healthwatch Bucks

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Buckinghamshire, Oxfordshire and Berkshire West
Integrated Care Board

Community-Based Participatory Research Workbook

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Introduction to the workbook

This workbook is for anyone interested in community based research. It is for someone new to research as well as someone who has more experience.

In this workbook you can make notes about a research project you would like to run.

This is a thinking space for you to work on as you go along. There's no set 'right' answers as each community will have different needs and changes they would like to make.

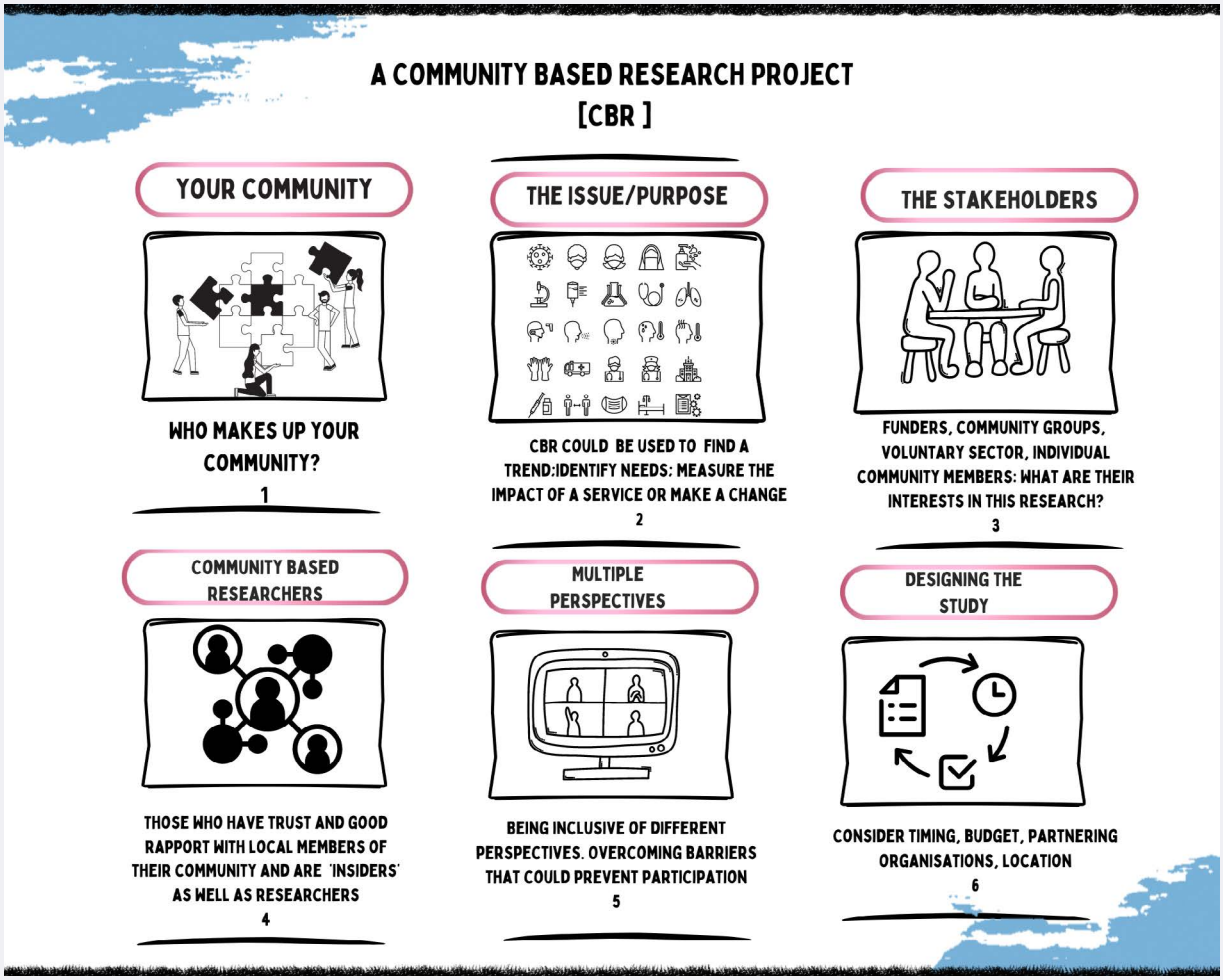
Each page takes you through a step in the research cycle. So, it starts with what your community needs and ends with how community members can get the best of out of the research project.

On each page there are links to external websites and videos to help you.

For more information about some technical sides to research, there are 'Information guides' which explain the subject in more detail.

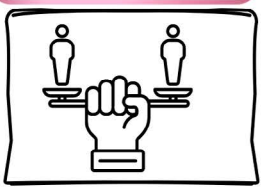
Storyboard

This storyboard, created by CBPR researchers, shows the the research journey.



A COMMUNITY BASED RESEARCH PROJECT

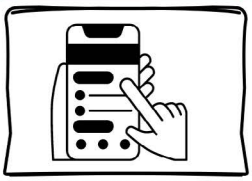
ETHICAL CONSIDERATIONS



RESEARCHERS NEED TO BE AWARE OF BIAS, INFORMED CONSENT AND PRIVACY. IS SAFE-GUARDING TRAINING NEEDED?

7

DOING THE RESEARCH 1



WILL YOU NEED QUALITATIVE (INTERPRETATIVE) DATA OR QUANTITATIVE (MEASUREABLE) DATA, OR BOTH FOR YOUR NEEDS?

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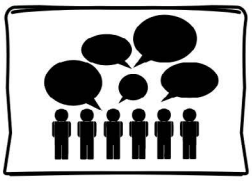
DOING THE RESEARCH 2



DECIDE ON YOUR TOOLS QUALITATIVE TOOLS COULD INCLUDE INTERVIEWS; OBSERVATION; PARTICIPATORY METHODS

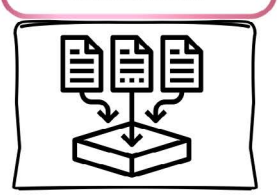
9

DOING THE RESEARCH 3

PARTICIPATORY METHODS COULD INCLUDE: PHOTOGRAPHS; WORKSHOPS; PUBLIC MEETINGS; JOURNALS;

10

DATA COLLECTION



WHICH DEVICES WILL YOU USE? HOW WILL THE INFORMATION YOU GATHER BE STORED SECURELY? DECIDE WHO WILL HAVE ACCESS.

11

DATA ANALYSIS

ANALYSING THE INFORMATION YOU'VE COLLECTED TO FIND THEMES. THIS COULD BE DONE THROUGH THEMATIC ANALYSIS FOR QUALITATIVE DATA

12

A COMMUNITY RESEARCH PROJECT

PRESENT FINDINGS

SOME WAYS TO SHARE INFORMATION ABOUT WHAT YOU'VE FOUND OUT ARE: LEAFLETS; POSTERS; EXHIBITION; A WEBSITE

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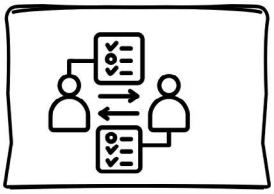
EVALUATION



WHAT DIFFERENCE DID THE RESEARCH MAKE? HOW DO YOU MEASURE THE EFFECT OF THE RESEARCH? HAVE ALL STAKEHOLDERS AIMS BEEN MET?

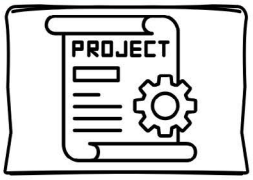
14

YOUR COMMUNITY

DO COMMUNITY STAKEHOLDERS FEEL EMPOWERED TO MAKE CHANGES? HAVE THEIR QUESTIONS BEEN ANSWERED

15

COMMUNITY ACTION PLAN



TO IMPROVE A SERVICE, OR START A PROJECT YOU NEED ALL STAKEHOLDERS TO COME TOGETHER AND PLAN THE NEXT STEPS BASED ON YOUR RESEARCH FINDINGS

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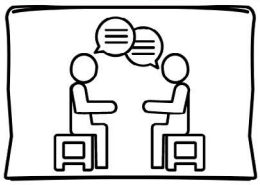
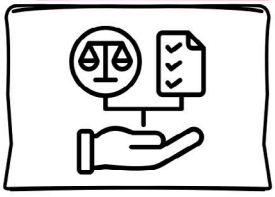
FURTHER OUTPUTS



THIS COULD BE A REPORT, A MEETING WITH LOCAL GROUPS; A SERIES OF INFORMATION EVENTS

17

POLICY MAKERS



THE DATA YOU COLLECTED IS NEEDED BY POLICY MAKERS TO MAKE CHANGES AND PROVIDE RESOURCES WHERE NEEDED

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Who is your community?

In order to plan your community based research project, a good starting point is to think about who belongs in your community. This will help to clarify what their priorities are the direction your research takes.

1.1.Who makes up your community?

1.2. What's the purpose of doing community research?

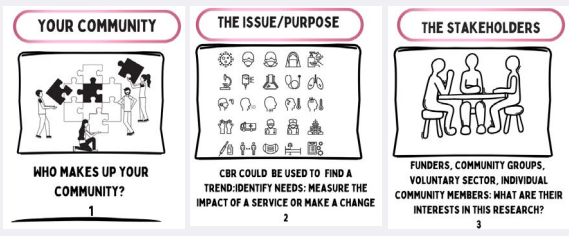
1.3. Who are the stakeholders and how can you reach them?

1.4. Can you think of both a positive and a negative side of your community? Which strengths and barriers do those represent?

1.5 Which topics are important to your community members?

1.6.Can you break this topic down into 2 or 3 smaller ones?

1.7. What questions need to be asked about this topic?



The stakeholders

In community based research, there may be a number of stakeholders. For example, members of a housing association; local council officials; a charity group; educational settings or a GP surgery.

Each member brings their own valuable point of view and experience.

Any organisation that funds the research, is also a stakeholder. They will be interested in their aims being met. Funders could offer support to your project through networking events and introductions.

Different members might not agree all the time as they have their own opinions, but they all need to be heard.

It's important to share what the benefits will be for each project member; the funders, stakeholders, community researcher, and most importantly, the community. What will they gain in the short, medium, and long term?

2.1 Thinking about your subject, which points of view do you need to keep in mind? Can you list four, or more below?

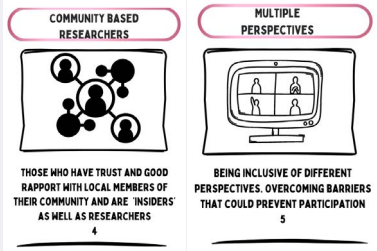
2.2 Funders are investing in community research to hear from the people they often can't reach. Are all those affected by the subject chosen going to be heard- and who might be hard to reach?

Can you think of individuals or organizations to connect you to those hard to reach people?

2.3 As a community researcher, does belonging to the same area or group you are researching create challenges for you?

Reflect on your thoughts about your own position in the research below.

2.4. Are you approaching the community with set ideas and beliefs about them?



Getting started

There are many parts to take into account when planning a research project. Some of these are:

The aim of the research	**Stakeholders**	**Budget**	**Ethics**
Designing the research	**Data collection**	**Data analysis**	**Sharing results**

3.1What is the main question you need answered?

3.2 Why is it important to carry out this research?

3.3 Is the research funded? If yes, what are the funder's requirements?

3.4 What results do you want this research to achieve?

https://www.youtube.com/watch?v=ehDrlcqaRfo&list=PLYwSkJsQT-91yoTuy9OI6CFodz_M-PNiB&index=2

Addresses children participants and covers consent & ethics. Informs them about their rights

Ethics

When doing research that involves the community, there are important ethical questions to keep in mind.

This includes making sure that the community research partners:

- represent the interests of the community
- compensate them for their contributions
- check for any risks to the community
- make sure decision-making between academic researchers and community partners is fair.

Ethics is about making sure the research process is fair and balanced.

Research ethics guide researchers to ensure no one is harmed in the research cycle from beginning to end.

Safe-guarding and safe recruitment policies of the organisation you are working with should be followed.

What are your thoughts about these statements below from a community researcher? Do you agree or disagree?

4.1 Consent:

'I can include a friend in this research study without asking their permission, because they trust me.'

4.2 Bias:

'I don't think my personal beliefs or background affects how I collect data.'

4.3 Anonymity:

'I always keep participants identities anonymous even if they say they don't mind being known.'

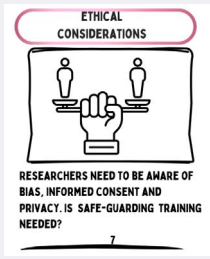
4.4 Privacy:

'When I gather data, I must have a secure way to store it, that includes password protected devices, my notes books and recordings on my phone.'

Further information in: Ethical Questions for Community Based Research
https://www.hra.nhs.uk/planning-and-improving-research/best-practice/informing-participants-and-seeking-consent/

Further information in: Ethics Guide
https://www.youtube.com/watch?v=9pCfq5QH_v4
(Owen Bardon Hope: basic definition, principles; what is harm and a few examples.)

Safeguarding
https://www.youtube.com/watch?v=cpWsw48jyuA
Further information in: Safeguarding Information Guide



Designing the research

To design your research you will need to choose the right tools to find the information you need.

Research helps us understand communities in different ways.

Qualitative research finds out how people feel and think, often using words or pictures. This type of research gives a deep and rich understanding of peoples' personal experiences but is difficult to gather a broad perspective.

Quantitative research uses numbers to measure things like how many people do something or think a certain way about something. It can give us a broad perspective easily- but can't give a deep understanding.

5.1 Which methods do you think best suit your project?

Write some initial ideas here:

5.2 What skills will you need for interviewing someone?

5.3 Are there IT methods you would like to know more about? Which IT skills might you or other community researchers need training on? Make a list of these and other skills you might need to undertake this research and discuss this with a mentor- or find out how you can get help.

Doing the research

Now that you have a draft of your research design, it's time to do the research. Things to keep in mind are:

- location and timing
- budget and other resources (for example consent forms)
- contacting and recruiting your participants

6.1 What's a good place and time to do this research? Think of visiting groups and events which are already taking place.

6.2 List the resources you need:

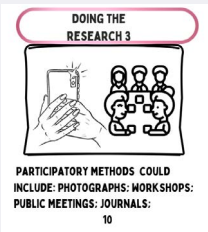
6.3 How will the budget be used, for example will it cover meeting expenses?

Participants:

6.4 Where in your community will you find the participants?

6.5 How will you contact them?

6.6 Will participants be renumerated?



Data Collection

Organising and storing data securely is essential. Always follow the stakeholder's policy and procedures on data protection.

Stakeholders such as the funders will need the data. It is important to know which format they would like to receive this in.

Think about the ways different sectors would need the data collected:

a) the health sector

b) the employment sector

c) social services

7.1 GDPR: what do you know about data protection already?

7.2 Excel or other forms: how will you collect and organize your data?

7.3 Forms with personal details. How will you store any documents or files?

7.4 Voice recordings: is there a secure file where these are transferred?

7.5 Sharing demographic information like gender, age, ethnicity, and disabilities helps to create a picture of the community to ensure fair treatment for everyone. Demongraphc information can help to understand different needs, where to provide services, or how to ensure these are targeted to specific groups. This information is personal and must be kept safe and separate from an individual's identity.

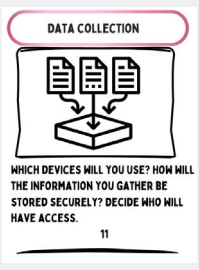
Demographic information can create a more inclusive and supportive community. How will you explain this message to people when asking for this information?

Further information in: GDPR Information Guide

What's it got to do with you? 10 reasons why you should fill in those funny box things at the end of forms (source: https://www.flintshire.gov.uk/en/PDFFiles/Diversity-and-Equality/Stonewall-Whats-it-got-to-do-with-you.pdf)

What is GDPR?
https://www.youtube.com/watch?v=Vll6V1MgZgY

(source: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/informing-participants-and-seeking-consent/)



Data Analysis

Analysing the data will provide you with the information needed for your project.

How you analyse data depends on the method you used.

For qualitative data, Thematic Analysis is a popular way to find themes and patterns from a dataset. This is done by a method of coding, becoming familiar with the themes and then re-reading the data a few more times.

For quantitative data, use an Excel spread sheet to calculate basic statistics and produce charts and graphs.

8.1 Is the data being approached with an 'open-mind' and objectively?

8.2 Do you have a system in place, using Word documents or Excel to record the analysis?

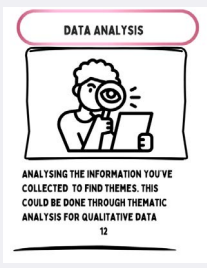
8.3 How can you use your observation notes and meeting notes to help you explain the data?

https://www.thematicanalysis.net/understanding-ta/

Further information in: Data Analysis Information Guide

What's the difference between Qual and Quant?
https://www.youtube.com/watch?v=4iws9XCyTEk

More about Qualitative research:
https://arvac.org.uk/community-research-toolkit/research-methods/#6b



Sharing the findings

Once the data is analysed, there should now be answers to your main research questions.

This is a good time to revisit the aims of all stakeholders.

These findings need to be shared with the community participants and all stakeholders.

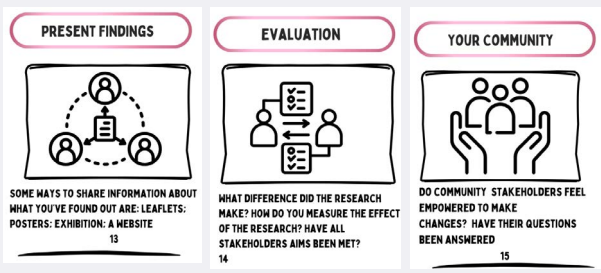
The results could help to highlight resources – people and groups - within the community that can make a difference to the project.

9.1 How do you plan to share your findings with the community stakeholders?

9.2 Have their questions and concerns been represented in the findings?

9.3 How will you involve participants in planning the next steps for a 'Community Action Plan?

Further information in: Reporting to Stakeholders Information Guide



Community outputs and policy

At the centre of community based research is the benefit and change it brings to the people who took part.

Connecting different groups for long term support and improvement is a key output.

There are many ways your community can benefit from the research. Use the questions below to help you decide which ways will be the most effective response to the project you are working on.

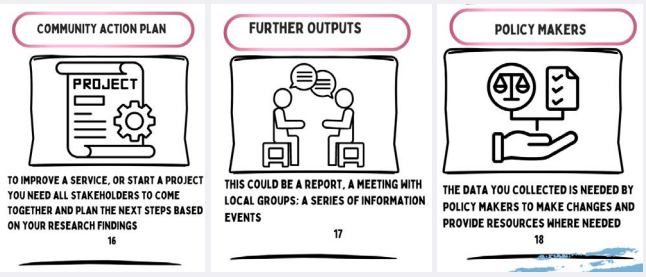
10.1 Who are the local partners to engage in an action plan?

10.2 Are there any local panels community reps can join to support the action plan?

10.3 Does the funding budget cover long term plans for example, to run follow-up sessions or workshops?

10.4 Which key community stakeholders do you need to share information with?

10.5 Have the funder's objectives been met?



When producing these resources, a variety of community organisations representing different interests, faiths and sectors were consulted. The feedback of individuals from these organisations was highly valuable at each stage. This toolkit was produced in response to their research needs.

Below are select examples of their input:

> I feel that more guidance and support are needed in community engagement methods and data analysis techniques
>
> **Community Connector**

> Key stakeholders should be kept in the loop during the study to ensure it is meeting key objectives.
>
> **I.R. Community Wellbeing Karima Foundation**

> From my experience, coming from south Asian community I do feel that we should be able to highlight that privacy/data will always be respected... Assurance is key and also familiarity.

S.A Mental Health Champion

> The link of the training webinar is helpful, I have gone back to it a few times

Community Connector

> I think it's a good workbook... brought down to the most important parts; the structure is clear.

V.S. Wycombe Refugee Partnership (WRP)

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This toolkit was produced with Marcela Heime as an independent consultant on behalf Healthwatch Bucks in conjunction with Buckinghamshire New University BNU and community-based researcher Suma Din.

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