

Developing recommendations for the UK Government on Haemophilia services and NHS Reform



Objectives

The project was undertaken to develop recommendations for the UK Government on the commissioning of specialist haemophilia services during the restructuring of the NHS in England.

Methods

Evidence was collected using online quantitative and qualitative surveys of patients, carers, and consultant haematologists specialising in haemophilia conducted by the Haemophilia Society and the All-Party Parliamentary Group on Haemophilia.

Results

304 responses were received from patients and carers and 31 responses were received from consultant haematologists specialising in haemophilia.

Key themes of patients' and carers' responses included quality of life, access to services, and quality of care. Patients indicated satisfaction with self-management and home treatment, but identified poor mobility and pain management as most significantly impacting on quality of life.

The need for further enhanced out-of-hours services and improved dentistry services were also noted. In general, the respondents praised the quality of specialist care they received, but called for improved care from GPs and other non-specialist healthcare professionals.

Responses from consultant haematologists identified ensuring access to new and emerging therapies as being most important for specialist services in the next five years. They also noted the importance of clinical research, specialist training, and the development of a national strategy for rare diseases.

Conclusions

Patients, carers, and consultant haematologists specialising in haemophilia identified significant improvements to specialised services during the restructuring of the NHS in England. The Haemophilia Society identified a series of recommendations for the UK Government on the establishment of the NHS Commissioning Board, service design, and care planning.

A report on the recommendations was published by the Haemophilia Society and launched in the UK Parliament. The Haemophilia Society continues to work with the UK Government to implement the recommendations.

"My son's specialist nurse and consultant have been brilliant and I could not of asked for better. They really are amazing."

"Trying to find someone who would take the lead in my general health care is confusing and I find myself unsure of who to speak to."

