

SELF-CARE AND HEALTH: BY ALL, FOR ALL— LEARNING FROM COVID-19

Maria Duggan

July 2020



About us

The Mitchell Institute for Education and Health Policy at Victoria University is one of Australia's trusted thought leaders in education and health policy. Our focus is on improving our education and health systems so more Australians can engage with and benefit from these services, supporting a healthier, fairer society. We are informed, independent and influential, with a proven ability to identify current and emerging problems in education and health and use evidence to develop achievable solutions.

Established in 2013, the Mitchell Institute is part of Victoria University, whose mission is to create exceptional value for any student from any background and uplift the communities in which it operates. Our close links with leading academics and institutes from across Victoria University means we are able to draw on cutting-edge research to inform and improve Australia's health and education systems.

About the author

Dr Maria Duggan is a Policy Fellow and Adjunct Associate Professor at the Mitchell Institute. She has an extensive track record in health policy development and implementation in the UK, Germany and the USA, as well as in Australia. In a long career she has been a practitioner, service manager and an academic, and was a mental health policy adviser to the UK Government from 1998 to 2007. Maria was the Director of Policy at the UK Public Health Association until its closure in 2010.

Acknowledgements

This report has been prepared by the Mitchell Institute as part of program of work on the role of self-care in population and individual health and wellbeing. The Mitchell Institute acknowledges the ongoing funding and support of the Australian Self-Care Alliance for the development of this paper and broader program of self-care work. Member organisations of the Australian Self-Care Alliance include Consumer Healthcare Products Australia (CHPA), The Hospitals Contribution Fund of Australia Ltd (HCF), Medicines Australia and the Pharmacy Guild of Australia. The Mitchell Institute and the Australian Self-Care Alliance would also like to thank and acknowledge the National Mental Health Commission for financially supporting other components of the overarching self-care program of work. The contract between Mitchell Institute and the Australian Self-Care Alliance is managed by specialist consultancy, THINK: Insight & Advice Pty Ltd.

Suggested citation

Duggan M, 2020. Self-Care and Health: By all, for all. Learning from COVID-19. Mitchell Institute, Victoria University.

ISBN: 978-0-6488001-2-5

Cover image by Tumisu via Pixabay

Contents

Summary	1
Introduction	2
Self-Care & COVID-19	3
Public messaging	3
COVID-19: Health and self-care inequality	3
Understanding self-care	4
What is self-care?	4
Benefits of self-care	5
Barriers to self-care	6
After COVID: a new business model for health care	6
Embracing digital health care	7
Implications for self-care	8
Box 1: Telehealth consumer case studies	9
COVID-19 and community-led innovations	10
Conclusions	11
References	13

Summary

Public messaging from Australian governments in response to the COVID-19 pandemic has emphasised the importance of self-care. Self-caring activities such as social distancing, wearing face masks and other preventative hygiene measure have been pivotal to the response to the disease by Australian governments and many others worldwide. The national campaign to tackle the virus with social measures deployed by citizens as well as the use of traditional public health interventions such as testing and contact tracing has been supported vigorously by a range of government, organisations, NGOs, media outlets and influencers in many sectors. The key message is that staying home and observing government guidelines is 'doing your bit' for others as well as yourself.

At the same time, healthcare systems and organisations have undergone extraordinary and rapid transformation, implementing with speed, and at a scale that was unimaginable a few months ago, a range of changes including telemedicine, digital triage, integrated care systems to assist in the management of caseloads and new workforce models involving multidisciplinary teamwork and role flexibility. These changes have the potential to address a range of long-standing inefficiencies and inequities in current operational models, provided efforts are made to mitigate any more negative consequences. There is some evidence that people became afraid to seek help from health services from fear of exposing themselves to COVID-19 infection. Some measures have acted as obstacles to patients accessing healthcare, putting their health at risk and there may be quality and safety risks from the development of an unregulated marketplace in digital health services, including telemedicine. However, many of these disruptions to traditional models also have the potential to support self-care and deliver better prevention of both communicable and chronic diseases by enhancing direct interactions between individuals and professionals and achieving greater personalisation of self-management of established health conditions.

Some have argued that the public messaging has shunted the responsibility for managing the risks of the pandemic away from governments and onto individuals. Others suggest that the emphasis on personal responsibility in the context of the pandemic ignores or denies the vast body of evidence that health is affected, for better or for worse, by a wide range of social factors, which may be more influential than individual characteristics in creating and managing certain of health risks. Whilst both critiques may have some validity, they do not tell the whole story. Several observations emerge from the experience of the pandemic. The most important of these are:

1. It is now clear that the management of health risks arising from infectious diseases necessarily involves actions by individuals as well as by health services and governments.
2. Health services have demonstrated through changed processes and practices that that they have a role in helping people to prevent communicable disease and to remain healthy during a public health crisis, and that they can apply the evidence emerging from these innovations to work differently to prevent and manage both communicable and chronic disease and support better self-care and self-management by individuals and communities.
3. The recognition at policy level that self-care happens in a social context and that the benefits of good self-care reach far beyond the individual to society at large has clear implications for the ethos and priorities of future health policy. The lessons of the pandemic must include a new direction for health policy, emphasising and investing in prevention and strengthening the health resilience of the population by enabling better self-care by all.

Introduction

The COVID-19 pandemic has disrupted taken-for-granted freedoms and ways of life for billions of people across the globe. Many of the more restrictive aspects of these shifts are expected to be temporary and to be relaxed as and when nations manage to contain or suppress the virus. Some may be permanent. Amongst the many changes, there has been an explicit recognition of the important contribution which individuals can make to overall population health by protecting their own. There has also been an extraordinary and rapid evolution of health and care systems and organisations to support individuals to manage their own health risks effectively. Both developments have the potential to function as game changers for how Australia manages the health of the public in the future.

The pandemic has revealed, as never before, the importance of effective self-care for individuals and communities in responding to communicable diseases. Self-caring activities such as social distancing, wearing face masks and other preventative hygiene measures, have been central to the response to the disease by Australian governments and many others worldwide. Whilst these measures undertaken by individuals have long been understood to be effective, alongside vaccines, in managing other viral illnesses which circulate in human populations, including influenzas, they have achieved a new salience in relation to COVID-19. The [Australian Health Sector Emergency Response Plan for Novel Coronavirus \(COVID-19\)](#) effectively set out a process to ensure that the management of the pandemic was to be co-produced by individuals, health services and governments working in partnership [1]. The Australian public was expected to self-care to reduce risks to individual health, avoid overwhelming health care services and to ‘flatten the curve.’

The scope of the self-caring measures set out in the Response Plan included the importance of staying healthy by protecting mental health, having a healthy diet, undertaking physical activity, and maintaining access to medicines. The Plan addressed the distinct needs of vulnerable groups including people living in residential care, Aboriginal and Torres Strait Islander communities and people with chronic conditions. It was supplemented by a range of online resources for individuals and health professionals, reprising the central message about the contribution of self-care to the control of the virus and providing information and practical advice about how to self-care during the pandemic. At the same time, health services were rapidly implementing measures to create capacity to treat COVID-19 patients and reduce the risks of viral transmission by reducing contact and reshaping interactions between health professionals and patients [2].

Whilst the messaging to support the Plan was subjected to initial criticism from, amongst others, the [Australian Medical Association](#) [3] and not all aspects of addressing the health emergency have been seamless, particularly around supply chains for personal protective equipment (PPE) [4] it is undeniable that the \$2.4 billion investment in the healthcare sector, has ensured that Australia has fared much better than many other countries in confronting COVID-19. These investments have rapidly driven health service adaptation and recognition of and support for proactive self-care by individuals. At the time of writing, Australia had one of the [lowest COVID-19 mortality rates per capita globally](#) [5]. The recent spike in case numbers seen in Victoria and the risk of further waves of infection means that vigilance must be maintained. Strategies and developments which have been so important in the first wave are likely to be sustained and extended. These shifts could be the early signals of powerful transformations of health policy, healthcare practices and, critically, in public understandings of health risks and of prevention.

There is a poignant irony in acknowledging that the pace and scale of the crisis generated by, possibly, the world’s greatest public health crisis may drive through radical changes which

have the potential to be of benefit to the overall health of the nation in the longer term. These benefits will be much greater if the vital contribution of self-care to the management of COVID-19 is mainstreamed and applied to the prevention and management of chronic diseases as well.

Self-Care & COVID-19

Public messaging

On Wednesday March 23rd, 2020, as the COVID-19 epidemic was escalating into a pandemic, millions of Australians began receiving text messages. The message read “*Coronavirus Aus Gov msg*”. *To stop the spread, stay 1.5m from others, follow rules on social gatherings, wash hands, stay home if sick. aus.gov.au.*”

The national campaign to tackle the virus with social measures undertaken by citizens, as well as the use of traditional public health interventions such as testing and contact tracing, was vigorously supported by governments and a range of organisations, NGOs, media outlets and influencers in many sectors. The core public message of the campaign is exemplified by this statement quoted on the online marketing industries platform [CMO from IDG](#) on March 30th 2020.

‘Now is the time for every person and every business – in Australia and around the world – to work together and help each other.’

This message was embraced and promoted by mainstream and social media in the same week in March. The front pages of The Canberra Times and key regional mastheads including the Newcastle Herald, Illawarra Mercury, Border Mail, The Courier in Victoria and The Examiner in Tasmania featured visual messages to highlight the critical role that every individual would play in the nation’s efforts to slow the spread of COVID-19 infections.

Under the headline 'In your hands' and a symbolic depiction of Australia, the newspapers implored their readers “*for the sake of the country you love, now is the time to protect yourself and others by following the official advice to stay home, practise social distancing and observe proper hand hygiene.*” The message also appeared over the coming week in social media feeds and on the front pages of over 150 local newspapers. The key message was that staying home and observing government guidelines was doing your bit for others as well as yourself. This message has not been confined to Australia. In the UK, taking care of yourself during the COVID-19 pandemic has been described as a ‘[civic duty](#)’ by the Health Minister [3].

Public attitudes towards the messaging in Australia and elsewhere have been overwhelmingly positive. Responding to the virus through ‘self-leadership’ is the ‘responsibility we all own’ according to one Australian commentator [6]. [Survey data from the UK](#) showed that the public have a strong degree of self-awareness about their own responsibility when it comes to resolving the crisis. The majority (75%) believed that they can personally influence whether they will become infected or not. Moreover, 76% reported that they follow the government’s guidelines of trying to spend less than an hour out of their home on a daily basis [7].

COVID-19: Health and self-care inequality

There is compelling national and international evidence that human health is affected by a wide range of economic, social, spatial, and demographic factors. Socio-economic influences on health are well understood in relation to the risks for chronic disease in Australia [8]. That the long recognised social gradient in chronic diseases is also seen in patterns of vulnerability to COVID-19 is one of the troubling lessons of the pandemic. Socio-economic deprivations as well as individual risk factors such as age and ethnicity are clearly implicated in the creation

of additional risks for some individuals and communities [9]. Having underlying chronic diseases intensifies the [risks of severe illness](#), hospitalisation and death from COVID-19. Evidence from the US, Italy and China shows that between 78% and 99% of people hospitalised with COVID-19 had a pre-existing chronic illness such as heart disease, diabetes, and high blood pressure [10]. Australian data on the impacts of COVID-19 on the most vulnerable populations is limited but data from the USA and the UK indicates that the elderly, those with disabilities, people in prison, Aboriginal and Torres Strait Islander communities, people with chronic conditions, and people from Culturally and Linguistically Diverse backgrounds, may be impacted disproportionately by COVID-19 [11, 12]. People from low socio-economic backgrounds, those who work in casual employment, and many other vulnerable groups, are also less likely to have the necessary financial flexibilities to make self-care activities such as home-working, access to technologies, physical distancing and self-isolation, a viable option for them [13].

Understanding self-care

The public messaging and the policy response to the pandemic emphasised the centrality of individual actions to complement strategies for managing the disease by governments, public health officials and health services. However, this was not described as self-care in these messages. Self-care as an active health measure was and remains an implicit concept. This may be because self-care is challenging to grasp conceptually and tricky to define. When it comes to self-care, social and cultural mores may affect individual interpretation of the term and there are widely divergent perspectives; from that of the black feminist writer Audre Lord who said that “*caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare*” [14] to the spiritual emphasis of the Daoist philosopher Zhuang Zi in the fourth Century BCE, “*The perfect man of old looked after himself first before looking to help others.*” [15]

Both quotations engage with the implicit idea that self-care is not only undertaken for individual benefit, but that it has the potential to have powerful social and political outcomes. This displaces the idea of self-care as a solely individualistic endeavour that has perhaps been exemplified by the iconic ‘because you’re worth it’ slogan from L’Oréal, which has been described as epitomising ‘*(the) banal narcissism of early 21st century capitalism; easy indulgence and effortless self-love all available at a flick of the credit card.*’ [16] Hence, care of the self, in some interpretations, is understood to be required for the achievement of human potential and is also intrinsic to notions of ‘the good life.’

However, the moral as well as the practical value of self-care as health protective activities carried out by individual citizens which have collective impacts is revealed, starkly, in the messaging around the pandemic.

What is self-care?

So, what is self-care for health? The simplest answer is that self-care begins with everyday behaviours, usually learned in childhood, such as washing your hands after visiting the toilet, cleaning your teeth, eating fruit, taking regular exercise or appropriately using over-the-counter-medications for minor illnesses. As the COVID-19 pandemic has demonstrated, self-care also contributes to preventing infections and chronic diseases and improving the health and wellbeing of people recovering from acute conditions and trauma and enabling people to live with chronic health conditions.

Self-care has been defined by the World Health Organisation (WHO) as “*the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider.*”

There is a plethora of other terms associated with it, including self-management, activation, self-directed care and health literacy, enablement, promoting independence, and collaborative care.

The term self-care carries with it an implicit emphasis on the autonomy and actions of individuals but the capacity to undertake self-care is not innate. Whilst it is tempting to assume that taking care of your own health and that of your family is just common sense, this is to deny the complexity of Australia's multicultural population and the lack of a unifying or consistent notion of common sense. After all, two decades ago, a chubby child was thought to be a healthy child. Today, childhood overweight and obesity is understood to be a long-term health risk [17].

Benefits of self-care

Hundreds of systematic reviews, randomised controlled trials and large observational studies have examined the impact of supporting self-care (often called self-management) for people with chronic conditions. A comprehensive summary of the international evidence for the efficacy of self-care is set out in the publication, '[Helping People to Help themselves](#)' from the UK Health Foundation [18]. The evidence indicates that supporting self-care has benefits for people's attitudes and behaviours, quality of life, clinical symptoms and use of healthcare resources. The evidence also suggests that it is the overall ethos of the response to condition management and risk reduction that is effective and not implementation of single, stand-alone interventions. There is a good understanding, based on this evidence, of the characteristics of effective approaches to supporting self-care with individuals. The UK Health Foundation suggests that these include:

- involving people in decision making;
- emphasising problem solving, developing care plans as a partnership between individuals and professionals;
- setting goals and following up on the extent to which these are achieved over time;
- promoting healthy lifestyles and educating people about their conditions and how to self-manage;
- motivating people to self-manage using targeted approaches and structured information and support;
- helping people to monitor their symptoms and know when to take appropriate action;
- helping people to manage the social, emotional, and physical impacts of their conditions (i.e. proactive follow up); and
- providing opportunities to share and learn from other service users.

There is limited information about how to scale self-care capability at population level. However, the experience of the pandemic sheds additional light on this and suggests that some of the individual-level elements are also important at population level; these include motivating and involving people, providing trusted information and professional support for individual action. In relation to managing the pandemic, the consistency and universality of the approach appears to have been a critical success factor, inspiring confidence, and collaboration amongst the population. It is important to note that disinformation or unclear or confused messaging from governments leads very quickly to [a loss of confidence](#) in the messenger and the risk of non-compliance [19]. This leads to the question of what might be achieved if similar, consistent Government messaging, about how individuals and health services can participate in health-risk reduction, could shape the Australian landscape for other infectious disease protection and for preventable chronic disease reduction as the world emerges from the pandemic.

The concept of self-care is complementary, and central, to the concept of prevention of both infectious and chronic diseases. People living with long-term chronic conditions are both the most frequent users of health care services in Australia and some of the most vulnerable individuals when it comes to being infected by, or dying from, COVID-19 infection. Therefore, chronic disease prevention should be considered an essential component of reducing the impacts of future pandemics. There is evidence that up to 80% of heart disease, stroke and type-2 diabetes, and over a third of cancers could be prevented through effective self-care, by eliminating or reducing exposure to the risk factors of tobacco use, unhealthy diet, physical inactivity and excessive alcohol consumption [20]. In Australia, this would mean that by 2025, an estimated 29,300 lives could be saved via the effective prevention of chronic disease [21]. Improving self-care practices and behaviours related to existing chronic conditions, is also associated with reduced numbers of hospital admissions and the occurrence of major health events [22-24].

Barriers to self-care

The ability to self-care is clearly integral to individual and population health protection yet many individuals and communities face obstacles in acquiring the skills, knowledge, and confidence to self-care effectively [25, 26]. There are numerous barriers affecting individual abilities to self-care. UK data indicates that health information is too complex for 60% of the public to understand [27] and, in Australia, up to 60% of the population is considered to have inadequate levels of health literacy [28]. A 2018 report on the State of Self-care in Australia suggested that barriers include low levels of health literacy amongst the Australian population and a lack of awareness of alternatives to the services provided by GPs and hospitals, such as pharmacies and allied health professionals [29]. It has been suggested that there is over dependence on health care services to 'take care' of the individual due to a risk-averse culture [27]. Moreover, these attitudes are not directly correlated with low levels of education, as many people with tertiary qualifications also exhibit poor health literacy. However, the overwhelming weight of evidence shows that people who lack knowledge about health and well-being are less able to take care of themselves and their families [30]. Low individual health knowledge is associated with higher use of health services, higher rates of preventable chronic disease and poorer health outcomes [31]

After COVID: a new business model for health care

Australia's health and government leadership success in flattening the COVID-19 curve has shown that health policies and health system arrangements are able to respond and adapt very quickly. This transformational process has taken place despite the persistence of well-recognised barriers to innovation imposed by the long-standing fragmentations between primary and secondary health systems, federal and state-level health systems and between public and private health systems [32]. These barriers are particularly detrimental to the prevention and management of chronic disease. The Grattan Institute reports that nearly a million Australians have been diagnosed with diabetes, but only about a quarter get the care that is recommended each year [33]. Ineffective management of chronic conditions in primary care leads to worse health outcomes and higher costs. Estimates of the costs of potentially preventable hospital admissions from chronic disease range from \$322 million to \$2 billion each year. And, of course, if Australians had better health overall, the country would be less vulnerable to COVID-19 or future threats from communicable disease.

The causes of these problems are complex and include adverse impacts of the Medicare fee-for-service model which 'encourages reactive rather than systematic care' [34]. Over the years, a number of reviews and reforms have proposed that these arrangements be reoriented. Medicare assessment, planning, coordination, and review items have been

grafted onto the fee-for-service model, but these payments are attached to individual consultations or treatments rather than to the quality of care and outcomes achieved for an individual or a community population overall. Moreover, the Medicare payment rules for these items have inhibited innovation in the way practices manage chronic disease, such as establishing multi-disciplinary teams with nursing and allied health staff to assess, plan, coordinate and review chronic disease prevention, in conjunction with GPs and specialists and patients [35]. The system, it is suggested, is *designed to deal with infectious diseases, wars and accidents*, not the chronic disease burden, which, up to now, has been the most pressing challenge for health systems across the globe [33].

COVID-19 has demonstrated that there is a direct relationship between risk factors for chronic disease and vulnerabilities to COVID-19. It is obvious that Australia's health system must be flexible enough to respond to both chronic and infectious diseases when required. More importantly, it needs a health system which recognises that the prevention of chronic diseases is a necessary and long-term strategy for managing the risks of future pandemics. The experience of the pandemic must become a catalyst for a new healthcare business model where the achievement of health and wellbeing by individuals and populations is valued and incentivised as much as the treatment of illness and injuries.

Embracing digital health care

Australia's response to COVID-19 had the dual aims of maintaining and expanding existing health system capability whilst mitigating the spread of the virus and protecting the health of the most vulnerable [36]. The response emphasised the essential role of primary care as well as that of hospitals. General practices, Aboriginal and Torres Strait Islander community-controlled health services, allied health services, pharmacies, residential and home care services and services for people with disabilities were all enlisted and resourced in the effort to support and protect the most vulnerable people. A vocal campaign was led by doctor's groups for the government to *'relax current restrictions around telehealth services by removing geographical constraints and permitting GPs to interact with their patients irrespective of location'* [37-39]. Doctors were asking for new flexibilities in the ways in which they were reimbursed for seeing patients with the recognition that these do not have to take place face-to-face. In response, the National COVID-19 Primary Care Response Plan expanded access to telehealth services and 24-hour health advice, provided for the establishment of dedicated community-based clinics to treat symptomatic patients and made rapid investments in education and training of the workforce.

Notably, the Government took the historic step of announcing that, within the \$2.4 billion health package to combat COVID-19, \$100 million would fund, temporarily, a *'new Medicare service'*, at no cost for patients. This would provide for telehealth consultations via phone or video by general practitioners, specialists, nurses, and mental health allied health workers to people at greater risk of COVID-19 infection, including those older than 70 years (older than 50 years for Aboriginal or Torres Strait Islander people), people with chronic conditions or who are immunosuppressed, women who are pregnant, and parents with new babies. A free 24/7 national triage phone line was also to benefit from additional funding of \$50.7 million. In addition, \$25 million was earmarked to fund Australians in isolation and at-risk groups to file their medication prescriptions online and have medicines home delivered free-of-charge [2].

These early developments were followed by the national roll out of a universal telehealth model for all Australians to enable health care access for both COVID-19 & non-COVID-19 symptoms through tele- or video consultations from home until September 30, 2020. A further \$74 million was provided to support telehealth consultations for those with mental health needs, including the development of a digital mental health portal and a "coronavirus hotline" for well-being and online support for health workers. \$10 million dollars was provided to

support the existing [community visitors scheme](#) (and to train volunteer visitors) to combat the social isolation caused by COVID-19 social distancing requirements. These incentives have had a dramatic impact on practice. Medicare Benefits Schedule (MBS) activity figures for the month of April 2020 reveal a steep rise in the number of consultations delivered by telehealth, comprising 36 per cent of all GP consultations and 37 per cent of specialist consults that month. The vast majority of GP telehealth was provided by telephone, reflecting similar figures from March. In April, 90.7 per cent of GP consults were by phone compared to 9.3 per cent by video conference [40].

These major strategic initiatives were supplemented by the somewhat piecemeal use of apps, some of which were already in circulation or being piloted within some local primary health networks in Australia [41-43]. As the pandemic has progressed, countries around the world have invested in the use of apps and other mHealth initiatives (the use of mobile or other wireless technologies in health care) to help communities manage the outbreak. The [European mHealth Hub](#) has curated nineteen of these apps to demonstrate their scope in providing support to individuals in responding to COVID-19 [44]. There are some signs that the supporting role of AI and other digital technologies in managing the pandemic is beginning to be recognised by health and social care agencies. Dr Norman Swan and the Digital Health Cooperative Research Centre organised a webinar on March 18, 2020, called '[COVID-19 and Digital Technology: The Roles, Relevance and Risks of Using Telehealth in a Crisis](#)', involving international experts [45]. New South Wales is planning to introduce a [virtual health care strategy](#) within the next five years. The Australian College of Remote and Rural Medicine is creating resources to support members in integrating these technologies into practice [46]. The Australian Digital Health Agency, having consulted on the issue of interoperability (the ability of health information systems to work together within and across organizational boundaries) in 2019, will publish a '[National Health Interoperability Roadmap](#)' in due course [47].

Implications for self-care

The rapid adaptations made by health and care services in response to COVID-19 have had many benefits. During the first six weeks after access to telehealth was expanded on 13 March there were 7 million telehealth services provided under the MBS, representing a substantial decrease in face-to-face interactions and subsequent reduction in risk of transmission between health service providers and consumers. [48]. Primarily, these shifts have supported the flattening of the curve by reducing COVID-19 exposure for both patients and health care providers, maintaining the primary health care frontline, diverting people from hospitals, and reducing the demand for personal protective equipment. These developments have also helped people to stay at home, supporting compliance with self-isolation and quarantine requirements. Whilst providers were expected to adopt a predominantly remote business model, face-to-face consultations took place when these were required because of the lack of technologies or clinical needs [49]. Beyond COVID, telemedicine can help to improve access to health services that would otherwise be unavailable or inaccessible for patients and carers to use because of distance, time or cost, which can inhibit the delivery of timely and appropriate health care.

Box 1: Telehealth consumer case studies

Case Study #1

Ms M has ankylosing spondylitis which she manages with exercise and pain medication. During the COVID-19 lockdown, the regular six-monthly review with the consultant rheumatologist was undertaken by phone, where she reported new symptoms. The consultant referred her to a specialist physiotherapist who carried out an assessment of function and pain by Zoom and then emailed a number of exercise sheets. The physio followed up with a Zoom call to guide Ms M through the exercise regime and offer adjustments and feedback. The Zoom sessions with the physio will continue monthly until Ms M has the next consultation with the rheumatologist. In the meanwhile, she has committed to doing the exercises daily and reports improvements in stiffness and pain as a result, as well as in her motivation to do what she can to manage her condition.

Case Study #2

Mr D was badly bitten on his upper arm by ants whilst gardening during the lockdown. Within a couple of hours, his upper arm had become very swollen, red and itchy and he was feeling unwell. He phoned his GP who discussed his symptoms and asked him to send a photo of his arm by email, which he was able to do during the consultation. The GP diagnosed a severe allergic reaction and prescribed prescription-strength anti-histamines and a steroid cream. The prescription was sent electronically to the local pharmacy who delivered the medication within two hours. Mr D was then able to manage the reaction at home and the inflammation subsided within 48 hours. On a previous occasion, Mr D had been hospitalised with cellulitis following an ant bite and delay in seeking treatment.

Examples of evidence to support the effectiveness of these innovations prior to the pandemic are diverse. There are now studies which demonstrate that technology-enabled healthcare responses may have particular efficacy in relation to the mental health burden of COVID-19 [50]. Specific evaluation data is necessarily limited given the short time scale since the COVID-19 Response Plan was implemented but this is beginning to emerge. For example, an evaluation of a shift to remote consultations in a regional public acute mental health setting during the pandemic found that the new model was workable although follow up data was required [51]. Other studies draw attention to the complexities of introducing such disruptive changes to patients and organisations and the likelihood of resistance to these changes by clinicians and patients, even when these show promise [52].

Moreover, the implementation of these changes is not without its challenges. GPs have expressed exasperation at the inconsistent messages coming from the numerous public health authorities and they report fearful patients turning up without warning, ignoring official advice to call first [36]. Concerns have been raised about the rise of telehealth corporates 'cashing in' on Medicare-funded phone and video consults, while leaving the patient with the most complex needs to GPs [36]. In addition, the rapid adoption of digital methods in response to the pandemic bring attendant risks from lack of regulation, quality assurance and accountabilities. There are questions about how human rights, privacy, and confidentiality will be maintained. Guidelines are required for when face-to-face medical assessment, diagnosis and treatment may be required [53]. It must also be recognised that many people, disproportionately those with the greatest needs, may not have (or cannot afford) smartphones or computers. Some, depending on location, have poor (or no) connectivity [54]. And, at the heart of this lies an important question about the appropriateness of these models for all Australians. Australian society is not homogenous, and one-size fits all approaches may mean

that the neediest, with the most health challenges and living with most deprivation, miss out once again. It will be important to find effective responses to this dilemma to ensure that, as beneficial changes and innovations are embraced and embedded in routine health care practice, they do not, inadvertently, widen the health gap.

The use of apps can enable people to share information such as heart rate and respiration with health services, even when these are accessed remotely, and receive support to safely manage health condition at home. This is of great importance when people are isolating but will remain of value when and if the virus abates. The **potential** importance of all these developments in creating a context for greater self-care at population levels is clear, at least in the context of the COVID-19 pandemic.

COVID-19 and community-led innovations

Broader societal shifts have also occurred in response to the pandemic. Familial and social networks have been disrupted, workplaces, restaurants, sports, and leisure facilities have closed, and people have been required to isolate themselves at home. In response, thousands of new 'mutual aid' groups have sprung up in Australia and internationally. The Australian website [Viralkindness](#) was established to act as an online community hub where people can find or set up local support groups, access resources and information and receive or offer to provide additional support, particularly for vulnerable community members. Viralkindness has already amassed over 300 listings for local support groups nationwide. Many of these groups grew rapidly, such as the [Love Your Neighbour Melbourne](#) that has, at the time of writing, more than 9,285 members. These networks use a wide range of communication methods, from traditional door-knocking and leafleting to mobile and e-messaging platforms and social media.

Community based services have also evolved their 'offer' to communities during the pandemic. In Victoria, DPV Health and the Hume Whittlesea Primary Care Partnership (HWPCP) have joined forces, with assistance from Whittlesea Community Connections (WCC) and Banksia Gardens Community Services, to develop the [Community Watch Partnership Project](#) in response to the disruptions caused by COVID-19. The Partnership has a shared interest to promote wellbeing amongst vulnerable members of the community impacted by COVID-19. Additionally, and importantly, in the context of the disproportionate impact of COVID-19 in some communities, these groups have been important sources of support for CALD communities through the provision of [multilingual information on COVID-19](#) as well as support for local women affected by domestic violence, isolated members of the LGBTQ community and others

Community-led developments have been vital, supportive pillars of government-led COVID-19 responses and have played a major role in enabling individuals and communities to care for themselves during the emergency. There is powerful evidence of the impact of bottom up approaches in health development, where people are seen as active participants, compared to the conventional "top down" approach, where people are considered as passive recipients of programmes designed for them by professionals and government officials [55]. Enhancing community ability to self-care requires the involvement and empowerment of people in promoting and caring for their own health [56]. The experience of the pandemic demonstrates that this needs strong, well-funded and trusted community organisations, with the awareness and credibility to engage with diverse groups and to work at grass roots level in partnership with health and other statutory services [57].

The energy and vitality of community-led programs during the pandemic stands in stark contrast to the lack of lay and patient voices in shaping the response to the emergency. Citing a *'precipitate loss of civil liberties and continued uncertainty around the efficacy of policies that*

profoundly affect how people live and work have eroded trust and prompt searching questions' the British Medical Journal, in a powerful editorial asked why, after decades of rhetoric about patient-centred care and public and patient involvement in defining health policy, this has not occurred during the pandemic [58]. This question is also a question for Australia [59]. The long-term sustainability of the pandemic management plan requires the public to understand that they are stakeholders and co-producers of the solutions. This cannot be achieved without a respectful relationship between the top and the bottom and the strengthening of local infrastructure for meaningful participation by local communities [60, 61]. To reap the benefits of the experience and lessons from COVID-19, health policy-making, more broadly, must involve listening to and collaborating with patients and the public [62, 63].

Conclusions

The COVID-19 pandemic has provided a powerful contemporary illumination and validation of the need for self-care capabilities and self-care support at population levels. During it, individuals have been required to care for their own health and that of their fellow-citizens in ways defined by Governments and public health scientists and in a context in which government and health systems were implementing, at scale, a range of complementary actions. This contrasts strongly with the fragmented approaches and lack of collaboration between citizens, services, and governments, which have, up to now, characterised Australia's response to preventable chronic disease [64]. The experience through the pandemic shows that enhancing individual and population capabilities to self-care to address health threats, wherever these arise and whatever their drivers, is of vital importance and offers immense benefits.

Several observations emerge from the experience of the pandemic.

1. It is now clear that the management of health risks arising from both infectious and chronic diseases necessarily involves informed and supported actions by individuals as well as by health services and governments.
2. There is a clear relationship between the risks of severe illness and death from COVID-19 and the presence of underlying, and preventable, chronic diseases
3. Health and community services have demonstrated through radically changed processes and practices that that they have a role in helping people to prevent communicable disease and to remain healthy during a public health crisis. The evidence emerging from these innovations may deepen the understanding of ways of facilitating self-care to prevent and manage chronic disease at population- level. Enhancing the ability of all Australians to care for their own health with support from professionals has the potential to be a catalyst for improved health of the nation in the future. This would strengthen the resilience of the population in the face of continuing threats from COVID-19 and emerging infectious diseases and reduce the avoidable burden of disease and premature mortality from chronic diseases.
4. The public messaging from governments and the health and scientific communities that individuals taking assertive action to protect their health and that of their families has a substantial social consequence. That the benefits of good self-care reach far beyond the individual to society at large has clear implications for the ethos and priorities of future health policy. The lessons of the pandemic provide a new direction for health policy, emphasising the value of investment in prevention and strengthening the health resilience of the population by enabling better self-care by all.
5. Self-care, by definition, is always undertaken by individuals, either alone or with support from others within the family or community or from health professionals and government. It is not merely common sense. There is long-standing evidence that

governments and policymakers are largely responsible for creating environments which either inhibit or enable self-care and play a major role in the development of self-care capabilities at the population level [65].

6. The role of governments in enhancing self-care capabilities extends far beyond a focus on healthcare to address the range of macro-societal factors that trap many individuals in a web of risk conditions which adversely affect their mental and physical health. These include social and economic deprivations, low levels of health literacy and lack of confidence about how to undertake self-care.
7. The need to tackle these unacceptable inequalities has been understood for decades but the importance and urgency of acting to directly redress them has been dramatically exposed by COVID-19. A robust, effective, policy response aimed at reducing the long-standing and well-understood societal deprivations which are so detrimental to health has been required from Australian governments during COVID-19, focussed on reducing both rates of infection and rates of mortality. The experience of the pandemic has demonstrated the vital importance of population resilience in the management of public health emergencies. Australia will be well prepared to respond to future threats if all its citizens can achieve their full potential for health through the reduction of chronic disease prevalence. This requires a population that is confident about working with health professionals and government to prevent and manage risks to health, wherever and however these arise. Enabling all Australians, individually and collectively, to undertake better self-care must become one of the pillars of a comprehensive strategy to strengthen resilience and health protection.
8. Governments also have the primary role in working with industries and health professionals to ensure the quality of new services and technologies through robust regulation. Governments must also set the priorities for the research effort, invest in research and, ensure that there is adequate monitoring and evaluation of the impacts of these developments on the health of the nation.
9. There is a vital role for community organisations and local governments in involving local people in the co-production of self-caring communities, tailoring these to meet the distinct needs of heterogeneous communities and places.

COVID-19 is not over yet. The worst may still be to come. The medium to long-term outcome depends on how societies manage the disease. For Australia, self-care offers an explicit strategy amongst the range of measures required for combating COVID-19 and future health threats. Looking to the future, self-care needs to become one of the norms that inform human social and political life, underpin human dignity, and support the common good. This requires all of us, individuals, organisations, institutions, and governments, to do their bit.

References

1. Australian Government Department of Health, *Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid-19)*.
2. Prime Minister of Australia, *\$2.4 Billion Health Plan to Fight Covid-19 11 March 2020*. 2020.
3. Australian Medical Association. *Letter to Ama Members About Covid-19 from the Federal Ama President 2020*; Available from: <https://ama.com.au/ausmed/covid-19>.
4. Woodley, M. *Concerns Grow over Global Ppe Supply Chains*. 2020; Available from: <https://www1.racgp.org.au/newsgp/clinical/concerns-grow-over-global-ppe-supply-chains>.
5. World Health Organization. *Who Coronavirus Disease (Covid-19) Dashboard*. [cited 2020 3rd July]; Available from: <https://covid19.who.int/region/wpro/country/au>.
6. Maak, T., *The Covid-19 Responsibility We All Own*. 2020: The University of Melbourne.
7. Connolly, J., *Public Attitudes and the Management of the Covid-19 Crisis: The Importance of Personal Responsibility*. 2020, LSE British Politics and Policy.
8. Turrell G, Stanley L, de Looper M, and Oldenburg B, *Health Inequalities in Australia: Morbidity, Health Behaviours, Risk Factors and Health Service Use*, Queensland University of Technology and the Australian Institute of Health and Welfare, Editor. 2006, Health Inequalities Monitoring Series No. 2. AIHW Cat. No. PHE 72: Canberra.
9. Niedzwiedz, C.L., C.A. O'Donnell, B.D. Jani, E. Demou, F.K. Ho, C. Celis-Morales, B.I. Nicholl, F.S. Mair, P. Welsh, N. Sattar, J.P. Pell, and S.V. Katikireddi, *Ethnic and Socioeconomic Differences in Sars-Cov-2 Infection: Prospective Cohort Study Using Uk Biobank*. BMC Medicine, 2020. **18**(1): p. 160.
10. CDC COVID-19 Response Team, *Preliminary Estimates of the Prevalence of Selected Underlying Health Conditions among Patients with Coronavirus Disease 2019 - United States, February 12-March 28, 2020*. MMWR Morb Mortal Wkly Rep, 2020. **69**(13): p. 382-386.
11. Kayman, H. and A. Ablorh-Odjidja, *Revisiting Public Health Preparedness: Incorporating Social Justice Principles into Pandemic Preparedness Planning for Influenza*. J Public Health Manag Pract, 2006. **12**(4): p. 373-80.
12. Pan, D., S. Sze, J.S. Minhas, M.N. Bangash, N. Pareek, P. Divall, C.M.L. Williams, M.R. Oggioni, I.B. Squire, L.B. Nellums, W. Hanif, K. Khunti, and M. Pareek, *The Impact of Ethnicity on Clinical Outcomes in Covid-19: A Systematic Review*. EClinicalMedicine, 2020. **23**.
13. Khalatbari-Soltani, S., R.C. Cumming, C. Delpierre, and M. Kelly-Irving, *Importance of Collecting Data on Socioeconomic Determinants from the Early Stage of the Covid-19 Outbreak Onwards*. J Epidemiol Community Health, 2020. **74**(8): p. 620-623.
14. Spicer, A., *Self-Care, How a Radical Feminist Idea Was Stripped of Politics for the Mass Market*, in *The Guardian*. 2019: UK.
15. Ausili, D., E. Rossi, P. Reborra, M. Luciani, L. Tonoli, E. Ballerini, S. Androni, E. Vellone, B. Riegel, and S. Di Mauro, *Socio-Demographic and Clinical Determinants of Self-Care in Adults with Type 2 Diabetes: A Multicentre Observational Study*. Acta Diabetol, 2018. **55**(7): p. 691-702.
16. Mulgan, G., *Because You're Worth It*, in *The Guardian*. 2006: UK.
17. Ebbeling, C.B., D.B. Pawlak, and D.S. Ludwig, *Childhood Obesity: Public-Health Crisis, Common Sense Cure*. The Lancet, 2002. **360**(9331): p. 473-482.
18. Da Silva, D., *Evidence: Helping People Help Themselves*. 2011, The Health Foundation.
19. Cushion, S., M. Kyriakidou, M. Morani, and N. Soo. *Coronavirus: Fake News Less of a Problem Than Confusing Government Messages – New Study*. 2020 June 12, 2020; Available from: <https://theconversation.com/coronavirus-fake-news-less-of-a-problem-than-confusing-government-messages-new-study-140383>.
20. World Health Organization, *Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020*. 2013: Geneva, Switzerland.
21. World Health Organization. *Noncommunicable Diseases (Ncd) Country Profiles 2018: Australia 2018*; Available from: https://www.who.int/nmh/countries/2018/aus_en.pdf?ua=1.
22. Ditewig, J.B., H. Blok, J. Havers, and H. van Veenendaal, *Effectiveness of Self-Management Interventions on Mortality, Hospital Readmissions, Chronic Heart Failure Hospitalization Rate and Quality of Life in Patients with Chronic Heart Failure: A Systematic Review*. Patient Educ Couns, 2010. **78**(3): p. 297-315.
23. van der Wal, M.H., D.J. van Veldhuisen, N.J. Veeger, F.H. Rutten, and T. Jaarsma, *Compliance with Non-Pharmacological Recommendations and Outcome in Heart Failure Patients*. Eur Heart J, 2010. **31**(12): p. 1486-93.

24. Purdy, S., *Avoiding Hospital Admissions: What Does the Research Evidence Say?*, T.K.s. Fund, Editor. 2010.
25. Australian Commission on Safety Quality in Health Care, *Australian Commission on Safety and Quality in Health Care Annual Report 2011/12*, ACSQHC, Editor. 2012: Sydney.
26. Ethnic Communities' Council of Victoria, *An Investment Not an Expense: Enhancing Health Literacy in Culturally and Linguistically Diverse Communities*. 20012, ECCV: Victoria, Melbourne.
27. PAGB, *Self-Care Nation Self-Care Attitudes and Behaviours in the Uk*.
28. Australian Bureau of Statistics, *Health Literacy, Australia*. Canberra: Australian Bureau of Statistics, 2008. 2008.
29. Duggan, M., W. Chislett, and R. Calder, *The State of Self-Care in Australia, Australian Health Policy Collaboration Commissioned Paper No. 02/2017*. 2017, AHPC: Melbourne.
30. Van Der Heide, I., J. Wang, M. Droomers, P. Spreeuwenberg, J. Rademakers, and E. Ueters, *The Relationship between Health, Education, and Health Literacy: Results from the Dutch Adult Literacy and Life Skills Survey*. Journal of health communication, 2013. **18**(sup1): p. 172-184.
31. DeWalt, D.A. and A. Hink, *Health Literacy and Child Health Outcomes: A Systematic Review of the Literature*. Pediatrics, 2009. **124**(Supplement 3): p. S265-S274.
32. Economist Intelligence Unit. *Healthcare; How Will Covid-19 Reshape Key Australian Industries?* . 2020 June 10th 2020; Available from: <https://eiuperspectives.economist.com/healthcare/healthcare-how-will-covid-19-reshape-key-australian-industries>.
33. Swerissen, H., S. Duckett, and J. Wright, *Chronic Failure in Primary Care*. 2016, Grattan Institute: Melbourne.
34. Harris, M. and N. Zwar, *Care of Patients with Chronic Disease: The Challenge for General Practice*. Medical Journal of Australia, 2007. **187**: p. 104-107.
35. Calder, R., R. Dunkin, C. Rochford, and T. Nichols, *Australian Health Services: Too Complex to Navigate: A Review of the National Reviews of Australia's Health Service Arrangements*. 2019, Mitchell Institute for Education and Health Policy, Victoria University: Melbourne.
36. Tanne, J.H., E. Hayasaki, M. Zastrow, P. Pulla, P. Smith, and A.G. Rada, *Covid-19: How Doctors and Healthcare Systems Are Tackling Coronavirus Worldwide*. BMJ, 2020. **368**: p. m1090.
37. O'Rourke G. *Revealed: The Rebates and Rules for Claiming the New Gp Telehealth Items*. 2020 March 13 2020; Available from: <https://www.ausdoc.com.au/news/revealed-rebates-and-rules-claiming-new-gp-telehealth-item>.
38. The Royal Australian College of General Practice. *Expanded Telehealth Items for Gps 2020*; Available from: <https://www1.racgp.org.au/newsgp/professional/expanded-telehealth-items-for-gps?feed=RACGPnewsGPArticles>.
39. Snoswell C, Mehrotra A, Thomas A, Smith K, Haydon H, Caffery L, and Smith A, *Making the Most of Telehealth in Covid-19 Responses, and Beyond*. 2020, Croakey.
40. Pulse IT. *April Mbs Figures Show Steep Rise in Consultations by Telehealth*. 2020 June 24th 2020 [cited 2020 July 4th]; Available from: <https://www.pulseitmagazine.com.au/australian-ehealth/5566-april-mbs-figures-show-steep-rise-in-consultations-by-telehealth>.
41. South Eastern Melbourne Primary Health Network. *Hello, My Name Is Nellie*. Available from: <https://www.semphn.org.au/resources/nellie.html>.
42. Byambasuren, O., E. Beller, and P. Glasziou, *Current Knowledge and Adoption of Mobile Health Apps among Australian General Practitioners: Survey Study*. JMIR Mhealth Uhealth, 2019. **7**(6): p. e13199.
43. Byambasuren, O., S. Sanders, E. Beller, and P. Glasziou, *Prescribable Mhealth Apps Identified from an Overview of Systematic Reviews*. npj Digital Medicine, 2018. **1**(1): p. 12.
44. European mHealth Hub. *Mhealth Solutions for Managing the Covid-19 Outbreak*. Available from: <https://mhealth-hub.org/mhealth-solutions-against-covid-19>.
45. Digital Health CRC. *Covid-19 and Digital Technology: The Roles, Relevance and Risks of Using Telehealth in a Crisis*. 2020; Available from: <http://www.digitalhealthcrc.com/telehealth-webinar/>.
46. Australian College of Rural & Remote Medicine. *Ehealth* Available from: <http://www.ehealth.acrrm.org.au/>.
47. Australian Digital Health Agency. *Better Connections: Your Health, Your Say*. Available from: <https://conversation.digitalhealth.gov.au/have-your-say>.
48. Snoswell, C., A. Smith, and L. Caffery, *Telehealth in Lockdown Meant 7 Million Fewer Chances to Transmit the Coronavirus*. 2020.

49. North Coast Primary Health Network. *New North Coast Telehealth and Mbs Resources*. 2020 March 30 2020; Available from: <https://ncphn.org.au/archives/news/new-north-coast-telehealth-and-mbs-resources-xhp>.
50. Zhou, X., C.L. Snoswell, L.E. Harding, M. Bambling, S. Edirippulige, X. Bai, and A.C. Smith, *The Role of Telehealth in Reducing the Mental Health Burden from Covid-19*. *Telemedicine and e-Health*, 2020. **26**(4): p. 377-379.
51. Kavoor, A.R., K. Chakravarthy, and T. John, *Remote Consultations in the Era of Covid-19 Pandemic: Preliminary Experience in a Regional Australian Public Acute Mental Health Care Setting*. *Asian J Psychiatr*, 2020. **51**: p. 102074.
52. Greenhalgh, T., J. Wherton, C. Papoutsi, J. Lynch, G. Hughes, C. A'Court, S. Hinder, N. Fahy, R. Procter, and S. Shaw, *Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-up, Spread, and Sustainability of Health and Care Technologies*. *J Med Internet Res*, 2017. **19**(11): p. e367.
53. Nittas V. *When Ehealth Goes Viral: The Strengths and Weaknesses of Health Tech During Covid-19*. 2020; Available from: <https://www.mobihealthnews.com/news/europe/when-ehealth-goes-viral-strengths-and-weaknesses-health-tech-during-covid-19>.
54. Thomas, J., C. Wilson, and S. Park. *Australia's Digital Divide Is Not Going Away*. 2018; Available from: <https://theconversation.com/australias-digital-divide-is-not-going-away-91834>.
55. Kickbusch I, *Self-Care in Health Promotion*. *Soc Sci Med*, 1989. **29**: p. 125-130.
56. Boivin A and R. G., *Community Initiative Co-Led with Patients Could Improve Care for People with Complex Health and Social Needs*. *BMJ Opinion*, 2020.
57. Ocloo J., *Being Heard, Not, "Seldom Heard": Democratizing Research with Diverse Communities During the Covid-19 Pandemic.*, B. Opinion, Editor. 2020.
58. Richards, T. and S. Scowcroft, *Patient and Public Involvement in Covid-19 Policy Making; Absent in the Early Stages of the Pandemic, It Must Now Move Centre Stage*. *BMJ*, 2020.
59. Prasad V, Sri BS, and Gaitonde R, *Bridging a False Dichotomy in the Covid-19 Response: A Public Health Approach to the 'Lockdown' Debate*. *BMJ Glob Health*, 2020. **5**.
60. Boivin, A., P. Lehoux, J. Burgers, and R. Grol, *What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation*. *The Milbank Quarterly*, 2014. **92**(2): p. 319-350.
61. Eurohealthnet. *What Covid-19 Is Teaching Us About Inequality and the Sustainability of Our Health Systems*. 2020; Available from: <https://eurohealthnet.eu/COVID-19>.
62. Redding D, *Service "Reset" Must Be Informed by Patients' Experience of the Covid-19 Pandemic*. *BMJ Opinion*, 2020.
63. Hanley B and Tarpey M. *Involving the Public in Covid-19 Research*. 2020; Available from: <https://www.hra.nhs.uk/about-us/news-updates/involving-public-covid-19-research-quest-blogbec-hanley-and-maryrose-tarpey/>.
64. Willcox, S., *Chronic Diseases in Australia: The Case for Changing Course, Australian Health Policy Collaboration Issues Paper No. 2014-02*. . 2014, Australian Health Policy Collaboration.: Melbourne.
65. Narasimhan, M., P. Allotey, and A. Hardon, *Self Care Interventions to Advance Health and Wellbeing: A Conceptual Framework to Inform Normative Guidance*. *BMJ*, 2019. **365**: p. 1688.



Mitchell Institute at Victoria University
300 Queen Street, Melbourne, Victoria 3000
+61 3 9919 1820
info@mitchellinstitute.org.au
mitchellinstitute.org.au