Health Care Consumers' Association Consumer-Based Research Framework

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About Health Care Consumers' Association Inc

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. In 2018we celebrated forty years of incorporation. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of human services.

More information about HCCA can be found at www.hcca.org.au.

Acknowledgements

The Health Care Consumers’ Association (HCCA) Research Framework was developed by the Health Policy and Research Advisory Committee (HPRAC) and drafted by Dr Sarah Spiller and Dr Kathryn Dwan. This document would not have been possible without the hard work and contributions of the following HPRAC members, present and past:

- Sue Andrews
- Wendy Armstrong
- Darlene Cox
- Kathryn Dwan
- Shelley McInnis
- Margaret Norington
- David Pearson
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- Fiona Tito-Wheatland
- Linda Trompf

Many thanks to HCCA members who have participated in HCCA research and have taught us so much about the importance and the process of involving consumers.

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1. PURPOSE

Health Care Consumers' Association (HCCA) believes in the value of consumer-based research. We have developed this framework to guide our internal processes, and to explain our approach to external organisations undertaking health research.

The Consumer-Based Research Framework defines and presents our ideal of consumer-based research. It explains what HCCA, as a consumer organisation, does to support and encourage consumer-based research. Specifically, we

- conduct research into consumer experiences and expectations of health and human services,
- increase the skills and knowledge of consumers, and
- build capacity in other organisations.

The Framework also explains why HCCA undertakes consumer-based research and the strategies we use. Finally, it describes how HCCA goes about

- deciding what to research,
- deciding how to do the research,
- doing the research,
- letting people know our findings, and
- deciding what to do next.

The Research Framework Overview (see Appendix IV) provides a one-page, visual summary.

2. CONSUMER-BASED RESEARCH

HCCA believes that *consumer-based research involves consumers at all levels and all stages of the research process*. Ideally, consumers are not just subjects of research but want to participate fully, and be involved, in the governance and conduct of research. Consequently, they are involved from the early stages of deciding what and how to research, through undertaking the research, to disseminating the findings and deciding what to do next. Involving consumers in this way increases the likelihood that the research will be relevant to community needs, deliver greater public awareness of research findings, and deliver better health outcomes.[i]

Researchers have conceptualized consumer involvement in different ways, most recognising gradations in the extent and depth of consumer participation. The three conceptual frameworks that most influence HCCA's approach are:

- Spectrum of engagement in research[ii] (Figure 1),
- Ladder of research involvement[iii] (Figure 2), and
- Consumer participation in research[iv] (Figure 3).

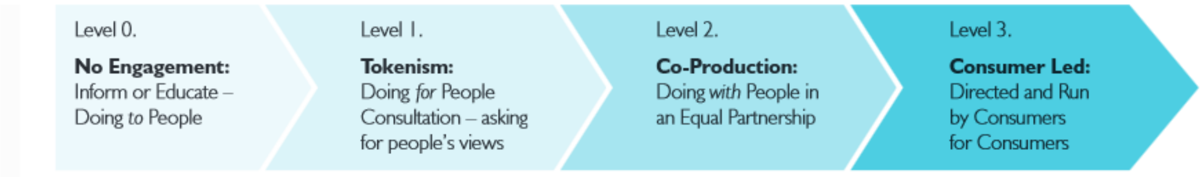

Figure 1: A spectrum of engagement in research

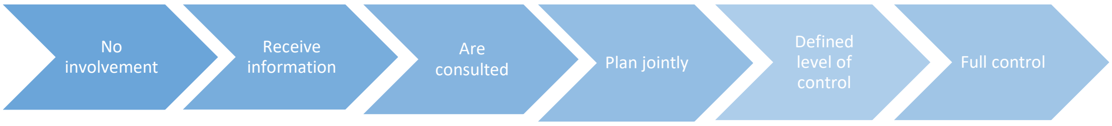

Figure 2: A ladder of research involvement

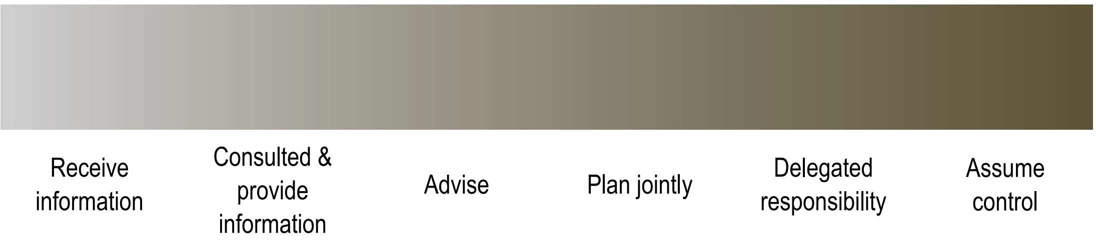

Figure 3: Consumer participation in research

HCCA tries to undertake research in a way that facilitates the rightmost end of the spectrum in all three figures. This is where consumers

- co-produce or lead the research (Fig 1),
- have defined or full control of the research (Fig 2), or
- assume control of the research (Fig 3).

2.1. HCCA's ideal of consumer-based research

HCCA's preference is to maximise consumer involvement and control of the research process, because this is the best way to generate research results useful for shaping the kind of health and human services consumers want.

All HCCA research projects are *consumer-initiated,* which means the research topic or question is identified as a priority by consumers or through a consumer-driven committee process.

Consumers are involved in the governance of all HCCA research, making it *consumer-directed*. Health Policy Advisory and Research Committee has oversight of all HCCA research projects. This Committee may also provide advice or feedback on individual projects. In addition, each HCCA research project has a consumer oversight or governance mechanism, often provided by a project-based Consumer Advisory Group (see 4.2.5 Project governance).

Where possible research is *co-produced*. This means that consumers with lived experience and/or with consumer representation skills are equal partners with researchers at every stage of the research process.

The day to day tasks of research are undertaken by members of the HCCA staff who are highly experienced and well-trained researchers.

3. HCCA'S APPROACH TO RESEARCH

3.1.What we do

HCCA is a consumer organisation that conducts research. Hence, our own research is always consumer-based. When other organisations undertaking research seek to work with HCCA or seek advice on undertaking consumer-based research we attempt to ensure that consumers are engaged from the outset: deciding what to research and how to research it; doing the research, letting people know the results and deciding how to use the results to influence health policy and service delivery. The way HCCA approaches research prioritises consumer voices and models best practice consumer engagement.

3.1.1. Conducting research into consumer experiences and expectations of health and human services

- Ensure HCCA's own research is only done on topics
    - that are focused on the *consumer experience*, identified by members and one of HCCA's *strategic priorities,*
    - for which there is *little existing evidence*, and
    - where HCCA is the *best placed* organisation to undertake the research.
- Involve consumers at *all stages* of the research process.

3.1.2. Helping increase the skills and knowledge of consumers

- Provide opportunities for HCCA members to participate at *all levels* of HCCA research projects.
- Advertise opportunities for *consumers involvement* in research conducted by other organisations.
- Provide *training* for consumers who want to be involved in research

3.1.3. Building capacity in other organisations

- Provide *advice* on request
- Undertake *collaborative research* with other organization, sharing our approach, knowledge and skills.
- Provide *training* for organisations wanting to involve consumers in research

3.2. Why we do it

HCCA undertakes consumer-based research, so that consumer priorities are better understood by researchers, decision-makers and the public. It also normalises and demonstrates the value of involving consumers in decisions and research that affects them.

Consumer-based research benefits consumers because it

- contributes to health care quality improvement and to better health policy and services,
- builds consumer capacity to co-produce and lead research, and
- raises the public and research profile of people's lived experiences of health care.

In undertaking consumer-based research HCCA aims to improve the safety, quality and consumer-centredness of health care in the ACT.

Consumer involvement in research is a right of health care consumers, and a responsibility of researchers.[v] The Australian Code for the Responsible Conduct of Research and the *National Statement on Consumer and Community Involvement in Health and Medical Research* recognise that both researchers and research institutions should encourage and support consumer involvement. The *National Statement* makes clear that meaningful consumer involvement demands a significant re-orientation away from the traditional conception that consumers' role in research is limited to being participants or subjects of research:

> Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them.[vi]

Research in which consumers are meaningfully involved as partners is more likely to

- be relevant to community needs,
- deliver greater public awareness of research findings, and
- deliver better health outcomes.[vii]

In short, consumer partnership in research delivers better research that is more relevant to consumer health needs.

3.3. What can make it difficult

Despite this high-level recognition of the value of consumer involvement in research, many challenges to meaningful involvement remain.

- Researchers lacking skills in consumer involvement or awareness of the benefits of consumer involvement.
- Systems that do not reward or support consumer involvement, including at the early stage of identifying problems and questions to research, both in academic and policy and service settings.
- Stigma around many lived experiences that prevent consumers from sharing such sexperience.
- Lack of skills and training for consumers in sharing their lived experience through research processes in ways that productively contribute to the governance, design, conduct and analysis of research projects.
- An entrenched power imbalance between consumers and research professionals, and an associated tendency toward tokenistic or lower-level engagement of consumers.[viii]

4. HCCA’s RESEARCH FRAMEWORK

HCCA’s Consumer-Based Research Framework sets out how we go about

- deciding what to research,
- deciding how to do the research,
- doing the research,
- letting people know our findings, and
- deciding what to do next (see Research Framework Overview at Appendix IV).

4.1. Deciding what to research

HCCA undertakes social research projects with a focus on the consumer actual and ideal experience of health and human services.

4.1.1. Criteria for consumer-based research project

- The topic focuses on the consumer experience of health or human services.
- The topic is a strategic priority for HCCA
    - It is identified or acknowledged as a consumer priority by one or more HCCA committees (i.e. Executive Committee, Health Policy and Research Advisory Committee or Consumer Reference Groups).
    - It is listed as a Policy Priority or otherwise mentioned in the HCCA Strategic Plan.
- The topic addresses a gap in knowledge.
    - The research will bring an otherwise missing consumer perspective to a topical, service delivery or policy challenge, and/or it is not otherwise addressed in the available literature.
- HCCA is the best placed organisation to undertake the work.
    - The topic applies to ACT circumstances and services, demands a consumer perspective, or both.
- HCCA has the necessary resources and funding to complete the work
- Project is likely to influence policy, service or quality improvement decision-making.

HCCA’s Health Policy and Research Advisory Committee must consider whether these criteria are met, and agree that this is this case, before research projects can begin.

From time to time HCCA may be approached by external stakeholder organisations to undertake research on a consultancy or project basis. HCCA may also seek external funding for research projects. These projects must also meet the criteria above.

4.2. Deciding how to do it

Determining how and the extent to which consumers are involved is the most important element in deciding how to go about doing consumer-based research. Other considerations include how the project will be governed, the choice of research method, the need or otherwise for formal ethical clearance, and the development of a research plan.

4.2.1. Consumer involvement

Ideally consumers are involved in the governance of the project, as researchers in designing and undertaking the research, and as participants. They also have key roles to play in shaping and sharing the findings.

It is important to consider the following questions in relation to consumer involvement.

- How are consumers involved in governance? (see 4.2.5 Project Governance)
- What level of control does the project offer to consumers? (see 4.3.2 Participant control and safety)
- What are the potential risks to participants and how can we minimise them? (see 4.2.7 Human research ethics)
- How can we ensure that the information we will produce and gather match consumer needs and preferences? (e.g. consumer consultation/advice to inform design of a Participant Information and Consent Form or summary of findings)
- How will consumers be involved in sharing the research findings with others (e.g. Consumer Reps on committees)?
- Which consumers should be invited to be participants in a project, and how can HCCA best engage with these people?

4.2.2. Under-represented consumer groups

HCCA is aware that research often overlooks the experiences of specific groups of consumers, including, socially or economically marginalised people, age groups, genders, and those who are culturally or linguistically diverse. One risk is that research can present or is assumed to present the experiences of *some* consumers as being applicable to *all* consumers. One practical consequence of this occurring is the exclusion of disadvantaged and other groups of health care consumers from public debate and health care improvement efforts.

HCCA research plans identify which people are to be involved as participants in the research, and any specific recruitment or engagement approaches that are required to involve these people. HCCA employs multiple strategies to minimise the risk of under-representation of relevant groups in its research.

- HCCA seeks to build relationships with consumer and community organisations representing diverse community cohorts and for advice on how to engage these communities in research or to seek assistance in promoting the opportunity to participate in research.
- HCCA endeavours to design research plans and processes that offer appropriate support to people from diverse backgrounds including people who are socially or economically marginalised (e.g. covering travel costs, using translators).
- HCCA clearly acknowledges when particular cohorts or perspectives are under-represented in the research, and the constraints that this places on the generalizability of the findings.

4.2.3. Other stakeholders

The outcomes of consumer-based research may be improved by involving decision makers and health care workers, community-based organisations, and other researchers or research organisations. HCCA may seek input to

- better understand the context,
- increase the appropriateness of the topic and approach,
- improve our recruitment strategies,
- increase the reach and impact of our findings.

The received wisdom suggests that *decision makers and health care workers* are more likely to accept and act on research findings if they have been aware of and involved in the research from an early stage.[ix,x]

HCCA only undertakes research where we are best placed to do so. However, our research may be improved by consulting or collaborating with other *community-based organisations*.

Prior to undertaking research HCCA considers whether any additional *research expertise* will be required (e.g. for statistical analysis of quantitative data sets).

HCCA may also choose to engage stakeholders as research partners (see 4.2.4 Research partnerships).

4.2.4. Research partnerships

HCCA may request or be invited to conduct research in partnership with other agencies or individuals. True partnership involves either equal status or collaborative ventures where HCCA or the other organisation takes the lead. When HCCA chooses to partner with other individuals or organisations the research plan will identify

- their roles and tasks,
- how information will be shared between partners, and
- approval processes for using the findings.

The Advisory Group and Health Policy and Research Advisory Committee can provide direction on appropriate individuals and organisations to involve in the research.

Possible research partners

- Community organisations
- Government agencies (e.g. funders, decision makers)
- Health care services and health care workers
- Students, consumers and volunteers[1]

4.2.5. Project governance

HCCA's research program is governed by Health Policy and Research Advisory Committee, comprising HCCA members with lived consumer experience and strong skills in consumer representation, health policy and/or research. Health Policy and Research Advisory Committee is responsible for ensuring that all projects meet HCCA's criteria (see 4.1.1 Criteria for consumer-based research).

If the criteria are met, the first step is to identify an appropriate structure for consumer governance of the research project. Generally, this occurs through a *Consumer Advisory Group* which is convened for each project. The Consumer Advisory Group is established as early as possible in the lifetime of the project and provides the following:

- Formulating the research question
- Developing a research plan
- Ethical considerations in research
- Selection of methods
- Participant recruitment
- Data collection
- Analysis
- Dissemination of findings
- Translation into policy/practice change

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[1] Students, volunteers and consumers who will be involved in research need to sign HCCA's Volunteer Policy

Consumer Advisory Group members bring relevant lived experience and also:

- an understanding of research, policy and advocacy,
- an understanding of the research process,
- critical and abstract thinking skills, and
- consumer representation and committee participation skills.

Members of the Consumer Advisory Group are core members of the research team. The Health Policy and Research Advisory Committee may be invited to advise on individual projects, providing an additional level of consumer review.

4.2.6. Research methods

HCCA research focuses on qualitative methods that allow consumers to share their experiences in their own words research. This helps illuminate consumers' lived experiences of health care and human services. Where appropriate HCCA uses the Real People, Real Data approach to interviewing consumers (see Appendix I).

Quantitative methods can provide important information about consumer experiences and may be used as an adjunct methodology when required. HCCA also uses applied participatory inquiry methods such as co-design to enable consumers to create and share knowledge relevant to health care improvement, and to translate research findings into practical strategies for health care improvement. Appendix II indicates the range of methods used in recent HCCA projects.

4.2.7. Human research ethics

All HCCA research abides by the *NHMRC National Statement on Ethical Conduct in Human Research*[xi]. When designing the research, we will assess whether the research we seek to conduct constitutes research or quality improvement.[xii]

In the case of *research*, we will identify the relevant Human Research Ethics Committee (HREC) or Committees, and work with them to complete the clearance process. If the project is considered to be a *quality improvement* exercise, we will confirm this understanding with the ACT Health HREC. The project will be conducted in line with the *NHMRC Ethical considerations in quality assurance and evaluation activities*.

Steps to ensure the ethical conduct of research:

- HCCA identifies which level of HREC approval is required, and from whom.
- HCCA liaises with the appropriate HREC(s) and HREC Secretariat(s) to successfully obtain HREC approval.
- HCCA allows time for HREC clearance
- HCCA reports on research activities as requested by the HREC(s).

4.2.8. Research plan

Traditionally, research plans have the following sections

- Aims objectives, and research questions
- Selection criteria
- Recruitment strategies
- Method, including analysis
- Ethical issues,
- Timelines and costings.

In addition, HCCA research plans specifically address the following:

- Consumers involvement in governing the research (see 4.2.5 Project governance)
- Research partners (see 4.2.4 Research partnerships)
- Other stakeholders (see 4.2.3 Other stakeholders)
- How the findings will be used to improve policy and practice
- The level and type of control offered to consumers (see 4.3.1 Consumer control and 4.3.2 Participant control and safety)
    - How will the findings be shared with consumers in ways that are accessible?
    - What strategies maximise participant control at each stage in the research to provide (e.g. providing opportunities to comment on and change interview transcripts)?
    - What consumer information will be required and how to ensure this best matches consumer needs and preferences (e.g. consumer consultation/advice to inform design of a Participant Information and Consent Form or summary of findings)?
    - How will consumers be involved in sharing the research findings with others (e.g. consumer representatives on committees)?

Table 1 provides a checklist for both HCCA and other researchers to ensure that they have considered whether all the relevant stakeholders are engaged at key stages of the proposed research.

Often, the research plan will form the basis of

- an application to the Human Research Ethics committee (HREC), if required, or
- a plan to address ethical considerations for quality improvement projects, which do not require HREC clearance (see 4.2.7 Human research ethics).

Table 1. A checklist for involving consumers and other stakeholder in research

	Consumers	Health care workers	Decision makers	Researchers	Others
Deciding what to do					
Deciding how to do it					
Doing the research					
Letting people know the findings					
Deciding what to do next					

4.3. Doing the research

4.3.1. Consumer control

HCCA conducts research in ways that maximise opportunities for consumer control and the research plan for each project explains how consumers are involved at all levels and stages.

4.3.2. Participant control and safety

Participants in HCCA projects often share personal experiences of health and health care with us. HCCA recognises that this creates some specific risks for participants. We manage these risks by acknowledging them, putting strategies in place to minimise risks and maximise participant control, and by fostering an organisational culture that respects consumer experience. HCCA supports participant control and safety by:

- providing clear and appropriate information to participants,
- protecting privacy and confidentiality, and
- modifying the research to reflect the principles of trauma-informed care, where necessary.

4.3.2.1. Providing clear and appropriate information to participants

HCCA provides information in a way that assists people to give their informed consent to participation.

All information provided to participants is written in *plain English* and readable by people with *Year 8 reading ability*. This applies particularly to Participant Information and Consent Forms (PICFs), which identify

- the possible benefits and the risks of participation,
- what participation involves,
- what HCCA will do with the information participants share with us,
- how HCCA will protect privacy and confidentiality,
- how HCCA will store participants' information and for how long, and
- the opportunity for participants to review and approve how information they provide is presented.

Discussing the written information with potential participants provides another opportunity for participants to consider the issues.

4.3.2.2. Protecting privacy and confidentiality

The Participant Information and Consent Form, which is developed for each project, provides clear information about how HCCA will protect the privacy and the confidentiality or anonymity of the information participants share. The Participant Information and Consent Form provides clear information about whether a participant's information will be anonymous or confidential.

Definitions

Anonymous data can never be linked to an individual.

Confidential data cannot be immediately linked to an individual, but it is possible to make this link.[xiii]

Participation in HCCA research projects is not usually anonymous. Participant Information and Consent Forms advise potential participants of the ways that HCCA will protect the confidentiality of the information they share. This will vary from project to project but may include, for example, assigning each participant in qualitative projects with a code, which is used to identify their transcript of interview. Only members of the HCCA research team can link the transcript to the name of the participant, which is stored separately in a password protected file.

When using the Real People Real Data approach to conduct interviews with consumers, HCCA invites participants to read their transcript (See Appendix I). This allows them to remove information that they are not comfortable sharing. It also gives participants the opportunity to highlight which parts of their experience were significant from their perspective.

When undertaking quantitative research, HCCA may use an online survey provider, such as Survey Monkey. HCCA provides

- a clear statement to potential survey participants that Survey Monkey data is stored on computer servers located outside of Australia, and
- a link to Survey Monkey's Privacy Policy.

HCCA avoids asking for potentially identifying information in surveys unless this is absolutely necessary for the purpose of a survey. We do this because of the possibility that an individual's identity could be inferred by a third party through a combination of IP address and answers to specific survey questions. In this case HCCA will provide a clear statement that confidentiality cannot be guaranteed.

4.3.2.3. A trauma-informed approach to consumer experience research

Trauma-Informed Care and Practice[xiv] is a strengths-based framework that is responsive to the impact of trauma, emphasising physical, psychological, and emotional safety for both service providers and survivors, and creates opportunities for survivors to rebuild a sense of control and empowerment.[xv] Where required, HCCA employs the principles of trauma-informed care – safety, trust, choice, collaboration and empowerment into the research process.

HCCA researchers will seek Health Policy and Research Advisory Committee and Consumer Advisory Group guidance in the development of research processes and tools to ensure participants feel respected and safe. Other individuals and organisation may also be consulted.

Strategies

- Qualitative interview participants tobe told in advance of all possible areas of questioning, so they can prepare;
- Participants will be advised that they can
    - choose to skip any question or stop any line of questioning,
    - raise other issues that are important to them,
    - stop or pause the interview at any time, and
    - withdraw from the research at any time.

HCCA research interviewers will undertake training in understanding trauma and its consequences.[xvi] They will attempt to

- use language acceptable to participants,
- acknowledge participants' trauma and affirm their coping mechanisms,
- be alert to signs that a consumer may not wish to discuss a topic, and

- employ practical strategies to help build participants sense of safety and trust
    - Send an introductory text message with the interviewer’s photo to participants 24 hours before an interview
    - Facilitate the presence of a support person, if desired
    - Arrange for support to be available immediately after the interview, if necessary

If a participant becomes upset during the interview they will

- moderate their tone of voice and body language,
- use ‘grounding’ techniques such as offering a glass of water, and
- offer a break from the interview.

HCCA researchers are not counsellors or personal advocates, nor is an interview a feedback or complaints process. HCCA researchers understand the limits of interviewing and what they can offer participants. However, if appropriate, HCCA may provide participants with information about options they could choose to pursue (e.g. formal complaints processes).

The Participant Information and Consent Form for all projects acknowledges that it can be upsetting to share a personal experience and provides contact details for free counselling services.

4.4. Letting people know our findings

HCCA recognises that it is important to close the loop by providing information about the research findings to participants and to stakeholders in the research. All research plans will identify ways that the findings can be used to improve policy and practice.

Those potentially interested in our findings include:

- Consumer participants
- HCCA members and relevant Consumer Reference Groups
- Decision-makers and health care workers
- Funding agencies
- Consumer and community organisations
- Other researchers and research institutes
- The wider consumer public

HCCA tailors the presentation of its findings to the target audience, so the formats will vary.

- Plain English summary for participants
- Research report
- Presentations
    - HCCA members and committees
    - Formal committees
    - Conferences
    - Funders and decision-makers
- Refereed articles
- HCCA's fortnightly newsletter *Consumer Bites*

Research reports will broadly adhere to the reader friendly writing approach.[xvii]

- 1 page – main messages and the lessons decision makers can take from the research
- 3 page – executive summary
- 25 pages – full report

The process for publishing a HCCA report (see Appendix III) includes the following steps:

- Obtain clearance for the report from HCCA and externally with research partners
- Publish on HCCA website
- Send a thank you letter and plain English summary for participants
- Send emails and link or copy of report to
    - Participants
    - Organisations who helped to promote the research
    - Others who should receive this information
- Apply for an ISBN and appropriate Creative Commons license, and lodge with National Library of Australia

4.5. Deciding what to do next

HCCA aims to undertake research that influences policy and health service improvement and leads to better consumer health outcomes. For each project, we attempt to:

- Identify opportunities for consumers/ consumer organisations to use the findings in their advocacy work (e.g. Consumer representatives)
- Identify decision-makers early in the research and develop a process to involve them in responding to findings/recommendations
- Identify opportunities to work with decision-makers to implement findings, and track implementation of changes over time
- Evaluate impact
    - This responsibility rests with Health Policy and Research Advisory Committee
    - What, if anything, changes because of the research? Why was this? What can be done better or differently next time?

5. APPENDICES

5.1.APPENDIX 1: Real People Real Data

The Real People Real Data approach was developed by the Consumers Health Forum of Australia (CHF), specifically to prioritise the consumer experience. [2]

Consumers are interviewed in a naturalist way which seeks to mirror their health journey. The interviews are generally recorded and professionally transcribed. Consumers are then invited to identify the most important elements of their story. This ensures that the research maintains a focus on the consumer's experience. The data are coded against the evidence-based domains of person-centred care. However, the data can be coded against other domains, such as those of trauma-informed care. Finally, a visual representation of the key points in the consumer or carer experience is produced in the form of a "Health Experience Wheel". The wheel allows key issues to be quickly communicated and, thus, is a useful tool for informing strategic healthcare decision-making.

The Real People, Real Data approach to eliciting consumer stories assists organisations to use this often-overlooked evidence base to ensure our health system delivers consumer-centred care. An independent evaluation of the Real People, Real Data approach found that the toolkit and process provides a robust, systematic, and transparent methodology for collecting, analysing and presenting consumer narrative to inform health decisions.[3]

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[2] Consumers Health Forum of Australia, "Real People, Real Data," https://chf.org.au/real-people-real-data-toolkit (Accessed 13 March 2019).

[3] Tong, Allison, CHF Real People, Real Data Project – Pilot Phase Evaluation. 2014, page 25. https://chf.org.au/sites/default/files/docs/chf_rprd_external_evaluation.pdf, (Accessed 13 March 2019).

5.2. APPENDIX II: Range of methods

Qualitative methods

	Data analysis	Examples
Real People Real Data (RPRD)	• Experience wheels • Criteria	• Home-based palliative care
In-depth interviews	• Thematic analysis	• Patient Care Navigation
Focus groups	• Thematic analysis	• Inquiry into end-of-life choices
Consumer stories	• Illustrative quotes • Case studies	• Policy submissions

Quantitative methods

	Data analysis	Examples
Online surveys	• Report percentages	• General practice & after-hours care report
Online surveys	• Tests of significance (e.g. correlation[4], factor analysis[5])	• Patient Care Navigation
	• Change over time in consumer sentiment and issues of concern	• Weekly surveys of consumer information needs during COVID-19

Mixed methods

	Data analysis	Examples
Evaluation	• Qualitative & quantitative	• Strategic planning process

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[4] This type of analysis tells us that certain characteristics are associated with certain behaviours (e.g. Whether people with chronic conditions are more likely to use ED than those without)

[5] This type of analysis gives us confidence that we are measuring the thing we think we are measuring (e.g. Do the questions we have asked in the last three surveys about consumers' experience of GP consultation measure how well GPs provide patient-centred care?)

5.3. APPENDIX III: HCCA’s publication procedure

Introduction

HCCA is registered as a publisher in Australia. This means we can apply an ISBN to our publications and also register our publications with the National Library of Australia (NLA) so that people can find them using the NLA catalogue. This makes it easier for people to find our publications. If someone wants to publish using the HCCA ISBN this needs to be done with approval of the Executive Director or Executive Committee

HCCA applies a Creative Commons license to our publications. This helps ensure that readers use and cite our work in the way we want them to.

1. When should I use this procedure?

- Put an ISBN and NLA catalogue data in reports that present the findings from major HCCA projects.
- Put a Creative Commons license on *most* HCCA publications (e.g. submissions and training material that will be shared outside the organisation).

2. Access HCCA’s publisher details

HCCA’s publisher information is held online by Thorpe-Bowker Identifier Services. To access our profile:

- Go to the Thorpe-Bowker website: www.myidentifiers.com.au
- [redacted] Log-in: [redacted]
- Password: [redacted]

3. Apply an ISBN

An International Standard Book Number (ISBN) is a unique identifier for publications. Because HCCA is registered as publisher, we can apply an ISBN to key publications. This does incur a cost. ISBNs can be purchased online from Thorpe-Bowker Identifier Services, with approval from the Executive Director.

To apply an ISBN:

- Go to HCCA’s publisher profile at the Thorpe-Bowker website (see 1.1).
- Complete the “Assign an ISBN” form for the publication.

4. Apply National Library of Australia cataloguing information

To use the National Library of Australia's cataloguing service:

- Go to https://www.nla.gov.au/content/prepublication-data-service)
- Complete and submit the form.
- Download the NLA Cataloguing Statement from http://www.nla.gov.au/cataloguing-statement, and include this on the inside sleeve of the publication.

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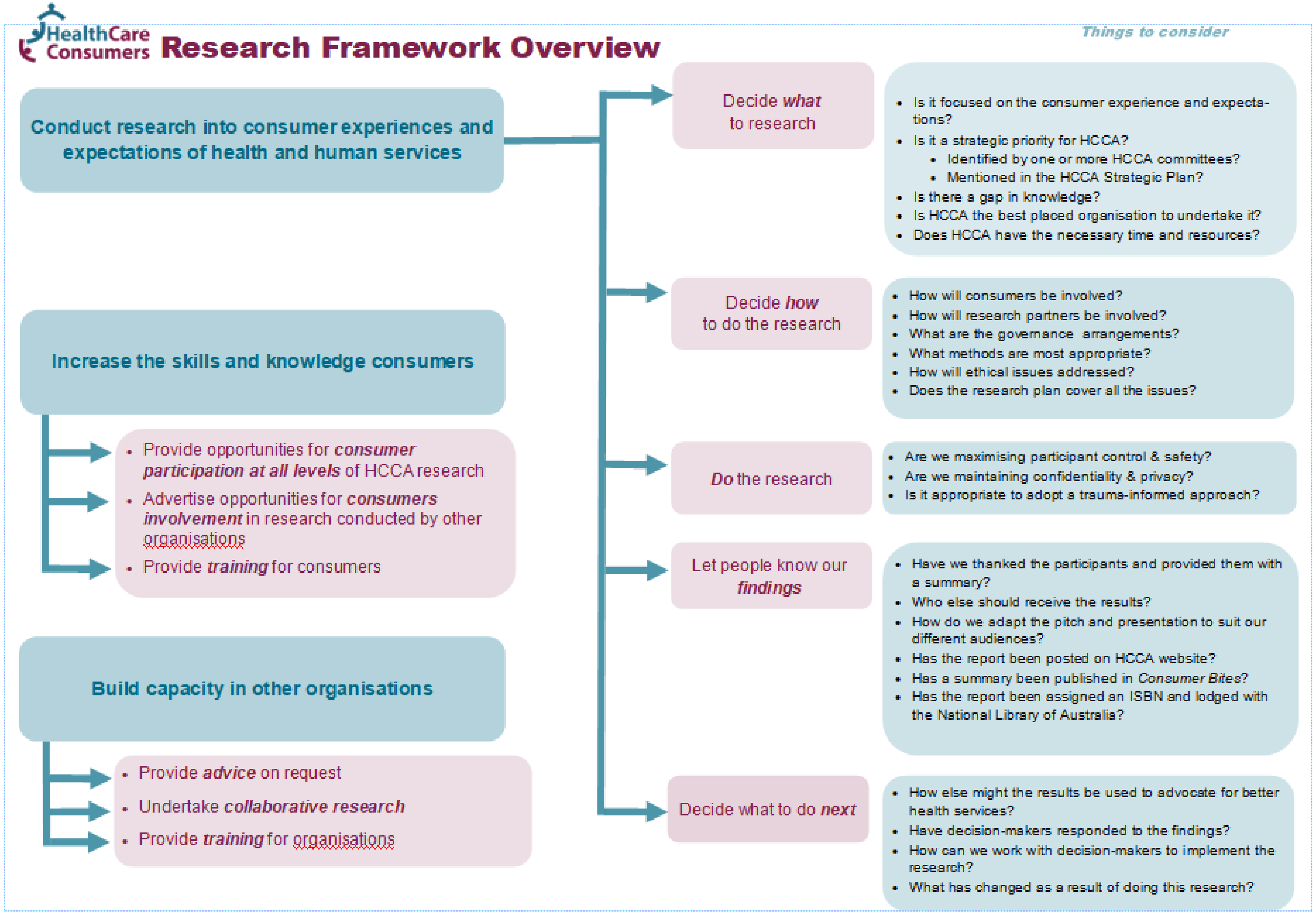
5.4. APPENDIX IV: Research Framework Overview



HealthCare Consumers

Research Framework Overview

Things to consider

Conduct research into consumer experiences and expectations of health and human services

Decide *what* to research

- Is it focused on the consumer experience and expectations?
- Is it a strategic priority for HCCA?
  - Identified by one or more HCCA committees?
  - Mentioned in the HCCA Strategic Plan?
- Is there a gap in knowledge?
- Is HCCA the best placed organisation to undertake it?
- Does HCCA have the necessary time and resources?

Decide *how* to do the research

- How will consumers be involved?
- How will research partners be involved?
- What are the governance arrangements?
- What methods are most appropriate?
- How will ethical issues addressed?
- Does the research plan cover all the issues?

Do the research

- Are we maximising participant control & safety?
- Are we maintaining confidentiality & privacy?
- Is it appropriate to adopt a trauma-informed approach?

Let people know our *findings*

- Have we thanked the participants and provided them with a summary?
- Who else should receive the results?
- How do we adapt the pitch and presentation to suit our different audiences?
- Has the report been posted on HCCA website?
- Has a summary been published in *Consumer Bites*?
- Has the report been assigned an ISBN and lodged with the National Library of Australia?

Decide what to do *next*

- How else might the results be used to advocate for better health services?
- Have decision-makers responded to the findings?
- How can we work with decision-makers to implement the research?
- What has changed as a result of doing this research?

Increase the skills and knowledge consumers

- Provide opportunities for ***consumer participation at all levels*** of HCCA research
- Advertise opportunities for ***consumers involvement*** in research conducted by other organisations
- Provide ***training*** for consumers

Build capacity in other organisations

- Provide ***advice*** on request
- Undertake ***collaborative research***
- Provide ***training*** for organisations

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