


‘Managing qualitative data for health research: a case study.
Health Experiences Research Group, University of Oxford’

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Who we are



Health Experiences Research Group

DEPARTMENT OF
PRIMARY HEALTH CARE

 UNIVERSITY OF
OXFORD

HOME

ABOUT

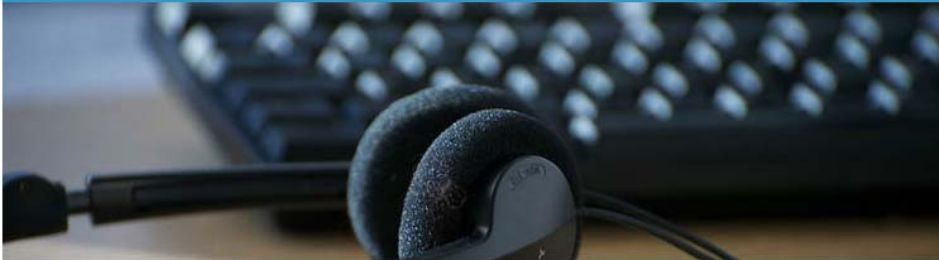
STAFF

WHAT'S NEW

BLOG

PUBLICATIONS

CONTACT



Welcome to the Health Experiences Research Group

Health Experiences Research Group is a flagship programme of work in the Department of Primary Healthcare at the University of Oxford. We research people's experiences of health and illness; we record one-to-one qualitative interviews with people about what it's like to live with a range of medical conditions including cancer, heart failure & autism, and publish findings on www.healthtalkonline.org and www.youthhealthtalk.org.

LATEST POSTS

Engaging with sleep: male definitions, understandings and...
[More >>](#)

Unruly bodies and couple's sleep
[More >>](#)

OUR TEAM

Our team members are funded to research a specific health condition. So far we cover 60 different conditions, which are now featured on healthtalkonline.org and youthhealthtalk.org.
[More >>](#)

OUR WORK

We invite people to tell us their story, so that their experiences can help others in similar situations and provide vital feedback which might otherwise be lost.
[More >>](#)

TRAINING COURSES

HERG is a flagship programme of work within international qualitative health research. We offer a number of professional training courses. Click below for more information.
[More >>](#)

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What does HERG do?

- Award-winning websites - Healthtalkonline & Youthhealthtalk
- Based on qualitative research studies of health experiences (over 60 covered so far)
- Cancers, mental health, chronic health issues, intensive care, screening, heart disease, bones and joints, autism, medical research, young people and women's health
- Free to patients and the public, families & health professionals

Search...

Search

See all conditions

Cancer

Nerves & brain

Mental health

Dying & bereavement

Chronic health issues

Intensive care

Heart disease

Bones & joints

Pregnancy & children

Carers

Autism

Medical research

Later life

Young people

Women's health

**"True stories are...nutritious and sustaining.
They feed the mind with information and the
heart with hope and strength..**

Philip Pullman

**People's stories: see, hear and read
their experiences...**

Healthtalkonline is the award-winning website of the DIPEx charity and replaces the website formerly at dipex.org. Healthtalkonline lets you share in more than 2,000 people's experiences of health and illness. You can watch or listen to videos of the interviews, read about people's experiences and find reliable information about conditions, treatment choices and support.

The information on Healthtalkonline is based on qualitative research into patient experiences, led by experts at the University of Oxford. These personal stories of health and illness will enable patients, families and healthcare professionals to benefit from the experiences of others. For more information on a particular condition, please click on one of the links to the left.

How to use this site...

Like 213



Welcome by
Jon Snow



An Introduction to
healthtalkonline.org



What people say
about us



support
our
work



Women's
health



“ in the news ”

Ann McPherson
wins MJA
lifetime
achievement
award



youth healthtalk



search

Search...



Youth Health Talk
on Facebook



141 people like Youth Health Talk.



Natalie



Viv



Steve



Facebook social plugin

Welcome to **Youthhealthtalk!**

This is a website about young people's real life experiences of health and lifestyle. This is not just a website about the medical facts, this is about **real people** and real lives.

Watch, listen and read young people talking about their experiences, and feel free to join in the forums.



Introduction by
Thom Yorke

Forum

Epilepsy

Teenage Cancer

Sexual Health

Diabetes type 1

Long term health conditions

Health and weight

Depression and low mood



Join

**My youth
healthtalk**

You could win an iPod touch!



Want to be interviewed?

Click here to see who our
researchers are looking for



Who is Healthtalkonline aimed at?

- Patients at all stages of their illness journey
- Patients' family and friends
- Teachers
- Health professionals
- Policy makers
- Researchers

Privacy and dignity

See and hear
people's real-life
experiences of
health and illness...



What do I do?

- Research Delivery Project Manager
- Scheduling projects – time management
- Training the researchers - systems, handbook, equipment, troubleshooting
- Data management and archiving
- Progress checks and meetings and copyediting all the delivered material ready for the website
- Updating websites – Information Standard



Project Management

- Currently have 61 projects published on Healthtalkonline & Youthhealthtalk websites
- 20 other projects in various stages which will deliver in the next 2 years
- 10 sites to be updated by the end of 2011



What data do we collect?

- Audio/ video interview (written interviews are still audio recorded for transcription)
- Transcripts of interviews
- Biographical details of the interviewee
- Contact details
- Consent and copyright forms



Data Archive

- 2500 interviews 80% of which are video or audio recordings
- Over 3000 hours of video/audio material
- Over 2500 transcripts, consent forms, copyright forms and biographical details.



How do we manage the data?

- Ethics requirements?
- Data protection requirements?



Ethics

- Our ethics state that all data must be kept in locked filing cabinets in a locked room
- Interviews are identified just by their interview number. Names and address are not stored with the interview transcript or biographical data.

Data Protection

- Electronic files with interviewee names & addresses are in password protected documents on a password protected drive only accessible to the research group
- List of what data is kept and where it is located which is used for auditing purposes or enquires.
- Response with 24 hours.

Systems - how & where to store the data

- Computer filing systems – what should be stored, where and who can change what
- Training the researchers on the systems
- Saving names and interview number separately
- Data storage - tape or digital – 2 copy system – who has access and who does the copying
- Paper work- Interviewee's details, consent forms, copyright forms. How and where to store them

Equipment- don't forget to budget!

- Storage equipment/ Space
- Hard drives or tapes for video storage
- Backup equipment?

Long term access to the data

- Electronic files – University maintained and backed up
- Digital copies of interviews - hardware replaced every 3 years
- Non digital interviews- clips on website backed up and hardware replaced every 3 years
- Programme of digitising old interviews.

Challenges?

- Long term access
- Making management understand the importance of maintaining a useable archive
- Time – manpower
- Cost
- Moving offices