How can we improve haemoglobinopathy services?

Thursday 16th January 2020

11:15 – 11.45

Background

- Historically, individuals with sickle cell disorders (SCD) and thalassemia, and their communities, have been **under-served**
- Exciting time for SCD and thalassemia, with **new treatments and new methods of delivery** offering hope for a step-change in care
- Growing awareness of how best to support individuals and families affected by haemoglobinopathies
- **Listening to patients and carers** places emphasis on holistic care – not just treating disease symptoms, but **maximizing wellbeing and quality of life**

How can we improve haemoglobinopathy services?

1. Joined up, prompt, appropriate, holistic, **patient-centred care**
2. Greater patient support, education and participation
3. **Expansion of haemoglobinopathy day care** support units
4. **Improved uptake of** effective disease modifying agents e.g. **Hydroxycarbamide (HU)**
5. **Improved transition** from paediatric to adult services
6. **National Haemoglobinopathy Panel** and **National MDM**
7. **Peer review**; **workforce planning**
8. **Research** and **new treatment** modalities (Voxelotor, Crizanlizumab, Luspaticept, gene therapy, stem cell transplantation)

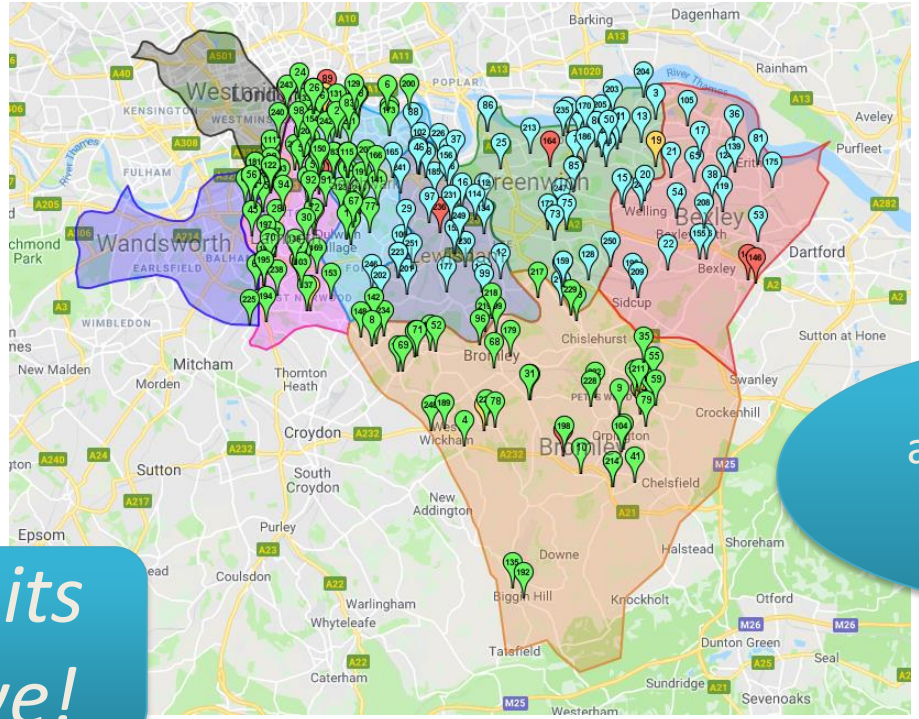
1. Joined up, prompt, appropriate, holistic patient-centred care

- **IT solutions**
  - Local Care Record
  - Co-ordinate My Care
  - National Haemoglobinopathy Registry, expansion to include Care Plans
- **Mind and Body teams**
  - Incorporating psychology, psychiatry, social work and therapies
- **IMPARTS screening**
  - Integrating mental & physical healthcare: research, training & clinical services
  - King's Health Partners initiative
  - Screening questionnaires for patients to complete on tablet during annual review/New patient clinics, including medication compliance, anxiety, depression, sleep, work/social functioning, alcohol and smoking history, electronically linked to Electronic Patient Record
- **PREM**
  - Validated Patient Reported Experience Measure survey
  - Act on results, remove / address stigma and inequities

Local Care Record

- **Improved secure sharing of patient information electronically** between local hospitals and GPs in Lambeth, Southwark and Bromley
- Allows clinicians to review relevant information
- Linked to Connect Care system in Bexley, Greenwich and Lewisham
- Connecting ~15,000 care professionals across SE London, ~ two million patients
- Records are **read only**
- **Information from GP record** - patient summary, problems, diagnosis, medications, warnings, procedures, vaccinations, investigations, examinations (BPs), events (encounters, admissions and referrals), patient demographics
- **Information from hospital records** – appointments, visits, medicines, allergies, test results, referrals, clinic letters, discharge information

Where is Local Care Record live?



30 million hits since Go Live!

LCR can be accessed by 251 sites across SE London

Coordinate My Care (CMC)

Role of CMC:

- Electronic patient centred urgent care plan accessible by NHS agencies, LAS, 111, hospices, and patients within London

What information does it hold?

- Diagnosis, medication, key contacts, patient preferences, DNAR status, ceiling of care
- myCMC portal for patients to initiate care plans and view signed off care plans

Users

- GP, community nurses, hospital team, out-of-hours doctors, specialist nurses, London Ambulance Service and NHS 111

Drawbacks

- Not developed specifically for SCD so requested information not always relevant
- LAS system linked to patient address – no automatic flag if LAS not called to home address
- Not all patients consent to CMC, fears about how information might be used?

CMC is currently available across London and funded by the 32 CCGs representing London

Single care plan with multiple collaborators across the London area NHS

Probable future roll out to other regions…

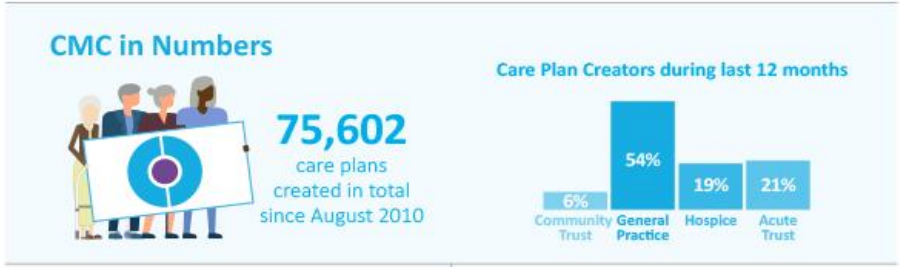
CMC at a glance

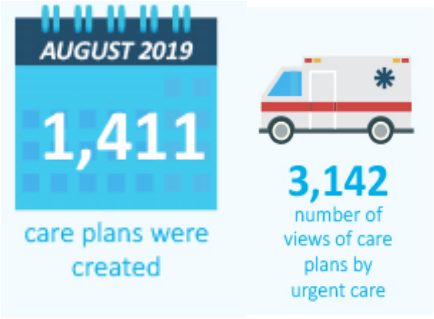
75,602
care plans in total

1,411
new care plans added in August 2019

3,142
views of CMC care plans by urgent care in August 2019

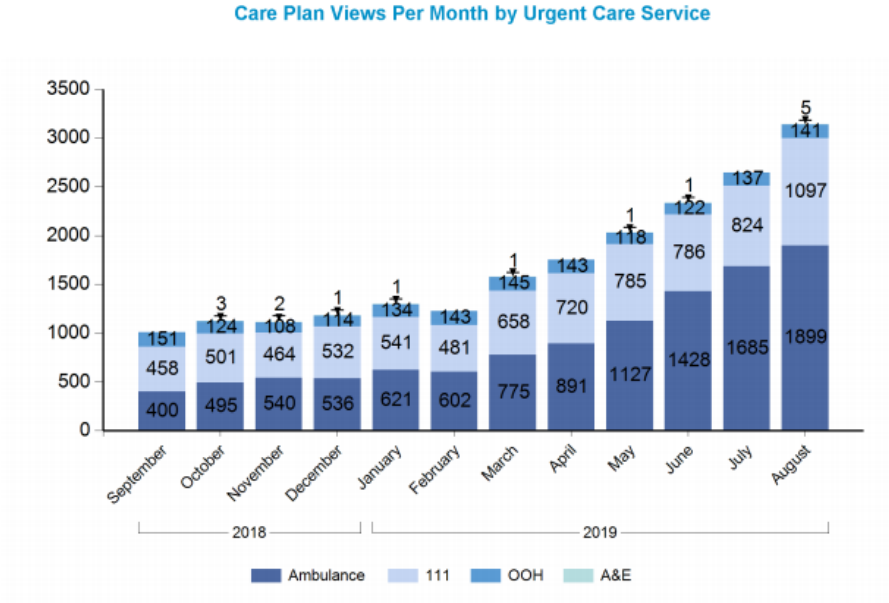
Why CMC?





Used by LAS
One London electronic care plan
Implemented by Sustainability and Transformation partnership (STP)

Link within Local Care Record



Benefits

Patient

- Quicker access to appropriate care/medications
- Don't have to repeat story to multiple health care professionals
- Can view their care plan online and input wishes/preferences
- Take ownership of care

Clinician

- Access to vital patient information when patient may be in too much pain to explain
- Improve care management
- Reduce time spent looking up history
- Can set alert if patient seen by urgent care

Urgent Care

- Reduce time spent looking up history
- Care plans available in real-time to enable effective management
- Help decide best on-going care for patient including **most appropriate location**
- Information available to other providers

Patient Experience

- More in control
- Feel listened to
- Smoother pathway
- Quicker access to care

Quality

- Accurate timely management
- Improved data collection
- Improved clinician to patient relationship
- Support MDT working

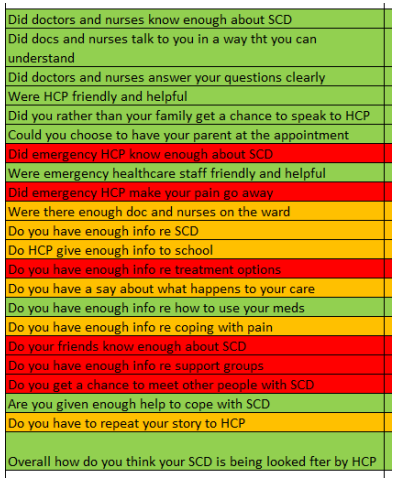
Value for money

- Reduction in unnecessary admissions
- Reduction in ED attendances

PREM results

Adults

Children



Carers

2. Greater patient participation, support and education

- Address barriers preventing those with SCD from receiving effective treatment e.g. HU
  - **Shared decision making tools** to facilitate patients to make informed choices about care
  - Regular local **support groups**
  - **Patient consultation** for patient information leaflets
  - **Education and awareness events**
  - Improved access to benefits and social support

Shared decision making tool:

Developed with input from patient groups to ensure relevancy and appropriate language

Hydroxycarbamide = Hydroxyurea (HU) in sickle cell disease (SCD)

Shared decision making tool

What is HU?

- A disease modifying medication taken long-term as once daily capsule(s) by mouth to reduce the severity of sickle cell disease by gradually improving symptoms and blood results over several months
- If treatment is stopped, the beneficial effects wear off within about two months

Who should be offered HU?

BSH Guideline, May 2018

- HbSS and HbSβ⁰ infants from 9 months - **offer regardless of clinical severity**
- HbSS and HbSβ⁰ children, adolescents and adults - **consider regardless of clinical severity**
- >3 pain episodes in a year, interfering with daily activities and quality of life (QOL)
- Severe or repeated acute chest syndromes
- After a transfusion program for children & adults with previous ischaemic stroke
- Sickle kidney disease with protein in the urine despite medication
- Low oxygen saturations and pulmonary hypertension and
- Anaemia causing symptoms which interfere with daily activities and QOL

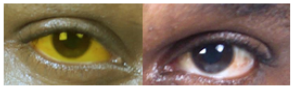
Published studies of benefits of hydroxycarbamide in SCD

- *9 year follow up (MSH study JAMA 2003; 289:1645.), 40% reduction in mortality*
- *17.5 year follow up (Am J Hematol 2010; 85:403), 50% reduction in mortality*
- *BABY HUG trial (Lancet 2011; 377:1663) showed treatment is safe and effective from 9 months of age*

Benefits:

- **Improved survival**
- Fewer and less severe pain episodes
- Fewer hospital admissions, transfusions, chest crises
- Less organ damage and jaundice
- Improved wellbeing, higher haemoglobin, improved exercise tolerance

Before HU | After HU



Yellow jaundice of eyes usually disappears or improves with HU treatment

Safety concerns?

- >30 years clinical experience and trials show:
  - No significant long-term toxicities in SCD
  - No increase in cancer, stroke or leukaemia in HU-treated SCD

Monitoring

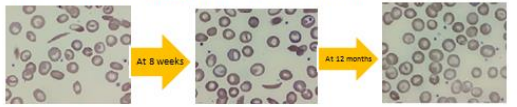
- Blood tests 2 weeks after starting treatment or a significant (>10%) dose change, and then at least every 12 weeks
- Monitor full blood count, reticulocyte count, kidney and liver function

Fertility

- Contraception during treatment and for three months after stopping treatment
- Normal births despite mother or father taking HU
- No effect on female fertility
- Some males have a reduced sperm count on or after HU treatment - consider sperm banking

Blood film changes on hydroxycarbamide:

Reduced numbers of sickle cells on blood film
Higher haemoglobin (more red blood cells)
Larger red blood cells (higher mean cell volume – MCV)
Higher foetal haemoglobin HbF (and lower sickle haemoglobin)



Before HU	After 8 weeks	After 12 months
Hb 76 g/l	Hb 79 g/l	Hb 100 g/l
MCV 84 Fl	MCV 96 Fl	MCV 113 Fl
HbF 4%	HbF 8%	HbF 16%

Increasing foetal haemoglobin during treatment hydroxycarbamide:

Foetal haemoglobin (HbF)% typically increases by 4-5 times

Higher HbF levels are associated with increased survival, fewer complications and less pain

Side effects:

- Well tolerated with no significant long-term toxicities
- Occasional gut discomfort, which is avoided by taking at night after food
- Rarely thinning of hair, which reverses when the medicine is stopped
- Reversible reduction in blood cells, which is why regular blood test are needed
- Darkening of nails and skin, which depends on the dose and reverses after stopping

Temporary darkening of nails can occur with HU

A dosette box can help you take medication regularly

3. Expansion of haemoglobinopathy support units

- Outpatient/day treatment to avoid Emergency Department (ED) use in high prevalence units
- Potential to avoid reported poor ED experiences
- Rapid review by usual specialist Haemoglobinopathy pathy team
- Potential to avoid admissions

4. Improved uptake of effective disease modifying agent Hydroxycarbamide (HU)

- **Virtual/telephone clinics** to support patients and avoid unnecessary hospital visits
  - e.g. blood monitoring
- **Home delivery** of specialist medications to avoid wait in pharmacy

Telephone Nurse Led Hydroxycarbamide Clinics:

Current vs New Pathway

Previous Pathway

- Wait in Phlebotomy = 30-60 mins
- Wait for blood results = 1.5 hours
- Wait to be seen by Dr = 30-60 mins
- Reviewed and given prescription = 15 minutes
- Attends pharmacy to collect meds = 1.5 hours

- **<u>Waiting time from start to finish = >5 hours</u>**

New Pathway

- Blood test at 'quiet phlebotomy time' or Supportive Therapy Unit HSU = 20 minutes
- Telephoned with results review = 5 mins
- Home delivery of hydroxycarbamide

- **<u>Waiting from start to finish = 25 minutes</u>**

Benefits

- Improved outpatient clinic capacity
- Decreased waiting time for consultant-led follow up appointments
- Reduced unnecessary waiting in hospital
- Reduced unnecessary face-to-face follow up appointments
- Good for patients with work/study/family commitments
- Increased uptake of hydroxycarbamide, with consequent improved clinical outcomes

5. Improved transition from paediatric to adult services

- **Specialist Transition CNS**
  - Named and easily contactable, focussed on 14-24 age group
- **Ready, steady, go!**
  - Prepare for transfer, inform decisions on timing of discharge from paediatric services
- **Transition pack**
  - Gym bag with NHR card, Care Plan, ARV, thermometer, dosette box, pen and notebook, team details and contacts, GP info (vaccinations, prophylactic antibiotics, emergency management)
- **Transition videos, open days / workshops**
- **Transition/Teenage clinics**
  - Paed and adult staff, based in adult clinic environment
  - After school/college hours

Transition from children's to adult's services

Specialist Transition CNS

Open day / workshop

Transition Pack

Thermometer

Dosette box

Transition pack with Care Plan

Supply of antibiotics

Paperwork – NHR card, clinic letters, notebook and pen

6. Haemoglobinopathy Coordinating Centre and National Haemoglobinopathy Panel

- KHP successful in bid to host National Haemoglobinopathy Panel (NHP)
- Prof Baba Inusa is interim Chair
- Main aims:
  - Improve experience of all haemoglobinopathy patients
  - Reduce inequalities
  - Improving timely access to high quality specialist care
  - Improve delivery of care
  - Increase standardisation among providers and commissioners

What are Haematology Coordinating Centre and National Haemoglobinopathy Panel?

Haemoglobinopathy Coordinating Centre

Aim

- Reduce levels of morbidity and mortality and improve experience of all haemoglobinopathy patients by reducing inequities and improving timely access to high quality expert care

Means

- Support provision of specialist and non-specialist haemoglobinopathy services
- Provide expert opinion and management for complex patients
- Provide coordinated leadership, improving clinical care by supporting local Specialist Haemoglobinopathy Teams

National Haemoglobinopathy Panel

Aim

- Improve delivery of haemoglobinopathy care and increase standardization among providers and commissioners

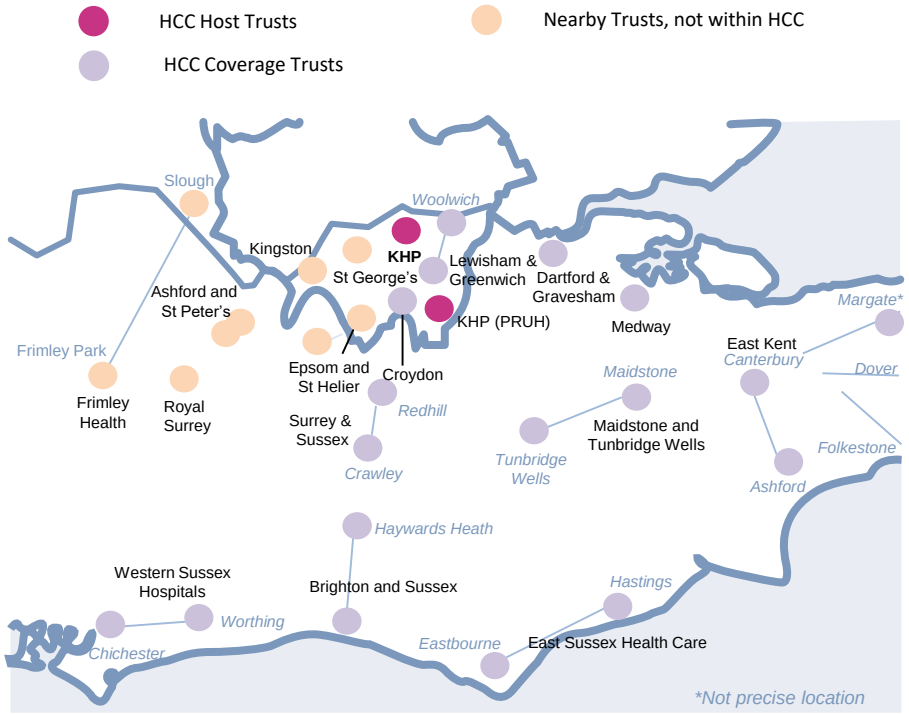
Means:

- Coordinate actions taken at SHT and HCC levels, increasing access to specialist knowledge and reduce unwarranted variation
- Drive innovation and quality by monitoring relevant data at a national level
- Promoting access to novel therapies and clinical trials for all patients, regardless of geography

KHP Haematology Coordination Centre and National Panel Map of HCC Coverage

- **KHP deliver the largest SCD Service in Europe:**
  - Key contributor to national SCD guidelines
  - Largest portfolio of clinical trials
  - Audited performance for hydroxycarbamide, pain management, and acute chest condition
  - Operate STSTN MDT

- **Large specialist workforce (adults/paediatrics):**
  - 9 SCD consultants (5/4)
  - 13 specialist nurses (8/5)
  - 8 psychologists (5/3)
  - 4 community nurse specialists
  - 1 benefits advisor



Source: 210619 – HCC Tender – Lot 8

HCC functions:

- Use existing structures to **support local services** with access to expert quality advice and care
- **Host Multidisciplinary Team Meetings** via telephone/video conference
- **Develop educational programme** to support guideline implementation
- Support local providers in **data collection and audit** to ensure quality and reduction in variation
- Develop **plan for improving emergency pathways** through education including use of digital tools to improve access to education, advice and best practice for local providers
- **Deliver outreach clinics** through virtual model to increase frequency
- **Publish quarterly newsletter** and **administer website** resource to inform local providers and to improve access of information for patients and families
- **Promote patient participation in service development** and use digital tools to ensure access from the wider network

National Panel

Structure and governance	Governing Board of NHP will include all HCCs, all relevant clinical specialists, and patients and will review relevant data, develop NHP activities, provide an escalation route, and facilitate NHP MDT structure
Operational Roles	Four main roles: ➢ Education (annual education days, quarterly training, review of complex cases, etc.) ➢ Defining and sharing best practice through a working group ➢ Maintaining lists of centres providing innovative therapies and conducting research ➢ Coordinating peer review of outcomes to reduce inequalities and increase consistency
Effectiveness Metrics	➢ Participant feedback from training sessions ➢ Volumes of patients accessing & aware of innovative therapies and clinical trials ➢ Number and percentage of SHT & HCC clinicians referring to NHP
MDT Structure	NHP will lead two-tiered MDT structure, with monthly videoconferences for complex cases, and shorter turnaround email-MDT providing expert opinion
Mobilisation	Widespread consultation and transparency on roles, job descriptions, referral processes and criteria

7. Peer review & Workforce planning

- **Peer review**
  - **Assessment of outcomes, processes and delivery of care**
  - Collaborative peer to peer reviews, self reporting with inspection of all underperforming units, and a proportion of self reported compliant units
- **Workforce planning**
  - Sufficient expert medical and nursing staff to look after expanding cohort
  - Training and investment in psychologists, psychiatry, social workers, CNSs and doctors, including community teams

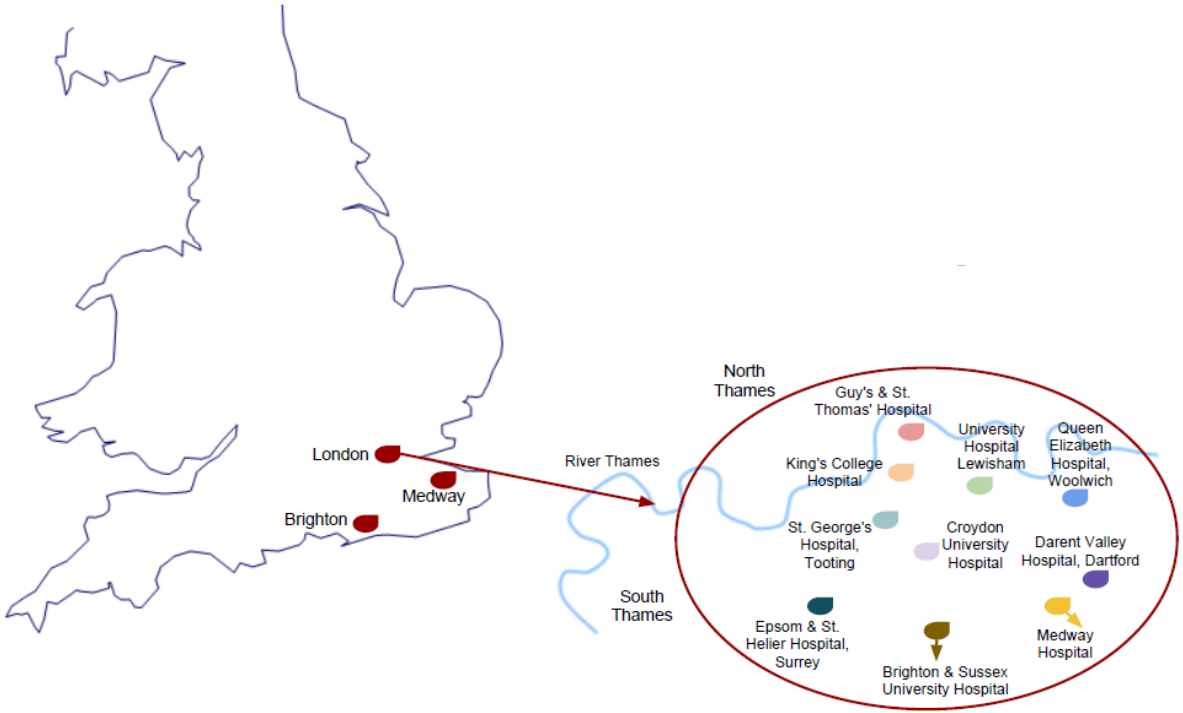
8. Research and new treatment modalities

- Voxelotor, Crizanlizumab
- Gene therapy, stem cell transplantation
  - Where will treatments fit into clinical practice?
  - How can we ensure **equitable access?**
  - **Ennsure appropriate use?**
  - National panel to screen all gene therapy, stem cell transplantation referrals

Stakeholder views

- October 2019 stakeholder group workshop discussed current and future delivery of care
- Included doctors, nurses, psychologists and administrators from KHP (King's Health partners) and STSTN (South Thames Sickle and Thalassaemia Network
- Vigorous wide-ranging discussion on degree of centralisation of services deliverable to best serve patients - each option had advantages and disadvantages
- Plan to consult widely across Network including patient representatives to ensure all stakeholders are engaged and aligned

South Thames Sickle Cell and Thalassaemia Network (STSTN)



www.ststn.co.uk

info@ststn.co.uk

King’s Health Partners

Our Strengths

We bring together 40,000 staff working in the NHS and university sectors.

We are teaching nearly 30,000 students across our partnership.

Nearly 4.8 million patient contacts are made by our partner hospitals every year.

KING'S College LONDON

NHS Guy's and St Thomas' NHS Foundation Trust

NHS King's College Hospital NHS Foundation Trust

NHS South London and Maudsley NHS Foundation Trust

1 – Strengths and Challenges

- KHP offer access to specialist services, including outreach from KHP and a high quality community service
  - High level of collaboration and multi- disciplinary working
  - Transition between paediatric and adult services
  - Joint specialist clinics to address comorbidities (liver, renal, orthopaedic, obstetric, pain, neurology, respiratory)
  - Working across disciplinary or organisational boundaries can be challenging

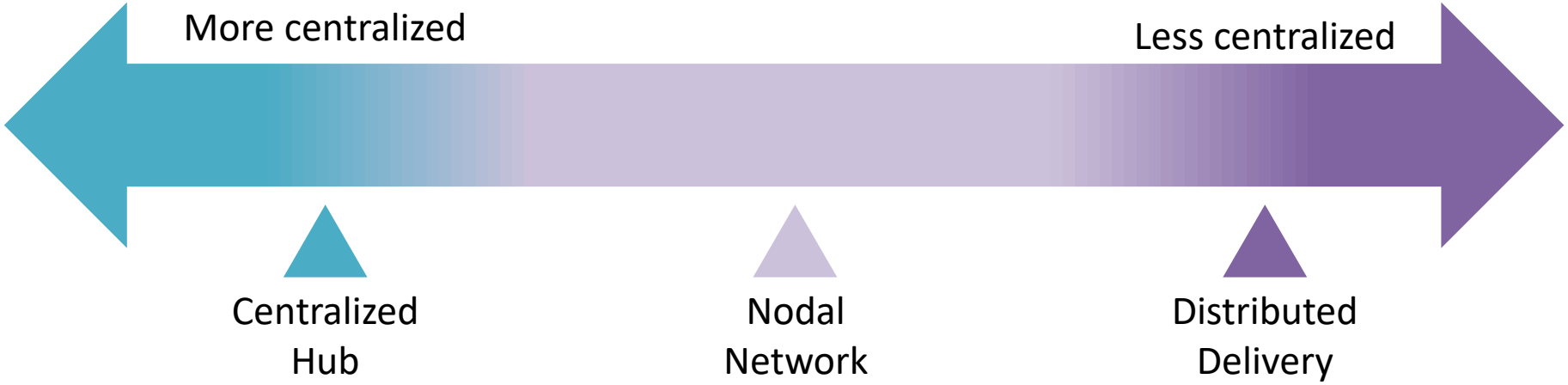
STSTN Network Issues

- **Staffing:** Gaps in staffing particularly around certain roles – welfare support, admin support, social work, physios, psychological support and CNS, lack of equity in manpower
- **Resources and funding:** generally challenging, absence of dedicated wards, geographically inconsistent automated apheresis resources
- **Patient Experience:** long clinic waits, inconvenient pharmacy, multiple clinics/investigations, poor ED experience, perception of inadequate specialist knowledge on non-specialist wards

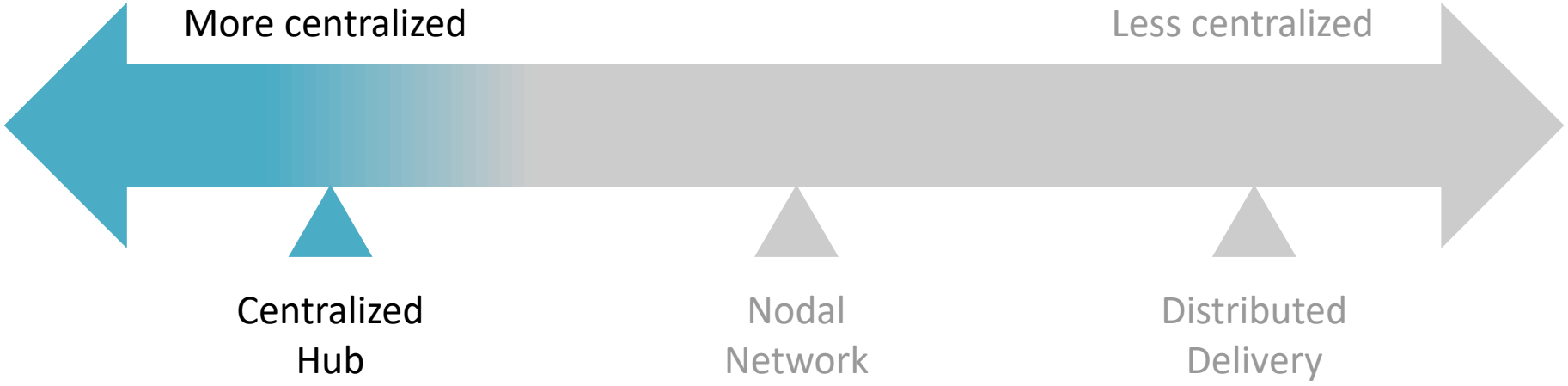
2. Model for future care based on degree of centralisation

- **Centralised Hub**
  - Centralise as much delivery at central hub as possible, from which all tertiary care would be managed and coordinated
  - Patients travel to hub for annual review
  - Emergency patients conveyed via ambulance to hub
  - Hub has dedicated inpatient and outpatient spaces for SCD, and dedicated TYA inpatient facilities
  - Hub would co-locate all research and most clinical staff, allowing for delivery at scale
- **Nodal Network**
  - Assets across Network, creating pockets of delivery at scale
  - Ambulance takes patients to nearest 'Node' where bulk of tertiary care is managed and coordinated, with links to main hub
  - Expand day case / day unit provision at Nodes and use digital technologies to link to hub
- **Distributed Delivery**
  - Use digital technology and Networks links to keep patients in local areas and empower local delivery
  - Additional training for Haematologists and nurses with SCD caseloads to provide uniformly high level of care, even in low prevalence areas
  - Invest in mobile capacity (e.g. mobile apheresis) to increase geographic availability of facilities

Degree of centralisation is key to considering the model for service delivery

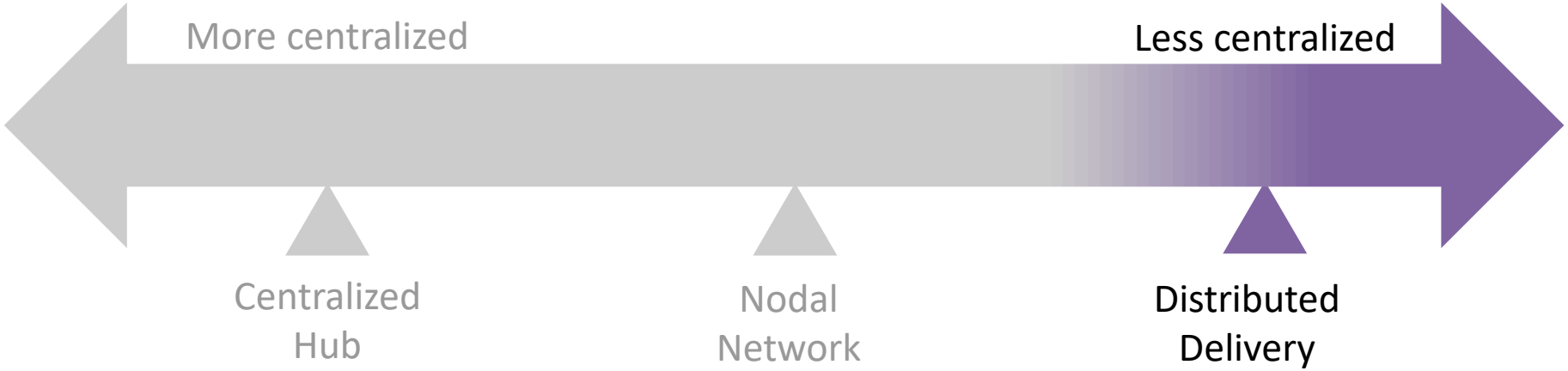


Centralized Hub model sees as much delivery at a single central site as possible



Centralise as much SCD delivery at a central hub as possible, from which all tertiary care would be managed and coordinated. Patients travel to hub for annual review, and emergency patients travel via ambulance to hub. Hub has dedicated inpatient and outpatient spaces for SCD, including dedicated TYA inpatient facilities. Hub would co-locate all research and most clinical staff, allowing for delivery at scale.

Distributed delivery keeps assets, staff and patients dispersed across the geography



Using digital technologies and Networks links, keep patients in their local areas and empower local delivery. Emphasise additional training for Haematologists and nurses with SCD caseloads to provide a uniformly high level of care, even where local SCD population is modest (increasing access). Invest in mobile capacity (e.g. mobile apheresis) to increase geographic availability of these facilities.

No perfect model – all have drawbacks

Model	Clinician description	Deliverability	Strengths	Weaknesses / Challenges
Centralised	• Coordination delivered from central hub(s), supports the network • Coordinates research • TYA Unit • Walk in day unit • Automated apheresis capacity • Specialist clinics • Expertise and experience • Pain management – no PCA local • Acute care, community team based in the hub • Choice of patients – complex v simple • Congestion, travel and tests • Increased capacity • Home delivery	• Hard to find location and capacity, requires investment • Far from patients presents challenges	• Improves coordination within hospital • Central hub has scale to support the network • Scale for specialised delivery (i.e. TYA dedicated ward) • Increased capacity • Scale for out of hours care	• Weak on emergency care • Requires management of research ethics/consents for all patients • Location and capacity are challenges • Patient migration makes location of hub more risky – patient population won't stay in locations for ever
Nodal	• Develops comms and overseeing coordinating guidelines • Makes use of digital delivery • Much overlap between Nodal and distributed	• Most deliverable – do nodal plus 'Care closer to home'	• Works well with outreach (Transcranial Doppler mentioned specifically) • Improves access to referral clinics • Better for emergency care – scale but close to patients • Helps support equitable access to research and trials • Creates sites for education	• Creates more layers of bureaucracy and thus difficulty • Patient migration makes location of nodes more risky – patient population won't stay in locations for ever • Not all nodes may have scale for quality out of hours care
Distributed	• Day unit transfusions • Integrated service between acute and community • Emergency consults might be helpful (moves towards Nodal) • Community sickle centre • Pharmacy F810 • Acute pain • Community nursing • Much overlap between Nodal and distributed	• Resources spread too thin • Likely preferred by patients	• Patients likely to prefer distributed • Reduces organisational siloes • Emphasizes digital delivery (like Skype), which are likely to be preferred by younger SCD individuals	• De-skill staff and spreads resources thinly • Hard to do education • Hard to deliver out of hours care

3. Model of interventions explored within a 5-category framework

Interventions assessed from patient perspective, focusing on stage of journey the change will impact:

Category	Intervention
Acute-Issue Management	Acute-issue management – reducing severity and/or duration of acute crises when they do occur
Acute-Issue Avoidance	Acute-issue avoidance – reducing likelihood of acute crises
Long-term conditions	Long-term conditions – avoidance and improved management of co-morbidities and sequelae of SCD, improving life expectancy and quality of life
Non-Acute Support	Non-acute support – improving outcomes and experience for individuals with SCD generally
New Treatment Modalities and Research Opportunities	New treatment modalities and research opportunities – potential for new methods to change how SCD is treated or managed

Workshop: acute management

Category	Intervention	Description and Impact
Acute-Issue Management	**Improve access to Sickle Day Unit**	Extend hours and improve pathway clarity into Day Unit (from ED, ambulance conveyance) Sufficient cohort in catchment would make consultant coverage for Unit feasible
	Improve rapid access to pain relief	Continued training for ED and LAS regarding rapid analgesia
	Shorten IP spells with management protocols, patient information sharing, psycho-social support	Pan-Thames/Network pain and management protocols, better patient information sharing, integrating psychologist and social support to reduce delays to discharge Improved education and training of health care providers
	Make new therapies available	Make latest drugs and treatments available to patients
Acute-Issue Avoidance	**Improve Hydroxycarbamide access**	Assist patients and clinicians in overcoming misconceptions around cancer/sterility
	Reduce patient burden through changes to OP clinics, MDT, GP-training	Outpatient clinics with extended hours, one stop clinics with access to MDT and specialist diagnostics Training/information for GPs
	Access to automated apheresis	Avoid acute deterioration, improve disease control
	Haematology units with integrated psychology, social, benefits support	Proactively address underlying psycho-social issues, such as housing or disability benefit payments
	Make new therapies and drugs available as soon as possible	Reduce frequency of acute issues and admissions

Workshop: non-acute management

Category	Intervention	Description and Impact
Long-term conditions	**Specialist Joint Clinics**	Aligning delivery of care for the increasing level of co-morbidities through more specialist joint clinics, build expertise. Chronic complications are more common cause of mortality than acute Sickle episodes at KHP
	Reducing patient burden through changes to OP clinics, MDT, and GP-training	Making better use of digital/online/phone-based methods to help patients manage their condition, sensitive to needs and capabilities of each individual
	Improve treatment of long-term complications	Help with chronic pain and potential opioid dependency through MDT support; pain specialists, psychologists, physiotherapists, community nurses Provide better infection management, vaccination and awareness for need for prompt treatment of infections, in view of hypersplenism and increased infection risk associated with SCD
Non-Acute Support	**Increase psychological support, educate patients, family and staff**	Education and increased psychological support to decrease stigma around psychological support; blood transfusions; opioids and other pain-relief Improve psychological support to staff when dealing with challenging patients
	Improve access to relevant patient information for patients, clinicians and other care providers	Digital methods to improve access to information across the Network , particularly the Outpatient area to reduce DNA rates (via text message, personal call, etc.) Helping disseminate relevant information in standard formats to help all patients, regardless of impediments to reading, appropriate, up-to-date information
	Provide age-appropriate care	Expand TYA unit to support transition from paediatric to adult services, which reduces risk at a critical period Appoint TYA lead to help coordinate support with in-post Welfare Support Officer Assist with co-morbidities through expanded multi-speciality clinics, education and clear referral pathways to specialist clinics

Workshop: new treatments and research

Category	Intervention	Description and Impact
New Treatment Modalities and Research Opportunities	**Ensure resources are available to perform research in clinical and psychological environment**	Research should translate to evidence based practice and improved patient outcomes and
	Improve access to and awareness of clinical trials among patients	Patients are not always aware of trials and clinicians/researchers can face difficulty in recruiting
	Haematopoietic Stem Cell Transplant Transplants (HSCT) and gene therapy	Pioneering new treatments such as Haematopoietic Stem Cell Transplant, gene therapy, and cellular therapies such as Gene therapy will open a non-drug-based avenue for managing and potentially curing SCD and thalassaemia
	Increase access and availability of other new drugs	Increasing access – trial or otherwise – to novel drugs such as: • Endari (oral L-glutamine powder) – reduces oxidative stress and acute complications, prevention of acute vaso-occlusive events • Voxelotor –daily oral therapy with potential to improve haemolytic anaemia and oxygen delivery • Crizaluzimab & Inclacumab –monoclonal antibody treatments could reduce vaso-occlusive crises[1]

Workshop: electronic voting results

- Ranking of each intervention by clinicians
- More needs to be done to capture patient voice

Category	Intervention	Count	Rank
Acute-Issue Management	Improve access to Sickle Day Unit	15	3rd
	Improve rapid access to appropriate pain relief	13	5th (T)
	Shorten IP spells by thorough management protocols, patient information exchange, and MDT psycho-social support	12	10th (T)
	Make new therapies and pain-relief drugs available	13	5th (T)
Acute-Issue Avoidance	Improve Hydroxycarbamide access from current levels of ~20% (18.6% GSTT adults)	13	5th (T)
	Reducing the patient burden through changes to OP clinics, MDT, and GP-training	8	17th
	Improve the availability of automated apheresis	12	10th (T)
	Enhancing MDT Haematology units with integrated psychology, social, and benefits support	13	5th (T)
	Make new therapies and drugs available to SCD patients as soon as possible	12	10th (T)
Long-term conditions	Specialist Joint Clinics focusing on the complications SCD patients face	21	1st
	Reducing the patient burden through changes to OP clinics, MDT, and GP-training	13	5th (T)
	Improve treatment of long-lasting side effects of SCD	9	16th
Non-Acute Support	Increase psychological support and educate patients and family, and staff especially around Mind & Body support and MDT staff	11	13th (T)
	Improve access to relevant patient information for patients, clinicians and other care providers to support their care and wellbeing	3	19th
	Provide age-appropriate care to patients	18	2nd
New Treatment Modalities and Research Opportunities	Ensure resources are available to do research in both the clinical and psychological environment	7	18th
	Improve access to and awareness of clinical trials among patients	11	13th (T)
	Haematopoietic Stem Cell Transplant Transplants (HSCT) and gene therapy	11	13th (T)
	Increase access and availability of other new drugs	14	4th

‘Count’ of votes given to each intervention

Ranking of interventions conducted at end of session via Mentimeter.com, allowing secret voting via smartphone

Conclusion

- **Services could be improved by combining:**
  - Holistic patient-centred care facilitated by information technology
  - Greater patient support, education and participation
  - Expansion of haemoglobinopathy day care units
  - Increased use of Hydroxycarbamide
  - Improved transition from paediatric to adult services
  - National strategies: National Haemoglobinopathy Panel and MDM, Peer review and workforce planning
  - Research
  - New treatments (Voxelotor, Crizanlizumab, Luspaticept)
  - Gene therapy, stem cell transplantation

Any questions?