ACI NSW Agency for Clinical Innovation

REPORT

The Sydney post-bone marrow transplant survey

ACI Blood and Marrow Transplant Network

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Contents

Section 1

Introduction

Improvements in the research and application of blood and marrow transplant (BMT) for cancer and blood disorders have led to a concomitant increase in the number of people undergoing this procedure as well as an improvement in survival. Worldwide, 90,000 allogeneic (donor) blood and bone marrow transplants were performed between 2001 and 2011 [1], with 1496 of these procedures occurring in Australia. [2] With improvements in donor selection, conditioning therapies and supportive care, 35–80% of BMT recipients can now be expected to become long-term survivors and be cured of their underlying disease.[3] While BMT provides a clear benefit for many patients with malignant and non-malignant disease, it is also associated with significant morbidity and mortality.[4]

In recent years there has been evolving literature on the long-term (or late) psychosocial and medical complications experienced by BMT survivors. Late complications are generally defined as any complication occurring three or more months post transplant. They are often separated into 'delayed' (3 months to 2 years), 'late' (2–10 years) and 'very late' (>10 years) time categories [5]. The long-term physical, psychological and social effects of treatment can include cardiac impairment [6], endocrine dysfunction [7], compromised fertility [8], compromised lung and respiratory function [9], renal impairment [10], liver dysfunction [11, 12], skeletal disorders [13, 14], chronic graft-versus-host disease (cGVHD) [15, 16], immunodeficiency and infection [17, 18], secondary malignancies [19, 20], ocular side effects [21], compromised functional status [22, 23], unemployment or underemployment [22] and compromised quality of life.[24] The collective impact of such comorbidities is profound, with bone marrow transplant survivors experiencing a 30% lower life expectancy than a matched population cohort [4]. While many survivors rate their quality of life highly at two years post transplant, a number of bone marrow transplant recipients experience considerable difficulty coping with the short-, medium- and long-term physical and psychological sequelae of BMT and with the uncertainties of their prognosis. Given the extent and impact of late complications of bone marrow transplant, ongoing long-term follow-up and multidisciplinary care of BMT recipients is essential.[25]

In recent years, improvements in outcomes following BMT, and increasing recognition of the long-term sequelae that may be associated with BMT, has led to an increase in research into the health, psychological and functional status of survivors [26]. International and Australian BMT organisations have recognised that this research is necessary both to enable better education and decision-making regarding BMT and to inform the design and delivery of healthcare services so that they are better able to meet the full needs of BMT recipients and their families.

Section 2

Aims

To identify gaps in the provision of long-term follow-up care of bone marrow transplant survivors in NSW, and to inform a case for change, we need to understand the population for which services are intended and to explore their existing access to, and barriers to uptake of recommended care. To this end, the long-term follow-up survey aimed to:

- describe the social, demographic and transplant-related characteristics of allogeneic BMT survivors who had a transplant in NSW between 1 January 2000 and 31 December 2012
- summarise the distribution and determinants of post-transplant morbidity in the survivor cohort, including chronic graft-versus-host disease, chronic diseases, infections, secondary cancers, dental problems, sexual dysfunction and mental health
- identify the range of medical services (specialist and allied healthcare reviews, dental care and hospital attendances), therapies (conventional and complementary) and investigations that are accessed by transplant survivors
- explore patient preferences for long-term follow-up, including preferences for providers and location of long-term follow-up care, and to further examine the social, medical and demographic factors associated with consumer preferences
- assess participation in, and barriers to the uptake of health promotion activities, including post-BMT cancer-prevention screening and vaccination
- investigate the prevalence of lifestyle choices that may influence health outcomes, including smoking, the consumption of alcohol, regular exercise, nutrition, 'sun smart' behaviour, types of occupation and overseas travel
- provide baseline data on the quality of life as this relates to recipients of bone marrow transplant in NSW, and to explore the contribution of physical and psychosocial factors, including fear of cancer recurrence, to measures of quality of life.

Section 3

Methods

Background to NSW BMT service

New South Wales is Australia's most populous state, with a population of approximately 7.5 million, and covers an area of 800,628 km^2. Over a third of residents live outside the greater Sydney area.[27] When the study began, there were four adult allogeneic centres in NSW, all based in Sydney and collectively performing approximately 132 BMT procedures annually.[28] BMT survivors were surveyed to explore their health status, demographics, service use and follow-up preferences.

Patients and procedures

Potential participants were identified from allogeneic transplant databases from all adult allogeneic transplant centres in NSW. Participants were eligible if they were 18 years of age or over at the time of survey; had undergone an allogeneic bone marrow transplant at an adult BMT centre between 1 January 2000 and 31 December 2012; could read and write English; and, could provide consent. Names and phone numbers were provided to the research team. Consenting participants were given the option to complete the questionnaire themselves or complete it via a phone interview with one of the researchers. A second round of telephone calls was made to participants who had not returned the survey within a month. All authors had access to primary clinical trial data. The study protocol was approved by the Northern Sydney Local Health District Human Research Ethics Committee (NSLHD Reference: 1207-217M).

Instruments

The research team developed the Sydney post–bone marrow transplant survey based on a review of the literature and discussion with patients attending BMT long-term follow-up clinics. The survey comprised 402 questions grouped into 20 domains and included questions relating to specialist referrals and long-term follow-up preferences with respect to location and provider. Other relevant domains included demographics, medical complications, tests and assessments, medications and therapies, infections, vaccinations, complementary therapy use, cancer screening, relationship status, income and lifestyle factors. The questionnaire used tick box responses, short answer questions and five-step Likert scales measuring attitudes and other factors. The survey took approximately one hour to complete. It was piloted with six bone marrow transplant survivors in clinic and phone interviews to assess face and content validity and to check for comprehension. For each consenting participant, dates of diagnosis and transplant, stage/remission status at transplant, transplant conditioning, graft-versus-host disease (GVHD) prophylaxis, stem cell source and donor type data were recorded.

Data on a range of long-term complications following BMT and consumer preferences for long-term follow-up, including specialist care and health service use, were analysed according to a range of demographic, transplant, psychosocial and lifestyle variables. Assessment tools included the Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT–BMT Version 4)[29, 30], The Depression Anxiety Stress Scale 21 (DASS21),[31-33] The Chronic GVHD Activity Assessment – Patient Self-Report (Form B)[34], the Lee Chronic GVHD Symptom Scale[35], the Posttraumatic Growth Inventory score[36, 37] and the Fear of Cancer Recurrence (FoCR) score[38] (a five-item scale for those with a background of malignant disease that explores uncertainty of cure, the fear of cancer relapse and the potential for this to distract from the enjoyment of life).

For ease of completion, all instruments were combined into one booklet.

Statistical analysis

Categorical responses were summarised using frequencies and percentages. Parametric continuous variables were summarised using means and standard deviations, and nonparametric variables using medians, interquartile ranges (IQR) or ranges. Odds ratios and 95% confidence limits, Pearson 2 test or Fisher's exact tests were used for comparative analysis of dichotomous categorical variables. Two sample comparisons of parametric and nonparametric data were determined using the independent t-test, and Wilcoxon Rank Sum tests, respectively. Comparisons of greater than two samples were determined using one-way analysis of variance and Kruskal–Wallis tests, respectively. Multivariable logistic regression and multiple regression analyses were used to adjust for confounders and to ascertain independent associations of explanatory variables with outcomes of interest. A two-tailed p value <0.05 was used as the level of statistical significance.

Statistical analysis was performed using Stata software (Version12.1).

Section 4

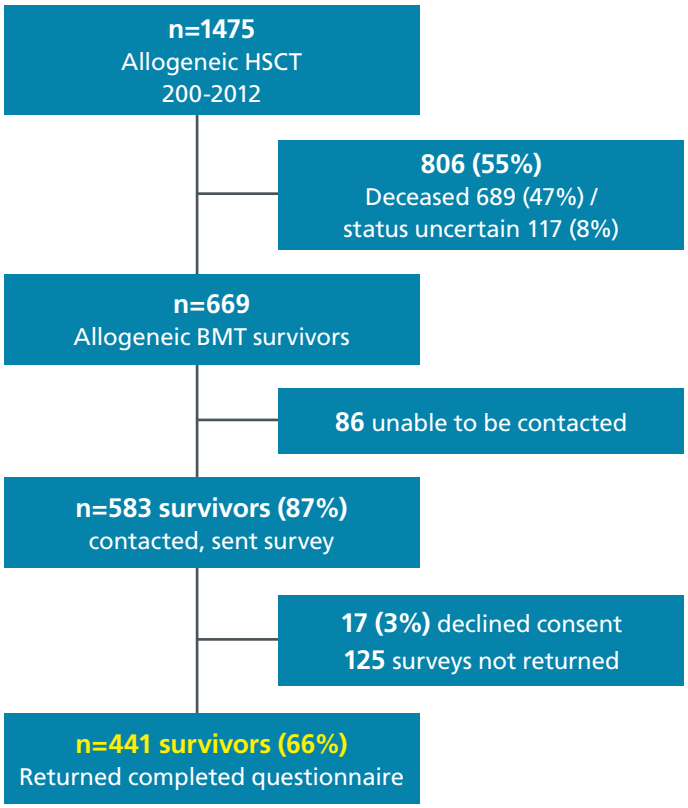
Results

Participating centres reported a total of 1475 allogeneic bone marrow transplants over the study period. Of the 669 recipients known to be alive at study sampling, 583 (87%) were contactable and were sent study packs (Figure 1). Four hundred and forty-one (66% of total eligible, 76% of those contacted) returned the completed survey. Three per cent declined participation. Eight hundred and six (55%) of the patient cohort were either deceased (689, 47%) or presumed lost to follow-up as their survival status was uncertain (117, 8%).†

Transplant survivors by transplant centre

Of the 441 survivors surveyed, 193 (43.8%) received their transplant at Westmead Hospital, 124 (28.1%) at St Vincent's Hospital, 72 (16.3%) at Royal North Shore Hospital and 52 (11.8%) at Royal Prince Alfred Hospital.

Figure 1: Sydney long-term follow-up participation



Demographics

Of those completing the survey, 250 (56.7%) were male and 191 (43.3%) female (Table 1). The median age of survey respondents was 54 years (range 19-79). The median age at time of the allogeneic transplant procedure was 49 years (range 17-71).

Fifty-eight patients (13%) were less than two years post transplant, 204 (46%) were two to less than six years, 117 (27%) were six to less than 10 years and 62 (14%) were 10 to 14 years post transplant.

Most allogeneic transplants survivors (396, 91.9%) were residing in metropolitan or inner regional centres. One hundred and thirty (39.0%) had completed university education and 36.6% were of low-income status (income $20,000–39,999 per annum). Almost one-third (31.8%) were in full-time employment and 79.3% were either married or in a defacto relationship.

Transplant-related factors

Underlying diagnosis, donor type and conditioning regimes are reported in Table 2. Of survey participants, 53.4% had an underlying diagnosis of acute leukaemia. Conditioning was myeloablative in 48.7%. Donor type was sibling related in 56.9%, matched unrelated in 36.0% and haploidentical or mismatched unrelated in 7.1%. Total body irradiation was administered in 101/214 (47.2%) of myeloablative (MA) and 26/225 (11.6%) of reduced-intensity conditioning (RIC) regimens. T-cell depletion was used in 122/426 (28.6%).

† During the study period, the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) reported a total of 1,496 allogeneic transplants on 1,408 patients ≥16 years that received allogeneic transplants (73 patients fewer than the numbers reported to the study team by the participating allogeneic centres). At survey 'close out' date, the ABMTRR reported 689 deaths in allogeneic transplant recipients in the study cohort of interest. Based on our study population of 1475, and the mortality figures provided by ABMTRR, we estimate that approximately 8% of patients were lost to follow-up. The ABMTRR has been provided with the transplant list from the four adult allogeneic transplant sites and will cross reference these numbers with the registry to investigate these discrepancies.

Post-transplant morbidity

Chronic graft-versus-host disease

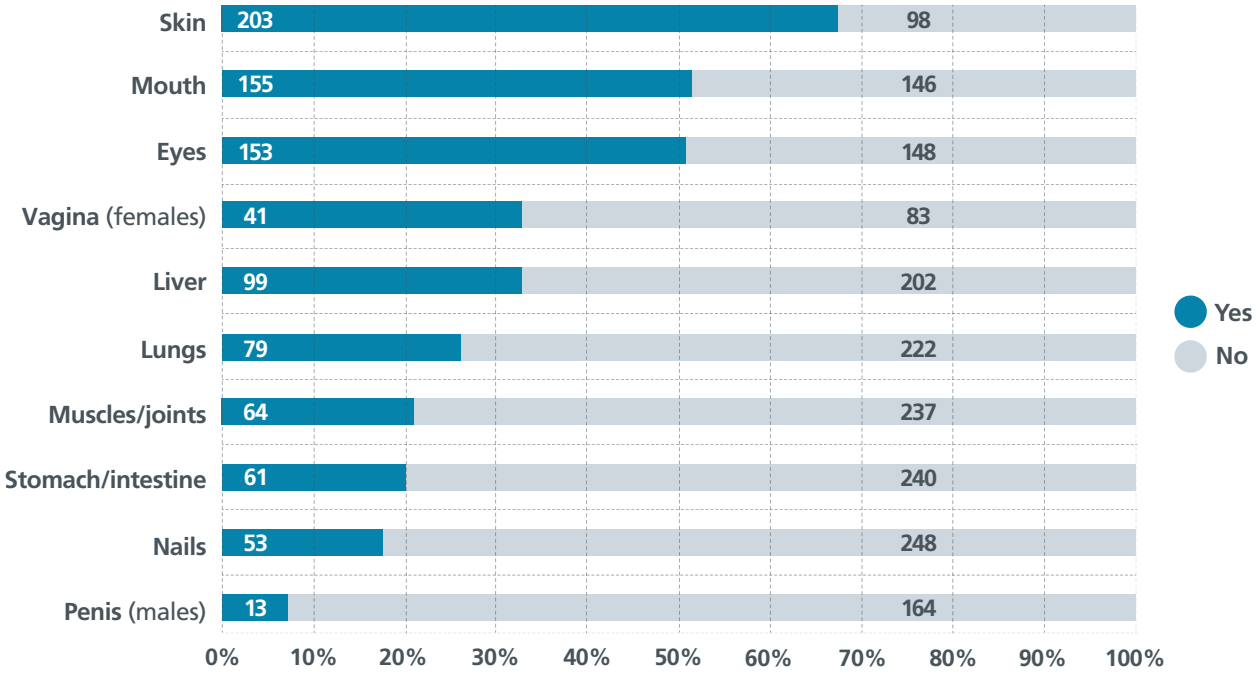
The frequency, distribution and severity of cGVHD symptoms are summarised in Table 3.

Out of 434 respondents, 301 (69.3%) reported GVHD symptoms since their transplant. Of the 56 within two years post transplant, 36 (64.3%) reported ever having a diagnosis of GVHD compared to 47 of 62 (75.8%) who were more than ten years since transplantation.

CHRONIC GVHD SYMPTOMS BY SITE

Of the 301 reporting chronic GVHD, symptoms were most commonly localised to skin in 203 (67.4%), mouth in 155 (51.5%) and eyes in 153 (50.8%). Of 124 females reporting cGVHD, 41 (33.1%) had vaginal involvement. In 177 males with cGVHD, penile involvement was reported in 13 (7.3%) (Figure 2).

Figure 2: Distribution of organ involvement in BMT survivors reporting cGVHD



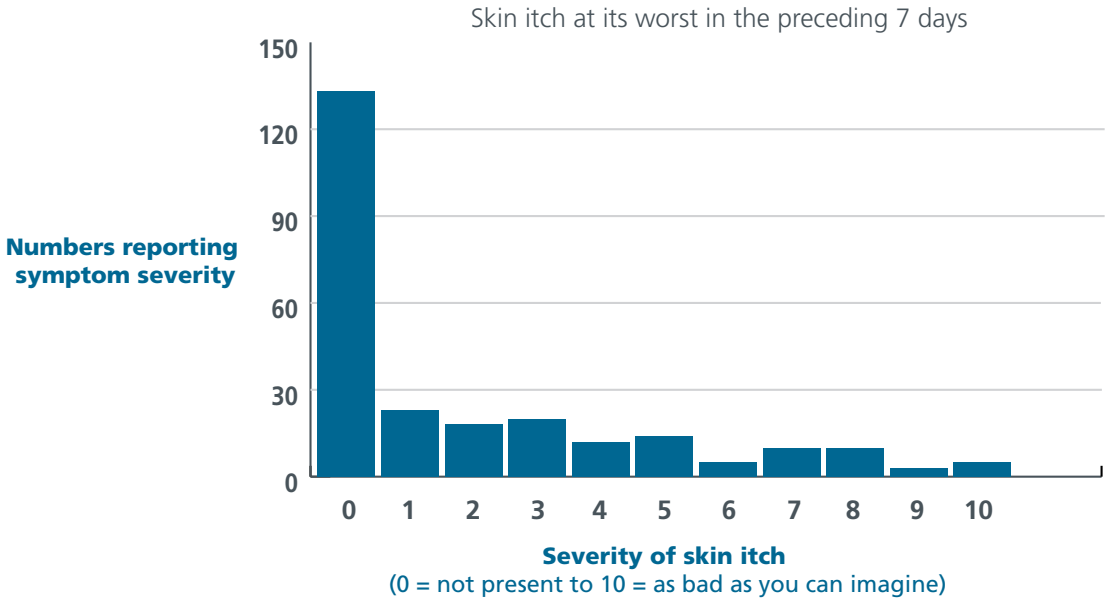
CHRONIC GVHD ACTIVITY ASSESSMENT

Patients were asked to rate the severity of GVHD symptoms in the seven days preceding the survey. Symptoms specifically elicited were skin itchiness, mouth dryness, mouth pain and mouth sensitivity at their worst. A score of zero indicated that the symptom was 'not present'; a score of 10 indicated that the symptom was 'as bad as you can imagine'.

Skin itch

Just over half of the patients (143/253, 52.6%) reported no skin itch and the remaining 120/253 (47.4%) reported some skin itch in the preceding seven days. Of those with any skin itch, 28/120 (23.3%) gave this a severity rating of 7 to 10 (Figure 3).

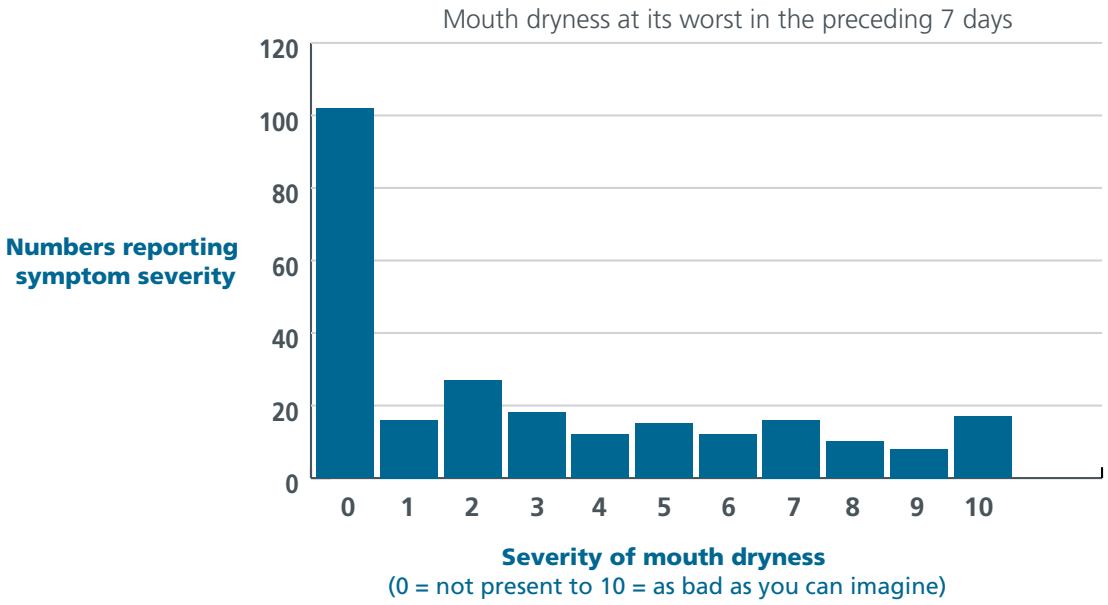
Figure 3: cGVHD activity – skin itch



Mouth dryness

Two-fifths of patients (102/253, 40.3%) reported no mouth dryness and 151/253 (59.7%) some mouth dryness in the preceding seven days. Of those with any mouth dryness, 26/151 (17.2%) gave this a severity rating of 7 to 10.

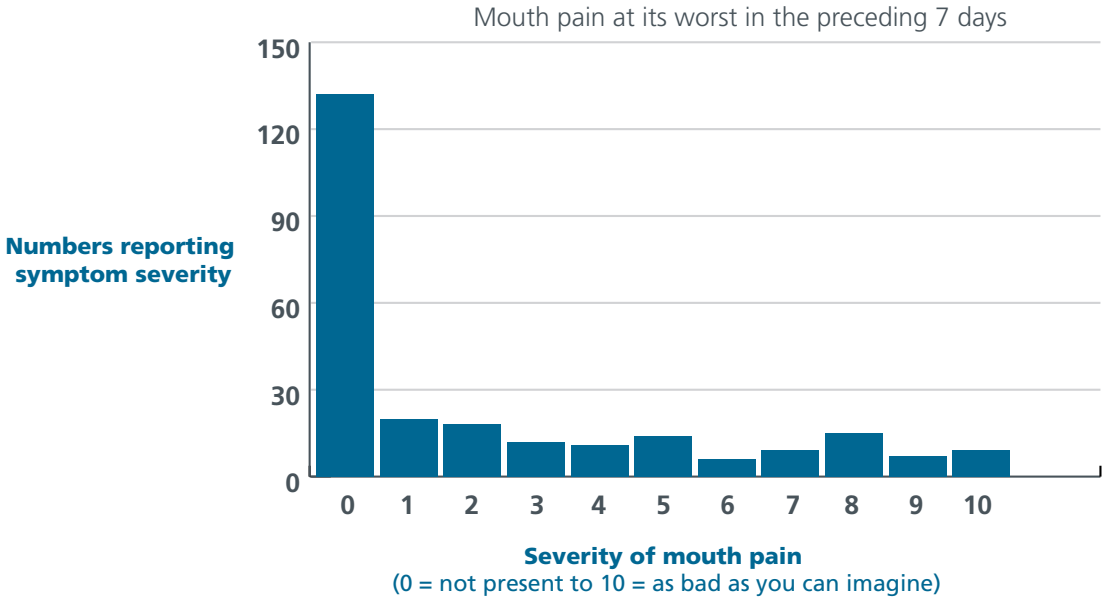
Figure 4: cGVHD activity – mouth dryness



Mouth pain

Almost two-thirds of patients (166/252, 65.9%) reported no mouth pain and 86/252 (34.1%) reported some mouth pain in the preceding seven days. Of those with any mouth pain, 23/86 (26.7%) gave this a severity rating of 7 to 10.

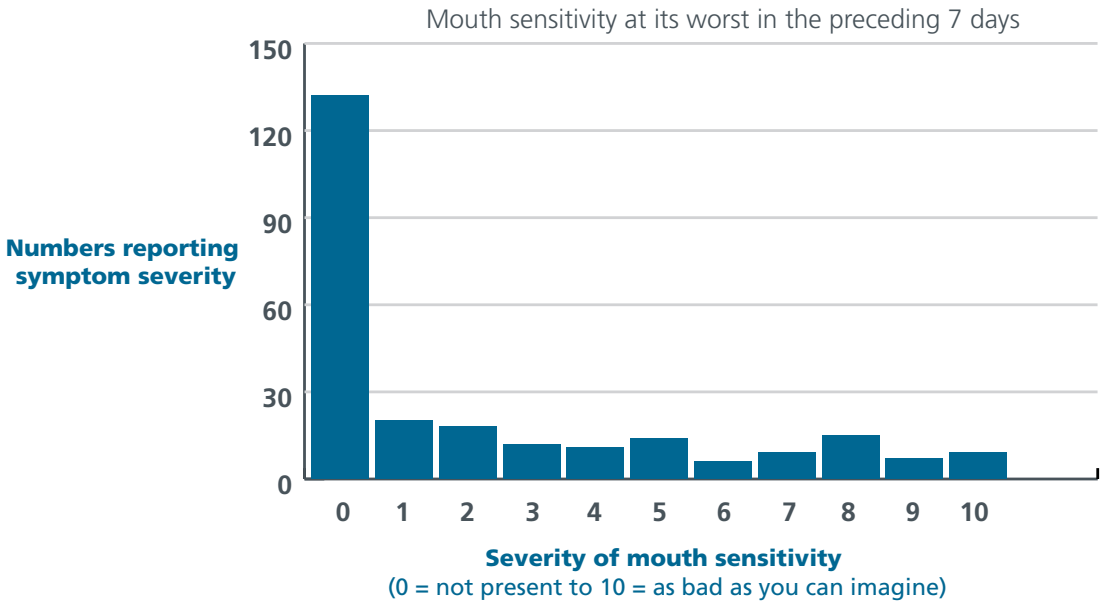
Figure 5: cGVHD activity – mouth pain



Mouth sensitivity

Just over half of the patients (132/253, 52.2%) reported no mouth sensitivity and 121/253 (47.8%) reported some mouth sensitivity in the preceding seven days. Of those with any mouth sensitivity, 40/121 (33.0%) gave this a severity rating of 7 to 10.

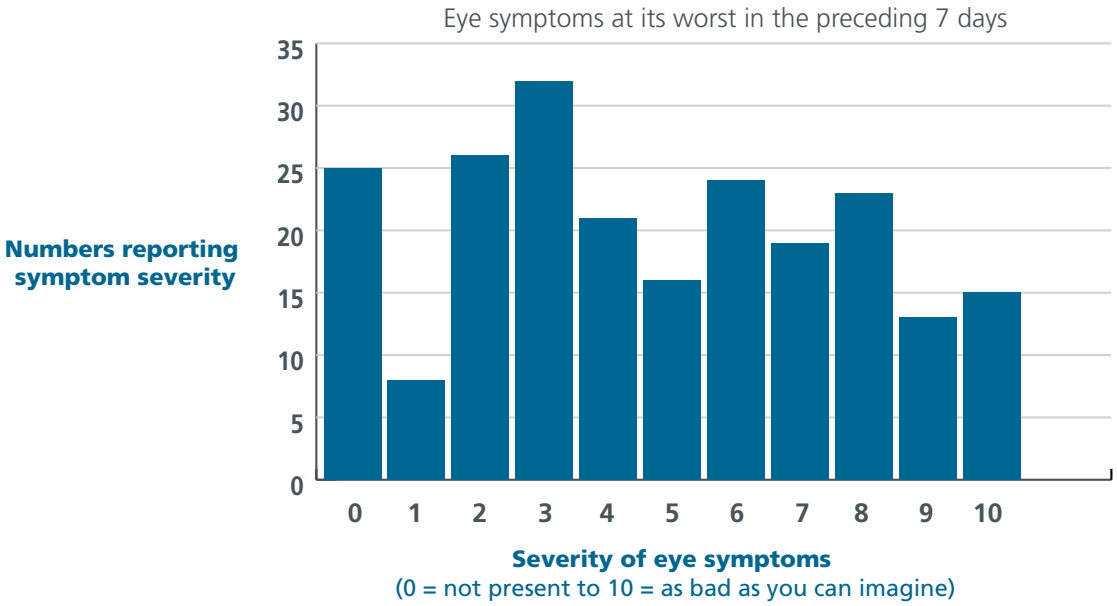
Figure 6: cGVHD activity – mouth sensitivity



Eye symptoms

Twenty-five of 222 (11.3%) patients reported no eye symptoms (itch, dryness, blurriness, pain, decreased tear production) and 197/222 (88.7%) reported some eye symptoms in the preceding seven days. Of those with eye symptoms, 70/197 (35.5%) gave this a severity rating of 7 to 10.

Figure 7: cGVHD activity – eye symptoms



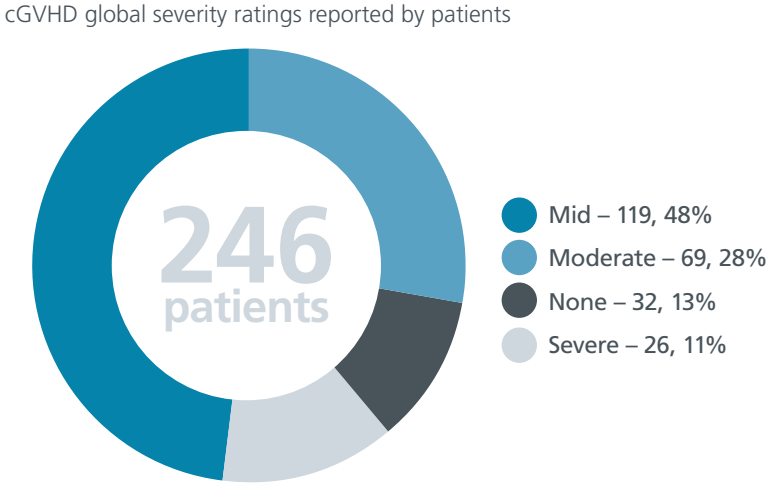
Vulvovaginal symptoms (females)

Forty-five of 96 (46.9%) females reported vulval, vaginal or labial burning pain or discomfort, or pain with sexual intercourse in the preceding seven days.

PATIENT GLOBAL RATINGS OF GVHD SEVERITY

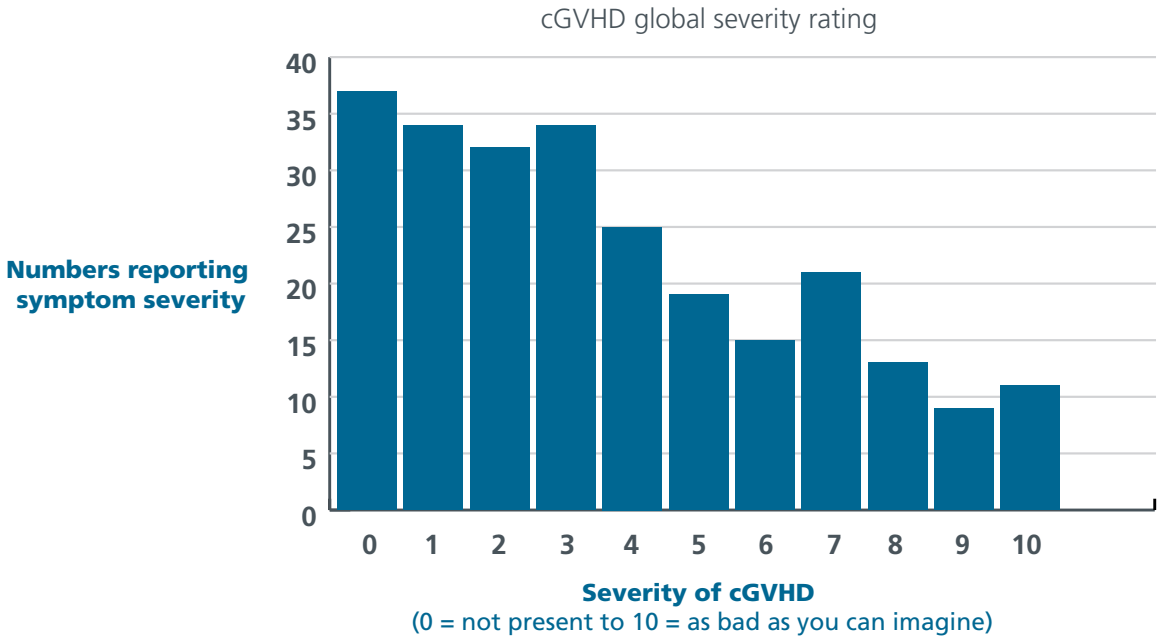
Global severity ratings for cGVHD were assessed against three criteria. The first was patients reporting whether they considered their symptoms as absent, mild, moderate or severe. Overall 246 patients who had reported cGVHD responded to this question of which 38.6% reported moderate–severe symptoms and 61.4% absent or mild symptoms.

Figure 8: cGVHD: severity by category



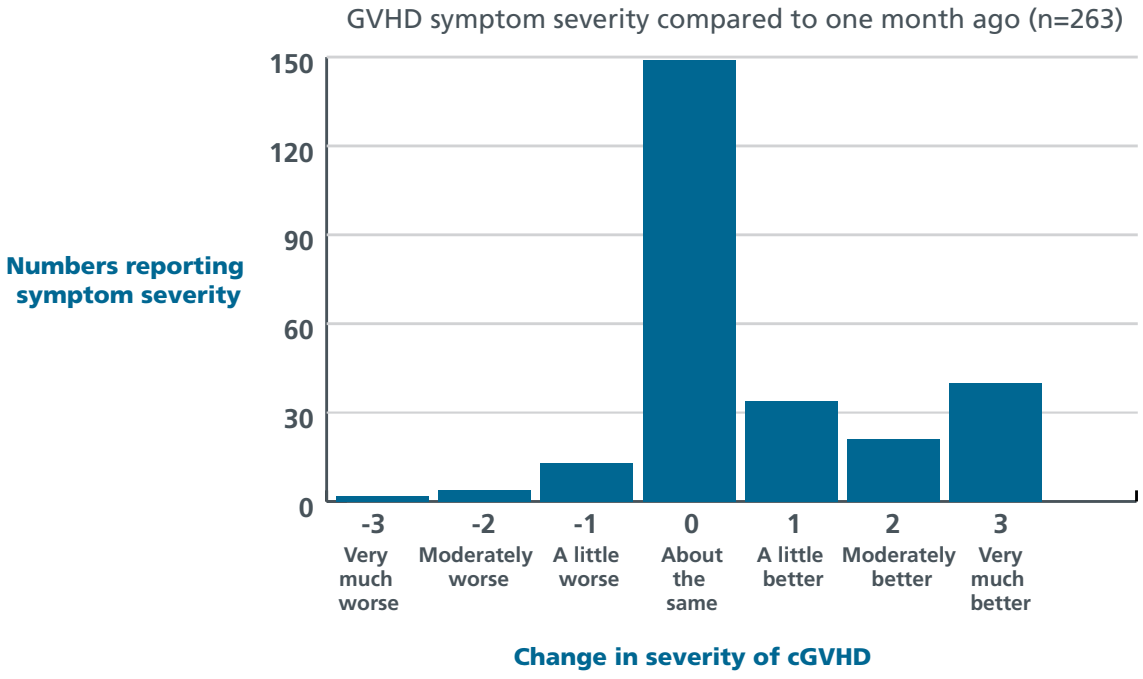
The second assessment of severity of cGVHD used a scale wherein patients reported cGVHD symptoms on a scale of 0 to 10. A reported score of zero corresponded to GVHD symptoms which were not at all severe and 10 to the most severe GVHD symptoms possible. Of the 248 patients who responded to this question, 37 (14.9%) indicated that their symptoms were not at all severe. Of the 211 patients reporting any severity score (that is, a severity score ≥1), 54 (25.6%) indicated a score of 7 to 10. Eleven of the 211 (5.2%) reported symptoms of GVHD at the most severe end of the spectrum.

Figure 9: cGVHD – by severity rating (Likert scale)



The third assessment of GVHD symptom severity was based on patients reporting how their current cGVHD symptoms compared to their symptoms one month ago. Overall, 149/263 (56.7%) reported symptoms that were about the same, 19/263 (7.2%) symptoms that were worse and 95 (36.1%) symptoms that were better.

Figure 10: cGVHD – severity of symptoms compared to one month ago



LEE CHRONIC GVHD SCORES

The Lee Chronic GVHD (cGVHD) symptom scale is a 30-item symptom scale with seven subscales covering system-specific cGVHD burden, including skin, eye, mouth, lung, energy, nutrition and psychological burden. Lee cGVHD scores were based on symptoms in the preceding month and correlated with patients' self-reported cGVHD symptom severity.

Lee cGVHD symptoms showed a strong correlation with self-reported symptom severity. Median Lee GVHD scores of >30 were associated with patients self-reporting moderate to severe GVHD symptoms. Similarly, Likert scales of 7-10 corresponded with median Lee cGVHD scores of >30.

Figure 11a: Relationship between self-reported cGVHD symptom severity (category) and summary Lee cGVHD scores

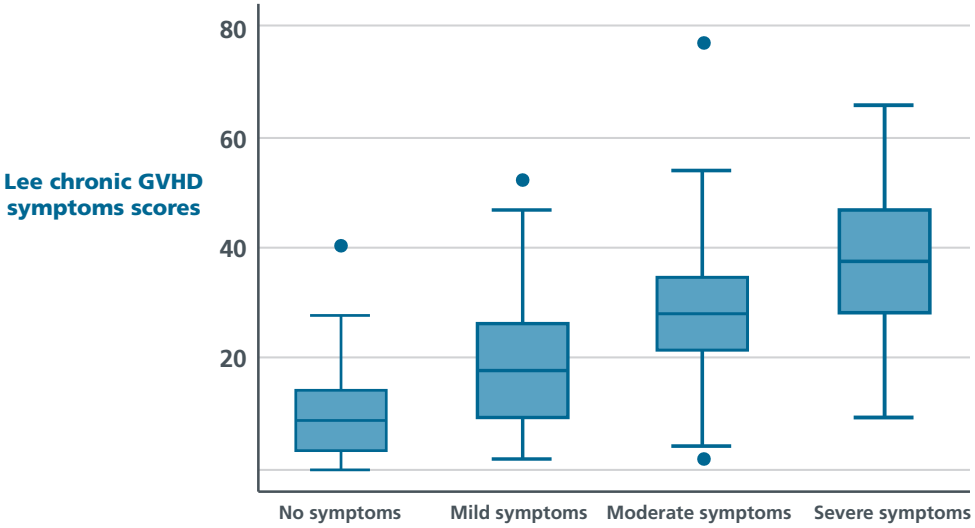
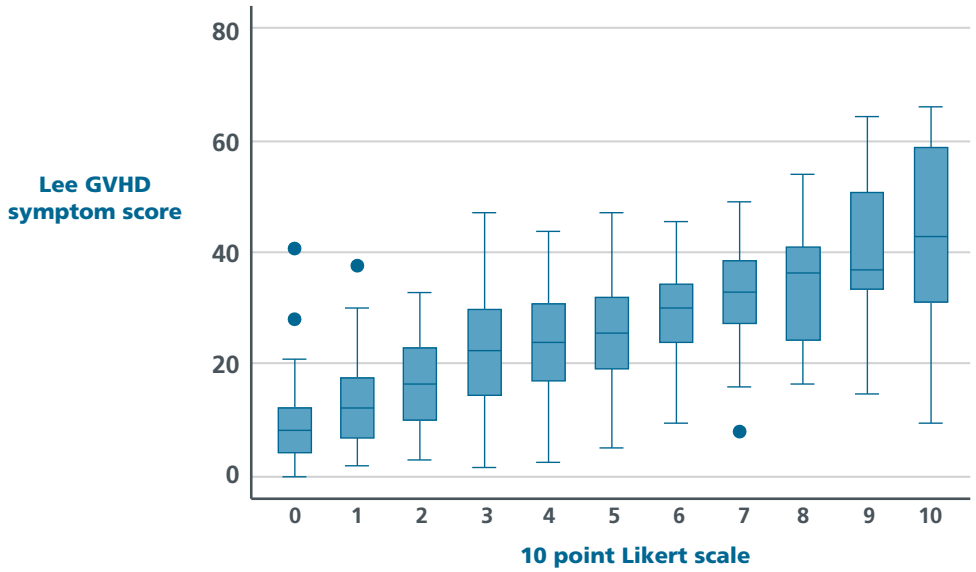


Figure 11b: Relationship between self-reported cGVHD symptom severity (Likert scale) and summary Lee cGVHD scores



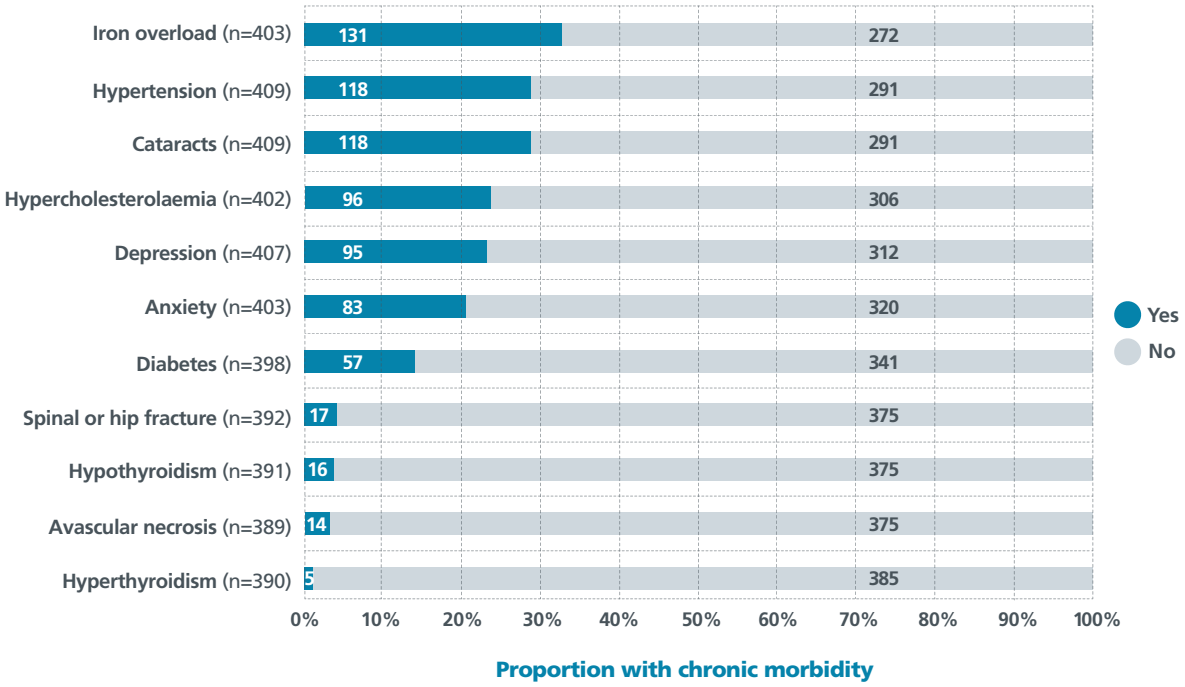
Chronic diseases post bone marrow transplant

Patients were surveyed about chronic endocrine, cardiovascular, musculoskeletal, and mental and other morbidity post transplant (Table 4).

Almost one-third 32.5% of BMT recipients reported iron overload, 29.1% osteoporosis /osteopaenia and 28.9% cataracts. Anxiety and depression were reported in 20.6% and 23.3% of those surveyed respectively. Spinal or hip fractures had occurred in 4.3% and avascular necrosis in 3.6%. Cardiovascular risk factors including diabetes, high cholesterol or hypertension were reported in 14.3%, 23.9% and 28.9% respectively.

Any endocrine morbidity (thyroid disease or diabetes) was reported in 19.0% of those surveyed; any bone disease (osteoporosis/osteopaenia/avascular necrosis or spinal or hip fractures) in 31.4%; any cardiovascular risk factors (diabetes, high blood pressure or high cholesterol) in 43.5%; any depression and/or anxiety in 28.8%.

Figure 12: Frequency and proportion of chronic diseases, anxiety and depression in BMT survivors



Infectious diseases

FREQUENCY AND DISTRIBUTION OF POST-TRANSPLANT INFECTIONS

Patients were asked about what infections they had been diagnosed with since transplantation (Table 5).

The most frequently reported infections included influenza (38.4%), herpes zoster (27.9%), recurrent colds (22.9%), fungal infection (15.2%) and pneumococcal disease (5.1%). Female patients were asked about Pap smear abnormalities detected since transplant; 9.8% reported a Pap abnormality. Genital warts were reported in 5% of males and 1.6% of female transplant recipients.

BMT survivors who reported having had pertussis or pneumococcal disease were significantly older than those without these diseases (Table 5a). The median age of those with pertussis was 65 years compared to 54 years of those without the disease (p=0.01). The median age of those with pneumococcal disease was 62 years compared to a median of 53 years for those without the disease (p=0.01). Females reporting Pap smear abnormalities were significantly younger than those reporting no Pap smear abnormalities (42 years compared to 52 years, p=0.01). The median time since transplant for those reporting common infections such as influenza and zoster was six years. This indicates that such infections are occurring more than six years post transplant in 50% of the BMT survivors surveyed who reported having influenza or zoster (Table 5a).

Hepatitis B, Bordetella pertussis (whooping cough), *Haemophilus influenzae* type b (Hib), *Streptococcus pneumoniae* (pneumococcus), *Neisseria meningitidis* (meningococcus) and Influenza A/B are infections for which vaccination is recommended in the first post-transplant year. Overall, 41.7% of the transplant cohort reported having had at least one of these vaccine-preventable infections. Most of these were due to influenza. If one were to exclude influenza, 10.6% of the cohort had one of the remaining vaccine-preventable diseases for which vaccination is recommended in the first year post transplant (Table 5b).

Hepatitis B, hepatitis C and tuberculosis were reported in six, four and three patients, respectively. It is not known whether these infections represented reactivated disease or *de novo* infections.

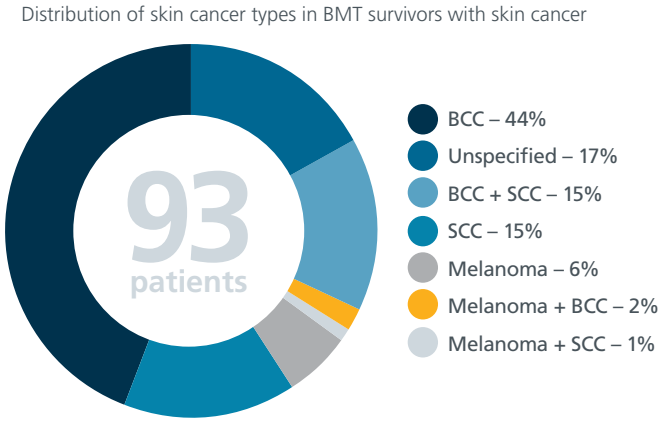
Secondary cancers post bone marrow transplant

One hundred and six (24.0%) reported a diagnosis of at least one cancer following BMT, of which 104 were non-relapse malignancies (Table 6).

Ninety-three (23.0%) of patients reported skin cancers, 6 (1.5%) oral cancers and 16 (3.6%) other malignancy types, including breast cancer (2), ovarian cancer (1), bowel cancer (1), bladder and/or prostate (5), myeloid sarcoma (1), non-relapse haematological malignancies (NHL 2; HL 2; PTLD 1), relapse haematological malignancies (2) and one cancer of the head (type unspecified).

Skin cancers accounted for the largest number of secondary cancers. The distribution of cancer types is depicted below. Basal cell carcinomas (BCC) accounted for the largest proportion (44%) of all skin cancers.

Figure 13: Distribution of skin cancer types



Oral health and dental morbidity

Patients were surveyed for dental morbidity (Table 7). The most common dental and oral health problems that patients reported included dry mouth (45.1%), mouth ulcers (35.3%), tooth decay (36.7%) and oral GVHD (35.1%). Six per cent reported having had a dental abscess and 1.5% a diagnosis of oral cancer.

Gastrointestinal morbidity and symptoms

Transplant survivors reported high rates of taste alteration (30.9%), smell alteration (20.7%), loss of appetite (20.2%), diarrhoea (19.4%), constipation (15.5%) and nausea (11.8%). Vomiting was the least frequently reported problem (4.5%) (Table 8).

Mental health

Depression and anxiety were reported in 23.3% and 20.6% of transplant survivors, respectively. Overall 28.8% of the surveyed population reported anxiety and/or depression.

The three depression, anxiety and stress subscales (DASS21) were individually summarised, as well as composite DASS21 scores (Table 9). Depression and anxiety subscale scores were investigated for their association with self-reported depression and anxiety. In addition, the relevant subscale scores were assigned normal, mild, moderate, severe and extremely severe labels, based on recommended cut-off scores.

The median DASS21 subscale score for depression was 4 (IQR 2, 14; range 0-40); anxiety 4 (IQR 2, 10; range 0-42) and stress 8 (IQR 2, 16; range 0-42). Overall 25% of patients had depression scores, 28.9% had anxiety scores and 19.9% had stress scores that were categorised as moderate, severe or extremely severe. Most patients with a depression score less than 24 and anxiety score of less than 20 had no self-reported depression or anxiety, respectively, and 25% of those who reported depression or anxiety had scores below these respective thresholds (Figures 14a and 14b). A small number of patients (seven reporting no depression and eight reporting no anxiety) had depression and anxiety scores that corresponded to moderate to extremely severe depression and anxiety, respectively. Although the numbers are small, this would suggest a subset of patients who may lack recognition of their psychological morbidity.

Figure 14a: Relationship between self-reported depression and depression scores using DASS21

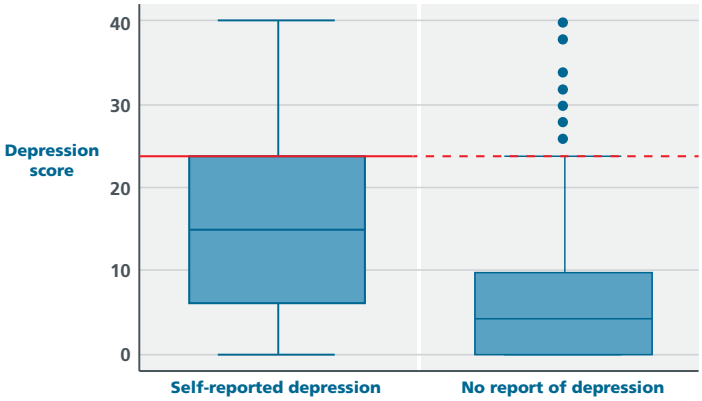
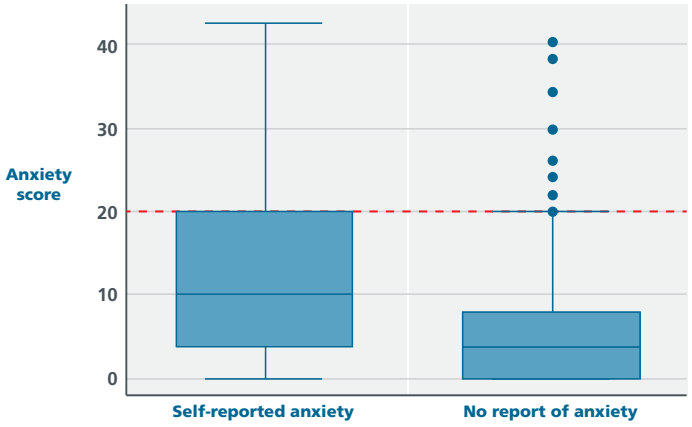


Figure 14b: Relationship between self-reported anxiety and anxiety scores using DASS21



Sexual dysfunction

Overall, 421 respondents provided information about sexuality, fertility and sexual activity post BMT: 241 (96.4%) of 250 males and 178 (93.2%) of 191 females.

One hundred and sixty-seven (69.2%) males and 122 (68.5%) females reported resumption of sexual activity post transplant; 30 (12.4%) of males and 21 (11.8%) of females had not yet resumed sexual activity post BMT. The remaining 44 (18.3%) males and 35 (19.7%) females reported being sexually inactive pre and post transplant.

Just over half (51.5%) of males who had resumed sexual activity since their BMT reported difficulties with sexual function since transplant (Table 10). Sexual difficulties in males mainly related to erectile dysfunction (76.7%); decreased libido was the second most commonly reported problem (61.6%). Pain with intercourse was reported in 9.3% of men with sexual difficulties. Of the 122 females who had resumed sexual activity since their BMT, 81 (66.4%) reported having difficulties with sexual function since transplant (Table 10).

Specific issues in those who had resumed sexual activity post transplant were compared across genders. Females had significantly less enjoyment of sex (OR 4.3 95% CI 2.2, 8.8, P<0.0001), less sexual desire (OR 3.0 95% CI 1.4, 6.6, P=0.002) and more pain with intercourse (OR 26 95% CI 10.2, 71.3, P<0.0001) when compared to their male counterparts. Sexual problems arising from partner issues were similar between the two genders.

Other problems described by females included vaginal bleeding/dryness/GVHD, mobility/flexibility issues, post gynaecological surgery problems and body confidence. Other difficulties described by males included recurrent hospitalisations, neurological damage to penis following an episode of shingles, reduced muscular strength and joint pains and breathing difficulties.

Frequencies located in Table 10.

Fertility

FERTILITY POST BMT

Questions regarding post-transplant conception were answered by 395 participants. Thirty-five of 395 respondents indicated that they had tried to conceive post BMT: 21 (10%) males and 14 (8%) females. Of these 35 participants, 15 (43%) were successful (11 males, 4 females). Females who successfully conceived were all less than 30 years of age at the time of transplantation; males were all less than 41 years of age (p=0.08).

Of the 15 successful pregnancies, six (40%) were the result of natural conception (two females, four males) and two were the result of natural conception that followed prior attempts at in vitro fertilisation (IVF). The latter included IVF for one male and his partner and IVF followed by implantation of a donor egg in one female. Seven successful pregnancies were the result of IVF; six (all males) with IVF alone and one IVF and donor egg (female). No association was found between the use of reproductive technologies by BMT survivors and residential location (major city vs inner or outer regional) or household income.

FERTILITY PRESERVATION PRE BONE MARROW TRANSPLANT

Forty-seven (20%) of 233 males reported banking sperm pre-BMT with a median age (at transplant) of 31 years (IQR 24-40; range 18–51 years). There were no statistically significant sociodemographic differences (income, residence) between males who did and did not bank sperm. Donor type had a significant effect on banking sperm, with those who had a haploidentical/matched unrelated donor (MUD) or mismatched transplant being 2.6 times more likely to bank than those who had a matched sibling transplant (95% CI 1.28, 5.44, p=0.004). Males who had a myeloablative BMT had a threefold higher rate of banking sperm than those who had reduced-intensity conditioning (95% CI 1.67, 6.58, p=0.0004), but this difference was not significant when adjusted for the effect of the younger age of those receiving myeloablative conditioning (adjusted OR 0.82, 95% CI 0.32, 2.08, p=0.67).

Three hundred and sixty-one participants responded to the question of embryo banking after a cycle of IVF. Overall six (2%) reported using this technology (two males and four females). Three hundred and twenty-nine participants reported whether or not they had donated ovarian tissue and frozen eggs for storage. Overall seven (2%) had used this procedure (six females and one male BMT recipient with his female partner).

The most common reasons for young women (aged 18–29) to have not pursued fertility preservation pre BMT were that they had already completed a family or that they had been too sick to do so. Forty per cent of females in the 30–39 age group declined fertility preservation, however, it was not offered in a significant proportion (23%) of cases. In females aged 40–49, the majority declined the procedure, although 15% reported that it had not been offered. Male BMT survivors who did not store sperm had mostly declined to do so (79%) or been too unwell to undergo the procedure (8%). Only eight (5%) men, two of whom were under 40 years of age, were not offered sperm storage.

Current medication use

Patients were surveyed about their current medication use. Medication use was assessed according to survival cohorts (early and late). (Table 4a)

ANTI-INFECTIVE MEDICATIONS

Of those surveyed, 27.2% reported taking antivirals (acyclovir, valaciclovir), 28.8% Bactrim/ Septrim(trimethoprim/sulphamethoxazole) , 19.7% penicillin and 12.0% azole antifungals. Rates of anti-infective use were highest in the first two years post transplant with antiviral use, trimethoprim/ sulphamethoxazole, penicillin and antifungals reported in 60.3%, 68.9%, 39.7% and 22.4%, respectively.

IMMUNOSUPPRESSION

Overall, 28.8% of transplant survivors reported taking prednisolone and 23.1% taking calcineurin inhibitors (cyclosporin, tacrolimus) or mycophenolate mofetil (MMF). In early transplant survivors (< 2 yrs post transplant), these medications were each used in 44.8% of patients. In comparison, for late transplant survivors (≥10–14 years post transplant), the rate of prednisolone use was 21.0% and the rate of cyclosporine, tacrolimus or MMF use was 12.9%.

ANTIHYPERTENSIVES AND CHOLESTEROL-LOWERING MEDICATIONS

Almost one-quarter of transplant survivors (24.9%) reported taking antihypertensive medications. In those who were late transplant survivors, 43.5% were taking an antihypertensive medication. Overall, 17.0% of transplant survivors were on a cholesterol-lowering medication; 12.1% of early transplant survivors reported taking a cholesterol-lowering agent. The use of cholesterol-lowering drugs was twofold higher (24.2%) in late transplant survivors.

DRUGS SUPPORTING BONE METABOLISM

Drugs such as bisphosphonates, vitamin D and calcium supplements were the most commonly prescribed drugs in transplant survivors. The rates of use of these drugs were fairly consistent across survival cohorts. Bone strengthening medications (such a Zometa) were used in 15.6% of transplant survivors overall; 12.1% of early transplant survivors and 14.5% of late transplant survivors reported use of these drugs. Vitamin D was used in 54.4% of transplant survivors overall; 55.2% of early transplant survivors and 46.8% of late transplant survivors. Calcium was used in 46.3% of transplant survivors overall; 43.1% of early transplant survivors and 37.1% of late transplant survivors.

ANTI-ANXIETY, ANTIDEPRESSANTS AND SEDATIVES

Anti-anxiety medications, antidepressants and sedatives were used in 6.3%, 11.8% and 10.7% of transplant survivors, respectively. The highest report of anti-anxiety medication and sedative use was in the early transplant survivors (<2 years): 12.1% and 15. 5%, respectively. Antidepressant use was 10.3% in the early post-transplant cohort and highest (14.5%) in those who were six to < 10 years post transplant.

IRON OVERLOAD

Although 32.5% of transplant survivors reported iron overload as a post-transplant complication, very few were taking iron-lowering medications (2.3%). Iron-lowering medications were being taken by 5.2% of early transplant survivors and by none of the late transplant survivors.

HORMONAL THERAPIES

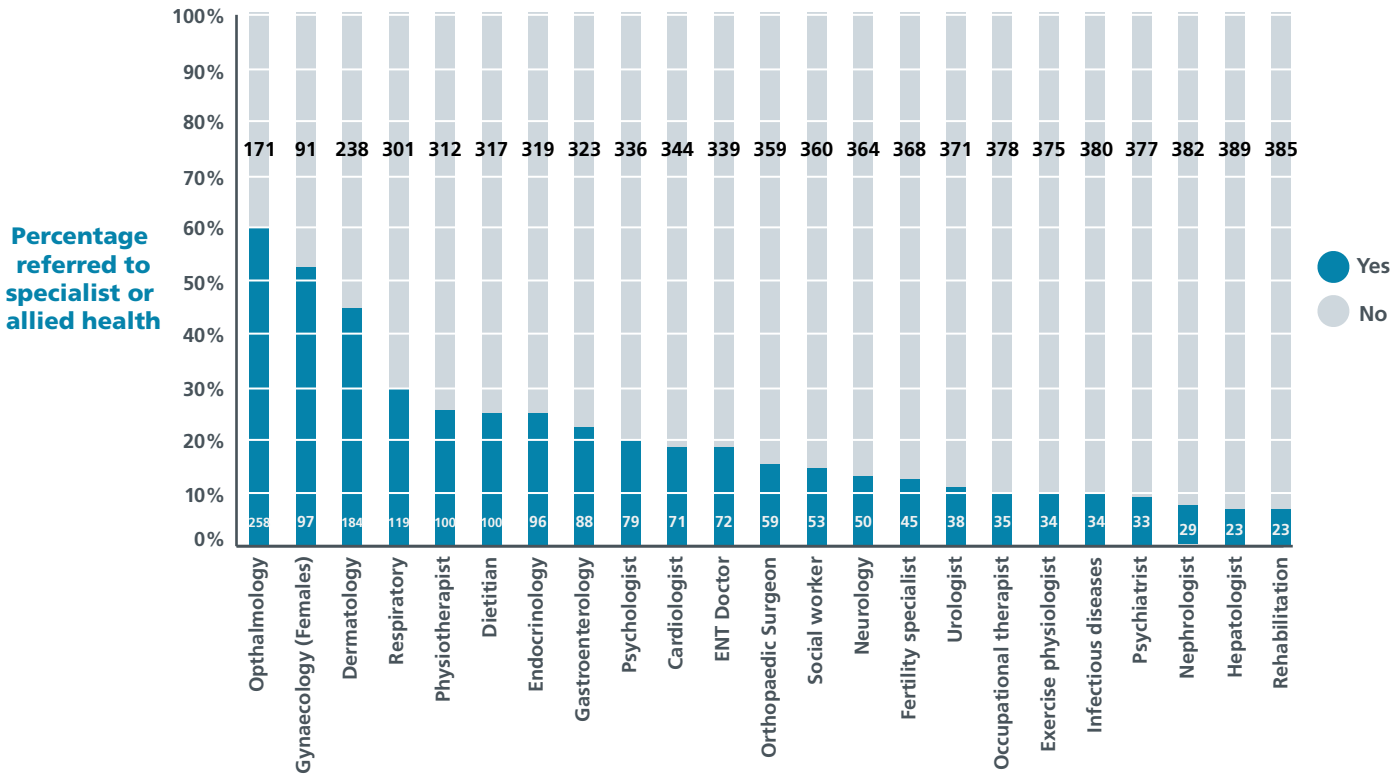
Reported rates for taking some form of hormonal therapy include 26.2% of females and 5.6% of males. The rates of hormonal use increased across survival cohorts in females: 13.6% of early transplant survivors were taking hormonal therapy compared to 35.7% of late transplant survivors. In males, the use of hormonal therapies was highest in the early and late survivors (8.3% and 8.8%, respectively). Males in the intervening survival cohorts reported rates of hormonal use between 4 and 5%.

Service use, referrals and long-term follow-up preferences

Specialist and allied health referrals

The median number of specialist medical referrals was three (IQR 1, 4; range 0-11), most commonly to ophthalmologists (60.1%), dermatologists (43.6%) and, for women, gynaecologists (51.6%) (Table 11, Figure 15). Almost half (215/441 , 48.7%) of survivors had been referred to one or more allied health professionals (range 0–6), including physiotherapists (24.3%), dietitians (24.0%) and psychologists (19.0%).

Figure 15: Specialist and allied health referral for BMT survivors



Frequency of hospital visits

One-third (19/57, 33.3%) of those who were within two years of transplantation were attending a hospital or medical/practice facility at least once per month. Of these, 9/19 (47%) were being seen at least weekly. Of those who were two or more years post transplant, medical practice or hospital attendances were reported at least monthly in 98/376 (26%), and of these 76/98 (77%) were attending a medical facility at least weekly. A requirement to stay overnight, close to the hospital/medical facility, was reported by 52/439 (11.8%) of survey respondents. Accommodation arrangements for those who are required to stay overnight included hospital accommodation (16/52, 30.8%) other subsidised accommodation (from charitable organisations/foundations (10/52, 19.2%)), lodging with friends or family (23/52, 44.2%) and paid accommodation (20/52, 38.5%).

Tests and assessments

Investigations that were reported in post-transplant follow-up included heart function tests (gated heart pool scan or cardiac echocardiogram) in 212/430 (49.3%), lung functions tests in 325/430 (75.6%), bone mineral density scans in 332/429 (77.4%) and thyroid palpation/ultrasound/scan in 99/416 (23.8%) (Table 11a).

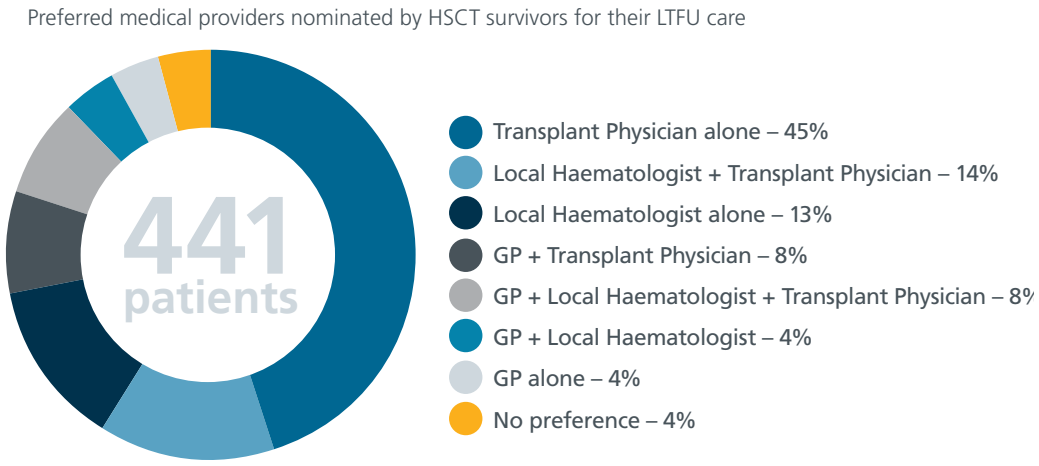
Provider preferences for long-term follow-up care

One or more preferences for medical follow-up were indicated by those surveyed (Figure 16). Overall, 275 (62.3%) preferred a single provider for their primary transplant follow-up (that is, general practitioner (GP) alone, local haematologist (LH) alone or transplant physician (TP) alone. An additional 149 (33.8%) preferred a combination of providers and 17 (3.8%) indicated no preference.

The preferred option (44.9%) of those surveyed was for their transplant physician (alone) to be primarily responsible for their long-term follow-up care. The second preferred option included a combination of TP and LH (14.2%), followed by LH alone (13.1%), GP and LH and TP (7.7%), GP and TP (7.7%), GP alone (4.3%) or GP and LH (4.1%) (Figure 16).

Of the 441 patients surveyed, 329 (74.6%) indicated a follow-up preference that included a transplant physician, 173 (39.2%) included a local haematologist, and 105 (23.8%) included a GP.

Figure 16: Preferred providers for long-term follow-up



Preferred location for long-term follow-up care

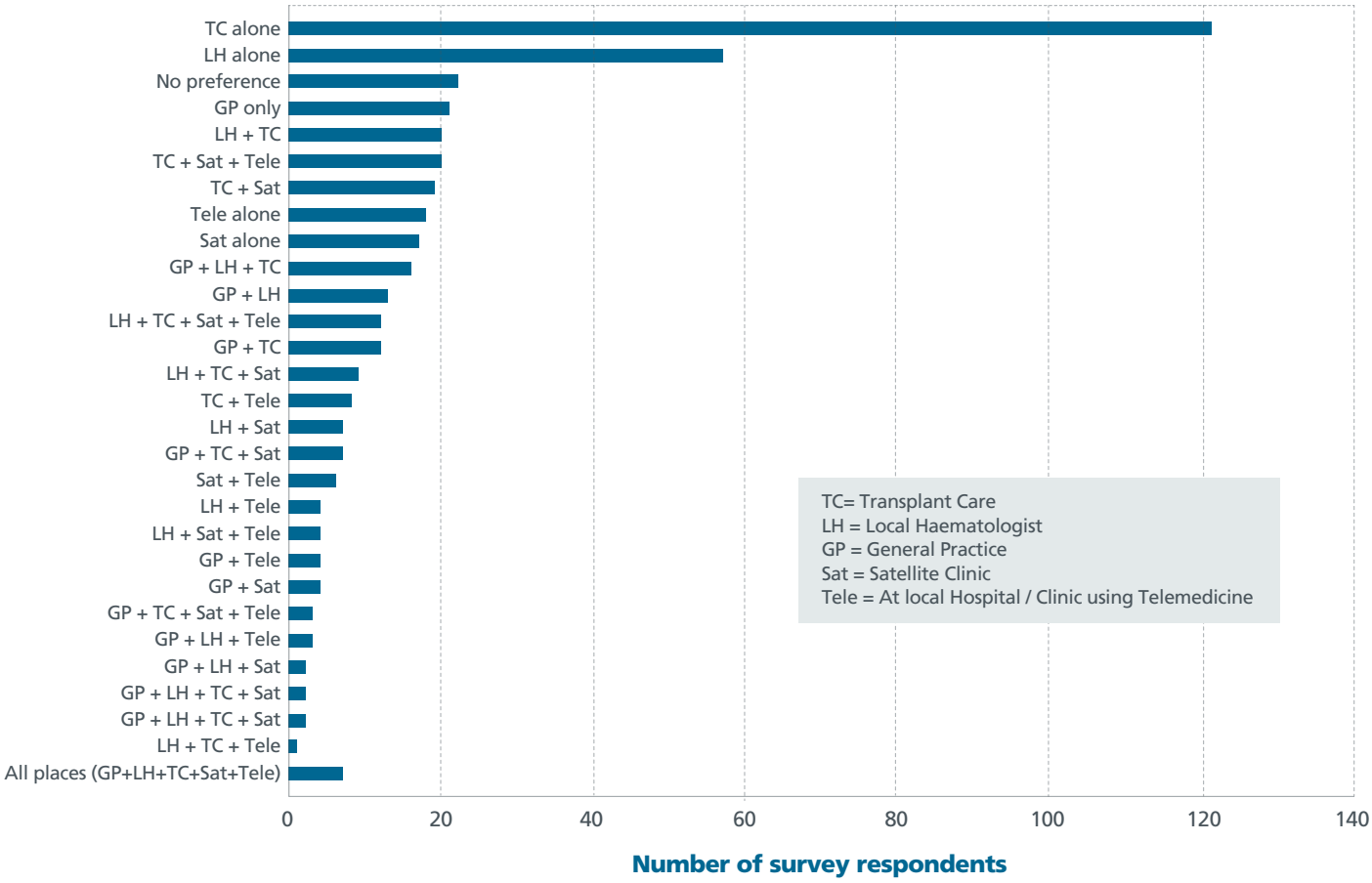
Of the locations for delivery of long-term follow-up care, 234 (53%) survey respondents indicated a single site as their preferred option and 185 (42%) preferred a combination of locations (Figure 17). Overall, 22 (5%) indicated no preference for long-term follow-up location.

TRANSPLANT CENTRE

Overall, 328 of 441 BMT survivors (74%) reported a preference for follow-up at transplant centres (TC) alone or in combination with other provider locations, such as satellite clinics or telemedicine locations administered or linked with a transplant centre. Of the entire cohort, transplant centres alone were the preferred option for 121 patients (27.4%) followed by local haematology practices alone for 57 (12.9%). Twenty-one (5%) indicated a preference for follow-up at their GP practice alone, 18 (4.1%) preferred telemedicine (TELE) alone and 17 (3.8%) preferred satellite clinics alone (Figure 17).

On multivariable analysis, no variables showed a significant association with a preference for transplant centre or transplant centre–linked follow-up (Table 12). Those reporting increased severity of GVHD symptoms demonstrated the strongest positive association with a preference for TC or TC-linked follow-up (adjusted OR 1.16, 95% CI 0.99, 1.36, p=0.06) and those in full-time or part-time employment showed the lowest preference for TC or TC-linked follow-up (adjusted OR 0.44, 95% CI 0.19, 1.03, p=0.06).

Figure 17: Preferred location for long-term follow-up care



SATELLITE CLINIC

Overall, 119 of 441 BMT survivors (27.0%) indicated a preference for long-term follow-up that included a satellite clinic, attended by a transplant physician from the centre where they had received their allograft. Of these, 17 (14.3%) indicated a preference for satellite clinic follow-up alone, with the remainder indicating a preference for satellite clinic in combination with other long-term follow-up options.

After adjusting for potential confounders, factors that retained a significant association with a preference for satellite clinic care included higher income status (adjusted OR 4.67, 95% CI 1.22,17.8, p=0.02), educational status (adjusted OR 3.26, 95% CI 1.28, 8.30, p=0.01) and sexual dysfunction (adjusted OR 3.27, 95% CI 1.21, 8.78, p=0.02) (Table 12a).

TELEMEDICINE

Overall, 92 of 441 (20.9%) BMT survivors reported a preference for follow-up that included a telehealth facility. Of these, 18 (19.6%) indicated a preference for long-term follow-up using telehealth alone; the majority indicated a preference for telehealth in combination with a local haematology practice, transplant centre, satellite clinic or general practice.

Higher psychological morbidity in those preferring telemedicine was reflected in higher median DASS21 scores (22 compared to 18, p=0.03), and a trend towards higher self-reported anxiety and/or depression (p=0.06). Sexual dysfunction was more commonly reported in those expressing a preference for telemedicine (OR 3.96, 95% CI 1.20, 16.8, p=0.06). Following adjustment for potential confounders using multivariable logistic regression, those factors that retained significance included educational status (adjusted OR 5.10, 95% CI 1.72, 15.1, p=0.003) and sexual dysfunction (adjusted OR 3.25, 95% CI 1.02, 10.3, p=0.05) (Table 12b).

A reduced odds of regular exercise (OR 0.6, 95% CI 0.4, 1.0, p=0.04) was reported in those patients reporting a preference for telemedicine. After adjusting for age, gender, chronic diseases and GVHD severity, exercise remained an independent and significant association with reduced telemedicine preference (adjusted OR 0.46, 95% CI 0.24, 0.87, p=0.02) (Table 12b).

Health promotion: health checks, cancer screening and vaccination

Cancer screening

SKIN CHECKS

A total of 436 (98.9%) participants provided a response to whether or not they had undergone skin cancer screening since transplant. Over half (228, 52.3%) reported having had a skin check and 208 (47.7%) reported never having had a skin check since BMT. Of those who reported having had a skin check, 75% had done so in the preceding 18 months (range 1 month to 9 years). Almost three-quarter of the 228 who had had a skin check (166, 72.8%) reported attending for skin checks at least once a year.

Demographic, social, transplant-related, treatment-related and behavioural factors were assessed for their association with having skin checks as part of cancer screening post transplant (Table 13). Note that skin checks were not significantly associated with skin GVHD, receipt of azole antifungals or outdoor occupations (gardening, construction or agriculture). Univariate analysis demonstrated significantly increased odds of skin checks with older age, higher education status, being in a married or defacto relationship and a high compliance with 'sun smart' behaviours, including the routine use of sunscreen, hats, sun-protective attire, sunglasses and sun avoidance during the daily periods for peak exposure. Factors associated with a reduced odds of skin checks included an acute leukaemia diagnosis, receipt of a myeloablative conditioning regimen, and being within two years of transplant. After adjusting for potential confounders, the factors that demonstrated an independent and significant association with having skin checks post transplant included older age (adjusted OR 1.03 95% CI 1.0, 1.05, p=0.03), higher educational status (adjusted OR 1.87, 95% CI 1.11, 3.15, p=0.02) and 'sun smart' behaviour (adjusted OR 1.89, 95% CI 1.06, 3.37, p=0.03).

Reasons cited for not undergoing skin cancer screening in 208 patients included lack of time (13, 6.2%), cost (5, 2.5%) and the belief that screening was not necessary (54, 26.0%). One hundred and forty-nine patients (71.6%) indicated that they had not been advised by their treating team to undergo skin cancer screening. Twenty-nine (13.9%) of those who had never undertaken skin cancer screening were receiving azole antifungal therapy.

BOWEL CANCER SCREENING

A total of 432 participants provided a response to whether or not they had undergone bowel cancer screening (either colonoscopy or stool haemoccult testing) since transplant. One hundred and forty (32.4%) reported having had a bowel check and 292 (67.6%) reported not having had a bowel check since BMT. Of those who reported having had a bowel check, 75% had done so in the preceding two years (range < 1 month to 11 years). Forty-seven of those who had had a bowel check (33.8%) reported having bowel checks at least every two years.

On univariate analysis, those of older age and those in a married or defacto relationship showed significantly increased odds of bowel screening. Transplant-related factors, including an underlying diagnosis of acute leukaemia and receiving myeloablative conditioning, were associated with significantly decreased odds of bowel screening on univariate analysis. On multivariable analysis, the only variable with an independent and significant increased association with bowel screening was older age (adjusted OR 1.06, 95% CI 1.03,1.08, p<0.0001) (Table 13a).

Of the 292 patients who did not have bowel screening, 8 (2.7%) cited time, 2 (0.7%) cost and 75 (25.7%) feeling that screening was not necessary as the main reasons for not having a bowel check since transplant. Two hundred and twenty-five patients (77% of those who had not had a bowel cancer check) reported that they had not been advised to have bowel cancer screening by their treating team.

CERVICAL CANCER SCREENING (PAP SMEAR)

A total of 186 of female participants provided a response to whether or not they had had a Pap smear since transplant. One hundred and eighteen females (63.4%) reported having had a Pap smear and sixty-eight (36.6%) reported not having had a Pap smear since BMT. Of those who reported having had a Pap smear, 75% had done so in the preceding two years (range 1 month to 5 years).

Younger age was significantly associated with having had a Pap smear (p=0.04) and women who were less likely to have had a Pap smear if within two years of the transplant procedure. Following multivariable analysis, the adjusted odds ratio for older age was 0.97 (95% CI 0.94, 1.0, p=0.09). For those who were less than two years post transplant, the adjusted odds of having a Pap smear was 0.30 (95% CI 0.11, 0.85, p=0.02) (Table 13b).

Barriers to cervical cancer screening included lack of time (8 respondents, 11.8%), cost (2, 2.9%) and a belief that Pap screening was not necessary (20, 29.4%). A total of 31 women (45.6%) reported that they had not been advised to have a Pap smear by their treating team.

MAMMOGRAPHY

A total of 184 female participants provided a response to whether or not they had had a mammogram since transplant. Ninety-eight (53.3%) females reported having had a mammogram and 86 (46.7%) reported not having had a mammogram since BMT. Of those who reported having had a mammogram, 75% had done so in the preceding two years (range 2.5 months to 4 years). The age of first mammogram was reported by 68 women: in their 20s (8), 30s (12), 40s (31), 50s (16) and 60s (1).

Older age (adjusted OR 1.11, 95% CI 1.07, 1.16, p<0.001) and residing in a city/inner regional centre (adjusted OR 5.33, 95% CI 1.37, 20.8, p=0.02) were the only variables associated with a significantly increased odds of screening mammography on multivariable analysis (Table 13c).

For those who had not had a mammography, five respondents (5.8%) reported lack of time, two (2.3%) had an issue with cost, 23 (26.7%) felt it was not necessary and 57 (66.3%) reported not being advised by their treating team to undergo breast cancer screening.

PROSTATE CHECKS

A total of 89/246 (36.2%) males reported having had a prostate check since transplant. Of those, 75% had done so in the preceding two years (range <1 month to 16 years).

Older age was associated with an increased odds of having had a prostate check (adjusted OR 1.12, 95% CI 1.07, 1.16, p<0.0001) and being on immunosuppression was associated with decreased odds of having had a prostate check (adjusted OR 0.48, 95% CI 0.24, 0.96, p=0.04) (Table 13d).

For those not having prostate checks, three (1.9%) reported lack of time, one (0.6%) had an issue with cost, 35 (22.3%) felt it was not necessary and 123 (78.3%) reported not being advised by their treating team to undergo prostate screening.

Dental reviews and oral health checks

REGULAR DENTAL VISITS

Overall, 288/436 (66%) of patients reported visiting a dentist on a regular basis. The proportion of those visiting a dentist was similar across survival cohorts with rates of dental review in early transplant survivors being comparable to rates in late survivors (Table 14).

FACTORS ASSOCIATED WITH REGULAR DENTAL REVIEW

Patients having regular dental follow-ups were significantly older (adjusted OR 1.02, 95% CI 1.008, 1.04, p=0.003), were more likely to live in the city/metro area (adjusted OR 1.70, 95% CI 1.08, 2.70, p=0.02) and were more likely to be from the middle/high-income group (adjusted OR 1.87, 95% CI 1.21, 2.88, p=0.005) (Table 14a).

Those who visited a dentist regularly had a higher odds of dental pathology (such as caries, dry mouth, oral GVHD) though none of these associations was statistically significant (Table 14b). The observed higher rates of dental morbidity in those attending a dentist regularly may reflect improved diagnosis. Alternatively, those with pathology may have been more likely to seek regular dental care.

TIME FROM LAST DENTAL VISIT

Those less than two years post transplant were more likely to have had a more recent dental review compared to later survival cohorts ($p<0.05$, Kruskal–Wallis test).

Two hundred and fifty-six (88.9%) of the 288 patients who visited a dentist on a regular basis reported the time since their last dental review. The median time since the last dental review was 10 months (IQR 7, 13, range <1 month, 34 months). Patients who were less than two years from transplant were more likely to have had a more recent dental review. Those who were more than 10 years post transplant reported a longer time (median of 13 months) since their last dental check up (Table 14c).

REASONS REPORTED FOR NOT REGULARLY ATTENDING A DENTIST

Among the reasons cited by the 148 who did not attend a dentist regularly were lack of time (28, 18.9%), cost (54, 36.4%), feeling it not to be necessary (55, 37.2%) or having not been advised to do so by the treating team (30, 20.3%).

Additional reasons for not attending a dentist regularly included being edentulous (13, 8.9%), fear of dentists (2, 1.3%), too great a distance to travel (1), more pressing medical concerns (3, 0.7%) or low platelets (1, 0.7%) (Table 14d).

Vaccination uptake

PRE-TRANSPLANT VACCINATION UPTAKE AND SETTING

Forty-seven per cent of patients reported having received an annual influenza vaccination pre transplant. Of these, 50% were older than 51 years of age at transplant. A much smaller proportion (15%) reported having ever had pneumococcal vaccination, and of these the median age at transplant was 53 years. Human papillomavirus vaccine (HPV) had been administered to a total of four females, three of whom were aged 17 to 25 years at transplantation, and one aged 58 years.

Pre-transplant vaccination was most often administered by a GP (40.4%), followed by hospital (5.4%) or a community clinic (0.5%). Of the 441 patients who responded to the question, 166 (37.6%) reported receiving a vaccination in an urban setting, 36 (8.2%) in a rural setting and two (0.4%) in a remote setting.

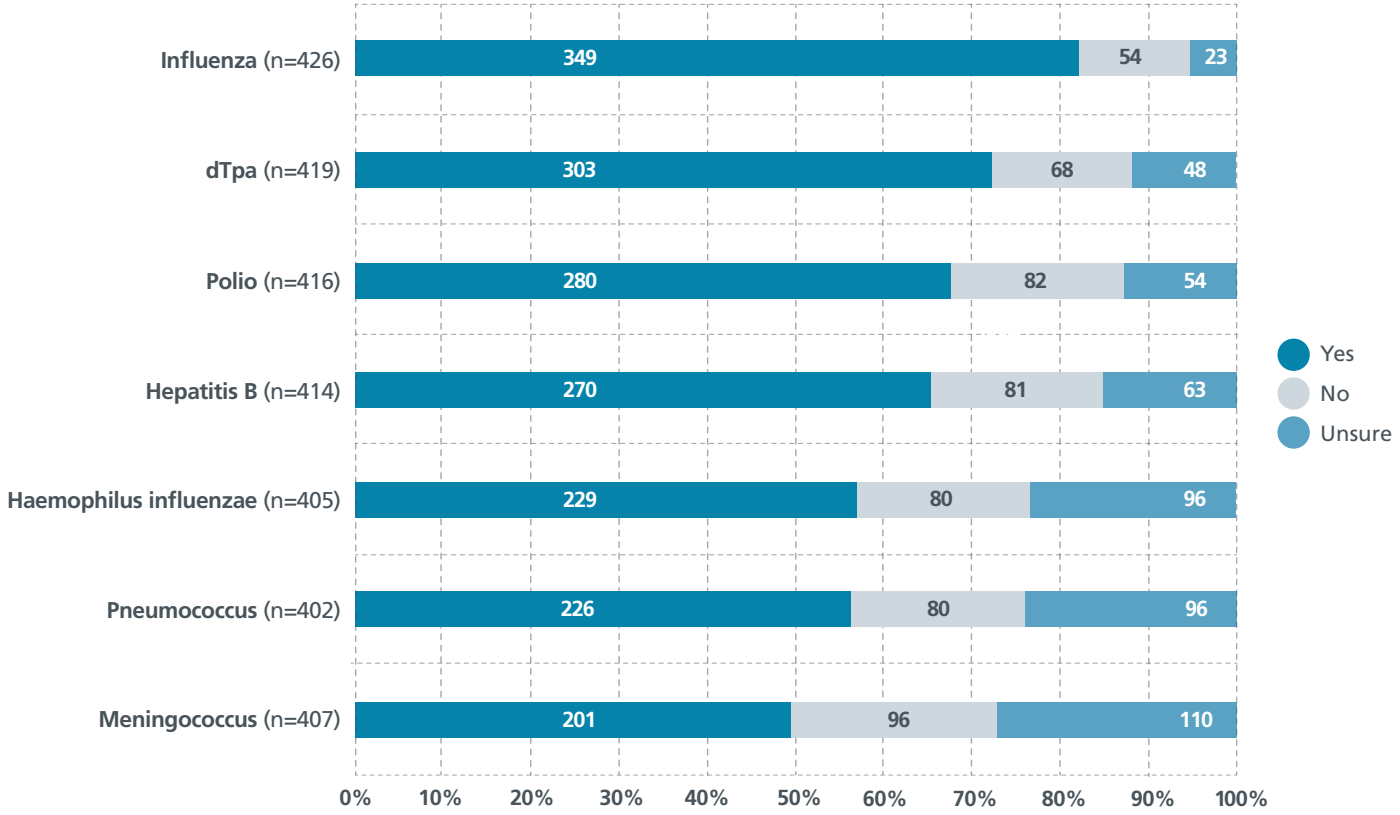
POST-TRANSPLANT VACCINATION: UPTAKE AND SETTING

BMT recipients are recommended to receive a number of reimmunisations in the first 12 months post transplant, including vaccinations against influenza, diphtheria, tetanus pertussis (dTpa), poliovirus, hepatitis B, haemophilus influenzae type b (Hib), pneumococcus and meningococcus.

Four hundred and twenty-eight BMT recipients gave a response on their vaccination status for the above-mentioned vaccines. Of these, 31.8% were fully vaccinated, 7.2% were unvaccinated; 57.9% were partially vaccinated and 3.0% were unsure as to their vaccination status against all of these vaccines. The most frequent vaccination received was for influenza (82%), followed by dTpa (72%), polio (67%) and hepatitis B (65%). Uptake of protein-conjugate vaccines, including *Haemophilus influenzae* type b (Hib), *Streptococcus pneumoniae* (pneumococcus) and *N. meningitidis* (meningococcus) was less frequently reported, at rates of 56%, 55% and 49%, respectively (Table 15, Figure 18).

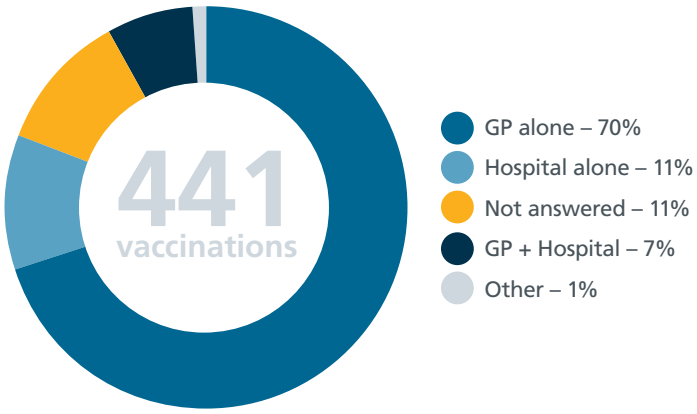
Patients with lower income showed a trend towards having not completed the recommended vaccination schedule in the first two years post transplant (adjusted OR 3.32, 95% CI 0.83, 13.4; p=0.09). Non-completion of the recommended vaccination schedule was less likely in those with a higher education (adjusted OR 0.5 , 95% CI.13, 1.91 p=0.31), but this was not statistically significant on multivariable analysis. A comparison of those patients who had completed all recommended vaccines compared to those who completed none, showed that time from transplant was the most important factor with the adjusted odds for receipt of no vaccinations being 12-fold higher in those who were early post transplant. Chronic GVHD was not shown to be a significant factor on multivariable analysis (Table 15a).

Figure 18: Uptake of recommended vaccinations in the first 12 months post transplant



Post-transplant vaccinations were administered by GPs alone for 308 respondents (69.8%), in the hospital setting alone for 48 (10.9%), in community clinics alone for two (0.5%), in other settings (not specified) for two (0.5%). A combination of settings for vaccination (GP + other, hospital + other) was used by 32 respondents (7.2%) (Table 15b, Figure 19).

Figure 19: Clinical setting for post-transplant vaccination



VACCINATION RECORDS

Of the 417 respondents to a question about a post-transplant vaccination schedule, 299 (71.7%) reported having been given a schedule, 75 (18.0%) had never received a schedule and 43 (10.3%) were uncertain if they had received one.

When asked if their GP had received a copy of the post-transplant vaccination schedule, 216 (52.1%) of 414 respondents said yes, 183 (24.9%) said no and 95 (23%) were uncertain.

When asked if they had a personal record (book) of any vaccinations they had received, 175 (41.8%) of the 410 respondents said yes, 230 (54.9%) said no and 14 (3.3%) were uncertain.

Lifestyle

A range of lifestyle factors were surveyed including smoking, alcohol consumption, being overweight or obese, exercise, nutrition and overseas travel.

Smoking

A total of 438 patients reported on their smoking status. Of these, 33 (7.5%) were smokers: 21 (8.5%) of the 247 males and 12 (6.3%) of the 191 females. Twenty-two of the 33 smokers (66.7%) were in the 40 to 60 year age group. Almost half of the smokers (16, 48.5%) were between six and 10 years post transplant. Sixteen (10.5%) of the 153 patients from a low-income group were smokers, compared with 16 (6%) of the 267 patients from a middle/high-income group (OR 1.8 95% CI 0.82, 4.04, p=0.09).

Alcohol

A majority of survey respondents reported that they consumed alcohol (282 of 441, 63.9%), including 179/250 (71.6%) males and 103/191 (53.9%) females. The consumption of alcohol across all age groups was consistent.

Alcohol consumption was quantitated in 273 of those who consumed alcohol. Of these 33 (12.1%) exceeded two standard drinks per day on average Of these 33, 29 were males (16.8% of 173 males) and four were females (4.0% of 100 females). An average daily alcohol consumption of four or more standard drinks per day was reported by 11 (6.3%) of the 173 males. The highest rates of heavy alcohol consumption were in males aged 60–69 (14/52, 26%) and females aged 50–59 (3/32, 9%).

No significant difference in alcohol consumption was observed across income strata: 9/82 (11,0%) from a low-income group and 23/180 (12.8%) from middle/high-income group reported heavier alcohol consumption (p=0.68).

Overweight and obesity

Self-reported height and weight for BMI determination of 405 patients revealed that 13 (3.2%) were underweight, 197 (48.6%) were of normal weight, 128 (31.6%) were overweight and 67 (16.5%) were obese (Figure 20).

Figure 21 shows the distribution of weight ranges by years post transplant. The proportion of survivors who were overweight was highest in the early post-transplant group. The proportion of survivors who were obese was greatest in survivors more than five years post transplant. The highest proportion of those with normal BMI was in the late transplant cohort (10–14 yrs).

Exercise

Two hundred and one (46%) of the 441 surveyed patients reported exercising at least three times per week. Almost half (218, 49.4%) indicated that their ability to exercise was compromised as a result of the transplant procedure and related complications.

Nutrition

Sixty-five per cent of survivors in the early transplant group (< 2 years) reported that their eating habits had returned to normal. Of the 379 survivors two or more years post transplant, 292 (77.0%) reported that their eating habits had returned to normal.

One hundred and thirty-one survivors (29.6%) reported changing their diet since having a BMT. The four most common changes included: avoiding particular food and food groups (48 respondents, 36.6%); focusing on healthy eating (46, 35.1%), reducing meat consumption (21, 16.0%) and choosing organic foods (14, 10.7%).

Twelve per cent (52/441) of survivors were taking oral nutritional supplements at the time of the survey.

Figure 20: Distribution of BMI in BMT survivors

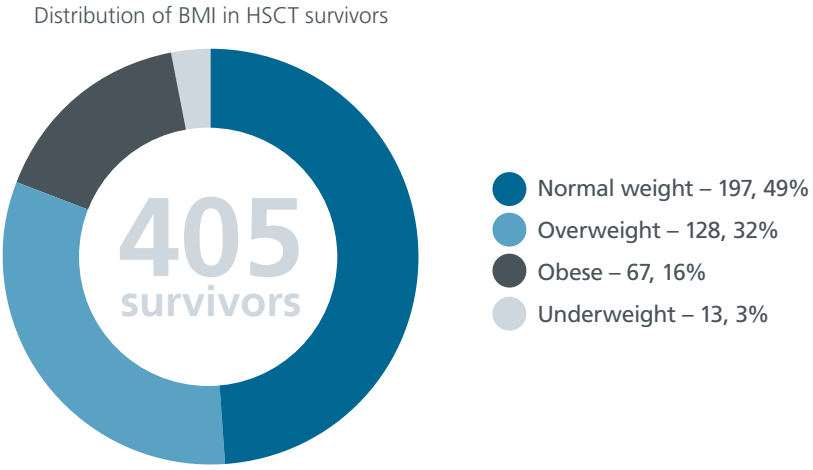
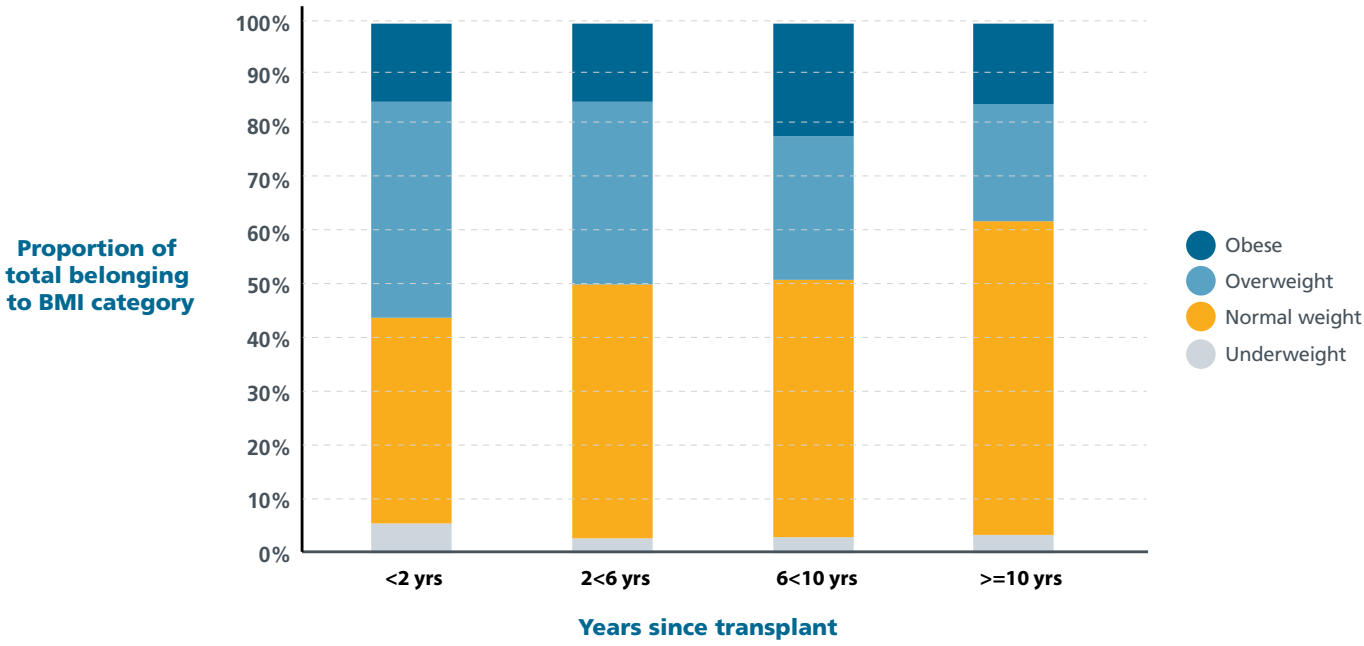


Figure 21: Distribution of BMI, stratified by years since transplant



Complementary and alternative medicine

At least one form of complementary and alternative medicine (CAM) was used by 238 BMT survivors (54%). These include diet modification (13.6%), vitamin therapy (including minerals and oils) (30%), mind–body therapy (including spiritual) (17.2%), herbal supplements (13.5%), manipulative and body-based therapies (26%), Chinese medicine (3.5%), Reiki (3%) and homeopathy (3%). A total of 150 patients (33.9%) used more than one form of CAM, ranging up to seven forms in three patients (0.7%).

Overseas travel

Just over half (233/433, 52.8%) of those surveyed reported travelling overseas since their transplant, with some travelling to multiple destinations. Travel destinations included South East Asia (77 respondents, 17.5%); North East Asia (40, 9.1%); South-Central Asia (6, 1.4%); Africa and/or South Africa (12, 3.1%); Central, South America and/or Caribbean (14, 3.2%); Middle East (41, 4.8%); Europe and/or UK (98, 22.2%); and New Zealand and/or the Pacific Islands (99, 22.4%).

Patients who had avoided overseas travel since their transplant gave a range of reasons, including having no interest in travel (43, 9.7%), physical limitations (96, 21.8%), the risk of exposure to new infections (155, 35.1%), the cost of travel (130, 29.5%) and the cost of travel insurance (86, 19.5%).

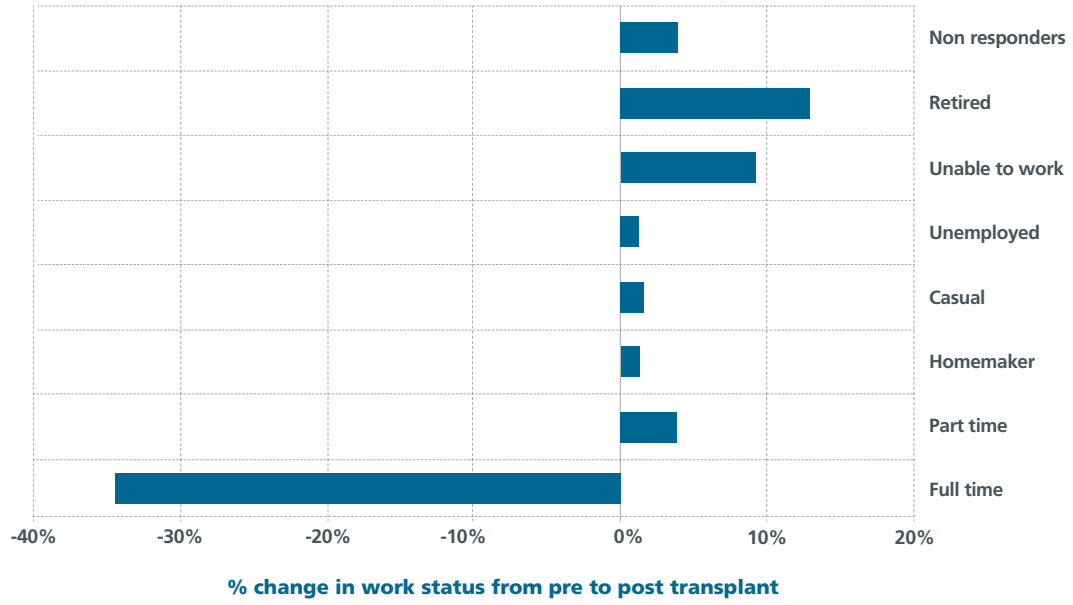
Of patients who travelled overseas, 189 (81.1%) reported taking out travel insurance. Those who did not take out insurance gave the following reasons: inaffordability (12.4%); no policy to cover existing or pre-existing conditions (27.8%); and not thinking travel insurance was necessary (21.6%). Other reasons for not taking out personal travel insurance included costs being covered by an employer (1) and having citizenship that would have enabled healthcare access when abroad (1).

Social factors

Occupational status

The most important changes in work status related to those who were in full-time employment pre transplant (Table 16). A total of 282/441 (64.2%) transplant recipients were in full-time employment pre transplant, as compared to 131/441 (29.7%) post transplant. This represents an absolute difference of -34.5% in full-time employment (Figure 22). The proportion in retirement increased from 5.0% pre transplant to 18.1% post transplant, representing an absolute difference of 13.1% in retirement (Figure 22).

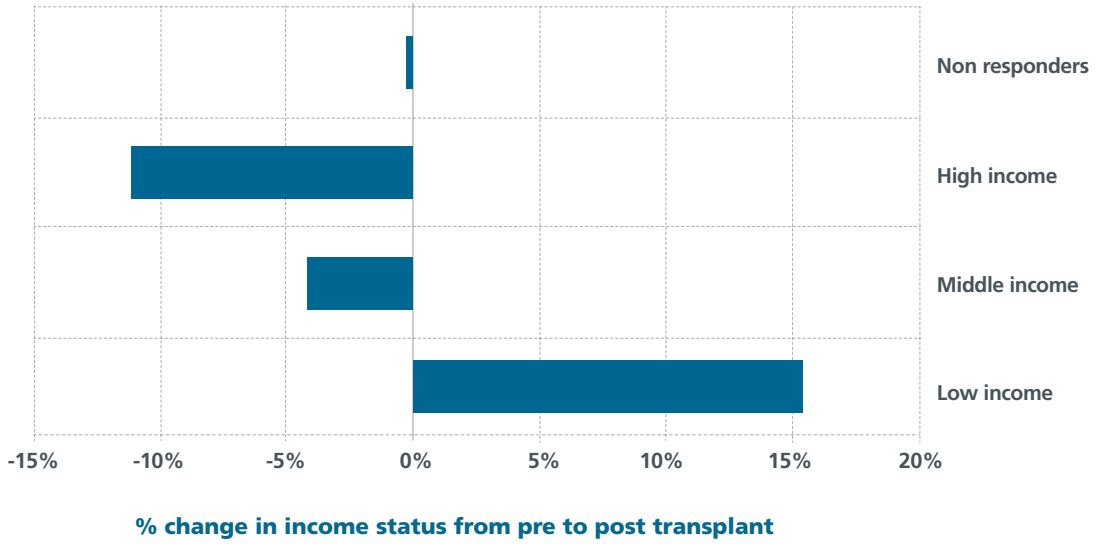
Figure 22: Changes in pre- and post-transplant occupational status



Income status

Of those surveyed, 19.7% reported being of low-income status pre transplant and 35.1% post transplant (Table 16a), representing an absolute change of +15.4% following transplant. Overall, 44.0% were of high-income status pre transplant and 32.9% post transplant, representing an absolute difference of -11.1% of those having high-income status. A less substantial decline in the proportion of those having middle-income status was reported pre and post transplant (-4.1%) (Figure 23).

Figure 23: Changes in pre- and post-transplant income status

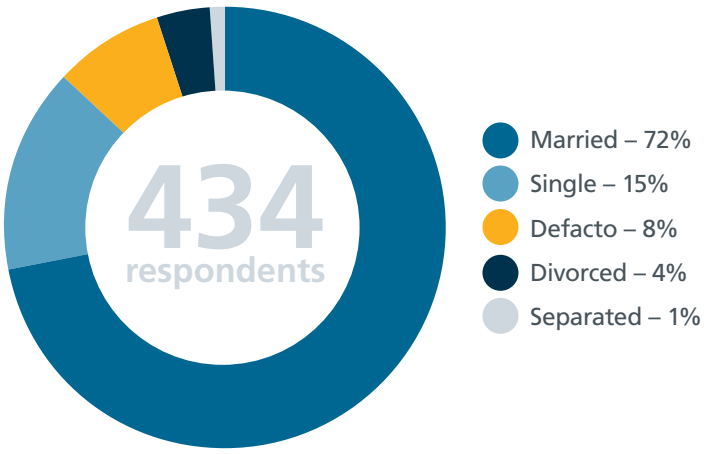


Relationship status

Sixty-eight (15.8%) of 431 survey respondents reported a change in their relationship status since transplant. Of these, 25 (36.8%) reported their pre-transplant relationship status as single; 20 (29.4%) married; 19 (27.9%) defacto; one (1.5%) divorced and two (2.9%) separated (Table 16b)

Current relationship status was reported in 434 survey respondents: 72% of these were married and 8% in a defacto relationship.

Figure 24: Current relationship status

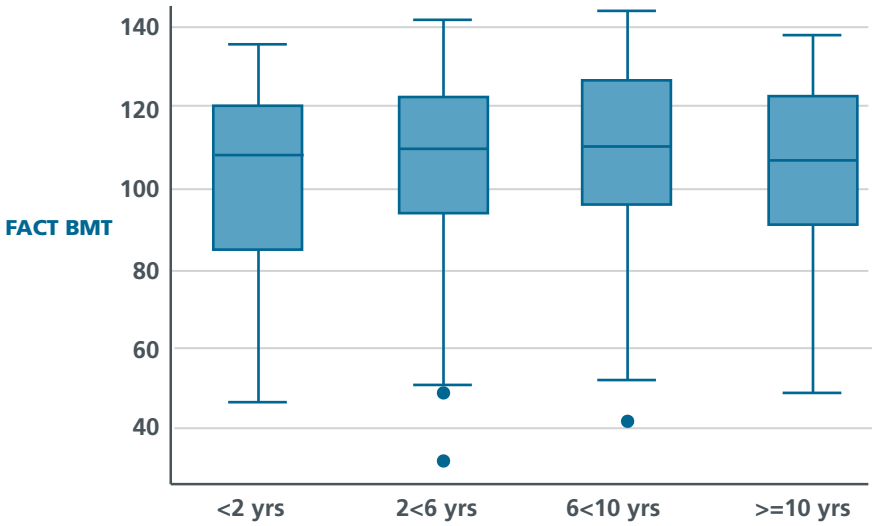


Quality of life

Years from transplant and quality of life

Overall, FACT–BMT scores and subscales did not differ across survival cohorts, by years from transplantation (Table 17 and Table 17a, Figure 25).

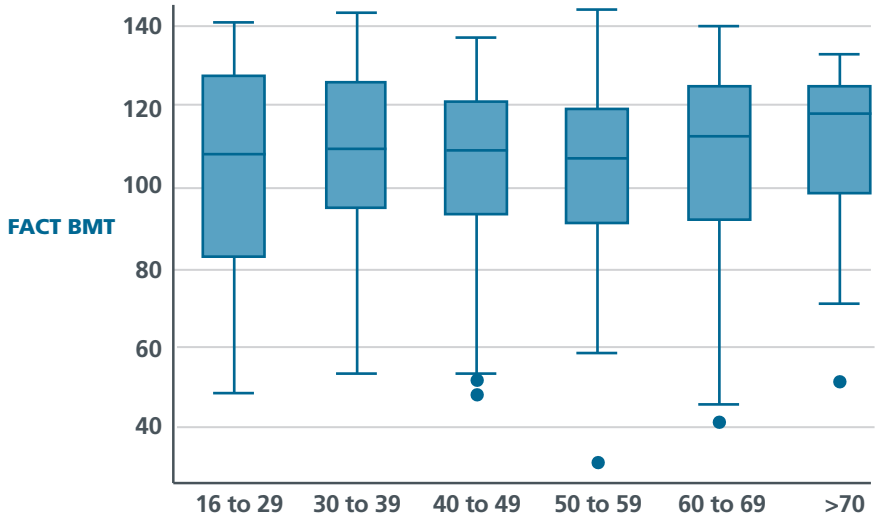
Figure 25: Quality of life (FACT–BMT score) by years since transplant



Age and quality of life

FACT–BMT scores and subscales did not differ between age groups (Figure 26).

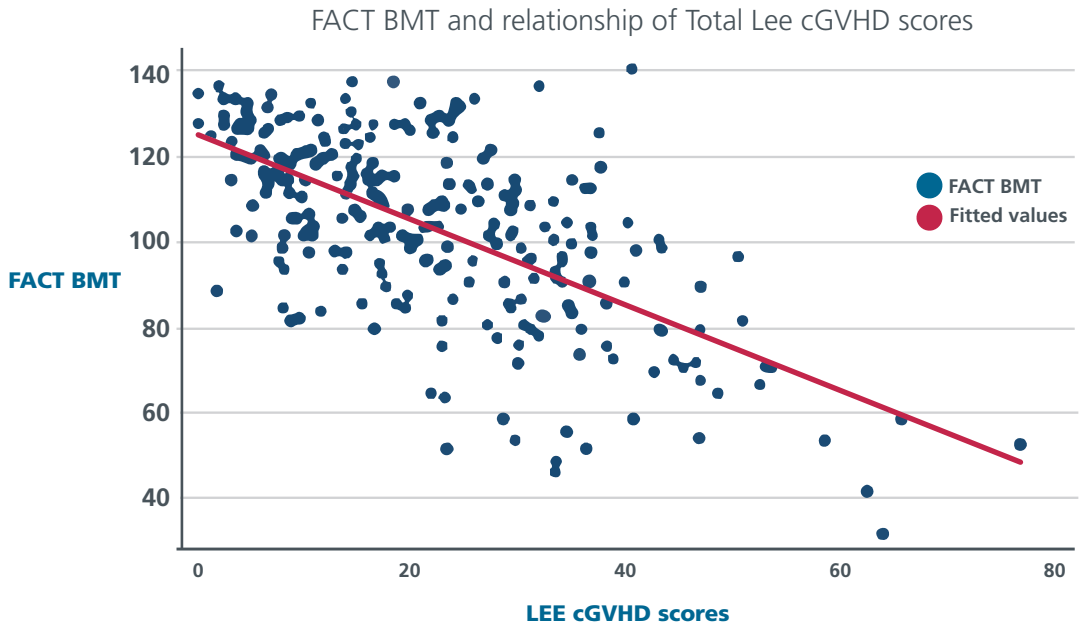
Figure 26: Quality of life, by age group



GVHD and quality of Life

Lee cGVHD scores showed a negative correlation with quality of life measures as assessed by FACT–BMT (Figure 27).

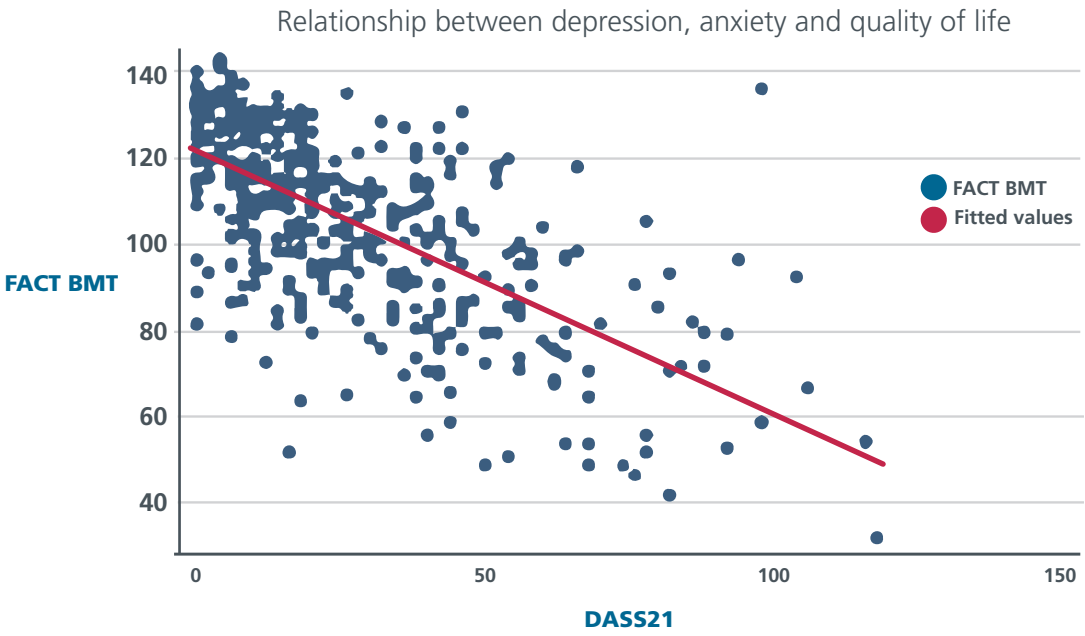
Figure 27: Quality of life, association with GVHD



Depression and quality of life

Depression, anxiety and stress showed a negative correlation with quality of life measures as assessed by DASS21 (Figure 28).

Figure 28: Relationship between quality of life and depression, anxiety, stress



Fear of cancer recurrence

In total, 364 (82.5%) of 441 survey respondents had a pre-transplant cancer diagnosis: acute myeloid leukaemia (169), acute lymphoblastic leukaemia (57), chronic myeloid leukaemia (21), chronic lymphocytic leukaemia (19), non-Hodgkin lymphoma (79), Hodgkin lymphoma (5), and multiple myeloma (14).

Of these, questions relating to fear of cancer recurrence (FoCR) were completed by 355 patients.

A multiple regression analysis for a number of predictor variables and their association with FoCR were included in a fitted model. Factors positively associated with FoCR in this model included age, depression/anxiety/stress, university education, pre-transplant diagnosis of acute leukaemia, married-defacto relationship, low income, full/part-time employment, use of psychotropic medication (antidepressant, anxiolytic or sedative) and exercise. Factors negatively associated with FoCR included years from transplant (that is, higher FoCR with a shorter duration from transplant), being in first or second complete remission at transplant (lower FoCR in CR1/2), male gender (lower FoCR in males), ethnicity (lower FoCR for Caucasian Europeans). (Table 18)

A stepwise regression of the above model determined that the variables most strongly associated with FoCR were quality of life (Beta=-0.10, p<0.0001); years since transplant (Beta=-0.20, p=0.02); being in first or second remission at transplant (Beta=-1.36, p=0.02); and being in a married /defacto relationship (Beta=1.36, p=0.05). Adjusted R2 for the model =0.26.

Increased FoCR was therefore associated with poorer quality of life measures, being closer to date of transplant, not being in CR1/2 at time of transplant and being in a married-defacto relationship.

Post-traumatic Growth Inventory scores

The Post-traumatic Growth Inventory (PTGI) is a standardised tool applied to survivors of BMT to assess growth that follows the intervention. It is essentially an attempt to identify positive outcomes that may arise from a traumatic event. The areas of growth that are covered by PTGI include (1) relationships (relating to others); (2) opening oneself up to new possibilities; (3) development of personal strength/resilience; (4) initiating spiritual changes in one's life; (5) newfound appreciation for life. All these factors are summarised in a final PTGI score.

The PTGI is calculated from 21 questions, each using a six-point Likert scale (0 = no change resulting from BMT procedure; 5 = a very great degree as a result of BMT).

The strongest areas of growth reported in BMT survivors pertained to personal strength and an appreciation of life, with median scores that mapped to these domains being at least half the maximum. The area of lowest personal growth pertained to the spiritual domain (Table 19). Personal growth in females following BMT was higher than in males overall, especially in those domains that pertained to relationships, personal strength and spiritual growth.

Section 5

Summary of findings

Four hundred and forty-one allogeneic BMT recipients, transplanted between 1 January 2000 and 31 December 2012, completed the Sydney post–bone marrow transplant survey. This represented 66% of known transplant survivors.

Half of those surveyed were at least five years post transplant. The median age of survey respondents was 54 years. A majority were male (56.7%).

Of those surveyed, 53.4% were transplanted for an underlying diagnosis of acute leukaemia. Overall 66.9% of patients with an underlying haematological malignancy were in first or second complete remission. Matched sibling donors were used in 56.9% of patients transplanted, and matched unrelated donors in 36.0%. Myeloabalative conditioning regimens were used in 48.7%. T cell–depleting therapies were used in 28.6% of conditioning regimens. Total body radiation was used in 47.2% of myeloablative regimens and 11.6% of reduced-intensity regimens.

Chronic GVHD was reported in 69.3% of survey respondents. Most active GVHD symptoms related to skin, eye, vagina and mouth; 32.4% of symptoms were moderate to severe.

Chronic diseases relating to endocrine and cardiovascular systems and bone metabolism were reported in 19%, 43.5% and 31.5%, respectively. Self-reported iron overload was also high (32.5%), as was the number of self-reported cataracts (28.9%).

Influenza (38.4%)and herpes zoster (27.9%) were the two most commonly reported infections.

Skin cancers were reported in 23% of respondents (44% of skin cancers were basal cell carcinomas), mouth cancers were reported in 1.5% and other cancers in 4.3%.

At least one-third of BMT survivors described oral/dental morbidities that included mouth GVHD, mouth ulcers, tooth decay and dry mouth.

Gastrointestinal symptoms were common, including taste alteration in 30.9% and diarrhoea in 19.4% of respondents.

Psychological morbidity (depression and/or anxiety) was reported in 28.8%. Severe or extremely severe symptoms of depression, anxiety and stress were reported in 10.2%, 15.7% and 10.8% of the respondents, respectively.

Sexual dysfunction was common, being reported in 66.4% of females and 51.6% of males.

Specialist referrals were most commonly reported to ophthalmologists, gynaecologists (for females), dermatologists and respiratory specialists. Of allied health professionals, physiotherapists and dietitians accounted for the most referrals.

Approximately three-quarters of the survey respondents had been assessed with bone mineral density scan and lung functions tests. Cardiac functional assessment (GHPS or echocardiography) was less commonly reported (49.3%), as was any thyroid assessment (palpation ultrasound or scan) (23.8 %). Approximately 9% of patients reported having none of these formal assessments.

Three-quarters of BMT patients reported a preference for follow-up with their transplant physician and in a location that either included, or was linked with, the transplant centre (such as a satellite clinic or telemedicine facility). A trend for this preference was particularly marked among respondents with severe GVHD symptoms. Those in full-time or part-time work showed a trend towards decreased preference for transplant clinic (or transplant centre–linked) follow-up. One-third of those who were within two years of transplantation were attending a hospital or medical/practice facility at least once per month and, of these, 47% were being seen at least weekly.

The highest compliance with recommended cancer screening was reported in females for Pap smears (63.3%) and mammography (53.4%). In comparison, 52.3% BMT survivors reported ever having had a skin cancer check, 32.4% had bowel cancer screening and 36.2% of males had a prostate check. The most commonly cited reason for not complying with cancer screening was lack of advice to do so by the treating team.

Of respondents, 31.8% had received all the vaccines that are routinely recommended in the first 12 months post transplant; 7.2% were unvaccinated; 57.9% were partially vaccinated and 3.0% were unsure of their vaccination status.

Approximately two-thirds of patients had been reviewed by a dentist since their transplant. Positive determinants for being reviewed by a dentist included being from a middle/high-income bracket, living in a metropolitan/inner regional centre and being older. Cost of dental care was indicated by 26% of respondents as a reason for not attending for dental reviews.

Lifestyle behaviours such as smoking and drinking alcohol were reported in 7.5% and 64% of the respondents, respectively. Eighty-eight per cent of those who consumed alcohol reported a consumption that averaged less than or equal to two standard drinks per day. Regular exercise (at least three times per week) was reported in 49%. Rates of overweight and obesity in the respondents were 32% and 16%, respectively.

Changes in social status were reported following transplantation: an absolute increase of +15.4% of low-income status; an absolute decline of 35.4 % of those in full-time employment. Furthermore, 15.3% reported a change in their relationship status. Approximately 80% reported that they were currently married or in a defacto relationship.

Factors affecting quality of life were notably psychological morbidity and GVHD. No clear associations could be seen between quality of life and age or years from transplant.

Lower fear of cancer recurrence was associated with improved quality of life measures, being in first/second complete remission at transplantation, and being further out from the date of transplant.

The strongest areas of growth reported in BMT related to personal strength and an appreciation of life. Female BMT survivors had significantly higher growth in those domains that mapped to relationships, personal strength and spiritual growth when compared to their male counterparts.

Section 6

Conclusions

The Sydney Post-BMT survey has provided useful insights into the background demographics and morbidity in BMT survivors. The survey has identified gaps in a range of recommended follow-up tests and procedures, and has captured information on consumer preferences. The study has highlighted a number of areas where health promotion could be improved.

Section 7

Research communication - publications and presentations

Papers accepted (As of July 2016)

1. Dyer G, Gilroy N, Bradford J et al. A survey of fertility and sexual health following allogeneic haematopoietic stem cell transplantation in New South Wales, Australia. *British Journal of Haematology.* 2016; 172:592-601.

2. Dyer G, Gilroy N, Brown L et al. What They Want: Inclusion of Blood and Marrow Transplanation Survivor Preference in the Development of Models of Care for Long-Term Health in Sydney, Australia. *Biology of Blood Marrow Transplant*. 2016;22(4):731–43.

3. Gifford G, Gilroy N, Dyer G et al. The Experience of Survival following allogeneic Haematopoietic Stem Cell Transplantation (allo-HSCT) in New South Wales, Australia. *Bone Marrow Transplantation*. 2016. May 23. doi:10.1038/bmt.2016.135

4. Dyer G, Larsen S, Gilroy N et al. Adherence to cancer screening guidelines in Australian survivors of Allogeneic Blood and Marrow Transplantation. *Cancer Medicine.* 2016. Apr 25. doi:10.1002/cam4.729

Papers submitted (As of July 2016)

1. Brice L, Gilroy N, Dyer G et al. Hematopoietic stem cell transplantation survivorship and quality of life: Is it a small world after all? 2015 (submitted to *Journal of Cancer Survivorship*).

2. Brice L, Gilroy N, Dyer G et al. Fear of Recurrence Post allogeneic Hematopoietic Stem Cell Transplant (HSCT) for malignant disease: Adapting to the 'New Normal'. 2015 (submitted to *Psycho-Oncology*).

3. Smith J, Poon C, Gilroy N et al. Nutritional issues and body weight in long term survivors of Allogeneic Haemopoietic Stem Cell Transplantation (HSCT) in NSW Australia. (Submitted to *Supportive Care in Cancer*).

4. Lindsay J, Kabbir M, Gilroy N et al. Complementary and Alternative Medicine Therapy (CAM) Use by Allogeneic BMT Survivorship Patients. (Submitted to *Cancer Medicine*).

Papers in preparation (As of July 2016)

1. Larsen S, Dyer G, Gilroy N et al. Primary preventative health behaviour post-transplant in Allogeneic Blood and Marrow Transplant survivors in NSW. 2016.

2. Dyer G, Brice L, Gilroy N et al. Financial and occupational impact of long term survival following allogeneic BMT in Australia. 2016 (in preparation).

3. Brice L, Gilroy N, Dyer G et al. Hematopoietic stem cell transplantation, survivorship and quality of life: The good, the bad and the ugly. 2016 (in preparation).

4. Dyer G, Gilroy N, Kabir M et al. Vaccination adherence post allogeneic BMT in Sydney, Australia. 2016 (in preparation).

5. Bhastia R, Schifter M, Gilroy N et al. Oral and Dental health in Australian survivors of allogeneic BMT. 2016 (in preparation).

Oral presentations

1. Clinical Oncology Society of Australia (COSA), 2015 Annual Scientific Meeting – 'The experience of survival following Blood and Marrow Transplant in NSW, Australia' (Nov 2015).

2. Cancer Institute NSW (CINSW), 2015 Innovations in Cancer Treatment and Care Conference – 'Secondary Cancers, Health Behaviour and Cancer Screening Adherence in survivors of Allogeneic Blood and Marrow Transplant (BMT) in NSW' and 'The experience of survival following Blood and Marrow Transplant in NSW, Australia' (Two presentations, Oct 2015).

3. University of Sydney Cancer Research Network and Lifespan Research Network, Cancer-Lifespan Research Symposium – 'Secondary Cancers, Health Behaviour and Cancer Screening Uptake in survivors of Allogeneic Blood and Marrow Transplant (BMT) in NSW' (Sept 2015).

4. NSW Agency for Clinical Innovation (ACI), BMT Network Senior Nurses Forum – 'The Experience of Survival following Allogeneic BMT in NSW; Cancer Screening Adherence, Sexuality and Fertility, Preferences for Long Term Care Delivery and Vaccination Adherence and Quality of Life' (Jul 2015).

5. Clinical Oncology Society of Australia (COSA), 2015 Annual Scientific Meeting – 'Fear of Recurrence Post allogeneic Hematopoietic Stem Cell Transplant (HSCT) for malignant disease: Adapting to the "New Normal"', Hobart, Tasmania (Nov 2015).

Poster presentations (As of July 2016)

1. Lindsay J at al. Complementary and Alternative Medicine Therapy (CAM) Use by Allogeneic BMT Survivorship Patients. *Biology of Blood and Marrow Transplant*; 2016;22(3):S476.

2. Brice L et al. Clinical Oncology Society of Australia (COSA), 2015 Annual Scientific Meeting – 'The Experience of Survival following Allogeneic BMT in NSW; physiological and psychological complications, and the functional status of survivors in Australia' (Nov 2015).

2. Brice L et al. Clinical Oncology Society of Australia (COSA), 2015 Annual Scientific Meeting – 'Fear of Recurrence Post allogeneic Hematopoietic Stem Cell Transplant (HSCT) for malignant disease: Adapting to the "New Normal"', Hobart, Tasmania (Nov 2015).

3. Brice L et al. Clinical Oncology Society of Australia (COSA), 2015 Annual Scientific Meeting – 'Hematopoietic stem cell transplantation survivorship and quality of life: Is it a small world after all?' Hobart, Tasmania (Nov 2015).

4. Dyer G et al. Haematology Society of Australia and New Zealand, the Australian & New Zealand Society of Blood Transfusion and the Australasian Society of Thrombosis and Haemostasis (Collectively HAA), 2015 Annual Scientific Meeting – 'Secondary Cancer, Cancer Screening Adherence, Health Behaviours in Survivors of Allogeneic Blood and Marrow Transplant (BMT) in NSW' and 'BMT Survivor Preference for Long Term Care in NSW' (two posters, Oct 2015).

Appendix

Tables

Table 1: Social and demographic characteristics of transplant survivors

Demographic and social variable (N=number of responses)	Results
Median years since transplant (IQR; range)	5 (IQR: 3, 8; range1-14)
Years since transplant, category (N=441)	Number with characteristic (%)
< 2yrs	58 (13.2%)
2 to <6 yrs	204 (46.3%)
6 to <10 yrs	117 (26.5%)
10 to 14 yrs	62 (14.1%)
Median age at survey, years (IQR; range)	54 (IQR: 44,62; range 19–79)
Median age at transplant, years (IQR; range)	49 (IQR: 38,56; range 17–71)
Age groups, years (N=441)	Number with characteristic (%)
19–29	30 (6.8%)
30–39	49 (11.1%)
40–49	83 (18.8%)
50–59	130 (29.5%)
60–69	127 (28.8%)
>70	22 (5.0%)
Gender (N=441)	Number with characteristic (%)
Male	250 (56.7%)
Female	191 (43.3%)
Culture, ethnicity (N=372)	Number with characteristic (%)
Australian/European	323 (86.8%)
Indigenous Australian	2 (0.5%)
Asian	30 (8.1%)
Middle Eastern	7 (1.9%)
Other	10 (2.7%)
Education (N=333)	Number with characteristic (%)
Some high school	53 (15.9%)
Completed High school	79 (23.7%)
Trade qualifications/diploma	47 (14.1%)
Some university	24 (7.2%)
Completed university	130 (39.0%)
Household income, post transplant (N=423)	Number with characteristic (%)
Low income $20,000–39,999	155 (36.6%)
Middle income $40,000–79,999	123 (29.1%)
High income ≥$80,000	145 (34.3%)

Demographic and social variable (N=number of responses)	Results
Employment status, post transplant (N=412)	Number with characteristic (%)
Full-time	131 (31.8%)
Part-time	78 (18.9%)
Homemaker	21 (5.1%)
Casual	26 (6.3%)
Unemployed	20 (4.8%)
Unable to work, poor health	56 (13.6%)
Retired	80 (19.4%)
Residential location (N=431)	Number with characteristic(%)
RA1 (Major city)	311 (72.2%)
RA2 (Inner regional)	85 (19.7%)
RA3 (Outer regional)	31 (7.2%)
RA4 (Remote)	4 (0.9%)
RA5 (Very remote)	0
Relationship status (N=434)	Number with characteristic (%)
Single	67 (15.4%)
Married	311 (71.7%)
Defacto	33 (7.6%)
Divorced	18 (4.2%)
Separated	5 (1.1%)

Table 2: Transplant factors

Transplant variables (N=number of responses)	Number of participants (%)
Numbers by transplant year (N=441)	
2000–2006	136 (30.8%)
2006–2012	305 (69.1%)
Transplant recipients by centre (N=441)	
Centre A (Westmead Hospital)	193 (43.8%)
Centre B (St Vincent's Hospital)	124 (28.1%)
Centre C (Royal North Shore Hospital)	72 (16.3%)
Centre D (Royal Prince Alfred Hospital)	52 (11.8%)
Underlying diagnosis† (N=423)	
AML/ALL	169/57=226 (53.4%)
CML	21 (5.0%)
CLL	19 (4.5%)
SAA	16 (3.8%)
NHL	79 (18.7%)
HL	5 (1.2%)
MM	14 (3.3%)
MDS/myeloproliferative disorder	39 (9.2%)
Other (unspecified)	4 (0.9%)
Remission status (N=405)	
CR1/CR2	271 (66.9%)
>CR2	22 (5.4%)
Chronic Phase	18 (4.4%)
Accelerated Phase and blast crisis	3 (0.7 %)
Refractory	22 (5.4%)
Partial remission	23 (5.7%)
Other	46 (11.4%)
Donor type (N=439)	
Sibling	250 (56.9%)
Haploidentical	10 (2.3%)
Matched unrelated	158 (36.0%)
Mismatched unrelated	21 (4.8%)
Stem cell source (N=441)	
Bone marrow	48 (10.9%)
PBSCT	381 (86.4%)
Cord	12 (2.7%)
Conditioning (N=439)	
Myeloablative – proportion with TBI	214 (48.7%)– TBI 101/214=47.2%
Bu/Cy	79 (36.9%)
Cy/TBI	99 (46.3%)
Bu/Flu	28 (13.1%)
Cy/ATGAM	5 (2.3%)
Cy/Flu/ATGAM	1 (0.5%)
Bu/Flu/Thymoglobulin/TBI	1 (0.5%)
Etop/TBI	1 (0.5%)
Reduced-intensity – proportion with TBI	225 (51.3%)– TBI 26/225=11.6%
Flu/Cy	24 (10.7%)
Flu/Cy/TBI	14 (6.2%)
Flu/Mel	98 (43.6%)
FLAMSA	1 (0.4%)
Flu/BCNU/Mel/ATG	42 (18.7%)
Flu/TBI	12 (5.3%)
Other (unspecified)	34 (15.1%)

Transplant variables (N=number of responses)	Number of participants (%)
GVHD prophylaxis (N=440)	
CSA+ MTX	157 (35.7%)
CSA+MTX+pred	166 (37.7%)
CSA+MMF+pred	4 (0.9%)
MTX+pred	10 (2.3%)
Tacro+MTX	0 (0.2%)
CSA+Tacro+MMF	9 (2.0%)
MMF+MTX	0
Other (unspecified)	94 (21.4%)
T depletion (N=426)	
Yes	122 (28.6%)
ATGAM/ATG (Fresnius/Thymoglobulin	113 (26.5%)
Alemtuzumab (Campath)	4 (3.2%)
Not reported	5 (4.1%)
No	304 (71.4%)

† AML=Acute Myeloid Leukaemia; ALL= Acute Lymphoblastic Leukaemia; CML= Chronic Myelogenous Leukaemia; CLL= Chronic Lymphocytic Leukaemia; SAA= Severe Aplastic Leukaemia; NHL= Non-Hodgkin Lymphoma; HL=Hodgkin Lymphoma; MM=Multiple Myeloma; MDS=Myelodysplastic Syndrome

Table 3: Chronic graft-versus-host disease

cGVHD variable (N=number of responses)	
Total patients with cGVHD (N=434)	301 (69.3%)
cGVHD by gender	Number of people (%)
Male (N=246)	177 (72.0%)
Female (N=188)	124 (66.0%)
cGVHD by age group (N=434)	Number of people (%)
19–29 (N =30)	19 (63.3%)
30–39 (N=49)	31 (63.3%)
40–49 (N=81)	58 (71.6%)
50–59 (N=129)	89 (69%)
60–69 (N=123)	85 (69.1%)
≥70 (N=22)	19 (86.4%)
cGVHD by years from transplant (N=434)	
< 2yrs	36/56 (64.3%)
2 to <6 yrs	140/201(69.7%)
6 to <10 yrs	78/115 (67.8%)
10 to 14 yrs	47/62 (75.8%)
cGVHD by body site (N=434)	Number of people (%)
Skin	203 (46.7%)
Eyes	153 (35.2%)
Lungs	79 (18.2%)
Mouth	155 (35.7%)
Liver	99 (22.8%)
Stomach & Intestines	61 (14.1%)
Nails	53 (12.2%)
Vagina (females, N=188)	41 (21.8%)
Penis (males, N=246)	13 (5.3%)
Muscle/joints	64 (14.5%)
Other organ (not specified)	18 (4.1%)
Not sure	10 (2.3%)
Lee GVHD scores (based on reported symptoms over last month)	**Median (IQR; range)**
Skin score	10 (IQR: 0, 25; range 0–100)
Eye score	33 (IQR: 8 , 75; range 0–100)
Mouth score	0 (IQR: 0, 25: range 0–100)
Nutrition score	0 (IQR:0, 5: range 0–100)
Lung score	5 (IQR: 0, 15: range 0–70)
Psych score	17 (IQR: 0, 33: range 0–100)
Energy score	32 (IQR: 17, 50: range 0–100)
Global score	19 (IQR 9, 30: range 0–77)
Self-reported GVHD severity (patient self-report Form B)	
Symptom severity (skin, mouth) N=number of respondents Scale 0=none; 10='as bad as you can imagine'	**Median (IQR; range)**
Skin itching (N=253)	0 (IQR 0,3; range 0–10)
Mouth dryness (N=253)	2 (IQR 0,5; range 0–10)
Mouth pain (N=252)	0 (IQR 0,2; range 0–10)
Mouth sensitivity (N=253)	0 (IQR 0,4; range0–10)
At least one eye symptom (N=441) (itch, blurring, dryness, loss of visual acuity, cataracts, watering)	Number with eye symptoms(%) 227 (51.5%)
Symptom severity (eyes) N=222 Scale 0=none; 10= 'as bad as you can imagine'	**Median (IQR; range)** 4 (IQR 2,4; 0–10)

cGVHD variable (N=number of responses)	
Vulvovaginal symptoms (females) (N=96)	Number of women (%)
Burning, pain or discomfort or any discomfort in the area of the vagina, vulva, labia or pain on intercourse	
Yes	45 (46.8%)
No	47 (49.0%)
Not applicable	4 (4.2%)
GVHD patient global ratings of symptoms (N=246)	Number with severity rating (%)
None	32 (13.0%)
Mild	119 (48.4%)
Moderate	69 (28.1%)
Severe	26 (10.6%)
Symptom severity (global) N=248 **Scale 0=none; 10= 'as bad as you can imagine'**	**Median (IQR; range)** 3 (IQR 1,6; 0–10)

Table 4: Chronic diseases/morbidity

Chronic disease (N=number of responses)	Number of people (%)
Endocrine	
Underactive thyroid (N=391)	16 (4.1%)
Overactive thyroid (N=390)	5 (1.3%)
Diabetes (N=398)	57 (14.3%)
Any of the above (N=395)	75 (19.0%)
Muskuloskeletal	
Osteoporosis/osteopaenia (N=399)	116 (29.1%)
Avascular necrosis (N=389)	14 (3.6%)
Any spinal/hip fracture (N=392)	17 (4.3%)
Any of above (N=400)	126 (31.5%)
Cardiovascular	
Hypertension (N=409)	118 (28.9%)
High cholesterol (N=402)	96 (23.9%)
Diabetes (N=398)	57 (14.3%)
Any of above (N=414)	180 (43.5%)
Ocular	
Cataracts (N=409)	118 (28.9%)
Other	
Iron overload (N=403)	131 (32.5%)
Recurrent colds (N=402)	92 (22.9%)

Table 4a: Distribution of currently used medications, stratified by years from transplantation

Medications (Number of responses=441)	Number using the medication (%)				
	Total	Years since transplant			
		<2 yrs N=58	2 to <6 yrs N=204	6 to <10 yrs N=117	≥10 yrs N=62
Anti-infectives					
Penicillin	87 (19.7%)	23 (39.7%)	42 (20.6%)	15 (12.8%)	7 (11.3%)
Bactrim/septrim	127 (28.8%)	40 (68.9%)	61 (29.9%)	20 (17.1%)	6 (9.7%)
Aciclovir/valacyclovir	120 (27.2%)	35 (60.3%)	61 (29.9%)	20 (17.1%)	4 (6.4%)
Azole antifungal	53 (12.0%)	13 (22.4%)	25 (12.2%)	11 (9.4%)	4 (6.4%)
Immunosuppression					
Prednisolone	127 (28.8%)	26 (44.8%)	62 (30.4%)	26 (22.2%)	13 (21.0%)
CSA/Tacro/MMF	102 (23.1%)	26 (44.8%)	51 (25%)	17 (14.5%)	8 (12.9%)
Cardiovascular					
Cholesterol-lowering drug	75 (17.0%)	7 (12.1%)	24 (11.8%)	29 (24.8%)	15 (24.2%)
Antihypertensive med	110 (24.9%)	13 (22.4%)	37 (18.1%)	33 (28.2%)	27 (43.5%)
Bone disease					
Bone strengthening drug	69 (15.6%)	7 (12.1%)	34 (16.7%)	19 (16.2%)	9 (14.5%)
Vitamin D	240 (54.4%)	32 (55.2%)	123 (60.3%)	56 (47.9%)	29 (46.8%)
Calcium	204 (46.3%)	25 (43.1%)	107 (52.4%)	49 (41.9%)	23 (37.1%)
Psychotropics					
Anti-anxiety drug	28 (6.3%)	7 (12.1%)	10 (4.9%)	6 (5.1%)	5 (8.1%)
Antidepressant	52 (11.8%)	6 (10.3%)	22 (10.8%)	17 (14.5%)	7 (11.3%)
Sleeping tablet/sedative	47 (10.7%)	9 (15.5%)	21 (10.3%)	11 (9.4%)	6 (9.7%)
Iron overload					
A drug to reduce iron (e.g. Exjade)	10 (2.3%)	3 (5.2%)	5 (2.4%)	2 (1.7%)	0
Hormonal therapy					
Hormone replacement/oral contraceptive (females)	50/191 (26.2%)	3/22 (13.6%)	23/89 (25.8%)	14/52 (26.9%)	10/28 (35.7%)
Hormone replacement (males)	14/250 (5.6%)	3/36 (8.3%)	5/115 (4.3%)	3/65 (4.6%)	3/34 (8.8%)

Table 5: Post-transplant infectious disease

Infectious disease (N=number of responses)	Number reporting the disease (%)
Bacterial	
Pertussis (412)	11 (2.7%)
Pneumococcal disease (N=415)	21 (5.1%)
Haemophilus influenzae type B (N=411)	12 (2.9%)
Meningococcal disease (N=412)	0 (0%)
Tuberculosis (N=412)	3 (0.7%)
Viral	
Influenza (N=419)	161 (38.4%)
Varicella zoster Infections: – primary (chicken pox) (N=416) – zoster/shingles (N=420)	 19 (4.6%) 117 (27.9%)
Hepatitis A (N=414)	1 (0.2%)
Hepatitis B (N=413)	6 (1.5%)
Hepatitis C (N=414)	4 (0.9%)
Measles (N=413)	3 (0.7%)
Mumps (N=414)	2 (0.5%)
Rubella (N=413)	2 (0.5%)
Human papillomavirus-related disease: – Pap smear abnormalities (females, N=184) Genital warts: – Male (N=230) – Female (N=182)	 18 (9.8%) 12 (5.2%) 3 (1.6%)
Fungal	
Fungal infections (N=408): – Mucocutaneous (thrush/candida/skin) – Aspergillosis/ Lung/sinus – Onychomycosis (nails) – Invasive mycosis (prosthetic valve) – Not specified	62 (15.2%) 29 (7.1%) 12 (2.9%) 7 (11.3%) 1 (1.6%) 14 (1.9%)
Unspecified	
Recurrent colds (N=402)	92 (22.9%)

Table 5a: Distribution of post-transplant infections by age and years post transplant

Infection (N=number of responses)	Number reporting infection (%)	Median age (range)	p value	Median years since transplant for those with disease (range)
Recurrent colds (N=402)				
Yes	92 (22.9%)	52 (19–74)		
No	310 (77.1%)	54 (21–79)	0.32	6 (1–14)
Influenza (N=419)				
Yes	161 (38.4%)	54 (19–79)		
No	258 (61.6%)	53 (21–75)	0.97	6 (1–14)
Pertussis (412)				
Yes	11 (2.7%)	65 (43–73)		
No	401 (97.3%)	54 (19–79)	0.01	7 (4–11)
Pneumococcal disease (N=415)				
Yes	21 (5.1%)	62 (30–73)		
No	394 (94.9%)	53 (19–79)	0.01	8 (1–13)
Haemophilus ib (N=411)				
Yes	12 (2.9%)	52 (29–68)		
No	399 (97.9%)	54 (19–79)	0.87	3 (<2–8)
Tuberculosis (N=412)				
Yes	3 (0.7%)	70 (51–71)		
No	409 (99.3%)	54 (19–79)	0.09	7 (4–10)
Hepatitis A (N=414)				
Yes	1 (0.2%)	34		
No	413 (99.8%)	54 (19–79)	N/A	9
Hepatitis B (N=413)				
Yes	6 (1.5%)	60 (47–66)		
No	407 (98.5%)	54 (19–79)	0.28	5 (<2, 11)
Hepatitis C (N=414)				
Yes	4 (0.9%)	60 (52–62)		
No	410 (99.1%)	54 (19–79)	0.31	6 (<2–14)
VARICELLA ZOSTER INFECTIONS				
Primary (chicken pox) (N=416)				
Yes	19 (4.6%)	56 (27–69)		
No	397 (95.4%)	54 (19–79)	0.72	5 (<2, 11)
Zoster/shingles (N=420)				
Yes	117 (27.9%)	56 (21–74)		
No	303 (72.1%)	53 (19–79)	0.09	6 (<2–14)
Measles (N=413)				
Yes	3 (0.7%)	61 (40–70)		
No	410 (99.3%)	54 (19–79)	0.46	2 (3–11)
Mumps (N=414)				
Yes	12 (0.5%)	61, 70		
No	412 (99.5%)	54 (19–79)	0.09	3, 11
Rubella (N=413)				
Yes	2 (0.5%)	61, 70		
No	411 (99.5%)	54 (19–79)	0.09	3, 11
Pap smear abnormalities (females, N=184)				
Yes	18 (9.8%)	42 (22–65)		
No	150 (80.6%)	52 (19–75)		
N/A	16 (8.6%)		0.01	8 (<2–14)

Infection (N=number of responses)	Number reporting infection (%)	Median age (range)	p value	Median years since transplant for those with disease (range)
Genital warts				
– Male (N=230)				
Yes	12 (5.2%)	55 (29–70)		
No	218 (94.8%)	55 (21–79)	0.74	7 (3–13)
– Female (N=182)				
Yes	3 (1.6%)	50 (30–58)		
No	179 (98.4%)	52 (19–75)	0.31	9 (3–11)
Meningococcal disease (N=412)	0 (0%)			
Fungal infection (N=408)				
Yes	62 (15.2%)	55 (21–73)		
No	346 (84.8%)	54 (19–79)	0.83	5 (<2–14)

Table 5b: Post-transplant infections that are vaccine-preventable with vaccinations administered in first 12 months post transplant

Infectious disease (Number of responses=441)	Number reporting the disease (%)
Any vaccine-preventable disease (VPD) for which non-live attenuated vaccines are recommended in the first 12 months post BMT (any of pertussis, haemophilus, pneumococcus, meningococcus, hep B, influenza)	184 (41.7%)
Any vaccine-preventable disease for which non-live attenuated vaccines are recommended in the first 12 months post BMT, **excluding influenza** (any of pertussis, haemophilus, pneumococcus, meningococcus, hep B)	47 (10.6%)

Table 6: Cancers post transplant

Cancer types (N=number of responses)	Number reporting cancer type (%)
Skin cancer (N=404)	
Skin cancer – all types	93 (23.0%)
Types of skin cancer (N=93)	
– Basal cell carcinoma (BCC)	41 (44%)
– Squamous cell carcinoma (SCC)	14 (15%)
– Melanoma	5 (6%)
– Unspecified/don't know	16 (17%)
– Mixed skin cancers	17 (18%)
comprising:	
BCC+SCC	*14 (15% of the 93 with skin cancer)*
BCC+melanoma	*2 (2%)*
SCC+melanoma	*1 (1%)*
Mouth cancers (N=392)	
Mouth cancers	6 (1.5%)
Other (N=370)	
Other cancers	18 (4.9%)
Other cancer types (N=18)	
– Urological(prostate and/or bladder)	5 (27%)‡
– Breast	2 (11%)
– Bowel	1 (6%)
– Ovarian	1 (6%)
– Myeloid sarcoma	1 (6%)
– Head (unspecified)	1 (6%)
– Haematological (non-relapse)	5 (27%)§
– Haematological (relapse)	2 (11%)§§

‡ 3 prostate, 1 bladder, 1 bladder + prostate

§ 1 NHL (primary = AML); 1 NHL (primary = SAA); 2 Hodgkin lymphoma (primary = NHL); 1 post-transplant lymphoproliferative disease

§§1 Relapse AML; 1 relapse mantle cell lymphoma

Table 7: Oral health and dental morbidity

Dental and oral morbidity (N=number of responses)	Number reporting disease (%)
Mouth GVHD (N=441)	155 (35.1%)
Mouth cancer (N=392)	6 (1.5%)
Mouth ulcers (N=408)	144 (35.3%)
Dry mouth (N=406)	183 (45.1%)
Gum disease/gingivitis (N=381)	61 (16.0%)
Tooth abscess (N=372)	23 (6.2%)
Decaying teeth/cavities (N=392)	144 (36.7%)
Other self-reported problems (N=441)	
– Wisdom teeth	6 (1.4%)
– Broken teeth or tooth loss	21 (4.8%)
– Root canal therapy	4 (1.0%)
– Gum recession	8 (1.8%)
– Edentulous or dentures	7 (1.6%)
– Osteonecrosis of mandible	1 (0.2%)
– Dental intervention (wisdom teeth, dental extractions and fillings)	17 (3.8%)

Table 8: Gastrointestinal symptoms and morbidity

Gastrointestinal morbidity (N=number of responses)	Number reporting disease (%)
Nausea (N=424)	50 (11.8%)
Vomiting (N=423)	19 (4.5%)
Constipation (N=427)	66 (15.5%)
Diarrhoea (N=427)	83 (19.4%)
Taste alteration (N=434)	134 (30.9%)
Smell alteration (N=426)	88 (20.7%)
Poor appetite (N=420)	85 (20.2%)
Any of above (N=428)	223 (52.1%)

Table 9: Psychological morbidity

Psychological morbidity (N=number of responses)	Number reporting depression and/or anxiety (%)
Self-reported symptoms of anxiety and or depression	
Self-reported depression (N=407)	95 (23.3%)
Self-reported anxiety or depression (N=403)	83 (20.6%)
Self-reported anxiety and/or depression (N=409)	118 (28.8%)
Depression anxiety and stress scores (DASS21)	
Depression score (median (IQR; range)) (N=438)	4 (2, 14; 0–40)
Depression category (by score range) (N=438)	
Normal (0–9)	287 (65.2%)
Mild (10–13)	41 (9.4%)
Moderate (14–20)	65 (14.8%)
Severe (21–27)	23 (5.2%)
Extremely severe (28+)	22 (5%)
Anxiety score (median (IQR; range)) (N=438)	**4 (2, 10; 0–42)**
Anxiety category (by score range) (N=438)	
Normal (0–7)	280 (63.7%)
Mild (8–9)	31 (7.1%)
Moderate (10–14)	58 (13.2%)
Severe (15–19)	23 (5.2%)
Very Severe (20+)	46 (10.5%)
Stress score (median (IQR; range)) (N=437)	**8 (2, 16; 0–42)**
Normal (0–14)	315 (72.1%)
Mild (15–18)	35 (8.0%)
Moderate (19–25)	40 (9.1%)
Severe (26–33)	34 (7.8%)
Very severe (34+)	13 (3.0%)
Total DASS21 score (median (IQR; range)) (N=437)	20 (8, 40; 0–118)

Table 10: Sexual dysfunction

Variable	Sexual dysfunction Females	Sexual dysfunction Males	OR (95% CI) p value
Resumption sexual activity post-transplant	122/178 (68.5%)	167/241 (69.2%)	
Number reporting sexual difficulties since resumption sexual activity	81/122 (66.4%)	86/167 (51.5%)	1.86 (1.11, 3.11)
TYPES OF PROBLEMS (as a proportion of sexual difficulties)			
Decreased sexual enjoyment	55 (67.9%)	28 (32.6%)	4.3 (2.2, 8.8) p<0.0001
Pain with intercourse	59 (72.8%)	8 (9.3%)	26.1 (10.2, 71.3) p<0.0001
Decreased libido	67 (82.7%)	53 (61.6%)	3.0 (1.4, 6.6) p=0.002
Erectile dysfunction	–	66 (76.7%)	
Difficulties with arousal	47 (58%)	–	
Difficulties with partner regarding sex	27 (33.3%)	28 (32.6%)	1.03 (0.5, 2.1) p=0.91
Other difficulties described	Vaginal bleeding/dryness/ GVHD(11) mobility/flexibility issues (1) post gynae surgery problems (1), body confidence (1), low libido (1), partner issues(1)	Recurrent hospitalisations (1), neurological damage to penis following episode of shingles (1), reduced muscular strength and joint pains and breathing difficulties (3)	

Table 11: Specialist and allied health referrals

Specialist or allied health professional (N=number of responses)	Number referred (%)
Ophthalmologist (N=429)	258 (60.1%)
Gynaecologist (females, N=188)	97 (51.6%)
Dermatologist (N=422)	184 (43.6%)
Respiratory specialist (N=420)	119 (28.3%)
Physiotherapist (N=412)	100 (24.3%)
Dietitian (N=417)	100 (24.0%)
Endocrinologist (N=415)	96 (23.1%)
Gastroenterologist (N=411)	88 (21.4%)
Psychologist (N=415)	79 (19.0%)
Cardiologist (N=415)	71 (17.1%)
ENT doctor (N=411)	72 (17.5%)
Orthopaedic surgeon (N=418)	59 (14.1%)
Social worker (N=413)	53 (12.8%)
Neurologist (414)	50 (12.1%)
Fertility specialist (N=413)	45 (10.9%)
Urologist (N=409)	38 (9.3%)
Occupational therapist(N=413)	35 (8.5%)
Exercise physiologist (N=409)	34 (8.3%)
Infectious diseases doctor (N=414)	34 (8.2%)
Psychiatrist (N=410)	33 (8.0%)
Nephrologist (N=411)	29 (7.1%)
Hepatologist (N=412)	23 (5.6%)
Rehabilitation specialist (N=408)	23 (5.6%)
Additional referrals: oncologist – breast cancer (1), cataract surgeon (1), chiropractor (3), counsellor (2), dentist (6), diabetes educator (1), drug trial (1), endocrine clinic (1), gastroscopy (1), haematologist (2), head/neck surgeon (1), lung transplant team (1), multiple specialists (1), maxillofacial surgeon (1), oral clinic (1), osteopath (1), palliative medicine (1), pelvic physiotherapy (1), podiatrist(2), rheumatologist(7), skin cancer specialist (1), upper gastrointestinal tract surgeon(1), hormone replacement review (testosterone) (1), tricologist (1), urogynaecologist (1), vascular surgeon(1), unspecified(1)	

Table 11a: Tests and investigations recommended in long-term BMT follow-up

Test type (N=number of responses)	Number reporting test recommendations (%)
Heart scan (Gated heart pool scan, cardiac echocardiogram) (N=430)	212 (49.3%)
Lung function tests (N=430)	325 (75.6%)
Bone mineral density scan (N=429)	332 (77.4%)
Thyroid examination (palpation, ultrasound/scan) (N=416)	99 (23.8%)
Any of the above (N=441)	391 (88.7%)
None of the above	41 (9.3%)
Missing	9 (2%)

Table 12: Factors associated with preference for long-term follow-up with transplant centre or a transplant centre–linked service (satellite clinic or telemedicine)

Factors (N=number of responses)	Preference for long-term follow-up with transplant centre, satellite clinic or telemedicine (N=328)	Preference for long-term follow-up with local haematologist or GP (N=113)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
Gender				
Male	188 (57.3%)	62 (54.9%)		1.36 (0.60, 3.05)
Female	140 (42.7%)	51 (45.1%)	0.32	p=0.46
Age, years		53 (43, 62;	1.00 (0.99, 1.02)	1.00 (0.97, 1.03)
Median (IQR; range)	54 (45, 62; 19–79)	21–74)	0.52	p=0.92
Postcode				
RA1/2 (major city/ inner regional)	298 (93.1%)	98 (88.3%)	1.79 (0.80,3.89)	1.62 (0.51, 7.22)
RA3/4 (outer regional/remote)	22 (6.9%)	13 (11.7%)	0.12	p=0.41
Relationship status				
Married/defacto	265 (81.5%)	79 (72.5%)	1.67 (0.97, 2.85)	1.15 (0.39, 3.39)
Single/divorced/separated	60 (18.5%)	30 (27.5%)	0.04	p=0.78
Income status (AUD)				
Middle/high income (>$40,000)	205 (64.9%)	63 (58.9%)	1.29 (0.80, 2.07)	
Low income ($20,000–39,999)	111 (35.1%)	44 (41.1%)	0.27	
Education status				
Some/completed university	117 (48.0%)	37 (41.6%)	1.29 (0.77, 2.18)	
Other (diploma, trade, secondary)	127 (52.0%)	52 (58.4%)	0.30	
Occupational status				
Full-time/Part-time	149 (48.2%)	60 (58.2%)	0.67 (0.41, 1.07)	0.44 (0.19, 1.03)
Other (home duties, casual, retired, unable to work)	160 (51.8%)	43 (41.8%)	0.08	p=0.06
Age (years) at transplantation				
Median (IQR; range)	49 (39, 57; 17–71)	46 (36, 55; 17–70)	0.35	
Time (years) since transplantation				
Median (IQR; range)	5 (3, 8; 1–14)	5 (3, 9 ; 1–14)	0.44	
Underlying disease				
Acute leukaemia	172 (54.3%)	54 (50.9%)	1.14 (0.72, 1.82)	
Other *	145 (45.7%)	52 (49.1%)	0.55	
Stage of disease at transplant				
1st or 2nd remission (CR1/2)	200 (61.0%)	71 (62.8%)	0.92 (0.58, 1.47)	
Other**	128 (39.0%)	42 (37.2%)	0.73	
Conditioning				
Myeloablative	158 (48.5%)	56 (49.6%)	0.96 (0.61, 1.50)	
RIC	168 (51.5%)	57 (50.4%)	0.84	
Donor type				
Matched (sibling, unrelated)	304 (93.2%)	104 (92.0%)	1.19 (0.47, 2.81)	
Haploidentical/mismatched	22 (6.8%)	9 (8.0%)	0.67	
cGVHD				
Yes	227 (70.7%)	74 (65.5%)	1.27 (0.78, 2.05)	
No	94 (29.3%)	39 (34.5%)	0.30	

Factors (N=number of responses)	Preference for long-term follow-up with transplant centre, satellite clinic or telemedicine (N=328)	Preference for long-term follow-up with local haematologist or GP (N=113)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
cGVHD severity score (0–10) Median (IQR)	3 (1,6)	3 (1,5)	1.06 (0.96, 1.17) 0.24	1.16 (0.99, 1.36) p=0.06
Chronic diseases Any chronic disease^ Any cancer^^	231/317 (72.9.5%) 80/287 (27.9%)	76/105 (72.4%) 27/101 (26.7%)	0.92 0.82	
Psychological and sexual morbidity Anxiety Depression	65/300 (21.7%) 72/303 (23.8%)	72/303 (23.8%) 23/104 (22.1%)	1.30 (0.71, 2.48) 0.36 1.10 (0.63, 1.96) 0.73	
Sexual dysfunction	138/222 (62.2%)	29/67 (43.3%)	2.15 (1.19, 3.90) 0.006	1.61 (0.73, 3.55) p=0.24

*; CML= Chronic Myelogenous Leukaemia; CLL= Chronic Lymphocytic Leukaemia; SAA= Severe Aplastic Leukaemia; NHL= Non-Hodgkin Lymphoma; HL=Hodgkin Lymphoma; MM=Multiple Myeloma; MDS=Myelodysplastic syndrome;

**greater than second remission, refractory disease, chronic phase, accelerated phase, blast crisis, partial remission, other (unspecified)

^ Any chronic disease includes hypertension, hypercholesterolaemia, diabetes, bone disease (osteoporosis, osteopaenia, spinal/hip fractures or avascular necrosis), iron overload, thyroid disease. ^^ Any cancer includes skin, mouth or other specified. ¥ Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, marital status, residential location (metro/inner regional), GVHD severity, sexual dysfunction.

Table 12a: Factors associated with a preference for long-term follow-up that includes a satellite clinic

Factors (N=number of responses)	Preference for long-term follow-up with satellite clinic +/-other option (N=119)	Preference for options that exclude satellite clinic (N=322)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
Gender				
Male	70 (58.8%)	180 (55.9%)	1.13 (0.72,1.77)	1.20 (0.49, 3.00)
Female	49 (41.2%)	142 (44.1%)	0.58	p=0.68
Age, years			1.0 (0.98, 1.02)	1.03 (0.99, 1.08)
Median (IQR; range)	54 (45,61; 22–75)	54 (44,62;19–79)	0.77	p=0.09
Postcode				
RA1/2 (major city/ inner regional)	106 (91.3%)	290 (92.0%)	0.91 (0.41, 2.21)	0.70 (0.12, 4.08)
RA3/4 (outer regional/remote)	10 (8.7%)	25 (7.8%)	0.82	p=0.70
Relationship status				
Married/defacto	96 (81.4%)	248 (78.5%)	1.20 (0.68, 2.15)	
Single/divorced/separated	22 (18.6%)	68 (21.5%)	0.51	
Income status (AUD)				
Middle/high income (>$40,000)	84 (74.3%)	184 (59.3%)	1.98 (1.20,3.33)	4.67 (1.22, 17.8)
Low income ($20,000–39,999)	29 (25.7%)	126 (40.7%)	0.004	p=0.02
Education status				
Some/completed university	54 (59.3%)	100 (41.3%)	2.07 (1.23, 3.49)	3.26 (1.28, 8.30)
Other (diploma, trade, secondary)	37 (40.7%)	142 (58.7%)	0.003	p=0.01
Occupational status				
Full-time/Part-time	55 (49.5%)	154 (51.2%)	0.94 (0.59, 1.48)	0.71 (0.25, 2.03)
Other (home duties, casual, retired, unable to work)	56 (50.4%)	147 (48.8%)	0.77	p=0.53
Age (years) at transplantation				
Median (IQR; range)	49 (39, 55)	49 (37, 56)	0.95	
Underlying disease				
Acute leukaemia	60 (53.6%)	166 (53.4%)	1.01 (0.64, 1.59)	
Other *	52 (46.4%)	145 (46.6%)	0.97	
Stage of disease at transplant				
1st or 2nd remission (CR1/2)	73 (61.3%)	198 (61.5%)	1.00 (0.64, 1.59)	
Other**	46 (38.7%)	124 (38.5%)	0.98	
Conditioning				
Myeloablative	59 (49.6%)	155 (48.4%)	1.05 (0.67, 1.63)	
RIC	60 (50.4%)	165 (51.6%)	0.83	
Donor type				
Matched (sibling, unrelated)	113 (95.8%)	295 (91.9%)	1.99 (0.73, 6.80)	
Haploidentical/mismatched	5 (4.2%)	26 (8.1%)	0.21	
cGVHD				
Yes	86 (74.1%)	215 (67.6%)	1.37 (0.83, 2.30)	
No	30 (25.9%)	103 (32.4%)	0.19	
cGVHD severity score (0–10)	2 (1,4)	3 (1,6)	0.05	0.99 (0.83, 1.18)
Median (IQR)				p=0.94
Chronic diseases			1.07 (0.64,1.80)	
Any chronic disease^	84/114 (73.7%)	223/308 (72.4%)	0.99 (0.58, 1.67)	
Any cancer^^	30/109 (27.5%)	77/279 (27.6%)	0.99	

Factors (N=number of responses)	Preference for long-term follow-up with satellite clinic +/-other option (N=119)	Preference for options that exclude satellite clinic (N=322)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
Psychological and sexual morbidity				
Anxiety	20/114 (17.5%)	63/289 (21.8%)	0.76 (0.41, 1.36)	
Depression	26/116 (22.4%)	69/291 (23.7%)	0.93 (0.53, 1.59)	
Sexual dysfunction	63/86 (73.3%)	104/203 (51.2%)	2.61 (1.46, 4.74)	3.27 (1.21, 8.78) p=0.02

^ Any chronic disease includes hypertension, hypercholesterolaemia, diabetes, bone disease (osteoporosis, osteopaenia, spinal/hip fractures or avascular necrosis), iron overload, thyroid disease. ^^ Any cancer includes skin, mouth or other specified.

*CML= Chronic Myelogenous Leukaemia; CLL= Chronic Lymphocytic Leukaemia; SAA= Severe Aplastic Leukaemia; NHL= Non-Hodgkin Lymphoma; HL=Hodgkin Lymphoma; MM=Multiple Myeloma; MDS=Myelodysplastic syndrome;

**greater than second remission, refractory disease, chronic phase, accelerated phase, blast crisis, partial remission, other (unspecified) ¥ Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, income , educational status, residential location (metro/inner regional compared to outer regional/remote), GVHD severity, sexual dysfunction.

Table 12b: Factors associated with a preference for long-term follow-up that includes telemedicine

Factors (N=number of responses)	Preference for long-term follow-up with telemedicine +/- other option (N=92)	Preference for long-term follow-up options that exclude telemedicine (N=349)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
Gender				
Male	55 (59.8%)	195 (55.9%)	1.17 (0.72,1.93)	
Female	37 (40.2%)	154 (44.1%)	0.51	1.02 (0.38,2.74) P=0.97
Age, years				
Median (IQR; range)	52 (43,58; 24–70)	55 (44,63;19–79)	0.99 (0.97, 1.01) 0.07	1.02 (0.98, 1.07) p=0.33
Postcode				
RA1/2 (major city/ inner regional)	81 (91%)	315 (92%)	0.87 (0.36, 2.29)	0.46 (0.08, 2.60)
RA3/4 (outer regional/remote)	8 (9%)	27 (8%)	0.74	p=0.38
Relationship status				
Married/defacto	74 (82.2%)	270 (78.5%)	1.26 (0.68, 2.47)	
Single/divorced/separated	16 (17.8%)	74 (21.5%)	0.43	
Income status (AUD)				
Middle/high income (>$40,000)	56 (62.9%)	212 (63.5%)	1.02 (0.61, 1.70)	
Low income ($20,000–39,999)	33 (37.1%)	122 (36.5%)	0.92	
Education status				
Some/completed university	42 (61.8%)	112 (42.3%)	2.20 (1.23, 3.98)	5.10 (1.72, 15.1)
Other (diploma, trade, secondary)	26 (38.2%)	153 (57.7%)	0.004	p=0.003
Occupational status				
Full-time/Part-time				
Other (home duties, casual, retired, unable to work)	35 (42.2%) 48 (57.8%)	174 (52.9%) 155 (47.1%)	0.65 (0.39, 1.08) 0.08	0.77 (0.26, 2.28) p=0.64
Age (years) at transplantation				
Median (IQR; range)	47 (37, 52)	50 (38, 57)	0.06	
Time (years) since transplantation				
Median (IQR; range)	5 (3,8)	5 (3,8)	0.56	
Underlying disease				
Acute leukaemia	48 (53.3%)	178 (53.4%)	1.00 (0.61, 1.63)	
Other *	42 (46.7%)	155 (46.5%)	0.98	
Stage of disease at transplant				
1st or 2nd remission (CR1/2)	58 (63.0%)	213 (61.0%)	1.09 (0.66, 1.81)	
Other**	34 (37.0%)	136 (39.0%)	0.72	
Conditioning				
Myeloablative	53 (57.6%)	161 (46.4%)	1.57 (0.96, 2.57)	1.80 (0.62, 5.22)
RIC	39 (42.4%)	186 (53.3%)	0.06	p=0.28
Donor type				
Matched (sibling, unrelated)	88 (96.7%)	320 (91.9%)	2.57 (0.76, 13.47)	
Haploidentical/mismatched	3 (3.3%)	28 (8.1%)	0.16	
cGVHD				
Yes	64 (70.3%)	237 (69.1%)	1.06 (0.62, 1.83)	
No	27 (29.8%)	106 (30.9%)	0.82	

Factors (N=number of responses)	Preference for long-term follow-up with telemedicine +/- other option (N=92)	Preference for long-term follow-up options that exclude telemedicine (N=349)	Odds ratio (95% CI) p value	Adjusted odds ratio¥ (95% CI) p value
cGVHD severity score (0–10)				
Median (IQR)	3 (1, 5)	3 (1,6)	0.79	0.95 (0.79, 1.16) p=0.63
Chronic diseases				
Any chronic disease^	66/89 (74.2%)	239/331 (72.2%)	1.10 (0.63, 1.97)	
Any cancer^^	19/94 (22.6%)	87/303 (28.7%)	0.71	
Psychological and sexual morbidity				
Anxiety and/or Depression	32/87 (36.8%)	86/322 (26.7%)	1.60 (0.93, 2.70) 0.06	1.34 (0.44, 4.02 P=0.60
Sexual dysfunction	48/62 (77.4%)	119/227 (52.4%)	3.96 (1.20, 16.8) <0.001	3.25 (1.02,10.35 P=0.05
Exercise/sport	55/92 (59.8%)	245/346 (70.8%)	0.04	0.46 (0.24, 0.87) P=0.02

^ Any chronic disease includes hypertension, hypercholesterolaemia, diabetes, bone disease (osteoporosis, osteopaenia, spinal/hip fractures or avascular necrosis), iron overload, thyroid disease.

^^ Any cancer includes skin, mouth or other specified.

*CML= Chronic Myelogenous Leukaemia; CLL= Chronic Lymphocytic Leukaemia; SAA= Severe Aplastic Leukaemia; NHL= Non-Hodgkin Lymphoma; HL=Hodgkin Lymphoma; MM=Multiple Myeloma; MDS=Myelodysplastic syndrome;

**greater than second remission, refractory disease, chronic phase, accelerated phase, blast crisis, partial remission, other (unspecified)

¥Adjusted odds derived from multivariable logistic regression fitting the following potential confounders : age, gender, occupational status, educational status, residential location (metro/inner regional compared to outer regional/remote), anxiety/depression, GVHD severity, conditioning at transplant, sexual dysfunction. Adjusted odds for exercise derived from multivariable logistic regression fitting the following potential confounders: age, gender, GVHD severity, any chronic disease.

Table 13: Demographic, social determinants and transplant factors and their associations with having skin checks

Factors (N=number of responses)	Skin check (N=228)	No skin check (N=208)	OR (95% CI) p value	Adjusted OR (95% CI)* p value
Gender				
Male	127 (55.7%)	121 (58.2%)	0.90 (0.61, 1.34)	
Female	101 (44.3%)	87 (41.8%)	0.61	
Age (years)			1.03 (1.02, 1.05)	1.03 (1.0, 1.05)
Median (IQR)	58 (48, 64)	51 (42, 59)	p<0.0001	p=0.03
Residence				
City/inner regional)	209/223 (93.7%)	182/203 (89.7%)	1.72 (0.81, 3.77)	
Outer regional/remote	14/223 (6.3%)	21/203 (10.3%)	p=0.13	
Relationship status				
Married/defacto	188/225 (83.6%)	152/205 (74.1%)	1.77 (1.08, 2.92)	0.80 (0.42, 1.51)
Single/divorced/separated	37/225 (17.3%)	53/205 (25.8%)	p=0.02	p=0.48
Household Income (AUD)				
Low income ($20,000–39,999)	71 (32.7%)	83 (41.3%)	0.69 (0.45, 1.05)	0.73 (0.42, 1.27)
Middle/high income (≥$40,000)	146 (67.3%)	118 (58.7%)	p=0.07	p=0.27
Education status				
Some/completed university	91/173 (52.6%)	60/156 (38.5%)	1.77 (1.12, 2.82)	1.87 (1.11, 3.15)
Other (diploma, trade, secondary)	82/173 (47.4%)	96/156 (61.5%)	p=0.03	p=0.02
Occupation				
Gardener	11/210 (5.2%)	1/187 (0.5%)		
Building/construction	17/211 (8.1%)	13/189 (6.9%)		
Agriculture /Farmworker	9/209 (4.3%)	7/189 (3.7%)		
Any outdoor occupation				
– Yes (gardener, builder, ag worker)	31/215 (14.4%)	20/192 (10.4%)	1.44 (0.77, 2.79)	
– No	184/215 (85.6%)	172/192 (89.6%)	0.22	
Years since transplantation				
<2 yrs	20/228 (8.8%)	37/208 (17.8%)	0.44 (0.23, 0.82)	0.69 (0.32, 1.48)
≥2 yrs	208/228 (91.2%)	171/208 (82.2%)	p=0.005	p=0.34
Underlying diagnosis				
Acute leukaemia	100/215 (46.5%)	123/203 (60.6%)	0.56 (0.38, 0.85)	0.70 (0.42, 1.16)
Other *	115/215 (53.5%)	80/123 (39.4%)	p=0.004	p=0.17
Donor type				
Matched (sibling, unrelated)	213/226 (94.2%)	190/208 (91.3%)	1.55 (0.70, 3.54)	
Mismatched (haploidentical/unrelated)	13/226 (5.8%)	18/208 (8.7%)	p=0.24	
Conditioning				
Myeloablative	98/226 (43.4%)	115/208 (55.3%)	0.62 (0.42, 0.92)	0.85 (0.49, 1.48)
Reduced-intensity	128/226 (56.6%)	93/208 (44.7%)	p=0.01	p=0.57
Self-reported skin GVHD				
Yes	113/228 (49.5%)	89/208 (42.8%)	1.31 (0.88, 1.95)	
No	115/228 (50.4%)	119/208 (57.2%)	p=0.16	
Medications				
Immunosuppression				
– Yes	73/228 (32.0%)	82/208 (39.4%)	0.72 (0.48, 1.09)	
– No	155/228 (68.0%)	126/208 (60.6%)	p=0.11	
Azole antifungals				
– Yes	24/228 (10.5%)	29/208 (13.9%)	0.73 (0.39, 1.34)	
– No	204/228 (89.5%)	179/208 (86.1%)	p=0.27	
Routine use of sun protection				
Yes	183/223 (82.1%)	147/203 (72.4%)	1.74 (1.07, 2.84)	1.89 (1.06, 3.37)
No	40/223 (17.9%)	56/203 (27.6%)	p=0.02	p=0.03

* Variables included in multivariable logistic regression model to adjust for confounding: age, education, income and marital status, time from transplant (< 2 years compared to later), underlying diagnosis (acute leukaemia compared to other), conditioning regimen (myeloablative compared to reduced intensity) and 'sunsmart' practices.

Table 13a: Demographic, social determinants and transplant factors and their associations with having bowel cancer checks

Factors (N=number of responses)	Bowel Ca screen (N=140)	No Bowel Ca screen (N=292)	OR (95% CI) p value	Adjusted OR (95% CI)* p value
Gender				
Male	79/140 (56.4%)	168/292 (57.5%)	0.95 (0.62, 1.47)	
Female	61/140 (43.6%)	124/292 (42.5%)	p=0.83	
Age (years)			1.06 (1.03, 1.08)	1.06 (1.03,1.08)
Median (IQR)	59 (53, 64)	50 (40, 60)	p<0.0001	p<0.0001
Residence				
City/inner regional)	128/137 (93.4%)	262/285 (91.9%)	1.25 (0.54, 3.15)	
Outer regional/remote	9/137 (6.6%)	23/285 (8.1%)	p=0.69	
Relationship status				
Married/defacto	116/136 (85.3%)	222/289 (76.8%)	1.75 (0.99, 3.20)	1.14 (0.63, 2.07)
Single/divorced/separated	20/136 (14.7%)	67/289 (23.2%)	p=0.04	p=0.65
Household Income (AUD)				
Low income ($20,000–39,999)	56/136 (41.2%)	95/280 (33.9%)	1.36 (0.87, 2.12)	
Middle/high income (≥$40,000)	80/136 (58.8%)	185/280 (66.1%)	p=0.15	
Education status				
Some/completed university	50/105 (47.6%)	101/222 (45.5%)	1.09 (0.66, 1.78)	
Other (diploma, trade, secondary)	55/105 (52.4%)	121/222 (54.5%)	p=0.72	
Years since transplantation				
<2 yrs	13/140 (9.3%)	44/292 (15.1%)	0.58 (0.27, 1.14)	0.61 (0.30, 1.21)
≥2 yrs	127/140 (90.7%)	248/292 (84.9%)	p=0.13	p=0.16
Underlying diagnosis				
Acute leukaemia	60/135 (44.4%)	158/279 (56.6%)	0.61 (0.39, 0.95)	0.23 (0.48, 1.19)
Other *	75/135 (55.6%)	121/279 (43.4%)	p=0.02	p=0.23
Donor type				
Matched (sibling, unrelated)	126/138 (91.3%)	274/292 (93.8%)	0.69 (0.30, 1.62)	
Mismatched (haploidentical/unrelated)	12/138	18/292 (6.2%)	p=0.42	
Conditioning				
Myeloablative	57/138 (41.3%)	155/292 (53.1%)	0.62 (0.40, 0.95)	1.19 (0.72,2.00)
Reduced-intensity	81/138 (58.7%)	137/292 (46.9%)	p=0.02	p=0.49
GVHD				
Yes	98/135 (72.6%)	196/290 (67.6%)	1.27 (0.79, 2.06)	1.30 (0.66, 2.58)
No	37/135 (27.4%)	94/290 (32.4%)	p=0.30	p=0.45
Self-reported skin GVHD				
Yes	26/140 (18.6%)	34/292 (11.6%)	1.73 (0.95, 3.12)	1.66 (0.90, 3.05)
No	114/140 (81.4%)	258/292 (88.4%)	p=0.05	p=0.10
Medications				
Immunosuppression				
– Yes	49/140 (35.0%)	103/292 (35.3%)	0.98 (0.63, 1.54)	
– No	91/140 (65.0%)	189/292 (64.7%)	p=0.95	

* Variables included in multivariable logistic regression model to adjust for confounding: age, marital status, time from transplant (< 2 years compared to later), underlying diagnosis (acute leukaemia compared to other), conditioning regimen (myeloablative compared to reduced-intensity) and gut GVH.

Table 13b: Demographic, social determinants and transplant factors and their associations with having Pap screening

Factors (N=number of responses)	Pap screen (N=118)	No Pap screen (N=68)	OR (95% CI) p value	Adjusted OR (95% CI)* p value
Age (years)			0.98(0.95, 1.00)	0.97 (0.94, 1.00)
Median (IQR)	50 (42, 58)	56 (42, 63)	p=0.06	p=0.09
Residence				
City/inner regional)	109/117 (93.2%)	58/65 (89.2%)	1.64 (0.48, 5.47)	
Outer regional/remote	8/117 (6.8%)	7/65 (10.8%)	p=0.40	
Relationship status				
Married/defacto	92/113 (81.4%)	52/87 (77.6%)	1.26 (0.55, 2.82)	
Single/divorced/separated	21/113 (18.6%)	15/67 (22.4%)	p=0.54	
Household Income (AUD)				
Low income ($20,000–39,999)	45/113 (39.8%)	25/66 (37.9%)	1.81 (0.86, 3.93)	1.13 (0.58,2.19)
Middle/high income (≥$40,000)	68/113 (60.2%)	41/66 (62.1%)	p=0.09	p=0.71
Education status				
Some/completed university	41/93 (44.1%)	19/54 (35.2%)	1.45 (0.69, 3.09)	
Other (diploma, trade, secondary)	52/93 (55.9%)	35/54 (64.8%)	p=0.30	
Years since transplantation				
<2 yrs	8/118 (6.8%)	14/68 (20.6%)	0.28 (0.09, 0.77)	0.30 (0.11, 0.85)
≥2 yrs	110/118 (93.2%)	54/68 (79.4%)	p=0.008	p=0.02
Underlying diagnosis				
Acute leukaemia	71/111 (64.0%)	39/66 (59.1%)	1.22 (0.62, 2.40)	
Other *	40/111 (36.0%)	27/66 (40.9%)	p=0.52	
Donor type				
Matched (sibling, unrelated)	108/118 (91.5%)	64/68 (94.1%)	0.67 (0.15, 2.47)	
Mismatched (haploidentical/unrelated)	10/118 (8.5%)	4/68 (5.9%)	p=0.58	
Conditioning				
Myeloablative	70/118 (59.3%)	33/68 (48.5%)	1.55 (0.81, 2.95)	0.98 (0.47, 2.03)
Reduced-intensity	48/118 (40.7%)	35/68 (51.5%)	p=0.15	p=0.97
GVHD				
Yes	78/117 (66.7%)	44/66 (66.7%)	1.0 (0.50, 1.98)	
No	39/117 (33.3%)	22/66 (33.3%)	p=1.0	
Self-reported skin GVHD				
Yes	25/118 (21.2%)	16/68 (25.5%)	0.87 (0.40, 1.92)	
No	93/118 (78.8%)	52/68 (76.5%)	0.71	
Global Lee GVHD score				
Median (IQR)	14 (8, 28)	21 (10, 31)	0.25	
Medications				
Immunosuppression				
– Yes	25/118 (21.2%)	21/68 (30.9%)	0.60 (0.30, 1.26)	0.78 (0.38, 1.61)
– No	93/118 (78.8%)	47/68 (69.1%)	0.14	p=0.50

* Potential confounders included in multivariable logistic regression: age, income status (low compared to middle/high income), early post transplant (within 2 years) conditioning regimen (myeloablative compared to reduced-intensity), taking immunosuppression (tacrolimius, cyclosporine, mycophenolate or prednisolone), or a history of vaginal GVHD.

Table 13c: Demographic, social determinants and transplant factors and their associations with screening mammography

Factors (N=number of responses)	Mammogram (N=98)	No mammogram (N=86)	OR (95% CI) p value	Adjusted OR (95% CI)* p value
Age (years)			1.09 (1.06, 1.13)	1.11 (1.07, 1.16)
Median (IQR)	57 (50, 63)	43 (32, 54)	p<0.0001	p<0.0001
Residence				
City/inner regional)	92/96 (95.8%)	73/84 (86.9%)	3.46 (0.97, 15.4)	5.33 (1.37, 20.8)
Outer regional/remote	4/96 (4.2%)	11/84 (13.1%)	p=0.06	p=0.02
Relationship status				
Married/defacto	80/94 (85.1%)	62/84 (73.8%)	2.03 (0.90, 4.64)	1.26 (0.48, 3.31)
Single/divorced/separated	62/94 (73.8%)	22/84 (26.2%)	p=0.06	p=0.63
Household income (AUD)				
Low income ($20,000–39,999)	39/96 (40.6%)	30/82 (36.6%)	1.18 (0.62, 2.28)	
Middle/high income (≥$40,000)	57/96 (59.4%)	52/82 (63.4%)	p=0.58	
Education status				
Some/completed university	35/83 (42.2%)	23/63 (36.5%)	1.27 (0.61, 2.63)	
Other (diploma, trade, secondary)	48/83 (57.8%)	40/63 (63.5%)	p=0.49	
Years since transplantation				
<2 yrs	6/98 (6.1%)	14/86 (16.3%)	0.33 (0.10, 0.99)	0.37 (0.11, 1.23)
≥2 yrs	92/98 (93.9%)	72/86 (83.7%)	p=0.03	p=0.10
Underlying diagnosis				
Acute leukaemia	57/96 (59.4%)	53/81 (65.4%)	0.77 (0.40, 1.50)	
Other *	39/96 (40.6%)	28/81 (34.6%)	p=0.41	
Donor type				
Matched (sibling, unrelated)	90/98 (91.8%)	79/86 (92.9%)	0.99 (0.29, 3.30)	
Mismatched (haploidentical/unrelated)	8/98 (8.2%)	7/86 (7.1%)	p=1.00	
Conditioning				
Myeloablative	49/98 (50%)	56/86 (65.1%)	0.53 (0.28, 1.01)	1.29 (0.56, 2.94)
Reduced-intensity	49/98 (50%)	30/86 (34.9%)	p=0.04	p=0.55
GVHD				
Yes	61/96 (63.5%)	60/85 (70.6%)	0.73 (0.37, 1.42)	
No	35/96 (36.5%)	25/85 (29.4%)	p=0.31	
Medications				
Immunosuppression				
– Yes	22/98 (22.5%)	24/86 (27.9%)	0.75 (0.36, 1.54)	
– No	76/98 (77.5%)	62/86 (72.1%)	0.39	

* Potential confounders included in multivariable logistic regression: age, residential status, marital status, early post transplant (within 2 years) and conditioning regimen (myeloablative compared to reduced-intensity).

Table 13d: Demographic, social determinants and transplant factors and their associations with prostate checks

Factors (N=number of responses)	Prostate check (N=89)	No prostate check (N=157)	OR (95% CI) p value	Adjusted OR (95% CI)* p value
Age (years)			1.10 (1.06, 1.13)	1.12 (1.07, 1.16)
Median (IQR)	62 (56,66)	52 (40, 58)	p<0.0001	p<0.0001
Residence				
City/inner regional)	82/90 (92.1%)	140/152 (92.7%)	0.92 (0.31, 2.92)	
Outer regional/remote	7/90 (7.9%)	11/152 (7.3%)	p=1.00	
Relationship status				
Married/defacto	77/88 (87.5%)	115/157 (73.2%)	2.55 (1.20, 5.84)	1.38 (0.56, 3.37)
Single/divorced/separated	11/88 (12.5%)	42/157 (26.8%)	p=0.009	p=0.48
Household income (AUD)				
Low income ($20,000–39,999)	24/85 (28.2%)	58/151 (38.4%)	0.63 (0.34, 1.16)	0.59 (0.30, 1.20)
Middle/high income (≥$40,000)	61/85 (71.8%)	93/151 (61.6%)	p=0.11	p=0.15
Education status				
Some/completed university	34/62 (54.8%)	59/119 (49.6%)	1.23 (0.64, 2.40)	
Other (diploma, trade, secondary)	28/62 (45.2%)	60/119 (50.4%)	p=0.50	
Years since transplantation				
<2 yrs	12/89 (13.5%)	23/157 (14.6%)	0.91 (0.39, 2.03)	
≥2 yrs	77/89 (86.5%)	134/157 (85.4%)	p=0.80	
Underlying diagnosis				
Acute leukaemia	30/84 (35.7%)	82/153 (53.6%)	0.48 (0.27, 0.86)	0.51 (0.25, 1.00)
Other *	54/84 (64.3%)	71/153 (46.4%)	p=0.008	p=0.052
Donor type				
Matched (sibling, unrelated)	82/88 (93.2%)	146/156 (93.6%)	0.94 (0.29, 3.25)	
Mismatched (haploidentical/unrelated)	6/88 (6.8%)	10/156 (6.4%)	p=1.00	
Conditioning				
Myeloablative	31/88 (35.2%)	78/157 (49.7%)	0.55 (0.31, 0.97)	1.74 (0.79, 3.83)
Reduced-intensity	57/89 (64.0%)	79/157 (50.3%)	p=0.03	p=0.17
GVHD				
Yes	68/87 (78.2%)	108/156 (69.2%)	1.61 (0.84, 3.14)	1.03 (0.47, 2.22)
No	19/88 (21.6%)	48/156 (30.8%)	p=0.13	p=0.94
Medications				
Immunosuppression				
– Yes	33/89 (37.1%)	72/157 (45.9%)	0.69 (0.39, 1.22)	0.48 (0.24, 0.96)
– No	56/89 (62.9%)	85/158 (54.1%)	p=0.18	p=0.04

* Potential confounders included in multivariable logistic regression: age, income, marital status, early post transplant (within two years) cGVHD and conditioning regimen (myeloablative compared to reduced-intensity).

Table 14: Proportion in survival cohorts (years since transplantation) and regular dental visits.

Years since transplant (N=number of responses)	Number visiting dentist on a regular basis (%)
< 2 yrs (N=58)	38 (65.5%)
2<6 yrs (N=203)	139 (68.5%)
6<10 yrs (N=115)	74 (64.3%)
≥10 yrs (N=60)	37 (61.7%)
All (N=436)	288 (66.1%)

Table 14a: Sociodemographic factors and association with regular dental reviews

Factors (N=number of responses)	Regular dental visit (N=288)	No regular dental visit (N=148)	OR (95% CI) p value	Adjusted odds ratio (AOR) p value
Age (years) Median (IQR)	56 (IQR 45, 63; 19–79)	52 (IQR 43, 60; 22–73)	p=0.007	1.02 (1.008, 1.04) p=0.003
Gender Female Male	 131/288 (45.5%) 157/288 (54.5%)	 58/148 (39.2%) 90/148 (60.8%)	 1.3 (0.85, 1.98) p=0.21	 1.38 (0.90, 2.13) p=0.14
Household income (AUD) Low income ($20,000–39,999) Middle/high income (≥$40,000 Missing	 185/274 (67.5%) 89/274 (32.5%) 14	 78/144 (54.2%) 66/144 (45.8%) 4	 1.76 (1.14, 2.71) p=0.007	 1.87 (1.21, 2.88) p=0.005
Residence City/inner regional) Outer regional/remote Missing	 213/281 (75.8%) 68/281 (24.2%) 7	 94/145 (64.8%) 51/145 (35.2%) 3	 1.70 (1.07, 2.69) p=0.02	 1.70 (1.08, 2.70) p=0.02

Table 14b: Dental morbidity and regular dental reviews

Dental morbidity (N=number of responses)	Regular dental visit (N=288)	No regular dental visit (N=148)	OR (95% CI)	p value
Mouth ulcers	97/265 (36.6%)	45/139 (32.3%)	1.2 (0.76, 1.91)	0.40
Dental caries	96/256 (37.5%)	46/132 (34.8%)	1.12 (0.71, 1.78)	0.61
Mouth GVHD	110/201 (54.7%)	43/96 (44.8%)	1.49 (0.89, 2.50)	0.11
Dry mouth	121/265 (45.6%)	60/137 (43.8%)	1.07 (0.70, 1.67)	0.72
Gum disease	40/249 (16.1%)	19/128 (15%)	1.10 (0.59, 2.12)	0.76
Tooth abscess	17/241 (7.1%)	5/122 (3.9%)	1.85 (0.63, 6.57)	0.26
Mouth cancer	4/251 (1.6%)	2/137 (1.4%)	1.09 (0.15, 12.2)	1.0

Table 14c: Relationship between years from transplant procedure and time to last dental visit

Time since transplant (N=number of responses)	Months since last visit to a dentist Median (range)
< 2 years post transplant (N=27)	8 months (<1 month–14 months)
2 to <6 yrs post transplant (N=128)	10 months (1–29 months)
6 to <10 yrs post transplant (N=66)	10 months (1–27 months)
≥10 yrs (N=35)	13 months (2–34 months)
All respondents (N=256)	10 months (<1 month–34 months)

Table 14d: Reasons for not attending a dentist regularly

Reason reported Number of responses=148	Number who did not attend dentist regularly (%)
Time	28 (19%)
Cost	54 (36%)
Feel it is not necessary	55 (37%)
Not advised by treating team	30 (20%)
Other reasons	Other includes: dentures/edentulous (13), fear of dentist (2), distance to travel (1), low priority/other more pressing medical concerns (3), low platelets (1)

Table 15: Vaccination uptake, stratified by years since transplant

Vaccination (N=number of responses)	Number vaccinated (%)	1 to <2 yrs (% total in cohort vaccinated)	2<6 yrs (% total in cohort vaccinated)	6<10 yrs (% total in cohort vaccinated)	≥10 yrs (% total in cohort vaccinated)
Diphtheria, tetanus, pertussis (N= 419)					
Yes	303 (72.3%)	36/56 (64.3%)	152/199 (76.4%)	75/107 (70.1%)	40/57 (70.2%)
No	68 (16.2%)	16/56 (28.6%)	29/199 (14.6%)	14/107 (13.1%)	9/57 (15.8%)
Unsure	48 (11.5%)	4/56 (7.1%)	18/199 (9.1%)	18/107 (16.8%)	8/57 (14.0%)
Polio (N=416)					
Yes	280 (67.3%)	36/58 (62.1%)	147/197 (74.6%)	65/106 (61.3%)	32/55 (58.2%)
No	82 (19.7%)	18/58 (31%)	32/197 (16.2%)	18/106 (17.0%)	14/55 (25.4%)
Unsure	54 (13.0%)	4/58 (6.9%)	18/197 (9.1%)	23/106 (21.7%)	9/55 (16.4%)
Haemophilus influenzae type b (N=405)					
Yes	229 (56.5%)	30/53 (56.6%)	129/196 (65.8%)	53/104 (51.0%)	17/52 (32.7%)
No	80 (19.7%)	18/53 (34.0%)	29/196 (14.8%)	19/104 (18.3%)	14/52 (26.9%)
Unsure	96 (23.7%)	5/53 (9.4%)	38/196 (19.4%)	32/104 (30.8%)	21/52 (40.4%)
Hepatitis B (N=414)					
Yes	270 (65.2%) 81	35/56 (62.5%)	144/199 (72.4%)	62/105 (59.1%)	29/54 (53.7%)
No	(19.6%) 63	17/56 (30.4%)	31/199 (15.6%)	20/105 (19.0%)	13/54 (24.1%)
Unsure	(15.2%)	4/56 (7.1%)	24/199 (12.1%)	23/105 (21.9%)	12/54 (22.2%)
Pneumococcus (N=402)					
Yes	226 (56.2%)	29/53 (54.7%)	118/190 (62.1%)	51/106 (48.1%)	28/53 (52.8%)
No	80 (19.9%)	17/53 (32.1%)	30/190 (15.8%)	23/106 (21.7%)	10/53 (18.9%)
Unsure	96 (23.9%)	7/53 (13.2%)	42/190 (22.1%)	32/106 (30.2%)	15/53 (28.3%)
Influenza (N=426)					
Yes	349 (81.9%)	40/56 (71.4%)	166/199 (83.4%)	95/113 (84.1%)	48/58 (82.8%)
No	54 (12.7%)	14/56 (25%)	24/199 (12.1%)	10/113 (8.8%)	6/58 (10.3%)
Unsure	23 (5.4%)	2/56 (3.6%)	9/199 (4.5%)	8/113 (7.1%)	4/58 (6.9%)
Meningococcus (N=407)					
Yes	201 (49.3%)	31/54 (57.4%)	107/195 (54.9%)	47/103 (45.6%)	16/55 (29.1%)
No	96 (23.6%)	16/54 (29.6%)	41/195 (21.0%)	22/103 (21.4%)	17/55 (30.9%)
Unsure	110 (27.0%)	7/54 (13.0%)	47/195 (24.1%)	34/103 (33.0%)	22/55 (40.0%)
Vaccination status reported for the above (N=428)					
All	136 (31.8%)	20/57 (35.1%)	76/200 (38.0%)	31/112 (27.7%)	9/59 (15.2%)
Partial	248 (57.9%)	25/57 (43.9%)	109/200 (54.5%)	70/112 (62.5%)	44/59 (74.6%)
None	31 (7.2%)	11/57 (19.3%)	12/200 (6.0%)	4/112 (3.6%)	4/59 (6.8%)
Unsure to all	13 (3.0%)	1/57 (1.7%)	3/200 (1.5%)	7/112 (6.2%)	2/59 (3.4%)
Missing	13	1	4	5	3
Measles, mumps, rubella (N=409)					
Yes	226 (55.3%)	16/52 (30.8%)	113/194 (58.2%)	66/106 (62.2%)	31/57 (54.4%)
No	121 (29.6%)	32/52 (61.5%)	56/194 (28.9%)	20/106 (18.9%)	13/57 (22.8%)
Unsure	62 (15.1%)	4/52 (7.7%)	25/194 (12.9%)	20/106 (18.9%)	13/57 (22.8%)
Varicella (N=399)					
Yes	106 (26.6%)	11/53 (20.7%)	59/193 (30.6%)	28/100 (28%)	8/53 (15.1%)
No	187 (46.9%)	35/53 (66.0%)	86/193 (44.6%)	42/100 (42%)	24/53 (45.3%)
Unsure	106 (26.6%)	7/53 (13.2%)	48/193 (24.9%)	30/100 (30%)	21/53 (39.6%)
Human papillomavirus vaccine (HPV) (females, N=174)					
Yes	26 (14.9%)	1/20 (5%)	15/82 (18.3%)	9/48 (18.7%)	1/24 (4.2%)
No	86 (49.4%)	15/20 (75%)	37/82 (45.1%)	21/48 (43.7%)	13/24 (54.2%)
Unsure	62 (35.6%)	4/20 (20%)	30/82 (36.6%)	18/48 (37.5%)	10/24 (41.7%)

Table 15a: Comparison of patients who have received no vaccines and those who have received all inactivated vaccines (excepting HPV) recommended in the first 12–24 months post-transplant

Factors (N=number of responses)	No vaccines (N=31)	All vaccines** (N=136)	OR (95% CI)	p value	Adjusted OR (95% CI) (p value)
Age (years) Median (IQR)	57 (48,63)	53 (45,62)		0.45	1.00 (0.94, 1.06) 0.93
GENDER Male (N=88) Female(N=79)	 22 (71%) 9 (29%)	 66 (48.5%) 70 (51.5%)	 2.60 (1.05, 6.85)	 0.03	 2.74 (0.81, 9.35) 0.11
Income Low (N=58) Middle/High (N=102)	14/26 (53.8%) 12/26 (46.1%)	44/134 (32.8%) 90/134 (67.2%)	 2.38 (0.92, 6.14)	 0.04	3.32 (0.83, 13.4) 0.09
RESIDENCE City/metro (N=117) Regional/remote (N=48)	 24/31 (77.4%) 7/31 (22.6%)	 93/134 (69.4%) 41/134 (30.6%)	 1.51 (0.57, 4.48)	 0.51	 1.27 (0.36, 4.52) 0.71
MARITAL STATUS Married/defacto (N=136) Other (N=28)	 25/31 (80.6%) 6/31 (19.4%)	 111/133 (83.5%) 22/133 (16.5%)	 0.82 (0.28, 2.75)	 0.79	 2.87 (0.45, 18.4) 0.26
EDUCATION Higher (N=64) Other (N=62)	 9/22 (40.9%) 13/22 (59.1%)	 55 (52.8%) 49 (47.1%)	 0.62 (0.21, 1.72)	 0.35	 0.50 (0.13, 1.91) 0.31
cGVHD Yes (N=111) No (N=55)	 21 (67.7%) 10 (32.3%)	 90 (66.7%) 45 (33.3%)	 1.05 (0.43, 2.71)	 1.0	 2.33 (0.62, 8.75) 0.21
Early post-transplant (< 2 yrs) Yes (N=31) No (N=136)	 11/31 (35.5%) 20/31 (64.5%)	 20/136 (14.7%) 116/136 (85.3%)	 3.19 (1.18, 8.24)	 0.007	 12.2 (3.02, 49.0) <0.001

** pertussis, tetanus, diphtheria, haemophilus, pneumococcus, meningococcus, hep B, influenza

Table 15b : Setting for post-transplant vaccination

Setting for vaccination	Number of people	%
GP alone	308	69.8%
GP+ hospital	30	6.8%
GP+ other setting	1	0.2%
Hospital alone	48	10.9%
Hospital + other setting	1	0.2%
Community clinic alone	2	0.5%
Other setting alone	2	0.5%
No answer	49	11.1%

Table 16: Occupational status: pre and post transplant

		POST –TRANSPLANT OCCUPATIONAL STATUS								
		Full-time	Part-time	Homemaker	Casual	Unemployed	Unable to work – ill health	Retired	Missing	Pre-transplant totals (%)
PRE-TRANSPLANT OCCUPATIONAL STATUS	Full-time	115	40	6	13	10	35	42	22	283 (64.2%)
	Part-time	5	32	4	2	2	8	8	0	61 (13.8%)
	Homemaker	1	1	10	0	0	2	0	1	15 (3.4%)
	Casual	3	2	0	10	1	0	2	1	19 (4.3%)
	Unemployed	5	1	0	0	6	1	1	0	14 (3.2%)
	Unable to work – ill health	1	1	0	1	1	9	1	0	15 (3.4%)
	Retired	0	0	0	0	0	0	22	1	22 (5.0%)
	Missing	1	1	1	0	0	1	4	4	12 (2.7%)
	Post-transplant totals (%)	131 (29.7%)	78 (17.7%)	21 (4.8%)	26 (5.9%)	20 (4.5%)	56 (12.7%)	80 (18.1%)	29 (6.6%)	441

Table 16a: Income status: pre and post transplant

		POST –TRANSPLANT INCOME				
		Low income	Middle income	High income	Missing	Pre-transplant totals (%)
PRE-TRANSPLANT INCOME	Low income	73	9	5	0	87 (19.7%)
	Middle income	53	73	14	1	141 (32.0%)
	High income	27	41	126	0	194 (44.0%)
	Missing	2	0	0	17	19 (4.3%)
	Post-transplant totals (%)	155 (35.1%)	123 (27.9%)	145 (32.9%)	18 (4.1%)	441

Table 16b: Current relationship status

Current relationship status (N=434 respondents)	Number %	
Single	67 (15.4%)	
Married	311 (71.7%)	
Defacto	33 (7.6%)	
Divorced	18 (4.1%)	
Separated	5 (1.1%)	
Totals	434	
For those who report a change in their relationship status since transplant (N=68):		
Pre-transplant relationship status	**Number %**	**Current status**
Single	25 (36.7%)	3 single; 14 married; 8 defacto;
Married	20 (29.4%)	2 single; 4 married; 2 defacto; 8 divorced; 3 separated
Defacto	19 (27.9%)	8 single; 7 married; 2 defacto; 1 divorced
Divorced	1 (1.5%)	1 defacto
Separated	2 (2.9%)	1 single; 1 married
Unspecified	1	
Totals	68	

Table 17: Quality of life: Functional Assessment of Cancer Therapy – Bone Marrow Transplant; all survivors

	Mean (sd)	Item-test correlation	Item-rest correlation	Cronbach alpha
Physical wellbeing (PWB) – 7 items	22.4 (5.4)	0.80	0.67	0.79
Social wellbeing (SWB) – 7 items	20.0 (5.6)	0.63	0.43	0.85
Emotional wellbeing (EWB) – 6 items	16.3 (3.6)	0.77	0.63	0.82
Functional wellbeing (FWB) – 7 items	19.3 (6.5)	0.90	0.80	0.75
BMT score (BMTS) – 10 items	27.8 (6.3)	0.87	0.76	0.76
FACT–BMT total score (37 items) (Summary score: PWB+SWB +EWB + FWB+ BMTS)	106.0 (21.5)	–	–	0.83

Table 17a: Quality of life: Functional Assessment of Cancer Therapy – Bone Marrow Transplant; categorised by years since transplant

	ALL survivors		< 2 yrs post transplant		2 to <6 yrs		6 to <10 yrs		10–14 yrs		p value*
	Mean (sd)	Cronbach alpha**	Mean (sd)	alpha	Mean (sd)	alpha	Mean (sd)	alpha	Mean (sd)	alpha	
Physical wellbeing (PWB)	22.4 (5.4)	0.79	21.2 (5.9)	0.83	22.4 (5.4)	0.79	22.7 (5.1)	0.79	22.8 (5.2)	0.72	
Social wellbeing (SWB)	20.0 (5.6)	0.85	20.1 (5.6)	0.89	20.5 (5.6)	0.85	19.9 (5.4)	0.84	19.5 (6.2)	0.84	
Emotional wellbeing (EWB)	16.3 (3.6)	0.82	15.5 (3.6)	0.86	16.4 (3.4)	0.83	16.7 (3.5)	0.81	15.9 (4.8)	0.77	
Functional wellbeing (FWB)	19.3 (6.5)	0.75	17.5 (6.8)	0.81	19.4 (6.3)	0.75	20.0 (6.6)	0.74	19.1 (6.1)	0.66	
BMT score (BMTS)	27.8 (6.3)	0.76	25.7 (7.8)	0.80	27.6 (6.1)	0.76	28.5 (5.7)	0.75	28.9 (5.7)	0.71	
FACT–BMT total score (PWB + SWB + EWB + FWB + BMTS)	106.0 (21.5)	0.83	100.0 (24.8)	0.87	106.3 (21.1)	0.83	108.3 (20.6)	0.83	106.7 (20.1)	0.78	0.12

*ANOVA

**Cronbach's alpha is a statistical measure of the internal consistency of a psychometric instrument – in this case quality of life (as measured using FACT–BMT). A high Cronbach alpha indicates that the subscales that make up the final score are highly correlated. When reporting on individual alphas for subscales (for example, physical wellbeing), we determine the impacts of removing PWB from the scale. In the above table, the alpha score for FACT–BMT would decrease from 0.83 to 0.79 if PWB were dropped (in other words, PWB should be retained as it is highly correlated with other measures). In contrast, removing social wellbeing would increase Cronbach's from 0.83 to 0.85. This would suggest that social wellbeing is the subscale that has poorest correlation with other measures (and thus is probably the term that is most redundant in quality of life instrument).

An alpha of 0.70 is generally considered to indicate that the instrument is reliable. From our quality of life measures in BMT survivors, we found FACT–BMT to demonstrate high internal consistency across all survivor cohorts; alpha=0.78–0.87).

Table 18: Fear of cancer recurrence

	Regression coefficient	95% confidence interval	p value	Adjusted**
Quality of life (FACT–BMT)	-0.09	-0.13, -0.04	<0.0001	-0.10 (-0.13,-0.07) <0.0001
Depression,anxiety,stress (DASS21)	0.02	-0.01, 0.06	0.18	
Age	0.04	-0.01, 0.09	0.14	
Gender (male)	-0.25	-1.39, 0.89	0.66	
Years since transplant	-0.19	-0.36, -0.03	0.02	-0.20 (-0.36, -0.04) 0.02
University education	0.07	-1.15, 1.30	0.91	
Acute leukaemia diagnosis	0.53	-1.05, 2.12	0.51	
First or second complete remission at transplant	-1.35	-2.99, -0.29	0.11	-1.35 (-2.54, -0.17) 0.025
Married or defacto relationship	1.16	-0.33, 2.65	0.13	1.36 (-0.01, 2.73) 0.052
Ethnicity (Caucasian/European)	-1.19	-2.75, 0.37	0.13	
Low-income group	0.36	-1.07, 1.79	0.62	
Full- or part-time employment	1.19	-0.17, 2.55	0.09	
Use of any psychotropic med	1.26	-0.21, 2.72	0.09	
Exercise sport	0.15	-1.15, 1.545	0.82	
Intercept (the expected mean value of Y when all X=0)	20.71	14.2, 27.22		

**Adjusted model, using backwise stepwise regression, removing variables with p value >0.10.

Table 19: Posttraumatic growth inventory

Area of growth	Median (IQR; range)	Males (N=250)	Females (N=191)	p value
Relating to others	23 (16, 27;0–35)	21 (14,26; 0–35)	24 (18, 28; 0–35)	<0.001
New possibilities	11 (6, 15; 0–23)	9 (5,14; 0–23)	11 (6, 16; 0–23)	0.13
Personal strength	12 (8, 15;0–20)	11 (6, 14; 0–20)	13 (10, 16; 0–20)	<0.001
Spiritual growth	2 (0,6; 0–10)	1 (0,4; 0–10)	3 (1, 7; 0–10)	<0.001
Appreciation of life	11 (9,13;0–15)	11 (9, 13; 0–15)	11 (8,13; 3–15)	0.58
Total PTGI score	58 (41, 70; 0–103)	54 (36,68;0–96)	61 (48, 73; 12–103)	0.002

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