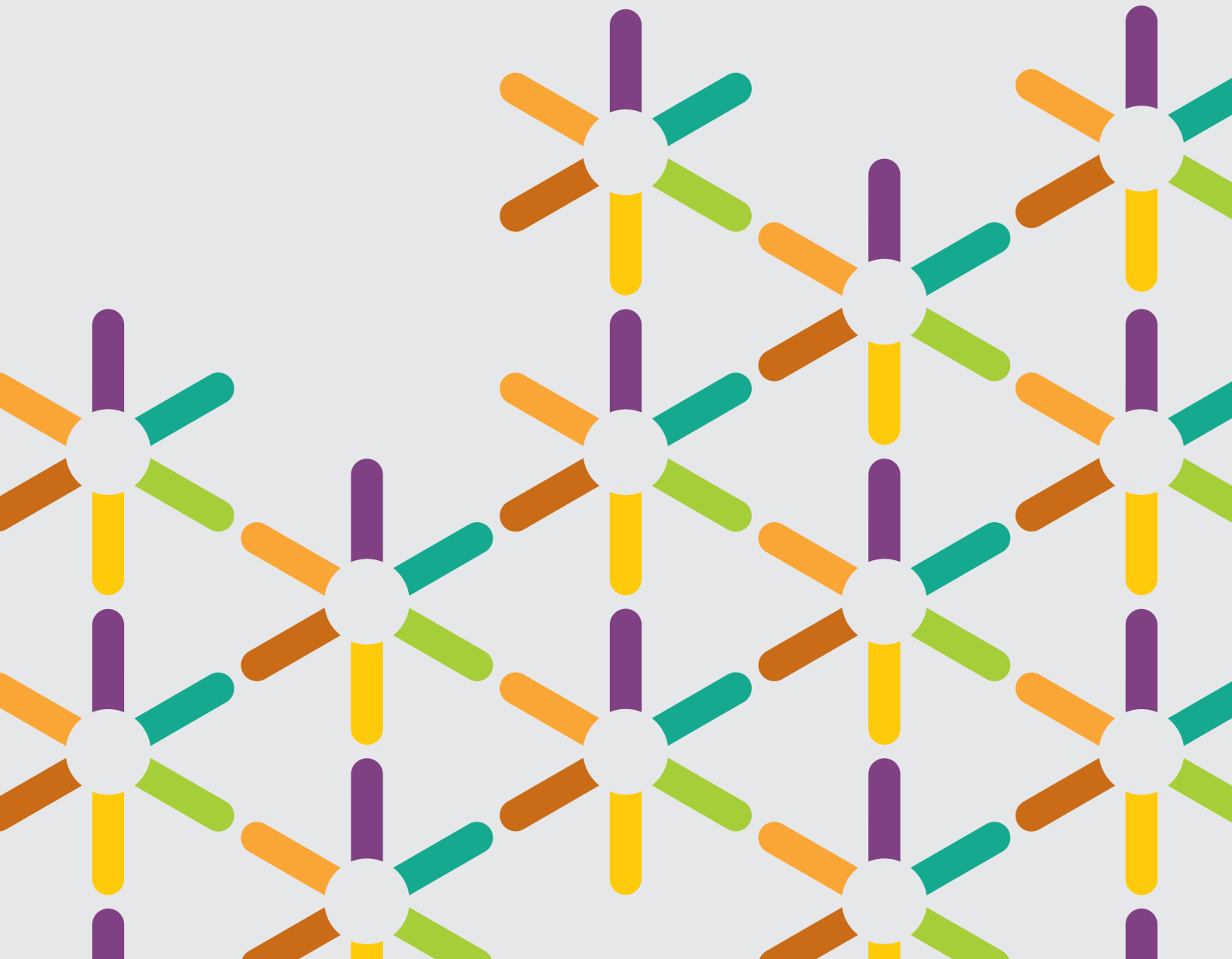




Government of **Western Australia**
Mental Health Commission



Working Together: Mental Health, Alcohol and Other Drug Engagement Policy 2021-2025





1. Vision and Purpose

The *Western Australian Mental Health and Alcohol and Other Drug Services Plan 2015-2025* (**the Plan**) describes a vision for:

“a Western Australian mental health, alcohol and other drug service system that: prevents and reduces mental health problems, suicide and suicide attempts; prevents and reduces the adverse impacts of alcohol and other drugs; promotes positive mental health; and enables everyone to work together to encourage and support people who experience mental health, alcohol and other drug problems to stay in the community, out of hospital and live a satisfying, hopeful and contributing life.” Western Australian Mental Health Commission (2015).

This document, the *Working Together: Mental Health, Alcohol and Other Drug Engagement Policy 2021-2025* (**the Engagement Policy**), sets out the Mental Health Commission’s commitment to engaging with stakeholders to achieve this vision, and:

- confirms the Mental Health Commission’s commitment to implementing the principles and approaches to stakeholder engagement described in the *Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025* (**the Engagement Framework**). (The Engagement Framework can be found at www.mhc.wa.gov.au/engagement);
- identifies challenges to implementing the principles and approaches, and sets out how these will be addressed; and
- considers changed governance structures and emerging issues impacting the mental health and alcohol and other drug sector, and how the principles and approaches will be applied to address these issues.

This work addresses the intention that the Engagement Framework will be reviewed on a bi-annual basis to ensure that it reflects current practices and up-to-date information (as identified on p30 of the Engagement Framework).

2. Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025 (the Engagement Framework)

On 23 November 2018, the Minister for Mental Health, Roger Cook MLA, released the *Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025*, together with the Working Together Toolkit. As stated by the Minister at the time of release:

“The Engagement Framework and Toolkit affirm the State Government’s commitment to progressing a mental health, alcohol and other drug system that improves outcomes across Western Australia. The documents provide a solid foundation for consistent, genuine engagement across all government and non-government organisations in the mental health and alcohol and other drug sectors.” Roger Cook MLA, Deputy Premier; Minister for Health; Mental Health (2018).



The Engagement Framework identifies five Guiding Principles, which are:

- Safety;
- Authenticity;
- Humanity;
- Equity; and
- Diversity.

In addition to the five Guiding Principles set out above, the Engagement Framework also identifies two further Supporting Principles, which are:

- Inclusivity and Flexibility; and
- Accountability and Transparency.

The Guiding Principles, additional Supporting Principles and Resources, and the levels of activity to which they will be applied are illustrated in Figure 1 below.

Figure 1: Adaption of Diagram 1, Working Together Mental Health and Alcohol and Other Drug Engagement Framework (P.4)

Achieving Quality Engagement

Across these levels

Individual

Service

Sector

System

Using the following principles

Safety: Start Here

Authenticity:
Be Real

Humanity:
People First

Equity:
Equals Fairness

Diversity:
Everyone In

Inclusivity
and Flexibility

Accountability
and Transparency

Supported by a range of **new** and **existing** resources and initiatives

Stakeholder
Connect

Working
Together: Mental
Health, Alcohol
and Other Drug
Engagement
Policy 2021-2025

Working
Together:
Engagement
Planning Guide
2021-2025

Working
Together: Mental
Health, Alcohol
and Other Drug
Engagement
Framework 2018-
2025

Working
Together Toolkit
2018-2025

Consumer,
Family, Carer
and Community
Paid
Participation
Policy



3. Who will be engaged?

3.1. Engaging with people with lived experience

The Mental Health Commission is committed to engaging with people with lived experience of mental health and alcohol and other drug issues.

The Mental Health Commission has already demonstrated this commitment by taking many important steps to engage with people with lived experience, thereby applying the Engagement Framework's principles and approaches. Notable examples include:

- appointing people with lived experience to the key governance and advisory bodies for the mental health and alcohol and other drug sector (discussed in more detail in the following section);
- engaging with people with lived experience in numerous service and program design processes, using the range of engagement approaches set out in the Engagement Framework;
- co-production and roll-out of the *Consumer, Family, Carer and Community Paid Participation Policy (Paid Participation Policy)*, released in 2016, which supports and recognises the involvement of people with lived experience in these engagement approaches; and
- establishing dedicated lived experience positions within the Mental Health Commission.

To support ongoing engagement with people with lived experience, the Mental Health Commission will continue to fund consumer and carer participation in line with the Paid Participation Policy. Additionally, where projects are contracted out to third party providers, the procurement arrangements will specifically reference the Engagement Framework and Paid Participation Policy to ensure their consistent application.

3.2. Ensuring people with lived experience of both mental health issues and alcohol and other drug use are included in engagement activities

The Mental Health Commission recognises that engaging people with lived experience of alcohol and other drug use can be challenging. This phenomenon is recognised in the research literature, which has found for example, that the 'layers of prejudice and stigma associated with illegal drug use appeared to be a significant barrier to successful engagement ... combined with the low self-esteem self-reported by many of the drug and alcohol users created an atmosphere far from conducive to mutually beneficial engagement'. This issue is discussed further in the literature review supporting this policy (Appendix).

Effective engagement with people with lived experience of alcohol and other drug use is important to developing effective alcohol and other drug services. Ultimately, it is also important to the achievement of broader Government policy priorities, including protecting children from abuse and neglect, reducing family and domestic violence, increasing community safety, contributing to a Healthy WA, community wellbeing, slowing the growth in the prison population, and addressing the over-representation of Aboriginal people in detention.

To address this issue, the guidance and resources associated with this Engagement Policy (discussed further below) will specifically address the engagement of people with lived experience of alcohol and other drug use.

3.3. Engaging with stakeholders outside the mental health and alcohol and other drug sector

A range of factors drive the development and continuation of mental health and alcohol and other drug issues. In the research literature, these driving factors are frequently referred to as the 'social determinants of mental health and alcohol and other drug use.' As shown in Figure 2, these factors include poverty, unemployment, family and domestic violence, other forms of abuse and neglect, and homelessness and housing insecurity.



Social Determinants of Mental Health, Alcohol and Other Drug Use



Figure 2

Achieving the vision set out in *the Plan* in the long-term, as well as providing effective prevention, early intervention, treatment and on-going support in the short and medium terms, requires that these drivers be addressed.

The Mental Health Commission has established relationships with stakeholders in the mental health and alcohol and other drug sector, including Commonwealth government agencies, peak bodies, other non-government organisations and individuals. However, many of the drivers identified above lie outside the mental health and alcohol and other drug sector, and outside the direct responsibility or influence of the Mental Health Commission.

The Mental Health Commission is committed to engaging with stakeholders who can address the drivers of mental health and alcohol and other drug issues, both directly and indirectly. This includes:

- other State Government agencies;
- Commonwealth Government agencies;
- local governments; and
- non-government organisations outside the alcohol and other drug sector, including sports and recreation organisations, arts and culture organisations, organisations supporting people with disabilities, and organisations formed by and for Aboriginal people and people from culturally and linguistically diverse backgrounds.

To encourage and support this broader approach to engagement, the Mental Health Commission has developed the Working Together Engagement Planning Guide and for internal use, an Organisational Stakeholder Register.

The Mental Health Commission will also incorporate actions to improve the capability of staff to engage with stakeholders outside the mental health, alcohol and other drug sectors in the Mental Health, Alcohol and Other Drug Workforce Strategic Framework 2020-2025.

When engaging with agencies, organisations and individuals outside the mental health and alcohol and other drug sector, the Mental Health Commission will:

- continue to apply the principles and approaches set out in the Engagement Framework; and
- use existing bodies, structures and arrangements that already exist in other sectors. This will create efficiencies, avoid duplication and increase effectiveness.



4. How will people be engaged?

4.1. Implementation guidance and resources

As Figure 1 indicates, the Engagement Framework identifies Guiding and Supporting Principles for engaging with stakeholders. The Engagement Framework also identifies and describes seven types of approaches that can be used to implement the Principles across all levels, individual, service, sector and system.

As mentioned above, the Engagement Policy and the Engagement Framework are supported by more detailed guidance and resources including the Working Together Toolkit, Engagement Planning Guide and the Consumer, Family, Carer and Community Paid Participation Policy. These materials are described in Figure 3 and can be found on the Mental Health Commission's website at: www.mhc.wa.gov.au/engagement. To support engagement activities, the Mental Health Commission has created the Stakeholder Connect initiative. Stakeholder Connect provides all subscribers with regular communication, engagement and consultation opportunities, allowing connection with a broad range of stakeholders including those outside the Mental Health and Alcohol and Other Drug sector. By subscribing to Stakeholder Connect, stakeholders will have the opportunity to keep abreast of new initiatives and contribute to a range of tailored planning, co-design and implementation activities that contribute to the delivery of key mental health and alcohol and other drug reform priorities. In addition to Stakeholder Connect, the Mental Health Commission is actioning a number of other actions and initiatives to increase lived experience and embed quality engagement across the organisation.



Overview of the Mental Health Commission's Stakeholder and Partnership Engagement Framework

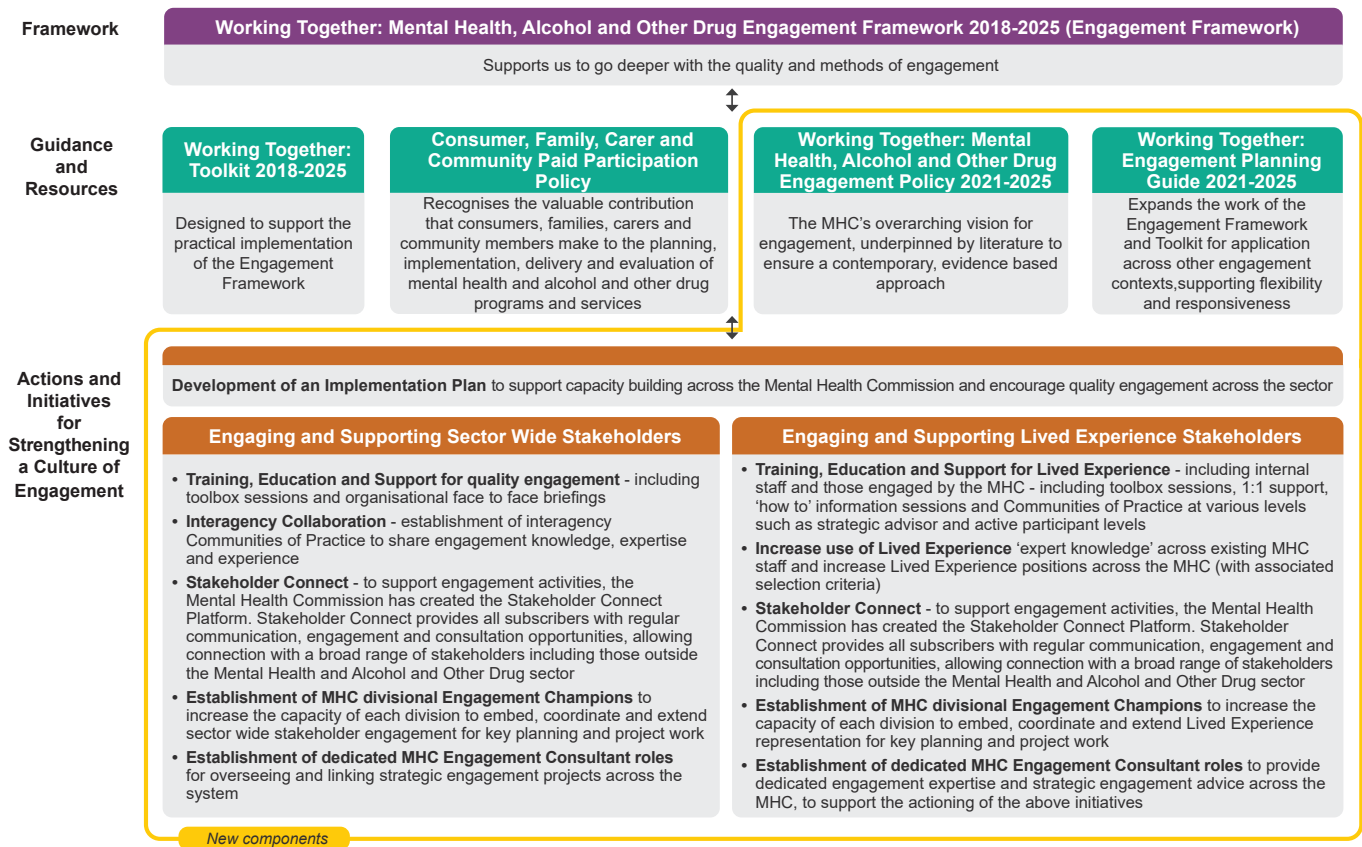


Figure 3



4.2. Strengthening a culture of engagement

The guidance and resources, discussed above, aim to increase users' knowledge and skills in how to undertake stakeholder engagement. However, cultural factors, as well as knowledge and skills, are important to effective engagement.

As a first step in strengthening a culture of engagement, the Mental Health Commission has developed this Engagement Policy. This statement of policy is supported by actions that specifically address ways of building a culture of engagement, both listed above in the enhanced engagement strategy, including introduction of engagement champions across the Mental Health Commission and as part of the Mental Health Commission's Workforce Development Plan.

4.3. Achieving engagement and responsiveness

The Plan was released in December 2015. As well as the vision identified in the opening section of this Policy, the Plan outlines the optimal level and mix of mental health, alcohol and other drug services required to achieve its vision and meet the needs of Western Australians until 2025. The Plan Update 2018, released on 7 May 2018, provides revised modelling of service types, levels and locations required in Western Australia until the end of 2025.

On 10 March 2020, the Minister for Mental Health released the *WA State Priorities: Mental Health, Alcohol and Other Drugs 2020 – 2024 (WA State Priorities)*, which focuses on the Government's immediate priorities to reform and improve the mental health and alcohol and other drug sector over four years from 2020.

In March 2020, the State Government declared a State of Emergency and Public Health Emergency in Western Australia in response to the COVID-19 pandemic. The impacts of the COVID-19 pandemic and the responses to it, on mental health and alcohol and other drug use, are anticipated to be long-running and far-reaching.

The Mental Health Commission is committed to engaging with stakeholders, including as part of its work to implement the WA State Priorities, during the COVID-19 pandemic and beyond. The Engagement Framework's Supporting Principles of Inclusivity and Flexibility, and Accountability and Transparency are particularly helpful here.

When discussing the Supporting Principle of Accountability and Transparency, the Engagement Framework recognises that the Mental Health Commission 'may be constrained by State Government priorities ... and a range of other accountabilities that govern the public sector' (p24). In these constrained circumstances, the Engagement Framework recommends:

Being clear and transparent from the beginning will result in purposeful and worthwhile engagement. It requires all stakeholders have an understanding of:

- desired outcomes;
- what can be achieved;
- the timeframe and stakeholder engagement;
- the amount of influence people can have on decisions;
- the constraints of different stakeholders;
- the responsibilities of different stakeholders; and
- who is ultimately accountable for decisions made.

This Supporting Principle provides guidance for circumstances in which decisions need to be made quickly and action needs to be taken urgently. To assist with the appropriate application of this Supporting Principle under such circumstances, the Mental Health Commission has developed the Working Together Engagement Planning Guide. This document works with the rest of the suite of Working Together documents to provide further guidance on how to identify, plan and conduct the most appropriate form of engagement in different scenarios with varying timeframes.



5. Engaging with stakeholders through new and existing governance and advisory bodies

Representation in governance and advisory structures is an important form of engagement.

The Government recently established the Mental Health Executive Committee (MHEC) and the Community Mental Health, Alcohol and Other Drug Council (CMC). The purpose of the MHEC and CMC is to lead the continuous development of a mental health, alcohol and other drug system that is efficient, sustainable, recovery-focused, consumer-led, and integrated. (The terms of reference for the MHEC and CMC can be found at www.mhc.wa.gov.au/about-us/sector-governance).

Some further details about the MHEC and CMC are set out in Figure 4 below. As identified in the diagram below, the MHEC and CMC (as well as the Mental Health Leads Sub-committee) include two representatives with lived experience, one carer and one consumer.

WA Mental Health, Alcohol and Other Drugs: New Governance Arrangements

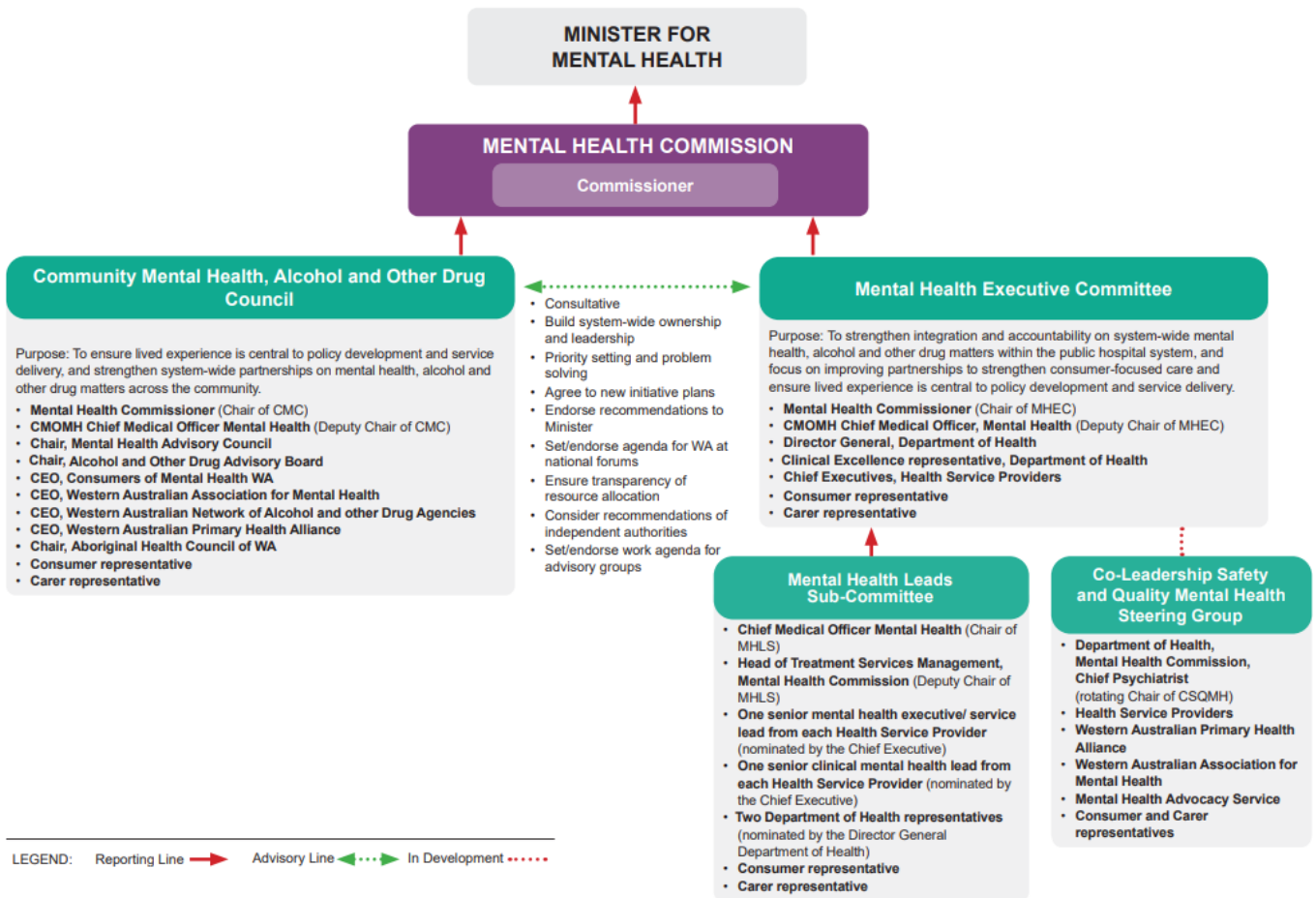


Figure 4

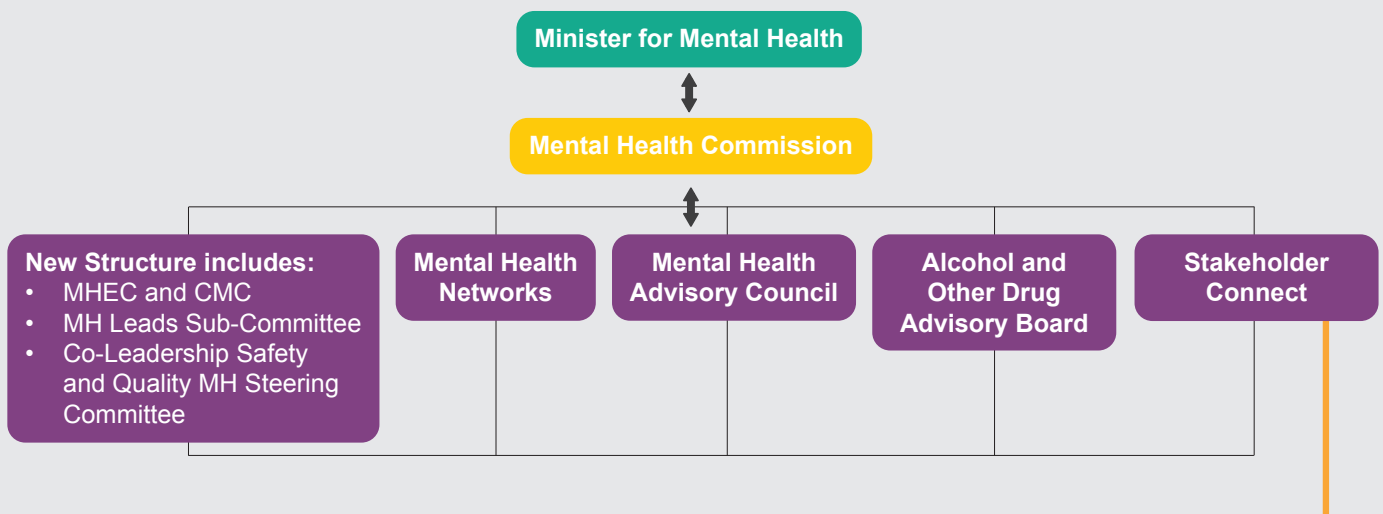


In addition, the Mental Health Commission is currently advised by a series of longstanding advisory bodies, namely, the Mental Health Advisory Council (MHAC) and the Alcohol and Other Drugs Advisory Board (AODAB). The Mental Health Commission is also advised by a series of Mental Health Sub Networks, each with a specific focus. The current Sub Networks are:

- Personality Disorders;
- Eating Disorders;
- Forensics;
- Youth;
- Perinatal and Infant;
- Older Adults;
- Neuropsychiatry and Developmental Disability;
- Multicultural; and
- Rockingham and Kwinana.

These advisory bodies are shown in Figure 5 below that depicts the Mental Health Commission’s pathways of engagement.

Mental Health, Alcohol and Other Drug Engagement Pathways



Stakeholder Connect Subscription Benefits

- Regular Commissioner Communiques alerting to upcoming key sector reform projects
- Regular updates on the progression of key sector reform projects
- Streamlining Engagement – Ensuring you/your organisation/group:
 - are informed about how to get involved in key reform projects
 - know how to provide comments and other advice to inform the Mental Health Commission’s key projects
 - receive membership opportunities for key project and governance Committees/Groups

Subscription to Stakeholder Connect is through the Mental Health Commission’s Lived Experience and Organisational Stakeholder Registers.

Figure 5



It is important that these advisory arrangements:

- are well-positioned to advise the Mental Health Commission about the achievement of the Plan and the WA State Priorities, including in the post-COVID-19 pandemic environment;
- reflect the principles and approaches set out in the Engagement Framework; and
- have a productive relationship with the bodies in the new governance structure.

To enable the above, the Mental Health Commission will collaborate with the existing advisory bodies to ensure their terms of reference, including their function, roles and responsibilities, reporting relationships and membership are appropriate in the new structure.

6. Monitoring and Evaluation

The Working Together documents will be reviewed on a bi-annual basis to ensure they reflect current practices and up to date information. However, the Mental Health Commission welcomes ongoing feedback on the whole suite of documents at any time. To submit feedback, please email Engagement@MHC.wa.gov.au.

Through the process of implementation, the Mental Health Commission will work with internal and external stakeholders to help us understand how best to evaluate this work and capture the progress of the desired outcomes.

7. Conclusion

This policy demonstrates the Mental Health Commission's commitment to engaging with all stakeholders to achieve better outcomes for people whose lives are affected by mental health and/or alcohol and other drug use.

When it comes to engagement, everyone has a role to play, be it from an individual, service, sector or system level. Through the use of the full suite of Working Together documents outlined in this policy, we can work together to implement the principles and approaches to stakeholder engagement described in the *Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025* and bring quality engagement into all that we do.



Appendix

Literature Review - System and Service Engagement

System and Service Engagement

A rapid review of models, processes and evidence for engagement approaches in the mental health sector

PROJECT | Engagement and Partnership Framework
CLIENT | Mental Health Commission
DATE | 26.10.2020
VERSION | Draft 1.0





When will you have your next **Aha!** moment?



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Preface

This literature review intends to provide an overview of some current conceptual models and academic literature that can inform a larger piece of work. It was not within the remit of this work to systematically assess all evidence in a comprehensive manner, or map processes across all jurisdictions. Therefore, in and of itself, the limitations of this literature review are considerable, however as a guide and part of a wider process this presentation of evidence is of value.

We would like to thank Dr Karen Gardner, Senior Research Fellow and Deputy Director in the Public Service Research Group at the School of Business, University of New South Wales, Canberra. Her many years of research in this field made her a great candidate for an informal interview, where she shared with us her insights and perspectives, which helped to shape this review and for us to easily identify emerging themes.

Due to our coverage of international academic and grey literature, a range of terms have been inherited in this review to refer to people seeking support for a mental illness – a client, a consumer, a person living with a mental illness. As we drew from the health research literature, at times ‘patient’ was also used. There is no one term that is appropriate for everyone.



1 Introduction and raising the questions

1.1 Background and historical context

In the past few decades, healthcare systems, and in particular the mental health sector, have increasingly considered the need to incorporate the views of people both within and outside their own boundaries – to engage with communities, with service providers, clinicians, with carers, and especially with consumers. While seemingly a common-sense idea, it is nonetheless a radical departure from what existed before.

Initially, it was Patient Centred Medicine that suggested the dominant biomedical paradigm was overly paternalistic, expert-driven and disempowering. According to Laugharne and Priebe (2006), trust, choice and power have become increasingly important in health and mental health settings:

“...consumerism and market economics are impacting on health. Patients may approach health care from a consumerist approach in which they expect to have more of a say in their treatment, and governments are looking for competition between service providers to improve quality of care and, perhaps, to reduce costs. This has led to a movement away from a more paternalistic relationship between doctors and patients towards giving patients more autonomy in the therapeutic relationship” (Laugharne & Priebe, 2006)

While these ideas started by critiquing power within the clinician-patient relationship, the lens has moved towards a broader look at who participates in the design of service systems. Governments have by and large adopted engagement principles – “being in favour of more consumer involvement is like being against sin; at a rhetorical level it is hard to find disagreement” (Coleman, Checkland, & Harrison, 2009).

A scan of government frameworks for mental health systems endorse the view that patient choice is sacred, the lived experience perspective is essential in all aspects of service delivery and empowering the user improves the quality of care. This language has become entrenched in the discourse of healthcare systems in Australia, the UK and elsewhere. However, there has been little work around deeply examining and evaluating what this means in practice. Authentic engagement across multiple perspectives can be considerably complex for bureaucracies, and the ideals have not always been faithfully translated into real world practice. Some may regard it as “still far more a fashionable claim or ‘wishful thinking’” (Graffigna & Barelo, 2015).

However, as more and more governments respond to this call, practice communities have also matured – especially in the last decade. While evidence is thin and evaluation mechanisms are not embedded, there are still learnings to be captured. Effective mechanisms for more effective engagement are better understood.



Engagement with clinicians and services, carers and family members and communities necessitates new tools for dialogue, and a range of communication pathways and feedback loops, to bring together “different, but complementary, sets of competences and expertise” (Graffigna & Barelo, 2015). Cautions and a fuller understanding of the limitations of engagement are also emerging. And, in some instances, the benefits of engagement are being realised in measurable ways, leading to improvements in service quality and outcomes for consumers.

1.2 Purpose of this review

This evidence has been gathered with the view to inform an overarching Engagement Framework for the Mental Health Commission (MHC) of Western Australia (WA). The Framework will provide a systematic overview of engagement practices and processes for strategic decision making, and program/service design and procurement. This will build on the current framework, Working Together, Western Australian Mental Health, Alcohol and Other Drug Engagement Framework (2018-2025), as well as the many years that the MHC have engaged across the mental health sector in WA.

We have focused this review on international peer-reviewed literature to better understand the empirical evidence for engagement; the ‘why’ - along with the ‘how’. Guiding questions include:

1. What models or processes are effective at ensuring engagement throughout strategic decision making (policy and system level change), service design and commissioning?
2. What barriers have hindered effective engagement in other jurisdictions?
3. “How” do other jurisdictions effectively implement the learnings from the engagement process into real-world action/services?

This will be informed by learnings from across the health sector, mental health as well as alcohol and other drug sector.

The primary jurisdictions under focus will be Australia (other states and territories), the United Kingdom (UK), Scotland, New Zealand and Canada, but not exclusively, as learnings from research in other jurisdictions have been included where pertinent.

Scotland’s mental health sector has made great strides in implementing and integrating sector-wide engagement models. This is our understanding, based on a scan of grey-literature government frameworks across the world (which were not analysed in detail in this literature review). Scotland’s leadership in this area has also been confirmed anecdotally, for example through an interview with Karen Gardner, who has been working in this space for many years and is co-author of a systematic review of the evidence for strategic commissioning, and engagement (Gardner, Dickinson & Moon, 2019). However, when it comes to academic review and publication of service user engagement processes and learnings, there is not a significant quantity of evidence emerging from Scotland,



compared with other jurisdictions such as the UK. Therefore, while this academic review may point to UK, New Zealand and Canada for learnings, any models developed may be well-served by considering Scotland.

This is not an exhaustive systematic review, but rather a rapid review of published evidence that aims to synthesise some key learnings that will inform the development of the Mental Health Commission’s Engagement Framework.

1.3 Defining engagement

The verb “to engage” can refer to a formal agreement (for example, between two persons intending to marry), an arrangement to do something at a certain time, to be taken on board, or to be involved as a primary actor in a course of activities (Oxford English Dictionary, 2010). Graffigna and Barelo (2015) point out that in all its different meanings, “to engage” implies *a dynamic and relational context*, in which two parties agree on the goals of an action and on the phase of its process.

In the mental health sector, the term implies taking on board the views of consumers and others “for a more efficient and effective process of care delivery” (Graffigna & Barelo, 2015).

The WA North Metropolitan Health Service (C4) Framework defines engagement as the process of involving people in decisions that will affect their lives/work. Engagement recognises that the people affected by decisions bring with them knowledge and understanding that should be a critical part of decision making (North Metropolitan Health Service, 2016).

The term ‘consumer engagement’ can refer to a consumer’s commitment to actively participate with a therapy, service or clinician, within the bounds of their own therapeutic journey. For this literature review our focus is broader, on engaging consumers as co-producers, co-designers and co-facilitators of mental health services. Engagement in this sense also strives to involve multiple stakeholders in the healthcare ecosystem – consumers, families and carers, clinicians, service providers, healthcare managers and policy makers (M. Gorli, L. Galuppo, & E. G. Liberati, 2015) and involves dialogue between these actors as part of system planning and management.

Commissioning models are relevant for understanding the broader meaning of engagement. The National Health Service in the United Kingdom proposes ‘commissioning’ as “the process of planning, agreeing and monitoring services [...] Commissioning is not one action but many, ranging from the health-needs assessment for a population, through the clinically based design of patient pathways, to service specification and contract negotiation or procurement, with continuous quality assessment” (NHS England, n.d.). Engagement in this context implies seeking and incorporating multiple perspectives across each of these commissioning stages.



Figure 1: Commissioning cycle as published in Sexton, 2010



Fig. 1 Commissioning cycle reproduced from Tindana et al. [12]

Sexton (2010) outlines how user engagement has been used in commissioning cycles. Their cross-sector examination found user involvement can contribute to:

- informing needs assessment
- providing feedback on quality assurance processes and activity
- providing insight into uptake and accessibility (physical and psychological) of services
- raising the profile of a particular service and translating it into funding allocations
- help in service redesign and/or decommissioning some services
- being involved in various stages of a tendering process including selecting a preferred provider.

Although relatively new in the Australian context, commissioning with strong user engagement has been a feature of the UK public service for over 20 years. Beyond the commissioning space, this literature review also considers the role of engagement in strategic decision making. How is engagement embedded in high-level strategic decision making, including policy decisions and system-level change?



The levels of engagement are summarised in Table 1 – adapted from a multilevel model proposed by M. Gorli et al. (2015) who applied it in a hospital setting.

Healthcare delivery level	<p>Participated decision-making</p> <p>Patients have an active role in decision making about their care, are offered choices and involved in planning their treatment processes</p> <p>Peer support programs, disease specific organisations and online and in-person communities that provide information about consumer rights are some mechanisms to assist with engagement at this level (Laugharne & Priebe, 2006)</p>
Organisational and managerial level	<p>Systematic collection of patients and families’ feedback and suggestions for performance monitoring</p> <p>Service users are involved in the renovation of and improvement of healthcare settings’ processes, structures and design, through systematic and regular collection of their views and experiences with services (M. Gorli et al., 2015)</p>
Political and strategic level	<p>Co-design and co-creation of the system</p> <p>This involves a purposeful dialogue between experts and other stakeholders such as consumers and carers, including about the design of care services</p>

1.4 Reasons to engage

While service improvement is at the heart of any engagement approach (Beresford, 2002), different stakeholders may have different motivations to be involved. Governments and decision-makers within healthcare systems may be concerned with improving efficiency and accountability (M. Gorli et al., 2015), whereas the public may be concerned with service quality and citizens’ rights (Buchanan et al., 2005). An increasingly health-literate population require increased involvement in decision-making about their care (Graffigna & Barelllo, 2015).

Mosquera, Zapata, Lee, Arango, and Varela (2001) describe these approaches as a “means to an end” (often with an efficiency or economic focus), or an “end in itself” where the democratic, inclusive and participatory values of the process are valued irrespective of measurable outcomes.

In the health sector, Luxford, Safran, and Delbanco (2011) found that user engagement allowed hospitals to become better learning organisations and supported continuous improvement. Hospitals who had best practice patient engagement were willing and able to redesign both their care practices and their overall organisational functioning. Effective patient and public engagement can help resolve controversy and result in a broad consensus on the way forward: inadequate consultation may lead to proposals being delayed



or ultimately being referred to higher authorities such as national governments (Independent Reconfiguration Panel, 2010).

2 Culture as foundation for effective engagement

Organisational culture may be as important as, if not more important than, processes and structure when engaging with service users in service design and delivery.

2.1 Cultural norms to support the work

Service sectors will have their own cultural norms about service user involvement, and this can make it difficult to transfer learnings between organisations. There also may be different assumptions within different parts of the system, for example differences in cultural underpinnings between a social model and a medical model (Bush, Chapman, Drummond, & Fagaloa, 2009). Culture is so important for supporting this work, that even frequent staff turnover (Beidas et al., 2016) – which may disrupt established understandings and relationships – may limit the benefits gained.

A related theme is where there is disinterest and resistance to the process, or resistance to the change that may flow from an authentic process. Siriwardena et al. (2014) suggests clinicians may be more sceptical towards change, particularly if it is seen as being imposed externally, particularly by ‘management’, or as undermining their own authority. Clinicians are also less likely to be attracted to abstract concepts that are not recognised as relevant to their day-to-day practice.

2.2 Cultural factors to ensure engagement is not tokenistic

Age Concern London (ACL) undertook research into service user involvement in commissioning across sectors, framed by the research question: What constitutes meaningful and viable service user involvement in commissioning, and strategic commissioning in particular? (Sexton, 2010). The research involved extensive interviews and data collection from six local authorities and seven different “user groups” in London: mental health service users, parents, offenders with alcohol, drug use and mental health difficulties, physically disabled people, people living with HIV, and people with learning difficulties. Examining this across different sites allowed researchers to better understand effectiveness.

A key learning is that the culture of an organisation is fundamental to effective engagement with service users in service design and delivery. In fact, the key difference between service user involvement which was considered ‘tokenistic’, and service user involvement which was valuable and probing, “lay in the grey area of culture and values that lie behind structures and systems” (Sexton, 2010).

Sexton (2010) explored differences between engagement that was more tokenistic, versus a more substantive commitment to engagement. Organisational cultural barriers to effective engagement include when people from all levels of the organisation did not feel it was safe to express views that did not align with policy, even if it was reflective of their experience. This lack of safety in expressing a perceived “wrong” view creates a chilling effect on the full



sharing of experiences and diverse perspectives. Other cultural barriers/assumptions to authentic engagement include:

- Elected members who felt that they were in a position to better reflect the wants and aspirations of their constituents (including service users) rather than a small group of individuals
- Situations where those in the room can be manoeuvred so that they agree to a position being proposed
- The technical requirements involved in commissioning can be used to exclude service users, citing the difficulties of equipping them to participate.

These types of barriers to meaningful engagement are often reflective of a broader organisational culture, leadership mindset and attitudes towards service user involvement. When it comes to user engagement, Sexton (2010) identified three broad types of organisational culture:

1. Open and willing to engage with service users
2. Ostensibly open but not actually willing
3. Neither open nor willing

In this second type – ostensibly open but not actually willing – there is a disjuncture between stated intent and action. Sexton (2010) found that this is likely to lead to breakdowns in communication, a lack of trust, confusion and mixed messages, and ultimately poor outcomes for everyone involved. Sexton (2010) emphasises the importance of “making explicit the implicit” in terms of the values and approaches of an organisation. Patterson et al. (2009), in their analysis of user involvement in drug and alcohol service development, found that tensions arose around conflicting priorities and cultural expectations. In particular, health service workers found that they were frequently pressured towards achieving and monitoring performance targets, creating a disjunction between the “politically correct” wording of the user involvement policy and what was actually happening within the organizational culture:

“... we are hauled over coals if we haven’t got enough people in treatment. I understand Accountability and rationing resources, but that’s the genuine culture, the bottom line, not genuine service-user involvement.” – NHS worker, as cited in Patterson et al. (2009)

Addressing organizational culture and bringing into the open underlying cultural tensions are vital steps to valuable engagement.



What does engagement with an “open and willing” culture look like?

A child, adolescent and family mental health service for Pacific young people in Aotearoa/New Zealand

In response to consistently low acceptance of mainstream mental health services by Pacific people in NZ, advocates called for the establishment of dedicated mental health services in Auckland and Wellington specifically for servicing the mental health needs of the Pacific population. The Health Pasifika Child, Adolescent and Family Service aims to provide a culturally-safe and accessible mental health service for young people of Pacific background. There was extensive engagement with Maori and Pacific peoples in the design of the mental health service. Their engagement model included:

- Regular consultation with a Pasifika consultant on the staff,
- Pacific team members are encouraged to share their cultural knowledge and perspectives.

Key elements of mainstream mental health services (such as specific booking times, a tendency to consider an individual outside of their extended family relationships, or even the Western cultural way of “welcoming” people into the clinic) were challenged and adjusted for the local context.

While the authors do not go into depth about the specific methods of engagement process (aside from the extensive consultation with local people, and building on previous work of culturally-safe mental health services in Samoa), what can be seen is an example of an “end result” service design that has engaged with the local community and is dynamically adapting and responding to feedback.

(Bush et al., 2009)



3 Methods and processes

Dalton et al (2016) found that multiple methods of engagement are used to capture the service user voice. Their systematic review found that there was no single ‘silver bullet’ method for effective engagement. However, methods that were considered more deliberative in nature and involved face-to-face interactions (see Abelson, Montesanti, Li, Gauvin, & Martin, 2010; Conklin, Morris, & Nolte, 2015; Daykin, Evans, Petsoulas, & Sayers, 2007; Mitton, Smith, Peacock, Evoy, & Abelson, 2009) and engagement efforts which included multiple methods (see Daykin et al., 2007) were found to be more productive and effective.

As a case study example, a project involving maternity service configuration in Sandwell and West Birmingham, utilised multiple engagement methods which resulted in the implementation of service user preference across the service design and implementation. Not only did the consultation appear to achieve broad consensus about future service provision, the resulting reconfiguration of the service was associated with improvements in patient health and safety, notably the percentage of “normal births” increased (NHS Confederation, 2013b).

3.1 Methods for external engagement

This section will explore the multitude of ways that systems can engage with others outside their own boundaries – for example with the public or special interest groups.

The language surrounding engagement can often be ill-defined, or inconsistently defined, in the literature. To better frame an understanding of ‘involvement’ and ‘engagement’ definitions and categories, Conklin et al. (2015) synthesised their findings into the following terminologies.

1. **Consultation** (see Abelson et al., 2003; Abelson et al., 2007; Alborz, Wilkin, & Smith, 2002; Crawford et al., 2003; Guttman et al., 2008; Kashefi & Mort, 2004)
2. **Participation** (see Goold, Biddle, Klipp, Hall, & Danis, 2005; D. Linhorst, Eckert, Hamilton, & Young, 2001; D. M. Linhorst, Eckert, & Hamilton, 2005)
3. **Engagement** (see Bauld et al., 2005)
4. **Partnership** (see Boydell & Rugkåsa, 2007; Mosconi, Colombo, Satolli, & Liberati, 2007; Thurston, Vollman, Meadows, & Rutherford, 2005)
5. **Community development** (see Crowley, Green, Freake, & Drinkwater, 2002)
6. **Representation** (see Peck, Gulliver, & Towel, 2002)



Differentiating between each approach may be an extensive academic exercise. Needless to say, there are various approaches to engagement that are all in their own right legitimate. Additionally, within each approach there are various methods, as outlined in the following table.

Table: Methods used to include public involvement and engagement in health-care policy decisions

Form of engagement	Involvement method(s) used	Goals of public involvement initiative Notes on effectiveness	Source
Consultation			
	Round tables, town hall meetings, open houses + population-specific events + issue-specific groups	To engage, enable and empower people for health through resource allocation function of local health integration networks	(Eliasoph et al., 2007)
	Citizen panel, using mail survey, telephone survey or face-to-face group meetings	To obtain citizen input to inform a community-wide health goal-setting process	(Abelson et al., 2003)
	Meeting (6 hours, plenary and small-group sessions)	To provide the sponsoring regional health authority (RHA) with public input on an issue of importance	(Abelson et al., 2007)
	Community health councils (CHCs) + local patient groups + public meetings	To involve and engage all stakeholders in shaping policies and decisions about primary care provision and delivery, including consulting and engaging local communities	(Alborz et al., 2002)
	Surveys + service audit + group meetings + delivering staff training + board membership	To involve service users in the planning and delivery of psychiatric services	(Crawford et al., 2003)
	Citizens' jury (5 days)	To understand better the needs of all sections of the community so that appropriate primary care services can be provided	(Kashefi & Mort, 2004)
Participation			
	Various: e.g. consultative role to government, guideline or indicator development groups, negotiation of collective contracts, lobbying activities	To contribute the patient perspective	(Mosconi et al., 2007)
	Client representation at council meetings	To develop a structure for gathering client information that will be useful for improving organizational performance	(D. Linhorst et al., 2001)
	Group simulation game using a roulette wheel	To promote participatory decision making in health-care priority-setting that is inclusive, deliberative and accessible for a diverse lay audience, especially low-income, low-education groups	(Goold et al., 2005)
	Consumer council + policy review process + hospital's performance improvement system	Varied by involvement method	(D. M. Linhorst et al., 2005)



	Citizens' jury (2.5 days)	To engage the public in priority-setting for health technology assessment	(Menon & Stafinski, 2008)
	Partnership-based collaboration among a collection of agencies, groups and individuals	To explore mechanisms for breaking through current organizational boundaries to tackle inequalities and deliver better services and better health care	(Bauld et al., 2005)
Partnership			
	Representation from community groups in collaborations	To reduce health inequalities through co-ordinated activity of different agencies	(Boydell & Rugkåsa, 2007)
	Various: for example, Women's Health Express Advisory Council, Salvation Army Health Council	To establish a formal mechanism for public participation in health policy decisions regarding the delivery of women's health services	(Thurston et al., 2005)
Community Development			
	Inclusive process of networked representation, especially for marginalized community members	To promote community participation in decision making about local health services	(Crowley et al., 2002)
Representation			
	e.g., consumer groups participating in regional health conferences	To serve as a mechanism for rendering debates more transparent and concrete	(Bréchat, Bérard, Segouin, & Bertrand, 2006)
	e.g., user representation on NHS Trust board, on locality reference groups, on staff training groups and on Joint Commission Board	To enable listening to and consulting users; to enable and enhance users' and carers' voices	(Peck et al., 2002)

3.2 Integrated methods to apply within organisations and systems

The following methods move beyond the discrete engagement activities and involve more systematic mechanisms that can both drive engagement and support other engagement processes.

Embedding service users as staff members

Another engagement method consists of creating meaningful part-time or fulltime paid positions for patients and family leaders to facilitate their systematic participation in strategic decision-making and to promote a service's connection with the local communities.

This has been explored by M. Gorli et al. (2015) in hospital settings. Some examples of these initiatives include the creation of stable patients or community advisory committees, which are integral to healthcare organizations' work by offering support in several ways. The different forms of support include:

- the evaluation and implementation of patient centred structures and clinical facilities;
- providing linguistic and multicultural training to hospitals' workforce; and



- connecting with the local communities through informative campaigns, basic health education, health screenings, local caregivers’ training, and/or services’ orientation (Johnson et al., 2008).

Peer information and support networks

New technologies and new forms of communication (e.g., Facebook group pages, blogs) foster peer exchanges about health and care (Graffigna & Barello, 2015). On these platforms people can safely share health information, experiences empathy, knowledge, and practices about self-management (Graffigna, Libreri, & Albino Claudio, 2012). Peers can be connected through face-to-face or online communications, and these social exchanges contribute to the construction of patients’ representations of health that are drivers of healthcare decision making and criteria to assess the quality of services received. (Graffigna & Barello, 2015).

While outside the scope of this literature review, the use of peer workers and peer researchers is an obvious way to engage and embed peer perspectives within existing structures, and to ensure that any views captured through peer support networks to create and sustain ongoing system improvement.

3.3 Skills and processes to manage complexity

Engagement should be a multiple-lane process, activating every potential stakeholder across the consumer journey – the community, carers and family members, clinicians, nurses and social workers, managers and policy makers, and of course consumers themselves; both consumers that seek mental health support as well as consumers who decide not to. As Selsky and Parker (2010) point out, it is not a reciprocal two-lane process:

“This multiple-lane investment allows for the construction of multi-stakeholder partnerships, that we believe are a key asset for guaranteeing an effective healthcare innovation that balances economic, environmental, and social sustainability. In considering the many system actors, this engaging partnership certainly presents highly complex challenges. Literature advises that such partnerships are not a simple, linear, and straightforward process”

M. Gorli et al. (2015) outlines the full complexity of these partners working together – each actor identifies with whom they wish to engage (O’Higgins, 2010), then negotiates the purpose and the nature of their relation according to each other’s stakes and concerns (Selsky & Parker, 2010), and according to the perceived reciprocal autonomy and mutuality (Thomson, Perry, & Miller, 2009). Actors will consider the different interests at stake; manage tensions and differences among the many views, needs, and powers in play; and adapt accordingly (M. Gorli et al., 2015; Selsky & Parker, 2010)

Multi-stakeholder partnerships therefore yield potential tensions among the different actors, and it its outcomes are not predetermined or always foreseeable (M. Gorli et al., 2015; Worley & Mirvis, 2013).



“Engagement can be difficult and claim much in terms of emotional resources”
(Gardner, Dickinson, & Moon, 2019)

Every (healthcare, in this case) organisation therefore has to find its own situated and specific way to develop an engaging partnership. In order to meet these challenges, hospitals are therefore asked to review their taken-for-granted ways of relating with patients and with the other actors in the overall ecosystem. At least two distinct and inter-related capabilities are needed.

First, there is a need for internally oriented capabilities, such as openness to bottom-up change and transformative learning, information seeking strategies, and governance processes capable of coping with multiple and competing demands (Smith & Lewis, 2011). Second, externally oriented capabilities are required, such as skills in joint problem solving, flexibility, adaptability, openness to influence, cooperation, and conflict management capacities. We believe that these represent key assets for making the innovation of hospitals towards patient engagement effective and sustainable. At the heart of sustainability, there is in fact the idea that meeting competing pressures for change requires building multiple stakeholders’ efforts and long-term alliances. Since complex challenges cannot be addressed through simple and individual responses, the action plan for innovating hospitals sustainably therefore implies multi-perspective answers based on collaborative ventures. Patients and their families represent unavoidable stakeholders, and making their voices heard must be a priority in all the other actors’ agendas (M. Gorli et al., 2015).

One case study implied the sustainability of multiple methods, reporting that at the end of the consultation period, the service users continued to engage in continuous dialogue (NHS Confederation, 2013a).

Two systematic reviews emphasised methods that encouraged partnership working and collaboration to create more sustainability. These reviews noted the potential for partnerships to become institutionalised beyond the active consultation stage (Abelson et al., 2010; Conklin et al., 2015).

Another review cited the ongoing application of multiple engagement methods over 4 years (Mitton et al., 2009). In one primary study, focus groups were designed to be easily replicable, and these were continued post-consultation (NHS Confederation, 2010). Multiple approaches, particularly deliberative methods of engagement, enables flexibility in targeting various population groups.

Information was sparse but the case studies indicated varied success in regular face-to-face meetings, discussions with politicians and local stakeholders, and initiatives to ensure that all interested parties are listened to (Conklin et al., 2015). Social media was highlighted as a particularly effective method for engaging young people in decisions about reconfiguration.



4 Implementation considerations

By understanding the experiences of other jurisdictions, we can better understand what needs to be considered in the implementation of effective Engagement Framework. The importance of having a culture that support engagement has been explored in Section 2.

This section will outline a range of other issues that must be considered to best support effective engagement. This is based on evidence regarding known challenges that have been associated with conducting meaningful and effective engagement (Attree, Morris, Payne, Vaughan, & Hinder, 2011; Carr, Sangiorgi, Büscher, Junginger, & Cooper, 2011). Where possible we have translated challenges into positive and solution-focused language.

It should be noted that gaining a clear view of these challenges is not always straightforward. For example, service users identify different issues from those of commissioners; when looking below the surface of the stated priorities, such differences may not be incompatible but reflect a difference of perspective and imperative.

4.1 Establishing the motivation

Hudson (2014) and O’Shea (2017) found that there can be a lack of clarity about what consumer engagement means. Without the purpose clearly established it is also difficult to understand people’s motivation to engage and there may be a perception of inadequate reward. When motivation is established, there is a mutual sense of development for all involved.

Dalton et al. (2016) found that organisational readiness and commitment to service user engagement effected its success. There needs to be clarity about the aims of engagement, which is well articulated, backed by adequate resourcing of the process.

4.2 Investing the time and money

Critical to success is a level of investment (time and money) made to ensure that all parties have the necessary level of skill, knowledge and trust in each other to engage as partners in a process (Alborz et al., 2002). Wolfson et al. (2009) adds that alongside inadequate resources there is the pressure of competing demands – thus resources need to be dedicated to engagement. There needs to be open recognition that genuine engagement is time consuming. According to Evans, Bacon, Greer, Stagg, and Turton (2015), time is one of the greatest resources for effective consumer engagement in commissioning, it is a “long-term process and often is more challenging and takes more time than professionals initially anticipate.”

The allocated budget should include money to reimburse participants, especially lived experience participants. Commissioning processes could include guidelines around remunerating consumers for engagement.



Alborz et al. (2002) studied English Primary Care Trusts. They were legally mandated to “communicate and consult with local people” but after 18 months of operation, even though most had planned to engage with the local population, only a fifth of PCTs had actually designated a budget for engagement.

4.3 Establishing proper governance and oversight

It is suggested that the governance and oversight function is critical for ensuring successful engagement. Fundamentally, corporate commitment in the form of leadership, resources and strategies is essential (Petsoulas, Peckham, Smiddy, & Wilson, 2015). Leadership involvement also enables the results of the consumer engagement to be embedded throughout the entire organisational change agenda, ensuring the engagement will be more than just a ‘tokenistic’ approach. Schehrer and Sexton (2010) state that it is important commissioners do not exceed their authority or fail to carry through on commitments, because doing so can lead to distrust.

The leadership buy in helps to support the whole of systems approach: “Best practice in user involvement implies a whole systems approach to ensure that participation/involvement becomes a part of daily life rather than one-off activity for the whole organisation - from senior management to frontline staff” (Schehrer & Sexton, 2010).

Levels of power and authority need to be articulated so that at each stage of the process all parties are aware of their boundaries of authority.

There is also potential for conflict of interest that needs to be managed: voluntary sector to facilitate service user involvement. There is potential for tension if such organisations, while facilitating user involvement, are also contracted with a local authority or PCT to provide services.

4.4 Skills and capabilities

Insufficient skills within an organisation, or a lack of understanding of the competencies that professionals and consumers require to engage is identified as a barrier to success (Dickinson, 2015; Russell et al., 2013). This also creates a tension for commissioners, who may not always want to work with ‘the usual suspects’, but at the same time they need to work with those who have skill and experience in working with commissioners. Wolfson et al. (2009) points out that a lack of information systems and training also inhibits this work.

As explored in Section 3.3, the skillsets of staff managing these processes need to be sophisticated enough to manage complexity, tensions and conflicts that arise from seeking out diverse perspectives.



4.5 Not knowing effective methods of engagement

Cotterell et al. (2011) claim that organisations struggle with selecting the most effective ways to engage consumers (with an evidence-base). This is especially so when needing to engage representation of different groups and sectors (so that they all participate equally or proportionally) - Petsoulas et al. (2015) and Alborz et al. (2002) claim there are limited established methods to ensure this.

4.6 Overcoming biases in representation

One of the cautions around systems that rely on engagement processes are the biases that are likely to result due to who will be more inclined to engage (Brown & Townley, 2015). As mentioned above, commissioners often draw from a small pool of people who are willing to engage and have the skills and experience of engaging with commissioners. This creates a sample bias and means the same voices are heard with every engagement. Patterson et al. (2009) also found that if a small group of consumers are engaged again and again – creating what one voluntary sector manager described as a “sort of VIP group” – it could lead to alienation of other consumers who may feel ‘undeserving of participation. One drug and alcohol sector worker described the effect of limited representation:

*You see them at every conference, the same five or six people ... I've heard what they've got to say time and time again ... I'd like to hear somebody else, but they don't facilitate that ... **the person who speaks the least is the person who needs to be heard the most** [emphasis ours]*

– Drug and Alcohol sector worker, as quoted in Patterson et al. (2009)

Brown and Townley (2015) examined the characteristics and determinants that promote engagement in mental health consumer-run organisations. One of the three measures of engagement was leadership involvement, which they understood as how people contributed to organisational operations and decision making. They looked at both characteristics of organisations as well as the individuals who engaged. While some characteristics that promoted engagement can be controlled by organisations – for example, creating a shared sense of community – they found that demographic characteristics affect the likelihood of individuals engaging, especially in leadership roles.

Brown and Townley (2015) found that race-ethnicity, relationship status, gender and educational attainment significantly predicted leadership involvement. For example, in the US context, white consumers (non-Hispanic) were significantly more likely to be involved in leadership compared to other ethnicities. Being single, never married and not living with a partner also predicted a significant decrease in leadership involvement. Males were less likely than females to be involved in leadership roles, and educational attainment predicted leadership involvement.

Therefore relying on consumers to come forward and be involved in decision making, even within smaller consumer-run organisations, may mean this privileges the voices of the dominant cultural group of a society, and the educated. There are risks that the voices of single people, males, people from minority ethnicity group backgrounds and those with



lower educational attainment will not be heard and therefore their needs not considered in engagement processes (Brown and Townley, 2015).

O’Shea et al (2017) conclude that “representation warrants greater attention, because when it comes to making decisions there will always be a few who decide on behalf of others” (p.485). It is important that minority groups do not become marginalised in these processes.

4.7 Considerations from the Drug and Alcohol sector

While the importance of culture was already discussed in section 2, it pays to reiterate the influence of cultural elements such as stigma and power hierarchies within implementation considerations. In the field of drugs and alcohol consumer engagement, Patterson et al. (2009) found that the illegality of drug use contributed to a context in which “stigma and power imbalances were pervasive” in user involvement within NHS service design. Extensive interviews revealed frequent tensions within the user involvement process among various stakeholders. There was a sense of frustration at the perceived failure of user involvement to achieve its potential, and a growing disconnect between the current ‘state of play’ and an assumed ‘ideal’. The researchers also noted some animosity between service users and workers – respondents noted the potential incongruity in partnership with “the enemy, the person you’re fighting against to get what you want” (quote from a respondent, cited in Patterson et al. (2009)).

The layers of prejudice and stigma associated with illegal drug use appeared to be a significant barrier to successful engagement – commissioners and managers, for instance, described doubts they held about service users’ ability to contribute to complex processes and sophisticated forums. These assumptions, combined with the low self-esteem self-reported by many of the drug and alcohol users, created an atmosphere far from conducive to mutually beneficial engagement:

“... it was like our opinion didn’t count but everyone else’s did ... they didn’t listen to us ... bit of a waste of time really.” – user, NHS service, as cited in Patterson et al. (2009)

“... I’m a dirty junkie, the dregs of society haven’t got a say ... it’s a hopeless position. Whatever happens, it’s down to ‘it’s because he’s on drugs’, but I held a job for 10 years. And you believe it’s self-inflicted, your own fault so you don’t deserve help.” – user, NHS service, as cited in Patterson et al. (2009)

Taking an active approach to countering stigma around drug use and users was perceived as “both an antecedent and a consequence” of consumer engagement. Suggested steps included an open acknowledgement of the “expert” role of users, and a commitment “at the top” from leaders to incorporating user involvement as a *right* for consumers, rather than as an obligation for the service.



5 Learnings about effective engagement from other jurisdictions

Dalton et al. (2016) undertook a systematic literature review of both peer-reviewed and grey literature (published 2000-2014) to examine what is known about effective patient and public engagement in health service reconfiguration processes. The focus was on large-scale health service reconfiguration (including relocation of hospitals, concentration of specialised services, or changes in provision across care settings). Their review considered eight systematic reviews, seven primary studies and 24 case studies.

A summary of key findings:

- There was no evidence for the impact of any particular single method of engagement.
- Engagement was most likely to be successful when started early, when led and supported by clinicians, and when it offered opportunities for genuine interaction.
- Guidance setting out stages of reconfiguration and opportunities for service user input could be a helpful practical framework for future engagement activity.
- Key drivers underpinning successful engagement included shared understanding of the case for change, the use of appropriate methods of engagement, consideration of location and access, and a strong clinical case for change, together with visible clinical leadership of the proposals.
- Some negative outcomes of engagement on service reconfiguration were noted - such as polarisation of user views arising from media coverage.

While information was sparse, the case studies indicated varied success in regular face-to-face meetings, discussions with politicians and local stakeholders, and initiatives to ensure that all interested parties are listened to.¹² Social media was highlighted as a particularly effective method for engaging young people in decisions about reconfiguration.

Key factors contributing to successful engagement and/or service reconfiguration:

- ➔ ensure a clear understanding of the local context
- ➔ early engagement, consult widely
- ➔ demonstrate clinical-led case for change, with focus on service improvement rather than cost savings
- ➔ demonstrate openness and develop shared understanding of change, potentially through local partnership working
- ➔ promote ownership of the change model and feedback results of engagement
- ➔ strong managerial leadership, such as championing the need for engagement
- ➔ use of multiple approaches, particularly deliberative methods of engagement, targeted where necessary for different population groups
- ➔ consider access and transport issues
- ➔ evaluate and follow-up

Source: (Dalton et al., 2016)



Other themes to emerge from the literature are summarised here.

5.1 Representation warrants consideration

“Representation warrants greater attention, because when it comes to making decisions there will always be a few who decide on behalf of others” (O’Shea et al., 2017).

Insufficient attention sometimes paid to those who are engaged, or on whether these individuals are broadly representative of the groups that are sort. Important that minority groups do not become marginalised in these processes.

5.2 Awareness and management of inequalities

“If inequalities are not addressed as part of involvement itself this can perpetuate injustice, reinforcing a lack of respect, lack of power and lack of resources. It can also isolate service users, instead of providing opportunities for their mutual support and empowerment” (Millar, Chambers, & Giles, 2016)

5.3 Efforts to be genuine

A poorly thought through engagement process without true leadership commitment to follow through on emerging findings may do more harm than good. Engagement processes must be planned with this in mind, otherwise there may be a risk to contributing to a “vicious cycle of cynicism” (Evans et al., 2015). As Sanders, Ben Omar, and Webster (2015) “[e]ngagement must be genuine— bad engagement is more damaging than no engagement.”

This will involve excellent communications, including, as suggested by Sexton (2010) “...making explicit the implicit in organisations that involve service users in planning”.

5.4 Consider local context

Important to remember that models cannot simply be replicated (if they worked) - it is important to identify their elements and then apply those elements in the new context. Involving service users early in planning will help.

According to Watt, Higgins, and Kendrick (2000): *“Getting local people on-board only to let them down, once again, acts as a further step towards disempowerment. Local people ... can only feel less powerful through devoting their time, energy and enthusiasm into a project which is later abandoned ... by the ultimately more powerful party”*



6 Outcomes and benefits

One of the important findings from the literature is the lack of peer-reviewed evidence about outcomes of engagement in mental health service design, procurement and commissioning. There are indicators that point to the positive impact of engagement – through case studies, understanding of needs and smaller qualitative studies. This work is rarely evaluated; or when evaluated the focus is process evaluation rather than outcomes evaluation.

Several empirical studies have also demonstrated the positive outcomes of patient engagement at the clinical, psychosocial, and economic levels (Graffigna & Barello, 2015).

6.1 Improving client outcomes at the service delivery level

We know that in the broader health domain, evidence points towards engagement being a means to improve individual and broader community health outcomes – as well as potentially leading to improved health system efficiency and efficacy (O'Mara-Eves et al., 2015). Evidence, however, is limited on the effectiveness of these approaches in improving client outcomes (Dickinson, 2015).

A report by Health Consumers Queensland summarised evidence of the benefits of consumer and community engagement for individual health outcomes, health services, networks and the overall health system. Similarly, a Canadian report found that community governance in health led to improved health outcomes for individuals and the broader community by the facilitation of empowerment and social capital (Ktpatzer Consulting, 2006).

6.2 Supporting recovery for individuals through engagement

A study by Segal, Silverman, and Temkin (1995) looked at the idea of empowerment in four client-run self-help agencies for persons with severe mental disabilities in the US. According to the authors, “empowerment” connotes a process of gaining control over one's life and influencing the organisational and societal structures in which one lives. This study defines and validates three measures: the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale (Segal et al., 1995).

While empowerment is not consistently defined, Segal et al. (1995) describe it as a process by which individuals with lesser power gain control over their lives and influence the organizational and societal structures within which they live. With the growing interest in the empowerment of consumers, it is likely that involving consumers in the development and delivery of mental health services is likely to contribute to their own personal recovery, and this study finds a relationship between personal empowerment and organisational and extra-organisational empowerment.

Authors point to self-efficacy as a bridging construct between personal and organisational/extra-organisational empowerment. They suggested that “this may be



because the construct measures the individual's confidence in his or her ability to be efficacious in common life activities and in political actions" (Segal et al., 1995).

6.3 Improving service integration

Using hospitals as an example, M. Gorli, L. Galuppo, and E. Liberati (2015) found that engaging with patients and families enhances hospitals' capability to connect and build partnerships with other organisations (i.e., patients' associations) and with the broader local community. They describe service users as having a 'bridging function' which helps hospitals to integrate with services outside the hospital, i.e., by joining in community-based healthcare initiatives or by providing resources to provide health education to households.

6.4 Economic benefits

Engagement processes are perceived to assist improve efficiency and effectiveness of healthcare and are often recognised by Governments as an important method to ensure scarce resources are allocated in the best way possible (M. Gorli et al., 2015).

6.5 Benefits for improving policy and strategic design

Moving away from the impacts on users when they are involved in service design, and into the realm of how engagement benefits mental health policy direction and strategic decision making, the evidence tends to thin out. Evidence surrounding the impacts of public involvement in health-care policy and strategic design (rather than patient involvement in service design) is extremely scarce.

Crawford et al. (2002) reviewed the literature on the effects of patient involvement in the development and planning of health services. While only a minority of studies actually described the *impact* of this patient involvement, those that did tended to demonstrate that involving service users did contribute to changes in care provision.

This was consolidated in an interview with Karen Gardner, Senior Research Fellow and Deputy Director in the Public Service research Group at the School of Business, UNSW. Dr Gardner was the co-author of a systematic review of the evidence for strategic commissioning, and engagement. While in some specific projects, there was evidence that user involvement influenced outcomes, often this was in relation to some specifics about service delivery, like food options or parking spaces. In the realm of higher-level strategic decision making or policy design, this is often not effectively tracked, and we have scarce evidence in the peer-reviewed literature for the benefits of consumer engagement.

A systematic review by Conklin et al. (2015) examined 19 peer-reviewed studies to evaluate the evidence base for public involvement in health-care policy. Florin and Dixon (2004) define public involvement as 'the involvement of members of the public in strategic decisions about health services and policy at local or national level' and is distinct from patient involvement, in which individuals, together with health professionals, make decisions about their health care.

Conklin et al. (2015) focused on outcomes of public involvement in health-care decision making, priority-setting, resource allocation and/or health service planning at the macro-and-meso level. They found that robust evidence of the outcomes of public involvement



activities in health care remains underdeveloped. Frequently, the indicators used to examine and demonstrate outcomes were “poorly specified and inconsistent”, as was the reporting of evidence. Where there was evidence, this was often related to process evaluation – an account of the type and development of the involvement initiative, rather than a discussion of impact (positive or negative).

Among studies that did look at benefits or outcomes, several studies found the impact or influence of public involvement on shaping strategic decisions in health-care policy to be minimal (Alborz et al., 2002; Bauld et al., 2005; Peck et al., 2002), geographically variable (Abelson et al., 2007; Bréchat et al., 2006) mixed (van de Bovenkamp, Trappenburg, & Grit, 2010). van de Bovenkamp et al. (2010) found mixed results of “successful influence” on policy outcomes. Their extensive interviews with representatives from patient organisations indicated that there were multiple (n=18) examples of unsuccessful attempts to influence organisational decision-making, but there also found examples of self-reported positive effect on the well-being of participants.

Dalton et al. (2016), in their systematic literature review of both peer-reviewed and grey literature (published 2000-2014), reported that some impact studies show that wide-reaching consultations added robustness to service tender specification for urgent care services. Other findings were modest, such as engagement leading to improving transport options for accessing health services. There was very little reported on the potential negative impact of service user engagement.



7 Evaluation

Importantly, this scarcity of evidence is not necessarily an indication that engagement is ineffective at the high-level strategic design and policy level. Rather, what it does point to is (1) the relatively novelty of integrating consumer engagement with this policy design and (2) where there is engagement, often this is not complemented by robust evaluation. A key learning for the development of the MHC engagement framework is thus whatever forms of engagement are implemented, there needs to be evaluation of outcomes and demonstration of impact of the engagement.

In the systematic review by Dalton et al. (2016), overwhelmingly, studies focused on processes rather than the outcomes of the health service reconfiguration. For example, outcomes could be focused on changes in service user views about services, organisational culture change with regard to commitment to user engagement, or shifts in learning about how future consultations might be carried out (Conklin et al., 2015; Crawford et al., 2002). While process evaluations can serve a useful purpose – primarily, for informing others about how an engagement initiative was carried out – if process evaluations are prioritised over outcome evaluations, our evidence base for the impacts of stakeholder engagement in health service design will remain weak. Dalton et al. (2016) summarised that the absence of measurable outcomes was problematic. They also noted that often the evaluations were run by the organisations carrying out the engagement process. The lack of independent research could be a considerable limiting factor.

Negative consequences of engagement were frequently not discussed, although some papers (see Watt et al., 2000) did point to a central tenet that “poor engagement is worse than no engagement at all”, owing to the potential to feed into any existing mistrust and cynicism.

There are potentially negative sides to consumer engagement that cannot be overlooked and may not be understood unless there are proper independent evaluation processes – for example, if inequalities are not addressed and people feel further disempowered by the engagement process where they are not heard. Some professionals may see it as a threat that undermines their own expertise (Gardner et al., 2019).



8 Conclusion

Coulter (2002) suggested that the twenty-first-century health service user is at once “a decision-maker, a care manager, a coproducer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers”. It is no wonder that bringing this perspective into service design and commissioning processes is a high value proposition. The current *zeitgeist* in service commissioning and policy design is to engage with those who will be the end-users of the system.

Key takeaway 1: Engagement has the potential to offer range of benefits, but is understudied and under-evaluated

We know that engagement can offer a range of benefits, however the opportunities for these benefits to be measured and documented through independent evaluation is limited, as is reflected in a limited evidence base on outcomes.

Key takeaway 2: Culture may be as important as, if not more important than, structure or methods when engaging with service users in service design and delivery

To facilitate effective engagement processes, organisations must first look internally. An appetite for risk, experimental approaches to policy and openness to change and iterative learning are required, all qualities that sometimes go against our current management paradigms especially in health settings.

Engagement done well will likely lead to negative views being expressed and therefore a safe, no-blame culture is needed, where mistakes and failures and negative experiences can be fairly assessed with a systems thinking approach, and without staff feeling threatened.

This is the work of ‘creating the space’. External facilitators may be required to support these processes.

Key takeaway 3: Excellent communication strategies and sophisticated skills such as conflict resolution are needed

Good information systems are also needed, excellent and open communication lines (so the full realisation of ‘feedback loops’ can be applied), and people with the skills to do conflict management and resolve tensions need to be involved in the process. Leaders need to endorse, and provide the time, and adequate resources. Mechanisms for reporting back to the board and having feedback loops to institutionalise findings in the organisation are also required.



Communication needs to recognise the nature of problems that you are trying to address, philosophy underpinning the change, rationale for the engagement within the local context needs to be expressed.

Key takeaway 4: Engagement needs to be considered within the local context

Although engagement has broadened out to be part of a sector-wide commissioning cycle, starting here could be overwhelming. It is wise to start small and support engagement in localised settings. One recommendation is to employ a data-driven approach, engaging stakeholders to reflect on data from localised settings, to help keep initial efforts grounded and manageable, as the sector builds its engagement skills, improvement pathways and mechanisms.

Key takeaway 5: Potential barriers to successful engagement need to be brought into the open and addressed

There are numerous barriers to successful engagement that are explored in this literature review. We need quality engagement but that does not always mean it is possible to run an extensive co-design process where all views have been comprehensively considered. A solid grounding in the ideals, and the real world constraints, and our ability to express these limitations clearly and honestly will be important as we build the culture needed for effective engagement.

Key takeaway 6: Start small and build on learnings slowly – a developmental approach is recommended

Examining the evidence from other jurisdictions should enable us to begin with some permissiveness. There is no need to achieve everything at once – as this has not been done elsewhere. There is also no one right method or approach – but multiple legitimate approaches that can be explored experimentally, as long as it is supported by openness and willingness to reflect iteratively.

With thanks to Dr Karen Gardner, who, through facilitated conversation with the research team enabled the emergence of these concluding insights - which are based on the findings of this literature review as well as Dr Gardner's years of research in this field.



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