



WFH

WORLD FEDERATION OF HEMOPHILIA

Hemophilia Patient Organization Self-Assessment



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Introduction

Hemophilia patient organizations, like many volunteer organizations, sometimes struggle to meet the needs of the community they serve. As an organization grows, priorities multiply, needs change, objectives evolve and new challenges appear.

A self-assessment is a useful exercise for organizations to take a closer look at what they do and how they do it. The process can help identify strengths and weaknesses and guide strategic planning. If done regularly, they can also be used to monitor progress. By involving as many people as possible in the self-assessment process, organizations encourage open dialogue between members, promote unity, and establish a common vision to work towards.

In 2011, the WFH developed the following self-assessment specifically for its national member organizations (NMOs). We started by identifying the main areas of activity common to our NMOs. Then, we developed a scoring system that would allow organizations to measure their performance in each area. Finally, we included a tool to help them establish an action plan to address areas that need improvement.

In order to get the best results, NMOs are encouraged to seek broad participation from members, volunteers, and board members of their organization. Individuals should complete the questionnaire on their own, then scores can be discussed as a group to reach consensus.

As you complete the survey, keep the following in mind:

- Not all the questions apply to all NMOs. If there is an aspect that you think should be changed or included in the questionnaire, feel free to change it.
- Be honest in your replies. The purpose of the self-assessment is not to judge but to help the organization grow.
- There is no right answer: two individuals from the same organization may answer the same question differently

We would love to hear from you!

You are welcome to share your organization's self-assessment with the WFH. The results will help guide the development of our programs and educational resources. Please email your completed assessment to wfh@wfh.org, or fax it to: +1-514-875-8916.

Hemophilia Patient Organization Self-Assessment

Organization name: _____

Country: _____

Using the scale below, rate your organization in the following areas:

- 0** = Not relevant/important for my organization
- 1** = Needs to start or take off
- 2** = Partially established
- 3** = Established but needs improvement
- 4** = Well established but can still be improved
- 5** = Fully mature, role model to other organizations

I. Organizational strength

A. Internal structure and operations	0 - 5	Areas to improve / Proposed action steps
1. My organization holds regular meetings (i.e. 3 or more times/year).		
2. My organization has a permanent address and suitable office/meeting space.		
3. My organization employs regular and fulltime administrative staff to support the work of volunteer officers and members.		
4. My organization is registered with the government.		
5. My organization has sufficient regional representation (i.e. chapters or board members) throughout the country.		
6. My organization consults with its members and chapters.		
7. My organization has a clear mission and follows it.		
8. My organization has a strategic plan with clear and measurable objectives.		
9. My organization has a formal budget and sufficient funding to support its mission.		
10. My organization has an elected and effective board of directors/members.		

B. Membership and volunteers	0 - 5	Areas to improve / Proposed action steps
1. My organization contributes to or maintains a national patient registry.		
2. The members of my organization are united in working towards achieving its strategic goals.		

3. My organization's membership includes carriers of hemophilia, people with von Willebrand disease and/or rare bleeding disorders.		
4. Young people are actively involved in my organization and its activities.		
5. My organization provides leadership training for young members.		
6. My organization has sufficient volunteers to carry out its activities.		
7. My organization's volunteers receive training, mentoring, and/or support.		
8. My organization plans for succession (when possible).		

C. External relations	0 - 5	Areas to improve / Proposed action steps
1. My organization has established a relationship with the Ministry of Health or Health Authorities.		
2. My organization works effectively with hemophilia care providers (hematologists, etc.).		
3. My organization works with other patient groups to pursue common objectives.		
4. My organization has the capacity to secure and/or maintaining government funding.		
5. My organization seeks funding from individual donors and institutions.		
6. My organization has the capacity to secure and/or maintaining private funding (pharmaceutical and other companies).		
7. My organization has a clear policy to guide pharmaceutical company relations.		
8. My organization has established a relationship with local and/or national media.		

D. Organizational relevance	0 - 5	Areas to improve / Proposed action steps
1. My organization is active in advocacy for hemophilia and other bleeding disorders.		
2. My organization is involved in the decision-making process for the purchase of factor concentrates.		
3. My organization is involved in the national care program.		
4. My organization monitors product safety and supply.		
5. My organization actively collects and analyses patient data to support advocacy efforts.		

6. My organization is aware of current research and advances with regards to bleeding disorders and new treatment products.		
7. My organization is constantly monitoring developments in technology, financial, economic and other external factors that may affect its operations.		

II. Programs and activities

A. Outreach and awareness-raising	0 - 5	Areas to improve / Proposed action steps
1. My organization conducts outreach to identify new patients with hemophilia.		
2. My organization conducts outreach to identify carriers of hemophilia, people with VWD and/or other bleeding disorders.		
3. My organization works to reduce stigma with regards to bleeding disorders in the community.		
4. My organization works to reduce isolation of people with bleeding disorders in the community.		
5. My organization uses World Hemophilia Day as an awareness-raising event.		

B. Education and training	0 - 5	Areas to improve / Proposed action steps
1. My organization produces or distributes materials to educate patients.		
2. My organization organizes workshops and/or training sessions to educate patients and families.		
3. My organization is involved in educating healthcare professionals about bleeding disorders and/or is lobbying the government for such training.		
4. My organization works with medical professionals and/or hemophilia treatment centres to provide education and/or training.		
5. My organization works to educate patients about the economics of hemophilia care.		
6. My organization has participated in online learning or training (webcasts, webinars, etc.).		
7. My organization informs patients and their families about research and opportunities to participate in clinical trials.		

C. Member development and community-building	0 - 5	Areas to improve / Proposed action steps
1. My organization has programs that enhance patient health (i.e. physical, mental, and psychosocial).		
2. My organization has programs that address the needs of the different sectors of its membership e.g. women, men and youth.		
3. My organization has programs that can help develop shared values among its members.		
4. My organization organizes social activities (summer camps, family day events, activities for the youths, etc.).		

D. Communication	0 - 5	Areas to improve / Proposed action steps
1. My organization communicates regularly and effectively with its members (newsletters, phone, pamphlets, etc.).		
2. Communication with members is largely done electronically (e-mail, text message, website, and other online tools).		
3. Communication is bi-directional (reciprocal) with chapters.		
4. My organization's website is an effective and important method of communicating with members and the general public.		
5. My organization uses social media to communicate with and engage members and the general public. <p>a. How often do you use the following? <i>(1 = not helpful at all; 5 = very helpful)</i></p> Facebook: _____ YouTube: _____ Twitter: _____ Other (please specify): _____		

III. Collaboration with the WFH

	Areas to improve / Proposed action steps
1. My organization communicates with the WFH. <input type="checkbox"/> Once a month <input type="checkbox"/> 4 times a year <input type="checkbox"/> Once a year <input type="checkbox"/> Don't know	
2. My organization understands the role of the WFH in providing guidance in developing a sustainable organization. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Don't know	
3. My organization communicates effectively with the WFH. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Don't know	
4. My organization co-organizes effectively with the WFH on joint activities/events. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Don't know	
5. My organization benefits from receiving WFH guidance. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree <input type="checkbox"/> Don't know	
6. My organization has participated in the following WFH programs: <input type="checkbox"/> Global Alliance for Progress (GAP) <input type="checkbox"/> Twinning <input type="checkbox"/> Advocacy in Action <input type="checkbox"/> Humanitarian Aid donations <input type="checkbox"/> WFH Country Program	
7. My organization participated in the last WFH Global Survey. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	
8. My organization uses WFH materials (publications, online resources, videos, etc.) for information and/or educational purposes. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	

<p>a. How useful do you find the following? (1 = not helpful at all; 5 = very helpful)</p> <p>WFH monographs: _____</p> <p>Other WFH publications: _____</p> <p>Hemophilia World: _____</p> <p>WFH website: _____</p> <p>WFH members-only website (NMO extranet): _____</p> <p>Discussion forums and other online communities (Facebook, Twitter, discussion forums, etc.): _____</p> <p>Other (please specify): _____</p>	
<p>9. My organization looks to the WFH for news and/or information about bleeding disorders.</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>a. How would you prefer to receive communication from the WFH</p> <p><input type="checkbox"/> Electronically (eblasts/emails)</p> <p><input type="checkbox"/> In print (by mail)</p> <p><input type="checkbox"/> From the WFH website</p> <p><input type="checkbox"/> From the members-only website (NMO extranet)</p>	
<p>10. My organization has translated WFH materials for educational purposes.</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>	
<p>11. In areas where your organization requires educational materials/training from the WFH, rate the following according to what would be most helpful (1 = not helpful at all; 5 = very helpful)</p> <p>Print publications: _____</p> <p>Workshops: _____</p> <p>Online training/distance learning (webinars, online workshops and/or presentations): _____</p> <p>Discussion forums and other online communities (Facebook, Twitter, discussion forums, etc.): _____</p> <p>Other (please specify): _____</p>	



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Additional comments:

This form was completed by: _____

Name: _____

Role at NMO: _____

Action Planning Worksheet

I. Organizational strength

Key areas of operation/activity	Standards for strong hemophilia organization – refer to questionnaire for numbered items	Current status/rating in this area	Gaps, areas of improvements	Goal	Timeline
A. Internal structure and operations					
B. Membership and volunteers					
C. External relations					
D. Organizational relevance					

II. Programs and activities

Key areas of operation/activity	Standards for strong hemophilia organization – refer to questionnaire for numbered items	Current status/rating in this area	Gaps, areas of improvements	Goal	Timeline
A. Outreach and awareness-raising					
B. Education and training					
C. Member development and Community-building					
D. Communication					

III. Collaboration with the WFH

Key areas of operation/activity	Standards for strong hemophilia organization – refer to questionnaire for numbered items	Current status/rating in this area	Gaps, areas of improvements	Goal	Timeline