



TOOLS TO HANDLE LIFE WITH A DISEASE: THE LIONBRIDGE PARTNERSHIP WITH THE DANISH HEMOPHILIA SOCIETY

CRITICAL DOCUMENTS

TWO LANGUAGES

LIFE-SAVING RESULTS



The Challenge

The Danish Hemophilia Society (DHS) works diligently to improve quality of life for patients living with a bleeding disorder. For this project, DHS focused on helping children with a specific bleeding disorder: Immune thrombocytopenic purpura, or ITP.

Children with ITP have a very low platelet count, which precludes their blood from clotting. ITP can be temporary or turn into a chronic condition. The disease is potentially life-threatening and there is no cure. Some palliative medicines do exist, but these treatments often have side effects so severe they rival the disease itself.

About the Client

The Danish Hemophilia Society was established in 1970 to establish hemophilia treatment centers and provide resources to Danish people living with the disease. Since its inception, the Society has grown in political importance and is deeply involved in improving conditions for patients with a bleeding disorder both in Denmark and internationally. Its main objectives include providing counseling and support to patients with a bleeding disorder and their families; disseminating knowledge about hemophilia and other bleedings disorders; focusing on new ways of treatment through information and debate; and promoting and supporting bleeding disorder research through cooperation with Denmark's two hemophilia treatment centers.



The Challenge (continued)

The Danish Pediatric Society, an association of pediatricians that promotes scientific and practical work in Denmark, recommends using medicine only in reaction to acute bleeding or as a prophylactic measure before surgery or any occasion that could likely result in bleeding. This assigns intense responsibility to parents, who must monitor their children and ensure they do not find themselves in situations that would likely produce a bleed.

A Canadian pediatrician specializing in ITP created a dialogue tool to help parents handle everyday life with the disease and allow them to communicate more effectively with healthcare professionals: three customized questionnaires aimed at children with ITP and their parents. Danish parents reacted positively to the English version of the tool and expressed interest in a Danish version. DHS needed to partner with a language service provider (LSP) with expertise and proven success in this type of translation.

The Solution

DHS engaged Lionbridge to translate the Patient Reported Outcome (PRO) questionnaires using Lionbridge's linguistic validation procedure. DHS selected Lionbridge for its combination of cost-effectiveness and extensive experience.

"The offer and price we got from Lionbridge gave me the feeling they had done this kind of work before," said Emilie Vraagaard, DHS Project Manager. "This was reassuring, because other translators have not necessarily done this kind of assignment. What I mean by that is the assignment goes beyond translation—these questionnaires must be translated in a very certain way, because they may be used to do medical research later. The initial offer that we got from Lionbridge really covered the bases and gave me the idea that it would be a good match."

Lionbridge worked closely with DHS, the Danish chief pediatrician with whom DHS had originally collaborated, and the author of the original English-version PRO. To meet DHS' needs, Lionbridge offered linguistic validation services including translation, back translation, comparative review, and reconciliation.

Lionbridge first provided English to Danish forward translation, working with the client to reconcile two forward translations and agree on a final forward translation. Lionbridge underscored its commitment to quality by completing a back translation, which laid a foundation for the next step in the process: a comparative review of the Danish to English back translation and the original English source text.

The Results

Lionbridge provided linguistic expertise on the linguistic validation process, including providing qualified linguistic resources and delivering a final translation according to industry standards and client preferences while considering target patient groups, style, intertextual coherence, consistency, and linguistic rules. The result is a comprehensive and compliant Danish questionnaire that provides critical information to parents of children with ITP insofar as they can use it to more effectively monitor their children and communicate in Danish with life-saving healthcare providers.

"It's been a very good process," said Vraagaard. "We have had a lot of collaboration. And it has been pleasant, which I think is important. There has been a good understanding and willingness to adapt the process."

Lionbridge has instituted an agile process that works well for DHS, which is a small organization working with volunteers.

"I would definitely recommend Lionbridge," said Vraagaard. "If I were talking to another patient organization or another health organization that needed something similar done, then I would recommend Lionbridge."

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