

A ROAD MAP FOR RECOVERY

**ANTHONY
NOLAN**
BE A MATCH, SAVE A LIFE



Ensuring every patient finds
the care they need after
bone marrow transplant.
September 2013

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FOREWORD



Henny Braund
Chief Executive
Anthony Nolan

When the Government announced its decision to reform the way in which the NHS commissions care for specialised and rare conditions, it outlined a single, underpinning principle - to secure access to treatment for every person who needs it.

It's an admirable ambition. But there is some way to go before it becomes a reality. And as this report demonstrates, for patients who have had a bone marrow transplant, this is an acute problem.

For people with blood cancer and other haematological disorders, a bone marrow transplant is often their only chance of survival. We are incredibly proud of our work over the last 40 years to provide bone marrow donors to help cure people of these devastating diseases.

But we know from the patients we work with and advocate for that the physiological and psychological effects of transplant can have a serious impact on the long-term quality of life they can expect after their treatment.

That's why we must acknowledge that for many, the transplant cure is only the beginning of their journey to rebuilding their lives.

And that's why we have partnered with 2020health to produce this report in order to demonstrate that NHS England's provision for these patients is falling short of what is required to help them back to an active and fulfilling life. In this report, we make suggestions as to how that can be addressed.

As you will discover, there is significant variation across the country in the availability of comprehensive post-transplant care for patients suffering long-term effects. This disparity is caused by the failure of NHS England to recognise the complex care needs of these patients in either the commissioning structure, or by expediting the creation of a seamless model of care for them.

At Anthony Nolan, we believe that the care you receive should be determined by the condition you have, not by the area in which you live and the hospital at which you are treated. Any deviation in care is unacceptable, particularly when the means of solving the problems that create it are right in front of us.

If implemented by NHS England, the recommendations made in this report will achieve a situation where no person who has had a bone marrow transplant is left to fall through the type of cracks that are currently created by a splintered and inconsistent care pathway.

Post-transplant patients have already gone through so much. They deserve the security of knowing that whatever their symptoms, whenever they occur, they can access the care they need. And we are determined to make that a reality.

‘We believe that the care you receive should be determined by the condition you have, not by the area in which you live and the hospital at which you are treated. Any deviation in care is unacceptable.’

ABOUT THE AUTHORS



Gail Beer
Director of Operations
2020health

Gail worked in the NHS for over 30 years latterly as an Executive Director at Barts and the London NHS Trust. She trained as a general nurse at St Bartholomew's Hospital before undertaking a course in Renal Nursing at the Royal Free Hospital.

After a number of senior nursing posts within London she moved into management taking a Masters in Health Management at City University, before becoming Director of Operations at BLT. Since leaving Barts and the London NHS Trust she has worked as an independent consultant in healthcare. Gail was a member of the team that produced the Independent Review of NHS and Social Care IT Commissioned by Stephen O'Brien MP.

Gail's main interests are in creating a society that values the contribution older people make, compassion in caring and preventing disease caused by poor lifestyle choices.



Matt James
Research Fellow
2020health

Matt has a particular interest in the intersection of values, health, technology and public policy.

As an independent consultant, he has a wide ranging portfolio of expertise which spans the arenas of public policy, academia and third sector, including working in Parliament as a parliamentary researcher for a MP and shadow minister. Skilled in research, administration and new media development, Matt has convened numerous series of public symposia which have helped initiate and bring together key stakeholders to discuss the ethical, social and legal implications of new technologies.

Matt has an undergraduate degree in political history and sociology as well as a Master's degree in bioethics and medical law. He was recently elected as a Fellow of the Royal Society of Arts and Commerce (FRSA).



Sean Summers
Researcher
2020health

Sean graduated in Biomedicine before undertaking a Master's degree in Public Health at the University of Sheffield's School of Health and Related Research (SchARR). His undergraduate studies crossed a broad range of biomedical subjects. He completed his undergraduate dissertation in cancer biology and genetics.

During his masters, he studied health policy, economics and management. Sean has particular interest in rare and forgotten conditions and the financial management of healthcare.

EXECUTIVE SUMMARY AND RECOMMENDATIONS

The aim of this project was to review bone marrow transplant (BMT) survival and the impact of long term and late effects, and how care for these patients is planned for and managed in England today.

It has been said that a transplant patient is a patient for life given the complexity of the transplant process and the potential long term effects and implications. A wide range of symptoms can be experienced with varying degrees of severity.

With rates of survivorship improving following BMT there is a need to look at long term strategies to improve the quality of life for BMT patients. As post-bone marrow transplant care involves meeting more complex needs than those encountered as a result of many other cancer treatments, careful consideration needs to be given to the form and delivery of post-transplant care to be delivered, and how it is accessed by patients across England.

What has emerged from our research is evidence that the provision of NHS services to help post-transplant patients with their long-term effects is not consistent across the country. Many of these late effects can be severe, debilitating, and for some, life-threatening.

The measures we suggest within this report would address this problem, and ensure every post-transplant patient, regardless of where they

reside, can access consistent care easily and quickly to meet their needs. From interviews and research we have identified the following key issues that need to be addressed:

- What constitutes a good late effects service
- Commissioning
- Data collection
- Recruitment to clinical trials
- Patient empowerment
- Workforce

As rates of survivorship improve and the number of those who require long term and late effects services increase, there is the need to ensure the appropriate services are not only in place but also equally available to all.

This report is not intended to be either exhaustive or prescriptive, but it is hoped that it will help stimulate further discussion and consideration amongst key stakeholders as steps are taken to improve post-transplant care and survivorship in BMT within the changing landscape of the NHS.

Based upon our analysis we offer five key recommendations of thirteen recommendations in total.

1.	NHS England to take commissioning responsibility for the whole pathway with shared care arrangements and subcontracting for key phases of the treatment.	NHS England
2.	A set of national guidelines should be drafted and adopted to make clear what constitutes a late effects service and how it should be delivered. Rehabilitation and psychological support should form part of this. These guidelines should be adopted and endorsed by commissioners and form a mandatory part of the commissioning process.	NHS England
3.	Returning to work and active life should be recognised as a key health outcome for BMT patients where appropriate. As children grow up, support in further education and work should form part of this strategy, recognising that time lost through treatment in earlier stages of life is likely to impede upon progress in later years.	Clinical Commissioning Groups (CCGs)
4.	Appropriate support services should also extend to family members, recognising the impact cancer and transplant care can have on them as they support family members receiving treatment.	CCGs Third Sector
5.	A BMT research and clinical trials network should be established to build capacity and strengthen the research community in this area.	British Society of Blood and Marrow Transplantation (BSBMT)

FULL LIST OF RECOMMENDATIONS

1.	NHS England to take commissioning responsibility for the whole pathway with shared care arrangements and subcontracting for key phases of the treatment.	NHS England
2.	The utility of the 100 days marker versus 1-year needs to be reviewed. If there is no longer a clinical basis for using 100 days as a marker then commissioning arrangements need to be reviewed.	NHS England Clinical Reference Group on Blood and Marrow Transplantation (CRG)
3.	Clear systems of shared care roles should be established between tertiary centres and primary and secondary care settings, so enhancing patient access to the complete range of services that constitute comprehensive post-transplant care.	Specialised Commissioning Groups (SCGs)
4.	A national audit of BMT centres should be carried out in order to help shape standardised treatment protocols for late effects services.	BSBMT NHS England
5.	A range of multidisciplinary services should form the basis of late effect clinics. The role and involvement of each specialist within the MDT should be clearly laid out in their job description.	NHS England
6.	NHS England to be responsible for the commissioning of late effects services.	NHS England
7.	A set of national guidelines should be drafted and adopted for what constitutes late effects service and how it should be delivered. Rehabilitation and psychological support should form part of this. These guidelines should be adopted and endorsed by commissioners and form a mandatory part of the commissioning process.	NHS England
8.	Returning to work and active life should be recognised as a key health outcome for BMT patients where appropriate. As children grow up, support in further education and work should form part of this strategy, recognising that time lost through treatment in earlier stages of life is likely to impede upon progress in later years.	CCGs
Data collection		
9.	Data collection should form a mandatory part of the contractual agreement with service providers and transplant centres should ensure adequate resources are in place to meet this requirement bearing in mind financial restraints.	NHS England
Research and clinical trials		
10.	A BMT research and clinical trials network should be established to build capacity and strengthen the research community in this area.	BSBMT
Patient at the centre		
11.	Patients should be empowered and fully informed to become an active participating member of the multi disciplinary team. Full access to their record including all relevant non-medical information and data should be given to them so that they are informed of their condition.	NHS England CCGs
12.	Appropriate support services should also extend to family members, recognising the impact cancer and transplant care can have on them as they support family members receiving treatment.	CCGs Third sector
13.	Further research is needed in order to build the necessary evidence base for commissioning extracorporeal photopheresis as a treatment for acute GvHD.	CRG Human Tissue Authority

INTRODUCTION

FOCUS

With rates of survivorship improving following bone marrow transplant there is a corresponding need to look at long-term strategies to improve the quality of life for BMT patients. Post-bone marrow transplant care involves meeting more complex needs than more general cancer aftercare, meaning specific consideration needs to be given to the form and delivery of post-transplant care and treatment. Currently there is variation in what is available across the country.

This report gives particular focus to improving post-transplant care and access to post-transplant services (often referred to as post-100 days), but with clear reference to the bigger picture, acknowledging the need for an integrated strategy within which late effects sits as a part of the solution. Given the constraints of time, the project looked exclusively at allogeneic haematopoietic stem cell transplantation (HSCT – also known as bone marrow transplantation).

BACKGROUND

Without doubt over the last three decades there have been significant advances made in the area of haematopoietic stem cell transplantation, with the result that it is now well established as an important curative therapy for patients with leukaemia and other haematological malignancies.

One of the greatest improvements has been allogeneic stem cell transplants in the UK which have steadily risen as a result of the increased availability of stem cells from unrelated donors. While this is an important step forward the issue of donation does not form the focus of this report.

Once a suitable donor has been found for the patient and transplantation occurs, there are a range of complications and issues which might subsequently arise. Even without complications, a transplant patient's pathway of care and treatment is a complex process and never linear.

There is a clear need to improve survivorship amongst post-transplant patients; but this objective needs to form part of a wider integrated strategy, prompted by the key question as to why allograft patients often fail to be cured from blood cancer and blood disorders.

There appear to be three key reasons why allograft patients do not have a long term survival from blood cancer and blood disorders:-

- A lack of an available donor within an appropriate time frame.
- Immediate post-transplant complications such as organ failure and acute Graft-versus-Host Disease (GvHD) at any time point post transplant.
- A 30 to 60 per cent relapse rate among patients, with the cancer returning within two years with fatal consequences.

The impact of long term conditions can also play a significant part in the patient's recovery, affecting high rates of morbidity as opposed to mortality. Both adults and children can develop conditions such as chronic GvHD and endocrine problems.

Bearing these three factors in mind, it is clear that a majority of patients will not live long enough to experience 'late effects'. In seeking to improve post-transplant care and survivorship, it is therefore important not to lose sight of the bigger picture and the corresponding need to improve donor availability and outcomes in terms of acute GvHD, infection and immediate toxicity.

PROJECT OBJECTIVES

This report seeks to inform and shape the development of post-transplant care and survivorship. The project had the following objectives:

- Evaluate the range, variation and 'best practice' of long term effects service
- Assess how services could be redesigned to better meet the requirements for post-transplant patients

- Explore new methods for managing care in view of changes to the commissioning structure
- Gain a greater understanding of barriers to providing late effects services and compliance to standards, the role of extracorporeal photopheresis (ECP) for the treatment of GvHD and commissioning, service arrangements for patients post-100 days and patient support arrangements.

This report is not intended to be either exhaustive or prescriptive, but it is hoped that it will help stimulate further discussion and consideration amongst key stakeholders as steps are taken to improve outcomes in BMT within the changing landscape of the NHS.

Part 1:

covers the project's methodology, detailing the approach and format of the three key strands which form the basis of the research.

Part 2:

reviews the many aspects of allogeneic stem cell transplantation for haematological cancer and disorders, including the treatment phases and commissioning process.

Part 3:

sets out the main emerging themes from the interviews and roundtable discussion.

Part 4:

summarises the key challenges and points for consideration.

METHODOLOGY

A selection of research methods were employed to gather evidence and perspectives for the project. The work was undertaken between May and July 2013 and consisted of three key strands:

1. Desk-based literature review and research

Reviewing and evaluating the range, variation and 'best practice' of BMT and post-transplant care, the commissioning process and long term and late effects and survivorship. This research was used to inform the telephone interviews and roundtable discussion.

2. Series of telephone interviews

A series of in-depth telephone interviews were conducted with 16 key stakeholders from across the UK. Participants included consultants, nurses, commissioners, patients and representatives from professional bodies. A semi-structured schedule was used to establish a basic interview framework, whilst also allowing opportunities for respondents to explore specific issues in depth, drawing upon their areas of expertise and experience. Interviewees were assured that their comments would remain unattributed and were encouraged to offer their own personal opinions.

The interviews prompted thoughts and opinions on how services could be redesigned, the implications for commissioning, and new methods and proposals for managing care, particularly in terms of late effects. Opportunity was given to evaluating the need for further research into the treatment of GvHD and new treatments such as ECP.

3. A roundtable discussion with key stakeholders

This forum was designed to gain greater understanding of the state of BMT care and treatment currently across the nation, evaluating what steps may need to be taken in the future. With a variety of key stakeholders in attendance, space was given for open dialogue and the exchange of ideas and opinions.

Interview process

The interviews were undertaken with a cross-section of professionals involved in BMT care and treatment and post transplant survival, as well as with representatives from the

patient and third sector communities. Patients interviewed were gathered from different age groups and interviewed as representatives of the wider patient community. The semi-structured interview schedule covered 14 open questions and a variety of issues relating to post-transplant care and survivorship. Particular focus was applied to how post-transplant care services could be redesigned and developed in the future, and the role research and data collection can help play in this.

Establishing interviewees' understanding and perceptions of the current state of post-transplant care was the first priority. Interviewees were also asked to reflect on what they perceived to be the strengths and weaknesses of the process. How late effects clinics are run was also addressed in order to identify best practice. Interviewees were asked to describe how they would redesign a late effects service that meets patient expectation.

The focus then switched to commissioning processes. Interviewees were asked about the current commissioning process, their understanding of how the process works and any concerns they had with it including suggested improvements. The focus then turned to data monitoring and collection and how the lack of comprehensive, contemporary long term outcomes data could be addressed. Following on from this, the current state of research into post transplantation conditions was discussed before exploring the use of ECP and its implementation across the country.

By reviewing and analysing the interviews and synthesising the key areas of discussion during the roundtable, significant and reoccurring themes were identified. The project has had the support of an external steering group of unpaid experts. 2020health discussed the emerging themes, findings and recommendations from the research with these experts in a number of meetings.

REVIEWING BONE MARROW TRANSPLANTATION

This section reviews post-transplant care and treatment. After a brief summary of allogeneic stem cell transplantation, post-transplant care and long term and late effects are discussed before addressing the impact of accreditation of centres, data collection and management and commissioning.

WHAT ARE HAEMATOLOGICAL CANCER AND HAEMATOLOGICAL DISORDERS?

Haematological cancer affects the blood, bone marrow and lymph nodes. Given that these three cancers are linked through the immune system, disease occurring in one of the three will often spread to the others as well. The fifth most common type of cancer in the UK, haematological cancers account and can be split into three main groups:

1. Leukaemias

malignant proliferations of blood forming stem cells within the bone marrow;

2. Lymphomas

malignant proliferations of lymphocytes, in which the abnormal cells are found mainly in lymph nodes or extra nodal lymphoid tissues;

3. Myelomas

malignant proliferations of plasma cells, which are highly specialised lymphoid cells normally responsible for production of antibodies.

Haematopoietic stem cell transplant is now a standard treatment for haematological cancer. On a global scale, the World Health Organisation estimates 50,000 haematopoietic stem cells transplants are carried out worldwide (2013). This type of transplantation can be broadly divided into two main groups: autologous and allogeneic transplantation.

Autologous HSCT involves the reinfusion of the patient's own bone marrow or peripheral blood stem cells, which are obtained prior to the patient receiving high-dose chemotherapy. Allogeneic HSCT involves replacing the bone marrow stem cells of a patient, following high-dose therapy, with stem cells from a matched or mismatched donor. Cord blood cells as well as haploidentical cells are increasingly being used as a source of stem cells in both adults and children. There remain risks due to genetic disparity between the donor and recipient.

This can result in a number of life threatening conditions, such as GvHD, graft rejection and delayed immune reconstitution. Once the donor stem cells are infused into the patient's body, they make their way from the blood to the bone marrow. Here they 'graft' onto the patient's marrow in a process known as engraftment. GvHD occurs when new blood cells start attacking the other cells of the patient's body, apart from their malignant cells. In the case of graft rejection, the patient's own immunity might also reject the new cells which are trying to graft onto their bone marrow. This report focuses exclusively on allogeneic HSCT.

HSCT: Some key facts (NHS Commissioning Board 2012).

- In the period 2001-2010 there was an apparent 45 per cent increase in the overall number of transplants performed annually. NB This does not take account of probable improvements in reporting and data capture.
- In 2009 there were 879 allograft transplants. In 2010 this number increased to 1321.
- In 2009 the top three diseases treated with allograft transplants were acute leukaemia (508), lymphoma (204) and MDS/ MPS (176).

Post transplant

It has been said that a transplant patient is a 'patient for life' given the complexity of the transplant process and the potential long term effects and implications. An example of one such post-transplant illness is graft-versus-host disease (GvHD). Every patient's experience of GvHD is different, meaning that treating and supporting each patient requires an individual approach. A wide range of symptoms can be experienced with varying degrees of severity.

GvHD is referred to as acute or chronic, relating to the point in time of GvHD onset. Table 1 provides a summary of the key facts which differentiate the two.

Acute GVHD	<ul style="list-style-type: none"> • Usually occurs within 100 days of the transplant or when the immunosuppression is being withdrawn or stopped • It can be quite frightening as the symptoms can change quickly • Close liaison and contact between the medical team and the patient is crucially important
Chronic GVHD	<ul style="list-style-type: none"> • Can follow on from acute GvHD or can occur without warning many months after the transplant and without acute GvHD having been experienced • Can affect the skin, gut and liver, but also affects other parts of the body such as the mouth, eyes, lungs, genital system and joints • May be mild or severe and life-threatening • For some the symptoms can be present for many months, or even years

Table 1 - GvHD - Summary of key facts

Approximately 50 per cent of patients who undergo an allogeneic transplant will develop GvHD (Kenyon and Shaw 2013: 29). The majority of patients will fortunately experience only mild symptoms which cause few problems. Nevertheless, in a small minority of cases, GvHD is a serious and sometimes life threatening condition that in turn impacts upon the patient's physical and psychological wellbeing. GvHD can affect the person's quality of life, prohibiting them from engaging in work, participating in family life and exercise.

Generally, patients with moderate to severe GvHD will often require:

- Much closer monitoring through blood tests and clinic visits
- More frequent and prolonged readmissions to hospital as a result

Late effects

There are a number of side effects that a BMT patient might experience both during and after the transplant. These 'late effects' may be immediate, or occur months or years later.

Some are more common than others and regular monitoring, through late effects services and clinics, offers the opportunity to pick up on early signs and allows for treatment to start as soon as possible.

The different late effects that can occur in the body are given in Table 2 against a spectrum from most to least common. The chance of developing these conditions depends on many different factors including:

- the type of transplant
- the drugs or radiation received
- age
- gender

'In a small minority of cases, GvHD is a serious and sometimes life threatening condition that in turn impacts upon the patient's physical and psychological wellbeing.'

Table 2 - The range of late effects (Kenyon & Shaw 2013: 48-58)

Most common to least common

Infertility
Premature menopause
Sexual function and dysfunction
Skin changes
Joints and muscles
Eyes
Mouth
Teeth
Bone changes
Thyroid and other glands
Bowel
Kidneys and bladder
Liver
Chest
Heart
Memory & other psychological changes
Immune system and late infections
Second cancers

Following transplant, life can be difficult for patients. Such are the complexities, it is challenging to know how best to treat patients with long term and late effects and ensure that the most appropriate care and treatment is offered at the right time, in the right place, by the right specialist teams. It is important to ensure that the necessary help and support is in place to enable both the patient and their family to cope with the ongoing treatment and recovery. Patients noted that travel and accommodation costs can have an impact, particularly if patients are travelling long distances. Emotional stress can also significantly affect family members, but is often recognised too late. This issue is addressed in more detail later in the report ('Patient at the centre').

Crucial to responding to this challenge is ensuring that the commissioning process is providing late effects services which meet patient need. With no clear mandatory guidance from NHS England on what constitutes a late effects service and how it should be delivered, the risk of shortcomings in provision across the country is increased. Some centres may simply offer follow up appointments with nurses without any provision of specific treatment for the combination of effects the patient is experiencing. Given the complex long-term effects many BMT patients experience there is a need to ensure a standardised level of service available to all, regardless of where they live.

ACCREDITATION OF BMT CENTRES

In England there are 34 transplant centres specialising in allogeneic HSCT which must be accredited by Joint Accreditation Committee of the International Society for Cell Therapy and the European Group of Blood and Marrow Transplantation (JACIE), and meet NICE's Improving Outcomes Guidance (IOG). JACIE was established to provide a means by which BMT centres across Europe could demonstrate compliance with accepted best practice. The initiative aims to promote high

quality medical and laboratory practice through a series of standards designed to provide voluntary minimum guidelines for programs, facilities, and individuals performing cell transplantation and therapy or providing support services for such procedures (JACIE Standards 5th edition 2012: 1). One of the important roles of the British Society of Bone Marrow Transplant (BSBMT) is to oversee JACIE in the UK.

For those centres specialising in allogeneic transplant, a minimum of 10 procedures of each specific type of transplant must be carried out per year in order to apply for accreditation (JACIE Standards 5th edition 2012). NICE 'Guidance on Cancer Services Improving Outcomes in Haematological Cancers - The Manual' (2003) states that transplants should only be performed in centres meeting the standards as set by JACIE. Evidence suggests that all units comply.

DATA COLLECTION AND MANAGEMENT

Part B9 of the JACIE standards states, '...the Clinical Program shall collect all the data necessary to complete the Transplant Essential Data Forms of the CIBMTR or the Minimum Essential Data-A forms (MED-A)' (5th edition 2012). While JACIE clearly acknowledges the important role data collection and management has in shaping good clinical care, it makes clear that the purpose of its data standard is not to assess patient outcomes, stating that the 'inspection will be made against the Standards only' (2012: 99). Therefore at present the JACIE standards offer skeletal, minimum requirements focusing only on the first 100 days.

In its recent report (NHS Blood and Transplant 2010) the UK Stem Cell Strategic Forum identified a lack of comprehensive, contemporary long-term outcome data. The report found that the reason for this was partly due to a lack of nationally agreed protocols for stem cell transplantation in the UK (UK Stem Cell Strategic Forum 2010).

An 'ad hoc' method of working coupled with insufficient funding and resource has helped to perpetuate the situation. The report noted the good work beginning to be undertaken by the BSBMT, which is beginning to apply a more formal method of collecting outcomes data, robust enough to help inform commissioning decisions. More work is required in this area so that service provision can be further improved through a strong and reliable data and evidence base, marked by clearly defined standards. The current funding stream for this work needs to continue and be secured for the long term. This data can then be used to benchmark individual performance and promote best practice (UK Stem Cell Strategic Forum 2010: 8).

COMMISSIONING

The Health and Social Care Act 2013 created new commissioning arrangements which came into existence on 1 April 2013. Commissioning is now split between:

- Clinical Commissioning Groups (CCGs), led by General Practice
- Specialised Commissioning Groups (SCGs) which sit within NHS England

These changes were to ensure that commissioning is a clinically-led process that delivers equity to the population of England. Clinical Reference Groups (CRGs) represent a model of devolved clinical leadership which act as a source of clinical advice to NHS England. CRG membership is drawn from each of the 12 geographical areas covered by the 12 senates. There are 65 of these service-specific CRGs, whose approach is coordinated through five National Programmes of Care (functional clustered services). BMT sits within the cancer and blood programme. CRGs maintain a focus on mental health and rare conditions alongside the bulk of specialised services through three strategic portfolios (NHS England 2013: 5).

The BMT clinical reference group is responsible for drafting the service

specification for BMT, commissioning policy for BMT, quality dashboards, Commissioning for Quality and Innovation (CQUIN) and Quality Innovation Productivity and Prevention (QIPP) agendas.

COMMISSIONING POLICIES

CRGs are a source of clinical advice and expertise and are responsible for the delivery of key 'products' (the management term used by NHS England), such as service specifications and commissioning policies. CRGs can make a case for best practice, testing models of care, before being adopted by other groups. These 'products' then allow NHS England to go on and commission services from specialist service providers. To date, in terms of clinical indicators for BMT in adults, broad clinical consensus has been reached through BSBMT recommendations which have until now formed the basis for most of the SCG commissioning policies for adult BMT.

The commissioning of stem cell transplantation is divided into distinct phases of treatment, through a contract specification. NHS England is responsible for commissioning treatment 30 days before transplant until 100 days post transplant, this including critical care related to the transplant episodes. After 100 days patient responsibilities move to the CCG with care and management carried out by the referring unit with an agreed care plan. A key component to commissioning cancer services is the Improving Outcomes Guidance (IOGs) devised by NICE, which offers a comprehensive package of guidance on all cancer services which all health authorities and NHS trusts are expected to implement.

A perceived strength of the new arrangements is that the CRG model provides a good range of representation from a variety of professional bodies, colleges and public and patient organisations. This approach has gained support from across the BMT community

and although there is much work to be done in terms of developing a consistent pricing model for the country (as opposed to regional variation in pricing for transplantation), there is a sense that the CRG provides a good basis of expertise and skill on which to build.

It became clear from the interviews that many did not understand and are confused by the commissioning process so it is difficult to assess the impact of splitting commissioning in this way. All recognised that the process is currently in a time of flux following its introduction on 1 April 2013 and therefore requires time to embed before any assessment can be made of what is working and what needs to be improved further.

The transfer of specialised commissioning to NHS England is viewed by many to be a step in the right direction, as a significant amount of cancer care is best commissioned for populations covering 1.5 – 2 million, which is larger than the population size of the average pathfinder CCG of approximately 202,000. A recent survey of GPs conducted by the Cancer Campaigning Group found that most GPs believed that cancer surgery, chemotherapy, and radiotherapy should be commissioned at a regional or national level, with only post-treatment support being coordinated at a local or CCG level (Cancer Campaigning Group 2011).

Nonetheless, given that commissioning responsibilities move to CCGs for post-transplant care, interviewees expressed uncertainty as to how provision will be made for post-100 day commissioning of services. Clinicians were concerned that CCGs would lack the ability and the resource to commission this level of complex care which requires a high degree of co-ordination.

Concern was also expressed that the contract specification lacks sufficient detail regarding the commissioning of post-100 days transplant services.

Key issues are:

- A lack of comprehensive understanding as to what constitutes post-100 days care.
- There is lack of clarity as to what is expected of referring units and CCGs in delivering post-100 days care.

NHS England's policy cites that transplant centres 'should aim to' provide a late effects service, without detailing what those services should be (NHS England 2013: 11). For example, this allows for the possibility that some centres could simply offer follow up appointments with nurses without any obligation to provide specific treatments.

The fact of this splintered commissioning pathway provoked interviewees to express concern over just how many of the component parts would actually work in isolation to one another with a lack of unity of the overall pathway.

While the new model of commissioning was acknowledged as a move towards a more integrated system in terms of pre-transplant and transplant, it was felt there was a greater role for other stakeholders to collaborate with commissioners in defining and improving the service. Thinking and talking across commissioning boundaries needs to be actively encouraged so that efficient and effective solutions can be found. The commissioning process needs to be truly collaborative, not an approach that sees all stakeholders coming together around the same table but still guarding their own budgets. Having separate groups holding the budget for different parts

of the pathway presents the real risk that commissioning does not unblock some of the problems currently experienced by the service.

It is therefore proposed that an alternative commissioning model (Model B - see Table 3) be adopted, whereby NHS England takes responsibility for oversight of the whole pathway with shared care arrangements and explores subcontracting for key phases of the treatment. A similar approach was developed by the London Pan Thames Consortium, which introduced a standardised approach to commissioning the service, clearly defining responsibilities across the patient's treatment pathway (NHS Blood and Transplant 2010: 69). Using a collaborative model, the SCG had procurement oversight of the whole patient pathway, which allowed for shared care arrangements in eight defined treatment phases: from the initial pre-transplant phase through to outpatient follow-up and the management of complex issues (such as GvHD), 100 days onwards.

This collaborative approach offers the opportunity to establish strong and effective connections between palliative care teams and specialist services, something that is crucial if effective care packages are going to be implemented. Equally it is vital that healthy links are made between these stakeholders and representatives at the local level to ensure that the care package is built around the patient. It is our belief that commissioning as a whole pathway is the only way to release 'value' and deliver the outcomes and resource benefits that integrated care affords.

'Clinicians were concerned that CCGs would lack the ability and the resource to commission this level of complex care which requires a high degree of co-ordination.'

Table 3 - Summary of commissioning responsibility

	Pre-transplant	Transplant	Post-transplant
Current model - A	NHS England		CCG
Current model - B	NHS England		

Recommendation 1:

NHS England to take commissioning responsibility for the whole pathway with shared care arrangements and subcontracting for key phases of the treatment.

Action to be taken by:

NHS England

Traditionally late effects has been seen as something that occurred years after transplant, but it is now more common to see incidences of post-traumatic stress disorder within a year, along with a range of other problems that could have been addressed much earlier. The question therefore needs to be

asked as to why the marker of 100 days is still used versus 1 year. If there is no longer a clinical basis for using 100 days as a marker then there are implications for commissioning, given that the new commissioning arrangements use 100 days to delineate commissioning responsibilities.

Questions to be considered moving forward are:

- Where should commissioning responsibilities begin and end?
- Should services be commissioned as a whole with no split in responsibilities or should a form of subcontracting take place?

Recommendation 2:

The utility of the 100 days marker versus 1-year needs to be reviewed. If there is no longer a clinical basis for using 100 days as a marker then commissioning arrangements need to be reviewed in terms of where commissioning responsibilities begin and end, and whether a split approach is appropriate.

Action to be taken by:

NHS England
CRG

SAM'S STORY

Sam, seven, lives with his mum Alex, dad Neil and brother and sister in the North East.

Sam was born in March 2006 and was diagnosed with Wiskott Aldrich syndrome, a rare blood disorder, within 6 weeks of his birth. He had a transplant in January 2007.

He is currently at primary school and his parents have noticed that despite efforts to treat him like a 'normal boy', his physical and educational needs are very different to the other children.

Sam's parents are concerned that Sam still has difficulties years after his transplant but at the moment they are unsure of where to go for help and support.

Alex says, 'I'm confident enough to be assertive about

Sam's needs but I do feel that support from the transplant centre for the long-term conditions that children may develop post-transplant should be made routinely available.'

'I can not fault the healthcare professional's who have cared for Samuel, but it would be useful to have a transplant nurse or coordinator within the community. Someone who is knowledgeable, friendly and approachable.

'I'd just like to be able to pick up the phone to someone and say, 'This is wrong - what should we do?' and knowing that my question would be answered.

'Fast tracking any long-term post transplant health issues would be of great benefit to the children and their parents.'

'I'd just like to be able to pick up the phone to someone and say, "This is wrong - what should we do?" and knowing that my question would be answered.'

SET OF EMERGING THEMES

Following the interviews and roundtable discussion, a set of emerging themes were identified. A simple model was devised in order to present these themes and the relationship between them.

The themes were as follows:

- **Hub and spoke**
Building up capacity at the centre in terms of skills, expertise and knowledge
- **Data collection**
Improving long term and robust data collection
- **Research and clinical trials**
Informing future understanding as to how the transplant should be carried out so the patient does not relapse, helping in turn to improve post-transplant care and survivorship
- **Workforce**
Having the human resources available and fulfilling the necessary roles is crucial to achieving successful and lasting change
- **Patient at the centre**
Recognising the patient as a member of the clinical team and as the ultimate focus of care and treatment. Full record access, including all relevant non-medical information and data, should be given to the patient so they are informed of their condition.



HUB AND SPOKE

A key theme from the interviews, from patients and clinicians alike, was recognition of the fact that HSCT is a highly complex procedure that requires highly specialised expertise. In the case of recipients of unrelated donor cord blood stem cells, the risk of dying from transplant related causes in the first year post-transplant is in the region of 30 per cent (NHS Blood and Transplant Annex 2010: 71). There are also

substantial long term morbidities associated with unrelated donor transplantation. Taking these points together, interviewees were clear that the complex and long term effects that post-transplant patients experience need to be addressed by a skilled team of clinicians, nurses and support staff.

Interviewees reiterated the point that a degree of variation occurs in how post-transplant care is

delivered across the country. As such, establishing central hubs would make a significant contribution to the improvement of care and treatment.

These hubs could also help to build capacity in the field of BMT. The findings from the interviews indicate that clinicians would value the chance to come together to build on the service and further enhance it, while patients want to be treated at transplant centres that deliver high quality treatment and care.

As the numbers of transplant survivors increase as treatments improve, the question needs to be addressed as to where best to treat them. In the case of long term effects it appears to make sense that the patient is treated at the specialist hub where there is a strong basis of expertise. In cases where the patient is simply living longer and encountering conditions as a result of growing old (such as hip replacements and dialysis) then it seems logical that they are treated in 'spoke' secondary centres, and if necessary with input from the tertiary centre team. This issue should be addressed moving forward, with risk assessments on an individual basis helping to inform the decision as to what is best for the patient.

Interviewees also pointed out that much of the work could be carried out using a 'hub and spoke' model, involving and building upon primary and secondary care services in conjunction with the specialist transplant centre. Improvements in stroke and cardiac services have been seen through the adoption of a similar approach of creating similar hubs. It was recognised that there is scope for further collaboration between the specialist tertiary centre and the primary and secondary care settings to help treat patients. To bring this about three factors are key:

- Ensure responsibilities and expectations are clearly defined for delivering long term and late effects services
- Create strong communication links

and close structured liaison between tertiary, secondary and primary care

- Ensure appropriate staff are in place to carry out treatment in the primary and secondary settings.

The importance of 'joined up' working between primary and secondary care and the tertiary centre was highlighted in a number of interviews. This was believed to be essential to improving the delivery of services but also in helping to improve patient experience by minimising the stress from travelling long distances. Mention was made of a system trialled in parts of the country where blood sample bottles were sent by the transplant centre to the patient, who would then visit their GP to have their blood taken. The sample was then sent back to the clinic in advance of the patient's appointment. This brought with it significant cost savings as well as helping to maximise the use of the patient's visit to the clinic by helping to identify any key clinical issues in advance. By sharing out of services in this way, there is the potential of relieving the tertiary centre of pressure to provide services which could be provided elsewhere. Nevertheless, interviewees pointed out that it needs to happen within a clear standardised structure that is well thought through and has responsibilities clearly defined, so as to avoid further confusion and break down in care.

The patients interviewed commented on the sense of insecurity they experienced when aspects of their care were not properly transferred when they moved between primary, secondary and tertiary care settings. From the patient's perspective, very often all that was needed was better communication and exchange of information between teams. Continuity of care emerged as a key value for patients. Where this breaks down or is disjointed, it does not inspire confidence in either the treatment being given or the medical team. While patients were open to using local services, they were quick to highlight that local services would need to be appropriately staffed

and equipped, otherwise they would prefer to travel to the transplant centre in order to receive expert care. Some cited experiences of receiving high standards of care at the centre, only to then move to services closer to home that were under equipped and where staff members were poorly informed about the patient's treatment or care. Consequently, patients generally felt that their time was being wasted.

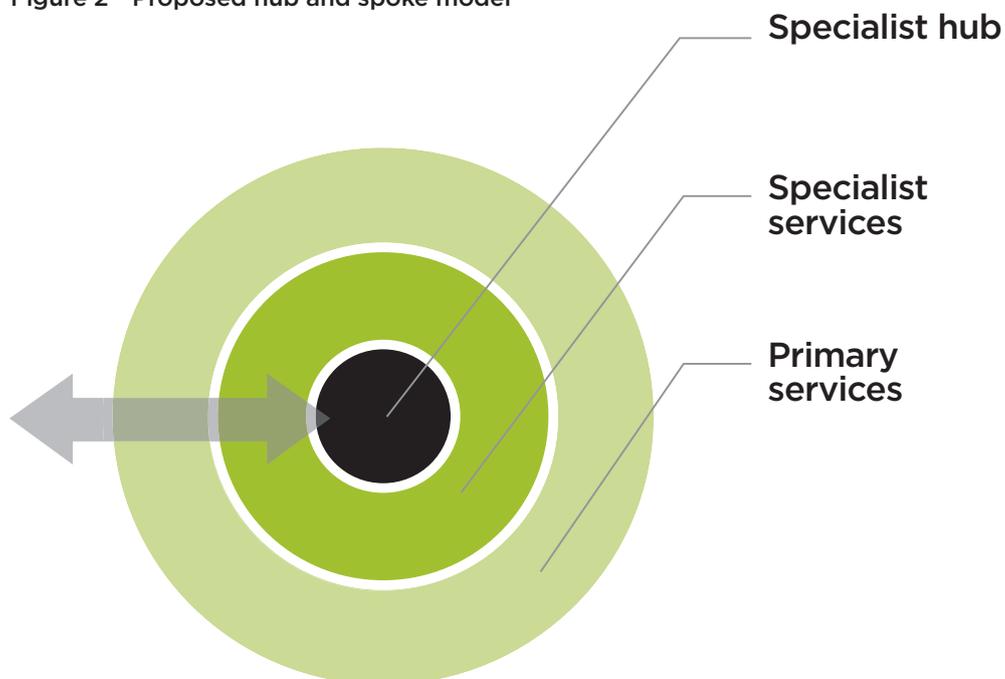
In establishing transplant centres as hubs, there is the need to ensure that the commissioning process takes account of the geographic reach of their services, the population base they serve and locally available services, a factor highlighted by the UK Stem Cell Strategic Forum (2010: 73). In remote parts of the country, patients may be far from a centre of excellence and unable to make the journey even if they wanted to. In those exceptional cases, there is even more need to give careful consideration to the effective use of primary and secondary care services, working with a tertiary centre.

The current approach (see Figure 1) often does not see adequate communication and relationship between the transplant centre and primary and secondary services, and causes variance in delivery of services. For effective post-transplant care, we propose a hub and spoke model that sees the recognising transplant centres as specialist hubs, which then build strong communication links and clear collaborative relationships between secondary and primary care services (see Figure 2). Through such an arrangement the three groups can work responsively to the care and treatment needs of individual patients. The specialist hub can build the resource capacity to help drive quality of outcomes for the first 100 days which can then go on and support an improved plan for post-100 days care.

Figure 1 -
Current model



Figure 2 - Proposed hub and spoke model



Recommendation 3:

Clear systems of shared care should be established between tertiary centres and primary and secondary care settings, so enhancing patient access to the complete range of services that constitute comprehensive post-transplant care.

Action to be taken by:
SCGs

Late effects clinics

Late effects clinics help pick up on early signs and treat side effects a BMT patient might experience post transplant. Given that the guidance from NHS England does not state that centres have a mandatory obligation to provide late effects clinics, there is a range of different approaches taken in the delivery

of late effects services. Difficulties experienced in commissioning late-effects services can be a deterrent in setting up late effects clinics and may help to explain regional variation. The findings from the interviews, supported by the roundtable discussions, are that clear national standards of care for late effects need to be drafted for implementation

across the country. While JACIE establishes minimum standards for care and treatment, it does not focus sufficiently on long term follow up and late effects. During the roundtable discussions, it was noted that NICE Improving Outcomes Guidance (IOG) is based on the best research at the time of publication.

It was therefore felt important for calls to be made to NICE to renew existing guidelines in line with latest research.

This highlighted concerns regarding research and clinical trials. Ongoing research needs to be fed into future recommendations and guidance, thereby ultimately improving outcomes for the patient. Research and clinical trials are essential to this process. This area is addressed later in this report (see 'Research and Clinical Trials').

Adopting the hub and spoke model could also help to improve the provision of a late effects service. As clearer collaborative links are established between the hub and the spokes of primary and secondary services, the range of services which are needed in providing a late effects services can be better organised and delivered, helping to meet the needs of individual patients. Providing services which can be delivered closer to the patient's home, working in relationship with the hub, can help save time and money. As highlighted in the interviews, patients do not mind travelling to a transplant centre 'hub', if they know the level and quality of care is good. When appropriate, they are equally open to care and treatment being delivered closer to home, providing quality of care is consistent and is provided in a 'joined up' way.

Many centres are conducting different approaches to late effects and in doing so have various ideas and suggestions on what constitutes best practice. Findings from the interviews appear to indicate that where late effects clinics work well there are four common key elements:

1. The clinic sits across the broader oncology service
2. The clinic is served by a multi disciplinary team
3. The clinic serves as an assessment point for access to other services
4. The clinic is nurse-led.

The clinic sits across the broader oncology service

There appears to be two approaches to establishing a late effects clinic: the clinic is run by a dedicated transplant service, or it spans the broader oncology services and therefore includes both transplant and non-transplant services. A clear advantage of having a late effects clinic run by a dedicated transplant service is that it is designed and tailored according to the needs of the transplant patient; however, a high through put of patients is required in order to justify its existence. The alternative of establishing a clinic that spans broader oncology services means that it is able to draw upon a broader range of services, skills and expertise and foster collaboration more easily, for instance across chemotherapy, mental health and psychology. This approach lends itself well to being incorporated into the hub and spoke model discussed earlier and highlights the need for whole pathway commissioning.

The clinic is served by a multi disciplinary team

The multidisciplinary team (MDT) approach is seen to be crucial in providing effective post-transplant care, particularly as transplant patients are beginning to live longer. It was noted that one of the challenges in this area is how to engage the necessary skills and disciplines in post-transplant care. Very often the standard haemato-oncology MDT for adults does not allow sufficient time or resources for the range of conditions that follows on from BMT.

Specific BMT MDTs are necessary for adults and children. General agreement emerged from the interviews and roundtable discussion that MDTs offer the best approach and that every transplant centre should have one, driven by IOG guidance. However, cost is one of the main obstacles to seeing this realised. NHS Trusts can often provide further

barriers by failing to acknowledge MDTs as a sessional or part-sessional commitment in job plans. If true then this has to be remedied urgently.

Some recommendations from the roundtable discussion included:

- Convening a meeting of major transplant centres in order to help facilitate an exchange of knowledge and best practice, based on the body of evidence now building concerning late effects.
- Carrying out a national audit in order to obtain the quantitative evidence needed to make the case for developing best practice for late effects in BMT. The BSBMT would be a perfect vehicle for such an audit of BMT centres and could help to draft these guidelines drawing upon the expertise and skills of its members. Appropriate resources would be required in order to conduct such a project so that savings could be made in the long term based on the evidence collected.

Recommendation 4:

A national audit of BMT centres should be carried out in order to help shape standardised treatment protocols for late effects services.

Action to be taken by:

BSBMT
NHS England

Recommendation 5:

A range of multidisciplinary services should form the basis of late effect clinics. The role and involvement of each specialist within the MDT should be clearly laid out in their job description.

Action to be taken by:

NHS England

The clinic serves as an assessment point for access to other services

An effective approach used in late effects clinics appears to be one where the clinic functions as an assessment point for patients, who can be then referred on to appropriate specialism. Hence the need for clear MDT involvement in the design and configuration of late effects services.

In addition to this, particular attention was paid to the psychosocial implications for transplant patients.

While there is good focus on the physical implications of survivorship, there is the ongoing need to continue to look at the psychological and emotional implications on survivorship. As rates of survivorship improve and transplant patients come through extensive and

complex treatment, there needs to be corresponding attention and support given to their mental and emotional wellbeing.

A patient quality of life survey published in December 2012 showed that a significant number of adult cancer survivors do not go back to work, and this is the biggest single factor in having a reduced quality of life (Corner & Wagland 2012).

In many places there are no or limited local psychologists, physiotherapists or other allied health professionals to provide this specialist support.

This point highlights the need for the commissioning of late effects services to be the responsibility of NHS England as CCGs are currently not focused on it. In some respects this is understandable as it is likely that there are not sufficient numbers of patients within the local catchment for the CCG to drive commissioning

for late effects services. Nevertheless it is clearly important for the patient concerned in terms of receiving appropriate care and treatment. This is where the commissioning process breaks down, requiring serious review of the split approach between SCGs and CCGs. Alternative models may be for SCGs to commission for the whole pathway or for the specialist hub to subcontract services.

Recommendation 6:

NHS England to be responsible for the commissioning of late effects services.

Action to be taken by:

NHS England

National guidelines for late effects services should include returning to work and living an active life as health outcome. Under JACIE standards, clinical programs 'should be able to demonstrate the processes by which

age-specific issues are addressed' (JACIE 2012: 74). In the case of teenagers, programs should be able to demonstrate that they have processes in place to 'accommodate psychological...and social needs',

while elderly patients (greater than 65 years of age) should have appropriate access to rehabilitation and social support (2012: 74).

Recommendation 7:

A set of national guidelines should be drafted and adopted to make clear what constitutes a late effects service and how it should be delivered. Rehabilitation and psychological support should form part of this. These guidelines should be adopted and endorsed by commissioners and form a mandatory part of the commissioning process.

Action to be taken by:

NHS England

JET'S STORY

Jet, 52, is a writer and charity volunteer from the East Midlands.

Jet was diagnosed with multiple myeloma in February 2011 and after other treatment failed, she had an unrelated donor transplant in May 2012.

As a result of the transplant, Jet now suffers from mild GvHD in the mouth and genital area. Her mouth is sensitive and tight and she finds it difficult to open it wide to yawn, for example.

The condition also affects her eating habits as she cannot eat hot, tangy or spicy foods. This discomfort is also mirrored in her vagina. Her vaginal GvHD is alleviated by medication, but the oral GvHD has not responded to any treatment so far.

She has also recently started experiencing reduced mobility in her limbs due to an unexplained tightening in her muscles. She says this affects her day-to-day activities like

taking off a t-shirt or climbing the stairs.

She mentioned the problem to her transplant centre, who carried out various blood tests, which all showed normal. She is currently waiting to see a Rheumatologist.

Jet has accepted that she will probably have to live with such symptoms for the rest of her life. 'None of these problems are at all life-threatening but they do affect my quality of life.'

She regularly visits her transplant centre which luckily is very close by. Despite the complications following her transplant, she is happy with the care she receives. 'Even though not all the problems have been resolved and may never be resolved, I feel I have had excellent support and suggestions for different treatments from everyone involved in my care. They treat me as a whole person. As well as keeping me alive, they are also keeping me well.'

'Even though not all the problems have been resolved and may never be resolved, I feel I have had excellent support and suggestions for different treatments from everyone involved in my care.'

Recommendation 8:

Returning to work and active life should be recognised as a key health outcome for BMT patients where appropriate. As children grow up, support in further education and work should form part of this strategy, recognising that time lost through treatment in earlier stages of life is likely to impede upon progress in later years.

Action to be taken by: CCGs

There are other gaps in the service which need to be addressed. If children do not qualify for special needs (in the case of paediatrics) then they are not provided with extra school support to catch up with time lost. This can be hugely detrimental to a child reaching their full potential and making the most of opportunities. In practice, savings and costs are not joined up, and making the economic case for reallocation or invigoration of funding is challenging. This enforces the argument for effective, integrated commissioning.

The clinic is nurse-led

Both patients and clinicians alike acknowledge that effective late effects clinics are led by nurses. Patients prefer nurse-delivered long term follow up to that delivered by other clinicians, a fact borne out through the interviews and findings from secondary research. Surveys indicate that patients feel nurses have more time and think more about the patient as a whole. There appears to be a case to be made for nurses taking on increased clinical roles for the ongoing management of more straight forward BMT cases.

Specialist hubs or 'centres of excellence' would help with this in allowing specialist staff with extensive experience to manage complex cases to a higher standard. There is a 'nurses school' model of care and a 'medical school' model of care and the two need to work together to provide the best experience for the patient.

Making the case for a late effects service

Further consideration needs to be given to building a good economic case for late effects services. Some examples of where management of late effects can provide savings elsewhere are:

- Early detection and treatment of secondary cancers. The saved cost for treating these cancers earlier rather than at a more advanced stage could be significant.
- Back to work rehabilitation. Costs could be recouped through future tax contributions: making young survivors fit for work raises their potential in the work place and increases their capacity to become economically productive.
- Pressure on mental health

services could also be reduced by rehabilitating patients more effectively. It is recognised that many young people lose ambition after bone marrow transplant due to psychological reasons and inadequate rehabilitation back to society.

This makes the point that there is a need to gather good data on the late effects experienced by patients in order to better understand and make the economic case for providing late effects services.

Technology

The effectiveness of post-transplant care could be increased with the efficient use of technology between patients and professionals. Findings from the interviews suggest that telehealth solutions are already being used to conduct consultations remotely.

Using VOIP platforms (such as Skype), consultations can take place within the comfort of the patient's home, saving on unnecessary travel time and costs. The video link provides opportunity for clinical staff to undertake examinations

remotely, supported by email and digital photographs which can also be sent in by the patient. Both patient and clinician alike were keen to point out that they saw this as being complimentary to face-to-face, meetings and not a replacement. Nonetheless it was perceived that the savings in time could be beneficial. Patients still valued the opportunity to meet face-to-face with the same members of the clinical team. It was perceived that this helps strengthen the patient-professional relationship and also allows for a more thorough examination to take place than what is possible through virtual means.

Obstacles identified included the NHS's general approach to IT. The cost of infrastructure can be prohibitive and the use of third party software can be problematic due to firewall restrictions. It is anticipated that as the opportunities are taken up more widely, with the growing momentum surrounding telehealth solutions and the use of technology in healthcare, these obstacles will be resolved, but more needs to be done in order to drive this forward. Greater demonstration of how technology can be used to enhance patient experience and reduce wastage of time and resources is needed.

DATA COLLECTION

To date, data collection has been patchy and inconsistent. This section looks at the need for high quality, reliable data and how to improve collection and use it to inform future decision making and service redesign.

Data collection is an essential for commissioners, who need robust data to help them horizon scan and make strategic decisions for the future. It is also essential for assessing outcomes. Having a greater understanding of outcomes in terms of late and long term effects, and rates of survivorship post-transplant, is crucial in order to ensure that post-transplant care is meeting the needs of patients. Data collection is also a central component of the 'information transparency agenda' in the 2010/11 NHS Operating Framework (UK Stem Cell Strategic

Forum: Annex 75). JACIE standards require data to be collected in order to meet skeletal and minimum standards.

Simply improving the method by which data is collected will not be enough. Accurate interpretation of data is also required and needs to be addressed, as highlighted by both the 'Review into the quality of care and treatment provided by 14 hospital trusts in England: Overview report' (the 'Keogh report') and 'A promise to learn - a commitment to act: Improving the Safety of Patients in England' (the 'Berwick report').

Very often there is a process and system problem, where providers and commissioners struggle to understand and exploit the rich sets of data available and act on them to drive improvement and change (Keogh 2013: 8; National Advisory Group on the Safety of Patients in England 2013:17).

However, it is a common perception that data management is under resourced by some hospital management teams as they do not adequately understand the importance of data collection to improving outcomes. Follow up data is often patchy and time consuming to collect. In terms of late effects and patients' progress and recovery, the paucity of data means that there is no clear way of assessing outcomes.

A full picture of current transplant outcomes and the performance of individual transplant centres can only be ascertained with current and regular data collection. Both commissioners and clinicians have a shared objective in the availability of high quality data and useful information.

While data is recognised as valuable by clinicians, there is a perceived lack of resource to generate and collect the kind of data which will actually to help improve care and treatment. The lack of contemporary long, term outcome data is something that all interviewees agreed needs to be addressed. It was welcomed

that BSBMT is now taking steps to formally collect outcome data to help inform the commissioning process, but more still needs to be done, with commitment for the long term to improving the generation of robust outcome data.

It was noted that in the London SCG it is now a mandatory part of the contractual agreement with service providers to make available additional resources to develop registration studies and clinical trials (NHS Blood and Transplant 2010: 75). Likewise, the BSBMT is now producing a five-year rolling outcome audit on all adult transplant patients using commissioning funds.

Coupled with this is the need to provide adequate support 'on the ground' to collect and manage this data. Very few centres have the luxury of a dedicated team member whose sole responsibility and focus is data collection. Making the case for collecting outcomes data and calling for a more robust process without putting the necessary infrastructure in place will lead to greater frustration.

Recommendation 9:

Data collection should form a mandatory part of the contractual agreement with service providers and transplant centres should ensure adequate resources are in place to meet this requirement bearing in mind financial restraints.

Action to be taken by: NHS England

RESEARCH & CLINICAL TRIALS

Noted throughout the interviews and roundtable discussion was concern over research and clinical trials. A large amount of discussion took place concerning the need to develop a network of randomised control trials (RCTs) to build upon the UK's already substantial investment in stem cell biology. This RCT network would inform and improve transplant practice, giving patients the best possible chances of recovery and minimising the risk of developing chronic and acute GvHD and other long term and late effects.

To date a substantial amount of observational research has been conducted. The role of observational studies should not be undervalued: this research has been extremely useful and should continue to be supported. Nevertheless, more RCTs are needed which can provide quantitative evidence. Survivorship RCTs also appear to be minimal. Critical to this is financial support, as clinical trials can be very expensive. It was recognised by some interviewees and roundtable guests that a good trial infrastructure needs to exist to better maximise the world-class stem cell knowledge base that exists in this country.

It is perceived that a key barrier to research significantly moving forward within the specific area of

survivorship appears to be due to two key factors:

- Slow rates of patient recruitment
- A lack of resource

Interviewees identified three keys to unlocking further research capacity and advancing a greater number of clinical trials:

a) Central hub

A central hub is needed to help lead, govern and manage research. The hub would be charged with responsibility for day to day running of the trials, data collection and all regulatory issues. It was proposed that it seemed to make sense to make the National Institute for Health Research (NIHR) this hub as it has much of the infrastructure already in place. Currently a hub of this kind is not funded within the transplant community.

b) People resource

Research nurses are needed in the transplant centres in order to help run the clinical trial. Giving staff added responsibility to help run the clinical trial, alongside their existing responsibilities, is considered problematic.

c) Supportive network

A network that champions and supports the trial is required to help bring incentive to participation.

One approach, which would help to recruit centres onto the clinical trial program, would be to provide funding and support for a research nurse. This nurse could help support patients, alongside ensuring that every eligible patient is invited to become part of the clinical trial.

This model has been seen to work with great success in the case of a network of leukaemia centres with a regulatory hub. The Leukaemia and Lymphoma Research Trials Acceleration Programme (TAP), part of the NIHR Translational Research Partnerships (TRP) initiative around early phase trials, has proved extremely effective. Funding was approved by Leukaemia and Lymphoma Research to establish a central hub of 8 trial coordinators, data managers and statisticians in Birmingham. A selection process for the identification of 6-10 participating Leukaemia Centres is ongoing. Each successful Leukaemia Centre receives funding for a research nurse for a three year period (Craddock 2012).

The TRP model demonstrates potential for the transformation of BMT services with the appropriate resources in place for the long term. The TAP model (or something similar) should be adopted in order to further research in BMT.

Without doubt the findings from the interviews indicate strong support for the BSBMT in helping to host a BMT research network. The Clinical Trials Committee (CTC) of the British Society of Blood and Marrow Transplantation (BSBMT) is respected and has strong support from across the UK transplant community.

Its track record in the delivery of retrospective studies of transplant outcomes is good. The BSBMT's CTC has the enthusiastic support of major transplant centres and represents an appropriate and informed forum for formulating future studies and a strong base on which to build a trials network. Interviewees were

unanimous that any plans for the future must involve participation from within BMT community so as to help bring traction to the proposals. These facts only serve to strengthen the case for an economic evaluation so that the financial benefits of providing a late effects services can be fully understood and appreciated.

Recommendation 10:
A BMT research and clinical trials network should be established to build capacity and strengthen the research community in this area.

Action to be taken by:
BSBMT

WORKFORCE

A key element to making many of the proposed changes work is having the necessary people in place. Human resource is a theme that cuts across each of the preceding sections, but is so crucially important that it demands closer attention in a dedicated section.

The focus is clearly on improving outcomes and driving standards of care for the patient, but a balance needs to be struck between introducing new roles and working within the financial constraints of NHS budgets. Four key roles appear to be vital to the delivery of the service:

1. Care coordinator
2. Research Nurse
3. Data collection and coding clerks
4. MDT coordinator

Care coordinator

Based in the late effects clinic, care coordinators would support the patient through gaining access not only to medical and nursing care but

also to other areas where support is so often required, for example in transport, benefits, lifestyle (diet and exercise), rehabilitation and back to work initiatives and counselling. The term 'care coordinator' is becoming more commonplace and may well be known by other job titles, such as 'care advisor' or 'key worker'; a specialist nurse may also fulfil the role.

In a UK-wide survey of the experiences of patients and families with rare diseases conducted by Rare Disease UK, one fifth (21 per cent) of respondents said that the role of care coordinator should be fulfilled by a specialist nurse (Rare Disease UK 2013). This idea was reflected in the interviews by patients who highlighted the valuable care coordinating role provided by nurses from the third sector such as Macmillan. Generally, these nurses were cited as playing a key part in the patient's recovery.

Building a long term relationship with the patient, continuity of care was provided along with clarity of

information as the nurse knew the patient and was able to interpret and apply information specifically to the patient's own situation. Given their understanding of the NHS system, the nurse was also able to guide the patient through the various stages of treatment as well as offering them guidance on how to access additional support if required.

Research Nurse

Many units already have research nurses who provide a valuable role in the care and treatment of patients. Where these roles do not currently exist further consideration needs to be given to appointing them.

RYAN'S STORY

Ryan, 23, is a PhD student from the North West.

Ryan received a transplant in February 2012, after being diagnosed with acute lymphoblastic leukaemia in September the previous year.

Ryan's experience of post-transplant care has been positive, particularly thanks to being able to contact a single transplant nurse co-ordinator whenever he needs to.

'If I ever need anything, even if it's just advice, I give the transplant centre a call and everything is taken care of,' Ryan explains. 'There have been occasions when breakdowns in communication between local NHS services have meant that I've received the wrong prescription for follow up treatment, but I can give the transplant nurse co-ordinator a call and she sorts everything out.'

Ryan was also grateful for the support his family has received from the transplant nurse co-ordinator. 'It really is important to a transplant patient to have

someone who's been there the whole way through, and it's great that she's there for the whole family whenever we need her.'

Ryan's experience also highlights the importance of specialist care, in light of any post-transplant complication, no matter how small it may seem. Ryan's treatment caused his toenails to grow very quickly and he developed an ingrown toenail. But because he'd had a transplant, several local NHS services refused to treat him.

'I tried for two months to get it treated, before I was forced to ask my transplant consultant to intervene. It was treated quickly after that, but by that point it had grown so badly that I needed to have it done under general anaesthetic,' Ryan explains.

'It was at a point in my recovery when I wanted to get active again, so it was frustrating that my local NHS services weren't able to take a risk in treating someone who had had a transplant.'

'If I ever need anything, even if it's just advice, I give the transplant centre a call and everything is taken care of.'

Data collection and coding clerks

As identified previously there are key issues over the way in which data is collected. Consideration needs to be given to how this is resolved.

One option could be for clinical coding groups to be more closely aligned to clinical teams. Clinical coding clerks are well trained in data capture and review and so it is important to ensure that these skills sets are aligned with the work of the BMT clinical team. That way the team can achieve the efficient inputting of data on to the required system. The collection and interpretation of data will help contribute to the evidence based needed to improve standards of care and forms of treatments for the post-transplant patient.

MDT coordinator

Recognised as the 'hub' of the MDT, the MDT coordinator offers specialised administration support to facilitate the effective and smooth running of the team. In some instances they are involved with the collation of data for the Cancer Waiting Times and the National Cancer Audits (Avon, Somerset and Wiltshire Cancer Services 2013).

Consequently there is scope here to support and augment collection, management and interpretation of data in terms of BMT.

All four of these roles currently exist, involving specific skill sets and performing certain functions. Consideration needs to be given as to how these roles might be fulfilled and combined within the BMT team in order to maximise benefit to the patient and meet their needs. This can then feed into the best practice recommendations for all BMT teams to follow.

PATIENT AT THE CENTRE

In its recent White paper *Equity and Excellence: Liberating the NHS*, the government has strongly endorsed

the principle that patients have got to be at the centre of NHS healthcare. A significant culture shift in healthcare is required for 'no decision about me, without me' to become the norm, and from the Government's own consultation it is clear there is strong support for this change.

This point has underpinned the key themes arising from the interviews and roundtable discussion. In this section we address issues that directly relate to ensuring the patient becomes the central focus. These include empowerment, patient records and peer support.

Empowerment

What steps can be taken to empower the patient so that they are recognised as part of the medical team? This is an issue faced by all clinicians today. Patients want to know and understand their condition in order to be part of the decision making process (Department of Health 2012:2). The Government responded that in order to create a patient-centred NHS, policies will work on embedding care planning, shared decision-making and providing the information and support necessary to enable people to manage their own condition, where they wish to do so (Department of Health 2012: 26).

Among patients interviewed, there seemed to be the general feeling that patients had to push hard to get answers to questions or find out further information about their current phase of treatment. Others were kept fully informed of what was happening and were given plenty of opportunity to ask questions. There appears to be a need to get the balance right between clinicians providing information for patients and signposting the patient to relevant and reliable sources of information that they can access themselves to learn more.

Relying too heavily on the internet without any appropriate guidance can result in spurious information being accessed. Mention was also

made of online resources that have been developed by individual centres for patients to access.

These could be built upon and developed further into fully fledged e-learning resources which could feed into the national NHS Choice Framework. This framework sets out clear expectations for NHS England commissioners about the choices patients ought to be able to make, and ensures that patients have clarity over what choices they can reasonably expect to have about where they go and who they see for treatment (Department of Health 2012: 30).

Recommendation 11:

Patients should be empowered and fully informed to become an active participating member of the multi-disciplinary team. Full access to their record including all relevant non-medical information and data should be given to them so that they are informed of their condition.

Action to be taken by:
NHS England
CCGs

Following on from this is also the need to give time and space for the patient to discuss the information with a healthcare professional in order to interpret and use the information appropriately, thus enabling them to participate in decisions about their care and treatment. Linked to this is the ability of patients to navigate their way through the administrative process of accessing services. From the interviews it became clear that either patients struggled through with little help or had to request help in accessing specialist services.

Very often they felt at a loss as to what support and resources were available to them, or experienced great frustration in filling out forms and completing paperwork in order to access services. The role of care coordinator could help address some of these issues. They could be charged with the responsibility to support the patient through gaining access to not only medical and nursing care but also to health information, while offering support in other areas such as transport, benefits and counselling.

All aspects of the patient's care from beginning to end is therefore

organised and 'joined up'. Utilising agencies and organisations from the third sector to provide this role could be an effective way of drawing upon skills, abilities and insights that already exist in the system.

Impact on wider family

Consideration also needs to be given to the impact of the patient's transplant on wider family members. To begin with, travel and accommodation costs can have an impact particularly if patients are travelling long distances. Some units provide hotel and other accommodation for patients and their families during treatment and visits, but there is often no means of recovering these costs of travel.

The emotional stress on a family member is reported as not being well addressed and is something that family members themselves do not recognise until it is perhaps too late. Siblings of children who undergo BMT may also be affected as parents focus their time and attention on caring for the child who is undergoing treatment.

Support for siblings is something many patient families point to as a resource much needed yet often

overlooked. The third sector could be well placed to help in this regard, offering support to family members, befriending them and allowing them a chance to talk through how they are coping and where they are struggling. This kind of role needs to be explored further as there is currently nothing provided to meet this need.

Recommendation 12:

Appropriate support service should also extend to family members, recognising the impact cancer and transplant care can have on them as they support family members receiving treatment.

Action to be taken by:
CCGs
Third Sector

Peer support

Patients would also value effective support from, and engagement with, other patients. Given the nature of BMT treatment and the gaps between each patient's visit to the transplant centre, it is often difficult to maintain long term contact with other patients.

Nevertheless, when face-to-face contact is made it can be extremely encouraging, providing a level of care and relationship support which online interaction cannot achieve. It has been recognised that even an annual or bi-monthly meeting is of benefit; where this has been organised by transplant centres around the country it has been of enormous value to patients and staff alike.

Patients acknowledged the value and usefulness of online interaction but at times pointed to the lack of moderation in comments posted online leading to more negative than positive experiences. Where a good mix of online and face-to-face interaction is achieved, patients report significant benefits in terms of support. Increased opportunities need to be given to patients to meet one another, exchange stories and experiences and provide mutual support networks. Ultimately this needs to be peer-led and is likely to require third sector involvement to help initiate and provide basic administration support. A function of

a care coordinator's role could be to help provide this level of support to peer-led groups.

Patient records

Patients do not like their time being wasted through notes being incomplete or lost and MDTs not communicating with one another. This in turn can lead to a break down in trust and confidence between the patient and clinician, which can take time to rebuild. Communication was therefore identified as an essential issue both between clinician and patient and clinician and clinician. The waste in time and money of repeated scans, lost notes or poor information given to patients has never been fully assessed; however best practice points to the fact that doing things right first time not only increases quality but drives down cost. The efficient exchange of information could therefore be a real help, especially swift access to patient records.

One way of addressing this is through the NHS's Information Strategy which sets out the vision of patients being able to access and share their own health and care records, thereby empowering the patient to take part in decision making in partnership with professionals (Department of Health 2012: 25). Based on nationally set information standards, the strategy is a way to encourage fully joined-up

systems, facilitating the sharing and communication of information and data in an efficient and swift manner across the health and care system.

Taking this still further, building on the Department of Health's '3 million lives initiative', there is scope to build elements of telehealth and app-based technology into this strategy, empowering the patient to manage their own lifestyle by recording and tracking their own progress. Data could be submitted electronically, helping to populate the personal health record with real time data, thus saving time in appointments with clinicians. When face-to-face appointments do take place they are informed by relevant data. Charged with responsibility to help manage this data, patients are empowered to play an active role in aiding their recovery.

Extracorporeal Photopheresis: A treatment for GvHD

Although this report did not look at the treatment of patients, one area that was consistently mentioned was the use of extracorporeal photopheresis (ECP).

A standardised approach for the commissioning of ECP was

highlighted as an issue that needs to be addressed. ECP has begun to be used as treatment for those post-transplant patients suffering with chronic GvHD.

ECP treatment is usually applied when other forms of treatment have not resolved the GvHD. Each treatment takes several hours

to complete and is typically undertaken every two weeks. While a complicated treatment, which is often delivered in specialist dermatological centres, it is usually very well tolerated by the patient and has minimal side effects. The number of ECP machines in England, by area of the country is given in Table 4.

Area of country	Number of machines
Midlands and the North	20
Greater London	8
South	2
West	2

Table 4 - ECP machines in England

Recommendation 13:

Further research is needed in order to build the necessary evidence base for commissioning ECP as a treatment for acute GvHD.

Action to be taken by:

CRG

HTA

Acute GvHD

Acute GvHD is where the bigger challenge lies. Without effective acute GvHD treatment it is unlikely the patient will live beyond 100 days. Practically, it is difficult to deliver ECP to treat cases of acute GvHD when the ECP unit is not located within the transplant centre.

Patients with acute GvHD are in a very sick and vulnerable condition and cannot travel any great distance to receive treatment, so ECP needs to occur within the transplant centre. There are limited centres in the UK which can truly deliver such a service. Satellite and mobile services could help to address this and are currently being explored.

Before the changes to commissioning came into effect on 1 April 2013, the perception was that access to ECP varied across the country due to lack of clear standardised protocols on the use of ECP for chronic GvHD.

Guidelines produced by the BSBMT provided useful clinical guidance as to how best to utilise the treatment, but 'on the ground' there were many different approaches being followed due in part to how the various funding streams worked. Under the new commissioning arrangements, the variance in access looks set to be addressed. The BMT CRG is drafting commissioning policy, including specific details on the number of patients affected, who could benefit from the treatment and potential

costs implications. It is anticipated that this policy will be adopted by NHS England.

While this is a welcomed development, it does not solve the problem. From a commissioning perspective, there is not sufficient agreement for ECP to be used as a treatment in acute cases, despite attempts being made to make the case for this. In order to move the conversation forward, commissioners need RCT data which is not currently available.

There are plenty of prospective and retrospective studies alongside single centre experience reports, but to date no evidence-based RCTs. This is largely because RCTs are expensive

to run, particularly when the target group is fairly small to begin with.

It was the opinion of some of the interviewees that there is scope to try and accrue some reliable data on the management of acute GvHD with ECP by pooling resources with the USA in order to construct an international registry. There may well be a role for CRGs to take this up and make the case to the commissioners for such a registry as a more viable option than RCTs at this stage.

A further proposal could be for the Health Technology Assessment (HTA) Programme to commission this further research as part of its activities to produce independent research about the effectiveness of different healthcare treatments.

JAMES' STORY

James, 32, is from Yorkshire.

James was diagnosed with Hodgkin's lymphoma in February 2009 and received a transplant from an unrelated donor in January 2013. Along with other transplant patients, James has experienced fatigue so challenging that getting dressed has taken all of his energy.

James has returned to hospital regularly following his transplant. He has been admitted due to picking up infections, but he most regularly had to attend to receive fortnightly blood transfusions, but also twice weekly magnesium transfusions, as immune suppressant drugs can prohibit its uptake. To reduce travel time, James tried to organise both transfusions on the same day.

'It could be very difficult to arrange all my appointments on the same day, as the hospital didn't always have a stock of the blood I needed,' explains James. 'They tried to order it from another hospital, but it didn't always arrive in time and my transplant centre didn't want me to go to my local hospital

instead, in case there were miscommunications over my care.'

James has also experienced GvHD, which affects his skin. 'After I was taken off immune suppressants, I noticed a rash which gave my skin a sensation like severe sunburn.'

The rash only subsided with steroid treatment, reappearing whenever the steroids were stopped, so James will be receiving ECP treatment from September. 'It's an hour long journey to the closest hospital that offers ECP, but needs must.'

James describes himself as lucky to have had a well paid job in the past, meaning he doesn't have to rush to return to work. 'I experience a numbness in my fingers which means I might not be able to go back to software development and my hospital appointments would make work difficult – you never know when something is going to come up. But what stops me more is the idea that I might not be around in a couple of years' time. When I am feeling well, do I really want to spend my time working?'

'It could be very difficult to arrange all my appointments on the same day, as the hospital didn't always have a stock of the blood I needed.'

CONCLUSION

Without doubt, after many years of extensive research and advances in science and technological development, BMT is an important curative therapy for patients with haematological malignancies. But a transplant patient is a 'patient for life' given the complexity of the transplant process and the potential long term effects and implications.

This in turn demands a complex arrangement of care and treatment. The clear challenge is to improve rates of survivorship and ultimately cure patients of blood cancer.

From our interviews and research we have identified the following key issues which effectively address this challenge.

- **Late effects**

National guidance for transplant centres, on what and how late effects services should be provided to patients, need to be drafted in consultation with the BMT clinical community and introduced by NHS England. There is a lack of clarity and guidance on the commissioning of the late effects service, which appears to be a common barrier and deterrent to transplant centres setting up these services.

- **Commissioning**

NHS England should take responsibility for oversight of the whole pathway, with shared care arrangements and subcontracting for key phases of the treatment and management of late effects.

- **Data collection**

There is urgent need to strengthen data collection and management in order to develop robust, long term outcomes data that can inform commissioning decisions for the development and configuration of long term and late effects services.

- **Recruitment to clinical trials**

Recruitment to RCTs is critical in moving forward. The evidence base needs to be strengthened and developed so that the very best forms of treatment can be delivered.

Ultimately, this will reduce patient relapse and enable more to return to active life.

- **Patient empowerment**

The patient must be empowered to become a participating member of the multi-disciplinary team; they should be provided with accurate and accessible information about their condition so they can make informed decisions.

- **Workforce**

A key element to effectively implementing many of the proposed changes is having the necessary people in place, fulfilling key roles. This could be achieved through combining and reconfiguring existing roles as opposed to creating new roles.

As rates of survivorship improve and the number of those who require long term and late effects service increase there is the need to ensure the appropriate services are not only in place but also equally available to all.

For these changes to gain real traction there needs to be the involvement of two key groups. First, clinicians from within the BMT community need to be involved and part of the process. This is why professional bodies such as the British Society of Blood and Marrow Transplantation and British Society for Haematology are important and need continued support and resourcing. They can promote inclusivity and 'buy in' from clinicians and avoid the perception that change is being imposed.

Human resource is a cross-cutting theme of the project and whilst the obvious solution might be to create new roles to take on responsibility, we propose that there are a number of existing roles, combined where appropriate, which still allow us to do more without increasing overall capacity. There is scope to improve delivery of care within financial constraints.

Second, running throughout these themes, is recognition that for success to be realised then all decisions must be patient centred, supported by a clear and transparent evidence base.

APPENDICES: STEERING GROUP MEMBERS

Julia Manning	Chief Executive	2020health (Chair)
Chiara DeBiase	Head of Patient Experience	Anthony Nolan
Richard Davidson	Director of Communications and Marketing	Anthony Nolan
Dr Adele Fielding	Co-Director of Research and Development	UCL Cancer Institute
Sarah Holtby	Quality Manager/Stem Cell Transplant Research Governance/Advanced Therapies, Cancer Centre	The London Clinic
	Executive Committee Quality Management representative	BSBMT
Matt James	Research Fellow	2020health
Michelle Kenyon	ELF post BMT Clinical Nurse Specialist	King's College Hospital London
	Executive Committee Nurse representative	BSBMT
Sally Penrose	Chief Executive	Lymphoma Association
Jonjo Rooney	Designer and Photographer	Patient Representative
Dr Rodney Reynolds	Teaching Fellow in Global Health and Anthropology Academic Lead	University College London
Dr Bronwen Shaw	Consultant Haematologist	Royal Marsden Hospital
	Executive Committee Clinical Trials Committee Chair	BSBMT
OBSERVERS:		
Katie Begg	Head of Policy and Public Affairs	Anthony Nolan
Victoria Moffett	Policy and Public Affairs Manager	Anthony Nolan
Iana Vidal	Policy and Public Affairs Officer	Anthony Nolan

APPENDICES: TELEPHONE INTERVIEWEES

Alex Heelis	Patient representative	
Daisy Brickhill	Patient representative	
Professor Charles Craddock	Consultant Haematologist	Centre for Clinical Haematology Haematology - University Hospitals Birmingham NHS Foundation Trust, and Chair of UK Stem Cell Strategic Forum NHS England
Claire Foreman	Senior Service Specialist / Regional Programme of Care Lead - Cancer & Blood (London Region)	
Nicola Glover	Survivorship and Mental Health & Psychology Project Manager and AHP Lead	London Cancer Alliance
Dr Maria Gilleece	Consultant Haematologist	Department of Haematology, Faculty of Medicine and Health, University of Leeds
Catherine Howell	Chief Nurse of Patient Services	NHS Blood and Transplant
Anne Jones	Patient representative	
Michelle Kenyon	ELF post BMT Clinical Nurse Specialist	King's College Hospital NHS Foundation Trust
John Murray	Nurse Clinician BMT	The Christie NHS Foundation Trust
Helen Morris	Matron for BMT and Paediatric Haematology and Oncology	University Hospitals Bristol
Professor Vanderson Rocha	Director of Bone Marrow Transplantation and National Blood Service UK Director of Stem Cell Services	Oxford University Hospital
Tuula Rintala	BMT Quality Manager; JACIE Quality Management Committee Member	King's College Hospital NHS Foundation Trust
Dr John Snowdon	Consultant Haematologist and Honorary Reader	Department of Haematology, Sheffield Teaching Hospitals, NHS Foundation Trust
Daffydd Tavinor	Patient representative	
Dr Peter Taylor	Consultant Haematologist; Director of the Rotherham Photopheresis Unit	Rotherham Foundation NHS Trust
	Honorary Senior Clinical lecturer	Sheffield University.
Dr Robert Wynn	Consultant Paediatric Haematologist, Department of Haematology	Royal Manchester Children's Hospital

NB: Interviewees were assured that their comments would remain unattributed and were encouraged to offer their own personal opinions.

APPENDICES: ROUNDTABLE DISCUSSION GUESTS

Mark Tami MP	MP for Alyn and Deeside	
Dame Helena Shovelton DBE	Chair	2020health
Professor Charles Craddock	Consultant Haematologist	Centre for Clinical Haematology Haematology - University Hospitals Birmingham NHS Foundation Trust, and Chair of UK Stem Cell Strategic Forum
Katie Begg	Head of Policy and Government Affairs	Anthony Nolan
Gail Beer	Director of Operations	2020health
Matt James	Research Fellow	2020health
Dr Rod Skinner	Consultant in Paediatric Oncology/Bone Marrow Transplantation	Great North Children's Hospital
Professor Vanderson Rocha	Director of Bone Marrow Transplantation and National Blood Service UK Director of Stem Cell Services	Oxford University Hospital
Ann Jarvis	Acute Portfolio Director (Specialised Services) & Women and Children's Programme Director	NHS England
Jane Nunnick	Senior Haematology Research Nurse	University Hospitals Birmingham NHS Trust
Professor John Gribben	Chair of Medical Oncology	Barts Cancer Institute, Queen Mary, University of London
Dr John Snowden	Consultant Haematologist and Honorary Reader	Department of Haematology, Sheffield Teaching Hospitals NHS Foundation Trust
Dr Emma Morris	Consultant Haematologist and Senior Lecturer in Immunology and Immunotherapy	University College Hospital
Professor Mark Baker	Director of the Centre for Clinical Practice	National Institute for Health and Care Excellence
Claire Foreman	Senior Service Specialist / Regional Programme of Care Lead - Cancer & Blood (London Region)	NHS England
Michelle Kenyon	ELF post BMT Clinical Nurse Specialist	King's College Hospital NHS Foundation Trust
Nicola Glover	Survivorship and Mental Health & Psychology Project Manager and AHP Lead	London Cancer Alliance

NB: The roundtable observed the 'Chatham Rule' ("When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received,

but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed").

GLOSSARY

Allograft	A form of transplant which uses stem cells from a tissue-type matched or mismatched donor.
Autograft	A form of transplant which uses the patient's own stem cells, which are harvested prior to high-dose therapy.
BMT	Bone Marrow Transplant
100 days	A milestone used in the follow up of BMT. e.g. GVHD may be acute (developing within the first 100 days) or chronic (developing beyond 100 days)
BCSH	British Committee for Standards in Haematology
BSBMT	British Society of Blood and Marrow Transplantation
BSH	British Society for Haematology
CCG	Clinical Commissioning Group
CQUIN	Commissioning for Quality and Innovation
CRG	Clinical Reference Groups
CTC	Clinical Trials Committee
EBMT	The European Group for Blood and Marrow Transplantation
ECP	Extracorporeal photopheresis
GvHD	Graft versus Host Disease
Haploidentical Cells	These cells share half of the same genetic information and are therefore 'half-matched'
HSCT	Haematopoietic stem cell transplantation (also known as blood and marrow transplantation)
IOG	Improving Outcomes Guidance
JACIE	Joint Accreditation Committee of the International Society for Cell Therapy
MDT	Multidisciplinary team
MED-A	Minimum Essential Data

NCRN	National Cancer Research Network
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
QIPP	Quality Innovation Productivity and Prevention
RCT	Randomised Control Trial
SCG	Specialised Commissioning Group
SHCA	Society for Healthcare Consumer Advocacy
TAP	The Leukaemia and Lymphoma Research - Trials Acceleration Programme
TRP	Translational Research Partnerships
VOIP	Voice over internet protocol

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NOTES



'WE HAVE A LONG, HARD
ROAD AHEAD BUT I LOOK
TO THE DAY WHEN NO
CHILD DIES LIKE MY SON.'

Shirley Nolan, whose son Anthony inspired the world's
first bone marrow register

Katie Begg
Head of Policy & Public Affairs
Anthony Nolan
0207 284 8261
0755 786 9327
campaign@anthonymolan.org

2020health
www.2020health.org
0203 411 8615
admin@2020health.org

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NOLAN**
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