

REPORT

Blood and Marrow Transplant Network

Long-term follow-up experience-based co-design

Project progress report



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Executive summary

Blood and marrow transplant (BMT) has an established role in the treatment of a range of haematological, immunological and metabolic conditions, and for many people provides the only possibility of long-term survival. However, people who have a blood and marrow transplant and survive long term are at an increased risk of late complications resulting from their disease, from the treatment they had received prior to transplant and from BMT.

In 2016, the BMT Network released clinical guidelines for BMT long-term follow-up (LTFU)¹ and submitted a successful proposal to pilot experience-based co-design (EBCD) to develop key principles for their implementation. EBCD is a quality improvement methodology that brings consumers, carers and clinicians together to improve health services in order to improve the design, delivery and experience of healthcare.

Between June 2016 and August 2017, the project team conducted eight consumer and carer interviews and three clinician focus groups to understand the experience of post-BMT survival and long-term care. The findings were visually mapped from diagnosis to post-transplant care ([Appendix 1](#)) in order to identify the key points and interactions that shaped clinicians', BMT survivors' and carers' experiences of healthcare.

The results of these interviews and focus groups were subsequently taken to a co-design workshop in November 2017 attended by 20 consumers, carers and clinicians. At this workshop the participants thematically analysed the 140+ emotions, experiences and touchpoints derived from the qualitative phase of the project in order to identify strategies for improving the quality and experience of post-BMT LTFU. These strategies were categorised into *quick win*, *rational*, *long-shot* and *biggest impact* opportunities for improving LTFU.

LTFU service improvement opportunities

QUICK WIN

1. Improved access to exercise equipment and support
2. Clear direction to rehabilitation support services
3. Peer support services

RATIONAL

1. Consumer and carer education resources on LTFU. Australian based and endorsed to be credible
2. Database of services and specialists
3. Build relationships with organisations that have existing consumer and carer resource platforms

BIGGEST IMPACT

1. Increasing service capacity
 - a. nurses
 - b. clinic
 - c. allied health
2. Increasing coordination of medical, nursing, and allied health services

LONG SHOT

1. 'One stop shop' LTFU clinic
2. Restructure healthcare system

The BMT LTFU Working Group is now looking to embed EBCD into its structure and work – redefining its Terms of Reference and expanding its membership to include consumers and carers. This will allow the group to design the scoping, implementation and evaluation of the ideas outlined above.

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Introduction

Advances in BMT technology and techniques have resulted in an increase in both the number of people undergoing transplant and in the number of long-term survivors. In NSW there are more than 1600 survivors of allogeneic BMT, with approximately 200 children and adults undergoing allogeneic transplants each year. With improvements in donor selection, conditioning therapies and supportive care, 35-80% of allogeneic BMT recipients are now expected to become long-term survivors and be cured of their underlying disease.^{2,3}

All I wanted while I was going through it was to meet someone who survived.

– Consumer

However, survivors are at an increased risk of late complications resulting from their disease, treatment and the transplant itself. These complications may not only impair physical functioning but may also have significant impacts upon a survivor's psychosocial and emotional function – potentially leading to unemployment, relationship difficulties, financial hardship and social isolation. The collective impact of these complications is profound. Allogeneic BMT survivors experience a 30% lower life expectancy compared with someone who has not been transplanted.⁴ Furthermore, 66% of those who survive more than two years post-BMT report at least one chronic complication of BMT and 18% report a life threatening health consequence of BMT.⁵

In that 15 minutes, you've got to see the patient for follow up of their GVHD and everything else that's going on.

– Clinician

These poor health outcomes are compounded by the limited institutional support for BMT LTFU across NSW allogeneic transplant centres. While some BMT centres have been able to secure support infrastructure or staffing for BMT LTFU, all BMT services report limitations in terms of dedicated staffing, data management and resources.

The BMT LTFU Experience-Based Co-Design (EBCD) project brought together clinicians, non-government organisations, transplant survivors and carers to work collaboratively to identify and prioritise key improvements that could be made to LTFU care in order to enhance patient and carer experience, improve clinical care and refine clinical services.

This report outlines the EBCD methodology applied, opportunities for improvement and the next steps for implementation. Throughout this report, survivors will be referred to as consumers as they continue to utilise health services to manage the long term effects of their condition and treatment.

The definition used for LTFU of BMT patients is two years post-transplant. While the focus of this project is on improving LTFU care and health outcomes, it is important to recognise that the timing of interventions to achieve this may occur at an earlier stage of the patient journey. For this reason, the entire journey (from diagnosis through to treatment, acute care and then to two years post-transplant) has been considered in this project.

Background and project purpose

Background

In 2016, the BMT Network released clinical guidelines for BMT LTFU.¹ It was anticipated that these guidelines would promote the standardisation and delivery of high quality long-term care across NSW to improve consumer outcomes, ensure sustainable healthcare and provide optimum quality of life for survivors of BMT. In addition, under the ACI Strategic Plan 2015-18, there was a commitment to pilot EBCD in a small number of projects across the organisation.

The original project proposal was to use EBCD to develop key principles to guide the implementation of the BMT LTFU clinical guidelines in NSW. However as the project progressed, it became apparent that EBCD was better suited to identifying opportunities and recommendations to guide service improvements within the context of BMT LTFU.

Project purpose

The aim of this project was to:

- use EBCD methodology to understand the experiences of consumers, carers and clinicians in LTFU post BMT
- collaboratively identify priority areas for LTFU improvements and make recommendations for action
- apply EBCD methodology to the design, implementation and measurement of recommended improvements.

Experience-based co-design

EBCD is a quality improvement methodology that brings consumers, carers and clinicians together to improve health services. The methodology is premised on creating better quality experiences and systems of healthcare. EBCD combines user-centred orientation and collaborative change processes to identify, implement and evaluate improvements to healthcare.⁶

Figure 1 shows the key project milestones achieved in each phase of EBCD methodology. The fifth phase (measure) will allow the project team to evaluate each improvement.

Qualitative methods are used to gather experiences in EBCD. The experiences are represented visually on a map, which presents emotions, experience and key themes across the continuum of care (see [Appendix 1](#)). This allows for the identification of common themes and experiences and informs workshops to recognise and prioritise areas for improvement.

Quite honestly, you don't get through something like this without support outside of the medical system.

– Consumer

Figure 1: Key project milestones

<p>Phase 1: Start-up and engage Jan – May 2016</p>	<ul style="list-style-type: none"> Project team formed from LTFU Working Group members: <ul style="list-style-type: none"> – ACI project lead – ACI patient experience and consumer engagement team representative – BMT consumer – BMT clinician. Arrow Bone Marrow Transplant Foundation engaged to identify and invite consumers to participate in face-to-face interviews. Chief executives from Western Sydney LHD, Northern Sydney LHD, and Sydney Children's Hospitals Network approve participation in the project.
<p>Phase 2: Gather Jun 2016 – Aug 2017</p>	<ul style="list-style-type: none"> Eight consumer stories collected by two members of the project team (interchangeably a consumer, clinician or ACI staff member). Three one-hour focus groups (two adult hospitals and one paediatric hospital) conducted. Participation from a variety of clinicians, including specialists, nurses and allied health staff members. Interviews and focus groups recorded and transcribed verbatim by an external service provider.
<p>Phase 3: Understand Aug – Sep 2017</p>	<ul style="list-style-type: none"> Each transcript reviewed by at least two members of the project team. Consumer and clinician experience map created through identification of key experiences and emotions. The map conveys the journey from diagnosis through to follow up beyond two years post-transplant. Key themes or touchpoints in the consumer and clinician journey revealed. Validation of experience map with the consumer and clinicians who conducted the interviews. Presentation to broader stakeholder groups for feedback.
<p>Phase 4: Improve Nov 2017 – onwards</p>	<ul style="list-style-type: none"> Prioritisation workshop held on 8 November 2017. More than 20 consumers, carers and clinicians worked together to identify and prioritise improvements based on the experience map. Agreement of the points in the BMT journey which are most significant to consumers and clinicians in the context of their LTFU experience. The top five points were taken forward so that the group could begin generating ideas for improvement.

Prioritisation workshop

The experience map was presented at the prioritisation workshop on 8 November 2017. As a number of workshop attendees had participated in the focus groups or interviews that informed the development of the map, it was vital that the map accurately reflected their experiences. Following facilitated discussion about the map, participants were invited to vote on which key themes or touchpoints should be prioritised for action. These represent the emotions and experiences that had the most significant impact upon the clinician's delivery of LTFU care, or consumer or carer quality of life following transplant.

Each attendee received five votes. Out of the 140+ key emotions, experiences and touchpoints on the experience map, those that received four or more votes were the following:

- 'LTFU capacity'
- 'Clinicians aware of the lack of resources for LTFU'
- 'Lack of information for long-term side effects (avascular necrosis, cataracts)'
- '[Resources] not written for me'
- 'Other hospitals (clinicians) don't understand'
- 'Long time in hospital'
- 'Very aware of some poor clinician support, e.g. eyes and skin'
- 'No other treatment options (other than BMT)'

Following the initial discussion, participants broke into smaller groups, with each group assigned to brainstorm answers to one of the following questions:

- How might we make in hospital experience better (e.g. exercise, support)?
- How might we increase capacity for LTFU?
- How might we increase equity of services/care?
- How might we provide better information and resources?
- How might we better support families?

A package gets mailed out [to patients], with about 12-15 different pieces of paper and requests for investigations and speciality referrals. They are asked to make their own appointments.

– Clinician

The ideas generated in the smaller groups were subsequently presented back to the wider group for further discussion. Workshop participants were then given another five votes that they could use to indicate the strategies for improving BMT LTFU that they felt would make the biggest difference to patients, carers and clinicians.

Results

The strategies identified as those that should be a priority for BMT LTFU services were categorised into *quick win*, *rational*, *long-shot* and *biggest impact* opportunities (Table 1).

Table 1: LTFU improvement opportunities

QUICK WIN	RATIONAL
<ol style="list-style-type: none"> 1. Improved access to exercise equipment and support 2. Clear direction to rehabilitation support services 3. Peer support services 	<ol style="list-style-type: none"> 1. Consumer and carer education resources on LTFU. Australian based and endorsed to be credible 2. Database of services and specialists 3. Build relationships with organisations that have existing consumer and carer resource platforms
BIGGEST IMPACT	LONG SHOT
<ol style="list-style-type: none"> 1. Increasing service capacity <ol style="list-style-type: none"> a. nurses b. clinic c. allied health 2. Increasing coordination of medical, nursing, and allied health services 	<ol style="list-style-type: none"> 1. 'One stop shop' LTFU clinic 2. Restructure healthcare system

During discussion, making Wi-Fi available in hospital was also noted as something that could enhance the inpatient and outpatient experience. As this was not related solely to BMT LTFU, it has not been included in the table above.

Recommendations and conclusion

Recommendations

The recommendations of this project are as follows:

- Embed greater consumer and carer involvement in the design and delivery of BMT LTFU by inviting broader consumer and carer representation of the BMT LTFU Working Group and amending the Terms of Reference accordingly.
- Work towards rational improvement ideas one and three (developing consumer and carer education resources on LTFU and building relationships with organisations that have existing consumer and carer resource platforms). These ideas are closely aligned to the current LTFU work plan, and therefore the group can build on existing work while building capability in using EBCD methodology.
- Develop the 2018/19 LTFU work plan to consider and include improvement opportunities ([Table 1](#)) for the year. This work plan will be implemented using EBCD wherever appropriate.

Conclusion

The use of EBCD methodology allowed clinicians, consumers and health managers to improve their understanding of each other's experiences of delivering and receiving LTFU care after BMT. In particular, EBCD led to the identification of priorities for improving long-term care and to the development of practical strategies for achieving these goals. Ongoing evaluation of the structure, governance and function of the LTFU Working Group and of its success in meeting its objectives will enable further reflection of the benefits of co-design.

I always say that I reckon they've [family] gone through a much harder time than I have because they have to watch me helplessly as I go through this.

– Consumer

References

1. Kerridge I, Shaw P, Gough J et al. *Blood and Marrow Transplant Long Term Follow-up Clinical Guidelines*. Agency for Clinical Innovation 2016.
2. Mohty B, Mohty M. Long-term complications and side effects after allogeneic hematopoietic stem cell transplantation: an update. *Blood Cancer Journal* 2011; 1 (4): e16
3. Khouri IF, McLaughlin P, Saliba RM et al. Eight-year experience with allogeneic stem cell transplantation for relapsed follicular lymphoma after nonmyeloablative conditioning with fludarabine, cyclophosphamide, and rituximab. *Blood* 2008; 111 (12): 5530-5536
4. Martin PJ, Counts GW, Appelbaum FR et al. Life Expectancy in Patients Surviving More Than 5 Years After Hematopoietic Cell Transplantation. *Journal of Clinical Oncology* 2010; 28 (6): 1011-1016
5. Sun C-L, Francisco L, Kawashima T et al. Prevalence and predictors of chronic health conditions after hematopoietic cell transplantation: a report from the Bone Marrow Transplant Survivor Study. *Blood* 2010;
6. Donetto S, Pierri P, Tsianakas V et al. Experience-based Codesign and Healthcare Improvement: Realizing Participatory Design in the Public Sector. *The Design Journal* 2015; 18 (2): 227-248

Appendix 1. Long-term care experience map

Experiences were represented visually during a mapping exercise, presenting the emotions, experience and key themes across the continuum of care.



Source: ACI