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Embedding lived experience in mental health and substance use research: Building collaborative and inclusive pathways

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Abstract

Background

Embedding perspectives of people with living and/or lived experience (LLE) of mental health and/or substance use conditions is increasingly recognised as best practice in undertaking relevant, ethical and impactful research. However, meaningful LLE engagement within academic research centres remains inconsistent, and practical guidance on implementation is limited. This study compared perspectives of people with LLE involved in research (members of the Lived Experience in ReseARch Network or 'LEARN') and staff at a mental health and substance use research centre to examine barriers and facilitators to engagement, and co-develop strategies to meaningfully embed LLE within centre processes.

Methods

A mixed-methods design was used. Phase 1 involved online surveys with LEARN members (*N* = 37) and staff (*N* = 52). Quantitative data were analysed descriptively, and group differences were compared using Fisher's exact tests. Open-text responses were inductively coded. Phase 2 involved a co-development workshop (*N* = 11) to discuss, refine, and translate Phase 1 findings into practical strategies for building collaborative pathways and aligning research priorities. Workshop sentiments were analysed using reflexive thematic analysis.

Results

Both groups strongly endorsed the importance of LLE involvement in improving research quality, relevance and translation. Most staff (*n* = 44, 88%) and LEARN members (*n* = 27, 93%) strongly supported LLE involvement in research, especially during idea formation and intervention development stages. Both groups wanted the research centre's engagement to increase from the current rating of 'advisory' level to 'co-production' or 'lived experience led'. Engagement was viewed as most valuable during early research stages; LEARN members expressed interest in contributing to measure development, ethics applications and data analysis. Key barriers included time and funding constraints, challenges ensuring diverse representation, inconsistent structural support, and risks of tokenism. Findings informed an 'ecosystem of engagement' model describing organisational facilitators, collaborative practices (e.g., power-sharing, adaptive feedback), and anticipated outcomes (e.g., strengthened research processes, LLE leadership).

Conclusions

These findings offer a roadmap for research centres seeking to embed lived experience sustainably, authentically, and equitably. Meaningful LLE engagement requires sustained organisational commitment including adequate remuneration, formalised infrastructure, capacity-building opportunities, and clear leadership pathways. Co-developing and co-evaluating these pathways can support authentic partnerships, improve research quality, and contribute to both organisational and system-level transformation.

Plain English Summary

People with living and/or lived experience (LLE) of mental health and substance use challenges offer valuable insights that can strengthen research and lead to better services and policies. However, many people with lived experience continue to face barriers when trying to participate in research, including stigma, tokenistic involvement, or being included too late in the process to make meaningful contributions. To create genuine partnerships, research organisations need structures, policies, and practices that actively support and value lived experience at every stage of research. This study explored how lived experience contributors and research staff at the Matilda Centre view the current state of lived experience engagement, what they see as the main challenges, and how engagement could be improved. We used a two-part, mixed-methods approach. First, online surveys were completed by members of the Lived Experience in ReseARch Network (LEARN; *n* = 37) and research centre staff (*n* = 52). These surveys asked participants about the benefits of lived experience engagement, the current and ideal levels of involvement, and any barriers they had observed. Second, a workshop (*n* = 11) brought together LEARN members and staff to reflect on the survey findings and co-develop practical strategies for improving engagement. Participants agreed that lived experience involvement improves the quality, relevance, and impact of research. They also highlighted key areas for improvement, including better access to training and capacity-building, clearer organisational structures to guide engagement, more opportunities for LEARN members to connect with each other and with staff, and ensuring that lived experience contributions are appropriately recognised and paid. Participants emphasised that meaningful involvement requires early and ongoing collaboration across the research process, not just at isolated stages. The study produced a model for engagement showing the organisational supports, collaborative practices, and positive outcomes that can help lived experience and conventional researchers work together effectively. These findings offer a roadmap for research centres seeking to embed lived experience in a sustainable, authentic, and equitable way. Investing in capacity-building, fair remuneration, supportive systems, and leadership pathways for people with lived experience is essential for improving both the research process and the real-world impact of mental health and substance use research.

1. Introduction

Embedding the perspectives of individuals with living and/or lived experience (hereafter referred to as ‘lived experience’ or LLE) is now recognised as essential to improving the quality, relevance and impact of research across disciplines [1]. Robust evidence shows that lived experience involvement improves priority setting, enhances intervention design and feasibility, strengthens dissemination, and contributes to meaningful service reform [1–5]. These benefits are most apparent when people with lived experience are meaningfully engaged as advisors, collaborators, and leaders, rather than passive participants [6]. Lived experience can expand conventional ways of doing research, leading to more impactful and

responsive outcomes designed to correspond directly with the needs of a community, helping to bridge the gap between research findings and the communities they aim to serve [7, 8].

Major research bodies and funding organisations have formally endorsed lived experience engagement as a best-practice approach to research [9–11], with some calling for research institutions to move beyond tokenistic consultation and toward meaningful partnerships and lived experience leadership [9, 12–15]. While these recommendations have accelerated cultural change, guidance on implementation remains limited. These recommendations must now move beyond *whether* lived experience should be involved, and towards frameworks for *how* to meaningfully embed it within traditional research centres where conventional academic practices, funding models, and operational structures were not designed with lived experience participation in mind [16]. In order to create substantive, long-lasting change where lived experience is embedded, rather than simply consulted, research institutions must build cultures and systems that genuinely value and integrate experiential knowledge [17].

Integrating lived experience in mental health and substance use research benefits both persons with lived experience and conventional researchers. Lived experience perspectives in this area are particularly important as these perspectives are inherently shaped by social, cultural and structural factors – such as stigma, marginalisation, social disconnection, yet also resilience and resourcefulness – that are often insufficiently captured by quantitative data or theory alone. By virtue of their direct engagement with various support systems (e.g., healthcare, welfare), people with lived experience are uniquely positioned to identify gaps, challenge assumptions, and inform research priorities to create meaningful change [10]. However, individuals with mental health and/or substance use conditions have historically been excluded from knowledge production, marginalised, disempowered, silenced, and subjected to coercive treatment practices [17–19]. Beyond this ethical imperative, personal and professional benefits for both lived experience and conventional researchers are widely evidenced [15, 17, 20]. For those with lived experience, meaningful engagement in research may positively impact mental health and recovery, increase confidence, knowledge and skills, and promote a sense of agency, inclusion and validation [7, 21]. For conventional researchers, integrating lived experience perspectives can be highly rewarding and has the potential to transform their research practice and its impact [17]. Shared priority setting with relevant individuals or communities also reduces costly research ‘waste’ (i.e., research affected by flawed design, poor reporting or inadequate dissemination) and improves intervention and translation outcomes [22, 23].

However, engagement is not without its challenges, particularly when implemented ineffectively. Despite increased participation in recent years, implementation can be inconsistent, with wide variation in the level and authenticity of engagement [18]. Barriers to meaningful engagement operate at each level – from individuals, teams and organisations, and systemically throughout the research ecosystem. Lived Experience researchers report facing barriers such as stigma, tokenism, lack of acceptance, unclear expectations, and inadequate training or support which can create tension and frustration between conventional and lived experience contributors [7]. Stigma towards mental health conditions and limited support in managing symptoms can also create additional barriers to participation [18]. Conventional

researchers report barriers including limited knowledge or training, time pressures, rigid funding or reporting requirements, and lack of institutional support [17, 24]. Stigma within academia may also deter conventional researchers from disclosing their own lived experience within a professional context for fear of appearing less objective and therefore less competent, reinforcing a 'false dichotomy' between conventional researchers and persons with lived experience [25–28], and deepening inequality in power dynamics [29, 30]. At a broader level, factors such as conventional indicators of 'success', funding stipulations (which often exclude Lived Experience researchers without academic qualifications from being lead investigators), and lack of lived experience representation throughout the research ecosystem (e.g., in leadership positions, ethics committees, or journal review boards) can create systemic barriers which disincentivise authentic lived experience engagement, and marginalise lived experience voices [31, 32]. Further, the hierarchical and competitive culture in many academic institutions which prioritises academic output over community collaboration, can disincentivise early- to mid-career researchers from investing in lived experience [16, 33]. These factors risk participatory methods reproducing the epistemic injustices which they may be trying to reconcile [14, 29, 34].

Ensuring successful research partnerships between conventional and Lived Experience researchers requires a whole-of-system approach [35] that considers barriers and facilitators at each level. Key individual facilitators of mutually beneficial research partnerships [3] include early involvement of lived experience contributors within the research process, clearly defined roles and expectations, frequent meetings, open communication, mentorship and relationship development, and co-developed approaches to decision-making and power-sharing [7, 32, 35–37]. At the organisational level, organised training and capacity building [33], adequate resource allocation (i.e., dedicated roles), and frameworks to re-negotiate expectations and power dynamics can support teams to overcome challenges [7]. Institutionally, recognition of co-produced outputs as legitimate scholarly contributions and financial investment at early- and mid-career stages is fundamental in demonstrating support for co-design [31], building capacity, promoting trust and facilitating long-standing partnerships between conventional researchers and those with lived experience [33].

Currently, most empirical guidance on engagement is project-based and contained to discrete, time-bound initiatives [17]. However, *embedding* lived experience requires structural and cultural change, long-term resourcing, shared priority-setting, and leadership throughout the entire research lifecycle. Previous initiatives [38–40] provide crucial frameworks for embedding lived experience into traditional mental health research institutions, however these examples remain the exception rather than the norm. Evidence and implementation gaps persist, including inconsistent definitions and understanding of lived experience engagement, lack of resources and training, and inadequate evaluation mechanisms through which to measure impact [32, 41]. Without co-developed resources and policies that integrate lived experience into the fabric of a research institution, efforts to embed lived experience risk remaining dependent on the commitment and subjective understanding of individual researchers [42].

To address these gaps, the present study explored the experiences of both conventional researchers and Lived Experience researchers within the context of a traditional academic research centre, and co-

identified actionable pathways to support sustainable, authentic lived experience engagement. Conventional researchers were staff at the Matilda Centre for Research in Mental Health and Substance Use at the University of Sydney, Australia. The Matilda Centre is a multidisciplinary research centre committed to improving the health and wellbeing of people affected by co-occurring substance use and mental disorders. The centre comprises approximately 120 academic researchers, clinicians and professional staff. Lived experience researchers were members of the Lived Experience in reseARch Network (LEARN), a database established by the Matilda Centre in 2019 to connect individuals with lived experience of mental health and/or substance use conditions to research opportunities. LEARN is facilitated by the Group for Lived Experience Engagement (GLEE) at the Matilda Centre. GLEE was co-established and is co-governed by a group of conventional and Lived Experience researchers. GLEE aims to support research partnerships between conventional researchers and people with lived experience. GLEE oversees the LEARN database and provides monitoring and evaluation of research experiences for both Matilda Centre researchers and LEARN members. At the time of the study, the LEARN comprised approximately 55 members across Australia.

As depicted in Fig. 1, this mixed-methods study involved two phases: i) an online survey tailored to each group, LEARN members and Matilda Centre staff, and ii) a workshop co-attended by members of each group, to share insights, explore survey findings, and collaboratively identify pathways for effective engagement. The project team comprised ten members, including two Lived Experience researchers, four conventional researchers, and four professional (non-academic) staff members.

1.1 Aims

The aims of this research were to:

1. Understand how perspectives and experiences of lived experience engagement in research differ between conventional and Lived Experience researchers
2. Examine the barriers and facilitators of meaningful lived experience engagement within an active mental health and substance use research centre
3. Draw upon the prior experiences of both conventional and Lived Experience researchers to identify key learnings and pathways to enhancing meaningful engagement within the centre

1.2 Language

To assess the benefits and challenges associated with lived experience research engagement, this paper differentiates various roles using the following definitions. The term ‘people/person with lived experience’ is used to refer to people with current or past experiences of mental health and/or substance use challenges, who may or may not be involved in research [43]. When referring to people with lived experience who are involved in research (such as members of the LEARN), we use the term ‘Lived Experience researcher’. Lastly, when referring to staff members and academic researchers, we use the

term ‘conventional researcher’ [44]. These terms have been used to distinguish the unique needs of each group, while still acknowledging that these roles and identities may overlap.

2. Methods

2.1 Phase 1 survey

2.1.1 Sample recruitment

Two separate online surveys were run concurrently (one for LEARN members and one for Matilda Centre staff) from August to September 2024. LEARN members were recruited via emails distributed to the LEARN database (approximately 55 members at the time) by a Lived Experience researcher (PH) on the project team. Eligibility criteria were set to include any LEARN member (noting that LEARN members must be over the age of 18 and currently residing in Australia). Matilda Centre staff were invited via a separate recruitment email distributed by a junior member of the project team (GB) to avoid potential bias or coercion from more senior project team members. Staff members in any role-type (i.e., professional, operational, or academic staff) were considered eligible to participate. Interested participants were directed to a secure Qualtrics (Provo, UT) survey link. After providing informed consent, participants were able to access the survey which took approximately 15 minutes. Participants in the LEARN group were remunerated with a $40 gift voucher for their time, and staff members were able to enter a prize draw to win 1 of 2 $100 gift vouchers.

2.1.2 Measures

Based upon previous studies (e.g., [39]), the online surveys (Appendix 2) collected a combination of quantitative (i.e., Likert scale, multiple choice) and qualitative (i.e. open-text response) data to gauge participants’ experiences and perspectives related to lived experience engagement in research. Demographic information was collected from both groups (see Appendix 1 for specific measures). Respondents from both groups were asked about their perspective on the importance of lived experience involvement in mental health and/or substance use research in general. Drawing on their prior experiences, all respondents rated their level of agreement with a series of statements on the specific benefits of, and barriers to engagement. They were also asked to indicate the level of engagement they believed the Matilda Centre is at currently, and the level they believe the Centre should *ideally* achieve using a framework adapted from Bellingham and colleagues [12], based upon Arnstein’s ladder of citizen participation ([39] see Fig. 2).

Additionally, participants identified the stages of the research process where they considered LLE engagement to be most beneficial. LEARN members were asked further questions about the skills and capacities they had developed through their involvement in research and those they would like to develop further. Many closed-ended questions were supplemented with an optional open-text response to capture additional qualitative insights.

2.1.3 Analysis

Quantitative analysis of categorical survey data was conducted in R (v4.5.0) [45] to describe and compare staff and LEARN members' responses. For rating-scale questions, relative frequency distributions were calculated for each group and presented as percent stacked bar graphs. Fisher's exact test was applied to test for group differences ($p < 0.05$) [46] .

2.2 Phase 2 workshop

2.2.1 Sample recruitment

Following Phase 1, both LEARN and staff members were invited to participate in a 5-hour workshop event in October 2024, and registered their interest and contact details via a secure Qualtrics form. LEARN members provided their age, gender, location and their lived experience (substance use, mental health, or both) to ensure diversity among attendees. Staff members provided their age, gender and role type (academic, professional or student) to ensure that the workshop included a range of perspectives. Preferred attendance mode (in person and/or online) and accessibility requirements were also collected. LEARN members were reimbursed for their time and travel according to NHMRC recommendations [47].

A total of 11 people (3 LEARN members, 6 staff, 2 designated Lived Experience researchers) participated in the in-person workshop held in late October 2024. The first hour was open to all LEARN and Matilda Centre staff members in-person and online (via Zoom) [48]. Preliminary findings from the Phase 1 survey were presented and an interactive group discussion was facilitated through Mentimeter [49]. The workshop was then closed to in-person attendees only, and included a panel discussion and collaborative research pitch activity. The panel, consisting of designated Lived Experience and conventional researchers, drew on their past experiences of co-design and co-production work, reflecting on challenges and key learnings which informed the identification of pathways for enhancing Lived Experience engagement at the centre.

2.2.2 Qualitative data

Qualitative data were gathered from two sources during the workshop: i) brief written responses to discussion prompts submitted via Mentimeter [49], open to all in-person and online workshop attendees, and ii) extended insights and reflections from in-person workshop panel discussions.

2.2.3 Thematic analysis

Analyses were conducted by two researchers independently (G.B. and L.S.) using NVivo 14 [50]. Initial thematic coding of the data was completed individually, following which, a consensus meeting occurred between coders. Themes were derived through a predominantly inductive (i.e., data-driven) analysis of written reflections and panel discussions, adopting an experiential orientation to thematic analysis that privileges participant-based meaning and lived perspectives [51]. The consensus meeting involved merging the independently coded NVivo data files to highlight and refine common themes and

subthemes. Themes and supporting quotes were discussed with disagreements and differences resolved through iterative discussion until final agreement was reached.

3. Results

3.1 Survey

3.1.1 Participants

A total of 52 research centre staff and 37 LEARN members completed the online surveys. As shown in Table 1, the majority of staff respondents identified as female (*n* = 46; 88%) and were aged 18–34 years (*n* = 38; 73%). Just over half were professional staff members (*n* = 29; 55%), followed by 35% (*n* = 18) academics and 10% (*n* = 5) research students. Most worked in prevention (*n* = 29; 56%) or translation and implementation (*n* = 23; 44%).

Approximately 70% (*n* = 37) of the total LEARN database completed the survey. The most common age range of LEARN participants was 45-54-years (*n* = 10; 27%) and 65% (*n* = 24) identified as female (30% male; 5% other). Just over half of respondents (*n* = 19; 51%) had been a member of LEARN for 1–3 years. 63% (*n* = 23) were located in metropolitan areas, 24% (*n* = 9) in regional areas and 14% (*n* = 5) in rural/remote regions. Detailed information is available in Additional file 1 (Tables A1 and A2).

Table 1
Summary of sample characteristics.

	Staff (*n* = 52)		LEARN (*n* = 37)	
	N	***%***	***N***	***%***
Gender				
Female	46	88.5	24	64.9
Male	6	11.5	11	29.7
Other	0	0	2	5.4
Age				
18–34	38	73.1	11	29.7
35–44	10	19.2	8	21.6
45+	4	7.7	18	48.6
Years with the centre/network				
< 1 year	14	26.9	12	32.4
1–3 years	17	32.7	19	51.4
4+	21	40.4	6	16.2

LEARN member experiences of research engagement

To better understand the value and impact of the LEARN, respondents provided feedback on their experiences with research engagement through the Network. Detailed information is provided in Additional file 1 (Tables A3 and A4).

Approximately 61% (*n* = 22) of LEARN participants reported previous engagement in research prior to joining the LEARN. Among these, the most commonly reported level of involvement was ‘co-production’ (*n* = 6; 27%), followed by ‘co-design’ (*n* = 5; 23%) and ‘advisory group’ (*n* = 4; 18%). In relation to the Matilda Centre (see Additional file 1, Table A3), 81% (*n* = 29) of respondents had been contacted by the Matilda Centre in the past 12 months. Fourteen respondents reported engaging in a research activity via LEARN. Of these, 57.1% (*n* = 8) reported enjoying their experience ‘very much’, followed by 36% (*n* = 5) who indicated they enjoyed their experience ‘quite a bit’.

Staff member experiences with LEARN engagement (feedback and recommendations)

Staff members also shared their experiences engaging with the LEARN. Of those who had engaged with the LEARN previously (*n* = 45), a large proportion had either not engaged with LEARN in the past two years (*n* = 22; 49%) or were unsure if they had (*n* = 18; 40%). Of those who had engaged LEARN members

in the last two years (*n* = 5; 11%), all indicated that it was either 'extremely' (*n* = 4; 80%) or 'somewhat' (*n* = 1; 20%) easy to do so. Similarly, all respondents believed that LEARN members' feedback improved their project either 'very much' (*n* = 3; 60%) or 'quite a bit' (*n* = 2; 40%), with the same proportions reporting that it was easy to implement the feedback provided. The most commonly reported stage in which LEARN members were engaged was in 'development of an intervention' (*n* = 2; 40%), followed equally by 'forming ideas', 'preparing grant applications' and 'reviewing case studies' (all *n* = 1; 20%). Details provided in Additional file 1, Table A5.

Comparing the perspectives of conventional and Lived Experience researchers

The Spectrum of Lived Experience Engagement in Research

Figure 2 shows the distribution of staff and LEARN member ratings, both in terms of where they think the research centre is currently placed on the spectrum of Lived Experience engagement and where they would ideally like the centre to the placed. Full details provided in Additional file 1, Tables A6 and A7.

A significant difference was seen in the distribution of ratings between staff and LEARN members in terms of the *current* level of lived experience engagement in research and related activities at the centre. The majority of staff (81%; *n* = 37) placed the current level of engagement at Level 2 'Advisory group' (48%; *n* = 22) or Level 3 'Co-design' (33%; *n* = 15). The remaining placed engagement at Level 4 'Co-production' (13%; *n* = 6) or Level 5 'Lived experience led' (4%; *n* = 2), with only 1 staff respondent indicating that engagement at the centre operates at the lowest level 'Consultation' (2%). Compared to staff, LEARN member ratings were more equally spread across levels. Similar to staff, the most frequently selected level was Level 2 'Advisory group' (32%; *n* = 7), although this was followed closely by an equal proportion of LEARN members placing engagement at the centre at either Level 4 'Co-production' (23%; *n* = 5) or Level 5 'Lived experience led' (23%; *n* = 5). The remaining LEARN members placed engagement at Level 1 'Consultation' (14%; *n* = 3) or Level 3 'Co-design' (9%; *n* = 2). No staff or LEARN respondent rated research at the centre as currently being 'Lived experience owned' (Level 6).

Conversely, there was no significant difference in the distribution of ratings between staff and LEARN members in terms of the *ideal* level of Lived Experience engagement at the centre, with both groups rating higher on the spectrum overall compared to current placement ratings. Among staff who answered this item (*n* = 46), most reported that they would like LLE engagement at the centre to be placed at Level 4 'Co-production' (35%; *n* = 16), followed closely by Level 5 'Lived experience led' (28%; *n* = 13). Among LEARN members who answered this item (*n* = 22), just over a third reported that they would like engagement to be placed at the highest level 'Lived experience owned' (35%; *n* = 8), followed by an equal number selecting either Level 4 'Co-production' (23%; *n* = 6) or Level 5 'Lived experience led' (23%; *n* = 6).

Perceived benefits of lived experience research

When asked how important it is for people with lived experience to be involved in research, a large majority of both staff (*n* = 44; 88%) and LEARN members (*n* = 27; 93%) responded 'Very much so'. Figure A1 shows the distributions of staff and LEARN member responses for items measuring the extent to which they endorsed specific benefits of LLE engagement across a five-point Likert scale. The item most strongly endorsed was 'enhance research quality and relevance', with high proportions of both staff (*n* = 46; 94%) and LEARN members (*n* = 25; 86%). By contrast, 'increasing study enrolment' had the lowest endorsement among both groups (staff: *n* = 24; 49%; LEARN *n* = 20; 69%), with 20% (*n* = 10) and 21% (*n* = 6) of staff and LEARN responding 'neither agree nor disagree', respectively. There was a significant difference observed for the item 'improve dissemination and implementation' ($p<.001$), with LEARN members reporting lower endorsement than staff. See Tables A8 and A9 for full survey items and responses.

Stage/s of research where lived experience engagement is most beneficial

Respondents were asked to select which stage/s of the research process they see as benefitting most from lived experience engagement, with Fig. 3 showing selection rates for each group (see Additional file 1, Table A10). Both staff and LEARN respondents most frequently identified '*forming ideas'* and '*development of interventions'* as the most beneficial research stages to receive LLE feedback (staff: 90%, *n* = 45; LEARN: 88%, *n* = 23, and staff: 90%, *n* = 45; LEARN: 96%, *n* = 25, respectively). The next most frequently selected stages were *designing protocols* (Staff: *n* = 36; 72%, LEARN: *n* = 20; 77%) and *dissemination* (Staff: *n* = 36; 72%, LEARN: *n* = 19; 73%). Differences in selection rates between the two groups were greatest for *development of measures* (Staff: *n* = 22; 44%, LEARN: *n* = 19; 73%), *ethics applications* (Staff: *n* = 16; 32%, LEARN: *n* = 18; 69%) and *data analysis* (Staff: *n* = 15; 30%, LEARN: *n* = 17; 65%).

Barriers to lived experience engagement for conventional researchers

As shown in Fig. 4, staff endorsement varied across statements. 'It is difficult to ensure representation from a diverse range of people with relevant lived experience' had the highest level of staff endorsement, with almost 90% of the responses (*n* = 42) indicating either 'Agree' (*n* = 8; 20%) or 'Somewhat agree' (*n* = 28; 68%). Conversely, of the total responses to 'it is difficult to maintain robust scientific design while incorporating feedback' (*n* = 42) there was low endorsement, with most respondents selecting either 'Disagree' (*n* = 11; 26%), 'Somewhat disagree' (*n* = 11; 26%) or 'Neither agree nor disagree' (*n* = 11; 26%). For the other three statements, responses were relatively varied and spread across the rating scale. Full details provided in Additional file 1, Table A11.

Development of skills and capacities through research engagement

As depicted in Fig. 5, LEARN members most frequently reported having developed *critical thinking* and *mental health literacy* (both *n* = 13; 50%) during their time in LEARN, followed by *empowerment* (*n* = 11; 42%) and *confidence* (*n* = 11; 42%). Least frequently reported were *public speaking* (*n* = 4; 15%) and *research skills* (*n* = 7; 27%). A large majority of LEARN members reported wanting to develop *research*

skills (*n* = 20; 77%), followed by *leadership* (*n* = 17; 65%). When asked to select which research skills they would like to develop further, each of the research skills was selected by at least 65% of LEARN respondents. Most frequently selected were *writing reports* (*n* = 16; 80%) and *critically review literature* (*n* = 16; 80%). Full details provided in Additional file 1, Table A12.

3.2 Workshop

3.2.1 Key Themes: Facilitators, pathways and outcomes

Several key themes emerged from the workshop, which are conceptualised as an 'ecosystem of meaningful engagement' in Fig. 6. In this model, each theme (and related subthemes) operate as components of a thriving 'ecosystem' of meaningful and productive lived experience-research collaboration. Theme 1 (Facilitators) highlights the structural and organisational supports required to create the conditions which precipitate 'fruitful' engagement. Theme 2 (Pathways) addresses the dynamic processes and practices which encourage the growth of meaningful lived experience engagement over time. Lastly, Theme 3 (Outcomes) represents the 'fruits' of these processes, in which LLE and conventional researchers harvest, regenerate and transform the landscape of research, both within an organisation and more broadly. This model aims to depict the reciprocal and collaborative preparation, nurturing and responsibilities required for productive and sustainable lived experience engagement in research.

Theme 1. Cultivating the conditions: Facilitators of meaningful engagement

Workshop participants identified organisational structures and conditions that enable meaningful engagement at the centre, with four sub-themes emerging, including: resources and capacity-building, sustainable resourcing, structural supports, and relationship development.

Enriching the soil: Specialised resources and capacity-building initiatives

Participants emphasised the need for capacity-building initiatives and resources to enhance skills and competencies for both LEARN and staff members. Mentoring or dedicated 'research buddy' programs were the most frequently recommended initiatives for mutual skill-transfer and capacity building. Participants also suggested additional facilitators supporting the development of research skills in LEARN members, including involvement in every stage of the research process, contributing to developing grants and writing papers, dedicated workshops and training resources, and extending access to University resources to LEARN members.

Staff members also discussed their need for guidance in effectively engaging lived expertise. One mid-career academic reflected, *"Often when devising a grant I think 'wow it would be wonderful to include someone with lived/living experience', but don't know where to start."* Staff suggested practical resources for building researcher capacity including templates for inclusion (e.g., in ethics applications, grants, workshops, interviews), best practice guidelines and 'how to' materials (e.g., quick tips, videos and

guides) for facilitating lived experience engagement throughout a project. Another researcher highlighted the benefit of these resources in *"reduc[ing] the amount of time that researchers have to spend in the initial stages of a project, when input from LEARN might be most valuable but there are so many other tasks to do that there is a risk of input being too late and tokenistic."* Many staff members also emphasised the importance of researcher training and education around *"what true lived experience engagement looks like"*, with one stating that researcher capacity involves a *"clear understanding of lived experience as a paradigm, beyond just individual perspectives."*

Sources of sustenance: Fair and sustained funding, remuneration and employment infrastructure

Participants consistently identified how crucial institutional infrastructure is in enabling sustainable and impactful participation. Dedicated funding and fair remuneration were recognised as essential for meaningful engagement of lived expertise and were viewed as a matter of equity and due recognition. As one staff member stated, *"Paid involvement is essential – you wouldn't ask someone with subject matter expertise in data analysis to work for free."* A LEARN member also noted the importance of funding type, stating; *"Pay us in cash rather than vouchers. Researchers are not paid in vouchers."* Participants discussed allocating budgets in research grants to support paid engagement, as well as establishing a dedicated pool of funding across the centre to ensure engagement beyond individual projects.

Identified Lived Experience roles, both project-based and organisational, were seen as critical for embedding lived expertise and supporting sustained engagement at the centre. Staff valued well-supported, project-based positions but also highlighted the importance of stability for Lived Experience researchers, noting that longer-term or continuing roles*" would make it more worthwhile for individuals interested in research to invest their time without fear of having to make ends meet."* A dedicated co-ordinator for lived experience was also proposed, with one staff member stating, *"It would be so wonderful to have an identified Lived Experience role at the Matilda Centre… perhaps this person could be the go-to person and triage to LEARN"*.

Participants acknowledged the challenges of grant funding constraints when creating employment opportunities: "*It would be good if we could have employed positions, but that wouldn't come out of the grants, it would be more university-level."* One researcher described the importance of *"keeping our eyes open for opportunities"* and suggested creative approaches, including pooling resources across projects and the potential for leveraging university contributions: *"building a Lived Experience research budget into a grant, it may only be a small proportion, but if we have a few projects then we can pool them together and we can say to the university 'we have 60% of this position would you match 40%?'"*

Garden beds, trellises and structural support: Formal processes, policies and procedures

This theme captures the importance of formal organisational processes and procedures that facilitate meaningful engagement at both the university- and centre-level. Participants emphasised that clear infrastructure, policies and support mechanisms are necessary to ensure engagement is sustainable, equitable and accessible. These included formal feedback and engagement mechanisms, transparent

decision-making protocols and accountability mechanisms, as well as more formal recognition of lived experience research within the centre strategy.

Staff and Lived Experience researchers alike noted that existing supports and wellbeing measures were critical, both for attracting more people with lived experience to the centre and to support the wellbeing of staff. However, as one Lived Experience researcher noted, existing supports are often left to individual managers and therefore applied inconsistently: *"Questions about adjustments should be asked of everyone – with physical disability, there are things in place, but with mental health it tends to be case-by-case, and the individualised approach may not be ideal for mental health conditions."* During the panel discussion, they also stressed the importance of framing supports and workplace adjustments as universal, rather than targeted, to avoid stigma and encourage equitable access: *"Some people feel comfortable having those sorts of conversations, but many do not, and the onus shouldn't be on them to overcome stigma… This is something you should account for, for everybody. When we frame something as only needed for a specific population, it's a barrier."*

Nurturing the ecosystem: Creating connection and community

Participants emphasised the importance of organisational-level activities that build relationships and strengthen connections between lived experience and conventional researchers beyond formal project work. They proposed regular, informal opportunities for staff and LEARN members to come together such as; optional recurring social events and greater involvement of LEARN members in broader organisational activities, thereby *"embedding lived experience at every level of the organisation*" (Lived Experience researcher). One staff member described the value of informal shared spaces and catch-ups: *"I like how [another research centre] had yarning circles, informal in-person catch-ups to provide casual advice that might lead to collaboration or just educate [staff] on a new facet of lived experience in an area that they work in."* Such activities were seen as vital for trust and rapport, helping to *"build partnerships over time", "make [staff] more approachable", "facilitate networking opportunities"*, and *"promote a culture of working alongside people with lived experience"*.

Building connection and community among LEARN members themselves was also recognised as highly important among LEARN members. Suggestions included; *"sending out a regular newsletter, so that LEARN members feel part of activities"* and *"host events, webinars, link members in with a community platform*". Opportunities for LEARN members to connect outside of project work, share knowledge and experiences, and mentor newer members were seen as valuable for building a community of practice and promoting collective learning within the Network.

Workshop panellists highlighted that meaningful engagement grows through supportive interpersonal relationships where trust and rapport are nurtured over time. As one Lived Experience researcher reflected, *"The relational aspect is one of the most important… [Lead researcher] has always been so great and supportive, they would say 'you're wonderful' and it felt authentic, rather than 'we're just excited to have "lived experience" here'. If I identified something I was passionate about, they really tried to see that*

through." These reflections show that engagement is sustained not only by formal structures, but by a sense of belonging and community within the organisation.

Theme 2. Tending the Garden: Pathways to improving meaningful engagement

Operating within the context of these facilitating structures, pathways are the processes and mechanisms through which meaningful Lived Experience engagement can be enacted. These pathways capture the *how* of individual-level practices, behaviours and attitudes that translate into genuine and impactful involvement of lived experience.

From seed to harvest: Embedding lived experience at every stage

Participants consistently emphasised that meaningful engagement begins at the earliest stages of research planning and idea generation. Early input ensures that research is relevant, impactful and authentically informed by lived expertise. One staff member noted that lived experience should *"help to shape research priorities and directions,"* highlighting the value of early collaboration in guiding questions and design to ensure research responds to real-world needs. Staff highlighted specific opportunities for early involvement, including enabling LEARN members to submit project ideas, influence research questions, and participate in grant development activities. One early-career academic described the need for greater flexibility and openness to early input among academics: *"I think so often we have so many pre-planned ideas about projects and research at the formative level that there is little space for lived experience perspectives."*

Sustaining close lived experience involvement through all stages of the research process was also viewed as crucial. Rather than confining engagement to isolated or infrequent consultations, one LEARN participant advocated for weaving lived experience throughout the process, explaining: "*It doesn't matter what the meeting is or who is involved in it, lived experience should be involved"*, with a staff member echoing this sentiment, stating, *"have them contributing every step of the way"*.

Co-grown: Authentic collaboration and shared power

Panellists described authentic collaboration as a cornerstone of meaningful lived experience engagement. True collaboration was understood as a process of shared power and decision making to ensure that the research is meaningfully shaped by those with lived experience in order to advance epistemic justice: *"Not just collaboration for collaboration's sake… if the research produced will inform services and policies, then it needs to be lived experience-led"* (Lived Experience researcher). Panellists emphasised the need for conceptual clarity to avoid tokenistic engagement, with one Lived Experience researcher stressing, *"Co-design is actually about co-deciding … if you're really going to do co-design, don't overpromise and underdeliver, understand what it actually takes".* Another panellist further reflected, *"I wish I had more understanding of what co-design actually is, it has become a buzzword in some spaces… I've used the term previously and it wasn't co-design work. It's important to understand what co-design is, rather than entering the tokenistic space".*

Explicit shared decision-making processes and addressing power differentials were framed as critical for reducing tokenism and improving collaboration. As one Lived Experience researcher noted, lived experience contributors should influence not only research choices but *"the choices of choices,"* ensuring that their perspectives shape priorities and outcomes. Transparent, structured and iterative decision-making processes were called for to define how decisions are made, whose voices are heard, and how disagreement is handled: *"Is it majority rules? Is it this many stakeholders from these key areas? How do we hold space for difference? Acknowledge harm?"* (Lived Experience researcher).

Active allyship and attention to power dynamics were also stressed. One Lived Experience researcher implored collaborators to *"have the discussion about power*" emphasising that collaboration is *"not neutral, it isn't an equal playing field."* Panellists echoed the importance of negotiating power, and argued that researchers must move beyond neutrality and toward active allyship: *"Rather than "you're all on the same page", you have to focus on power differentials and how we're all positioned"* (Lived Experience researcher).

Lived Experience researchers also reflected on the subtle yet persistent challenges of power dynamics, internalised bias and imposter syndrome. One noted, *"there is a very subtle 'othering' that happens, but it's easy to recognise."* Another Lived Experience researcher stated that this was especially noticeable when lived experience is outnumbered by academics in decision-making spaces, stating that *"it doesn't feel like it's going to be our vote that counts the most… but I am the expert of my own experience".* Regarding how this could improve, one LEARN member suggested; *"involve people who don't have degrees … There is still a level of academic elitism within the centre and you're missing out on people with lived experience who are managing serious illness but have the intellectual capacity to contribute."*

Organic growth and seasonal change: Transparency and adaptive feedback loops

Transparency, reflection and open dialogues were noted as key pathways towards meaningful engagement. Authentic collaboration was seen to require ongoing openness and transparency regarding limitations and areas for improvement. One staff member emphasised the *"humility and ability to reflect on what we aren't doing well or could do better"* as central to meaningful engagement, with another noting that *"it is important to reflect honestly and iterate from there."*

Clear channels of communication, ongoing two-way dialogue and regular feedback were described as mechanisms for ongoing refinement and improvement. This mechanism was framed as iterative and adaptive, requiring teams to adopt feedback loops to continuously reflect on and adjust approaches to respond to the unique needs of each project and team, thereby strengthening collaborative engagement over time. During the panel discussion, one Lived Experience researcher stated, *"It matters to keep inviting the dialogue, because there's no way you're going to get it right every time. All teams have specific needs, specific people, specific environments—you may have an idea of what you're going into, but you need to keep the dialogue open."* Inviting frequent and consistent feedback throughout the project, rather than just at its completion, was described as critical for enhancing meaningful and productive collaborations:

“Encourage feedback during and after every project - give both sides a space to discuss what worked, what didn't, and what could go better next time” (Lived Experience researcher).

Balancing the load: Acknowledgement and awareness of labour and capacity

Panellists emphasised the need for researchers to recognise the cognitive and emotional demands placed on Lived Experience collaborators. Drawing on personal experiences can be deeply meaningful, but also taxing. As one conventional researcher reflected, *“You’re asking [people with lived experience] to draw on their most traumatic experiences... researchers should recognise it’s a massive emotional labour and remain aware of that.”* To mitigate burden, practical considerations – such as clear processes, manageable expectations, and timely remuneration – were also emphasised: *“If you are involved in co-design work, you should have the simple things ready to go, the little processes, because you don’t want to add to the burden - if you’re asking someone to involve themselves, do the right thing and pay them as soon as you can et cetera”*.

Transparency around individual capacity was also viewed as crucial for Lived Experience researchers, who valued being able to express boundaries or step back as required. One Lived Experience researcher emphasised the need for *“open communication around capacity and encouraging people to put their hand up and say, ‘now is not a good time for me’”*. They also described the burden associated with self-advocacy, particularly in environments where openness around mental health is not yet normalised: *“It takes a lot of energy and labour to have that approach, especially when it’s not welcome or expected. It’s exhausting, and of course it doesn’t feel comfortable, but it shouldn’t have to.”*

Theme 3. Harvest and Transformation: Outcomes of meaningful engagement

Learning from patterns of growth: Lived experience-led evaluation

Participants emphasised that meaningful engagement should be measurable and accountable, requiring evaluation processes that are guided by lived experience perspectives. As one staff member identified, effective evaluation must ensure *“that the voices of Lived Experience experts are heard and truly embedded in the centre’s approach at every step”*.

Participants proposed co-producing assessment tools, annual evaluation, and using data to drive improvement. Outcome measures were also suggested, including LEARN member co-authorship on publications, consistent inclusion of lived experience in grant applications, and active engagement across multiple research projects at the centre.

Importantly, staff expressed that evaluation should be led by those with lived experience, to ensure genuine feedback and accountability. Establishing a Lived Experience Evaluation board, or systematically surveying LEARN members and sharing findings with staff, were suggested as ways to embed accountability. As one staff member suggested, *“it is up to the Lived Experience folk to determine if the Matilda Centre is doing [engagement] well.”*

Stewards of the land: Lived experience in leadership positions

Beyond just collaboration, participants envisioned meaningful engagement at the centre as requiring greater inclusion of Lived Experience in leadership positions, both within research projects and at a governance-level. Several respondents emphasised the importance of moving beyond co-design and co-production, calling for more opportunities for lived experience-led research: *"I think we do [co-design] quite well at Matilda, but there may be ways to integrate and call upon people with lived experience to an even greater extent and really let people with lived experience take a genuinely* leading *role in some of our research projects [original emphasis]."* Lived experience leadership was framed not only in terms of project-level involvement, but also in terms of broader organisational power-sharing and decision-making, with one staff member suggesting the need to *"embed lived and living experience at a governance level, on par with the Board"*.

Transforming the landscape: System-level change

Panellists articulated that meaningful engagement has the potential to drive social and systemic change, highlighting that Lived Experience researchers are often motivated by a personal desire to create tangible impact: *"People [with lived experience] aren't just there to climb up to Professor, but because it really matters to them"*. As one panellist expressed, *"Should we be trying to fit in? You don't want people coming in and trying to fit in; rather, it's about changing the ideas, changing the organisation"*.

Another panellist drew on their personal experience to reflect on how lived experience contribution to research has transformed language, research culture, and practice over time: *"I was working on a project with people who'd been in prison and were going back into the community… the original title was something stigmatising like 'correctional', but it was eventually renamed 'people seeking community re-entry'… reflecting the change and shift towards a strengths-based framework in research"*.

In this vein, the benefits of collaborative research were characterised as extending far beyond immediate research output: *"You're not just part of doing research anymore, it's something bigger—a social movement to change the system."*

4. Discussion

This study explored how perspectives and experiences of lived experience engagement compare between conventional and Lived Experience researchers within a mental health and substance use research centre. Using a two-phase, mixed-methods approach, this study provided insights into the current perceptions of, attitudes towards, and capacity for, engagement among LEARN members and Centre staff. Consistent with existing principles of lived experience engagement [9–11, 17] this study found a strong and shared recognition of the importance of meaningfully embedding lived experience into mental health and substance use research. Both groups were closely aligned on the benefits of inclusive lived experience research, with each strongly endorsing the value of lived experience in improving research quality, relevance and translation of research. These findings reflect broader

recognition of engagement as an ethical imperative underpinning epistemic justice, as well as a methodological best-practice which strengthens the legitimacy and impact of research [19, 20, 52, 53]. However, the structural and practical barriers identified in this study also mirror longstanding concerns throughout the literature, with restrictive research and institutional processes often limiting the extent to which the knowledge and skills of those with lived experience – for which they were chosen to contribute – are fully utilised [54]. Similarly, institutional and professional structures disincentivise conventional researchers from disclosing their own lived experience, reinforcing a rigid separation between *research* and *lived experience* that does not reflect their inherent overlap, and may contribute to stigma and perceived barriers to engagement[55] [56]. While dedicated lived experience expertise remains a distinct and important positionality within research environments, the high prevalence of mental health conditions across both academic and general populations underscores the fluidity of these roles and perspectives in practice. In this context, embedding *universal* supports for staff mental health and wellbeing within institutional structures – such as flexible working arrangements or counselling access – were seen as necessary for developing a culture which facilitates engagement for everyone, and minimises unintended stigma or 'othering' [57, 58].

Further, a lack of adequate time, funding, and institutional support may increase barriers for conventional researchers, such as the ability to ensure engagement is meaningful, non-tokenistic, and representative of a diverse range of experiences. In turn, these factors may deepen the barriers described by Lived Experience researchers in this study and throughout existing literature, such as limited involvement throughout the research process, a lack of adequate funding and training, unrecognised emotional labour, and a lack of support for the unique needs of people with mental health and/or substance use conditions [16]. Thus, while both groups in this study strongly valued and endorsed lived experience engagement, this endorsement does not in itself equate to meaningful engagement, which requires structural, cultural and operational investment throughout the research ecosystem.

Promisingly, several pathways for strengthening meaningful engagement were identified, and are well-supported by previously reported facilitators to engagement [7, 17, 32]. Pathways included practical tools to support engagement, capacity-building opportunities, investment in lived experience roles and leadership, and ongoing iterative evaluation of engagement. Additionally, LEARN members emphasised the need for community-building, power-sharing, and wellness support, while staff highlighted the need for organisational structures to guide engagement, and stronger institutional valuation of lived experience research methods and outputs. These findings reinforce international recommendations that sustained investment in training, secure and equitable remuneration, and career progression are essential for mitigating common barriers to engagement [59]. Practical supports (e.g., capacity-building initiatives) were seen as fundamental in equipping LEARN and staff with the knowledge and skills required to engage effectively. However, this pathway must be considered in the context of existing individual and organisational level barriers (e.g. inadequate time and funding, and national recommendations for institution-level investment in innovative professional development for people with lived experience, along with sufficient funding to support regular, equal opportunities for all staff to build skills [59]. Similarly, remuneration, secure funding, and clear employment structures were also

considered critical for equity and sustainability of engagement. A growing body of evidence suggests that dedicated, ongoing lived experience roles are essential in mitigating common barriers to meaningful engagement, and in improving research processes and outcomes [60, 61]. However, the effectiveness of such roles depends on how they are embedded within institutional structures more broadly. When implemented in isolation, single-role models risk reinforcing stigma and tokenism, overburdening individuals, and under-representation of the diversity of lived experience perspectives [55, 62]. More diverse and distributed approaches across roles and career stages may therefore better support sustainability, inclusion, and institutional change. Importantly, both groups identified a need for lived experience leadership pathways, echoing national and international recommendations for institutions to move toward genuine power-sharing through leadership structures that enable shared authority [59, 63]. While advisory and partnership models have contributed to progress, their impact is, at best, limited by barriers identified through this study (i.e., time-bound or project-based [64]), and at worst, tokenistic or harmful [65]. Lived experience leadership in advocacy and consumer-led organisations has driven broad social and structural change, and created highly effective interventions (e.g., needle exchange programs, peer-distributed naloxone [65]) however this leadership often remains under-recognised in research contexts [66]. Thus, in order to create equity and shift the research culture, researchers have a responsibility to create meaningful leadership opportunities that genuinely centre and value the expertise of people with lived experience [65]. In turn, this can reduce stigma, improve inclusivity, and promote authenticity in the workplace [67]. Institutionally, leadership must also be supported by the removal of structural barriers (e.g., stigma, requirement for formal qualifications, and criminal record policies [65]). Alongside existing frameworks [26, 65, 66], the pathways identified in this research add to growing calls for organisational and institutional investment in clear engagement guidelines, practical supports (such as training, capacity- and community-building), identified lived experience roles, and lived experience leadership.

By identifying differences between the two groups, this study also contributes valuable insights for other research centres and academic institutions. For example, a slight discordance was observed between LEARN members and staff in perspectives of the current level of lived experience engagement at the centre, as well as ideal level of engagement. Notably, LEARN members rated the centre as higher on the participation ladder [12] compared with staff. One possible explanation for this discrepancy is that LEARN members' familiarity and prior experiences with the centre may have enhanced perceptions of overall participation. By virtue of their membership, LEARN members experiences with the centre will almost exclusively have had a lived experience focus, which may bias perceptions. In contrast, only a small number of staff reported having exposure to lived experience engagement in their research or professional work and therefore, may be more likely to perceive a lower level of participation. Another possible explanation is that staff are more familiar with the range of projects and lived experience opportunities at the centre, and their perceptions may more accurately reflect the level of engagement within the centre as a whole. However, as the majority of LEARN respondents had experience with research engagement prior to joining the LEARN, thereby providing points of comparison, their higher perceived ratings likely reflect the performance of the centre relative to the broader landscape of lived

experience engagement in research. As such, staff members may underestimate the extent or quality of lived experience engagement at the centre. Rather than reflecting disagreement, this finding likely reflects existing concerns surrounding the wide variation in how engagement is conceptualised, defined and reported [53]. Previous research has shown that the proliferation of terms used for engagement, and their inconsistent application – including 'participatory research', 'consumer involvement', 'patient involvement', 'co-design' and 'co-production' - may impede the ability to form a clear understanding of the impacts of engagement, on individuals and research processes. This makes the measurement of engagement difficult, and in this instance, uneven across groups with different levels of exposure to and understanding of research practices more broadly. Growing use of standardised reporting tools may help promote consistency and transparency – however, as yet reporting guidelines such as the GRIPP2 checklist are not tailored to mental health and substance use research and remain underutilised in the field [17, 68].

Another important consideration identified in this research relates to differing views on the stages of research where engagement is most valuable. While fewer staff endorsed lived experience engagement as valuable in stages such as ethics applications, measure development, and data analysis, Lived Experience researchers consistently expressed strong interest in contributing throughout all stages of the research process. Although this interest has been widely reported in the literature [17{Hawke, 2025 #246], our findings provide essential context for why this discrepancy may occur. Staff appeared to hold assumptions about these tasks being undesirable (i.e., complex, laborious, or 'boring'). However, as acknowledged by Hawke and colleagues [69], conventional researchers may be more aware of fundamental constraints and structural limitations such as access to data or software that may be restricted by institutional policies. Additionally, staff noted that a lack of resources to support engagement might impose time burdens on conventional researchers during the busy early stages of a project, resulting in engagement that occurs too late and risks being tokenistic. These stages of research are critical timepoints for decision-making and interpretation of a project, but are often dominated by academic contributors [18]. These discrepancies reveal an important gap whereby staff members may be inadvertently denying vital opportunities for Lived Experience researchers to build skills throughout every stage of research. Increasing support and training for both groups may reduce such assumptions and ease logistical burdens that lead to limited engagement in early stages. Taken together, these differences further demonstrate the need for lived experience leadership and decision-making to support involvement throughout the entire research lifecycle.

A key strength of this research was the mixed-methods approach, which enabled richer insights that helped shape the 'ecosystem of engagement' model. This model highlights the interdependence of various conditions, pathways and outcomes that have been previously identified, and offers a framework through which organisations can better understand and operationalize engagement. Rather than conceptualizing engagement using linear frameworks (e.g., Arnstein's participation ladder [12]), the ecosystem model aims to capture the dynamic, cyclical, and relational nature of lived experience engagement, and aligns with innovative frameworks for LLE participation [63]. This analysis frames

transformation not as an endpoint, but an ongoing process of growth that requires sustained investment in funding, leadership, and adaptive learning.

4.1 Limitations

The findings of this study should be considered in light of some limitations. First, as our sample comprised only researchers within our organisation, the findings are not widely generalisable. Future studies could aim to replicate this study across multiple organisations to assess differences and similarities that exist throughout the field. Second, as this study focused on the perceptions of individuals engaged with the centre (i.e., LEARN and staff members), there is the potential for bias in self-reporting. Despite survey responses being anonymous, both groups may have had incentive to report positively on engagement at the centre. Third, the workshop was held in person in Sydney during typical working hours which broadly limited LEARN member attendance. Although transport costs (including taxis, public transport fares and, in one case, flights and accommodation) were provided and organised for LEARN members, budget constraints limited the number of people who could be supported to attend. As a result, the workshop did not capture the full breadth of perspectives within the network. Similarly, only a small proportion of staff had engaged with the LEARN in their role. While the aim of this study was to understand and improve the level of engagement, it is nonetheless important to note that the results may be impacted by a limited number of staff being able to offer insights. Regardless, these responses were important in our analysis as they provide an understanding of broader barriers to engagement, beyond those that exist during engagement. Finally, this study did not explicitly evaluate the level and effectiveness of engagement and therefore is unable to measure and assess unique factors involved in individual experiences of engagement.

4.2 Current and future implementation

The findings of this study have been used to inform internal procedures and structural supports at the Matilda Centre, with several facilitators and pathways translated into actionable strategies. These include capacity-building initiatives, such as training workshops and information sessions (1a); formal processes and resources to guide lived experience engagement (1c); and community-building activities for LEARN members, including a quarterly newsletter and networking events (1d). Each capacity-building activity is accompanied by a short evaluation survey to support ongoing, iterative feedback and inform future initiatives (2c). This feedback is reviewed by Lived Experience Researchers and incorporated into longer-term planning throughout the centre (3a). The research has also contributed to broader structural change, including the establishment of a Lived Experience pillar (1c, 2a, 3c) within the Centre's 5-year Strategic Plan, the creation of ongoing paid roles for people with lived experience (1b), and support for a paid lived experience position on the Centre's board (3b). Collectively, these examples demonstrate how the ecosystem of engagement model can be implemented to strengthen the conditions, pathways, and outcomes of lived experience engagement.

5. Conclusion

These findings hold important implications for conventional and Lived Experience researchers working in research organisations, particularly for those in mental health and substance use research centres. Meaningfully embedding lived experience requires both structural and cultural commitment across individual, organisational and institutional levels. The co-produced 'ecosystem of meaningful engagement' model presented here offers a key contribution by conceptualising lived experience involvement as relational, dynamic, and ongoing. Rather than treating engagement as a discrete, project-bound, activity, our model emphasises the interconnected facilitators, pathways, and outcomes required to sustain meaningful partnerships over the long term. For research centres, these findings underscore the need to move beyond individually-led, project-level involvement toward organisation-wide systems that embed lived experience through governance, workforce structures, resourcing, and accountability mechanisms.

Abbreviations

LLE = Living and/or lived experience

LEARN = Lived Experience in reseARch Network

GLEE = Group for Lived Experience Engagement

Declarations

Ethical approval and consent to participate:

This study was conducted in accordance with the Declaration of Helsinki and received ethical approval from the University of Sydney Human Research Ethics Committee (HE000732/2024). All participants provided written informed consent.

Clinical trial number

Not applicable.

Competing interests:

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Author Contribution

SK, PH, EP, CC, EB, and MB contributed to the conception of the work. SK, GB and MB contributed to the study design. All authors contributed to the acquisition and interpretation of data. LS and GB undertook data analyses and draft initial manuscript. All authors contributed to drafting and substantive revision. All authors read and approved the final manuscript.

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Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Figures

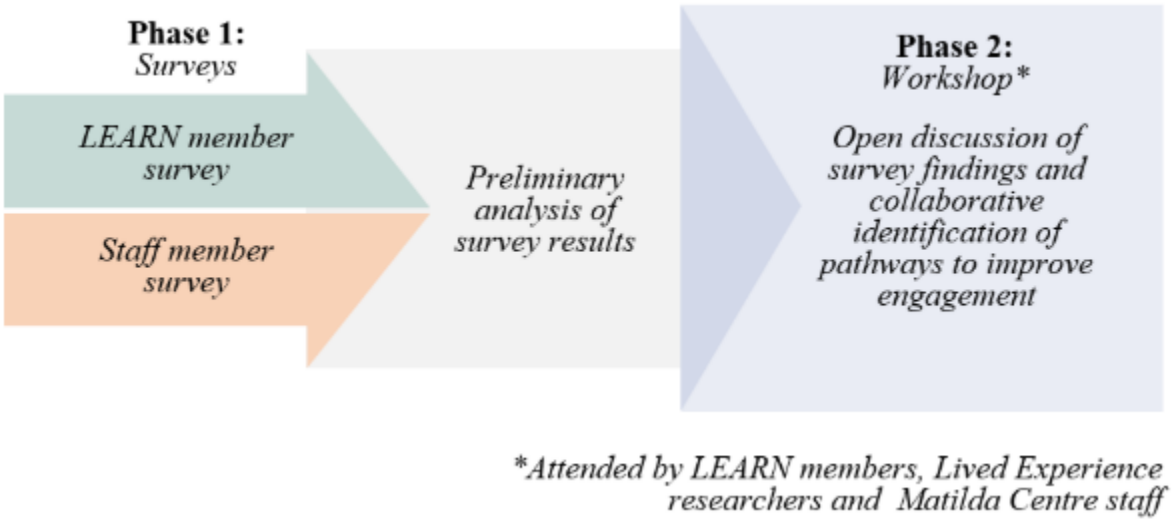


Figure 1

Phases of the study

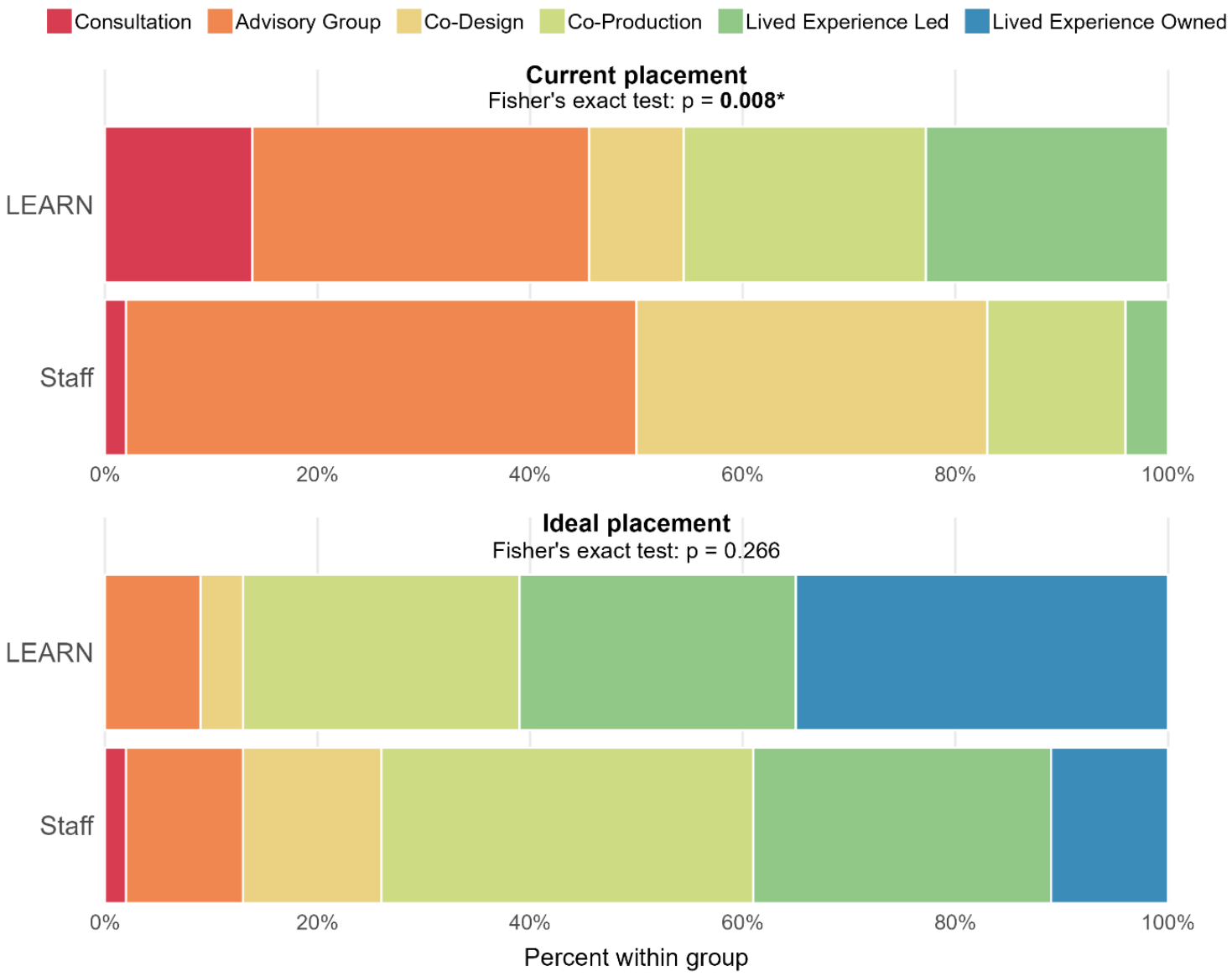


Figure 2

Percentage distributions of lived experience engagement level ratings by staff and LEARN members for both current placement and ideal placement of engagement at the research centre. Significant Fisher's exact test results ($p < 0.05$) indicated with bold and asterisk.

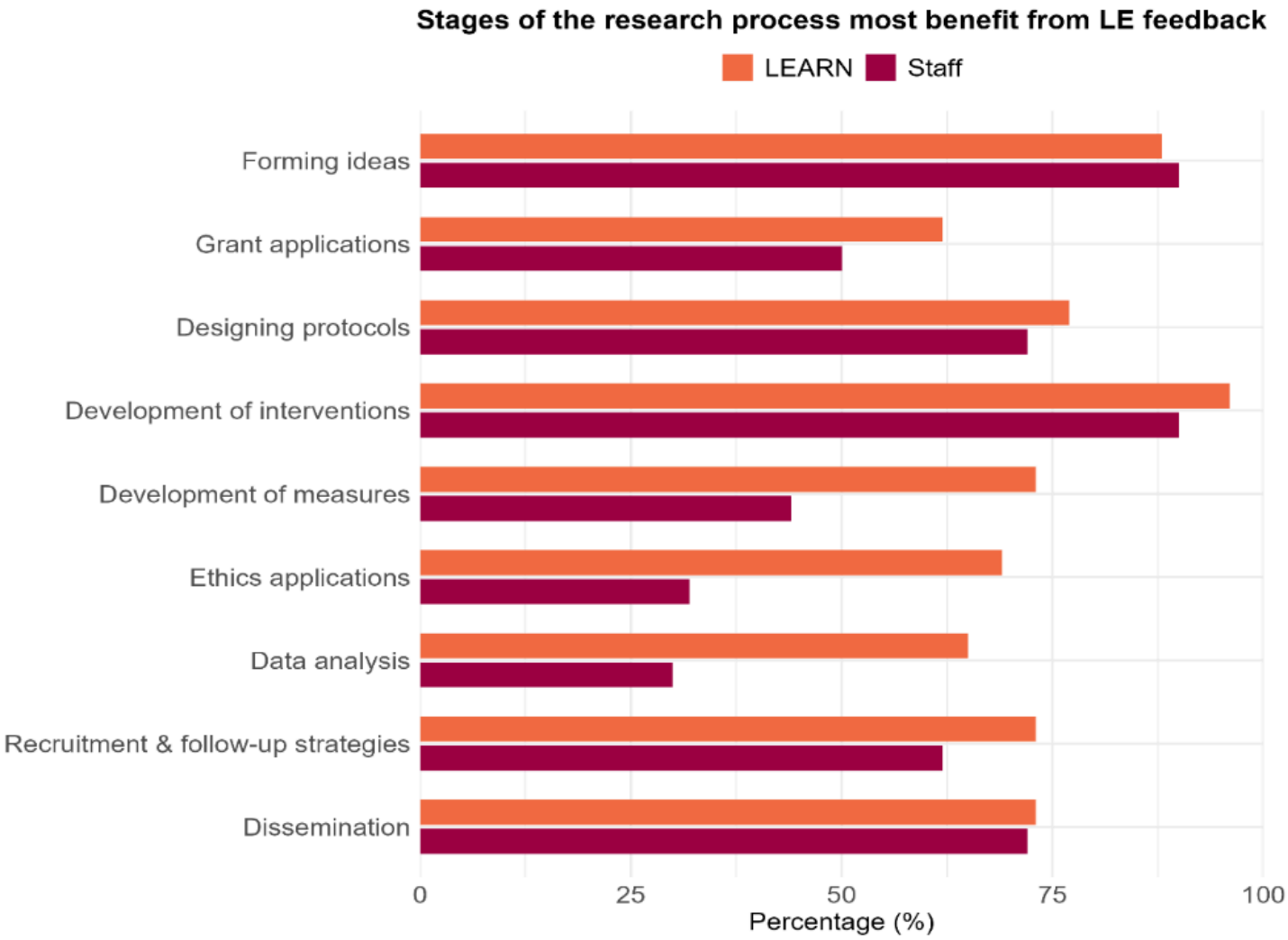


Figure 3

Staff and LEARN respondent selection rates for each stage of the research process, expressed as percentage of total sample for each subgroup.

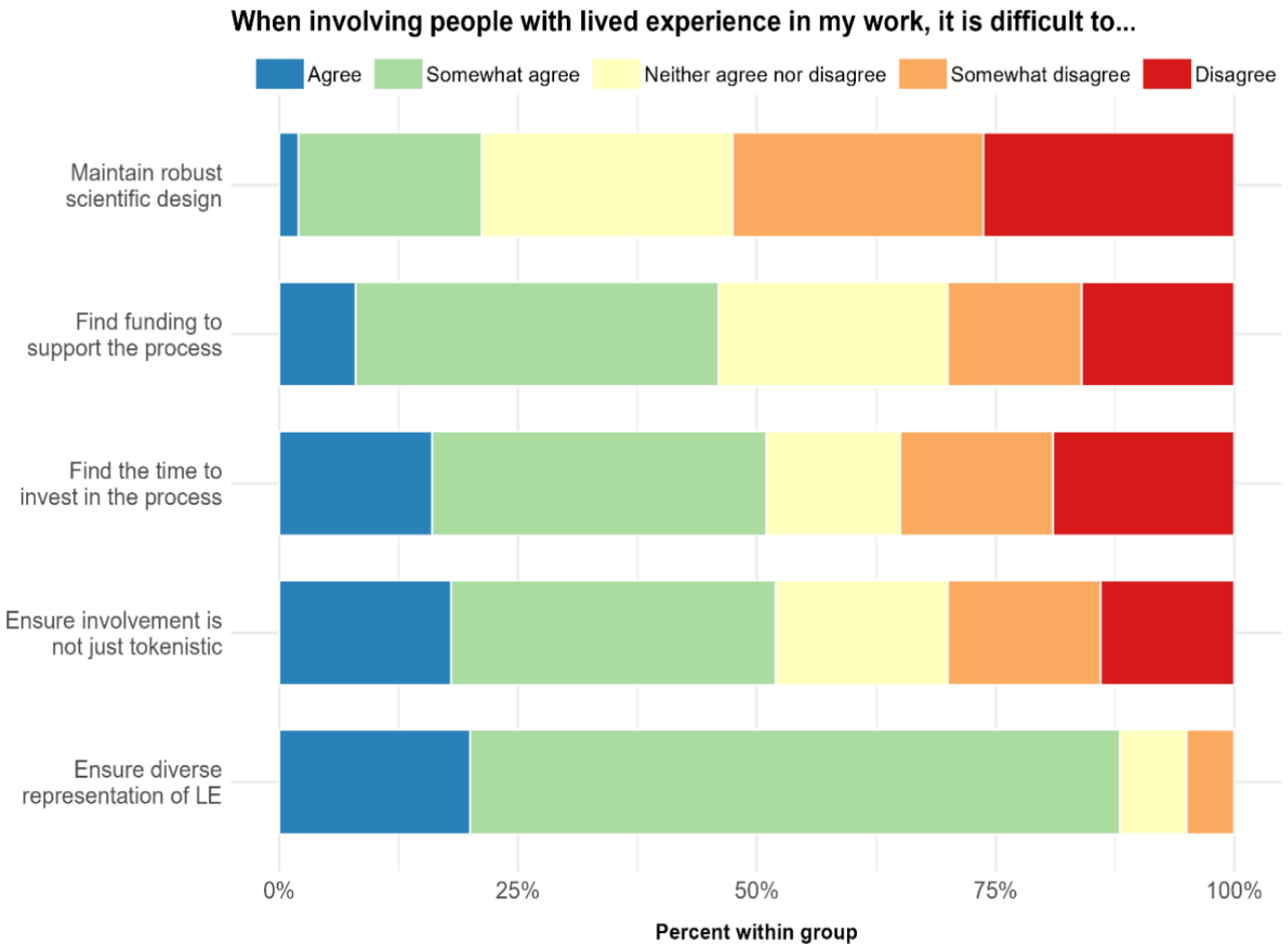


Figure 4

Percentage distributions of staff agreement ratings for each challenge of lived experience engagement in research.

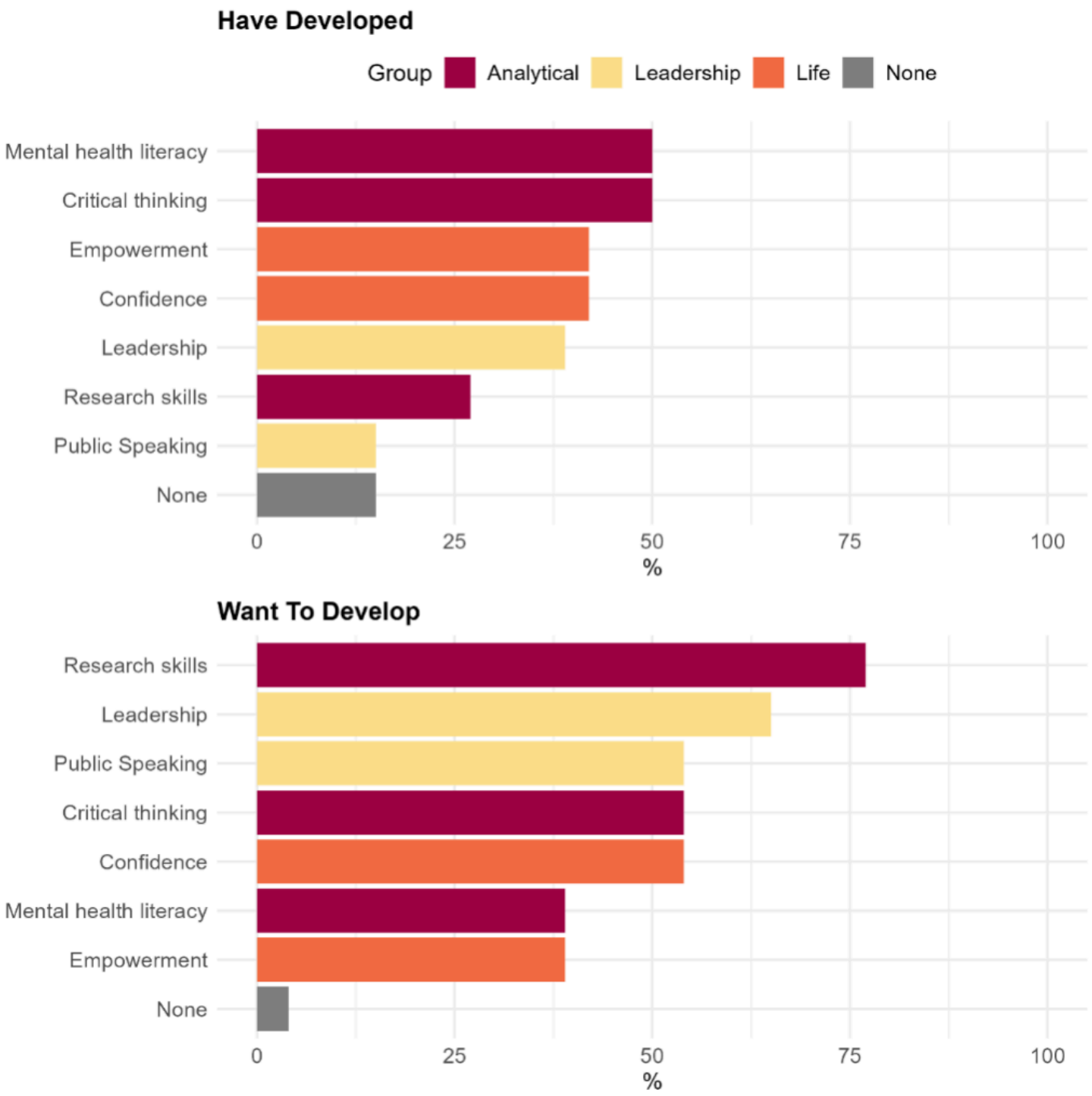


Figure 5

LEARN respondent percentage selection rates for skills and capabilities developed through LEARN involvement so far (above) and skills and capabilities that respondents wanted to develop in future (below).

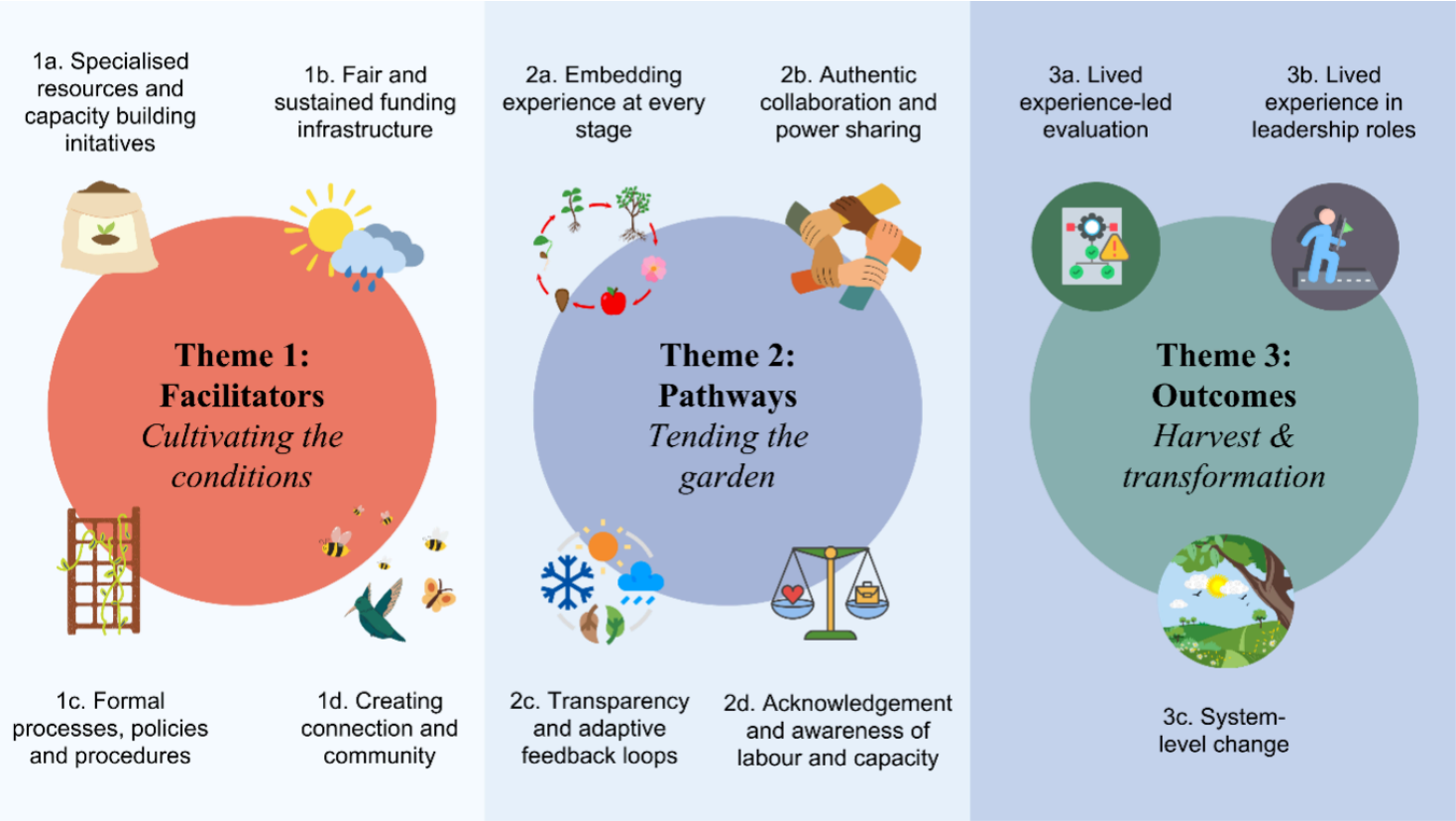


Figure 6

‘Ecosystem of meaningful engagement’ model

Supplementary Files

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