



# Evaluation of the Haemophilia Society

## Executive summary

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# 1. Executive summary

## 1.1 Introduction

The work of the Haemophilia Society was evaluated by Charities Evaluation Services over 2010/11, using monitoring data, member surveys and 43 stakeholder interviews.

## 1.2 Outcomes

### Outcomes for members

Society services are making a real difference to members. Important outcomes included:

- *Improved quality of life.* 21% (48) of survey respondents said their quality of life was better as a result of the Society.
- *Gaining knowledge and information.* Respondents reported gaining knowledge of their situation, or of the 'bigger picture'. One explained that:  
*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.*
- *Support with accessing treatment.* Interviewees reported getting support from the Society in accessing treatment. One explained that the Society had helped him get treatment that ultimately helped him walk again.
- *Welfare benefits gained.* The Haemophilia Society benefits service has been successful in getting a considerable amount of benefits awarded to clients.
- *Access to peer support.* Many respondents said the Society had put them in touch with others who had similar experiences; this was particularly valuable given the rarity of the condition. One member described the phone support he had received:  
*People helped me through difficult times, through operations; times when I have had recurring bleeds... it's just pick up the phone and ask 'what works for you?' 'Have you tried this?... this has helped me a lot.*

### Campaigning outcomes

The Society is contributing to improved treatment and care for people affected by bleeding disorders. There is significant anecdotal evidence that the Society has positively influenced the contaminated blood campaign. Alongside MPs, the Society was recently successful in getting a debate on contaminated blood in the House of Commons, and later a review of the payments for people infected with hepatitis C which resulted in improved compensation. There is also good evidence of the Society's effect on treatment and care locally and nationally.

### 1.3 What people think of the Haemophilia Society

Feedback on the Society and its staff was overall very positive. Members and external professionals felt the Society was doing well and was inclusive and patient-focused. Some felt that just having the Society there was reassuring. A few felt that the Society could communicate better with members.

Overall satisfaction in the 2010 survey was quite high. Across all services, respondents gave 36% 'excellent' ratings, 52% 'satisfactory', 8% 'not satisfactory' and 3% 'awful'. Low ratings were given by a relatively small number of people; reasons for these ratings are not known. Satisfaction has remained at similar levels since 2007; this is an achievement over a period of great change and reduced capacity.

General awareness of services amongst the membership is quite high, and has remained so over the last few years. Awareness of the Society's involvement in the contaminated blood campaign was also high. Interviewees were slightly less aware of the Society's general work campaigning for better treatment and care.

### 1.4 What the Haemophilia Society does

#### **The membership**

The Society has just over 4000 members. About 60% have bleeding disorders; the rest of the membership is primarily family or friends of people with bleeding disorders. The membership contains a good mix of men and women, from a wide range of ages, from all over the UK. The membership is 93% white, similar to the UK population as a whole.

The Society has email addresses for about 1500 of its members, which affects communication with the remainder.

A small number of respondents wondered if the Society had become 'too broad a church'; a few women said that they felt women were slightly 'sidelined'. However, other respondents valued the range and diversity of the membership.

#### **The Society's activities**

##### *Services*

Where monitoring data is available, services are well used. Society staff have worked hard to deliver a wide range of services in four key areas:

1. *Information services* (eg, websites, magazines, leaflets, research).
2. *Individual advocacy and support* (eg, benefits advice, telephone helplines, physiotherapy Microclinics, community fundraising support).
3. *Opportunities for people to meet and support each other* (eg, events for children and families and for people affected by inhibitors, HIV or hepatitis C, support to local groups, Facebook group).
4. *The Scottish Development Project* (eg, outreach, events, and sessions at centres).

### *Campaigning and influencing*

The Society has been heavily involved in the contaminated blood campaign. It also campaigns for better treatment and care for people affected by haemophilia. For example, the Society has recently become involved in the procurement process and in regular meetings with the Department of Health.

### *Get Involved, Get the Best (GIGTB)*

The innovative GIGTB project started in 2009, supporting people affected by bleeding disorders to get involved in improving care and treatment. The project is currently focused on bringing the patient perspective to three areas of work:

1. Local commissioning.
2. The auditing of haemophilia centres every three years.
3. The Pan-Thames Haemophilia Consortium and services reconfiguration.

### *Work with volunteers*

The Society involves volunteers well within its services, and has some innovative models of involvement. The Society has a small number of long-term volunteers helping to deliver some key services. Recently the Society has involved some Youth Leaders. This group was very positive about their work with the Society, and the way the Society involved them. Two GIGTB volunteers interviewed also felt supported and appreciated, but felt the Society could do more to clarify their roles, and to support GIGTB volunteers in general.

### *Reduced resources*

Like many third sector organisations, the Society recently experienced funding difficulties, resulting in a restructure and reduced staffing numbers. This has meant the staff team have been unable to deliver all the outputs planned for this period. Services to women and children and families, and work with local groups and healthcare professionals, have been reduced over the last few years.

Respondents were concerned that the Society might have to close or reduce services because of lack of funding. Only a few respondents felt the lack of resources had adversely affected service quality. However, reduced capacity has affected internal work. For example, monitoring systems were not developed, and staff have found it hard to find time to update the website. The Society has also not yet been able to review its services in the light of reduced capacity.

## 1.5 The future

### **Needs**

Over 50% of 2010 survey respondents said they had problems with managing pain, sleeping, mobility and managing anxiety/depression. Problems associated with HIV and employment were experienced most severely.

Need is affected in part by what other services are available. Most interviewees were only accessing support from the Society and their local haemophilia centre. Many interviewees felt they had nowhere else to go for the information they could get from the Society, or nowhere that was as 'bespoke' and 'unbiased'.

Although treatment for most bleeding disorders is now generally good, survey respondents identified areas for improvement both in quality of services (for example

some doctors lacked knowledge of bleeding disorders) and access to services (some respondents did not fully understand what they were entitled to).

#### *Suggestions from members*

Members made recommendations for the future of the Society, including more services to adults affected by contaminated blood, children affected by bleeding disorders and people with inhibitors, and support to local groups. Members also suggested the Society had a continued role in campaigning for better treatment and care – or at least for maintaining consistent, high quality care, particularly in the light of NHS budget cuts.

#### **Strategic decisions**

The Society needs to decide whether to continue its current level of involvement in the contaminated blood campaign. Involvement in this campaign has been an important part of the Society's work, but it has been mostly unpaid, which has had a detrimental effect on services. The Society needs to decide whether continued involvement is in the best interests of the majority of its members. Support for the campaign is understandably high among the membership. However, it is not clear whether the majority would still support a continuation of the fight if it were fully aware of the repercussions. The recent government announcement of increased compensation for those affected by hepatitis C may also affect the views of the membership.

Upcoming benefits changes mean there may be potential to expand the benefits service if this is seen as a priority. However, the Society may first need to decide how best to deploy existing benefits staff, whether for casework or campaigning for benefits reform.

### **1.6 Key recommendations**

The Haemophilia Society has three strategic issues to consider:

1. A review of the breadth of its services in the light of reduced capacity.
2. Whether to continue to fight for the full implementation of the Archer recommendations.
3. How best to deploy the time of the Society's Benefits Worker.

The Society should also consider:

1. Ways to extend its reach into the target group.
2. Increasing the number of members for whom it has email addresses.
3. Keeping the website more up to date.
4. Centralised, consistent monitoring of its services and outcomes.
5. Further research into why ratings for some services have slipped.