

# Prepare for Health Care 2030

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#### **SUMMARY**

By 2030, nobody will accept poor results in health care. In most cases of chronic illness, people will benefit from becoming active partners in their own health care journey. Medical professionals will focus on communication skills to become trusted navigators rather than impersonal technicians. Patient advocates and multidisciplinary teams will be key sources of support in a borderless healthcare system. Patients and paymasters will drive these innovations. Doctors will recognise them as an opportunity to avoid burnout. There is room for optimism. The healthcare system has the potential to deliver better outcomes at a lower cost.

# **Key Words**

Health Care; Innovation; Patient Engagement; Patient participation; Communication

#### INTRODUCTION

Even before the COVID-19 pandemic, people expressed dissatisfaction with a healthcare system that seemed to serve the *business* and *bureaucracy* of health care rather than the mission.<sup>1</sup> In their 2000 report Rogers et al. concluded "expressions of dissatisfaction arise from a sense of being 'devalued,' 'dehumanized,' or 'disempowered' and from situations in which the 'rules' governing the expected health professional–patient relationships were broken." <sup>1</sup>

The sentiments patients and families who have accessed health care worldwide have expressed to us, and what authors, guests, and interviewees have shared in *The Journal of Health Design*, *The Health Design* podcast, and in the videos produced by Unfixed Media, respectively, suggest that even since 2008 little has changed in health care to address these levels of dissatisfaction.<sup>2,3,4</sup> In fact, outcomes for vulnerable patients at the margins, especially Black and other minority groups in North America, as elsewhere, remain disappointing.

Rogers et al.'s' report indicates dissatisfaction in eight domains:

- 1. **Communication:** How hospital staff communicate with patients, especially when "breaking bad news" or giving details of a poor prognosis.
- 2. **Information:** Difficulties in getting information concerning the patient's condition and likely prognosis from hospital staff.
- 3. Communication between acute and community health service providers: Lapses in patient care on discharge from the hospital.
- 4. **Personal care:** Instances in which the patient was not treated as an individual or where their specific needs had not been recognised.



- 5. Bureaucracy: Bureaucratic imperatives appear to override an individual patient's needs.
- 6. Diagnosis: Prolonged or late diagnoses after a patient complaint had not been taken seriously.
- 7. **Interventions:** Medical interventions offered or given that detracted from the patient's quality of life.
- 8. **Hospital environment:** Hospital(s) were dirty and run down or the wards were unhygienic.<sup>1</sup>

# Consumerisation of Health Care

Traditional businesses, including health care, that depend on customers traveling to a location with money in their pockets have started to fail. Two factors are driving this trend. First, people are accessing services and goods online more than ever before driven by the pandemic and the need to isolate at home. Accessing services online has reduced costs while increasing the convenience of what is available 24/7. Second, there is more choice and higher quality in what people are able to obtain conveniently. Because of these trends, people now expect continuous access and convenience from all services and goods they require, including health care.

According to a study by Epsilon,<sup>6</sup> 80 per cent of respondents indicated they are more likely to do business with a company if it offers personalised experiences, and 90 per cent indicated that they find personalisation appealing. This perspective implies that services informed by the context of their customer's situation are now favoured. Granted, those seeking health care may not have a choice about who they pay, as it is mostly dictated by insurance and geographic location, but as more specialised services are created outside of health care to address the needs of patient populations, traditional health care should take note. The eight domains noted by Rogers et al. give a roadmap for where this personalisation can start to take shape. Since 2019 those organisations that do not respond in this way are more likely to face an uncertain future.

This shift in focus to the individual consumer rather than the market as a whole is inevitable and many healthcare providers are already pivoting in very tangible ways:

- 1. Telehealth, once an exceptional route to accessing doctors, is now commonplace.
- 2. Patient advocacy organisations are more actively involved in supporting people with many conditions, including cancer and other chronic illnesses.<sup>8</sup>

Creative strategies noted during the pandemic that will play a part in the short- and medium-term include

- 1. New ways to provide patient-centred, convenient care, even when telehealth is not an option. For example, so-called curbside clinics or more cancer treatments delivered at home rather than in a hospital.<sup>9</sup>
- 2. The rise of the "cosmedics", advocates forcing us to think about and imagine more-than-human patient advocacy.<sup>10</sup>



# The Rise of Advocacy and Importance of Carers

Advocates who primarily sought greater funding for research are now serving as guides for those whose cause they espouse. Dr Alison Jones, an educator from the University of Sydney, predicted these changes in her 2010 paper. <sup>11</sup> She opens with what, in light of the pandemic, reads like a prophecy: "The internet with its many modes of publication, has facilitated growth of high profile advocates by giving them a powerful platform from which to be heard. Their success in garnering a sizable audience of chronic health sufferers is playing a central role in challenging traditional notions of authority in the health care field."

When clinics were forced to shut their doors to reduce of the spread of infection, people with specific conditions turned to the internet for information and guidance. Jones mentions the democratisation of medical power and the more ubiquitous availability of medical information, including scientific research papers, symptoms lists, treatment protocols, medication side effects, and usage guidelines. <sup>11</sup> It is not uncommon, especially in the case of rare diseases, for patients or advocates to know as much as, if not more, than their clinician.

The pandemic also boosted our understanding of the role of carers and the immense work they undertake. People with chronic illness often struggled to access health practitioners either because the service was overbooked or unavailable or because the person with the condition was house-bound due to the restrictions imposed due to the pandemic. Family members who were previously "surrogate decision makers" have been playing a more active role. Occasionally, health practitioners have advised them on how to care for their loved ones living some distance away. The idea of a doctor as the only expert who is able to address every aspect of the illness now seems untenable. Evidence of this is the fact that during the pandemic outcomes for people relying on access to a doctor in the traditional office setting have deteriorated.

#### The Rise of Chronic Illnesses and the Necessity of Care Teams

Generally incurable and ongoing, chronic diseases affect approximately 133 million Americans, representing more than 40 per cent of the country's total population.<sup>14</sup> Globally, approximately one in three of all adults suffer from multiple chronic conditions (MCCs).<sup>15</sup>

Long COVID cases are only increasing these cases of chronic illness and comorbidities globally. In a study by the UK Office of National Statistics that tracked more than 20,000 people following a positive COVID test, it is estimated that more than 1 in 10 who became infected with SARS-CoV-2 have gone on to get long COVID. <sup>16</sup> If the UK prevalence is applicable elsewhere, that's more than 16 million people worldwide. <sup>16</sup>

Chronic illness patients often turn to advocacy and online groups after repeated experiences of inadequate clinician care. Due to the complex nature and long-term disability of their illnesses, this population has the best opportunities for thriving with coordinated, multi-disciplinary care teams.<sup>17</sup> Teams may consist of the following: nurse case managers, medical specialists, clinical pharmacists, social workers/mental health therapists, and lay health workers.<sup>18</sup>



Patient care teams have the potential to improve the quality of care for patients with chronic illness and also to address levels of dissatisfaction in care across the board through a more specialised/personalised approach and by increasing opportunities for communication between the patient and their clinician(s). The very nature of "chronic illness" allows for clinicians to shift their focus from curing to caring.

# Clinician Burnout and Moral Injury

The workforce is another important aspect of this trajectory from larger market to individualised care. Without a robust, resilient community of providers, health care will be hard-pressed to make the switch to personalisation and customer service that consumers have come to expect.

The pandemic has greatly affected those who work within the provider setting. The literature suggests at least four areas of concern:

- 1. Training of doctors has been impacted such that the flow of newly qualified specialists into the system will be hampered.<sup>19</sup>
- 2. The wellbeing of healthcare staff already working in the system has been damaged.<sup>20</sup>
- 3. Absenteeism among healthcare workers increased.<sup>21</sup>
- 4. At least one study concluded that the toxic effects of stress may negatively impact cognition, learning, engagement, and empathy of medical students, and can also increase risks to patients and adverse outcomes.<sup>22</sup>

The good news is that the wellbeing of clinicians and patients alike are more closely aligned than ever. Improving how care works will benefit all involved.

# The Future

Currently, health care is not on pace to match consumers' desire for personalisation in a way that will meet the demands for better communication and truly individualised care (ie, optimal care). While outside companies and services are working to fill the gaps that the healthcare system has created, most patients and families are still fending for themselves within a broken system that too often causes harm. It is becoming more evident that the consumers of care will need to advocate for themselves and find new platforms for support and guidance.

By 2030, we predict that the landscape of health care will have evolved to include

- 1. A much greater role for patient advocates and multidisciplinary teams as advisors for people with specific conditions.
- 2. Healthcare practitioners who may not always be providing health services but will help families navigate the complexities of their local healthcare system.
- 3. Cheaper and more convenient access to health care or to professional guides in health care via telehealth.
- 4. More options for treatment delivered closer to home.
- 5. A greater emphasis on improved doctor-patient communication. This improved communication will not necessarily mean longer consults (as this would increase costs) but



via a more effective exploration of the context of the patient's issues—so-called social determinants of health—and more realistic appraisal of the limitations of the healthcare system and thoughtful guidance on how to navigate it well.<sup>23</sup>

For those involved in either seeking or serving in health care, we will need to take control over our own challenges. The wealthy knight in shining armour is not coming. We will need to turn for assistance to our neighbour, the one who is now a mouse click away.

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