Access to unscheduled symptom management support: a multisite evaluation of patient and caregiver experiences of Symptom and Urgent Review Clinics

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All participants

Steering committee members

Elizabath Walkley

Background

Symptom and Urgent Review Clinics (SURC) are **nurse-led services** that aim to **increase access** to symptom management support for community-dwelling individuals who are receiving systemic anti-cancer therapy in the outpatient setting.

Since their inception in 2013, there has been no formal evaluation of their impact in optimising timely access to care and support.

Aim

To examine how access to a nurse-led clinic for unscheduled symptom support, known as SURC, is enabled and experienced and to identify factors that influence access, acceptability and resource adequacy.

Evaluation questions

EQ1. To what extent are the intended users of SURC aware and knowledgeable of the SURC?

EQ2. To what extent are the intended users of SURC able to reach the service when required?

EQ3. To what extent does SURC provide outreach care?

EQ4. To what extent do patients and carers have the ability to perceive the need to contact SURC?

EQ5. To what extent is the SURC acceptable to end-users?

EQ6. To what extent does the SURC have adequate resources to deliver care to it's intended users?

EQ7. To what extent do patients and carers see SURC as an affordable service?

EQ8. To what extent is care delivered via SURC efficient?

EQ9. To what extent do patients and carers perceive SURC as providing high quality care?

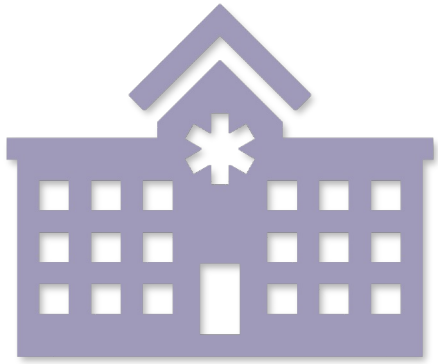
Methods

Descriptive mixed-methods approach

- surveys
- semi-structured interviews
- focus groups
- retrospective audit of medical records
- audit of SURC-related documentation

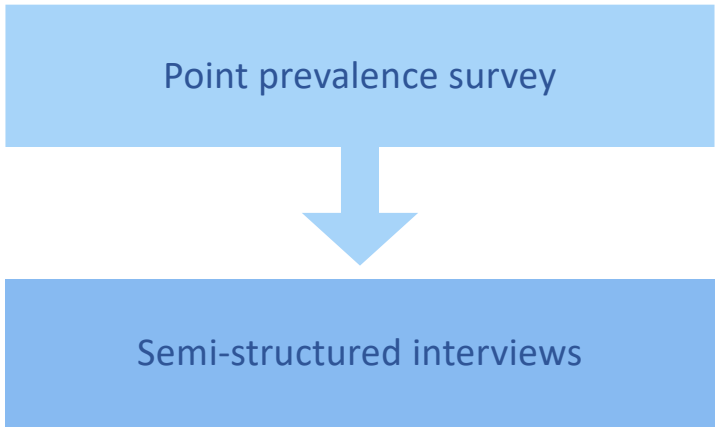
Data were gathered over a 6-month period (August 2023 – January 2024)

Guided by prior research and Levesque's framework for patient-centred access to health care



Seven Victorian health services
five metro & two regional

Methods – patients and carers



Eligibility

- Patients / carers receiving SACT in outpatient unit
- Eligible to access the local SURC
- English speaking or carer as proxy

All eligible patients and carers were approached over a 5-day period

Carers invited to participate if present at OP SACT appointment, otherwise consent obtained to call and invite to participate

Patients and carers invited to participate in a semi-structured interviews if they reported to have used SURC previously

Methods - HCPs

Focus groups	Nurses working on cancer inpatient wards
Survey	SURC nurses NUMs of SURCs
Document audit	Any SURC related documentations e.g. promotional material, operations/orientation manuals
Retrospective audit OP SACT and SURC episodes of care	All OP SACT and SURC episodes of care between 1st March 2022 – 28th February 2023

Results

Monthly average OP SACT episodes ranged from 292 to 845

Monthly average SURC episodes ranged from 101 to 310

SURC Nurse FTE ranged from 1.0 to 3.2 across sites

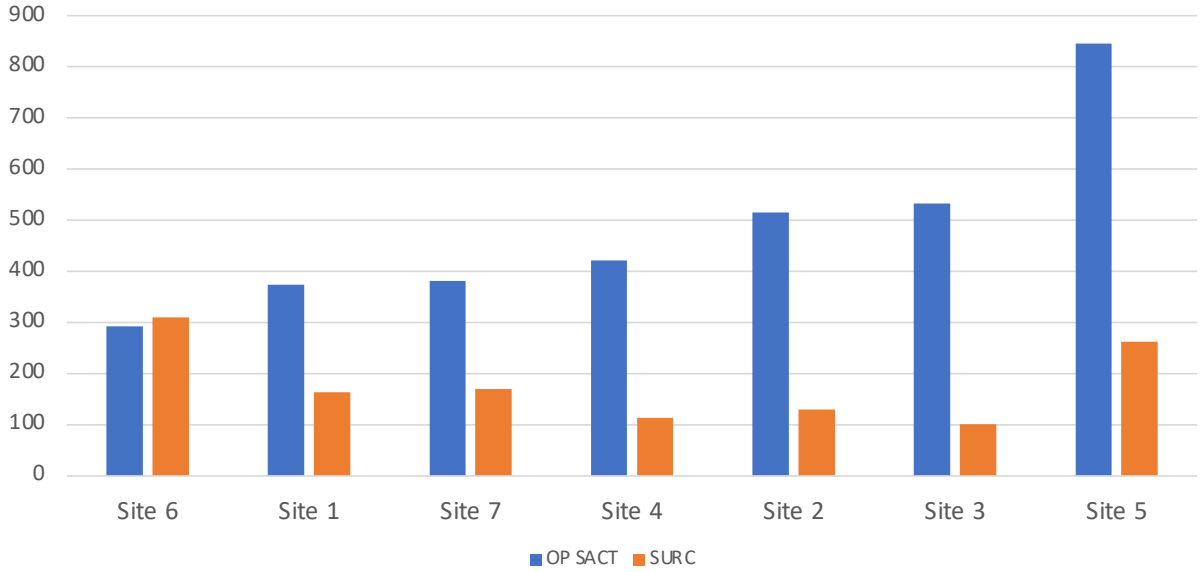


Figure 1. Average monthly OP SACT and SURC episodes of care across participating sites

Results - Participation

- Point prevalence survey - 550 patients and 102 carers participated
- Semi-structured interviews – 65 patients, 9 patient-carer dyads, and 6 carers participated (80 in total)
- Focus groups – 32 nurses participated across seven focus groups
- SURC Nurse survey – 39 SURC nurses completed the survey

EQ1. To what extent are the intended users of SURC aware and knowledgeable of the SURC?

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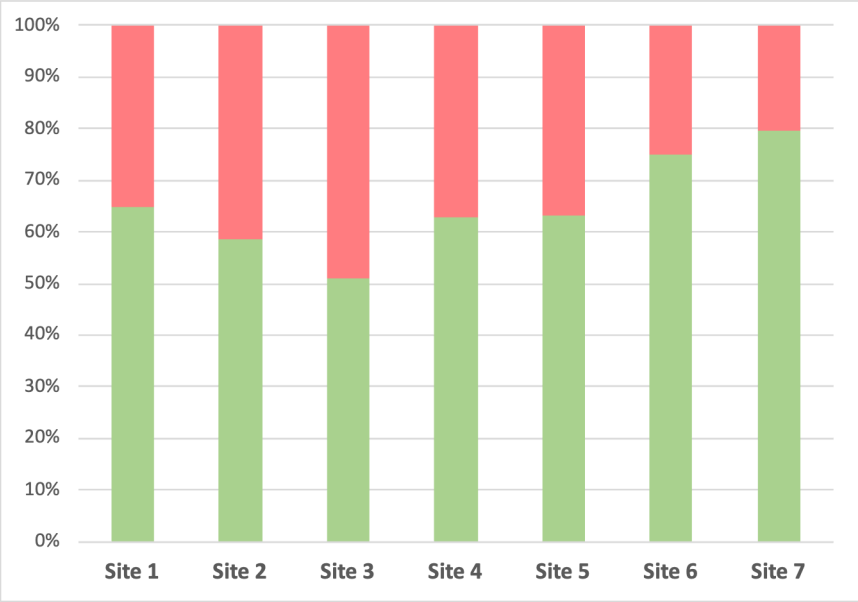

Figure 2. Responses to 'have you heard of the SURC before? (patients) N = 550

Across sites, 66% of SURC eligible **patients** reporting having heard of SURC before the survey

EQ1. To what extent are the intended users of SURC aware and knowledgeable of the SURC?

Figure 3. Responses to 'have you heard of the SURC before? (carers) N = 102

Across sites, 58% of SURC eligible **carers** reporting having heard of SURC before the survey

EQ2. To what extent are the intended users of SURC able to reach the service when required?

- All sites provided access to SURC Monday through Friday during business hours (8:30am – 4:30pm)
- Two sites had extended hours Monday through Friday providing extending hours to 8pm or 10pm
- Two sites operated a weekend service either Saturday only or limited hours across both Sat and Sun

EQ2. To what extent are the intended users of SURC able to reach the service when required?

Patients and carers reported that they were able to contact SURC within an acceptable timeframe.

"Every time I called, they'd answer, or I'd leave a message, they call me back really quickly. And they'd always follow up the things, you know, if they had to ask the doctor, they'd call me back that day, you know, I didn't have to wait anxiously." Participant 10 (patient, site 4)

A small number reported delays in having their phone call returned but described a short, acceptable period to receive a return phone call.

EQ2. To what extent are the intended users of SURC able to reach the service when required?

All sites provide instructions about who to contact outside SURC hours of operation in promotional material

- 3 instructed pts to go to ED
- 2 instructed pts to contact hospital switchboard and ask to speak to relevant drs
- 2 instructed pts to ring inpatient ward

Patients and caregivers (interviews) expressed concern about ability to access quality support outside SURCs hours of operation

- Calls going unanswered
- Not perceived as same level of quality

"It's just if anything was to happen outside of those hours, I would panic." Participant 5 (site 6, caregiver)

EQ2. To what extent are the intended users of SURC able to reach the service when required?

SURC eligible patients and caregivers were asked *'what would you do if you needed to speak to someone about symptoms you were experiencing outside of SURC operating hours?'*

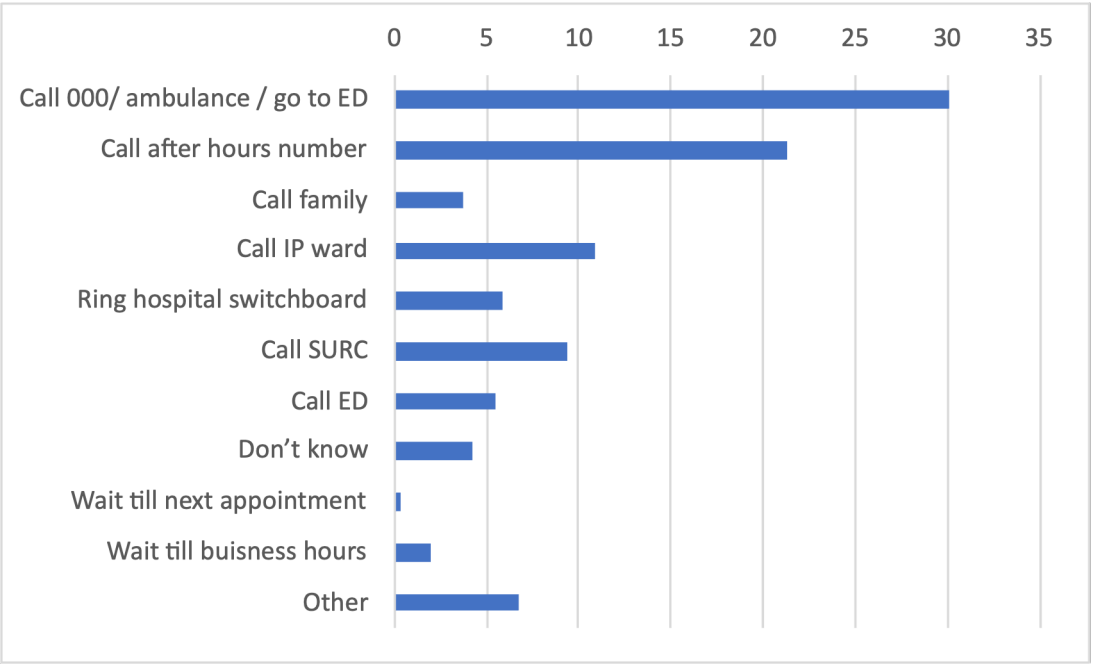

Figure 4. Responses to what would you do if you needed to speak to someone after hours? (patients) N = 545

EQ2. To what extent are the intended users of SURC able to reach the service when required?

During the focus groups, nurses caring for people admitted to the inpatient area described a **lack of confidence** in triaging patient calls and a **lack of time** to undertake an in-depth assessment as barriers to effectively managing patient symptoms and concerns. This, at times, resulted in recommending patients present to the ED.

EQ3. To what extent does SURC provide outreach care?

- There were mixed responses within each site about whether SURC provided proactive/outreach care with some SURC nurses responding yes and others no (SURC nurse survey).
- Nurses from six of the seven sites indicated that outreach or proactive care was provided following referral by medical staff (SURC nurse survey).

EQ3. To what extent does SURC provide outreach care?

Three sites had written criteria to identify patients who may be at risk of poorer outcomes (documentation audit).

- At one site, criteria were provided as a prompt for a referral to SURC
- At one site, criteria were listed for those who may be more likely to make an unplanned ED presentation, but no specific direction about additional support or action that should be taken is provided at either site.

EQ3. To what extent does SURC provide outreach care?

- Telephone triage was categorised as either incoming or outgoing calls at six of the seven sites.
- Outgoing care accounted for **31%** (n = 3,355) of all care delivered via phone (including routine calls made to patients in the week after commencing SACT).
- The proportion of care categorised as outgoing ranged from 16% to 53% across the sites.

EQ4. To what extent do patients and carers have the ability to perceive the need to contact SURC?

- Patients and carers reported **difficulty determining the importance of symptoms, particularly during the initial stages of receiving SACT** (interviews).
- Across all sites, **95%** of both patients (n = 345) and caregivers (n = 56) were able to identify **appropriate reasons to contact SURC services** (point prevalence survey).
- Patients and caregivers described a key benefit of SURC as helping them **understand the severity of their symptoms, the need for care, and the most appropriate place to seek care** (interviews).

EQ4. To what extent do patients and carers have the ability to perceive the need to contact SURC?

A key theme from the patient and caregiver interviews was the integral role caregivers often played in making the decision to contact the SURC.

"So, I had blinding headaches for at least a week at home and then started to get vertigo. And I rang [caregiver]. And she said, Oh, that's not right. We've gotta ring SURC." Participant 2 (patient, site 5)

EQ5. To what extent is the SURC acceptable to end-users?

Overwhelmingly, patients and caregivers reported that SURC services were responsive to and able to address their needs.

> *"It makes you feel better. My wife said it makes you feel relieved because she's had dealings with them too for me, and it just makes you feel at ease. I've never not got an answer." Participant 12 (site 5, patient)*

A small number of patients described not being satisfied with the advice provided and subsequently reported not anticipating using SURC again.

EQ6. To what extent does the SURC have adequate resources to deliver care to it's intended users?

- 3/7 sites provide pre-treatment education sessions
- 3/7 sites provide care to patients on oral SACT
- There was substantial variation in other local nurses supporting various cohorts of patients

EQ6. To what extent does the SURC have adequate resources to deliver care to it's intended users?

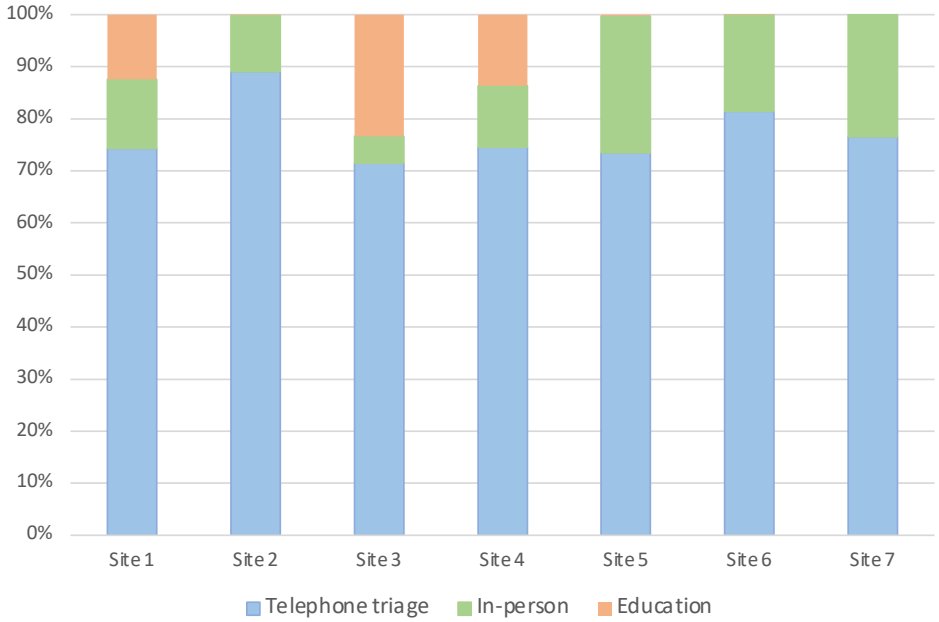

Figure 5. Proportion of activities of SURC nurses

Activities such as patient education accounting for nearly 25% of activity at some sites

EQ6. To what extent does the SURC have adequate resources to deliver care to it's intended users?

87% of SURC nurses (n = 34) identified barriers to being able to deliver care as intended and respond to unscheduled requests for care and advice from patients and caregivers via SURC.

Barriers reported across the sites included:

- Physical space
- Human resources to respond to demand
- Scope, specifically delivering pre-treatment education
- Availability of timely medical support

EQ7. To what extent do patients and carers see SURC as an affordable service?

The patients described **no direct out-of-pocket costs** associated with using SURCs but did describe costs associated with **travelling to** and **parking at the hospital** if they needed to be seen in person, as well as costs associated with filling prescriptions obtained via SURCs.

"Oh, here we go, another bloody trip down into the hospital. That week, I ended up at the hospital four days in a row. So, I had appointments that cost me bloody $200 in petrol. So, I was annoyed, and [that] was my main emotion" Participant 6 (patient, site 3)

EQ8. To what extent is care delivered via SURC efficient?

Care delivered via SURC services was efficient/timely.

- delays when care needed to be escalated care to medical staff
- minimal wait time when presenting in person to SURC, specifically in contrast to presenting to the ED.
- SURC facilitated timely access to further investigations, such as medical imaging and in-person medical reviews.

When pts were sent to the ED from a SURC to facilitate an inpatient admission, that they felt abandoned and "dumped" in the ED.

"For me, it felt like the difference from being, I guess, sort of, I felt like we've kind of been dumped by the 'we're all shutting at 4.30 and so you've got to go down to ED.'" Participant 14 (Patient, site 5)

EQ9. To what extent do patients and carers perceive SURC as providing high quality care?

Knowledgeable and highly skilled in assessment and care

SURC nurses had between 8.9 and 24 years of experience, with an average of 14 years (SD 5).

SURC was preferred than non-cancer specialist services (ED / GP)

92% of SURC nurses had a postgraduate or masters level qualification

Limitations

Language

Participation likely by those with positive experiences

Inconsistency in data collection

Recommendations

Based on the findings, eight recommendations were made to SURCs about access.

Recommendations

Awareness and knowledge

1. Ensure that there is a **documented process for introducing SURC to all eligible patients**. The documented process should include details of who is eligible to access SURC and at what time point/s patients are informed of the SURC.
2. Ensure that there is a documented process (separate from the process to inform patients) to **introduce SURC to all eligible caregivers**. The documented process should include details of who is eligible to access SURC and at what time point/s patients are informed of it. It should also include checking whether the caregiver has received the information.

Recommendations

Access

3. Ensure there is a documented process for patients and their caregivers to **access support and advice outside of the SURC operating hours** and that this is clearly documented on SURC promotional material

4. Ensure there is a documented process to **identify people who may be at-risk** of adverse events or poorer outcomes and a process to, or pathways for, a tailored response in consideration of other resources available at each hospital

Recommendations

Resource

5. Ensure **resources are appropriately allocated**, including SURC nurse FTE and availability of physical space

6. Ensure SURC nurses have access to **timely medical support**

7. Ensure an annual review of SURC's **scope of practice**, including eligibility criteria, activities and outputs, and opportunities to expand the scope of practice.

Recommendations

Acceptability

8. Develop a standardised process to regularly **monitor patient and caregiver experience**

Take home message

SURCs play an important role in ensuring patients and carers have timely access to quality cancer care. It is important to ensure they are reaching the intended users, are working to the top of their scope of practice and are adequately resourced.