
Community Report on the Lithgow Community Forums on Health

(Incorporating the results of the
online Lithgow Health Community Survey)

held Friday 16 November 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.nbmml.com.au/CommunityForums

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The community forums were developed and organised by consumers for consumers. Thank you to the health 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 Lithgow, Penrith, Hawkesbury and Blue Mountains and who worked hard to ensure that consumers had this opportunity to have their say, and to be heard. We would like to acknowledge the support of the following organisations and people.

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Map of the Lithgow Local Government Area



Source: Lithgow City Council

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 health care 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.
Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)	IPTAAS is a subsidy program that provides financial assistance to help with travel and accommodation costs for people (and eligible escorts) who need to travel long distances to access specialist treatment not available locally. Patients travelling at least 100 km each way, or at least 200 km per week cumulative distance, are eligible to apply for IPTAAS subsidies. ²

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

²NSW Ministry of Health, <http://www.health.nsw.gov.au/transport/Pages/default.aspx>

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).
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.
NDGP	Nepean Division of General Practice
Primary health care	Primary health care is a first level of care as 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.

EXECUTIVE SUMMARY

The Lithgow 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 Lithgow Community Forums on Health were held on Friday 16 November 2012 and attended by 91 people. The forums were supplemented with an online survey for residents of the Lithgow Local Government Area (LGA) to have their say on health services in the region, to which 44 residents responded.

Many problems were identified. Some were specific to the Lithgow LGA while others were shared by participants at the Community Forums on Health held in other LGAs (Blue Mountains, Nepean and Hawkesbury). The proposed Lithgow Health Consumer Working Group will have an important role in progressing the recommendations arising and in ongoing consumer and community consultation.

The main problems identified include:

Transport difficulties: The requirement to travel beyond the Lithgow LGA to access specialist and hospital services creates hardship and presents many problems, for example the cost of private transport and parking and limited public transport.

Distance is a key issue for residents, especially for consumers living in the more remote reaches of the LGA. As well as cost and time issues, the provision of cross-border health services creates communication and coordination challenges that need to be addressed.

Accommodation: Residents who don't qualify for the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) subsidy incur the same transport costs, and in some cases higher transport costs, than those who do, due to way that the eligibility boundary applies to Lithgow. These costs also affect the visiting family members and can isolate the person from their local support.

Aged care: There is an urgent need to improve access to aged care services and support, both in-home care and residential care. Lack of aged care assessment services is a major problem. Carers need increased respite, support and access to information. Palliative care and advanced care planning were also identified needs.

Knowledge, community expectations and where to go to get information: Across all the issues raised there are major gaps in knowledge and public awareness of what health services are available and how to access them, leading to misunderstanding and frustration.

Boundaries and cross-border use of health services: Consumers want flexibility to access health services in other areas, and are aware of people from other areas accessing Lithgow services. Some were concerned about how services cope with the demand from outside their own area. Service coordination and communication problems can occur in cross-border care.

Workforce problems: Consumers identified a shortage of GPs, specialists and allied health providers. Some GPs have closed their books and it can be difficult to arrange home visits. Telehealth is one means of accessing specialist and allied health services and should be expanded. Consumers want to know which visiting specialists will continue to use rooms at the hospital.

Aboriginal health services: Aboriginal community members told us that there is a shortage of Aboriginal health services in the Lithgow area. Better consultation with the Aboriginal and Torres Strait Islander community is needed to enable better health care.

Mental health services: Acute mental health services are not available in Lithgow. Having to go to Katoomba or Bathurst isolates consumers from support systems and services. Psychiatric services are available by telehealth.

Communication: Consumers want better communication between health services and between health professionals and consumers. They want to be kept informed of service changes and they feel that some health professionals could improve their communication skills.

Recommendations

Following the Lithgow Community Forums, the Interim Joint Health Consumer Committee made 16 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 and the Local Health District advocate for Lithgow to be included in the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS).

Recommendation 5: The Medicare Local advocates for increased service and coordination for aged care, particularly the urgent need for increased Aged Care Assessment Team (ACAT) services in the region.

Recommendation 6: The health workforce (GPs, nurses, allied health professionals and hospital staff) is increased 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 Medicare Local and the Local Health District work collaboratively with the Lead Clinicians Group to increase provision of relevant specialist and allied health services to consumers in Lithgow via various means, for example extra telehealth sessions.

Recommendation 8: The proposed Working Group agenda includes further consultation with Aboriginal and Torres Strait Islander community members and people from different cultures living in the area, as well as with people living on low income, with families, men, and young people.

Recommendation 9: The Working Group explores and advises the service network on access issues for residents living in remote parts of the LGA.

Recommendation 10: The Medicare Local and the Local Health District engage with the Aboriginal and Torres Strait Islander community to provide relevant and culturally appropriate health services.

Recommendation 11: 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 12: 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 13: Consumers who are admitted to hospital and their relatives are given clear instructions on what process they should follow if they experience any difficulties, and that outcomes are reported on within the health system and to the consumer.

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

Recommendation 14: The Medicare Local advocates for inclusion of the Lithgow area in the discharge planning section of the Personally Controlled Electronic Health Records (PCEHR) project.

Recommendation 15: The Blue Mountains GP Network Consumer Reference Group for Chronic Disease takes immediate action to address the need for a support group for people with cardiac conditions in the Lithgow area.

Recommendation 16: The Working Group works in partnership with local and community organisations and other relevant stakeholders to address the issues and gaps outlined in this report and provides regular feedback to the community.

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. Consultation outcomes will inform the planning and priorities of the proposed Health Consumer Working Groups, and form part of the quality improvement cycle of health service provision for the region.

Overview – The Lithgow Community Forums on Health

The Lithgow Community Forums on Health were held on Friday 16 November 2012 with 91 participants attending. The forums were supplemented with an online survey for all residents of the Lithgow Local Government Area (LGA) to have their say on health services in the region, to which 44 residents responded.

The forums represented the beginning of a new joint consumer and community engagement program being rolled out jointly by the Medicare Local and the Local Health District. With the support of these organisations, the forums were initiated, organised and conducted by health consumers. Sheila Holcombe, (Chief Executive Officer of the Medicare Local), Kay Hyman (Chief Executive Officer of the Local Health District) and Jill Marjoram (General Manager of Lithgow Hospital) attended the forums. Participants heard presentations from each of them and asked questions in relation to the changes to Lithgow Private Hospital.

Participants at the Lithgow Community Forums on Health want the issues they raised to be taken on board. They are also expecting to be kept informed of actions that arise. This report of what consumers told us at the forums and in their survey responses is both feedback to the participants and an action agenda for the proposed Lithgow Health Consumer Working Group.

About the Lithgow Area

The Lithgow LGA is located about 140 kilometres west of Sydney. It covers an area of 4,551 square kilometres, from the Capertee and Wolgan Valleys in the north to Little Hartley in the east, Tarana in the south and Meadow Flat in the west.³

The LGA has a population of 20,160 people.⁴ Eighty-five per cent of residents were born in Australia, which is much higher than the state average (67%). Compared to the NSW average, there are fewer residents aged 20–44 years and a higher proportion of residents aged over 60.

Initially established as farming and then a mining community in the late 19th century, the Lithgow LGA developed into a booming mining, power generation and manufacturing region during the 20th century. Since the mid-1980s however, reduced demand, automation and rationalisation have caused the loss of nearly 2,000 jobs. Today farming continues with cattle, sheep, goats and apples, while industries include coal mining, light engineering works, munitions and food manufacturing, pyrotechnics, quarrying and timber milling.

³ Lithgow City Council <http://www.lithgow.nsw.gov.au/>

⁴ Australian Bureau of Statistics, 2011 Census
http://www.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/LGA14870?opendocument&navpos=220

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 communities⁵. 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 local communities to ensure services are effective and of high quality.

In 2012 the Nepean-Blue Mountains Medicare Local commenced operating in the Lithgow, Blue Mountains, Hawkesbury and Penrith LGAs. The Lithgow LGA has 32 practising GPs (January 2013), as well as 15 Practice Nurses working across four practices. The area has an ongoing GP workforce shortage.

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.

⁵ Department of Health and Aging, www.yourhealth.gov.au

Lithgow Health Services consists of the 46-bed Lithgow Hospital and the Lithgow Community Health Centre which is co-located. The Community Health Centre provides and refers to a broad range of generalist and specialist programs and services, ranging from lifestyle and family health to specialist mental health and drug and alcohol services. Nepean Hospital at Penrith is the main referral centre. It is 90 minutes away by road.

Working Together

The Medicare Local and the Local Health District share the same boundaries, covering a total land 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, eHealth, and improving the information flow between the two organisations to facilitate improved services.

An early success of this partnership is the Joint Consumer Engagement Strategy which resulted in forums in the four LGAs: Lithgow, Blue Mountains, Nepean 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.⁶ These volunteers are working with the Local Health District and the Medicare Local to find out what is important in relation to health services for local residents.

The Lithgow community is represented on the Committee by two members of the Lithgow Branch of Arthritis NSW (Lorna Fitzpatrick and Judith Davies) and one representative from the Lithgow Health Council (Anne Anderson). These members played active roles in the planning, delivery and facilitation of the forums.

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).

⁶ See Appendix 1 for the list of health consumer representatives.

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 also engaged in research activities with the Medicare Local. Consumer engagement in research and 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.

The role and benefits of involving consumers in research can be:⁷

- 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.

⁷ NHS National Institute for Health Research,
<http://www.peopleinresearch.org/find-out-about-involvement/what-difference-does-involvement-make>

LITHGOW COMMUNITY FORUMS

The Lithgow Community Forums on Health were held across two sessions (morning and evening) on Friday 16 November 2012 at the Lithgow and District Workmen's Club.^{8,9} During the design and planning phase, the Interim Joint Health Consumer Committee focused on making the events as accessible as possible to the Lithgow community.

Preparation for the forums was supported through the goodwill and willingness of several consumer groups in the Lithgow area, including the Capertee Valley Alliance Inc and the Lithgow Community Forum. The Chairman of the Capertee Valley Alliance invited the Medicare Local to make a presentation on health issues at a community meeting held in the Glen Alice Hall on 9 June 2012. This presentation was followed by the Lithgow Community Forum discussing local issues. Members of the two groups later circulated information about the Community Forums on Health.

The forums were promoted through the local media, community facilities including libraries and post offices, and community organisations listed in the Council's community guide, as well as on the Medicare Local website and through general practices and health support groups such as the Lithgow branch of Arthritis NSW.^{10,11}

The aims of the forums were to:

- consult with the Lithgow community about local health issues
- provide advice on the formation and membership of the Lithgow Health Consumer Working Group
- 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.

⁸ See Appendix 2 for the Lithgow Community Forum Agenda

⁹ See Appendix 3 for story in the *Lithgow Mercury*.

¹⁰ See Appendix 4 for the list of Lithgow Health Support Groups.

¹¹ See Appendix 5 for information on the Lithgow Branch of Arthritis NSW.

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 given the opportunity to describe their experience with health services, using 'Your Story' sheets. Issues raised in the stories are 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 the Local Health District and the Medicare Local. The process aims to maximise their impact on quality improvement in service provision and delivery.

Online Survey

In order to provide as many avenues as possible for consumers to have a say on health issues in the Lithgow LGA, 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 strong support from those present.

Positive Health Service Experiences

Participants provided a number of positive stories and comments about local health services. Very positive feedback was provided for the local ambulance service and Lithgow Hospital. Other comments included: *'The new cancer clinic at the hospital is great'*; *'Good service at Lithgow Hospital for knee injury'*; *'GP care is excellent'*; *'The experience with Notre Dame medical students has been excellent'*; *'Very positive experiences staying at Hope Cottage¹² ... treated like family'*; *'My healthcare hasn't cost me a cent'*.

Key Health Issues

Transport emerged as a major issue for Lithgow consumers along with the associated cost. The location of health services and the requirement to travel beyond the Lithgow LGA to access some specialist and hospital services means that residents and their families must rely heavily on private transport and limited public transport to access health care.

Aged Care was also a key theme. Consumers told us more aged care services are required urgently. Lack of aged care assessment services emerged as a major gap, with an Aged Care Assessment Team (ACAT) vacancy exacerbating the problem.

Knowledge, community expectations and where to go to get information: Across all the issues raised it became clear that there are major gaps in knowledge and public awareness of what health services are available and how to access them. The lack of awareness and mixed community expectations leads to misunderstanding and frustration. Improved internet access and uptake would be part of an effective strategy for boosting service access in the area.¹³

Boundaries and cross-border use of health services: One issue that repeatedly came up was people living outside the region needing to use health services within the Lithgow area and vice versa. Careful communication between services is needed to prevent problems for consumers. Consumers appreciate the flexibility to access health services that are most convenient or best able to meet their health needs, but are concerned about how those services cope with the demand from outside of their region.

¹² Hope Cottage is a short-term accommodation facility at Nepean Hospital for relatives of critically ill patients undergoing treatment.

¹³ A consideration in National Broadband Network (NBN) planning for the area.

Workforce problems: Forum participants reported a shortage of GPs, specialists and allied health providers. Some GPs have closed their books and it can be difficult to access home visits. Telehealth is seen as one means of accessing specialist and allied health services and it is important that this facility is available. Residents want to know which visiting specialists will continue to use rooms at the hospital. People are required to travel to Nepean or Orange for radiation therapy incurring a significant time and cost burden. Rehabilitation services are located at Bathurst or Katoomba. There is a shortage of podiatry services so consumers need to travel. There is no specialised palliative care facility in Lithgow.

Distance was an overarching issue for residents. Consumers who live in more remote parts of the LGA must travel significant distances just to reach the health services available in Lithgow. All residents are forced to travel beyond Lithgow for services that are not available locally.

Accommodation. Residents who don't qualify for the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) subsidy incur much higher transport and accommodation costs than those who do. Some who don't qualify live just outside the qualifying area, and actually travel the same distance or more than some who do qualify. These costs also affect visiting family members and can isolate the person from their local support.

Aboriginal health services: Aboriginal community members told us that there is a shortage of Aboriginal health services in the Lithgow area and urged consultation with the Aboriginal community on what they need and want.¹⁴

Communication with and from health services: Consumers told us clearly that they want better communication between health services, health professionals and consumers. They want to be kept informed of service changes and they feel that some health professionals could improve their communication skills.

Mental health services: Acute mental health services are not available in Lithgow and patients are transferred for inpatient care to Katoomba or Bathurst which isolates them from support networks. The health professional most likely to identify mental health issues is the GP. Psychiatric services are only available by telehealth.

Affordability: Consumers were concerned that people with low incomes do not receive adequate support to access services and information.

¹⁴ Census data show an increase in the population of people identifying as Aboriginal and Torres Strait Islander from 605 persons in 2006 to 904 persons in 2011.

Online Survey Summary and Analysis

Of the 44 people who completed the survey ('respondents') more fell in the 50–59 age group, followed by people over 70 then the 60–69 age group. Three quarters identified as female and six had children living at home. Almost all (95%) respondents used health services in the Lithgow area, 35% travelled to Penrith, 23% to the Blue Mountains and 28% travelled beyond. Survey responses were largely consistent with the forum findings. The top five health care concerns chosen from a list were:

- access to specialist health care services (74%)
- distance to health care services (60.5%)
- access to GPs and general practice (47%)
- access to hospitals (47%)
- support for self-management of illness (47%).

Additional issues identified included the need for a Pace Maker Support Group, the practice of sending x-rays to Nepean Hospital to be read by a specialist radiologist rather than having them read locally. Partnerships with other stakeholders such as Lithgow Council were seen as important for better health service access and coordination.

Other Relevant Information

During 2012 a needs assessment was undertaken for the Medicare Local based on existing information including 2006 Census data from the Australian Bureau of Statistics.¹⁵ In the paragraphs below the numbers have been updated with 2011 Census data wherever possible.

Increased demand for aged care services was predicted. In 2011 the population over 60 years was already 25.3%. Between 2006 and 2011 the population aged 60–84 increased by 731 people. Over the same period the LGA lost 467 people aged 25–49.

Overall, Lithgow LGA is relatively disadvantaged by Australian standards. In 2011 the unemployed percentage of the labour force was 7.2% (NSW average 5.9%). The percentage of households with a weekly income of less than \$600 was 35.7% (much higher than the Australian average of 24.7%). Internet connectivity was low, with 36.7% of dwellings reporting no internet connection. NSW Health data indicates 18% of families are single-parent families and 30% of mothers smoke during pregnancy.¹⁶

¹⁵ Conducted by JustHealth Consultants and the Menzies Centre for Health Policy.

¹⁶ This compares with 9.4% in the Blue Mountains, 14.2% in the Hawkesbury and 15.5% in Penrith, http://www.healthstats.nsw.gov.au/Indicator/mum_smomum_lgamap

RECOMMENDATIONS

Overall, the forums indicated a breakdown in communication about a range of issues, both within and across health services, and with the community. Beyond formal complaints processes consumers are asking for clearer mechanisms for two-way communication between health services and the community. Following the Lithgow Community Forums, the Interim Joint Health Consumer Committee made 16 recommendations. 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. This would allow quick access to information about what services are available and how to access them, especially for consumers seeking aged care and chronic diseases services. This could be achieved with the collaboration of relevant stakeholders 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 communications manager position.

Recommendation 3: The complex transport, parking and accommodation issues raised by consumers are tabled and addressed by high-level transport stakeholders. Consumer representatives should be invited to contribute to this process.

Recommendation 4: The Medicare Local and the Local Health District advocate for Lithgow to be included in the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS).

Recommendation 5: The Medicare Local advocates for an increase in the number of nursing home beds, for an urgent increase in ACAT services in the region, and for greater coordination of all aged care related services across primary care, acute care, community services and council services.

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

Recommendation 7: The Medicare Local and the Local Health District work collaboratively with the Lead Clinicians Group to increase provision of relevant specialists and allied health services to consumers in Lithgow via various means, for example extra telehealth sessions.

Recommendation 8: The proposed Working Group agenda includes further consultation with Aboriginal and Torres Strait Islander community members and with people from different cultures living in the area, and with families, people on low income, young people and men.

Recommendation 9: The proposed Working Group explores and advises the service network on access issues for residents living in remote parts of the LGA.

Recommendation 10: The Medicare Local and the Local Health District engage with the Aboriginal and Torres Strait Islander community to provide relevant and culturally appropriate health services.

Recommendation 11: Carer support services and resources are increased as per the NSW Carers Charter and the NSW Carers (Recognition) Act 2010.

Recommendation 12: The Medicare Local and the Local Health District collaborate to implement illness prevention and wellbeing programs that address population needs.

Recommendation 13: Consumers who are admitted to hospital and their relatives are given clear instructions on what process they should follow if they experience any difficulties, and that outcomes are reported on within the health system and to the consumer.

Recommendation 14: The Medicare Local advocates for electronic discharge planning for the Lithgow area.

Recommendation 15: Immediate action is taken to address the need for a support group for cardiac conditions, drawing on the experience of the Blue Mountains GP Network Consumer Reference Group for Chronic Disease.

Recommendation 16: The proposed Working Group works in partnership with local and community organisations and other relevant stakeholders to address the service gaps and issues outlined in this report and provides regular feedback to the community.

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 Working Groups during 2013. 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 have a voice and to be heard.

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

- **Communication and information:** The Medicare Local has committed to employing a Senior Communications 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**).
- **Workforce:** The Medicare Local has submitted information to the Independent Review into the Australian Government's health workforce programs (**Recommendation 6**).
- **Specialists and allied health:** The Medicare Local has commenced working in partnership with the NSW Rural Doctors Network to provide improved access by visiting specialists for the residents of Lithgow (**Recommendation 7**).
- **Engaging consumers from the diverse groups in the community:** The new Working Group will be advised of this agenda (**Recommendation 8**).
- **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 11**).
- **Mental Health:** The Medicare Local, Local Health District and community partners have submitted a funding application for the Partners in Recovery program for mental health care coordination and support (**Recommendation 16**).

WHERE TO FROM HERE

The process from here involves reporting back to the community on the outcomes of the forums and establishing the proposed Lithgow Health Consumer Working Group.

Role of the Health Consumer Working Groups

During 2013, Working Groups comprised of 10-12 health consumers will be established in each LGA. They will meet four times a year. A recruitment process for the groups 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 Working Group's representative on the Consumer Reference Committee of the Boards of the Medicare Local and the 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 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 on the plan to consumers, the community and the Boards of the Medicare Local and the Local Health District
 4. receiving information from health consumers regarding new health issues.
- local consultation with consumers as requested by the Boards and the Consumer Reference Committee. Consultation on health resources and programs, including providing advice on program design, planning, evaluation and the 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.

The level of community and consumer participation in the forums and the online survey was very encouraging. It could be broadened through outreach to young families, youth and men, and to people from culturally and linguistically diverse communities in the area. There was Aboriginal and Torres Strait Islander representation at the forums; however established community links could be strengthened. There is a need to connect effectively with mental health service consumers.

Consumer Reference Committee of the Boards

The Consumer Reference Committee will report directly to the Boards of the 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 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 6.

Appendix 7 contains a sign-up form for the Nepean-Blue Mountains Health Consumer Network.

Appendix 1 Interim Joint Health Consumer Committee

Consumer representatives

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

Secretariat

Sheila Holcombe	CEO, 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

Appendix 2 Lithgow Branch of Arthritis NSW

Since the inaugural meeting in March 2007 the Lithgow Branch of Arthritis NSW holds informal meetings every second month at the Lithgow Hospital and when possible there are guest speakers who address a specific topic of interest to people who have arthritis. The Branch is run by volunteers and made up of members of Arthritis NSW – people who live with arthritis.

In 2006 to support people living with arthritis, Arthritis NSW worked with the Liaison Officer for Blue Mountains to establish the Lithgow Branch. The branch and was instrumental in setting up warm water classes in the hydrotherapy pool at Lithgow Hospital and running regular Tai Chi classes. Every second month on the 3rd Friday members enjoy a social outing having lunch at a local venue.

The Branch fundraises through stalls at the Lithgow shopping complex, holding raffles when members have kindly donated prizes and information stalls at community events. All money raised goes towards Research and sponsoring children living with Arthritis to attend Camp Footloose - an annual camp for children with Juvenile Idiopathic Arthritis.

NEWS

HEALTH ISSUES: Public can have input

Story and photo: TROY WALSH

LITHGOW residents can now play a part in improving health services in the area.

Consumers who attended the Lithgow Community Forum on Health listened to a panel of speakers outline the role the community will have in the future of health care.

They were told a Lithgow Health Consumer Working Group will be formed early next year to collaborate with the newly formed Nepean-Blue Mountains Medicare Local (NBML) and Nepean Blue Mountains Local Health District (NBMLHD).

Nominations for the consumer working committee were called for at the forum along with residents being asked to discuss and record what works and what is needed for health services locally.

Four Health Consumer Working

Groups will be formed in the LGAs making up the Nepean Blue Mountains area—Lithgow, Blue Mountains, Hawkesbury and Penrith.

Consumers have been given a way to provide input with the formation of the Nepean-Blue Mountains Medicare Local. Medicare Locals are primary health care organisations established this year to coordinate primary health care delivery and tackle local health care needs and service gaps as part of the National Health Reform Agenda.

The proposal for the NBML, included consumers participating at all levels of the organisation.

A partnership was formed between the NBML and NBMLHD to ensure consumers would inform the health care delivered in the community and at the hospitals.

The importance of the consumer in

training future health workers and for research and evaluation purposes was highlighted at the forum by Professor Jennifer Reath.

The speakers at the forum were president of the Lithgow Arthritis NSW Lorna Fitzpatrick, CEO of NBML Sheila Holcombe, Director of Clinical Governance NBMLHD Debbie Wyburd, Chair of the Joint Consumer Committee Nepean Blue Mountains and the head of the General Practice Department at the University of Western Sydney Professor Jennifer Reath.

Consumers can get started on what works and what is needed in the Lithgow area by completing an online survey. Go to www.surveymonkey.com/s/LithgowHealth.

Call 4758 9711 for a paper copy. The survey is open until December 3.



COMMUNITY HEALTH FORUM SPEAKERS: From left rear are MC John Haydon, Sheila Holcombe and Prof Jennifer Reath; front Debbie Wyburd, Diana Aspinall and Lorna Fitzpatrick.

im111612forum

Lithgow Mercury 20 November 2012

Appendix 4 Agenda for Lithgow Community Forums on Health



Health
Nepean Blue Mountains
Local Health District



AGENDA - Lithgow Community Forum on Health

Friday 16th November 2012 - 10.00 am to 1.00 pm

Lithgow Workmens Club, Tank Street, Lithgow

*Co-hosted by the Joint Health Consumer Committee of the
Nepean-Blue Mountains Medicare Local and the Nepean Blue Mountains Local Health District
and the Lithgow Branch of Arthritis NSW*

Aims of Day:

1. *To consult with the Lithgow community about local health issues.*
2. *To provide advice on the formation and membership of the Lithgow 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, Joint Consumer Committee Nepean Blue Mountains

- 10.00 am **Acknowledgement of Country**
Aunty Helen Riley, Mingaan Aboriginal Corporation
- 10.05 am **Welcome to the Forum**
John Haydon
- 10.10 am **The role for consumers in health care**
- Lorna Fitzpatrick, President, Lithgow Branch Arthritis NSW
 - 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
 - Prof. Jennifer Reath, Head Dept. of General Practice, University of Western Sydney
- 10:40 am **Questions so far**
- 10:55am **Morning Tea**
- 11.10 am **Hearing from you: table discussions**
Facilitator: Serena Joyner, Nepean-Blue Mountains Medicare Local
- 12:15 pm **Report back**
Table spokespersons reporting highlights to the forum
- 12.40 pm **The process from here, discussion**
Diana Aspinall
- 12.55 pm **Close** – John Haydon

Appendix 5 Lithgow Health Support Group Directory



Lithgow Health Support Groups *Quick Find Directory*

Alcoholics Anonymous Family Support Group: 1300 252 666

Alcohol and Drug Support: 63 502 780, 63 502 750

Alzheimer's Australia: 1800 100 500

Arthritis NSW Branch: 63 52 1984

Cancer Support Group Helpline: 63 514 298

Breast Cancer Support Group: 0417 371 581

Women and Children Crisis Centre: 63 53 1277

Children: Adolescent and family counselling: 63 545 912

Disabilities – LINC: 63 545 902

Diabetic Support Group: 63 514 214

Portland Mens' Shed: 63 555 600

Lithgow Mens' Shed: 63 514 746

Mental Health – Rose Cottage: 63 540 600

Youthworks: 63 522132

LINC Aboriginal Group: 63 54 5902

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

Contact us if:

- You would like to receive more copies.
- Your group or service is listed and you would like to update or edit your entry.
- Your group or service is not listed and you wish to have it added to the next version.

www.nbrmml.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

Appendix 6 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

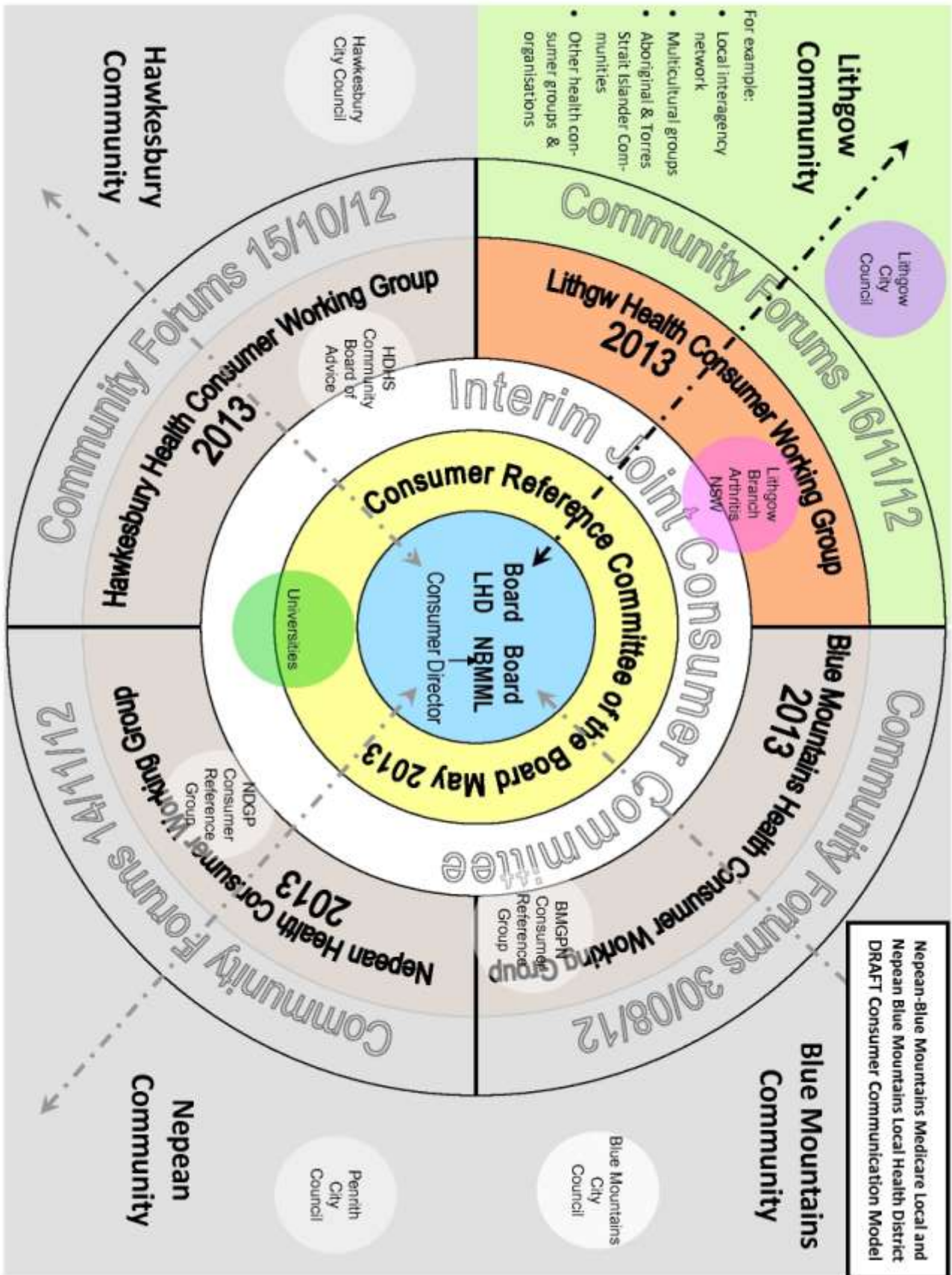
There will be a recruitment process formulated by consumers and signed off on by the two organisations for the membership of these groups. Health consumer applicants are to be drawn from the local community, primary health care and hospital settings.

- 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 7 Health Consumer Network Sign-up Form

Lithgow Health Consumer Network

If you wish to be included in the Lithgow-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 write 'none'.)

Postal Address: _____

Town/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 Lithgow area?

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

Consent to inclusion in the Lithgow Health Consumer Network:

(Please tick the applicable boxes)

- (Essential)** I consent to the Nepean-Blue Mountains Medicare Local securely and privately storing these contact details for the purposes of contacting me about the consumer engagement activities of the Medicare Local or Local Health District.
- I consent to my contact details being added to the mailing and email list for health consumers across the broader Nepean, Blue Mountains, Lithgow and Hawkesbury area.
- I consent to receiving communication from the future Lithgow 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