Article:
Hamblin, A., Greenfield, D.M., Gilleece, M. et al. (9 more authors) (2017) Provision of long-term monitoring and late effects services following adult allogeneic haematopoietic stem cell transplant: a survey of UK NHS-based programmes. Bone Marrow Transplantation, 52. pp. 889-894. ISSN 0268-3369

https://doi.org/10.1038/bmt.2017.67

TITLE

Provision of Long-Term Monitoring and Late Effects (LE) Services Following Adult Allogeneic Haematopoietic Stem Cell Transplant (HSCT): A Survey of UK NHS-Based Programmes.

RUNNING TITLE

Survey of UK Late Effects Service Provision

AUTHORS & AFFILIATIONS

Angela Hamblin[1], Diana M Greenfield[2,3], Maria Gilleece[4], Nina Salooja[5], Michelle Kenyon[6], Emma Morris[7], Nicola Glover[8], Paul Miller[9], Henny Braund[9], Andy Peniket[1], Bronwen E Shaw[10], John A Snowden[3,11] on behalf of the British Society of Blood and Marrow Transplantation (BSBMT)[12]

[1]Department of Clinical Haematology, Oxford University Hospitals NHS Trust, Oxford, UK

[2]Department of Clinical Oncology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

[3]Department of Oncology & Metabolism, University of Sheffield, UK

[4]Department of Clinical Haematology, Leeds Teaching Hospitals NHS Trust, Leeds, UK

[5]Department of Haematology, Hammersmith Hospital, London, UK

[6]Department of Haematological Medicine, King's College Hospital, London, UK

[7]Department of Immunology, Royal Free London NHS Foundation Trust and UCL Medical School, London, UK

[8]London Cancer Alliance, London, UK

[9]Anthony Nolan, London, UK

[10]Center for International Blood and Marrow Transplant Research (CIBMTR), Department of Medicine, Medical College of Wisconsin, Milwaukee, Wisconsin, USA

[11]Department of Haematology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

[12]British Society of Blood and Marrow Transplantation, London, UK

CORRESPONDING AUTHOR

Dr Angela Hamblin

Department of Clinical Haematology, Churchill Hospital

Old Road

Headington

Oxford OX3 7LE

UK

Telephone number: 01865 572824

Fax number: 01865 221778

Email address: angela.hamblin@ouh.nhs.uk

CONFLICTS OF INTEREST

There are no conflicts of interest to declare relating to any of the named authors of this manuscript.

ABSTRACT

Despite international guidelines, optimal delivery models of late effects (LE) services for HSCT patients are unclear from clinical, organisational and economic viewpoints. To scope current LE service delivery models within the UK-NHS, in 2014 we surveyed the 27 adult allogeneic HSCT centres using a 30 question online tool, achieving a 100% response rate.

Most LE services were led and delivered by senior physicians (>80% centres). Follow-up was usually provided in a dedicated allograft or LE clinic for the first year (>90% centres), but thereafter attrition meant only ~50% of patients were followed after 5 years. Most centres (69%) had an SOP for long-term monitoring but access to a LE Multi-Disciplinary Team was rare (19% centres). Access to medical specialities necessary for LE management was good, but specialist interest in long-term HSCT complications was uncommon. Some screening (endocrinopathy, cardiovascular) was near universal, but other areas were more limited (mammography, cervical smears). Funding of extra staff and investigations were the most commonly perceived barriers to implementation of LE services.

This survey shows variation in the long-term follow-up of allogeneic HSCT-survivors within the UK-NHS and further work is warranted to optimise effective, sustainable and affordable models of LE service delivery among this group.

INTRODUCTION

Since the first recorded allogeneic haematopoietic stem cell transplant (HSCT) using a donor other than an identical twin in 1968,[1] the worldwide annual number of patients undergoing this procedure has risen to more than 23,500.[2] Over the same period improvements in conditioning regimens[3] (e.g. reduced intensity conditioning [RIC]) and supportive care (e.g. management of infectious complications[4,5] and graft versus host disease [GVHD]),[6] as well as widening of indications to include non-malignant disorders (e.g. haemoglobinopathies)[7] and availability of alternative HSCT donor sources[8] have led to increasing numbers of long-term survivors (i.e. alive two years post-allogeneic HSCT).[9] However, with improved survival, even in the absence of disease relapse, normal life expectancy is not restored:[10] Survivors are susceptible to organ dysfunction[11,12] (aside from chronic GVHD) and subsequent malignancies[13] resulting in a significant morbidity burden[14] and premature mortality. In addition to physical sequelae, allogeneic HSCT survivors are at risk of psychological complications, including post-traumatic stress disorder,[15] which may have major impact on quality of life.[16]

The increased morbidity and non-relapse mortality exhibited by long-term allogeneic HSCT survivors led to recognition of the need for long-term follow-up and screening of this patient population to allow pre-emptive action to try and mitigate the increased risks. Accordingly, the Center for International Blood and Marrow Transplant Research (CIBMTR), European Group for Blood and Marrow Transplantation (EBMT) and American Society for Blood and Marrow Transplantation (ASBMT) produced consensus recommendations on the subject in 2006[17] (subsequently enshrined in JACIE [sixth edition] standard B7.6.8).[18] These were updated in 2011 with additional representation from the Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO)to ensure their international applicability.[19] Owing to lack of prospective (randomised)

controlled trials in this area these are based on retrospective studies, non-transplant data and expert consensus opinion, but nevertheless are considered to be the most comprehensive guidance available for management of this patient population.

However, there is little consensus on how the international guidelines are best applied and data is limited as to the extent of their implementation.[20,21] On behalf of the British Society of Blood and Marrow Transplantation (BSBMT), we therefore sought to establish how services for late post-transplant effects were delivered by UK adult allogeneic HSCT centres within the governmentally funded National Health Service (NHS). Although ultimately all NHS services are state funded, HSCT procedures are nationally commissioned while care from day 100 post-transplant is locally commissioned.[22]

MATERIALS & METHODS

Survey Development & Design

A 30 question web-based survey was developed following consultation with senior UK allogeneic HSCT physicians and nurses with an interest in LE services for allogeneic HSCT survivors and representatives of organisations concerned with allogeneic HSCT patient welfare (e.g. Anthony Nolan). Questions were designed around four themes; service organisation, access to other specialist services necessary for the management of LE, multi-disciplinary team (MDT) provision and patient engagement, service evaluation and improvement. Most questions required respondents to select one/several options from a range of possibilities although, where relevant, there was the ability to enter free text. The survey was piloted with members of the BSBMT-Clinical Trials Committee (CTC) prior to wider circulation.

For the purposes of this survey the National Cancer Institute definition of Late Effects was used: ‘A health problem that occurs months or years after a disease is diagnosed or after treatment has

ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems and second cancers'.[23] The definition was extended to patients with non-malignant diseases who had been treated with allogeneic transplantation, where LE may be caused by the disease or disease treatment. In several questions respondents were asked to provide the percentage of patients in whom a particular activity took place; this was intended to be a best estimate for surviving patients at that time point rather than an exact calculated figure. The survey is available in the Supplementary Information.

Survey Administration

The survey was circulated via the BSBMT to programme directors of the 27 adult UK NHS allogeneic HSCT centres with an invitation for the most appropriate personnel to complete (medical or nursing). One generic reminder was sent to all centres after which individual approaches were made by the survey authors to non-responding centres. The survey was completed during 2014. Statistical associations between overall allogeneic HSCT centre activity, co-existent paediatric HSCT activity in the centre and the long-term follow-up patterns were explored using 2014 activity data from the BSBMT registry.[24]

RESULTS

Centre Demographics

A 100%[a] response rate was achieved, with most surveys (85%) completed by allogeneic HSCT physicians (Table 1). All centres were engaged with the JACIE accreditation process; 82% were fully accredited (Table 1) having completed a median of two accreditation cycles. The lower age of allogeneic HSCT recipients ranged from 16-20 years (Table 1) with almost half of adult centres (46%)

[a] Although all centres (27) submitted a response, some centres omitted to answer particular questions; results from these questions are reported as percentages of the responding centres with the number or responses used indicated by n=x.

performing allogeneic HSCT in patients under 18 years of age (both the EBMT and UK legal definition of an adult).

LE Service Organisation

The LE service was most frequently organised and administered by medically qualified staff (88% centres) with the remainder being nurse led (Table 1). Most LE services were delivered in either a dedicated clinic (63%) or within the general allogeneic HSCT clinic (33%) with only one centre routinely reviewing patients in a general haematology clinic (Table 1). Figure 1a shows there was an attrition rate over time in the percentage of surviving post-allogeneic HSCT patients being followed up by the transplanting centre. Although 96% of centres followed up all patients from day 100 to 1 year, by 5 years post-allogeneic HSCT only 48% centres routinely reviewed all patients and 11% of centres were actively following up fewer than half their patients. In some centres part of this attrition was due to formal discharge of patients at 5 years post-allogeneic HSCT back to either their referring non-HSCT-performing haematology centre or primary care physician if they had received a RIC HSCT and were free of complications including GVHD. Other patients however were lost to follow up (e.g. moved away geographically from the transplanting centre). Centre size and co-existent paediatric activity were not significantly associated with long-term follow-up patterns for adults (see Supplementary Table 1).

A standard operating procedure (SOP) for long-term monitoring of LE (as indicated by JACIE [sixth edition] standard B7.6.8)[18] was available in 69% of responding allogeneic HSCT centres (n=26), with 39% of these centres having audited their adherence to the policy (Table 1). All SOPs included the physical assessment of patients but only 28% made any reference to psychological evaluation (Table 1). The use of a standard template to communicate treatment summaries and potential complications to other health care professionals (as recommended by the National Cancer

Survivorship Initiative; example template available at http://www.ncsi.org.uk/wp-content/uploads/Treatment-Summary-Template1.doc) was undertaken in 41% of centres (Table 1).

Access to Specialist Services

Figure 1b illustrates the range of specialist services available to allogeneic HSCT centres (n=26) in the management of LE. All the medical specialities were accessible to >80% of responding centres. Easiest access was reported to endocrinology, sexual health and respiratory services (96%, 93% and 93% centres respectively) while more limited, but still good, access was available for oral medicine and dentistry services (81% centres). Access to allied health specialities was more varied: Although most centres (89%) had access to a dietician, availability of physiotherapy, occupational therapy and psychology support was not universal with only 62%, 65% and 69% of centres being able to access these respectively.

In contrast to the overall good access to specialist services for allogeneic HSCT survivors, the number of centres reporting personnel in these specialities with an interest in the LE of allogeneic HSCT was low (Figure 1b). With the exception of key workers and clinical nurse specialists, the majority of whom had an interest in HSCT LE as might be expected (94% and 84% respectively), fewer than 50% of centres reported personnel with a specialist interest among any medical or allied health speciality. Greatest interest was seen in specialities likely to have the most contact with post-HSCT patients; endocrinology, dietetics, sexual health and respiratory medicine (46%, 39%, 39% and 35% respectively).

Respondents reported variable compliance with screening recommendations in the international guidelines:[19] Although routine rates of implementation of endocrine and cardiovascular screening were good (89% and 78% respectively), lower rates of cervical screening and mammography were reported (52% and 48% respectively) despite the existence of established National Breast[25] and

196 Cervical Cancer[26] Screening Programmes within the UK for the general population (Table 1). Only
197 30% of centres found it easy to access these National Screening Programmes.

198 There was near universal implementation of revaccination post allogeneic HSCT (96% centres)
199 although only 23% of centres undertook antibody testing in the majority of patients (>90%) to
200 monitor vaccine efficacy (Table 1). Among the remainder of centres there was variation in post-
201 vaccine antibody response monitoring; some never undertook such testing while others targeted it
202 to patients with recurrent infections or those felt to have a particularly high infection risk (e.g. HLA
203 mismatch, alternative stem cell donor source). Post-allogenic HSCT vaccination practice has been the
204 subject of a separate more detailed BSBMT survey.[27]

205 MDT Provision

206 Only 19% of centres had access to a specific LE MDT (Table 1) and where available this was mostly
207 (60% MDTs) limited to patients under 25 years (data not shown). Where LE MDTs were available
208 membership varied: Although all included a senior haematologist and clinical nurse specialist there
209 was less regular support from other speciality physicians (including paediatrics), psychologists and
210 social workers.

211 Patient engagement, service evaluation and improvement

212 A patient support group whose target audience included long-term allogeneic HSCT survivors was
213 available in 41% of centres (Table 1) variably led by nurses, social workers, psychologists or patients
214 themselves. Where available most (73%) met at least every 3 months (data not shown). Given a
215 central theme of JACIE standards relates to education, service evaluation and audit in order to bring
216 about service improvement, centres were asked how often they engaged in such activities which
217 included some aspect of LE monitoring or care. At least one formal educational event covering an
218 aspect of LE management had been delivered by 67% of centres in the preceding three years, while
219 a clinical audit or service evaluation had been performed by 59% of centres (n=26) over the same

period. However, only 41% of centres had sought patient input regarding their satisfaction with LE and long-term follow-up arrangements over this time (Figure 1c).

During consultations with relevant stakeholders prior to development of this survey it became apparent there were a number of differences between the realities of the LE services provided by allogeneic HSCT centres and what they felt should be available. In order to ascertain the impediments to LE service delivery, centres rated potential barriers to implementation of an idealised service (suggested both by the survey authors and in the literature).[28] These are summarised in figure 1d, and the three highest rated obstacles all relate to finance/resource provision, with lack of funding for psychological support considered to be the greatest limitation.

DISCUSSION

To our knowledge, this is the first survey examining the practical provision of long-term follow-up and LE services for allogeneic HSCT patients across a national healthcare system. It provides a comprehensive view of how care is being delivered to this complex patient population. Despite national publically funded delivery of HSCT care, the survey demonstrates variability in almost every aspect of the service. Some variation may reflect the historical, opportunistic way LE services have evolved in individual centres. Although we were unable to show any relationship with centre activity and co-existent paediatric activity, other factors such as centre specialisation, geography and referral base may be contributory and further work is required in this area.

This survey highlighted some positives in that all centres had a LE service and most had a standard operating procedure outlining its processes. Additionally, most centres reported good local availability of a range of medical and some allied health specialities necessary for the management of LEs. Free text comments indicated many centres are engaged in active development of their LE

service through the appointment of new personnel and by establishing separate clinics (in some cases combined with cGVHD management).

However, this survey also emphasised general weaknesses and limitations of LE services throughout the UK, including limited access to LE MDTs. Despite good provision of most other specialities necessary for the management of LE within tertiary NHS hospitals, most specialists delivering this care did not have a particular interest in post-allogeneic HSCT care. Although national screening programmes exist for both breast[25] and cervical cancer[26] detection, enrolling post-allogeneic HSCT patients in these outside of standard age-dictated times was problematic. Both these points highlight a need for better engagement and education of health care professionals outside of haematology.[21,29]

This survey also demonstrates a bias of LE services towards screening activities within the normal remit of transplant physicians and associated personnel: Assessment of endocrine and cardiovascular function was generally carried out well while in contrast, implementation of specialised services where transplant physicians have less control (e.g. mammography, cervical screening) was much poorer. In common with other post-HSCT populations,[30] there was limited access to specialist psychological services in this susceptible population.[15] Only 28% of LE SOPs had any reference to psychological function despite international guidelines and recommendations.[19]

The emphasis of many LE services on the management of medical symptoms may not always correlate with patient concerns: A recent audit of patient-reported symptoms in a nurse-led post-HSCT LE clinic indicated that the most prevalent problems were pain, sleep disturbance, fatigue and sexual function concerns,[31] none of which are easily attributable to a particular physiological system. The apparent misalignment of the LE service agenda[32] and patient concerns[33] is something that could be addressed by better engagement of patients through support groups and quality of life[34] or service satisfaction surveys.[35] Ultimately patient interests are likely to be best served with long-term follow-up LE services led and delivered by a combination of medical and nursing staff with the

flexibility for patients to be seen by either group of health care professionals depending on their specific symptoms and needs. Perhaps as expected, all allogeneic HSCT centres identified lack of financial resources as the major constraint on the implementation of ideal services, particularly with regards to the delivery of psychological support.

As with any survey, it is necessary to exercise some caution with result interpretation. Firstly centres can only report activities they have direct control over: The survey suggests that patients from only 30% of centres undergo lifelong follow-up (i.e. beyond 10 years) as recommended by international guidelines[19]. However, it is possible that many of the remaining 70% of centres refer patients back to either their referring hospital or primary care provider to follow a recommended late effects surveillance plan; activity which would not necessarily be known to the transplanting centre.

Secondly, the results inevitably reflect what a centre reports to be doing rather than what has been independently verified as taking place. Nevertheless, given the deficiencies in the LE service reported by almost all centres, it seems likely that the responses represent a consistent summary of service provision and operation. Finally, although this survey documents variation in practice it does not provide information about how this affects patient outcome: In order to optimise long-term follow-up and LE service provision it is necessary to collect data on patient outcomes with the different models of care delivery.

In summary, this survey provides valuable feedback on the current delivery of LE service provision for post-allogeneic HSCT survivors within the UK, which is likely to be applicable to other healthcare systems internationally. It provides information of where international guidelines and recommendations[19] are being easily met and areas where services are deficient and require additional resource investment. Further research into which models of care provide the most clinically effective and cost-efficient means of service delivery is warranted.

ACKNOWLEDGMENTS

The authors would like to acknowledge the contribution of both British Society of Blood and Marrow Transplantation staff and personnel in the 27 UK adult allogeneic HSCT centres in the execution of this survey. They also specifically thank Rachel Pearce & Julia Perry, BSBMT Registry, for their assistance in providing the registry data.

312 **REFERENCES**

[1] Gatti RA, Meuwissen HJ, Allen HD, Hong R, Good RA. Immunological reconstitution of sex-linked lymphopenic immunological deficiency. *Lancet* 1968; **2**: 1366-1369.

[2] National Marrow Donor Programme. Media fact sheet: 1 million blood stem cell transplants Worldwide. http://www.wbmt.org/fileadmin/pdf/01_General/One_Million_Transplants_Fact_Sheet_FINAL.pdf. (accessed Jan 5, 2016).

[3] Farag SS, Maharry K, Zhang MJ, Pérez WS, George SL, Mrózek K et al. Comparison of reduced-**i**ntensity hematopoietic cell transplantation with chemotherapy in patients age 60-70 years with acute myelogenous leukemia in first remission. *Biol Blood Marrow Transplant* 2011; **17**: 1796-1803.

[4] Tomblyn M, Chiller T, Einsele H, Gress R, Sepkowitz K, Storek J et al. Guidelines for preventing infectious complications among hematopoietic cell transplantation recipients: a global perspective. Preface. *Bone Marrow Transplant* 2009; **44**: 453-455.

[5] Center for International Blood and Marrow Transplant Research (CIBMTR); National Marrow Donor Program (NMDP); European Blood and Marrow Transplant Group (EBMT); American Society of Blood and Marrow Transplantation (ASBMT); Canadian Blood and Marrow Transplant Group (CBMTG); Infectious Disease Society of America (IDSA); Society for Healthcare Epidemiology of America (SHEA); Association of Medical Microbiology and Infectious Diseases Canada (AMMI); Centers for Disease Control and Prevention (CDC). Guidelines for preventing infectious complications among hematopoietic cell transplant recipients: a global perspective. *Bone Marrow Transplant* 2009; **44**: 453-558.

[6] Martin PJ, Rizzo JD, Wingard JR, Ballen K, Curtin PT, Cutler C et al. First- and second-line systemic treatment of acute graft-versus-host disease: recommendations of the American Society of Blood and Marrow Transplantation. *Biol Blood Marrow Transplant* 2012; **18**: 1150-1163.

[7] Saraf SL, Oh AL, Patel PR, Jalundhwala Y, Sweiss K, Koshy M et al.Nonmyeloablative Stem Cell Transplantation with Alemtuzumab/Low-Dose Irradiation to Cure and Improve the Quality of Life of Adults with Sickle Cell Disease. *Biol Blood Marrow Transplant* 2016; **22**: 441-448.

[8] Kekre N & Antin JH. Hematopoietic stem cell transplantation donor sources in the 21st century: choosing the ideal donor when a perfect match does not exist. *Blood* 2014; **124**: 334-343.

[9] Wingard JR, Majhail NS, Brazauskas R, Wang Z, Sobocinski KA, Jacobsohn D et al. Long-Term Survival and Late Deaths After Allogeneic Hematopoietic Cell Transplantation. *J Clin Oncol* 2011; **29**: 2230–2239.

[10] Bhatia S, Francisco L, Carter A, Sun CL, Baker KS, Gurney JG et al. Late morality after allogeneic hematopoietic cell transplantation and functional status of long-term survivors: report from the Bone Marrow Transplant Survivor Study. *Blood* 2007; **110**: 3784-3792.

[11] Tichelli A, Bucher C, Rovó A, Stussi G, Stern M, Paulussen M et al. Premature cardiovascular disease after allogeneic hematopoietic stem-cell transplantation. *Blood* 2007; **110**: 3463-3471.

[12] DeFilipp Z, Duarte RF, Snowden JA, Majhail NS, Greenfield DM, Miranda JL et al. Metabolic Syndrome and Cardiovascular Disease After Hematopoietic Cell Transplantation: Screening and Preventive Practice Recommendations from the CIBMTR and EBMT. *Biol Blood Marrow Transplant* 2016; **22** 1493-1503.

[13] Majhail NS. Secondary cancers following allogeneic haematopoietic cell transplantation in adults. *Br J Haematol* 2011; **154**: 301-310.

[14] Sun CL, Kersey JH, Francisco L, Armenian SH, Baker KS, Weisdorf DJ et al. Burden of morbidity in 10+ year survivors of hematopoietic cell transplantation: report from the bone marrow transplantation survivor study. *Biol Blood Marrow Transplant* 2013; **19**: 1073-1080.

[15] Hefner J, Kapp M, Drebinger K, Dannenmann A, Einsele H, Grigoleit GU et al. High prevalence of distress in patients after allogeneic hematopoietic SCT: fear of progression is associated with a younger age. *Bone Marrow Transplant* 2014; **49**: 581-584.

[16] Norkin M, Hsu JW, Wingard JR. Quality of life, social challenges, and psychosocial support for long-term survivors after allogeneic hematopoietic stem-cell transplantation. *Semin Hematol* 2012: **49**: 104-109.

[17] Rizzo JD, Wingard JR, Tichelli A, Lee SJ, Van Lint MT, Burns LJ et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation: joint recommendations of the European Group for Blood and Marrow Transplantation, Center for International Blood and Marrow Transplant Research, and the American Society for Blood and Marrow Transplantation (EBMT/CIBMTR/ASBMT). *Bone Marrow Transplant* 2006; **37**: 249-261.

[18] FACT-JACIE International Standards for Hematopoietic Cellular Therapy Product Collection, Processing, and Administration, Sixth Edition.

[19] Majhail NS, Rizzo JD, Lee SJ, Aljurf M, Atsuta Y, Bonfim C et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation. *Biol Blood Marrow Transplant* 2012; **18**: 348-371.

[20] Syrjala KL, Martin PJ, Lee SJ. Delivering care to long-term adult survivors of hematopoietic cell transplantation. *J Clin Oncol* 2012; **30**: 3746-3751.

[21] Hashmi S, Carpenter P, Khera N, Tichelli A, Savani BN. Lost in transition: the essential need for need for long-term follow-up clinic or blood and marrow transplantation survivors. *Biol Blood Marrow Transplant* 2015; **21**: 225-232.

[22] Prepared by NHS England Specialised Services Clinical Reference Group for Blood and Marrow Transplantation. Clinical Commissioning Policy: Haematopoietic Stem Cell Transplantation (HSCT) (All Ages): Revised 2015. Reference: NHS England B04/P/a

[23] http://www.cancer.gov/dictionary?cdrid=390292 accessed 09/10/13

[24] Crawley C, Kirkland K & Pearce R. BSBMT 7TH REPORT TO SPECIALIST COMMISSIONERS: The outcome of haematopoietic stem cell transplantation: An analysis of registry data for UK transplants performed 2008-2013 inclusive *and* A detailed analysis of transplant activity and outcomes in 2014.

[25] Prepared by – Cancer Screening, Early Diagnosis and Skin Cancer Prevention Team, Department of Health. Public health functions to be exercised by NHS England Service specification No.24 Breast Screening. 2013.

[26] Prepared by – Cancer Screening, Early Diagnosis and Skin Cancer Prevention Team, Department of Health. Public health functions to be exercised by NHS England Service specification No.25 Cervical Screening. 2013.

[27] Miller PDE, de Silva T, Skinner R, Gilleece M¸ Peniket A, Hamblin A et al. Routine Vaccination Practice after Adult and Paediatric Allogeneic Haematopoietic Stem Cell Transplant: A Survey of UK NHS Programmes. *Bone Marrow Transplant* (in press).

[28] Majhail NS, Rizzo JD. Surviving the cure: long term follow up of hematopoietic cell transplant recipients. *Bone Marrow Transplant* 2013; **48**: 1145-1151.

[29] Bhatia S. Caring for the long-term survivor after allogeneic stem cell transplantation. *Haematology Am Soc Hematol Educ Program* 2014; **2014**: 495-503.

[30] Mosher CE, DuHamel KN, Rini CM, Li Y, Isola L, Labay L et al. Barriers to mental health service use among hematopoietic SCT survivors. *Bone Marrow Transplant* 2010; **45**: 570-579.

[31] Shanklin VE, Snowden JA & Greenfield DM. Late treatment effects following bone marrow transplant: efficacy of implementing international guidelines. *Eur J Cancer Care* (in press).

[32] Greenfield DM, Absolom K, Eiser C, Walters SJ, Michel G, Hancock BW et al. Follow-up care for cancer survivors: the views of clinicians. *Br J Cancer* 2009; **101**: 568-574.

[33] Absolom K, Eiser C, Michel G, Walters SJ, Hancock BW, Coleman RE et al. Follow-up care for cancer survivors: the views of the younger adult. *Br J Cancer* 2009; **101**: 561-577.

[34] Absolom K, Eiser C, Turner L, Ledger W, Ross R, Davies H et al. Ovarian failure following cancer treatment: current management and quality of life. *Hum Reprod* 2008; **23**: 2506-2512.

[35] Hwang JP, Roundtree AK, Giralt SA, Suarez-Almazor M. Late effects and healthcare needs of survivors of allogeneic stem cell transplantation: a qualitative study. *BMJ Support Palliat Care* 2012; **2**: 344-350.

FIGURE LEGEND

Figure 1

A demonstrates the proportion of patients followed up by the transplanting centre at varying time points post-allogeneic HSCT.

B illustrates the percentage of allogeneic HSCT centres with access to specialist services involved in the long term follow up and LE care of patients who have undergone allogeneic HSCT. The percentage of centres with personnel delivering these specialist services with an interest in the complications of allogeneic HSCT are indicated by the pale grey bars.

C shows the percentage of allogeneic HSCT centres which have held educational events, clinical audit/service evaluation or patient questionnaire/satisfaction survey over the last 3 years and the number of such events undertaken.

D indicates the opinion of allogeneic HSCT centres as to the barriers to implementation of the 'ideal' late effects service. Respondents were asked to rate potential barriers on a numerical scale from 0-10 where 0 represents no barrier while 10 is a major barrier to implementation.