

Involvement of patients in research - Interaction between patients and professionals in clinical activities and research

**Researcher experiences,
Musholm, October 1, 2022**

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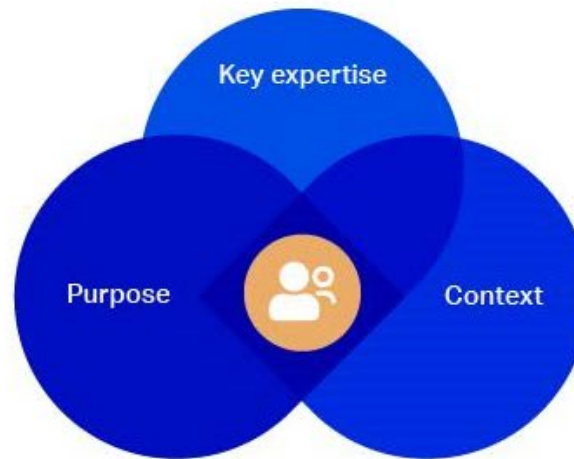
The National Rehabilitation
Center for Neuromuscular Diseases

The RCFM model

Societal level



Organizational level



Individual level



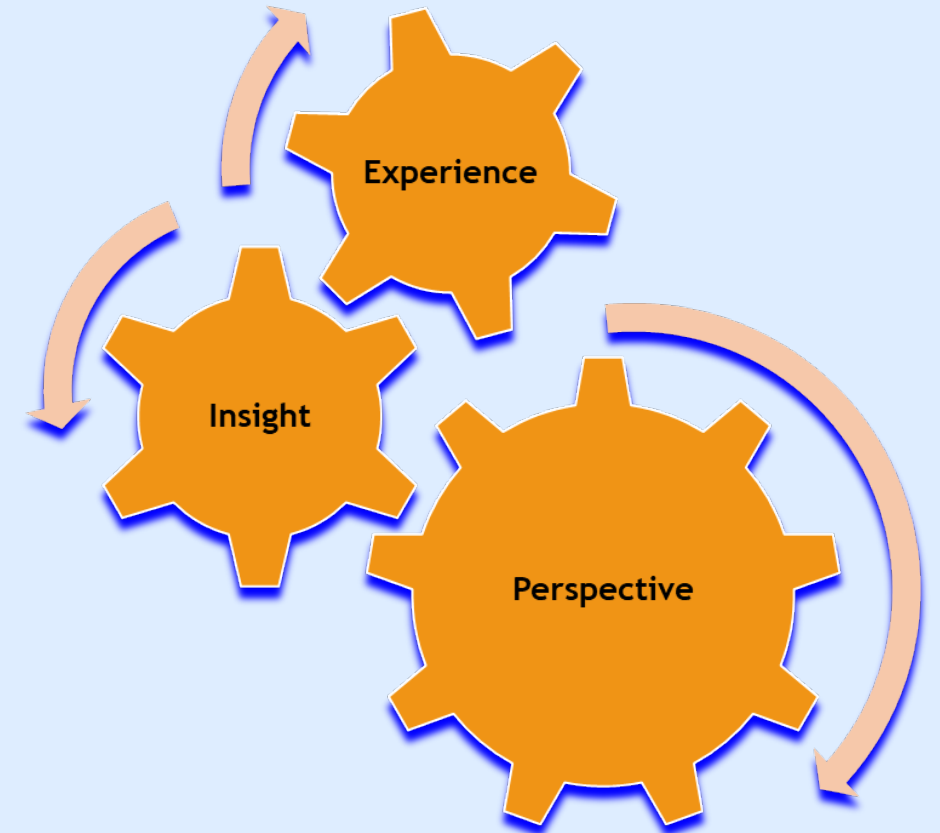
Aim of Patient Involvement in RCFM

To involve the patients in our work to a much greater extent, and to gain insight into the needs of the patients with the aim of providing highly specialized rehabilitation services

Corporate group on involvement

Lene Busk, Merete Vægter, Anne-Sophie Brandenborg, Annette Mahoney, Liv Brandstrup, Heidi Aagaard & Charlotte Handberg

...and everybody else at RCFM



Strategy for Patient-Oriented Research (SPOR)



<http://www.cihr-irsc.gc.ca/e/48413.html>

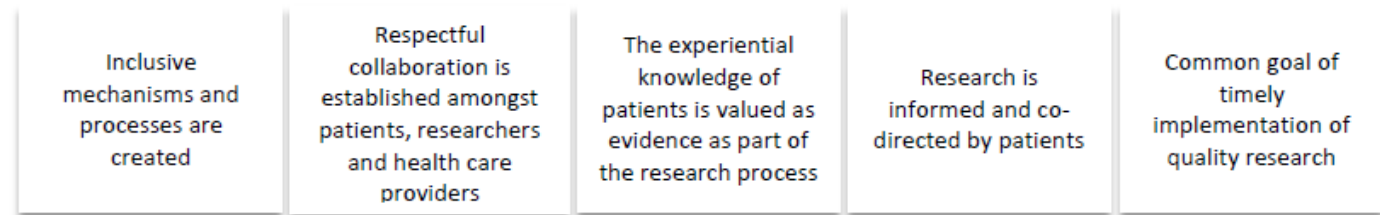
VISION

Patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system

OBJECTIVE

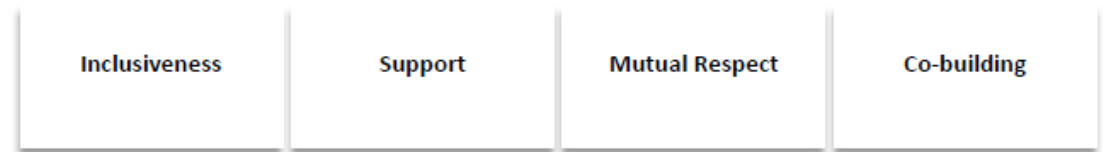
The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

DESIRED OUTCOMES OF PATIENT ENGAGEMENT



GUIDING PRINCIPLES

Underpinning this Framework are guiding principles to which SPOR partners will adhere in pursuing the goal of integrating patient engagement into research.



Patient involvement in writing

Corporate plan

- We take the **lead in patient involvement**
- We **involve our patients throughout** the rehabilitation process:
 - organization, process and services
- We involve the patients **in the development** of our services
- We make **systematic patient surveys**
- We **target and adapt our courses** to the needs of the patients
- We **cooperate** with The Muscle Dystrophy Foundation
- We **consolidate** our patient courses and membership activities



Patient involvement in writing

Research plan

- **We are specialists in patient involvement** in relation to all research projects
- **We involve patients to qualify** our research projects
- We conduct **systematic patient surveys**



Patient involvement in doing

Developed a patient involvement panel

The aim was that the panel is composed in such a way that it represents gender, diagnoses, age, relatives etc.

- 45 patients and relatives
- Ad hoc recruitment



Patient involvement in doing

Development of rehabilitation services

- Courses
- Education
- Website
- Etc.

Qualification of research

- Relevant and crucial parts of the research process
- Continuously involved and informed on projects and progress
- Budgeted with the involvement of the patient panel
- Co-authorship - a possibility



Example 1

An investigation of N
knowledge - with
specialized r

"I am a little sad that you do not plan to include ALS patients, especially because RCFM wants to embrace that group as well. Personally, I have had a lot of need for their skills, specifically because my disease is progressing so quickly. I think you can easily include a newly diagnosed ALS patient. As to ethics, I think it's pretty straightforward, I think you have it all covered".

Study I
Community-
based

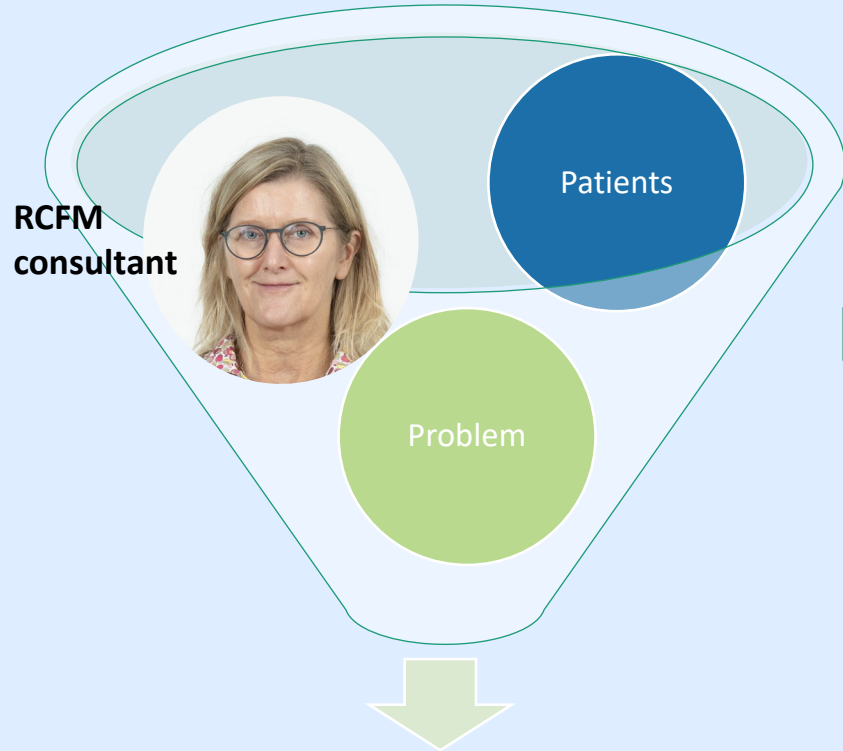
Study II
Hospitals

Study III
Patients
at RCFM

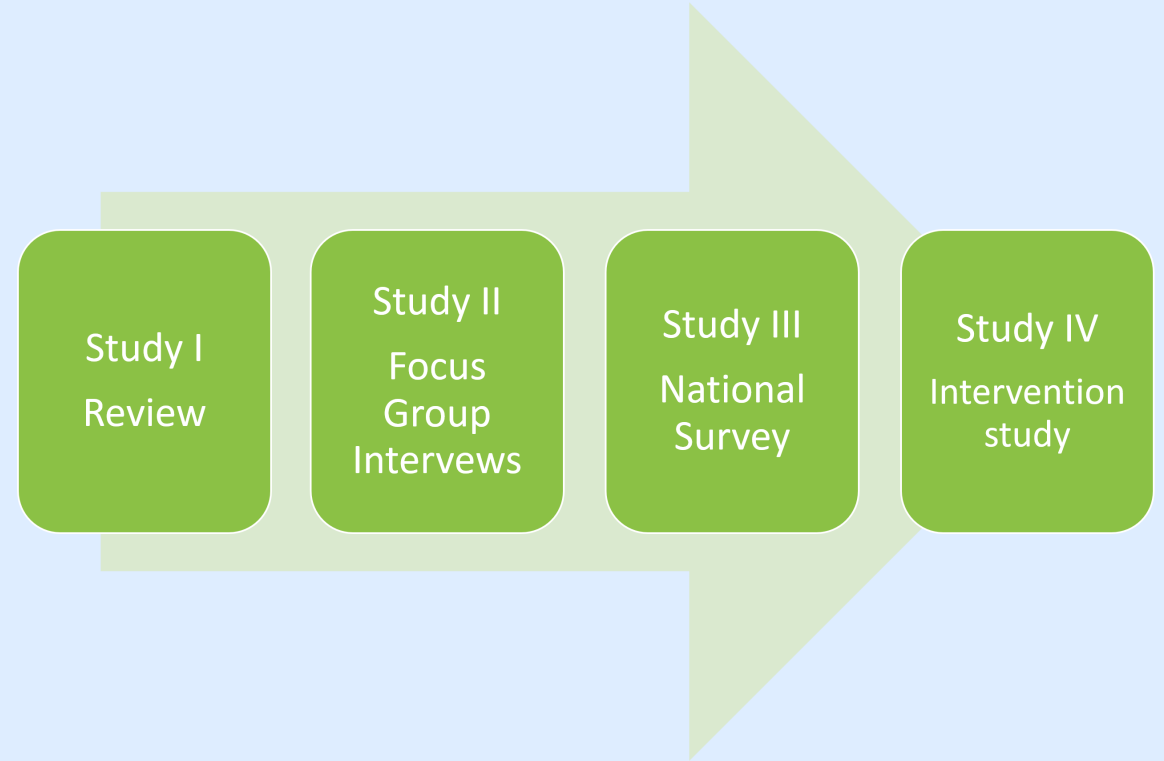
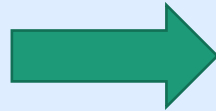
Study IV
Patients not
using RCFM



Example 2



**Initial project on urination
when away from home (2010)**



**HAP-PEE - Challenges in urinating when
away from home faced by women with
neuromuscular diseases (2019-2023)**



Example 2

HAP-PEE - Challenges in urinating when away from home faced by women with neuromuscular diseases

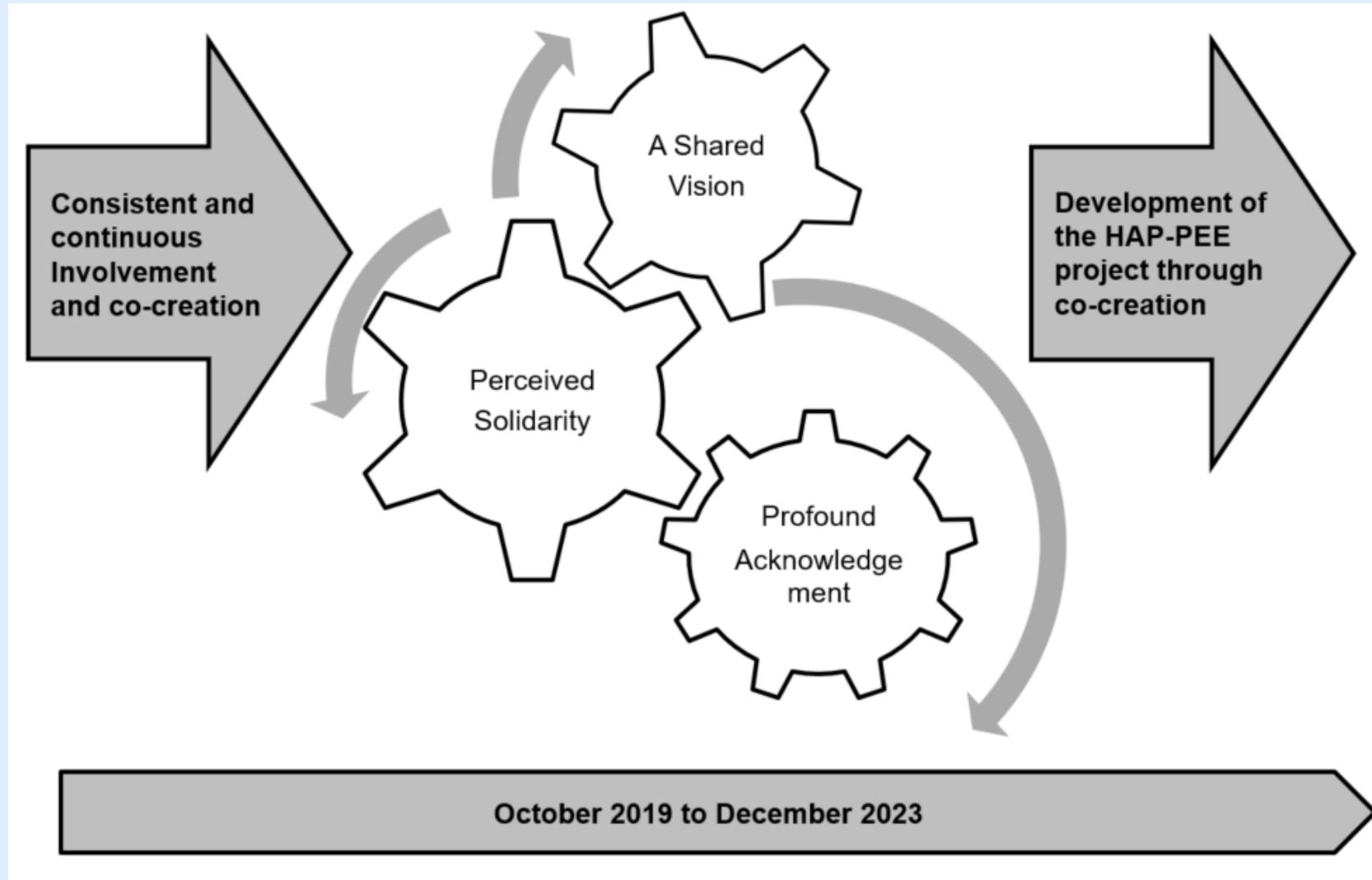


Project group

Sarah Glerup, Jeanette Strøm, Antoniett Vebel Pharaoh, Bente Kristensen, Bente Thoft Jensen, Charlotte Graugaard-Jensen, Ulla Werlauff & Charlotte Handberg



Example 2



Perspectives

RCFM seeks to **obtain patients and relatives' perspective** on all our services, development work and research

Patients and relatives have the knowledge and experience that RCFM can use to enhance research and rehabilitation efforts

Based on patient-identified priorities RCFM can **create improved rehabilitation services that meet the needs and preferences** of patients and their relatives



Questions?



The National Rehabilitation
Center for Neuromuscular Diseases

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