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SOCIETY

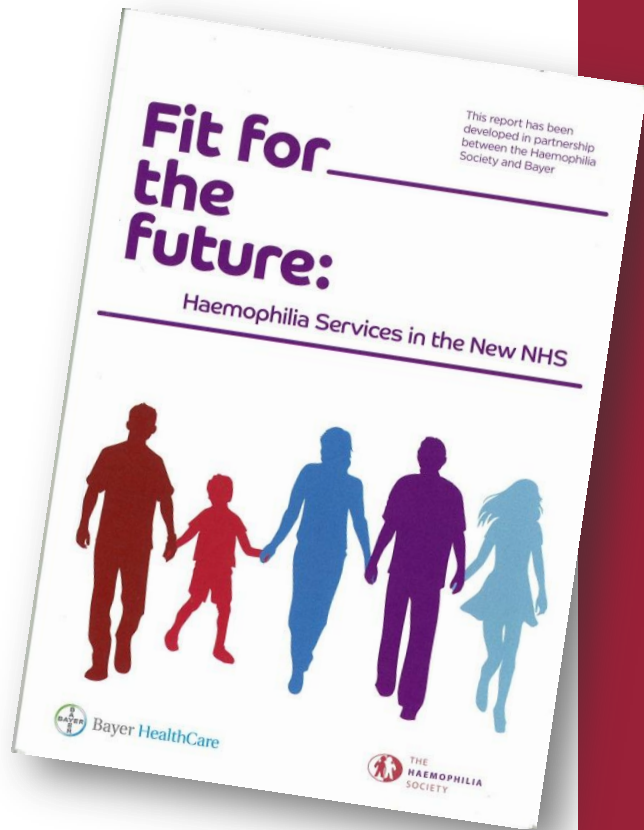
# Fit for the future

Haemophilia Services in the New NHS





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# Aims of the report

- Provide a platform for our members to have their say
- Improve policy-makers' understanding of the needs of people with bleeding disorders
- Influence the NHS reforms
- Secure political support for the best possible treatment and care



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# Whose views?

- Haemophilia Society members (304)
  - Patients
  - Partners
  - Parents & Carers
- Healthcare Professionals (36)
  - Consultants and Nurses
  - Paediatric and Adult



We made use of Survey Monkey to collect and analyse results



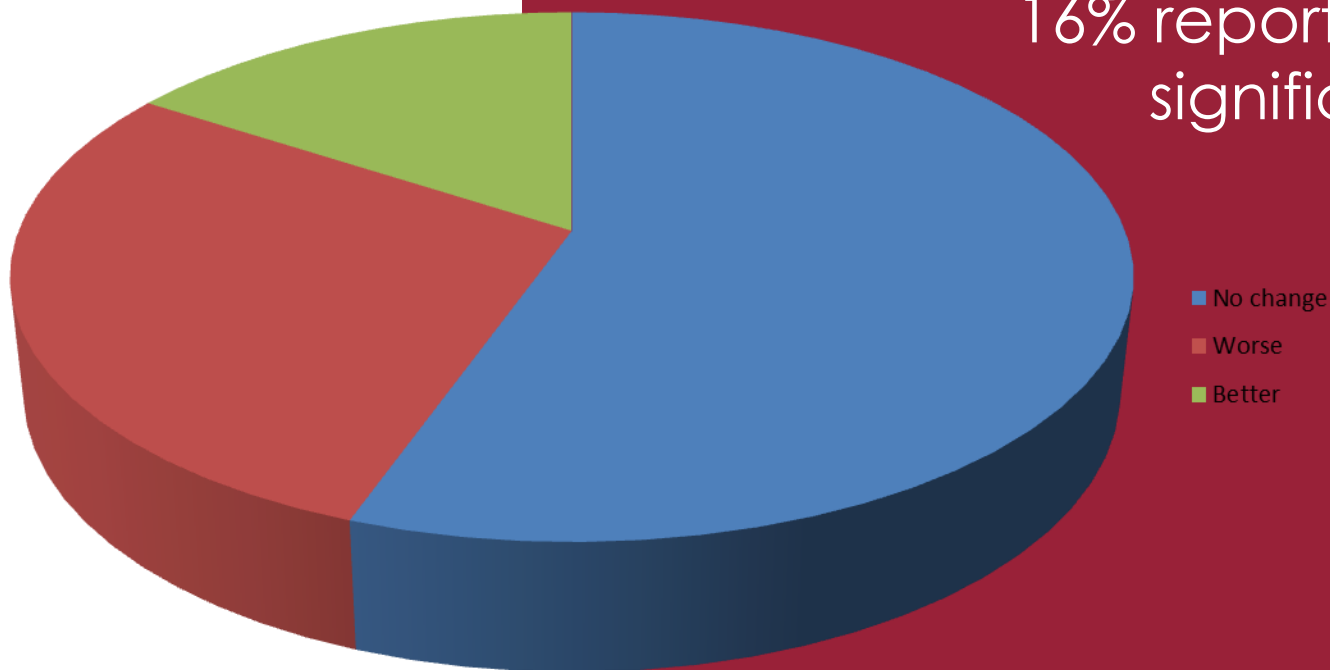
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# Quality of Life

56% said there had been no change in the last two years

29% reported worse or significantly worse

16% reported better or significantly better

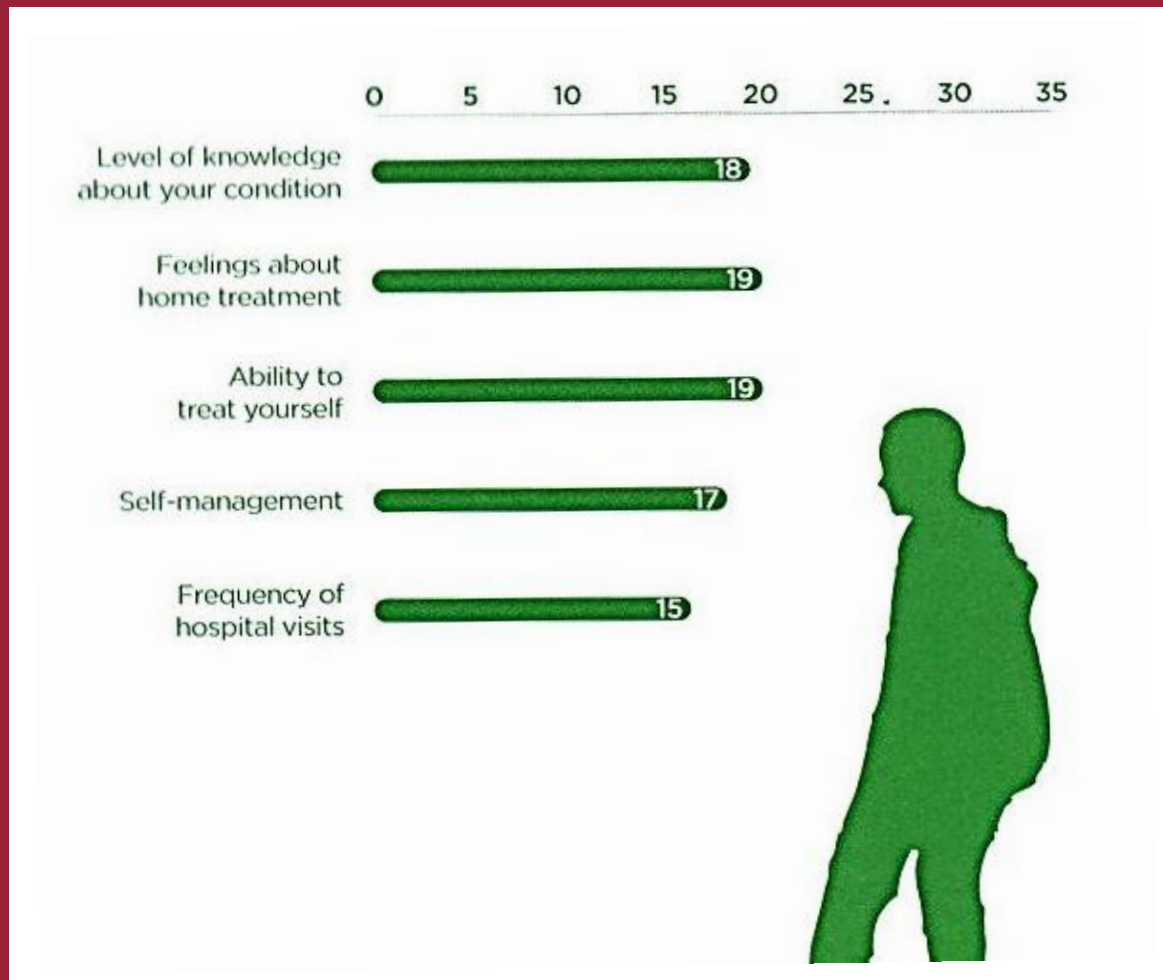




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*"I have started treating my son at home and it is fine so I'm happy about that. This has also improved our family independence."*

# Improvements

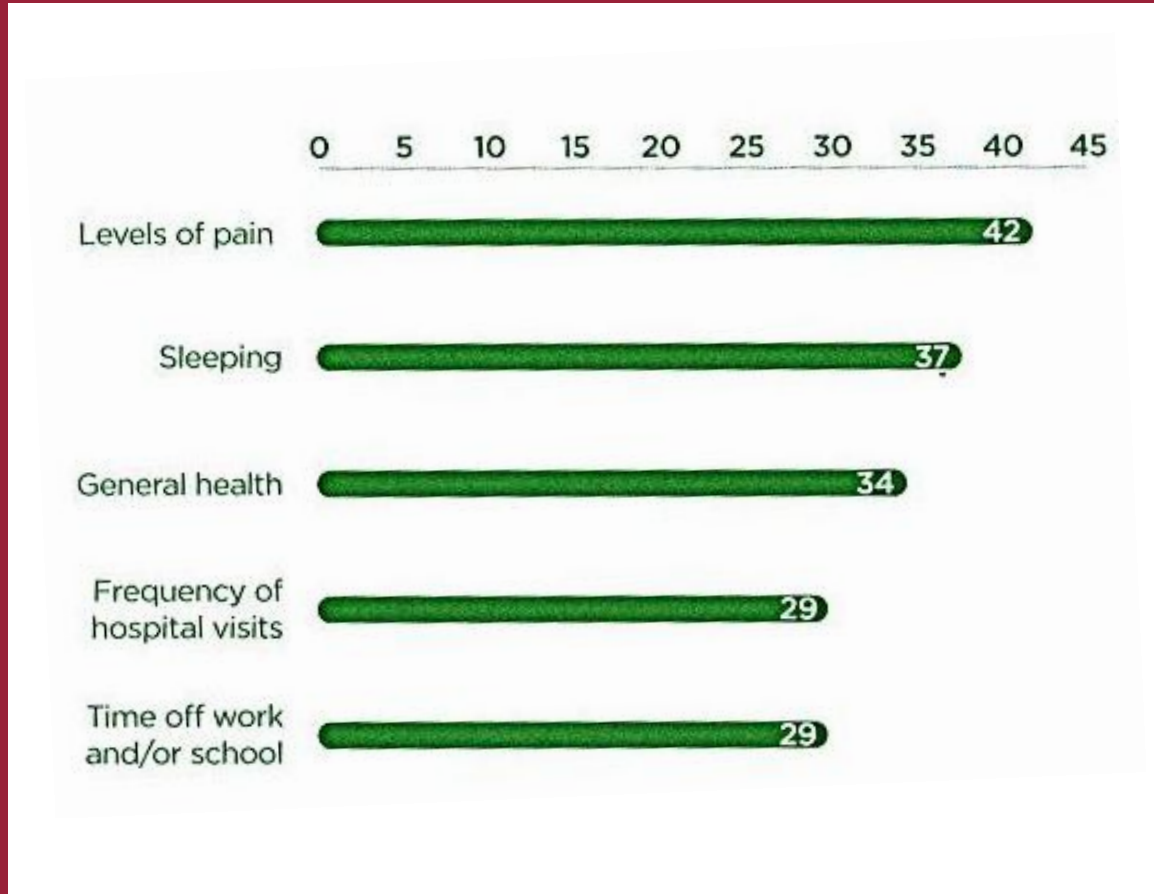




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*"I have needed to go to A&E because of painful bleeds twice this year. I would prefer to be able to go straight to a haematologist to be treated by more knowledgeable staff."*

# More to do





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# More specifically

Average scores for problems experienced in the last 12 months.

The higher the score the more severe the problems caused.



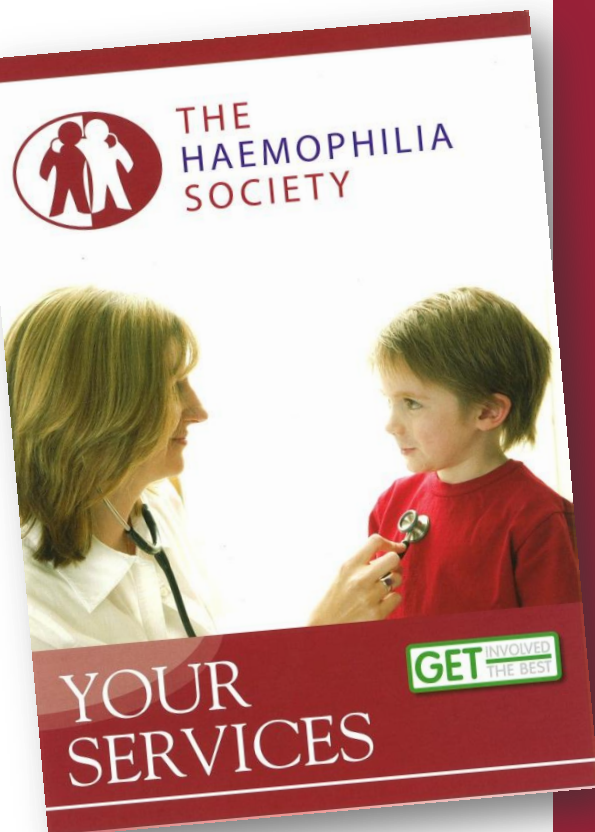


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# Access to Services

The vast majority said they understood the services they could access from their Centre well or very well (84%), more than half (52%) would like more information about the services that they offer.

*"Haemophilia is a 24-hour, life-long condition and I would like to see a huge improvement in access to 24-hour, 7 days a week advice and support."*





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*"The team can be considered as part of my extended family when issues arise, they are known to me and any time I need to contact them they are always sympathetic and react in the most positive way."*

# Quality of care

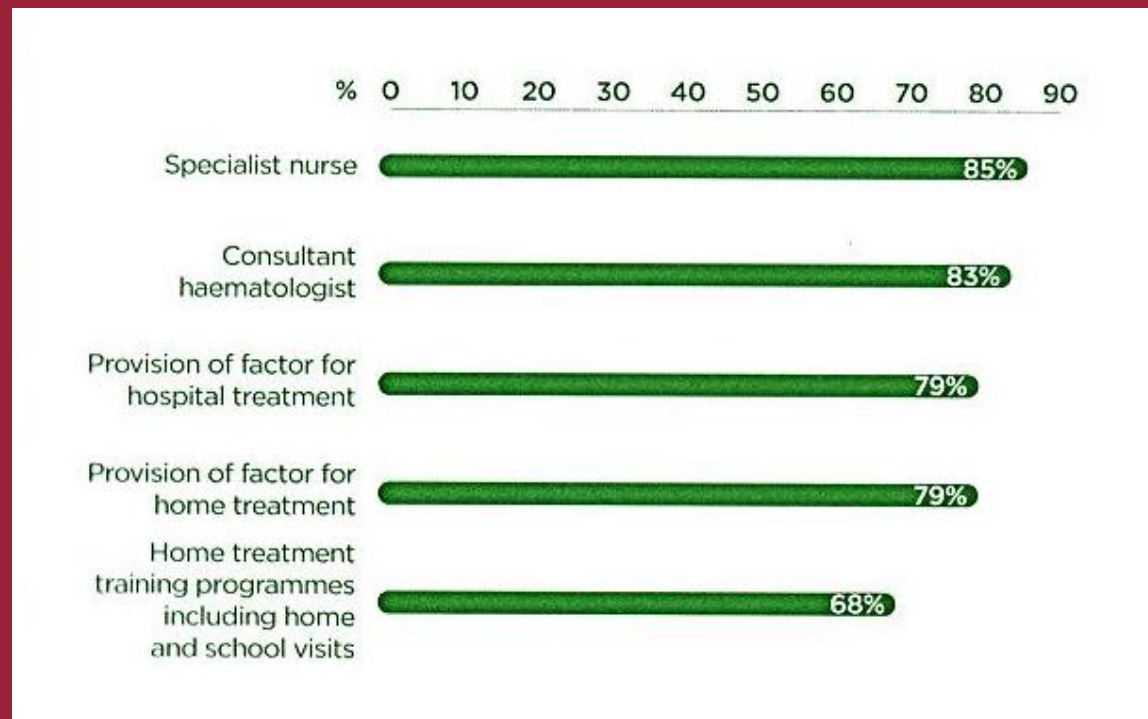
- Satisfaction with Haemophilia Centres is still very high.
- Many specific problems relate to interaction between Haemophilia Centres and other services:
  - GPs
  - Other Departments
  - Social Care
  - Benefits



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

# Good or very good

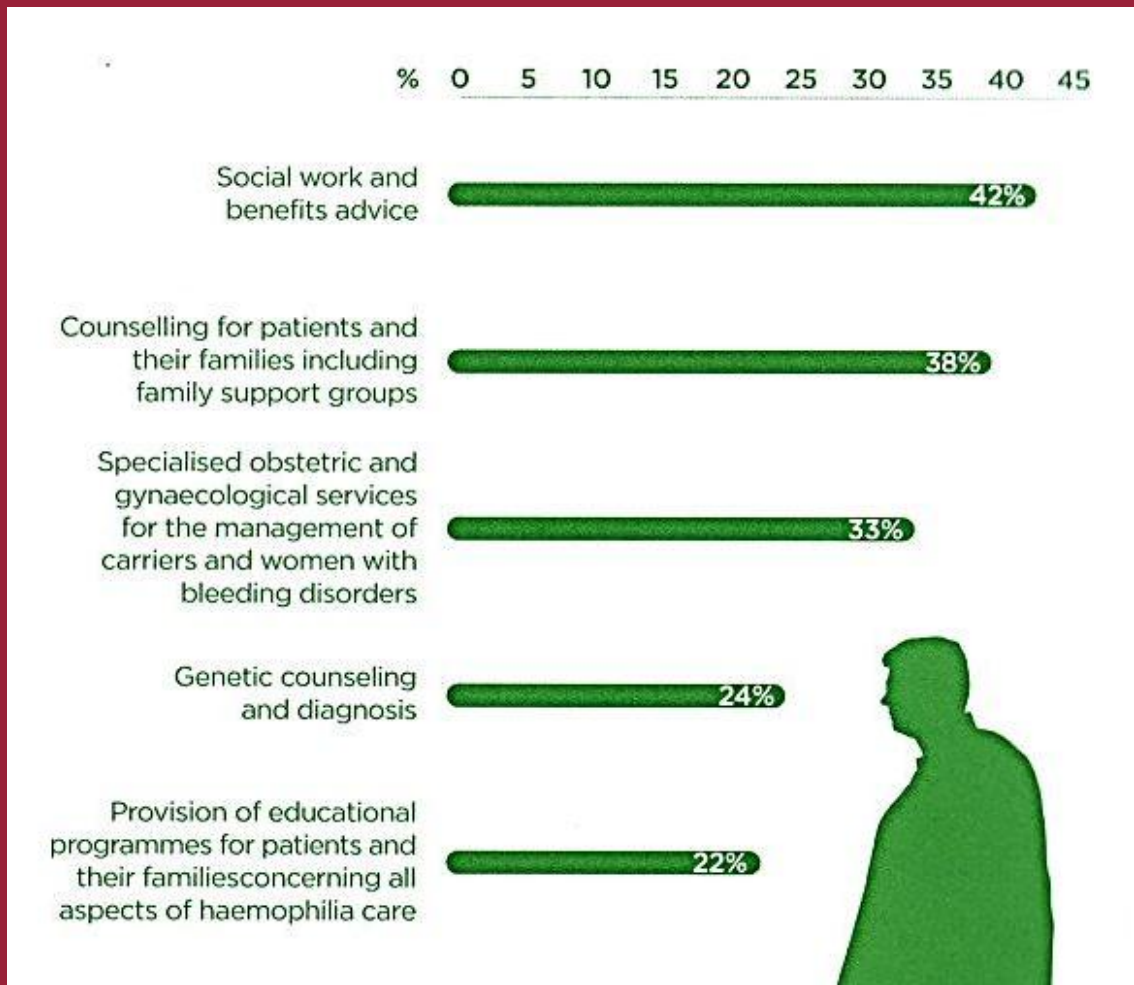




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*"Trying to find someone who would take the lead in my general health care is confusing and I find myself unsure of who to speak to."*

# Poor or very poor





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What will be the most important to bleeding disorder services over the next 5 years?

# Professional perspective

1. Improved access to new and emerging therapies
- = 2. Improving access to physiotherapy services
- = 2. Developing a national strategy for rare diseases
4. Increasing funding for bleeding disorder services
5. Better information for patients and carers
6. More bleeding disorder specialist doctors & nurses



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# Professional Perspective

“I’m concerned that low profit margins after tendering will make most companies lose interest in the UK market and also not conduct clinical trials”

“Will there be sufficient funding for emerging therapies e.g. longer factor concentrates when they become available?”



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# Commissioners Perspective

“A national strategy for rare diseases would counter the current short-termism in favour of prolonged health gain for minority patient groups”

“Information for patients/carers, and an understanding of the increased responsibilities in relation to managing their condition, recording product usage and attendance at clinics will also have benefits for resourcing the services”



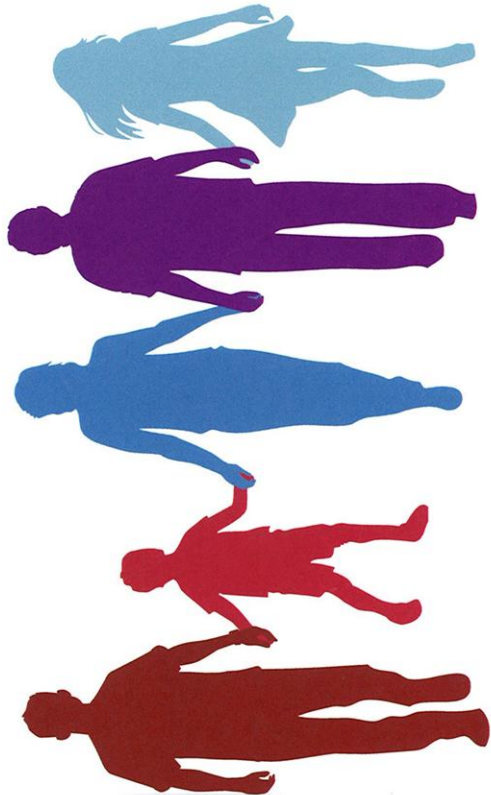
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# What next?

- Fit for the Future  
Recommendations
- The Newcastle Initiative
  - Specialised Healthcare Alliance
  - North East Specialised Commissioning Group
  - Patients, Commissioners, Clinicians, Other Healthcare Professionals and the Haemophilia Society



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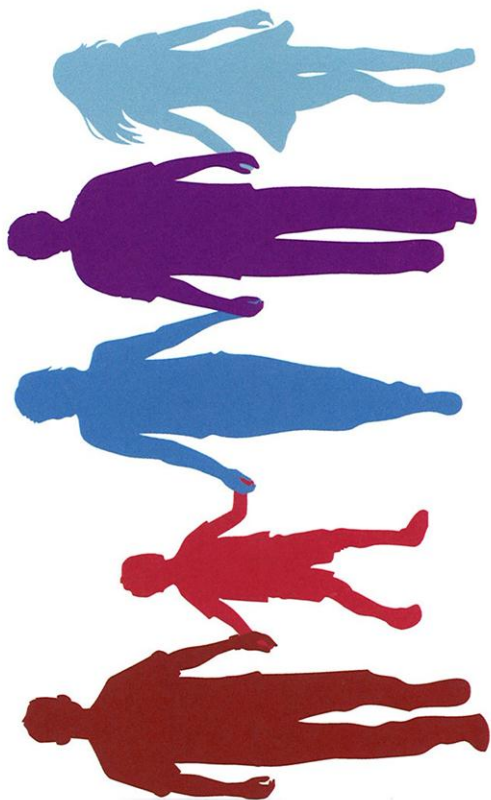


# Fit for the Future

1. Maintain resources and levels during the NHS reforms
2. All patients be offered comprehensive care plan in partnership
3. Single comprehensive information resource about the services available and access
4. Access to services out-of-hours care and telephone support



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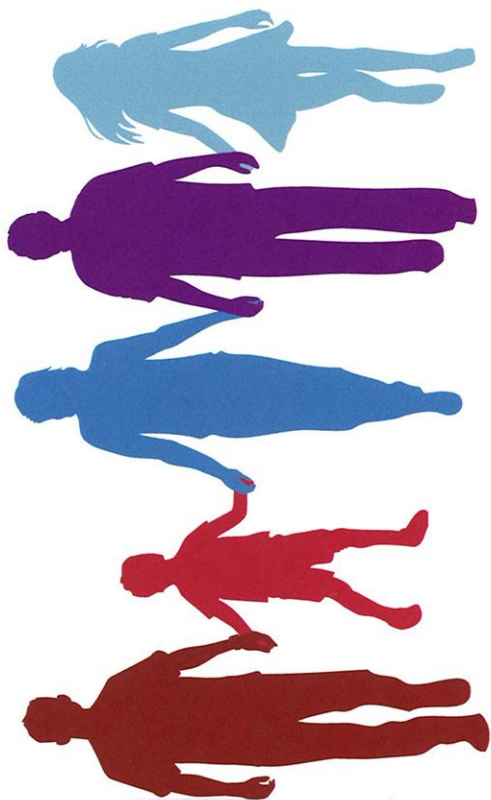


# Fit for the Future

5. Improve access to appropriate psychological and social support
6. Establish local networking and support groups for patients and their families
7. Regular dental check-ups and access to specialist dental services
8. Access to specialist physiotherapy services for all patients who require them
9. Government should work with clinical and patient groups to develop benefits and work-related support for people with bleeding disorders



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# Fit for the Future

- 10. The Government should develop and implement a national strategy for rare diseases to set clear standards for services for patients with bleeding disorders and other rare diseases
- 11. The National Commissioning Board and specialist commissioners should ensure that patients with bleeding disorders continue to have access to new and innovative therapies



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Newcastle Initiative

informing the future of haemophilia care

# Newcastle Recommendations

1. Recombinant remains the treatment of choice for safety reasons, subject to the needs of individual patients
2. Patients should be involved in all decisions affecting their treatment, both clinical and non-clinical
3. A nationally agreed approach to outcome measures is an urgent priority, while taking care to avoid unintended adverse consequences



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# Newcastle

## Recommendations

4. Adult prophylaxis should be extended on a targeted basis, starting with young patients entering adult services with good joint scores following prophylaxis as children
5. Guidance on orthopaedic surgery, prioritised as the first of a series of policies informing more consistent decision-making
6. Home treatment should be the norm for all patients, built around their needs
7. Haemophilia networks should be developed across the country as a means of ensuring equitable access to comprehensive care, underpinned by robust auditing



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# Thank You

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