COMMUNITY-ENGAGED RESEARCH

TRAINING MANUAL

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GUGULETHU HEALTH COMMITTEE | MAYENZEKE IMPILO™
"Right to Health for All"

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Khayelitsha Health Forum

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INTRODUCTION

Who is this manual for?

This training manual on community-engaged research is for laypeople with no or little experience in research. It aims to facilitate collaboration in research projects with academic researchers and practitioners. It provides participants with a basic understanding of principles of research and community-engaged research, standard methods in social science research, the research process, and ethics. The manual is designed with a variety of exercises to draw on participants' experiences and promote engagement with the material presented. It should ideally be used in workshops with experienced researchers or trainers. After having finished the manual, participants should be ready to be part of collaborative research projects.

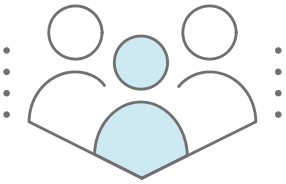
What this manual has been used for?

The manual was created for a research project with health committees in Cape Town in 2020. The training took place over five days. Subsequently, health committees worked on identifying community-engaged research projects, which they were going to conduct in collaboration with researchers from the University of Cape Town. However, when the COVID-19 pandemic began, the plans had to be abandoned. In August 2020, the steering committee for the project discussed health committees' involvement in the COVID-19 pandemic. It became evident that many questions about how communities responded to the pandemic and non-pharmaceutical interventions were not well understood. We decided to undertake a research project on the knowledge, understanding and perceptions of COVID-19 in the communities. The plan was to use this knowledge to better design interventions.

KEY TERMS

Community-engaged research

This manual uses the term community-engaged research for research projects where laypeople are involved in some or all aspects of research, with academic researchers as partners. There are many terms for such research, such as community-engaged research, participatory research, and community-based participatory research. Different researchers may use the terms differently, but we use them interchangeably when referring to research where laypeople work collaboratively with academics in this manual.



Community/community members

The terms community and community members are sometimes contested terms. In this manual, the term community members is used to refer to people without experience in research. These individuals may be bound by common interest, a common geographic location, or a particular demographic characteristic. However, they are not researchers. When this book refers to community members or laypeople, it uses these terms interchangeably.

LEARNING OBJECTIVES

By the end of this training, participants should:

- Understand key principles in research and community-engaged research.
- Know the difference between traditional research and community-engaged research.
- Understand key aspects of the research process.
- Be able to formulate simple research questions/hypotheses.
- Know commonly used methods in social science research.
- Understand basic research ethics principles.
- Feel confident to engage as partners in community-engaged research projects.

WHAT IS RESEARCH?

Learning Objectives:

By the end of this chapter, participants should have:

- An understanding of principles of traditional research.
- An understanding of principles of community-engaged research.
- An understanding of why research may be conducted.
- An understanding of how research can be used.

Research is about gathering new information and produce new knowledge. There are many types of research. Some involve human beings; other types of research do not. This can be research that involves other matters, such as animals, plants, soil, rocks, etc. A geologist may, for example, study sediments in a laboratory. An archaeologist may study bones of ancient people; a biologist may dissect animals or plants; a chemist may mix two substances in a laboratory to see how they react. A medical researcher may take blood samples to analyse cells, and a psychologist may conduct behavioural or social experiments with humans.

The type of research that this manual is concerned with can best be described as social science research. It is characterised by focusing on humans, and how humans behave, think, understand and perceive phenomena in their world. Social science research is also characterised by the way it gathers this information. There are two main ways in which this type of research collects information and produces knowledge. The first is through observing people. The second is through asking people questions in standardised ways, for instance, using questionnaires, interviews or focus groups. This manual's focus is on research where people provide answers to the research question.

Though many people find it challenging to define research if they are asked to, most people have come across research in some form or other. Maybe you have had a researcher come to ask you questions. Perhaps you have been part of a focus group discussion. Maybe you have filled out an evaluation form after a training programme. You have possibly participated in an online survey, or someone has phoned to ask you some questions. All of these are examples of research. Research can answer essential questions, and give us knowledge and information.

Exercise

In groups or pairs, discuss what research is and why you think it is important (or not). What is your experience with research? Note your answers in the box below:

There are many different ways of defining research. Here are some examples:

- "The systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions." (Oxford Dictionary)

- "Research is creative and systematic work undertaken to increase the stock of knowledge. It involves the collection, organisation, and analysis of information to increase understanding of a topic or issue." (Wikipedia)

The next two definitions relate to social science research:

- "Social science is, in its broadest sense, the study of society and the manner in which people behave and influence the world around us." (Economic and Social Research Council UK)

- “Social Science Research is the activity of gathering, analysing and interpreting information for a variety of social, economic, educational and political purposes.” (The University of Waikato)

In this manual, we define research as systematically collected data analysed to produce and generate knowledge. Let’s look at some of the key terms.

By systematic, we mean that there is a specific planned way of collecting the data, which uses specific methods. Data refers to the information that is collected. There are many different types of information that can be collected. Generally, the data collected in social science research is either something that has to do with numbers, something that is observed, or something that is answered in words.

But research is not just about collecting the data. It is also about making sense of the data: what is it telling us? We call this data analysis. Analysing data can be as simple as adding numbers – for instance, numbers of people that answered ‘yes’ to a specific question. It can also be about observing people. For example, how many people stopped when the traffic light was yellow? Analysis can also be the process of finding patterns in the data. In a set of interviews, specific topics may show up in a certain way.

There are many different ways of analysing data. The important thing to remember when doing research is that it is not just about collecting data. We need to analyse (make sense of and explain) the data. When we analyse data, we produce knowledge, or evidence.

Exercise

Discuss the following questions and note your answers:

Where have you encountered research?
How did you participate?
What did you think about participating?
Did you get to know about the results?
Did the research seem useful to you?

Note your thoughts in the box below:

The purpose of research

Research can have many purposes and uses. It can be used in academic settings such as universities, other higher learning institutions, or research institutions for pure knowledge generation. Sometimes research does not have a specific goal beyond creating new knowledge.

But that does not mean that the research cannot be used. The knowledge may be used later, or by other people. Sometimes research is designed with a specific goal. For example, it can be to evaluate something. It can be applied in marketing for finding out how consumers choose products or think about products. It can form part of evaluating programmes or products (including research programmes or training). It can also inform interventions, policies and practices.

Exercise

In pairs, discuss research you have come across that had practical use. How was it used? Note your answers below:

Community-engaged research

Who does research? The research described above can be called traditional research. Typically, this research is conducted by trained, highly-educated researchers as part of their full-time work.

Much research is done at universities or other research institutions such as the Medical Research Council, Health Systems Trust, to name some. Institutions such as government agencies and NGOs also do research, and private companies may also do research. For instance, pharmaceutical companies that develop products do research. That research can be about creating products, testing products, selling products. Likewise, marketing companies that want to know what people like to sell products conduct research.

People who conduct research are usually called researchers, whether they work at universities, research institutions, government, NGOs or private companies.

Discussion

Think about 'ordinary' people involved in research. Are there any opportunities you can imagine where people other than researchers might be involved in research? What would this look like?

Make notes on the discussion below:

In traditional research, people are the participants of the study. They are asked questions in interviews or focus groups, asked to fill out questionnaires or being observed. That is their primary role in the research. When we refer to traditional social science research, we refer to research where a researcher conducts a study and is in charge of deciding what should be researched, as well as collecting and analysing data, and determining how the research findings should be used.

But there are alternatives to this type of research: where laypeople or communities are more involved in the research. There are many different names for this kind of approach, including: community-engaged research, participatory research, and community-based participatory research.

In this manual, we will use the term community-engaged research. There are many definitions of community-engaged research. Common to them is that they involve communities in some way beyond traditional research. Often this involves identifying the topic, helping with accessing the community and recruiting participants. In more involved studies, communities may be part of formulating the research question, deciding on methods, collecting and analysing the data and, finally, deciding how findings should be used. Below are some definitions of community-engaged research:

- “A collaborative approach to research that equitably involves all partners in the research process and recognises the unique strengths that each brings” (WK Kellogg Foundation).

- “The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting the wellbeing of those people” (Scripps Translational Science Institute).

- "Collaborative partnerships between researchers and community members that are grounded in the views, consideration, and cooperation of the community in which the research is taking place. Community members are involved in the research taking place within their community in a meaningful way."

- "The term '**community engaged**' is broad and includes the full spectrum of approaches that involve the community in the research process" (Harvard Catalyst).

As the figure below shows, community-engaged research is often placed on a continuum according to how involved communities are in different aspects of the research. This can be a valuable way of looking at community-engaged research.

Figure 1: Continuum of engagement in research

More intensive

Collaborating fully in all aspects of research, including defining study questions, writing the funding proposal, designing the methods, implementing the research project, analysing the results and disseminating the findings.

Medium

Assisting with implementation of a researcher- designed study, including participant recruitment, and data collection, and/or providing feedback on aspects of study design or findings; the community partner often acts as a subcontractor with a defined set of responsibilities.

Less intensive

Assisting in discrete steps of a researcher-designed study, such as participant recruitment.

(From: Community-Engaged Research. Community Engagement Program. Clinical And Translational Science Institute, University of California)

However, in this manual, we take a slightly different approach. We describe community-engaged research as:

"Collaborative partnerships between academics and communities involving communities meaningfully in aspects of the research process to address issues affecting the community."

It is important that community members, or laypeople, are meaningfully involved in the research. But that does not necessarily mean that they need to be involved in all parts of the research. In some instances, it makes sense that researchers 'do the work', but community members should know what is going on and be involved in decisions.

An important reason for doing community-engaged research is to draw on the strengths of both academics and community partners. While researchers may be very good at conducting research and writing up the results, they may not know much about the communities or how to recruit participants. Laypeople may provide knowledge about the context that the researchers have not thought about. They may also be better at ensuring that the research is used and benefits their communities.

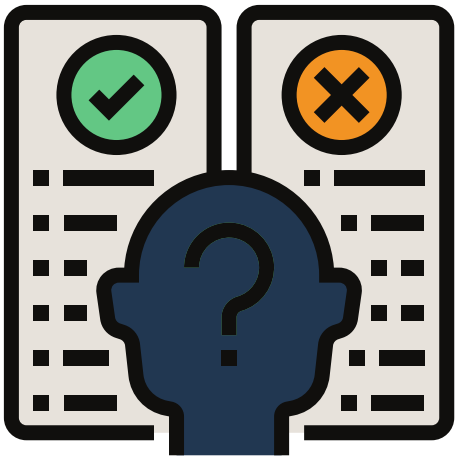
Thus, rather than saying that community partners should be involved in all aspects of the research, we focus on ways in which academics and community partners can leverage their own strengths to ensure meaningful engagement and collaboration.

The table below highlights the differences between traditional and community-engaged research

Table 1: Differences between traditional and community-engaged research

	Traditional research	Community-engaged research
Relationship with community	Research 'in' communities	Research 'with' communities as collaborators
Research problem and question	Researcher-defined Based on literature, theory, scientific evidence, funding	Defined by the community or jointly by the community and researcher. Based on community needs/priorities
Research design	Researcher Based on scientific rigour, feasibility, funding	May include community input
Data collection	Led by researcher	Likely to include community members

	Traditional research	Community-engaged research
Data analysis	Researcher	Likely to include community members
Knowledge acquisition	Researcher gains knowledge	Community members and researchers gain knowledge
Control of research process and decision-making	Researcher	Joint
Data ownership	Researcher owns data	Joint ownership over data
Dissemination	Primarily in academic journals	Academic journals and dissemination through channels identified by communities.



Community-engaged research has many advantages, but may also be challenging as it is a form of collaboration that is often new to both community members and academics. How communities and academics work together depends on many factors. It all depends on the project and partnership. A community-engaged research project should be decided for a specific context and use the strengths of each partner. An essential aspect of community-engaged research is that community members are part of determining what should be researched and how the study should be used. It is not just about getting community members to assist with access to a specific community or collecting the data.

Below is a list of characteristics of community-engaged research. The list below is adapted from the Scripps Translational Science Institute, based on our experience.

- Community and researcher contribute meaningfully to the research.
- Trust, collaboration and shared decision-making are integral parts of the process
- Findings and knowledge benefit all partners.
- Researchers and community members recognise each other's expertise in a bidirectional co-learning process.
- Researchers embrace the skills, strengths, resources and assets of local individuals and organisations.
- Core elements include local capacity building, systems development, and empowerment and sustainability.

The table below highlights some of the strengths and weaknesses, or challenges, of community-engaged research.

Table 2: Strengths and weaknesses of community-engaged research

Strengths	Weaknesses
Relevance to local community	Time consuming
Community ownership	Potential loss of control (researcher)
Build community capacity	May not be generalisable
Build researchers' skills	Requires flexibility
Supports social action	Conflicts between partners may arise due to different agendas
Imparts in-depth knowledge of community Context, needs and assets.	May not be valued in academia
Results may be easily used for change/ Translational	

(Adapted from Hacker, K. Community-Based Participatory research)

According to our definition, community-engaged research can vary in how much laypeople are involved. The level of community involvement may depend on several factors, including the type of research, the researchers' experience with involving communities, the skills of community members, and time constraints. The important thing is that communities are involved in important decisions regarding the research project, and that the research can be used to address the problem they have been part of defining.

Community-engaged research can be complicated because it includes different ways of understanding the world: the academic way through study and laypeople's experiential way of making sense of the world. The table below highlights some of the differences:

Table 3: Where is power in Knowledge Production

Knowledge Production	Local Knowledge	Professional Knowledge
Who holds it?	Members of community (often linked to identity geographical location)	University, industry, government
How is knowledge acquired?	Experience, interpersonal communication	Systematic data, experimental
What makes evidence credible?	Evidence of one's eyes, experience	Statistical significant Adheres to research standards

(Adapted from: Corburn, Jason. Street Science: Community Knowledge and Environmental Health Justice.)

Discussion:

Based on the table above, discuss your thoughts on community-engaged research, for instance: Note your thoughts in the box below:

What are the strengths of community-based research?
What are some of the critical contributions from community partners?
What are some of the important contributions from the academic partners?
Where can communities be involved?

Test your knowledge 1

1. What is the purpose of traditional research:
   a. To generate knowledge that can be applied ☐
   b. To generate knowledge ☐
   c. To foster social change ☐

2. Which of the following is true of community-engaged (CoE) research:
   a. It is conducted in partnership between academics and community members ☐
   b. Community members conduct the research on their own ☐
   c. Researchers engage with communities at the end of the research to discuss how it can be used ☐

3. Who formulates the research question in community engaged research?
   a. Researchers ☐
   b. Community members ☐
   c. Researchers and community members ☐

4. Which of the following is a strength in community engaged research?
   a. It is of high scientific quality ☐
   b. It is relevant to local communities ☐
   c. It is highly valuable in academia ☐

5. Dissemination in community engaged research:
   a. Is not important ☐
   b. Is only concerned with dissemination findings at community level ☐
   c. Disseminate findings both at community level and academic journals ☐

THE RESEARCH PROCESS AND RESEARCH QUESTION

Learning Objectives:

By the end of this chapter, participants should:

- Understand the research process.
- Understand how to define a research question.
- Understand how to define a hypothesis.
- Be able to create a simple research question or hypothesis.

Chapter 2

In the previous chapter, we defined research as a systematic way of generating new knowledge. In this section, we will focus on how researchers decide what knowledge they want to generate. But first, we describe – briefly – the research process, which entails several steps:

Overview of steps in the research process:

- **Identify research question**. Find out what is already known (for instance, from a literature review or a consultation in the community). Consider if the research question is measurable and doable. Consider the **purpose of the research**.

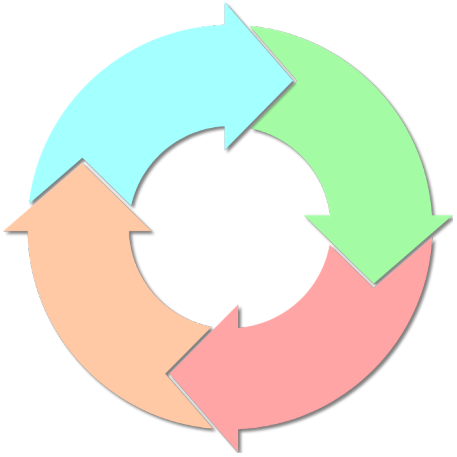
- **Study design and methods**: Design your study and choose data collection methods and an analytic approach.

- **Sample and Recruitment:** Decide how to sample and recruit participants.

- **Consider ethical questions**: What are the risks and benefits? How can risks be reduced? How can benefits be enhanced?

- **Prepare the research:** Develop research instruments, consent and information sheets. Negotiate access. Consider practical things such as budget, resources, timeframe.

- **Dissemination**: Develop a strategy for how to share findings.



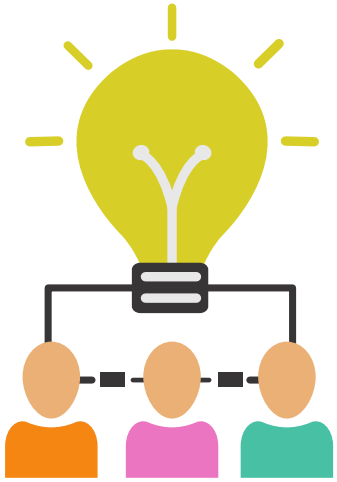
What is research question?

In the following chapters, we describe each step of the process. In this chapter, we start with the research question. All research begins with defining a research question. A research question is a question that describes what it is we want to know, and what knowledge we are trying to obtain through our research. This could be:

Why is something happening?
How often is it happening?
When is it happening?
Where?
To whom?

Examples:

What are the reasons for low adherence to non-pharmaceutical protocols?
How many adolescents drink alcohol regularly?
How common is obesity among the elderly?
What are the reasons for people choosing not to get the Covid-19 vaccine?



But where do the questions come from? As seen in the previous chapter, there are differences between traditional research and community-engaged research.

In traditional research, research questions may be inspired by literature, including academic articles, in that area of research. This literature may point to gaps in knowledge and thus lead the researcher to an area that should be researched to generate new knowledge. Research questions may also come from problems experienced and observed in practice. Say, for instance, we know that many older people have not had a vaccine against COVID-19. The next logical question may be, “why not?”

In community-engaged research, research questions likely come from experience. Research questions may also come from something we want to change. To change, we need knowledge.

Exercise

Discuss some potential research questions based on your own experience or your observations

Hypothesis

Sometimes the research question is set up as a hypothesis. A **hypothesis** is an assumption or an educated guess that the researcher wants to test through the research. It can often be answered with a yes or no answer.

Examples of hypotheses:

- Is it true that walking 10 000 steps a day, reduces your risk of heart disease?
- Prolonged usage of medication “a” leads to severe headaches.
- People with short hands are poor piano players.
- Older people do not vaccinate because they don’t know how to register for the vaccine on cell phones.

Exercise

Come up with some hypotheses:

Sometimes you will have one main research question, but several sub-questions that will assist in answering the main question. Often you start with a topic and brainstorm to get to the best way of formulating a research question or a hypothesis.

Whether you choose a research question or a hypothesis to guide your research depends on what kind of knowledge you are looking for. It also depends on how much you know in advance. You can't formulate a hypothesis for something you do not know much about and cannot make a qualified guess about. In that case, it is much better to formulate a research question.

It can be a good idea to think about the purpose of the research before or while you are working on your research question. For instance, if you want to create an intervention around drug use, you may want to know why people use drugs. If you're going to try to get more people to be vaccinated, you may need to understand why they haven't yet been vaccinated.

Formulating a good research question can take time. It often starts with a loose idea, but before it becomes a good question, you need to consider many issues. A research question should not only address an important issue. It should also answer a question that we do not already know the answer to, and a question that can be answered.

Some tips to formulate a good research question:

1.**What is known**: Find out what is already known about the topic you want to study. This can be done through a literature review, through reading what is already known about the subject. It can also be helpful to speak to people who have knowledge about the topic.

2. **Define a research gap**: Once we identify what is already known about a topic, we can also identify what is unknown. To formulate a good research question, we focus on what is not known. On what we can add to what is already known about the topic. We sometimes call this a 'research gap.'

3. **Is it achievable?** In other words, is there an answer to the question that the research is likely to uncover? After defining the research gap, we have an idea about what we would like to know. To formulate a good research question, we need to consider whether our question is doable, including how we can 'measure' or assess or answer it. Some research questions may be interesting, but they are not very useful if we do not know how to answer them. When you think about an achievable research question, you may also need to consider practical issues such as your resources, time, etc.

2. **Make sure the research question is specific.** Avoid terms that are loosely defined. You need to create a question that is precise to get the knowledge you are looking for.

Example:

Say your interest is in young people's drinking habits. Your interest could come from observing young people drinking in bars or taverns or speaking to parents concerned about alcohol consumption. As a health committee member, you also know that many young people end up in the clinic due to alcohol use/abuse or other issues related to alcohol.

From this experience, you are now asking the following question: **how many adolescents drink alcohol regularly?**

In collaboration with a researcher, you have researched alcohol consumption among youth in South Africa, and you know that there is some evidence available. However, you want to know about alcohol use and abuse in your area because your clinic and health committee is discussing doing something about the problem.

- The first way of defining your research question is, therefore, to specify where it takes place.
- The next step is to determine precisely which group you are talking about. Which age group do you define as adolescence - is it between 13 and 19?
- The next step is to define your way to measure the question. Your original research question also talks about 'regularly', but regularly is a vague word. Do you mean every day, once a week, twice a week? And what about the amount? What level of alcohol consumption are you concerned about, and why?
- You also need to consider what you want to get out of the research. Do you only want to know how many young people drink, or do you also want to know why? If you are researching to create an intervention, knowing how many, who, and why may be necessary.

As a result of these adjustments, you may want to refine your research question to look something like this:

How many young people in location x, age 13-19, drink more than five units of alcohol per week?
What are the reasons for drinking?

Exercise

Use one of the research questions you formulated above and refine your research question. Consider what is known, what we want to know, and how to use the new knowledge the research will generate. Remember to avoid vague terms and be precise.

Test your knowledge 2

1. What is a research question:
    a. A question that describes the way research will be conducted. ☐
    b. A question that states what knowledge the research is seeking to get. ☐
    c. A question that addresses gaps in participant's knowledge. ☐

2. Which of the following sentences can be considered a hypothesis?
    a. Getting vaccinated for Covid-19 lowers the risk of contracting the disease by over 60%. ☐
    b. What are the reasons for people choosing not to vaccinate? ☐
    c. Getting vaccinated for Covid-19 increases the risk of getting cancer. ☐

3. Do you consider the following a good research question: 'Living on Mars increases life expectancy':
    a. Yes ☐
    b. No ☐
    c. Don't know ☐

4. What is a research gap:
    a. A gap in knowledge on a specific topic ☐
    b. A gap between what can be researched and what cannot be researched ☐
    c. A gap in researchers' capacity to research a specific topic ☐

5. What should you consider when you formulate a question:
    a. Whether the question is easy to answer ☐
    b. Whether the question is answerable ☐
    c. Whether the question leads to more exciting research questions ☐

STUDY DESIGN AND METHODS

Learning Objectives:

By the end of this chapter, participants should:

- Be able to identify the differences between qualitative and quantitative research methods
- Be aware of commonly used research methods such as observations, interviews, focus groups and surveys
- Understand what multiple and mixed methods are
- Understand the basics of how to choose methods

Chapter 3

Once you have defined a precise and doable research question or hypothesis, you need to develop a study design and choose methods. You need to consider carefully what kind of question you are asking, and how it can best be answered.

This chapter will introduce you to commonly used social sciences methods and share ways in which these methods can be combined into study designs.

Some key terms:

- Methodology: the overall plan for how to answer the research question by collecting and analysing data.
- Data collection methods: specific ways of collecting data.
- Data analysis: specific ways of analysing data. This will be dealt with in a later chapter.

A helpful analogy may be that data collection and analytic methods are the ingredients, and the study design is the recipe.

The research questions describe what we want to know. The study design and methods describe how we are going to get the data. There is a close connection between research questions and the study design and methods. Certain types of research questions can be most easily answered with certain types of methods.

Different research methods

In social science research, there are two basic forms of data collection: qualitative and quantitative. **Quantitative** means that the research question can be answered with numbers. Sometimes they will answer questions that respond to 'how many' questions. **Qualitative** means that the questions can be answered with words. They are sometimes questions that explain 'why' and 'how'.

Studies can use one method or combine two or more methods. When we use more than one method and the methods used are either exclusively qualitative OR exclusively quantitative we talk about multiple methods studies. When we use both qualitative and quantitative methods in the same study, we talk about mixed methods studies. When we talk about study design, or methodology, we talk about how different methods come together to provide data to answer our research question.

The table below provides an overview of different study designs, data collection methods and data analysis.

Table 4: Characteristics of different research methods

Type of research	Focus	Number of study participants	Common data collection methods
Quantitative	Concerned with numbers Answers: how many questions	Involves many people	Surveys Observations
Qualitative	Concerned with words Answers how, why questions	Involves fewer people	Focus groups Interviews Observations
Multiple methods	Multiple methods can consist of more than one qualitative method OR more than one quantitative method	It depends on whether the study is qualitative or quantitative	It depends on whether the study is qualitative or quantitative
Mixed methods	Involves both quantitative and qualitative methods. It can be combined in different ways	It can involve many or few. It depends on which methods are involved	Both quantitative and qualitative

So how do we decide on study design and methods? In short: The research question (or hypothesis) guides the study design and the methods chosen. As the table shows, some methods are best suited for research that can be answered with numbers. And there are methods best suited for research questions that can best be answered with words. Here qualitative methods are best. If research questions ask both number and explanatory questions, we may choose quantitative and qualitative methods.

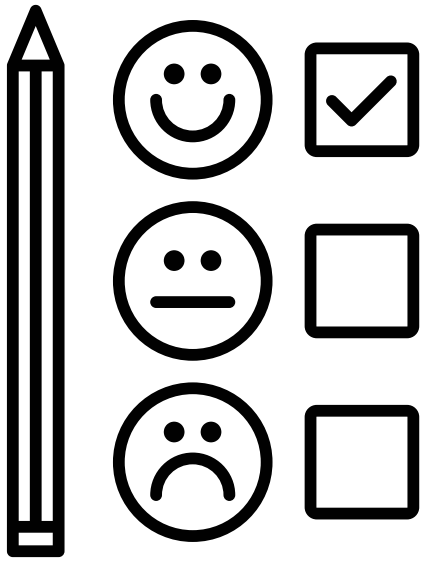
For instance, take the question on alcohol consumption from our previous chapter. The research questions ask about quantity, and reason. (**How** many young people drink a certain amount, and **why**?) For the first part of the question, we would need to use a quantitative method, and we would want many participants to get as accurate an answer as possible. The next part of the question asks about reasons: why? There are many ways of answering that question. It can be done quantitatively, where you provide potential answers, which the participants chose. Or, it can be done qualitatively where you interview participants either individually or in a focus group.

There are strengths and weaknesses in both. If you choose a quantitative method, you can get an answer that explains how common a particular reason is. The downside is that you may miss reasons because you ask participants to choose between reasons you have determined as important but may miss reasons you had not considered. If you interview people, you can ask open-ended questions, which will ensure that all causes can be incorporated. You may also get more in-depth answers, explanations and understandings. There are many ways of combining methods into a study design.

An example is below:

Common research methods

There are many research methods to choose between, and researchers constantly develop and try out different methods. However, there are a set of commonly used methods in social science research which are described below. For some research questions, there is an apparent 'link' to a specific method or a specific study design. For others, there are many possible ways of generating the data.



Questionnaires / Surveys

Surveys are a widespread research method with which most people are familiar. It can be done on both a small scale and a large scale. It will often be large scale with many hundred or thousand participants because surveys often want to quantify answers – that means giving numerical answers.

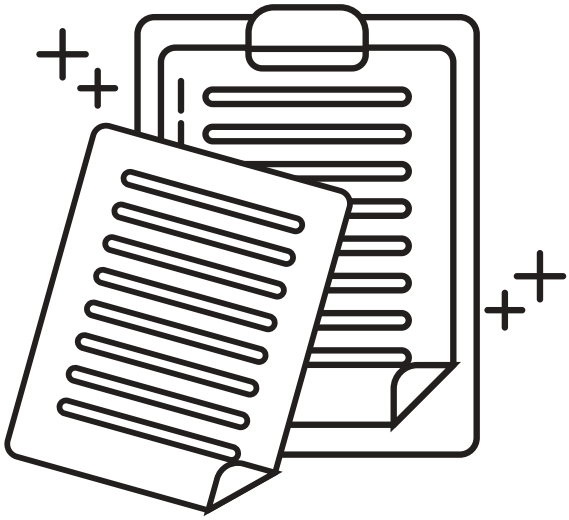
A survey can contain both quantitative and qualitative questions and ask closed (where the respondent chooses options) and open questions (where the respondents describe their answers in words).

Often, it may be a good idea to mix different ways of asking questions. Again, the best way to pose a question is linked to what you want to know. As with all research, the important thing when designing the questions in a survey is to be clear about what you are asking and avoid ambiguity. That way, you will get the most reliable answers.

Surveys can be done in person, written or oral; they can also be done via email or telephone. Before conducting a survey, you need to consider a number of factors.

Important things to consider when designing questions:

- Order questions according to the topic.
- Include demographic data. This enables you to analyse differences between different groups based on gender, age, and economic status.
- Provide a clear introduction.
- Which type is best: open or closed question.
- Choose between different types of questions
    a. Yes/No questions
    b. Multiple choice questions
    c. Likert scale
    d. Open-ended questions
    e. True/false
- Avoid ambiguity. Use precise wording and familiar language.
- Provide clear direction on how to fill out the questionnaire.
- Avoid bias.
- Ensure all options are covered. Example for gender: include 'Other' in addition to male and female.



The example below shows five different types of questions.

There are different types of questions. Below are five typical ways of asking questions:

1. The first type of question gives you two options: yes or no. *(Instruction to data collectors: Give participant all options and ask them to choose one answer)*

Example: Is it important for a pregnant woman to attend a pregnancy clinic? Choose one answer.

a) Yes ☐
b) No ☐
c) Don't know ☐

2. The second type of question has several options but only one answer. *(Instruction to data collectors: Read all the options and ask the participant to choose one. You must tick only one box.)*

Example: Why should a pregnant woman take folic acid tablets during pregnancy? Choose one answer. *(Instruction to data collectors: give participants options and ask them to choose one answer)*

a) It prevents early labour ☐
b) It decreases the risk of serious birth defects ☐
c) Too much folic acid can harm the baby ☐
d) Don't know ☐

3. The third type of question gives the participant several options. The participant can choose as many answers as they want. You need to read all the options and tell them to choose as many as they like. This is important, as we want them to choose as many answers as they like, not just one. If they only give one answer, ask them whether they think any other answers are also applicable.

Example: Where do you usually get health information? *(Instruction to data collectors: Give participant all options and ask them to tick as many boxes as they find appropriate)*

a) Written material ☐
b) Internet ☐
c) SMSs ☐
d) Friends, family, colleagues ☐
e) Other ☐
f) I don't get any information about health ☐

4. The fourth type of question asks the respondent for a number. Here, you must write a number.

Example: How many times have you been pregnant?
(insert number) ☐

5.The fifth type of question will ask the participant to explain. Here, you must write the answer in words. If they do not have any comments, please write 'no comments'.

Example: Please explain how you reacted when you got the SMS messages about pregnancy:

_____

_____

6.The last type of question is Likert scale questions where the participant must choose how much they agree or disagree with a statement. You read a statement to the participant and ask them to decide whether they strongly agree, agree, neither agree/disagree, disagree or strongly disagree. You must give them all options and ask them to choose only one.

Example: The clinic gives sufficient information on pregnancy:

Strongly agree	Agree	Neither agree/disagree	Disagree	Strongly disagree

Exercise

Choose a research question and design a survey or at least some questions for the survey. You can write the questions in the box below or on separate papers.

In plenary: What were some of the challenges when designing a survey?

Do you think a survey was the best method, or which other method could have been used to answer the research question or part of it?

Interviews

Individual interviews are a common qualitative form of data collection. The researcher or data collector sets up an interview with a participant individually and interviews them. There are many different types of interviews. The primary way of categorising them is in terms of how structured they are.

- A structured interview means that all questions are framed and written down beforehand, and the researcher sticks to those questions. The advantage of this interview form is that all research participants are asked the exact same questions, and interviews can easily be compared. The disadvantage is that the researcher cannot probe questions to get more information if something relevant comes up.

- A semi-structured interview allows for more flexibility. Here the researcher will have a set of questions but may add questions, probe and follow up. The advantage is that it allows for more in-depth questions and unexpected answers to be probed more in-depth.

- An in-depth interview. Here, the research is guided by a topic guide, and questions are more open and follow a conversational style where the researcher may follow the interview's direction. The researcher will use a topic guide to frame questions.

Below is a structured interview schedule used to explore why people participate in Parkruns, an outdoor timed run taking place on Saturday mornings across the world.

Example of a structured interview guide

1. What's your age?
2. Which gender do you identify as:
3. Which race do you identify as?
4. Why do you participate in Parkrun?
5. What is your exercise history?
6. What prompted you to first come to Parkrun?
7. How long have you been doing the Parkrun?
8. How many times in a month would you say you do Parkrun?
9. Do you come to Parkrun alone or with other people?
10. How would you describe the atmosphere at the Parkrun?
11. Is the fact that the runs are timed a significant incentive?
12. What impact has participating in Parkrun had on your life?

Below is a topic guide used to explore how health committees are involved in managing complaints at the clinic.

Example of topic guide for a semi-structured interview

- Explain the way the process works. Are they involved beyond calling to get more information?

Probe

What works well?
What does not work well?
What could you do better?
What would you like to change?

- Is anything holding you back? If so, what
- Who decided you should be part of complaint management?
- Has your view of how to do complaints changed?
- Why?
- Do you have any personal experiences with complaints?
- What is the aim of complaints/purpose of your involvement
- What have you achieved?
- What do you hope to achieve?
- Discuss examples of complaints and how they were resolved? How could they have been resolved? Was it a good way? How could it have been used to strengthen the health system?

Your choice between the different interview forms depends, again, on your research question. What type of interview is most likely to give you the data that will help you answer your research question.

Exercise

In pairs, choose a research question and choose a type of interview. Then develop the interview questions or the topic guide and practice. Take turns.

Focus group discussions

Focus group discussions (FGDs) are group discussions where the researcher invites people to come and discuss a specific topic. The discussion is often similar to the in-depth or semi-structured interview as the researcher will probe, look for understandings, and clarify meanings. An FGD can be particularly useful when the study concerns groups and includes group dynamics. The researcher may be able to do observations during the FGD that are useful and can be raised in the discussion. For instance, if you research gender roles in leadership and you have invited leaders to a focus group to discuss this and observe that women are quiet, that men interrupt them and belittle their input, you may want to ask direct questions about that.

When you do a focus group, you need to consider who to invite. It may be a natural group, such as a health committee, but it may also be a group of people whose views and experiences you want to explore. For instance, if you study gender dynamics, you may want to have separate discussions with different genders (in addition to joint FGDs.) FGDs can be very efficient ways of generating data. The group setting can help create ideas and a space for sharing experiences that are not as easily generated in an interview setting. An FGD is guided by a topic guide, similar to an interview guide.

Exercise

In groups, choose a research question and develop a topic guide. Choose a 'researcher' and conduct a FGD. Discuss your experience.

Observations

When a researcher uses observations as a method, they observe what happens in a natural setting without influencing the setting. Observations can be both quantitative and qualitative.

Observation can be structured or unstructured. A simple example of a structured observation could be how many drivers drive through a yellow traffic light. Here you know precisely what you are looking for. Unstructured observations are observations where you observe a situation without having defined precisely what you are looking for. You could, for instance, observe a meeting. You will note everything that happens and try to make sense of your observations later. Observations can also provide information in framing questions if your research design incorporates both observations and other forms of data collection.

The advantage of observations compared to other methods mentioned above is that it observes what occurs in contrast with surveys, interviews and focus groups, which all rely on people answering questions. In other words: surveys, interviews and focus groups collect self-reported data. There is no guarantee that they do answer honestly. In particular, sensitive and contentious topics may lead to respondents not answer truthfully.

For instance, if a researcher asks people if they use corporal punishment to discipline their children, they may answer truthfully if they believe this to be the best way to raise children. But if they think that this is not socially acceptable or that the researcher has strong views against it, they may not answer truthfully. We call that social desirability. It means that you answer what you believe is considered the right and acceptable answer.

When you observe behaviour, you can lessen the risk of this. However, observations are also tricky because people may modify their behaviour if they know they are being observed. You always need to consider social desirability when designing a question that relies on people to answer questions. Still, you also need to consider what impact your presence may have on observation.

When including observations in a study, researchers also need to be aware that researchers can be biased (researcher bias). A possible way of minimising this could be to have someone else than the researcher doing the observations.

Exercise

In groups or pairs, choose a research question and consider how observations could be useful. If possible, observe a similar situation and take notes on your observation.

Once you have decided on your study design and methods, you can begin developing your research instruments. These are interview schedules, topic guides, surveys etc. This is what you have practised above. (Tip: while working on your research instruments, check that they will help you answer your research question or test your hypothesis). You will also need to decide how you are going to select your participants. We will deal with this in the next chapter.

Test your knowledge 3

1. Which of the following describes a qualitative research study?
   - a. The study will, through 20 in-depth interviews, ascertain students' experiences of mental health during the COVID-19 pandemic. ☐
   - b. A survey with 400 respondents were used to assess knowledge about hypertension in the study population. ☐
   - c. The study combines a randomised survey with in-depth interviews. ☐

2. A quantitative study is concerned with:
   - a. Word answers ☐
   - b. Number answers ☐
   - c. Word and number answers ☐

3. Observations are which type of method:
   - a. Can be both quantitative and qualitative ☐
   - b. Quantitative ☐
   - c. Qualitative ☐

4. A mixed-methods study can be described as:
   - a. A study that uses more than one method ☐
   - b. A study that uses both qualitative and quantitative methods ☐
   - c. A study that uses at least two methods ☐

SAMPLING AND RECRUITMENT

Learning Objectives:

By the end of this chapter, participants should:

- Understand the definition of a study population
- Understand the definition of sampling
- Understand non-random and random sampling
- Be familiar with convenience and snowball sampling

Chapter 4

Sampling is the process of selecting participants for your study. Depending on what type of study you are conducting and the topic of your study, you will select a sampling technique and decide how many participants you will include in your study.

Before you decide on your sampling method, you need to define your study population. Your study population is the group of people you are interested in studying. You only sample (select) participants from within that population. Examples of study populations might include: high school students, residents of Manenberg, health committee members, female librarians. For instance, in the example with the study on adolescent alcohol use, the group is defined as young people between 13-18 in location x. Your study population is people between the age of 13 and 18 in location x. You need to get your sample from this group.

Sampling is informed by methods, but also your access to your study population and by what is possible, including your capacity and funding. There are two main forms of sampling: random and non-random.

Random sampling

Random sampling means that person a in the study population has the same chance of being selected for the study as person b. In other words: there is no pattern in how participants are chosen. We aim at randomness because we want the sample to represent the entire study population, as this enables us to generalise from the sample the entire study population.

A good illustration of randomness is if you put names in a hat and then draw the names you want to include in the study from that hat. You might also have a list of people, and you choose every tenth person for your survey. Often you will have a sample frame, a list of people. Say you want to study how satisfied patients are with the local clinic. You could possibly get a list of names of patients and then randomly choose every tenth patient. You could also choose to approach every tenth patient that leaves the clinic.

But how do you choose how to sample? You need to consider your method. If it is a purely quantitative study, you want to select a representative sample. A representative sample means that the results from the sample are very likely to be the same as if you sampled the entire study population. To ensure that your sample is representative, two things are important: 1) you need to make sure that your sample is big enough, and 2) make sure that it is random. There is a mathematical formula that can be used to calculate the sample size. However, in a collaborative community-engaged research project, you would often let the academic researchers calculate the sample size. The sample size for randomised depends on the size of the study population.

When you do random sampling studies, you sometimes need to consider different groups within the study population you want to sample equally. For instance, you may want to know if there is a difference between men and women, between young people and older adults, between people living in informal settlements and suburbs. If so, you need to sample within these groups. You can still do random sampling, but you will then do it within these groups. Another example could be the study with youth. You may want to make sure that all age groups are represented equally. This is called stratified sampling, but again that is a technical aspect that researchers in collaborative research should be responsible for.

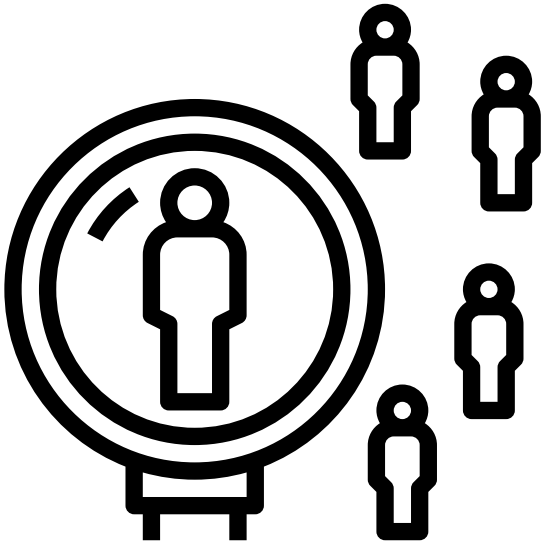
Non-random sampling

For qualitative studies, you are not necessarily looking for representative samples (though you may). Therefore you use non-random sampling techniques, often called purposive sampling. Because your aim in qualitative research is not necessarily to generalise to a large population but to get in-depth knowledge of experiences and phenomena, qualitative methods do not place much emphasis on representativity. Instead, you are often interested in people with specific expertise or experiences. In qualitative studies, you will often use purposive sampling. That means that you choose your study participants with a 'purpose' because they possess specific knowledge and have particular characteristics and experiences. The participants obviously still have to belong to the study population. Like with quantitative methods, you may also want to do stratified purposeful sampling.

When sampling, you will have to consider practicality. Sometimes you will have a clear sampling frame that you can use. A sampling frame means that you have something you can choose your participants from. This could be a list. For other studies, it is not that easy to access your study population. This could, for instance, be a 'stigmatised' population or populations wary of researchers.

Say you want to study sex workers' experience of health care. You may be able to access them via organisations. You may have to use a method called convenience sampling. Convenience sampling simply means that you enrol participants from the study population that you have access to. Sometimes you can use what is called snowballing. That means that you ask study participants if they know someone you could interview, and then you ask that person to refer you to another person within the study population.

For some studies, your method and study design may suggest that it would be best to do random sampling with a large sample, but practically this is not possible. For instance, you may not have easy access to the study population and cannot identify sufficient numbers to do random sampling. In that case, you may use convenience sampling even though it is not the best match for your study. Here, you must note why you have chosen the sampling strategy even though it is not the best for your study.

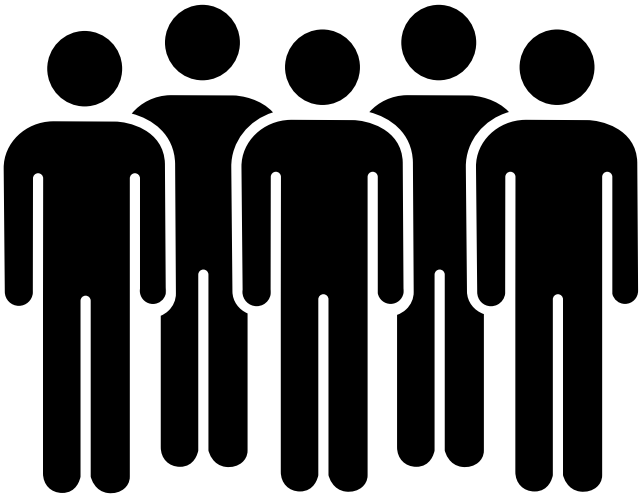


For studies where you use multiple and mixed methods, you will sample for each method/component of the study.

Exercise

Discuss in groups. For your chosen research question: Consider how you would sample and recruit. Which sampling strategy would you use. Explain your reasoning below:

Once you have decided on your sampling method, you need to consider how you will recruit participants. Again, it depends on whether you are going to recruit large numbers or smaller numbers. The important thing to remember when recruiting is to give the participants sufficient information for them to be able to make a about whether to participate or not. Recruitment can be done via adverts, SMSes, phone calls, public meetings or personal contacts.

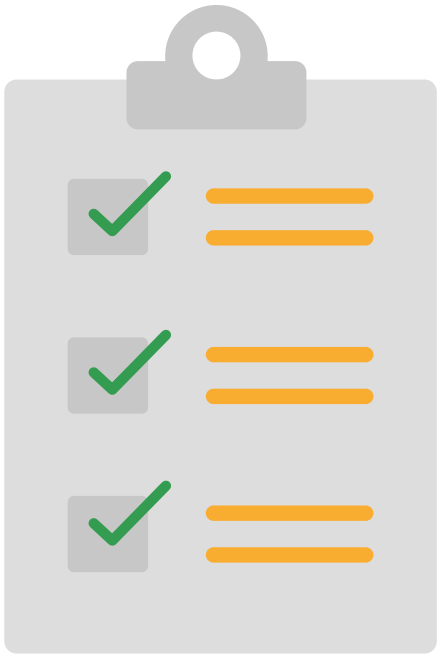


Planning and preparation

Once you have decided on your research question, study design, sampling technique, developed research instruments, project information sheets, and consent, you are ready to begin the practical planning of the research. You need to consider what you need at every step of the research process.

Here are some issues to consider:

- What is the timeframe you need to conduct the research?
- Do you have the resources (human and financial resources)?
- Do you have the technical expertise or the right team?
- Do you need any equipment?
- Do you need to do training?
- Do you need translators?



Test your knowledge 4

1. A study population is:
   a. The group of people that takes part in the study.
   b. The group of people that they research question is concerned with
   c. The group of people that study the results of the research.

2. Sampling is the same as:
   a. Selecting research participants.
   b. Selecting study population.
   c. Selecting research assistance

3. Random sampling is used in:
   a. Qualitative studies
   b. Studies where researchers have limited access to potential study participants.
   c. Quantitative studies

4. Which statement is true for purposive sampling:
   a. Participants are chosen based on their knowledge or experience.
   b. Participants are chosen randomly if possible.
   c. Participants do not have to be part of the study population.

5. Representivity is always a goal when sampling:
   a. Yes
   b. No
   c. don't know

DATA ANALYSIS

Learning Objectives:

By the end of this chapter, participants should:

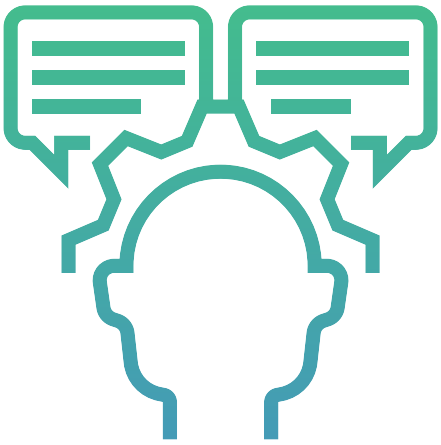
- Understand the basic principles for analysing quantitative and qualitative data
- Be familiar we simple descriptive statistical analysis
- Be familiar with coding

Chapter 5

Quantitative data

We have described two main forms of data collection methods: quantitative and qualitative. Similarly, there are two main ways of analysing data. For quantitative data, when we collect numbers, we will analyse numbers and conduct a statistical analysis. Some of these methods can be very complicated. The most simple form of statistical analysis is descriptive statistical analysis, where you may calculate the percentages that give a specific answer to a question.

These methods consist of calculating the percentage of specific answers. For instance, say you asked participants about their favourite ice cream flavours and gave them 10 different options to use: chocolate, vanilla, strawberry, mint, coconut, nougat, pistachio, salted caramel, coffee and granadilla. If you have included 1000 participants in your study and 139 say they prefer strawberry, you can calculate how many percentages of the total prefer strawberry 139x100/1000 = 13.9%.



In particular, analysing data can be left to researchers who are part of the community-engaged research team, where more complicated statistical analysis is needed. Rather than doing the actual calculation, community partners could be part of choosing the method, and they should be able to understand the results and what these results mean. It may be the researchers' task to explain how the statistical analysis can be interpreted.

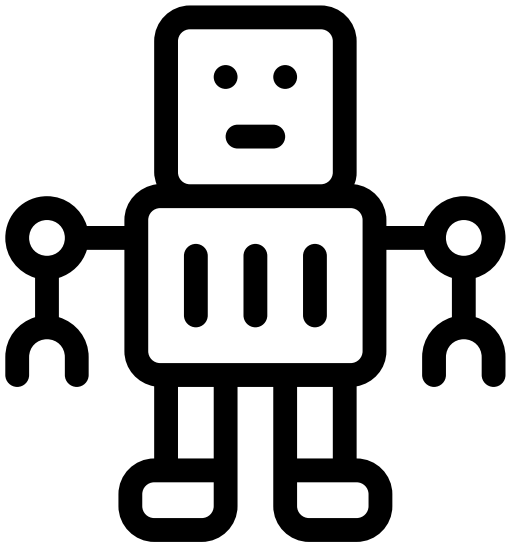
Qualitative data

For qualitative data, a common way to analyse data is called thematic content analysis. That means that we 'code' and look for themes in the text, which then form the basis for our analysis. Thematic content analysis is the most commonly used qualitative analysis method and forms the basis of other more advanced qualitative analysis methods.

There are several qualitative data analysis methods, but they all depend on finding themes in the text, whether it is interviews, focus groups, or combinations. The process of finding themes is often called coding.

When coding, the researcher identifies themes and ascribe selections of text to a specific theme. Often the researcher will identify a set of codes which (s)he may group into categories. These may be broader themes or more abstract concepts. The researcher may also identify relationships between different codes and categories. Often (s)he will go through the text several times to code the next. Coding may involve many different ways of coding.

There are computer programmes that can help manage the coding process, but if you don't have access to such as programme, a simple way can be to use highlighters for different codes. The text below are excerpts taken from a focus group transcription that explored how deaf women perceived an SMS campaign on information on pregnancy and antenatal care.



Examples of thematic coding

Improved knowledge and awareness

Difficult words/medical terminology

Sign language structure suggestion as improvement

Poor educational background as a reason for difficulties

Researcher	Ok, so now I would like to know why, what you liked about the SMSes? Why did you like them?
No. 38	The SMSes are actually helping so that I can wake up. So because I never get before the information such like this. So it helped me actually improve my knowledge.
Researcher	Ok, anybody else? What did you like about them
No. 20	The SMSes about the pregnancy, uhm so, so, they give us ehhh the awareness. Because we, as a deaf community, we don't have the people who can actually explain about it. So what we would need is if you guys can actually explain more about the SMSes, the words. It's only the words that we struggle with.
Researcher	Ok, anybody else? What did you like about them
No. 20	Like for example, if I have pain (someone whispers "abdominal pains") abdominal pains, so uhm, those are the things we are actually confused about.
Researcher	So it's the words, for instance, "abdominal"?
No. 20	Yes, it is.

Researcher	Ok. So sometimes the words are too difficult to understand?
No. 20	Yes.
Researcher	Does anybody else want to say something about why they liked the SMSes?
No. 18	So if you can just make it like easier for us deaf people. You can put in a sign language structure (Ok). That will be actually helpful for us.
Researcher	Ok. Sign language structure. [08:11]
Researcher	Ok, and who had something to say also...eh No.40
No. 40	Yes, I did receive the SMSes. Yes, like, for instance, some of the words I know, but the only thing that I want to know is what it is that they mean. So if someone can actually explain to us because our background of education is very poor, so...I started from Eastern Cape, so it's my first time here in Cape Town to come and learn such a big word like this. So, it's very difficult from my side.
Researcher	Ok, anybody else?
No. 31	So, yes, I did like the SMSes, but I'm still learning actually because the way of deaf people like I said before we are not actually being educated like the proper way so my...I am willing to learn more about the SMSes.

Researcher Ok. So I just wanted to...anybody else first that wants to say something about why they liked the SMSes? About what they liked about them?

Researcher You can say anything.

No. 20 The SMSes were very good for deaf people.

Researcher Sorry, can I pick up...one of you said that ehhh...you struggled with...actually two of you said you struggled with some of the messages. That the words were difficult. Is that something that all of you felt at times? That the words were difficult?

All Yes, sometimes. [11:00]

No. 8 Some I understood, some I didn't understand, but the SMSes were a bit clearer.

Researcher Ok, so that is a general problem then? Sort of medical words are difficult to understand. Ok, I see lots of people nodding.

Researcher And something...another one of you said it would be better with sign language structure. How does the rest of you feel about it?

No. 38 If its sign language structure, it would be very, very nice, and uhm...then it would be easy for us to understand because like each word would be simplified if they were using sign language structure as well.

Researcher And that's something all of you sort of agree on, or is there someone who doesn't have a problem with this structure?

Exercise

The following interview transcript explores why people participate in Parkrun. In groups, code the text.

Interviewer 1: So, uh, why do you participate in Parkrun?

Oh, I have been trying to get fit and lose a bit of weight and doing a bit of exercise and running is the best sort of weight-loss activity, I am let to believe. (Interviewer 1: uhm, Interviewer 2: yah aha)

Interviewer 1: Any other reasons?

Uhm, I think it is also linked to fitness, just in general being healthy. I have struggled with back problems, and obviously, the less weight I am carrying, the better for me.

Interviewer 1: Do you have any other specific health concerns?

Other than that problem, not really. Uhm, I have been playing cricket for many years, and cricket is a sport where you spend a lot of time down. And I twisted my back twice playing cricket, so I do struggle, so the less weight I can carry on my upper body, the better for me. (interviewer uhm hu)

Interviewer 1: Do you have sort of specific goals?

Uhm, My original goal for this year was to lose 40 Ks. It hasn't quite happened. Uhm. I lost 20 last year (Interviewer 2: wow). Ja. But I have stagnated at the moment.

Interviewer 1: And... what is your sort of experience.... Tell me a bit about your history with exercise?

So I played cricket my entire life from I was pretty young. I was always involved in sport. I always ate a lot (interviewer 2: uhm), so I was always a big guy, but I am fairly athletic, and I could carry my weight. It wasn't a major problem. It probably was a problem that I couldn't go further, but at the level I was playing, it was comfortable, uhm, so I exercised often uhm it was a summer sport, so in the winter, I didn't do much to. Uhm. But I did it more for the love of the game than to keep healthy. This is a little bit different now as I am trying to get into a different space health-wise.

Interviewer 1: But you were quite fit that time?

Uhm, I wouldn't say quite fit, I was never running fit, but I was a lot fitter than I am now. I could do more with my body.

Interviewer 2: You mentioned that you stopped playing cricket at one point. How long ago was that?

4 years ago. I had a break in between, but it was when I twisted my back. (Interviewer 1: ah-ha) so actually, when I twisted my back the first time, I was playing again the next week, so (inaudible)

Interviewer 1: So did you start - you said one of your goals was weight loss – did you start gaining weight after you stopped exercising?

Uhm. Yes. I picked up some weight, but I think more importantly, uhm, my other bad habit caught up with me, smoking. Uhm, I wasn't particularly healthy. Over the summer months, I would lose some weight, but it would come back. Once I stopped, it would just layer it on.

.....

Interviewer 1: And what prompted you to start Park running?

So what happened was when I started 'gyming'. Right. I gymmied twice a week initially, and I didn't even eat that much healthier, but I started losing a little bit of weight, and I travel about a month. I came back and - it was three weeks - and I came back and, I realised, actually, I am not going to lose more if I don't start doing more things. Uhm, so once I lost those 20 Ks, I thought, o,k if I want to get to the next twenty, I need to add to what I am doing. And that's why I decided, ok, let's get into running. Uhm, I tried getting into running. So this is where I am now. I do the Park runs. The Parkruns I only do really to pay for the watch, and it gives me some sort of measurement. The goal for this year is to do a half marathon. Uhm, we are doing a race tomorrow, which is 10 Ks. I have done three races already, so I want to get into that sort of that side of it.

Interviewer 1: So Park running is only part of a broader running...

Ja. broader running goal.

Interviewer 2: So that is an Apple watch from Discovery?

Ja. From Discovery -if you do the Parkrun you get the points, and that pays for the watch.

Interviewer 1: And is that important?

I like that idea that they pay for the watch (interviewer 2: laughing) Look, I was … (Interviewer 1: laughing)

Interviewer 1: So Discovery Points are part of the reason why Parkrun and not other runs?

I think there are two components. The one is the Apple watch. And the second piece in this is where I can pick up on my progress. Often you run in different sort of uhm routes, different terrains, and you maybe run a 10 K in 1 hr 20 minutes, and then you run another in 1 hour 40 minutes, and you don't know what the difference i,s and you think you have done bad. So you try to use Park run as a barometer (interviewer 2: ja) cause it is the same run, so you can pick up your progress over week after week. Or if you are like me at the moment, when you go backwards, you can see how much backwards.

Interviewer 1: So the fact that it is a timed run is important?

It is the timed run. It is the fact that it is a consistent run, and there is a little bit of social element also. Lots of my friends are doing it as well. (Interviewer 1: uhm hu) We generally go for a coffee afterwards.

Interviewer 1: So do you come here with friends or do you make arrangements to meet them?

Ah, we meet them here. But also like you meet people here, and you are friends with them, but uhm and I am part of the sleek geek group, so you start seeing people you have seen online and kind of meet people. I am a little bit antisocial like that, so I don't normally meet people. I am a shy person generally. Uhm, but I meet my own friends here, which is another couple, and we pick up one or two people and go for coffee.

Interviewer 1: So how important is that for you?

Uhm. I actually enjoy it.Like I said at the moment, I am 'gyming' three times a week. I am running twice a week in the evening so on a Monday, Wednesday and Friday I gym from 6 till 7 in the morning. Tuesday and Thursday I am doing a run from about say 6:30 till 7:30 in the evenings. And then I study as well, so I am doing one of these online advanced diplomas, so there is quite a lot of work you got to get through. Most of my week is really about work, doing things on my own, so the social element kind of helps you know while you are doing something. It could get more social, but it wouldn't be as healthy. (interview 1: ok)

Interviewer 1: So, do you mostly set up arrangements to go for coffee afterwards?

It's a standing thing. They are probably waiting for me over there (points to friends). We come and do the run, and then we go for coffee with breakfast.
.....

Interviewer 1: So again, having someone to do it with?

Ja.

Interviewer 1: Is that just the social thing, or is it also sort of an accountability thing?

It is both. It is a social thing, and it is also an accountability thing. And also, I am quite competitive. So I like that I am better? (a,h ok laugh)(Interviewer 1: ok) so there is that aspect as well. Here is he now (pointing to a friend).

Now that you have worked on both data collection methods and analytical methods, you are ready to choose a study design and methods for the research question you identified earlier – or choose another question.

Exercise

Choose methodology: data collection and analytical approach. Consider what the best approach is to make the research question measurable and doable. Note your responses in the box below:

Test your knowledge 5

1. What type of data analysis can be used in qualitative research?
    a. Thematic content analysis ☐
    b. Descriptive analysis ☐
    c. Both of the above ☐

2. What type of data analysis can be used in quantitative research?
    a. Thematic content analysis ☐
    b. Descriptive statistics ☐
    c. Both of the above ☐

3. What type of data analysis would you use for a mixed methods study?
    a. Thematic content analysis ☐
    b. Descriptive statistics ☐
    c. Both of the above ☐

ETHICS

Learning Objectives:

At the end of the chapter, the participants will

- Understand the importance of ethics in research with human subjects.
- Understand the principles of the Belmont report.
- Be able to consider ethical principles in relation to research projects.

Chapter 6

What does the word “ethics” mean to you? Ethics can be defined as a set of moral principles that governs a person’s behaviour or the conduct of an activity. It can also be described as the discipline of dealing with what is good and bad, right or wrong. It is concerned with moral duty and obligations.

Ethics is important because research has sometimes been used to cause harm. In particular, ethics in medical research has received a lot of attention. An important historical example is research done on humans, for instance, during the Second World War by the German Nazi regime. In concentration camps, many medical experiments were conducted. For example, prisoners were deliberately infected with typhoid to test vaccines.

Another example is the Tuskegee Syphilis Study, which enrolled African-American males in a study aimed to study the natural history of untreated syphilis. The men were promised free health care as part of the study, but did not receive any. For instance, the researchers did not inform the participants of their diagnosis and disguised the use of placebos, medicine with no effect used to test whether a treatment is effective. The study began in 1932 and lasted for four decades, despite the men being told it would only last six months. When penicillin, effective in treating syphilis, was discovered in 1947, the men in the study were not offered this treatment.

As a result of the Tuskegee experiment, which caused a public uproar when its motives came to light in 1972, a report called the Belmont Report was published in 1974. The Belmont report developed a set of principles for ethical behaviour in research and tools that should be applied.

The main ethical principles for research with humans are:

- Respect for persons.
- Beneficence
- Justice

With regards to respect for persons, an important principle is that people's autonomy should be respected. In other words, participation in research should be voluntary. It also means that special consideration should be given to vulnerable groups, such as people who perhaps do not have the capacity to understand the research and make an informed decision about their participation.

Regarding **beneficence**, it refers to the quality or state of doing or producing good. This relates to the rule of 'doing no harm', which means that researchers should not cause harm to research participants. Additionally, researchers have an obligation to making efforts that research ensures participants wellbeing.

The third principle is **justice**. This principle ensures that the 'burden' and the 'benefit' of research are equally distributed. For instance, in the Tuskegee study, Black men bore the burden of research but did not receive the benefit (treatment when available). The principle of justice means that some groups should not unduly bear the burden of research. Likewise, the benefits should not just flow to one group.

The examples mentioned above are obvious examples of harmful research, but research can also harm people in more subtle ways. Some examples of studies that cause harm could be studies that reignite trauma, disclose people's illness status or withholding knowledge of potential side effects when testing the efficacy of the medicine.

Exercise

In plenary: Discuss the benefits and harms of research—experiences and examples of when research benefits or harms people. Examples can be known examples or hypothetical ones (something you come up with). Also, discuss how potential harm could be mitigated. Note some of the answers below:

Informed consent

To ensure that research adheres to these principles, the Belmont Report also outlines ways of applying these principles. The important tools are:

- Informed Consent.
- Assessment of benefits and risks.
- Selection of subjects.

Consent means permission. When you consent to be part of a research project, you say yes to being part of it. However, as we have noted, ethics principles state that you need to show respect for people. When people give their consent to participate in a research project, it means that they need not only to do so voluntarily but also to have enough information about the study to make a decision. We, therefore, talk about informed consent.

In practice, the informed consent process means that researchers need to provide participants with information sheets that explain the study, including potential risks and benefits. The information sheet will also inform potential participants about issues such as anonymity, protection of personal information and confidentiality and the extent to which participants' anonymity can be guaranteed.

The information sheets must enable people to give their informed consent. The researcher also needs to make consent sheets, where the participants give their consent to be part of the study. Information sheets and consent forms need to be in a language that participants understand. Below are examples of Information Sheets and Consent forms. Doing research with children and people that are not capable of giving informed consent, such as intellectually challenged people, require additional ethical consideration, which is outside the scope of this manual.

Example of Project information sheet, interview, health committee member

Dear health committee member,

Thank you for taking the time to read this letter, which explains the project I would like you to be part of. The purpose of this letter is to give you information so you can decide on whether to be part of the study or not. But first, let me introduce myself. (introduction) I work at the University of Cape Town's School of Public Health. I am also a Ph.D. student. For the past six years, I have been involved with community participation in health and have worked with health committees. Health committees are also the topic for my Ph.D. research.

My Ph.D. study looks at community participation in health committees and how effective participation is. It is particularly interested in how well health committees represent and give voice to community needs. It will also look at how different forms of power, understandings, experiences and beliefs may impact participation. Finally, it will look at how people are able to exert agency to realise the right to health and improve health service delivery. The reason for doing the study is to find ways to improve health committee participation and improve health services through this.

The study period is expected to be between 12 and 18 months. During that period, I will visit the community regularly and observe what happens in the community, at the clinic and during health committee meetings. I will also interview people individually, and I will have discussions with groups of people. Towards the end of the study period, I will conduct workshops where I will present what I have found out and discuss how this can be useful for people that were part of the study. I will organise all study activities in collaboration with study participants – they will take place at a time and a place convenient to you.

This particular information sheet relates to interviews. The interview is expected to last approximately 45 minutes.

Participation is entirely voluntary, and even if you decide to say yes, you can withdraw your participation at a later stage. You can do this by telling me or informing my supervisor, Name and telephone number.
You will not receive any money from participating. But if you have transport costs related to being part of the research, I will repay you the money you spent. I will also make sure that we have refreshments for research activities.

I don't foresee any risks for you as a participant. However, some of the topics we discuss may cause tension either in the health committee or between the committee and the health facility. If this occurs and it is necessary to have outside mediators, please tell me to organise this.

While there is no direct benefit to you as a participant, I believe there are many indirect benefits. You may learn about how health committees function and how they could function better. You may become aware of things that limit your health committee participation and the impact the committee have on health service delivery. In the end, this could be used to improve health services. There could also be benefits to other people in the health system, such as facility managers, other managers and policymakers. If they learn more about health committee participation, they have information that they can use to improve participation.

I will ask for your permission to record the interview, which will then be transcribed by a research assistant. The transcribed interview will be stored on my computer, which has a password so only I can access it. I will not use your real name when I write about my research. I will make sure that people will not be able to tell who you are from my writing.All information you share with me will be treated confidentially. However, I may not be able to maintain as confidential information about known or reasonably suspected incidents of abuse or neglect of a child, dependent adult or elder, including, but not limited to physical, sexual, emotional, and financial abuse of neglect.

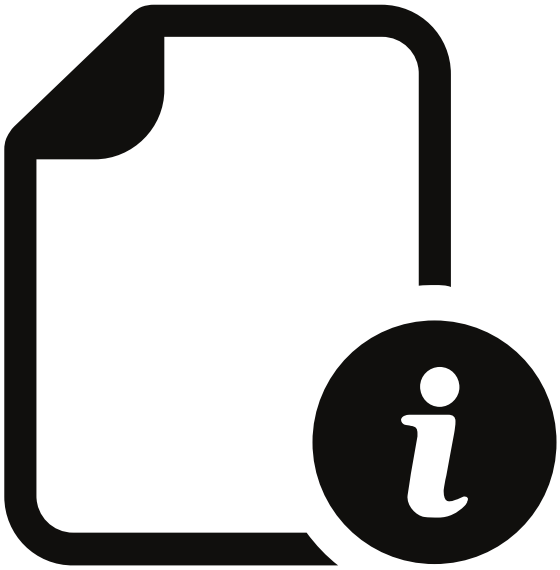
Once I have completed my research, I will write a thesis, which will be submitted to the University of Cape Town as my Ph.D. thesis. I will send my Ph.D. thesis to the Western Cape Health Department and publish the research in academic journals. I will present the research at conferences. Finally, I will invite all research participants to a colloquium (a big meeting) where I will present the research and discuss it with participants and other people interested in health committees.

Please feel free to ask any questions you have about the research, risks and benefits etc., either now or later. May I ask you some questions to make sure that I have explained everything well?

The University has approved this research of Cape Town's Health Faculty's Human Research Ethics Committee. Their job is to make sure that my research respects your rights. If you have any questions, complaints or concerns about this research, about your rights or welfare as a participant in the study, please contact them on the following phone number: 021 406 6338.

If you decide to participate in the study, I will ask you to sign a consent form, where you agree to participate. You do not have to make the decision immediately. If you need more time, let me know.

Regards,
Name of researcher



Example of consent form: Consent form, facility manager, interview

Dear facility manager member,

This consent form asks you for your permission to be part of my Ph.D. research on health committees. The consent form relates interview, which is expected to last approximately 45 minutes.
You have read the project information sheet and had a chance to ask questions about the research to enable you to decide on whether to be part of it or not.

I understand that taking part is voluntary, and my signature indicates that I agree to be part of the project.

Name and signature of the research participant.

Name Date

Signature

I agree to have the interview recorded

☐

Yes

☐

No

Name and signature of researcher

Name Date

Signature

Exercise

In pairs, practice how to take consent, one person being the researcher, the other being the participant. You can either use the information sheet and consent form above. Or come up with your own study. Note how the process went below and any questions you may have. After you have practised, we will do the exercise in the plenary.

The second application of ethical principles is an assessment of risks and benefits to participants. It relates to the principle of beneficence. Here the researcher assesses potential risks to participants. In a medical study, this could, for instance, be side-effects of the medicine. In social science research, it could be the disclosure of illness status. For each risk, the researcher needs to consider how (s)he can mitigate risks. The researcher also assesses the benefits. These could be on a personal level. For instance, a participant may receive free treatment. Or it could be on a societal level: the research may provide knowledge that could improve treatment or access. The researcher then needs to weigh benefits versus risks, and the benefits should outweigh the risks.

Exercise

In plenary. Read the outline of the study below. Based on this case study, consider risks and benefits and whether the risk-benefit ratio favours benefits. Which other aspects would you add to the study's ethic section to make sure you adhere to the ethical principles. Make your notes in the box below the case study.

A study examines rape survivors' experience of health care service. The research question for this study is to explore the kind of health service rape survivors receive and how satisfied they are with these services. Some key questions that will be explored are: are victims offered treatment for injuries, are they offered PEP for HIV and prophylaxis for other sexually transmitted infections, are they offered a forensic examination? In addition, the study will explore staff attitude and competence and the availability of trauma counselling for participants. Participants will be provided with appropriate medical care that they may not have been offered when they sought medical care after the rape. They will also be offered counselling. The method used will be semi-structured interviews.

The third application relates to justice and is concerned with the selection of study participants. The research must consider how selecting study participants does not place an undue burden on certain participants. For instance, in the Tuskegee study, only African-American men were chosen for no particular reason. They were probably chosen because they were poor, mariginalised and unlikely to object to the study. On the other hand, researchers should also consider that not only one group benefits from the research.

Exercise

Consider the case study below. Is this a good way of selecting people, or are there better ways to ensure fairness in burden and benefit from the study?

A virus has resulted in a global pandemic where different types of the virus circulate in different regions of the world. A group of researchers decide to study a virus prevalent in one continent to develop a vaccine. They decide to test it only in rich countries where they know governments and individuals may be able to afford to buy the vaccine. Once their tests show that the vaccine is safe, they want to test how effective it is.

Some research requires permission from a regulatory body or a research institution. For instance, if you want to research at the University of Cape Town's Health Science Faculty, you need ethics permission from the faculty's Human Research Ethics Committee. The ethics application is built on the principles in the Belmont Report. If you want to conduct research at health facilities in the Western Cape, you also need permission from the provincial Health Department. Make sure you have permission before you start your research.

Once you have considered the ethics of your study, you need to write information sheets and consent forms. Make sure that you translate these into the languages your participants prefer to use. Tip: Write in simple language to make sure they understand the information and consider adding a question probing whether they understood the information.

Test your knowledge 6

1. Which of the following descriptions describe the meaning of research ethics?
    a. Moral principles for researchers. ☐
    b. Principles about how research participants should conduct themselves. ☐
    c. Principles that ensures that research questions are answered properly. ☐

2. How did the Tuskegee study harm participants?
    a. It did not pay them for participation. ☐
    b. It used their personal data. ☐
    c. It did not provide treatment for them when this became available. ☐

3. Which three principles make of the Belmont principles:
    a. Respect for persons, Beneficence, Justice ☐
    b. Respect for persons, ethics, no maleficence ☐
    c. Beneficence, justice, right to information ☐

4. What is the term for asking adults for their permission to take part in a research project?
    a. Informed permission ☐
    b. Assent to participate ☐
    c. Informed consent ☐

5. What should the risk and benefits to participants be in order for a study to be considered ethical?
    a. There should be no risks. ☐
    b. Benefits should outweigh risks. ☐
    c. Benefits and risks should be the same. ☐

DISSEMINATION AND USE OF RESEARCH

Learning Objectives:

By the end of this chapter, learners should be able to.

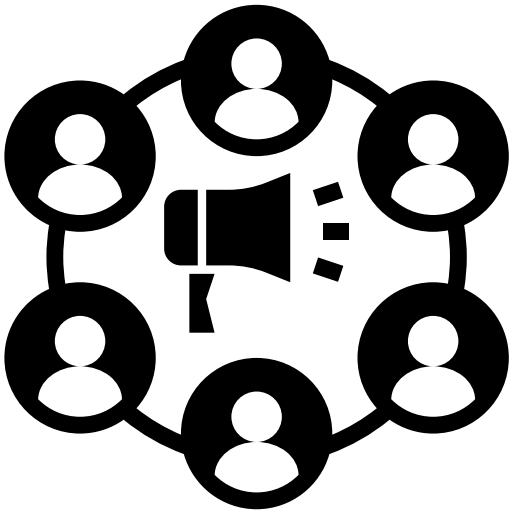
- Understanding the definition and purpose of dissemination
- Have an idea of how to disseminate research results to communities

Chapter 7

You have now collected your data and analysed it. Hopefully, you have been able to get the information you needed to answer your research question (or test your hypothesis). Your work is done— or is it? Sometimes the research aims to generate knowledge, and often research results end up on a shelf in an office or a library. In other words, it does not have an impact and is not used for any real-life purpose.

However, for participatory-based research or community-engaged research, research must have a purpose beyond knowledge generation. It should address a real problem or change something. Some research directly addresses a practical problem, while other research does not. Still, you can think about how the knowledge can be used, and you can share your results with others.

One way of making sure research is used is to make sure the information/research is disseminated. Often, academics present their research in peer-reviewed academic journals and at conferences. But for community-engaged research, that is not enough. It must also be disseminated to other stakeholders, including those who were part of the research and the research communities. There are many ways of disseminating research, including community meetings, pamphlets, videos, and posters.



Exercise

For your research question, discuss how you would disseminate your research. Also, discuss how the research could be used.

Test your knowledge 7

1. Dissemination is the same as:
    a. Finalising the analysis of research findings ☐
    b. Sharing the research findings ☐
    c. Making sure the research findings are used ☐

2. Traditionall research is often disseminated in:
    a. Academic journals ☐
    b. To business people ☐
    c. Not disseminated at all ☐

3. Community-engaged research disseminates findings in:
    a. Only in community settings ☐
    b. Both in community settings and academic journals ☐
    c. Does not emphasize dissemination ☐

GLOSSARY

Beneficence	an ethical principle and refers to the quality or state of doing or producing good. It is translated into concepts such as ‘do no harm’ and ensures participants’ wellbeing.
Benefits	considering what participants get out of this research. This could, for instance, be increased knowledge, medical care etc.
Community-engaged research	There are many ways of defining community-engaged research. For instance, “Collaborative partnership between academics and communities involving communities meaningfully in aspects of the research process to address issues affecting the community.”
Convenience sampling	Sampling method where those participants the researcher has access to are included in the study.
Data analysis	This is the process of making sense of the collected data.
Data collection	The process of collecting the data or doing the research, for instance, interviewing people.
Dissemination	Refers to the sharing of the findings, results and analysis of the research.
Ethics	set of moral principles that governs a person’s behaviour or the conduct of an activity.
Findings	Research findings refer to what you discovered through your research. In other words, it is the answers to your research questions.
Focus groups	A qualitative method where a group of people come together to discuss a topic.

GLOSSARY

Hypothesis	An assumption or an educated guess that is tested through the research.
In-depth interviews	An interview form based on open-ended questions and a conversational style, where the research explore the topic in-depth.
Informed consent	The process where research participants agree to be part of a study after being informed about the study, its risks, and its benefits.
Interview schedule	A list of questions that guides interviews.
Justice	An ethical principle that ensures that the 'burden' and the 'benefit' of research are equally distributed among different populations.
Methods	Methods refer to the way things are done.
Mixed methods	Methods that consist of both qualitative and quantitative methods.
Multiple methods	Methods that consist of more than one qualitative method or more than one quantitative method.
Observation	A method where the researcher observes what happens.
Project information sheet	A piece of paper or a pamphlet explaining what the research is about, what is expected of people participating in the research, potential risks and benefits, and other relevant information.

GLOSSARY

Qualitative methods	Qualitative that the answers can be answered with words. Qualitative research is often concerned with how and why questions and in-depth exploration of a topic. In-depth exploration is more important than the number of participants.
Quantitative methods	Quantitative means that the research question can be answered with numbers. Quantitative methods are often used to answer how many questions and often require many research participants.
Questionnaire	A questionnaire is a research instrument consisting of several questions that research participants must answer. Questions can be both quantitative and qualitative.
Random sampling	Random sampling means that a particular person in the study population has the same chance of being selected for the study as another person. In other words: there is no pattern in how participants are chosen. Random sampling is used in quantitative studies.
Recruitment	Refers to the process of identifying and signing people for a research project.
Research question	The question we want to get answered through the proposed research.
Respect for persons	An important principle meaning that people's autonomy is respected and that they have the right to decide whether they want to participate in research or not.
Results	The same as findings.
Risks	In research, participation can be associated with certain risks. In other words: the research can result in unwanted negative consequences.

GLOSSARY

Sampling	The way you choose research participants from your study population.
Survey	A research method used for collecting data from a predefined group of respondents to gain information and insights into various topics of interest.
Semi-structured interviews	A form of interview where you follow an interview schedule but also have the flexibility to probe issues that come up during the interview.
Snowball sampling	A form of sampling used with hard to reach groups. You start by identifying one or a few participants and ask them to identify others.
Structured interview	An interview form where questions are predetermined, and the researcher sticks to the questions.
Study design	The overall plan for how to collect and analyse your data.
Study population	The group of people your research is concerned with.
Thematic content analysis	This is the most commonly used analytic approach for qualitative data analysis. The researcher analyses the text for themes and generates an analysis of different themes.
Topic Guide	A list of topics to be covered in an in-depth interview or focus group.

ANSWERS TO TEST YOUR KNOWLEDGE

Test your knowledge 1

1. b
2. a
3. c
4. b
5. c

Test your knowledge 2

1. b
2. a
3. b
4. a
5. b

Test your knowledge 3

1. a
2. a
3. a
4. b

Test your knowledge 4

1. b
2. a
3. c
4. a
5. b

Test your knowledge 5

1. a
2. b
3. c

Test your knowledge 6

1. a
2. c
3. a
4. c
5. b

Test your knowledge 7

1. b
2. a
3. b