LIVED EXPERIENCE COMMITTEES & INVESTMENT IN RESEARCH

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Please find following a summary of a literature search and relevant results. All articles can be provided in full - email library@monashhealth.org for a list of the articles you require.

TOPIC

Best practice regarding lived experience committees which help inform investment in research.

RESULTS

ONLINE RESOURCES (GREY LITERATURE)

LIVED EXPERIENCE & GRANT REVIEW

Western Australian Future Health Research & Innovation Fund. (2024). **Seeking nominations for participation on grant review panels** [*News item*]. Link.
- Call-out for Consumer Grant Reviewers to participate on grant review panels.

CheckUP. (2024). **Role description – Grants Assessment Panel lived experience representative**. Link.
- Position on Queensland Mental Health Week Grants Assessment Panel.

PxP (For Patients, By Patients). (2023). **Engaging patient partners as peer reviewers of grant applications: Tips for everyone involved**. Link.
- Tips for patient partners and for organisations, covering before/during/after peer review meetings.

Dementia Centre for Research Collaboration. (2021). **A guide to reviewing research grant applications**. Link.
- Information provided to Lived Experience Experts on the grant assessment process.

Institute for Voluntary Action Research (UK). (2020). **'Lived experience' in grant-making practice** [*briefing paper*]. Link.
- Explores how and when to involve people with lived experience in grant-making, with recommendations. Based on work the Institute has done with Comic Relief and funders.

National Institute for Health and Care Research. (n.d.). **Become a reviewer.** Link.
- Information for the public on applying to review research proposals.

ENGAGING WITH PEOPLE WITH DISABILITY

ACT Dept. of Social Services. (2023). **Good practice guidelines for engaging with people with disability**. Link.
- Guidelines for activities including research. Covers aspects such as accessible design (timing, location, group size etc.)

Disability Innovation Institute. (2022). **Doing research inclusively: Co-production in action**. Link.
- Outlines key questions and roles for each stage of the research process, from initiating a project to reflecting on it.

Disability Innovation Institute. **Doing research inclusively: Guidelines for co-producing research with people with disability**. (2020). Link.
- Discusses strategies of co-production: Creating a research project; Conducting a research project; Evaluating the impact of a research project

GUIDES & TOOLKITS

American Institutes for Research. (2024). **Leading a highly engaged community advisory board**. Link.
- Discusses CAB processes and considerations in establishing and working with CABs.

Implementation Science Center for Cancer Control Equity, Harvard University. (2024). **Community Health Center Community Advisory Board Toolkit**. Link.
- Practical guidance on establishing CABs, from recruitment to meeting facilitation to evaluation.

Primary Health Network Tasmania. (2023). **Seven steps to develop an organisational lived expertise engagement framework**. Link.
- High-level steps presented as checklists. The guide also provides information on best practice in ongoing engagement with people with lived experience.

Cardiff University. (n.d.). **Introduction to co-production and participatory research: Workbook**. Link.
- Part of a capacity building program introducing participants to community consultation and research. Discusses aspects of theory (e.g. main principles of a participatory approach on p. 7) and practice (e.g. notetaking on p. 11).

Community Services, ACT Govt. (n.d.). **Guide: Lived experience in commissioning**. Link.
- Covers 'Lived experience and commissioning' and 'Methods of key cohorts'.
- *Related:*
  - Lived experience advisory panel – information sheet and nomination form.
  - Lived experience checklist – checklist to guide engagement with people with lived experience.

CONFERENCE ABSTRACTS

The following studies have been published as abstracts only; no full-text is available.

C. M. Thompson, et al. (2024). **A Burn Survivor- & Burn Community Stakeholder-Generated & Prioritized Research Agenda**. *Journal of Burn Care and Research*, *45*(Supplement 1), S185. Click to read complete abstract.
The goal of the work presented here was to produce the first research agenda generated & prioritized by burn survivors & other invested members of our burn community. Method(s): A research collaborative with a focus of co-production with burn survivors was formed in early 2022.

K. Stevenson, et al. (2023). **Lessons learned from co-production in public health research: the MAMAH case study involving underserved migrant mothers in the UK**. *Lancet (London, England)*, *402*(Supplement 1), S87. Click to read complete abstract.

We summarise learnings from our study, which aimed to co-produce solutions to improve maternity care for migrant women in the UK, by working with women to identify the most important research priorities. Our initial research priorities did not align with those of the women, and this helped us to reshape our work.

L. M. Phillips, et al. (2022). **Community Research Academy: Lifting Community Voices for Equity in Health Research and Innovation**. *Journal of Clinical and Translational Science*, *6*(Supplement 1), 25-26. Click to read complete abstract.

The Academy workshop curriculum supports an in-depth examination of the translational research process, introduction to the CTSC Community Advisory Board; as well as to community based participatory research; grant evaluation process, and the need for active community involvement in various cores, and clinical trials.

PEER-REVIEWED LITERATURE – MOST RECENT FIRST

Articles are grouped as follows:

- Research grants, investment, & priority-setting
- Developing lived experience committees & advisory groups
- Guidance on consumer involvement
- Engaging with children and young people

Each article summary contains excerpts from the abstract and an online link.

RESEARCH GRANTS, INVESTMENT, & PRIORITY-SETTING

K. Rittenbach, et al. (2019). **Engaging people with lived experience in the grant review process**. *BMC medical ethics*, *20*(1), 95. Click to read full-text.

The value of including the viewpoints of people with lived experience in health policy, health care, and health care and systems research has been recognized at many levels, including by funding agencies. However, there is little guidance or established best practices on how to include non-academic reviewers in the grant review process. Here we describe our approach to the inclusion of people with lived experience in every stage of the grant review process. The proposed model offers further practical insight into including people with lived experience in the review process.

P. Obegu, et al. (2022). **Centering equity and lived experience: implementing a community-based research grant on cannabis and mental health**. *International Journal for Equity in Health*, *21*(1), 113. Click to read full-text.

Mental health research in Canada is not only underfunded but there remains an inequitable distribution of funding to address unmet needs especially in clinical and applied research. Method(s): In 2020, the MHCC implemented an innovative community-based research (CBR) program to investigate this relationship among priority populations including people who use cannabis and live with mental illness, First Nations, Inuit and Metis, two-spirit, lesbian, gay, bisexual, trans and/or queer (2SLGBTQ+) individuals, and racialized populations. Key program components included a review committee with representation from diverse priority populations. Result(s): Of the 14 funded research projects, 6 focus on and are led by Indigenous communities, 5 focus on other equity-seeking populations, and 9 explore the perceived patterns, influence and effects of use

including benefits and harms. Lessons learned include the importance of a health equity lens and diverse sources of knowledge setting the CBR research agenda.

N. Vera San Juan, et al. (2022). **Priorities for Future Research About Screen Use and Adolescent Mental Health: A Participatory Prioritization Study**. *Frontiers in Psychiatry*, *13*, 697346. Click to download full-text.
This study aimed to identify research priorities for future research on screen use and adolescent mental health, from the perspectives of young people, parents/carers, and teachers. Method(s): The study design was informed by the James Lind Alliance Priority Setting Partnership approach. A three-stage consensus-based process of consultation to identify research priorities using qualitative and quantitative methods. Research was guided by a steering group comprising researchers, third sector partners, clinicians, parents/carers and young people. A Young People's Advisory Group contributed at each stage. Result(s): Initial steps generated 26 research questions of importance to children and young people; these were ranked by 357 participants (229 children and young people and 128 adults). Consensus was reached for the prioritization of four topics for future research.

E. A. Fowler, et al. (2022). **Involving Patient Partners in the KRESCENT Peer Review: Intent, Process, Challenges, and Opportunities**. *Canadian Journal of Kidney Health and Disease*, *9*. Click to read full-text.
The Kidney Research Scientist Core Education and National Training (KRESCENT) is a national Canadian training program for kidney scientists, funded by the Kidney Foundation of Canada (KFOC), the Canadian Institutes of Health Research (CIHR), and the Canadian Society of Nephrology (CSN). We describe our first year of incorporating patient partners into a scientific peer-review committee, the 2017 committee to select senior research trainees and early-career kidney researchers for funding and training, in the hope that it will be helpful to others who wish to integrate the perspective of people with lived experience into the peer-review process.

Note: Patient partners' views on research applications were considered in funding decisions.

DEVELOPING LIVED EXPERIENCE COMMITTEES & ADVISORY GROUPS

A. V. Bennett, et al. (2024). **Development of a Lived Experience Panel to inform the design of embedded pragmatic trials of dementia care interventions**. *Journal of the American Geriatrics Society*, *72*(1), 139-148. Request the full-text.
Background: The National Institute on Aging (NIA) Imbedded Pragmatic Alzheimer's Disease and Alzheimer's Related Dementia Clinical Trials (IMPACT) Collaboratory convened a Lived Experience Panel (LEP) to inform the development of research priorities and provide input on conducting embedded pragmatic clinical trials (ePCTs) of dementia care interventions. Given the importance of people with lived experience to dementia research, and the unique considerations of engaging people with dementia, we report on our process for the recruitment, selection, and initial convening of the IMPACT LEP.

S. R. Partridge, et al. (2024). **Engaging adolescents in chronic disease prevention research: insights from researchers about establishing and facilitating a youth advisory group**. *Research involvement and engagement*, *10*(1), 29. Click to read full-text.
Our comment discusses our experience establishing a youth advisory group focused on chronic disease prevention research. The comment highlights three key learnings: the need for researchers to adapt their working style, the importance of redefining the power dynamics, and disrupting traditional research structures to align with co-researcher engagement models.

J. M. McCarthy, et al. (2024). **Creation of a Psychotic Disorders Research Advisory Board as a Shared Resource**. *Psychiatric services (Washington, D.C.)*, *75*(4), 387-390. Click to read full-text.
Community engagement is important for research, yet many researchers do not routinely seek feedback from people with lived experience. A key barrier to this engagement is that the resources required to create an advisory board may be unavailable to individual investigators, and creating an advisory board for a single study may often be impractical. In this column, the authors describe how to create a standing research advisory board that can serve as a shared resource for researchers and community members and provide a psychosis research advisory board example to aid discussion.

E. R. Weinstein, et al. (2023). **Promoting health equity in HIV prevention and treatment research: a practical guide to establishing, implementing, and sustaining community advisory boards**. *Therapeutic Advances in Infectious Disease*, *10*. Click to read full-text.
This article synthesizes already established guidelines and frameworks for community advisory board (CAB) development while specifically outlining unique steps related to the three main stages of CAB formation - establishment, implementation, and sustainment. Throughout this article, the authors offer tension points, generated from the literature and with consultation from a CAB working alongside the authors, that researchers and community partners may need to navigate during each of these three stages. In addition, best practices from the literature are identified for each step in the guidelines so that readers can see firsthand how research groups have carried out these steps in their own practice.

P. Barn, et al. (2022). **Better Together: Launching and Nurturing a Community Stakeholder Committee to Enhance Care and Research for Asthma and COPD**. *Chest*, *161*(2), 382-388. Click to read full-text.
We describe our experience with creating and developing an ongoing Community Stakeholder Committee to guide lung health research for disease prevention and health care improvement. This committee is central to the integrated knowledge translation approach of Legacy for Airway Health, which is dedicated to preventing and improving care for lung diseases. We conducted a baseline evaluation survey after 1 year (October 2020), using a modified version of the Patient Engagement in Research Scale (PEIRS-22). Whereas individual scores suggested varied levels of meaningful engagement within the committee, overall results indicated strong personal relationships and a sense of feeling valued and respected, as well as a desire for increased opportunities to contribute to research within the program.

GUIDANCE ON CONSUMER INVOLVEMENT

K. L. Smith, et al. (2024). **Moving from principle to practice: A researcher's guide to co-leading engaged research with community partners and patients with lived experience to reduce maternal mortality and morbidity for maternal sepsis**. *Maternal and Child Health Journal*. Click to read full-text.
This article details the application of principles of community-engaged research in a federally funded phased research project focused on understanding disparities in maternal sepsis to develop better clinical and community interventions. Specifically, it discusses early steps in the research partnership to create a sustainable partnership with a Community Leadership Board guided by the principles of transparency, respect, compensation, and increasing research justice. Based on the authors' experience, recommendations are provided for funders, researchers, and institutions to improve the quality and outcomes of community-engaged research.

M. Bottomley, et al. (2024). **Co-producing ethics guidelines together with people with learning disabilities**. *British Journal of Learning Disabilities*. Click to read full-text.
Background We are a research team of clinical, academic and advocacy-based researchers with and without learning disabilities, working on the Humanising Healthcare (for people with learning disabilities) project. The project is dedicated to finding and sharing healthcare practices that enhance the lives of people with learning disabilities. As part of our ethics applications to access National Health Service study sites for fieldwork, we worked together to write guiding principles for co-producing research ethics with researchers with learning disabilities. In this paper, we introduce these Participatory Ethics Good Practice Guidelines and reflect on our collaboration.

A. Hilton, et al. (2024). **What really is nontokenistic fully inclusive patient and public involvement/engagement in research?** *Health expectations : an international journal of public participation in health care and health policy*, *27*(2), e14012. Click to read full-text.
Patient and public involvement and engagement (PPIE) is critically important in healthcare research. A useful starting point for researchers to understand the scope of PPIE is to review the definition from the National Institute for Health and Care Research (NIHR) as, 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them'. PPIE does not refer to participation in research, but to actively shaping its direction. This editorial showcases how the TIMES project maximised inclusivity, and we share our experiences and top tips for other researchers. We have a Lived Experience Advisory Forum on Sleep, which includes people with dementia, family carers, representatives of the South Asian Community and the Chinese community.

S. J. Fitzpatrick, et al. (2023). **Co-ideation and co-design in co-creation research: Reflections from the 'Co-Creating Safe Spaces' project**. *Health expectations : an international journal of public participation in health care and health policy*, *26*(4), 1738-1745. Click to read full-text.
INTRODUCTION: Numerous frameworks for defining and supporting co-created research exist. The practicalities of designing and conducting co-created research are clearly important, yet the utility of these frameworks and their operationalisation within local contexts and involving a diversity of stakeholders and interests are currently not well-researched. METHOD(S): Using an instrumental case study approach, we examined the utility of a published systematic framework designed to improve clarity about co-creation as a concept and approach. The framework is explored based on the first two processes that correspond to our own work to date: co-ideation and co-design. RESULT(S): Our study showed that diverse stakeholders bring challenges regarding research priorities, methods, language and the distribution of power within co-creation processes.

J. Onwumere, et al. (2023). **Amplifying the voices of Black racial minorities in mental health research through public involvement and engagement: The importance of advisory roles**. *Health expectations: An international journal of public participation in health care and health policy*. Click to read full-text.
Ensuring adequate representation and the active, meaningful and visible involvement of groups likely to be most impacted by research findings and/or the lack of research inquiry are increasingly acknowledged. This is particularly relevant for Black racially minoritised groups who are less visible as research participants and in patient and public involvement and engagement (PPIE) roles. Our viewpoint article sought to discuss reflections and insights on their involvement experience, with particular attention to perceived barriers and enablers to PPIE involvement. METHOD(S): Qualitative data were collected as part of facilitated group discussions from nine Black racially minoritised experts-by-experience involved in a PPIE advisory group. RESULT(S): Five main themes were identified that reflected factors linked to practicalities: role unfamiliarity, benefits for the larger community, acknowledgement of previous harm and mental health stigma.

D. Ayton, et al. (2022). **Barriers and enablers to consumer and community involvement in research and healthcare improvement: Perspectives from consumer organisations, health services and researchers in Melbourne, Australia**. *Health & social care in the community*, *30*(4), e1078-e1091. Request the full-text.
To understand the barriers and enablers to meaningful consumer and community involvement (CCI), a qualitative descriptive study was undertaken with researchers, health professionals, representatives from consumer organisations, and health services and ethics committees in Melbourne, Australia. Twenty-eight semi-structured interviews and one focus group were conducted in May-August 2019. Training of researchers and health professionals in CCI, benefits and systems and processes to undertake CCI, alongside incorporating CCI as a requirement for funding were identified as enablers. Lack of time and resources for CCI, challenges in finding consumers for projects and a perceived lack of evidence of the impact of CCI were barriers.

E. Ni She, et al. (2019). **Clarifying the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research: A collaborative rapid realist review process**. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*, *22*(3), 298-306. Click to read full-text.
Methods: A rapid realist review of the literature that included: (a) a systematic search of CINAHL, PsycINFO, PubMed and Open Grey (2007-2017); (b) documents provided by expert panel members of relevant journals and grey literature. Six reference panels were undertaken with homeless, women's, transgender, disability and Traveller and Roma organizations to capture local insights. Conclusions: While there is growing evidence of the merits of undertaking PPI, this rarely extends to the meaningful involvement of seldom heard groups. The 33 programme theories agreed by the expert panel point to a variety of mechanisms and resources that need to be considered. Many of the programme theories identified point to the need for a radical shift in current practice to enable the reciprocal involvement of seldom heard groups.

ENGAGING WITH CHILDREN AND YOUNG PEOPLE

K. A. Wyatt, et al. (2024). **Involvement of children and young people in the conduct of health research: A rapid umbrella review**. *Health expectations : an international journal of public participation in health care and health policy*, *27*(3), e14081. Click to read full-text.
Patient and public involvement and engagement (PPIE) have long been considered important to good research practice. There is growing, yet diverse, evidence in support of PPIE with children and young people (CYP). We must now understand the various approaches to involvement of CYP in research. RESULT(S): The 26 reviews included were predominately systematic and scoping reviews, published within the last decade, and originating from North America and the United Kingdom. CYPs were involved in all stages of research across the literature, most commonly during research design and data collection, and rarely during research funding or data sharing and access. Researchers mostly engaged CYP using focus groups, interviews, advisory panels, questionnaires, and to a lesser extent arts-based approaches such as photovoice and drawing.

L.-M. Brady, et al. (2023). **"We know that our voices are valued, and that people are actually going to listen": co-producing an evaluation of a young people's research advisory group**. *Research involvement and engagement*, *9*(1), 11. Click to read full-text.
BACKGROUND: Children and young people's (CYP) involvement is an increasing priority in UK healthcare and in heath research, alongside recognition that involving CYP in research requires different considerations to involving adults. Underpinned by children's rights and a co-production

ethos this paper, co-authored with young evaluators, explores the learning from a co-produced evaluation of eyeYPAG, a young persons' research advisory group (YPAG) for eye and vision research based at Moorfields Eye Hospital, London, UK.

E. McCabe, et al. (2022). **Youth engagement in mental health research: A systematic review**. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*, No-Specified. Click to read full-text.
At present, there is little evidence to guide mental health researchers on youth engagement. This systematic review aims to describe the impacts of youth engagement on mental health research and to summarize youth engagement in mental health research. Results: Youth were involved at nearly all stages of the research cycle, in either advisory or co-production roles. We produced a list of 35 recommendations under the headings of training, youth researcher composition, strategy, expectations, relationships, meeting approaches and engagement conditions.

G. Pavarini, et al. (2019). **Co-producing research with youth: The NeurOx young people's advisory group model**. *Health expectations : an international journal of public participation in health care and health policy*, *22*(4), 743-751. Click to read full-text.
Young people's advisory groups (YPAGs) are a widely used method to enable young people's involvement in all research stages, but there is a lack of academic literature to guide researchers on how to set up, run and evaluate the impact of such groups. OBJECTIVE(S): In this paper, we provide a step-by-step model, grounded in our own experience of setting up and coordinating the Oxford Neuroscience, Ethics and Society Young People's Advisory Group (NeurOx YPAG). This group supports studies at the intersection of ethics, mental health and novel technologies. Our model covers the following stages: deciding on the fit for co-production, recruiting participants, developing collective principles of work, running a meeting and evaluating impact.

APPENDIX

SEARCH METHODOLOGY

A systematic search was conducted for literature. The results were screened by librarians using Covidence.

SEARCH LIMITS

- English-language
- Published within the last 5 years

DATABASES SEARCHED

- Medline – index of peer reviewed articles across health sciences and medicine.
- Embase – index of biomed and pharmacological peer reviewed journal articles.
- APA PsycINFO – index of behavioural sciences literature.
- Cochrane Library – collection of databases containing high-quality independent evidence.
- Grey literature – Google, Google Scholar, Trip database, Biomed Central Proceedings.

SEARCH TERMS

Concept	MeSH headings	Keywords
Lived experience committees	Community Participation/, Community Support/, Patient Participation/, Community-Based Participatory Research/. Advisory Committees/, Governing Board/.	Lived experience(s) or co-produc(ed/ing) or co-lead(ing) or participatory or community participation + committee(s) or board or panel or advisory or reference group(s).
Research investment	Research/, "Research Support as Topic"/. Financial Support/, Fund Raising/, Financing, Organized/, Investments/.	Research or study or studies or trial(s) or pilot(s). Invest(ment/s) or invest(ing) or invest(ed) or invest(s) or fund(ing) or fund(s) or fund(ed) or fund(er/s) or grant or grants.

MEDLINE SEARCH STRATEGY

Ovid MEDLINE(R) ALL <1946 to July 02, 2024>

1 (Community Participation/ or Community Support/ or Patient Participation/ or Community-Based Participatory Research/) and (Advisory Committees/ or Governing Board/) 700

2 (Community Participation/ or Community Support/ or Patient Participation/ or Community-Based Participatory Research/) and (committee* or board or panel or advisory or reference group*).ti,kf. 621

3 (Advisory Committees/ or Governing Board/) and lived experience*.ti,ab,kf. 14

4 (lived experience* adj10 committee*).mp. 18

5 (lived experience* adj10 (board or panel or advisory or reference group*)).mp. 128

6 ((co-produc* or co-lead* or participatory or community participation) and (committee* or board or panel or advisory or reference group*)).ti,ab,kf. 1996

7 1 or 2 or 3 or 4 or 5 or 6 3102

8 (exp Research/ or "Research Support as Topic"/) and (Financial Support/ or Fund Raising/ or Financing, Organized/ or Investments/) 3980

9 (exp Research/ or "Research Support as Topic"/) and (invest* or fund* or grant or grants).ti,kf. 14251

10 (Financial Support/ or Fund Raising/ or Financing, Organized/ or Investments/) and (research or study or studies or trial* or pilot*).ti,kf. 2562

11 ((research* or study or studies or trial* or pilot) adj10 (invest* or fund* or grant or grants)).mp. 1420007

12 8 or 9 or 10 or 11 1429709

13 7 and 12 296

14 limit 13 to english language 290

15 limit 14 to yr="2019 -Current" 160

PRISMA CHART

Identification of studies via databases and registers

Identification

References imported for screening (n= 549):

    Embase (n=232)

    Medline (n=160)

    Cochrane (n=80)

    PsycINFO (n=77)

Studies removed before screening:

    Duplicate studies removed (n=148)

Screening

Studies screened against title and abstract (n=323)

Studies excluded (n=286)

Studies assessed for full-text eligibility (n=55)

Included

Studies included (n=20)