




Slide 1



Haemoglobinopathy Registry in the
Clinical Management of Patients:
Progress & Update

7th July 2004

Presented By:


Dr Mark Layton
Annette Gilmore

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1

Slide 2



Haemoglobinopathy Registry
Project Team

- **Hb Registry Board**
 - Dr M Layton
 - Dr N Philpott
 - Dr G Hughes
 - Dr M Soljak
 - Mr S James
 - Jean Griffiths
 - Dr M Alli
 - Mr K Martin
 - Annette Gilmore
 - Priscilla Plocki
- **EHR Team:**
 - Prof. Sally C Davies
 - Dr Jo Howard
 - Annette Gilmore
 - Sameer J Patankar

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2

Slide 3

North West London Participants

- **Central Middlesex and Northwick Park:**
 - ⊙ Prof. S C Davies
 - ⊙ Dr J Howard
 - ⊙ Dr S Allard
- **Ealing:**
 - ⊙ Dr C Michie
 - ⊙ Dr N Philpott
 - ⊙ Dr G Abrahamson
- **Hammersmith:**
 - ⊙ Prof. I Dokal
 - ⊙ Dr M Layton
- **West Middlesex:**
 - ⊙ Dr G Hughes
 - ⊙ Dr M Sekhar
 - ⊙ Dr A Davies
- **Data Co-ordinators:**
 - ⊙ Annette Gilmore
 - ⊙ Priscilla Plocki

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3

Slide 4

EU Participants: Hydroxyurea Registry

- Yves Beuzard
- Christina Borgna-Pignatti
- Maria Domenica Cappellini
- Sally C. Davies
- Lucia de Franceschi
- Pierre Fondu
- Frederic Galacteros
- Renzo Galanello
- Robert Girot
- Dimitri Loukopoulos
- Marianne de Montalambert
- Eliazar Rachmilewitz
- Corrina McMahon

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Cagliari
Paris
Athens
Paris
Jerusalem
Dublin

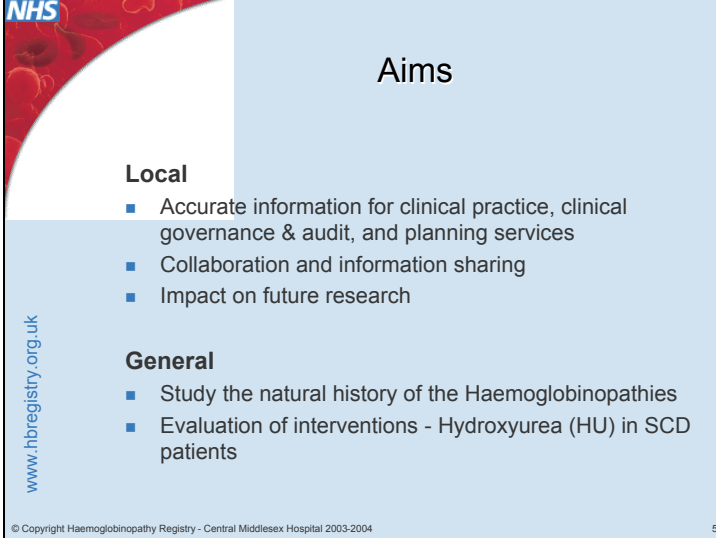
Co-ordinated by: **Dr M Roberts-Harewood**

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4

Slide 5



Aims

Local

- Accurate information for clinical practice, clinical governance & audit, and planning services
- Collaboration and information sharing
- Impact on future research

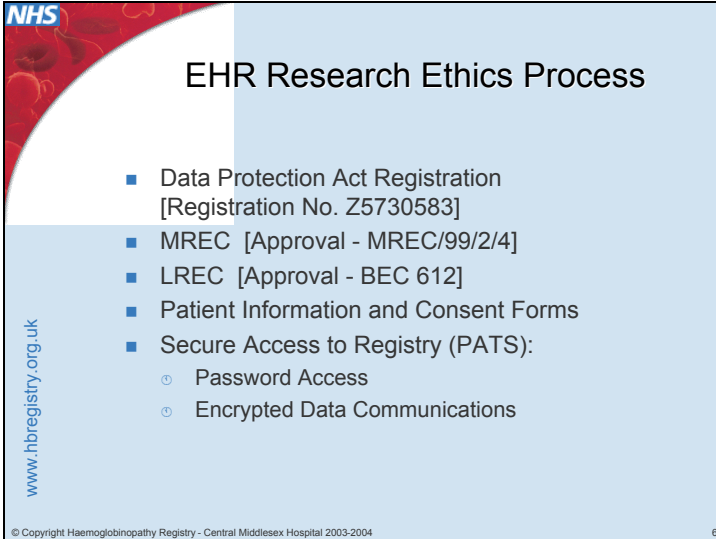
General

- Study the natural history of the Haemoglobinopathies
- Evaluation of interventions - Hydroxyurea (HU) in SCD patients

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Slide 6



EHR Research Ethics Process

- Data Protection Act Registration [Registration No. Z5730583]
- MREC [Approval - MREC/99/2/4]
- LREC [Approval - BEC 612]
- Patient Information and Consent Forms
- Secure Access to Registry (PATS):
 - Password Access
 - Encrypted Data Communications

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Slide 7

The slide features a red circular graphic in the top-left corner with the NHS logo. The background is light blue. The text is centered and right-aligned.

EHR Process (1)

Standardise Data Collection:

- Proformas (MDS & EDS) – Adobe Acrobat (PDF)
- Data Dictionary and Guidelines for Completion
- Proformas, Consent Forms, Guidelines, etc. – External Secure Website
- Submitted to Registry by Post or Fax

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Slide 8

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EHR Process (2)

Data Processing and Storage:

- Automated Data Validation & Processing
- Automated Data Log for Validation by Data Collector ('To Be Approved' Report)
- After Final Validation ('Final' Report) – Data Entered in to Patient Analysis & Tracking System (PATS Database) – Dendrite Clinical Systems

Data Outputs:

- Automated Reporting:
 - ① Clinical Reports (Microsoft Word)
 - ① Data and Reports to Clinicians (Microsoft Excel) (*Data and Reports Returned on CD*)

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Slide 9

NHS

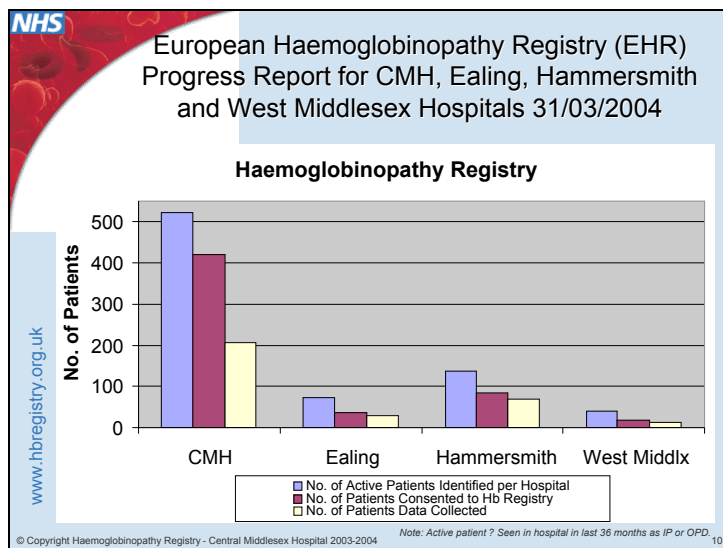
Achievements of the Registry

- Demographic Information for Monitoring & Service Provision
- Individualized Clinical Patient Reports
- Monitoring and Evaluation of Hydroxyurea Treatment
- Developed in Collaboration with EU and UK Doctors
- Haemoglobinopathy Registry Website www.hbregistry.org.uk

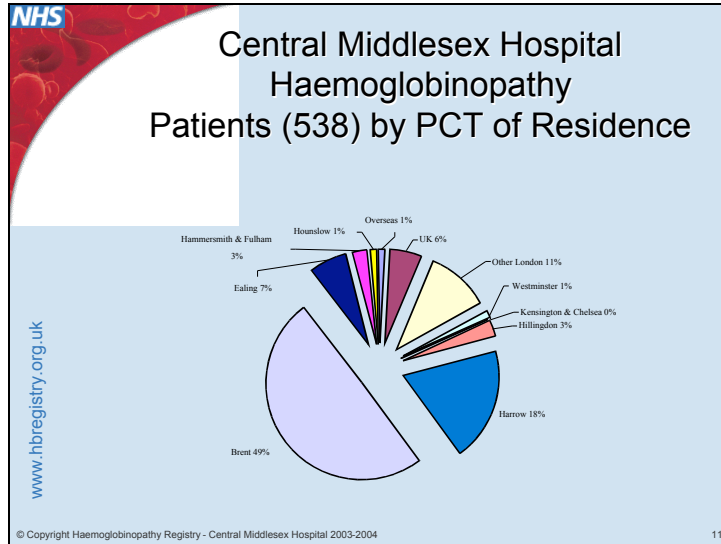
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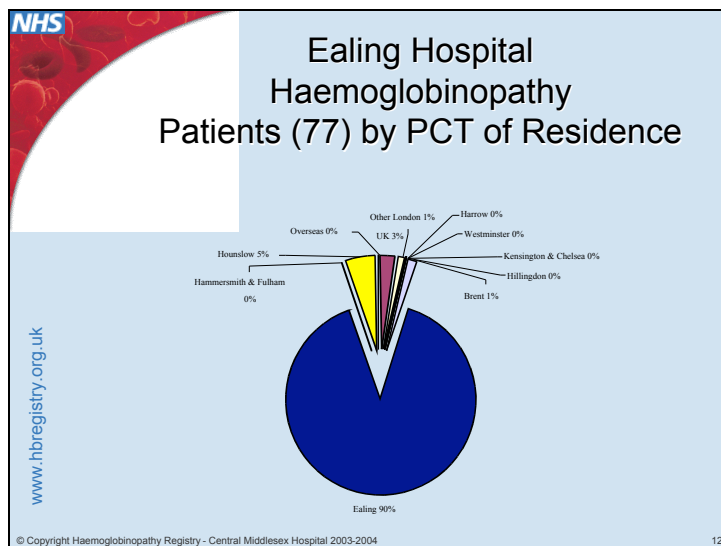
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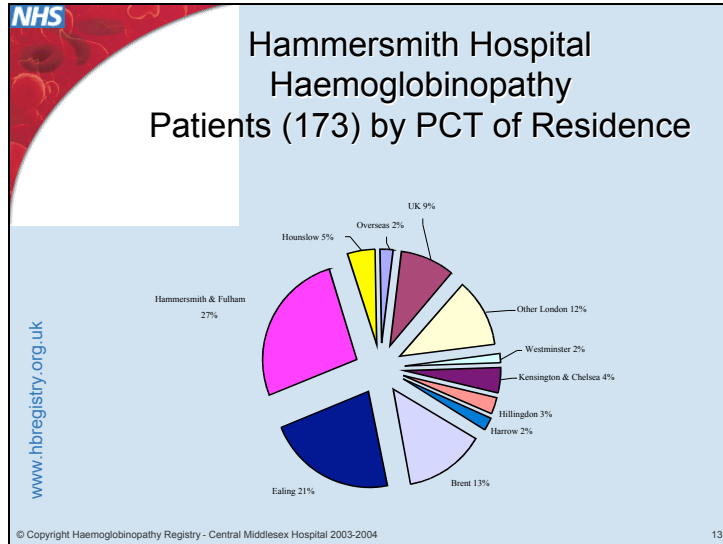
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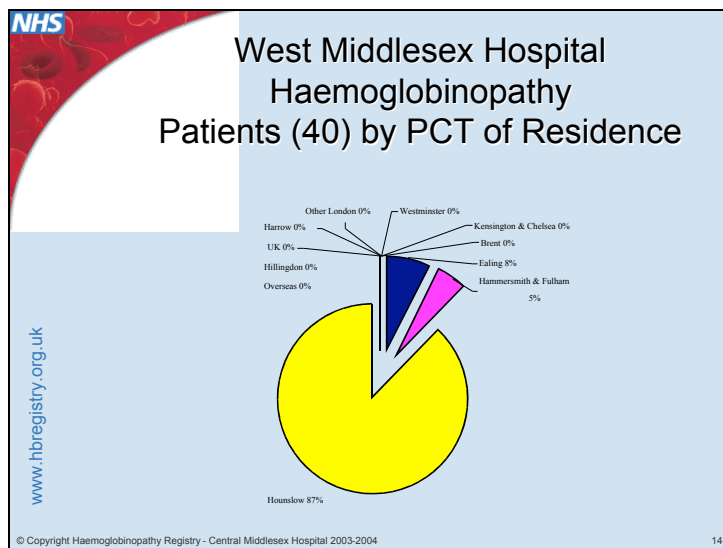
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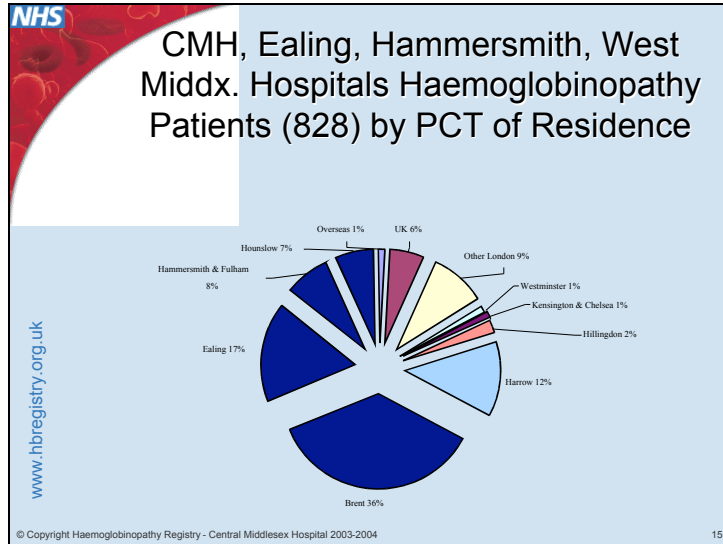
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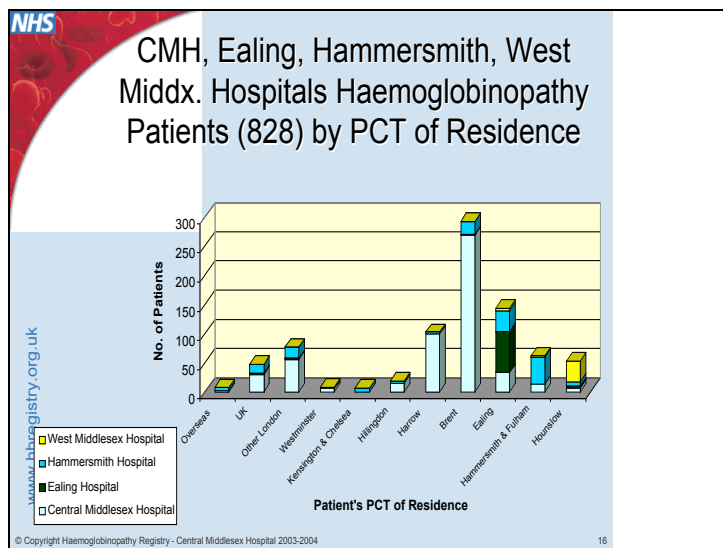
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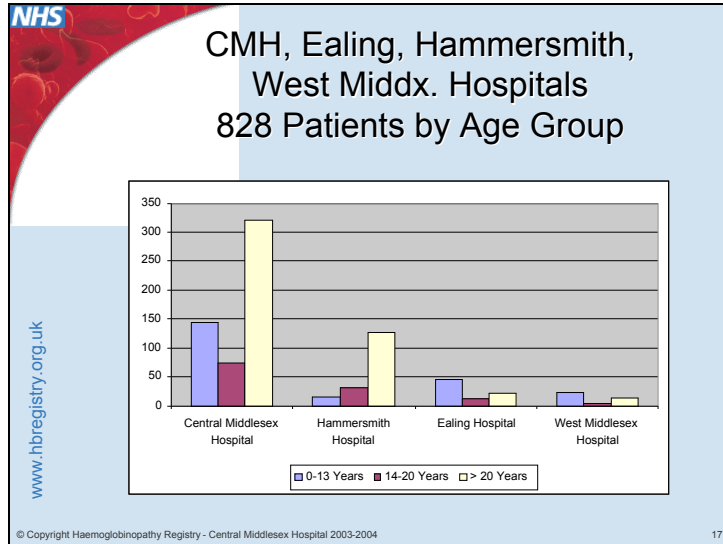
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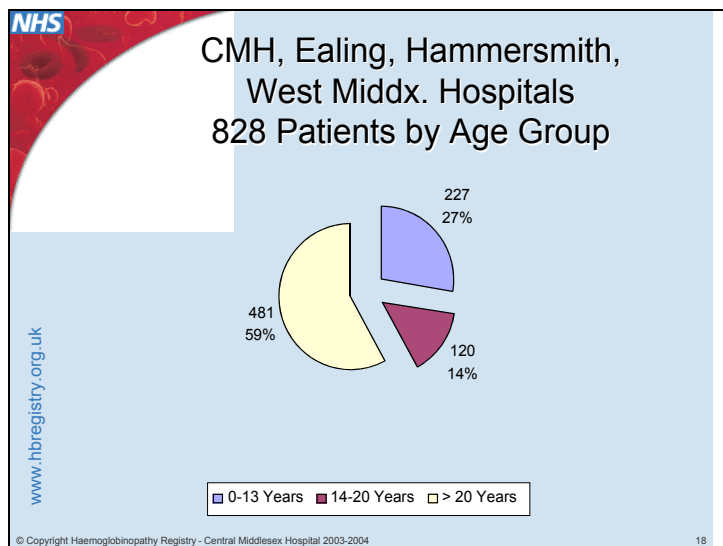
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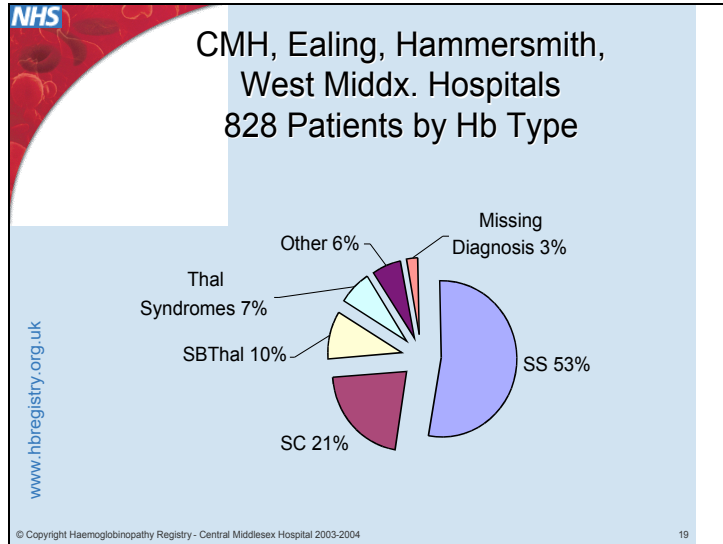
Slide 17



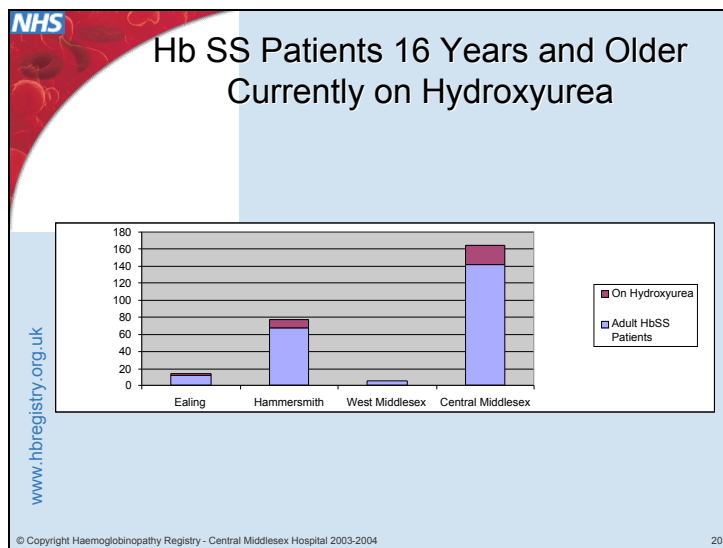
Slide 18



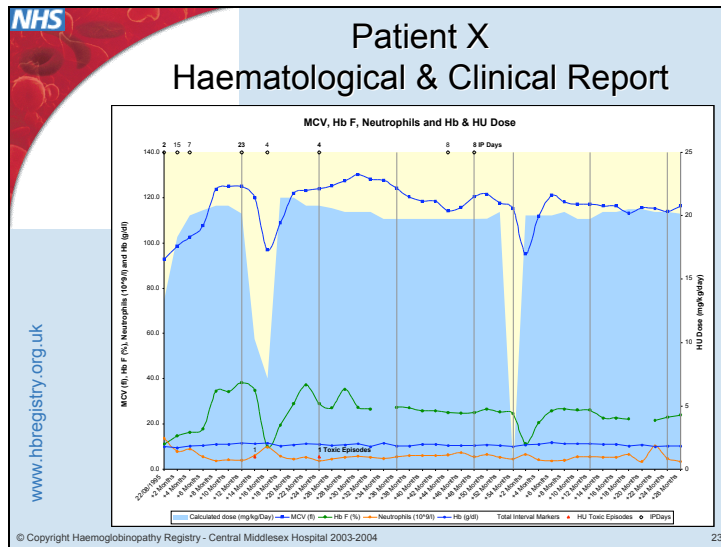
Slide 19



Slide 20




Slide 23



Slide 24

- NHS
- ## Lessons Learned (1)
- Central Registry Model Works
 - Significant Resources Required to Complete Collection and Processing/Reporting of Retrospective Data
 - Adequate Resources Required to Continue Longitudinal Follow-Up: Clinical Follow-Up and Research
 - Improved Patient Care:
 - Compliance
 - Follow-Up
 - Monitoring & Evaluation
 - Service Planning
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Slide 25



Lessons Learned (2)

- Need to Improve the Efficiency of the Data Submission and Processing using Web based Technology:
 - ① Online Data Submission
 - ① Online Data Validation
 - ① Online Data Retrieval
 - ① Ability to View PATS Data Online
- Require more IT Specialist Input: Web based PATS Server and Additional Software Development

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Slide 26



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