

Submission

4 September 2015

'Better Outcomes for People with Chronic and Complex Health Conditions through Primary Health Care'

Purpose: To inform people living with HIV (PLHIV), the NSW Ministry of Health and NGO HIV sector partners on the Positive Life NSW position in relation to the Commonwealth Inquiry into *'Better Outcomes for People with Chronic and Complex Health Conditions through Primary Health Care'*.

Background/Context: On 4 August 2015, the Australian Government released an options discussion paper *'Better Outcomes for People Living with Chronic and Complex Health Conditions through Primary Health Care'*. The Government announced that it was committed to finding better ways to care for people with chronic and complex health conditions and ensuring they received the right care, in the right place, and at the right time.

The Primary Health Care Advisory Group asked a series of questions via an online portal to examine options for health reform and to provide a report to the Australian Government in late 2015. A response was provided on 3 September 2015 and the principal points are detailed below. The response is framed in relation to people with HIV (PLHIV) with chronic and complex health conditions and is based on consultations with community. It should be noted that there was a word limit to questions, so the Positive Life NSW responses do not cover all issues that we would have liked to raise with the Primary Health Care Advisory Group.

Inquiry questions and responses:

Overall

1) "What aspects of the current primary health care system work well for people with chronic or complex health conditions?"

- PLHIV have close working relationships with their accredited (s100) primary health care providers. They rely on them to manage their HIV clinical care and other chronic and complex health conditions. There are 121 s100 accredited prescribers in NSW providing specialist care to approximately 10,800 diagnosed PLHIV. These specialist primary health care providers manage the clinical care of PLHIV. This includes the clinical management of HIV and other chronic and complex health conditions experienced by the PLHIV. They diagnose, treat, monitor and refer to other specialists, community care teams and allied health care services. Without access to quality health care, PLHIV would experience rapid HIV disease progression, morbidity and mortality.
- The relationship between the primary health care provider and the person with HIV is an extremely important one built on trust and confidence in the ability of the health care provider to effectively manage HIV and other chronic health conditions. Once trust is established, PLHIV often stay with the same primary health care provider for long periods of time and report significant distress when they are forced to change provider due to a change in their circumstances or the primary health care provider's.
- s100 accredited primary health care providers have extensive knowledge and experience in HIV clinical management and access pathways to specialist and allied health care services in their local areas. Shared care arrangements between s100 accredited doctors and non-s100 accredited GPs is used where access to s100 primary health care providers is unavailable, difficult, or limited. In these cases, HIV clinical care can be co-managed with support from the s100 prescriber while the GP manages other chronic health conditions. Good communication between health care providers

is an established process in shared care arrangements for PLHIV with chronic and complex health conditions and can work well for PLHIV.

- Some PLHIV with chronic and complex health conditions are fortunate to have care coordination support from specialist HIV community outreach teams. These teams work with PLHIV, primary health care providers and other health care specialists to develop patient centred case management plans that meet the specific needs of the individual. Access to HIV Community Outreach Teams for rural and regional PLHIV is more difficult.

2) *“What is the most serious gap in the primary health care system currently provided to people with chronic and complex health conditions?”*

- There is limited availability of primary health care providers in regional and rural areas with experience in treating PLHIV and PLHIV with chronic and complex health conditions. There are gaps in allied specialist health care (e.g. HIV community outreach teams and specialists in general) and in experienced mental health services. Consequently PLHIV in regional areas are forced to travel to Sydney for specialist treatment and care (other chronic and complex health conditions).
- There is a gap in affordable dental care. The Medicare Chronic Diseases Dental Scheme provided significant benefit to people with chronic disease and PLHIV in particular. Since its closure, the oral health of PLHIV has been negatively impacted. Poorer oral health has a flow on effect to general health, nutrition, mental health and employment participation.
- There is a gap in health service provision for people with mental health and psychiatric conditions. PLHIV with mental health and psychiatric conditions can experience memory loss, confusion and behavioural abnormalities, particularly those experiencing HIV-related neurocognitive impairment and/or psychiatric conditions. Challenging behaviours are frequently misunderstood by health care service staff and the implementation of a ‘Zero Tolerance’ policies in response to these behaviours can result in a health care service being withdrawn and people having no access to essential treatment and care. A duty of care and better care coordination is required to make sure these people are retained in care and not refused health care.
- Community surveying by Positive Life has identified that 60% of PLHIV have one or more chronic health conditions in addition to HIV and 25% have 3 or more health conditions in addition to HIV. These rates are significantly higher than the HIV-negative and/or general population. PLHIV with multiple chronic and complex health conditions often need significant levels of care coordination and referral to other health care services. If the primary health care provider does not have the time, interest or skill to effectively manage chronic disease, referrals are delayed, health care information sharing is impaired, errors are made, access to timely treatment and care is missed and patient health outcomes become worse.
- There is also a gap between primary health care, Centrelink and support for people needing access to public or community housing. PLHIV with mental health, neurocognitive issues and drug and alcohol use often struggle to engage with public housing application processes and to sustain a tenancy. Homelessness amongst PLHIV is an ongoing concern and often leads to disengagement with health care, non-adherence to HIV and other medication and risk of onward transmission of HIV.

3) *“What can be done to improve the primary health care system for people with chronic or complex health conditions?”*

- The health literacy of PLHIV with chronic and complex health conditions varies across a spectrum of ability. Language barriers and cultural sensitivities impact on communication between primary health care providers and people with chronic and complex health conditions. PLHIV want to work in partnership with primary health care providers and develop skills to better understand chronic disease self-management. However, the current system does not support PLHIV with chronic and complex health conditions to easily improve health literacy, and self-advocacy and navigational skills. More resources need to be allocated to improve the health literacy, navigational skills and

self-advocacy of PLHIV in NSW so they can manage their health care in partnership with their primary health care provider.

- The utility of the *My Health Record* (formally the PCEHR) has the potential to help people with chronic and complex health conditions to manage their health care records and better communicate their health care needs with primary health care services. The *My Health Record* is underutilised and more work needs to be done to educate people with chronic and complex health conditions about the benefits of EHealth records.
- Better use could be made of funded specialist NGO consumer organisations (for example Positive Life NSW) to provide information, support and navigational guidance to people with HIV with chronic and complex health conditions who struggle to understand access pathways for a complex health system.
- Greater emphasis needs to be placed on educating primary health care workers to manage and co-manage PLHIV with chronic and complex health conditions (including shared care arrangements). The population of PLHIV is growing and maintaining access to HIV accredited (s100) primary health care providers is becoming increasingly challenging.
- Health care planning for PLHIV is becoming more about process than outcome. For example – “if we do this care plan you can have six appointments with your psychologist” – rather than, “this care plan is a mechanism through which we are going to coordinate your care and work towards your short, medium and long term objectives”. A decoupling of care planning from Medicare billing incentives for practitioners should be considered.

4) *“What are the barriers that may be preventing primary health care clinicians from working at the top of their scope of practice?”*

- People with chronic and complex health conditions and their primary health care providers experience barriers and structural limitations. Many of these barriers are due to Medicare item numbers and restrictive Medicare policies.
- Cost barriers impacts on access. PLHIV who experience higher rates of multiple chronic health conditions often struggle to have sufficient time to discuss HIV and other chronic and complex health care needs in the time limits of a standard primary health care consultation. The more chronic health conditions PLHIV have, the more challenging health management becomes. PLHIV are in some cases unable to meet the cost gap for a double/triple consultation that may be necessary to cover all health issues. Consequently, monitoring of chronic conditions and discussions about emerging health conditions can be delayed, deferred or even forgotten. In the interim, health conditions are not monitored and may become worse and lead to hospitalisation.
- There is also insufficient resourcing of primary health care providers. The assumption is that when new health initiatives or systems are introduced, that the primary health care providers will carry and absorb the extra costs. This is unrealistic in a small business model.
- PLHIV and homosexually active men are at elevated risk of anal cancer from infection with high risk HPV16. Early detection of anal cancer is critical to reducing anal cancer morbidity and death. High resolution anoscopy (HRA) diagnostic services are the most effective means of confirming diagnosis of anal cancer in high risk groups. Access to high resolution anoscopy services is limited and there are extensive waiting times for HRA in areas with concentrations of populations at high risk of anal cancer. Currently primary health care providers have limited options to refer people with anal symptoms for HRA diagnostic services and there is no Medicare item for HRA procedures.

Effective and appropriate patient care

5) *“Do you support patient enrolment with a ‘health care home’ (where patients enrol with a single provider which becomes their first point of care and coordinates other services) for people with chronic or complex health conditions?”*

- Yes, as long as that service is appropriately resourced and staffed by experienced nurse practitioners who have expertise across a spectrum of care needs for people with chronic and complex health conditions.
- Enrolment with a primary health care provider has been the standard of care for PLHIV and people with HIV and chronic and complex health conditions since the mid-1980s. The primary health care provider coordinates other health care services for PLHIV. The specialist primary health care provider arranges access to testing, diagnosis, advice, HIV treatment and care plans, and coordinates ongoing monitoring and treatment of acute and chronic health conditions, as well as referral to other specialised HIV and support services.

6) *“Do you support team based care for people with chronic or complex health conditions?”*

- Yes, with acknowledgement that the health consumer is expert in their health care and should be considered to be central to, and head of, their care team.
- About 300 PLHIV in Sydney with multiple chronic and complex health conditions are case managed or case coordinated between primary health care providers and specialist HIV community outreach teams in a shared care arrangement. The HIV community outreach teams provide access to home nursing staff, social workers and occupational therapists. These staff support PLHIV to organise and attend medical appointments, access other specialist services and adhere to HIV and other treatment regimens. In addition, about 60 PLHIV in NSW who have HIV-associated neuro-cognitive disorder and psychiatric conditions are case managed by Adahps (formally the AIDS Dementia and HIV Psychiatry Service). Both services are able to cross traditional service delivery boundaries to effectively deliver integrated care and provide team based care and access to specialist services. This model works well for PLHIV with chronic and complex health conditions and may have applicability for other disease groups where there are high population concentrations.
- The use of ‘Zero Tolerance’ policies for people with challenging behaviours can produce a range of retention and care issues that become difficult to solve. The problem has been that no effective alternate care pathway have been organised or implemented and no services have been willing to take responsibility and coordinate care. In these circumstances people with chronic health conditions and behavioural issues are unable to access treatment and care, experience worsening health outcomes and can be lost to follow-up unless a solution can be brokered with a health care service to reengage them in care.

Increased use of technologies

7) *“What enablers are needed to support an increased use of technology to improve team-based care for people with chronic and complex health conditions?”*

- Case conferencing across disciplines, monitoring individuals’ health, long distance consultations with a GP or Nurse Practitioner present with the patient. Apps that access risks for falls/frailty, social isolation, nutrition etc., and that report back to the primary care provider.
- Poverty can impact on access to and use of technology. Some PLHIV are not able to afford smart phones or high speed internet services. In addition, Internet access and download speeds are an issue in some rural and regional areas. Technology subsidies could be explored to increase access and uptake of technology devices for people with chronic and complex health conditions. Expansion and greater awareness of public library facilities may be a cheap method of improving access for these populations.

8) *“How could technology be used to improve patient outcomes?”*

- The use of *My Health Record* allows PLHIV to not only share vital health information with members of their health care team, but to also decide which members get access to which particular sections of their health record. Endlessly repeating complex medical histories to new

health care providers is time consuming, emotionally distressing and inefficient. Campaigns promoting the benefits of EHealth records would increase uptake of the *My Health Record*. In addition, we have received consumer feedback that registering for a *My Health Record* is not a straight forward process and people have given up rather than persist with the difficult online registration process.

- PLHIV with mental health, neurocognitive impairment and drug and alcohol issues may experience difficulties remembering to raise issues with the doctor, adhering to medication and organising and attending medical appointments. The use of smart phone apps and SMS has been shown to improve communication between primary care providers and PLHIV with chronic and complex health care needs, particularly in relation to test results, appointment reminders, and medication adherence reminders.
- Access to mental health services (counsellors and psychologists with experience of HIV-related issues and LGBTI issues) is limited in rural and regional areas, with most specialist counselling services in NSW being Sydney-based. The use of web-based technologies to provide face-to-face access to experienced counsellors and psychologists would greatly assist PLHIV to gain access to mental health services in acute, chronic and crisis mental health situations.
- Access to affordable technical diagnostic devices (such as point of care and home-based testing devices and blood pressure machines etc.) would significantly improve the capacity of PLHIV to better self-manage a range of chronic health conditions.
- Increasing community understanding of weekend and evening access to phone doctors/nurses and the GP2U service would increase self-management of chronic and complex health conditions and reduce the need for face-to-face consultations, accident and emergency attendance and produce greater health system efficiencies.

Measuring outcomes

9) *“Is it important to measure and report patient health outcomes?”*

- Yes, but also acknowledging that outcomes will be short, medium and long term and that what is considered to be an achievable outcome for the consumer may not be what the health care provider/health system has in mind as an optimal outcome. However, it is still an outcome and a progression toward better health.
- If there is no improvement in health outcomes, people with chronic and complex health conditions become disengaged, withdraw from care and go on to develop further co-morbidities and poorer health outcomes.
- It is important for a ‘patient centred approach’ to health care to be front and centre in any health care interaction.

10) *“How could measurement and reporting of patient health outcomes be achieved?”*

- Most PLHIV with chronic and complex health conditions have chronic disease management plans (GP Management Plan and Team Care Arrangements) to coordinate multi-disciplinary care. These plans have short, medium and long-term health goals with agreed outcomes between the primary health care provider (usually a GP) and the patient. Reviewing outcomes against the plan on a regular basis is one way of measuring outcomes. In our experience, the reviewing of GP Management Plans and Team Care Arrangements rarely happens. Once the PLHIV has signed off on the plans it is seldom referred to again. There needs to be a process where people with chronic and complex health conditions are more engaged in the planning process and are given time to consider the plan and what has been agreed to.
- Complaints and disputes between primary health care providers and patients can also be useful to identify problems and point to potential systemic solutions.
- In addition the introduction of meaningful involvement of health consumers in the development, implementation and evaluation of health care services (National Standard 2) is crucial in making

sure that health services are responsive to consumer needs and that health services work towards a patient centred approach to health care.

11) *"To what extent should health care providers be accountable for their patients' health?"*

- This should be a mutually agreed upon target/outcome.

12) *"How could health care provider's accountability for their patients' health outcomes be achieved?"*

- Patient feedback is a powerful indicator of achievement. Patients with chronic and complex health conditions can be asked by the primary health care provider to contribute feedback as to whether their health care needs have been/are being met. The process needs to be a simple and meaningful one. Too many layers of complexity will lead to the process becoming burdensome for both the patient and the primary health care provider.

13) *"To what extent should patients be responsible for their own health outcomes?"*

- This is a matter of negotiation between the primary health care provider and the patient.

14) *"How could patient responsibility for their own health outcomes be achieved?"*

- PLHIV with chronic and complex health conditions are entitled to the same human rights as everyone else, including the right to access appropriate services, self-determination and participation in decision making affecting their health care and quality of life. Better educated health consumers, will lead on to better health outcomes at individual and community levels. PLHIV with chronic and complex health conditions should be considered equal partners with their primary health care providers when managing their chronic health conditions.

15) *"Do you have anything to add?"*

- Positive Life NSW considers that there is a strong case for the introduction of policies/mechanisms that provide improved and affordable access for people with chronic health and complex health conditions, particularly those with multiple chronic health conditions. This might be described as a *"Chronic Diseases Health Care Access Card"*.
- The cost of clinical care and polypharmacy for people with chronic health conditions is a significant lifelong burden and the more chronic health conditions people have, the more difficult and costly health maintenance becomes. It is particularly burdensome for people who are unable to work full-time and who are living on low incomes and do not have a Health Care Concession Card. They have to meet a considerable cost gap between the fee for service and the Medicare reimbursement for multiple visits to their primary health care provider each year. They also are required to meet the cost associated with access to specialists, who rarely bulk-bill.
- In addition, an access improvement scheme could provide weighted Medicare rebated consultations, where people with more than one more chronic health condition could have additional weighted consultation time at a subsidised cost to address their complex clinical and other care and referral needs.
- Currently, PLHIV and other people with chronic health conditions get some benefit from the PBS Safety Net; however there is no safety net for costs associated with primary health care. Private health insurance has not been widely taken up by PLHIV with chronic and complex health conditions. This is due in part to the high proportions of PLHIV who access Public Funded Sexual Health and HIV Specialist Clinics which are free services. It is also due to the 12 month claims deferral period for people taking out private health insurance with pre-existing conditions (such as HIV).
- There needs to be an acknowledgement that the consumer is more than a mere active partner in the coordination of their care, and is in fact, an expert in their own care and best placed to

coordinate care (subject to the caveat that each consumer will have different levels of capacity and expertise).

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