IMPROVING OUTCOMES FOR ADULT PATIENTS WITH HLH IN THE UNITED KINGDOM

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Background

Haemophagocytic lymphohistiocytosis (HLH) is rare and associated with severe morbidity and mortality. Inequity of access to specialist services, under-recognition and lack of evidence base contribute to the high mortality and morbidity.
The UK National Health Service (NHS) provides universal coverage free at the point of access to 67.5 million people. Treatment guidelines and high-cost drug use is centrally managed.
Herein, we describe how cross-speciality, cross-site working can drive national change to improve patient outcomes.

Methods

In 2017, two UK rheumatologists (RST and JJM) with a shared interest in improving HLH care decided to combine learning and develop cross-speciality HLH services in their hospitals (Sheffield teaching Hospitals, and UCLH, London). A literature search was conducted, and a standard approach across both institutions was developed. Data were collected on patient outcome and cost.

Results

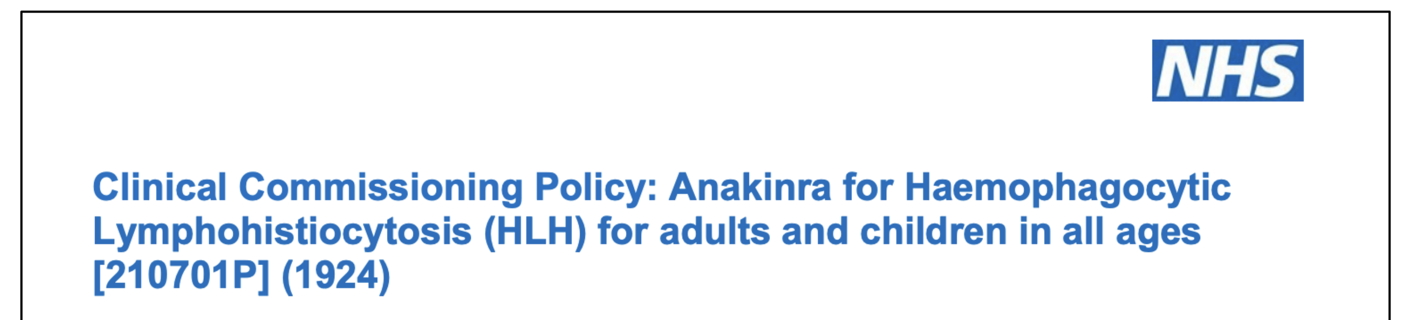
Guidelines and best practice achievements from one site were used to drive change at the other. Local agreement for anakinra use in London led to national NHS-mandated access in 2021.Key to this was demonstrating cost savings from reduced use of intravenous immunoglobulin resulting from anakinra at UCLH of £199,248 for 24 patients over 4 years. An evidence-based, cross speciality guideline agreed in Sheffield provided the template for the London site, with subsequent national adoption.

Patient numbers significantly increased; from <5 to 30 patients per year at UCLH over 6 years. Mortality decreased at both centres after introduction of the joint approach, from 72% to 31% at Sheffield, and from 55% to 36% at UCLH.

Initially there was no upfront investment with internal reorganisation and streamlining of services being the focus. Latterly, only £24,500 pa total additional staff costs were incurred

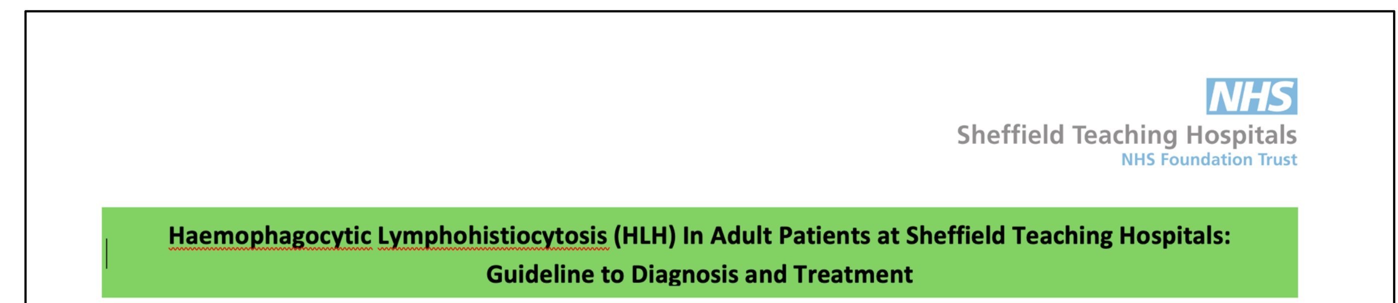
Summary Data

1.
Shared learning used to drive consistent practice across the UK



NHS

Clinical Commissioning Policy: Anakinra for Haemophagocytic Lymphohistiocytosis (HLH) for adults and children in all ages [210701P] (1924)



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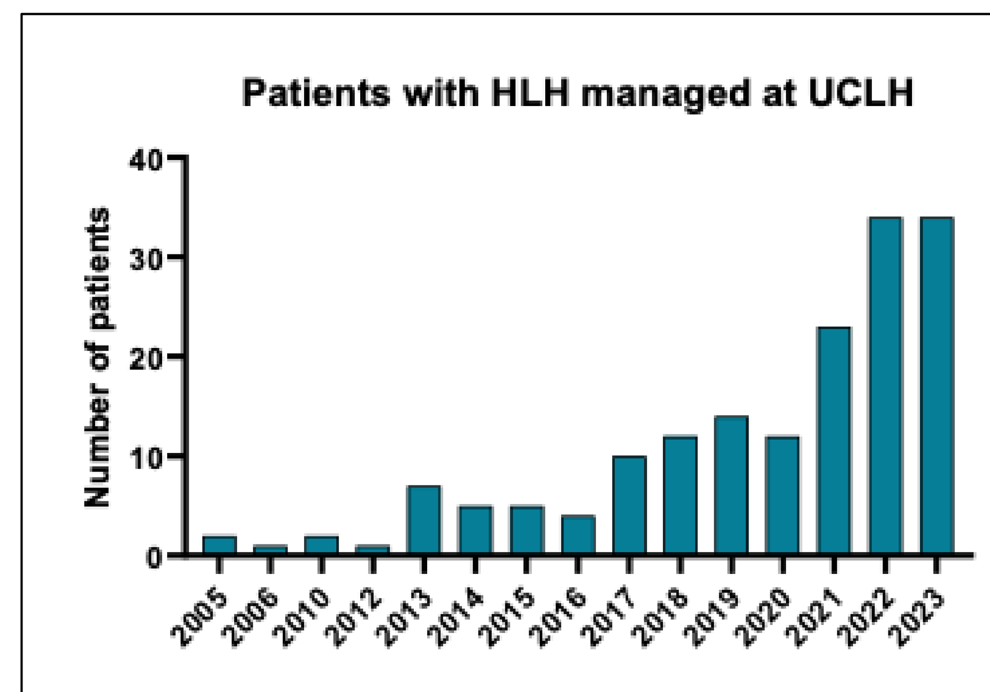
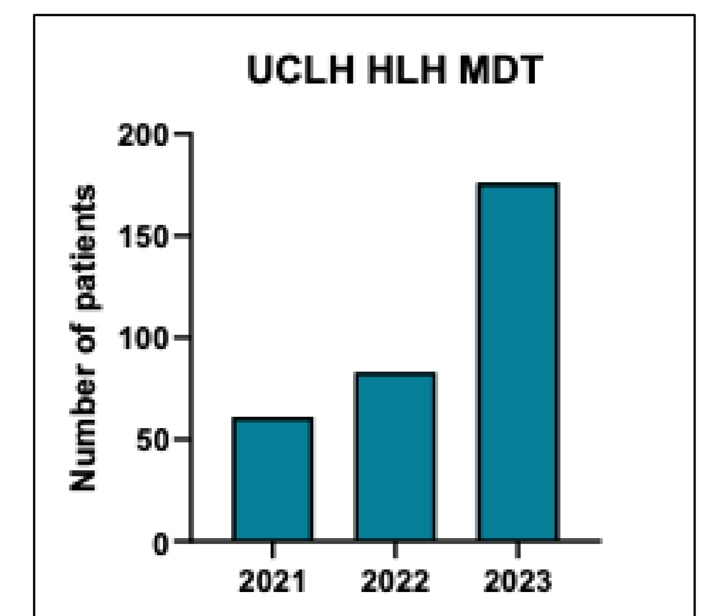
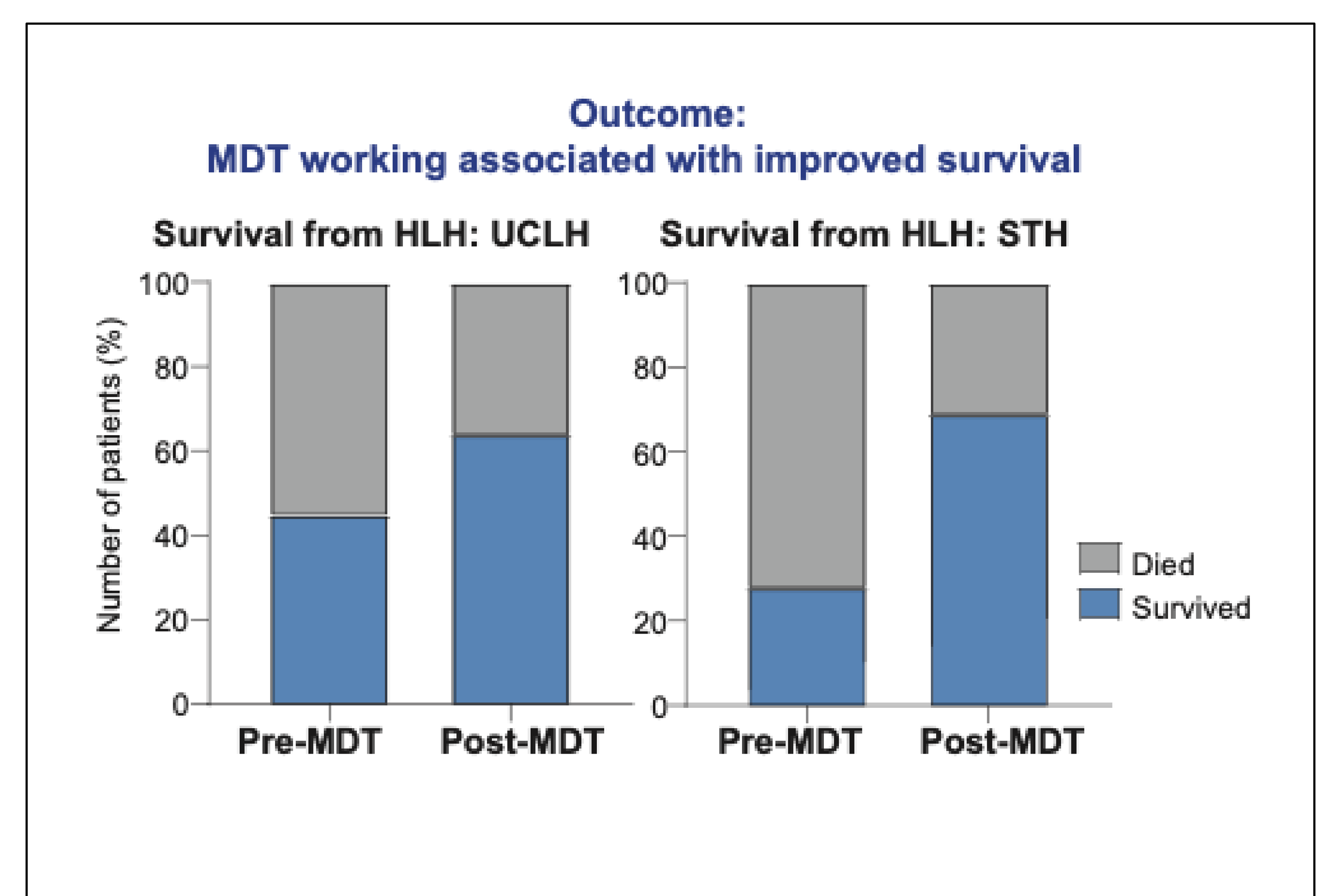
Haemophagocytic Lymphohistiocytosis (HLH) In Adult Patients at Sheffield Teaching Hospitals: Guideline to Diagnosis and Treatment

2.
Number of patients managed in-house, and referred to advisory panel increased year-on-year





3.
Cross-speciality working and shared learning associated with improved mortality from HLH in both centres.



Conclusions

Here, we describe a real-world approach to the development of HLH services in a universal healthcare system. Further work will prospectively evaluate this approach.

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Acronyms

HLH = Hemophagocytic Lymphohistiocytosis