Deaths with haemoglobinopathy/rare inherited anaemia on death certificate so appears on ONS

Deaths not appearing on ONS

Deaths discussed early (1) locally (2) HCC
Deaths to be discussed at NHP: (1) all paediatric deaths (2) some adult NHP – criteria below
No specified timeline to when NHP discussion takes place. Can bring back cases if further info required.

Produce an annual national deaths report via NHR or NHP
Will include themes e.g. whether deaths caused by haemoglobinopathy or rare inherited anaemia, whether expected deaths, whether a patient safety incident review was needed, transplant related deaths, transfusion related deaths...

Future: Identify which cases were NOT discussed in HCC and feedback to HCC/SHT/LHT to ensure they are discussed

NHR mortality dataset (ongoing work via NHR/Noemi)

- *date of death*
- *expected death / not*
- *reported to coroner?*
- *discussed in NHP?*
- *PM and outcome*
- *cause of death*
- *location of death*
- *discussed in HCC*
- *…*

Discussion at NHP

- ***All*** *child deaths*
- ***Some*** *adult deaths*
  - *Unexpected deaths related to underlying red cell disorder, where there were delays, clinical errors or specific learning involved e.g. those with prevention of future deaths report*
  - *Patient safety incident report/Structured judgment review*
  - *Transfusion reactions*
  - *Any other case clinician wants to discuss further*
  - *[Transplant deaths will be discussed via transplant mortality pathway but may come to NHP if specific learning]*