

Impact assessment 2018



Self-infusion training in Samarinda as part of the Indonesia 2 project will reduce the number of hospital visits required in case of a bleed.

Impact assessment 2018 methodology

The 2018 impact assessment uses quantitative and qualitative data from three sources: a partner survey, NNHF project portfolio data and project partners' progress reports.

Partner survey

Conducted in December 2018 and distributed using an online survey development tool¹, this survey collects data on impact creation in our three focus areas: capacity building; diagnosis and registry; education and empowerment.

The survey was sent to partners from 43 NNHF programmes across 32 countries which were running or completed in 2018. Representatives from 41 programmes responded, meaning 95% of NNHF running or completed programmes are represented in the results. Respondents were given the option to provide their name or stay anonymous.

Programme portfolio data

We use programme modules to categorise activities taking place within programmes, which facilitates Better Practice Sharing and tracking of the distribution of funds per category.

Project partners' progress reports

To monitor their activities and measure impact, our partners complete half-yearly progress reports throughout the duration of their projects. We use these reports to highlight success and areas for Better Practice Sharing, and to identify where we can provide further support. Quantitative data is extracted from these reports to allow for cross-portfolio data analysis.

Unless otherwise stated, the data presented in this impact assessment overview is from the 2018 partner survey.

¹ <https://www.surveymonkey.com/>

Following the NNHF Leadership workshop in Egypt, participants from the Ethiopia 1 project put their new skills into practice at a workshop to empower the youth group.





Capacity building

Our partners build capacity in their projects by developing expertise, creating medical networks and establishing or strengthening care centres, facilities and service delivery.

Building skills amongst healthcare professionals comprises basic as well as in-depth training which is delivered in the project country or abroad.



Skilled experts

41,500

healthcare professionals trained¹



Care facilities

493

centres established or strengthened¹

198

of these are satellite and primary care sites¹



Organisation of care delivery

National care guidelines

updated, printed or distributed through NNHF projects by 60% of partners

Fewer hospitalisations

per patient observed by 85% of partners



"The training on management of haemophilia included aspects of how haemophilia patients can perform first aid at home, so we are now better placed to advise them how they can care for themselves before they report to hospital."

Dr Yohannie Mlombe
haematologist,
Malawi

Reduced distance to receive care

according to 81% of partners



"In the state of Pará, many people with haemophilia live in remote locations and have no immediate access to care and expertise. Our training activities throughout the state mean that first level care is now available outside the capital"

Christianne Oliveira Costa
President of patient organisation, Pará,
Brazil

Improved quality of care

with 77% of partners with national guidelines using them to provide better care



"The national physiotherapy protocols we produced will be used by our network of physiotherapists across India, meaning those in tier 2 and even less than tier 2 towns know what to do for a haemophiliac who has had an acute joint bleed."

Dr Pamela Narayan
physiotherapist, India

¹ Source: NNHF programme portfolio data 2005-2018.



Diagnosis and registry

Only one in four of those living with bleeding disorders has been identified, and of these, many do not have a diagnosis which shows the type or severity of their disorder.

Our activities with partners in this area include training, improving lab infrastructure and sponsorship of the World Federation of Hemophilia (WFH) International External Quality Assessment Scheme (IEQAS). Our partners also develop and update registries through their projects, which provide the quality data needed to engage decision makers and allocate resources adequately.



Diagnosis
expertise
and staff

3,100

lab technicians trained¹



Diagnosis
facilities

287

labs established or strengthened¹



Quality
data

25,500

patients have been re-tested
or newly diagnosed¹

40

countries developed or improved
registries¹

Improved quality of diagnosis

through NNHF supported activities,
say 100% of partners



"We are now able to test for factor levels free of charge. Before this project in Mandalay, we had to travel over 500km to be screened"

Myo Aung

President of patient organisation
(Mandalay Chapter),
Myanmar

Increased diagnosis rate

observed by 100% of partners



"After establishing a new haemostasis lab outside of the capital city, we have been able to diagnose more people with haemophilia, and these patients are able to get this diagnosis quicker than before."

Dr Teresa Faguaga

transfusional medicine specialist,
Uruguay

Informed policy makers

with 91% of partners saying they have
gained commitment for the continued
support of diagnosis activities



"We have used the data from the registry to lobby the county government of Garissa to allocate space for setting up of a haemophilia clinic due to the many numbers of patients travelling the 350 km to Nairobi to seek treatment."

James Kago

Secretary General of patient
organisation, Kenya

¹ Source: NNHF programme portfolio data 2005-2018.



Education and empowerment

Educational sessions unite people with haemophilia and family members to learn, voice their community's needs and form a support network. Activities with patient organisations include developing skills and organisational capacity.

Topics covered in educational sessions include amongst others how to cope with the condition in daily life, psycho-social support and specific areas of haemophilia care such as exercise and self-infusion. We work together with patient organisation members to develop leadership, communications and advocacy skills.



42,500

people with haemophilia and family members educated¹



Empowered leaders within the patient organisation

say 86% of partners



Members active in engaging with authorities

say 91% of partners

Improved understanding of the condition

leading to overall health improvements, observed by 93% of partners



"Parents and people with haemophilia now see that treatment with coagulation factor is important but quality of life will be better if we develop a rehabilitation programme to strengthen their musculoskeletal system."

Dr Nancy Loayza

Head of Clinical Haematology Service, Peru

Stronger organisational structure

according to 80% of partners



"Our Hemophilia Foundation-Pakistan (HFP) activities have had the greatest impact as the organisation in Pakistan is matured and in a position to lobby more effectively with health authorities for the rights of the bleeding disorders community in the country."

Masood Fareed Malik

President of patient organisation, Pakistan

Changes in policy around bleeding disorders

say 86% of partners



"With the help of meetings in the framework of projects supported by NNHF, the authorities changed their attitude towards haemophilia and decided to improve the comprehensive approach to treatment in the regions."

Gulnara Huseynova

President of patient organisation, Azerbaijan

¹ Source: NNHF programme portfolio data 2005-2018.