

# Doing research together: How to make sure things are fair and no one is harmed



This is an EasyRead version of - Community-based participatory research: A guide to ethical principles and practice

February 2013



# What is in this guide



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## Why do we need to think about how we do research together?

Research is looking into something to find out more about it. Here are 2 examples of research:



- finding out why young people don't go to their local youth club



- finding out whether older people living in a town feel safe when they walk in the park.

All research needs to be done properly. It needs to be right and fair so people will trust the things it finds out. It must also be safe so no one is hurt.



Sometimes the people who are being looked at in the research also help to do it.



There are lots of things we need to think about when we do research together. Things like:

- who has the power and control?



- how are people's stories used?



- how do we include the things people want in the way the research is done?

When the research is about people's own lives these things matter even more.



This type of research is called **participatory research**. In this EasyRead paper we call it 'doing research together'.

It means that lots of different people get involved in doing research, not just people whose job it is to do research.



There has been some very good research done that includes lots of different people. This EasyRead guide tells you more about the things that helped them when they did that research.



The longer version of this guide was made in 2012 by a big group of people who got money from the Arts and Humanities Research Council.

If you need more details please see the longer version, Community-based participatory research: A guide to ethical principles and practice, which you can get on the internet:



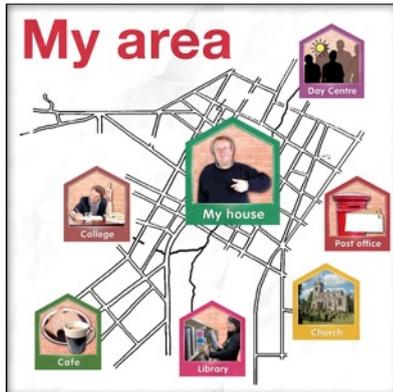
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## What is doing research together?

Doing research together starts when groups of people want to find out more about something that matters to them.



It is a way of sharing the power and money with groups of people in the community. These could be groups like:

- people living in one area like an estate or village
- groups who have something the same, like women's groups, groups of people with learning disabilities, youth groups or gay or black groups
- a sports team like football or netball
- or people with the same illness like breast cancer or HIV.





This research is different from usual research because it is done together by people in the community and the people whose job is research.



The ways people are involved could be:

- helping plan the research

- getting information



- putting the information together



- looking at what the information means



- deciding what to do about what has been found out.



People in these groups will not agree on everything. They must not let the main researchers have too much power and control, this must be shared.



**Research needs to be done in a way that is right and fair, what does this mean?**

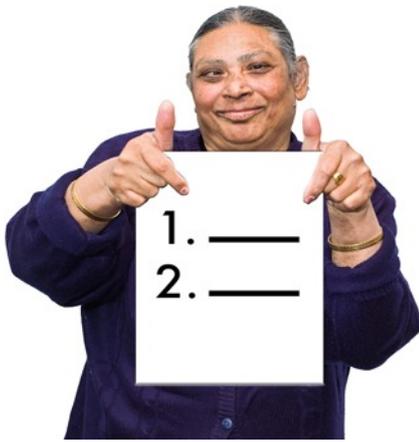
Doing things in a right and fair way is called **ethics**. So a right way is **ethical** and a wrong way **unethical**. When people do research together, it must be done in a right and fair way, it must be ethical.



This means looking at:

- what harm or good does the research do?
- the rights people have to information and privacy
- how researchers behave.





We have written a full list of these areas in Part 1 of the guide. Part 2 looks at how to do research that involves people working together in an ethical way.

## This guide

This guide is to:



- help researchers do this sort of research well



- help people who want to take part in this sort of research



- show others that it takes time and thinking to do this type of research well



- get people or organisations to change how they work if they are including people in research

- make research that involves people working together better.



It is important that everyone understands these issues so they can work out what the issues mean for their own work or project and do a better job.

## How to use this guide

This guide can be used in lots of different ways like:

- in training.

Where people want to learn about including people in research





- getting ready to do research yourselves.

Where people are starting out helping with research, or other researchers are new to this sort of work



- checking how well research is doing.

When people check their research is following this guide



- when checking plans to do research that involves people working together.

When organisations that give money for research look at people's plans to see if they are right and fair.



# Part 1 – What to think about when you do research together

These are some things to think about when you are doing research together.



## 1. Respecting each other

This means you will find ways to:

- agree to treat each other well
- make sure everyone is listened to
- realise some people will have different ways of seeing things.



## 2. Including people and treating everyone equally

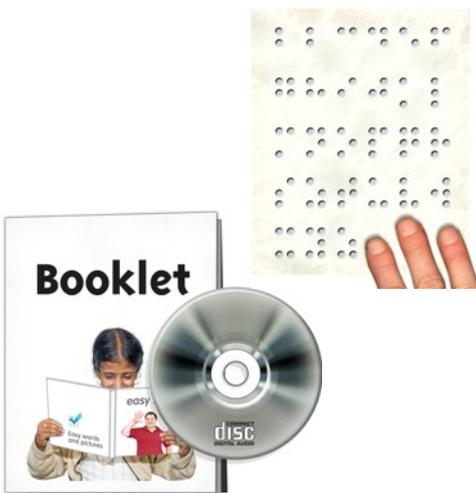


This means making sure you:

- find ways to include people from different backgrounds and beliefs, especially people who are often left out



- do something about anyone behaving badly or not treating people equally and fairly



- have accessible information and meetings so everyone can understand.



### 3. Everyone taking part in making decisions and doing the research

This means you will:

- help and support people to take part in making decisions



- think about what skills and interests people have



- share power more equally

- use words everyone understands



- use ways of doing research that use the skills people have, helps them learn new ones and get better.



## 4. Learning from each other

This means you will:

- make sure people are helped to learn from each other
- have time for people to tell others what things they have learnt
- share the work on looking at what the research finds out and what should be done next.



## 5. Making a difference

This means you will:



- think that people learning and getting things from the research is important



- do research that plans to make good changes for the people involved



- go to meetings with an open mind not thinking you know the answers.



## 6. Making change together

This means you will:

- find out the things you and the others involved in the research want it to do



- agree how to share information and power equally and stick to it



- realise the different rights and interests people have and work with that.

## 7. How you behave

This means you should:



- be reliable, honest and can be trusted



- respect other people



- follow this guide



- make sure your research is right and says what you found out



- be OK about people asking you difficult questions and work well with people who do not agree with you.

## Part 2 - How to do research together



This part looks at the 3 stages of research.

### 1. Planning and getting ready



### 2. Doing the research



### 3. Looking at what the research tells us and telling others about that.



We cannot tell you everything you need to do to include people properly, but we can look at some of the things you need to think about. This will help you look at anything else in the right way.

# 1. Planning and getting ready



Before you start the research everyone needs to get together to talk about what they think they will get from the work.

You also need to check whether everyone thinks the research is a good idea or whether it needs some changes.



Some people might not want to do it anymore – it is OK if they want to leave.

The first meeting:



- get to know each other
- talk about what you want from the research and what you are worried about
- do people want the same things?





- is working together going to work?

- if it looks like something isn't going to work can you change it?



- talk about how other work went and see if people agree with the plans for the research.

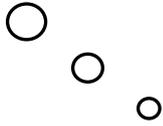


### **Who should be involved?**

- are there some people or groups who need to be asked to join in because of what they know?



- have you sorted out anything that might stop them joining in?



- is there a group that leaves some people out? And what can you do about that?



- find ways to cope when some people are involved a lot and some a little.

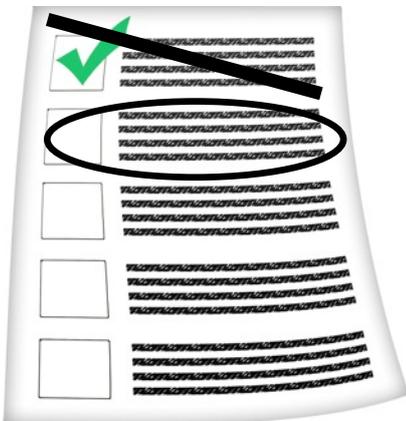


## Be clear about what you want the research to do

- involve as many people as possible in planning what the research will do



- does everyone understand why they want to do the research and what they want to get from it?



- be clear about what could change and what everyone should agree to.

## 2. Doing the research

### A work plan



- have a plan about how to work together that people agree with



- check how the plan is going every so often and change it if you need to



- be clear about the best ways people should stay in contact with each other



- be clear about when and where meetings will happen and how they are run so everyone gets a say



- have safety rules, for example about working by yourself
- decide how to sort out any problems



- agree what you want the research to do



- agree how the research needs to be done and who does what
- agree what group or people are in charge



- agree how much money there is and how do people get paid for time or expenses



- agree what training people need



- agree what jobs people have to do



- agree time to look at how the research is going and what you are finding out.

## How you get information and what you do with it



- you will need to ask people to agree to give you information



- they will need to know about what this information is for. You will need to explain this in a way they can understand



- they need to know what you are going to do with it and how you will keep it safe or private



- people need to be able to say 'yes' or 'no' when you ask them to give you information

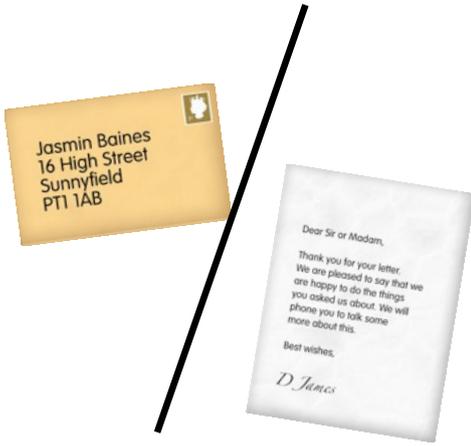


- sometimes a group needs to agree to take part



- if the research changes you might need to go back and check people still agree you can use their information.

## People's names and addresses



- any information that says who a person is should usually be kept separately from the research information they have given you



- information needs to be locked away safely



- computer files need to be protected with passwords



- everyone involved needs to know how important it is to keep information safe.

## Keeping information private



- when you are getting information from people you know or live near you must be very careful about keeping it private
- if someone says something they do not want anyone else to know that must be kept private and not be used in the research, unless it can be changed so no one can ever know who said it



- people must be told that things like facebook or twitter are not private and to be very careful



- sometimes people tell you something that might need to be passed on to the police or social workers, like a child being abused.

At the start of talking to them you might want to say 'If you tell me information about you or someone else being in danger I will have to tell the police'.

Have this as a rule so people know it could happen and if it does, go to the police.

## Using names or keeping them private



- talk about what might be good or not good about using some names of people, organisations or places



- sometimes using a place or an organisation's name might mean you can find out who the people were that gave information



- sometimes people want their names used, but talk about this because it might mean other people's names don't stay private.

## Who owns and controls the research findings?



- it is important to decide who owns the information you find out
- the owner is the person or people who decide what to do and how to use the information



- if there are several owners you need to agree how this will work, does everyone have to agree to use information in a certain way or just one person in the group?



- tell people if those paying for the research own it
- if the community has helped make new information they should get something out of it, like money or the right to own it and use it.

### 3. Looking at what the research tells us and telling others about that



#### What should you tell people?

- think about when and who you want to tell about what you have found out



- sometimes the more experienced people want to look at the research to see what it has found out.

Involving others helps them learn to do this as well



- give people the time and training to be able to look at what the research has found



- sometimes it might be helpful to tell some people, like local communities, what you are finding out as you go along



- telling communities what you have found out may be good or bad



- it might mean people think their area has more problems than they thought it had



- talk about what to share and how it is best to share it and what effect it might have.

## How should you tell people?



- it is important to be as accessible as possible

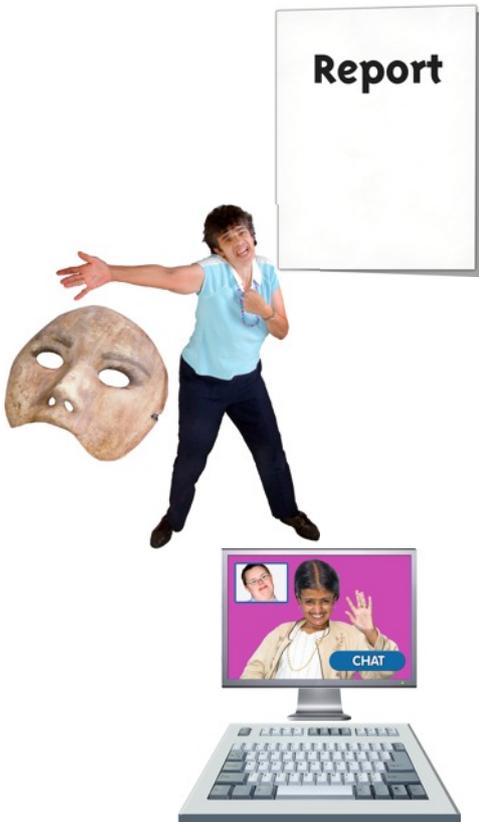


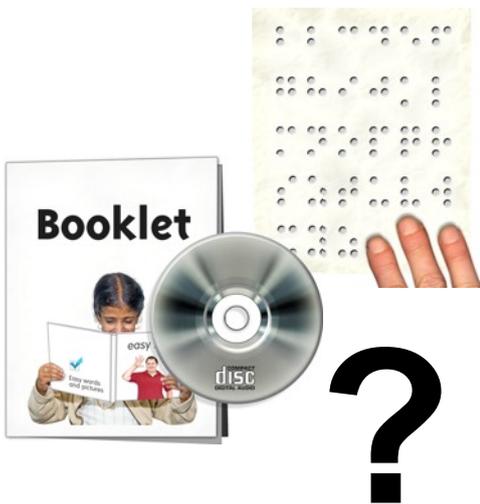
- what is the best way to tell people, what formats should you use?



- think about using:

- film or art
- cartoons
- plays or music
- written reports, articles or books
- conferences and workshops
- a party
- the internet.



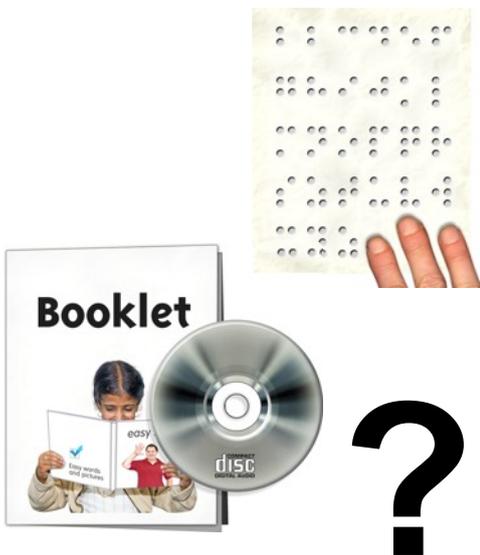


- what format is best for the research team?
- is it best to do several things?



### Who writes reports?

- tell everyone whose job it will be to write reports



- what format will the reports be in and how will they look?



- how will you involve and support others to help with this



- teach people how they can be involved and learn to do new things



- agree whose names will go on the reports
- make sure people who have helped have their names in it.



## Making sure your research is used

- having the report is not the end of the work



- think about what you have found out and how it could make changes in your area or other areas



- tell other people what you have found out, this could be people from other communities, researchers, councils or government



- get the whole group to think about what they have learnt as they have done the research



- think about whether the people who are now trained in research can do more research in the future



- have a good end to the work so people don't feel let down.



For more information, please see the longer version of this guide.



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