Australian National University

Framework for the engagement of people with a lived experience in program implementation and research

Review and report prepared for the LifeSpan suicide prevention project

Dr Aino Suomi, Mr Ben Freeman & Dr Michelle Banfield

Centre for Mental Health Research

+61 2 6125 6547

Michelle.Banfield@anu.edu.au

Acknowledgement

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Part 1. Background

Introduction

The active participation of the public in decision-making, particularly policy and economic processes, has a long history internationally. Most literature on participation points to Sherry Arnstein's provocative 1969 paper on citizen participation as a pivotal piece in the development of the rationale and methods for encouraging participation. (1) Arnstein's "Ladder of Citizen Participation", in which she proposed eight levels progressing from non-participation (levels where the powerholders maintained all control) through degrees of active participation is the basis for many current frameworks for participation worldwide. (e.g., 2, 3) The guiding principle of these frameworks is that people have a right to affect these processes. (1)

Active participation of people with a lived experience of a health or social condition in policy, programs/services and research has been a particularly common application of the principle of participation. (4, 5) Several Western countries including Australia have formulated policies promoting the active involvement of health consumers and the community, both in health practice and research (see for example the *National Mental Health Strategy*, (6-11); *Statement on Consumer and Community Participation in Health Research,(12)*). Many authors have also argued that to be relevant and effective, health research and services' design and implementation must be informed by end users. (4, 13, 14) This grassroots approach to the design of research and services suggests that the people who use services are the best placed to identify existing gaps and how their needs may best be met. (15, 16)

Recent research (17, 18) on the impact of active involvement (as opposed to participation as a "subject") in the research context provides some useful and practical perspectives on participation that are applicable more broadly. Active involvement has demonstrable positive effects on people with lived experience of the condition or topic of a study, including feeling heard and empowered, learning new skills and increased trust in researchers; researchers also discovered fresh insights into their work and enjoyed greater connection with the community. (17) However, involvement is not without its negatives, particularly if it is done poorly: people with lived experience can feel unheard and marginalised, find it difficult to negotiate changes to rigid protocols, may feel ill-equipped to participate equally with researchers and clinicians if there is no training and report there is often a lack of feedback on how their input was used and affected the project. (17) Researchers also found it difficult to manage tensions between traditional research rigour and lived experience perspectives on appropriate methods and could not

always accommodate the necessary extra time and resources to manage this, leading to tokenism. (17)

There are a number of clear messages from the literature on involvement, most of which entail good planning as early in the project as possible: it is important to build in time and resources for involvement of people with lived experience in projects; plan appropriate forms of involvement that account for the skills and experience with participatory research or practice of both the people implementing the project and the people with lived experience; and invest time understanding expectations, defining boundaries for elements that cannot be changed (e.g., it may not be possible to alter the content or implementation of an evidence-based program) and exploring possibilities for flexibility. (2, 3, 12) The engagement framework provided in Part 2 and the research involvement planning tool provided in Part 3 are designed to facilitate effective planning for engagement of people with a lived experience of suicide across the entire LifeSpan project (implementation and research), with guidance and references for useful methods and support tools.

A final consideration for any process of engagement is understanding its impact. Similar to continuous quality improvement cycles in health services, it is important for everyone involved in a project to examine what worked, what didn't and what effect the engagement is judged to have had to inform future processes. Further, it is important that everyone, especially people with a lived experience, have an opportunity to contribute to the evaluation of engagement and to discuss its effect. The strategies elaborated in Part 2 describe ways in which this may be achieved. However, Staley's (18) reflection that this is "experiential knowledge" rather than traditional evidence, and its impact highly dependent on contextual factors is important. Factors such as the scope of the influence of the people involved, the action taken in response to recommendations and the assumptions all players brought to the project will all influence how impact is rated, but these may be different from one project to the next. When looking to fill the gap in our understanding of how engagement is effectively achieved, it should therefore be examined carefully within the context in which it was implemented. (18)

Scope and purpose

The purpose of the current project was to develop a framework and recommendations for accountability mechanisms for the engagement of people with lived experience of suicidality, bereavement by suicide and mental illness in the implementation of the LifeSpan systems approach to suicide prevention. The scope included a rapid review of the evidence for effective engagement frameworks for people with lived experience, their families, support people and carers, focused on suicide, mental illness and health consumer literature. Searches included black (peer-reviewed) and selected grey (non-peer-reviewed) literature. The framework for engagement was developed based on the findings of the literature review, including recommendations for engagement in project development, governance, delivery, measurement and evaluation, focused on specific, practical and measurable actions for sites to take for meaningful engagement. Recommendations on measurement strategies form part of the framework.

Methods

Terminology

One of the challenges of reviewing work in this area is that terminology varies substantially internationally and even locally according to the customs and preferences of the groups concerned. It is acknowledged that the preferred terms for the LifeSpan project are "engagement" and "people with a lived experience" and these are used throughout this document where possible. The exception is in the names of specific methods, measures and tools. An adapted version of the Suicide Prevention Australia definition of lived experience has been followed: "…*experienced suicidal thoughts, survived a suicide attempt, cared for someone who has been suicidal or been bereaved by suicide.*"

However, in order to capture the broadest range of literature, it was also necessary to incorporate terminology commonly used in the mental health and health sectors, including consumer, service user, patient, involvement and participation. Each of these terms is subtly different in meaning and use, but the underlying principles and purpose align.

The framework has incorporated the guiding principles of the inclusion of lived experience of suicide prevention by Suicide Prevention Australia: (1) People with a lived experience have a valuable, unique and legitimate role in suicide prevention; (2) Lived experience helps change the culture surrounding suicide and to preserve and promote life through compassion and understanding'; (3) Inclusion and embracing diversity of individuals, communities and cultures enriches suicide prevention; (4) Empower and

support those with lived experience to share their insights and stories with a view to preventing suicide; (5) Utilise our lived experience to educate, promote resilience, inspire others and instil hope; (6) People with lived experience support, advocate for and contribute to research, evidence-based practice and evaluation; (7) All suicide prevention programs, policies, strategies and services will at all levels include genuine meaningful participation from those with lived experience; and (8) Encourage and nurture collaboration and partnerships between organisations and stakeholders.

Grey (non-peer reviewed) literature

Identification of models and frameworks that could be used directly or adapted for use in the LifeSpan project commenced with a search of grey literature in October 2016. Grey literature consists of reports, websites and other materials published outside the academic or peer-reviewed literature. Suicide prevention websites, peak health and mental health consumer organisation websites and known participation sites such as INVOLVE were searched for frameworks and evidence of their implementation and effectiveness. This was supplemented with searches of Google and Google Scholar using a combination of keywords including: [suicid*, OR self-harm] [health, mental health] and ["framework", "prevention", "intervention", "program", "policy", "strategy", "evaluation", "co-design", "Experience Based Co-Design (EBCP)"] and ["consumer" "lived experience"]. Other terms searched included "patient and public involvement (PPI)", "patient/public involvement", "user involvement" and "lay involvement". Further possible sources were identified by hand-searching reference lists of included materials. A coding sheet was developed to extract and summarise key information from each source to underpin the framework and measures presented in the next section. Full coding of all included websites is contained in Appendix 2, including links to sites.

Black (peer-reviewed) literature

To complement the frameworks and strategies identified in the grey literature, and to compile available research evidence on the effectiveness and impact of strategies, a search of the peer-reviewed literature was undertaken in November 2016.The PsychINFO and PubMed databases were searched using the terms in Box 1.1. The searches returned 3147 records in PsychINFO and 2685 in PubMed. After duplicates were removed, there were 5147 records for screening.

1. Lived experience	2. Suicide	3. Mental health	4. Engagement
consumer	suicid*	"mental health"	PPI (patient and Public involvement)
client	"self-/ harm"	"mental disorder"	"co-/ design*"

lay	"mental disease"	EBCD (Evidenced-Based Co-Design)
"treatment-/ seek*"	"mood disorder"	"user exp*"
citizen	depress*	"public involvement" "patient engagement" "user perspective"
"help-/ seek*"	bipolar	collaborative
"service-/ use*"	"emotional disorder"	"user-/ led"
stakeholder	"affective disorder"	"expert panel" "advisory
carer	"personality disorder"	"advisory board"
survivor	"psychopathology"	"reference group"
family	psychiatr*	consultative
spouse	borderline	"patient satisfaction" -/ cent*" -/ led" activation"
"significant other"	anxi*	"peer-/ led"
"lived exp*"	psychos*	"peer work"
bereave*	"mental illness"	participatory
"treatment-/ seek*"	addiction	"shared decision"
	"alcohol use" "drug abuse" dependence"	"clinical governance"
	AOD	redesign, "re-design"
	"substance use"	
	"substance abuse"	
	"harmful use"	
	"gambling disorder"	
	"gambling problem*"	
	"problem gambl*"	

Box 1.1. Review search terms

Figure 1.1 summarises the screening process according to the PRISMA guidelines for systematic reviews. (19) Screening was undertaken by four researchers. An initial subset of abstracts was screened by multiple people to refine the inclusion and exclusion criteria (see Appendix 1) and check for consistency. The full set was then divided between the four researchers for screening. Due to time constraints, abstracts were not double-screened. At the conclusion of screening, the full text of 79 papers was retrieved for inclusion in the review. Due to the slightly different nature of the black literature compared with the grey literature, a separate coding sheet was developed for extraction of key information from peer-reviewed papers. Findings are summarised in the next section with full coding contained in Appendix 3.
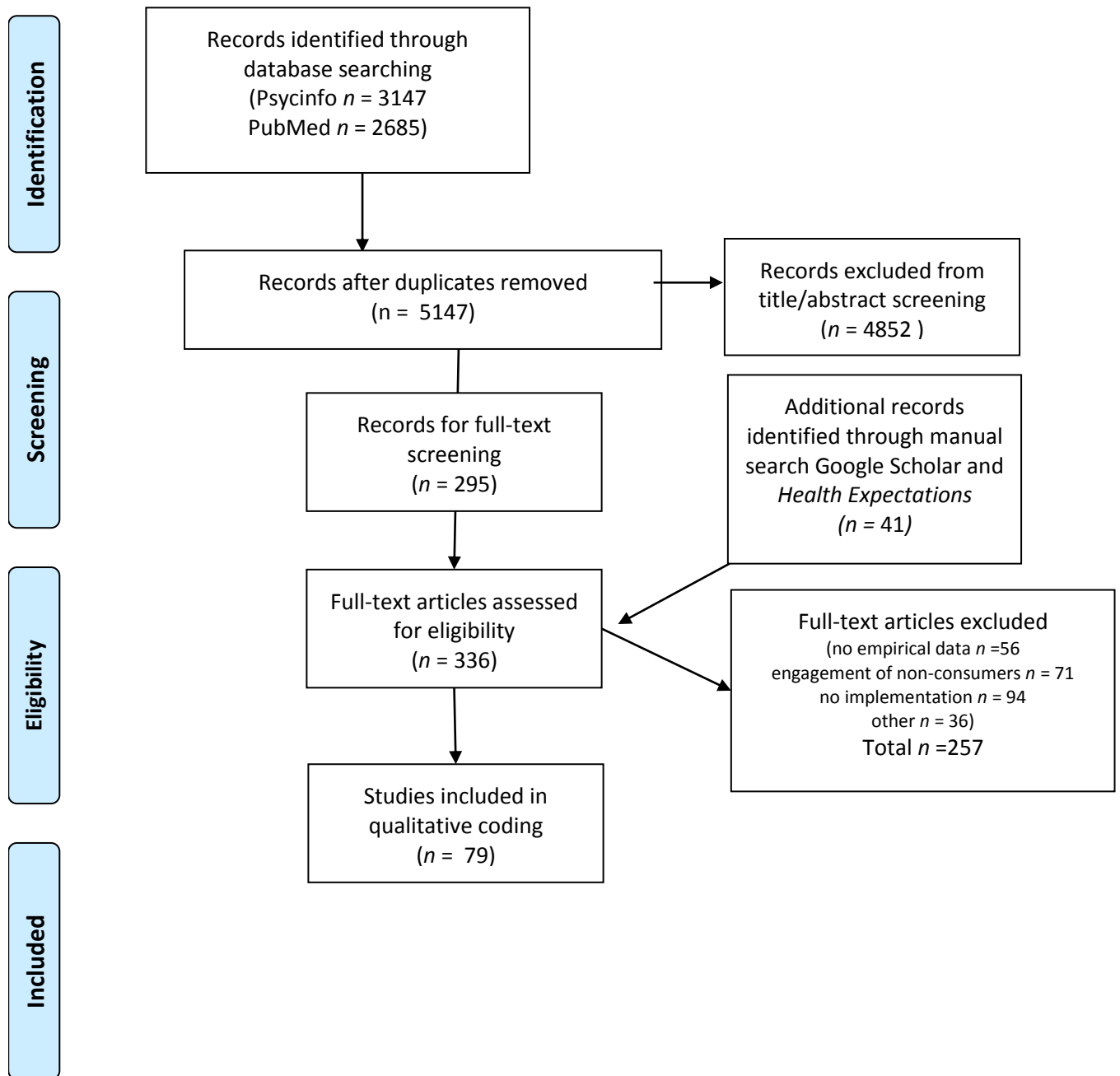
Figure 1.1 PRISMA flow diagram for black literature search

Part 2. Findings

No single, comprehensive framework for engagement of people with lived experience of suicide was identified and measures of the effectiveness of engagement strategies tended to focus on "experiential knowledge" rather than traditional evidence. (18)

The engagement strategies that satisfied the inclusion criteria for black literature fell into the following 'types':

1. Advisory groups/committees ($n = 6$)
2. Co-design ($n = 17$)
3. Focus groups ($n = 14$)
4. Forums ($n = 3$)
5. Patient/client/consumer-led ($n = 10$)
6. Peer programs ($n = 13$)
7. Multiple strategies; no clear primary strategy ($n = 16$)

Given that the grey literature consistently pointed to the use of 'patient/client satisfaction' surveys and 'engagement in own treatment', another round of screening was conducted identifying an additional two engagement strategies. These two groups did not fully meet the selection criteria and are thereof not part of the formal systematic search findings but are summarised in the next section: Elaboration of the framework.

8. Satisfaction surveys ($n = 36$)
9. Tools to engage a person in own treatment decisions (including shared decision making) ($n = 37$)

Notwithstanding the lack of comprehensive measures of effectiveness for different types of engagement, both grey and black literature have some suggestions and examples of what 'effectiveness' may entail and how it could be quantified. Studies from the peer-reviewed literature matching the criteria and the types of outcomes of 'effective' engagement were:

- Improved health/wellbeing/skills of the individual ($n=12$)
- Positive experience of being involved by the individual ($n=6$)
- Increased/better understanding of what is 'good' engagement ($n=25$)
- Improved tools, services ($n=31$)
- No impact ($n=5$)

The framework that follows was developed from a range of literature, and is constructed with consideration for the core values for engaging people with lived experience of suicide and recommendations from "The Way Forward" – developed by Suicide Attempt Survivors Task Force [p10 (20)]:

All activities designed to help people with lived experience of suicide should be consistent with one or more of the following core values.

1. Foster hope and help people find meaning and purpose in life
2. Preserve dignity and counter stigma, shame, and discrimination
3. Connect people to peer supports
4. Promote community connectedness
5. Engage and support family and friends
6. Respect and support cultural, ethnic, and/or spiritual beliefs and traditions
7. Promote choice and collaboration in care
8. Provide timely access to care and support

Draft framework for engagement of people with lived experience

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of services and programs	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference groups Representatives on committees	10. Lived experience-led committees, equal representation in all decision-making bodies	
Delivery	3. Self-help programs/tools	7. Peer workers, peer-led programs	11. Lived Experience-led training for staff	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Lived experience feedback, co-evaluation	12. Interviews with Lived Experience reps, regular audit of engagement activities	

Elaboration of the framework

A systemic approach for involving people with lived experience means implementing engagement strategies at each aspect of an organisation in health care delivery and programs across a number of levels of the organisation. (21) There are numerous ways to categorise these levels of engagement; a widely recognised model across health and mental health literature that is implemented across health organisations (22) (23) (21) recognises four levels for engagement:

1. Individual level
2. Service program level
3. Organisational level
4. Policy/strategy level

Each of the four levels includes a set of strategies that are relevant to the design, management, delivery and evaluation. This approach aims to provide opportunities and platforms for people with lived experience to be involved at each level.

Detailed elaboration of the implementation of this Framework within the LifeSpan project is outside the scope of this report and will be undertaken by LifeSpan Implementation Managers. As a highly complex project, many elements of LifeSpan could be considered "microsystems" to which all levels of the engagement framework could be applied, in addition to the "macro" view of LifeSpan as a whole. For example, strategy level methods could be applied both at the governance level of the entire project as well as within the governance of a particular service provider involved in implementation. Appendix 4 comprises recommendations for the broad alignment of engagement strategies across the nine LifeSpan strategies.

Measuring engagement and its impact

Measuring outcomes for engagement

Measuring the impact of engagement is not an easy task. There is no consistency in measurable outcomes of engagement reported in health or mental health literature. This frustration around the lack of measures and tools is prominent in the relevant literature and a small number of attempts to integrate the evidence of possible outcomes have been made. Health Issues Centre (24) conducted a series of rapid reviews on engaging consumers in health decision-making effectively. Table 1 below lists a number of tools that the review found can be used to evaluate engagement on all levels. However, the review concluded that tools at the *individual level* of engagement have been well

implemented and evaluated but more work is required for the other levels. In particular, the reviews found strong evidence on the effectiveness of interventions at the individual level of care, which enable individual consumers and their carers to be involved in decision-making processes. However, there is a dearth of evidence on the effectiveness of consumer involvement at the program, organisation and government level.

Table 1. Summary of engagement tools and evidence for impact - adapted from (24)

Level of engagement	Focus of common tools	Tools for engagement	Evidence of impact
Individual	Decision-making processes	Question prompt list; information packages; chronic disease self-management groups; shared decision making tools	Ability to engage consumers in decision-making processes
Program	Feedback from consumers on possible improvements or on involving consumers in planning	Involvement of consumers on committees and reference groups	Consumers' input into the design of resources has the greatest potential to successfully contribute to committees and working groups
Organisational	Seek the input of consumers and community members for planning or reforms	Community advisory committees and community councils	Minimal evaluations; tools designed to produce benefits for health services than individual consumers
Government/ community	Consult and engage with consumers and communities; engage consumers and community to input into future health planning	Legislation, policy and resources to guide the implementation of engagement; citizen juries, interviews, surveys, focus groups public forums and advocacy	Minimal and ad-hoc evaluations; all methods identifying useful data to inform future health planning

Simpson and House (25) reviewed evidence from studies on the effects of involving users (patients) in the delivery and evaluation of mental health services. Their main results point to a range of ways the users could be involved in improving services. Half of the reviewed studies (*n* = 12) considered involving users in case management and they

found having users as employees was associated with clients' greater satisfaction with their personal circumstances and with fewer hospitalisations. Providers of services who had been trained by users had more positive attitudes toward users, although – perhaps surprisingly – clients reported being less satisfied with services when interviewed by users. More recently, Conklin et al. (26) reviewed literature on outcomes of public involvement in health-care policy and found that the concept and indicators used to examine and determine outcomes remain poorly specified and inconsistent. There was some evidence, however, of the developmental role of public involvement (enhancing awareness, understanding and competencies among lay people).

One systematic review (27) focused on evaluating involvement of service user and caregivers in strengthening the mental health system. The review examined service user and caregiver involvement in low- and middle income countries and included studies with direct involvement of mental health service users and caregivers in: (i) development of policies or strategies; (ii) planning or development of services; (iii) training of health workers in mental health care; (iv) service monitoring, evaluation or quality control; or (v) mental health research. Most of the literature included in the review reported service user and caregiver involvement at the service-level (for example, self-help and support groups) rather than the systems-level (e.g., policy, planning, monitoring or evaluation level). Overall they found a lack of high quality research and weak evidence base for the work that was conducted in service user involvement.

Types of engagement outcomes

One example drawn from the most recent literature (28) used a framework for monitoring and evaluating patient participation in developing guidelines for the process or employment and re-employment for people with severe mental illness. They made a clear distinction between *the process* of involvement and *the outcomes* of involvement or patient participation. The quality of patient involvement was determined by the extent to which the process and the outcomes meet an explicit criteria. The *process* criteria included:

1. Balancing the number of patients with professionals (50/50)
2. Addressing diversity in the patients
3. Adequate expression/involvement/contribution by the patients
4. Transparency of the process
5. Clarity of expectations
6. Involvement throughout the process
7. Involvement in all levels of decision-making
8. Facilitation of patient involvement - use of different forms of participation
9. Addressing patients' needs in the process

10. Positive attitude towards patient involvement

Additionally, the *outcome* criteria included:

1. Direct outcomes:
   a. Consensus on the content
   b. Incorporation of patient input in the final product
   c. Practical relevance of the guideline
   d. Dissemination (and implementation) of the guideline
2. Indirect outcomes – (self-reported) learning process of patient representatives and the organisations.

One example of tangible and measurable outcomes for engagement in a particular context is that of The Southcentral Foundation's Nuka System of Care where the Alaska Native people are in control of health care delivery. It recognizes that disease and its treatment has social, psychological and cultural components as well as the traditional biomedical issues. (22) The consumer is treated as a customer and as an owner of their own healthcare. The governing board, which is composed entirely of 'customer owners', sets the direction and the CEO creates an environment that ensures the organisation is working towards its vision and measures progress along the way. This relationship-based, customer-owned Nuka System of Care has demonstrated measurable improvements in health care including:

- 52% increase in consumers enrolled to an integrated primary care team,
- Decrease in the average delay to schedule a routine appointment from 4 weeks to same-day access,
- Reduction in the number of individuals on the behavioural health waiting list from about 1,300 to nearly zero in a year.
- Reduction in Phone waiting times from 2 minutes to less than 30 seconds.
- 36% reduction in hospital days,
- 42% reduction in emergency care and urgent care usage, and 58% reduction in specialty clinic visits have been sustained for 10 and above years.
- Reduction in staff turnover to one quarter of the level it was 5 years earlier.

Increasingly organisations are using volunteers and peer support to bridge the gap between the service provider and consumer. Repper and Carter (2010) describe models of peer support that have been developed and evaluated as having merit. These include informal and ad hoc support among consumers (often naturally occurring); organised but unpaid peer support generally undertaken by volunteers who take on roles as 'mentors' or 'peer buddies'; and paid peer support, where participants will generally be part of a

team contracted to provide services to consumers. Using patients to educate clinical professionals also has potential to change the culture of the organization and decisions about treatment (KPMG International, 2014).

VIC Health: Doing it with us not for us (29) lists a range 'standards' for service user engagement that vary according to the organisational context. For example: "Standard 2: consumers, and, where appropriate, carers are involved in informed decision-making about their treatment, care and wellbeing at all stages and with appropriate support" (VIC Health, 2011; p19). Each standard includes a number of indicators, for example, (i) maternity services; (ii) community health services; and (iii) mental health for the abovementioned Standard 2 (p20). Each indicator includes a numerator and denominator, for example, 'community health services' -indicator for Standard 2 the numerator is "The percentage of clients/carers satisfied or highly satisfied with their involvement in decisions about their care or treatment" and the denominator "The total number of clients/carers who participated in consumer/carer surveys". Target for community health services within this plan was 90% but it is crucial that these numerators, denominators and targets are appropriately matched to the context. The Standard 4, for example, includes "consumers, carers and community members are active participants in the planning, improvement and evaluation of services and programs on an ongoing basis" (p26) where the numerator is "the number of dimensions or specified activities where consumers, carers and community members are active participants" and denominator are the six dimensions of specified activities including:

1. Strategic planning
2. Service, program and community development
3. Quality improvement activities.
4. Developing and monitoring feedback, complaints and appeals systems and in the review of complaints.
5. Ethics, quality, clinical and corporate governance committees
6. Consumers, carers and community members are involved in the development of consumer health information

These standards, their numerators and denominators are consistent with a range of other indicators and standards reported elsewhere (30). This approach could be partly adapted to the nine LifeSpan strategies: Standards corresponding to the nine strategies and each Standard would have an engagement Indicator, Numerator and Denominator for measurable outcomes appropriate for each context.

Engagement outcomes from the current review

Similar to a previous systematic review (27), our review of the peer-reviewed literature found mostly evidence of individual treatment and service level engagement strategies and a negligible amount on organisational or policy level and higher level governance or decision-making. The studies included in the current review mostly reported improvements in services or treatment methods/tools as possible outcomes of implementing engagement strategies (n=31). Almost as common (n=25) was an increased or improved understanding of what is good engagement. A group of studies (n=12) reported improved health/wellbeing or skills of the individual as the outcome measure. Only a handful (n=6) reported positive experience of engagement as the outcome and some (n=5) reported no impact.

General recommendations for measuring involvement/engagement:
- o Validated tools e.g., satisfaction surveys – reported by most engagement frameworks with evaluation component. The highest standard for using satisfaction surveys is to have a quality improvement process attached to the use of these surveys.
- o Fidelity with protocols, guidelines, checklists e.g., service meets a certain number of criteria for engagement
- o Measurable targets e.g., executive boards have a minimum number of people with lived experience
- o Numerators (%) e.g., the percentage of clients satisfied with their involvement in decisions
- o Denominators (#) e.g., number of programs that have a peer-mentor attached to it

Throughout the description of the methods of engagement to follow, a number of options for possible measures of accountability and outcomes have been included. The most appropriate choice depends on whose perspective on the process or outcome is being sought. In most cases, when examining engagement and its impact, self-report measures from people with lived experience who have been involved should be the first choice. Where possible, such measures that were co-developed with people with lived experience are identified, to increase the likelihood that items are acceptable and relevant for a lived experience perspective.

Four levels of engagement (adapted from Carman et al. (31))

Individual level engagement

At the individual level, engagement integrates a person's values, experiences, and perspectives related to prevention, assessment and treatment, including managing their own health and wellbeing and selecting the best ways to engage with professionals and services. Individuals are empowered to make decisions about their own care and they are active participants in evaluating the care they received. Engagement here need not involve interaction with clinicians or other professionals. Individuals may also engage with a range of information resources and groups to initiate or sustain personal care preferences—for instance, seeking information about health, wellbeing and treatments, or participating in community-based self-management support groups.

1. Shared decision-making (SDM) tools

Purpose: To engage and give people control in decision-making about their own care. To engage family members to support the person.

Rationale: Shared decision-making interventions improve autonomy, information sharing, and collaborative decision-making; grants the person seeking care lower stress, a greater sense of control and better functional outcomes (32) (33).

Activities: 'Patient activation' (the person's knowledge, skill, and confidence to manage his or her health) interventions; information regarding own health and wellbeing; provision of relevant information about care options (33) (34).

Measurement (accountability):

- Independent observer rating of SDM: OPTION-scale (35, 36)– to assess the extent to which practitioners involve people in decision-making processes about their own care (available at: http://www.optioninstrument.org/uploads/2/4/0/4/24040341/option_12_rater_manual.pdf)
- Consumer self-report measure: CollaboRATE, a 3-item consumer-reported measure of SDM (37) available at http://www.collaboratescore.org/collaborate-measure.html

Measurement (outcome/impact):

- Patient Activation Measure-13 (PAM-13) (38) to assess the degree of patient activation. (Licensing information available at: http://www.insigniahealth.com/products/product-licensing)

2. Treatment preferences

Purpose: Allow for preferred ways of looking after own health and wellbeing with (or without) family/carer support.

Rationale: People are more motivated to attend to their own well-being if they feel like active participants in its management (39)

Activities: 'Decision Aids', provision of information and care options for individuals and their support network (40-42)

Measurement (accountability): Self-reported experience of being involved in treatment decision-making (43, 44)

Measurement (outcome/impact): Improved health and wellbeing as an objective measure

3. Self-help programs and tools

Purpose: Engage individuals in independent management of their own wellbeing

Rationale: There are fewer barriers to reach out to self-help programs than attend face-to-face or tele support.

Activities: Online resources, programs, networks, forums. Online resources for family members for both bereavement and concerns about a loved one; Patient accessible electronic health records (PAEHRs); 'Wellness Planner' - client-held medical record/crisis plan in booklet form (45-47) (48) (49) (50, 51) (52) (53)

Measurement (outcome/impact): Improved health and wellbeing, activation/enablement (54)

4. Satisfaction surveys

Purpose: Feedback, active engagement in improvement/evaluation.

Rationale: Surveys provide direct feedback from people attending services/programs

Activities: Online surveys, pen-and-paper surveys, instant feedback surveys at the service.

Measurement (accountability): Embedding of satisfaction survey in quality improvement processes with demonstrable plan for use of feedback.

Measurement (outcome/impact): Increase/decrease in patient satisfaction. Organisations to set a goal, cut-off score or percentage improvement.

Examples of validated scales from peer-reviewed literature:

- The Your Experience of Service (YES) questionnaire (55). Basic questionnaire consists of 28 items plus demographics. Includes some outcome questions (mental health recovery-based). Developed and evaluated through the National mental health consumer experiences of care project in Australia; project focused on extensive consumer involvement in survey development, testing and refinement. Designed for use in public mental health services in Australia. Licencing available at: https://mhsa.aihw.gov.au/committees/mhissc/YES-survey/;
- Client Satisfaction Questionnaires (CSQ) (56) Multiple lengths available (3-18 items). Requires permission of copyright holder and fees apply. Used widely internationally in inpatient and outpatient mental health, case management for severe mental illness, alcohol abuse programs, primary care, employee assistance programs and psycho-educational groups. http://www.csqscales.com/;
- Perceptions of Care (PoC) survey (57). Consists of 21 items. Developed at the McLean Hospital (USA) to understand acute mental health care experiences (inpatient and outpatient). Based on literature reviews, but tested and refined with consumer input. Requires permission to use and fees possibly apply. Licensing information available: http://ebasis.org/poc.php;
- Patient Perspective Survey (PPS). Consists of 38 items. Designed to encourage active involvement in healthcare consultations and increased satisfaction with general practitioners. Primarily tested with people with psychosocial or musculoskeletal conditions in primary health care. (58, 59);
- Patient Satisfaction questionnaire (PSQ) (60). Available in 18, 50 and 80 item versions. Language very oriented towards medical care. Freely available for use. http://www.rand.org/health/surveys_tools/psq.html

Most scales measure a combination of various dimensions of patient experience, including access to services, interpersonal communication and trust (61). These dimensions are applicable across a wide range of services.

Service/program level

At the service/program level of engagement, individuals with lived experience help design services, training programs, community campaigns, physical spaces such as health care facilities; serve on services' patient and family advisory councils; participate in the design and execution of treatments, services and quality improvement projects; and assist with staff hiring, training, and development.

5. Co-design of treatment/services/programs

Purpose: Involvement of individuals with lived experience at each stage of the development service/treatment/program from initial design to testing and evaluation (62) (62, 63) (64) (65)

Rationale: People who use the service will be experts in what they need from a service; they know what has worked and what has not.

Activities: Using co-researchers each stage of the project; co-design; re-design; Experience-Based Co-Design (EBCD) (66) (67) (45) (68) (69) (70) (71) (72) (73) (67) (45) (69) (71) (74) (75) (76) (77) (78).

Measurement (accountability): The percentage of programs that have been co-designed; the number or percentage of people with lived experience as part of the team.

Measurement (outcome/impact): Improved experience of services (79) (see satisfaction surveys under 4 above)

6. Reference groups, representatives in program/service delivery management

Purpose: To seek advice from individuals the programs are aiming to help.

Rationale: People who have used or who have aspired to use services are experts in the preferred ways of service/program delivery and/or management.

Activities: Ongoing 'lived experience' reference groups for general consultation; focus groups for specific projects; representatives in program management. (80) (75) (81) (82, 83) (83) (84, 85) (86)

Measurement (accountability): Percentage/number of representatives, percentage/number of programs/treatments that consult reference groups; interviews of representatives and group members of their experience of being involved

Measurement (outcome/impact): Improvement in specific programs (satisfaction, health outcomes)

7. Peer workers, peer-led services/programs

Purpose: To link people with lived experience with those who come in to contact with services/actively seek help.

Rationale: Peers are in a unique position to promote recovery, assist to find a pathway out of crisis and build a sense of connectedness. Thus, providing and receiving help from someone who has experienced a similar crisis provides a potential for empathy and role model of recovery (71).

Activities: Peer mentors/workers at each point of contact; peer-led programs that take place after or during formal treatment/intervention (87) (88) (89) (90, 91) (92) (93) (94) (95) (96) (97) (98).

Measurement (accountability): Number/percentage clients provided access to peer-worker, number of/increase in the peer-led programs, number/percentage of clients have access to such programs.

Measurement (outcome/impact): Improvements in measures such as suicidal ideation, social isolation, mental health (99)

8. Lived experience feedback, co-evaluation

Purpose: Translate feedback into quality improvement through formal mechanisms.

Rationale: Quality/service improvement should respond to the needs of people who use services in a direct and timely manner.

Activities: Regular 'survey-to-feedback-to-practical-measures' mechanism, interviews or focus-groups with targeted 'co-evaluators', 'quality improvement teams'. (100) (66) (62) (70) (37) (101) (102) (103) (72)

Measurement (accountability): Embedding of feedback/evaluation in quality improvement. Set goals for future satisfaction scores. (104)

- Developing Recovery Enhancing Environments Measure (DREEM) (105) provides a user-led structure, which enables services to measure their commitment to, and effectiveness in, providing recovery-based care.
- Consumer Evaluation of Mental Health Services (CEO-MHS (72)) a consumer constructed scale for a comprehensive service evaluation. This tool is constructed as well as designed to be used by service users.

Measurement (outcome/impact): Increase in program satisfaction (90, 106)

Organisation level

At the organisational level, engagement integrates a person's values, experiences, and perspectives into the design and governance of organisational practices. Individuals are engaged early, meaningfully and systematically at each level of the organisation; they are not token or single representatives. For example, people with lived experience will participate as decision-making members in continuous quality improvement teams, take part in hiring decisions, and develop and provide staff training.

9. Advisory group, representatives in committees/working groups

Purpose: People with lived experience responsible for high-level organisational design.

Rationale: A systematic approach to engage people with lived experience in all levels of organisational design. Suicide prevention organisations will benefit from unique insight of lived experience in designing organisational processes and products that better suit the needs of their target audience.

Activities: General expertise steering committees; specific advisory groups (for specific subject matters). (107) (108)

Measurement (accountability): Number/percentage of representatives; annual audits of the use of advisory committees

Measurement (outcome/impact): Regular interviews with representatives about their own experiences of being involved.

10. Lived experience-led executive boards, equal representation in decision-making events/bodies

Purpose: People with lived experience involved and responsible for high-level organisational decision-making.

Rationale: A systematic approach to engage people with lived experience in all levels of decision-making. Involving people with lived experience will hold the organisations accountable to the needs of people they exist to service.

Activities: Leaders and representatives in Board of Executives/committees, representatives in all decision-making bodies, Lived Experience governors, Lived Experience involvement in staff recruitment, Lived Experience posts in organisations. (109) (110) (32) (111)

Measurement (accountability): Equal number of representatives on boards; annual audits of the use of advisory committees; possible outcomes of engagement listed as part of the organisational structure and planning.

Measurement (outcome/impact): Regular interviews with people with lived experience representatives about their experiences of being involved.

11. Lived experience-led training for staff

Purpose: Provide staff insight in the lived experience of suicide (bereaved, concerned and attempt survivors) and its relevance to the organisational context (organisation specific).

Rationale: A systematic approach to engage people with lived experience in all levels of decision-making - organisations dealing with suicide prevention will benefit from the unique insight of lived experience in all levels of management. Provides people with lived experience the opportunity to take a position of expertise and power where they are listened to and respected (77).

Activities: Staff training for all levels of organisation by people with lived experience of suicide; workshops; themed events led by people with lived experience.

Measurement (accountability): Number of events/workshops/training a year.

Measurement (outcome/impact): Improved staff knowledge/understanding; improved experience/satisfaction.

12. Interviews with lived experience reps, regular audit of engagement activities

Purpose: To evaluate the engagement experience of people with lived experience on the organisational level to reflect on the experiences of the people involved.

Rationale: Meaningful engagement entails people having their voice heard and feeling that their involvement serves a real purpose.

Activities: Interviews with people with lived experience, formal annual audit of all engagement activities involving people with lived experience.

Measurement (accountability): Audit (annual/bi-annual).

Measurement (outcome/impact): Regular interviews/focus groups and feed back to the organisation

Policy/strategy level

At the policy/strategy level, engagement focuses on developing, implementing, and evaluating organisational suicide prevention policy and strategy. Engagement in policy/strategy helps ensure that the organisational system (including the ways in which the organisation collaborates and communicates between different levels) is oriented around and responsive to perspectives of people with lived experience. At this level, engagement may include single individuals as well as representatives of consumer organisations who speak on behalf of a general constituency.

13. Co-design of policy/strategy

Purpose: Involve people with lived experience in high level decision-making on strategic planning and policy development.

Rationale: Ensure that policy and strategy adequately and appropriately reflect the needs of people with lived experience.

Activities: Co-design of policy documents; workshops for policy development including people with lived experience. It is important to use different individuals for separate roles. For example general 'policy experts' for consultations across a range of activities should be separate to 'specific experts' for more focused strategies (112) (113).

Measurement (accountability): Goal for every piece of policy and organisational strategy to have at least (a number of) people involved in its development; this number depends on the context and needs to be carefully adjusted depending on the purpose of the policy or strategy.

Measurement (outcome/impact): Little guidance in the literature on measuring the impact of involvement at the policy/strategy level. (24) Policy impact itself is also difficult to measure. Could consider assessment by people with lived experience of the acceptability and relevance of co-designed versus other policies.

14. Regular review of policy and implementation by people with lived experience

Purpose: Involve people with lived experience in the evaluation of organisational strategy and policy

Rationale: People with lived experience have unique expertise on what type of policy/strategy is effective and appropriate in the context of suicide prevention

Activities: Annual reviews of policy by people with lived experience followed by focus groups/workshops for discussions and recommendations for quality improvement. Involving lived experience in individual amendments of policy/strategy

Measurement (accountability): Number of reviews annually; minimum number of reviewers with lived experience; formal mechanisms in place how to implement recommendations from the reviews.

Measurement (outcome/impact): Little guidance in the literature on measuring the impact of involvement at the policy/strategy level. (24) As for co-design, could consider assessment by people with lived experience of the acceptability and relevance of policies updated with lived experience input compared with pre-review versions.

Part 3. Research involvement

Model

This flexible model of involvement was originally developed by Dr Elspeth Macdonald for practice-based research networks and has most recently been applied to primary health care research involvement. (2) It was designed to facilitate involvement of various stakeholders in a health research project. Thinking about the various stakeholders with an interest in the LifeSpan project and its research outcomes and planning for their involvement will ensure the research makes the best contribution to ongoing implementation. The model is sufficiently general that it may also be adapted for use in an implementation context. The stages and stakeholders are substantially similar which would allow the use of the matrix for planning engagement in site and program implementation as well as research.

The model has three separate dimensions. When combined, these dimensions form an easy to use matrix to plan the involvement of stakeholders at the initiation of the project. The model is designed to break planning into manageable pieces and move away from black and white thinking such as "involve or not". Researchers are encouraged to involve stakeholders in the engagement planning process. This encourages thinking "outside the box" in terms of design and methods, giving stakeholders the opportunity to decide how they would like to contribute and reducing the chances of imposing the researchers' plans upon them.

The three dimensions are:

- The stakeholders to involve;
- The stages of the research at which they will be involved; and
- The level of involvement for each stakeholder group at each stage.

Stakeholders

The variety of stakeholders with an interest in actively participating in health research has variably been conceptualised as a puzzle with interlinking pieces or a wheel in the style of a pie graph (Figure 3.1 reproduced with permission from (3)). Both require all pieces (stakeholders) to be included to make a whole. The proposed model encourages researchers to think about which groups may wish to play an active role in a research project when they are formulating ideas and ideally develop those ideas in conjunction with the stakeholders. For example, a project to examine crisis care in the emergency department might consider involving people with a previous lived experience of crisis care, a range of emergency department staff involved in providing crisis care, other service providers who may be involved in care designed to prevent crises occurring and possibly administrators and policy makers who make decisions about the way care is funded and supported by policy. By considering and consulting with stakeholders *early* in the process, a solid basis for relevant research with greater likelihood of uptake is established.

Figure 3.1. The stakeholder wheel

Stages of research

The second dimension of the model follows what the NHMRC & CHF term the "quality improvement cycle" for research. (114) As illustrated in Figure 3.2, the cycle identifies the broad stages of the research process, all of which offer specific opportunities for stakeholder involvement. The stages are not exhaustive or necessarily mutually exclusive, but they offer a guide to the research process which may be more useful than thinking of a project as a whole entity. The NHMRC & CHF offer some suggestions on putting involvement into practice at each stage and the responsibilities or questions that researchers and other stakeholders may wish to address.

Figure 3.2. The research cycle

(114) Anne McKenzie of the University of Western Australia and Telethon Kids' Institute has further developed extensive materials targeting specific strategies for each of these research stages, offering practical tools and ideas to guide planning (see www.involvingpeopleinresearch.org.au).

Level of involvement

The final dimension of the model is the level of involvement of each stakeholder group. As described in the introduction to this report, the literature often describes involvement as a ladder from low to high or along a continuum. As illustrated in Figure 3.3, our model draws on the idea of a continuum, with the addition of markers indicating the amount of involvement. The markers can be easily transferred to the planning matrix as discussed in the next section.
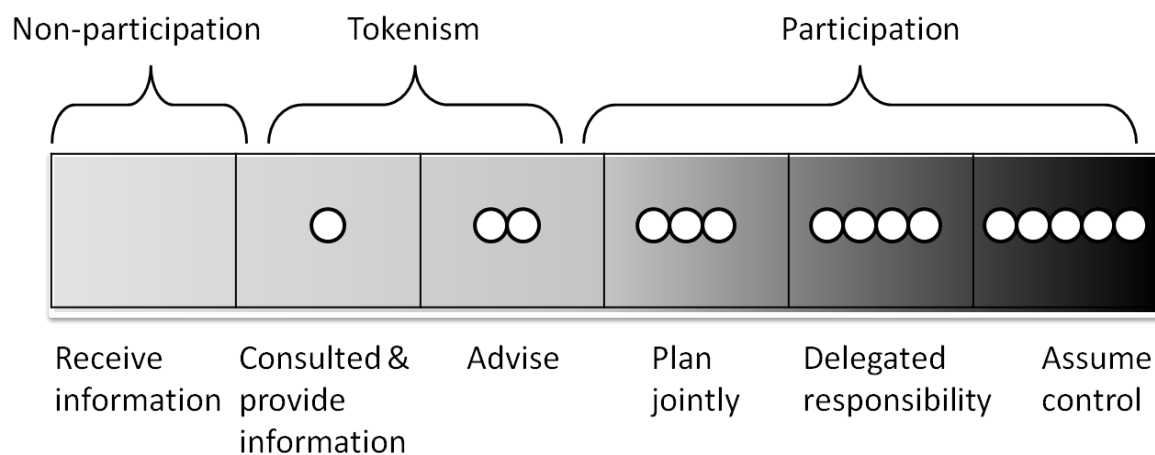
Figure 3.3. Continuum of involvement

The original model as developed by Dr MacDonald included stars as markers, but these may be misinterpreted as value judgments (e.g., five stars are better than four stars) when in fact the markers simply illustrate the increasing amount of involvement. The "best" involvement is that which is appropriate to the project as well as the skills and experience with collaborative research of all stakeholders including the researchers. This is not always at the highest end of the scale.

The model matrix

When the first two dimensions of the proposed model are combined, they form a blank table matrix into which research planners can insert the level of involvement markers to complete the plan of involvement in their project (Figure 3.4).

Stakeholders

Deciding what to research				
Deciding how to do it				
Doing it				
Letting people know the results				
Knowing what to do next				

(row labels shown above appear under the vertical axis label "Stages")

Figure 3.4. Stakeholder involvement matrix

An example

Figure 3.5 represents a fictitious example of how a completed plan for a project with a service focus may look. In this example, there is joint planning between all stakeholder groups when deciding what to research. This might include asking stakeholders to identify practice and/or policy problems and assist in developing the proposal.

Researchers have greater responsibility for deciding on methods and carrying out the project in this plan, with some consultation and advice from stakeholders. If a project is methodologically complex, it may not be practical to have a greater degree of involvement of non-researchers at these stages of research, but it is still important to seek advice on issues such as data collection methods that are sensitive to participants and the acceptability of information sheets. A recent study on clinical trial information sheets in the UK found that 66% of participants showed understanding of all aspects of the trial when provided with an information sheet revised by consumers, compared with only 15% of participants given the original sheet. (115)

Consumers and practitioners have more responsibility when the research findings are disseminated in the example plan. This is a key way to effect broad dissemination of results for translation into effective practice. Stakeholders could help collate the study findings in a format that is accessible to other professionals or consumers and facilitate actions such as distribution to networks and presentations to stakeholder groups.

Completing the cycle (and beginning a new cycle) with decisions on the next steps such as implementation plans and further research is again a joint planning process. This stage is particularly amenable to actions such as roundtable discussions and interactive

workshops. However, care must be taken to ensure that power imbalances and tensions are skilfully managed by including more than one representative of disempowered groups like consumers and possibly the use of a professional facilitator.

	Consumers	Practitioners	Policy advisers	Researchers
Deciding what to do	OOO	OOO	OOO	OOO
Deciding how to do it	OO	OO	OO	OOOO
Doing it	OO	OO	OO	OOOO
Letting people know the results	OOOO	OOOO	OOO	OOO
Knowing what to do	OOO	OOO	OOO	OOO

Figure 3.5. Example stakeholder involvement plan

A key feature of the proposed model is flexibility. Researchers are not constrained by applying one level of involvement to their entire project or to all the involved stakeholders. Further, the plan should not be considered as fixed, but rather to be modifiable throughout the course of the research if necessary. For example, if consumers showed particular interest in data collection and capacity existed to train them, it would be possible to update the above plan to reflect delegated responsibility for consumers in carrying out the research.

Finally, the proposed model is designed to encourage researchers to think about their own capabilities in managing the involvement process and design a project that maximises the opportunity of all to succeed. Many researchers strongly support stakeholder involvement in research but feel they do not have sufficient experience and skills to undertake higher level involvement such as employing a consumer researcher. The proposed model allows these researchers to start with involvement in specific parts of their research and build on their successes in a continual cycle of improvement and extension.

Practical strategies and impact

A recent systematic review undertaken by Brett and colleagues (116) aimed to identify the impact of research involvement across all the key stages of the research process. The review included 66 studies and concluded that whilst there is evidence of impact across the research process, much of the evidence is weak and requires enhancement. In the initial stages of research such as choosing the topic and designing the research, the review found positive effects of involving people with lived experience in prioritising research topics for the agenda and in developing research questions relevant to the group targeted by the research. (116) When undertaking projects, the evidence supported comment and pragmatic criticism on research protocols and measures including appropriateness of design from consumer perspectives and assistance with language for a lay audience. (116)

Knapp and colleagues (115) provide a particularly thought-provoking example of the effect of consumer involvement in adjusting the language in a clinical trial participant information sheet. Concerned that participants were not providing true informed consent when agreeing to participate in a trial for acute myeloid leukaemia in the UK, the authors redeveloped the information sheet with the assistance of a consumer group. In a subsequent randomised controlled trial to compare understanding of the trial by people who received the original participant information sheet with those who received the redeveloped version, they found 66% of people who received the redeveloped sheet could demonstrate understanding of the trial versus 15% of those who received the original. Further, 87% of people said they preferred the redeveloped version.

Brett et al (116) also found evidence to support active involvement of people with lived experience of a condition or illness as interviewers. Studies found that there was greater rapport provided by a shared understanding, resulting in participants reporting better resonance of questions and a more honest flow of information. Similarly, at analysis and write-up, involving non-researchers brought different perspectives to the interpretation of findings, helping to seat results in gaps relevant to clinical and community interests. This also applied to dissemination of results: community connections provided influence when results were released and implemented. (116)

The review also identified a number of challenges across the research process. In the initial stages, tensions between user-friendly versus scientifically rigorous methods sometimes resulted in power struggles and tokenism. Researchers also reported difficulty in recruiting and retaining a range of people to involve, particularly when it was not clear how the consumers' input was being used in the project. Many researchers also struggled with the additional time and cost of managing consumer involvement within the limitations of a study. (116)

Part 4. Supporting engagement

Box 4.1 Guiding principles for effective engagement

- Engagement needs to be appropriate – don't set people up to fail, so consider
  - Skills of the people offering the engagement opportunity
  - Skills of the people being engaged
- Build in plenty of time and resources for engagement – it should be central to program and research design, not an afterthought
  - Ensure people involved in your work are not out-of-pocket (reimburse costs)
- Shared expectations are crucial to a good experiences for all parties
  - Document your own assumptions about engagement, what you want from the process, boundaries of things that cannot be altered and areas of flexibility
  - Document the same for the people being engaged
  - Invest time discussing documented positions to reach a shared understanding
- Be prepared to negotiate and ensure you are in a position to use the feedback provided: it is tokenistic to consult people with lived experience if you are unwilling or unable to use their recommendations

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A final consideration for effective engagement is how to best support the process and maximise the chance for people with a lived experience to have a positive experience of being involved. The literature on supporting engagement focuses on general principles which should be elaborated for each engagement exercise rather than specific strategies which may not apply in all contexts. These principles are summarised in Box 4.1. (2, 3, 12, 114, 118)

As described in the introduction to this report, good planning underpins successful engagement. Taking the time to identify expectations and the support needs of both the people running the project and the people they wish to engage are key factors in creating a successful partnership. For example, health consumers in Telford and colleagues' (118) consensus study on successful research involvement agreed that consumers should be offered training and mentoring that *they* identified as necessary during discussions at the beginning of each research project, and that researchers should also identify their own training needs to support engagement. In the Australian context, this may entail offering consumers and researchers a short workshop such as that offered by the Consumer & Community Health Research Network

(www.involvingpeopleinresearch.org.au) or through ACACIA: The ACT Consumer & Community Mental Health Research Unit (http://cmhr.anu.edu.au/acacia). Assigning a research mentor experienced in conducting participatory projects who can facilitate understanding between researchers and consumers is another good method and builds capacity both with researchers and people with lived experience.

Outside the research context, engaging with consumer and community organisations and peak bodies that have representative programs is a good way of accessing people who have received training in contributing to services and policy, and usually have added support from their organisation to facilitate engagement. Initiatives such as the Suicide Prevention Australia Lived Experience Network or Health Consumers NSW Consumer Representatives Program help people with lived experience contribute from both their own personal perspective and a broader representative view. It can be useful to approach these organisations as a source of people who may have an interest in being engaged; however, it is also worthwhile establishing ongoing relationships with organisations so that people from the community without training or established membership can be directed to these sources of training and support. With larger scale projects, it may also be possible to establish workshops that are somewhat tailored to the processes in which people will be specifically engaged. This would require adequate resourcing to ensure the community organisations were not bearing extra cost.

One criticism often levelled at training and mentoring of people with lived experience is that it may result in "professionalising" of their views and potentially loss of some of their unique perspective. (116) Whilst it is important to acknowledge this risk, it should not be a reason not to offer training and support. Representative and research training for people with lived experience is generally aimed at increasing people's understanding of the health system and research so that they can contribute with confidence amongst clinicians, decision-makers and researchers. The risk of only engaging "professional" consumers can be mitigated by deliberate engagement with a range of people, both experienced and new to active involvement in each project.

A final consideration in supporting engagement is financial recognition for contributions. The literature reflects agreement that people with lived experience engaged in projects should at a minimum have any costs incurred reimbursed, including indirect costs such as carer support (114, 118) and this is also an expectation of community organisations providing representatives. However, any further financial compensation such as sitting fees or incentives should be considered on a case-by-case basis and agreed with individuals engaging with the project. Ethical conduct of research requires that any incentive offered should be commensurate with what is being asked of participants, and this can be extended to offers made to people who are actively engaging with a project's

processes. However, payments such as sitting fees can have taxation implications and should therefore always be agreed with individuals.

With careful thought and planning, engagement can be a rich and positive experience for all concerned. Most negatives reported in the literature such as unmet expectations reflect a failure to plan rather than a failure of the process. Investing the time to discuss the "who", "how" and "how much" of engagement in a collaborative way and being open to change will maximise the chances of success.

Appendix 1: Inclusion and exclusion criteria

Search generated 5147 articles to be screened (title and abstract)

SPLIT FOR SCREENING on EndNote, 3 researchers screening **-** each record will be screened by one of three researchers, record numbers for each researcher as follows:

AS: 1-1250, 2001-2500

BF 2501-3800, 4001-5000

OF 1250-2000, 3800-4000

AG screened 1300 records in alphabetical order for records 1-1250, 2501-3750 for discussion of consistency and refining of criteria

SCREENING CRITERIA 16/11/216

Inclusion:

1. ANY mention of *framework* OR *strategies* for **engagement/involvement** of consumers with "lived experience" in one or more areas related to the service
    a. design and development
    b. governance
    c. delivery
    d. evaluation of services
2. Evaluations of the *framework* OR *strategies* for **engagement/involvement** of consumers with "lived experience"
3. 'Health' and 'mental health' -related
4. Empirical papers only

Exclusion:

1. Commentaries
2. Editorials
3. Policy papers
4. Evaluations of treatment outcomes/trials (unless interventions specifically targeting engagement to a-d)
5. Treatment adherence studies
-

Additional limits to make criteria stricter added 22/11/16

(1) Is an engagement strategy used (not just mentioned)

(2) Which strategy is mentioned as the primary strategy □ drag to a relevant group (also 'other' and 'multiples' available where this is not clear)

Additional limits 24/11/16

Include studies that use engagement strategy ONLY if they include the implementation of the results.

Examples;

- Study uses a consumer focus group as a strategy in the design of new program for depression INCLUDED

- Study uses a consumer focus group to evaluate the efficacy of depression treatment NOT INCLUDED

Appendix 2: Grey literature

					AUSTRALIA					
Score*	**Organisation**	**Framework/ source**	**"Aim" or purpose of the organisation**	**Engagement strategies**	**Individual**	**Service**	**Organisation**	**Strategy**	**Evidence of effectiveness /accountability measures**
5	**Roses in the Ocean**	http://rosesintheocean.com.au/lived-experience-suicide/	Works with suicide prevention experts in research, policy and service delivery to innovate better options to support those who are struggling to find a life worth living.	- Members with lived experience on board of directors - Roses Radio - Trainers and facilitators deliver a range of training programs and workshops informed by their personal story of suicide and that of the members of the Lived Experience Collective. - Suicide Prevention Speakers Hub - Aids in the design of suicide prevention reference groups for other organisations - Lived Experience Collective comprising lived experience champions across Australia **The following programs:** - "Voices of In-Sight" workshop - "Our Voice" –capacity building workshop - "Our Voice Reference Groups" - Lived Experience Reference Group - Host an Awareness Event Workshop - "Living Perspective of Suicide" – workshop	x	x	x	x	An advisory body consisting of people with a lived experience is written in in the **governance structure** of the organisation

				- "Media Training" - 'Living Perspectives of Suicide" – workshop					
5	**MIND**	*Enhancing Consumer Engagement: A framework for action* https://www.mindaustralia.org.au/assets/docs/Enhancing%20Consumer%20Engagement%20Framework%2011_11.pdf	Provider of community mental health services	- Establishment of Consumer Family and Carer and Peer Engagement (CFC&PE) unit. - **Training and mentoring package** to all clients that support consumers participate formally and informally - **Consumers' Skills Bank** — matching consumers to paid referent and speaking opportunities - Co-design of **Resource Kit** to resource clients who wish to participate and contribute to organisation's processes. - *The Vine* - an organisation-wide client focused **newsletter** - Opportunities for **client feedback** – client satisfaction surveys - **Formal feedback mechanisms** through technology - Structured feedback into existing processes - **Peer-programs** - Peer support groups - Peer-led groups - Peers on line (eService) - Peer warm lines (phone line) - Peer volunteers - Area based **client forums and peer workers** - **Client focus groups**	x	x	x	x	- **Integrate consumer engagement** into the organisation's Research and Evaluation framework - Undertake **evaluations of specific actions** (such as peer training) - **Disseminate learning** through publications and presentations

				- Sponsor selected clients to attend **national and international forums**					
5	**Headspace**	*Clinical Governance Framework* https://headspace.org.au/assets/EOI/ATTACHMENT-C-headspace-Clinical-Governance-Framework.pdf	National youth mental health organisation, provides early intervention mental health services to 12-25 year olds	- Headspace Youth National Reference group (hY NRG) https://www.headspace.org.au/about-us/headspace-youth-national-reference-group/ - **Training for hY NRG members** which maximise youth participation and representation - Supervision and mentoring of hY NRG Members - **Family and friends advisors** (family or friend of someone who has sought help from Headspace) - **Involvement of family and friends** in the development, planning, delivery, and evaluation of mental health services	x	x	x	x	- Evaluation of hY NRG headspace - Independent Evaluation - Ongoing internal evaluation - including data monitoring - Family and Friends Subcommittee Service - Activity Data - Centre Work plans - **Headspace independent evaluation**
5	**The Mental Illness Fellowship of Australia**	*Carer and Consumer Participation Framework* http://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0006/1391505/carer_and_consumer_particip	National network of mental health based membership organisations. Provides support through local services	**INFORM** - Through Mi Recovery, Well ways, factsheets, newsletters, resources **CONSULT** - Consumer and Carer Advisory Committee on practice improvement, individual participation plans, Focus Groups, Surveys, Involvement in developing evaluation **INVOLVE** - Staff orientation, planning, interviewing and training; Peer workforce, PHAMS employment, Home Based Outreach, Helpline; Respite services; Volunteer in OP shops	x	x	x	x	**Benchmarking and linkages**: - develop performance measures that assist in measuring the effectiveness of carer engagement and facilitate benchmarking opportunities for quality improvement

		ation_framework_2014.pdf		**COLLABORATE** - Involvement in organisational strategy and governance, Doorway, Co-design and Evaluate Programs; Choir, Brainwaves & Speakers Bureau; Peers on interview panels; NDIA services purchased by consumers **CONSUMER & CARER LED** - Drive personal wellbeing and recovery process; Govern, design and deliver services; Mental Health Advocacy					
5	**QLD Health**	*Consumer and community engagement strategy 2016-18* (Townsville Hospital) https://www.health.qld.gov.au/townsville/Documents/executive/thhs-engage-con-com.pdf	QLD state government health organisation	- "Partners in Healthcare" quarterly **newsletter** distributed to patients and the community - **Newspaper articles** informing the community about progress related to the re-introduction of birthing services in Ingham - "Big Smiles" annual preschool oral health **awareness activities** - Adult Acute Mental Health Inpatient Unit **consumer forums** - Annual maternity services **survey** - Patient and family **interviews** related to changes to inpatient visiting practices - Consumer perspectives **workshop** - Attendance of THHS staff at the local Intercultural Services Meeting - **Consumers reviewing patient brochures** in the THHS Patient Information and Health Literacy Meeting - Consumers on the End of Life Program Board	x	x	x	x	- Reporting on consumer and community engagement activities through routine service reporting schedules - Evaluation of the six THHS Consumer and Community Engagement Principles - Feedback and consultation from consumers, communities and staff - Measurement against formal standards

				- **Consumer surveyors** during the annual Queensland Bedside Audit - **Co-development** of patient information with consumers for the Adult Acute Inpatient Mental Health Unit - **Consumer Advisory Network** meetings in the Rural Service Group - **Co-design** of Ingham Birthing Services with local community members - **(Committees):** Consumer members on the THHS Clinical Governance Committee, Healthcare Standards Committee, Research Development Committee, Person Centred Care Meeting etc. - **Consumer participation** on the planning group for the Child and Youth Services Strategy - Consumers as members of **interview panels** for staff in mental health services. - **Community membership on the Board**.					
5	**Tasmanian Government's Department of Human Health and Services**	*Consumer and Carer Participation Framework* http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0010/63586/Consumer	Tasmanian state government health organisation	**Lists very generic policy interventions (page 12):** - Direct involvement with service provider in development of individual plans - Participation in case conferences with service providers - Family/carer meetings with service provider - Workers e.g. consumer consultant, carer consultant, peer support worker in Mental	x	x	x	x	- Regular public meetings with engaged consumers and carers - Providing feedback to consumer about how their participation is being used

		_and_Carer_P articipation_Fr amework.pdf		Health Services and non-government organisation services - Consumer advisory groups set up within services and programs - Consultation processes e.g. when new services are being set up - Delegated representative at planning meetings, in reference and working groups for projects, on job selection panels as appropriate - Reviewer in accreditation processes - Workers e.g. consumer consultant, carer consultant, peer support worker in Mental Health Services and non-government organisation services - Representative on Mental Health Services state-wide management group, on policy working groups, in Accreditation processes, on national policy forums - Specific programs designed to make social environments more consumer-friendly (e.g. government working parties to improve access to sport or employment programs - Representative on Ministerial Advisory Group or through peak body					
5	**State Government of Victoria, Department of Health**	*Doing it with us not for us – Strategic direction 2010–13*	Victorian government health organisation	**Individual level** - Accessible information to consumers - Resources through consumer/carer engagement - Well-written health information based on: *A guide in the development of health information*	x	x	x	x	**Participation standards and associated indicators (in detail p 12), for example:** **Indicator 2.3 *Community health services:***

		file:///C:/Users/u4671994/Downloads/1104007_DIWUNFU_StratDirection_FA3_web%20-%20PDF%20(1).pdf		**Program or departmental level** - Training to staff in communication skills and how to involve consumers and carers in decision making - Promote the importance of consumers and carers providing feedback to improve services - Links with community organisations to provide emotional support and ongoing information to consumers - Involve consumers in the development of clinical guidelines and research. - Use consumer experience and satisfaction surveys to improve service delivery **Health service organisational level** - Resource consumer/carer participation in developing and reviewing strategic plans, designs, annual reports, and action plans - Resource consumers, carers and community members to participate on your quality, ethics, and governance committees **Department of Health level** - Training and education to staff on how to use evidence based consumer/carer engagement strategies.					- **Numerator:** The percentage of clients/carers satisfied or highly satisfied with their involvement in decisions about their care or treatment - **Denominator:** The total number of clients/carers who participated in consumer/carer surveys - **Target for community health services is 90%** Percentage goals and outcomes are discussed for the publication or consumer engagement resources and the participation of consumers in decision making (measured by number of publications, and number of activities involving consumers/carers in decision making).
5	**SA Health**	*Caring Together – An Action Plan for Carer Involvement in Victorian*	SA state government health organisation	- Family sensitive training - Respite for carers available as planned - Direct support for carers of people with a mental illness through the carer support program	x	x	x	x	- Carer feedback consumer file - Outcome measurement data - Development of local carer information/support kits and associated distribution data

| | | *Public Mental Health Services* http://tandemcarers.org.au/images/Resources/State%20Gov/Caring_Together.pdf | | - Carer support and resource workers located in metropolitan and rural Victoria
- Funding of carers of people with a mental illness (organisation, carer network, advocacy group?)
- Funding of Koori support (carer support program)
- Creation of a part time academic position for a person with lived experience
- Consultation with carer advisory committees
- Resource kit for carers
- Website with directory of public mental health services, links, and relevant resources
- Carer representatives for mental health initiatives
- Carer-led research
- Website to provide information about carer engagement
- Funding of carer advocacy networks
- Encourage carer participation in undergraduate/pre-service and in-service training of mental health staff, police and other relevant professions.
- Conduct education sessions on the impact of mental illness on families and friends
- Create a new information toolkit
- Carer information sessions for local areas
- Discussion groups, carer representatives on committees, formal internal complains mechanisms, carer input into staff in-service | | | | | - Clinical audit of individual carer plan development
- Carer Participation Plan
- National Survey of Mental Health Services (to 2004-05) and the Mental Health Establishments National Minimum dataset (from 2005-06)
- National Standards for Mental Health Services Monitoring and analysis of Carer Experience Survey
- Clinical service reviews
- Documentation and other reports on carer consultations and strategies developed/local carer participation plans
- Progress and evaluation report on the above framework |

				- training, planning, delivery through to evaluation - Creation of a formal carer participation policy					
5	**National Mental Health Consumer and Carer Forum**	*Consumer and Carer Participation Policy* http://nmhccf.org.au/publication/consumer-and-carer-participation-policy	Consumer advocacy organisation aiming to give consumers and carers a united, national voice	- Satisfaction and evaluation surveys - Focus groups - Support groups - Regular meetings with local, State / Territory representatives - Public, private, and non-government community advisory groups - Newsletters - Mental health consumer and carer networks - Meetings with senior management - Websites - Consumer and carer representation on steering committees - Reference groups - State / Territory ministerial committees	x	x	x	x	**Page 16:** An evaluation and ongoing review process of consumer and carer participation will occur annually within all public, private, and non-government mental health organisations, to ensure sound principles and practices are maintained and mental health organisations remain accountable for their actions. This may occur in conjunction with continuous quality improvement processes and accreditation against the National Standards for Mental Health Services.
5	**EACH Social and Community Health**	*Consumer, Carer and Community Engagement Framework* http://www.each.com.au/wp-content/uploads/2016/03/CC	Provides health, disability, counselling and community mental health services across Australia	- Consumer engagement working group - Develop a consumer, carer and community engagement framework - Newsletters, brochures, intranet networks - Advisory group with input at the organisational and strategic levels - Use marketing strategy to invite consumers and carers to advisory committee - Multiple feedback collection strategies (none actually listed)	x	x	x	x	**Page 19:** A list of measurable targets, e.g. ''the consumer engagement working group will be successful if it meets a certain number of times a year, is established before a certain date, etc.''

					x	x	x	x	
		C-framework.pdf		- Map all existing consumer, carer and community engagement activities across each professional training for staff in consumer engagement - Create a consumer, carer, and community engagement feedback database					
5	**Prahran Mission**	*Carer Participation and Involvement Strategy 2012-2014* http://tandemcarers.org.au/images/Prahran%20Mission%20Carer%20Participation%20and%20Involvement%20Strategy%202012-2014%20-%20FINAL.pdf	Agency of the Uniting Church in Australia, provides rehabilitation services to those experiencing mental illness	- Individual level engagement: consumer involvement in treatment, care planning & decision making - Develop and implement carer identification policy, procedures and pro formas - Provide orientation for all new staff regarding carer engagement - Develop protocol for communication between workers/management and carers - Provide training to staff on issues of engagement, confidentiality and consent - Develop generic carer information pack in consultation with carer representation organisations - Carer newsletter, handbook and manual - Source carer representation from all program areas and develop an advisory group: "Advisory Group will be formulated to ground carer needs in practice and to advise on the development of policy, processes and procedures, and to develop the CC/CL role and position description, and recruit to it"	x	x	x	x	**Pages 19-20.** Very detailed and organisation specific. In general **checklists, formal guidelines and principles that spell out the organisation's general expectations of consumer engagement, protocol on information delivery, orientation processes**, **updating case management documentation, checklists, surveys, and evaluation forms** The table on page 32 mentions that an **advisory group** could provide accountability.

5	**Agency for Clinical Excellence**	*Patient Experience and Consumer Engagement: a framework for action* https://www.aci.health.nsw.gov.au/networks/peace	Works with clinicians, consumers and managers to design and promote better healthcare for NSW	**Extensive list of possible interventions and suggestions for cultural/organisational change, starting on page 9. For example:** - Surveys, patient stories and interviews, rounding, patient experience videos, focus groups, co-design, patient-reported outcome measures, patient reported-experience measures, patient experience trackers **Discusses and provides examples for all four levels of engagement (five levels in this framework)**	x	x	x	x	**Page 14 recommends:** - an annual review of the volume of projects the PEACE (patient experience and consumer engagement) team has been involved in, from basic involvement through to more complex involvement. - measurement of website traffic (internal and external) and website analytics (user location, frequent users, and searches). - development of new toolkits - NGO's and community group member consultation, projects involved in and level of contributions - Survey of consumers engaged with ACI
5	**Australian Commission on Safety and Quality in Healthcare**	*Development of a Consumer Engagement Statement for the Commission*	Australian government commission: leads and coordinates national improvements in safety and	**Australian Commission on Safety and Quality in Healthcare conducted consultations on the development of a consumer engagement framework. Key practical measures discussed/recommended during the consultation process included:**	x	x	x	x	**Report acknowledges that evaluation is a general issue with consumer engagement. Does suggest that evaluation is of critical importance, and that it should cover outcomes, practice, process and**

		https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Development-of-a-consumer-engagement-statement-for-the-Commission.pdf	quality in health care	- supporting consumers meeting together to facilitate learning and capacity building - establishing a **database** of all consumer representative groups - building the capacity of **consumer representative bodies**, including through specific funding of their projects - establishing a **consumer participation clearinghouse** or resources collection, to build capacity and raise the profile of consumer research - annual or biannual **conferences** on safety and quality - **support consumers to give papers** at conferences - build on existing consumer and community groups - **phone line** for consumers to provide feedback to the commission - consumers on **project advisory** groups - consumers within the **governance structure** of the organisation					**management of policies and initiatives**.
5	**Central Victorian Primary Care Partnership**	*Consumer Engagement in Central Victoria – a literature review for health and*	Primary care partnership supporting health and community services to collaborate for	**Recommendations from the lit review Strategies mentioned in table on page 30:** **Individual level**: Question prompt list, information packages, chronic disease self-management groups, shared decision making tools	x	x	x	x	Various examples of formal consumer engagement tools are listed (page 31): - The partnership self-assessment tools (USA)

		community services http://centralvicpcp.com.au/wp-content/uploads/2015/02/Consumer-Engagement-Literature-Review-2015.pdf	improved community health and wellbeing	**Program level**: involvement of consumers on committees and reference groups **Organisational level**: community advisory committees and community councils **Government level:** legislation, policy and resources are being created to guide the implementation of community participation **Community level:** citizen juries, interviews, surveys, focus groups, public forms, advocacy groups					- Patient based care challenge (Aus.) - Well Connected (UK) - Community participation evaluation tool (South Australian Community Health Research Unit) **Also discusses other less formal evaluation methods, such as document reviews, annual reports, media coverage, informal feedback, surveys, etc.**
4	**National Mental Health Commission**	*Participation and Engagement Framework* http://www.mentalhealthcommission.gov.au/media/79498/FINAL%20PEF%20-%2011%20September%202013.pdf	National government commission: aims to bring attention to mental health and suicide prevention and influence policy reform	- Co-chaired expert groups - Involving people with a lived experience of mental illness in commission events - Community forums at all commission meetings - Workshops, forums and surveys - Reaching out to members of the public through: - Engagement with consumer representatives and peak bodies - Targeted media engagement - Social media campaigns - Peer support strategies	x	x		x	Consumer engagement measures include the following (Page 14): - The number of stakeholders participating in key projects - Number of people reached who may be isolated by distance, discrimination, lack of resources or other barriers - Whether other organisations adopt our participation and engagement framework

| 4 | Self Help Addiction Resource Centre | *Straight from the Source: A practical guide to consumer participation in the Victorian alcohol and other drugs sector*

 http://sharc.org.au/wp-content/uploads/2014/02/NP69876-APSU.pdf | Promotes self-help approaches to recovery from severe alcohol and drug related issues | - Suggestion boxes
 - Provision of information (noticeboards, newsletters, pamphlets, handbooks, etc.)
 - Consumer rights, (charters, formal policies, accountability mechanisms, etc.)
 - Informal and formal complaints mechanisms
 - Client feedback mechanisms
 - Surveys
 - Interviews
 - Focus groups
 - Service user groups
 - Service user advisory groups
 - Peer workforce, peers in service delivery
 - Quality assurance
 - Strategic planning
 - Consumers on committees, organisational committees and reference groups and boards of management
 - Consumer-led training | x | x | x | | **Participation guidelines** for recruiting new staff:

 - Consumers to actively contribute to the discussion during the short-listing of applicants
 - Consumers to participate in the development of questions
 - Consumers to directly question the interviewee
 - Consumers to participate in post interview discussion
 -
 Specific mechanisms for feedback:

 - Reports and reflective evaluations
 - Journal
 - Feedback forms
 - Focus groups |
| 4 | **ACT Health** | *Consumer and Carer Participation Framework* http://health.act.gov.au/node/2053 | ACT state government health organisation | - **Call centre (health direct), online portal, websites**, annual reports, the provision of **health service directories** and the running of **health campaigns**
 - **Patient journeys** recorded and shared with staff
 - ACT Healthcare Consumer Satisfaction **Survey**
 - Consumer **needs analysis** | x | x | | x | HEALTH DIRECTORATE

 - Listening and Learning: Consumer Feedback Policy and Standards
 - Implementation of the Australian Charter of Healthcare Rights and |

				- **Consultation** with consumer and carers prior to major developments (such as the design of a new hospital) and consumer consultation on the development of **resources, guidelines and campaign materials** - Regular meetings of a **User Group** to advise on the redevelopment of the Neonatal Department - ACT Listening and Learning Standards detail quality processes for managing consumer initiated **feedback** - Consumers and **peak agencies** participate in annual ACT Budget consultation - **Consumers involved** in accreditation processes in line with Australian Council on Healthcare Standards - PatCH **Consumer Network** assists with developing **Patient Held Records** (PHR) that contain a parent-driven summary of medical records - **Funding** of mental health consumer groups - Family initiated medical emergency team **call line** - Consumers involved in various **committees** - **Respecting Patient Choices** program allows patients to document decisions about their future health care - Opening of West Belconnen Health Cooperative provides **consumer controlled health services**				Charter on the Rights of Children and Young People in Healthcare Services in Australia - Consumer, Carer and Community Representative Program and Reimbursement Policy - Relationships with consumer advocacy agencies through service funding agreements; and - Respecting Patient's Choices. - REPORTING THROUGH - Annual Reporting - Implementing and reporting on specific frameworks and policies such as the *Consumer Feedback Management Policy*, the *Mental Health Consumer and Carer Framework* - Assessment and accreditation against the National Safety and Quality Health Service Standards

				- Mental health consumers employed as **consumer advocates & consultants** - Expansion of jointly-owned & democratically-controlled **health care co-operatives** across ACT - Winnunga Nimmityjah Aboriginal Health services funded as an Aboriginal **community controlled health organisation**					
4	**QLD Health**	*CALD Consumer Participation and Mental Health*	QLD state government health organisation	- Reference Group - National Advisory Group provides expert advice in regard to consumer participation to people with CALD background - Workshops - Information resources to increase health literacy of CALD communities - Engagement with CALD community leaders - Media campaigns - Consumer groups to provide input into a model of CALD participation in mental health	x	x		x	**Various indicators are used throughout the document. Examples of indicators for the assessment of communication with consumers and community:** - The wealth of comments, input and feedback that is collected from consumers - The expressions of interest from consumers to continue participation/actual participation - Low levels of attrition from consumer sessions - Quality of input gathered from employed consumer workers who are members of these communities

					x	x	x		The quality of input gathered from the bilingual workers employed - The quality of linkages with leaders
4	**NSW Government Health**	*Guideline to Consumer Participation in NSW Drug and Alcohol Services* http://www0.health.nsw.gov.au/policies/gl/2015/pdf/GL2015_006.pdf	Runs various programs and services treating drug and alcohol related health issues in NSW	- Involving service users in individual treatment plans - Consumer representatives/advocates - Advisory committees - Consultations with potential service users - Complaints mechanisms - Focus groups - Consumer feedback surveys, (online, consumer experience trackers, paper passed, etc.)	x	x	x		**Some accountability mechanisms and evaluation frameworks within the case studies:** CASE STUDY: INCREASING ENGAGEMENT WITH CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) CONSUMERS — DRUG AND ALCOHOL MULTICULTURAL EDUCATION CENTRE (DAMEC) SYDNEY - Paper-based surveys to be filled in on exit or posted to consumer's homes after exit - Online surveys on applications such as Survey Monkey and/or in computers in reception areas. (Note that such options are not possible in a custodial setting where

									consumers do not have Internet access.) - Telephone surveys of consumers after exit. n Hand-held devices fixed in services, such as Patient Experience Trackers (PET) (see the Case Study: Hunter New England LHD PET NGO CASE STUDY: KAMIRA DRUG AND ALCOHOL REHABILITATION FACILITY FOR WOMEN - Evaluation groups are held every five weeks on different parts of the program and every week in the activities of that week. Program planning days also occur every quarter, which involve reviewing all jobs, rules, group topics, and timetables, as well as planning for gardening and other extra-curricular activities.
4	**SA Health**	*Guide for Engaging with*	SA state government	- Surveys - In-depth interviews	x	x	x		**Measurable goals and outcomes:**

| | | *Consumers and the Community*

http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Guide+for+Engaging+with+Consumers+and+the+Community_June2016.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9 | health organisation | - Focus groups
- Public meetings and forums
- Consumer representatives on
- Committees
- Workshops | | | | | - Measuring consumer experience (feedback forms, surveys, etc.)
- Committee terms of reference, membership, selection criteria, papers, minutes demonstrate consumer engagement in strategic and operational planning
- Consultation processes held with consumers and community and feedback documented. Input is incorporated into strategic and operational planning process.
- Planning day or forum with consumers and community held with agenda, attendees and feedback documented. Input is incorporated into strategic planning
- Policies or processes involving consumers and the community in developing state wide health policies |

| 4 | **Mental Health Foundation ACT** | *Consumer and Carer Participation Policy*

http://www.mhf.org.au/carersconsumers/policies-and-procedures/item/consumer-and-carer-participation-policy | Community organisation providing support services to mental health consumers and carers in the ACT | - **Empowerment:** Consumers and carers are delegated decision-making and management responsibility for a specific purpose or task.
- **Collaboration**: Consumers and carers partner with MHF Staff participating in development, planning and decision making regarding individual supports and recovery planning.
- **Involvement:** Consumers and carers participate in decision making, organisational development and planning as members of working groups, representative committees or advisory groups.
- **Consultation:** Consumers and carers provide information and input via information gathering tools such as consumer feedback surveys, or information gathering workshops or focus groups.
- **Provision of Information:** Consumers and carers are provided with relevant information about changes, specific relevant issues, or services. | x | x | x | x | none |
| 4 | **NEAMI** | *National Service Improvement Report*

http://www.neaminational.org.au/our- | Community mental health service: aims to improve mental health in local communities | - Complaints and feedback process
- Health prompt launches
- Communications working group
- Consumer participation expert working group
- Youth working group
- Research and evaluation committee
- Peer health coaching steering group
- Northern region youth working group
- Risk assessment working group | x | x | x | x | none |

| | | approach/cons umer- participation | | - Collaborative recovery model (crm) fidelity study
- Health prompt evaluation review
- Launching pad leadership program
- Eat plant learn evaluation
- Co-facilitation of the eat plant learn program
- Neami policies and procedures review
- Planning of the activ8 program in collaboration with banyule community health
- North east mental health alliance working party showcase
- Logo design for the victorian mental health complaints commission
- Emhsca collaborative care planning training
- Attendance at 'combobulate' information and planning session
- Attending the day to day living conference
- Oral health project
- Partners in recovery launch
- Eastern metropolitan region shared care partnerships working group
- Speaker on parenting and navigating the mental health system at showcase on families
- Service improvement report
- Being on interview panels
- Participating in research
- Membership of working groups and committees
- Co-presenting at conferences
- Contributing to the development and evaluation of programs. | | | | | |

				- Focus groups					
4	**Beyondblue**	https://www.beyondblue.org.au/get-involved/bluevoices	Provides information and support to people with mental health issues	- Online forum and reference group that provides people with a lived experience of mental illness the opportunity to: - Become involved in research - Provide feedback on Beyond Blue's resources and campaign materials - Participate in committees and advisory groups - Take part in media opportunities	x		x	x	Online surveys to gauge participant satisfaction, reasons for membership, etc. An independent evaluation of Beyondblue from 2014 https://www.beyondblue.org.au/docs/default-source/research-project-files/bw0265.pdf?sfvrsn=0
3	**The Mental Illness Fellowship of Australia**	Peer work policies and principles http://www.mifa.org.au/images/PeerworkPosition_Statement_2016.pdf	A longstanding group of membership organisations involved with consumer advocacy and education initiatives	**Lived experience forum on the website, posting requires registration.** **Position statement on the concept of a peer workforce. The following principles guide the organisation:** - "Peer work approaches influence all program and policy development at MIFA and its member organisations. - peer workers receive the support and assistance of their colleagues and employers to develop their knowledge and skills while contributing an important perspective to the support of people affected by mental illness - members have well developed structures for induction, training, supervision and support of our peer workforce including specialist peer to peer structures where possible.	x	x		x	**NONE**

				- members have clear position descriptions and service documents that support best practice in peer work. - policy and advocacy activities are undertaken from the perspective of people affected by mental illness, and their stories and actions contribute to building community understanding and a more effective mental health system"					
3	**Consumers of Mental health WA**	*Consumer Participation Policy* http://www.comhwa.org.au/consumer_voice/consumer-participation/	Aims to gather and give attention to the views of members, consumer networks and supporters in WA	- Collaboration with members and networks to bring an informed and inclusive perspective to consumer issues. - Representation of consumers in state-wide service and systemic level mental health service and policy settings - Coordinating consumer participation - Advertising of consumer participation opportunities in newsletter - Relevant training to consumers	x	x			- CoMHWA will maintain relevant records of its consumer participation activities for reporting purposes. - CoMHWA will periodically evaluate its consumer participation activities, in consultation with members and consumers.
3	**NSW Health**	*Corporate Governance Compendium* http://www.health.nsw.gov.au/policies/manuals/Documents/corporate-governance-	NSW state government health organisation	- The development and implementation of a **Community Participation Framework** - Development of a Communications Plan with key internal and external stakeholders - Active engagement with community organisations and groups to promote **community participation** in the development, implementation and review of health service plans, operations and health programs - **Activity-based funding** programs and services	x	x		x	none

		compendium-section10.pdf		- The provision of **public health informatio**n including on emerging health issues and public health trends, the outcomes of research and technological innovations and developments and participation in specialist technical, clinical and consumer forums						
3	**WA Health**	*WA Health Consumer Carer and Community Engagement Framework for Services/Staff* http://www.health.wa.gov.au/HRIT/docs/10278_WA_Health_Consumer.pdf	WA state government health organisation	- Consumer and Carer **Engagement Teams** - Review and recording of current Consumer, Carer and Community Engagement - Consumer and Carer **Advisory Council** at area level - Consumer, Carer and Community Partnership and **support modules** for staff, consumer and carer representatives - **Reviews** of consumer, carer and community engagement activities within service divisions.	x		x			Formal evaluation by independent investigator will look at the structure of consumer engagement activities, levels of consumer participation, and staff, as well as looking at consumer thoughts/attitudes/feelings towards engagement.
3	**Consumers of mental health WA**	Consumer participation policy: http://www.comhwa.org.au/consumer_voice/consumer-participation/	Aims to gather and give attention to the views of members, consumer networks and supporters in WA	- "**Consumer consultation**: we seek the views of and work collaboratively with our members and networks to bring an informed and inclusive perspective on consumer issues. - Consumer representation: we directly represent the views of mental health consumers in **state-wide service and systemic level mental health service and policy settings.**	x	x				- Record and report to members, consumers and other relevant stakeholders on Implementation and outcomes of it consumer participation activities via its Annual Report

				- **Coordinating consumer participation**: we offer consumer participation design and recruit, coordinate and support **consumer representatives** on behalf of services and agencies. - **Promotion and support**: we offer free advertising of consumer participation opportunities in our **newsletter,** and offer relevant **training** to consumers and services."						- maintain up to date records of any significant feedback about consumer participation - ensure and protect consumers' right to choice of participation and privacy in reporting and evaluation processes - evaluate its consumer participation activities on an ongoing basis with a formal review every two years, or earlier if indicated Measurement tools: **The Fidelity Assessment Common Ingredients Tool (FACIT) and the** Peer Outcomes Protocol
2	**Suicide Prevention Australia**	Lived Experience Network: https://www.suicidepreventionaust.org/projects/learning-lived-experience	Prevent suicide in Australia	- Newsletter - Online resources - Advocacy toolkit and training - Speakers bureau - Opportunity to participate in research and policy design - Local community activities/events	x				x	none

| 2 | **Health Consumers NSW** | *Consumer and Community Engagement Model 2015* http://www.hcnsw.org.au/data/Resources/2015_07_17_Final_report_and_template.pdf | Membership-based organisation promoting and practicing consumer engagement in the NSW health sector | - **Implementation assistance** (establishment of the WentWest consumer engagement staff network)
 - **Toolkit** supporting consumer and community to engage
 - **Online training modules** for competency in consumer engagement for consumers and staff | x | | | | | **Engagement model draws on the recommendations of the Australian Commission on Safety and Quality in Healthcare. Suggests the following evaluation mechanisms:**

 - Quantitative surveys and qualitative narrative-based sources of consumer experience data

 - Creating key organisational and patient metrics over time

 - Outcomes of engagement: consumer experiences, effectiveness of meetings and consultations, improving access to specific services |
| 2 | **SA Health** | Lived Experience Register: http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+heal | SA state government health organisation | **Lived experience register, involving:**

 - newsletters
 - surveys
 - email updates
 - forums
 - mental health consumer and carer representatives | x | | | | | Representative complaint and feedback form for carer representatives |

2		th+internet/hea lth+services/m ental+health+s ervices/mental +health+lived+ experience+re gister							
2	**The Mental Health Coalition of SA**	Lived Experience Workforce Project: http://www.mh csa.org.au/live d- experience/lew p/	Peak body for the non- government mental health sector in South Australia	- **Reference groups** - Including lived experience workers, carers and consumers, NGO leadership & human resources staff. - **Surveys** to contribute knowledge and information to the project. - **Stakeholder consultation** aimed at gathering information from the wider sector and expert groups. - **Training and professional development** - engage in workshops and professional development activities and access to relevant resources.	x	x			none
2	**Anxiety Disorders Association of Victoria**	Information taken from website: https://www.ad avic.org.au/	Independent organisation providing support, information and resources to individuals suffering from or affected by	- Phone and Email support, information and referral - Facebook support - Weekly support group meetings - Information sessions, seminars, and workshops - Professional development events - Social Events & Outings	x		x		none

			anxiety, depression, and related issues	- Referrals to therapists specialising in anxiety and depression					
2	**Being**	Information taken from website: http://being.org.au/resources/yes/	Encourage mental health consumers to provide input into decision making at all levels concerning the way mental health services are provided	- Your experience of service survey - Provides a forum at training events and forums - Focus on consumer voices in service and policy development via feedback mechanisms	x			x	
2	**LivingWorks Australia**	Various programs listed on website: http://www.livingworks.com.au/	Provider of suicide intervention training. Develops and delivers programs with the goal of saving lives from suicide.	- **SuicideTALK** provides training sessions to carers, gatekeepers and others to raise awareness of suicide prevention strategies within communities - **Esuicide** program involving a virtual classroom and training opportunities based on the SuicideTALK program - **SafeTALK** is a half-day alertness workshop that prepares anyone over the age of 15, regardless of prior experience or training, to become a suicide-alert helper.	x				**Detailed evaluations of programs, mainly assist, have been carried out. Summary report available at:** file:///C:/Users/u4671994/Downloads/Review-of-ASIST.pdf Techniques included surveys of participants, evaluations of knowledge and skills exhibited by participants during training programs and in simulated interventions, measures of increases in interventions after assist programs, and

				- Presentations and guidance from two LivingWorks registered trainers - A scientifically proven intervention model - Audio-visual learning aids - Group discussions - Skills practice and development					measurement of changes in the rate of suicide attempts at schools known to have implemented the assist program.
1	**Support after Suicide**	Website: http://www.supportaftersuicide.org.au/	Program of Jesuit Social Services funded by the Department of Health under the National Suicide Prevention Strategy	Online resources (information) and online forum	x				none
1	**Black Dog Institute**	Website: http://www.blackdoginstitute.org.au/public/getinvolved/overview.cfm	Not-for-profit organisation involved in the diagnosis, treatment and prevention of mood disorders	- Social advocacy opportunities - Fundraising - Workplace education	x				none
1	**Sane Australia**	Website: https://saneforums.org/t5/Our-experience-	National charity: improve prevent suicide and improve the lives of people	Lived Experience Online Forum	x				none

		stories/The-Self-and-OK/m-p/136361	with mental illness						
			UNITED KINGDOM						
5	**Avon and Wiltshire Mental Health Partnership (NHS based)**	*Engagement and Involvement Strategy: 2013 to 2016: "You matter, we care"* http://www.awp.nhs.uk/media/434284/engagement_and_involvement_strategy.pdf	NHS foundation trust providing mental health services across a core catchment area covering Bath and North East Somerset (B&NES), Bristol, North Somerset, South Gloucestershire, Swindon and Wiltshire	**Very detailed strategies pages 6-11. For example:** **Individual level** - Improve care planning through **staff training**, (developed and delivered by service users, carers and staff) and supervision - Ensure **carer engagement in care planning** - Support access to **advocacy** - Consistent use of **Recovery star (outcome measure)** **Team and ward level** - Establish information **"review" groups** for each service - Extend use of **social media** to provide information and advice - Provide links to **peer mentors** at point of discharge from hospital or from community services to provide additional support - **Supervise and monitor** staff communication skills - Provide **clear contact information** - Provide mechanisms for "instant" **feedback**	x	x	x	x	**Engagement group to ensure the implementation of the strategy and that accountability mechanisms are followed:** **The Engagement group will be able to:** - Oversee the Trust's engagement and involvement activities, setting priorities and approving policies - **Monitor** progress against the planned actions to improve those activities - **Scrutinise information** which captures service user and carers experiences (**such as complaints, patient environment assessments, incidents etc.**) - **Seek assurance** that action is being taken to respond to issues identified

				- Capture the carer experience through implementation of the **Triangle of Care self-assessment**				- **Report** to the Quality and Standards Committee.
				Locality level				**Success measures for day to day engagement of service users (page 4):**
				- Develop **peer mentoring**				- Improvement in Friends and family test results via IQ
				- Develop **informal support mechanisms**				- CQC compliance against standards for involving service users
				- Employ **Involvement Coordinators**				- Completion of Triangle of Care self-assessment for all teams
				- Establish local **audit mechanisms** for ensuring individual involvement in care planning				**Success of strategies relating to the measurement of and response to people's experiences of services (page 8):**
				- **Training** developed and delivered by service users, carers and staff				- Planned audit programme that incorporates SU/Carer led assessment
				- Continue self-management and recovery **training** in Specialist Drug and Alcohol services and consider wider application across other groups				- Service User and Carer led piece of work to see what measures are currently in place for assessing engagement and determine what else is needed.
				Strategy level				
				- Ensure high numbers of **trained staff in CPA**, customer care and diversity				- CQC self-assessment
				- Support **readers panel** Improve accessibility of information on the **website** and in other formats				- Triangle of Care self-assessment tools
				- Improve service provided through **central switchboard**				
				- Provide opportunities for individual feedback				
				- Respond to feedback in a timely and helpful way				
				- Improve mechanisms for listening to and understanding service user and carer experience				
				- **Establish forums that scrutinise**				

				- feedback from service users and Management - Encourage participation in surveys - Groups to have feedback as standing items on agendas - Develop standards for communication - Increase customer care training - Provide clear contact information - Staff to involve service users and carers in care plan - Staff to support individuals to access advocacy support - Establish forums that scrutinise feedback from service users					- Carers to go in and check the RAG ratings to verify self-assessment Compliance with NICE recommendations for Community Engagement (2008) **Success of service user engagement in the design and delivery of services is measured by (page 10):** - Programme office to **develop project template**s which include reference to service users and carer involvement - **Senior management team** to scrutinise all improvement projects for engagement and involvement - **Engagement group** to monitor achievement of accreditation standards (as outlined above) across all Service Delivery Units.
5	**Derbyshire health care (NHS based)**	*Engagement 4 Improvement Framework 2012 - 2015* http://derbyshir ehealthcareft.n	NHS foundation trust providing mental health, learning disabilities and s ubstance misuse services	**Level 1: Corporate (page 9):** - **Listening First events** across Derbyshire to hear the views of stakeholders - learning from the Francis Report into the failings of Mid Staffordshire Hospitals – March 2013 - Complaints monitoring - Concerns monitoring	x	x	x	x	This framework will be **monitored through the Trust governance process** and delivered across the four organisational levels. This will ensure engagement is owned and that services and care delivery are designed, delivered

		hs.uk/easysite web/getresour ce.axd?assetid =3941&type=0 &servicetype= 1&filename=/Fi nal_Engagem ent_4_Improve ment_Framew ork_March_13 _Word__versi on_HDhaliwal. pdf	in Derby city and Derbyshire county.	- Positive feedback and compliments monitoring Serious Untoward Incident reviews - Carers Forum Mental Health Action Group - Patient Survey Action Group Monitoring against national drivers: - Mid Staffordshire Report - NICE guidance - Delivering Dignity - 74 Deaths and Counting **Level 2: Division (page 10):** - Divisional Engagement Meeting - Ensure patients attends future visits - Clinical Reference Groups - Annual Divisional EDS assessment and improvement action plans **Level 3 (page 10): Team, ward or service:** - Multi-Disciplinary Meetings and Ward Rounds - Secret shopper within crisis and home treatment teams Board to Ward Core Care Standards implementation Recruitment & Selection Training - Continued audit of patient care through robust supervision, case discussion and case file audit **Level 4 (page 1): Individual:** - Care planning & evaluation - Core care standards implementation - Volunteers within service areas - Patient survey - Advocacy - Involve patients in policy development			around the needs of the patient, carers and the community. Very detailed and precise (percentage based) list of measurement goals and key performance indicators pages 9-22. Most based on surveys. For example, here are some of the key goals/measurement criteria for the individual patient level (page 11): - We will see an improvement in patient surveys particularly with regard to Care Planning and being involved in their care. 68% of service users stated that they were involved in the care planning. 54% of service users said they had a care plan. We will see a significant improvement in year up to the value of 95% by 2013 - Patient survey results with on-going maintenance of this target in year 2014 & 2015. - Independent face-to-face interviews with 80% BME Patient

				- Real Time Surveys - Effective care plan coordination through CPA or named nurse. - The independent interviewing of BME patients within services to gather qualitative information about individual experience that is fed back into service improvement - carried out in partnership with Southern Derbyshire Voluntary Sector Mental Health Forum (CQIN L4)					- Experience Engagement 4 Improvement Framework ratified Detailed joint analysis of BME patient interviews and recommendations for change having been fed into appropriate service improvement structures with action plan for implementation (CQIN L4). - We will see a maintenance of 7 day follow up performance (2011/12 data indicates 99.24% against a target of 95%). - We will see a maintenance of performance regarding CPA reviews (2011/12 data indicates 97.35% against a target of 95%). We will see a maintenance of Crisis Team Gatekeeping performance (2011/12 data indicates 100% against a target of 90%).
5	**HealthWatch**	*The Freedom to Be, the Chance to Dream: Preserving user-led peer*	The consumer champion for health and social care: overarching national body for	- Focus groups - Appreciated inquiry - Scenario planning - Conflict resolution - Story dialogue - Community conferences	x	x	x	x	**Supporting patient and carer representatives checklist (examples):**

		support in mental health http://www.together-uk.org/wp-content/uploads/2012/09/The-Freedom-to-be-The-Chance-to-dream-Full-Report1.pdf	local Health Watch organisations	- Open space events - Interactive displays - Public scrutiny - Community auditing					*- Is there a briefing sheet about the meeting that you can share?* *- Does the person know who the key contact is for arranging the meeting?*
5	**Patient Voice South**	*Patients in Control Programme Final Report, May 2015* https://www.patientvoicesouth.swcsu.nhs.uk/media/medialibrary/2015/08/pvs_pic_finalreport.pdf	Offers support and networking opportunities for anyone promoting patient and public participation (PPP) in the design and delivery of healthcare	**The Patient Voice South PiC programme funded 12 individual projects (page 5), also see appendix 1, page 14 for more detailed information about each project):** - My Life Plan: **holistic personalised care planning** for people with long-term conditions (acute and voluntary phase…involves staff training - **Peer support** service for patients in crisis: assessment from those with lived experience of mental distress - **Training** to empower and enable carers and those being cared for to gain vital life skills - **Co-production** of supported self-management services with people and professionals	x	x	x	x	**Programme evaluation (page 4):** - A cohort of people involved in the project were interviewed; they spanned CCGs, voluntary sector organisations, NHS England, AHSNs and SCNs, Healthwatch and healthcare providers. - Qualitative feedback was generally positive

				- Dorset Voices: person-centred care films…**patients and carers create and deliver educational films** using their lived experience - Testing a co-designed **peer support** model for patients with long-term conditions delivered through GP practices - **Peer support groups** for people with eating disorders, tackling an unmet need within the large student-aged population - **Recruit, train, and support** volunteers to help patients develop informed care plans - Using pathology infographics to support people with long-term conditions to manage their own care - **Narrative-based discharge** from maternity care - **Person-centred planning** for patients diagnosed with long-term conditions - **Advisory Panel**: virtual panel included expertise from health, social care and voluntary sector alongside patient representation. The panel was created to guide early programme design, as well as to judge the applications for funding across both rounds					
5	**National Health Service (NHS)**	*Transforming Participation in Health and Care*	Publicly funded national healthcare system for England and one of the four National	**Individual participation (page 16):** - Group education - The Expert Patients Programme - Patient Activation - Peer support - Patient leaders	x	x	x	x	**Specific feedback mechanisms discussed on pages 44-46:** - Surveys - Friends and family test - Patient stories

		https://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf	Health Services of the United Kingdom	- Patient online: the road map - Health literacy - Health Champions. - Patient Decision Aids (PDAs) - Training professionals in shared decision-making (SDM) - Information on options - Patient-held records - Prompts for professionals. - Personalised outcome focused goal setting - Electronic care plans - Collaborative GP consultations - Information, support and advocacy e.g. Age UK - Social prescribing - Personal Health Budgets **Public participation (page 22):** - Providing the facility for patients and the public to proactively suggest improvements at any time e.g. a suggestion box or online feedback page - Ensuring all plans are communicated to patients and the public as soon as they begin to be considered - Providing regular opportunities for patients and the public to meet commissioners. - Regular e-bulletins - Information posted locally on notice boards in GP practices, pharmacies, dental practices etc. - Information disseminated through local voluntary and community organisations				- Focus groups and in-depth interviews - Engagement and consultations - Social media - Observational work - Peer research - A feedback process to be used by NHS England and CCGs each year, aiming to achieve at least 80% satisfaction from stakeholders regarding the ways in which they have involved people in planning and commissioning services

				- Local authority newsletters and circulations - Online survey tools - Dedicated events to enable discussion about proposals - Seeking views from the community at local events or venues e.g. attending festivals, markets, schools, leisure centres, libraries etc. - Understanding the assets within your local community and collaborating to identify and solve problems together - Pro-active work through local voluntary and community sector organisations, including small grass roots organisations in order to collaborate and solve problems together, particularly with communities of interest e.g. mental health charities, homeless organisations					
5	**NHS Confederation**	*Patient and Public Engagement: a practical guide for health and wellbeing boards* http://www.nhsconfed.org/~/media/confederation/files/publicatio,m,ns/docu	Membership body that brings together and speaks on behalf of all organisations that plan, commission and provide NHS services	**No practical consumer engagement strategies. Check list for health and wellbeing board members:** - The board has discussed PPE. - Levers have been used to facilitate interest, for example the need for clinical commissioning groups (CCGs) to demonstrate local engagement to achieve authorisation. - A public statement of intent has been made about engaging patients and the public in the work of the board.	x	x	x	x	**The whole document can be considered as an accountability 'checklist' for board members**

					x	x	x	x	
		ments/patient-public-engagement.pdf		- The board takes account of what PPE is being done by local partners and uses the outputs to inform its work. **Some discussion of individual level, shared decision making and co-production of services on page 2.**					
5	**NHS Leicester City**	*Patient and Public Involvement* https://www.nottingham.ac.uk/clahrc-ndl-nihr/documents/ppi/leicester-engagement-techniques-guide.pdf	Local branch of the NHS	**Taken from page 6 (some overlap with accountability mechanisms):** - Patient Leaflets - Service prospectus - Patient held record (smart cards) - Internet provision - Access to patient correspondence - Annual reports on PPI - Strategy for PPI - Annual Plans Performance information - Clinical Governance reports - Press and media publicity - Individual complaints - Patient feedback/comment card - PALS enquiries - Patient diaries - Patients Panel - Complaints monitoring Patient surveys (local and national) - Focus Groups - Wider consultation about needs and priorities - Patient Participation Groups	x	x	x	x	**Page 48 recommends defining and measuring outcomes:** - Patient advice and liaison service allows general feedback and informal complaints and queries to be registered. - Formal complaints registration process **Page 49:** - "Regular reports are sent to the Board (the trust board) to update them on progress. The PCT (NHS Leicester City) therefore needs to be aware of all patient and public activity that is going on across the organization so that it can be fed into the Trust Board reports. The Commissioning Framework

					x	x	x	x	
				- Citizens juries - Stakeholder conferences - Local health alliances - Priority setting - Partnership Forum - Lay representation on NHS bodies - Lay role on clinical governance					indicates that all service planning/redesign and commissioning processes should include a PPI strategy and PPI involvement. The PPI and Communications Template can be used to effectively plan and record PPI activities within projects."
4	**Young Minds**	*Children and Young People's Participation* http://www.youngminds.org.uk/training_services/training_and_consultancy/resources/commissioners/1191_children_and_young_peoples_participation	Charity aiming to improve the mental health of children and young people, by campaigning, researching, and influencing policy and practice.	**List of examples of the organisation's consumer engagement initiatives:** - vik project (young minds staff **working directly with service users)** - a **panel of young people** aged 13-25 all of whom have a lived experience of mental illness - **staff training program** on how to involve young people in service development (program developed in collaboration with young people with a lived experience of mental illness) - involving young people in **mental health campaigns** - developing **campaigning resources** for people with a lived experience - **consumers may have an input** to the **design** of the organisations events, service providers may **consult** with consumers to provide a needs **analysis/priority setting**, young people may be involved with **evaluating** the	x	x	x	x	None

				organisation's services (service inspections and reviewing commissioned services). - young people have input into staff recruitment, service evaluation, and input into steering committees					
4	**Together**	Website: http://www.tog ether-uk.org/	Major UK charity, established in 1879, aiming to support people living with mental illness to live independent, fulfilling lives	- Online resources and guides for consumers - Work with public, private and voluntary organisations to research and publish guides on service user involvement - Peer support training - Peer led initiatives (peer support models and self-management) - Consumer led research (The 'Enrich' project). - Work with Interrelate (international mental health coalition) to share the experiences and perspectives of those with a lived experience of mental illness - Together's national steering group consists of people with a lived experience - Involvement and leadership grant scheme — a service allowing people to submit ideas around service user or involvement or leadership. Applications are judged by a management committee formed of people who have a lived experience of mental illness	x	x	x	x	None
4	**National Survivor User Network**	*No Decision About Us Without Us*	Independent mental health service user/survivor led organisation, set	**Specific involvement strategies/opportunities:** - Mental health service providers can create an **organisational culture based on service user engagement** and co-production.		x	x	x	**Organisational goals, examples, Page 10:** - By 2013, new Strategic Clinical Networks will have

| | | http://www.nsun.org.uk/assets/downloadableFiles/no_decision_about_us_without_us2.pdf | up by service users to build a more united and confident mental health service user movement | - Primary care services (GP surgery-led) can arrange **evidence-based training** for their workforce in relation to mental health (including suicide awareness).
- Local authorities can involve **service users in service pathways and in service design**
- CCG governor roles CCGs must have two **representatives from the lay community** on their governing body – one with an overview of Governance, and one for Patient Engagement and Experience
- Health and wellbeing boards must **involve people in** all aspects of **development** of Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies (JSNAs and JHWSs).
- **Overview and scrutiny committees** (OSCs) particularly health scrutiny committees, can involve mental health organisations, people with mental health problems and carers in their work.
- **CCGs will have a legal duty to involve and consult people who use services.** NHS Trusts and Foundation Trusts also have this duty. They must consult local communities about planned services, or changes to services, where decisions affect the way in which services are provided or how they are delivered.
- An example of **co-production is** a model called 'reverse commissioning', developed by | | | | | been established in each of 12 geographical areas across England. They will help local commissioners reduce variation in services, improve quality and encourage innovation 20
- Each network will have an accountability and governance framework to work to |

					x	x	x		
				the BME NHS Network, which calls on the expertise of black and minority ethnic (BME) groups to ensure that mental health needs are met					
4	**London Health Programs**	*Making a Real Difference: strengthening service user and carer involvement in NIMHE* http://www.londonhp.nhs.uk/wp-content/uploads/2011/10/MaRD-Final-Report.pdf	NHS department running and coordinating a number of London health programs and services. No longer active as of 31 March 2013	**Implementation basis for the NIMHE Consumer Engagement Framework (page 8):** - **A national communications strategy** including innovative methods of feedback. - **Induction packages for new employees** to effectively involve service user and carers in all of their work. - **Training packages for existing staff** to support awareness - **A network** for people with experience of using mental health services to provide expertise to NIMHE at a national level	x	x	x		- Quality Assurance responsibility held by Steering Group (page 20) - Quarterly reports received by NIMHE Management group from Project Director regarding the status of Project (page 20)
4	**NHS**	A guide to Community-Centred Approaches for Health and Wellbeing https://www.gov.uk/government/uploads/syst	Publicly funded national healthcare system for England and one of the four National Health Services of the United Kingdom	**General guidelines for community engagement, discusses the following:** - Community development - Asset based methods - Social network approaches - Bridging roles - Peer interventions - Peer support - Peer education and mentoring - Volunteer health roles	x	x		x	**Pages 32-35 contain a fairly detailed but short literature review on the effectiveness and economic aspects of community engagement in a general sense (no mention of specific strategies):** "A rapid scoping review undertaken to inform this report identified 128 reviews of

		em/uploads/att achment_data/ file/417515/A_ guide_to_com munity- centred_appro aches_for_hea lth_and_we		- Community based participatory research - Area based initiatives - Community engagement in planning - Co-production projects - Pathways to participation - Community hubs - Community based commissioning - Access to community resources – where approaches focus on connecting people to community resources, information and social activities					relevance; 32 of these were systematic reviews. Most of these reviews report positive outcomes from working with communities, although some also report insufficient evidence to draw firm conclusions or have mixed results. Some reviews point to the importance of avoiding negative effects for those who volunteer and supporting people to engage."
4	**Panos London**	*Beyond Consultation: a guide for health commissioners* *How staff and service users can work together to improve health services* http://panoslon don.panosnet work.org/wp- content/files/2	London branch of the Panos organisation, which aims to ensure that information is effectively used to foster public debate, pluralism and democracy	**Makes the following recommendations:** - Develop a clear, **one-page description of the project**. It should outline what service users and staff will gain from engaging as individuals and as a group - Take time to go and talk to people as well as using a variety of communication channels used by different groups (**texting, social media, leaflets etc**) - Use **trust-building exercises** to help individuals gain confidence and build group rapport - Provide **training to service users** and **health staff** who may have different levels of familiarity and skills with communication tools. Encourage	x	x		x	**Page 9:** - Build evaluation and learning into the process from the **planning phase** and address it regularly throughout, so you can track important changes and make improvements as the project progresses **Page 13:** - Evaluate staff and service users' experiences and perceptions of their participation **in the process** and how this changes over

| | | 012/03/Beyond-Consultation-a-guide-for-health-commissioners.pdf | | participants to help each other develop and share skills.
- **Hold a 'dialogue day'** to bring together service users and staff who have been involved in the process with a wider group of service users and health stakeholders. Together they can review what the project has found and reflect on these findings
- **Allow participants to review all existing resources.** Include any quotes, audio recordings, posters or collages, digital stories and short films
- **Draw a 'system map'** with the assembled participants to identify priority concerns and their causes and consequences. Begin to identify who and what may need to change to address them (see overleaf). See www.panos.org.uk/bcdialogue
- **Support participants to talk to their peers** and contacts to gather more information and experiences on key issues
- Methods could include **interviews, diaries of activity, online surveys or text messages** to feedback experiences of services or regular appointments
- Organise a **multi-stakeholder review** event to bring all the participants back together. People can review piloted changes and consider together what may be needed to further the | | | | | time. To what degree, for example, did they feel they shaped the topics under consideration and the agenda for change?

- **Track changes** in relationships and networks between service users and staff, and between the project and other organisations involved in the issue. Such relationships can be important to building project sustainability and influence. Network evaluation tools can help to identify evolving relationships and how these contribute to changes in practice and behaviour (for more on network evaluation tools see www.mande.co.uk/special-issues/network-models/).

- **Regularly monitor and document** activities to support potential improvements to the project and responses to issues as they emerge. Such |

				work. They can also address new emerging issues					documentation can also form the basis for lessons that can be shared with others who work with engagement processes.
3	**Scottish Mental Health Research Network**	Website: http://www.nhsresearchscotland.org.uk/research-areas/mental-health	Promotes excellence in clinical and translational research in Scotland so that patients can benefit from new and better treatments. Formed through a partnership of Scottish NHS Boards and the Chief Scientist Office (CSO) of Scottish Government	- An 'online activist army', serving as a network for mental illness campaigners - The opportunity for people to become a member of 'a regional committee' involved in policy, campaigns, and communication work - The opportunity for mental health consumers, carers and professionals to become expert reviewers (checking to see that fact sheets are accurate, clear and relevant) - Opportunities for people to become involved in media campaigning.		x	x	x	**None** Some training and support provided to people who become involved in Rethink's mental illness committee work.
3	**Healthwatch Isle of Wight**	Adult mental Health Services in the Community	Isle of Wight Health Watch monitoring and responding to the needs and	**Strategies (starting on page 6):** - Consultations in relation to policy and priority setting	x	x		x	none

		http://www.healthwatchisleofwight.co.uk/sites/default/files/update_report_-_adult_mental_health_2015_final.pdf	views of health consumers	- Peer led recovery programme (My Life a Full Life) - Emphasis on recovery oriented care and self-care - Workshops - Surveys - Engagement initiatives - Working together – listening and recovery in action (a public(?) event involving collaboration between mental health service users, unpaid carers and professional workers) - Public publication of feedback received from service users						
3	**Involve**	*Not Another Consultation! Making community engagement informal and fun* *http://www.involve.org.uk//wp-content/uploads/2011/09/Not-Another-Consultation.pdf*	National advisory group bringing together expertise, insight and experience in the field of public involvement in research. Part of, and funded by, the National Institute for Health Research.	**Page 71 makes the following suggestions:** - Community meetings involving participant voting and discussion of priorities - 'World Cafes', community meetings in Cafés - Open space events (another type of community meeting) - Citizens Juries - Asset based community development - Appreciative inquiry **Number of case studies incorporating these and other strategies throughout the document**	x	x				Appendixes one and two contain evaluation forms and feedback forms for participants Most case studies covered in the document made use of some participant feedback mechanisms **Page 63 recommends circulating feedback to participants and key stakeholders. Following mechanisms are recommended:** Written reports, summary posters, newsletters and short briefings,

| 3 | **National Institute for Health and Care Excellence (NICE)** | *Community Engagement: improving health and wellbeing and reducing health inequalities*

https://www.nice.org.uk/guidance/ng44/resources/community-engagement-improving-health-and-wellbeing-and-reducing-health-inequalities-1837452829381 | Organisation aims to improve the outcomes for people using the NHS and other public health and social care services | **Emphasises the importance of consumer engagement in the design, implementation and evaluation of service, but no specific strategies for higher level governance/policy design. Other strategies include:**

- Using evidence-based approaches to community engagement
- Carrying out 'peer interventions'. That is, training and supporting people to offer information and support to others
- Community health champions who aim to reach marginalised or vulnerable groups and help them get involved
- Volunteer health roles whereby community members get involved in organising and delivering activities
- Recognise that volunteers will need their expenses to be paid so that participation does not leave them out of pocket

- Identifying and working with community networks and organisations, particularly those reaching vulnerable groups or recently established communities
- Feedback the results of engagement to the local communities concerned, as well as other | x | x | | | presentations at meetings of interested groups and press releases
- **Involve community members** and community and voluntary organisations **in planning, designing and implementing an evaluation framework** for both community engagement approaches and health and wellbeing initiatives.

- **Routinely evaluate community engagement activities** to see what impact they have on health and wellbeing and health inequalities, including any unexpected effects. This could include a mixture of quantitative and qualitative evidence. **Use existing evaluation tools if available.** Examples include the School for Public Health Research's Public Health Practice Evaluation Scheme and HM Treasury's Magenta Book – guidance on |

				partners. This could be communicated in a range of ways, for example, via the local newspaper or community website, via community groups or via public events in community venues or other widely accessible places - Community-based participatory research						evaluation. **Use a range of indicators** to evaluate not only what works but in what context, as well as the costs and the experiences of those involved - **Provide regular feedback to the local communities** involved (including people and groups outside the target communities) about the positive impact of their involvement and any issues of concern - **Find ways to record, share and publish local evaluations and good practice relating to community engagement**
3	**Carers Trust**	*A Guide to Best Practice in Mental Health Care in England* https://carers.org/sites/files/carerstrust/triangl	Charity aiming to provide those working with carers in health, education or social care with access to the information and resources they	**Provides a list/framework of key elements of a successful carer engagement plan:** **See page 9:** - carers' views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies to support treatment and recovery take shape	x	x				- Good practice checklist for carers in community settings (Avon and Wiltshire mental health partnership NHS trust). - Carers survey (Avon and Wiltshire) mental health partnership NHS trust). - Carer's checklist (Avon and Wiltshire mental health

		e_of_care_2016_latest_version_0.pdf	need to deliver the highest quality of support	- staff need to be aware of and welcome the contribution carers can make and be mindful of carers' own needs - staff need knowledge, training and support to become carer aware - guidelines on confidentiality and sharing information – a three-way process between service users, carers and professionals - information release forms and protocols - advance statement forms and protocols - carers lead or champion for all wards and teams irrespective of which service - carers links delegated for each shift/team - an introductory letter from the team or ward explaining the nature of the service provided and who to contact, including out of hours - an appointment with a named member of the team to discuss their views and involvement. - ward orientation/induction procedure and leaflet - carer information packs - discharge planning and aftercare support - carer needs assessment - family intervention support service						partnership NHS trust) – review of components of engagement. - Community team carer checklist (south London and St George's NHS trust). - From page 25: **Guidance notes** have been developed as a result of feedback from members of the Triangle of Care Steering Group who have started engagement services. - **Initial benchmarking** processes established to measure current levels of carer engagement and guide future policies. - Six key elements serve as an **organisational guide/checklist.** - **Regular auditing** via feedback from carers
2	**MIND**	*Mental Health Peer Support in England: Piecing*	Provides advice and support to empower anyone experiencing a	**Paper has a fairly generic list of types of peer support:** - self-help groups - mutual peer support	x	x				None

		together the jigsaw https://www.mind.org.uk/media/418956/Peer-Support-Executive-Summary-Peerfest-2013.pdf	mental health problem. Campaigns to improve services, raise awareness and promote understanding	- peer mentoring - online peer support						
2	**South Tees Hospitals**	*The Patient Experience Strategy 2010* http://southtees.nhs.uk/content/uploads/Patient-experience-strategy.pdf	Hospital trust covering hospitals in Middlesbrough, Redcar and Cleveland, Hambleton and Richmondshire	- Information leaflets - Raise awareness of patient experience and involvement strategy - Establishment of patient experience panel - Development of annual programme for obtaining patient experience feedback - Development of patient engagement toolkit - Training of staff - Real time surveys - Database for sharing and dissemination of good practice - Engagement and increased partnership with patients, staff, LINKS, membership governors, external agencies. - Creation of a feedback dissemination strategy	x					- Establishment of a process for reporting into the Trust's governance structure to assure the Board of progress against the Strategy and ensure that the Board is fully aware of what patients and carers report about their experience at the Trust and actions taken to improve that experience
1	**Healthwatch Dorset**	*Good Practice Principles for Consultations on Possible*	Isle of Wight Health Watch monitoring and responding to	**Very generic list of guidelines:** - Set out clearly why you believe change is needed.						Recommendation 11 suggests that recording, analysis and evaluation of people's feedback should be published, together

		Service Changes http://www.healthwatchdorset.co.uk/sites/default/files/consultation_principles_0.pdf	the needs and views of health consumers	- Involve people from the beginning, to develop solutions jointly. - Use plain language. No jargon. - Make your engagement and communication tailored to the needs of each audience. (Ask people what will work best for them.) - Give particular attention to seeking the views of people and communities who experience the greatest health inequalities and the poorest health outcomes. Make it easier for people to take part. Identify barriers and remove them. - Be honest, transparent and open about what's possible and what's not (including how and to what extent people can influence decisions). - Welcome different views and perspectives. Don't be defensive. - Give people equality and respect (including patients and the public having an equal voice to clinicians and professionals). - Allow enough time for people to receive information, question it, understand it and respond to it. - Allocate sufficient resources and support so that engagement and communication can be effective. - **11. Arrange for independent recording, analysis and evaluation of people's feedback. Publish it, together with an account of how it has influenced decision-making.**					with an account of how it has influenced decision-making

| XX | **London Health Programs** | *Involvement: Strengthening service user and carer involvement in NIMHE*

http://www.londonhp.nhs.uk/wp-content/uploads/2011/10/Valuing-Involvement-monitoring-and-evaluating-service-user-and-carer-involvement.pdf | NHS department running and coordinating a number of London health programs and services. No longer active as of 31 March 2013 | **Accessing Involvement a framework for assessing involvement itself.**

The selection of service users and carers: Data gathered through a fair access form would be analysed quarterly to produce results reflecting the local population of the geographical area from which people were recruited. Completion of the end of involvement questionnaire.

Experience of Being Involved (page 8)

Post Selection Questionnaire:

- The experience of the selection process to be evaluated by an audit of post-selection questionnaires (to be completed by service users and carers) that could be completed either immediately after the selection event, taken away to be completed and then returned, completed through email or through a telephone interview (choice to be made by each person)
- Audit of involvement plans
- End of involvement questionnaire
- Individual Testimonial Forms
- Service user and carer network event
- **Impact / Outcomes of Involvement (page 10)**
- Involvement Plans | | | | | Accountability mechanisms for involvement level, other levels dealt with separately throughout document (from page 6):

Quarterly review of audit information to be undertaken by a development centre with the input of consumers.

Analysis of audit information related to recruitment and selection to include: methods of "advertising" opportunities for involvement, with rationale for each choice made.

The types of information sent out to people with a minimum requirement being:
a. a role description
b. an outline of the initiative/project
c. Development Centre (DC) expectations of involvement
d. information about the DC with relevant contact information
e. level of formality/informality of the selection process, selection criteria used, with a minimum being by personal |

				- End of Involvement Questionnaire - Specific requests to service users, carers and salaried members of CSIP staff - Follow up interview with a stated proportion of service users and carers 3-6 months after their involvement has ended. - A follow-up questionnaire will be sent to all people who have been involved (by email and post), followed by a quarterly analysis of the results and then by an annual review. - Staff Appraisals — Inclusion of the need to reflect and evaluate the impact of service user and carer involvement in NIMHE work within CSIP staff appraisals and the subsequent analysis of and response to this information (without breaking confidentiality).					experience (including being a service user and/or carer), selection methods used
**CANADA**
5	**Canadian Mental Health Association**	*Caring Together: Families as partners in the mental health and addiction system*	Nation-wide, voluntary organization promoting the mental health of people experiencing mental illness through	- Improve access to consumer support services (i.e. social / recreational, education, training, employment programs) - Provision of family education, support and counselling by clinical addiction and mental health programs - Comprehensive, well-coordinated, easy-to-access, culturally competent programs available in each LHIN	x	x	x	x	- -Formal recognition of families as key stakeholders by MOHLTC

		http://ontario.cmha.ca/public_policy/caring-together-families-as-partners-in-the-mental-health-and-addiction-system/#.WDUMsrJ96Ul	advocacy, education, research and support services.	- In-service training to educate and sensitize staff to working with families - Annualized and sustained funding for peer support and mutual aid organizations - Equitable access to peer support in every LHIN - Integration of peer support within existing addiction and mental health programs - Training to ensure staff are knowledgeable of and supportive of peer support and mutual aid, and they make appropriate referrals - Development of a MOHLTC policy framework and standards for working with and integrating families as members of the care team - Family led education to assist practitioners in working with, and understanding families - Organizational policies and procedures to support working with families - Core curriculum on working with families incorporated into accreditation training for professionals - Formal recognition of families as key stakeholders by MOHLTC - Inclusion of family representatives on LHIN advisory committees - Inclusion of family representatives on boards and committees of mental health and addiction organizations					- Inclusion of family representatives on LHIN advisory committees
4	**Canadian Collaborative**	*Working together*	Self-help for people suffering	- Peer support - Peer advocacy - Chat room/forum	x	x	x	x	None

	Mental Health Initiative	*towards recovery* http://www.schizophreniaandsubstanceuse.ca/sitepages/files/EN_Workingtogethertowardsrecovery.pdf	from schizophrenia	- Discussion forum - Message board - Newsletter - Self-help/information resources for consumer and carers - Toolkit - Magazines (publications dedicated to research, self-help strategies, lived experience, etc.) - Advocacy - Opportunities for people to be involved in advisory boards and the governance structures of mental health organisations (see page 60)					
5	**Ontario Centre for Excellence for Child and Youth Mental Health**	Website: *http://www.excellenceforchildandyouth.ca/*	Partners with agencies across Ontario to support effective, efficient and accessible mental health services for children, youth and their parents and caregivers	- Consumer led strategic advisory committee - Consultation with family members/carers - Consumer (youth) advocacy program - Youth engagement toolkit and online learning modules - Family engagement training guide (online information resource)	x	x	x	x	Opportunities for people to submit online feedback and recommendations (through an email link). Also feedback opportunities through an online blog
5	**Canadian Mental Health Association**	*Engage People with Lived Experience of Mental Health*	Nation-wide, voluntary organization promoting the mental health of	**From page 14:** - Living Life to the Full (Interactive self-help course for mental health consumers)	x	x	x	x	**(page 5):** Create a charter alongside participants Involve participants in audits Use regular participant satisfaction questionnaires

| | | *Conditions and Addictive Behaviours Workbook*

http://www.cmha.bc.ca/ | people experiencing mental illness through advocacy, education, research and support services | - Consumers In Action Leadership Skills Training Program (Training course in advocacy and leadership skills)
- Peer Support
- Bounce Back (skill building, educational, self-hep program)
- Reclaim your Health
- Strongest Families (telephone service providing educational resources and information to families/carers)
- Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES)
- Wellness Recovery Action Plan (WRAP)
- The following are also mentioned as examples of consumer engagement recommended/noted by the Canadian mental health association:
- Use a 360 degree appraisal approach
- Involve participants in policy review on a regular basis
- Get participants to run their own meetings
- Recruit participants for the Board of Directors
- Involve participants in the recruitment of new staff
- Encourage participants to access training alongside staff
- Use group peer support—do participants want to set up a self-help group?
- Explore volunteer opportunities available to participants | | | | | Use questionnaires about up and coming changes
Ensure you have a complaints procedure which is active, up to date and transparent

(page 15): To address standardization, the Peer Support Accreditation and Certification (Canada) [PSACC] was formed. PSACC is a not-for-profit organization created to provide national certification and accreditation services in accordance with nationally endorsed standards of practice for mental health peer supporters |

				- Involve participants in the delivery of training - Get participants involved in delivering conferences and presentation - Involve participants in leaflet design and branding - Get participants to help with fundraising - Introduce peer research - Involve participants in creative groups—newsletters, interactive websites, forums, video, drama, arts					
5	**Ontario Centre of Excellence for Child and Youth Mental Health**	*Developing a Family Engagement Training Strategy Phase 1 Final Report October 2011* http://www.excellenceforchildandyouth.ca/sites/default/files/family_engagement_report.pdf	Works with mental health agencies to strengthen mental health services and build an accessible system of care for children, youth and their families and caregivers	**At the individual level families can be:** - Recognized as an expert in the role of parent/family member and supported in that role - Informed of treatment options and outcomes in a way that is meaningful, and consulted and collaborated with in determining treatment plans, goals and outcomes - Meaningfully involved to support their child through treatment - Consulted before decisions are made with respect to treatment - Engaged in the assessment of their child and family's needs - Recipients of workshops and/or training - Create an environment for open and honest communication, free from judgment - Consider parent/family support network part of the treatment circle **At the service level families can be:**	x	x	x	x	- Fidelity Scales - - Clinical practice guidelines - Performance measures – - Standards and benchmark: these are numerical thresholds for performance and can be established by individuals or groups using arbitrary decisions, consensus or statistically derived thresholds.

				- Involved as parent-support staff - Involved in the design of programs - Involved in quality improvement processes - Involved in the design and implementation of evaluations - Co-trainers in education and training of mental health professionals - Trainers in education and training of family operated groups - Developers of resources (educational, advocacy, or otherwise) for families - Involved in the recruitment of staff - Consulted either individually or through a family advisory regarding language of agency communications **At the policy level families can:** - Participate in task forces, work groups or councils that affect policy - Review and writing of policy - Actively involved in gathering evidence about best practices - Actively involved in the governance of child and youth community mental health settings - Involved in all levels of family advocate organizations Included as members on the Board of Directors					
5	**Health Quality Ontario**		Advisory body for Ontario, provides advice and	- One-on-One Interviews - Group Discussion (e.g., Focus Groups, World Cafés) - Surveys	x	x	x	x	**Uses the Better Together, Partnering with Families Self-Assessment tool/checklist:**

			recommendations on health care services in the province and seeks to involve service users in the design of the health care system	- Anonymous Comment Boxes - Storytelling - Experience Based Co-Design - Patients as public advisors - Advisory council that helps set strategic direction					http://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/better-together-organizational-self-assessment_eng.pdf?sfvrsn=2 **The McMaster patient and public engagement evaluation tool:** https://fhs.mcmaster.ca/publicandpatientengagement/ppeet.html
5	**Sunnybrook Health Sciences Centre**	*Achieving Patient Experience Excellence in Ontario: an idea book* https://www.oha.com/KnowledgeCentre/Library/Documents/Final%20-%20Idea%20book.pdf	Health science centre and hospital in Ontario	- Calling after discharge, follow up information - Mental health survey - Peer led services - Implementing 5P rounding - Health magazine for young patients - Designing frameworks, models, guidelines for community engagement - Patient and family council and advisors - Survey postcard for family feedback - Patient advisors in psychiatry - Real-time patient feedback	x	x	x	x	- Survey data examined for trends, used to guide action plans. - Qualitative feedback was sought from staff - Qualitative feedback sought from consumer participants - Quantitative satisfaction surveys - Performance indicators developed for some projects - Some practical measures and policy developments can be traced to consumer input on advisory councils

| 5 | **Manitoba Health** | https://www.gov.mb.ca/healthyliving/mh/docs/consumerparticipation.pdf | Local provincial government health organisation | **Various suggestions for consumer engagement throughout document:**

- participation in the planning of their individual treatment and rehabilitation services and supports
- participation on boards and committees involved in planning mental health services
- participation in the evaluation of mental health services
- enhanced and meaningful participation including fair, equitable and competitive employment opportunities for consumers in all levels of the mental health system

- communication regarding the purpose and process of consumer participation, clearly articulated to consumers and service providers
- provision of resources and support to facilitate the consumer participation process and enable effective consumer participation, including education and training supports such as instruction on the process of meetings, government processes, best practices in mental health planning and service delivery, and leadership skills development
- significant consumer representation in any forum in which services are being planned and/or developed that will directly affect the lives of consumers | x | x | x | x | - Feedback in the form of surveys and other complaints mechanisms |

				- support for consumer advocacy groups, networks and self-help opportunities - preparation of the work environments and staff for change - multiple participation activities with common objectives in each of the key areas i.e., Policy, Service Development, Staff Training and Selection, Specific Service Feedback and Surveys, Complaints Mechanisms, Information and Rights, and Consumers Treated with Respect					
5	**Canadian Policy Research Networks**	*Handbook on Citizen Engagement: Beyond consultation* http://www.cprn.org/documents/49583_EN.pdf	Advises Canada's leaders on issues and the policy options to 'move Canada forward'	- Citizen Juries and panels - Consensus conferences (dialogue between experts and citizens open to the public and the media) - Scenario workshops (participants use hypothetical scenarios to formulate new ideas, solutions and recommendations) - Deliberative polls (polls participants, involve in discussion, poll again) - Citizens dialogues - Creation of a community engagement team - Consultations, round tables, commissioned research and site visits - Websites and online consultations - Forums involving participants to decide on budgetary measures and governance issues - Citizens assembly	x	x	x	x	- Feedback mechanisms - Surveys - Relaying findings/feedback to participants - Follow up sessions and progress checks - Issuing of public written reports either electronic or print, emphasising the outcomes of engagement activities - Online forums/discussion groups

| 5 | Health Council Canada | *Turning We Know Into Action: A commentary on the National Symposium on Patient Engagement*

http://www.healthcouncilcanada.ca/n3w11n3/NatSymp_Comm_ENG_WEB8.pd | Informs Canadians and their governments on how the vision laid out in the health accords is progressing. Aims to inform decision-making at all levels | - **Patients as Partners** collaborates with health authorities, NGOs, physician collaborative committees, and other key stakeholders to identify opportunities for patient and public engagement in program and service design, and system and community health care transformation
- Patients are engaged through the **Patient Voices Network**, a mechanism to recruit, train, and support patients, families, and caregivers to participate in health care changes at the individual (patient to provider), program and service design, and community and system levels
- **health literacy** for indigenous populations through personal agency and self-determination
- **recruit, train, and support patients** and their families to participate in health care changes for authentic engagement
- A **forum** for administrators and also front-line providers to learn from experiences of patients and their families
- **Patients as active members on quality improvement teams** | x | x | x | x | "**Patient experience measures are central to the overall Integrated Primary and Community Care evaluation, accountability, research, and quality improvement framework. Patients as Partners will know that patient and public voices in the change process have 'stuck' when they see an improvement in population health, an improved patient and provider experience of care, and lower per capita costs overall**. And, patients will be engaged in the design of the provincial evaluation framework." |
| 5 | **Canadian Institutes of Health Research (CIHR)** | *CIHR's Citizen Engagement in Health Casebook* | Government funded organisation working to support and implement | **List of case studies. Various consumer engagement strategies implemented in the case studies.**

- Discussion groups | x | x | x | x | - Consultations with participants
- Public consultation report published on website
- Survey report, annotated on-line report, community |

		http://www.cihr-irsc.gc.ca/e/documents/ce_health_casebooks_eng.pdf	health related research in Canada	- Regional and focused dialogues and online consultations - Community based health and Well-being needs assessment - Working groups - Consultation forum - Interviews - Focus groups - Survey - Steering committee with intersectoral stakeholders and project champions - Community outreach initiatives - Train the trainer sessions - Citizens advisory panel - Iterative, generative and deliberative dialogues - Table work, plenary discussions, and keypad voting. - 'Knowledge networks'					meetings, community newsletter, newspaper were used to disseminate findings and provide feedback to participants about the process - Specific organisational goals and key performance indicators were developed for some projects, written feedback and formal audits were conducted for some projects
4	**Health Canada**	*The Health Canada Policy Toolkit for Public Involvement in Decision Making* http://www.hc-sc.gc.ca/ahc-asc/pubs/_public-consult/2000d	Canadian federal department responsible for monitoring and implementing government funded health services in Canada	- Advertising and social marketing - Public invitations for public comment/requests for proposals - Community mapping - Fact sheets/backgrounder - Focus groups - Info fair or exhibit - Information kits/resources - Mail outs - Media events - Site visits - Bilateral meetings with stakeholders	x	x	x	x	**none**

		ecision/index-eng.php		- Parliamentary committees involving public testimony - Public hearings and seminars - Questionnaires - Workbooks (information resource inviting readers to contribute solutions, etc.) - Computer assisted participation, electronic conferencing - Discussion groups - Tele-voting - Nominal group process - Charrettes (working groups) - Constituent assemblies (extra parliamentary bodies formed by consumers/citizens to influence constitutional issues or reforms) - Delphi Process - Retreats - Round tables - Citizens Juries , panels, conferences (more direct public involvement in decision making)					
4	**Michael Smith Foundation for Health Research (MSFHR)**	*Patient engagement: How can research help us get it right?* http://www.msfhr.org/sites/default/files/McGavin_Holmes_N	Empowers British Columbia's health researchers to pursue world-class research	- Self-management programs - Community reference group - Patient partners on governing councils - Brief action planning (consumer led self-management) - Patient partners attending semi-annual leadership forum	x	x	x	x	none

		ov10_FINAL.pdf							
4	**Infoway**	*Patient Engagement Framework* https://www.infoway-inforoute.ca/en/what-we-do/blog/consumer-health/7035-infoway-s-patient-engagement-framework-helps-us-connect-with-patients-and-consumers	Aims to improve the health of Canadians by working with partners to accelerate the development, adoption and effective use of digital health solutions across Canada	- Annual survey of Canadian health consumers - Public education campaign - Public information resources to feedback the results of surveys and questionnaires - Consumers involved in policy and change management - Consult with advocacy groups - Patient centred care, electronic access to health information	x	x	x	x	none
4	**Health Council Canada**	*Primer on Public Involvement* http://healthcouncilcanada.ca/tree/2.31-	Informs Canadians and their governments on how the vision laid out in the health accords is	**General overview of consumer engagement. Uses the strategies to illustrate the different levels of engagement:** - Advertisements, publication of reports, newspaper inserts, press releases, news conferences, and websites.	x	x	x	x	**none**

		PublicInvolvementPrimer_EN.pdf	progressing. Aims to inform decision-making at all levels	- Public meetings, public opinion polls, public hearings, focus groups, referenda, and meetings with stakeholders. - Citizens juries, citizens' panels, consensus conferences, scenario workshops, deliberative polls, and citizens' dialogues					
4	**Office of the Provincial Advocate for Children and Youth**	http://provincialadvocate.on.ca/main/en/about/aboutus.cfm	Independent organisation providing advocacy for Ontario's children and youth who are either "in care" or on the margins of government care. Partners with children and youth to elevate their voices and promote action on their issues	- Youth led and produced radio show - Youth advisory committee - Opportunities/programs/events allowing children with special needs to communicate their experiences of care - Extensive list of publications containing the lived experiences of children in care	x	x	x		- Inquest database - Surveys and other related feedback mechanisms

4		*Peer Support Resource Manual* http://www.health.gov.bc.ca/library/publications/year/2001/MHA_Peer_Support_Manual.pdf		- A set of guidelines regarding the development and implementation of **peer support programs**. For example, **steering groups and advisory bodies** are discussed in the context of providing a governance/advisory structure to peer support programs. Provision of information is discussed throughout document.	x	x	x		- Develop a process (or use an existing process) for evaluating the performance of the coordinator(s), bookkeeper and peer supporters - Develop a process for evaluating the program as a whole, including: - Consumers/survivors satisfaction - Satisfaction of peer supporters - Satisfaction of the person who - referred consumers/survivors (if not self-referred) - An advisory board may provide guidance for problems, ensure that the program is reaching its goals and objectives and stays on budget
3	**Canadian Association for Suicide Prevention**	http://suicideprevention.ca/get-involved/	Aims to reduce the suicide rate in Canada and minimise the consequences	- Leadership/Steering Committee - Suicide Prevention Awareness - Mental Health and Wellness Promotion - Training - Suicide Intervention & Ongoing Clinical/Support Services	x	x	x		None (generic strategies taken from LivingWorks website)

			of suicidal behaviour	- Suicide Bereavement - Evaluation Measures - Capacity Building/Sustainability					
3	**Saint Elizabeth Hospital**	*A Practical Guide to Implementing Person-Centred Care Education for PSWs in the Home, Community and Long-Term Care Sectors* https://www.saintelizabeth.com/getmedia/3b053be0-3313-45e5-8aea-872781c0b76d/Practical-Guide-for-Implementing-PCC-Education-for-PSWs-October-2013.pdf.aspx	Hospital in Ontario	- Train-the-trainer Sessions for Supervisors (staff training in person centred care – PCC) - Overview of PCC & purpose of the workshops - Review of workshop material - Workshop content development – staff training in person centred care (developed with import from consumers and carers through surveys and interviews) - Train-the Trainer sessions - PFCC (patient and family centred care) workshops (more staff training) Adult learning principles to assist with facilitation - Supervisors Facilitate Workshops with PSWs - Delivered in-person with their teams of PSWs - Three workshops, delivered separately or at one time Online option for missed workshops	x	x			- Evaluated train-the-trainer sessions & PCC workshops surveys & focus groups - PSWs (personal support workers) & PSSs (personal support supervisors participated in the evaluation Pre/post self-assessment surveys - Longer term measures of client satisfaction and employee engagement

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3	**Health Canada**	*Health Canada and the Public Health Agency of Canada Guidelines on Public Engagement* http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/guidelines-public-engagement-publique-lignes-directrice/alt/pub-eng.pdf		- Multi-stakeholder roundtables, crowdsourcing - Bilateral meetings, technical workshops with specific groups - Request for feedback, fact-based questionnaires - Fact sheets, social media postings - Online consultation tools and in person discussions are also mentioned on page 17	x	x			Surveys complaints mechanisms Other consumer feedback processes
3	**Canadian foundation for Healthcare Improvement**	*Advisor Brochure* http://www.cfhi-fcass.ca/sf-docs/default-source/hub-pe/KGH-PT-	Aims to deliver demonstrable results for Canadians by improving patient and family experience and	**Patient experience advisors can:** - Create educational material - Share stories and lived experience - Participate in committee work - Contribute to websites and forms - Work on short term projects	x	x	x		none

		EX-Advisor-Brochure-E.pdf	care, population health and value-for-money	- Serve on a patient and family advisory council					
2	**Calgary Association of Self-Help**		Community Mental Health Centre aiming to provide a safe and accepting environment where living, learning, working and socializing in the community becomes possible	- support group, - peer support, - resource provision	x	x			none
2	**Family Outreach and Response Program**	*Peer Support Group (Talk To Youth Now)* http://familymentalhealthrecovery.org/peer-support-group	Offers recovery oriented mental health support services to families and youth. Promotes an inclusive, equitable and non-discriminatory approach to mental wellness	- Peer support group for youth Families FOR recovery (8 week mental health recovery advocacy group for families who feel they would like to contribute to changes in the mental health system) - Peer led family education and skills training - Families healing together: online educational course for families and individuals dealing with mental health issues	x	x			none

2	**Schizophrenia Society of Ontario**	*Strengthening Families Together* http://www.schizophrenia.on.ca/Search?searchtext=engagement&searchmode=anyword	Educates and support people living with schizophrenia, advocates on their behalf	- Peer support group providing resources and information on relevant topics to family members and friends of individuals with serious a serious and persistent mental illness. Also run as an online course/forum - Youth peer support/advocacy program - Volunteer opportunities - Newsletter - Scholarship program for individuals with Schizophrenia	x	x			none
2	**Mood Disorders Association of Ontario**	http://www.mooddisorders.ca/	Ontario based community organisation providing support and services to people suffering from a mental illness	- Online forums - Open family forum (internet forum) - Substance Use and Mood Disorder Group (peer support group) - Youth living well (interpersonal skills building group for youth and young adults – facilitated peer support group) - OCD Peer support groups for families and individuals - WRAP for families alumni peer support - Newsletter - Blog	x	x			none
2	**Parents for Children's Mental Health**	http://www.pcmh.ca/familyengagement	Organisation aiming to improve the lives of families raising children and youth with	- Peer to peer support groups - Family information resources - Family engagement training - Advocacy toolkit - Information toolkit for families in emergency situations	x	x			none

					x	x				none
			mental health disorders/illness by building the capacity of families to advocate for and access child and youth mental health services	- Education and workshop opportunities						
2	**Family Association for Mental Health Everywhere (FAME)**	http://www.fam eforfamilies.co m/speaker-series/	Organisation aiming to facilitate the development of resilience in families living with mental illness by providing support, education, coping skills and self-care strategies. Advocates for a family centred perspective on mental health issues in our community	- Monthly educational speakers series with professionals and community members - Online resources - Various peer support groups - Training courses - Online training courses - Information tool kits for young carers	x	x				none

| 2 | **Canadian Mental Health Association** | *Brief to the Canadian Mental Health Association (CMHA) National Board of Directors*

http://www.cmha.ca/wp-content/uploads/2012/08/NCAC-Draft-Brief-to-Canadian-Mental-Health-Association.pdf | Nation-wide, voluntary organization promoting the mental health of people experiencing mental illness through advocacy, education, research and support services | - Toolkits about barriers and strategies for engagement
- Lead in the development of three resource packages on consumer participation for information sharing on strategies across CMHA
- Lead a survey of consumer participation within CMHA 1998
- Provided input on policy statements on Consumer Involvement, 1992, and Consumer Volunteers, 1998
- Assisted with encouraging nominations of consumers to the National Board
- Produced the Consumer Participation Celebration Package, a history of consumer participation within CMHA in honour of CMHA's 75th anniversary, 1992
- Established the Consumer Participation Award in 1990 | x | | | | - Monitors, encourages and supports implementation of consumer participation initiatives at all levels of the Canadian Mental Health Association.
- Provides consultation and advice to the National Board of Directors and Committees on current issues
- NCAC representative services on the CMHA National Office's Awards Committee
- Provides advice to the CMHA National Board of Directors related to emerging issues as identified by the board or as identified by NCAC members |
| 2 | **E Health** | *Mental Health Engagement Network (MHEN): Facilitating Mobile Patient Centric Care*

http://www.e-healthconferen | E-Health conference and tradeshow showcasing e-health related technologies | **Lists the following as potential e-strategies:**

- Create C&Y Specific PHR and Monitoring Tools. Support eConsults, Messaging and Tracking Use of Health and Social Support Systems
- Medication Management Tool for Patients and Families to become more knowledgeable and empowered | x | | | | - Brief mention of **surveys** and **focus groups** as accountability mechanisms |

		ce.com/pastpr esentations/20 15/201462646 477/CS381.pdf		- Online Supervised Open Discussion Periods - supported by a team parent, provider and kid - anyone can enter and start the discussion - MYM & Kelty & TMH - create digital collaboration and linkages to themselves & with National Web Forum - Inventory Resources Available In Regions and Provinces and Accessing Advice						
2	**Auditor General of British Columbia**	*Public Participation: Principles and Best Practices for British Columbia* http://www.bca uditor.com/site s/default/files/p ublications/200 8/report11/rep ort/public-participation-principles-and-best-practices-british-columbia.pdf	Independent legislative body providing financial and performance audits of government programs and initiative	**Overview of consumer engagement. Higher levels of engagement are discussed (see page 6) but no specific strategies are mentioned. The following are mentioned:** - Press release, website announcement - Issue paper, presentation - Open house, public meeting - Survey, telephone interviews - Workshop, online forum - Letter, website announcement	x	x				**none**
1	**BP Hope**	*http://www.bph ope.com/curre nt-issue-2/*	Magazine and online forum dedicated to	- Magazine - Online forum providing information and support to people with bi-polar disorder.	x					none

			supporting people with bi-polar disorder	- Emphasis on lived experience and consumer engagement.					
1	**Moodsmag**	http://www.moodsmag.com/moods/index.php	National publication providing educational information on the topic of mental health	**Magazine and blog** providing information and support for people with a range of disorders. Emphasis on lived experience and consumer engagement.	x				none
1	**Canadian Institute for Health Care Information**	https://www.cihi.ca/en/health-system-performance/quality-of-care-and-outcomes/patient-experience#_about_survey	Aims to deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care	**This patient experience survey is part of a nationally coordinated effort to monitor the experiences of health consumers in Canada**	x				- The survey is an accountability mechanism for evaluating general health services

1	**British Columbia Health**	*Integrated Primary and Community Care Patient and Public Engagement Framework* http://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/primary-health-care/patients-as-partners-public-engagement-2011.pdf	Provincial government health department/website	**Abstract and theoretical, no specific engagement strategies (see accountability mechanisms)**					**Various suggestions about criteria for evaluating consumer engagement. For example:** - The goal of engagement was clear - Information provided during the engagement process was timely, balanced and easily understood - The appropriate stakeholders were identified - Design and implementation of the engagement process enabled meaningful participation
				NEW ZEALAND					
5	**Matua Raki**	*Matua Raki: Service user, consumer and peer workforce*	National centre for addiction workforce development in New Zealand. Works with other	- Ensuring an effective consumer voice at key levels of the addiction sector - Facilitating forums for the Addiction Consumer Leadership Group - Supporting the ongoing development of consumer advisory roles	x	x	x	x	- Evaluation guidelines - Line management - Individual and group peer supervision - Non-peer managers of peer workers benefit from access to an internal or external peer

| | | *A guide for managers and employers*

http://www.matuaraki.org.nz/uploads/files/resource-assets/service-user-consumer-and-peer-support-workforce-a-guide-for-managers-and-employers.pdf | organisations and people across the country and around the world to support the addiction workforce | - Developing the peer support worker role within the addiction sector
- Providing peer supervision and mentoring skills training
- Developing relationships at a national level with mental health service user bodies
- Identifying and negotiating changes to any policies and practices to align with peer values
- Liaising with human resources on adapting employment policy and processes for peer workers 16
- Ensuring training for peer and other staff
- Consumer resource and information service for information, education and networking (taken from the national service framework… see page 6). | | | | | | - Peer workers are pivotal in evaluating services
- Acting as a conduit for feedback from peer workers within the organisation and people who use the service. |
| 3 | **Mental Health Advocacy and Peer Support** | http://www.mentalhealthadvocacypeersupport.org/ | Provides and supports a variety of peer led and peer support services and advocacy initiatives | - Peers support workers
- Support to engage in advocacy
- Group peer support programs
- External speakers ("Themes") to help people make decisions about their own care
- "RecoveryWorks" workshop programme
- "WorksforMe" employment help
- "WRAP" (Wellness Recovery Action Plan) for individuals to become their own best advocate to maintain own wellbeing
- Support groups for a range of MH disorders | x | x | | | | **Reports on a peer health coach pilot in Australia: Peer Health Coaching Pilot in Australia Peer Health Coaching Pilot Project showed:**

- an improvement in both physical health and mental health
- 73% of clients achieved their goal within the 6 sessions, or achieved it enough to feel |

									- confident to complete it independently - an overall improvement in health literacy
2	**Mental Health New Zealand**	https://www.mentalhealth.org.nz/get-help/faqs/consumertangata-whaiora-networks/	Provides free information and training to mental health consumers, and advocates for policies and services that support people with an experience of mental illness, as well as their families and friends	**A list of external organisations for self-help and peer support – this is 'information hub' providing information**	x	x			**none**
2	**Awareness Canterbury**		Self-help network of people who have either used mental health or addictions services or who identify with experiencing mental illness, substance use	- Consumer advocacy group- a network of volunteers who have used mental health or addictions services, or who have experience mental distress or substance use issues. - Monthly meetings - Writing submissions on local and national policy - Producing a short film and training resource for inpatient staff - Organising a mental health market	x	x			

			issues or distress	- Running forums on topical issues (mental health consumers human rights through the Cantebury earthquakes) - Helping organisations that want consumer feedback, and consumers who want to have their thoughts heard link up for projects - Creating a youth mental health working group - Running training for tangata whai ora to gain skills and possible paid work in areas such as sitting on staff interview panels for services						
2	**Comcare**	http://www.comcare.org.nz/what-we-do/jobconnect/peer-support/	Provides a range of support services to people living with a mental illness or addiction in NZ	- Percival House - Warmline - Intentional Peer Support Training - Peer Health Coaching	x	x				
1	**Question Persuade Refer (QPR)**	http://www.qpr.org.nz/getting-help/community-concern-about-suicide.aspx	Provides mental health services to government, non-government agencies and to the community in the areas of suicide prevention and postvention	**Postvention support service provides:** - meetings between all the different sectors involved (e.g., community groups, Child Youth & Family, Mental Health services, Group Special Education, Victim Support) so that the sectors can plan together and have a co-ordinated approach. - training in suicide screening, or refresher training for professionals in suicide risk assessment as soon as it is requested - assistance to the community with strategies for working with media to ensure safe and helpful media reporting	x					**none**

				- collaboration with agencies to help them identify which people in the community may be at risk for suicide attempts, and planning how to mitigate the risks. - resources on topics such as bereavement by suicide, suicide contagion, and how to form effective postvention working groups - the provision of training to gatekeepers, organisations and individuals on topics related to suicide prevention					
1	**Clinical Advisory Services (CASA)**	http://www.casa.org.nz/images/CPRS-Information-Sheet.pdf	Aims to share clinical expertise through training, supervision, support and consultancy. Particular emphasis on the delivery of effective suicide prevention and postvention services to organisations and communities	- Collects and verifies of information about suicides and possible psychosocial connections between them. - Helps to identify key stakeholders to take part in an interagency meeting. - Facilitates and Co-ordinates of initial interagency meetings to help implement an evidence-informed postvention response. - Provides of psycho-education and information on contagion management. - Identification of barriers and gaps in service provision. - Develops of a community postvention plan for the current situation. - Managers media to minimise harm and maximise its potential for benefit	x				

*Score is out of 5 where each point gets a score for an organisation: (1) individual level; (2) service level; (3) organisation level; (4) policy level engagement strategy; and (5) evaluation/accountability mechanism reported. The highest standard for engagement get organisations that score 5/5 and the lowest is 0/5.

Appendix 3: Black literature

#	Citation	Aim of the study	STRATEGIES FOR ENGAGEMENT					Evidence of effectiveness/effective outcomes
			Method(s) of engagement	Design	Governance	Delivery	Evaluation	
1	Ungar, M., et al. (2015).	Evaluate community-based gang prevention program for children	Evaluation advisory committee	x			x	Decrease of risk factors for the target youth, increase of the use of supports,
2	Terry, J., et al. (2015).	Explore the role of world café as an effective learning strategy (mental health consumers and social work students)	Service user and carer involvement group in the design of the world café Focus groups in the evaluation	x		x	x	Positive shared learning experience for students and service users
3	Sacchetto et al., (2016)	Construction of capabilities measure Capabilities Questionnaire for the Community Mental Health context (CQ-CMH)	Focus groups (develop consumers gain/goals) Steering Committee (consumer oriented data-analysis, item and rating scale development and review) Consumer volunteers (check face validity)	x			x	Collaborative approach (engaging consumers in the process) improved the ecological validity of the measure

4	Larkin et al., 2015	To use EBCD to improve services and the Experience of 5Hospitalization for Early Psychosis	**In-depth interviews** of service users, families and hospital staff **Focus groups** of the above to provide feedback on the analysis **Co-design event** where an edited film of service-user and family narratives was shown and participants worked in groups to co-design service improvements **Implementation** of co-design activities	x		x	x	Audit at 9 months and re-audit at 12 mo to track improvements by the steering group – frustrations around delays in implementation of the 'action plan'→ participants were left feeling disappointed and dissatisfied. It is crucial that the changes they co-design are then implemented to avoid causing further dissatisfaction and alienation
5	Ennis et al. (2014)	The development of an ePersonal Health Records system for people with severe and enduring mental health problems, and provide a model of involving stakeholders throughout	An advisory board (including consumers) was set up to guide the project. A lot of the work was completed by researchers within the Service User Research Enterprise.	x	x			Involving stakeholders at each stage of the development was crucial to its success. The eventual success will depend upon embedding it within routine practices (implementation) in services
6	McKay et al (2014)	Collaborative adaptation and development of family program for HIV	Collaborative planning team of young kids, families and professionals	x		x	x	Improved mental health at 3 month follow up (emotional problems, conduct, functional impairment)

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		affected youth and their families	Another independent working group of professionals and older youth Caregiver/youth dyads to test the intervention					Better attendance for all groups.
7		Describing the involvement of persons with lived experience of mental illness in development of a self-help tool.	Practice research team (including 3 service users), monthly 4 hour meetings to build trust and mutual learning	x		x	x	Starting down the path of service user involvement in intervention design fosters commitment to follow through in the remaining implementation and research phases.
8	Vargo et al. 2013	to Develop a Framework for Assessing Quality of Care in Children's Mental Health Services	Stakeholder input (parents of children) in the development of the Quality Care framework; and Creating quality care indicators A mail survey to test the final product designed by a focus group of caregivers → sent to families of 400 children	x	x			• Improvement in child functioning & stability • Improvement in overall family stability and functioning • Child's needs are met • Child/family satisfaction
9	MacDonald et al. 2014	explore the experience of service user governors	The Council of Governors in three foundation trusts was observed for a year		x			The dislocation of the service user governor role from other forms of service user activity and involvement result in confusion about notions of

		in foundation trusts and their capacity to hold boards to account	Focus groups with service user governors were undertaken at each trust					holding a trust to account and representation of other service users.
10	Litva et al 2009	Explore variations in lay perceptions of user involvement in clinical governance	Patient user groups Citizen groups Health interest groups		x			Groups had different desires in involvement in clinical governance: **Patients**: as a strategy to improve their own access to the best health care. **Advocates** used their specialist knowledge to seek to improve health-care services for the 11collective benefit of similar users. **Citizens**: will act in their capacity as citizens and taxpayers with rights to use public services and will contribute to or participate with others collectively in the society in which they live
11	Meyer 2007	to construct a comprehensive self-help website for students for depression	Focus group of students (Student interviews Focus group commentary) Expert professional group	x				Both student and expert groups were impressed with final site quality and usefulness

			Funding charity steering group					
12	Rise et al. 2015	To investigate whether implementing a development plan intending to enhance user participation in a mental hospital had any effect on the patients' experience of user participation	Development plan including user representatives THE PLAN A patient education centre An office run by paid 'expert' users Strategy for education of user reps Budgeting for patient education Improving info materials	x	x	x	x	**NON-randomised controlled trial:** The development plan had no effect on the patient self-reported experience on user participation (in fact, some measures showed improvement in the control sites). NO STAFF WERE INCLUDED.
13	Rise et al. 2016	To investigate the long term effect on the professionals' knowledge, practice and attitudes towards user involvement after four years	**See the above, same study 4 years later** This follow up only includes interviewing *professionals working at the hospital*	x	x	x	x	**Consumer Participation Questionnaire (CPQ) used as an outcome measure -** reported significantly more events that educate consumers and that patients were informed about confidentiality. A higher proportion of professionals in the intervention hospital involving users in planning and/or carrying out the mental health service. Overall there were more changes after four years (this study) compared to after

								16 months. NO USERS WERE INCLUDED. **[12,14,28,35,36].**
14	Owens, C., et al. 2015	To help young people who self-harm and health professionals to communicate with each other about self-harm and its management, and whether they could agree on what constituted safe and relevant advice.	Online forum of 77 young people with experience of self-harm and 18 health professionals	-	-	-	-	The young people were keen to share their lived experience of self-harm and its management with health professionals. They engaged in lively discussion and supported one another during emotional crises. Despite registering to take part, health professionals did not actively participate in the forums.
15	Van der Ham 2015	To gain insight into the quality of patient participation in the development of clinical practice guidelines (Multidisciplinary Guideline on Employment and Severe Mental Illness)	four patient representatives in the development group and advisory committee two focus group discussions with patients, a dialogue session and eight case studies	x	x		x	Evaluation criteria (for the group) balancing the number of patient reps and professionals addressing adversity of the patient population adequate patient representation transparency of the process clarity of expectations, roles and tasks involvement throughout the process involvement in decision-making

									facilitation of patient involvement – addressing patient needs in the process positive attitude towards patient involvement **DIRECT OUTCOMES** criteria consensus on content incorporation of patient input practical relevance dissemination of the
16	Buckingham et al. 2015	To develop a decision support system (DSS), myGRaCE, that integrates service user (SU) and practitioner expertise about mental health and associated risks of suicide, self-harm, harm to others, self neglect, and vulnerability.	Step-by-step process of involvement Individual interviews Focus groups (practitioners and Sus) Software development with SUs	x				x	Practitioner expertise can be reformulated in a format that simultaneously captures SU expertise, to provide a tool highly valued by SUs. A stepped process adds necessary structure to the assessment, each step with its own feedback and guidance.
17	Van Draanen et al 2013	To examine lessons learned from the People with Lived Experience Caucus in the Toronto Site of the At Home/Chez Soi Research	Caucus of People with Lived Experience (project advisory body)	x	x				Facing time constraints and given little direction, the Caucus developed through a tumultuous process related to both internal and external barriers to meaningful inclusion. **Recommendation for future consumer**

		Demonstration Project on Homelessness and Mental Health						**engagement:** early involvement, purposeful selection of members, clear communication of roles and responsibilities, a consumer coordinating group, and space for critical dialog throughout the engagement process.
18	Whiteside et al. 2014	To get user input and feedback on acceptability of messaging content intended to engage suicidal individuals.	Individuals who reported suicide ideation and who were waiting to be seen for a mental health appointment completing anonymous online survey. They were recruited through flyers at the service.	x				A model of engagement for including target users in the development of uptake strategies for online mental health interventions.
19	Perry et al 2013	Review on involvement of people who have experienced mental health difficulties in teaching mental health students communication skills.	User-led education for mental health students		x	x(?)		**1.** When service users teach about communication there is a move in student's practice towards improved attitudes towards people with mental health difficulties. **2.** Some students were concerned that the users were not sufficiently representative of most people with mental health difficulties. **3.** This type of teaching made professionals reflect more

#	Author	Aim	Method						Findings
									deeply on the way they communicate.
20	Hester et al., 2015	To develop a quality of care instrument (SEQUenCE (SErvice user QUality of CarE) that is grounded in the service user perspective and validate it in a mental health service	Focus groups of service users in all stages of the scale development (design, test, validation)	x					SEQUenCE is a valid, reliable scale that is grounded in the service user perspective and suitable for routine use. It may serve as a useful tool in individual care planning, service evaluation and research.
21	Barbato et al., 2014	Review three recent studies involving stakeholder participation in service evaluation	Questionnaires for focus groups of service users and carers/family Focus groups involved in the design of surveys and completing the surveys	x				x	**Survey findings:** Insufficient information, underinvolvement of users/relatives in planning, no choice of clinician, psychiatrist domination, and limited helpfulness of interventions. With stakeholder participation in service evaluation, the present medical framework will need reshaping.
22	Shattell et al., 2014	To describe the lived experience of community, recovery-oriented, alternative crisis intervention environment "The Living Room", an alternative to ED environment	non-directive in-depth interviews of staff and persons in psychiatric patients in emergencies					x	non-clinical care settings are perceived as a helpful and positive alternative to ED by staff and consumers.

23	Mohatt et al. 2013	To engage a large and diverse audience and built a new community around suicide prevention through participatory public art, including community design and production of a large public mural about suicide, storytelling and art workshops.	seven first person accounts of "Finding the Light Within", a community mobilization initiative to reduce the stigma associated with suicide				x	Arts participation can address suicide: from raising awareness and reducing stigma, to promoting community recovery, to providing healing for people and communities in need
24	Simons et al. 2007	Evaluate the impact and process of consumer involvement in the process of developing Mental Health Service User Academic post.	Key stakeholder groups User group Academic staff group Mental health nursing students group	x			x	Adopting an inclusive model can help to integrate user perspectives. Support needs for innovative service user posts are not met by traditional employment induction practices. The Service User Academic is a powerful role model for students and challenged elitist attitudes by confronting notions of expertise.
25	Fortune et al., 2007	Develop an appropriate process/model for NWAMHP, which extends/integrates with	Consultations with existing adult mental health service consumers and consumer consultants regarding models used	x				**the key recommendations** Employing consumer consultants to promote consumer participation A structure to support consumers to develop their

		an existing carer consultant program	in the aged care settings.					own consumer participation activities, for example a Consumer Action Group supportive environment for the consumer consultants Working in parallel with the Carer Peer Support Program
26	Gardner-Elahi & Zamiri, 2015	Discuss the use of collective narrative practice in forensic recovery service through the use of 'Knowledge Group' and evaluate the use of Knowledge Group	"Knowledge Group" was a purpose-designed narrative group, targeted at those recently discharged and those coming up to discharge. Focus group of group members and 'outsiders' to evaluate the 'effectiveness' of the knowledge group	x			x	Service users were placed in a position of expertise and power where they were listened to and respected, different to their usual position. They were able to tell their story and demonstrate their knowledge.
27	Brown & Townley, 2015	Examine the predictors of consumer engagement in mental health consumer-run organizations (CRO)	Surveys to 250 CRO members attending 20 CROs. Leaders of each CRO reported organizational characteristics through a separate questionnaire.	x			x	CROs that can effectively promote sense of community, organizational empowerment, shared leadership, and peer counseling may be better able to engage participants
28	diMambro & Doody, 2009	Evaluate the introduction of service user-led teaching on	Service-user led educational program was compared to			x		No significant differences in the content, relevance or presentation of the two

		experiences of psychiatric services and interview style into the educational programme of trainee psychiatrists	psychiatric staff led education to psychiatric trainees						programs. Service user-led teaching can be integrated into a trainee's education programme without reducing the perceived quality or relevance of their education
29	Rush, 2008	Investigate the impact on student nurses' practice following service user involvement in the classroom.	Service user sessions in the classroom Interviews of the students afterwards about their experiences			x			Service user involvement in the classroom can act as a catalyst for transformative learning and positive actions in practice.
30	Dinniss et al., 2007	Evaluation of DREEM (Developing Recovery Enhancing Environment Measure)	Collaboration of service staff, residents and service user group representatives				x		As an experimental measure DREEM provides a user-led structure, which enables services to measure their commitment to, and effectiveness in, providing recovery-based care.
31	Cowling et al., 2007	Development of professional education seminar aimed at service providers who work with children of parents with mental illness and their families.	A collaborative project by professionals, mental health consumers and carers	x					project was successful in achieving the initial aims of developing consumer-focused professional education The program is now an integral component of an innovative mental health promotion project in Victoria

32	Agrawai et al., 2016	Describe a novel teaching course that pairs service users as advisors to senior psychiatry residents	Service users who had experience working as peer support workers and/or system advocates met up monthly with psychiatric residents for 6 months. Residents were interviewed about their experience.			x		Positioning service users as advisors to psychiatry residents holds promise as a powerful way of reducing distance between future psychiatrists and service users and facilitating system reform toward person-centered recovery-oriented care.
33	Austin et al., 2014	clarify the characteristics that constitute peer support and its contribution to recovery	ethnographic fieldwork and semi-structured interviews with nine peer advocates at a consumer-run organization					three themes describe how peer support influences recovery: (1) transforming experience into expertise, (2) understanding the mechanics of peer support, and (3) launching peers towards their own recovery Peer support plays a critical role in helping clients move beyond their patient role to an empowered sense of personhood.
34	Oades et al., 2010	Develop a consumer satisfaction questionnaire in which consumers work as collaborative researchers to	Mental health consumers as researchers to develop a model of consumer directed evaluation of mental health services	x			x	The final questionnaire has satisfactory internal consistency and appeared to be useful with inpatients and outpatients.

				x					
		increase its face validity and relevance.	and a set of instruments to evaluate the services						
35	Owens et al. 2011	engage a group of people with relevant lived experience in the development of a text-messaging intervention to reduce repetition of self-harm.	A series of six participatory workshops and invited service users and clinicians to help us work out how to get the right message to the right person at the right time, and to simulate and test prototypes of an intervention.	x					Service users rejected both the idea of a generic, one size fits all approach and that of audience segmentation maintaining that text messages could be safe and effective only if individualized. This led to a way of supporting individuals to author their own self-efficacy messages and store them in a personal message bank for withdrawal at times of crisis.
36	Hansen et l. 2010	Validate a user-friendly, brief scale measuring patient satisfaction (PatSat scale).	Over three phases, patients were involved in developing and validating the scale against the Verona satisfaction subscale	x					The PatSat is a new patient satisfaction scale validated in a psychiatric out-patient population. It appeared popular with patients and took less than 1 minute to fill in.
37	Ruiz et al., 2008	Develop and validate a multidimensional generic questionnaire measuring satisfaction with treatment with medicines SATMED-Q	debriefing process with an expert panel of six members and 21 chronic patients in four focus group on the questionnaire items	x					Valid measure?

38	Turner-Bowker et al., 2009	inform the development of a comprehensive asthma PRO assessment with input from patients and clinical experts	adult asthma patients participated in either one of three focus groups (n=21) or individual cognitive item debriefing interviews (n=20) to discuss how asthma impacts their health-related quality of life (HR-QOL), and provide feedback on a preliminary set of asthma impact survey items and prototype patient reports	x					Incorporating input from patients, clinicians, and measurement experts in the early stages of product development should improve the construct validity of this PRO measure and enhance its practical application in healthcare
39	Hayes et al., 2010	to identify appropriate measures for examining the well-being of spouses assisting with veterans' recovery from PTSD	Two focus groups with spouses of veterans in identifying domains for assessment	x					Focus group interviews yielded valuable input on the domains of experience and key questions that should be included in an assessment battery.
40	Rathod et el., 2010	produce a culturally sensitive adaption of an existing CBT manual for therapists working with patients with psychosis from specified ethnic minority communities	Ethnographic approach 4 Focus groups (two with mental health consumers from ethnic minorities and two professionals groups)	x					Practical guidelines and cultural adaptations for professionals using CBT with ethnic minorities

No.	Author	Aim	Method					Findings
41	McAndrew et al., 2012	better understand the needs of young people who care for mentally ill parents through a World Café event	2 'World Café' events led by young service users and carers Audience made of up social workers and nurses	x				insight into what local young carers need to improve their mental health, and more importantly, how we can utilize our skills to help them achieve their goals
42	Fallon et al., 2012	develop a partnership consortium, bringing together local organisations involved in promoting the mental well being of young people.	'World Café (a detailed account of the process of one of the above 'cafes')	x				The event resulted in three collaborative research proposals and the realisation that young people need opportunity to participate through utilising more innovative ways of engaging with the professional adult world
43	Chaplin et al., 2012	Examine the first stage of development of a guided self-help (GSH) pack called the Self Assessment and INTervention pack (SAINT)	Delphi methods and focus groups on 2 expert groups: professionals or clinical experts and service users to inform the contents of the SAINT	x				Delphis on two focus groups generated the contents of the SAINT and demonstrated versatility in this dual approach by being able to gain a consensus from both groups
44	Storm et al., 2010	test the generalizability of this finding to the implementation of Computerised CBT in a service user-led, third sector Self Help Clinic	User led self- help clinic			x	x	Improvement on multiple well-being measures after 2 sessions CCBT can be effectively implemented in a service user-led, Self Help Clinic, increasing access to psychological

				x					therapies for depression and anxiety
45	Robinson et al., 2009	create acceptable and effective prototype technologies to facilitate independence for people with dementia	scoping stage (five focus groups, 10 people with dementia and 11 carers); participatory design stage (five workshops, 22 participants) prototype development stage (two people with dementia and one carer).	x					not clear, acceptable prototype created?
46	Storm et al., 2011	study the effect of an intervention program designed to (1) increase attention to user involvement and (2) increase user involvement at the departmental level	Intervention with activities to: (1) inform, (2) collaborate, (3) consult and (4) involve in their own/family members care - Survey for staff and patients	x				x	intervention led to improvements in providers' reports on organizational user involvement, patient collaboration, and carer involvement, service users did not report better satisfaction of care after the intervention
47	Segal et al., 2010	determine the effectiveness of combined Self Help Agency (SHA) and community mental agency and community mental health agency (CMHA)	Randomised trial comparing regular CMHA services or to combined SHA-CMHA services	x				x	Based on five recovery-focused outcome measures, member-empowering SHAs in combination with CMHA services produced more positive recovery-focused results than CMHA services alone

48	Taylor et al., 2010	Evaluation of a consumer driven mental health service. The Station Inc. in rural South Australia	Twenty-five in-depth interviews were conducted with the Station members, volunteers, management committee members, and staff			x	x	The benefits of consumer-driven services are that they provide flexibility and adaptation, and they overcome the power differential that exists between professionals and 'patients' or 'clients
49	Berry et al .2011	evaluation of the experiences of two peer support specialist (PSS) workers and their managers within one UK mental health trust	PSS workers and managers were interviewed individually using a semi-structured format				x	Positive experiences and challenges were identified in relation to PSS employment, both for PSS workers and their teams
50	Fukui et al., 2010	examine the positive effects on recovery outcomes for people with severe and persistent mental illness using peer-led groups based on Pathways to Recovery: A Strengths Recovery Self-Help Workbook (PTR)	a baseline survey before the group and again at the completion of the 12-week sessions				x	statistically significant improvements for PTR participants in self-esteem, self-efficacy, social support, spiritual well-being, and psychiatric symptoms after 12 weeks
51	Olin et al., 2010	examine the impact of a collaboratively developed training model, called the	A group of family peer advocates were trained by PEP trainers throughout 10 weekly 4 hour sessions				x	no significant increase in knowledge about mental health content, but post-training assessments indicated increased collaborative skills

		Parent Empowerment Program (PEP),	Interviews of participants						and mental health services self-efficacy
52	Callander et al., 2011	Trial new ways of capturing consumer and carer experiences of mental health services, and integrate that feedback into service quality improvement	Consumer and carer research teams discussing two 1–1.5-hour sessions, held over two separate days same teams transcribing and 'coding' the discussion as co-researchers	x					the importance of having strong support and belief at leadership levels, opportunities to build the relationship and develop mutual trust and respect, a common vision and a clearly articulated set of values, targeted training appropriate to the needs of the team members, independent work bases, and mutual support to overcome challenges
53	Bell et al., 2010	assess the message preferences of individuals affected by depression as part of a project that will evaluate interventions to encourage at-risk patients to talk to their physicians about depression	Online conjoint survey, 249 volunteer respondents with depression rated their liking of the messages					x	Individuals with depression respond differently to depression care messages, underscoring the need for careful message development and evaluation
54	Ben-Zeef et al., 2013	development of a smartphone illness self-management system for people with schizophrenia.	Stage 1: Survey for 904 individuals with schizophrenia on their current use of mobile devices						Through a comprehensive development process, we produced an mHealth illness self-management intervention that is likely to be used

			Stage 2: A multidisciplinary team used consumer and practitioner input and employed design principles for the development of mHealth intervention Stage 3: 12 consumers participated in laboratory usability sessions					successfully, and is ready for deployment and systemic evaluation in real-world conditions
55	Crawford et al., 2003	identify methods for involving service users in the planning and delivery of psychiatric services and factors which may assist and impede this process	A cross-sectional postal survey of user groups and providers of psychiatric services of barriers and enablers of User Involvement (UI)	x		x		**Factors that promote UI** The support of managers Acceptance by staff that UI is required Good personal relationships between managers and users User groups have the required skills∕expertise National policies which make UI a requirement Project has clear issue with tangible outcomes The subject is considered a priority Avoidance of jargon during discussions
56	Lasalvia et al., 2012	compare the perceptions of staff,	Community mental health services				x	Significant discrepancies between patient and staff

				x					
		patients, and their family members on mental health outcome measures - needs for care and service satisfaction - to identify potential areas of discrepancy	Their outpatient adult patients with a diagnosis of psychosis The patients' family members						perceptions of service needs, as well as staff and family members service needs and between family members and patients. Lack of information appears to be a strong factor in dissatisfaction with psychiatric care for both patients and their relatives
57	Louch et al, 2004	Examine the experiences, expectations and needs of service users with depression in primary care, and what factors are important to the service user that could inform how future services are developed	Qualitative interviews of adults on depression medication managed by their GP	x				x	Structured care is important in the management of depression Written information about depression is very useful Written information about the side effects of antidepressants helps adherence to treatment Patients experience fear and anxiety when the time comes to stop antidepressant medication
58	Paul et al., 2004	develop an evidence-based information booklet for patients and relatives preparing for transfer from intensive care units.	Semistructured interviews were used to elicit the views of patients and relatives regarding their information needs	x					the importance of including patients and relatives in booklet development to ensure that their needs for information are being met need for more staff education in relation to patients and

				x					relatives needs when transferring
59	Solomon et al., 2016	To incorporate meaningful participation of people living with HIV [PHAs]) in the development of evidence informed recommendations for rehabilitation practice	PHAs were involved in a process to develop practice recommendations internally as members of a project team and externally through formal endorsement of the recommendations	x					providing time to develop as a team and understand the roles, biases, and expertise of each member, engaging community in initial discussions to determine the most meaningful involvement, realizing that participation in research may trigger anxiety and stress in community members developing terms of reference to clarify roles and expectations providing opportunities for skill development, conducting formal evaluation of the process and satisfaction of community
60	Van Oostrom et al., 2007	development, implementation and evaluation of a return-to-work intervention for sick-listed employees with stress-related mental disorders (SMDs)	Intervention Mapping - all stakeholders were involved in focus group interviews: employees recently sick-listed with SMD, supervisors and occupational health professionals.	x		x	x		Intervention Mapping was found to be a promising method to develop interventions tailored to a specific target group in the field of occupational health

61	Perreault et al., 2010	describe the experience of a standing panel of psychiatric outpatients over a period **of five years**	Panel of Mental Health Service Users is a standing panel that joins representatives of the institute's decision makers 13 meetings were held, involving a total of 22 patients as active members of the panel. 11 decision makers of the institute consulted the panel regarding service organization, quality of services, and client satisfaction		x		x	In a context of internal evaluation, by giving direct and rapid access to service users' perspectives on key issues regarding service provision, the panel appeared to be a practical procedure for use in complement with other satisfaction assessment methods
62	Greenfield et al., 2008	compare the effectiveness of an unlocked, mental health consumer-managed, crisis residential program (CRP) to a locked, inpatient psychiatric facility (LIPF) for adults civilly committed for severe psychiatric problems.	**Randomised controlled trial**			x	x	Participants in the CRP experienced significantly greater improvement on interviewer-rated and self-reported psychopathology than did participants in the LIPF condition; service satisfaction was dramatically higher in the CRP condition
63	Rivera et al., 2007	Compare consumer-assisted and non-	203 clients with severe and persistent mental			x		no one program emerged as categorically superior to the

				x					others i.e., there was no evidence that the presence of consumers enhances case management outcome
64	Biddiss et al., 2013	To design an innovative interactive media display in a pediatric hospital clinic waiting space that addresses the growing demand for accessible, contact-surface-free options for play	Ten staff members, 11 children/youths, and 6 parents participated in the design and evaluation of ScreenPlay: an interactive screen play for positive distraction in a hospital waiting room	x					All participants strongly agreed that the interactive media display would improve the healthcare waiting experience.
65	Davison, 2006	develop a toolkit that outlines the role of the registered dietitian (RD) and advocates for RDs in primary health care (PHC) mental health programs	(1)a comprehensive literature review, (2) a focus group discussion with a national working group, (3) interviews with consumers about RD services, and (4) evaluation of the toolkit	x					The evaluation of the final draft of the RD toolkit confirmed that it reflected the visions of PHC. Dietitians are encouraged to use its contents to advocate for positions in mental health PHC settings
66	Rathod et al., 2010	produce a culturally sensitive adaption of an existing CBT manual for therapists working with patients with psychosis from specified ethnic minority communities	individual semi-structured interviews with patients with schizophrenia, focus groups with members of ethnic communities.	x					There was consensus from the respondent groups that CBT would be an acceptable treatment if culturally adapted.

67	Ducharme et al., 2001	develop and evaluate, through a participatory approach, an intervention to promote the mental health of women caregivers in institutions	Focus groups of family members in the scoping Workshops with family members in the program creation Co-investigators in the experimentation of evaluation	x			x	The aims of the study were met: to increase empowerment and self-efficacy and to decrease stress and psychological distress of caregivers
68	Badger et al., 2010	examined a sample of burn survivors to learn about their views of peer support and the services of a national burn survivor organization	a random sample of burn survivors from a national burn support organization, The Phoenix Society, were surveyed about their perceptions of peer support, and the value they placed on it relative to the key burn recovery.			x	x	peer support is a promising resource in burn rehabilitation warranting further investigation
69	Chien et al., 2004	Test the effectiveness of a mutual support family- intervention for schizophrenia in terms of improvements in patients' functioning, use of services, and re-hospitalization compared with a psychoeducation	Controlled trial was conducted including 96 Chinese families who were caring for a relative with schizophrenia in Hong Kong			x		mutual support intervention was associated with consistently greater improvements in patients' functioning and rehospitalization and stable use of mental health services over the follow-up period compared with the other two interventions

		intervention and standard care						
70	Chien et al., 2008	1 year follow up of the above study						mutual support group experienced significantly greater improvements in families' burden, functioning and number of support persons and length of patients' re-hospitalization at 12 month follow up
71	Griffiths et al., 2005	determine the effectiveness of a culturally-adapted lay-led self-management programme Chronic Disease Self-Management Programme (CDSMP) for Bangladeshi adults with chronic disease	Bangladeshi adults with diabetes, cardiovascular disease, respiratory disease or arthritis from general practices and randomised them to the CDSMP or waiting-list control.			x	x	The programme improved self-efficacy and self-management behaviours. Communication and healthcare use were not significantly different between groups.
72	Lawn et al., 2007	test the feasibility and utility of combining a generic, clinician administered and peer-led self-management group approach for people with serious mental illness.	GPs and case managers used a patient-centred care model to assist patients with serious mental illness to identify their self-management needs, and match these with interventions			x	x	Collaborative care planning, combined with a problems and goals focused approach, resulted in improved self-management and mental functioning at 3 to 6 months follow-up

			including peer-led, self-management groups and one-to-one peer support.					
73	Leung & Arthur, 2004	examine the effectiveness of self-help groups in the rehabilitation of people recovering from mental illness	individual interviews of clients and four focus group interviews of professionals and volunteers, in a Hong Kong self-help organization			x	x	self-help group involvement provided positive experiences for the members and led to some changes in their lives which contribute to the rehabilitation of their illness
74	Nicolaidid et al., 2013	develop and evaluate a multifaceted, community-based depression care program for African American women with a history of Intimate Partner Violence (IPV)	a community-based participatory research (CBPR) approach to develop, implement, and evaluate the intervention 6-month intervention where a peer advocate provided education, skills training, and case management services	x		x		significant improvements in depression severity, self-efficacy, self-management behaviors, and self-esteem. Common themes to why the program was helpful: the program was by and for African American women, it fostered trust, and it taught self-management strategies with practical, lasting value.
75	Treloar et al. 2013	examine two community-controlled peer support services aimed at increasing access to Hep C care and treatment for opiate substitution	Semi-structured interviews in two clinics with three groups of participants: clients, staff and peer workers and examined the operation of the service				x	All groups of participants noted that the service met its goals of engaging clients, building trusting relationships and providing instrumental support for clients to access Hep C treatment

		treatment (OST) clients, ETHOS	in relation to process, outputs and impacts					
Key publications								
76	Weinstein et al., 2005	compare two Quality Assurance (QA) reviews of a Mental Health Day Centre, one as a traditional inspection-type event and one as a collaborative process with a user-led QA agenda	The study compares the management, style, evaluation tools and service user responses for the two reviews; it considers staff perspectives and discusses the implications of a collaborative, user-led QA process for service development.				x	Because both users and staff had participated in most aspects of the second review they were more willing to work together and action plan to improve the service. It is suggested that the process contributed to an evolving ethos of more effective quality improvement and user involvement within the organization.
77	Harding et al., 2010	elicit users' perceptions of their involvement in the development of NICE mental health guidelines	Semi-structured interviews of service user guideline development group representatives	x				Four main categories of how users felt their contribution were valuable Drawing expertise from experience Overcoming stereotypes to demonstrate value Unwritten rules influence deliberations Social comparisons affect confidence
78	Tambuyzer et al, 2013	To examine the relationship between perceived patient	Survey of mental health service users asking about service			x	x	Perceived involvement in own mental health care (decision making, taking control) is

		involvement associated with satisfaction and empowerment	satisfaction, patient involvement and empowerment.					associated with greater patient satisfaction
79	Tong et al., 2011	describe a targeted EFFECTIVE approach for involving consumers actively in guideline development, by focusing on topic and outcome selection, and to discuss the impact on content and structure of the final guideline.	Patients and carers from a Sydney hospital attended three peer-facilitated workshops to complete group-based exercises on topic and outcome selection for guidelines for early stage chronic kidney disease. These workshops were run in parallel with the guideline-writing group. The topics and outcomes identified by the workshops were fed back to the guideline writers.	x				Four main changes to guideline-related outputs were observed. A new guideline subtopic was introduced, guidelines were consumer-endorsed, guideline recommendations and suggestions for clinical care were augmented with consumer-focused issues, and plain English guidelines were developed.

Summary of engagement strategies in black literature.

Strategy	Design	Governance	Delivery	Evaluation
Consumer specific advisory/steering committee/board/group	2	2		4
Representatives in other groups/committees	5			4
Focus/user group	20			4
Event	3			
Consumer part of a collaborative (interdisciplinary) project	11			3
Interviews/consultations with individual consumers	11			11
Survey	6			6
Workshop	3			
Peer-led/controlled			9	

Appendix 4: Broad alignment of engagement strategies across LifeSpan

Note: the following recommendations as to broad alignment of engagement strategies across the nine LifeSpan strategies is based on a high level understanding of the scope of each strategy. A more detailed analysis and implementation of engagement will be undertaken by LifeSpan staff throughout the project.

1 Aftercare & crisis care

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Patient activation, information sharing on care options	5. Co-design of Aftercare & crisis care services	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Patient activation, on care options with professionals,	6. Reference/advisory groups used managing aftercare & crisis care	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Online tools provided after crisis for patient/family	7. Peer workers at the programs, peer led self-help, peer mentors	11. Lived Experience-led training for staff	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	Surveys on satisfaction/ shared decision making (OPTION-scale; CollaboRATE)	8. Feedback mechanisms, ESQ/YES,	12. Interviews with Lived Experience reps, regular audit	
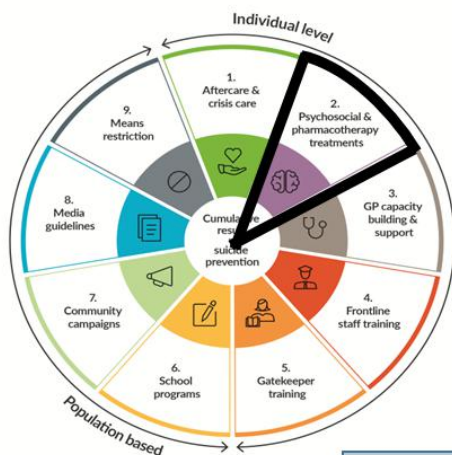
2 Psychosocial & pharmacotherapy treatments

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Patient activation, information sharing on care options	5. Co-design of interventions and programs	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Patient activation, Decision Aids on the course of treatment	6. Reference/advisory groups in treatment programs	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Online tools provided for self-help, adjunct management	7. Peer led programs, peer mentors at each site	11. Lived Experience-led training for staff	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	Surveys on satisfaction/ shared decision making (OPTION-scale; CollaboRATE)	8. PoC, MHSIP surveys, PPS, PSQs	12. Interviews with Lived Experience reps, regular audit	
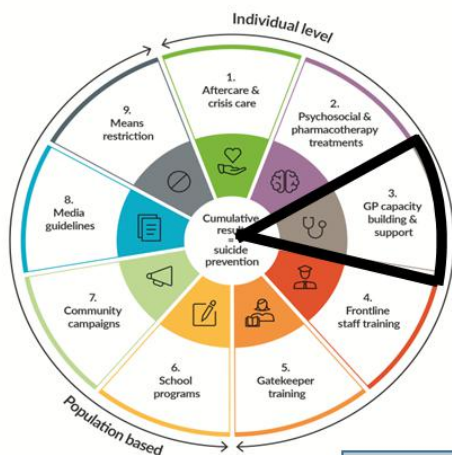
3 GP capacity building and support

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of capacity building activities	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference/advisory groups in capacity building activities	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. Lived experience led training, peer mentors at each site	11. Lived Experience-led training on the importance of GP capacity building	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanism for clients, impact on care	12. Interviews with Lived Experience reps, regular audit	
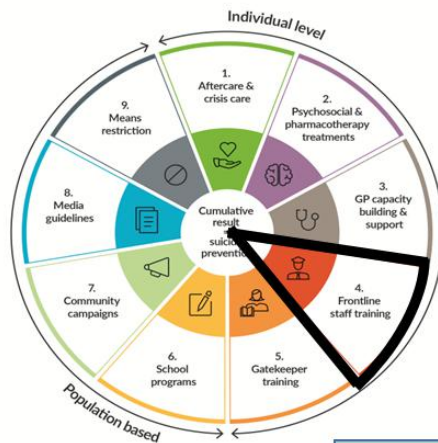
4 Frontline staff training

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of staff training protocols	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference/advisory groups in training protocols	10. Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. Lived experience led training	11. Lived Experience-led training on the importance frontline staff training	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanism for patients, impact on care & wellbeing	12. Interviews with Lived Experience reps, regular audit	
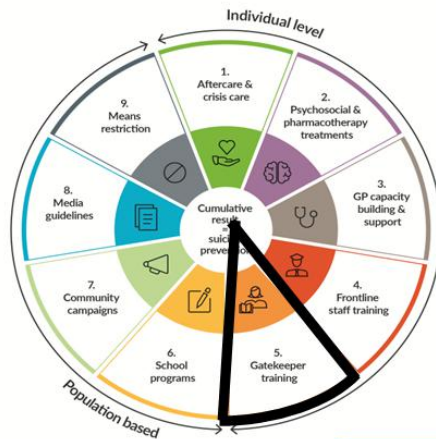
5 Gatekeeper training

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of staff training protocols	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference/advisory groups in training protocols	10. Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. Lived experience led training	11. Lived Experience-led training on the importance for gatekeepers	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanism for communities; impact on help-seeking	12. Interviews with Lived Experience reps, regular audit	
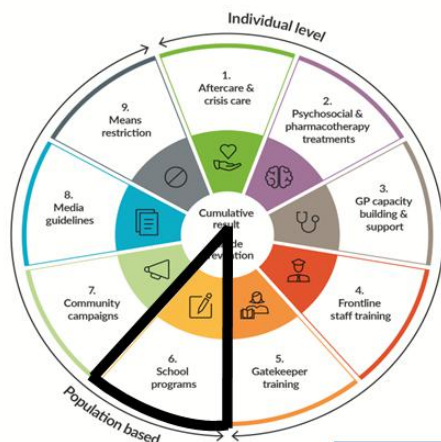
6 School programs

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of targeted school programs	9. Advisory group/reps (parents and students with lived experience)	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference/advisory groups of students in managing programs	10. Lived experience-led student committees, representatives in all levels of decision-making in school, parents with lived experience in school boards	
Delivery	3. Self-help SP programs, online tools	7. Students with lived experience leading/delivering programs	11. Lived Experience-led training on the importance for gatekeepers	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanism; students as co-evaluators	12. Interviews with Lived Experience reps, regular audit	

7 Community campaigns
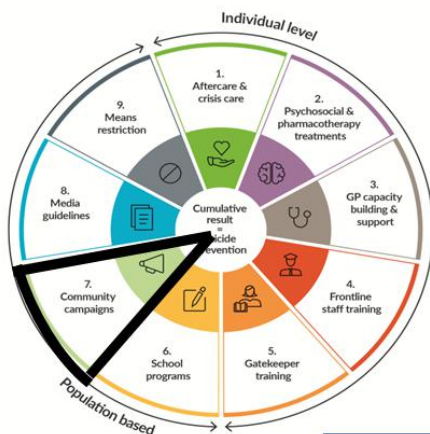
	Individual	**Service/ program**	**Organisation**	**Policy/ strategy**
Design	1. Shared decision-making	5. Co-design of community campaigns	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Reference groups Representatives on committees	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. 'Peer champions' in the community, Lived Experience -led campaigns	11. Lived Experience-led training for staff	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanism for clients, co-evaluation	12. People with lived experience monitoring	

8 Media guidelines
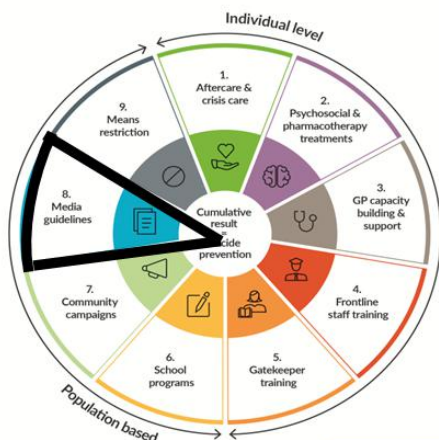
	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design of media guidelines	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Focus groups	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. Lived-Experience led guideline development	11. Lived Experience-led training for staff of the impact of media	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanisms for the community, co-evaluation of guidelines	12. People with lived experience monitoring process/any progress	
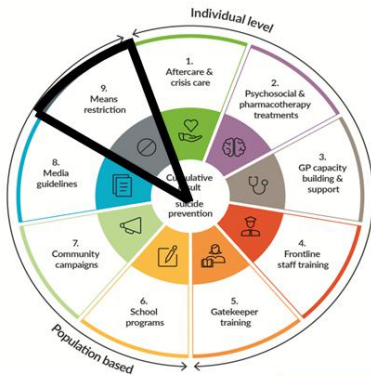
9 Means restriction

	Individual	Service/ program	Organisation	Policy/ strategy
Design	1. Shared decision-making	5. Co-design	9. Advisory group, representatives in working groups	13. Co-design of policy/strategy
Governance/ Management	2. Treatment preferences	6. Focus groups	10 Lived experience-led committees, representatives in all levels of decision-making	
Delivery	3. Self-help programs/tools	7. Lived-Experience led development for means restriction	11. Lived Experience-led training for staff of the impact means restriction	14. Regular reviews of policy and its implementation by Lived Experience reps
Evaluation	4. Satisfaction surveys	8. Feedback mechanisms for the community	12. Interviews with Lived Experience reps, regular audit	

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