
Better Outcomes **FOR PEOPLE**

with Chronic and Complex Health Conditions

December 2015

**REPORT OF THE
PRIMARY HEALTH CARE
ADVISORY GROUP**

Primary Health Care Advisory Group Final Report
Better Outcomes for People with Chronic and Complex Health Conditions

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The Hon Sussan Ley MP
Minister for Health
Minister for Aged Care
Minister for Sport
Parliament House
Canberra ACT 2600

Dear Minister,

It is my pleasure to present this report of the Primary Health Care Advisory Group: “Better Outcomes for people with Chronic and Complex Health Conditions”.

Our current primary health care system works well for the majority of Australians. However, for the growing number of people with chronic and complex conditions, care can be fragmented and the system can be difficult to navigate.

Through consultations with patients, carers, doctors, allied health professionals and health system organisations we have identified a model of care supported by a new way of funding that can transform the way we provide primary health care for Australians with chronic and complex conditions.

Central to the reform is the establishment of Health Care Homes, which provide continuity of care, coordinated services and a team based approach according to the needs and wishes of the patient. This new approach is supported by new payment mechanisms to better target available resources to improve patient outcomes.

Our new approach offers an opportunity to improve and modernise primary health care and maximise the role of patients as partners in their care. It represents innovative, evidence-based best practice that harnesses the opportunity of digital health care. Importantly, it has strong support from consumers and health care professionals alike.

On behalf of the Advisory Group, I commend this report to you and thank you for the opportunity to contribute to building a healthier Medicare.

Yours sincerely



Dr Steve Hambleton

Chair

Primary Health Care Advisory Group



Executive summary

The current primary health care system is high performing and works well for most Australians. However, in common with a number of developed nations, Australia is experiencing increasing rates of chronic and complex conditions, which challenge our current primary health care system and its connection to secondary care.

35% of Australians, over 7 million people, have a chronic condition, and an increasing number have multiple conditions, making care more complex and requiring input from a number of health providers or agencies. The Australian Institute of Health and Welfare (AIHW) reported in mid-2015 that approximately 20% of the population have two or more chronic conditions (multiple morbidity)[1]. This population group has different service needs depending on the level of complexity of their conditions. A risk stratification approach can more effectively support identification of patients with specific needs and target services accordingly.

Patients with chronic and complex conditions are high users of health services. Very high general practice (GP) attenders saw three times as many different general practitioners (GPs) compared to low attenders (4.8 compared to 1.5). Just one third (34%) of very high and frequent GP attenders combined saw three to four GPs in 2012–13, while a further 36% of very high and frequent GP attenders saw five or more[2].

Currently, primary health care services in Australia for this patient cohort can be fragmented, and often poorly linked with secondary care services, making it difficult for patients to be confidently engaged in their care as evidenced by the experience of patients that can be found in the Appendices. Most patients with multiple chronic conditions receive treatment from many health providers: most of them working in different locations, and often working in different parts of the health system. As a result, effective communication between the health ‘team’ can be challenging and may be inconsistent. This leads to concern regarding the quality and safety of patient care.

Submissions to this review also suggest that resources for some patients with chronic and complex conditions could be better targeted to improve quality of care and access, minimise waste and maximise appropriate use of available resources across the whole of the health system.

A new model of primary health care for patients with chronic and complex conditions

This report details the evidence for change and recommends broad adoption of a new model of care and supporting reforms to better meet the needs of Australians with chronic and complex conditions into the future. Given the time constraints it has not been possible to cost the model, however the implementation section of the report outlines a staged approach to progressing the model that will include an assessment of affordability.

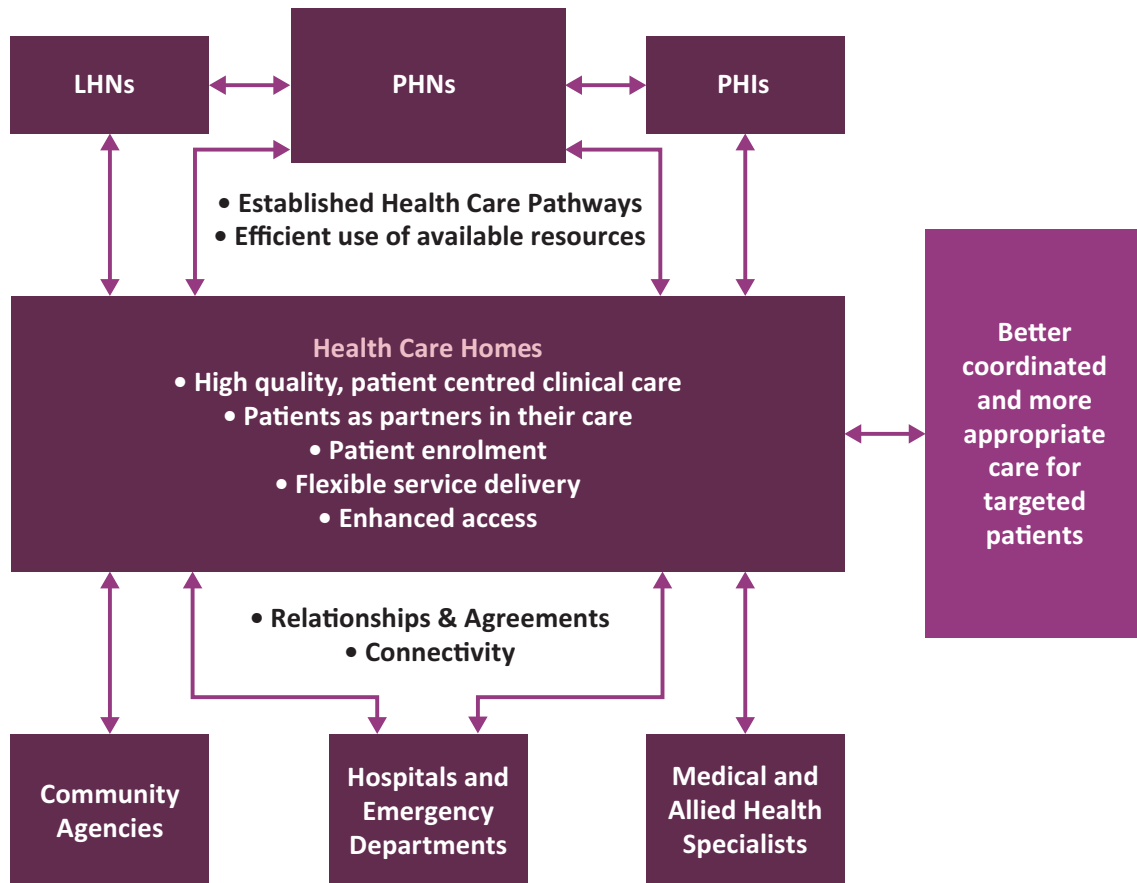
Central to the proposed reform is the formalisation of the relationship between the patient with chronic and complex conditions and their Health Care Home: a setting where they can receive enhanced access to holistic coordinated care, and wrap around support for multiple health needs.

Key features of the Health Care Home are:

- **Voluntary patient enrolment** with a practice or health care provider to provide a clinical ‘home-base’ for the coordination, management and ongoing support for their care.
- **Patients, families and their carers as partners in their care** where patients are activated to maximise their knowledge, skills and confidence to manage their health, aided by technology and with the support of a health care team.
- **Patients have enhanced access** to care provided by their Health Care Home in-hours, which may include support by telephone, email or videoconferencing and effective access to after-hours advice or care.
- **Patients nominate a preferred clinician** who is aware of their problems, priorities and wishes, and is responsible for their care coordination.
- **Flexible service delivery and team based care** that supports integrated patient care across the continuum of the health system through shared information and care planning.
- **A commitment to care which is of high quality and is safe.** Care planning and clinical decisions are guided by evidence-based patient health care pathways, appropriate to the patient’s needs.
- **Data collection and sharing** by patients and their health care teams to measure patient health outcomes and improve performance.

Many patients will recognise features of the Health Care Home in their existing general practices.

Figure 1: The Health Care Home



Better targeting of services for patients with chronic and complex conditions in accordance with need

A risk stratification approach is needed to more effectively support the identification of patients with high coordination and team needs and target services accordingly. For the population who have multiple chronic conditions, the Advisory Group has identified three tiers of the population who may benefit from a Health Care Home, differing in their complexity and need for coordinated care and support in relation to patients' abilities to self-manage.

Many of the submissions to the Advisory Group recommended a much broader application of the Health Care Home model beyond the scope of this review. Some of the recommendations from those submissions may be considerations for the Medicare Benefits Schedule Review Task Force and others recommendations may be considered over time.

System integration and improvement

Care within the Health Care Home is supported by better integrated community and acute care within the broader health system. This allows the patient, family and health care team to more readily access important care within their own community. This might be a specialist opinion or visit, videoconference or additional home service to avoid a preventable hospitalisation.

This will require Primary Health Networks (PHNs) to work with Local Hospital Networks (LHNs) to strengthen and promote regional collaboration in commissioning services to support local and out of hospital health care. PHNs should collaborate with LHNs, Private Health Insurers (PHIs) and providers to develop or build upon locally relevant hospital admission and discharge approaches or protocols, including locally relevant patient health care pathways. Patients and providers are supported to develop more formal arrangements to involve PHIs in supporting policy holders' access to relevant chronic disease services.

Change management

Overseas experience has shown that such changes to care delivery models require significant change management support. Professional colleges and associations should be engaged early and in an ongoing way to: support the substantive cultural change required to establish Health Care Homes; assist the integration of primary and secondary care; and support uptake of the recommended reforms to policies, practice, training and professional development.

New payment mechanisms

Existing payment systems should be redesigned for eligible patients to more appropriately cover the wide range of services to be provided under the new approach. These should include the introduction of bundled payments, block payments and pooled funding to support the new approach, while preserving fee for service for episodic care. Payment approaches need to preserve regional flexibility, equity of access for patients, support evidence-based and non-face to face care, and encourage efficient use of resources. Nationally, there is significant capacity within the existing health system to redirect and re-profile existing expenditure to support the new approach.

Measuring the achievement of outcomes

Health Care Homes and the community reforms around them should support a continually improving primary health care system. The Advisory Group recommends that a nationally consistent, de-identified data set is developed and used at a regional and national level to understand the impact of service change with a view to improving population health outcomes and informing ongoing health system improvements.

Elements of the Practice Incentives Programme should be refocused to support practices to use relevant data to undertake quality improvement activities in a structured way.

The process of data collection and analysis should be part of the establishment of Health Care Homes and related service-integration initiatives and is necessary to understand the impact of and progressively improve the quality of the new models of primary and integrated care.

Strong support by the sector and the public

Key elements of the recommended model are strongly supported by the feedback from the consultation processes:

- 77% of respondents indicated that they support patient enrolment with a Health Care Home for people with chronic and complex conditions.
- 92% of respondents supported team based care for people with chronic and complex conditions.
- 90% of respondents agreed that it is important to measure and report patient health outcomes.

Implementation considerations

Australia is well placed to progress the recommended reforms. There are many elements of the existing health care system that already provide a solid foundation from which to establish the proposed new model of care.

A staged rollout of the model is recommended, to enable the individual elements of the model to be properly defined, established and evaluated before proceeding to a national rollout.

States, Territories and the Commonwealth, PHNs and PHIs are already conducting (or in the process of developing) trials that could be built upon or expanded as part of the first stage of implementation.

The Advisory Group recognises the need to work within existing resources as far as possible. International evidence demonstrates that a strong, well-resourced primary health care system leads to high quality care and is a more efficient use of available resources. However, the Advisory Group cannot rule out the requirement for additional resources to support the model. The proposed staged rollout provides the opportunity to assess the affordability of the model and should look to apply existing resources within the system.

An effective overarching governance mechanism is required to ensure that funders, providers and patients are engaged in the detailed design and implementation process. This should link with existing reforms underway, including the Reform of Federation, the Review of the Medicare Benefits Schedule (MBS) and other Commonwealth reviews.

Early and ongoing communication and engagement with governments, PHNs, LHNs, provider organisations, and PHIs and consumers is essential to ensure optimal support for the new model of care and the cultural changes and developments necessary to support the rollout of the new model of care.

Summary of recommendations

Appropriate and effective care

Key Recommendation 1: Better targeting of services for patients with chronic and complex conditions in accordance with need

- Identify suitable case finding processes, drawing on existing validated Australian and international risk stratification tools to identify patients requiring high levels of coordination and team care.

Key Recommendation 2: Establish Health Care Homes

- Develop appropriate Health Care Home specifications, evidence-based education and training and other tools to enable providers, patients, practice managers and the broader health care sector to operate and engage with Health Care Homes.

Key Recommendation 3: Activate patients to be engaged in their care

- Develop an effective and standardised approach to support patients and providers to engage in shared goal setting and decision making.
- Develop advice on the application of digital health devices and any health system changes required.
- Enhance access to targeted online patient information and education and self-help resources.

Key Recommendation 4: Establish effective mechanisms to support flexible team based care

- Reduce barriers for allied health professionals and community-based specialists accessing and contributing to the patient record, complementing recommendations of the 2013 *Review of the Personally Controlled Electronic Health Record*.
- Ensure Health Care Homes use clinical software that is compatible with the Australian digital health infrastructure to support the integration of information technology (IT) systems.
- Formalise the roles and responsibilities for clinical and non-clinical care coordinators within the Health Care Home.

System integration and improvement

Key Recommendation 5: Enhance regional planning

- Assess and share the benefits of evidence-based patient health care pathway tools that are currently available and being applied in Australia.
- Require PHNs to collaborate with LHNs, PHIs, providers and patients to support regional planning, including the establishment of locally relevant patient health care pathways and admission and discharge protocols.

Key Recommendation 6: Maximise the effectiveness of private health insurance investment in the management of chronic conditions

- Support a single care plan developed by the Health Care Home that better coordinates the provision of all relevant services, whether funded publicly, by PHIs or by patients.
- Source or develop protocols, including patient consent, to share relevant information between providers and PHIs.
- Further encourage PHIs to fund the prevention and management of chronic conditions, including through consideration of the use of the risk equalisation pool in relation to chronic disease management programmes to support patients in the Health Care Home.
- The private health insurance consultations should further consider ways to address disincentives for PHIs to support care service delivery in non-hospital settings, such as hospital in the home.
- Review the outcomes of current PHI chronic disease trials to further define the future role of PHIs in supporting management of chronic and complex conditions.

Key Recommendation 7: Coordinate care across the health system to improve patient experience

- Assess the applicability of existing care coordination capability in aged care and mental health for inclusion in the Health Care Home planning and patient and family service support.
- Ensure that all Health Care Home care coordinators identify the existence of, and engage with, care coordinators from other sectors in planning and delivering patient care.

Key Recommendation 8: Support cultural change across the health system

- Support PHNs, professional colleges, associations and consumer groups to develop and implement education and training for health care providers and consumers on the development and staged rollout of the new service delivery and funding models, to ensure all stakeholders are engaged and ready for the new model of care as it is rolled out nationally.

Payment mechanisms to support a better primary health care system

Key Recommendation 9: Restructure the payment system to support the new approach

- Restructure the payment system to include alternative payment approaches that appropriately cover the wide range of proactive, coordinated and ongoing services to be provided under the new approach.
- Test upfront and quarterly bundled payments to Health Care Homes to support the new approach prior to wider rollout.
- Consider the range of Medicare Benefits Schedule (MBS) items and other Commonwealth funding programmes that could be brought together to support a more targeted and flexible approach to funding.
- Test new payment models to PHNs to enable them to commission appropriate non-general practice clinical care and coordination services for enrolled patients in their region based on the patient's allocated risk stratification level, prior to wider rollout.

Key Recommendation 10: Pursue opportunities for joint and pooled funding

- Explore opportunities for State and Territory governments, PHIs and local industries to contribute to the funding base for enrolled populations (through funding or in-kind contribution).

Key Recommendation 11: Patients contribute to their health care costs to the extent that they are able

- There should be no change to the expectation of Australians to continue to contribute to some of their health care costs to the extent that they are able to pay, consistent with current approaches.

Measuring the achievement of outcomes

Key Recommendation 12: Support a quality and continually improving primary health care system

- Require Health Care Home practices to be appropriately accredited or have registered for accreditation (and achieve full accreditation within 12 months). Accreditation should reflect practice type and setting.
- Strengthen the focus of the Practice Incentives Programme towards quality improvement activities by providing payments to support general practices identifying as Health Care Homes to undertake quality improvement activities in a structured way, informed by data.

Key Recommendation 13: Establish a national minimum data set (NMDS) for patients with chronic and complex conditions

- Establish a suitable data governance mechanism to develop and implement a NMDS for patients with chronic and complex conditions, in consultation with health care providers, relevant organisations, patients and carers.
- Health Care Home practices and care providers to provide de-identified data to support a NMDS.
- Explore IT infrastructure requirements to support the automated extraction of deidentified data from clinical software, data analysis and reporting.
- Ensure PHNs are sufficiently supported to assist Health Care Homes to collect and report data and utilise it to improve local care quality.

Key Recommendation 14: Establish new performance reporting arrangements

- Provide NMDS summary data to practices, regional level data to PHNs and LHNs and build on the existing national reports on chronic disease management to support system improvements and resource allocation.

Key Recommendation 15: Integrate evaluation throughout implementation of the reforms

- Develop and implement an evaluation framework to ensure early and ongoing learning, and application of this learning, through the staged implementation of the reforms.

Introduction

The case for reform

Overall, Australia has a strong health system that is supported by a highly trained and dedicated workforce. However, we face some significant challenges in delivering quality health care to people with chronic and complex conditions, including mental illness, while ensuring health system sustainability.

Australians are now living an average of 25 years longer than they were a century ago. But we are increasingly living with chronic conditions such as heart disease, diabetes, cancers, respiratory diseases and mental illness. These conditions are the leading causes of illness, disability and death in Australia:

- 35% of Australians, or around 7 million people, have a chronic condition[3];
- many people experience multiple chronic conditions[3];
- people with severe mental illness and Aboriginal and Torres Strait Islander peoples are three times more likely than the general population to have diabetes and are at increased risk of cardiovascular disease[4, 5]; and
- risk factors for chronic conditions, such as obesity, are at high levels and increasing and will inevitably drive growth in rates of diabetes and other preventable conditions over time[6][7].

Our current health system is not optimally set up to effectively manage long term conditions. Increased and poorly targeted service use is resulting in variable patient outcomes and significant financial impacts across the entire health system.

The average cost of a single hospital admission for heart failure or chronic obstructive pulmonary disease without any other complications is around \$5,500[8]. While not all hospital presentations for chronic or other conditions can be prevented through primary health care interventions, it may be possible to prevent many:

- in 2013–14, 48% (285,000) of potentially avoidable hospitalisations were for chronic conditions[9]; and
- nearly a quarter (23%) of people who visited an emergency department felt their care could have been provided by a general practitioner[2].

Our public consultation process has revealed that patients often experience: a fragmented system, with providers and services working in isolation from each other rather than as a team; uncoordinated care; difficulty finding services they need; at times, service duplication and at other times, absent or delayed services; a low uptake of eHealth and other health technology by providers to overcome these barriers; difficulty in accessing services due to lack of mobility, transport, language, financial barriers and remoteness; and feelings of disempowerment, frustration and disengagement.

There are many factors contributing to poor patient outcomes, for example: every 2–3 hours in Australia there is an amputation that could have been prevented with better management of diabetes[10, 11]. Patient choice, expectations and participation in their care can significantly influence patient health outcomes. Variations also exist in the care received – between clinicians, services and geographic locations. This can result in patients experiencing poorer quality care and increased rates of adverse outcomes.

Poor outcomes are more likely for Aboriginal and Torres Strait Islander peoples, people with mental illness, people from culturally and linguistically diverse backgrounds, and those living in rural and remote areas.

More sustainable use of health system resources is critically important, since national health care costs continue to grow at a rate faster than the national economy.

The Advisory Group believes that better integrated and coordinated primary health care services for patients with chronic and complex conditions are the best way to achieve better outcomes for patients and ensure a sustainable health system into the future.

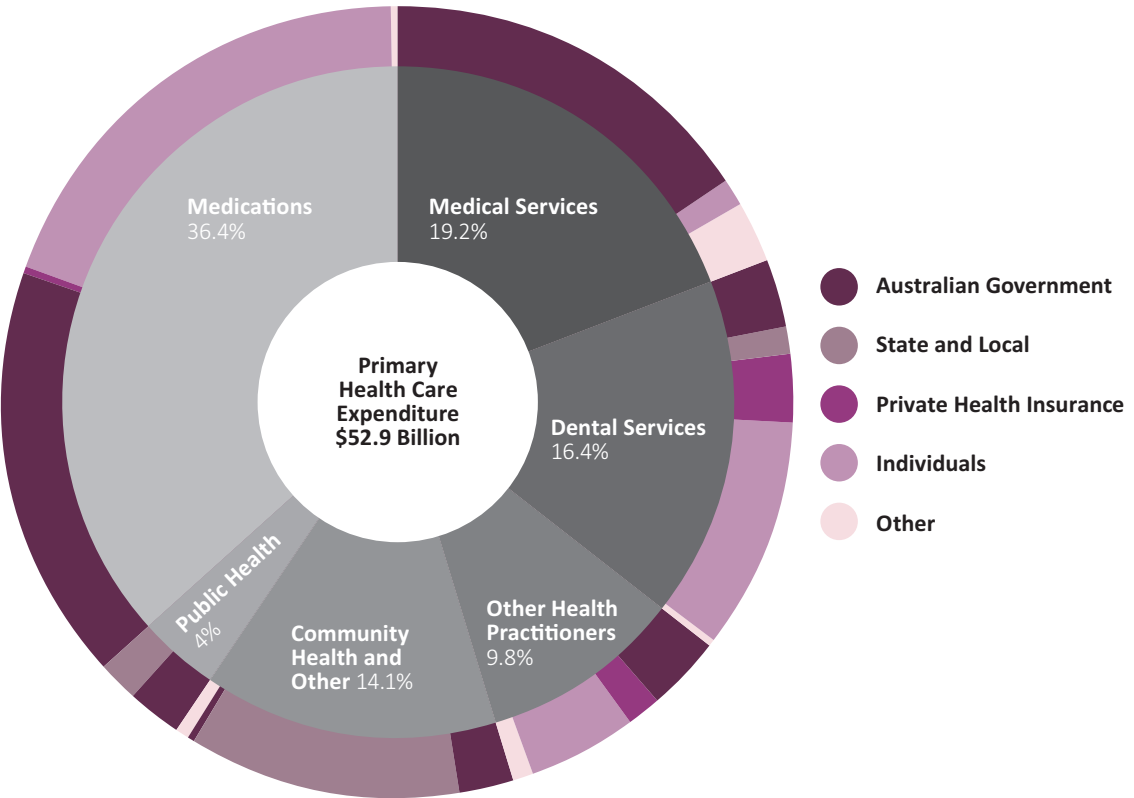
Governance of the primary health care system is complex

The Australian primary health care system has divided responsibilities for funding and performance. For example, Commonwealth and State governments provide the most funding, but local governments also contribute, as do non-government organisations, private insurers and people out of their own pockets (Figure 2 refers).

People with chronic and complex conditions will often require health care from a range of disconnected providers. Responsibility for funding and delivering these services may be spread across the entities described above. This can result in confusion for patients and poorer health outcomes and a lack of continuity of care.

These issues are compounded in primary health care, which often appears to be more a collection of separate services than a coordinated and integrated system.

Figure 2: Proportion of primary health care expenditure[12]



Building on past primary health care reforms

The challenges in our primary health care system are not new. There have been numerous reforms to primary health care in the past; our recommended reforms build on them. They build on efforts, starting in the 1990s, to strengthen the primary health care workforce: initiatives such as the Australian Government's General Practice Reform Strategy (implemented in 1991) and establishment of Divisions of General Practice, both of which aimed to improve service delivery at the local level.

The recommended reforms build on initiatives such as the first National Primary Health Care Strategy and associated National Primary Health Care Strategic Framework, the Practice Incentives Programme (implemented in 1998), and changes to the MBS – for example introducing Enhanced Primary Care and later Chronic Disease Management items – that enabled GPs to provide more comprehensive and structured care to patients with chronic and complex conditions[13].

Our reform proposals build on the previous trials of coordinated care and alternative payment models – namely, the Coordinated Care Trials conducted between 1997 and 1999 (round one) and 2002 and 2005 (round two), and the more recent Diabetes Care project conducted between 2011 and 2014.

These trials are important because they have already tested the feasibility and implementation of some of the key elements of our reform proposals: namely, individualised care plans for selected patients, alternative ways of funding care, and care coordination. Through these trials, we have learnt the importance of:

- involving care providers in the design and implementation of reforms;
- recognising and funding 'care coordination' as a discrete area of care-related activity;
- developing robust governance, management and performance monitoring arrangements at the beginning of the reform process;
- having sophisticated and effective electronic communication, networking and data flow processes in place;
- including flexible funding changes as part of the suite of reforms; and
- carefully targeting resources towards patients most able to benefit from care coordination[14–17].

The lessons learnt through these earlier trials, current innovative service models, and our research on international experience have informed the design of the recommendations for reform outlined in this report.

Effective and appropriate care for people with chronic and complex conditions

Strategic Directions:

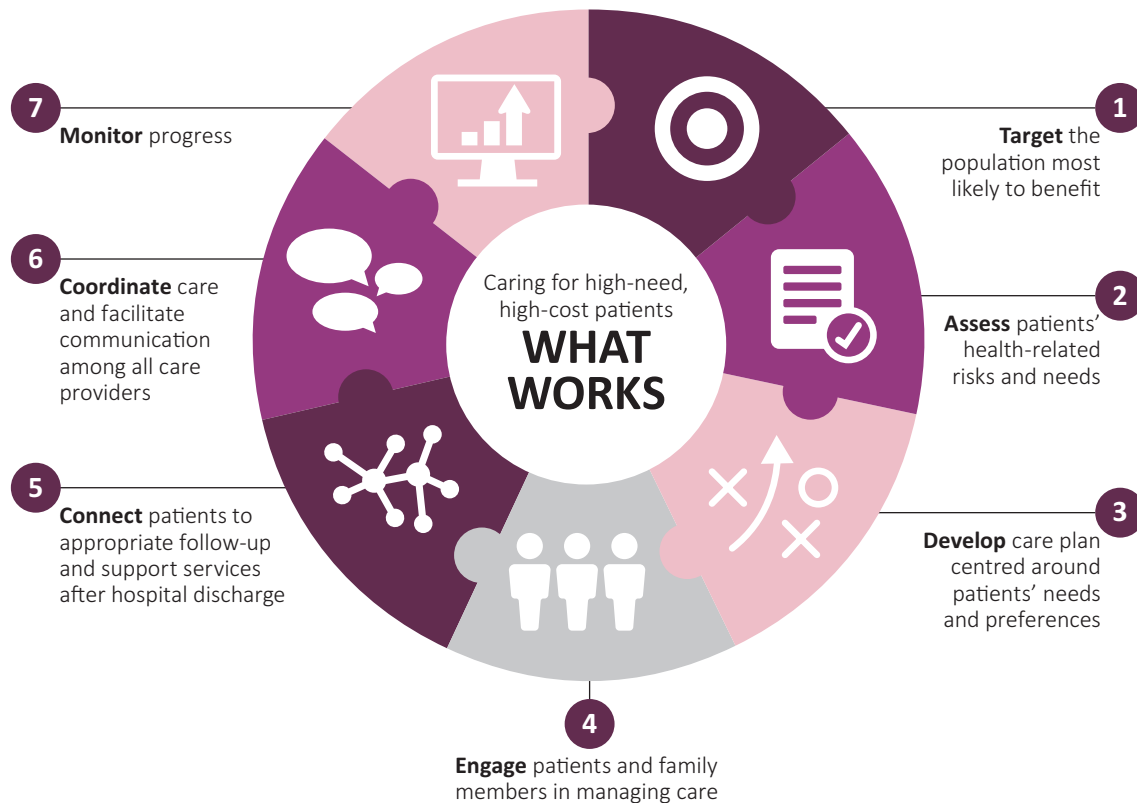
- Patients who can most benefit from more intensive care and support are able to be identified through application of an evidence-based approach.
- Patients have a Health Care Home to support and coordinate their care across the health care system.
- Care plans are developed and refined in partnership with patients and their families and carers, and implemented through a flexible team based care approach.
- Patients (and carers where appropriate) are active members of the care team, involved as partners in setting shared goals and making shared decisions.
- Patients are supported to learn more about their conditions and how they can participate in managing them.
- Care plans build upon a foundation of local patient health care pathways to ensure care is evidence-based and delivered in a local health care framework.
- More effective and efficient use of resources to deliver better patient outcomes.

The current primary health care system works well for most Australians. It is built around a strong general practice foundation and has proven critical to the efficiency and cost effectiveness of the Australian health care system. The primary health care system is currently optimised for volume and access, therefore it is well equipped to respond to short-term ailments. In 2013–14, more than 85% of standard consultations with a GP at a general practice were less than 20 minutes long, with the median length consultation of 13 minutes [18][19].

However, along with a number of developed nations, Australia is facing the challenge of providing optimal care for increasing numbers of patients with chronic and complex long-term conditions. Concurrently, the poor management of the often multi-morbid physical conditions of people with severe and complex mental illness (many of which can be managed in primary health care) is a major factor in their reduced life expectancy. Around one third of people (31.8%) with a psychotic disorder in Australia are also experiencing chronic pain, around a fifth (20.8%) have diabetes – over three times the rate of the general population – and just over a quarter (26.8%) have heart or circulatory problems[4].

If Australia is to be prepared to respond or even reduce the burden of these diseases, the delivery of primary health care in Australia must be better targeted, patient-centred, and characterised by services that are better suited to support people with multiple chronic conditions and should include self-management support wherever possible. A review of the evidence of what works in caring for high-need high-cost patients was recently released by the Commonwealth Fund (Figure 3 refers).

Figure 3: Caring for high-need, high cost patients: what works[20]



Key Recommendation 1: Better targeting of services for patients with chronic and complex conditions in accordance with need

Identifying and assigning risk levels to patients with chronic and complex conditions

The Advisory Group believes that linking the patient with the right intensity of treatment is important. Too much care complexity for a patient who is largely self-managing wastes both their time and resources. Too little care, results in sub-optimal support for Australians with chronic and complex conditions. Internationally, and within Australia, tools to help patients and clinicians 'match' the right treatment suite to the level of need have been developed[21].

These tools use information including patient diagnoses, previous medical history and health service use, socioeconomic and demographic factors to correlate patients' needs for services. For example, by using statistical methods to identify the factors that can predict avoidable hospital admissions, or by finding people already in hospital that could be effectively treated in better supported primary health care or in palliative care, we would improve health and quality of life, whilst also improving the cost efficiency of the system overall.

Figure 4: CHronic disease by complexity in Australia

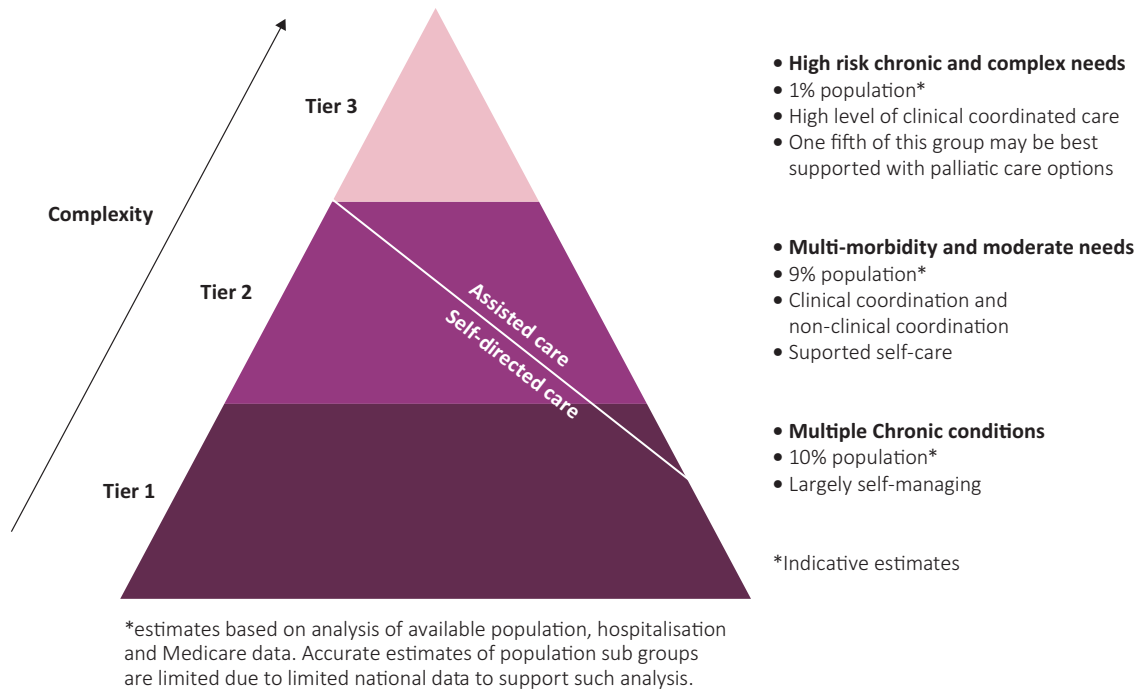


Figure 4 above draws from existing utilisation data, to identify the intensity of care support required for Australians with chronic disease that the Advisory Group is recommending be offered the enhanced care available in a Health Care Home.

The diagram illustrates that increasing patient physical or mental health complexity, such as a higher number of health conditions to manage at the same time (multiple morbidity), or more severe symptoms, will require a greater level of support from health services. For example, severe mental health conditions may greatly impact on risk stratification, particularly in terms of management of physical health and the patients' own abilities to self-manage sufficiently to avoid hospitalisations. Patients with multiple chronic health conditions but with lower complexity, however, may be most effectively and appropriately assisted through increased support for self-management.

The characteristics of patients across the three tiers of complexity are outlined in Table 1 below.

Table 1: Patient characteristics by complexity

Tier 3: Highly complex multiple morbidity
<ul style="list-style-type: none">• Many Tier 3 patients will require frequent ongoing clinical care within an acute setting, including those with cancer requiring complex care, or patients with severe, persistent and treatment resistant mental illness.
<ul style="list-style-type: none">• Up to 20% of patients in Tier 3 will have a high likelihood of mortality in the next twelve months, based on the progression of their health conditions. Many of these patients could be better supported through enhanced access to palliative care.
<ul style="list-style-type: none">• Some Tier 3 patients could be better managed in primary health care settings but all would benefit from better linkage.
Tier 2: Increasingly complex multiple morbidity
<ul style="list-style-type: none">• Most patients in Tier 2 are or should be managed in primary health care settings. They will have complex conditions requiring increased access to services, and are likely to be on multiple pharmacotherapies, but are able to function in the community with appropriate support.
<ul style="list-style-type: none">• Some patients in Tier 2 may be in residential aged care settings.
<ul style="list-style-type: none">• Tier 2 patients will have an increased risk of potentially avoidable emergency department presentations and hospitalisations as their conditions worsen or if not properly supported.
Tier 1: Multiple morbidity – low complexity
<ul style="list-style-type: none">• Patients have multiple diagnosed chronic conditions but are largely high functioning and experiencing limited reductions in quality of life associated with their diagnoses and stand to gain significant long term benefit from improved engagement and structured support.

For the highest tier (Tier 3) of people with chronic and complex conditions, many will have advanced disease or a very high number of multi-morbid conditions, likely with severe symptoms requiring regular interaction with acute and secondary care providers. This does not necessarily mean that all Tier 3 patients access care in a hospital environment. For some people with advanced health conditions, earlier support to make decisions about end of life care and access to home based palliative care can greatly improve quality of life.

At the lower end of the complexity continuum, patients identified as Tier 1 may benefit from more assertive approaches to promoting healthy behaviours that will reduce or delay the likelihood of their conditions worsening – such as smoking cessation, medication adherence, fitness and weight loss education.

Many of the submissions to the Advisory Group recommended a much broader application of the Health Care Home model than recommended by the Advisory Group in this paper. Some of the recommendations from those submissions may be further assessed by the Medicare Benefits Schedule Review Task Force and others may evolve over time.

Current status of risk stratification in Australia

At present, the use of risk stratification in primary health care in Australia has largely been limited to research and innovative trials. The Diabetes Care Project is a recent example however, the evaluation of this project was limited in its investigation of any predictive qualities of the risk framework and its interaction with costs and models of care or clinical outcomes[17].

Systematic risk stratification has been used in Victoria since the late 1990s, for their Hospital Readmission Risk Programme (HARP), based on the Kaiser Permanente and Wagner Chronic Care models of the United States of America. The HARP risk framework uses clinical information, service use history, psycho-social and other complexity factors to calculate a score associated with the probability of hospital readmission within the next 12 months. A hierarchy of risk scores is aligned with three tiers, and patients stratified to the highest two tiers are enrolled in intensive models of care.

The New South Wales Agency for Clinical Innovation has recently published a risk stratification handbook intended for use by health organisations with system administration responsibilities, including Local Health Districts, Specialty Health Networks and PHNs[22]. The handbook provides evidence-based guidance on the establishment and expansion of risk stratification models to inform service delivery and system orientation.

Activities

- Identify suitable case finding processes, drawing on existing validated Australian and international risk stratification tools to identify patients requiring high levels of coordination and team care.

Key Recommendation 2: Establish Health Care Homes

People with multiple health conditions frequently move across many parts of the health care system, encountering a range of service providers. This can complicate clinical decisions where a patient's health history may be unknown or incomplete, and can result in poor decision-making about care, duplication and wasted time and resources.

It is time to address barriers within health systems that can prevent patients from receiving optimum care including: misaligned financial incentives; change inertia; culture and workforce; infrastructure; and lack of application of evidence[20].

Health Care Home

A Health Care Home tailored for the Australian context (Figure 5 below) can take responsibility for coordinating the ongoing and comprehensive care of patients with chronic and complex conditions. The Health Care Home model of care reinforces the central role of primary health care within the health system, with the following aims:

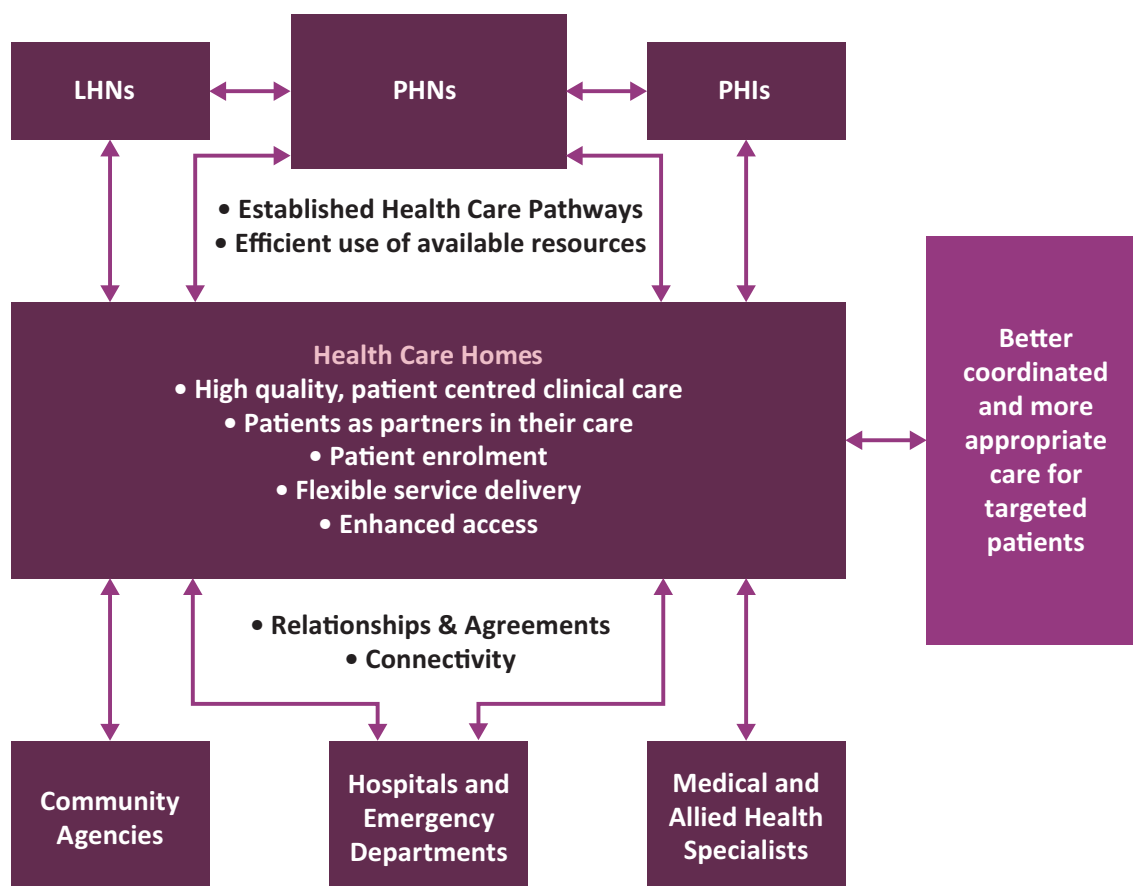
- better coordinated, more comprehensive and personalised care;
- empowered, engaged, satisfied and more health literate patients, families and carers;
- improved access to medical care and services, including through appropriate use of non face-to-face phone and internet based digital health options;
- improved health outcomes, especially for patients who have chronic conditions;
- increased continuity and safety of care, including more consistent adherence to clinical guidelines;
- increased productivity of health care service providers;
- increased provider satisfaction, working to full scope of their license; and
- enhanced sharing of up to date health summary information.

Such models have been increasingly prominent in primary health care discussions in Australia, including recommendations within the 2009 National Health and Hospitals Reform Commission.

Central to the Advisory Group's recommended reform is the formal establishment of Health Care Homes that: provide holistic support and coordinated care for patients; support enhanced team based care; are underpinned by shared information; and are supported by new payment models.

Internationally, similar innovative models centred around a ‘medical home’ have been at the forefront of improved preventive health and treatment services and improved patient satisfaction, while also reducing hospital admissions, particularly for people with chronic and complex conditions. Reported benefits include higher patient satisfaction, improved clinical quality and patient outcomes, and reduced ‘burnout’ of health service providers[23, 24].

Figure 5: The Health Care Home



Principles of the Health Care Home

The Health Care Home is built upon 7 key principles. Some of these principles are complementary to or refinements of current approaches to the provision of primary health care in Australia, while others represent transformational reform.

1. Voluntary patient enrolment with a provider in a practice establishes a formal agreement between patients and a clinical ‘home-base’ for the optimal coordination, management and support for their chronic and complex conditions. For patients with chronic and complex conditions, voluntary enrolment would mean voluntarily agreeing to see, on an ongoing basis, the local primary health care practice of their choice.

This agreement would establish an ongoing partnership between the patient and the Health Care Home, each with responsibilities for shared goals and outcomes according to an agreed care plan. In making this agreement, patients and providers commit to working together in partnership to address the cause of the conditions where possible, optimally address their impact, maximise quality of life and identify the best local clinical and other services appropriate to their needs.

In order to be enrolled in a Health Care Home, patients and providers will agree to establish and keep updated a shared electronic health summary for the patient.

The use of shared electronic health records within a flexible team based care model will: empower patients to take active roles in their care; assist them to understand and communicate with their preferred clinician and other care providers about their health problems, treatment goals and progress; reduce duplication of services and unnecessary tests; and support better health care across the system supported by current and accurate information.

2. Patients, families and their carers as partners in their care. The aim is to put patients in control of their own care with the knowledge, skills and confidence to manage their health, supported by their health care team, and families and carers where appropriate. Factors that contribute to this outcome include engaging and supporting patients in: keeping healthy; shared decision-making; self-management; the choice of provider; and evaluating services through structured feedback using evidence-based tools such as patient reported outcomes and patient reported experience measures.

Patients often need help to understand the treatment options and outcome probabilities, especially if they have multiple health conditions to manage to support evidence-based patient choice.

3. Patients have enhanced access to services through their Health Care Home which will include non face-to-face services where clinically appropriate and effective. These services may be enabled by telephone, email or videoconferencing and may also be supported and augmented by digital health and home-monitoring devices.

The Health Care Home should also include access to after-hours support including advice or care for enrolled patients to avoid unnecessary emergency department and hospital admissions out of hours.

4. Patients nominate a preferred clinician within the Health Care Home who is aware of their problems, priorities and wishes, and is responsible for their care coordination. They have the clinical expertise and accountability to lead the ongoing care of the patient, oversee the delivery of continuous and comprehensive care, and to provide the all-important link between the patient, their family and carers and the health system more broadly. The preferred clinician would usually be their GP or in some cases a nurse practitioner, working with a team of health care professionals within and outside of the Health Care Home who collectively care for the patient in accordance with a co-designed personal health care plan.

5. Flexible service delivery and care teams are enabled through shared, integrated care planning that spans primary health and acute care, as required. The Health Care Home coordinates care across all elements of the health care community, enabled where appropriate by digital health, electronic medical records and health information exchange, supported by appropriate funding models.

The model supports different clinical leadership and expertise within the health care team, empowering specialists to contribute to the development and refinement of the care planning and service delivery, where appropriate. The model acknowledges patients' health status and care needs change over time.

6. The Health Care Home is committed to care which is of high quality and is safe. Care planning and clinical decisions are guided by evidence-based patient health care pathways and supported, where possible, by best-practice decision-support tools. Health Care Homes are involved with their local PHN and LHN in developing and localising those evidence-based health care pathways, such as Map of Medicine and Health Pathways.

7. Data collection and sharing by patients and their health care teams to measure patient health outcomes and improve performance. To ensure ongoing, high standards of service delivery, Health Care Homes would be expected to participate in quality improvement and performance measurement programmes, including measures of patient experiences of care.

While these principles are already being applied in some areas of the Australian primary health care system their use is not yet formalised and there is not a consistent approach across the country. The case study below illustrates how the principles of the Health Care Home can improve both patient experience and health outcomes.

The Health Care Home – Patient-Focused Care

Michael is a retired wood turner whose health is failing. He lives in the family home alone having lost his wife and with adult children who have moved on. He has multiple medical problems including: depression; heart disease; osteoporosis; diabetes; cataracts; and chronic obstructive pulmonary disease. Michael is not looking after himself, he is eating poorly, has had multiple recent hospital admissions, and he is taking a number of medications that are causing serious side-effects.

The GP in Michael's Health Care Home involves the local care team to help manage his issues with the focus being on making Michael's life easier and safer. The GP develops a chronic disease management plan around Michael's preference to continue to live independently. He is referred to the visiting dietician, diabetic educator and physiotherapist to enable him to better manage his medical care. A community pharmacist is asked to develop a medication management plan.

The Health Care Home also coordinates social services offered and funded by different Government and community programmes to improve Michael's quality of life and provide the support he needs to continue to live independently. These include: organising the regional aged care assessment service to visit Michael in his home to assess his needs and access to care packages; engaging a cleaner; finding a builder to address home modifications recommended by a hospital based Occupational Therapist; and organising Meals on Wheels to deliver food.

As a result of these interventions Michael's nutritional status improves and he feels stronger, more informed, better supported and more engaged with his care team. His GP and community pharmacist together rationalise the timing of use and the range of his medications. This improves his understanding of them and leads to increased compliance while minimising their side effects.

The future for Michael is looking much brighter as he regains autonomy.

Establishing Health Care Homes in Australia

Australia's primary health care system is well placed to establish Health Care Homes, with many individual elements and 'building blocks' of the model outlined above already available. For example, it is already common for patients to register or 'be on the books' with their GP, and the vast majority of Australians receive most of their services from a single general practice. National digital health infrastructure has been established to support secure health information sharing. My Health Record is already interoperable with general practice, pharmacy and aged care patient records systems and will be further developed by the Australian Digital Health Agency.

Additionally, since the late 1990s there have been MBS items specifically intended to support chronic disease management and team care arrangements, although these will need to be reconfigured in the context of supporting new, more effective risk stratified service models.

There are a number of trials of innovative primary health care models that are underway in several States and Territories that are testing elements of Health Care Homes. These trials, such as 'CarePoint' in Victoria and Western Australia in collaboration with PHIs, may inform broader establishment and potential mainstream implementation of the Health Care Homes across Australia. In addition, the recently agreed sixth Community Pharmacy Agreement (2015–2020) presents an opportunity for an increased role for pharmacists to integrate with Health Care Homes. The aged care, disability support and mental health systems may also provide a foundation to support new primary health care service delivery, particularly through the application of existing care coordination services and shared care planning across sectors.

Activities

Develop appropriate Health Care Home specifications, evidence-based education and training and other tools to enable providers, patients, practice managers and the broader health care sector to operate and engage with Health Care Homes.

Key Recommendation 3: Activate patients to be engaged in their care

“I want to be part of the solution... You have to listen to the people around you, and be a part of your care team. Ask questions and be proactive.”

Patients can and should be supported and encouraged to be more active and effective partners in their health care. The concept of “patient activation” goes beyond person-centred and holistic approaches to service delivery and is about patients having the knowledge, skills, and confidence to manage their health. An increasing body of research is showing that improving patient activation has great potential as a means to improved health outcomes[25].

More broadly, the impact of improving patient activation on the organisation of health systems should not be underestimated. Improving information available to patients and better recognising their importance in directing their own care can have a significant effect on how teams of providers work together with patients to pursue improved health outcomes.

Supporting health literacy and patient activation through Health Care Home – care planning

Health literacy is fundamental to patient engagement. If people cannot access or understand basic health information, they will not be able to look after themselves well or make good decisions about their health.

Health literacy is also about empowerment. Patients with low health literacy have poorer health status, higher rates of hospital admission, are less likely to adhere to prescribed treatments and care plans, experience more drug and treatment errors, and make less use of preventive services[26]. Achieving greater health literacy is essential to activating patients in their own care, and at the population level is integral to tackling health inequalities.

In August 2014, the Commonwealth, State and Territory Health Ministers endorsed the National Statement on health literacy, developed by the Australian Commission on Safety and Quality in Health Care, as Australia’s national approach to improving health literacy. The Health Care Home model presented in this report aligns with the objectives of this national statement. Health Care Homes should:

- provide tailored education to patients on their conditions and support for self-management skills;
- participate in the localisation of patient health care pathways and developing individualised health care plans based on them, which provide evidence-based guidance on the planned treatment course; and
- enhance access to clinically-endorsed information on health conditions and care management.

This role of the Health Care Home in improving health literacy will support work already undertaken by professional bodies such as the Royal Australian College of General Practitioners (RACGP), Pharmacy Society of Australia, State and Territory governments, Health Direct and community health organisations in improving patient health literacy.

As part of care planning with the patient through the Health Care Home, an assessment of the level of patient health literacy and their motivation for adopting healthier behaviours to support their care should be included. A patient activation measure or similar short survey would define the role of the patient in the care plan, including guiding patients to tools and information that can help them to know more about their health conditions and how to manage them.

Clinicians within a Health Care Home will need skills to enable them to engage and equip patients to manage their conditions. There is already training available for those clinicians who need to augment these skills. For example, the Flinders Chronic Condition Management Programme assists clinicians to enhance skills such as communication, motivational counselling, case-management, holistic chronic condition management, and strategies for organisational change to better support integrated and patient-centred care.

Health literacy and patient activation measures can be established at baseline and reviewed periodically alongside care plans, informing patients and providers of care plan efficacy and informing care plan updates. Measures of health literacy and motivation to change can then be reviewed as part of the rolling care plan reviews.

Home-based solutions to improve health monitoring by patients and providers

“The best place for a person is at home... A person’s lifestyle might have to change, but they can adapt and be where they’re more comfortable.”

Technology can be used to provide flexible care, support, and assist with self-management by activating patients as partners in care. Online platforms can be used to educate patients on their health needs, while information and communication technology enabled support services may improve patient engagement and motivation, and self-monitoring and home based monitoring devices can provide helpful feedback to patients and enable them to make positive behavioural changes to their health.

As there is a wealth of information available online, there is a need to ensure that the information accessed by patients is evidenced based. This could potentially be achieved through a national patient information and education portal like Health Direct to support access to online self-help resources. This could be further supported by telephone, video and other non-face to face service delivery that maximises the use of digital health technology from the Health Care Home.

An emerging array of wearable devices encourages people to make healthier choices and to seek early intervention. Some ‘smart devices’ encourage active lifestyle, good sleeping patterns and weight loss, while more clinically oriented products can track the movements of the elderly to detect falls or patient decline and provide important reminders, including for medication or measurements for blood pressure, blood glucose, and oral anticoagulation.

Self-monitoring devices may also measure vital statistics and facilitate real-time or delayed review by health care professionals and can aid in the early detection, management and deterioration of chronic conditions.

Research into home based telecare and self-monitoring devices is still in its infancy, and the evidence for and cost effectiveness of remote tele-monitoring is variable. Considering the costs of some devices can be high, their use will depend on decisions by patients and providers and other circumstances, such as patient mobility and access to services in rural and remote areas.

Activities

- Develop an effective and standardised approach to support patients and providers to engage in shared goal setting and decision making.
- Develop advice on the application of digital health devices and any health system changes required.
- Enhance access to targeted online patient information and education and self-help resources.

Key Recommendation 4: Establish effective mechanisms to support flexible team based care

Health care has not always been recognised as a team responsibility, as we have recently come to think of it. Over several decades, increasing life expectancy and medical technologies have meant that an increasing number of health conditions can be treated and managed. This also means that many people, particularly older people, are living with multiple chronic conditions.

The increasing complexity of health care has been mirrored with the increased specialisation of health care providers. In order to provide the full range of appropriate and available support to people with chronic and complex conditions, providers now work in teams to provide holistic and complementary care.

Multiple perspectives and decisions by members of the care team offer the benefits of diverse knowledge and experience, but also create problems. A corollary of increased complexity of health conditions and the health sector is increased difficulty in navigating the health system, for patients and providers alike.

To ensure that innovative service delivery models such as the Health Care Home are feasible and successful, a preferred clinician with lead responsibility needs to be identified, teams of providers must be enabled to work together efficiently, and patients and providers need guidance on how the best evidence-based care translates to the health care resources in their community.

Developing and maintaining care plans with teams and patients

The Health Care Home will be expected to develop a care plan, through a flexible team based approach that is agreed by the preferred clinician and the patient. Personalised care is essential to addressing individuals' full range of needs.

While this is already occurring in some areas there are concerns that in the present environment, chronic disease management planning can be completed by a sole provider or expressly automated more towards satisfying requirements for payment rather than the needs of the patient.

In the Health Care Home, providers must work with and support their patients to set shared goals and make shared decisions about the inclusions of their care plan that are aligned and appropriate to their needs, circumstances, preference and context.

A care plan should be a living document that is inclusive of all providers' expertise and experience while being consistent with localised patient health care pathways which would include planned follow up consultations and reviews.

Care plans for patients with chronic and complex conditions need to provide a guide to care for a period of time, such as 12 months, as well as serve as a motivational tool and central point of interaction between members of the care team. A wealth of evidence points to the importance of productive interactions and cooperation in developing, maintaining and updating team care plans, and making that common care plan available for all providers and the patient[27–29].

Maximising digital health in team based care

Technology should be used as far as possible to support care plans as living documents and, for example, for them to be linked to a My Health Record. This would enable real time opportunities for providers involved in the care of a patient to develop and update care plans, assess progress against goals, monitor the activities of the rest of the team and to share other documentation including event summaries, current medications, referrals, discharge and diagnostic information.

In order to enable health care teams and patients to better plan and coordinate care, software and web-based portal solutions that are compatible with the national digital health infrastructure will need further development. This is likely to require additional resources in the short term, as it is central to the application of successful team based care. In this way, one of the major criticisms of the current system heard by the Advisory Group during consultation – that there is insufficient coordination between multiple providers – can be addressed.

In particular, the barriers to accessibility of the My Health Record by allied providers and specialists must also be addressed and, some additional capabilities must be developed. This could include the production of 'at a glance' summaries of useful health information on My Health Record and enhanced capacity for patients to provide feedback on their record or care plan to facilitate collaboration across the team.

Activities

Reduce barriers for allied health professionals and community-based specialists accessing and contributing to the patient record, complementing recommendations of the 2013 *Review of the Personally Controlled Electronic Health Record*[30].

Care coordination

“I don’t have a huge support structure outside of hospital... There’s a lot in the community if you can source it, but it’s hard because most people don’t know what’s available.”

Social and psychological factors can accelerate progression of chronic disease, impact access to treatment and restrict self-management of care. Often people with chronic and complex conditions access a variety of clinical and non-clinical supports.

While not universal, the most effective international implementations of innovative primary health care and hospital avoidance programmes often incorporate a dedicated care coordinator role[31]. In Australia, 69% of people who currently see multiple health professionals for the same condition already have their care coordinated – but this could be improved, and should be embedded for people with chronic and complex conditions[32].

The example earlier in this report, entitled *The Health Care Home – Patient-Focused Care*, demonstrates that care coordinators can proactively assist patients to manage their conditions in many ways by:

- supporting the patient and the health care team in assessment and development of the care plan, including identifying service options;
- assisting the patient and their health care providers in implementation of the care plan;
- helping patients better understand their conditions and to self-manage them; and
- working with other sectors also supporting the patient to better align their clinical and community supports.

To ensure that the care received by a patient with chronic disease makes effective use of all available clinical and non-clinical supports and to minimise conflicting advice, it will be imperative for care coordinators in the Health Care Home to liaise with their counterparts in other programmes. Knowledge of these ancillary programmes will also enable care coordinators to help patients navigate the system to find supports and services that may assist them to better manage their care.

Activities

Ensure Health Care Homes use clinical software that is compatible with the Australian digital health infrastructure to support the integration of information technology (IT) systems.

Formalise the roles and responsibilities for clinical and non-clinical care coordinators within the Health Care Home.

System integration and improvement

Strategic Directions:

- Regional planning is enhanced to ensure that patient health care pathways: harmonise service delivery across systems; maximise access, quality and efficiency; and promote regional planning in accordance with patient need.
- Services delivered in primary health care are better integrated with clinical and support services provided through acute care, specialist mental health care, aged care and disability support sectors, including through embracing the potential of digital health to support this.

Health, social and psychological factors can all profoundly impact the effectiveness of chronic disease management. Individuals with chronic and complex conditions are more likely to require services and supports from a range of sectors, both within and outside the health system, including aged care, community services, mental health services, disability support and welfare.

Existing silos within the health system and between relevant support systems make it harder for those most in need to identify and access services critical to the effective management of their conditions.

In order for the Health Care Home model to be effective, sectors within and outside the health system need to be engaged to support its establishment and promote its application to deliver effective whole of patient care. Concordantly, care within the Health Care Home should be supported by better integrated community and acute care within the broader health system. This allows the patient, their family and carers and the health care team to more readily access appropriate care outside the practice, but within their own community. This might be a specialist opinion or visit, videoconference or additional home service to avoid a preventable hospitalisation.

A continued focus on primary health care research to further develop the body of knowledge and enhance the evidence base will also be important to underpin the implementation of the new model of care.

Beyond the scope of this review, the Advisory Group notes that the Commonwealth Government has committed to a process of systematic and coordinated reform of the health care system.

Reforms being considered to aged care, mental health and private health insurance, as well as review of key health care enablers such as digital health and the MBS, are designed to improve health system integration and highlight a shift in the service delivery paradigm towards better integrated, more regionally relevant, patient-centred care.

Key Recommendation 5: Enhance regional planning

Australia's size, cultural and regional diversity and population distribution create profound variation in the types of care that are delivered in different regions. Over the past quarter of a century increasing control of health care governance has been passed to regional non-government organisations to better tailor services to local needs and give local communities and health professionals a greater voice in the delivery of health care. This section explores ways in which regional governance can be leveraged to better integrate care to people with chronic and complex conditions.

Regional governance as a lever for system integration

Regional governance of aspects of primary health care has evolved progressively in Australia, commencing with the introduction of regional networks of GPs, called Divisions of General Practice, in 1992. The transition from Divisions of General Practice to Medicare Locals, and finally to PHNs, has been designed to:

- increase the involvement of communities in system design and funding decisions;
- increase collaborative service planning and commissioning with the acute care sector; and
- reduce the number of regional governance bodies to increase negotiating power through improved economy of scale.

In parallel to the changes to primary health care governance, in 2011 responsibility for governance of hospital services was devolved to regional organisations called LHNs. This arrangement was intended to improve integration of Commonwealth and State-funded health care services and promote better management of chronic and complex conditions.

The National Health Reform Agreement, ratified by COAG, directed the then Medicare Locals (now PHNs) and LHNs to collaborate on population health planning and develop local strategies to reduce preventable hospital admissions[33].

Collaborative PHN and LHN regional governance is essential to progressing system integration and enhanced care delivery for people with chronic and complex conditions.

PHNs were established on 1 July 2015 in response to the Review of Medicare Locals, conducted by Professor John Horvath AO, which found that Medicare Locals: variably addressed poor integration of health services; duplicated state-funded health initiatives; and had been ineffective in engaging GPs and private hospitals. The design of PHNs supports the delivery of integrated team based care through:

- closer alignment of the jurisdictional boundaries between PHNs with LHNs to encourage collaborative population health planning and service commissioning;
- the formation of GP-led Clinical Councils, with membership including other health professionals and hospital representatives to advise PHN boards on the development of regionally-relevant patient health care pathways and local strategies to improve delivery of health care;
- the development of Community Advisory Committees to ensure that PHN investment in health initiatives is patient-centred and aligns with local care experiences;
- flexible funding to enable PHNs to invest in locally-relevant health care; and
- funding to support continued locally relevant innovation[34].

Commissioning services

PHNs are regional fund holders with responsibility for commissioning services to meet the primary health care needs of their jurisdictions. However, the commissioning process is not simply transactional and involves several features to improve system integration. For example, population health planning will be conducted in collaboration with LHNs to minimise service gaps and duplication of state-funded services. Clinical Councils, Community Advisory Groups and local health professionals will also be involved[34].

The PHN commissioning role enables strategic approaches to purchasing that can ensure that services meet the health needs of the population and sub populations, such as enrolled patients, and contribute towards service and system improvement and innovation.

Joint management of the 4-year trial of the NSW Integrated Care Strategy by PHNs and LHNs highlights the potential of collaborative commissioning to address regional health priorities[35].

Further, joint and pooled funding between PHNs, LHNs, local government and PHI could be considered to improve the integration of health services delivered by different funders and reduce areas of potential waste and inefficiency. It will be critical for governments, LHNs, PHIs, professional colleges and local service providers to support PHNs to deliver the new model of care.

Patient health care pathways

“My cardiologist has written me a letter that I can take into emergency when I need intravenous fluids, and that’s been a God-send. Most of the time, the people I see don’t know anything about my condition, and I’d get sent home after drinking a couple of glasses of water.”

It is difficult to determine how much health care delivered in Australia aligns with evidence-based best practice. Latest National Health Performance Authority data identifies threefold or higher variations in prescribing and service delivery patterns across differing primary health care network boundaries.

Patient health care pathways are clinical support tools that assist health care professionals to plan care delivered across primary, community, secondary and tertiary care. Patient health care pathways are developed collaboratively by local health professionals, based on current clinical evidence, but reflecting local service availability and knowledge.

A patient health care pathway is a local interpretation and agreement on how to best manage and provide care for specific health conditions or combinations of health conditions. This is particularly important for providers who enrol patients with chronic and complex conditions, but can have broader benefits for whole populations of patients who have needs for health care services that traverse community-based and hospital-based health services.

The development of patient health care pathways offers many benefits. Spelling out for patients and providers how their care plan is going to be delivered in their region assists with patient activation and joint direction of their care plan with their preferred clinician.

Meanwhile, the process of mapping clinical guidelines to regional resources helps to minimise unwarranted variation from best practice.

The patient health care pathway process, coupled with information on the number and the needs of patients enrolled in a Health Care Home and other population health data can assist PHNs, LHNs, PHIs and providers to identify any deficits in local health system capacity or potential improvements in efficiency through reduction of duplication.

Poor management of care during transition between primary health care and acute care can impact health outcomes for patients[36]. Common errors in transitional care management include: delays sending discharge summaries to general practice; a lack of patient engagement in discharge planning; no care coordinator; and the patients’ GP not being sufficiently involved in discharge management[37, 38].

The contribution of care providers in the Health Care Home and hospital clinicians to co-designed local patient health care pathways can reduce inappropriate referrals to hospital, reduce hospital readmissions and improve patient outcomes[39][40]. PHNs and LHNs should be tasked with developing the transitional health care pathways and agree on the content to be provided in patient discharge summaries and referrals.

A number of PHNs, along with their predecessor Medicare Locals, have already invested in establishing patient health care pathways in their jurisdictions and as a sector they are required and funded to do so. However there was significant variation in approaches taken by Medicare Locals, and the importance of evidence-based health care pathways is essential to derive most benefit. More formalised collaboration between PHNs and LHNs, with advice from Clinical Councils and Community Advisory Committees, is needed to prioritise and effectively implement these in a whole of system approach.

Patient health care pathways are intended to support, rather than supplant sound clinical judgement. These pathways provide guidance on local treatment solutions to individual health conditions. However, patients with complex needs may have other conditions that make a recommended course of treatment for one condition unsuitable. Instead, patient health care pathways should provide a treatment framework upon which the health care team can build an individually-tailored health care plan that reflects the specific needs of the patient.

The Canterbury Experience

In New Zealand, Canterbury Care's *HealthPathways* is an online repository of more than 500 patient health care pathways which provide information on referrals, specialist advice, diagnostics, GP procedure subsidies and consumer handouts.[41, 42], Support for patient health care pathways amongst health professionals is strong with 90% of Canterbury GPs and 97% of practice nurses stating that these tools improved the care that they delivered to patients[43].

HealthPathways has already been adopted by approximately one quarter of PHNs in Australia [41]. Similarly, a European decision support platform utilising regional patient pathways called *Map of Medicine* is being rolled out in Metro North PHN in Brisbane.

PHNs, Clinical Councils, Community Advisory Committees, LHNs, hospitals and community health professionals should be supported to localise patient health care pathways to improve service integration and system navigation.

Regional and remote communities

"When I got home, two weeks later, I got a letter in the post asking me to go back into the city next week. That's a 450 kilometre drive on short notice. I can't drive, and my husband has to take off work, and we have to bring the kids. They weren't coordinating with my GP."

People living in regional and remote communities generally have poorer access to health services and higher incidence of chronic conditions than people in metropolitan areas[32][3].

Coordination of care remains a challenge in many rural practices. Increasing care continuity for high needs patients through enrolment in the Health Care Home and increasing communication between health care providers through more effective use of digital health records holds considerable promise for the delivery of care in rural communities.

Flexibility in health care funding models is also an important enabler of effective regional care and enables local practices to manage challenges such as transient populations. PHN funding models have been developed to provide regional communities with the ability to develop locally relevant service models and harness health innovations to improve service access and care coordination.

A number of key health strategies and innovations that have the potential to support the Health Care Home in regional communities include:

- ‘Virtual Health Care Homes’ operated or supported by health professionals living outside communities without local providers could provide care to people living in remote areas via telephone or fly-in services.
- Access to metropolitan based specialist supports for local providers could be facilitated to increase the ability for patients to remain in their community rather than have having to travel for their care.
- New health innovations could improve patient access to health services. This could include services such as the remote monitoring of patient symptoms by a nurse care coordinator[44].
- Expanded telehealth service models could provide greater flexibility in providing care and supporting team based care for regional and remote patients. Examples of innovative telehealth solutions include the Royal Flying Doctors’ Service (RFDS) Medical Chest programme which enables RFDS medical practitioners to dispense medicines using telehealth consultation services[45].
- The development of patient-friendly educational resources to improve patient self-management skills in circumstances where patients have poor access to health services.
- Upskilling local care providers to deliver services in circumstances where access to other professional services is limited. This approach has proven successful in innovative programmes such as Tele-Derm National, which enables patients to receive enhanced dermatology care locally.

While leveraging technology for remote populations may help address service gaps, PHNs should ensure that existing local innovation and effective service partnerships are appropriately supported.

Activities

- Assess and share the benefits of evidence-based patient health care pathway tools that are currently available and being applied in Australia.
- Require PHNs to collaborate with LHNs, PHIs, providers and patients to support regional planning, including the establishment of locally relevant patient health care pathways and admission and discharge protocols.

Key Recommendation 6: Maximise the effectiveness of private health insurance investment in the management of chronic conditions

Current PHI involvement in the management of chronic disease

In Australia, public and private health insurance exist to help patients meet the costs of their health care. The public health insurance scheme, Medicare, provides Australians with universal access to free hospital treatment and subsidises a range of clinically appropriate services provided outside the hospital setting. Alongside the public health care system, voluntary PHI offers Australians greater choice in the provision of treatment, may offer shorter waiting times for some procedures and coverage for some service costs not included under Medicare arrangements.

A core principle of PHI in Australia is that insurers are not permitted to exclude members from cover or alter the price of insurance policies on the basis of a person’s health status or risk factors for disease such as age, race or gender. This arrangement, referred to as community rating, is designed to ensure that PHI is accessible to people with pre-existing conditions or higher risk factors.

Private health insurers offer two types of health cover:

- hospital treatment insurance covers all or some of the costs of hospital treatment received as a private patient, including fees for medical services and hospital accommodation; and
- general treatment (also referred to as ancillary or extras cover) assists members with the costs of approved services received outside of the hospital setting which are not covered by Medicare, including dental, optical, dietetics and physiotherapy.

As at 30 June 2015, 55.8% of Australians (13.28 million people) held general treatment insurance[45, 46].

The Private Health Insurance Act 2007 also makes provision for PHI general treatment policies to fund an expanded range of primary health care services for people with chronic conditions or multiple risk factors for chronic conditions through Chronic Disease Management Programmes (CDMP) and Health Management Programmes (HMP).

CDMPs support the development of a written treatment plan by a qualified health professional, coordination of service delivery and treatment review and the provision of a defined list of allied health services.

Few CDMPs fund team based care, with most focusing on assisting members to self-manage their care, modify behaviours or address risk factors for disease. From 2007–08 to 2013–14, planning services increased as a proportion of total CDMP services from around 32% to 63% across the same period, the more expensive coordination and allied health services have decreased from 62% of total CDMP services to 36%. Allied health services represent only 7.7% of services funded through CDMPs[46].

Insurers can also fund lifestyle and wellness services such as weight loss programmes where these services are provided as part of a HMP, designed by a health professional to ameliorate the person's health condition.

In 2014–15, insurers contributed approximately \$50 million in benefit payments for CDMP and \$44 million towards HMP. Despite the increasing pressure on PHI affordability investment in CDMP dropped by 16.7% in 2014–15[47]. In 2014–15, investment in CDMP and HMP represented only 0.6% of total insurance expenditure.

PHI funding of health care innovation provides flow on benefits to the public health system.

Pilot studies of care coordination, enrolling people with and without PHI, have been developed through public-private partnerships[48]. Likewise, health support systems developed for private health care have been adopted by the public system to improve service delivery, such as the use of BUPA's Health Dialog service by the Department of Veterans Affairs to identify patients who would benefit from inclusion in the Coordinated Veterans Care programme[49, 50].

PHI investment in chronic disease management

While community rating of PHI ensures that Australians can access health insurance products for the same price, regardless of their health status, it places constraints on the ability of insurers to manage the financial risk posed by their membership pool.

To reduce the impact of community rating on insurers, in 1976 the Commonwealth Government introduced a system of risk equalisation. Risk equalisation enables insurers to share the risk posed by high cost members, by pooling their benefit claims. This risk pooling arrangement effectively results in younger, healthier members paying a proportion of the benefits incurred with older, higher risk members, both within and across insurers.

Hospital treatment benefits are eligible for risk equalisation, while only general treatment benefits associated with the delivery of CDMP are subject to pooling. These benefits may be risk equalised only if they are claimed by people who: are aged 55 or over; or make claims exceeding \$50,000 in a rolling four quarter period. In 2014–15, approximately 87% of CDMP benefits were paid to people aged 55 years and over[47].

Consideration could be given to enabling insurers to risk equalise CDMP services for all members to reduce the disincentive to deliver these programmes and make the development of products aimed at targeting disease earlier in the treatment cycle more cost effective.

Similarly, insurers note that existing legislation prevents them from risk equalising key health services through CDMP, such as nursing and community pharmacy. Consideration could be given to expanding the range of clinically appropriate health services provided through CDMPs that are eligible to be risk equalised to improve incentives for PHIs to fund chronic disease prevention and management.

Improving integration of public and private primary health care services

The Private Health Insurance Act 2007 prevents PHIs from funding primary health care services for which a Medicare benefit is payable, including GP services[51]. The unintended consequence of this regulation is that health care interventions managed by insurers and GPs are rarely coordinated, undermining the effectiveness of this investment.

Insurers observe that a lack of access to primary health care data on their members prevents them from identifying individuals who would benefit from CDMP support, prior to them being admitted to hospital. Similarly, GPs observe that they are often unaware what their patients' insurance status is or what PHI-funded services their patients are eligible to receive. They also note that they have an incomplete clinical picture of private patients because they are often not informed about treatment being provided through a PHI-funded CDMP.

Since community rating prevents private health insurers from using a patient's health status to restrict access or adjust pricing of PHI policies, fostering better communication between care providers and PHI offers an opportunity to deliver more effective health care to the chronically ill without exposing them to the risk of financial disadvantage through higher premiums on the basis of their health status.

The role for PHI in the new model of team based care

Along with Commonwealth and State and Territory governments, private health insurers, as funders of acute care, have a strong incentive for investment in primary health care services that reduce avoidable hospital admissions. If the model for team based primary health care outlined in this report is adopted, a number of health services currently funded by PHI, including care planning, care coordination and specific allied health services, may instead be accessed by eligible patients through the Health Care Home to ensure that patient care is consistently delivered in line with regionally-designed patient health care pathways.

However, PHIs should retain an important role in the new model of chronic disease management. Ongoing participation of PHI in primary health care is important to ensure the ongoing sustainability of health care funding and provide insurers with the ability to fund services that improve the health outcomes of their members as well as continue to invest in health care innovation. To achieve these objectives the role for PHI could include both new and existing functions:

- investing in disease prevention through the expansion of health and wellness programmes;
- assisting members with chronic conditions to pay for additional services;
- collaborating with State and Territory and Commonwealth governments to fund trials of innovative care solutions to promote ongoing improvement in clinical practice;
- partnering with PHNs to fund or provide services where gaps in care delivery exist; and
- funding hospital substitute services and palliative care to provide patients with choice to receive care outside the hospital environment.

Activities

- Support a single care plan developed by the Health Care Home that better coordinates the provision of all relevant services, whether funded publicly, by PHI or by patients.
- Source or develop protocols, including patient consent, to share relevant information between providers and PHIs.
- Further encourage PHIs to fund the prevention and management of chronic conditions, including through consideration of the use of the risk equalisation pool in relation to chronic disease management programmes to support patients in the Health Care Home.
- The private health insurance consultations should further consider ways to address disincentives for PHIs to support care service delivery in non-hospital settings, such as hospital in the home.
- Review the outcomes of current PHI chronic disease trials to further define the future role of PHIs in supporting management of chronic and complex conditions.

Key Recommendation 7: Coordinate care across The Health system to improve patient experience

Social and psychological factors can accelerate progression of chronic disease, impact access to treatment and restrict self-management of care. Reciprocally, chronic physical conditions are an important risk factor for developing mental illness[52]. As a consequence, people with chronic and complex conditions often access a variety of clinical and non-clinical supports and services managed by care coordinators through other funding mechanisms. Effective coordination of these supports is important to enable the Health Care Home to meet the complete care needs of patients.

Programmes that provide coordinators to manage the delivery of clinical and/or non-clinical supports include: the Home Care Packages Programme; the Partners in Recovery Programme; the Care Coordination and Supplementary Services Programme; the National Disability Insurance Scheme; and Coordinated Veteran's Care Programme.

Coordinators are also funded through programmes operated by State and Territory governments and private health insurers. These programmes offer an array of services including allied health services, palliative care, home-based care, hospital substitute treatment, assisted living, transport and medical and medicine aids.

Of particular importance is identifying opportunities to enable patients to receive care in the most appropriate environment. Service provided to support patients to receive care in their home or residential care facilities, where appropriate, could enhance their experience of care and reduce the burden on the hospital system.

Activities

- Assess the applicability of existing care coordination capability in aged care and mental health for inclusion in the Health Care Home planning and patient and family service support.
- Ensure that all Health Care Home care coordinators identify the existence of, and engage with, care coordinators from other sectors in planning and delivering patient care.

Key Recommendation 8: Support cultural change across the health system

The model presented in this report for managing chronic and complex disease represents a significant change to current practice for many health professionals and consumers. The process of transitioning to this new model of care must be carefully staged to enable care providers and recipients to prepare for the change, to assist industry to develop the necessary infrastructure and workforce capacity required and to minimise service disruption.

Consultation with the sector and consumers on these changes will be essential. Staging should also include a scaled evaluation of the model at selected demonstrator sites to enable evaluation and refinement before national rollout.

The process of managing change to primary health care should be guided by the lessons learned in the US through the introduction of the patient-centred medical home[53].

Key challenges that are likely to be faced during implementation include:

- **Improving communication between health professionals.** Improving communication between health professionals in primary health care, acute health care and community based specialists by involving them in the process of designing patient health care pathways. In New Zealand, co-design was shown to break down professional silos and improve communication[54].

Likewise the widespread adoption of digital health technology, including patient summaries, secure messaging services between health professionals and online referral and prescribing services are critical to delivering more efficient and timely care. The opt-out trials for My Health Record may provide a strategy for increasing the adoption and use of this system and identify barriers that need to be overcome.

- **Supporting change through education, training and workforce development.** The health workforce needs to be engaged in the change process to be prepared to deliver the new model of care. PHNs, LHNs and professional colleges will need additional support for ongoing education and training for all health professionals associated with the management of patients with chronic and complex disease in order for the workforce to be ready. Clinical councils will have a very important role in ensuring that PHNs are responsive to local concerns by the health workforce over implementation challenges that may arise.

Additional training will need to be provided to existing care coordination personnel to support them to upskill to manage their expanded role and curricula need to be developed and resourced to train the new care coordination workforce to ensure that they have the skills necessary to deliver the new model of care.

PHNs will need to work with professional colleges to develop educational resources for health practitioners and also work with consumer groups to educate the public to help them engage in patient-centred care.

Activities

Support PHNs, professional colleges, associations and consumer groups to develop and implement education and training for health care providers and consumers on the development and staged rollout of the new service delivery and funding models, to ensure all stakeholders are engaged and ready for the new model of care as it is rolled out nationally.

Payment mechanisms to support a better primary health care system

Strategic Directions:

- Payment mechanisms that support the delivery of safe, high quality primary health care through Health Care Homes to people with chronic and complex conditions.
- Payment mechanisms that also support: regional flexibility and responsiveness; equity of access for patients; improved patient outcomes; efficient use of resources; and sustainability of every segment of the primary health care system.

The development of a new primary health care service delivery model will need to be underpinned by a payment system that appropriately supports the range of primary health care services and supports required by people with chronic and complex conditions.

Existing payment mechanisms need to be reviewed to ensure that they are structured in ways that best support the management of chronic and complex conditions delivered through Health Care Homes.

Key recommendation 9: Restructure the payment system to support the new approach

Overview of the new payment system

Key elements of the recommended restructure to the existing payment system include:

- the establishment of new bundled payments to fund chronic and complex condition management delivered through Health Care Homes, including an upfront and quarterly payments to general practice – Table 2 provides an overview of the proposed bundled payment structure;
- assessment of patient eligibility for enrolment in a Health Care Home through an existing fee-for-service benefit, such as a MBS level B standard consultation benefit;
- block funding to PHNs to commission appropriate non-general practice clinical care and non-clinical care coordination services for the enrolled population in their region;
- no change to patients' existing ability to contribute to their health care costs; and
- no change to fee-for-service for episodic care not attributed to the care plan.

The key principles underpinning these elements are:

- the level of primary health care funding for chronic and complex condition management will be maintained and will be better targeted and made more flexible through Health Care Homes;
- payments to providers need to be appropriate for the range of services that will be delivered under the new service delivery model;
- opportunities for State and Territory governments, private health insurers and local industries to contribute to the primary health care funding base for chronic and complex condition management will be explored; and
- the new payment mechanisms proposed will be tested and refined before wider rollout so that they best support patients and providers to participate in Health Care Homes.

Table 2: Proposed payments structure

Payment Type	Services
Standard level B consultation	<ul style="list-style-type: none"> Assess patient eligibility for enrolment with a Health Care Home
Upfront payment	<ul style="list-style-type: none"> patient assessment and needs stratification of eligible patients (based on patient complexity as stratified under Tier 1, 2 or 3) Health Care Home enrolment, including establishing a patient provider commitment initiation of a patient care plan development with input from the health care team, including providing necessary referrals
Quarterly payments (services may be delivered by preferred clinician or delegated to other members of the practice team)	<ul style="list-style-type: none"> preferred clinician role – first point of contact, continuous and comprehensive care as identified in patient’s individual care plan, including the planned management of the patient with the chronic and complex conditions patient education and self-management support review and renewal of patient care plan, including input from the health care team clinical care coordination administrative elements of enrolment maintenance of patient’s My Health Record and shared health summary non-face to face communications patient monitoring, including through use of recall and reminder systems ensuring access, including after hours and urgent care commitment to quality improvement and outcomes measurement, including: implementation of integrated software systems that support secure data collection and transfer transition to include outcomes based measures in the medium to long term

Existing MBS payments for Chronic Disease Management by general practitioners

Management of chronic and complex conditions by GPs is currently funded under the fee-for-service based MBS using a mix of timed and untimed items. It is well recognised that the current fee-for-service payment model is in conflict with the proactive, coordinated and ongoing team based approaches that are needed to support the prevention and optimal management of chronic and complex conditions.

The introduction of five ‘untimed’ Chronic Disease Management (CDM) service benefits (MBS items 721, 723, 729, 732) acknowledged a need for payments to enable GPs to assess, plan, coordinate and review the health care of patients with chronic or terminal medical conditions and complex care needs. Patient eligibility for CDM services is a clinical judgement for the GP taking into account the patient’s medical condition and care needs as well as the general guidance set out in the MBS.

The following information provides a high level overview of how MBS CDM service benefits are currently used and identifies potential opportunities for improvement.

CDM services are high-cost services that make up only a relatively small proportion of total GP services.

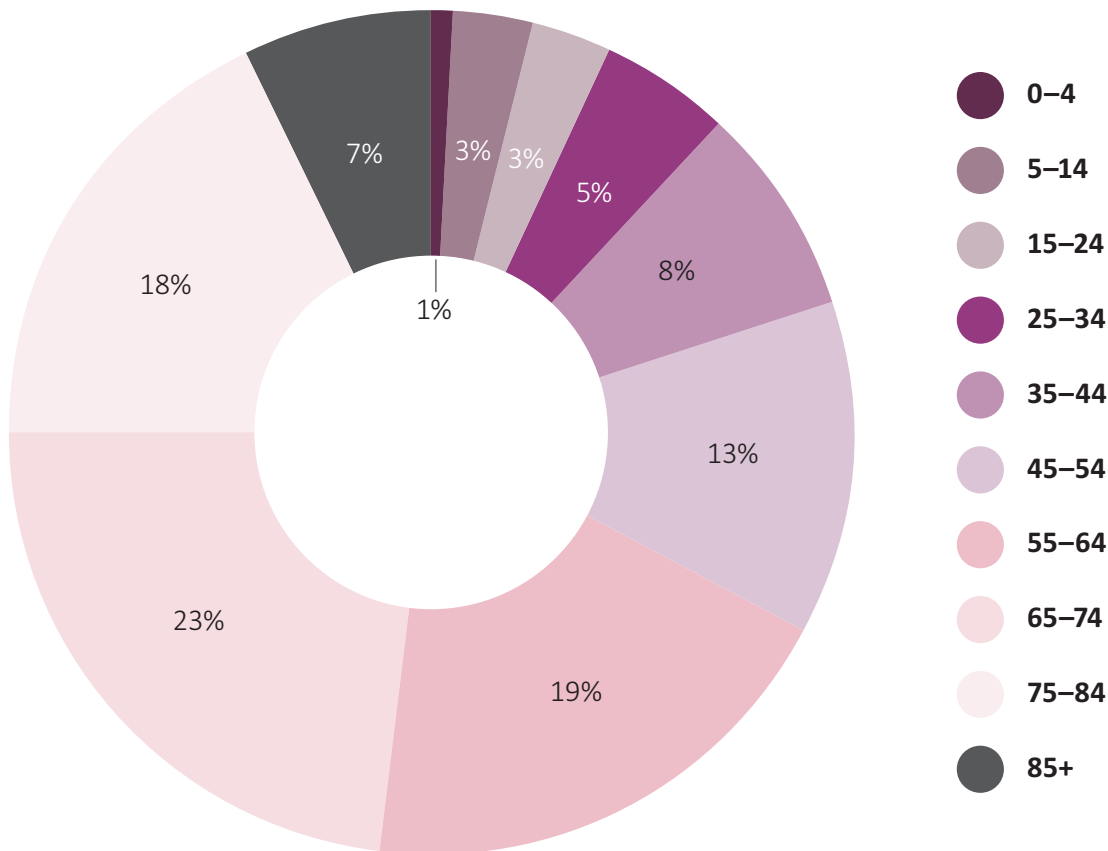
In 2014–15, CDM items (721 to 732) represented over \$682.7 million in benefits paid compared with \$503.4 million in benefits paid in 2012–13, which is a growth in benefits of 36% in two years (as illustrated in Figure 6).

Figure 6: Total MBS CDM items (721–732) benefits paid in 2012–13 to 2014–15[18]



CDM items are used to support the management of chronic and complex conditions across all age groups. In 2014–15, the majority of CDM item benefits (79%) were paid for people aged 45 years and over and 47% of benefits were paid for people aged 65 years and over, as shown in Figure 7.

Figure 7: Total MBS CDM item (721–732) benefits paid from July 2014 to June 2015 by age[18]



While the CDM items have proven popular, they have also been widely criticised by providers, particularly in relation to their complexity. An analysis of Medicare data indicates that there is potential to better structure the CDM item benefits in a number of ways including:

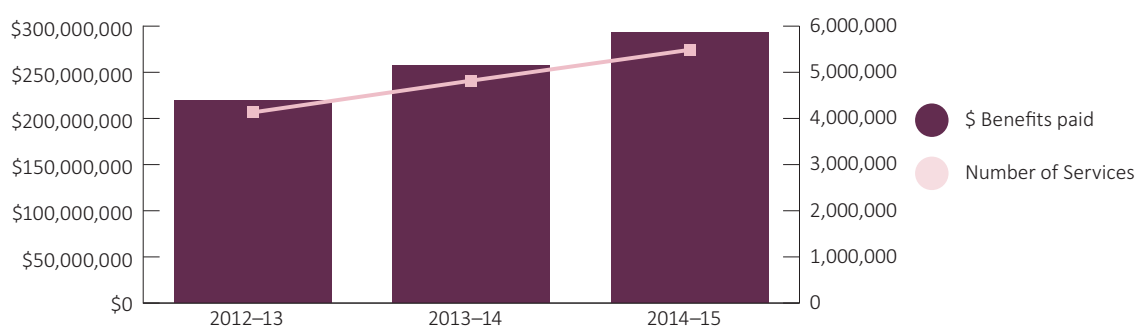
- restructuring the CDM items so that they have a greater weighting on review payments to support the delivery of continuous comprehensive care and regular review; and
- tiering payment arrangements to better target funding and support the difference in provider time spent managing patients with different levels of complexity.

Existing MBS payments for Chronic Disease Management by allied health providers

The inclusion of payments for allied health care services for patients with a chronic condition under Medicare recognises the important role of allied health in supporting self-management and optimising patient health and well-being. These services were not intended to fully cater for all patients who require more intensive ongoing treatment. They were intended to complement services provided by State and Territory governments and to increase access to private allied health services by making them more affordable.

Graph 3.3 demonstrates that in 201415, 5.5 million individual allied health services (items 10950–10970) were provided, representing \$293.5 million in benefits paid. In 201213, 4.1 million individual allied health services were provided and \$219 million in benefits were paid. This represents 34% growth in services and 33% growth in benefits paid.

Figure 8: MBS individual allied health service item (10950–10970) benefits paid in 2012–13 to 2014–15[18]



Podiatry and physiotherapy remain the highest services provided each year under the individual allied health items. Of the 5.5 million individual allied health services provided in 2014–15, 45.8% were podiatry services and 30.5% were physiotherapy services[18].

The number of services claimed against different allied health service provider types can vary by age of the person making the claim. Similarly, access to different allied health service items can vary widely depending on the State and Territory in which the person resides. This suggests that regional differences can impact on which allied health services are accessed and vary according to referrer preferences and service availability.

The MBS also currently includes provision for people with type 2 diabetes to access allied health group services provided by eligible diabetes educators, exercise physiologists and dieticians on referral from a GP (items 81100–81125). These items appear to be relatively underutilised despite the established benefits of group based approaches.

The development of a new service delivery model provides an opportunity to better structure the funding of allied health services and address criticisms raised by providers and through the consultation process. The use of risk stratified payments linked to a patient care plan and a flexible funding approach could help to target funding for allied health services to those most likely to benefit and to services appropriate for the individual needs of enrolled patients and could expand access to those evidence-based group services.

Other existing MBS payments and funding programmes used to support the management of chronic and complex conditions

There are other MBS service benefits (for example, MBS annual health assessment benefits) and funding programmes (for example, the Practice Nurse Incentive Programme) that can be used by primary health care providers for chronic and complex disease management. Each of these additional MBS service benefits and funding programmes has different requirements that a primary health care provider must meet and different levels of funding. This contributes to the complexity of funding for chronic and complex disease management, which is often described as a maze of individual benefits and programmes that can be confusing and difficult to negotiate.

There is potential for the Health Care Home model to better target the current funding arrangements used to support patients with chronic and complex conditions through the Health Care Home and make it less confusing, involve less red tape, and make it more flexible for both providers and patients.

Activities

Restructure the payment system to include alternative payment approaches that appropriately cover the wide range of proactive, coordinated and ongoing services to be provided under the new approach.

Blended payment models

Blended payment methods are being increasingly used across the world to overcome some of the shortcomings of traditional fee-for-service payment mechanisms. Blended or mixed payment methods involve using combinations of payments and/or funding systems. In this way the right mix of incentives can be utilised to improve care access, quality, integration and effectiveness while also trying to efficiently allocate resources and minimise any weaknesses of the different payment systems.

In Australia, a blended payment approach is currently supporting the operation of Aboriginal Community Controlled Health Organisations (ACCHOs). In ACCHOs, GPs work in community or mixed governance practice teams and receive a salary plus a mix of benefits and/or incentives.

The conduct of the National Coordinated Care Trials in the late 1990's and early 2000's and the Diabetes Care Project in 2011 to 2014 provided opportunities to trial different blended funding approaches in the Australian primary health sector. This included the use of bundled payments, pay-for-performance payments, and pooled funding mechanisms. These trials demonstrated the potential for new funding models to increase access to primary health care services and improve health outcomes.

The online consultation survey identified that there was broad support for the use of a blended funding model to support the implementation of a new Health Care Home model of care in the Australian primary health care sector.

This is reflected internationally, where blended payment models are increasingly being used to support patient enrolment approaches, including in Canada and New Zealand[55][56].

In Australia, there is potential to implement a new blended payment model aimed at improving the care provided to Australians with chronic and complex conditions through Health Care Homes. In this situation, blended payments could include a mix of bundled, fee-for-service and block payments, as well as opportunities for pooled funding,

Bundled Payment Approaches

It is important that a new model of care is supported by a funding model that is easy to understand and be accessed by both providers and patients, and that aligns financial incentives for providers to deliver high quality care and control costs.

A bundled payment typically provides a single funding amount that links:

- the multiple services that a particular provider might deliver over a fixed period of time to manage a whole episode of care; or
- various providers to deliver defined services for an episode of care over a fixed period of time that span the continuum of care, including primary, acute and post-acute health care.

In contrast, in the Netherlands a 'bundled payment' is a single fee paid by insurers to a principal contracting partner (a care group often exclusively owned by GPs) to cover an integrated bundle of care for a specific chronic disease over a period of one year, often covering a particular geographical region[57, 58].

There is potential to design a bundled payment approach that could be used in Australia to provide payments to fund Health Care Home services. In this situation, the provision of bundled payments would be aimed at encouraging the delivery of comprehensive, proactive, coordinated and continuous care to patients with chronic and complex conditions, typically through existing general practice relationships.

By bundling payments together to fund a whole episode of care, providers would be incentivised to better organise the whole episode of care by implementing new and innovative approaches that reduce fragmented and siloed care and that increase the coordination and integration of care across settings[59].

The use of bundled payments to support the provision of Health Care Home services (as described previously under Table 2) would represent a significant shift in how general practice services are remunerated in Australia. While bundled payments may shift some financial risk to practitioners, with this comes the potential for financial reward for those who are efficient and effective care coordinators. Under the proposed Health Care Home model, this risk to practitioners would be mitigated through the inclusion of payments that are risk stratified to reflect patient complexity and care needs.

A benefit of using bundled payments is that it would encourage providers to be innovative and flexible in how they communicate and deliver care (for example, through increased use of telehealth services in rural and remote areas and non-face to face patient consultations where appropriate).

To recognise the need for Health Care Home services to be comprehensive and ongoing, the total funding provided to general practices to support the new service delivery model could be balanced across the bundled payments, with a higher weighting on quarterly payments rather than the upfront payment.

The use of bundled payments to support the provision of Health Care Home services should be tested and refined before wider rollout. This could include exploring:

- the range of services required to be provided by a Health Care Home and payment levels;
- whether episodic services should be included in the bundled payments or continue to be funded through fee-for-service payments;
- options to address access and equity in rural areas; and
- options for how the different bundled payments could be administered.

Activities

- Test upfront and quarterly bundled payments to Health Care Homes to support the new approach prior to wider rollout.
- Consider the range of Medicare Benefits Scheme (MBS) items and other Commonwealth funding programmes that could be brought together to support a more targeted and flexible approach to funding.

Block Funding for care coordination and non-general practice clinical care (allied health)

Under a Health Care Home model of service delivery, payments for appropriate non-general practice clinical care and non-clinical care coordination services could be made using block funding arrangements.

Block funding could be made available to PHNs to commission appropriate non-general practice clinical care (initially allied health care) and non-clinical care coordination services for the enrolled population in their region. This would enable services to be purchased from local private providers (general practices, pharmacists and allied health care providers), State and Territory governments, private health insurers and/or non-government organisations. This approach would also provide flexibility in the way in which non-clinical care coordination and non-general practice clinical care services are delivered and when they are delivered, which could include increasing access to group based allied health services where appropriate for individual patient care needs and circumstances.

Under this model, PHNs would be able to flexibly adapt funding to fit regional and local needs, and commission a range of services to meet the needs of specific populations. This approach is likely to be of the most benefit in rural and remote regions and/or areas of workforce shortage.

Providing block funding in this way recognises that non-clinical care coordinators do not necessarily need to reside in a general practice setting and can potentially be supported through PHNs to provide in-reach services to a range of practices within a region while still being considered part of the Health Care Home team.

PHNs are well placed to undertake this role for the following reasons:

- PHNs' role in working with local health care providers on the development of patient health care pathways provides them with a strong base on which to support general practices in care planning and coordination;
- PHNs were established with capacity to better target resources in line with regional requirements through the use of commissioning approaches; and
- PHNs can support a managed competition model among service providers to achieve value for money and ensure the delivery of high quality, integrated health care services in their region.

Funding for block payments to PHNs for care coordination and non-general practice clinical care should be considered in the context of the existing availability of care coordination programmes within the region. Integration with existing programmes, such as is available through aged care, the National Disability Insurance Scheme, and the community mental health sector is a priority consideration in planning additional commissioning for these services.

Payments to PHNs could be based on the allocated risk stratification level (i.e. Tier 1, 2 or 3) of patients within their jurisdiction, and/or could be proportional to the complexity of care required.

Activities

- Test new payment models to PHNs to enable them to commission appropriate non-general practice clinical care and coordination services for enrolled patients in their region based on the patient's allocated risk stratification level, prior to wider rollout.

Key Recommendation 10: Pursue opportunities for joint and pooled funding

Pooled funding approaches enable funding from different organisations to be combined to create a single budget. A single local commissioning approach could then be used to commission integrated services in a region based on a common set of shared goals and outcomes for their population[60].

The pooling of funds from different governments or portfolios, as well as private funders (such as insurers, employers, and NGOs) represents better value for the health care systems as it can:

- provide flexibility to address local gaps and challenges;
- provide opportunities to improve service integration;
- promote innovation;
- enable quick responses and faster decision-making;
- provide a greater ability to match resources to local needs;
- increase local accountability;
- reduce service duplication and waste;
- overcome cost shifting; and
- deliver efficiency gains through lowering of administrative costs.

Pooled and joint funding approaches under the Health Care Home model

In Australia, an individual's health care is financed by a range of funding sources using different payment models. The diversity in funders can create service duplication, gaps in service delivery, siloed working arrangements, conflicting priorities, barriers to service delivery, a lack of coordination and integration, a lack of collaboration, and delays in decision-making.

The move to a new primary health care service delivery model creates an opportunity for State and Territory governments, PHNs, local governments, private health insurers (PHIs) and local industry to contribute to joint or pooled-funding approaches (through funding or in-kind contributions). This funding could then be used to provide enrolled patients with chronic and complex conditions with more flexible access to health care services that are coordinated and integrated across sectors, when and where they are needed.

Where pooled funding may be too administratively challenging, joint funding approaches can achieve most of the benefits of a pooled funding model, especially when administered utilising collaborative commissioning approaches. Under a joint funding arrangement, two or more parties contribute funding, resources, expertise, time and effort and share the burden of a program in which they are all equally invested.

The Reform of Federation Discussion Paper 2015 set out a possible option for the Commonwealth and States and Territories to jointly fund care for patients with chronic and complex conditions, including integration of care. Under this 'Option 3', the paper proposes that the Commonwealth and the States and Territories could be jointly responsible for funding individualised care packages for patients with, or at risk of developing, chronic and complex conditions.

An example of where fund pooling has been used successfully to improve sustainability of health services in rural communities in Australia is the Multipurpose Service (MPS) Programme. The MPS was established in 1993 and involves the pooling of Commonwealth and State funding and sets aside the normal programme guidelines and constraints to allow small communities to integrate acute and aged care services[61].

Fund pooling models were also piloted as part of the Coordinated Care Trials conducted in 2002–05. A national evaluation of the Coordinated Care Trials found that flexibility afforded by the pooling funds allowed trials to deliver a broader range of services than is usually available[14]. However, a lack of access to comprehensive data on which service use could be estimated and to support funding allocation resulted in reluctance on the part of State and Territory public hospital and community care funders to fully commit to a fund pooling approach.

There is potential for a range of organisations other than governments to contribute to a fund pool to support the new service delivery model. In some regions, local industries already contribute funding to support local health care service delivery that would otherwise not be sustainable. The mining industry in Western Australia is often a major contributor to local health services in nearby remote communities.

PHIs are another potential contributor to a fund pooling approach as they have an established interest in reducing the use of acute care services, where appropriate, by better supporting patients in primary health care rather than acute health care settings. Some PHIs are currently funding trials of innovative service delivery models in the Australian primary health care sector with a particular focus on high risk patients with chronic and complex conditions. In the medium to longer term, PHIs could also make risk-equalised contributions to a future funding pool with governments.

The role of PHIs in the Health Care Home model will need to align with any reforms that may result from the consultation process that the Australian Government is currently conducting to improve the value of private health insurance for consumers and its long term sustainability.

Pooling funding into a single budget is increasingly being used internationally to address regional challenges, maximise the use of available resources, reduce waste and unnecessary servicing, improve local integration and improve the patient experience for all contributing organisations.

The Better Care Fund was established in the United Kingdom in 2013 as a single pooled budget to enable health and social care services to work more closely together in local areas based on a plan agreed between the National Health Services and local authorities[62]. The Better Care Fund will enable regions to bring resources together to address pressures on services and lay foundations for a much more integrated system of health care by facilitating a substantial shift of activity and resources from hospitals to the community[62].

In Australia, there is potential to distribute pooled funding through collaborative planning between PHNs and LHNs based on local patient health care pathways and population needs. This could subsequently involve the use of commissioning approaches to purchase services based on patients' individual needs and according to their care plan. Using pooled funds in this way could enable enhanced targeting of resources, improved health care quality and value for money for the patient group. Pooled funding could support a range of commissioning approaches, including any combination of fee-for-service, bundled payment or salaried arrangement.

Activities

- Explore opportunities for State and Territory governments, PHIs and local industries to contribute to the funding base for enrolled populations (through funding or in-kind contribution).

Key Recommendation 11: Patients contribute to their health care costs to the extent that they are able

Medicare is Australia's universal health care system, which gives people access to cost effective medical, optometry and hospital care and, in special circumstances, allied health services.

Australians incur out-of-pocket expenditure when they meet the full cost of a health good or service and when they share the cost of goods and services with third-party payers such as governments or private health insurance funds [63].

In 2012, Australians spent nearly \$2.9 billion on primary health care out-of-pocket medical services expenses for 'gap payments,' accounting for approximately 12% of total out-of-pocket health care expenditure (including pathology and imaging services).

The Australian Institute of Health and Welfare data indicates that the proportion of total health expenditure funded by individual out-of-pocket payments remained fairly constant over the ten years between 2001–02 and 2011–12 [63].

Out-of-pocket-costs can influence patients' decisions about when they access health care. Australian Bureau of Statistics data indicates that Australians with poor or fair self-assessed health and people with a long term health condition are more likely to avoid going to the GP because of cost than are people with better health[64]. Similarly, the 2013 Commonwealth Fund International Health Policy Survey found that the more prescription drugs a person has to take regularly, the more likely they are to avoid filling a prescription due to cost [65].

There are several additional mechanisms put in place by the Government to support Australians to meet their health care costs. Both the Medicare system and Pharmaceutical Benefits Scheme include safety net arrangements which operate to assist Australians with high out-of-pocket costs for out-of-hospital services and prescription medicines.

Australia's high bulk billing rates indicate that many providers also offer bulk billing for patients, such as concession card holders and those who are vulnerable. In 2012–13, 82% of GP services were bulk billed (i.e., practitioners billed Medicare directly without an additional charge to consumers)[3].

Australians also have an option to purchase two different types of private health insurance: hospital cover for inpatient services; or general treatment (also known as 'extras') for dental, physiotherapy and other allied health services, or both. At this point in time, Australian legislation prohibits PHIs from covering general practice services against which an MBS reimbursement can be paid.

Patient contributions under the Health Care Home model

Finding an effective balance of bulk billing, patient out-of-pocket costs, and insurance and safety net arrangements is important to the sustainability of Australia's health care system. It is also important to ensure that those Australians who will benefit most from coordinated primary health care can access it when they need it.

Under the proposed model, the intention is to not shift away from the current balance of patients contributing towards their health care costs to the extent that they are able to pay and consistent with current approaches.

However, it is important to ensure that consumer contributions provide for effective and efficient care. Under the Health Care Home model there is a strong focus on proactive prevention and management of diseases, health literacy and self-management. In this way, patients could be supported to access appropriate resources in the community earlier. This could keep patients healthier longer and potentially reduce costs associated with unplanned disease exacerbations.

Greater patient engagement in care planning would also help patient contributions to be more targeted and could contribute to improved patient experience and outcomes. There is also potential for the block funding arrangements to PHNs to achieve more affordable access to allied health services for enrolled patients.

Activities

- There should be no change to the expectation of Australians to continue to contribute to some of their health care costs to the extent that they are able to pay, consistent with current approaches.

Compliance mechanisms under the Health Care Home

The stakeholder consultations identified that there was strong support for ensuring that any new service delivery model introduced should be supported by a robust compliance framework.

Detailed guidelines will need to be developed that clearly define the scope of activities that are to be delivered under a bundled payment approach, as well as those that will be funded through alternative mechanisms.

Together, these strategies will ensure that:

- providers have a good understanding of the services that need to be delivered under the Health Care Home model of care and appropriate funding mechanisms, and
- Health Care Home services are appropriately targeted and delivered against the requirements identified in evidence-based care plans.

Compliance mechanisms supporting the Health Care Home should be effective in ensuring that:

- there is accurate use of risk stratification models;
- all eligible patients are encouraged to enrol with the provider of their choice;
- patients are provided with a copy of all components of the agreement to participate in the Health Care Home;
- patients are engaged and understand the benefits and commitments inherent in enrolment;
- all members of the health care team contribute to the development of evidence-based care plans;
- care plans are based on locally developed, best practice patient health care pathways;
- GP services provided to enrolled patients are high quality, comprehensive and proactive;
- all members of the health care team and referred non-GP clinical care providers actively participate in review processes;
- block payments to PHNs are used appropriately and that:
 - > the non-GP clinical services provided are consistent with individualised patient care plans;
 - > non-clinical care coordination support is effective and centred around the individual needs of enrolled patients; and
- all providers, practices and PHNs have appropriate data collection and analysis processes in place to support outcome based payment approaches.

Measuring the achievement of outcomes

Strategic Directions:

- Health Care Homes are actively using data to drive quality improvement, leading to improved patient experience and outcomes.
- Nationally consistent aggregated data is used at a national and regional level to target health resources and interventions, leading to improved population health and health system outcomes.

It is important that the outcomes of the reforms outlined in this report are regularly measured and reported to support ongoing learning and refinement of the reforms over time and ultimately, to ensure the reforms achieve their aim of providing better coordinated and more appropriate care to people with chronic and complex conditions. Improved primary health care data will be required to measure the achievement of outcomes.

Supporting a continually improving clinical practice and primary health care system, establishing a national minimum data set for patients with chronic and complex conditions, and evaluation of the reforms will improve both primary health care data and outcomes at patient, health system and population health levels.

The consultation process and survey respondents from all segments agreed that measuring and reporting outcomes was useful for understanding whether care was effective, and could be used to learn about and continually improve care for people with chronic and complex conditions.

Key Recommendation 12: Support a quality and continually improving primary health care system

The principles of the Health Care Home outlined earlier in this report, highlight the requirement for Health Care Homes to provide high quality care. Practice and service accreditation provides a basis for the provision of high quality care by demonstrating that a practice or service is committed to providing high quality, safe and effective care to standards of excellence determined by the relevant profession or authority.

General practice accreditation is already widespread. In 2014, 5,940 practices (~85% of practices) were either accredited (5,645 practices) or registered for accreditation (295 practices)[66].

Requiring Health Care Home practices to be accredited will ensure that these practices have the structures and supports to enable general practitioners and practice teams working within them to provide quality care to patients.

To help meet the requirement to provide high quality care, and as one element of accreditation, Health Care Home practices should engage in quality improvement activities and thereby contribute to a continually improving primary health care system.

Most accreditation frameworks require health services to undertake quality improvement activities in a structured way. For example, RACGP *Standards for General Practices (4th Edition)* includes Criterion 3.1.1 Quality improvement activities which states that “Practices are required to demonstrate that the practice:

- can describe aspects of the practice that have improved in the past three years; and
- uses relevant patient and practice data for quality improvement[67].”

Widespread engagement in quality improvement activities will also help to improve primary health care data in Australia.

Continuous quality improvement programmes and supports

Continuous quality improvement (CQI) is characterised by a forward looking, on-going systematic approach to improve patient care by improving organisational systems and service delivery (or clinical practice)[68]. The CQI process involves: collecting and reviewing data or information to identify problems or opportunities for improvement, developing solutions to those problems, implementing the solutions, evaluating the effect of the planned activities, and going back to assess the need for more improvements.

Implementation of CQI processes in health services affords a variety of organisational and system benefits including:

- promoting improved patient care[69, 70];
- promoting consistent clinical practice and alignment with clinical guidelines for best practice[71];
- fostering a collaborative environment with all staff engaged to improve the delivery of care[71];
- reinforcing a patient-centred focus for service provision[72];
- developing an adaptable practice culture supporting change management[73]; and
- supporting improvements in key non-clinical functions such as data collection and review and instituting formalised practice meetings[73].

Quality improvement activities may take the form of participation in a formal CQI programme, contracting an organisation to assist in quality improvement activities or using in-house expertise to analyse patient data and implement improvements.

Many formal CQI programmes and tools are already available, a number funded by the Commonwealth to assist primary health care providers to collect and analyse practice data and improve patient outcomes. The Australian Primary Care Collaboratives Programme (APCCP) run by the Improvement Foundation, MedicineInsight run by NPS MedicineWise and the Primary Care Practice Improvement Tool (PC-PIT) are just three examples of current programmes available in primary health care. The decision on appropriate quality improvement methods lies with individual health services[74][75].

The APCCP is one of a number of quality improvement activities in the primary health care setting. Similar to most existing activities, it is an evidenced-based programme which aims to promote a culture of ongoing innovation and quality improvement within general practices and health services.

Under the programme, practice teams attend learning workshops, plan and undertake rapid quality improvement activities and collect monthly data to track their progress against agreed indicators. De-identified patient data is extracted from practices’ clinical software using a data extraction tool. Practices then lodge reports generated by the data extraction tool through a web portal.

The web portal allows practices to track and review their progress. Data can be viewed through dashboards, charts and graphs to assist in identifying areas for further improvement and allow improvement to be monitored over time. Practices can also compare and benchmark their data against local, regional and national aggregate data.

Similar to other quality improvement projects throughout Australia, the APCCP activities have included setting up registers and recall systems for patients, and improving the way that health providers work together, and can be particularly beneficial to patients with chronic and complex conditions. In line with this, APCCP ‘waves’ have focused on diabetes, coronary heart disease, chronic obstructive pulmonary disease and chronic disease prevention and selfmanagement.

The Improvement Foundation states that, over the past ten years, approximately 1,500 primary health services (including general practices, allied health providers, pharmacies and Aboriginal Medical Services) have been supported to participate in the APCCP through Commonwealth funding. The Improvement Foundation reports that in the two years to 30 June 2015, approximately 360 health services participated in APCCP. It is likely that the APCCP will transition from Commonwealth funding to a self-funded model in the future.

The Commonwealth funded MedicineInsight programme is another example of a quality improvement activity in the primary health care setting and aims to improve understanding of GP prescribing behaviour. It provides medical practitioners and nurse practitioners with data driven insight into their prescribing and clinical activity to assist in determining where improvements can be made. The additional benefit of MedicineInsight is its contribution to the Governments Quality Use of Medicines initiatives.

Like the APCCP, MedicineInsight collects de-identified patient data from practices' clinical software using a data extraction tool. NPS MedicineWise analyse and interpret the data. Data on clinical indicators is reported back to practices every six months. There is capacity for practices to compare and benchmark their data against local, regional and national aggregate data. NPS MedicineWise can also visit practices to discuss the data with the practice team and assist with identifying potential quality improvements. To date, more than 500 Australian general practices have participated in MedicineInsight.

The PC-PIT is an online form designed to engage all members of general practice to get a broader view of practice performance. The seven core elements of general practice performance that the PC-PIT is designed to assess were selected following a systematic review of practice performance literature and were iteratively refined through ongoing input from professional bodies representing nurses, GPs and practice managers as well as the Improvement Foundation and the Australian Commission on Safety and Quality in Health Care[73, 76]. 'Information and IT technology' is one of the core elements. Currently, 46 practices are enrolled in a pilot study to evaluate this tool[76].

There are existing initiatives that support a continually improving primary health care system, including the PIP and PHNs.

The PIP supports general practice activities that encourage continuing improvements, quality care, enhancing capacity, and improving access and health outcomes for patients[77]. Over 5,330 general practices received PIP payments during the 2014/15 financial year.

There is mounting evidence that the PIP should be changed to reflect changes in demand for health services and the imperative for effective and efficient health care into the future. There is also evidence that quality improvement initiatives have the potential to improve chronic disease management, health promotion and disease prevention. With this in mind, the Department of Health has been working on redesigning the PIP within existing resources to provide financial incentives to improve the quality of care and patient outcomes. This process should consider how it can best support the Health Care Home model.

PHNs have been tasked with supporting general practices in attaining the highest standards in quality and safety. This includes providing support to general practices and collecting and reporting data to support continuous improvement. Many PHNs, and their predecessors have been undertaking work in this area for some time.

Activities

- Require Health Care Home practices to be appropriately accredited or have registered for accreditation (and achieve full accreditation within 12 months). Accreditation should reflect practice type and setting.
- Strengthen the focus of the Practice Incentives Programme (PIP) towards quality improvement activities by providing payments to support general practices identifying as Health Care Homes to undertake quality improvement activities in a structured way, informed by data.

Key Recommendation 13 – establish a National Minimum Data Set for patients with chronic and complex conditions

While quality improvement programmes will make an important contribution to improving primary health care data, additional reforms are required to achieve consistent national primary health care data.

Existing primary health care data collections and gaps

Primary health care has not experienced the same national focus on data as other parts of the Australian health system. While there are some national data collections that provide information on the primary health care system, there are many gaps in the types of information we currently collect.

Existing national data collections that provide some information on primary health care include:

- GP surveying arrangements for example, the Bettering the Evaluation and Care of Health (BEACH) Programme;
- population health surveys for example, the Australian Health Survey and the Australian Bureau of Statistics Patient Experience Survey;
- administrative data sets for example, MBS and Pharmaceutical Benefits Scheme data sets;
- other collections – for example, data collected by organisations such as NPS MedicineWise (for pharmacy, diagnostic imaging and pathology, linked to NPS MedicineInsight) and the Improvement Foundation (linked to the APCCP and Indigenous health services, including the Indigenous primary health care Key Performance Indicators, (nKPIs)).

The nKPIs are an example of collection of clinical information on primary health care in Australia. The nKPIs provide information on over 200 primary health care organisations (both ACCHOs and those with other governance arrangements) that receive funding from the Department of Health to provide primary health care services primarily to Aboriginal and Torres Strait Islander people. The nKPIs currently include 24 indicators that focus on chronic disease prevention and management and maternal and child health. They include a combination of process indicators and clinical outcome focussed indicators.

De-identified data for the nKPIs is electronically extracted from the organisations' clinical software and then submitted by the organisation via a web portal called OCHREStreams.

The nKPIs integrate national primary health care performance data with a continuous quality improvement method. The AIHW maintains the data submitted via OCHREStreams and publishes a report on the nKPIs on an annual basis. Organisations benefit from tracking their results over time and from benchmarking their performance against similar organisations. Data can be used as part of broader CQI processes to identify opportunities and measure progress toward achieving change.

The collaborative efforts of some Medicare Locals/PHNs to use existing data (including selected de-identified data from GP clinical software) to support their needs assessment and quality improvement processes are also important. MAGNET, a Monash University and Melbourne East General Practice Network collaboration is one example[78].

Although existing data collections provide some useful information about primary health care in Australia, they cannot be used to build a complete picture of why a typical patient went to a primary health care provider, what occurred during the consultation, what actions were recommended and taken, and with what outcome and cost[3]. There are gaps in the picture of primary health care provider-patient encounters and of health care over time.

De-identified data that may be derived from Australia's e-Health system may help to address these gaps. Activities under the My Health Record Budget measure, for example those relating to governance arrangements and participation, will make this contribution clearer. To support the e-Health system to reach its full potential in this area, Health Care Home practices should use clinical software that is compatible with the Australian digital health infrastructure to support the integration of IT systems and automated data collection and analysis.

Developing and implementing a National Minimum Data Set (NMDS)

As a step to address the gaps in existing primary health care data, a NMDS for patients with chronic and complex conditions should be developed. A NMDS is a minimum set of data elements agreed for mandatory collection and reporting at a national level[79]. Health care providers participating in the model would be required to provide data to the NMDS. This would provide information similar to what is available for other parts of the health system, particularly in relation to specific conditions.

There is a large body of preparatory work required to ready the primary health care sector for a NMDS for patients with chronic and complex conditions. Key elements of this work relate to health provider education and training, data governance arrangements (including patient consent and privacy) and the integration of IT systems.

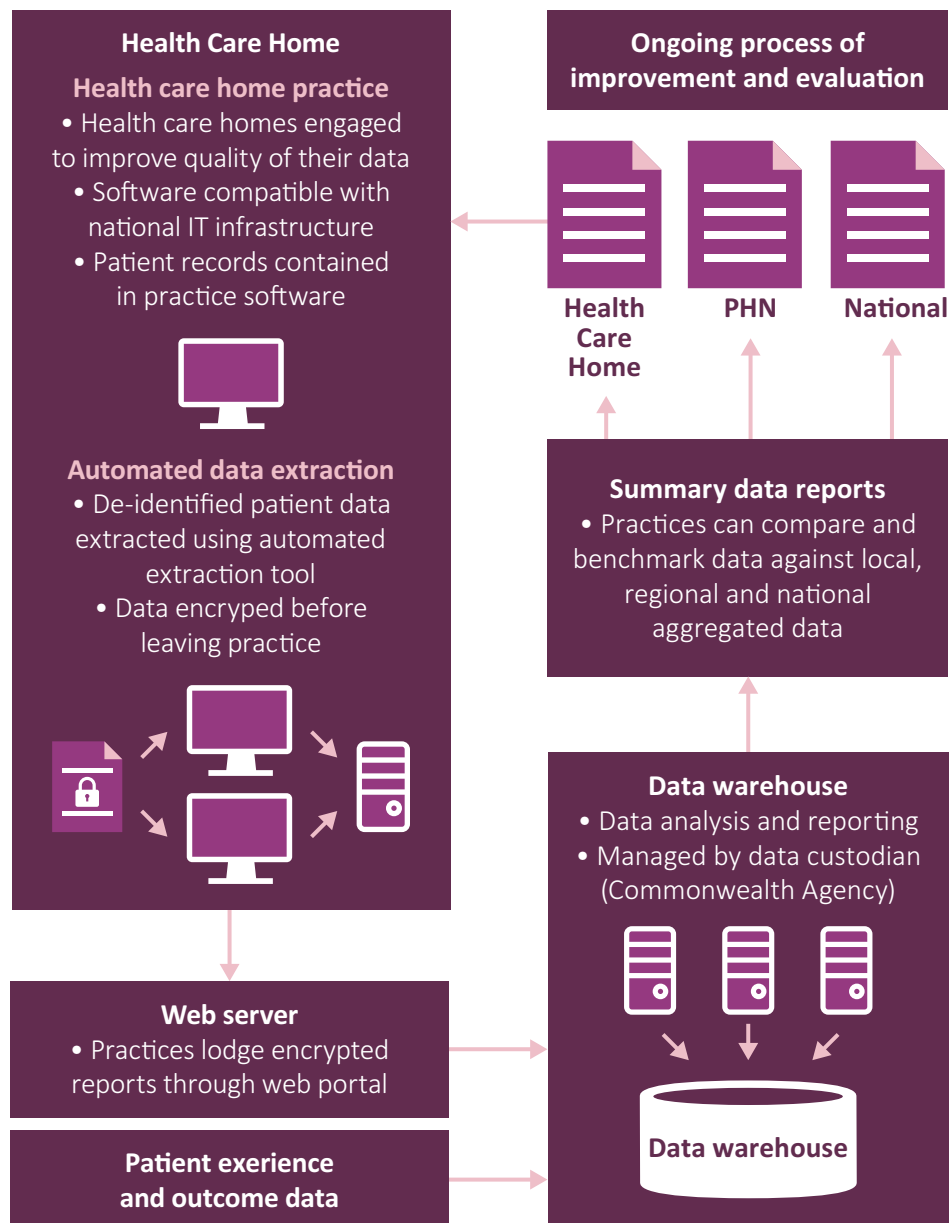
Education for health care providers could draw on the RACGP *Quality health records in Australian primary healthcare: A guide*[80]. This guide was developed by an inter-professional Advisory Group in consultation with health providers across the Australian primary health care sector and includes coverage of electronic health records.

A staged approach to the development of a NMDS will be key to its success. Initially, a small set of data elements should be agreed and tested, then refined and expanded over time in line with improvements in primary health care data. Population, care process, health outcome, and patient experience and outcome indicators should be included. Patient measures are important performance indicators.

Development of a NMDS should be informed and guided by consultation with health providers, patients and carers. PHNs will also have a role to play. Many PHNs have valuable experience in data extraction and pooling clinical data.

A NMDS for patients with chronic and complex conditions may require additional initial investment in data collection and reporting, but has the potential to reduce the costs in the longer term. For example, IT infrastructure to support the automated extraction of deidentified data from clinical software, data analysis and reporting should be explored. A model of a possible process to extract and use data from Health Care Homes to enable performance reporting and inform ongoing quality improvement processes is below (Figure 9).

Figure 9: Data collection model



A NMDS is closely linked with other elements of the new model of care. For example, NMDS data could help to identify patients who would benefit from the new model of care and match them to the level and type of health care they require.

Activities

- Establish a suitable data governance mechanism to develop and implement a NMDS for patients with chronic and complex conditions, in consultation with health care providers, relevant organisations, patients and carers.
- Health Care Home practices and care providers to provide de-identified data to support a NMDS.
- Explore IT infrastructure requirements to support the automated extraction of deidentified data from clinical software, data analysis and reporting.
- Ensure PHNs are sufficiently supported to assist Health Care Homes to collect and report data and utilise it to improve local care quality.

Key Recommendation 14: Establish new performance reporting arrangements

NMDS data should be used to support performance reporting at local, regional and national levels. As the focus of performance reporting is on quality improvement, reporting should avoid crude comparisons, and instead examine improvement from established baselines, noting that these baselines will vary, for example from one region to another.

Local reporting will enable practices to benchmark their performance against other local practices to help them identify opportunities for service improvement. Providing timely summary data to practices to facilitate ongoing improvement must be prioritised to enable the sector to be more agile. Costs associated with establishing performance reporting would be offset by improvements in quality of care that result in more efficient and effective primary health care service delivery.

Regional reporting will assist in evaluating the effectiveness of PHN commissioning strategies. PHNs should be benchmarked and this information publically reported to promote regional management of service performance.

In the long term, the development of a national report on chronic disease management using NMDS data will help policy makers evaluate progress made towards addressing national priorities in health and identify parts of the system that require remedial attention. Improved availability of data on primary health care will also support primary health care research.

Activities

- Provide NMDS summary data to practices, regional level data to PHNs and LHNs and build on the existing national reports on chronic disease management to support system improvements and resource allocation.

Key Recommendation 15: Integrate evaluation throughout implementation of reforms

A commitment, throughout the staged implementation of the reforms, to use evaluation to refine and continuously improve the model will be critical to the success of the reforms. By embedding formal evaluation into the rollout of the model, feedback loops can be established to ensure learnings can be identified and incorporated.

The early development and implementation of a comprehensive evaluation framework will support this. It will be important that the evaluation framework:

- includes formative real time practical evaluation and summative elements;
- includes both qualitative and quantitative methods;
- enables consistent evaluation of the elements of reform cognisant that variations of the elements will be tested, as well as implementation in different contexts; and
- provides regular reporting to support learning and refinement of the reforms along the way.

Formative evaluation will be used to assist to refine and evolve the model. It will provide 'real time' information to allow practical changes to be made at early stages of the implementation process. It will also help to identify information requirements and inform the development of the national minimum data set for chronic and complex conditions.

Summative evaluation will be used to assist in the assessment of the quality, outcomes and impacts of the reforms and to determine the aspects of the model that contribute to success across a range of circumstances.

Activities

- Develop and implement an evaluation framework to ensure early and ongoing learning, and application of this learning, through the staged implementation of the reforms.

Implementation considerations

Australia's health system is well placed to progress the recommended reforms. There are elements of the existing health care system that provide a solid foundation from which to establish the proposed new model of care.

A staged rollout of the model is recommended to enable the individual elements of the model to be defined, established and evaluated in large demonstration sites before proceeding to a national rollout of the model.

A number of jurisdictions, including partnerships with PHNs and PHIs, are already trialling or are in the process of developing trials that could be built upon or expanded as part of the first stage of implementation.

The Advisory Group recognises the need to work within existing resources as far as possible. However, it cannot rule out the requirement for additional resources to support the model. The staged rollout provides the opportunity to assess the affordability of the model. The first stage of development and establishment of the model should look to apply existing resources within the system.

An effective overarching governance mechanism is required to ensure that funders, providers and patients are engaged in the detailed design and implementation process.

Early and ongoing communication and engagement with health care providers is essential to ensure the cultural changes necessary to support the new model of care are realised.

Many of the submissions to the Advisory Group recommended a much broader application of the health care home model. Consideration could be given beyond the recommendations of this report to exploring the relevance of the model to broader populations beyond people with multiple chronic and complex conditions, including preventative and early intervention applications.

Staged rollout

Stage 1 – Detailed design of model elements

There are a number of activities required to develop the individual elements of the model before the model can be implemented. Key elements of the model such as the establishment of Health Care Homes are new in an Australian context, and would benefit from refinement best achieved through further implementation design, establishment, evaluation and adjustment, prior to rolling out nationally.

Further work is also required to define and model the revised payment mechanisms to ensure changes are not adversely impacting on patients or providers and are making best use of available resources as far as possible prior to transitioning to the new model of care. Modelling is also required to determine the cost benefits of investing in the Health Care Home model.

The digital health elements critical to implementing flexible team based care require further development to be able to deliver a secure, common platform for a range of providers to access, compatible with the My Health Record and the Australian digital health infrastructure

Stage 1 – Bilateral large scale demonstration sites

In order to establish the model effectively in Australia, Commonwealth, State and Territory governments, PHNs, LHNs, providers, and PHI will need to work collaboratively. Regional commissioning, patient health care pathways and coordination across sectors cannot be achieved within the primary health care system alone.

A number of jurisdictions, including New South Wales, Victoria, South Australia and Queensland, are actively trialling or developing trials of new models of care for people with chronic and complex conditions.

It is recommended that the Commonwealth seek interest from jurisdictions to partner on a bilateral basis to establish a number of large scale demonstration sites as an initial stage of implementation.

Opportunities may exist through current COAG discussions on health under the Reform of Federation process to support this approach.

Following evaluation and refinement, these sites can be scaled up to the remainder of the jurisdiction and the remainder of the health system nationally. This would not preclude individual jurisdictions from establishing additional sites in their regions in this time towards a more expedient transition to national implementation.

Stage 2 – National rollout

Following initial establishment and refinement of the model through the demonstration sites, it is recommended that the Commonwealth transition, in partnership with jurisdictions to a national rollout of Health Care Homes and associated reforms.

Appendices

Accronyms

ACCHOs – Aboriginal Community Controlled Health Organisations

Advisory Group – Primary Health Care Advisory Group

AIHW – Australian Institute of Health and Welfare

APCCP – The Australian Primary Care Collaboratives Programme

CDM – Chronic Disease Management

CDMP – Chronic Disease Management Programmes

COAG – Council of Australian Governments

CQI – Continuous Quality Improvement

GP – General Practice

GPs – General Practitioner

HARP – Hospital Readmission Risk Programme

HMP – Health Management Programmes

IT – Information Technology

LHNs – Local Hospital Networks

MBS – Medicare Benefits Schedule

MPS – Multipurpose Service Programme

NGOs – Non-Government Organisations

nKPIs – Indigenous primary health care Key Performance Indicators

NDIS – National Disability Insurance Scheme

NMDS – National Minimum Data Set

PC-PIT – Primary Care Practice Improvement Tool

PHCAG – Primary Health Care Advisory Group

PHIs – Private Health Insurance

PHNs – Primary Health Networks

PIP – Practice Incentives Programme

RACGP – Royal Australian College of General Practice

RFDS – Royal Flying Doctor's Service

Primary Health Care Advisory Group Terms of Reference

Australia's health system is under increasing pressure to provide better quality, affordable and accessible health care, built on universal access to Medicare. A long term strategy for the health system is needed, including providing better management of patients with complex and chronic conditions, eliminating waste and improving efficiency. To support this endeavour, a Primary Health Care Advisory Group (PHCAG) is being established to develop advice to Government on short, medium and long term opportunities to reform the primary health care system.

Role and deliverables

The role of the PHCAG will be to examine opportunities for reform and to develop them into a series of proposals for consultation, prior to reporting to Government.

The PHCAG will be supported by the Department of Health to identify opportunities for health system reform, with a particular focus on:

- primary/acute care interface, including the proposed and potential roles of PHNs;
- innovative care models for target groups such as those with complex, chronic disease;
- funding models that best support proposed service improvements;
- potential revised roles for existing players in the health system that support proposed service improvements; and
- better recognition and treatment of mental illness.

In conjunction with the Department the PHCAG will:

- assess the current system and review national and international literature;
- consider learnings from innovative service model trials and other service models innovations within Australia, and where appropriate, internationally;
- analyse and model potential impacts across the system, key target groups and individuals;
- undertake targeted consultations; and
- develop concrete proposals for short, medium to long term reform options for consideration by Government.

Reporting

The PHCAG will report to the Secretary and the Minister as required throughout the process, with a final report to be submitted to Government by 30 November 2015.

Membership

The PHCAG will be chaired by Dr Steve Hambleton. Membership of the Advisory Group includes:

Name	Committee members
Dr Steve Hambleton	Chair
Prof Bruce Robinson	Expert (MBS Review)
Dr Brian Morton	Expert (Specialist)
Dr Eleanor Chew	Expert (GP)
Dr Ewen McPhee	Expert (Rural GP)
Ms Karen Booth	Expert (Practice Nurse)
Mr Marcus Dripps	Expert (Allied Health)
Dr Mary Foley	State Health Administrator
Ms Leanne Wells	Expert (Consumer)
Dr Malcolm Parmenter	Expert (Private Provider)
Mr Rob Bransby	Expert (Insurance)
Dr Michael Wright	Expert (GP/Economist)
Prof Claire Jackson	Expert (Academic/PHNS)
Prof Geoff Riley	Expert (Mental Health)
Dr Catherine Engelke	Expert (Indigenous Health)
Mr Bruce Elliot	Expert (Pharmacy)

External Members are appointed as individual experts, but will be expected to drive interest with their respective sectors to support the PHCAG work programme. Members will be required to sign confidentiality agreements and declare any real or potential conflicts of interest at the commencement of each meeting.

Governance and Engagement

A targeted but comprehensive stakeholder engagement process will be essential to the development of achievable and pragmatic proposals for reform. The process will include a range of consultation mechanisms including forums, issues papers, public submissions and targeted clinician, industry, and consumer consultations.

State and Territory governments are key stakeholders and will be fully engaged. They have specific expertise as systems managers and have access to unique data sets and a range of analytical and planning tools and are also trialling a number of innovative service delivery approaches which the PHCAG should consider in formulating their advice.

Terms and Conditions

The PHCAG will be a departmental non-statutory committee and will be managed according to the Department's External Committee Framework.

Conflicts of Interest

Members shall declare any real or potential conflicts of interest in relation to specific agenda items for meetings of the PHCAG.

- The opportunity to do so must be provided at the start of all PHCAG meetings. All declarations must be recorded in the minutes of the meeting.
- A member who has declared a real or potential conflict of interest may participate in the discussion on that matter, subject to the approval of the PHCAG.
- Any decision reached by the PHCAG under a real or potential conflict of interest will be recorded in the minutes of the meeting. The Minutes will include:
 - > the nature and extent of the conflict;
 - > an outline of the discussion; and
 - > the actions taken to manage the conflict.

Convening Meetings

The PHCAG is expected to meet face to face up to six times in the life of the process and teleconference as required. The department, in consultation with the Chair, may determine that a meeting be held by telephone or other means of communication.

Rules

The following rules apply to the PHCAG and its members:

- a member may resign by notice in writing given to the department, through the Chair;
- the PHCAG may act as long as a quorum (half the PHCAG membership plus one) is present; and
- should the PHCAG not be able to reach a consensus, the Chair will have responsibility for a final decision.

Support

The department will provide secretariat support to the PHCAG, including provision of policy support with regard to:

- data analysis;
- evidence identification and analysis;
- modelling of options identified by the PHCAG; and
- other expert advice as required to support the work of the PHCAG.

Timeframe

It is expected that the PHCAG will continue to exist until 31 May 2016, unless otherwise determined by the department or Minister.

Process of the review

On 22 April 2015, Minister for Health, the Hon. Sussan Ley MP, announced the establishment of the Primary Health Care Advisory Group as part of the *Healthier Medicare Initiative*. The Advisory Group has been tasked with providing the Commonwealth Government with short, medium and long term options to reform the primary health care system. The focus is better management of chronic and complex health conditions, including mental health conditions, to deliver better patient outcomes.

Membership of the Advisory Group includes individuals with a wide range of experience and expertise in primary health care services, including clinicians, consumer representation, academics, nurses, allied health professionals, and a state health administrator.

Members were appointed as individual experts, but were expected to drive interest with their respective sectors to support the Advisory Group's work programme. The Advisory Group is led by Dr Steve Hambleton, the Immediate Past President of the Australian Medical Association and a practising GP.

Meetings and establishment

The Advisory Group has met face-to-face on five occasions, in addition to a number of sub-group teleconferences: 4 June 2015, 14 July 2015, 6 September 2015, 27 October 2015 and 25 November 2015.

The Advisory Group developed a vision and set of guiding principles to frame its work programme.

Vision

A primary health care system that achieves the best possible patient outcomes, health status and community participation; and efficiently targets health system resources.

Guiding Principles

A sustainable primary health care system for patients should:

- Engage patients and carers as active partners in decisions about their health and wellbeing.
- Ensure service and funding models are based on best practice to maximise patients' health improvement, service safety and quality, and allow flexibility.
- Deliver efficient health care, eliminating waste and duplication.
- Ensure potentially avoidable hospitalisations are minimised.
- Facilitate integration and coordination of patient care across care settings and support health care professionals to work as multidisciplinary teams.
- Encourage all primary health care professionals to work to their full scope of practice.
- Support the collection, reporting and use of primary health care outcome.

Consultation and collaboration

Discussion paper

On 4 August 2015, the Advisory Group released a discussion paper. The discussion paper set out the Advisory Group's initial views on opportunities for reform. It called for consumers, carers, health care providers, professional organisations and other stakeholders to contribute to the reform process.

A background document was released in conjunction with the discussion paper. The background document was prepared by McKinsey and Company. It provides an overview of Australia's primary health care system, with a particular focus on people with chronic and complex health conditions and summarises potential alternatives to the current system that have been adopted internationally.

Survey

An online survey was developed to collect responses to the discussion paper. The survey was open between 6 August and 3 September 2015.

A total of 1,047 survey responses were received, including 255 organisations and 770 individuals. Consumer and carer input through this process was strong, with 340 respondents identifying as having a chronic or complex health condition; and 291 respondents identifying as caring for someone with a chronic or complex health condition.

Public briefings

A total of 17 public information briefings were held across all States and Territories. These briefings were well attended by a diverse range of stakeholders including consumers and carers, practitioners and health service organisations. Members of the Advisory Group outlined the drivers behind the need for change and the options presented in the discussion paper. Comments and questions were invited from attendees. Approximately 450 people attended the public information briefings.

The national public briefing held in Canberra on 21 August 2015 was broadcast live on the internet. Members of the public were encouraged to participate in the conversation by submitting questions for the panellists and comments on the day via the Livechat facility or Twitter. This innovative approach was attended or watched online by over 480 participants.

The webcast was available to view on demand from late August to December 2015.

Public Information Briefings

New South Wales: Sydney (CBD): 10 and 11 August, Sydney (Parramatta): 11 August, Dubbo: 12 August

Queensland: Brisbane: 10–11 August, Cairns: 13 August, Rockhampton: 14 August

Victoria: Melbourne: 12 August, Geelong: 13 August

Tasmania: Hobart: 14 August

Western Australia: Perth: 18 August, Broome: 19 August

Northern Territory: Alice Springs: 19 August, Darwin: 20 August

South Australia: Adelaide: 18 August

Australian Capital Territory: Canberra City: 21 August

Targeted consultations

A first round of 46 targeted consultation sessions were held during August 2015. These involved briefings with 27 peak organisations, as well as meetings with Primary Health Networks (PHNs) in each jurisdiction and State and Territory health departments. Briefing sessions were also held for specific sectors such as allied health, nursing and private health insurance.

Following the formal consultation period, Advisory Group members continued to meet and consult with stakeholders, both within their sectors and with peak organisations, to assist with the Advisory Group's deliberations on potential actions for reform.

Consumer focus groups

Focus groups were held to better understand how patients and carers are currently managing chronic and complex health issues and to seek their views on the opportunities for reform presented in the discussion paper.

A total of ten focus groups were held. Nine groups involved consumers with chronic or complex conditions and one group involved carers of people with chronic or complex conditions. Between six and eight people attended each group. The sessions were held in Sydney, Melbourne, Adelaide, Townsville and Dubbo.

Written submissions

The Advisory Group received 72 unsolicited written submissions, and 46 organisations or individual survey respondents chose to provide supplementary information to the Advisory Group via email.

Consultation feedback and findings

Each consultation mechanism presented and sought comment on the themes of the Discussion Paper – *Better Outcomes for People with Chronic and Complex Health Conditions through Primary Health Care*.

In comments provided about the current primary health care system, through the various mechanisms, Medicare and the existence of bulkbilled or subsidised services for people with chronic and complex conditions were frequently cited as a positive feature of the current system. Other aspects that were seen as most important for people with chronic and complex conditions included:

- access to health services, especially low-cost health services;
- prevention measures and health education;
- the coordination of care across different health care services, involving multi-disciplinary teams;
- care and effective communication and collaboration between different health care providers; and
- knowledge and understanding of chronic and complex conditions, and the associated care requirements for people with them.

Survey respondent support for the concepts detailed in the Discussion Paper, against each of the themes, was analysed and highlights from these results include:

Theme 1 – Effective and appropriate patient care

- 77% of respondents indicated that they did support patient enrolment with a health care home for people with chronic and complex conditions.
- 92% of respondents supported team based care for people with chronic and complex conditions.
- 62% of respondents ranked patient participation as the most important aspect of effective coordinated care.

Theme 2 – Increased use of technology

- The overarching themes that emerged centered on the role of technology in improving communication, shared access to standardised records, and efficiencies coupled with a reduction in administration and duplication.

Theme 3 – How do we know we are achieving outcomes?

- 90% of respondents agreed that it is important to measure and report patient health outcomes.
- Over 300 of the respondents felt it would lead to a better understanding of whether the treatment was appropriate and effective.
- Measuring and reporting was also widely considered to form the basis for learning and improving (over 200 responses).

Theme 4 – How do we establish suitable payment mechanisms to support a better primary health care system?

- A blended payment model was the most highly supported model by respondents. It was also the most favoured model by organisations, practitioners and non-practitioners.

In addition, key messages against the themes of the discussion paper from the records of the consultation process and written submissions include:

Theme 1 – Effective and appropriate patient care

- There is strong support for voluntary patient enrolment for people with chronic and complex conditions.
- The mechanism and impact of enrolment requires clarification, particularly in relation to patient choice of provider.
- In many areas, particularly rural and remote locations, a health care home may already be the default model of service, although it is not formalised as such.
- Attributes of health care homes and care coordination are part of the current service experience, particularly identified in some specific areas such as community controlled health services and palliative care, but are not consistently applied. There is a lot that can be learned from these examples and their current effectiveness should not be undermined.

Theme 2 – Increased use of technology

- There is general support for My Health Records and an opt-out approach.
- This is an untapped opportunity to engage patients in their own care, particularly with technology that people already want to use (e.g. smart phones), although accessibility and useability are important, particularly for some sub populations and communities (e.g. older people, people living with a disability).

Theme 3 – How do we know we are achieving outcomes?

- There is general support for the reporting of outcomes and changes in health status at an aggregate level.
- Any approach should not be punitive and benchmarks need to recognise different starting points. Related to this is how to incorporate/acknowledge the impact of patient accountability as providers can not only do so much. Also connected to this are the limits on improvement/better management due to the impact of social determinants of health.

Theme 4 – How do we establish suitable payment mechanisms to support a better primary health care system?

- There is support for a blended payment mechanism which recognises and caters for different complexities and levels of care needed.
- Within such an approach, there should be elements of care provision, for example acute primary care presentations, where fee-for-service would remain an effective option.
- Payment mechanisms should also support ongoing engagement across the sector and disciplines to deliver better outcomes.
- Funding mechanisms need to support clinicians working to scope of practice.
- Care should be taken as to not create perverse incentives and concerns were raised about the risk of “cherry picking” of patients in an enrolment model.

Related reviews

The Australian Government is undertaking a number of reviews aimed at ensuring that consumers can access affordable, quality and timely health services into the future. The Advisory Group has actively considered other reviews that are also underway, including the MBS review and the review of mental health services. Mechanisms were established early in these processes to support communication between review committees, including the Chair of the Advisory Group and the MBS Review Committee holding membership of the other group.

Patient experiences provided by the consumer health forum

Consumer Story: “Paul”

Paul was diagnosed with Type 2 diabetes in his late twenties. However, without adequate advice on how to manage his condition, he ended up needing amputations on both feet within a few years. This cost him his job working on a warehouse floor, and he now lives off his income protection. Paul says he’s getting better advice these days on how to manage his diabetes, and he uses what he’s learned as a chronic patient to identify gaps in health plans for other consumers.

Stable chronic condition with need for self-management

I was diagnosed about twenty years ago with Type 2 diabetes. I had the normal symptoms like tingling feet and going to the bathroom a lot at night. When I finally went to the GP, all it took was a simple blood test. But even though I got a quick diagnosis I didn’t know as much then about the disease as I do now. You never really heard about the risks of diabetes back then, that it could lead to amputations and the like if not managed well.

I was young and did the typical man thing, you know? “I’m tough and invincible,” so I had pretty poor management. Only once I started to have chronic problems did I start to take things seriously. However, the original recommendation was just to get my eyes tested. I thought I could handle the rest. I kept on with this for about 10 years before I had my first amputation.

It changed my livelihood. My employer was good about accommodating me after my first infection by giving me some more work on the business side of things until I recovered. But in six months, I had another amputation, and my occupational therapist said I couldn’t wear the right safety boots. So my employer determined that they didn’t have suitable duties for me, and so I had to go off work. Fortunately I had income protection, and I’ve been living off that since.

Without the income protection, I would be in a really poor position. My wife is out of work, and the government wouldn’t have been able to cover very much. I’m not disabled enough to get a pension, so I would have needed work elsewhere, which would be problematic with my regular hospital visits. I also couldn’t afford my private health insurance.

In Queensland, the public health system will admit private patients, and they will cover the excess, because they get funding off the insurers. The last time I had to go into hospital, I presented at the public hospital’s emergency department. They decided it was the wrong hospital for me, and so then I transferred to the private hospital, where I stayed for six nights.

But private health insurance doesn’t cover emergency presentations at private hospitals, so you get charged that plus excess. So I’ll always present to public system emergency. If they want me to stay, I’ll stay, or else then I’ll go on to private. People are always going to present to public hospitals first. Public hospitals are about getting people well and getting people out. So there’s the emphasis on high quality, “bang for buck” equipment. In the private hospital, they’ll buy equipment to improve the patient’s stay, but they can’t justify shortening a person’s stay and meeting their equipment costs.

The real disappointing thing is that I'm basically a self-funded, invalid pensioner. I fall through the gaps on most support schemes. For me to get the best care for my feet, for example, I need customized, medical-grade footwear. They're about \$1,500 a pair. The health fund only pays \$500 every two years for those shoes – and that was before I had to reduce my fund due to financial stress.

The health fund says they're held back by what they can reimburse because it's "standard" across the board; but they haven't adjusted the reimbursement since 2003. The cost of the shoes has nearly doubled in the meantime.

My private insurers, on the other hand, are happy to pay for me to spend however long in hospital due to issues with my feet. However, they won't pay for the shoes that would have avoided the hospital stay in the first place. If I'd had the correct footwear, I probably would have fewer or shorter stays in hospital.

I was once in a working group of something like one-third consumers and two-thirds health professionals, and all the professionals wanted to talk about was remuneration to the health providers. They didn't think about the costs to the consumers, or whether it would be better for the consumer to be able to get everything done in one go. You can't just peel back one layer of the onion, but that's what they were on about.

The best place for a person is at home. In hospital, you're looking at hundreds-of-thousands of dollars per night per patient, and it's a worse place for the sick person because of the number of possible infections. A person's lifestyle might have to change, but they can adapt and be where they're more comfortable.

But it's a question of how much government wants to open the doors and purse strings to get community support. You're never going to meet everyone's particular needs, but they could meet the needs of 80 percent of the people 80 percent of the time, and that would be huge.

I don't have a huge support structure outside of hospital. I've got my regular GP, because I have to have the same form filled out every two to three months saying I can't return to work. There's a lot in the community if you can source it, but it's hard because most people don't know what's available.

I see an endocrinologist six to twelve months, and I used to see a diabetic educator, but they stopped that position. The strongest point I've taken away is that the better I have my diabetes managed, the sooner I will heal. When it wasn't managed, it took a long time to heal. The last time I was in hospital for amputation, it was only a week, versus six weeks for the first time. The last amputation, with community nursing support, took four to six weeks fully to heal, whereas the first time took four months. So that really opened my eyes.

Being a regular patient is a bit like going off on holiday. I've got all my toiletries and medicines packed and ready to go. When you do have a chronic condition, you learn to be a patient. "What do I have to do to get well again?" That's the attitude you have to have. I want to be part of the solution. If you're going to complain, you've gotta come with a solution. I'm trying to encourage as much as anything. I've taken from my hospital stays what works, what doesn't, and what can be improved.

For example, once on my regular visits, I was being weighed in a room full of other patients, and the nurses called my weight across the room to each other! They might not have done that otherwise, but their professionalism slipped in that moment. It's so easy to go from a caring and supportive environment to being made to feel uncomfortable.

I'm part of a hospital group that helps to make sure that patients are getting the right care and equipment. I'm doing this work at a hospital where I haven't been a patient. They had someone who used to do it, but his life situation changed, and they asked me. Even though I haven't been a patient there, I can still walk them through the patient experience, and I think they can understand that without feeling criticised.

I think what I'd want to tell people diagnosed with a chronic condition is that it's not the end of the world. You're still alive. What the health professionals are going to say to you is that you've got to learn to live with it. We're very adaptable, and we will find a way. You have to listen to the people around you, and be a part of your care team. Ask questions and be proactive. They aren't going to cure you, but they can help you get the most out of life.

Consumer Story: “Katy”

Katy is a young adult who lives in Victoria. She has been grappling with chronic health issues since childhood. She lives with dysautonomia, chronic fatigue, an immune disorder, asthma, and chronic pain. Her health has deteriorated to the point that she had to stop pursuing a degree in nursing and is now unable to work. She sees multiple specialists on a regular basis in order to manage her multiple diseases, as well as presenting regularly to emergency departments for acute care management.

Complex and chronic conditions with high needs

I’ve been unwell since I was very young. I had chronic sinus infections and asthma, and was very sick from when I was five. I was seeing an allergist and ENT specialists and an asthma doctor. I ended up having surgery when I was eight for my sinuses. That kind of helped. It meant I could come off my antibiotics, which I’d been on for years.

But I became quite depressed in my teens. I tried to get help with that in school. I tried to see the school counselor, but she wasn’t very good. My mother ended up suggesting that I see a psychiatrist, and eventually I was hospitalized for several weeks in a private psychiatric hospital when I was 15. It helped, but I was still very stressed.

I was still having problems with my sinuses, and I was injuring myself frequently. My joints are hyper-flexible and aren’t stable; so I’d have a significant injury every year or so. But my main, more seriously chronic stuff started in my first year of university. I caught a virus, and I had it for three months. I felt exhausted, had joint pain, fever, and the like. My father had it too, but he got better, and I didn’t.

I saw an infectious disease expert, and he pretty much did every test that he could think of. It was like I was back in childhood and having a bunch of tests that I couldn’t understand. Despite that, he couldn’t find specifically what was wrong.

I ended up seeing a chronic fatigue specialist, and he diagnosed me with Chronic Fatigue Syndrome – but without any further testing or anything, just from my history. There’s no treatment for that, and I lived with that for five years. I ended up doing a private rehabilitation program, which sort of started my recovery. I got to the point where I was ninety percent recovered, and I went back to university.

When I was in my graduate year of nursing, I got sick again because I was catching everything going around the hospital. I ended up missing a lot of work.

After a holiday trip with friends, I ended up getting sick that required me to go to the hospital and be treated with intravenous antibiotics. I missed my last two weeks of the graduate year, and I decided to not renew my contract because I was so sick and needed to recover. Since then, my health has deteriorated, and I’m unable to work.

A friend of my mother’s was having similar issues and was being seen by a cardiologist. I went on my mother’s recommendation, and the cardiologist was the one who diagnosed me with dysautonomia. I probably had it when I was diagnosed with Chronic Fatigue Syndrome, but I hadn’t seen the right people and didn’t have the right tests done.

I ended up moving back home with my parents at the start of this year because I wasn’t well. My mornings consist of waking up and taking my medication, then having breakfast and taking more medication. The rest of my day is pretty much timed around when I have to take my medication. I have weekly physiotherapy, monthly infusions of blood product, and an exercise program that was written up by my physiologist.

I'm not able to drive very far, so if I have an appointment that's farther away, I have to get someone to drive me. Often I need to use a cane to get around – not necessarily because I need it to walk, but to conserve my energy.

There are thousands of people with dysautonomia, but most go undiagnosed because of a general lack of awareness. It's all about finding the right person, and that can have a lot of luck involved.

My GP is fantastic and my cardiologist is also fantastic. My cardiologist has a great network of specialists that she sends her patients to, and she is great at talking to all of my specialists and ensuring that their care is incorporated into what she's doing. So I'm very lucky in that respect.

It hasn't always been the case. I'm seeing an immunologist now who's the third person I've seen in the last ten years. The first person just didn't seem that interested. He's not the only person I've seen who's been like that – not very helpful for people who are a little bit more complicated, like myself. I've gotten, "No, we can't treat that, because the only treatment is human blood treatment, and that's highly regulated and in short supply."

It wasn't until this year that I was further diagnosed with an underlying autoimmune deficiency that I've had my entire life. My white blood cells are unable to remove infectious bacteria. Again, it just took me a while to finally get the right test. There are only two hospitals in Melbourne that have the ability to do the right test, and they're only recent.

The public and private systems are very different. One of the acute treatments is intravenous saline, because I get low blood volume. People turn up to emergency, and it's guarded like liquid gold. It's salty water. It takes ten minutes to hook someone up, and then you send them home after two hours. It's not that difficult, but it's ridiculously hard to organise and access.

If I were to go to a private hospital, it would be easy to get that, because I'm paying for the service. I'm not saying the service in public is bad, but they're more likely to cater to your needs in a private hospital because you're paying. I've only been admitted in private hospitals. I have private health insurance, and I don't have to go on waiting lists for surgeries. As a patient with a lot of insight into my condition, the nurses will listen to me.

However, in the public system, there's a lot more waiting. In emergency in particular, there are a lot of doctors who think they know everything, but they don't know about my condition. They're not great for young, single women. They think I have anxiety or am pregnant. I've encountered this in the private system, too, so it's not just the public hospital.

When we study nursing, we're taught to listen to our patients and take what they're saying on board. But when you get into the industry, that culture isn't there as much. They see so many people and you get so many different experiences but so many similarities that it's often very easy to build up a picture or knowledge base that leads to assumptions.

When you're in an emergency facility and you're used to seeing people with heart attacks, broken arms, and diabetic crises, you know what to do and what to expect. But when someone comes in with something else that you're not familiar with, you still have that experience – that knowledge base – and you apply that to them, but it doesn't work.

They often think they know what's going on based on what they see and have seen before. So with dysautonomia, one of the main symptoms is tachycardia, and that can cause shortness of breath, and that can cause you to feel anxious and chest pain. So people present to the emergency department and are told that they're having an anxiety attack when that's not the case. But because there is that assumption based on previous experience, the people making the diagnosis discount what the patients are saying and aren't willing to investigate further.

My cardiologist has written me a letter that I can take into emergency when I need intravenous fluids, and that's been a God-send. Most of the time, the people I see don't know anything about my condition, and I'd get sent home after drinking a couple of glasses of water. I've had to argue my point with other doctors who think they know everything because they're in charge of the emergency department.

Understanding my condition does me a bit of a disservice because I can say, "I'm getting 'this' because of 'this,'" and so I don't get investigated for other things. I was getting migraines, and I didn't think it was because I had low blood volume, but because I needed to change my medications. Then I ended up getting chest pains, and when I went to emergency, I got intravenous saline, and my migraines went away. But because I had them before, I thought they were due to something else. Other people who don't get chronic migraines might have gotten that treatment sooner.

But having said that, I've had some really great doctors who wanted to know more about my condition, and have done research and gone away knowing more about the condition.

We had a family health insurance policy for years. But when I went onto my own policy with the same provider, I wasn't getting much back for physiotherapy; so I changed policies. I changed my policy again two years ago to address my endometriosis and adenomyosis, which were getting a lot worse, so I got a different policy that would cover more obstetrics.

The mental health plan gives people 10 visits per year, but people with chronic illnesses need more than that. We're at a greater risk of developing mental health issues. I used all my 10 visits last year, and then had to pay out of pocket. That's partially covered by my insurance, but it's not a great amount. The chronic health plan gives you five visits per year, but people like me use a lot more than five – *a lot more*. I see a physio once per week – that's fifty-two visits right there. I'm lucky my mother covers a lot of my health costs, or else I just wouldn't be able to afford it.

My health insurance gives me a lot of cover for physiotherapy, but it's spread out into small increments throughout the year. But it's only \$17 per visit, and each visit is a lot more than \$17. I have exercise physiology, which was a couple hundred dollars for the assessment and program. My health insurance will only pay per visit, and not the total amount. I have to wear compression stockings, and I can only claim one-third of the price of those, and only three per year. They last a while, but I get about four pairs per year.

There needs to be a lot more awareness and understanding of lesser-known conditions. I know it's really easy when you see the same thing all the time, but there are a lot of us out there who don't have the usual things, and we don't get treated properly. It takes us a long time to get diagnosed, and we don't get the right treatment when we go into emergency.

There are not the same things put in place for us that there are for other conditions, and that makes it a lot harder – things like support outside the hospital and access to medications. Several of the medications that are used to treat my condition are not approved specifically for use, so they're not on the PBS. Some people have to pay \$10 per tablet, and they'll go through two or three of those per day. Drugs that are available overseas require special access here. I applaud organisations that have succeeded in getting their medicines on the PBS for their conditions, but there are so many more people out there who need the same access. It shouldn't matter what condition you have.

Consumer Story: “Jane”

Jane lives in outer regional South Australia with her husband and two young children. She was diagnosed with intracranial hypertension after going for years with a misdiagnosis of lupus. Her obesity adds a level of complexity to the regular course of treatment. Jane also has anxiety owing to childhood trauma that impacts on her ability to recover from regular therapies in hospital if improperly staffed. She requires regular visits with specialists, many of whom are several hours from her home, and other specialist services not readily available at her local hospital.

Multiple morbidities with ongoing needs

Back in 2010, I had a misdiagnosis of lupus. I had been having symptoms for quite a while, but just sort of shrugged it off. I was told it was so mild that medication wouldn't really help. The side-effects from the medication would be worse than the disease, so I just put up with it.

But when things got to a crisis point, I ended up in hospital.

There were a lot of things that remained unexplained. I was getting dizzy spells, but they couldn't find anything for that – even after multiple CT scans. The dizziness didn't go away, and I was falling over. I was showing stroke-like symptoms.

When I got to the hospital, they had a panic attack and said, “Something really bad's happening.” They put me on a flight with the Royal Flying Doctor Service to the city. They put me through a bunch of tests, which I ended up running away from. They'd thrown me on a plane, told me I might have brain tumors or multiple sclerosis. I was away from my family in all this. This was a few days before Christmas, and I was terrified out of my mind.

At the time, I was having an allergic reaction to Stemetil that made me jittery and super anxious. So I was high strung. They put me in an MRI machine without sedation, which I'd been begging for – I'm incredibly claustrophobic – so they only got half an MRI because I was hysterical.

I did eventually get an MRI after a doctor made special accommodations, but I went home as soon as my husband and kids came at my own expense. We had to find and book accommodation for two nights for us and our kids and drive over five hours. But the hospital lost it, and gave me an initial diagnosis based on the partial MRI. I had to argue with them until they found the full MRI and gave me the diagnosis of intracranial hypertension.

I was in hospital for a week when I had what I call a “funny turn,” but I woke up from one with a crash cart next to me. I'd been resuscitated, but nobody was giving me any information. So then I went back to the city for a lumbar puncture. I had a failed puncture because the doctor tried to do it through my stomach and then roll me on my side. I'm obese. I could have told you that the needle was going to move.

When I got home, two weeks later, I got a letter in the post asking me to go back into the city next week. That's a 450 kilometer drive on short notice. I can't drive, and my husband has to take off work, and we have to bring the kids. They weren't coordinating with my GP.

My GP is fantastic. She found a neurologist who visits two hours from us, and is also willing to do teleconference. We can do a day trip if we need. He's also given me all of his contact information that I can give to the hospitals so they can call him directly.

My GP also coordinates with the local optometrist, the ophthalmologist, dietitian – basically has put the team together. The city hospital is great, because when you show up, you see everyone at once. It's great, but I can't do that every six weeks; so we've had to build our own team down here. It's great, but it does get hard.

When the pressure gets bad, it gets very painful, and I do start to exhibit stroke symptoms. My arm will drag, I fall over, I can't talk properly, and so on. But because I'm waiting for a procedure, I'm not high up on the needs list. Sometimes I'm not afforded privacy in the emergency department while I'm waiting and getting limited treatment.

The local hospital also doesn't like to do the lumbar punctures on me. It's a simple procedure which they do all the time, but I do have extra weight and am short; but people haven't said I'm really hard to do. It just takes a little extra time. There's no extra danger or risk, but often I have to spend extra time in emergency until someone is willing to do the procedure.

I actually had to throw a tantrum to get the hospital to allow a specialist to perform the treatment here. I have to have treatments every six to eight weeks, and I was having to travel for two hours. And because the roads are poor, that puts pressure on my back. It costs a fortune, and my husband has to take time off work. So I had to stand my ground to get the hospital to make the appointment, even though they charge me each time when before I was being bulk-billed.

After I threw that tantrum, that's when I was told that they have a weekly specialist who flies in. Nobody told me or my GP they had that service. There's a lack of information being passed around if you don't know the right people.

I really wanted to apologise for throwing the "tantrum," but it just seems that's what needed to get things done. I've seen other people do it, and thought that it was unreasonable, but it's exactly what I ended up having to do. The squeaky wheel gets the oil.

My biggest issue with the health system is that there's really no one solution. My care at the moment is to keep having lumbar punctures every six to eight weeks – which carries risks, is painful, and has a lot of downtime – until someone can come up with a solution or I can get a surgery.

There are also the little things. For example, I'm allergic to Maxolon. It's written down in my notes, and it's on my wristband. Yet every time I get nauseous, they try to give me Maxolon. If I'm having a panic attack, my words don't come out well; and so sometimes I've had to literally hit the tablets out of their hands. So now it's been written down in my notes that I'm violent towards the nurses. I've had to go through official channels to get that written out.

I'm an abuse survivor from childhood. I told the hospital – the nurse – not to have male nurses, and she put that information in my file so that I didn't have to say that over and over. But despite that, I was put into a room with two men.

I've given the hospital instructions on how to help me out regarding my child abuse. It's not men in general, but I can't deal with being woken up by men. But there is no procedure in place for someone in my position to tell someone, "If you're feeling vulnerable, go speak to someone in a pink blouse," or whatever. There is no information.

As a survivor, we generally know our triggers, but there are no processes set up for anyone who is in my situation to be able to say to someone, “These are my needs. I’ve had a traumatic past, these are my triggers, and you need to be sensitive to that.”

It’s in my file as “anxiety” because I wanted to be sensitive about it. I had given them full permission to put details so they could understand where I was coming from. I don’t mind people knowing and understanding, I just don’t want to have to tell them and discuss it. I feel like if everyone understands, things will go smoother.

So you have to find someone whom you feel is the least threatening and say, “Hey, look, you have to keep the male nurses out.” You’ve got to explain that without seeming like a crazy person or alienating the male nurses. Here it isn’t a big problem – they just swap you – but in the city, it’s an issue. The information doesn’t always get passed on. Every nurse that comes along has their own idea of how they want you to be.

I can understand that living in the country that I’m not going to have everything in one place. I’m not expecting the world. But I think that at least having visiting specialists would help – or being told when they do have one – or central registries that doctors could access. That would be helpful. There is so much information out there, but nobody can get it.

The government is consolidating a lot of services. My local hospital is beginning to use the RFDS almost as a taxi. They do liaise with the city doctors – and I understand that when someone rucks up with a complex condition, you only get the information that the person gives you at that time. You have to think on your feet. I get that. I do have something that’s not well known. I understand that.

Having a way for [the city] primary care teams to reach the country would be fantastic. If they could set up a way to teleconference, that would be fantastic. I’m on a mission to bully my way to make them do that. It doesn’t cost a lot. It’s time, but it wouldn’t cost them a lot to do. Yes, there would be certain constraints on consults, but they could make something work.

As it stands, we’re scraping together what we can so we can move to the city to be closer to care. We have no other choice. We’re going to have to move from a place where we’ve lived all our lives to a city where we don’t know anyone, and where we’re not going to be able to afford a house. All just so I can get better health care. That’s basically the fix that we’ve got.

Consumer Story: “Rose”

Rose is a pensioner who lives with her husband in the Northern Territory, and has for most of her life. Her primary chronic condition is osteoporosis that has left her in pain and a misaligned spine. She also manages diabetes, high blood pressure, and other cardiovascular conditions – all of which were recently complicated by a hospital-acquired infection. She wants to be able to stay in her home and maintain a good quality of life in retirement, but is finding that her health conditions – and lack of access to providers and community services – are putting that dream in jeopardy.

Multiple morbidities with ongoing needs

I’ve probably had osteoporosis all my life, but it started to be a problem in my 20s. I just started fracturing bones very easily. It wasn’t diagnosed for quite a number of years. It was in the early days – there wasn’t a great deal known about osteoporosis, it was just a word that you heard. Nobody ever suggested that it might be the problem. So it was quite a number of years by the time it was diagnosed.

By the time it was diagnosed, it was classified as severe. I’d already fractured several vertebrae, had several fractured ribs – all sorts of things had happened. I’ve had two fractured hips. One of them was due to a fall, which I had repaired at Alice Springs. But a year later, I had to have a total hip replacement because the bone was dying.

High blood pressure happened over time. The doctor noticed just during visits for other things that my blood pressure was up a bit. So I had to start monitoring it, and I’m on medication now. It was the same with diabetes.

The diabetes is not very severe – I’m not on insulin, it’s controllable with Diabex – but it has gotten worse over time. I have to take more Diabex now, and I’ve got a lot of other associated complications that you get with diabetes – with the feet in particular. But I’ve got some other significant health issues that are impacting on those, like cardiovascular disease.

I’ve got a lot of damage to my spine. Because of the osteoporosis, the spine crushes – the vertebrae are crushed and fractured. Things don’t line up right anymore in the spine. So I’ve got to keep pressure off the spine, which is why I have to use crutches for walking. But even sitting in a chair, I have to sit in a chair with arms on it to take pressure off the spine.

I manage pain with implants I had done a few years ago. I saw a pain management specialist in Adelaide, and had electronic implants put in my back. They’re not 100 per cent. They probably work at 70 per cent to reduce the pain; but with something like Panadol Osteo, they work okay.

We have a hospital here, but it’s very basic. Specialist pain services and management [aren’t available]. Sometimes I can go a few months with [no visits], and sometimes once or twice a week. I was actually treated at the hospital a couple of days ago. I couldn’t get an appointment with the doctor for a week and a half, and I needed treatment urgently. It’s a bit hard.

Some of the doctors who are here are only here on a six week contract. One doctor in the hospital I spoke to recently said he had a contract for two years, but he didn’t know if they were going to renew it. Six months is the standard length of the contract.

What I’ve found [with the staff turnover] is a difference in view of what kind of treatment is appropriate.

I have cellulitis in one of my legs – from an infection I picked up at hospital in Alice Springs – and last year I ended up three times in hospital for a week or more at a time. They couldn’t clear the infection, and eventually I was put on a long course of low dose antibiotics. They couldn’t think of any other way to keep it under control and stop it. It was pretty successful, and I’m off the antibiotics now.

But the last doctor I spoke to at the hospital – the same hospital that thought this was appropriate treatment – said, “I don’t think much of that regime of treatment.” This will always be a problem when you’ve got such a high turnover of staff. They keep restarting the treatments.

The health authority keeps saying, “We can’t get doctors to come here, to stay here,” and yet I’ve lost count of the number of doctors I’ve talked to who’ve said they’d love to stay, but they’re not given the opportunity. Having this constant high turnover of medical staff is a problem.

There’s no issue with the hospital staff saying, “You have to go to a private doctor,” or whatever. They know what the situation is. It’s the hospital that has to provide the staffing at the general practice anyway. But if I go to the hospital here and say that I want to be treated as a private patient, they’ll say, “Yeah, all right, but we haven’t got any private rooms.” I raised a stink about it once, and the only place they could put me was in the palliative care room.

Anything more major, you have to be sent to Alice Springs or somewhere else. The only way to get there is to go by Flying Doctor, or by bus or by your own transport. I can’t even get on a bus because I’m disabled. They’ve got no lifts or anything. They’ll carry a wheelchair under the bus, but won’t take a mobility scooter; and the only way I can get around is a mobility scooter, so the bus is useless to me.

It’s a 500 kilometer road trip to Alice Springs, and then there’s only one flight per day between Alice Springs to Adelaide. So it’s going to Alice Springs in one day, staying overnight, and then flying to Adelaide and getting there some time in the afternoon. There’s all that time gone already, and obviously you wouldn’t be able to arrive on the day of your appointment. Plus you’ve got all the accommodation charges.

I’ve also got a hernia. But any surgical services – I’m due to go to Alice Springs for a consultation, and this will be the third time for the same issue. But it hasn’t gotten to the stage yet of them organizing when it’s going to be done yet.

There’s a problem with one of my implants at the moment, because I’ve been having trouble trying to charge it. There’s a special docking station – the implants are charged wirelessly – and to fully charge one takes five hours. I have to lay in one position for five hours to recharge these things. So sooner or later, I’m going to have to try to get to Adelaide again, see the specialist, and organize something about the implant. There’s nothing wrong with the charging unit, so it’s something to do with the implant. And I just keep thinking, “Oh my God, what if it has to be removed and replaced?”

The process for having this done originally – and thank God for the insurance – was nearly \$75,000. I couldn’t have gotten it done in the public service. But we’re going to have to let the insurance go, because our only income is our pension. It’s costing us \$240 per month to maintain it, but there are no private facilities here for us to use it.

Last year I had an emergency. I had pneumonia, and I’ve also got emphysema, and I can’t get any kind of checks done here for emphysema – like what’s happening with the lungs. I have to go to Alice Springs to get my checks done, and sometimes you’ll wait months and months for an appointment.

Even in Alice Springs it’s the same. When I was there last year, I was hemorrhaging really badly, and the only reason why I wasn’t in intensive care was because they had no bed there. They put me in a room with another patient who wasn’t very hygienic, and so I picked up the cellulitis.

So why am I paying all this money for private health insurance when I can’t get private health care? But then what if I have to have this implant replaced and I haven’t got the coverage? So we’re kind of caught between the Devil and the deep blue sea.

Because of the osteoporosis, I’m really careful about what I’m doing because of the possibility of falls. As I get older, I know I’m more prone to falls, and I’m starting to get to the stage where I’m almost trapped in my house

We’re trying to get a ramp put up at my house, and I can’t get any services here for getting this ramp done. At the moment, I’ve got four steps to get up and down – and it’s hard on two crutches. Going down is worse because I have to hold on to the crutches and not the handrails. If I fall, I’m really in trouble.

The services just aren't here. I look around the community, and it seems like everyone else is able to access free mobility scooters because there's no public transport, and they've all got ramps put on their houses. Well why can't I? Things like this are very frustrating.

We have got NDIS here, but it's only for people up to the age of 65. I don't know when that decision was made. As far as I'm aware, it's because they didn't have enough money for everybody, and presumably they could get those people back into the workforce.

Up until we had NDIS, there was a lady employed [at the hospital] who looked after all disabled elderly people. She was really good. But then the NDIS was brought in, and they abolished her position and haven't replaced it with anybody else. Now all the disabled people over 65 have nobody representing them.

I used to be able to just ring her and say, "So and so's happened, and I need some help. What can I do?" She'd organize things. When I had the first hip replacement surgery, I was still a real mess when I got home from hospital. I couldn't even lay in my bed – get in or get out. She organized one of the hospital beds to be delivered to the house, and I had it on loan for weeks. It was an electronic bed that could be raised up and down. When everything had healed enough that I was a little more mobile to get in and out of my own bed again, she organized the guys from the hospital to come in and take it out. Things like this were like a life-saver to me, and she would just do them for me. There's no one to do anything now.

I actually rang NDIS and My Aged Care Services to see if they knew who it was I could go to, and they pointed me to the indigenous services. They don't provide those services; and what they do provide is only for indigenous people. And the other place they pointed me to was the nursing home. I already get some services from the nursing home, but they don't provide all of them for disabled persons [in the home].

The nursing home staff here are pretty good. I get in-home care about once a day. I have bleeding in the legs – because of the cellulitis and cardiovascular problems, I have vascular eczema – but because of my spine, I can't bend over to treat it. So the nursing home staff come over to massage my legs and check the condition. It seems like a minor thing, especially compared to what other people need, but it's also very important.

I know quite a few of the other clients they've got, and I know how serious their conditions are. I've certainly got nothing in comparison. They've got patients who are totally paralysed. I'm not at that stage, but I'm at the stage where if I don't get help, I'm in trouble.

The nursing home is getting the same run-around on getting answers. You feel like tearing your hair out. Why is it impossible to be able to do what everyone else does – and takes for granted – and that's safely get in and out of my house?

I haven't had any advice from doctors, because they know there's little they can do here. Going back a couple of years, one of them said, "You should move somewhere else where there's better medical care." How insulting! Why isn't he saying, "Look, this is really bad, we should be putting pressure to try and provide better services."?

I'm in my 70s, and so is my husband. [My husband and I] have been residents in various places around the Northern Territory getting on to 40 years now. We're just supposed to leave here and go somewhere we don't know anyone and have no family? Even if we sold our property here, we couldn't get enough money to buy something in one of the bigger cities. There's no way we would be able to do it.

We like it here, but it'd be nice to have some decent medical service. As nice as the medical staff are, they're very limited in what they can do because they don't have the facilities. And then they're limited in what they're allowed to spend. Basically, decisions on what treatments you're going to access are decided by the administration of the hospitals.

Everyone's constrained by funding. Money's being taken away from services. We've spent all these years working and being told the country would look after you – and you could do this and do that – and what happens when you need the services? All of sudden, they've got different priorities, and all the hard work you've done for years is for nothing. We spent all these years working and slugging our guts out – putting everything away to make sure we had our home, make sure we wouldn't be dependent on public housing, try and do as much as we can for ourselves – and now I can't get any help with my home.

You've got to laugh about it, otherwise you'll cry. But what else can I do?

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