

Minutes of the UKSCSF Oversight Committee Launch Meeting

Monday 26th June 1.15-4.45pm

Attendees

- Ann O'Leary, Director of Donor and Transplantation Services, Anthony Nolan
- Ben Doak, National Senior Programme of Care Manager, NHS England
- Beki James, Consultant Paediatric Haematologist, Leeds Teaching Hospitals NHS Trust
- Charles Craddock (Chair), Academic Director of the Centre for Clinical Haematology, University Hospitals Birmingham NHS Trust, Birmingham and Professor of Haemato-oncology, University of Warwick
- Daniel Eve, National Programme of Care Senior Manager, Specialised Commissioning, NHS England
- Eduardo Olavarria, President, British Society of Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT)
- Gail Miflin, Chief Medical Officer and Director of Clinical Services, NHSBT
- Guy Parkes, Head of Stem Cell Donation and Transplantation, NHSBT
- Henny Braund, Chief Executive, Anthony Nolan
- Jacqueline Barry, Chief Clinical Officer, Cell and Gene Therapy Catapult
- Jonathan Graves, Department of Health and Social Care
- Lauren Watson, Department of Health and Social Care (Observer)
- Lilian Hook, Director, Cell, Apheresis and Gene Therapies, NHSBT
- Orin Lewis, Chief Executive, African Caribbean Leukaemia Trust
- Peter McCleave, 10,000 Donor project (Observer)
- Robert Danby, Consultant Haematologist, Oxford University Hospitals and Chief Medical and Scientific Officer, Anthony Nolan
- Victoria Potter, Consultant Haematologist (and Director), Kings College Hospital
- Alexandra Ross, UKSCSF Programme Director, NHSBT
- Yasmin Sheikh, Head of Policy and Public Affairs, Anthony Nolan (Secretariat)
- Greg Judge, Senior Policy and Public Affairs Manager, Anthony Nolan (Secretariat)

Apologies

- Andy Clark, Consultant Haematologist, NHS Greater Glasgow and Clyde
- David Burns, Consultant Haematologist, University Hospitals Birmingham
- Fiona Dignan, Chair BMT CRG, Consultant Haematologist, Manchester Royal Infirmary
- Hugh Allen, Chief Strategy Officer, Anthony Nolan
- James Griffin, Consultant Haematologist at NHSBT and University Hospitals Bristol
- Marc Turner, Professor of Cellular Therapy, Director SNBTS
- Robert Wynn, Director of Paediatric Blood and Marrow Transplant Programme, Royal Manchester Children's Hospital

Agenda

1. Welcome and overview of the UKSCSF report and objectives – Charlie Craddock
2. DHSC perspective – Jonathan Graves
3. Reports from Delivery Group Chairs:
 1. Stem cell supply – Ann O’Leary and Guy Parkes
 - a. NBTA recruitment strategy – Orin Lewis
 2. Equity and outcomes – Henny Braund
 3. HSCT and ATMP data; Data Commission – Victoria Potter
 4. Research – Charlie Craddock for RW
 5. Infrastructure – Victoria Potter and James Griffin
4. Ensuring Delivery – Alexandra Ross
5. Next steps and date of next meeting – Charlie Craddock

Minutes of the Main meeting

1. Welcome and overview of the UKSCSF report and objectives – Charlie Craddock

- The Chair (Professor Charlie Craddock) welcomed all those attending the first meeting of the Oversight Committee as the Forum commences this new implementation phase and provided some remarks:
- The Strategic Forum has proven itself over the last 13 years to be an effective means to enabling change and transformation that drives improvement in patient outcomes. We continue to welcome open discussion into our approach to delivering this change.
- The UKSCSF was first established in 2010, at the request of the UK Government. We continue our work today thanks to the voluntary commitment of community partners from across all four nations of the UK. Working together, we’re better able to understand the ambitions of HM Government and respond to developments across the wider life sciences sector.
- It is encouraging to see so many parts of the UK well-represented at this Oversight Committee meeting, and a personal thanks given to representatives of the National Black, Asian and Minority Ethnic Transplant Alliance (NBTA) for their attendance.
- The progress overseen by the UKSCSF includes:
 - Building and formalising the UK Aligned Registry – creating a singular search process across all major UK stem cell donor registries.
 - Launching the UK “fit panel” of young male donors – each typed to high resolution to better serve clinical demand.
 - Investment into the UK cord blood bank – widening access to lifesaving donor grafts for patients from minority ethnic backgrounds.
 - Delivering on the work of the IMPACT clinical trials partnership, and most recently the ACT trial network – each working to grow access and recruitment to UK stem cell transplant trials across the UK.
- Going forward, our ambition for the next decade is to continue learning from examples of best practice developed during the COVID pandemic, and ensure greater equity in patient access to treatments and outcomes. We also have the opportunity to build the nimble and agile clinical trial infrastructure the UK needs, as

highlighted in Lord O'Shaughnessy's recent independent review into the UK commercial clinical trials landscape.

- We should also recognise the role of the global pharmaceutical industry – they are both capable and willing in helping us build solutions to the challenges we face, which are inherently global by nature.

2. Introduction from the Department of Health and Social Care – Jonathan Graves

- Jonathan Graves is the DHSC's advanced therapies lead and shared the department's perspective on the Forum and its future plans:
- The Forum's widened remit to include advanced therapies was welcomed by the department, and reflects the recent move in NHS policy and performance management, as we see more ATMPs beginning to shift from R&D and into patient care settings.
- There is still a lot of activity and defining of scope taking place within the advanced therapies landscape, and DHSC is keen to help coordinate the sector as we move towards greater standardisation and simplified access to system resources that will enable further development and adoption of new ATMP products.
- Existing bodies such as the Forum will be critical to this harmonisation process, and in due course, we'll be wanting to align our work with that of the Forum's and others', as we move into delivering mainstream NHS services.
- Jacqueline Barry from the Cell and Gene Catapult commented that we're starting to see the number of licensed products ramping up. As more come online, coordination within the NHS will be crucial, and it's important for industry to have access to the same clinical trial resources too.

3. Reports from Delivery Group Chairs

a) Stem Cell Supply – Delivery Group Co-Chairs Ann O'Leary (Anthony Nolan) and Guy Parkes (NHSBT)

- The 10-year strategy recommendations for improving the sustainability and resilience in the UK of the stem cell donor supply chain cover three distinct areas:
 - Donor and cord recruitment
 - Delivery
 - Availability
- *Recommendation 1: The UK aligned registry partners should increase the availability of UK young male donors, typed to the highest HLA resolution with CMV status made available.*
 - Current progress: Ann commented that following a recent World Marrow Donor Association (WMDA) conference, there is a stronger and clearer consensus than ever before that young male stem cell donors are an important donor resource. The Delivery Group will consider its implementation plan in due course.
- *Recommendation 2: NHSBT and Anthony Nolan should maintain and replenish a cord blood inventory of 30,000 clinical grade cord blood units.*
 - Current progress: The UK cord blood inventory is approaching 30,000 clinical grade units.

- *Recommendation 3: In 2022/23, the UK aligned registry should aim for 20% of new donors added to the aligned registry to be from a minority ethnic background.*
 - Current progress: The UK aligned registry are collectively working to understand how best to deliver this target and welcome the input and support of all partners including the NBT.
- *Recommendation 4: The UK aligned registry should continue expanding their community-partnerships to increase recruitment of minority ethnic stem cell donors.*
 - Current progress: NHSBT and Anthony Nolan both contribute to the Community Grants Fund, supporting on-the-ground donor recruitment efforts which focus on specific communities.
- *Recommendation 5: Anthony Nolan, NHSBT and the clinical community should expand cord blood education and research.*
 - Current progress: Anthony Nolan and NHSBT are collaborating closely on cord support and education. A series of educational webinars on cord blood usage was recently launched, and there is a Cord Blood Educational Residential in the pipeline.
- *Recommendation 6: NHSBT and Anthony Nolan should expand supply of clinically surplus high-quality donor materials for ATMP research and development.*
 - Current progress: Anthony Nolan continues to build a cell and gene therapy programme, to support the provision of cells for research, development and as starting materials for ATMPs. NHSBT recently brought together key leadership from across apheresis, cellular therapy, registry and the cord blood bank to coordinate on delivery for ATMPs.
- Delivery Group's approach going forward:
 - Working groups will be established by October 2023 to cover the three distinct areas, and will include aligned registry members, recognised experts and community partners. Anyone with interest is welcome to approach about joining.
 - Each working group will develop actions plans, with the Delivery Group providing regular progress reports to the Oversight Committee (OC).
- Discussion:
- It was noted that globally, the donor panel has increased from 20 million to 40 million prospective stem cell donors in the past 20 years, but the rate of patient/donor matching has not seen a similar increase. A significant proportion of those recruited to the unrelated donor registry are never matched to a patient.
- Eduardo Olavarria referenced the use of mismatched unrelated donors (MMUD) in the forthcoming results (due 2024) of a clinical trial using post-transplant cyclophosphamide (PTCy) by the National Marrow Donor Program (NMDP). The trial may indicate that PTCy can deliver improved outcomes from MMUD, which could mean more potential donor options for patients, which will be especially important for those from a minority ethnic background. It is possible that transplant centres will adopt PTCy for MMUD in due course, though this will depend on the emerging trial data.
- Tracey Rees from the Welsh Blood Service suggested that a 'Donor Focus' working group could also be established to consider how best to recruit and retain donors. Ann said this was a fantastic idea, and important to consider donors' insights and behaviours, and the Delivery Group would consider this as part of their planning.

- Henny Braund commented that Anthony Nolan and international registries are observing an increasing global trend in donor unavailability which can cause significant distress for patients and lead to slower time to transplant. Donor registries are monitoring this and trying to understand what is driving it.
- Eduardo prompted a discussion around UK domestic vs international supply of donor cells. Guy and Ann emphasised that UK donors offer the NHS the most cost-effective options, and that is why improving the quality and retention of UK donors is important for domestic resilience. However ultimately the first priority on an individual patient basis should always be securing the best transplant source for that patient, whether from a UK or international donor.
- Orin Lewis (Chief Executive, African Caribbean Leukaemia Trust) presented the NBTA's proposed strategy on donor recruitment to the Oversight Committee. Peter McCleave introduced himself to the group and followed up to support Orin's comments.
- Orin and Peter highlighted three areas where they would like to propose an alternative strategy to recruitment:
 - The current aim for 20% of new donors recruited to the UK registry to be from minority ethnic backgrounds is a start, but Orin and Peter feel it should be a higher target.
 - There are gaps in data that should be addressed to better understand the unmet need for patients from a minority ethnic background waiting for a stem cell transplant.
 - Orin and Peter proposed a unified 16-55 age criteria for signing up to the donor registry across all UK Aligned Registry partners.
- Orin noted the NBTA's desire to formally engage and work with Forum, which was welcomed by Charlie Craddock.
- Charlie Craddock thanked Orin and Peter for their presentation and opened the floor to discussion:
- Beki James offered to pick up directly with Orin Lewis about some of her observations from the paediatric transplant centre in Leeds.
- Eduardo noted that with more migrant families access to family/sibling is increasingly challenging and an area for the Forum to consider.
- The group also noted that there are likely to be increasing numbers of transplants performed in the future for disease such as sickle cell that primarily affect people from a minority ethnic background.
- Victoria Potter noted Orin's points on data and agreed that this would be an important aspect of the Forum's work.
- Charlie Craddock noted that another challenge is understanding how many patients don't even get referred to transplant, and noted that this is a priority for the Forum.

b) Equity and outcomes – Delivery Group Co-Chair Henny Braund (Anthony Nolan)

- Henny introduced herself and noted Fiona Dignan's role as Co-Chair. Henny and Fiona are establishing a Delivery Group focused on improvement and equity in access, patient experience and outcomes.
- Henny noted that some promising progress has been made in line with a number of the recommendations within the section of the UKSCSF report, including:

- NIHR funding has been secured by NHSBT and Anthony Nolan, to investigate inequities in referral and access to stem cell transplantation in England and Wales.
- The BSBMTCT and Anthony Nolan have conducted the first UK study examining outcomes from transplant by ethnicity and are submitting for publication.
- Anthony Nolan's project to develop a stem cell transplant patient reported outcomes measure tool which will eventually link socio-economic and other data to outcomes data.
- Beki James noted the potential negative impact on patients who live a distance away from their treating centres, which is a potential inequality for the Forum to consider. She shared an example from her own clinical experience in paediatric care of geographic distance having a negative impact on patient experience.
- Charlie Craddock suggested the Delivery Group consider whether a randomised study of pre-habilitation may be worth pursuing.

c) HSCT and ATMP data; Data Commission – Victoria Potter

- Victoria Potter reminded the OC members of the principles agreed at the Data Workshop. i.e: accessible, sustainable and integrated.
- Victoria noted it had also been agreed to adopt and promote a federated approach to data which builds on existing datasets and innovation; and to adopt a Data Change Commission to help realise our data transformation vision.
- Charlie Craddock noted that Beki James has been appointed to position of Data Commissioner, as per the process agreed at the Data Workshop earlier in the year.
- Beki will start to develop, in collaboration and consultation with the UKSCSF and others, 2-year strategic plan to prioritise and accelerate short-term development projects, and scope future plans.
- Eduardo updated the group on the BSBMTCT's plans for the publication of outcomes data. The BSBMTCT Executive Committee endorse the importance of transparency and recommend that each centre should make their data accessible to the public. There is still work to be done to understand how best to adopt this in practice and avoid any unintended consequences. The BSBMTCT is going to produce an approach by end of the year.
- Prompted by Eduardo, the group agreed on the importance of being able to track the number of patients who have entered into clinical trials, including by ethnicity. There was also consensus on the need for more investment in data management capacity.
- Charlie also highlighted the recommendation in the UKSCSF report to explore AI and other technologies as part of future stem cell transplant and ATMP data capabilities.
- Ben Doak asked for thoughts on how the UKSCSF would avoid duplicating efforts already underway in other areas? Victoria noted in response that the Commission is to involve all relevant parties, as a way to ensure efforts are complimentary and not duplicative. She also noted that a big focus of the Commission will be on the *quality* of the data available.
- Ben Doak also prompted the group to think about agreeing a clear definition for ATMPs - are we talking just about blood cancers, or other diseases? Charlie Craddock

agreed and suggested that the Data Commission members take this as an action to be brought back to a future Oversight Committee meeting for agreement.

- Jacqueline Barry agreed with the earlier points made on data interoperability, noting that even gender is recorded differently depending on the NHS dataset. Catapult are exploring how to standardise data in Scotland.
- Jacqueline and Ben also noted an upcoming piece of work exploring equity of access into ATMPs from the Genetic Alliance which they will share with the group once published.

d) Research – Charlie Craddock

- Charlie Craddock noted that Rob Wynn has agreed to chair the Research Delivery Group.
- Charlie provided a recap of the UKSCSF's recommendations for research, which span the expansion of stem cell transplant and ATMP clinical trials, the establishment of a paediatric trials network for cell therapies, and development of a mechanism to re-invest in trial savings into services and infrastructure.

e) Infrastructure – Victoria Potter

- Victoria introduced herself as Co-Chair of the Infrastructure Delivery Group along with James Griffin.
- Victoria provided a recap of the Group's priorities, which include:
 - Expansion of ambulatory capacity
 - Expansion of apheresis services and cell processing laboratories to support HSCT and ATMP delivery
 - HSCT and ATMP workforce benchmarking
 - Development of real-time capacity mapping tools
 - Development of ATMP workforce training and development
- Charlie highlighted a growing consensus amongst the clinical community that moving some activity to ambulatory care settings would be beneficial for patients and services.
- Robert Danby suggested the UKSCSF's work in this area should encompass the full HSCT and ATMP workforce including nurses, pharmacists and other roles.
- Eduardo noted that a lot of current HSCT/ATMP staff are due for retirement in the next 10 years; set against a rapid increase in the projected patient numbers eligible for these treatments in the UK this could mean an imminent workforce crisis.

4. Ensuring Delivery – Alexandra Ross (20 mins)

- Alex introduced to herself as the new UKSCSF Programme Director, together with the other secretariat members she will be providing support to Delivery Group Chairs and programme management.
- As part of the secretariat Alex and team will support Delivery Chairs to deliver their plans; and will also provide risk management support.
- Alex noted that the UKSCSF OC will meet every six months, next meeting to be scheduled for November/December 2023.
- The OC agreed the UKSCSF Terms of Reference in principle, subject to Tracey Rees' review for any amends to reflect the Welsh members' involvement.

- Alex Ross and Henny Braund noted that the secretariat will convene a Community Advisory Group which will act as a lived experience reference group for all Chairs. The secretariat will circulate the draft terms of reference of this Group for approval.

5. Next steps and date of next meeting – Charlie Craddock

- Charlie Craddock thanked all attendees for their engagement and support, with particular thanks to Orin and Peter; and commissioning colleagues from DHSC and NHS England.
- He reiterated that the purpose of the UKSCSF is to be highly innovative and pull all parties together with a single focus – to improve patient outcomes.
- The UKSCSF has a demonstrable track record of implementing actions that both improve efficiencies and deliver patient benefit.
- Gail Mifflin concluded by thanking all those joining on behalf of NHSBT and its role as UKSCSF sponsor. She also noted that the UKSCSF Steering Group will work with Jonathan Graves to highlight the ongoing work and plans to the UK Government.