



The BSBMTCT: The Role of National Registries in Data Management - The UK Experience

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Disclosures

I have no disclosures

Talk Overview

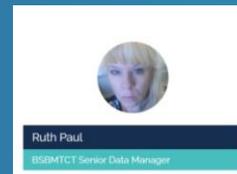
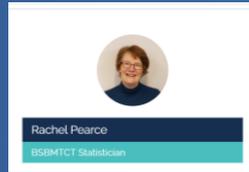
- The BSBMTCT Registry
- Introduce the Registry Team
- Where and What Types of Centres?
- The Functions of the BSBMTCT Registry
- The BSBMTCT Registry partnerships
- How we support our centres
- Annual outcomes reports
- Data Management support
- How has COVID-19 affected the Registry
- Upcoming projects
- Summary

The BSBMTCT Registry

- BSBMT Established in 1995, Registry started in 2001
- Changed name to BSBMTCT in 2019
- First ever transplant registered in the UK was in 1974
- Annually 4500 transplants
- Over 75K registrations
- Purpose:
 - Collect data on patients who receive an autologous or allogeneic transplant or cellular therapies
 - Understand their roles in disease
 - Look at the outcomes of these treatments
 - Use data collected to perform studies
 - **Improve patients lives**

The BSBMTCT Registry Team

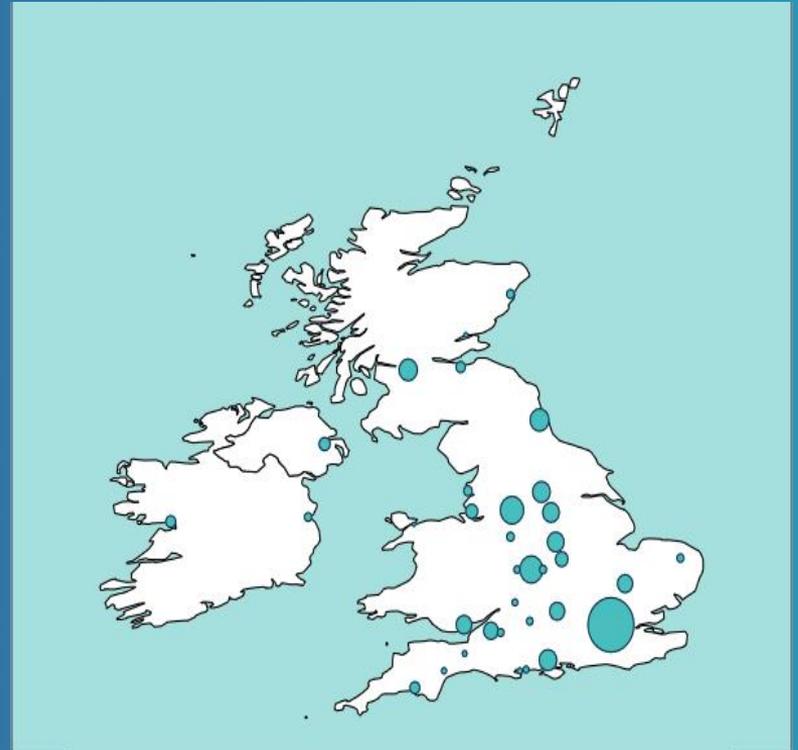
- Team of 5
 - 1 – Head of Registry – Julia Lee
 - 1 – Statistician – Rachel Pearce
 - 3 – Senior Data Managers – Marie Wilson, Ruth Paul, Clementina Abamba



- Offices in London, at Guy's and St Thomas' Hospital
- Close proximity to EBMT London Registry Office

Where and What Type of Centres?

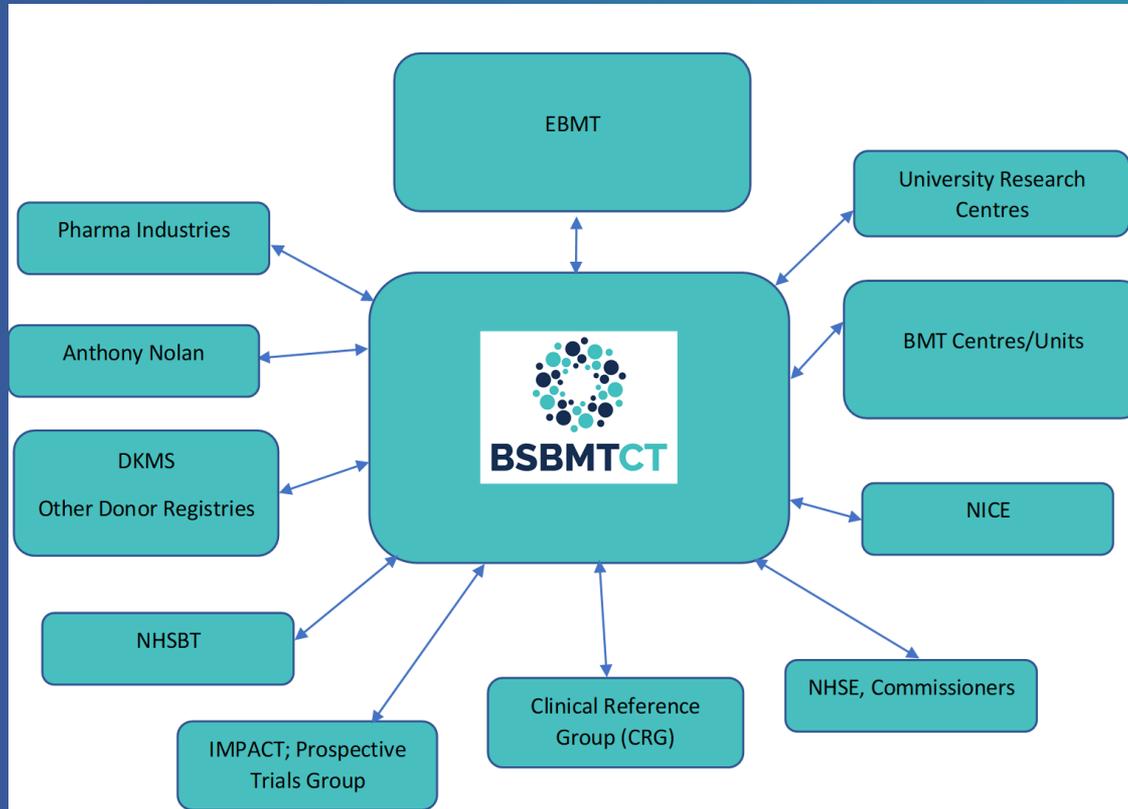
- 53 BSBMTCT Member centres from the UK and Republic of Ireland (ROI)
- 3 Private London centres
- 40 England, 5 Scotland, 2 Wales, 1 Northern Ireland, 2 ROI
- 21 Autologous only centres
- 32 Allogeneic and Autologous centres
- 35 Adult only centres, 9 Paediatric only centres, 9 Adult and Paediatric
- 12 CAR-T centres



The Functions of the BSBMTCT Registry

- Collect and coordinate data submissions from our 53 member centres
- Ensure accurate and complete data
- Provide UK outcome data and bench mark against the rest of EBMT
- Supports the Clinical Trials Committee group in retrospective studies and surveys
- Preparation of data requested by centres and other organisations
- Act as an interface between the EBMT and the UK/ROI centres
- Keep website updated and relevant
- Support centres in areas of data management

The BSBMTCT Registry Partnerships



Simplified
Diagram

How we support our Centres

- Provide training in ProMISe and MACRO
- Offer data entry support – Med A/B, HLA, HSCTs, CTs
- Ad hoc reports as requested
- Provide advice and guidance
- Quarterly registry newsletters – launched January 2021
- Produce annual outcome reports including centre reports

BSBMTCT Annual outcome reports

- 2021, 12th Edition
- Comprehensive outcomes report on 5-year cohort, plus detailed analysis of transplant data and outcomes for more recent year
- Split by malignant and non-malignant diagnoses, adult and paediatrics, Autologous and Allogeneic transplants
- Includes section on Cellular Therapies, CAR-T
- Traffic light system – for follow up and registration compliance
- Centre reports compare individual centre with rest of BSBMTCT
- Reports are sent to centres and commissioners
 - Used as a form of benchmarking
 - Commissioners use to monitor services
 - Excellent centres are asked to share best practice
 - Support given to centres when required



Data Management Support – I

- 2 DM surveys were sent in 2016 and 2019
- To understand the DM needs and requirements
 - A real need for training
 - No protected time or resources for training
 - Centres with no data management
 - Lack of support from clinicians
 - Time devoted to data management is not 100%
 - Variations in employment “bands” and hence salaries

Data Management Support - II

- We launched the Data Managers Training Day in Sept 2017
 - Full day event based in central location
 - Educational sessions from experts, patient speaker
 - Centre experience sessions
 - Networking opportunities
 - Completely free, all travel expenses paid for
 - Subsequent training days in 2018 and 2019
- Grants to attend EBMT congress
- Dedicated secure area on website for Data Managers
 - Discussion forum
 - Contact details of other DMs
 - Useful updates

How COVID-19 has affected the Registry

- Team is largely based at home since the 1st wave in March 2020
- Adapted working methods, regular virtual meetings
- Virtual training via MS Teams or GoToMeeting
- Increase requirement for data from commissioners
 - transplant numbers during pandemic
 - patient transfer patterns
 - collection of failed donations for related transplants
 - surveying centres on staff/patient testing
 - surveying centres on vaccination rollout
- Increased data support for COVID-19 studies
 - EBMT prospective study
 - Study on effect of cryopreservation

Upcoming Projects

- Data Managers Induction Manual
 - A comprehensive free online resource
 - To support new and existing DM in their roles
 - To contain modules on all aspects of SCT
 - Certification on completion
- Data Managers Virtual Training Day - 2021
 - Free event
 - Education sessions/centre experience
- Annual EBMT Data Management Session Poster
 - Gender Disparity in Autologous HSCT; Fact or Myth? A BSBMTCT registry study looking into possible male predominance in HSCT particularly in Multiple Myeloma (2021)

Summary

- The registry was established to collect and provide outcome data on patients receiving transplants and cellular therapies to ultimately improve patient lives for those diagnosed with malignant and non-malignant disease
- The registry is an invaluable resource of data and information for all our partners
- The registry will continue to play an important and central role in the transplant community

Acknowledgements

BSBMTCT Registry Team

Rachel Pearce

Marie Wilson

Ruth Paul

Clementina Abamba

BSBMTCT Executive Committee

EBMT Registry Office London

Anthony Nolan

NHSE

A special Thank You to all our Centres,
the Patients and their Families

www.bsbmtct.org

Twitter @BSBMTCT

Thanks! & Questions?

