

Project:
Peru 2

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delivering
life-changing
impact

Social workers registering for a haemophilia training session in Chiclayo.



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A training session for social workers in Lima, one of five cities covered by the project.

The challenge

In 2015, navigating through the haemophilia care system in Peru could be a stressful process for patients. **Patients did not have a point of contact close to home** who could help them access the right care, at the right time. The **bureaucratic processes involved were often lengthy and complicated**.

The achievements

Within six months, **282 social workers from 5 cities across Peru had been trained** to understand haemophilia and how to provide appropriate support and guidance to ensure patients could access care when they need it.

Partner: Peruvian Haemophilia Association Represented by: Carmen Emperatriz Castro Abad Start/end date: Q1 2016–Q3 2016

Peru 2: Engaging social workers to support access to care

In 2015, Carmen Castro Abad, who has FVIII deficiency, was hospitalised for several weeks following a bleed. Whilst Carmen eventually received the care she needed during this period, the process of accessing this care was not an easy one. As many healthcare professionals did not have specialist knowledge of bleeding disorders, gaining the correct referrals and care was a lengthy process.

At her own expense, Carmen turned to her social worker for help, explaining the care needs specific to people with bleeding disorders. This proved an enormous support for Carmen – whereas before she found herself navigating the complex bureaucratic system alone, she was

now guided by a professional who was accustomed to working within the care infrastructure in Peru.

Social workers to play a pivotal role

Given her role as President of the Peruvian Haemophilia Patient Association, Carmen was accustomed to explaining haemophilia and allied bleeding disorders and was aware of her rights, so was able to brief her social worker effectively. This would not be the case for less empowered patients who lacked this understanding, so Carmen developed a project to give social workers a pivotal role in signposting haemophilia patients to appropriate care and guiding them through

the necessary processes.

As the specific care needs of people with haemophilia were not necessarily known to social workers in Peru, Carmen's starting point was to bring together a team who could cover the wide scope of knowledge required when providing a holistic care package to patients. This scope included understanding haemophilia on a clinical level, the psycho-social impact of haemophilia, as well as knowledge of patients' rights and the healthcare system.

Engaging a multi-sectoral network to support training

As president of the patient association, Carmen was well placed to reach out to her network, who could support the delivery of this training. This included social workers from Lima and other haemophilia healthcare professionals both from Lima and the regions, as well as representatives from the healthcare system and hospital authorities. A series of six training sessions were planned to take place over 12 months in five cities – two in Lima, and one each in Arequipa, Cajamarca, Chiclayo and Trujillo.

This collaborative and cross-sector approach paid off. Participants were so keen to learn about the role they could play, that most training sessions went on longer than planned. 97% of participants agreed that the course objectives were of high or very high relevance to their jobs, with one participant adding, "The course was excellent and very interesting, I learned a lot about these patients, such as how to help and understand the moments when support is needed".

Topics covered included the social impact of haemophilia on the family, the importance of proper and timely treatment, and patients' rights according to different healthcare systems. Participants also put their theoretical learning into practice through case study group work. Thanks to the enthusiasm and dedication of the training team, the training of all 282 participants from across the five regions was completed in just six months – half the time originally anticipated.

Patients to benefit from efforts of dedicated team

As a result of this project, patients in five cities across Peru now have the possibility to access support and guidance when navigating the healthcare system. The project has proved to be a model of cross-sector collaboration, driven by a dedicated core team of patient association members and social workers.

"We've worked on creating more resources, training social workers and now it will be to the next generation to use these resources and continue building on the past achievements" says Carmen.

Following this project, a new project for Peru was approved by the NNHF Council in 2016. Led by the Peruvian Haematology Society, the project will create and strengthen multidisciplinary care and diagnosis in Lima and other provinces and create a national web-based registry for people with bleeding disorders.



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Members of the Peru 2 project team plan the training sessions.

Recognising collaborative efforts

The NNHF and Peru 2 project team thank the following, whose efforts were fundamental to the success of the social worker training programme:

Peruvian Haemophilia Patient Association

Carmen Castro Abad
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Social worker organisers

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Coordinators in the regions

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