

Minutes of the UKSCSF Oversight Committee Update Webinar

Friday 20th September

Attendees (online)

- Alexandra Ross, UKSCSF Programme Director, NHS Blood and Transplant
- 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 Children's Hospital
- Charles Craddock (Chair), Academic Director of the Centre for Clinical Haematology, University Hospitals Birmingham NHS Trust, Birmingham and Professor of Haematology, University of Warwick
- Deborah Pritchard, Head of Transplant Services, Welsh Blood Service
- Eleni Tholouli, Consultant Haematologist, Manchester University, Chair of The BSBMTCT Workforce Sub-Group
- Gail Mifflin, Chief Medical Officer and Director of Clinical Services, NHS Blood and Transplant
- Greg Judge, Senior Policy and Public Affairs Manager, Anthony Nolan
- Guy Parkes, Head of Stem Cell Donation and Transplantation, NHS Blood and Transplant
- Harveen Ubhi, Policy and Public Affairs Manager, Anthony Nolan
- Hugh Allen, Chief Strategy Officer, Anthony Nolan
- James Griffin, Consultant Haematologist at NHSBT and University Hospitals Bristol
- Keith Wilson, Director, Director, South Wales BMT Service
- Kath Bainbridge, Head of Rare Diseases and Emerging Therapies, Department of Health and Social Care
- Orin Lewis, Chief Executive, African Caribbean Leukaemia Trust
- Peter McCleave, Managing Director, DKMS UK
- Robert Danby, Consultant Haematologist, Oxford University Hospitals and Chief Medical and Scientific Officer, Anthony Nolan
- Tom Coats, Consultant Haematologist, Royal Devon and Exeter NHS Foundation Trust
- Victoria Potter, Consultant Haematologist and Transplant Director, King's College Hospital

Apologies

- Alan Prosser, Director, Welsh Blood Service
- David Burns, Consultant Haematologist, University Hospitals Birmingham
- Deborah Richardson, President Elect, British Society of Blood and Marrow Transplantation and Cellular Therapy, Consultant Haematologist and Honorary Clinical Senior Lecturer, University Hospital Southampton, Director, Wessex Blood and Marrow Transplant & Cellular Therapy
- Fiona Dignan, Chair BMT CRG, Consultant Haematologist, Manchester Royal Infirmary
- Henny Braund, Chief Executive, Anthony Nolan

- Jacqueline Barry, Chief Clinical Officer, Cell and Gene Therapy Catapult
- Lilian Hook, Director, Cell, Apheresis and Gene Therapies, NHS Blood and Transplant
- Marc Turner, Professor of Cellular Therapy, Director Scottish National Blood Transfusion Service
- Robert Wynn, Director of Paediatric Blood and Marrow Transplant Programme, Royal Manchester Children's Hospital
- Tara Steeds, Policy and Public Affairs Manager, Anthony Nolan
- Yasmin Sheikh, Head of Policy and Public Affairs, Anthony Nolan

Actions

- **ACTION: Tom/Beki** to keep group updated on progress of NHS number work, particularly how it could impact consent.
- **ACTION: Tom** to share AI slides with Kath.
- **ACTION: Secretariat** to ensure we feed into Stephen Powis' review of the ORP.
- **ACTION: Secretariat** to pick up with Ann on inviting someone along to discuss the summit at the January Oversight Committee meeting.
- **ACTION: Harveen** to pick up with Beki if a decision is made to do this in paediatrics too.
- **ACTION: All** to contact secretariat if they have any questions or projects to put forward that will require funding.

Agenda

1. Welcome and chairs update
2. Update from DHSC priorities
3. Delivery Group 3: Data commission update
4. Delivery Group updates
5. AOB and close of meeting

Minutes

1. Welcome and chairs update – Professor Charles Craddock, Forum Chair

- Charlie welcomed attendees to the virtual meeting, including welcoming Peter McCleave, Managing Director, DKMS UK, to the Oversight Committee.
- A reminder that the forum was set up in 2010 by the minister, with a collaborative aim to improve outcomes for patients.
- Charlie shared some reflections from his recent attendance at the ATTC launch, as well as acknowledging the progress of this group.

2. Updates from the Department of Health and Social Care (DHSC) Priorities – Dr Kath Bainbridge

- Dr Kath Bainbridge provided updates from the department since the new government.
- Key updates:
 - Lord Darzi review was published on 12th September.
 - 10 Year Health Plan to be developed. Sally Warren appointed to lead this. Expect to see outputs in Spring.
 - Submission for 1 year spending review has been made. A multi-year spending review commission will come out early in the New Year.
- New minister
 - We have a new minister, Baroness Merron, with a responsibility for stem cells.
 - Baroness Merron's portfolio covers patient voice and patient experience, patient safety, blood transplant and organs, research, life sciences and innovation.
 - Charlie is scheduled to meet with Baroness Merron at the start of November.
 - She is also visiting the NHSBT site at Filton today.
- Apheresis group
 - A group on apheresis has been formed, with representatives from NHS England and the aligned registry.
 - The first meeting is taking place on Friday 27th September.
 - The aim is to bring together data on existing apheresis capacity and look at this in the context of future need.

3. Delivery Group 3: Data Commission update – (Chairs: Beki James, Tom Coats)

- Tom gave an overview of the new vision for HSCT and ATMP data, as outlined in the 2022 report. The role of the data commission is to come together to ensure we are

working towards this model, by progressing projects of the forum and influencing wider initiatives that are positively impacting HSCT and ATMP data.

- Three key areas of activity for the data commission:
 - System-level transformation to influence
 - Federated Data Platforms (FDP), Secure Data Environments (SDE) and Outcomes Registries Programme (ORP)
 - HSCT-CT specific data projects to deliver
 - Bringing the HSCT-CT community along with us
- 5 key projects for the forum to work on:
 - Data visualisations for patients/family members
 - Predictive tool for clinicians
 - Update EBMT database to include NHS number (priority)
 - Public access to HSCT-CT outcomes data (priority)
 - Data management resource & capability (priority)
- Next steps
 - Data workshop
 - Continue to progress key projects, working with other stakeholders and supporting BSBMTCT
 - Input from the Community Advisory Group (CAG)
 - Meet with FDP and SDE contacts
- Charlie updated on the progress of the AML registry.
- **ACTION: Tom/Beki** to keep group updated on progress of NHS number project, particularly how it could impact consent.
- **ACTION: Tom** to share AI slides with Kath.
- **ACTION: Secretariat** to ensure we feed into Stephen Powis' review of the ORP.

4. Delivery group progress updates

4.1. Delivery Group 1: Sustainability and resilience of the stem cell supply chain (Chairs: Ann O'Leary & Guy Parkes)

- Recruitment and retention summit:
 - First UK face-to-face recruitment and retention summit.
 - Digital privacy laws and phasing out of third-party cookies are making a big impact on the digital landscape.
 - Paid advertising does not have the same reach/impact.
 - Recruitment and retention is impacted (positively and negatively) by changes in behaviour post-covid and attitudinal shifts in younger generations.
 - Patient appeals can drive increased recruitment, but there is often an unseen impact on the patient and their family/friends.
 - There are key factors associated with improved donor availability (eg enriched donors, donors recruited online), but recruitment mustn't focus only on these factors as it would limit diversity.
- Next steps
 - Formation of targeted aligned registry working group on donor availability and broader education/awareness
 - Mapping of existing projects and activity
 - AN/DKMS UK to create standards for patient appeals

- Next summit will take place in early 2025
- General progress updates:
 - Male donors 16-30 added to the registry - FY22-23 24K and FY23-24 22K
 - Donors from minority ethnic backgrounds added to the registry – FY22-23 20%, FY23-24 21%
 - As of 1st April 2024, there are 28,400 clinical grade cord blood units available for provision
 - Growth of partnership-based approaches to recruiting minority ethnic donors
 - FY23-24 2 cord blood webinar series took place, first ever cord blood residential in March 2024
 - Anthony Nolan and NHSBT have both established adult donor panels and both provide materials to academic and commercial partnerships. Both organisations in the process of expanding apheresis capacity. We will be developing this workstream further by inviting relevant stakeholders to a short series of meetings to explore barriers and potential solutions.
- **ACTION: Secretariat** to pick up with Ann on inviting someone along to discuss the summit at the January Oversight Committee meeting.

4.2. Delivery Group 2: Securing improvement and equity in access, experience and outcomes for patients (Chairs: Henny Braund and Dr Fiona Dignan)

- Diversity in Clinical Trials
 - Harveen presented on the Diversity in ATMP Clinical Trials project being led by Anthony Nolan.
 - Progress to date:
 - Identifying what data already exists
 - Identifying interventions used in clinical trials more broadly.
 - Speaking to other stakeholders doing research in this area, including BCUK.
 - Hoping to work with Wales and Midlands ATMP, who have a report coming out in March 2025 on diversity in clinical trials.
 - Eventual aim is to test interventions for ATMP clinical trials.
 - **ACTION: Harveen** to pick up with Beki if a decision is made to do this in paediatrics too.
- Other updates
 - BMT and CT workbook project; initial funding period completed with good progress made on training materials.
 - Prehab project – draft recommendations and guidance document are under review at present. Further update at January meeting.

4.3. Global leadership in HSCT and ATMP research – (Chair: Professor Rob Wynn)

- Charlie provided an update on Rob’s behalf.
- Key updates:
 - Paediatric network to open fully in 2025, with soft launch at the end of September.
 - Several trials already with potential to run through the network.
 - DIDACT training academy launched last September, rolling 6-month programme.

4.4. A strong and sustainable world class infrastructure (Chairs: James Griffin & Victoria Potter)

- James provided an update on apheresis:
 - House of Lords roundtable last week. PQ and letter to go to Minister regarding this.
 - DHSC committee being set up, James will be co-chairing.
 - Anthony Nolan and NHSBT have also been working up ways of increasing capacity.
- There are many workstreams addressing workforce education and training issues too.
- Presentation from Eleni Tholouli on the BSBMTCT workforce survey 2022 – key findings:
 - High variation of workload and staffing across centres
 - Variations are related to size and complexity of services but its not regional
 - Cell therapies require a highly skilled NHS workforce across all aspects and take time to train
 - No national training curriculum for key SCT/ATMP staff groups despite the complex requirements
 - SCT/ATMP services are running at maximum capacity
 - Chronic staff shortages (58% will retire in next 5-10 years)
 - Move away from charity funded hospital posts
 - Some quick fixes available
 - Need for standardisation across services
- Eleni outlined some recommendations for paediatric SCT/ATMP services:
 - Minimum of 2 HSCT consultants per centre and a minimum 4 senior doctors with 12 months HSCT experience per centre to provide 24 hour on call.
 - Consultants with other responsibilities to manage up to 5 HSCT patients pa, full time HSCT consultants to manage up to HSCT patients pa.
 - One nurse per 2 HSCT in-patients with flexibility to provide 1-1 care.
 - One CNS per 10 HSCT patients per annum.
 - Data manager: minimum band 5; 27-hrs/week+2.9 hrs for every 10 patients per year
 - Pharmacy: 1 dedicated WTE per 20 HSCT patients
 - Social worker: 1 WTE per 25 HSCT patient
- James confirmed that links with NHS commissioners have been established but will be beneficial to utilise this more.

5. AOB and close

- Gail acknowledged the progress of the commission and highlighted the importance of putting any projects forward for the Spending Review bid.
- **ACTION: All** to contact secretariat if they have any questions or projects to put forward for the Spending Review.
- Orin noted that the NBTA will continue to engage with the aligned registry to see how we can make progress on diversifying recruitment.
- **Next meeting:** Friday 31st January 2025, 12.30-15.30, face-to-face. Venue TBC, please forward any items for the Agenda to the secretariat.