Improving digital health access for excluded groups

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About one third of people experiencing homelessness do not use the internet or have poor online skills, according to a recent study that looked at the digital health readiness of this population.

However, half said they used the internet every day. These respondents tended to class themselves as having better skills and tended to be younger. This, perhaps, contradicts the stereotypical notions of the digital readiness of the homeless population.

The study was carried out by the charity Pathway (*Box 1*), which aims to improve healthcare for people who are homeless or socially excluded.

The project, a form of patient public involvement, was run by the Pathway Expert by Experience team (*Box 2*). The team members are drawn from people with personal experience of the issues.

Boxes 1 and 2 outline the background to the project and explain the role of Experts by Experience.

Who took part

The study consisted of 90 surveys and five focus groups of 7–8 participants each, with a total of 38 involved.

Four Experts by Experience helped design the surveys and formulate focus group questions, and undertook most of the study delivery. The experts – Jose Bell, Joe Ellis, Lee Snowball and project lead Stan Burridge – supported participants who had language and literacy issues to fill in the survey, and helped those lacking confidence to speak in the focus groups.

There is consensus that participants are more likely to open up and share their thoughts and views with a researcher whom they perceive as being 'like me' and with whom they feel comfortable. The proposition is that this leads to the collection of more credible, valid data, and Experts by Experience are central to this mode of research.

What people said

While half the respondents said they used the internet daily, 33% either did not use it at all or described themselves having 'below average' or 'poor' skills.

The digital exclusion normally experienced by older people in the general population was found to apply to younger ages in the homeless population, but this did not preclude interest from older people.

- 'I can't read and write that good. I don't even know how to switch one [a computer] on....'

### Box 1. Digital inclusion and the Pathway project

Digital inclusion is a hot topic in the NHS, with digital technology solutions promising to revolutionise services by bringing aspects of healthcare closer to the patient and potentially improving efficiency and cost effectiveness.

Many patients want more control of their own health, underlined, for example, by the popularity of wearable fitness trackers. However, some people will be 'digitally excluded' and less able to benefit from digital advancement.

The Pathway project set out to assess digital knowledge among homeless and socially excluded populations, and identify their online needs. Central to its work was the involvement of Experts by Experience (*Box 2*).

The project was commissioned by NHS Digital's Widening Digital Participation team in discussion with the NHS England Patient Online team. The report, *Digital Health Inclusion for People Who Have Experienced Homelessness – A Realistic Aspiration?*, can be downloaded at https://tinyurl.com/pathway-research

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Box 2. Experts by Experience
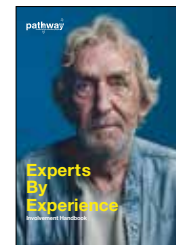
A Pathway Expert by Experience is able to articulate lessons and make suggestions about, for example, health services and/or health policy based on their own lived experiences of health services and homelessness. The term is widely used in mental health, general health and homelessness services.

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Joe Ellis, one of the Expert by Experience team members involved in the Pathway project, talks to a survey participant at Deptford Reach drop-in centre, London

- 'If someone could help me. Even for me at my age… I think it would be good for me.'

  Half the respondents said they would benefit from some sort of internet training, a response that spanned across the age groups.

- 'I went to the library, but I was very slow. I had to ask for help a lot… I felt I was being a nuisance.'

  Importantly, 66% of respondents said they had some sort of access issue, with problems cited across all age groups. There was visible frustration around the issue, for example:

- 'My hostel has wifi, but there's no reception around the hostel… it doesn't work.'

- 'I don't have access now, but I used to… when you haven't got access to a computer you feel like third-class citizen.'

  Despite these issues, participants were enthusiastic about the potential of digital healthcare. For example, 63 out of 79 (80%) people who did not have online access to their GP records at the time of the study said they would be interested. Their comments included:

- 'It's a good thing. It's really fantastic. It could save lots of trips and calls.'

- 'Yes, that's important. We don't know what is written about us, and we should.'

  People were also interested in finding out about online health applications, including those linked to more contentious services such as sexual health screening. The suggestion was positively received:

- 'I get dodgy looks from young teenagers when I go… it makes me feel like paedophile. I'm just a normal bloke. I think it [the screening app] is a good thing.'

  Internet security was an understandable concern for 43% of the survey respondents and also came up in the focus groups, with 23% of participants requesting training.

The challenges

The findings are very much in line with existing knowledge on digital inclusion. For example, the government's Digital Inclusion Strategy (Cabinet Office, Government Digital Service, 2014) identifies four main challenges:

- Access: the ability to go online and use the web
- Skills: practical competence in using the internet
- Motivation: not fully understanding the reasons why internet use would be a good thing in a personal context, or not wanting to learn new skills
- Trust: fear of internet crime, or not knowing where to start to go online.

In 2015, Martha Lane-Fox, founder of lastminute.com and lobbying group Doteveryone, whose interests span digital inclusion, was commissioned by health secretary Jeremy Hunt to look at ways to increase digital inclusion across the NHS. In her subsequent report she suggested that the National Information Board should focus on 'reaching the furthest first' and not leave anyone behind (NHS England, 2015). Her recommendations were to:

- Reach the 'furthest first', making sure that those with the most health and social care needs were included first in any new digital tools being developed across the NHS
- Offer free wifi in every NHS building
- Build the basic digital skills of the NHS workforce
- Take on an ambitious target of getting at least 10% of registered patients in each GP practice using digital services, such as online appointment booking by 2017.

Mr Hunt responded in 2016 by, among other things, tweeting on New Year's Day that everyone would have access to their records by the end of the year. Understandably, this target proved to be overly ambitious. The reality is that around 10% of the general population currently have online access to their GP notes.

In a recent policy paper, the government (Department for Culture, Media and Sport (DCMS), 2017) acknowledged the ongoing risks of digital exclusion, noting that one in 10

adults had never used the web (Office for National Statistics (ONS), 2016).

The document includes a commitment to invest £1.1 million through the NHS to support digital inclusion projects, targeting on the most excluded groups. This includes focusing on, for example, homeless people, those with disabilities, people with mental health problems and prisoners, to develop their digital skills and give them the confidence to use online tools to manage their health.

The initiative builds on existing programmes. In 2013, the Widening Digital Participation (WDP) programme was established to provide support to patients lacking the confidence and skills to go online and benefit from digital health services, transactions and information.

The first phase of the programme ran from July 2013 to April 2016. It focused on reaching digitally excluded groups and giving them access to information. Over the three years more than 380 000 people learnt more about their health, including how to use online resources, contact their GP online, manage medical conditions and make healthy choices. Some positive outcomes for patients included increased confidence levels, more self-care and greater use of online health services.

For example, the recent Reboot UK project from the Good Things Foundation, focused on homelessness and digital skills. It offered personalised basic digital skills training and community-based support for homeless people. Clients were assisted to access relevant information, apply for benefits or find support online, such as food banks.

Almost 1 000 clients improved their digital skills, but interestingly there was also an increase in their mental wellbeing scores. Clients' average scores rose from 21.41 to 23.46

compared with the national mean of 23.6 (Steven, 2016).

Over the next four years, the WDP programme will be developing and piloting new approaches to tackling digital health exclusion in 22 areas across all four NHS regions. It will work with specific groups to build on this work, partnering with government and non-governmental digital skills initiatives (for example, in the DCMS or Lloyds Bank) to expand its reach and share best practice.

Recommendations

The Pathway study underlined the fact that there is work to be done. Recommendations and suggestions for follow-up work were put forward by the Experts by Experience and discussed with NHS Digital and included:

- Undertaking a digital inclusion pilot with people experiencing homelessness, for example, focusing on patient online access
- Developing training for public library staff to help them better understand the needs of people who are homeless
- Liaising with supported housing providers and commissioners across London to improve homeless hostel and day-centre wifi
- Developing targeted online mental health resources to support clients with complex trauma
- Compiling a directory of free public wifi
- Promoting schemes that recycle mobiles/laptops for homeless people to health professionals so they can make referrals
- Advertising online health services such as sexual health screening to homeless hostels and day centres
- User experience forums run by NHS England around online health applications to include people experiencing homelessness.

Positive outcomes

The study has provided insights into digital inclusion for certain groups, but also offers a valuable approach to public patient involvement. The inclusion of Experts by Experience teams ensures that real, 'on the ground' issues are considered and reduces the power dynamic between researcher and participant that can consciously or unconsciously alter research.

In addition, the work has provided the experts with work experience, combatting the negative impact that homelessness can have on employment history. Since participating, 10 team members at Pathway have gone on to take up paid work. BJHCM

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■ *Those with an interest in inclusion health issues can join the Faculty of Homeless and Inclusion Health, a network of clinicians and others focusing on topics related to homelessness and health. To find out more, visit www.pathway.org.uk/faculty/join*

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