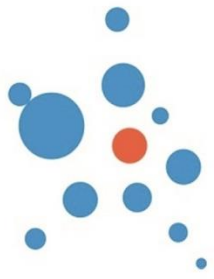


Rare Diseases Denmark



Navigators helps people with a rare disease manage

Project manager Stephanie Jøker Nielsen
Rare Diseases Denmark

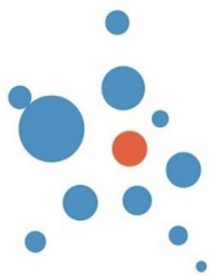


Rare Diseases Denmark

The Project

- A project in the process (2015 – 2017)
- A grant from the Danish Health Authority (DHA) to 1 NGO and 3 municipalities aiming to promote health literacy in the most vulnerable patients based on voluntarism
- 18 navigators supports 20 – 25 patients and families



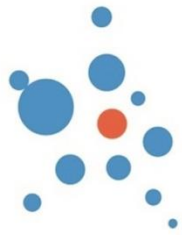


Rare Diseases Denmark

The task

- Studies shows that people living with rare diseases gets more challenged and vulnerable
- The systems becomes more standardized
 - Calls on structured support
 - to fill in the gaps
 - prevent patients from falling into cracks





Rare Diseases Denmark

The roles

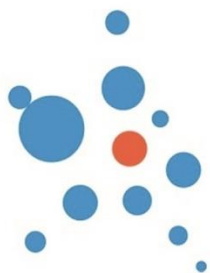
Navigators supports citizens/patients:

- Acknowledging their personal situation
- Creating an overview of options
- Encouraging health literacy and support compliance

By:

- Seeking information
- Helping to structure and systemize treatment plans, appointments, daily life etc.
- accompany the patient to meetings with professionals





Rare Diseases Denmark

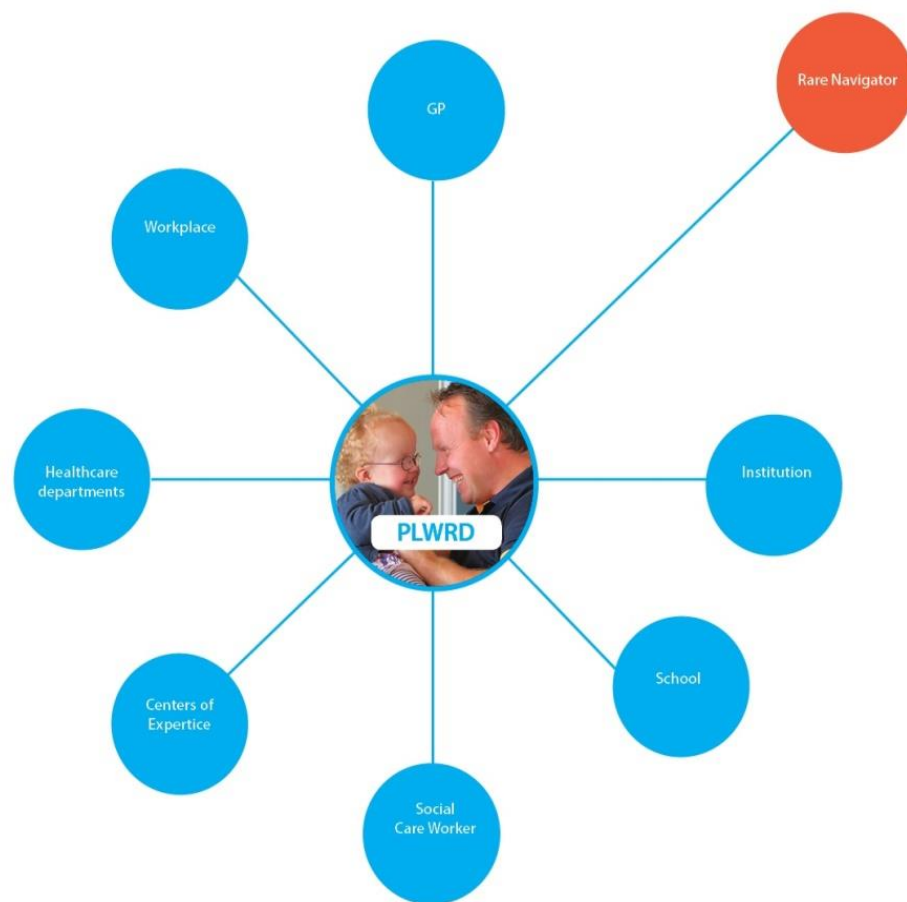
Navigation

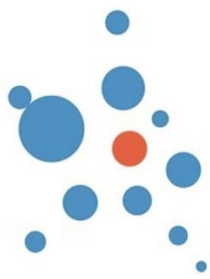
The frame:

- Navigation runs for 9 – 12 months
- Max. 3 hours pr. week

In reality:

- Navigation runs for 4 – 11 months
- An average of 2 hours pr. week





Rare Diseases Denmark



What works?

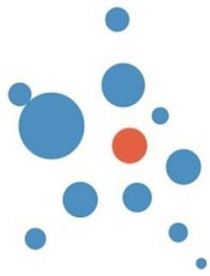
Navigators perspective:

- The fact that Navigators supports with their experience-based knowledge – personal and professional skills
- Help patients/citizens and families to help themselves

Patients perspective:

- Gaining back confidence in their own abilities
- Getting control over their lives
- Finally getting the right treatment

And much more....

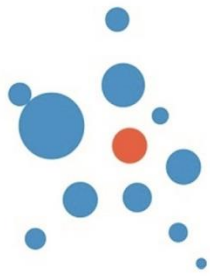


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A few bumps on the road...

- Navigators either suffers from a rare disease or are a relative of a person with a rare disease - that makes them unstable at times
 - Sometimes a navigator gets replaced in the middle of a navigation which is disturbing
- With a handfull navigators down and a high demand on navigators it's necessary to recruit more navigators
 - This requires considerable temporal and economic resources



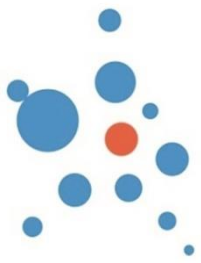


Rare Diseases Denmark

Co-creation?

- The voluntarism perspective
 - Works out as a supplement, but more is needed
 - Making public authorities perform their best...
- Recruiting and training volunteers.
 - RDD is doing far better than the municipalities!
 - Navigators
 - Patients looking for support
- Other
 - What kind of navigator support?
 - Implementation after project?





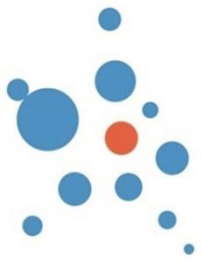
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Patient to patient



“I support a woman with an ultra-rare disease. She has lost confidence in the social- and health-care systems. She no longer dares to ask for the social support and the treatments she needs to live a good life. As a patient myself and a social worker I am supporting her to take responsibility for her own life. She is so brave and is slowly gaining back confidence”

Tells Rune who is one of Rare Diseases Denmark's 18 navigators.



Rare Diseases Denmark

Thank you for your attention

Do not hesitate to call or write me
for more detailed information.

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