



Annual report 2018-19



Welcome from our Chair

Welcome to the Dipex Charity Annual Report; thank you for taking the time to find out more about us.

The Dipex Charity was established in 2001 to provide balanced information about the way health and social issues impact people's lives. When our late founders, Dr Ann McPherson and Dr Andrew Herxheimer, were both faced with their own health challenges, they felt that their medical knowledge wasn't enough to prepare them for what to expect.

They decided to create a health website with one unique difference; the information would be based on real people's stories. As you will read in this report, healthtalk.org now helps millions of people every year in a variety of ways. In addition, we have new plans on the horizon to further our work.

But first, we have some team updates to share. I am delighted to let you know that Dr Tess McPherson has become a Trustee, not only bringing a wealth of clinical and patient involvement expertise, but also extending the deep involvement of the McPherson family with the charity. Juli Beattie, a member of our Senior Advisory Panel, is giving us considerable support in our governance and strategic reviews.



However, I'm sad to report the recent deaths of three of The Dipex Charity's staunchest supporters; Sir David Weatherall, a patron; Dr Jane Kirk, a former Trustee and Fred Hucker, our Vice-president and former Chairman. We will miss them greatly and are immensely grateful for their contributions.

Finally, in summer 2018, the trustees appointed Adam Barnett to the role of Chief Executive. Adam had managed the charity's operations for more than 10 years. The Trustees are very pleased with the progress Adam and the team have made so far in forging our new path.

Prof. Sean Hilton
Chair of Trustees



Introduction

Adam Barnett
Chief Executive

Over the past year we have really taken the time to think about our strengths and past successes. We wanted to find new and interesting ways to draw on these strengths to achieve our aims.

In this report you will find details of the impact we continue to make via healthtalk.org, along with exciting new plans that we have been working on, including:

- Reaching more people with healthtalk.org
- Working more closely with our DIPEX International colleagues
- Developing a new website focused on social care experiences
- Publishing health and social care research from a wide range of sources

The charity is now working with 13 universities from around the world in pursuing these aims including the University of Cambridge and Yale University as well as our long-term partners based at Oxford University.

To reflect our new broader focus, we have re-branded and developed a new charity website which can be found at dipexcharity.org. We are also in the process of finalising a review of the charity's structure and governance.

I hope that you enjoy reading about our plans. I'd love to hear from you so if you are interested in working together, please feel free to contact me.

Adam Barnett
CEO
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healthtalk.org

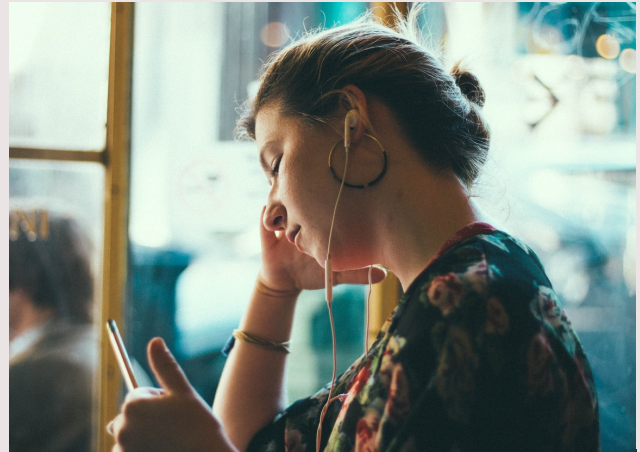
healthtalk.org is a health website with a focus on real life stories shared on film, collected through qualitative research. We have resources on more than 100 health conditions. The site was used more than 7 million times in 2018 by visitors from all over the world.

In 2018 we added new sections on:

- * Pre-eclampsia
- * Psychosis in young people
- * Pregnancy loss at 20-24 weeks.

In 2019 we will add:

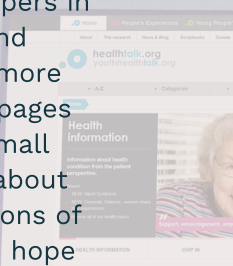
- * Weight change
- * Experiences of taking part in the 100K Genomes project
- * Experiences of nurses, midwives and allied health professionals in research.



"I LOVED the fact the testimonies are in video form, so I could "see" the people are real and [have] gone through the same thing."

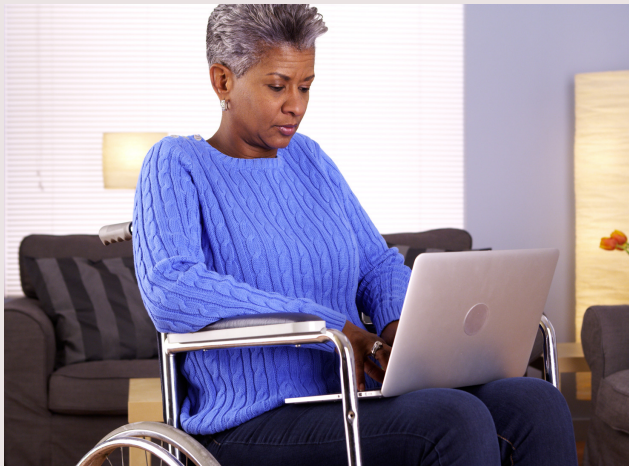
Website redesign

Work is underway on a new look for healthtalk.org. The charity team have been working with web developers in Oxford to update the design and functionality of the site. With more than 25,000 videos and 8,000 pages to consider, a redesign is no small feat. However we are excited about improving the site for the millions of people we help every year and hope the new version of the site will extend our reach and encourage deeper engagement with the content.

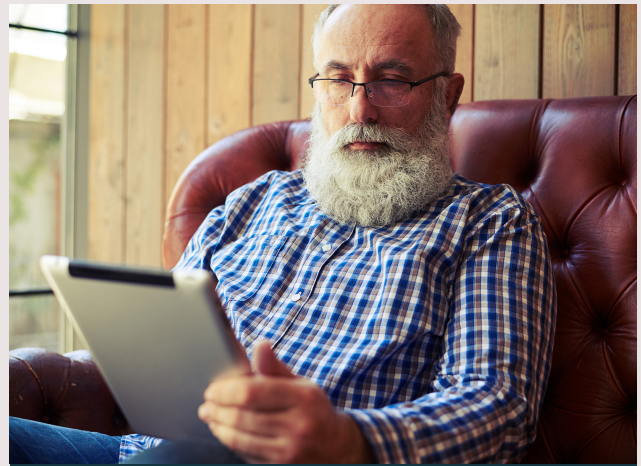


NHS online diabetes support

NHS England has announced a pilot scheme for an online diabetes self-management tool that includes videos from healthtalk.org. The tool was developed by researchers from University College London who showed it to be effective at helping people reduce their blood sugar levels and improving mental health among those newly diagnosed with the condition. The pilot starts this autumn with the service rolling out nationally from 2020.



"Thank you very much, you have helped me considerably & given me hope for dealing with my injuries"



"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."

Feedback

81% of visitors said they felt better prepared for their next medical appointment.

80% said they found information on healthtalk.org they hadn't found elsewhere.

70% said they felt reassured, better prepared and less alone.

62% felt encouraged to take a more active role in their health care.

60% said they felt more confident about discussing their health.

30% felt that their need to see a health professional had decreased.

DIPEX International



Dipex International (DI) now has members in 13 countries, working to replicate the work of healthtalk.org for local audiences. The Dipex Charity has supported the development of DI since it began in the mid-2000s and offered advice and support to our fellow members along the way.

In November our Chief Executive, Adam Barnett, presented to our colleagues at the annual meeting in Groningen, Netherlands to share our insights from managing healthtalk.org for 18 years. The talk was well-received, and we learnt from their experiences too. We look forward to meeting DI members again at the annual conference in Oxford in the autumn.

We continue to manage the DI website - dipexinternational.org - having redesigned it over the summer.

Health Experiences USA

healthtalk.org has always enjoyed a high rate of visitors from overseas, particularly the US. So it seemed like a natural progression for the team to start work on a website build for the US version of healthtalk.org. We are thrilled to be working with colleagues from the Health Experiences Research Network in the USA to offer Americans health information that is specific to their health system and culture. The redesigned healthexperiencesusa.org website will go live later this year, initially with information on:

- * Young adults' experiences of depression
- * Traumatic brain injury in veterans

socialcaretalk.org

Work is underway on a new social care information website for the public and professionals. We're developing socialcaretalk.org in partnership with The School for Social Care Research and the Health Experiences Research Group at Oxford University.

As with healthtalk.org, the information will be based on qualitative research into real people's experiences with an emphasis on video content. The first project will look at the experiences of people who fund their own care, led by Dr Kate Baxter at the University of York and funded by The NIHR Research for Patient Benefit.

DETERMIND dementia study

The Dipex Charity team is pleased to be joining the team behind a new, 5-year, ESRC-funded study looking at inequalities in dementia care. The DETERMIND study is being led by Prof. Sube Banerjee at The Brighton & Sussex Medical School, in partnership with 7 UK Universities.

This ambitious study will follow the progress of 900 people who have recently

been diagnosed with dementia, and their carers. It will examine costs, barriers, inequalities, planning and decision-making around dementia care and suggest ways to improve outcomes for people with dementia.

The Dipex Charity has developed a website for the project - determind.org.uk - and will support communication about the project to the general public.

