

# SMSPRO – Final Report

The Integrated Cancer Services are supported by the  
Victorian Government

July 2024

**Authorship** .....2

**Abbreviations** .....2

**Acknowledgements** .....3

**Key Messages** .....4

**Executive Summary** .....5

**Project Overview** .....6

Project Background .....6

Aim .....7

Objectives .....7

Governance .....7

Scope .....8

Methodology .....10

Deliverables .....11

Participant Recruitment .....12

**Project Outcomes** .....14

Patient responses and resulting escalations .....14

User Feedback .....18

**Budget and Expenditure** .....24

**Lessons and Challenges** .....24

**Recommendations** .....26

**Appendix** .....27

**References** .....44

# Authorship

This report has been prepared by Hannah Ryan-West (GICS Service Improvement Facilitator) and Kerry Davidson (GICS Director).

## Abbreviations

Abbreviation	Definition
BAU	Business As Usual
BHS	Ballarat Health Services
BRICC	Ballarat Regional Integrated Cancer Service
EGHS	East Grampians Health Service
GH - Ballarat	Grampians Health - Ballarat
GICS	Grampians Integrated Cancer Service
HREC	Ballarat Health Services and St John of God Healthcare Human Research and Ethics Committee
McGrath BCN	Breast Care Nurse
MOU	Memorandum of Understanding
PCN	Prostate Cancer Nurse
PCG	Project Control Group
PI	Principal Investigator
PRO	Patient Reported Outcomes
PROMs	Patient Reported Outcome Measures
SMS	Short Message Service
SMSPRO	Short Message Service Patient Reported Outcomes
SRH	Stawell Regional Hospital
WCC	Wimmera Cancer Centre

# Acknowledgements

Acknowledgements and gratitude to the following teams and individuals for their project contributions.

## GICS Program Team:

- Glenn Reeves
- Hannah Ryan-West
- Kerry Davidson.

## Ballarat Health Services and St John of God Human Research Ethics Committee (HREC):

- Ashleigh Clarke
- John Hand.

## Project Governance Group members:

- Steven Medwell      Director of Cancer Services - Grampians Health  
(*formally Operational Director - Medical Services and BRICC, BHS*)
- Ashleigh Clarke      Director Research Operations, Grampians Health - Ballarat  
(*formally Manager Research & Partnerships, BHS*)
- Liz McEncroe      Nurse Unit Manager, SJOG Ballarat
- Carmel O’Kane      Cancer Nurse Practitioner and Wimmera Cancer Centre Nurse  
Unit Manager
- Kerry Davidson      Director GICS
- Alan Crouch      Member of the GICS Consumer Advisory Group.

## Software Provider:

- *Personify Care* - who provided the online platform and analytics for this project.

## Clinical teams at pilot sites:

- East Grampians Health Service
- Wimmera Cancer Centre
- McGrath Breast Care Nurses (GH - Ballarat)
- Oncology Dietetics (GH – Ballarat)
- Prostate Cancer Nurses (GH - Ballarat)
- St John of God Hospital (Ballarat).

# Key Messages

This project was initiated in late 2019 in response to a perception and increasing literature on the value of incorporating Patient Reported Outcome Measures (PROMs) within clinical care delivery. Traditionally, patients commencing on cancer treatment are provided with a central point of contact and requested to advise treating teams if difficulties or concerns arise in relation to treatment or its side effects. For a variety of reasons patients do not consistently seek advice or assistance when needed, impacting on treatment delivery and ultimately patient outcomes.

In response to this gap, GICS sought to secure a software provider able to customise clinical questionnaires and responses for clinical teams with varying focus. Selection of these teams was based on demonstrations to several clinical teams across the region and then the self selection of those wishing to participate.

Initially 7 sites were recruited to participate in a pilot program, however, due to the effects of the COVID 19 pandemic, staffing challenges and competing priorities, progress of this project did not follow anticipated milestones. An iterative process was adopted, and modifications made along the way, resulting in 3 sites progressing to a full pilot of the SMSPRO project.

In total, 87 patients participated in SMSPRO across the 3 pilot sites over the two phases of this project.

Generalisation of findings is difficult due to the low numbers of patients participating in the study across all sites, though a substantial conclusion can be drawn from patient and staff feedback, that whilst useful, the introduction of SMS based patient reporting did not offer significant time saving or complement existing pathways of care to justify the cost of the intervention long-term.

# Executive Summary

The SMSPRO project trial was a novel concept that introduced an SMS-based communication platform with potential to substantially benefit staff and patients through enhancing staff efficiencies and improving communication with patients.

At the outset, it set out to understand the acceptability and feasibility of using online based questionnaires to improve communication between health service staff and community-based cancer patients living in the Grampians region.

Over the project duration, impacts of the Covid -19 pandemic, site staffing challenges, and project team alterations resulted in changes to the project timelines and project nuances were ultimately difficult to uphold.

Despite the challenges, most staff found the platform relatively easy to use, noting it was helpful in tracking patient symptoms and or problems while they were at home, with many staff also agreeing they would recommend the SMSPRO questionnaire to other cancer service providers. However, staff timely response to patients flagged as requiring urgent contact was dependent on staff logging in to check the system – which for participating staff was not routine, which may have resulted in the opposite of the intended purpose.

Patient participants mostly found the platform easy to use with the majority noting it made them feel better cared for and connected, noting they would recommend it to other patients.

An oversight at the project outset was the setting of an evidence-based target participant recruitment number, making generalisation of recommendations difficult. Furthermore, a method to measure the financial viability of such technology ongoing, which ultimately is required to determine feasibility of such a system was also not accounted for. In summary, despite staff and patient users overall accepting the SMSPRO approach, for similar projects it is essential to incorporate financial viability measures at the project outset to inform long term viability.

# Project Overview

## Project Background

It is undeniable that cancer and its treatments can have significant impacts on health status, quality of life and functioning of patients (Payne et al., 2023). Conventionally, when leaving hospital after treatment, people with cancer are commonly instructed by their care team to make contact if they experience health problems. Unfortunately, in many instances patients don't make contact as advised on occasion resulting in health deterioration requiring emergency department visits, increased stress for the patient and their family, as well as heightened risk for sub-optimal patient outcomes.

Pleasingly, in the last decade, innovative pro-active communication methods facilitated via electronic platforms have been introduced, enabling patients to report on their symptoms, and other aspects of their health and well-being in real time, while also allowing health professionals improved opportunity to intervene as required in a timely manner. These methods are referred to as a Patient Reported Outcome Measures (PROMs) or Patient Reported Outcomes (PROs).

PROs have become a popular method to improve communication between clinical staff and patients residing in the home, while also encouraging patients to take a more active role in their health. Research supports the benefits of this novel communication modality, indicating that the use of PROs in cancer care leads to improved communication, better symptom control, prolonged survival, and a reduction in hospital admissions and emergency department attendance (Ishaque et al., 2019; Locklear et al., 2017; Greenhalgh et al., 2018; Lordon et al., 2020; Yang et al., 2018).

In addition to the anticipated communication benefits of a PRO, the added potential for staff efficiency improvement provided sufficient rationale to explore the introduction of PROs for people with cancer in the Grampians Region.

The enhanced communication modality trialled in this project involves the health provider sending patients an SMS containing a link to a questionnaire asking them how they are feeling. Responses can then be accessed by staff in real time through an online portal for review and follow up (if required). Alerts can also be set up to highlight patient responses that need urgent attention. Pathways developed are based on existing care pathways with the only addition being the proactive nature of information seeking and the delivery mode of this messaging.

## Aim

To assess the acceptability and feasibility of using online based questionnaires to improve communication between health service staff and community-based cancer patients living in the Grampians region.

## Objectives

### Primary Objective:

To assess patient and health service acceptability and feasibility of using an SMS based PRO system to track patient progress whilst residing at home after cancer treatment.

### Secondary Objective:

To understand the proportion of patient responses that are considered to be high, medium and low priority as per the SMSPRO staff response escalation logic.

## Governance

Project governance was achieved through the establishment of a Project Control Group (PCG) comprising a Ballarat Health Service (BHS) executive, a BHS Ethics Consultant, a Grampians Integrated Cancer Service (GICS) Consumer Advisory Group member, Strategic Director of GICS and a Cancer Nurse practitioner for the wider Wimmera region.

The committee functioned to monitor study progress and develop strategies to ensure timely project completion and dissemination, while also working to collaboratively explore and resolve issues and concerns relating to intellectual property and the use of a third-party provider external to the health service.

The first governance group meeting occurred on 14 December 2020 and Terms of Reference for the committee were developed and endorsed by the group (Appendix A).

Soon after this first meeting, the PCG believed the original 'easyPRO' project name would not give patients clear representation of what the survey pertained to, as such the project was soon after renamed 'SMSPRO'.

Working groups were additionally convened with staff representation from each of the pilot sites meeting on a regular basis to inform project implementation.

This project involved the introduction of a new technology and subsequent ethics approval was sought and granted, HREC 75057 (Appendix B), by the Ballarat Health Services and St John of God Healthcare Human Research Ethics Committee (HREC) on the 17 August 2021.

## Scope

SMSPRO site selection was achieved through presenting and demonstrating the technology to clinical teams across the Grampians Region. 7 sites expressed interest in piloting the technology and were subsequently recruited to the study:

Grampians Health - Ballarat (formerly Ballarat Health Services - BHS)

1. Specialist Prostate Cancer Nursing Services
2. McGrath Breast Care Nursing Service
3. Oncology Dietetics

Grampians Health - Horsham (formerly Wimmera Health Care Group - WHCG)

4. Wimmera Cancer Centre (WCC)

East Grampians Health Service (EGHS)

5. Day Oncology Unit

Grampians Health – Stawell (formerly Stawell Regional Health - SRH)

6. Day Oncology Unit

St John of God Healthcare - Ballarat

7. Chemotherapy Day Unit (Anam Cara)

Although the initial project proposal was to involve 7 sites across the Grampians region, due to time constraints and staffing deficits, only the below 3 sites were able to proceed:

- McGrath Breast Care Nursing Services
  - Specialist Prostate Cancer Nursing Services
  - Wimmera Cancer Centre
- Grampians Health - Ballarat  
Grampians Health - Ballarat  
Grampians Health – Horsham

### Inclusion Criteria:

Inclusion criteria varied across the sites and was customised based on clinical activity provided and team preferences.

Site	Inclusion Criteria
Prostate Cancer Nursing Ballarat	People diagnosed with prostate cancer, under the care of a Medical Oncologist that have been referred to the Ballarat Specialist Prostate Cancer Nurses during the study window.
McGrath Breast Care Nursing Services - Ballarat	People diagnosed with breast cancer with curative intent that have been referred to the McGrath Breast Care Nurses during the study window.
Wimmera Cancer Centre	People commencing chemotherapy treatment within the study window.

*Table 1. site inclusion criteria*

Exclusion Criteria:

The below exclusions were common to each of the pilot sites:

1. Patients that do not own a smart phone
2. Patients that require an interpreter \* (non-English speaking)  
*\* Funding did not allow for questionnaire translation.*
3. Patients lacking capacity to give informed consent

Site specific exclusions were as below:

<b>Site</b>	<b>Exclusion Criteria</b>
Prostate Cancer Nursing Pilot	Patients diagnosed with prostate cancer who were under care of a Radiation Oncologist
McGrath Breast Care Nurses - Ballarat	Patients diagnosed with Breast Cancer who had metastatic disease or were private patients

*Table 2. site exclusions*

## Methodology

Project Phase	Deliverable
Secure technology solution	The vital component of this project was engagement of a digital platform provider to support the PRO questionnaire process. Negotiations were initially undertaken with 3 providers, ultimately engaging Personify Care to provide the technology due to platform usability, safe and secure data storage, customer service and affordability.
Pilot Site Selection	In partnership with Personify Care mock questions were developed for site demonstration purposes. Meetings were initiated with 17 Oncology clinical teams across the Grampians Region including Day Oncology Units, Care Coordinators and Allied Health teams. Based on these interviews, 7 sites were recruited to participate in the pilot.
Create custom prototype for each site	Following the engagement of Personify Care, 6 months was spent liaising with sites to design the patient information and consent forms (Appendices C & D) along with the questionnaire process (Appendix E) and questionnaires that would be sent to patients (Appendices F, G & H). During this time designing and assigning escalation logics (flag trigger system) was also undertaken so clinicians could be notified accordingly if patient contact was required following their question responses (Appendix I). Additionally, system functionality was trialled with site staff to identify any issues requiring resolution prior to SMSPRO going live.
Training and Launch	One-on- one training, the development of a written training manual and access to ongoing support throughout the pilot was provided
PDSA Cycle 1	In response to ongoing challenges in progressing the project, change readiness assessments were undertaken. Sites interested and able to be supported to move forward were collaborated with to review methodology and tools. Amendments were made to individual site questionnaires to reduce challenges to recruitment and to target suggested interventions to a more refined cohort of patients in some sites
PDSA Cycle 2	Amended questionnaires were used along with refined participant recruitment process.

Table 3. project methodology

## Deliverables

Project deliverables and milestones included:

Description	Deliverable	Due Date
Research and identification of software provider	Competitive tender process initiated	Feb 2020
Procurement and contracting	Contract delivered – Personify Care engaged as software provider	March 2020
Software demonstration	Demonstrations delivered to 17 clinical teams across the region	November 2020
MOU's established	MOU's finalised for 7 sites	November 2020
Project Control Group established	First meeting held	December 2020
Customised questionnaire and response matrix developed	Developed for each participating site	May 2021
Software training	Face to face training delivered to all users	May 2021
Ethics approval	BHS SJOG HREC Ethics approval	May 2021
PDSA Cycle one	Launched in 4 of 7 sites	June to Nov 2021
Change readiness	Assessments carried out for each site	Nov 2022
PDSA Cycle 1 analysis	Analysis and report completed	July 2023
Ethics amendment	Streamlining of consent process	July 2023
Questionnaire and eligibility amendments made	Implement recommendations arising from PDSA One	August 2023
PDSA cycle two	8-month pilot launched in 3 sites	September 2023
PDSA cycle two analysis	Evaluation and final report	July 2024

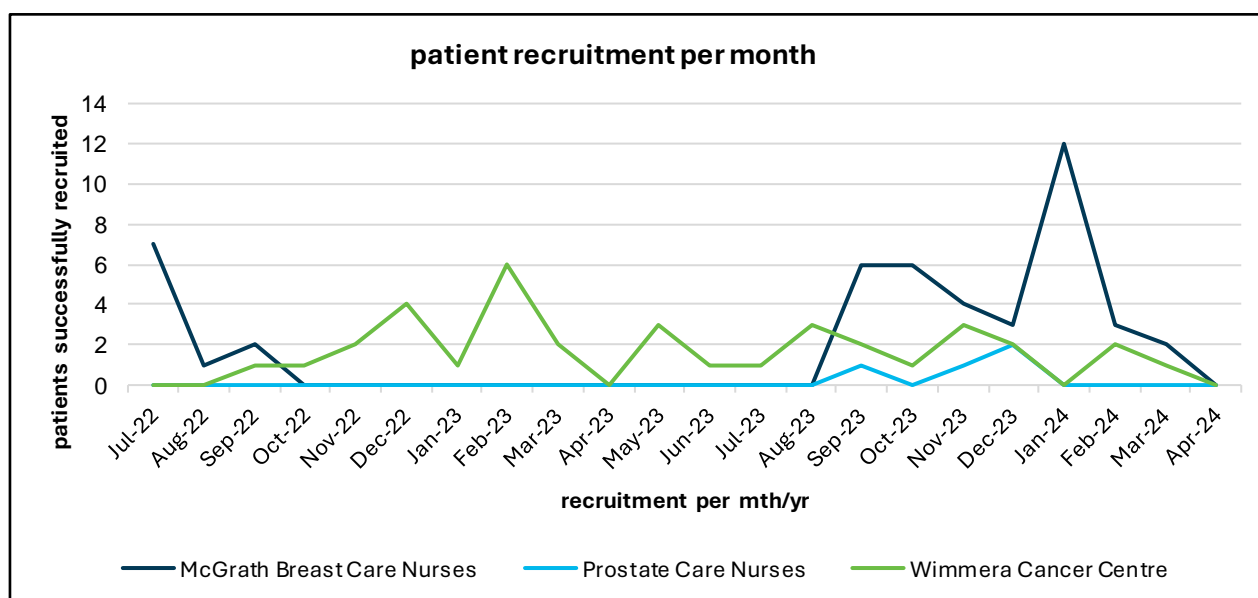
*Table 4. project timeline & deliverables*

## Participant Recruitment

Pilot Site	Patients invited to participate (sent SMS invitation)	Patients accepting invitation (% accepting invitation)
McGrath Breast Care Nurses	53	44 (83%)
Prostate Cancer Specialist Nurses	5	4 (80%)
Wimmera Cancer Centre	45	39 (87%)
<b>Total patients</b>	<b>103</b>	<b>87 (84%)</b>

Table 5. participant recruitment

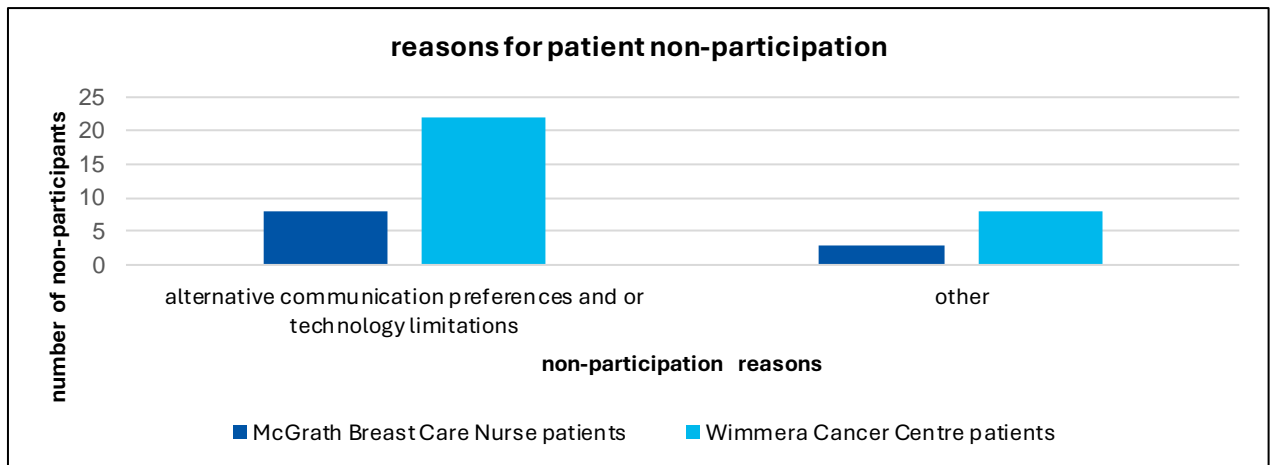
Patient recruitment for SMSPRO overall was successful (n=87), however recruitment numbers for the Prostate Cancer Specialist Nurses was noticeably fewer. The major contributing factor for this was the concurrent implementation of a new process to improve patient follow-up and contact. This process was introduced during the project commencement delay period resulting from Covid -19 impacts. Subsequently, when SMSPRO recruitment resumed, there was a reluctance to recruit patients due to work duplication and perceived minimal benefit in what it would offer for the patient cohort focused on.



Graph 1. Monthly SMSPRO participant recruitment

Recruitment of participants over the project duration was most consistent for the Wimmera Cancer Centre (WCC), while for the other sites, staffing challenges and competing demands attributed to a lengthy period of no recruitment as indicated between October 2022 and August 2023.

Non-participation themes:



*Graph 2. SMSPRO patient non-participation reasons*

Across both phases of the project, staff in the McGrath Breast Care Nurse and Wimmera Cancer Centre sites recorded patients who would have been eligible, though did not participate in the pilot and the associated reason for this. 41 reasons for patient non-participation were captured between the Wimmera Cancer Centre and Breast Cancer Nurse Specialist sites, with 68% (n = 30) of people declining due to alternative communication preferences and or technology limitations. Of these patients, it was noted the majority (n=22) had preference for direct contact via mobile phone, while technology limitations included such things as poor phone/internet reception and reduced digital literacy. Other reasons for non-participation included such things as patients noting they had sufficient external support, patient refusal with no explanation and nursing staff deeming a phone call a more suitable option due to individual patient situational factors.

To note, patients who were imminently moving or having care transferred were noted by staff as non-participants, however given these patients would have become ineligible these numbers were not included in non-participation data.

Non-participation reasons for Prostate Cancer Nurse Specialist patients were not recorded.

# Project Outcomes

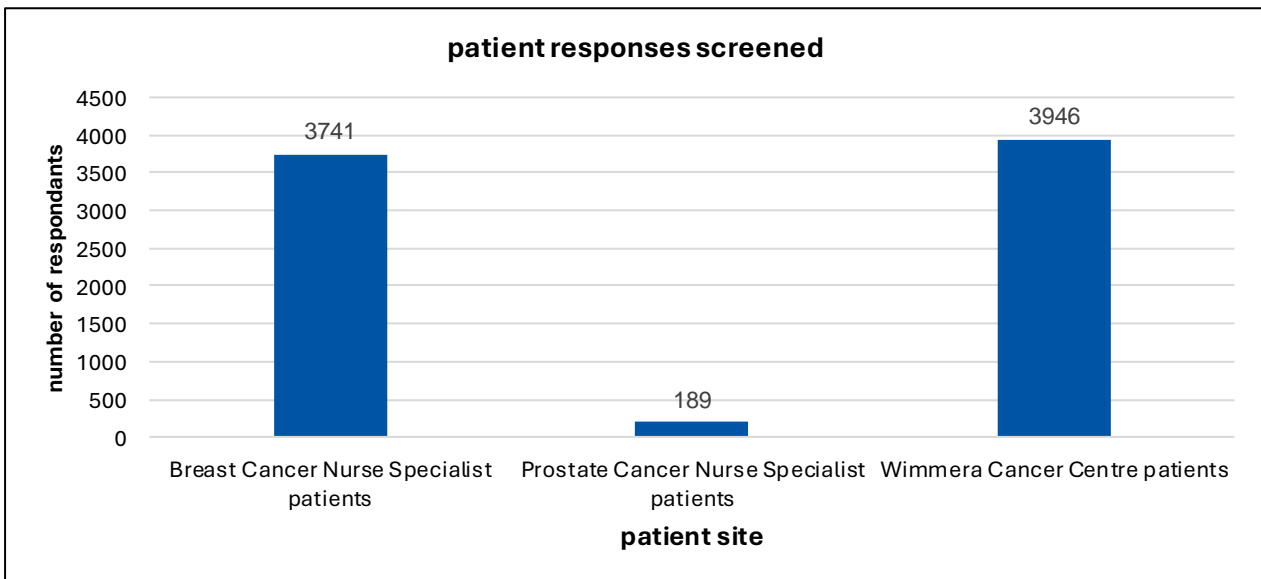
The below information details project findings including resulting escalations from patient responses as well as user (patients and staff) acceptability of SMSPRO.

## Patient responses and resulting escalations

### Patient responses screened through PROMs platform

The total patient responses screened pertains to the total number of questions asked and screened via SMSPRO over the project duration.

Across the 3 participating sites there were a total of 7876 patient question responses screened from 87 patients. As part of the screening, patient responses were assigned a flag according to the flag trigger/staff response matrix (Appendix C, D & E), indicating if staff were required to contact the patient, and if so within what time period.



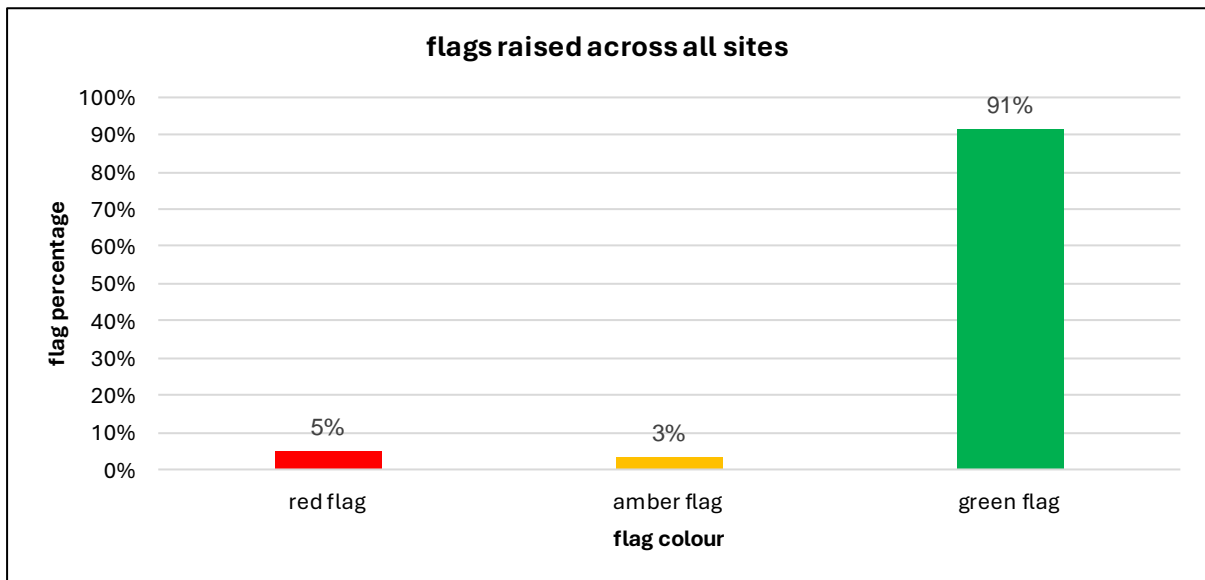
Graph 3. Patient responses screened through SMSPRO

### Care escalations/flags raised per site

The flag trigger/staff response matrix was collaboratively designed between the Principal Investigator, the clinical teams and personify care and customised per site (Appendices C, D & E), with flags assigned representing the following:

Flag colour	Response priority	Action required
green/no flag	low	no action required
amber	medium	call participant within 5 working days
red	urgent	call participant ASAP

Table 6. flag explanation

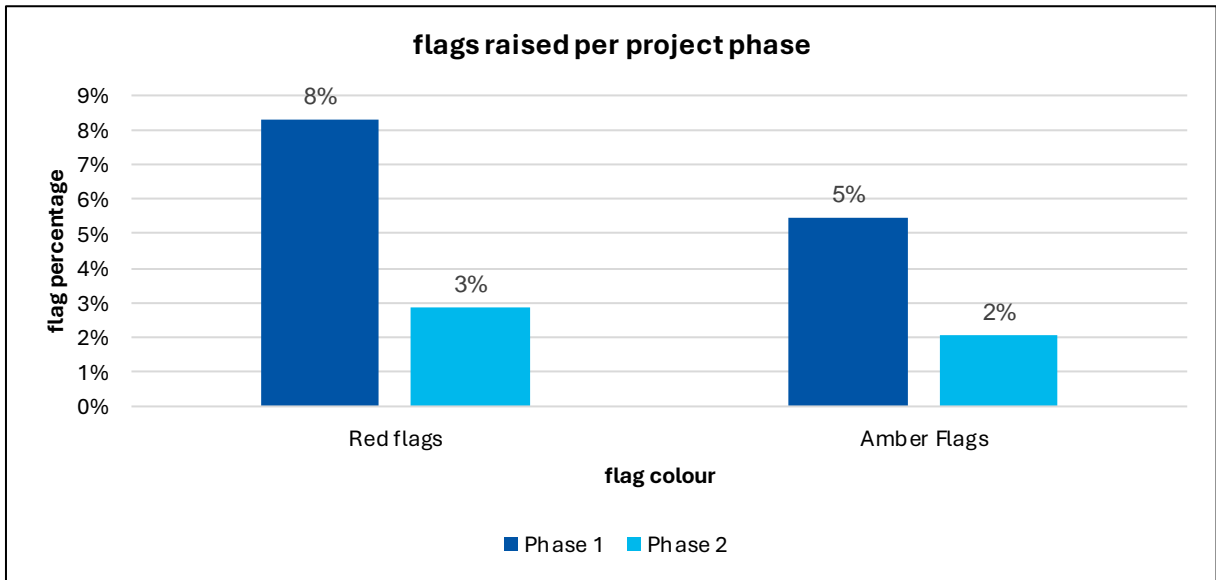


*Graph 5. Percentage of flags raised across all sites*

Over the course of the project, from the 7876 responses across the sites, the overwhelming majority of responses (n= 7200) received a green flag (91%), indicating no action was required. Amber flags were raised on 273 occasions (3%), requiring staff to contact patients within 5 days, while 403 red flags were raised (5%) indicating staff need to contact patients as soon as possible.

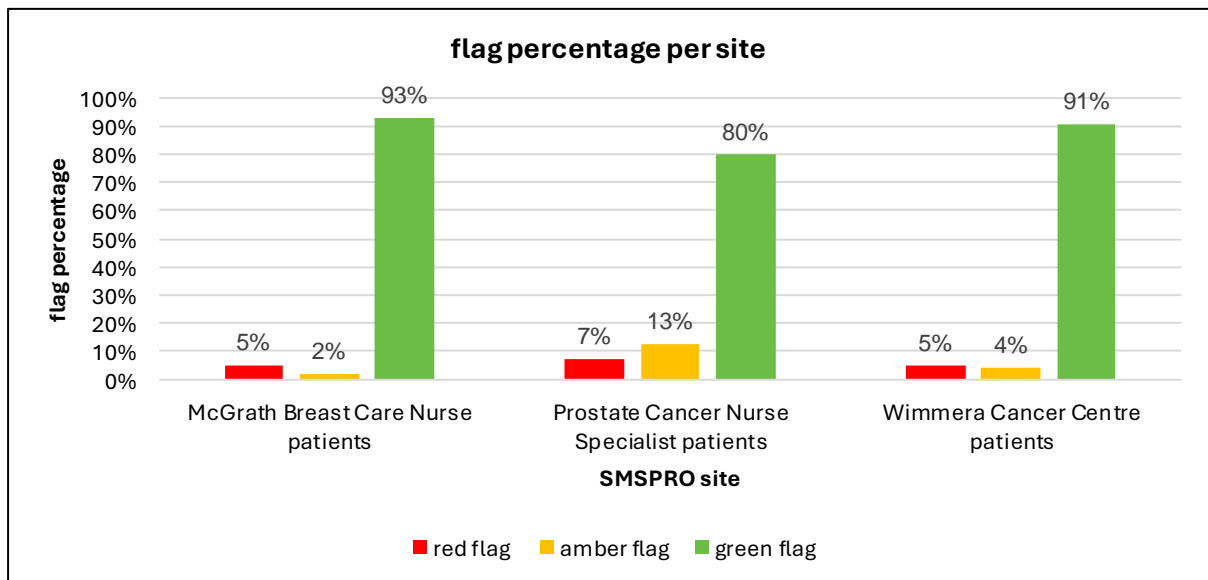
Of the red flags raised across the sites, 193 resulted from McGrath breast care patients (48%), 196 from Wimmera Cancer Centre patients (49%) and 14 from prostate cancer patients (3%).

Amber flags were activated by 171 patient responses from Wimmera Cancer Centre (63%), 78 from McGrath Breast Care patient responses (29%) and 24 from prostate cancer patient responses (8%).



Graph 6. Flags raised per project phase

As noted earlier in this report, slight adjustments were made to the patient questionnaires during Phase 1, as patients at times were reporting on chronic ailments which did not require the resulting escalations. As can be seen above, this had a positive impact resulting in the decline of patient responses requiring action (red or amber flag) in phase 2 of the project.

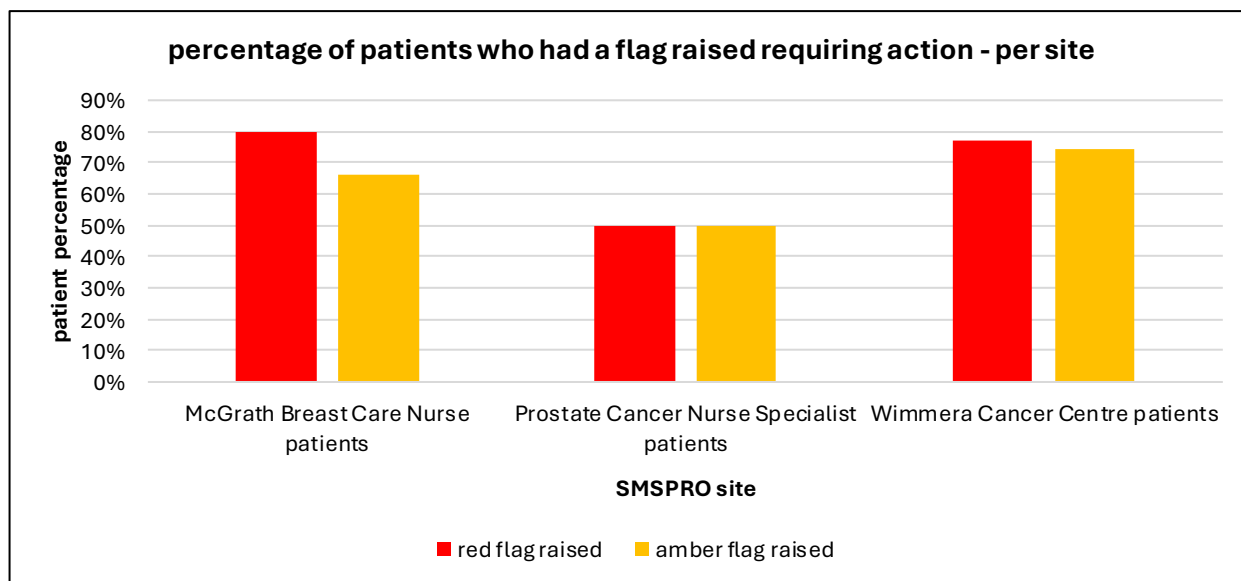


Graph 7. Resulting flags raised from response screening.

Looking at the percentage of flags raised per site, as shown in the graph above, 5% of McGrath Breast Care responses received a red flag (n = 193), while 2% received an amber flag (n=78).

Of the prostate cancer nurse specialist responses 7% received a red flag (n=14) while 13% received an amber flag (n=24). For responses coming from WCC 5% of responses were assigned a red flag (n =196) and 4% an amber flag (n=171).

As evidenced by green flags above, the overwhelming majority of patients (n=7200) on treatment did not require supportive intervention, thereby allowing clinician resourcing and responses to focus on those who required them, while giving added reassurance to clinical teams that patients not flagged did not require contact to be made.



Graph 8. Percentage of patients with flags activated.

Of the SMSPRO participants, some may have received multiple red or amber flags over duration they participated, as determined by their question responses.

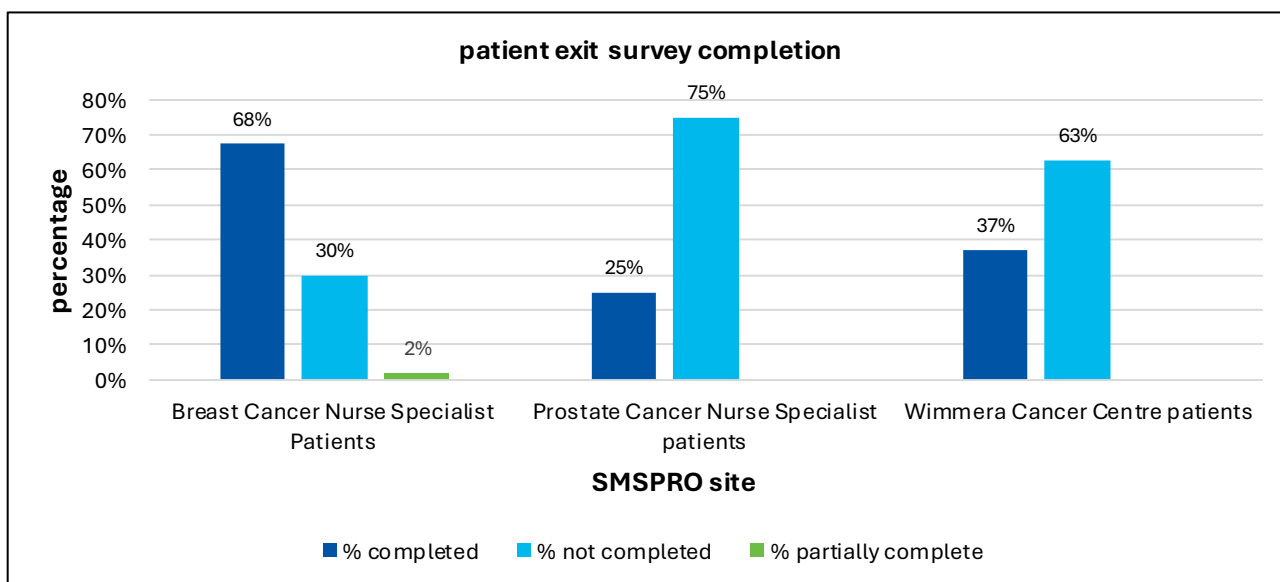
Of the McGrath Breast Care Nurse patient cohort, 35 patients (80%) received a red flag at some stage during the study, while 29 (66%) received an amber flag. 2 patients (50%) under the care of Prostate Cancer Nurse Specialists had an amber flag raised, while the same number (n=2) also had red flags raised. From the Wimmera Cancer Centre 30 (77%) patients had a red flag activated while 29 (74%) had an amber flag activated.

## User Feedback

To obtain information on the functionality and benefits of the SMSPRO platform, an exit survey was undertaken for both staff (Appendix J) and patient participants (Appendix K).

The patient survey was conducted as a questionnaire delivered in the same format as other SMSPRO questionnaires (vis SMS), whereas the staff exit survey was carried out face-to-face.

### Patient Feedback on using SMSPRO

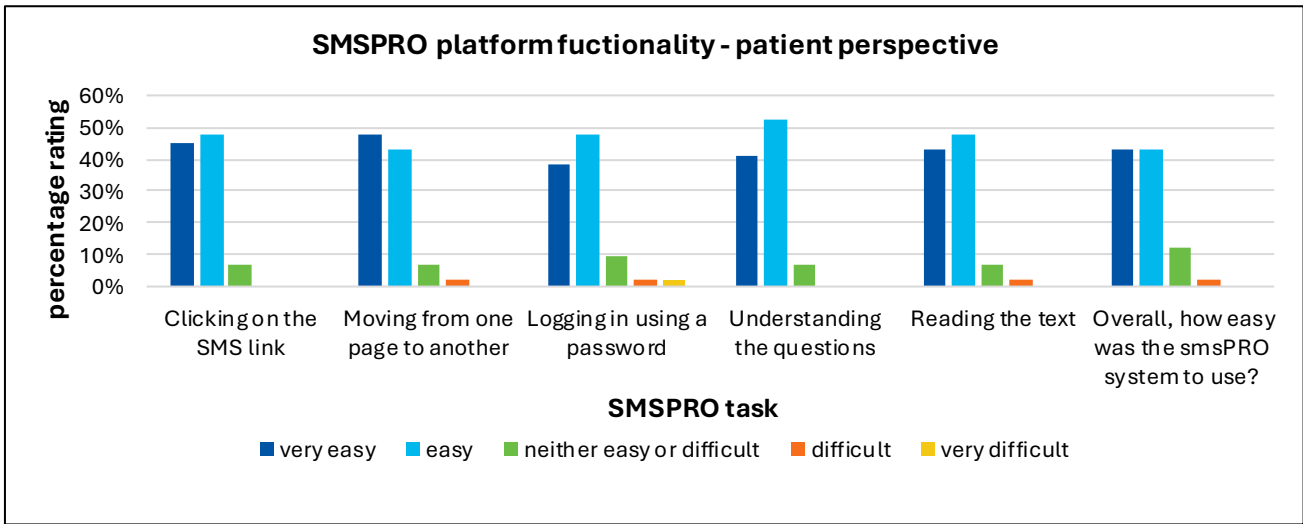


Graph 9. Patient exit survey completion rates.

Across the 3 participating sites, a total of 79 patient exit surveys were sent, with a combined completion rate of 51% (n = 41). Patients under the care of the McGrath Breast Care nurses had the highest completion rate (68%), likely due to them receiving a phone call prior, advising them of the impending survey and the importance of its completion.

A complicating factor in analysing feedback from respondents was deciphering and filtering of the exit surveys from patients of the Wimmera Cancer Centre.

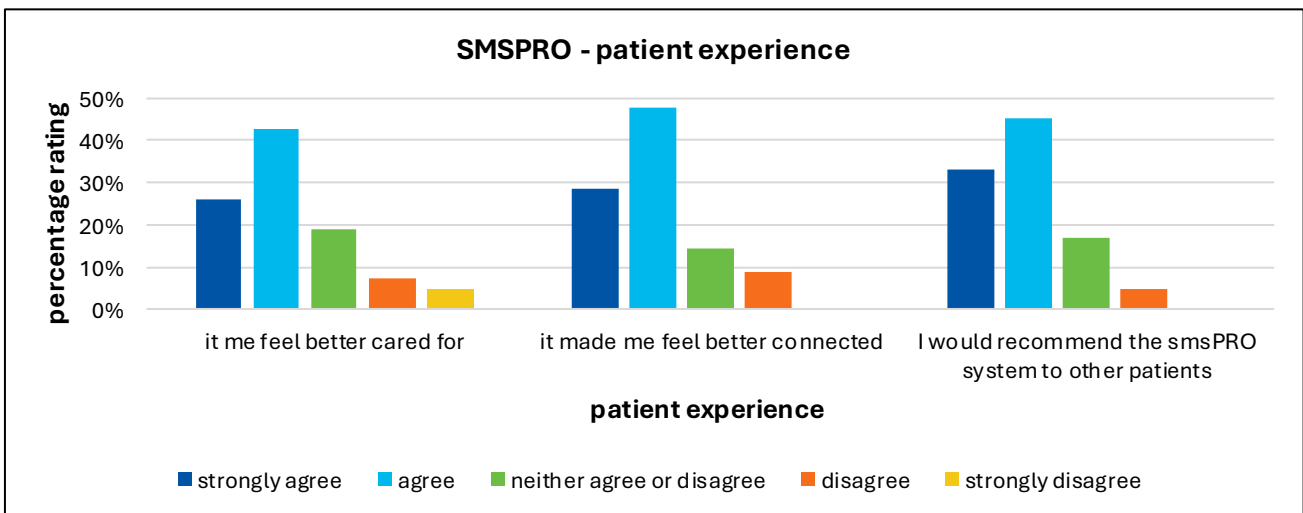
As a result of these confusions 51% of patients from Wimmera Cancer Centre received more than one exit survey (n=35) and 33% of those patients completed the survey more than once (n=6). In these instances, only the most recent survey responses were included in the exit survey analysis. Further details on this situation are included under the project challenges section.



Graph 10. SMSPRO patient usability perspective

Regarding SMSPRO platform usability, 86% of respondents across all sites found it easy (n=18) or very easy (n=18) to use. With participants across sites noting reasons for this being that the platform was quick & easy to understand, easy to navigate, questionnaires were quick to complete and relevant to their treatment and wording easy to understand.

For patients who responded they had difficulties (n=2) this was associated with difficulty remembering their platform password.



Graph 11. SMSPRO patient experience

Reflecting on how the SMSPRO method of communication made SMSPRO patient participants feel, the majority agreed it made them feel better cared for (n=11 strongly agree, n=18 agree) and better connected (n=12 strongly agree, n=20 agree).

In responding to whether patient participants would recommend the SMSPRO system to other patients, again most patients agreed (n=19) or strongly agreed (n=14) they would recommend it. The survey however did not offer this group of participants opportunity to expand on their responses.

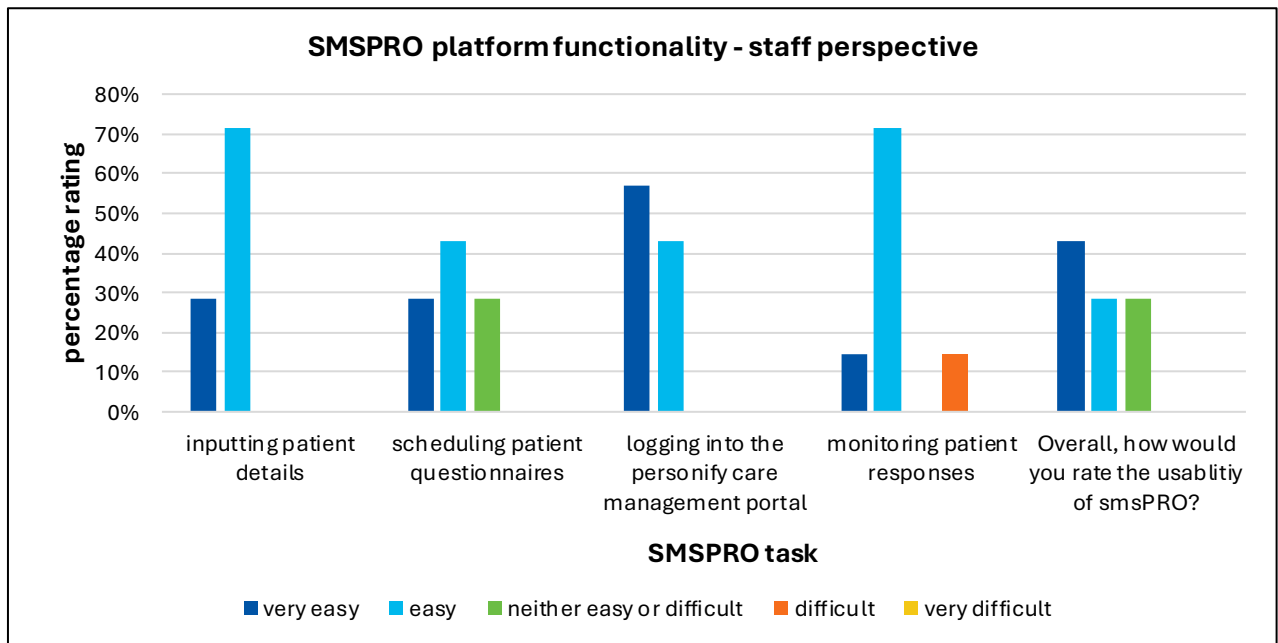
## Staff Feedback on using SMSPRO

Across the 3 participating sites, there were a total of 13 staff (excluding principal and associate investigators) who were registered to access and interact with the SMSPRO platform. The McGrath Breast Care & Prostate Cancer teams each had 2 staff registered (100% of their staff), while the Wimmera Cancer Centre had 9 staff registered.

Of the registered staff, 100% of staff from the McGrath Breast Care and Prostate Nurse Specialist teams interacted with the platform, while 78% (n=7) of Wimmera Cancer Centre registered staff interacted with the platform.

7 staff from the 3 sites participated in the staff exit survey, comprising 1 Breast Care Nurse, 2 Prostate Nurse Specialists and 4 Wimmera Cancer Centre Nurses. To note, nurses providing feedback from the WCC were the predominate users, with the other 3 registered staff interacting minimally with the SMSPRO platform.

In person interviews were conducted with the McGrath Breast Care and Prostate Cancer Nurse Specialists, while interviews with the WCC staff were conducted using MS teams due to distance of location.



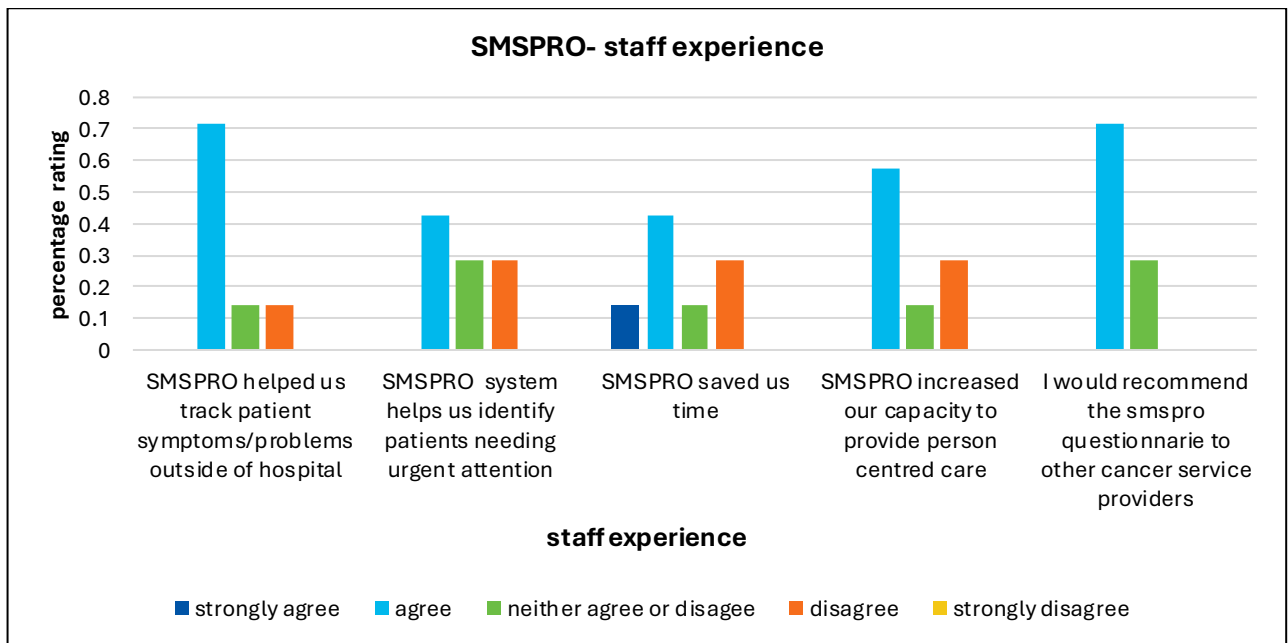
Graph 12. SMSPRO staff usability perspective

While there were differing views on the overall usability of SMSPRO, 43% agreed it was very easy (n=3) to use while others felt it was easy (n=2) or neither easy or difficult (n=2) to use. There was however majority agreeance (n=5) that inputting of patient details and monitoring of patient responses was easy, while logging into the platform was perceived by all respondents to be very easy (n = 4) or easy (n=3).

For staff who found it neither easy nor difficult to schedule patient questionnaires (n=2), reasons for this were associated with initial platform teething problems in the automatic scheduling of questionnaires which did not necessarily line up with patient treatment requirements, thus requiring additional surveys to be manually sent. This issue was however addressed early after the project launch.

For the single staff member reporting that monitoring of patient responses was difficult, this was due to their infrequent use of the system and associated increased effort required to reset forgotten passwords and navigate the platform.

While the platform offered the ability to upload patient survey responses to the medical record no staff who were interviewed used this functionality, instead making a manual note of any relevant responses and interventions carried out.



Graph 13. Staff perspective on the impact of SMSPRO on patient care and contact

It was widely agreed (n=5) by staff across the participating sites that SMSPRO was helpful in tracking patient symptoms and or problems while they were at home, with 71% of staff (n=5) also agreeing they would recommend the SMSPRO questionnaire to other cancer service providers.

Respondents however were divided in their opinions on whether SMSPRO helped identify patients needing urgent attention, saved them time or increased their capacity to provide person centred care.

### Time saving

While 57% of respondents strongly agreed (n= 1) or agreed (n=3) that SMSPRO helped save them time, 43% of participating staff were neutral on their opinion(n=1) or did not feel it saved them time (n=2).

For staff in agreeance there was recurring conversation noting it allowed them to be more efficient with their time as it assisted prioritising who did and didn't need to be called, as well as allowing staff to pre-prepare specific material prior to patient interaction.

Of the staff member who was neutral in their opinion, although they felt SMSPRO was time saving as it identified patients who potentially didn't need to be called, early on some unnecessary flags were generated resulting in unnecessary phone calls, however as noted previously, this was addressed and rectified by altering the questionnaire following phase 1 feedback.

Staff members who felt SMSPRO did not save them time were from the Prostate Cancer Nurse Specialist site (n=2). This response was due to perceived work duplication resulting from processes that had been implemented to improve contact with their patients, however comment was made that it may have been time saving had it been introduced for a different patient cohort under their care.

## Person centred care

Of the 4 staff (57%) who agreed SMSPRO increased their ability to provide person centred care, rationales included that SMSPRO provided opportunity for staff to pre-emptively gather relevant materials prior to contacting the patient, thereby improving timely information provision, while also providing patient reassurance knowing staff would be in contact if concerns were flagged.

For the remaining staff who were neutral (n=1) or disagreed (n=2), this was primarily due to existing processes already being implemented to improve person centred care.

## Identifying patients needing urgent attention

Staff feedback was mixed as to whether SMSPRO assisted to identify patients requiring urgent attention, with 43% of staff (n=3) agreeing it assisted, 29% remaining neutral (n=2) and the same percentage (n=2) disagreeing.

Staff agreeing with the statement noted it allowed them to be more efficient with their time, specifically, identifying who needed to be called urgently, and who could wait.

For staff who were neutral on their responses, it was noted that although SMSPRO successfully flagged patients requiring urgent attention, whether this was acted on urgently was dependent on the staff member going into the system to check flagging and undertake the recommended action. Additionally, if a flag was raised late Friday the response would not be urgent. In these situations, respondents felt a staff-initiated phone call on patients they were concerned about was more efficient.

For those staff who disagreed with SMSPRO assisting to identify patients requiring urgent attention, there was comment that the risk of these questionnaires is that some patient's responses may not necessarily reflect what they need - some just want a chat. Thus, patient suitability assessment for SMSPRO was quite important as some questions were not specific enough and open to interpretation, thereby potentially initiating/not initiating a flag when it was/wasn't needed. The remaining respondent who also disagreed did so due to the platform being a perceived hinderance - as it was not part of their regular routine and was related to them having to remember to go into the system to check participant responses.

## Budget and Expenditure

Expense	Project Milestone	Budget	Comment
Personify Care	Phase One	\$20,000	Access to software platform, development training and support
	Phase Two	\$20,000	
	Total	\$40,000	

Table 7. project expenses

## Lessons and Challenges

### Lessons

#### Consideration of financial implications

The initial project design lacked focus on the financial implications of introducing an SMS based PRO in the clinical sites. Efforts were made to amend the design of the project to capture this information though were not successful in obtaining meaningful data to inform service planning, due to late stage in the project this was factored in.

#### Having full understanding of technology capabilities

It is noted that the full scope of the platform was not utilised with the possibility of using email messaging for patients discovered at the latter phases of the project. It is possible that this would have enabled more patients to participate in the study.

Though included as a consideration in the planning of this project lower emphasis was placed on supporting staff to utilise the function to upload the questionnaire to the patient's central medical record. This resulted in missed opportunities to address the duplication of effort for staff who manually entered notes capturing the outcome of the survey and their associated response.

#### Ensuring an evidence-based target participant number

For a feasibility study such as this, having an evidence-based participant recruitment target to ensure the data collected is representative of its intended purpose would enhance the validity of the study as well as enhancing reliability of recommendations generated as a result of the study.

#### SMSPRO Questionnaire Distribution / mode of delivery

At the latter stages of the project, it became apparent that the scope of the project had been limited to SMS based delivery only. This resulted in limitations to the study whereby patients could have also received the questionnaire via email in situations where there were challenges to them receiving and responding to the questionnaires via SMS.

The study also did not explore the use of a third party known to the patient to offer the required assistance e.g. an adult son or daughter in the case of an elderly patient without the ability to navigate the SMS process.

## **Challenges**

### Consent Process

The original patient consent process occurred over two face-to-face meetings between patients and staff, over the course of which the patient was informed about the study and provided a Patient Information Statement to take home and read. During the second meeting, staff could answer any questions and the patient was asked to consent.

Covid -19 restrictions created challenging circumstances in how staff and patients interacted, thus making the ethics approved process of obtaining patient consent face-to-face unsuitable. Additionally, several patients and staff were frustrated with the 2 step -appointments for consent.

These barriers were addressed, and changes applied in consultation with the sites, Personify Care and the ethics team when the project entered Phase 2. The resulting amended process entailed the consent process occurring digitally via an SMS at home 3 days after the initial meeting, while still providing the patient opportunity to ask questions.

It can also be surmised from patient decline reasons that the requirement to obtain patient consent may have deterred some patients from participating in the study.

### Unanticipated increased staff workload due to flags being triggered

All sites initially reported a higher than anticipated level of contact with patients due to flags being triggered by patients reporting known or long-standing issues that were not necessarily in need of follow up.

In response, a qualifying question was added, asking patients to indicate whether issues identified were “new or unmanaged” and whether they would like to have staff contact them. This restructuring resulted in improved suitability of flags that were raised and enhanced appropriateness of patient contact as shown in the flags raised per project phase graph (graph 6).

### Changes to patient cohorts (end of PDSA1)

Having briefly used SMSPRO, the specialist Prostate Cancer Nurses narrowed focus to patients undergoing hormone therapy, thereby excluding those on active surveillance, post-surgery or post-radiation.

Rationale being this would assist lower the patient volume and reduce time commitment required from staff.

### Principal Investigator Changes – project continuity

Due to long term leave and the subsequent resignation of the Principal Investigator/GICS project lead, issues were encountered in terms of maintaining project momentum in relation to project continuity. The project faced multiple barriers and the response to these barriers as they arose led to an iterative project design. Some of the nuances of this project have been lost as a result.

### Eliciting staff feedback

In order to maximise staff feedback on SMSPRO, the intended staff exit survey was slightly amended. These amendments included the survey taking place in person or virtually (as opposed to online), addition of respondents site location, as well as allowing opportunity for open ended responses (see Appendix J for amended survey). In order for these changes, an ethics amendment was required, and this took time in undertaking the associated documentation for this to be approved.

### Filtering of Duplicate Patient Exit Surveys

From the Wimmera Cancer Centre, 51% of patients (n=18) were inadvertently sent duplicate (2 or 3) exit surveys. Of these patients, 33% (n=6) completed an exit survey more than once, with differing responses. The impact of this situation required significant time investment from the principal investigator to liaise with Personify Care to reformat and analyse data to obtain the relevant responses.

### Project Governance

There were gaps in the frequency of convening between the principal investigator, sites and governance group which led to sub-optimal input to progress the project and address issues that arose in a timely manner.

## Recommendations

1. At the project outset determine how economic benefits will be measured to understand financial viability of a similar system long term
2. Ensure that participant recruitment targets are set, and in doing so ensure a quantifiable method is utilized.
3. Explore if the system under trial is a viable model to be integrated into usual care pathways ongoing
4. Ensure governance group and site meetings are scheduled at pre-determined intervals to maximise opportunity to address project challenges in a timely manner
5. Ensure broad system capabilities are understood in detail prior to project initiation to optimise participation.

# Appendix

## Appendix A: Project Control Group – Terms of Reference

### The easyPRO Project

#### Project Control Group Terms of Reference

##### Background

Currently, patients suffering cancer-related symptoms or treatment related side effects are instructed to contact their treatment team. The problem is that many patients, for a variety of reasons, don't make this call when they should. An increasing body of symptom management research has demonstrated the effectiveness of using a more proactive approach to stay in touch with patients and monitor their symptoms and supportive care needs. GICS plans to run a 12-mth trial providing access of a PRO platform to a number of health service entities within the Grampians region. The purpose of this project is to make it easy for oncology service providers, within the Grampians region, to trial the use of SMS based PROMs to monitor patient symptoms and/or supportive care needs.

##### Purpose

The easyPRO Project will establish a Project Control Group to ensure successful project implementation, and stakeholder engagement.

##### Objectives

- Approve the Project Plan for the Project
- Approve the trial participants and sub-projects
- Monitor the Service Agreement with the vendor, Personify Care
- Monitor progress of the Project Plan and problem solve when required
- Monitor project expenditure
- Establish and monitor a Project risk register and escalate risks accordingly
- Ensure appropriate and timely reporting to the GICS Governance Group
- Oversee the evaluation of the project
- Advise on and ensure effective stakeholder engagement

##### Key Relationships

DHHS, Wimmera Health Care Group, Stawell Regional Health, Eastern Grampians Health Service, BHS/BRICC/BAROC, St John of God Ballarat, GICS

##### Meeting Frequency

Meetings will be held monthly or as decided by the Project Steering Group.

##### Agendas

The Project Manager will prepare the agenda for circulation 1 week before the meeting.

##### Minutes

Minutes will be recorded by a GICS representative and distributed to members of the Project Steering Group within one week of each meeting to enable follow up of actions to occur.

##### Membership

- Steve Medwell, Operational Director - Medical Services and BRICC, BHS
- Ashleigh Clarke, Manager Research & Partnerships, BHS
- Liz McEncroe, Nurse Unit Manager, SJOG Ballarat
- Carmel O'Kane, Cancer Nurse Practitioner and Manager, Wimmera Cancer Centre
- Kerry Davidson, Acting Strategic Director, GICS
- Alan Crouch, Member of the CICS Consumer Advisory Group.

## Appendix B: Ethics Approval letter



Ballarat Health Services and St John of God Healthcare Human Research Ethics Committee

### ETHICS APPROVAL

Mr Glenn Reeves  
1 Drummond St (BRICC)  
Ballarat Victoria 3350

17 August 2021

Dear Mr Reeves,

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<b>Project Title</b>	The smsPRO project
<b>Project ID</b>	75057
<b>Review Reference</b>	HREC/75057/BHSSJOG-2021-273713(v2)
<b>Local Reference Number</b>	

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I am pleased to advise that the above project has received ethical approval from Ballarat Health Services and St John of God Healthcare Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007), and all subsequent updates, and in accordance with the *Note for Guidance on Good Clinical Practice* (CPMP/ICH/135/95), the Health Privacy Principles described in the *Health Records Act 2001* (Vic) and Section 95A of the *Privacy Act 1988* (and subsequent Guidelines).

#### Participating Sites

Ethical approval for this project applies at the following site(s):

Site	State/Territory
Ballarat Health Services	VIC
Wimmera Health Care Group	VIC
East Grampians Health Service	VIC
Stawell Regional Health	VIC

#### Approved Documents

The following documents have been reviewed and approved:

Document Type	Document Name	Date	Version
HREA Application form	HREC/75057/BHSSJOG-2021-273713(v2)	22/07/2021	1
Victorian specific module (VSM)	Victorian-specific-module_Version 1	09/04/2021	-
Protocol	smsPRO_Protocol_version 2.0	09/04/2021	1

Protocol (tracked)	smsPRO_Protocol_version 2.0 tracking changes	09/04/2021	1
Peer review	Peer review_SMSPro_AWS	06/04/2021	-
PICF - BHS	Participant Information Form - Version 2.0	18/06/2021	2
PICF - BHS (tracked)	Participant Information Form - Version 2 - track changes	18/06/2021	2
PICF - BHS - Oncology Dietetics	Participant Information Form - Version 2.0 - Oncology Dietetics	18/06/2021	2
PICF - BHS Specialist Breast Cancer Nurses	Participant Information Form - Version 2.0 - Specialist Breast Cancer Nurses	18/06/2021	2
PICF - BHS - Specialist Prostate Cancer Nurse	Participant Information Form - Version 2.0 - Specialist Prostate Cancer Nurse	18/06/2021	2
PICF - EGHS	Participant Information Form - Version 2.0 - EGHS	18/06/2021	2
PICF - SRH	Participant Information Form - Version 2.0 - SRH	18/06/2021	2
PICF - WHCG	Participant Information Form - Version 2.0 - WHCG	18/06/2021	2
Report forms	Protocol Breach Form_Version 1	-	1
Questionnaire	Questionnaire & Response Schedule_Version 1	-	1
Questionnaire	Participant & Staff Survey_Version 1	-	1
CV	Glenn Reeves CV	-	Current
CV	Glenn Reeves CV	-	Current
CV	Allan Crouch CV	-	Current
CV	Jaclyn Bishop CV	-	Current
CV	Carmel O'Kane CV	-	Current
CV	Gay Corbett CV	-	Current
CV	Rebecca Nunes CV	-	Current
CV	Leanne Storer CV	-	Current
CV	Tracey Walters CV	-	Current
CV	Joylene Fletcher CV	-	Current
CV	Kerry Davidson CV	-	Current
CV	Steve Medwell CV	-	Current
Other	75057 HREA Ethics response version 1.0 18062021	-	-
Agreement	Personify Care Agreement	02/12/2020	-

## Research Governance Authorisation

Research governance/site specific assessment (SSA) authorisation must be obtained by each participating site before the research project can commence at that site.

You are required to provide a copy of this HREC approval letter to the principal investigator of each site covered by this ethics approval. A copy must be included in each site's research governance/SSA application.

Please note, Ballarat Health Services do not undertake governance authorisation for Wimmera Health Care Group, East Grampians Health Service or Stawell Regional Health. To complete your records, you are welcome to print off an SSA form for Wimmera Health Care Group, East Grampians Health Service and Stawell Regional Health and obtain signatures, this does not need to be submitted to our office however.

## Conditions of Ethics Approval

- You are required to submit to the HREC:
  - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on **30th April 2022**. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the scheduled date. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with *Safety Monitoring and Reporting in Clinical Trials Involving Therapeutic Goods* (NHMRC, 2016).
- Notify the reviewing HREC of your inability to continue as Principal Investigator.
- Notify the reviewing HREC of the failure to commence the research project within 12 months of the

- HREC approval date or if a decision is taken to end the research project at any of the sites prior to the expected date of completion.
6. Notify the reviewing HREC of any matters which may impact the conduct of the research project.
  7. If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency *Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes'* Radiation Protection series Publication No.8 (May 2005) (ARPANSA Code).
  8. The HREC, authorising institution and/or their delegate(s) may conduct an audit of the research project at any time.

Yours sincerely,



**Ms Kirsty Broadbent**

Research Governance Officer, Ballarat Health Services

## Appendix C: Information for Participants

### INFORMATION FOR PARTICIPANTS

Full Project Title	smsPRO: Evaluating the acceptability of an online questionnaire for gathering cancer patient reported outcomes from community-based cancer patients?
Researchers	Glenn Reeves, Jaclyn Bishop, Alan Crouch, Carmel O’Kane, Gay Corbett, Joylene Fletcher, Leanne Storer, Rebecca Nunes, Tracey Walters

#### Introduction

You are invited to take part in this research project (smsPRO) because you are a cancer patient at either Ballarat Health Services (BHS), Wimmera Health Care Group (WHCG), East Grampians Health Service (EGHS) or Stawell Regional Health (SRH). This study aims to evaluate the acceptability of using an online questionnaire to understand how a patient is feeling when residing at home. To do this, we want to send you an online questionnaire, at different times when you are at home, asking you questions about your health.

This Participant Information Statement should help you decide if you want to take part. The next time we see you we will discuss the study and give you an opportunity to ask questions. You may want to talk to a relative, friend or your doctor before deciding whether or not you want to take part.

Participation in this study is voluntary. If you do not wish to take part, you do not have to. It will not affect the treatment or care you receive.

The study is conducted and funded by Grampians Integrated Cancer Service (GICS).

#### What is the purpose of this research project?

People with cancer may have symptoms or supportive care needs that decrease their quality of life. We think patient care can be improved through the combination of:

- Patients regularly completing questionnaires to report their symptoms / supportive care needs when they are residing in the home.
- Review of the questionnaires by your health care team will help them understand patient needs better and respond before they worsen.

#### What does participation in this research project involve?

The study involves completing an online questionnaire on your mobile phone approximately once a month for up to a 10-month period. It is anticipated that the questionnaire will take less than 5 minutes to complete.

The next time you meet with your care team you will be asked whether you have any questions in regard to the study and whether you would like to participate. If you choose to take part in the study you will be sent a text message (SMS) to create an online account where you will be asked to consent electronically.

By consenting you are telling us that you:

- understand what you have read
- consent to take part in the research study
- consent to the collection and use of your questionnaire answers for the purposes of managing your care.

Once you have provided consent, staff will provide a run-through of the questionnaire so you know what to expect when you receive it whilst residing at home.

If you do not wish to take part, you do not have to. However, your care provider would like to document (de-identified) the reason why you chose not to take part in the study. If you would not like to provide a reason, you can decline to answer with no impact on their future care.

At the end of the trial period, you will also be asked to complete a survey asking you questions about how easy the technology was to use. It is anticipated that this questionnaire will also take less than 5 minutes to complete.

You will not be paid for taking part in this study and there are no costs to you involved.

### **What are the possible benefits of taking part?**

Though we cannot guarantee that you will receive any benefits from being in this study, possible benefits may include earlier care for severe or worsening symptoms / supportive care needs when they occur. This might lead to improved quality of life, decreased distress and improved emotional well-being. Other benefits include, taking part in a study that has the potential to improve communication between future patients and their care provider resulting in reduced emergency visits & hospitalisations and increased quality of life, treatment tolerance and survival outcomes for patients.

### **What are the possible risks?**

It is unlikely that there will be any risk to you if you decide to take part in this study. However, you will be asked questions about your health. Should you become upset or distressed as a result of taking part in this study, you are encouraged to call your care provider within working hours or other appropriate support outside of working hours such as Beyond Blue (1300 22 4636). You are also encouraged to contact the researchers (contact details are listed below). The researcher will be able to arrange for counselling or other appropriate support with trained professionals.

### **Do I have to take part in this study?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project. Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with the researchers or your health service.

If you decide to withdraw, please notify a member of the research team as soon as possible. Personal information collected up until you withdraw will be kept unless you tell the researchers you do not wish for this to occur.

## What will happen to information about me?

Identifiable information will be treated as confidential and securely stored for at least 7 years before being destroyed. The de-identified information you provide may be used to inform other research projects, provided they have ethical approval. Results from this study will be published and presented in a variety of forums. Information will be presented in such a way that you cannot be identified, and results will only be reported as summary findings.

Information about your participation in this study may be recorded in your hospital records. You have the right to request information collected about you and stored by the research team and to ask that information that you disagree be corrected.

## How will I be informed of the final results of this research project?

If you would like to be informed of the overall research findings, please contact Glenn Reeves (details below).

## Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Ballarat Health Services and St John of God. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

## Who can I contact?

Please contact the person who best fits your query.

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### General

For more information or to discuss issues which may be related to your involvement in the project

Glenn Reeves

Principal Investigator

Telephone:  
0404 818 658

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### Complaints / Feedback

Feedback about the research project or complaints about the conduct of the project should be made in writing and directed to:

Diane Clingin

Research Governance Officer

Ballarat Health Services and St John of God  
Healthcare Human Research Ethics  
Committee

Email: [diane.clingin@bhs.org.au](mailto:diane.clingin@bhs.org.au)

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## Appendix D: Patient Consent / Opening Online Account Process

1. Patient receives PICF. During their first meeting with staff, eligible participants will be informed of the project and provided the Patient Information Statement to read in their own time. If the first meeting is face-to-face the participant will be handed a physical copy of the Patient Information Statement. If the first meeting is over the phone the Patient Information Statement will be sent to the patient by email or post depending on their preference (funded by GICS).
2. Patient opens PersonifyCare online account. During the first meeting patients are asked to register by creating an account. This ensures all participant information is stored securely within the Personify Care platform. Opening an account includes the following: Staff member enters the participant's mobile phone number into the Personify Care Online Dashboard and the participant receives an SMS on their mobile phone inviting them to open an account. Participant clicks on the SMS link and enters their details (name, age, gender, postcode, password) to open an account.
3. Patient takes PICF home to read and consider.
4. Patient receives an SMS (2 days after the meeting in step 1) asking the patient to opt-in to the smsPRO study by clicking on a link. The patient then opts in by clicking on a series of boxes on their phone screen that include:
  - I have read the Participant Information Sheet.
  - I understand the purposes, procedures and risks of the research described in the project.
  - I have had an opportunity to ask questions and I am satisfied with the answers I have received.
  - I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future relationship with my care team. Study Name: smsPRO Protocol Number: Version & date: version 4.0 dated 14th May 2024 Page 18 of 29.
  - The questionnaire is not intended for emergency situations and what the participant needs to do and/or who to contact if they are experiencing severe distress. They are reminded that smsPRO does not replace standard care.
5. Patient opts-in by signing a digital version of the PICF on the PersonifyCare online platform. Patients choosing not to consent will be asked why and the reason will be recorded in a spreadsheet. However, the patient can decline to answer with no impact on their future care. This is outlined in the Patient Information Statement.
6. Staff schedule participant questionnaires into calendar. This is done within the Personify Care Online Staff Dashboard.

## Appendix E: Participant Questionnaire Process

1. Participant receives SMS link to questionnaire. Consenting participants will receive an SMS on their mobile phone with a link inviting them to participate in a questionnaire.
2. Participant logs-in to their Personify Care online account. After clicking the link, participants are required to log-in using their user password to ensure all participant data is stored securely.
3. Participant provided important information. After logging-in to their online account, participants will be taken to an information page that reminds them once again that the questionnaire is not intended for emergency situations.
4. Participant answers questionnaire. After reading the information page, the participant starts the questionnaire.
5. Participant thanked for completing questionnaire. At completion of the questionnaire the participant is thanked for their participation and once again is reminded that the questionnaire is not intended for emergency situations.

# Appendix F: Breast Cancer Nurse Specialist Patient Questionnaire & Flag Trigger/ Staff Response Matrix

Q1. In the last 7 days, what was your level of need for help with PERSISTENT WORRYING?



No action required

Call participant with 5 working days

Call participant ASAP

Q2. In the last 7 days, what was your level of need for help with FEELINGS OF SADNESS?



Q3. In the last 7 days, what was your level of need for help with HOT FLUSHES?



Q4. In the last 7 days, what was your level of need for help with VAGINAL DRYNESS or SEXUAL DISCOMFORT?



Q5. Are you experiencing difficulties with normal PHYSICAL ACTIVITIES?



Q6. In the last 7 days, has there been (or about to be) a CHANGE TO YOUR CANCER TREATMENT?



Q7. Are you continuing to take your HORMONE BLOCKING TREATMENT?



Q8. Do you feel well supported?

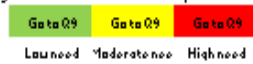


Q9. Do you have any OTHER NEEDS that you wish to report ?



Q10. What NEED would you like to report (please write in text box below)?

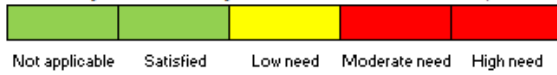
Q11. In the last 7 days, what was your level of need for help with this NEED?



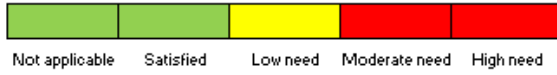
# Appendix G: Prostate Cancer Nurse Specialist Patient Questionnaire & Flag Trigger/ Staff Response Matrix

## HORMONE THERAPY

Q1. In the last 7 days, what was your level of need for help with concerns about WORRY?



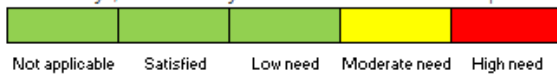
Q2. In the last 7 days, what was your level of need for help with concerns about FEELINGS OF SADNESS?



Q3. In the last 7 days, what was your level of need for help with concerns about ERECTILE DYSFUNCTION?



Q4. In the last 7 days, what was your level of need for help with concerns about your PSA RESULT?



Q5. In the last 7 days, what was your level of need for help with concerns about the SIDE EFFECTS OF HORMONE THERAPY?

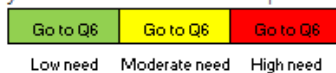


Q6. Do you have any OTHER NEEDS that you wish to report ?

Go to Q7	Go to END
Yes	No

Q7. What NEED would you like to report (please write in text box below)?

Q8. In the last 7 days, what was your level of need for help with this NEED?



# Appendix H: Wimmera Cancer Centre Questionnaire & Flag Trigger/Staff Response Matrix

Q1. In the last 7 days, how OFTEN did you have NAUSEA (feeling sick)?

Skip to Q3	Skip to Q3	Go to Q2	Go to Q2	Go to Q2
Never	Rarely	Occasionally	Frequently	Almost constant

No action required

Call participant with 1 working day, 2 or more yellow = escalate to RED

Call participant ASAP

Q2. In the last 7 days, what was the SEVERITY of your NAUSEA at its WORST?

Very severe	Red	Red	Red	Red
Severe	Red	Red	Red	Red
Moderate	Yellow	Red	Red	Red
Mild	Yellow	Yellow	Red	Red
	Occasionally	Frequently	Almost constant	

Q3. In the last 7 days, how OFTEN did you have VOMITTING?

Skip to Q5	Skip to Q5	Go to Q4	Go to Q4	Go to Q4
Never	Rarely	Occasionally	Frequently	Almost constant

Q4. In the last 7 days, what was the SEVERITY of your VOMITTING at its WORST?

Very severe	Red	Red	Red	Red
Severe	Red	Red	Red	Red
Moderate	Yellow	Red	Red	Red
Mild	Yellow	Yellow	Red	Red
	Occasionally	Frequently	Almost constant	

Q5. In the last 7 days, how OFTEN did you have DIARRHOEA (loose stools)?

Skip to Q7	Skip to Q7	Skip to Q7	Go to Q6	Go to Q6
Never	Rarely	Occasionally	Frequently	Almost constant

Q6. In the last 7 days, what was the SEVERITY of your DIARRHOEA at its WORST?

Very severe	Red	Red	Red
Severe	Red	Red	Red
Moderate	Yellow	Red	Red
Mild	Yellow	Red	Red
	Frequently	Almost constant	

Q7. In the last 7 days, how OFTEN did you have TROUBLE SWALLOWING?

Skip to Q8	Go to Q8	Go to Q8	Go to Q8	Go to Q8
Never	Rarely	Occasionally	Frequently	Almost constant

Q8. In the last 7 days, what was the SEVERITY of your TROUBLE SWALLOWING at its WORST?

Very severe	Red	Red	Red	Red
Severe	Red	Red	Red	Red
Moderate	Yellow	Red	Red	Red
Mild	Yellow	Red	Red	Red
	Rarely	Occasionally	Frequently	Almost constant

Q9. In the last 7 days, how OFTEN did you have CHEST PAIN?

Green	Red	Red	Red	Red
Never	Rarely	Occasionally	Frequently	Almost constant

Q10. In the last 7 days, how OFTEN did you have PAIN?

Skip to Q12	Go to Q12	Go to Q11	Go to Q11	Go to Q11
Never	Rarely	Occasionally	Frequently	Almost constant

Q11. In the last 7 days, what was the SEVERITY of your PAIN at its WORST?

Very severe	Red	Red	Red	Red
Severe	Red	Red	Red	Red
Moderate	Yellow	Red	Red	Red
Mild	Yellow	Yellow	Red	Red
	Occasionally	Frequently	Almost constant	

Q12. In the last 7 days, how OFTEN did you have MOUTH ULCERS OR SORE MOUTH?

Skip to Q14	Skip to Q14	Go to Q13	Go to Q13	Go to Q13
Never	Rarely	Occasionally	Frequently	Almost constant

Q13. In the last 7 days, what was the SEVERITY of your MOUTH ULCERS OR SORE MOUTH at its WORST?

Very severe	Red	Red	Red	Red
Severe	Red	Red	Red	Red
Moderate	Yellow	Red	Red	Red
Mild	Yellow	Yellow	Red	Red
	Occasionally	Frequently	Almost constant	

Q14. In the last 7 days, have you had a TEMPARATURE OVER 38 DEGREES?

Red	Green
Yes	No

Q15. Do you have any OTHER SYMPTOMS that you wish to report (e.g. constipation, shortness of breath, urinary problems, rash, infection)?

Go to Q16	Go to END
Yes	No

Q16. What symptom would you like to report (please write in text box below)?

Q17. In the last 7 days, how OFTEN did you have THIS SYMPTOM?

Go to Q18	Go to Q18	Go to Q18	Go to Q18
Rarely	Occasionally	Frequently	Almost constant

Q18. In the last 7 days, what was the SEVERITY of THIS SYMPTOM at its WORST?

Very severe	Go to Q15	Go to Q15	Go to Q15	Go to Q15
Severe	Go to Q15	Go to Q15	Go to Q15	Go to Q15
Moderate	Go to Q15	Go to Q15	Go to Q15	Go to Q15
Mild	Go to Q15	Go to Q15	Go to Q15	Go to Q15
	Rarely	Occasionally	Frequently	Almost constant

## Appendix I: Staff Response Process

- Participant completes questionnaire.
- Online Staff Dashboard automatically updates. The moment a participant completes a questionnaire, the patient responses are available to staff within the Personify Care Online Staff Dashboard. Staff access the dashboard online using a password.
- Staff monitor Online Staff Dashboard. Each working day, a staff member will log-in to the Online Staff Dashboard to review completed questionnaires.
- Online Staff Dashboard automatically triages participants. The Online Staff Dashboard includes an escalation flag outlining gradient thresholds for each completed questionnaire using a traffic light system (green, orange, red). Site Response Policies (Appendices E, F, G & H) will be used to guide the logic determining how the colors are assigned for each department. For example, below is an extract from WHCG's Site Response Schedule. In this example, if a participant answers that they never or rarely have nausea, the patient will be flagged as green, and they will skip the next question asking about severity. If a participant answers that they have nausea occasionally, frequently or almost constantly they will be asked the severity of their nausea and they will be subsequently flagged as either red or yellow.


Q1. In the last 7 days, how OFTEN did you have NAUSEA (feeling sick)?


Skip to Q3	Skip to Q3	Go to Q2	Go to Q2	Go to Q2
Never	Rarely	Occasionally	Frequently	Almost constant


Q2. In the last 7 days, what was the SEVERITY of your NAUSEA at its WORST?

Very severe	Red	Red	Red
Severe	Red	Red	Red
Moderate	Yellow	Red	Red
Mild	Yellow	Yellow	Red
	Occasionally	Frequently	Almost constant

- Category red participants sent SMS. Category red participants will be sent an SMS with advice to contact their care team or emergency department as soon as possible.
- Staff action. Staff action will be guided by staff response standards set for each color category. For example, if a patient responds that they were experiencing frequent and severe nausea the participant would be flagged red and staff would call the participant as soon as possible.

 No action required

 Call participant with 1 working day, 2 or more yellow = escalate to RED

 Call participant ASAP

- Staff update medical record. Currently information kept within the Personify Care Online Staff Dashboard is not integrated with patient medical records. Each site chooses their own method to update the medical record based on what works best with their systems. Options include file uploading, printing & scanning, and cutting & pasting.

## Appendix J: Amended Staff Exit Survey

### smsPRO Staff Exit Survey:

#### Participant information and consent

Thank you for participating in the smsPRO project which aimed to understand if an online based questionnaire could be used to improve communication between health service staff and community-based cancer patients living in the Grampians region.

It is anticipated this interview should take approximately 10 minutes of your time.

The first section of the interview will require you to rate your experience of various elements of smsPro, you will then be provided opportunity to share any additional information on your experiences using smsPRO.

This research project has been ethics approved by Grampians Health and St John of God Health Research and Ethics Committee (HREC 75057).

Your participation is entirely voluntary, and you may withdraw from participation at any time. We will endeavour to remove all identifiers from the collected data; however, due to the very small sample size, responses may still be identifiable. Interviews will be undertaken face-to-face or using MS Teams. Responses will be recorded in MS Forms (on the Grampians Health secure server). By participating in the interview, you affirm that you give your consent to participate and for your responses to be used in this research project. If you have any questions or concerns about this research before or after you complete the interview, please contact me or the Grampians Health Research Ethics and Governance Office.

Do you understand this information and agree to continue?

Which study site did you work at when participating in the smsPRO study?

- Breast Care Nurse – Grampians Health Ballarat
- Prostate Care Nurse - Grampians Health Ballarat
- Wimmera Cancer Centre – Horsham

Overall, how would you rate the usability of smsPRO?



Please select how easy it was to do the following:

Inputting patient details	<input checked="" type="radio"/> Very difficult   <input type="radio"/> Difficult   <input type="radio"/> Neither easy or difficult   <input type="radio"/> Easy   <input type="radio"/> Very easy
Scheduling patient questionnaires	<input checked="" type="radio"/> Very difficult   <input type="radio"/> Difficult   <input type="radio"/> Neither easy or difficult   <input type="radio"/> Easy   <input type="radio"/> Very easy
Logging into the Personify Care management portal	<input checked="" type="radio"/> Very difficult   <input type="radio"/> Difficult   <input type="radio"/> Neither easy or difficult   <input type="radio"/> Easy   <input type="radio"/> Very easy
Monitoring patient responses	<input checked="" type="radio"/> Very difficult   <input type="radio"/> Difficult   <input type="radio"/> Neither easy or difficult   <input type="radio"/> Easy   <input type="radio"/> Very easy
Uploading patient responses into the participant's medical record	<input checked="" type="radio"/> Very difficult   <input type="radio"/> Difficult   <input type="radio"/> Neither easy or difficult   <input type="radio"/> Easy   <input type="radio"/> Very easy

Please select your level of agreement with the statements below:

The <u>smsPRO</u> system helps us TRACK patient symptoms / problems outside of the hospital	<input checked="" type="radio"/> Strongly Agree   <input type="radio"/> Agree   <input type="radio"/> Neither Agree or Disagree   <input type="radio"/> Disagree   <input type="radio"/> Strongly Disagree
The <u>smsPRO</u> system helps us IDENTIFY patient's needing urgent attention	<input checked="" type="radio"/> Strongly Agree   <input type="radio"/> Agree   <input type="radio"/> Neither Agree or Disagree   <input type="radio"/> Disagree   <input type="radio"/> Strongly Disagree
The <u>smsPRO</u> system saved us time	<input checked="" type="radio"/> Strongly Agree   <input type="radio"/> Agree   <input type="radio"/> Neither Agree or Disagree   <input type="radio"/> Disagree   <input type="radio"/> Strongly Disagree
The <u>smsPRO</u> system increased our capacity to provide person centred care	<input checked="" type="radio"/> Strongly Agree   <input type="radio"/> Agree   <input type="radio"/> Neither Agree or Disagree   <input type="radio"/> Disagree   <input type="radio"/> Strongly Disagree
I would recommend the <u>smsPRO</u> questionnaires to other cancer service providers	<input checked="" type="radio"/> Strongly Agree   <input type="radio"/> Agree   <input type="radio"/> Neither Agree or Disagree   <input type="radio"/> Disagree   <input type="radio"/> Strongly Disagree

Is there any other information about your experiences using smsPRO that you wish to share?

# Appendix K: Patient Exit Survey

Q1. Overall, how easy was the smsPRO system to use?



Q2. Why did you respond in this way?

Q3. Please select how easy it was to do the following on your mobile phone:



Q4. Please select your level of agreement with the statements below:



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