

Blood Group Genotyping - samples, Progress and Challenges at Whittington Health and UCLH



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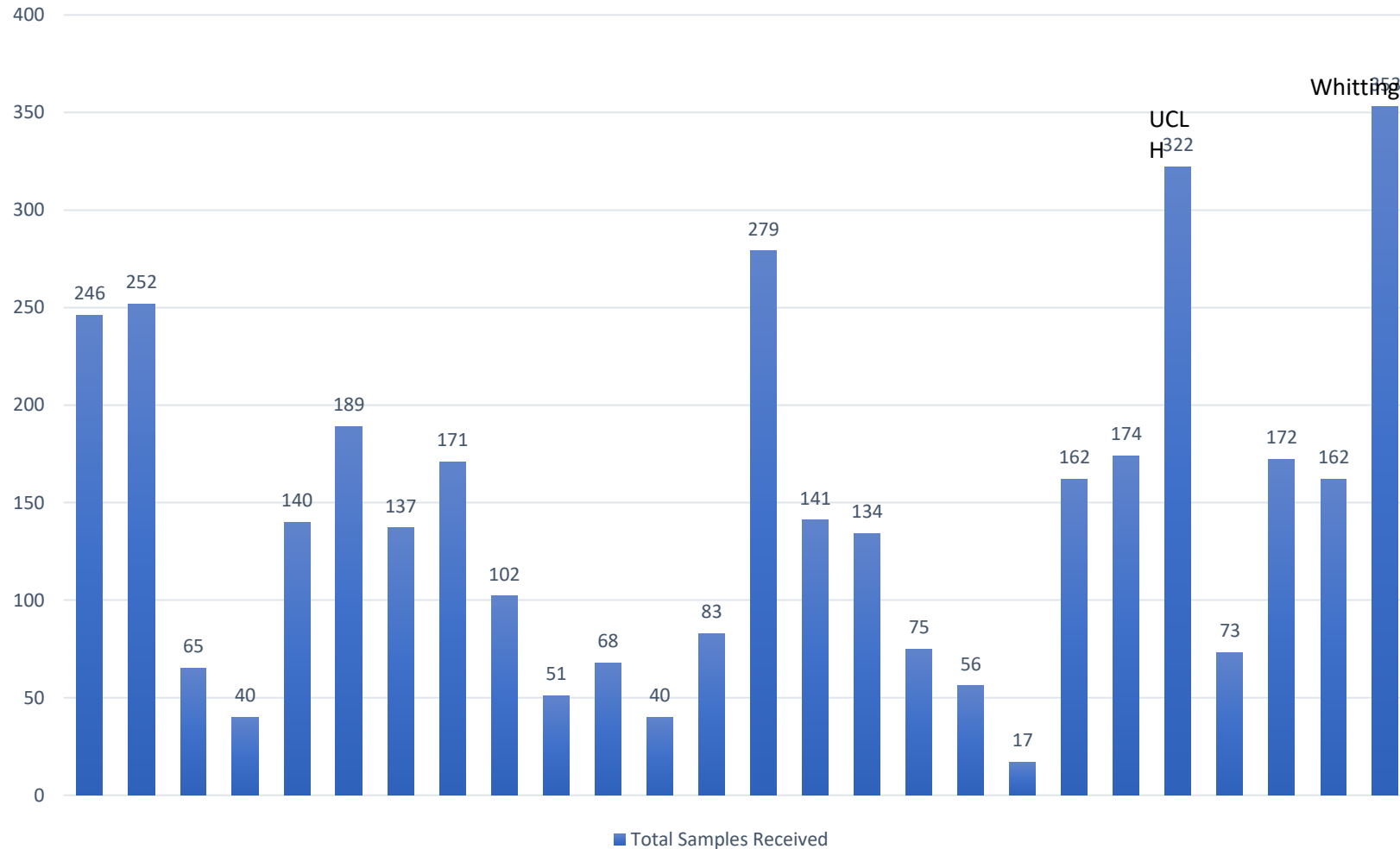
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NHS Foundation Trust

Sample Collection Metrics – NHSBT data



- 4,787 samples received from 100 hospitals, September 2024

Challenges and Barriers – Trust/operational

- Cynicism about the test/conspiracies about DNA sharing
- Tying in with treatment cycles to avoid extra blood tests
- Errors in early samples: wrong labelling
- Samples rejected due to no consent documented on request

Challenges cont.

- Staff/different departments (i.e. phlebotomy/day unit/path reception) being unaware of the project and the process needed
- Building into relevant hospital systems if electronic health record systems
- Previous poor experiences for service users with new projects i.e. projects offered and then not completed or expected outcome not delivered

Challenges cont.

- Batch resulting – patients not wanting to wait
- Clarity on who has been tested/ who is outstanding
- More virtual consultations, and getting the test organized to completed at a later date

Challenges and Barriers – Patients

- Lack of trust from patients if they do not know the team/staff member
- Cynicism about the test/conspiracies about DNA sharing
- Tying in with treatment cycles to avoid extra blood testing
- Errors in early samples requiring repeat testing
- During the consenting process - providing all available information and allowing sufficient time for discussion

What helped?

- Sharing information early on and updating
 - Face to face
 - Mailshots to all patients
 - Printed materials in patient areas (PIL/posters)
 - Peer information sharing
 - Social media
 - NHSBT video
- Transparency and open discussion
- Discussion between patients and a health care professional they know and trust

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- Peer discussion with other patients – pt support groups/meetings
 - Support from trust communication teams and departmental discussions
 - Engaging nurse specialist team to be at the front line of the process
 - Dedicated haemoglobinopathy day units
 - Allowing time to think about it and return for the test later for those who are unsure

Outcomes

- In general – most patients are very happy to have the test and pleased at the progression in care provision, they might just need some thinking time!
- Patients report added reassurance for treatment in the future
- Initial high uptake that has slowed (UCLH) - team to revisit and continue discussions with patients
- Consideration needed on how results will be fed back to patients once processed and discussion about what it might mean for the individual
- Continuing to involve patients in next steps and share updates

Questions?
