



Let's do this together - healthcare development driven by patient advocates and healthcare professionals

A project designed and piloted by Rare Diseases Sweden together with and for PLWRD

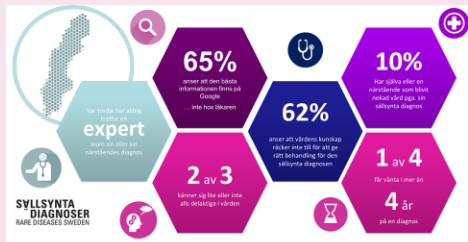


Figure 1: Summary of our 2019 member survey⁽ⁱ⁾ showing challenges for PLWRD in Sweden. QR-code for download.

Problem: The public healthcare system in Sweden fails to provide adequate quality of care for people diagnosed with a rare disease (RD). This in turn has a tremendous impact on the quality of life for those people and their relatives⁽ⁱ⁾.

Remedy: We from Rare Diseases Sweden have in our 3-years project "Let's do this together" educated

patient advocates (PA) and initiated their collaboration with healthcare professionals from six national Rare Disease Centers, located over Sweden. Our aim has been to establish collaboration between PAs and professionals, and to promote harmonization of the center's objectives and services with a person-centered point of view.

Why this project?

The Swedish healthcare system is steered by 21 counties (figure 2, white borders). Six Centers for Rare Disease are located at the six university hospitals (figure 2). They have differing resources, aims and goals, leading to inequalities for patients. To harmonize their work and initiate collaboration between PAs and professionals, we organized, coordinated and documented continuous twin, triple and plenary meetings with three PAs from each of our six regional networks and three professionals from each center over a period of three years; see figure 3.

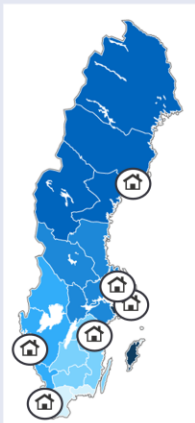


Figure 2: Map of 21 counties and six Centers for Rare Diseases in Sweden.

Networking and teambuilding

are the basis for successful collaborations; getting to know each other, sharing experiences and learning from each other. In parallel, we designed and conducted a PA education. We conveyed knowledge about the Swedish and European RD landscape and Sweden's healthcare system. We empowered PAs by developing guidelines for the PA mandate and shaped and completed PA tools⁽ⁱⁱ⁾.



Project outcome

The centers now have a structure for regular plenary meetings and are developing common goals, beyond the end of the project. After presenting their working routines for each other, good examples were spread, leading to harmonizing of the centers' work. Centers and PAs together continue working on a coherent care-plan.

Patient advocates were educated in

- Representing the RARE community
- Details about Sweden's healthcare system
- Collaborating with healthcare professionals to drive healthcare development

Patient advocates were empowered by

- Identifying their areas of expertise
- Identifying why they wanted to become a PA

Patient advocates were provided with

- The template patient CV; see figure 4
- A clear statement of tasks for their PA role



Figure 3: Project structure for collaboration between care professionals and patient advocates



Figure 4: Template patient CV to compile individual collaboration with healthcare professionals in our project "Let's do this together".



Conclusion: A common understanding of the problem, common goals and concrete projects are advantageous for developing sustaining collaborations that help shaping a successful person-centered healthcare system for people affected by a rare disease, gaining both patients and caregivers.

References:

- http://www.sallsyntadiagnoser.se/wp/wp-content/uploads/2019/04/S%C3%A4llsyntmeninteovanlig_rapport.2019.pdf
- <https://www.sallsyntadiagnoser.se/verksamhet/gemensamt-larande/>

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Rare Diseases Sweden

is an association for individuals with a rare disease, gathering about 16.000 members from 65 member associations. As an interest

organization we strive for public attention for rare diseases, we influence politicians and policymakers, nursing staff and societal influencers and we drive own work on improvement.

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