

**AN EVALUATION OF  
THE CURRENT METHODOLOGY  
FOR FUNDING OF NATIONAL HAEMOPHILIA  
PATIENT ORGANISATIONS**

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## Introduction

The survey “An Evaluation of the Current Methodology for Funding of National Haemophilia Patient Organisations” was prepared, carried out and analysed from February-October 2014 and took into account the data of the financial year 2013 and earlier, provided by the respondents. The aim of the survey was to ascertain and identify the current sources of funding for haemophilia National Member

Organisations (NMOs) in Europe; to evaluate the extent to which organisations had policies regulating funding received from pharmaceutical industry, where such funding was received, as well as to examine results and recommend best practice for the future.

## Introduction

There is a great diversity among the NMOs within the European Haemophilia Consortium (EHC) in terms of size of the membership, the structure of the organisation, intensity and complexity of activities, the country-specific accessibility to treatment and care, and many more aspects. All these factors also greatly influence the availability and practices of funding.

In order to better meet the needs of people who live with rare bleeding disorders in Europe, it is crucial to have joint approaches and to speak with one voice. Having in mind the great gaps in haemophilia treatment that still exist in Europe, there is doubtlessly need for the patient organisations to remain strong, sustainable and well governed, as well as to be regarded as an equal stakeholder when decisions

about treatment and care are made. To achieve this as a status quo it is essential to establish sustainable frameworks and governance with regards to funding. The first step in seeking to establish such a framework is to explore the existing funding practices.

By carrying out the “An Evaluation of the Current Methodology for Funding of National Haemophilia Patient Organisations” survey, it was possible to outline the trends of funding sources within the national membership of the EHC. In addition, the EHC was able to research how those funding sources were used by each NMO and to analyse the opportunities, as well as the potential weaknesses and threats, brought about by each of those funding sources in the work of the organisations.

## Survey methods

The questionnaire was designed in cooperation between the Irish Haemophilia Society (IHS), the EHC and the French Haemophilia Association (AFH). The initial design of the survey was developed by the IHS, taking into account the various areas related to the funding sources and usage of the haemophilia patient organisations in Europe. The draft design of the survey was shared with the EHC and the AFH, including as many perspectives as possible and seeking to reduce the possible language barriers. In order to access a broader target group the survey was made available in English and Russian.

The survey was distributed in electronic format using Survey Monkey software and was sent to each of the 44 NMOs of the EHC. 32 NMOs took part in the survey; therefore the results are geographically balanced and represent 14,828 individual members of the NMOs and altogether 52,091 patients with haemophilia A or B, Von Willebrand Disease or related rare bleeding disorders in Europe.

The NMOs in Albania, Austria, Azerbaijan, Belgium, Bulgaria, Croatia, Czech Republic, Estonia, Finland, France, Greece, Hungary, Iceland, Ireland, Latvia, Lithuania, Macedonia, the Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine, and Scotland – as a regional organisation - participated in the survey.

To support the quantitative findings, the survey employed a sample group to outline more concrete results from the NMOs, which are diverse in terms of the size, number of staff and complexity of the activities of the organisations. The NMOs in Latvia, the Netherlands, Poland and Portugal constituted the sample group. Both the results of the survey and the follow-up communications with the sample group were analysed and broad findings were noted, which offered a clear overview of the challenges and opportunities facing NMOs in terms of funding in different contexts.



## Survey results

### Annual budget

In order to understand the policies and practices related to funding, it is necessary to gain an overview of the annual budgets of the NMOs, as well as the sources on which the budgets were built.

From the 32 NMOs that participated in the survey, 28 gave response to this question. The results show that the funding gaps between the NMOs are very evident.

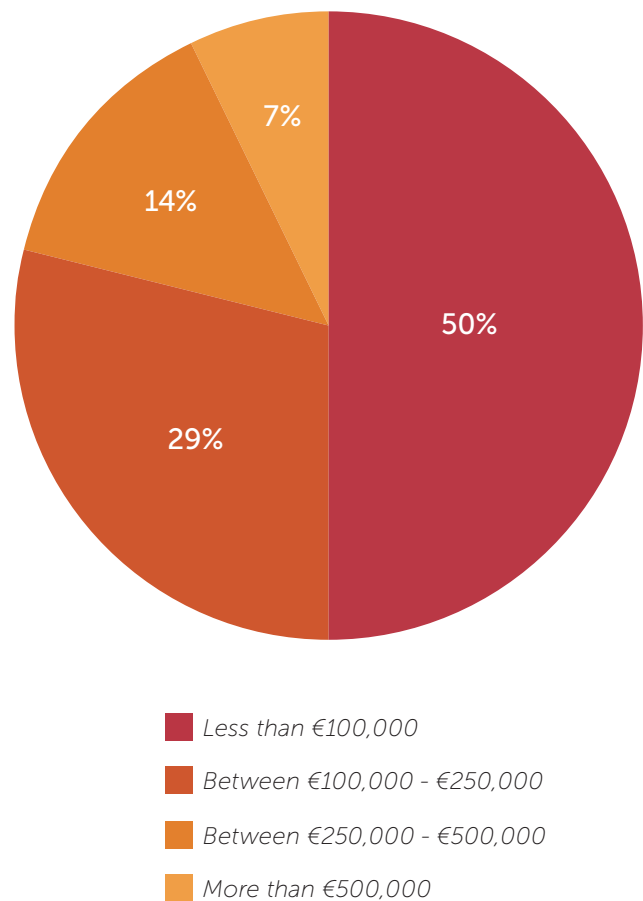
In 2013, half (50 per cent) of the NMOs who responded to this question operated with an income of less than €100,000; 29 per cent of the NMOs had a budget of between €100,000 and €250,000, whereas 14 per cent operated with a budget of between €250,000 and €500,000. Only seven per cent of the NMOs had a budget of more than €500,000 at their disposal.

The distribution of the budgets within Europe shows that either less wealthy countries or countries with a relatively small number of people with rare bleeding disorders have smaller NMO budgets all in all.

The size of the budget of the NMOs can presumably have an impact on their approach to funding. A bigger annual budget might allow a better position to negotiate the terms and conditions of funding sources, as well as the comfort not to accept funding which might give one donor an uncomfortable share of influence over the activities implemented.

The NMOs with larger and more varied sources of funding in general also had higher instances of non-restricted funding, whereas those with a

Annual Budget 2013

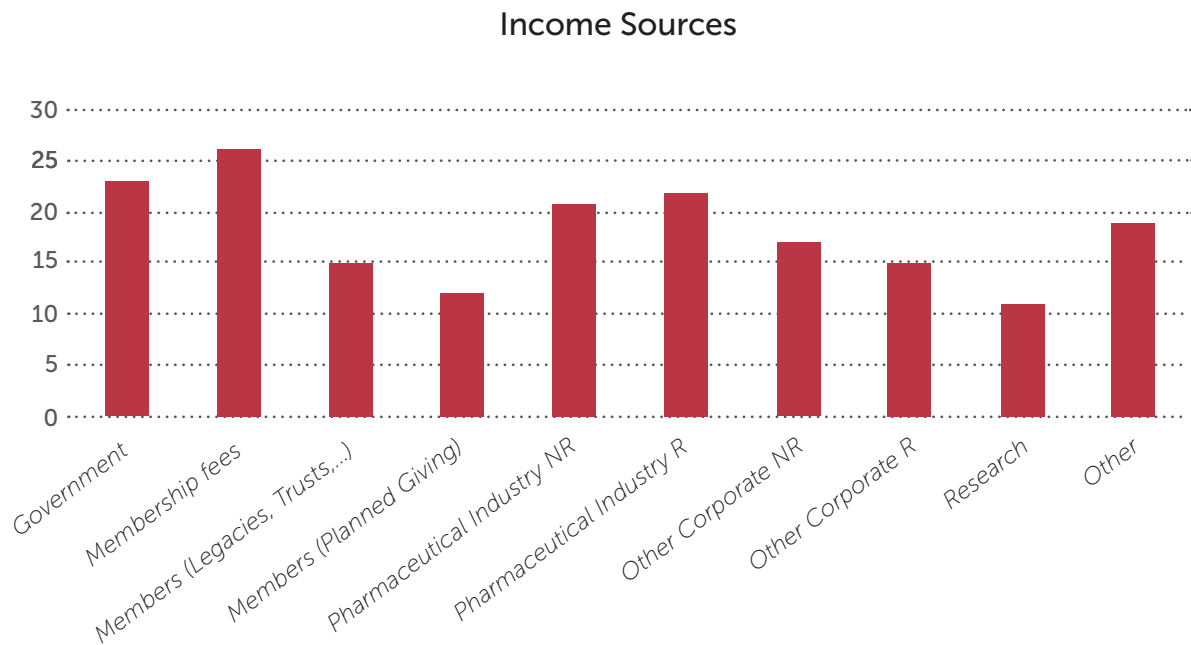


smaller variety of funding sources tended to have access primarily to restricted funding.

Interestingly, many of the NMOs with bigger budgets and more diverse funding sources were more successful with compensation claims connected to contaminated blood products, and were also more involved in the larger haemophilia society, e.g. through their active participation in the international haemophilia meetings.

## Income sources

Respondents were asked to identify the variety of sources that constituted their annual budget of 2013. Thirty of the 32 respondents provided responses; these showed a trend that the government, the membership of the organisation and pharmaceutical companies were the three most frequently mentioned sources of funding among the NMOs.



In total, 23 NMOs (77 per cent) received government funding, 26 NMOs (87 per cent) received funding from membership fees, 15 NMOs (50 per cent) received donations from members through legacies and trusts and 12 NMOs (40 per cent) received donations from members through planned giving and fundraising. The survey also shows that 21 NMOs (70 per cent) received non-restricted funding from the pharmaceutical industry and 22 NMOs (73 per cent) received restricted funding from the pharmaceutical industry. Finally, 17 NMOs (57 per cent) received non-restricted donations, 15 NMOs (50 per cent) received restricted donations from other corporate sources, 11 NMOs (37 per cent) from research and 19 NMOs (63 per cent) from other sources, which were not specified.

However, looking at what proportion each of these sources constitutes in the NMO budgets it is clear that the amounts received from membership-related sources were considerably smaller in comparison to the other two most frequently indicated sources. For example, the proportion of the mean amounts received from the membership-related sources in the budgets of NMOs was two per cent in comparison to 17 per cent of government funding and 26 per cent of pharmaceutical industry funding.

The crucial issues for the patient organisations are financial sustainability and independence. This is quite closely related to the designation of the funding received. The organisations can only then grow stronger and build their capacity, if they are free to manage their budget in a way that is sustainable and

beneficial for people with rare bleeding disorders. This is reflected in the responses received on the two aspects regarding the funding of the NMOs – reliability and operational freedom.

The survey shows that the most reliable/secure funding sources are the contributions from the membership, yet this income constitutes only a small part of the budget. At the same time, the government funding, which often constitutes the majority of the income received by the NMOs, is found to be moderately reliable (17 per cent), unreliable (33 per cent) or even difficult to access (50 per cent) by the 23 NMOs who received government funding. In comparison the 22 (50 per cent) NMOs that received pharmaceutical funding stated that the income from the pharmaceutical industry was either moderately reliable (25 per cent) or reliable (also 25 per cent).

At the same time, the degree of financial independence of the NMO can be reflected through the type of the funding that it receives – non-restricted or restricted. Apart from focusing on the thematic and streamlined activities, the non-restricted funding generally helps the organisation to maintain its structure, become stronger in its membership and grow in its capacity.

In contrast, the restricted funding means that the NMO can only use the funds for specific purposes or activities as agreed by the funder.

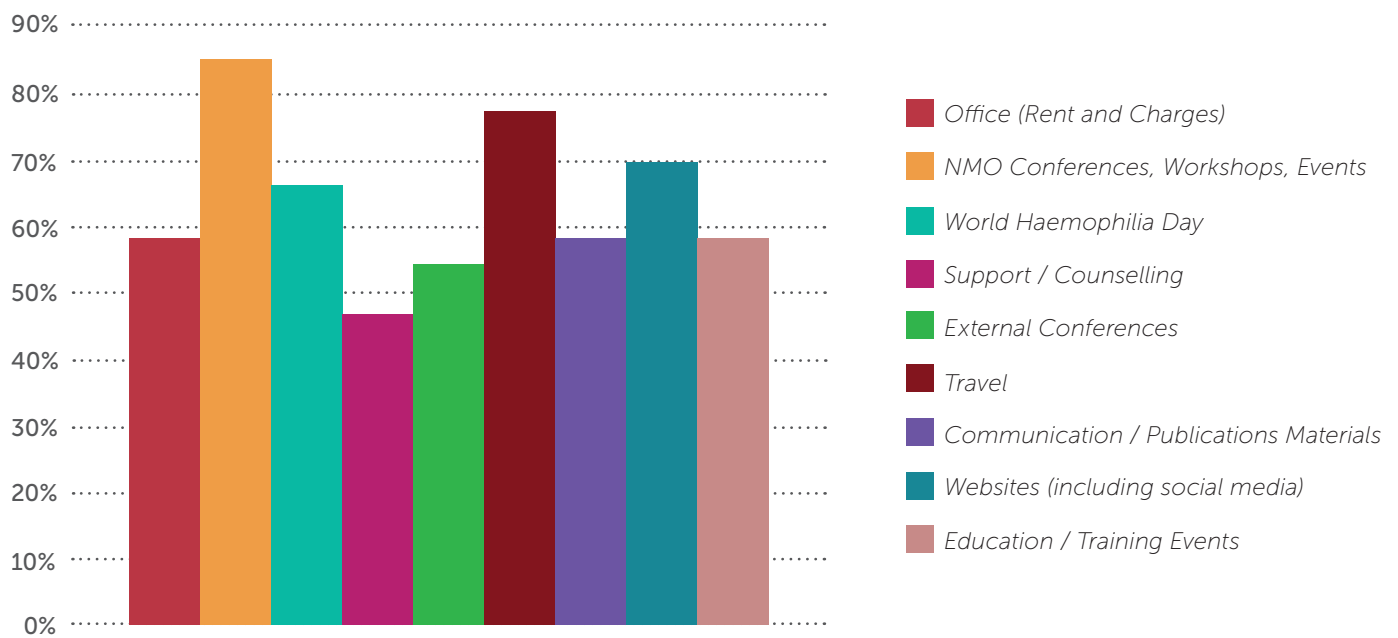
Overall 21 NMOs indicated that they received non-restricted funding, whereas 11 did not receive non-restricted funding from the pharmaceutical industry, still leading to the conclusion that they did receive restricted funding. Of the 11 NMOs that did not receive non-restricted funding, six received restricted funding from the pharmaceutical industry and two received restricted funding from other corporate sources.

The survey also shows that six out of the 11 NMOs sought to receive non-restricted funding, even though it was not always available in their respective countries. In six of the 11 countries the non-restricted funding was actually not available due to various reasons, such as state legislation or financial crisis. On three occasions the NMOs lacked information about the availability of non-restricted funding. Nevertheless, on average the restricted funding constituted a larger part of the budget in terms of the amounts received.

## Use of funding

Of the 32 NMOs who took part in the survey, 26 responded to questions regarding how the annual budget of the NMO was spent. The responses covered a wide range of activities, however, some major trends could be identified.

Funded Activities



How funds were spent can be divided into content and member-focused activities, communications and online activities, and infrastructure and representations.

Regarding the content and member-focused activities, among the 26 NMOs that answered this question, 22 (85 per cent) used funds for NMO conferences, workshops and events, 20 (77 per cent) for NMO annual meetings and 17 (65 per cent) invested in World Haemophilia Day activities, whereas 12 (46 per cent) used funding for support and counselling. More membership-focused expenditures were linked to 19 (73 per cent) NMOs, spending the funds for camps and activities (where

19 (73 per cent) used funds for children camps, 11 (42 per cent) for adolescent camps, 16 (62 per cent) on families/new parents' camps and 11 (42 per cent) for seniors), 15 (58 per cent) for education and training events, and nine (35 per cent) for databases/registries.

In terms of infrastructure and representation expenditure, 15 NMOs (58 per cent) used funds for office expenses, including rent and charges, 15 (58 per cent) for professional costs (i.e. staff, consultants, etc.), 14 (54 per cent) for external conferences and events (e.g. registration), and finally 20 (77 per cent) for travel (travel, accommodation, subsistence).

A bigger section within the expenditure of the NMOs was dedicated to communications and online activities. The survey showed that 15 NMOs (58 per cent) used funds for communication materials and publications (where 13 (50 per cent) spent on NMO magazines, eight (31 per cent) on newsletters, nine (35 per cent) on annual reports, five (19 per cent) on healthcare professional or lay-person publications and five (19 per cent) on product information leaflets). Also, online activities were important in terms of expenditure and 18 NMOs (69 per cent) invested in websites (including social media) and four (15 per cent) in developing apps.

A clear link could be observed between the activities and the receipt of the non-restricted funding, where those NMOs with a larger and more diverse funding base could provide more comprehensive services to their members and offer a more diverse range of activities, e.g. camps, conferences, workshops etc., as well as attendance in international events, such as conferences of the EHC and the World Federation of Hemophilia (WFH). At the same time, the organisations with smaller or limited income had less and more limited activities.

The use of restricted or non-restricted funding in implementation of the various activities listed above was explored and the results showed that the majority of the restricted funding was used for camps and conferences. This might suggest that through receiving funding only to implement these activities, certain limitations were posed on the work of the NMO. In addition, the NMOs that used more restricted funding for their activities also tended to give a higher proportion of access to the events and visibility to the sponsors as further described below.

Using restricted funding for the work of the NMO also means granting funders certain visibility and access to the activities. The survey sought to explore to what extent certain access was granted to the funders.

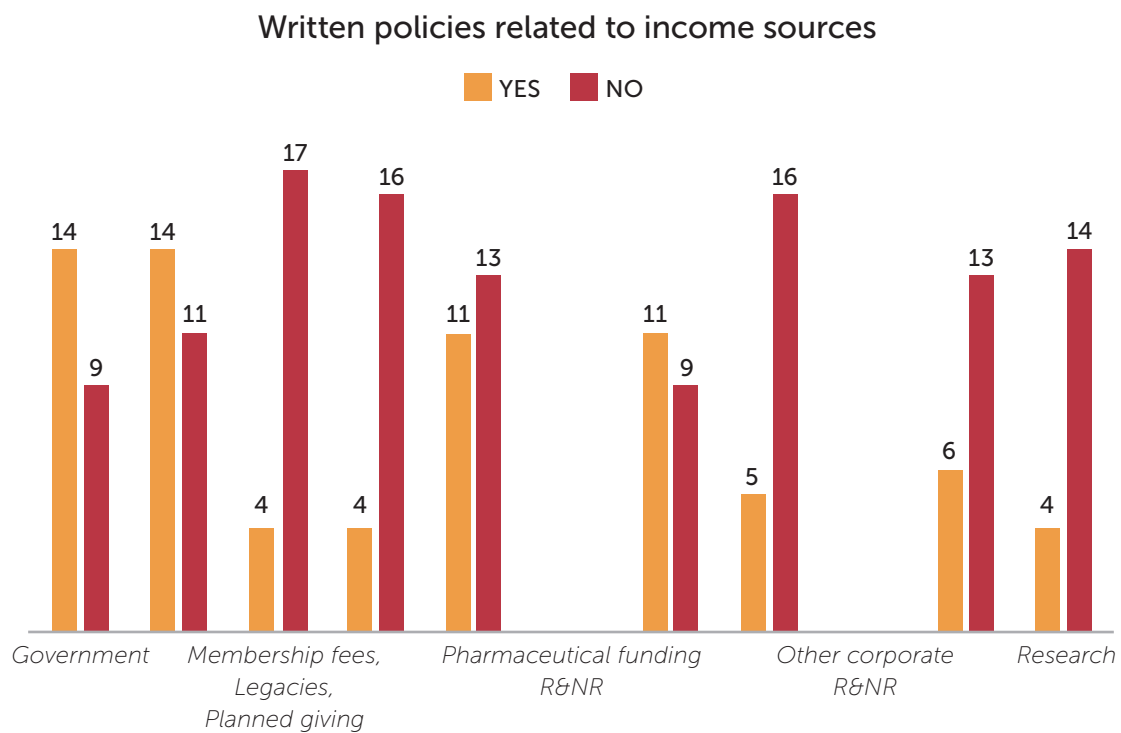
After examination of the government funding and the conditions related to that, the questionnaire responses show that there are no particular concerns regarding the visibility or access to the activities of the NMO. At the same time, the research with the sample group shows that government influence on patient organisations has become quite substantial, where the governments can to an extent influence the organisational structure and ideology, as well as accountability of the organisation in terms of holding the organisation financially accountable after having funded it.

With regards to the funding from the pharmaceutical industry, the results show that NMOs granted the funder a large amount of visibility and access to NMO activities, meaning that the acknowledgement of funding, either spoken, written or visual is often mandatory. However, none of the NMOs indicated the admittance of any of the funders to the annual conference of the NMO.

## Written policies related to funding

Referring to the above-mentioned access to and visibility at activities of the NMO, as well the impact on the content of the activities, it is crucial to discuss the policies that are in place to regulate this cooperation and protect the NMOs.

Therefore the survey also examined whether and to what extent those policies are in place.



Of 32 NMOs, 26 responded to this question; the results show variability depending on the source of income. The income that the NMOs receive from government-based sources, the membership fees and non-restricted funding from the pharmaceutical industry seem to be most frequently regulated by written policies, whereas the income from other sources seems rarely to be regulated.

The follow-up interviews with the sample group looked deeper into areas such as NMO details, income sources, funded activities and written policies. For example, interviews noted that although 54 per cent of NMOs stated they had no written policies when it comes to non-restricted pharmaceutical funding, some structures were in place nevertheless, even though not in a written form. All the NMOs had

to follow particular guidelines or legislation from government, industry or their own membership. In many cases, however, structures were not very transparent.

In addition, it can be noted that the European Union (EU) is guiding and regulating many policies within Europe, therefore current and future considerations relating to governance, accountability and transparency must remain in line with the respective EU policies. Also, the funding received from the sources listed above support many activities that are crucial for the development and sustainability of the NMOs, yet the lack of policies and absence of a clear framework would make it difficult to resolve problems that might occur.

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## Discussion and recommendations

As the movement towards patient empowerment continues to grow, it brings with it the need for NMOs to become better-qualified and professional in terms of structure and organisation of work, including the need to act in a clear and transparent manner regarding finances and fundraising. These steps are crucial to prove that patient organisations are serious contenders in the competition for funds.

To achieve better transparency, the following recommendations should be taken into account, to the extent possible:

- ▶ Patient organisations should avoid accepting funding from one major source in the pharmaceutical industry as it may be perceived as having the potential to lead to bias and lobbying for products or legislation that may not be in the patients' interest, lead to queries as to whether all stakeholders are involved for the right reasons, as well as lead to control issues and potential reluctance to relinquish control.
- ▶ Patient organisations are generally advised to seek to limit the amount of funding received from the pharmaceutical industry, where possible. According to Rose, S. L. (2013) the funding received from the pharmaceutical industry should be limited to 25% of the annual budget. However the reality of many rare disease patient organisations makes this a difficult objective to achieve and other measures (such as those outlined below) should be implemented.
- ▶ Where available the overall budget of non-profit organisations such as NMOs should include the financial value of all pro-bono or voluntary contributions and services provided to the NMO (e.g. time of volunteers, free/donated office space/ use of equipment etc.) in line with the common practice of many non-government organisations (e.g. Eurordis) .
- ▶ Funding received from the pharmaceutical industry should, at least in part, be non-restricted.
- ▶ Written guidelines, policies and agreements should be developed and used.
- ▶ Good governance (e.g. declaration of interest policies, codes of conduct) need to be developed and implemented within the NMO.
- ▶ Government and EU guidelines for the patient organisations (NMOs) or other non-profit organisations/charities, as well as existing documents regulating the relationship with the pharmaceutical companies, should be consulted.

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