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Welcome everyone to our One Day Short Course – An Orientation to Applied Research for Lived-Experience Researchers: Context, Method, Process and Practice. This hybrid learning event is hosted by The ALIVE National Centre for Mental Health Research Translation and the Lived-Experience Research Collective.

The intensive course forms a part of the National Centre’s capacity building strategy for growing the next generation of mental health research leaders. It has been created by, for and with people with lived-experience who may be engaging in research as co-designers, implementers, translators or researchers.

The day will cover:

1. An orientation to research design
2. An introduction to research methods
3. Situating lived-experience within research principles, processes and practices
4. An overview of ethics review processes, research integrity and context-based ethics
5. Reading published papers, appraisal and reviews.

Before we start, let’s settle into some ways of working together for the day. In our co-design program of work, we call this our working together agreements or principles of participation.

For those joining online you see the working together agreements on the shared Mural board. The longer version of the principles of participation are included as an attachment in this workbook and you can read ways to engage online with The ALIVE National Centre here:

<https://go.unimelb.edu.au/9tps>

# ORIENTATION TO

# RESEARCH DESIGN

# & METHODS



## Reading List:

* This is a wonderful introductory site for all things related to research methods, data collection and activities. You can find videos, examples of data that people have shared for trying out new methods and explore case studies: <https://methods.sagepub.com/>
* This is an introduction to the analysis of qualitative data only – it was developed for a partner organisation working with the ALIVE National Centre for Mental Health Research Translation and is suited for a people already familiar with research practices and data collection: <https://aci.health.nsw.gov.au/__data/assets/pdf_file/0006/660867/ACI-qualitative-analysis-of-research.pdf>
* Roberts, R. 2020. Qualitative Interview Questions: Guidance for Novice Researchers. The Qualitative Report. 5(9): 3185-3203.
* Braun, V. & Clarke, V. 2013. Successful Qualitative Research: A practical guide for beginners. London: SAGE.

## Notes:

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# SITUATING LIVED-EXPERIENCE

# WITHIN RESEARCH PRINCIPLES,

# PROCESSES AND PRACTICES



## Reading List:

* The Family Violence Experts by Experience Framework Research Report and Framework 2020 <https://safeandequal.org.au/wp-content/uploads/DVV_EBE-Framework-Report.pdf>
* An Australian Framework for the ethical co-production of research and evaluation with victim survivors of domestic, family and sexual violence (June 2023 Draft) <https://alivenetwork.com.au/wp-content/uploads/2023/07/Final-post-racv-edits-2.pdf>
* The concept of experiential evidence has always been important but in recent times, the central role of experience and experiential (lived-experience) in systems change and research has increased. Here is an interesting taxonomy from the Agency for Clinical Innovation at NSW Health: <https://aci.health.nsw.gov.au/support-for-innovation/evidence/experiential>
* The experiential evidence unit at the Agency for Clinical Innovation also houses a typology to support people to mix and match their methods too: <https://aci.health.nsw.gov.au/support-for-innovation/evidence/experiential/typology>

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# ETHICS

# IN RESEARCH



## Reading List:

* Privacy Principles

<https://www.oaic.gov.au/privacy/australian-privacy-principles/australian-privacy-principles-guidelines>

* Ethics

<https://www.nhmrc.gov.au/research-policy/ethics/national-statement-ethical-conduct-human-research>

* Research integrity

<https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018>

* Lived experience work on ethics practice

Morse AR, Forbes O, Jones B, Gulliver A & Banfield M.(2021)Whose story is it? Mental health consumer and carer views on carer participation in research. *Health Expectations,*24(Suppl. 1):3-9 <https://doi.org/10.1111/hex.12954>

Morse AR, Forbes O, Jones BA, Gulliver A & Banfield M. (2019) Australian mental health consumer and carer perspectives on ethics in adult mental health research. *Journal of Empirical Research on Human Research Ethics,*14(3): 234-242 <https://doi.org/10.1177/1556264619844396>

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# PRINCIPLES FOR

# READING PAPERS

# AND CRITICAL APPRAISAL



## Reading publications and critical appraisal of research, by Dr Julia Dray

Critical appraisal describes the process of critiquing the quality and rigour of research evidence and/or other content put forward in research publications usually systematically or against a set of criteria (e.g. risk of bias, quality of reporting, value, validity). Critical appraisal in research is often formally completed using a myriad of checklists or frameworks, the selection of which varies based on preference of rigour of the authoring institution, type of study or studies you are planning on appraising (such as those described in the glossary of terms below) and/or the purpose of that appraisal (e.g. your own literature review for writing for publication or completing a systematic review).

This extract of glossary of terms (Page et al, 2020, full reference below) may be helpful for learning in this space and as we cover some content on critical appraisal during the course:

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Glossary of terms extracted from: Page M J, McKenzie J E, Bossuyt P M, Boutron I, Hoffmann T C, Mulrow C D et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews BMJ 2021; 372 :n71 doi:10.1136/bmj.n71

Here you’ll also find a list and links to some of the most commonly used critical appraisal checklists and frameworks. No need to study them furiously and memorise them, but rather this forms a handy list of some resources that may be referred to in the final session of the day:

* Cochrane: Cochrane is an international network with headquarters in the UK. Cochrane is considered by many to be the highest level of systematic review evidence, supporting researchers and professionals to use high-quality information. Cochrane conduct training in how to complete a systematic review, have handbooks that support this process, and risk of bias templates to assist with critical appraisal of studies. Cochranes tools are usually best for appraising quantitative studies.
  + The Cochrane handbook: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane Handbook for Systematic Reviews of Interventions* version 6.3 (updated February 2022). Cochrane, 2022. Available from [www.training.cochrane.org/handbook](http://www.training.cochrane.org/handbook).
  + Cochrane risk of bias tools and resources are available here: <https://methods.cochrane.org/risk-bias-2>
  + Cochrane also have a suite of short online courses (30-45 minutes) on their ‘Evidence essentials’ site: <https://training.cochrane.org/interactivelearning>
* Joanna Briggs Institute (JBI): JBI is an international research organisation that has a series of critical appraisal tools including checklists for randomised controlled trials, qualitative research, economic evaluations and prevalence studies. We have included the link to their checklist for qualitative research in the suggested readings list below, which is also available with other JBI Critical Appraisal tools here: <https://jbi.global/critical-appraisal-tools>
* PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis): PRISMA refers to a flow diagram that helps make sense of the stages of a systematic review. Some journals make it mandatory that researchers who are wanting to publish the results of a systematic review report against the PRISMA Statement, a 27-item checklist, to clearly demonstrate the journey of studies through their review, rigour and quality of their review. See: <https://www.bmj.com/content/372/bmj.n71>
* Critical Appraisal Tools and Worksheets by:
  + the Centre for Evidence Based Medicine, University of Oxford: <https://www.cebm.ox.ac.uk/resources/ebm-tools/critical-appraisal-tools>
  + the Critical Appraisal Skills Programme (CASP): <https://casp-uk.net/casp-tools-checklists/>

Finally, when we talk about reading publications and critical appraisal we often describe how to look for ‘good science’ which is spoken about in this TED talk ‘Battling bad science’ by Dr Ben Goldacre: <https://www.ted.com/talks/ben_goldacre_battling_bad_science?language=en>

## Reading List:

* How to critically appraise an article <https://www.researchgate.net/publication/23801220_How_to_critically_appraise_an_article>
* Critical appraisal of qualitative research: necessity, partialities and the issue of bias <https://ebm.bmj.com/content/ebmed/25/1/9.full.pdf>
* Critical appraisal <https://www.tandfonline.com/doi/full/10.1080/1750984X.2021.1952471>
* Checklist for Qualitative Research - Critical Appraisal tools for use in JBI Systematic Reviews <https://jbi.global/sites/default/files/2020-08/Checklist_for_Qualitative_Research.pdf>
* Assessing the methodological quality of published papers <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2127212/pdf/9274555.pdf>

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# ATTACHMENT 1: PRINCIPLES OF PARTICIPATION STATEMENT

This is our working together agreement for the co-design sessions conducted within the primary care mental health research program (ethics approval no: 1954193.2). These are reviewed together as a group at the start of a session and we encourage everyone to share additional principles they feel are important before we get started.

These have been formulated from when our Co-Design Living Labs program was established in 2017 and are based on an explanatory theoretical model for co-design and co-production (see link below). We have adapted these mechanisms over time – we see this as central to setting the table for co-designing together. Think of the eight principles/mechanisms with the following in mind, ***“at all times we agree to”:***

1. **Recognise**

* recognise that we all bring lived-experience to contribute to the group, and we agree to value what you say, and always treat you with respect as co-creators.
* recognise that sometimes we hold a different point of view, and we will all listen respectfully to the views all people have for sharing in the group.
* acknowledge that conflict happens — and that diverse points of view all deserve attention and respect.
* foster a free, but always *respectful* conversation. Though conflict is okay, conversations should always be conducted with civility and respect, everything talked about within a meeting is treated as confidential.
* that feeling safe is important, while there are different views these can be shared with consideration and sometimes we also may experience discomfort and it’s okay to talk about that.

1. **Dialogue**

* that our roles in co-design sessions are a part of a dialogue, with multiple voices and backgrounds.
* accept that people will not always agree.
* that we commit to valuing all points of view as part of the conversation to foster healthcare improvement where ever possible.

1. **Co-Operation**

* co-operation is collaborative. We recognise that co-design sessions are a collective effort that can make a difference.
* to work together as equals and collaborators in research – knowing sometimes we might have to work on power differences as researchers and co-design members.
* to work together, alongside participants to change research and influence practice and policy using research to inform this.

1. **Accountability**

* to be accountable to each other.
* be transparent and open with co-designers about the outcomes of research and to value your co-productive efforts when contributed within research, service design or health care improvement studies.
* to share the outcomes of research and providing opportunities for participants to engage at all stages of the research cycle.

1. **Mobilisation**

* to put what we learn, create and build in sessions into action in research and translate this to government and practice where applicable.
* to acknowledge that our program primarily works to improve healthcare design, delivery and transformation and this can take time to implement and see change in.
* to acknowledge that these sessions are shaped by experiences, but we share these to help shape the research process and do not have to share our full stories in co-design sessions.

1. **Enactment**

* to use what co-design produces to change the mental health and healthcare system broadly.
* to implement (as much as we can) from the outcomes of sessions in order to improve the mental health research and, as a result, the mental healthcare system.
* to be collectively committed to implementation where ever possible.
* to recognise that we cannot change everything that we seek to change – sometimes important changes are smaller than the bigger ones and sometimes we do not have the resources to change the big issues.

1. **Creativity**

* to creatively engage in the meetings, to explicitly use co-design techniques, tools and activities for ideation to creation.
* to producing creative and engaging ideas to be used in sessions.
* to find imaginative ways to run the sessions, so that sessions in turn spur your creativity.
* to thinking creatively alongside you.

1. **Attainment**

* to improve research and change in mental healthcare design, delivery and improvement.
* to do *everything we can* to improve the way research is done in Australia and around the world to honour lived-experience and collectively celebrate the strengths we all bring.
* to improving the mental health system in all its forms, and at all stages of care.
* to a space of co-creation, to ideate and share the things that we sometimes think are a good idea but may not be 100% possible.
* to encourage people to share ideas no matter how much they think they cannot be done because by working together we might find a way to do this—you never know?

***Now that we have read this working together agreement is there anything else that is important to you that we add to this statement for this particular meeting?***

