

Experiences of patient and public involvement in medical research – a Healthtalkonline study

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Oxford Biomedical Research Centre

Healthtalkonline – what and why?



- Originally the Database of Individual Patient Experience (DIPEX)
- Now nearly 80 topics or conditions covered
- Health and wellbeing as well as illness
- Around 3000 interviews in total and counting

People's experiences

Information and support from other people, in the same situation.

Related:

- ▶ Find out how we can help you
- ▶ Friends, family and carers
- ▶ NEW: Living with and beyond cancer

[PEOPLE'S EXPERIENCES](#)[YOUNG PEOPLE'S EXPERIENCES](#)[HEALTH PROFESSIONALS](#)[LEARNING & TEACHING](#)

Welcome to HealthTalkOnline

Find information on a range of illnesses and other health-related issues from seeing and hearing people's real life experiences. Thousands of people have shared their experiences on film to help others understand what it's really like to have a health condition such as breast cancer or arthritis. Find out more or select from our list of health conditions above.



How we do the research

- Each collection is based on a rigorously conducted qualitative research project
- For each condition - a sample of 40-50 plus patients from all over U.K, from different backgrounds and with different experiences are interviewed
- Patients are interviewed until no new ideas, or experiences are voiced to get the widest possible range of experiences (a 'maximum variation' sample)
- Aim is to represent *this range* of perspectives, not a majority view

How we do the research

- The interviews are unstructured and semi structured starting with ‘Tell us your story.....’
- People review their transcript and take out anything they don’t want used
- They give permission for use on the website, in research, education, service improvement...
- Qualitative analysis looking for the themes which matter most to participants
- Each collection approx 25 summaries of the main themes in the collection, illustrated by video, audio and written interviews clips

Medical research

Overview

BIOBANKING	CLINICAL TRIALS	CLINICAL TRIALS: PARENTS' EXPERIENCES	CLINICAL TRIALS: YOUNG PEOPLE'S EXPERIENCES	SCREENING FOR UNRECOGNISED HEART VALVE DISEASE
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News

For the desperately ill, trials of new drugs offer one last hope



Clinical trials

Overview

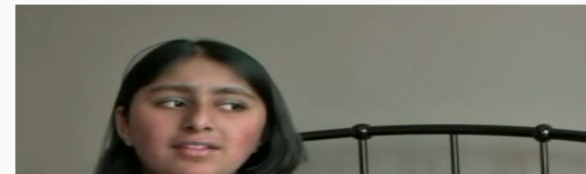
- [Clinical trials in children and young people \(3\)](#)
 - Why do we have clinical trials in children and young people?
 - Different types of trials
 - Other types of medical research
- [Making the decision about taking part, or not \(5\)](#)
 - Being invited to take part in a clinical trial: information and questions
 - Making the decision to take part and giving assent and consent
 - Reasons for wanting to take part: personal benefit
 - Reasons for wanting to take part: helping medical science and others
 - Deciding not to take part although eligible to take part in a clinical trial
- [Being in a trial \(6\)](#)

Overview

In this section you can find out about the experience of taking part in a clinical trial, by listening to people share their personal stories on film. [Our researchers](#) talked to 32 young people in their own homes. Find out what people said about issues such as why they took part in a trial, what is involved in a trial, and what it was like for them. We hope you find the information helpful and reassuring.

You can start viewing topics by clicking 'Next Topic' above, or selecting from the list on the left. You can also view 'People's Profiles' from the tab above.

You may also be interested in our other sections [Clinical trials: Parents' experiences](#) and [Clinical Trials](#).



Now Playing
See a preview of 'Young people's experiences of clinical trials'



▶ A-Z

▶ Categories

▶ Young people



Search

People's Experiences

Medical research > Clinical Trials > Topics > Finding out about a trial > Being asked about taking part in a trial

Clinical Trials

Topics

People's Profiles

Resources & Information

Credits

Overview

▼ Finding out about a trial (5)

What are clinical trials and why do we need them?

Different types of clinical trial

Being asked about taking part in a trial

Information and questions

Difficulties finding a trial to join

▼ Deciding whether to take part – risk and benefits (5)

Reasons for wanting to take part – personal benefit

Reasons for wanting to take part – helping medical science

Deciding not to take part

Thinking about withdrawing from a trial

Why people may not be eligible to join a trial

▼ Being in a trial (8)

◀ Previous Topic

Next Topic ▶

Being asked about taking part in a trial



How people are asked to take part will depend on the type of trial. At one end of the spectrum, people may themselves actively look for trials to join, or answer adverts in newspapers, newsletters or notice boards. Often people will be contacted through their GP. The GP may speak to patients personally or send a letter on behalf of the trial, or the trial may get the GP's permission to contact suitable patients directly. In some cases, trials are based in GP surgeries.



◀ Now Playing [view profile](#)

Jenny was pleased to be invited by her GP to take part in a trial of different treatments for very heavy periods.

◀ [view profile](#)

Harry got a letter from the trial clinic saying his name had been put forward by his doctor. It seemed like a good opportunity to have some health checks.

◀ [view profile](#)









Rosamund got a letter about

Clinical Trials

Topics	People's Profiles	Resources & Information	Credits
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- ▶ **Cancer drugs and radiotherapy - randomised trials (5)**
- ▼ **Long term conditions (9)**
- Harry - Interview 07
- Phil - Interview 11
- Kate - Interview 13
- Elvan - Interview 15
- Angela - Interview 23
- Danny - Interview 26
- David - Interview 34
- Sergio - Interview 37
- Sarah - Interview 38
- ▶ **Trials involving surgery (3)**
- ▶ **Mental health trials (2)**
- ▶ **Not taking part in a trial (7)**
- ▶ **Cancer - Non-randomised studies (5)**

Long term conditions

	<p>Harry - Interview 07</p> <p>Harry took part in a trial of medication for high blood pressure. He had some side effects...</p>		<p>Phil - Interview 11</p> <p>Phil took part in a trial of medication for high blood pressure and cholesterol. He had...</p>
	<p>Kate - Interview 13</p> <p>Kate and her husband took part in a trial comparing injections of grass pollen antigen...</p>		<p>Elvan - Interview 15</p> <p>Elvan took part in a trial of medication for hypertension. His blood pressure did not...</p>
	<p>Angela - Interview 23</p> <p>Angela was diagnosed with Parkinson's disease after taking part in a trial on nerve...</p>		<p>Danny - Interview 26</p> <p>Danny joined a trial of high blood pressure medication, but stopped because of side...</p>
	<p>David - Interview 34</p>		<p>Sergio - Interview 37</p>

Experiences of 'PPI'

- New study funded by Oxford Biomedical Research Centre
- Interviews with approximately 40 people with a range of different types of PPI experience – from beginner to 'old hand', from ethics
- Currently in analysis – emergent findings on:
 - How and why people get involved
 - What helps and hinders meaningful involvement
 - What benefits people derive from involvement
 - Payment
 - Expertise over time
 - Impact of PPI – examples, how to capture

Routes to involvement

- Phil was a research participant – but hungry for more
- Research participation as a common but underestimated route

Routes and reasons

- Mix of personal benefit and benefiting others
- General moral/community duty, volunteering
- Intellectual curiosity
- Keeping busy
- Own or family member's illness
 - making sense or gaining control
 - giving back to NHS and/or helping other similar people
- Chance encounters or rational processes

Ben: a chance encounter

- Video clip will be available on www.healthtalkonline.org by April 2014

Meaningful involvement?

- ‘Make your own involvement’
- What helps and what hinders
 - Practicalities (money, time, training, etc.)
 - Opportunities for inclusion (language, ways of participating, effective chairing)
 - What looks like it might be helpful can be otherwise (e.g. teleconference)
 - Attitudes (valuing people, giving feedback)

Brin: valuing people

- Video clip will be available on www.healthtalkonline.org by April 2014

Benefits from involvement

- As well as benefits which motivated people initially, some evolved over time
 - Giving back
 - Learning (new skills, about research, family health)
 - Feeling valued
 - Improving self-confidence and self-esteem
 - Intellectual stimulation ('fascinating' and 'seductive')
 - Maintaining your professional edge
 - Enriches life and gets you out of the house
 - Challenges and pushes you to work outside of your comfort zone

“Well at a personal level I've gained a lot from it. I've gained knowledge of things which directly bear upon our family health. I have gained satisfaction and enjoyment of working with some very bright people and the sort of reward of feeling that what I've done has actually been useful [...] If you retire at the end of a long career then, and maybe if your physical opportunities are limited in some way – and ours were limited by my wife's orthopaedic problems – then a lot of the drive force of your life has suddenly been removed from you. And your self-regard and intellectual stimulation, all of those things are suddenly taken away. [...] And I suppose the icing on the cake would be if in five years' time, one of these guys came back to me and said, ‘You know that project that we did? Well it's really, really worked.’ I would think that was great.”

Charles

Maxine: developing expertise

- Video clip will be available on www.healthtalkonline.org by April 2014

Payment

- Strongly competing views
- Payment as an indicator of PPI's value
 - Or should PPI as a 'civic duty' be voluntary?
 - May result in attracting the 'wrong people'
 - Necessary to attract the right people
 - Professionalisation could mean people would not be as committed

Dave: the thorny question of payment and benefits

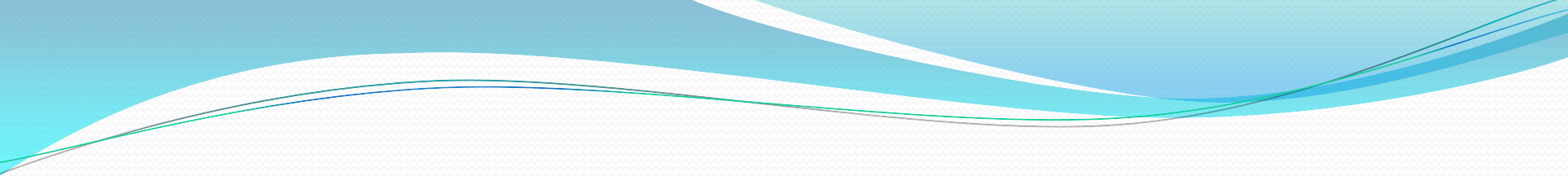
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Expertise over time

- From 'losing patient-ness' to a 'conveyor-belt of involvement'
- Preserving expertise, experience, training and skill
- Retain grounding in patients' experience

“...After all these years there's got to be question marks about when I stop being really lay and I become professionalised, if I'm not already [...] I am aware that I need to be careful that I don't lose, or haven't lost, what it is I thought I was bringing in the first place. [...] I think you should refresh membership of all committees like that and you need new people coming along, both clinicians and lay. [...] I think I do bring that awareness of what it's like on the ground, and I do talk to a lot of people just even people in the street, friends, neighbours about their experiences and I still feel that they help to inform how I see things. But I am mindful of that loss of freshness and I need to think hard about if what I'm contributing is different now and that's quite a sad thought really [laughs], you know, giving it up.”

Janice



“I was becoming a much more informed patient, a much more informed citizen researcher if you like and I could do the job better because I understand what research was. I had a lot of confidence in how research goes forward. I wasn't frightened to make my views known in a professional way within the group...”

Dave Y

Impact

- More on this tomorrow!
- To measure or not and how?
- Qualitative ways to capture the impact of ‘that one little thing you said’, perhaps by interviewing researchers

“I think that's a very big question because it can't just be anecdotal [...] and I think that the way forward in PPI is finding a way of measuring that as being real. [...] We have done it by asking researchers to feedback what they felt the impact or the input was. But I know that there needs to be a lot of more – in inverted commas – “research” done in how you measure that. I am very convinced of the impact, but there has to be some tangible way of presenting that.”

Margaret

Roger: capture impact qualitatively

- Video clip will be available on www.healthtalkonline.org by April 2014

The next study will be....

- ...researchers' experiences of involving patients/families and public
- Volunteers now sought (including the sceptics and the downright hostile)

Uses for the PPI site

- Will go live in March/April
- Help new people decide if PPI is something they'd like to do?
- Play examples at meetings to set a different tone?
- Training for involvement?
- Training for researchers?
- How might it be useful for you?
- New scrapbook feature – please use!

Anything else you'd like to know...

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