

Chronic Disease Consumer Issues Paper

Message from the Chair:

In early 2012, Health Consumers NSW established a Chronic Disease Consumer Network, representing the broad range of consumers and carers affected by chronic conditions in this state. Participants in the Network were nominated by our voting organisation members representing a chronic illness as well as individual members who had registered as consumer representatives with an interest in chronic illness.

This group brings together a broad range of people with experience of having or caring for someone with a chronic condition. Through their involvement we have been able to identify some of the generic issues which come with the diagnosis of a chronic condition.

This paper collates the views of those consumers and outlines some of the issues they identified as important to them. We found that consumers want a strong relationship with those that care for them. They want secure eHealth systems. Consumers would also like to see better support for informal carers and for the health and care workforce.

The experience of consumers as the users of our health system makes them uniquely qualified to comment on the way it works. We hope that discussions like the one we have now started with the Chronic Disease Consumer Network will inform health policy and delivery in this state and help deliver the best health outcomes for everyone.



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Hot off the press! A note on the Serious and Continuing Illness Policy and Practice Study:

In late 2011, Health Consumers NSW participated in a series of Roundtables held by the Menzies Centre for Health Policy as part of the Centre's Serious and Continuing Illness Policy and Practice Study (SCIPPS).

The outcomes of these roundtables, along with a summary of the larger study, have just been published. We asked Associate Professor Jim Gillespie, Deputy Director of the Centre, to provide some words on the relevance of SCIPPS to the outcomes of our discussion:

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) is a National Health and Medical Research Council-funded project by the Menzies Centre for Health Policy at the University of Sydney and the Australian National University. It has researched the experience of the health system faced by people living with long-term diabetes, chronic heart failure and chronic obstructive pulmonary disease. The study aims to find policy and health systems solutions for people with serious and continuing illness and those who care for them.

Extended interviews with people and carers living with chronic illness in Western Sydney and the Australian Capital Territory identified three major themes:

1. *Multi morbidity.* Most participants reported more than one illness. The extra burden and the confused and contradictory messages given by health care providers – focusing on individual diseases – are major barriers to self-management.
2. *Economic hardship.* Despite safety nets and Medicare, many interviewees reported that the economic burdens of illness, compounded by poor transport and physical access to services, can create as much stress and anxiety as clinical conditions.
3. *Health literacy.* Our health system does a poor job in giving people usable information to help them understand and manage their conditions. Too much indigestible information is given when people are at their most vulnerable, with too little follow-up. SCIPPS underlined that health literacy is not just a matter of individual learning but a social activity.

SCIPPS has used these consumer-identified themes to evaluate the response of the health care system to chronic illness.

Although health care professionals agreed with the concerns raised by patients, each professional group saw poor coordination and health literacy as someone else's fault and problem.

SCIPPS is completing formal evaluations of experiments in healthcare reform, aimed to overcome professional and organisational barriers. HealthOne Mt Druitt draws together primary care and community health. Care Navigation (Nepean Hospital) is a new model of improving chronic care in hospital and building better links and information sharing between hospitals and community-based services.

Further studies have included an award-winning report on the management of chronic conditions amongst Indigenous people in western Sydney and the ACT, and a survey of how people with multiple conditions use their time: the work of chronic illness.

For more information, see: www.menzieshealthpolicy.edu.au/research_scipps.php

Health Consumers NSW (HCNSW) is the state-wide voice for health consumers in NSW which helps to shape the health system by representing and involving consumers in health policy and program development.

Our Chronic Disease Consumer Network was established in 2012 in order to provide an independent consumer perspective about generic issues across the spectrum of chronic conditions.

HCNSW held the first forum of the Network in March 2012. Consumers participating in this forum discussed and identified common issues faced by people with chronic conditions and their carers in NSW. Following the forum, further feedback was sought from members of the Network.

In our request for feedback, we asked consumers to provide some details about themselves. The average respondent:

- Had been diagnosed with multiple chronic conditions
- Typically spoke to a health professional at least once a month
- Accessed 5 or more health services on a regular basis
- Was satisfied with the level of control they have over health care decision-making processes
- Stated that their GP, or another health professional, often takes responsibility for coordinating their care
- Had a good or very good understanding of the basic health information needed to make appropriate health decisions
- Had just a good or not very good understanding of the range of services available which could help them make appropriate health decisions

This paper draws on the responses of consumer participants in both the forum and secondary feedback processes in order to present a snapshot of health consumer concerns in relation to chronic disease management in NSW.

Key points:

A good relationship between consumer and health professional is essential for effective communication and consumer confidence in managing their health. Health literacy is key to this.

Consumers want self-management – on their terms and embedded throughout the health system.

Consumers are concerned about the overburdened health and other associated care workforces.

Consumers would like to see better support for carers, particularly in the provision of better information and training.

There is strong consumer support for eHealth systems, but consumers are also concerned about system security.

We would like to thank all of our members who contributed to this discussion.

Health Consumers NSW – September 2012

Stakeholder Communication

“Certainly communication has improved in comparison to 5 or 10 years ago, but as someone with a chronic condition you still have to go into a consultation with your issues/questions well planned to make best use of limited time”

Three major issues were identified by Network members regarding communication and health:

1 Poor communication between different health providers has a negative effect on health outcomes and creates difficulties in continuity of care. Participants identified their GP or other primary health care professional as the most appropriate people to help them manage and coordinate their health care.

A good relationship with health professionals and good access to health services appear to both be key to consumers' confidence in understanding and acting on health advice.

“I have longstanding relationships with most who treat me. My concern is what I do as these people retire?”

2 Consumers often feel that health professionals they see don't take the time needed to have meaningful discussions about treatment options with consumers and carers. There was agreement among participants that a supportive environment and a sense of mutual trust and respect is crucial.

“The difficulty is that [doctors] are very busy and it feels like sometimes what they say goes”

3 Medical 'jargon' can be a barrier to consumers and carers fully understanding what health professionals are trying to tell them. Consumers noted a need for better consumer health literacy. There is a need for health professionals to recognise the importance of the language they use.

“You can't have confidence unless you understand what's being said. Only then can you act on that advice”

Feedback from Network members revealed a range of experiences – consumers found that some health professionals communicate well, giving clear explanations and using lay language – while others can be distracted or can even ignore the consumer and carer.

Research of note:

For many consumers, medical jargon can be a barrier to achieving good health outcomes. It can also reinforce an unequal relationship between health professionals and consumers. A recent study from the Netherlands demonstrated that lay people are more likely to have confidence to participate in their health management when they understand medical terms used (Pieterse et al, 2012).

Self-Management and Self-Care

“[Self-management] is a change in practice and culture which I believe is overdue... A multidisciplinary approach that is focused on the individual's needs and concerns is critical and a relationship with a case manager who is responsible for co-ordinating the care with the family, patient and carer”

Network members discussed various definitions of self-management and identified the following issues.

Consumers felt that health professionals' 'gatekeeping' role is essential. However, the way this relationship is sometimes constructed can put people off managing their own health. Consumers suggested that patients' specific needs should be central to decision making and communication.

Feedback indicated strong support for appropriate self-management systems. Some consumers commented that this would require a change in system practice and culture. Others emphasised the role of the individual consumer. There was concern that unless self-management is fully embedded in

existing systems, it will not work.

"I think self-management is an ideal we should strive for but we don't even have a fraction of the required services in place. Many GPs are not up to this challenge"

It was also noted that the expected level of consumer self-management is sometimes unclear or inappropriate. Self-management is not appropriate for those consumers who cannot, or do not want to self-manage their condition.

Self-Management and Health Literacy

Members stated that self-management is tied to empowerment, where a consumer has the skills, information and support to confidently make decisions about their health needs. Forum participants discussed the role of health literacy and knowledge in empowering consumers and carers.

"I was confident I understood the information but much of the information was wildly contradictory so I was not able to act with any confidence. When I sought clarification I found professionals annoyed by my questioning"

It was noted that quality, professional, timely and reliable health information is not available to all consumers. Consumers have different needs and cultural backgrounds, and will access health information in different formats and from different sources. For example, some people will be more likely to access brochures in a pharmacy than online information.

"Information about home help, nursing help, support information, transport etc. is essential whilst caring at home"

Feedback on this issue demonstrated the varied needs of consumers, and the range of ways in which different people access information - some emphasised the importance of TV health promotion

campaigns, others called for more consumer peer support groups.

Several respondents noted that online information would not be useful or accessible to them.

"I think another [useful resource] could be a self-management group linked via Medicare Locals. These groups would aim to provide opportunities for consumers with similar health issues to learn from each other, hear from health professionals and grasp an understanding of 'what they can do to manage their own disease' with the potential to develop a support network with other participants"

Research of note:

Much has been written about self-management in health. The Health Foundation from the UK has conducted a review of 550 pieces of research on the self-management of long-term conditions. They found that: "Research suggests that supporting self-management works, and can have a real impact on how people think, feel and act. The challenge is to explore the best ways to support self-management and to help service users, clinicians and managers make this a reality" (de Silva, 2011).

Affordability and Access

A further key area of concern for Network members was the high financial cost of living with one or more chronic illnesses.

"My family have private health insurance, and this is an out of pocket expense"

"Managing chronic diseases is hard on the budget, requiring very careful household budgeting"

Examples of financial impacts experienced by network members include:

- Loss of income because of their condition
- Cost of prescription medications not covered by the PBS, and other medications

- Cost of essential medical devices
- Inability to access the full range of essential care
- Cost of paid care
- Cost of transport to health services

Consumers we spoke with were particularly concerned about the cost of accessing allied health services and other medical specialists.

The impact of these costs is magnified for rural and remote health consumers.

“I was under heavy financial strain when I had to pay full price for MRI scans, specialist fees, mammograms, ultrasounds, etc. Even though I was working, I was on a low income, and at the time was paying half my income in rent, so was unable to save. Also, my extras cover on my private health insurance did not cover any of the above”

Several respondents to our call for feedback had experienced extreme financial hardship due to their accessing essential care.

“Due to the combination of suddenly not being able to work, and the high out of pocket costs of my illness, we had to sell our family home”

Most respondents experienced some health-related financial strain. Several mentioned the invaluable role of other financial support systems in reducing their out-of-pocket costs - such as family, the Department of Veteran Affairs and pensioner discounts.

“Have not attended a cardiologist since February 2011. Cannot afford to”

Consumers often miss prescriptions or appointments as they are unable to pay for them at the time.

Consumers believed that further public funding should be made available for health transport and home-based health care, including crisis teams. It was understood that these services are costly, but it is important to understand the positive impact they have

on improving chronic disease management and outcomes, particularly for older people and people with disability.

Participants agreed that access to health services in NSW is unequal. There was much concern that there are barriers for some groups in accessing health systems and services; this includes people with disability and complex care needs, from culturally and linguistically diverse (CALD) and Aboriginal communities, pensioners and those living in rural and remote areas. In a more inclusive health system, services could be accessed as easily by members of these communities as they are by others.

Health Service Delivery

Consumers called for health services and service delivery that are flexible and respond to the needs of all consumers and carers. This would necessarily include consumers experiencing smoother connections between the different services they need.

It was noted that mental ill health, both as a chronic illness and as a comorbidity of other chronic illnesses, must be better incorporated in chronic disease service planning and delivery.

Participants believed that increased, sustainable funding for primary and allied health services is necessary for all of the above to occur.

It was suggested that consumers are not receiving quality treatment. Specific problems identified included too brief appointments with health professionals, extensive waiting times to access specialist services, and poor referral processes. Many consumers questioned the effectiveness of disease-focused funding of services, suggesting a person-centred system to be more effective and fair.

We asked consumers what one change to how health services are delivered would make living with chronic disease better. There were a range of different responses

to this question. Common themes included:

- Person-centred systems and funding
- Increased staffing in care services and improved staff pay and conditions
- Better information from care providers on how to access services

Sample consumer responses:

“More public education for health literacy. Chronic disease is something you will live with for the rest of your life”.

“We need more staff in both critical care and other care settings. We also need to address pay and career structure. Too many people see ‘care services’ as temporary work, often left to immigrants whose first language is not English, leaving us with chronic care needs feeling very vulnerable”.

“Pay the patient or carer according to need, determined by the disease/severity as a start, then adjusted according to personal need”.

“People with chronic illnesses would be greatly assisted if their generalist doctors would assist in giving clear information as to where and which required services they need to access”

Workforce

Members raised a number of issues around the health and care workforce.

Consumers would like to see the health and care workforces better supported to deliver quality care. A common concern was the aging workforce, and the potential of the future workforce to meet projected increased demand.

Participants thought the existing health workforce could be better utilised. In particular, the potential benefits of extending the roles of nurse practitioners, nurse coordinators and social workers were supported. In rural and remote areas an increase in the number of generalist doctors was seen as a vital way to improve health outcomes.

Carers’ Role

Carers can be a crucial member of the health care team. Participants noted that for chronic disease self-management to be effective, carers must have access to appropriate information and resources regarding the health needs of the person they care for.

“There is still a strong view that the ‘professionals’ know best. Ironically, if I am hospitalised, nurses, doctors etc will happily step back and let my mother deal with my disability and care needs”

It was noted that often carers are not given the opportunity to support consumers in making decisions about their care in the most appropriate way for them. There was general agreement that carers are not sufficiently supported and involved.

“I personally benefited a great deal from carer training”

Consumers called for training and health information specifically targeting carers, including support for carers’ health needs.

“Carers must be the crucial part of team when the patient doesn’t have capacity or will!”

Several participants noted that where consumers are unable to make decisions regarding their own care, health professionals must provide as much information as possible and relevant to the carer about the condition of the person they care for.

“GPs and medical specialists need honest information on their shortfalls [regarding] not disclosing full information of the patient’s condition, needs, prognosis to their carer”

Consumers also believed that health professionals need training in how to work with carers. There was some concern that an emphasis on self-management within health services could lead to increased responsibilities for carers.

eHealth Reform

This is a confusing area for health consumers, as the term 'eHealth' means different things to different people. The eHealth topics discussed at the forum were Personally Controlled Electronic Health Records (PCEHR) and telehealth.

Forum participants believed that PCEHR technology could improve health management. However, concern remained regarding the records' security, particularly the right of the consumer to control who accesses their information.

Participants recognised telehealth as a positive development for consumers, with particular benefits for rural and remote communities. They understood the benefits of telehealth and were positive about how these kinds of services could help consumers. However, they expressed concern about how this would be funded – by the system or the consumer. They acknowledged an anxiety and lack of full understanding about telehealth and how it might be implemented.

Participants suggested that some people will have difficulty accessing and using telehealth services – particularly older people, those with disability or mental health issues and CALD populations. There was also concern that potential decreased face-to-face contact with health workers could have a negative impact on socially isolated people.

It was suggested that education forums for consumers could help them understand how eHealth systems work (including electronic health records and telehealth) and their role in managing health.

We asked consumers to identify what they saw as the strengths and weaknesses of an eHealth system. Identified potential strengths were:

- Allowing the consumer to share their medical history with their health professionals (PCEHR)
- Improving rural and remote health service access (telehealth and PCEHR)

- Reducing travel time for consumers to and from appointments (telehealth)

Identified potential weaknesses were:

- Lack of privacy and the potential abuse of health data (PCEHR)
- Reducing personal relationships between professionals and consumers (telehealth)
- 'Personal control' means that relevant health information could be hidden from health professionals (PCEHR)

Sample consumer responses: eHealth

"With the cost of health care, utilising new technology to improve access to services is a relevant strategy to ensure equal access for all"

"The best method for managing health is having a strong personal relationship with your GP... relationships will not be the same through a computer screen"

"It is a different way of doing business and if it holds the client, family and carer at the centre of care with the focus on that relationship then it can add value"

Sample consumer responses: PCEHR

"The strength of the eHealth system is the immediate and full availability of the patient's history to the attending medical practitioner"

"I am not confident in the Government's ability to implement a reliable system. I would want to own my e-record and have the ability to sue those who released it"

"I have no problem [with my medical records being held on a database], as long as there are good security measures"

"I would not be comfortable [with my medical records being held on a database], due to security issues. A locked filing cabinet in a GP's surgery would be much harder to access than computer records, which potentially could be seen by unlimited people, not all of them health professionals"

References

- Access Economics (2010). *The economic value of informal care in 2010* Canberra: Report for Carers Australia.
- Australian Institute of Health and Welfare (AIHW) (2006). *Chronic disease and associated risk factors in Australia 2006* Canberra: Authors.
- Bodenheimer, T., MacGregor, K., & Shafiri, C. (2005). *Helping patients manage their chronic conditions* California: California Healthcare Foundation.
- Britt, H. C., Harrison, C. M., Miller, G. C., & Knox, S. A. (2008). Prevalence and patterns of multimorbidity in Australia. *Med J.Aust., 189*, 72-77.
- de Silva, D. (2011). *Evidence: helping people help themselves* London: Health Foundation.
- Health Workforce Australia (2011). *National health workforce and reform strategic framework for action - background paper* Canberra: Authors.
- Jan, S., Essue, B. M., & Leeder, S. R. (2012). Falling through the cracks: the hidden economic burden of chronic illness and disability on Australian households. *Med J.Aust., 196*, 29-31.
- Jowsey, T., Jeon, Y. H., Dugdale, P., Glasgow, N. J., Kljakovic, M., & Usherwood, T. (2009). Challenges for co-morbid chronic illness care and policy in Australia: a qualitative study. *Aust.New Zealand.Health Policy, 6*, 22.
- Menzies Centre for Public Health (1-9-2011). Serious and Continuing Illnesses Policy and Practice Study (SCIPPS) Snapshot: Self-Management and the Reform Context. Retrieved 13-6-2012, from http://www.menzieshealthpolicy.edu.au/research_scipps.php
- Moffatt, J. J. & Eley, D. S. (2010). The reported benefits of telehealth for rural Australians. *Australian Health Review, 34*, 276-281.
- National Health Priority Action Council (NHPAC) (2006). *National Chronic Disease Strategy* Canberra: Australian Government Publishing Service.
- Pieterse, A. H., Jager, N. A., Smets, E. M., & Henselmans, I. (2012). Lay understanding of common medical terminology in oncology. *Psychooncology., Retrieved 13-6-2012 from* <http://www.ncbi.nlm.nih.gov/pubmed/22573405> (Epub ahead of print).
- Yen, L., McRae, I., Jeon, Y. H., Essue, B., & Herath, P. (2011). The impact of chronic illness on workforce participation and the need for assistance with household tasks and personal care by older Australians. *Health Soc.Care Community, 19*, 485-494.

Health Consumers NSW

Established in late 2010, and funded by the NSW Health Ministry through a Ministerial grant, Health Consumers NSW is the state wide voice for health consumers in NSW, which helps to shape the health system by representing and involving consumers in health policy and program development.

We are an independent member-based organisation with members coming from all areas of the community and health sector. Our voting members are health consumer organisations and are representative of a wide range of disease groups and consumer health issues. Associate members include individuals, organisations and other stakeholders with an interest in health consumer issues.

Through its diverse membership HCNSW can ensure the consumer perspective is heard and included by government, policy makers and other health stakeholders - balancing the view of health care professionals, service providers and industry.

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Collated consumer responses from the Chronic Disease Consumer Forum

Consumers attending the Forum represented and had experience of a wide range of chronic illnesses including asthma, Alzheimer’s, diabetes, mental health, cancer, heart disease, stroke, cystic fibrosis and Parkinson’s, as well as consumer representation from a Medicare Local and Local Health Districts. Participants were asked to provide comment on issues relevant to five key topics – self-management and self care, access and affordability, gaps in services, telehealth and primary care – as well as any other significant issues.

Consumers’ post-it note comments were collated into the series of tables below, which identify their concerns and divide each topic into areas of concern. Some of the comments address issues consumers have experienced within the current system, while others suggest actions to improve the experience of people with chronic conditions in this state.

Topic: Self-Management and Self Care

Consumer feedback provided	
Information/ education	<ul style="list-style-type: none"> • Definition, education, health literacy, quality of information • Access to quality education-websites from professional organisations with reliable information • Need for education • Health books and CDs done in chapters • Quality of care info, need for support • Better education info about illness • Access to info about services • CDSM programs should increase literacy-preventative-proactive –not reactive • Literacy: need to explain the terms self-management etc so individuals can work for it and know what’s expected • Seek Holistic care to include all info about condition • Health literacy essential for success in self-management
Other supports	<ul style="list-style-type: none"> • Need support for those who rely on others to manage their care • Support needed for someone to make a choice • What to do for those who don’t have networks? • Effective triage systems in hospitals that recognise co morbidities • Peer supports access to others coping with similar situations • Emphasis on Tele-health - more Gov’t support • Need for support
Personal Care	<ul style="list-style-type: none"> • Gives a sense of control over your conditions • Gatekeeping role of health professionals deters access to self-management • Empowerment of consumers • Person’s ability to make appropriate choices • I don’t feel that people are really managing themselves just surviving and falling in gaps not living on to best of life under the circumstances

Consumer feedback provided	
Sharing information with consumer	<ul style="list-style-type: none"> • Importance of lists of medication-any changes need to be logged with GP and patient • BSL and blood tests, Dia. Aust., weight control/obesity, blood pressure tests Personal responsibility personal/GP shared • Tell me talk to me with trust and respect - Supportive environment and individual conversation • What about obesity - GPs don't address with patient
Confidentiality	<ul style="list-style-type: none"> • Information who gets it, who gives it, who has access to it • How confidential is confidential • Who gets access to personal information of client
Costs	<ul style="list-style-type: none"> • Save cost-those with dementia need Familiar surrounds need hugs- best provided at home with carer - Carers need more help for living and passing on at home • Health care costs /time • Financial constraints prevent access to doctors/Specialists when needed
Carer involvement	<ul style="list-style-type: none"> • Self-care can shift burden to carer and patient- stress- ill prepared, lack of training • Respect and care of the carers as well as the cared for • Carer need help more for live pass "on" at home
Health services	<ul style="list-style-type: none"> • Resistance from medical and allied health services • Effective triage system in hospitals that recognise co morbidities
NESB specific issues	<ul style="list-style-type: none"> • Different cultures have different requirements

Topic: Access and Affordability

Consumer feedback provided	
Coordination of Services	<ul style="list-style-type: none"> • Equality across socioeconomic groups to access the same quality of care regardless of economic status • Equitable access to health services varies greatly due to geography, affordability, Interpreter services- Some clients have no speech due to various issues • We don't need any more waste of money on a system that is only servicing itself E.A.C.H ran out of money. No service yet department of E.A.C.H still paid • Linkage between GP and Specialists to reduce waiting time • Age of GP workforce and likelihood of retirements with no replacements • The gestapo surgery manager • Waiting time to see specialists especially as chronic diseases not regarded as urgent • Palliative care access is patchy and difficult, Coordination is minimal. Community level –access to home

Consumer feedback provided	
	<ul style="list-style-type: none"> • Access to care providers – chronic disease management plan needs revision • Lack of connections across the local area for multiple health departments e.g. Hospital allied health, mental health services etc • Where is the holistic approach? • Treatment slots at GP not conducive to a full consultation • Not enough support accommodation for Mental Health consumers • Difficulty in seeing doctors, no places for new patients- mental health issues GPs- refuse care • Lack of coordination of health professionals (working from the same page). Should work together as a team with consumer and carer
Costs	<ul style="list-style-type: none"> • Cost of travel time from rural areas • Massive costs associated with health care in Australia • Costs of multiple consultations with numerous doctors/specialists etc • Gaps- inability to access services because of financial constraints – Co-payments and Medicare Doctors not accessible. Specialists out of the question • Means testing • Being unable to work and relying on pension – drop in income and loss of super • Pensions are below poverty line
Transport/ Location	<ul style="list-style-type: none"> • Long travel times and cost of travel from rural areas • Access to country groups-often long waits • Transport should cover all including Mental Health • Geography and transport
Carer Support	<ul style="list-style-type: none"> • We need to take control of our taxpayer money for carers at home, not force them into a broken down system -Go the Tele-health • Carer input at all levels • Pressure on the carer to manage multiple appointments, medications, conditions etc
NESB services	<ul style="list-style-type: none"> • Lack of culturally appropriate services act as a barrier to CALD communities • Doctors from non-English speaking backgrounds whose referral networks are non-existent • Cost and availability of interpreters • Aboriginal people may seek services that are culturally sensitive and understand their values etc- this is often not possible
Availability of services	<ul style="list-style-type: none"> • People with a disability & chronic health issues have trouble finding a GP who will take on their care –due to complexity and time • Long waiting times • Need crisis teams to go out and visit consumers in home • Availability and time of specialist treatment- not very friendly • Availability of doctors to conduct home visits
Technology	<ul style="list-style-type: none"> • New technologies should help tele-consultations, www to help increase health literacy

Topic: Gaps in Services

Consumer feedback provided	
Services	<ul style="list-style-type: none"> • Palliative Care services have gaps between community – hospitals – acute hospitals • Coordination of care at the end of life- to many gaps no single coordination point • Not enough crisis team intervention/prevention • Gaps in bowel cancer screening • Waiting times for services • Less patient waiting time per GP • Not enough support accommodation • Appropriate assessment of presenting problems, referral • Rehab and support across all chronic issues • Having to be covered by private health insurance to gain comprehensive service usage • Not enough emphasis on cure – gap in research and hospital practices • Support at times of transition e.g. when they reach 18 years old, leave hospital
Consumer participation	<ul style="list-style-type: none"> • Recognise different levels of ability to communicate needs • Assumptions made by medical personnel re quality of life issues and end of life care, with minimal consultation • Lack of consumer participation in services • Mental health need more respect and to be treated with dignity • Illness should not be defined by popularity • Prevention not disease focused, client focus • General health and chronic disease and people with mental health issues need to be reconnected • Together holistically and from other cultures
Carers/ Family	<ul style="list-style-type: none"> • Support for carers –support groups, health and wellbeing counselling • Lack of carer support –area for telehealth • Carer not listened to or asked to have input • Needs of carers not considered, their own health ignored • Families often left out of the crucial decision making • Lack of training of carers on how to care • Mental health need to have primary carer input at beginning not as an after thought
Costs/ Funding	<ul style="list-style-type: none"> • Pulmonary rehab- continuing care- need funding for physios to support programs. • Suggest going to clubs for venues, need to look at insurance issues • Government not supporting Chronic networking with funds • Funding need to be rational and ongoing • Free health care do people want to adopt bottom line funding- Medicare • Cannot access cardiologist- cannot afford it \$500 a visit plus Medicare • Services underfunded therefore programs not available due to system mismanagement – this is rampant in the in homes service area

Consumer feedback provided	
Communication of Information	<ul style="list-style-type: none"> • “Maze” we don’t need more cost waste of a “Gateway” – just put it on internet • There is no link to other services e.g. we don’t talk to them • Increase focus on medical research • The services are not talking to each other • Gap in understanding where to access quality services • Lack of info and measures • Separate services to talk to each other across disciplines
Age issues	<ul style="list-style-type: none"> • Need flexibility in age related programs • Arbitrary decisions made on the basis of age create inequality
Training	<ul style="list-style-type: none"> • More training places • Training at the installation of equipment
NESB/ Special needs	<ul style="list-style-type: none"> • People with special needs disabilities, NESB, communication problems are ignored. Not assessed holistically. Get discharged early because they are difficult needs not met

Topic: Telehealth

Consumer feedback provided	
Usability	<ul style="list-style-type: none"> • Integrate It systems with other devices such as iPads, various communication devices for non-verbal people • Computer illiteracy for older people • CALD/NESB populations may limit benefits from the eHealth revolution • Language availability • Cognitive impairment limit use • Aged and disability people would have problems physically accessing equipment need care/ staff support • Benefit of knowing you have access when needed • Need good internet • Save time and money due to reduced travel • Seen overseas works fantastically have a unit in a Community health centre, specialist • Visiting nurse to help people change to use Telehealth (BP, BSL, Tests)
Access	<ul style="list-style-type: none"> • A good thing needs to be limited to certain members of the population • Access to info on a one on one question and answer basis is better than just internet and personal interaction to GP. E.g. scripts on line saves time, cost, travel etc • Consumer may stop access, withholding or controlling illness info • Rural inclusion • I don’t think this would work with consumers with mental illness • Immediate access to help • Improves efficiency • Access to allied health services

Consumer feedback provided	
	<ul style="list-style-type: none"> • Provision of scripts by pharmacy instead of returning to GP • Physical capability to utilise system
Confidentiality	<ul style="list-style-type: none"> • User control who gets access to what • Privacy issues – consumer right to control extent of access • eHealth – needs to be totally secure for confidentiality for use across Australia- not just State • Security and data • Safeguard of confidential records with consumer rights to control access only by need to know • Personalised records required • Archived data not being used by third parties • Confidentiality
Cost	<ul style="list-style-type: none"> • Cost • Cost • Is this out of some consumers' and families' pockets • The cost to the consumer would be exorbitant – Centrelink recipients would be excluded • Tele-health should be free to people in remote areas, people without carers or family and people with mobility issues • Pensioners simply would not be able to afford the identified cost
Technology	<ul style="list-style-type: none"> • Let's get it happening faster • Reliability what happens when the technology fails • Use of interactive devices
Increase isolation	<ul style="list-style-type: none"> • Less personal contact so confirms isolation, or does it? • Isolate people – decreased community inclusion
Empowerment	<ul style="list-style-type: none"> • Power to consumers • Empowering increase awareness self-management
Carers	<ul style="list-style-type: none"> • Carer included in tele-health process

Topic: Primary Care

Consumer feedback provided	
Service provision	<ul style="list-style-type: none"> • Move away from episodic primary care model • Primary care needs to include access to outpatients at local hospital • Service provider “case manager” is a conflict of interest. GP is better choice for carer /patient • GPs books are closed, won't take more patients, won't see patients with mental health issues or disabilities • GPs to have full access to e-health records, including medications • Involve me in my health patient centred care • Treatment that works for me • Primary should be recognised as the coordinator of chronic disease • Hospital in the home is nonsense- they do not have the staff to deliver

Consumer feedback provided	
	<p>basic services</p> <ul style="list-style-type: none"> • GPs not always patient focused • Primary carer includes carers being involved in all discussions re chronic condition • Demarcation lines between services • Some GPs reluctant to see people with disabilities-very difficult for continuation of care especially post hospital discharge
Cost	<ul style="list-style-type: none"> • Need funding for all health services • Cost of primary care with fewer bulk billing • Medicare to fund chronic care consultations • Primary care need to include access to allied health on Medicare system as part of primary care • Cost free health cover • Government funding for blood tests to encourage widespread early diagnosis • Accessibility available and affordable- cost savings due to better outcomes • Cost is prohibitive GPs upwards of \$80 plus Medicare specialists \$500
Training/ staffing	<ul style="list-style-type: none"> • Liability of GPs to handle pain management • GPs that do not diagnose above and beyond symptoms presenting • GPs address obesity • Need for GPs to keep up with the latest info share experience • More medical places in universities increase numbers of doctors • We need nurse practitioners in every Medicare Local • Nurse Practitioners in GP practices would minimise time for GP • Staffing availability for community health centres • Aging and retiring of GPs – How to replace them
Information sharing	<ul style="list-style-type: none"> • GPs have no time to give information to you • Medicare Locals not always willing to work with the health consumer • Better communication with consumers and carer, health staff and community health • Short appointment or long appointments, cost of appointments • Communication about person-centred care all important • Ongoing relationships with GP and allied health • NGO information not getting through to doctors to educate them re services and resources available
Legal issues /Research	<ul style="list-style-type: none"> • Research into value of general practice and private allied health • Primary Care needs to be defined as it is a legal form in the Mental Health Act
Equipment	<ul style="list-style-type: none"> • Need to access point of care technology

Topic: Other Key Issues

Consumer feedback provided	
Workforce	<ul style="list-style-type: none"> • Too much bullying, hierarchy and status between doctors, nurses and between each other, managers sideways shifting of people who fail and lack of innovation • Health visitors check work • Lack of accountability in NGO service provider not welcome feedback nor act on it • Allied health people working in the system don't know how to cross boundary issues • Will workforce supply meet demand, now and in the future? • Greater use of nurse practitioners and nurse coordinators, social workers (incentive payments) • Upstairs don't take advice from the ground floor up and down • Staff who show empathy • Lack of innovation depressed workforce stigmatisation
Coordination	<ul style="list-style-type: none"> • Coordinated health plan by GPs and specialists • Lack of integration- HACC services-Specialisations- Orgs- e.g. health care needs to be promoted and demanded • eHealth ensures an improved chronic disease "journey" • Integrated health care - the whole patient • Care coordination: NSW Health should listen to consumers and carers about health workers, we are not a case to be managed and carried around • Have a standardised service across all areas
Information	<ul style="list-style-type: none"> • Access to directories of allied health • Access to quality information- health site • Finding ways of getting to people who don't use the web.
Evidence and best practice	<ul style="list-style-type: none"> • Doesn't exist in certain areas and used as an excuse • Over clinicalisation, no debate because "we know best", freedom of thinking, stifles innovation • Consumer perception and experience often ahead of research examples from the past. Break down the medical model
Carers	<ul style="list-style-type: none"> • Lack of respect for carers, not listened to despite their knowledge of the patient • Young carers needs are not met they should be introduced in schools • Carers not listened to
Volunteers	<ul style="list-style-type: none"> • Volunteer policy is stopping volunteerism legislation about volunteers will put us all out of business, risk management not an excuse
Palliative Care	<ul style="list-style-type: none"> • Inadequate access plus workforce supply • Lack of coordination of care at end of life
Service delivery	<ul style="list-style-type: none"> • Dietitians telling people they can't won't be able to come
Costs	<ul style="list-style-type: none"> • Cost to orgs in providing job e.g. police checks coordination stopping practice • Costs to patients how influences access to care and advice • Service cuts are always the allied health

Consumer feedback provided

	<ul style="list-style-type: none">• Inequality in refunds across disease groups very unfair, IV users diabetes• Timely reduced cost equipment to help self-manage
Parking and transport	<ul style="list-style-type: none">• Within Hospital centre there needs to be transport around, also from home to home to visits- shuttle buses, golf buggies inside the facility• Parking at health centres, hospitals GPs, the lot
CALD	<ul style="list-style-type: none">• Meeting multicultural needs