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WESTERN SYDNEY
An Australian Government Initiative

# Community Forum Report Western Sydney Primary Health Network

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## Glossary of Terms and Acronyms

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|---|---|
| Allied Health | Allied health includes all health professionals (other than medicine, nursing and pharmacy) that require a tertiary degree to practice. 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 & Consumer engagement | The involvement of healthcare consumers and the wider community in the design and delivery of health services and health service research |
| GP | General Practitioner – often referred to as 'doctor' |
| Health Consumer | A person who uses health information, products or services, including carers of health consumers |
| LGA | Local Government Area – the administrative boundaries of local government i.e. city council boundaries |
| LHD | Local Health Districts - responsible for providing community health, hospital care and tertiary health care. Funded by the NSW Government (state government) |
| NGO | Non-governmental organization - an organisation that is neither a part of a government nor a conventional for-profit business. Usually set up by ordinary citizens, NGOs may be funded by governments, foundations, schools, businesses, or private people. |
| PHN | PHNs 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) |
| SCHN | The Sydney Children's Hospitals Network - incorporates The Children's Hospital at Westmead, Sydney Children's Hospital, Randwick, Bear Cottage, the Newborn and paediatric Emergency Transport Service, the Pregnancy and newborn Services Network and the Children's Court Clinic. Funded by the NSW Government (state government) |
| WSLHD | Western Sydney Local Health District – serving the residents of the Auburn, Blacktown, The Hills Shire, Holroyd and Parramatta Local Government Areas (LGAs) and tertiary care to residents of the Greater Western Region. |
| WSPHN | Western Sydney PHN – serving the residents of the Auburn, Blacktown, The Hills Shire, Holroyd and Parramatta LGAs |

## Community Forum Overview & Methodology

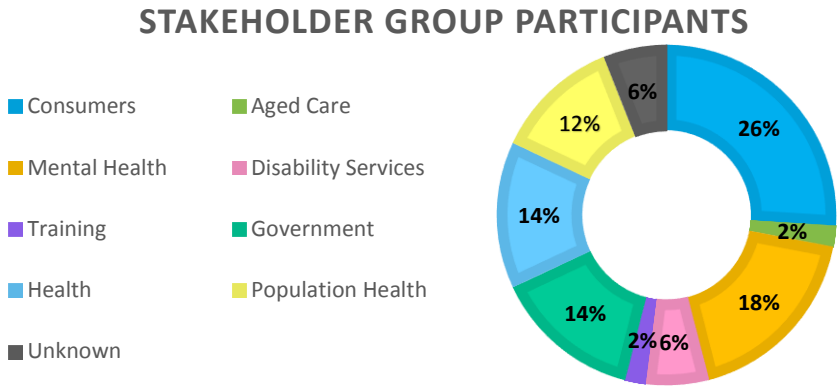
As part of an all-inclusive approach to the Western Sydney Primary Health Network (WSPHN) Needs Assessment process a Community forum was organised in partnership with the Western Sydney Local Health District (WSLHD) and Sydney Children's Hospital Network (SCHN).

The forum was organised in a key population hub relevant to the WSLHD and the WSPHN catchment areas. The details of the forum were as follows

| Address | Date/Time | Participants* |
|---|---|---|
| WentWest Learning Centre, Lev 8, Westpoint Office Tower, Alpha St, Blacktown | 10:30am – 1:00pm | 50 |

*Participant numbers do not include WSPHN, WSLHD, or SCHN staff in attendance for the purpose of presentation or facilitation.

The forum was attended by a varied mix of stakeholders including health consumers, carers, health professionals, service providers, local health district staff, and local government agencies.




The Forum was organised into two sections. The first was the presentation of pertinent information applicable to consumer engagement in WSPHN, WSLHD and SCHN. This information aided to frame the group discussions. The stated purpose of the forum was that the consultation be a process of listening and learning from the community to develop an understanding of the health care needs of our community so that planning for future programs and activities are targeted to address service gaps

The Presenters were:

- Walter Kmet, WSPHN CEO, who gave the welcome to country and overview of WSPHN
- Jasmine Glennan, Acting Director, Community Development and Partnerships WSPHN, who provided details about the newly launched "Healthy Western Sydney" consumer health information Portal
- Dr Anthony Brown, Executive Director, Health Consumers NSW, who gave an overview of the activities and role of Health Consumers NSW
- Dr Coralie Wales, Manager Community and Consumer Engagement, WSLHD, & Laura Griffin, Network Manager – Consumer Engagement, SCHN, who provided a snapshot of how consumer engagement is used as a tool within their organisations
- Naomi Van Steel, Strategic Partnerships Manager, WSLHD, & James Stormon, Clinical Program Director, SCHN, who spoke about the role of partnerships and the positive outcomes across the WSPHN, WSLHD & SCHN.

The second part of the forum involved running small group round-table discussions over the course of the morning based on 5 key questions:

- What services / supports work well in this area?
- What services / supports don't work well in this area?
- How can services / supports in this area be improved?
- How can we create / sustain a strong consumer voice in this area?
- What are your top three recommendations in this area?

Representatives from WSPHN, WSLHD and SCHN were involved in facilitating and scribing the discussions around the following topics

- Mental Health, Drug & Alcohol & Suicide Prevention
- Aged Care
- Population Health
- Aboriginal Health
- Access & After Hours
- Child & Family

The forum had sufficient level of interest from participants to warrant 2 full discussions on Mental Health. These groups were divided into Mental Health and Drug & Alcohol Services, and Mental Health and Suicide Prevention. For the purpose of this report, discussion summaries have been listed seperately but Needs and priorities have been combined.

A plenary session was held after the round-table discussions to allow all participants to hear the key health issues identified in each health area and comment. This report is based on both the detailed group discussion notes and the plenary disscussion.

Participants at the forum want the issues they raised to be acknowledged. They expect to be kept informed of actions arising as a result of the forum. This report is both feedback to the participants and an action agenda for the WSPHN Community & Consumer Council.

# Background to the Community Forum

## Western Sydney PHN

Primary Health Networks (PHNs) are a federal government health initiative, established with the key objectives of increasing the efficiency and effectiveness of health services for patients, particularly those at risk of poor health outcomes and improving coordination of care to ensure patients receive the right care in the right place, at the right time.

Since 2002 WentWest has been part of the western Sydney community, delivering support and education to primary care and working with key partners to progress the region's health system. From 1st July 2015, WentWest took on the role of Western Sydney Primary Health Network, this new era will see WentWest continue to work with its partners to deliver better health outcomes for the region.

In its role as the Western Sydney Primary Health Network, WentWest will focus on addressing national and regional health priorities in consultation and partnership with local GPs, Allied Health Professionals, consumers and community bodies and the broader health sector.

## Western Sydney LHD

The Western Sydney 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

Western Sydney Local Health District provides a range of clinical and non-clinical health services ranging from nationally funded health promotion/education programs to primary health services. Significant tertiary and quaternary clinical services are also provided to other Local Health Districts and health services in NSW.
Major WSLHD facilities include:

Hospitals:

- Auburn
- Cumberland
- Blacktown Mount Druitt (two campuses)
- Westmead

Community Health Centres:

- Auburn
- Blacktown
- Mount Druitt
- Parramatta
- Doonside
- The Hills
- Merrylands

Services are also provided in residents' homes as well as community settings such as schools and residential aged care facilities.

## Sydney Children's Hospital Network

The Sydney Children's Hospitals Network is the largest network of hospital and services for children in Australia. Each year the services manage:

- 51,000 inpatient admissions
- 92,000 Emergency Department presentations
- Over one million outpatient service visits
-

The Children's Hospital at Westmead and Sydney Children's hospital, Randwick, provide care for children locally, across the state, nationally and internationally.

The Newborn and Paediatric Emergency Transport Service (NETS), the Pregnancy and the Children's Court Clinic (CCC) are also part of the Sydney Children's Hospitals Network providing key specialised services.

The Network also provides significant state-wide and national services, including:

- The Heart Centre for Children at The Children's Hospital at Westmead
- The National Centre for Immunisation Research and Surveillance
- The NSW Poisons Information Centre
- The Australian Paediatric Surveillance Unit
- The Liver Transplant Centre at The Children's Hospital at Westmead
- The NSW Newborn Screening Service
- The NSW Paediatric Burns Unit at The Children's Hospital at Westmead
- Bear Cottage, located at Manly

## Working Together

The WSPHN and WSLHD share the same geographical boundaries, covering an area of 766 square kilometres with an estimated population above 904,000 people.

Together with the SCHN they have established a productive working relationship. Agreed shared priorities include Aboriginal health, aged care, mental health, improving access to after-hours GP services, child and family health initiatives, population health and planning, eHealth, and the information flow between the three organisations to facilitate improved services

## Local Government Areas

The LGAs of Auburn, Blacktown, Hills Shire, Holroyd and Parramatta and the respective councils are all major providers of many services that impact on the health of the people who live and work in Western Sydney. These Councils' actions can facilitate healthy lifestyles through the provision of services and facilities such as parks, footpaths and leisure centres.

Councils advocate for equitable access to health services and work in partnership with health agencies to promote community health issues. As the Western Sydney population grows there is increased demand for appropriate facilities and events that promote recreation, mental wellbeing and connectedness.

## Consumer & Community Engagement Program

In 2013 a partnership between WentWest and Health Consumers NSW was established to embark on a joint consumer engagement project. The project aims included embedding consumer involvement across WentWest and developing tools and resources for use across NSW.

The major project outcomes included:

2014: WentWest Gap Analysis and recommendations

2014: WentWest implementation assistance (e.g. Establishment of WentWest Consumer Engagement Staff Network)

2015: Consumer and Community Engagement Model: Report, Poster and Brochure

2015: Online Toolkit supporting consumers and community to engage

2015: Establishment of the WSPHN Consumer Working Group

2016: Community Health Forum project with WSLHD and SCHN

2016: Establishment of the Community & Consumer Advisory Council

# Discussion Summaries

Below are the detailed discussion summaries from each round-table group.

## Mental Health, Drug & Alcohol

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • CHIPS – Community Housing Implementation program<br>• PIR, Partners in recovery program<br>• Hoarding group treatment program<br>• Cumberland Hospital (Anxiety Clinic)<br>• Day to day Living programs<br>• Education and awareness programs improving<br>• Consumer run social activities. e.g. Monthly day trips<br>• Healthy Western Sydney new website<br>• Partnerships<br>• Hospital to Home program<br>• Partnerships with University Research Centres re; service mapping<br>• Multidisciplinary community mental health care, promotion and early interventions for older people.<br>• Reducing isolation and loneliness among older people |
| What services / supports don't work well in this area? | • Communication between mental health facilities and GP's<br>• Mental Health Info line – Triaged – long wait, told to go away and not taken seriously<br>• Mental health workforce – need to increase and expand<br>• Need to work with other partners and sectors i.e. Housing NSW, Centrelink |
| How can services / supports in this area be improved? | • Creation of community hub with multitude of services e.g Richmond PRA<br>• Step up/down approach - hospital to community transitions<br>• Road blocks in the system/red tape need to be removed and consistency in reporting measures<br>• HASI – looked at the different jobs needed to be done by different partners, manual developed, clear roles and regular evaluations<br>• Easier transition through services<br>• Excessive hospital focus, change of mindset needed<br>• Funding reallocation – more peer workers needed<br>• Short term contracts, projects – need ongoing 3-5yr funding |
| How can we create / sustain a strong consumer voice in this area? | • Education and training<br>• Health department has many mandated requirements need for mandated number/ratio of carer & consumer reps<br>• Being.org.au – look at what is already existing<br>• Award consumer participation – use mainstream existing rewards and add consumer participation reward<br>• Collaboration with University and research organisations |

## Mental Health, Suicide Prevention

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • Increased collaboration between clinical / non-clinical (& NGO) services<br>• NGO Services e.g.: PIR, aftercare, Personal Helpers And Mentors Program, Richmond PRA, UnitingCare, Catholic Care<br>• PIR (support time not stipulated)<br>• Increased opportunities for consumers to engage<br>• Not locking patients away – more acceptance<br>• Services willing to take on consumers in support role despite diagnosis (more flexible eligibility)<br>• Many support groups<br>• "Lived" experience Framework<br>• "lived" psychosocial supports available, but only few services have this holistic model<br>• Person centred focus (however, still not implemented in all programs / organisations) |

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|---|---|
| What services / supports don't work well in this area? | • Services less available to migrant groups<br>• Migrant groups have less knowledge of services that are available<br>• Consumers with low literacy have less ability to access services<br>• Health Campaigns not reaching migrant groups<br>• No known CALD groups for mental health consumers (some services available through refugee status however these are limited)<br>• Limited access to technology reduces access to resources and information<br>• Mental health help line refers to Emergency Departments (this is not suitable for some consumers)<br>• Limited knowledge of services available<br>• Post hospital referrals are poor. Consumers should be referred pre discharge to recommended programs<br>• LHD staff have limited time to facilitate referrals to external services.<br>• Referral pathways need to be simplified<br>• GP's have limited knowledge at available mental health Specialists / Services<br>• Need to work with other partners and sectors i.e. Housing NSW, Centrelink |
| How can services / supports in this area be improved? | • Ensure support for those who do not 'fit' the NDIS to remain able to access supports and services. This will reduce 'falling through the gaps'<br>• Ability links funded to 2018 – increase awareness of services that will continue over the 'transitional period' to NDIS<br>• Directories of services – increase community awareness of the directories<br>• Awareness of services like mental health first aid/suicide assist to community members – help communities help themselves. Option of funded training through accessible sites e.g. workplaces, schools etc<br>• CALD communities – find ways to better support these consumers with mental health education and support<br>• Make resources 'user friendly' not all IT based<br>• Invest in CALD communities to speak a language that is understood as interpreters often have issues discussing mental health and sensitive issues – co-design/co-deliver programs with CALD services to assist with this<br>• Use everyday opportunities and human interactions to support mental health in the community e.g. using RSLs to sponsor programs that could be delivered for community members/groups. Mindfulness of sensitive topics in certain communities<br>• Look for 'champions' who the community members seek out (e.g. religious leaders, LHD Chaplains) regarding options for reaching more people |
| How can we create / sustain a strong consumer voice in this area? | • Consumers are worried their input is a 'tick the box' exercise – provide feedback and outcomes to consumers whom engage and provide support<br>• Consumer roles have been reduced<br>• Standing consumer reps at relevant meetings – what are the other options for consumer engagement<br>• Remunerate consumers for participation<br>• Keep consumers well informed of their role and position |

## Aged Care

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • Relationships between private sectors and Not for profit sector improving – still needs work but there is a relationship building<br>• Links between hospitals & community care improving<br>• Acute care/episodic care<br>• End of life care<br>• Outpatients clinics – if you know about them<br>• Private sector nursing home & palliative care work well |
| What services / supports don't work well in this area? | • Community doesn't know what services are available – only receive information if you go to Emergency Department/ experience disaster<br>• Communication<br>  – Lack of information, don't go to hospital as you can disappear<br>  – Visibility in hospital<br>  – Duty of care should go beyond patient care<br>  – Services close down and patients don't know |

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| | – GPs need the full story of patient history<br>• Aged care & housing<br>– Large population in housing<br>– Possibility of register with over 65 yrs living alone – regular health checks for ones that are isolated<br>– Drs services renamed to 'family practice'<br>– Relationship building between patient & health professionals<br>• Patients "Own Care"<br>– Need to take responsibility for own health<br>– Don't know who to go to<br>– Consulting with GPs, especially "men's health"<br>– Trust building 'soft approach' especially vulnerable population<br>• Education<br>– Educate GPs on services within aged care<br>• Palliative Care<br>– No physiological care for patients<br>– Supporting patients – Church life & connections, community e.g. 93 yr old upset that people making decisions on her behalf without asking. Is the 93yr old of sound mind??<br>• Perception – Not sexy, people don't want to go to a nursing home<br>• Aged care mental health services<br>• Approval of aged care for mental health consumers e.g. consumer too young + complicated medications |
| How can services / supports in this area be improved? | • Educating the community that there is a shared responsibility<br>• Support & maintain community connections<br>• Support Of GPs and nurses<br>• Person centred care – GPs as 'home'<br>• Support regarding palliative care<br>• Mental Health<br>– Aging young with mental health<br>– Premature nursing home accommodation and care<br>– Balance of mental/physical health care<br>• National Disability Insurance Scheme<br>• Carer support<br>• Increased support & focus on community nursing – expand services<br>• Information sharing<br>• Support for dementia awareness, Alzheimer's etc. |
| How can we create / sustain a strong consumer voice in this area? | • Set a standard based on areas that have been done well<br>• Over 65s<br>• CALD groups<br>• Carers<br>• Consultation with GPs – capturing perceptions of what is/not working<br>• Salvation Army, Vinnies, Meals on Wheels<br>• Not For Profits<br>• Service providers<br>• Local geographical areas<br>• Soft entry "I care about you" |

## Population Health

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • Partnerships – Community health (WSLHD), PHNs & NGOs<br>• Projects working with local community<br>• Community organisations do it great and are now getting involved in health e.g. Healthy lifestyle, mental health, pre/post measures – follow up<br>• Consumer Reps being more involved and more respect for consumers<br>• Perceived waiting times (private specialist)<br>• Education needs e.g. Arabic women's English classes<br>• Carer support groups (SCHN)<br>• Cancer unit in Blacktown (co-design) |

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|---|---|
| | • Health as a holistic issue – word of mouth working within community/neighbours<br>• Empowering community with health literature |
| What services / supports don't work well in this area? | • Too much health jargon/abbreviations<br>• Health literature – expectations of prior knowledge<br>• If patient advocacy groups are not being utilized<br>• Getting connected into 'education groups' & other community groups e.g. if run from SCHN<br>• Health Western Sydney consumer website – translated<br>• Lack of parking available at hospitals/discounted parking not advertised<br>• Transport<br>• Transition care e.g. SCHN – Adult care<br>• Information (in general) is not transparent and it's who you know<br>• Engage multicultural/Non-english speaking with key leaders and isolated & different cultures<br>• Ageing population – grandparents as carers<br>• All different types of groups/families – doesn't include new groups that are emerging<br>• Data & population numbers under represented<br>• Intergenerational gaps |
| How can services / supports in this area be improved? | • Include translated materials<br>• Finding local health providers that speak language<br>• Consumer voice – stories/forums<br>• Additional or moving resources (human) to consumer engagement<br>• Creating 'consumer experts' within the health sector and rolling out to rest of organisation<br>• Getting data demographic right as funding is dependent on that – don't just look at the usual markers – case study<br>• Integration of health & community e.g. walking groups, social problems because of health & vice versa<br>• Access of info for public health advocacy groups/ support groups e.g. advertise on Healthy Western Sydney site<br>• Drop-in area for information/ health info & support (community health hub/ physical of Healthy Western Sydney site)<br>• Assumption of everyone having access to 'online' access<br>• Council run leaflet/ newspaper access to info with all info of what's on for seniors |
| How can we create / sustain a strong consumer voice in this area? | • Focus on 'Wins'<br>• Advertisement of current networks<br>• Involving all residents<br>• Engaging in cultural groups<br>• Everyone knows customer feedback process<br>• Sustainability – funding? Paying consumers<br>• Making the process less complex<br>• Everyone |

## Aboriginal Health

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | No Aboriginal consumers or providers were in attendance for this forum. Present attendees did not feel adequately informed to discuss what is working well in Aboriginal Health. This discussion will be held at an Aboriginal specific forum planned for 5th April 2016 |
| What services / supports don't work well in this area? | No Aboriginal consumers or providers were in attendance for this forum. Present attendees did not feel adequately informed to discuss what is not working well in Aboriginal Health. This discussion will be held at an Aboriginal specific forum planned for 5th April 2016 |
| How can services / supports in this area be improved? | • Talking to Aboriginal people<br>• Going where they go<br>• Making the services more inviting to their needs<br>• Work with trusted existing networks<br>• Let them be involved & lead and own it<br>• Trust the communities and not work in a paternalistic way<br>• Organisations across the board to have cultural sensitivity training<br>• Consider developing RAP (Reconciliation Action Plan) |

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| | • Ensure the service works within the ATSI community & involves other services in partnership, collaboration and network |
| How can we create / sustain a strong consumer voice in this area? | • Pay them<br>• Link to existing networks and gatherings e.g. 'the shed' in Mt Druitt<br>• Build relationships with the community<br>• More listening<br>• Make them feel comfortable<br>• Build trust<br>• Aboriginal workers to develop relationships with the service<br>• Understand local dynamics, protocols for introduction |

## Access & After Hours

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • Consumer Point Of View<br>– GP after hours' time and extended opening hours and aged care<br>– GP home visit services<br>– Community transport for business hours – connected to Home And Community Care service (fear this will not continue with NDIS)<br>– ATAPS program, particularly the broad referral services/systems, no gap costs, can be tailored to client's needs, greater number of visits available<br>– Outsourcing of mental health services to NGOs<br>– No co-payments for hospitals or GPs<br>– Measures in hospitals to reduce waiting times such as a buzzer system in the Children's hospital<br>– The coordination of cancer care by multiple services and transport services e.g. Princess Mary cancer centre Westmead<br>– The carers centre at Westmead Children's hospital<br>• Service provider Point Of View<br>– Transport<br>– The multiple clinic facilities e.g. pathology, allied health<br>– The usefulness of super-clinic facilities<br>– Free parking at facilities |
| What services / supports don't work well in this area? | • Aged care mental health<br>– Resident access and referrals are poor<br>– There is default behaviour of medications e.g. aged care clients with anti-psychotics, even without their knowledge<br>– Emergency presentations in aged care do not reflect the actual numbers<br>– Aged care workers are not equipped/trained to handle the residents issues/behaviour<br>– Nursing homes refusing people with mental health concerns<br>• Some schools refusing enrolment of students with developmental concerns<br>• Lack of resident access to transport<br>– Cancer care is not considered a disability so not able to access<br>– Lack of community awareness including health workers<br>– Limited after-hours access<br>• No mental health services available to come to home for assessment/treatment<br>• Hospitals will often refer patients away unless acute mental health presentation<br>• Age limits in services like headspace<br>• Persons responsible will have no rights in the public system if not legal guardian<br>• Poor transition of care from child to adult health/hospitals<br>• No grief support for disability presentations/diagnosis<br>• Communication of care plans between various hospitals or hospitals to patients is poor<br>• Standardisation of scorecards<br>• No complaints venue for patients |
| How can services / supports in this area be improved? | • Support the key stakeholders to support family advocacy and carers NSW to change the legislation so that primary carers/parents of children automatically receive guardianship<br>• Have a pre-admissions clinic at Westmead hospital who work with families to develop a plan of support. This should be extended to ambulance and police, should focus on |

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| | mental health. A virtual clinic might be an option. This should be designed to cover pre-crisis<br>• The education of health services to acknowledge patient/parents connection and needs<br>• The change of policy in aged care requiring the families to choose the residents doctor and including the residents care plans during intake<br>• The structural framework of a nursing home prevents full equity access of residents and the utilisation of innovation programs. Family members and aged care staff need to be educated on the family's place/value in the residents care.<br>• Mental health services and assessments<br>• Community awareness campaign around transport options<br>• Ensure continuity of care for patients<br>• Consistency in times that after hours doctors are available |
| How can we create / sustain a strong consumer voice in this area? | • Make sure feedback is not always typed or written (oral option)<br>• Alternative communication systems<br>• Family advocacy<br>• Consumer advocacy<br>• Change the perception of carer vs family |

## Child & Family

| Focus Question | Discussion Summary |
|---|---|
| What services / supports work well in this area? | • Partnerships with Mt Druitt Community Health<br>• Partnerships with community groups and key stakeholders who are facilitating the 'hands on' programs<br>• Family Support – helping vulnerable families to support their children<br>• Lots of referrals – supporting families to access services, information, education etc.<br>• FACS & Housing and Community development working with preschools. Engage with families who Housing have identified as vulnerable. Community development work with preschools to get information and community engagement, referring into services. Spreading news!<br>• Therapy 4 Kids at Auburn hospital/Community health centre providing care for family and child<br>• ACT for kids Blacktown<br>• Integrated services are working well<br>• Partnerships with schools e.g. CHC and Doonside Public school<br>• Trade schools – High schools partnering with TAFE learning in to school. Assists with wellbeing, fulfilment, education, support with mental health. 1 day per week at TAFE, 4 days at School e.g. Colyton High Trade School<br>• Sydwest and Blacktown & Mt Druitt community health centres work together to run information sessions to newly arrived families to understand about the Australian health system, how to access services. Info about getting health check-ups each year, preventative health, seeing GP regularly<br>• DVCAS – Domestic violence court advocacy service referrals to support services. Identification of vulnerable women early and refer on<br>• Carer support group Mt Druitt – for people with children with disabilities. Identify needs of carers. Need more support to care for children. Ability to express their needs in a group support environment<br>• Some great GPs who are dedicated and passionate about western Sydney and the clients they see<br>• Family Referral service getting GP referrals for child mental health is well supported and they are getting the counselling services they need<br>• Sydwest supported playgroups - Refugees & humanitarian entrants' playgroups where parents can get involved. Sydwest is able to link refugees with GPs, particularly GPs that speak their language<br>• Increase in communication for community health, safe start with community/consumers<br>• Initial contact by child and family health nurse for universal health home visit – Safe start families are visited earlier and services put in place. Collaboration between hospitals and community health has improved and is working well<br>• ECICP joint meetings are working well |

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|---|---|
| What services / supports don't work well in this area? | • Domestic Violence – Family court process lengthy<br>• Not enough protection for women experiencing domestic violence and the focus is not on children too<br>• Services only work in one LGA not the whole of western Sydney<br>• Not enough women's & children's refuges<br>• Not enough accommodation/ emergency housing support/ social housing<br>• No one doing emergency accommodation<br>• No one providing accommodation for people not involved with Department of housing<br>• Access to interpreter services<br>• Access to housing for families in crisis – only given short term e.g. day by day accommodation<br>• Changes to systems/services not evaluated, impacts, negative results not evaluated<br>• Abortion services<br>• Shift from early intervention to next step up – more urgent cases. High intervention<br>• More support for families, carers<br>• Lack of availability of services towards Blue Mountains<br>• Mental health – finding services for those who don't fit the services eligibility criteria<br>• Not enough hands on, practical support – housework, gardening for people with mental illness<br>• Lack of services in isolated areas<br>• Short term contracts, projects – need ongoing 3-5yr funding<br>• Funding for community support groups<br>• Lack of funding for consumers to pay for specialists or where to find free specialists e.g. speech language, assessments at services and psychiatric services<br>• Waiting lists |
| How can services / supports in this area be improved? | • Continuing to build relationships between services. More time focused on partnerships, communication, joint meetings, focus groups<br>• Change funding models to encourage partnership (currently competitive)<br>• Notice to develop submissions for funding proposal is far too short e.g.1 week notice. Have a schedule of when funding is coming out<br>• Organisations prepare a draft proposal, partner together to have one ready if short notice<br>• Education & training – GPs, hospitals, consumers, schools e.g. mental health, peer group support, healthy relationships, general health<br>• Trauma informed care. Education on trauma and how to change practice to suit that.<br>• Sensitivity around providing bad news to consumers<br>• Consultation – meaningful with feedback |
| How can we create / sustain a strong consumer voice in this area? | • Meaningful consultation – consumers get info/feedback on where the information has gone, actions taken<br>• Marginalised communities – how to involve them to have a voice e.g. through organisations like migrant resource centres, Sydwest, auburn diversity services<br>• Continuing relationships with consumers so they know where their input has gone<br>• Gout into the community. Go to where they are<br>• Department of housing – want to get in touch with people who are not linked with services, NGOs. Clients may fear that services may report against them<br>• Bringing similar consumers of CALD backgrounds together to become more confident, voice their opinions, in a supported group setting |

## Needs and Priorities in Specific Health Areas

Based on each round-table group discussion as well as the plenary discussion the below were considered the priorities relating to each health area. These priorities will be presented to the WSPHN Community & Consumer Advisory Council for recommendations to address service gaps in the area.

### Mental Health, Drug & Alcohol, Suicide Prevention

- Greater effective inter-connectedness of services and resources, which are well publicised across consumer and provider populations.
- Create a greater flexibility of mainstream services to account for CALD and other diverse communities
- Make the outcomes known and provide feedback to the group so we sustain improvements and avoid just "ticking the box".

### Aged Care

- Increase Access – knowledge & sharing of information services for both consumers & health professionals, suggestion of an aged care advocate as conduit, increased support for mental health in aged care/ aging of mental health clients
- Ensure consumer & carer representation – consumer decision making in every instance
- Person centred care – having care around person, connected care, discussion between everyone involved, respecting privacy

### Population Health

- Involve the Multicultural health/ social disadvantaged/ hard to reach (not dependant on postcode boundaries)
- Have a 'physical' hub for Healthy Western Sydney website. Local knowledge of services/resources including consumer engagement networks. Don't rely solely on online resources.
- Getting meaningful data because funding and resources are based on this.

### Aboriginal Health

- Working with trusted and existing networks & organisations in a non-paternalistic and equal way
- Going where the ATSI people and communities are and listen
- More Aboriginal workers and support to build capacity of Aboriginal community members to participate

### Access & After Hours

- An assessment service in Mental health that does home visits
- Family advocacy and a greater voice for patients and families that is independent of the hospital although located on the hospital's premises
- Policy change to allow for transition of care models from child health care to adult health care to be seamless and to include carers.

## Child & Family

- Education and training across all organisations and consumers on for example mental health, healthy lifestyle, prevention of domestic violence, trauma, sensitivity in delivering bad news, cultural sensitivity
- Meaningful consultation, using existing organisations such as CALD organisations. Including feedback to consumers of what their input is changing, what outcomes are resulting0
- Changing funding models to encourage partnership, improved notice of funding submission timelines, not at short notice. Organisations partnering ahead of time. Process of co-designing with community and consumers

## Cross Program & Jurisdictional Issues

There were a number of cross program and jurisdictional issues raised during the forum. There was a clear feeling that community engagement and participation was the key to positive outcomes for people, both in the system understanding the needs of consumers, and also consumers navigating the system effectively.

Pertinent systemic issues raised across multiple health areas included

- People not feeling supported in times of transition. These transitional phases comprised of the transition from child to adult services, adult to aged services, and home to hospital
- The lack of communication between services. This was especially prevalent in the mental health and aged care sectors in regards to hospital admissions
- The need for more health literacy across all sectors
- More support needed for navigation through the health service. This was especially important for CALD and ATSI communities
- The need for access to community transport outside 9-5 and to a broader consumer base.
- The health system to focus care on a more holistic level. This was especially prevalent in the mental health, chronic disease and aged care sectors

# Where To From Here

The process from here involves reporting back to the community on the outcomes of the forums, and the two consumer groups within WSPHN.

## Consumer Working Group

The Health Consumer Working Group (CWG) are representatives of the local Government areas. There will be one working group representing the four LGAs in the region with up to 20 consumer representative members. The Working Group has a minimum of two representatives on the Board Community & Consumer Advisory Council.

The purpose of the Western Sydney Health Consumer Working Group is to represent and advocate for the health care issues that impact on the health and wellbeing of the people of the Western Sydney region, and to consult with and advise WentWest on these matters through reporting to the Boards.

## Community & Consumer Advisory Council

WentWest has established a Community & Consumer Advisory Committee to provide advice to the Board and Management on matters and issues affecting primary health care consumers. Its purpose is to bring the consumer voice to PHN activities, and to assist WentWest in working towards a patient centred system of primary health care that delivers better health outcomes. Membership is drawn from consumer representatives and community organisations as well as Board representation.

## Acknowledgements

The Darug people are acknowledged as the traditional Aboriginal owners of the land in area where the forum was held.

The forum was developed and organised for consumers. Thank you to the consumer members of the Consumer Committees of the Western Sydney PHN, Sydney Children's Hospital Network and Western Sydney Local Health District who represented their local government areas and who worked hard to ensure that consumers had an opportunity to have their say, and to be heard.

We would like to acknowledge the support of the following organisations and people.

- The Western Sydney PHN who provided support and funds towards the joint consumer engagement strategy, as well as working in partnership with local residents and health consumers to plan, develop and run the forums.
- We acknowledge the tremendous support of our co-host, Sydney Children's Hospital Network and the Local Health District, particularly Coralie Wales, Laura Griffin, Naomi Van Steel and James Stormon, for supporting and contributing to the forums.
- Thanks to Andrew Brown, Executive Director at Health Consumers NSW, for presenting information about the consumer and community roles in health.
- Thanks to PHN, Sydney Children's Hospital Network and Local Health District staff for providing executive support, project support, forum facilitators and a secretariat for the consumers.

## Contact Details

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

For permission to use any part of this document for other than personal and consumer group information, please contact:

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# Appendices

## Appendix 1 Map of the Western Sydney PHN Catchment Area

Available at http://www.cancerscreening.gov.au/internet/main/publishing.nsf/Content/PHN-Western_Sydney

# WSPHN Community Forum Agenda

| | | | |
|---|---|---|---|
| **Venue** | WentWest Learning Centre<br>Level 8 Westpoint Tower | **Date** | Tuesday 8 March 2016 |
| | Westpoint Shopping Centre<br>Entry via Alpha Street, Blacktown | **Time** | **10.30am – 1.00pm** |

**10.30am – 10.40am (10 mins)**

Acknowledgement of Country - *Walter Kmet – CEO, WentWest*
Progressing Health Now Video & Overview of the WSPHN.

**10.40am – 10.45am (5 mins)**

"Healthy Western Sydney" Launch **–** *Jasmine Glennan – Acting Director, Community Development and Partnerships*

**10.45am – 10.55am (10 mins)**

Overview of Health Consumers NSW – *Dr Anthony Brown –Executive Director, HCNSW*

**10.55am – 11.10am (15 mins)**

Consumer Engagement - *Dr Coralie Wales, WSLHD & Laura Griffin, SCHN*
Partnerships - *Naomi Van Steel, WSLHD & James Stormon, SCHN*

**11.10am – 11.15am (5 mins)**

Forum Purpose & Group Discussion Process - *Mike Brooke – Director, Outcome Services*

**11.15am – 11.45am (30 mins)**

Small Group Discussions – Session 1.

**11.45am – 12.00pm (15 mins)**

**Morning Tea**

**12.00pm – 12.30pm (30 mins)**

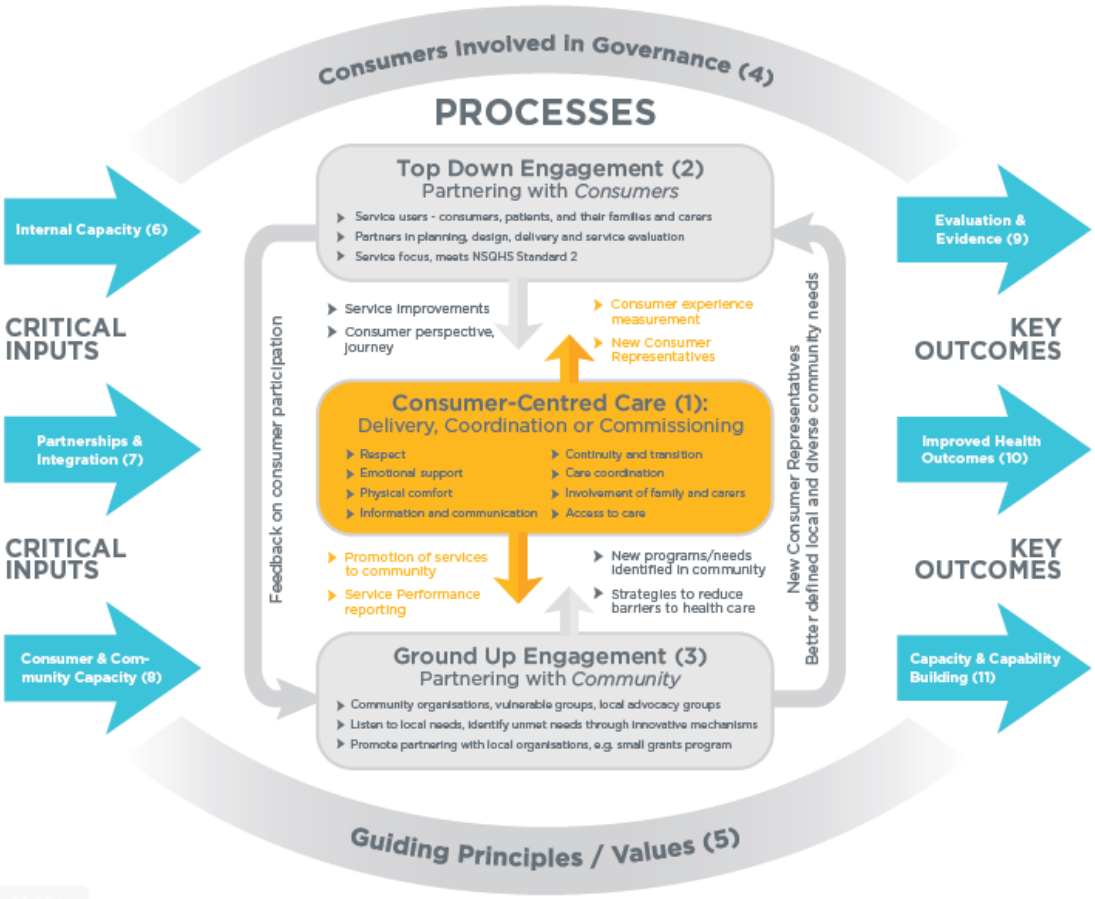
Small Group Discussions – Session 2.

**12.30pm – 1.00pm (30 mins)**

Reporting Plenary - *Mike Brooke*

**1.00pm**
Close

## Appendix 4 WentWest/ Health Consumers NSW Consumer Engagement Model



## Appendix 5 WentWest Consumer Working Group Expression of Interest

**Have a say about *your* local health services**

Do you have experience as a user (consumer) of health services or as a carer of a person who is a consumer of health services?

You are invited to express your interest in becoming a member of a Health Consumer Working Group by completing the form below. Please return it addressed to the Consumer & Stakeholder Project Officer.

**Post:** WentWest, PO Box 5 Blacktown NSW 2148

**Email:** consumers@wentwest.com.au

**Hand delivered:** WentWest office, Level 1, 85 Flushcombe Road, Blacktown

For more information, please phone WentWest 02 8811 7100

# What we are looking for

We are seeking people who live in the Western Sydney area who are well connected with their local community and have the skills, or can be trained, to be health consumer representatives.

A local community representative will need to:

1. **Speak as a health consumer**: Do you have experience as a consumer (i.e. user) of health services or as a carer?

2. **Represent health consumers**:
   - Are you able to address and communicate issues from a consumer perspective? Health services may be GP care; community health; other health care accessed outside hospital; care received within hospital; or any combination of these.
   - Do you have an understanding of health issues generally?
   - Do you have knowledge of, and interest in, local community health issues?
   - Do you have an established broad network of organisations within your area you can consult with? (e.g. P&C associations, Rotary or Lions clubs, mothers' groups etc)
   - Have you undertaken, or be willing to undertake, consumer representative training?

3. **Communicate effectively**:
   - Do you have good communication skills or are you willing to develop these skills with appropriate training and support?
   - Are you prepared to report back to your local community with written and/or spoken communication?
   - Do you have an understanding of and commitment to observe confidentiality and privacy when it is required?
   - Are you able to use simple office-based software including email or have a willingness to develop these skills with appropriate training and support? (Please note that not having these skills does not exclude you from becoming an Advisory Group member. Any members without access to a computer or the Internet will be

supported.)

4. **Work collaboratively with others:**
    - Are you able to work effectively in a team environment?
    - Do you have, and can demonstrate, respect for all consumers, fellow committee members and staff from a variety of backgrounds and viewpoints?
    - Are you able to work effectively on a committee or are you willing to develop these skills with appropriate training and support?

5. Previous experience as a health consumer or community representative

6. The ability to mentor and support other consumer representatives.

**Note:** Health care providers or employees of a health service are not excluded as Consumer Representatives but would be expected to participate on the basis of their health consumer and/or carer experience, as well as being careful to avoid and disclose conflicts of interest. However, employees of WentWest are excluded as consumer members of the Advisory Group. Candidates who are unsuccessful in being appointed to an Advisory Group may be invited to join another health consumer committee.

# Expression of Interest Form

(Please print)

Mr Mrs Miss Ms

**First Name _____ Last Name_____**

**Address**

**_____**

**Phone: (H)_____**
**Mobile:_____**

**Email**

**_____**

**Please select your Local Government Area (where you live):**

Auburn Holroyd Parramatta Blacktown Hills Shire

**Please outline WHY you would like to be a member of a Health Consumer Advisory Group (as outlined in the information package document *Consumer Representatives – What we are looking /or)***

| |
|---|
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| |

**Please outline HOW your experience or skills match what we are looking for (as outlined in the information package document *Consumer Representatives – What we are looking /or)***

| |
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| |

**Have you had any previous experience as a consumer representative?**

Yes

No

If yes, please describe:

| |
|---|
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| |
| |
| |
| |

**Do you have the ability to mentor and support other consumer representatives?**

Yes No

**Please note:** Health care providers or employees of a health service are not excluded as consumer representatives but would be expected to participate on the basis of their health consumer and/or carer experience, as well as being careful to avoid and disclose conflicts of interest. However, employees of WentWest are excluded as consumer members of committees.

**Signed:** _____ **Date:**_____