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The PRMs HOPE program process evaluation

Summarised report findings

October 2023

NSW GOVERNMENT

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Executive Summary

The first process evaluation of the Patient Reported Measures (PRMs) Health Outcomes and Patient Experience (HOPE) program was conducted in 2022.

This report is for PRMs HOPE program stakeholders across NSW Health. It provides an update of the 2022 evaluation findings, recommendations and related program progress. Included are:

- evaluation findings in response to five of the eight key evaluation questions from the PRMs HOPE evaluation plan
- focus areas for improvements to the PRMs HOPE program in response to the evaluation findings
- recommendations stemming from the evaluation endorsed by the Self-Reported Information Steering Committee
- relevant context and interpretation of the results from a program perspective including related progress.

This summary document was developed by the Ministry of Health, the Agency for Clinical Innovation, and eHealth NSW with input from local health district (LHD) and specialty health network (SHN) PRMs leads and executives before being endorsed by the Self-Reported Information (SRI) Steering Committee.

The PRMs HOPE program is a partnership across NSW Health to enable collection and use of PRMs at point of care for multiple purposes including shared care decision making, on-going monitoring of patient progress, to inform service improvement, and for evaluations and system-level decision making when aggregated over time. The collection and use of PRMs are important enablers of NSW Health's Future Health Strategic Framework. The HOPE platform facilitates the digital collection, use and reporting of PRMs data.

The endorsed process evaluation report for the first phase of the PRMs HOPE program evaluation focuses on five key evaluation questions (KEQ) from the overall monitoring and evaluation plan:

- KEQ1: Is the PRMs HOPE program being implemented as intended?
- KEQ2: What is the uptake of PRMs?
- KEQ3: What is the clinician's experience of using HOPE and PRMs?
- KEQ5: To what extent is the PRMs HOPE program achieving the changes and outcomes expected at the clinician level?
- KEQ6: What are the barriers and facilitators to the PRMs HOPE program achieving its expected outcomes so far?

The process evaluation was intended as an early review of progress to identify areas for improvement and refinement. The scope of the evaluation included the implementation of HOPE and PRMs with a particular focus on the period between February 2021 to December 2021 for the uptake analysis. Out of scope was a full technology assessment of the HOPE platform, patient experience of using the platform and economic assessment. These elements will be covered in future evaluations.

The findings stem from the synthesis of three main data sources: uptake analysis using linked data, stakeholder consultation and a clinician survey.

There is a total of 36 proposed recommendations to address the findings and opportunities identified at the individual, service and system level in the evaluation.

Many of the recommendations are already underway due to the genuine iterative nature of the HOPE program.

The process evaluation identified six focus areas for consideration to enhance achievements of the intended outcomes of the program. The six focus areas are described below and are detailed through each of the five KEQ areas.

1. Targeted implementation for patient cohorts and conditions where PRMs are integrated into the model of care

The experiences of implementing PRMs within HOPE may be improved through the revision of models of care (MoC) for cohorts within the program to include key enabling elements. Critical elements within a MoC may include, but not be limited to a) creating a referral pathway for patients in which PRMs identify additional health needs beyond the scope of current service, b) alternative surveys or PRMs data capture methods relevant to population and patient cohorts for whom PRMs HOPE have limited suitability, and c) guidelines to support the resourcing of the collection of PRMs HOPE.

2. Explore targeted and tailored methods for PRMs data capture to increase uptake

PRMs collected via survey may not suit all patient cohorts and populations. HOPE is designed to gather PRMs via surveys. The use of a digitised system may limit some patients in completing the measures, some technical support and support for completion may be needed for key patient groups.

Several other strategies are being used by clinicians in NSW Health that may provide complimentary or alternative tools and methods for gathering PRMs to support the intended changes and outcomes of PRMs HOPE to be realised [at the individual level]. Exploration of the potential for clinicians to have flexibility in survey selection and whether items may be marked as not applicable may be valuable.

3. Optimise reporting from HOPE to deliver meaningful insights and support greater use of PRMs results for patient care

Optimising the reporting of information in HOPE through engagement with stakeholders may support greater use of PRMs results for patient care. User engagement to determine the types of reports and suitable formats required may be valuable.

4. Reviewing the use of identifiable patient reported experience measures (PREMs) at the point of care in HOPE to ensure intended outcomes are being achieved

The process evaluation indicates that HOPE PREMs are being under-utilised due to several existing well-used PREMs. Given the collection of PREMs at service and system level in NSW Health, it may be pertinent to explore the contribution of HOPE PREMs to the intended changes and outcomes of the PRMs HOPE program in the context of existing PREMs data collection and use through other mechanisms in NSW.

5. Clarifying, aligning and communicating the intended scope of PRMs in HOPE beyond the Leading Better Value Care (LBVC) and Integrated Care (IC) cohorts

Lack of clarity regarding whether PRMs HOPE are to be limited to LBVC clinics or may ultimately be used system-wide was apparent among stakeholders. Given that experiences outside of LBVC clinics were less favourable in the use of PRMs HOPE, clarity regarding the scope of this program may be pertinent to consider and articulate to stakeholders.

6. Consideration of resources needed to support the initial implementation and ongoing participation of services collecting and using PRMs via HOPE

PRMs HOPE leads and administrative staff to support completion are critical. The scope of PRMs leads extends beyond the implementation of the HOPE platform to engage services in collecting and using PRMs via HOPE. Consideration of the resourcing of PRMs leads and administrative staff to support the program is required.

Further, the recommendations are summarised to include actions at the system, service and individual level. Within the recommendations, the owners are defined as follows:

- System refers to state-wide partners of the Agency for Clinical Innovation (ACI), eHealth NSW and/or Ministry of Health.
- Service refers to Local Health District or Specialty Health Network.
- Individual refers to clinicians or an individual clinic/individual service.

The recommendations are outlined below. They have been grouped according to the key evaluation questions (KEQ) and are linked to the findings.

Process Evaluation Findings

KEQ 1: Is the PRMs HOPE program being implemented as intended?

The opportunities for improvement within KEQ1 focused on targeted implementation of HOPE and PRMs (four recommendations), resource implementation and ongoing practice (four recommendations). While the process evaluation couldn't conclusively answer this question due to a lack of formalised targets, there were still clear opportunities to strengthen implementation.

Most clinicians felt they had received sufficient education and training to collect PRMs using the HOPE platform. Respondents interviewed largely reported the training and preparedness activities were valuable.

Recommendations	Lead	Status
To support consistent implementation across cohorts: • Review MoC and pathways to assist with the targeted implementation of collection and use of PRMs through HOPE. This includes reviewing existing MoC and building in standardised collection and use of endorsed PRMs.	ACI in partnership with LHD/SHN	Commenced
To address the learning and development needs in LHDs/SHNs: • Develop a flexible localised approach to training activities, aligned with clinician availability to increase engagement, sustainable education, and capability development. This includes executive sponsor engagement and communication of capture and use of data at an LHD executive level, this should be monitored through established and purposeful LHD/SHN governance of PRMs.	LHD/SHN in partnership with ACI	Yet to commence
To address the lack of consistent referral pathways: • Improve localised referral pathways for multidisciplinary teams reviewing and responding to patient reported outcome measures (including as an example, HealthPathways), inclusive of the development of referral pathway checklists as part of the scoping for local services to implement PRMs HOPE.	LHD/SHN in partnership with ACI	Yet to commence
To resolve systematic recommendations for referral pathways: • Review of state-based HealthPathways to align referral pathways for endorsed cohorts in the HOPE PRMs program.	Ministry of Health	Yet to commence

To address resourcing and workforce: • Review of resourcing required within services to effectively sustain PRMs HOPE. This could include service redesign, review MoC and guidelines to support implementation and business case for resourcing as appropriate.	LHD/SHN in partnership with ACI	Yet to commence
To ensure system demand is met for implementation: • Define and deliver an accelerated model of implementation for engaged and appropriate services and cohorts. This will enable increased engagement across LHDs/SHNs and ensure PRMs HOPE is embedded across appropriate MoC where there is need or demand.	ACI in partnership with LHD/SHN	Commenced and to be delivered within HOPE Phase 2
To build on clinician led engagement and sustainability: • Hosting of 'roundtable' aimed to identify exemplars of local engagement and readiness. Benchmark self-reported uptake, implementation and the use of PRMs at point of care to identify areas for strengthening.	ACI in partnership with LHD/SHN	Yet to commence
Increase transparency of existing PRMs work, including: • Amongst the ACI networks where PRMs are available and have a presence to communicate to network members on the progress of PRMs. • Coordination of LHD/SHN executive sponsors and leads to present local work systematically in order to increase cross collaboration with LHDs/SHNs.	ACI in partnership with LHD/SHN	Commenced

KEQ2: What is the uptake of PRMs?

The opportunities for improvement focused on tailored methods for PRMs data capture (three recommendations), resource implementation and ongoing practice (two recommendations).

- The evaluation revealed the need to create awareness across the system that PRMs collection and use isn't solely based on dedicated disease or condition specific services, rather PRMs focuses on the whole of patient journey across settings, clinics and cohorts. This complicates aggregate reporting where patients are associated with many services, clinics and clinicians working outside of dedicated LBVC clinics, therefore PRMs are attributable to many services.
- The evaluation suggested allowing clinicians or patients to mark individual questions as 'not applicable' to skip questions that didn't seem relevant. This is unable to occur due to pre-defined business rules and the state-wide governance agreement to answer mandatory patient reported outcome measures (PROMs). This would create further issues with scoring, longitudinal data, reporting and missing data.

- The number of new sites that started to use HOPE varied considerably across the evaluation period between February 2021 and November 2021. On average, 12 clinics per month went live and started using the HOPE platform to capture PRMs. Locations commencing implementation were dependent on local PRMs lead and executive sponsor scoping and endorsement. Work has commenced to review processes for scoping new sites that will take up the use of HOPE, including education activities for stakeholders. Future work will include further review and education for future scoping and go-live processes will be reviewed for consistency.
- The evaluation found that most PRMs surveys were completed face-to-face. This is an expected workflow as many patients completing PRMs for the first time would be with a clinician in the location, clinic or service when consenting to complete.
- Data to analyse Aboriginal and culturally and linguistically diverse populations were out of scope for this evaluation, however, will be evaluated in future phases.

Recommendation	Lead	Status
To address concerns regarding HOPE functionality: • Where it already exists, or improvements have already been made based on local feedback, local PRMs leads to develop regular education on existing capabilities, for example, transcribing view or carer/proxy functionality. • Flexibility of survey selection for programs and cohorts. • Ability to choose or remove selected surveys if not clinically appropriate.	LHD/SHN in partnership with ACI	Yet to commence
To address concerns of quality of life survey appropriateness: • Develop communications and awareness building ahead of the implementation of the Patient-Reported Outcomes Measurement Information System (PROMIS) computer adaptive testing (CAT) so clinicians are aware they will, in future, be able to choose suitable domains for their patient group and domains that are not relevant can be left out.	ACI in partnership with LHD/SHN	Commenced and will be delivered in HOPE Phase 2
Develop an understanding of collection mechanisms: • Identify and understand the drivers changing from paper-based to electronic data capture and use to improve usability and acceptance versus migration from one electronic system to another, and communicate future and new enhancements within HOPE addressing these barriers.	ACI in partnership with LHD/SHN	Yet to commence

To create system-wide awareness of the strategic vision: • Dissemination of system-wide communications on scope and expansion, linked to broader strategic Self-Reported Information (SRI) work to create awareness and linkages across key stakeholders' groups to clarify the intended scope of the PRMs HOPE program, with updates to scope and narrative completed as required.	Ministry of Health in partnership with ACI	Yet to commence
To better sustain local implementation: • Review and refine readiness for implementation of PRMs locally, (including appropriate pre-implementation checklists and governance are met) to ensure LHD/SHN preparatory activities are completed and within identified scope of the program.	ACI in partnership with LHD/SHN	Commenced

KEQ3: What is the clinician experience of using HOPE and PRMs?

The opportunities for improvement spread evenly over three areas, with one recommendation in each as follows: optimise HOPE reporting; resource implementation and ongoing practice, and; clarify and align intended scope of PRMs HOPE.

- A system usability survey was undertaken to determine clinician experience of using the HOPE platform. It revealed that the HOPE platform achieved a mean usability score of 50.84 ± 19.59, which indicated usability below the acceptable level of 68. However, it was noted there was substantial variation across the sample. To address the reported below average system usability score of HOPE, the recommendations specifically outline key action items to resolve concerns and to increase the active participation and engagement of clinicians and consumers in the design of the platform.
- Clinicians highly valued patient-reported information and are using this data to improve person-centricity in care. However, experiences of gathering PRMs HOPE were varied and determined by the patient cohort and service context. Significant associations were identified between usability scores and professional groups, patient cohorts, frequency of HOPE use, and previous experience with PRMs. The nature of these relationships was that those who had significantly higher usability scores for the HOPE platform were allied health professionals compared to nurses and doctors, those who collected PRMs HOPE in admitted and non-admitted LBVC cohorts as compared to other patient cohorts, those who used HOPE frequently (i.e., daily, weekly, or monthly) as compared to those using HOPE occasionally or rarely, and those who used HOPE with more than 50% of eligible patients.
- A key challenge reported by clinicians using the HOPE platform include the platform being perceived as cumbersome to use and/or being unnecessarily complex. However, two thirds of respondents reported they did not need the support of a technical person to use the HOPE platform.
- Collecting PRMs and utilising them to improve person-centricity in care was highly valued across all stakeholder cohorts. Yet respondents had reservations about being able to achieve

the proposed value of PRMs by collecting them via HOPE surveys and reviewing those results in the HOPE platform. The issue of survey fatigue was reported, with some participants indicating that the centralised nature of HOPE was a solution to the burden of multiple surveys for patients and staff, while others raised concern that PRMs HOPE added to this burden.

- Of note, the iterative nature of PRMs and the HOPE platform will mean some concerns have already been addressed through the lifecycle of the PRMs HOPE build and development. Further it was noted some usability elements self-reported in the evaluation were already completed, such as the ability to have people from culturally and linguistically diverse backgrounds complete surveys in languages other than English. These actions are detailed further in the report to ensure local teams are aware of enhancements and usability functionality.

Recommendation	Lead	Status
To address the concerns of HOPE platform usability: • Reintroducing the production and sharing of wireframes to demonstrate functionality and workflows to clinicians and consumers prior to HOPE build to gain feedback. • Usability testing to be re-introduced alongside user acceptance testing once the functionality in HOPE is ready to be tested by clinicians and consumers. • Review of functionality placed on hold and given lower priority, including platform enhancements to be reviewed and prioritised where they enhance clinician and/or consumer usability of HOPE.	eHealth in partnership with ACI	Commenced and will be delivered in Phase 2
To build increased engagement and input of clinical leads and consumers: • Increase participation (as able) in existing PRMs governance and existing PRMs HOPE demonstrations (showcases) to inform timely feedback and shared decision making.	ACI in partnership with LHD/SHN	Commenced
To create visibility of integration milestones of HOPE: • Develop communications and awareness across all key stakeholder groups, specifically to address the issues of reported lack of integration. Phase 2 seeks to address several identified concerns of scope and functionality.	ACI in partnership with LHD/SHN	Commenced and will be addressed at completion of Phase 2

KEQ5: to what extent is the PRMs HOPE program achieving the changes and outcomes expected at the clinician level?

The opportunities for improvement spread evenly over two areas with one recommendation each in the following areas: targeted implementation, and; tailored methods for PRMs data capture.

- The report demonstrated an association of clinicians who frequently used HOPE with an increase in positive changes to clinical practice. The clinical group were also more likely to be allied health professionals within LBVC programs. Surveyed groups of clinicians identified they may also capture PRMs information in more organic ways (outside of HOPE), with resourcing perceived to be barrier for sustained implementation.
- Within the report, respondents described positive change from collection and use of PRMs in HOPE, such as increased understanding about individual needs and preferences, enhanced interactions with patients and making referrals to address patient needs. Negative impacts were also noted on clinical practice, for example increasing their workload without perceived gain. Overall, the value and importance of PRMs was recognised, yet there was less clarity on whether the HOPE platform provides a mechanism to enable their capture and use for care experiences to be improved.

The future phases of PRMs HOPE and integration into hospital electronic medical records will assist in alleviating some of the barriers. However, there are still opportunities to strengthen this work.

Recommendation	Lead	Status
Workshops and peer learning sessions to be facilitated to better understand: • The drivers for nurses and medical staff to incorporate PRMs into business as usual. • From clinical groups, the lack of agreement from consumers to participate, perceived lack of value in surveys including suitability and formulation of an action plan to address concerns.	ACI in partnership with LHD/SHN	Underway
To enable improved experience across existing cohorts: • Progress engagement and discussions within IC cohorts to communicate shared agreement on PRMs point of care implementation, engagement and partnership.	Ministry of Health in partnership with ACI and LHD/SHN	Underway

KEQ6: What are the barriers and facilitators to the PRMs HOPE program achieving its expected outcomes so far?

- The opportunities for improvement are spread over multiple areas: Optimise HOPE reporting (four recommendations), resource implementation and ongoing practice (five recommendations), review use of PREMs in HOPE (one recommendation), and tailored methods for PRMs collection (one recommendation).
- The report highlighted opportunities for potentially increasing the number of patients invited to participate in HOPE and complete surveys per cohort. Additional sites and cohorts have commenced implementation since the evaluation report period. This work seeks to address and identify opportunities for broader system wide implementation. There were numerous reports in the process evaluation that referenced resourcing, implementation support and lack of awareness of PRMs scope, enhancements and/or functionality within HOPE at the local level.
- In general, there was strong agreement the education and training of PRMs and HOPE prior to go-live was sufficient. However, for most respondents, service-level implementation barriers were reported. Notable barriers to implementation were the substantial number of respondents who perceived lack of opportunity to engage in decision-making locally about how to collect and use PRMs or how the HOPE platform would be implemented in their service. There was also a range of views and associations with having strong and visible management endorsement of the PRMs HOPE program, associated with a stronger and successful sustained implementation.
- LHDs/SHNs were provided with dedicated, permanent full-time equivalent (FTE) resources to lead local implementation of PRMs through HOPE. Ensuring these FTE resources continue to be dedicated to HOPE will be essential to support the local engagement, awareness, education and ability to implement and sustain PRMs as the HOPE platform is further scaled.
- Several respondents indicated that for PRMs to realise their expected outcomes, LHDs must be able to capture and use data from PRMs HOPE to inform change in their services. Several respondents suggested linking HOPE to key performance indicators or service agreements, and that LHDs should be able to access and use HOPE reports for LHD planning to support change at the service level. Clinicians further suggested that PRMs HOPE would be more readily used to change clinical practice if information was displayed in a different way in HOPE relevant to their needs, and if data could be shared more readily between practitioners towards patient care. Respondents also reflected on current status and opportunities to enhance functionality of reporting capabilities within HOPE.
- A common sentiment was the great potential for PRMs data to inform change, but a lack of clarity around how to access and use reports in HOPE.

Recommendation	Lead	Status
To address reported lack of local engagement of clinicians: • Engage clinicians in specific work areas linked with their subject matter expertise to inform local and state-based opportunities within PRMs.	ACI in partnership with LHD/SHN	Underway
To address HOPE usability and data reports: • Review and restructure the current PRMs lead data working group to review each current report, purpose, functionality and to propose changes to meet clinicians' needs. • Develop a communication plan for education, engagement, and awareness of the systems manager dashboard requested. The dashboard will be delivered as part of Phase 2. • Re-establish clinician reference groups for timely clinical engagement and feedback on core PRMs HOPE related functionality.	Ministry of Health in partnership with ACI and LHD/SHN	Underway
To address usability of PRMs HOPE data reports at a system level: • Review the need for population level data out of HOPE for system level uses to determine if this can be achieved from another source, e.g.,Enterprise Data Warehouse (EDWARD).	Ministry of Health	Underway
To address HOPE platform usability at service management level: • PRMs executive sponsors to champion use of local mangers' dashboard. • Local PRMs leads to identify stakeholders within LHD/SHN who require access, provide education and training, and continued sustained implementation. • PRMs executive sponsors to identify appropriate forums for self-reporting of this data at LHDs/SHNs by local managers.	Local PRMs lead / executive sponsors in partnership ACI	Yet to commence

To address the value-add of PREMs in HOPE: • Continue partnership work with Bureau of Health Information (BHI) to determine minimal question set for PREMs taking a core and modular approach to adapt to cohorts and settings. • Continue to lead focus groups to identify PREMs that would benefit from being able to identify respondents for enhanced planning care and treatment.	ACI in partnership with Ministry of Health and BHI	Underway

Key evaluation findings

Due to the defined scope of the process evaluation, there are critical areas that have not been explored. These areas would benefit greatly from a process of developing formal recommendations to ensure current and future phases of PRMs captured at the point of care through HOPE realise their full potential. The aim being to deliver benefits at the individual, service and system levels. The recommendations seek to apply key evaluation findings to all areas of the current -PRMs HOPE program, including:

- Work currently underway in primary care to enable a one systems approach through the PRMs Phase 3 work (integration to GP desktop software).
- A strategic approach to implementation through push-pull mechanisms to align with LHD/SHN and system priorities and needs in order to scale implementation.
- Improving functionality and communications within HOPE to ensure clarity and scalability.
- Build on early research approaches using PRMs from HOPE.
- Clarify accountability for data analysis at a systems level for PRMs HOPE.
- Building capacity within analytics of PROMs to support use, linkages with other LHDs/SHNs data sets and informing practice.
- Aligning PRMs HOPE reporting with the Future Health Strategic Framework.

Next steps

A state-wide workshop to further refine recommendations in response to the evaluation findings will be held in June 2023. The ACI will work with district and network PRMs executive sponsors and leads to incorporate and implement the recommendations following the workshop.

The findings will be incorporated into the design and implementation of future phases of the HOPE platform. The integration of PRMs surveys into hospital electronic medical records as part of Phase 2 of HOPE has already allowed for greater uptake and usability due to the ready-made availability of PRMs to be completed, used and followed up across all district and network services.

Phase 2 of HOPE commenced in early 2023 and is expected to be completed mid-2024. Planning for Phase 3 has commenced in collaboration with the NSW Primary Health Networks.

Conclusion

The PRMs HOPE program process evaluation highlighted the value held in PRMs by clinicians. The proposed recommendations seek to strengthen the value-add of not only PRMs on their own, but also the digital enablement for real-time capture and use in HOPE. The proposed recommendations seek to address the reported barriers for scoping, engagement, implementation, collection, use and sustainability across all cohorts.

While consumers, people from culturally and linguistically diverse backgrounds and Aboriginal peoples were not specifically included in the direct feedback or analysis, it will be critical to ensure a true co-design approach with consumers and community groups is taken across all populations to ensure proposed recommendations are truly fit for purpose for addressing their needs.

It is envisioned all proposed recommendations should be fully implemented within two years, aligning future phases of PRMs HOPE with strategies such as the NSW Health Joint Statement and the Future Health Strategic Framework. This will ensure outcomes and experiences for consumers are improved through the collection and use of PRMs and HOPE, aiming to decrease burden and add value to multidisciplinary teams across the care continuum in NSW.