PATIENT EMPOWERMENT

What can we learn from rapidly developed patient decision aids produced during the covid-19 pandemic?

Supporting people to make decisions during the covid-19 pandemic created new opportunities for shared decision making and rapid development of patient decision aids, say Michael Barry and colleagues.

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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.1 This grim toll might be an undercount of the true burden.2

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.3 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; although distribution of vaccine varies widely.4 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 (box 1).5

Box 1: Health decisions people and families faced during 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

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.

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). 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.6

Patient decision aids are tools that can support shared decision making. The International 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 2 gives the criteria used to define a decision aid.7

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Box 2gives the criteria used to define a decision aid.
Box 2: 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. 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 learnt during the pandemic

During the pandemic, visits to clinicians were frequently postponed or canceled. 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. Nevertheless, further research is needed to determine how “virtual shared decision making” can help achieve decision quality.

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. This inventory was established in 2006. Each decision aid is appraised against the IPDAS criteria for a patient decision aid (six items, box 1), 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.

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 1. Of these, 13 met all six IPDAS defining criteria for patient decision aids (table 1). 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 1 | Publicly available English language covid-19 patient decision aids (search date August 2021)

| Developer | Date   | Title of aid                                                                 | Topic                                      |
|-----------|--------|-----------------------------------------------------------------------------|--------------------------------------------|
| 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                             |
| Canadian Rheumatology Association      | 2021   | I have an autoimmune rheumatic disease, should I get a vaccine for covid-19? | Vaccines                                  |
| 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 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                                  |
| 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                                  |
| 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                                  |
| 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                         |
| EBSCO Clinical Decisions               | 2021   | Covid-19 vaccine: is it the right choice for me? | Vaccines                                  |
| University of Massachusetts Medical School - Baystate Health | 2021   | Covid-19 vaccine in pregnancy decision aids | 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                                  |
| 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                                  |
| Ask Share Know (ASK) NHMRC Centre of Research Excellence | 2021   | Should I have the covid-19 AstraZeneca vaccine? | 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. 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. 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. Given legal differences between publicly funded nursing homes and private retirement homes in Canada, two decision aids were created. The aids were paper based, 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 before the pandemic, supplemented

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by available regulations and policies. The decision aid template used had previously shown effectiveness in 24 randomized trials.\textsuperscript{18} 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.\textsuperscript{19} Many of these decision aids have been certified by the Washington State Healthcare Authority, the only certification program in the United States, to signal to users that they are trustworthy.\textsuperscript{20}

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.\textsuperscript{21} 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 of 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 5302 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 26% 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 to 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.\textsuperscript{7} They cover vaccine decisions for the general population, people with rheumatologic 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.\textsuperscript{22} 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.

**Conclusions**

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 proved templates like the Ottawa Framework and the IPDAS criteria that have consistently led to improved decision quality.\textsuperscript{19} Decision aids that are developed rapidly and efficiently are desirable for many health problems beyond covid-19. Box 3 summarizes some of the lessons from the case examples.

**Box 3: 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.

**Key messages**

- The covid-19 pandemic has created many new decisions for people relating to the prevention and management of infection
- Patient involvement in decision making has been supported by rapidly developed decision support tools with endorsement by trusted sources
- Shared decision making can be implemented in new ways, including digital consultations facilitated by asynchronous communication by email and through patient portals in electronic medical records
- Evidence is beginning to emerge that these approaches might improve the quality of covid-19 related decisions and the rapid development and dissemination methods could be applied to other decisions urgently requiring decision support

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Collaboration. MB has expertise in health informatics and digital health to empower patients and clinicians. DS performed and provided the clinical experience of patient decision aid and the Canadian survey to identify decisions and related needs during the pandemic described in the paper. All authors contributed to the writing of the paper and developing the list of references. MB is the guarantor.

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