

THE ASTHMA AND COPD PATIENTS' DIGITAL JOURNEY IN EUROPE



DIGITAL



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DIG_IT

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LIST OF ABBREVIATIONS

COPD	Chronic obstructive pulmonary disease
COVID-19	Coronavirus disease 2019
DiGA	Digital therapeutics, or Digital Health Applications
DIG_IT	EFA's project on the asthma and COPD patient's digital journey
EC	European Commission
EFA	European Federation of Allergy and Airways Diseases Patients' Associations
EHDS	European Health Data Space
EU	European Union
GDPR	General Data Protection Regulation
GP	General practitioner
IT	Information technology
OECD	Organisation for Economic Co-operation and Development
WHO	World Health Organization

FOREWORD

Crises accelerate history. Sometimes it feels like life moves at a steady speed – then everything seems to change at once. That's how it felt for people with chronic conditions in spring 2020. For years, we've heard people talk about the dramatic impact technology would have on healthcare. It would usher in a new era of patient-centred care, we were assured.

Those of us advocating for people with asthma and chronic obstructive pulmonary disease (COPD) for decades have often wondered if this vision would ever translate into day-to-day patient care during our lifetime. While most of us have smartphones and can read the news or book cinema tickets online, the story of information technology in healthcare has unfolded more slowly.

You know what happened next: a pandemic. The fast-forward button was pressed. To ensure continuity of care while minimising social contact, healthcare providers turned to new tools which were embraced by many patients. Video calls and e-prescriptions spared us visits to the clinic, as health systems – with varying degrees of success – underwent the most rapid period of change most of us will ever witness in our lives. Patients were offered a more central, more active role, in the healthcare and the health data ecosystems.

Our asthma and COPD community of patients is diverse in its appetite and aptitude for this technological shift. For some of us, the leap to digital tools wasn't a big one; for others, it was a major adjustment that strained our connections with our clinicians. And we know that there are some people – perhaps still a minority – who have gone beyond remote consultations and are using everything from apps to digital spirometers to monitor and manage their lung care.

The question now, as we hope to slowly emerge from the COVID-19 pandemic, is how this experience has changed healthcare for people with asthma and COPD. To understand the impact of the crisis and how patients view digital healthcare, we need data. Will patient care revert to the pre-2020 status quo? Are the changes permanent? Are there differences between countries, age groups, or socio-economic groups? These are but a few of the questions that the EFA DIG_IT study sets out to answer.

Striking elements of this data-rich report include the comments received from patients. We see a patient community that will use tools that make their lives easier, but that still values direct contact with healthcare professionals. Technology, it seems, is complementary to – rather than a substitute for – healthcare services. However, the report shows that those patients who use digital tools view them favourably. The digital technology sector should therefore take these findings as a springboard for enhancing engagement with the patient community. Together, industry and patients can address barriers to adoption and the future needs of technology users.

We also see that access to technology varies widely, with significant differences between countries: those countries that had invested in eHealth over a sustained period of time were best placed to make the shift towards more use of technology at a moment of crisis. There are differences too between better off, higher-educated patients and those with less education and fewer resources. Here, investment in health literacy and digital skills is essential. As patients value training from healthcare professionals, we need to equip clinicians with the tools and with enough time to coach their patients. It is also clear that patients – like other European citizens – have concerns about their health data, and that their privacy and security must be comprehensively addressed whenever digital equipment is used.

We hope that in reading these pages you find EFA's report enlightening and its recommendations insightful. For us the key message to policymakers, healthcare providers and industry, including the digital sector, is clear: patient empowerment is the future of digital health. If we want to build modern, patient-centred health systems using technologies designed to improve patients' lives, patient voices must be included early and often in the process.



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—

Carla Jones, EFA President

”

EXECUTIVE SUMMARY

Digital technologies are aimed at making healthcare more efficient, data-driven and patient-centred. While patients with asthma and COPD (chronic obstructive pulmonary disease) have indicated a willingness to embrace tools that empower them and improve outcomes, uptake of innovative devices and services has been slower in healthcare than in other sectors.

The COVID-19 pandemic has been a catalyst for digital transition in healthcare. Many patients have used remote consultations and other online tools to ensure continuity of care at a moment of crisis. As Europe begins to look beyond the pandemic, and the European Commission (EC) is developing the framework for its European Health Data Space (EHDS), it is vital that the patient voice is heard.

The DIG_IT survey was conducted by the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) in the summer of 2021. It set out to capture the views of asthma and COPD patients on Europe's digital future. The initiative surveyed close to thousand patients in five countries (Belgium, the Czech Republic, Ireland, Norway, and Spain) to understand their needs, perceptions, and use of digital technologies throughout their patient journey.

The survey showed that some tech-savvy asthma and COPD patients routinely use digital tools in their daily lives. For many, video calls and electronic prescriptions are becoming the norm. However, awareness and use of tools, such as smart inhalers or digital peak flow meters, are low.

The research also revealed variation between countries and patient communities. Some disparities arise from the availability of digital services, while others are a function of patients' age. For example, the findings showed that patients in Spain are more likely than those in the Czech Republic to use digital tools. This finding reflects the stronger digital public services and better connectivity in the former.

Beyond access, some patients are hesitant about a variety of aspects of digital products and services. Many raised data privacy and security concerns, others saw little benefit from new technologies or had low levels of awareness. There are real worries, on the part of patients, that technologies could replace face-to-face contact with healthcare providers.

However, the survey points to a broad willingness by patients to try out new tools which present clear benefits from trusted providers. Patients are more likely to share personal health information if it improves their condition, but are also open to data sharing if they expect this will contribute to overall improvements in how diseases are understood and managed. The good news is that, when patients have embraced digital technologies, satisfaction is high. Patients appreciate the convenience and control that these tools can bring.

The results emerging from the DIG_IT survey offer a series of detailed recommendations for policymakers, academia, and industry which will inform the publication of a Charter for Digital Asthma and COPD Care. This report offers a timely contribution to a fast-moving area of health policy, helping to add evidence of how technologies are used today and the factors that will shape their future adoption. As the European Union's health data policy takes shape, it is vital that patients are included in the conversation from the beginning of this new phase.

INTRODUCTION

Digital technologies are frequently used by the majority of people in Europe¹. From e-government^{2,3}, to e-commerce⁴, societies and economies are increasingly digital, with two in three believing these tools have a positive impact on their lives⁵. **Most Europeans view digitisation⁶ as an opportunity**, while some have reservations on access and data security. Privacy concerns and internet access also present challenges. However, people tend to develop a positive view of digital tools once given the opportunity to use them.

More than half of EU adults report having searched online for health-related information in the first quarter of 2020, this number is lower for those using health apps and remote consultations⁷. **Technology has the potential to improve the diagnosis and management of certain chronic conditions**, although more evidence is needed to support the effectiveness of some emerging tools^{8,9,10}. Innovative medical technologies promise to **make healthcare more efficient and more patient-centred**¹¹. By empowering patients to play an active role in their own care, apps and wearables offer new ways to monitor wellbeing and improve access to services by connecting patients to providers as evidenced in areas such as diabetes¹² and smoking cessation¹³.

People living with asthma and COPD, the two most common long-term respiratory conditions¹⁴, have expressed **a desire for effective and secure digital tools to improve health outcomes and the patient experience**¹⁵. The EFA 2019 Active Patients Access Care report, based on a survey of asthma and COPD patients in Europe, urged policymakers to accelerate the use of digital technologies that can empower patients while safeguarding their health information.

This is in line with wider policy trends, notably the growing momentum behind patient engagement and the development of data-driven healthcare systems¹⁶. At an EU level, it reflects the drive to create a society fit for the digital age, and the EC's commitment to establish a European Health Data Space (EHDS)¹⁷, as well as the World Health Organization (WHO) Regional Office for Europe's Empowerment Through Digital Health Flagship Initiative¹⁸. These trends have been gaining momentum for several years with the advent of **new technologies becoming more readily available** and the EC developing Europe's regulatory framework in consultation with stakeholders.

That was the state of play until early 2020 when COVID-19 struck Europe. The sudden emergence of a pandemic respiratory infection disrupted healthcare, as well as citizens' social and working lives. For people with asthma and COPD, COVID-19 brought additional anxieties and uncertainties about the risks associated with infection. Slow and steady progress on the use of digital tools was suddenly replaced with dramatic changes to how diagnosis, monitoring and care were delivered^{19,20}.

In the initial phase of the pandemic response, where speed and patient safety were of the essence, the use of digital tools may have been uneven and imperfect²¹. In Europe, some countries had already advanced in making the digital transition in health, including Spain and Norway, whose digitalisation is partially assessed in this report^{22,23}. However, **COVID-19 provided a catalyst all over Europe for the wider and daily use of technologies such as video conferencing** – a phenomenon which could have a lasting impact.

Today, as patients and health systems adapt to the 'new normal', and policymakers step up efforts on digital health, it is vital that the patient voice is heard. In the summer of 2021, EFA launched the DIG_IT survey to ensure that the views of asthma and COPD patients are at the centre of Europe's digital health future.



What is asthma?

Asthma is a chronic inflammatory lung disease. It often starts in childhood and affects one in five school children (20%) in Europe. There are 30 million people under 45 years of age who live with asthma in Europe.

What is COPD?

Chronic obstructive pulmonary disease (COPD) is an irreversible disease that makes breathing progressively more difficult. COPD mainly affects people over the age of 40 and becomes more common with increasing age.

What is patient empowerment?

Patient-generated data can give people with asthma and COPD greater control over decisions and actions affecting their health. Such empowerment can improve communication and encourage equitable partnerships between patients and health care professionals (HCPs).³¹



What is digital health?

Digital health refers to healthcare practices supported by electronic processes and communication tools. It includes electronic medical records, telemedicine, evidence-based medicine and health apps and personal equipment.

For patients with respiratory diseases, tools such as digital peak flow meters can be used to assess lung function; apps are used to keep track of symptoms and aid compliance; while patients can even harness environmental data to gain insights on the risk of symptom exacerbation.

TERMINOLOGY

Digitisation: converting information from a physical to a digital format e.g. electronic patient records

Digitalisation: the use of digital tools and data to change how healthcare is delivered

Wearables: small electronic devices, placed on the body, that can measure temperature, breathing rate, blood oxygen, location etc.

eHealth: healthcare practices supported by electronic tools and processes

mHealth: the use of mobile devices (phones/tablets) to support healthcare

Digital health in respiratory care

New digital tools are playing a role in the shift towards patient-centred healthcare. The wealth of data generated by eHealth and mHealth applications raises fresh questions about data security and privacy. Trust, affordability and intellectual property of data are increasingly important features of the current policy debate on the use of digital health solutions.

A growing digital health sector, populated by the established medical technology industry as well as IT companies, are poised to take an increasingly prominent role in the future of healthcare. Many of these companies have a strong track record of developing consumer technologies, some have links to academia, and all stand to benefit from engaging with patients to understand their needs and concerns.

The benefits of digitalisation can outweigh the potential downsides, as long as digital health issues are carefully managed, and major policy decisions are made with patients. Patient empowerment is one of the key benefits of digital health in the management of chronic respiratory conditions^{24,25}. Equipped with an unprecedented amount of data, patients gain knowledge, insights and control over their disease and wellbeing. Digital tools demonstrate that timely, accurate information is power.

Diagnosis and digitalisation

Among the major clinical concerns for patients with asthma or COPD are underdiagnosis and misdiagnosis^{26,27}. In fact, more than 75% of people with COPD remain undiagnosed²⁸. Earlier diagnosis could be improved using data to help researchers better understand the cause of disease, anticipate its development, and address it as soon as possible to preserve lung function. This could enable earlier and more specific treatments, leading to enhanced quality of life. In short, data-driven health can become a critical enabler of a more personalised approach to medicine.

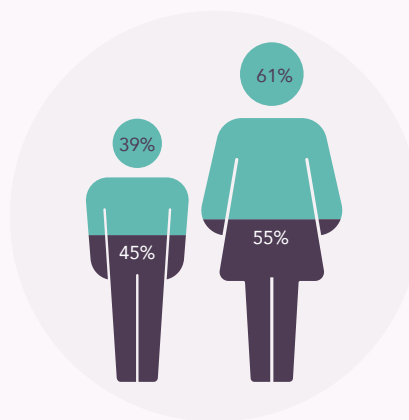
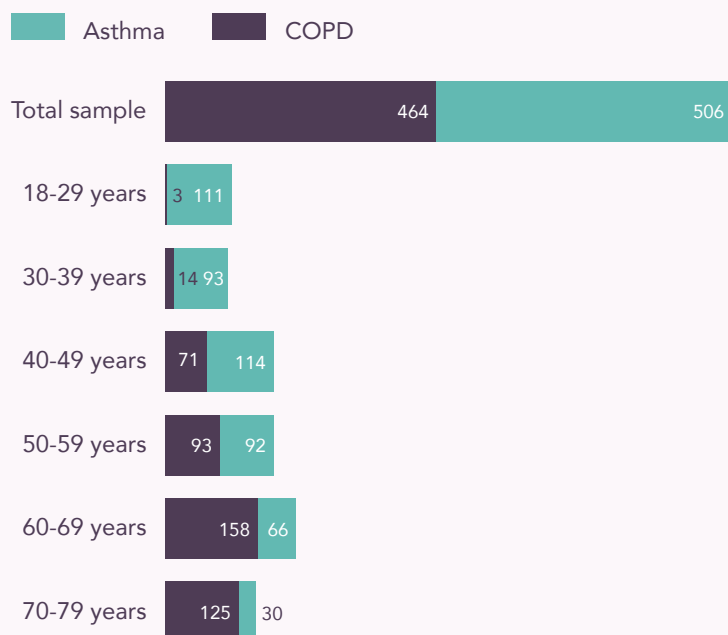
Treatment and digital tools

The analysis of datasets from digital tools, such as apps or wearable devices, provides excellent information to improve efficacy. This can help to increase adherence – a persistent challenge for people with long-term conditions – by enabling behavioural changes in patients²⁹. In addition, monitoring can help improve understanding and predict different patient outcomes in response to medicines, leading to more precise prescriptions, personalised medicine and innovation.

Care through digital means

People with chronic respiratory diseases can better manage their own conditions when equipped with their data and health status along with data on external factors which may lead to exacerbations^{30,31}. Digital health can combine information on the patients' condition with crucial variables such as air quality, temperature and humidity, or the presence of pathogens. This broader spectrum of information can assist patients in taking informed decisions and achieving optimal daily care. Digital tools enable stronger and faster dialogue with healthcare providers.

Table 1. DIG_IT 2021 Survey sample structure



The EFA's DIG_IT project

The early 2020s are a crucial moment in the short history of digital health. Three factors, the COVID-19 pandemic, forthcoming EU regulation on the infrastructure of health data, and the growing number of innovative technologies entering the health market, have together moved digital solutions centre stage. It is therefore time to dig deep on the impact, opportunities, and challenges of the digital revolution in healthcare.

The EFA's DIG_IT Information Technology (DIG_IT) Project aims to put patient voices at the heart of these conversations. In doing so, it paves the way to a patient-informed transformation of digital technology use throughout health services.

From this strong foundation, EFA's DIG_IT Project will build a framework for continued digitalisation in the respiratory conditions' field. In addition to providing a deeper understanding of the benefits, barriers, and concerns around digital health, the initiative aims to develop insights into the patient digital journey in respiratory health.

We have surveyed 970 patients (506 with asthma and 464 with COPD) in five countries (Belgium, Czech Republic, Ireland, Norway, and Spain) to understand their needs, perceptions, and use of digital technologies. The participating countries were selected according to several criteria such as access to digital solutions, impact of COVID 19 on national healthcare systems, and with regards to a geographical representation of EFA's European membership. In addition, EFA preferred to conduct the survey in countries where no much data on digitalisation in the respiratory area were available.

The survey findings have been translated into patient recommendations for policymakers, academia, and the technology sector. The evidence generated by this survey will inform forthcoming regulations and the continued evolution of a fast-moving field, and it will also serve to develop an EFA Charter for Digital Asthma and COPD Care. By building on insights from the patient community, EFA will ensure that its positions reflect the current perspectives of the association's members and patients it represents.

DIG_IT survey sample

The typical asthma patient responding to the survey is of middle age while most COPD patients were more than 70 years of age. In terms of educational attainment, 89% of asthma patients has a secondary or higher level of education, compared to 70% of COPD patients.

The average degree of severity is higher in COPD patients interviewed: 74% have moderate to severe COPD, while 61% have moderate to severe asthma. The typical respondent lives in an urban area (49%) with smaller numbers in suburban and rural settings.

ACCESS TO HEALTHCARE IN THE INFORMATION AGE



ACCESS TO HEALTHCARE IN THE INFORMATION AGE

Tech-savvy patients use digital services in their daily lives, but healthcare lags behind sectors like entertainment and communication. COVID-19 accelerated the widespread use of digital health, especially among asthma patients.

Whether the examples are social media, streaming platforms such as Netflix, or online shopping – for most people in Europe, online services and digital devices are a fact of life. Booking cinema tickets, ordering food, or transferring money can be done at the click of a button. However, health systems are embracing the digital revolution at a slower pace. For example, health systems handle very sensitive personal data.

Wary patients are cautious about the use of personal health information: some prefer the direct personal/human touch of the healthcare system, while others see little need to engage with apps and online tools. These kinds of viewpoints have historically been hard to shift. But in recent years, other patients – especially younger people with long-term conditions – have tapped into social networks for advice, engaged with health and fitness apps, and shown a willingness to use telemedicine to supplement real-world interactions with health professionals.

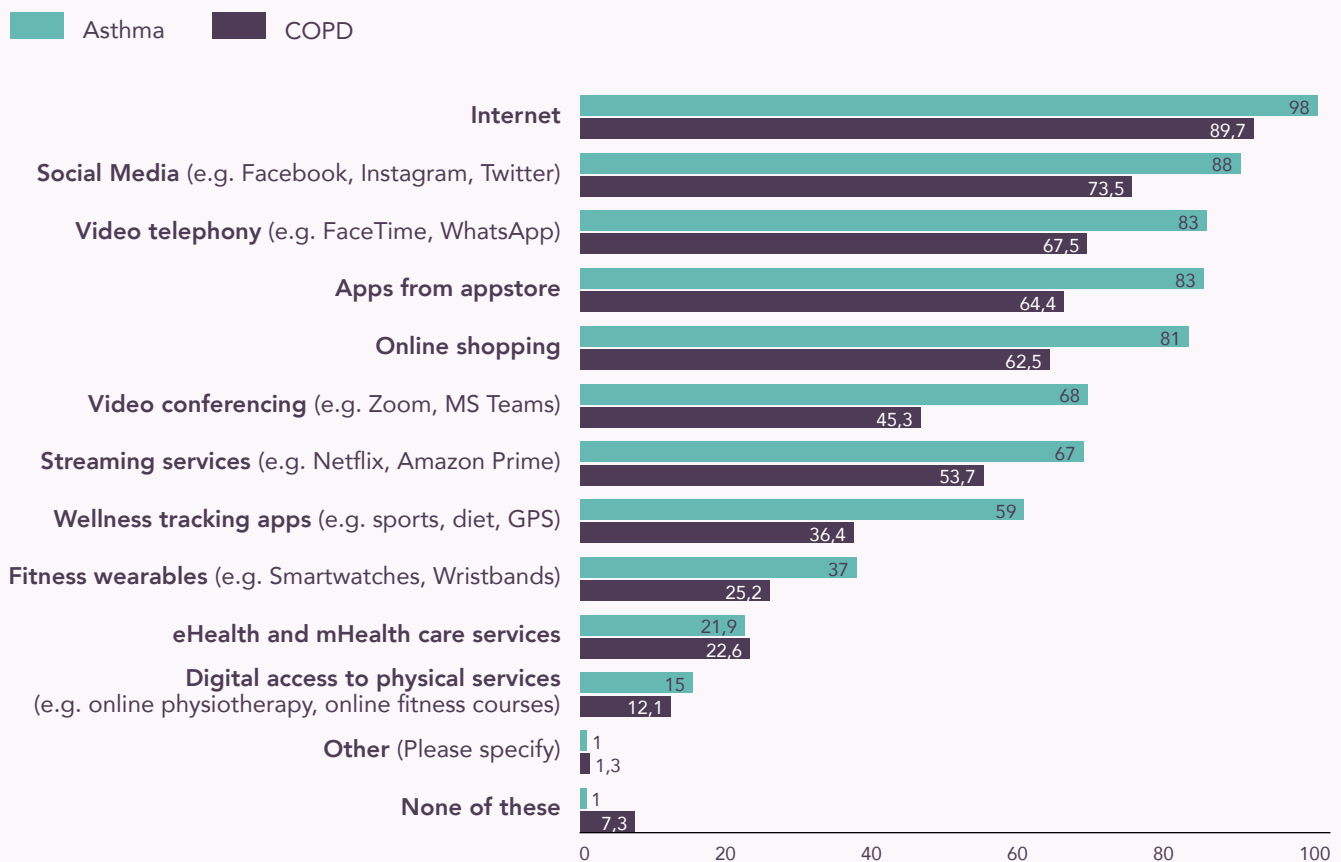
Early adopters aside, this trend was generally far from the norm – until the COVID-19 pandemic sparked a mass movement into the use of online spaces. At a time when health systems were under immense strain, patients sought continuity of care while reducing their risk of contagion during the series of lockdowns.

Today, a growing and dynamic industry, which includes the consumer-facing information technology (IT) sector, is increasingly focused on meeting the health and wellbeing needs of the public.

Access to digital healthcare

The DIG_IT survey, conducted in the summer of 2021 when the most intense waves of the pandemic had receded, finds use of digital services is high overall, particularly among people with asthma. This group is on average younger than the COPD patient community. However, eHealth and mHealth and wellness apps are not yet widely used, and familiarity with these tools is relatively low. Overall, women are more inclined to use digital services and digital health services, while people in urban areas tend to be more open to digitalisation than those in rural areas.

Table 2. Asthma and COPD patients' use of digital services



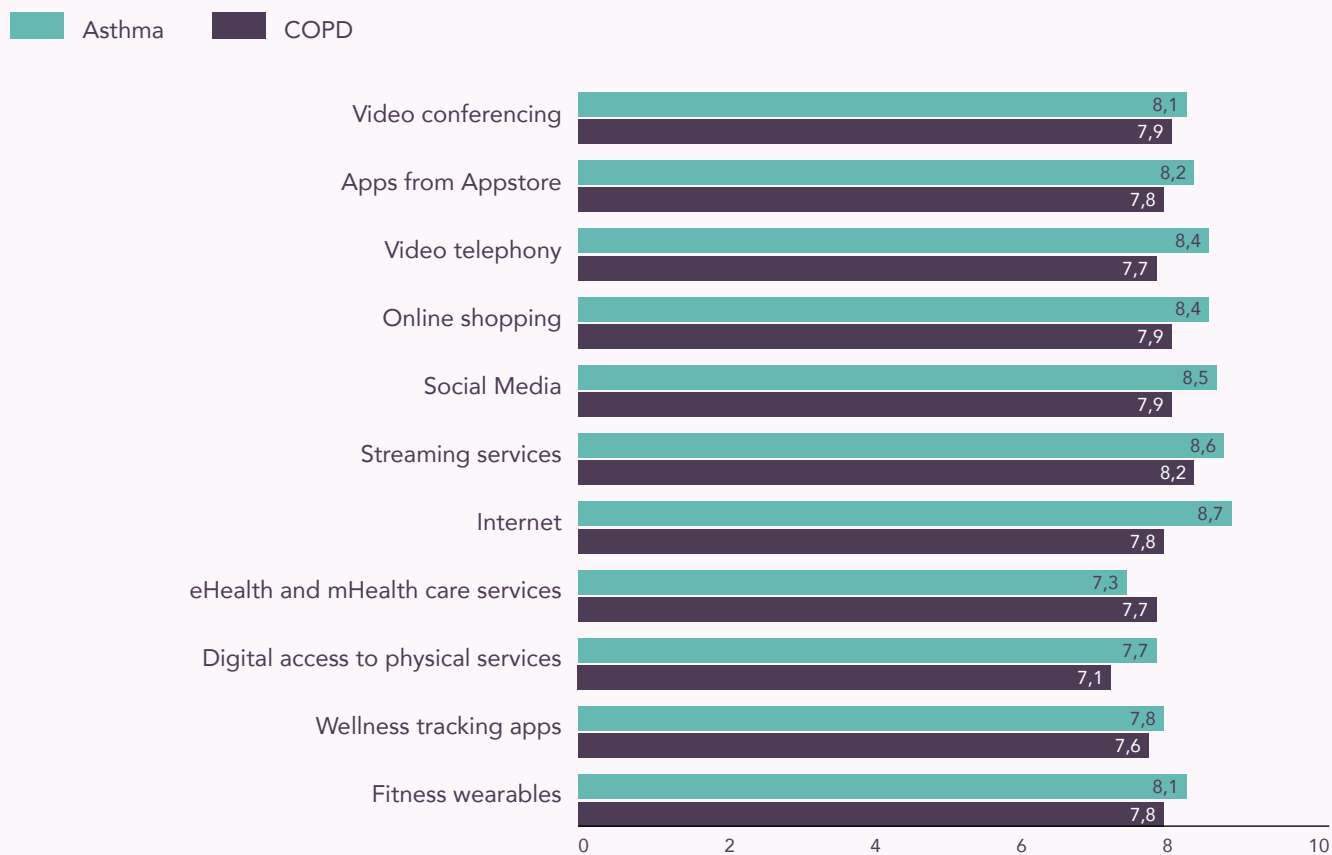
Question 13: Which of the following digital services and tools do you use, or have you used within the past 12 months?

Basis: n=970 asthma/COPD patients

Those people who have used digital health services report high levels of familiarity with these services and tools. In fact, while COPD patients are generally less digitally engaged than asthma patients, they are more inclined than people with asthma to use eHealth and mHealth services. This suggests that user-friendly digital health tools can be accepted by patients of all ages, provided that such tools address their needs, and they are given the time and training required to use them. Patients who are hesitant about digital health may find reassurance in the positive experiences of some of their peers who have taken the leap into the world of online services. Experience with video telephony, fitness wearables, and other online booking systems can be readily transferred to digital health where patients see real potential benefits to using them.

Asthma and COPD patients' familiarity with digital services

Table 3. Asthma and COPD patients' reported familiarity with general digital services

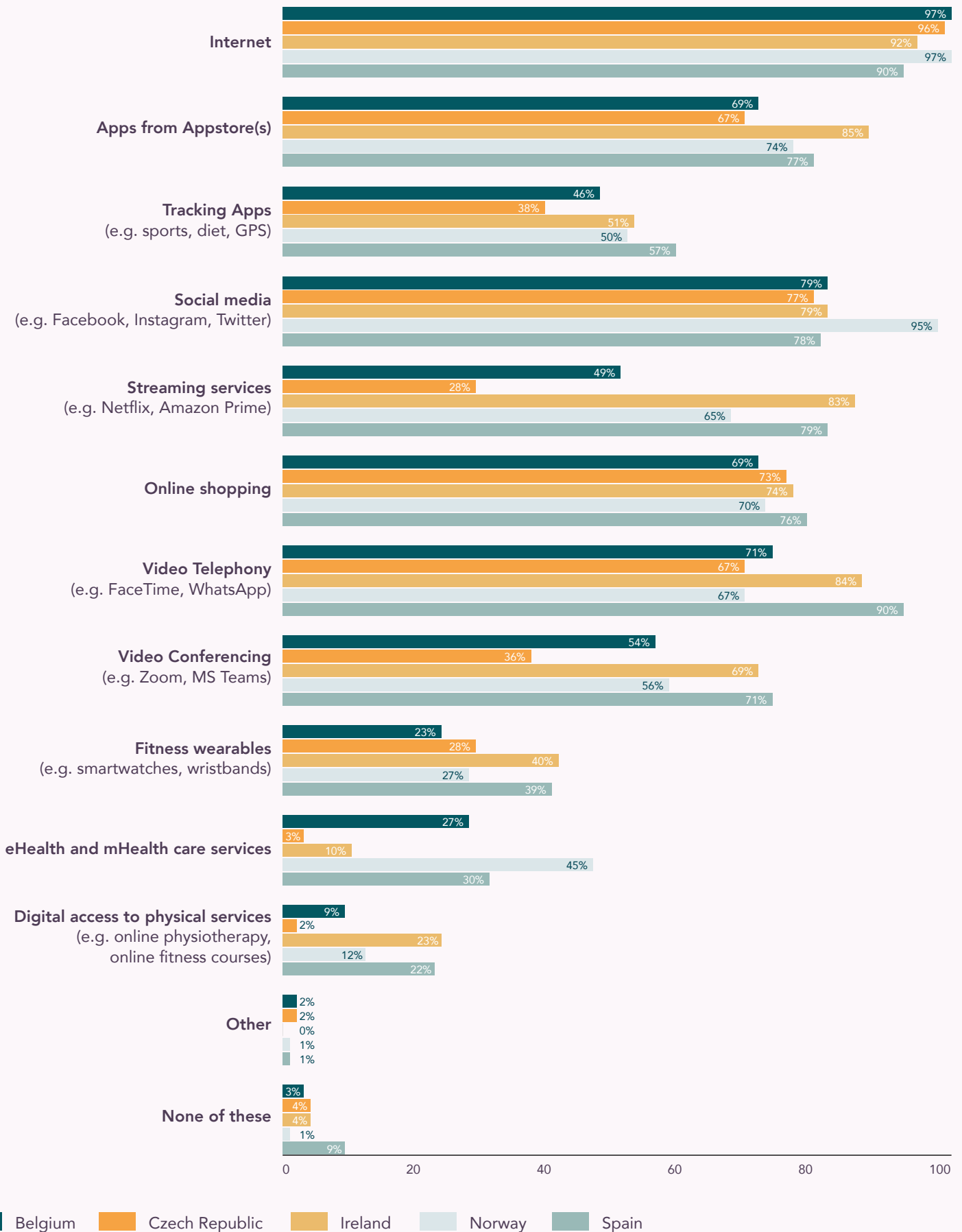


Question 14: For all that you use, how would you describe your familiarity with it on a 1-10 scale, where 1 is 'I am not very familiar' and 10 is 'I am very familiar with it'.

Basis: asthma n=506, COPD n=464

While the use of digital services is high across the five countries surveyed, the range of services is higher in Ireland, Norway and Spain than it is in the Czech Republic and Belgium. When it comes to e-health and m-health, Norway, Spain and Belgium report higher levels of use than Ireland or the Czech Republic since the beginning of the COVID pandemic. This broadly reflects national digitalisation policies and higher levels of investment and use prior to the pandemic.

Chart 1. Use of various digital services among asthma and COPD patients in different European countries



Question 13: Which of the following digital services and tools do you use, or have you used within the past 12 months?

Basis: asthma n=506, COPD n=464

Usage of health services: welcome to the age of the e-prescription

Given the routine use of digital services outside the field of healthcare, it is perhaps unsurprising to find that a slim majority of respondents have booked medical appointments online and made use of e-prescriptions. Most asthma patients, who are generally younger than their counterparts in the COPD patient community, use online booking systems. 41% say they use 'only digital' options for making appointments, with a further 20% saying they use both digital and physical methods. COPD patients are not far behind: a total of 49% state that they use only digital tools to book their appointments or that they have booked their appointments online at least once.

Meanwhile, respondents with COPD eclipse their peers in the asthma community when it comes to using electronic prescriptions. In fact, 48% of people with COPD – surveyed in summer 2021 – say they use 'only digital' prescriptions. A further 21% use both digital and paper for this purpose, suggesting that the digital option is becoming the norm. Although 40% of people with asthma use e-prescriptions, 28% declare that they use both digital and physical options, meaning more than two in three patients have embraced the online option.

The results indicate that there is a lot of potential to facilitate care through digital services and tools. The majority of asthma patients are only engaging with treatment plans, disease monitoring, consultations and examinations/ diagnostics through physical means, but this could change with the right support. Better access to, and familiarity with, digital tools could make care more accessible. This is particularly clear for asthma patients who already use or are more familiar with digital tools than their COPD counterparts.

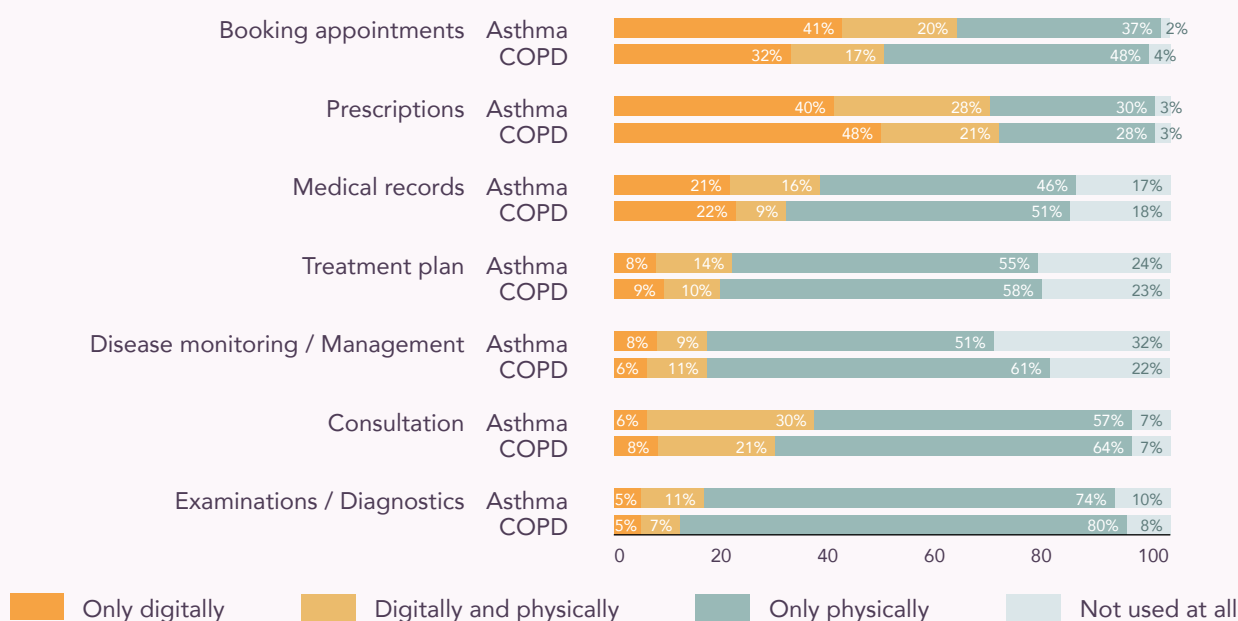


I am very much in favour of digital – it solves problems quickly. But sometimes it is necessary to have an in-person consultation

— Asthma patient from Spain



Table 4. Use of healthcare services among asthma and COPD patients



Question 16: Which of the following healthcare services do you use either digitally or physically or both?

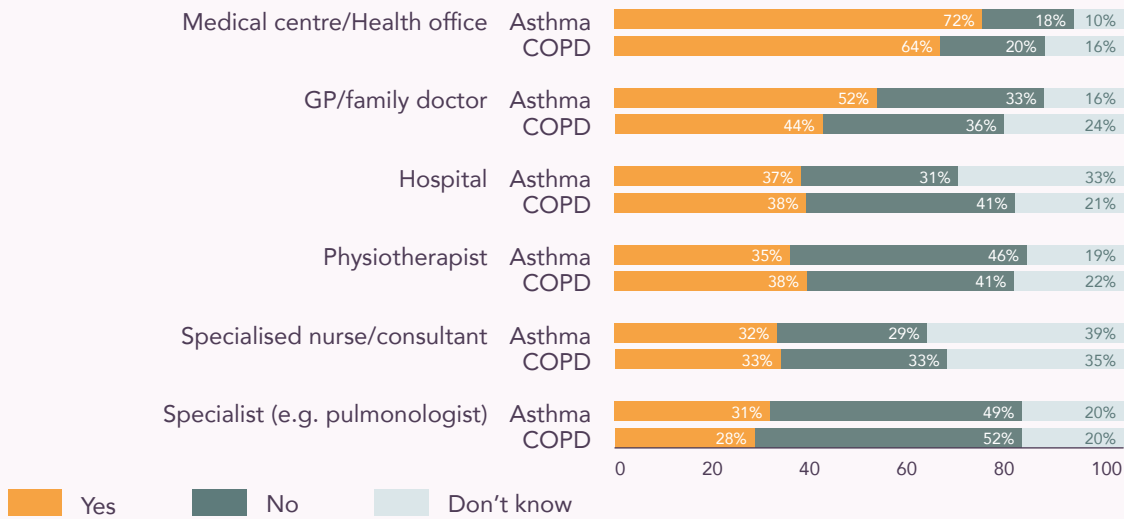
Basis: asthma n=506, COPD n=464

Healthcare providers: national differences and local service gaps

For people with COPD and asthma, general practitioners (GPs) and specialists play a key role in disease monitoring and management³³. People with COPD see more specialists than those with asthma. Previous research has indicated that 61% of healthcare professionals believe they have not received sufficient training in digital skills³⁴. This is reflected in an Organisation for Economic Co-operation and Development (OECD) report suggesting that between 30% and 70% of frontline health professionals do not have the skills required to use digital technologies³⁵.

The DIG_IT survey finds that, for both asthma and COPD, engagement with digital tools can be influenced by where patients receive care. Medical centres offer digital services most frequently (72% and 64% for people with asthma and COPD, respectively), followed by GPs (52% and 41%), The study shows that there are gaps in digital services offered especially among respiratory and allergy specialists (31% and 28%).

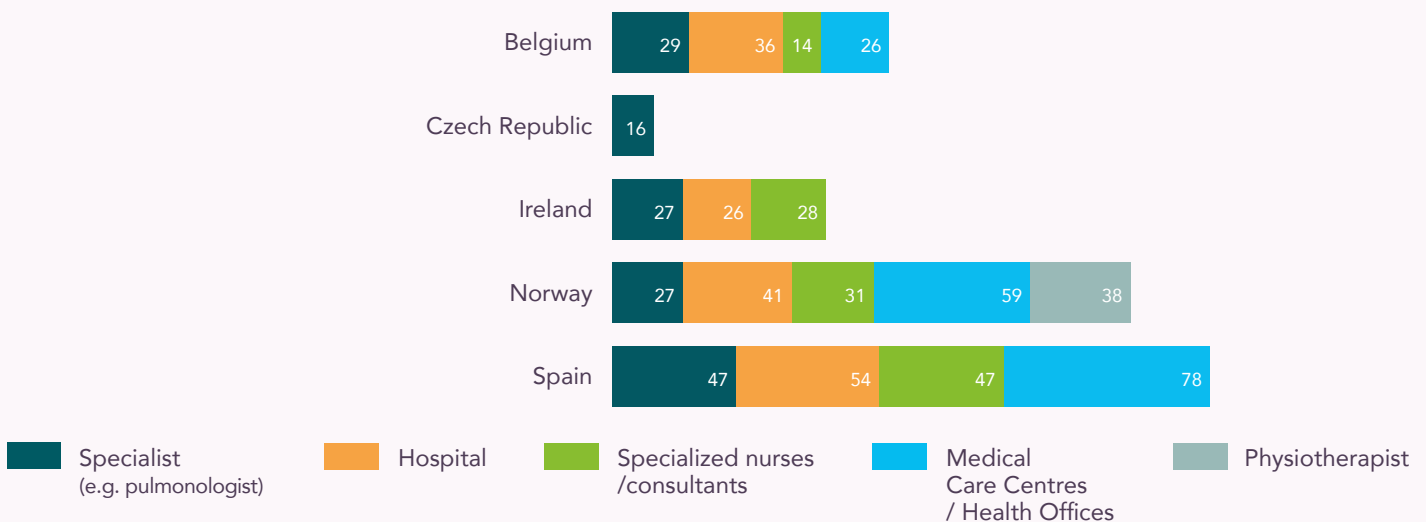
Table 5. Healthcare professionals providing digital services to asthma and COPD patients



Question 18: Which of these offer digital healthcare services?

Basis: All patients who declare using the specific healthcare service

Table 6. National differences in healthcare professionals providing digital services to asthma and COPD patients



Question 18: Which of these offer digital healthcare services?

Basis: All patients who declare using the specific healthcare service

Significant differences between countries are also evident, with Spain and Norway most likely to offer health services digitally^{36,37}, while Ireland and Belgium – and the Czech Republic, in particular – have been slower to embrace digital tools^{38,39,40}.

Patients’ openness to digitalisation

Looking to the future of healthcare provision, one of the big questions is whether patients want digital healthcare to become standard. The survey finds a broad willingness to use new tools, but also highlights barriers to their widespread uptake. Overall, asthma patients tend to be more open to digital healthcare solutions, while the number of COPD patients who are ‘very sceptical’ is higher, as compared to asthma patients. The majority of asthma (76%) and COPD (67%) patients are very or somewhat open to digital healthcare solutions. Service providers must take this into account in any transition to digital services. Crucially, patients have a role to play in co-designing how technologies and services are delivered.

COPD patients are more sceptical of digital healthcare solutions than asthma patients. While they use fewer digital tools in their daily lives, COPD patients use slightly more eHealth and mHealth services than asthma patients and report higher levels of familiarity. This suggests that more widespread use of tools is feasible for COPD patients but there are other barriers to understand in promoting their use.

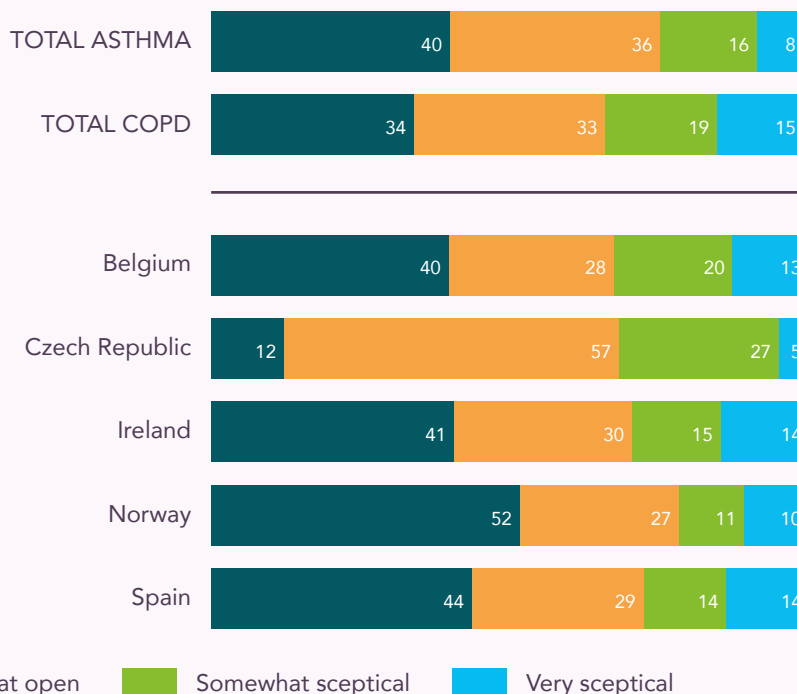


Doctors can examine us remotely, but they must be skilled – and they must know their patients

—
COPD patient from Czech Republic



Table 7. Asthma and COPD patients’ openness towards digital services and tools



Question 19: In general, how open are you to using digital services and tools in the context of your Asthma/COPD?
Basis: Total n=970, asthma n=506, COPD n=464 / BE n=200, CZ n=200, IE n=200, NO n=170, ES n=200

Evidence suggests patients in Norway are among the most tech-savvy while those in the Czech Republic are less familiar with digital tools, in parallel patients display greater openness to digital health in Norway, while Czechs are the most reluctant. This is likely the result of better integration of digital tools in healthcare over several years.

RECOMMENDATIONS FROM THE LEARNINGS ON COVID-19



POLICYMAKERS:

- Adopt digital health and public health policies that **increase asthma and COPD patient empowerment** in digital health and put them at the centre of decisions regarding their health through the sep up of Stakeholder Expert Groups attached to
- National Digital Authorities
- Share European **best practices on digital health frameworks**, processes and solutions that improve asthma and COPD clinical outputs
- Support the integration of **Patient Reported Outcomes** (PROs) arising from digital means, including evidence on ashtma and COPD patient quality of life
- Strengthen the **digital infrastructure** at regional, national and EU levels, to grant access to digital health services to all patients
- Invest in the **digitalisation of healthcare services for chronic respiratory diseases** to offer patients a broader range of chances and choices for self-management
- Incentivise patient use of digital health tools, establishing **reimbursement** and digital insurance frameworks and providing subsidies for digital devices for people living with chronic respiratory diseases
- Integrate **digital health** education, use and design in the medical curricula
- Accelerate the **cross-border application** of digital health services and tools to ensure seamless delivery of care



FOR HEALTHCARE PROVIDERS:

- Enhance digital health **lifecourse training** for healthcare professionals, including continued medical education for respiratory specialists in primary, secondary, and tertiary settings
- **Communicate** clearly about digital services and actively promote and offer appropriate options to patients
- Improve **patient familiarity** with digital tools through information and training sessions delivered by trusted professionals, such as respiratory nurses
- Partner with patient groups and medical societies to develop and disseminate **educational material** on the use of digital health in their disease area and engage in sustained dialogue with community groups and services



FOR THE DIGITAL SECTOR:

- **Identify the needs and areas of development** for patient-centered digital health, in close collaboration with asthma and COPD patients and healthcare providers
- **Co-design** and co-create with respiratory patients disease-specific digital health tools that offer real solutions to them. Tools that provide holistic digital services, responding to patients' disease and accessibility needs, and demographics
- Build solutions **using technologies that patients are already using**, to ensure interoperability, easier transition for the users, and lower costs for patients



FOR PATIENTS:

- Individual patients should proactively discuss with healthcare professionals about **digital health choices** to monitor and self-manage their disease
- **Patients should propose, participate in the evaluation, validation and recommendation of solutions** addressed to respiratory diseases
- Patient groups should **engage with digital health developers** to inform them about patient needs, use and expectations of digital health solutions
- Engage with professional medical societies to **disseminate evidence** showing patient interest in digital tools



COVID-19: CATALYST FOR THE DIGITAL TRANSITION IN HEALTHCARE





I was able to continue my treatment during COVID. I prefer the real thing, but it was better than nothing

—
Asthma patient from Belgium



COVID-19: CATALYST FOR THE DIGITAL TRANSITION IN HEALTHCARE

The sudden introduction of restrictions on travel and social gatherings in March 2020 had a significant effect on people with life-long lung conditions. As a novel respiratory virus spread globally, people with asthma and COPD faced added uncertainty and anxiety.

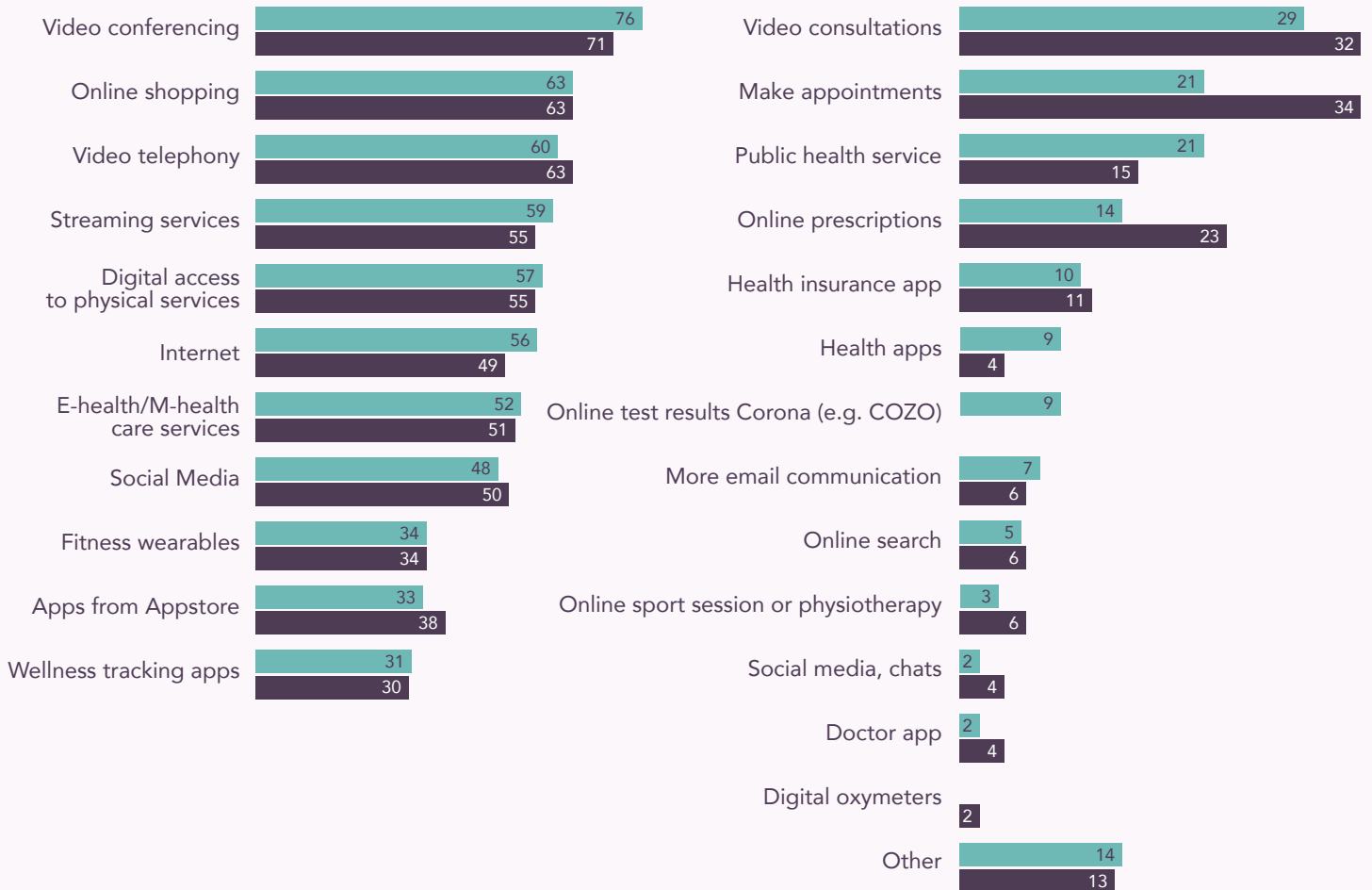
Face-to-face services, including medical appointments, were cancelled. For many, this moment of crisis was marked by a rapid shift to online tools for work, entertainment and healthcare – a move which helped preserve a degree of access to services while minimising personal contact. Remote medical consultations, enabled by phone and video conferencing platforms, quickly became the norm for patients previously diagnosed with chronic conditions, while the use of electronic prescriptions also grew^{41,42}.

Table 8. Asthma and COPD patients' reported increased use of digital services during COVID-19 pandemic

■ Asthma ■ COPD

Question 15a: In case your usage of digital devices and services has increased during the Corona pandemic. What usage has specifically increased?

Question 15b: Please indicate what exactly you have used more (or started using) during the Corona pandemic.



Basis for Q15a: Patients that use each specific service

Basis for Q15b: asthma n=58, COPD n=53

The survey, taken at a time when patients were beginning to look beyond the pandemic, explores this catalyst from a patient perspective to determine whether the use of digital health technologies is likely to continue as the acute phase of the pandemic fades. It finds that not only has the COVID-19 pandemic increased usage, but there are also signs of more positive attitudes towards digital services. This suggests that, rather than being a transient change in response to a short-term and exceptional crisis, the digital trend is here to stay and support healthcare services and delivery. Rather than being on the periphery of healthcare, the digital sector is now an integral part of the patient experience, creating new opportunities and responsibilities for the IT industry.

In patients with asthma and COPD, there is a clear increase in positive sentiment towards digital health services and devices. One in two asthma patients reported a more positive view of these tools over the past 12 months, while 41% of COPD patient say the same. It can be concluded that exposure to these technologies had a generally positive impact on attitudes.

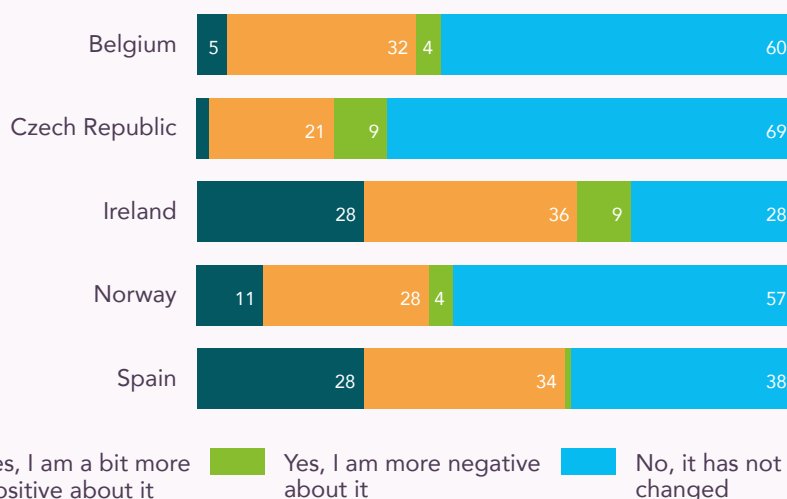
“

I've had three video calls with my consultant in the past year: check-ups, follow-up on blood test results, and tweaking medication

—
COPD patient from Ireland

”

Table 9. Changed attitudes towards digital devices and services due to the COVID-19 pandemic in different European countries



Question 15: Has your attitude towards digital devices and services changed in the last 12 months, due to the Corona pandemic?
Basis: Total n=970, asthma n=506, COPD n=464 / BE n=200, CZ n=200, IE n=200, NO n=170, ES n=200

Between nations were discerned a variety of attitudes, this in relation to the range of digital services and in the degree to which attitudes shifted. In Spain and Ireland, the range of digital services used increased most. In line with this, Spanish and Irish patients reported the highest increase in positive attitudes towards digital devices and services (64% and 62%, respectively). For Norway, the increase in usage is relatively low, but this is likely to be due to Norway's higher level of use of digital tools prior to the pandemic.

The increase in usage of digital health is lowest in the Czech Republic. The relatively low use of digital tools in the Czech Republic is also reflected in Czech patients' infrequent use of eHealth and mHealth services.

Patients in need of care will use whatever channels and tools are available to ensure their needs are met. While the use of digital services increased out of necessity, the patient population was ready to embrace the change in order to ensure continuity of care. Rather than seeing an increase in scepticism among patients towards digital tools, familiarity with them led to greater acceptance. In short, the more people use digital health, the more they seem to like it.

“

I had a video call with a psychologist to manage mental health issues during the lockdown

—
COPD patient from Ireland

”

For policymakers, one of the lessons from the pandemic is that when research is tightly connected to implementation – for example when vaccine science is swiftly translated into policy action – public buy-in is strongest. Meanwhile, the positive experience with digital prescriptions has illustrated to healthcare professionals that digital tools can make constructive contribution to improving the patient experience as well as the efficiency of health systems. COVID-19 also showed that the digital sector now has an established role both in everyday healthcare and in responding to health emergencies.

RECOMMENDATIONS ON THE DIGITAL TRANSITION OF HEALTHCARE



FOR POLICYMAKERS:

- Invest in **health emergency preparedness and response** based on an expanded use of digital means for the delivery of care in chronic patients, including targeted processes and tools to follow up at the post-diagnosis stage and through broad operational partnerships with civil society organisations such as patient groups
- Develop **crisis communication plans** to respond to health crisis with specific messages addressed to vulnerable groups and respiratory patients
- Invest in **digital systems for public health education** by identifying a set of trusted sources of information, solid health networks and crisis communications plans developed during quiet times



FOR HEALTHCARE PROVIDERS:

- Build capacity and knowledge in digital technology to create resilient healthcare systems to sustain chronic management and care. This requires thorough **planning** of minimum chronic care services and the availability of digital health and care
- **Educate and train healthcare professionals** to deliver non-urgent prevention and care through digital means
- Enable **nurses** to liaise with chronic respiratory patients during health emergencies, and support their function with emergency interventions from social services and patient groups
- Test **patient-to-patient training** as a means of familiarising patients with technologies and reducing fear of the unknown
- Provide smooth **access to eHealth during emergencies**, through pre-agreements on reimbursement for digital



FOR THE DIGITAL SECTOR:

- Support healthcare providers and academia in building **population-based data systems** to health
- Become a **frontline sector responding to health emergencies**, by adapting existing telehealth to a broader digital use



FOR PATIENTS:

- Request a **written self-management plan** from your doctor and make it digital
- Become a member of a **patient organisation** and develop a support network
- Familiarise yourself with digital solutions and technologies by **accessing digital health services** such as online physiotherapy, electronic consultations and prescriptions during non-emergency times



THE ASTHMA AND COPD PATIENT JOURNEY IN A DIGITAL AGE



THE ASTHMA AND COPD PATIENT JOURNEY IN A DIGITAL AGE

“

Now I make my appointments online and ask for electronic prescriptions to be sent directly to the pharmacist

—
COPD patient from Belgium

”

“

I use a digital oximeter, linked to Bluetooth to my tablet. I can send the results to my GP or the hospital

—
COPD patient from Ireland

”

When patients embrace digital technologies, satisfaction is high. However, awareness of key digital respiratory devices is low, and uptake varies widely among countries

The patient journey is the entire sequence of events that a patient experiences within the healthcare system. It entails all the interactions between patients and the healthcare system: access, diagnosis, treatment, adherence, education, and behavioural changes. Understanding this pathway is essential to identifying areas and methods in which digital technologies can deliver improvements. At every step of this journey, the medical technology and IT industry has developed a growing range of tools for people living with chronic respiratory disease.

People with asthma and COPD can benefit from practical services, such as online booking systems, as well as more sophisticated digital peak flow devices to measure their lung function and connected asthma inhalers to take their medication. In addition, new apps and wearables have opened up unprecedented possibilities for monitoring, that help reduce the risk of exacerbations and create opportunities for early intervention at the first sign of a deterioration in a patient's condition.

The trouble is that the use of many of these digital options remain low for patient use. The picture is a little brighter for digital diagnosis than for technologies used in disease management, but overall uptake is hampered by poor awareness. Among patients who do not use digital tools, some are aware of these technologies but prefer not to use them. Most of those not currently engaging with digital care are simply unaware that this option is available to them. On the other hand, where patients have embraced digital tools and technologies, satisfaction is high.

As described earlier in this paper, it appears that there is a large cohort of patients open to using technologies – who would most likely enjoy the benefits of these innovations. If issues of access, cost and familiarity are addressed, there is real potential to offer patients tools that would improve their healthcare experience. It is also clear that healthcare professionals play a key role in the use of digital tools. By offering or recommending specific technologies, and familiarising patients with how they work, physicians and nurses can be trusted guides to the large – and sometimes – non-patient-centric range of technologies on the market.

Awareness and usage of digital diagnostics is low

Overall, awareness of digital diagnostic tools and services is quite low apart from online searches and appointment booking. This is equally true for asthma and COPD patients, although awareness and accessibility of digital offerings in diagnosis is generally greater among asthma patients. Awareness of digital peak flow, which is used to monitor patient lung function capacity, or spirometry, which can determine the degree of airway obstruction, is much more limited. This must be addressed by policymakers and healthcare professionals if patients are to embrace new technologies.

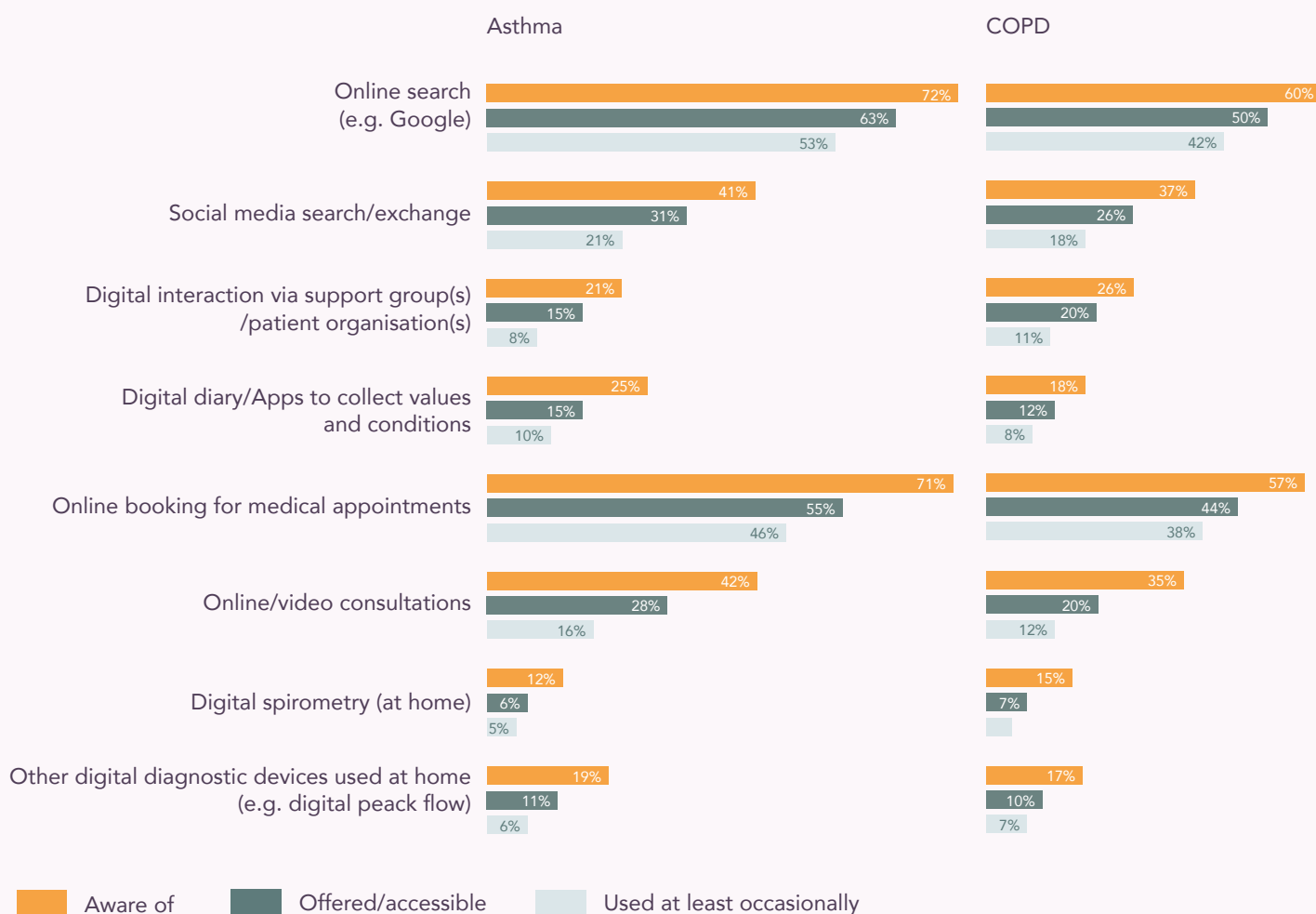


When the doctor can listen to your chest, it's better. That can't be done online

Asthma patient from Ireland



Table 10. Asthma and COPD patients' use of digital tools and services to diagnose respiratory disease



Question 22: Which ones are you aware of? Which of these are offered or accessible for you, regardless, if you use them or not? Do you use them and if yes, how often do you use them?
 Basis: asthma n=506 COPD n=464

“

I would like to be offered more tools to use to control my illness

—
COPD patient from Spain

”

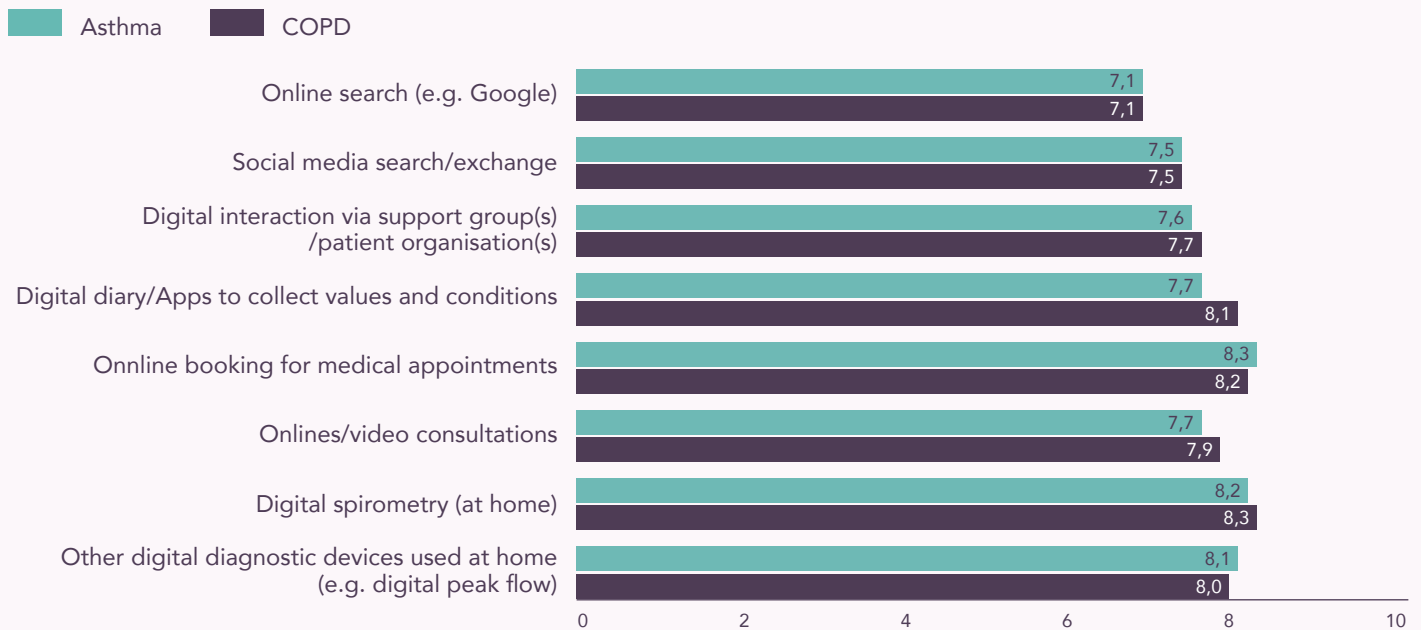
Patients may not use digital tools, despite high levels of awareness

Awareness does not always translate into uptake. Consider online booking systems, for example. The majority of patients are aware of this service but only 16% of asthma patients and 18% of COPD patients use this regularly. Similarly, while awareness of video conferencing reaches 42% among asthma patients, only 3% use this feature frequently with a further 13% saying they use video consultations occasionally. The reasons for sub-optimal uptake are teased out in the later section on barriers to usage, but one thing is clear: cost is not a major deterrent. Most respondents report that they are fully or partially reimbursed for the cost of digital tools that they use.

Patients who have tried digital technology like it

Self-management is critical to the treatment and management of asthma⁴³. For example, the self-monitoring of asthma with a connected mobile spirometer is feasible, safe and satisfactory for patients with asthma, yet it remains to be established whether unsupervised home spirometry measurements improve early diagnosis and outcomes of self-management in cases of exacerbation or loss of asthma control⁴⁴. Patients and health systems can benefit from self-management by improving clinical outcomes, quality of life and reducing the costs of chronic conditions such as COPD⁴⁵.

Table 11. Level of asthma and COPD patients' satisfaction with digital tools and services for diagnosis



Question 22e: How satisfied are you with the tools you have used?

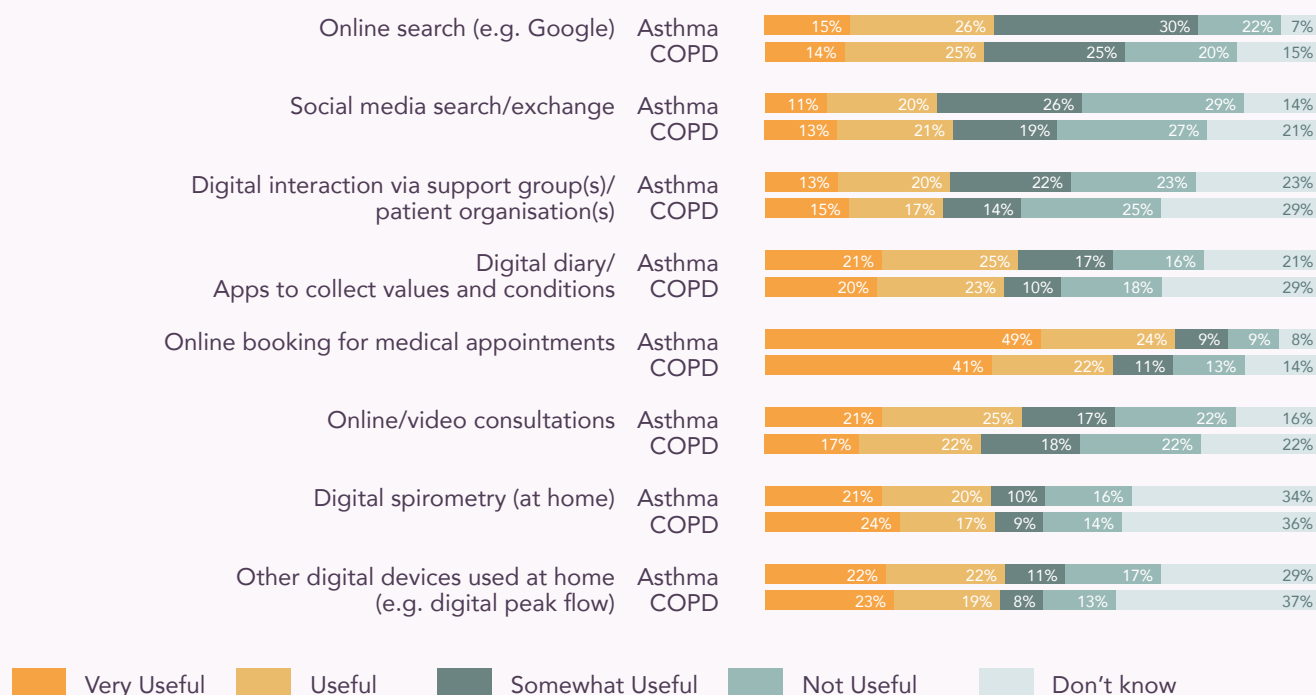
Basis: All patients who declare using the specific healthcare service

Most patients are not using digital tools and services to diagnose asthma or COPD. However, for those who have experience with these technologies, the verdict is in: they like it. Based on the minority of asthma patients who have tried online tools, digital booking systems, digital spirometry and other devices that can be used at home (such as digital peak flow devices), support is strong. For digital spirometry – a technology for which awareness and usage are low – satisfaction ratings hit 8.2 out of 10. It's the same story for COPD patients: most have never used a digital spirometer or peak flow device, but those who have report positive experiences.

Convenience is an attractive feature of new technologies

As in other aspects of life, the most appealing aspect of any digital tool is its convenience: if it makes our lives easier, we will use it. This explains the strongly positive rating of systems such as online appointment booking which a solid majority of patients with asthma (73%) and COPD (63%) view as useful. This is a clear signal that increasing the uptake of existing digital tools depends on how convenient they are for patients. Similarly, this should be kept in mind when developing new technologies. This can best be achieved by involving patients from the start.

Table 12. Asthma and COPD patients' perception of the usefulness of digital solutions for diagnosis



Question 23: Where do you feel digital options are specifically useful when it comes to diagnostics? Please use a 1-4 scale, where 1 means 'not useful at all' and 4 means 'very useful'.

Basis: asthma n=506, COPD n=464

National differences: past investments pay off

In keeping with earlier results, the findings for the usage of digital diagnostic tools are not universal across the five countries surveyed. When it comes to online booking systems or the use of video consultations, there is a clear frontrunner: Spain. Patients in Spain, supported by their healthcare providers, are much more likely to have integrated these tools into their diagnostic experience. This reflects previous investments in digital services and connectivity⁴⁶.

While the figures for Ireland and Norway are also high, awareness and accessibility of digital offerings for diagnosis is markedly lower in the Czech Republic – continuing the trend emerging from the data which suggests Czech asthma and COPD patients are the least likely to use digital tools. Czech respondents are also least likely to rate digital technologies as highly useful.

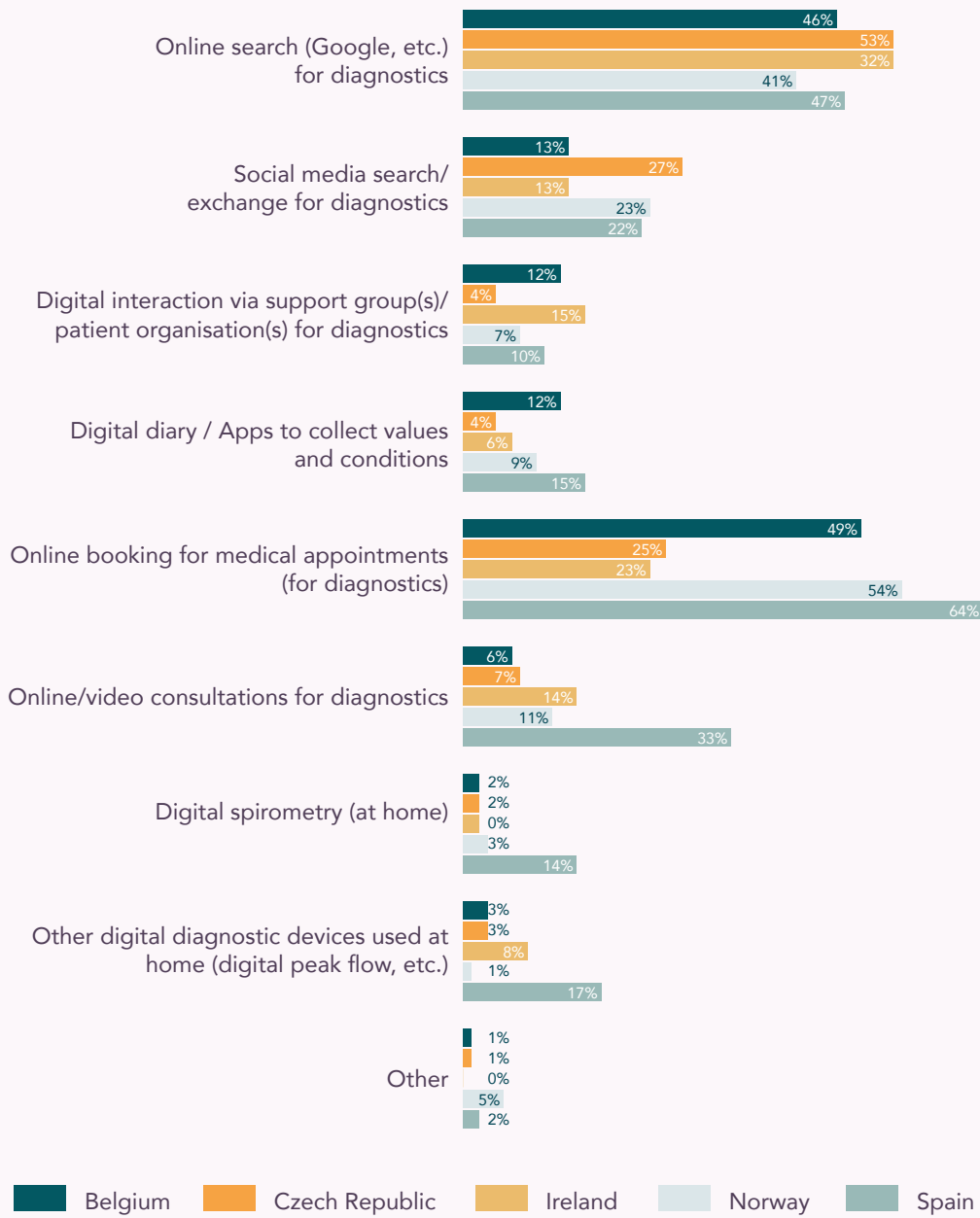
“

It does have advantages when it comes to making appointments and talking to the doctor, but he prefers to go physically to the examination

Asthma patient from Ireland

”

Chart 2. Use of digital tools and services to diagnose asthma or COPD



Question 22c: Do you use digital health solutions for diagnosis and if yes, how often do you use them?

Basis: Total n=970, asthma n=506, COPD n=464 / BE n=200, CZ n=200, IE n=200, NO n=170, ES n=200

“

It's not always easy to get an appointment with my doctor so if I could see him faster online, I'd jump at the chance

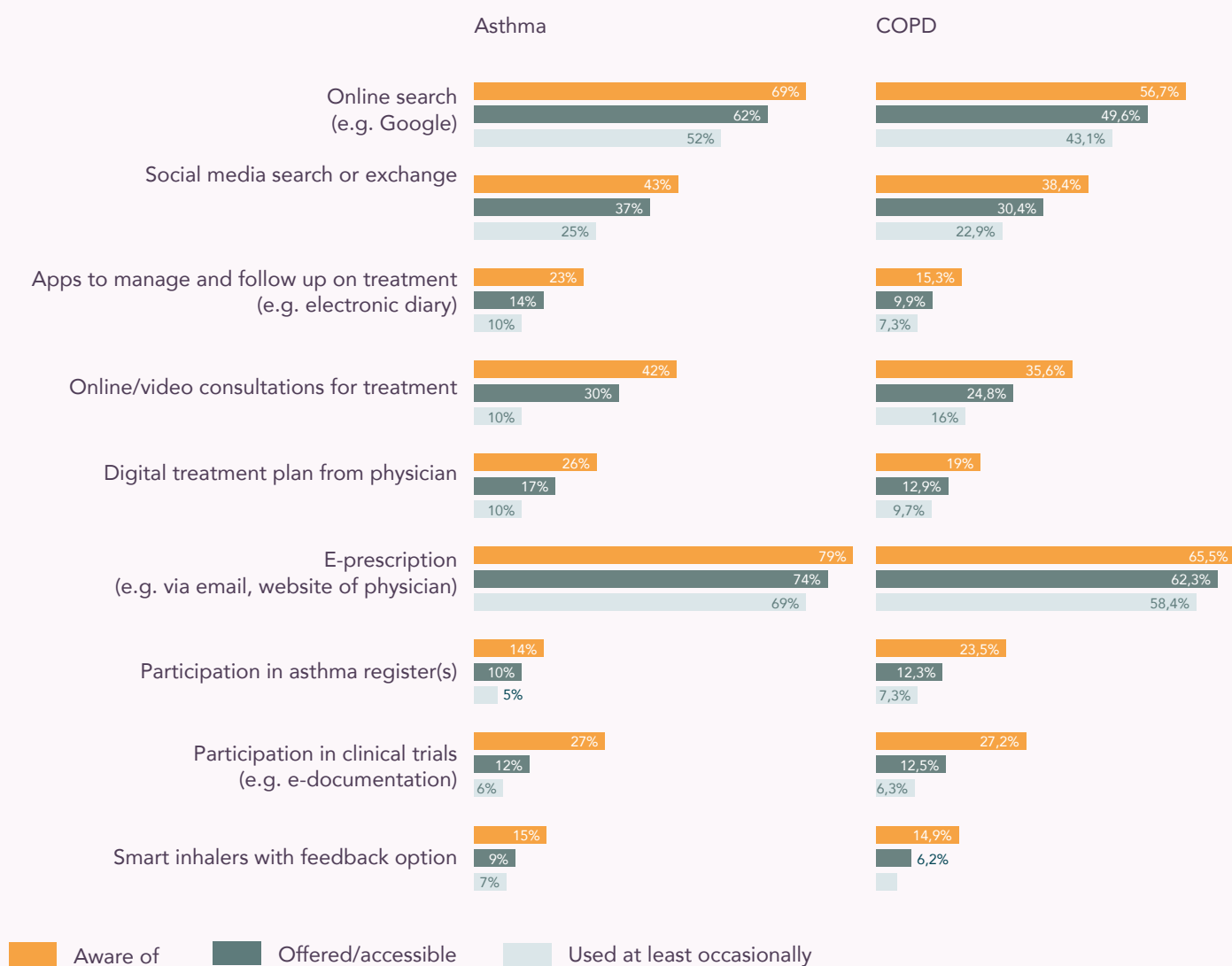
— Asthma patient from Ireland

”

Digital tools in asthma and COPD treatment

When it comes to the use of digital tools in treatment, the key takeaways from the survey echo the findings for digital diagnostics. Awareness and usage are strong, but only for a limited number of tools and, again, Spanish patients are the most likely to use new technology. E-prescriptions are now an everyday fact of life for a majority of people with asthma and COPD. Of course, these are tools that can be used by patients being treated for any condition, reflecting a broader shift to digital healthcare. Meanwhile, the use of disease-specific technologies, such as smart inhalers and disease management apps, is considerably less common.

Table 13. Asthma and COPD patients' use of digital tools and services to treat respiratory disease



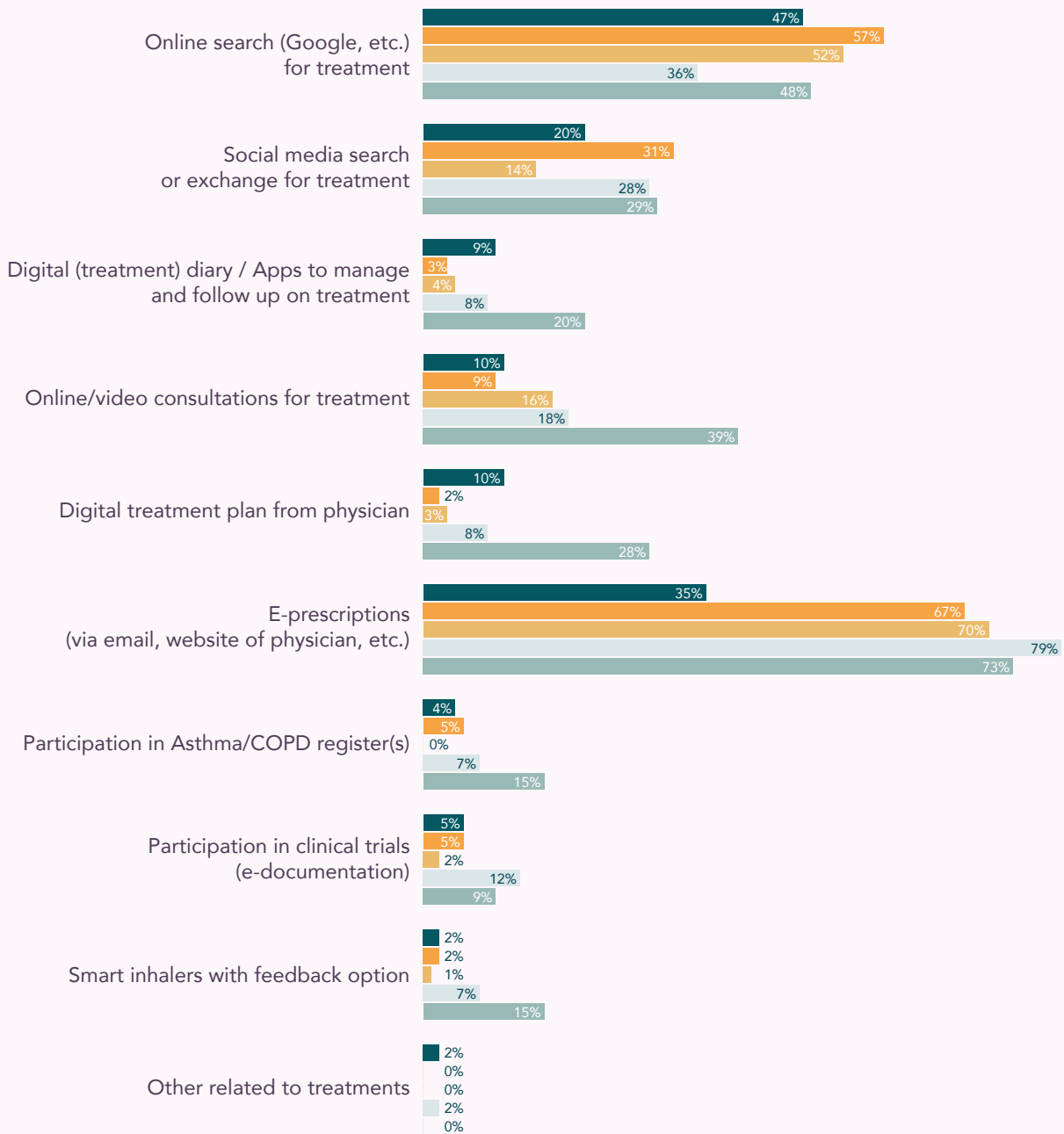
Question 24: Which ones are you aware of? Which of these are offered or accessible for you, regardless, if you use them or not? Do you use them and if yes, how often do you use them?

Basis: Total n=970, asthma n=506, COPD n=464 / BE n=200, CZ n=200, IE n=200, NO n=170, ES n=200

Ranges of use: early adopters versus laggards

Once again, Spain is ahead of the pack. In fact, it appears to be the only country of the five included in the DIG_IT survey where digital services – aside from social media and online prescriptions – are used to a significant degree. Spain shows a higher uptake of digital treatment diaries and applications, video consultations and online treatment plans devised by physicians.

Chart 3. Use of digital tools and services to treat asthma or COPD



Legend: Belgium (dark teal), Czech Republic (orange), Ireland (yellow), Norway (light blue), Spain (medium teal)

Question 24c: Do you use digital health solutions for treatment and if yes, how often do you use them?

Basis: Total n=970, asthma n=506, COPD n=464 / BE n=200, CZ n=200, IE n=200, NO n=170, ES n=200

Patients in most countries say their use of digital tools for disease management are usually reimbursed, with lower reimbursement rates for the use of apps and smart inhalers. Moreover, online connectivity does not appear to be a key factor in shaping uptake of digital health: 94% of respondents have a good or very good internet connection, and the majority have a computer or smartphone (87% and 91%, respectively).

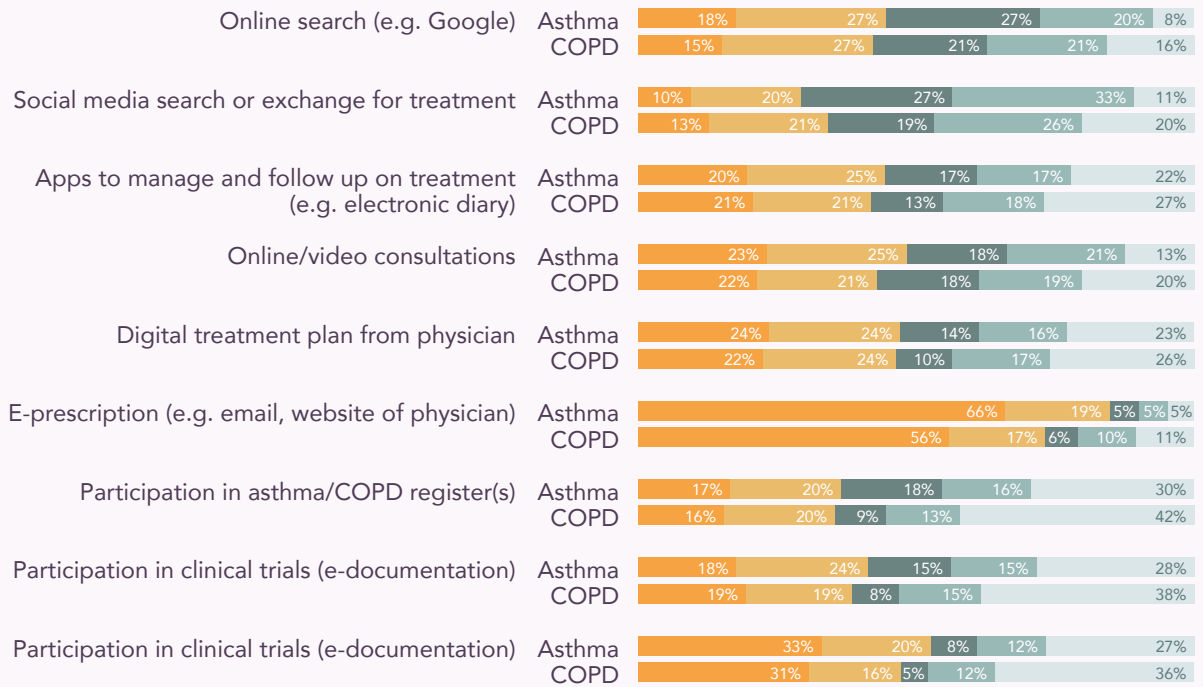
When looking at the results from patients in the other countries surveyed a few results stand out. A notable outlier in the data collected is the relative lower use of e-prescriptions in Belgium, despite generally good awareness of digital tools. However, the situation in Belgium may improve following the introduction of new rules in September 2021 allowing general practitioners to stop giving paper prescriptions by default⁴⁷. Furthermore, Irish patients report lower usage of social media for seeking information on treatment. Finally, Norwegian patients reported being less inclined than others to use online search engines to inform treatment decisions. This finding is at odds with previous surveys showing Norwegians to be more inclined than other Europeans to seek health information online⁴⁸. The DIG_IT survey's finding that 48% of respondents use search engines to seek treatment information is in line with previously findings showing one in two EU patients searches for health information.

However, the situation in Belgium may improve following the introduction of new rules in September 2021 allowing general practitioners to stop giving paper prescriptions by default⁴⁶. Furthermore, Irish patients report lower usage of social media for seeking information on treatment. Finally, Norwegian patients reported being less inclined than others to use online search engines to inform treatment decisions. This finding is at odds with previous surveys showing Norwegians to be more inclined than other Europeans to seek health information online⁴⁸. The DIG_IT survey's finding that 48% of respondents use search engines to seek treatment information is in line with previously findings showing one in two EU patients searches for health information.

Strong satisfaction with e-prescriptions and demand for smart inhalers

Levels of satisfaction with digital tools and services is generally high, notably for e-prescriptions. This service is also considered to be by far the most useful digital offering. Again, the message is plain: patients are willing and ready to use digital technologies that they find to be beneficial. Strikingly, one in two patients considers smart inhalers to be a useful digital tool – a significant number given the relatively low current usage of these technologies.

Table 14. Perceived usefulness of digital solutions to treat asthma and COPD



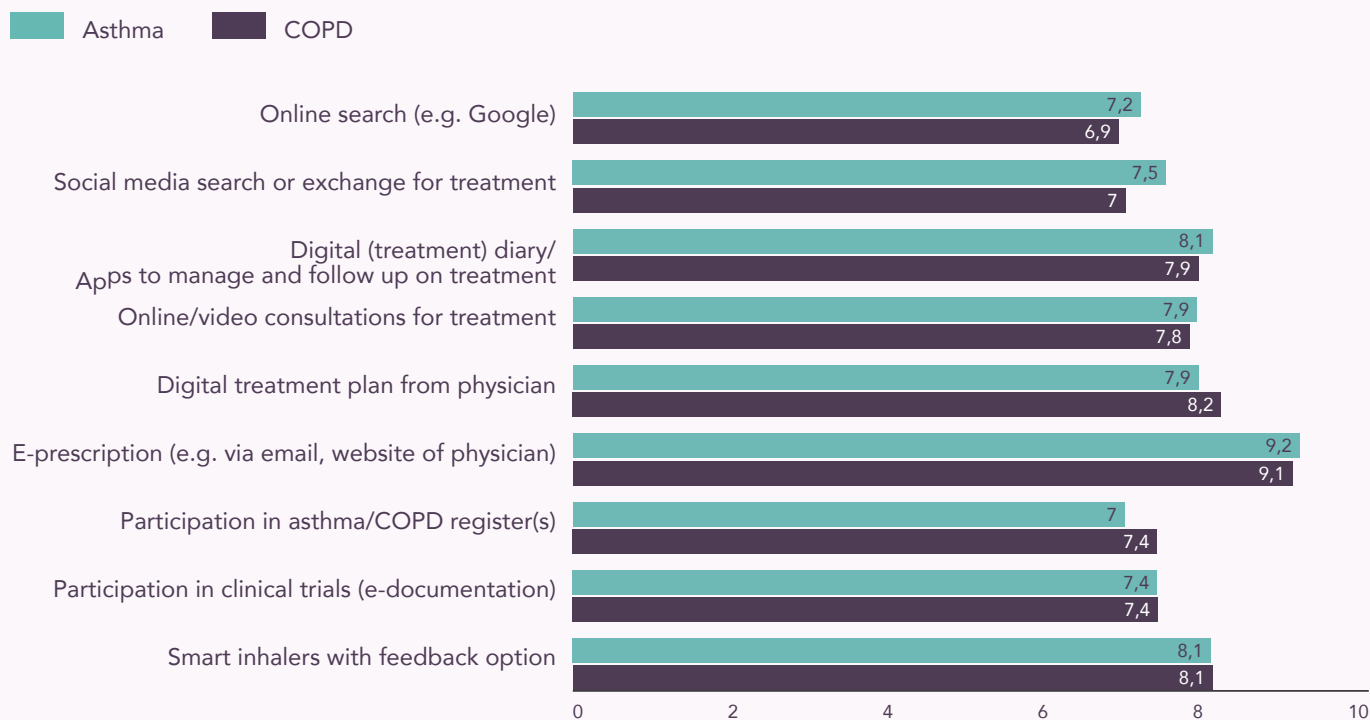
Very Useful Useful Somewhat Useful Not Useful Don't know

Question 25: Where do you feel digital options are specifically useful when it comes to the treatment for asthma/COPD? Please use a 1-4 scale, where 1 means 'not useful at all' and 4 means 'very useful'

Basis: asthma n=506 COPD n=464

Despite rather low levels of use, patients in most countries consider digital options for treatment to be useful. According to chart 3, ratings are especially high for patients in Ireland and Spain. As before, the benefit of digital solutions is rated lowest in the Czech Republic. (When interpreting the figures for Norway, it should be noted that many respondents did not express an opinion and that the overall response level is therefore low.)

Table 15. Patients' satisfaction with digital tools and services used for treatment



Question 24e: How satisfied are you with the tools you have used? Please use a 1-10 scale, where 1 means 'I am not satisfied at all' and 10 'I am extremely satisfied'?

Basis: All patients who declare using the specific healthcare service

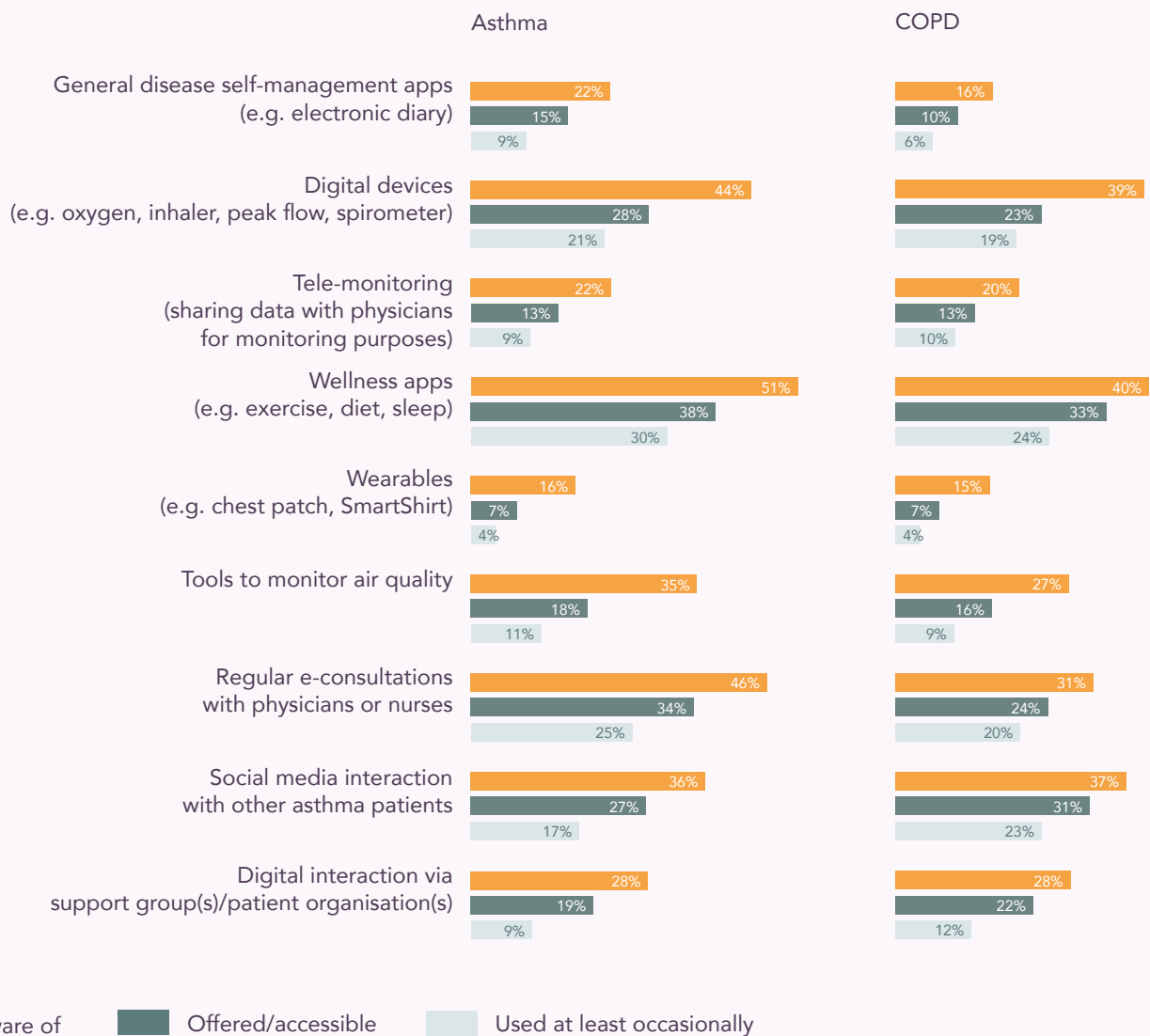
Many patients are unaware of digital care

The DIG_IT survey investigated how patients' perceived the use of digital tools and services to manage care for their respiratory conditions.

Digital technologies are least commonly used in the 'care' part of the patient journey. Compared to digital diagnosis and treatment, digital care is barely on the radar. In fact, for both COPD and asthma patients, awareness of digital care solutions is low and access to these technologies is even lower. The most familiar and accessible digital care tools are general health apps, digital devices, electronic consultation, and interaction with peers on social media. However, frequent users of these tools constitute a small minority of the patient population.

Intriguingly, while asthma patients generally enjoy better awareness and access than COPD patients, the latter has more social media interaction with peers from the patient community. Given the age profile of COPD patients – who tend to be older than people with asthma – this may be surprising, but it reflects the fact that people with COPD use digital tools to avoid the loss of human contact. These observations are also reflected in a United States of America study indicating that chronic disease patients aged above 50 years of age show an increase in online search for information⁴⁹.

Table 16. Asthma and COPD patients' use of digital tools and services to manage care for respiratory disease



Question 26: Which ones are you aware of? Which of these are offered or accessible for you, regardless, if you use them or not? Do you use them and if yes, how often do you use them?

Basis: asthma n=506 COPD n=464

In terms of national differences, the spectrum of volumes of people who use digital tools/services to manage the care of their respiratory conditions is highest in Spain and lowest in Czech Republic (we refer to this as 'from technophiles to technophobes'). In Spain, two-thirds of the patients surveyed are aware of digital devices such as electronic inhalers, and one in two say they have access to such devices. Conversely, both awareness and access in the Czech Republic are much lower. Belgium and Ireland indicate higher numbers of people showing awareness and accessibility for digital interaction via support groups and social media.

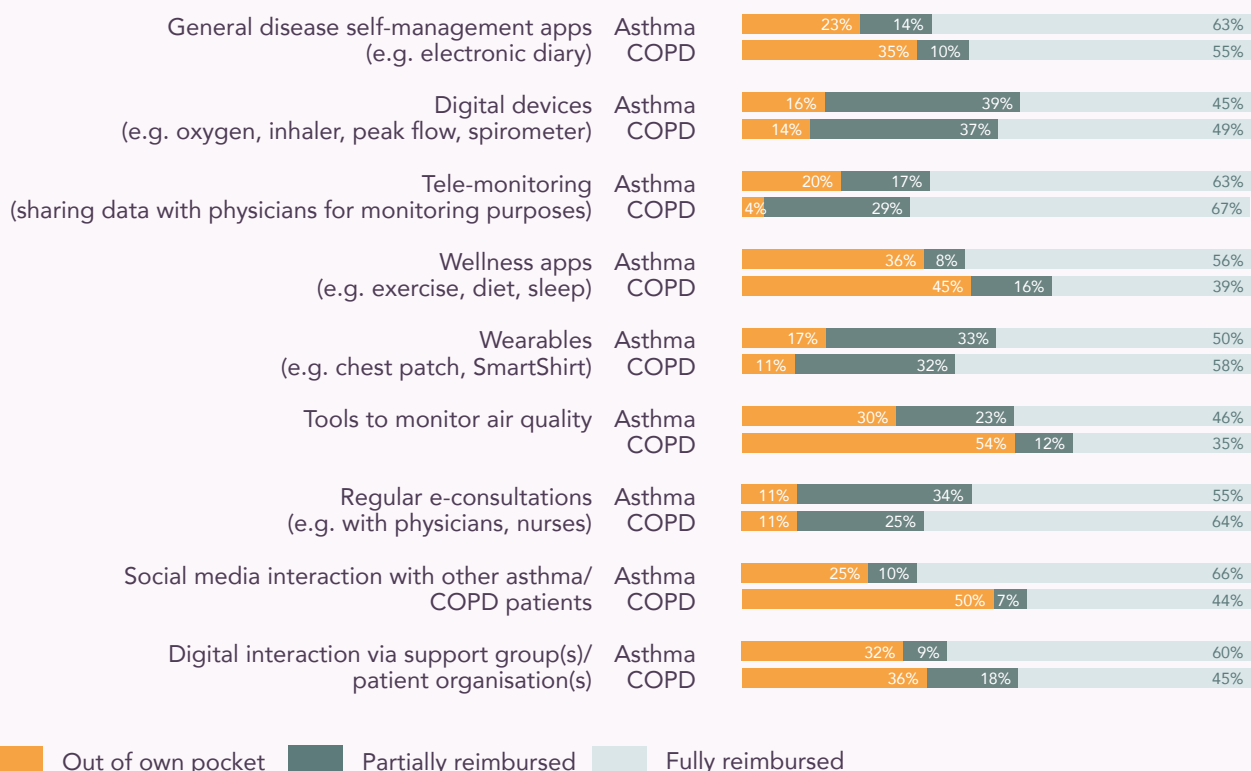
Most patients do not use digital tools for care

Only a handful of asthma and COPD patients frequently use digital technologies in their care. The highest level is among asthma patients (16%) for general health apps, and among COPD patients for digital devices (13%) and general health apps (14%).

Paying for apps leave patients out of pocket

The share of costs covered by patients themselves appears to be the highest in digital care. Namely costs for general health apps and tools to monitor air quality (COPD), are paid in large by the patients themselves which may be a factor in low patient reported use of digital tools for care.

Table 17. Reported reimbursement of costs for digital tools and services in asthma and COPD care



Question 26d: Do you have to pay for this service fully out of your own pocket, with partial re-imbusement or does it get fully reimbursed?

Basis: All patients who declare using the specific healthcare service

“

I have learned to live with my asthma so I feel that I do not need any of the digital tools offered today

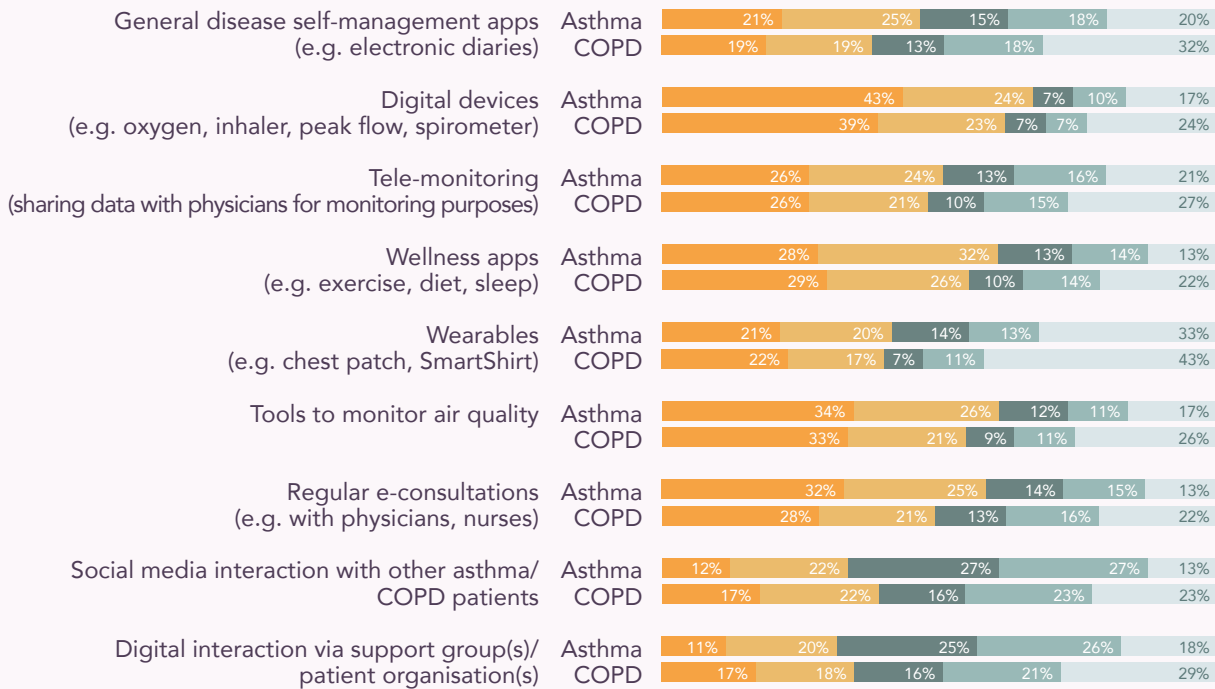
— Asthma patient from Norway

”

Digital devices rated most useful

Although most patients are not using digital tools in their care, those who do report high satisfaction levels. In this cohort of digital care users, digital devices for oxygen, inhalers, and peak flow are considered most useful. This is especially true for Spain, Ireland and Belgium, with Czech patients rating digital tools for care as least useful. Given that these tools are viewed positively but are not widely used, access may likely be the key barrier to uptake.

Table 18. Perceived usefulness of digital solutions to manage care for asthma and COPD



Very Useful Useful Somewhat Useful Not Useful Don't know

Question 27: Where do you feel digital options are specifically useful when it comes to care for asthma/COPD? Please use a 1-4 scale, where 1 means 'not useful at all' and 4 means 'very useful'

Basis: asthma n=506 COPD n=464

“

We are even more isolated with our diseases and human contact is essential in recurrent diseases

— COPD patient from Belgium

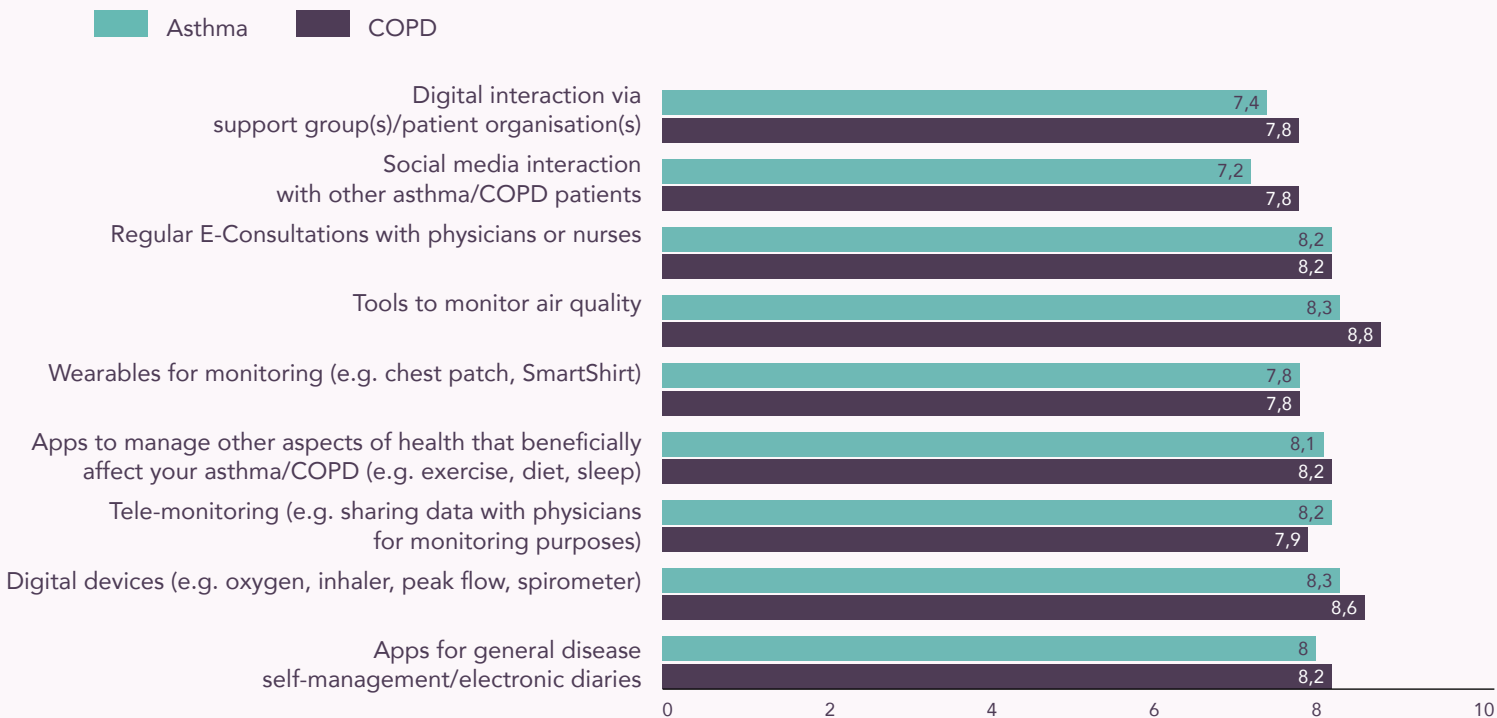
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Patient satisfaction: new technologies can drive empowerment

Most patients are broadly satisfied with their disease management and feel personally involved in their wellbeing. However, almost two thirds believe there is scope for further empowerment through digital solutions. The remaining one third is not sure. For the digital sector, this highlights opportunities for innovations that empower patients, as well as the need for raising awareness and delivering training to users. However, if the digital sector is to succeed in improving its uptake of digital tools they need to address the factors that affect satisfaction.

Satisfaction seemed to differ depending on the demographics of the respondents. Overall, female respondents expressed lower levels of satisfaction than males. The divide was also present when looking at age with older patients reporting lower satisfaction than younger patients. Socio-economic status also appears to determine satisfaction, satisfaction rates were higher among those with higher incomes than those with lower incomes. Education also a factor in patient satisfaction with those with higher education levels reporting higher rates.

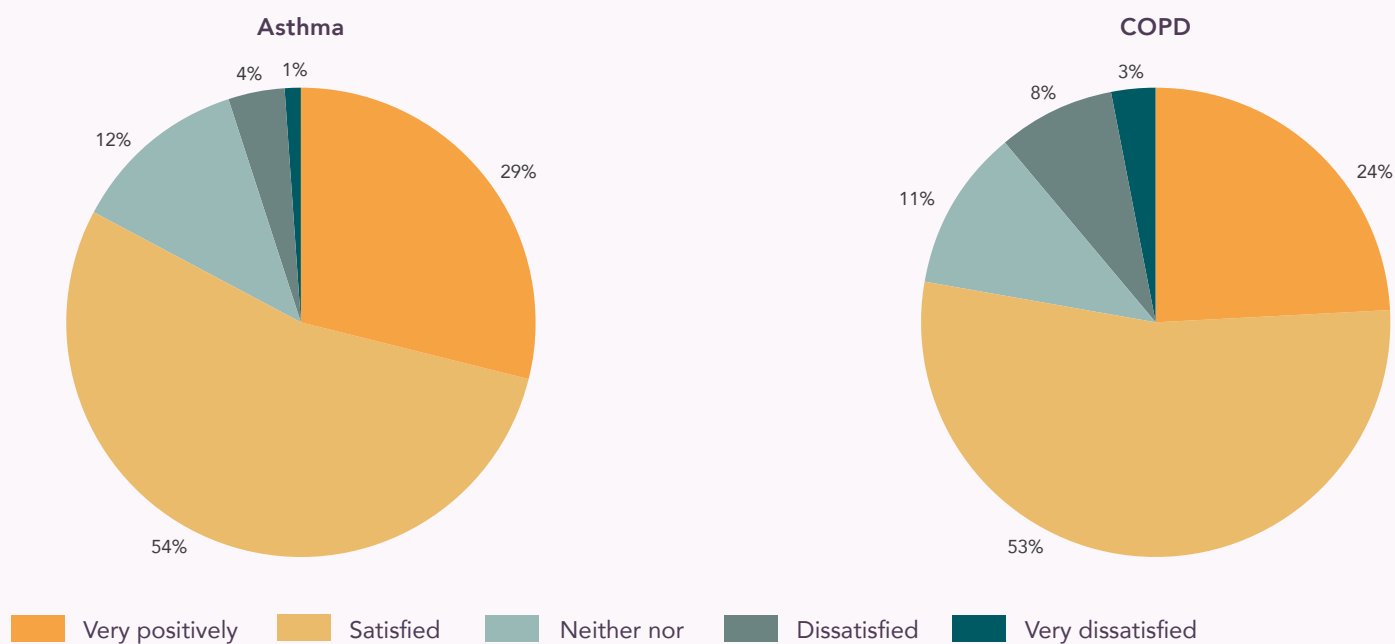
Table 19. Patients' satisfaction with digital tools and services used for care management



Question 26e: How satisfied are you with the tools you have used? Please use a 1-10 scale, where 1 means 'I am not satisfied at all' and 10 'I am extremely satisfied'?

Basis: All patients who declare using the specific healthcare service

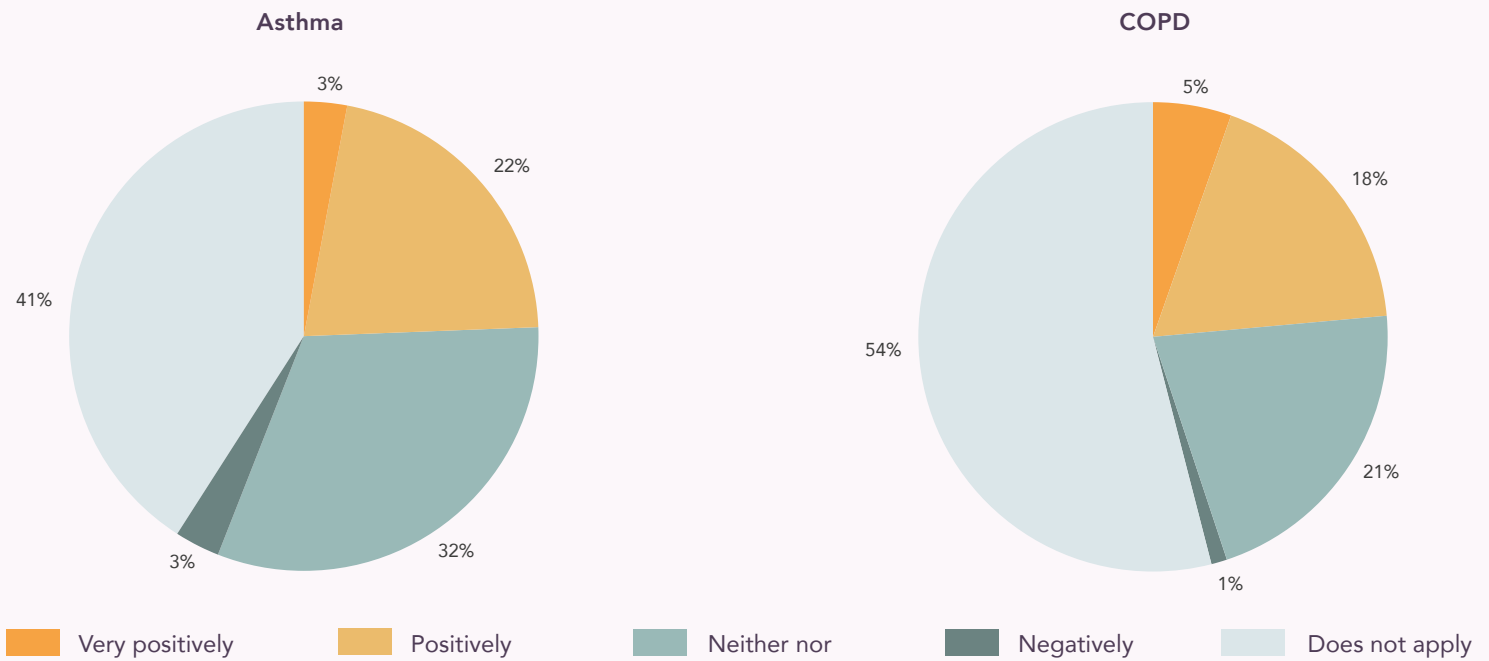
Chart 4. Asthma and COPD patients' satisfaction with how their disease is currently managed



Question 37: Overall, how satisfied are you with your current disease management?

Basis: asthma n=506, COPD n=464

Chart 5. Asthma and COPD patients' perceived impact of digital services and tools on their health



Question 38: Would you say that the usage of digital services and tools has overall impacted your health condition?

Basis: asthma n=506, COPD n=464

Lack of awareness and access prevent some patients from 'going digital'?

Those using digital services and tools see benefits for their health and are embracing new opportunities to connect with providers and to move care to locations convenient to them – outside the clinic or hospital. However, many experience fundamental barriers such as awareness and accessibility which impede their ability to embrace. This section explores some of the spontaneous reasons patients gave for not using digital tools and services. (Further analysis of future barriers and drivers are addressed in page 48)

The most cited barrier is lack of knowledge and availability but one cannot neglect that there is also a sizeable minority (25% and 17% of asthma and COPD patients, respectively) who simply do not see the need for using digital devices. 16% of all respondents express a preference for personal contact, while COPD patients also cite a lack of skills and devices as a reason for not opting in.

“

I wish devices were more available in Belgium, we are lagging behind in comparison to the Netherlands

—
COPD patient from Belgium

”

RECOMMENDATIONS ON THE ASTHMA AND COPD PATIENT JOURNEY IN A DIGITAL AGE



POLICYMAKERS:

- Policymakers should ensure that commercialised digital technologies are **evidence-based and effective** in delivery to patients, using such indicators as: quality of care, convenience, and the prospect of better outcomes. Non-evidence-based solutions should be better regulated
- Policymakers and payers should increase the uptake of high-quality apps and devices by **offering reimbursement for patients and incentives for healthcare providers** who transition their care services to also offer digital health services
- Digital healthcare tools and services should be **reimbursed according to the appropriate scheme** for diagnosis, treatment, and management of respiratory disease



FOR HEALTHCARE PROVIDERS:

- **Monitor and refer patients who use digital devices and programmes** according to their clinical outcomes, and always monitor and adjust digital management plans at each consultation
- Encourage physicians and nurses to best become acquainted with the upcoming vast range of devices and which ones are worth recommending.
- In line with patient preference for training by healthcare professionals, **ensure clinicians have the capacity to deliver education and coaching** to service users
- Increase the use of digital tools in **physiotherapy services**
- Enhance **awareness and accessibility of digital tools** designed to be used in patient care rather than in diagnosis
- Build on **patients' positive experiences** with online tools to raise awareness and uptake of advanced digital tools



FOR THE DIGITAL SECTOR:

- Seek **patients and patient organisations** in planning committees to discuss phases and areas in the respiratory care pathway where innovation is most needed
- Involve patients in developing standards/standardisation
- Engage with patients in concrete planning and design procedures of new apps and devices and via use of "design methodologies"
- Offer patients tools and services that are **embedded in the patients' lives**, which include digital management plans and are designed to improve their health outcomes and user experience, through Patient-Reported Outcome (PROs) and Patient-Reported Experience Measures (PREMs)
- Seek user-patient input and evaluation through ePolls and eSurveys



FOR PATIENTS:

- Communicate about the **benefits of digital health** such as access to a range of diagnosis, treatment and management formats, and how daily engagement with digital tools can change the relationship with healthcare professionals and hugely boost patient **self management**
- Inform patients about **access to basic equipment** or tools to enable self monitoring at home
- Participate in the development of digital tools through **partnerships with companies** and focus on substantial problems and unmet needs



HEALTH DATA IN ASTHMA AND COPD: BALANCING EMPOWERMENT WITH PRIVACY



HEALTH DATA IN ASTHMA AND COPD: BALANCING EMPOWERMENT WITH PRIVACY

Patients view personal health data as highly sensitive information, with many having concerns about privacy and security.

Privacy is the dilemma of our time: people want a data-driven, personalised service, but are uneasy about handing over personal information. Nowhere is this tension more acute than in the health sector. People's individual and collective hesitancy to hand over their own data explains, at least in part, why healthcare lags behind other sectors in embracing the tools of the digital age⁵⁰. The public at large feels more comfortable about sharing sensitive data with banks and insurance companies than it has been to hand over personal health details, especially when patients perceive a risk of discrimination and stigmatisation arising from their health status.

Part of the problem with personal health data handling is a lack of trust, as well as a sense that sharing data may not bring clear benefits to the individual. Banks have generally managed data well and consumers rarely incur losses arising from information sharing. The benefits – the ability to securely transfer funds online or purchase items with a credit card – outweigh the perceived risks. In healthcare, patients are not always certain who holds the data in which part of their health records; they may worry about how careful a commercial app developer is with the data they collect. On the other side of the equation, patients need to see personal benefits to data sharing if they are to take the leap into using more data-driven services.

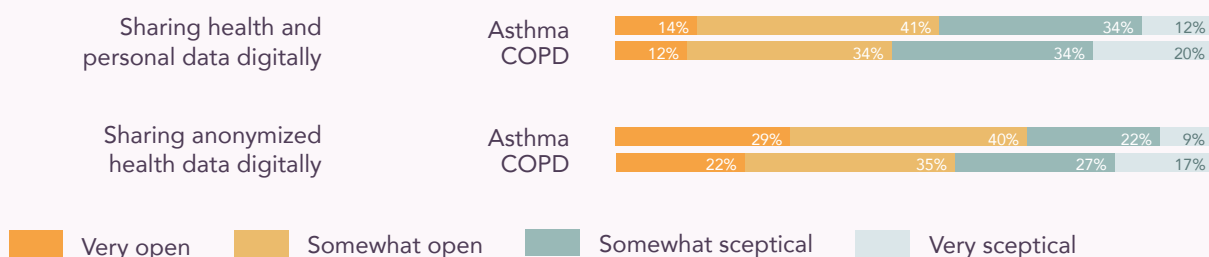


The one thing that would concern me would be privacy issues and hacking

— Asthma patient from Ireland



Table 20. Asthma and COPD patients' views on digitally sharing health and personal data



Question 32: How do you feel about digitally sharing health and personal data?

Question 33: And how do you feel about digitally sharing anonymized health data?

Basis: asthma n=506, COPD n=464



From a security point of view,
I'm afraid of sharing too
much data

—
COPD patient from Ireland

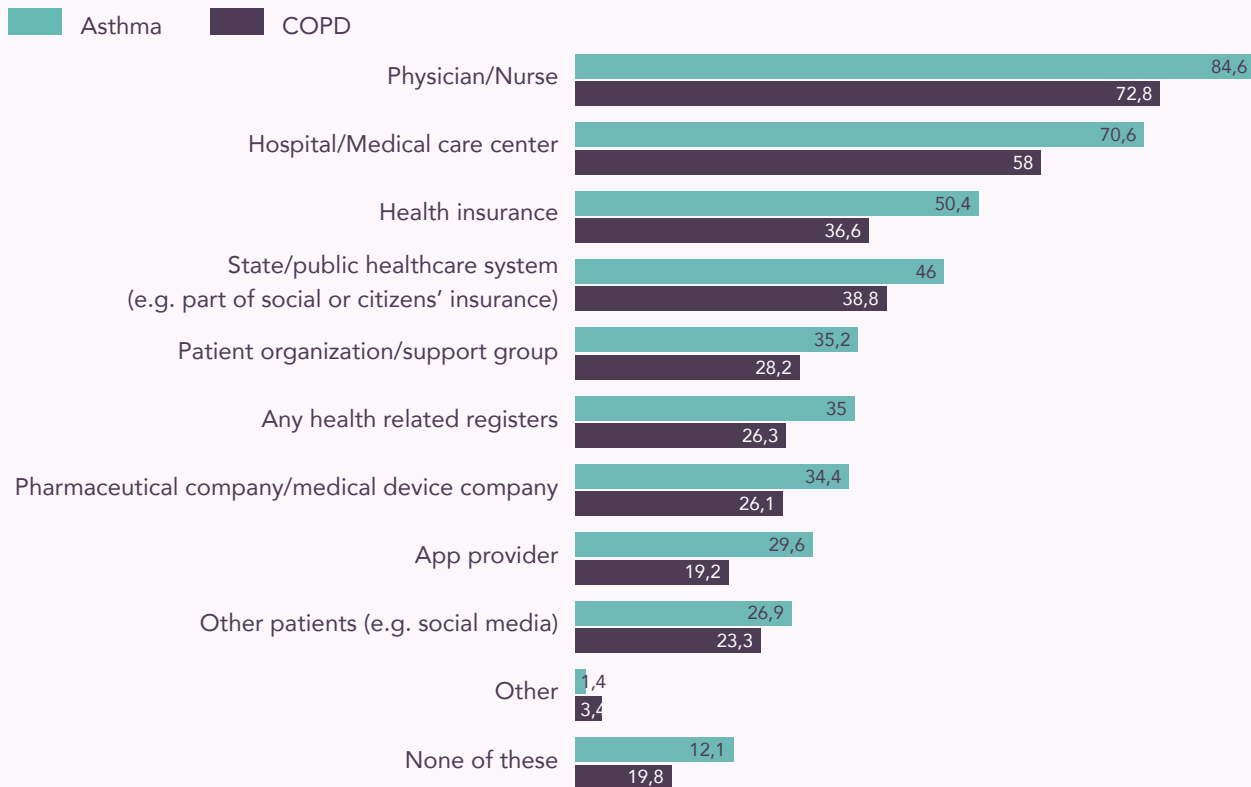


Trust is key to data sharing

Patient data are the building blocks of digital healthcare. Patients have significant power to generate and choose to share this valuable asset. Willingness to share health information depends on the type of data requested and the entity requesting it. Patients share *some* data, *sometimes* with *some* healthcare professionals. Overall, asthma patients tend to be more likely than COPD patients to share all types of data. This may be due to the age differences revealed by the survey: younger patients are broadly less concerned about privacy and more willing to share data, regardless of whether they have COPD or asthma.

Personal data, such as names and contact details, are shared most frequently overall and mainly with physicians/nurses (69% for asthma patients, 57% for COPD patients), but also with hospitals or medical centres (55% and 45%, respectively). All the statistics that follow refers first to asthma patients, and then to COPD patients. General health data (67% asthma, 51% COPD) and specific health data (50%, 45%), as well as treatment data (60%, 52%), are also frequently shared digitally with physicians/nurses. Sports tracking data are less frequently shared and, when it is, it is most frequently forwarded by COPD patients (23%) to physicians/nurses. This trend may reflect the fact that promoting physical activity is an important part of COPD patient care. Other personal information is disclosed only 30% of the time, mainly to healthcare professionals.

Table 21. Asthma and COPD patients' views on digitally sharing their anonymised health data, according to data holders



Question 34 i: And with whom would you share anonymized health data?

Basis: asthma n=506, COPD n=464

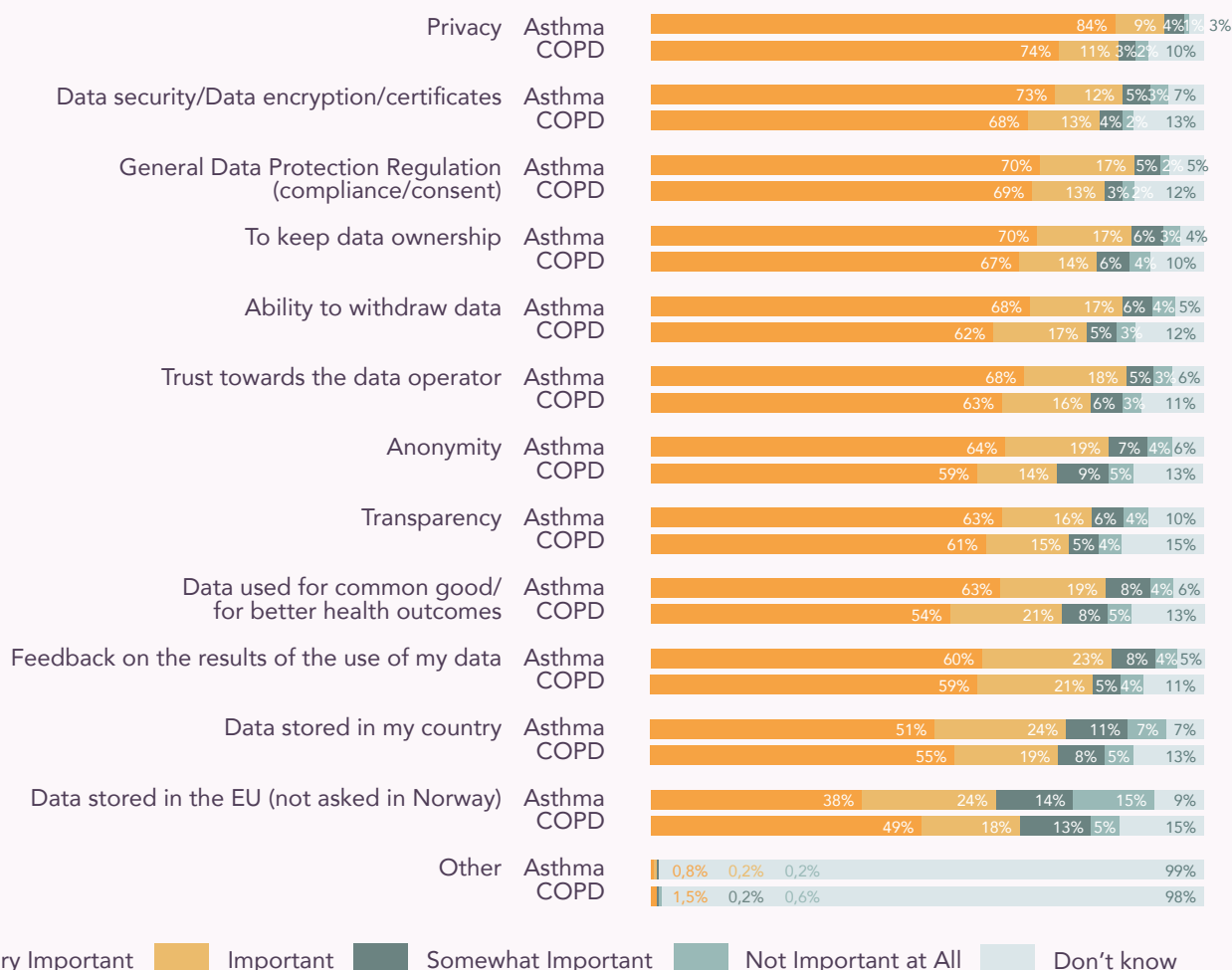
Patients have mixed feelings about sharing data digitally and COPD patients are more sceptical than asthma patients (54% are 'rather concerned' or 'very concerned'). Adding the factor of anonymisation did little to increase patient trust: 44% of COPD patients remain sceptical when data are anonymised. For asthma, it is 46% in general and 31% for anonymised data. This tendency may be due to the fact that patients view anonymised data as impersonal and therefore less likely to bring direct personal benefits.

However, levels of education also influence a shift of attitudes towards anonymisation, suggesting a role for health literacy in ensuring informed decisions on data sharing. The percentage of patients with low education levels who are very or rather concerned about sharing their digital health data goes from 61.7% to 51.1% when data are anonymised, while in patients with higher education levels, the percentage goes from 43.5% to 26.2%. This reveals that data anonymisation provides more comfort to patients with higher education. The low level of comfort with sharing data through apps may reflect a general lack of trust in apps. Efforts to overcome this lack of trust should include involving patients in developing apps for use in their own patient community.

It is also clear from the survey that patients are most comfortable with sharing information with individuals and organisations close to them e.g. physicians/nurses and hospitals. Patients are less willing to share information with pharmaceutical companies, app providers and via social media, all of which are relatively distant from the patient. This reluctance has implications for policymakers legislating on the primary, secondary and tertiary uses of health data in the context of the future European Health Data Space (EHDS). It also points to the need for the digital sector to engage proactively with patients to address their concerns and build trust.

However, despite the overall scepticism, the majority of patients (90% of asthma patients, 87% of COPD patients) are open to sharing personal and health data with healthcare professionals. In other words, just one in 10 remain uncomfortable with sharing health data with a healthcare professional. Such findings show that chronic respiratory disease patients can be frontrunners in the use of digital services and technologies. The percentage of people that do not want to share data with health professionals rises with age and is higher among people with a low income and

Table 22. Asthma and COPD patient priorities when sharing data digitally



Question 35: How important are the following aspects to you when it comes to sharing data digitally?
 Basis: asthma n=506, COPD n=464

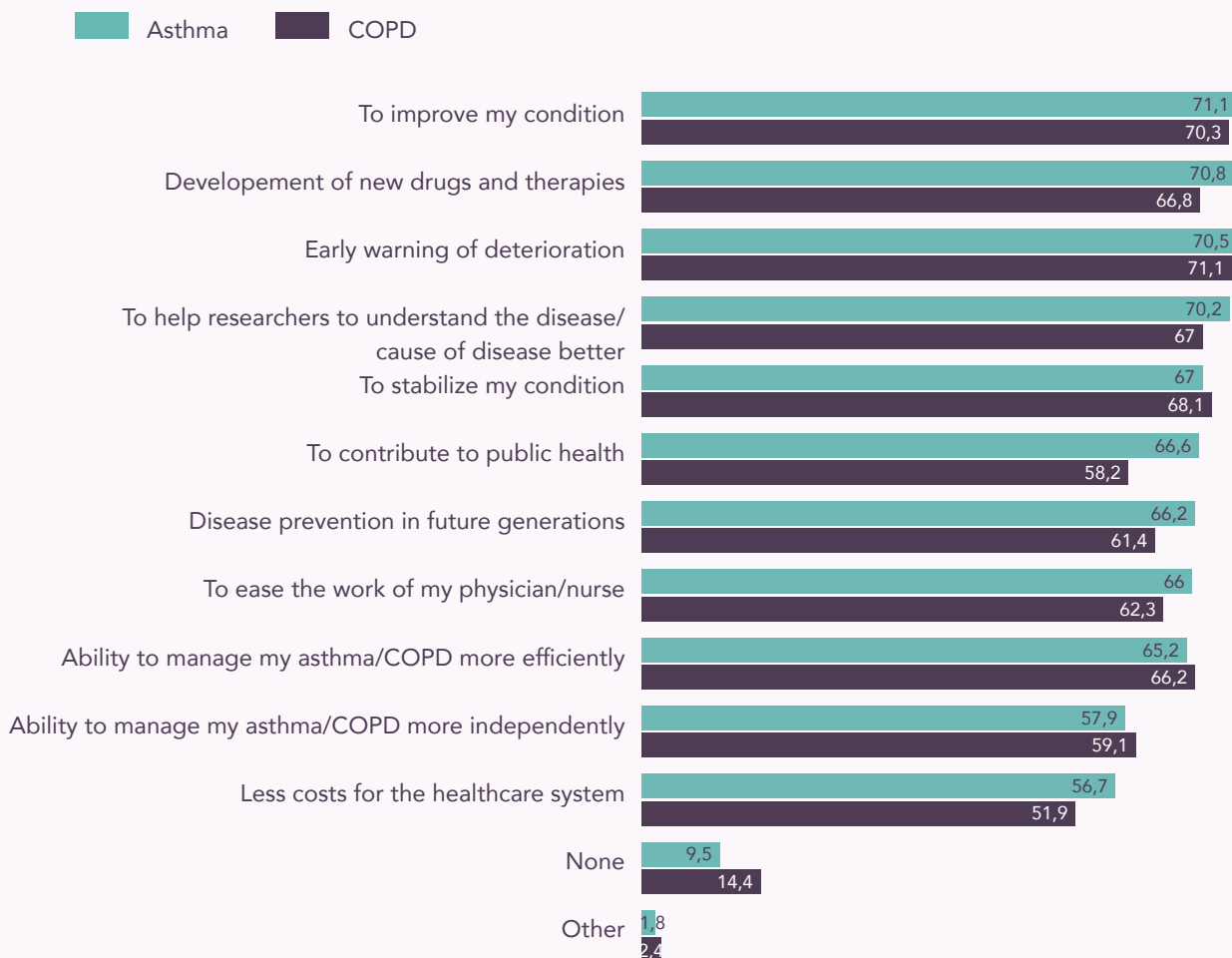
low educational attainment. Among the issues that matter most to patients when sharing data, are privacy and data security (93% and 85% among asthma patients; 85% and 81% for COPD patients). Compliance with data protection rules, retaining ownership and control of data, and trust in operations are also ranked highly in terms of their importance to patients. However, patients have relatively fewer concerns about where their data are stored geographically.

Patients' reasons for sharing data

Despite their misgivings, most patients are sharing digital data with healthcare providers. They are most likely to do so when they are incentivised by the prospect of better health outcomes. The most important reasons given for sharing data are 'to improve my condition' (71% for asthma patients, 70% for COPD patients), 'early warning of deterioration' (71% for all patients), and to 'stabilise my condition' (67% for asthma, 68% for COPD).

However, patients also look beyond their own immediate wellbeing. They are open to sharing information if it improves the understanding of their condition and, ultimately, leads to better care for the wider patient community. 71% of asthma patients and 67% of COPD patients say they share data to help the development of new drugs and therapies', while 70% and 67% hope 'to help researchers to understand the disease/cause of disease'. A further 67% and 58% justify data sharing to 'contribute to public health', with similar levels of support for 'disease prevention in future generations'.

Table 23. Asthma and COPD patients' motivations for sharing their health data digitally



Question 36: Which of the following aspects justify the sharing of your data digitally?

Basis: asthma n=506, COPD n=464

RECOMMENDATIONS TO BALANCE EMPOWERMENT WITH PRIVACY ON ASTHMA AND COPD DIGITAL HEALTH



POLICYMAKERS:

- Adopt digital health legislation and policies that put patients at the core of digital healthcare, recognising the **ownership** of patients over their data and the **rights and responsibilities** of digital health solutions providers and users conditional on continuous informed consent by the patient
- Standardise European digital health legislation around the **primary, secondary and tertiary** use of patient health data and allow for an operational European Health Data
- Space that allows data sharing in the benefit of the patient
- Define new models for **big data** collection and use at national level, together with patient organisations especially on respiratory diseases such as asthma and COPD
- Support **public confidence** on data systems by legislating and scrutinising how health data are used through centralised, unbiased, expert oversight and clear and simple information on consent, access and withdrawal options



FOR HEALTHCARE PROVIDERS:

- **Build confidence in data security and privacy** by adopting transparent mechanisms for consent and data use and reuse, in compliance with the General Data Protection
- Regulation (GDPR) and future data legislation
- **Seek patients informed consent** before collecting any of their health and personal data digitally, with clarity around context specific and ongoing consent, facilitating the opportunity to remove data from platforms and prioritising data anonymisation
- Continuously **assess** each digital system or tool before using it
- **Share patient data and outcomes** with other related healthcare providers, in an efficient way agreed with patients
- **Advise patients on the importance of collecting data** as part of consultation and update them regularly on how data sharing have improved their care
- **Prioritise digital health literacy** within patient education in daily practice



FOR THE DIGITAL SECTOR:

- Digital health solutions designed for patient use should be **designed with patients** to ensure resulting tools respond to patient privacy needs and empowerment expectations
- Adopt the approach **"privacy by design"** for all patient programmes, rather than retrospective application of data policies
- Make **consent for digital opt-ins short, clear and easy to understand**
- **Foster transparency** about digital tools and systems conceived and make sure they lead to data-driven research, communicating results to patients and making them public
- Ensure that individual health data collected by patients through digital means is primarily gathered and used to **improve the individual patient's clinical outcomes**
- Invest in **accessibility** of digital health solutions for asthma and COPD, with clear instructions and support services, including tutorials or trainings tailored to patients



FOR PATIENTS:

- **Put value on your data** and be open to sharing health data strategically, namely towards the improvement of clinical and quality of life outcomes
- Always ask to be **fully informed** about how your data will be used and the implications of your consent
- Advocate for asthma and COPD **patient registries** with information on where the data are stored, what they are used for and how they can be accessed and withdrawn



THE FUTURE OF DIGITAL HEALTH FOR ASTHMA AND COPD: BARRIERS AND OPPORTUNITIES



THE FUTURE OF DIGITAL HEALTH FOR ASTHMA AND COPD: BARRIERS AND OPPORTUNITIES

Patients are keen to save time, and many appreciate the safety of remote consultations – especially during the COVID-19 pandemic. But low awareness of some digital tools, and concerns about data privacy and loss of personal contact must be addressed.

The COVID-19 pandemic has been a worrying time for patients with respiratory conditions. The availability of certain digital technologies, including remote consultation and electronic prescription spared them unnecessary trips to busy clinics without sacrificing contact with healthcare professionals. It brought benefits that many patients want to see continued, even as society returns to a degree of normality. Why spend hours travelling to appointments and waiting in clinics – often accompanied by a family member who may have to miss work – when a teleconference would do the trick?

Additional benefits arise from new opportunities for disease monitoring and timely access to information. Not only might this help patients to have informed conversations with health professionals, but continuous monitoring can also help to detect and address problems before they become more serious.

The digital transformation offers opportunities in industry, the technology sector, skills development and healthcare. Despite the benefits that have been seen by many patients, uptake of digital tools in healthcare is uneven. There are differences based on age and location, and varying degrees of enthusiasm depending on the technology. For many of the more advanced connected devices in the respiratory field, awareness is low.

This chapter aims to put the spotlight on the major barriers for digital tool usership and opportunities to build on positive experiences reported by some patients. It is based on patient responses to a series of questions, including open questions which allowed patients to offer spontaneous views on the barriers and drivers of digital health.

“

My doctor is quite traditional and doesn't suggest digital options

—
Asthma patient from Belgium

”

“

Online GP consultations make my life easier – the doctor lives quite far away so it's more convenient to be online

—
Asthma patient from Ireland

”

Technology is no substitute for face-to-face care

While the convenience of online consultations or remote monitoring are viewed by some patients as an opportunity for additional contact, many are concerned that digital connections could replace direct contact with healthcare professionals. There is a strong preference for face-to-face personal consultations – and an aversion to anything that might come at the cost of continued real-world contact.

Figure 1. Asthma and COPD patients' reasons for not using digital services and tools

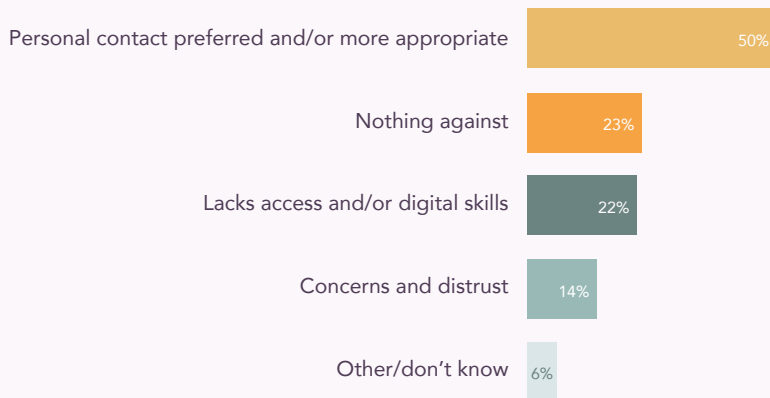


Figure 2. Reasons against using digital services and tools (selected by patients from a list of options)



Question 28: what are the main reason for not using any or more digital services or tools for diagnosis, treatment and care?

“

I don't see the need for it. I'm quite happy with things the way they are

— COPD patient from Belgium

”

One in five respondents spontaneously express their preference for in-person care. In addition, COPD patients also indicate a lack of knowledge about digital tools and services, and say they lacked familiarity with digital technologies in general. More than one in five of respondents also see no major barriers to digitalisation.

These results are also mirrored by the answers to the list-based question where patients ranked their concerns rather than offering spontaneous responses. Almost two in three patients prefer personal contact and fear losing it. However, other barriers were also rated highly, notably the fact that more than half of respondents have not been offered digital services.

The findings also highlight a fundamental concern about misuse of data. Patients have fears about the misuse of personal information, concerns over data security, uncertainty about who can access their data and for what purpose, and the perceived risk of handing over too much sensitive data.

Drivers of digitalisation

A sizeable number of patients use at least some digital tools and services. Those offered the opportunity to benefit from them express high rates of satisfaction. The question is why do they do it? What are the leads patients to accept digital technologies when they are offered – and to continue using them once they have become more familiar with them? Existing evidence points to several factors in driving uptake, including clinical evidence; motivation; involvement of physicians and patients in design; reimbursement; and suitable business models for digital products and services⁵¹. The DIG_IT study points to the reasons people with asthma and COPD embrace digital tools.



I don't feel technically competent with digital technologies

—
COPD patient from
Czech Republic



Figure 3. Reasons cited spontaneously by patients for using digital services and tools

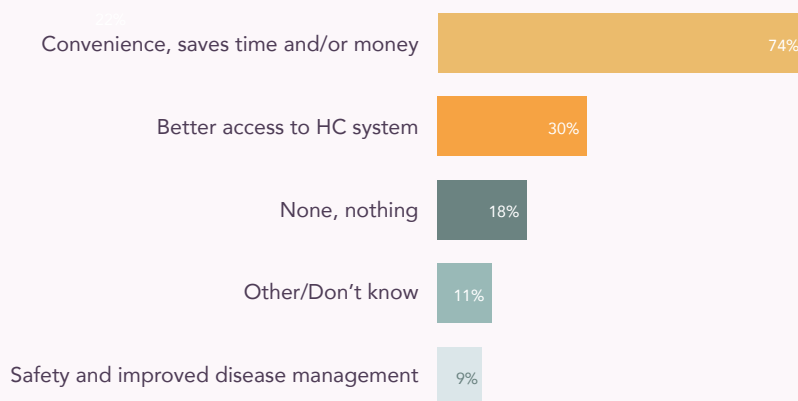


Figure 4. Reasons for using digital services and tools (selected by patients from a list of options)



Question 30: In general, what could trigger or increase your usage of digital health services?

When asked about the benefits of digital services and tools, asthma patients tend to see more advantages than their counterparts with COPD. People with asthma, who are generally younger than those with COPD, say digital services and devices are fast, time saving, convenient and easy to use. The ability to arrange care from home and avoiding travel are also mentioned by some patients. COPD patients see the same advantages, but to a lesser extent. However, 23% of COPD patients – primarily older people with higher levels of satisfaction with how their condition is managed – stated that they see no reasons for digital services at all, and another 10% cannot spontaneously think of any benefits.

These results are in line with the responses patients gave to questions where a range of possible answers was suggested. Overall, when prompted, patients

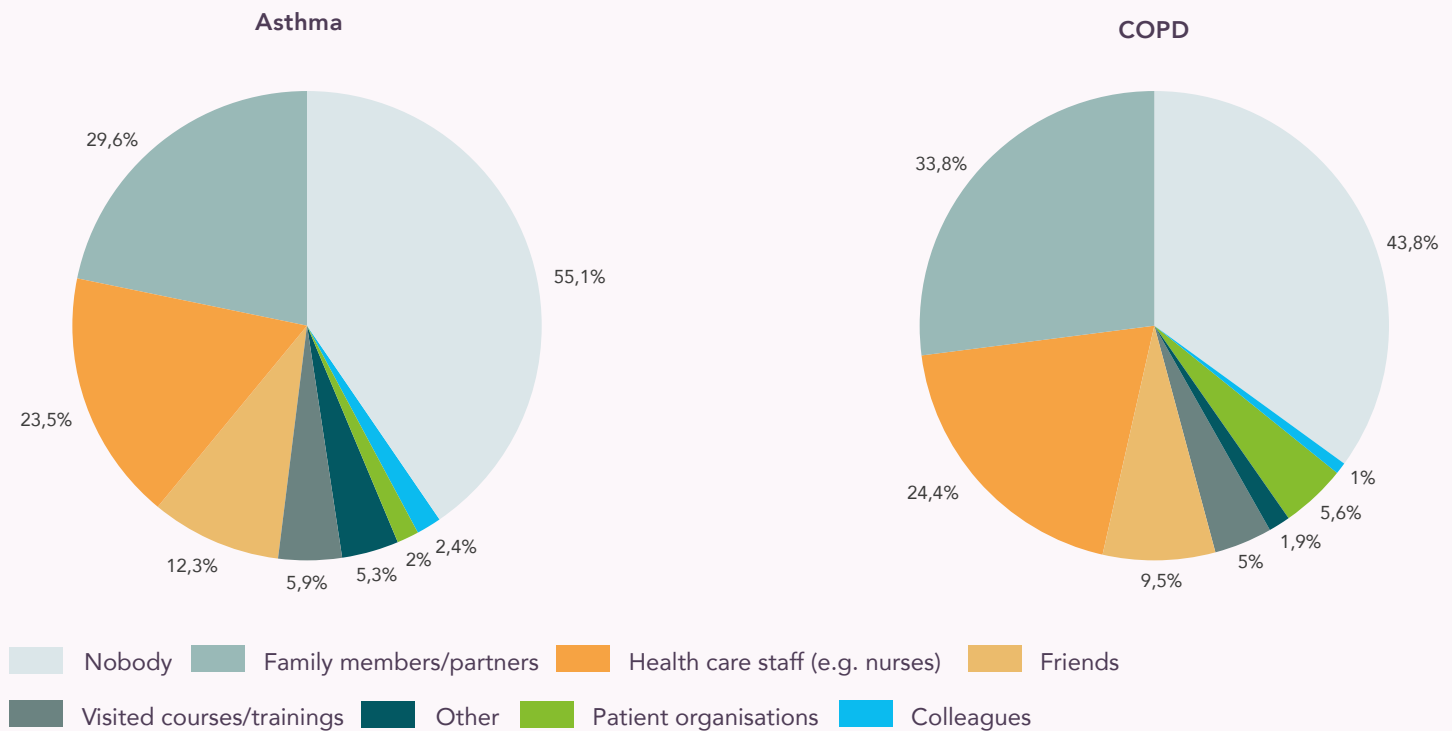
selected a range of motivations for using digital tools, with convenience, better access to healthcare professionals, and early warnings of deterioration ranked highly.

At a national level, in terms of possible drivers, respondents in Spain were generally most positive about them, followed by Ireland, while those in Belgium and the Czech Republic were more reserved. A quarter of the Czech respondents did not cite any positive drivers for digitalisation. However, this may also reflect the Czechs' overall low level of familiarity with digital offerings.

Some patients need a network of support to use digital tools

Using digital devices, navigating online booking forms, and setting up video calls require some technical competence, along with equipment and a reliable internet connection. Patients with limited competence or confidence in the use of digital technologies may turn to family members, neighbours and friends for help.

Chart 6. Asthma and COPD patients' received support to use digital tools



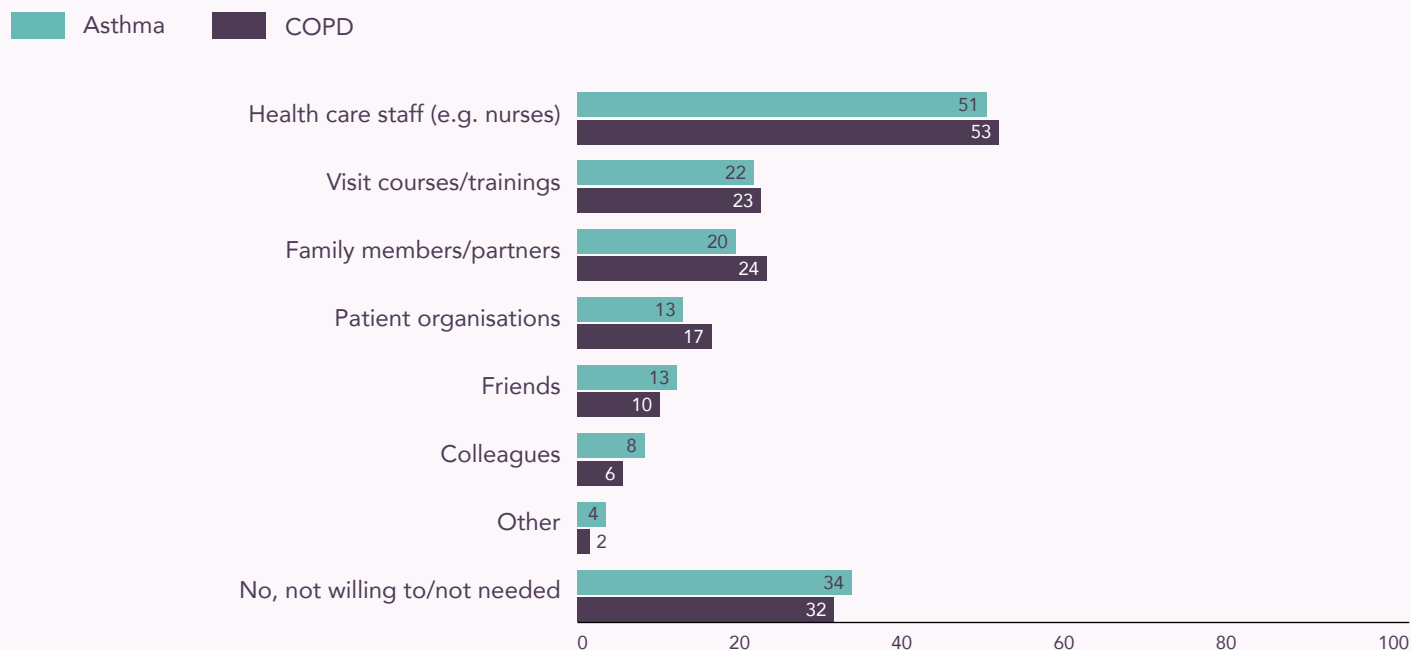
Question 42: In case someone supports/supported your use of digital tools, who did/does?

Basis: asthma n=506, COPD n=464

Those without an immediate and willing source of support struggle to keep up with the latest technological advances and may miss out on the potential benefits for their health. Health professionals also play a role in introducing new tools and training patients to use them.

About a third of respondents receive help from family members or partners to use digital devices, while a quarter are assisted by healthcare workers. Overall, more asthma patients (55%) do not receive support, and at least 34% of them say they do not want or need to receive training. For COPD patients, 44% receive no assistance with one in three saying do not want any help.

Table 24. Asthma and COPD patients' preferences for digital tools training



Question 43: Would you be willing to be trained on the usage of digital tools? If yes, by whom?

Basis: asthma n=506, COPD n=464

Interestingly, over half of those who responded say they would prefer support from healthcare staff rather than family or partner. In fact, healthcare staff are the most popular source of support in using digital tools. These findings echo previous work showing that healthcare provider support is a key success factor in achieving higher levels of compliance with self-care telehealth projects⁵². The highest levels of compliance are observed in studies involving an active health literacy or health education element⁵³. Previous studies looking specifically at self-management in asthma patients found that education and training increased adherence with inhaled therapy, perceived control of asthma, and certain clinical outcomes.

The findings of the DIG_IT survey reinforce the importance of digital literacy in general, and equipping healthcare professionals to provide patients with training and support. It is a reminder to the digital sector that patients are not looking for a high-tech replacement for in-person care: they appreciate tools that make their lives easier and complement their relationships with health professionals.

“

Living in a rural area, reliable Internet can be a problem

—
Asthma patient from Ireland

”

Opportunities to expand the use of digital health

Technology is transforming the healthcare ecosystem, potentially changing the role of patients. In a diverse patient community, some are keen to embrace their new role; others have little appetite for major changes. While almost half of all patients (49%) do not see scope for greater digitalisation, some see potential for the additional application of digital tools. Those who see opportunities to expand the use of technology suggest home testing and monitoring from home as an area of interest. They also say digital information about the disease in general, and daily updates about air quality and other relevant issues, would be welcome. In addition, participants repeatedly express a desire for additional health-related digital communication, especially regular follow-ups from doctors.

RECOMMENDATIONS ON THE BARRIERS AND OPPORTUNITIES ON THE FUTURE OF ASTHMA AND COPD DIGITAL CARE



POLICYMAKERS:

- Invest in the **digitisation** of healthcare systems to save costs and create benefits across multiple sectors such as healthcare, industry, technology, research and skills
- Focus on **patients who are underserved** by the system, such as people living in remote places or with difficult access to healthcare professionals of their choice
- **Establish criteria** that require new digital health technologies authorised by a healthcare system **to be patient-centred**
- Strongly support the **digitalisation of public health surveillance**, enabling health and environment cross-data sharing leading to targeted public information (i.e., air pollution alerts and messaging for chronic respiratory disease patients)
- Enable and support the use of **Big Data, machine learning, Artificial Intelligence** and robotics for the prevention and alleviation of respiratory disease in populations at risk
- Collaborate with regulatory bodies to set criteria and standards for Real World Data and **Real World Evidence** to inform clinical trials



FOR HEALTHCARE PROVIDERS:

- **Equip healthcare professionals** to offer both in person and digital healthcare services when possible, according to patient choices, and train them to improve digital health literacy among their patients
- Collaborate and adopt a **multidisciplinary approach to address respiratory diseases** (with doctors, nurses, nutritionists, physiotherapists) to reduce current silos
- Launch **consultations and satisfaction surveys** towards patients to align with their use and demand of digital technologies specifically addressing respiratory disease



FOR THE DIGITAL SECTOR:

- Update and develop new digital tools based on what matters to patients: **convenience and efficiency**
- For new innovations, **prioritise existing technological devices** that are familiar for patients, such as laptops, smartphones and smartwatches
- Conceive diagnostic **tools to measure lung function for personal use** without compromising the accuracy of clinical results



FOR PATIENTS:

- **Express your preference and satisfaction** with certain digital health services to your healthcare professionals
- **Request training** before using a new digital health tool, or an updated one
- **Use digital health to develop a closer relationship** with your healthcare professionals
- **Take the opportunity to become key stakeholders** in the field of healthcare: “no digital health decision without us”

CONCLUSIONS

In Europe, 30 million children and adults aged under 45 years are living with asthma while up to 10% of the European population have COPD⁵⁴. These figures represent a sizeable portion of our communities and a significant demand for healthcare resources. For those people affected, and for their families, technologies with the potential to improve clinical outcomes and quality of life are welcome. For policymakers and healthcare providers, digital tools and services that make efficient use of resources while ensuring appropriate diagnosis and care are an essential feature of a sustainable future. A structured, long-term approach should be taken to implement digital health, with a strong focus on regular reviews to ensure policies keep up with technological innovation. Meanwhile, there are opportunities for the digital sector, provided that companies active in the field such as (pharmaceutical companies, community pharmacists or even environmental and climate businesses) respond to the care needs, preferences and concerns of the patient community.

The COVID-19 pandemic was a shock to the system. It triggered a dramatic shift in the management of life-long conditions, inspiring patients and providers to embrace innovative solutions to enhance safety without sacrificing continuity of care. The crisis changed the clinician-patient relationship and cast patients in a new role within a rapidly changing healthcare and health data ecosystems.

The DIG_IT survey shows that many of those who had experience in using digital tools view them positively. However, for others, access remains low.

There are also clear differences between easy-to-use technologies – such as online booking forms and video calls – and the more advanced, connected technologies specific to patients with chronic respiratory conditions. Stark contrasts are also found between countries. For example, in Spain, where the first wave of COVID-19 was particularly severe, use of digital tools was higher than in the Czech Republic⁵⁵.

Among the other barriers to adoption that emerge from the survey are concerns over data privacy and security, and fears that remote connection to health services could replace the highly trusted one-on-one care to which patients are accustomed. There is also a significant number of patients who say they see no need for new digital tools, a fact that could be explained by demographic differences.

It is vital that technologies are offered to patients especially when they are likely to be of real value to their health and wellbeing. Technology for technology's sake is not the goal. At the same time, some patients may miss out due to their reluctance to try digital tools. To ensure no one is left behind, access and training should be offered to those who want it.

As with all new technologies – and policies that address them – it is essential that patient voices are central to the conversation. This means including patients in setting priorities for research to ensure that new technologies developed by industry address clear unmet needs identified by patients. This also implies that patients are involved in product design from the earliest stages. It is not enough for IT companies to bring a close-to-market product to a focus group of patients: the patients should be 'in the room' from the start. Not only is this continuous presence in the interests of patients, but it is of benefit to developers who want to make products that deliver value.

Finally, at this critical moment in the evolution of EU policy of health data, policymakers must continue to maintain a two-way conversation with patients. At both EU and national levels, it is vital that decisions are made with patients, rather than for them. This continued dialogue could be structured through Expert Stakeholder Groups attached to the European Health Data Board and the Digital Health Authorities. Nothing about us without us.

REFERENCES

- ¹ "The Digital Economy and Society Index (DESI)." Shaping Europe's digital future. European Commission, 2020. <https://digital-strategy.ec.europa.eu/en/policies/desi>.
- ² "eGovernment and Digital Public Services." Shaping Europe's digital future. European Commission. Accessed 2021. <https://digital-strategy.ec.europa.eu/en/policies/egovernment>.
- ³ "E-Government." UNeGovKB United Nations. United Nations. Accessed 2021. <https://publicadministration.un.org/egovkb/en-us/about/unegovdd-framework>.
- ⁴ "E-Commerce Rules in the EU." Shaping Europe's digital future. European Commission. Accessed 2021. <https://digital-strategy.ec.europa.eu/en/policies/e-commerce-rules-eu>.
- ⁵ "Attitudes towards the Impact of Digitisation and Automation on Daily Life." Digital Single Market. European Commission, May 16, 2017. <https://wayback.archive-it.org/12090/20190328172256/https://ec.europa.eu/digital-single-market/en/news/attitudes-towards-impact-digitisation-and-automation-daily-life>.
- ⁶ "Definitions." Eurofound. European Foundation for the Improvement of Living and Working Conditions. Accessed 2021. <https://www.eurofound.europa.eu/data/digitalisation/definitions#digitisation>.
- ⁷ "Percentage of People Using the Internet for Health-Related Activities." Epthinktank. European Parliamentary Research Service, April 14, 2021. <https://epthinktank.eu/2021/04/15/the-rise-of-digital-health-technologies-during-the-pandemic/percentage-of-people-using-the-internet-for-health-related-activities/>.
- ⁸ Chongmelaxme, Bunchai, Shaun Lee, Teerapon Dhippayom, Surasak Saokaew, Nathorn Chaiyakunapruk, and Piyameth Dilokthornsakul. "The Effects of Telemedicine on Asthma Control and Patients' Quality of Life in Adults: A Systematic Review and Meta-Analysis." *The Journal of Allergy and Clinical Immunology: In Practice* 7, no. 1 (2019). <https://doi.org/10.1016/j.jaip.2018.07.015>.
- ⁹ Verhoeven, Fenne, Karin Tanja-Dijkstra, Nicol Nijland, Gunther Eysenbach, and Lisette van Gemert-Pijnen. "Asynchronous and Synchronous Teleconsultation for Diabetes Care: A Systematic Literature Review." *Journal of Diabetes Science and Technology* 4, no. 3 (2010): 666–84. <https://doi.org/10.1177/193229681000400323>.
- ¹⁰ Vegesna, Ashok, Melody Tran, Michele Angelaccio, and Steve Arcona. "Remote Patient Monitoring via Non-Invasive Digital Technologies: A Systematic Review." *Telemedicine and e-Health* 23, no. 1 (2017): 3–17. <https://doi.org/10.1089/tmj.2016.0051>.
- ¹¹ Aceto, Giuseppe, Valerio Persico, and Antonio Pescapé. "The Role of Information and Communication Technologies in Healthcare: Taxonomies, Perspectives, and Challenges." *Journal of Network and Computer Applications* 107 (2018): 125–54. <https://doi.org/10.1016/j.jnca.2018.02.008>.
- ¹² Wu, Cong, Zixiang Wu, Lingfei Yang, Wenjun Zhu, Meng Zhang, Qian Zhu, Xiaoying Chen, and Yongmiao Pan. "Evaluation of the Clinical Outcomes of Telehealth for Managing Diabetes." *Medicine* 97, no. 43 (2018). <https://doi.org/10.1097/md.00000000000012962>.
- ¹³ Liao, Yanhui, Qiuxia Wu, Brian C. Kelly, Fengyu Zhang, Yi-Yuan Tang, Qianjin Wang, Honghong Ren, et al. "Effectiveness of a Text-Messaging-Based Smoking Cessation Intervention ('Happy Quit') for Smoking Cessation in China: A Randomized Controlled Trial." *PLOS Medicine* 15, no. 12 (2018). <https://doi.org/10.1371/journal.pmed.1002713>.
- ¹⁴ Xie, Min, Xiansheng Liu, Xiaopei Cao, Mingzhou Guo, and Xiaochen Li. "Trends in Prevalence and Incidence of Chronic Respiratory Diseases from 1990 to 2017." *Respiratory Research* 21, no. 1 (2020). <https://doi.org/10.1186/s12931-020-1291-8>.
- ¹⁵ Rep. Active Asthma and COPD Patients ACCESS Care Report, 2019. https://www.efanet.org/images/Active_Patients_ACCESS_Care__EFA_Report_2019.pdf.
- ¹⁶ "Better citizens' access to & sharing of health data White Paper". Digital health Europe (2021), <https://digitalhealtheuropa.eu/wp-content/uploads/White-Paper-Better-Citizens-Access-to-and-Sharing-of-Health-Data.pdf>
- ¹⁷ "European Health Data Space." Public Health. European Commission. Accessed 2021. https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en.
- ¹⁸ "Empowerment through Digital Health." Health Topics. World Health Organization Regional Office for Europe. Accessed 2021. <https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work/flagship-initiatives/empowerment-through-digital-health>.
- ¹⁹ Madurai Elavarasan, Rajvikram, and Rishi Pugazhendhi. "Restructured Society and Environment: A Review on Potential Technological Strategies to Control the COVID-19 Pandemic." *Science of The Total Environment* 725 (2020): 138858. <https://doi.org/10.1016/j.scitotenv.2020.138858>.
- ²⁰ Golinelli, Davide, Erik Boetto, Gherardo Carullo, Andrea Giovanni Nuzzolese, Maria Paola Landini, and Maria Pia Fantini. "Adoption of Digital Technologies in Health Care during the COVID-19 Pandemic: Systematic Review of Early Scientific Literature." *Journal of Medical Internet Research* 22, no. 11 (2020). <https://doi.org/10.2196/22280>.
- ²¹ Rep. Use of Digital Health Tools in Europe: before, during and after COVID-19. European Observatory on Health Systems and Policies, September 15, 2021. <https://eurohealthobservatory.who.int/publications/i/use-of-digital-health-tools-in-europe-before-during-and-after-covid-19>.
- ²² Pérez Sust, Pol, Oscar Solans, Joan Carles Fajardo, Manuel Medina Peralta, Pepi Rodenas, Jordi Gabaldà, Luis Garcia Eroles, et al. "Turning the Crisis into an Opportunity: Digital Health Strategies Deployed during the COVID-19 Outbreak." *JMIR Public Health and Surveillance* 6, no. 2 (2020). <https://doi.org/10.2196/19106>.
- ²³ Baltaxe, Erik, Thomas Cypionka, Markus Kraus, Miriam Reiss, Jan Erik Askildsen, Renata Grenkovic, Tord Skogedal Lindén, et al. "Digital Health Transformation of Integrated Care in Europe: Overarching Analysis of 17 Integrated Care Programs." *Journal of Medical Internet Research* 21, no. 9 (2019). <https://doi.org/10.2196/14956>.

- ²⁴ Rep. Global Strategy on Digital Health 2020-2025. Licence: CC BY-NC-SA 3.0 IGO. Geneva: World Health Organization, 2021.
- ²⁵ McHaney, Roger, Iris Reychav, Joseph Azuri, Mark E. McHaney, Rami Moshonov, Cristina Trocin, and Croda Enrica. "Empowering Patients Through Digital Technologies: The Case of Mobile Health Applications." Essay. In *Impacts of Information Technology on Patient Care and Empowerment*, 34–57. Hershey, PA: IGI Global, Medical Information Science Reference (an imprint of IGI Global), 2020.
- ²⁶ Kavanagh, Joanne, David J. Jackson, and Brian D. Kent. "Over- and under-Diagnosis in Asthma." *Breathe* 15, no. 1 (2019). <https://doi.org/10.1183/20734735.0362-2018>.
- ²⁷ Rep. The Global Asthma Report 2018. The Global Asthma Network, 2018. http://globalasthmareport.org/resources/Global_Asthma_Report_2018.pdf.
- ²⁸ Lamprecht, Bernd, Joan B. Soriano, Michael Studnicka, Bernhard Kaiser, Lowie E. Vanfleteren, Louisa Gnatiuc, Peter Burney, et al. "Determinants of Underdiagnosis of COPD in National and International Surveys." *Chest* 148, no. 4 (2015): 971–85. <https://doi.org/10.1378/chest.14-2535>.
- ²⁹ Merchant, Rajan, Stanley J. Szeffler, Bruce G. Bender, Michael Tuffli, Meredith A. Barrett, Rahul Gondalia, Leanne Kaye, David Van Sickle, and David A. Stempel. "Impact of a Digital Health Intervention on Asthma Resource Utilization." *World Allergy Organization Journal* 11 (2018): 28. <https://doi.org/10.1186/s40413-018-0209-0>.
- ³⁰ Hui, Chi Yan, Robert Walton, Brian McKinstry, Tracy Jackson, Richard Parker, and Hilary Pinnock. "The Use of Mobile Applications to Support Self-Management for People with Asthma: A Systematic Review of Controlled Studies to Identify Features Associated with Clinical Effectiveness and Adherence." *Journal of the American Medical Informatics Association* 24, no. 3 (2016): 619–32. <https://doi.org/10.1093/jamia/ocw143>.
- ³¹ Miller, Lisa, Benjamin Schütz, Julia Walters, and E Haydn Walters. "Mobile Technology Interventions for Asthma Self-Management: Systematic Review and Meta-Analysis." *JMIR mHealth and uHealth* 5, no. 5 (2017). <https://doi.org/10.2196/mhealth.7168>.
- ³² Alexander, Jeffrey A., Larry R. Hearld, Jessica N. Mittler, and Jillian Harvey. "Patient-Physician Role Relationships and Patient Activation among Individuals with Chronic Illness." *Health Services Research* 47, no. 3pt1 (2011): 1201–23. <https://doi.org/10.1111/j.1475-6773.2011.01354.x>.
- ³³ Rep. Active Asthma and COPD Patients ACCESS Care Report, 2019. https://www.efanet.org/images/Active_Patients_ACCESS_Care_EFA_Report_2019.pdf.
- ³⁴ Rep. Digital Skills for Healthcare Professionals, 2016. www.healthparliament.eu/wp-content/uploads/2017/09/Digital-skills-for-health-professionals.pdf.
- ³⁵ Rep. Empowering the Health Workforce: Strategies to Make the Most of the Digital Revolution. OECD, 2020. <https://www.oecd.org/health/health-systems/Empowering-Health-Workforce-Digital-Revolution.pdf>.
- ³⁶ Pérez Sust, Pol, Oscar Solans, Joan Carles Fajardo, Manuel Medina Peralta, Pepi Rodenas, Jordi Gabaldà, Luis Garcia Eroles, et al. "Turning the Crisis into an Opportunity: Digital Health Strategies Deployed during the COVID-19 Outbreak." *JMIR Public Health and Surveillance* 6, no. 2 (2020). <https://doi.org/10.2196/191106>.
- ³⁷ Zanaboni, Paolo, and Asbjørn Johansen Fagerlund. "Patients' Use and Experiences with e-Consultation and Other Digital Health Services with Their General Practitioner in Norway: Results from an Online Survey." *BMJ Open* 10, no. 6 (2020). <https://doi.org/10.1136/bmjopen-2019-034773>.
- ³⁸ Baltaxe, Erik, Thomas Czypionka, Markus Kraus, Miriam Reiss, Jan Erik Askildsen, Renata Grenkovic, Tord Skogedal Lindén, et al. "Digital Health Transformation of Integrated Care in Europe: Overarching Analysis of 17 Integrated Care Programs." *Journal of Medical Internet Research* 21, no. 9 (2019). <https://doi.org/10.2196/14956>.
- ³⁹ Schulz, Thomas, Karrie Long, Kudzai Kanhutu, Ilana Bayrak, Douglas Johnson, and Timothy Fazio. "Telehealth during the Coronavirus Disease 2019 Pandemic: Rapid Expansion of Telehealth Outpatient Use during a Pandemic Is Possible If the Programme Is Previously Established." *Journal of Telemedicine and Telecare*, 2020. <https://doi.org/10.1177/1357633x20942045>.
- ⁴⁰ Ćwiklicki, Marek, Francesco Schiavone, Jacek Klich, and Kamila Pilch. "Antecedents of Use of e-Health Services in Central Eastern Europe: A Qualitative Comparative Analysis." *BMC Health Services Research* 20, no. 1 (2020). <https://doi.org/10.1186/s12913-020-5034-9>.
- ⁴¹ Richardson, Erica, Dalhia Aissat, Gemma A Williams, and Nick Fahy. "Keeping What Works: Remote Consultations during the COVID-19 Pandemic." *Eurohealth* 26, no. 2 (2020).
- ⁴² Rep. Use of Digital Health Tools in Europe: before, during and after COVID-19. European Observatory on Health Systems and Policies, September 15, 2021. <https://eurohealthobservatory.who.int/publications/i/use-of-digital-health-tools-in-europe-before-during-and-after-covid-19>.
- ⁴³ Rep. 2021 GINA Report, Global Strategy for Asthma Management and Prevention. GINA, 2021. <https://ginasthma.org/gina-reports/>.
- ⁴⁴ Kupczyk, Maciej, Anna Hofman, Łukasz Kołtowski, Piotr Kuna, Mateusz Łukaszyk, Krzysztof Buczyłko, Anna Bodzenta-Łukaszyk, Paweł Nastafek, Mateusz Soliński, and Piotr Dąbrowiecki. "Home Self-Monitoring in Patients with Asthma Using a Mobile Spirometry System." *Journal of Asthma* 58, no. 4 (2020): 505–11. <https://doi.org/10.1080/02770903.2019.1709864>.
- ⁴⁵ Newham, James, Justin Presseau, Karen Heslop-Marshall, Siân Russell, Oladapo Ogunbayo, Paul Netts, Barbara Hanratty, and Eileen Kaner. "Features of Self-Management Interventions for People with COPD Associated with Improved Health-Related Quality of Life and Reduced Emergency Department Visits: A Systematic Review and Meta-Analysis." *International Journal of Chronic Obstructive Pulmonary Disease* Volume 12 (2017): 1705–20. <https://doi.org/10.2147/copd.s133317>.
- ⁴⁶ "The Digital Economy and Society Index (DESI)." Shaping Europe's digital future. European Commission, 2020. <https://digital-strategy.ec.europa.eu/en/policies/desi>.
- ⁴⁷ "Dans Quel Délai Un Médicament Peut-Il Être Délivré Et Remboursé ?" INAMI. Institut national d'assurance maladie-invalidité, November 2, 2022. <https://www.riziv.fgov.be/fr/themes/cout-remboursement/par-mutualite/medicament-produits-sante/remboursement/Pages/default.aspx?p=1>.

⁴⁸ "One in Two EU Citizens Look for Health Information Online." Eurostat. European Commission, April 6, 2021. <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/edn-20210406-1>.

⁴⁹ Madrigal, Lillian, and Cam Escoffery. "Electronic Health Behaviors among US Adults with Chronic Disease: Cross-Sectional Survey." *Journal of Medical Internet Research* 21, no. 3 (2019). <https://doi.org/10.2196/11240>.

⁵⁰ Keshta, Ismail, and Ammar Odeh. "Security and Privacy of Electronic Health Records: Concerns and Challenges." *Egyptian Informatics Journal* 22, no. 2 (2021): 177–83. <https://doi.org/10.1016/j.eij.2020.07.003>.

⁵¹ Daruwalla, Zoish, Vidhi Thakkar, Monica Aggarwal, Anahita Kiasatdolatabadi, Aziz Guergachi, and Karim Keshavjee. "Patient Empowerment: The Role of Technology." *Studies in Health Technology and Informatics* 257 (n.d.): 70–74.

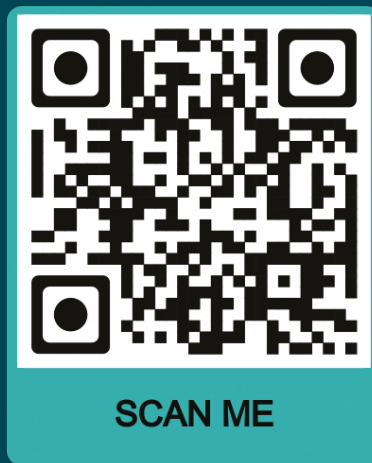
⁵² Maeder, Anthony, Nathan Poultney, Gary Morgan, and Robert Lippiatt. "Patient Compliance in Home-Based Self-Care Telehealth Projects." *Journal of Telemedicine and Telecare* 21, no. 8 (2015): 439–42. <https://doi.org/10.1177/1357633x15612382>.

⁵³ Mc Namara, K. P., V. L. Versace, J. L. Marriott, and J. A. Dunbar. "Patient Engagement Strategies Used for Hypertension and Their Influence on Self-Management Attributes." *Family Practice* 31, no. 4 (2014): 437–44. <https://doi.org/10.1093/fampra/cmu026>.

⁵⁴ The European Lung White Book. European Respiratory Society, 2020. <https://www.erswhitebook.org/>.

⁵⁵ Legido-Quigley, Helena, José Tomás Mateos-García, Vanesa Regulez Campos, Montserrat Gea-Sánchez, Carles Muntaner, and Martin McKee. "The Resilience of the Spanish Health System against the COVID-19 Pandemic." *The Lancet Public Health* 5, no. 5 (2020). [https://doi.org/10.1016/s2468-2667\(20\)30060-8](https://doi.org/10.1016/s2468-2667(20)30060-8).

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