

Community Report on the Hawkesbury Community Forums on Health

(incorporating the results of the
online Hawkesbury Health Community Survey)

held Monday 15 October 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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- We were honoured to have as guests at the forums Aunty Edna Watson, and her granddaughters Krystal Mervin and Rhiannon Wright, who Welcomed participants to Country. We thank you for your contribution to the forums.
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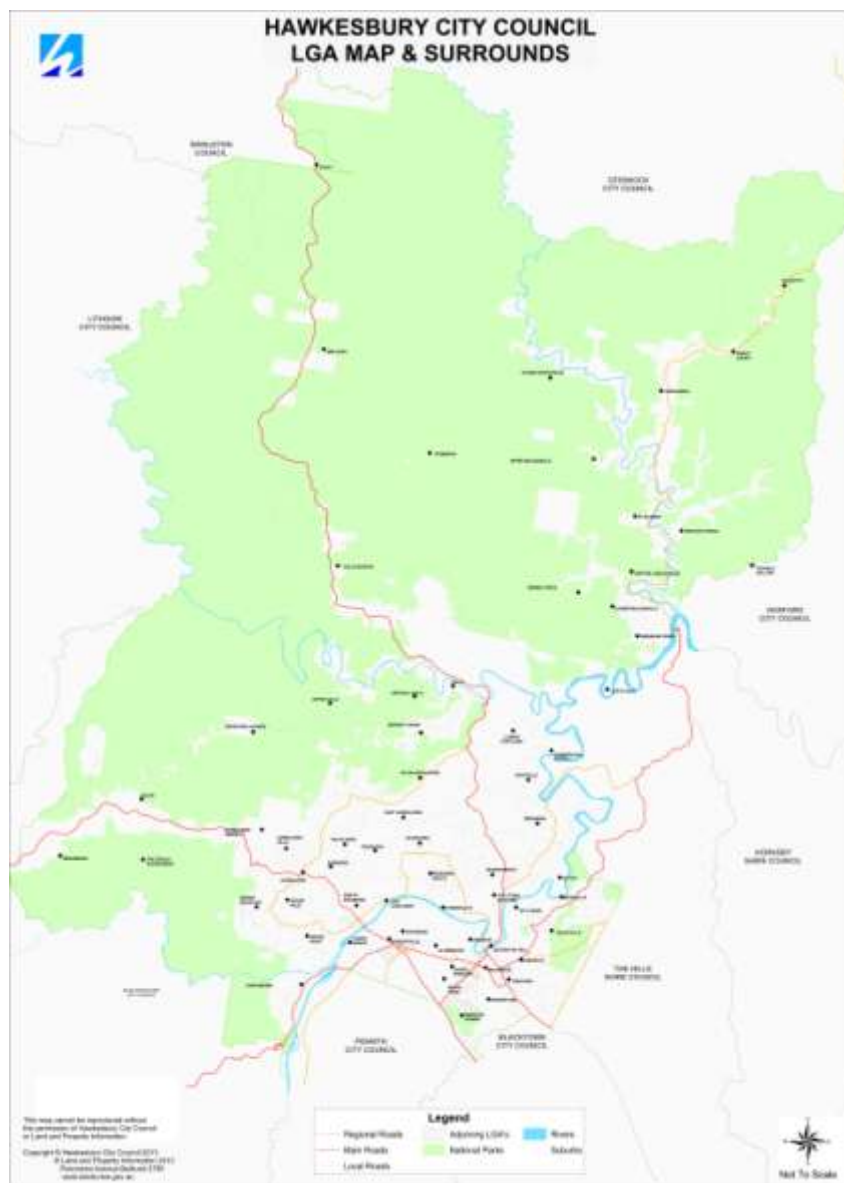
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Map of the Hawkesbury Local Government Area



Source: Hawkesbury 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 would 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 (definition from NSW Health).
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.
CBOA	Community Board of Advice to the Hawkesbury District Health Service
Community or consumer engagement	The involvement of healthcare consumers and the wider community in the design and delivery of health services and health services research.
GP	General Practitioner – often referred to as 'doctor'.
HDHS	Hawkesbury District Health Service
Health consumer	A person who uses health information, products or services, including carers of health consumers.

¹Aged Care Australia

<http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Glossary+Index+A>

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 Hawkesbury, Lithgow, Penrith and Blue Mountains local government areas.
NBMML	Nepean-Blue Mountains Medicare Local, serving the residents of the Hawkesbury, Lithgow, Penrith and Blue Mountains local government areas.
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.

EXECUTIVE SUMMARY

The Hawkesbury 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 forums were held on Monday 15 October 2012 and were attended by 120 people. The forums were supplemented by an online survey for residents of the Hawkesbury Local Government Area (LGA) to have their say on health services in the region, to which 32 people responded.

Forum and survey participants provided positive feedback about health services including the Hawkesbury District Health Service (HDHS) volunteers and staff, Peppercorn Community Transport, the local ambulance service, and GP care and diagnosis. They also identified a range of problems. Some were specific to the Hawkesbury while others were shared by participants at Community Forums held in other LGAs. The main problems identified include:

Transport and the related issues of distance, time, cost and parking, as well as aged and disability friendly transport, were considered significant issues for Hawkesbury consumers. They present impediments to accessing health services not available locally, for example services for cancer patients, some sexual and reproductive health services and services for victims of sexual assault.

Aged care services: Consumers told us there is a strong need for increased Aged Care Assessment Team (ACAT) services and aged care beds. The problem is compounded by insufficient residential services for other high needs groups who share the aged care facilities.

Workforce shortage and access to specialist care: Consumers told us of many problems related to the health workforce shortage, especially problems in access to specialists.

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; these are major barriers to timely access. Consumers want greater information about services available in both hospital and the community.

Mental health services: Consumers were very concerned about the often limited mental health services, distances involved accessing inpatient care, use of sedation and restraint

whilst being transferred, and the need for simpler pathways to mental health support. It was reported that youth-specific mental health services appear to have been withdrawn.

Impact of flood and bushfire on access to health care: Participants told us that when flood affects the Hawkesbury region it has a major impact on people's access to services. There is no ambulance service west of the river. Consumers want to know that adequate disaster planning has been undertaken and that it includes how emergency and basic health needs can be met in such circumstances. Bushfire can have a similar impact.

Cancer treatment: Lack of access to cancer treatment locally, and the resulting travel to the closest centre in Penrith, has a negative impact upon patients and their families.

Carer support and respite: Support for carers was another theme that emerged. Participants told us about the difficulties faced by carers and the limited resources available to support them. They want more say in the care of their loved one, and a more flexible approach.

Boundaries and cross-border use of health services: One issue that repeatedly came up concerned people who live outside the region who need to use the health services in the Hawkesbury, and Hawkesbury consumers using out of area services. While consumer wanted this flexibility they were concerned it may have negative resource implications for their region.

Recommendations

Following the Hawkesbury 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 pages 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 communication 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, home care support and ACAT services.

Recommendation 5: The Medicare Local and the Local Health District advocate for improved mental health services (acute services, youth access and transport) based in the Hawkesbury.

Recommendation 6: Resources and funding for health services be increased to meet the special needs of the Hawkesbury, a regional area on the outskirts of a major city.

Recommendation 7: The health workforce, in particular GPs, specialists and aged care professionals, is increased to reduce waiting lists and improve timely access for both acute and primary care.

Recommendation 8: The agenda for the proposed Hawkesbury Health Consumer Working Group includes consultation with Aboriginal and Torres Strait Islander community members and people from other cultures living in the community.

Recommendation 9: Research is conducted into gaps and access problems in the provision of women's health services, sexual and reproductive health services and services for sexual assault victims.

Recommendation 10: The Medicare Local connects with the local disaster management committee regarding consumers' health needs in the event of disaster.

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 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 14: The Working Group engages with relevant stakeholders to address the health issues and service gaps identified in this report and to provide regular feedback to the community about progress.

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 Health Consumer Working Groups, and forms part of the quality improvement cycle of health service provision for the area.

Overview – The Hawkesbury Community Forums on Health

The Hawkesbury Community Forums on Health were held on Monday 15 October 2012 with 120 participants attending the morning and evening sessions. The forums were supplemented with an online survey for Hawkesbury residents to have their say on health services in the region, to which 32 residents responded.

The forums represented the beginning of a new joint consumer and community engagement program being rolled out by the Medicare Local and the Local Health District. Supported by these organisations, the forums were initiated, organised and conducted by health consumers.

Participants at the Hawkesbury Community Forums on Health wanted the issues they raised to be heard. They are expecting to be kept informed of action that arises from the forums. 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 Hawkesbury Health Consumer Working Group to be established in 2013.

About the Hawkesbury Area

The Hawkesbury Local Government Area (LGA) lies on the north western fringe of Sydney and covers 2,800 square kilometers, much of which is national and state park, with some residential, commercial, industrial and military land. It borders the Lithgow and Blue Mountains LGAs to the west, Singleton and Cessnock LGAs to the north, Gosford and The Hills Shire LGAs to the east, and Penrith and Blacktown LGAs to the south.

The LGA has a population of 62,353 people.²The main population centres are Windsor and Richmond, with the satellite villages of North Richmond, Glossodia and Wilberforce all northwest of the Hawkesbury River. These communities and smaller outlying villages have no direct public transport links to services in Windsor and are isolated in times of flood.

Residents of the Hawkesbury access public hospital services from Hawkesbury Hospital run by the Hawkesbury District Health Service (HDHS) under contract with the NSW Government. Residents also travel beyond the LGA to access public hospital services through Nepean Hospital, and further into western and north west Sydney. Hawkesbury LGA experiences small rates of growth; however the spillover from population growth in the northwest sector of Sydney sees residents travelling into the area to access health services.

² Australian Bureau of Statistics, 2011 Census, 'Quickstats' data released at 11:30 AM (AEST) 30/10/2012http://www.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/LGA13800?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 will 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 local communities to make sure services are effective and of high quality.

In early 2012, the Nepean-Blue Mountains Medicare Local commenced operating in the Hawkesbury, Penrith, Blue Mountains, and Lithgow LGAs. The Hawkesbury LGA has 71 GPs working within its boundaries (January 2013), as well as 19 Practice Nurses working across 9 practices. The area continues to experience a GP workforce shortage.

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

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.

Hawkesbury District Health Service

The Hawkesbury District Health Service Limited (HDHS), part of Catholic Healthcare Limited, is contracted to provide comprehensive health care services for the individuals, families and communities of the Hawkesbury and surrounding areas. Services include a public hospital, community health and allied health. Hawkesbury Hospital is a teaching hospital of the University of Notre Dame.

The Community Board of Advice (CBOA) is the voice of the Hawkesbury community to the health service, and provides the opportunity for local community participation in health service planning, development and evaluation. The CBOA convenes discussion with a wide range of community groups to monitor views on health care and identify any service deficiencies. The findings are fed directly into the health service management.

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 the LGAs of Hawkesbury, Penrith, Lithgow and Blue Mountains.

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.⁴These 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 Hawkesbury community is represented on the Committee by two members of the Hawkesbury District Health Service Community Board of Advice. These members had 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). Both the forum outcomes and the overall survey findings are incorporated in this report.

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, and general practice placements for students.

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 in the education of health students is encouraged. 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:⁵

- identifying health issues of concern to the community
- developing research questions that are relevant and pertinent to consumers
- 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.

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

⁵NHS National Institute for Health Research

<http://www.peopleinresearch.org/find-out-about-involvement/what-difference-does-involvement-make>

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.

HAWKESBURY COMMUNITY FORUMS

The Hawkesbury Community Forums on Health were held during morning and evening sessions on Monday 15 October 2012 at the HDHS Conference Centre. During the design and planning phase, the Joint Consumer Committee focused on making the forums as accessible as possible to the community. They were promoted through the local media (Hawkesbury Radio, Hawkesbury Gazette, Hawkesbury Courier and The Independent), community facilities including libraries and post offices, on the Medicare Local website and through existing networks (including general practices, the HDHS CBOA networks, the Home and Community Care network and other consumer networks).⁶

The aims of the forums were to:

- consult with the Hawkesbury 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.⁷

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

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 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 Directors of the

⁶See Appendix 2 for list of Hawkesbury Health Support Groups.

⁷See Appendix 3 for Hawkesbury Community Forum Agenda.

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 Hawkesbury 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 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:

- Consumers reported generally excellent experiences of treatment and care from the HDHS including volunteers and staff.
- Peppercorn Community Transport is excellent and greatly valued.
- Consumers gave high praise for the local ambulance service.
- Consumers cited experiences of excellent GP care and diagnosis.

Key Health Issues

Transport is a major issue for the Hawkesbury. There is a heavy reliance on costly private services and inconvenient public transport *'Reduced services, more buses needed on some routes.'* This is particularly a problem for older people with disabilities as Aged Care Packages do not include community transport. Transport for cancer care was raised as services must be accessed outside the LGA, placing cost, time and emotional burdens on all affected. People with a physical and intellectual disability face reduced mobility and problems with public transport, community transport and inadequate bus stops: *'If the individual has disabilities normal transport does not cater for them.'* Some may end up not accessing the service at all, e.g. whilst there is no cost for ambulance transfer to Nepean hospital for victims of sexual assault, delay can be several hours and some victims choose not to wait. *'Many just go home'*

Mental health services: Limited access to hospital mental health services has implications including the use of sedation and restraint whilst being transferred. Local services are not perceived as accessible. *'You are made to feel that they are trying to deflect you possibly because of the fact that they are stretched due to [limited] resources.'* General and after-hours services are difficult to access. *'Answering machine [message says we] will return [your] call within 5 days.'* Poor links were reported between services and community-based support. Consumers also reported difficulty accessing adolescent mental health care quickly.

Aged care services: Consumers called for urgent attention to increase the limited health resources which directly and indirectly impact on aged care, in particular aged care services and beds. The shortage is exacerbated by 'inappropriate' use of beds: co-location of young people with disabilities along with the elderly, high care dementia patients are alongside regular patients, and nursing homes struggle to cater for the special needs of people with mental and physical disabilities. *'Only 12 beds for dementia specific care (security ward) across the whole area. Nursing home care is inadequate and inappropriate for individuals who cannot communicate.'* Shortage of geriatric and other specialists (e.g. endocrinologist, diabetes educator, 'hand' specialist) impacted on older patients. Delays in access to ACAT were frustrating consumers. *'Access to aged care facilities has long waiting times. [There's a] lack of understanding of the system and process for families and individuals accessing the services.'*

Impact of disaster on access to health care: When flood affects the Hawkesbury region, it has a major impact on the accessibility of health services. When flood forces closure of the North Richmond, Windsor and Yarramundi bridges, residents quickly become cut off from essential services including hospitals and GPs. 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 affected by disaster.

Workforce issues: Limited availability of specialists in the Hawkesbury results in access issues, particularly travel and long waiting lists. Specialist gaps mentioned include geriatrician, endocrinologist, female obstetrician and gynecologist, hand specialist and diabetes educator. Some reported long GP wait times and difficulty arranging home visits, and shortages in allied health providers. Others had excellent access to flexible GP services.

Knowing what services are available across all health services: Across all the issues raised by forum participants it became clear that there are major gaps in knowledge of what is available and how to access it. Health services working together to improve communication with consumers could raise public awareness of what is available and how to access it, increase understanding of the role of public allied health providers i.e. what services are available publically and what are available privately, and end confusion over which public

hospital outpatient services are available at Hawkesbury Hospital. Consumers also need to know how long the waiting lists are.

Palliative care: Consumers identified a gap in dedicated palliative care places. Specific beds are not allocated but the service is made available in the hospital ward when it is required on a short term basis. Long term care is provided by HDHS staff in the patient's home.

Cancer treatment: Inadequate access to cancer treatment in the Hawkesbury region, and the resulting travel to the closest centre in Penrith, and sometimes to Westmead, adds to the emotional, financial and time burden upon patients and their families. Participants reported positively on the establishment of a cancer support group in the region.

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 (aged care and disability care) left carers unable to utilise respite, and this elicited strong concern at the forums. Consumers called for greater flexibility of existing services, for more information about what services are available, and for greater recognition of carers. They also called for recognition of young children who are carers in families too.

Disability services and facilities suffer from shortage of resources, and care facility placement protocols adversely impact on the standard of care for people with disabilities.

Women's, reproductive and sexual health services: It was reported that there is limited local access to female GPs, obstetricians or gynecologists, and sexual health services generally, including services targeted at young people.

Boundaries and cross-border use of health services: Participants discussed consumers from outside the region using health services within the Hawkesbury area, and Hawkesbury consumers using out of area services. Recognising the need for flexibility, consumers want health services to take a clear, consistent and reasonable approach to this issue.

Online Survey Summary and Analysis

Of the 32 people who completed the survey ('respondents') 21 did not plan to, or did not, attend the forums. The largest number of respondents was in the 60–69 age group followed by the 40–49 age group. Most identified as female and 11 indicated that there were children living in their household. Eighty-eight percent of respondents use health services within the Hawkesbury, while 47% travel to Penrith and 22% travel to The Hills District. Six respondents travel beyond these areas for health care.

To a significant extent the survey findings reinforced the key forum findings. The top five health care concerns chosen from a list were:

- access to specialist health care services (67%)
- quality of hospital care (50%)
- access to GPs and General Practices (47%)
- cost of health care (43%)
- access to hospitals (40%).

Survey respondents made specific and frank negative comments about quality of care or 'customer service' concerning services in and out of the Hawkesbury area. There were also comments reflecting disillusionment and cynicism with the process of consultation.

Other Relevant Information

During 2012 a needs assessment was undertaken for the Medicare Local based on existing information and using 2006 Census data from the Australian Bureau of Statistics.⁸

There was good agreement between what consumers said about health care needs and what was in the needs assessment. When consumers tell us that some cannot afford to get a taxi to or from a health service they refer to a sizeable proportion of the Hawkesbury population. The needs assessment found:

- 23.9% of people have difficulty paying their rent
- 18.4% hold Centrelink concession cards
- 11.3% of families with children under 15 years of age are jobless.

The call for more preventative care and health promotion reflects health risk factors affecting many Hawkesbury residents:

- 15.6% of mothers smoke during pregnancy
- 23.6% of people are physically inactive
- 15.2% of men over 15 are overweight
- 10.5% of all men are smokers.

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 consumers are asking for clearer mechanisms for two-way communication between health services and the community. Following the Hawkesbury Community Forums, the Interim Joint Health Consumer Committee made 14 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 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 requires the establishment of a senior communication manager position.

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

Recommendation 4: The Medicare Local advocates for an increase in the number of available nursing home beds for the future management of the ageing population, for an increase in ACAT services in the region, and for coordination of all aged care related services across primary care, acute care, community services and council services.

Recommendation 5: The Medicare Local and the Local Health District advocate for improved mental health services (acute services, youth access and transport) in the Hawkesbury LGA.

Recommendation 6: Resources and funding for health services are increased to meet the needs of the Hawkesbury, a regional area on the outskirts of a major city.

Recommendation 7: The health workforce (GPs, specialists and aged care) is increased to reduce waiting lists and improve timely access for both acute and primary care.

Recommendation 8: The agenda for the proposed Hawkesbury Health Consumer Working Group includes consultation with Aboriginal and Torres Strait Islander community members and people from the range of different cultures within the community.

Recommendation 9: Further research is conducted into gaps in the access and provision of services e.g. women's health services, sexual and reproductive health services, and services for sexual assault victims.

Recommendation 10: The Medicare Local connects with the local disaster management body regarding consumers' health access needs in relation to flood or bushfire disaster in the Hawkesbury.

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 appropriate to the population.

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 there is a satisfactory outcome reported on within the health system and to the consumer.

Recommendation 14: The Working Group works in partnership with local and community organisations and other relevant stakeholders to address the health issues and gaps identified in this report. The Working Group provides regular feedback to the community and partners, including the HDHS CBOA, about what action has been taken and outcomes achieved in relation to these recommendations.

PROGRESS ON RECOMMENDATIONS

The Medicare Local and the Local Health District is continuing to implement the Joint Consumer Engagement strategy by recruiting consumers to the Health Consumer 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 each of the LGAs continue to have a voice and be heard.

A number of actions are already underway that begin to address the recommendations.

- **Communication and Information:** There is a commitment at the Medicare Local to employ a Senior Communication Officer (**Recommendations 1 and 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**).
- **Resources and funding:** 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 regional classification (**Recommendation 6**).
- **Workforce:** The Medicare Local has submitted information to the Independent Review into the Australian Government's health workforce programs and has commenced working in partnership with the NSW Rural Doctors Network to provide improved access by visiting specialists for the residents of the Hawkesbury (**Recommendation 7**).
- **Engaging consumers from the diverse community groups in the community:** The Working Group will be advised of this agenda (**Recommendation 8**).
- **Disaster Management:** The Medicare Local works with the appropriate Disaster Management Plan led by the local emergency services (**Recommendation 10**).
- **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**).
- **Service gaps:** A consumer-led research proposal to develop a pilot post-diagnosis support model of care for people living with cancer has been submitted to the Board of the Medicare Local. 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**).

WHERE TO FROM HERE

The process from here involves reporting back to the community on the outcomes of the forums and establishing the proposed Hawkesbury 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, and meet four times per year. A recruitment process for these 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 Hawkesbury 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 on the plan to consumers, the community and 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 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.

Consumer consultation could be broadened by further outreach to young people, a more representative group of men, and people from culturally and linguistically diverse communities in the Hawkesbury. Established links with the Hawkesbury Aboriginal and Torres Strait Islander community need to be strengthened. Ways need to be found to connect effectively with mental health service consumers and other vulnerable groups.

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 4.

Appendix 5 contains a sign-up form for the Hawkesbury Health Consumer Network.

Appendix 1 Interim Joint Health Consumer Committee

Consumer representatives

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)
Diana Aspinall (Chair)	Blue Mountains LGA
Annette Wickens	Blue Mountains LGA
John Haydon	Blue Mountains LGA
Joseph Rzepecki	Penrith LGA
Rosemary Chapman	Penrith LGA
Yung Yung Mitchell	Penrith LGA
Anne Anderson	Lithgow LGA
Judith Davies	Lithgow LGA
Lorna Fitzpatrick	Lithgow LGA

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
Carmel Vagg	Nepean Blue Mountains Local Health District

Appendix 2 Hawkesbury Community Forum Agenda



Health
Nepean Blue Mountains
Local Health District



Hawkesbury Community Forum on Health

Monday 15th October 2012 - 10.00 am to 1.00 pm

Conference Centre, Hawkesbury District Health Service, 2 Day Street, Windsor

*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 Hawkesbury District Health Service Community Board of Advice*

AGENDA

Aims of Day:

1. To consult with the Hawkesbury community about local health issues.
2. To provide advice on the formation and membership of the Hawkesbury 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: Bryan Smith, Hawkesbury District Health Service Community Board of Advice

10.00 am **Welcome to Country**
Aunty Edna Watson, Darug Elder

10.05 am **Welcome to the Forum**
Bryan Smith

10.10 am **The role for consumers in health care**

- Peter Blanchard, General Manager, Hawkesbury District Health Service
- 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**

10:55am **Morning Tea**

11.10 am **Hearing from you: table discussions**
Facilitator: Ellen Spyropoulos, HDHS Community Board of Advice, with table facilitators.

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** – Bryan Smith

Appendix 3 Hawkesbury Health Support Groups



Hawkesbury Health Support Groups *Quick Find Directory*

- Alcoholics Anonymous:** Support Group — 4560 5714
- Alcohol and Drug Support:** Support Services — 4560 5714
- Alzheimer's Australia:** Support Group 1800 100 500
- Arthritis:** Support Group of Arthritis NSW — 4574 1928
- Asperger's Syndrome:** Support Group — 4754 4312
- Autism and Asperger's Syndrome:** Support Group — 0425 380 576
- Acquired Brain Injury:** Support Group — 4588 6222
- Bipolar Disorder:** Bipolar Bears — 0400 149 881
- Cancer:** Hawkesbury Cancer Support Group — 0414 574 003
- Children:** Hawkesbury Kinship Carers Group (raising relatives children) — 45877277
- Children:** Hawkesbury Nuturegroup (premature/sick babies) — 1300 622 243
- Children:** LINC'S Volunteer Home Visiting Support Service for
parents/carers/families — 4560 5747
- Dementia:** Hawkesbury Dementia Careers Support Group — 4560 3700
- Disabilities:** Bridges Disabilities Services — 4587 021
- Disabilities:** Koomaroo Disabled Persons Support Group — 4579 6919
- Diabetes:** Support Group of Australian Diabetes Council — 0414 265 203
- Dystonia:** Dystonia Support Group — 4784 3368 / 0414 648 571
- Haemochromatosis:** Blue Mountains Support Group — 4787 7937

www.nbmmil.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

Living With Loss: Support Group — 4571 3748

Men: Hawkesbury Men's shed — 4578 4459

Men: Men's Health Support Group HDHS — 4560 5714

Mental Health: GROW — Peer Support for Mental Health — 1800 558 268

Mental Health: Hawkesbury Mental Health Carers Support Group — 4578 1144

Mental Health: Lifeline Harbour to Hawkesbury — 9498 8805

Multiple Sclerosis: MS Hawkesbury Support Groups — 4571 1023

Parkinson's: Hawkesbury Parkinson's Support Group — 4578 0545 / 4575 1403

Prostate Cancer: Prostate Cancer Support Group — 4730 3122

Stroke: Blue Mountains Stroke Recovery Club — 9807 6422 / 1300 650 594

Vision Impairment: Hawkesbury Vision Support Group — 4572 3287

Women's cottage: Women's and Children's Support — 4578 4190

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

Contact us if:

- You would 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.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

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

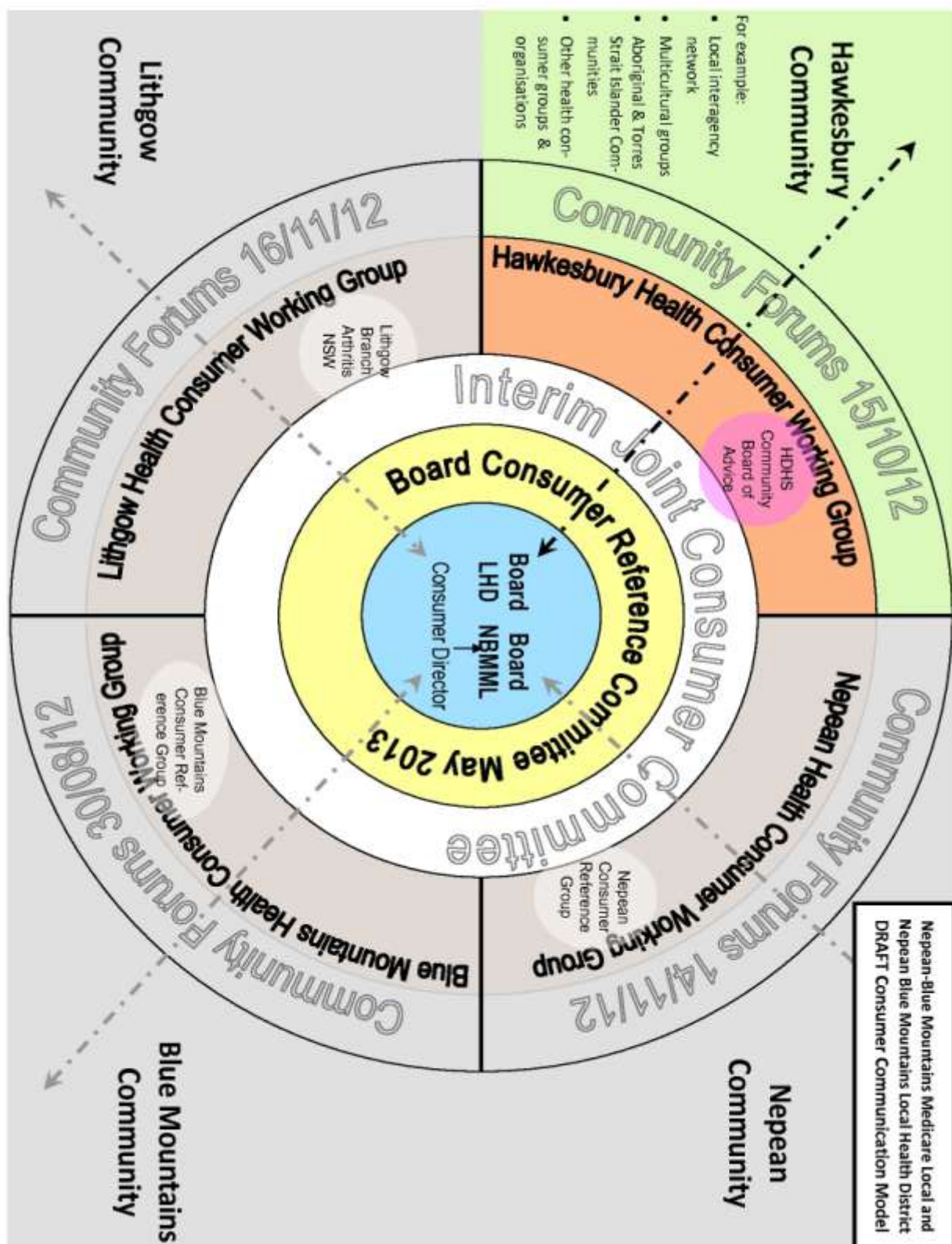
There will be a recruitment process formulated by consumers and signed off on by the two organisations for the membership of these groups. Health consumer applicants are to be drawn from the local community, primary health care and hospital settings.

- 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

Hawkesbury Health Consumer Network

If you wish to be included in the Hawkesbury 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 Hawkesbury?

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

Consent to inclusion in the Hawkesbury Health Consumer Network email/Internet group:

(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 future opportunities to participate as a consumer representative in the activities of the Medicare Local.
- ☐ I consent to my contact details being added to the mailing and email list for health consumers across the Hawkesbury area and broader Nepean, Blue Mountains, Lithgow and Hawkesbury area.
- ☐ I consent to receiving communication from the future Hawkesbury 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. (separate?)**

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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