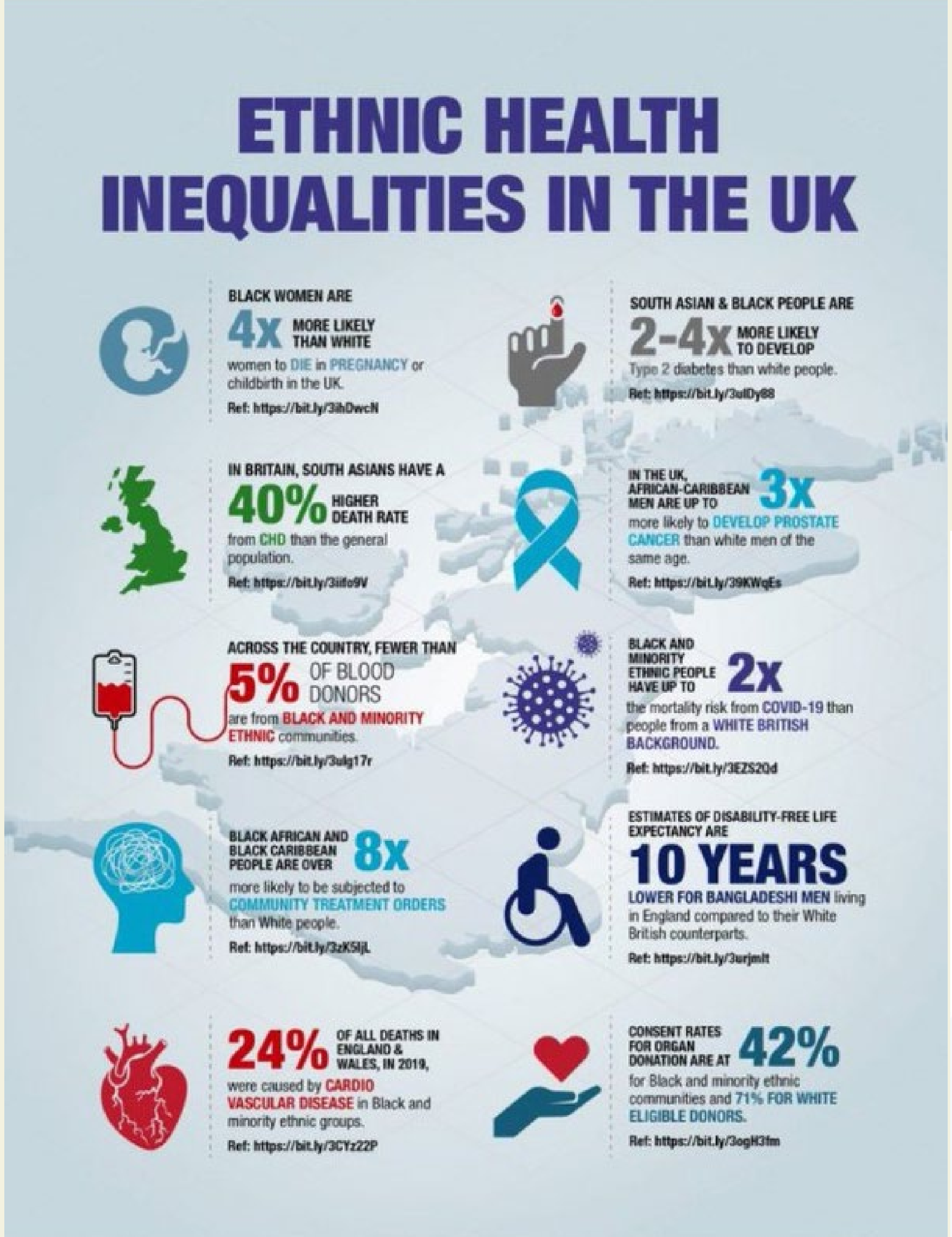
NHS
Blood and Transplant

Health Economics & Health Inequity Effecting the Patient Pathway

Guy Parkes – NHS Stem Cell Donor Registry & NHS Cord Blood Bank

Caring Expert Quality



ETHNIC HEALTH INEQUALITIES IN THE UK

BLACK WOMEN ARE **4x** MORE LIKELY THAN WHITE women to **DIE** in **PREGNANCY** or childbirth in the UK.

Ref: https://bit.ly/3ihDwcN

IN BRITAIN, SOUTH ASIANS HAVE A **40%** HIGHER DEATH RATE from **CHD** than the general population.

Ref: https://bit.ly/3iifo9V

ACROSS THE COUNTRY, FEWER THAN **5%** OF BLOOD DONORS are from **BLACK AND MINORITY ETHNIC** communities.

Ref: https://bit.ly/3ulg17r

BLACK AFRICAN AND BLACK CARIBBEAN PEOPLE ARE OVER **8x** more likely to be subjected to **COMMUNITY TREATMENT ORDERS** than White people.

Ref: https://bit.ly/3zK5ljL

24% OF ALL DEATHS IN ENGLAND & WALES, IN 2019, were caused by **CARDIO VASCULAR DISEASE** in Black and minority ethnic groups.

Ref: https://bit.ly/3CYz22P

SOUTH ASIAN & BLACK PEOPLE ARE **2-4x** MORE LIKELY TO DEVELOP Type 2 diabetes than white people.

Ref: https://bit.ly/3ulDy88

IN THE UK, AFRICAN-CARIBBEAN MEN ARE UP TO **3x** more likely to **DEVELOP PROSTATE CANCER** than white men of the same age.

Ref: https://bit.ly/39KWqEs

BLACK AND MINORITY ETHNIC PEOPLE HAVE UP TO **2x** the mortality risk from **COVID-19** than people from a **WHITE BRITISH BACKGROUND.**

Ref: https://bit.ly/3EZS2Qd

ESTIMATES OF DISABILITY-FREE LIFE EXPECTANCY ARE **10 YEARS** **LOWER FOR BANGLADESHI MEN** living in England compared to their White British counterparts.

Ref: https://bit.ly/3urjmlt

CONSENT RATES FOR ORGAN DONATION ARE AT **42%** for Black and minority ethnic communities and **71% FOR WHITE ELIGIBLE DONORS.**

Ref: https://bit.ly/3ogH3fm

In the UK, our universal healthcare system aims to offer equitable access to care for all patients but barriers to treatment and care still exist.

The NHS is still here to look after you during the pandemic.

Inequity and the unmet need in the field of stem cell transplantation in the UK are not known!

- Previous work and most publications in the field has focussed on improving access for minority ethnicity patients who find it harder to find a well-matched donor. The actions associated with this have been to try and increase donor recruitment in under-represented ethnicities combined with increasing use of alternative donor sources such as MMUD, Cord and Haplo.

- However, we recognise there are a wide variety of clinical and non-clinical factors that create barriers to HSCT:

Clinical –	Age, co-morbidities, fitness and disease status will all influence transplant eligibility
Non-Clinical -	Social, culture, economic and geographical factors also impact access and outcomes

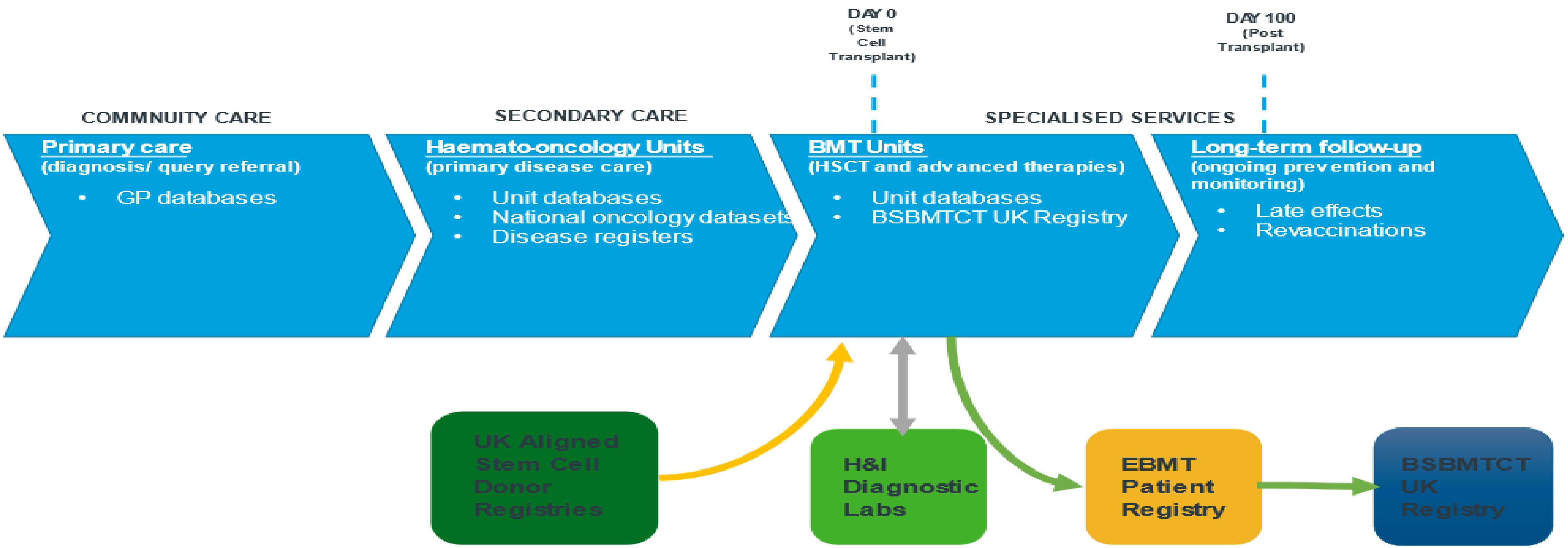
- There are data blind spots along the HSCT patient pathway where we cannot access a coherent picture to inform strategic decision making and resource planning to address these potential barriers.

Data Challenge – A Single Version of 'Truth'

NHS
Blood and Transplant

- In the UK HSCT patient pathway, collation of data and access to that data is fractured across a number of institutions and databases.

BMT & advanced therapies Patient Pathway – data flows



DAY 0
(Stem
Cell
Transplant)

DAY 100
(Post
Transplant)

COMMNUITY CARE

SECONDARY CARE

SPECIALISED SERVICES

Primary care
(diagnosis/ query referral)
- GP databases

Haemato-oncology Units
(primary disease care)
- Unit databases
- National oncology datasets
- Disease registers

BMT Units
(HSCT and advanced therapies)
- Unit databases
- BSBMTCT UK Registry

Long-term follow-up
(ongoing prevention and monitoring)
- Late effects
- Revaccinations

UK Aligned Stem Cell Donor Registries

H&I Diagnostic Labs

EBMT Patient Registry

BSBMTCT UK Registry

What are the drivers for change?

NHS
Blood and Transplant

A ten year vision for stem cell transplantation and cellular therapies

Innovative Transformational Sustainable

UK Stem Cell Strategic Forum
July 2022

1. NHS Long Term Plan to address increasing health inequalities.
2. Key recommendations of the UK Stem Cell Strategic Forum's report 'A 10-year vision for stem cell transplantation and cellular therapies': *The UK HSCT-CT community should establish a pilot research project to better understand the impact of ethnicity and socioeconomic factors on patient access to HSCT and ATMP treatment and outcomes (ref)*
3. An NHS Blood and Transplant (NHSBT) high-level priority R&D area to determine the unmet need and future demand for HSCT
4. 2021 All Party Parliamentary Group reports on Stem Cell Transplantation report on barriers to patients.

NHS
Blood and Transplant

NIHR Funded Study Protocol

Title: How to improve referral and access to stem cell transplantation through better understanding of inequity, barriers and unmet need, especially in the context of ethnic minority patients.

The questions we are interested in answering in this project are why certain patients are referred for SCT and others not, when they have a blood cancer which can be treated using SCT, the reasons for this and improvements we can make by working with patient focus groups, service providers and commissioners to address the findings and create recommendations to level up access.

NHS
Blood and Transplant

3 Year Study in partnership with Birmingham University

Aim of study

To explore factors influencing referral and access to SCT by evaluating trends in SCT receipt and association with demographic characteristics including age, gender, ethnicity, socioeconomic factors, geographical area (distance from a stem cell transplant centre) and any relevant clinical factors.

Objectives of study

1. Rate of referral to SCT according to geographical location, socio economic factors, age, gender, ethnicity, date of diagnosis, treatment date, co-morbidities
2. Short- and long-term outcomes including receipt of a transplant, access to transplant, patient survival

Team

- Research Fellow, Zareen Deplano, appointed as primary researcher
- Chief Investigator – Dr James Griffin, NHSBT
- Other Investigators/collaborators Include: – University of Birmingham Public Health team, NHSBT Statistics and Clinical Research Team and Anthony Nolan

Caring Expert Quality

Data Sources to link

CPRD - Clinical Practice Research Datalink, anonymised patient data from networked GP practices

ONS Death Registration Data

NCRAS Cancer Registration Data

HES Admitted Patient Care– Hospital Episode Statistics

Technical Summary

All AML and MDS patients, with patient data linked across the data sets, admitted between 1st January 2001 to present date.

- **Cohort 1** – received SCT
- **Cohort 2** – Did not receive SCT

Patient sociodemographic information such as age at diagnosis, gender, ethnicity, geographic location, co-morbidities and socioeconomic status using IMD will be used to analyse differences between Cohort 1 and 2.

Cohort 2 then split into Cohort 3 & 4 and same analysis to take place

- **Cohort 3** – referred but did not receive SCT
- **Cohort 4** - eligible but no referral

Outcomes to be Measured

- SCT rates within AML and MDS population according to socio-economic status SES, geographical location, ethnicity, age, gender

- Actual and eligible SCT referral rates within AML and MDS population according to SES, geographical location, ethnicity, age, gender

- Survival rates

How will we use findings?

- These data analyses will be used to identify the causes of inequities in access to HCT
- Work with focus groups including patients, service providers and commissioners to identify where the possible inequities are generated through the system at the point of diagnosis through management and longer-term clinical outcomes.
- Work with relevant stakeholders to create recommendations to address these inequities from informing more effective and targeted donor recruitment and cord blood collection to local, regional and national changes to policies and practices relating to HCT.

Aspiration example - The UK Organ Donation/Transplant Registry

The ODR is now operated by NHS Blood and Transplant (NHSBT). NHSBT’s responsibilities include maintaining the organ donor register, managing the donation process, commissioning the retrieval service, supporting centres, matching and allocating, maintaining transplant lists and monitoring outcomes.

It is a legal requirement to report all organ donors and transplants in the UK, as per the Human Tissue Act. This means that the data that is available is a high level of completion, and includes:

- Organ Donor Registrants
- Potential and actual organ donors
- Patients on the waiting list for transplant
- Organ transplant recipients (NHSBT have started working on collecting and reporting on PROMs and PREMs data)

Donor data is also highly comprehensive, collected from 30 centres across the UK. It includes adults and paediatrics data on people both living and deceased and includes demographic and clinical factors. Recipient clinical data is comprehensive and includes comorbidities, virology, HLA tissue types, operative details, immunosuppression, graft function, dates and causes of failure/death.

Aspiration example - The UK Organ Transplant Registry (cont.)

Registry data is used for a number of purposes including:

- Legal purposes,
- Auditing with annual reporting by organ, geographical region and by centre to review performanceas well as median waiting time for patients, which can be broken down by ethnicity.
- Analysis such as reviewing data by demographics, showing trends in transplants.
- Monitoring outcomes over time for each individual transplant centres using cumulative-sum methods (CUSUM). The outcome of each successive transplant is plotted and any breach of defined chart ‘control limit’ triggers an enquiry to the transplant centre.

The registry team use multi-variable modelling of survival data to identify factors influencing wait times to transplant for each organ type. This informs clinical practice and organ allocation policy.

Questions?

Thank you to SABMR, WMDA, organisers and sponsors for organising the IDRC/WMDA 2024 meeting in such a beautiful city and giving me the opportunity to watch a sunset from the top of Table Mountain ☺