



**Health Issues Centre**  
Consumer voices for better healthcare

**Health Issues Centre**

**Submission to the  
Inquiry into Chronic Disease Prevention and  
Management in Primary Health Care**

*August 2015*



**Health Issues Centre**  
Consumer voices for better healthcare

Level 8  
255 Bourke Street  
MELBOURNE VIC 3000

Phone: (03) 9664 9343  
Fax: (03) 9663 7955  
[www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)  
[info@healthissuescentre.org.au](mailto:info@healthissuescentre.org.au)

## EXECUTIVE SUMMARY

Health Issues Centre consults with consumers in order to represent their perspectives (informed by lived experience) on key health matters.

While there is a growing momentum for the health system to become more consumer centric based on person centred practice and engagement pathways that involve consumers in service design and program delivery, these principles are yet to be applied to the process of system review.

It stands to reason that the effective engagement of consumers and carers at the beginning of a reform process will result in their better understanding of and subsequent compliance with health prevention and management initiatives.

We suggest that creating pathways for consumer participation should not only be a core output of the inquiry but should be adopted as a core principle of the inquiry process.

Our conversations with consumers identified a significant disenchantment with both the inquiry process and the prospect of meaningful and enduring change. Consumers cited previous inquiries and examples of successful pilot programs that failed to become entrenched. They view their designated role as to be adaptive to the consequences of review rather than partners in the review process.

We submit that a good chronic care system promotes informed activated consumers, prepares proactive health professionals and reflects a well organised health care system, one with a delivery system designed to provide systematic planning, delivery and coordination of care that is responsive to community and individual needs.

## THE CONSUMER LENS

Health Issues Centre (HIC) welcomes the opportunity to provide input into the *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*.

HIC works with consumers, carers and citizens to channel their unique insights and experiences as health service users in order to create a better health system for everyone. HIC actively promotes the involvement of consumers and the community in shaping policy and practice. In this regard we note the inherently limiting nature of the Terms of Reference in framing this discussion from a systems perspective. As its key stakeholders, consumers apply a different lens when evaluating the health system - theirs is a perspective defined by lived experience not by structural reform.

It is through this consumer lens that we respond to this consultation paper albeit there has been insufficient time available for the broad and in-depth consultation good practice would dictate.

Addressing the challenges posed by chronic disease prevention and management is not a new discourse for consumers. The core systemic change and investment commitments needed to make a difference have been well articulated not least of all in the Commonwealth's *"Building a 21st Century Primary Health Care System: Australia's First National Primary Health Care Strategy, 2010"*. Many of the recommendations outlined in this document were adopted in the National Chronic Disease Strategy produced by the Commonwealth in 2005. Furthermore, current overlapping inquiries including the Ministerial *Healthier Medicare Initiative* with specific attention to chronic care through

its *Primary Health Care Advisory Group* as well as broader reviews such as the work of the *Reform of the Federation* Task Force are contributing to a sense of “review déjà vu”.

Many consumers are veterans when it comes to engagement with health care reform and some with whom we consulted for this submission felt disinclined to participate in what they perceived as a ground-hog moment. Others alluded to ‘review fatigue’ whereby the various past reviews and subsequent changes of the whole health system across all jurisdictions has contributed to greater complexity, frustration and anxiety among consumers and their carers.

There have been many initiatives over the past decade that have focussed on providing more client centred care and improving integration and coordination of care. These initiatives have often been project based with differing funding models that are usually time bound. This has been a source of confusion and frustration for consumers as the randomness of project based funding often results in some consumers having access to services whilst others don’t. Or just as consumers and service providers become familiar with a service, funding changes and those services are withdrawn or modified. They cite many examples of proven programs that were nonetheless withdrawn with little or no input or evaluation from consumers and carers.

This leads to concern that yet another package of measures will leave consumers once again scrambling to adapt to outcomes designed in their best interests but without their collaborative input leaving them with little confidence that the reforms will be enduring.

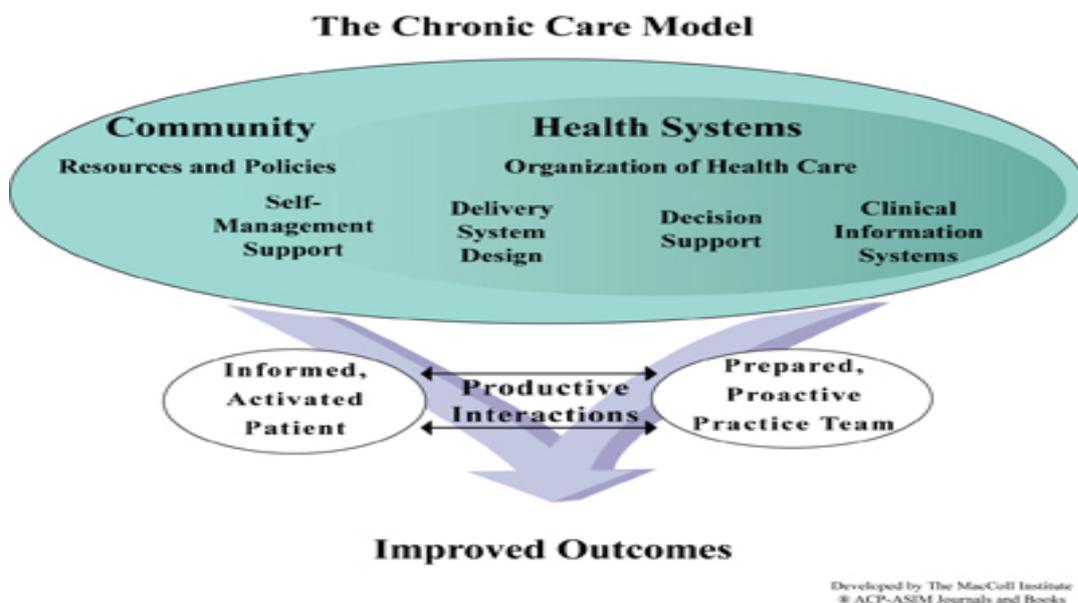
Apart from their concern over the process of reform, consumers also express cynicism regarding preventative health initiatives. While governments acknowledge the discounted future cost of precautionary measures taken now, this foresight invariably takes a back seat to the immediacy of service delivery demands and budget constraints. We acknowledge the disappointing reality that prevention and better management need to be delivered through innovation within a contracting funding envelope. While that is challenging it also creates an opportunity for new paradigms. Hence rather than proposing incremental improvements through service delivery efficiency we approach this discussion with the proposition: “What happens to chronic disease prevention and care if you redefine the roles and relationships between the key stakeholders (clinicians, carers and consumers)?”

It seems that what needs to change is clear and relatively uncontested. Single, integrated multidisciplinary care plans, greater attention to preventative initiatives, price signals that reward prevention and early intervention and an enhanced role for consumers in managing their own affairs and co-designing program solutions. The indispensability of consumer input to inform and shape that change is not however embedded in the reform process. It stands to reason that the effective engagement of consumers and carers at the beginning of a reform process will result in better understanding of and subsequent compliance with health prevention and management initiatives.

There is a general acceptance that adopting a patient and carer centred approach to service delivery and creating opportunities for consumers to participate in system design leads to improved safety and quality and delivers efficiency and productivity dividends. We suggest that creating pathways for consumer participation should not only be a core output of the inquiry but should be adopted as core principle of the inquiry process.

## BEST PRACTICE CHRONIC CARE

The model below from the Improving Chronic Care group in the US has become a highly accepted model for looking at how chronic care can be improved. The key premise of the model is that to get improved outcomes in chronic care, consumers need to be informed and activated. This requires a prepared and proactive health care team and a well organised health care system. Wagner and colleagues (authors of the model) argue that even if health professionals are well trained and skilled to provide good quality health care, if the structure they are working in is flawed *“People behave badly in badly structured and badly performing systems ... when [organisational] transformation is authentic and real, the biggest improvement is in staff joy in work, staff satisfaction and, associated with that, staff behaviours improve without extra training or incentives.”*



The chronic care model suggests that to promote informed activated consumers and to have prepared and proactive health professionals you need a well organised health care system, one with a delivery system designed to provide systematic planning, delivery and coordination of care that is responsive to community and individual needs.

## Co-ordinated care requires a co-ordinated system

The biggest challenge we are facing in Australia is that we don't really have a system so much as a range of disconnected health providers such as hospitals, general practice, specialist services and a variety of home and community care providers. Through this maze it is the consumer who must fashion their own health care system by coordinating their care across providers. This works for some but for many it is time consuming, stressful and expensive.

The chronic care model suggests that for consumers to be informed and activated they need a clear point of entry into our health care system, their needs identified and a collaborative care plan developed (ie worked out **with** the individual not **for** the individual). If they need to access services from other organisations this should be facilitated to allow ease of access, sharing of information, clear and consistent communication and integration to provide complimentary care.

We have seen a number of initiatives to improve the planning of care for people with chronic conditions particularly in relation to a greater recognition of the need for care plans such as the introduction of MBS items to improve care planning in general practice, Individual Recovery Plans (IRPs) in Mental Health and Goal Directed Care plans in Aged Care. Unfortunately because of our fragmented health care system this can often mean someone with a chronic condition may find they have 2-4 different care plans. In most cases they will have had minimal input into the care plan and in the majority of cases there will not be an attempt by the organisation to share care plans or ensure that there is consistency between them. All too often this leaves people overwhelmed, eroding their confidence and often leading to people disengaging with health care.

In principle the philosophy and model used in Mental Health Partners in Recovery Program (PIR) provides a beacon of what we can aspire to. PIR aims to ensure services and supports for people experiencing severe and persistent mental illness with complex needs are matched to the individual's needs. The program aims to facilitate better coordination of clinical and other supports and services to deliver **'wrap around'** care, individually tailored to the person's needs. This model involves providing individuals with a support worker who works with them to develop IRP that focuses on the individual's goals and supports them to remain well. The prevalence of chronic health conditions is far higher in those experiencing long term mental health issues and so whilst the PIR program may be a beacon for how we can provide a more consumer focused approach to care there is still considerable fragmentation of care. For clients of the PIR program their physical health care needs are mostly provided by General Practice and whilst care planning processes have improved in many general practices, the capacity of general practice to articulate their care plans with other providers is very limited. There is a variety of reason for this including lack of remuneration, no organisational relationship, poor management skills and incompatible IT systems.

General Practice remains the key access point for health care for most people with a chronic condition. Even for individuals that have only one physical health condition (which is not the case for the majority of people with a chronic condition) what is currently on offer from general practice is unlikely to meet the needs of people with a chronic condition.

## The foundations of good care planning

The Chronic care model sets out the care that we should be aspiring for:

- A focus on active aging and managing life with a chronic condition;
- Assessments that focus on the individual and the problems as perceived by them;
- Care plans based on client identified goals;
- Emphasis on skill development and building self-confidence;
- Client focused, services configured around a person's needs;
- Systematic follow up and early intervention;
- Greater involvement of clients in planning and delivery of programs;
- Focus on integrating care across services;

This vision highlights the need to take a more holistic approach to health care, understanding that to support individuals to be active partners we need to provide care that focuses on keeping them well rather than waiting to treat an illness and care that supports people to manage the social as well as the physiological aspects of their health. The evidence would suggest that skill development and building self-confidence is best achieved by helping people manage the changes to their life roles and relationships that occur when they have a chronic health condition. This involves developing a care

plan that focuses on their goals, working with them to develop actions to achieve those goals, providing information tailored to their needs and linking them with others experiencing the same issues. This is likely to require access to a range of services and interventions that are beyond the skill and scope of general practice and hospitals. Nor has general practice been able to demonstrate a capacity to coordinate this process due to the constraints previously mentioned.

NGO condition specific organisations provide very valuable information and some services that many individuals access to supplement the care they receive from fee for service providers. But this is reliant on individuals having the resources to seek this help themselves. We also have the situation whereby those with more than one chronic condition are forced to access information from multiple points and to assimilate that information into a plan of action that is coherent and meaningful for them.

## REDEFINING STAKEHOLDER ROLES AND RELATIONSHIPS

Within the constraints of our current fragmented system, how can we redefine the roles and relationships between the key stakeholders in chronic disease care to meet the vision of care we have articulated above?

### **A focus on active aging and managing life with a chronic condition**

- Consumers are consulted to understand what is needed to achieve this
- General Practice is reimbursed for providing proactive care
- PHNs work with local suppliers to ensure appropriate services are available within their region and to ensure GPs are aware of and refer to preventative health care services
- Private health insurers reimburse costs for preventative health actions

### **Assessments that focus on the individual and the problems as perceived by them**

Currently for most health care services assessment is based on identifying the deficit that their service can fill. For example general practice and specialist medical services undertake a physical health assessment to identify areas that they can “treat”. This process often provides a very narrow picture of the issues confronting the individual and often fails to address the real problems as perceived by the individual.

For an individual with a number of health conditions this can often involve a number of assessments – involving much of the same information and test and all too often no sharing of data to minimise this process for the individual.

PHNs could play a role in developing common assessment processes across services that would reduce duplication, support the development of care pathways based on identified needs and better alignment of resources.

### **Care plans that focus on client identified goals**

This necessitates a single common care plan that all providers contribute to and share. Our current funding models provide little incentive to providers to join up their care. Incompatible IT systems and lack of a common health care record are additional barriers as are outcome measures that focus on delivery of service rather than consumer outcomes.

## **Emphasis on skill development and building self confidence**

This requires health care providers to work in partnership with the individual and their carers and health professionals. Providing a service and complimentary programs that can support individuals to:

- Know their condition and various treatment options
- Negotiate a plan of care
- Engage in activities that protect and promote health
- Monitor and manage the symptoms and signs of the condition
- Manage the impact of the condition on physical functioning, emotions and interpersonal relationships -

Community Health is well placed to provide these complimentary services but not sufficiently resourced and not well coordinated with general practice.

## **Systematic follow up and early intervention**

Current funding and care models still focus on episodic care. There is no incentive for proactive or early intervention. There is a role for GPs to work in partnership with Community Health to provide a more holistic approach to all aspects of follow up and early intervention .

## **The role of the Medicare payment system**

More than 90 per cent of primary health care funding in Australia is paid on a fee-for-service basis, with less than 10 per cent linked to quality of care (eg the Practice Incentives Program). The system incentivises greater levels of service provision however not population health outcomes or value for money and it encourages supply-driven demand. There are numerous examples around the world where innovative funding models have contributed to improved outcomes and consumer experience whether through capitation, payment for outcomes or hybrid models including some fee-for-service

The first step in this move away from payment per consultation is to recognise that the current model generates perverse outcomes. There is an opportunity to refocus the work of GPs toward prevention by changing the model of financial incentive.

General practice is still the centre of care however Medicare could drive a more integrated approach by recognizing a broader spectrum of skills and incorporating a range of disciplines in treatment. We acknowledge the trend in Aged Care & Disability to shift funding (and therefore health management responsibility) to individuals. A similar approach should be considered for chronic disease management.

## **The role of Primary Health Networks**

The establishment of PHNs provides an opportunity to bring a high level focus to the co-ordination and support of chronic disease prevention and management over fairly large geographic areas. There is a need however to ensure that there is capacity for smaller local coordination, relationship building and knowledge sharing. PHNs will need to link in with smaller locally based integration and coordination efforts and build their capacity rather than impose or overlay a higher order agenda.

There is real opportunity for PHNs to take local learnings and identify shared understandings about common themes, needs and capacities in integrated care and build that knowledge up to inform a more general, higher level way forward.

If PHNs are to have an impact in the prevention space there will need to be a focus placed on population health planning rather than service level planning. If a population health focus is applied it should be grounded in preventing disease based on responding to the key social determinants and risk factors that lead to and exacerbate chronic illness and complex health concerns.

PHNs should seek to engage more with community health or other primary health care organizations however they would be better suited in a GP liaison role rather than as providers of care. PHNs might play a part through the provision of incentives to GPs around identified potential population health risks and by working across catchments to mitigate them.

We also highlight the opportunity for PHNs to become the funder/trainer for a care coordinator role within GP practice. Such funds should be located where the best service can be provided according to the principles of right care, right time, right place.

### **The role of private health insurers**

According to data provided by Medibank Private, payments for chronic disease related claims (where the chronic disease was the primary reason for hospital admission) have almost doubled from \$332 million 10 years ago to \$600 million. The top three chronic diseases paid out were osteoarthritis, coronary heart disease and depression.

It is clearly in the interest of private insurers to invest in preventative health through a strong link with primary health organizations or providers to promote tertiary prevention on chronic condition. There is no doubt that through the judicious application of a range of price signals, the private sector can affect positive change to prevention and management. Incentives could include:

- Prevention programs offering incentives to reduce occurrence and or prevent/ reduce decline.
- Developing education programs in partnership with health practitioners targeting consumers and carers at risk
- Offering reduced private health cover rates to consumers who actively demonstrate efforts at remaining healthy or as healthy as possible
- Offering incentives for prevention and for reduction in hospital presentations
- Initiating and supporting psycho-social programs for people with cancer and other chronic conditions

### **The role of State and Territory Governments**

All state and federal chronic care policies focus on improving the integration of care. There are many examples of how this has improved individual programs but we are yet to see system wide approaches that target the whole population. Government clearly has a unique role in reducing duplication and administration overheads for programs straddling different tiers of government.

State governments can provide an important leadership role in identifying and minimizing system barriers to the implementation of effective and efficient prevention and practice.

Government leadership and support is particularly needed to unpack and respond to barriers that naturally arise when different services/agencies within or between sectors are trying to provide shared care responses. Funding models, policy, quality standards and reporting requirements need to reflect these challenges. Training for individuals is critical but equally important is resourcing and supporting processes for implementing and sustaining organizational and system change. These higher level changes need to occur over time to ensure integrated and coordinated approaches to complex issues including risk management, communication difficulties, differences in philosophical and service delivery and care requirements.

### **Innovative models**

The E Care Planning work being undertaken by a number of Primary Care Partnerships across Victoria provides a model of integrated chronic and complex care that improves communication between health providers, creates a shared framework for planning and acting to implement care responses (eg development of shared goals, identification and documentation of clear roles and responsibilities, common health outcomes and shared review processes).

This project is also working towards improving electronic access for clients and carers so they are more easily able to participate in a dynamic way in the development and implementation of their shared Innovation. Efficiency is welcomed, ensuring the complexity of client presentation and demands on the allied health worker when working in primary health care is acknowledged.

### **Best practice Multidisciplinary teams**

The changes to the MBS items that provide support to general practice to develop care plans and coordinate team care arrangements along with access to subsidised allied health appointments are changes that have been built into our health care system and are theoretically universally available to everyone with a chronic condition. Despite this there is still significant variability across general practice in relation to the uptake and implementation of these items into routine care for people with chronic conditions. This variability along with the limited capacity of most general practices to take on the coordination role many people with multiple chronic conditions require and desire should lead us to look for other strategies/players to supplement the care that general practice provides rather than continuing to ask more of an already stretched and limited resource.

### **Acknowledgement**

This submission has been authored by Sophy Athan (Chair), Marie Gill and Danny Vadasz (CEO) of Health Issues Centre with input provided by the Outer East Primary Care Partnership based on discussions held with the providers of chronic disease services in the Primary Health area of EACH Social and Community Health.