

You Matter

A guideline to support engagement with consumers, carers, communities and clinicians in health



better health • better care • better value

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- Health Consumers' Council of WA
- HelpingMinds
- Mental Health Commission
- Mental Illness Fellowship of WA
- People with Disabilities WA Inc
- Richmond Wellbeing
- Royal Perth Hospital Consumer Advisory Committee
- St John of God Midland Public Hospital
- WA Association for Mental Health
- WA Country Health Service
- WA Primary Health Alliance.



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Executive summary

This document was developed to support WA Health Services Providers in their engagement with consumers, carers, communities and clinicians to improve health services.

Partnerships at all levels are necessary to ensure the health system achieves the best possible outcomes for all involved. The focus of this Guideline is engagement at the service and organisational level – it will not impact individual care and will assist in:

- health service planning
- service delivery
- policy.

This guideline aims to strengthen existing engagement activity by:

- facilitating a consistent approach to engagement with consumers, carers, communities and clinicians
- increasing the participation of consumers, carers, community and clinicians in the planning, design, delivery and evaluation of health care services
- enabling patients to develop a greater sense of ownership over services and their own health-related options and decisions
- providing information and strategies to effectively engage vulnerable groups
- identifying successful strategies for engagement.

Engagement with vulnerable, or hard to reach groups by health services can be challenging. This guideline provides direction and strategies to enable effective engagement with specific groups recognised as vulnerable.

The diagram below provides a visual overview of the Guideline.

Principles Collaboration Clear Purposeful Commitment Inclusiveness Transparency Respect and Partnership Communication **Vulnerable Groups Process** Children and young people Scope Culturally and linguistically diverse trust Aboriginal people **Engagement Plan** Evaluation Leadership Rural, regional and remote **Effective** Engage Other/Multiple vulnerabilities Engagement Value input Lesbian, gay, transgender, bisexual and intersex **Evaluation** Homelessness Feedback People with disability **Documentation** People living with Spectrum of Engagement Collaborate **Empower**

Health Consumers' Council foreword

Since the Australian Commission on Safety and Quality in Health Care developed and implemented the National Safety and Quality Health Service Standards in 2011, the landscape of consumer engagement fundamentally changed. The Standards provided a mechanism for enhancing and developing health services' engagement with its patients, carers and community.

The Health Consumers' Council (HCC) believes that the new opportunities in engagement call for a renewed approach. Instead of aiming for a patient centred health care system, we need to aspire collectively to a person-centred health care system. Just as the patient has an experience when having an intravenous catheter inserted, so too does the health care provider when inserting that catheter. In a person-centred healthcare system the patient, their loved ones, the health care providers and the whole team are partners working towards the shared goal of a healthier person, and a healthier Western Australia. For our health system to continue to develop as a relationship based industry, consumer, carer, community and clinician engagement are essential ingredients.

This Guideline is a welcome addition to the documents and mechanisms to support engagement at all levels. The principles outlined in this Guideline draw on the latest thinking and have been developed in partnership with consumers, carers, family members and health professionals. The inclusion of specific strategies to engage with diverse communities is essential to support the aim of health equity regardless of race, ethnicity, language, education, sexual preference and identity, and so on.

Policies and guidelines are only valuable when implemented, and HCC will remain committed to support the ongoing change management journey required to manifest a person-centred health care system.

Carers WA foreword

Carers WA is the peak body representing carers in Western Australia. Carers provide unpaid care and support to family members and friends who have disability, mental illness, a chronic condition, terminal illness, an alcohol or other drug issue or who are frail. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. The caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location. Caring is a significant form of unpaid work in the community and underpins our formal and funded aged care, disability, health, mental health, and palliative care systems.

Within the health setting carers play an important role in providing valuable information to health staff regarding the patient due to usually having a longer term and more intimate knowledge of their health and care needs. Carers should also be included and consulted by health professionals in relation to any decision making that may impact on their caring role in compliance with the Carers Recognition Act 2004, which includes the Carers Charter.

Consumers and carers have different perspectives and needs, therefore it is important to engage with both groups when designing, developing, delivering and evaluating health and disability services. Carers WA fully support the engagement principles outlined in this document in relation to family and friend carers.

Introduction

Health services are highly committed to engaging with consumers, carers, the community and clinicians to improve the quality of health care in WA. This Guideline aims to improve and support Health Service Providers (HSPs) engagement with consumers, carers, communities and clinicians.

For the purposes of this document engagement is defined as informed dialogue between the organisation and consumers/carers/community/clinicians - encouraging sharing of ideas, options and collaborative decision making across planning, service delivery, policy, research, and quality improvement.

A visual overview of the Guideline can be seen on page one.

Engagement activity throughout the WA health system has significantly changed since the WA Health Consumer, Carer and Community Engagement Framework (2007) release. The Australian Commission on Safety and Quality in Health Care (ACSQHC) National Safety and Quality Health Service Standards (the Standards) were endorsed in 2011. National accreditation to the Standards commenced in 2013 requiring consumer, carer and community involvement in the planning, design, delivery and evaluation of health services. The ACSQHC is currently reviewing the Standards with completion expected late 2017.

The active participation of consumers, carers and community in the health care system is key to delivering person-centred health care.^{2,3} Clinicians also play an important role in designing and delivering patient-centred care.4 Clinician engagement is central to safety, quality, effectiveness and efficiency of organisations delivering health care.⁵ Clinician involvement is necessary to achieve health reforms that are effective, safe and efficient.

The Australian Charter of Healthcare Rights (2008) describes the importance of a genuine partnership between consumers and health services to achieve the best possible outcomes. Patients have the right to make decisions and choices about their care and health service planning.6

The Western Australian Strategic Plan for Safety and Quality in Health Care 2013–2017 describes the vision for consumer and carer centred healthcare. Principles include establishing, developing and supporting partnerships of consumers, carers, community and clinicians with health services at the:

- individual level to make decisions about their own care
- service level where participants:
 - influence service planning
 - designing care
 - · delivering care
 - safety and quality measurement and evaluation
- organisational level where participants are involved in the development of policy and broader strategies.

Partnerships at all levels are necessary to ensure the health system achieves the best possible outcomes for all involved. Engagement at the individual level to support personal care is important and provides the foundation for individuals to engage at the service and organisational level. The main focus of this Guideline is engagement at the service and organisational level, to assist in health service planning, service delivery, policy and will not impact individual care.

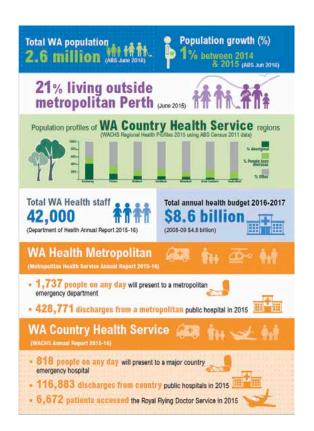
Process of developing the Guideline

The Quality Improvement and Change Management (QICM) Unit, at the Department of Health coordinated the development of this document. The process included:

- a workshop to explore the need for, and structure, of a statewide engagement document
- a review of state, national and international literature relating to engagement
- stakeholder consultation with clinicians, non-clinical staff and external stakeholders
- a survey to explore current awareness and use of the existing engagement framework and identify preferences for the content of a revised framework
- the establishment of a working group of eight consumer and carer representatives to work collaboratively to develop a draft document
- two rounds of public consultation requesting written submissions on the draft
- updating of the draft document using the consultation feedback.

Western Australian context

The provision of health services is challenging with a growing and ageing population, consumers' expectations for increasing quality of care, increasing patient complexity and budget constraints.8 Our State is the largest geographically, making health service delivery more difficult and costly. Inequities in health status and health service access exist across our widespread and diverse communities. The infographic below displays the variation in population profiles of the health regions and contains information regarding the level of activity in the WA health system.



The Health Services Act 2016 governs health services in WA.9 The WA health system consists of the Department of Health, Health Services Providers (HSPs) and Boards, and Health Support Services. HSPs include Child and Adolescent Health Service, East Metropolitan Health Service, North Metropolitan Health Service, South Metropolitan Health Service and WA Country Health Service.

The Health and Disability Services Complaints Office (HaDSCO) is established under the *Health and Disability* Services (Complaints) Act 1995 and is an independent Statutory Authority offering an impartial resolution service for complaints relating to health, disability and mental health services in WA and the Indian Ocean Territories. HaDSCO seeks to empower health service users and providers to collaboratively improve health and disability services throughout WA.¹⁰ HaDSCO engages across the health system with consumers, carers, community and service providers to resolve complaints and support service improvements. Information on HaDSCO's complaint resolution service is available via www.hadsco.wa.gov.au. An online platform 'Collaborate

and Learn' has been established to facilitate engagement between consumers, providers of health, disability services and mental health services. Access is available at Collaborate and Learn.

Who is engaging with the WA **Health Service Providers?**

Consumers

Consumers can be defined as potential, current or previous user of health services. Consumers and health professionals can work together to improve health services, providing better health outcomes for patients.¹¹ Consumer engagement refers to strategies where consumers are involved in the design, planning, delivery and evaluation of health services. 12

While it can also include partnerships between patients and health professionals in the provision of individual care, this is not the focus of this Guideline.

Consumer or Community Advisory Councils (CACs), local consumers, carers and communities can advise metropolitan hospitals and health services on local health needs and issues. Engagement with WA HSPs can also occur via public meetings, forums, working groups and networks. In regional WA, District Health Advisory Councils (DHACs) facilitate health consumers, carers, community members and service providers to work together to improve planning, delivery, access, safety, quality and evaluation of rural and regional health services.

The Health Consumers Council (HCC) is the peak health care consumer and patient advocate body in WA. The HCC Consumer and Community Engagement Program provides support, education and networking opportunities to health consumers and health providers to promote partnerships in healthcare and improve the quality of health services. Free training is offered to health consumers interested in becoming a consumer representative. Further information is available at www.hconc.org.au/services/consumer- community-engagement-program/.

Patient Opinion provides a social platform for conversations between consumers and/or carers and health services.¹³ The feedback can be used to advise service improvements. Access is available at Patient Opinion.

Carers

A carer is a person who provides ongoing unpaid care and support to family members and friends who have a disability, a mental illness, chronic condition, terminal illness or are frail.¹⁴ Collaborative partnerships between carers, families and health services can result in the most appropriate care for an individual and facilitate improvements in the planning, delivery and evaluation of health services.

Carers have unique knowledge and expertise regarding the person they care for.¹⁴ Carer engagement is the process of incorporating the aspirations, concerns, needs and values of carers in decision making and the planning, delivery and evaluation of services. 15 Carers can use their lived experience to improve health services and increase awareness of the carer's point of view.¹⁴

Support workers also support people's health needs, they may know the patient well and have a role in advocacy.¹⁶ Support workers are likely to know the changes that are required to improve patient care, although they are not identified as carers due to the paid nature of the work. 17,18

The Carers Recognition Act 2004 18 includes the Western Australian Carers Charter and mandates that carers are to:

be included in the assessment, planning, delivery and review of services that impact on them and their role

- have their views and needs taken into account along with those people receiving care when decisions are made that impact on them and their role
- be treated with respect and dignity
- have complaints in relation to services that impact on them and their role as carer given due attention and consideration.

Carers WA is the peak body that represents the needs and interests of carers in WA and have a Carer Representation Program to recruit, develop, support and remunerate carers to participate in engagement activities with health services. 19 The aim of the program is to support carers in voicing the carer perspective in policy development and health services planning.

Communities

A community is a group of people who share something in common, such as a location, interests, culture, language, beliefs, values or traditions. Community engagement involves two-way interaction between health services and communities to bring about change to improve the health of the community and its members. Community engagement encompasses a wide variety of activities including public consultations, community development and community-capacity building. 20,21 Communities can advise HSPs and other health care providers on local health needs and issues. In WA, this is facilitated by CACs, DHACs, the HCC and community forums. HSPs can work collaboratively with existing community groups or organisations to improve patient outcomes. The WA Primary Health Alliance (WAPHA) Community Engagement Committees provide a community, consumer and carer voice and work collaboratively with other networks to design primary health care models and improve the coordination of care. Multiple and innovative engagement methods will inspire community interest and maximise participation.²²

Engagement has positive outcomes for both HSPs and the community when done respectfully and appropriately. As a result, HSPs can:

- develop an understanding of local community needs, unmet needs and barriers preventing access
- become more efficient and responsive
- provide more appropriate services.

Increased community awareness and support of local health services can lead to improved consumer experience, increased health literacy and better health outcomes.²³ Community awareness can be increased through the utilisation of social media, the internet and community newspapers.

Clinicians

Clinicians are health professionals who spend the majority of their time providing direct patient care. including medical, nursing and allied health staff. Clinician engagement is defined as the active and positive contribution of clinicians within their normal working roles to maintain and enhance the performance of the organisation, which itself recognises this commitment to support and encourage high quality care.24

Clinician engagement has shown to be critical to improving health outcomes. Research suggests that without clinician engagement, care will continue to be delivered in isolated clinical pockets, preventing coordinated action and system wide improvement.²⁵

Clinician engagement is rapidly becoming one of the key priorities for executives and senior managers and an indicator of better-performing hospitals.²⁵ Achieving high levels of clinician engagement can be challenging but when done well can result in significant benefits, such as staff satisfaction and retention, improved organisational performance, innovation and improved patient outcomes. 25,26

Engagement principles

The principles that underpin the Guideline aim to create consistency in the way WA HSPs approach consumer, carer, community and clinician engagement to facilitate high quality engagement. It is important for HSPs to reduce perceived power differences between staff and participants to create a safe environment to provide input.²⁷ These principles can also be used to develop indicators to evaluate how well the engagement process was conducted. The following table outlines the engagement principles.

Table 1. Engagement Principles

Engagement Principle	Explanation
Purposeful	 To build lasting good will with stakeholders, we will: have clear reasons for engaging engage for the time required to deliver the quality information needed commit to actioning the outputs. We are driven by our strategic priorities, but remain aware of our stakeholders' objectives, environment, expertise, capacity to engage and level of influence.
Collaboration and partnership	 We strive to build understanding, connections, capacity, trust. We promote open dialogue. We involve stakeholders from the very beginning and agree on when and how to engage. We encourage stakeholders to share ownership of the process and decisions. We are all accountable for the eventual outcomes. We respect our stakeholders' expertise and appreciate the benefits of mutual learning. We foster a culture of sharing ideas, knowledge and resources
Clear communication	 We facilitate two-way communication. We clearly identify and explain the process. We negotiate timelines with stakeholders whenever possible. We provide timely information so stakeholders can understand the content and contribute in a meaningful way.
Inclusiveness	 We create an environment to enable a diverse range of stakeholders to fully participate and engage in: planning decision-making implementation evaluation. We encourage diverse opinions and use engagement techniques to enable all voices to be heard. We recognise the different communication needs and preferences of stakeholders and will meet these whenever possible.
Transparency	 We encourage all participants to be candid, willing to acknowledge mistakes and open to identifying what is not known. We demonstrate integrity. We build trust and compassion. We are open about the stakeholder level of influence. We inform stakeholders of how their input was used to affect decisions.

Engagement Principle	Explanation
Respect	 We are open to alternative views. We listen and speak with empathy. We build trust, and identify shared benefits and outcomes beyond self- interest. We foster mutual respect. All participants recognise and value each other as equal contributors
Commitment	 We have committed leaders who communicate a strategic vision of partnership and act to facilitate effective engagement. We embed engagement into everyday practices.

Engagement levels

Consumer, carer, community and clinician engagement with the WA health system can occur on the following levels:

- individual
- clinical department
- health service/hospital
- Health Service Provider.

The International Association for Public Participation (IAP2) Public Participation Spectrum outlines five levels of engagement across a continuum that describes an increasing degree of engagement, participation and influence in the engagement process.²⁸ The IAP2 is the leading professional body for engagement practitioners that promotes and improves the practice of public participation. The IAP2 Quality Assurance Standard aims to provide a standardised process to assess the quality of engagement projects in Australia.28

The spectrum can be used to assist with determining the level of influence required and sets out the commitment being made to ensure transparency. Careful consideration should be given to the engagement level utilised in relation to the stakeholders involved, the issue being addressed and the intended outcomes of the engagement.²⁹

Table 2 demonstrates the increasing levels of engagement and methods to engage using the IAP2 continuum. For the purpose of this table, stakeholder refers to consumers, carers, community and clinicians.

Table 2. Spectrum of stakeholder engagement

	Increasing levels of stakeholder impact →	holder impact →			
	Inform	Consult	Involve	Collaborate	Empower
	Information giving	Information seeking	Information sharing and joint planning	Participatory decision making	Stakeholder leadership
Purpose of engaging stakeholders	To provide information to stakeholders to assist them in understanding issues, alternatives and / or solutions.	To gather stakeholders, especially to capture lived experiences.	To involve stakeholders in the planning, policy development, delivery and evaluation of services.	To work in partnership with stakeholders.	To place final decision- making in hands of stakeholders.
When to use	One-way exchange of information, e.g. to assist in access to and management of health issues.	Two-way exchange of information, share views, needs and interests.	To ensure stakeholder views are considered and reflect in decisions and outcomes.	To jointly develop solutions and initiatives.	To enable stakeholders to decide and implement solutions/ outcomes (often within specified guidelines).
Commitment to stakeholders	We will keep you informed.	We will keep you informed, listen to you, acknowledge your views and provide feedback.	We will work with you, consider your views and provide feedback on how your input influenced the outcomes.	We will look to you for advice and innovation in the formulation of solutions and incorporate your advice to maximum extent.	We will implement what you decide.
Methods of engagement	 public meetings public notices announcements website fact sheets newsletters education programs social media. 	 public meetings public hearings focus groups surveys e-Consult. 	 workshops forums deliberative polling panels taskforces working parties e-Consult. 	 reference groups working Groups consumer and Community Advisory Councils and Groups district Health Advisory Councils policy roundtables clinical networks clinical redesign. 	steering committees quality committees boards participatory governance standing strategic committees
Level of stakeholder influence	Minimal influence.	Low influence.	Moderate influence.	High involvement and influence.	Stakeholder control.

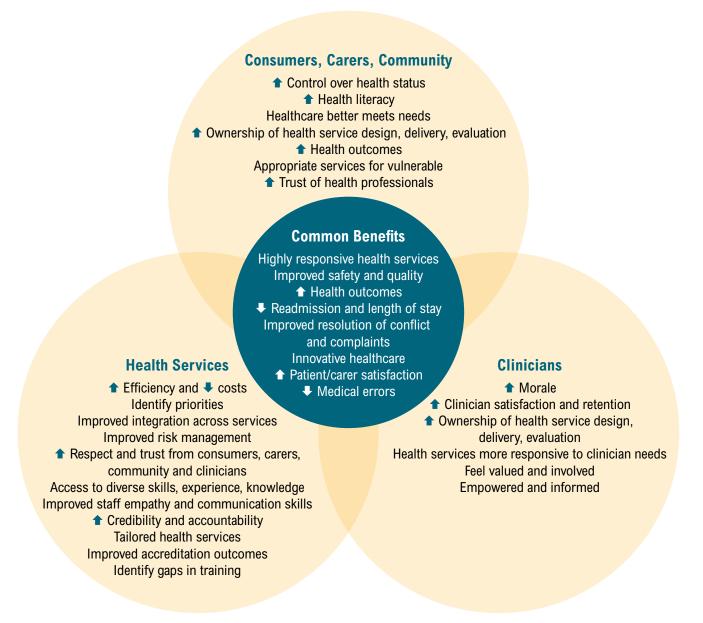
	Increasing levels of stakeholder impact →	holder impact →			
	Inform	Consult	Involve	Collaborate	Empower
	Information giving	Information seeking	Information sharing and joint planning	Participatory decision making	Stakeholder leadership
Capacity of consumer	Health literacy.	Communication abilities. Understanding of context.	Understanding of objectives. Strategic thinking. Ability to represent the broad view.	Credible knowledge and experience. Shared responsibility. Produce mutual objectives.	Steer to clear objectives.
Capacity of organisation	Capacity of organisation Effective communication.	Effective consultation.	Building stakeholder involvement into all aspects of organisation. Networking.	Stakeholders fully integrated into boards, working groups, best practice improvements and all aspects of organisations.	Commits objective/s to consumers and acts on outcomes. Stakeholders involved in setting objectives, policies and strategic directions.

Adapted from the Northern Territory Government Department of Health Stakeholder Engagement Framework 2012

Benefits

Effective engagement practice has many benefits for consumers, carers, communities, clinicians and health services. Figure 1 displays the benefits of engagement for each stakeholder group. 15,20,21,23,30-33

Figure 1. Benefits of engagement



Process

A clear process for engagement can assist organisations to successfully plan, manage and implement consumer, carer, community and clinician engagement activities. Flexibility in the engagement process is important. Continual review and adaptation of the process ensures that participation continues to be effective.¹⁵ Suggested steps of engagement are outlined in Table 3 below.

Table 3. The process of engagement

1. Scope	 Clearly define the purpose and rationale of the engagement activity. Identify objectives, decisions to be made, resources required, responsibilities and risks. Determine where the activity belongs on the engagement spectrum to identify appropriate engagement methods. Identify groups who are directly involved, likely to be affected by the project outcome and/or need a voice. Look at the different levels of stakeholder influence. Assess the capacity to engage. Ensure there is organisational understanding of and commitment to engagement, with adequate resources, meeting stakeholder needs and going to communities if required.
2. Engagement plan	 Document the purpose, stakeholder recruitment strategies and appropriate engagement methods. Establish a timeline, risk management plan, budget, roles and responsibilities. Develop a communication strategy. Determine legislative requirements. Develop an evaluation plan detailing how to measure success. Manage expectations and overcome barriers.
3. Engage	 Use communication methods to suit participants, including the use of interpreters if required. Facilitate two-way communication. Develop clear agendas, objectives, record-keeping, action plans. Provide convenient meeting times, suitable venues, accessibility and inclusive participation. Enable participants to feel free to voice their opinions and concerns. Provide reimbursement where appropriate. Collect feedback, analyse and feedback to participants. Specify what has happened to inputs, how they were used or not used and the reasons why. Include issues and consider the privacy of participants. Build relationships and manage conflict.
4. Evaluation	 Evaluate the outcomes and process. Collate lessons learnt. Review how well the engagement requirements and stakeholders were identified. Confirm the achievement of project objectives and stakeholder satisfaction. Compare the actual level of influence to the intended influence and the impact of engagement.
5. Documentation of evidence	Document what has been learnt. Collate evidence for successful engagement. Share and implement lessons learned to improve future engagement.

Evaluation

The evaluation of engagement activities can be challenging but is essential to measure outcomes, inform future engagement and improve engagement practices. To evaluate the success of engagement, it is recommended that evidence be collected before, during and/or after the engagement process.³³ Engaged consumers, carers, community and clinicians should be consulted when determining the evaluation strategy as they will hold valid views on what should be measured and what constitutes a good or poor outcome.23

The main reasons to evaluate engagement activities are to:

- assess the effectiveness of engagement activities against their objectives and determine whether they should be continued, expanded or made permanent
- identify and address problems
- to ensure the engagement is meeting the needs of the majority
- keep stakeholders informed of progress
- keep individuals engaged and enthusiastic by demonstrating whether goals are being met
- build an evidence base for innovative approaches to engagement and inform future projects
- provide ongoing quality improvement
- provide evidence to increase support for the engagement of consumers, carers, community and clinicians with health services.30

Both formative and summative evaluations of an engagement process are recommended. Formative evaluation, conducted during the stages of planning and early engagement, monitors progress and enables continuous improvement.³⁴ Qualitative methods are most commonly used in formative evaluation (refer to Table 4). Summative evaluation, conducted following the conclusion of engagement activities, assesses the effectiveness of the engagement activity in its entirety. Summative evaluation involves both quantitative and qualitative measurements (refer to Table 4).

Table 4. Quantitative and qualitative evaluation

	Example type	Methods
Quantitative evaluation	Who? How many? How often?	Survey, frequency, interviews, participant statistics.
Qualitative evaluation	Why? What happened? What difference did it make? How did the participants feel about the engagement activity?	Interviews, focus groups, story- telling, observation and open-ended questionnaires, case studies.

Figure 2. Stages of the evaluation process

Plan

- Evaluation questions based on what happened, what we can do better, was the activity successful and what have we learned.
- Time, skills, budget and resources required.
- Decide on the quantitative and qualitative methods to use (see Table 3 above).
- Decide when and how often information will be collected, and who from.
- Identify indicators (align to principles) to judge how well the engagement process was conducted. (see Table 4 on p19).

Investigate

- · Consider an external evaluator.
- · Ethics and confidentiality.
- · Collect data.
- Information may be collected from existing documentation.
- · Data collection during and after engagement.

Analyse

- · Analyse quantitative and qualitative information.
- · Look for trends and common themes.
- Interpret the findings.

Report

- Summarise findings to answer evaluation questions.
- Ensure the report is user-friendly and unbiased.
- Include lessons learned.
- The report should comply with confidentiality requirements.

Share evaluation findings

- Communication plan.
- · Provide feedback to participants and stakeholders.
- Report the results of the evaluation in an appropriate format. Some audiences may prefer a visual presentation.
- Report findings within a time frame that is useful to decision-makers.
- · Conferences, staff meetings, discussions.

Engaging with vulnerable groups

Identifying, understanding and engaging population groups that experience disadvantage is important to provide better health services for these groups and improve health equity.³⁵ Engagement of vulnerable or hard to reach groups by health services can be challenging. It is important for health services to be flexible, recognise diversity and use appropriate language.²⁷ Often vulerable groups are overlooked, resistant to engagement and/or perceive engagement activities as inaccessible, inappropriate or irrelevant.³⁶ Engagement methods need careful consideration and planning. The benefits of engaging with vulnerable groups include:

- better informed policies and programs that promote inclusion and prevent discrimination
- increased awareness of the issues and needs of vulnerable groups
- the identification of barriers to health service delivery.

The following sections detail information and suggest strategies to enable effective engagement with the groups recognised as being harder-to-reach when it comes to engagement with health services. These groups have been identified as being vulnerable through existing engagement literature.

Table 5 below outlines strategies to improve engagement with all stakeholders, specifically vulnerable groups.

Table 5. Top tips for engaging with all stakeholders

Careful planning and preparation	Engage groups early. Involve communities in the planning stage to promote effective engagement and prevent heading in a direction that will not work for the particular community.
Recognise that each community is unique	Recognise that differences exist between communities, within groups, language groups, and between urban and rural groups.
	Take time to understand communities and their diverse needs.
	Offer a range of engagement strategies.
Allow time	Take sufficient time to build respect and trust, encourage the participation of community members, circulate information and allow decision making. Gaining feedback may be a slow proces
Provide flexible meeting	Consider after hours meetings to support involvement. Participants may work full time.
times and places	Consider meeting participants within their community.
Use appropriate engagement methods	Talk to individuals, carers and services regarding the preferred method for engagement. Attendance by video conference may be the most suitable option.
Build capacity	Work with participants to build their capacity to engage, including orientation and training programs. Build trust and support the participation of participants, families, carers, support workers, friends and advocates. Be aware of the support needed to empower participants, their families, carers and friends.
	Work with health service staff to build their capacity to effectively engage and include training such as cultural awareness, customer service and communication. Provide training for staff to develop an understanding of the issues affecting participants and communities and deliver non-discriminatory services. Identify champions.
Provide access	Provide fully accessible venues and provision for wheelchairs, hearing or vision impairments, and guide dogs.
	Design accessible websites.

Address social disadvantage	Facilitate government departments to work across key sectors such as housing, justice, education, employment and health.
	Develop innovative programs to enable services to collaborate to remove barriers in accessing healthcare
Provide adequate resources	Ensure resources are available for remuneration, appropriate venues, capacity building, transport, interpreters, catering and child care.
Manage expectations	Be clear, honest and realistic.
	Ensure participants understand the participation process in terms of confidentiality and the influence of their input.
	Refrain from committing to any actions which are not achievable.
Offer remuneration	Ensure participants feel their time and effort is valued. This should be negotiated and agreed to prior to the engagement activity, and may include non-monetary options.
Avoid over-consultation	Plan well and liaise with others who may want to engage the community. Seek advice from the relevant sector.
	Source information about recent/current consultations.
Respect confidentiality	Two-way respect and consideration.
and privacy	Develop and discuss rules around protecting confidentiality and identity. Anonymity may be important, especially in smaller communities.
	Consider alternative methods of engagement.
Provide feedback	Offer timely and ongoing feedback.
	Acknowledge participant contribution and provide a summary of the outcomes in an understandable format.

Children and young people

In 2013, there were over 570,000 children and young people under the age of 18 living in WA.³⁷ Young people are enthusiastic and can share ideas to assist health organisations improve the quality of their services.³⁸ Children and young people also benefit from being involved in health organisations through having a say on issues that affect them, learning new skills and helping to create health services that better reflect their needs. It is recommended that HSPs use a creative approach when engaging young people.

Table 6. Top tips for engaging with children and young people

Use suitable recruitment processes	Distribute invitations to participate through appropriate channels such as email networks, social media, schools, youth workers and child health nurses.
Obtain consent to participate	May require informed consent from the child and their parent and/or carer for participation and to use the material they contribute.
Ensure safety and wellbeing	A safe and healthy environment for young people to participate is essential. Do not overburden participants as young people have school, homework and job responsibilities.
Use appropriate engagement methods	Consider the age, developmental stage and characteristics of the children. Meetings should be less formal, flexible with regular breaks.
	Engagement techniques may need to be more family friendly, creative and innovative.
	Use jargon-free language.
	Ask young people how they would like to engage.

Refer to Appendix A for supporting resources for engaging with children and young people (Page 35).

"People might say 'you're young, what would you know?' But I'm a young person, I have thoughts, I know how to express them and I'm ready to get involved."

Sarah, a member of the Commission's 2000 Young People's Reference Group. Participation: Sharing the Stage. NSW Commission for Children & Young People.

Aboriginal people

Within WA, the term Aboriginal is used to refer to Aboriginal and Torres Strait Islander. Aboriginal and Torres Strait Islanders may be referred to in the national context and Indigenous may be referred to in the international context. In 2014, the estimated resident Aboriginal population was 713,589 people, representing 3 per cent of the total Australian population.³⁹ Aboriginal people represented 3.6 per cent of the total WA population in 2014.³⁹ Approximately 62 per cent of the WA Aboriginal population lived in regional or remote areas.⁴⁰ There are 70 Australian Aboriginal languages in WA.⁴¹

Aboriginal health outcomes continue to be poorer with respect to premature death rates, chronic disease, injury rates and health risk factor profiles. Life expectancy is increasing but is still around 10.5 years less than non-Aboriginal people.⁴² To improve Aboriginal health, initiatives need to encompass social, cultural, economic and environmental factors and involve collaboration with communities.⁴³

Aboriginal Community Controlled Health Services (ACCHSs) are owned and managed by an elected board of Aboriginal people from the local community. Aboriginal community ownership and involvement in these services delivers holistic and culturally appropriate health care to improve health outcomes for Aboriginal people. By partnering with health professionals and other organisations, ACCHSs can help to improve the health system and the quality of care available to Aboriginal people.

The Aboriginal Health Directorate, Department of Health, have developed a WA Aboriginal Health and Wellbeing Framework. The Framework, released in 2015, has guiding principles to underpin engagement activities and increase the participation of Aboriginal people in the planning, design and implementation of health services.40

Table 7. Top tips for engaging with Aboriginal communities

Demonstrate cultural respect	Respect identity, culture and values. Observe community priorities and protocols, men's and women's information, language, interpreters and story-telling. Aboriginal people view the person as living and being in a relationship with the family, community, the land and the spiritual beings. A holistic viewpoint is important. Develop initiatives to prevent and reduce systemic racism. Provide cultural awareness training for health service staff.
Consult with community leaders	Aboriginal leadership can be invisible to those outside it. Show respect and try to identify and build relationships with community Elders and leaders.
Involve the Aboriginal Community Controlled Health Services (ACCHSs)	The ACCHSs across WA provide important links with Aboriginal community members.
Involve specialised health service staff	Aboriginal Health Strategy teams, Aboriginal Liaison Officers and Aboriginal Health Workers are important in improving community and consumer engagement at the health service level.

Refer to Appendix A for supporting resources for engaging with Aboriginal communities (Page 35).

"Elders and other senior community members should be engaged as key stakeholders to champion culturally appropriate choices and approaches to health and wellbeing."

Participant, Brisbane Community Consultation, National Aboriginal and Torres Strait Islander Health Plan 2013–2023.

Culturally and Linguistically Diverse (CaLD) groups

Australia is a multicultural country with 27 per cent of the population were born overseas, over 200 spoken languages and more than 11 per cent of the population in WA speaking a language other than English at home. 44,45 The WA population also identifies with over 100 religious faiths. 41

Engagement can be an unfamiliar term and can be understood differently across various cultural groups.⁴⁴ CaLD consumers, carers and communities engage with health services less frequently than the general population. Cultural insensitivity is a significant barrier to participation.

Refugees experience challenges accessing health services due to cultural differences, low health literacy and language barriers. Health needs of refugees may be further complicated by the impact of war, torture and trauma.⁴⁶ People with refugee backgrounds may also lack the support of family and community.⁴¹

New and emerging communities are small populations with the majority being new arrivals to Australia through humanitarian programs. Family networks, support systems and community structures are lacking. These communities need additional assistance and resources for health care and can have health problems due to lack of healthcare in their home country or refugee camps.⁴⁷

Table 8. Top tips For engaging With CaLD communities

Demonstrate cultural respect	Acknowledge community beliefs, protocols and practices. Avoid stereotyping. Provide cultural competency training to health service staff.
Address language issues	Arrange interpreters if required. Written, electronic and verbal information may need to be translated. Implement the WA Language Services Policy 2014.

Refer to Appendix A for supporting resources for engaging with CaLD communities (Page 35).

Multicultural communities and consumers are often unfamiliar with how to participate in consumer engagement processes. Building trust and capacity within these communities is important.

Health care providers' guide to engaging multicultural communities and consumers. Queensland Government 2012.

Rural, regional and remote communities

In rural and remote WA the delivery of health services is very complex, magnified by unique characteristics and challenges. Health care planning, programs and service delivery models must be adapted to meet the widely differing health needs of rural communities and overcome the challenges of geographic spread, low population density, limited infrastructure plus the significantly higher costs of rural and remote health care delivery.

The WA Country Health Service (WACHS) is the major provider of hospital, health and aged care services across country WA. There are six regional health campuses, 15 district health campuses and 49 small hospitals.⁴² The WA Country Primary Health Network is responsible for improving the coordination of services for patients between primary care and hospital and other community services.

WACHS serves a population dispersed over a vast geographic area covering 2.55 million square kilometres - more than 10 times the size of the United Kingdom.

WACHS Strategic Directions 2015–2018:

Healthier Country Communities through Partnerships and Innovation.

WACHS has 21 District Health Advisory Councils (DHACS) established across its seven regions to represent the consumer voice at local, district and state health service levels, and are one of its key mechanisms for community, carer, and consumer engagement.⁴⁸ Additional ways of engaging include Governing Councils, the DHAC Chairs Network, regional primary health networks, local government advisory groups, community reference groups, safety and quality committees, governance committees and local health advisory groups. 49

Effective engagement empowers local communities to have a greater say in planning, design, delivery and evaluation of their hospital and health services, contributing to more efficient and effective healthcare delivery.⁵⁰ Health service improvement is important as the life expectancy for country people is around two years less than for metropolitan people.⁴²

Table 9. Top tips for engaging with rural, regional and remote communities

Use technology	Consider phone, video-conference, and other methods of communication as alternatives to face-to-face attendance. Be aware that not everyone has access to reliable mobile or internet connection, and consider the computer literacy of participants.		
Involve District Health Advisory Councils (DHACs)	DHACs are made up of consumers, carers, community members and health service providers, and are central to consumer, carer and community participation.		
Establish links with community organisations	Utilise established relationships between community and organisations to facilitate engagement and avoid over-consultation.		
Provide resources to overcome the barrier of distance	Provide sufficient funding to enable travel and access to remote populations		
Involve the Aboriginal Community Controlled Health Services (ACCHSs)	The ACCHSs across WA provide important links with Aboriginal community members whose voices are important in country health service processes.		

Refer to Appendix A for supporting resources for engaging with rural, regional and remote communities (Page 36).

People with disability

In 2015, there were an estimated 4.3 million Australians with disability, with 14 per cent of the WA population living with disability.⁵¹ The gap between the health of individuals with disability and those without disability remains large despite improvements in the health of the general population. 52 People with disability experience significantly poorer health than people without disability and are more likely to have three or more long-term health conditions (74% versus 23 per cent).⁵³ 50 per cent of people with disability also had mental health conditions, compared with 8 per cent for those without disability.⁵³ People with disability use hospital services more than the general population, stay in hospital longer and experience multiple access barriers. 54,55 The life expectancy of people with severe intellectual disability can be 20 years lower than the general population.⁵⁶

The WA health system is committed to providing people with disability, their family and carers, full access to health services, facilities and information. 57,58 This commitment is reflected in the WA Disability Health Framework 2015–2025 which seeks to improve the health care of people with disability. This is achieved by its vision for 'An inclusive Western Australian health system that empowers people with disability to enjoy the highest attainable standard of health and wellbeing throughout their life'. 52 If this vision is to be realised, it is particularly important that people with disability and; where appropriate, their family, friends, carers, support workers, disability service providers and advocates; actively participate in planning, delivery and review at the individual, service and organisational levels to improve health outcomes.⁵⁹ The Disability Health Network Commitment to Inclusive Engagement provides a useful resource for communication and engagement with people with disability.60

Table 10. Top tips for engaging with people with disability

Communicate appropriately	Speak directly to the person with disability (wherever possible), provide all relevant information to enable informed decisions to be made and treat the person with respect and courtesy. If in doubt about how to communicate – ask the individual, their carer, family member or advocate. Use appropriate communication devices. Interpreters to be made available where necessary.		
Reimburse participation costs	Consider the cost of using wheelchair accessible taxis, payment for the carer, and payment for family members to obtain respite care to attend.		
Provide information	Make information available in alternative formats such as plain text versions to suit screen readers, Braille, audio, short sentences, jargon free, pictures and plain English. Provide as much information as possible so people know they can participate easily, and also in multiple formats to reach the widest possible audience. Send information out through disability networks and gain advice on the most appropriate format to use.		

Refer to Appendix A for supporting resources for engaging with people with disability (Page 36).

Always focus upon the person first, not their disability, and recognise their abilities.

Engaging Queenslanders: A guide to engaging people with a disability, 2007.

People living with mental illness

People living with mental illness are among the most vulnerable and disadvantaged in the community. Mental illness is a clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities. 61 This includes many disorders, such as anxiety, depression, eating, schizophrenia, bipolar, hoarding, and psychoses which can occur in people of all ages. Mental illness can be associated with poorer physical health due to poor diet, lack of activity and higher rates of smoking, drinking and/or drug use.⁶²

Mental illness is common in Australia, with 45 per cent of people estimated to experience a mental health condition in their lifetime. In 2014 to 2015, 20 per cent of Western Australians had a mental illness. 63 Mental health consumers experience a 12 to 15 year life expectancy reduction in WA compared than the general population, with an estimated 80 per cent of lower life expectancy attributable to preventable chronic diseases such as diabetes, heart and lung diseases.⁶⁴

A holistic, collaborative approach to health care with a commitment to reducing mental health discrimination in health care is important.⁶⁴ Optimal mental health and wellbeing requires support for whole-of-life outcomes beyond the immediate health setting, such as employment, physical health, community inclusion, coping mechanisms, relationships and housing. 65

Mental health services, under the WA Mental Health Act 2014, must take a collaborative approach to decision making in planning, undertaking, evaluating and improving consumers' treatment, care and support.⁶⁷ Engaging people with or recovering from mental health problems, their families and carers as partners in the development and delivery of services helps to achieve a high quality mental health system. 65 Consumers and carers have unique perspectives due to their lived experience of mental illness, and these perspectives can be used to improve mental health services. Peer support workers with lived experience of mental health recovery offer valuable support and insight and can improve engagement. trust and recovery of consumers within the service. 68,69

The Community, Family, Carer and Community Paid Partnership Policy demonstrates the commitment of the Mental Health Commission to work with consumers, families, carers and community members in their projects, programs and services.⁷⁰

Table 11. Top tips for engaging with people living with mental illness

Offer support and flexibility	Mental health issues can affect the capacity of participants to engage. Engagement needs to be managed in a supportive and understanding manne		
Accommodate mental health and well-being needs	Consider the impact of engagement on the participant's wellbeing. Participants may want to attend with a friend, peer support worker for support and meet in an environment where the participant feels most comfortable.		
Respect and value lived experience	Lived experience of mental health issues and clinical knowledge are important to recovery and service quality. There is an extensive network of peer support workers and recovery leaders available to assist with engagement.		
Empowering approaches	Use peer support workers to engage, or ensure people have a say in how they are engaged, so participants can feel confident that the engagement is meaningful and their wellbeing needs are supported.		
Appreciate diversity	Where possible, reach out to a diversity of people (and their carers, families and communities) living with mental health issues. Harder to reach groups are at greater risk of poor mental health outcomes.		

Refer to Appendix A for supporting resources for engaging with people living with mental illness (Page 37).

"Being heard and valued has been hugely empowering. It has transformed me as a person. Being able to be included has helped me feel accepted and comfortable. It has empowered me to think that my voice is valuable. It has given me back control, to be able to give back."

Consumer, Queensland Health Mental Health Services Consumer, Carer and Family Participation Framework 2010.

People from the Lesbian, Gay, Bisexual, Transgender and **Intersex (LGBTI) community**

Groups within the LGBTI community have specific social, cultural, psychological, medical and care needs. They share the experience of being part of a minority population likely to have been subjected to exclusion, social isolation, hate crimes, discrimination and stigma throughout most of their lives. LGBTI Australians are more likely to experience higher rates of self-harm, suicide and mental health issues. Higher rates of use of alcohol, tobacco and illicit drugs are also experienced by this group. Family support structures can be different or fewer.^{71,72}

While the inclusion of LGBTI people has grown over time, the older generation of LGBTI people grew up knowing that they could be imprisoned or forced to undergo medical 'cures' if their sexual orientation or gender identity was known. Consequently, many older people hide their sexual orientation and gender identity from service providers, believing that it is still not safe to disclose. Fear of discrimination can lead to delays in seeking health care, lower use of services and underuse of screening.⁷³

Up to 11 per cent of the Australian population may be of diverse sexual orientation, sex or gender. National LGBTI Ageing and Aged Care Strategy, 2012.

This population is now recognised by the Commonwealth Government in some federal legislation, policies, and programs. From 1 August, 2013 the Sex Discrimination Act 1984 has provided federal protection from both direct and indirect discrimination on the basis of sexual orientation, relationships status, gender identity, and intersex status. LGBTI people are also recognised as a special needs group in the Aged Care Act 1997.74

There are many benefits to engaging with the LGBTI community. Policies and programs can be designed to promote inclusion and prevent discrimination, vilification and harassment based on gender identity and sexual orientation. There is increased awareness of issues and needs within the community. increased community understanding of the lived experience of LGBTI people and the identification of barriers to health service delivery.⁷²

Table 12. Top tips for engaging with LGBTI groups

Communicate a welcome to the LGBTI community	Utilise inclusive images, information, posters and resources. Promote through channels accessed by the LBGTI community and organisations, such as social media and radio broadcasts.	
Respect privacy	Respect that some members of the LGBTI community may want to keep their orientation private.	

Refer to Appendix A for supporting resources for engaging with LGBTI groups supporting resources (Page 37).

People experiencing homelessness

In 2014, there were 9.595 people experiencing homelessness in WA.⁷⁵ Of these, nearly 16 per cent were under the age of 12. The health of people experiencing homelessness is extremely poor and life expectancy is between 43-48 years.⁷⁶ People who are homeless experience increased health risks due to adverse weather, inadequate sleep, poor nutrition, violence and environmental hazards.

Improved health and wellbeing is essential to breaking the cycle of homelessness.⁷⁷ Approximately 75 per cent of homeless Australians experience some form of mental illness.⁷⁸ The two main barriers preventing a homeless person seeking healthcare are the lower priority of seeking healthcare compared to the priority of basic survival and previous negative health service experiences. 76 Understand the hierarchy of needs where basic survival comes first and basic comfort comes second. Planning for change and the future can only be achieved when their basic needs are first met.

Table 13. Top tips for engaging with the homeless

Facilitate one-on-one engagement	The quality of the time spent with a consumer is more important than the frequency of contact.		
Build trust	Take the time to build rapport and knowledge about the client's background and life. A non-judgemental, non-threatening, calm and friendly attitude is essential. Offer to meet with the consumer and their support people, if possible.		
Meet in non-threatening locations	Meet at locations where homeless people are comfortable.		
Provide client directed assistance	Investigate what clients want and need rather than making assumptions and imposing services.		

Refer to Appendix A for supporting resources for engaging with the homeless (Page 38).

The biggest cause of homelessness in Western Australia is domestic violence (34 per cent), followed by financial difficulties (28 per cent).

Homelessness Australia fact sheet, 2014.

Case Study: Royal Perth Hospital



An example of organisational commitment

Royal Perth Hospital (RPH) has recognised the critical importance of meaningful consumer engagement. There is now an appointed Director of Consumer Engagement, a Consumer Engagement Strategy, a Consumer Advisory Committee with a Chair and more than 50 Consumer and Carer Representatives. There is strong executive support and a dedicated budget which allows the Consumer Engagement Strategy to be embedded throughout the organisation.

In 2015, RPH committed to a 'what matters most' approach to consumer engagement. The Consumer Advisory Committee (CAC) was established to bring the consumer and carer voice into decision making to ensure the hospital provides the care and services people want and need. The CAC consists of consumers carers and community members who are passionate about helping RPH to make the best decisions for planning, delivering and evaluating our health services. Recruitment to the CAC is ongoing and members are actively involved in committees and activities throughout the hospital.

In addition to the CAC, there are several working groups involved in the improvement of health services. The Aboriginal, Mental Health, Carers and Paediatric Transition working groups provide a more flexible approach to consumer, carer and community engagement. Previously, the Wayfinding and Cognitive Impairment working groups have enabled a focused approach to engagement for hospital projects.

RPH aims to be the leading hospital in Australia for consumer and carer engagement. Part of this is integrating the experience and voices of consumers and carers into health service planning and provision. The second part is working at the 'coal face' of clinical care to better involve patients and their carers in treatment plans, providing them with options which allow them to plan the patient journey.

"Being able to use consumer feedback to drive true change in our organisation is very rewarding. Staff are embracing feedback from consumers and carers and you can see it improving our service delivery. I sincerely believe as an organisation we are leading the way in consumer and carer engagement and patient-focused care. To see other hospitals looking to us as a leader in this area makes me proud to be part of the Royal Perth Hospital team."

Todd Gogol, Director of Consumer Engagement. The Royal Pulse, December 2015.

The organisation has embarked on an innovative program to improve health service delivery to one of the most marginalised and vulnerable groups in our community – rough sleeping homeless people. The RPH Homeless Team is delivering patient-centred, individualised care to this cohort of RPH patients, with their complex mix of social and medical issues. RPH's hospital care is now directly linked to Perth's largest homeless medicine GP practice, Homeless Healthcare. Daily GP-led ward rounds at RPH brings this expertise directly to the hospital bedside. This is coupled with strong links to Perth's homeless community services which now operate both within RPH and via connections to many outside agencies.

The 50Lives50Homes project involves over 15 organisations, coordinated by Ruah Community Services. The project is actively housing Perth's most entrenched and complex street homeless individuals, providing long term housing and support to over 25 individuals in the first six months of operation between April and October 2016. Both RPH and Homeless Healthcare staff sit on the working group and Steering Committees of the 50Lives50Homes project in a new model of directly linking hospital, primary care and community support agencies.

This trans-agency initiative is reaping major benefits for street homeless people whose social and medical needs are being met simultaneously, with far smoother transition of care between agencies. The RPH Homeless Team started work in June 2016. In the first four months of operation, 160 homeless individuals were assisted with individualised care and support. The discharge planning for homeless people now involves in-depth social planning and many patients are now being discharged to safe destinations rather than back to the streets.

"Putting in place practical individualised management plans allow Royal Perth Hospital to provide the very best care for some of our most vulnerable patients. Along with the support of community services, we help patients get the right care and stay out of the Emergency Department."

Dr Amanda Stafford, Emergency Medicine Consultant. The Royal Pulse, 2015.

Case Study: St John of God Midland Public Hospital



Consumer involvement from the start

St John of God Midland Public Hospital (SJGMPH) is committed to the engagement of consumers, carers, community and clinicians to improve the design, delivery of health services. The Community Advisory Council (CAC) actively promotes community participation to improve and enhance the patient experience. It meets on a bimonthly basis, is well attended and supported by the executive (including the Chief Executive Officer and Directors of Nursing) and senior officers of the hospital. The CAC was consulted during the planning and commissioning of the new hospital, providing valuable feedback on wayfinding, signage and patient information content. The group receives a full review of the safety and quality performance of the hospital at each meeting, including detailed incident and complaint reports.

The hospital also engages with patient and carer advocacy and support groups. The Swan Stroke Patient Support Group meets monthly at the hospital. The Head of the Department Aged Care and Rehabilitation, Head of the Stroke Unit and the Chief Executive Officer attend every six months to allow for direct feedback on matters such as services and support, access and post-discharge liaison. These meetings have led to positive outcomes, such as the engagement of a stroke liaison nurse. Liaison with clinicallyorientated lead Non-Government Organisations and patient advocacy groups, such as the National Stroke Foundation, occurred in the commissioning of the new hospital, with the model of care at our stroke unit reviewed at a national level by this key advocacy group.

The hospital serves 11 per cent of all Aboriginal people in WA. The SJGMPH Aboriginal Health and Workforce Strategy emphasises the importance of:

- community engagement through family mapping in Whadjuk Noongar country and the appointment of representatives from the local family/clan groups to honorary liaison officer and advisory roles to the new hospital
- workforce development to achieve high levels of cultural security and thereby safe and effective utilisation of services. This has involved utilisation of section 50D of the Equal Opportunity Act to drive dedicated Aboriginal recruitment to key roles at the hospital including medical (the strategy is led by an Aboriginal doctor, for example), nursing (operational and leadership appointments), allied health, clerical, reception, security and others
- engagement with Aboriginal agencies including, critically, the local Aboriginal Community Controlled Health Service (Derbarl Yerrigan Health Service) which has resulted in the early commencement of the development of a memorandum of understanding for referral and post-discharge arrangement for Aboriginal and Torres Strait Islander consumers. Specific service streams in child development paediatrics and ophthalmology now also exist at SJGMPH for the care of Aboriginal patients.

Clinician engagement across the community is also welcomed and this is strong at SJGMPH, with structured opportunity for feedback on services. For example, the Chief Executive Officer regularly attends general practices across the east metropolitan region and Wheatbelt to hear directly from practitioners with regard to the services, their efficacy, access and amenity of the hospital. GP groups are also invited regularly to this hospital to view the facilities, meet key staff and 'follow' the patient journey in the departments of the hospital to help build familiarity with the service range and role delineation. A strong GP education program emanates from SJGMPH and is well attended.

Glossary of terms

Advocate: A person who speaks, writes or acts on behalf of an individual or group to defend their right to accessible, safe, quality healthcare.

Allied health professional: A term used to describe the broad range of health professionals who are not doctors, dentists or nurses. Allied health professionals aim to prevent, diagnose and treat a range of conditions and illnesses and often work within multidisciplinary health teams to provide the best patient outcomes. Professions include but not limited to physiotherapy, dietetics, social work, pharmacy, occupational therapy and speech pathology.

Carer: A person who provides ongoing unpaid care and support to family members and friends who have a disability, a mental illness, chronic condition, terminal illness or are frail aged. An individual is not a carer merely because he or she is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual, or lives with an individual who requires care.

Carer engagement: The process by which the aspirations, concerns, and values of carers are incorporated in government, and private sector decision making, planning service delivery and evaluation.

Clinician: A healthcare provider, trained as a health professional. Clinicians include registered and nonregistered practitioners, or a team of health professionals providing health care who spend the majority of their time providing direct clinical care. This care can be provided in a hospital, skilled nursing facility, or patient's home.

Clinician engagement: The active and positive contribution of clinicians within their normal working roles to maintain and enhance the performance of the organisation, which itself recognises this commitment to support and encourage high quality care.

Community: A group of people who share something in common. It may be location, interests, culture, language, beliefs, values or traditions. Communities often identify and form around issues. These issues may magnify the similarities or differences of community members.

Community engagement: A two-way interaction process between a health service and its communities. which enables the communities to have a role in the planning and decision making for health services and policies that affect their lives

Consumer: Potential, current or previous user of health services.

Consumer engagement: A wide range of strategies in which consumers are involved in the planning, service delivery and evaluation of care. It covers partnerships between patients and staff when care is provided at an individual level as well as partnerships with consumers at a health service level.

Cultural and Linguistic Diversity (CaLD): Refers to the wide range of cultural groups that make up the Australian population and Australian communities. The term acknowledges that groups and individuals differ according to religion and spirituality, racial backgrounds and ethnicity as well as language. It is used to reflect intergenerational and contextual issues, not just the migrant experience.

Department of Health: The System Manager responsible for the overall management of the WA health system.

Disability: The United Nations Convention on the Rights of Persons with Disabilities recognises that disability arises from the combination of impairments and barriers that hinder full and effective participation in society on an equal basis with others. The impairments can include long-term physical, mental, intellectual or sensory impairments whilst the barriers can be attitudinal or environmental.

Engagement: Informed dialogue between the organisation and consumers/carers/support workers/ community/clinicians that encourages sharing of ideas, options and collaborative decision making in areas including planning, policy, research, service delivery and improvement.

Health service: A service for maintaining, improving, restoring or managing people's physical and mental health wellbeing. A health service includes hospitals, public health services, support services.

Health Service Board: Legally responsible and accountable for the delivery of safe, high-quality, efficient and economical health services for its Health Service area. Each Board consists of up to 10 professionals with experience across the fields of medicine and health care, finance, law, and community and consumer engagement.

Health Service Provider: A Health Service Provider as established under the Health Services Act 2016 and includes Child and Adolescent Health Service, East Metropolitan Health Service, North Metropolitan Health Service, South Metropolitan Health Service, WA Country Health Service, and Health Support Services.

Hospital: Premises where medical, surgical or dental treatment, or nursing care, is provided for ill or injured persons and at which overnight accommodation may be provided.

Homelessness: The state of people sleeping rough, couch surfing, staying in temporary accommodation, have no fixed address and those housed in long-term hostels and shelters.

Partnership: Working together collaboratively to make decisions, sharing responsibility for decisions and collectively owning outcomes.

Patient centred care: an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Peer support worker: People who identify as having lived experience of mental ill-health, traumatic circumstances, and/or alcohol and other drug issues who are employed (either paid or volunteer) in designated roles within the public or non-government sector. They use their common experience to support and inspire hope and recovery in others.

Refugee: A person who is outside their own country and is unable or unwilling to return due to a wellfounded fear of being persecuted because of their: race, religion, nationality, membership of a particular social group or political opinion.

Stakeholder: A person or group that are involved in the health care system and are affected by changes to that system. Stakeholders may be patients, caregivers, clinicians, advocacy groups, professional societies, businesses, policymakers, researchers or others.

Support worker: A person paid to contribute to the care and well-being of an individual who has a disability, mental illness, chronic condition, terminal illness or is frail aged. Support workers may know the changes that are required to improve individual patient care.

WA Primary Health Alliance (WAPHA): The organisation that oversees the strategic commissioning functions of the three Western Australian Primary Health Networks, funded by the Australia Government. Their primary objective is to improve health outcomes and patient experiences through the commissioning of appropriate services where they are most needed.

Young people: In Australia, the terms 'youth' and 'young people' are used interchangeably and refer to people between the ages of 12 and 25 (inclusive).

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Apppendix A – Supporting resources

Supporting resources for engaging with children and young people

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- Involving Children and Young People. Participation Guidelines. Commissioner for Children and Young People WA. 2009.
- Engaging Canberrans: A guide to community engagement. ACT Government. 2011.
- Citizen Me! Engaging children and young people in your organisation. Written by Melissa Goldman, NSW Commission for Children and Young People. 2012.
- Understanding and supporting children and young people's participation. NSW Advocate for Children and Young People, 2015
- Carers WA Young Carers Advisory Group http://www.youngcarerswa.asn.au/info-help/young-carers-advisory-group/
- Young Men's Christian Association (YMCA) http://ymcawa.org.au/

Supporting resources for engaging with Aboriginal communities

- WA Health Aboriginal Workforce Strategy 2014–2024. WA Health. 2014.
- WA Health Strategic Intent 2015–2020. WA Health. 2015.
- WA Aboriginal Health and Wellbeing Framework 2015–2030. WA Health. 2015.
- Aboriginal Services and Practice Framework 2016–2018. WA Department of Child Protection and Family Support. 2016.
- Engaging Queenslanders: Introduction to working with Aboriginal and Torres Strait Islander communities. Queensland Government. 2005.
- Engaging Canberrans: A guide to community engagement. ACT Government. 2011.
- Guide for Engaging with Aboriginal People. SA Health. 2013.
- National Aboriginal and Torres Strait Islander Health Plan 2013–2023. Australian Government. 2013.
- Aboriginal Cultural Inclusion Framework 2015–2018. NSW Family and Community Services. 2014.
- Aboriginal Health Impact Statement and Declaration for WA Health. WA Health. 2014.
- The Aboriginal Health Council of Western Australia www.ahcwa.org.au
- Aboriginal Health Policy Directorate, Department of Health ww2.health.wa.gov.au/Improving-WA-Health/About-Aboriginal-Health
- Kimberley Interpreting Service (KIS) (08) 9192 3981 www.kimberleyinterpreting.org.au
- Translating and Interpreting Service (TIS). Phone 131 450 www.tisnational.gov.au

Supporting resources for engaging with CaLD communities

- Engaging Queenslanders: An introduction to working with culturally and linguistically diverse (CaLD) communities. Queensland Government. 2007.
- Cultural Diversity in Western Australia A Demographic Profile. Office of Multicultural Interests, Government of Western Australia. 2008.
- Implementing the Principles of Multiculturalism Locally: A planning guide for Western Australian local governments. Office of Multicultural Interests, Government of WA. 2010.
- Engaging Canberrans: A guide to community engagement. ACT Government. 2011.
- Engaging Culturally and Linguistically Diverse Communities: A guide for the Western Australian Public Sector, 2014.
- Framework for Mental Health in Multicultural Australia: Towards culturally inclusive service delivery. Mental Health in Multicultural Australia (MHiMA). 2014.
- Western Australian Language Services Policy 2014 and Guidelines. Office of Multicultural Interests. Government of Western Australia, 2014.
- Delivering for diversity: Cultural diversity plan 2016–2019. Victoria State Government. 2016.
- Office of Multicultural Interests www.omi.wa.gov.au
- Cultural Diversity Unit www.health.wa.gov.au/multiculturalhealth/home
- Association for Services to Torture and Trauma Survivors (ASeTTS) www.asetts.org.au
- Translating and Interpreting Service (TIS) www.tisnational.gov.au
- Humanitarian Entrant Health Service www.healthywa.wa.gov.au/Articles/F I/Humanitarian-Entrant-Health-Service-HEHS
- Princess Margaret Hospital Refugee Clinic www.pmh.health.wa.gov.au/services/refugee_clinic
- Ishar Multicultural Women's Health Centre www.ishar.org.au

Supporting resources for engaging with rural, regional and remote communities

- Queensland Government Community Capacity Building Toolkit for Rural and Regional Communities, 2008.
- National Strategic Framework for Rural and Remote Health. Australian Health Ministers Advisory Council (AHMAC). 2012.
- Partnering with Consumers Guideline. WA Country Heath Service. 2014.
- District Health Advisory Council Guidelines. WA Country Heath Service. 2014.
- Strategic Directions 2015–2018: Healthier Country Communities through Partnerships and Innovation. WA Country Health Service. 2015.

Supporting resources for engaging with people with disability

- Engaging Queenslanders: A guide to engaging people with a disability. Queensland Government. 2007.
- Engaging Canberrans: A guide to engaging and communicating with people with a disability. ACT Government, 2010.
- National Disability Strategy 2010–2020. Commonwealth of Australia. 2011.
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- Engaging Canberrans: A guide to community engagement. ACT Government. 2011.
- Count Me In: A better future for everyone. Disability Services Commission. 2013.
- Disability Access and Inclusion Policy. Western Australian Department of Health. 2014.
- Commitment to Inclusive Engagement, Disability Health Network, Western Australian Department of Health. 2014.
- Disability Health Core Capabilities Resource: Shared attitudes and behaviours for healthcare workers. Western Australian Department of Health. 2015.
- WA Disability Health Framework 2015-2025: Improving the health care of people with disability. Health Networks, Western Australian Department of Health. 2016.
- Disability Services Commission www.disability.wa.gov.au
- Developmental Disability WA www.ddc.org.au
- People with Disabilities WA Inc https://pwdwa.org/
- Nulsen Disability Services www.nulsen.com.au
- Supporting resources for engaging with people living with mental illness
- Mental Health Services Consumer and Carer Participation Framework. Department of Health and Human Services. Tasmanian Government. 2006.
- Consumer, Carer and Family Participation Framework. Queensland Health mental health services. 2010.
- Mental Health 2020: Making it personal and everybody's business. Mental Health Commission. 2011.
- Mental Health Consumer, Carer and Community Engagement Framework, North Metropolitan Area Health Services Mental Health. 2011.
- Consumer, Family, Carer and Community Paid Partnership Policy. Mental Health Commission. 2016.
- Consumers of Mental Health WA (Inc) www.comhwa.org.au
- Consumers of Mental Health WA (Inc) Consumer Advisory Groups Resource Pack www.comhwa.org.au/wp-content/uploads/2014/05/CAG-PACk-2014-08072014.pdf
- Mental Health Commission Consumer, Family and Carer Participation https://www.mhc.wa.gov.au/about-us/consumer-family-and-carer-participation/
- Western Australian Association for Mental Health (WAAMH) https://waamh.org.au/
- Mental Illness Fellowship of WA www.mifwa.org.au
- HelpingMinds (formerly Arafmi) http://helpingminds.org.au/
- Consumer and Carer eLearning about the *Mental Health Act 2014*. Mental Health Commission https://mha2014.e3learning.com.au/

Supporting resources for engaging with the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) community

- Beyond: 'we treat everyone the same'. A report on the 2010–2011 program: How2 create a gay, lesbian, bisexual, transgender and intersex inclusive service. Catherine Barrett and Kylie Stephens. Gay and Lesbian Health Victoria, Melbourne Australia. 2012.
- National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy. Commonwealth of Australia. 2012
- Lesbian, gay, bisexual, transgender and intersex: A guide to engagement. Tasmanian Government. 2014.
- National LGTBI Health Alliance www.lgbtihealth.org.au
- Living Proud LGBTI Community Services of WA www.livingproud.org.au
- Pride in Diversity www.prideindiversity.com.au
- The Gender Centre www.gendercentre.org.au/index.htm
- Parents, Families and Friends of Lesbians and Gays (PFLAG) www.pflagwa.org.au
- GLBTI Rights in Ageing Inc. (GRAI) www.grai.org.au
- World Professional Association for Transgender Health (WPATH) www.wpath.org

Supporting resources for engaging with engaging with the homeless

- Homelessness Australia www.homelessnessaustralia.org.au
- Homeless Healthcare www.homelesshealthcare.org.au
- Shelter WA www.shelterwa.org.au
- Ruah Community Services www.ruah.com.au
- **Homeless Connect** www.perth.wa.gov.au/living-community/community-programs-and-initiatives/homeless-connect
- United Way WA www.unitedwaywa.com.au
- Lighthouse Foundation <u>www.lighthousefoundation.org.au</u>



This document can be made available in alternative formats on request for a person with disability.

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