Improving haematopoietic stem cell transplant survivorship through patient reported outcome measures.

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As Australian Commission on Safety and Quality in Health Care refers to consumer, this term will be used in our when referring to the study consumer representatives, however as patient reported outcome measures refers to patients, this term will be utilised in the context of PROMs.

Executive Summary

Blood cancers are the third most diagnosed cancer in Australia and the second leading cause of cancer-related deaths annually (Leukaemia Foundation, 2023). Advances in transplant technology have made allogeneic stem cell transplantation a viable curative treatment for many of these cancers. However, this cure often comes with a significant treatment burden, commonly described as trading death from cancer for life with a chronic illness. As the population of transplant survivors grows, the long-term side effects and their impact on both patients and the broader healthcare system are becoming increasingly evident. In South Australia, patients have reported that their concerns can be under-considered, highlighting the need to shift focus from short-term management to long-term survivorship care.

Patient-reported outcome measures (PROMs) offer a non-invasive way to monitor patients' self-reported health status over time, enabling healthcare providers to better understand the issues most important and impactful to patients. The benefits of PROMs include improved self-management and earlier interventions, thereby preventing costly hospitalisations due to late presentation, and enhancing survival and quality of life (Basch, 2017).

Consumer involvement has been integral to this study, ensuring that the project closely aligns with the needs of post-transplant patients. By actively engaging consumers from the initial design phase, the study has benefited from valuable patient perspectives. This collaboration underscores the critical role of consumer input in healthcare research, demonstrating that meaningful engagement is essential for developing solutions that truly address the challenges faced by transplant survivors.

This study explored the potential of PROMs to improve survivorship care for allo-HSCT patients by understanding the symptoms they experience and identifying the requirements for an effective PROM mechanism. Supported by funding from the Commission on Excellence and Innovation in Health, the study was conducted in two phases and highlights the complex and ongoing challenges faced by allo-HSCT survivors, which are often poorly prioritised, inadequately captured, and variably addressed. Participants emphasised the need for a platform to document and communicate their concerns, enabling self-monitoring and facilitating targeted support from healthcare teams.

The study's recommendations aim to address these challenges and improve the care experience for allo-HSCT recipients. Key recommendations include implementing a digital platform for real-time PROM collection, integrating educational and self-management tools, ensuring ongoing consumer involvement in platform design, incorporating multidisciplinary care into routine follow-up, enhancing consumer partnerships in project design, strengthening collaboration with ethics committees, and securing funding to support these initiatives. While ambitious, these recommendations are crucial for improving outcomes and quality of life for allo-HSCT recipients.

We sincerely appreciate all participants, supporters, and contributors to this study, including the Commission on Excellence and Innovation in Health, Central Adelaide Local Health Network, South Australian Health and Medical Research Institute and South Australia Health Library Service. We are especially grateful to those who openly shared their experiences and insights, providing invaluable guidance on how we can enhance allo-HSCT care moving forward.

Background and vision

People with cancer are at risk of a range of side effects and symptoms caused by their cancer treatment. These symptoms are complex and highly individualised, reflecting unique demographic variables of the patient, disease/treatment-related variables and other risk factors (e.g. genetic), (Wardill et al., 2020). Almost no organ system is spared from the side effects of cancer therapy, with people often experiencing a multitude of co-occurring symptoms/complications including, diarrhoea, constipation, nausea, cognitive impairment, neuropathy, pain, infection, mouth ulcers, rashes, sexual dysfunction, fatigue and cardiovascular disease. The ongoing burden of these symptoms has a profound ripple effect for the patient, leading to psychosocial impacts (e.g. social isolation, low self-esteem, post-traumatic stress disorder, anxiety and depression, and financial hardship due to un/under-employment for both the person with cancer as well as their family members who may have to provide ongoing care for their loved one (Carrera, Kantarjian & Blinder, 2018). Despite calls to prioritise the prevention and management of these symptoms, they are still considered a necessary evil in the quest for a cure, with many people simply “putting up with them” throughout and after their cancer treatment (Berman et al., 2020).

Our long-term aim is to embed supportive cancer care and survivorship services into local health networks in South Australia, providing multidisciplinary, patient-centric care for people affected by cancer. This has been informed through our ongoing engagement with consumers, who have expressed their frustration over the fragmented and reactive approach to symptom management, and their desire for their care teams to prioritise both surviving cancer and living well with or after cancer.

Central to realising this goal is streamlining the way in which the symptoms and side effects of cancer treatment are assessed. Typically, they are measured using a range of clinical assessment tools and biomarkers. However, there is mounting evidence suggesting routine clinical assessment of these symptoms and side effects is inadequate (Basch, 2017). Due to the infrequency of patient assessments, symptoms and other impairments go undetected almost 50% of the time, particularly when patients are in the community or treated as out-patients (Basch, 2017). Coincidently, symptoms and side effects, when assessed by clinicians, under-estimate their impact and severity when compared to patient-reported outcomes (Basch et al., 2006). As a result, early indicators of treatment complications go unnoticed, and opportunities to proactively intervene are missed. There is therefore a need to improve communication mechanisms between patients and their care teams to identify these symptoms early and provide the best supportive care possible.

Recent advances in technology and survey methodologies have enhanced our ability to capture the patient voice in the form of patient reported outcome measures (PROMs). Their use in cancer care is increasing rapidly, reflecting their utility in monitoring treatment-related symptoms in real-time. When PROMs are routinely embedded into patient care, there are improvements in quality of life, number of hospital presentations and survival (Basch, 2017; Snyder et al., 2012; Pakhomov et al., 2008). This reflects that when patients are given the opportunity to report their symptoms, they receive the care they need in a timely manner, preventing these symptoms from worsening. In fact, when supportive care is implemented early (e.g. for pain), there is a 3-month survival benefit that results from the patient being able to tolerate their intended cancer therapy, thus avoiding dose reductions or treatment delays (Bandieri et al., 2012).

The successful implementation of PROMs in cancer care requires the unmet needs of people living with or beyond cancer to be better understood. In 2021, co-investigator Dr Nadia Corsini described the first set of core PROMs that represent important priorities in people with cancer (Ramsey et al., 2021). These highlighted patient’s desires to have improved support services to help them navigate life with or after cancer, with particular

emphasis on psycho-social support. While an important step forward in PROM implementation, there was low representation of people with blood cancers (n=2) who are recognised to have particularly complex supportive care needs.

Blood cancers (BC) (when combined) are the third most diagnosed cancer in Australia, and the second most common cause of cancer-related deaths each year (Leukaemia Foundation, 2023). There are more than 110,000 people living with BC in Australia today. People with BC have a particularly high burden of support care needs due to the intensity of treatment they receive. Despite this, the Australian Commission on Safety and Quality in Health Care does not recognise BC as a high burden cancer, nor does it endorse any validated PROMs for use in BC (Australian Commission on Safety and Quality in Healthcare, 2023).

Haematopoietic stem cell transplantation (HSCT) is a commonly used, curative approach for some BC. It requires the patient to be treated with extremely high dose chemotherapy to completely ablate their immune system. They then receive new, healthy immune cells harvested from themselves (autologous) or a healthy donor (allogeneic). HSCT is a gruelling treatment, with a range of acute complications including diarrhoea, ulcers, nausea, infection, anaemia, constipation, malnutrition. To manage these symptoms, patients are kept in hospital for weeks at a time under strict monitoring. After their immune system rebuilds, patients are at risk of chronic, late effects. These include low performance status, endocrinopathies, musculoskeletal disorders, cardiopulmonary disease, secondary cancers, and Graft versus Host Disease (GvHD) - a chronic, difficult to manage complication of allogeneic haematopoietic stem cell transplant (allo-HSCT) with high morbidity. These are complex, highly burdensome symptoms that are best managed proactively. For example, acute GvHD is the biggest predictor of chronic GvHD, and once chronic GvHD has been diagnosed at Grade ≥3, 5-year survival is <5%, (Majhail, 2017).

The Royal Adelaide Hospital is the sole provider of allo-HSCT, and majority provider of autologous HSCT for SA, NT, and rural NSW, performing on average 150 HSCT's annually. Working towards our long-term goal of establishing patient-centric, multidisciplinary supportive and survivorship care for people with BC, we must understand the priorities of this unique patient population. While we can be guided by the prevalence of these conditions, we see great value in engaging with HSCT recipients and their carers/loved ones. Through a structured consultation process, we will identify their unmet needs and the best tools to capture these needs. This will ensure we are well positioned to co-design a digital platform to facilitate the collection of PROMs in allo-HSCT recipients for routine clinical use within the Central Adelaide Local Health Network.

Project rationale

We aim to minimise the burden of allo-HSCT on patients, their carers/loved ones and the healthcare system by routinely and effectively collecting PROMs. While curative, allo-HSCT has been described as trading an acute illness (blood cancer) for a chronic, life-threatening condition. In fact, the number of allo-HSCT patients that die due to complications within 5-years of their transplant out-numbers those that die due to their disease 4 to 1 (Majhail, 2017). Those that survive face a life of chronic complications that can cause physical disability which have profound psychological impacts for both the patient and their loved ones/carers.

Reflecting on the complexity of a life after transplant, allo-HSCT recipients require a high level of interaction with the healthcare system for specialist care. The average duration of inpatient hospitalisation for the transplant itself is 36 days. Once discharged, patients require twice-weekly blood testing and weekly outpatient follow-up with their transplant clinician for the first 12 weeks post allo-HSCT. Appointments are only 20 minutes in length, with the primary focus being on blood result review and pharmacological titrations, leaving little to no time for patients and carers to raise their concerns and worries. There is currently no facility for multidisciplinary team members to be involved due to a lack of integrated care systems and limited access to the consultative specialist services which are often required in routine care of this cohort. Additionally, day treatments are often necessitated (e.g. blood product transfusion) and patients can expect to be readmitted at least once for inpatient treatment of related complications in the first year post-transplant. This places considerable burden on the patient and carer/s, especially those from remote/rural areas, who comprise over 20% of our local transplant population, and are required to relocate to metro Adelaide for such duration.

Following this period, care is less frequent and often fragmented, placing burden on the patient and carer to appropriately identify and report new symptoms between scheduled appointments. This is magnified the longer one survives after their transplant, with many long-term survivors becoming lost to this critical follow up. These appointments can be difficult to attend due to decreased performance and increased frailty, disability from chronic complications and returning home to remote/rural residence. As a result, patients often only present once symptoms have become moderate to severe, with such delays in care leading to more severe complications that are difficult to manage.

Consequently, the financial cost of allo-HSCT and its associated complications is profound. A 2009 report determined the average cost for the first year of allo-HSCT care in Australia to be $114,316 per patient, with a projected 10-year cost increase of 62%. Locally, this equates to an over $9m expenditure for HSCT annually. Additionally, the cost of standard outpatient care alone for long-term survivors was reported at $8,363 per patient annually, equating to over $2.3m locally (Gordon et al., 2009). When coupled with the benefits of capturing the patient experience using PROMs, this underscores the rationale to improve supportive and survivorship care in this cohort within which PROMs are firmly embedded.

We anticipate the benefits of our long-term vision to South Australian healthcare consumers will include:

- Improved health-related quality of life for allo-HSCT recipients
- Earlier diagnosis and intervention of transplant complications
- Reduced interaction with the healthcare system through reduction in disability
- Support for a multidisciplinary care model to reduce isolation of clinicians/specialists in managing complex conditions

This will result in:

- Personal benefits to the patient and their family.

- Reduced incidence of severe transplant related side effects in allo-HSCT recipients.
- Economic benefits achieved through fewer rates of hospitalisation and the provision of expensive, supportive care.

To realise these benefits, we set out to identify and understand the priorities in allo-HSCT recipients and their carers, and to establish mechanisms that effectively promote the longitudinal collection of PROMs in allo-HSCT recipients. In doing so, we will shine an important light on the needs of allo-HSCT recipients. These will be used to inform future supportive and survivorship care plans, including our own.

Consumer Partnership

Consumers have been at the centre of this initiative, including from the initial application, developing methodology, and facilitation of the forum. The consumers and their supports are at the centre of the vision. This design was recognised as unique, and the first time such an initiative had been submitted to the Central Adelaide Local Health Network Human Research Ethics Committee (CALHN HREC).

It is essential to partner with consumers, as recognised by both the Australian Commission on Safety and Quality in Health Care (Standard 2) and the SA Health Consumer, Carer and Community Engagement Strategic Framework (Australian Commission on Safety and Quality in Healthcare, 2024; Government of South Australia, 2021). These aim to strengthen and improve consumer partnering.

Consumer involvement should not be perfunctory. We did not partner with consumers to merely fit the grant criteria. We desired, and drove, meaningful collaboration which had a positive impact on methodology and ultimate outcomes.

This initiative was the first of its kind for South Australia, with limitations to both time and budget to meet the grant requirements. Achievable methodology had to be arrived at, balancing research integrity with open-ended inquiry of patient experiences post allo-HSCT, a process that could be described more akin to market research.

Collaboration with consumers prompted a revision of the methodology, shifting direction based on their recommendations to the most effective ways to gather information. Consumer leads advised that facilitated interview would be less effective than survey methodology for the first phase, considering impacts of fatigue and cognition (‘chemobrain’). Survey methodology allowed the participant the time to consider their response and add additional responses as they further considered their day-to-day life and impact of treatments.

The consumer leads at the forum assisted participants to be amongst peers, aiming to reduce risk of the participants feeling like subjects, instead focussing on a team approach, open to sharing in a supported environment. The participants, along with the research team, were motivated to drive health care improvements. Consumer leads were well placed to share the role of facilitators and scribes at the forum event in Phase 2, demonstrating skill beyond that of providing feedback alone or merely perfunctory. This was, and continues to be, a unique and positive partnership.

As with all research projects, certain requirements were required by CALHN HREC. As participants are receiving health care from CALHN (as outlined in the participant inclusion criteria), they may be perceived as vulnerable. However, the participants were able to opt to participate, or not, and thereby the concern of being vulnerable or persuaded was minimised. Due to the perceived vulnerable cohort, the initiative required a full ethics review, which could be perceived as overzealous for an initiative where contact initially only comprised of providing contact details to initiate a letter of invite, where invitee could either indicate that they wanted or participate, or not. The need for further governance, as required by CALHN Research services, including a Site-Specific Assessment (SSA), created additional requirements which could be perceived as bureaucratic. To improve upon this, we recommend deeper collaboration between CALHN HREC and research team (including consumer leads) to understand and meet the needs of the organisational requirements, as well as being informed regarding delays and barriers from research progressing. It was imperative to balance the requirements of CALHN Research Services with the passion of the team members and requirement to deliver outcomes within the limited time availability.

All team members strongly believe that lived experience should guide the development of this research, and its future implementation. It is also recognised that the breadth of experiences post-transplant is varied, and the group has aimed to take this into account when considering how to engage with consumers who may or may not have complications following their allogeneic transplant.

Project aim

Identify the most important issues impacting allo-HSCT recipients and carer/s to inform the development of an electronic patient reported outcome measure (PROM) platform for post-transplant survivorship care.

Phase 1:

To identify the most burdensome/impactful concerns of allo-HSCT recipients.

Phase 2:

To explore the preferences for reporting these concerns in the post allo-HSCT setting.

Our approach (Methodology)

Phase 1

Participants were recruited utilising the CALHN registry of existing SA based allo-HSCT patients (n=178, see Figure 1). Of these, 84 (47%) expressed interest in participating, with 76 (43%) completing demographics data.

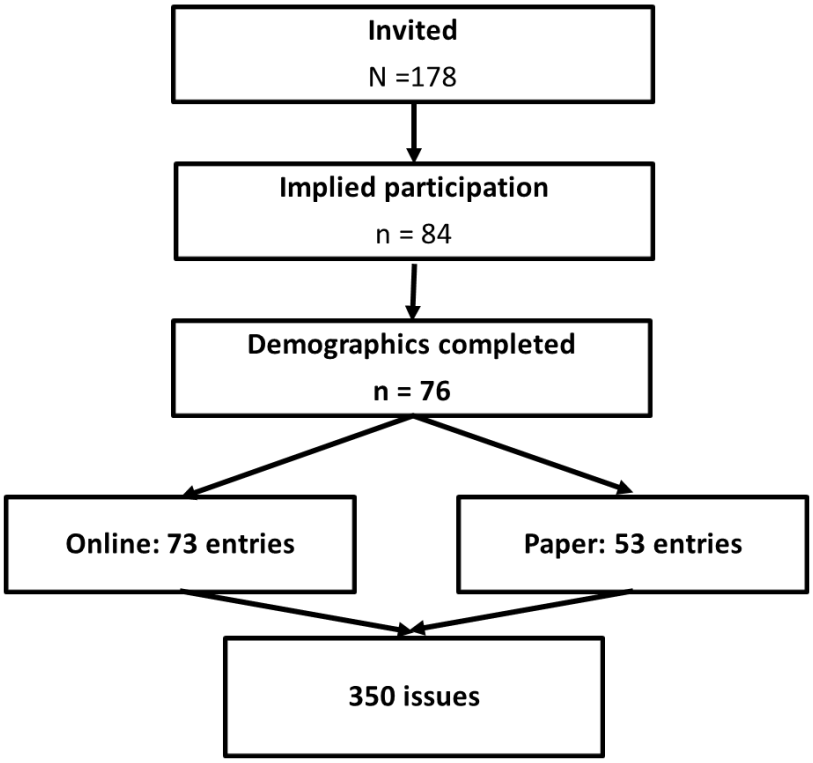

Figure 1, Phase 1 recruitment and participation schema.

Participation was voluntary, and consent was gained prior to data collection. A breakdown of participant demographics is presented in Table 1. Identical electronic and paper-based surveys were distributed. These surveys asked patients to identify at least one issue/difficulty/concern or unmet need they had experienced following transplant (see Appendix 1). Whilst participants were asked to focus on one issue at a time, they were directed to complete for as many issues that they wished to report on. For each issue, patients rated a) the impact on a scale of 1-10, b) indicated onset timing, and c) whether the issue persisted at present. Participants were also given the opportunity to provide any further information about the issue and its impact in free text comments.

Surveys were collected over a seven-week period. Following this, data was de-identified and collated. Thematic analysis was performed on all issues raised within the entries. This involved reviewing the data, identifying themes, assigning themes with codes and categorising the data. Further revisions were completed, producing a final list of themes. The codes underwent multiple reviews, with input from a wider team including consumer representatives. These revisions identified the final seventeen domains across the three themes.

It is noted that this study inherently selected for a population that was not lost to follow up. Patients who have no concerns and are relatively healthy are more likely to be disengaged

than those still engaged strongly in the health system. Conversely, patients who are severely disabled by their treatment and are unable to access appropriate support may also be lost to follow up.

Phase 2

Participants from Phase 1 were invited to attend a forum. These participants were also invited to share the invitation with a support person or carer to attend also (n=33 participants, see Figure 2 for recruitment overview and Table 1 for participant demographic details). A further 3 participants had indicated their interest but were unable to attend the event.

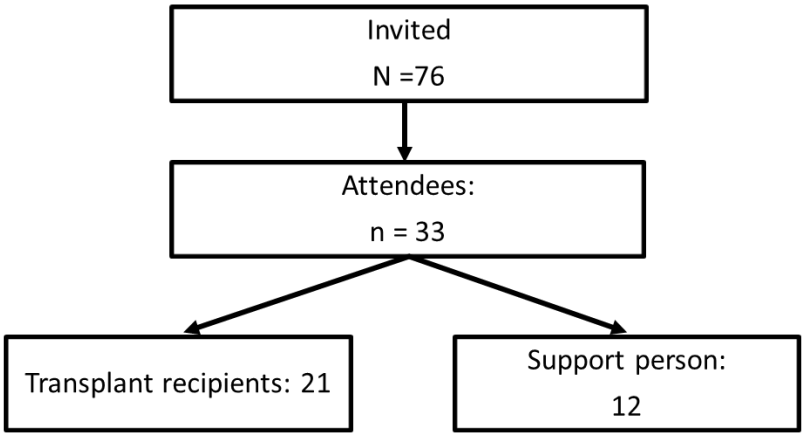

Figure 2, Phase 2 recruitment and participation schema

The forum was prefaced by an introduction to the research team, and the supporting team members present from the Commission for Excellence and Innovation in Health Patient Reported Measures program. Key principles of peer support were outlined, to assist forum members to feel comfortable to share their experiences openly. The introduction presentation also shared with the consumers that this is a research project, seeking their feedback, however there were no guarantees as to outcomes or deliverables. An overview of learnings from Phase 1 was shared with forum participants (see Figure 4).

The concept of a 'tool' to report issues/concerns was introduced, using the below pictorial (Figure 3). Whilst the term usually refers to the specific survey or questionnaire used to capture the patient experience, for the purpose of the forum it was used to encompass both the data input and digital platform.

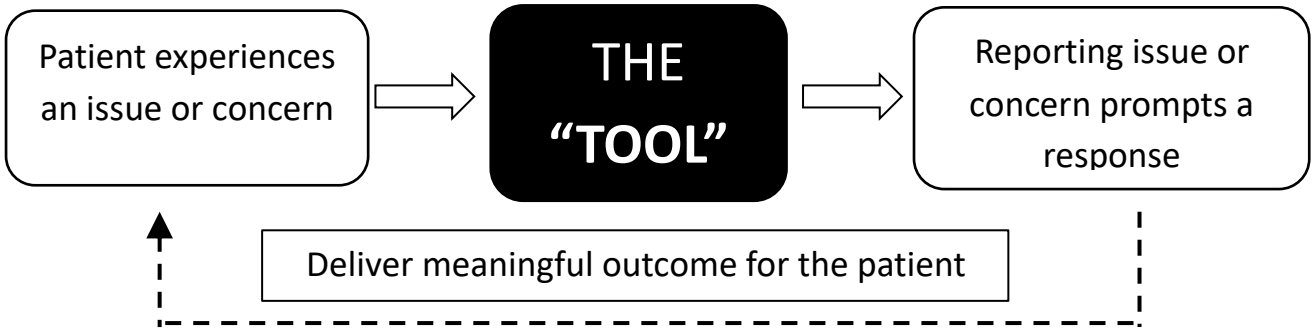

Figure 3, Pictorial shared at Phase 2 forum

A follow-up survey was conducted to confirm the results found in Phase 1 (Appendix 2). This survey asked participants whether they experienced symptoms within the key themes, and if so, to rate the severity experienced. It also asked participants whether they agreed the theme would be important to monitor in allo-HSCT survivors.

Following this, breakout groups were formed. Each breakout group had representation from the study team and/or the CEIH PRM staff. This supported the groups to have a facilitator and a scribe. The study team had prepared guiding questions for the facilitator to utilise as required. Discussions were facilitated regarding the tool. Discussions included:

- What the tool should include.
- When participants should report.
- Where patients should report – online, as a downloadable app, as a mailed-out survey, or as a paper-based survey in clinic prior to appointments
- How reporting should occur (i.e. as a multiple-choice survey, journal, or as prompt with optional response sections).
- Who should be allowed to use the tool.
- Potential barriers and facilitators to reporting.
- What patients would like the response to their inputs to be. For example, who should respond, what should the response be, and within how long after the patient submits their data to the tool.

Facilitated whole-forum discussions were intermittently performed, providing further consensus on matters. These discussions were also recorded.

Following the forum, the survey was analysed and compared to Phase 1 results. Scribes from each breakout group took notes throughout the event which were also compiled for evaluation.

Results and discussion

Table 1 describes the breakdown of demographics for participants across the two phases of the project. Over 50% of participants experienced chronic graft versus host disease, which is higher than the median experienced within the CALHN cohort, with local data revealing incidence of 30%, congruent with national and international data.

Table 1, Demographics of transplant recipient participants

Characteristic	Phase 1 (n=76)	Phase 2 (n=22)
Median age years (range)	60.5 (19 to 80)	52.5 (19 to 75)
Gender n(%)		
Female	35 (46%)	10 (45%)
Male	41 (54%)	12 (55%)
Years since allo-HSCT (Median + Range)	5 (2 - 31)	5 (2 - 26)
Rurality (MMM* 3-7), n(%)	19 (25%)	5 (23%)
Remission n(%)	67 (88%)	20 (91%)
GVHD n(%)		
Acute	33 (43%)	8 (36%)
Chronic	39 (51%)	13 (59%)

** Modified Monash Model remoteness classification*

Phase 1

Allo-HSCT patients experience a wide variety of symptoms. Within each broad symptom category, the description of symptoms was distinct, suggesting a fine level of nuance within the patient experience. For analytic purposes, symptoms (of which there were 350 in total) were broadly categorised into 3 areas: physical, psychological, and environmental. Within these areas, symptoms were grouped into 17 key domains, as seen in Figure 4.

Physical:

Ten physical symptoms were consistently reported (Table 2). Secondary illnesses ranked as the most experienced physical issue. Secondary conditions were diverse including GvHD, recurrent infections, vaccine induced shingles, donor-derived myelodysplastic syndrome, and blood circulation issues (peripheral clots, haemorrhages). Tiredness was commonly reported and is a well-known symptom of aggressive treatments that allo-HSCT patients receive. Sexual issues were wide-ranging, including impotence, loss of libido, early onset menopause, infertility, low oestrogen and pain during sex. Gastrointestinal issues were another commonly reported issue, however, this category is broad with a range of conditions experienced/reported such as diverticulitis, mucositis, diarrhoea, emesis, faecal incontinence and diet-related restrictions. Sleep issues were reported as distinct from tiredness, as this category included disordered or interrupted sleep and night sweats. Eye issues included

gritty feeling, dry eyes, blurred vision, a heightened sensitivity to brightness and general eye irritation.

Psychological:

Mental health was the most commonly reported issue. Patients described depression, anxiety, grief and PTSD. Loss of lifestyle was also consistently reported, at a rate higher than all physical symptoms excluding secondary illnesses. Cognitive issues such as memory loss, reduced executive function, and a general decline can be termed broadly as chemobrain. This term signals the unfortunate offside effects of the extreme treatment protocols that patients complete. Chemobrain should not be underestimated as it limits a patient's ability to self-manage other symptoms and comorbidities, and to improve all other facets of their post-treatment life. Social isolation is a commonly reported issue as patients re-integrate into society following years of treatment and altered abilities. It is also an issue due to the nature of allo-HSCT treatment which is associated with a long-term immunocompromised state.

Environmental:

Whilst environmental issues did not rank highly compared to physical and psychological issues, they nonetheless represent significant issues experienced by patients and families. Patient's felt they lacked knowledge and support. Almost half of patients still experience this (Figure 9). The "knowledge" domain included a lack of knowledge about one's condition, the red flags to watch out for, how the treatment process works, or a lack of knowledge on the services available to patients and their families. This can be considered as contributing to the family stress some patients reported.

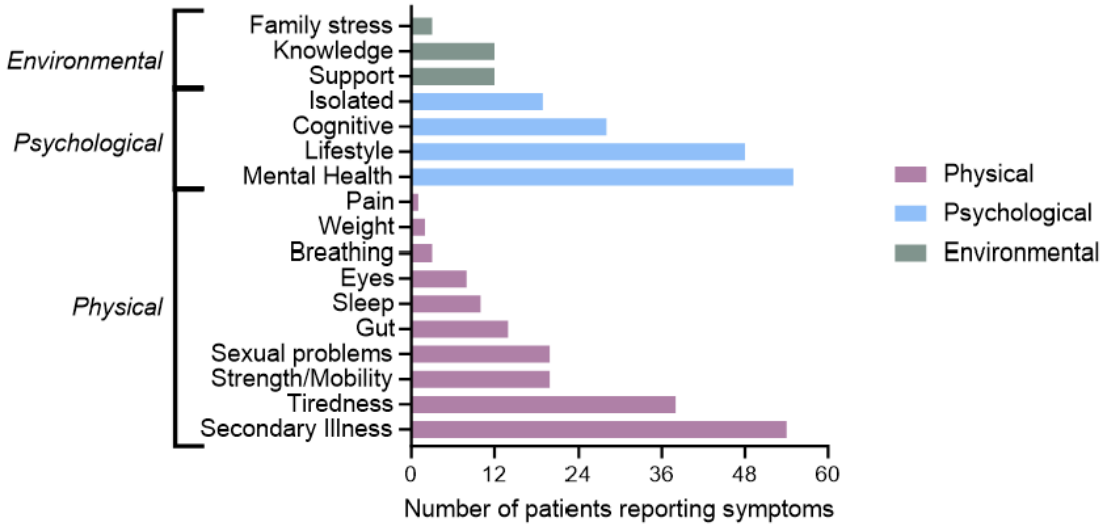

Figure 4, Survey participants reporting symptoms across all domains.

Sample quotes for each symptom have been provided in Table 2. Whilst an effort has been made to provide representative excerpts, quotes may not be representative of each domain given the diversity of cohort experience.

Table 2, Survey results including participant excerpts.

Domains	**Quotes**
Theme 1: Physical	
Gastrointestinal	*"This was extremely bad. I would wake up and vomit so many mornings... Constant nausea was horrible, sometimes if I didn't like [scent] that was enough for me to vomit… I had vomit bags EVERYWHERE in case I needed to vomit. I still get nausea some mornings. Especially taking [tablets] because it is so big. I cut it in half, but it doesn't go down smoothly so sometimes I choke and vomit."*
Breathing	*"I was diagnosed with pneumonia... I had shortness of breath which meant even… walking to the toilet it was difficult to breathe. About a month later I was diagnosed with pneumonia again, but this time I had extreme shortness of breath to the extent I had real difficulty walking anywhere… I was even awoken gasping one morning… Simple tasks like making the bed, having a shower, getting dressed are difficult, due to [ongoing] lack of breath. Cleaning the house, I have to do it over days as I get tired, especially doing the floors."*
Strength and Mobility	*"My physical weakness means that I have to rely on my partner to do things for me e.g. hang the washing on the line, drive the car."*
Eyes	*"This is one of the hardest things to deal with [reduced/lost vision]. I could not read my phone or do colouring in books which is the main things I was doing in hospital ward… I was an artist and I find it extremely hard to paint like I used to. It has improved a little but have been told it will not improve anymore… I find my eye problems has increased my depression severely."*
Weight	*"I put on 40 plus kilos during my transplant… my body hasn't been the same… I struggle even being confident."*
Sleep	*"I do not have a problem going to sleep but wake up [middle of night] and find it hard to go back to sleep… My doctor has prescribed sleeping tablets."*
Excessive tiredness	*"Wear out quickly and easily. Often need an entire day to recover from 'too much in a row'. Often take naps. Fatigue increases if I have a bad night of sleep. This worsens my memory and word recall."*
Sexual health	*"Have no interest in sex due to the fatigue and I had narrowing of the vagina passage. I didn't know there was such a thing as GVHD of the sexual organs until I joined [online support group]. I was referred to a gynaecologist who confirmed GVHD. I now treat it every night with a cream or a suppository... Sex has become painful."* *"When diagnosed with AML [in early 20's] I was unable to freeze my eggs… as treatment needed to start immediately… We now need to explore surrogacy in order to have a family. This has had an enormous impact on mine and my husband's well-being. I understand that at the time the priority was to save my life - however I feel as though there was very little consideration for my fertility… I feel as though I was not included in making this decision - I was never given the opportunity to postpone my treatment to harvest my eggs… Obviously being alive is of most importance however I can't help but wonder if I could have also*

	stored my eggs and avoided this long-standing pain and disappointment."
Chronic pain	*"I am under the care of a pain specialist and have been prescribed pain relief by [them]. Every time I come into the RAH via the ED - the Doctors are always trying to reduce my pain medications or change it to something else… without notifying my specialist of my admission."*
Secondary illnesses arising from transplant	*"Scarred areas on my scalp so [hair] can't grow properly."* *"Dark marks on my face that make me self-conscious."* *"[After] transplant the skin on my hands and feet thickened and went yellow making it very painful to hold anything or walk. This particularly was bad for walking the dog on a lead."* *"Loose thin skin on upper arms which make me self-conscious."*
Theme 2: Psychological	
Memory, ability to concentrate and/or problem solve	*"It was quite jarring for me at the time to not be able to keep up mentally, unsure if I would be able to return to work etc. and I felt very reliant on others… It did get better 12 months [later], and as time went on, but it did have the most impact for me, i.e. not able to read and retain information."* *"Pre-transplant I would complete a daily Difficult Sudoku with 95% success rate however lately I would be lucky to complete 25%."*
Feelings of depression, anxiety and/or low self-esteem	*"Once I realised a lot of the side effects from chemo + transplant were permanent or long term I became very depressed and found myself grieving a lot of nights before bed or during/after specialist appointments."* *"I had very severe depression while in hospital the first few months I would constantly be thinking how I could kill myself in the hospital wardroom. Although I don't think about suicide as much, I… struggle with daily life. I often wish I had killed myself in the time frame I was in hospital. I see a psychologist and a psychiatrist and have been to mental health hospitals a few times."*
Feelings of one's lifestyle being lost	*"Because of so many problems and appointments I am not able to work. I am on a disability pension which limits finances - [rent], social events, having spending money, hope for anything like a car or big costs."*
Feeling isolated or alone	*"When going through transplant, you don't feel or think about being removed from society as your focus is to improve. It is not until later due to the length of being away and time of recovery, I have felt disconnected. The lack of understanding of others is especially challenging too… I can't participate in physical activities."*
Family related stress arising from transplant	*"I have been left with a lot of serious side effects after spending [time] in ICU after transplant. Six years post-transplant I still can't work. My family has been left with everlasting mental problems, especially my daughter."* *"Lockdowns, leaving children w/ relatives/carers, kids in school interstate (home state) etc. was very difficult. I know there is little that the team could do as it is an external/environmental factor, but this was a cause of great stress and worry. What if I die and my family aren't here with me?".*

Theme 3: Environmental	
A lack of support	*"Felt I had to do a lot of my own research and alone in my struggles with GVHD. There has never been a home assessment done so that it can be understood better what I have to do each day. I have been through some terrible grief in losing a very close friend, caring for my [parent] up to their death and then performing CPR on my [other parent] at a witnessed arrest - which they did not survive - all of this year at the same time as my own health has been declining."* *"I have now got severely reduced range of movement/pain/cramps/breathlessness on exertion and chronic fatigue that makes housework and activities of daily life difficult. Having some kind of help would be so wonderful."*
A lack of control or knowledge about one's condition and/or treatment	*"No one has quite ever explained to me what having VRE really means. I know people have to gown up when I am in hospital but what about if I kiss or have sex with someone? Do they get VRE too? And what are the consequences for them?".* *"Prior to the transplant I felt very prepared, I met with my haematologist and Transplant Coordinator… I was very aware of the statistics for success, that I could end up in ICU and that GVHD was a real possibility, as well as the number of drugs I would need to have. What I wasn't aware of was all the other possible issues such… I feel as though a lot of energy (and rightly so) went into preparing patients leading up to and during the transplant and initial time post but from 3 months post is really up to patients to bumble their way through... A list guiding patient's what to expect or suggest such as after 6 months go get your eyes checked, after 3 months see an exercise physiologist, if you notice [symptom] then contact [clinician]."*

Symptoms experienced are individual and nuanced, with these individualisms extending to the severity of symptoms experienced. However, irrespective of domain, the majority of participants rated their symptom severity as moderate to severe in all domains but weight (Figure 5).

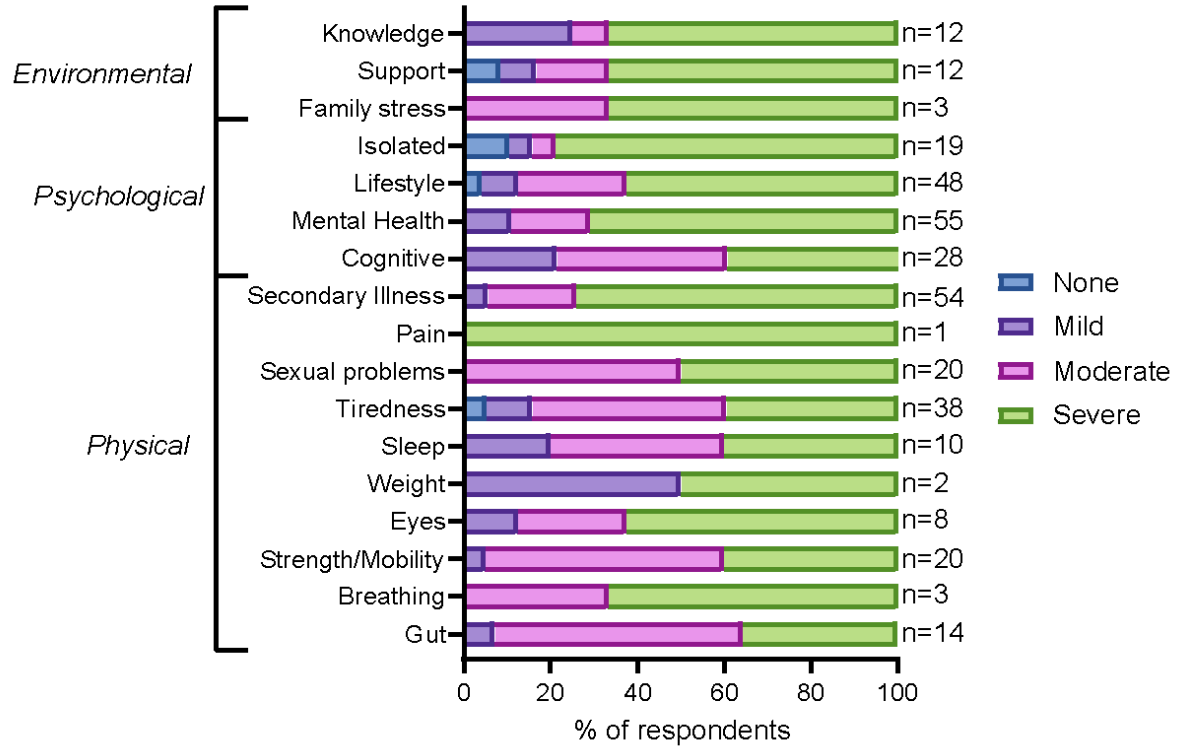

Figure 5, Reported symptom severity across domains, Phase 1 survey.

Another variability is the timing of symptom onset. Broadly, for physical and psychological symptoms, onset is generally within the first 3 months (Figures 6 and 7). For environmental symptom onset, there was no clear pattern (Figure 8). It may be the case that patients generally struggle with a lack of information within the first 3 months and adjust. However, given the nature of the current follow-up system, a lack of support is felt before the transplant, and after the initial monitoring - approximately one-year post-transplant - has finished. Given the psychological stress of a loved one undergoing an uncertain procedure when already unwell, it is unsurprising that family stress is high in anticipation of transplant. Although it is unclear why family stress does not re-peak with onset of physical and psychological symptoms at <3 months after transplant, instead re-peaking at 3-12 months post-transplant.

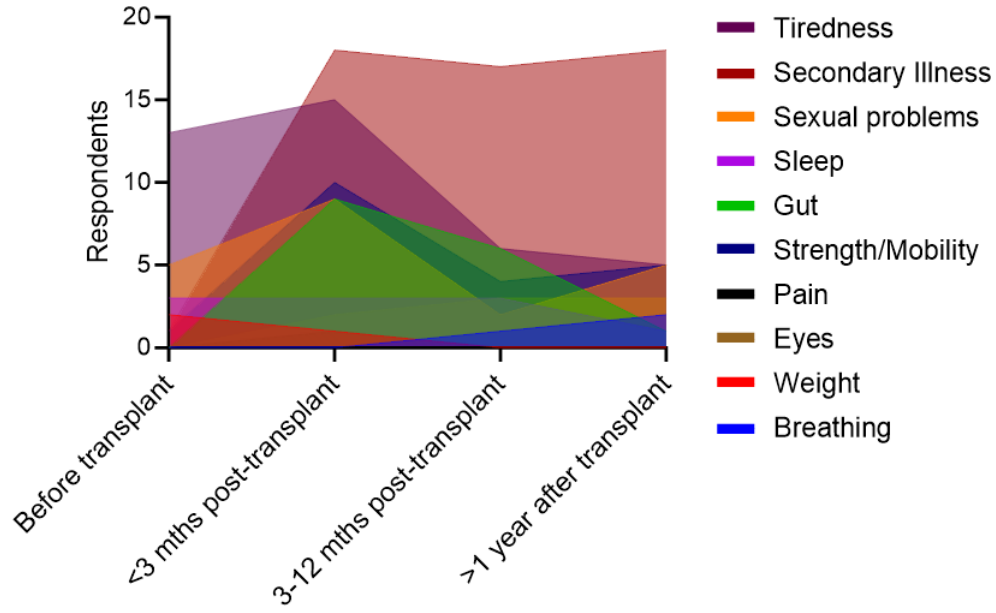

Figure 6, Onset of Physical Symptoms, Phase 1 Survey

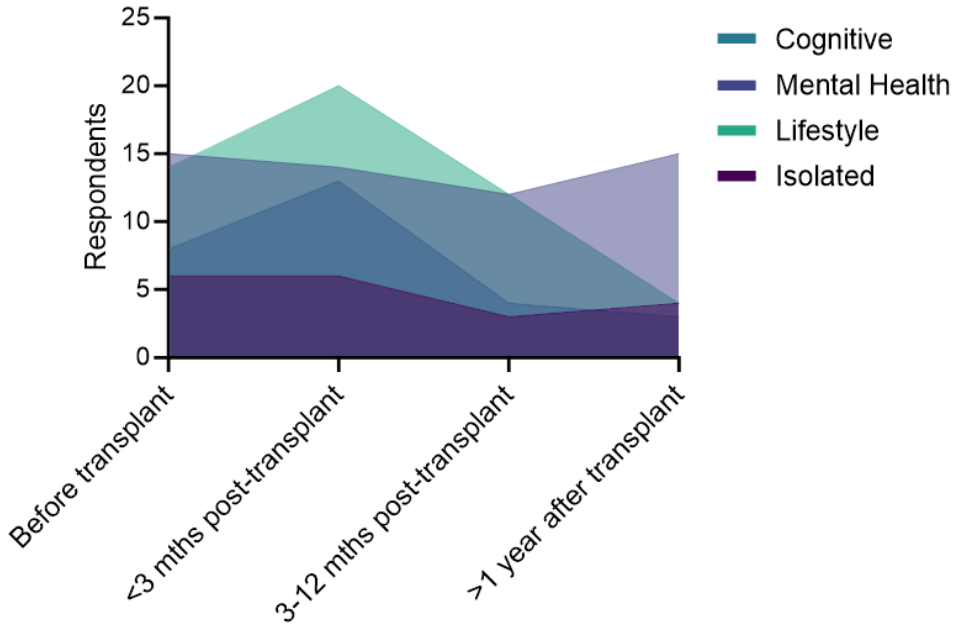

Figure 7, Onset of Psychological Symptoms, Phase 1 Survey

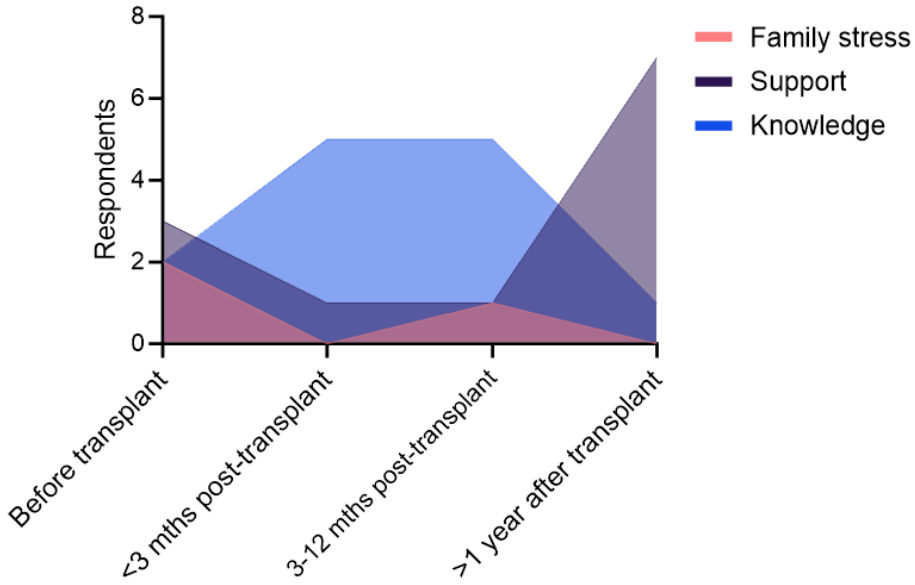

Figure 8, Onset of Environmental Symptoms, Phase 1 Survey

A large proportion of patients continued to experience the complications of their condition at the time of survey (Figure 9). Patients were a median of 5 years post-transplant (range 2 to 26 years). Yet, their complications, particularly physical and psychological, persist.

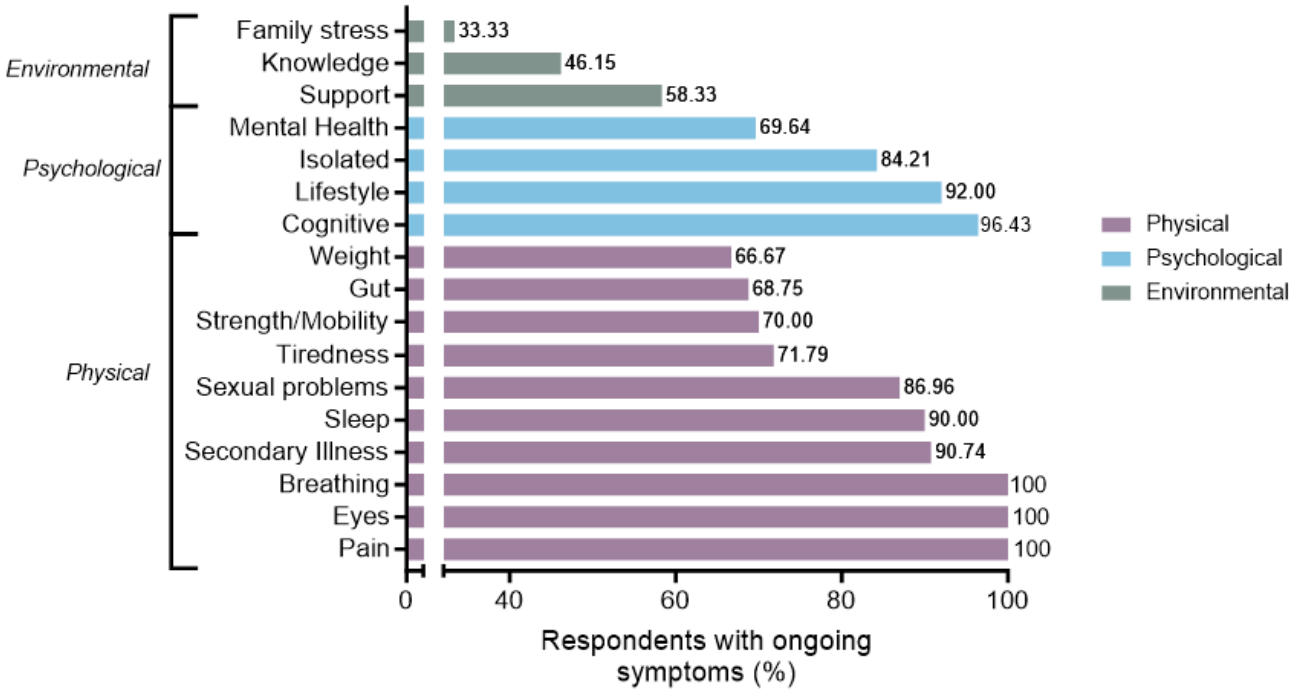

Figure 9, Proportion of respondents with ongoing symptoms, Phase 1 Survey

Phase 2

At the forum, a survey was used to enquire regarding patients experience of symptoms within the identified domains. Patients reported a high symptom load, with a median number of 13.5 symptoms per patient, (range 5 to 17, Figure 10).

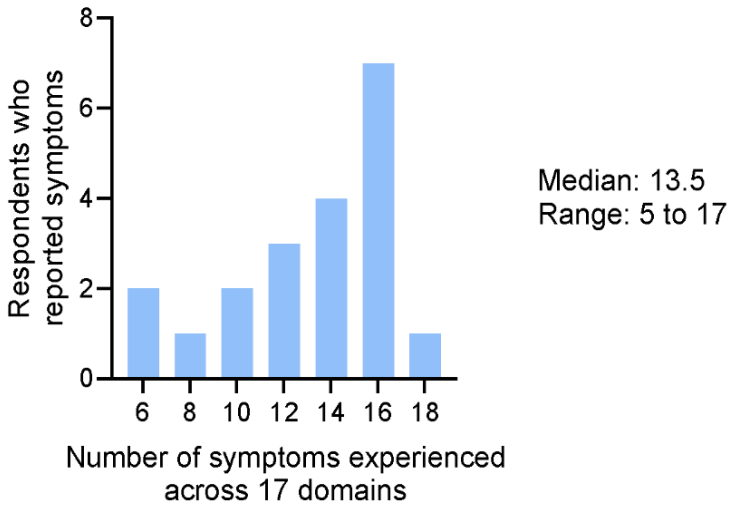

Figure 10, Number of symptoms reported by Phase 2 respondents.

Physical symptoms such as secondary illnesses, strength/mobility and gut issues, persisted for above 50% of respondents, (n=20, see Figure 11). The questionnaire did not explore whether symptoms were ongoing.

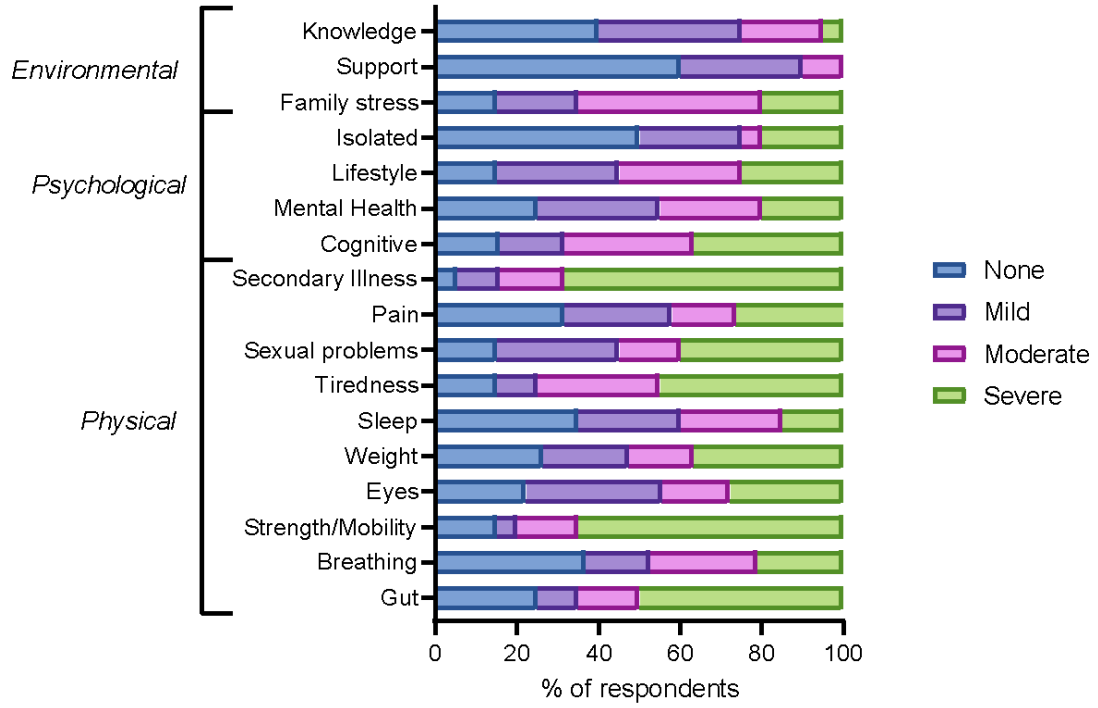

Figure 11, Severity of symptoms reported by Phase 2 respondents.

Severity of symptoms are compared in Figure 12. With the exception of strength/mobility, severity decreased at follow-up compared to the initial survey. As the forum was an optional self-selected cohort, it is perceivable that participants with mobility issues and may have opted out of attending the in-person forum. Thus, the values given may underestimate the real figure. This effect may also be present when interpreting results for the support domain and psychological symptoms. i.e. those suffering from a lack of support or are suffering psychological hardship are at increased risk of being lost to follow up.

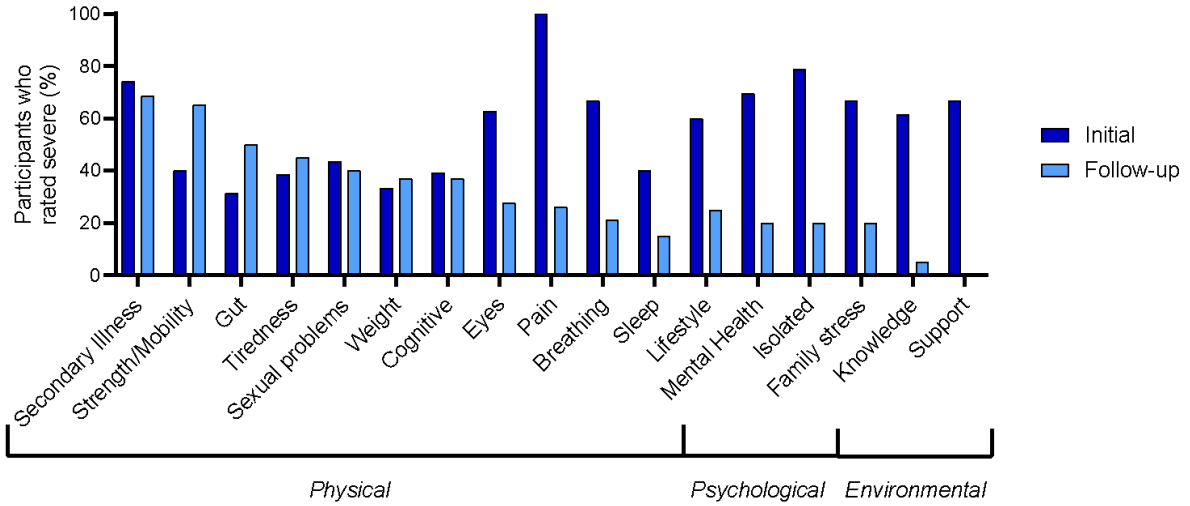

Figure 12, Comparison of symptoms severity across Phase 1 and 2 surveys.

The forum also facilitated broader discussions on the requirements of a patient reporting mechanism to undertake remote symptom monitoring for PROMs. Key themes are identified in Table 3. There was consensus amongst the group that allo-HSCT related concerns are currently poorly prioritised, not adequately captured and variably addressed. Infrastructure such as an electronic tool was strongly endorsed to facilitate human interactions, but not replace them. The patient reporting mechanism should be flexible, specific to each patient, transparent, educational and allow patients to track their symptoms over time. The concept arose that this tool should be a medical 'passport' for patients to use throughout their health journey, where members of their care-team have access, and patients are able to update and maintain ownership of their reports. Key themes and illustrative quotes are below (Table 3). Please note that in the illustrative quotes in Figure 3, participants refer to the data input and output as the 'tool'.

Table 3, Key Findings from Forum.

Key Themes	Illustrative Quotes
The PROM solution needs to be flexible in terms of reporting time, how to report, what to report on, who can enter data and who can respond. The tool should not simply be a series of surveys.	*"People must know what symptoms to look out for so that important issues do not go undetected or ignored".* *"There must be opportunistic reporting so that people can report issues that come up at any time (photo-capability is important too)."*

	"The tool should store information in a way that can be easily shared with other health professionals as needed." *"The tool must support carers who are often the ones taking charge of symptom monitoring and reporting."*
Data entered should be reviewed by an experienced clinician and support the patient to know what requires timely escalation and how to escalate their concerns.	*"People need to know that someone is taking an interest in what they report. People prefer to know that the response is coming from someone with expertise and who they know."*
The PROM solution needs to provide escalation advice so that patients are not reliant on it in critical situations.	*The "tool must have a mechanism for triggering a response to serious issues that are reported ('red flags') … no-one should 'fall through the cracks' because they didn't know what was important."*
The solution should consider patient history and comorbidities beyond their chemotherapy and allo-HCST procedure.	*"The tool should store information in a way that can be easily shared with other health professionals as needed… It should feel like a diary or passport with key information [such as] treatment plan, common symptoms, rarer symptoms that may be important."*
Patient privacy is important. Patients should own their data.	*"The tool must ensure privacy of data and protect patients as owners of their health information."*
Patients want to connect with their peers. The tool should facilitate this.	*"Peer-support and ways to self-support are so important to people."*
Patients want to be more than their set of symptoms. The PROM solution should take this into account	*"The tool should facilitate cutting through the chaos of appointments but providing information that directs the conversation on matters the patient and carer wish to discuss."*
The PROM solution should provide education in a clear format to avoid overwhelming patients. It should also enable patients to engage with GPs and other specialists in a meaningful way, and assist identify relevant resources.	*"It is crucial that the tool has an education section with relevant links.* *This needs to be in dot points so that overwhelmed patients and carers can digest it. It also needs to be practical - what to look out for, what to do if you feel such symptoms… the tool should also have education section for GPs and non-specialists."*
The PROM solution should have multiple capabilities: • Speech recognition software • Photo-capable • Shareable online (e.g. to GP, allied health professionals) • Printer-friendly • Record results (e.g. blood tests) • Record vitals • Calculate QALYs • Accessible to those with ESL • Accessible to AV impaired	*There is a "desire for [the] tool to be a live document to be added to as long as needed. Whilst surveys may be required, there was a strong message to avoid the tool simply being a series of surveys."* *It is "important to get the design right. The tool should be electronic to facilitate instantaneous reporting and response."* *"The tool should provide a mechanism for basic reporting of vitals."*

• Accessible to individuals without internet or smartphones	*"There could be questions to report 'holistic' wellbeing."* *"It should feel like a diary or passport with other key information: Treatment plan, common symptoms, rarer symptoms that may be important."*
The PROM solution should have multiple sections: • Education • Journal • Symptom reporting with tracking to see trends over time • Patient history section to stop patients having to constantly repeat their story • A place to record both the positives and negatives of their healthcare journey • Health history	*"In post-transplant phase you are in almost every way a newborn. Such a need for information & support as you take on new roles - pharmacist, physio, nurse etc."* *"Need information about what symptoms to expect (however information overloaded leaving hospital)."*

It is recognised that participants in this initiative may not fully represent the broader population of allogeneic stem cell transplant survivors. Individuals with significant health challenges or limitations might not have had the energy or physical ability to participate. Conversely, those who are thriving without complications may have felt they had little to contribute.

While this project identified key opportunities for improvement, it is recognised that the transplant service has implemented various initiatives that have impact upon the transplant trajectory, including symptom burden and long-term care. These previously implemented measures might not have affected patients who underwent transplantation before these interventions were introduced.

Key Findings

In Phase 1, it was identified that participating allo-HSCT survivors experience a breadth of concerns across numerous domains. These concerns are temporally dynamic, with many persisting years into survivorship. The impact of these concerns are personal and nuanced, impacting both the individual and their broader network of friends and family.

In Phase 2, participants expressed that their concerns are poorly prioritised, not adequately captured and variably addressed. Consumers identified the necessity of a platform to easily capture their concerns enabling patients to self-monitor, document and reflect, report symptoms before a routine appointment, get more targeted support/care for unmet needs and concerns, aid communication between healthcare teams and patients; identify problems outside of routine appointments, and enable early interventions.

Recommendations

The outcomes from this study have led to the following recommendations, to address the challenges faced by allo-HSCT recipients and their supports and to improve their care experience.

1. Implement Remote Monitoring and Early Intervention:

    - **Recommendation:** Implement a digital platform for PROM collection, enabling patients to report symptoms and concerns in real-time. This platform should trigger alerts to care teams for early intervention when patients report moderate to severe symptoms. As the symptoms reported are nuanced, the data input should have capability for the user to add their specific concerns for monitoring. The ability to incorporate free text or open-ended questions may assist to identify and monitor such symptoms and should be considered for adaptation into a PROM tool for this cohort.
    - **Rationale:** Early identification and management of complications can prevent the progression of symptoms and reduce the need for hospitalisations, ultimately lowering healthcare costs and improving patient quality of life. The breadth of issues faced by this cohort is vast and varied, and existing symptom assessment tools do not allow for adaption to incorporate the nuanced symptoms that may be experienced following allo-HSCT.

2. Patient Education and Self-Management:

    - **Recommendation:** Integrate educational and self-management tools within the PROM platform. These could include information on recognising critical symptoms to report, self-management strategies and accessing available services.
    - **Rationale:** Empowering patients with knowledge and resources for self-management can alleviate some of the burdens associated with allo-HSCT and reduce reliance on the healthcare system. This is particularly important for patients in remote or rural areas who may have limited access to specialised care. It is essential patients know what to report, and how, to assist early intervention.

3. Consumer-Centric Design of platforms:

    - **Recommendation:** Continue to involve patients and their caregivers in the design and refinement of the PROM platform. Ongoing iterative testing and feedback loops to ensure the platform meets their needs and preferences.
    - **Rationale:** A consumer-centric approach ensures that the platform is user-friendly, relevant, and effective in capturing the nuances of the patient experience. This can increase patient engagement and improve the quality of data collected, which can then better inform future initiatives.

4. Further Integrate the Multidisciplinary team into care:

    - **Recommendation:** Develop a comprehensive care model that integrates multidisciplinary team members (e.g., psychologists, physiotherapists, social workers) into the routine follow-up of allo-HSCT patients. This should be hosted

on the electronic platform where all care providers can access patient-reported outcomes and collaborate on care plans.
- **Rationale:** Allo-HSCT patients face complex, multi-faceted challenges that go beyond the expertise of a single clinician. Integrating multidisciplinary care ensures a holistic approach to managing both physical and psychological symptoms, which can improve patient outcomes and reduce the burden on individual clinicians.

5. Enhance Consumer Partnership:

   - **Recommendation:** Consumer partnership was demonstrated to be beneficial throughout the project, and should be incorporating into future initiatives, with active involvement from the outset in design and methodology.
   - **Rationale:** A robust consumer partnership, as recognised by the Australian Commission on Safety and Quality in Health Care and SA Health's frameworks, leads to meaningful contributions that can shape a project's direction and outcomes. This approach ensures the research is relevant and respectful of the lived experiences of allo-HSCT patients.

6. Collaborate with Research and Ethics Committees:

   - **Recommendation:** Foster deeper collaboration with the CALHN Human Research Ethics Committee (HREC) to streamline the process for future initiatives. Consider collaborative meetings between research teams (including patient representatives) and HREC to explore and clarify processes and align research goals with ethical and governance requirements.
   - **Rationale:** Strengthening the relationship between the research team and ethics committees can facilitate smoother project implementation, reduce delays, and ensure that the needs of both patients and researchers are met.

7. Secure Funding and Resources:

   - **Recommendation:** Assess the costs and features associated with the digital PROM platforms on the market, allo-HSCT recipient and support team education tools, and multidisciplinary care integration models. Identify opportunities for funding to secure resources for platform maintenance, team training, and user support.
   - **Rationale:** Funding and resource allocation are essential for the successful implementation and sustainability of these initiatives. They ensure the platform remains fit for purpose, educational tools are current, and multidisciplinary care is well-supported, ultimately enhancing allo-HSCT outcomes and care quality.

While acknowledging that these recommendations may not be immediately feasible, they address the critical needs identified for allo-HSCT recipients and their support systems to enhance their overall care experience. Implementing these recommendations would strengthen support for allo-HSCT recipients, leading to improved outcomes and a better quality of life.

Acknowledgements

We would like to thank all participants, supporters and enablers of this study, including the CEIH, SAHMRI, CALHN, and SA Library Services. In particular, we would like to express our sincere gratitude to everyone who generously shared their experiences so candidly, and their thoughts on how we can improve allo-HSCT care in the future.

Awards

This initiative was awarded the Patients as Partners award at the CALHN Word-Class Care Quality and Improvement Showcase, 2024.

Presentations

Loft, N. *Patient Reported Outcome Measures (PROMs) in allogeneic stem cell transplant survivorship*, Blood Haematology Conference, Melbourne, 2023 [invited speaker presentation].

Loft N, Cibich A, Corsini N, Morton A, Sharplin K, Knox A, Lewis G, Wardill H. *Engaging with allo-HSCT survivors highlights implementing PROMs into routine survivorship care as key priority,* RAHsearch, [poster and oral presentation], Adelaide 2023.

Loft N, Cibich A, Corsini N, Morton A, Sharplin K, Knox A, Lewis G, Wardill H. *Patient Reported Outcome Measures (PROMs) in allogeneic stem cell transplant survivorship*, CALHN Cancer Showcase [presentation], Adelaide, 2023.

Knox, A, Loft, N. *Building a bridge between patient experiences and clinical knowledge,* CEIH Patient Reported Measures Research Symposium [presentation], Adelaide, 2022.

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Appendix

Appendix 1, Phase 1 Survey Excerpt

1. Please share **one** issue (or any difficulty, concern, or unmet need) you have experienced following your transplant.

_____

2. Please rank the impact this has had on you and/or your family.
For example, this may be the physical impact, social impact, financial impact, etc.

	1	2	3	4	5	6	7	8	9	10	
No impact	○	○	○	○	○	○	○	○	○	○	Most impact

3. When did this begin?

Before transplant

Within first 3 months after transplant

3-12 months after transplant

More than 1 year after transplant

4. Is this still a problem or concern for you?

Yes

No

5. Do you want to provide further information about this issue?

Perhaps you would like to share what this issue means to you, your experience at the time it developed or how it impacts you now. **This is optional.**

6. Would you like to list another issue (or difficulty, concern or unmet need) with us?

Yes – please go to the next page, if you want more pages, please contact us

No – please go to the last page

Appendix 2, Phase 2 Survey Excerpt

Validation Survey

Our survey that you complete late last year identified more than 300 different concerns and/or issues that allo-SCT (transplant) survivors face. We synthesised these down to 17 key themes. Based on these key themes, we would now like to know:

1. Did you experience *[theme]* and if so, how burdensome was it?
2. Do you *[theme]* is important to monitor in allo-SCT survivors?

This survey is anonymous

I am a:

- ☐ allo-SCT survivor
- ☐ carer/support person of an allo-SCT survivor (*Please answer based on **your experience of caring for someone** after allo-SCT and the **impact on you**)*

Concern / Issue	**How much did this impact you (at any time following the allo-SCT)?** **Please tick the relevant column:** **0 = no impact, 1 = mild impact, 2 = moderate impact, 3 = significant impact**				**Do you think this is important to monitor after allo-SCT?** **Please tick the relevant column.**		
	0	**1**	**2**	**3**	**Yes**	**No**	**Unsure**
Problems with your gut							
Problems with your breathing							
Problems with your strength or mobility							
Problems with your eyes							
Problems with your weight							
Problems with your sleep							
Problems with excessive tiredness							
Problems with your sexual health							
Problems with persistent pain							
Did you experience another illness/condition as a result of your transplant? *This could include problems with medications such as steroids.*							
Problems with your memory, or ability to concentrate or problem solve *(aka "chemo-brain)*							
Feelings of depression, anxiety, or low self-esteem							
Feeling like your lifestyle has been lost							
Feeling isolated or alone							
Feeling of stress to your family because of transplant							
A lack of support							
A lack of control or knowledge about your condition and treatment							

Appendix 3, Forum Group Photo