

Abstracts Booklet for the Poster Presentation at the
Conference:

Patient and Public Involvement in Complex Intervention
Research



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Title:

Engaging patients in medicines optimisation in general practice: a development study of the “PREparing Patients for Active Involvement in medication Review” (PREPAIR) tool

Authors and their organisations:

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Background:

Many patients have multiple health conditions and take several medications (polypharmacy). Active patient involvement may improve treatment outcomes and ensure patient-centred care. Yet, patient involvement remains a challenge in clinical practice. We aimed to develop and pilot test a tool to facilitate dialogue about medication between patients with polypharmacy and their general practitioner (GP): the PREparing Patients for Active Involvement in medication Review (PREPAIR) tool.

Methods:

We conducted a literature review followed by a co-production process to develop the tool: a workshop with six GPs and pilot testing, including observations and interviews with 22 patients, three GPs and three practice staff. During this process, we made continuous adaptations of the prototype. We analysed the qualitative data thematically, focusing on development process and mechanisms of impact.

Results/If work is in progress, describe how far along in the process you are:

The final PREPAIR tool included five items: 1) adverse drug reactions, 2) excess medication, 3) unnecessary medication, 4) medication satisfaction, and 5) medication topics to discuss with the GP (open-ended question). The patient completed the tool before the GP consultation to encourage reflection on the medication. During the consultation, the GP turned the attention to the patient, and GP and patient reviewed the patient's responses and discussed potential medication-related problems. The improved patient preparedness and the increased GP awareness provided a more patient-centred consultation. The patient was empowered to speak. This gave the GP a better understanding of patient perspectives, and through the dialogue the patient's sense of security, satisfaction and insight into own medication were increased.

Conclusion/If work is in progress, describe how far along in the process you are:

We developed a brief tool to support active patient involvement in medication review in general practice, which was well received by both patients and GPs. Future research will explore whether the PREPAIR tool can improve patient outcomes and quality of care in different settings or populations.

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Title:

Developing and evaluating a motivation-enhancing intervention to retain participants in a randomised controlled trial evaluating allergy immunotherapy

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Background:

In ILIT.NU, participants are asked during three consecutive grass pollen seasons daily to report medication use and symptom score in an online 12 items questionnaire. Participant attrition is expected to be 20% and 15% among participants receiving placebo and verum, respectively. Participant response during the season of 2021 before receiving treatment ranged from a median of 90% in the first week after all participants had started reporting, to 78% in the last week of the season. Future participant retention may be affected by lack of motivation.

Methods:

The framework for complex interventions is used as design as severity of allergy, motivation and patient involvement in the research process are components that can interact and influence whether the intervention is successful. The Self Determination Theory is used to understand how to motivate participants to continue reporting. Patient and public involvement in research is used to ensure an intervention relevant for the participants and able to improve retention in the trial.

Results/If work is in progress, describe how far along in the process you are:

Results from two online design workshops including ten participants suggested that an efficient and easy-to-use smart phone app configurable to personal preferences needs to be developed. Improvements included (a) only complete the entire questionnaire on days with symptoms, (b) individual choosing the time of response, (c) accepting/rejecting reminders, (d) access own data, (e) showing personal and total response rate, (f) integration of grass pollen counts and forecasts, (g) status of study and (h) option to complete a second questionnaire in the app.

Conclusion/If work is in progress, describe how far along in the process you are:

The app will be evaluated with workshop participants before tested in a pilot study spring 2022. The app will be tested by 50% of participants in the trial in the grass pollen season of 2022 to document its effect. If it shows feasible results, it may be used by all participants in the trial in 2023.

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Title:
Co-creating with families and healthcare professionals: shaping a context-sensitive health promotion intervention 'Face-it'

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Background:
Participatory methodologies have become imperative to developing health promotion programs. However, the concrete adoption of co-creation and with what implications for intervention development are less reported. This paper aims to convey how co-creation can shape intervention components by presenting and analyzing concrete involvement practices across an intervention development process.

Methods:
The Face-it program was initiated to prevent diabetes and increase the quality of life in women at high-risk of diabetes by supporting the whole family in their health practices. Building on existing evidence, we applied co-creation as the main strategy to develop intervention content. We relied on participatory methods and anthropological fieldwork involving families with prior gestational diabetes as intervention receivers and healthcare professionals as potential intervention deliverers.

Results:
We show how co-creation a) influenced the intervention content, b) broadened the scope of intervention development methodology and c) upheld both premises of the RCT design (fidelity) and flexibility in intervention activities (adaptation) in the intervention development and implementation.

Conclusion:
Co-creation facilitated a context-sensitive approach which helped tailor content to families and strengthened empowerment and ownership among intervention deliverers and GDM carers.

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Title:

Development of a patient decision aid to reduce barriers in clinical trial participation within proton therapy among patients with head and neck cancer

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Background:

As the only hospital in Denmark, Aarhus University Hospital offers proton therapy (PT) to cancer patients. The majority of patients are offered PT by participating in clinical trials (CTs). Patients with head and neck cancer (HNC) are a heterogeneous group, but compared with the population in general they are socioeconomically and psychosocially disadvantaged. Research has shown, that socioeconomically disadvantaged patients have a lower participation rate in CTs and that the geographical distance to treatment affects the number of referrals. Studies are needed to understand the factors influencing decisions concerning CT participation and thus the opportunity to receive PT.

Methods:

In a cross-sectional study, the correlation between non-attendance in CTs and socioeconomic, psychosocial, clinical and geographical factors will be analysed. Data are collected in questionnaires and in a clinical database.

A qualitative study based on Interpretive Description will be conducted to explore perceptions and barriers regarding CT participation and use of PT among patients with HNC. The methods used are participant observation in radiotherapy clinics in Denmark and semi-structured interviews with patients and clinicians.

The patient decision aid will be developed within The framework of complex interventions and the International Patient Decision Aid Standards.

Patients and clinicians will be engaged throughout the research process using dialogue meetings and workshops.

Results:

Data collection is in process.

Conclusion:

This study investigates potential inequalities in the access to PT in Denmark and contribute with new knowledge on the barriers affecting CT participation and use of PT for patients with head and neck cancer. Furthermore, it will lead to the development of patient decision aid to support patients and clinicians in the shared decision concerning CT participation and thus referral to PT.

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Title:

"Foot on the lived life" with treatment-requiring Dibabetic FooT Ulcer, INvolvement of patients, and significant others – The DiFTU-IN study

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Background:

Diabetic foot ulcer (DFU) affects approx. twenty-two thousand Danes' daily life. In the Region Zealand approx. two hundred citizens annually have an amputation caused by diabetic complications.

DFU is a significant debilitating health problem and a serious and socio-economically expensive complication of diabetes. Living with treatment-required DFU may be experienced as demanding work from the patient and relatives' perspective, formed by personal capacity for decision-making, goal setting, and enacting these in life.

Research recommends improving strategies and resources to develop and implement preventive acts embracing social relationships and the patient-family perspective. The involvement of patients and relatives at the outpatient clinic may support their manageability and potentially prevent amputation or help facilitate decision-making when necessary.

We aim to investigate stakeholders' experiences, needs, and preferences related to patients' and relatives' involvement in the treatment trajectory of DFU in Region Zealand.

Methods:

The feasibility study is a preparative part of developing a complex intervention using a qualitative design; individual and focus group interviews will be conducted, comprising informants from four clinics, analyzed by qualitative content analysis.

A support group including 1-3 patients/relatives secure the study base of relevant clinical needs.

The Danish Data Protection Agency approved the study (REG-181-2020).

Allocated funding from Steno Diabetic Center Zealand.

Results/If work is in progress, describe how far along in the process you are:

The study is at the startup point; the research and support group are constituted in Sep. 2021.

Conclusion/If work is in progress, describe how far along in the process you are:

At the current time point of the feasibility study, we expect to contribute to the knowledge of convincing incentives for increased involvement.

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Title:

It takes three levels of learning design for 'blended learning' to be successful: A qualitative evaluation of an educational course

Authors and their organisations:

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Background:

Diabetes entails an increased risk of prolonged hospitalization, wound infections and unintended events during hospitalization for orthopaedic surgery. This educational intervention aimed to create, conduct and evaluate a 'blended-learning' program on diabetes treatment for orthopaedic surgical staff to increase knowledge and promote interdisciplinary collaboration on diabetes treatment.

Methods:

- 1) Three orthopedic surgical departments participated in identifying learning objectives via Group-Concept-Mapping. Orthopedic and endocrinology staff participated in workshops, that led to the development of 5 case-based e-learning activities and a toolbox.
- 2) A total of 93 doctors and nurses completed the e-learning and 174 participated in follow-up joint face-to-face (F2F) teaching.
- 3) The evaluation was based on participant observation of nine F2F lessons with 108 participants (doctors and nurses) and four focus group interviews with 13 nurses.

Results

The e-learning was positively perceived and resulted in the participants gaining relevant knowledge about diabetes treatment. Implementing successful blended learning was complex and involved detailed development at three interrelated levels of learning design/didactics:

- 1) Micro level: Design of relevant, efficient and motivating interactive e-learning, differentiated to learners with various educational backgrounds and levels of experience.
- 2) Meso level: Design of problem-based, well-argued, efficient, F2F lessons, that related to the e-learning. Support for the participants co-study-methods in e-learning, and cross disciplinary discussions.
- 3) Macro level: Management of time and space for the educational activities and leadership which clarifies the expectation that everyone in the target group participates in the teaching.

Conclusion

In order for blended learning to be effectively implemented and have impact, it is necessary to create a learning design at micro, meso and macro level.

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Title:

Public involvement in developing services; - results from a systematic scoping review and a thematic synthesis of public involvement methods used in developing, evaluating and implementing community health services including examples of the methods used in research.

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Background:

Public involvement has gained increasing interest for the past decade. This interest is also maintained within the development, evaluation, and implementation of public health services. A growing body of highly diverse research literature on public involvement promotes uncertainty about which involvement methods to apply and the possible values related to carrying out these public involvement processes.

Methods:

A systematic scoping review of public involvement methods (paper 1) was conducted inspired by the five step approach as outlined by Arksey and O'Malley, 2005 and Levac et al, 2010: 1) identifying the research question 2) identifying studies 3) selecting studies 4) charting data 5) collating and summarizing the results.

A thematic synthesis of the values related to public involvement in developing services (paper 2) was carried out inspired by the six-step thematic analytical strategy by Braun & Clark, 2006.

Results/If work is in progress, describe how far along in the process you are:

The results of the systematic scoping review and the thematic synthesis of the value of public involvement has been presented in two scientific papers of which one is published (paper 1) and one (paper 2) is in review.

The identified involvement methods (from paper 1) is presented in a Danish catalogue with an overview of the public involvement methods and knowledge on how to apply them in practice.

The results from the study will be presented in the poster, including an overview of the identified involvement methods followed by examples from ongoing research (not published yet).

Conclusion/If work is in progress, describe how far along in the process you are:

The results included in this poster presentation contributes with new knowledge based on a systematic literature search and an overview of involvement methods in planning, developing and implementing community health services. The results of the study contributes also with knowledge about the value of using the identified involvement methods and the potential harm when carrying out public involvement processes.

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Title:

Involving people with aphasia in research on supported communication

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Background:

People with aphasia after stroke and other acquired neurological conditions are often excluded from research since the core of aphasia is communication difficulties. Many researchers are not aware of how to include people with aphasia since it requires special support materials, supportive oral communication strategies and general knowledge of aphasia. One way to solve this issue would be to involve consultants with aphasia in the planning and execution of studies including people with aphasia.

This poster will report on the collaboration we have had with three consultants with aphasia in a project aiming at exploring how health professionals are communicating with people with aphasia while in hospital.

Methods:

The methods in the overarching project are inspired by phenomenology and ethnography. Video observations of patient with aphasia/health professional conversations during care and therapy have been made, and semi-structured interviews with the participating people with aphasia have been conducted.

Results/If work is in progress, describe how far along in the process you are:

In the preparation for the data collection, the consultants with aphasia were consulted in terms of creating aphasia friendly consent forms, interview guide and written/pictorial support materials for the interview process. Their input resulted in the replacement of pictures and words.

At a later stage we have been discussing the preliminary results as well as the publication strategies with the consultants. The perspectives of the consultants have contributed to validating the results and rethinking the publication strategies.

Conclusion/If work is in progress, describe how far along in the process you are:

The project ends this year. So far, we can conclude that the involvement of consultants with aphasia has nuanced and improved the research process and will likely also have a positive influence on the results and dissemination hereof.

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Title:

ParTNER-STEPs: Parents in Transition – a Nurse-led Support and Transfer Education Program – a complex intervention

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Background:

Transfer from paediatric to adult care for chronically ill adolescents is associated with no-shows and low treatment adherence among adolescents, as well as anxiety and concerns among parents. Studies show that supporting the parents results in better transitions, but there is lack of interventions. The aim of this complex intervention study was to develop, test and evaluate a brief transition intervention targeting parents of chronically ill adolescents (aged 16,5 – 17,5).

Methods:

The study is based on The UK Medical Research Council's guidance on developing, evaluating and implementing complex interventions. To increase the program's feasibility and relevance, participatory design (PD) was chosen as the overall method in the development. During this phase, a collaborative group of parents, adolescents and health care professionals (HCP) were actively involved in the assessment of needs and ideas generation.

Results/If work is in progress, describe how far along in the process you are:

Together with the collaborative group we developed a brief transition program called ParTNER-STEPs using workshops, individual interviews, online brainstorms and multiple pilot tests. The collaborative group were continuously asked to suggest elements in the program and give their feedback on preliminary initiatives.

ParTNER-STEPs consists of three different initiatives, 1) an informative website, 2) online educational events and 3) transfer consultations across the paediatric and adult department.

Conclusion/If work is in progress, describe how far along in the process you are:

By incorporating the principles of PD in the development phase we ensured that parents' and adolescents' needs were represented and met in the program. Furthermore, the involvement of HCP secured the feasibility and relevance of the intervention in clinical practice and will increase the chances of successful implementation.

The program will be evaluated in a RCT study.

Trial status: Recruitment started in July 2021 and is ongoing.

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Title:

Current trends in patient and public involvement in cancer research: A systematic review

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Background:

Patient and public involvement (PPI) in health research is on the rise worldwide. Within cancer research, PPI ensures that the rapid development of medical and technological opportunities for diagnostics, treatment and care corresponds with the needs and priorities of people affected by cancer. An overview of the experiences, outcomes and quality of recent PPI in cancer research would provide valuable information for future research.

The object of this study was to describe the current state of PPI in cancer research focusing on the research stages, applied methods, stated purposes and outcomes, and challenges and recommendations.

Methods:

A search was conducted on PubMed, CINAHL and PsycINFO for literature published from December 2006 to April 2017. Original research studies describing the involvement of cancer patients, stakeholders, and carers as active partners at any stage of the research process were included.

Results/If work is in progress, describe how far along in the process you are:

Twenty-seven studies were included, the majority reporting PPI at the early stages of research, that is, during the definition and prioritization of research topics and the development of recruitment strategies. Few studies reported PPI at later stages and across the research process. Challenges and recommendations were only briefly described, and critical reflection on the PPI process was lacking.

Conclusion/If work is in progress, describe how far along in the process you are:

PPI needs to be integrated more broadly in the cancer research process. The quality of reporting PPI should be strengthened through greater critical reflections including both positive and negative experiences of the PPI process. This will contribute to the further development of PPI and its potential in cancer research.

The study was published in 2019:

Pii, K. H., Schou, L. H., Piil, K., & Jarden, M. (2019). Current trends in patient and public involvement in cancer research: a systematic review. *Health Expectations*, 22(1), 3-20.

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Title:

Conversation cards for person-centred self-management support of people with type 2 diabetes (T2D) in nursing clinics: an innovation project

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Background:

People with T2D are advised to take care of regulating their blood sugar level every day by taking medication, eating and drinking healthy, exercising, etc. For many, this is hard work and difficult to implement in everyday life, which is why self-management support is needed. Thus, we aimed to develop a tool to facilitate person-centred self-management support in the annual T2D status consultations practiced by nurses in diabetes clinics and general practices.

Methods:

This innovation project at SDCC involved people with T2D, nurses, and a dietician in the five stages of design thinking (emphasize, define, ideate, prototype, and test) to improve the quality of the consultations. The methods were professional meetings, informal interviews, guideline and literature review, ethnographic field studies, individual semi-structured interviews, workshops, survey, and registration of card choices.

Results:

The nursing clinic was challenged by cultural and structural forces that pulled the focus towards 'all-round documentation' in the patient record. To counteract these forces, we created conversation cards (in playing card format) for use in the consultations to clarify a common agenda between the person with T2D and the nurse. The seven theory-informed and guideline-based conversation cards introduced a wide spectrum of topics to foster.

Conclusion:

The conversation cards pushed the consultation in the desired person-centered self-management support direction. Survey and interviews demonstrated high user satisfaction. Several measures are needed to support implementation of this, seemingly simple, but in practice rather complex intervention.

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Title: Chronic Musculoskeletal Pain - what should future research prioritise?

Authors and their organisations:

Authors

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Background

Chronic Musculoskeletal Pain (CMP) poses a huge challenge within the global society. Acknowledging the importance of end-users lived experience, have been largely neglecting in the generation of research for this population. This have led to a substantial production of research-waste and clinical irrelevant research. To accommodate this, we initiated a study to establish future research priorities within the field of CMP with end-user participation from the entire Denmark.

Methods

This study used the James Lind Alliance Priority Setting Partnership (JLA-PSP) framework to establish the top research priorities for patients living with CMP, relatives to patients living with CMP, HCPs and researchers who were working with patients living with CMP. In order to comply to the framework, we utilised a national survey and a workshop which informed the final list of priorities.

Results

1010 participants responded to the survey, revealing 3121 potential research questions. Based on feedback from 97 participants, 7 research questions were deemed lesser important, leaving 40 research questions for a final workshop. 26 stakeholders, participated in the final workshop and voted for the most important research priorities in relation to CMP.

Conclusion

Improving specialized pain clinics, minimizing errors in diagnosis, improving education for patients were among the highest priorities for future research and policy making.

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Title:

A process evaluation examining how user involvement impacts BackTraceDigital development of a digital solution for patients with low back pain.

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Background:

In recent years, user involvement in research has received increasing recognition as a method for achieving better research practice, clinical practice and healthcare. Both the growing interest and demands for user involvement in the research process makes it relevant to investigate what effects it has on research and the development of research-based solutions. However, this is not often clarified in research papers. To accommodate this, the research project BackTraceDigital (BTD), wishes to investigate the impact of user involvement on the development of a digital health solution, BTD.

Methods:

A two-part retrospective process evaluation aiming to understand the impact of user involvement (involving patients, relatives and professionals) used in BTD development, how, why and to which extent user involvement was carried out and additionally the effect it had on development. First part; qualitative interviews with the project management to describe, through INVOLVE conceptual framework, the range and content of user involvement used during the research. Second part; analysing field notes from workshops and meetings with users, identifying the users inputs toward developing the digital solution and then thematises those inputs using text condensation.

Results:

The interviews are conducted, but the transcription and analysis are not complete. Initial findings show a clear description of how and why user involvement has carried out through the research development phase.

The identification and text condensation of users inputs is done and several themes, which show an impact from the inputs towards developing the digital solution, but the results it is still in progress.

Conclusion:

The initial analysis of data, has shown a positive impact through workshops in the development of BTD. They helped ensure relevant content, which empowers patients by engaging them as an active part in their treatment and helps professionals making a shared treatment plan.

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Title:

Developing the NASSS-CAT-PaR for managing and researching complex challenges of participatory health research

Authors and their organisations:

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Background: Participatory health research is constrained by many so-called barriers. There is little explanation of what these mean for whom and when. We believe participatory challenges are complex and should be dealt with as such. For health technology projects, the NASSS-CAT (Nonadoption, Abandonment, Scale-up, Spread, and Sustainability Complexity Assessment Tools) is designed to guide the management and research of complexities that inhibit implementation. Within a diabetes research setting, we will examine to what extent the NASSS-CAT can be adjusted to the context of participatory health research projects.

Methods:

- Interviews and focus groups with researchers, health professionals, and people with diabetes who have experience with participatory research to inform a draft of the NASSS-CAT for Participatory Research (PaR).
- A systematic review of participatory diabetes research where challenges are interpreted as simple problems, dilemmas and more complex paradoxes. The challenges will be categorised as to which of the NASSS-CAT-PaR domains they relate.
- Co-design workshops to form a NASSS-CAT-PaR prototype with researchers, health professionals, and people with diabetes involved in participatory research. The collaborators' evaluation of the feasibility and acceptability of using the tools will be investigated in a focus group study.

Results: The project is looking for funding and partners to develop and test the NASSS-CAT-PaR, which we expect will help researchers and practitioners understand and manage participatory research challenges. Next steps will be:

- Assessment of the prevalence and incidence of participatory challenges on individual and organisational levels and across research disciplines.
- Mapping and matching challenges with appropriate responses and available resources to assess the need to develop new resources or increase dissemination of any available.
- Evaluation of the NASSS-CAT-PaR beyond the diabetes research setting.

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Title:

Reflections of family caregivers and health professionals on the everyday challenges of caring for a person with amyotrophic lateral sclerosis and cognitive impairments: a qualitative study

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Article is in review

Background:

Family caregivers of people with amyotrophic lateral sclerosis and cognitive impairments (PALS/CIs) are highly burdened and at great risk of psychological sequela. Health professionals (HPs) working with these families can be negatively affected on their well-being and are at risk of burnout.

Aim to explore reflections of family caregivers and HPs regarding the challenges involved in caring for PALS/CIs. Next to develop a targeted palliative rehabilitation program to support family caregiver in coping with challenges related to the PALS/CIs.

Methods:

The design was a qualitative interview study.

One focus group and 10 individual semi-structured interviews were conducted with seven family caregivers and nine health professionals after the death of a PALS/CIs. The analysis was guided by the Interpretive Description methodology and the theory of Sense of Coherence.

Results

The family caregivers' challenges regarding coping with everyday needs related to the sick person were associated with "Accepting that nothing else matters", "Adjusting to new roles while balancing", and "Realizing different values in relationships"; whereas the HPs' challenges were related to "Collaboration a balancing act", "Working in a home of sorrow", and "Coordinating threads to tie".

Conclusion

Family caregivers found coping with the complexity of the diseases a challenge, and their everyday life needed constant adjustment to new roles, coping with inappropriate behavior, and navigating through the progression of the diseases of their sick relatives whilst collaborating with numerous professionals. The HPs struggled with coordinating and collaborating with the families and with other colleagues due to the severeness and complexity of diseases.

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Title:

Design and development of an e-learning patient education program for self-management support in patients with rheumatoid arthritis

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Background:

Patient education with the aim of supporting patients to self-manage their disease is integral to the treatment and care of patients with rheumatoid arthritis. Change is taking place in the organisation of healthcare systems because of a demographic shift towards ageing populations and advancements in digital technologies, allowing for new interventions. However, evidence on how to provide online patient education within arthritis is limited. The aim of this study was to develop an e-learning education program targeting patients with rheumatoid arthritis.

Methods:

The development involved content specification and creative design with contributions from the investigators, patient research partners, and experts in communication, digital design, and e-learning. It was theoretically framed within theories of multimedia learning and entertainment education and empirically based on the evidence of patient education in rheumatoid arthritis and focus group discussions with stakeholders. We conducted a feasibility test to assess the acceptability and usability of the program to identify areas to be adjusted.

Results/If work is in progress, describe how far along in the process you are:

The four following themes for educational needs were found in focus group discussions: *"Knowledge of rheumatoid arthritis," "the disease course and prognosis," "Medical treatment," "A new life situation" and "Daily life with rheumatoid arthritis."* Based on this, an e-learning program covering the disease course, examinations, treatment, and daily life with rheumatoid arthritis, was created. It combines animations, videos, podcasts, text, speech, and tests. The test persons found the program feasible—that is, clear in content and easy to understand with a suitable pace and coherence between graphics, speech, and text.

Conclusion/If work is in progress, describe how far along in the process you are:

This e-learning program is based on solid theoretical knowledge that meets users' needs and is easy to use. Our study describes possible elements integrated in the development of web-based educational tools that can guide future development processes.

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Title:

Patient and public involvement in developing a shared decision making intervention for patients with end stage kidney disease planning end-of-life care

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Background:

The overall aim of this research is to develop and evaluate the feasibility of a shared decision making (SDM) intervention used to support advance care planning and end-of-life care decisions in patients with end stage kidney disease (ESKD). SDM interventions are complex interventions (CI), with several components supporting health professional skills (e.g., decision coaching), patient understanding (e.g. patient decision aids), and patient-professional communications (e.g., service prompts). We report on how we include patient and public involvement (PPI) in our research process.

Methods:

The project addresses the first two phases of the UK Medical Research Council framework for CI 1) intervention development research, investigating empirical evidence in a scoping review and interviewing patients, relatives, and staff, and 2) intervention feasibility/piloting testing using a stepped-wedge design across five renal units, assessing if the SDM intervention is acceptable to patients, relatives, and staff. Our research team includes: a person with ESKD and a relative of a patient with ESKD (PPI); methodologists; decision scientists; health professionals.

Results:

Our PPI members are involved in all aspects of the research process: members of the research steering committee, commentators on research materials, advisors on data collection methods, co-authors on publications, and dissemination activities. Their experiences and knowledge provide guidance on how to invite study participants, content of interview guide, and facilitate discussions around methods for developing the intervention.

Conclusion:

PPI in the research process is essential to ensure the processes are fair and accessible to patient and relative participants. Their perspectives are important in interventions with multiple stakeholders, and those impacting on patient experience of care.

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Developing interventions with intravenous anticancer treatment for children and adolescents at home (INTACTatHome) – a complex intervention study**Authors and their organizations:**

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Background:

Children and adolescents with cancer undergo intensive treatment causing several hospital visits and admissions leading to disruptive everyday lives for the whole family. The aim of the present study is to develop feasible and safe interventions with intravenous anti-cancer treatment (IAT) of children and adolescents at home to reduce the disruption. However, moving IAT to the home is a complex intervention generating changes for both patients, caregivers and health care professionals (HCP). To secure feasibility including safety, acceptability and implementation, it is imperative to involve patients, caregivers and HCP in the development process.

Methods:

This study is part of a PhD-project based on the Medical Research Council's guide to develop and evaluate complex interventions. The study constitutes the development phase comprising a patient and public involvement (PPI) approach focusing on priority-setting and feasibility. We conducted:

1. Two workshops based on the nominal group technique method comprising several assessment instruments involving expert HCP (n = 13).
2. Nine semi-structured qualitative interviews with parents of children and adolescents with cancer with home care experiences (n= 9).

Results/If work is in progress, describe how far along in the process you are:

Preliminary results:

1. Most appropriate IATs for home care are prioritized
2. Most important barriers and facilitator related to IAT at home are defined and discussed
3. Criteria of eligibility and success of IAT at home are defined and discussed
4. Risks and consequences of IAT-related adverse events are defined, discussed and assessed.

Data collection has been completed and thematic analysis of the qualitative data is ongoing.

Conclusion/If work is in progress, describe how far along in the process you are:

We conclude that a PPI approach focusing on priority-setting and feasibility using NGT and qualitative interviews is highly beneficial in the complex intervention development phase.

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Title:

Effects and experiences of a 2-year transition program for competence development of newly graduated nurses

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Background:

One in four new graduate nurses intends to leave their nursing profession, causing shortage of nurses and high turnover. It is a global problem for healthcare organizations. Graduates' intention to leave increases during the first years of employment, partly because they do not feel prepared for clinical practice.

A 2-year nurse transition program has been developed for introduction and training in a medical department

In collaboration with an expert group, we aim to investigate how the program affects the graduated nurses' intention to stay in the medical department and whether it is associated with patient outcome.

Methods:

An expert group consisting of nurse students, newly graduate nurses, managers, and patients will be involved repeatedly throughout the research period. The expert group will discuss ethical considerations and define relevant measurable patient outcomes and compose information for participating new graduate nurses in the study.

This study is prospective and uses a mixed method design. Data on staff retention will be collected from the medical department and compared to a similar department not using the transition program.

Participants will be interviewed during the program to explore their experiences of job satisfaction and whether the program supports them in their job.

Results/If work is in progress, describe how far along in the process you are:

We are in process with inviting the expert group and planning how the expert group meets the researchers and becomes integrated in the project. The expert group will be involved from the start which is expected to be from January 2022 and three years ahead.

Conclusion/If work is in progress, describe how far along in the process you are:

We expect the results to be used by healthcare organizations considering implementing a transition program. The results may display which factors are important in a transition program to support graduates towards higher job satisfaction and thereby enhance the intention to stay in the nursing profession.

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Title:

Patient and public involvement - experiences from a Danish peer-mentor complex intervention project

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Background:

In health research, there is a growing tendency of using 'Patient and public involvement' (PPI). In Denmark, different approaches to PPI are utilized and empirical examples are warranted. The aim of this study is to report the preliminary experiences of utilizing PPI in an ongoing (2019-2023) research project 'Heartened' (in Danish: 'HjertensGlad'): a complex intervention of peer-mentoring among older, vulnerable patients with myocardial infarction in a Danish rehabilitation setting.

We provide empirical examples of how PPI can be used in 1) Development of a complex intervention, 2) Recruitment of research participants, 3) Development of written material, 4) Validation of results, and for 5) Dissemination of scientific results.

Methods:

Involvement of experienced cardiac patients in 1) official PPI-board and 2) informal feedback from patients involved in the intervention.

Results/If work is in progress, describe how far along in the process you are:

PPI-feedback helped us develop a feasible complex intervention and enabled us to implement the intervention according to patient preferences. PPI also contributed to revision of original inclusion criteria and enabled more clinically relevant inclusion criteria to be applied. PPI contributed in the development and revision of written material ensuring that materials were adapted to health literacy-levels of the target population. The PPI-board contributed in the analysis of qualitative data and helped strengthen 'credibility' of study findings by 'member check', thus validating findings. Further PPI will be used in the later dissemination of scientific results, as we view them as valuable partners, competent of disseminating research results to a broader audience in the public.

Conclusion/If work is in progress, describe how far along in the process you are:

PPI have contributed substantially in 'HjertensGlad' and helped develop a research project which both patients, researchers, and external foundations view as important and relevant. There are many advantages of using PPI in research. However, researchers must be apt to work with research in a new way if they initiate a PPI collaboration.

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Title:

Delphi process defining a Core Outcome Set for the general critically ill patient in ICU – a protocol

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Background:

Clinical trials in the critically ill use different outcomes, and no generally applicable core outcome set (COS) is available for this population. We aim to develop a generally applicable COS for critically ill patients with involvement of relevant stakeholders and to describe how the identified outcomes could be assessed or how they are defined.

Methods:

The COS will be developed in accordance with the COMET Handbook using a Delphi consensus process and semi-structured interviews, involving adults who have been acutely admitted to an intensive care unit (ICU), relatives or close caregiver to ICU patients/survivors and clinical/research stakeholders who have an attentiveness and interest in improving the care and treatment of the critically ill ICU. The COS is developed to be generally applicable for clinical trials conducted in adult patients with critical illness (life-threatening illness requiring treatment in an ICU).

The Delphi process will be performed in 2 steps. First, development of a survey in collaboration with relevant stakeholders and at least two survey rounds, with refinement of the COS following first survey round and parallel semi-structured interviews with key stakeholders. Upon consensus among relevant stakeholders, we will further assess the developed COS by agreeing on instruments to be recommended in step two of the Delphi process.

Results/If work is in progress, describe how far along in the process you are:

We are working on the inclusion of stakeholder members, involvement of relevant stakeholders and the first survey round in the Delphi process.

Conclusion/If work is in progress, describe how far along in the process you are:

The outlined multiple methods study will establish a generally applicable COS for critically illness, which may be used to increase standardisation and comparability of results of trials conducted in the critically ill patients in the ICU.

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Title:

Is Group Concept Mapping a Feasible Approach for Patient and Public Involvement in Research? A Research Protocol of User Involvement in Systematic Reviews of Continuous Medical Education

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Background:

Effectiveness studies of Patient and Public Involvement (PPI) in research has called for new ways to improve the scientific quality of PPI practices.

Group Concept Mapping (GCM) is a method that structures collaborative group processes with a transparent and rigorous data-collection and analysis. GCM has not yet been evaluated in the context of PPI in research.

We aim to evaluate whether GCM is a feasible method to systematically involve, collect and organize knowledge from professional and service users and evaluate how this knowledge impacts the research findings of a series of planned systematic reviews of continuous medical education.

Methods:

We will carry out three workshops with 20 users from Steno Diabetes Center Copenhagen of which 10 are professional users (health care professionals and educators) representing knowledge of medical education in diabetes care and 10 are service users (type 1 and type 2 diabetes) representing knowledge of diabetes care. GCM will guide the three workshops in a stepwise procedure and collect and organize data (brainstorming, sorting and rating, multidimensional scaling and cluster analysis) from users to inform research activities at three review phases:

1. Defining scope (aim, research questions)
2. Identify (search, extract, quality-assessment)
3. Report (synthesize, analyze)

Multi-variate analysis will organize user-knowledge to visually represent data from each workshop in three group concept maps with the software 'GroupWisdom. Three criteria (acceptability, practicality, integration) will guide the evaluation of the feasibility of GCM and criteria from GRIPP2 will guide the evaluation of how knowledge from users has influenced the research activities and findings of the study.

Results/If work is in progress, describe how far along in the process you are:

Planning phase (protocol)

Conclusion/If work is in progress, describe how far along in the process you are:

Planning phase (protocol)

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Title: Partners in heart disease - a mixed methods study of social inequality in health among individuals with cardiovascular disease and their partners

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Background:
 Cardiovascular disease (CVD) is the leading cause of mortality and morbidity in Europe. Over the past decades, CVD mortality rates have decreased due to improvements in medical care, but at the same time prevalence of CVD has increased due to improved survival rates, increasing age and prevalence of risk factors. Marital status is known to affect the development of and prognosis after CVD, and partners of individuals with CVD are known to be psychologically affected by the situation. In spite of this, little is known about the social different influence of partners and social differences in how partners are affected by the disease. Consequently, interventions aimed at couples with CVD are lacking. The purpose of this study is to generate knowledge about social inequality among individuals with CVD and their partners.

In WP1 we study social inequality in health behaviour, mental health and health literacy among cohabiting individuals with CVD. In WP2 we study social differences in health behaviour, mental health and health literacy among partners of individuals with CVD. WP3 is a qualitative study focusing on CVD couples with a high risk profile. In WP4 we develop and pilot test an intervention targeted individuals with CVD and a risk profile and their relatives.

Methods:
 WP1 and WP2 are based on data from the population-based health survey "How are you", linked with the Danish National Registry of Patients. WP3 uses semi-structured interviews and participant observation. WP4 is based MRC guidelines for developing and evaluating complex interventions and uses results from the prior WPs and a literature review, and this WP includes process evaluation and pilot effect evaluation.

Individuals with CVD and partners are involved in all phases of the research process. The patients and partners are recruited from a patient's association panel. They are included in the advisory group of the project and will be involved in planning of the complex intervention and generally in all processes where patient and relative perspectives are relevant.

Results/If work is in progress, describe how far along in the process you are:
 The study runs from 2020 to 2023; WP1 is in process and preparation for WP2 and WP3 has started.

Conclusion/If work is in progress, describe how far along in the process you are:

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Title:

Engaging patient research partners in the research process of a clinical controlled trial

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Background:

The interest in patient and public involvement (PPI) in health research is increasing. PPI may improve quality and relevance of research. However, little is known about PPI throughout the entire research process and especially in the analysis. In a clinical study investigating the effect of using patient-reported outcomes (PRO) as a dialogue-based tool in oncology consultations, we explored ways to embrace the perspectives of patients in a research process, and the impact and challenges our collaboration has had on patient research partners, researchers, and the research outcomes.

Methods:

In total, five patients and six researchers and clinicians were involved in the project' steering group established in 2017. In the design phase, the steering group selected relevant PRO measures and composed a patient information sheet. To test the intervention fidelity, six consultations based on the PRO-based dialogue tool were audiotaped. In the analysis phase, two patient research partners and three researchers and clinicians received training in order to analyse these audiotaped consultations using the Verona Coding Definitions of Emotional Sequences (VR-CoDES). The analysis was done individually before consensus-meetings were held. Additionally, in the dissemination phase, the patient research partners were involved in communicating results at national and international conferences and meetings. The outcomes, impact, and challenges of our collaboration were explored through a workshop.

Results/If work is in progress, describe how far along in the process you are:

In the design phase, patient research partners advocated for inclusion of PRO measures to enable discussions with both clinicians and relatives in the consultation, which was not considered by the researchers beforehand. The title and wording of the information sheet were adjusted in light of the patients' suggestions. The analysis of the fidelity study showed that patient research partners and researchers had a high consensus on the coding of emotional cues and concerns. The patient research partners contributed with a new vocabulary and perspective on the dialogue, and they validated the results. Arranging meetings, additional expenses, ethical considerations about the extent of involvement, and death of involved patient research partners were challenging elements in the process.

Conclusion/If work is in progress, describe how far along in the process you are:

Engaging patient research partners in several phases of the research process was feasible and beneficial. Moreover, our collaboration provides ideas of ways to operationalize PPI. An evaluation workshop revealed considerations about emotional, administrative and intellectual investments – best described as tacit, yet important 'work'. This knowledge and experience can be applied to other studies where patients are partners in the research.

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Title:

State of the art for patient and public involvement in the Nordic Countries - a scoping review

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Background

Public health care systems in the Nordic countries are similar in building on equal access to societal resources and entitling the citizens to free health care services. During the last decades the interest has increased in patient and public involvement (PPI) in health care research from the patients, public, funders and researchers; all with different perspectives. There is a lack of knowledge in how PPI is conducted in the Nordic countries and its impact on the research, across specialties and populations. We aim to map the state of the art in the Nordic countries and identify research gaps.

Methods

The scoping review is conducted according to the PRISMA framework and Arksey and O'Malley's methodological description: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarizing and reporting the results and (6) consultation. Our protocol will be posted online at Research Registry for transparency. Together with an information specialist several interdisciplinary electronic databases and grey literature will be searched for papers published between Jan. 1992 to Sep. 2021. Covidence will be used to manage screening and data extraction. Two independent researchers will screen the sources of evidence. Two sources of evidence laid the foundation for the literature search: i) those with primary focus on PPI and ii) those with a primary focus on a health care topic where PPI was integrated into the research process. For the latter we will use GRIPP 2 to assess the type and level of PPI.

Status

The review is currently being prepared for publication. The literature search will be conducted in Aug/Sep. 2021.

Conclusion work is in progress

Submission is planned in Feb. 2022. We hope to gain knowledge of the status and dissemination of PPI and point towards areas with gaps in evidence. This scoping review will facilitate Nordic collaboration in the advancement of PPI.