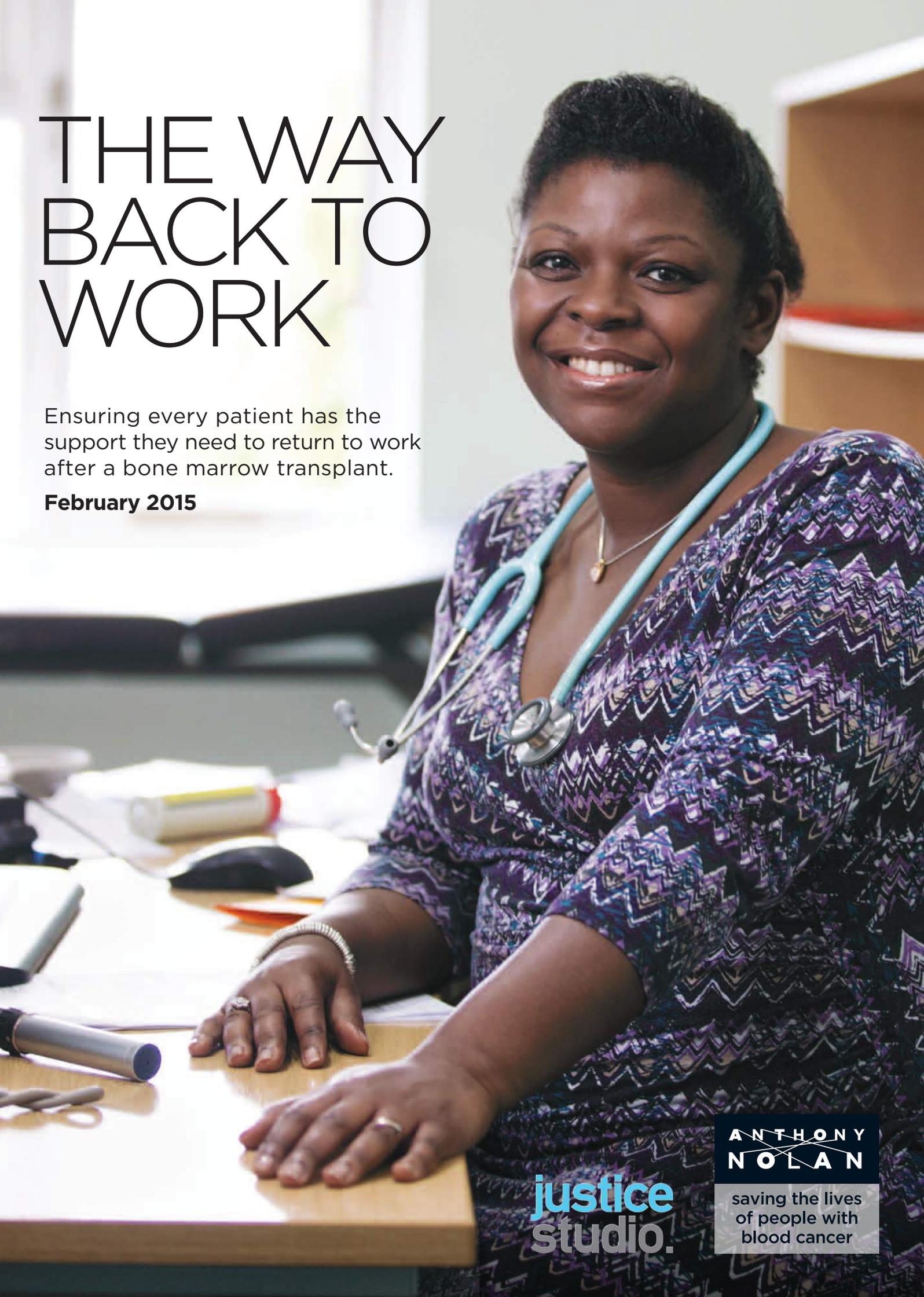


# THE WAY BACK TO WORK

Ensuring every patient has the support they need to return to work after a bone marrow transplant.

**February 2015**



justice  
studio.

~~ANTHONY  
NOLAN~~

saving the lives  
of people with  
blood cancer

# CONTENTS

FOREWORD	4
ABOUT THE AUTHORS	5
EXECUTIVE SUMMARY	6
METHODOLOGY	8
1. THE VALUE OF RETURNING TO WORK	10
CASE STUDY: AARON	11
2. CHALLENGES FACED BY TRANSPLANT PATIENTS	16
CASE STUDY: BRIAN	17
CASE STUDY: CHARLIE	23
3. ADDRESSING SUPPORT GAPS	26
CASE STUDY: DAVID	29
CONCLUSIONS AND RECOMMENDATIONS	32
APPENDIX 1: LITERATURE REVIEW SEARCH STRATEGY	33
APPENDIX 2: RATES OF RETURN TO WORK	34
ENDNOTES	35
BIBLIOGRAPHY	38

# FOREWORD

**For people with blood cancer and other blood disorders, a bone marrow or stem cell transplant may be the only chance of survival. But while a transplant offers the prospect of a cure, it's also the beginning of a long road to recovery.**

For post-transplant patients, going back to work is a key milestone in that journey. It represents a return to normality, a chance to feel useful again, and an opportunity to focus on something aside from recovery. Returning to work is a key part of an active lifestyle, and it's associated with improved general wellbeing and a higher quality of life.

Unfortunately, the journey back to employment is rarely simple for those who are dealing with the physical and psychological impact of a transplant. Our new research highlights a range of challenges that patients face upon returning to work, including fatigue, lack of concentration, and the need for sick leave – all of which can make it harder to perform their roles.

In our 2013 report, 'A Road Map for Recovery', we highlighted the complex, long-term care needs of post-transplant patients, and the unacceptable disparity in the availability of that care across England.

In that report, we made the case for recognising the return to work and an active lifestyle as key health outcomes for post-transplant patients. Ensuring that all patients have access to the right support would not only help them to make this important transition and achieve a higher quality of life, but could also deliver economic returns through future tax contributions and increased productivity.

This report picks up where 'A Road Map for Recovery' left off. It looks more closely at the challenges facing those who return to employment after their transplant, identifies the gaps in support which may prevent or prolong that transition, and proposes how we can work together to bridge these gaps.

Over a third of post-transplant patients who are not in paid work would like to be employed. We must support these people to achieve that ambition. We must do better.

As this report identifies, there should be a network of support which all patients can count on during their journey back to work. We can strengthen this network by ensuring that all late-effects services offer appropriate physical and mental support, and by supporting employers to offer flexibility and a phased return to work for those who need it.

Finally, we recognise the role that can be played by third-sector organisations like us in providing the information and guidance that patients, their families and employers need. In this respect, Anthony Nolan will continue to develop the existing support we offer at every stage of the transplant journey.



**Henny Braund**  
Chief Executive, Anthony Nolan

# ABOUT THE AUTHORS

## **Marianne Moore**

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Marianne is a consultant specialising in qualitative research, strategy, project management and design. Marianne has vast experience working for bilateral bodies such as UNICEF and the Council of Europe, central and local government, charities and not-for-profits. She has an MSc from Cass Business School, an MA from the University of Middlesex, and her first degree was from Oxford University.

## **Anita Mehay**

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Anita is an experienced health researcher with varied experience across academic institutions, government organisations and the third sector. She has developed her expertise in conducting robust mixed-methods research, with a particular interest in health inequalities that exist between groups as well as between conditions. She has published work in academic peer review journals and health-professional magazines, and currently holds academic advisory roles within NHS England and the London Mayor's Office.

## **Justice Studio**

Justice Studio is a UK-based, young and dynamic consultancy and research organisation. They provide intelligence services to enable governments, charities, and not-for-profit organisations better promote social justice. They seek to work efficiently, effectively and ethically.

[justicestudio.org](http://justicestudio.org)

## **Anthony Nolan**

Every day, Anthony Nolan matches incredible individuals willing to donate their blood stem cells or bone marrow to people with blood cancer and blood disorders who desperately need lifesaving transplants.

It all began in 1974. With her three-year-old son Anthony hoping to find a bone marrow transplant, Shirley Nolan set up the world's first register to match donors with the people who needed them. Now the charity helps three people find that lifesaving match every single day, while conducting world-class research into stem cell matching and transplants to ensure that every person gets the best possible treatment.

[anthonymolan.org](http://anthonymolan.org)

# EXECUTIVE SUMMARY

## WHY IS RETURNING TO WORK IMPORTANT?

Returning to work helps bone marrow transplant (BMT) patients feel normal again, and is an important part of getting back to reality for many of them. Patients, their family members, and their employers have all explained that returning to work was an important milestone and helped with their recovery. Respondents who were in paid work at the time of the survey demonstrated improved wellbeing, a higher health-related quality of life and better health in general.

Returning to work is linked with patient survival, long-term success of the transplant, and successful engraftment. Of the 87% of survey respondents who were in paid work before their transplant, significantly fewer (46%) were in paid work at the time of the survey, giving an overall return-to-work rate of 50.5%.

However, we found that patients who had their transplant more than one year before the survey were significantly more likely to have been able to return to work; 56.8% were in paid employment, compared to 18.2% of patients who'd had their transplant in the past year. Those most likely to return to work were younger and had a higher level of education.

## WHAT CHALLENGES DO TRANSPLANT PATIENTS FACE?

Bone marrow transplantation is a demanding treatment. The majority of survey respondents had received a transplant from an unrelated donor, and all of the respondents experienced at least one side effect after their transplant. Fatigue, Graft versus Host Disease (GvHD) and nausea or vomiting were the most commonly cited.

Although the financial implications were given as one of the main reasons for returning to work, the majority of patients told us that it had always been their intention to return.

However, patients differed in their confidence and ability to negotiate the terms of their return with their employers. Just over half of our respondents in paid work reported a change in their role. Returning to work was not easy; those who returned to work had difficulties in their physical capabilities, had to take sick days, and felt pressure to perform as they used to.

Qualitative aspects of our research suggest that returning to work full-time is a bigger jump from initial part-time work than most patients, their family members, and their employers realise.

## ADDRESSING SUPPORT GAPS

Support provided by an employer, such as a phased return to work, was rated by post-transplant patients as the most beneficial type of support. Patients, family members and employers also gave us a number of suggestions for additional support that might be required when someone returns to work:

- Information and guidance: More information for patients, family members and employers about what to expect
- An advocate or intermediary: An impartial third party to aid communication between employer and employee
- Social and emotional support: Support from a knowledgeable advisor, professional emotional support, and the ability to communicate with others with a similar background.

## CONCLUSION AND RECOMMENDATIONS

Returning to work after a transplant is both an indicator of successful recovery, and can also aid the process of ongoing recovery for patients. Its importance is beneficial to the patient psychologically, socially and often financially.

However, returning to work for patients is a difficult process, and one that is rarely as straightforward as they, their family members,

or their employers expect. Once a patient has returned to work initially, returning to work full-time is another milestone that takes longer to achieve. Some patients may never go back to working at the same levels as they did before their transplant.

In general, there appear to be significant gaps in the support and information available to patients when they're returning to work, and addressing these gaps is likely to significantly improve the transition. In line with the 'A Road Map for Recovery' report, our findings support the conclusion that returning to work and an active lifestyle should be recognised as a key health outcome for transplant patients where appropriate.

To strengthen the network of support for patients during the transition back to work, we recommend the following:

**NHS England** should ensure that all BMT patients have access to a high-quality late-effects service, which includes rehabilitation and psychological support.

**Employers** should:

- Ensure they have adequate insurance policies in place to cover long-term absences
- Offer employees a phased transition back to work and an open environment to determine an appropriate workload, what kind of support may be required, and a timetable for return.

**Anthony Nolan** should develop research, materials and services which provide information and support for BMT patients and their employers about the transition back to work.

# METHODOLOGY

## THE PROJECT

In 'A Road Map for Recovery', Anthony Nolan identified that returning to work was a key health outcome for bone marrow transplant (BMT) patients.<sup>1</sup> However, there was no data or research available in the UK to understand this indicator within the context of the transplant and recovery process. To gain further insight, Anthony Nolan commissioned Justice Studio to undertake research into patients' experiences of returning to work post-transplant.

The aims of the research were:

- To explore in more detail the importance of returning to work as a key health outcome for patients, as recommended in the 'A Road Map for Recovery' report
- To provide insight into the challenges that BMT patients experience post-transplant
- To collect evidence to inform the services that Anthony Nolan provides for BMT patients.

## EXISTING LITERATURE AND LIMITATIONS

The existing literature on return to work for cancer patients highlighted a number of gaps which underlined the need for further research. In particular, it was found that:

- There is a general lack of research and insights into the factors associated with return to work<sup>2</sup>
- Very few studies have explored interventions that aim to support return to work
- People from low socio-economic backgrounds are underrepresented in the studies, with most samples including high numbers of educated and high income participants
- Out of 33 studies of cancer patients' experiences, only one was conducted in the UK.

Furthermore, inconsistencies within the existing research made it difficult to highlight specific factors that are associated with BMT patients.<sup>3</sup>

## RESEARCH METHODOLOGY

Our research was conducted between September and December 2014, and used a number of methods, including:

- A review of the available literature
- A survey of 121 people
- A focus group with patients who had recovered from a transplant
- Telephone interviews with those who had returned to work, a close family member and their employer.

### Literature review

A literature review was conducted to explore the current published research into return to work in BMT patients. The aim was to highlight the return-to-work rate in this group and key themes relating to return to work, and to identify the research gaps.

We then carried out a rapid review of the evidence to explore the literature systematically. Search terms were agreed with the team at Anthony Nolan, and searches across the main health research databases were conducted (see Appendix I for the complete strategy). We then deduplicated search results and applied new limits to reduce the number of irrelevant hits (e.g. results were limited to English-only language). A single researcher scanned the remaining articles to judge their relevance to this study. Relevance was judged by whether the research was empirical and made specific reference to return to work. A final 33 research papers were identified.

### Survey

The survey was designed to explore the experiences of transplant patients in returning to work. It was designed from our findings from the literature review, in conjunction with the team at Anthony Nolan. A draft survey was piloted with several members of the Patient and Family Panel at Anthony Nolan, and their feedback was incorporated into the final survey.

The survey was active from 25 September until 25 November 2014 (nine weeks). It was distributed online (via SmartSurvey) to reach a broad sample, and a link to the online survey was shared among the Anthony Nolan transplant community, social media, and Patient and Family Panel, as well as via other relevant stakeholders such as Leukaemia and Lymphoma Research. A paper survey was also distributed at transplant clinics for patients to complete and return. Prior agreement to distribute the survey within the clinics was obtained.

There were a total of 121 completed full survey responses. Respondents were largely White British, educated and married. There was an even gender split, and a broad range of age groups (mostly between 35 – 64 years old). Although most respondents were educated, 39% had school-level education or below.

Survey results were analysed in a statistical software package (IBM SPSS (Version 22)). The data was initially explored by analysing the different survey responses and examining any associations and differences between the answers. The data was analysed using statistical tests, including chi-squared tests (for categorised data) and t tests (for numerical data).

### **Focus groups**

One focus group was held with patients who indicated their availability on the survey. There were four focus group participants aged between 28 and 62; three men and one woman who'd had their transplants between 205 days and 8 years previously. Three of the participants had received a stem cell transplant from an unrelated donor, and one had received a transplant from a related donor. The patients were from a predominantly professional background: one chief executive, one production journalist, one student, and one recruitment manager.

### **Telephone interviews and case studies**

In order to collect sufficient qualitative information for case studies, we aimed to undertake telephone interviews with five patients, and for each patient, a family member, and an employer – a total of 15 telephone interviews. However, one employer was unable to participate and therefore only four complete sets of patient, family member and employer were conducted. These four interview sets were analysed and summarised into a case study of patients' experiences of returning to work.

The remaining two interviews of the patient and their family member were analysed alongside the focus group findings. We asked each of the case-study patients three general questions regarding support in returning to work. Their responses were also analysed, along with all of the other focus group and interview data.

### **Triangulation**

We analysed the qualitative data using an approach similar to Glaser & Strauss (1967); after an initial reading of the interview and focus group transcripts, themes were identified and drawn. Once the quantitative and qualitative data had been analysed, we triangulated the results which are presented in this report.

# 1. THE VALUE OF RETURNING TO WORK

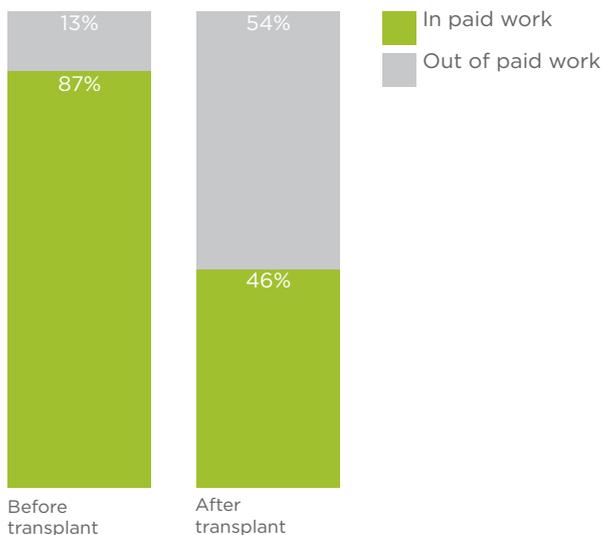
**Existing research showed that returning to work is linked with patient survival, engraftment and success of the transplant.<sup>4</sup>**

Of the 87% (n=105) of survey respondents who had been in paid work before their transplant, 50.5% had returned to work at the time of the survey. The rate increased with time elapsed since their transplant. In our research, transplant patients who returned to work said it was an important part of helping them to feel 'normal' and our survey found that those who had returned to work scored higher on health and wellbeing scales.

## RETURNING TO PAID WORK

Of the 121 survey respondents, 105 (87%) stated that they had been in paid work<sup>5</sup> before their transplant. Fewer respondents reported that they were currently in paid employment at the time of the survey, with 56 (46%) in any paid work (p=0.03). Of the 56 who were currently in paid work, 53 had previously been in paid work before their transplant, reflecting a 50.5% 'return-to-work' rate.

### PAID WORK



### OUR SURVEY FOUND THE FOLLOWING RETURN-TO-WORK RATES

	In paid work	Not in paid work
<One year	18%	82%
One-three years	54%	46%
Three years +	60%	40%
Overall	51%	49%

The return-to-work rate within one year of a bone marrow transplant (18%) is considerably lower when compared to a Finnish study, which found that 66% of patients were back at work.<sup>6</sup> Furthermore, our return-to-work rate in patients within one to three years post-transplant (54%) was far lower than what has been reported in other international studies; the same Finnish study found rates of 76% and 74% for one and two years post-transplant respectively,<sup>7</sup> and an Australian study found a return-to-work rate of 70% for two years post-transplant.<sup>8,9</sup>

These differences might be due to different sample characteristics, such as a range of ages, types of treatments, or diagnosis. Alternatively, they could be the product of societal differences, such as access to financial support. However, the significant differences in return-to-work rates highlight the need to ensure that people having bone marrow transplants in the UK receive the same support and opportunities in returning to work as in other countries.

Additionally, the return-to-work rates in our respondents were much lower when compared to a study in the Netherlands on people who have received other types of organ transplants and treatments for cancer:

### RETURN-TO-WORK RATES, ONE TO THREE YEARS AFTER TRANSPLANT<sup>10</sup>

Our respondents	54%
All cancers combined	69%
Lung cancer	41%
Genital cancer	85%
Skin cancer	68%
Blood malignancies	68%

This further highlights the long-term impact of bone marrow transplants on returning to work, which is specific to this type of transplant. This also stresses the importance of further research with this specific patient group.

## CASE STUDY

‘Everyone had to let Aaron set his own pace. He’s increased his engagement and people are increasingly able to rely on him. So everyone is pretty comfortable.’

Aaron’s employer

# AARON

**Time since transplant:** 16 months

**Type of transplant:** Donor stem cell transplant

Aaron was working as a marketing manager when he was diagnosed with cancer for a second time. Despite protracted time off work, they were able to cover his salary for the entire three years, because his company had insurance in place for critical illness.

Aaron’s wife said, ‘I was still working full-time when he was having his transplant. So I was going to work then going to the hospital until late, then coming home and doing the washing.’

Once he was feeling well enough to work, Aaron got in touch with his employers, and it was agreed that a new role would be created for him with a reduced workload to keep the pressure off.

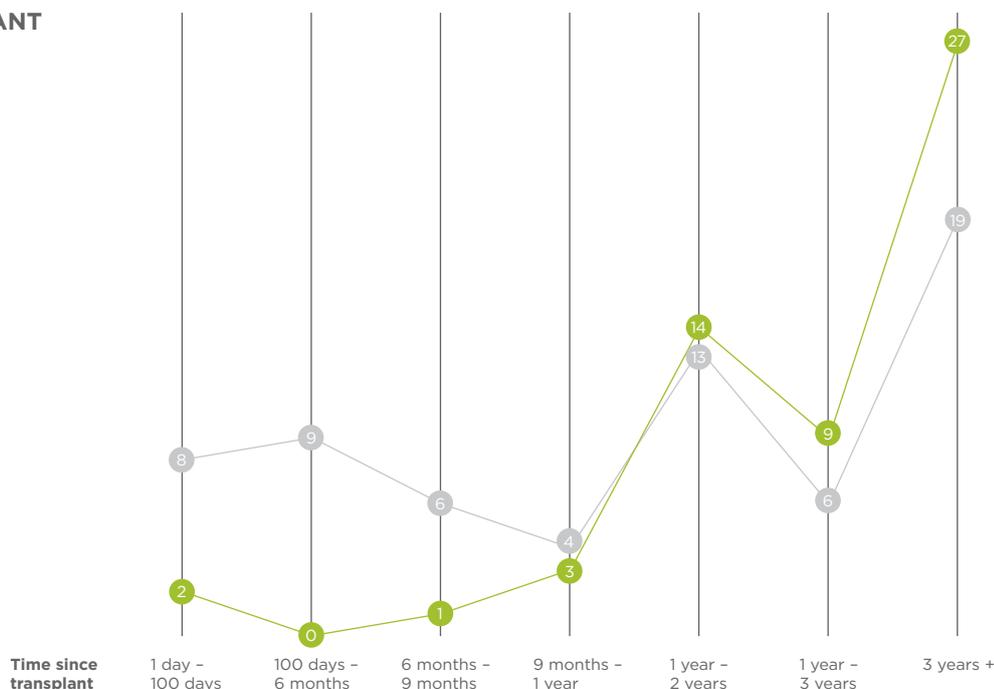
Aaron felt ‘excited and also apprehensive – I was excited about the prospect of getting back to normal life and exercising the grey matter again. I’d been in hospital for unbelievably long periods of time; it was pretty depressing and boring. But I was nervous about whether I’d still like the work and be able to make a contribution.’

To begin with, Aaron was very tired. ‘I started off doing two half-days a week when I first went back, and I’m now at two full days a week. I had a lot of hospital appointments, but they’re thinning out now so I think four days will be possible, and then [in a few months time] I’m hoping I should be back at work full-time.’

Aaron feels lucky to have had such a supportive employer. ‘Returning to the workforce has been extremely straightforward and enjoyable. I haven’t lost my old verve and passion for the role. And I haven’t lost my analytic capabilities. I found that a long period of therapy addled your mind a little bit. You don’t know if your mind will serve you afterwards.’

## TIME SINCE TRANSPLANT AND BEING IN WORK

- In paid work
- Out of paid work



## WHO RETURNS TO WORK

The factors associated with return to work in bone marrow transplant patients are broadly similar to experiences in other cancer patients.<sup>11</sup> However, studies report that among cancer survivors, those with haematological malignancies are among those at the greatest risk of delayed return to work, unemployment, reduced working ability and early retirement.<sup>12</sup>

One study into the work experiences of male cancers (prostate, testicular, lymphoma) found that post-treatment employment experiences varied considerably by cancer type. The study demonstrated that those with prostate or lymphoma cancers were less likely to be employed and specifically, that those with lymphoma were less likely to report work as an enjoyable place to be.<sup>13</sup>

Results from our survey highlighted that the factors associated with those most likely to return to work are:

- **Being younger:** Those who were younger were more likely to be in paid work following their transplant ( $p=0.001$ ). Some studies also found an association between higher age at transplant and a lower return-to-work rate.<sup>14</sup> One study found that allogeneic transplant patients in their 50s and autologous transplant patients in their 40s or 50s had lower rates of returning to work.<sup>15</sup> Later age was also associated with early retirement.<sup>16</sup> Some studies found no association between age and return to work.<sup>17</sup>

- **Having a higher level of education:** Those in paid employment at the time of the survey were more likely to have received a higher level of education ( $p=0.056$ ). Other studies also found low educational level at diagnosis was associated with decreased rates of return to work.<sup>18</sup> Low education and low income were also associated with early retirement.<sup>19</sup> However, income and educational level before diagnosis did not seem to be predictors of return to work in two studies.<sup>20</sup>
- **Time since transplant:** Those who had received the transplant longer ago were more likely to be in paid work ( $p=0.007$ ).

Being in paid work at the time of the survey did not differ significantly by gender, marital status or prior income in our study. However, other studies have found that being female was associated with a delayed time in returning to work,<sup>21</sup> and females were 50% less likely to return to work overall.<sup>22</sup> Being female was also associated with working part-time.<sup>23</sup> In terms of marital status, one study found that marital status did not predict time to return to work.<sup>24</sup> However, another study found a lower return-to-work rate in allogeneic transplant patients who had a partner.<sup>25</sup>

In a cohort study of 281 patients who had received an allogeneic or autologous transplant, neither diagnosis nor treatment type predicted time to return to work during a five-year follow-up period<sup>26</sup>.

'Going back to work means returning to your 'home group'. It meant returning to the camaraderie of people I've worked alongside for many years.'

**Crispin**, stem cell recipient and Post Office worker



'The whole treatment and the way you are handled is not normal and you're always trying to get back to doing what you did before.'

However, other studies suggest that patients who have received an allogeneic transplant experience more problems returning to work than autologous patients<sup>27</sup> and that those with lymphoma are less likely to be working on follow-up when compared with other germ cell cancers.<sup>28</sup> Those currently receiving therapy and treatment also have lower return-to-work rates.<sup>29</sup>

The challenges facing post-transplant patients are discussed in further detail in section 2.

## WELLBEING AND HEALTH-RELATED QUALITY OF LIFE

Survey respondents who were in paid work at the time of the survey demonstrated improved wellbeing compared with those not in paid work.<sup>30</sup>

Being in paid work at the time of the survey was also associated with four of the five domains of health-related quality of life when compared with those not in paid work (as measured by the EQ5D), including: Mobility (p=0.000), Self-care (p=0.001), Performing usual activities (p=0.000), Pain/Discomfort (p=0.000). Being in paid work was not associated with self-reported anxiety or depression. However, this might be due to the reluctance to reveal any anxiety or depression through a survey format. Being in paid work at the time of the survey was also associated with a higher self-reported general health (p=0.01).

These outcomes corroborate the findings from other cancer studies, where employment was significantly associated with quality of life. Specifically, among transplant patients from a Swiss cohort who were fully employed, 73% reported a good quality of life, as opposed to 22% of those on disability insurance and 28% of those on part-time work.<sup>31</sup> Other studies also demonstrate the association between greater financial and work stress on quality of life<sup>32</sup> and functioning status, particularly in those patients who have had a transplant from an unrelated donor.<sup>33</sup>

## FEELING 'NORMAL'

Returning to work helps patients to feel 'normal' again. A return to work and normality was identified by patients as a key concern (after physical symptoms and survival) in the wider cancer literature.<sup>34</sup> Similarly, our cohort consistently cited the need for a 'return to normality'<sup>35</sup> and 'getting back to reality'.<sup>36</sup> One patient said, 'The whole treatment and the way you are handled is not normal and you're always trying to get back to doing what you did before.'<sup>37</sup>

Others said that returning to work was an important 'milestone' and helped with recovery itself.<sup>38</sup>

One patient told us, 'It helps to keep your mind focused on the recovery, so that helps in the transplant and the recovery, particularly if you are facing off-days. Back in the workplace, it gives me key things - it helps me to get the brain matter working again and gets me back into a working way of life. Additionally I've been able to test myself to see if I still enjoy the work and if I can still do the work.'<sup>39</sup>

Working provided patients with a distraction and a different focus away from the medical world of the transplant. One patient said, 'When you're back at work there is a lot more going on with other people and distractions so there is another focus to your life which is not cancer.'<sup>40</sup> Another agreed that it 'gives you a focus and a means for getting on with your life.'<sup>41</sup>

Patients' family members also felt that returning to work helped the patient to recover, and feel more confident and normal. One mother of a patient explained how returning to work had helped her son mentally; 'he is starting to get his confidence back - he got very low.'<sup>42</sup> Another patient's wife said that 'it got him interacting with people out of the house and got him thinking about things again, and I think that really helped.'<sup>43</sup>

Although the employers interviewed felt that returning to work was an important part of recovery, they were less clear that it was entirely positive.

‘Having been off sick for so long, I was reluctant to take further sick leave because I didn’t want any adverse conclusions to be drawn about the fact that I was sick again.’

One employer said, ‘On the times when he (the patient) wasn’t able to work, he felt he was letting us down or that he was obliged to do the work, when really his recovery was the most important thing.’<sup>44</sup>

Other employers were more at ease with the ongoing situation. One told us, ‘The process of getting back to work allows individuals to achieve a sense of closure on an illness. If you’ve been out of work for a long time you probably feel very detached from the workplace. So reattaching yourself to friends, family and work can only be a good thing as long as the balance is right and everyone is comfortable.’<sup>45</sup>

There appear to be greater negative mental and physical issues for those who are not working following a transplant. The impact of not working had a big psychological impact on some patients.

One interviewee told us that ‘without work, depression was a massive problem...I think also that when you are going through a transplant it is very easy to get bored, and that’s when depression does hit you. In the times in between hospital and being alone, there is nothing to do’.<sup>46</sup> In turn, those survey respondents who were not in paid work were more likely to report experiencing joint and muscle pain ( $p=0.01$ ) and difficulty eating or weight loss ( $p=0.02$ ).

# 2. CHALLENGES FACED BY TRANSPLANT PATIENTS

Existing research has shown that returning to work is difficult for transplant patients.<sup>47</sup> Experiencing a transplant and pre-transplant conditioning therapy, which includes chemotherapy and sometimes radiotherapy, is an extremely difficult process.

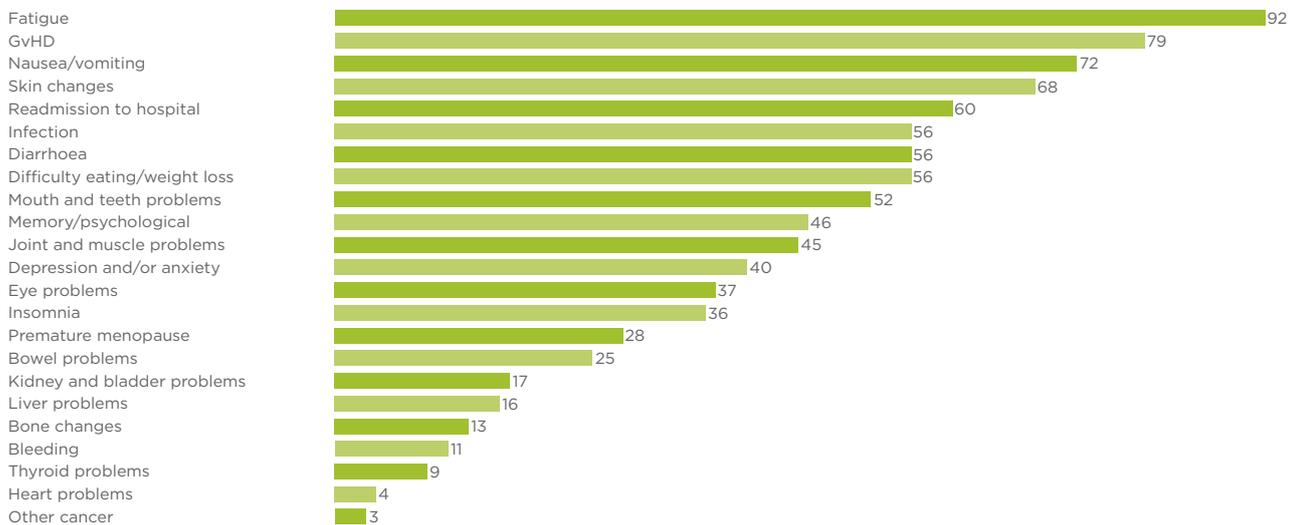
The long and short-term effects of these treatments can greatly alter the lifestyle of the patient, even for those who do return to work; a third of patients in one study reported that they were not able to do as much as before their diagnosis.<sup>48</sup> Loss of income from work, together with other mental and physical factors associated with illness, can make life difficult for patients and their families. Under these circumstances, returning to work is not always a viable option.

## TRANSPLANT AND SIDE EFFECTS

Being diagnosed with cancer can affect every aspect of a person's life, including their ability to work. Bone marrow transplantation is a demanding treatment, and it's associated with enduring physical and psychological complications. The majority of survey respondents received a transplant from an unrelated donor, and nearly three quarters (72%) were one year or more post-transplant at the time of completing the survey.

All of the survey respondents experienced at least one side effect after their transplant. Fatigue, GvHD and nausea/vomiting were the most commonly-reported side effects.

### SIDE-EFFECTS EXPERIENCED AFTER TRANSPLANT



‘Sometimes I would take something on, then fall ill that afternoon and not be able to do it.’

# BRIAN

**Time since transplant:** Over three years  
**Type of transplant:** Bone marrow from an unrelated donor

Until the age of 33, Brian was operations manager at a company in the North-East. Then he was told he wouldn't see the year out unless he had a bone marrow transplant.

Initially he expected to be back to work after a year. However, soon after he received his transplant, his company went into administration.

‘I was going through the second round of chemo and I got a call to say I'd lost my job as well.’ The family struggled. They were not able to access help from a major cancer charity because of the rarity of Brian's illness; in the meantime, he was only receiving minimum government allowances.

Brian's mum told us, ‘We felt so alone – and he was in a bad way mentally, as well, because he felt useless.’

At first, returning to work was impossible to consider ‘because there wasn't anywhere to go or even anyone to discuss it with’. Soon Brian became depressed. Although he felt ‘stale and bored’, and wanted to work, ‘it was difficult because I kept getting infections and I had to spend months on end in hospital.’

Then a friend contacted Brian, offering him part-time work. The arrangement wasn't without difficulty.

As Brian began to feel better, he started looking for something more permanent. Returning to full-time work, however, was a big step.

He told us, ‘I used to be a fairly outgoing person, but over the last few years, and after having to spend so much time in isolation, I lost all my confidence. Every little bit of it had been drained out of me.’

Nevertheless, Brian feels that returning to work has ‘just been brilliant. It's allowed me to build my confidence up again; it's made a massive difference to me and my health. I'm still not the person I was – I'm not sure if I ever will be. But it's an awful lot better than it was.’

'I am lucky my wife has a decent salary. When my sick pay ran out, our lifestyle had to change a little so I couldn't do everything I normally do, but then I wasn't doing those things anyway.'

There were no significant associations between the number of side effects experienced with the type of transplant received, or with the time since receiving a transplant. However, GvHD and fatigue were more likely to be reported in those who had the transplant longer ago (p=0.03 and p=0.04, respectively). No other side effects were associated with the length of time since the transplant.

### FINANCIAL STABILITY

Patients had a wide variety of experiences in terms of the financial support they had while unable to work. Whereas one focus group respondent found his household income was unaffected,<sup>49</sup> another described himself as being 'completely broke'.<sup>50</sup>

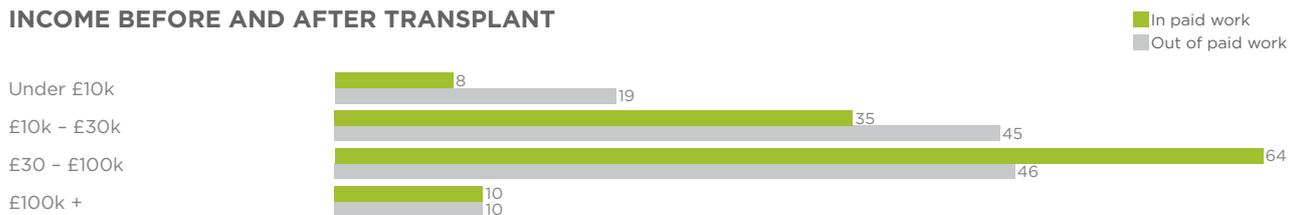
One patient said, 'I am lucky my wife has a decent salary. When my sick pay ran out, our lifestyle had to change a little so I couldn't do everything I normally do, but then I wasn't doing those things anyway.'<sup>51</sup>

In general, there appears to be a lack of knowledge about benefit entitlements. The majority of patients interviewed stated that they received very little information about returning to work or accessing benefits while they were in hospital.

One patient said, 'I applied for some benefits, including ESA (Employment and Support Allowance) and PIP (Personal Independence Payment), which gave me an extra allowance and helped a little. But this took 26 weeks to process and the form is really long and drawn out. I didn't realise I needed to apply well before my sick pay ran out. Finance was part of the reason for going back - I feel guilty for relying on my wife's income and I wanted to go back to work for myself. I got sick pay for six months full-time in total. My parents helped financially too.'<sup>52</sup>

The survey respondents reported significantly lower income levels at the time of the survey compared to what they were earning before their transplant (p=0.000); this may be due to changes in their work roles, or because they were working part-time.

### INCOME BEFORE AND AFTER TRANSPLANT



'It's difficult to connect with other people because I've been kept in isolation. You lose that connection of being able to talk to people.'

## FACTORS IMPACTING ABILITY TO WORK

Those respondents who were in paid employment at the time of the survey (n=52) reported a range of difficulties in returning to work. Most said that they'd felt tired and had difficulty with their concentration. However, most respondents felt confident about their ability to do the work and felt that colleagues understood them.

### Physical difficulties

The patients in the focus group reported that they had problems with fatigue, and 'concentration and memory'.<sup>53</sup> One interviewee explained that, 'because of the high dose of chemotherapy and the total body radiation I had four fractures in my back – you then feel that throughout the day. Mentally, every day is a struggle. Every day you do something – something will crop up in the back of your mind – you do feel differently about everything. Sometimes they say it's getting better now, but it's difficult to connect with other people because I've been kept in isolation. You lose that connection of being able to talk to people.'<sup>54</sup>

The literature also suggests the significance of fatigue, which is associated with impaired functioning and impacts return to work.<sup>55</sup> Poorer general health and having multiple morbidities also impacts return to work,<sup>56</sup> as does the development of GvHD<sup>57</sup> and cognitive difficulties.<sup>58</sup>

Employers felt that having a better understanding of the physiological impact of the transplant would help. For example, one employer said, 'More understanding of what the

physical constraints might have been' would have been useful, because 'if someone could have said that he (the patient) wouldn't be able to do this, it would have helped us to plan.'<sup>59</sup>

### Sick leave

Although other research has found that there was no difference in the number of sickness days in those with blood malignancies when compared to other cancers,<sup>60</sup> having to take sick leave was a continuous difficulty for transplant patients returning to work in our research. Some felt more able than others to take days off.

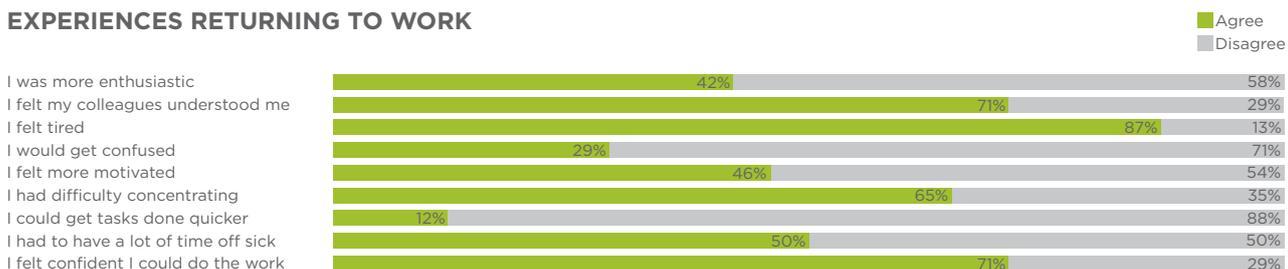
One patient said, 'Concentration and tiredness were the two main factors that I struggled with. I'd lost an enormous amount of weight during the transplant so I was quite fragile, and because of the transplant process I picked up illnesses quite easily.'<sup>61</sup>

The unexpected need for sick leave could make things difficult for employers. As one employer explained, he was left in a difficult position with his clients when the patient could not finish work due to being sick.<sup>62</sup>

### Pressure

Many patients felt pressure to perform well on their return to work. One focus group participant said, 'I will do a staggered return and will see how it goes. I get the impression that others don't realise you are still ill and I feel that pressure. I feel my employer doesn't understand... It's difficult for me, as I wanted a different job and a promotion, so I feel the pressure to impress.'<sup>63</sup> However, another participant told us, 'I can take time off when I need for my depression... [my] employer has been very positive.'<sup>64</sup>

## EXPERIENCES RETURNING TO WORK



'My colleagues were very protective of me. They made sure they didn't overload me and kept checking I was OK. All the way through from the doctors to the receptionist they all looked after me.'

**Chantel**, stem cell recipient and GP



## THE PROCESS OF RETURNING TO WORK

### Motivations

The majority of survey respondents who were currently in paid work stated that it had always been their intention to return to work. Financial difficulties were one of the main reasons for returning to work (n=24, 36%) and being the only breadwinner was a factor for 16% (n=9) of respondents.

Wellbeing, the sense that work was an important part of one's identity, and the fear that they would be bored were other important reasons patients cited for working after transplant. This was similar to focus group reports.

One patient told us, 'I was desperate to go back because I had been cooped up at home, and because of the nature of the treatment being restricted in terms of what I can do - I wanted to get on with my life. Also, the financial implications were starting to show, because I was starting to get better and do more things and I wasn't earning anything.'<sup>65</sup>

An additional reason mentioned by a focus group participant was concern about his career. He said that he was worried about having gaps in his CV which could reflect negatively when competing with someone else for a position.<sup>66</sup>

### Returning to work initially

Although other research shows that the majority of transplant patients return to work and normal activities after the first year of transplant,<sup>67</sup> our qualitative research suggests

that there is a big difference between returning to work initially and returning to work full-time.

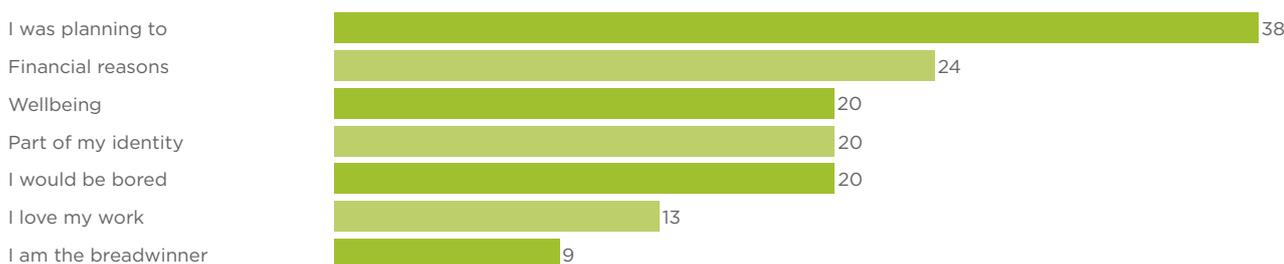
The law requires employers to make reasonable adjustments to ensure patients are not disadvantaged in the workplace. This includes allowing for sick leave, a phased return to work, allowing flexible working hours, and changing job descriptions to remove tasks that are difficult.

Some patients felt more confident than others about negotiating with their employers. One focus group participant explained how before his transplant he had felt frustrated in his role and wanted more opportunities. However, now that he was returning, he felt he could not make the same demands or ask for more as his employers had been supportive and generous during his illness.

He was concerned, because his working life had been fast-paced with short deadlines and required lots of concentration. Now he found himself wanting to have a less intense role due to his fatigue; however, he did not feel as if he was in a strong negotiating position. He felt he owed his employers for their loyalty.<sup>68</sup>

When embarking on the transition back to work, patients' confidence in being able to explain to their employers what they can and cannot do differs dramatically. For example, one focus group participant explained how he 'had a back-to-work interview to discuss what I can and can't do. I wanted to tell them that my concentration isn't that great but I didn't feel able to tell them.'<sup>69</sup>

## REASONS FOR WORKING AFTER TRANSPLANT



'I was trying to avoid the trains at rush hour – so they were really accommodating. I just changed my working hours slightly to allow me to go on a different train, and it took me some time to be able to cope with getting back to work again.'

Another patient said, 'I would be willing to tell my employer and make sure the law and policies are being adhered to. I straight away went to my employer and told them my needs. But it might be different as I was in a new role rather than going back.'<sup>70</sup>

Patients needed to be aware of certain practicalities as well. One interviewee explained how 'I was trying to avoid the trains at rush hour – so they were really accommodating. I just changed my working hours slightly to allow me to go on a different train, and it took me some time to be able to cope with getting back to work again.'

### **Returning to work full-time**

Returning to work full-time is a bigger jump than most patients realise. Those interviewed consistently reported surprise at the length of time it took them to return to work full-time as opposed to part-time. This was echoed by the loved ones of patients, as well as the employers themselves.

One focus group patient had a speedy return to work with a total of seven months off, and just 6-7 weeks before she was working full-time. However, this experience was at the extreme end of the spectrum, and it was not without its issues. She explained that 'people assume you are 100% well again. There is limited empathy, especially as you look and sound and say the same things as before.'<sup>71</sup>

Similarly, one interviewee explained that going back to full hours 'was actually very difficult' and this was compounded by the fact that she didn't realise that she could have asked for more of a phased return to work. Because she was unaware of her rights, she felt compelled to go back and pretend she was healthier than she actually was.'<sup>72</sup>

## CASE STUDY

'It's so frustrating for a young person. They have a lot to give but they also want job satisfaction – even if they can't do as much as before.'

Charlie's mum

# CHARLIE

**Time since transplant:** Four years

**Type of transplant:** A non-related donor with a 10 out of 10 match

Charlie was working for a large accountancy firm when he was diagnosed with blood cancer. He'd be away from work for the next 21 months.

Financially, Charlie was fine. His firm kept him on full pay, and 'I had my own critical illness policy which paid me a lump sum.' However, he found it difficult being physically unable.

He told us, 'It took me six months to be able to walk a mile. Over the next six months I began to feel stronger, and then... I felt better and I felt bored. So I started talks with my employer.'

The key to Charlie's return to work was a change in his role. Previously, he'd been working with clients, to schedules that were unpredictable and sometimes stressful. His employer began planning with him to create a new role revolving around training and coaching.

There were challenges on both sides; Charlie found some of his new duties boring, while his company had to plan around an employee who had to keep taking time off work.

During Charlie's gradual return to work, his lack of energy surprised and frustrated him. 'When I first went back to work – for two hours, three times a week – I found it exhausting. My colleagues used to spot that I was tired and they'd send me home.' More than once, he pushed himself too hard and fell ill.

As a result, he's come to terms with how much he can handle. 'Earlier this year I went up to five days a week and my body said no. I almost had to leave the firm, but then I went back to four days a week, and I'm much more comfortable with that.'

‘Now I would like to work in the third sector... But it is hard to change jobs, as how and when do you reveal your illness?’

## CHANGES IN ROLE AND DUTIES

Just over half (n=27)<sup>73</sup> of our survey respondents who were in paid work reported that there was a change in their role or duties when they did return to work.

The majority of our interviewees also described having to change their role or duties when they returned to work. One focus-group patient described having to change his entire career path as the result of his illness. Prior to his transplant he’d been planning to train as a nurse. However, because of his weakened immune system, the physical demands of the work and the shift patterns, he felt that it would be too difficult for him.<sup>74</sup>

Another focus group participant said, ‘Now I would like to work in the third sector... But it is hard to change jobs, as how and when do you reveal your illness?’<sup>75</sup>

Other studies have similarly found that cancer patients are likely to change roles following their treatment. A large longitudinal cohort study found that 30% of patients with lymphoma changed employers after cancer treatment, with a quarter of those stating that this was due to their cancer, the physical demands of the role, and the overall lack of support received from health professionals and employers.<sup>76</sup>

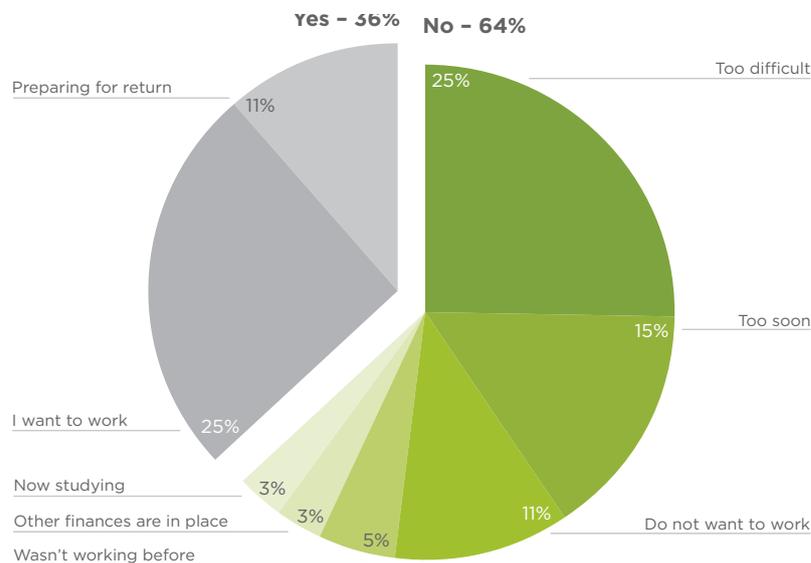
Patients who reported a good climate at work and a commitment to the organisation largely reported less impairment.<sup>77</sup> A large Scandinavian study reported higher rates of changing employers due to their diagnosis of lymphoma (25%) when compared with testicular and prostate cancer (20% and 10%, respectively).<sup>78</sup> Blood cancer (along with brain and CNS, lung, and liver cancer) was a significant predictor of early job loss or delayed re-employment in a Korean cohort when compared to all cancers.<sup>79</sup>

## REASONS FOR NOT RETURNING TO WORK

In the wider cancer literature, not being able to perform work duties, the time and travel required for ongoing treatment and monitoring, and being a burden on caregivers and exposure in the workplace were all reasons identified for not returning to work.<sup>80</sup>

22% of our survey respondents who weren’t in paid work at the time of the survey had previously tried to work.<sup>81</sup> Additionally, most of those who were not in paid work stated that they would not like to be working now, as they felt it was too difficult and too soon.

## WOULD YOU LIKE TO BE WORKING NOW?



**Factors associated with not returning to work**

The literature suggests that being female,<sup>82</sup> being older<sup>83</sup> and having a lower level of education and lower income prior to transplant may be associated with a delayed return to work.<sup>84</sup> Our survey supported the literature findings; being older (p=0.001) and having a lower level of education (p=0.05) were both associated with not working. In addition, the literature suggests that not returning to work is associated with having a transplant from an unrelated donor,<sup>85</sup> but our survey found no difference in transplant type and return to work.

**Early retirement**

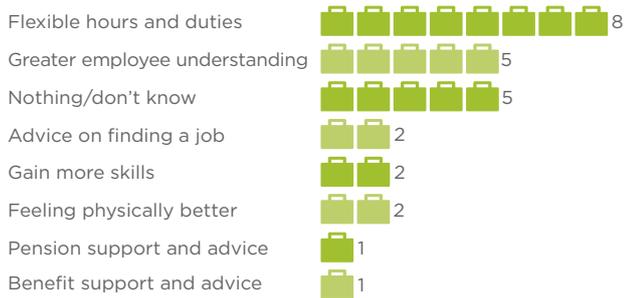
The wider cancer literature shows that cancer survivors are more likely to take early retirement. For example, a Danish cohort study into early retirement in cancer survivors identified that leukaemia patients are a high-risk group for early retirement (along with prostate and ovary cancer) with a two-fold increase even after 8 years.<sup>86</sup>

Our survey found that four respondents reported they had taken early retirement. One focus group participant explained his situation; at 62, before his transplant, he'd been planning to work until he was 65.

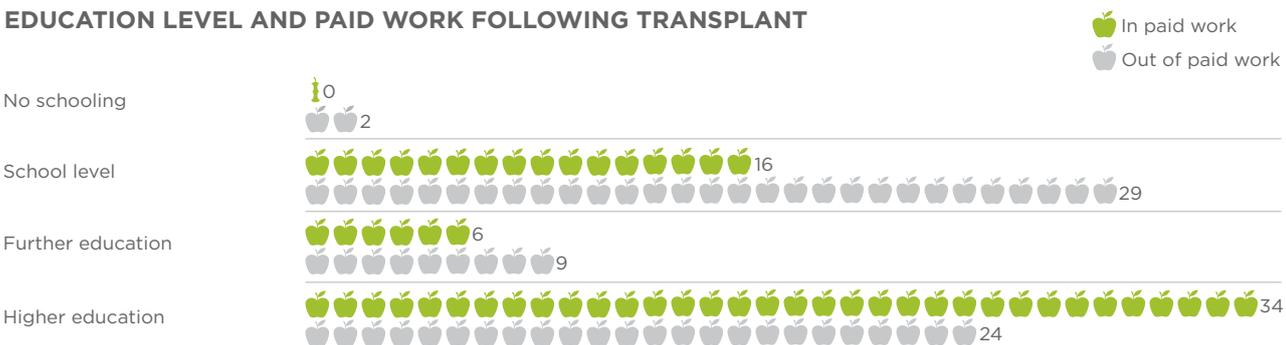
However, after his transplant he decided it was not worth going back just for two years, as it would take that long to settle into the role. Although he had not previously thought of taking early retirement before, now he sees it as the 'silver lining' to his transplant.<sup>87</sup>

The majority of survey respondents who were not in paid work stated that they would like to work at some point in the future (n=45, 65%). Over half (58%, n=26) provided additional details highlighting the factors which would help them return to work. The broad themes are outlined in the chart below.

**WHAT WOULD BE MOST BENEFICIAL IN HELPING YOU RETURN TO WORK?**



**EDUCATION LEVEL AND PAID WORK FOLLOWING TRANSPLANT**



# 3. ADDRESSING SUPPORT GAPS

**According to the wider cancer literature, more effective interventions to increase work-related capabilities, improve social support, and manage depression were likely to improve the experience of the return to work.<sup>88</sup>**

In our research, patients reported that they received support from their families and their employers in returning to work.

However, there were a number of suggestions for improvement in the support they received. In turn, family members and employers sought additional information to be able to assist patients' return to work.

## SUPPORT RECEIVED

The survey respondents who returned to work stated that support from their employer was the most beneficial in helping their return. The support they valued the most from their employer included having a phased return and flexible working.

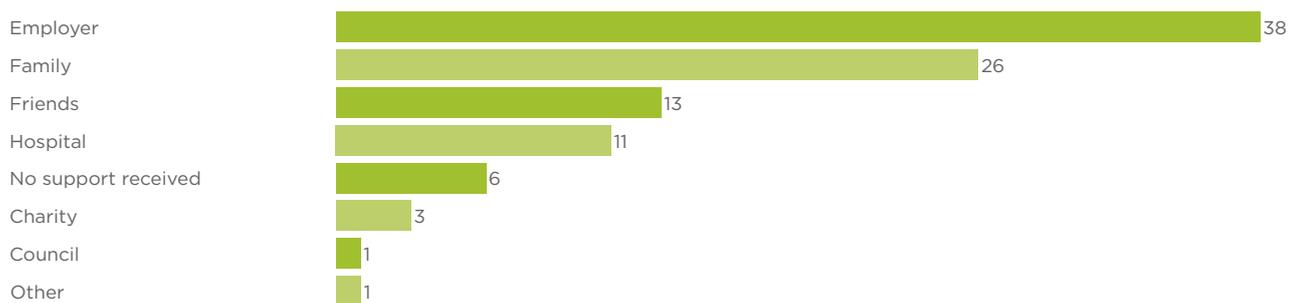
## SUPPORT GAPS

The majority of patients, their family members and employers had a number of suggestions for additional support that might be required for the return to work. The main areas of support that interviewees felt they needed were:

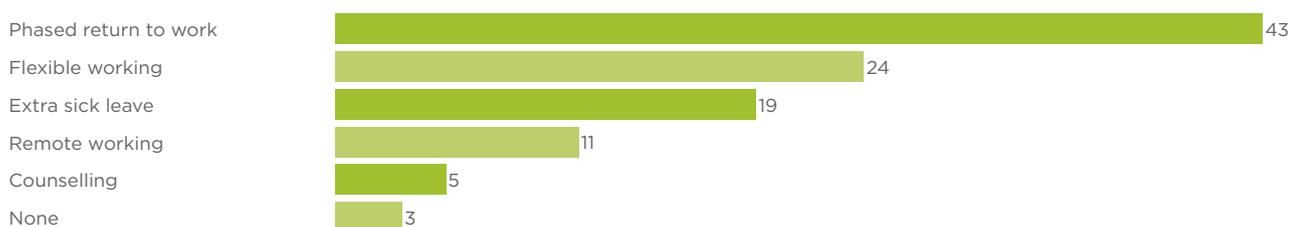
- Information and guidance: More information for patients, family members and employers about what to expect
- An advocate or intermediary: An impartial third party to aid communication between employer and employee
- Social and emotional support: Support from a knowledgeable advisor, professional emotional support and the ability to communicate with others with a similar background.

In addition, focus group participants agreed they would like advocacy support, peer-to-peer support and advice on when and how to bring up one's illness if changing employers.<sup>89</sup>

## MOST BENEFICIAL SUPPORT IN RETURNING TO WORK



## SUPPORT RECEIVED FROM EMPLOYER



'Infection control was an issue, as my immune system was very weak. But I was able to work from home for a few months which worked really well.'

**Paul**, stem cell recipient and Quality Assurance Programme Manager



‘The reality is that both the company and the individual shouldn’t expect things to be the same as they were before.’

### 1. Information and guidance

Patients, their family members, and their employers all felt that they would benefit from more information about what to expect on the journey back to work.

For patients, it felt like ‘a lot of things are coached and hidden. The nurses and the doctors don’t want to scare you but they could be a little bit more honest about the realities of the recovery.’<sup>90</sup>

Patients highlighted that they would value more information about:

- What to expect during recovery, in particular knowing that it can be a long process
- Issues that transplant patients face in going back to work
- More about the Equality Act and what their employer should be doing to support them – e.g. making reasonable adjustments
- Benefits and financial support they may be entitled to, and guidance about claiming them
- Training schemes and ways to maintain skills while they are unable to work.

They also stated that having accurate, balanced information would help the people around them feel better prepared and have more accurate expectations. Patients and family members were also keen to have more information and support around benefit entitlements.

One family member told us, ‘I have been surprised at how long the recovery takes. All our friends and family seemed to think that once he had the transplant that’s it – it’s done, he’s better. I don’t think I realised – I still get the feeling from quite a few of my friends that they can’t understand how he isn’t completely bouncing around and completely better.’<sup>91</sup>

Employers were also keen to have more information provided to them about what to expect. This included:

- The possibility that patients may not have a straightforward recovery, and may have fluctuating symptoms – e.g. feeling fine one day, but unable to get out of bed the next
- Advice about communicating with patients who are on long-term sick leave
- Information about how best to support their employee
- How other companies approach similar situations
- Relevant government policy and guidance.

There was a preference for short videos or leaflets explaining what to expect, which it was felt would help both employers and employees be more prepared.

One employer said, ‘Employers need to understand that just because someone has come back to work for a few hours, that is not even the same as half the time... So something to clarify the length of time it takes to return and get up to full capacity would be useful’.<sup>92</sup>

Another employer told us, ‘The reality is that both the company and the individual shouldn’t expect things to be the same as they were before.’<sup>93</sup>

## CASE STUDY

‘For him it was about proving he was back to normal – he’s always been very driven about going back to work.’

David’s wife

# DAVID

**Time since transplant:** Three years  
**Type of transplant:** A cord stem cell transplant

David was working as a sales director at a start-up company when he discovered he had leukaemia. Within four days, he was in hospital.

David found it difficult to stop work. ‘I worked throughout the chemotherapy. I never stopped – people could ring me and I was working on the computer. Being ill on your own in a hospital room isn’t much fun.’ When he did stop, he was supported by his employer. ‘My boss said, “I’m going to keep paying you for as long as it takes.”’

David’s employer told us, ‘My boss and I went to see him in hospital. David being David, he still had his laptop with him in hospital. It was a bit of a coping mechanism for him.’

David returned to work ‘for sanity reasons more than anything else. I could have stayed off and the doctors would have let me. But because of the job I do, I can be at home anyway – it’s not a 9 to 5 job where I have to be in the office all the time, so it wasn’t a big ask.’

David’s wife said, ‘For him it was about proving he was back to normal – he’s always been very driven about going back to work.’

When he first returned, David says, ‘I was a bit worried about whether I’d be able to do it. But everyone was brilliant – there was no pressure on me to come back five days a week and see customers.’ As such, his return to full-time work was relatively quick. ‘I had a three-month build-up, and by Christmas I was back full-time.’

David’s role hasn’t changed. He couldn’t fly for a while, and had to be careful when meeting people who might be ill. But gradually, and with the support of his colleagues, he’s returned to where he was before.

David’s employer said, ‘We joke that when he had his transplant, he was reborn. We celebrate birthdays in the office... and now we celebrate two birthdays for him.’

‘Even three years on, not everything is quite right and I don’t know if it ever will or whether this is the new me... if it is, then it’s something that I have to accept.’

## 2. An advocate or intermediary

Patients and employers felt that having an impartial third party to act as an advocacy or intermediary between the employer and the patient would help them both to better understand the other’s point of view.

A person fulfilling this role could meet with both employer and employee to provide information and support, and to achieve the following:

- Explain how the employer and colleagues can best support the patient in their transition back to work
- Provide other practical information about transplant recovery and the workplace, e.g. that the patient will have a compromised immune system and need to minimise risk of infection while in the workplace
- Emphasise that recovery can take a long time and provide advice about how quickly or slowly they should go back to work.

One employer explained, ‘Having an intermediary who could sit between the employee and the employer makes a lot of sense. Because I think the employee is keen to get back to work and establish themselves in the workplace and it’s a question of knowing about how you would get the path right – and both parties need support to ensure they get the most out of it.’<sup>94</sup>

Patients had mixed feelings regarding the worth of occupational health in this role. Some felt that occupational health did not help in sufficiently practical ways,<sup>95</sup> whereas others told us that ‘occupational health are good as they are confidential and are just there to help you. They are in between you and the company.’<sup>96</sup>

## 3. Social and emotional support

Patients and their loved ones agreed that they wanted more emotional support from a specialist who understood the specific reality of recovering from a transplant. This could help them deal with people’s responses to their recovery, and come to terms with changes to their identity.

One patient told us, ‘Even three years on, not everything is quite right and I don’t know if it ever will or whether this is the new me... if it is, then it’s something that I have to accept.’<sup>97</sup>

Family members in particular expressed the need for counselling and other sources of emotional support for the patient, to be available locally and long-term.<sup>98</sup> There was also a desire to have the opportunity to talk to other transplant patients about their experiences, as underlined by the suggestion of a ‘buddy’ scheme.

One patient told us, ‘One of the key things I would have asked a ‘buddy’, if I had one, would be: How did you find getting back to work particularly in terms of your strengths in your work – did you find you were up to the challenge and how long did it take you to regain your mental abilities?’<sup>99</sup>

Online forums were also seen as a useful source of support, a point which was particularly emphasised by partners and family members.

One family member said, ‘People like to tap into other people who have had a similar experience – I think that’s really important... It can be a very lonely business... so any way of bringing people together is really positive.’<sup>100</sup>



'I had started working in the patient transport service in 2003, but I had to take two years off. My colleagues were fantastic; they kept my job open and were so supportive.'

**Harun**, stem cell recipient and paramedic

# CONCLUSION AND RECOMMENDATIONS

## CONCLUSION

Returning to work following a bone marrow transplant is an indicator of successful recovery, and can also further aid the process of ongoing recovery for patients. It is beneficial to the patient: psychologically, socially and often financially.

However, returning to work is a difficult process, and one that is not as straightforward as they, their family members, or their employers expect. Many patients take much longer to recover sufficiently enough to be able to return to work than they might initially assume.

Furthermore, once a patient has returned to work initially, returning to work full-time is another milestone, and one that takes patients longer to achieve. Some patients may never go back to working at the same levels as they did before their transplant.

For some, this helps them to achieve a better work/life balance and ensure they have a less demanding and stressful job, but for others this can be a frustrating downside to returning to work following illness. While some patients have been given support to aid the process, in general there appear to be significant gaps in the support and information available to patients when they are returning to work.

Addressing these gaps is likely to significantly improve the transition for patients.

## RECOMMENDATIONS

In line with the 'A Road Map for Recovery' report, this report supports the conclusion that returning to work and active life should be recognised as a key health outcome for transplant patients where appropriate.

To strengthen the network of support for patients during the transition back to work, we recommend the following:

**NHS** England should ensure that all BMT patients have access to a high quality late effects service, which includes rehabilitation and psychological support.

**Employers** should:

- Ensure they have adequate insurance policies in place to cover long term absences.
- Offer employees a phased transition back to work and an open environment to determine an appropriate workload, what support is required and a timetable for return.

**Anthony Nolan** should develop research, materials and services which provide information and support for BMT patients and their employers about the transition back to work.

# APPENDIX 1

## LITERATURE REVIEW SEARCH STRATEGY

### Search Terms<sup>101</sup>

((bone marrow OR transplant OR haematopoietic\* OR stem cell OR haematopoietic OR blood stem cell OR hematopoietic\* OR hematopoietic OR allogeneic OR allograft OR umbilical cord blood OR blood cord OR autograft OR autologous OR blood cancer OR Leukaemia OR Lymphoma OR Myeloma) AND (occupation\* OR employment OR vocation\* OR finance\*))

Database	Hits	Limits applied <sup>102</sup>	Relevant
Medline (EBSCO Platform)	4559	479	43
CINAHL (EBSCO Platform)	556	147	21
PsycInfo (EBSCO Platform)	204	81	4
ASSIA (Proquest Platform)	86	47	18
BNI (Proquest Platform)	48	44	28
EconLit (Proquest Platform)	50	31	0
ERIC (EBSCO Platform)	40	6	1
Social Services Abstracts (Proquest Platform)	16	12	6
Sociological Abstracts (Proquest Platform)	49	20	2
Embase (EBSCO Platform)	3607	139	15
Pubmed	9283	1071	63
Scopus	462	10	0
Total relevant after de-duplicating (Cancer)	-	-	33
Total relevant after de-duplicating (other transplants)			35

Additional searches conducted: Cancer Research UK, Macmillan Cancer Support

# APPENDIX 2

## RATES OF RETURN TO WORK

Country	Patient Group	RTW						Range	Authors
		6 months	1 year	2 years	3 years	4 years	5 years		
UK (our survey)	Stem cell Transplant		18.2% (<1year)	54% (1-3 years)		60% (3+ years)		Overall RTW: 50.5%	
Finland		44.00%	66.00%	76.00%	74.00%				Wong, Francisco, Togawa, et al., 2012
USA							84% (5 years+)		Syrjala, Langer, Abrams, et al., 2006
Australia				70% (2 years)					Gifford, Sim, Horne, et al., 2015
Switzerland								60% (1-21 years)	Bieri, Roosnek, Helg, et al., 2009
USA								No difference with controls by 10 years	Syrjala, Langer, Abrams, et al., 2005
Italy								No difference with controls by 20 years	La Nasa, Caocci, Efficace, et al., 2014
Germany								55% (1-12 years)	Hensel, Egerer, Schneeweiss, et al., 2003
Iran								52% 8-28 years)	Sayadi, Jafaraghaee, Jeddian, et al., 2014
USA								36% (within 5 years)	Goodwin, Coleman, Sullivan, et al., 2014
Canada								41% (mean 43 months)	Cheung, Imrie, Friedlich, et al., 2010
Netherlands		Range of cancers			85%/69%				
	Lung Cancer			65%/41%					
	Genital Cancer			94%/85%					
	Skin Cancer			87%/92%					
	Breast Cancer			88%/68%					
	Blood malignancies			83%/68%					
Italy	Thoracic (lung or heart transplant)							39% (between 18-84 months)	(Petrucci, Ricotti, Michelini, et al., 2007)
Netherlands	Prostate or Endometrial cancer							66% (5-15 years)	(Mols, Thong, Vreugdenhil, et al., 2009)
USA	All Cancers (excl. skin, prostate, testicular)		73.00%			84.00%			(Short, Vasey & Tunceli, 2005)
Nordic countries: Finland Norway Denmark Iceland	Breast, testicular, Prostate or lymphoma							90% (1-8 years)	(Lindbohm, Kuosma & Taskila, 2011)

- 1 Beer et al (2013) A Road Map for Recovery. Anthony Nolan.
- 2 Horsboel T a., De Thurah A, Nielsen B, Nielsen C v. Factors associated with work outcome for survivors from haematological malignancies – a systematic literature review. *Eur J Cancer Care (Engl)*. 2012 Jul 1;21(4):424–35.
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- 43 Loved one interview (1)
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- 68 Focus group participant G
- 69 Focus group participant G
- 70 Focus group participant J
- 71 Focus group participant R
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- 94 Employer interview (1)
- 95 Patient interview (3)
- 96 Focus group participant R
- 97 Patient interview (2)
- 98 Loved one interview (4)
- 99 Patient interview (1)
- 100 Loved one interview (4)
- 101 Terms such as 'employ\*' and 'work' were excluded as yielded a high number of irrelevant hits.
- 102 Limits included: publication year 2004 - current, human subjects only, exclude under 18 years/over 65years, basic science research, English only.

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LIKE A PATIENT – I WAS SOMEBODY  
CONTRIBUTING TO SOCIETY AGAIN.’

**Chantel**, stem cell recipient and GP

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