



## Demystifying Consumer and Community Involvement (CCI) in research

### Resources list

#### Introduction to CCI

- Cambridge Clinical Trials Case Study - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0104-4>
- The Statement on Consumer and Community Involvement in Health and Medical Research (2016) NHMRC <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvementhealth-and-medical-research>
- WAHTN Involving Consumers in Health Medical Research Handbook [https://wahtn.org/wp-content/uploads/2021/09/WAHTN-CCI-Handbook\\_29092021.pdf](https://wahtn.org/wp-content/uploads/2021/09/WAHTN-CCI-Handbook_29092021.pdf)
- Australia Clinical Trials Alliance Consumer and Community Involvement Tool Kit <https://involvementtoolkit.clinicaltrialsalliance.org.au>
- Consumer and Community Involvement in Health and Medical Research: An Australia-wide Audit [https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI\\_Final-Report\\_Full\\_Dec2018.pdf](https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI_Final-Report_Full_Dec2018.pdf)
- South Australian Health and Medical Research Institute (SAHMRI) Framework [https://www.sahmri.org/m/downloads/20140606\\_Health\\_Consumers\\_in\\_Research\\_Report\\_FINAL.pdf](https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf)
- South Australian Health and Medical Research Institute (SAHMRI) Value Statement <https://healthtranslationsa.org.au/wp-content/uploads/2020/11/The-value-of-CCI-report-v2.pdf>
- Cancer Australia: National Framework for Consumer Involvement in Cancer Control [https://www.canceraustralia.gov.au/sites/default/files/publications/national\\_consumer\\_framework\\_web\\_504af020f2184.pdf](https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf)
- Miller et al (2017), Integrating consumer engagement in health and medical research – an Australian framework <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-017-0171-2>

#### Operationalising CCI

##### Planning

- Quick tools to figure out *your* 'why' (in what components) you want/need CCI: Cancer Australia checklist: [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15\\_checklist\\_researchers.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15_checklist_researchers.pdf) AND Western Australia Health Translation Network Handbook (resource 7): [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15\\_checklist\\_researchers.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/researchers/r4.0-15_checklist_researchers.pdf)
- General considerations. Telethon Kids [https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple\\_planning\\_book\\_271015.pdf](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf) AND Barriers and Enablers [https://www.hcnsw.org.au/hcnsw\\_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/](https://www.hcnsw.org.au/hcnsw_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/)

## Terms of Reference

- Writing terms of references: <https://hic.org.au/writing-terms-of-reference-for-consumer-committees/> and [https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m\\_4\\_1-14-a\\_12\\_guide\\_writingtermsofreference\\_2\\_2.pdf](https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m_4_1-14-a_12_guide_writingtermsofreference_2_2.pdf)

## Budget

- Deciding whether you should pay your CCI partner: <https://hic.org.au/should-money-come-into-it-a-tool-for-deciding-whether-to-pay-patient-engagement-participants/>
- Preparing a budget: Cost calculator: <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>
- Reimbursement guidelines: Monash <https://monashpartners.org.au/wp-content/uploads/2020/05/Remuneration-Guidelines-1.pdf>; Health Consumers NSW <https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/>; To board/committees: <https://www.vic.gov.au/guidelines-appointment-remuneration>

## Funding sources (other than LHD)

- [Philanthropy Australia](#)
- [Our Community](#)
- [Grant Guru](#)
- Local Government Area Council!

## Recruiting

- NSW Regional Health Partners role description template: <https://nswregionalhealthpartners.org.au/wp-content/uploads/2021/12/Position-Description.pdf>
- Common Forums: Health Consumers NSW, Consumers Health Forum of Australia,

## Training and orientation

- Common barriers and enablers here: [https://www.hcnsw.org.au/hcnsw\\_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/](https://www.hcnsw.org.au/hcnsw_resource/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/)
- Communicating with people with a disability: [http://www.daru.org.au/wp/wp-content/uploads/2013/05/Inclusive-Consultation-and-Communication-with-People-with-a-Disability\\_04.pdf](http://www.daru.org.au/wp/wp-content/uploads/2013/05/Inclusive-Consultation-and-Communication-with-People-with-a-Disability_04.pdf)

## 'Doing'

- International Association for Public Participation Spectrum: <https://iap2.org.au/resources/spectrum/>
- Selecting methods <https://dpmc.govt.nz/sites/default/files/2020-10/policy-project-community-engagement-selecting-methods.pdf> OR <https://involve.org.uk/sites/default/files/field/attachemnt/People-and-Participation.pdf>

## Communication

- National Safety and Quality Healthcare Service Standards Health Literacy: <https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/health-literacy>
- Written - general info: <https://www.sahealth.sa.gov.au/wps/wcm/connect/fcb907004e455125ab8eaf8ba24f3db9/HLT-AssessingReability-T7-PHCS-SQ20130118.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-fcb907004e455125ab8eaf8ba24f3db9-nKKxi3l>
- Written - Flesch Kincaid Grade and Simple Measure of Gobbledygook (SMOG) assessments: <https://readable.com/readability/smog-index/>

## Evaluation

- Standards: <https://www.safetyandquality.gov.au/sites/default/files/migrated/User-Guide-for-Measuring-and-Evaluating-Partnering-with-Consumers.pdf>
- General guides and available tools: <https://www.ourcommunity.com.au/files/books/MeasuringWhatMattersBooklet.pdf> ; [https://ahra.org.au/wp-content/uploads/2021/10/AHRA\\_CCI\\_Measuring\\_Impact\\_web.pdf](https://ahra.org.au/wp-content/uploads/2021/10/AHRA_CCI_Measuring_Impact_web.pdf); <http://www.evaluationtoolbox.net.au/>