

HPCC

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**HAEMATOLOGY
PATIENT
AND CARERS
CONGRESS '24**

Powered by **Sanius Health**

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Join us at HPCC 2025

Welcome to the Haematology Patient & Carers Congress '24

As I write this, I reflect on the day we decided we were going to deliver a Haematology Patient and Carer Congress, just a little over a year ago. The team and I attend congresses all the time for hundreds of haematology professionals, but it was surprising to us that an event of this size didn't exist specifically for our patients.

Today, each of us in the room are working together to make history, by being a part of the largest congregation of Haematology patients and carers – ever. There are over a thousand of us here today – patients, carers, clinicians, nurses, pharmacists, industry leaders, NHS executive leaders, patient organisations, charities. We've all taken a Friday out of our week to celebrate our patients and join a community.

From the day of my own diagnosis to today, I can hardly believe the journey it's been. I've had the unique pleasure of experiencing a community like no other. Not just the sharing of stories from amazing patient warriors, but of dedicated carers, clinicians who work unprecedented hours to deliver patient care and industry leaders focused on delivering better outcomes for patients.

Our hope is that HPCC enables others to feel even a small part of that community.

The inaugural HPCC is focused on creating a space for patients and carers to share their experiences, exchange knowledge, and learn from one another across a range of haematological disorders, while supporting collaboration and the leveraging of their collective expertise to drive advancements in haematology.

At Sanius, the driving force that sits at our core is supporting patient populations to take control of their health. The HPCC is just the next step in us working towards that mission for patients, a mission for improved outcomes, access and empowerment.

Today would not be possible without our incredible Clinical Advisory Board, Patient Advisory Board and Charities/Patient Organisation Board, who have worked for months curating today's agenda, and to them I say an enormous thank you.

The team and I can't wait to meet as many of you as possible today, look out for some amazing people in a Sanius t-shirt if you need anything at all during the day, and once again, we truly can't thank you enough for taking time out of your week to spend the day with us.



Orlando Agrippa

Chief Executive Officer & Chief Patient Officer, Sanius Health

About the Organisers | Sanius Health

Sanius Health was founded with a mission to harness cutting-edge technology to improve outcomes for patients, accelerate the latest research into rare conditions and alleviate some of the burden being placed on hospitals.

“I’ve noticed my quality of life is much better, and tracking my medication has been so helpful... Being on the app has made me so much more health conscious”

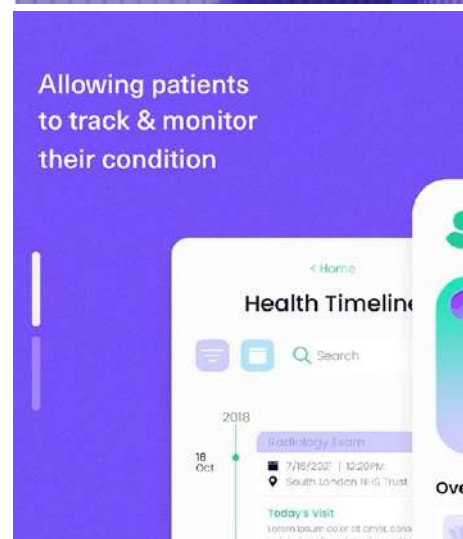
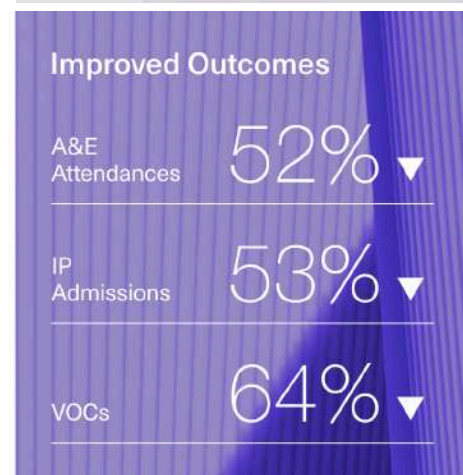
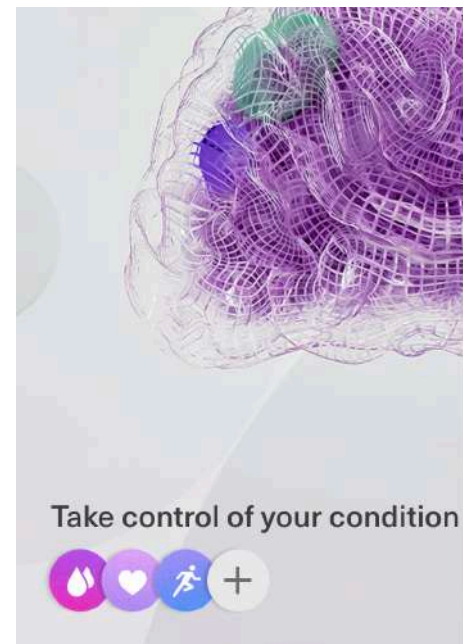
Member of Sanius Ecosystem

The Sanius platform works by combining data inputted by patients - including psychological and pain scores - with biometric information collected through wearable technology. The insights created give patients and their clinicians a round-the-clock, detailed view of their condition, and can help to flag potential complications at an early stage.

The data collected also supports research into these conditions by providing new information on patient wellbeing and quality of life, while the Sanius platform gives users access to the latest information on clinical trials and other relevant opportunities for communities.

Sanius Health is revolutionising healthcare through this innovative approach of prediction, prevention and empowering patients in their own care.

You can start your own journey with Sanius by visiting www.saniushealth.com



Empowering patient monitoring & personalised care.



Understand

Track your health progress

Monitor

Get insights into triggers

React

Improve your quality of life

Used by patients with Sickle Cell Disease, CML, Waldenstrom's Macroglobulinemia and other haematological conditions.

HPCC24 in Numbers

1000+

One thousand plus
Patients.

200

Two hundred
Clinicians.

200

Two hundred
NHS Executives.

30

Thirty
Industry Partners.

30

Thirty
**Thought Leadership
Speakers.**

20

Twenty
Patient Organisations.

Agenda and Flow of the Day

09:00	Registration Foyer	Registration and Exhibition Hall Opens
09:30	Level 3	Breakfast and Networking
10:05	Level 3	<p>A Welcome to the HPCC from Orlando Agrippa - Founder & CEO, Sanus Health</p> <p>Achieving Best in Class Patient Flow with Value-Based Care a Focus on Rare and Chronic Disease Care and Innovation: Orlando Agrippa Founder & CEO, Sanus Health</p>
10:30	Level 3	An Introduction to Haematology from Dr Sue Pavord, President, British Society of Haematology and Consultant at Oxford University Hosps.
10:40	Level 3 <i>Video</i>	<p>Care in the Community and Flow: Improving Clinical Access, Research and Outcomes for Patients</p> <p>Professor Stephen Powis, National Medical Director of NHS England and Professor of Renal Medicine at University College London</p>
10:50	Level 3 <i>Video</i>	<p>Accelerating Health Equity: The Latest on New Sickle Cell Disease NHS Programmes.</p> <p>Professor Bola Owolabi, Director of the National Healthcare Inequalities Improvement Programme, NHS England</p>
11:00	Level 3	<p>"How Embracing My Community Has Helped Me To Live Well With Sickle Cell Disease." Chukwumaihe Nzerue, Patient Representative</p> <p>Q&A Session</p>
11:15	Level 3	<p>Panel Discussion</p> <p>Looking to the Future of Value-Based, Patient-Centred Care: Global Approaches, Innovation and Access.</p> <p>Chaired by Claire Harrison, Professor of Myeloproliferative Neoplasms and Deputy CMO at Guy's and St Thomas' Hospital, and Shirley D'Sa, Consultant Haematologist and Clinical Lead for the UCLH Centre for Waldenström's macroglobulinemia (WM) and Associated Disorders.</p>
11:45	Level 3	<p>Concluding Thoughts and Thanks</p> <p>from Orlando Agrippa - Founder & CEO, Sanus Health</p>
11:50	Level 3	Lunch, Exhibitions & Research Posters

Disclaimer | Please note that the agenda might change on the day. Please ask a member of staff if you have any questions

Patient Plenary Sessions

13:30	St James	Welcome - Eric Low, Former CEO of Myeloma UK How Patients and Carers Can Support Health Technology Appraisals and NICE processes Eric Low, former CEO of Myeloma UK
13:45	St James	Exploring Innovative Trials in Haematology: Ensuring Safety, Diversity, and Patient Advocacy Professor Adele Fielding, Professor of Haematology, University of York and former President of the BSH
14:00	St James	An Update on New Technology/ Therapies- CAR-T, Gene Editing, Stem Cell Transplant - Malignant and Non Malignant Professor Mhairi Copland, Professor of Translational Haematology at the University of Glasgow & Dr Sanne Lugthart, Consultant Haematologist at University Hospitals Bristol
14:15	St James	Ask A Patient - Sharing Experiences and Stories Lizzie Dean, Mark Nicholas and Geoff Thomas, Patient Representatives
BREAK		
14:45	St James	Ask An Expert Panel Dr Shirley D'Sa, UCLH; Professor Claire Harrison, GSTT; Professor Ashutosh Wechalekar, Royal Free; Dr Paul Telfer, Barts Health.
15:05	St James	Rare Blood Disorders, Cancers, and Brain Fog: Exploring Challenges and Coping Strategies Dr Carol Sampson, Consultant Clinical Neuropsychologist and Director, INSneuro Dr Debbie Cook, Counselling Psychologist, Maggie's Cancer Centre, Glasgow.
BREAK		
15:45	St James	Treatment Challenges and How Healthcare Professionals Can Better Support Patients and Carers? Dr Kofi Anie MBE, Consultant Psychologist & Honorary Clinical Senior Lecturer, London North West University Healthcare NHS Trust. Dr Lina Eliasson, Chartered Psychologist & Founding Partner, Sprout Health Solutions
16:05	St James	Shared Decision Making: Choosing Medicines That Align With Personal Beliefs (Non-promotional education session by Viatrix) Nick Duncan, Consultant Haematology Pharmacist, University Hospitals Birmingham



Small Talks



Small Workshops



Big Workshops



Small talks- 15 minutes unless specified

13:45 Sessions

Room I Chaucer (13:45-14:00)



A Guided Tour Round Your Blood Count

Dr Simon Stern, Consultant Haematologist

Room I Keats (13:45-14:15)



The LGBTQ+ Experience of Healthcare and Ethnic Minority Representation in Trials

OUTpatients Charity Representative & Dr Pinkie Chambers, Honorary Associate Professor, UCL and Lead Pharmacist, UCLH

Patient Workshop Rooms

Room I Wesley (13:45 - 14:25)



Sickle Cell Education Series | Dr Rossby Awadzi

BREAK- 5 mins

Room I Wesley (14:30 - 15:10)



Sickle Cell Education Series | Dr Rossby Awadzi

BREAK- 5 mins

Room I Wesley (15:15 - 15:55)



Sickle Cell Education Series | Dr Rossby Awadzi

13:45

Room I Burns

A Guide to Your Bone Marrow

Dr Priya Sriskandarajah, GSTT, Consultant



14:00

Room I Byron

Patient & Public Inclusion: How Patients Can Get Involved

Michael Howard, Patient Representative, Kirsty Crozier, Advanced Nurse Practitioner



14:30

Room I Burns

Exercising With A Haematological Condition: Benefits & Staying Safe

Dr Orla McCourt, Dr Paul McLaughlin, Clinical Physiotherapists



14:40

Room I Byron

Nutrition: Tips, Tricks & Plans

Dr Claudine Matthews, Dietician



Small Workshop Sessions

Room I Wordsworth (13:45-14:45)



Digital Support & Improving Outcomes in MPN

Deb Street, MPN Voice; Patrick Harrington, Consultant, GSTT

Room I Wordsworth (15:15 - 16:15)



Surviving Parenthood With A Chronic Illness

Reia DaCosta, Patient Expert

14:30

Room I Chaucer

Improving Quality of Life and Patient Empowerment

Kirsty Crozier, ANP; Claire Woodley, ANP



15:00

Room I Burns

Managing Your Finances - Advice and Options

Dany Bell, Strategic Advisor at Macmillan Cancer Support



15:45

Room I Chaucer

How Primary Care Can Support You On Your Rare Disease Journey

Dr Mina Gupta, Group Clinical Chair, Modality Partnership; Ade Williams MBE, Superintendent Pharmacist



Key-Note Speakers



Sir James Mackey

NHSE National Director for Elective Recovery, Chief Executive Officer, Northumbria NHS Foundation Trust



Professor Stephen H Powis

National Medical Director of NHS England & Professor of Renal Medicine at University College London



Ade Odunlade

Chief Operating Officer, South London & Maudsley NHS Foundation Trust



Vincent Sai

Chief Executive Officer, Modality Partnership



Orlando Agrippa

Chief Executive Officer & Chief Patient Officer, Sanius Health



Sue Barnett

NHS Turnaround Director and Former NHS Board Member



Professor Claire Harrison

Professor of myeloproliferative neoplasms and Deputy CMO at Guy's and St Thomas' Hospital NHS Foundation Trust



Dr Shirley D'Sa, MD, FRCP, FRCPATH

Consultant Haematologist & Clinical Lead | Honorary Associate Professor at the UCL Cancer Institute. UCLH NHS Foundation Trust



David Probert

Chief Executive Officer, University College London Hospitals



Sue Pavord

President of British Society for Haematology, Consultant Haematologist at Oxford University Hospitals NHS FT, Director of Oxford Iron Clinic



Dr Mohammad Al-Ubaydli

Founder & Chief Executive Officer, Patient Knows Best



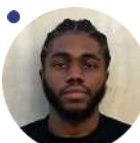
Dr Bahman Nedjat-Shokouhi, PhD, FRCP

Founder & Chief Executive Officer, Medefer



Professor Bola Owolabi

(MRCGP, MFPH Hon, FRSPH) is Director of the National Healthcare Inequalities Improvement Programme at NHS England



Chukwumaihe Nzerue

Patient Representative

What is On The Menu?

Breakfast

- Unlimited teas and coffees
- Fairtrade coffees and a selection of teas (Includes fruit and herbal infusions and decaffeinated coffee)
- Vivreau filtered water
- Selection of mini pastries
- Selection of juices and smoothies

Breaks Throughout the Day

- Unlimited teas and coffees
- Fairtrade coffees and a selection of teas (Includes fruit and herbal infusions and decaffeinated coffee)
- Home-made cookies

Lunch

STARTERS

- Wholewheat pasta salad, grilled courgettes, sun blushed tomatoes, rocket pesto
- Chicken tikka salad, Lentils, cucumber, cherry tomatoes, coriander leaves and lemon dressing

DESERT

- Peach cobbler, vanilla cream (ve) (warm)
- Chocolate pannacotta, summer berries compote (ve)

MAIN COURSES

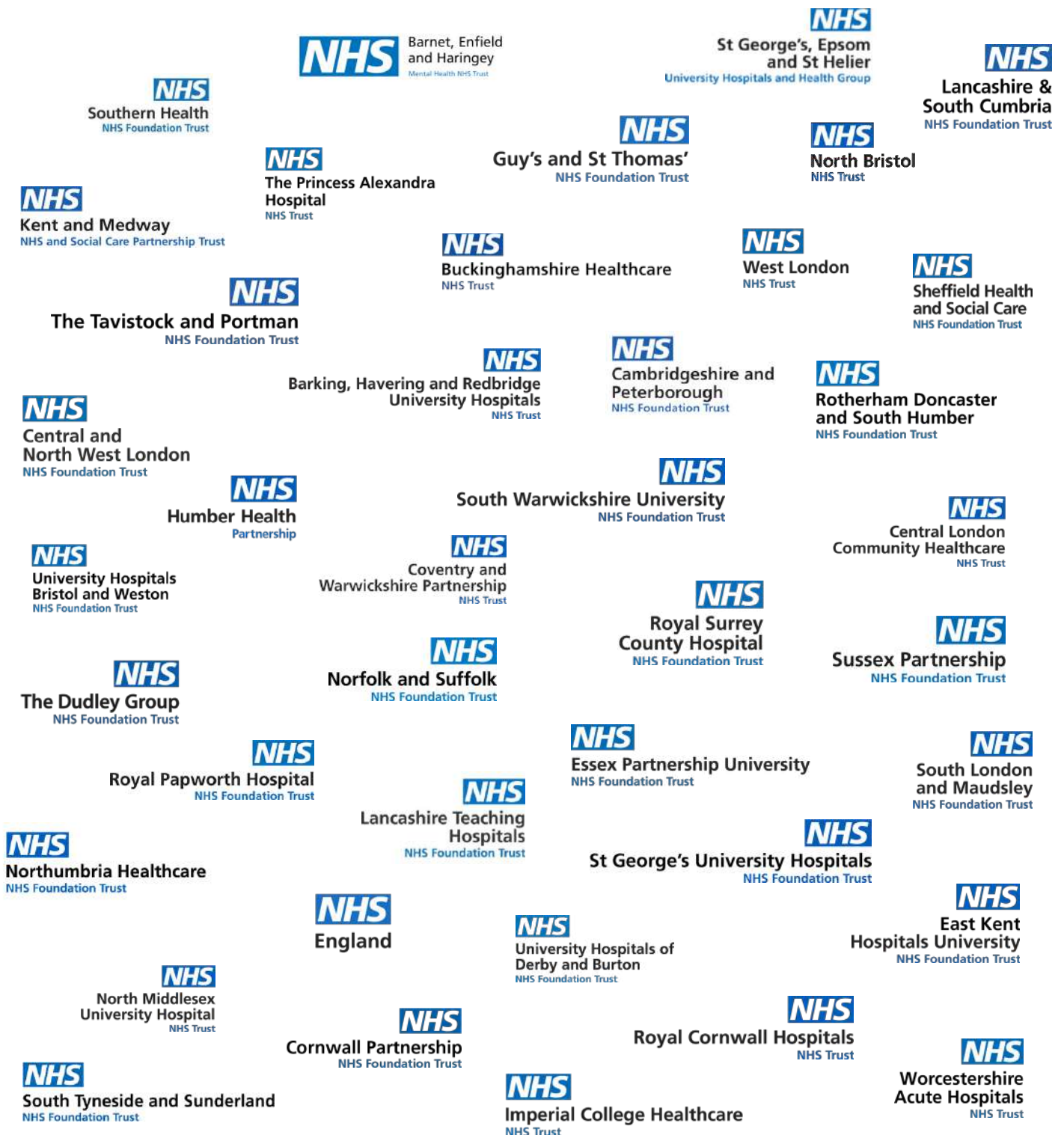
- Tomato & potato Gnocchi chargrilled asparagus, peas and courgette, red onion salad and basil (ve)
- Jamaican jerk and London honey spiced lamb 'rice and peas', chargrilled tenderstem, jerk jus

End of Day Ice Cream

- Stracciatella Gelato (Contains Milk)
- Chocolate Gelato (vegan, allergens free)
- Mango & Lime Sorbet (vegan, allergens free)
- Raspberry Sorbet (vegan, allergens free)



Trusts In Attendance



Trusts In Attendance



Essex Partnership University
NHS Foundation Trust



Practitioner Health



Royal Free London
NHS Foundation Trust



Berkshire Healthcare
NHS Foundation Trust



Salisbury
NHS Foundation Trust



**Leicester, Leicestershire
and Rutland**



The Mid Yorkshire Hospitals
NHS Trust



East and North Hertfordshire
NHS Trust



Nottinghamshire Healthcare
NHS Foundation Trust



**University College
London Hospitals**
NHS Foundation Trust



West Suffolk
NHS Foundation Trust



North East London



The Newcastle upon Tyne Hospitals
NHS Foundation Trust



North Tees and Hartlepool
NHS Foundation Trust



**James Paget
University Hospitals**
NHS Foundation Trust



Isle of Wight
NHS Trust



**Mid and
South Essex**
NHS Foundation Trust



**Portsmouth Hospitals
University**
NHS Trust



Frimley Health
NHS Foundation Trust



Chelsea and Westminster Hospital
NHS Foundation Trust



**County Durham
and Darlington**
NHS Foundation Trust



Derbyshire Healthcare
NHS Foundation Trust



Arden&GEM



**Cambridge
University Hospitals**
NHS Foundation Trust



Bedfordshire Hospitals
NHS Foundation Trust



**Bedfordshire, Luton
and Milton Keynes**
Integrated Care Board



Camden and Islington
NHS Foundation Trust



East Sussex Healthcare
NHS Trust

The Royal Marsden



NHS Foundation Trust



King's College Hospital
NHS Foundation Trust



Mersey Care
NHS Foundation Trust



North East London
Integrated Care Board



Bradford District Care
NHS Foundation Trust



**The Clatterbridge
Cancer Centre**
NHS Foundation Trust



**South West
Yorkshire Partnership**
NHS Foundation Trust



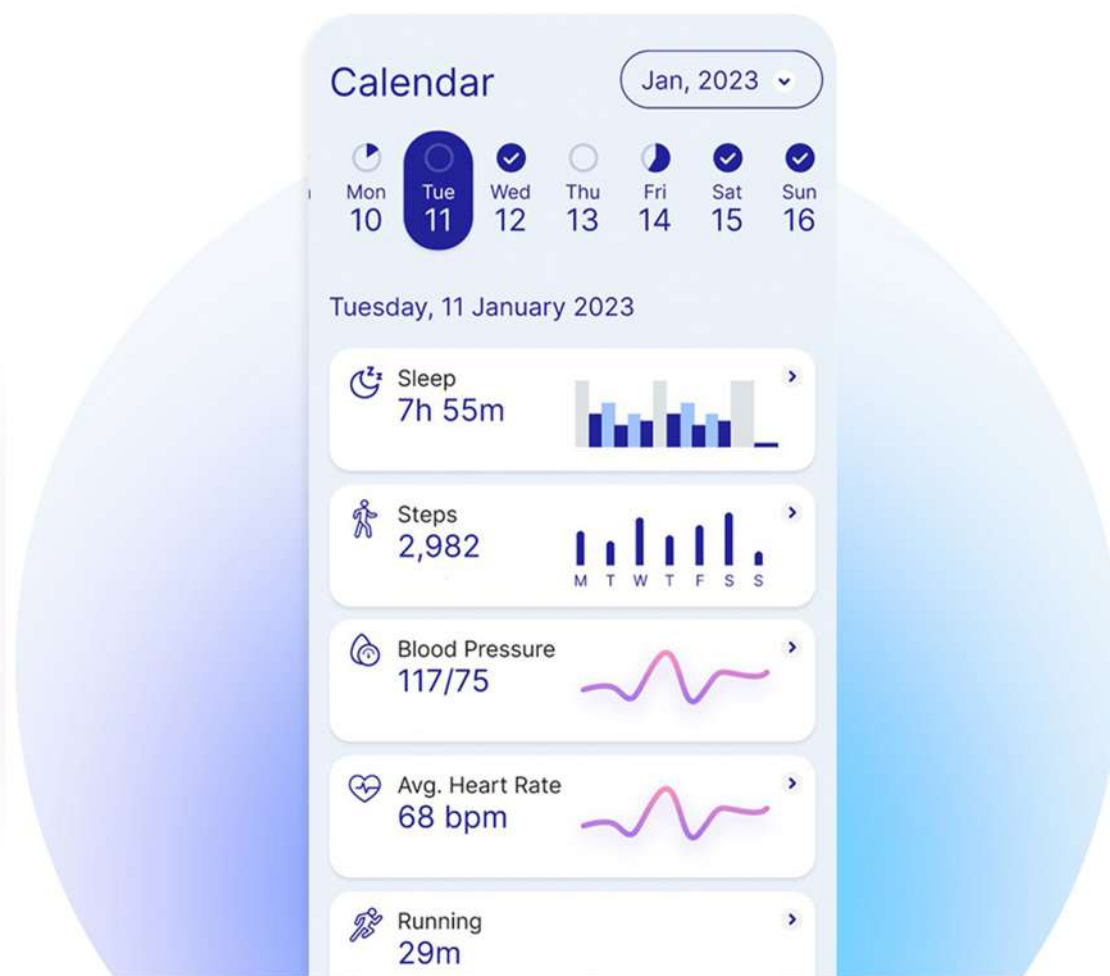
**Rotherham Doncaster
and South Humber**
NHS Foundation Trust

Our Partners



AstraZeneca, Beigene, Pfizer, Viatriss, Kite/Gilead and Roche have kindly provided financial support purely for the organisation of this meeting. These organisations have had no input into the meeting content, nor are sponsoring any meals or gift bags. Financial support has been provided to Sanius Health Limited as a grant from Pfizer Ltd for this Patient Congress.

Giving you an insight into your health.



Take control of your health with Sanius. Our innovative app and wearable device empowers individuals with rare and chronic conditions to better monitor symptoms and uncover insights. Sanius puts the power of data and knowledge in the hands of patients, providing personalised tools to track health trends, detect changes, and gain clarity around complex conditions. Say goodbye to unpredictability and mystery and hello to greater understanding and improved wellbeing.

Nursem

nursem

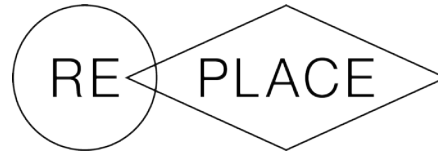
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SHORE
THE SCOTTISH SEAWEED CO.
EST. WICK

Remedy



Replace London



The Tea Makers of London



Planet Organic

**PLANET
ORGANIC**

Bird & Blend Tea Co.



Aqua Libra



A Special Thank You to

Our Gift Bag

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HPCC 25

HPCC

**We can't wait to
welcome you back to
the community!**

Join us at the next
Haematology Patient
and Carer Congress



Join us next
year by
scanning the
QR code.



Connect with a Community

Symptom Management

Mental Health Support

Self-Care and Wellness

Support for Carers

Clinical Trials

Join us next year by scanning the QR code above.



HAEMATOLOGY PATIENT AND CARERS CONGRESS '24

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Friday 10th May 2024, 9am - 4:30pm

Queen Elizabeth II Centre, London