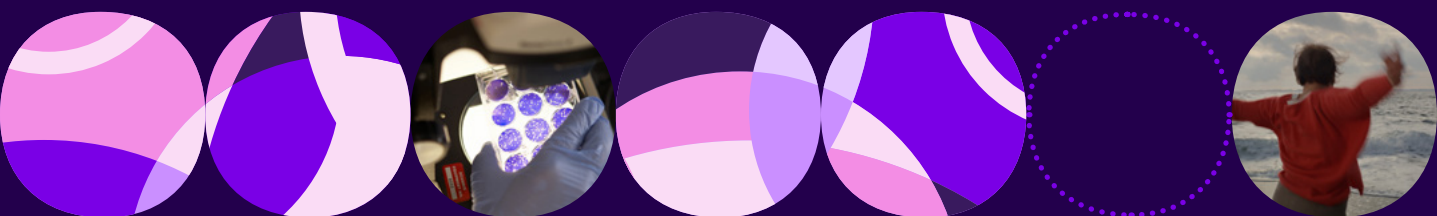


A vision for change

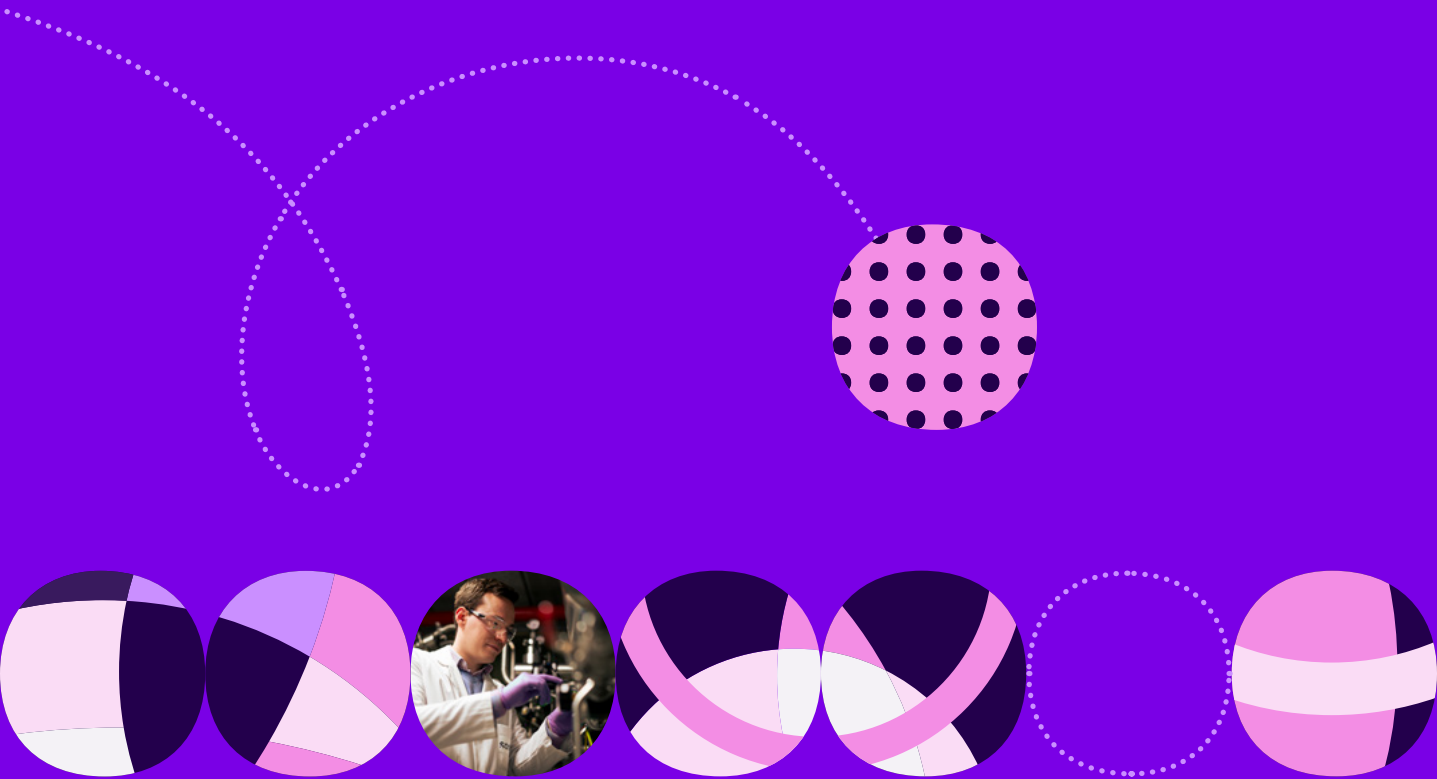


The graft vs host disease care pathway



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Developing policy recommendations based on expert insights

Graft-versus-host-disease (GvHD) is a potentially life-threatening immune response, which affects 30 to 40 per cent of people who undergo stem cell or bone marrow transplants.¹ The donor cells (the graft) recognise the recipient's tissues (the host) as foreign and begin to attack them.²

The symptoms of GvHD are wide-ranging and affect each individual differently – but its impact can be life-changing.² It can affect nearly any organ in the body, with symptoms ranging from rashes and skin dryness, painful joints and muscles, nausea and vomiting, and shortness of breath.² These symptoms can have a significant impact on mobility, independence and quality of life.³ Further, we know that the risk of developing GvHD following a transplant can be higher for people from ethnic minority backgrounds, due to challenges in finding a donor match.⁴

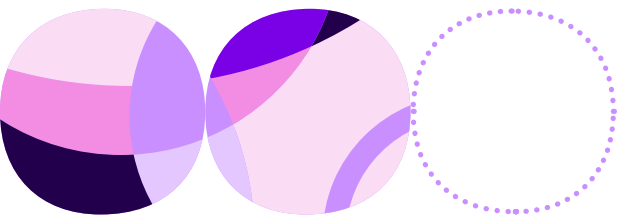
From our conversations with the community, we have heard that people who receive stem cell transplants often believe that their transplant will resolve their health problems – not anticipating that they may experience the life-altering symptoms of GvHD. In some cases, these symptoms can have such a severe impact that recipients experience transplant regret, wishing that they had not undergone the transplant in the first place.⁵

“With every treatment that any doctor gives you, they explain very carefully what the complications are. But as the patient, you’re sure it will turn out all right [...] But the doctors can’t predict what impact all these treatments are going to have on you.”

GvHD roundtable participant.

To better understand the challenges within the transplant care pathway and identify opportunities for meaningful improvement, a group of leading voices from across the transplant clinical and patient community came together alongside system voices for a roundtable discussion in September 2025 – with the support of Sanofi. The shared goal was to develop a robust, patient-insight informed set of recommendations for policy change – to help support interventions which could improve GvHD care outcomes.

In the context of ongoing health system reform, this work comes at a pivotal time for the commissioning and delivery of GvHD services.



Why is change needed in GvHD care and treatment?

“Everyone undergoes stem cell transplant, hoping it will be a cure. But GvHD is the thing in the corner you worry about.”

GvHD roundtable participant.

Despite its impact, we have heard that the care pathway for GvHD can be complex and challenging to navigate, making it hard for patients to access the high-quality, ongoing care and support they need.⁶

Beyond clinical needs, people also face the physical, psychological, and social/economic impacts of GvHD, which are not always addressed by the current support pathway. In 2022, with the help of Anthony Nolan, Sanofi commissioned a survey of 27 participants, to understand the physical, psychological, and social/economic impact of cGvHD (chronic GvHD).^{3*}

It found that:

69%

of patients with cGvHD surveyed reported that it impacted their mental health, and

78%

felt they were a burden to others due to their condition.

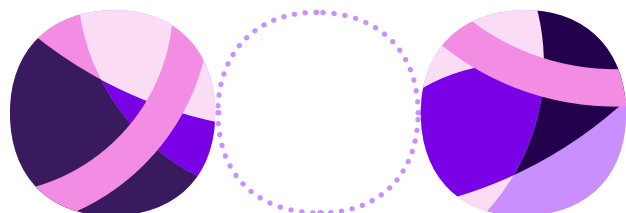
More than **50%** of respondents reported that cGvHD had a high impact on patients' ability to work, exercise, enjoy life, and plan for the future.

*Please note, symptoms are not exhaustive and patient experiences may differ.

Yet there is significant potential within the healthcare system to deliver change for people impacted by this condition. Discussions at the roundtable showed that through harnessing emerging technologies, better utilising data and adopting more effective models of care, improved care is within reach.

The NHS is undergoing a critical period of reform and development, further to the publication of the Government's 10 Year Health Plan which includes the establishment of a Neighbourhood Health Service⁷ – alongside the consolidation of Integrated Care Boards (ICBs),⁸ and the delegation of specialised services to ICB level.⁸

As the NHS moves forwards with these changes, it is imperative that GvHD care is not left behind. NHS reform provides an opportunity to transform GvHD care – demonstrating the Government's commitment to supporting the transplant community and ensuring that the needs of the GvHD patient and carer community are not overlooked.



Roundtable participant Steve Bennett shares his story*

Steve was diagnosed with acute myeloid leukaemia, for which he received chemotherapy and eventually a stem cell transplant. Steve did not anticipate that his transplant would mark the start of his GvHD journey, which would lead to him being in and out of hospital for years.

“Leukaemia was one thing, but the aftermath of the transplant was a huge thing to deal with.”

Steve’s severe symptoms from GvHD included dry skin, which would often break down, gut issues, incontinence and bladder problems, and issues with his eyesight which reduced to just 20% vision. He became critically ill with sepsis 9 times, and was admitted to hospital a further 21 times for acute health problems caused by GvHD treatment complications, including atrial fibrillation and haemorrhagic cystitis. The treatment to tackle this wide range of symptoms also led Steve to develop steroid-induced diabetes.

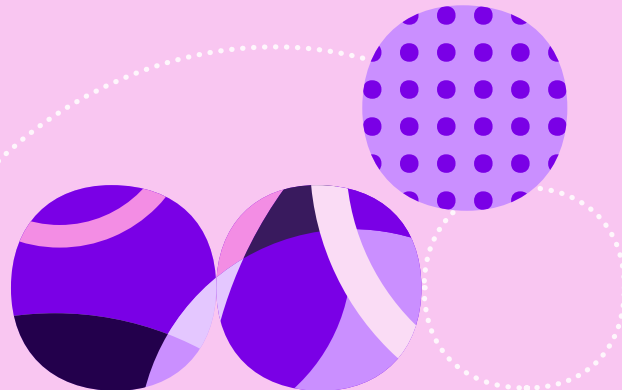
Alongside these debilitating symptoms, Steve and his wife and carer Elsa needed to navigate a complicated care pathway. Steve saw over 160 different clinicians whilst being treated for GvHD. Elsa is a professional nurse, and she emphasised that her background knowledge was vital in supporting Steve through GvHD. Elsa asked:

“If you don’t have the background knowledge we had... how do so many people manage?”

Along his care pathway Steve was readmitted to hospital many times – yet these readmissions, through different access routes and to different hospitals, weren’t reviewed collectively or considered in the round as part of his post-transplant journey.

Stories like Steve’s demonstrate the wide-ranging impact of GvHD, and the need for improvements in the health system to deliver consistently high-quality care and support for GvHD.

*These experiences are individual to the patient. Experiences may vary from patient to patient.



Key priority areas to drive change in the GvHD care pathway

1. Improving access to multidisciplinary team care, to improve patient experiences and outcomes

GvHD can affect multiple organs across the body, and therefore often necessitates treatment and insight from a range of specialist healthcare professionals including haematologists, dermatologists, physiotherapists, gynaecologists, urologists and more.⁶

Yet discussions at the roundtable showed that there are often significant challenges in getting the cross-speciality support people with GvHD need – with patients reporting accessing the system multiple times over the course of their care journey, but without these appointments and conversations being connected. This disjointed care can lead to symptoms being treated in isolation, rather than via a holistic approach which tackles a person's experience of GvHD as a whole.

Beyond physical support, it was emphasised that whilst some GvHD patients do receive excellent psychological support, access can be variable. There are examples of where the patient advocacy community has provided this support, such as Anthony Nolan's funded specialist clinical psychologist posts.⁹ Such valuable support should be scaled nationally and put on a sustainable footing.

Improved understanding of the patient pathway is required to ensure optimal post-transplant patient care and utilisation of healthcare resources, as patients currently enter and re-enter the health system across multiple access points.

We are calling for:

Short-term (within the next three years)

- NHS England and ICB leads to consider the role of Neighbourhood Health Services in better supporting post-transplant care and enabling patients to remain out of hospital and receive care closer to home.
- NHS England and Government to consider transplants, including stem cell and bone marrow transplants, as part of the Getting It Right First Time (GIRFT) programme to improve treatment and care by reviewing health services across England, to ensure patients can access the right care and that resource is effectively utilised.

Longer-term (over the next five years and beyond)

- NHS commissioners to ensure mental wellbeing is properly factored into the post-transplant care pathway, by implementing Anthony Nolan's recommendation for every transplant centre to have a dedicated clinical psychologist.¹⁰ This recommendation should be delivered via increased funding of specialist stem cell clinical psychologist positions.
- DHSC to work with NICE to support the development of a quality standard for stem cell and bone marrow transplants, which includes a focus on comprehensive, high quality post-transplant care.

2. Utilising data and research to identify, and reduce, the risk and severity of GvHD

The UK has a track record as a world-leader in stem cell donation and research,^{11,12} and there are now over 2,000,000 people on the UK stem cell donor registry.¹³ Yet there is further to go. At the roundtable, we heard that there is now widespread recognition of the need to drive improvements in outcomes for transplant recipients. This includes addressing ongoing inequalities: patients who do not have access to a close genetic match to a stem cell donor are at greater risk of developing GvHD,⁴ and patients from Black, Asian and minority ethnic (BAME) backgrounds face challenges in finding a suitable donor match.⁴

The UK IMPACT transplant trials network was developed to examine the best ways of improving transplant outcomes.¹⁴ The network has supported over 1300 patients to access transplant trials designed to improve patient outcomes and reduce complications such as GvHD,¹⁵ informing clinical research and driving improvements for blood cancer patients across the UK.¹²

A particular area of focus for GvHD is biomarker data, which has the potential to guide how GvHD is managed clinically, as well as the development of future clinical trials.¹⁶ Efficient use of this data could support much-needed improvements in GvHD care and treatment. Contributors at the roundtable emphasised the potentially transformative impact for patients in knowing their GvHD risk, and feeling confident that a personalised treatment plan is available to them, prior to receiving their transplant.

The group highlighted that there is further research needed, building on existing data, to understand how GvHD can be best prevented, as well as how inequalities faced by people from ethnic minority groups in access to high-quality matches for stem-cell and bone marrow donation can be addressed.

We are calling for:

Short-term (within the next three years)

- DHSC to review the ongoing data collection work of the British Society of Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT) registry, and work with partners in the space to identify opportunities to support further development of the registry.

Longer-term (over the next five years and beyond)

- NHS England to work with partners within the system to implement a clear pathway for post-transplant care to ensure early identification of GvHD and optimal outcomes for people diagnosed with GvHD, in alignment with ongoing patient organisation work in this area.
- Relevant government bodies, including the National Institute for Health and Care Research (NIHR), to invest in research and clinical trials to assess the most effective ways of preventing and treating GvHD – as well as more effectively matching donors and recipients ahead of a transplant.

3. Harnessing technology to support holistic, patient-centred follow-up care

At the roundtable, patients and healthcare professionals expressed that pre-transplant care and support is often more consistent and of higher quality than post-transplant care, with a sense of ‘abandonment’ experienced by some patients at this point in their care.

They told us that patients can find it challenging to achieve timely access to treatment within specialities beyond transplant care, despite the multi-disciplinary impacts of GvHD. Moreover, if a patient with GvHD requires admission to hospital, as agreed with their specialist, their only option is then to present at A&E, or to call an ambulance, and go through triage. We heard that this process places increased pressure on A&E departments, and means that people with GvHD, who are often undergoing complex treatment for multiple issues, may have to wait longer to receive the specialist treatment they need.

We also heard that these issues with follow-up care are exacerbated by problems with interoperability of healthcare systems, including challenges accessing full patient records and background information, so that healthcare professionals can take the most appropriate action with this data in mind.

We are calling for:

Short-term (within the next three years)

- The NHS app and NHS webpages on stem cell transplantation to include explicit provision for signposting to patient support resources, such as the Anthony Nolan online forum, helpline and patient family network.
- NHS England to review provision and management of inpatient support for patients with complex, long-term conditions, including how they are triaged in A&E.

Longer-term (over the next five years and beyond)

- DHSC to work with NHS England to ensure the NHS app, or a specific digital tool for post-transplant care, includes functionality for users to manage their ongoing care and treatment. This could include information on key symptoms of GvHD and how to quickly access advice and treatment.
- In alignment with ongoing DHSC and NHSE work to digitise and link patient data across different settings, the data in this digital resource should be utilised to ensure a transplant recipient’s full journey is visible to all healthcare professionals who may be treating them, including GPs.

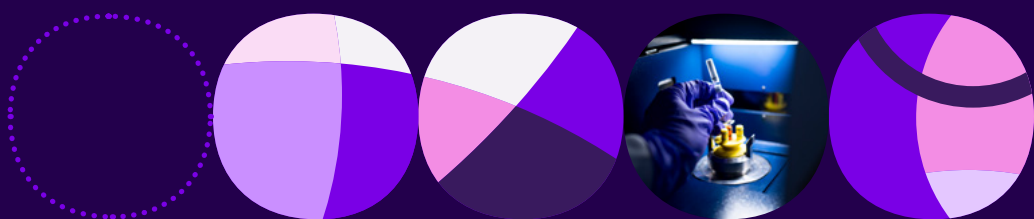
Next steps

Raising awareness of the significant impact of GvHD on patients, and the need for change

To drive change for people living with GvHD as a policymaker, you can:

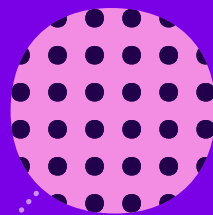
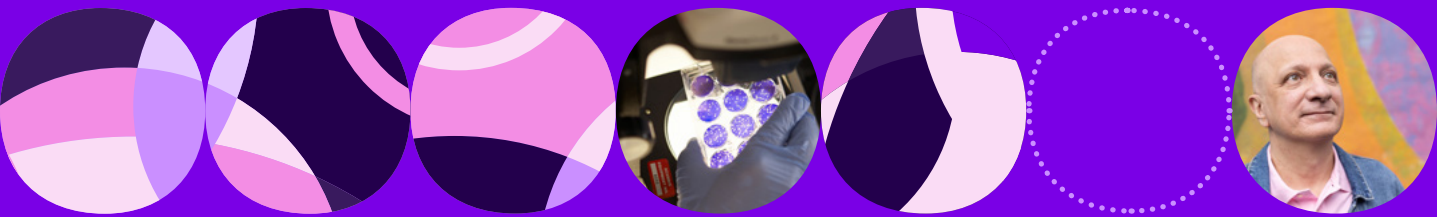
- Champion these calls in Parliament and raise them with the Government, to help deliver improvements for the GvHD and transplant community.
- Meet with Sanofi and representatives from the transplant community, including patient organisations and people with lived experience of GvHD, to hear first-hand the challenges they face and how you can advocate for them in Parliament and in discussions with relevant bodies.
- Table parliamentary written and oral questions on the care and support available for people with GvHD, and plans to action the recommendations in this consensus statement.

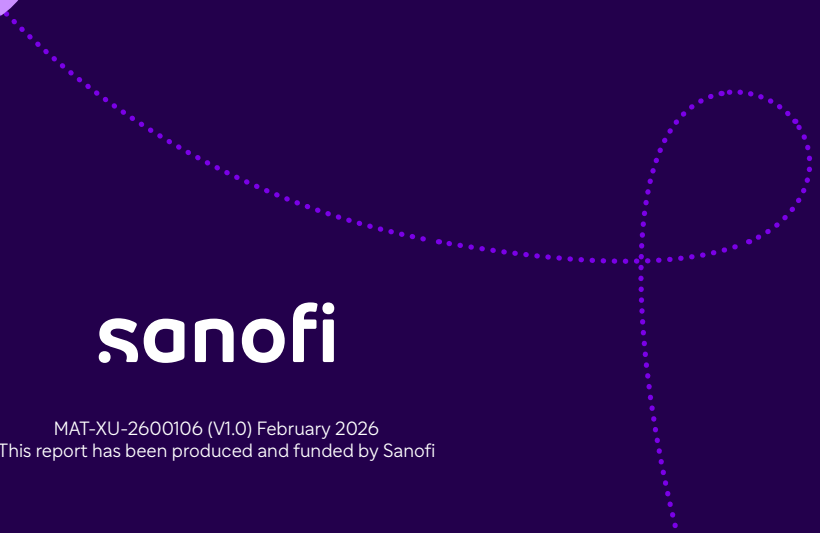
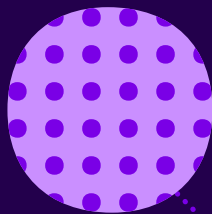
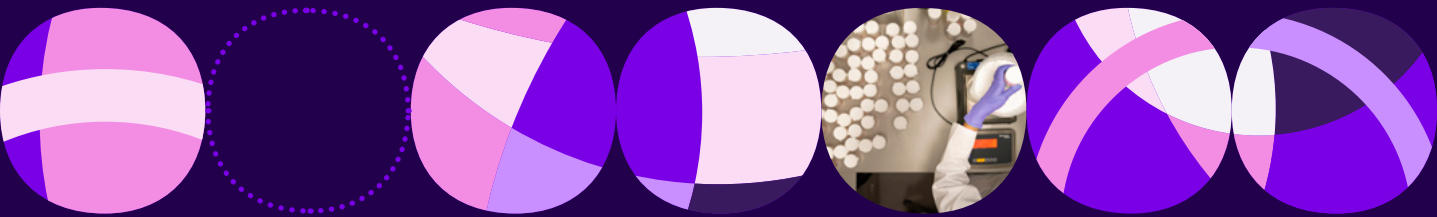
For further information on how you can support this ongoing work, contact **Laura Wetherly**, at Laura.Wetherly@sanofi.com



References

- 1 Anthony Nolan. Analysis of hospital activity and costs following allogeneic stem cell transplantation in England. 2021. Available at: <https://www.anthonynolan.org/sites/default/files/2021-03/analysis-of-hospital-activity-and-costs.pdf> [Accessed February 2026]
- 2 Anthony Nolan. An Essential Guide to Graft-versus-host Disease (GvHD). 2021. Available at: https://www.anthonynolan.org/sites/default/files/2021-07/2630PA%20Essential%20Guide%20to%20GvHD_Website.pdf [Accessed February 2026]
- 3 Hart D, et al. 2022. Investigating the Impact of Chronic Graft-Versus-Host Disease on Patient and Carer Health-Related Quality of Life: A Quantitative Study.
- 4 Anthony Nolan (2025) "Increasing treatment options for patients from a minority ethnic background: The hope of PTCy". Available at: <https://www.anthonynolan.org/blog/2025/06/27/increasing-treatment-options-patients-a-minority-ethnic-background-hope-ptcy> [Accessed February 2026]
- 5 Kirsch, JL, et al. (2025). "Predictors of Transplant Regret: A Case–Control Study Nested Within a Prospective Cohort of HSCT Recipients" *Cancer Med.* Apr 1;14(7) e70828. Available at: <https://onlinelibrary.wiley.com/doi/10.1002/cam4.70828>
- 6 Anthony Nolan. "Graft versus host disease (GvHD)". (n.d.). Available at: <https://www.anthonynolan.org/patients-and-families/recovering-a-stem-cell-transplant/graft-versus-host-disease-gvhd#gvhd-different-organs> [Accessed February 2026]
- 7 Department of Health and Social Care (2025). 10 Year Health Plan for England: fit for the future. Available at: <https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future> [Accessed February 2026]
- 8 NHS England (2025). "Implementing integrated care board mergers and boundary changes to take effect in April 2026 and 2027." Available at: <https://www.england.nhs.uk/long-read/implementing-integrated-care-board-mergers-and-boundary-changes-to-take-effect-in-april-2026-and-2027/> [Accessed February 2026]
- 9 Anthony Nolan (2019). Anthony Nolan funds three transplant clinical psychologist posts. Available at: <https://www.anthonynolan.org/blog/2019/02/28/anthony-nolan-funds-three-transplant-clinical-psychologist-posts> [Accessed February 2026]
- 10 Anthony Nolan (n.d.). Improving the mental health and wellbeing of cell therapy patients. Available at: <https://www.anthonynolan.org/what-we-do/influencing-change/influencing-change-throughout-transplant-pathway/mental-health-and-wellbeing> [Accessed February 2026]
- 11 Anthony Nolan (2024). "SFRS celebrates 15 years of saving lives with Anthony Nolan". Available at: <https://www.anthonynolan.org/blog/2024/08/30/sfrs-celebrates-15-years-saving-lives-with-anthonynolan> [Accessed February 2026]
- 12 Cure Leukaemia (n.d.) "Impact Network". Available at: <https://www.cureleukaemia.co.uk/patient-hub/impact-network/> [Accessed February 2026]
- 13 DKMS (2020). "UK's aligned stem cell registry reaches two million". Available at: <https://www.dkms.org.uk/get-involved/stories/uk-s-aligned-stem-cell-registry-reaches-2-million> [Accessed February 2026]
- 14 Anthony Nolan (n.d.) "The Impact of our Research". Available at: <https://www.anthonynolan.org/what-we-do/our-research/impact-our-research> [Accessed February 2026]
- 15 Charles Craddock et al (2023), "The UK Impact Transplant Trials Network: An Effective National Strategy to Accelerate the Delivery of Randomized Trials in Stem Cell Transplantation" *Blood*. Volume 142. Supplement 1. p.5097. Available at: <https://doi.org/10.1182/blood-2023-188490>.
- 16 Crossland, Rachel E et al. (December 2020) "Potential Novel Biomarkers in Chronic Graft-Versus-Host Disease." *Frontiers in immunology* vol. 11 602547. doi:10.3389/fimmu.2020.602547





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