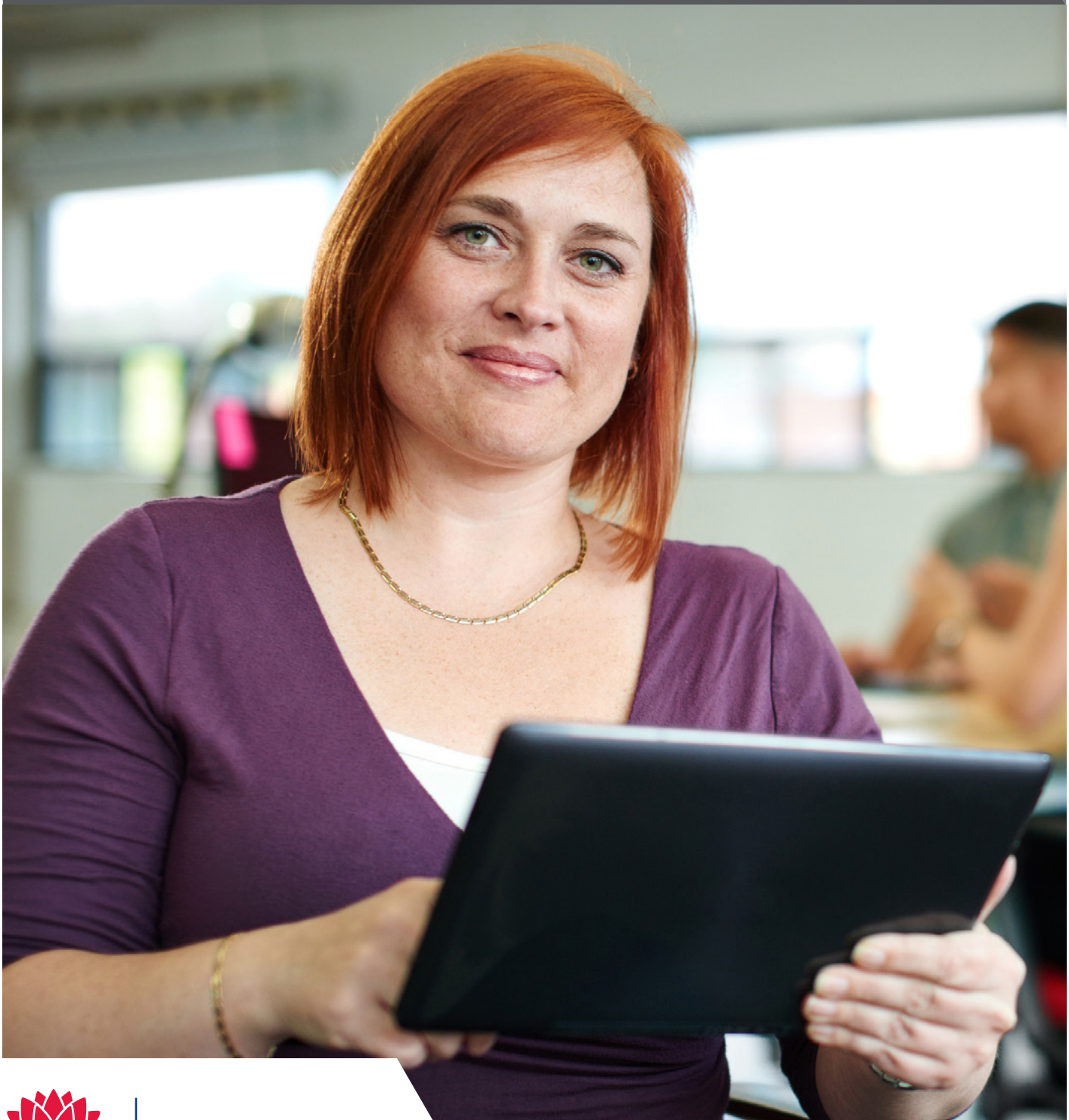
REPORT

Agency for Clinical Innovation

Patient Reported Measures

Formative Evaluation 2017



NSW GOVERNMENT

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Glossary

ACI	Agency for Clinical Innovation
AQoL	assessment of quality of life
HRQoL	health related quality of life
ICT	information and communication technology
IT	information technology
K10	Kessler Psychological Distress Scale (K10)
LHDs	local health districts
PHNs	primary health networks
PREMs	patient reported experience measures
PRMs	patient reported measures
PROMIS	patient-reported outcomes measurement information system
PROMs	patient reported outcome measures
REDCap	Research Electronic Data Capture
SF-36	The Short Form (36) Health Survey
SHNs	specialty health networks
Strategy	NSW Integrated Care Strategy

Executive summary

The formative evaluation of the Patient Reported Measures (PRMs) Program, a component of the NSW Integrated Care Strategy (the Strategy), has been undertaken by Urbis on behalf of the NSW Agency for Clinical Innovation (ACI).[1] This report presents the findings from the first year of a three-year evaluation.

The Strategy was released in 2014 and provides direction for the development and improvement of seamless care across the NSW Health system. The ACI has led a program to introduce the systematic collection of PRMs as a driver for clinical improvement, and to test the effectiveness of PRMs in 11 (geographically located) proof of concept sites. The PRMs program has captured both patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) in a range of clinical settings across the state including general practices, outpatient speciality clinics, community services and hospitals. The evaluation analysed a range of qualitative and quantitative data including interview data from consultations with program stakeholders, clinicians and managers, and a focus group of three patients; an online survey of participating health services; a review of PRMs data; and a clinical and system review.

Given the small number of participating sites, and the early stage of the program implementation, the amount of data was relatively small. At the same time, there was consistency across data sources regarding the effectiveness of the implementation to date, and the challenges of embedding PRMs into clinical practice.

It was universally acknowledged that the program has demonstrated the proof of concept for the systematic use of PRMs in clinical practice in a range of settings. Likewise, there was considerable praise for the role of the ACI in providing leadership in implementing the program and in providing training and support for staff at participating sites.

Most sites were at an early stage of implementation and several sites are not yet regularly collecting and using PRMs, for a range of reasons. As a result, there is little quantifiable data to demonstrate the benefits of the use of PRMs. However, as discussed in this report, evaluation participants were able to identify real or potential positive outcomes for patients and clinicians, including: the use of PRMs in triage; the use of PRMs in tracking change over time; improved engagement of patients in their own care.

Appropriate information and communication technology (ICT) infrastructure is considered critical for future success, and was noted by many as being a barrier to implementation given the need for any PRMs system to be integrated within existing patient information systems. Where frustrations were experienced by clinicians and managers, they were largely around the use of information technology (IT) and the capability of the current system for data to be collected and reported.

Evaluation participants were consistent in identifying the necessary components required to embed PRMs sustainably within the health system. In addition to IT, these included further training and support to ensure staff know how to use the data once it is collected; system support to ensure that the process of collecting and analysing data is seamless; and a targeted change management approach to ensure that each element of the health system can adapt to accommodate the addition of PRMs into regular clinical routines.

Contents

Introduction

This document

This document presents the results of the formative evaluation of the Patient Reported Measures (PRMs) Program, which is a component of the NSW Integrated Care Strategy (Strategy).[1] The evaluation was commissioned by the NSW Agency for Clinical Innovation (ACI) in consultation with patients and program stakeholders (including clinicians and health managers).

Program overview

Policy context

The NSW Ministry of Health (Ministry) released the Strategy in March 2014, in acknowledgement of an increased focus on the delivery of integrated care within the NSW health system. This Strategy – which initially committed $120 million in funds over four years (expanded to include $180 million in funds over six years) – comprised three predominant directions for the provision of integrated care:

- keeping people healthy
- providing world class clinical care
- delivering truly integrated care.

The Strategy identified key enablers (e.g. PRMs) and demonstrator and innovator sites to implement integrated care.

- Demonstrators have been allocated funding from the Ministry's commitment of $180 million over six years to progress system-wide approaches for integrating care at a local level, and are working in partnership with primary health networks (PHNs) and other health agencies in the primary care, not-for-profit and private sectors to develop and progress approaches to integrated care to address the coordination and provision of services for patients in full understanding of local factors.[1]
- Innovators were allocated funding for new, innovative models of integrated care from the Planning and Innovation Fund to support discrete and innovative integrated care initiatives run by local health districts (LHDs) and specialty health networks (SHNs) with their partner organisations.[1]

The enablers of integrated care that were identified and prioritised for investment included the development and implementation of PRMs. The ACI is responsible for leading and managing this component of the Strategy. PRMs enable patients to provide direct, timely feedback about their health-related outcomes and experiences to drive improvement and integration of health care across NSW.

PRMs are typically divided into two groups:

- Patient Reported Outcome Measures (PROMs)
- Patient Reported Experience Measures (PREMs).

The former capture the patient's perspectives about how illness or care impacts on their health and wellbeing, whereas the latter capture a person's perception of their experience with healthcare systems or services.

Program design

The design of the PRMs program is iterative. It uses a co-design approach between ACI, clinicians and consumers in the proof of concept sites, who have implemented PRMs at a local level across acute care and primary healthcare settings. Four early adopter sites were initially self-selected to develop and implement PRMs programs locally. This included two sites from the LHD demonstrators (Western NSW and Western Sydney), and two innovator project sites (North Sydney and Mid North Coast).

Due to heavy demand for support and broadening of the program, at the time of the evaluation, there were 11 proof of concept sites developing and implementing PRMs within the following geographical locations (and including LHDs, SHNs, PHNs and general practices).

- Far West
- Illawarra Shoalhaven
- Mid North Coast
- Nepean Blue Mountains
- Northern NSW
- Northern Sydney
- South Eastern Sydney
- Southern NSW
- St Vincent's Health Network
- Sydney
- Western Sydney.

Patient cohort

Within the integrated care context, the ideal patient population includes people living with chronic and complex conditions who may (or may not) be eligible or receiving integrated care. Throughout the program local services and sites have worked collaboratively with the ACI PRM program to define appropriate patient populations. It is also recognised that local services and sites may also be guided by the risk stratification model, which aims to identify people with current or emerging complex health situations and needs who are at risk of suffering health deterioration or an unplanned hospital admission.

Patient Reported Outcome Measures

There is a multitude of validated PROMs to choose from and the appropriate selection of a validated tool for the measurement of specific patient population characteristics, conditions or symptoms requires careful consideration. The ACI PRMs program staff provide expert advice to sites, services and systems as to the choice of PROMs. The initial selection of validated PROM question sets was informed by consultations with experts, literature reviews, and testing in appropriate clinical settings.

The final recommended question set for each site comprises, at a minimum, a health related quality of life (HRQoL) tool. The use of a generic quality of life tool across care settings and patient populations is important as it provides a holistic overview of a person and how they are managing with multi-morbid conditions or complex situations. The use of a generic quality of life tool across care settings and populations was adopted and implemented by sites to enable a greater holistic approach to care and treatment.

The preferred quality of life tool used has been the PROMIS (Patient-Reported Outcomes Measurement Information System) 10.[2]

PROMIS 10

The PROMIS 10 includes 10 validated questions about the person as a whole, including physical, mental and social aspects. It can be used with the general population and with individuals living with chronic conditions.

It should be noted that one site in the North Sydney Local Health District is currently using AQoL (Assessment of Quality of Life) in lieu of PROMIS 10 to assess health related quality of life.[3]

Condition-specific (optional) question set

The selection of condition-specific measures was completed through consultations with experts and, when appropriate for specific conditions, reviews of literature related to validated PROMs tools.

Validated condition-specific question sets cover outcomes for specific patient populations (e.g. patients with arthritis) in more detail than generic quality of life measures. Expert advisory groups comprising specialist providers and clinicians within proof of concept sites were established to determine condition-specific measures. Examples of condition-specific measures include DASS-21 (Depression Anxiety Stress Scale – 21 Items), HOOS (Hip disability and Osteoarthritis Outcome Score), and KOOS (Knee injury and Osteoarthritis Outcome Score). The use of condition-specific measures is often an optional part of a PROMs program of measurement, and their use is dependent on the decision of the local clinicians.

Patient Reported Experience Measures

The selection of PREMs questions was informed by reviewing existing organisations and validated patient experience questions, extensive consultations, workshops and an expert reference group (comprised of researchers, policy areas, clinicians, consumers and experts in the field) who provided input and advice over a lengthy period. The proposed questions were then reviewed by local clinical groups, a series of consumer focus groups, cognitive testing with consumers, and further refinement. The PREMs questions are designed to measure and evaluate a person's experience of care across settings for the purposes of improving the experience of integrated care. The question sets focus on a number of domains of healthcare (e.g. access to care, being involved in care).

Infrastructure

At the commencement of the program, a stand-alone web-based application (REDcap) was implemented to facilitate the collection and use of PROM data. The application has the capability to disseminate real-time feedback and reports to clinicians, allowing the results to be used during consultations. All sites have been provided with tablet devices to support the routine collection of PROMs and PREMs. The collection typically occurs in health service waiting rooms or while patients are waiting to see their care provider. All sites received training and education in the stand-alone IT system and were provided with user guides and quick reference sheets.

Subsequently, the ACI has involved key stakeholders in the user acceptance testing of the current system to inform and define future requirements to support integration with existing electronic record systems.

Implementation

The 11 proof of concept sites have implemented PRMs as part of their everyday routine practice. Working alongside local sites, the ACI PRMs team is supporting local PRM implementation by:

- identifying opportunities to increase value and decrease burden on clinicians and patients when implementing PRMs
- mapping local PRMs patient journeys and clinical workflows to assist in local needs
- providing education, training, workshops and local one-on-one support with clinicians including capability building
- providing resources such as tablet devices, and educational and promotional materials
- providing access for clinicians to PRMs.

Under program specifications, proof of concept sites are required to:

- establish appropriate local governance arrangements
- nominate a project sponsor, clinical champion and project manager for the duration of the proof of concept period
- identify a target population or patient cohort from which to collect PRMs
- share de-identified PRMs data with the ACI and the NSW Integrated Care Strategy Evaluation team for evaluation purposes.

Evaluation objectives

Under the ACI definition of formative evaluation (monitoring), programs or projects are typically assessed during their development or early implementation to provide information about how to revise and modify for improvement.[4] In terms of the Leading Better Value Care program, there are two realms of formative evaluation.[5] The first is the formative evaluation of the statewide program to indicate if programs are progressing towards goals and to define what improvements can be made to the overall program. The second realm is the assessment of the program at a site level to determine what is needed for local improvements.

The data and findings from a formative evaluation can be used:

- as the basis to determine the impact that a model of care might have if it was implemented systematically across NSW Health
- to refine a model of care by establishing early outcomes arising from programs and to identify areas requiring improvement
- to enhance the probability of achieving program outcomes in the short, medium, and longer term and to identify the barriers and enablers that could influence these outcomes.

In line with this definition, the formative evaluation of the PRMs program will assess program design, early implementation (including success or otherwise of capability building activities), barriers and enablers in PRMs programs, and early outcomes for the 11 proof of concept sites. Key evaluation objectives are as follows.

- Assess the short-term and intermediate-term outcomes, including barriers and enablers to program implementation (including success or otherwise of capability building activities).
  - Findings relating to program implementation are discussed in Program co-design and implementation.
  - Findings relating to short-term and intermediate-term outcomes are discussed in Evidence of impacts.
  - Findings relating to program sustainability and scalability are discussed in Considerations for sustainability and scalability.
- Assess any intended and unintended program impacts of program implementation.
  - Findings relating to intended and unintended program impacts are discussed in Evidence of impacts.

Method

Data collection for this evaluation comprised the following elements.

- Qualitative evaluation activities
  - in-depth interviews with program stakeholders (n=9)
  - in-depth interviews with clinicians and managers (n=17)
  - mini-focus group with program participants (n=3).*
- Quantitative evaluation activities
  - online survey of health services (n=11).
- Program data review
  - PRM data review (n = 974 PROMs and 652 PREMs)
  - Reviews of systems for collection of PRMs locally.

In-depth interview with program stakeholders

Urbis conducted in-depth telephone interviews with PRM program stakeholders between 18 April and 8 May 2017. Each interview lasted for between 15 and 45 minutes. Stakeholders comprised representatives from:

- ACI (n=4)
- Ministry (n=4)
- Cancer Institute NSW (n=1).

Participants for this phase of the evaluation were identified by the ACI and other stakeholders and selected for their ability to comment on the PRM program, with a focus on overall implementation and potential for system level outcomes.

* Due to the small number of consumers consulted for the current evaluation, all findings from this group should be interpreted with extreme caution

In-depth interviews with clinicians and managers

Urbis conducted in-depth telephone interviews with staff and managers from 10 of the 11 proof of concept sites (n=17 interviews in total) between 18 April and 16 May 2017. Each interview lasted for between 15 and 30 minutes.

In line with the approach taken for program stakeholders, participants for this phase of the evaluation were identified by the ACI and other stakeholders (including site managers), and selected for their ability to comment on the PRM program, with a focus on service level implementation, and evidence of patient and service level outcomes.

Mini-focus group with program participants

Urbis conducted a mini-focus group with three program participants on 30 May 2017. This focus group was held at the ACI Sydney office; one participant attended in person and two attended via teleconference. The focus group lasted for approximately 30 minutes. In order to protect participant privacy, the ACI took full responsibility for participant recruitment, working with sites to identify and recruit consumers who would be able to comment meaningfully on program experience and outcomes. It will be important to capture consumer views more comprehensively in the summative evaluation, which is scheduled for April-May 2019. Due to the small number of consumers consulted for the current evaluation, all findings from this group should be interpreted with extreme caution.

Online survey of health services

Staff of participating health services were given an opportunity to provide feedback via an online survey. This survey aimed to quantify staff experience of and satisfaction with the use of PRMs in the management of chronic and complex conditions, including administrative burden, perceived changes to clinical or management practice, and satisfaction with service changes.

In order to protect the privacy of service staff, site managers were emailed a link to the questionnaire, which they then distributed to clinicians, managers, and support workers (if deemed appropriate). The online questionnaire was active between 15 May and 10 June 2017. The questionnaire was completed by a total of 11 respondents.

PRM data review

Data analysis was limited to overall completion of measures and completion of measures by proof of concept site up until May 2017, as early implementation stage and small sample size prohibits outcome tracking as a mechanism for assessing program success, either at a patient or service level. This analysis will be undertaken as part of the summative evaluation in 2019.

System review

A limited system review was undertaken to ascertain number of tablet devices (n=80) and training sessions (n>100) provided the proof of concept health services staff to support PROM and PREM completion.

Presentation of findings

Qualitative analysis

All consultations were recorded and transcribed for analysis. A thematic analysis approach was taken, with transcripts read iteratively to identify common themes and to develop a structure of perspectives from different stakeholder groups. A qualitative evaluation approach does not allow for the number of participants holding a particular view on individual issues to be quantified. This approach therefore provides an analysis of themes and reactions among participants rather than exact proportions of participants who hold a particular perspective.

In this report, qualitative evaluation refers to data collected during the in-depth interviews with clinicians, managers, and other stakeholders. Quotes have been provided throughout the report to support the main results or findings under discussion.

Quantitative analysis

Due to the small number of completed questionnaires (n.b. n=11), results are reported and charted as whole counts rather than proportions, so as not to mislead the reader.

Key successes and barriers

Key successes

Stakeholders were generally of the view that program implementation to date had met the desired output of a proof of concept; that is, demonstrating that it is possible to implement the systematic collection of PRMs in NSW primary and acute care settings. This is consistent with feedback from clinicians and managers, many of whom noted that, with support from the ACI, their service is currently collecting either PROMs and/or PREMs and using the resulting data to guide patient care and support, and to improve service delivery. Specific examples of service provision, and outcomes for clinicians and patients, are contained in Program co-design and implementation. Feedback from stakeholders and clinical staff is supported by the PRM data, with a total of 974 PROMs and 652 PREMs completed over approximately 12 months up until May 2017.

It should be noted, however, that stakeholders generally acknowledged that the program had, in their view, fallen short of initial expectations, with only a limited number of measures completed at some sites (see Table 1, below). Most stakeholders attributed this shortfall to a lack of inducement (either through encouragement or enforcement) for sites or clinicians to change their practices, with the following quote being typical of stakeholder responses.

> ***I think we need to get more surveys completed … Need a bit more pressure placed on them [proof of concept sites] to be able to hurry that along. I think they've been quite patient, the Ministry and the ACI… I think there needs to be some sort of mild pressure applied in terms of numbers.***
>
> **– Program stakeholder**

Table 1 – Number of completed PROMs & PREMs captured through REDcap & PREMs reporting system

Geographic area	Completed PROMs	Completed PREMs
Central Coast	60	0
Far West	0	0
Illawarra Shoalhaven	121	57
Mid North Coast	126	58
Nepean Blue Mountains	51	1
Northern NSW	0	0
Northern Sydney	1	284
South Eastern Sydney	408	0
Southern NSW	2	50
St Vincent's Hospital	77	16
Sydney	0	0
Western Sydney	128	186

Note: Some sites collected PROMs through their own internal stand-alone databases.

Barriers to success

The following key themes emerged in clinician, manager, and stakeholder feedback on barriers (and enablers) to program success:

- issues with ICT
- limited inducement to change and resource availability
- variable understanding and engagement amongst staff
- staff turnover.

Each of these themes is discussed in turn below.

Issues with information and communication technology

Stakeholders, clinicians, and managers consistently reported that issues with ICT (especially failure to integrate with existing data systems) had negatively impacted program implementation, with the following quote typical of feedback.

> ***My understanding is that the clinicians like the idea and the patients like the idea but the actual technology itself is very clunky and difficult to wrangle.***
>
> **–Program stakeholder**

These issues, reportedly, led to a decrease in clinician (and sometimes patient) engagement, as the potential benefits of PRMs were not seen as substantive enough to justify the additional burden (e.g. time) placed on clinicians (and patients). This was considered especially true in fast-paced, business-oriented primary care settings, where there is often a need to see many patients in short periods. Clinicians working in this environment, it was suggested, will only embrace – as opposed to tolerate – new technology when it:

- is easy to navigate
- links to existing systems
- does not duplicate other activities
- is likely to benefit patients and clinical staff.

Conversely, clinicians and managers who reported greater success withICT (including access and integration), were more likely to indicate that they had used the data to guide patient care, and tended to be more satisfied with program implementation.

> ***They [the ACI] are very clear about being able to provide support for staff training [for IT] and they provide the tablets and they will, in the future once we do start collecting the data they'll be able to provide us with reports. Therefore, I have a high level of confidence in the support that we are getting from the ACI with this project.***
>
> **– Clinician**

Limited inducement to change and resource availability

Several program stakeholders suggested that implementation at select sites had been slowed by lack of inducement to change work practices and a limited increase in resources. According to these stakeholders, it was originally envisaged the potential benefits to clinicians and patients would be sufficient to promote a change in clinical practice; however, the ACI was in fact required to play a significant role in promoting this behaviour change (e.g. education, on-call support, and so on).

This is consistent with feedback from clinical staff, with the following comment typical of feedback.

> ***The only thing I am finding challenging is that there is a lot of local project management workload and change management that needs to be led. I think that if the [program] was standalone from the ACI what I would be suggesting to you is there needs to be some funding for local project management.***
>
> **–Clinician**

Variable understanding and engagement amongst staff

There was evidence of variation in program understanding and engagement amongst clinical staff. Some interview participants suggested that this had impacted implementation success. Put simply, full implementation (i.e. data collected from all eligible patients and used to maximum potential) was most likely in sites where PRM data collection – from mechanics through to potential benefits – was comprehensively understood by all staff. This comprehensive understanding was sometimes achieved through unexpected means.

Champions were also considered to be key to program success, as these staff members assisted in maintaining program implementation in the absence of the ACI staff (i.e. after completion of initial training). Some stakeholders further suggested that dedicated time allocated to implementation would increase likelihood of success.

> ***There was a multitude of reasons [the program] has not been successfully implemented at [select services] but I think when it came down to it, it was because they were all so busy they didn't have time to think about how to start to introduce it.***
>
> **–Clinician**

Staff turnover

A few clinicians noted that program implementation had slowed, or even halted, when trained staff (especially 'program champions') moved on from a practice or service. While the ACI was reportedly quick to train new staff, the program sometimes lost some momentum in the period between engagement and training of new staff. This suggests that implementation success, at least partially, currently rests with the ACI, and that the program is unlikely to be self-sustaining in its current form. Possible program refinements to promote scalability, with a focus on inducements to change, are discussed in Considerations for sustainability and scalability of this report. Some specific suggestions made by clinicians with regard to training included online training resources and assisting service providers who have successfully implemented PRMs to mentor other local providers.

> ***Something like a YouTube video [would be useful] … I think over time the other things that might be really useful is to talk to practices like us who have managed to integrate a lot of the PRMs in the work that we do …to be able to mentor others.***
>
> **–Clinician**

Summary

The PRM program has met the desired outcome of a proof of concept, demonstrating that it is possible to implement the data collection of PRMs in NSW primary and acute care settings. Nevertheless, some stakeholders suggested that PRM completion rates had fallen short of initial expectations, a situation which was variously attributed to:

- issues with information and communication technology
- limited inducement to change and resource availability
- variable understanding and engagement amongst staff
- staff turnover.

Program co-design and implementation

This section of the report will more specifically consider program co-design and implementation, with a focus on communication and consultation, training and support, and data collection and access.

Communication and consultation

Clinicians and managers nearly universally praised the ACI-led communication and consultation efforts, including:

- co-design between ACI and clinicians and managers of data collection tools
- provision of tailored resources, especially face to face briefings and quick reference guide
- ongoing face to face, telephone, and email contact.

Program stakeholders external to the ACI also praised the ACI's communication and consultation efforts, including formal approach to governance and accountability, capacity for building support amongst clinicians and other frontline staff, and strong leadership. However, some stakeholders also expressed concerns about whether this level of engagement could be maintained upon program expansion, with the following quote typical of stakeholder views.

> ***I think from a capacity point of view too there's a limit to how far [the ACI] can stretch things so it's that kind of how do you build a ground swell around [it]. The more people you've got talking about it, the more conversations and myths you can debunk and all that kind of stuff.***
>
> **–Program stakeholder**

Key strengths and suggestions for improvement for communication and consultation are discussed in turn below.

Key strengths

Genuine co-design process

Clinician and managers alike were pleased with the way in which the ACI staff took the time to understand their models of service delivery and care, and worked with their key stakeholders to develop a version of the program that could be implemented within their health service, including tailored data collection tools. This co-design process sometimes incorporated multiple face-to-face meetings with senior managers, education sessions with clinicians, and the ongoing provision of support material. Interview participants sometimes reflected that this level of flexibility in implementation – especially modifying models to allow implementation across the primary and acute sectors – was rare in programs developed and managed by the 'pillars'.

> ***The fact that ACI was willing to entertain the notion of engaging with us as a PHN when clearly their core business would appear to be Ministry type projects, we were really pleased about that … we had to go through a process of validating our own (PREMs) tool … and the support that ACI have given us through that process has been good.***
>
> **–Clinician/Manager**

Interview participants did, however, also acknowledge that flexibility in implementation was necessary to maximise the likelihood of meaningful data, and garner the necessary clinician support. The latter point was considered especially important, given that there was only limited extrinsic motivation for clinicians to change their behaviour (i.e. it was not mandated and the benefits were not always understood or acknowledged).

Face-to-face meetings

Face-to-face consultation and ongoing communication were considered by clinicians and managers to be a critical driver of staff engagement, and most interview participants praised the ACI's efforts in this area. Managers were also pleased that the ACI staff seemed to understand why face-to-face meetings are important, and embraced opportunities to visit sites and potential sites, including those located in regional and remote locations. While acknowledging the importance of local champions, some interview participants suggested that clinician engagement, and likelihood of successful implementation, would have been substantially reduced without the level of face-to-face consultation, especially building knowledge on potential benefits.

> ***Given we cover a large area it's not easy to get practices that are in far flung places … I think they've done a great job of getting there physically to be face to face with the practices and recognising how important that is.***
>
> **–Clinician**

Suggestions for improvement

Clinicians and managers made very few suggestions for improvement in relation to communication and consultation; however, the following recommendations were put forward by a small number of interview participants.

Greater responsiveness

A few clinicians and managers noted that the ACI staff were sometimes slow to respond to email and return telephone calls, and occasionally questions remained unanswered. This situation was typically attributed to program staff being 'on the road'; however, some interview participants were also unclear on points of contact within the ACI.

> ***There have been a couple of emails, a couple of questions that haven't been responded to yet, so whether or not I'm sending it to the wrong person or whether they're away … there's been a little bit of lack of one on one follow up***
>
> **–Clinician**

Ongoing availability

After praising the initial engagement process, a small number of interview participants went on to suggest that the ACI's availability had dwindled slightly through implementation. Specifically, one clinician requested ongoing support, be available when we want to ask any questions while another felt that the ACI could do a bit more work around what to do once the information is gathered and how it should inform your practice.

Training and support

Clinicians and managers typically reported that their knowledge of PRMs – from tool administration through to potential benefits – had increased since program engagement, and many provided positive feedback on the ACI's education and training efforts, including number of face-to-face training sessions and the quick reference guide. Increases in knowledge were most commonly attributed to the ACI; however, a few clinicians and managers acknowledged proactively seeking out additional information. This is supported by the system review, which found that the ACI have provided over 100 training sessions to heath service staff and managers.

More broadly, clinicians tended to acknowledge increased understanding of the role patient reports could have in diagnosis and treatment, including reports collected via PRMs or less formal methods. This was typically attributed to an initial and ongoing formal, and especially informal, dialogue with the ACI. For example, one primary care clinician explicitly stated: I'm starting to look a little bit more at the patient experience. However, overall the interviews suggested that understanding of data use (as opposed to data collection and extraction) amongst clinicians and managers is relatively limited, and further training is both desired and required.

Data collection and access

While the majority of clinicians and managers were thankful for the ACI's effort to assist with data collection and access, most also suggested that the utility of PRM data is currently limited due to access and integration issues. Most notably, interview participants near universally stated that the data would be far more useful – and far more likely to be used by clinicians – if it could be (a) linked to client management systems (e.g. in the general practice setting to Best Practice and Medical Director), and (b) immediately available for review upon tool completion. The following comment is typical of clinician and management feedback.

> ***The problem with REDCap is that it doesn't integrate well into the client management systems we use … ideally that would be sweet if we could actually find a way to harmonise that.***
>
> **–Clinician**

This is consistent with feedback from program stakeholders, most of whom acknowledged that issues with communication technology had been a significant barrier to program implementation. The ACI stakeholders were keen to point out, however, that a contract is currently being negotiated with a new platform supplier, and therefore many of these issues may soon be addressed.

> ***I've lots of expectations around the new product and I'm hopeful it does wonderful things like prompts the person when PRMs are due for review and, you know, can maybe provide a real-time chart on how the patients' scores have changed over time but I suppose we'll have to wait and see.***
>
> **–Program stakeholder**

Clinicians and managers also expressed concern about PRM tool suitability for some patients and staff.

- Patients with intellectual disability, cognitive impairment, visual impairment.
  Some [patients] have an intellectual disability and I haven't found it appropriate to do it … I don't think it's suitable for everybody .(Clinician/Manager)
- Patients with low-literacy skills.
  Because we have areas of low health literacy we wanted visual responses … that has yet to happen but I believe there is work in progress. (Clinician/Manager)
- Health staff without a clinical background.
  Some of the tools may be implemented by one of our Aboriginal health workers … their strength is they have really strong connection with community … but often what they won't have is the clinical background … if they're supported with a trained clinician to back them up it provides some structure to be able to do some more clinical stuff. (Clinician/Manager).

Clinicians and managers who expressed these concerns typically went on to suggest that issues with accessibility should, ideally, be addressed in the next stage of program implementation.

Summary

Stakeholders, clinicians, and managers are in general agreement that the ACI has played a crucial role in PRM program implementation. Clinicians and managers spoke especially favourably of the ACI-led consultation and co-design processes (e.g. development of tailored data collection tools), the availability of the ACI staff, and were appreciative of face-to-face visits. Stakeholders with a broader view of program implementation tended to praise the ACI's formal approach to project governance and accountability, capacity for building support amongst clinicians and other frontline staff, and strong leadership.

Further training in data use may improve usage rates and program engagement. Addressing IT issues including data access and integration issues – especially linking data to client management systems – should also positively impact utilisation and engagement.

Evidence of impacts

This section of the report will cover early evidence of program impacts, with a focus on patients.

Overview of impacts

Stakeholders, clinicians and managers alike were typically hesitant to comment on program impacts, instead suggesting that it is too early in implementation to draw any meaningful conclusions, even at a patient level. However, some clinicians reported anecdotally on the ways in which the program had, in their opinion, positively impacted either patients or staff at their health service. Specific examples of positive impacts for patients and staff are discussed under 'patient impacts' and 'service impacts', respectively, below. Clinicians sometimes also suggested that the mere presence of the program had the unintended impact of sparking increased discussion on the patient perspective, both at a site level and more broadly (e.g. at clinical forums). Clinicians reflected that these discussions – in addition to the results of proof of concept sites – were an important first step in building broad acceptance of the collection and use of PRMs across NSW Health.

Clinicians were most keen to recount the ways in which the program had facilitated more patient-centred and holistic care, with several noting that they had substantially altered patient care plans based on PROM data. This is also reflected in the quantitative data, with 7 of 11 health services' staff indicating that PRM data had resulted in care at their site being 'more patient centred' and 'more responsive to patients' needs'. The small number of patients (n=3) interviewed for this evaluation confirmed that their formal care plan had been altered (including introduction of new medication and an emergency response plan) using PRM data.

Table 2 – Program impacts (health service respondents)

Statement	Number of respondents
Care is more patient-centred	7
Care is more responsive to patients' needs	7
Clinical practices are better	3
Service delivery is more effective	3
Patients play a more active role in directing their healthcare	3
Management practices are better	2
Service delivery is more efficient	2
Patient management has improved	2
Not sure / Don't know	1
I'd prefer not to say	1

When prompted to comment further on whether alterations to care planning had resulted in improved health outcomes, both patients and clinicians were hesitant to assign attribution, instead stating or suggesting that PRMs are only one element of care, and that positive outcomes are typically the result of a combination of factors (e.g. patients' disease trajectory, responsiveness to clinical interventions, and so on).

The remainder of this chapter will draw upon feedback provided by clinicians and managers, and to a lesser extent stakeholders and patients, to outline early evidence of patient, service, and health system impacts of the PRM program.

Patient impacts

When discussing potential patient impacts, clinicians and managers tended to focus on the use of individual data in promoting holistic or patient-centred care, including through uncovering preferences or unknown health quality states (e.g. mental health issues such as undiagnosed depression or anxiety, or mobility issues such as trouble navigating one's home environment in the absence of assistive technology). According to clinicians, this more holistic approach may, on occasion, have contributed to improved health outcomes through:

- more appropriate initial care and support provision (i.e. triage tool)
- guiding of ongoing care and support provision
- uncovering of mental health and wellbeing issues
- enabling patient engagement in care.

Each of these points is discussed in turn below.

More appropriate initial care and support provision (i.e. triage tool)

Clinicians and managers working in larger facilities and within multidisciplinary teams noted that PROMs are a useful triage tool, with data assisting with determination of care provision, including timing of care. For example, one clinician described typically using a patient's first PROMs to:

- guide treatment planning (including necessity for referrals)
- promote initial conversations with the patient
- ascertain whether physical and other supports are required.

Clinicians and managers who reported using the PROM data as a triage tool tended to be of the view that their engagement in the PRMs program had streamlined early consultations, as triage processes are now far more systematised.

> ***The patient reported outcome measures will help us triage appropriately and make sure the patient sees the right health practitioner, kind of gauge a referral platform.***
>
> **–Clinician**

Guiding of ongoing care and support provision

Clinicians commonly reported using PROM data (when collected at multiple time points), as well as other clinical measures, to track change in a patient's health status and wellbeing over time, and to consequently alter care and support provision. By way of example, one clinician noted that longitudinal PROM data allows the team to: have a look at [a patient's] function, quality of life and mood and then we can also see changes throughout the program just to make sure it's impacting on them in a clinical framework. Clinicians were most likely to cite this use when involved in the delivery of longer-term programs or interventions, as this care structure allowed for more systematic administration of measures than ad hoc appointments.

Assessment of mental health and wellbeing

A significant number of clinicians noted that PROM data is useful for uncovering undiagnosed mental health conditions, especially anxiety and depression. These clinicians typically suggested that if a patient's health-related quality of life measure is low, they would have a discussion with the patient about their mental health, and possibly undertake further diagnostic testing or referrals.

Enabling patient engagement in care

While typically not reported as a primary use, some clinicians suggested that PROM data (when collected at multiple time points) could be used to demonstrate to a patient how a symptom or condition had altered as a result of an intervention. Using PROM data in this way was considered to be especially valuable when an intervention required substantial effort from the patients (e.g. an exercise program), or when changes were unlikely to be either immediate or substantive.

Service impacts

There was limited discussion of service impacts among clinicians and managers, with most indicating that the level of data collected had not been substantial, or compelling, enough to prompt noteworthy changes to clinical protocols or governance. That said, a few managers noted that aggregate PRM data (including comparisons across sites) had been used to refine service delivery. For example, a few clinicians noted that aggregate PREM data is being used at their service as a 'quality indicator', ensuring that care is 'timely, efficient, and targeted correctly'. Some managers also reported that data had, on occasion, led to updating of models of service delivery or care.

> ***We are here to provide good value healthcare with good outcomes so being able to show that, demonstrate that benchmark of reduced variation and give pretty close to real time feedback to teams about how they're going at a service and system level is going to be important.***
>
> **–Stakeholder**

Feedback on PREM use was very limited; however, most interview participants were cognisant of the potential impacts of aggregate experience measures on service provision, especially the promotion of consistent, quality care. Further training on PREM use would help to ensure that these impacts are realised to their full potential, with clinicians commonly indicating that they are unsure about how to use PREM data to guide service delivery or requesting further training. The following quote was typically of feedback from clinicians and managers.

> ***And in terms of the patient reported experience measures I think it's still early days, I think that there will be a lot of really important information that we can extract from that but I don't think we've been tapering or changing quite a bit of it and I think that will provide future important information but it's still really early days for measures and service delivery.***
>
> **–Clinician**

A few clinicians further reflected that PRM data had led to service-level efficiencies, as care and other resources could be targeted and provided at the most appropriate time (n.b. before a condition escalates).

> ***I'm using resources more effectively from two years ago to now I definitely feel that I'm engaging with the patient a little bit more and using the resources effectively.***
>
> **–Clinician**

Health system impacts

While feedback on potential health system outcomes was limited, it was mostly consistent but, at this early stage of implementation, was understandably mostly about 'theoretical' impact reported by stakeholders rather than tangible impact being reported by clinicians and managers. The majority of interview participants focussed on the potential for the PRMs program – or at least some form of patient outcome and experience tracking – to contribute to a reduction in unplanned hospital admissions, and associated efficiency gains. This feedback was most common amongst stakeholders who were familiar with the NSW Integrated Care Strategy, or had experience working with chronic disease patients. These interview participants commonly suggested that PRMs (especially PROMs) could assist in reducing unplanned hospital admissions by:

- ensuring that patients are provided the most appropriate treatment in primary care
- uncovering unknown health states and barriers to service access
- enabling integration of care planning (and therefore more integrated care), including across the primary and acute systems.

Summary

While it is too early in implementation to draw firm conclusions about program impact, the available evidence suggests that the collection of PRMs (especially PROMs) could contribute to positive health outcomes for patients, the enhancement of service delivery, and a reduction in avoidable hospital admissions. These impacts will be explored more fully, including potential quantification, in the summative phase of this evaluation, to be undertaken in 2019.

Considerations for sustainability and scalability

As noted above, this formative evaluation has taken place at an early stage of program evolution and early implementation. For that reason, there is little data available on the actual experience of PRMs in practice, with which to assess sustainability and scalability at this stage. Later stages of the evaluation will be able to look at these questions in greater detail.

However, even at this early stage issues of sustainability and scalability have been recognised by stakeholders. Those who were interviewed for this report, particularly those who consider PRMs to offer potential for improving patient health outcomes, are already anticipating the challenges that will need to be addressed in order to ensure that PRMs can be embedded in the NSW health system as a sustainable element of clinical care. The essential role of the ACI to date in the implementation of the program has been acknowledged and this is both an enabler for the current program and an indicator of the extent of investment required to expand the program successfully.

This chapter considers the major factors raised by stakeholders as key to the future sustainability and scalability of PRMs across NSW Health, which have been identified as:

- information and communication technology
- enablers to routine practice
- system enablers
- change management.

Each of these factors is discussed in turn below.

Information and communication technology

While at the patient interface the PRM technology may appear simple – a hand-held tablet on which to complete a brief survey – the technology architecture required to embed PRMs in practice is complex. This is due to the variety of systems that are used in different clinical settings including general practice, and in different LHDs, as well as the lack of IT integration between service settings. LHDs are also making changes to their medical record systems to allow the entry of PRMs, and this is occurring in different ways across the participating LHDs.

The essential components of an effective system were identified by one stakeholder as:

> ***… identity management, security management and seamless integration with the GP desktop are probably the first three things that I would raise and underneath all of that you've got all the enabling technology that allow a seamless integration to occur.***
>
> **–Program stakeholder**

This seamless integration was noted by stakeholders to be critical. For PRMs to work, the interface for the user needs to be simple and immediate. Clinicians are time-poor and anything that adds more than one additional step to their consultation is unlikely to be welcomed. As identified by interview participants, for PRMs to be sustainable the system needs to be easy at all points of contact: for the patient in completing the survey; for the clinician in accessing the data; for the service in storing and monitoring data over time.

> ***The IT is important because it's got to be simple and it's got to be simple to get meaningful responses from the patient too.***
>
> **–Program stakeholder**

The IT system used during the proof of concept was a trial structure and it was clear from initiation that it would not be likely to fit smoothly into all existing routines of patient care or into existing data systems. To accommodate this, clinicians and managers noted that their service had been required to develop mechanisms to fit the PRMs project into their current routines, which in some instances has been time consuming. In this sense, the trial of PRMs has contained an artificial component in that the currently available IT architecture has had to be explicit and visible whereas, ideally, once a seamless IT system is developed and PRMs are embedded into the data systems of a clinic, the whole process would be invisible to the practice except for the patient or clinician interface. The interface itself might need to

look different in different clinical settings depending on the type of software already in use. The key to sustainability will be to design a process that is flexible enough to fit into the routines of a primary care clinic as well as the routines of a tertiary outpatient clinic, or an inpatient ward.

Likewise, expanding the program to other service settings will only be possible once the IT system is more integrated and easy to navigate and there are clinical champions who can demonstrate the benefits and ease of this new process. Many stakeholders emphasised the importance of having clinical champions to help other clinicians appreciate the potential for PRMs to improve their practice. Any system will need to be essentially invisible to the user; that is, the user should experience a minimal burden in incorporating the new process and the new data into practice. This is important for managers and administrators for set up and evaluation purposes but particularly for clinicians who could be engaged with the system with each patient that they see on a daily basis.

The ACI stakeholders noted that proof of concept sites contributed to the user acceptance testing of the current IT system; sites have also been involved in designing a minimum set of requirements for the new system, which the ACI and eHealth NSW are currently working to deliver. These stakeholders further suggested that they are hoping to achieve 'an integrated system that will allow seamless, routine and systematic collection and use of PRMs.'

Enablers to routine practice

Once the technology is developed and has demonstrated its value by being painless to incorporate into daily practice, a key to sustainability will be to ensure that people know what to do with the data once they have it. As noted above, several stakeholders reflected that they had received appropriate training or information on how to collect the data, but little help in figuring out how best to use the data once it is collected.

> ***Every month we get sent [a PREM report which shows] kind of how we did in the last month and there's this kind of spider diagram, I don't know if that's what it's called and it gives you an indication of whether you're doing better or worse but I'm not sure what we're doing better or worse at.***
>
> **–Clinician/Manager**

There also appears to be variation in use, with some interview participants recounting the numerous ways in which the data had been used to guide service delivery and treatment, and others expressing genuine confusion about how and when data could be used, if at all. This finding is also reflected in the quantitative data, with only four of nine health services' staff indicating that PRM data is 'very useful', and one indicating that it is 'not very useful'. Clinicians were especially unclear about how aggregate data could be used to promote positive outcomes at service or system level. Similarly, some stakeholders were only able to articulate a theoretical understanding of the potential impact of the PRMs, as aggregated data had not yet been used widely in practices in the program to improve care.

> ***One of the real positives about this is that we will be able to show outcomes and give them clinical and patient reported data about the quality of their work and they haven't been able to get that.***
>
> **–Program stakeholder**

At this stage of the evaluation it is natural to find a focus on the implementation of the program, but stakeholders were already indicating a need for assistance to move to the next level, which is to feel confident and comfortable with using the data in practice.

It is too early to determine what is needed to ensure sustainability of usage, given that many sites are not yet in a routine of using the PRM data. That said, clinicians and managers who expressed strongest support for the program, and were the furthest along in terms of implementation, tended to possess a solid understanding of how and when PRMs could be used, to both guide patient care and service refinement. These clinicians and managers also tended to be early adopters, suggesting that improving understanding may lead to a more scalable model (see Figure 1, below). It will be important, to demonstrate how a broader group of clinicians will accept it. It will also be important to ensure that efforts to improve understanding do not rest solely with the ACI (especially if it involves face-to-face contact), but that e-training resources (e.g. videos) and mentoring (i.e. by staff at other sites) should be used as much as possible.

Figure 1 – Impact of understanding on sustainability

Incorporation of PRMs into routine practice is as reliant on patients as it is on clinicians. Put simply, patients must be both willing and able to complete PRM tools; otherwise there will be no data for analysis or interpretation at any level. Currently, there appear to be two barriers to patient completion of PRMs.

Low accessibility

Patients with intellectual disability, cognitive impairment, or visual impairment are currently not able to complete PRMs in the existing IT system without substantial assistance, increasing the burden on patient and staff, and decreasing likelihood of completion. As such, improving accessibility may assist in embedding PRMs into routine clinical practice, and tool completion should be as minimally burdensome as possible on patients with accessibility needs. It is not clear the extent to which this barrier has had an impact on the number of completed PRMs; however, it was mentioned by several clinicians. It should be noted that although the PRMs can also be completed by a proxy, for instance by a carer completing the questions on behalf of the patient, the collation and interpretation of this data will need to be considered by clinicians in the context of an understanding of the potential for carer data entry to influence the patient's subjective report.

Questionnaire fatigue

Several clinicians expressed concerns about questionnaire fatigue, stating that patients were sometimes overwhelmed by multiple measures, and did not always see the value of the data being collected. As with all data collection, usefulness of data items needs to be balanced with the likelihood of questionnaire completion, as some feedback may be better than no feedback at all. While the ACI has worked in consultation with sites to develop targeted measures, further streamlining will need to be continued over time to increase the likelihood of completion, further enhancing the likelihood of incorporation of PRMs into routine practice.

> ***The challenging thing is really looking at the meaningfulness of questions, what that means and patient time, I think the biggest difficulty at the moment is really questionnaire fatigue.***
>
> **–Clinician**

System supports

Taken together, feedback collected for this evaluation suggests that it would be very difficult, if not impossible, to incorporate the systematic collection of PRMs across the NSW health system without substantial system-level supports. While PRM collection is currently occurring at multiple proof of concept sites, the ACI is playing a substantive role in initiating and maintaining collection; an approach which, while admirable, simply could not be taken to scale.

> ***I think the only other thing that springs to mind and I guess this goes back to the scalability thing of it is that it's been very hands on by Mel and the team to implement and to get things up and running and there's various reasons for that and there's various reasons that were probably needed.***
>
> **–Program stakeholder**

To be scalable, program ownership, and the momentum for change, needs to rest at an LHD or service level, with the ACI for example, assisting with system level processes such as IT system development, measure selection and guidance, coordinating implementation and ensuring adherence to clinical governance.

While system level supports were not the focus of this evaluation, it is possible to conclude that perceived benefits of PRMs alone are not sufficient to motivate clinicians to change their behaviour, especially if technology is cumbersome and data usefulness is unclear. There are two possible system level supports, or a combination of these supports, that could induce behaviour change in this context.

Provision of additional resources or funding

Clinicians and managers interviewed for this evaluation typically cited time and resources as a significant barrier to program implementation. Currently, even if the technology works perfectly, patients, service staff and clinicians – all very busy people – must work together to make the collection and use of PRMs a reality. This view was echoed by stakeholders.

> ***I'm hopeful that we can take it to scale but I have concerns because there are so many clinicians are time poor that's the biggest challenge so making sure the right enablers are in place … [particularly for] general practitioners who are independent businesses where there isn't a huge incentive for them to change behaviour.***
>
> **–Program stakeholder**

Additional funding or resources, including hiring of designated staff or allocation of staff time, would assist in ensuring that PRMs receive the attention required to maintain momentum for implementation, a role typically being played by the ACI staff. Designated staff members could be project champions and take responsibility for training and support, with a focus on data uses. Potentially this role could be placed within a LHD or a PHN to work across a number of clinics or general practices.

> ***I think there's going to have to be a structure involved and it will take up time of primary care and other clinicians in an acute setting to use, so I think a lot of information access, a lot of training, it will take some resources.***
>
> **–Clinician/Manager**

Mandating change

Alternatively, it is possible to promote behaviour change in clinical environments through the introduction of mandated clinical protocols or models of care. The collection of PRMs could be mandated, or at least strongly encouraged, as a means of contributing to health service quality and safety accreditation. It should be noted that the barriers described above would remain and a strategic change management process is likely to be required to drive behaviour change. Any mandate for general practitioners would need to involve the Commonwealth in negotiations and development of mandated models of care.

Change management

The collection of patient reported measures in NSW is not new. There are a number of validated and well known tools which have been in use in some clinical practice settings for many years, such as the Kessler Psychological Distress Scale K10 for mental health, the medical outcomes study 36, short form health survey SF-36 for general functioning, and so on.

This current, more structured and comprehensive, introduction of PRMs into the NSW Health system is in some ways a natural extension of the existing use of PRMs, by incorporating patient reports into systematic clinical assessment across entire patient cohorts. The sustainable use of PRMs, however, will mean that the collection of PRMs is prompted by the system rather than by a decision made by a clinician in a single patient encounter. For that reason, the system itself needs to be adapted to drive new behaviour by patients and clinicians, and to support that new behaviour with appropriate information and other mechanisms. To be sustainable and scalable, PRMs will need to become as routine and unremarkable as, say, completing a change of address form for a patient, or reading an x-ray for a clinician.

Feedback from evaluation participants suggests that the following factors should be considered in developing an enhanced co-design process for strategic change management for the PRMs program.

Ensure there is leadership at all levels

At the moment, the ACI holds the designated leadership of the PRMs program. This leadership is valued by all stakeholders for the purpose of demonstrating the proof of concept; at the same time, participants noted that such intensive involvement of the ACI will not be sustainable in the long run. A number of evaluation participants suggested the need for 'champions' at the local level to provide leadership in implementing PRMs and using the data to improve clinical practice. While there was consensus among stakeholders that this champion would be a clinician, there is a reasonable argument to be made for several champions at different levels of the health system. This might include, for instance, leadership from a (clinical or non-clinical) role within a PHN or LHD to facilitate further integration of PRMs into regional practice; leadership from a practice manager within a general practice or an outpatient clinic; leadership from one specialist within a large clinical speciality in an LHD. This blending of designated leadership (e.g. the ACI) and distributed leadership through champions scattered throughout the health system is likely, based on the evidence, to assist in driving uptake of PRMs and, over time, improvements to clinical practice. The importance of more than one change champion is also further highlighted but the reports from the evaluation about the negative impacts on program development of staff changes in local practices.

Identify clinical champions

In addition to identifying leaders throughout the system, it will be essential to identify clinical leaders who can become champions within their service setting. Put simply, if clinicians (particularly general practitioners or specialists) do not see the value of the PRMs, the program will fail. While this is true for both medical and non-medical clinicians, the role of the medical champion can be particularly influential. Many doctors will be willing to participate initially to test the usefulness of the PRMs, but if sufficient benefit is not demonstrated, the program will not be sustainable. Most stakeholders agree that doctors are more likely to be convinced by the experiences of other doctors, so medical leadership is likely to encourage other doctors to participate. Medical practitioners tend also to be the leaders within their service setting and, as such, are able to drive changes in clinical practice where non-clinical staff may find this more difficult. Finally, medical practitioners will bring their own knowledge and experience to decisions regarding how to make most effective use of PRM data in clinical practice. Clinicians will need to embrace the introduction of PRM data and make it work for them, in order for PRM data collection to be sustainable.

Include patients and families

This concept is a foundation of PRMs themselves, so in one sense is obvious. At the same time, if patients do not see the benefits for themselves, as a result of completing the PRM tool, over time they will become resistant to completing the survey. Patients should be included in all aspects of the PRM process, from completing the tool to discussing the results with their doctor. It will be important for patients and their families to see that their feedback is being used to improve services. A next step could be to monitor the inclusion of patients in conversations about PRM data with the increased consideration of their own perceptions of outcomes and experiences.

Establish feedback loops

As noted in previous chapters, several clinicians commented that they were unsure how to use the PRM data effectively in clinical practice or for quality improvement purposes. There is an identified need, based on evaluation evidence, for further support or training to establish effective feedback loops so that clinicians are using the data that is being collected. It will also be important for patients to be part of this feedback loop and to see their data used in practice, as evidence of its use is more likely to motivate patients to continue to complete the PRMs over time.

A number of stakeholders, including clinicians, identified the potential for PRMs to be used at a service level, above and beyond the patient encounter, to examine trends in patient reported outcomes and link these back to clinical activities. This is not occurring regularly yet, although some clinicians or managers did indicate an intention to use future data in this way. A service-level feedback loop will need to ensure that clinicians see the benefits of this type of clinical audit and are willing to participate in continuous improvement activities. To embed PRM data at a service level, clinicians will need to see that the information is meaningful and beneficial to them and to patients.

As discussed above, the IT architecture will need to be in place to facilitate easy access to and use of PRM data, before these feedback loops can become embedded in routine practice. In addition, reporting will need to be straightforward and clearly articulated for clinicians to absorb quickly; such a report could also highlight potential actions in response to findings.

In the short term, a next step could be to provide more training in how to use PRM data, and increase support for clinical teams in the active use of data.

Attend to the local context

There will be many factors that influence the uptake of PRMs in each service setting. These may include such intangibles as the levels of tolerance for innovation and risk within the service, the quality of leadership, and the value placed on consumer input. It may be useful, as the evaluation progresses, to examine more closely the mechanisms that have contributed to successful change initiatives in the past, in different environments. For instance, one stakeholder could identify why PRMs were relatively easy to incorporate into their practice, based on their leadership, proactive approach, configuration of clinicians, current systems of data collection and use, and so forth. As the PRM program continues to be implemented, analysis of the environments in which the project seems to be most successful will help to identify factors that contribute to successful uptake, and to ensure that these factors are present or in development in future sites where PRMs are introduced.

A next step could be to undertake an analysis (potentially using a realist frame) to identify what components encourage success at the service delivery level, and apply these components when considering expansion of the program to other clinical settings.

Summary

While it is early in the implementation process and the quantum of data is relatively small to date, stakeholders from participating services have identified the potential benefits of using PRM data to improve practice. Evaluation participants have also identified some of the challenges in implementation, including the need for information systems to facilitate data collection, the need for training and ongoing support for clinicians and patients, and the need to engage staff in the process so that it becomes part of the daily clinical routine.

Participating sites are at various levels of implementation. There is evidence that those who are furthest along in the process are most able to see the benefits and potential for sustainability, and also least reliant on the ACI for support. This suggests that embedding PRMs in practice is necessary for both sustainability and scalability.

Stakeholders at all levels were appreciative of the leadership that the ACI has provided in implementing the PRMs program, including the tailored support provided to individual sites and the training available for clinicians and frontline staff involved in establishing PRMs.

Evaluation assessment

In this first year of the evaluation, the evidence suggests that the PRMs program has achieved its objective of demonstrating that the concept of collecting PRMs and using them to improve clinical practice is feasible in the NSW primary and acute care settings.

The plan for this evaluation identified a number of outputs to be assessed at this point in the program's implementation. These are summarised in the table below, with a brief summation of the evidence. A lack of data in some instances, particularly regarding patient experience, has meant that some outputs are unable to be assessed. These should be explored more thoroughly in the second and third years of the evaluation.

PRMs Outputs (ongoing)	Evidence from year one evaluation activities
Key evaluation questions • To what extent has the program been implemented and delivered at each site? • To what extent are patients provided with consistent information at each site?	
Patient education resources are easily available, and are used by patients.	There were too few patients participating in this formative evaluation to make an overall judgement; however, evaluation participants considered that they were provided with information to help them complete the PRMs.
Patients are able to complete the PRMs tool easily.	As above, evaluation participants did not identify any difficulties with completing the PRMs tool.
Health service staff and clinicians are provided with useful education resources and training.	As reported by staff and clinicians, the ACI has been proactive in providing resources and training to ensure people know how to collect the data. Some participants have identified the need for further training on how to make the most of the data now that the collection processes are well established.
PRMs are analysed for each patient, and individuals' needs are assessed.	To the extent reported by clinicians, and the three patients who participated in the focus group, it appears that clinicians are using PRM data in their assessment of individual patients. Table 2 on page 17 provides responses by survey respondents with regard to the impact of PRMs on service provision.
PRMs reports are documented for all participants.	Data collection is not fully implemented at all sites, but the number of participants is reportedly increasing continually.
Care pathways for specific conditions are identified, including referral pathways to other services.	Clinical review of records was not included at this stage of the evaluation.
Clinical staff are using PRMs regularly in their consultations with patients.	To the extent reported by clinicians, and the three patients who participated in the focus group, it appears that clinicians are using PRM data in their consultation and, particularly, in the development of care plans.
Data collection and management systems are established and in use.	This varies between sites, but is progressing.
All participating health service sites are provided with adequate infrastructure and support from the ACI to implement the PRMs program.	The ACI's leadership and support are well regarded by all evaluation participants at the proof of concept sites.
Lessons from implementation and establishment are recorded at each site to inform future program development or expansion.	This varies between sites but evaluation participants did identify using their own experience to further embed PRMs in practice. Services that were at advanced stages of implementation did consider that they could assist newer services by sharing their experience and learning as the use of PRMs expands into new service sites.

At this stage, the patient voice is not strong within the evaluation; this is due to low numbers as well as the method for engaging with patients. It was not possible to gather enough evidence from patients to analyse the benefits or impact of PRMs at a population level. At the same time, the three patients who participated in a focus group could articulate a sense that their doctor had used their feedback in developing a care plan and supporting their self-management, and appeared satisfied that their doctor was listening to them and responding appropriately. Given the focus of the project on patient-reported outcomes and experiences, including the patient voice in later stages of the evaluation will be crucial. The availability of quantitative data should continue to increase and this will allow patient outcomes to be explored in greater detail in the summative phase of the evaluation in 2019.

Overall, the evidence suggests that PRMs, if embedded and incorporated into routine clinical practice, can contribute to improved clinical care for patients, with corresponding health benefits including, potentially, a reduction in unnecessary tertiary presentations.

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