

REACHING OUT: Connecting with harder to reach older people in Central Victoria

A Literature Review



CENTRAL VICTORIAN
Primary Care Partnership

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1. Executive Summary

The objective of this paper is to identify effective strategies that promote the engagement of 'harder to reach (HTR)' older people in rural and regional Victoria by health and social services. It is based on a review of literature from publically available documents. The limited literature on older rural HTR people as well as the breadth of the topic resulted in a broad scoping review rather than an in-depth systematic review of a specific focused intervention or strategy.

The ambiguity of the term 'HTR' increases the complexity of defining and identifying the HTR groups. Broadly, HTR consumers are those who are inaccessible to most traditional and conventional methods of engagement and are categorised into three groups: minority groups, those who are unable to articulate their needs and 'slip through the net' and the service resistant. The success of strategies to engage and retain HTR consumers is important to evaluators, policy makers and service providers because these groups are often the main intended beneficiaries of early intervention and chronic disease management initiatives. They experience poorer health and lower health literacy and are not sufficiently engaged in system and program planning, nor adequately represented in system and program design in order to more effectively meet the needs of the most vulnerable. Many organisations and local government councils in particular, identify HTR populations using demographic definitions. These groups include people with health and social issues, minority ethnic groups, geographically isolated and sexuality, sex and gender diverse communities. The HTR risk factors are compounded in older people who have increased vulnerability due to increasing physical and/or mental frailty associated with ageing and chronic disease. It is also important to define characteristics of HTR groups looking at psychosocial characteristics that will provide a greater understanding of not only who these individuals are but also the reasons that they are not engaging.

Despite the strong policy direction at commonwealth, state and local government levels to support equity¹ of access and quality health care, health services are struggling to implement sustainable, integrated systems to facilitate the participation of HTR consumers. Health services are increasingly recognising that the responsibility of engaging with HTR consumers lies with the health system and considerable effort is required to break down the organisational barriers. These include: insufficient or poorly presented consumer information, cost, previous bad experiences with the service, negative staff attitudes, location and transport accessibility, complicated or inadequate organisational processes and systems, funding models, poor service integration and lack of partnerships.

Although there was limited information on strategies for engaging HTR consumers in the older population, the principles and learnings from other HTR groups are applicable and transferrable. Engagement of HTR consumers requires identifying and understanding who is the targeted group, what is the most appropriate method(s) to make contact, what is their

¹ equity in health means eliminating health disparities that are associated with underlying social disadvantage or marginalisation (Braverman and Gruskin, 2003)

motivation to engage (or not) and identifying any barriers to participation. The development of new relationships and implementation of innovative strategies to engage the target groups may also be required, as well as applying additional effort and resources. This should not be seen as a discrete, time limited project but a process to integrate inclusive practice into the normal organisational operational systems.

One of the most powerful enablers to engage with HTR consumers is treating them with respect and creating a welcoming environment. The quality of the relationship that develops between staff and consumers is dependent on trust and respect; being non-judgmental and being able to relate to and empower people. It also means acknowledging and respecting cultural differences. Services need to be flexible in their approach, for example, providing outreach services, listening to feedback, offering flexible opening hours and giving consumers the services they want. Partnerships and integration models are essential to reach consumers through referral practices and recommendations between services.

Many of the successful engagement strategies used volunteers and peer support to bridge the gap between the service provider and consumer. Other enablers include service location that is convenient, safe and familiar. A key strategy to engaging older people in health promotion initiatives is to market the activities as a social interaction opportunity. Effective communication strategies are essential; not only to engage HTR consumers, but also to maintain an ongoing relationship. Without such efforts, the service system will continue to reinforce existing patterns of social exclusion and disadvantage.

2. Introduction

The focus of this paper is to identify effective strategies that promote health and social services engagement of 'harder to reach (HTR)' older people in rural and regional Victoria. It is based upon a review of literature from publically available documents. However, given the paucity of research literature on HTR older people, a more general search examined the literature with other HTR populations including people with substance abuse, mental illness and vulnerable family populations.

Aged care services operate to meet the needs of frail older people and people of all ages with disabilities and their carers to keep them as well as possible and independent in their homes and communities (Victorian Department of Health, 2012a). Ensuring equity of access to appropriate aged care services for all Australians is a key component of the Australian Government's Aged Care Reform (Australian Government, 2012a). It is also acknowledged that certain groups are marginalised from services and therefore harder to reach for health services (Osborne, et al, 2013).

People aged 65 and over constitute Australia's fastest growing age group, increasing from 11.6% (1993) to 14.4% (2013). Victoria's population follows the trends seen in the wider Australian population. In 2011, 13.7 per cent of Victoria's population was aged 65 years and over (Australian Bureau of Statistics (ABS), 2011). By 2021, it is estimated that 16.7 per cent of the population will be 65 years and over (Department of Planning and Community Development, 2012). In Macedon Ranges Shire, the proportion of population aged 65 years and over in 2026 is estimated to be 20%. Similarly in Central Goldfields Shire and Mount Alexander Shire the proportion of older people in 2026 is estimated at 34% and 28% respectively (CVPCP, 2013).

With the growing proportion of older people, aged care services are looking at better and equitable ways of delivering services to their most vulnerable populations. There is a growing concern that this population is not being heard and not accessing support services. These populations are often referred to as "hard to reach". Generally, they have poorer health, lower health literacy and are poorly represented in consumer consultation and governance processes (Department of Health, 2012b).

3. Methodology

The short project timelines necessitated a rapid review approach. The objectives of the literature review are to identify the HTR older people in rural and regional Victoria, the contributing factors that sustain a 'harder to reach' status, enabling factors that promote engagement and identify opportunities that promote the physical, social and emotional wellbeing of HTR older people in rural and regional Victoria.

The limited literature on older rural people who are HTR as well as the breadth of the topic resulted in a broad scoping review rather than an in-depth systematic review of a specific focused intervention or strategy. To be comprehensive as a scoping review, the breadth of focus was considered justified and strategic. It insured there was provision for the complex, multi-faceted, inter-sectoral nature of the topic. Given the potential breadth of the topic it was acknowledged that the literature search could not be exhaustive.

The types of literature included were peer reviewed and grey written documents, with the aim of restricting the search within the last 15 year period, where possible. The following were included in the search:

- Systematic reviews on the engagement (recruitment) processes and strategies (interventions or methodologies) that addressed the health and wellbeing needs of those HTR across the breadth of the service system.
- Non-systematic reviews in the form of reports, guidelines, evaluations, editorials and commentaries were also included due to the nature of the project and focus on service system development, and the limited academic information available.
- Primary research studies evaluating effectiveness of engagement (recruitment) processes and strategies (interventions or methodologies) that addressed the health and wellbeing needs of the HTR across the breadth of the service system. This included both quantitative and qualitative studies.

The review only included written material that was published in English, using the following sources:

- Systematic review clearing houses (free library access): the Cochrane Library, the Effective Public Health Practice Project (Canada), the Evidence for Policy and Practice Information and Coordinating Centre (United Kingdom), the Campbell Collaboration; Centre for Reviews and Dissemination, York (United Kingdom) and the National Institute for Health and Clinical Excellence (United Kingdom)
- Internet search engines such as Google and Google Scholar
- Key websites such as: Australian government department websites; Age specific evidence reviews and knowledge hubs
- The review of references and citations within key literature or documents with project synergies (bibliography snowballing) was also used to ensure key elements, such as foundational theories, were included in the literature.

4. What does 'Hard to Reach' mean

Despite the growing use of the term 'HTR populations' by mainstream organisations and government bodies, there appears to be a lack of consensus about the meaning of the term (Flanagan and Hancock, 2010). The term HTR is used interchangeability with 'hidden' (Benoir, et al, 2005), 'underserved' (Lindenberg, et al, 2001) and 'marginalised' (Barlow, et al, 2005) to name a few. It is used broadly in relation to accessing services, awareness and educational programs, resistance to interventions, research sampling and community consultation. In the service delivery context HTR refers to those communities or groups which are "inaccessible to most traditional and conventional methods" (Health and Safety Executive, 1994).

A study found that the interpretation of HTR is influenced by factors such as the type of services being delivered, previous experience of working with different groups and locally defined priorities (Doherty, 2004). In a study by Doherty (2004) professionals from a range of agency backgrounds, including health, education, social services and the voluntary sector were interviewed and three main definitions were found to be applicable to all participants.

These were:

- **Minority groups:** The traditionally under-represented groups, the marginalised, disadvantaged or socially excluded. This includes service users who fall into well-

used categories, often linked to population characteristics, such as minority ethnic groups, Aboriginal and Torres Strait Islanders (Aboriginal), travellers or asylum seekers, gays and lesbians or homeless.

- **Slipping through the net:** The overlooked, 'invisible' or those unable to articulate their needs. This includes those caring for others, those with mental illness, cognitive and communication limitations. This may also include people who fall just outside the statutory or usual remit of a service provider.
- **The service resistant:** Those unwilling to engage with service providers, the suspicious, the over targeted or disinterested. This includes people who are distrustful and potentially hostile to service providers, possibly due to a link to drug use, alcohol abuse or criminal behaviour or people with mental illness. It may also include those people that do not believe that the service is of value to them.

5. Policy Context

The Australian Government aims to ensure that all frail older Australians have timely access to appropriate care and support services as they age, by providing: information assessment and referral mechanisms, needs-based planning arrangements, support for special needs groups and for carers, a choice of service types and high quality, accessible and affordable care through a safe and secure aged care system (Australian Government, 2012b).

5.1 Australian legislation

One of the objectives of the Aged Care Act 1997 is to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location. The Act recognises that there are groups of people with special needs that may find it difficult to access aged care information and services and receive appropriate care. These include: Aboriginal people, people from culturally and linguistically diverse (CALD) backgrounds, people who are veterans, people who live in rural or remote areas, people who are financially or socially disadvantaged, people who are homeless, or at risk of becoming homeless, and people who are care-leavers. From 1 July 2012, lesbian, gay, bisexual, transgender and intersex (LGBTI) people were included within the definition of people with special needs (Australian Government, 2012b)

5.2 Commonwealth Government

One of the key elements in enabling healthy ageing is the development of strong public policy. Recent Australian Government health policies and initiatives that have an influence on healthy ageing include the *Living Longer Living Better* aged care reform and the *National Partnership Agreement on Preventive Health*. The aim of the new aged care reform package, which is being implemented, is to deliver benefits to older Australians including: more support and care to remain at home, better access to residential care if needed, increased recognition of carers and those from culturally diverse background, strengthened aged care workforce, more support for those with dementia and better access to information (Australian Government, 2012c).

5.3 State Government

In a Victorian context, policies include the Victorian Health Priorities Framework, the Public Health and Wellbeing Plan, Improving Care for Older People: a policy for Health Services,

the HACC Active Service Model (Department of Health, 2012), and Diversity planning and practice (Department of Health, 2011a) and provide direction for the Victorian health system.

From a policy perspective, the Victorian health department's *Improving care for older people: a policy for health services* is pivotal to improving integration within and between health and community services. Partnership with other services can assist in finding and reaching HTR consumers through recommendations and referral practices between agencies. The *Diversity planning and practice*, implemented by the Home and Community Care (HACC) Program in Victoria, is designed to contribute to an equitable, accessible, person-centred, responsive and high quality HACC service system. The diversity plan will inform the local approach to maximising access to services for the HACC special needs groups, inform the allocation of resources for improved service access and outcomes for diverse people.

The Loddon Mallee Region Home and Community Care (HACC) Diversity Plan 2012-2015 identified five special needs groups. These include people:

- from Aboriginal backgrounds
- from culturally and linguistically diverse (CALD) backgrounds
- with dementia
- living in rural and remote areas and
- experiencing financial disadvantage (including people who are homeless or at risk of homelessness).

5.4 Local Government

Victorian legislation and government policy reiterates the importance of local government in leading local policies and developing programs and infrastructure that can influence the health of local community members. The aim of the *Victorian Public Health and Wellbeing Plan 2011–2015* is to improve the health and wellbeing of Victorians by engaging communities and strengthening systems for health protection, health promotion and preventive healthcare across all sectors and levels of government. There is a strong emphasis in this plan on identifying and developing interventions to address the needs of the vulnerable and minority population groups. It recognises that local government, with health and social services play an important role in promoting acceptance of diversity and social inclusion to build resilient and connected communities (Department of Health, 2011b).

6. Who are the 'Hard to Reach'

6.1 HTR Groups

Many organisations and local government councils in particular, identify HTR populations using demographic definitions (Brackertz, 2007). These groups include people with health and social issues, minority ethnic groups, geographically isolated and sexuality, sex and gender diverse communities, as further discussed below. The HTR risk factors are compounded in older people who have increased vulnerability due to increasing physical and/or mental frailty associated with ageing and chronic disease. The difficulty of allocating HTR people into broad groups assumes homogeneity, when in fact there is great diversity within each group.

6.1.1 Health factors

Frail older people who live in their own homes with mobility, sensory, and sometimes cognitive decline or disabilities, due to the aging process or chronic disease, often find it difficult or impossible to travel to attend appointments, access information or participate in telephone consultations or interventions, which are all common engagement methods (AgeUK, 2010).

Dementia is the single greatest cause of disability in older Australians (Access Economics, 2009) and the third leading cause of disability burden overall (Australian Institute of Health and Welfare (AIHW), 2012). Because of its deleterious effects on symptom perception, and awareness of deficits, dementia impairs the ability to pinpoint symptoms and alert others to their presence, it may remain undiagnosed and unmanaged until a crisis point when more intensive intervention is required (Phelan, 2012).

Equitable access to primary care for people with common mental health issues remains problematic, with many in need not seeking help. One study identified that many regard their mental health problems as being rooted in social problems and employed a variety of self-management strategies to maintain function (Lamb, 2012). Other reasons for not accessing services were the unavailability of acceptable mental health services, lack of effective information and multiple forms of stigma (Kovandžić, 2011).

6.1.2 Social factors

Accessing the health system can be challenging for many older people, but potentially even more so for the socially isolated, homeless, alcohol and drug users and disadvantaged. Vinson (2007) defines disadvantage as “a range of difficulties that block life opportunities and which prevent people from participating fully in society”.

Poverty is one of the most basic and enduring causes of disadvantage. Living in poverty can negatively impact on housing standards and reduce access to medical services. Low educational attainment can affect the ability to obtain information on health services and health risk prevention (ABS, 2010). To measure the level of disadvantage the Australian Bureau of Statistics uses the Index of Relative Socio-Economic Disadvantage (IRSED). This index is derived from Census variables related to disadvantage, such as low income, low educational attainment and unemployment. An IRSED score below 1000 indicates increasing disadvantage. Nine out of the ten LGAs within Loddon Mallee region have scores below 1000, with Macedon Ranges Shire Council the only LGA to score above 1,000 (ABS, 2011).

A report from Alcohol Research in UK indicates that complex physical and social factors often mask timely detection of alcohol problems among older people resulting in under reporting and presenting a barrier for older people to seek help. This is further exacerbated by a lack of awareness and understanding among health professionals about complex factors affecting older adults and alcohol misuse (Anstey, 2008).

Elder abuse is a hidden social issue that results in poor health outcomes and increases mortality (Lachs, et al, 1998). From both Australian and overseas studies, it has generally been estimated that around 3 -5 per cent of people aged 65 years and over have suffered some type of abuse (McCallum, 1994; Sadler, 1994). Victims are often incapable, either physically or psychologically, of seeking help to stop the abuse. Fear of further punishment

or abandonment keeps others quiet, as does the shame and guilt associated with the fact that the abuser is often a close family member. Moreover, if the perpetrator is the person in the caregiver's role, they would normally be most likely to identify and seek assistance for physical or emotional problems, but has a strong vested interest in keeping such problems hidden (Pinkerton James, 1994).

Social isolation is defined as "a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and (is) deficient in fulfilling and quality relationships" (Nicholson, 2009). There is evidence that social isolation is a major health issue among older adults, leading to numerous health morbidities, decreased lifespan and increased risk of hospitalisation. (Mistry, et al, 2001; Nicholson, 2012).

Accessing and engaging with services is more challenging for those who have limited capacity for meaningful social interaction in the face of the challenges associated with their illness. They do so alone without the support and sharing of knowledge which is part of being in a good social network (Findlay, 2003).

Social exclusion is a complex and multi-dimensional process driven by unequal power relationships interacting across four main dimensions – economic, political, social and cultural – and at different levels including individual, household, group, community, country and global levels. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole (Taket, 2013).

The process of social exclusion is as a consequence of multiple disadvantage, primarily linked to poverty and low income, but other factors such as low educational attainment, difficulties finding and keeping a job, housing stress, poor health and lack of access to services also underpin it. Substance misuse, mental illness, disability, family violence, discrimination and homelessness (and combinations of these) can contribute to and further entrench multiple disadvantages (Pierson, 2001; Unit, 2009).

The smaller size of rural populations and their geographical isolation are physical characteristics that differentiate rural communities from their urban counterparts. These characteristics interact to impact upon the privacy, distribution of power and acceptance of diversity within communities, ultimately affecting social inclusion and cohesion (Marchant, 2013).

6.1.3 Cultural factors

In 2008, the National Aboriginal and Torres Strait Islander Social Survey found that about 26% of Indigenous people aged 15 and over living in non-remote areas had difficulty accessing health services (AIHW, 2011); in contrast, only 2.6% of the general population has difficulty (ABS, 2012a). The Victorian Auditor-General Report (2014) identified barriers to mainstream services for Aboriginal Victorians which include lack of culturally safe services, racism and lack of awareness of services in local areas. Additionally, some of the older generation may be embarrassed by their low literacy levels and there is a pervasive fear of

government that prevents people from accessing services, or influences their perception of a service.

The issues are similar for CALD populations, with added language barriers, unfamiliarity with services and systems and different concepts of health and illness which may affect understanding of treatment and impact compliance (Howe, 2006; Victorian Auditor-General, 2012). Ethnic groups which are particularly vulnerable are those who have entered under the Humanitarian Program, as they can be suffering the effects of trauma and have little or no English skills. This contributes to the magnification of a variety of complex support needs, with the additional risk of falling through gaps in service provision (Women's Centre for Health Matters, 2009).

6.1.4 Geographical factors

While Australia's population is becoming increasingly urbanised, the proportion of older people living in regional areas is higher than those in the capital cities (CVPCP 2013, ABS 2012). People living in rural and remote areas tend to have higher levels of disease risk factors and illness than those in major cities and can have difficulty accessing services and staying connected with others (AIHW, 2010). This is reflected in the Accessibility/Remoteness Index of Australia that indicates people in outer regional areas are more likely than people in major cities to have a comparatively high proportion of people needing assistance (ABS, 2008).

Health and social service options for older people in rural and remote areas are more limited and less specialised than in the metropolitan areas. People living in more isolated areas, even a few kilometres from a small country town, have to travel to access even basic services. Rural and remote communities have also suffered over recent times from the reduction and loss of local services, including aged and community services, and community infrastructure as a result of local and global economic forces (Aged and Community Services Australia and the National Rural Health Alliance, 2005).

In the last decade the Loddon Mallee region has experienced severe drought, floods, bushfire and storms, all wreaking devastating effects on residents, both those living in towns and on farms. Some communities have been fractured and there is considerable concern about mental health and general wellbeing. Rural communities' vulnerability to mental health problems is greatly increased by socioeconomic disadvantage. This is compounded by the farming communities' stoic culture that inhibits seeking assistance (Berry, 2011). Innovative and targeted outreach models were needed to provide mental health support to the farming communities, particular in the context of climate change (Berry, 2008).

6.1.5 Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) people

There has been little attention paid to the needs of LGBTI people within strategic planning and service delivery of aged care services in Australia. In general approaches have been adopted which assume that people are heterosexual. Such approaches make a sizeable group of Australians invisible, as data sources indicate that up to 11% of the Australian population are LGBTI (Australian Government., 2012d).

Despite recent changes at both a legal and social level that have led to greater equality for LGBTI people, the older Australians have experienced stigma, discrimination, family rejection, social isolation and inequitable treatment. A UK study found that older LGB people

are more likely than older heterosexuals to have mental illness, more likely to need services and less likely to access services that they need for fear of discrimination (Guasp, 2011).

In Australia, a number of small studies have explored the experiences of older LGBTI people accessing aged care services. One study documented how older LGBTI people hid their sexual orientation or gender identity when accessing aged care because they feared discrimination or the loss of valued home care workers (Barrett, 2008). As a consequence, the older people interviewed described feeling devalued, depressed, stressed, resulting in unmet care needs.

From the perspectives of service providers, studies found that in the absence of education, the responses of aged care service on caring for older LGBTI were often grounded in an individual's discriminatory values and beliefs (Barrett, et al, 2009). The fear or experience of discrimination reinforces to that many older LGBTI people need to continue to hide their sexual orientation or gender identity. This results in aged care services believing that there are no LGBTI consumers accessing their services (Barrett, et al, 2009).

6.1.6 Gender factors

Social service may find that older men are more difficult to engage with than older women. Some specific barriers for older men are that they tend to have smaller social networks and weaker interpersonal connections with family and friends than women (Kaye and Crittenden, 2005). They feel a loss of identity tied to leaving employment and greater reluctance to seek assistance, especially from social service providers. Men have greater difficulty accepting their declining health and mobility and a feeling that they are 'yielding up' or admitting 'defeat' by attending groups for older people (AgeUK, 2010; Galdas, et al, 2005; University of Western Sydney, 2009).

Women have a greater life expectancy than men and as the population ages older women will comprise an increasingly larger proportion of the Australian population. Older women who are married (or cohabitating) may become carers of increasing frail or ill husbands and this may limit their capacity to look after their own health. When the women are widowed they may suffer financial disadvantage and difficulty maintaining their homes (Byles, 2011).

A serious, persistent and hidden issue impacting on service access for older women is sexual assault. While it is difficult to estimate the overall prevalence of sexual assaults of older women aged 65 years and over, the literature suggests that it occurs in a wide range of domestic contexts, settings and relationships. The negative health and social impacts of sexual assault, both short and longer term, are highly significant for older women yet they remain largely unexplored or documented. Like most sexual assaults of adult women, it remains a largely unreported experience and is frequently silenced by shame, fear and a lack of awareness or responsiveness of the general sector (Mann, et al, 2014; Phillips and Park, 2004). Older women who are victims of sexual assault in rural areas have reported particular challenges due to fewer services and compromised access because of lack of anonymity, isolation and increased dependency on people in their community (Mann, et al, 2014).

6.2 HTR characteristics

Using the demographic grouping to identify and engage with HTR consumers becomes more complex in different contexts or locations and compounded when people fall into multiple groups (Brackertz, 2007). It is also beneficial to define characteristics of HTR groups and link these to successful approaches to contact or involve them (Health and Safety Executive, 1994; Jones, 2001) or to establish causal links. Exploring psychosocial and cognitive characteristics of HTR consumers will provide a greater understanding of not only who they are but why they are not engaging (Victorian Cytology Service, 2010). The table below provides examples of HTR characteristics and how they can relate to different groups.

Concentrating on the characteristics of the targeted population may avoid generalisations which are potentially stigmatising and misleading. It may also provide a more objective approach, working from the needs of the hard to reach group to identify a range of interventions. Where similar characteristics can be identified of otherwise disparate groups, it is easier to exchange information about what works (Health and Safety Executive, 1994).

Table 1: Characteristics of the hard to reach [Source: modified from Health & Safety Executive (1994)]

Characteristics	Attributes	HTR Groups
Demographics: The quantity & characteristics of the group	<ul style="list-style-type: none"> • Large numbers • Dispersed population • Place of residence • Occupation and employment status • Age • Gender • Educational level attained • Income • Tenancy status • Lower socioeconomic status • Health literacy 	<ul style="list-style-type: none"> • Farmers • Unemployed persons • Tenants • New residents • Older people • Young people • Women\men • Mental illness (Dementia) • Community groups and organisations
Cultural: The way of life of a group of people	<ul style="list-style-type: none"> • Lack of established information networks • Unable to access services easily • Language spoken • Ethnic or cultural background • Social isolation/exclusion • Lack of knowledge of services 	<ul style="list-style-type: none"> • Aboriginal people • CALD • Faith based communities • High rise apartment dwellers
Behavioural & Attitudinal: The way the group's attitude to health and social services influences their behaviour	<ul style="list-style-type: none"> • Distrust of government agencies • Fear/shame • Unwillingness to access services • Participation in activities is a low priority • Lack of time • Diffuse or poorly organised internal structure and communication • Previous bad experience • Do not believe that the service is of value or needed 	<ul style="list-style-type: none"> • Drug users • Sex workers • Homeless people • Problem gamblers • Residents of hostels and boarding houses • Busy people

7. Benefits of engaging the 'Hard to Reach'

The HTR consumers experience poorer health, lower health literacy and are inadequately represented in consumer consultation and governance processes. To turn this around requires a system approach which starts with improving HTR consumer participation in system and program design to more effectively meet the needs of the most vulnerable. The success of strategies to engage and retain HTR consumers is important to evaluators, policy makers and service providers because these groups are often the main intended beneficiaries of early interventions and management of chronic conditions (Cortis, et al, 2009). The aim of improving access to early intervention programs is to reduce preventable and costly hospital presentations.

7.1 Consumer consultation

The development of community participation has also been a means to address health problems through social policy, legislation and engagement of the public in health planning. At a national and state level, a variety of models for community participation have been developed in Australia ranging from incorporating individuals into existing organisational committees to public partnerships, advisory committees, community health councils and citizen juries (Centre for Clinical Research in Health, 2006).

Older people have a vital contribution to make. Giving them a voice in the planning, design and prioritising of services ensures that the services will meet the needs of the community and direct resources where they are needed. Consumer consultation can be used beyond the planning process and integrated into organisational continuous improvement processes. It may highlight issues at an early stage, allowing an opportunity for service providers to learn from the consumers who use their services and make the necessary improvements (Department of the Environment, Heritage and Local Government, 2005).

Effective consumer consultation creates transparency and a sense of trust, ownership and help ensure those services are well received. It will also support a better working relationship with the community, and lead to a mutual understanding and trust in the services. Meaningful consumer consultation illustrates a service provider's commitment to quality consumer service (Department of the Environment, Heritage and Local Government, 2005; South Western Sydney Local Health District, 2012).

Diversifying approaches to community consultation to meet the needs of groups within society is becoming more widely recommended (Brackerz, 2005). Determining who is representative of the community is a complex and sometimes contentious issue, particularly where a small group is taken to represent a larger population. There are many older people who are active advocates for the rights of their peers. These are the easiest to reach. While engaging with this group adds weight and depth to an organisation understanding, it will not give a full picture of needs if these older people are the only one involved. It is important to reach out to engage HTR people who are not the 'usual suspects' and ensure the diversity of the community is represented (Foot, 2009).

7.2 Early intervention

Services are not being accessed by HTR populations and therefore are missing opportunities for screening and early intervention opportunities. With increasing life

expectancy, a decline in physical function becomes more prevalent. Half of people aged 65 years and over have one or more health condition, including cognitive impairment, falls, incontinence, low body mass index, dizziness and vision impairment or hearing impairment (Cigolle, 2007). These conditions can have a great impact on health and wellbeing if undetected in the early stages and not treated in a timely manner. Early detection and intervention of functional impairment in the elderly is the key to minimise disability, maintain independence at home and prolong survival as age-related conditions are preventable and reversible (Lang, et al, 2009).

7.3 Chronic health conditions

Population groups experiencing the highest burden of disease and injury include older people (especially the frail aged), people experiencing socio-economic disadvantage, Aboriginal people and people with disabilities. The total burden of disease and injury per head of population increased with remoteness, with remote populations having 26.5% greater burden than populations in major cities (Begg, et al, 2007).

Timely access to health and social services and appropriate management can result in better outcomes and a better quality of life for people with chronic illness. At a broader level, community-based disease management programs have the potential to improve population health, reduce the burden of disease and achieve reductions in avoidable hospitalisations (Department of Human Services, 2000).

Australian literature demonstrates between 7.7 – 15% of hospitalisations could have been avoided with better access to quality primary and preventative care (Clinical Epidemiology and Health Service Evaluation Unit, 2009). Many studies have shown that minority groups, and those of lower socioeconomic status are at greater risk of potentially preventable hospitalisation. Age, gender, marital status, socioeconomic status and ethnicity are associated with increased risk of potentially preventable hospitalisations related to chronic conditions (Clinical Epidemiology and Health Service Evaluation Unit, 2009).

8. Barriers

The labelling of HTR consumers is a potentially stigmatising terminology with the connotation of these people being viewed as problems to the system, rather than as individuals with needs (Brackertz, 2007). Traditionally, service providers have tended to allocate the reasons for marginalisation with groups of consumers rather than seeing the organisational barriers that prevent access to the diversity of the community in which they operate (Doyle and Visano, 1988).

8.1 Lack of knowledge/information

Navigating Australia's complex health and social system is challenging for most people but even more so for people with low health literacy, which can lead to disengagement (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2013). Similar to other developed countries, almost 60% of adult Australians have low individual health literacy (ABS, 2009). Low health literacy skills are associated with poorer health knowledge, poorer health status, higher mortality, increased hospitalisation and higher health care costs (Schnitzer, et al, 2011). Low health literacy often coexists with other social disadvantages such as poverty and low education (Liechty, 2011). This is an issue for Australia's vulnerable

groups because it can exacerbate underlying access and equity issues that consumers from these groups may be experiencing. The design of health care facilities may make it more difficult for people with lower individual health literacy to find the information and services that they need (ACSQHC, 2013).

Increasingly, services are relying on internet communication for a wide coverage. However, it must be noted that older people are less likely to use the internet in contrast to other age groups. In 2012–13, 46% of older persons were internet users and 44% accessed the internet from home in the previous 12 months compared to the Australian use of 83% (ABS, 2014). This number may be even lower in rural areas where the household internet use in local government areas within the Loddon Mallee rural region ranges from 56.7%-73% across all ages (Profile ID, 2014).

8.2 Previous experiences of accessing services

Previous experience of services can influence a person's willingness to access them, or the ways in which they approach services. This is particular prevalent in minority groups and the socially disadvantaged. A 2010 Australian report documented the experiences of 80 parents on income support in terms of their needs, their level of formal and informal support and their interactions with services (McArthur, et al, 2010). Parents reported that they were treated differently because of their status or circumstances. Some reported being discriminated against because they were on income support, a refugee or a father, or because they had a child with a disability or they suffered from mental health issues. Parents also said they were made to feel embarrassed, humiliated or judged when seeking assistance at some services. They also felt disinclined to access a service because of a fear of rejection based on past experience. Other HTR groups have reported similar experiences, including injecting drug users (Neale, et al, 2008), people with mental illness (NSW Consumer Advisory Group - Mental Health Inc, 2013) and older people (AgeUK, 2010).

Health inequalities and poor access to services are well documented for Aboriginal people. Some of the reasons for poor access to services include lack of engagement, fear of discrimination and poor treatment arising from previous experiences, and the lack of culturally appropriate services (Victorian Auditor-General, 2014). Many factors can inhibit the acceptability of health services. These include a failure to acknowledge differences between Indigenous and non-Indigenous notions of health; lack of awareness of the ongoing effects of colonisation; poor relationships between Indigenous consumers and non-Indigenous health professionals due to lack of trust and respect and poor cross-cultural communications (Ware, 2013).

Some groups harbor substantial myths about and distrust of the medical system, which could be related to experiences in a person's country of origin (Scheppers, et al, 2006). This may be a particularly important consideration when trying to engage with humanitarian entrants into Australia (Federation of Ethnic Communities' Councils of Australia, 2006). For some services, their target group may not have the confidence that the service will meet their needs or make a difference to their health or their social situation. For some it may not be a priority and are not willing to give up time that is already stretched by other demands (Barlow, et al, 2005). For refugee families and Aboriginal people the decision to seek health care was intimately related to the issue of trust and is integral in the ongoing relationships with the health service (Peterson, et al n.d; Ware, 2013.).

8.3 Physical Factors

For older people, the ability to move around independently may be an important factor in determining their social or community interaction away from the home. They may also face physical challenges such as visual, auditory, mobility and cognitive impairment, which make accessing services more difficult. Such disabilities may be assisted through sensitive design and awareness, for instance helping with entry or use of a site – with wheelchair ramping or lifts, automatic doors, or specially equipped bathrooms and seating designed for people with disabilities (AgeUK, 2010).

In 2007, the World Health Organisation, in response to recommendations of focus groups in 33 cities, developed a guide to age-friendly cities. The guide was developed to encourage active ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age. In many cities, including Melbourne, reference is made to improving accessibility to buildings for older people. Generally, the features that were identified as barriers to access were a lack of: elevators, ramps, insufficiently wide doorways and passages, suitable stairs (not too high or steep) with railings, non-slip flooring, rest areas with comfortable seating, adequate signage and public toilets accessible to those with a handicap (World Health Organisation, 2007).

8.4 Cost

In 2011, around 7% of people who needed to see a GP in the previous 12 months had delayed seeing or had not seen one because of the cost (ABS, 2012b). Studies involving Aboriginal people have also cited health care cost as one of the main barrier to accessing services (Ware, 2013). In the May 2014 Budget, the Federal Government proposed introducing a co-payment for selected GP services, out-of-hospital pathology testing, imaging services and prescribed medications subsidised by the Pharmaceutical Benefits Scheme.

The University of Sydney, using 2013-14 BEACH data, estimated the additional out-of-pocket cost to general practice patients resulting from these budget proposals (Bayram, et al, 2014). If the co-payment were introduced the average, conservative annual additional cost to a patient would increase **with age** from \$36 for children to \$122 for patients aged 65 years or more. This analysis demonstrates that these policies will create a larger price signal than previously suggested in the media. This cost can be quite significant, especially for patients aged 65 years and over or for those who have one or multiple chronic condition(s) requiring regular management. With the introduction of co-payments, health groups expect a rise in those delaying or not seeking care (Royal Australian College of General Practitioners, 2014).

8.5 Location and Transport

The location of an organisation may be a barrier to accessing services by potential consumers. The organisation may be difficult to find, may be a long distance away, especially in the rural context and may not easily accessible by public transport. An organisation may be in a location that is uncomfortable to access. This may be due to perceived stigma associated with a service and people do not want to be seen entering the premises, especially in relation to welfare and mental health services (Flanagan and

Hancock, 2010). It may also be located in an area that feels unsafe for older people, for example in a high crime area.

Ongoing difficulties associated with access to transport are commonly referred to as 'transport disadvantage'. As Australia has comparatively high levels of car ownership, difficulties associated with maintaining private transport (eg financial stress related to initial cost of purchase, as well ongoing costs such as petrol, insurance, car purchase and maintenance) could also be included in the overall definition of transport disadvantage. In addition, many older people will need to surrender their driving licenses due to deteriorating health associated with ageing (Department of Infrastructure, Policy and Intergovernmental Relations Division, 2007). The most affected by transport disadvantage are specific sub-groups in the population, for example, families with young children, people with a disability, people on low incomes and Indigenous Australians (Rosier and McDonald, 2011).

The Australian Bureau of Statistics (2012c) shows that most older people with a disability could use at least some forms of public transport (80%). However, 39% found it difficult to do so, with steps reported as the most common problem (21%), followed by a lack of seating or difficulty standing (8%) and pain or discomfort (7%). Factors such as accessibility, communication about changes or cancelled services and malfunctioning equipment (eg lifts to train platforms) can all contribute to transport disadvantage for people with a disability (Rosier and McDonald, 2011).

Transport disadvantage is also common in specific geographical locations such as outer-urban (or 'fringe') areas, rural and remote Australia. This is the result of a range of intersecting factors including poor public transport infrastructure, a higher proportion of low-income households and the need to travel further distances in order to get to places of employment, services and activities (Rosier and McDonald, 2011).

8.6 Organisation business, process and systems

Many mainstream organisations do not provide appropriate and accessible services to the diverse groups within their communities, nor systems which seek input from consumers from diverse groups or support quality improvement. The absence of these factors highlights the need to challenge the way mainstream health services engage with the diversity of consumers who make up Australian communities. Until these services recognise that 'the mainstream' is diverse, and does not only consist of individuals who are all from the same backgrounds, it is unlikely that mainstream services that are appropriate to all members of the community will be developed (National Resource Centre for Consumer Participation in Health, 2000).

Health services report challenges in recruiting and retaining (consumer) committee members who reflect the diversity in the local community, and/or building the capacity of members to operate at a strategic level. Organisations struggle to involve consumers in strategic planning, staff training and health service performance monitoring, with little evidence of consumer participation in evaluation activities (Victorian Auditor-General, 2012).

Organisation systems, processes priorities, staffing and funding models may be a barrier for HTR consumers to access services. A lack of leadership and the low priority given to reaching HTR consumers will impede engagement (AgeUK, 2010). It may seem too difficult,

time-consuming and expensive to engage with HTR consumers, especially in an environment of limited resources. Determining the cost benefit analysis is complicated by the difficulty in quantifying the HTR consumers, who are often 'hidden' in the community; it is further complicated by the lack of data to evaluate services and the time required to define outcomes related to cost benefit or effectiveness. Identifying HTR consumers is challenging and accessing these consumers can be even more complex.

Processes and structures of an organisation can be difficult for consumers trying to navigate the health and social system. The following structures and processes may act to disengage consumers such as appointment systems, waiting lists, admission criteria, complex administrative processes, follow-up, staffing, agency policies and practices, eligibility criteria, costs/charges structure, proximity, transport, physical environment of service premises and parking facilities (AgeUK, 2010). Compliance with administrative or bureaucratic requirements can be perceived as very removed from client centred care and its delivery.

8.7 Interpreter Services

Service providers experience a range of challenges in implementing interpreter policies for the CALD community. Health services report that funding for interpreter services has not kept pace with consumer needs, demand is increasing, and there is a shortage of interpreters in some languages. Health services in rural and regional areas face additional barriers in accessing face-to-face interpreter services, such as a smaller local pool of accredited interpreters and increased travel time and costs. Health services also report a gap in the availability of reliable, up-to-date information about a range of health conditions and treatments translated into community languages (Victorian Auditor-General, 2012).

Some studies have successfully used bilingual volunteers or workers, who are representative of culturally and linguistically diverse communities to engage consumers from these communities (Unger, et al, 2007). However, being bilingual without the skills to fully articulate one's views can act as a barrier, reinforcing that bilingual workers do not replace interpreters but are a complimentary communication tool. The distinction the literature makes between a bilingual worker and an interpreter is that a bilingual worker engages in a two person (dyadic) communication encounter whereas an interpreter engages in a three person (triadic) communication encounter: provider, consumer and interpreter (Centre for Culture, Ethnicity and Health, 2007; Perez-Stable, et al, 1997). In smaller CALD communities, where interpreters and/or bilingual workers may be scarce, there are concerns about privacy and confidentiality of sensitive information about health or wellbeing.

8.8 Funding and Partnership work

Strong partnerships between local services provide opportunities to share information and resources to provide better access to services (no wrong door) for the community and in particular the more isolated or 'difficult-to-reach'. However, continuous changes in political priorities and funding models make sustaining effective partnerships difficult. Rigid governance structures delay decision making and may not support the flexibility and responsiveness required for partnership work (Robertson and Wilkinson, 2010). Effective and sustainable partnerships require considerable time, effort and commitment and this may be perceived as synonymous with "extra work" and therefore avoided (Flanagan and Hancock, 2010).

There are increasing financial pressures on public services. Where organisations compete against each other for funds, they may find it difficult to work effectively in partnership to establish a common vision and develop shared responses. Organisations are competing for funding of services which may be measured by episodes of care; this in turn may foster competition for consumers. This will become more of a challenge as funding constraints tighten (Flanagan and Hancock, 2010).

Integration of health services with social services has also been reported as problematic. Health practitioners stated they would like to see better ways of organising services to support patients with complex and multiple needs, but said that they did not know enough about the social services or how to access them to assist consumers and did not have time to spend in this area (Australian Research Council, 2013).

Funding that is insecure and short term creates barriers to accessing HTR groups as it fosters uncertainty, program instability and high staff turnover, thereby increasing service disruption and consumer disengagement (Unger, et al, 2007 cited in Cortis, et al, 2009). Work done with consumers from marginalised groups is often undertaken as a once-off project, outside of any integrated approach to the development of appropriate services. This means work with HTR groups is ad hoc and seen as something to be added on when funding is available, rather than being part of the core business of mainstream services (NRCCP, 2000). Services under pressure to be more cost effective may adopt a one-size-fits-all approach, which risks compromising the flexibility required to meet diverse consumer needs (Unger, et al, 2007 cited in Cortis, et al, 2009).

There is also a concern that disproportionate attention is given to the 'low hanging fruit', those things that are easier to measure at the expense of those things that are harder to quantify such as partnership work and accessing the smaller population of HTR consumers (Flanagan and Hancock, 2010). Demand management is integrated into health and social services' business, policies and processes and for some services waiting times to a service is reported to their funding bodies. For some organisations increasing demand by reaching out to the HTR and potentially increasing their waiting times will require a shift of culture. However, it needs to be reinforced that demand management is about fair and equitable access to services, with disadvantaged people provided priority access to reduce the inequality in health status (Victorian Government, 2008).

8.9 Staff skills and attitudes

There may be a lack of skills and/or experience within the organisation to effectively recruit and retain HTR groups. Staff attitudes and poor communication skills may result in poor quality care and disengage the consumers, especially in minority ethnic (Scheppers, et al, 2006) and older groups (Katz, et al, 2011). Healthcare workers are considered to be at particular risk of developing ageist² attitudes because they are exposed to a disproportionate

² Ageism is a systematic stereotyping of discrimination against people because they are old' (Butler, 1975)

percentage of ill or dependent older people (Doherty, et al, 2011). Ageist views can come from a lack of knowledge, a lack of close interactions with older people, and as a defence strategy against personal anxiety of growing old (Bodner, 2009; Ory, et al, 2003).

Ageist attitudes are pervasive in our society and harmful to older people's psychological well-being, and physical and cognitive functioning (Ory, et al, 2003). Ageism can negatively affect older people's health by; limiting access to health care due to beliefs that ill health is just a normal part of ageing; reducing opportunities for participation in the workforce, due to negative beliefs about older workers; and limiting access to social activities (Department of Health, 2012). The media and government rhetoric on the increasing ageing population and the impact and cost to society reinforces the portrayal of older people as a burden (Andrews, 2014).

Internationally, aged care services have difficulty in attracting and retaining staff which may be influenced by the negative attitude generated by the under-resourced care environments experienced when working with older people (Doherty, et al, 2011). This may also be exacerbated where risks of working with target groups are high and the safety of service providers is threatened (Doherty, et al, 2003).

8.9.1 Acceptability

Acceptability refers to the cultural and social distance between services and consumers. The focus is mainly on the characteristics of the health providers, excessive bureaucracy, and cultural safety³. According to the Federation of Ethnic Communities' Councils of Australia (2006), 'newly arrived migrants' lack of knowledge about existing health and social services, and lack of transportation may be compounded by services providers' inability or lack of interest in providing culturally sensitive services that address consumers' needs.

9. Strategies

Although HTR are often viewed as having characteristics that reduce the likelihood of engaging with services, it could be argued that what may label some people as HTR are not their distinctive characteristics, but simply the inability or unwillingness of service providers to seek involvement in the appropriate manner. As a result, the 'problem' of the HTR groups rests not so much with the consumers, but rather with the service providers (Brackerz, et al, 2005; Flanagan and Hancock, 2010).

The engagement approach used for HTR groups will need to extend beyond standard techniques. It should feature greater consideration of identifying who is the targeted group, what is the most appropriate method to make contact, what are their motivations and identify barriers to participation. Developing new relationships and identifying innovative ways to engage the target groups may also be required, as well as applying additional effort and

³ Cultural safety refers to an environment in which people feel safe, that they are respected for who they are and what they need, and that their cultural identity is unchallenged (Victorian Auditor-General's Office from the *Victorian Aboriginal Affairs Framework, 2013*)

resources. Without such efforts, the service system will continue to reinforce existing patterns of social exclusion and disadvantage (Brackerz, et al, 2005).

9.1 Identifying target group

Clear understanding of who is accessing the service is the first step to identify who is missing. This requires clearly identifying the objectives of service being delivered and the demographic, health and social profile of the community. For example if a service is located in an area that includes Aboriginal communities or refugees and they are not accessing the service, then the service needs to determine reasons for this.

The numbers of people included in some HTR populations may be difficult to estimate for a range of different reasons. For example, there are likely to be large numbers of people with long-term mental health problems and learning disabilities who are not currently in contact with services. Some groups may be in contact with services but not identified as members of a particular HTR group, such as people from LGBTI communities and homeless/insecurely housed people. Some groups are by their nature more transient, such as migrant workers and travellers.

The Victorian Cytology Service (VCS) reviewed approaches to identifying and engaging individuals, groups and communities, including the HTR, to participate in organised cancer screening. To better understand the factors that influence participation, six domains were classified:

- Demographics – Age, gender, ethnicity, socioeconomic status, education
- Cognitive - Literacy, health literacy, cancer-related knowledge, perceived risk, perceived ambiguity
- Psychosocial - Fear/anxiety/worry, coping style (emotion regulation), social networks
- Health and lifestyle- Physical/mental health, drug use, previous participation
- Cultural factors - Acculturation, fatalism, modesty/embarrassment/shame, medical mistrust, collectivism/communalism, spirituality/religiosity
- Health system - Availability, accessibility, affordability, acceptability

After a comprehensive data analysis and literature review the VCS concluded that although the demographic data identified broad groups who are non-adherent to cancer screening, it offered little information about underlying reasons for the non-adherence. A major finding of the review is the importance of the way in which information is presented to target populations due to the low literacy levels. It is likely that addressing issues of fear/worry/anxiety of people's cancer worries as well as the screening process itself would have a positive impact on screening uptake. However, strategies for achieving this will need to take account of cognitive and cultural factors that may impact on these feelings. VCS demonstrated a clear association between increased screening uptake and existing health service supports eg doctor referral, screening taking place in usual source of care (Victorian Cytology Service, 2010).

Tools have been developed to help identify target audiences and generate ideas to reach them. The UK Health and Safety tool looks at the demographic, behavioural, attitudinal and administrative (how service configurations hinder access) characteristics to identify the HTR consumers (Health and Safety Executive, 1994).

9.2 Engaging HTR communities

Engaging with HTR communities is a slow process that requires creative thinking, a network of local contacts and the development of local understandings (Wilkinson, et al, 2009). To determine the best approach to contacting the target group requires a clear understanding of the characteristics of the HTR group including the geographical location; the volume (which may influence the feasibility of more intensive contact methods); what do they have in common; where do they get together and whom they trust (Health and Safety Executive, 1994). Information about target groups and their environments may be collected in numerous ways, including conducting stakeholder surveys, focus groups and interviews.

An important consideration in engaging a HTR group is determining who presently has contact with them. The target group may be accessing other service providers that services can work with to develop an information network or a referral pathway. If the target group trusts this service they may be able to influence them to participate in other services. Some people need to hear about programs and their efforts from several trusted different sources before they will use or contact the service (DeChiara, et al, 2001).

For example, Australians report a high trust in general practitioners, who are the most commonly visited health professional in Australia, with 83.8% (2011-12) of people seeing a GP in the last 12 months (ABS, 2012a; Hardie E, 2008). As expected, older Australians were more likely to consult health professionals with almost all people aged 85 years and over (98.0%) consulting a GP in the last 12 months and around 70% of people aged 75 years and over seeing a GP four or more times a year (ABS, 2012a). Developing working partnerships and initiatives with local GPs will provide access to most of the older people in the area.

Most health services rely on consumers accessing services by self-referral or referral by another service. Other forms of contact may include written information in the form of posters, leaflets and articles in local community papers. Some of the HTR groups eg disadvantaged, Aboriginal, refugees have generally have low health literacy so all written material need to comply with health literacy principles (ACSQC, 2013). Other forms of contact may include telecommunication eg telephone, sms and online communications via email, blogs or websites. However, services need to be aware that older people are less likely to use the internet compared to other age groups (ABS, 2014) and outside metropolitan areas there is a lower proportion of households with internet connections.

The literature supports a more active/outreach approach to engaging with HTR consumers (Watson, 2005). Going out to places where people are and engaging individuals directly and in person was generally a more productive strategy than making other forms of remote contact such as email and telephone calls (Wilkinson, et al, 2009). A case study of a local service 'City Reach' demonstrates that a service can overcome barriers in accessing the HTR. The representatives of HTR advocacy groups reported that City Reach provided easy access by bringing clinics to homeless hostels, traveler's site's, women's refuge and with the help of a specially designed van, the 'red light district'. They also point out that the attitude displayed by health workers is of utmost importance to the members of HTR groups (Pfeil and Howe, 2004).

A research technique that is used to attempt to include the HTR and hidden population is 'Snowball sampling'. Snowball sampling takes advantage of the social networks of identified

respondents to provide a researcher with an ever-expanding set of potential contacts. This process is based on the assumption that a 'bond' or 'link' exists between the initial sample and others in the same target population, allowing a series of referrals to be made within a circle of acquaintance (Atkinson and Flint, 2001). In essence, the respondent is asked to name other persons that fit the criteria described by the researcher. The newly identified persons are then interviewed and in turn asked to nominate others that fit the criteria and so on (Brackertz, 2007). This technique has been used to access marginalised people including drug users, sex workers, pickpockets, HIV sufferers and the homeless (Atkinson and Flint, 2001). Although primarily used in a research context a variation of this approach may have clinical application.

9.3 Enablers/facilitators

9.3.1 Treatment of Consumers - trust, respect

A recurring theme in the literature is the recognition that those wishing to involve HTR communities need to overcome their own prejudices about the people they wish to engage. At the same time they must address the preconceptions (often misconceptions) of those with whom they wish to involve (Barlow, et al, 2005; McDonald, n.d.). A factor which facilitates the engagement of consumers is the positive way services communicate with and treat consumers. The quality of the relationship that develops between staff and service user is a major factor in engaging consumers; building trust and respect; being non-judgmental and being able to relate to and empower people (Flanagan and Hancock, 2010). It is also acknowledged that it takes time to build relationships with people and organisation (AgeUK, 2010; Cortis, et al, 2009).

A welcoming environment starts at the first point of contact whether it is an outreach worker or entering the service site. Ensuring that an organisation projects a welcoming and non-judgement environment for all cultures can go a long way to facilitating rapport (Minkoff and Cline, 2004). An image which reflects a welcoming, multicultural feel will encourage the participation or support from people from diverse communities and provide a sense that the service is able to accommodate a diverse range of needs. Organisations need to look at all aspects of their service such as the location, external appearance, the foyer and reception area, through the eyes of their consumers (Action on Disability within Ethnic Communities Inc., 2003).

In 2004, the Victorian Department of Health introduced the *Improving Care for Aboriginal and Torres Strait Islander Patients* (ICAP) program. The ICAP program has key result areas for health services that include establishing relationships with ATSI communities, staff cultural training, and addressing the cultural needs of ATSI people. A Victorian Auditor-General report (2012) found that health services are making sound efforts to improve participation by the ATSI community. These include identification of Aboriginal people, staff training, and awareness-raising in the ATSI community. Cultural symbols are important to create a welcoming and culturally safe environment for ATSI consumers. The most common examples seen at the audited health services were flying the ATSI flags, and displaying artwork and cultural artefacts, and a plaque recognising the traditional owners. Additional examples at some health services include celebrating major events such as National Aborigines and Islanders Day Observance Committee (NAIDOC) week, holding smoking and cleansing ceremonies, and allocating a space that meets the spiritual and cultural needs of ATSI patients, families, staff and community members.

9.3.2 Flexibility

Offering flexible services that respond to the needs of the community including running outreach services, listening to feedback, flexible opening hours and providing consumers with the kinds of services they want were all key facilitators for participation (Flanagan and Hancock, 2010).

Outreach services maybe a more accessible model for people with limited mobility or for services that have perceived personal or cultural stigma attached, for example, HIV, family and child services, mental health and alcohol and other drug services (Watson, 2005). Organisations may use an outreach model to increase access to services or increase awareness of services among potential users and those services that will refer them. If lack of transportation is a barrier to services, an outreach solution may include resourcing volunteers to drive them to the site, or work with a local taxi company to provide reduced fare rides (DeChiara, et al, 2001). There is also evidence that innovative models of care, such as multidisciplinary team targeted home visits for elderly people, particularly those living alone, can improve access and quality of care (Beck, et al, 2009).

Flexible opening hours and adapting program times for specific target groups will help remove some access barriers. A physical activity program for HTR men, which included financially disadvantaged, low literacy and socially isolated, was held in the evening so that employed men were able to engage and remove the stigma of men that are available during the day due to unemployment (Carroll and Kirwin, 2014). However, evening activities may not be appropriate for older people as many do not feel safe venturing out after dark and public transport options may be more limited in the evening (AgeUK, 2010).

Increased flexibility doesn't come without organisational and financial challenges. Evening opening hours can place a strain on staffing and resources. Staff involved in outreach roles need transport resources and processes in place to ensure their safety (Doherty, et al, 2003). However, if delivery of the service is deemed a priority which is causally linked to improved health and wellbeing outcomes, then there will be a longer term cost benefit enjoyed by the client and ultimately the community and funding bodies.

9.3.3 Partnerships

Partnerships and collaboration models are strongly integrated into Australian government policy and guidelines. In reality, partnerships exist along a continuum, which is dynamic and partnership work requires commitment, trust and at times extra resources, especially in rural areas that may need to sustain networks and partnerships over long distances. To facilitate and support partnerships and service integration, the Commonwealth Government funded Medicare Locals to improve coordination and integration of primary health care in local communities, address service gaps and make it easier for patients to navigate their local health care system. In Victoria, the state government funds Primary Care Partnerships to improve access to services and continuity of care for people through improved service coordination, as well as chronic disease prevention, integrated health promotion, and partnership development.

Having a partnership or relationship with other services can assist in:

- promoting services to other organisations

- finding and reaching consumers through referral practices and recommendations between services;
- meeting the diverse needs of consumers by providing access to a range of different types of services
- building the capacity of other local services and programs to meet the needs of the target group (Flanagan and Hancock, 2010).

Partnerships also support a shared understanding of partner agencies' work and suitability for clients.

'Towards a Healthy Heart' is an example of a partnership model, where services worked together to engage a HTR group to reduce heart disease. 'Towards a Healthy Heart' was a structured primary prevention program which addressed the risk factors for heart disease in 'hard to reach men' within the high-risk age group of 30–60 year old industry workers. Initiated by the Portland District Health and Southern Grampians Glenelg Primary Care Partnership, the program involved 16 agencies including the Portland YMCA, Physiotherapy Centre, district health, the Leisure and Aquatic Centre, a range of sports clubs, local industries, local general practitioners (GPs) and Monash University.

The five industries involved supported the program through enabling access to employees and enabling the program to occur in work time with no penalties to employees. The result was ninety men took part in the program and their risk factors for heart disease had reduced, they were less depressed and anxious, and their eating was healthier. Alcohol consumption and cigarette smoking were also reduced or ceased. Most importantly, the men were linked in with their local GPs and had established a better connection with the health system (Department of Health, 2010).

9.3.4 Empowering User involvement

The government and health services acknowledge the benefits of consumer participation in areas such as quality, safety and patient experience. There is evidence that having consumers on committees and working groups, and the use of consumer feedback have improved health service delivery, for example, in hospital signage, food services, information materials and physical facilities (Victorian Auditor-General, 2012).

In Australia, a great deal of innovative work is being done to increase consumer participation in the health system. However, policy makers, service providers and consumer organisations often find it difficult to ensure the diversity of consumers and community members is reflected in participation initiatives. There is little resourcing provided to consumers, especially marginalised consumer groups, to develop their capacity to participate (National Resource Centre for Consumer Participation in Health (NRCCPH), 2000).

Several reports identified a range of strategies and organisational tools that need to be considered if feedback from consumers from diverse groups is to be incorporated into mainstream systems development. These include leadership, commitment, an integrated quality improvement approach, systematic ways to involve and seek feedback from diverse consumer groups and incorporation of consumer participation into all levels of the organisation (NRCCPH, 2000).

Increasingly organisations are using volunteers and peer support to bridge the gap between the service provider and consumer, which is particularly important when engaging HTR consumers. Repper and Carter (2010) describe models of peer support that have been developed and evaluated as having merit. These include informal and ad hoc support among consumers (which often occur naturally, without prompting), organised but unpaid peer support generally undertaken by volunteers who take on roles as ‘mentors’ or ‘peer buddies’ and paid peer support, where participants will generally be part of a team contracted to provide services to consumers.

A qualitative study of voluntary and community sector demonstrated that using consumers as part of the team encourages other consumers to participate and feel more settled. They can share with each other and use that relationship as a bridge and a way to open doors (Flanagan and Hancock, 2010). Recruiting consumers as workers has also been identified as a way to both engage consumers and improve the status, self-confidence and skills of consumers who were initially HTR (Barrett, 2008).

South West Foundation in England has successfully implemented more than 50 older people’s forums, run by older people in partnership with local agencies, often including ex-councillors who understand how to ensure their voices are heard by policy makers and service providers. The forums stay in touch with members, who cannot attend meetings via newsletters and community radio stations. The evaluation demonstrated that the forums are a productive approach to connection and communication as well as being a social event. The project is extensively evaluated by the older people themselves, using monitoring forms and training older people as evaluators (The Evaluation Trust and South West Foundation, n.d.).

A Healthy Changes program was implemented in the United States using a peer-led group format to promote physical activity and healthful eating practice, using culturally relevant materials and measures. The evaluation reported that the Healthy Changes program was successfully led by trained peer leaders and was in fact a key to effective program implementation (Klug, et al, 2008). Peer support models are a potentially low-cost, flexible means to supplement formal health care support. Peer support models also potentially benefit both those receiving and those providing support (Heisler, 2007).

9.3.5 Location of services

Location of an organisation is a factor for older people when accessing services. Services need to be accessible by public transport, have parking facilities and cannot require consumers to travel extensively (Doherty, et al, 2003). A location that older people are familiar with and where they feel safe plays a crucial role in motivating people to participate in activities (Big Lottery Fund, 2009). A study targeting HTR populations found that when determining outreach locations, people are more likely to go to familiar locations in their neighbourhoods that they know and trust (Vlahov, et al, 2007).

Service venues have also been identified as important for ensuring that service provision is offered in places that are not stigmatising. Delivering services in a universal venue may reduce the potential for stigma because these venues are not associated with a specific type of “problem” (Cortis, et al, 2009). An example within the Macedon Ranges area, is the Emergency Relief program, which helps people address their immediate basic needs in times of financial distress or hardship. This is located within a Community Health Service

that delivers a wide range of health and social services. This means people who may be embarrassed to ask for financial assistance will be able to access the service anonymously.

9.3.6 Socialisation

Social isolation is a major and prevalent health problem among older adults. Being able to socialise and make friends are two important factors which motivate older people to take part in activities. It has been found that a key strategy to engaging older people in health initiatives, such as physical activity, healthy eating programs, is to market the activities as a social interaction opportunity (Big Lottery Fund, 2009).

Qualitative research shows that older people's peer-run community organisations can play an important role in promoting social engagement, which assists members to cope with the transitions and losses common to growing old. Companionship, mutual support, a choice of enjoyable activities, and the opportunity to contribute life-time knowledge and skills to the running of the group helped to foster feelings of wellbeing, resilience and coping (MacKean and Abbott-Chapman, 2012).

An example of an innovative way to improve outreach within a social context, is the creation of a network of well-being cafés where carers and older people who feel isolated, depressed or who are becoming a little forgetful, can meet up with others going through a similar experience, in a social and relaxed environment that increases their social interaction with others. These cafés help their individual well-being, and whilst there, they can gain access to information about a range of services that are available to them (Robertson and Wilkinson, 2010). Another example is the Opening Doors Project in the UK, which offers social events for older members of the LGBTI community. These activities include film shows, lunches, and guided walks, but further activities have included counselling and buddy schemes for those confined to their homes. This in turn gives a feeling of safety and belonging and encourages the members of the groups to be more proactive within the wider community, representing LGBTI needs (AgeUK, 2010).

9.3.7 Communication

Effective communication is integral to engaging HTR consumers and improving their retention with services or programs. There are a number of dimensions to this that must recognise and respond to potential physical and cognitive changes in older people that are barriers to communication and understanding. Frequent communication helps maintain contact until a relationship has developed between the service and consumer (Watson, 2005). Collecting a number of family contacts at the initial meeting can increase the retention rate significantly (Giard, et al, 2005). Reminder or follow up phone calls are important for helping to clarify the service process and address any emerging concerns before they prevent attendance (Moran, et al, 2004).

Reducing barriers in the health system related to health literacy⁴ has the potential to support consumers to navigate the complex health and social system and give them the confidence to access the services they need. Better understanding of health information empowers consumers, providing them with greater access to useable health information and improving the capacity of consumers to use and act on this information (ACSQHC, 2013). The National Health and Hospitals Reform Commission (2009) identified health literacy as a key factor to encourage stronger consumer engagement.

Responsibility for addressing health literacy rests with policy makers, healthcare providers and consumers. There are different approaches and tools for measuring health literacy at a population, individual, organisation and environmental level. Health care organisations and support services can take action to address health literacy by developing strategies to simplify the health literacy environment for consumers. This includes developing and implementing health literacy policies and processes that aim to reduce the health literacy demands of information materials, the physical environment and local care pathways. In addition, provide and support access to health literacy and interpersonal communication training for staff (ACSQHC, 2013).

10. Conclusion

While there is a selection of literature related to 'hard-to-reach' populations, very little literature is specific to older adults or to older adults living in rural or regional Victoria. Much of the literature which considers engaging HTR consumer relates to consumer consultation in the local government context. The literature that did target specific 'harder-to-reach' groups in the health and social setting focused on children and families, specific issue-based populations groups eg drug users, sex workers or research sampling techniques to include HTR groups.

The literature review highlights the challenges faced by sections of our community to access quality health and social care. There is also considerable evidence that services are struggling to implement integrated systems to ensure the participation of HTR consumers. The ambiguity of the term 'HTR' increases the complexity of defining and identifying the HTR groups, who may be marginalised, invisible, resistant or transient. Health services are increasingly recognising that the responsibility of engaging with HTR consumers lies with the health system and considerable effort is required to break down the existing organisational barriers, which are well documented.

There is limited information on strategies for engaging HTR consumers in the older population. However, the principles and many of the learnings from other HTR groups are applicable and transferrable to the older population. Developing new relationships and implementing innovative strategies to engage the older HTR groups may be required, as well as applying additional effort and resources. This should not be seen as a discrete, time

⁴ Health Literacy is the knowledge, motivation and competencies of a consumer to access, understand, appraise and apply health information to make effective decisions and take appropriate action for their health and health care (Sørensen, et al., 2012).

limited project but a process to integrate inclusive practice into the normal organisational operational systems. Without such efforts, the service system will continue to reinforce existing patterns of social exclusion and disadvantage.

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