dipex charity

Working with
The Dipex Charity

### Introduction

healthtalk.org and socialcaretalk.org are about people's real experiences of health and social issues.

The content for the websites is gathered by academic researchers using qualitative research methods. The websites are run by us, The Dipex Charity. We are an independent UK-registered charity that shares first-hand experiences of health and social care for the benefit of the public and professionals working in those sectors.

The current team has been in place since 2010. We understand the world of academic research, particularly qualitative health research and have skills in web development, copy editing, project management, video and audio production, social media and more.

We help people feel less alone, better informed and better prepared.

One in three users of our websites say that we decreased their need for an appointment with a health professional.

"We look forward to working with you!"

Adam Barnett, CEO of The Dipex Charity

#### About us

The charity was founded in 2001 by a GP, Dr Ann McPherson and Clinical Pharmacologist Dr Andrew Herxheimer who found that their own medical knowledge and experience was lacking when experiencing their own health challenges.

They wanted to hear how other people had experienced the same issues and managed the impact on their everyday lives. Together with a steering group, it was decided that the best way to collect these experiences was through academic qualitative research interviews and analysis.

We see our role as different to other health websites and charities that provide up to date and in-depth medical information. healthtalk.org and socialcaretalk.org exist to let people find out what it is like to experience a health or social care issue first-hand, by hearing the stories of others. That is our focus, and it sets us apart from other health websites.



Dr Andrew Herxheimer and Dr Ann McPherson

# Lay dissemination and impact

Many funders now expect research bids to include a plan for wide dissemination and impact beyond the papers. We know that researchers are passionate about this too; every month we talk to academics who want their research to help the public directly. We share their belief that publicly funded research should be available to a wider audience than those who are able to pay costly journal fees and decipher academic writing.

For more than 20 years, The Dipex Charity has been sharing outputs from qualitative research with millions via our websites.

Surveys from thousands of our website users say that by accessing the experiences of others, they found information in our sites they hadn't found elsewhere. They also felt:

- Less alone
- Reassured
- Better able to manage their own health
- Less inclined to need a medical appointment
- Better prepared for medical appointments

"Research is of no use unless it gets to the people who need to use it"

Professor Chris Whitty, Chief Scientific Adviser for the Department of Health

# Other applications of our websites

### Promoting self-care

We help people feel encouraged to take a more active role in their health care and reduce their need to see a medical professional.

By way of example, a successful online diabetes intervention that includes our clips, is being adopted by the NHS.

A recent study looked at how people with psychosis can benefit from other people's narratives of psychosis and included clips from healthtalk.org.

Murray et al (2017) Web-based self-management support for people with type 2 diabetes (HeLP-Diabetes): randomised controlled trial in English primary care. BMJ Open 2017; 7.

Ng et al. (2019) The mechanisms and processes of connection: developing a causal chain model capturing impacts of receiving recorded mental health recovery narratives BMC Psychiatry 19:413

## **Educating professionals**

Our clips are used in teaching all over the world, for a variety of subjects and levels. An academic study showed that using our patient interview clips in teaching improved medical students' exam results and confidence.

#### See:

Rosamund Snow, Joanna Crocker, Katherine Talbot, Jane Moore & Helen Salisbury (2016) Does hearing the patient perspective improve consultation skills in examinations? An exploratory randomized controlled trial in medical undergraduate education, Medical Teacher, 38:12, 1229–1235, DOI: 10.1080/0142159X.2016.1210109

### Improving services

Research has demonstrated that our content can help prompt useful discussions among hospital staff about service improvements. We created short films made up of healthtalk.org video clips of patient interviews, interspersed with questions designed to prompt discussion amongst staff and service users. These lead to tangible results, comparable to those brought about with local user groups.

Darbyshire, JL, Hinton, L (2018) Using patient narratives to design an intervention to reduce noise in the intensive care unit. Journal of Health Design. 2018;3(2):109–112.

Locock et al (2014) Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Health Services and Delivery Research. No. 2.4

### Changing policy

In 2021, former healthtalk.org collaborators Professors Jenny Kitzinger and Celia Kitzinger won the ESRC Impact Prize for "Outstanding Impact on Public Policy". The award recognised work that built on insights and networks established during their research for the healthtalk.org website section, for families of people in minimally conscious states.

Their research found that doctors were continuing to treat coma patients in cases where families and clinicians agreed it was no longer in the patient's best interests. The only way to challenge this was through the courts. The Kitzinger sisters worked with families, healthcare and legal professionals to change this.

This was their second award from the ESRC. The first recognised the 'Outstanding Impact on Society' of the website itself in 2014.

# FAQ about working with The Dipex Charity.

# What research can appear on healthtalk.org and socialcaretalk.org?

Research must be conducted by a qualified researcher who is (or has been) based at a recognised academic institution, charitable organisation, or public entity. The quality of the proposed project will be vetted by the charity's staff for its suitability. The charity has the right to decide against allowing dissemination on its websites.

### What kind of content can appear on the websites?

We are open to discussing qualitative research projects and any outputs that cater to the needs of the proposed audience. We have experience in producing content in a variety of formats including video and audio interviews, podcasts, animations, written text etc.

# What about the funding of projects which appear on healthtalk and socialcaretalk?

The majority of our funding comes from the NIHR and charitable sources. The funding of any proposed project will be vetted by the charity's staff for its suitability.

"I have an inquest coming up into my son's suicide. I wanted to know what happens at an inquest and have found and heard lots of useful information to help prepare me."

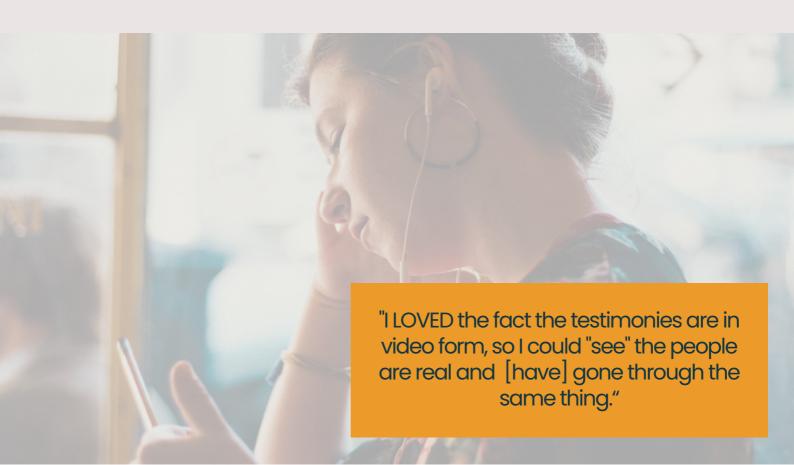
# What support can the charity provide for the funding bid?

Our CEO, Adam Barnett, has been a co-applicant on numerous successful research bids, and can also offer a letter of support. We can provide website user statistics and data from user surveys that show how the website helps people. We can also provide responses to reviewer questions/comments.

# How do things like intellectual property & legal agreements work?

The charity does not, in general, claim any intellectual property rights (IP), over the data used on its websites. All copyright and IP remains with the institution that conducted the research.

Instead, the charity requires a license agreement which gives them the right to publish the output on their websites and use for various educational purposes.



#### What agreement is needed from the participants?

Participants must sign to give consent that their material can be distributed in the ways mentioned above (the charity can provide an example/template for this).

All participants are anonymised, and no identifying material is ever kept by the charity. The participants can also withdraw at any time by contacting the charity directly, even after the project funding/lifespan has ended.



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# Price Guide

As a non-profit, we create quality websites and aim to keep them available indefinitely, thereby maximising the potential impact of your research and funding.

However, we too require funding for developing and publishing website content and for the ongoing maintenance of the websites.

The below, are flat costs for publishing on our websites.

All costs depend on the size and nature of the material and figures here are intended as a guide.

### 10 pages of web content = £720

These web pages share the findings of the research and give context to the media and text clips (see below).

This cost includes copy-editing of text (required for accessibility reasons)

### 100 media clips added to website = £7,200

The charity believes the best way of sharing people's experiences of health and social care is by video and audio.

This cost includes auto-captioning of the clips (required for accessibility reasons).

Automated captioning may result in minor errors (though we always provide accurate full transcripts of clips on the website).

For manual caption checking and correction service an additional £6,000 is required per 100 clips.

#### 100 text clips = £1,440

Some participants will only be comfortable providing their experiences in a written format.

# 10 minutes of training/educational video using clips from an existing section on our websites = £2,160

Educational films with voiceover, music, titles and interview footage can be created. These might pose questions, provoke discussion, or provide valuable insight into people's experiences of health and social care.

# 1 minutes Animated video (includes script editing, voiceover) = £3,600

Animated, 'whiteboard' style films can be made which are ideal for use in service improvement or training. These can also contain media clips created in research, or simply be a way of disseminating research findings in a succint and direct way.

### Research report design = £720

Research reports can be made more visually engaging.

Creating an easily shareable format for dissemination on our websites.

#### **Additional costs**

Every project will have additional costs which are dependent on project size and length.

These will be composed of:

- Project management
- Administration

The charity also charges a **20% publishing fee** to the total cost of the above towards the sustainability of the charity and its websites, which it aims to maintain and make available indefinitely.

Contact the team now to discuss how they could help your research project by emailing info@dipexcharity.org