# Consumer and provider engagement: people with complex needs

In September 2017, Dr Nancy Sturman conducted focus groups with 12 men currently or recently residing in a central Brisbane homeless hostel to understand their experience of accessing care in the health system. Following this, Dr Sturman and Prof Don Matheson conducted two focus groups with primary healthcare providers (general practitioners, nurses and a physiotherapist) to understand their experience of delivering healthcare to people with complex needs.

## Summary of findings

Mainstream services appear to be responding to the needs of these clients with variable effectiveness. In many cases excellent care is provided, but there are also credible reports of less effective and less compassionate care.

Mainstream services, including both hospital and general practice sectors, appear to be under substantial levels of strain in responding to people with complex needs. The time and economic constraints under which both sectors operate present a major barrier to providing good care. Fragmentation and duplication of services also appears to be an important issue. Effective and timely communication between and within sectors remains difficult to achieve, although IT initiatives such as the GP viewer appear promising; more work remains to be done in achieving adequate communication between general practices, and in making general practice management plans available to hospital-based and other community services. Much of the additional work taken on by GPs who advocate for people with complex needs appears to be unpaid, and is not widely sustainable.

Many clients present reluctantly to health services, and report experiences of feeling “classed”, disbelieved, and even assaulted by security personnel, in emergency departments. Both people with complex needs and primary healthcare providers suggest that as a group, people with complex needs have a distinctive culture, and that mainstream service providers (including police, hospital security, and healthcare providers) often had little cultural awareness and training in responding appropriately, especially when people were unwell or upset. People with complex needs are often unsuccessful in navigating mainstream referral, attendance and follow-up pathways effectively. Patient-centred goals of care are important to articulate, and may differ from conventional goals for mainstream patients.

Clients reported presenting to emergency departments in the context of significant mental distress which they found difficult to articulate effectively. Primary healthcare providers suggest that mental illness was probably the key factor in frequent presentations to emergency departments, although most people with complex health and social needs, including severe and persistent mental illness, did not present frequently. GPs believed that a sustained, trusting relationship with a GP could improve health and wellbeing in this group, and reduce hospital presentations and admissions. The men who were interviewed reported variable expectations of, and experiences with, GPs. They appeared to be confused and frustrated by different approaches to prescribing across and within health sectors, especially for pain and anxiety, and reported adversarial encounters both in general practice and hospital sectors. The men appeared to appreciate a personal, caring case worker who made extra efforts to support and advocate for them, and volunteers who provided various forms of support.

## Discussion and recommendations

Some people with complex health and social needs may also have poor social, organisational and coping skills, and low health literacy and self-efficacy. As group, they tend to have high rates of mental illness, substance use disorders, and experiences of trauma and abuse, and they can be reluctant to seek healthcare, and sometimes have negative experiences when they do so. Training which takes a cultural awareness approach to the different perspectives, priorities, skills and mental state of these clients may assist workers across multiple sectors (including police, security, general practice and hospital services) to provide more effective care.

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Current health services are under strain in attempting to provide care to clients with complex health and social needs, and at times care appears to be ineffective and/or lacking in compassion and respect. The Frequent Presenters response out of the Royal Brisbane and Women's Hospital (RBWH) is an example of an effective organisational response, and responses which similarly support general practice and other sectors (ideally by extending across multiple sectors) are needed. A personal case worker who follows the patient across multiple sectors (including hospital, general practice and community sectors), providing support and advocacy, should be formally piloted for this population group.

There also appears to be room for improvements in communication and collaboration within and between health and social sectors, and recent successful IT initiatives should be further extended. There appears to be potential for reducing inefficiencies due to fragmentation and duplication of care, as well as improving the effectiveness of care. Mainstream services and processes (including referrals, appointments and follow-up) are less effective with this group, due to very high rates of non-attendance and transience. It may be helpful to formulate non-conventional goals for care which acknowledge the agendas and priorities of the people themselves, and either provide extra support to navigate through mainstream health systems, or develop more flexible and responsive processes for this group.


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