

# Patients are decision makers too

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## Abstract

Involving patients in decisions about their care attracts wide support in theory, but making it happen in practice has proven quite difficult. Embracing shared decision-making with patients will be more important than ever when healthcare organisations emerge from the COVID-19 crisis and must face the inevitable backlog of unmet health needs.

## Shared decision making

“Build back better” is the oft-heard plea from those hoping that something good will emerge from the COVID-19 crisis. Medical decisions made without the involvement of patients is one area that is ripe for improvement, but shared decision-making has been conspicuously absent during the pandemic. Why does this matter, and what can be done about it?

Prior to the pandemic, the requirement to inform and involve patients was moving up the policy agenda in many countries, with governments, health authorities, and professional bodies espousing more collaborative models of care, encouraged by patient advocates. Examples were beginning to emerge on what could be done to encourage a more equal relationship between patients and clinicians by involving patients in decisions about their care. Case studies from several countries underscored the importance of effective leadership, appropriate infrastructure, training, and practical demonstrations to encourage collaboration and partnership.<sup>1</sup>

It felt as if real progress was being made, but then along came COVID-19 and the mood changed. On the advice of public health experts, governments adopted a directive, authoritarian approach to dealing with the emergency, laying down rules of behaviour to prevent the spread of the virus. While this abrupt change represented a rational and probably unavoidable response to

the crisis, it was a major setback for advocates of patient and public involvement, especially when autocratic patterns of decision-making were replicated in the clinic or by the bedside.

Too often, doctors tell patients what they have decided to do – instead of laying out the options and asking the patient which they would prefer. This is the response of clinicians trained to believe they are the only expert in the room and are uniquely qualified to decide on the best treatment. In doing so, they ignore vital information essential to good decisions, namely the patient’s knowledge of their own situation, their experiences, and their values. A medical condition can usually be treated in more than one way, so it seems obvious that patient’s views and preferences should be sought. The result

otherwise is poor-quality decision-making, less adherence to recommendations, and more unwanted, inappropriate care.

**Patients who are actively engaged in the decisions about their condition feel more responsible and motivated to cope with their disease; this, in turn, improves compliance and adherence, and thus also treatment outcomes.**

Shared decision-making is the antidote to this. It is a process in which clinicians (doctors, nurses, therapists, and other health professionals) and patients work together to select tests, treatments, prevention strategies, or support packages, based on clinical evidence and the patient’s informed preferences. It involves asking patients about their experiences, listening actively, providing them with information about all feasible options, eliciting their preferences, and jointly agreeing on a plan of action. The aim is to help patients engage in a deliberative process, enabling them to





understand, think about, and weigh up the balance between likely benefits and harms of the different options.

For major or complex medical decisions, the process can be supported by the use of patient decision aids. These are evidence-based information packages outlining likely outcomes and uncertainties. They can take several forms, from brief summaries designed for use as conversation aids in medical consultations to more detailed booklets, websites, or videos for the patient to review at home. Such tools are available to support decision-making for many of the most common medical conditions, and their effectiveness has been demonstrated in numerous studies.<sup>2</sup> Most patients find this type of well-designed information helpful, including those from disadvantaged groups who are especially likely to gain benefit from it.<sup>3</sup>

Shared decision making can also strengthen people's capacity to manage long-term conditions. Evidence suggests that a collaborative

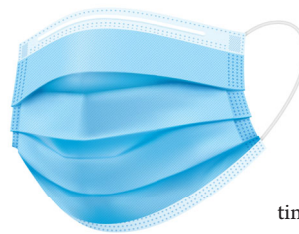
approach to care planning – learning about an individual's concerns, finding out what changes they feel able to make, and supporting them in doing so – leads to improvements in their physical and emotional health and their self-management capabilities.<sup>4</sup> Patients who are actively engaged in the decisions about their condition feel more responsible and motivated to cope with their disease; this, in turn, improves compliance and adherence, and thus also treatment outcomes.

### Making it happen

Shared decision-making draws together two of the major goals of modern healthcare – evidence-based medicine and person-centred care – into a pinnacle of excellence that many aspire to.<sup>5</sup> Recommended more than 30 years ago by a US Presidential Commission, shared decision-making was seen as a way to reform doctor-patient communications and make informed consent more meaningful. It explicitly recognises that clinicians and patients bring different, but equally important forms of expertise to the decision-making process. The clinician's expertise is based on knowledge of the diagnosis, likely prognosis, treatment and support options, and the range of possible outcomes, while the patient has expert knowledge of the impact of the condition on their daily life and their personal attitude to risk. Good-quality decisions draw on both types of expertise.

This approach is now widely recognised as relevant for people facing major treatment decisions when there is more than one feasible option, for decisions about screening tests and preventive strategies, for diagnostic decisions, for maternity care choices, for setting goals and developing action plans in relation to long-term conditions, for advance care planning for mental health problems, and for end-of-life care. However, despite its many advantages, the uptake of shared decision-making into mainstream care has been slow and highly variable.

A disturbing consequence of the health crisis is the fact that much of the care needed by patients with non-COVID conditions was halted, delayed, or went online, causing a huge backlog and lengthening waiting times that will take several years to work through.



Most people want to be involved in decisions about their care, but their opportunities to do so are often thwarted by clinicians unwilling, or unable, to cede control.<sup>6</sup> It is quite common for doctors to do most of the talking instead of listening to patients and responding to their concerns. Others believe they practise shared decision-making when in fact they don't – or think their patients don't want it when in fact they do. It is true that some patients who are used to a

more paternalistic style are surprised when they are expected to play an active part. They may need preparation and encouragement for this role, but the essential point is that this should be a *shared* process and not a delegation of responsibility to the patient.

Many clinicians believe that informing patients about options for treating or managing their conditions, asking about their preferences, and making decisions together takes far too long and cannot be accommodated within a standard consultation. Yet the evidence refutes this, showing it does not have to be burdensome if it is well-supported.<sup>7,8</sup>

### Dealing with the post-pandemic backlog

A disturbing consequence of the health crisis is the fact that much of the care needed by patients with non-COVID conditions was halted, delayed, or went online, causing a huge backlog and lengthening waiting times that will take several years to work through. The pandemic has also brought the shocking nature of health inequalities to the forefront of public awareness, and the unfair burden of ill-health borne by those in the most vulnerable groups, can no longer be ignored. Dealing with this reservoir of unmet need will require building a public consensus on health priorities, doing everything possible to eliminate unnecessary treatments, and providing effective support for self-care.

Whether it comes from leaflets or newspapers, much published health information has tended to present a biased, uncritical

perspective on the benefits of medical care.<sup>9</sup> This leads both patients and professionals to overestimate the benefits and underplay the harms of medical interventions.<sup>10,11</sup> This fuels the demand for unnecessary treatments, for interventions that prioritise longevity over quality of life, and for screening programmes that promise early diagnosis of conditions that cannot be cured or may not require treatment. In the post-pandemic world, the aim should be to correct this imbalance to ensure that a better-informed public will be more critical of false promises and less tolerant of clinicians who fail to involve them or ignore their views.

Providing access to reliable, evidence-based information about treatment options, benefits, harms, and uncertainties and ensuring that this informs discussions between doctors and patients are key steps in the path to high-value care. It has been shown to produce more realistic expectations and greater congruence between patients' values and treatment choices.<sup>12</sup> Informed patients often modify their expectations and opt for less aggressive interventions when they have a better understanding of the trade-offs between benefits and harms. Examples include reductions in rates of elective surgery and less use of unnecessary antibiotics.<sup>13,14</sup> A large US trial found that supporting patient involvement in treatment decisions resulted in fewer hospital admissions and fewer elective procedures, leading to an overall reduction in medical costs.<sup>15</sup>

Redoubling efforts to promote more collaborative relationships in which decisions are shared between clinicians and patients should be a central focus of efforts to build more resilient health services in the aftermath of the COVID-19 pandemic. This is what is needed to set us on the path to enhanced self-care and less dependence, fewer inappropriate interventions, more effective prevention, improved targeting of resources on those with the greatest needs, and better health outcomes.

### Conflicts of interest

The author declares no conflicts of interest.

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