ENGAGING WITH DIGITAL HEALTH TOOLS – CHECK BEFORE YOU CLICK

As individuals, there are many ways in which personal health data can be collected, even when we are not being actively monitored in a medical setting.

In the past, our health data was largely confined to medical records stored personally or in a family doctor's practice or hospital. Today, while some European countries still rely on paper records, digital health devices are part of everyday life. Many people wear a **smartwatch or fitness tracker**. These personal wearable devices can be used to monitor our sleep patterns, track levels of activity or calorie consumption or record pulse rate. Patients with certain health conditions may use **sensors to monitor vital signs** such as blood sugar or heart rate. Even if we do not own fitness trackers, many of us **download apps** to help manage our health. We may contribute to online patient groups or take part in online health-based surveys. Often, we make use of digital health tools without giving data protection a second thought.

This section of the **Data Saves Lives** toolkit highlights some of the issues associated with the use of digital health tools, providing advice on how to protect sensitive health data. It will support you in answering questions your members may have in this area.

What are the different types of digital health tools?

Digital health tools use computer platforms, software, apps and sensors to measure different health parameters (e.g. activity levels or sleep patterns) and collect health data about these parameters. They include:

- Smart watches
- Fitness trackers
- Mobile health trackers, e.g. to monitor heart rate
- Biosensors to monitor specific health functions, such as blood glucose levels
- Health-based apps
- Online health-based surveys

The impact of **COVID-19** on medical care

During the COVID-19 pandemic, the number of face-to-face medical consultations declined sharply and increasing numbers of people turned to apps to access support on related topics such as mental health and weight loss. Many healthcare providers also started providing remote consultations, using teleconferencing and digital health tools to help them care for patients.

Can we trust digital health tools?

Digital health tools have transformed the way people engage with their own health, allowing them to play a greater role in their own well-being. These tools make it far easier to manage some conditions and can alert healthcare professionals to potential problems at an early stage.

However, it is important to remember that all of these activities generate data about our health and well-being, some of which can be of a sensitive nature. Digital health tools increase our 'digital footprint' – the traces of information that record where we've been. And some of these tools routinely share our data with third parties, sometimes without our knowledge or adequately informed consent. Before signing up to a digital health tool, it is vital to find out what will happen to your personal data and to check whether it will be shared.

Attitudes towards sharing health data

73% of EU citizens want to share health data on the precondition that data is secure and only accessible by authorised parties.

Some 42 % of the respondents fully agree or agree that a lack trust in services providers prevents them from using digital services. The proportion of the respondents who held this view was the highest in Germany (48 %) and the lowest in the Netherlands (38 %).

How can your community feel more confident using digital health tools?

Hospital and medical records are legally protected in terms of privacy, but this protection does not currently extend to other forms of digital data. For example, when a person signs up to a clinical trial, they are specifically told how the data will be used and are asked to sign a consent form.

In the case of an app, for example, information regarding data protection may be buried deep in a lengthy set of Terms and Conditions that is hard to navigate and even more difficult to understand. How many of us click the box signifying we have read and agreed to the Terms and Conditions without even glancing at the information?

As in so many aspects of life, knowledge is power. Encourage your members to ask a few key questions before signing up to an app or setting up a new fitness tracker. Most online tools will have a Privacy Policy in their Terms and Conditions that sets out how and why data will be used and how it will be protected. It is good practice to check this before proceeding.

Key questions to consider

- What personal data will be held? Will it be identifiable or anonymised? Remember that even if data is anonymised, it can sometimes be linked up with other information to form a more detailed profile
- Where and how will the data be stored?
- How will the data be protected?
- How will the data be analysed and used?
- Who will have access to the data? Will it be shared with third parties?
- Will any of the data be sold to third parties?
- Is there a possibility to opt-out of (i.e. restrict) certain aspects of data sharing?
- In the case of online support groups, who is hosting the site and what is their commitment to data policy? Who will see the information shared?
- Does the company commit to notify users if there is a data breach?
- Can I access my personal data, or ask for it to be deleted or corrected?

What is the role of the GDPR?

The General Data Protection Regulation (GDPR) is a 2018 EU law on data protection and privacy, which includes the transfer of personal data in and outside the EU. This means that the personal data of EU citizens is legally protected, and people must be told how their data will be used, for what purposes and how it will be protected.

It is perhaps not surprising that with concerns about privacy and data breaches hitting the headlines from time to time, some people are hesitant about engaging with digital health tools. Trust can certainly be an issue for some people.

It is all a question of balance. Digital health tools are here to stay. They are accessible, easy to use and most offer benefits in terms of convenience and patient empowerment. To ensure they are used safely, we need to improve patient literacy and equip consumers with the information they need to make informed choices about digital health tools. In many cases, a few simple checks can be sufficient to reduce fears and ensure that consumers engage with these tools in a safe and confident manner.

How can we identify trustworthy and useful apps?

Some patient-led organisations have already reviewed apps for patient communities. For example, MyHealthApps, which was developed in collaboration with patient organisations and launched in 2013, is maintained by PatientView. The website curates hundreds of health apps tried and recommended by patient and health consumer groups worldwide.

As a patient group or individual advocate, you might consider inviting known app developers or industry partners working in your disease area to involve you in the design process of a digital tool. This could help ensure that any new app in your disease area is truly useful for affected patients and their families and importantly, that you understand how data will be collected and used.