Chronic Disease Consumer Issues Report
May 2014

Introduction

In 2012 and 2013 two chronic disease workshops were facilitated by Health Consumers NSW (HCNSW). We are a statewide voice for health consumers to help them shape the NSW health system through involvement in health policy and program development.

The first workshop brought together a broad range of consumers and carers affected by chronic conditions in this state who form part of a Chronic Disease Consumer Network. 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. Chronic conditions which were represented included asthma, Parkinson's disease, diabetes, cancer, heart disease, mental health, cystic fibrosis, stroke and Alzheimer's disease.

The second workshop comprised Chief Executives and senior staff from non-government chronic disease organisations. This workshop gave these non-government organisation (NGO) representatives the opportunity to discuss the issues raised by the consumers and also to identify gaps which needed to be included.

This report collates the views from both the consumers and the chronic disease NGO's. Recommendations for action have been included for each of the identified priority areas.

The experience of consumers as the users of our health system makes them uniquely qualified to comment on the way it works. When these comments are combined with those of organisations whose roles it is to advocate for these consumers and provide services to meet their needs, the information obtained is extremely well informed and quite powerful.

This report will be provided to NSW Health to inform health policy and service delivery to assist to provide the best health outcomes for everyone. Underpinning the formal recommendations is the philosophy that respect for consumers and carers must be integral to all health service delivery in NSW. This respect must begin with decision makers in the Ministry of Health and Local Health Districts, but must also be implicit in the work of staff at all levels of care.

Priority Areas Identified by Consumers and Consumer Organisations

- **Self-Management and Self Care**
- **Access and Affordability**
- **Health Literacy**
- **Health Service Delivery and Workforce**
- **Communication**
- **e-Health Reform**
- **Carer Support**

A wide range of issues were identified under each of these key areas and these will be expanded in this report. However all were focused on improving the patient and carer experience.

Key Points Raised from the Sessions
- A good relationship between the consumer and health professional is essential for effective communication and consumer confidence in managing their health.
- Consumers want self-management on their terms and embedded throughout the health system.
- Consumers are concerned about overburdened health and other associated care services.
- 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 still concerned about system security.

Information about Consumer Participants
From the background information provided by the consumers, the average participant identified as:
- Having been diagnosed with multiple chronic conditions.
- Consulting a health professional once a month.
- Accessing 5 or more health services on a regular basis.
- Being satisfied with the level of control they have over health care decision making
- Having their health care coordinated by the GP, or other health professional.
- Having a good understanding of the basic information needed to make appropriate decisions.
- Having only just a "good" or "not very good" understanding of the range of services available to help them make appropriate health decisions.

1. Self-Management and Self Care

"Self-management is a change in practice and culture which I believe is long 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 coordinating the care with the family, patient & carer".

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

Self-management is tied to empowerment. Consumers understand the health professional's "gate keeping" role; however the way this relationship is structured sometimes puts people off managing their own health. Consumers suggested patients' specific needs should be central to decision making.

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.

The following **barriers** to self-care and self-management were identified:
* Lack of knowledge of facilities and resources available.
* Lack of assistance for people who want to improve their self-management skills.
* Self-management motivation must come from the consumer.
* Poor community knowledge of preventative strategies.

Recommendations for the health system:
1. Staff need to take time to understand a person's social life and motivating factors.
2. Service providers need to be aware of the needs of consumers.
3. Medicare Locals need to convince GP's of the worth of helping consumers pursue self-management and self-care strategies.
4. More facilities to promote physical activity are needed.
5. Training in self-management is needed for providers and carers.
6. Increased utilisation of practice nurses to promote better self-care.
7. Improved information for new arrivals to Australia.
8. Support models of care that promote self-care and self-management.

The role of NGO's:
1. Provide or refer to, appropriate self-management programs available in the community.

2. Access & Affordability

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

"Have not attended a cardiologist since February 2011. Cannot afford to do so."

All consumers agreed that living with a chronic illness creates a financial strain on individuals and families. Consumers were particularly concerned about the cost of accessing allied health services and medical specialists. It was recognised that some consumers miss appointments or fail to fill prescriptions because they cannot pay for them at the time.

People with one or more of the following situations are particularly disadvantaged:
* Aboriginal and Torres Strait Islander background
* Disability
* Living in rural and remote communities
* CALD background
* Low incomes

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

Access to services was hindered not only by affordability, but also a **lack of information i**n relation to the following:
- Availability of services and subsidies.
- Programs which can assist consumers with expenses.
- Transport, including community and volunteer transport options.

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.

Poor communication and links between services result in a poor consumer experience. The **cost of some services** puts them out of the reach of the average consumer.

Recommendations for the health system:
1. Increased information on means testing for general health services.
2. More equitable distribution of Medicare rebates across different chronic conditions, for example people with diabetes are eligible for rebates for exercise programs while people with respiratory disease are not.
3. Greater awareness amongst health service staff that private health insurance is out of the reach of many consumers.
4. Consult with a wide range of relevant consumer groups to ensure different points of view are taken into account when developing services, for example consult widely across the Aboriginal community.
5. Mental health services need to be treated the same as other health services.
6. NSW Ministry for Health website should have a consumer portal to relevant NGO disease organisations.
7. Introduce more "one stop shops" and single point of access for services to improve the consumer experience.
8. Move more services to community based, accessible locations, away from the acute setting.
9. Maintain acute specialist services for complex care and treatment.
10. Provide more after hours and weekend services.

The role of NGO's:
1. Ensure information is accessible across language groups.
2. Utilise the appropriate medium for the age group such as blogs for younger people.
3. Ensure new technology enables location of services on website.
4. Ensure that a range of stakeholders and service providers, such as hospitals and GPs, have access to this information.

3. Health Literacy

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

Consumers and NGO representatives agree that health literacy impacts on the capacity of a consumer to play an active role in their self-management and self-care.

Recommendations for the health system:
1. Health professionals need to encourage questions from consumers and not assume a certain level of knowledge. Given not everyone is the same or has the same circumstances, alternatives need to be discussed.
2. Health professionals need to ask consumers to repeat information to ensure they have understood and not just ask whether they understand.
3. Plain language needs to be used when health professionals are talking with consumers.
4. Consumers need to receive information on what other services they need to see and what they can expect from those services.
5. Consider layout and design of printed material.
6. Provide information both online and on paper, for those people (particularly older people) who may not have access to a computer.
7. Fund "Information Officer" roles in Local Health Districts.
8. Promote greater coordination between Medicare Locals, Local Health Districts and NGO's.

The role of NGO's
Provide peer support opportunities.
1. Promote services to consumers through various means and through a Ministry of Health portal.
2. Develop relationships with Medicare Locals and Local Health Districts.

4. Health Service Delivery and Workforce

"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".

Consumers called for health service delivery which is flexible and able to respond to the needs of all consumers and carers. It was noted that mental health both as a co-morbidity and a chronic illness needs to be better incorporated into chronic disease service planning and delivery.

Consumers would like to see the health and care workforces better supported to deliver quality care. A common concern was the ageing 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.

Issues relating to primary care and in particular the GP role, were also a major concern to consumers and the comments made are listed in Appendix 2. While it is recognised that GP's have the main role in coordination of care, there are many shortcomings in care coordination.

Consumers with experience of disability services reported negative experiences with NGOs providing care and employment services. Concern was expressed by some consumers about the

increasing number of NGOs providing services and the lack of appropriate regulation and oversight, linked to receiving government funding.

Other issues identified by consumers in relation to health service delivery were:
- Poor transition planning between adolescent and adult health services.
- Appointments with health professionals are too brief.
- Extensive waiting time to access specialist care.
- Poor referral processes,
- A person centred service may be more effective than funding a disease focused service.

Recommendations for the health system:
1. Move to a person centred funding model.
2. Promote increased staffing in care services through improved conditions and pay.
3. Improve the information from care providers about how to access services.
4. Continued training for health professionals in "person centred care".
5. Develop a greater awareness of how people live and take that into account in planning health care.
6. Be more aware of what motivates patients.
7. Provide more "one stop shops" which provide holistic, multidisciplinary care and lesson the travel burden for consumers.
8. Consider carers when planning patient health care.
9. Promote self-management programs for people living with chronic disease.
10. Integrate proven good practice models into the system.
11. Develop a new skills mix which removes the need for all care to be delivered by clinical staff.
12. Undertake early planning to prepare young people to move from adolescent to adult health services.
13. Involve appropriate NGO's in the development of new models of care.
14. Support NGO's to develop appropriate clinical governance frameworks and to employ their own staff to deliver person centred care. (The UK has models which can provide learning such as the Terrence Higgins Trust and other HIV services).
15. Develop and enforce appropriate regulatory frameworks to ensure high quality service delivery and accountability by NGOs.
16. Provide a multidisciplinary service for the patient which includes the GP.
17. Provide NGO's with a case management budget.
18. Health professionals need to understand not all consumers have a GP.
19. Make greater use of pharmacists to disseminate information and education.
20. Provide special funding for GP's to undertake targeted work in partnership with NGO's.

The role of NGO's:
1. Collate patient journey information which can be used by HCNSW to raise issues with NSW Health and Local Health Districts.
2. Be an active partner in the development of new models of care.
3. Share examples of good practice.
4. Collaborate on development of a training program on consumer participation, for health professionals.
5. Collaborate with GP's on the coordination of care.
6. Work with Medicare Locals to improve information and education dissemination.

9.   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".

"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."

Consumers understand that health professionals have limited time. Therefore there has to be good communication between the consumer and health care provider. 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.

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

Three major issues were identified regarding communication and health:

- 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.
- Consumers and carers often feel the health professionals they see don't take the time needed to have meaningful discussions about treatment options. There was agreement among participants that a supportive environment and a sense of mutual trust and respect are crucial.
- 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 improved consumer health literacy. There is a need for health professionals to recognise the importance of the language they use.

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 even leave the consumer and carer feeling ignored.

Recommendations for the health system:
1. Health professionals to encourage questions from consumers and carers and not assume knowledge.
2. Collaborate with teaching institutions to promote communication training for health professionals. This training needs to also address discrimination and stigma issues.
3. Provide education for staff and consumers in health literacy issues.
4. Alternative treatment options needs to be made known to consumers and carers.
5. Rather than asking "do you understand", consumers should be asked to repeat the information they have received.
6. During a consultation, consumers should receive information about what services they need to see next and what they can expect to receive from that service.
7. Consumers should be included in all discussions about their health.
8. Consistent terminology needs to be used.
9. LHD's need to consider a trial of a "Health Information Officer" position.

The r*ole of NGO's:*
1. Provide education for consumers in how to speak up and assert their right to receive appropriate answers to their questions.

10. eHealth Reform

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

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

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

The area of electronic health information systems is a confusing one for consumers and opinion is divided. The two topics discussed with consumers were the Personally Controlled Electronic Health Record (PCEHR) and Telehealth.

Consumers believe that PCEHR technology could improve health management; however the security of the records remains a concern. In particular this centred on who would have access to this information.

Telehealth was recognised as a positive development for consumers, with significant benefits for rural and remote consumers. There were questions raised however in regard to how these systems were to be funded and whether the financial burden would fall on the consumer.

It was acknowledged that consumers have limited understanding of this area which leads to anxiety and various questions about how it would be implemented. There was also concern about the potential for increased use of telehealth leading to decreased face to face time with health professionals. This could have a negative impact on people who are already socially isolated.

Consumers identified the strengths of eHealth to be:
- allowing consumers to share their medical history with different health professionals
- improving rural and remote access
- reducing travel time for consumers to and from appointments

Weaknesses which were identified were:
- lack of privacy and potential for abuse
- reduction in personal relationships between professionals and consumers
- "personal control" could lead to certain health information being hidden from health professionals

Recommendations for the health system:
1. Organise information forums in various locations in NSW to explain how the eHealth systems work and their role in managing health.

The role of NGO's:
1. Work with NSW Health to arrange consumer information and educations sessions about eHealth.

11. Carer Support

"Carers must be the crucial part of the team when the patient doesn't have the capacity or will!"

"I personally benefited a great deal from carer training".

Participants in the sessions run by HCNSW noted the importance of the carer's role. Carers can be a crucial member of the health care team. It was highlighted that for self-management to be effective, carers must have access to the appropriate information and resources regarding the health needs of the person they care for.

It was also 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.

While being integral to the ongoing health of patients, carers can become unwell themselves because of their caring burden. There are also significant costs associated with caring for someone with a chronic illness, or disability.

Recommendations for the health system:
1. Health professionals need to consider the carer's needs and situation when planning appointments.
2. Health professionals need to recognise that carers need support from other carers (peer support) as well as counselling and respite.
3. Health professionals must listen to carers.
4. Provide day programs which are suitable to the needs of the individual, the most pressing example being that young people need to be with other young people and not with older people.
5. Locate services together to reduce travelling time.

The role for NGO's:
1. Advocate for the needs of carers in relation to their chronic disease target group.
2. Collaborate with the health system in education and support for carers.

Conclusion

This report has been put together by HCNSW staff from consultations held with health consumers and carers affected by chronic diseases, as well as the Chief Executives and senior staff of health NGOs. The concerns raised by consumers and carers have been given prominence in this report.

This report will be presented in its entirety to the NSW Ministry of Health and will inform our ongoing discussions and advocacy efforts with the Ministry and other decisions makers.

This report was a joint effort and HCNSW would like to thank everyone who contributed. In particular to the health consumers and carers who volunteered to their time, as well as the staff from the various non-government organisations who contributed so generously. We also acknowledge and thank the HCNSW members who reviewed and commented on the earlier drafts of the report.

Appendix 1

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	• 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	• 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	• 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
Sharing information with consumer	• 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

Consumer feedback provided	
Confidentiality	• 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	• 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	• 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	• Resistance from medical and allied health services • Effective triage system in hospitals that recognise co morbidities
Cultural Issues	• CALD and Aboriginal communities have different requirements

Topic: Access and Affordability

Consumer feedback provided	
Coordination of Services	• 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 • 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 conclusive 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

Consumer feedback provided	
	• Lack of coordination of health professionals (working from the same page). Should work together as a team with consumer and carer
Costs	• 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	• 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	• 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
Culturally appropriate services	• 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	• 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	• New technologies should help tele-consultations, www to help increase health literacy

Topic: Health Service Delivery & Workforce

Consumer feedback provided	
Services	• 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

Consumer feedback provided	
	- 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	- 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 reconnected - Together holistically and from other cultures
Carers/ Family	- 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	- 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
Communication of Information	"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

Consumer feedback provided	
Age issues	• Need flexibility in age related programs • Arbitrary decisions made on the basis of age create inequality
Training	• More training places • Training at the installation of equipment
Cultural and Special needs	• People with special needs, disabilities, CALD communities and Aboriginal communities communication problems are ignored. Not assessed holistically. Get discharged early because they are difficult needs not met

Topic: Telehealth

Consumer feedback provided	
Usability	• 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	• 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 • Provision of scripts by pharmacy instead of returning to GP • Physical capability to utilise system
Confidentiality	• 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

Consumer feedback provided	
	• Personalised records required • Archived data not being used by third parties • Confidentiality
Cost	• 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	• Let's get it happening faster • Reliability what happens when the technology fails • Use of interactive devices
Increase isolation	• Less personal contact so confirms isolation, or does it? • Isolate people – decreased community inclusion
Empowerment	• Power to consumers • Empowering increase awareness self-management
Carers	• Carer included in tele-health process

Topic: Primary Care

Consumer feedback provided	
Service provision	• 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 basic services • 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	• Need funding for all health services • Cost of primary care with fewer bulk billing • Medicare to fund chronic care consultations

Consumer feedback provided	
	• 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	• 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 • Ageing and retiring of GPs – How to replace them
Information sharing	• 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	• 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	• Need to access point of care technology

Topic: Other Key Issues

Consumer feedback provided	
Workforce	• 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)

Consumer feedback provided	
	• Upstairs don't take advice from the ground floor up and down • Staff who show empathy • Lack of innovation depressed workforce stigmatisation
Coordination	• 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	• 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	• 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	• 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	• Volunteer policy is stopping volunteerism legislation about volunteers will put us all out of business, risk management not an excuse
Palliative Care	• Inadequate access plus workforce supply • Lack of coordination of care at end of life
Service delivery	• Dietitians telling people they can't / won't be able to come
Costs	• 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 • Inequality in refunds across disease groups very unfair, IV users diabetes • Timely reduced cost equipment to help self-manage
Parking and transport	• 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
Cultural Needs	• Meeting multicultural needs and the needs of Aboriginal communities

Appendix 2

Attendance at CEO workshop:

ORGANISATION	NAME
Alzheimer's Australia NSW	Jo-Ann Brown
Arthritis NSW	Nettie Burke
Association for the Wellbeing of Children in Healthcare	Anne Cutler
Asthma Foundation NSW	Michele Goldman
Australian Diabetes Council	Janice McLay
Cystic Fybrosis NSW	Heidi Bock
Motor Neurone Disease NSW Inc	Graham Opie
Physical Disability Council of NSW	Ann-Mason Furmage
Positive Life NSW / Health Consumers NSW	David Crawford
Schizophrenia Fellowship of NSW Inc	Robert Ramjan AM
Stroke Recovery Association	Michelle Sharkey
Unicorn Foundation / Health Consumers NSW	John Leyden
Health Consumers NSW	Karen Filocamo
Health Consumers NSW	Alice Gentle
Health Consumers NSW	Morag Morrison

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Health Consumers NSW

Established in 2010, and funded by the NSW Ministry of Health 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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