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ACT Partners in Recovery Program Evaluation Framework

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Part 1: Background

The Partners in Recovery (PIR) initiative was funded in the 2011/12 Budget to provide people with severe and persistent mental illness with support for coordinated and integrated care across a range of services.¹ The Program's aim is to strengthen the system response to people with complex needs through improving tailored, wrap-around care, strengthening cross-sectoral collaborations and referral pathways and promoting a recovery model. Improvement of these mechanisms will in turn improve outcomes for people experiencing severe mental illness.¹

A National evaluation is underway to assess Program level success, including system improvements, the effectiveness of the PIR approach and key factors underpinning success/challenges.² However, as the Program is designed to be flexible and locally responsive, the National evaluation will not provide specific information to PIR Organisations on the characteristics of their own Program. As such, an evaluation of the PIR Program at the local level is required to enable PIR Organisations to identify successes and challenges of their local approach and assess the impact of the Program on participant outcomes. This will assist in quality improvement processes for the duration of Program funding and identify key issues for sustainability of system and process changes beyond the end of the funding period.

1.1 Scope of Work

The purpose of this project was to develop an evaluation framework for the Partners in Recovery Program implemented by the ACT Medicare Local. The framework has been designed to focus on local processes and outcomes. This includes both qualitative and quantitative measures to complement the existing National evaluation³ with particular attention paid to gaps in National measures. To facilitate feedback and quality improvement, the evaluation framework incorporates a plan for the implementation of the evaluation as part of Program processes. However, implementation of the evaluation is outside the scope of the current project.

1.2 Objectives

The objectives of the project were to:

1. Provide a framework for evaluation that can assess the extent to which the ACT PIR Program is effective in achieving its goals;
2. Identify key research questions and the research design that would be required for the evaluation;
3. Identify data from routine Program collections and any additional qualitative and quantitative data that will be needed to support the evaluation, including:
 - a. Process and outcome measures for all participants;
 - b. Detailed participant journeys for a small number of participants;
 - c. System-level measures;
4. Develop a flexible plan for the implementation of the evaluation by Program staff with possible collaboration with consultants.

1.3 Methods

The methods used to develop the evaluation framework were as follows:

- Brief literature review
- Analysis of the Program's goals through relevant reports, Program guidelines and processes, and discussions with key staff
- Identification of the priorities for the evaluation in collaboration with ACT Medicare Local and PIR staff
- Identification of appropriate brief quantitative process and outcome measures
- Identification of tools for collecting participant journey data
- Development of a staged implementation framework, including suggestions for assistance for more comprehensive measures
- Provision of a draft report for feedback
- Discussion of the framework and measures with the PIR Consortium and Support Facilitators
- Submission of this final report detailing the framework and plan for implementation.

Part 2: Evaluation design

2.1 Individual level key questions

- Has the Program improved the participant's mental health (clinical measures)?
- Has the Program improved the participant's quality of life?
- Has the Program improved the participant's social inclusion?
- Has the Program improved the participant's perception of recovery?
- Has the Program improved carers' quality of life?
- Are participants satisfied with the Program?
- Do participants experience better coordination of their care?

2.2 System level key questions

- Have new/improved partnerships been forged?
- Has a local model of coordination been implemented?
- What are the key features of the model of coordination?
- Does the coordination model depend on Program funding?
- Has coordination improved according to the local model?
- Are PIR organisations satisfied with the model?
- What are the factors that facilitate effective partnerships and referrals?
- What are the challenges that affect implementation?
- What are the main factors that may affect sustainability of the model, both within and beyond PIR Program funding?

2.3 Research design

Whilst many evaluations are conducted post-program only, it is usually more useful to conduct the evaluation across multiple time points to detect changes in key outcomes and use findings in continuous improvement cycles.⁴ Administration of participant measures on entry to the Program, at a change of service intensity to “monitoring only” and on exit from PIR will allow evaluation to be built into the existing participant assessments and record-keeping. This also minimises peaks of administrative burden associated with surveying all participants at the same time, instead allowing continuous data collection, analysis and feedback for quality improvement. Regular use of the system level measures with providers will augment the participant measures, allowing a more complete and inclusive quality assessment and improvement process. Figure 1 provides an overall representation of the evaluation framework, depicting all data collection options including core, highly desirable and optional measures as described in Part 3.

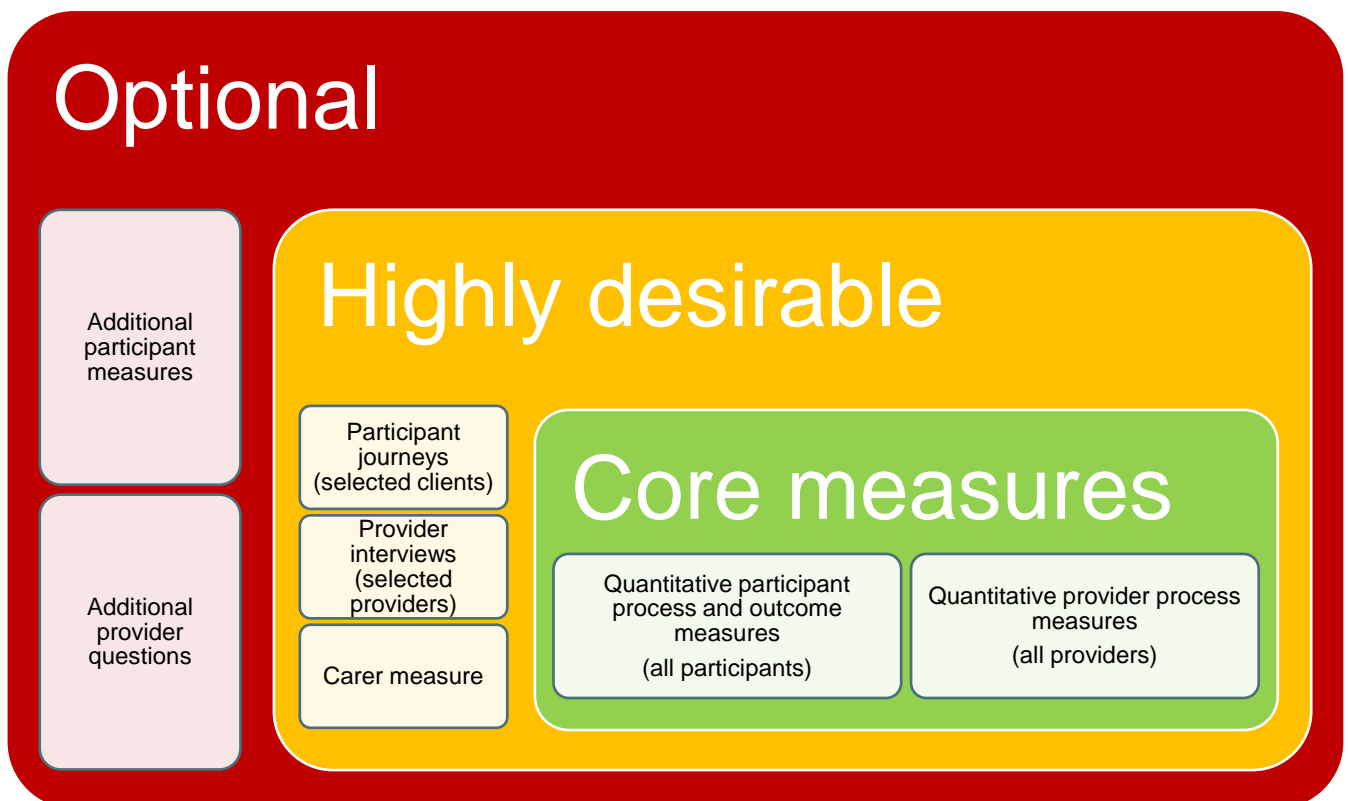


Figure 1. ACT PIR Evaluation framework design

Part 3: ACT Partners in Recovery evaluation framework

The evaluation framework is designed for flexibility. Table 1 details the framework according to the key individual and system level questions listed in Part 2 and is divided into three levels – core, highly desirable and optional - colour-coded for easy identification. Each level includes and builds on the previous; thus, the amount of information gathered, burden on participants and the resources required to implement the evaluation framework increase as follows:

- Green (core): brief, mostly quantitative measures for all participants, focusing on participant recovery and experiences at the individual level, and measures of coordination and sustainability at the system level.
- Orange (highly desirable): inclusion of participant journeys for selected participants, additional measure for carers, more extensive interviews for providers.
- Red (optional): additional questions for interviews, clinical measure and a longer participant recovery measure.

Full details of quantitative measures, including key references, instructions, questions and response options are contained in Appendix 1. Appendix 2 provides additional information on collection of participant journeys, including mapping service pathways.

To highlight how the local evaluation complements the National approach, the final column of Table 1 outlines proposed measures for each question as described in the National PIR Evaluation Framework.³ Most National-level measurement is for selected participants and providers at selected sites, at few time points. By contrast, the ACT PIR evaluation framework is designed to collect information on all participants (subject to informed consent) as part of Program implementation on a continuous basis. The ACT evaluation also addresses some key questions not covered in the National framework.

The chosen quantitative measures have all been developed and/or validated with consumers. However, all measures and qualitative questions should be piloted with a small number of PIR stakeholders (participants and providers) to assess burden and acceptability of processes before implementation and to minimise the possibility that key areas of importance for the evaluation “critical reference group” are missed.⁴

Table 1: ACT PIR Evaluation framework

Level	Measurement	Question/Area of interest	Measures	National approach
Individual	Quantitative measurement (all participants) <i>Three time points:</i> <ul style="list-style-type: none"> • <i>Entry to PIR</i> • <i>Mid-point (switch to monitoring)</i> • <i>Exit from PIR</i> 	Has the Program improved the participant's mental health (clinical measures)?	Kessler-10 (K10) (10 items)	K10 from National Outcomes and Casemix Collection data, final report only
		Has the Program improved the participant's quality of life?	Personal Wellbeing Index (PWI) (8 items)	World Health Organisation – Quality of Life (WHO-QoL), pre/post with sample in longitudinal sites
		Has the Program improved the participant's social inclusion?	Community Integration Measure (CIM) (10 items)	Self-report outcome survey, pre/post with longitudinal sites; Qualitative, annual with sample

Level	Measurement	Question/Area of interest	Measures	National approach
		Has the Program improved the participant's perception of recovery?	Self-Identified Stages of Recovery (SISR) (1 item, five statement choices)	Not measured directly
			Recovery Assessment Scale (RAS) (41 items)	
		Has the Program improved carers' quality of life?	Schizophrenia Caregiver Quality of Life Scale (S-CGQoL)(25 items)	Carer Assessment Tool pre/post with sample at longitudinal sites, annual consultations

Level	Measurement	Question/Area of interest	Measures	National approach
	Quantitative measurement (all participants) <i>Two time points:</i> <ul style="list-style-type: none"> • <i>Mid-point (switch to monitoring)</i> • <i>Exit from PIR</i> 	Are participants satisfied with the Program?	Canadian Institute for Health Information (CIHI) questions from domains: interpersonal communication, comprehensiveness of services, impacts of care	Satisfaction survey, single or ongoing Qualitative, annual
		Do participants experience better coordination of their care?	CIHI questions from continuity and coordination domain	Not measured directly with participants
	Participant journey (selected participants). <i>Interviews at three time points:</i> <ul style="list-style-type: none"> • <i>Entry to PIR</i> • <i>Mid-point (switch to monitoring)</i> • <i>Exit from PIR</i> <i>Mapping of all referrals and service use across complete journey</i>	What does the journey of an ACT PIR participant look like, from entry to the Program to exit? <ul style="list-style-type: none"> • Entry: what are their goals and expectations? • Mid-point: are goals and expectations being met? What is good/what isn't? Suggestions for improvement • Exit: What was the overall experience? Were goals and expectations met? Were suggestions acted upon? 	Narrative, probing overall experience, satisfaction, types of assistance, referrals, goals Process mapping to follow referral patterns and service use	Annual consultations with selected participants Minimum Dataset (MDS) & Camberwell Assessment of Needs Short Appraisal Scale (CANSAS) data

Level	Measurement	Question/Area of interest	Measures	National approach
System	Quantitative measurement (selection of PIR members) <i>Approximately every 6 months.</i>	Has a local recovery-based model of coordination been implemented?	Recovery Self-Assessment provider version (RSA) (32 items)	Annual consultations with selected PIR Network members + National stakeholders
		Provider experiences (coordination, satisfaction)	Sections C (Team Functioning) and D (Health Care Service Delivery) of Canadian Institute for Health Information Primary Health Care Provider survey (adapted 14 items)	Pre/post survey of PIR Orgs and PIR Network members Annual consultations with selected members
	Interviews with service level PIR stakeholders, Support Facilitators, PIR Consortium reps and PIR Lead Agency reps <i>Interviews spread across several time points to identify issues and assess success of solutions. Focus on local level issues, particularly those raised by local participants.</i>	Have new/improved partnerships been forged?	PIR network interviews	Pre/post survey of PIR Orgs and PIR Network members Annual consultations with selected members
		Has a local recovery-based model of coordination been implemented?	PIR network interviews	Annual consultations

Level	Measurement	Question/Area of interest	Measures	National approach
				with selected PIR Network members + National stakeholders
		What are the key features of the model of coordination?	PIR network interviews	Annual consultations with selected PIR Network members + National stakeholders
		Does the coordination model depend on Program funding?	PIR network interviews	Not asked in this way (see sustainability)
		Has coordination improved according to the local model?	PIR network interviews	Pre/post survey of PIR Orgs and PIR Network members Annual consultations with selected members
		Are PIR organisations satisfied with the model?	PIR network interviews	Not specifically asked in this

Level	Measurement	Question/Area of interest	Measures	National approach
				way (see facilitators)
		What are the factors that facilitate effective partnerships and referrals?	PIR network interviews	Annual consultations with selected PIR Network members + National stakeholders
		What are the challenges that affect implementation?	PIR network interviews	Annual consultations with selected PIR Network members + National stakeholders
		What are the main factors that may affect sustainability of the model, both within and beyond PIR Program funding?	PIR network interviews	Annual consultations with selected PIR Network members + National stakeholders

Part 4: Evaluation implementation

4.1 Ethics

According to the National Health and Medical Research Council (NHMRC) guidelines^{5, 6} if the primary purpose of the evaluation is internal quality improvement, approval by a Human Research Ethics Committee (HREC) is not a formal requirement. However, it is good practice to adhere to the values and principles of the National Statement on Ethical Conduct in Human Research, including respect, research merit and integrity, justice and beneficence. Adherence to these guidelines helps to manage the risks and benefits of the evaluation for those taking part (PIR participants and providers), particularly informed consent to participate, the management of unequal relationships (e.g., participants dependent on the Program), the burden on participants and the protection of privacy. The Statement is available online at

<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e72.pdf> and further information regarding quality assurance/evaluation oversight is contained in a separate statement

http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e111_ethical_considerations_in_quality_assurance_140326.pdf.

As noted in the latter document, consideration should be given to the intended and possible future use of data collected for quality improvement and the vulnerable nature of the population involved, both of which are listed as triggers for ethical review.⁵ In particular, it is important to consider whether the findings from the evaluation might be published/used for research purposes in the future (e.g., to ensure the wider dissemination of the findings for the benefit of service planning and policy making). The ANU ethics committee advises they do not commonly grant retrospective approval for the use of data collected prior to the submission of an ethics application. If there are plans to use findings beyond internal quality improvement processes, ethics approval should be sought prior to commencing data collection.

Several options exist for accessing an HREC. Partnering with a research organisation with access to a constituted HREC and well-established research governance procedures is one option and would allow the evaluation to contribute to the scant literature regarding coordination for people with serious mental illness and complex needs. Possibilities for such a partnership are outlined in section 4.2. Alternatively, the ANU offers ethics review

to organisations without access to a committee, currently at a cost of \$2000+GST. Any variations or amendments to the approved protocol incur additional cost. Protocols that involve people with serious mental illness go before the full ANU HREC, which meets monthly (except December). The committee usually requests clarification and amendment to submitted protocols before approval. The overall timeframe for preparation, submission, amendment and approval of an ethics protocol is approximately 1-3 months.

Informed consent

Implementation of the local evaluation will require some minor modifications to the existing PIR participant information sheet and consent form as detailed below. These changes are needed regardless of whether formal ethical approval is sought.

- An explanation of why there is a local evaluation as well as a National one and that they may be asked to take part in both is needed. During feedback sessions, one suggestion was to identify the local evaluation with a different name, such as “Quality Improvement Review.”
- Plans for linking participant responses across time points (e.g., by code) should be developed and details included.
- To address the management of the dependent relationship between participants and local PIR staff, it should be made clear to participants that they are providing feedback for local evaluators but that their choice to participate and the answers they provide will not affect the services they receive.
- Information on how the locally collected information will be used and stored, and who will have access to it should be added.
- Specific consent to participate in the local evaluation should be added to the consent form.

An information sheet and consent form should also be developed for PIR providers to participate in the evaluation.

4.2 Implementation options

Core measures (green)

The measures highlighted in green in Table 1 form the core of the framework. The full measures and response options are provided in Appendix 1 together with key references and information on appropriate permissions or source acknowledgement. The measures and questions have been selected to provide information on core participant outcomes

(quality of life, social inclusion and recovery) together with the key system process/outcome (coordination) from the participant perspective. Measures of system level outcomes from the provider perspective are also included in the core framework. This level of implementation is designed to be conducted entirely within the Program and existing resources (i.e., without the assistance of external evaluators or researchers).

Individual measures

Implementation of the core measures involves administration of a 20-item self-report questionnaire at entry to the Program measuring participant quality of life, social inclusion, perceptions of recovery and confidence in the system. At the change to “monitoring only” (or similar) and at exit from the Program, these areas are measured again to identify changes, and 22 participant experience of services questions are also added to form a 42-item self-report questionnaire. These measures are in addition to the current Minimum Data Set (MDS) and Camberwell Assessment of Need Short Appraisal Scale (CANSAS)⁷ collections, which provide demographic and needs assessment information. The goal-setting section of the PIR Action Plan can also form part of the evaluation of participant outcomes if it is reviewed at the mid-point and exit from Program to assess achievement of goals. The questionnaires can be administered by Support Facilitators or other PIR stakeholders as part of usual participant contact, but it is important that participants understand that their answers will not affect the services they receive. If it is not considered essential to link individual ratings of system level outcomes over time, the opportunity to return the participant experience section of the questionnaires anonymously (e.g., in a feedback box) may encourage frank feedback on service delivery. Other suggestions raised in consultations with PIR Consortium members and Support Facilitators included having “survey completion sessions” with catered morning tea and support to complete questionnaires from peer workers or the ACT Mental Health Consumer Network, or providing reply paid envelopes for participants who may not attend services where feedback boxes are located.

The majority of measures use rating scales that assess agreement with statements or score degree of satisfaction. These are easy for participants to complete and also straightforward to analyse and interpret. Analysis of individual items for each participant separately can give detailed information on specific issues within each outcome (e.g., satisfaction with personal relationships). Total scores can also be calculated for the Personal Wellbeing Index (PWI)⁸ and the Community Integration Measure (CIM)⁹ by simply summing item scores to give overall measures of quality of life/wellbeing and social

inclusion. Change scores on both individual and total scores can be calculated across the three time points to examine how a participant's wellbeing and social inclusion change over the course of the Program. Movement in responses to the single-item Self-Identified Stages of Recovery (SISR) will track changes in perception of recovery.¹⁰ Some members of the PIR Consortium were uncertain about the stages of change model underpinning the SISR and did not feel its wording, such as use of the term "illness" was consistent with recovery. However, Support Facilitators disagreed and thought it was a useful measure that could be used at regular contacts.

To report results at the Program level, mean scores across all participants can be calculated for the PWI and CIM at the three time points. The most meaningful reporting for the participant experience questions is the percentage of participants who endorsed each response option. This allows direct identification of domains in which participants are giving positive and negative ratings and can inform quality improvement processes.¹¹

System measures

The core service provider measures include a 46-item self-report questionnaire, consisting of a scale to measure recovery-oriented care and selected provider experience questions regarding coordination and team functioning,¹² along with three open-ended questions to explore barriers and facilitators for Program effectiveness and sustainability. The richest data would be obtained by asking the open-ended questions as part of provider interviews, as discussed in the next section. However, if resources do not permit interviews, useful information on key issues for quality improvement could also be gained by including long-answer questions at the end of the self-report questionnaire. There are no clear time points at which to conduct provider evaluations, but these should be done at least six-monthly with all providers in the PIR Program who consent to participate.

The Recovery Self Assessment (RSA) scale is scored by calculating the mean of ratings across all items to give a recovery-oriented service summary score for each respondent.¹³ These summary scores can then be used to calculate the mean score for the entire Program. Consortium members liked the RSA and there was some support for also using the consumer (participant) version of the RSA as a recovery measure, so that participants and providers were being measured on the same items. However, others felt the scale was too long for inclusion with the other core measures, and previous feedback from consumers has suggested many items are not liked.

As for the participant experience measures, the quantitative provider experience measures are best reported as the percentage of providers who endorsed each response option.

These aggregated results will provide information on the Program as a whole from the provider perspective, and together with the participant results will inform quality improvement processes.

The open-ended questions, whether asked in written or interview form, will require qualitative analysis for key themes. There are many good books to guide rigorous qualitative analysis (Liamputtong & Ezzy's *Qualitative Research Methods*¹⁴ is a good Australian text) but a basic thematic analysis can be conducted without specialist training. For rigour, responses should be analysed separately by more than one person to identify the key themes. The separately-developed themes should then be compared and any differences discussed so that a final list of key points is agreed upon. Responses to the open-ended questions will provide information both for Program operation and for system changes necessary to continue Program achievements beyond the end of PIR funding.

Highly desirable measures (orange)

The sections of the framework highlighted in orange in Table 1 build on the core measures to provide significantly greater qualitative information about participants and providers. In particular, this level of evaluation introduces participant journeys. An overview of participant journey methods is provided in Appendix 2.

Whilst it may still be possible to implement some or all of the orange level measures within existing PIR resources, engaging assistance to implement this level of evaluation is strongly recommended. Options for assistance may include: contracting an external consulting or community group to assist with data collection; engaging an experienced research/project officer within the Program to conduct data collection and analyses; making part or all of the evaluation available as a medical student, Masters or PhD project; or engaging a research centre to carry out the entire process. The latter two options constitute formal research requiring ethics approval; therefore, if these are desired options for any part of the evaluation, ethics approval should be sought before the evaluation is commenced.

Individual measures

Using participant narratives/stories and careful recordkeeping, participant journeys are designed to elicit very detailed and complete information on how participants with particular characteristics of interest (e.g., NDIS participants) move through the PIR Program and their experiences as they do so. Collection of stories involves a lightly-structured in-depth interview at the three participant measurement points, exploring goals,

expectations and experiences with the Program. This is coupled with detailed records of all mental-health-related appointments, referrals, emergency department visits and hospitalisations.¹⁵ The collection of participant journey information is intensive both for participants and for those conducting the evaluation but the opportunity to tell stories in their own words (rather than be restricted to closed questions) is often very rewarding for participants and results in rich information that provides a “human face” to the evaluation findings and reports.^{16, 17} A number of tools are available to guide the collection of participant journeys: some key tools developed and/or used in Australia are described in Appendix 2.

The highly desirable level also includes a measure of carer quality of life, the Schizophrenia Caregiver Quality of Life (S-CGQoL).¹⁸ This relatively new measure was developed to explore the quality of life of carers of people with schizophrenia, beyond the usual scales measuring burden, coping and caregiving alone. Despite its name, questions do not appear to be specific to the experience of caring for someone with schizophrenia and are likely to be relevant for carers of people with any severe and persistent mental illness. The S-CGQoL consists of 25 items measuring seven dimensions: psychological and physical wellbeing, psychological burden and daily life, relationships with spouse, relationships with psychiatric team, relationships with family, relationships with friends and material burden. Results consist of dimension scores, calculated as the means of the individual items on each dimension, and a global S-CGQoL index, calculated as the mean of the dimension scores. Changes in scores on the S-CGQoL across the three participant measurement time points may provide information on the impact of PIR on carers.

System measures

The additional questions for providers suggested at the highly desirable level include specific investigation of the model of coordination and how it operates. These questions, when combined with the core questions on barriers, facilitators and sustainability, are more suited to individual interviews and are therefore more resource-intensive. Interviews should be conducted with PIR stakeholders in various roles (Support Facilitators, staff in organisations providing services, PIR Lead Agency members etc.) at a range of time points throughout the Program. Individual and/or group discussions about problems identified by participants and by providers may be used to develop informed responses as part of quality improvement and Program sustainability efforts.

Optional (red)

The final measures included in the framework, highlighted in red, provide the most complete picture of the Program and its impacts when added to the previous core and desirable measures. Two of the optional measures address issues not directly addressed in the National evaluation framework. However, they are listed as optional because they represent additional burden on participants and/or they are difficult to measure.

Individual measure

The first optional additional quantitative measure for participants is the Kessler 10 measure of psychological distress (K-10).¹⁹ The K-10 is a short measure of depression and anxiety symptoms that is easy to complete and interpret. On a five-point scale, participants rate the amount of time in the last four weeks that they have felt each of the 10 symptoms. Individual item scores are summed to give an overall measure of psychological distress. Using the K-10 across the three measurement time points would allow tracking of changes in participants' clinical symptoms and comparison of the cohort against Australian norms.²⁰

The second optional participant measure is a longer recovery scale, the Recovery Assessment Scale.²¹ This 41 item scale provides a very detailed understanding of participant recovery in easy language. However, its inclusion would double the length of the participant self-report questionnaire. Previous work conducted by NIMHR to pilot evaluation measures with people with serious mental illness has indicated that questionnaires should be as brief as possible, so the added value of detailed information should be weighed against the burden on participants.

System measures

Two additional areas are listed as optional questions to include in interviews for providers: partnerships and satisfaction. The formation and improvement of partnerships is well-covered by the National evaluation framework, using the Partnership Assessment Tool, surveys and annual consultations with providers. However, it may be of interest at a local level as part of the suite of interview questions to identify how partnerships have been created and built upon. Provider satisfaction with the PIR model is not directly covered by the National evaluation but may be difficult to address. Adding a general question to provider interviews about how satisfied they are with the model may nevertheless add a unique dimension to information about how the model works, its successes and challenges.

4.3 Practical considerations for implementation

During consultations with PIR Consortium members and Support Facilitators, some important issues for designing materials and conducting the evaluation were raised as follows:

- Careful instructions and context are needed, both on the questionnaires themselves and as instructions to staff administering the evaluation or supporting participants to complete the questions. This will help participants understand why the questions are being asked, reassure them that there are no right or wrong answers and encourage answers based on personal experience.
- When questionnaires are designed, response options should be labelled and scored consistently. It is easier for participants to answer if all response options are presented with wording in the same direction (usually from low agreement/rating to high). It is also easier to interpret scoring if higher scores equal better outcomes. For example, a five-point scale of agreement might run from Strongly Disagree (score of 1) to Strongly Agree (score of 5), with a higher total score indicating a more positive result overall.
- The possibility of spreading the evaluation measures across contacts with participants should be explored. Some stakeholders felt that in combination with existing measures, there were too many questions, especially on intake. This might be facilitated by providing the baseline/entry questionnaires when participants are wait-listed for the Program and conducting the supported “survey morning teas” at later intervals as suggested in Section 4.2.
- For more in-depth knowledge on participant experience questions, the addition of an open-ended sub-question asking for explanation of responses may help to identify specific issues and understand differences in expectations of the Program. For example, the question on inconsistent information from different providers may additionally ask “What happened?” Similarly, the question on provision of everything expected may ask people who respond “no” to elaborate on how their needs were not met.

The key to a successful evaluation of the PIR Program is to ensure that the framework is well implemented. Careful consideration is required to determine who will take overall responsibility for the implementation of the framework, how it will be implemented and how the implementation process will be monitored and sustained.

References

1. Australian Government Department of Health. Partners in Recovery (PIR) Operational Guidelines for PIR Organisations. . Canberra: Commonwealth of Australia: , 2013.
2. Australian Government Department of Health. Partners in Recovery (PIR) PIR Reporting Framework. Canberra: Commonwealth of Australia, 2013.
3. Australian Government Department of Health. PIR Evaluation Framework. Canberra2013.
4. Wadsworth Y. *Everyday evaluation on the run*. Third ed. Walnut Creek, CA: Left Coast Press, 2011.
5. National Health and Medical Research Council. Ethical considerations in quality assurance and evaluation activities. In: Council NHaMR, (ed.). Canberra: Australian Government, 2014.
6. National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors' Committee. National Statement on Ethical Conduct in Human Research (Updated March 2014). Canberra: Australian Government, 2007.
7. Trauer T, Tobias G and Slade M. Development and evaluation of a patient-rated version of the Camberwell Assessment of Need short appraisal schedule (CANSAS-P). *Community mental health journal*. 2008; 44: 113-24.
8. Cummins R, Eckersley R, Pallant J, van Vugt J and Misajon R. Developing a National Index of Subjective Wellbeing: The Australian Unity Wellbeing Index. *Social Indicators Research*. 2003; 64: 159-90.
9. McColl MA, Davies D, Carlson P, Johnston J and Minnes P. The community integration measure: Development and preliminary validation. *Archives of Physical Medicine and Rehabilitation*. 2001; 82: 429-34.
10. Andresen R, Oades L and Caputi P. The experience of recovery from schizophrenia: towards an empirically validated stage model. *The Australian and New Zealand journal of psychiatry*. 2003; 37: 586-94.
11. Wong S and Haggerty J. Measuring Patient Experiences in Primary Health Care: A review and classification of items and scales used in publicly-available questionnaires. Vancouver, Canada2013.
12. Johnston S and Burge F. Measuring provider experiences in primary health care: Report on the development of a PHC provider survey for the Canadian Institute for Health Information. Ottawa2013.
13. O'Connell M, Tondora J, Croog G, Evans A and Davidson L. From rhetoric to routine: assessing perceptions of recovery-oriented practices in a state mental health and addiction system. *Psychiatric rehabilitation journal*. 2005; 28: 378-86.
14. Liamputtong P and Ezzy D. *Qualitative research methods*. 2nd ed.: Oxford University Press, 2005.
15. Trebble TM, Hansi N, Hydes T, Smith MA and Baker M. Process mapping the patient journey: an introduction. *BMJ (Clinical research ed)*. 2010; 341: c4078.
16. NSW Health and Redesign. Collecting patient and carer stories: A guide for frontline health service managers who wish to understand and improve patient and carer experience. In: NSW Health, (ed.). Sydney: NSW Health, 2008.

17. Consumers Health Forum of Australia. Real People, Real Data Project Literature and Practice Review: Capturing, analysing and using consumers' health experience narratives to drive better health outcomes. Canberra: Consumers' Health Forum of Australia, 2013.
18. Richieri R, Boyer L, Reine G, et al. The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL): development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia. *Schizophrenia research*. 2011; 126: 192-201.
19. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological medicine*. 2002; 32: 959-76.
20. Slade T, Grove R and Burgess P. Kessler Psychological Distress Scale: normative data from the 2007 Australian National Survey of Mental Health and Wellbeing. *The Australian and New Zealand journal of psychiatry*. 2011; 45: 308-16.
21. Corrigan PW, Giffort D, Rashid F, Leary M and Okeke I. Recovery as a psychological construct. *Community mental health journal*. 1999; 35: 231-9.
22. Ben-Tovim DI, Dougherty ML, O'Connell TJ and McGrath KM. Patient journeys: the process of clinical redesign. *The Medical journal of Australia*. 2008; 188: S14-7.

Appendix 1: Evaluation measures

Table A1: Measures and sources

Area of interest	Name of scale/measure (length)	Key reference	Permissions
Participant measures			
Assessment of need, goals	Camberwell Assessment of Needs Short Appraisal Scale (CANSAS) (22 items)	Trauer T, Tobias G, Slade M. (2008). Development and evaluation of a patient-rated version of the Camberwell Assessment of Need short appraisal schedule (CANSAS-P). <i>Community mental health journal</i> .44(2):113-24..	Part of PIR records.
Clinical mental health	Kessler 10 (K-10) (10 items)	Kessler RC, Andrews G, Colpe LJ, et al. (2002). Short screening scales to monitor population prevalence and trends in non-specific psychological distress. <i>Psychological Medicine</i> , 32(6), 959-976.	Freely available for use from http://www.hcp.med.harvard.edu/ncs/k6_scales.php
Well-being / quality of life	Personal Well-being Index (PWI) (8 items)	Cummins, R.A., Eckersley, R., Pallant, J., Van Vugt, J., & Misajon, R. (2003). Developing a national index of subjective wellbeing: The Australian Unity	Manual including scales and scoring freely available from http://www.acqol.com.au/index.php Author contact robert.cummins@deakin.edu.au

		Wellbeing Index. <i>Social Indicators Research</i> , 64, 159-190.	
Social inclusion	Community Integration Measure (CIM) (10 items)	McColl, M.A., Davies, D., Carlson, P., Johnston, J. & Minnes, P. (2001) The Community Integration Measure: Development and Preliminary Validation. <i>Archives of Physical Medicine and Rehabilitation</i> , 82, 429-34	Specific information on permission not in article but full measure and scoring included in publication. Author contact is mcollm@post.queensu.ca
Perception of recovery	Self-Identified Stages of Recovery (SISR) (Single item)	Andresen R, Oades L, Caputi P. (2003). The experience of recovery from schizophrenia: towards an empirically-validated stage model. <i>Australian and New Zealand Journal of Psychiatry</i> , 37, 586–594.	Scale free to use but authors ask for registration on this page http://socialsciences.uow.edu.au/iimh/psyc-rec/UOW117817.html
Recovery	Recovery Assessment Scale (RAS) (41 items)	Corrigan, Patrick W.; Salzer, Mark; Ralph, Ruth O.; Sangster, Yvette; Keck, Lorraine. (1999). Recovery as a psychological construct. <i>Community Mental Health Journal</i> , 35 (3), 231-239.	Unclear. Contact details for Patrick Corrigan found here: http://www.adherenceandselfdetermination.org/people/48
Participant experience (satisfaction, coordination)	Selected items adapted from CIHI Measuring Patient	Wong, S. T. & Haggerty, J. (2013). <i>Measuring patient experiences in health care: A review and classification of</i>	Freely available. Authors encourage use of most relevant dimensions.

	Experiences in Primary Health Care Survey (23 items)	<i>items and scales used in publicly-available questionnaires</i> , Vancouver, Centre for Health Services and Policy Research, University of British Columbia.	
Carer quality of life	Schizophrenia Caregiver Quality of Life (25 items)	Richieri R, Boyer L, Reine G, Loundou A, Auquier P, Lancon C, et al. (2011) The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL): development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia. <i>Schizophrenia research</i> . 126(1-3):192-201.	Free of royalties. Contact the authors at laurent.boyer@ap-hm.fr for permissions and instructions.
System measures			
Provider perception of recovery model	Recovery Self-Assessment (RSA) provider version (32 items)	O'Connell M, Tondora J, Croog G, Evans AL, Davidson L. (2005). From rhetoric to routine: Assessing perceptions of recovery-oriented practices in a state mental health and addiction system. <i>Psychiatric Rehabilitation Journal</i> , 28 (4), 378-386.	Unclear. Author contact is maria.oconnell@yale.edu
Provider experience (satisfaction, coordination)	Selected items adapted from CIHI Attributes of	Johnston, S., & Burge, F. (2013) <i>Measuring provider experiences in primary health</i>	Freely available. Authors encourage use of most relevant questions/dimensions.

	<p>Primary Health Care Provider Survey (14 items)</p>	<p><i>care: Report on the development of a PHC Provider Survey for the Canadian Institute for Health Information.</i> Bruyere Research Institute, Ottawa</p>	
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Table A2. Detailed quantitative measures

NOTE: Wording changes and other suggestions from consultations are marked in red.

Area of interest Measure	Questions	Response options
Participant measures – 3 time points (pre/mid/post)		
Clinical mental health Kessler 10 (K-10)	These questions concern how you have been feeling over the past 4 weeks. Tick a box below each question that best represents how you have been feeling.	
	1. In the past 4 weeks, about how often did you feel tired out for no good reason?	All of the time Most of the time Some of the time A little of the time None of the time
	2. In the past 4 weeks, about how often did you feel nervous?	
	3. In the past 4 weeks, about how often did you feel so nervous that nothing could calm you down?	
	4. In the past 4 weeks, about how often did you feel hopeless?	
	5. In the past 4 weeks, about how often did you feel restless or fidgety?	
	6. In the past 4 weeks, about how often did you feel so restless you could not sit still?	
	7. In the past 4 weeks, about how often did you feel depressed?	
	8. In the past 4 weeks, about how often did you feel that everything was an effort?	

Area of interest Measure	Questions	Response options
	9. In the past 4 weeks, about how often did you feel so sad that nothing could cheer you up?	
	10. In the past 4 weeks, about how often did you feel worthless?	
Well-being / quality of life Personal Well-being Index (PWI)	The following questions ask how satisfied you feel, on a scale from zero to 10. Zero means you feel no satisfaction at all and 10 means you feel completely satisfied.	Scale 0-10 0 means no satisfaction at all and 10 means completely satisfied
	1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	
	2. How satisfied are you with your standard of living?	
	3. How satisfied are you with your health?	
	4. How satisfied are you with what you are achieving in life?	
	5. How satisfied are you with your personal relationships?	
	6. How satisfied are you with how safe you feel?	
	7. How satisfied are you with feeling part of your community?	
	8. How satisfied are you with your future security?	
Social inclusion	For each of the following statements, please indicate whether you agree or disagree:	

Area of interest Measure	Questions	Response options
<p>Community Integration Measure (CIM)</p> <p><i>This measure was subject to much discussion during consultation. Social inclusion is covered to some extent in the CANSAS and PWI, but with the suggested amendments people felt it is still important to measure social inclusion separately.</i></p>	<ol style="list-style-type: none"> 1. I feel like part of this my community, like I belong here. 2. I know my way around this my community. 3. I know the rules rights and responsibilities in this my community and I can fit in with them. 4. I feel that I am accepted in this my community. 5. I can be independent in this my community. 6. I like where I'm living now. 7. There are people I feel close to in this my community 8. I know a number of people in this my community well enough to say hello and have them say hello back. 9. There are things I can do in this community for fun in my free time. 10. I have something to do in this community during that main part of my day that is useful and productive. [Concern was expressed about this phrasing but no conclusion was reached.] 	<ol style="list-style-type: none"> 1. Always disagree 2. Sometimes disagree 3. Neutral 4. Sometimes agree 5. Always agree
<p>Perception of recovery Self-Identified Stages of Recovery (SISR)</p>	<p>People who are told they have a serious mental illness can feel differently about life with the illness at different times. Below are five statements describing how people may feel at times when living with a mental illness. Please read all five statements below (A-E) and answer the question that follows.</p>	

Area of interest Measure	Questions	Response options
<p><i>Stakeholders consulted expressed some concern about this measure. Possible alternate wording has been included for consideration.</i></p>	<p>Of the <u>five</u> statements, which one would you say <i>most closely</i> describes how you have been feeling over the past month about life with the illness?</p>	<p>A. “I don’t think [recovery from mental illness is possible] [people can recover from mental illness]. I feel that my life is out of my control, and there is nothing I can do to help myself.”</p> <p>B. “I have just <i>recently</i> realised that people can recover from serious mental illness. I am <i>just starting</i> to think it may be possible for me to help myself.”</p> <p>C. “I am <i>starting</i> to learn how I can overcome the illness. I’ve decided I’m going to start getting on with my life.”</p> <p>D. “I can manage the illness reasonably well now. I am doing OK, and feel fairly positive about the future.”</p> <p>E. “I feel I am in control of my health and my life now. I am doing very well and the future looks bright.”</p>
<p>Recovery Recovery Assessment Scale (RAS)</p>	<p>Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes the extent to which you agree or disagree with the statement. Circle only one number for each statement and do not skip any items.</p>	
	<p>1. I have a desire to succeed</p>	<p>Strongly disagree Disagree</p>
	<p>2. I have my own plan for how to stay or become well</p>	

Area of interest Measure	Questions	Response options
	3. I have goals in life that I want to reach	Not sure
	4. I believe I can meet my current personal goals	Agree
	5. I have a purpose in life	Strongly agree
	6. Even when I don't care about myself, other people do	
	7. I understand how to control the symptoms of my mental illness	
	8. I can handle it if I get sick again	
	9. I can identify what triggers the symptoms of my mental illness	
	10. I can help myself become better	
	11. Fear doesn't stop me from living the way I want to	
	12. I know that there are mental health services that do help me	
	13. There are things that I can do that help me deal with unwanted symptoms	
	14. I can handle what happens in my life	
	15. I like myself	
	16. If people knew me, they would like me	

Area of interest Measure	Questions	Response options
	17. I am a better person than before my experience with mental illness	
	18. Although my symptoms may get worse, I know I can handle it	
	19. If I keep trying, I will continue to get better	
	20. I have an idea of who I want to become	
	21. Things happen for a reason	
	22. Something good will eventually happen	
	23. I am the person most responsible for my own improvement	
	24. I'm hopeful about the future	
	25. I continue to have new interests	
	26. It is important to have fun	
	27. Coping with my mental illness is no longer the main focus of my life	
	28. My symptoms interfere less and less with my life	
	29. My symptoms seem to be a problem for shorter periods of time each time they occur	
30. I know when to ask for help		

Area of interest Measure	Questions	Response options
	<p>31. I am willing to ask for help</p> <p>32. I ask for help, when I need it</p> <p>33. Being able to work is important to me</p> <p>34. I know what helps me get better</p> <p>35. I can learn from my mistakes</p> <p>36. I can handle stress</p> <p>37. I have people I can count on</p> <p>38. I can identify the early warning signs of becoming sick</p> <p>39. Even when I don't believe in myself, other people do</p> <p>40. It is important to have a variety of friends</p> <p>41. It is important to have healthy habits</p>	
<p>Confidence in the system Adapted from CIHI Measuring Patient Experiences in Primary Health Care Survey</p>	<p>On a scale of 0 to 10, how confident are you that you can get the services you need to manage your mental health?</p>	<p>0-10 rating scale</p>
<p>Carer quality of life</p>	<p>For the last 12 months have you:</p>	

Area of interest Measure	Questions	Response options
Schizophrenia Caregiver Quality of Life scale (S-CGQoL)	1. Felt sad, depressed?	1. Never/not at all 2. Rarely/a little 3. Sometimes/somewhat 4. Often/a lot 5. Always/very much
	2. Felt overworked, burnt-out?	
	3. Lacked energy?	
	4. Been tired, worn-out?	
	5. Felt anxious, worried?	
	6. Had to give up doing things that you were very keen to do?	
	7. Had to reduce the amount of time devoted to your leisure activities (outings, gardening, shopping, odd jobs)?	
	8. Been embarrassed to leave your child to attend your day or professional life?	
	9. Had the feeling that you didn't devote enough time to the rest of your family?	

Area of interest Measure	Questions	Response options
	10. Had the feel that you weren't free?	
	11. Had the feeling that you led a day-to-day existence?	
	12. Had difficulty in making professional or personal plans?	
	13. Been helped, supported by your spouse?	
	14. Been listened to, understood by your spouse?	
	15. Had a satisfying emotional and sexual life?	
	16. Been listened to, understood by doctors and nurses?	
	17. Been helped, supported by doctors and nurses?	
	18. Been satisfied with information given by doctors and nurses?	

Area of interest Measure	Questions	Response options
	19. Been helped, supported by your family?	
	20. Been listened to, understood by your family?	
	21. Been helped, supported by your friends?	
	22. Been listened to, understood by your friends?	
	23. Encountered difficulties because of your child's illness when applying to administration departments?	
	24. Had financial troubles in facing your child's illness?	
	25. Had material difficulties (housing, transport...)?	
Participant measures – 2 time points (mid/post)		
Participant experience Selected items adapted from CIHI Measuring Patient Experiences in	We are interested in your experiences with the Partners in Recovery Program. We are interested in how care is organized in this Program. Answering these questions will help us. Before you answer, please remember that <ul style="list-style-type: none"> • You can choose whether to fill in the survey or not. You can even stop answering at any point. • Your choice will not affect how well you are treated. 	

Area of interest Measure	Questions	Response options
Primary Health Care Survey	<ul style="list-style-type: none"> No one will know who answered this survey. There are no right or wrong answers. 	
Access	How easy was it to make an appointment?	Not at all easy Not very easy Fairly easy Very easy
<i>Interpersonal communication</i>	How would you rate the amount of time that the services arranged by PIR gave you?	Very poor Poor Fair Good Very good
	How would you rate the way that the people in services arranged by PIR listened to you?	
	How would you rate the way that the people in services arranged by PIR involved you in decisions about your care support ?	
	Did they really find out what your concerns and issues were?	No, not at all No, not really Yes, a little Yes, mostly Yes, completely
	Did they let you say what you thought was important?	
	Did they take your mental health mental health concerns and issues very seriously?	

Area of interest Measure	Questions	Response options
	Were they concerned about your feelings?	
	Did they discuss with you your main goals or priorities for your condition?	
	Did you and your PIR Support Facilitator work out a recovery plan together?	No Yes, sometimes Yes, often
<i>Continuity and coordination</i>	Were there times when the people in services arranged by PIR did not know your most recent mental health history?	All the time Often Sometimes Rarely Never
	Were there times when the people in services arranged by PIR did not know about changes in your recovery plan that another person had recommended?	
	Were there times when you had to repeat information that should be in your PIR records?	
	In general, do you feel that <u>you</u> yourself have to arrange the care you receive through PIR from different people or places?	Yes, I have to organize my care too much and it is too difficult Yes, I have to organize my care more than I would like Yes, but it is my choice to do so No, my support facilitator <u>sometimes</u> does it for me No, my support facilitator <u>always</u> does it for me

Area of interest Measure	Questions	Response options
		<i>[Consideration should be given to how responses are scored. It was suggested by stakeholders that the two “no” responses are not actually consistent with PIR aims and may not be indicative of a good service.]</i>
	Were there times when the people in services arranged by PIR told you different things that didn't make sense together?	Often Sometimes Never
	Were there times when the people in services arranged by PIR did not seem to work well together?	
	Were there times when the people in services arranged by PIR did not seem to know who should be doing what for you care?	
	How comfortable do you feel talking with the people in services arranged by PIR about personal problems?	Hardly comfortable at all Only somewhat comfortable Moderately comfortable Very comfortable Completely comfortable
<i>Comprehensiveness of services</i>	Since you started the Program, has Partners in Recovery provided everything you expected? need to help you manage your mental health?	No, not at all No, not really Yes, to some extent Yes, definitely

Area of interest Measure	Questions	Response options
	Since you started the Program, have you had enough support from local services or organisations to help you to manage your mental health concerns?	
<i>Impacts of care</i>	Did your participation in the PIR Program give you a sense of control over your life mental health?	
	Did the people in services arranged by PIR help you feel that sticking with your recovery plan would make a difference?	
	Did the people in services arranged by PIR help you feel confident about your ability to take care of your self health?	
System measures		
Provider perception of recovery model Recovery Self-Assessment (RSA) provider version <i>Reactions to this scale were mixed. It was supported for use with providers and some also wanted the consumer and carer versions used to provide direct comparison.</i>	Below is a list of statements that describe the activities, the values, the policies, the actions and the practices of the PIR Program. Please read each one carefully and circle the number to the right that best describes how accurate the statements are of the PIR Program. Circle only one number for each statement and do not skip any items.	
	1. Staff make a concerted effort to welcome people in recovery and help them to feel comfortable in this program.	Strongly disagree Disagree Not sure Agree Strongly agree Not applicable Don't know
	2. This program/agency offers an inviting and dignified physical environment (e.g., the lobby, waiting rooms, etc.)	
	3. Staff encourage program participants to have hope and high expectations for their recovery.	

Area of interest Measure	Questions	Response options
	4. Program participants can change their clinician or case manager if they wish.	
	5. Program participants can easily access their treatment records if they wish.	
	6. Staff do not use threats, bribes, or other forms of pressure to influence the behaviour of program participants.	
	7. Staff believe in the ability of program participants to recover.	
	8. Staff believe that program participants have the ability to manage their own symptoms.	
	9. Staff believe that program participants can make their own life choices regarding things such as where to live, when to work, whom to be friends with, etc.	
	10. Staff listen to and respect the decisions that program participants make about their treatment and care.	
	11. Staff regularly ask program participants about their interests and the things they would like to do in the community.	
	12. Staff encourage program participants to take risks and try new things.	
	13. This program offers specific services that fit each participant's unique culture and life experiences.	

Area of interest Measure	Questions	Response options
	14. Staff offer participants opportunities to discuss their spiritual needs and interests when they wish.	
	15. Staff offer participants opportunities to discuss their sexual needs and interests when they wish.	
	16. Staff help program participants to develop and plan for life goals beyond managing symptoms or staying stable (e.g., employment, education, physical fitness, connecting with family and friends, hobbies).	
	17. Staff routinely assist program participants with getting jobs.	
	18. Staff actively help program participants to get involved in non-mental health/addiction related activities, such as church groups, adult education, sports, or hobbies.	
	19. Staff work hard to help program participants to include people who are important to them in their recovery/treatment planning (such as family, friends, clergy, or an employer).	
	20. Staff actively introduce program participants to persons in recovery who can serve as role models or mentors.	
21. Staff actively connect program participants with self-help, peer support, or consumer advocacy groups and programs.		

Area of interest Measure	Questions	Response options
	22. Staff actively help people find ways to give back to their community (i.e., volunteering, community services, neighbourhood watch/clean-up).	
	23. People in recovery are encouraged to help staff with the development of new groups, programs, or services.	
	24. People in recovery are encouraged to be involved in the evaluation of this agency's programs, services, and service providers.	
	25. People in recovery are encouraged to attend agency advisory boards and management meetings.	
	26. Staff talk with program participants about what it takes to complete or exit the program.	
	27. Progress made towards an individual's own personal goals is tracked regularly.	
	28. The primary role of agency staff is to assist a person with fulfilling his/her own goals and aspirations.	
	29. Persons in recovery are involved with facilitating staff trainings and education at this program.	
	30. Staff at this program regularly attend trainings on cultural competency.	
	31. Staff are knowledgeable about special interest groups and activities in the community.	

Area of interest Measure	Questions	Response options
	32. Agency staff are diverse in terms of culture, ethnicity, lifestyle, and interests.	
Provider experience Selected items adapted from CIHI Attributes of Primary Health Care Provider Survey		
<i>Team functioning</i>	<p>Indicate how satisfied you are with the following:</p> <p>a. How members of the Program communicate among themselves about participants and the Program</p> <p>b. The level of understanding others have of my scope of practice</p> <p>c. My level of understanding of my role with the team</p> <p>d. My level of understanding of the role of others within the team</p> <p>e. The frequency with which the Program team is able to meet as a group</p> <p>f. The collaboration across Program team members in setting goals and plans for participant care</p> <p>g. Your participation in administrative decision-making within the Program</p>	<p>Not at all satisfied</p> <p>Not very satisfied</p> <p>Neutral</p> <p>Somewhat satisfied</p> <p>Very satisfied</p>

Area of interest Measure	Questions	Response options
<i>Service Delivery</i>	To what extent are you able to coordinate with other service organisations in the community concerning planning and providing care for participants with complex needs?	Unable to Occasionally able to Usually able to Able to always or almost always when necessary
	I believe I am aware of all other health and social care provider consultations and hospitalisations or emergency department visits for ____% of my participants	0-20% 20%-40% 40%-60% 60%-80% 80%-100%
	For participants receiving care from multiple providers outside your own service...	No, not at all No, not really Undecided Yes, to some extent Yes, to a very great extent
	a. Are you able to communicate with the other providers involved in a timely manner to advance the care of the patient?	
	b. Do all providers caring for these participants have the same information available to them when working with the participant?	
	c. Do you collaborate with other providers when establishing goals and recovery plans?	
	During the past month, did the following occur with any of your PIR participants?	Yes No
	a. A participant's records or other relevant information was/were not available at the time of the participant's scheduled visit	

Area of interest Measure	Questions	Response options
	b. A participant experienced problems because care was not well coordinated across multiple sites or providers	

Appendix 2: The use of participant journey methods

There are numerous methods for collecting detailed information on participant experiences of a Program, service or system. Participant journey methods focus on examining the care pathway, identifying problems and suggested improvement from the participant perspective, recognising that participants are the only ones who can accurately provide that perspective.^{15, 17, 22} Outlines of possible methods and their sources are listed here to allow the most appropriate choice to be made within the overall scope and scale of the evaluation. The methods presented are not mutually exclusive: some focus on how to collect and analyse qualitative information whereas others look more broadly at following the journey in its entirety.

Participant stories

Participant stories are narrative accounts of a participant's experiences with the system, which can give in-depth knowledge of what is and is not working and add a "human face" to evaluation and quality improvement data that is absent from quantitative data.¹⁶ The interviews are typically only lightly structured, allowing participants to tell their stories in their own way, focusing on the issues of importance to them. In this way, participant experience data gathered from participant stories can both supplement the information gathered through surveys and potentially reveal additional areas of importance or need.¹⁶

NSW Health has produced an easy-to-follow guide for service managers on collecting participant stories.¹⁶ The guide outlines methods for sampling, choosing suitable interviewers, principles of effective interviewing such as active listening, questioning style and dealing with problems, and also outlines methods for analysis and service improvement based on participant stories. The guide is available online at http://www.archi.net.au/resources/patientexperience/collect_stories along with a suite of other useful tools.

Another option for guided collection and analysis of participant stories is the Consumers Health Forum (CHF) tool under development in the *Real People; Real Data* project.¹⁷ (See also <https://www.chf.org.au/real-people-real-data-project.php>.) The tool has been piloted by a number of organisations around Australia, including the ACT Medicare Local and Health Care Consumers' Association of the ACT. It is designed to be an easy-to-use tool for both health services and consumers to gather stories for service improvement, guiding

both the collection of stories and the analysis and presentation of findings in an accessible and useable way.

Process mapping

Tebble and colleagues¹⁵ describe a participant journey technique they term “process mapping”, which identifies the steps evaluators can follow in order to follow the participant journey and implement change in response to findings. Process mapping involves the following steps.

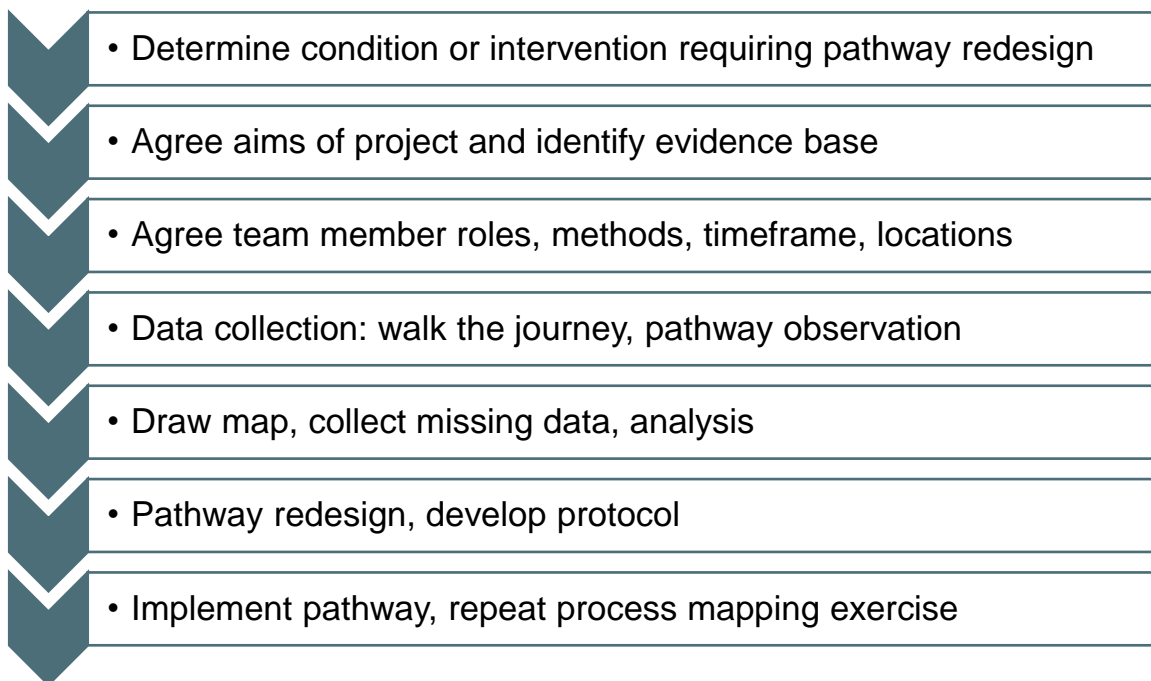


Figure A2.1 Process mapping¹⁵ p395

The data collection can be conducted in a number of ways, but usually involves in-depth interviews with participants and their families (and often staff members) along with direct observation of the pathway (services/professionals seen, movement of information etc.) at several time points or in real time.¹⁵ The data are used to create a large map of how the participant moved through the system and identify the areas needing redevelopment or improvement. Tebble and colleagues note that this technique is simple and valuable to use but can reveal quite complex journeys that are time-consuming to map and analyse. The technique has successfully been used in clinical service redesign in NSW, involving patients and staff in the process of improving health care quality whilst reducing the “blame shifting” that is often a feature of redesign processes that are not a complete or continuous record of the journey.²²