Have your say: digital health

Appendix 2

Appendix 2: Focus group feedback

The focus groups provided an opportunity for us to have more detailed conversations with our communities. We met with a wide range of groups, including: younger and older people; people in and seeking employment; people from different cultural and socio-economic backgrounds; people with learning disabilities; people with hearing impairments and people with sight impairments.

We heard about people's experiences and discussed ideas for the future and how digital health can be improved and become more inclusive for people with varying needs and abilities.

We engaged with 185 people in 12 groups:

1. **Milan Ladies group** – an Asian ladies group in Blackburn
2. **East Lancashire Deaf Society** - deaf people in East Lancashire
3. **Darwen Aldridge Enterprise School** – Childcare students in Darwen
4. **Age UK -** older adults group (aged 55 plus) in Barrow
5. **People First group** - people aged 50 plus with mixed disabilities and lifelong health conditions in Barrow
6. **Voice for All Group** - people with learning disabilities in Central Lancashire
7. **Empowerment workforce group** - professionals with experience of diverse groups in Blackpool
8. **Blind Veterans UK** - blind people residing in and around Blackpool
9. **Fulfilling Lives** – staff working with people with poor mental health, presenting as homeless, involved in substance misuse and/or offending behaviour in Blackpool
10. **Just Good Friends** - reducing social isolation for older adults in St Anne's
11. **Fylde and Wyre Patient and Public Engagement Group** - professionals with experience of diverse groups in Fylde and Wyre
12. **Preston College -** Health and Social Care students in Preston

The pages that follow provide detailed feedback from each of the focus group sessions.

1. Digital health workshop – Milan Ladies Group, Blackburn

Overview of the group

This group of ladies of mixed Asian heritage and mixed language ability are members of a constituted group that meet on a weekly basis for social, religious and health-based activities. The group membership is predominantly aged 40 plus.

Twelve ladies participated in the workshop on Tuesday 9th October 2018.

Below is a summary of the key responses to three questions we posed to the group.

What do you currently access digitally to support your health and wellbeing?

Only one member of the group used Patient Access, and another had downloaded the myGP app for repeat prescriptions.

Members of the group had used the NHS website and Google to look up health conditions online, but mainly used their Smartphones for WhatsApp, text messaging and calls.

Practicality, confidentiality and trust were seen as essential features of any health app or website for members of the group to feel confident enough to use it.

What barriers do you face in being able to access health information digitally?

Members of the group felt that GPs themselves were a barrier to accessing health information online because they felt that they did not promote this opportunity to patients.

Ease of access and navigability are necessary features of health apps for the group, otherwise they would not use them and simply call the doctor instead. One lady stated, "I need to feel comfortable first".

Data and phone storage were raised as issues for people to download and access apps on their phones.

Language barriers were also raised as a concern, with apps such as Patient Access not available in languages other than English.

Religious views were raised as a potential barrier to accessing health information online. One lady highlighted that any app or site which is lottery funded would not be accessed by Muslims.

Another felt that religious views might be used, in ignorance, by some older members of the community for not accessing health information, on the basis that lifespan is pre-determined by Allah therefore there would be no point trying to make changes in your lifestyle. The group felt that this was an education issue.

Members of the group felt that it would be hard to be able to reach out to socially isolated members of the community to access information online – these are people who do not leave home and, although they may live with family members, are still socially isolated. The concern was that digital technologies could make already socially isolated people more isolated.

How could we encourage or support you to access digital health?

The group felt that if they were supported to access digital health information and online appointment and prescription booking through workshops in community venues, then they would feel confident to carry on doing so. They felt if they were sold the benefits of "being in control", then they would use digital health options.

One lady felt that a "nudge" approach from GPs could encourage residents to access digital health - such as a letter from the GP explaining how to do so.

The group felt confident that once they knew how to use apps, they could act as a local connectors or champions, cascading knowledge to both their families and other community members. As one lady put it, "If you educate the ladies, you're educating the whole house".

They felt that men might at first be resistant to change, but if they had the opportunity to manage their health by themselves online without the barrier of having to speak to others about it that would be a great sell. They felt that connecting with the mosques to spread the message could help with this.

Some of the group felt that WhatsApp video consultations with GPs would be a useful and time-saving approach, especially for working people.

TV marketing for apps was also suggested by the group as a means of raising awareness of digital health – especially at teatime prime TV slots.

2. Digital health workshop – East Lancashire Deaf Society, Blackburn with Darwen

Overview of the group

This group was made up of staff members of East Lancashire Deaf Society, who are all deaf. ELDS manage two buildings in Blackburn town centre as well as providing a range of services including community support and the provision of British Sign Language (BSL) videos for Blackburn with Darwen Council's Local Offer Directory for families of children and young people with special educational needs and disabilities. (https://www.bwd-localoffer.org.uk)

Twelve members of staff participated in the workshop on Tuesday 9th October 2018.

Below is a summary of the key responses to three questions we posed to the group.

What do you currently access digitally to support your health and wellbeing?

Despite the entire group having smartphones, there was a lack of knowledge amongst the group of how to book appointments online, with only two people currently using Patient Access. None of the group was aware of myGP.

The group mainly use their smartphones to access videos, YouTube, TypeTalk, Facetime, Signlive and 111 BSL.

What barriers do you face in being able to access health information digitally?

There was an overriding view within the group that the deaf community is seldom consulted on health and wellbeing issues.

Several members of the group felt that websites often have a lot of information which they struggle to understand and thought that it would be better if they had BSL videos which members of the deaf community can watch to support their health and wellbeing.

Patient Access does not currently allow for booking an interpreter for a GP appointment so deaf residents are currently forced to make appointments face to face at the surgery.

How could we encourage or support you to access digital health?

Being able to have a video call with an interpreter at GP appointments or to be able to book a signer online as part of the appointment booking process would be beneficial and could reduce the waiting time for appointments, which are currently affected by the need to have a GP and interpreter available at the same time (1-2 weeks waiting time generally). However, members of the group were concerned about the need for confidentiality and Wi-Fi/data availability at the GP surgery.

The group felt that it would be very beneficial to them if a similar video call process could be rolled out to other health services such as dentists, eye checks and so on.

Members of the group felt that having a BSL option on apps would support them to access apps more readily, for example a video BSL signer in the same way as on TV. They felt that the NHS Online Orb was very accessible, and the colour scheme worked well – "keep it simple and easy to access!"

One member of the group suggested that ELDS could be used as a community asset to cascade digital health awareness amongst the deaf community – they have a team of community developers who could deliver this work.

Further research required by the Healthier Lancashire and South Cumbria team

- One member of the team asked how Emergency Services can contact deaf residents once they are near their house – do they use a GPS? Would they send a text message? (rather than phoning)
- Another member of the group asked the team to consider having a function to be able to contact Emergency Services quickly in an emergency through the NHS Online Orb.
- The A-Z list of health conditions on the NHS website has too much jargon and too many long words. Would it be possible to have one summary BSL video on each section?
- Is there an option on the myGP app to indicate special requirements?
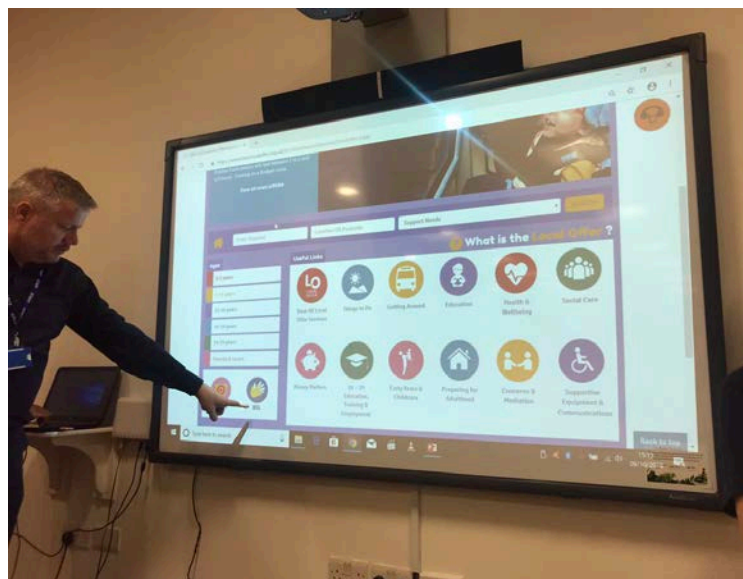
3. Digital health workshop – Year 13 Child Care Students at Darwen Aldridge Enterprise Studio School, Darwen

Overview of the group

The group was made up of Year 13 (aged 16-17 years old) students at the school. The school is a small mainstream school that specialises in Creative Digital Media, ICT and Health, Social and Child Care and encourages development of students' employability skills whilst focusing on their resilience and wellbeing.

Five female students participated in the workshop on Friday 12th October 2018.

Below is a summary of the key responses to three questions we posed to the group.

What do you currently access digitally to support your health and wellbeing?

One member of the group uses the myGP app to book GP appointments and another uses Patient Access and both reported that these were easy to use. The member of the group who uses the Patient Access app stated that she was able to access her medical records online but needed a code from her GP to be able to do so and as a result has not yet tried this. Other members of the group stated that they would ring the surgery to make an appointment or simply avoid making an appointment!

The group mainly used their smartphones for YouTube, games, Facebook, Snapchat and Instagram. They do use some apps to support their health and wellbeing which they find on either the Apple App Store or Google Play – these include iPhone health apps, Sweatcoin, Headspace, Change4Life, Stoptober as well as wearing Fitbits.

What barriers do you face in being able to access health information digitally?

One member of the group did not think that her GP offered online access.

One of the members of the group stated that she was afraid of the results she might find when researching her symptoms online and that she would need to be able to trust the source of information.

The group felt that data storage issues on their phones can be for a barrier to them downloading and accessing apps.

Although the group felt that producing apps with a game element would be a means of making accessing health and wellbeing apps appealing, there would need to be a series of new challenges built into them to keep their interest. They also felt that if the apps involved a competitive aspect that they might not engage in this to the same extent as adults, particularly avoiding competing against their siblings.

How could we encourage or support you to access digital health?

The group felt that the gamification of apps or apps facilitating a reward system would encourage them to engage in healthier lifestyle behaviour. Further consideration was needed to consider suitable rewards other than food and money.

The students felt that apps would help young people who are afraid of talking about their health issues to research for themselves initially before opening up to a GP. They felt that sessions in schools demonstrating apps such as the NHS Online Orb would help them to understand how to use them and encourage them to make more use of them. They felt that the ratings of apps on ORCHA (https://lancashire.orcha.co.uk) was a good idea and that they would choose apps based on the user feedback ratings provided.

A focus on fun was shared by the group – they thought games such as Wii Sports would appeal to other young people because they encourage fitness through activities that are also fun to participate in. One member of the group said that it would be beneficial to have all their fitness activity apps in one place, in a similar fashion to the NHS Online Orb.

Key influencers on the group are YouTube vloggers and local football clubs – the group felt that if digital health was promoted to them through these channels they would be more likely to try out and use health and wellbeing apps. YouTube vloggers referred to by the group included Rose and Rosie (who are currently promoting mental health as well as more generic apps and products on their videos), sisters Sophie and Jasmine Clough, Shane Dawson (USA) and Saffron Barker (UK).

Further areas to explore for the Healthier Lancashire and South Cumbria team

- myGP app registration for Darwen Health Centre requires a PIN – why is this? This was not required by another member of the group who had registered on myGP for the Centre earlier in the year.
- Does Witton Health Centre have Wi-Fi?

4. Digital health workshop – Age UK Group, Barrow in Furness

Overview of the group

This was a mixed group of men and women all age 55 plus who use Age UK Barrow in Furness services. Many of the group were attending the weekly Age UK 'Job Club' which enables people who are unemployed to produce CVs, seek vacancies and make online applications.

Fifteen people participated in the workshop on Wednesday 24th October 2018.

What do you currently access digitally to support your health and wellbeing?

One member of the group used a home laptop to access his GP surgery, make appointments and see health records. Three members used a computer to communicate with their surgery to make appointments and request repeat prescriptions, but nothing more.

What barriers do you face in being able to access health information digitally?

The lack of digital equipment was said by most to be the main barrier. Some of the group had no mobile phones of any kind, the remainder did have mobile phones but only one person had a smartphone. One husband and wife couple had a laptop at home that they shared to make GP appointments and seek online information; none of the others present had any smartphones, computers or laptops: their only access to digital information was by attending the local library who offered 2 hours per day free of charge to users.

In the discussion that followed, some people said that they found that communicating with receptionists was difficult and unhelpful when they have enquired about accessing medical records and other information.

They commented that when using the internet to gather information about their condition and then spoke with their GP, one person felt that their GP had been dismissive (told "why are you looking things up that's what I'm here for"): "doctors may be funny about information from the internet."

In contrast it was agreed that pharmacies were doing a lot to promote their online services, and actively signing people up for notifications about prescriptions.

The lack of information about what services were available digitally in individual surgeries and other health establishments was a point raised.

Some of the group said that they would like to use digital systems more but did not feel confident about their own ability, having what they described as "basic knowledge" only.

How could we encourage or support you to access digital health?

The group suggested several ideas that they felt would encourage and enable them to use digital technology more to support their health.

Digital Health upskilling sessions would help, possibly by organisations such as Age UK and other community groups and at locations such as libraries.

Knowing what is actually available would help, particularly as there was some inconsistency between different surgeries. Suggestions how this could be addressed included: conversations with the GP when attending review; many surgeries have TVs with messages on - perhaps details could be shown on them; maybe a video of the NHS Online Orb to prompt patients to ask about it. Many surgeries have electronic sign-in systems: perhaps a dedicated laptop or similar that people could use within the surgery would help, particularly if staff were available to help if necessary.

Overall, there was interest in knowing and doing more but a little help and support was needed. It was interesting that, as the group session was being held at the Age UK premises, once this was raised as something the group would benefit from, the Deputy CEO immediately agreed to run sessions as a training module.

5. Digital health workshop – People First Office, Barrow in Furness

Overview of the group

This was a mixed group of age 50 plus men and women, all with long-term or lifelong health conditions.

Six people participated in the workshop on Wednesday 24th October 2018.

What do you currently access digitally to support your health and wellbeing?

The entire group had smartphones and access to computers and laptops but did not use them often for health purposes other than to search for information of the internet.

What barriers do you face in being able to access health information digitally?

One of the attendees was deaf so would welcome more visual opportunities to find out about services that are available, at the moment they find messages left on the mobile and home telephones which they are unable to listen to.

Another member of the group was from Eastern Europe and did a lot of work with other nationalities and said that language was a frequent barrier.

In the main, the group felt that they would benefit from knowing what information and/or services was available digitally with some support to use initially to increase their confidence and usage.

How could we encourage or support you to access digital health?

A digitised 'Hospital Passport' would be good, this could be updated by the individual and professionals and could be used in case of admission to hospital for example if it included communication needs, religious and cultural issues in addition to purely medical information.

Support to use digital appliances and apps

People with sensory impairment may benefit from an app. That would help them navigate hospitals for example ('digital wayfinding') and in waiting areas for notifying when they are next to be seen.

Being able to access nurse appointments online would be good as the group said that they see the practice nurse more often than their GP.

Case studies of how others have benefited from using digital technology to support or improve their health condition would be beneficial to promote usage.

Dispelling myths about online security would be a great help as health issues are private and personal, people do have worries about hacking and other intrusions into their private lives.

The use of apps such as Ava for hearing impaired people to aid communication was mentioned, but the lack of general awareness indicated that more information needs to be made available about the possibilities and the best digital tools to use as technology is advancing very quickly.

6. Digital health workshop - Voice for all group – Lancashire

Overview of the group

Voice for All is a user-led advocacy group run by and for people with a learning disability and currently has thirteen members on the committee, who meet on a Monday afternoon. All representatives are elected for a two year term. There is a chair and vice-chair within the group. In addition, minutes are recorded by a volunteer who supports the group.

Twelve group members, as well as three support workers, one volunteer and the Self-Advocacy group lead participated in the workshop on Monday 29th October 2018. The age of group members attending ranged from 31 years to 76 years and there was an even split of male (6) and female (6) members.

What do you currently access digitally to support your health and wellbeing?

To support wider discussion the main group split into three smaller groups.

In the first group of five people, three did not use mobile phones and had limited access and interest in using other digital technology. The other two members of the group did have smartphones (but not tablets or computers) and also used assistive technology (Telelink) to support their health and wellbeing needs.

In another group of four people, only one person had use of a mobile phone but this was not a smartphone. It was evident, however, that there was some awareness within the group of health and wellbeing digital applications in a responding to a demonstration of the NHS Online Orb.

The third group had five participants, two of which said they already use technology successfully.

"It would be good for prescriptions; I use technology a lot otherwise so it would be easy for me."

"I know how to use a computer and how to look for health information."

What experiences would you like to share?

One person spoke about a medical emergency that they had experienced in Manchester and how frightening the experience had been – particularly being in an unfamiliar hospital environment and due to the lack of medical history information available.

Another person shared their experience of the waiting time in Accident and Emergency through the various stages of his visit. He was with his support worker who helped him as he was very anxious and unsure of what was happening.

Another member of the same group shared their experience of receiving test results and not having them explained in a way that could be understood. Fortunately as a family member was also a doctor they were able to discuss the results in a way that could be understood so that they were informed and involved.

There was a general consensus from this particular group of a feeling of the unknown when stepping foot into different health settings - due to a lack of information and communication that is user-friendly pre-appointment, whether that is at a hospital, a GP practice or other healthcare facility.

In terms of engaging with health care services, one person did not like having to explain herself (and her health care needs) every time she visited the GP practice. Another person did not like having to wait for long periods in waiting areas (before having their blood pressure checked).

How could we encourage or support you to access digital health?

The groups liked the idea of videos (based on the NHS Healthcheck video shared: https://youtu.be/n56F-qKAwHs) for informing people about what to expect when visiting a health centre, clinic or hospital. Such videos were considered to be useful in providing information about what to expect when visiting a health and care setting as well as potentially helpful in reducing any anxiety or uncertainty prior to a procedure or treatment visit. It was considered good to involve people with learning disabilities within these videos (as with the example one shared). There might be an opportunity for developing new videos in the future. Two group members, who currently had a very limited access to digital technology, liked the idea of a "video call" with a doctor or nurse, as visiting the surgery or health centre could be stressful and caused anxiety, particularly if there was a long wait.

A big concern for the group surrounded their challenge of trying to share their needs with health and social care professionals in advance of health appointments

or treatment. The Voice for All group use a system of 'Red, Amber and Green' reports which are developed to support people with learning disabilities to share their particular needs or concerns with health and social care professionals in advance of health appointments or treatment. Unfortunately despite these reports being shared in advance, quite often health and care professionals don't seem to be aware of their needs. The Voice for All group feel that there should be a better way of health and care services taking note of the specific needs of patients with learning disabilities. Is this something that the digital health team could explore? Would there be a way that GP referrals to hospital could highlight or flag the needs of patients going for appointments or treatment?

Another matter raised by the group was whether it might be possible to develop an app that included all the health and social care needs of an individual with learning disabilities. This could include a link to any personal needs that might need to be considered (as identified by the 'Red, Amber and Green' report), personal health records, information around wellbeing activities, as well as any health and care appointment details and associated transport details to support such visits.

Alongside having learning disabilities, some of the group members also had other needs – for example, visual and hearing impairments. One group member identified that when they went for a health appointment at their doctors the announcement screen only had a visual display (with their name coming up when they were being called) and that it would be helpful if it had an audio announcement calling their name could also be offered too. This addition would be beneficial to meet this particular individual's visual impairment needs.

A general consensus was that communication needs to be in a format that is easy to understand and suits the needs of the individual whether verbal, easy read, audio, video or pictures so that they are informed and involved. In reference to The NHS Online Orb one of the groups commented that the supporting how to

videos were not very user friendly for people with learning disabilities due to the speed at which information was provided.

People talked about the things they might do to benefit their emotional health and wellbeing. A member of the group said they enjoyed art and being creative and they said they would benefit from an app which helps them to learn and try out new things. "I would like to use apps for relaxation and to calm down, to teach me how to do art or stories."

Social media platforms are not regularly used by the group currently, but the members of the group said they would like to use them, if they knew how. The need for guidance and training was a recurring theme throughout the conversations. There could be a wealth of resources out there, but people may need support to be able to use them effectively. There needs to be an emphasis on making health information as simple as possible - for everyone, not just adults with learning disabilities. Health professionals use a lot of jargon and medicalised language and this might be a barrier to access and understanding for all sections of the community.

Other ideas

One of the groups suggested that it would be really useful if information could be made available after health appointments. This would help group members remember what has been discussed at an appointment so that they can talk about this with their family, a support worker or friend. Sometimes it can be difficult to take everything in at the time, particularly if they are feeling anxious about the appointment or being in a different environment. Again, any information produced would need to be in a format to suit the needs of the individual.

Members of the group were aware of Amazon Alexa but did not currently have access or know what potential functions it had. It was suggested that Alexa could be a useful tool and potentially used to ring services such as the GP practice, so

that people did not have to remember phone numbers. It could also be used to remind people to take their medication.

One person said that they would specifically like an app that helps with healthy eating. They want to know what food to buy from the supermarket to help build their shopping list. They want to eat a balanced diet, but need help with ideas and suggested a traffic light system so that they could independently make healthier choices. The group also wanted more accessible information about alcohol consumption and easy to understand guidance around units.

Another person said:
"I would like an app that has all the phone numbers I need to know."

It was suggested that an app or programme could be developed which is a directory of information with contact details that could encourage independence.

There was a discussion of an initiative in Chorley and Preston that identified 'hubs of safety' for people with a learning disability. This idea could be extended to include health services and to provide a navigation system to help people find the right services.

7. Digital health workshop - Empowerment Workforce

Overview of the group
The Empowerment workforce group is made up of professionals with experience of working with and for diverse groups in Blackpool. The group of eleven included advocates, administration staff, volunteers, and managers. The workshop ran on the 6th November 2018 at The Empowerment Base, Blackpool.

What is the group's knowledge and experience of digital health and general use of technology?

Half of the group access their GP records online and some were aware that they could access their GP patient records. Some members reported using mobile phones, tablet devices, computers and Fitbits.

Individually members of the group use technology for booking GP appointments and ordering prescriptions online; managing their household bills; banking and online shopping.

Barriers and challenges in accessing digital technology

Individually members of the group shared the following as barriers: the idea of accessing GP online services can be off putting due to the long passwords and the requirement of proof of ID taking too long; GP opening hours are not accessible to the working population; discouragement from GPs with accessing online portals to manage their care; and reluctance for patients to give permission to share medical records, particularly those from vulnerable groups.

People found it difficult to navigate digital systems, especially with outdated technology and those with low incomes have a lack of money for technology in the first place. Some people prefer to see a health and social care professional face to face to provide reassurance and some felt technology can be seen as a disabler as it may increase isolation.

Other concerns people shared included concern over who has the ownership of medical records and issues with the transfer of medical records for people moving in and out of the social care footprint - including those who reside in institutions, offenders, armed forces personnel and so on. Similarly, there were concerns over cultural differences meaning that technology may not meet their needs, technology replacing person centred care and concerns over mental capacity to share consent. On the contrary, it was expressed that patients who "know their own body" may wish to use online portals to assist with managing their own care.

Ideas that the group wish to share that may encourage them to access digital technologies

Apps were considered convenient and useful to enable flexible access to health related information, as was support, such as developing a Fitbit that prompts activity e.g. to take medication, do exercise, make appointments etc. Other ideas suggested included having a single point of entry system that enables the patient to have access to results at the same time the doctor receives them, to ensure a swifter diagnosis and treatment and a system that reviews and monitors technology to ensure accuracy and relevance.

Some people liked the idea of digital bracelets (containing secure patient information, and / or GPS location information), though consideration is required for patients who would be reluctant to wear and dispose of it. Some liked the Amazon Alexa approach and the idea of a single app – the NHS Online Orb and having a live chat system with health and social care professionals. Others thought Skype or similar video conferencing technology in some circumstances could be advantageous and mentioned that some technology can be accessed 24/7 365 days a year. However the group was concerned that health services are not always currently offered at times which suit patients and thought there should be a broadening of availability of slots for appointments and treatment.

People liked the idea of patients having their own repository to include their medical records etc. and to have the ability to input their own data such as blood pressure readings, sugar levels, log details about the administration of their own medication and changes in body and health (including side effects from medication and so on). They felt that the introduction of community champions would be encouraging.

Other ideas were to alleviate the issue of patient reluctance to share personal information with GP receptionists: members of the group like the idea of a colour flagging system that was recognised only by the GP and patient; to avoid people having to explain their symptoms if they didn't feel comfortable doing so. They also felt that there needs to be an efficient and effective system that provides awareness on services, support and eligibility.

8. Digital health workshop - Blind Veterans UK members, Blackpool

Overview of the group

The group comprised of four members of Blind Veterans UK, one of whom was accompanied by his spouse/carer, two support workers from Blind Veterans UK, two representatives from N-Vision Blackpool and one additional representative from Blind Veterans UK. The workshop ran on 6th November 2018 at The Empowerment Base, Blackpool.
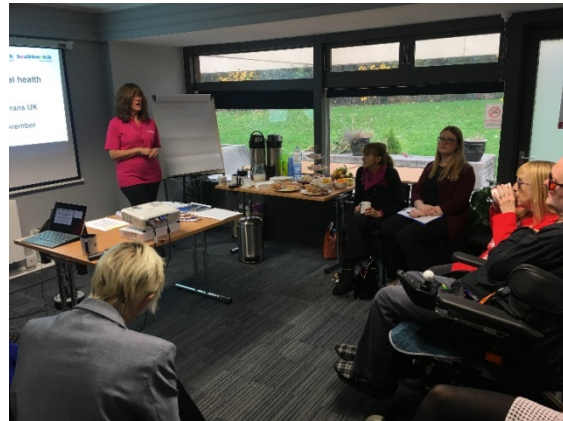
What is the group's knowledge and experience of digital health and general use of technology?

The majority of the group understood what an app is and what technological devices are, some were aware that they could access their GP patient records and some members use phones, Amazon Alexa and tablet devices.

Individually members of the group use technology for a range of things, including: booking GP appointments online; ordering prescriptions online; audio and visual patient calling systems; emails; Skype to communicate and shopping online. Members of the group have found that the use of 'external control button' (assisted technology) to access devices has proved beneficial.

Barriers and challenges faced by people who are visually impaired in accessing digital technology

Individually members of the group shared the following: GP patient calling and information screens are visual and not auditory therefore, leading to patients missing appointments. Additionally, visual screens are not tailored to meeting the needs of visually impaired patients who have some sight. However, Fleetwood Health Centre has an excellent system, why is this not replicated as the norm? There are instances where audio communication systems in GP surgeries have been removed without alternative system being put in place and inconsistencies between different organisations flagging/considering visual impairment on patient records, leading to the patient constantly having to explain their impairment and needs. Amazon Alexa does not always recognise voices that are impaired.

The process for and experience of ordering prescriptions online is inconsistent depending on whether you are ordering medicines, ointments or equipment, as these are supplied separately, either from the pharmacy or direct from an external company. When trying to address this issue, a member of the group has experienced organisations blaming each other and saying "the issue is on the Spine". In relation to this, the main issue for this group found with the pharmacy dispensing processes is due to the use of printed leaflets and the labelling of medication, which cannot be read by visually impaired patients. This is a significant risk to visually impaired patients.

Concern was expressed about the security of patient records: access should be on a "need-to-know basis", people were worried about "nosey staff" and friends and relatives over stepping professional boundaries at work. It was felt that the lack of a national shared patient record system leads to a lack of understanding of the patients' needs e.g. allergies, medical history including current treatments etc. This is particularly relevant in Blackpool, where there is a transient population and visiting tourists.

Being visually impaired can often mean that, before the consultation starts, the patient needs to explain their visual impairment. Therefore only limited time is then left for the consultation or it increases waiting times for following patients. Also, when visiting hospitals out of hours, there are no navigators, resulting in a need to rely on signage/way markers which are not suitable for people with visual impairments.

Some members have pointed out that there is a lack of knowledge by technology manufacturers regarding their needs of the visually impaired community, considering each person will have their own distinct needs and therefore a blanket approach is not appropriate. There is also a lack of awareness and co-ordinated holistic approach to the delivery of health and social tailored to the needs of blind and partially sighted people.

The expectation of the patient having control and the choice about their care may be unrealistic when some patients with disabilities are unable to use the technology: it is easier for some people to pick up the phone. Some people (a high percentage in Blackpool) do not have the financial means to purchase the basic devices to access health and social care technology.

Funding for organisations is unpredictable, resulting in closure/reduced services therefore leaving the patient in limbo!

Often patient records are not flagged 'patient with visual impairment' and therefore the patient's needs are not met: even when patient records are flagged, staff do not check.

What training will be available to support the use of new technologies? Is it good practice to have digital health? Does this replace person centred care/professional human contact? Why are new builds/services not fully equipped to meet the needs of patients?

Other comments

The introduction of free Wi-Fi in NHS venues is great.

Blackpool is unique for accessibility as there are a number of initiatives including the 'tactile pavements'.

The health and social care system already has a significant amount of intelligence about the needs of people with visual impairments, is this being considered?

Ideas that the group wish to share that may encourage them to access digital technologies

Champions from the visual impaired community who are encouraged to engage in a non-tokenistic way should be embedded across localities to support their peers and the system. People should be included and involved in the redesign of new and improving services that utilise local champions to support access to new technology. This will support those less able or skilled to learn from how other visually impaired patients have personally innovated their own solutions to the issues they encounter for example colour coding medication. A co-production approach with visually impaired individuals or organisations working with the system would work well to assist with the recruitment and training of health and social care professionals.

Testing/sense checking of new innovation/systems should be undertaken with a sufficient cross section of the disabled communities of interest. To alleviate concern about inappropriate access to health records it was suggested that an audited monitoring system is put in place.

It was asked whether technology could support the issue of inpatient hospital prescriptions and improve the current GP/pharmacy process. Skype or similar video conferencing technology could be used, where appropriate, for appointments.

It was suggested that we learn from other countries' digital health innovation - such as 'intelligent personal audio satellite navigation' and the use of a pharmacy 'bar code' information scanning system.

9. Digital health workshop - Fulfilling Lives, Blackpool

Overview of the group

The Blackpool Fulfilling Lives workforce group was made up of advocates, team leaders, support staff and navigators who work with some of the most vulnerable citizens in Blackpool: in particular those who present with two or more of the following complex needs; homelessness, substance misuse, offending behaviour and poor mental health. Eighteen team members attended. The workshop ran on 7th November 2018 at Winstone House, Blackpool.

Group's knowledge and experience of digital health and general use of technology

Individually members of the group use technology for a range of activities, including: booking GP appointments online, ordering prescriptions online, shopping online and online search. Once registered with a GP online, group members found that it is quick and easy to use and is better than being in a lengthy telephone queue. As part of their role at Blackpool Fulfilling Lives, group members are required to access health service technology to support their service users.

Barriers and challenges in accessing digital technology

One group member felt that the requirement for ID, lengthy passwords being asked and "too many questions" were barriers to them accessing online GP services. Another commented that accessing 'digital booths' in health settings excludes those that are barred from certain services, where do these patients go? It was felt that Blackpool Fulfilling Lives service users are unlikely to have the means to obtain technological devices (due to the cost of devices and issues securing contracts for devices or internet access), and if supplied with them, would likely sell devices.

The 'emergency appointments option' is not always available for vulnerable people who need them, because of people telephoning in for on the day appointments at 8am. There was a particular concern that health and social care services are not available at times that the most vulnerable require them. A perception of other

people's negative experience of using technology influences some people's decision not to use technology. Some people expressed a preference to see a health professional face to face.

There were some concerns raised: including that the NHS financial budget will not enable the digital vision/strategy to be fully implemented; concern about hacking of records, lack of ability to access historical medical records and this history not being considered and some people's capacity to consent to share information and records. If a digital strategy reflecting a redesign of the workforce (reduced GPs?) does not work, what happens next?

Shared email address prevents individual patient logon access, for example if a couple share one email address for the household; they are not able to use this to register for online GP access.

Using Skype for a consultation without hands-on examination may result in misdiagnosis etc. Human factor – patients have observed first hand clerical errors on their patient records, resulting in lack of confidence in the system. Current paper based systems/medical records not fit for purpose as they are not updated, lost, inaccurate and not available to the wider health and social care network.

Other comments

Some members experienced technology as negative and a hindrance/barrier especially encouraging social isolation, there was concern that the NHS is moving towards privatisation. Where people receive personal health budgets what is the likelihood of this being spent on technology?

Ideas that the group wish to share that may encourage them to access digital technologies:

- 'Drop-in centres' to access digital technology, this could include third sector venues, job centres/benefit offices, council offices etc.
- Person-centred health apps that are specifically designed for vulnerable groups and individuals.
- All health and social care professionals should have their own digital device provided by their organisation so they can access patient records at the point of need.
- Some members said they would like a Google type system as this is favourable and often used by many as it is seen to be the most up to date source of information.
- Trusted champions who understand the needs of the most vulnerable.

10. Digital health workshop - Just good Friends, St Annes

Overview of the group

Just Good Friends aims to combat loneliness, isolation and bring people together in friendship - making sure that no-one is **ever** on their own again.

"It's about being there for each other, making new friends, enjoying life and each other's company. Special friendships are formed and someone recently has met a best friend. They would never have known each other had it not been for Just Good Friends. Loneliness is a terrible problem which we at Just Good Friends are trying hard to change. It's about changing loneliness to happiness, it's about laughter and fun and being there for each other."

The workshop ran on **Wednesday 7th November**. More than 50 people were in attendance at this event, along with Just Good Friends co-ordinators and volunteers. The age of participants ranged from 60 – 90 plus years (with the addition of two younger members). There was a higher attendance of women (70:30 split). The workshop was fairly informal with Healthier Lancashire and South Cumbria and Healthwatch colleagues joining smaller groups (6 – 8 people) at different tables throughout the morning session. We collected a combination of group feedback and individual personal experiences of digital health.

"I love technology. I play online games and have a Fitbit to measure the number of steps I do. In terms of online games, I connect with both my daughter and son online sometimes for a couple of hours at a time. I do everything online (on a computer), except banking and contacting the doctor. I prefer to phone the GP practice and talk to someone directly about my health and to make an appointment. I don't normally search for health symptoms online, although I will visit the NHS website about symptoms once I have seen the doctor. I live in an independent living facility, which is supported with pull-chords, pendants and pre-arranged phone calls from the warden". (Pat, 80 years)

"Unfortunately I have never used technology. I have tried using a mobile phone, but I just never used it frequently enough to remember the functions" (Dave, 76 years).

"I am happy using my tablet and going online, although I haven't yet booked a health appointment online, as there are never any appointments available when I have checked" (Joe, 75 years). "I have had a Patient Access app for some time and book my appointments and repeat prescriptions through this app" (David, 80 years). Both David and Joe commented that as they use 'pay-as-you-go' phones and tablets, they are reliant on having access to public Wi-Fi. Getting Wi-Fi access in the GP surgery is a problem.

Other members of this group also used digital technology for many every day activities but not specifically for engaging in their healthcare.

In another group of eight people; five had use of a mobile phone, two of whom used it for emergencies only. The others consciously chose not to have a computer or a mobile phone "to live life in the slow lane". One lady who was partially sighted could not read anything as she had no vision in one eye, we spoke to her about accessibility features on tablets and smartphones (using audio description), which was of interest and she was going to discuss with her daughter.

A number of the group had a good level of awareness of their GP websites and used online booking for advanced appointments to see their GP; others were receptive to the idea. What appointments are available online varied - some of the group mentioned they were unable to book appointments to see the practice nurse and none were able to book emergency appointments.

"I don't book appointments online but I know you can on the My GP app."

"I go to Ansdell medical practice, I want to do things online but I asked the receptionist and they didn't know how to get me set up. I took in a photo; passport, everything that I needed and they couldn't help. It was a waste of time."

"I have an app on my iPad, its called Patient Access. This practice is the second one I have been with in this area, at both I have used online systems."

The overall consensus from one group was how difficult it was to book an emergency appointment as phone lines were constantly busy and when eventually they did get through the appointments had already been allocated. On these occasions they are asked to call back the next day. One lady described how she called a taxi for 8am to take her to the surgery as soon as it opened to book an emergency slot.

The idea of shared care records/data sharing was

received well.

We talked about technical support in independent living facilities including the use of pendants, bracelets and emergency pull cords; we discussed how other members of the group could access these services. We also discussed with one lady the option of 'virtual reality' digital solutions for pain management – this she felt might be useful for a family member.

In another group of seven people, four people had mobile phones and the same users had use of tablets and computers. As with the previous group they were receptive to online booking and some ordered medication online.
Two of the group received text reminders for their future appointments; others thought this a good idea.

One lady accessed health and wellbeing information online and found this to be of use when researching symptoms however would ultimately seek professional advice.

This group also highlighted concerns about booking emergency appointments on the day, busy phone lines and then appointments not being available.

"I go to Park surgery, they are using digital but I'm not connected yet. You have to bring your passport in to the surgery and all that, it's quite complicated."

Some people felt there are restrictions to booking and changing appointments online, having a conversation is sometimes more efficient, possibly!

"I do have technology but I'm not interested in booking appointments, I would rather do it on the phone. It's also hard to re-book online, sometimes you might want to change the time not just completely cancel."

There seemed to be a mix of answers from another group – some people using technology and are "digitally savvy" when it comes to social media. There was a fear from some of 'getting it wrong', being put off by the process and all the documents you have to bring with you. Although with others there seemed to be a willingness to learn and would use digital pathways but needed to be shown how.

"Booking appointments online feels like a minefield. If the appointments were actually updated, and I could use the system then I would. I just need to be shown how, my grandchildren could show me. I am happy to learn but it is a bit scary, I don't want to make a mistake. I am on Facebook but health is different."

11. Digital health workshop - Fylde and Wyre Patient and Public Engagement

The Fylde and Wyre Patient and Public Engagement Group's role is to support NHS Fylde and Wyre Clinical Commissioning Group (CCG) and its Governing Body and committees on Patient and Public Engagement (PPE) and participation, ensuring that the voice of the CCG's patients, their carers, and the public, including the seldom heard groups is embedded in the business of the CCG, embracing the "no decision about me without me" promise.

At this meeting on the 8th November there were 14 representatives in attendance.

There was a lot of interest from the group in the development of the NHS Online Orb app with particular questions around when it would be available to download on iOS and whether a 'family access' version would be available. There was a further question about accessing this app on older devices and whilst this needed to be checked, the group were advised that there would also be a desktop version of this too (to access on PCs and laptops). The group was also keen to know about whether this app would "interact with health professionals". It was explained in response, that the Orb was more of a "front door" for other online health and wellbeing information (including websites and apps) – allowing individuals to bring together apps that were relevant to their needs. The interaction with health services would continue to be through apps like Patient Access and My GP that would sit behind the Orb.

The group asked about how digital health improvements were taking account of the needs of people with visual impairments. It was explained that - as part of the wider engagement programme - Healthwatch and Healthier Lancashire and South Cumbria had met with wide range of different groups (including a sight impaired group) to address the needs of different and seldom heard groups.

There was some discussion about whether group members were able to access their health records online. At the moment this was still quite limited for most people – reflecting the need for further work with local GP practices. One group member commented that often her GP would ask her when she last had a

procedure – surely, this is information that should be kept within medical records and it would certainly be helpful for people to have access to this information so that they are informed, as well as their health professional.

There was a further point raised that health staff don't really encourage patients to register for online services. At the moment there is a two page form and two levels of documentation required before you can even register, let alone mastering passwords that cannot be changed and are not memorable. Simple suggestions such as the GP practice texting the link to patients would certainly help the process. There appeared to be contraditions with simple requirements to register for an app (date of birth and phone number) compared with having to rigorously prove identity when registering within the practice. There needed to be more of a can do approach and willingness for health professionals to support the online registration within GP practices. One member of the group shared her experience of trying to register for the recommended app from the practice. Unfortunately when she had visited the GP practice to resolve her difficulties she was advised that her problem was probably having "too many photos of grandchildren on her phone."

It was commented that there are some good examples of GP practices with high levels of online registration and access to online health records amongst their patient population – so it is achievable.

In terms of online prescriptions, one group member highlighted that they had to wait 6 days following ordering an online prescription – this seemed unreasonable and much slower than traditional methods for re-ordering prescriptions.

Finally, the group discussed some of the concerns around patients being scared by online search of symptoms – what was expressed as using 'Dr Google' by members of the public involved in some of the digital health engagements. Fortunately many people were using the NHS websites to access more balanced and considered guidance. The group suggested that such (NHS) websites should be 'NHS approved' to guide people when they do search for symptoms.

12. Digital heath workshop - Preston College

The focus group comprised of 15 Level 2 Health and Social care students who were aged between 16 and 19. The workshop ran on Friday 9th November.

Overview of the group

The focus group was fairly informal, beginning with introductions from Healthwatch Lancashire and our colleagues from Healthier Lancashire and South Cumbria. We then discussed "What is Digital Health?", and the importance of involving and capturing the views of local people.

We recorded feedback from the whole group discussion, and then we split into smaller groups of between 3-5 students. Representatives from both Healthwatch Lancashire and Healthier Lancashire and South Cumbria supported a group each.

All the students had access to either a smartphone or a tablet. The group used Messenger, Snapchat, Instagram, and watched videos on YouTube.

Their experience of using digital health was fairly limited, their engagement was primarily through health apps such as: Healthify Me: Weight Loss Plan (an app to help you monitor nutrition and physical activity); Flo Period and Ovulation Tracker (which helps with ovulation monitoring, tells you the chance of pregnancy and gives advice) and Glow Cycle and Fertility Tracker (which tells you about fertility, ovulation and has a calendar). Headspace was also mentioned, this app helps with meditation and mindfulness.

"I have thought about mindfulness, like a sleeping aid or just for relaxing."
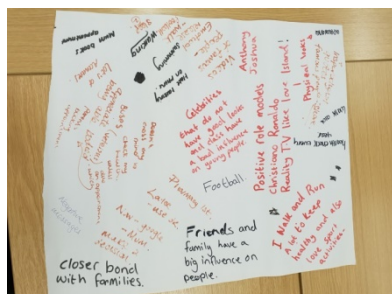
The group talked about positive role models who they follow online, for example: Christian Ronaldo and Anthony Joshua. They liked inspirational quotes and would share and watch videos of their role models.

Some of the group discussed the negative influence that celebrities can have, for example Little Mix and The Kardashians. The group discussed the impact on young people of celebrity culture, and suggested this encouraged body shaming.

"There are so many people on Instagram selling dietary products and nutritional information: they get paid for it so you can't necessarily trust what they say."

"The reactions people have sometimes can be negative on social media."

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The majority of students weren't accessing appointments or health services online; most would discuss health concerns with a family member and then decide a course of action which might include a visit to the pharmacy first.

"My Mum books [appointments] online and orders prescriptions."

"If I need to go to a sexual health clinic, I will look up the information online. It usually says when the drop-ins are and where to go."

"I feel better having personal contact, a human to speak to. I would rather see my doctor, they can't examine you online."

The students raised a number of challenges in their discussion groups. These included: trusting online information when googling symptoms, having too much information, and that information not always being user friendly. Security was also a factor, people wanted to know the information they share online is secure and privacy is upheld.

"I think people worry about the security and privacy of information. They could be sharing personal details about their health."

"I use Google, but that sometimes gives false information and it convinces me that I have something seriously wrong or a life threatening condition."

The groups shared their experiences of going to a doctor's appointment, and some expressed negative feelings about time constraints. In some cases they felt that professionals talked at them, rather than listening to what they had to say. They experienced a lack of interest and felt 'fobbed off' with a prescription rather than receiving information and support.

As part of the smaller group discussions we demonstrated the NHS Online Orb which was received positively by the students.

"I would use the NHS Online Orb, it sounds brilliant for information."

Other opportunities were to use people's stories and shared experiences through video, for example, Snap Chat stories and links on social media to websites and apps. The group also suggested using technology to communicate with people more instantaneously: for example sharing information about waiting times for out patient's appointments.

"Live chat" for example could be used to ask a healthcare professional about symptoms. This could help with the fear that can be initiated by looking online.