



AUSTRALIAN  
HEALTH POLICY  
COLLABORATION



# The State of Self Care in Australia

Commissioned Report No 2017-02  
February 2018

Australian Health Policy Collaboration

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## Acknowledgements

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The views expressed in this document are those of the authors of the report.

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## About the Australian Health Policy Collaboration

The AHPC is a public policy think tank at Victoria University focused on health and related public policy. AHPC's mandate is to translate the evidence of 'what works' to improve health outcomes in Australia and help reduce the impacts of socioeconomic disadvantage on health and chronic diseases in the population.

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## Foreword

Informed, health-aware citizens can play a critical role in contributing to the overall health of the Australian population. Individuals who understand what helps them to achieve or maintain good health, who act to address minor illnesses promptly and seek help from health care services when necessary are likely to live healthier and longer lives and to achieve better outcomes from health services when they need to use them. Health-aware individuals, actively taking care of their own health and that of their families, also reduce demand on health services, facilitating appropriate use of health care resources for those with significant health care needs.

Currently, the evident potential of responsible self-care carried out by informed individuals is not being effectively harnessed. Whilst self-care should be the first option for people wishing to maintain their own health, it is often not considered at all, by either individuals or clinicians. The reasons for this are complex and rooted in the ways in which health and illness have been thought about and organised in Australia and other developed countries. This narrative needs to shift in response to profound social changes, including in patterns of disease in the population.

Overwhelming evidence suggests that most individuals, families and communities are willing to take some responsibility for their health but that many need support to do so. The system contains numerous socio-economic and other barriers, which need to be tackled through new policy, better regulation and reformed practice. In the context of this evidence, the longstanding debate about whether health is an individual or a social responsibility is redundant. A healthy population is achieved through a functional relationship between active and informed individuals, health care services that empower and support people, and governments that invest in the capabilities of individuals and communities to look after their health.

As Australia struggles to respond to a rising tide of chronic diseases, two things need to happen. Firstly, governments, industries and citizens must understand and accept their joint responsibilities for health. Secondly, the healthcare system must adapt to respond efficiently and effectively to changing health needs and the scientific and technological opportunities of the 21st century. There are some emerging signs that a shift towards greater co-creation of health and wellbeing, requiring new kinds of relationships between individuals and professionals, is not only feasible but desirable. The Australian Government has, for example, committed \$20 million to pilot a new initiative to support people in using medications for chronic pain. Under the Pain MedsCheck trial, pharmacists will assist patients who are taking medication to deal with chronic pain lasting three or more months. However, as interesting as this and other current initiatives are, it is clear that discrete programs and projects are not enough to shift self-care practices in the population; this requires a sustained and comprehensive policy approach and proactive leadership.



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## Executive summary

This report attempts to assess the overall status of self-care in Australia in health policy and in the practices of individuals and health services.

The evidence considered in this review establishes that the state of self-care and self-management policy, programs and support in Australia is fragile at best. While many health policy documents talk about the importance of health literacy – the understanding and ability of individuals to understand and make better-informed choices about their health and health care – and sometimes about either self-care or self-management in health care, these terms are ill-defined, poorly understood and not backed by systematic and programmatic support. Typically, the terms are used but not defined in policy documents, with the benefits of both asserted rather than demonstrated.

Evidence suggests that people are mostly willing to take some personal responsibility for enhancing their health and that of their children and families through self-care and many see it as ‘natural’ to assume some responsibility for self-care. However, most health policies have focused, and continue to focus, on discrete programs and interventions to tackle risk factors for poor health such as smoking, obesity or lack of exercise. The term ‘self-care’ is not commonly used in Australian health policy documents; however, the term ‘self-management’, generally implying the active participation of individuals in the management of established health conditions, is used in a range of health policy statements. Both of these terms are implicit in the widespread development of peer group support programs, particularly for mental health and established chronic diseases. However, government-supported programs for self-care and self-management lack a firm conceptual foundation, are not integrated with the wider health system, and few are properly evaluated. Some good ideas and notable practices exist but these are not shared or promoted. As a result, self-care activity, including policy and best practice, is uncoordinated and invisible.

There is no evidence that people who most need support with self-care and self-management are being effectively targeted by existing programs. There is no coherent approach to establishing clear priorities for self-care, particularly in populations where the need is greatest, as evidenced by their poorer health. Indeed, there is strong evidence that people with poor access to financial resources – those in the lowest socio-economic quintiles of the population – have much worse health outcomes than other Australians. These people – 40% of the Australian population – are 33% more likely to have diabetes and 172% more likely to die from diabetes. They are much more likely to be obese, to do little or no exercise, and much more likely to smoke. Australia has been very slow to adopt evidence-based approaches for reaching these groups, including social prescribing and community referrals.

People living with chronic health conditions, their families and carers may be advised they need to engage in their own care, but receive little support to do so. There is likely to be a significant unmeasured and unmet demand for structured and supported self-care and self-management guidelines and programs, particularly amongst those at most risk of poor health and living in the most disadvantaged localities in Australia.

There are extensive and longstanding gaps in data and evidence in many relevant areas in which self-care and self-management are either implicit or explicit concepts, including in relation to the management of chronic diseases and their mental and physical comorbidities and the impacts of environments on health. This is compounded by the rise of technology: hand-held Internet-capable devices, applications to assist people with health conditions, and an endless supply of poorly-curated information. Those offering support for self-care and self-management include peers (people living with the same or similar health conditions), commercial interests promoting their products or services, and providers who may or may not disclose ideological prejudices or commercial interests.



In the absence of programmatic support, a regulatory framework which is fit for purpose in a rapidly changing landscape or systematic evaluation, a plethora of self-help and self-management resources have become available in the market. Much of the information available for self-care or self-management is unspecific, appears to be unqualified and there are concerns that it might be wrong. Some may be harmful. There appears to be a developing requirement for much better quality assurance or a 'trusted branding' process to reassure consumers about the safety and integrity of the information provided through these resources.

There are numerous obstacles to developing strong policy on self-care. The evidence considered in this review suggests these obstacles include that:

- Self-care is not seen as an essential component of a comprehensive approach to support and improve individual and population health
- While self-care is considered to be a personal responsibility there is a tradition and social expectation in which responsibility for maintaining health is substantially 'delegated' to doctors and the health system; and
- Self-care, is not, yet, a demand-driven concept; hence, policy is focused mostly on the supply side, with some limited attention paid to tackling poor health behaviours and supporting priority groups, albeit in piecemeal ways. Change may not be in the interests of health care providers given current business models based on fees for service, episodic care and rewards for treating sickness, not supporting health;
- Long-established institutional and professional practices and cultural and social mind-sets that prioritise the treatment of sickness and not the maintenance of health and disease prevention
- Reforms in the disability and aged care sectors in the last five years have focused on a shift to consumer-driven service delivery, and a greater emphasis on consumer choice of service and provider, with payment arrangements providing eligible individuals with a pre-determined fixed subsidy that may include some services which fit the self-care definition. However, their potential is undermined by the absence of a national strategy which provides definitions of self-care and additional guidance on the ways in which self-directed purchasing could enhance the opportunities for individuals to engage in self-care that fits within the objectives of these initiatives.

On the positive side, there is emerging evidence of the efficacy of both self-care and self-management in several contexts. For example, peer support has emerged as a component of health care and self-management. Peer support groups for people with like chronic health conditions, particularly mental health needs, are encouraged by a range of organisations and are referenced on state and federal health websites. Literature suggests individuals who attend 'illness-affiliated' peer-support groups manage their chronic conditions better and have better health outcomes than others. There is evidence that regular and ongoing peer support significantly improves and enhances the impact of clinical treatment.

Research on the self-administration of medications for the management of health ailments and for health improvement and maintenance suggests that this can alleviate health system strain. Evidence indicates 80% of Australian adults and 40% of Australian children have used over-the-counter (OTC) medications in any given month, and that annually, an estimated two thirds of Australian adults use at least one complementary and alternative medicine (CAM) product. There is little consideration in health policy and service provision of how to address this rising level of participation in self-care and self-management.

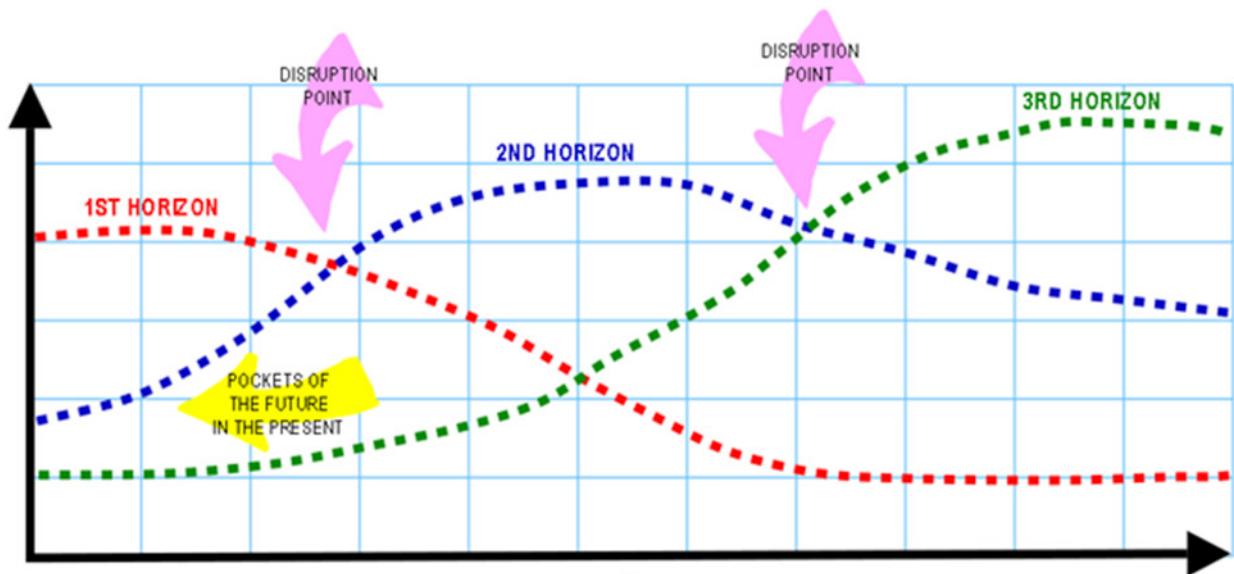
The National Strategic Framework for Chronic Conditions (Australian Health Ministers' Advisory Council 2017) and other developments in the broader policy environment, including moves to extend the scope of pharmacy practice and the roll-out of the National Digital Health Strategy, offer opportunities to translate

the policy rhetoric surrounding self-care into meaningful practice. The introduction of Health Care Homes to improve the quality of care for patients with chronic and complex conditions may offer opportunities for increased support of self-care. However, these developments are still not implemented at any scale in Australia (or anywhere else).

There may be lessons for Australia from developments in the United Kingdom (UK), where there are some signs of a significant strategic shift towards systematic support for self-care focusing on ‘patient activation’. An active, broadly-based Self Care Forum has had some success in influencing policy.

Overall there are significant challenges in embedding self-care into people’s lives and in public policy. Nevertheless, economic and political pressure will continue to mount as the rise of chronic diseases swamps health and social systems. Up to 80% of heart disease, stroke and type 2 diabetes, and over a third of cancers could be prevented by people self-caring (that is, eliminating the risk factors of tobacco use, unhealthy diet, physical inactivity and excess alcohol consumption).

In this context, the report takes account of the work of the International Self-Care Foundation (ISF) and concludes that the goal in Australia should be for incremental rather than radical change. The conceptual framework provided by the Three Horizons Model offers a way of understanding the current landscape for self-care in Australia and clarifying a process for bringing about change



**The Three Horizons Model (adapted from Sharpe, 2014) <sup>1</sup>**

Application of this model suggests that, in relation to self-care, Australia is currently at horizon 1. Self-care is not a health policy priority, not core business for most health care organisations and not promoted as a core competency for individuals. If this argument is accepted, the consequent challenge is how to begin to move incrementally towards horizons 2 and 3, bearing in mind that the broader context of policy and social change may not, as yet, be receptive to these ideas or open to disruption.

This report provides a context and makes a case for Australia to progress towards a national policy framework that will articulate the role of self-care in preventive health and in management of health conditions. This includes some immediate priority tasks, including to:

1. Agree next steps in the development of a broad consensus statement, involving key stakeholders, on



the role of self-care in promoting health and preventing disease in Australia based on agreed definitions and the best available evidence of benefit and impact;

2. Agree a communication strategy to support the dissemination of the consensus statement amongst key stakeholders
3. Consider how to develop a platform for national and international information sharing, best practice promotion and horizon scanning;
4. Identify priorities for research on self-care in Australia.



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## List of Abbreviations

ABS	Australian Bureau of Statistics
ACVR	Absolute Cardiovascular Disease Risk Assessment
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
ANDA	<a href="#">Australian National Diabetes Audit</a>
ASC	Australian Sports Commission
ASMI	Australian Self Medication Industry
<a href="#">BEACH</a>	Bettering the Evaluation and Care of Health
CAM	Complementary and alternative medicine
COAG	Council of Australian Governments
GAP	Global Access Partners
GPs	General Practitioners
HiaP	<a href="#">Health in All Policies</a>
ISF	International Self-Care Foundation
LGAs	Local Government Areas
MBS	Medicare Benefits Schedule
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
NHS	National Health Service [UK]
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
OTC	Over-The-Counter
PAM	Patient Activation Measure
SPAs	Strategic Priority Areas
TAC	Transport Accident Commission
UK	United Kingdom
US	United States
WHO	World Health Organization



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## 1. Introduction

Terms such as ‘looking after yourself’ or ‘taking care of yourself’ are used widely. Everyone knows someone who seems to be able to look after themselves particularly well, or, conversely, appears not to be looking after themselves or their families. This taken-for-granted, common sense understanding that there are things that individuals should do, and may want to do, to be as healthy as possible has not translated into widespread social and cultural understanding that acknowledges and supports health protective or health-enhancing behaviours at the population level. Many people’s willingness and ability to undertake self-care is not yet sufficiently advanced to serve as an effective means of tackling the avoidable aspects of chronic diseases or the inappropriate use of expensive health care resources.<sup>2</sup>

## 2. Purpose of report

This report provides an overview of the contemporary practices and expectations of self-care for health in Australia through a review of the literature on self-care in health policy, service provision, in consumer health organisations and within the Australian health services and health industry context. The report assesses the overall status of self-care in Australia and makes a case for promoting the importance of self-care in preventing and managing chronic disease by identifying and tackling barriers and influencing policy and practice.

### 2.1 Scope and limitations

The information discussed in this report is drawn from the literature and data from publicly available sources; this evidence base has numerous gaps. The analysis provided here has not been triangulated with direct research into stakeholder views, including the views of consumers, patients, clinicians, industry leaders or policymakers. Undertaking further research would be a productive step in developing the case for a comprehensive policy focus on self-care in Australia.

This report touches on the international literature on self-care only briefly, and no attempt is made to compare how Australia fares in promoting self-care as a core component of health policy. Overall, the literature indicates that several international patterns are emerging in relation to self-care and self-management, including the use of consumer-directed information on lifestyle change targeting the major risks to health, support for peer support initiatives, the development of ‘integrated’ chronic disease care models, and enhanced roles for pharmacists. There are also shared challenges in transforming the current way in which health is thought about and delivered to generate greater levels of confidence and engagement among consumers, including low levels of health literacy, lack of evidence to guide informed decision-making, and system inertia. We need collaborative international research into ways to inform future policy development in this area.

### 2.2 Terminology

The report highlights the ways in which self-care is understood and applied in various contexts and its relationship to a plethora of other terms including self-management, activation, self-directed care and health literacy, enablement, promoting independence, and collaborative care. The shifting terminology reflects variations in the context of the discussion, the target audience, the specific behaviours or practices being addressed and variations in the aims and objectives of interventions and programs. This changing terminology is problematic in that it can lead to imprecision in conceptualisation and use, challenges in locating evidence and difficulties and gaps in measurement. It confuses the research agenda and obscures specific priorities for

policy attention. It is also the case that many individuals and bodies are uncomfortable about the term ‘self-care’, considering it to be a euphemism for a lack of care.<sup>3</sup> Whilst recognising and discussing these issues, this report uses the term self-care throughout to describe the range of ways in which individuals care for their own health and the ways in which these could be supported in future.

### 3. The evidence for self-care

The evidence indicates that many people lack skills and confidence in managing their own health and health care and look for support and assistance from professionals. These people are less likely to play an active role in staying healthy.<sup>4</sup> They are less likely to seek help when they need it, to follow professional advice, and to manage their health when they are no longer being treated.<sup>5</sup> People who are not active in looking after their own health derive significantly worse outcomes from health service use.<sup>6, 7</sup> In fact, lack of ‘activation’ in self-care is a better predictor of adverse health outcomes than traditional socio-economic factors such as ethnicity or age.<sup>8, 9</sup>

The social and economic value of self-care has been demonstrated in several studies and has been acknowledged for some time. There is convincing evidence that better self-care by people with chronic diseases reduces costs in primary and secondary care.<sup>10, 11, 12, 13, 14</sup> People who lack the skills to undertake self-care effectively incur higher health service costs.<sup>15, 16</sup> Patient activation scores and cost correlations show less activated patients have initial costs approximately 8% higher than more activated patients, and 21% higher a year later.<sup>17</sup> At the same time, studies of interventions to improve engaged self-care show that those who start with the lowest activation scores tend to increase their scores the most, suggesting that effective interventions can help even the most disengaged.<sup>18, 19, 20</sup>

There is international evidence of positive impacts from ‘social prescribing’,<sup>21</sup> sometimes referred to as community referral, which is a means of enabling general practitioners (GPs), nurses and other primary care professionals to help people living in socially disadvantaged neighbourhoods to manage their health.<sup>22</sup> Social prescribing has been shown to provide significant alternatives or value-adds to health care planning, particularly when clinical treatments are not indicated, for:

- people’s nutrition and non-harmful behaviours or healthy choices;
- individual capability for health improvement;
- better health and community wellbeing; and
- Individuals’ connectedness to community.

Evidence suggests that there are three main benefits of social prescribing:

- improving mental health outcomes;
- improving community wellbeing; and
- reducing social exclusion.<sup>23</sup>

The [Active Script](#) and [Life Scripts](#) programs (1998 to 2007), funded first by the Victorian and then the Australian Government to systematically support GPs to promote self-care and positive lifestyle behaviours to their patients, can be seen as a form of social prescribing. Since their withdrawal, no substantial social prescribing or community-based referral schemes have operated in Australia.

Social prescribing, it is suggested, has been normalised in routine primary care practice in some places in the UK, suggesting that it can sustain transformative change in ways of delivering primary care.<sup>24</sup> In New Zealand,

the [Green Prescription Scheme](#) allows health professionals to refer physically inactive people to community resources and provide advice and monitoring of lifestyle change.<sup>25</sup>

An evaluation of a multi-national trial of a weight loss program found positive impacts in Australia and elsewhere.<sup>26</sup> There is some Australian evidence that clinician-delivered advice can promote physical activity and other kinds of behaviour change, but also that few clinicians provide such advice frequently.<sup>27</sup>

Some evidence points to the potential for savings from capitalising on consumer's willingness to seek advice on the treatment of minor illnesses from pharmacies instead of general practitioners.<sup>28 29</sup> Medicines are undoubtedly a cornerstone of treatment for many health problems and many strategies exist to help people to use medicines safely and effectively, but research in the area is poorly organised across diseases, populations and settings. There is a particular dearth of high-quality information about what works for children and young people, carers and people with multimorbidity.<sup>30</sup> This makes it difficult for policymakers, health professionals and others to find and use the evidence about what works and what does not. There are indications that social value is realised when individuals manage common health problems at home or with support from local pharmacies without involving the broader healthcare system. In this way, public resources for treating minor ailments can be redirected towards more serious illnesses that have large impacts on individuals and public health.<sup>31</sup> However, this value can only be realised when the risks of self-medication are understood and managed by individuals and professionals.<sup>32 33 34</sup> A recent Cochrane review identified the need for further research in this area, and called for the development of an evidence-based 'intervention taxonomy' to identify the strategies required to support consumers in decision-making in relation to the use of medications overall.<sup>35</sup>

## 4. Prevention policy in Australia

### 4.1 A failure to thrive?

Australian governments have, historically, had a strong presence in relation to prevention and population health promotion. In 1947 the Federal government passed the *National Fitness Act 1941* to improve the fitness of the youth of Australia and better prepare them for roles in the armed services and industry. Federal funds were made available at a local level through state-based National Fitness Councils, which coordinated promotional campaigns, programs, education and infrastructure for physical fitness. The Act was repealed in 1994 as fitness had become associated with leisure and recreation rather than understood as equipping people for everyday life and work. In 1975 the Victorian Government introduced the *Life Be in It* campaign, which promoted health and physical activity through advertising campaigns and funding community events, fitness programs and events. The campaign spread to all states and was federally funded. The campaign ended in 1981, with funding directed towards elite sports through the Australian Sports Commission (ASC). However, current plans to develop a [National Sports Strategy](#) and an enhanced role for the ASC, which is consulting on a definition of 'physical literacy', may represent a return towards population-level measures to enhance physical fitness and overall health. As noted earlier, from 1998 the [Active Script](#) and [Life Scripts](#) programs supported GPs to promote self-care and positive lifestyle behaviours, but these programs were terminated in 2007.

In many ways, it seems that, notwithstanding the numerous examples of good practice in place throughout the country (some of which are identified in Appendix 1), Australia has lost ground in recent years in relation to disease prevention and the promotion of individual engagement in health-enhancing activities, including self-care. The *Australian National Preventive Health Agency Act 2010* led to the establishment of the Australian National Preventive Health Agency in 2011, but it was [abolished](#) in June 2014. [The Council of Australian](#)



[Governments National Partnership Agreement on Preventive Health](#) was also abolished in 2014, removing \$374 million of funding [Moodie et al.](#) (2016) concluded that “Australia has had some outstanding successes in areas such as smoking, road trauma and heart disease. However, we lack a sustained, comprehensive and strategic approach to prevention, together with adequate funding, coordination and monitoring.” This “places Australia out of step with similar countries.”<sup>36</sup> In fact, as AHPC has noted in several reports, Australia’s spending on prevention and public health as a share of total recurrent health spending was 2% in 2011, much less than in New Zealand (6.5%) and Canada (5.4%).<sup>37</sup> The lack of policy and programmatic support for self-care, broadly defined, appears to be a reflection and a consequence of this low level of government investment in prevention.

### 4.2 Self-care rhetoric versus policy

The social and economic rationale for promoting greater levels of self-care in Australia is well understood and is implicit in past and current health policy. Figure 1 illustrates the ways in which policy reform and targeted investment in self-care is required to modify current trends in health service utilisation.

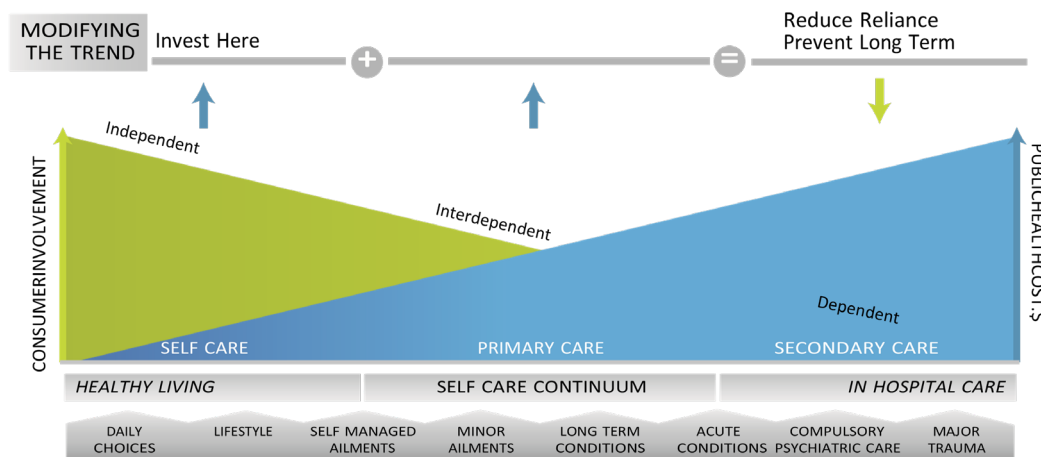


Figure 1. Modifying trends in health service utilisation through investment in self-care (Daley et al., 2013).

Progress towards this goal has been slow to non-existent despite policy rhetoric and growing evidence of effectiveness and favourable consumer attitudes. A 2014 Global Access Partners (GAP) report describes the outcomes of an independent cross-disciplinary (health professional) taskforce that examined the potential of self-care to improve individual and public health outcomes and play a greater role in health policy.<sup>38</sup> The taskforce focused on “three of the multiple components of self-care – access to medicines within the context of Australia’s National Medicines Policy, the role of community pharmacy in primary health care delivery, and health literacy as a universal enabler of greater self-care.” The GAP report notes:

*“the importance of health literacy and the role pharmacies and non-prescription medicines can play in supporting responsible self-care and reducing government expenditure. As well as enabling a more efficient health system, these factors are consistent with a growing desire by health consumers to become more involved in their own health care.”*

The focus on self-medication, whilst an important element of a comprehensive approach to self-care, should not impede the development of a better understanding of the multiple ways in which individuals attempt to practice it or of ways of supporting those judged to be effective. In this context, it needs to be acknowledged that in the Australian health system, it is vital to recognise and involve the private health industry in promoting

and supporting self-care. Many private health insurers offer healthy lifestyle promotion or chronic disease management programs to members, and this has the potential to expand.<sup>39</sup>

The Gap report recommends that self-care should form an integral part of national health policy, but warns that its encouragement must be part of comprehensive health care reform. This has yet to materialise. Structural reform and health service reorientation in Australia is impeded by the fragmentation and duplication of responsibilities between the Australian and state governments, splintered lines of payment, a plethora of providers, the lack of an adequate preventative policy framework and the absence of a strategic national effort to promote self-care involving cooperation and partnership between public and private systems, particularly by individuals and communities most at risk of chronic diseases.<sup>40</sup>

Evidence suggests that leveraging the potential of people to care for themselves is particularly beneficial in Australia, which has high rates of primary care consultations, irrespective of the nature of the condition and whether it is amenable to self-care. Figure 2 illustrates levels of consulting in OECD countries.<sup>41</sup> These figures show that there may be scope to reduce current levels of demand on primary care.

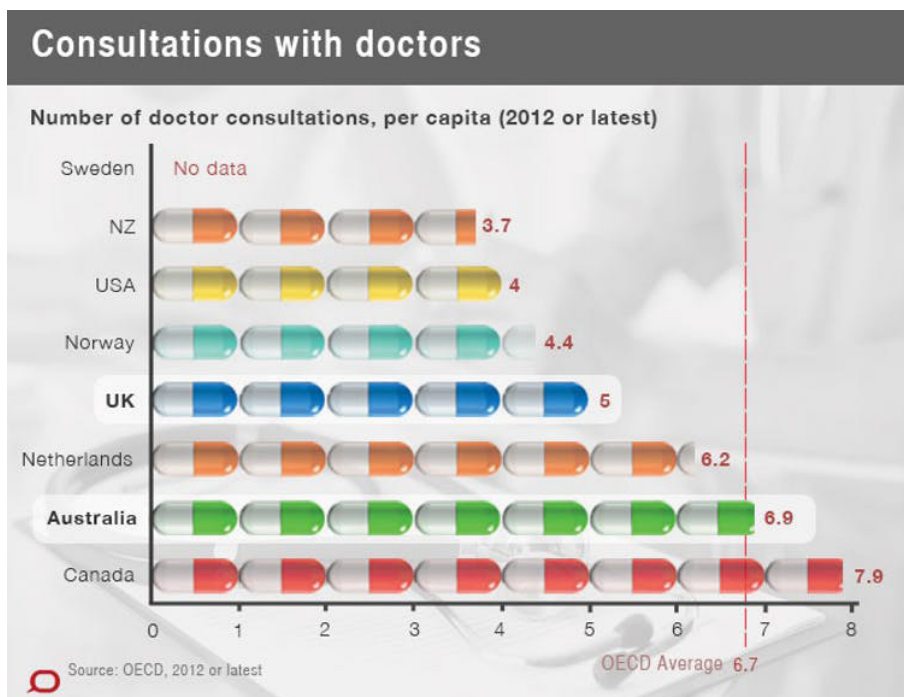


Figure 2. Consultations with doctors in OECD countries (Norman & Robinson, 2014)

### 4.3 Self-care in the 21st century: an issue whose time has come?

There is increasing interest in self-care globally as governments grapple with the need to reimagine health care systems in the context of profound demographic, technological and social change and the emergence of new communicable and chronic diseases. These changes are testing the limits of traditional health care delivery systems and health care budgets, demanding more strategic approaches to enhancing capabilities amongst populations. Ernst & Young (2012) suggested that the scale of increasing need and demand for health and health care services requires a fundamental shift “from the two places in which health care has traditionally been produced, delivered, consumed and paid for – the hospital and the doctor’s office – to a third place; the patient.”<sup>42</sup> The Kings Fund (2010) emphasised this point in identifying the critical role of self-care in sustaining the UK’s National Health Service. Active support for self-management and primary

and secondary prevention feature as the first three of their 10 priorities for commissioners.<sup>43</sup> They suggest that “projected need requires a strong reorientation away from acute and episodic care towards prevention [and] self-care.” However, recent research in the UK suggests that there is, overall, a lack of a whole-system approach to self-care, a lack of coherent strategy to increase self-care and significant tensions between policy intentions and the reality on the ground, where support for self-care is “notably absent.”<sup>44</sup>

Our findings indicate that conditions are very similar in Australia. It is clear that there is extensive good practice and innovation taking place across the health system, involving both public and private sectors. The [Report of the Inquiry into Chronic Disease Prevention and Management in Primary Care](#) (2016) summarised the activity of the private health industry in self-care (pp. 57–62), noting extensive investment notwithstanding the constraints imposed by a regulatory framework which is seen as unfit for purpose in the contemporary environment and as “shackling.”<sup>45</sup>

Despite burgeoning levels of activity, as the above report makes clear, national policy and programs to prevent and manage chronic disease, including the scaling up of evidence-based practice in support of self-care, are fragmented and there is a lack of serious strategic intent to change this. There are deeply embedded structural and cultural barriers to change. While many key policy documents implicitly acknowledge the importance of ‘individual responsibility’ or motivated self-care or self-management in the avoidance of ‘lifestyle diseases’, these terms are ill-defined and not backed by programmatic support. There is, in addition, no current baseline from which to measure any shifts in levels of health literacy or self-care, even amongst priority population groups.

In summary, whilst there is strong and increasing evidence that self-care is important and beneficial, particularly to those most at risk of poor health, it remains an ‘add-on’ in decision-making about health for both governments and for most individuals. As a result, the enormous potential of informed and supported individuals to improve their own health, contribute to the more efficient use of health care resources and improve the overall health of the population has not yet been grasped.

## 5. Self-care: the concept

### 5.1 Everyday meanings and activities

Self-care refers to the activities which people undertake for themselves and their family members to prevent accidents or illness and to maintain or increase their health and wellbeing following minor ailments or when living with chronic diseases. Self-care begins with the simplest of everyday behaviours, usually learned in childhood, such as washing your hands after visiting the toilet, cleaning your teeth, eating fruit, taking regular exercise or using OTC medications for minor illnesses. 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 problems.

### 5.2 Evolving definitions

Webber et al. (2013) provided a summary of the ways in which self-care has been defined over time and in various settings, pointing to reinterpretations and reformulations.<sup>46</sup>

The World Health Organization (WHO) provided the first formal, high-level definition of self-care in 1983.

*“Self-care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are*

*undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals.”<sup>47</sup>*

A later WHO definition is more specific in several areas, identifying a very broad arena for individual action to protect and enhance health.

*“Self-care is what people do for themselves to establish and maintain health, and to prevent and deal with illness. It is a broad concept encompassing hygiene (general and personal), nutrition (type and quality of food eaten), lifestyle (sporting activities, leisure etc.), environmental factors (living conditions, social habits, etc.), socio-economic factors (income level, cultural beliefs, etc.) and self-medication.”<sup>48</sup>*

More recently, a WHO working group convened for World Health Day 2013 produced the following self-care definition

*“Self-care is 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.”<sup>49</sup>*

This definition widens the scope of the concept beyond the habits and context of healthy daily living to the active management of minor illnesses, the use of self-administered medications and managing chronic conditions. This in turn lays a foundation for a continuum of self-care (Figure 3). The continuum model is proposed by the [UK Self Care Forum](#) and many other bodies nationally and internationally.



## The self-care continuum

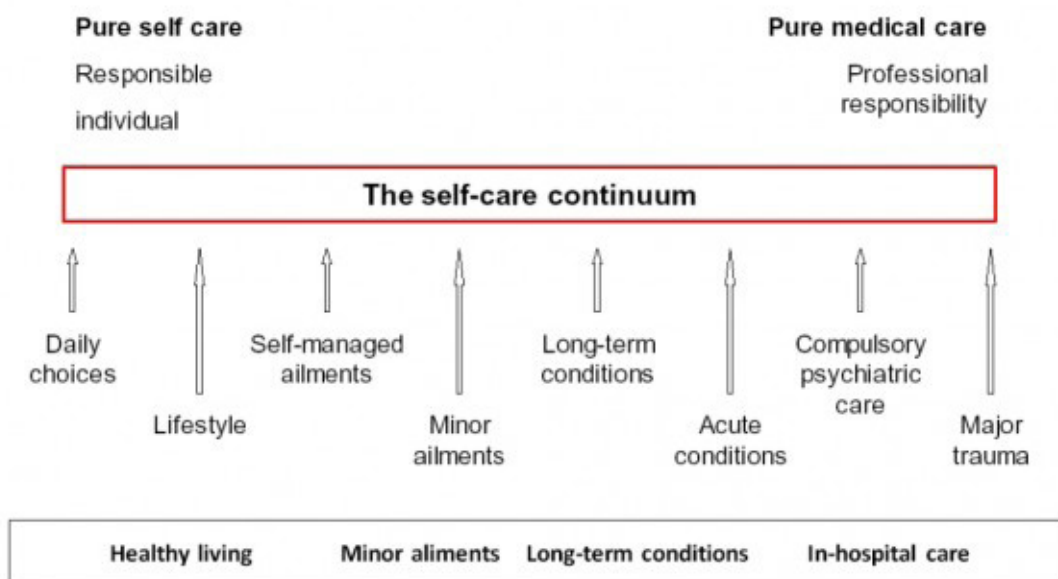


Figure 3. The continuum of self-care ([Self Care Forum UK](#), 2018).

Other bodies have given explicit definitions of self-care. The UK Department of Health definition of self-care, for instance, taken from the paper [‘Self-care – a real choice’](#) (2005) states:

*“Self-care is a part of daily living. It is the care taken by individuals towards their own health and wellbeing, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities. Self-care includes the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after acute illness or discharge from hospital.”*

These definitions are compared in Table 1.

Themes	WHO 1983	WHO 1998	WHO 2009	UK DOH 2005
<b>Prevention</b>	Self Care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, <b>preventing</b> disease, limiting illness, and restoring health	Self-Care is what people do for themselves to establish and maintain health, and to <b>prevent</b> and deal with illness	Self-Care is the ability of individuals, families and communities to promote health, <b>prevent</b> disease (...)	Self-Care includes the actions individuals and carers take for themselves, their children, their families and others to (...) <b>prevent</b> illness or accidents (...)
<b>Self-medication</b>		It is a broad concept encompassing hygiene, nutrition, lifestyle, environmental factors, socio-economic factors and <b>self-medication</b>		
<b>Teamwork with healthcare provider</b>	They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals		“ (...) with or without the support of a healthcare provider”	
<b>Who engages in the activity (individual, family, community)</b>	The activities <b>individuals, families and communities</b> undertake	Self-care is what <b>people</b> do for themselves	The ability of <b>individuals, families and communities</b>	It is the care taken by <b>individuals</b> towards their own health and well being, and includes the <b>care extended to their children, family, friends and others in neighbourhoods and local communities</b>
<b>Health -promotion</b>	Self Care in health refers to the activities individuals, families and communities undertake with the intention of <b>enhancing</b> health	Self-Care is what people do for themselves to <b>establish and maintain health</b> , and to prevent and deal with illness	Self-Care is the ability of individuals, families and communities to <b>promote health</b> , prevent disease, and maintain health and to cope with illness and disability	

Table 1: Themes in recent definitions of self-care (Webber et al., 2013)

Some common themes emerged in Webber et al.’s analysis (2013):

- all of these definitions are aimed primarily at healthy people;
- all definitions refer to prevention of disease or illness as one of the primary aims of self-care. Most health care systems are designed to treat illness as it presents. The behaviours that maintain health or prevent disease often relate to aspects of lifestyle (e.g. diet, exercise and risk avoidance), which are matters of personal choice no matter how much healthcare professionals seek to influence them

(although these are amenable to modification);

- several definitions encompass the concept of collaboration between individuals and healthcare providers. Conceptually, everything that happens outside a doctor’s office is part of self-care; the aim for collaboration recognises that a patient must be an active participant in, rather than a passive recipient of, treatment; and
- all definitions include the behaviour of individuals as self-care, but several broaden this to families and communities. This recognises that carers essentially practise self-care by proxy, and that some aspects of self-care (for instance, accident prevention, providing facilities to encourage exercise) cannot be achieved unless people act together.

Webber et al. also argued that these definitions ignore some emerging features of modern life, such as the ubiquity of smart technologies. Increasingly individuals carry devices, including smartphones and wearable aids that allow them to seek information about their health, motivate and measure behavioural changes and monitor their own mental and physical health. The prospect of utilising smart technologies to give individuals a better understanding overall of their self-care risks, capabilities and deficits is clearly one of the potential levers for positive change in population behaviours within a comprehensive strategic approach to promote and facilitate greater levels of self-care. The technological innovations of the 21<sup>st</sup> century may assist some individuals to undertake self-care more easily than in the past, although this also creates new risks, including the widening of both digital and health inequalities.

### 5.3 Shared responsibilities

Jordan et al (2013) also attempt to describe the relationship between the multiple constructs that have been used to describe self-care .

**Responsibilities for self-care**

**Self-care:** Taking responsibility for the health of self, children and family

**Self-management:** Active participation of patients in their treatment to minimise the impacts of their condition

**Self-management support:** Patient, health care practitioner and health care system intervention to increase self management behaviour

**Box 1: Responsibilities for self-care (Jordan et al., 2013).**

Jordan et al. emphasised that people need to have the capacities to participate in all these levels and types of self-care. Health literacy is therefore seen as the fundamental building block to better self-care in the entire population.<sup>50</sup>

Health literacy has been defined as:

*“represent(ing) the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.”<sup>51</sup>*

The International Self Care Foundation recognises that self-care is a multi-faceted and multi-level phenomenon, and identifies ‘Seven Pillars of Self Care’, of which knowledge and health literacy (adapted to utilise the technological resources available in the 21st century) is the first.

It is notable that Webber et al. (2013) suggest that the Seven Pillars should not be seen merely as an illustration of what comprehensive self-care involves, but as a framework for facilitating individual behaviour change. With “appropriate weighting of individual items within each domain (eg. smoking status), and derivation of measures meaningful for each behaviour, it may be possible to arrive at a “personal self-care index or score”). This kind of approach has been applied to managing the risks of a range of conditions, including several identified in a recent AHPC publication on cardiovascular risk management.<sup>52</sup>

The Seven Pillars are illustrated in Figure 4 below.



Figure 4: *The Seven Pillars of Self Care*. International Self Care Foundation, 2018.<sup>53</sup>

### 5.4 Australian conceptions of self-care

There is no single or overarching definition of self-care to be found in Australian policy. Conceptions of self-care in a range of Australian Government-initiated or funded reports into chronic conditions, including substance dependence and mental health, have identified self-care as a consumer capability requiring consumer information from and education by health service providers.<sup>54</sup> The Australian Institute of Health and Welfare (AIHW) lists self-care as a core activity of daily living (self-care, communication and mobility).<sup>55</sup>

The Australian National Diabetes Audit (ANDA) is an education and patient self-care-focused diabetes data collection initiative of the National Association of Diabetes Centres.<sup>56</sup> It collects standardised data from diabetes centres and specialist endocrinologists on patients with diabetes. The ANDA report identifies self-care by a range of specific measures including whether people with diabetes understand how to prevent and manage ‘hypos’ (episodes of low blood glucose); whether they carried identification as diabetics; hypo therapy and information about who should be contacted if they required health care; and, for those who drove a motor vehicle, whether they had advised the relevant traffic authority of their health condition.

An evaluation of the GP Super Clinics Program (established in 2007–2008) identified self-management as an important approach to supporting patients with chronic and complex conditions.<sup>57</sup> The report states that self-management approaches were implemented in all GP super clinics and that most clinicians reported that they included self-management approaches to patient care as part of consultations.

*“In addition, some clinicians provided specific self-management programs. The extent of planned*

*approaches to self-management as part of care coordination, apart from where specific group programs were run, was not as evident. Almost two-thirds of patients (65%) indicated that their GPs or other health professionals discussed with them ways of better managing their health”.*

Numerous terms relevant to self-care can be identified in the literature and there are distinct international variations. The term ‘patient activation’, a behavioural concept defined as “an individual’s knowledge, skills and confidence for managing their health and healthcare”, for example, is not found conceptually or practically in the Australian literature but is a key concept in the UK.<sup>58</sup> In Australia, the complementary and overlapping terms ‘health literacy’, ‘self-management’, ‘self-management support’ and, more recently, ‘collaborative care’ are commonly used. A clear consensus on the meanings of these terms remains to be achieved in Australia, although the emphasis in the literature is that self-care is an individual capability.<sup>59</sup>

## 6. Self-care trends & practices in Australia

Research undertaken in the European Union suggests that people want more independence and responsibility in the management of their health, but require more information about options, risks and about what constitutes responsible self-care.<sup>60</sup> Ninety-six per cent of UK citizens agree with the statement that “individuals should be responsible for their own family’s health.”<sup>61</sup> The respected Menzies-Nous Australian Health Survey (2012) found a similar picture in Australia.<sup>62</sup>

More recently, multi-national research involving adults in nine major cities in the UK, the USA, Australia and Japan examined the extent of self-care, self-care expenditure, and sources of self-care information in each country.<sup>63</sup> Of these four countries, the prevalence of self-care was lowest in Australia (40.4%) and highest in Japan (54.9%). This interesting survey found distinct national variations in reasons for undertaking self-care (45.7% of Australian participants said the main reason for undertaking self-care was ‘to manage my healthcare myself’ compared with 4.1% of participants in the USA). Respondents in all countries cited cost-effectiveness as the second main reason. Significant negative linear associations were observed between age and the prevalence of self-care in all countries except Japan, but there appears to be a strong positive correlation between ageing and the use of self-care. This survey highlighted patterns in the use of products including OTC medications, supplements and nutraceuticals and in information-seeking activities, with increasing use of online information in all countries.

A recent PwC Health Research Institute survey found that consumers are willing to abandon traditional care venues for more affordable and convenient alternatives, often closer to their homes and communities.<sup>64</sup> This shifting preference for localised care may pose a threat to the incomes of traditional health providers. Nearly half of the respondents to the PwC survey said they would choose new care options for more than a dozen common medical procedures, such as using a do-it-yourself kit to diagnose strep throat or having chemotherapy administered at home. This and the research described above suggest that public willingness and propensity to undertake self-care is a significant emerging social and cultural phenomenon in Australia and developed countries.

These studies do little to illuminate the characteristics, motivations or needs of people who do not or cannot undertake self-care and who experience multiple chronic diseases, the so-called ‘lifestyle’ illnesses. There is a distinct and universal social gradient in these diseases and in exposure to their risk factors, as evidenced in the AHPC’s recently published Australia’s Health Tracker by Socio-Economic Status.<sup>65</sup> This publication presents, in accessible format, alarming data which demonstrates that families in the lower two socio-economic quintiles – over 10 million Australians – are at much greater risk of poor health and premature mortality than those in more affluent quintiles. The AIHW states that rates of premature death in the Australian population attributable to inequality based on sex, geographic region, socioeconomic disadvantage, occupation



and country of birth is large and that much of this burden is avoidable.<sup>66</sup> This burden is particularly high amongst Aboriginal and Torres Strait Islander peoples.<sup>67</sup> Deaths attributable to inequality constitute a loss of economically productive members of society and raise health care costs.<sup>68</sup>

The reasons for the clustering of health risk factors and behaviours in areas of socio-economic disadvantage are complex and there is a lack of consensus about what should be done to address them. Some of the effectiveness literature argues that the focus of policy and intervention should be on upstream factors affecting the whole population (for instance, smoke-free legislation, alcohol minimum pricing or regulations, eliminating dietary trans fats) rather than ‘traditional’ prevention strategies usually targeting the four major risk factors of poor diet, tobacco use, alcohol misuse and physical inactivity, which depend on a sustained ‘agentic’ individual response.<sup>69</sup> People with low levels of health literacy and/or living in socio-economically deprived areas are difficult to recruit into self-management programs, placing many people in double jeopardy in relation to managing health risks.<sup>70</sup> Given the contested nature of the debate it seems prudent to take account of all the existing evidence and speculate that limited capacity and lack of support and guidance for self-care should be considered as factors driving significant inequalities in health status in the Australian population.<sup>71</sup> Many interventions are effectively addressing capability gaps throughout the country; <sup>however</sup> these initiatives are occurring in a fragmented landscape and could achieve far more with comprehensive programmatic support.<sup>72</sup> In addition, as the AHPC has argued previously, if Australia is to meet its commitments to reduce current burdens of chronic disease, support for self-care must be embedded within an overarching social policy commitment that can address the structural risks bearing down on deprived communities and individuals and which undermine both health and agency.<sup>73</sup> In the meantime, it is inevitable that people with the capability to undertake self-care will continue to do so whilst those at most risk of avoidable chronic diseases, who lack capability, will continue to be unable to do so and be increasingly disadvantaged through unequal access to digital resources to support health and well-being and lack of the necessary capabilities to use the new technologies effectively or to weigh and interpret information and data acquired through these resources.

## 7. Environmental scan

### 7.1 Approach and challenges

The AHPC reviewed Australian and state government websites as well as those of a range of professional bodies, NGOs and service providers to understand the self-care landscape in Australia. Websites were searched using the terms ‘self-care’, ‘self-management’, ‘chronic disease self-management’, ‘prevention’, ‘health literacy’, ‘patient engagement’ and ‘citizen engagement’. The high-level findings of the scan are set out in tabular form in Appendix 1. The themes emerging from the scan are contextualised with reference to a range of academic literature and data. These inform the subsequent discussion and conclusions.

This environmental scan is not designed to be a comprehensive summary of the Australian policy landscape in this area, but aims to highlight current characteristics in order to improve understanding of the policy challenges and identify opportunities for strengthening self-care capabilities and enhancing self-care behaviour. A more granular, parallel review was undertaken of the landscape with respect to peer support as a self-care and self-management strategy. The findings of this review are incorporated into Appendix 1 and are discussed briefly below. Evidence for the efficacy of peer support in the management of chronic diseases, whilst contested, is growing.<sup>74</sup>

Undertaking the environmental scan proved challenging due to the variety of terms in use in Australia,

the varied targets of policy, research and intervention, the myriad of institutions, organisations and bodies involved in discussing or promoting these concepts and critical differences in organisational objectives. Much of the literature on measurement of the prevalence of self-care, attitudes and economic benefits is from overseas; of this, a significant proportion relates to self-medication, for example, [Self Care Nation](#) – self-care attitudes and behaviours in the UK 2016.<sup>75</sup>

The Australian Bureau of Statistics (ABS) includes ‘self-management’ in several surveys, identifying self-management as a vital consumer capability when living with chronic diseases. The ABS does not define the term, and the information provided does not enable any measurement of current capabilities or describe specific self-care practices in priority populations, nor enable assessment of need for specific support or of changes in attitudes or behaviours. See for example, the [National Health Survey First Results 2014–15](#), or [Health Service Usage and Health Related Actions 2014–15](#).

The AIHW provides extensive and well-presented data about current trends in health and wellbeing in Australia. The search term ‘self-care’ yields few results on the AIHW website. The search term ‘self-management’ produces a plethora of results in relation to specific physical and mental health conditions that generally emphasise the importance of individual behaviours in addressing the causes and the consequences of avoidable chronic diseases and mitigating risks. This information does not enable assessment of capability or need for support. (See the AIHW webpage on [chronic diseases](#), for example.)

There is very little Australian literature which uses the term ‘self-care’ or has a specific focus on self-care as a means primary prevention of chronic disease. There is however, a large body of research and policy work in chronic disease management and services that addresses the self-management end of the self-care continuum. The frame through which health policy is viewed continues to be, primarily, that of clinical treatment and management.

There is no Australian portal for data and information about self-care, broadly defined, in policy and practice such as the [Self Care Forum](#) in the UK. The website of the [Australian Self Medication Industry](#) (ASMI), the peak body for the consumer health industry, is the largest repository of data and analysis on self-medication and the evidence for enhanced consumer engagement in self-care in Australia. (Naturally, the information tends to favour the interests and objectives of the self-medication industry.)

The 2016 Report of the Inquiry into Chronic Disease Prevention and Managements in Primary Health Care summarises a wide range of Australian and international best practice in the provision of chronic disease prevention and management programs, and highlights a wide range of current prevention activities.<sup>76</sup> Importantly, the Inquiry concluded that a ‘one-size fits all’ approach to chronic disease prevention is challenged by the nature of the health care delivery system in Australia generally, with its fragmentation, mix of providers, the differing needs and access to resources of remote and rural inhabitants, and in particular the needs of Aboriginal and Torres Strait Islander peoples. If self-care is to become an effective tool in chronic disease prevention and management, policy and practice must be contextualised within a geographical, cultural and demographic context which is relevant for Australia.

## 7.2 Information gaps

Information about the prevalence of support for self-care and self-management in health and community services is extremely difficult to find using publicly available sources. This is in part to do with current data collection practices and gaps in datasets, which have consistently been identified as an impediment to health care reform in Australia. In the hospital system, each state and territory is responsible for data collection, working to national minimum datasets, and data collection is funded by the Australian Government. Different

conditions exist in primary care, where there is no mandatory routine data collection. Given that 87% of Australians [visited a GP](#) at least once in 2015–16, the lack of routine data collection is extremely problematic.<sup>77</sup> The Bettering the Evaluation and Care of Health ([BEACH](#)) program actively collected [nationally representative data from](#) GPs for [18 years](#), but was defunded in 2016.

Medicare has information about attendance patterns, visit frequency and GP service items, but no details about the content of these visits, such as what conditions are managed and how. Moreover, general practices operate in silos, keeping their own records about their patients. As with hospitals, patients may receive care from different practices, creating multiple records for the same individual in multiple facilities. Moreover only 71% of GPs have completely [paperless patient records](#);<sup>78</sup> the rest use a mix of electronic and paper records (25%) or paper records only (4%), which reduces data quality and availability. Moreover, there is no regulation of GPs' electronic health records. GPs use approximately eight different software products and there are no nationally agreed and implemented standards for these.<sup>79</sup> They have different data structures, terminology and classification systems (or none) and different data elements, labels and definitions. There is [no standardised minimum data](#) set to specify what data should be recorded at every patient encounter.<sup>80</sup> There are no data links between conditions and the management actions taken. These problems contribute to the current lack of information about self-care and self-management practices, trends and outcomes and about the support needs of primary care professionals in these areas.

This situation led the Grattan Institute to opine that:

*“The primary care ‘system’ is not so much a system as an uncoordinated rabble. Each individual general practice works in its own way, with hit-and-miss referral arrangements and [no guarantee of good feedback](#) about what happened to patients admitted to hospital. Just as government is flying in the dark about managing primary care, so GPs are to some extent flying in the dark about managing their patients.”<sup>81</sup>*

The development of [MedicineInsight](#) holds some promise for improving data coordination. MedicineInsight is a quality improvement program funded by the Australian Government Department of Health which allows GPs to reflect on their own patterns of prescribing and patient care and compare these with other GPs in their practice. Participating practices are offered customised quality improvement activities that support alignment with best practice and identify key areas for improvement. This resource is centralised and in digital format, and numerous researchers are taking advantage of it to analyse episode and encounter.<sup>82</sup> This resource has the potential to address the data gaps about trends in self-care and self-management in primary care.

The AHPC (2016) has also addressed the data problem, calling for “(a) comprehensive Australian Health Survey involving biomedical, nutritional and physical activity measures, as a permanent, routine survey conducted every five years.”<sup>83</sup> Additionally, the AHPC has called for national implementation of absolute cardiovascular disease risk assessment (ACVR).<sup>84</sup> This process relies on identifying people at highest risk of heart-disease at a sufficiently early stage to enable effective treatment, support, risk management and self-care. The widespread adoption of ACVR in Australia would identify people at the highest risk of suffering heart disease and associated conditions of both body and brain and reduce their risks, but would require the use of standardised risk assessment tools in routine general practice.

### 7.3 Self-care in chronic disease policy

Current national Australian policy that addresses self-care explicitly is very hard to find. Self-care is buried in myriad policies, schemes and programs. At the policy level, attention to self-care has predominantly been articulated through the concept of self-management for chronic diseases, with a series of education

programs established through the previous National Chronic Disease Strategy and the now-defunct Sharing Health Initiative.<sup>85</sup> The term ‘self-care’ is not defined and mostly not used in the 2017 [National Strategic Framework for Chronic Conditions](#), although it is implicit in some of its strategic priority areas (SPAs),<sup>86</sup> and the enhancement of self-care capabilities in the population is an essential requirement of several (see text box below). Health literacy is identified as one of the cross-cutting enablers of this framework.

SPA 1.1 – Promote health and reduce risk

SPA 1.2 – Partnerships for health

SPA 1.3 – Critical life stages

SPA 1.4 – Timely & appropriate detection & intervention

SPA 2.1 – Active engagement – described as “(embodying) a person-centred approach that puts people at the centre of their own health care and empowers them to play an informed role according to their interest and abilities. People with chronic conditions should not manage their health in isolation, nor be expected to play a passive role. Wherever possible, individuals should be actively engaged in shared decision-making processes, with care partnerships created between individuals and their health care providers, carers, families and communities as appropriate’. This is more than just effective self management.” (p. 31)

**Box 2: Strategic Priority Areas relevant to self-care (Australian Health Ministers’ Advisory Council, 2017).**

The Australian Government-funded Information website [healthdirect](#) asserts that it provides trusted information for self-care for several episodic or once-off health conditions (for instance, for abdominal pain, back pain, breathing problems) and a free smartphone app is available. Data about the use and impact of the healthdirect website are not available, but it is a resource for self-care and a potential platform for a high-profile strategic initiative designed to increase self-care prevalence.

## 7.4 Self-care in healthcare, disability and aged care policy

Reforms in the Australian disability and aged care sectors in the last five years have focused on a shift to consumer-driven service delivery and a greater emphasis on consumer choice of service and provider.

Under [Consumer Directed Care](#) arrangements, eligible older adults receive a pre-determined fixed subsidy. Consumers have significant involvement in deciding what their care plan will involve. While the subsidy can be used for a wide range of care services which can include activities that fit the self-care definition (for example, exercise and fitness, social engagement and inclusion and equipment), it cannot be used to purchase medication. Carers can access respite services which are related to their own wellbeing and self-care.

[The National Disability Insurance Scheme](#) (NDIS) is based on an insurance model and eligible participants have their needs assessed by a third party, which determines the level of their payment.<sup>87</sup> The services that can be accessed must be assessed as being ‘reasonable and necessary’ to assist the recipient to carry out their daily activities. Carers cannot access respite for their own self-care.

It is unlikely that Consumer Directed Care or the NDIS will have a significant impact on self-care practices and prevalence in Australia in the absence of a deliberate national strategy which provides a formal definition of self-care and additional guidance on the ways in which these funds can be used to support self-care.

A recent discussion paper on future reform in the aged care sector, *Future reform – an integrated care at*

home program to support older Australians, flags a shift from a system still largely geared towards ongoing service provision addressing symptoms of functional decline to one with greater emphasis on independence, wellness, empowerment and a restorative focus.<sup>88</sup> The Department of Health is currently studying how such approaches can be embedded in the home care sector. There may be an opportunity to insert a formal definition of self-care into work at an early, formative stage.

The [Health Care Homes](#) initiative, which has yet to be implemented, aims to improve the quality of care for patients with chronic and complex conditions. It may offer opportunities for increased use of self-care practices for people with chronic and complex health needs. The scheme will use a bundled payment model, paid monthly, the amount depending on the complexity of the client. Once again, this initiative could be adapted to ensure that self-care, self-management and health literacy are incentivised and supported. Health Care Homes will be supported by the [Healthier Medicare](#) package trial (announced by the Australian Minister for Health in 2016) aimed at improving chronic care patients' access to GPs and giving GPs more control over those patients' care.

The Council of Australian Governments (COAG) is currently discussing plans to provide incentives for [GPs to prevent readmission of patients with chronic conditions](#) (and fining hospitals for readmissions). This is clearly a much-needed reform; nationally, there were 600,267 hospitalisations in 2013–14 for the 22 conditions for which hospitalisation is considered potentially preventable. There is, once again, a marked social and geographic gradient in the age-standardised rate of potentially preventable hospitalisations; in more than 300 local government areas (LGAs) the age-standardised rate of potentially preventable hospitalisations was nine times higher than in the best LGAs.<sup>89</sup> Policies and programs should be harnessed to improve self-management and position better health literacy as a key lever for reducing preventable hospital admissions.

## 7.5 State and territory policies and programs

Each state and territory in Australia has a strategic health plan that sets high-level objectives for both the health system and population health. The strategic health plan typically links with other plans, such as those for hospitals or primary care, remote and rural health services, and strategies for priority groups. Progress on strategic goals is measured through a variety of outcome frameworks.

There are notable differences in policies and approaches between the states and territories. Most states adopt 'downstream' prevention-based approaches addressing specific risk-factors. These include personal advice, health education, 'nudge' or primary prevention medications. In contrast, South Australia's [Health in All Policies](#) (HiaP) approach aims for an 'upstream' approach by subjecting all major policies to health impact assessment to ensure that it achieve added health value. Emerging evidence demonstrates that where HiaP has been applied, it has been effective in developing positive joined-up policy solutions, strengthened capacity for collaboration and partnerships within government, and has increased the focus on health and wellbeing in public policymaking processes.<sup>90,91</sup> The [ISF](#) states that the HiaP approach is vital for a systemic approach to promoting self-care. It suggests that "countries need to institutionalize self-care by incorporating it into the building blocks of public policy, putting health in all policies" and that "one-off initiatives are not enough to create the fundamental shifts in practice that are required."<sup>92</sup>

All states and territories provide extensive web-based, generic resources to support health literacy and to encourage healthy living to support their strategic goals for population health. The term 'self-care' is rarely used explicitly in policy or in the provision of information, although it is evident that the purpose of the information provided is to encourage individuals to prevent and manage risks to health. There appears to be little evidence of resource or information-sharing, between the states and territories.

Few state or territory policies and programs explicitly support self-care and aim to develop health literacy amongst priority groups. Most states and territories provide information and programmatic support relevant to chronic disease self-management, frequently in the form of funding for peer support or guidelines and discussed in the context of primary care reform and integrated care. Examples of developments in this area include the [Gold Coast health system's Integrated Care Program](#), based on a partnership between Gold Coast Hospital and Health Service and the Primary Health Network. It aims to deliver improved, patient-centric holistic care, optimise the management of chronic disease, and involve GPs to focus on disease prevention and reduce the need for acute hospital care. Sites in NSW, with some seed funding from the NSW Ministry of Health, are also looking at both disease-specific and whole-of-population [integrated care models](#). Both the Queensland and Victorian governments are pursuing integrated care strategies with innovation funding and the [HealthLinks program](#) respectively. Increasing use of electronic health records in the Northern Territory, which began in 2002 as part of the Australian Government's [HealthConnect](#) trials, is an example of how technology is supporting integrated service delivery.

## 7.6 Self-care in health and community services

Self-management and self-management support are both considered to be key aspects of optimal chronic disease care.<sup>93</sup> A distinction needs to be drawn between self-management and self-management support in this discussion: the former involves individual patients' actions to take care of themselves and the latter refers to the facilities that health and care services provide to patients to enhance self-management.

Self-management is not the same as self-care. Gruman and Von Korff's (1996) definition, which underpins Flinders University's respected [Chronic Condition Management Program](#), is that:

*Self-management involves [the person with the chronic condition] engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimens.<sup>94</sup>*

Self-management training, focusing on the development of 'self-efficacy', is synonymous with the work of Kate Lorig in the United States (US). Working originally with arthritis patients, Lorig developed a structure of self-management programs, which, following randomised controlled trials, showed overall benefit in arthritis and other chronic diseases.<sup>95</sup> Lorig's work and the outcomes achieved gave rise to the concept of the 'expert patient', which has influenced publicly-funded primary and community care organisations in Australia, the US and the UK.<sup>96</sup> It has also generated international interest in the framing of what has been termed 'the modern patient', who is empowered and has legal and moral rights to autonomy, self-determination and information.<sup>97</sup> It is possible to see the contours of this in concepts of patient and public participation and involvement and in the newer concept of [collaborative care](#) introduced at the World Self Medication Industry Conference held in Sydney in October 2017.

A review by Zwar et al. (2006) proposes self-management as the key component of chronic care models in the US, UK, New Zealand and Australia.<sup>98</sup> Self-management refers to a patient's efficacy in navigating his/her health after diagnoses of a chronic condition and initial treatment/care provided by a health professional. It is dependent on patients obtaining relevant knowledge, skills, confidence and support to manage their chronic conditions.<sup>99</sup> Self-management requires support infrastructure to maintain adherence.<sup>100</sup> Wagner suggests the current culture and structure of medical practice limit health professionals' abilities to address the clinical and self-management requirements of patients living with chronic conditions.<sup>101</sup>

Whilst no data was located on the prevalence of self-management support in health and community services, there can be no doubt that self-management is encouraged and self-management support is provided by

many health care and community services in Australia. Important themes about the nature of this provision can be observed in the literature. Self-management support in Australia has been focused on education programs or assisting health professionals to provide self-management through changes to the Medicare Benefits Schedule (MBS) in the form of care plans and multidisciplinary team support. Patients who meet certain chronic disease criteria may receive several MBS-subsidised allied health interventions per year as part of an enhanced primary care initiative. This apparently small number of consultations has achieved meaningful change in clinical status in certain conditions (for instance, for chronic back pain).<sup>102</sup> These kinds of consultations provide opportunities to introduce self-management practices to patients. Peer support, discussed below, is also identified in the literature as a key component of chronic disease care.<sup>103</sup> Structured telephone support or telemonitoring programs have also been found to be beneficial and may have particular utility in remote and rural locations in Australia.<sup>104</sup>

## 7.7 The private health industry and self-care

The private sector in Australia is a strong promoter of informed self-care. The [Report of the Inquiry into Chronic Disease Prevention and Management in Primary Care](#) (2016) referred to previously summarises many of the innovations taking place within the private health industry. Submissions to the Inquiry from several health insurance companies outlined healthy lifestyle promotion programs for their members, or associated programs for their members with chronic disease, that emphasise the benefits of healthy lifestyles for overall health and the impacts of their particular disease or diseases (p. 76).

The Report identified that the role of private health insurers in relation to chronic disease management has potential to expand, but the foundation for their involvement in chronic disease prevention already exists. Given the increasing number of Australians with private health insurance, access to tailored lifestyle and health programs that aid chronic disease prevention could play an important role. The report cites the collaboration between Medibank Private, the Victorian Department of Health, HBF and the Western Australian Department of Health in the [CarePoint](#) trials as evidence that partnerships and collaborations already exist and are achieving results (p. 76).

Finally, governments are encouraging investment from the private sector in different ways to get access to the right resources and deliver outcomes, such as in [NSW and Queensland's social investment strategies](#). In these models, financial institutions are being encouraged to put forward the resources needed for private sector providers to deliver innovative services and models of care delivered through outcomes-oriented contractual models.

## 7.8 Non-government organisations, professional bodies and self-care

Information and support with self-care and self-management for both physical and mental health conditions is provided for lay people, patients and professionals by a wide range of non-government organisations (NGOs), consumer organisations, professional and peak bodies, some with funding from federal and state governments. These include training and learning modules. Of these the Pharmaceutical Society of Australia has, perhaps unsurprisingly, gone beyond the provision of self-help guidance and resources to produce a strategy for pharmacy support for the self-care capabilities of consumers. There is an implicit acceptance in much of this literature that professionals, as independent actors, can and should undertake self-care to look after wellbeing but may require information and other forms of support to do so. Consumers, on the other hand, are viewed through a different lens and require self-management support. This changing language appears to reflect different expectations of individuals based on social role, even though most of us occupy multiple roles at the same time. The continuing segmentation of the population into patients/consumers and others reflects wider difficulties in adopting a whole-system approach to self-care.

## 7.9 Self-medication in self-care

Literature suggests that the self-administration of medications for the management of health ailments is a growing area of self-care and/or self-management. This presents potential benefits of alleviating health system strain.<sup>105</sup> One aspect of self-medication is OTC medication use for symptom management and preventative health and another is CAMs, for example mineral, vitamin and nutritional supplements.<sup>106</sup>

There is a lack of accessible data on current OTC and CAM use in Australia, so little understanding of how non-prescription medications contribute to overall health outcomes. The studies we reviewed assessed the use of specific non-prescription and OTC medications (for instance, analgesics or non-steroidal anti-inflammatory drugs – NSAIDs); sample size varied greatly and made generalisability difficult. Results also suggested inconsistencies in the data and intentions behind assessing non-prescription medication use. The types of OTC medications that appeared in the search included analgesics, NSAIDs, antacids, CAMs and cough medications. The literature provides a poor understanding of what drives self-medication in Australia; however, some population-specific data does exist (ie. use by the elderly, children, pregnant women, pharmacy customers). A search of the peer-reviewed literature turned up few relevant results, but some industry and government reports provide insight.

While little literature or readily accessible nationwide population data describe the extent of non-prescription medication use in Australia, some studies show that the population of non-prescription users ranges from children to the elderly and across all categories of health ailments. 2013 data from Macquarie University's Centre for the Health Economy suggested 80% of Australian adults and 40% of Australian children used OTC medications in any given month.<sup>107</sup>

The literature implies OTC medications are often taken in conjunction with prescription medications, and health professionals often suggest patients use non-prescription medications for their ailments.<sup>108,109</sup> One study of medication use amongst dyspeptics found 12% had self-medicated without ever consulting a health professional.<sup>xxvi</sup> Given the risks associated with polypharmacy; (the concurrent use of multiple medications by a patient). Particularly amongst elderly people and people with comorbidities, it is important that ways are found to manage the risks arising from interactions between medicines whilst promoting more agency and engagement in the management of chronic diseases.<sup>110 111</sup> Similar considerations arise in relation to the use of self-medication by and for children and other vulnerable populations including pregnant women.<sup>112</sup>

While self-medication has potential benefits, including savings to public healthcare costs, the inherent risk of misuse suggests consumer education and information about safe OTC use are necessary.<sup>113</sup>

## 7.10 Peer support and self-care

In recent decades, the importance of social interactions and relationships to health outcomes for people with chronic conditions has been recognised and the role of community in supporting self-management has emerged as a component of health care.<sup>114 115</sup> Peer support groups have been observed across populations and cultures globally, and in the healthcare context are identified by four standard features.<sup>116 117</sup>

1. assistance in daily management, such as in creating plans for pursuing goals developed with a clinical team;
2. social and emotional support to encourage management behaviours and coping with negative emotions;
3. linkage to clinical care and community resources; and
4. ongoing support reflecting the lifelong nature of prevention and chronic disease management.



Peer support groups are considered assets to the healthcare system, because they provide a sense of community for people whose diagnosis has ostracised them from the mainstream.<sup>118</sup> By removing the power dynamic created by the medical model between health professional and patient, peer support groups “can offer a culture of health and ability as opposed to a culture of illness and disability.” “Given that self-management does not stop when a patient leaves the educator’s office, self-management support must be an ongoing process.”<sup>119</sup>

Given the *chronic* nature of chronic conditions, and the usually episodic nature of interactions with health professionals and services to treat and manage them, peer support may be useful to self-management in chronic conditions because of its ability to provide time, rehearsal and problem-solving around key health behaviours, and emotional and social support and encouragement. Peer support groups’ effectiveness in improving quality of life and health outcomes of group members is well documented across several chronic conditions; the most commonly cited in the literature are peer support groups for diabetes, mental health and substance use.<sup>120,121 122,123,124, 125,126</sup>

A large body of literature suggests individuals who attend ‘illness-affiliated’ peer-support groups manage their chronic conditions better and have better health outcomes than those who solely rely on medical interventions. Peer support has also been reported to improve access and exposure to additional health services as well as greater confidence in individuals approaching or going through treatment.<sup>127</sup> Additionally, peer support groups have been promoted as a cost-effective strategy<sup>128</sup> to improve hope and quality of life in mental health patients after hospital discharge.<sup>129</sup> Such evidence implies peer support groups improve the impact of medical interventions by providing regular and ongoing support for self-management.

Little information exists on the range or scope of peer support groups in Australia and what value they add to the current health landscape. For this report, each state and territory’s Department of Health website, Google, Facebook and the websites of prominent health organisations were searched using the term ‘peer support groups’ to try to understand the nature, breadth and scope of their use for health.

The results of our search suggests peer groups are a prominent part of referral services offered and encouraged by a range of organisations. Results from state/territory and national health websites were varied; some websites had virtually no information about peer support groups, while others yielded hundreds of results, some of which were direct links to active support groups. Some health department websites (for example, for ACT and QLD) had well-established links and information about peer support services, while others provided no relevant information.

All states and territories provide some support for peer groups, particularly in the areas of mental health and substance use. State and territory government websites suggest peer support groups offer peer-led advocacy, assistance and education around issues relevant to the particular health condition. Peer-support services are normally free of charge and advertised as a self-help option based on connecting with peers who have similar conditions. Some states outsource the management of peer support services to NGO collectives who provide a platform for consumers and peer-support groups to connect. Some states also recognise peer-support services as an essential component of public health strategies; and have written strategies of how to incorporate and build a peer workforce.

Four websites for state-based self-help collectives were found; these were SHOUT (Self Help Organisations United Together, ACT); Self Help Queensland; COSHG (Collective of Self Help and Social Action Group, VIC) and Connect Groups WA. These collectives serve as points of contact for consumers looking to find health-specific peer support groups in their region. Funding for these collectives is provided by grants and membership from state governments, health organisations and community organisations.

Major organisations (the Transport Accident Commission (TAC, Victoria), Diabetes Australia, Heart Foundation, Cancer Council, Stroke Foundation and Arthritis Australia) all mention the benefits of peer support groups for the self-management of health conditions. The TAC provides information on the benefits of peer support services as well as direct links to groups. Diabetes Australia indicates that “70% of people with diabetes find peer support helps their diabetes self-management.” The Heart Foundation supports and organises peer-support walking groups that function as a form of self-management. The Cancer Council offers a Peer Support Guide to what support groups are, how to start one, how to run one and how to recruit members.

### 7.11 Online resources for self-care and e-health

Australia’s health marketplace is changing. Today one of Australia’s [largest health technology](#) suppliers is the leading provider of mobile phones and devices and home phone and Internet services. Much of what this company offers is focused on keeping people well and closer to their homes and communities for longer. Other [technology vendors](#) have entered the market with solutions for referral sharing, shared care planning and digital applications to support self-management.

There is a plethora of online and interactive resources available in Australia and internationally to support self-care generically and in relation to specific behaviours and risks. Young people are particularly likely to use online resources.<sup>130</sup> A 2013 study counted more than 13,500 smartphone-based health apps (certain to be much smaller than the corresponding figure for 2018).<sup>131</sup> Data on the use and impact of these resources are scarce, but the literature highlights the increasing use of on-line resources by professionals, patients and citizens. Their impact on the consumer–provider relationship and their design for special user groups, such as the elderly and/or disabled, CALD and indigenous people, and those with low health literacy needs to be explored.<sup>132</sup>

In general, evaluations of online and interactive health tools are rare; further research is needed to determine their impacts, benefits and limitations and to overcome current restrictions, which include:

- the lack of standards to combine incompatible information systems;
- the lack of an evaluation framework for considering legal, ethical, organisational, clinical, usability and technical aspects;
- the lack of proper guidelines for practical implementation of home telehealth solutions.
- the need for a framework to assess the risks of health and lifestyle apps and related technologies;<sup>133</sup> and
- concerns that research on e-health often relies on self-reported health outcomes.<sup>134</sup>

Online and interactive tools have clear potential for supporting self-care, including self-monitoring, but this will require substantial research to develop an evidence base. In the short term, the national roll-out of [My Health Record](#) in the context of the newly endorsed [National Digital Health Strategy](#) and the formation of the National Digital Health Agency potentially provides a platform to promote patient empowerment and enhance self-care through digital and interactive tools.

## 8. Health literacy

In 1993, a report to the Australian Government entitled *Goals and targets for Australia's health in the year 2000 and beyond* recommended three goals for health literacy:

- improving general language skills and literacy levels in the population;
- improving knowledge and health literacy to enable people to make informed choices about health; and
- improving knowledge and health literacy in ways that enable people to take an active role in bringing about change in environments which influence their health.<sup>135</sup>

A quarter of a century later, poor health literacy remains a significant issue in Australia. The ABS, which in 2006 undertook a national survey of adult literacy and life skills, reported that 60% of Australian adults have low health literacy (as a by-product of poor literacy and life skills in other domains).<sup>136</sup>

The GAP report, cited previously, considered the role and importance of health literacy in health care for consumers and noted that a stocktake of health literacy initiatives, undertaken by the Australian Commission on Safety and Quality in Health Care (ACSQHC) in 2011–12, had criticised Australian activities to improve health literacy as “largely fragmented” and lacking local collaboration and national leadership.<sup>137</sup>

ACSQHC identified the following impacts of poor health literacy.<sup>138</sup>

- Low individual health literacy is associated with higher use of health services, low levels of knowledge among consumers and poorer health outcomes.
- People with low individual health literacy are between one-and-a-half and three times more likely to experience an adverse outcome.
- There are additional costs associated with low individual health literacy. At a system level, these additional costs were equivalent to approximately 3–5% of total healthcare spending.
- At an individual level, people with low health literacy spent between US\$143 and US\$7798 more per person per year than people with adequate health literacy.<sup>139</sup>

Health literacy is identified as an underlying driver for the National Strategic Framework for Chronic Conditions 2017 (discussed previously). It is difficult to discern from publicly available information what programs or processes are in place to assess baseline health literacy, levels and patterns of self-care or needs for support with self-care, including self-management, or to support the goals of the Chronic Disease Strategy. The ABS has responsibility for the metrics in this area, and it may be fruitful to engage with the ABS regarding the definitions, processes and measures which will be used and to assess the feasibility of influencing the data collection exercise to obtain greater understanding of population needs.

International evidence points to a consistent pattern indicating that although people are mostly willing and many see it as ‘natural’ to take some personal responsibility for self-care, there is also a high expectation that governments and health services share this responsibility. This paradox may be a reflection of what has been termed a “health literacy epidemic,” discussed in detail below.<sup>140</sup> As a result there are uncertainties about what constitutes safe and responsible self-care by adults in relation to the maintenance of their health and that of their children and other family members and when it is appropriate to seek professional advice and support in the form of health care services.<sup>141 142 143</sup> This confusion is also evident in the literature. Nutbeam (2008), for example, points to the different (and opposing) ‘medical’ and ‘public health views’ on health literacy, involving a ‘clinical risk’ and a ‘personal asset’ approach respectively. He suggests that these are rooted in three very different traditions: clinical care, adult learning and health promotion. Given this

fundamental lack of conceptual or semantic clarity it is hardly surprising that the population is uncertain about how to behave in relation to the maintenance of health and prevention of disease and disability.<sup>144</sup>

A great deal of work to promote and enhance health literacy is taking place in research, health, education, justice, social services, local government and many other areas in Australia (see Appendix 1). However, these activities reflect the overall self-care landscape discussed in this report. They are disconnected and opportunities for shared learning are few. Current systems to support improvements in health literacy at local, regional, state and territory levels are difficult to locate and are variable in focus and scope, and no national system exists.<sup>145</sup>

The ACSQHC has called for a “climate of national action and collaboration” to develop a coordinated approach to health literacy for Australia by:

- embedding health literacy into high-level systems and organisational policies and practices;
- ensuring that health information is clear, focused and useable and that interpersonal communication is effective; and
- integrating health literacy into education for consumers and healthcare providers.

Increasing the ability of Australians to undertake self-care is, very clearly, dependent on raising levels of health literacy in the population and particularly amongst those most at risk of poor health. However, it appears that despite evidence and advocacy, most recently from ACSQHC, advancing health literacy has generally failed to find political or community traction in Australia or equivalent countries. Tangible actions to advance health literacy are hard to identify. Responses to these challenges may have been put aside because the concept of health literacy has been considered too difficult to define and measure in terms of providing a practical basis for programmatic responses. In addition, when such responses have been developed, it is suggested that they have been narrowly conceived as health mass communication campaigns and not as development programs requiring whole-of-government responses and action across the life course and in all settings.<sup>146</sup>

## 9. Making sense of the self-care environment in Australia

### 9.1 Paddling below the surface

Understanding the self-care landscape in Australia is not easy. This review suggests that notions of self-care and practices and processes to support it are widespread and growing phenomena. This emergent cultural norm and the activity which it generates are, to some extent, below the radar of public policy and have not yet made a significant impact on the organisation, funding and accountabilities of the public health system or other publicly funded services, including education. Moreover, social and geographical gradients in health status suggest that some individuals and populations are being excluded from full participation in a more engaged and active health culture in Australia. There are, however, signs that the private health industry is embracing notions of self-care and self-management more actively. This is an important and interesting trend with the potential to improve the health of the 40% of Australians who have private health insurance, but it could also widen the health inequalities gap.

### 9.2 System-inertia

There are still numerous barriers to mainstreaming self-care, which is not yet a demand-driven concept; hence, policy is focused mostly on the supply side, with some limited attention to tackling unhealthy behaviours and supporting specific health conditions and groups. However health care providers may have

little incentive to change given current business models based on fees for service, episodic care and rewards for treating sickness rather than supporting health. Whilst the development of national schemes for ageing and disability support and care for people with chronic and complex health conditions show some promise in changing this business model, these developments are still not implemented at any scale in Australia (or anywhere else) and, as technical health care reforms, will not address the underlying narrative that frames the ways in which health is thought about and managed. This shapes cultural and social mind-sets as well as the entrenched institutional and professional structures and practices of the health care system, which respond to the treatment of sickness in the main and not to the maintenance of health and prevention of disease. The arrival of new entrants into the market, including new technologies, expanded roles for pharmacists and other clinicians, developments in precision medicine, integrated forms of care and home care may, in time, begin to threaten the incomes of traditional health care providers. Both public and private ‘commissioners’ of healthcare have the financial power and strategic power to stimulate and incentivise change.

It may be difficult for politicians to promote self-care due to the prospect of accusations of cutting funding for health services or of ‘victim blaming’. Health services and professionals have traditionally been oriented towards treating sickness, and the medical community in particular has concerns over how people can take more responsibility for their own health without compromising safety. Health system managers and policymakers rightly point to the fragmented and incomplete evidence for (holistic) self-care programs and policies. An additional challenge is that most self-care occurs in the home and community, entirely outside health systems. Health literacy, which is a vital 21<sup>st</sup>-century capability, is a by-product of education across the life course and not the health ‘system’. Hence, enhancing the ability of the Australian population to undertake self-care requires whole-system policy development and action.

### 9.3 Directional confusion

As our understanding and exposure to chronic disease management has expanded, so too has advocacy towards patient-centred and patient-driven care. However, recognition of the importance of co-creating better health through an informed partnership between individuals and professionals has not led to precision in defining what these partnerships should be aiming to achieve. The concepts of self-care and self-management are very poorly understood in policy and practice. This review has found that the policy rhetoric in Australia has two main aims:

- enabling and supporting individuals and populations to develop and exercise the capabilities for self-care; and
- enabling and supporting/incentivising health care organisations and professionals to support chronic disease management for individuals.

These terms are not defined and there is no explicit policy framework for enhancing self-care to support the overall goals of health policy. This may be because, in part, developing a health-literate population is difficult and requires a multi-faceted approach that is beyond the remit of health policymakers in isolation from other areas of policy.

There is notable confusion everywhere about what kind of self-care is being thought about or considered to be legitimate or feasible for policy action, perhaps reflecting a conceptual uncertainty about whether ‘taking care of the self’ as an aspect of human behaviour is not a legitimate area for policy. Policymakers appear to be more comfortable with a focus on the role of the ‘patient’ in managing existing conditions and secondary prevention rather than on primary prevention and overall population health literacy capabilities. There is very low investment in prevention in Australia compared to other countries.<sup>147</sup>

## 9.4 Extensive invisible activity

Extensive self-care activity, including policy and best practice in Australia, is uncoordinated and invisible. There is no coherent approach to establishing clear priorities for self-care, particularly in populations where the need is greatest (populations with low socio-economic status), or to developing a national conversation about its importance or supporting and spreading best practice. There may be lessons for Australia from developments in the UK, where there are some signs of a significant strategic shift towards systemic support for self-care. Developments include National Health Service (NHS) England's establishment of an NHS Programme Board to promote the NHS reform agenda, which focuses on 'patient activation' and the deployment of the [Patient Activation Measure](#) (PAM tool). PAM is a validated tool that enables a better understanding of an individual's ability to manage their conditions and captures the extent to which they feel engaged and confident in taking care of their health. The PAM is being incrementally rolled out across primary care driven by local 'commissioning bodies' (the payers and strategy -leaders in the UK system, with some similarities to Primary Health Networks in Australia), and through the evolution of 'accountable care organisations' (ACOs). These bodies, which are evolving in a number of countries, typically, tie payments to quality metrics and the cost of care. ACOs in the United States are formed from a group of coordinated health-care practitioners.<sup>148</sup> ACOs have the potential to shift the current, fragmented health care delivery-system towards an approach that relies on collaboration between the different organisations delivering care, such as hospitals, GPs, community services, mental health services and social care and the organisations paying for it.

There is an active, broad-based lobby group, the [Self Care Forum](#), which has had some success in influencing policy in the UK. Overall, in Australia, lobbying on this issue has not had broad stakeholder engagement nor been sustained for the length of time required to influence policy in complex areas.

## 9.5 Lack of evidence

Numerous gaps in data prevent an accurate assessment of baseline self-care capabilities in the population and the extent to which self-care is practised by individuals and professionals and its outcomes. Underlying structural problems in data collection in primary care in Australia are partly responsible and compounded by the burgeoning of e-health and web-based resources and a lack of reliable data about their use and impacts. Given the rise of technology – handheld internet-capable devices, applications to assist people with health conditions, and an endless supply of poorly-curated information – those offering support for self-care and self-management are either peers (people living with health conditions), commercial interests promoting their products or services, or providers who fail to disclose ideological prejudices or commercial interests. Finally, there has been very little adoption of evidence-based practices such as social prescribing or community referral in Australia.

## 10. Developing self-care policy in Australia

The evidence considered in this review mirrors the international evidence that self-care is not seen holistically, but rather as a largely disconnected set of activities that are often embedded in separate or conflicting health policies. Further, although self-care is a personal responsibility, there is a dependency culture in which responsibility for health is substantially 'delegated' to doctors and the health system. The United Nations, the WHO and Australian governments tend not to use the term self-care, preferring to focus on separate interventions to tackle smoking, obesity or lack of exercise. These perspectives at least partly explain why progress in introducing self-care into practice and policy is slow and difficult.

Overall there are significant challenges in embedding self-care into people’s lives and in public policy. Nevertheless, economic and political pressure will continue to mount as the rise of chronic diseases swamps health and social systems. The simple fact is that up to 80% of heart disease, stroke, type 2 diabetes and over a third of cancers could be prevented by people self-caring (that is, by individuals eliminating the risk factors of tobacco use, unhealthy diet, physical inactivity and excess alcohol consumption).

Webber (2017) has argued that it is important to determine whether the strategic promotion of self-care involves radical or incremental policy change, noting that most policy focus is on the latter.<sup>149</sup> In essence, incrementalism builds on the logic of existing policies and their underpinning ideas, often presented in healthcare as a ‘reform’ agenda. Radical policy is transformative, breaking new ground. In this context, the conceptual framework provided by the three horizons model may be helpful (Figure 5).

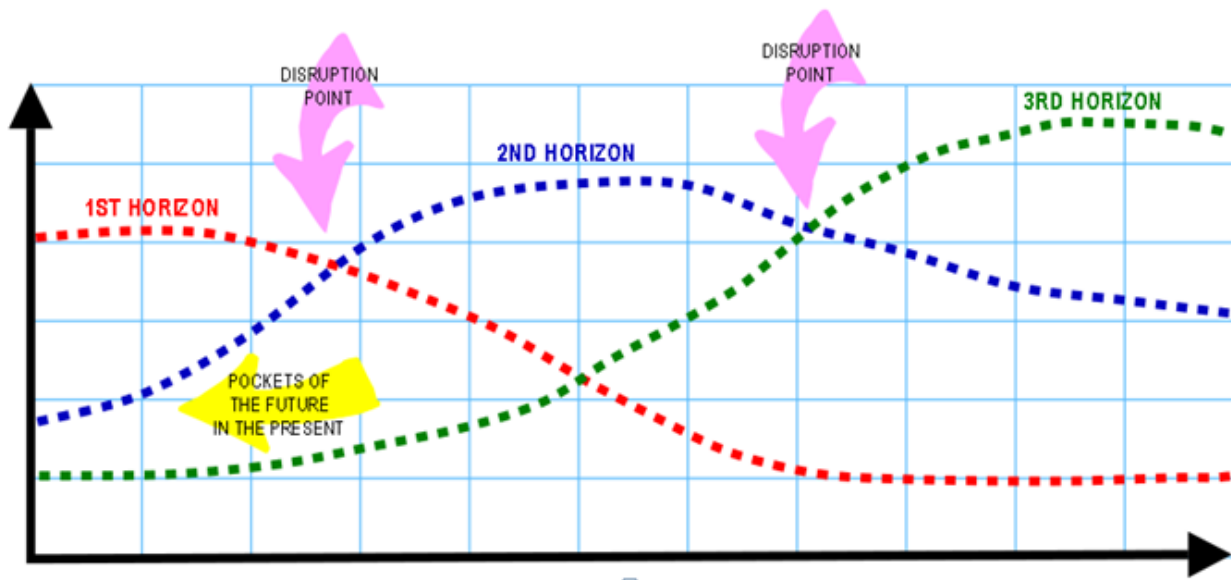


Figure 5: The Three Horizons Model (Adapted from Sharpe, 2014)

Application of this model suggests that, in relation to self-care, Australia is currently at Horizon 1. Self-care is not a health policy priority, not core business for most health care organisations and not promoted as a core competency for citizenship. If this argument is accepted, the challenge is to build collective will in Australia to move incrementally towards Horizons 2 and 3. This report demonstrates that the broader context of policy and social change is not, as yet, receptive to these ideas or open to disruption.

So, what is the way forward for self-care policy generation and development? The ISF’s view is that a dual approach is required:

- continue to articulate the case for and promote self-care, both holistically and by emphasising that individual activities (healthy diet, exercise, quitting smoking, etc.) are also self-care activities; and
- undertake and publishing research into what works in encouraging self-care in the home and community. Many self-care-related programs are underway in Australia and around the world, and could be the basis for sharing, learning and developing future policy choices.<sup>150</sup>

In Australia, it is unclear whether there is a lack of public and professional support to take a systems approach to holistic self-care or whether it is simply too hard to do so. There is some evidence in the consistent nature of the policy rhetoric and the ubiquity of self-care activity, coupled with indications of Australian

citizens' willingness to undertake self-care that governments would welcome support from a credible source in developing a stronger policy approach to self-care, particularly in relation to closing the health gaps in deprived communities. This is a significant policy challenge for Australia. 'Health in all Policies' approaches are desirable but are not being implemented nationally.

## 11. Next steps

Developing strong policy and practice in relation to self-care is a complex undertaking given the environment described in this report. Change is likely to be incremental and slow and will follow the existing policy reform path, as outlined by the Three Horizons Model. It will be important to determine achievable 'Horizon 2' goals for the policy effort whilst, at the same time, scanning for the transformational 'Horizon 3' developments that may already be emerging. Attempts to influence policy will need to be sustained and various stratagems should be used to achieve influence. Strong and consistent communication with politicians, clinicians and the public is vital. Whilst the development of public policy always involves efforts by competing interest groups to influence policymakers, coalitions of credible actors can exert powerful pressure. The evidence of this review is that a concerted effort is required to move from Horizon 1 to Horizon 2 and beyond in self-care in Australia.

This report makes a case for recognising self-care as a component of an effective chronic diseases strategy and identifies many of the gaps and obstacles which must be overcome to achieve it. Vocal leadership on this issue could bring together the range of stakeholders needed to create a plan to get self-care onto the national agenda. The following initial proposals are made to that end.

1. Agree next steps in the development of a broad consensus statement, involving key stakeholders, on the role of self-care in promoting health and preventing disease in Australia based on agreed definitions and the best available evidence of role, benefit and impact;
2. Agree a communication strategy to support the dissemination of the consensus statement amongst key stakeholders
3. Consider how to develop a platform for national and international information sharing, best practice promotion and horizon scanning;
4. Identify priorities for research on self-care in Australia.



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