

# Nothing About Us Without Us: Co-designing HLH Services with Stakeholders

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## Background

People with haemophagocytic lymphohistiocytosis (HLH) and their family/carers often experience devastating illness and prolonged hospital stays; some must deal with the death of a loved one from HLH. The psychological toll and traumatising effects of HLH are increasingly recognised<sup>1</sup>. The importance of meaningful involvement of patients and families in their care is increasingly recognised.

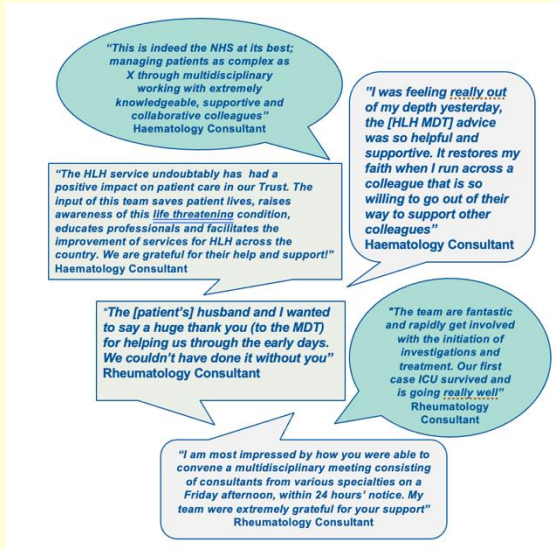
Healthcare professionals (HCP) are also important stakeholders in HLH care and their unmet needs are poorly characterised. Sparse training in HLH and patchy, inequitable services across the United Kingdom expose HCP to the prospect of managing very ill patients without clear infrastructure or appropriate support.

Here, we describe learning from UK HLH Network stakeholder engagement used to inform co-designed service and research development.

## The UK HLH Network and patient engagement

The UK HLH network consists of

1. A **weekly National Advisory Panel (NAP)** accepting referrals from any service in the UK. The NAP is staffed by haematology, rheumatology, infectious diseases and critical care physicians providing real-time clinical advice
  2. **HiHASC: a professional network** [www.hihasc.org](http://www.hihasc.org) of interested clinicians meeting bimonthly to deliver education, guide policy and improve awareness of HLH. HiHASC is supported by HistoUK a patient charity advocating for patients with histiocytic disorders [www.histiouk.org](http://www.histiouk.org)
  3. **Histonode: a research infrastructure** developing a biobank and associated research to improve HLH knowledge and care
- The network partners with patients/family/carers through a **formal Patient and Public Partnership Involvement and Engagement (PPIE) structure** facilitated by an HLH specialist nurse.



## Methods

1. **Improving patient resources:** through work with our PPIE network and HistoUK we recognised an absence of well designed, patient-friendly resources for patients and families of adults with HLH. We co-designed leaflets and films to provide information in a useful and patient-centred way hosted on Histo UK website, freely available to download.
2. **Improving professional resources and understanding the needs of HCPs looking after people with HLH:** we collated feedback about the impact of the NAP that confirmed the vulnerability, isolation and stress HCPs encountered when managing people with HLH. We worked with HistoUK to host 'bite-size learning' in video format for professionals on the HistoUK website.
3. **Ensuring the patient voice shapes and is reflected in research priorities for HLH:** a key pillar of Histonode is a truly embedded PPIE strategy with the PPIE group providing 'critical friendship' in all aspects of the program from research priorities to acceptability of materials to recruits and their families at a time of critical illness.
4. **Ensuring the patient and professional voice informs service development:** the PPIE strategy revealed the unrealised burden of the trauma experienced by families and people with HLH. A tertiary service (UCLH) used a charity grant to appoint the first specialist HLH nurse to support patients and their families during their acute HLH illness and in recovery.

## Results

The UK HLH network facilitated stakeholder consultation with patients, families, carers and healthcare professionals encountering HLH. This consultation delivered

1. co-designed patient information materials (freely available through charity HistoUK [www.histiouk.org](http://www.histiouk.org))
2. Educational film using patient experience/voice to inform HCPs of patient/carer perspectives for professional education and policy/service innovation in HLH.
3. PPIE input as 'critical friends' on research proposals (integral to research priority setting and successful research grants) and service innovations including a post-HLH psychology service.

Patients/families value the opportunity to 'give back' to benefit others. HCP feedback identified significant unrecognised stress related to managing critically ill patients alone and the benefits of the UK HLH network for clinician support/education.



Use the QR code to hear from our PPIE group

## Conclusions

Managing HLH is stressful for patient, family and HCP alike. Through the UK HLH network we defined unmet stakeholder needs. Taking the 'nothing about us without us' approach and meaningfully involving all stakeholders will improve care in this important, relatively invisible, disease. Further research planned is a mixed-methods quantitative/qualitative approach to define the unmet needs of HLH stakeholders to guide service development, staff support and research programmes.