

2021-2022 Funding Program FINAL REPORT

Real-time patient-reported outcomes measures (PROMs) and patient-reported experience measures (PREMS) in oncology: enhancing inclusivity and toward a new standard of care.

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SMICS acknowledge Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land. We acknowledge and pay respect to their Elders, past and present.

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Executive Summary

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are validated self-report questionnaires that allow patients to systematically report their symptoms and concerns to treating teams in a structured fashion. Despite a large and growing evidence base for their incorporation into routine cancer care, real-world implementation in Australia has been extremely limited.

Building on the work from their pilot study, the Monash Health PROMs and PREMs research team implemented a suite of these instruments into routine practice at two busy oncology outpatient clinics located at Moorabbin Hospital. The project intervention was deployed both remotely and in-person at the clinics, which managed patients with breast cancers and thoracic cancers. This implementation was also designed to enhance inclusivity by providing language translations of the intervention for patients from culturally and linguistically diverse (CALD) backgrounds.

The implementation proved feasible and acceptable to patients, carers, clinicians, and clerical staff. Patients and carers strongly preferred to remotely complete the PROMs and PREMs rather than completing them in-person. Overall, participation rates were similar to the findings from our pilot study. Participation in the PROMs and PREMs among those who spoke a main language other than English remained low, which reflected in the lower than expected uptake of the language translations. Patients were also less likely to participate if they were older, not receiving active cancer treatment, and were treated with curative intent.

Participation in the PROMs and PREMs had minimal impact on consultation duration, which remains a commonly cited barrier to the implementation of such initiatives. Among participants at the first appointment, health-related quality of life, symptom severity, and unmet supportive care needs reported were consistent with those reported in the literature. There were some differences in the responses to the PROMs and PREMs between participants attending the breast clinic and those attending the thoracic clinic. In particular, the severity of symptoms differed such as lack of appetite, shortness of breath, and sleep disturbance.

Preliminary analyses suggest that participation in the PROMs and PREMs at the first appointment was not associated with a reduction in emergency department (ED) presentations and unplanned hospital admissions within 30 days of that appointment. However, completing the PROMs and PREMs at the first appointment was associated with an increased likelihood of receiving a supportive care or allied health referral at that appointment. Longitudinal analyses of the large amount of data collected are ongoing.

The local experience from this project reflects previously reported international data in this space in two busy outpatient oncology clinics. There remains further work to be done to improve uptake of the opportunity to utilise real-time PROMs and PREMs among non-participants, including subgroups of the CALD population and older adults. There is a need to determine whether the implementation can be sustainably upscaled to other busy oncology outpatient clinics at Moorabbin Hospital as well as other Monash Health sites.

Introduction

PROMs and PREMs are validated self-report questionnaires that allow patients to report the severity of their cancer-related symptoms and concerns, quality of life and their experience of care in a structured manner. The benefits of using PROMs in routine cancer care are well-established. Multiple systematic reviews have demonstrated that using PROMs can improve symptom detection, patient-provider communication, and patient satisfaction (1-4). From a health system perspective, routine use of such measures is associated with a reduction in emergency department (ED) attendances (5, 6). Randomised trials and real-world implementation data have demonstrated improvements in overall survival when patients are given the opportunity to utilise PROMs in a routine fashion (7, 8). Equally, PREMs are proven to provide services with important feedback on quality care and patient's unmet needs (9). Accordingly, the Clinical Oncology Society of Australia (COSA) published the position paper "Patient-reported outcomes and personalised cancer care", which advocated for routine implementation of PROMs as the elusive final frontier to putting the patient at the centre of truly personalised cancer care delivery (10).

Despite this large and growing body of evidence and support from professional bodies, routine use of PROMs has not been implemented into cancer care in Australia, due to factors including cost, lack of clinician familiarity, and the logistics of administration (11, 12). Additionally, the majority of research on PROMs and PREMs has focussed on English-speaking patients, thus the use of PROMs and PREMs tools among culturally and linguistically diverse (CALD) communities in Australia is yet to be explored. Additional challenges (and opportunities) have arisen subsequent to the COVID-19 pandemic, which has seen a rapid adoption of telehealth in lieu of face-to-face consultations across cancer services for patients at all stages of their cancer journey. Real-time assessment to systematically screen for symptoms and concerns is even more important in circumstances where patients are not being seen in-person, often for multiple sequential consultations.

The Monash Oncology PROMs and PREMs research team were uniquely placed to address these needs and support implementation in a local context. The team developed a real-time PROMs and PREMs intervention, which was successfully piloted in the Monash Health Oncology Clinics at Berwick Healthcare in 2019-2021. The intervention was initially administered via patient completion of questionnaires on iPads in the waiting room prior to clinic consultations. With the advent of the COVID-19 pandemic and the rapid transition to telehealth, the project pivoted to remote online questionnaires, completed up to 48 hours prior to a scheduled consultation.

In the pilot project, the PROMs utilised were the EQ-5D-5L (13), Edmonton Symptom Assessment Scale (revised; ESAS-R) (14) and Supportive Care Needs Survey, Short Form 34 (SCNS-SF34) (15), all administered online via a REDCap hosted platform. These instruments were selected to capture functional quality of life, common physical and psychological symptoms, and supportive care unmet needs respectively. The SCNS-SF34 also served as a PREM, as it captures domains related to health service experience. These are generic tools, applicable to cancer patients with all primary tumour diagnoses. Notably, ESAS and EQ-5D-5L have been widely utilised in cancer settings worldwide, including in the largest real-world implementation experience from Ontario, Canada, where outcomes in over 128,000 patients have been reported with demonstrated benefits in terms of both ED presentation and survival outcomes (6, 8).

During the Monash Health Berwick pilot pre-COVID-19 phase, PROMs and PREMs data were collected from 150 consultations, representing 100 individual patient participants. The patient participation rate was comparable to international experience at 68.5%, but notably, participation was approximately 50% lower among patients who did not speak English as their first language (36% vs 73%, $p=0.01$).

Since the transition to telehealth, data has been collected from 346 consultations, representing 181 individual patient participants. The remote patient participation rate during the COVID-19 phase has been 46%. Again, this was approximately 45% lower among patients who did not speak English as their first language (27% vs 49%, $p=0.02$).

Patient and clinician evaluations from both phases have indicated that the intervention was well-received and facilitated communication with clinicians regarding participants' symptoms and concerns. This is consistent with the literature on the patient and clinician acceptability of using electronic PROMs in routine cancer care (16).

There was minimal impact on consultation time (a commonly cited barrier to implementation of such initiatives). Importantly, a trend to reduced emergency department presentations among participants compared to non-participants has emerged (18 vs 37 ED presentations over a 6-month period, $p=0.094$), indicating potential benefit to the health service for implementation of real-time PROMs and PREMs translating into health economic savings and improved patient quality of life. Among participants, higher means scores for pain, fatigue and sleep disturbance on the ESAS were associated with a subsequent ED presentation within 30 days of the consultation, suggesting areas for targeted intervention to reduce such events.

Our early local experience seemed to be reflecting previously reported international data in this space, albeit in a small clinic staffed by an engaged clerical and clinical team. There remains further work to be done to improve uptake of the opportunity to utilise real-time PROMs and PREMs in the CALD population. The feasibility and acceptability of implementing real-time PROMs and PREMs in the somewhat busier and larger oncology outpatient clinics at the Monash Health Moorabbin campus also needs to be determined. This project sought to address these unresolved questions, and thereby enhance accessibility of this intervention to all oncology patients at Monash Health.

Aims and objectives

Objectives

1. To implement and assess the impact of phased translational rollout of real-time PROMs and PREMs on:
 - a. reporting of cancer-related physical and psychological symptoms, side effects of treatment and health-related quality of life
 - b. unmet supportive care needs
 - c. referrals to allied health and supportive care services
 - d. emergency department presentations and inpatient hospital admissions.
2. To confirm our preliminary findings that implementation of routine PROMS and PREMs did not adversely impact the length of clinical consultation when implemented into a larger outpatient oncology facility.
3. Assess the feasibility and acceptability of the collection and clinical use of translated PROMs and PREMs among patients and survivors whose preferred language is not English, their interpreters, clinicians, and other staff.
4. Identify the barriers and enablers to broader implementation of PROM and PREM collection and use among patients and survivors who communicate in languages other than English.

Outcomes of interest were assessed for the cohort overall, and with a focussed comparison between patients speaking a language other than English and those confident to complete PROMs questionnaires in English.

Method

The project utilised a mixed-methods approach conducted in two phases, qualitative and implementation phases.

Qualitative Phase

We qualitatively assessed patients, including those from CALD backgrounds, their caregivers, clinical staff, and clerical staff to understand current practices, barriers, and facilitators to the implementation of pre-consultation PROMS and PREMS and for post-study implementation feasibility and acceptability.

At pre- and post-study points, we conducted focus groups and interviews with patient participants and carer participants, including those from CALD backgrounds. Clinical and clerical staff were qualitatively assessed using semi-structured interviews.

Focus group and interview data were analysed by the investigator team using framework analysis, which is a seven-step systematic hierarchical, matrix-based method developed for applied qualitative research. Data analysis was managed using NVivo (qualitative data analysis software). In line with this, we constructed an initial thematic framework from the interview objectives and existing literature. The interview data were then mapped onto this framework. The framework was revised to include new concepts or themes introduced during the interviews. Once all the data were mapped onto the framework, each main theme was summarised using tables and were interpreted to address the qualitative interview objectives.

Implementation Phase

The Implementation Phase was conducted from February to August, 2023. Patients attending two selected Monash Health Moorabbin Oncology Outpatient Clinics were invited to complete the PROMs and PREMs before their appointment.

The PROMs utilised were the EQ-5D-5L (13), Edmonton Symptom Assessment Scale (revised; ESAS-R) (14) and the Supportive Care Needs Survey - Short Form 34 (SCNS-SF34) (15), all administered online via a REDCap hosted platform (Appendix 2). These instruments were selected in our pilot study. They are used to capture functional quality of life, common physical and psychological symptoms, and supportive care unmet needs, respectively. The SCNS-SF34 also served as a PREM, as it captures domains related to health service experience. The instruments are generic tools, applicable to cancer patients with all primary tumour diagnoses.

Two days before their scheduled oncology outpatient clinic appointment, patients received a Short Message Service (SMS) invitation to complete the PROMs and PREMs (Figure 1). They could use the SMS link to remotely complete the PROMs and PREMs on their own personal electric device at home. If patients were scheduled to attend a face-to-face appointment, they were also offered the option to complete the PROMs and PREMs on a hospital iPad in the clinic waiting room.

Responses to the PROMs and PREMs were provided to the treating oncologists for review during clinical consultations. Clinicians were provided with an algorithm to guide the management of any symptoms or concerns raised by patients in their responses. The

algorithm was developed by the project team in consultation with clinical staff, and contained links to relevant patient information materials (e.g. Cancer Council resources) and contact details for appropriate referrals, for each of the PROMs and PREMs items (Appendix 3). Patients' responses to the PROMs and PREMs were then uploaded to the Scanned Medical Record (SMR), such that they became part of the medical record for the consultation and progress of symptoms and concerns over time could be tracked.

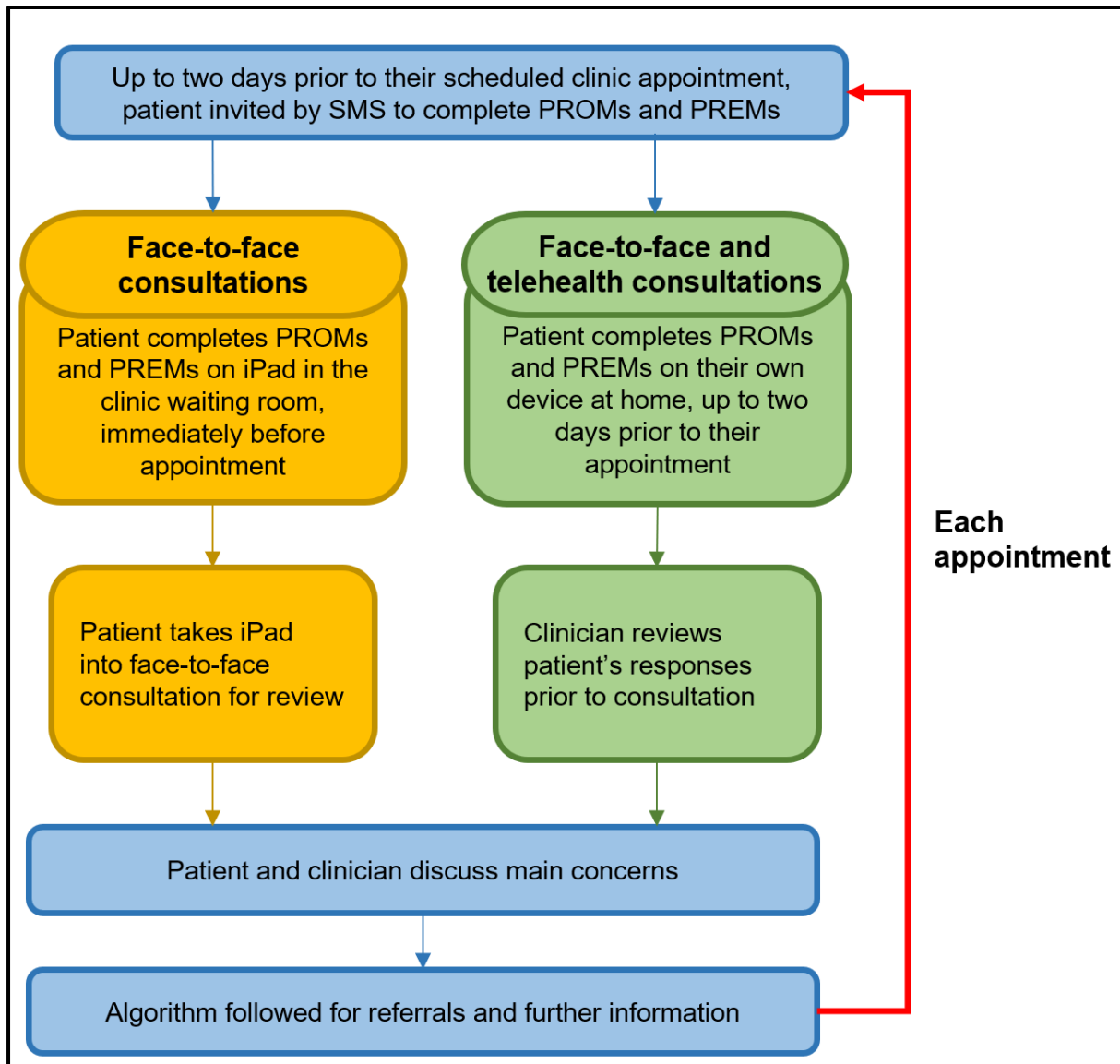


Figure 1. Flow diagram depicting the implementation of pre-clinic administered PROMs and PREMs.

To enhance CALD inclusivity, the SMS invitations and PROMs and PREMs instruments were also made available in different languages. The 10 most prevalent non-English languages identified across the Monash Health oncology outpatient clinics for the Financial Year 2021-2022 were included (Table 1). All patients attending the designated oncology clinics were eligible to participate to reflect the real-world implementation goals of the project. The SMS invitations and questionnaires were sent in the patients' chosen language where available. The PROMs and PREMs could also be completed in English with the

assistance of a caregiver. Patients who did not have a mobile phone and were attending a face-to-face appointment were invited by the project officer to complete the PROMs and PREMs questionnaires on an iPad in the clinic waiting room.

Table 1. The 10 most prevalent non-English languages identified across the Monash Health oncology outpatient clinics in the Financial Year 2021 – 2022.

| No. | Language |
|-----|------------|
| 1 | Chinese* |
| 2 | Greek |
| 3 | Dari |
| 4 | Vietnamese |
| 5 | Bosnian |
| 6 | Khmer |
| 7 | Italian |
| 8 | Turkish |
| 9 | Tamil |
| 10 | Arabic |

Notes: *Chinese refers to both Mandarin and Cantonese. The two standardised character sets for Chinese are Simplified Chinese and Traditional Chinese, which their written translations of the PROMs and PREMs and SMS invitations were made available in during the Implementation Phase.

Immediately after completing the PROMs and PREMs, patients and caregivers were invited to complete a Rolling Patient Feedback Survey (Appendix 2). The survey briefly captured contemporaneous feedback about the experience of completing the questionnaires. Separately, to evaluate the feasibility and acceptability of the PROMs and PREMs amongst patients and their carers on a larger scale, a Patient Evaluation Survey was circulated to all patient participants towards the end of the Implementation Phase.

The outcomes of interest were assessed as follows:

1. The impact of participation in the PROMs and PREMs intervention on emergency department presentations, hospitalisations, and referrals to allied health and supportive care services were extracted from clinical records. Rates of such events were compared between participants and non-participants. Among participants, associations between events and PROMs/PREMs responses were sought.
2. Feasibility and acceptability of the collection and clinical use of translated PROMs and PREMs among patients and survivors whose preferred language is not English, their interpreters, clinicians, and other staff.
3. Assessment of readiness for transition to routine care with the Patient Evaluation Surveys valuation surveys and focus groups with patients, clinicians and support staff.

A core data set was extracted from medical records for participants and non-participants, including demographic characteristics, cancer diagnosis, treatment type and intent, along with any ED presentations, hospitalisations, or allied health referrals during and for 30 days after the intervention period. These characteristics were compared between participants and

non-participants. Among participants, associations were sought between PROMs and PREMs responses and ED presentations/hospitalisations within 30 days.

Consultation Duration

To evaluate the impact of the PROMs and PREMs intervention on the duration of clinical consultations, an audit was completed at the two selected Moorabbin Oncology Outpatient Clinics, comprising a 4-week period prior to, and a 4-week period during the Implementation Phase.

Non-Participation

In July and August 2023, an audit of patient non-participation at the two selected oncology clinics was conducted during six weeks of the Implementation Phase. Convenience sampling was used. Patients attending a face-to-face or telehealth video appointment at the clinics and who had not completed the PROMs and PREMs for two consecutive appointments were invited to participate in this optional audit. They were asked to provide a reason for non-participation, if they felt comfortable doing so.

Project Governance

Clinical champions (named investigators) were responsible for communication regarding the project within their unit and ensuring adherence to protocol-specified activities within their relevant areas.

A project oversight committee comprised of the investigators and consumer advisors met monthly to review project progress against milestones and to identify barriers/enablers to implementation.

Results

This section provides a summary of results collected from December 2022 to October 2023. Due to delays with project commencement, the project team planned to conduct an abridged 4-month Implementation Phase. However, after a relatively smooth early implementation, it was deemed feasible to undertake the full 6-month Implementation Phase as planned, in order to optimally explore the long-term impact of the implementation and increase the sample size to analyse for effects.

Quantitative

A wealth of data was collected during the Implementation Phase

During the 6-month Implementation Phase, data were collected from 1753 oncology outpatient appointments attended by 688 patients. Patients had a median age of 65.6 years (range 22.7 – 92.6 years) and 505 (73.4%) were female. There was a higher proportion of patients who attended the breast clinic (363, 52.8%), compared to those who attended the thoracic clinic (325, 47.2%). Most patients (450, 65.4%) were being managed with palliative intent. A small proportion of patients (119, 17.3%) were diagnosed with a recurrent cancer.

Most patients participated in the PROMs and PREMs for at least one appointment.

Of the 688 patients, 464 (67.4%) completed the PROMs and PREMs for at least one appointment. The participation rates are similar to those reported in the literature, as well as those from our pilot study which was conducted at Monash Health Oncology Berwick (pre-COVID-19 phase: 68%; COVID-19 phase: 46.5%).

When comparing baseline characteristics with participants, non-participants were more likely to be older, speak a language other than English, not be receiving active cancer treatment, and were treated with curative intent (Table 2). No differences were detected for sex, relationship status, working status, clinic type, and cancer recurrence.

Table 2. Patient Baseline Characteristics, by participation (n = 688).

| Characteristics and categories | Participants (n = 464) n (%) | Non-Participants (n = 224) n (%) | p-value* | Phi** |
|-----------------------------------|------------------------------------|--|----------|--------|
| Median Age (IQR) | 64.8 (IQR 18.6) | 68.9 (IQR 17.4) | 0.01 | 0.095† |
| Sex | | | 0.28 | 0.05 |
| - Male | 117 (63.9%) | 66 (36.1%) | | |
| - Female | 347 (68.7%) | 158 (31.3%) | | |
| Relationship status | | | 0.15 | 0.06 |
| - Partnered | 181 (64.2%) | 123 (30.3%) | | |
| - Not partnered | 283 (69.7%) | 101 (35.8%) | | |
| Working status | | | 0.08 | |
| - Working | 344 (64.8%) | 187 (35.2%) | | |
| - Not working | 120 (76.4%) | 37 (23.6%) | | |
| Language spoken at home | | | <0.001 | 0.16 |
| - English | 386 (71.2%) | 156 (28.8%) | | |
| - Language other than English | 78 (53.4%) | 68 (46.6%) | | |
| Clinic attended | | | 0.45 | -0.03 |
| - Breast | 250 (68.9%) | 113 (31.1%) | | |
| - Thoracic | 214 (65.8%) | 111 (34.2%) | | |
| Receiving active treatment | | | 0.03 | 0.09 |
| - Receiving treatment | 312 (70.4%) | 131 (29.6%) | | |
| - Not receiving treatment | 152 (62.0%) | 93 (38.0%) | | |
| Treatment Intent | | | 0.046 | -0.08 |
| - Curative | 147 (62.3%) | 89 (37.7%) | | |
| - Palliative | 317 (70.1%) | 135 (29.9%) | | |
| Recurrent cancer | | | 0.12 | 0.06 |
| - Recurrent | 88 (73.9%) | 31 (26.1%) | | |
| - Not recurrent | 376 (66.1%) | 193 (33.9%) | | |

Notes: *p-value for between-group differences; ** Phi coefficient value is the effect size statistic reported for the Chi-squared tests for independence.; † r-value is the effect size statistic reported for the Mann-Whitney U test. Abbreviations: IQR, interquartile range.

Uptake of the language translations for the PROMs and PREMs was low

Of the 688 patients who attended the clinics during the Implementation Phase, a total of 146 patients (21.2%) spoke a main language other than English (Figure 2). The most prevalent 10 languages were similar to those selected for translating the PROMs and PREMs.

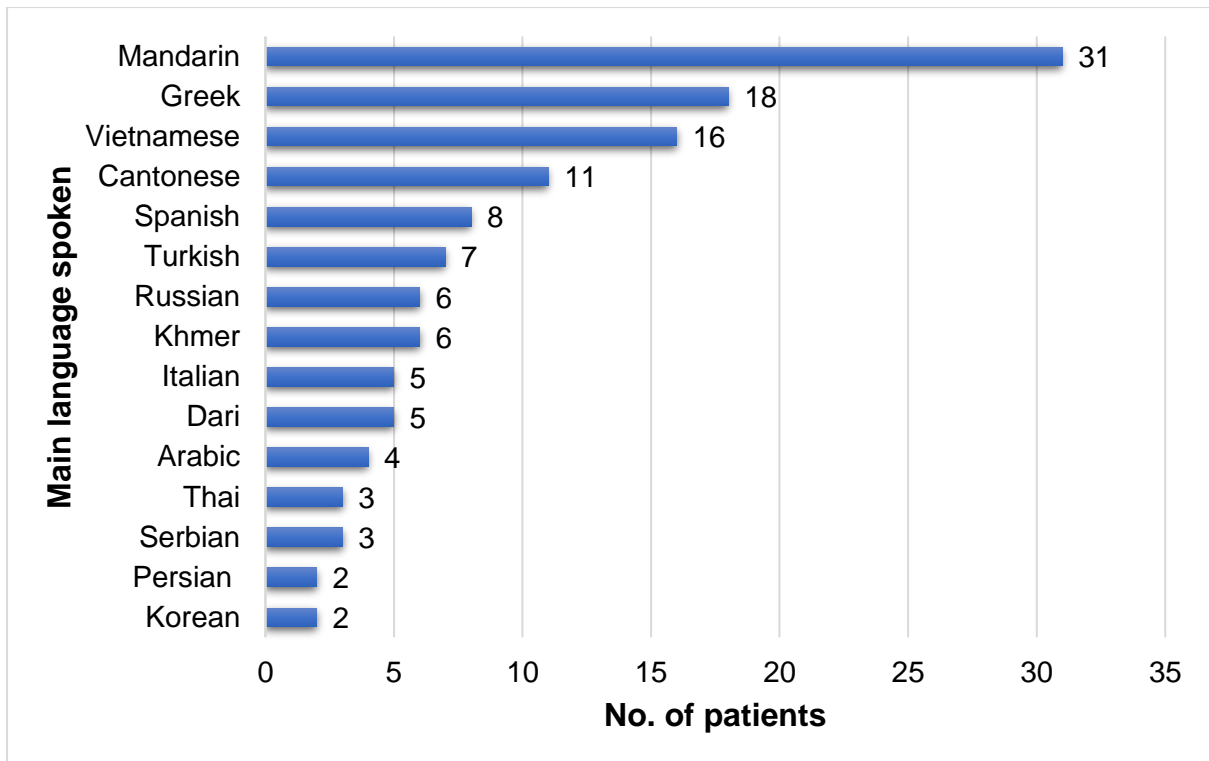


Figure 2. The main non-English languages spoken at home by patients (n = 127). Note: 19 other languages were not included as they only one patient spoke each language.

Across the 6-month Implementation Phase, the PROMs and PREMs were completed using language translations a total of 40 times, by 23 patient participants. Simplified Chinese was the most selected language translation and it was used by 14 patient participants (Figure 3). In total, it was used 30 times, accounting for 75% of the total use of the language translations. Despite their availability, the following six language translations were not used by any patient participants: Arabic, Bosnian, Khmer, Italian, Turkish, and Tamil.

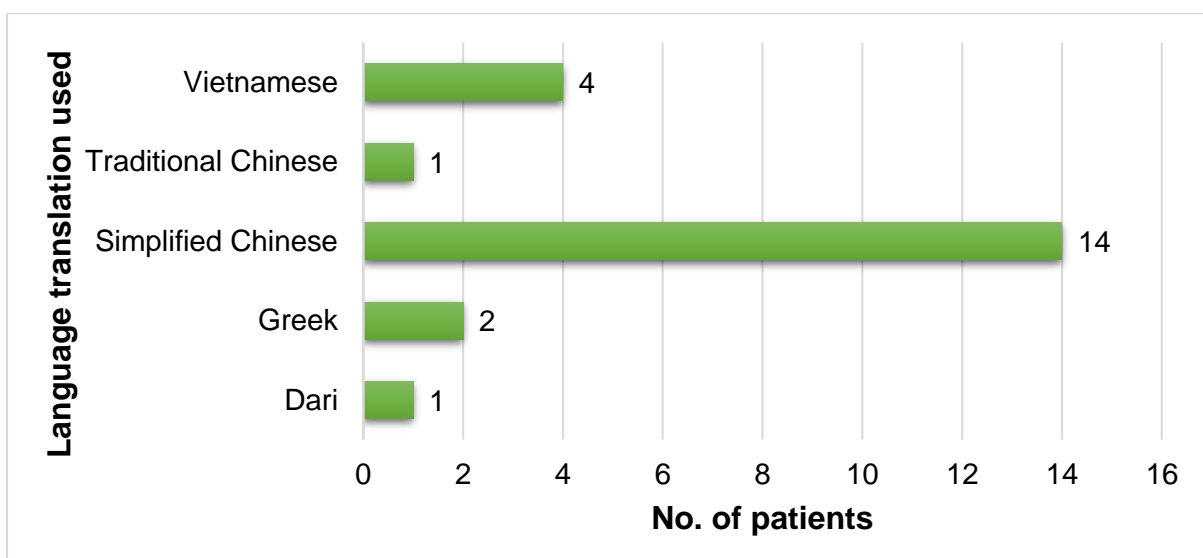


Figure 3. The five language translations for the PROMs and PREMs that were used during the Implementation Phase, by patients (n = 23).

Patients strongly preferred to remotely complete the PROMs and PREMs

Of the 822 responses to the PROMs and PREMs completed during the Implementation Phase, 806 (98.1%) were completed remotely by patients on their own device. The remaining 16 responses to the PROMs and PREMs were completed on an iPad by 15 patients, usually assisted by either a carer or the project officer.

The PROMs and PREMs were completed by patients on 705 occasions (83.4%) and by carers on 117 occasions (16.6%).

Contemporaneous feedback captured by the Patient Rolling Feedback Survey indicate patients perceived the PROMs and PREMs to be mostly easy to complete in an acceptable amount of time (Figure 4a and Figure 4b).

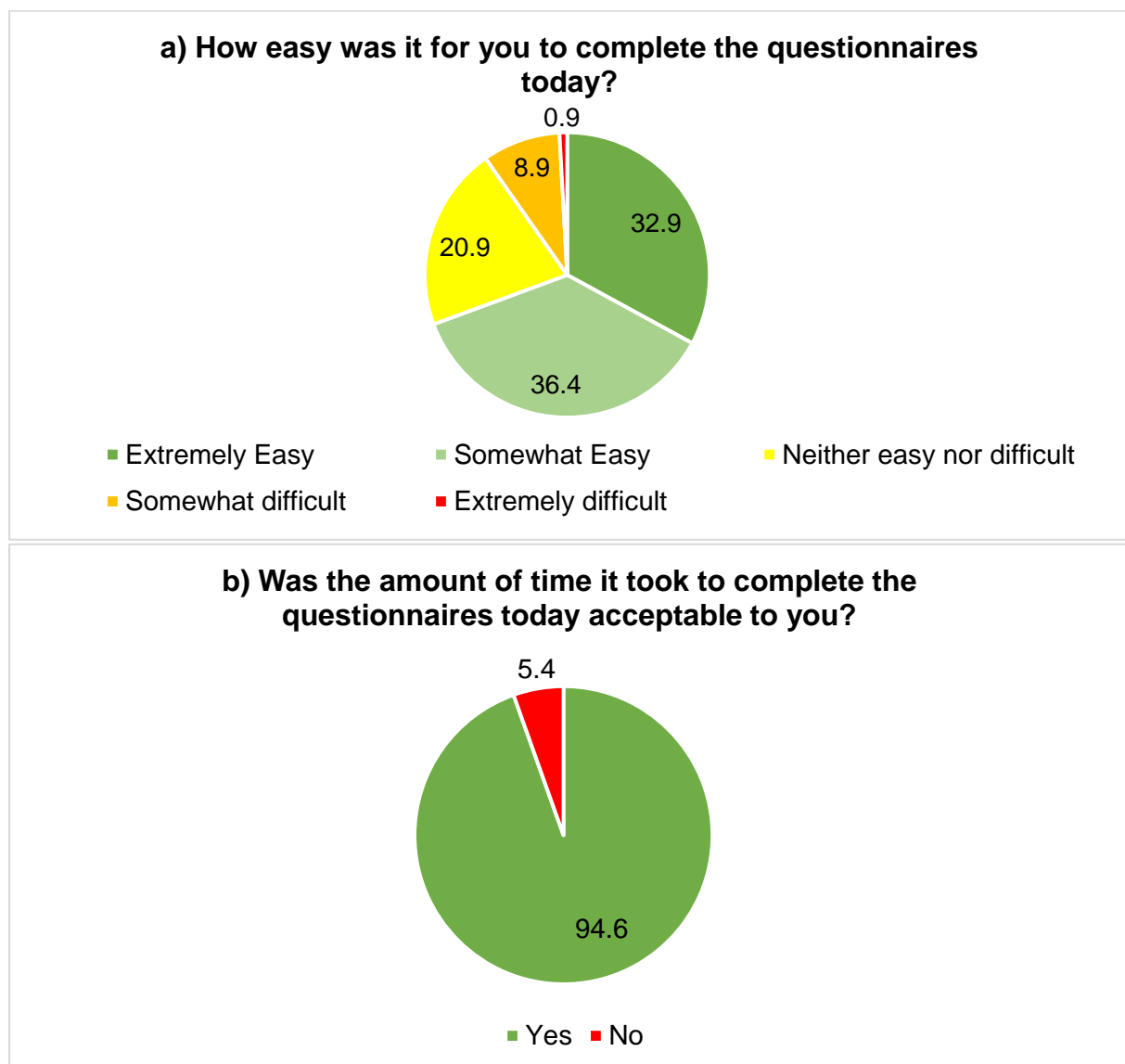


Figure 4. Proportion (%) of patient selected response choices for the Rolling Feedback Survey: a) How easy was it for you to complete the questionnaires today (n = 689) and; b) Was the amount of time it took to complete the questionnaires today acceptable to you? (n = 679).

The most prevalent symptoms and concerns reported by patients were not surprising

The EQ-5D-5L Visual Analogue Scale (VAS) score item is the sixth and final item of the EQ-5D-5L instrument. It was rated by participants on a scale between a possible score of '0' (worst health the patient can imagine) and '100' (best health the patient can imagine).

Of the 822 responses to the PROMs and PREMs, 714 (86.9%) had completed the EQ-5D-5L VAS. The median score for this self-reported health score item was 70 (IQR 32). The EQ-5D-5L VAS item was the most skipped item among the total of 57 PROMs and PREMs items, with missing data recorded on 108 responses.

The most prevalent symptoms on the ESAS-R that were rated at $\geq 7/10$ among 20% or more of the PROMs and PREMs responses were: tiredness/fatigue (32.2%), sleep problems (23.9%), wellbeing (22.7%), drowsiness (22.5%), appetite (21.1%), and concentration and memory (20.7%). These are consistent with the concerns commonly reported among oncology patients.

Participation at the first appointment was related to the likelihood of receiving a supportive care referral but not to an ED presentation or unplanned admission

Of the 688 patients, 391 patients (56.8%) participated in the PROMs and PREMs at their first appointment during the Implementation Phase, whereas 297 (43.2%) did not participate. Analyses were conducted to explore whether participation at the first appointment was associated with an event (i.e. ED presentation or unplanned admission within 30 days of that appointment, or a supportive care or allied health referral being made).

The likelihood of a patient presenting to ED within 30 days of their first appointment was similar between patients who participated and those who did not (11.8% of participating consultations vs. 10.1% of non-participating consultations, $p = 0.57$, Phi coefficient = 0.026) (Figure 5). This was similar for the likelihood of an unplanned hospital admission within 30 days of this appointment (9.2% of participating consultations vs. 8.1% of non-participating consultations, $p=0.70$, Phi coefficient = 0.02).

A total of 197 supportive care referrals were made among participants and non-participants, following the first appointment. Patients who completed the PROMs and PREMs at their first appointment were more likely to receive at least one supportive care referral than those who did not (45.9% of participating consultations vs. 22.7% of non-participating consultations, $p<0.001$, Phi coefficient = 0.15) (Figure 5). The most common supportive care referral received by patients at their first appointment was to a Monash Health nurse ($n = 164$), followed by Monash Health social work ($n = 11$), and palliative care ($n = 8$).

Among participants at their first appointment, associations detected between the reported ESAS-R item score and an event were few with small effect sizes. The median score for the ESAS-R concentration and memory item was slightly lower among the 43 participants who presented to ED (median score = 2, IQR = 5) compared to the 329 participants who did not present to ED (median score = 3, IQR = 5), $p = 0.03$, $r = 0.11$. Regarding the ESAS-R pain item, 35 participants who had an unplanned admission reported a higher median score (median score = 5, IQR = 3) compared to the 338 participants who did not have an unplanned admission (median score = 3, IQR = 4), $p = 0.04$, $r = 0.11$. Participants who received a supportive care referral at their first appointment reported a higher median score on the ESAS-R anxiety item (median score = 3, IQR = 5) than patients who did not (median score = 2, IQR = 5), $p = 0.01$, $r = 0.13$.

Longitudinal analyses after subsequent appointments are ongoing.

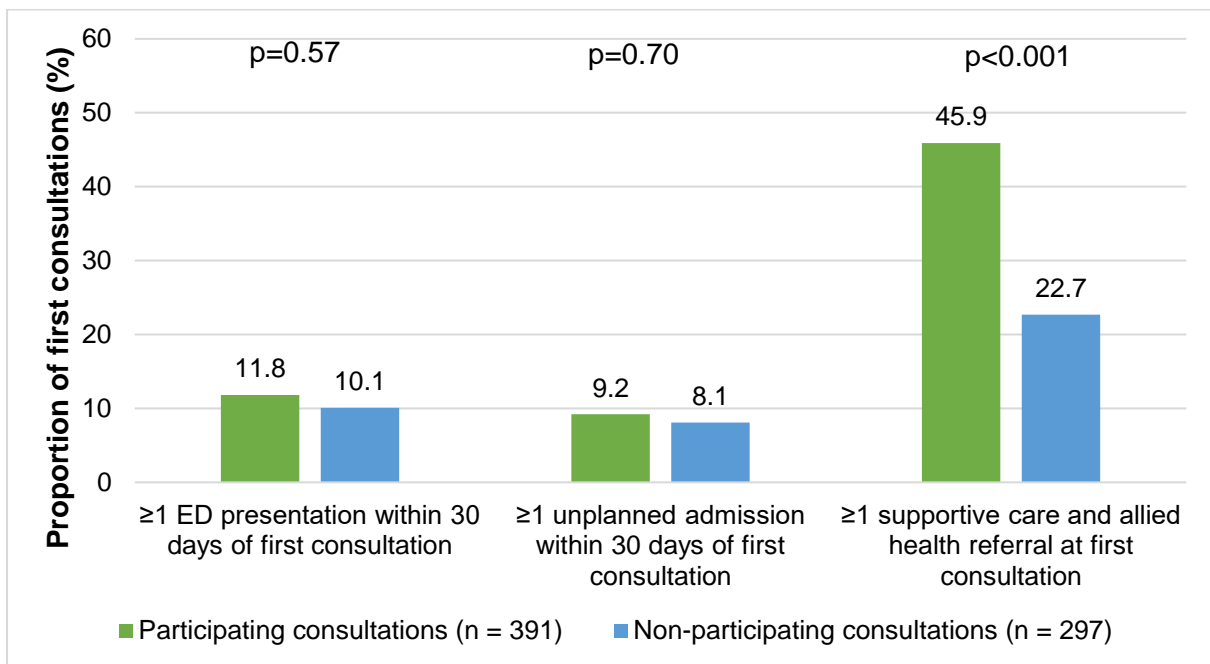


Figure 5. The occurrence of at least one ED presentation, unplanned admission, or supportive care referral following the first appointment during the Implementation Phase, categorised by participation at the first appointment (n = 688). p-values indicate the between-group differences in proportion of first consultations, between participants and non-participants.

Between the two clinics, some differences in reported symptoms and concerns at the first appointment were observed.

The participants' responses to the PROMs and PREMs at their first appointment during the Implementation Phase were analysed for differences between the breast and thoracic clinics.

When compared with the thoracic clinic participants, breast clinic participants were more likely to be younger, identify as female, working in paid employment, receive active treatment, be treated for curative intent, and be diagnosed with recurrent cancer (Table 3). No differences were detected for relationship status and language spoken at home.

Table 3. Participant Baseline Characteristics at the first appointment, by clinic (n = 391).

| Characteristics and categories | Breast clinic (n = 216) n (%) | Thoracic clinic (n = 175) n (%) | p-value* | Phi** |
|-----------------------------------|-------------------------------------|---------------------------------------|----------|-------|
| Median Age (IQR) | 60.3 (IQR 18.8) | 67.0 (IQR 14.3) | <0.001 | 0.22† |
| Sex | | | <0.001 | -0.60 |
| - Male | 1 (1.1%) | 91 (98.9%) | | |
| - Female | 215 (71.9%) | 84 (28.1%) | | |
| Relationship status | | | 0.42 | 0.05 |
| - Partnered | 85 (58.2%) | 61 (41.8%) | | |
| - Not partnered | 131 (53.5%) | 114 (46.5%) | | |
| Working status | | | <0.001 | -0.20 |
| - Working | 78 (70.9%) | 32 (29.1%) | | |
| - Not working | 138 (49.1%) | 143 (50.9%) | | |
| Language spoken at home | | | 0.61 | -0.03 |
| - English | 183 (58.0%) | 144 (44.0%) | | |
| - Language other than English | 33 (51.6%) | 31 (48.4%) | | |
| Receiving active treatment | | | <0.001 | -0.22 |
| - Receiving treatment | 162 (63.0%) | 95 (37.0%) | | |
| - Not receiving treatment | 54 (40.3%) | 80 (59.7%) | | |
| Treatment Intent | | | <0.001 | -0.23 |
| - Curative | 96 (71.1%) | 39 (28.9%) | | |
| - Palliative | 120 (46.9%) | 136 (53.1%) | | |
| Recurrent cancer | | | 0.01 | -0.13 |
| - Recurrent | 46 (69.7%) | 20 (30.3%) | | |
| - Not recurrent | 170 (52.3%) | 155 (47.7%) | | |

Notes: *p-value for between-group differences; ** Phi coefficient value is the effect size statistic reported for the Chi-squared tests for independence.; † r-value is the effect size statistic reported for the Mann-Whitney U test. Abbreviations: IQR, interquartile range.

Regarding health-related quality of life, the proportions of participants who responded that they were experiencing 'any problem' (i.e. a score of 2 to 5) to the five EQ-5D-5L dimensions were mostly similar between the two clinics (Table 4). However, participants attending the thoracic clinic were more likely to report experiencing any problem with their usual activities, compared with those attending the breast clinic, $p = 0.01$. The median score for the EQ-5D-5L VAS self-reported health score was similar between the breast clinic participants ($n = 184$, Median = 71, IQR = 35) and the thoracic clinic participants ($n = 160$, Median = 67, IQR = 30), $p = 0.07$, $r = 0.099$.

Table 4. Patient responses to the five EQ-5D-5L dimensions at the first appointment during the Implementation Phase, by clinic.

| EQ-5D-5L dimensions and response categories | Breast Clinic n (%) | Thoracic Clinic n (%) | p-value* | Phi** |
|---|------------------------|--------------------------|----------|-------|
| Mobility (n = 388) | | | 0.15 | 0.08 |
| - No problem | 130 (58.6%) | 92 (41.4%) | | |
| - Any problem | 84 (50.6%) | 82 (49.4%) | | |
| Self-Care (n = 369) | | | 0.26 | 0.07 |
| - No problem | 169 (57.5%) | 125 (42.5%) | | |
| - Any problem | 37 (49.3%) | 38 (50.7%) | | |
| Usual Activities (n = 387) | | | 0.01 | 0.13 |
| - No problem | 108 (62.1%) | 66 (37.9%) | | |
| - Any problem | 104 (48.8%) | 109 (51.2%) | | |
| Pain/Discomfort (n = 373) | | | 0.88 | -0.01 |
| - No problem | 63 (55.3%) | 51 (44.7%) | | |
| - Any problem | 147 (56.8%) | 112 (43.2%) | | |
| Anxiety/Depression (n = 387) | | | 0.84 | -0.02 |
| - No problem | 92 (54.4%) | 77 (45.6%) | | |
| - Any problem | 122 (56.0%) | 96 (44.0%) | | |

Notes: All patient responses for each EQ-5D-5L item were dichotomised into: 1) 'no problem' (i.e. a score of 1) and; 2) 'any problem' (i.e. a score of 2 to 5). *p-value for between-group differences; **Phi coefficient value is the effect size statistic reported for the Chi-squared tests for independence.

When compared with breast clinic participants, thoracic clinic participants were more likely to report a severe score (i.e. a score of 7 to 10) for several symptom items on the ESAS (Table 5). These five symptoms were tiredness, appetite, shortness of breath, feelings of wellbeing, and sleep, which are mostly consistent with the common symptoms reported by patients diagnosed with thoracic cancers. No other differences in the proportions of participants reporting a severe symptom were found between the two clinics.

Table 5. The five ESAS-R symptom items in which the proportion of participants reporting a severe score differed by clinic.

| ESAS-R symptom item and response categories | Breast Clinic n (%) | Thoracic Clinic n (%) | p-value* | Phi** |
|---|------------------------|--------------------------|----------|-------|
| Tiredness (n = 377) | | | 0.02 | 0.12 |
| - None, mild, moderate | 150 (59.5%) | 102 (40.5%) | | |
| - Severe | 58 (46.4%) | 67 (53.6%) | | |
| Appetite (n = 372) | | | <0.001 | 0.18 |
| - None, mild, moderate | 181 (59.7%) | 122 (40.3%) | | |
| - Severe | 25 (36.2%) | 44 (63.8%) | | |
| Shortness of breath (n = 387) | | | <0.001 | 0.23 |
| - None, mild, moderate | 187 (59.9%) | 125 (40.1%) | | |
| - Severe | 18 (29.5%) | 43 (70.5%) | | |
| Wellbeing (n = 372) | | | 0.048 | 0.11 |
| - None, mild, moderate | 163 (58.2%) | 117 (41.8%) | | |
| - Severe | 42 (45.7%) | 50 (54.3%) | | |
| Sleep (n = 374) | | | 0.001 | 0.17 |
| - None, mild, moderate | 172 (60.1%) | 114 (39.9%) | | |
| - Severe | 35 (39.8%) | 53 (60.2%) | | |

Notes: All patient responses for the ESAS symptom item were dichotomised into: 1) 'none, mild, moderate' (i.e. a score of 0 to 6) and; 2) 'severe' problem' (i.e. a score of 7 to 10). *p-value for between-group differences; **Phi coefficient value is the effect size statistic reported for the Chi-squared tests for independence.

Regarding unmet needs, the SCNS-SF34 standardised scores for the five domains of need were calculated with higher scores indicating greater level of need for that domain. The standardised scores for the domains of need were generally similar between participants who attended the breast clinic and those who attended the thoracic clinic (Table 6). A higher median standardised score for the Health System and Information domain was reported by the thoracic clinic participants compared with the breast clinic participants, $p = 0.049$. The thoracic clinic participants also reported a higher median standardised score for the Physical and Daily Living domain; however, this was only approaching significance ($p = 0.055$).

Table 6. The standardised scores for the five SCNS-SF34 domains of needs at the first appointment during the Implementation Phase, by clinic.

| Domain of need | Breast Clinic | | Thoracic Clinic | | p-value* | r-value** |
|--|---------------|-----------------|-----------------|-----------------|----------|-----------|
| | n | Median score | n | Median score | | |
| Psychological (n = 359) | 200 | 35 (IQR 35) | 159 | 40 (IQR 35) | 0.21 | 0.003 |
| Health System and Information (n = 359) | 194 | 27.3 (IQR 23.3) | 155 | 34.1 (IQR 31.8) | 0.049 | 0.11 |
| Physical and Daily Living (n = 358) | 199 | 35 (IQR 40) | 159 | 40 (IQR 40) | 0.055 | 0.10 |
| Patient Care and Support (n = 355) | 198 | 25 (IQR 26.8) | 157 | 25 (IQR 30) | 0.07 | 0.096 |
| Sexuality (n = 349) | 194 | 8.3 (IQR 25) | 155 | 8.3 (IQR 25) | 0.50 | 0.04 |

Notes: *p-value for between-group differences; **r-value is the effect size statistic reported for the Mann-Whitney U tests. Abbreviations: IQR, interquartile range.

Real-time PROMs and PREMs had minimal impact on consultation duration

The consultation duration audit collected data for four weeks, prior to the implementation and during the implementation. It collected data from 196 Pre-Implementation Phase medical oncology appointments (153 face-to-face and 43 telehealth video) and 223 Implementation Phase medical oncology appointments (196 face-to-face and 27 telehealth video). Using the Mann-Whitney U analyses, no differences in the median consultation duration were detected for either between the Pre-Implementation Phase and the Implementation Phase (Table 7) or between participants and non-participants (Table 8).

Table 7. Median consultation duration, by phase (n = 419).

| Consultation Type | Pre-Implementation Phase | | Implementation Phase | | p-value* | r-value** |
|-------------------|--------------------------|---------------|----------------------|---------------|----------|-----------|
| | n | Median (mins) | n | Median (mins) | | |
| All | 196 | 16 (IQR 11) | 223 | 15 (IQR 12) | 0.51 | 0.03 |
| New | 18 | 41 (IQR 21.8) | 20 | 48.5 (IQR 21) | 0.62 | 0.10 |
| Review | 178 | 14 (IQR 8) | 203 | 14 (IQR 11) | 0.43 | 0.04 |

Notes: *p-value for between-group differences; **r-value is the effect size statistic reported for the Mann-Whitney U tests. Abbreviations: IQR, interquartile range.

Table 8. Implementation Phase median consultation duration, by participation (n = 223).

| Consultation Type | Participants | | Non-Participants | | p-value* | r-value** |
|-------------------|--------------|---------------|------------------|---------------|----------|-----------|
| | n | Median (mins) | n | Median (mins) | | |
| All | 112 | 15 (IQR 13.8) | 111 | 15 (IQR 12) | 0.54 | 0.04 |
| New | 15 | 50 (IQR 23) | 5 | 47 (IQR 24.5) | 0.97 | 0.01 |
| Review | 97 | 14 (IQR 10.5) | 106 | 14 (IQR 11.3) | 0.64 | 0.03 |

Notes: *p-value for between-group differences; **r-value is the effect size statistic reported for the Mann-Whitney U tests. Abbreviations: IQR, interquartile range.

Most patients perceived the PROMs and PREMs to be helpful

A total of 109 Patient Evaluation Survey responses (24.7%) were collected. The mean age of survey respondents was 64.7 (SD 10.7) years, 77 (70.6%) were female, and 83 (76.1%) spoke English as their main language.

The frequency of PROMs and PREMs completions amongst the survey respondents were: 1-2 times (77.1%), 3-4 times (17.4%), and 5+ times (5.5%). Of 107 responses, 103 (96.3%) reported completing the PROMs and PREMs on their own device whereas 4 (3.7%) completed it on a hospital provided iPad in the clinic waiting room.

Overall, the majority of survey respondents indicated that the PROMs and PREMs questions were relevant to them and their cancer treatment/follow-up (Figure 6). Most patients indicated that their doctor discussed the concerns they raised in the PROMs and PREMs although only 67% of patients reported being happy to complete the PROMs and PREMs each time they had an appointment.

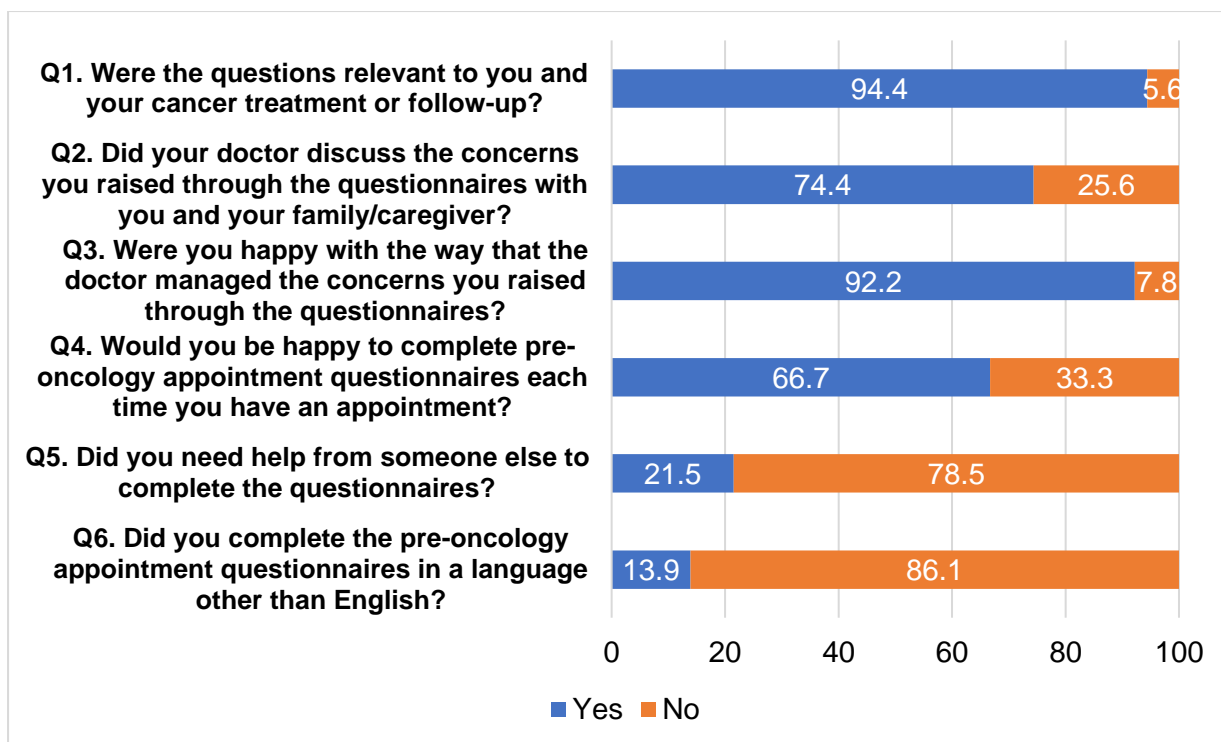


Figure 6. Proportion (%) of response choices to six of the questions included in the Patient Evaluation Survey. The number of responses collected for each question and analysed were: Q1 (n = 107), Q2 (n = 90), Q3 (n = 90), Q4 (n = 78), Q5 (n = 79), and Q6 (n = 79).

Non-Participation Reasons

The audit of patient non-participation was completed with 72 patients, assisted by either a carer or interpreter as required. The non-participation reasons collected were categorised, where possible (Figure 7). The five most common non-participation reasons reported were: limited digital literacy/access to device (n = 15), followed by SMS-related (n = 14), lack of interest or dislike of questionnaires (n = 10), no reason provided (n = 10), and forgotten to complete the PROMs and PREMs (n = 7). SMS-related reasons include patients and carers not routinely checking their SMSes on their mobile phone or being overwhelmed with receiving multiple SMSes, including those that are unsolicited.

The overall non-participation reasons are consistent with those collected during our pilot study (except for SMS-related reasons) as well as those in the literature.

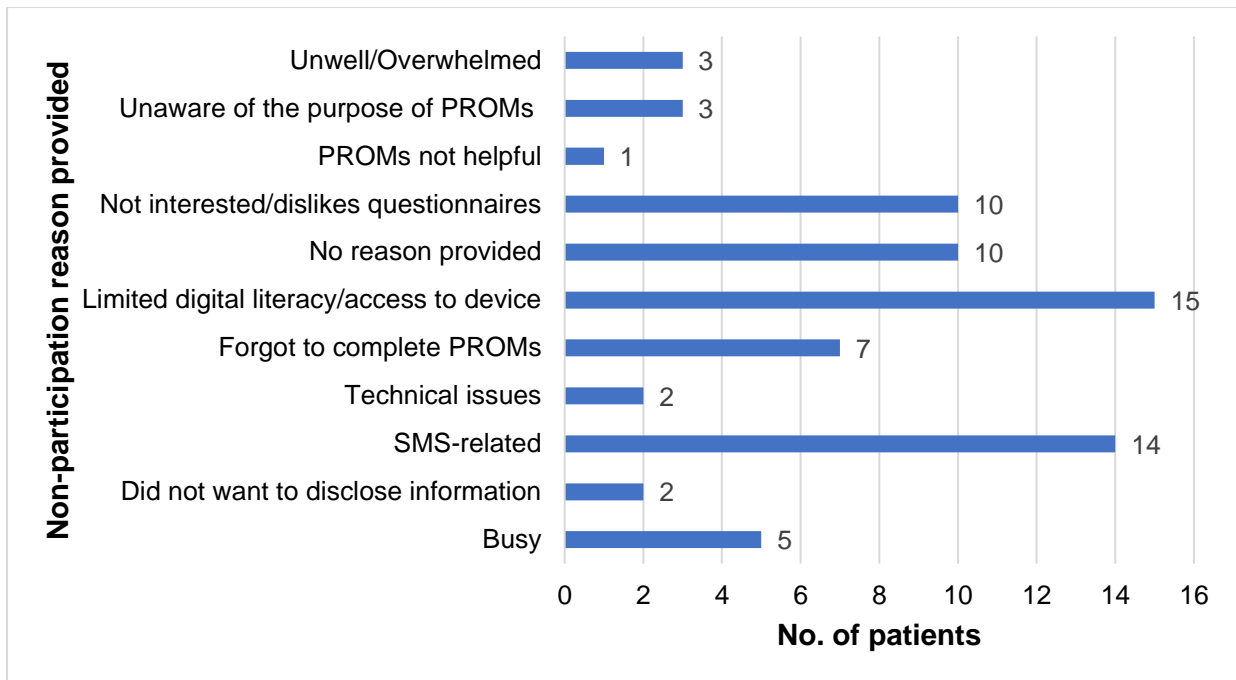


Figure 7. Non-participation reasons provided by patients or their carers (n = 72).

Qualitative – Pre-Implementation

A total of 21 patients, four carers, six medical staff, four nursing staff, and four clerical staff members participated at the pre-implementation point.

Of the 21 patients, three spoke Mandarin Chinese as their main language and nine spoke English as their main language and were from a CALD background. Although patients who spoke Greek as their main language were also invited to participate, they declined to take part due to reasons such as feeling unwell, being busy, or a lack of interest.

Participants’ perceived enablers and barriers prior to the implementation of the PROMs and PREMs were similar to the published literature

Patients, carers, and healthcare staff identified key enablers and barriers that were grouped into three categories (Table 9).

Table 9. Key enablers and barriers identified at the pre-implementation point.

| Category | Enablers | Barriers |
|-------------------------------|---|---|
| Patient-related | Improves communication with treating team | Health and digital literacy |
| | Facilitates discussion of sensitive topics with treating team | Length of PROMs and PREMs |
| | Translated PROMs and PREMs to improve access | Feeling unwell or busy |
| Clinician-related | Monitor patient's progress | Concerns about longer consultations |
| | Identification of concerns and symptoms not routinely discussed | Increased workload through generation of new referrals |
| | Enhances patient-centred care | |
| Organisational-related | Support from the organisation | Inadequate IT systems |
| | | Inadequate resources/services/nursing support to address issues raised by patients from the PROMs and PREMs |

The availability of the PROMs and PREMs in multiple languages was important for CALD inclusivity

There was broad agreement from patients, carers, and healthcare staff participants that including translations of the PROMs and PREMs in multiple languages could improve engagement with patients from CALD backgrounds. Non-English speaking patient participants were particularly supportive of the inclusion of different language translations as it facilitated their completion of the PROMs and PREMs.

Patients preferred to be invited to complete the PROMs and PREMs by SMS

Most patients and carers reported that they preferred to receive an SMS invitation to complete the PROMs and PREMs on their mobile phone. Some patients preferred an email invitation as they reported it was easier for them to complete questionnaires on their computer or laptop. Concerns were expressed that patients with limited digital literacy would find it difficult to remotely complete the PROMs and PREMs. Patients and carers were supportive of the option for patients to complete the PROMs and PREMs on a hospital iPad, assisted by a project officer. One patient anticipated that she would find it challenging to

complete the PROMs and PREMs on an electronic device and advocated for the availability of hard-copy PROMs and PREMs.

Qualitative – Post-Implementation

A total of 21 patients, six carers, nine medical staff, four nursing staff, and four clerical staff members participated at the post-implementation point. Of these participants, seven patients, two carers, six medical staff, four nursing staff, and three clerical staff members also took part at the pre-implementation point.

Of the 21 patients, three patients spoke Mandarin as their main language, one patient spoke Cantonese as their main language, and eight spoke English as their main language and were from a CALD background. Despite broadening the eligibility criteria to include patients who spoke any main language other than English, recruitment of these patients remained challenging.

The implementation of the PROMs and PREMs was well-received

The majority of patients, carers, and healthcare staff spoke positively about the implementation of the PROMs and PREMs and they were supportive of it continuing at the clinics. Most patients and carers reported that completing the PROMs and PREMs enhanced their consultations and improved their relationship with the treating team.

Clinical staff reported that the PROMs and PREMs assisted with identifying their patient's symptoms and concerns, particularly those that may not be routinely discussed such as mental health and sexual health. Clerical staff were supportive of the implementation of the PROMs and PREMs, and that it had minimal impact on the clinics. They reported receiving minimal queries from patients and carers about the PROMs and PREMs.

Barriers to the completion of the PROMs and PREMs are mostly similar to those identified at the pre-implementation

Patients and carers were generally satisfied with the content and layout of the PROMs and PREMs. Some suggested reducing the length of the PROMs and PREMs to facilitate completion, as a few patients recalled that they experienced difficulty with completing the PROMs and PREMs when they were feeling either unwell, overwhelmed, or busy. A few patients and carers also reported that particular PROMs and PREMs items were triggering for them, particularly those related to sensitive topics such as death and cancer recurrence.

Concerns were also expressed by some patients and carers about whether their responses to the PROMs and PREMs were being reviewed by their clinician. A few patients reported that if they felt their clinician had not reviewed their responses, they proceeded to cease completing the PROMs and PREMs at subsequent appointments. Other patients and carers indicated they were not deterred by this, and they continued to complete the PROMs and PREMs for their subsequent appointments.

The Simplified Chinese translation of the PROMs and PREMs facilitated completion

Four patients, of whom two participated with their carer, completed the PROMs and PREMs using the Simplified Chinese language translation. These patients and their carers indicated that the language translations were helpful, as they would have otherwise either been

unable to complete the PROMs and PREMs, or spent a lot of time completing them using a bilingual dictionary or software. Patients and carers reported that they would continue to complete the PROMs and PREMs, regardless of whether their clinician reviewed their responses during consultations.

The PROMs and PREMs were used in different ways by clinical staff during their consultations

Most clinical staff reported reviewing their patient's responses to the PROMs and PREMs and using them indirectly to guide the consultation. They discussed they would prefer to have additional time to be able to review the responses, especially when their patients raised multiple concerns and symptoms in their responses. Some clinical staff described how the PROMs and PREMs assisted them with broaching sensitive topics, such as death and sexual health, with their patients.

A few clinical staff participants indicated they initially had reservations about the implementation of the PROMs and PREMs, but after using them, they reported that the tools had been helpful in their consultations.

A few clinical staff members reported not being able to use the PROMs and PREMs for most of their consultations. Their explanation was because of the length of the PROMs and PREMs and having limited consultation time. These participants indicated they would be more likely to use them, if a one-page summary of their patient's responses to the PROMs and PREMs were made available.

Although the Referral Resources Pathways document was acknowledged by clinical staff as a useful tool to guide the use of the PROMs and PREMs, most participants discussed that they did not routinely use it. It was highlighted that most participants were already familiar with the available referrals and resources and that this would be most helpful to clinicians who are new to the clinics. A few participants suggested embedding the Referral Resources Pathways document into a one-page summary of the patient's responses to the PROMs and PREMs. They envisioned that relevant referral and resource links would be displayed on the summary, adjacent to the patient's ratings of the symptoms and concerns.

The overlap between the PROMs and PREMs and the Oncology Supportive Care Screening Tool may hinder their effectiveness

The Oncology Supportive Care Screening Tool (OSCST) is routinely administered to new patients and some returning patients at the oncology outpatient clinics. Some clinical staff members expressed concern about the similarities between the OSCST and the PROMs and PREMs. These similarities include the purposes of both tools to identify supportive care needs, physical, and emotional concerns. A few clinical staff members reported it was challenging for them to effectively use their patient's responses to both the OSCST and PROMs and PREMs during consultations. They also highlighted that completing multiple questionnaires can be fatiguing and confusing for some patients.

Adequate nursing support required

Medical staff reported that their capacity to respond to their patient's responses to the PROMs and PREMs was influenced by limited allocated consultation duration and available nursing support. For medical staff who were supported by adequate nursing staff during their

consultations, they highlighted their appreciation to the nursing staff for facilitating the necessary supportive care referrals and addressing mental health and emotional concerns. Conversely, medical staff who did not receive adequate nursing support discussed that did not have the time to be able to thoroughly discuss and address the concerns raised by their patients' PROMs and PREMs. One medical staff participant highlighted that they would be able to effectively use the PROMs and PREMs in the private setting, where allocated consultation duration are more generous than those in the public setting.

Dedicated resourcing is required for long-term implementation

There was broad agreement among healthcare staff for the requirement of dedicated staff resourcing to sustain the collection and use of PROMs and PREMs at the two selected clinics. This included distributing the SMS invitations, facilitating the availability of the PROMs and PREMs to clinical staff, and assisting patients with completing the PROMs and PREMs on iPads. It was highlighted by most staff members that these tasks could not easily be absorbed into the existing workloads of either the clinical staff or clerical staff.

In the absence of dedicated staffing to coordinate the collection and use of the PROMs and PREMs, healthcare staff suggested automating the processes as a solution.

Conclusion

The implementation of real-time PROMs and PREMs in two busy outpatient oncology clinics was well received by patients, carers, and the healthcare staff team clinicians. It facilitated communication between patients and their clinicians on symptoms and concerns. There was minimal impact on consultation time, which is a commonly cited barrier to implementation of such initiatives. Ongoing data analysis will identify whether participation in the PROMs and PREMs are associated with different clinical outcomes.

Our experience suggests that collecting and using real-time PROMs and PREMs in busier settings can be feasible and acceptable, building on the body of work from our pilot study and previously reported international data in this space. There remains further work to be done to improve uptake of the opportunity to utilise real-time PROMs and PREMs amongst non-participants, including subgroups of the CALD population. The Monash Health PROMs and PREMs team are committed to ongoing work in this space, to bring these valuable tools into routine practice to enhance delivery of truly person-centred care.

Recommendations

1. Revised PROMs and PREMs

Our results indicate the PROMs and PREMs were generally well-received by patients, carers, and the healthcare staff team. However, revision of the PROMs and PREMs, such as its length, could improve patient completion rates and engagement. We recommend that patients are invited to complete the primary symptom focussed questionnaires, the EQ-5D-5L and ESAS-R, (approximately 20 questionnaire items) at each of their outpatient oncology appointments. The SCNS-SF34 is a longer instrument, and whilst it was found to provide helpful information about a patient's healthcare experience, and also served as a conversation starter for some sensitive topics such as sexuality and death, it added to the overall questionnaire length substantially. Many of the themes raised on this instrument are unlikely to change at a short interval for most patients. As such, we recommend that it become positioned as a separate questionnaire, which can be completed after submission of the EQ-5D-5L and ESAS-R, and perhaps at set-time intervals rather than every visit. A proposed schedule might see this added at the patient's second clinic visit (noting that they will receive the OSCST at their first visit), and then perhaps at intervals of 3-6 months or after a significant clinical change. This would reduce the burden of questionnaire completion, yet retain the opportunity to gain this useful patient experience data from oncology patients.

For clinicians, a simplified one-page summary of the patient's responses made available on the medical records could assist with their use during appointments. The summary would still use visual indicators and include a table of the results that is clearer and quicker for clinicians to review the responses. Ideally this summary would also include longitudinal trends in responses, however the system utilised to date does not have such capacity.

2. Harmonisation of the PROMs and PREMs with the OSCST

Harmonisation of the PROMs and PREMs questionnaires with the established OSCST at Monash Health Oncology is recommended. The overlap with the items and domains covered by the two questionnaires can be reduced by revising the PROMs and PREMs, as per Recommendation 1. This can also minimise the effect of questionnaire fatigue on patients. Further consultation with stakeholders is recommended. These stakeholders include patients, nursing staff, and SMICS, to develop a set of guidelines with distributing and using both the PROMs and PREMs and the OSCST.

At present, the OSCST is completed on paper using a clipboard in the waiting room. As our results suggest remote completion of PROMs and PREMs is strongly preferred, the addition of the OSCST onto REDCap can provide choice for patients wishing to complete the OSCST electronically. The study team have already commenced piloting an electronic version of the OSCST on the REDCap platform, which may form the basis of an important subsequent quality improvement initiative arising from this work.

3. Nursing support

Our qualitative results indicate that adequate nursing support at the outpatient oncology clinics would support the medical staff with addressing concerns and symptoms identified in the patient's PROMs and PREMs responses. At present, there is inequity between medical oncology clinics and tumour streams as to the level of specialist nursing support assigned to

their respective patient cohorts. Addressing this inequity would facilitate the appropriate provision of supportive care and allied health referrals arising from the PROMs instrument, to optimise the potential benefits of the intervention.

4. Integration of PROMs and PREMs with current health service processes and systems

The current project was fortunate to have the support of a dedicated project officer, however long-term sustainability will depend upon transition of several of their roles into business-as-usual service delivery, whilst minimising the impact on costs and staff time. For example, the invitation to complete the PROMs and PREMs and questionnaire link could be embedded into routine SMS appointment reminders that are already distributed by Monash Health to oncology outpatients. Working with the Health Information Services team, there may be an opportunity to set-up a process to automate the upload of the patient's PROMs and PREMs responses onto SMR. This can ensure the responses are readily available for the clinical staff and minimise the need for dedicated staff to coordinate this step.

By automating the steps involved in coordinating the collection and use of real-time PROMs and PREMs, integrating the remaining steps into the existing workload of clerical staff and clinical staff would be more feasible and acceptable.

REDCap continues to receive updates with new features that may facilitate further automation. The availability of newly developed software that is dedicated to the collection and use of PROMs and could be easily implemented into the hospital IT ecosystem should also be considered. In particular, software that can integrate with Monash Health systems, such as Cerner EMR. Monash Health has commenced the process of transitioning to using Cerner EMR in both the inpatient and outpatient settings, with the recently opened Victorian Heart Hospital being the first Monash Health site to do so. However, plans for transitioning at the other sites are currently unclear.

The team recommend that the health service consider investment in IT systems to integrate PROMs responses into patient medical records in a more sophisticated and automated fashion, given the benefits to the organisation which can be achieved with interventions of this nature (e.g. Improvements in patient satisfaction, reductions in ED presentations, data availability for QA and research purposes).

5. Development of education materials for patients and staff

The development and provision of a multi-media education campaign can support patient completion of PROMs and PREMs and their use by healthcare team staff. Patients and caregivers can be educated on the benefits to complete the PROMs and PREMs with brief written materials and a short informational video. These materials can be accessed digitally in the SMS invitation and they can be made available physically in the clinic waiting room to target a broad patient cohort. Furthermore, to enhance completion rates for patients from CALD backgrounds, the materials could be made available in multiple languages. Consideration should also be given to updating the patient educational video prepared for the pre-COVID-19 pilot project to incorporate information regarding remote completion of PROMs and PREMs.

A one-page information sheet on the purpose of the PROMs and PREMs, how they can be used on consultations, and further information and training resources should be made available and displayed in the clinics for new and existing staff.

6. Patient-related supports to facilitate PROMs and PREMs participation.

There is an ongoing need to identify and deploy various no-cost or low-cost patient-related supports to facilitate the completion of the PROMs and PREMs.

The demographics of patients attending Monash Health are constantly changing and this should be monitored annually. For instance, ongoing collaboration with Monash Health Language Services can inform the need to include additional language translations available for the PROMs and PREMs (e.g. Spanish, Russian).

However, relatively low uptake of the translated versions of the questionnaires indicates that simply having the instruments available in a variety of languages was not sufficient to optimise their use among patients from CALD backgrounds. Moreover, patients who chose not to complete the questionnaires despite availability in their preferred language also proved difficult to recruit to interviews and focussed groups. Targeted, culturally appropriate education may be required to optimally reach these cohorts of patients.

Hospital volunteers and clerical staff can engage with patients who have limited digital or health literacy and assist them with completing the PROMs and PREMs on the iPads. Older patients are a key subgroup who may benefit from this, as we found they were less likely to participate. As our findings indicate that only a small proportion of patients require assistance, it is anticipated the increased workload for hospital volunteers and clerical staff would be minimal.

Assistive technologies are increasingly embedded in different software platforms, such as REDCap. The availability of text-to-speech to assist the completion of PROMs and PREMs can improve access to patients who have visual impairments, low literacy, and speak languages other than English. Text-to-speech functions are becoming more available on various software platforms. They are also becoming more commonly powered by artificial intelligence to synthesise more intelligible speech.

Next steps

- The project team plan to internally disseminate the project findings to various stakeholders including:
 - Display of brief research findings for patients in the clinic waiting rooms as well as electronic copies for patient participants and carer participants;
 - Presentation to the Monash Health Oncology clinical staff;
 - Discussion with support services including Monash Health IT and clerical teams regarding sustainable implementation.
- External dissemination strategies include:
 - A poster of the pre-implementation analyses was presented at the Psycho-oncology Co-operative Research Group (PoCoG) Scientific Meeting 2023 and at the COSA ASM 2023;
 - Story for the SMICS newsletter and related educational forums;
 - Presentation to consumers at the Breast Cancer Network Australia (BCNA);
 - Planned abstract submissions to upcoming oncology conferences including the American Society of Clinical Oncology (ASCO);
 - Planned manuscript submissions to oncology journals.
- A sustainability plan has been outlined to address the steps that the project officer coordinates as part of the Implementation Phase (Appendix 4). It will require support and resourcing to execute, with initial steps having been taken by the team to progress this, including:
 - Initiated discussions with the clerical team management, such as the inclusion of the SMS invitation into the current Monash Health Oncology appointment reminder;
 - Engaged with the new Monash Health Director of Medical Oncology and have included PROMs and PREMs on her agenda;
 - Contacted Professor Chris Bain, the inaugural Professor of Practice in Digital Health in the Faculty of Information Technology at Monash University, regarding the potential development of a streamlined software solution for collecting and using PROMs and PREMs, that can be integrated into Cerner EMR.

Financial acquittal

The project was funded for \$100,000 and the details of the projected budget and actual expenditure are detailed in Appendix 5. Actual expenditure reflects changes in resources and project requirements.

Interpreter costs were much lower than anticipated due to a revised recruitment strategy of non-English speaking patients. The project team invited patients by contacting carers first, where possible. Non-English speaking patients were also invited prior to their medical oncology appointment in the clinic waiting room, with interpreters who had been booked for the appointment assisting with the recruitment process.

These surplus funds were then re-allocated to project expenses (e.g. SMS invitations to patient participants, patient participant car parking), and the project officer salary. Due to delays with conducting the 6-month implementation phase, the project officer was funded for an additional two weeks to meet the additional workload during peak periods for data collection and data entry.

The majority of the funds have been expended. The final budget report was extended to include costs related to outstanding transcription fees (to be incurred in November 2023 and invoiced in December 2023) due to a delay in data collection. Of the \$2,500 funding allocated to the analysis and reporting of outcomes, \$1,250 have yet to be incurred for the following planned activities: 1) Biostatistician support (\$1,050) and abstract submission fees to two ASCO conferences held in 2024 (\$100 each).

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Appendix 1: Glossary

| Abbreviation | |
|--------------|--|
| ASCO | American Society of Clinical Oncology |
| ASM | Annual Scientific Meeting |
| CALD | Culturally and linguistically diverse |
| COSA | Clinical Oncology Society of Australia |
| ED | Emergency Department |
| ESAS | Edmonton Symptom Assessment Scale |
| IQR | Interquartile range |
| PoCoG | Psycho-oncology Co-operative Research Group |
| PREMs | Patient-Reported Experience Measures |
| PROMs | Patient-Reported Outcome Measures |
| SCNS-SF34 | Supportive Care Needs Survey Short Form 34 |
| SD | Standard deviation |
| SMICS | Southern Melbourne Integrated Cancer Service |
| SMR | Scanned Medical Records |
| SMS | Short Message Service |
| VAS | Visual Analogue Scale |

Appendix 2: PROMs and PREMs Questionnaires and Rolling Feedback Survey



Implementation Phase - Questionnaire
Record ID 929_en

Pre-Oncology Clinic Questionnaires

Response is only partial and is not complete. Response was added on 06/08/2023 1:57pm.

| | |
|---|--|
| Record ID | 929 |
| Monash Health URN (office use only) | <input type="text"/> |
| Your full name <small>* must provide value</small> | <input type="text"/> |
| Your date of birth (DD-MM-YYYY) <small>* must provide value</small> | <input type="text"/> D-M-Y |
| Who is completing the questionnaire today? <small>* must provide value</small> | <input type="radio"/> 1. Patient <input type="radio"/> 2. Carer |

Your treating team will look at your answers to these questions during your next oncology appointment. If you have an urgent problem, please contact the Monash Health Cancer Support Nurses on 0428 024 793 (during business hours) or go to your nearest hospital's Emergency Department.

Under each heading, please tap the ONE circle that best describes your health TODAY.

- MOBILITY**
- I have no problems in walking about
 - I have slight problems in walking about
 - I have moderate problems in walking about
 - I have severe problems in walking about
 - I am unable to walk about
- SELF-CARE**
- I have no problems washing or dressing myself
 - I have slight problems washing or dressing myself
 - I have moderate problems washing or dressing myself
 - I have severe problems washing or dressing myself
 - I am unable to wash or dress myself
- USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)**
- I have no problems doing my usual activities
 - I have slight problems doing my usual activities
 - I have moderate problems doing my usual activities
 - I have severe problems doing my usual activities
 - I am unable to do my usual activities
- PAIN/DISCOMFORT**
- I have no pain or discomfort
 - I have slight pain or discomfort
 - I have moderate pain or discomfort
 - I have severe pain or discomfort
 - I have extreme pain or discomfort
- ANXIETY/DEPRESSION**
- I am not anxious or depressed
 - I am slightly anxious or depressed
 - I am moderately anxious or depressed
 - I am severely anxious or depressed
 - I am extremely anxious or depressed

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the **best** health you can imagine. 0 means the **worst** health you can imagine.
- Please tap on the scale to indicate how your health is TODAY.

100 - The best health you can imagine

50

0 - The worst health you can imagine

Change the slider above to set a response

Please tap the number that best describes how you feel (on average, in the **last 24 hours**):

| | | | | | | | | | | | |
|---|------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|------------------------------------|
| | 0 | | | | | | | | | | 10 |
| | No Pain | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Pain |
| Pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Tiredness | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Tiredness |
| Tiredness (lack of energy) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Drowsiness | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Drowsiness |
| Drowsiness (feeling sleepy) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Nausea | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Nausea |
| Nausea | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | Best appetite | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Appetite |
| Appetite | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Shortness of Breath | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Shortness of Breath |
| Shortness of Breath | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Depression | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Depression |
| Depression (feeling sad) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Anxiety | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Anxiety |
| Anxiety (feeling nervous) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | Best Wellbeing | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Wellbeing |
| Wellbeing (how you feel overall) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Trouble Sleeping | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Sleep |
| Sleep | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| | 0 | | | | | | | | | | 10 |
| | No Swelling | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Worst Possible Swelling |
| Swelling | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Swelling (puffiness or enlarged arms and/or legs)

0 No Constipation 1 2 3 4 5 6 7 8 9 10 Worst Possible Constipation

Constipation (less poo than usual/hard poo)

0 No Diarrhoea 1 2 3 4 5 6 7 8 9 10 Worst Possible Diarrhoea

Diarrhoea (more poo than usual/watery poo)

0 Best Concentration and Memory 1 2 3 4 5 6 7 8 9 10 Worst Possible Concentration and Memory

Concentration and memory

Please list any other problem you may have in the last 24 hours:

Instructions

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer.

Tap the circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

| | | |
|-----------|---|---|
| NO NEED | 1 | Not applicable - This was not a problem for me as a result of having cancer. |
| | 2 | Satisfied - I did need help with this, but my need for help was satisfied at the time. |
| SOME NEED | 3 | Low need - This item caused me concern or discomfort. I had little need for additional help. |
| | 4 | Moderate need - This item caused me concern or discomfort. I had some need for additional help. |
| | 5 | High need - This item caused me concern or discomfort. I had a strong need for additional help. |

For example

| In the last month, what was your level of need for help with: | No need | | Some need | | |
|--|----------------|-----------|-----------|---------------|-----------|
| | Not applicable | Satisfied | Low need | Moderate need | High need |
| 1. Being informed about things you can do to help yourself to get well | 1 | 2 | 3 | 4 | 5 |

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now please complete the survey on the next 3 pages.

In the last month, what was your level of need for help with:

NOTE: Tap one circle for each question.

| | | | | | |
|-----------------------------|-----------------------------|------------------------|-------------------------|------------------------------|--------------------------|
| | Not applicable (No need) | Satisfied (No need) | Low need (Some need) | Moderate need (Some need) | High need (Some need) |
| 1. Pain | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Lack of energy/tiredness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 3. Feeling unwell a lot of the time | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Work around the home | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Not being able to do the things you used to do | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Anxiety | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Feeling down or depressed | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Feelings of sadness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Fears about the cancer spreading | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Worry that the results of treatment are beyond your control | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Uncertainty about the future | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Learning to feel in control of your situation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

In the last month, what was your level of need for help with:

NOTE: Tap one circle for each question.

| | Not applicable (No need) | Satisfied (No need) | Low need (Some need) | Moderate need (Some need) | High need (Some need) |
|---|-----------------------------|------------------------|-------------------------|------------------------------|--------------------------|
| 13. Keeping a positive outlook | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Feelings about death and dying | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Changes in sexual feelings | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Changes in your sexual relationships | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Concerns about the worries of those close to you | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. More choice about which cancer specialists you see | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. More choice about which hospital you attend | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Reassurance by medical staff that the way you feel is normal | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 21. Hospital staff attending promptly to your <u>physical</u> needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 23. Being given written information about the important aspects of your care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

In the **last month**, what was your level of need for help with:

NOTE: Tap one circle for each question.

| | Not applicable (No need) | Satisfied (No need) | Low need (Some need) | Moderate need (Some need) | High need (Some need) |
|--|-----------------------------|------------------------|-------------------------|------------------------------|--------------------------|
| 25. Being given explanations of those tests for which you would like explanations | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 27. Being informed about your test results as soon as feasible | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 28. Being informed about cancer which is under control or diminishing (that is, remission) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 29. Being informed about things you can do to help yourself to get well | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30. Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 31. Being given information about sexual relationships | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 32. Being treated like a person not just another case | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 33. Being treated in a hospital or clinic that is as physically pleasant as possible | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 35. Concerns about your financial situation | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 36. Concerns about getting to and from the hospital | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Thank you for completing these questionnaires. Your responses will be made available to your doctor during your next appointment.

Please tap **Next Page** to save your answers.

Dear Monash Health Patient,

We would like to understand how you felt about completing the questionnaires today. This is an optional survey, which involves answering the next two questions.

• **If you wish to take part in this survey**, please answer the next two questions and then submit your answers.

• **If you do not wish to take part in this survey**, you can close this window.

1. How easy was it for you to complete the questionnaires today?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

2. Was the amount of time it took to complete the questionnaires today acceptable to you?

- Yes
- No

Please tap **SUBMIT** to save your answers.

Form Status

Appendix 3: Sample algorithm

Modified Edmonton Symptom Assessment System – Revised (ESAS-R)

| Modified ESAS-R | Trigger and referral resources pathway actions | | |
|----------------------|---|--|--|
| Item | Mild (0 to 3) | Moderate (4 to 6) | Severe (7 to 10) |
| Q1. Pain | <p>Assess nature of pain.</p> <p>Discuss pain management strategies and prescribe analgesia as clinically indicated.</p> | <p>As for mild pain.</p> <p>Investigation and referrals (e.g. radiation oncology, Virtual Palliative Care <email referral to pallcarevirtual@monashhealth.org>, community palliative care via GP or Monash Health) as clinically indicated.</p> <p>Oncopain clinic (for patients who aren't necessarily palliative). (Fortnightly at Moorabbin Hospital) Dr Scott King T: 0404 045 898 (Refer via SMS e-Referrals)</p> | <p>As for mild/moderate pain.</p> <p>Consider admission/ED presentation for urgent assessment and management, as clinically indicated. Inform ward staff prior to admission.</p> <p>RAPID via HITH. T: 0419 882 619 E: rapidpc@monashhealth.org (outside of Monday to Friday, 8:30am to 4:00pm).</p> |
| | <p>1. Cancer Council booklet: Understanding Cancer Pain https://www.cancervic.org.au/downloads/resources/booklets/Understanding-Cancer-Pain.pdf</p> | | |
| Q2. Tiredness | <p>Assess nature of tiredness.</p> <p>Discuss strategies to manage tiredness such as graded exercise as clinically indicated.</p> | <p>As for mild tiredness.</p> <p>Exclude medical causes.</p> <p>Referrals as clinically indicated (exercise physiologists and physiotherapists via GP CDMP or Monash Health, Monash Oncology Online Rehabilitation Program<email icareaccess@monashhealth.org>).</p> | <p>As for mild/moderate tiredness.</p> |
| | <p>1. Cancer Council factsheet: Fatigue and Cancer https://www.cancervic.org.au/downloads/resources/factsheets/Fatigue%20and%20Cancer.pdf</p> <p>2. Cancer Council booklet: Exercise for People Living with Cancer https://www.cancervic.org.au/downloads/resources/booklets/exercise-and-cancer.pdf</p> | | |

Referral Resources Pathways for SMICS PROMs and PREMs in Oncology – Implementation Phase V2 24-01-23

9

Appendix 4: Sustainability Plan

| Step | Stakeholder (s) | Strategies to address at step | Strategy rationale |
|--|---|--|--|
| Invitation to complete PROMs and PREMs | Clerical staff | Integrate PROMs and PREMs link into the current Monash Health appointment reminder SMS template | Minimal input required from clerical staff |
| Completion and use of PROMs and PREMs | Patients and Caregivers, Clinical staff | Revised and shorter PROMs and PREMs | Reduces burden on patients completing the PROMs and PREMs, and clinical staff using them. |
| | Patients and Caregivers | Brief education highlighting the rationale for completing PROMs and PREMs (e.g. host a 1-2 min video on REDCap, can be subtitled for multiple languages) | Improved understanding of PROMs and PREMs can enhance completion rates. |
| | Patients and Caregivers | Text-to-speech function to support completion of PROMs and PREMs, which can be supported in multiple languages. | Supports patients with visual impairments, low literacy levels, and those from CALD backgrounds. |
| Upload of PROMs and PREMs to medical records | Clerical staff, Clinical staff | Automate REDCap to send an email with the patient's PROMs and PREMs responses to the SMR Support Team upon patient completion | Reduces the clerical staff workload to ensure that the PROMs and PREMs responses are available to clinical staff in a timely manner. |
| Use of PROMs and PREMs | Clinical staff | Delegate a clinical staff member as a PROMs and PREMs champion in each clinic. They can liaise with new clinic staff members and provide a brief introduction and the available resources to use the PROMs and PREMs in the clinics. The PROMs and PREMs champions can check-in with the clinic team every month regarding updates and address any issues or concerns with long-term implementation. | Delegates key clinical staff members with supporting the clinic team during long-term implementation, particularly new clinic staff members. Regular communication and problem-solving support by the champions will promote long-term implementation. |

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