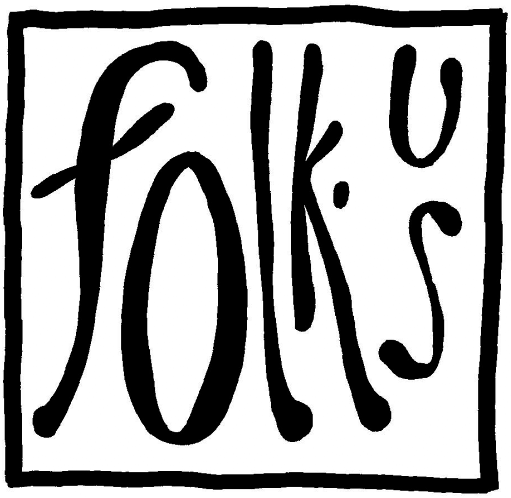

Knowing How

A guide to getting involved in research

University of Exeter
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Acknowledgements

We would like to thank all the people who have been involved in this project: the research steering group, members of Folk.us and the people who so kindly hosted us in order to learn about their research projects as case studies. Thanks also to go to everyone who read and commented on this booklet.

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The numbers you will sometimes see after a word in this report (e.g. Henwood[6]) are there to tell you where we found the information. At the end of this booklet there is a list of reports that you could read if you want to find out more (Folk.us has copies of all of these or can tell you where to find them)

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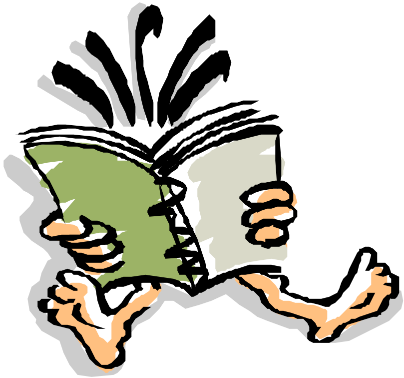
Introduction

The aim of our project was to find out how much lay people are actively involved in research outside the health service, and to use what we learned to make recommendations for health research. We also learned about how lay people feel about becoming involved in research and what they think is important.

We found out about these things by searching for books, articles and reports about research where lay people have been actively involved. We looked on Internet databases such as Medline and PsycInfo. We also went to meetings and talked to people about the research they were doing.



We also visited 8 research projects where lay people had been actively involved so that we could talk to people and learn more about the research.

Definitions used in this booklet

We use the term 'lay people' because it includes consumers, service users, local people, citizens and carers.

'Lay' (involvement): *Becoming involved using 'life experience' and not specialist professional or academic training.*

Involvement: *Having a say that is listened to, in some or all of the research process.*

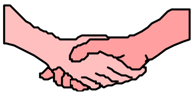
Research: *A process of collecting, ordering and evaluating information so as to provide further understanding, and/or new knowledge, and/or a basis for decision making and action or change (or finding out about something then changing it).*

Community: *A group of people sharing a common interest – for example, cultural, social, political, health, economic interests.*

Empowerment: *A process by which people gain increasing control over their lives and circumstances.*

Participatory Research: *Research in which power is shared so that it is carried out 'with' and 'by' lay people rather than 'on' them. This may employ a variety of methods.*

Partnership: A *mutually respectful relationship based on sharing responsibilities, costs, and benefits leading to outcomes that are satisfactory to all partners.*



Stakeholders: *People, groups or institutions who have an interest in something because it affects them in some way.*

What we found

We looked for research projects and background information within the following areas:

- Social Care
- Education
- Public Health/Health Promotion
- Community Development UK
- Housing/Regeneration
- Agriculture/Environment
- Development Overseas.

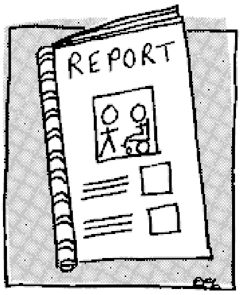
We also looked at specific groups of people who may particularly benefit from being involved in research. These are:

- carers
- young people
- older people
- people with physical or sensory disabilities
- people with learning difficulties
- people with mental health problems
- homeless people, and
- people experiencing poverty.

We found out about projects that had been set up by professional and lay people. We found examples of people from all the above groups being involved in research except for carers. This could be because such projects are not easy to find, or because carers have not yet been involved in doing research.

What kind of research did people get involved in?

We found that most of the research projects involving lay people looked at specific services, like support for young people leaving care[23] [24] or supported housing for people with mental health issues.[15] They looked at how services can be made better. In community and overseas development, lay people were more interested in how quality and conditions of life could be improved. For example, finding out what people would like in their new local community centre.[17] People tended to use questionnaires and interviews to collect information.

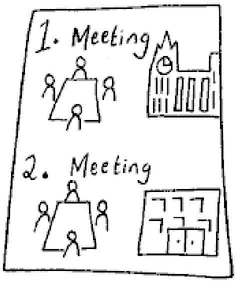


Case Study

Briardale Community Centre **– local people were recruited to carry out a door-to-door survey of people's wishes for facilities in the new community centre.**[17] [16]

The local Community Association wanted to be sure that the new community centre would offer the facilities that local people wanted. Local people were recruited to carry out door-to door surveys. They visited people in their homes and asked them questions from a questionnaire. They had a day's training when they practised asking the questions and recording answers. They also discussed how to deal with any difficult situations that could arise. The information collected was analysed and written up by a professional research team.

Another popular way of finding out information was Participatory Appraisal (PA). PA developed as a way of empowering lay people to investigate their own problems and find possible solutions. It has been used a lot in overseas development projects. It is a quick way of finding out about community needs, using local knowledge about issues and problems. Local people choose how much they get involved and how much of their experiences they want to share. Participatory Appraisal usually takes place in familiar settings such as the street or community centres.



PA uses lots of different ways to collect people's experiences, thoughts and ideas – like drawing maps, putting things in order (ranking) or placing important events on a calendar. You do not need to be able to read and write so everybody can get involved. For more information try looking at the book 'Participation Works!'[10] or the book 'Participatory Learning & Action: A Trainer's Guide'.[14] PA can be done by independent facilitators or local people can be trained to do the work themselves.

Case study

***Preston Road Estate* – local people used participatory appraisal (PA) to find out what needed to be done to improve quality of life on their housing estate.**

Local people were trained in PA methods and went out to different parts of the estate to talk to the people who live there. The local researchers found that it was a relaxed and flexible way of working, and that they were able to speak to people who don't usually get a chance to voice their opinions. It was possible to talk to people of all ages and backgrounds, as they did not feel under pressure to respond in a particular way. One result of the work is that people in the community are now more willing to work with the local authorities. Another big issue was the need for a new community centre. Now the land for the centre has been bought.[9]

We also found some examples of lay people becoming involved in scientific research. Overseas, farming (and fisheries) scientists and lay people often work together towards solutions to problems. One very good example is on-farm client-oriented research (OFCOR).[2] In OFCOR, researchers and farmers are partners in the research process. Farmers tell the scientists if they have already tried to find out about a problem or used a certain technology before a project starts. They are also asked for ideas of how to test things, for example, a new kind of seed.

In health research, lay people are now beginning to be more involved in randomised controlled trials (RCTs). These are experiments where people are randomly chosen to try out different interventions or treatments. The results are compared with a non-intervention (control) group. Lay people have advised on priorities for research and the general design of studies. Some have also been responsible for reading drafts of the information given to people taking part as well as writing up and disseminating results.[5]

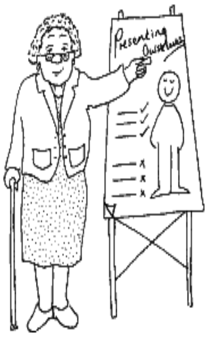
How people got involved

We found examples of lay people getting involved at lots of different stages of the research, for example:

- Professionals inviting lay people on the steering/advisory group of their research project, from the planning stage onwards.

Example
The Joseph Rowntree Foundation (JRF) funds research. Anyone funded by the JRF has to report to a project advisory group. The JRF now invites lay people/users to be members of advisory groups and, in some cases, sets up additional advisory groups with 100% lay membership.[19]

- Lay people asked to advise on the questions that should be asked or help with analysis and interpretation of results.



Example
Researchers asked Puerto Rican older people to help interpret survey results about care available to disabled people from different ethnic and social groups. They spent an hour discussing the results and possible reasons for them. This gave the professionals an insight that they would not otherwise have had and helped them make recommendations for changes to services for the elderly.[7]

- Lay people doing their own research

Example
Young people in Belfast found out about attitudes and experiences of drug use by posting questionnaires and talking to other young people. They visited the Netherlands to find out what people thought there, where some drugs are legal. They presented their findings to policymakers.[8]

Lay people also had different levels of control and responsibility within projects:

- User groups commissioning professionals to do research for them and taking a managerial role.

Example
Living Options, a user group for people with physical disabilities in Devon, paid a researcher to find out about how people with sensory disabilities and associated professionals felt about the registration process for sensory disabilities.[3]

- Lay people and professionals working in equal partnership, sharing their knowledge.

Case Study
***Barrow Community Gym* – research to find out how well a community gym for mental health service users did in its first year.**[20] [21]
Professional researchers formed a research group including four gym users and a staff member. Early in the research process, gym users began to take more control. They designed, piloted and distributed a questionnaire. Some people were also interviewed. They collected the information, entered it on computer and helped with analysis. Two gym users have now taken over the evaluation.

- There may also be occasions when a project started by lay people benefits from some professional advice.

Example

The North Staffordshire Pensioners' Association asked a university department if they would do some research for them about the 'real' living costs of older people on pensions. The academics did not agree to carry out the research, but offered to help the group conduct their own project. They trained the older people in research techniques and helped them make decisions about exactly what they wanted to find out.[13]

Reasons why you might want to become involved in a research project:

- Being unhappy about something – for example, The Bristol Women's Cancer Group was angered by results of a flawed study that found their treatment centre to be ineffective.[18]

- wishing to defend a service - Cornwall's Healthwatch action group was established because of threatened closures of community hospitals.[6]

- to make things better – research can lead to action

- to learn about a particular issue

- to find out if other people are experiencing the same things as you

Case Study

Finding Out **– people with learning difficulties found out if the experiences of other self-advocacy groups were similar to theirs.**[26]

Members of Bristol Self-Advocacy Group visited other people with learning difficulties and carried out group discussions and interviews. They talked about what self-advocacy meant to them and practical things like finding jobs and using public transport. They wrote up their findings in a range of formats: as a booklet accessible to people with learning difficulties[4], as a chapter in a published book[11] and in journals such as Community Care[25] and the RCSLT Bulletin.[12]

Members of the group became more confident and improved their listening and communication skills. They feel that by carrying out this research they have gained power in their lives, and for the group, through increased knowledge and shared experiences. They have presented their findings to People First and national conferences.

Things to consider if you're going to become involved in a research project or if you want to carry out your own research

We all do research every day. Things like looking for a bus to a certain place at a certain time or calling a travel agent about holidays are ways of finding out. Professional researchers and scientists can learn a lot from lay people because they are experts of the experiences they want to find out more about. We are all experts in our own right.

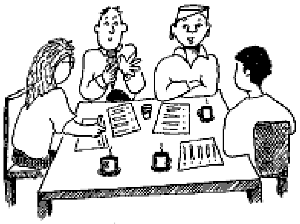
We learned a lot from reading the reports of research that lay people had been actively involved in. We learned about some things that are making it easier for lay people to become involved in research and some other things that still make it difficult. The thing to remember is that the more people get involved, the easier it will become! Some suggestions of things you might like to think about before getting involved in or starting a research project are outlined below.

When are you getting involved?

Everyone should be involved as early as possible in the research process, so that the direction of the research is clear, everyone knows what they are doing and there is commitment to the project. This is especially important for professionals so that they will be committed to making any necessary changes at the end of the project.

It is possible to be involved in ALL stages of the research process, as a researcher or by guiding research on a project steering group.

Who else is involved?



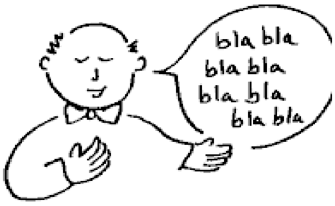
If you become a steering group member, you should not be the only lay person in the group. Ideally, there should be equal numbers of lay people and professionals. In reality, a good compromise is to try to make sure that at least two or three lay people are involved, so that you feel okay about speaking up at meetings and have support from someone with a similar perspective to you.

Professionals are often very keen on making sure that lay people on a steering group, or becoming involved in research, are ‘representative’ (of disabled people, carers, service users etc). Usually, this means they look for someone typical of the group of people they want to study. However, a representative can **also** be someone who has been nominated to represent a group of people, like a Member of Parliament. Professionals may also refer to a representative sample, meaning people who have been deliberately selected and can be considered to represent a known population.[1] It is important to discuss what kind of representative is wanted at the beginning of a research project so that everyone understands what is expected of them (this applies to projects led by lay people and by professionals). Sometimes the fact that professionals do not know who to involve is used as an excuse not to include people at all.

Lay people who choose, or are invited, to become actively involved in research may not directly represent others, any more than professionals can be said to represent other professionals. What is most important is that the people involved have had relevant experiences that they are willing to share, so that a wide range of people, rather than a representative sample, of people influence the research. The influence of a variety of people with different experiences and views is likely to lead to a better research process.

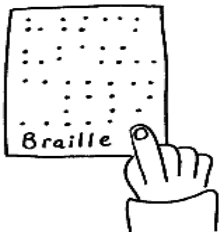
Is it clear what the research is about?

If the research is relevant and easy to understand, people are more likely to be motivated to become involved. This applies to professional and lay-led research.



It is important that everyone understands each other in terms of the language they speak, as well as words used only by particular groups.

It is also important that all information is presented in formats and terms that are accessible to the particular group of people involved. If you do not understand something, the chances are that you are not alone and will be thanked if you speak up and ask for an explanation. Even professionals don’t always understand everything!



When planning the project

More professionals are now involving lay people in their research. This is because they are starting to see the relevance of involving the people who are going to be affected by the project findings. If you are starting your own research project, there will probably be professionals near you who are happy to share their research skills and knowledge with you and give you any support you need if you get in touch with them. Folk.us keeps a list of current health research projects in North and East Devon so that people can see what types of project they could get involved in. There may be organisations near you that can help you find out what is going on too. We have written a list of possible organisations to contact at the end of this booklet.

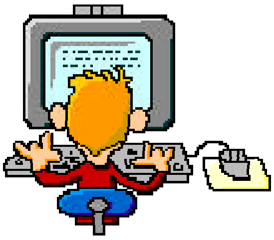
Another thing to look out for is that some research projects (especially those about health issues) have to be approved by ethics committees. Ethics committees are set up to make sure that research projects are genuine and that no one will be hurt in the process. However, they often seem more concerned with protecting individuals than taking into account lay people's concerns and giving them the power to make a difference by getting involved. Procedures for gaining approval for a research project are usually very complicated and time-consuming. Currently, only professionals can apply to NHS Ethics Committees, meaning that lay people wanting to do their own research have to find a professional to go through this process for them.

It may also be helpful to consider that some professionals fear that involving lay people will lead to demands that they are unable to meet. Honesty, openness and trust between professionals and lay people are very important if the partnership is going to work. It is very important that people's roles and responsibilities and the aims of the project are clear right from the beginning. Different groups of people will have different perspectives on the aims and objectives of research. There will also be differences within groups.

Working in partnership also usually means a shift in power from professionals to lay people, which some professionals may find hard to deal with at first.

Don't forget that you might be in charge of the research project and be looking for professionals to help you!

How can you find out if similar research has been done before?



You can look for examples of research in journals and books. Libraries may be a good place to start looking (if there is a university library nearby, this is likely to have the most information). It is possible to look up many published research projects on computer databases. However, many of these are only available on subscription or through professional institutions, like universities. Folk.us is happy for people to make an appointment to come to the office and use one of our computers to carry out searches (or you could visit our website and look at some of the links). There may be organisations near you that can help you too.

Doing The Research

Be prepared for the research to change direction as it progresses. This is likely to happen when people from different backgrounds and with different views work together. Different people may like to become involved in different ways. It is up to you how much you join in. Some people may not like speaking at a discussion group, but would be happy with a one-to-one chat. That's fine.

Meetings are usually more productive if they are informal and take place somewhere that people are used to, like a community centre. Providing lunch is a good way to put people at ease and often leads to relaxed discussion. Remember that research can and should be fun! Learning and development will only happen in an atmosphere of enjoyment and motivation.

How will information be collected?

The way that you collect information will shape the kind of information that you find. If you have not done research before, then it is a good idea to do some training to learn about different ways of collecting information (if you are working with professionals, they should be able to offer you such training). It is important that you collect information in a way that means your findings will be taken seriously.

There are two main kinds of ways of collecting information. These are known as quantitative and qualitative research. Quantitative research tends to be science-based and values objectivity, validity, reliability and generalisability. The researcher must not get personally involved, must stand back from the process and remain outside (*objectivity*). The research should measure what it is intended to measure (*validity*), it must produce similar results if repeated over time (*reliability*) and it must be *generalisable* from the sample being studied to other similar populations. Quantitative methods include questionnaires, surveys, structured observations and experimental studies.

In qualitative research, transparency, trustworthiness and transferability are emphasised. Qualitative researchers believe that nobody can be totally objective and neutral, and bias is minimised by acknowledging researchers' opinions and being open about all aspects of the research process (*transparency*). The methods for gathering and analysing information should be *trustworthy*. Enough should be known about the sample being studied to help in judging the extent to which the findings are applicable elsewhere (*transferability*). Qualitative methods generally include unstructured or semi-structured interviews, participant observation, focus groups and other approaches that involve researchers actively listening to what research participants have to say.

One way of breaking down possible language barriers is to use ways of collecting information that rely more on visual images than spoken or written language. There are many flexible visual methods that can be used instead of, or with, traditional surveys.

It is also important to think about *who* will collect the information. People are often more open and willing to share knowledge with people with whom they have shared experience. Lay people have collected information on many successful research projects.

Case study

Alternative Choices – finding out about alternative ways of coping with mental health problems.[22]

Members of Camden Mental Health Consortium held discussion and focus groups with service users looking at three themes: alternative/ complementary therapies, self-help approaches, and religious/spiritual beliefs and practices. People's experiences, the benefits and disadvantages of these approaches, and their availability locally area were discussed. There was a strong feeling that the research was more successful because it was carried out by and with people with experience of mental distress/using mental health services. This made it a mutual learning experience and exchange of information – a two way process.

Funding

Some funding and commissioning bodies (such as The Joseph Rowntree Foundation and The Alzheimer's Society) have a positive attitude towards active lay involvement. This makes it easier for professionals to invite lay people to work with them, as they can ask for extra money to cover training and expenses for lay people, as well as the time it will take to recruit people.

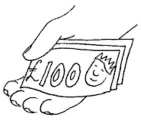
If you want to carry out your own research, there are some agencies that are more likely to help you. Folk.us hopes to create a list of these funding bodies to help people know who to contact. At present, however, such information can be found in the public library (for example the Directory of Grant-Trusts), by visiting your local Council for Voluntary Service or volunteer bureau or by searching the Internet.

Will your needs be met?

If you, or any members of the research group, have specific needs, these should be considered when meetings are arranged, e.g. wheelchair access, an interpreter for people who communicate with sign language, assistance getting to the meeting. Make sure you let the person organising the meeting know what your needs are.

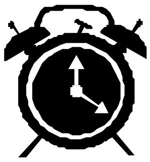
What support are you being offered/will you offer?

Lay people getting involved in research will usually need support in the following areas:



- payment for work undertaken and out of pocket expenses
- practical support in terms of transport, accessible meeting places etc
- emotional support. For example, advocacy where appropriate.

How long will the project take?



This is an important consideration if you are becoming involved in a research project. People are always surprised how long it takes for a project to go from planning stage to completion. Some take months or years. A good estimate would be to take your first calculation and times that by at least four!

If you are starting your own project, you will need to be flexible about the timing and location of meetings, and recognise changes in people's availability (due to illness, impairment, caring responsibilities etc).

What will happen at the end of the research?

One of the aims of involving lay people in research is to suggest changes that will really make a difference. Sometimes, research ends with the writing of a research report and nothing more. People often give little thought to making sure that the findings are used to bring about the suggested changes. It is important to think about what extra money and/or time will be needed to make changes based on the findings. Professionals should only actively involve lay people in their research if there is some way of acting upon the findings (this could mean applying for more funding once the research is complete).

It is helpful if there is already commitment from service providers to co-operate with the research group and to make changes in the future. How to implement the results and plans for on-going support should be included in the project design. When the research is over, most people like to be able to see that what they have found out has or will make a difference.

Example
Help and Care in Bournemouth recruited older people to do some research about barriers to independence for older people. Their sponsor is the local Social Services Department, who recognise the value of service users and carers being actively involved in research into issues that affect their lives. Although they have not specifically allocated resources for implementing the findings of this project, they are committed to understanding and improving the quality of their clients' lives, and have assured Help and Care that they will take the findings seriously.

Finding Out more about getting involved in research

You might get ideas from the reading suggested below and also by contacting some of the organisations we list.

Useful reading:

- Croft,S & Beresford,P. Getting Involved: A Practical Manual, Open Services Project & Joseph Rowntree Foundation. 1993.

- Consumers in NHS Research. Getting involved in research: A guide for consumers. September 2001.

- Hackett, C. Out of Our Mouths, not Out of Our Heads. Belfast: West Belfast Economic Forum/Save The Children. 1996.

- The Mental Health Foundation. The DIY Guide to Survivor Research: Everything you always wanted to know about survivor-led research but were afraid to ask. London: The Mental Health Foundation, 1999.

Useful organisations and contacts

- **Your local NHS Research and Development Support Unit (RDSU)**
  You could look for this in the telephone directory or find out from your local library or local health authority where it is. RDSUs provide support to lay people and professionals wanting to carry out research about health issues. They can help with ideas for funding, writing your research ideas down and deciding how you want to carry out research.

- **Your local Council for Voluntary Services (CVS)**
  The address of your local office should be in the telephone directory or your local library will be able to tell you where it is. CVS

- **Consumers in NHS Research Support Unit**
  The Help for Health Trust, Highcroft House, Romsey Road,
  Winchester SO22 5DH. Email: conres@hfht.org
  Website: www.hfht.org/ConsumersinNHSResearch

- **The Mental Health Foundation**
  20/21 Cornwall Terrace, London NW1 4QL.
  Telephone 0207 5357400.
  Email: mhf@mhf.org.uk Website: www.mentalhealth.org.uk

- **Alzheimer's Society**
  Alzheimer's Society, Gordon House, 10 Greencoat Place, London
  SW1P 1PH Telephone: 020 7306 0606
  Email: info@alzheimers.org.uk
  Website: http://www.alzheimers.org.uk/index.html

- **National Children's Bureau**
  8 Wakley Street, London EC1V 7QE. Tel: 020 7843 6047/6080.
  Website: http://www.ncb.org.uk/

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