COMMUNITY VOICE:

Qualitative Research Guide

for

Community Researchers

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Community Voices:

A Qualitative Research Guide for Community Researchers

EXECUTIVE SUMMARY

> **Qualitative Research:** *"The science of using words"* **to communicate and strengthen a message, make information more memorable and to assist in creating understanding and empathy.**

Community Voices: A Qualitative Research Guide for Community Researchers has been developed under the guidance of the Consumer Reference Group (CRG) of the Outer East Primary Care Partnership (OEPCP). The Guide provides a range of practical advice and tools to support community researchers undertake effective and ethical qualitative research.

Traditionally, research in the health sector has been based in the *‰cience of numbers+*, or quantitative research. More recently however, the power and value of *‰he science of words+* has emerged as an incredibily powerful way to understand, communicate and strengthen the messages around key health and wellbeing issues.

Qualitative research involves the studied use and collection of a variety of materials such as case studies, personal experience, life stories, interviews, observations and cultural texts (National Statement 2007 . Ethics). It is exploratory in nature and examines the meaning, ideas, beliefs and experiences of human life and social worlds. It helps us understand the context within which the topic we are interested in exists, it is subjective and inductive and is driven by the perspective of the participants. Qualitative research is useful when seeking to:

- understand complex or poorly understood phenomena
- explore the impact of social, cultural, political factors on health and disease
- examine the interactions and behaviours of individuals and groups

This Guide seeks to provide community researchers with academic insight into different research designs for gathering and using qualitative data. It provides a broader framework for thinking about qualitative research, and highlights how the gathering and the telling of a story can be undertaken, using a range of different research methodologies designed to inform a number of different research purposes.

The Guide highlights the value of storytelling as a mechanism for bringing the voice of the community to health planning, service design, quality improvement and advocacy processes. It also provides cautionary advice and guidance for community researchers about the significant and inherent responsibilities associated with the gathering and the telling of someone story. It highlights the core ethical considerations of conducting qualitative research, strongly emphasising the value of this type of work, but providing cautionary advice about how research should be conducted to ensure 'no harm' to the story tellers.

On a practical level the Guide provides examples and resources including:
- how to write a good qualitative purpose statement
- choosing question and research design
- understanding the role of the researcher
- selecting participants
- data collection techniques
- coding and analysis of data

It also provides advice and practical examples of how qualitative data can be translated into statements and disseminated to advocate for changes that are desired and needed by a community.

The Guide has been developed for use by OEPCP member agencies, but it will also be of value to service providers from across the broader health and community support sector. We are keen to receive feedback about its usefulness for community researchers and also from community members who have the courage, passion and desire to tell and share their stories.

CHAPTER 1:   QUALITATIVE RESEARCH

The purpose of research is to increase understanding and knowledge on a particular topic through a planned and systematic approach. When we undertake a research project, there are three approaches we can use: quantitative, qualitative and mixed methods research (which is a combination of both).

Qualitative research is exploratory and examines the meanings, ideas, beliefs and experiences of human life and social worlds. Qualitative research helps us to understand the context within which the topic we are researching exists. Hence this research approach is subjective and inductive and is driven by the perspectives of the participants. For example, qualitative research can explore the experience of cancer patients undergoing chemotherapy, the decision making processes and influences on parenting practices or how useful a local community garden and kitchen has been for its community members. Qualitative research generates words and is characterised by small participant numbers, community engagement, field work and the development and use of theories or frameworks.

Qualitative research is appropriate when seeking to:
- understand complex or poorly understood phenomena
- explore the impact of social, cultural, political factors on health and disease
- examine the interactions and behaviours of individuals and groups

(Fossey et al, 2002)

> ***Quantitative Research* – the science of numbers**
> ***Qualitative research* – the science of words**

See ***Appendix 1*** for a description of quantitative and mixed method research methodologies.

This guide focuses on qualitative research. It includes the different study designs, data collection methods, ethical considerations and analysis techniques required to conduct a qualitative research project. The information in this guide has been drawn from academic literature and books, as well as the experience of the authors. Examples and resources have been included throughout the guide to provide further guidance to conducting a qualitative research project. We have included examples from the academic literature to provide an indication of how qualitative research has been used to address topics such as the perspectives of health of consumers and carers and the implementation of community focused health initiatives and support service systems.

Practice Box 1: Why use qualitative research?

- To understand social phenomena or patterns: at an individual and/or community level
    - → Why is it happening
    - → How does it vary under different circumstances, eg situation, context and group
- To focus on meanings, ideas and experiences
- To introduce new areas of research
- To provide/obtain a richness and depth to data
- To articulate complex, multifaceted issues
- To include marginalized groups
- Allows the researcher to see things through participants' eyes, rather than on researcher's terms or answering researcher's pre-determined questions
- Can be used to answer *why, what and how* questions

1.1   Deciding on the scope of the research and its purpose

Firstly, it is important to articulate the purpose of the research in a specific statement referred to as the purpose statement or aim of the research. It articulates the scope of the project and guides the researcher to investigate a phenomenon or process of social life and how participants or the phenomenon relate to it (Saldana, 2011). The statement needs to indicate the researchers role to explore, to investigate, to determine, the type of inquiry **how, what, in what ways, why** and the participants or phenomenon.

See **Practice Box 2** for tips on how to write a good qualitative research purpose statement.

Examples of purpose statements

Purpose statement:	The focus of this study is to document the concerns of ethnically diverse, urban, impoverished women related to anxiety and depression, and to identify culturally sensitive interventions
Study participants:	61 women, 5 focus groups Black, Hispanic, and White women
Publication reference:	Doornbos, MM, Zandee, GL, DeGroot, J & Warpinski (2013). Desired Mental Health Resources for Urban, Ethnically Diverse, Impoverished Women Struggling With Anxiety and Depression. *Qual Health Res* 23:78
Researcher role:	To document and to identify
Type of inquiry:	What . concerns
Participants:	Ethnically diverse, urban, impoverished women experiencing anxiety and/or depression
Purpose statement:	To understand how individuals in an urban American food desert make grocery-purchasing decisions, and specifically why unhealthy purchases arise. Publication reference: Zachary DA, Palmer, AM, Beckham, SW & Surkan, PJ (2013). A framework for understanding grocery purchasing in a low-income urban environment. *Qual Health Res* 23(5) 665-678
Researcher role:	To understand how individuals make food purchasing decisions
Type of inquiry:	How and why
Participants:	Individuals buying groceries in an urban American food desert

Practice Box 2: Writing a good qualitative purpose statement

A good qualitative research purpose statement has the following characteristics:

- One concise and clear sentence
- Describes the purpose of the study
- Identifies the central phenomenon under study
- Uses qualitative words such as explore, understand, discover
- Includes information about who the participants are (e.g. young people with depression living in Victoria)
- Identifies the research site (e.g. Melbourne).

A script for writing a purpose statement is below:

The purpose of this _____(narrative, phenomenology, grounded theory, ethnography, case etc) study is to _____(understand, describe, develop, explore, discover) the _____ (central phenomenon under study) for _____ (the participants) at (the site).

For further information please see the link below:

See: http://masscommtheory.com/2011/05/05/writing-good-qualitative-research-questions/

The use of theory in qualitative research

Researchers rely on theories from the social sciences and humanities to guide their research practice and provide insight to their findings. Theories provide comprehensive and conceptual foundations for complex social processes. For example, how organisations work, how people make decisions and how people interact with each other. Researchers use theories as a means of exploring different views of the world and to examine their data in light of these views, hence these theories are used as a framework for analysis (Reeves, Albert, Kuper & Hodges, 2008). Qualitative researchers draw on theories from a variety of disciplines such as economics, sociology, political science, psychology and anthropology (Tavallaei and Abutalib, 2010). For example, feminist theories can be used when researching gender inequality; critical theories may be applied when investigating power relations of individuals or groups (for example gender, race, culture) and functionalist theory can be employed when exploring social trends and welfare (Kralik and van Loon, 2008; Reeves et al, 2008; Willis et al, 2007). The use of theory can be complicated and therefore academic support from an experienced researcher may be necessary.

1.2   Choosing questions and research designs

Your choice of study design will depend on the research question(s) being asked about your topic. The research question captures what it is that you are trying to find out and serves to narrow the purpose of the research - therefore the research question(s) will relate closely to the purpose statement or aim. A study will have one central research question and a few sub questions, usually no more than five.

Firstly, qualitative research corresponds to questions which ask **why, how or what** and secondly the process can be charactered through words such as ±discoverq ±generateq examineq and describeq Therefore these words are often found within the research question. Words such as ±associationq **effect, cause** and **relationship** are more suited to quantitative research and hence should be avoided.

Qualitative research is a research approach which comprises a number of different study designs. The term ±research designqis defined as the plan for collecting and analysing evidence that will make it possible for the investigator to answer whatever questions he or she has posed. The design of an investigation touches almost all aspects of the research, from the minute details of data collection to the selection of the techniques of data analysis (Ragin, 1994, p 191 as quoted by Flick 2007, p 36). Therefore choosing the correct research design to answer your research question is critical to good research practice. Below is an overview of the different types of qualitative research methods or designs and the type of research questions they seek to answer.

Table 1: Summary of qualitative study designs

Dimensions of Qualitative Design Types	Qualitative Design Types					
	Narrative	**Phenomenology**	**Grounded Theory**	**Ethnography**	**Case Study**	**Action Research/ Participatory Action Research**
Focus	Explores the life of an individual in depth	Seeks to understand the experiences related to a phenomenon	Develops theory from qualitative data	Describes, interprets and seeks to understand a cultural or social group	Develops an in-depth understanding of a single case or multiple cases	Aims to deal with real world problems and integrates change and evaluation into the research process
Type of research question	Questions about the life experiences of an individual and how they unfold over time	Questions about what is at the essence that all persons experience about a phenomenon	Questions about experiences over time or changes that have stages and phases	Questions about culture, group dynamics, social interactions and how these provide insight into issues	Questions about developing an in-depth understanding about how different cases provide insight into an issue or a unique case	Questions about how changes occur in a community
Data collection	Long, extensive interviews with few individuals and document analysis (for example diaries)	Interviews with approximately 10 people	Interviews with 20-30 people to reach saturation and detail a theory	Observations and interviews with people, analysis of physical artefacts . characterised by extensive time in the field (6-12 months)	Multiple sources . document analysis, interviews, focus groups, analysis of physical artefacts, observations	Interviews and focus groups with key people and stakeholders who may be able to bring about change. Intervention designed and evaluated throughout process.
Data analysis	Stories Epiphanies Historical context	Statements Meanings Themes General description of the experience/ phenomenon	Different levels of coding . open, axial, selective Conditional matrix	Description Analysis Interpretation	Description Themes Assertions	Descriptions Intervention planning Evaluation
Narrative Form	Detailed picture of an individuals life	Description of the essence of the experience	Theory or framework	Description of the cultural behaviour of a group	In depth study of a case or cases	Problem solving Change making

adapted from Creswell and Clark – Principles of Qualitative Research – Designing a qualitative study (2004)

Narrative Research

What is it?

Narrative research is the process of studying one or two individuals through collecting data from their stories and experiences and ordering the meaning of these chronologically (Creswell, Hanson, Clark Plano & Morales, 2007). There are a number of different forms of narrative research. A biography is a form of narrative where the researcher writes about the life experiences of another person. An individual who writes about their own life and experiences is said to have produced an autobiography. Life histories is the telling of a persons entire life, whereas a personal-experience story is the telling of a persons experience in a single or multiple episodes . for example, encounters with health professionals. Narrative research may take a contextual focus, for example the narrative is embedded within a particular organisation or community which influences the story. Narrative research may also draw upon a theoretical or conceptual lens . for example, the stories of women using a feminist lens to highlight how their voices are muted, multiple or contradictory (Creswell et al, 2007).

When is it used?

Narrative research is used when detailed stories help to understand the problem or issue (Creswell et al, 2007).

Key features:

Narrative research usually consists of extensive and lengthy interviews with the participant. The interview lacks structure and is driven more by the participant. The researcher actively listens and guides the participant in the telling of their stories. Chronology of the story is important to capture, and the researcher may examine diaries or other documents to assist in this process (Creswell et al, 2007). During the research process, the researcher actively collaborates with the participant to ensure their story is being represented accurately and in chronological order (Creswell et al, 2007).

Example 1: Narrative Research

A narrative research example: 'We don't have a box': Understanding hidden disability utilising narrative research methodology. *Disability Studies Quarterly* 2010*:* 30(3/4).

Aim: To understand the identity processes of six adults who grew up with unapparent physical medical conduction.

Data collection: Two hour face-to-face guided conversation . 'tell me about what your life has been like living with your condition, from the beginning' Participants were emailed transcripts and were given the opportunity to add or delete aspects of their narrative.

*Sampling technique***:** Purposive and snow ball sampling

Participants: three men and three women aged between 21 and 53

Analysis: Researcher communicated with participant via email, telephone or face-to-face to gauge reactions to the transcript and their responses to the preliminary findings the researcher was developing. Research guided by the questions 'How does an unapparent medical condition affect identity?' and 'How are self-disclosure decisions negotiated?'

Key findings:
- Participants spoke of flexible identities that could not be classified into a box and that they travel in and out of identity categories . this was conceptualised as *bi-ability* . the ability to travel between two worlds of health and illness
- Identities are complex and influenced by multiple factors of family, gender, religion, culture, education and socioeconomic status which interconnect, overlap and confound each other
- Participants talked about learning to live in grey areas . developing unique strengths, adaptation and resiliency while acknowledging the challenges of living with a disability

Phenomenology

What is it?

Phenomenologist highlight the individual life world . the experiences, beliefs, attitudes, perceptions and meanings, values, feelings and emotions of the individual. Phenomenology seeks to understand, describe and interpret human behaviour and the meaning individuals make of their experiences in order to understand the 'essence' of the experience (Creswell et al, 2007).

When is it used?

Phenomenology is a powerful method to explore subjective experiences, explore the motivations and actions of people, and attempting to understand the 'taken-for-granted' assumptions about human behaviours and experiences (Lester, 1999).

Key features:

Phenomenology is suited to small scale research. The description of experiences can tell an interesting story. The most common data collection method is in-depth interviews (see section on data collection for further information). There are two types of phenomenology: descriptive and interpretive/hermeneutic (Creswell et al 2007).

- Descriptive phenomenology is the study of the way 'things' appear to understand essential human consciousness and experience.
- Interpretive/hermeneutic phenomenology focuses on describing the meanings attributed by individuals.

Example 2: Phenomenology

A phenomenology   example: ±iving Positively: The Experiences of Thai Women Living with HIV/AIDS in Central Thailandq. Qualitative Health Research 2012: 22(4): 441-451

Aim: To examine the lived experiences of women living with HIV and AIDS

Data collection: In-depth interviews with some participant observation

Sampling technique: Purposive and snow ball sampling

Participants: 26 Thai women with HIV or AIDS

Analysis: Thematic

Key themes associated with living positively – dealing with the illness:
- Taking care of self
- Accepting faith
- Disclosure to family members
- Joining AIDS support groups

Grounded Theory

What is it?

Grounded theory is a research design which aims to build theory from the ground up. Hence, grounded theory is both a "method of inquiry and the product of inquiry" (Charmaz, 2005). Grounded theory arises from the inductive study of the phenomenon of interest through qualitative research methods, and is "an iterative process in which the researcher becomes more and more grounded; in the data and develops increasingly richer concepts and models of how the phenomenon being studied really works" (Ryan & Bernard, 2003, p. 279).

When is it used?

It is often utilised when little is known about a topic or phenomena. The focus is on discovering concepts that explain social processes, actions and interactions rather than a full description of what is happening. This is what forms the basis of the theories which are generated systematically through research and discovered from data rather than hypothesised and tested against data (Liamputtong, 2009).

Key features:

Researchers should make sure that they have no preconceived theoretical ideas before starting the research and should make sure that they do not impose concepts onto the data . concepts should emerge from the data (Creswell et al 2007). Grounded theory uses interviews and observations to build theories about social phenomena (Kuper et al 2008).

NOTE:

Grounded theory is a process predominantly adopted by academics and is not well suited to community researchers due to the rigour and extensive theoretical analysis required. It is recommended that an academic experienced in grounded theory research is consulted if this is the desired approach for the exploration of a social issue.

Example 3: Grounded Theory

A Grounded theory example: Patient participation in nursing care from a patient perspective: a Grounded Theory study. *Scandinavian Journal of Caring Sciences* 2007; 21(3): 313-320

Aim: To explore the meaning of patient participation in nursing care from a patient point of view

Data collection techniques: Six focus groups with 26 Swedish informants. Informants were a combination of inpatient and discharged patients from somatic inpatient care

Data analysis: Constant comparative analysis

Findings: The patients emphasised the importance of collaboration to improve participation. Four categories were identified: (i) Obliging atmosphere; (ii) Emotional response; (iii) Concordance; and (iv) Rights and their 15 subcategories

Ethnography

What is it?

Ethnography aims to understand the meanings and behaviours associated with the membership of groups, teams, organisations and communities (Kuper et al, 2008; Reeves et al 2008). Ethnographic studies provide rich, holistic insights into the views and actions of people as well as the context of the setting or location through detailed observations and interviews (Reeves et al 2008).

When is it used?

Ethnography can be used in a variety of settings. In relation to the health system, it can provide rich and detailed descriptions of the professional and inter-professional relationships of clinicians, clinician interactions with patients, approaches to delivering care, as well as in-depth accounts of patients care experiences.

Key features:

Ethnography is characterised by the collection of participant observation which requires direct engagement and involvement with the setting, group, team, community they are studying (Reeves et al 2008). For example, this may require the researcher to become a volunteer at the organisation under study (Carey, Braunack-Mayer & Barraket, 2009). Ethnographers generally take extensive field notes to record observations and reflect on the complexity of what they are observing. Ethnographers also strive to be unobtrusive and therefore interviews tend to be casual in nature. Documents relevant to the research are also analysed such as meeting minutes, diaries and photographs (Reeves et al 2008). Because of the relationship between ethnographers and participants, reflexivity is the central part of the ethnographic process (Reeves et al, 2008). Reflexivity requires the researcher to reflect and be aware of the effect they have on the process and outcomes of the research. In qualitative research it is impossible to remain subjective and situate oneself outside of the subject matter. Additionally, the presence of a researcher in a setting or during data collection will have some type of effect and this needs to be acknowledged (Anderson, 2008). This is typically described in the field notes where the researcher will reflect on their own beliefs, values and background and how this influences their conduct in the research as well as how participants (and non-participants) react to them.

Example 4: Ethnography

An Ethnography example: "Assessing the promise of user involvement in health service development: ethnographic study" *BMJ* 2008 Feb 9; 336 (7639): 313-317

Aim: To understand how the policy of user involvement is interpreted in health service organisations and to identify facts that influence how user involvement is put into practice

Setting: Stroke services serving ethnically diverse populations in two London boroughs. These stroke services have recognised that they have not been meeting the needs of patients and families. In 2004 a three year program of service improvement was initiated which aimed to reduce the incidence of first time strokes and to improve acute and community stroke services.

Data collection techniques:
Participant observation:
- meetings (management, training, information group, user involvement subgroup, recruitment, planning)
- training sessions
- events at general practices to increase awareness of stroke
- join in events for potential participants and family members
- program conference

Semi-structured interviews:
- 7 interviews with people who did not participate in the program
- 9 interviews with people taking part in the program
- 3 interviews with professionals working with service users (2 program staff and 1 GP).

Documentary evidence:
- program newsletter
- program documents
- minutes from meetings (management group, user involvement subgroup, information group, training group)

Field notes and reflexive diary

Sampling: Purposive
Participants: Service users, clinicians, National Health Service managers
Analysis: Thematic analysis
Findings: User involvement occurred most often in less technical aspects which required the least input from clinicians. This may be due to organisational structure, a lack of understanding of the concept of user involvement, the value attributed to service users' experiential knowledge, and variations in professional and service user understandings of and commitment to involvement. The benefits of user involvement were described, such as personal gains for those involved, a sense of satisfaction of feeling listened to by professionals, social opportunities of meeting others in a similar situation, and increased knowledge about stroke and services available.

Case Study Research

What is it?

Case studies explore contemporary phenomena in-depth within real life contexts (Yin, 2009) to address research questions which commence with a how or why, with the ±caseqranging from individuals, organisations, processes, programs, neighbourhoods or events (Yin, 2009). While some researchers describe case studies as a method, others refer to the case study as an %approach+(Stark & Torrance, 2005; Yin, 2009). A case is studied in its real life context, and therefore a number of variables are explored and thus a combination of evidence sources and research methods are used (Yin, 2009).

Case study research is often described as an approach to qualitative research as opposed to a specific design. This is because it draws on a number of different designs. The goal of qualitative case study research is to explore a phenomenon within context through providing an in-depth account of events, relationships, experiences or processes.

When is it used?

Yin (2003) outlines four main points for choosing when to use a case study:
1. focus of the study is to answer how and why questions
2. cannot manipulate the behaviour of those involved in the study
3. contextual conditions are relevant to the phenomenon under study
4. boundaries between phenomenon and context are not clear

For instance, a study of the decision making of nursing students conducted by Baxter (2006) sought to determine the types of decisions made by nursing students and the factors that influenced the decision making. A case study was chosen because the case was the decision making of nursing students, but the case could not be considered without the context, the School of Nursing, and more specifically the clinical and classroom settings. It was in these settings that the decision making skills were developed and utilised. It would have been impossible for this author to have a true picture of nursing student decision making without considering the context within which it occurred.

Key features:

There are two types of case studies . discovery led and theory led.

Discovery led case studies include:

- Description . describes what is happening in the case study setting
- Exploration . explore the key issues affecting those in the case study setting
- Comparison . compares settings to learn from the similarities and differences between them

Theory led case studies include:

- Explanation . explains the causes of events, processes or relationships within a setting. Can be used for evaluations
- Illustration . uses a case study as an illustration of how a particular theory applies to a real life setting
- Experiment . use a case study as a test bed for experimenting with chances to specific factors or variables

Within these types – case studies can be:

- Single case e.g. Decision making of one woman regarding reconstructive surgery post mastectomy
- Single case with embedded units e.g. Decision making of women attending different clinics at the same hospital
- Multiple case studies . decision making of women across multiple health care facilities
- Intrinsic . unique situation
- Instrumental . insight and understanding of a particular situation or phenomenon

Determining the unit of analysis (case). The most difficult aspect of case study designs is determining what the case is.

A case can be:

- A person
- A program
- An organisation/group
- A process (eg decision making)

Example 5: Case Study

A Case Study example: The impact of consumer involvement in research: an evaluation of consumer involvement in the London Primary Care Studies Program. Family Practice 2008: 25: 154-161

Aim: To evaluate consumer involvement in the London Primary Care Studies Program (LPCSP) and understand what impact consumers had on the research process and outcomes.

Setting: 11 primary care-based project when combined make the LPCSP

Data collection techniques: Multi-method case study
- surveys (61 completed by academics and service users)
- semi-structured interviews (44 consumer, academics and service users)
- focus groups (2 consumers, academics and service users)
- observations (15 hours)
- document analysis

Analysis: The projects . 11 different units in this analysis

Findings: Nine projects had consumers as co-applicants. Consumers that were involved in the research process were involved in the initial design of the study, recruitment, developing data collection tools, collecting data and in the analysis and dissemination of findings. This demonstrates that the involvement of consumers in research impacts the research process and outcomes.

Action Research

What is it?

Unlike other qualitative research designs, action research incorporates a call for change and integrates education and social action to improve health and reduce health disparities (Wallerstein & Duran, 2006). Also termed participatory action research or community based participatory research; it typically involves an intervention or ±actionqof some type to address the identified issue. The framework for action research combines activism with systematic and rigorous research to achieve social justice goals (MacKinnon, 2009).

When is it used?

Action research is conducted *for* and *with* communities, not on or about communities. This research approach values empowerment and is solution focused with the knowledge and experience of community members being an important part of the process. Hence it is often used in community, public health and government advocacy efforts.

Key features:

Researchers and community members are involved in planning and carrying out the research, analysing, reporting and acting on the findings (Kuper et al, 2008; Creswell et al 2007). Researchers build community capacity by sharing knowledge of how to do research. The researchers are committed to social change through practical or policy outcomes. Primary forms of data collection include interviews, focus groups, document analysis and participant observations are common data collection methods (Saldana, 2009). Action research is a cyclical process as it involves a feedback loop where initial findings generate possibilities for change which are then implemented and evaluated as a prelude to further investigation.

Wallerstein and Duran (2006) discuss some of the key challenges and considerations required when undertaking action research. These points have been summarised in dot points below and should inform both the development and practice of action research:

- What is community participation? Who is participating? Who is excluded? Whose interests are being served? In which aspects of the research are they participating? Who has control?
- Degree of involvement . is the involvement of community members nominal or

comprehensive throughout the whole research process?

- Community consent . who represents the community? What is the process of gaining access to the community and permission to undertake the research? Who needs to be involved?

- Power relations . need to consider the role of power and privilege in the research process. Researchers are often perceived by the community has being experts.

- Race, Racism and Ethnic discrimination . is there fair representation of different cultural and ethnic groups. How has this been facilitated to ensure safe and positive interactions with others?

Example 6: Action Research

An Action Research Example: Having a yarn about smoking: Using action research to develop a ±no smokingqpolicy within an Aboriginal Health Organisation. Health Policy 2011 . 92-97.

Aim: To develop a smoke free workplace policy within VACCHO (Victorian Aboriginal Community Controlled Health Organisation).

Data collection:

Warning . ±a process that requires the researcher to develop and build relationship that is accountable to Indigenous people participating in the researchq(Bessarab and Ngqandu, 2010. p 38). Yarning is an informal process and participants are able to take the conversation where they wish without feeling like they are being interviewed (Fletcher et al, 2011):

- informal yarns between project officer and VACCHO staff members (both smokers and non-smokers)

- ±etqs yarn about smokingqdrop in sessions . all staff invited to attend

- ±etqs yarn about smokingq for managers . once the draft policy had been developed to explore manager response to policy

- meeting notes kept and circulated via organisation email to allow staff to comment/contribute anonymous online survey

CHAPTER 2: COLLECTING & ANALYSING QUALITATIVE DATA

2.1 Collecting data

Once you have decided on your research design, the next step is to go out into the field and collect data to answer your research questions. Before embarking on this activity, there are a few factors to consider about how you will collect your data and what may influence the way you collect this data.

The role of the researcher

In qualitative research, the researcher is the principal data collection tool. The researcher is the person(s) responsible for deciding on which questions to ask, observing the individual and setting characteristics in participant observation and conducting the interviews and focus groups. Therefore, the background, expertise, values and attitudes of the researcher will influence the research design and conduct and needs to be acknowledged throughout the research process.

Human perception is subjective. Our observations of the world, people, events and circumstances are influenced by our interests, biases, culture and background (Patton, 2002a). Insider research is a term used to describe when the researcher is directly involved in or has connection to the research topic or setting. The researcher may share participantsqidentity, language and experience (Dwyer & Buckle, 2009; Kouritzin, Piquemal, & Norman, 2009). Insider research contrasts to ±outsider researchqwhere the researcher is not familiar with the participants or setting. Being an inside researcher has advantages and disadvantages.

Advantages	Disadvantages and cautions
• faster and more complete acceptance of the researcher by the participants, which may allow a greater depth of data to be collected (Dwyer & Buckle, 2009) • greater knowledge of the setting and the processes within the setting (Asselin, 2003) • an understanding of the culture of the setting; and the ability to ascertain the accuracy of responses to questions (Hockey, 1993)	• the tendency of the researcher to believe that they know the culture of the setting, population or community, and so fail to question its underlying premises or to view the setting from a different perspective (Asselin, 2003) • difficulties associated with the possibility of the objective collection and analysis of data; the perceptions, expectations and concerns about confidentiality by the study participants which may influence how and what the participant divulges (Asselin, 2003) • role confusion where the researcher may step into the role of the participants under study (Asselin, 2003)

The role of consumer researchers

Consumer led research (also referred to as user-led research) is where consumers are involved in all stages of the research process: design, recruitment, ethics, data collection, data analysis and dissemination (Rose, 2003). Collaborating with consumers in the research process is a valuable process, however can also be complex. Consumers can contribute insider knowledge and expertise, provide feedback about the appropriateness of the research methods and increase mechanisms of dissemination to the consumer population. Evans and Jones (2004) propose a continuum of consumer engagement and empowerment in the research process *(see Figure 1)*.

Figure 1: A continuum of user engagement and empowerment (adapted from Evans and Jones, 2004)
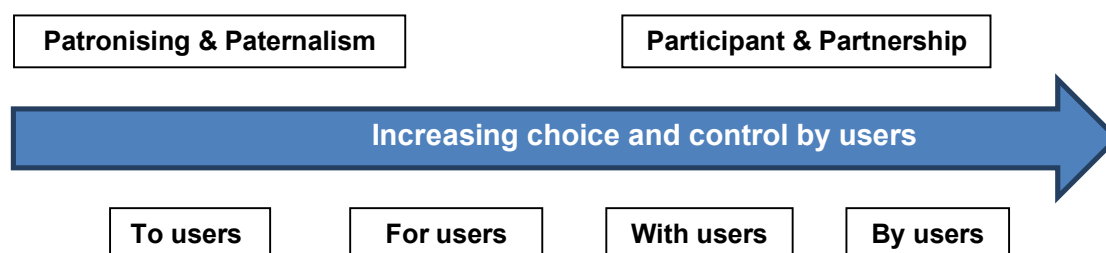
It is important to ensure that consumer involvement in research is not tokenistic and positioned at the left of the continuum. The process of involving consumers is influenced by power relationships. As Holman (2001) writes "Researchers have power— decisions about the nature of research are made by powerful agencies and rarely by the users of social services"(as quoted by Evans and Jones, 2004, para 15).

Building on *Figure 1,* Truman and Raine (2001) developed a table outlining different levels of participation by consumer researchers and how this may translate into research practice.

Mode of participation	Nature of consumer involvement	Relationship between researcher and consumer
Co-option	Token: representatives are chosen, but no real action	**ON**
Compliance	Tasks are assigned, with incentives researchers decide agenda and direct process	**FOR**
Consultation	Consumer opinions asked, researchers analyse and decide on a course of action	**FOR/WITH**
Co-operation	Consumers work together with researchers to determine priorities. Responsibility remains with researchers for directing process	**WITH**
Co-learning	Consumers and researchers share knowledge to create new understanding and work together to form action plans with researcher facilitation	**WITH/BY**
Collective action	Consumers set their own agenda and mobilise to carry it out without outside researchers or facilitators	**BY**

Source: Truman, C. and Raine, P (2001) 'Involving Users in Evaluations: the Social Relations of User Participation in Health Research', Critical Public Health, 11(3): 215-229

Practice Box 3

To determine whether research is being conducted in a manner which promotes and includes consumer involvement . the following questions can be asked (Evans and Jones, 2004; Brown and Vega, 2008)

1. How will the research processes and outcomes serve the community?
2. Will consumers (community members) be hired?
3. Will consumers be trained in research methods?
4. How does it address long term needs?
5. Who identifies and defines the issue or topic to be studied?
6. Who identifies and defines the questions to be asked?
7. Who determines the methodologies to be used?
8. Who undertakes the research and collects the data?
9. Who is responsible for data management?
10. Who is involved in analysing and interpreting the data?
11. Who decides what conclusions should be drawn?
12. Who decides how to present the research findings?
13. Who draws the lessons for policy and practice?
14. Who follows through to see action results?
15. What perceptions about the community are likely to be created or persist as a result of analysis and publication of the findings?
16. Will confidentiality be compromised as a result of making the research findings public?

Selection and sampling of participants

The participants you select for your study must be able to answer your questions and therefore selecting the right participants is very important. Sampling methods in qualitative research do not seek to be generalisable i.e. applied to the whole population under study. Four main types of sampling are usually utilised in qualitative research:

Table 2: Qualitative sampling techniques
(Liamputtong, 2010; Family Health International, 2009)

<table>
<tr>
<th colspan="2"></th>
<th>Definition</th>
<th>Example</th>
</tr>
<tr>
<td rowspan="4">Sampling Technique</td>
<td>Purposive sampling</td>
<td>Deliberate selection of certain individuals, events or settings.</td>
<td>Research that is looking at how patients with chronic fatigue cope with their symptoms through acupuncture . instead of randomly selected patients with chronic fatigue, you would be select patients with chronic fatigue who get acupuncture.</td>
</tr>
<tr>
<td>Snowball sampling</td>
<td>This method is used when members of the research population are difficult to locate, such as homeless individuals, migrant workers, undocumented immigrants. Participants or informants involved in the study are asked to use their networks to refer the researchers to other people who are eligible to participate in the study.</td>
<td>Nickasch & Marnocha (2009) conducted a study which explored the healthcare experiences of homeless individuals. The researchers contacted a key informant from a local community clinic who introduced the researcher to two potential participants. One of these participants agreed to take part in the study and was able to refer other eligible individuals to the researcher.</td>
</tr>
<tr>
<td>Convenience sampling</td>
<td>Individuals who are conveniently available and willing to participate in a study.</td>
<td>Shoppers entering a particular supermarket between 10am and 12pm asked for their opinion about a product. This sample of shoppers is easy to access, however they may not be representative as people who shop at that store at that time may be different from people who shop at other stores or other times.</td>
</tr>
<tr>
<td>Quota sampling</td>
<td>A matrix detailing how many people with certain characteristics are required in the study. These characteristics may include age, gender, class, marital status, health/disease status, place of residence. This matrix enables the researchers to focus on people who are most like to have insights about the research topic.</td>
<td>Aubry et al (2012) used quota sampling in their study examining the housing trajectories of different homeless populations. Participants were recruited to represent the groups of homeless adult males, homeless adult females, homeless youth males and homeless youth females.</td>
</tr>
</table>

How many participants do you need?

The question of how many participants are required for a qualitative research study is not straightforward. The research is not designed to be generalisable and therefore strategies used to determine sample size in quantitative research are not applicable. Qualitative researchers talk about the concept of theoretical saturation which is where no new information is being gleaned from the data collection. Guest (2006) found that this is generally achieved with at least 12 participants. However, in determining the appropriate number of participants the following should be taken into consideration:

- The research question
- The sampling method being employed
- The research population size
- The accessibility of your population group
- The sensitivity of the topic . the more sensitive the harder it is to get participants who are willing to talk about it

Recruitment

Access to participants

Access to participants can be undertaken via a range of strategies . some formal (health services recruitment, schools recruitment) and some informal (friendship networks, facebook).

Advertising for participants

Advertising for research participants is a common approach, particularly in the areas of clinical research. This is often done through placing advertisement flyers or posters in strategic places such as hospital waiting rooms, libraries, health centres, churches and shopping centres. Radio and newspaper advertising is also a strategy that is used. Ethics committees tend to preference this route of gaining access to participants as there is less chance of coercion (Liamputtong, 2009).

Gatekeepers

Gatekeepers can be used to distribute information sheets or flyers to potential participants. For example, a doctor not involved in the research, can provide information about research projects to their patients (Liamputtong, 2009). However, there are concerns about this strategy in relation to coercion and power imbalances between the potential research participant and the gatekeeper. See *Section 3* for more information on ethics and research.

2.2   Data collection techniques

Traditional methods

Interviews

Interviews are a method of collecting data about the social world of individuals by asking them to talk about their lives, experiences, thoughts, and beliefs in depth. An interview is more than a conversation, as it requires a degree of skill by the interviewer in knowing strategies to elicit in depth and accurate information (Liamputtong, 2009). When compared to other methods of data collection, interviews increase the rapport between researchers and participants. Manderson and colleagues (2008) report how the process of participating in an interview can be of therapeutic benefit, as the researcher asks questions which may not have been posed to the participant before . particularly around their experiences and thoughts about life events. Interviews also allow researchers to clarify the interpretation of responses immediately, which increases the validity. There are two main interview styles that are adopted in qualitative research. These are briefly outlined below.

Semi structured interviews

These interviews are used when very specific answers are sought for specific questions (Leech, 2002). Semi-structured interviews are generally organised around predetermined open ended questions which are properly worded (DiCicco-Bloom & Crabtree, 2006). The interviewer however, still has flexibility to probe and prompt the participant beyond this interview schedule to ensure clarity and that the topic is explored fully.

In-depth interviews

In-depth interviews are usually face-to-face and involve one interviewer and one participant. The researcher aims to elicit the participant's perspectives on the research topic. These interviews are a useful method for asking people about their thoughts, feelings, opinions or experiences, particularly for sensitive or personal topics. The participant is seen as the expert and the interviewer as the learner (Family Health International, 2005). In-depth interviewers tend to use a 'theme list' of areas to explore with the participant as opposed to exactly worded questions which are used consistently in each interview. Hence questions may vary in wording and order from interview to interview, however this is acceptable as long as the main concepts are covered.

Sample interview transcript – semi-structured interview

Interviewer	Respondent
Interview from the COACH Community Mentoring Program Evaluation – Research conducted by Ayton	
How did you become involved in the COACH program?	This is testing my memory now! What bought it about is that I was looking for some support with my daughter, just being able to get out into the community to do activities and things like that...and I forgot how we got onto it...I think another service provider mentioned that there was an upcoming program called the COACH program which didn't necessarily fit exactly my criteria but would be able to provide me with some support to do some outside activities with my daughter. Due to my disability, cerebral palsy, having my daughter, she was about 6 months old or 7 months old when we first started the program and she was getting to the stage where she wanted to do more activities and be more active and for me that's a bit difficult in my situation. So I was looking for some more support programs. Originally I started looking in the area of disability because that's what I have, cerebral palsy, but there was nothing available so that's how I came about the COACH program to assist me in activities and parenting.
When you initially started meeting with your mentor, what did you do when you met?	Probably the first few sessions it was...they are couple...I suppose you would say elderly couple but they are very active, I think they are in their 70's and very involved in the community. The first few times I just met with the wife who is absolutely lovely...I met with her in my home and we played with [my daughter] on the floor and did some floor play which is what they do at that age. We met at home a few times just to get to know each other and build up a rapport and that sort of stuff. And then we started going out to mother's group so she would assist me with my daughter in going to mother's group. She would stay with me for the first few sessions just so I knew what was expected and if I had to do anything extra with [my daughter] she was there to help me. She provided a lot of support and she was good at giving advice and she was also happy for me to build upon my own mother's skills. And we went to the park and just really...got out and about more which was really what I wanted because at the time I wasn't able to do that with [my daughter]. When you go out with a baby you have to pack a lot of stuff, I can't drive and so that was definitely a benefit to go to local places with [my mentors].
Can you give me an example of what kind of advice they would give you?	Oh um...so [my daughter] was getting to the stage of being in between lying on the floor and crawling and they would give me advice on sort of what to watch out for and what to expect and not to worry if she was a little bit behind because she was a premmy baby....just...other than those general things...just general...like when I used to heat her bottles up I used to do it the old way in water and not the microwave where a lot of new mums do it in the microwave. Personally I don't like to use the microwave for the bottles and when we talked about that, I can't really think of anything beyond the general stuff. It was just everyday stuff that impacted our lives, I mean it would not be significant to others, but at that time but you are very focused on your little one and all the different things that you have to learn and it was really good to have that positive reinforcement, like am I doing the right thing and [my mentor] would be, yeah yeah yeah. And then [my daughter] would get colds and things and I would be worried thinking am I not giving her enough vitamins and [my mentor] would reassure me that it's important for them to get lots of colds at this time of their lives because it builds their immune system. Positive reinforcement of things I already knew and that reassurance.

Theme list for an in-depth interview
NHMRC Funded Research by Dr Narelle Warren, Monash University

Sociodemographic information (date and country of birth, household composition, education level, occupation, religion, have a health care card?).

Start with their story about their illness . understandings of causation, what event triggered this off? What led up to it? What were they going through at the time? What was it like for them?

How did this impact upon their family?

What are the main concerns for them . now and in the future?

Understandings of prognosis - do they have any fears? Concerns? Contingency plans?

How do they manage their condition (e.g. bodily management, medication regimes, etc) on an everyday basis? Where do they access information about their condition?

How did they access care? Who provides them with formal and informal care? Do they receive support from other members of the community? How were decisions about care and support made? Probe on the social, cultural and economic factors that may have influenced this decision.

Focus groups

Focus groups are focused discussions involving four to 12 participants facilitated by a researcher or moderator. The participants share particular characteristics (e.g. working for the same company, mothers, patients undergoing chemotherapy) and the discussion is focused on a specific topic (e.g. the work environment, parenting identity, challenges of treatment). The conversation is usually audio or video recorded for later transcription (Hollander, 2004). Whilst focus groups were originally developed as a means for gathering individual information quickly, they are now used as an analysis of group dynamics and social context (Hollander, 2004). The researcher can fade into the background and allow the participants to drive the discussion, responding to the comments and thoughts of each other (Hollander, 2004).

Group interactions bring out different data (experiences/perspectives) when compared to individual interviews, and these interactions will vary depending on whether the group is homogenous (e.g. female year 9 students at a school) or heterogeneous (e.g. patients undertaking cancer treatment from different ages, gender and ethnic backgrounds) or friends or strangers. Focus groups are used when little is known about either the participants or the topic, when researchers want to test ideas or the acceptability of a new program and as a means of triangulating the data.

Focus groups however, may give rise to what is termed problematic silences and problematic speech. Problematic silences is when participants do not share their true thoughts or experiences with the group and problematic speech is when participants offer opinions or information that does not represent their true beliefs or experiences (Hollander, 2004). The participants can be influenced by groupthink and social desirability. However, focus groups can help participants break their silence when they understand that their experiences are shared by others. It can be a way of validating their feelings and opinions.

Participant observation

Participant observation is the process researchers undertake to learn about the activities and setting of the people under study through observing and participating in those activities (Kawulich, 2005). Reeves and colleagues (2008) highlight nine dimensions to observe and document when undertaking participant observation:

Table 3: Participant observation – dimensions to observe

Space	The physical layout of the place(s). This can be done through drawing diagrams of, for example, the room layout or the building plan or the streetscape.
Actor	The range of people involved. It is important to take note of the different players involved, including their power relationships between each other.
Activity	A set of related activities that occur . for example during the course of observing a mothers group what different activities were run during the morning including morning tea, free play time with the children, a speaker event for the mother.
Object	The physical things that are present . for example, what brochures and information packs are available for patients at a doctors waiting room.
Act	Single actions people undertake . for example, someone making tea.
Event	Activities that people carry out
Time	The sequencing of events that occur
Goal	Things that people are trying to accomplish
Feeling	Emotions felt or expressed

Keeping a research journal and field notes

Keeping a research journal and field notes is important for increasing the quality of analysis. It is important to write immediately after interviews and observations. You may wish to comment on:

Interaction

- What was the rapport like?
- What was the exit like?
- How ±qfelt
- Describe participant
    → How did they =seeqyou?
    → Sense of participants feelings
        o Setting - describe the scene of the interview like a play script
        o How the researcher might have influenced or affected the content and process of the interview
- Links to other work, theories or research
- Things to note that need to be followed up on . emerging concepts that you want to discuss in other interviews or forms of data collection

Emerging methods

Qualitative research methods are continually evolving to reflect changes in social processes and phenomena. Methods need to be adapted and created that best explore the phenomena under study. Below we outline a number of emerging methods . photo-elicitation, video diaries and social networking sites.

Photo-elicitation uses photographs to help explore aspects of life or experiences. It is a method that has predominantly been used in research where participants are children or young people. Smith et al (2012) used this method to evaluate school-based outdoor education programs. The photos taken by participants were used to understand their experiences as the participant has control of what and how they photograph their experiences. The participants are also asked to provide an interpretation of the photograph to the researchers which provides insight into the people, places and things associated with the experience. The participants were secondary school students who attended a three day outdoor education camp. The students were provided with cameras and asked to take photos to show =what school camp was like for themq and were provided with the following scenario to help explain the process:

> *Pretend you are going to post the series of photos you take on your personal webpage (for example, Bebo, MySpace or Facebook), so you can show your friends what your time at school camp was like for you. I am interested in what school camp was like from your point of view. These photos may be of anything, as long as they show something about what school camp is like for you.*

The students participated in an interview where they were asked to describe and discuss the photos they had taken and the meanings associated with them. This method of data collection is not one that can stand alone as it is important to engage in a =descriptionqphase with the participants. With mobile phones being equipped to take photos, this form of data collection can be efficient and cheap while offering the opportunity to capture the day to day events of an individualos life.

Video diaries are similar to written diaries whereby information about participants is collected over a period of time. The participants are supplied with a video camera and are asked to conduct a daily camera session where they share information regarding their feelings, reflections and other aspects of their day (Buchwald et al, 2009). This type of data collection is not common, however it has been used in research involving children. Buchwald and colleagues use video diaries in their research with children and highlight some of the opportunities and challenges. Opportunities include not requiring the child to write, which some may find difficult or time consuming when trying to convey their feelings and experiences. Video diaries provide access to non-verbal data that can be reanalysed after the data collection encounter. Also, children are increasingly becoming more comfortable with technology and are provided an opportunity to engage in a research experience that may otherwise have been more challenging. Limitations of this method include ethical concerns of being able to identify participants and how the images/video will be used after data collection. The researcher is unable to probe or prompt during the interview, and participants are able to prepare themselves for the interview and may therefore put on an act in front of the camera (Buchwald et al, 2009).

Social networking sites have grown in popularity in the last decade. Facebook users now number approximately 1.23 billion people worldwide with nine million Australians accessing Facebook daily (Ross, 2014). Social networking sites can be useful for researchers for the following reasons (Murthy, 2008):

- They are virtual ±gatekeepersqwith access to ±friendsqwho are potential research respondents
- They contain large amounts of multimedia materials by even marginal social movements or groups
- Researchers can observe the social interactions of page members unobtrusively
- Pages can be created by researchers for the explicit purposes of data collection, research and dissemination
- The hierarchies, structures and interaction of online relationships can be monitored and analysed
- Users of social media post about significant life events and day to day activities and interact with each other via comments, posts and ±ikesq

Williams and Merten (2008) explored the content posted and interactions occurring on an online social networking site to understand adolescent development and wellbeing. The content of 100 profiles by adolescents aged 16 to 18 was coded with themes of family and social issues, risk behaviours, disclosure of personal and private information and peer interaction being identified. Wilson and colleagues (2009) examined how young people used social networking sites to determine the different types of people that use the sites. The study aimed to predict the use of social networking sites and addictive tendencies based on personality characteristics and self-esteem. The study found that extroverted and unconscientious individuals reported increased use of social networking sites and addictive tendencies.

As demonstrated by these two studies, the analysis of social networking sites provides insight and understanding of how young people are engaging with this medium, and the impact it has on their mental and physical wellbeing. A limitation of this method is that it excludes those who do not access these sites, computers or internet access. However, it may increase access to those for who mobility is an issue and participation does not require face-to-face contact with a researcher (Murthy, 2008). This method is best used when the research aims to examine phenomena that is captured in social media. Ethical cautions have been highlighted in the use of social media in relation to informed consent and the use of ‑publicallyq available data.

2.3   Analysing data

Qualitative research data is produced in the form of interview transcripts or observational field notes (Pope, Ziebland and Mays 2000). Analysing this data requires a systematic process in order to interpret important meanings and answers to the research question(s) (Ezzy, 2002). Data analysis can be time intensive and laborious, therefore it is important to have a clear plan of action. Data analysis commences when the researcher first becomes familiar with the data to form a continuing and cyclical process of analysis. Qualitative data analysis does not occur in one sitting, instead the researcher immerses themselves in ‑storyqemerging from the field notes and transcripts generated from the data collection phase.

he process of analysing qualitative data involves ±classifying, comparing, weighing and combining material (obtained during data collection) to extract the meaning and implications, to reveal patterns or to stitch together descriptions of events into a coherent narrativeq(Rubin and Rubin 2005, p201). As the researcher, you must consider the following prior to starting analysis:

- " Aim of your study
- " Research questions
- " Data collection tools
- " Theory or concepts from the literature

The importance of data management

Qualitative research usually generates masses of data. Not all data collected is collected at the same time and in the end some data may not be helpful. Systematic data management is therefore crucial for rigorous analysis.

Practice Box 4: Data management
Data management strategies include:
1. Labelling all materials gathered
2. Saving data electronically or in hardcopy or both
3. Managing transcripts, audio, video, field notes...and your brain
4. Deciding on means of backing up your data

Coding qualitative data

Coding is the process of labelling or tagging a word or short phrase to create themes of understanding from the text (Punch 2005). Liamputtong and Serry (2010) state that coding allows us to:

- retrieve data
- pull together themes
- compare themes
- find patterns
- make conclusions

Coding occurs in different phases creating an ongoing process. There are four phases of coding:

1. *Open (descriptive) coding* – sort and organise the data for further coding. Open coding is the first step in the coding process and it consists of going through a transcript line by line to break down the data.

2. *Focussed coding* – start engaging with codes and determining their relationships

3. *Axial (interpretive) coding* – reassembling and reorganising to abstract themes and understanding. The codes generated from open coding are connected via categories or sub-categories.

4. *Selective coding* – identification of core themes which are linked to theories or concepts

A coding guide is often used in the analysis process, particularly in situations where more than one person is involved in coding the data. This is to ensure consistency and clarity in the coding process. The coding guide can be developed prior to analysis based on concepts and theories from a literature review (deductive codes). The guide evolves through the process of coding with codes being added to further explore issues that emerge from the participants (inductive codes).

To start the coding process (open or descriptive coding), the aim is to sort the data for further analysis (see *Figure 2* for an example of open coding), (Strauss and Corbin 1998). It involves working intensively with your data, reading line by line, identifying themes and categories that seem of interest (Esterberg 2002). During this phase, it is important to remain open to whatever is in the data . never use someone else's pre-established codes, or even your own. From this, you should generate abstract conceptual categories and you will naturally begin to see patterns and commonalities. Punch (2005) lists three important questions you can ask yourself while reading through your data:

" What is this piece of data an example of?

" What does this data stand for or represent?

" What category or property of a category does this piece of data indicate?

*Figure 2: Open coding example – COACH evaluation by Ayton*

Relationship-ex partner

At the moment....trying to stay out of jail. Because I keep breaching the AVO order and um I don't know...I've got all the phone records in my phone but they might not care about all the phone calls I've received...they just care about what I've done wrong. And not caring about the threats and intimidation that I'm getting. I'm worried about that. I was threatened with that again last night. I'm worried that I'm not going to be able to see my son for several months. So it's really hard for me to focus on goals.

Blamed

Victim?

Relationship - son

Threatened

Goals – lack focus

I actually got some work. Just some part time work, three hours a week through the COACH program with [Katie]. So then I lost my any ambition because the depression had hit so hard, I couldn't get out of bed, I can't stop thinking about my son, I can't stop thinking about how to get out of this position and that interfered with it. I'd wish to do some part time work and of course me teeth like you said...

Depression - impact

Part-time work

Relationship - son

Physical appearance

But to learn how to be a better parent because even though I say about his mother, like I don't swear anymore and my son doesn't swear around me unless he is throwing a tantrum and then he apologises later to me. He no longer hurts me like he used to...Where before I've had him kick me in the face several time, punch me in the face, head butt me and make me bleed. Call me maggot because he has heard his mum call me it so many times. Say really degrading things. He doesn't do that any more and he hasn't done it for quite a while.

swearing

abuse

Parenting

Attacked

Relationship - son

Relationship between son and ex

Practice Box 5: What can be coded?	
- Setting and context - Definition of situation - Perspectives - Ways of thinking about people and objects - Process - Activities - Relationships and social structure	- Actions - Events - Conditions - Consequences - Strategies - Meanings

During focused coding and axial coding, you are reading through the data a second and third time where you are working with the codes you have created. You may want to review codes, collapse codes into broader concepts or expand into a greater number of categories (Liamputtong and Serry 2010; Strauss and Corbin 1998).

Finally, selective coding is the process where core themes are identified. This is the last phase of analysis, so at this stage the researcher is drawing conclusions and formulating propositions about the data to answer the research question (See *Figure 3*), (Miles, Huberman and Saldana 2013).

**Figure 3: Axial and selective coding example –
from the COACH evaluation by Ayton**
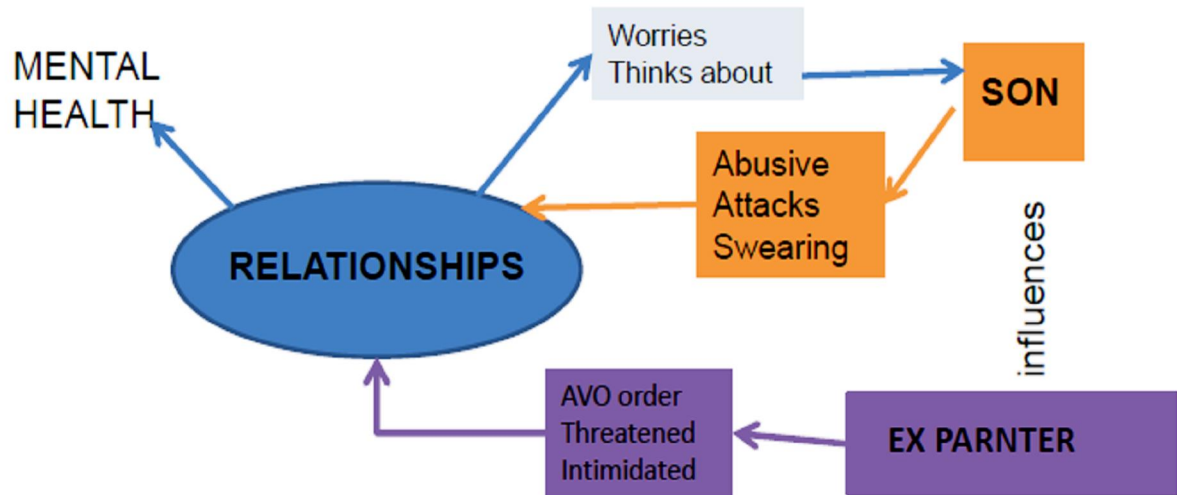
Practice Box 6: Coding Process (Charmaz, 1991)
1. Begin by exploring the general research question
2. Gather data, and code for respondentsqmeanings, feelings and actions
3. Look for processes and relationships between specific events and general processes
4. Coding leads to new categories
5. Collect more data on the developing categories
6. Go back and read earlier data for the new categories and to formulate new questions
7. Constantly compare individuals, different events, and the categories
8. Write memos all the time about categories, processes and ideas
9. Move towards memos that are more conceptual and codes that are more abstract

CHAPTER 3: ETHICAL CONSIDERATIONS FOR COMMUNITY BASED RESEARCH

When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed in regard for their welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.q(National Statement, 2007).

The National Statement on Ethical Conduct in Human Research (2007) is a set of guidelines developed by the National Health and Medical Research Council, the Australian Research Council and Universities Australia (National Statement, 2007). Researchers conducting research with human participants need to operate within these guidelines, and a judgement as to whether a research proposal meets the criteria of the National Statement is required before research commences.

3.1   Values and principles of ethical conduct

The principles and values of ethical research practice are based fundamentally on the principle of respect. In all aspects of the research process, the dignity and safety of people should be upheld including welfare, beliefs, perceptions, customs and cultural heritage of the participants, communities and researchers involved.

Research merit and integrity

Research should not be conducted for the sake of research. The need for research to be undertaken and the potential benefits of the research should be clearly articulated. Potential benefits can include increasing knowledge and understanding and improving social welfare and individual wellbeing. In the area of community based research it is important to consult with relevant communities, to ensure that the research proposed is useful for the community and to ensure that it is conducted in a respectful manner.

Research that is conducted with integrity seeks to improve knowledge and understanding, recognises and follows principles of research conduct, is administered honestly and ensures that findings are communicated to allow

accountability and scrutiny as well as contribute to public knowledge and understanding.

Justice

The principle and value of justice in research relates to the fairness and accessibility of research participation. It is critical that researchers consider whether the exclusion and inclusion criteria for participation is fair and equitable and accurately described when presenting the results of the research.

A researcher must:

1. Avoid imposing on particular groups, who are likely to be subject to over researching, an unfair burden of participation in research (for example twins, people with disabilities).
2. Design research so that the selection, recruitment, exclusion and inclusion of research participants is fair.
3. Not discriminate in the selection and recruitment of actual and future participants by including or excluding them on the grounds of race, age, sex, disability or religious or spiritual beliefs, except where the exclusion or inclusion of particular group is essential to the purpose of the research.

Beneficence

The potential benefits of the research must be greater than any risks of harm or discomfort to the participants. Benefits for the participant can range from the experience of taking part in research, feeling and fostering a sense of hope, identity, relations, being able to contribute to an act of public service, being involved in interventions for health conditions. For the public good, benefits may include increases in practitioner knowledge, identification of determinants of health and disadvantage and the ability to challenge injustice and promote equality. In some cases the participants of the research may not benefit, however the research may provide benefits for others or for the greater public good. In these situations, it is critical that the risk to the participants be lower than would be acceptable if they were to benefit from the research. The design of the study needs to minimise the risk of harm or discomfort and needs to ensure the welfare of the participants in the research context.

> **Risk:** The likelihood that a harm (or discomfort or inconvenience will occur AND the severity of the harm including consequences
>
> **Potential kinds of harm:**
>
> - Physical harm (injury, illness, pain)
> - Psychological harm . feelings of worthlessness, distress, guilt, anger, fear related to, for example, disclosure of sensitive or embarrassing information
> - Devaluation of personal worth
> - Social harms . damage to social relationships, discrimination, stigmatisation
> - Economic harms . direct and indirect costs of participation (taking time off work, transport or child-minding costs)
> - Legal harms . discovery and prosecution of criminal conduct
>
> National Statement pages 15 & 16

Questions to consider:

- Have the risks and benefits of the research proposal been identified and fully evaluated?
- Do the potential benefits justify any risks?
- Does the research project involve an unacceptably high degree of risk to participants in the light of the expected benefits of the research?
- Have participants been adequately advised of the risks and benefits involved in the project?
- Where the major potential benefit from the project will accrue to certain members of society in the future, rather than to the individuals actually taking part in the study, has this been made clear to potential research participants?

Autonomy

Ethical research recognises the capacity of human beings to make their own decisions. In situations where people have impaired decision making (due to age, health status, cultural and linguistic barriers), it is important that researchers empower these people or provide protection. This concept of *informed consent* aims to capture what is considered as the appropriate relationship between researcher and participant (Miller & Boulton, 2007). It is critical that the researcher assess whether the potential participant is competent to understand what participation in the

research involves and decide for themselves as to whether they want to participate. This may require a third party (such as a doctor, social worker, and psychologist) to indicate whether the person is able to provide informed consent. For example, in a recent research project that Ayton was involved in, neuropsychologists were required to screen patients as to whether they were able to provide informed consent based on cognitive ability, and hence whether it was appropriate for the person to be approached for participation. In some cases, others need to be involved in participation decisions . this may be a statutory body with legal authority, formally constituted bodies, institutions, families or community elders (National Statement, 2007). For further information on this see *Chapter 4* of the National Statement.

The requirements for consent are summarised by the following principles stated in the National Statement (2007, p.19):

- Consent should be voluntary by choice
- Consent should be based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it

To fulfil these requirements, it is critical that the researcher consider the nature of the project and how the project is impacted by codes, laws, ethics and cultural sensitivities of the community context. How consent information is communicated to potential participants should aim for mutual understanding between researchers and participants. The potential participants should be given the opportunity to ask questions and discuss the information and decision to participate with others if they prefer (National Statement, 2007). The participant can indicate consent either orally, in writing (for example signing a consent form or wording to that effect), or by implied consent (for example via returning a survey). The National Statement (2007) states that the following information should be communicated to participants:

- Any alternatives to participation
- How the research will be monitored
- Provision of services to participants adversely affected by the research. For example, offering access to counselling services at no cost if participation causes distress
- Contact details of a person to receive complaints (distinct from the researchers . this can be the ethics committee or the head of the institute)
- How privacy and confidentiality will be protected

- The participant's right to withdraw from further participation at any stage, along with any implications of withdrawal, and whether it will be possible to withdraw data.

- The amounts and sources of funding for the research

- Financial or other relevant declarations of interests of researchers, sponsors or institutions

- Any payments or gifts to participants.

- The likelihood and form of dissemination of the research results, including publication.

- Any expected benefits to the wider community

The above is often provided to the potential participant in a written document termed a participant information and consent form. Templates of these forms are provided in *Appendices 2 and 3*.

Participants also need to be able to renegotiate consent. Ayton is currently involved in a research project involving three interviews with participants over two years. At each interview point, consent is renegotiated and the participant is given the option to discontinue participation if they prefer. Research participants also need to be informed if any changes to the research protocol is changed (National Statement, 2007).

Coercion

Issues of coercion can be significant in qualitative research, particularly when there is a power imbalance between the researcher and the participant. Examples where coercion may occur include:

- *The researcher is involved in delivering a program or treatment in which the potential participant is partaking*. In these situations, the invitation to participate should not come from the researcher and should instead be from a third party who does not have contact with the participant. In some circumstances it will not be appropriate for the researcher to be involved in the data collection phase of the research, and again this should be conducted by a researcher unknown to the participant. The participant may feel compelled to participate as they are

worried that not participating may compromise their ability to take part in the program or treatment. Additionally, the participant may not share their thoughts honestly, as negative opinions may compromise their relationship with staff or participation in the program.

- *The researcher is an employer of the participant.* For example, an employer may be conducting an evaluation on work place policies and is involved in the design, data collection and analysis of the research.

- *The researcher is a community leader or elder.* In qualitative research, particularly designs such as action research, researchers engage with the ±gatekeepersq of communities which are often community leaders or elders. Consequently this may bias who then feels comfortable to participate in the research project and also it may pressure community members to participate.

- *The researcher offers financial incentives to participate.* It is not uncommon for researchers to ±eimburseqparticipants for the time and effort of participation. This can range from vouchers or money, to token gifts. To enhance participation, particularly in difficult to reach populations, researchers may provide participants with the opportunity, through a draw, to win for example, an ipad. It is important that issues of coercion are well considered in these situations.

Question to consider: How is the research designed to respect participants who can and cannot make informed choices?

Confidentiality and anonymity

In all research projects steps should be taken to protect the privacy, confidentiality and cultural sensitivities of the participant and where relevant, their communities (National Statement, 2007). As stated throughout this guide, research needs to be of benefit to participants and/or to the greater public good. Therefore it is important that the findings of the research are communicated to the public, relevant organisations, and individuals who are able to act on any recommendations discussed in the research. However, this raises issues of confidentiality and anonymity. It is important to understand the different terms used to describe the processes protecting participant privacy.

- Confidential – data is considered confidential if there continues to be a link between the data and the individual who provided it. Researchers are required to protect the data from disclosure to those outside of the research and must align with what is written in the research proposal and informed consent form documents. To protect confidentiality, the participant's name and other identifiers should be stored separately from the research data and a unique code of pseudonym should be used instead (University of Michigan, nd).

- Anonymous – data is anonymous if not even the researcher can connect the data to the individual. Identifying information is not collected from the participant. However, researchers need to be aware of indirect identifiers which may reveal the participants identity (University of Michigan, nd).

- De-identified – data is de-identified when direct and indirect identifiers linking the data to the participant's identity are destroyed (University of Michigan, nd).

Even if a researcher assigns pseudonyms to the participants in the study, it is important to make sure that they cannot be identified via indirect identifiers such as where they live, ethnic background, risk behaviours, workplace or school or other key features. In some cases, the name of suburbs and the details disclosed by participants may need to be changed to protect their privacy. In sensitive situations the researcher should include the participant in this process to ensure they are comfortable with the way their data is being represented.

The National Health and Medical Research Council guidelines on research conduct highlight the importance of researchers disseminating their research findings to a range of audiences. To protect the participants and researchers, a number of points were noted in relation to publicly communicating research findings. Points relevant to community researchers have been included and described below.

Further information can be found at the following link:
http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r39.pdf
- Researchers should promptly inform those directly impacted by the research (participants, stakeholders) of the research outcomes before making the findings

public. An individual who participates in qualitative research divulges personal thoughts and experiences. How their data is then combined with the information of other participants, analysed and written up, may not be what is expected by the participant. This process should be discussed with the participants to ensure that there are no misunderstandings.

- Any restrictions on communications that have been agreed with participants and stakeholders should be honoured.

Other ethical considerations for qualitative research
- The research friendship

Researchers often research topics that they are interested in and at times this may be because they share an identity with prospective participants. Miller and Boulton (2007) describe the shifting boundaries between personal and professional relationship between researcher and participant in their research of exploring the experience of parenthood. They describe how the participants felt that Boulton had a natural interest in understanding motherhood and hence felt a ±genuine rapportq and thus ±they willingly described in detail their daily lives and reflected openly on what they had learned from their own experience. This openness in their accounts to someone about whom they knew very little, reflected the high level of trust they placed in her, and their expectations that she would understand (and benefit from) what they were saying simply because she was another womanq(Miller & Boulton, 2007, p2204).

They go on to write that ±there were also greater expectations placed on the researcher who . reflecting shifts in the role expectations . was at different times expected to be a professional, expert, friend, confidante and counsellorq(Miller & Boulton, 2007, p2205).

Another issue to be cautious of is faking friendships with potential participants to gain their interest and participation in the research. This can be an issue in ethnography research where the researcher is gaining access to the participant community in order to understand the phenomenon under study. In doing so, the researcher may interact with potential participants in a manner whereby they interpret the behaviour of the researcher to be efforts to be friends.

Further reading on this issue can be found at the following links:

- http://www.sagepub.com/gray3e/study/chapter17/Book%20chapters/Feminist_Research_Rapport_Ethics.pdf

- http://www.lsbu.ac.uk/__data/assets/pdf_file/0017/9440/up-close-personal-relationships-emotions-families-research-working-paper.pdf

3.2   Ethics committees

Human research can only be conducted once the research proposal has received ethical approval. Human Research Ethics Committees (HREC) and other ethical review bodies are responsible for reviewing research proposals and assessing whether the risks are justified by potential benefits. Only a HREC is able to review and approve research that involves more than low risk, or research involving active concealment or planned deception or aims to expose illegal activity. The National Statement outlines the responsibilities and requirements for research governance for institutions and organisations involved in human research. These can be found from page 77 of the National Statement. A summary of the points is provided below.

Must ensure that the research:

- is designed and conducted in accordance with the Australian code for the responsible conduct of research

- is ethically reviewed and monitored in accordance with the National Statement

- meets relevant scholarly and scientific standards

- ensures individuals involved in conducting the research are appropriately experienced and qualified OR supervised. They also need to be able to assess risks to their own safety and that of the participants and understand that they are free to withdraw from the research on conscientious grounds

Institutions are able to establish their own HREC, and guidelines for this can be found in the National Statement. An important requirement is the composition of the HREC. The minimum membership of a HREC is eight with the members comprising:

- equal numbers for men and women

- at least one third of the members from outside the HREC institution

Membership should comprise:

- a chairperson with suitable experience

- two lay people . one man and one woman with no affiliation to the institution and do not currently engage in medical, scientific, legal or academic work

- one person with knowledge of and current experience in professional care counselling or treatment of people (nurse or allied health professional)

- a person who provides a pastoral care role in a community

- a lawyer

- at least two people with current research experience

A list of ethics committees and their contact details can be accessed via the web link below:

https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs/list-human-research-ethics-committees

SECTION 4: KNOWLEDGE TRANSLATION & ADVOCACY

4.1   Translating qualitative research for advocacy purposes

Many qualitative researchers work with populations who are unable to get their voices heard in policy or practice . for example those experiencing poverty, disability, discrimination or vulnerability (Stake, 2010). Whilst it is a noble endeavour to give these populations a voice through the process of qualitative research, there is contention as to how researchers should use their research findings to advocate for particular solutions or change on behalf of particular population groups. Stake (2010) writes of qualitative researchers:

"We do advocate, yet we are troubled. We are troubled by the possibility that our advocacies will cause us to search more vigorously for aspiration-focused evidence than for other evidence. We cling to some advocacies more than to neutrality, believing these well-considered biases to be compatible with the interests of the profession, our clients and society" (p202).

Therefore, when assessing data for use in advocacies efforts it is important to consider:

- *Who do the participants represent?* Qualitative research does not seek to be generalisable. Stake (2010) writes about how qualitative research focuses on the micro level, whereas significant social problems require understanding of both micro and macro level information. For example, the pathways study by Warren and Ayton is a qualitative study which includes interviews with 11 carers of people who have experienced stroke. The participants described issues around health service access, financial burden of treatment and lack of care support through home cleaning and respite services. This information is at the micro level as it represents the experiences and thoughts of the 11 participants. However, drawing upon cost of caring economic data, health service access and burden of disease data (prevalence and incidence of stroke) from the Australian Institute of Health and Welfare, provides macro level information to support the micro findings. Stake (2010) cautions against only using micro level qualitative data to advocate for change. Further research and the validation of research findings through other means such as census data, health services information and other research studies is required.

- *What changes are you advocating for?* Effective advocacy depends on clear aims and objectives . what is it you want to make happen? How does this relate to your research findings? How can you use your data to highlight why change needs to happen? An example of how findings can be disseminated via a number of different channels is presented below (see *Section 4.2*).

- *Test your advocacy messages with your participants and broader population group.* This is a helpful way of ensuring that extreme cases are not used to represent broader groups and that the participants are not being represented in a way that may be harmful or disenfranchising. This can be done through focus groups or meetings and will provide an extra level of confidence that you are advocating the right messages using the right channels.

4.2   Knowledge translation and dissemination

Knowledge translation is an interactive process between researchers and consumers (Kothari & Armstrong, 2011). Community based knowledge translation differs to the approaches undertaken in clinical and biomedical knowledge translation, where evidence is based on research from experimental studies (e.g. clinical trials). Community based organisations rely on a different evidence base, including tacit knowledge (field experience and professional expertise) and community views (Kothari & Armstrong, 2011). These organisations often need to engage in their own research (needs assessments, health service planning) with target populations in the area. Knowledge translation in this context requires researchers to develop processes to assist community based organisations to adapt local research findings to advance decision making (Kothari & Armstrong, 2011).

Academics have access to knowledge translation and dissemination techniques that are not readily available to community researchers. For example, academic researchers are able to publish their findings in journal articles and present at national and international conferences. However, the key to effective dissemination is to explore and understand *who needs to know the research findings*. This requires a consideration of *why they need to know* about the findings and *what they can do* to address the issues raised through the research. Fundamentally, how will the

research findings make a difference? The method of dissemination will therefore depend on the audience and key stakeholders.

In research conducted by Warren and Ayton (in press) on the experiences of people who have had a stroke or diagnosis of Parkinson's disease and their carers, it was important for research dissemination to occur via a number of channels. The research participants were kept informed about the preliminary findings through newsletter updates. Academic journals and research conferences are being used as a method of dissemination for clinicians and researchers. The researchers also actively engaged with key organisations (eg. Parkinson's Victoria, Carer's Victoria), to communicate the study findings to help these organisations advocate for changes in support services, and to put different issues raised on the agenda of government and health services.

Other methods used to disseminate research findings include
- social media (facebook, twitter)
- blogs
- newspaper articles
- online reports
- television

The research findings and methods of data collection can be used in knowledge translation and advocacy efforts, particularly for data collected through methods such as photo voice, video diaries or visual arts. *Example 7* below demonstrates how stories have been incorporated into a campaign to raise awareness and change perceptions of asylum seekers.

Example: Asylum Seeker Resource Centre – "Just Like Us" Campaign

The Asylum Seeker Resource Centre began in 2001 and is now Australia's largest asylum seeker organisation assisting over 10,000 people seeking asylum. Their "Just Like Us" campaign has clear advocacy and communication goals:

- Change perception: change the public perceptions of asylum seekers

- Recognise positive contributions: that asylum seekers have and will continue to make to our community

- Change the language of fear, ie boat people, detainees, detention centre, border protection

- Increase opportunities: for asylum seekers to contribute to Australia

- Increase independence: increase asylum seekers' independence and control of their lives

- Educate employers: educate prospective employers of asylum seekers

The campaign tells the stories of refugees who have settled in the Goulburn Valley through the use of audio and photos. These stories highlight the plight of refugees and their experiences of settling in Australia. One of the participants emphasises that "we are human beings, we have got the same feeling" The stories are powerful and are used to try and change the perceptions of the Australia public.

Source: https://open.abc.net.au/projects/one-on-one-goulburn-valley-02ue3ea/contributions
http://www.asrc.org.au/news/latest-campaigns/#gallery-details-3215

Television shows such as *Insight SBS, Four Corners, Australian Story* and the *7pm Project* are often utilised for advocacy efforts by different groups in the community. Researchers, consumers and organisations are able to share their knowledge and experiences on these TV shows in efforts to raise awareness of social issues. For example, an Insight episode from 2013 titled "What's Best for the Child" delves into the issue of how an intellectual disability may affect a parent's capacity to raise their child. Guests on the show included parents with an intellectual disability and their children, as well as child protection workers and Professor Gwynnyth Llewellyn from the Centre for Disability Research and Policy at the University of Sydney. Professor Llewellyn was able to draw upon her research to make arguments regarding the determinants associated with this issue.

More information about this episode can be found at the link below:

http://www.sbs.com.au/insight/episode/transcript/534/What-s-Best-For-The-Child

Feedback to participants about how their information has been used

It is important to consider how the data from the research will be conveyed to the public and how this will impact on the participants. As stated in the ethics section of this guide, respect for human participants is of utmost importance in the conduct of research. However, ethical guidelines do not adequately dictate methods for how this can be achieved and in a number of cases the responsibility to protect the wellbeing and interests of participants lies with the researcher. In qualitative research, the harms associated with participation are predominantly emotional and social . for example the risk of exposure, humiliation and embarrassment, loss of respect or self-respect, loss of respect at work or in a social group.

Prior to consenting to participate in the research, individuals should be informed about how the data will be used and in what ways findings will be disseminated. This includes articulating how participant privacy and confidentiality will be protected (e.g. through the use of codes or pseudonyms). Researchers will often send participants interview and focus group transcripts, to allow the participant to delete information they would not like published, or to clarify anything they may have said. It is very important to notify participants of any changes that will be made to *how* the research will be disseminated. If findings are disseminated in a public forum such as the internet, television commercials or radio shows, it is best practice to discuss this with participants, including showing or explaining how their information will be used. It is

also critical to inform participants of dates and times that their information will be broadcast.

For more information, please contact:

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GLOSSARY

Deductive . process of data gathering to test predefined theory or hypothesis

Epistemology . theory of knowledge; scientific study which deals with the nature and validity of knowledge

Hawthorne effect . impact of the researcher on the research subjects or setting, notably in changing their behaviour

Hypothesis testing . a process by which a researcher tests a statistical hypothesis

Inductive . process of moving from observations/data towards generalisations, hypotheses, or theory

Methods . what you do to collect and analyse data

Objective . judgement not influenced by personal feelings or opinions in considering and representing facts

Phenomenon . an ±objectqof human experience (Creswell et al 2007)

Reliability - extent to which a measurement yields the same answer each time it is used

Subjective . based on or influenced by personal feelings, tastes, or opinions

Validity . extent to which a measurement truly reflects the phenomenon under scrutiny

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Appendix 1: Quantitative and Mixed Method Research Methodologies

Quantitative research approaches can answer social questions which seek to objectively *quantify* phenomena (Liamputtong, 2010). For example, quantitative research can assess the rate of disease (termed prevalence and incidence), the risk of disease due to lifestyle or behaviours and the effectiveness of medication. Quantitative research is numerical and is characterised by counting, statistical analysis, large participant numbers, the need to be generalizable, and research questions that start with ±whatq (Liamputtong, 2010). This research approach is deductive or hypothesis testing, in that it seeks to determine if an assumption about a topic or phenomena is true. The methods adopted in this type of research include surveys (with closed ended questions for example tick boxes, yes/no and scales to gauge levels of response to a question) and biological and physiological measurements (weight, height, blood pressure, cholesterol). Quantitative research methods can be used by community researchers to gauge the thoughts, beliefs, attitudes and interests of community members through surveys. Questions can be derived from previously existing quantitative tools or can be developed based on qualitative data or knowledge and experiences of the community. Below is an example of quantitative survey questions.

Question: How safe do you think your community is for people of different ages? (adapted from Bowchung consulting, 2011)

Type of person	Safe all the time	Safe some of the time	Not safe some of the time	Not safe all the time	Don't know
Children	☐	☐	☐	☐	☐
Young men	☐	☐	☐	☐	☐
Young women	☐	☐	☐	☐	☐
Men	☐	☐	☐	☐	☐
Old men	☐	☐	☐	☐	☐
Old women	☐	☐	☐	☐	☐

Question: Which forms of transport do you use most often apart from your journey to and from work? (please tick one box ONLY per line)

- adapted from the Physical Activity Questionnaire

http://www.srl.cam.ac.uk/epic/questionnaires/epaq2/epaq2.pdf)

Distance of journey	Usual mode of transport			
	Car	Walk	Public Transport	Cycle
Less than 1kms	☐	☐	☐	☐
1-5 kms	☐	☐	☐	☐
More than 5kms	☐	☐	☐	☐

Google is also a good source of existing survey tools. Using the Google search engine input the topic and include the word ±surveyq or ±questionnaireq Questions may need to be adapted however they will provide you with a starting point.

Mixed methods research is the term given to a research study which combines qualitative and quantitative data collection and analysis, either concurrently or sequentially to answer the research question or questions (Greene et al., 2005; Tashakkori et al., 2003). Mixed method designs are considered by many researchers to be more rigorous as they provide stronger conclusions and the opportunity to investigate and present a diversity of differing views (Tashakkori et al., 2003). Mixed methods research has become increasingly common in the social sciences in the last decade. Tashkokori (2009) writes that it is important to be explicit about why you are mixing methods and that this should only be done when there is a specific reason to do so. Five main reasons for mixing methods are:

- Triangulation . seeks to validate findings between different methods.
- Complementarity . seeks to enhance, illustrate and clarify results from one method with the results from the other method.
- Development . uses the results of one method to develop or inform another method. For example, qualitative semi structured interviews are used to inform the development of a quantitative survey.
- Expansion . seeks to increase the breadth and depth of the research by using different methods for different inquiry components.

Appendix 2: Participant Information Form (template)

[Title of project]

[Participant group]

[Date]

[Organisation(s) and researcher(s) names involved in the research]

This information sheet is for you to keep

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

Explain the aim of the study.

Explain what the participants will be asked to do, and how much time it will take.

Why were you chosen for this research?

Describe why you chose this particular person/group of participants and how (from whom?) you obtained their contact details.

Source of funding (optional)

Declare the source of funding and any conflict of interest of sponsors or researchers

Consenting to participate in the project and withdrawing from the research

Explain what the consent process involves (e.g. signing and returning the consent form)

Explain the participants right to withdraw from further participation at any stage, along with any implications of withdrawal, and whether it will be possible to withdraw data. For example, if the project involves participation in an interview, the participant may choose not to have their transcript included in the analysis.

Possible benefits and risks to participants

Describe the presence or absence of possible benefits for participants and/or society. (optional)

Describe any potential level of inconvenience and/or discomfort to the participant.

List all possible or reasonably foreseeable risks of harm or side-effects to the potential participants (outlining likely incidence and severity).

Include any risk that may come from others identifying the person's participation in the research. This information must be included so that potential participants can give genuinely informed consent to take part.

Services on offer if adversely affected (optional)

Include a list of services and contact details who are not related to the researchers/research team

Payment (optional)

Describe any payment or reward offered, financial or otherwise.

Confidentiality

Describe how you will manage the confidentiality or anonymity of the data you have collected and **how you will manage the information when published**. If applicable, mention use of pseudonyms/codes etc.

Storage of data

Data collected must be stored in accordance with Monash University regulations. Describe where and how the data will be stored and who will have access to the data.

Use of data for other purposes (optional)

Include a statement to clearly explain future use of data if relevant to your project. Assure participants that only aggregate de-identified data may be used for other projects where ethics approval has been granted.

Results

Include a statement to explain where and when the results will be made available, and how the participants can access the findings.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact [insert details and contact information of a person other than the researcher who can be contacted].

Thank you,

(insert researcher's signature)
Researcher's name

Appendix 3: Consent Form Template

[Title of project . as it appears on the Participant Information Form]

[Participant group]

[Date]

[Organisation(s) and researcher(s) names involved in the research]

I have been asked to take part in the research project specified above. I have read and understood the Explanatory Statement and I hereby consent to participate in this project.

I consent to the following: (delete or add as appropriate)	Yes	No
Audio recording during the interview / focus group	☐	☐
Taking part in a focus group of up to <insert the general number> people	☐	☐
Taking photos for use by the researcher	☐	☐

The data that I provide during this research may be used by _____ in future research projects.

Name of Participant

Participant Signature

Appendix 4: A qualitative research checklist

Please circle the appropriate response for each of the questions below

Prior to commencing your research project		
1. **Have you developed a comprehensive research proposal?**	The research proposal should describe the following: research aim and questions, research design, participant recruitment, data collection methods (including interview/focus group questions), ethical issues identified.	YES NO IN PROGRESS
2. **Are consumers included in all aspects of the research process?**	In qualitative action research it is important for consumers to be involved in all aspects of the research process: planning, design, implementation, analysis and dissemination. Consumer involvement can be demonstrated through involvement in steering committees, as an active member of the research team and/or as a consultant to the researchers.	YES NO IN PROGRESS
3. **Is someone trained in research methods involved in the research project?**	This may be a team member who has experience in research, a consultant or a staff member at a University. Research is a complex undertaking and therefore it is important to ensure that a sufficiently trained person is involved in the project.	YES NO IN PROGRESS

Research ethics		
4. **Have you developed a participant information document and consent form**	This document provides all the information about the research project including what it involves (e.g. what will they be required to do), how their confidentiality will be protected and how their stories will be used.	YES NO IN PROGRESS
5. **Has someone outside of your team reviewed the research proposal to check for any ethical issues?**	Most research is submitted to an ethics committee for review. In the absence of this process it would be helpful to receive feedback about your research proposal by someone external to your organisation.	YES NO IN PROGRESS
6. **Have the power relationships between the researcher/s and the participants been described?**	This process is to ensure that you are aware firstly that there are power relationships and that these have been articulated and addressed in the research design.	
7. **Have processes been put into place to support participants in the event that they experience distress during data collection.**	Researchers have an ethical duty to minimise harm experienced through the research process. Therefore it is important to provide participants with appropriate follow up if required including counselling, referral to support and debriefing.	
8. **Does the participant information document detail who to contact if complaints about the research process need to be made?**	This should be someone other than the researcher and in some cases should be someone external to the organisation.	YES NO IN PROGRESS

During your research project		
1. **Prior to data collection, is the following explained clearly and explicitly to the participants?** • **The purpose of the research** • **What participation involves** • **How their stories will be used?**	What is the process for informing research participants of the research purpose, participation requirements and how their stories will be used? IF research participant stories are going to be used in a public forum, the participant should approve the content.	YES NO IN PROGRESS
2. **Is data collected and participant information stored in a secure manner?**	Only those involved in the research process should have access to the data. Data should be stored securely. Important to ensure data storage does not compromise the confidentiality and privacy of participants.	YES NO IN PROGRESS
3. **Have the risks to the researcher and participant been articulated?**	Data collection often involves talking to participants in their homes or at a location convenient to the participant. Therefore it is important to ensure that other staff know the location of the researcher undertaking data collection and that there is a plan to manage the safety and welfare of the researcher	YES NO IN PROGRESS
At the completion of the research		
1. **Have you communicated the findings of your research to appropriate groups/organisations?**	For example, key stakeholders, service providers, government, community organisations	YES NO IN PROGRESS
2. **Have you provided your participants with a summary of the findings of your research**	This can be in the form of a newsletter, website or report. It is important to provide participants with information about the findings and outcomes (for example, changes to services) of the research.	YES NO IN PROGRESS