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Involvement and innovation in healthcare

PARE0028

LEAD PATIENTS – A RESOURCE FOR IMPROVEMENT OF THE HEALTH CARE SYSTEM

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Background: The project "Lead Patients – a new resource for health", led by researcher Sara Riggare at Karolinska Institutet and financed by Vinnova, the Swedish innovation authority, launched in 2017 and the Swedish National Organization for Young Rheumatism was one out of 14 partners. One of our tasks was to develop training courses for health care staff, and to try out what happens when lead patients are giving the opportunity to educate. We developed and produced nine different courses, and during the Autumn of 2019, we had the chance to try out two of them within the project.

Objectives: The aim was to switch the perspective and see what would happen when patients' expertise and knowledge is used to educate health care professionals and challenge the norm about health care professionals being superior. The objective with first training course, "Teams that enable self-realization", was to create conditions and find new methods for the health care professionals to better support patients with what actually matters to them. The objective with the second training course, "Anti-oppressive pedagogy and language impact", was to create new knowledge as a group and find methods for inclusion and anti-discrimination.

Methods: "Teams that enable self-realization" was conducted as an interactive lecture with a concluding workshop. The lecture was based on results from the Swedish Young Rheumatism Report, teamwork and the Swedish Patient Act. The workshop consisted of a case, where the participants were supposed to come up with a plan for a first meeting and treatment of a patient. "Anti-oppressive pedagogy and language impact" was conducted in two parts, with one week in between the two occasions. The first one was mainly a lecture with background and theory about anti-oppressive pedagogy, norms and power structures, followed by a workshop where the participants analyzed the organizations' own value principals. The second occasion was a deepened discussion with the purpose of identifying new methods for work and strategies to move forward.

Results: The main goal with the training was to highlight positive examples and create creative conditions to be able to identify these new methods and tools. And during the training, there was a great will from the staff to work in a more patient-centered way and let what is most important for the patient to be what is directing the meeting. Some suggested that the patient should be considered a part of the health care team, but that methods are missing for making it work

today. There was also a great will to reflect over what consequences the current health care system might have, and to discuss possible changes. It was exciting to see the traditional hierarchy, where patients are seen as passive receivers of care, being challenged for real and letting patients not only talk about "what it's like to live with a chronic disease" but actually be seen as capable and qualified educators.

Conclusion: If lead patient-led training becomes an obvious and vital part in building and develop the health care system, it will lead to new opportunities and possibilities to better form the health care based on patients' needs, both strategically and operational. Because converting to a patient focused care isn't just about changing old attitudes and organizational culture, it's also about building new adapted structures and methods for governing the health care system.

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PARE0029

THE JOURNEY FROM PATIENT AND PUBLIC ENGAGEMENT (PPE) TO INVOLVEMENT: FACILITATING PATIENT PARTNER RESEARCH WORKSHOPS WITH A FOCUS ON FIBROFOG IN FIBROMYALGIA

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Background: The Bath Institute for Rheumatic Diseases (BIRD), a registered charity in the United Kingdom (UK), supports research, education and patient engagement for the benefit of people with rheumatic diseases. Event feedback from two Fibromyalgia Information Days showed patients valued the sessions and were keen to be involved in research. Fibrofog in fibromyalgia was identified by patients as one topic of interest.

Objectives: To facilitate Patient Research Partner Workshops to generate research questions and inform the design of clinical research into fibrofog in fibromyalgia.

Methods: Three Patient Research Partner Workshops, focusing on fibrofog in fibromyalgia, were run between January 2018 and April 2019. All were co-facilitated by a clinician, SD, and BIRD Patient and Public Engagement (PPE) lead, MB. Ethical approval was not required¹. Patients were invited to participate by email. A Patient Partner Information Sheet accompanied the workshop invitation. Audio recordings of the discussions were made to aid data capture, following informed written consent by all workshop participants. Travel expenses were offered to all participants.

Results: 25 (n=25) women with fibromyalgia attended the workshops. Workshop 1 (n= 5) explored, 'What areas do you think we should research around fibrofog in fibromyalgia?' Patient partners felt research into fibrofog in fibromyalgia was needed to identify and validate symptoms, and to inform discussions with healthcare professionals. They also called for research into coping strategies to help with fibrofog symptoms. This reflected similar patient calls for research into fibrofog in fibromyalgia².

Workshop 2 (n=10) and Workshop 3 (n=9) explored 'How do you think we should research fibrofog in fibromyalgia?' Both workshops identified a broad range of research questions and designs, reflecting individual experiences, knowledge and symptom severity. Suggested research questions included: How severe is fibrofog for each person? What triggers fibrofog? How does fibrofog affect daily tasks? How does fibrofog affect work? What do people with fibromyalgia, their partners, family members and healthcare professionals understand about fibrofog?

Suggested data collection methods included interviews, focus groups and questionnaires. Use of online surveys or interviews had mixed responses. This reflected computer literacy skills and access to hardware. Discussions around recruitment of participants to future studies revealed a wealth of local knowledge including access to community venues and healthcare facilities, support groups and local networks.

Participants were very satisfied with the workshops, finding them helpful, informative and thought provoking. All wanted to continue their involvement in research.

Conclusion: Patient Research Partner Workshops are integral to the generation and delivery of clinical research into fibrofog in fibromyalgia. Research designs need to offer multiple methods of data collection to be as inclusive as possible. Next steps will be to formally recruit Patient Research Partners to co-develop a research grant application to explore fibrofog in fibromyalgia.

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