of commitment?		
	4. Who will advocate for and mentor the LEEs throughout the project?		
Study design	5. What are the research questions you want to address with co-design?		
	6. Is the study design feasible for participants?		
	7. What outcomes are important to measure, and when?		
	8. Consider project evaluation at this stage - how will you know if your partnership has been successful?		
Collaboration	9. What responsibilities will LEEs have?		
	10. How will you ensure that communications with LEEs meets their needs?		
	11. Will LEEs roles and responsibilities be reviewed regularly to ensure they are not overburdened?		
Procedural	12. Have you considered funding to cover the cost of LEEs participation in your project?		
	14. Have you co-produced terms of references for the collaboration with your LEEs so that expectations can be outlined before the research begins?		
	15. Have you considered steps and procedures to manage conflicts?		
	16. Have you assessed risks for the team in this research project?		
	17. Do you have a plan to mitigate the risks?		



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P for Plan: Involvement of Lived Experience Experts

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Power Dynamics	18. What are the power dynamics within your team that may need to be addressed?		
	19. Have you considered the balance between LEEs and researchers in your group?		
	20. How is the 'fit', or, the combination of people (researchers and LEEs)?		
	21. How will you welcome LEEs to the team?		
Sensitivities	22. How are you being sensitive to the population you're working with and what specific considerations are you making for the group that you're engaging with, given their health condition/s or 'typical' shared experiences?		
	23. Are you using a trauma-informed model?		



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O for Onboard

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Recruitment	24. How will you identify LEEs appropriate to your area of research?		
	25. How will LEEs be able to express an interest in joining the research team?		
	26. How will prospective LEEs be screened for suitability?		
	27. Will there be an interview process?		
	28. Have you developed an Induction package specific to LEEs?		
	29. Do you need to ask for and store contact and bank details (for payment)?		
	30. Who will provide an orientation to the environment for on-site activities?		
	31. Will LEE team members need names badges/security passes?		
	32. Does your institution require LEEs to undertake any mandatory training?		
	33. Have you considered the use of mentors for any LEE on your team? What will the scope of a mentor be? What will their responsibilities be?		
Education	34. How will you train and provide education to LEEs about the research process?		
	35. Have you developed plain language versions of relevant research documents, e.g. HREC forms, to share with your LEEs?		
	36. Have you created a glossary of key definitions or scientific terms relevant to your study area?		
	37. Can you make the research materials available in multiple languages or provide an interpreter service to increase diversity?		
	38. Are there other local systems or organisational processes that LEEs may need an introduction to, or training for, in order to participate fully?		
Resources	39. What resources will be required so that LEEs can do their work?		
	40. Are you able to provide a letter of support to their employer for sign-off or can meetings times be dictated by the LEEs?		
	41. Will LEEs in your project require any specific technology to enable them to participate?		
	42. Can you provide LEEs a physical space to work with you if they require one?		



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	43. Would LEEs need to be provided reimbursements or resources for transportation to complete their research activities?		
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P for Participate

	CRITERIA: <i>Using the right columns please indicate if each question has been addressed and where in your main document you have discussed it (if not incorporating the checklist with answers into the main document as a separate section)..</i>	Yes/ No/ NA	Document section, page
Work Plan and Task	44. Have you co-designed a realistic project roadmap so the LEEs can plan their involvement over the course of the study?		
	45. How will the group (researchers and LEEs) meet for the duration of the study, e.g. in person, online, hybrid?		
	46. How will communications be managed, e.g. email, cloud documents, paper?		
	47. What are the time expectations for meetings, review work, etc.?		
	48. 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?		
	49. How will the team address issues if “life happens” and the LEE needs to step back to a different level of engagement?		
	50. What sorts of work might LEEs undertake during the study?		
Safety	51. What are the standards and structures in place to welcome LEEs and support positive working relationships between LEEs and researchers?		
	52. Have LEEs been introduced to the established processes for reporting risks or complaints to research project leaders or stakeholders?		
	53. How will you prevent harm related to engaging in this research for LEEs? Have you considered a trauma-informed approach?		
	54. Has the safety of researchers within this team been considered?		
Evaluation	55. How will you evaluate the collaboration; what worked, what didn't?		



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For each item that was not addressed, or deemed not applicable may be explained here.

Criterion not addressed
<ul style="list-style-type: none">(e.g., item 19 - provide brief explanation)
Criterion deemed not applicable
<ul style="list-style-type: none">

PI Signature		Date	
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