



# Empowering and engaging patients

Unlocking access to patient  
records and aiding decision-making

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## **Unlocking access to patient records and aiding decision-making**



WISH 2022 Forum on Patient Empowerment

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## FOREWORD



Empowered and engaged patients have been described as “the blockbuster drug of the century,”<sup>1</sup> but all too often this aspect of patient care is neglected. The COVID-19 pandemic has, and continues to be, an immense challenge for individuals, communities and health systems. However, it has also been an opportunity to rethink how care is delivered and patients are engaged. The response to the pandemic meant that physical interactions were restricted in many countries and digital tools have often been seen as a solution.

In this report we use the lens of the COVID-19 pandemic to examine how digital tools can empower and engage patients. We start by reflecting on how digital tools can support patients as they manage their health and their interactions with a health system (Section 1). We then focus on two examples that are fundamental to empowering patients to make choices around their care: patient portals allowing people to access their medical records (Section 2), and patient decision aids to facilitate informed involvement in treatment choices (Section 3).

Developments in electronic medical record systems and techniques for linking data from different sources have made it technically possible to provide patients with access to their complete medical record (from primary, secondary and community sources). However, access is currently available in only a few countries. During the pandemic many people accessed their vaccination records for use as ‘COVID passports’ when travelling and data scientists made extensive use of aggregated personal data from electronic medical records to track the virus and its effects, but in most cases patients’ access to their full records continued to be restricted. Awareness of this anomaly has led to calls for improved patient access to, and control over, their personal records.

Shared decision-making (doctors and patients working together to select tests, treatments, or support packages based on clinical evidence and the patient’s informed preferences) has had a long gestation, the idea having been first introduced in the United States in the 1980s.<sup>2</sup> It is now on the policy agenda in many countries and is seen as an important means of empowerment as well as being ethically the ‘right thing to do’. An extensive body of evidence exists on its effects and how it can be done, but it has been slow to filter into mainstream clinical practice. Evidence-based patient decision aids (online or on paper) have been available in several countries to support the process, but traditionally they have drawn on laboriously conducted systematic reviews and take a long time to develop

and make available. The challenge posed by the pandemic was whether the system could be sped up to enable shared decision-making for the numerous decisions facing patients and their carers during the emergency.

We invited leading experts on digital patient empowerment to review recent examples of developing and using these tools and to summarize what has been learnt from their use during the pandemic. These two examples illustrate the complexity of these interventions (and digital interventions more generally) and the need for careful monitoring and adaptation to maximize beneficial outcomes. They also show that these tools have the potential for much wider adoption, empowering and engaging patients outside the pandemic context.



A handwritten signature in black ink that reads "Angela Coulter".

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# SECTION 1. DIGITAL TOOLS AND THE COVID-19 PANDEMIC



**Angela Coulter**

The World Health Organization defines patient empowerment as “a process through which people gain greater control over decisions and actions affecting their health”. It is a policy goal espoused by many national governments, but making it a reality has proved challenging.<sup>3</sup> This was especially true at the height of the COVID-19 pandemic when healthcare staff working under intense pressure felt they had to resort to directive rather than collaborative approaches to prevent virus transmission. Use of healthcare services was estimated to have decreased by about a third during the pandemic, and in many countries those requiring medical attention were forced to rely on telephone or online advice.<sup>4,5</sup>

While the restriction in direct access to professional help was no doubt disastrous for some, it helped to focus attention on how digital tools might be used to support patients at home, empowering them to have a greater role in their treatment and care and enhancing their sense of control over their health. Furthermore, if these tools were found to be beneficial, they might help to relieve pressure on overburdened health systems while reducing travel time and inconvenience for patients.

## The rise of digital tools

Health systems that had already adopted the use of digital tools to support patient empowerment saw large increases in uptake because the way patients accessed health advice during the pandemic needed to change. Some tools were rapidly introduced to enable remote monitoring. For example, pulse oximeters, an established cheap technology used for respiratory conditions, were widely implemented for patients with COVID-19 to enable self-monitoring of oxygen saturation levels.<sup>6</sup> Other digital tools may have helped to deal with pressure on services resulting from the pandemic and the public health response. Electronic questionnaires completed by patients after treatment to enable patient initiated follow-up, for example, could potentially reduce unnecessary attendance at outpatient clinics.<sup>7</sup> In some cases existing initiatives were sped up or adapted during the pandemic to empower people to self-manage their health when direct access to health professionals was restricted – for

example giving patients online access to their electronic medical records (Section 2) and the rapid development of digital decision aids to help patients make decisions about prevention and treatment (Section 3).

Myriad digital tools are now available aimed at supporting patients to take an active role in personalized self-care (see Table 1).

**Table 1. Examples of digital tools to support patient empowerment and self-care**

	Access and appointments	Online portals enabling choice of location and timing of appointments or online consultations; electronic symptom-monitoring systems to support patient-initiated follow-up
	Information and education	Online portals or smartphone apps providing access to reliable information about health conditions; apps plus email or telephone access to health coaching
	Record access	Online portals or smartphone apps enabling patient access to their electronic medical records, including the facility to add comments or amend incorrect information
	Self-management of long-term conditions	Smartphone apps providing information, advice and reminders; digital platforms to record and share personalized care and support plans; databases providing information about peer support groups, patient organizations and other community facilities; digital platforms to support management of personal care budgets; online pharmacies
	Self-monitoring	Wearable sensors to measure heart rate, etc; smartphone apps and other electronic monitors to measure blood pressure, blood glucose, oxygen saturation, etc; electronic questionnaires to monitor symptoms or track moods; electronic patient reported outcome (e-PRO) questionnaires to enable symptom monitoring and outcome measurement
	Shared decision-making	Online patient decision aids to support informed choice of tests, treatments or preventative strategies, with help to clarify patients' values and record and implement their preferences

No digital tool is a magic bullet. All require careful introduction with support and training for health professionals and patients and rigorous monitoring of their effects. As Sections 2 and 3 of this report show, digital tools are complex interventions that carry potential risks as well as benefits. Learning from these digital self-management tools, and adapting them where necessary or ceasing their use if they prove ineffective or inefficient, is an important priority for policymakers. In so doing, it is essential to take on board the experience and opinions of those at the

frontline of healthcare, both patients and clinicians.<sup>8,9</sup> Relevant outcomes to be measured will depend on the specific goals of the initiative but may include any or all of the following:

1. Usability and acceptability of the tool
2. Effect on patient–clinician relationships
3. Effect on physical, psychological or subjective health
4. Effect on health-related behaviors
5. Effect on self-management capabilities and sense of self-efficacy
6. Effect on resource use, costs and safety.

Each of these outcomes may be affected by factors specific to particular population groups, so ideally studies should also consider possible effect modifiers, including demography, multimorbidity, health literacy and other vulnerabilities.<sup>10</sup> Unfortunately such modifiers are rarely followed in single studies, and even if they were, the results are usually context specific and may not be applicable to different settings, countries or health conditions. Newer, faster, more continuous methods of evaluation may be required. These should be formative, aimed at generating continuous learning, and allowing for rapid modification where necessary, rather than the traditional summative studies, where results are produced long after the implementation process has been completed. In future it may be possible to use built-in electronic monitoring tools or artificial intelligence to measure the use and effectiveness of these tools, making evaluation simpler and quicker.<sup>11</sup>

## Unlocking access to patient records and aiding decision making

In the following sections, this report focuses on two examples that are fundamentally important in empowering and engaging people to make decisions around their health. First, if patients are to make informed choices, they need access to their information. When patients need access to their medical records, it should be readily available to them. Second, when patients are faced with decisions about their treatment, (digital) tools can support them to make informed choices, whether on their own or with the support of a clinician. The two case studies highlight the complexity of these interventions and the need for careful monitoring and adaptation to maximize beneficial outcomes.

## SECTION 2. PATIENT EMPOWERMENT THROUGH ONLINE ACCESS TO HEALTH RECORDS



**Maria Hägglund, Brian McMillan, Robyn Whittaker, Charlotte Blease**

The need for digital health solutions to manage health and care became more apparent than ever during the COVID-19 pandemic.<sup>12</sup> Patient empowerment is essential in such a health crisis. Empowerment requires both access to information and the tools and competence to make informed decisions.

During the pandemic, digital provision of information and access to care was implemented and adopted at rates never seen before. Having online access to personal health records has proved an important tool for patient empowerment.<sup>13-15</sup> To cope with social distancing measures, use of telemedicine soared and use of patient portals increased rapidly. In some health systems, platforms for telemedicine visits were offered only through logging into a portal, so patient access to online health records was spurred by video visits.<sup>16</sup> Patients were also asked to report COVID-19 symptoms through various mobile apps and to carry digital proof of vaccination and COVID-19 test results.

In parallel with this increased use of digital health solutions, the importance of accessible and structured health data was also emphasized by policymakers internationally. In the United States, a federal rule from the 21st Century Cures Act mandated US healthcare providers to offer patients access to all the health information in their electronic medical records without charge.<sup>17</sup> In Europe, the European Health Data Space was proposed in May 2022, with the aim to empower people to control and use their health data in their home country or in other member states and to offer “a consistent, trustworthy, and efficient framework to use health data for research, innovation, policy making, and regulatory activities, while ensuring full compliance with the European Union’s high data protection standards.”<sup>18</sup> In South Korea, the MyHealthWay app was launched in February 2021,<sup>7</sup> designed to give people control of their personal medical data with the plan to store all personal health records in a single app; by 2023 all medical records and health records, including data from personal ‘wearable’ medical devices, are expected to be integrated and saved into the app.<sup>19</sup>

## Box 1. Implementing access to patient records in three countries

### **England**

Adult patients in England can register for online services through a variety of providers.<sup>20</sup> Although 46.6 percent of patients had registered for online services and were able to access at least one online service in March 2022, only 13 percent were able to see their detailed coded record. The coded record provides basic health information held in their GP record but does not include free text consultation entries or record attachments such as hospital letters.<sup>21</sup> In March 2022 around 40 percent of patients were registered to book appointments online, and 46 percent were able to order repeat prescriptions online. Which parts of the primary care record are visible to patients is currently under the control of the GP surgery, although NHS England and NHS Improvement have announced plans to enable full prospective access by default to the primary care record in November this year. It is generally not possible for patients to access their secondary care hospital records online because progress away from paper-based records has been slow.<sup>22</sup>

### **New Zealand**

New Zealand has several different patient portals that provide electronic access to approximately 70 percent of primary care practices. Most people who sign up use them to make GP appointments or request repeat prescriptions, but, as in England, the degree of access to their health information through the portal is under the control of the individual general practice. There is generally no electronic access to hospital held healthcare information owing to the complexity and inconsistency of electronic records,<sup>23</sup> although the Ministry of Health has released a strategy to develop nationally consistent electronic access to personal health information.

### **Sweden**

A national patient portal provides Swedish patients with several online services. In contrast to England and New Zealand, the national portal includes appointment booking, prescription renewals, and full online access to electronic health records from both primary and secondary care, including free text notes and lab results. Record access was launched in one of Sweden's 21 regions in 2012 and has since spread throughout the country. Over 1.85 million people use the online health record every month, with over six million logins a month.<sup>24</sup>

There has been progress in many, mainly high income, countries in providing patients with access to their clinical records, but even in these countries not everyone can access their health records online (Box 1). We argue that there are good reasons to offer patients immediate and full access to their records to increase patient empowerment.

## Impact of COVID-19 pandemic on patients accessing their records

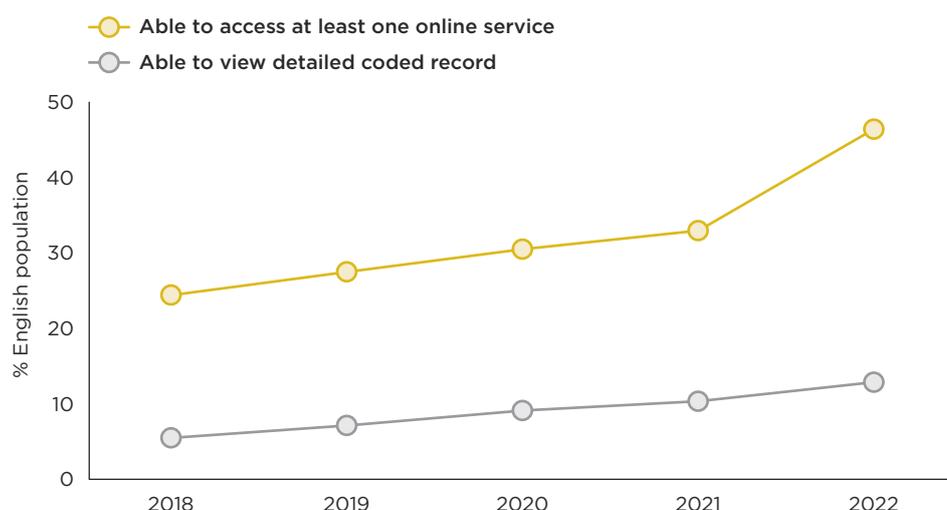
The implementation of digital health solutions during the pandemic was rapid, and we can only hypothesize why adoption was so much quicker than previous attempts. Before the pandemic, individual patients were the most likely to benefit from having access to digital health solutions such as online records and telemedicine. During the pandemic, however, the urgent societal need ensured that resources were quickly allocated to digital health. Healthcare professionals also had more incentives to use digital solutions that allowed communication of test results and for them to see patients without requiring a physical meeting, to reduce the spread of COVID-19. Patients across the globe were asked to provide data on their health, symptoms, and vaccinations on a magnitude never seen before.

As people began to see the benefits of having access to their health data, new opportunities for patient empowerment through health data access emerged. In New Zealand, the population was encouraged to sign up to a national COVID tracer app (with both QR codes and Bluetooth available for tracing contacts only after a positive COVID-19 case is detected) and following that, to a 'My Covid Record' digital health account.<sup>25</sup> This account provides access to personal COVID-19 vaccination records, a smartphone vaccine pass, COVID-19 test results, and more recently the ability to upload self-testing COVID-19 results. Approximately, 64 percent of the New Zealand population now has a digital health account.

In England, the percentage of people who were registered for and able to access at least one online service increased rapidly during 2021 when vaccination passes were introduced. But record access did not noticeably increase in the same way over the same period (see Figure 1).

In Sweden, where all patients already had online access to their records before the pandemic, the increase in use was substantial (see Box 2). Having immediate online access to COVID-19 test results was essential in empowering people to make informed decisions about their health and to take action to reduce the risk of spreading the virus.

**Figure 1. Increase in people registered for and able to access at least one online service in England<sup>26</sup>**



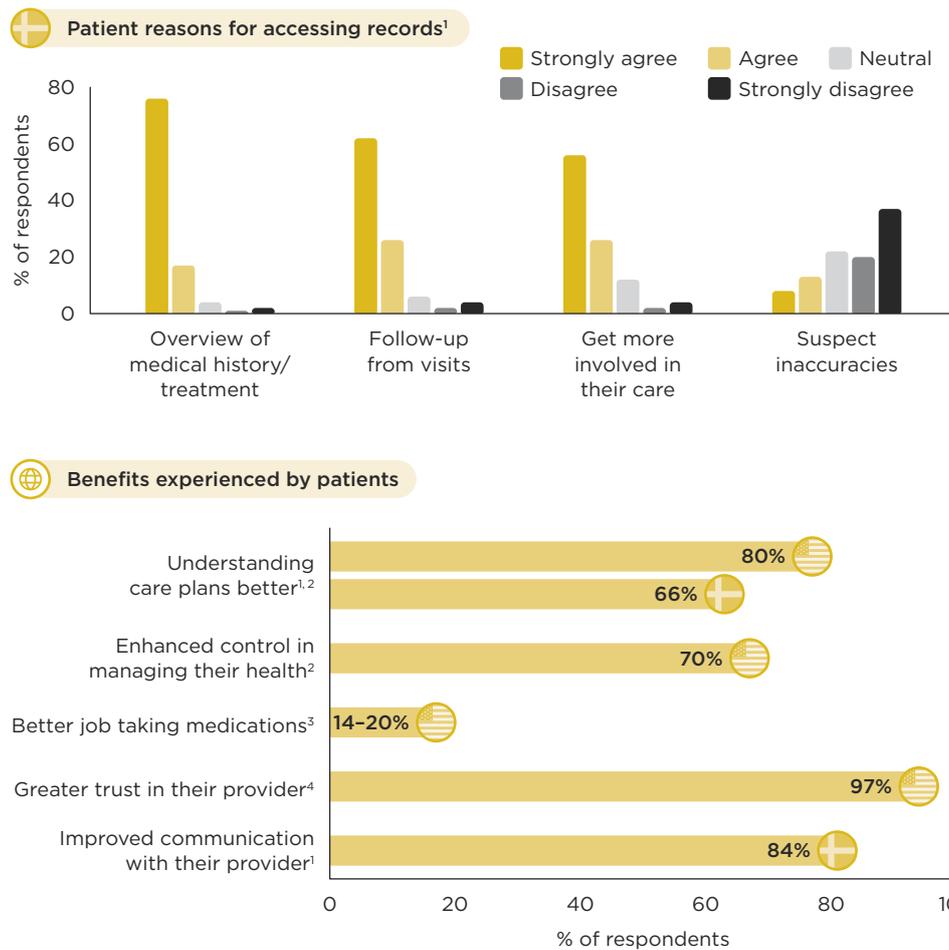
### **Box 2. Impact of COVID-19 pandemic on use of record access in Sweden<sup>27</sup>**

In April 2022, 6.2 million citizens (of the total population of 10.2 million) had logged into their online health records at least once, compared with 3.4 million in January 2020. This suggests that patients' motivation to access their health records online had increased, to access COVID-19 test results for example, and that a greater proportion of the population was accessing their records than ever before.

## **Benefits of patients' online access to their records**

Patients who have access to their records report using them to become more involved in their care, to follow up on doctor visits, and for an overview of their healthcare visits, test results and treatment history.<sup>28</sup> Beyond the advantages of access during the pandemic, multiple surveys show that most patients who access their online records (including clinical notes) are positive about the experience, reporting many benefits, such as understanding their care plans better,<sup>29</sup> greater trust in their provider,<sup>30</sup> and enhanced control in managing their health,<sup>31-33</sup> including doing a better job taking their medications<sup>34</sup> (see Figure 2 for examples).

**Figure 2. Patients' online access to their records**



Sources: 1: Moll et al. (2018)<sup>35</sup>; 2: Walker et al. (2019)<sup>36</sup>; 3: Blease et al. (2021)<sup>37</sup>; 4: Bell et al. (2021).<sup>38</sup>

In a US survey with responses from 21,664 patients, 96 percent of the respondents reported that they understood all or nearly all of their notes.<sup>39</sup> Patients in a New Zealand study also emphasized that, despite the risk that they might not understand everything, patients should still be granted access out of respect and because the information is about them.<sup>40</sup> In a Swedish study, 84 percent of patients agreed or strongly agreed that having access to their records online improved their communication with clinicians.<sup>41</sup>

It is not uncommon for patients to find errors in their records; 21.1 percent (n=4,830) of note readers in a US study found a mistake in their notes.<sup>42</sup> Although this might sound troubling, patients and their families have the potential to contribute to improved patient safety when given access to their full records.<sup>43</sup> An analysis of 20 randomized clinical trials related to sharing clinical notes, involving 17,387 patients, concluded that sharing electronic health records could improve patient safety.<sup>44</sup> This was also a conclusion reached by the US National Academy of Medicine in 2016.

They recommended patients have access to their records as a mechanism to improve diagnostic accuracy by closing feedback loops on care with more engaged patients.<sup>45</sup>

In addition to patients' positive experiences and the potential to improve patient safety, a meta-analysis of 20 randomized controlled trials found a beneficial effect on haemoglobin A1c reduction for patients with type 2 diabetes.<sup>46</sup> They also identified small studies showing improved effectiveness for outcomes such as blood pressure, anxiety, cardiac symptoms, and low-density lipoprotein cholesterol.<sup>47</sup>

## Risks of patients' online access to their records

Despite generally positive experiences reported by patients, there are risks and unintended consequences of giving patients access to their records. In a small qualitative study in England, patients described finding unexpected information in the record that they had difficulty interpreting. GPs reported spending extra time on documentation to reduce potential misunderstandings and on administration of record access and sometimes excluding information to prevent patients worrying.<sup>48</sup> In Norway, clinicians, especially in psychiatric care, reported keeping shadow records to prevent patients from accessing and potentially being harmed by the content of their records.<sup>49</sup>

Other concerns arise around the language used by clinicians. A large US-based study in three centers found that 11 percent (n=2,411) of patients who accessed their notes felt judged or offended by what they read, which included errors, surprises, forms of labeling, and disrespectful wording.<sup>50</sup> Linguistic analyses of documentation in the US recently found that stigmatizing language was significantly more common in notes written about black patients than notes about white patients,<sup>51,52</sup> and among patients with diagnoses of diabetes,<sup>53</sup> substance abuse disorders, or chronic pain.

But, when reflecting on the potential risks of access, we should also be mindful of the alternative – keeping the record and notes inaccessible to patients. When patients are unable or not encouraged to read their health information, they might miss out on important opportunities to support understanding and interpretation of their diagnosis and treatment plan.<sup>54</sup> Many patients report feeling anxious as they await test results, and instant access can reduce those concerns. Access to records might prevent results inadvertently being missed or not followed up by clinicians, particularly in transitions of care (from secondary to primary care, for example). As surveys show, patients who are more vulnerable

to communication breakdowns in face-to-face visits might have the most to gain from access. In short, not offering patients access might also incur negative consequences for care that must be balanced against access.

## Challenges in implementing patients' online health record access

Despite the benefits reported by patients, implementation of online record access is often slow and challenging.<sup>55,56</sup> In England, for example, the proportion of patients that can currently view their detailed coded record is low (13 percent).<sup>57</sup> The percentage of patients with access to all the data in their primary care record is likely to be much lower, although this information is not in the public domain.

### Clinician concerns

Barriers or resistance among clinicians often relate to concerns about malpractice,<sup>58</sup> technical challenges, fears of contributing to workload, increases in patient confusion and anxiety, safeguarding risks, or changes to current work practices.<sup>59</sup> Some concerns might be justified, especially with respect to rapid access to test results. A study in the US, for example, found that, after implementation of mandatory patient access to their online health record, there was a doubling in the number of messages sent by patients within six hours of reviewing a test result.<sup>60</sup> Moreover, healthcare professionals' concerns are strikingly similar across different countries.<sup>61,62</sup>

### Interoperability

Poor interoperability between electronic health record systems and other data sources remains a problem, causing fragmentation and frustration.<sup>63</sup> A comparison between implementation in Sweden and the Netherlands found that clinician resistance and technical challenges were common barriers.<sup>64</sup> Even when national regulations allow or mandate patient access, that might not be enough to guarantee patients easy access to their full health records.<sup>65</sup> Poor usability, challenging registration processes and accessibility requirements can also be barriers to adoption,<sup>66</sup> which can, in turn, be used as an argument to not pursue further implementation as patients are not inclined to use the service.

## Inequality

When offered, the extent to which patients access their records varies. Studies in Sweden<sup>67</sup> and Norway<sup>68</sup> have shown that older people, people with lower levels of education and those with lower socioeconomic status are less likely to read their records online. Reduced rates of access might be due to lower digital or health literacy (or both) or lack of other resources such as broadband connection at home.

In a US study, patients with a lower socioeconomic status were less likely to read their records, but those who did reported higher benefits than other users.<sup>69</sup> Perhaps these patients are offered less information initially in person, have more difficulty processing the information, or ask fewer questions, making the written information in the record all the more important.<sup>70</sup>

In qualitative studies from Norway and England, patients who chose not to read their records reported that they found them impersonal, unnecessary, best left to healthcare professionals, and incomprehensible.<sup>71,72</sup> A UK study among families with a teenager who was treated for cancer found a connection between coping strategy and use of a patient-controlled electronic health record,<sup>73</sup> indicating that patients or families with an avoidance coping strategy showed lower motivation to read their records. The choice to read will always be that of the individual patient. But for all patients to be able to make an informed decision and reap the potential benefits of reading their records, it's essential to lower the barriers to accessing records and to ensure that all patients are informed and encouraged to read them.

## Data security and confidentiality

Confidentiality and security of protected health information contained in electronic health records is a key consideration during any information exchange. Advanced security techniques and safeguards are required to allay patient anxieties, comply with local laws and protect data integrity.<sup>74</sup> These include reporting on data breaches, robust access controls, data encryption, authentication and authorisation, and audit trails.<sup>75</sup>

## Conclusion

During the COVID-19 pandemic, patients became more accustomed to remote and electronic methods of accessing care. Use of patient portals increased, including access to online health records. Yet, uptake remains low in some contexts – especially where barriers to access remain. These barriers are often related to prolonged and cumbersome processes to gain access or systems in which record access is not the default. Transitioning

to record access by default might lead to an increase in workload for clinicians in the short term but is likely to reduce workload in the longer term and make access more uniform and useful for patients. Studies have found that limitations in information access are a common cause of frustration for users of patient portals.<sup>76,77</sup>

To overcome these barriers, resources are needed to implement record access and to facilitate the process of gaining access (see Box 3). The default should be enabling record access while implementing flexible functionality to ensure access can be delayed or blocked in high-risk situations. In England, for example, records access will become the default in November 2022, and GPs will need to choose when to restrict access and be able to justify why access should be restricted.

Granting access to records for patients will require education interventions to support clinicians and encourage more confidence in sharing notes and in writing notes that patients will read, as well as greater guidance about the benefits and risks of note reading among patients. Patients need greater support for digital literacy, which is now considered a social determinant of health. Education of users will, however, never be enough unless we also improve the design of online solutions to access health records to make them useful for patients without overburdening health-care professionals.

As health systems around the world digitize, developing systems that will enable patients to access their patient records will become an increasingly important way of empowering patients to make decisions about their health and care.

## Key recommendations

- Decision-makers globally are encouraged to ensure their populations have easy online access to their health records.
- Investments are required in several areas:
  - technical infrastructure, including interoperability of health data
  - support in legislation
  - education of both patients and healthcare professionals
  - well-designed patient portals with high usability, including support for patients (e.g. how to use the portal, explanations of content and functionality, glossary of medical terms).
- We recommend learning from current implementations, in which default patient access increases patient adoption and use, but flexible solutions to delay or block access can be used in high-risk situations.

## SECTION 3. WHAT CAN WE LEARN FROM RAPIDLY DEVELOPED PATIENT DECISION AIDS PRODUCED DURING THE COVID-19 PANDEMIC?



**Michael J Barry, Martin Härter, Mowafa Househ, Karina Dahl Steffensen, Dawn Stacey**

The World Health Organization reports that over half a billion confirmed cases and over six million deaths are attributed to the virus SARS-CoV-2 worldwide.<sup>78</sup> This grim toll might be an undercount of the true burden.<sup>79</sup>

Since the beginning of the COVID-19 pandemic, the scientific, medical, and public health responses have been remarkable. Scientific developments include an understanding of viral transmission, the effectiveness of public health measures, and the deployment of effective vaccines and antivirals.<sup>80</sup> Although much work still needs to be done to ensure that these measures are equitably implemented worldwide, the speed of progress was remarkable. WHO estimates, for example, that over 11 billion vaccine doses have been given by May 2022; although distribution of vaccines varies widely.<sup>81</sup> These scientific developments have led to a wide variety of health decisions related to COVID-19 – including those made by governments, particularly by public health authorities; the vaccine and drug industry; and groups of health professionals. In this article, we focus on the decisions people had to make to prevent, test for, or treat COVID-19 for themselves or their families (see Box 3).<sup>82</sup>

We also consider the ways in which patients can be supported in making decisions about COVID-19 and other rapidly evolving health challenges. People were making health decisions in the setting of fast-moving scientific evidence and often in the face of widespread misinformation. We acknowledge that, in many settings, people did not have the resources to make these decisions.

## Box 3. Health decisions people and families faced during the COVID-19 pandemic



### Decisions about prevention: public health measures

- The degree to which they should isolate from others, including whether to travel
- Whether and when to wear a mask
- Whether to keep a vulnerable family member in an assisted living facility or nursing home



### Decisions about COVID-19 vaccination

- Whether to accept COVID-19 primary vaccination, including during pregnancy
- Whether to get a COVID-19 booster vaccination



### Advanced care planning decisions in the event of infection

- Home versus hospital care
- Treatment in an intensive care unit
- Treatment with mechanical ventilation
- Therapeutics for infection and prevention of transmission
- Accepting or declining monoclonal antibody treatment
- Accepting or declining antiviral treatments
- Duration of isolation
- Preventive therapies for exposed family members



### Decisions about healthcare for other conditions

- Seeking or avoiding care for acute and chronic illnesses, including cancer care, dental care, preventive care, and surgery

Based on the authors' experiences as clinicians and researchers, as well as a survey of Canadians, describing the decisions they faced during the early phases of the pandemic.<sup>83</sup>

## Shared decision-making and patient decision aids

Shared decision-making empowers patients (and others, including family members) to make informed values-based medical decisions between reasonable options with a clinician and often a clinical team (see Figure 3). The patient, once informed, participates in decision-making to the extent that they desire. In the process, the clinician shares information about the health condition, the management options, and the possible outcomes. The patient shares information about how they value the possible outcomes and ultimately, if they want, their preferences for management. Together, they reach and implement a decision informed by the best evidence and patients' preferences.<sup>84</sup>

**Figure 3. Six elements of shared decision-making**



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Patient decision aids are tools that can support shared decision-making. The International Patient Decision Aid Standards (IPDAS) Collaboration describes patient decision aids as “interventions designed to help people make specific, deliberative choices. They make explicit the decision, providing balanced information on the options and outcomes that are relevant to a patient’s health status, and help patients clarify personal values for features of options. They are intended as adjuncts to counseling.” Box 4 gives the criteria used to define a decision aid.<sup>85</sup>

### **Box 4. IPDAS definition criteria for patient decision aids**

- Describes the condition (health or other) related to the decision
- Describes the decision that needs to be considered (the index decision)
- Lists the options (healthcare or other)
- Has information about the positive features of the options (such as benefits and advantages)
- Has information about negative features of the options (such as harms, side effects, disadvantages)
- Helps patients clarify their values for outcomes of options by asking people to think about which positive and negative features of the options matter most to them; or describing each option to help patients imagine the physical, social, or psychological effects; or both.

Abundant evidence shows that shared decision-making supported by patient decision aids improves the quality of health decisions. A 2017 Cochrane systematic review of 105 trials, with 31,043 participants, covering 50 treatment or screening decisions, found that patient decision aids significantly improved participants' knowledge, accuracy of risk perceptions, and congruency between informed values and care choices compared with usual care.<sup>86</sup> They also reduced uncertainty about which decision to take (decisional conflict), indecision about personal values, and the proportion of people who were passive in decision-making. In a subgroup analysis, similar effects on knowledge and risk perceptions were seen for patient decision aids used in preparation for or during a consultation.

The many new health decisions people faced during the pandemic provided ample opportunities to use shared decision making and patient decision aids to help people make choices. But the urgency and disruption of the pandemic presented challenges to the traditional shared decision-making model and introduced a need for rapid development and deployment of decision aids.

## Lessons learned during the pandemic

During the pandemic, visits to clinicians were frequently postponed or canceled.<sup>87</sup> Traditional shared decision-making at consultations was no doubt greatly affected. But shared decision-making can also occur using telehealth with clinician interactions happening synchronously (such as by telephone or video calls) or facilitated through asynchronous communications (such as email or text messaging), which greatly accelerated during the pandemic.<sup>88,89</sup> Nevertheless, further research is needed to determine how ‘virtual shared decision-making’ can help achieve decision quality.<sup>90,91</sup>

Patient decision aids had to evolve through rapid development methods and were sometimes used outside of clinician relationships. Given rapidly changing information, frequent updating was often required to keep up with the evidence. Research on patient decision aids and their implementation that began before the pandemic was also greatly affected, as many studies had to be put on hold as staff were not able to perform study procedures or were redeployed to clinical work. New methods to study the dissemination, implementation, and effects of shared decision-making and patient decision aids were developed in parallel to evolving the processes and tools themselves.

## Environmental scan of COVID-19 decision support tools

With newly identified health decisions during the pandemic, we updated the Hospital of Ottawa’s international inventory of patient decision aids.<sup>92</sup> This inventory was established in 2006. Each decision aid is appraised against the IPDAS criteria for a patient decision aid (see Box 4), to minimize risk of making a biased decision (six items, such as providing information about funding for development of the aid), and other quality criteria, such as how the evidence was selected or synthesized.<sup>93</sup>

We conducted an English language environmental scan in August 2021 using Google searches with the following keywords in combinations: ‘coronavirus 2019’, ‘covid’, ‘vaccine’, ‘decision making’. We appraised the 51 COVID-19 educational resources that we found using the IPDAS criteria in Box 4. Of these, 13 met all six IPDAS defining criteria for patient decision aids (see Table 2). When scored against a checklist aimed at reducing biased decisions, all 13 gave equal detail to the various decisions that were covered by the aid, 12 provided a publication date (but few reported their update policy), 10 reported evidence sources used (without necessarily describing the strength of evidence), and five reported on funding.

**Table 2. Publicly available English language COVID-19 patient decision aids (search date August 2021)**

Developer	Date	Title of aid	Topic
 Ask Share Know (ASK) National Health and Medical Research Council Centre of Research Excellence	2021	Should I have the COVID-19 AstraZeneca vaccine?	Vaccines
 Canadian Rheumatology Association	2021	I have an autoimmune rheumatic disease, should I get a vaccine for COVID-19?	Vaccines
 Centre for Ageing Population Studies and Centre for Dementia Palliative Care Research, University College London	2020	Supporting you to make decisions while caring for someone living with dementia during coronavirus (COVID-19) and beyond	Dementia
 EBSCO Clinical Decisions	2021	COVID-19 vaccine: is it the right choice for me?	Vaccines
 Gerontological Society of America	2020	A COVID-19 decision aid: how do I choose when to interact with people or take part in activities outside my home during the pandemic?	Social distancing
 Nova Scotia Vaccine Expert Panel and the Reproductive Care Program of Nova Scotia	2021	I'm pregnant or breastfeeding. Should I get the COVID-19 vaccine?	Vaccines
 Patient Decision Aid Research Group, Ottawa	2020	During the COVID-19 pandemic, should I go to live elsewhere or stay in my retirement/assisted living home?	Assisted living
 Patient Decision Aid Research Group, Ottawa	2020	During the COVID-19 pandemic, should I or my family member go to live with family or stay in the long term care or nursing home?	Nursing homes
 Provincial Council for Maternal and Child Health, Ontario	2021	Vaccination in pregnancy and breastfeeding patient decision making tool: I am pregnant or breastfeeding. Should I get the COVID-19 vaccine?	Vaccines
 University of Massachusetts Medical School - Baystate Health	2021	COVID-19 vaccine in pregnancy decision aids	Vaccines

Developer	Date	Title of aid	Topic
 University of Waterloo, School of Pharmacy	2021	“I got AstraZeneca for my first dose. Which vaccine should I get for my second?” A guide to help you make an informed decision about your second COVID-19 vaccination	Vaccines
 University of Waterloo	2021	COVID-19 vaccine decision making tool: when it’s best to get the first COVID-19 vaccine available to you	Vaccines
 Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, UK Teratology Information Service, MacDonald Obstetric Medicine Society	2021	I am pregnant and have been offered a COVID-19 vaccination. What are my options?	Vaccines

A limitation to this environmental scan was that it searched only English language sources, so resources in other languages would have been missed. The Robert Koch Institute (Berlin), for example, developed many decision support tools for COVID-19 in German.<sup>94</sup>

## Three COVID-19 decision support tools

Even though the evidence evaluating COVID-19 decision aids is sparse, it is useful to consider published studies that tackled common decisions that people faced during the pandemic and how the developers endeavored to develop aids at pace while the evidence around COVID-19 was uncertain.

### Decisions about moving elders out of retirement or nursing homes

A team of Canadian researchers developed two decision aids early in the pandemic that focused on whether to move a resident out of their group living situation back into a private family home when outbreaks were beginning in many group living facilities.<sup>95</sup> The vulnerability of elderly residents to COVID-19 morbidity and mortality, as well as the risk of transmission, made this decision particularly salient. The researchers rapidly assembled a multidisciplinary stakeholder team and developed decision aids based on the Ottawa Decision Support Framework. The need for tools tackling this decision was evident from hundreds of responses to a newspaper article on the topic.<sup>96</sup>

Given legal differences between publicly funded nursing homes and private retirement homes in Canada, two decision aids were created. The aids were paper based as well as suitable for downloading as a PDF file. The researchers abbreviated some of the steps of the Ottawa framework to produce the tools in just two weeks. For example, decisional needs were gathered from the responses to a newspaper article that recommended family members be removed from these living situations rather than a more formal prospective qualitative research process. Evidence on location of care for elderly people was taken from reviews from before the pandemic, supplemented by available regulations and policies. The decision aid template used had previously shown effectiveness in 24 randomized trials.<sup>97</sup> Alpha and beta testing to revise the decision aid through user feedback were done with just a handful of people.

Despite the condensed approach and fast timeframe, the patient decision aids were endorsed by the Canadian National Institute of Ageing (as a 'trusted source') and disseminated in English and French through multiple websites. The decision aids were downloaded around 10,000 times in the first three weeks after publication. Although clinicians were involved in the development of the tool, most residents and families that used them to make the decision to stay in a group living facility or not did so on their own.

## **Decisions about advanced care planning**

The speed with which elderly people could contract COVID-19 and rapidly deteriorate lent new urgency to the documentation of people's wishes regarding hospital admission, intensive care and mechanical ventilation. Advanced Care Planning (ACP) Decisions, a non-profit foundation that supports patient empowerment by promoting shared decision-making, has previously developed short video decision aids focused on end-of-life planning.<sup>98</sup> Many of these decision aids have been certified by the Washington State Healthcare Authority to signal to users that they are trustworthy.<sup>99</sup>

Early in the pandemic, ACP Decisions produced some additional short videos, including 'What is COVID-19' and 'COVID-19 vaccination'. These videos are available through a provider or health system license with ACP Decisions and were therefore not identified in the environmental scan.

A study evaluating the decision aid videos as part of a non-randomized intervention has been published.<sup>100</sup> The intervention involved clinicians at 22 practices in a large New York City health system during the 'second wave' of COVID-19, from January to June 2021. The clinicians were offered training in end-of-life care communication skills, and patients aged 65 or

older were given the option of viewing the decision aid videos two weeks before or at a consultation (either in-person or virtual). During the intervention period, about 15,000 eligible patients had healthcare encounters, and the videos were viewed 5,302 times, mostly at consultations.

The study's primary outcome was documentation of an advanced care planning conversation during a healthcare encounter. Clinical records showed that 24% of patients in the intervention period from January 2021 to June 2021 had discussed advanced care planning compared with 18% in the six months before COVID-19 (October 2019–March 2020), and 13% during the first wave of COVID-19 (April–September 2020); both differences were statistically significant. A subgroup analysis found that increases in documentation of an advanced care planning conversation were larger for black and Hispanic patients than for white patients.

## **Decisions about COVID-19 vaccination**

Nine decision aids covering choices related to COVID-19 vaccination are listed in the Hospital of Ottawa's international inventory of patient decision aids.<sup>101</sup> They cover vaccine decisions for the general population, people with rheumatic diseases, and people who are pregnant or breastfeeding. The French College of Teachers in General Practice has published a decision aid about whether to have the Pfizer-BioNTech vaccine.<sup>102</sup> The developers wanted to tackle vaccine hesitancy through shared decision-making. They used the IPDAS criteria and a literature review and qualitative interviews with patients, focused on vaccine hesitancy, to develop the aid. A 'fact box' was developed with probabilities addressing vaccine efficacy and side effects. A steering group of clinicians and patients was assembled, and the two-page decision aid available as an online file for downloading was constructed iteratively through meetings and alpha testing with clinicians and patients. Beta testing was done during clinician–patient encounters. The decision aid was supported by the French National Authority for Health (again another trusted source), which provided input during the development. So far, no details have been provided regarding dissemination.

## **Conclusion**

The COVID-19 pandemic created a host of new health decisions for people and families. Empowering patients to participate in these decisions required rapid development of decision support tools, including patient decision aids, without formal evaluation. Several of the patient decision aids, however, used proven templates like the Ottawa Framework and the IPDAS criteria that have consistently led to improved decision quality.<sup>103</sup>

Decision aids that are developed rapidly and efficiently are desirable for many health problems beyond COVID-19. Box 5 summarizes some of the lessons from the case examples.

### **Box 5. Considerations for developing patient decision aids rapidly for urgent health problems**

- Use an existing framework for development, such as the Ottawa Decision Support Framework.
- Meet the IPDAS definition and quality criteria.
- Recruit a multidisciplinary stakeholder team to participate in development.
- Join with a 'trusted source' of information for both development and dissemination.
- Be flexible about how people will access the decision aid to make a more informed decision.

In addition, shared decision-making needed to evolve to encompass interactions outside the traditional face-to-face encounter with a clinician. The potential for technology to facilitate these interactions, both synchronously and asynchronously, holds great promise. In some cases, like the example of moving a relative out of a group living facility, decision aids were used for decisions that were being made largely outside the context of a clinician-patient relationship.

While the pandemic catalyzed new developments in decision support and shared decision-making, similar approaches are likely to be applicable to support other health decisions.

## SECTION 4. CONCLUSION AND RECOMMENDATIONS



While some key gaps in the evidence remain, the digital patient empowerment tools examined in the preceding sections clearly offer potential benefits to patients and to health systems. The two examples we have highlighted show the complexity of these interventions and the need for careful monitoring and adaptation to maximize the chance of beneficial outcomes.

Many people welcome the opportunity to view their medical records through a user-friendly portal. The evidence suggests that this can lead to improved communication with medical staff, better understanding of health information, and more effective self-monitoring. There is plenty of evidence that patients benefit from being given appropriate information and support to enable them to be actively involved in decisions about their care, so it was encouraging to learn that even during the height of the pandemic while evidence was still accumulating, patient decision aids could be rapidly produced to help people make personally relevant choices.

Many challenges remain, however. It is important to be reminded that a solution developed in one context should not be transplanted to another without careful implementation and monitoring. Tools and delivery plans should be co-designed with patients and clinicians to ensure they are fit for purpose and appropriate to the local context. Those described in the case studies may not suit everyone, especially people without access to smartphones and computers, or lacking the digital skills to use them. There is some evidence that people with lower health literacy and those with greater vulnerabilities can derive greatest benefit from these tools if they are designed with their needs in mind, but some people will require extra support and others may prefer more traditional routes to medical advice. Clinical leadership is key to effective implementation, but some clinicians may feel uncomfortable about the new developments or reject the whole notion of patient empowerment.

Most of the research has been carried out in high-income countries, and implementing digital patient empowerment in countries where health systems face more basic challenges or where cultural norms favor paternalistic care may not be viewed as a priority. Relevant resources and technical skills must be readily available – not always the case in low- and middle-income countries.<sup>104</sup> However, if these barriers can be overcome, we believe there is a strong case for the wider adoption of

a more personalized approach to healthcare delivery in which patients are encouraged and supported to take an active role in their care. Many of the digital innovations reviewed here could be useful in this endeavor.

Empowered and engaged patients, once hailed as “the blockbuster drug of the century”<sup>105</sup> but too often ignored in policy developments, may yet provide the key to more efficient ways of managing care. Digital tools may help to facilitate this, but those at the frontline of care, or their representatives, both clinicians and patients, should be invited to help shape all such developments to ensure they meet their needs and are of practical use in their local settings.

## Recommendations

- Policy makers should consider methods for empowering patients and personalizing care as key elements in their efforts to improve the quality, effectiveness, and efficiency of health systems. Digital tools may help to facilitate this.
- Those responsible for implementing digital tools should be mindful of the goals of care and the needs of patients and clinicians. The best way to achieve this is to involve patient and clinician representatives in co-designing the tools and their implementation.
- Care is needed when translating digital innovations from one setting to another. This requires continuous monitoring and formative evaluation involving all stakeholders, including patients and clinicians, to enable rapid modification when necessary.

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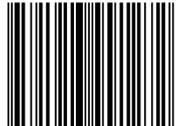
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