

Frequently Asked Questions about HERO

1 What is the HERO Programme?

HERO stands for Haemophilia Experiences, Results and Opportunities. HERO is a global outreach programme focusing on psychosocial aspects of life with haemophilia, initiated and supported by Novo Nordisk. The programme will listen to people with haemophilia, with or without inhibitors, their parents/caregivers and ensure that their voices are heard to bring about action and change.

2 Why is the HERO programme needed?

Psychosocial issues affect the ability of people to manage their condition and live their lives as they would wish to, even if those people have access to effective treatments. In order to make a real difference – not just to talk, but to take action - it is critical to understand the issues and where the biggest unmet needs prevail, so we can build a body of evidence to bring about real and sustainable change.

3 Hasn't this type of research been done before?

Based on an extensive literature review we know that there is a wealth of research conducted in the related field of "Quality of Life". Even so, it is also clear that there is still much we can learn about the psychosocial needs of people with haemophilia. This will be the largest international research ever carried out into the social and psychological impact of haemophilia, involving responses from over 1300 people from 12 countries.

4 What do you hope the programme will do? How will the information be used?

The HERO programme will help us better understand the psychosocial issues facing people with haemophilia, giving us valuable insights into the broad impact of this condition on both individuals and the community. It will also provide us with new tools to help deal with the barriers encountered by people with haemophilia.

Through publications and presentation of the findings, it will also be possible to kickstart a productive conversation in the medical community about what can be done to provide care that encompasses the psychosocial needs of people with haemophilia. Lastly, the results will provide a strong platform for approaching governments and key decision makers to encourage action and develop powerful local initiatives. Local patient organisations will be critical in rolling out action programmes and solutions, but the support, credibility and authority of global knowledge and a structured body of evidence immeasurably increase their power and effectiveness.

5 What is the scale of the research? / How many people will be interviewed?

We expect over 1300 people from 12 countries to be interviewed, making this the largest international research ever carried out into the social and psychological impact of this condition. Those involved will include people with haemophilia, with and without inhibitors as well as parents and caregivers.

6 How do you recruit participants in such a small population group?

Depending on the situation in each of the participating countries, eligible individuals may be identified by one of three possible routes:

Membership records held by National Haemophilia Organisations (NHOs)

Patient records held by commercial haemophilia health services providers

Patient records held by HTC's

Eligible individuals will be invited to participate in the survey via a letter or email, which will contain the contact details for Kantar Health.

7 Will a study of this size provide meaningful data?

The study has been designed so that it is possible to draw valid conclusions between the category of respondents (patients and parents) by combining those from different countries or between different countries by combining the types of respondents.

8 Don't we know the answers already?

We know that psychosocial issues affect the ability of people to manage their condition and live their lives as they would wish to, even if those people have access to effective treatments. We do, however, still need more in-depth insights into the various aspects of life with haemophilia before we can conclusively say what needs to be done to effectively change awareness, attitudes and health care practices to address those needs. With this study, which is the largest international research ever carried out into the social and psychological impact of this condition, we will have a strong starting point for change.

9 What is the design of the research?

The study is divided into two phases. The first phase comprises of face-to-face semi-structured interviews with 150 people (including patients with haemophilia, parents, physicians, nurses, psychologists and physiotherapists) in seven countries.

The second phase will be conducted via an online web survey, will cover 1200 patients from 12 countries , This phase will quantify the extent that these issues actually affect the haemophilia community and provide the evidence base for the generation of future publications, presentations and advocacy activities.

10 In which countries is the HERO programme being carried out?

The first phase of the research was carried out in seven countries: Algeria, Brazil, France, Germany, Italy, UK and USA. This number of countries is expected to be increased to 12 in the second phase of the research by adding Argentina, Canada, China, Japan and Spain.

11 Which Patient Organisations in each of the countries have you engaged with?

We currently have representatives on the International Advisory Board from The UK Haemophilia Society, The German Haemophilia Society, the Fondazione Paracelso in Italy, the National Haemophilia Foundation in the USA, the Kyoto Haemophilia Society in Japan and the Psychosocial Committee of WFH,. As the programme develops we hope to reach out and involve many more Patient Organisations, getting them actively involved in the programme.

12 How were the countries chosen?

The selection was carried out in consultation with the International Advisory Board. The countries were chosen to represent a mix of those where haemophilia treatment is well established, those where it has become established more recently and those where there is a need for increased development.

13 Can countries ask to be included?

In order to meet our projected timelines we are not intending to include additional countries in this phase of the research. However we intend to make the methodology available so if other countries are interested in carrying out the same type of research they will be able to do so.

14 When will the results be available?

The preliminary findings of the first, qualitative phase of the research were presented at the WFH Congress in Buenos Aires in July 2010. These findings will then inform the final design of the second, quantitative, phase of the research, which is expected to be completed at the end of 2011 .

15 Who is paying for the programme?

The programme was initiated and is supported by Novo Nordisk.

16 What is the role of the International Advisory Board?

The International Advisory Board comprises physicians, patients, carers, patient group representatives, nurses, psychiatrists and physiotherapists from nine countries. The board first met in Montreal in 2009 to discuss psychosocial issues in haemophilia and at that meeting it was agreed that a research programme, now called HERO, would provide much-needed evidence on which to base future publications, presentations and advocacy activities. The HERO IAB has developed the survey protocol and questionnaires.

The HERO IAB members are responsible for the contents of the study and are not affiliated to the financial sponsor of the study.

Its ongoing role is to advise and comment on the development of the research and its rollout both globally and locally to help improve the lives of people with haemophilia.

17 Who is the Chairperson of the International Advisory Board - is he/she available for comment?

There is no Chairman of the International Advisory Board, which comprises physicians, patients, carers, patient group representatives, nurses, psychiatrists and physiotherapists from nine countries, each with an equal voice.

Key international investigators in the HERO survey are Frederica Cassis, Psychologist, Haemophilia Centre, Hospital das Clinicas, São Paulo, Brazil and Dr Alfonso Iorio, MD, McMaster University, Hamilton, Ontario, Canada.

18 Is HERO part of the work of the WFH Psychosocial Committee?

No, we hope the HERO programme will complement the work of the WFH Psychosocial Committee. HERO is designed to build a database of evidence on the need to address psychosocial issues in haemophilia and is intended to offer further insight into what the key issues are. We are very happy to make the findings from the community consultation available to the WFH.