

Healthtalk and the Oxford Health Experiences Research Group (HERG)

Dr Louise Locock. 18 May 2015



The basic idea....a **D**atabase of **I**ndividual **P**atient **E**xperiences

- Using qualitative research to gather people's stories (on video if possible) to understand how people experience illness and what really matters to them
- Using the results to support other people going through the same thing, and give clinicians insights
- And increasingly – using the results to inform policy, service improvement, guidelines....

Research and dissemination

- Research is led by Health Experiences Research Group (experienced social scientists)
- Unique dissemination route through Healthtalk (run by the DIPEX Charity)
- Research-based nature is key – the only source of patient experience evidence listed in the NICE process and methods manual (National Institute for Health and Care Excellence)

Young people's experiences

Reliable health information from young people, for young people.

Related:

- ▶ Find out how we can help you
- ▶ Friends, family and carers
- ▶ NEW: Young people and arthritis



“

It's reassuring to know that there are other people going through the same as me.

”

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What's different?

- These days many health information sites have a few patient videos or written stories
- But they often aim to inspire/be positive – may alienate some
- Anecdotal, under-analysed
- Our aim is to represent the broadest possible range of perspectives, *based on thorough research*
- All studies have UK National Health Service ethics approval

How we do the research

- Each collection is a standalone qualitative research project (grant funded) – open-ended interviews
- For each condition - a sample of 35-55 patients from all over UK, from different backgrounds, recruited through a range of avenues, and with different experiences are interviewed
- Patients are interviewed (at home) 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 – so everyone can find reflections of their experiences

Long term conditions

Overview

[ARTHRITIS IN
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Topic summary - diabetes and exercise

▼ The long view (4)

Managing diabetes at work and driving

Home and social life

Adjustment to diabetes and changes in self-image

Misunderstandings about diabetes

Not everyone wants to take 'exercise' in a formal or structured way. It may suit some people much better to do extra bits and pieces of physical activity in the course of their daily lives. Strategies such as getting off the bus one or two stops early and walking the extra distance to work or the shops or going out for a walk at lunchtime, were two kinds of informal exercise that people said had helped them lower their blood glucose levels and also lose weight.



Now Playing [view profile](#)

Helen says even a 20 minute walk at lunchtimes helped lower her blood glucose levels.

Show Text Version [Print transcript](#)

Those who felt they did not exercise enough and those who used to exercise regularly but no longer did so, gave a variety of reasons for not getting round to regular exercise. Reasons included the cost and time involved in taking exercise - several people said they couldn't afford gym membership, others said they felt too tired after a day's work to go out and exercise. Several people said that they were too busy with other more immediate problems in their lives such as caring for their families to devote time to themselves. Several people said they just didn't like taking exercise.



Now Playing [view profile](#)

Harold knows he needs to lose weight but feels that 'human nature' often gets in the way.

[view profile](#)

Stuart says he has a 'series of excuses' of not taking as much exercise as he should at the moment.

Asthma experiences

- Not realising it could be asthma (Julie) and getting inhaler technique right (Melissa)

- Watch the patient videos:

<http://www.healthtalk.org/peoples-experiences/chronic-health-issues/asthma/julie>

<http://www.healthtalk.org/peoples-experiences/chronic-health-issues/asthma/melissa>

Academic outputs

- Over 100 peer review articles based on these data by Oxford group including clinical and social science journals
 - Locock L, Ziebland S, Dumelow C. Biographical disruption, abrupture and repair in the context of Motor Neurone Disease. *Sociology of Health and Illness* 2009; 31: No 7: 1-16
 - Chapple A, Ziebland S, McPherson A. Stigma, shame and blame: a qualitative study of people with lung cancer. *BMJ* 2004; 328: 1470-1473
- Collections used as secondary analysis resource by other social scientists
 - Charteris-Black, J. Seale, C. Men and emotion talk: Evidence from the experience of illness. *Gender and Language*, Vol 3, No 1 (2009)

How health experiences on the internet are used

- Alan explains how his wife benefited from practical tips on living with Motor Neurone Disease, view the clip here:

<http://www.healthtalk.org/about/overview>

How might Healthtalk support you and your patients?

- ‘Information prescription’ for your patients – DH Information Standard member
- Helping them frame questions: *“Asking for help is a lot easier when you know what you're talking about. For information on care and choices, healthtalk.org is superb, featuring a range of illnesses and health-related issues via real-life experiences.”* Phil Hammond
- Knowing they are not alone with illness – 24/7 social support
- Seeing how others have made treatment decisions

How might Healthtalk support you and your practice?

- Resources and ideas for local service improvement
- Use of clips to trigger discussion with practice patient involvement groups
- Resource for GP trainees, practice nurses and receptionists

Recent additions

- Chronic Kidney Disease
- Asthma
- Giving up smoking
- Carers of people with MS
- Gout

Areas we are currently recruiting for – how you can help us!

- Young people's experiences of primary care (14-25)
- Young people and skin conditions (eczema, **psoriasis**, **alopecia**, **acne** – more males, more 12-16 year olds)
- ARCHIE study - parents of children aged 12 or younger with physical disability/long term condition who have had a flu-like illness
- Hypertension (site updating)
- Adults in Oxfordshire within six months of lung or bowel cancer diagnosis
- Women with learning disabilities who have had a baby in last 3 years
- Please take packs and posters.....