



Deciding on the Society's Priorities

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Chief Executive



Haemophilia Society Evaluation

- Charities Evaluation Service
- Monitoring Data
- Members Survey
- Interviews with members
- Interviews with staff
- Interviews with external agencies
- Interviews with volunteers
- Interviews with Local Group members



Evaluating the Society's Work

1. The Society and its Members
2. What the Society does
3. Views on the Society
4. Outcomes of the Society's activities
5. The Future



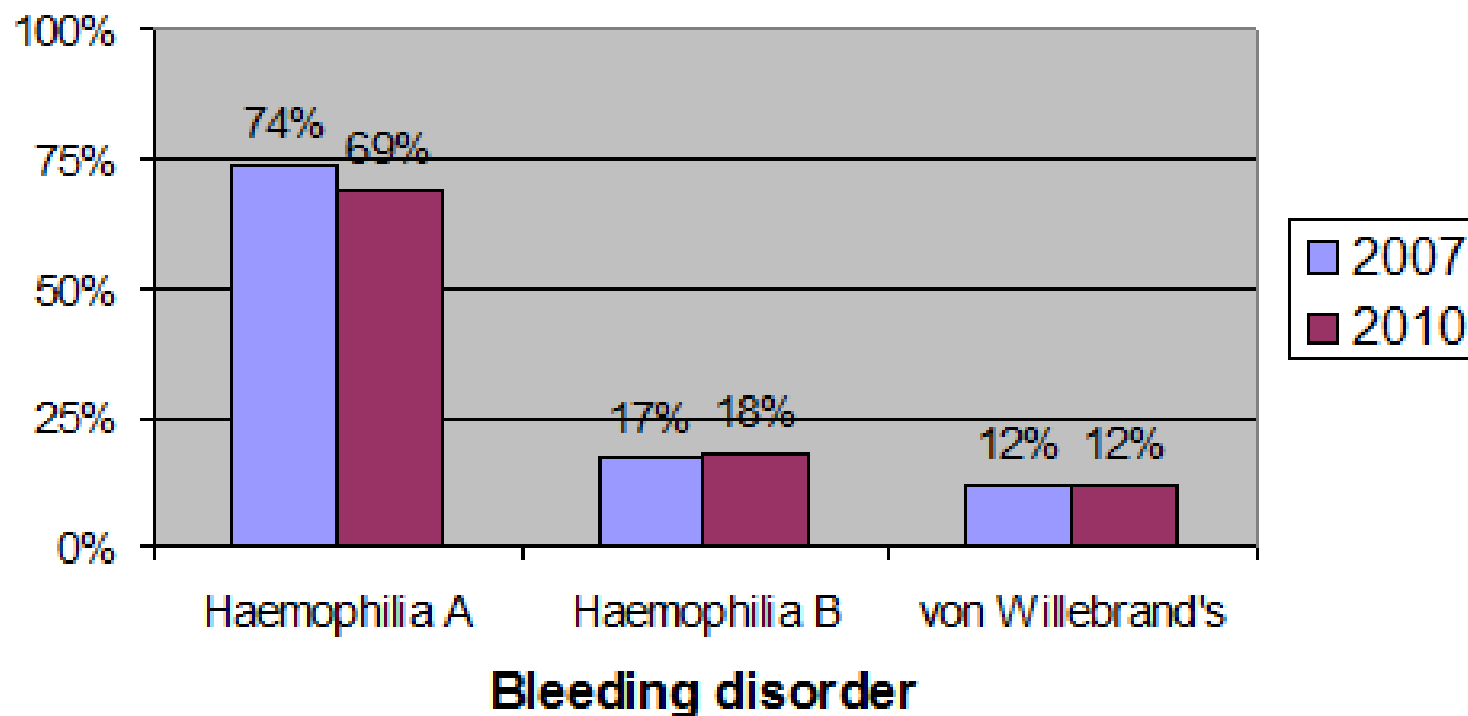
Changes at the Society

- Funding
- The Restructure
- Governance



Breakdown of type

**Chart 1: Bleeding disorders affecting members:
comparison of 2007 and 2010 survey data**





Member Awareness of activities

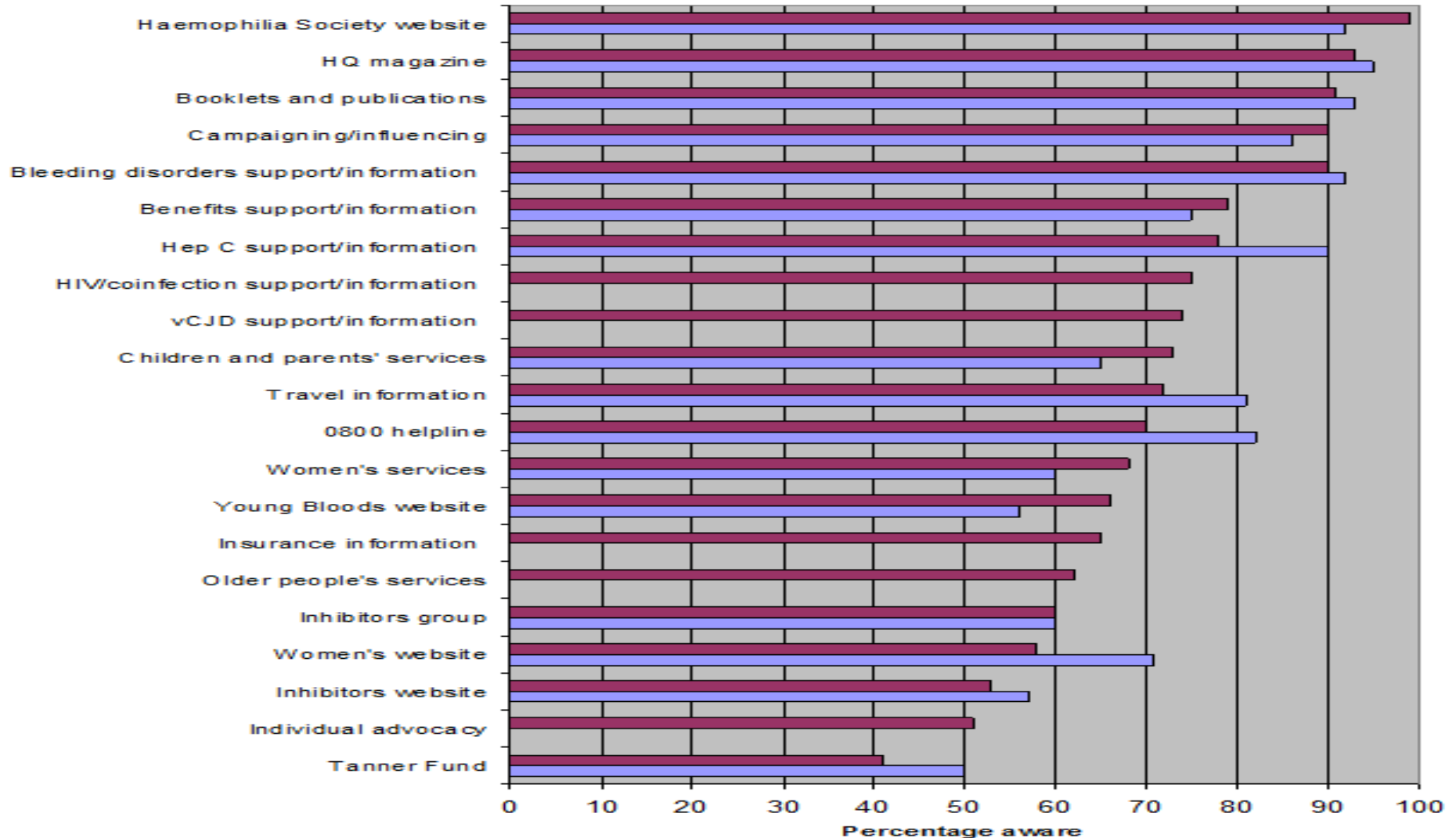
- Quite high- almost all aware of key services
- Lower for – HCV, 0800 helpline, travel information, women’s services, and Tanner Fund
- Low awareness in 2 women with vWBs
- Campaigning- very aware but lacked detail



Awareness of Services

Chart 3: Respondent awareness of Haemophilia Society services: 2007 and 2010 surveys compared

■ 2010
■ 2007





Views on the Society

Majority had positive things to say:

“In the times I have used the Haemophilia Society I have found them to be a great help and support. I am also going to be ringing up shortly for some help and advice on a current situation I have and I’m sure they will be just as helpful and friendly as they always are!!!”



Views on the Society

- Staff and Trustees - 'run by people who care'
- Lack of resources – real concern about folding – few negatives – inertia – nurses concern about info
- Patient Focus – improved- bring issues to table
- Appropriateness – sideline vWB – all things to all people
- Involvement of people with bleeding disorders
- Work with youth leaders – very positive



Outcomes of Society's Activities

- 21% life was better or significantly better
- 15 interview respondents had benefited
- Microclinics – reported improvement to well-being – increased funding for services
- 29% access info more easily due to Scottish Development Project



Outcomes of Society's Services

- Inhibitor Event – almost all reported increased knowledge
- MFT/Society Events – reported learning about their condition and using that learning to make changes in their lives
- Learning how haemophilia affects others – more able to care – not to wrap in cotton wool
- Nurse – positive learning



Outcomes of Society's Services

- “ As we have only discovered that my son has severe haemophilia in the past year and that I am also a carrier, our knowledge of our condition has increased 100%. The level of information and the way we have been informed has been amazing and we are very grateful to the staff that have provided us with this.”
- “ I have met other families affected by haemophilia. It's interesting to share information about treatment and support. It makes me realise the treatment we get at [our local centre] is very good. Others not so lucky”



Outcomes on Society's Services – Getting appropriate treatment

- Important outcome was getting information and support to fight for their rights to good treatment – Society has given ‘bigger voice and a sounding board’
- 8 out of 16 attending IG Weekend – felt more confident discussing their treatment with their centre
- Considerable amount of benefits awarded



Outcomes – for better treatment and care

- Being in the right places – audits – procurement – meetings with DOH
- Working with pharmas to get better products
- Improved services by centres
- Positive effect on purchase decisions
- GIGTB – leaflet on self-treatment – SHCA input – local commissioner agreement



Peer support at events for young people

You have no idea how this weekend [in Paris] has helped Bobby. [1] Firstly he thought it was great spending time with boys his age with his condition. Secondly he really appreciated the history and art work he's seen in Paris. We unfortunately are on a low income and could not afford to take Bobby to Paris.

As a result of the trip Bobby has access to a network of other teenage boys with haemophilia. This is invaluable to him, especially at the age he is just now, this has let him see that there is a community out there that have his condition and have the same problems and hurdles to overcome just the same as he has. He understands the importance of self injecting and he has promised to make an effort with this. They all laughed at the stories they had regarding trying to explain to people about their condition. This trip was of tremendous benefit to my son.

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[1] All names have been changed



Contaminated Blood Campaign

- Early Day Motions – 199 MPs
- House of Commons Debate
- Review of payments
- Liberal Democrat manifesto
- Positive part in the campaign
- Varied views on the Society's impact

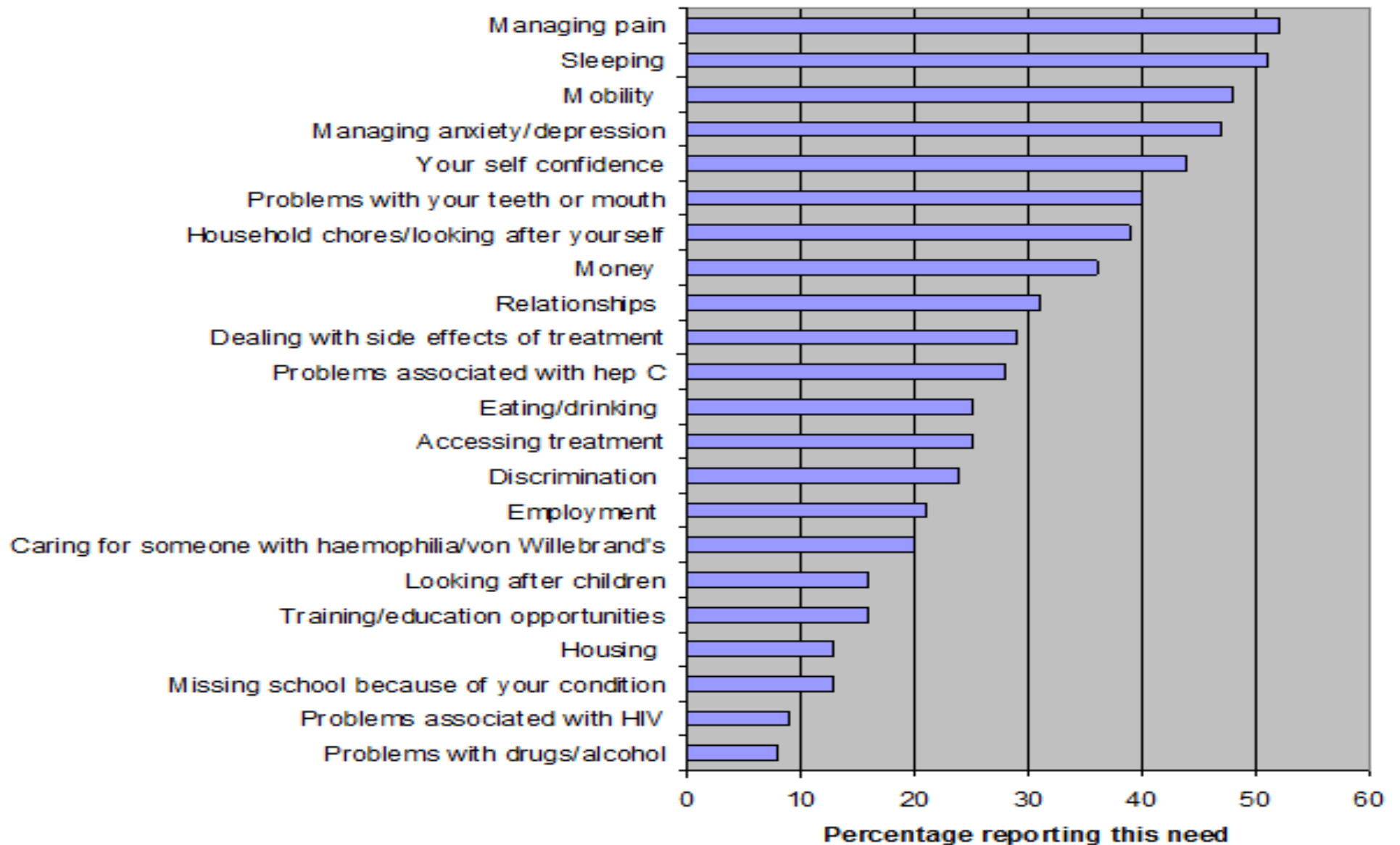


Summary on Outcomes

- Valuable access to peer support
- Increased knowledge and understanding
- Welfare benefits awarded
- Improved ability to get appropriate treatment and care
- Influenced the contaminated blood campaign
- Innovative methods of user involvement

The Future

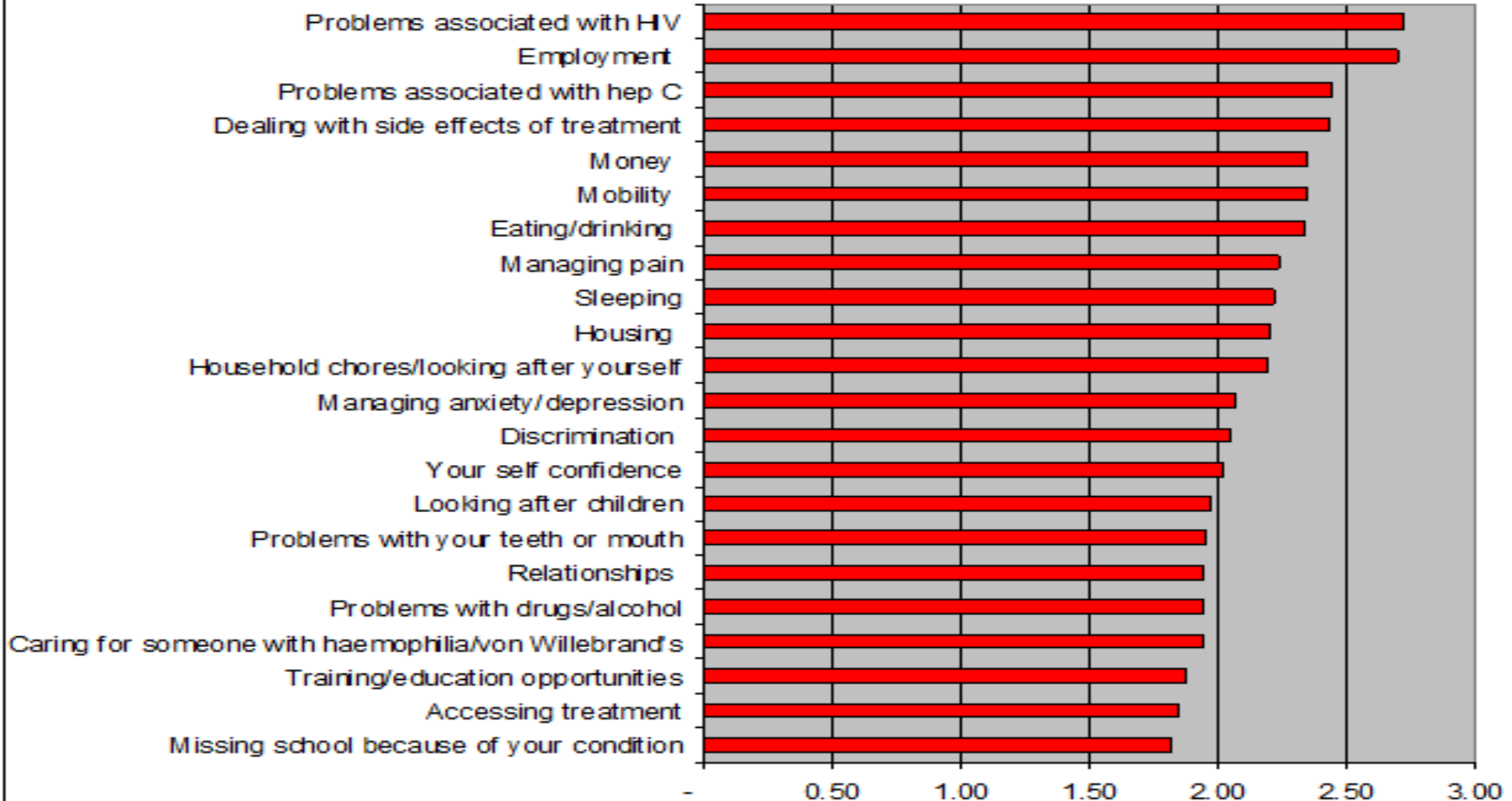
Chart 5: Prevalence of need (member's survey 2010)



The Future

**Chart 6: Severity of need:
personal ratings (members' survey 2010)**

Understanding this table: 2010 members' survey respondents who reported experiencing this need were asked to rate its severity from 1-4, where 4 is high. This table gives average scores.





What affects need?

- Quality of treatment available
- Move to home delivery
- Scope and nature of other services
- Family History
- When diagnosed
- Age



Need for continued campaigning for better treatment and care

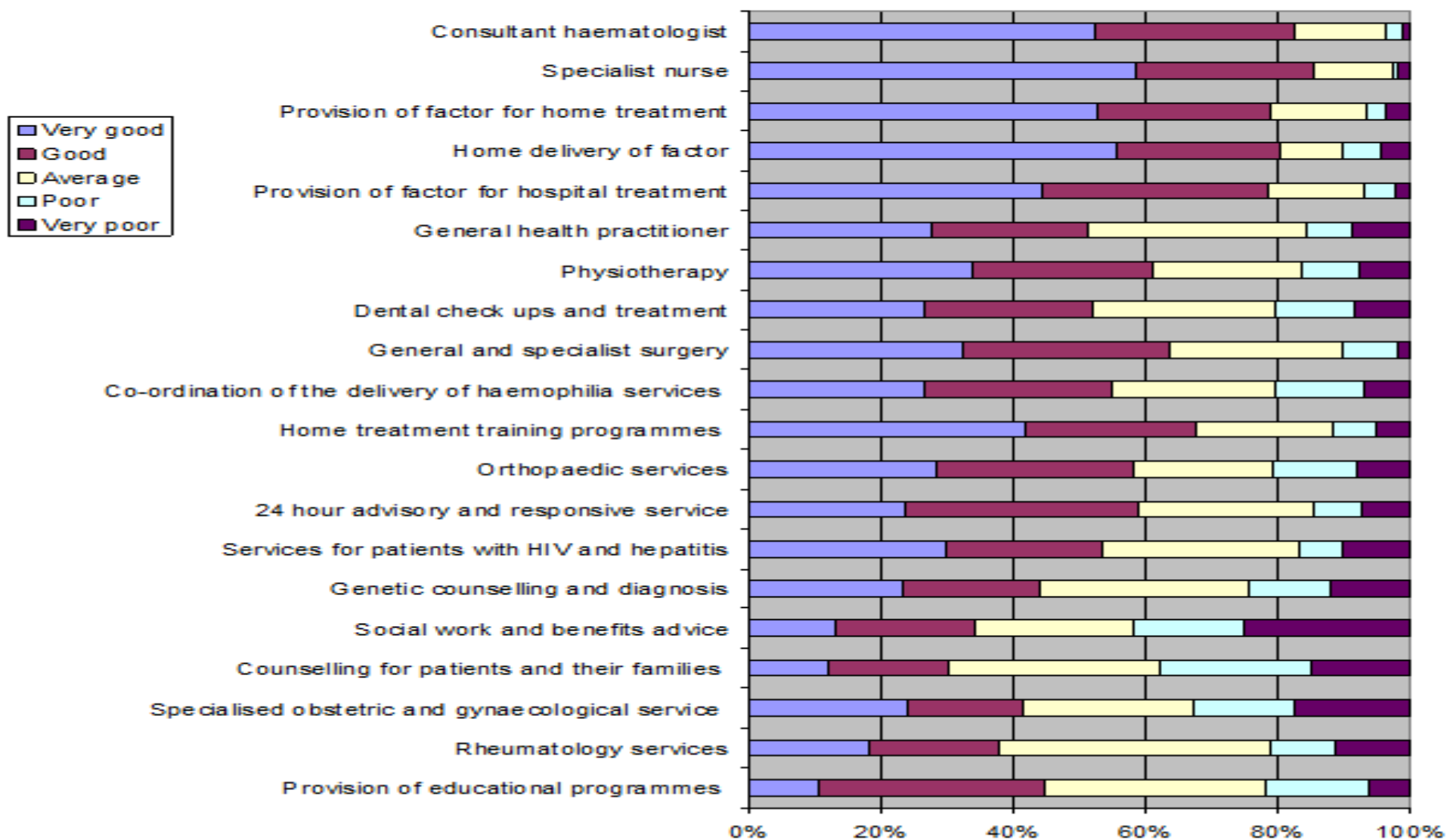
- 15% did not fully understand what services they could access from centre
- 51% wanted more information on the services that could be offered
- 60% not been offered a care plan
- 54% rated A & E doctors level of understanding of their condition poor or very poor



Care

Chart 7: How would you rate your care over the last two years?

(members survey 2010, n=210)

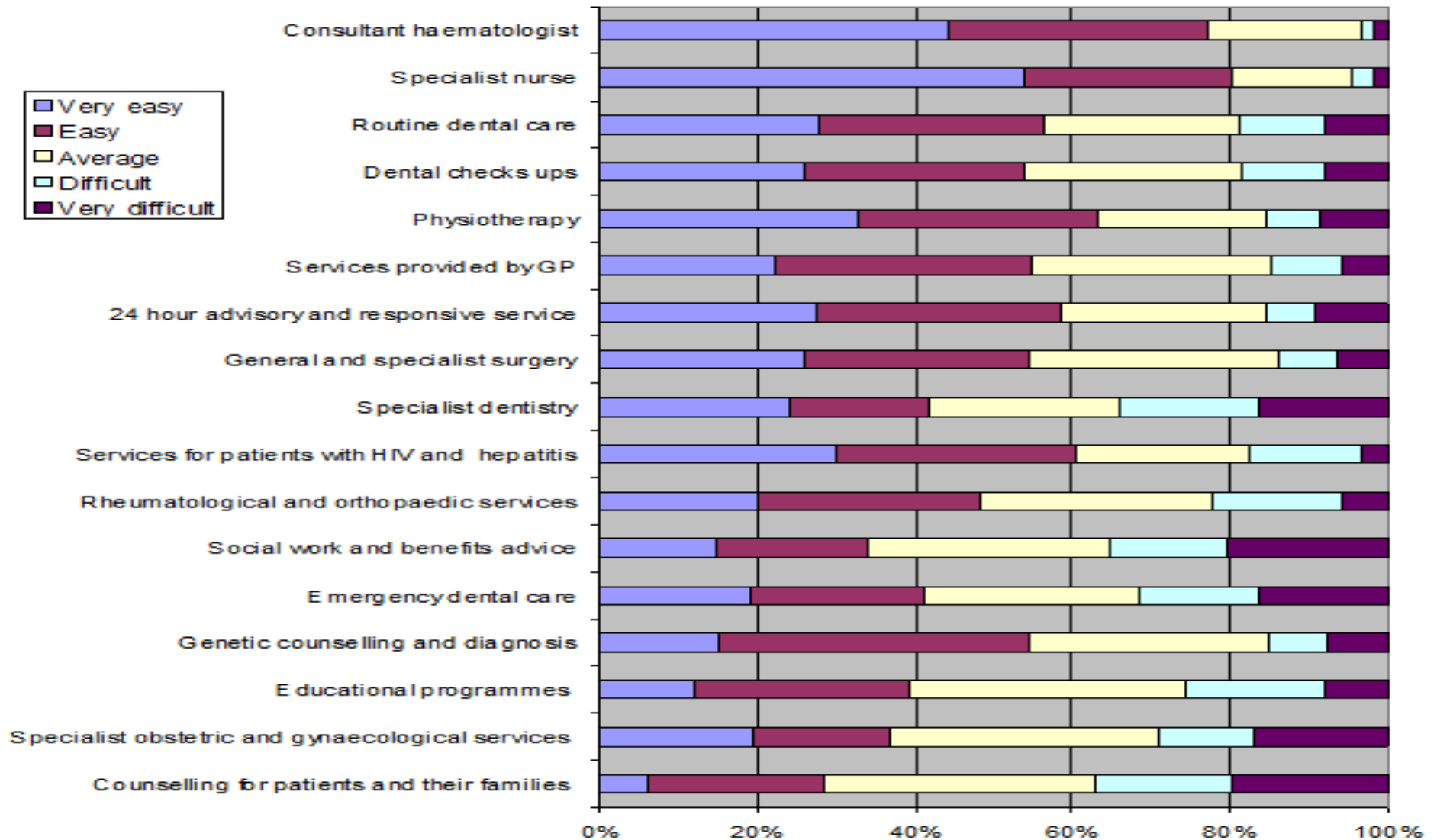




Services

Chart 8: Ease of access to services

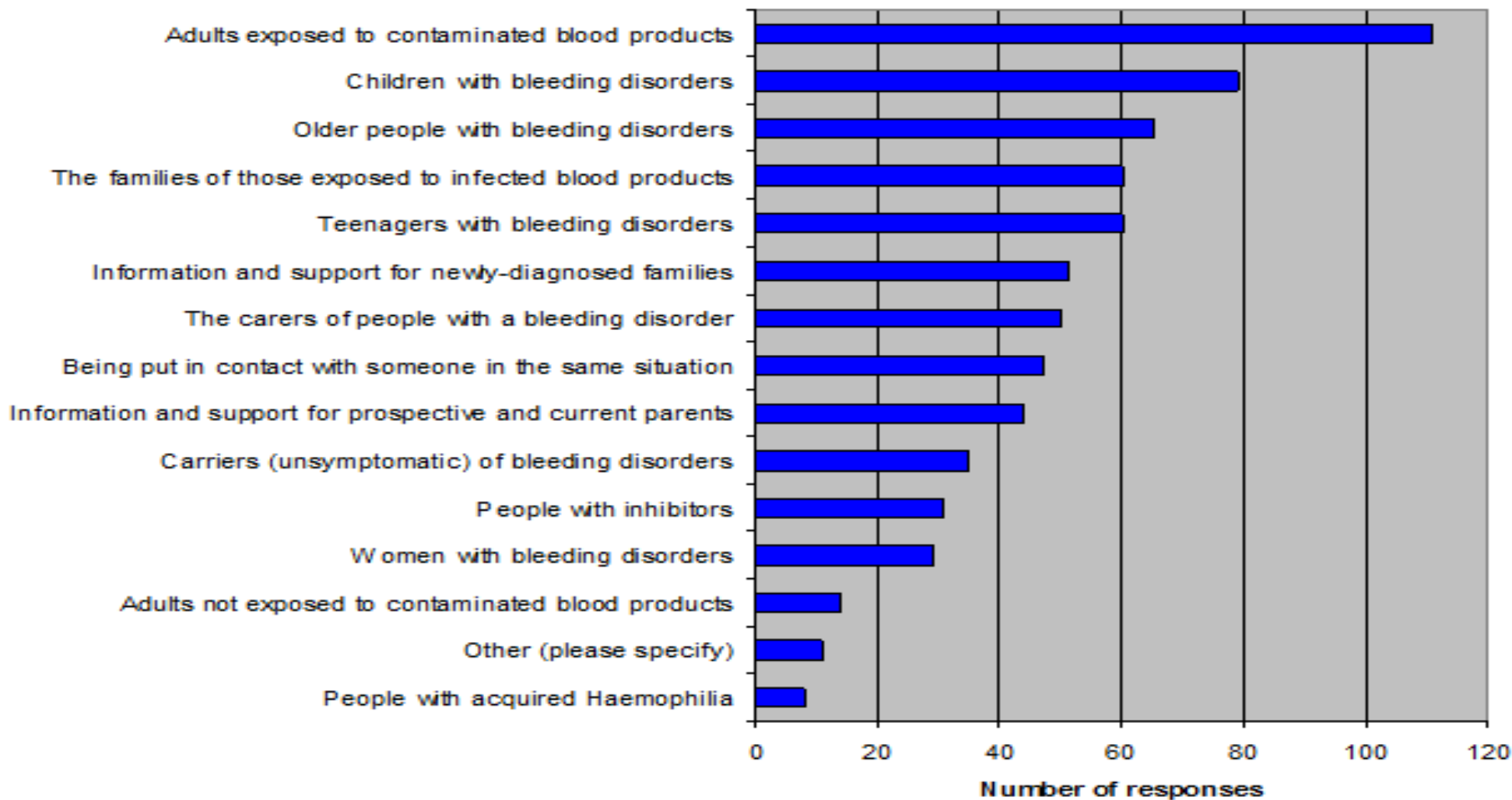
(members survey 2010, n=209)





Expansion of Services

Chart 9: How the Haemophilia Society should expand its services
(from members' survey 2010, multiple responses possible, n=200)





Summary

- Membership – less than half members email addresses
- Inclusive and good patient focus
- Wide range of services – well-used
- Heavily involved in campaigning and influencing
- Financial difficulties mean some objectives not met e.g. loss of support to local groups. Women and Children and Families
- Work with local groups



Summary

- Possible lack of focus in trying to provide such a wide range of services
- Resulting reliance on project funding
- Feedback on services – some slippage –further investigation
- Good evidence of positive outcomes
- Positively influenced contaminated blood campaign



Strategic Decisions

- Reviewing Services – breadth of its services – better outcomes data – needs of women and children
- Contaminated Blood – continue to fight of move on
- Benefits – campaigning or service delivery



Recommendations

Recommendations about the membership

- The Society should consider:
- Ways to extend its reach into the target group and increase member numbers.
- Increasing the percentage of members for whom it has email addresses. This could make it cheaper and easier to communicate with members, and could increase accessibility. This could also be used as an opportunity to increase the completeness of the data held on the membership.

Recommendations about the way the Society works

- The Society should consider:
- Prioritising things that might save time, for example putting up standard responses for benefits enquiries on the website. Some of the latter could be targeted at healthcare professionals or the staff of other welfare benefits advice organisations.



Recommendations

Recommendations for specific services

- The Society should consider:
- Clarifying the respective purposes of the helpline and administration line.
- Keeping the website more up to date. This may involve additional support to enable all the staff team to feel confident in working on the website.

Recommendations about evaluation and research

- The Society should consider:
- Centralised, consistent monitoring of its services and outcomes. This should be implemented alongside plans to ensure the data is used as fully as it can be.
- Further research into why ratings for some services have slipped



Thank You