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# Influencing & Advocacy

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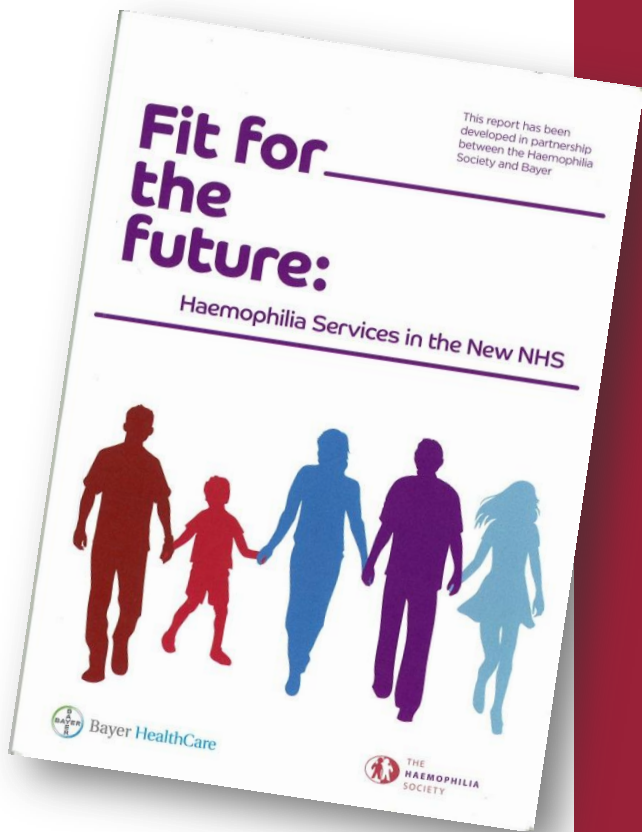




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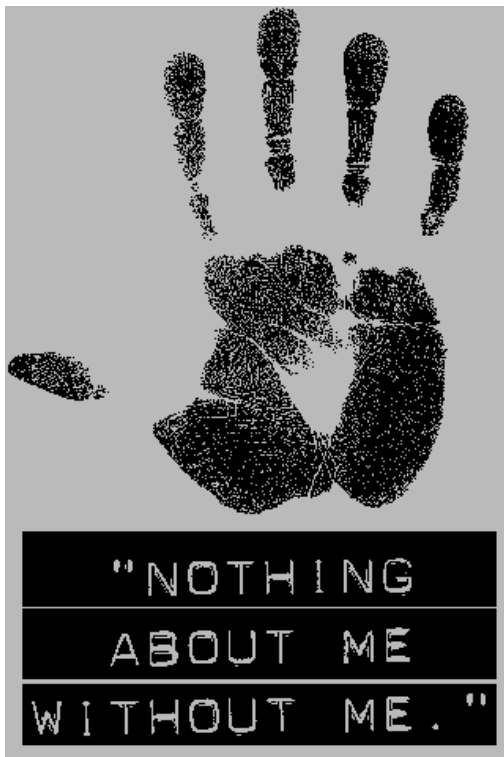
# Why are we here?

- However, strong the Society some things can only be delivered by other people.
  - Department of Health
  - Devolved Administrations
  - Specialized Commissioners
  - UKHCDO
- For example, 'Fit for the Future' presents our members' survey to influence policy makers.





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‘Nothing about me  
without me’

The Haemophilia Society believes that no decisions which impact on the lives of people affected by bleeding disorders should be taken without your involvement.



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# What is coming down the tracks?

- New focus on 'outcomes'
- Patient Partnership Agreement
- New Health Bill in England
- Stronger Comprehensive Care Centre Audits
- National Tender for Clotting Factor Products
- Changes to the benefits system



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*We want to make sure what is measured is important and not just easy to measure.*

# Outcomes

You know what treatment works for you.

Measuring outcomes is about being able to prove it to the money men.

*All data must be used for improving care and not collected for its own sake.*



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What do you think?



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# Patient Partnership Agreement

- What is it?
- Who wrote it?
- What does it say?
  - Your responsibilities
  - Your Centre's responsibilities
  - Home delivery



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# Keeping Records

We believe that if more data is required then it has to be as easy as possible to collect it.



HOME THERAPY SUPPORT SERVICE

If your centre is ready you can register at:

**[www.haemtrack.nhs.uk](http://www.haemtrack.nhs.uk)** if not then you can ask your centre to take part in the scheme.



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We want the  
NHS  
Commissioning  
Board to lead  
by example  
when it  
commissions  
services  
directly

# The Health Bill (England)

## Changes to the internal market

- Moving from regional decisions to the new NHS Commissioning Board
  - Central contracts measured against outcomes
  - One service specification. An end to regional variation?



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# Scotland

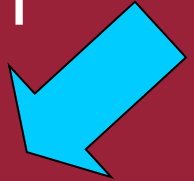
- In common with Wales and Northern Ireland there is no internal market
- National Services Division
  - Pay for treatment
  - All health boards are in it together



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# Advice from the World Federation of Hemophilia





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# Comprehensive Care Centre Audits

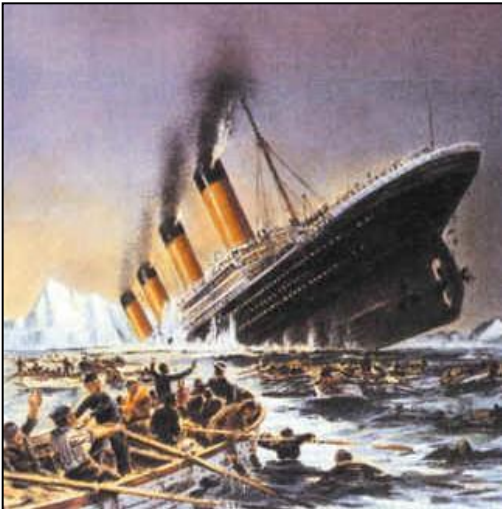
- 2012 – more than just the Olympics
- Patient Questionnaire
- Smaller Centres included
- Training for Auditors



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*The Press and Journal*

## **Aberdeenshire Man Lost at Sea**



15 April 1912

# Together we are stronger

We are much more effective with your help:

- Local and regional media is more interested in any story if they can talk to someone locally.
- MPs, MSPs, AM and MEPs all prioritise letters and emails from the people they represent. Especially, when they are being asked to do something.



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What can I do?



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# Thank You

[www.haemophilia.org.uk](http://www.haemophilia.org.uk)