How to do a Research Project

Simple guidance and ideas for DEEP groups

Drawing on our learning from the Dementia Enquirers programme

Version: February 2023

Caution!

This guide tries to answer questions about all aspects of research. Don't feel you have to read every page. A lot of it will not be relevant to your project. We have designed it to be used as a manual – to be dipped into in search of clear answers to your questions.

deep
The UK Network of Dementia Voices

Dementia Enquirers

iD
Innovations in Dementia

COMMUNITY FUND

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Section 1

Planning your project

What is research?

Research is an activity that involves finding out things you did not know, or trying to answer a question that you're interested in.

How do you decide what topic to focus on?

- It should be something you feel passionate about
- It should be something that you feel will help yourselves and others
- It should be something that has not been focused on very much up until now or something to which you can bring a new perspective.

For example: You may have seen research that says 'being able to get out and about is not important to people with dementia'. If you disagree with this you could do your own research to find out the truth.

What do you do once you have decided on a topic?

Research can often seem big and scary. This is partly because there are lots of different ways the research can be done. **"If it looks too big and frightening – break it down and make it manageable."** The way you choose the 'research method' (examples on the following pages) will shape the type of questions you can answer.

Choosing the right 'method(s)' for your particular project can help prove to people that your conclusions are soundly based.

Examples of research methods you might use:

Group work:

Pros

Brings people together to share ideas and experiences. Captures a lot of information in one go.

Cons

Can be more difficult for some people to share their views or to get to a group venue.

Interviews:

Pros

Can be done one-to-one. You can do interviews at people's home if preferred.

Cons

They can take a long time. You will have a lot of information that you need to decide how to summarise.

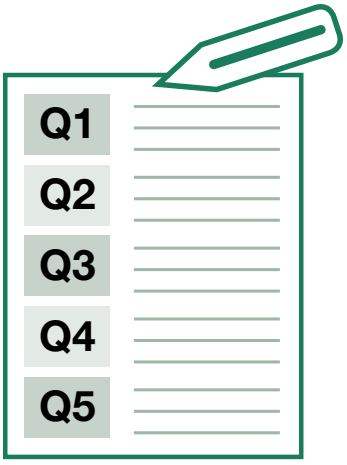
Questionnaires/ surveys:

Pros

They can be a lot quicker than other options and it's easier to summarise people's answers.

Cons

They are often quite impersonal. They can be frustrating if you do not get to explain your answers.



Aim for a narrow, focused idea. It will help if you consider:

Your aim:

- What do you want to achieve by the end?
- Is your aim feasible?
- Do you have everything you need to make it work?

Your questions:

You won't be able to answer everything at once. When you start research it can often lead to a lot more questions.

Take it one step at a time:

Step 1	What do you want to find out?
Step 2	What should you focus on?
Step 3	How do you find out?
Step 4	Who will be involved?

Your 'methods':

This simply means - how will you go about your project?

- Choose which research method you think will be the most useful in helping you to find the answer to your question.
- Decide if you have the skills for your chosen method. And if not, what other help do you need and where can you get this from?

A timetable:

- It's important to set out a simple timetable so you are clear what you need to do each month in order to get finished on time.
- Sometimes you may need to build in a gap of a few weeks.

> **For example:** When waiting for questionnaires to come back – or between inviting people to an event, and actually putting it on.

- Research can be unpredictable. It is always best to include extra time 'just in case' you need it.

Who do you need to involve?

- Can members of the group do all the work?
- If you do need other volunteers, how will you get them?
- Would it help to be linked to your local University?

If this all sounds a bit daunting, remember that you don't have to do it all on your own. Most researchers have help from other people, and you can too. Dementia Enquirers projects have had help from group facilitators, from students or volunteers, and from academics. They were still able to keep control.

A budget:

- What money will you need to spend on different things?
- How much will that add up to?
- Who will check you don't spend too much?
- You may not know exact costs, so include your best 'guesstimate'.

Here's some examples of things you could include

- [ ] Time (you can cost for extra time for the facilitator and/or group members)
- [ ] Travel costs
- [ ] Refreshments
- [ ] Venue hire
- [ ] Accommodation costs (if staying overnight)
- [ ] Equipment e.g. iPad, camera, recording device
- [ ] Printing and design
- [ ] Transcribing (if you are making recordings)
- [ ] A launch event

Case study 1: Support from volunteers

Forget-Me-Nots, Canterbury

The Working Party of people with dementia was supported by placement psychology students and volunteers. They would help to set up virtual meetings, keep notes and help to chair meetings.

Themes for questions were developed in the Working Party. And then the students and volunteers contacted other people with dementia in the Forget-Me-Nots group to discover their thoughts and opinions about the question themes. The questions to be asked in the survey were redrafted based on this information.

Students or volunteers ensured that the consent forms were filled in and they set up the online interviews at a mutually convenient time.

A student or volunteer attended the meeting to support each person with dementia to access the meeting. But they played little or no role in the interview itself. Once the interviews were complete, the students and volunteers conducted informal transcription and thematic analysis to establish key points.

The group acknowledged that the students helped them to see considerable growth in their abilities and knowledge, by allowing the project to run very smoothly.

Safety and ethics:

What do you need to think about to ensure you are honest, respectful and appropriately careful towards anyone involved in your project?

Do you need to get ethical approval?

Some research cannot be published unless a group of people have reviewed your work to check it looks after the people involved. Find out more in 'The Dementia Enquirers Gold Standards for Ethical Research' here **https://bit.ly/3XF6EwW**

Project Description:

Think about how you might describe your project?

This is important as it provides information that people need to know when...

- deciding if they want to take part in the research
- understanding how, or where they might be able to help
- recognising how the research results might make an impact

Section 2

Ethics

What are research ethics?

'Ethics' is simply about being honest, respectful and appropriately careful towards anyone involved in your project.

An ethical research project would…

…be honest and clear

…be respectful of everyone taking part

…look after the health and wellbeing of people taking part

…have a clear plan to complete the research

…have a clear purpose/reason to be done

The amount of detail people need to focus on for ethics will vary depending on the type of research. **Some examples:**

Testing a new drug treatment for Alzheimer's Disease

Participants would be given a new medication to take every day

Generally higher risk than non-medical research.

May be invasive.

Can be a big commitment e.g. lots of appointments.

Could make someone feel worse.

Exploring experiences of receiving a dementia diagnosis

Participants are asked to share their experiences in an interview

Lower risk than medical studies.

Talking about sensitive topics can be upsetting.

Potentially less benefit to the person taking part.

Things to think about:

Respect:

How will you demonstrate respect and courtesy to all involved?

- Ensure language is not patronising or disparaging.
- Avoid bias, stereotyping, discrimination, prejudice, intolerance and discrimination (i.e. treating somebody negatively because they are different to you in some way).

If people with dementia are involved:

- Think about how information is presented. Is it easy to understand? Is it clear?
- Does the research involve a lot of concentration? If so, will there be enough breaks?
- What might you adjust to avoid taxing people's memory or communication skills?

Safety:

- Could your project hurt anyone? – physically and/or emotionally?
- What could be put in place to support people if they get upset?
- How can you minimise any potential risks?

For example:

Include plenty of breaks.

Be flexible to people's preferred time of day.

Include time for non-research activity e.g. for a cup of tea.

Avoid research activities on days where other support might be limited, such as Friday evenings.

Consent process:

- Before somebody agrees to take part in research, it is important that they understand what it involves.
- People should be able to weigh up the 'pros and cons' of research and therefore how it might affect them.
- Once someone has all the information they need to decide whether to take part, they are then asked to give consent/agreement. This process is known as **informed consent**.
- If your research involves seeing people more than once, they should be asked on each occasion whether they are still happy to take part.

Researchers show that someone has agreed to take part using a **consent form** like this:

I agree to take part in this study. ☑

Name: Jessica Jones

Signature: J Jones

Date: 20th February 2019

Confidentiality and anonymity:

Whenever you ask someone to give information about themselves, it is important to think about how this will be protected.

Be aware that revealing information of a sensitive nature could do damage to the participants or to other people.

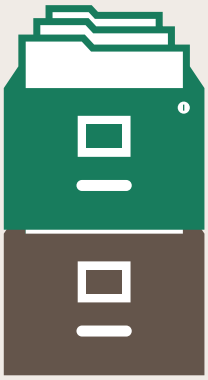
- If sensitive information is relevant to the research, it must be presented in a way that protects a person's privacy.
- You must devise a storage system that is safe and only accessible to you (or the other researchers in your project).

Possible ways to manage confidentiality:

Secure storage.

Keeping identifiable information separate to research answers e.g. name and address are stored separately to questionnaires.

Only sharing information between people that the person has agreed to.



Possible ways to manage anonymity:

If participants do not want to be identified, then using an ID or pseudonym (a different name) protects their identity from others.

Being anonymous can make people feel more comfortable about sharing personal information or things they are worried about.

Some people suggest participants pick their own pseudonym.

Some people use a theme for pseudonyms e.g. kings and queens... Kathy, Sophie, Ben and Connor become Elizabeth, Mary, George and Henry.

Some people use a participant ID e.g. PAD1.

Acknowledgments:

Using the thoughts, ideas and words of others without acknowledging their source (even if you re-write it), is unethical (it's called **'plagiarism'**). You avoid this by acknowledging the sources and their originators in your own text (that's called **'citation'**).

For example: you might want to refer to work related to what information people might want following a diagnosis of dementia.

The Department of Health published a 'Dementia Strategy' which encourages good-quality information to be available post-diagnosis.

There are two ways that you could present this information.

Quoting directly means you should use quotation marks, and give the name of the source, the year it was said, and which page it was written.

QD example:
The Department of Health (2009: pg.11) say that "providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care."

Quoting indirectly is where you say the information in your own words, but add the name and year of the information alongside it.

QI example:
It is very important for people to be given the right type of information after they receive a diagnosis, to make sure they know what support and services are available to them (Department of Health, 2009).

At the end of the document, you then direct people to where the full paper is available. Known as the reference list or bibliography:

Department of Health. (2009). *Living Well with Dementia: A National Dementia Strategy.*[1]

1 http://bit.ly/2Hvj5aS

Information sheets:

Once you have thought about how to address the elements of ethics within your research (respect, confidentiality etc.), you will need to create an **information sheet** which summarises the work you want to do, why you are doing it, and how you will look after participants.

Then, any potential participant reading your information sheet, should have had all of the information they need to make an **informed decision about whether to take part in your study**.

Ethics 'approval':

If you are finding people to take part in your research through the NHS (e.g. a doctor or health unit), you will need to send evidence that you have thought about all the things discussed in this section to an **Ethics Committee**.

An 'Ethics Committee' is a group of people who look over the project and see whether they feel it meets the necessary 'ethical standards' and can therefore be carried out.

This is quite complicated and time-consuming.

If you are working with a University, they will also have to go through their own University Ethics Committee.

Do I have to go through an Ethics Committee?

You don't always need to do this, for example, if you're finding people through contacts, adverts, social media etc. However, some academic publishers will only publish research that has been reviewed by an ethics panel of some kind. Therefore, the findings of your research can be shown to more people.

If you are unsure if your work requires ethical approval, you can contact your local NHS Research and Development Office, Innovations in Dementia, or a University you are linked with.

There is more information and also a detailed checklist in The Dementia Enquirers Gold Standards for Ethical Research

Available at: **https://bit.ly/3XF6EwW**.

Section 3

Consent forms

Not all consent forms look the same. It depends on the researchers, the style of project and who is approving the form. For example, the NHS provide a consent form template for people to use e.g. Health Research Authority (2019):[2]

(Form to be on headed paper)

IRAS ID:

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Title of Project:

Name of Researcher:

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. (If appropriate) I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. (If appropriate) I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. (If appropriate) I agree to my General Practitioner being informed of my participation in the study. / I agree to my General Practitioner being involved in the study, including any necessary exchange of information about me between my GP and the research team. ☐
6. (If appropriate) I understand that the information held and maintained by _____ [*(enter name of organisation(s) that will be providing you with data, including any NHS/HSC organisations)*] may be used to help contact me or provide information about my health status. ☐
7. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

2 http://bit.ly/2UDS5K4

Create your own Consent Form

You can design a consent form however you like, as long as it includes the key information e.g.

Research Project's Name

I have been told the potential benefits and risks of the study.

(tick if agree) ☐

I understand that I am able to leave the project at any time without giving a reason.

(tick if agree) ☐

I know my personal information will be anonymous and stored securely.

(tick if agree) ☐

I know who to ask for help if I have any questions.

(tick if agree) ☐

Name: _____

Signature: _____ Date: _____

Section 4

Group discussions

Group discussions (sometimes called **'focus groups'** or **'roundtable discussions'**) are when you get a group of people together to try and answer your **research question**.

- They are quite a simple way to hear people's views.
- They are not too intense for any individual.
- They let people respond to each other's ideas.
- There is usually one person there to guide the discussion, to sometimes take notes, and to ask for clarity on answers when needed. This person is known as the **facilitator**.

Here are some things to think about:

Who will be taking part? People with dementia? People with dementia and family members/friends? Health professionals?

- Some research mixes groups for discussions.
  Having a diverse group might make it more likely to hear a wide range of ideas.
- Other research tries to make the group members as similar as possible.
  Doing this might make it easier to understand consistent and inconsistent answers.

You will need someone to control the discussion (your 'facilitator') – to make sure everyone is heard and that the topics are covered in the time you have.

- The number of facilitators generally depends on the group size.
- Using DEEP's yellow 'I want to speak please' cards will make sure everyone has an equal chance to talk.

How will you record the discussion?

- You could ask someone to take notes (including writing down some good quotes).
  Note-taking is the quickest option (especially if several people take notes); but you can miss some of the richness in conversations.
- You could record it on a phone or a recorder (but it takes a lot of time to listen back to all this).
- You could video the group meeting (also takes a long time to listen back).

Timing

- One and a half hours is typically long enough, especially if people with dementia are involved.
- If you think you need longer than this, give people plenty of notice, arrange lots of breaks and refreshments, or schedule another meeting.

Number:

- 6 -10 people is generally considered the best number.
- The number may also depend on whether the group members know each other or not.

Example structure for a group

1	Start with introductions and try to make people feel at ease. Name badges using a large and clear font are a good idea.
2	Explain the purpose of the project and what you will do with the information you collect. It is worth having this information written down too, so that the group can refer back to it if needed.
3	Check that everyone understands the project and what they are doing, and that they freely agree to take part (have 'capacity'). By capacity we mean, can they weigh up the risks and benefits of involvement, and are they able to decide if they want to take part?
4	Agree with them if you will use their names or not. Some people may prefer to be anonymous or have a 'pseudonym' i.e. Bill is referred to as Charles in anything written or spoken about in the group. Some groups create a group name which can be used instead of referring to anyone individually. This also means that group members can choose to say they are part of the group or not.

5

Explain how you will feed back to them what comes out of the project. Will you send them your report?

Some projects send a ‘summary of results’.

Other projects use a newsletter.

Or you could put on an event where the findings of the project are discussed.

6

Think about the practicalities that will make everything easier for them.

Before the group...
invitations; reminders; travel arrangements.

During the group...
signs to show which room the group will be in; accessible toilets; enough time and refreshments for breaks.

After the group...
expense payments.

7

Have a list of a few questions you want to ask, or key points to be covered (a ‘topic guide’).

Group the questions into themes that follow a logical sequence.

Work through the questions methodically to keep the group on track.

But you can also move back and forth between questions or topic areas, as your group may naturally move on to another subject.

Example of a focus group project:

A group of researchers wanted to explore people's experiences of dementia care and dementia services.

They held 3 focus groups with 6-10 people in each.

- The groups included people with dementia and family members of people with dementia. They also had group facilitators.
- The focus groups had a discussion guide to help structure their meeting.
- Participants received a £20 voucher for their contribution.

The focus group had several key findings:

- People hoped for a quick diagnosis.
- Carers welcomed support and breaks from their 'care role'.
- More training was needed for people who work with people with dementia.
- It would be helpful to have a single point of contact to help navigate support services.

The people who took part had been in similar groups in the past which may have made it easier for them to feel comfortable and share their views.

It can be very hard to get people involved if they are less familiar with research or group work.

The research was done by Sutcliffe and colleagues in 2015 and would be acknowledged as:

Sutcliffe, C. L., Roe, B., Jasper, R., Jolley, D. and Challis, D. J. (2015). People with dementia and carers' experiences of dementia care and services: Outcomes of a focus group study. Dementia, 14(6), 767-787.

Section 5

Interviews

Interviews are essentially just a conversation.
They are quite a simple way to hear people's views.
The format can be very similar to focus groups, but they are likely to be with only one or two people.

Individual interviews are good because they ensure the person has the time and space to speak.

They can also feel more confidential and personal than a group discussion. And the interviewer can probe and clarify as needed.

They can be done face-to-face, or perhaps on the phone or online by Skype/Zoom (but always make an appointment in advance).

Here are some things to think about:

Recording information

- How will you record the discussion?
- You could take notes while you do the interview - but it's not easy to do both and it can make it difficult to feel like a conversation.
- You could ask someone to take notes (including writing down good quotes).
- Or you could record it on a phone or a recorder (but it takes a lot of time to listen back to all this).

Timing

- An hour is probably long enough, especially if the person has dementia.
- It is also worth thinking about the time of day you start the interview - What time best suits the person's routine? Avoid meal times etc.
- Timing can be flexible – some people have more or less to say than others.

Example structure for an interview

Before the interview:

Confirm the time and day of the interview in advance.

Decide with the participant the preferred location for the interview.

- For example, in the person's home, a neutral place; Day Centre, café etc.
- Unless you are going to their own home or office, think about the practicalities, such as...
  Invitations; reminders; travel arrangements; signage; toilets; refreshments; expense payments.

Contact the person you will be interviewing on the day (or the day before), to make sure it's still suitable to meet.

When you arrive:

Start by introducing yourself and try to make the person feel at ease.

- It can help to add in some time for general conversation and getting to know each other.

Explain the purpose of the project and what you will do with the information you collect.

Check that the person understands the project and what they are doing.
i.e. Has 'capacity' - by which we mean, can they weigh up the risks and benefits of involvement, and are they able to decide if they want to take part?

Agree with them if you will use their name or not
(**see Section 2** *Confidentiality and Anonymity* for more information)

Explain how you will feed back to them what comes out of the project.

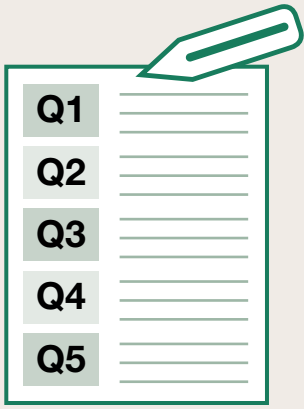
- Will you send them your report?
- Some projects use a 'summary of results'
- Other projects have used a newsletter
- There may be events where the findings of the project are discussed.

Starting the interview

Within research there are several styles of interviews:

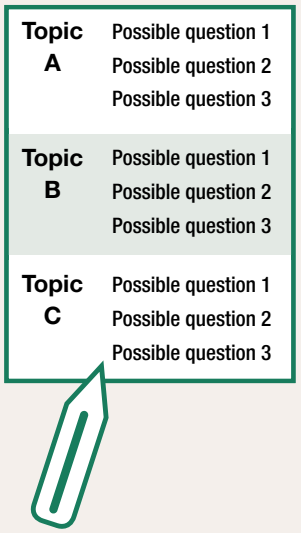
Structured

- All of the questions are decided upon beforehand
- More like reading out a questionnaire
- Less flexible than the other options, so it can be harder to get a 'flowing conversation'
- Easier to compare people's answers, as they have all been asked the same thing.



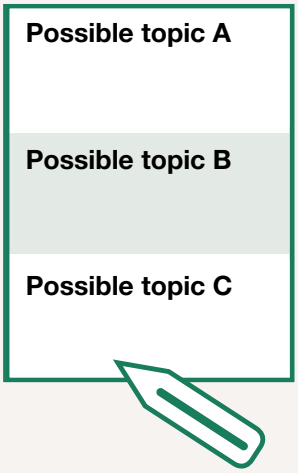
Semi-structured

- A general structure to the interview is prepared
- Cover the key ideas and questions you are hoping to answer
- Flexible enough to let people share more of their story and potentially answer in different ways
- Can feel more personal, and you might find out things you might not have expected/asked about
- Can take longer to do than a structured interview, but may have more depth to answers.



Unstructured

- Unstructured interviews are probably the most conversational
- Person being interviewed leads the discussion
- A general focus is presented at the start but there are no set questions
- It's harder to bring together people's answers, as they may have focused on very different things
- Can be tiring for the researcher, as you need to be thinking about possible directions, while listening and taking notes.



Things to think about when creating a TOPIC GUIDE

It can be useful to have a list of a few questions you want to ask, or key points to be covered (a **'topic guide'**).

- Try to group them in themes that follow a logical sequence. Then work through them methodically to keep on track.
- You can also move back and forth between questions or topic areas, as your interviewee may naturally move on to another subject.
- The amount of flexibility you have, or amount of 'back and forth' between questions, will depend on how structured your interview is meant to be.

You should ask similar questions of each person you interview

- We suggest this so that people have a similar experience, and so that you get answers that you can compare to each other. This consistent approach is often referred to as **standardisation**.
- Depending on your interview style, additional questions can be asked as appropriate.

Project Title — **Topic Guide**

Questions to ask	**Points to Cover**
Theme A	Theme C
Q1 - How did....	Point 1....
Q2 - Why do...	Point 2...
Q3 - When you...	Point 3...
	Point 4...
Theme B	
Q4 - How can...	Theme D
Q5 - What if...	Point 5....
Q6 - Can it...	Point 6...

It is particularly important to avoid **'leading questions'**. Make sure people are free to give their own, honest answers.

Below are examples of leading questions	And here is how you might re-word the question
"How upsetting was your diagnosis experience?"	The leading question assumes the experience was upsetting. **You could change it to:** **"Could you tell me about your diagnosis experience?"**
"I really hated the day centre I went to. How did you find it?"	By including the interviewer's opinion, the person answering may feel pressured to just saying the same. **You could change it to:** **"How did you find the day centre you attended?"**
"Do you agree that dementia is less stigmatised now?"	The leading question asks for agreement rather than leaving it open for people to say yes or no. **You could change it to:** **"What do you think about other people's understanding of dementia in society?"**

There are several types of question asked in interviews which you should keep in mind when you are composing your topic guide:

Introducing questions for starting a topic...

‘Why did you...?’
‘Can you tell me about...?’

Follow up or probing questions to get more detail/ go further into the topic or first answer...

‘What did you mean...?’
‘Can you give more detail...?’
‘Do you have any examples?’
‘Could you say more about...?’

Specifying questions...

‘What happened when you said that?’
‘What did he say next?’

Direct questions have a yes or no answer.
You might want to leave these questions until the end, so you don’t lead the interviewee to answer a certain way.

Indirect questions are a ‘softer’ way to get people’s opinion and usually include a phrase such as ‘could you tell me…’ or ‘do you know...’

Direct = “How long did it take to get a diagnosis?”

Indirect = “Could you tell me how long it took to get a diagnosis?”

Structuring questions help to move the interview on to the next subject...

“Moving on to...”
“We’ve been talking about X, how has that shaped experiences of Y?”

Pace and Silence:

Before you do an interview, practice the questions you are going to ask.

The more familiar you are with them, the more the interview will flow or be 'conversational'.

During the interview, you might find if you have long pauses in your questions, the person you are interviewing will think you are expecting an answer.

Practicing the questions beforehand can help significantly with that.

Give people time to reflect on your question and compose their answer. Don't hurry them.

Interpreting questions can be asked, to clarify that you have understood correctly...

'Do you mean that...?'
'Is it correct that...?'

What to do with people's answers

When you have done your interviews, you will need to analyse the information you have collected. You can you pick out key points and quotes to illustrate your analysis.

Be mindful that some of the information won't be useful for answering your research question, perhaps because the person didn't keep to the subject, or gave background information which is not needed.

Coding answers

You could also code the information by turning a qualitative interview into quantitative data i.e. words into numbers.

You would do this by identifying passages of text and applying labels to them to show that they are an example of a theme.

For example: If you asked 20 people how they travelled to work, and one of the answers given was 'by car', this would be one thematic code. 'By bike' could be another, as could 'walking', etc. You could the perhaps code 'car = 1' and 'bike = '2' etc.

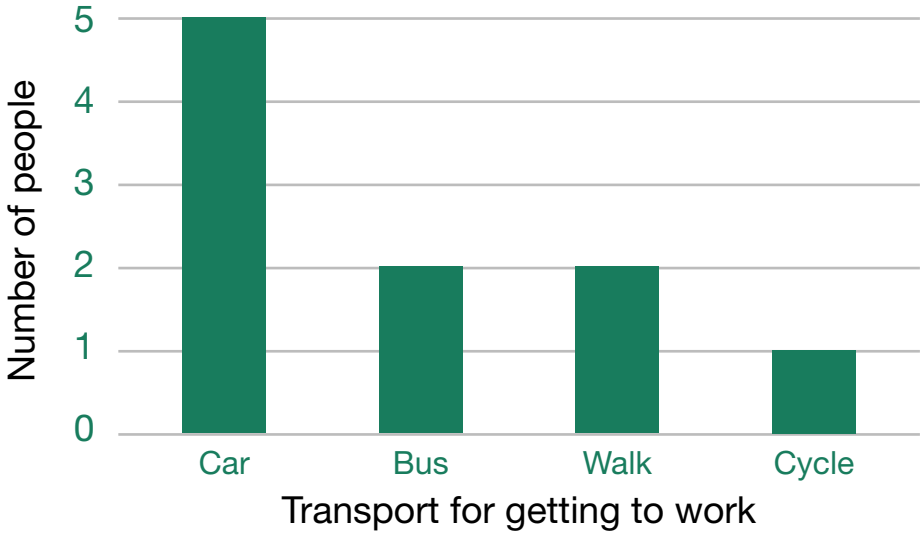
A spreadsheet can be a helpful tool for bringing your information together. For example if you were looking at the different transport people used to get to work, you would include some information about the person travelling and the way they travelled e.g.

A12 f_x

	A	B	C
1	**Participant Identifier (ID)**	**Transport**	**Code**
2	001	Car	1
3	002	Bus	2
4	003	Car	1
5	004	Walk	3
6	005	Cycle	4
7	006	Car	1
8	007	Car	1
9	008	Walk	3
10	009	Bus	2
11	010	Taxi(Car)	1

Software like MS Excel allows you to make charts and graphs to better illustrate your answers.

If you have a small sample, you could simply create a table on a piece of paper, listing how many people said ‘car’ and how many said ‘bike’.



For more information - The Open University website http://bit.ly/2JcymzH has some excellent information about doing interviews. **A full list of links to useful resources is provided at the end of the handbook**.

Example of an interview project:

A group of researchers wanted to explore people's experiences of day care, and whether it increased independence.

- Researchers interviewed 17 people with dementia (10 women and 7 men).
- Interviews took place in the day centre the participant attended. It was felt that participants would feel more comfortable talking about the day centre whilst they were there, rather than from their homes, where it would rely more on memory.
- Interviews were semi-structured (Researcher had a checklist of topics and questions to help with the interview.) and took between 10 minutes and 35 minutes (depending on how much the participants expanded on their answers).

The interviews were audio-recorded, transcribed (listened through and written out) and divided into 3 different themes:

1	The first meeting at the day centre – adapting to the environment.
2	The content of the day care service- explored activities available.
3	Day care integrated into everyday life- how the structure of the day centre encourages socialising, shapes family relationships and prevents people from feeling alone.

The researchers found that day care was a positive part of the life of people with dementia, particularly if the social setting was positive and staff helped people to have all their needs met.

The research was done by Gausdal Strandenaes and colleagues in 2016 and would be acknowledged as: Gausdal Strandenaes, M., Lund, A. and Mork Rokstad, A. M. (2016). Experiences of attending day care services designed for people with dementia- a qualitative study with individual interviews. *Aging and Mental Health, 22(6), 764-772*.

Case study 2: Interviews

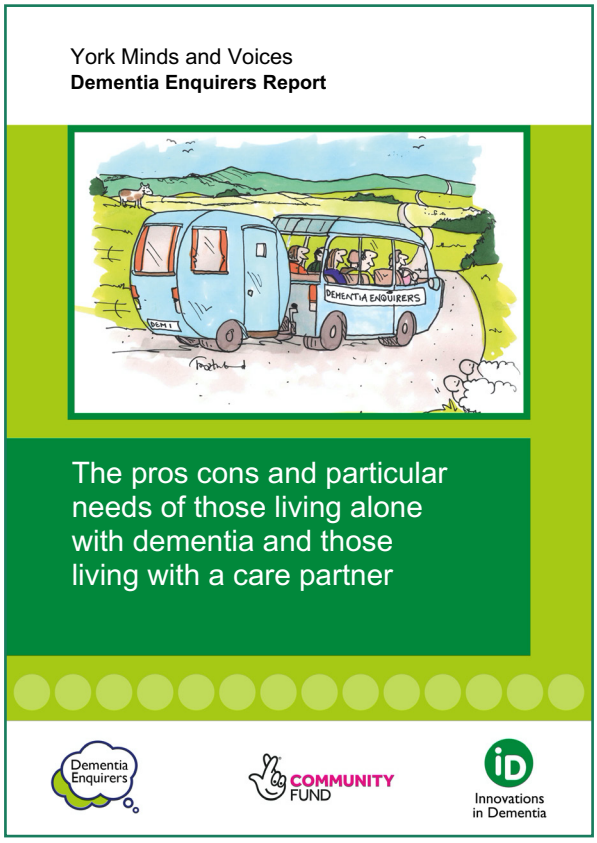
York Minds and Voices

This group wanted to find out about the experiences of people with dementia who lived alone, compared to those who lived with a care partner.

They carried out five individual interviews and one group interview. Beforehand, they agreed an approach about how they were going to run the interviews. They asked the group facilitator to be in charge of some of the research protocols. This included organising the Zoom meetings and going through a consent process with the interviewees, which reduced some of the administrative burden for group members.

The interviewers with dementia agreed the format of each interview, and how the questions would be asked consistently. They also discussed the importance of confidentiality and anonymity. Interviewees were sent the interview questions beforehand to allow them to prepare, including being able to write down comments that they might want to make.

The interviewers with dementia understood how stressful and distracting it can be to be asked interview questions without being able to remember what you want to say. They reflected that the shared experience of dementia had built a quicker rapport between interviewer and interviewee. There was a strong (and instant) sense of trust between people, and the interviewers felt they could 'get to parts that other people couldn't reach' because of their shared experience of dementia.



Section 6

Surveys (questionnaires)

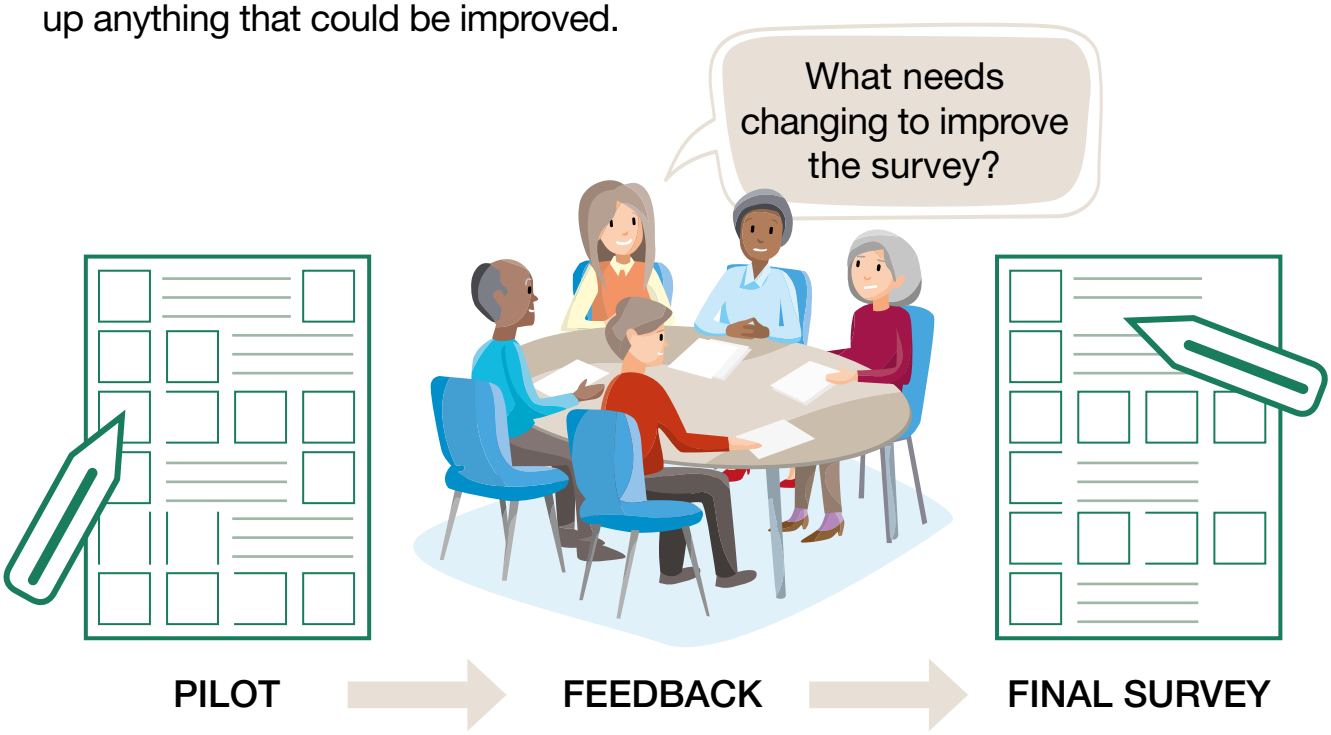
Surveys are best when you want to reach a larger number of people (maybe over a large geographical area).

They are generally quicker to complete than an interview. However, they are less able to give you in-depth answers, so it is harder to get the full context.

Surveys can be done by self-completion (on paper or online); or as a structured interview (face-to-face or over the phone).
Using a questionnaire enables you to organise your questions and get replies, without having to talk to everyone individually.

- It's cheap and quick, and can cover large areas.
- They do need a lot of time and skill to design and develop.
- They need to be short and simple to follow – and remember, not all people with dementia are able to do them.

It's a good idea to test the questionnaire on a small number of people before it is used for the project. This is known as a **pilot** and it's a very good way to show up anything that could be improved.



The questionnaire should be easy to read, with the questions spaced out clearly.

You should give clear information on:

- The aims and purpose of the questionnaire.
- What topic you are asking about and how people's answers will be used.
- Who to contact for more information - i.e. researcher's name/ group's contact details.
- What happens next? After they complete the questionnaire, will there be another one? Or maybe a follow-up interview?
- What happens to the information collected?
- Instructions on how to answer the questionnaire.

If you are posting the questionnaire – Include instructions for how to send it back (including any deadlines):

- Do you need the participant's contact details?
  - If so, why do you need them?
  - How will they be used?
- The respondent should be assured of confidentiality and anonymity (**see section 2** on ethics).
- The questionnaire itself should not have the participant's name on it.
- If you need the participant's name, it should be on a separate document to the questionnaire.

Question types

There are two question types to think about, **Open** and **Closed**.

Closed questions:
The respondent must choose from a set of given answers. By having set answers, you can assign a 'score' for each answer in advance which makes it easier to analyse. In the example below it uses a code such as 1 to 4.

How are you feeling today?

	I feel terrible	I feel low	I feel alright	I feel great
Assign a score →	**1**	**2**	**3**	**4**

Open questions:
The respondent is free to answer how they want.

This takes them (and you!) more time – but can provide very useful information or context. Here's an example...

Could you tell me how you are feeling today?

I am generally feeling ok, but I have been very tired. I had a particularly bad day yesterday...

The Open University has more useful guidance on designing questionnaires.[3]

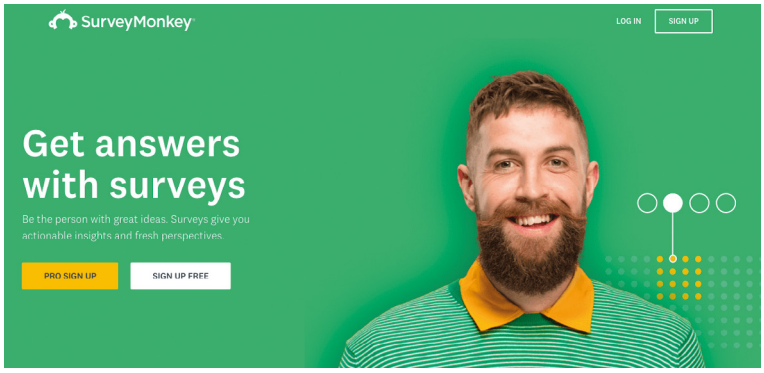
3 http://bit.ly/2Hw8vQF

Online surveys

An online survey can be very popular. Instead of relying on posting out and posting back surveys, or knowing participants' contact details, they can be completed by people across the UK using an internet address.

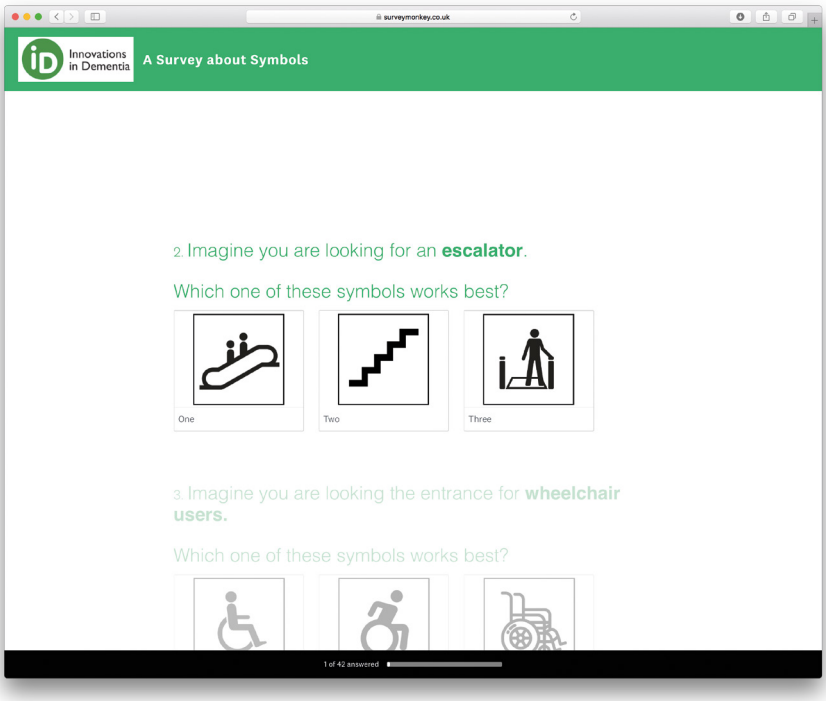
- If you want to do an online survey, you could use **Survey Monkey** (or similar), which you can join for free.

  www.surveymonkey.co.uk



- This takes you step-by-step through designing your survey, collecting responses, analysing results and presenting your findings.
- You can use checklists; randomised questions; multiple choice and much more. You can even add an explanatory video if you wish.

Here is an example of a survey we did using SurveyMonkey:[4]



To get the survey to as many people as possible, it helps to use social media e.g. Facebook or Twitter.

4 http://bit.ly/2HxpvWH

Things to think about for online surveys

- How many questions should you have?
  - Piloting the questionnaire can help with deciding this.
- Will questions be compulsory?
  - Can they be missed out or skipped?
  - Will people's answers be kept if they do not finish the survey?
- Wording of questions (same considerations as in interviews e.g. avoid leading questions).
- What do you need to know about someone to understand their answers?
  - age, diagnosis of dementia, length of time since diagnosis etc.
- Who will be sent the questionnaire link?
- Can people answer only once, or multiple times?
- How many response options should be given?
  - odd numbers mean that there will be a 'middle' answer
  - even numbers mean people will have to answer in a particular direction.

How are you feeling today?

Response is a forced choice between Positive or Negative options

OR

Response has a Neutral option for respondent to pick

Example of a questionnaire project:

A group of researchers wanted to explore people's attitudes towards dementia so they distributed a questionnaire called "Approaches to Dementia" to people living in Bristol and Gloucestershire.

The researchers adapted the original questionnaire with the permission of the creators to be more user-friendly for online completion and to include more person-centred language.

The questionnaire was mostly collected online, 20 questions were included. Responses were given by 2201 people. The researchers excluded people who had worked with people with dementia as they are not representative of public knowledge.

Overall 794 people's responses were analysed.

The findings suggest public attitude towards dementia was generally positive (particularly among younger people).

The questionnaire scores can act as a 'benchmark or baseline' so that if the same questions are asked later, they will be able to see whether people's attitudes are changing over time.

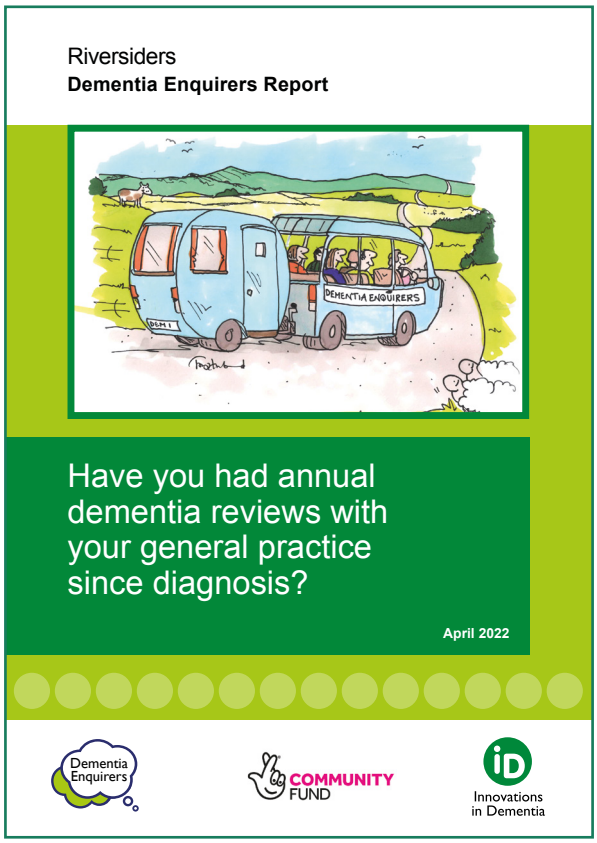
The research was done by Cheston and colleagues in 2016 and would be acknowledged as:

Cheston, R., Hancock, J. and White, P. (2016). A cross-sectional investigation of public attitudes toward dementia in Bristol and South Gloucestershire using the approaches to dementia questionnaire. *International Psychogeriatrics*, 29(10), 1717-1724.

Case study 3: A survey

The Riversiders group (Shrewsbury)

This group carried out a survey to look into annual dementia reviews. The numbers in the survey are small (net number of usable questionnaires was 73), and firm conclusions can only be made if this is replicated with a much larger sample. However the data are very useful because they suggest that there are problems with the annual review system which need further exploration. The data suggest that very few people living with dementia get an annual review with their general practice that is in any way meaningful to them, in terms of wellbeing and future planning. Care plans, in so far as they exist at all, had only been given to two people, and clearly future care planning was not discussed at all, even though it is specified in the annual review guidelines on the EMIS system. Only five people said they felt their GP understood how dementia affects them.



Section 7

Listening to experts (Inquiry)

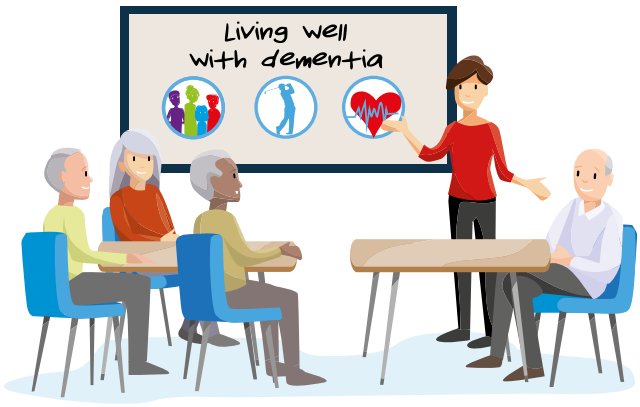
An Inquiry takes 'evidence' from people with different experiences ('the witnesses') about the issue you are focusing on.

This is quite a simple way to hear people's views.

Inquiries are good because they mean you have access to a wide range of views and expertise.

How to start an inquiry:

- You could simply draw up a list of people who you think have expertise on a certain topic.
- Invite them each to come and talk to your group of people with experience and expertise in dementia (**your 'Inquiry Panel'**).
- The 'Inquiry Panel' is not the same as individual interviews.
- The 'experts' (who can of course include people living with dementia) will be invited to prepare and give a presentation (maybe 15-20 minutes), and then be asked questions by your group.



- The Panel will need to meet a number of times to hear all the chosen 'experts' and to discuss the issues themselves.
- You will end up with quite a lot of different views and information about the topic.

You will then need to go through your notes, and think about all this.

Some things to think about in setting up an Inquiry:

You will need someone to control the discussion

To make sure the topics are covered in the time you have, there should be one or two co-chairs.

Works in a similar way to facilitators in group work **(section 4)**.

How will you record the discussion?

You could ask someone to take some notes for you (particularly writing down any good quotes is very useful).

Or you could record it on a phone or a recorder (but it takes a lot of time to listen back to all this).

Timing:

One hour is probably long enough for each witness/ expert, especially if people with dementia are involved.

Getting started with your inquiry...

1	Start with introductions and try to make the person feel at ease.
2	Explain the purpose of the project and what you will do with the information you collect.
3	Check that the person understands the project and what they are doing (has 'capacity').
4	Decide with them if you will use their names or not (some people are happy to have their name shared, others may not be).
5	Explain how you will feed back to them what comes out of the project. - Will you send them your report? - Some projects use a 'summary of results' - Other projects have used a newsletter - There may be some events where the findings of the inquiry are going to be discussed further.
6	Think about the practicalities e.g. invitations; reminders; travel; signage; toilets; refreshments.
7	Have a list of questions you want to ask (a 'topic guide') to keep them and you on track **(see section 5 on interviews for ideas)**.
8	You could combine other methods with your Inquiry. - A review of the published literature **(see Section 8)** - An online survey **(see Section 6)** - Group discussions **(see Section 4)**.

A good example of an Inquiry is the Mental Health Foundation's report 'What is Truth? *An Inquiry about Truth and Lying in Dementia Care'* 2016[5].

The Mental Health Foundation led an enquiry in 2014 to understand what living with dementia means to people, and the challenges people may face.

The inquiry focused on the perspectives of people with dementia, as well as family members and practitioners around the idea of truth-telling or non-truth telling to support people to live well in different contexts.

The inquiry panel was made up of 2 people with dementia, 2 carers of people with dementia and 17 professionals/ academics who specialise in dementia. The panel met 10 times across 2 years. There were 3 co-chairs (1 being a person with dementia).

The panel invited 18 'expert witnesses' to discuss the topic together.

The main panel that maintaining a positive relationship between people with dementia, families and health care professionals. There is a constant balance between acknowledging different realities and when full truth is the more ethical option.

The full report is available at **http://bit.ly/3HBS2bb**

It would be acknowledged as: Kirtley, A. and Williamson, T. *What is Truth? An Inquiry about Truth and Lying in Dementia Care*. London: Mental Health Foundation.

5 http://bit.ly/2Fyozk0

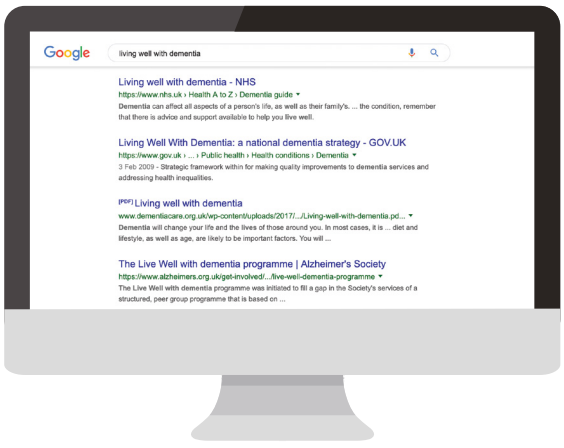
Section 8

Exploring the literature

When you decide on a research topic, it is important to check what has already been researched around it. How might your project be different, or add to what we know so far?

- To find out what has already been studied and written about a topic, you would do a **'literature review'** (often shortened to a 'lit. review'). Essentially, this just means a search of texts to see what has already been shared on the topic.
- You might also come across the term **'scoping review'**, which is where people use pre-selected search terms to see how much is available on a topic i.e. whether it is worth continuing to a bigger review.
- Or, a **'systematic review'** which is a more structured literature review. Several researchers will work together to see whether the information found is relevant. They will judge the quality, and see whether it adds to their topic area.

Literature reviews can be done by one or more people over a period of time. Most of it will be done on the Internet. You can use your search engine (e.g. Google) to find reports about the topic you are interested in.



Search Terms

You will need to decide on **'search terms'** – this means the words or phrases you will search for.

- To reduce the number of 'hits' (articles that come up) to a more manageable and relevant list, search on a short string of connected words that relate to your topic.
- Depending on how well the topic is known you can do a search using more or fewer terms.
- **Worth noting:** Some terms are often used interchangeably, such as Alzheimer's disease, although this is only one type of dementia, it is often used as a reference to cover all dementia.

Search method examples

If you are looking at 'living well with dementia' you could search:

"Living well"
"Live well"
"Dementia"
"Alzheimer Disease"

...to broaden this out further use similar terms such as:

"Quality of life"
"Well-being"
"Adjust* to dementia"
"Alzheimer's Disease" etc.

If a search term could have several different endings, using an asterisk on the end of the word will enable the search to include results for all of them
...so Adjust* would deliver results for:
Adjust,
Adjusting,
Adjusted,
Adjustment,
Adjusts

Unfortunately there can be a lot of rubbish on the Internet! (or low quality sources)

We recommend focusing on web addresses that end in:
.ac.uk; .edu; .edu.au; or **.gov**
These are usually academic or official sites. You can also check the name of the author, to see if they have produced other academic work.

Wikipedia[6] can be a useful source of further references. But it is not a **reliable source** of academic information on its own–because there are no checks on the **academic credibility** of the material that is posted there.

Academic credibility includes things like:

- Did other academics review the research before it was published? This is known as **peer review**, to see whether it is clear and carried out well
- If the research was repeated, would it get the same findings?

Google Scholar will show you better reports. However there may be a charge for some of the articles you want to read (though if you are linked to a University you may not have to pay anything).

And of course there are other important sources you can use as well

If you want to explore the way dementia is talked about in the media, it would be appropriate to refer to examples such as the 'Daily Express, The Telegraph, etc newspapers'.

You can also search in **libraries** (online or physical), and look through journals.

6 http://bit.ly/2SZlqNj

Once you've found some promising reports, try to assess whether or not it is relevant to your research, so you don't waste time reading material of little value. The evaluation questions shown below are a useful reference to evaluate whether a report is worth reading in more depth.
(credit: The Open University)[7]

Evaluation questions

Theme	Questions
Relevance Look at the introduction or overview to check what it's about	Does the information match my needs?
Provenance Don't be tempted to use information that may not have academic credibility	Is it clear where the information has come from? Can I identify the authors or organisations responsible? How was it published? Has it been peer reviewed?
Objectivity Look for an introduction or overview that describes affiliations or funding sources	Is the author's position or interest made clear? Does the author declare any connections that might compromise their independence? Is the language emotive? Are there hidden vested interests?
Timeliness Don't risk using obsolete evidence or data	Is it clear when the information was produced? Does the date of the information meet my requirements?

7 http://bit.ly/2HiGs82

Theme	Questions
Presentation Look at language, layout and structure to check whether you can use it confidently	Is the information clearly communicated?
Method Be aware of the differences in research methods	What research methods were used, and how are results reported? Do I need to check how significant the results actually are?

All this may sound a bit daunting, but...

- Could you find a student who can help practice their skills by doing a literature review for you?
- Could you break down the different tasks and share them?
- Be realistic about what you can do in a certain amount of time.
- Have a look for literature reviews which focus on similar topics.

Section 9

Evaluating an activity or service

This involves collecting information (**'data'**) and using it to make judgements about an activity, project, service or organisation. Either one you run yourselves, or someone else's.

An evaluation will help you answer questions like:

- Is the activity (or project, or service or organisation) having an impact (making a difference)?
- What is it doing well?
- What could be improved?
- Is it worth the time, effort and cost?

A good evaluation can help your group to:[8]

- Develop a plan for the future
- Use your time, energy and money as efficiently as possible
- Report to funders and attract further funding
- Increase understanding of what you achieve
- Motivate staff and volunteers

An 'action research' approach can also be used. This involves cycles of planning a specific change or intervention, acting, developing, and reflecting. The information collected from observation or reporting helps the reflection process.

8 http://bit.ly/2VTYVLu

An evaluation can help you understand the *outputs, outcomes and impact* of your work... and then plan new work.[9]

Outputs – products, services or facilities that result from an organisation's or project's activities. This really means tangible things you have produced e.g. number of sessions; number of leaflets; number of people involved etc.

Outcomes – measurable changes, benefits, learning or other effects that happen as a result of a project or organisation's work.

Impact – broad or longer-term effects of your work. This can include effects on people who are direct users of a project or organisation's work, effects on those who are not direct users, or effects on a wider field such as government policy.

9 http://bit.ly/2EVSwIS

Monitoring:

Developing an evaluation framework helps you to clarify what information you might need in order to evidence your story of change and to describe your impact.[10]

Monitoring is the routine, systematic collection and recording of information ('data') about a project. This is mainly for the purpose of checking its progress against its plans.

The quality of your evaluation will depend on the quality of the information (data) you have to hand.

- This means that systematically collecting and recording information that can be used as part of an evaluation (your monitoring) is absolutely key.
- Developing a sensible, robust evaluation framework will help to make sure that your monitoring collects everything you need for your evaluation and nothing more.
- An evaluation framework avoids gaps, unhelpful duplication, and needless frustration further down the line.
- Understanding exactly what information you need allows you to build a practical plan for data collection, including deciding how and when to go about gathering data, and who should be responsible for collecting it.

You will need to decide on **indicators** – the way you will measure change. These might be numbers or levels of satisfaction.

10 http://bit.ly/2UAUvZA

Case study 4: Action research

Ashford Phoenix group

Wanted to find out if individuals living with dementia would benefit most, emotionally and cognitively, from creating a piece of music, by all learning a new instrument, or by just being participants in music sessions. They collectively planned, organised and took part in 12 music sessions. These sessions were facilitated by a local musician and involved learning the ukulele and composing a piece of original music. For 11 of the 12 sessions, the group completed before and after questionnaires relating to their mood and cognition, as well as beginning, middle and end focus groups. One-to-one interviews were also completed at the halfway stage of the sessions. Numerical data collected indicates a positive effect (immediately after sessions) on group members' mood, but not a change in cognition between sessions. Focus group and interview data indicates the project has given group members a focus, de-stigmatised the idea that individuals with dementia cannot achieve goals or learn new skills, a lift in mood from the project. The implications of this project and reflections on running this project are also discussed in the report, see **https://bit.ly/404LhHf**.

Section 10

Outcome measures

The research pack has shown that there are lots of different types of research/ or different ways to answer questions.

In the previous section **outcomes** are described as measurable changes, benefits, learning or other effects that happen as a result of a project or organisation's work.

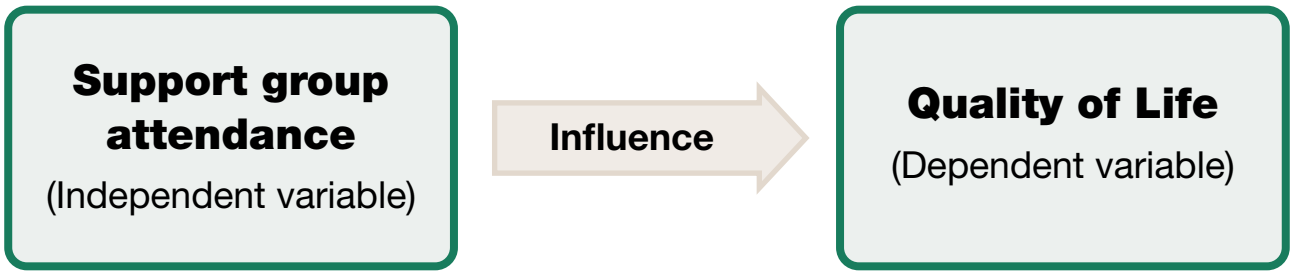
How do we decide on outcome measures?

The type of measure will depend on the type of research you are conducting.

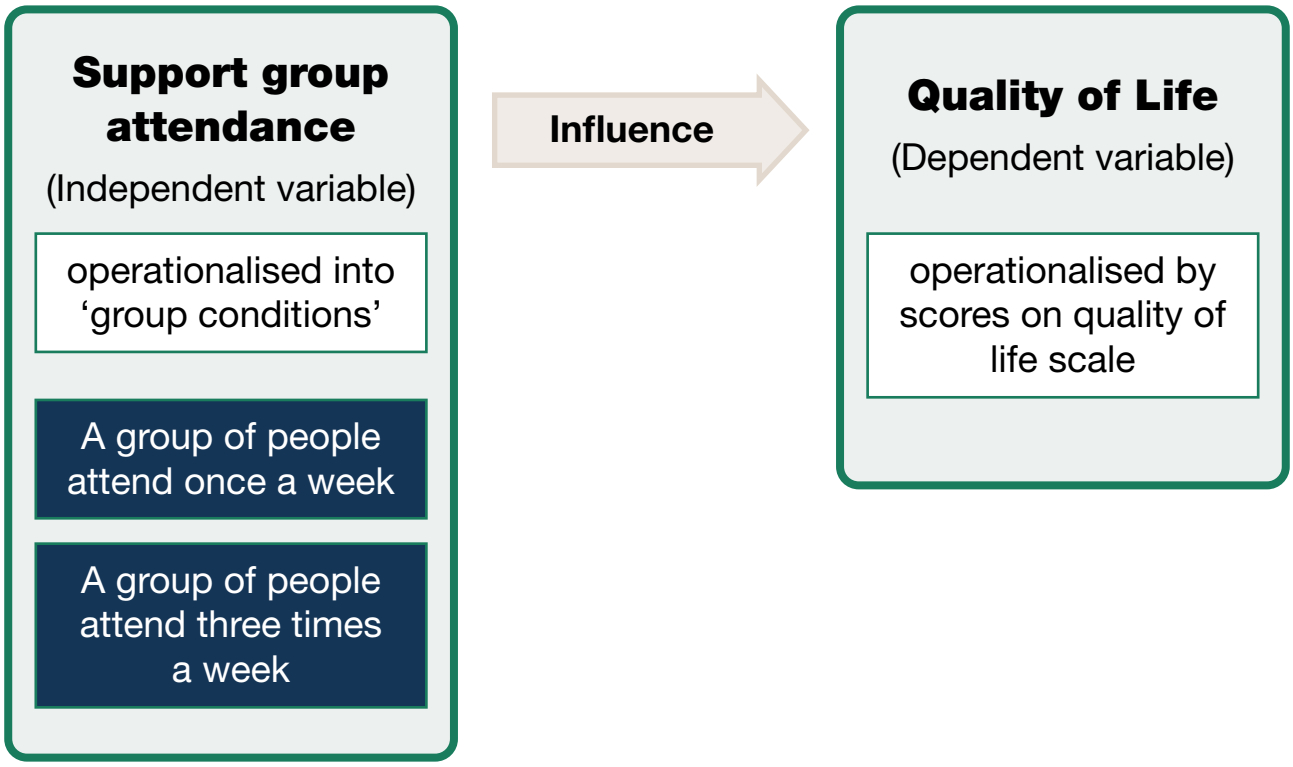
- Outcome measures are sometimes called the **dependent variable** i.e. the measure that is dependent on a change.
- Comparatively, an **independent variable** is one that you might change to see whether it makes a difference to your outcome.

Example:

If you wanted to look at whether the number of times someone attends a support group has a positive effect on their quality of life, a possible experimental design would be:



The next step is to operationalize your variables i.e. how will you measure them?

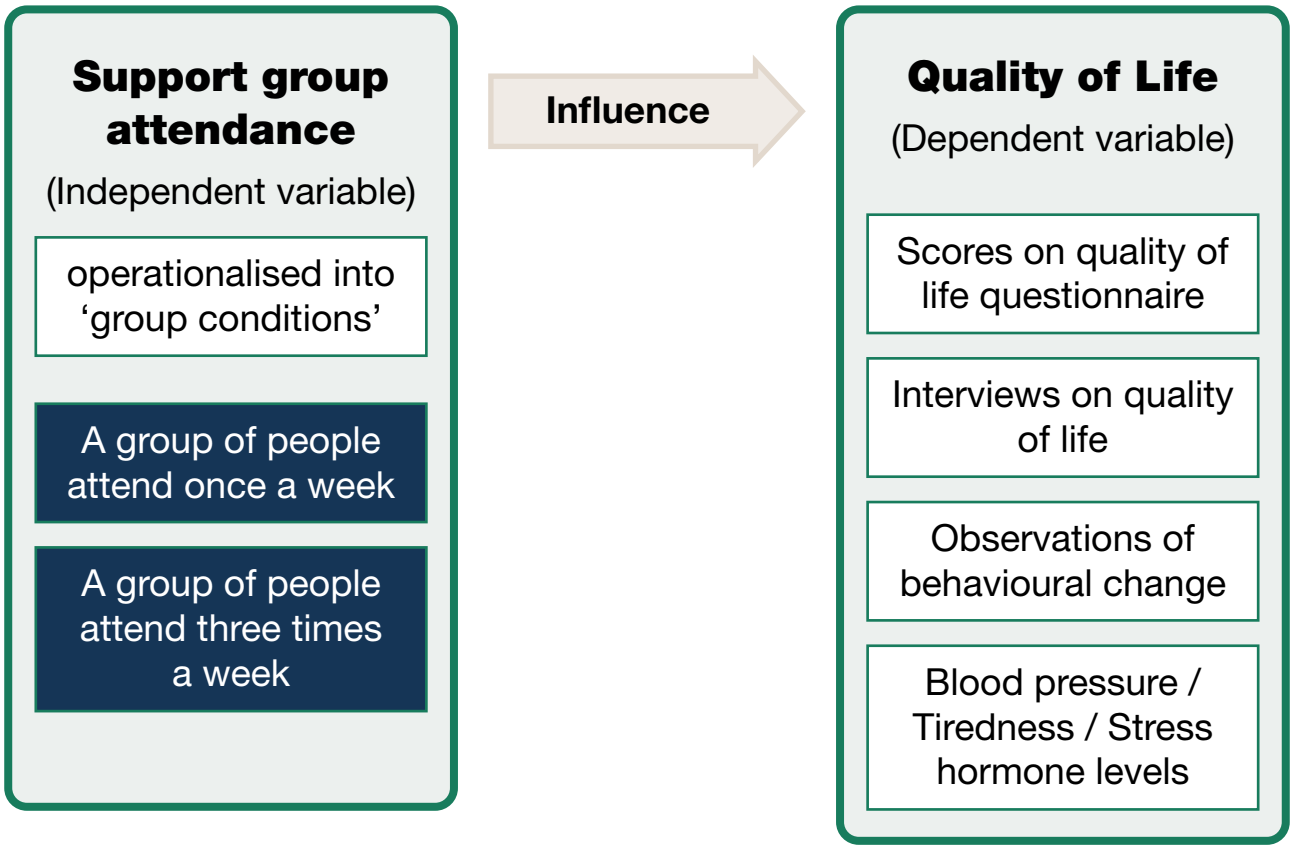


There are two different ways you could use this design, known as 'between subjects' or 'within subjects' design.

'Within subjects' design would mean that a group of people attended a support group once a week and were scored on the quality of life scale. **The same group** would then attend a support group for three times in a week, and be measured on the quality of life scale again. The scores on the two quality of life scales would then be compared to see if they were higher, lower, or stayed the same.

'Between subjects' design would mean that a group of people attended a support group once a week and were scored on the quality of life scale. **A new group** would then attend a support group for three times in a week, and be measured on the quality of life scale again. The scores on the two quality of life scales would then be compared to see if one group scored higher, lower, or the same as the other group.

A quality of life measure would not be the only outcome measure that could be used for this example.



The option that is chosen depends on what you are most interested in. For instance, if a researcher wanted to get a score of somebody's quality of life, they might use the quality of life questionnaire.

A researcher who wanted to know more about the *effect* of a support group might do an interview to understand more about the context.

If the people involved are less able to participate in a more in-depth study, you might consider observing behaviour e.g. is the person less anxious after attending regular support groups?

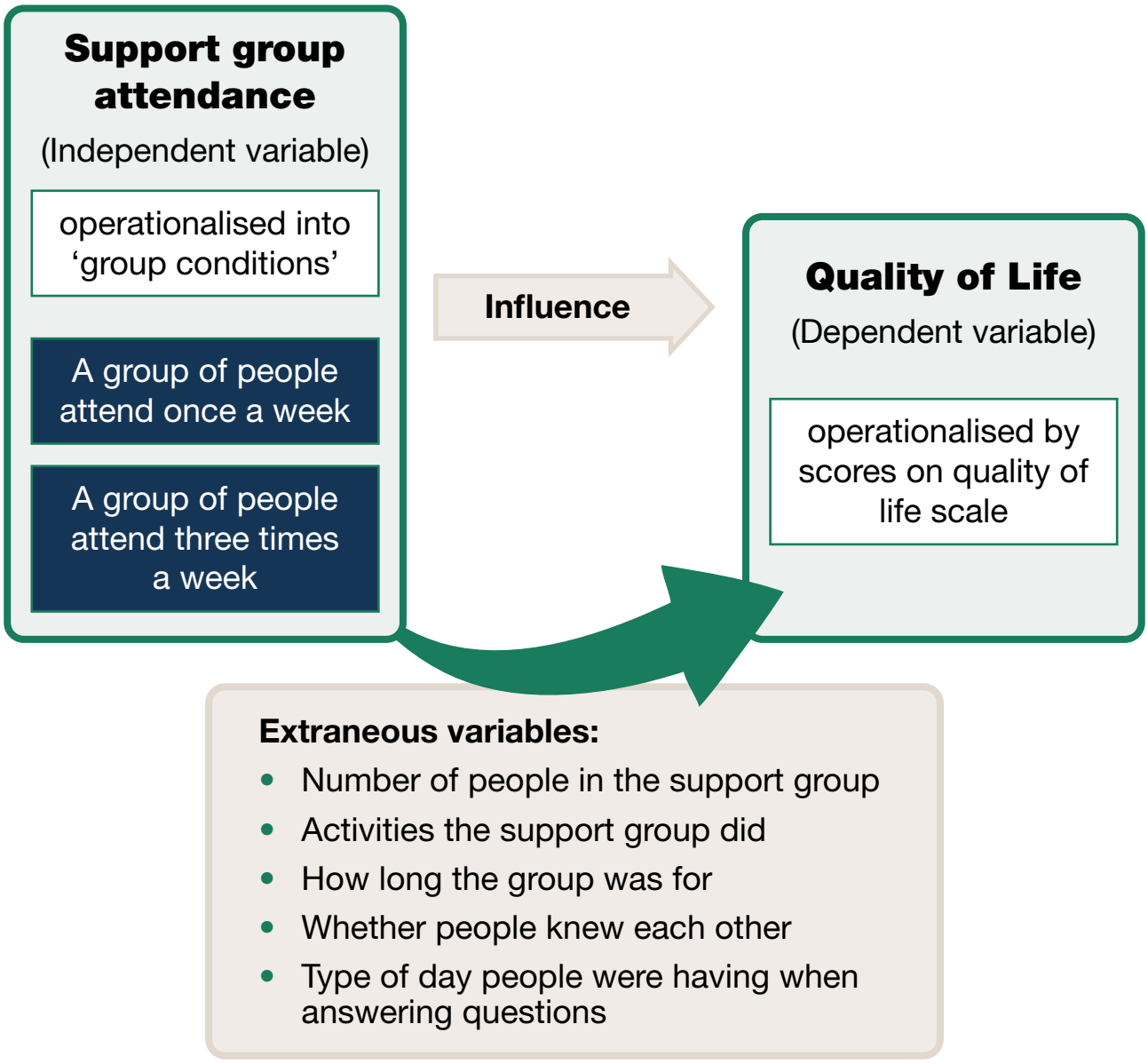
From a very clinical perspective, you could look at **biomarkers**, such as blood pressure, and levels of cortisol in our blood (stress hormone). These might show stress levels which could also influence quality of life.

What else might affect the outcome measure we pick?

One of the things you will need to think about when you design your research and decide what you would like to measure, is what other things might affect the measurement. This is often called the **extraneous variables**, which, if they impact on the outcome, could be called **confounding**.

This area of research can get a bit confusing and there are different levels of detail you could go into. Essentially it is about how much control you have of anything that might shape your research.

Following on from the example on the previous page, these extraneous variables could be: the number of people who attended the group; previous support group options; preferred activities; quality of life outside of the groups etc. If, in the **analysis** stage, these variables seem to be changing the result, they are labelled as **confounding**.



Section 11

Needs assessments

Understanding the issues experienced by people with dementia is the starting point for impact planning.[11]

A 'needs assessment' involves reviewing the challenges they face, so that you or others are best placed to respond.

You can also consider the assets and resources (**strengths**) that they or the wider community already have, and where there are opportunities to involve them in developing solutions.[12]

In your needs assessment, you could:

- look at reports, or local or national statistics
- talk to existing or potential 'beneficiaries' or other stakeholders
- draw on your own expertise

And this will help you to find out:

- who and where the people you want to help or influence are
- what they want, what challenges they are facing, and what assets they might have to address these
- what available resources, services or community assets may provide solutions to the challenges
- which organisations are working in the same field, and whether partnerships are possible
- whether there are any gaps in existing provision or activity

11 http://bit.ly/2F8c1z4
12 http://bit.ly/2O5bTna

The issues that you identify don’t need to be ones that your group can solve quickly or on your own. They may be long-term problems where your work will be part of a solution.

Try to consider the causes of any problems you identify, as these may suggest ways in which your work can contribute to a solution.

Section 12

Visiting other places or services

It may be that you want to visit other places or services to compare them with what is available (or maybe not available) locally.

You could also set up a number of interviews (for example, with staff or service users) while you are there.

You will need to think carefully about how you record the visit. You could use:

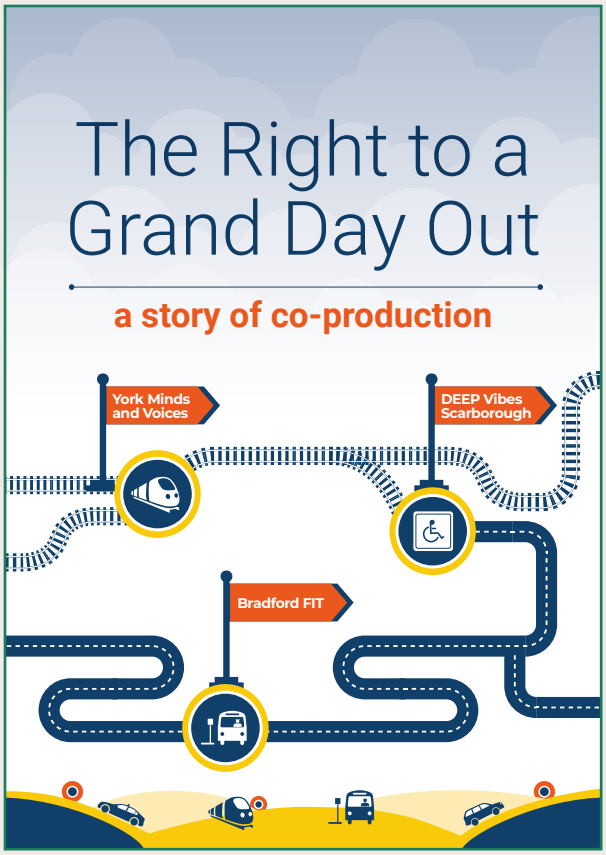
- **Note-taking:** this is not so easy when you're walking round, so it might take a bit of practice. Or you could ask one person to do it.
- Take notes on what you see, what you hear, what you think, what you feel
- Straight after the visit, you could interview each person from the visiting group to get their immediate impressions.
- **Recording:** you can do this on a smart phone or on a simple recorder. You could buy a small microphone to fit into your phone which will improve the quality of the sound recording.
- **Photos:** ensure you get permission first, and leave out anyone who doesn't give permission (or doesn't have capacity to do so, for example if you are visiting a care facility).
- **Video:** you can do this from a smart phone or iPad. Again, ensure you get permission first and leave out anyone who doesn't give permission (or doesn't have capacity to do so, for example if you are visiting a care facility).

Remember to hold the device *horizontally* (*landscape*) not vertically (portrait), and to hold it as still as possible (a small tripod could help.) Again, a small microphone will improve the sound quality.

You can turn this into a simple film using an App such as iMovie (which might already be on your Apple phone or iPad), or FilmoraGo for android devices.

Keep the film short. When it's finished, you can upload it to YouTube (choose either a public or a private setting).

For example: the FIT group in Bradford have used videos and 'walk the patch' techniques to collect evidence about how hard it is to use local buses. You can read the report "The Right to a Grand Day Out a story of co-production" here: **bit.ly/3JkGlZ8**



Section 13

Analysis: what does it all mean?

Analysing Research Data

One of the hardest parts of research is understanding what you have found.

As we know from the previous sections, there are several different ways to collect data (information) e.g. questionnaires, interviews, focus groups, observations.

These approaches produce different types of data, perhaps audio and/or video recordings, images, number-based data, word-based data etc. It can be very daunting to be faced with a lot of data to go through.

Numbers (quantitative data)

Quantitative analysis can include descriptive analysis and statistical analysis.

Examples of descriptive analysis are:

- Number of participants who provided the data
- Gender, age, ethnicity
- Type of dementia, time since diagnosis, memory scores
- The most common answer and the range in answers

Statistical analysis looks at how the numbers you have collected compare to the numbers you would expect from your target population. The statistical test you pick will depend on what type of data you collect.

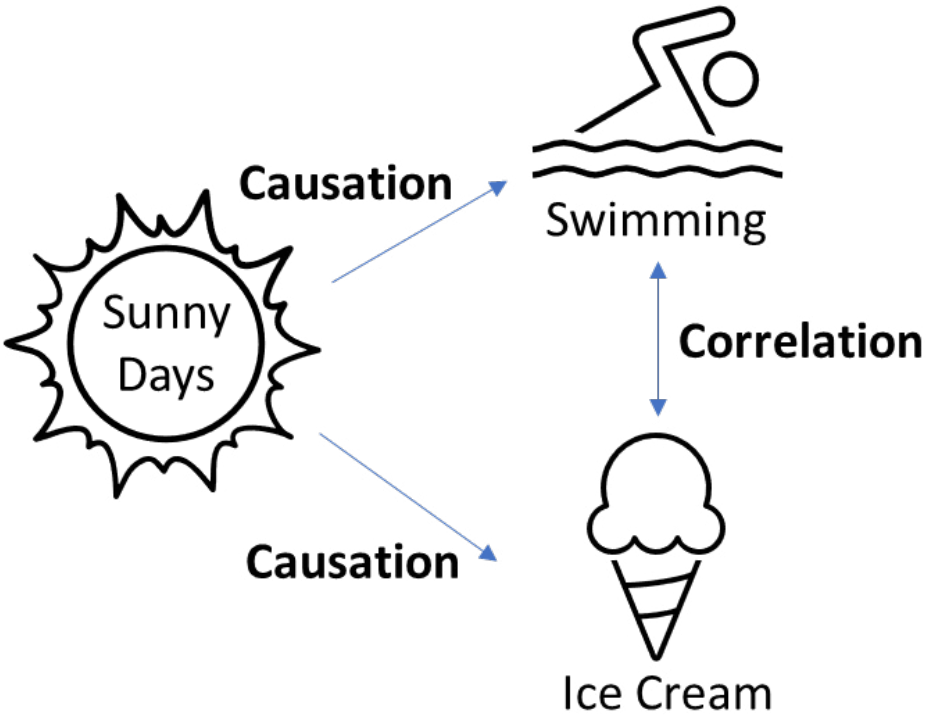
The key point is that statistics are complex. You need to understand the test and why it is the right one in order to trust what you have found. Researchers are trained in different types of analysis depending on the type of data they collect.

Statistical tests can compare differences between data and look for cause and effect relationships. There are also tests that look for data that is associated with each other, known as correlations.

The difference can be seen in the following example:

Sunny days may cause people to swim more, and people to buy ice cream. There are both cause and effect relationships.

You may also find a correlation between swimming and ice cream, but swimming more doesn't cause more ice cream buying, and buying ice cream doesn't cause more swimming.



Words (qualitative data)

Analysing word-based data is just as complicated as number-based data. There is not one way to do it, and it is very dependent on the research question, how the data is collected, and the underpinning view of knowledge.

Qualitative analysis can be very time-consuming, as there is often a lot of information to sort through to pull out the key information. It can also depend whether the word-based answers are part of an open-ended question in a questionnaire, or answers in an unstructured interview i.e. how direct the relationship between the question and answer is.

A common method is organising data based on themes (thematic analysis). To develop themes, the researcher goes through the data and labels key information, known as coding. The researcher may want to look at the data with a ‘blank slate’, or they may choose to acknowledge what they are expecting to see before adding in new information.

Themes are based on similar codes being brought together. Themes should be independent from each other. For example, if your research question was about ‘how the general public view dementia’, common themes could be ‘stigma-negative assumptions’ and ‘education-lack of knowledge’.

Mixed Methods data

Finally, you may have a mix of number and word-based information to look at. You will have to know before you start whether you are looking to analyse the different types of data separately, and how you intend to bring them together.

Case study 5: Deciding how to analyse data

SUNshiners

The SUNshiners group created a survey to find out what the public knew about dementia, including what they thought about the invisibility of dementia. It was really important to the group that the general public responded (not just people who had experience of dementia). So they created the survey online, which was passed to a lot of people via social media networks. They also printed 100 copies and left them in local shops, cafes and groups. They were astounded to receive 347 completed surveys, which was very exciting, but also completely overwhelming!

In a university research team an early career researcher would be called upon to input all the data and to do top level analysis. So the SUNshiners called in help!

Rosie came to the rescue. She took each question and asked the group to think about the different reasons people might give for their answers. These made categories for Rosie to start sorting answers into. When Rosie had gone through several responses, she added in categories that had come up. A set of criteria for what was put in each category was then given back to SUNShiners so that they could go through some more answers. Finally, Rosie grouped the rest of the answers following the same criteria, as designed by the SUNShiners.

Section 14

Writing your report

Your report needs to follow a simple structure.
A good way to start is by making a list of section headings such as these:

- Title (make sure it includes some key words)
- Names of the authors
- Introduction (a summary of what the report is about and its structure)
- Background to the research – don't assume the reader knows anything about the subject
- Your research question and your aims
- What you did to collect information (your methods)
- A description of the research actions and their results
- Your conclusions
- List of references (include any other reports that have helped you with your findings)
- Acknowledgments (to thank those who have helped in any way)

It's great to include some quotes, case studies and photos (with permission) to bring the human touch.

Think about what the report will look like...

- the font you use (Arial 14 is a good one)

- how you space the lines (1.5 is good)

- colours; page numbers etc.

Always get someone (or several people) to read through it (proof-read) as they will spot typos and errors that you have missed.

Referencing the sources you use in your work is important because it [13]:

- enables your readers to find the sources you have used, so that it can be verified that you used the material in an appropriate and accurate manner.
- acknowledges the sources of any material you used that is not your own, so preventing any charge of plagiarism against you.

You will need to keep careful notes while you are gathering material from academic literature.

One common system for references is the Harvard referencing system. This uses brackets within the text, rather than footnotes and endnotes which means you only have to include essential reference information in the actual text (the citation). Full details are then held in a reference list or bibliography at the end.

The texts listed in your bibliography should be presented alphabetically by author's surname.

You only need to include a reference to the sources you used in your writing; (not the sources you have looked at but haven't referred to).

13 http://bit.ly/2TxEVlc

Section 15

Sharing what you have found out

If you have done a good piece of work, it's really important to share what you have found out with others (even if it didn't tell you what you expected or hoped!).

Here are some ideas:

Having a good report that is easy to read and understand (see previous section) is the foundation.

You will also need to produce a short, ***accessible*** summary, which people with dementia will be able to read and understand.

Think about how many hard copies (if any) you need to get printed. There is obviously a cost involved here, but they are useful to give out to people you meet, and at events. 500 will probably be plenty.

Having the report online (not just on paper) makes it much easier to share. You could ask for it to be made available on the DEEP website.

You should send your report (with a covering letter or email) to anyone who will find it relevant to their work e.g. your local service providers or commissioners (the local council and/or Clinical Commissioning group); your MP; your councillors. Include any that you particularly want to influence. You could also ask if your group can present the report to them personally.

You can use social media (Twitter or Facebook) to promote your report and put a link to it. Having a photo or other picture helps people to notice it. If you don't use social media, ask others (e.g. DEEP) to promote it for you.

You could turn your summary into a short article and send it to relevant journals (e.g. Journal of Dementia Care).

You could also send it to your local newspaper, TV or radio station – you might get an interview! NCVO have good advice on pitching to the media.[14]

You could present the work at an event or conference (local or national). You may have to send in your idea ('submit an abstract') several months beforehand, so watch out for deadlines.

And importantly, make sure you send it to all those who were directly involved (e.g. your interviewees).

25 small research projects were carried out as part of the Dementia Enquirers programme between 2020-2023. You can find them all here **https://dementiaenquirers.org.uk/individual-projects/**

14 http://bit.ly/2u2e6X6

Section 16

Acknowledgments

We are very grateful for the following sources, on which we have drawn heavily:

The Open University website: **http://bit.ly/2JcymzH**

The NCVO website: **https://www.ncvo.org.uk/**

Research Methods: The Basics. Nicholas Walliman 2011 Routledge: **https://bit.ly/3Y3WV3i**

Kvale S. (1996) Interviews: An Introduction to Qualitative Research Interviews, Sage Publications, California

We would also like to acknowledge the substantial contribution of Dr Rosie Ashworth.

Notes

Dementia Enquirers

Dementia Enquirers was a DEEP project which ran from 2018-2023 and was funded by the National Lottery Community Fund. It aimed to develop a new approach to research, or 'enquiry', that is led and controlled by people with dementia. It has supported over 20 DEEP groups in conducting their own research projects. It also explored with people with dementia, the lessons that emerged from their work.

Visit **www.dementiavoices.org.uk/dementia-enquirers/** for more information and resources.