
Community Report on the Blue Mountains Community Forums on Health

(Incorporating the results of the
online Blue Mountains Health Community Survey)

held Thursday 30 August 2012

Conducted by the
Interim Joint Health Consumer Committee
of the Nepean-Blue Mountains Medicare Local
and the Nepean Blue Mountains Local Health District



Health
Nepean Blue Mountains
Local Health District



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This document is available to download at www.nbmmml.com.au/CommunityForums

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Published June 2013

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ACKNOWLEDGEMENTS

The Darug and Gundungurra people are acknowledged as the traditional Aboriginal owners of the land where the Blue Mountains Community Forums on Health were held. This project has been conducted across Darug, Gundungurra and Wiradjuri lands.

The community forums were developed and organised by consumers for consumers. Thank you to the consumer members of the Interim Joint Health Consumer Committee of the Nepean-Blue Mountains Medicare Local and Nepean Blue Mountains Local Health District who represented their local government areas of Blue Mountains, Lithgow, Penrith and Hawkesbury who worked hard to ensure that consumers had an opportunity to have their say, and to be heard. We would like to acknowledge the support of the following organisations and people.

- The Medicare Local and the Local Health District have provided their support and funds towards this joint consumer engagement strategy. These organisations share the same boundaries and have worked in partnership with local residents and health consumers to plan, develop and resource these local consumer-focused community forums.
- We were honoured to have as guests at the forum Aunty Sharon Halls and Uncle Graeme Cooper who provided a Welcome to Country and an acknowledgement of the Traditional Owners of the land of the Blue Mountains. Aunty Carol Cooper also was a participant and contributed to the forum discussions and stories.
- We acknowledge the assistance of all the Consumer and Chronic Disease Networks in the Blue Mountains who circulated information about the forums to their people.
- Thanks to Blue Mountains City Council Library for distributing flyers via their early morning lending library at Katoomba and Springwood stations.
- Thanks to Professor Tim Usherwood, Professor of General Practice at the University of Sydney, Professor Jennifer Reath, Peter Brennan Chair at the School of Medicine, University of Western Sydney (UWS) and Doctor Louella McCarthy Senior Lecturer, Medicine in Society, UWS, for presenting information about the consumer and community roles in health research.
- Thanks to Medicare Local and Local Health District staffmembers for providing executive support, project support, forum facilitators and a secretariat for the consumers.

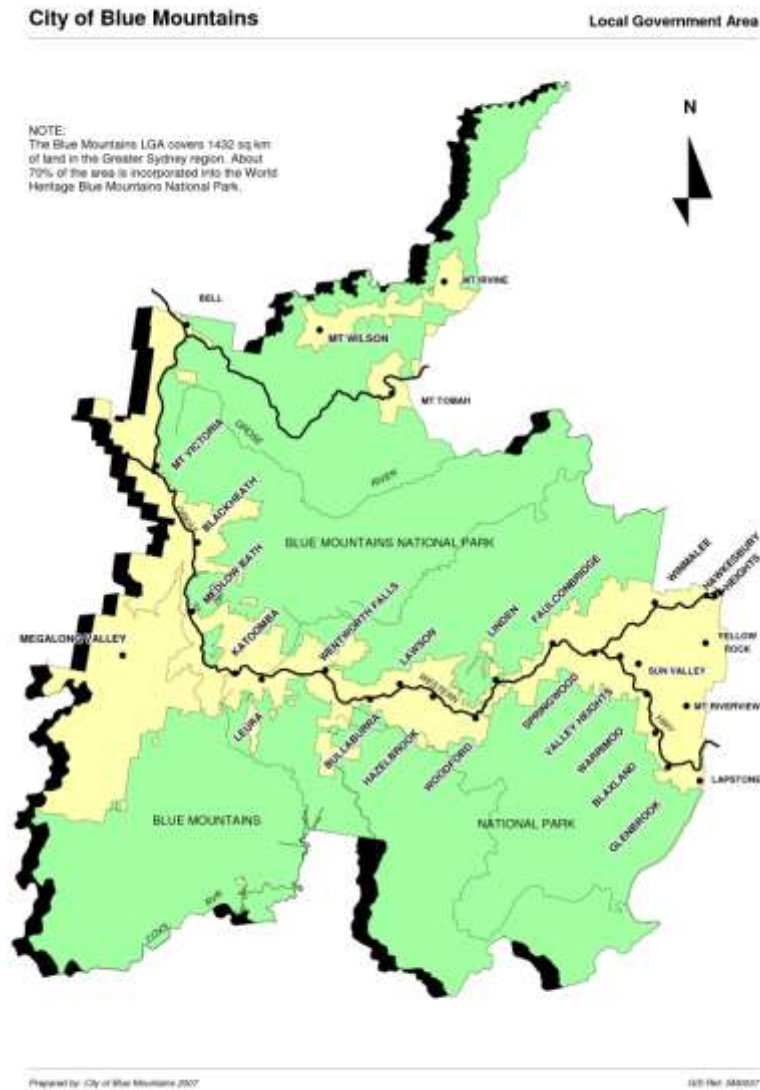
TABLE OF CONTENTS

- Acknowledgements 1
- Table of Contents 4
- Glossary of Terms and Acronyms 6
- Executive Summary 8
 - Recommendations 10
- Introduction 12
 - Overview – Blue Mountains Community Forums on Health 12
 - About the Blue Mountains 12
- Background to the Community Forums 13
 - Nepean-Blue Mountains Medicare Local 13
 - Nepean Blue Mountains Local Health District 13
 - Working Together 14
 - Consumer and Community Engagement Program 15
 - Involving Consumers in Research and Teaching 15
- Blue Mountains Community Forums 17
 - Round-table Discussions 17
 - Consumer Stories 17
 - Online Survey 18
- Community Forums Feedback and Analysis 19
 - Positive Health Service Experiences 19
 - Key Health Issues 19
 - Online Survey Summary and Analysis 21
 - Other Relevant Information 21
- Recommendations 22
- Progress on Recommendations 24
- Where to From Here 25
 - The Role of the Health Consumer Working Groups 25
 - Consumer Reference Committee of the Boards 26

Appendices

Appendix 1 Interim Joint Health Consumer Committee.....	27
Appendix 2 Blue Mountains Community Forum Agenda.....	28
Appendix 3 Blue MountainsHealth Support Groups	29
Appendix 4 Draft Consumer Communication Model	31
Appendix 5 Health Consumer Network Sign-up Form	33

Map of the Blue Mountains LGA



Source: Blue Mountains City 2007

GLOSSARY OF TERMS AND ACRONYMS

ACAT Assessment	An ACAT assessment is an assessment of your care needs. It is carried out by one or more members of your local Aged Care Assessment Team (ACAT). ACAT members will visit you in your home or in hospital to talk with you about what services you may need and what is available in your area. ¹
Acute health care	Acute health care is generally considered to be short-term medical treatment, usually in a hospital.
Allied health	Allied health includes all health professions (other than medicine, nursing and pharmacy) that require a tertiary degree to practise. Allied health practitioners form part of the public and private health systems.
CALD	Culturally and Linguistically Diverse – a general term for communities of Australia’s non-Indigenous ethnic groups other than the English-speaking Anglo-Saxon majority.
Community and consumer engagement	The involvement of healthcare consumers and the wider community in the design and delivery of health services and health services research.
CRG	Consumer Reference Group of the Blue Mountains GP Network
GP	General Practitioner – often referred to as ‘doctor’.
Health consumer	A person who uses health information, products or services, including carers of health consumers.
LGA	Local Government Area – the administrative boundaries of local government i.e. city council boundaries.
Local Health District	Local Health Districts are responsible for providing community health, hospital care and tertiary health care. Funded by the NSW Government (state government).

¹Aged Care Australia,
<http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Glossary+Index+A>

Medicare Local	Medicare Locals are primary health care organisations established to coordinate primary health care delivery and tackle local health care needs and service gaps. Funded by the Australian Government (federal government).
NBMLHD	Nepean Blue Mountains Local Health District, serving the residents of the Lithgow, Penrith, Hawkesbury and Blue Mountains LGAs.
NBMML	Nepean-Blue Mountains Medicare Local, serving the residents of the Lithgow, Penrith, Hawkesbury and Blue Mountains LGAs.
Primary health care	Primary health care is a first level of care or the entry point to the health care system for consumers e.g. general practice.
Secondary health care	Secondary health care includes services provided by medical specialists and other health professionals who generally do not have first contact with patients.
Tertiary health care	Tertiary health care includes specialised consultative health care, usually for hospital inpatients and those referred from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment.

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EXECUTIVE SUMMARY

The Blue Mountains Community Forums on Health were part of a series of forums organised by the Interim Joint Consumer Committee of the Nepean-Blue Mountains Medicare Local (the Medicare Local) and the Nepean Blue Mountains Local Health District (the Local Health District).

The Blue Mountains forums were held on Thursday 30 August 2012 and attended by 100 people. The forums were supplemented by an online survey for residents of the Blue Mountains Local Government Area (LGA) to have their say on health services in the region, to which 38 people responded.

Forum and survey participants provided a number of positive stories and comments about health services. In particular, participants were clear about praising doctors, nursing staff and other health professionals, administrative and community transport staff, community services and hospital care. They recognised that there were severe resource shortages both in the hospital and the community; however the members of staff were doing their best.

A wide range of concerns was aired. Some were specific to the Blue Mountains while others were shared by participants at the Community Forums on Health held in other LGAs. The main problems identified include:

- **Transport** access and cost and the related issue of parking. The geography of the Blue Mountains and the location of health services create many access problems which are compounded by the limited availability and high cost of transport, limited suitable public transport and set down areas, and lack of affordable and convenient parking. Transport is especially challenging on weekends and at night.
- **Aged care services:** The population is ageing and consumers were concerned about the inadequate number of residential care beds. They were also concerned with the cost of services and accessing them, discharge planning and social isolation. Carers need increased support and access to information. Palliative care and advanced care planning were also identified needs.
- **Workforce problems:** Forum participants were concerned about the shortage of GPs and the aging GP workforce. Some GPs have closed their books and it can be difficult to arrange home visits.
- **Access to information:** Across all the issues discussed it became clear there are major gaps in knowledge and public awareness of what health services are available and how to access them. Consumers want increased information about services available in both the hospital and the community (including primary care).

- **Carer respite and support** was another strong theme. Participants told us about the difficulties faced by carers and the limited resources available to support them, including flexible respite. Education and information are needed, and there is a need to recognise young children who are carers in families.
- **Impact of bushfire on access to health care:** Consumers want to know that adequate disaster planning has been undertaken, and that they know what to do in the event of an emergency for the management of their health.
- **Access to health services:** Participants told us that having to travel long distances for access to health services caused them difficulties when they are ill. Long waiting lists for GPs and specialists meant that people often attended emergency departments instead.
- **Renal Dialysis:** Participants told us that people who require dialysis need to be able to access that service at Katoomba. They currently travel to Nepean Hospital where they have to carry heavy equipment a long distance due to the parking situation. They cannot travel by train because of the possibility of infection.
- **Increase in holistic care:** Consumers told us that there is a need for people who have mental health and cancer conditions and who are elderly to be able to access affordable holistic care. They want support and advocacy for holistic care.

Recommendations

Following the Blue Mountains Community Forums, the Interim Joint Consumer Committee made 14 recommendations. These are listed below, with consumer quotes *italicised*, and in more detail on pages 20-21. Progress on the recommendations to date is reported on page 22. It is recommended that:

Recommendation 1: A centralised information access point is developed and resourced for the entire region for consumers and health service staff.

'Knowing what services are available and who and where to contact.'

Recommendation 2: The Medicare Local and the Local Health District develop a comprehensive communication plan that covers internal and external communications for consumers, including the establishment of a senior communications manager position.

'People like to be listened to and to know about health services and why decisions are made.'

Recommendation 3: The complex transport and parking issues raised by consumers are tabled and addressed by high-level transport stakeholders.

'The cost of transport and parking is just too high.'

Recommendation 4: The Medicare Local advocates for improved aged care services including the provision of nursing home beds and home care support.

Recommendation 5: More information is made available to workers and consumers about planning for end of life care.

Recommendation 6: The health workforce (GPs, nurses, allied health professionals and specialists) is increased in order to reduce waiting lists and improve timely access to both acute and primary care.

'Waiting lists for GPs and specialised services are huge.'

Recommendation 7: The Blue Mountains Health Consumer Working Group agenda includes consultation with Aboriginal and Torres Strait Islander community members and the diverse groups in the community including culturally and linguistically diverse communities and youth, as well as people with low incomes, the homeless and other vulnerable groups.

Recommendation 8: Carer support services and resources are increased as per the NSW Carers Charter and the NSW Carers (Recognition) Act 2010.

'Carers are integral to health care and need to be recognised and be part of the process.'

Recommendation 9: Consumers who are admitted to hospital and their relatives be given clear instructions on what process they should follow if they experience any difficulties.

'When things go wrong we don't know where to turn for help.'

Recommendation 10: The Medicare Local engages with the Local Disaster Plan led by the Blue Mountains City Council and local emergency services regarding consumers' health needs and access to services in the event of disaster.

Recommendation 11: The Medicare Local and Local Health District collaborate to implement illness prevention and wellbeing programs appropriate to the population.

'Preventative health care needs a higher priority to prevent health problems eventuating.'

Recommendation 12: The Working Group works in partnership with local organisations and other relevant stakeholders to address the health issues and gaps identified, and provides regular feedback to the community.

Recommendation 13: Resources for health services are increased to meet the special needs of the Blue Mountains, a regional area on the outskirts of a major city.

Recommendation 14: Best practice holistic care is researched and supported, especially for people who have a mental health condition, cancer, or are elderly, and the Medicare Local advocates for better access to holistic care.

INTRODUCTION

The Interim Joint Health Consumer Committee of the Nepean-Blue Mountains Medicare Local (the Medicare Local) and the Nepean Blue Mountains Local Health District (the Local Health District) wanted this consultation to be a process of listening to and learning from the community; it does not replace a complaints process. This process will inform the planning and priorities of the proposed Blue Mountains Health Consumer Working Group, and is part of the quality improvement cycle of health service provision.

Overview – Blue Mountains Community Forums on Health

The Blue Mountains Community Forums on Health were held on Thursday 30 August 2012. The forums were supplemented with an online survey for Blue Mountains residents to have their say on health services in the region.

These forums represent the beginning of a new joint consumer and community engagement program being rolled out by the Medicare Local and the Local Health District. With the support of these organisations, the forums and the engagement program have been initiated, organised and conducted by health consumers.

This report provides some background on the Blue Mountains, together with a brief description of the Medicare Local and the Local Health District. The community forums and survey are outlined and their results are summarised.

Participants at the Blue Mountains Community Forums on Health didn't want the engagement process to be 'just another talkfest'. They are expecting to be kept informed of actions that arise. This report is both feedback to the forum and survey participants and an action agenda for the proposed Working Group.

About the Blue Mountains

The Blue Mountains LGA covers 143,000 hectares of land in the Greater Sydney Region. About 70% of the area is incorporated into the World Heritage Blue Mountains National Park, with approximately 11% of the total land area in private ownership. In 2011 there were 75,942 people living within or nearby the 27 towns and villages along the Great Western Highway between Lapstone and Mt Victoria.²

² Blue Mountains City Council, <http://www.bmcc.nsw.gov.au/index.cfm>

BACKGROUND TO THE COMMUNITY FORUMS

Nepean-Blue Mountains Medicare Local

Medicare Locals are primary health care organisations established as part of the Australian Government's National Health Reform Agenda. They exist to coordinate primary health care delivery and tackle local health care needs and service gaps. Medicare Locals drive improvements in primary health care and ensure that services are better tailored to meet the needs of local communities³. Medicare Locals are working with local health providers, stakeholders and the communities they serve to:

- improve access to services by linking local General Practitioners (GPs), nursing and other health professionals, hospitals and aged care, Aboriginal and Torres Strait Islander health organisations and by maintaining up to date local service directories
- work closely with the NSW State Government funded Local Health Districts to make sure that primary health care services and hospitals work well together for their patients
- plan and support local after-hours face-to-face GP services
- identify where local communities are missing out on services they might need and coordinate services to address those gaps
- support local primary care providers, such as GPs, practice nurses and allied health providers, to adopt and meet quality standards
- be accountable to communities for ensuring that services are effective and of high quality.

The Nepean-Blue Mountains Medicare Local commenced operating in early 2012 across a region that takes in the Blue Mountains, Hawkesbury, Lithgow and Penrith LGAs. In the Blue Mountains LGA the general practice workforce includes 73 GPs and 30 Practice Nurses (March 2012). The LGA has experienced a chronic GP workforce shortage, which is likely to increase as 60% of practising GPs are aged over 55.

Nepean Blue Mountains Local Health District

The Nepean Blue Mountains Local Health District is one of 18 Local Health Districts funded by the NSW State Government. Local Health Districts are responsible for public hospitals, community health services and public health. Hospitals are located at Katoomba and Springwood in the Blue Mountains. Many residents need to travel out of the LGA to receive specialist or complex care at the Nepean Hospital in Penrith.

³Department of Health and Ageing, www.yourhealth.gov.au

Blue Mountains District ANZAC Memorial Hospital at Katoomba provides emergency services and a range of general inpatient services including obstetrics and gynaecology, paediatrics, general medicine and surgery, mental health, rehabilitation and geriatrics, and palliative care. These services are supported by on-site pathology, medical imaging and pharmacy as well as allied health services such as occupational therapy, physiotherapy, speech pathology, nutrition and dietetics, and social work. Outpatient clinics and services include hydrotherapy, physiotherapy, dental, antenatal, psychiatry and sexual health.

Springwood Hospital provides day surgery, palliative care, rehabilitation, geriatrics and a physiotherapy outpatient service. Medical inpatient treatment is predominantly Level 2, including geriatrics, rehabilitation and palliative care. Allied health services are available to inpatients.

Katoomba and Springwood Community Health Centres provide a range of services from health promotion, through prevention and early detection to assessment, treatment and continuing care. Community health staff work in partnership with schools, general practices, hospitals, non-government agencies and other organisations. Services include child and family health nursing, developmental screening and parenting groups, speech pathology and occupational therapy for children, playgym, counselling services, women's health, and mental health and drug and alcohol services. Springwood also provides diabetes education and oral health services.

Working Together

The Medicare Local and the Local Health District share the same boundaries, covering a geographic area of almost 9,179 square kilometres with an estimated population of almost 350,000 people.

They have established a productive working relationship. Agreed shared priorities include aged care, mental health, improving access to after-hours general practice care, child and family health initiatives, population health and planning, eHealth, and improving the information flow between our two organisations to facilitate improved services.

An early success of this partnership is the Joint Consumer Engagement Strategy which resulted in the community forums in each of the four LGAs: Blue Mountains, Nepean, Lithgow and Hawkesbury.

Consumer and Community Engagement Program

In early 2012, the Medicare Local and Local Health District partnership established a new program to increase engagement between health services and the people who use those services ('consumers').

By February 2012, the Interim Joint Health Consumer Committee of the Medicare Local and the Local Health District had been formed, comprising health consumers residing in the four LGAs.⁴ These volunteers are working with the Medicare Local and the Local Health District to find out what is important in relation to health services for the residents of the region.

The Blue Mountains community is represented on the Committee by three members of the existing Blue Mountains GP Network Consumer Reference Group for Chronic Disease. This reference group was formed in 2009 with the goals of improving self-management support for people living with chronic conditions and strengthening the voice of health consumers.

The major aim of the Committee was to plan, design and conduct a Community Forum in each LGA. The forums were seen by the Committee as an important first step in the process of engaging with health consumers across the region and establishing ongoing communication processes. In order to reach as many community members as possible the forums were held in conjunction with an online survey (also available in paper format).

Involving Consumers in Research and Teaching

The Medicare Local and the Local Health District both have strong partnerships with:

- The University of Sydney – Nepean Hospital is a teaching hospital
- The University of Western Sydney – general practice placements for medical students
- The University of Notre Dame – Lithgow Hospital and Hawkesbury Hospital are teaching hospitals.

The Universities of Sydney and of Western Sydney have strong relationships with many general practices in the area, providing placements for students. Both universities are engaged in research activities with the Medicare Local. Consumer engagement in research and in the education of health students is encouraged and supported. The partners are working to foster engaged research i.e. research undertaken *with* or *by* consumers, and not *to*, *about* or *for* them.

⁴See Appendix 1 for the list of health consumer representatives.

The role and benefits of involving consumers in research can be:⁵

- identifying health issues of concern to the community
- developing research questions that are relevant to consumers e.g. asking pertinent questions
- ensuring that the consumer perspective remains central throughout the research process
- ensuring that findings are going to have 'real life' application
- engaging the community in learning.

Consumer involvement in education of health students ensures students:

- understand that health services need to reflect the needs and priorities of the communities and consumers they serve
- appreciate experiences of consumers living with health problems
- gain insight into the barriers and difficulties that consumers may face in accessing health care
- learn to engage with consumers as partners.

⁵NHS National Institute for Health Research,
<http://www.peopleinresearch.org/find-out-about-involvement/what-difference-does-involvement-make>

BLUE MOUNTAINS COMMUNITY FORUMS

The Blue Mountains Community Forums on Health were held during morning and evening sessions on Thursday 30 August 2012 at the Springwood Sports Club.⁶ The Interim Joint Health Consumer Committee wanted to make the forums as accessible to the community as possible. They were promoted through the local media, and through community facilities including libraries and the library commuter service, the Medicare Local website and existing networks – general practices, the Blue Mountains Health Consumer Network, the Home and Community Care Network, Blue Mountains City Council networks and others.⁷

The aims of the forums were to:

- consult with the Blue Mountains community about local health issues
- provide advice on the formation and membership of the local Working Groups
- start discussion around the role consumers can play in health service planning, delivery, evaluation and research
- foster collaboration between health consumers, the Medicare Local and the Local Health District.

Participants were invited to register their interest in applying to join the Blue Mountains Health Consumer Working Group in 2013, or to suggest someone else they felt would make a good consumer representative for the Blue Mountains.

Round-table Discussions

Facilitated round-table discussions, during which key points were documented, were followed by the presentation of urgent issues back to the forum.

Consumer Stories

Participants were also given the opportunity to describe their experience with health services, using 'Your Story' sheets. Issues raised in the stories have been included in the analysis that follows. In addition, as agreed with participants, the stories have been de-identified and will be shared with providers at many levels of service provision, including with the Boards of Directors of the Local Health District and the Medicare Local. The process aims to maximise their impact on quality improvement in service provision and delivery.

⁶See Appendix 2 for the Blue Mountains Community Forum Agenda.

⁷See Appendix 3 for a list of Blue Mountains Health Support Groups.

Online Survey

In order to provide as many avenues as possible for consumers to have a say on health issues in the Blue Mountains an online survey (using Survey Monkey) was opened in the month leading up to the forums and for several weeks afterwards.

This report incorporates the overall findings from both the forums and the survey.

COMMUNITY FORUMS FEEDBACK AND ANALYSIS

Several issues arose repeatedly throughout the forums and received a strong degree of support from those present.

Positive Health Service Experiences

The forums elicited a number of positive stories and comments about local health services:

- Most hospital systems are working well.
- The commitment of many helpful staff, including nursing, administration and community transport drivers, is appreciated.
- Hospital staff and others are trying to make it all work better under severe resource shortages.
- Consumers are included in Medicare Local and Local Health District activities.

Key Health Issues

Transport and access emerged as major issues for Blue Mountains consumers. The geography and the location of health services mean that many residents must rely on limited public transport to access health care, often across large distances. The distances to and from bus stops, train stations, homes and services can also be considerable. Public transport is scaled down at weekends, while suitable transport for people living with a disability is very scarce. The cost of transport is also a problem: *'a taxi home 60 km away is not affordable'*. The excellent local community transport service is unable to cope with the demand and the long trips required.

Parking Very limited parking at hospitals and at health facilities right across the LGA, as well as the cost of parking, means that consumers park a long way from the hospital. *'You have to take [50 kg of peritoneal dialysis equipment] but can't park in the car park.'*

Implications for discharge Limited transport at weekends or after-hours can be a significant problem for consumers, particularly difficult for those with a disability.

Consumers receiving aged care packages cannot access community transport. In some cases family members and carers cannot travel together as their travel is funded separately.

Knowing what services are available across all health services: Across all the issues there are major gaps in awareness of what is available and how to access it. For example, consumers were unaware of the Pain Clinic at Nepean Hospital. Consumers also identified a duplication of some services. Consumers want more information to be provided about both hospital and community services (including primary care).

Aged care: The local population is ageing and aged care needs will increase. Consumers advised that a bed review conducted approximately 15 years ago removed 60 nursing home beds from the Blue Mountains. The area has had a chronic shortage of nursing home beds and consumers gave examples of people being admitted to nursing homes as far away as southern Sydney. The shortage of services sees conditions get worse for want of urgent attention. Participants pointed out the value of maintaining and enhancing services within the community to keep the elderly at home as long as possible, not just for their own sake but also to keep the strain off the aged care facilities.

Palliative care: Consumers requested more information about planning for the activities that will assist their care at the end of their life.

GP workforce shortage: Access to GPs in the Blue Mountains is difficult. Frustration was expressed at long waiting lists and the fact that many practices close their books to new patients on a regular basis to manage the demand. There was also recognition of the ageing GP workforce and the fact that many are nearing retirement.

Carer respite and support: Carers face difficulties and social isolation due to the limited support services. Some reported that the rigidity of available respite care left them unable to utilise respite. They called for greater flexibility of existing services and for more information about what services are available. They also called for recognition of children who are carers.

Social isolation affects many elderly consumers and others in the community. *'Community lives along a long strip [which] leads to isolation. Wellness relies on maintaining connections in community. [We] need social transport [in order to affordably] attend social events.'*

Impact of bushfire on access to health care: Consumers want to know that adequate disaster planning has been undertaken that includes how they can access urgent and basic health services when the area is bush fire affected and roads are cut.

Access to health services: Travelling long distances for health services is difficult when ill. Waiting lists for GPs and specialists lead consumers to attend the emergency department.

Gaps in support and services: Consumers need information and support services on chronic conditions including haemochromatosis and Parkinson's Disease. Home care support services are insufficient. Greater awareness of services to aid in management of chronic pain is needed.

Renal Dialysis: Participants told us that there is a need for people who require dialysis to be able to access that service at Katoomba Hospital and not have to travel to Nepean Hospital. The equipment is very heavy, parking is problematic and they cannot travel by train because of the possibility of infection.

Increase in holistic care: Consumers told of many instances illustrating a need for more holistic care. It was considered usual to treat an individual's mental health condition but to overlook their physical condition; one example described the family also being overlooked although they required assistance to help their relative. Post diagnosis cancer patients told us that they wanted access to affordable holistic care treatments to improve their quality of life. Carers gave examples of care being fragmented and uncoordinated.

Online Survey Summary and Analysis

Of the 38 people who completed the survey ('respondents') 31 did not plan to, or did not, attend the forums. The largest numbers of respondents fell into the 70 or older age group, followed by the 40–49 and 60–69 age groups. Eleven people had children living in their household. Overall, 79% of respondents use health services within the Blue Mountains, while 58% travel to Penrith, and 21% also travel further for health care.

The survey findings were in close agreement with the issues raised at the forums. The top five health care concerns of survey respondents, chosen from a list, were:

- access to GPs and general practices (67%)
- access to specialist health care services (61%)
- cost of health care (44%)
- access to hospitals (42%)
- quality of hospital care (33%).

Other Relevant Information

During 2012 a needs assessment was undertaken for the Nepean-Blue Mountains Medicare Local based on existing information including 2006 Census data from the Australian Bureau of Statistics.⁸ By 2020 people over 65 years of age will make up 20.6% of the Blue Mountains population. Rates of chronic disease are high, with 15.2% of the population with circulatory conditions and 28% of the population with musculoskeletal conditions.

As we learned in the forums, there are significant socio-economic factors affecting peoples' ability to pay for services and transport in the Blue Mountains LGA:

- 29.8% of people have difficulty paying their rent
- 28.7% of households are not connected to the internet
- 22.4% hold Centrelink concession cards
- 8.5% of families are single-parent with children under 15.
- 11% of families with children under 15 years of age are jobless

⁸Conducted by JustHealth Consultants and the Menzies Centre for Health Policy.

RECOMMENDATIONS

Overall there was an indication of a breakdown in communication about a range of issues within and across health services and with the community. Beyond formal complaints processes there is no mechanism for two-way communication between health services and the community. Following the Blue Mountains Community Forums, the Interim Joint Health Consumer Committee made 14 recommendations. It is recommended that:

Recommendation 1: A centralised information access point be developed and resourced for the entire region for consumers and health service staff. This would allow quick access to information about what services are available and how to access those services, especially for consumers seeking aged care and chronic diseases information and services. This could be achieved with the collaboration of relevant stakeholders, by coordinating this information and making it available through a 1800 telephone number and through the internet.

Recommendation 2: The Medicare Local and the Local Health District develop a comprehensive communication plan that covers internal and external communications for consumers, including regular feedback to the community concerning changes to the provision of health services and recognition of consumer stories. To achieve this requires the establishment of a senior communication manager position.

Recommendation 3: The complex transport and parking issues raised by consumers through this process are tabled and addressed by high-level transport stakeholders and consumer representatives are invited to contribute to this process.

Recommendation 4: The Medicare Local advocates for an increase in the number of available nursing home beds and Aged Care Assessment Team (ACAT) services in the region, and improved coordination of aged care services across primary care, acute care, community services and council services.

Recommendation 5: More information is made available to workers and consumers about planning for end of life care.

Recommendation 6: The health workforce (GPs, nurses, allied health professionals and specialists) is increased in order to reduce waiting lists and improve timely access for both acute and primary care.

Recommendation 7: The Working Group agenda includes further consultation with Aboriginal and Torres Strait Islander community members, and representatives of groups including culturally and linguistically diverse communities and youth, as well as people with low incomes, the homeless and other vulnerable groups. The Working Group explores the most effective way of communicating with and including these groups as a priority.

Recommendation 8: Carer support services and resources are increased as per the NSW Carers Charter and the NSW Carers (Recognition) Act 2010.

Recommendation 9: Consumers who are admitted to hospital and their relatives be given clear instructions on what process they should follow if they experience any difficulties and that there is a satisfactory outcome reported on within the health system and to the consumer.

Recommendation 10: The Medicare Local engages with the Local Disaster Plan led by the local emergency services regarding consumers' health needs and access to services in the event of disaster.

Recommendation 11: The Medicare Local and the Local Health District collaborate to implement illness prevention and wellbeing programs across the area that are appropriate to consumer needs and the needs assessment for the LGA.

Recommendation 12: The Working Group maps the actions required to address the gaps and health issues identified in this report, and works in partnership with local organisations and relevant stakeholders to address them and provide feedback on progress.

Recommendation 13: Resources for health services in the Blue Mountains are increased to meet the needs of the population. This requires recognition of the distinctive character and needs of this regional area on the outskirts of a major city.

Recommendation 14: Best practice holistic care is researched and supported, especially for people who have a mental health condition, cancer or are elderly, and the Medicare Local advocates for increased provision of holistic care treatment within the Medicare scheme.

PROGRESS ON RECOMMENDATIONS

The Medicare Local and the Local Health District are continuing to implement the Joint Consumer Engagement Strategy by recruiting consumers to the Health Consumer Working Groups. Once these groups have commenced, the Consumer Reference Committee of the Nepean-Blue Mountains Medicare Local Board will be formed. This will ensure that consumers from all of the LGAs continue to speak and be heard by the two health organisations.

A number of actions already underway have begun to address the recommendations.

Communication: There is a commitment at the Medicare Local to employ a Senior Communication Officer (**Recommendation 2**).

Transport: A meeting of high-level transport stakeholders has been convened by the Medicare Local with the Local Health District and consumers (**Recommendation 3**).

Resource allocation: The Medicare Local and the Local Health District are communicating with State and Federal Members of Parliament and other relevant stakeholders to address the issue of classification (**Recommendation 5**).

Workforce: The Medicare Local has submitted information to the Independent Review into the Australian Government's health workforce programs (**Recommendation 6**).

Gaps in engaging consumers from the diverse groups within the community: The Working Group will be invited to prioritise and address the needs of these consumers (**Recommendation 7**).

Carer support: The Local Health District runs a carer support program and provides support directly while the carer interacts with the hospital. The Medicare Local will focus on carer recognition and support in primary care (**Recommendation 8**).

Management: The Medicare Local works with the appropriate Local Disaster Plan led by the Blue Mountains City Council and local emergency services (**Recommendation 10**).

Renal Dialysis: A Renal Dialysis Unit for the Blue Mountains is a priority for the Local Health District (**Recommendation 12**).

Mental Health: The Medicare Local in conjunction with the Local Health District and community partners has submitted a funding application for the Partners in Recovery program for mental health care coordination and support (**Recommendation 14**).

Cancer care: A consumer-led research proposal to develop a pilot post-diagnosis model of cancer care has been submitted to the Medicare Local Board (**Recommendation 14**).

WHERE TO FROM HERE

The process from here involves reporting back to the community on the outcomes of the forum and establishing the Blue Mountains Health Consumer Working Group.

The Role of the Health Consumer Working Groups

During 2013 a Health Consumer Working Group, comprised of 10-12 health service consumers, will be established in each LGA. They will meet four times a year. A recruitment process will be developed by consumers and signed off by the Medicare Local and the Local Health District. Consumers with experience in and exposure to health issues, primary health care and/or hospital settings will be drawn from the local community.

A Chairperson will be appointed by the membership. One member will be the group's representative on the Consumer Reference Committee of the Boards of the Medicare Local and Local Health District. The Working Groups will advise on both the membership and the functions of the Consumer Reference Committee of the Medicare Local Board.

The Agenda for the Blue Mountains Health Consumer Working Group will include:

- addressing and prioritising the health issues identified by consumers at the community forums (as encapsulated in this report) and within their local communities:
 1. considering the key issues, priorities and recommendations tabled for action through this report
 2. developing an action plan for the LGA
 3. reporting findings to consumers and community, the Boards of both the Medicare Local and the Local Health District
 4. receiving information from health consumers regarding new health issues.
- local consultation with consumers as required by the Boards and the Consumer Reference Committee. Consultation on health resources and programs, including providing advice on program design, planning, evaluation and development of resources such as brochures
- providing effective communication and feedback in their local community
- providing and supporting community representatives on health service committees
- connecting with consumers for the purposes of health education and health research.

Community participation in the forums and the online survey was encouraging. Consumer consultation could be broadened by further outreach to families, youth and community members with culturally and linguistically diverse backgrounds. While there was Aboriginal and Torres Strait Islander representation at the forums, established community links could be strengthened. There is a need to connect more effectively with mental health consumers.

Consumer Reference Committee of the Boards

The Consumer Reference Committee of the Medicare Local Board will report directly to the Boards of Medicare Local and the Local Health District. Membership will be drawn from consumer representatives identified by the four Local Health Consumer Working Groups and will include Board representation. The Committee will oversee the whole consumer engagement strategy for the Boards.

These groups and their relationship to each other are illustrated in the Draft Consumer Communication model for the Medicare Local and the Local Health District contained in Appendix 4.

Appendix 5 contains a sign-up form for the Nepean Blue Mountains Health Consumer Network.

Appendix 1 Interim Joint Health Consumer Committee

Consumer representatives

Diana Aspinall (Chair)	Blue Mountains LGA
Annette Wickens	Blue Mountains LGA
John Haydon	Blue Mountains LGA
Bryan Smith	Hawkesbury Local Government Area (LGA)
Ellen Spyropoulos	Hawkesbury LGA (member up to January 2013)
Barry Adams	Hawkesbury LGA (commenced February 2013)
Jennifer Gilder	Hawkesbury LGA (former member)
Anne Anderson	Lithgow LGA
Judith Davies	Lithgow LGA
Lorna Fitzpatrick	Lithgow LGA
Joseph Rzepecki	Penrith LGA
Rosemary Chapman	Penrith LGA
Yung Yung Mitchell	Penrith LGA

Secretariat

Sheila Holcombe	Chief Executive Officer, Nepean-Blue Mountains Medicare Local
Debbie Wyburd	Director, Clinical Governance, Nepean Blue Mountains Local Health District
Serena Joyner	Project Coordinator, Nepean-Blue Mountains Medical Local
Rochelle French	Nepean Blue Mountains Local Health District
Jill Hoff	Nepean-Blue Mountains Medicare Local
Leanne Waters	Nepean Blue Mountains Local Health District
Carmel Vagg	Nepean Blue Mountains Local Health District

Appendix 2 Blue Mountains Community Forum Agenda



Health
Nepean Blue Mountains
Local Health District



Community Forum on Health

Thursday 30th August 2012 - 10.00 am to 12.30 pm
Springwood Sports Club, 83 Macquarie Road, Springwood NSW

*Hosted by the Joint Health Consumer Committee of the
Nepean-Blue Mountains Medicare Local and the Nepean Blue Mountains Local Health District*

AGENDA

Aims of Day:

1. To consult with the Blue Mountains community about local health issues.
2. To provide advice on the formation and membership of the Blue Mountains Health Consumer Working Group.
3. To start discussion around the role consumers can play in health service planning, delivery, evaluation and research.
4. To foster collaboration between health consumers, the Nepean-Blue Mountains Medicare Local and the Nepean Blue Mountains Local Health District.

Chair: John Haydon, Chair, Consumer Reference Group of the Blue Mountains GP Network

- 10.00 am **Welcome to Country**
Aunty Sharon Halls, Gundungurra Aboriginal Heritage Association
Uncle Graeme Cooper, Darug Mountains Group
- 10.10 am **Welcome to the Forum**
John Haydon
- 10.15 am **The role for consumers in health care**
- Sheila Holcombe, CEO, Nepean-Blue Mountains Medicare Local
 - Debbie Wyburd, Director, Clinical Governance, Nepean Blue Mountains Local Health District
 - Diana Aspinall, Chair, Joint Consumer Committee Nepean Blue Mountains
 - Professor Tim Usherwood, Head of General Practice, University of Sydney
- 10:40 am **Questions so far**
Facilitator: Serena Joyner, Nepean-Blue Mountains Medicare Local
- 10:55am Morning Tea
- 11.10 am **Hearing from you: table discussions**
Facilitator: Serena Joyner, with table facilitators
- 11:50 pm **Report back**
Table spokespersons reporting highlights to the forum
- 12.10 pm **The process from here, discussion**
Diana Aspinall
- 12.25 pm **Close** – John Haydon

Appendix 3 Blue Mountains Health Support Groups



Blue Mountains Chronic Disease Support Groups *Quick Find Directory*

- Arthritis:** Support Group of Arthritis NSW — 4787 1124
- Cancer:** Blue Mountains Cancer Help — 4782 4866
- Cancer:** Bosom Buddies—Lower Mountains Breast Cancer Support—0423 343 193
- Cardiac:** Nepean/Blue Mountains Cardiac Support Group — 4731 2039
- Cardiac:** Pacemaker Support Group— 4784 2506
- COPD / Respiratory:** Blue Mountain Airs — 4751 8117 / 4754 1458
- Diabetes:** Support Group of Australian Diabetes Council — 4751 2749 / 4754 2150
- Dystonia:** Dystonia Support Group — 4784 3368 / 0414 648 571
- Haemochromatosis:** Haemochromatosis Support Group — 4787 7937
- ME/Fibromyalgia/Chronic Fatigue:** Support Group — 4759 2592
- Mental Health:** GROW — Peer Support for Mental Health — 1800 558 268
- Multiple Sclerosis:** Upper and Lower Mountains Support Groups — 1800 042 138
- Parkinson's:** Blue Mountains Parkinson's Support Group — 4757 1778
- Prostate Cancer:** Nepean/Blue Mountains Prostate Cancer Support Group —
4730 3122
- Stroke:** Blue Mountains Stroke Recovery Club — 9807 6422 / 1300 650 594

"Becoming a member of a Support Group can bring you a gift of camaraderie and an understanding and knowledge of how you and others can live with any chronic condition." John Haydon, Chairperson, Consumer Reference Group—Blue Mountains GP Network.

Contact: Serena Joyner, Project Coordinator, serena@bmdgp.com.au, 02 4758 9711.

www.nbmmi.com.au
PO Box 903, Penrith NSW 2751
Suite 5B, Level 1, 61-79 Henry St, Penrith NSW 2750
T 02 4721 1150 F 02 4721 1176

Medicare Locals gratefully acknowledge the financial and other support from the Australian Government Department of Health and Ageing
Wentworth Healthcare Limited (ABN 88 155 904 975) trading as Nepean-Blue Mountains Medicare Local

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Appendix 4 Draft Consumer Communication Model



NEPEAN BLUE MOUNTAINS LOCAL HEALTH DISTRICT (NBMLHD) & NEPEAN-BLUE MOUNTAINS MEDICARE LOCAL (NBMML)

These two organisations formed a partnership to resource and implement the consumer engagement across the whole area.

CONSUMER COMMUNICATION MODEL EXPLAINED

Inaugural Interim Consumer Committee Meeting – Feb 2012.

- Membership was made up of consumers from existing health consumer groups across the four Local Government Areas and they came from Primary Health Care and Local Hospital settings
- The committee aimed to over six months period plan, design and conduct health consumer forums in the four LGAs with an outcome of a report of health issues identified by consumers for the Boards to consider
- A contact register has been compiled for existing health consumer representatives and the committees they are on in order to coordinate support and training for existing and new consumer representatives
- Committee members to be involved in the analysing, writing and making recommendations in a report outlining the findings of the health consumer forums
- With consent a mail out list of all health consumers and consumer organisations has been compiled

Local Health Consumer Forum meetings (4) were held in the local communities of Lithgow, Hawkesbury, Nepean and Blue Mountains.

- The aim was to have consumers identify local health issues
- Provide suggestions for possible membership of a permanent local Health Consumer Working Group 2013

Role of Health Consumer Working Groups (4) one in each LGA meeting 4 times per year

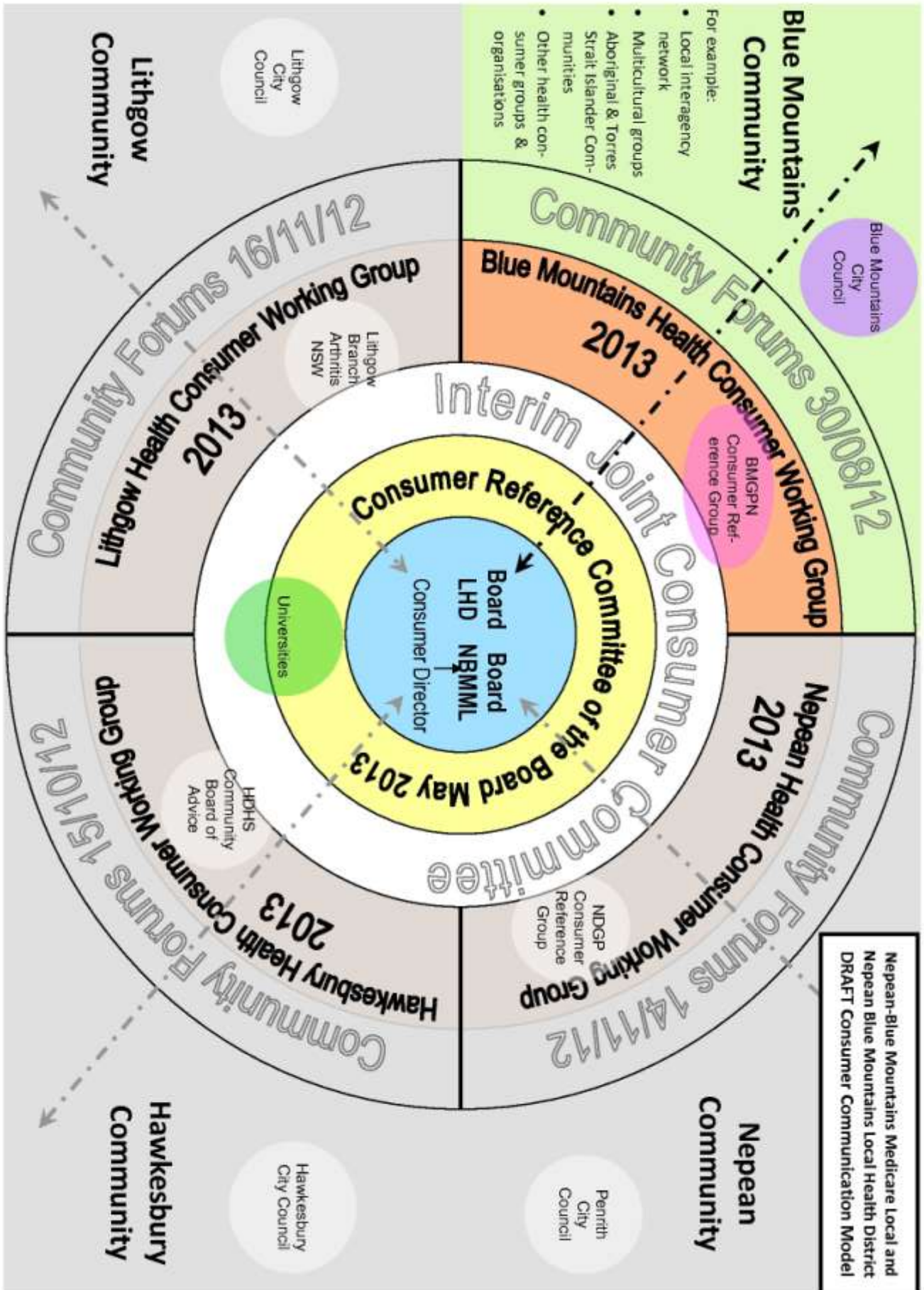
There will be a recruitment process formulated by consumers and signed off on by the two organisations for the membership of these groups. Health consumer applicants are to be drawn from the local community, primary health care and hospital settings.

- Membership will be between 10 and 12 local health consumers and a Chairperson will be appointed
- One member (most probably the Chair) will be the groups representative on the Consumer Reference Committee of the Board
- The Health Consumer Working groups will advise on both the membership and the functions of the Consumer Reference Committee of the Board
- The Agenda for these meetings will include: the health issues identified by consumers at the forums and in their local communities, local consultation with consumers as required by the Boards and the Consumer Reference Committee, effective communication and feedback in their local community, and providing community representation on health committees

Consumer Reference Committee of the Board

- Membership will be made up of the representatives identified by the four Local Health Consumer Working Groups with the NBMML Director–Consumers and a Director of the NBMLHD Board
- This committee will report directly to the NBMML and NBMLHD Boards and communicate back to the local Health Consumer Working Groups through their representatives.
- This committee will have a role to overview the whole consumer engagement strategy for the Boards

FOR FURTHER INFORMATION PLEASE CONTACT: Serena Joyner on 02 4758 9711, serena@bmdgp.com.au



Appendix 5 Health Consumer Network Sign-up Form

Blue Mountains Health Consumer Network

If you wish to be included in the Nepean Blue Mountains Health Consumer Network please provide your details below:

Full Name:(essential) _____

Phone: _____ **Mobile:** _____

Fax: _____

Email: _____

(We prefer to communicate with you by email, but if you don't have an email address or prefer to receive updates by mail please 'none'.)

Postal Address: _____

Suburb: _____ **Postcode:** _____

Are you connected to a support group, consumer group or a service that connects with health consumers? Please indicate the group here:(optional)

Do you know of any other groups or people that should be invited to participate in this network?

Would you like to contribute in some way towards the health consumer engagement across the Blue Mountains?

Yes No, not at the moment but please keep me informed.

Consent to inclusion in the Blue Mountains Health Consumer Network email/internet group:

(Please tick the applicable boxes)

- I consent to my contact details being added to the mailing and email list for health consumers across the Blue Mountains area and broader Nepean, Blue Mountains, Lithgow and Hawkesbury area.
- I consent to the Nepean-Blue Mountains Medicare Local securely storing my details for the purposes of contacting me about future opportunities to participate as a consumer representative in the activities of the Medicare Local.
- I consent to receiving communication from the future Blue Mountains Health Consumer Working Group and the Joint Health Consumer Committee of the Nepean-Blue Mountains Medicare Local and the Nepean Blue Mountains Local Health District.

Name (please print): _____ Date: _____

Signature: _____

Please hand in your completed form at the end of the forum. Thank you.

Alternatively, return to :

Nepean-Blue Mountains Medicare Local

PO Box 74, HAZELBROOK NSW 2779

Email: admin@bmdgp.com.au

Fax: (02) 4758 9722

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