

# The research

## Introduction

Here we explain the research methods we use to create each project on this website. We use qualitative research methods to understand how people experience illness and make treatment choices. A systematic collection of interviews, carefully analysed, is just as important in qualitative research as well-designed, randomised controlled trials and systematic reviews are in quantitative research into the effectiveness of medical interventions.

These methods have been recommended by the NHS National Knowledge Service as the 'gold standard' for research into patient experiences.

## Researchers and research supervision

Each set of interviews is collected and analysed by an experienced and trained researcher who specialises in this sort of study. Researchers within the Health Experiences Research Group are all social scientists by training with backgrounds in sociology, anthropology, health policy, psychology, discourse analysis and history. We have a careful recruitment process to ensure that we appoint excellent and sensitive researchers.

Each researcher is fully trained in the research process, and is given a detailed handbook to refer to. The research director has overall responsibility for ensuring the research process is adhered to and approving any changes to it, and conducts annual appraisals of each researcher. The full research team meets together every 4-6 weeks to monitor progress with the individual studies, provide mutual help and advice, and deal with any questions or problems. A particular strength of the process is that each researcher is assigned another researcher who acts as 'buddy'. The buddy supports and advises their colleague at all stages.

## Advisory Panel

Each study has an expert advisory panel including patients, health professionals and researchers with a special interest in the condition or topic being covered. The advisory panels are very important to the projects, and play a key role in ensuring we produce high quality research-based information. They provide advice to the researcher throughout the project, help us to ensure that we interview an appropriate range of people and have included all of the main treatments and perspectives, check that the material we write is clinically accurate, sensitive and accessible to a lay audience, and promote the project in their own spheres. (See 'credits' section on each module for a list of the advisory panel members for the project).

Before the researchers start interviewing, they read published books and papers on the subject to help identify issues for the interviews and to find out what sorts of people we need to include in the study. Their reading includes up-to-date reviews of clinical evidence on the particular topic as well as social science studies, and will include recommendations from the advisory panel.

## Recruiting interviewees

We recruit people to take part in interviews through a number of different routes including GPs and hospital consultants, support groups and newsletters, advertising in the press, on websites, in social media and by word of mouth. Doctors and nurses hand out recruitment packs (which include a 'study information sheet', an introductory letter, a reply slip and stamped addressed envelope) to potential participants, who can get in touch with us if they are interested in hearing more.

Sometimes people hear about the study and contact us directly, in which case we send them a pack to help them decide if they want to take part. To make sure that a wide range of experiences and views are included we use a method called purposive (or maximum variation) sampling (Coyne, 1997). We carry on collecting interviews until we are convinced that we have represented the main experiences and views of people within the UK. Often this requires between 40 and 50 interviews.

## Interviews



The interviews take place throughout the UK, often in peoples' homes but people can be interviewed elsewhere if they prefer. We usually interview people on their own, but sometimes a partner or friend may be present during the interview. All the interviews are audio tape recorded for analysis. If the respondent is happy to consent, interviews are also filmed.

In the first part of the interview people are asked to tell the story of what has happened to them, perhaps from when they first began to suspect there was 'a problem'. The researcher does not interrupt the person while they are telling their story but asks additional questions later, which may have been prompted by issues raised by the interviewee, identified in earlier interviews or from the literature review .

It is usual for qualitative interview studies to have an overlap between collecting and analysing the interviews. Two members of the research team (the main researcher and their 'buddy') discuss the emerging themes after a few interviews have been completed and new ideas may be suggested. This may lead to changes in the interview guide for subsequent interviews to enable issues that are important in peoples' stories to be explored more fully.

## Copyright

The interview tapes are fully transcribed and the transcript is returned to the interviewee for review. Participants sometimes decide that there are sections of the interview they would rather did not appear on the website, in which case the researcher removes them from the final version. After reviewing the transcript (if they wish to) the interviewee is asked to sign a copyright form (to the University of Oxford) which allows the interview to be used for research, teaching, broadcasting and on the website.

## Analysis

Before analysis starts we draw up a list of categories of topics for analysis. These are initially identified from the literature and from the first few interviews. As the analysis progresses, additional categories are added. A computer assisted software package is used to help organise the interview transcripts for analysis which begins soon after the first interview (Tesch 1990).

During the analysis we group and link all of the sections of the interviews that cover a similar topic (for example 'diagnosis' or 'talking to the doctor'). When this 'coding' is finished we can then look at what everyone has said about a particular topic, gathered together in one or more reports. These reports are the basis for the analysis and for writing the topic summaries (the individual pages within a health condition on the site).

The researcher and their buddy look at the reports and together they make sure that important points, and every respondent's perspective, have been included in the topic summaries (see below). The role of the buddy is to be a 'critical friend' who takes an independent view of the data collected. At this stage there may be some discussion about meaning and interpretation of points made during the interviews. The analysis process is described in more detail in Ziebland and McPherson (2006, see references for details).

## Writing for the website

Two qualitative researchers from the team look at the interview transcripts and discuss which topics should be written up into individual pages for the site (topic summaries). The list of topics is also discussed with the advisory panel. In writing the topic summaries, the researcher represents the full range of perspectives collected during the interviews, not just a majority view or a few selective opinions. The findings are set in the context of the latest clinical evidence and current best practice.

Each topic summary is drafted by the researcher, checked by their buddy, revised and then sent to at least one appropriate member of the advisory panel for additional contextual material and checking. Finally, the summaries will be given a final edit for 'plain English'. The research team are given regular refresher training in writing for a lay audience.

## Selecting video clips



The researcher identifies video, audio and written excerpts from the interviews to illustrate the range of views and experiences in the interviews. Only a few clips from each interview appear on the site, however the full interviews are used for the analysis and as the basis for papers for conference presentations, peer reviewed journals and chapters.

## Publishing papers

We aim to publish one or two papers in peer reviewed journals from each of the studies. These are sent to social science and specialist and general medical journals. Hundreds of articles have been published since 2001. We regard this as an important way of disseminating our results widely to all types of professional readers as well as ensuring that the quality and academic credibility of the studies is maintained.

The Research Assessment Exercise (RAE), which happens every few years, rates university departments according to the quality of their publications. The research group's publications have been submitted as part of the submission of the University of Oxford Department of Primary Care, which consistently achieves the highest rating. It was one of only 5 top-rated departments of primary care in the country in the last RAE.

## Updates

We are committed to reviewing all research projects on the website every three years to identify material that needs updating or requires new interviews.

## References

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