ELF Patient Organisation Networking Day 2021
Digital Health breakout discussion groups summary

Introduction

During the ELF virtual Patient Organisation Networking Day on 2 September 2021 delegates discussed the following questions in 9 breakout groups:

- ➢ Which digital solutions are most important for patients right now, and why?
- ➢ What are the areas where you think digital solutions can best support the unmet needs/gaps for respiratory patients going forward?
- ➢ What are the biggest challenges that we face with digital technology in health?

The main discussion points arising from these questions have been summarised and grouped into the themes below in this short report. Key points included how the pandemic has brought digital change out of necessity rather than choice; that there is an urgent need for more digital health literacy through education; that the future for healthcare should incorporate both face-to-face and digital solutions and that the voices of patients and patient organisations are key to help forge a future that is beneficial to patients and meets their needs.

The main ways that patients and patient organisations use digital health solutions currently are through Apps and Garmin/Apple watches to monitor heart rate, activity levels, asthma attacks as well as home testing tools e.g. home spirometry and sputum sampling.

There has been a big increase by patients in accessing webinars and video conferencing for networking and gaining information as well as social media e.g. WhatsApp and Facebook groups for peer support. Some research into children with interstitial lung disease (ChILD) revealed that they are also using social media, smartphones and wearables. However there is a gap in tailored and available devices.

It was also recognized that some patients do not interact digitally very much as they prefer face-to-face interactions.

Summary of key discussion points:

The COVID-19 pandemic created more digital health opportunities such as reduced costs, less travel, digital vaccination certificates, online pulmonary rehabilitation sessions and digital appointments and there is now a need to drive solutions and infrastructure forward.

The pandemic also uncovered the need for patients to share their anxieties and mental health issues and that we need to rely more on each other as a community.

The pandemic has made it more socially acceptable to share what patients do to self-manage their own disease.

We can better access some technology thanks to the pandemic and recognise that some digital solutions can support prevention by highlighting problems early e.g. remote spirometry.

A blended approach to healthcare is the most likely future as a hybrid model could be the new care pathway for many patients where digital solutions are used alongside face-to-face care.

Some digital changes that patients would like to see long-term include: help to manage chronic diseases at home and a combination of remote consultation and monitoring e.g. 6-minute walking test while being watched by a doctor.

However, a blended approach requires culture change and this is difficult even with the pandemic and do we have the financial resources to sustain a blended model? It is also important to include family members to gather their needs also.

It is important that if patients want to purchase something to help track their health, they know that it is medical grade and reliable.

The areas where digital solutions can best support unmet needs for respiratory patients were in the use of Artificial Intelligence (AI) to provide more accurate diagnosis; through wearables for daily monitoring of conditions and early warning signs; the digital provision of information e.g. video demonstration of techniques for homes testing, inhaler use etc. and peer support to better connect with each other. Improved digital communication with healthcare professionals was also highlighted.

The specific role of patient associations was discussed at length and that the voices of patients and patient organisations are very important to help forge a future that is beneficial to patients and meets their needs. There is an opportunity to put patients at the centre and find evidence-based solutions.

Social media, webinars and messaging platforms are important elements of digital health offering connection, education and peer support and patient organisations have been at the fore of much of this. Patient organisations have a role to play in providing patients with education and helping to instil trust.

It was felt that a key role for patient organisations is in helping to prepare patients and support them to be ready for e-health interventions as well as in building partnerships and bringing people together to have a shared voice.

Some concerns were raised about how much patient organisations can influence innovation and how happy patients are with this? Are they accepting this because there is no alternative rather than it being what they want? And is the digital infrastructure good enough?

Digital literacy and digital poverty was identified as a key issue due to high levels of digital illiteracy across Europe. It is essential that people are not left behind, and those who do not have IT skills or know how to use technology need support to be included. Digital poverty is also a problem as not everyone has access to WiFi or has space for private conversations.

Generational differences also exist as adults and young people use different platforms and older people may not be as technically proficient. Special considerations are needed around

using digital health with children and young people in terms of the platforms they use, privacy and legal implications.

Some solutions offered were that hospitals can be instrumental in helping patients access technology and that alternative logistic networks such as pharmacies could be used to fill gaps. In Portugal, a good example is where councils help people with digital tools. This cooperation could be formalised through established partnerships.

'Digital advocates' are needed to help patients get to grips with technology e.g. expert patient programmes could be used to help the older generation and it was suggested that training to use apps properly including how do tests and treatments at home as well as how to interpret data correctly is also required.

It was recognised that most people own smart devices now and that moving away from computer-based interventions towards smart phones will help to increase access.

Some of the challenges around the digital sharing of patient data raised included the fact that many patients do not fully understand data protection and GDPR regulations and that patients need to better understand the benefits of sharing their data and to be assured that their health information is safe.

There is the need for greater transparency about what data is being collected and how it is being used. Many patients appreciate the importance of sharing their health data to advance research but there are fears about privacy and potential discrimination from employers and insurance companies as well as how their information will be protected. More education is needed around this and what consent means.

Discussions also focused on who accesses health data and how it is used. Healthcare professionals and patients need access to the same data so that good decisions can be made e.g. information needs to be better connected up including medical records and national databases and registries. Data ownership is key as health data is very sensitive – not everyone feels that good safeguarding and protective measures are in place. An example given was where pharmaceutical companies have increased drug prices hugely resulting in reducing access for patients to drive their own profits. Decisions based on patient data need also be ethically sound.

Clinician buy in and partnerships are very important and there is a need for clinicians, as well as patients, to be involved in the development of digital solutions.

Some clinicians lack confidence with technology and do not think digital solutions will meet their needs, and perhaps do not want their patients to be empowered, highlighting a need for digital advocates for healthcare professionals too. It can be difficult to get healthcare professionals and hospitals on board and safe and transparent agreements need to be developed with all partners involved from the very beginning.

Healthcare professional-patient partnerships are needed to build the digital ecosystems needed for the future. Working together on digital health literacy and building trust is imperative as a joint approach will be more effective and better results obtained by working together to build programmes and information.

Funding and re-investment is needed for effective solution development and implementation, and education e.g. funding for home testing devices is very limited.

Highlighting research that shows how technology reduces costs needs to be available.

Reinvestment of profits back into research is the best thing for patients and there is concern over developments such as the Philip Morris takeover of Vectura.

And finally, some of the suggestions for how ELF/ERS can help were as follows:

- Produce a list of reputable devices.
- Develop a quality stamp / quality standard for respiratory apps and digital tools.
- Distribute best practices similar to this event where we come together to discuss collective experiences.
- Patients coming together helps us influence healthcare from the bottom up and we need to frame and record the patient voice. Connect people in a way they weren't connected before e.g. bronchiectasis patient conference.
- Set up an ELF digital health working group/patient council to share practices, experiences and what we need to do. If organisations have experience (legal, data protection, implementation, IT development etc.) it would be useful to contribute into this kind of expert working group.
- Produce or signpost to easy guides on GDPR legislation; cross-border care; data sharing and data safety.
- Bring together the patient and healthcare professionals to work together on best practice experiences in research and care delivery where the collective knowledge can contribute to future health and care needs.