

GOTHENBURG SERIES IN PERSON-CENTRED CARE

# The first Global Conference on Person-Centred Care: Knowledge(s) and Innovations for Health in Changing Societies

Abstract Book



Axel Wolf & Joakim Öhlén  
Editors



UNIVERSITY OF GOTHENBURG

## Abstract

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This is the abstract book for the first *Global Conference on Person-Centred Care* (GCPCC), taking place in Gothenburg, Sweden, from 13<sup>th</sup>–16<sup>th</sup> May, 2024. The conference has been organized by the University of Gothenburg's Centre for Person-Centred Care (GPCC), which has been conducting research and supporting knowledge utilisation on person-centred care as a strategic government-funded research area since the centre was inaugurated in 2010. Within the conference theme, *Knowledge(s) and Innovation for Health in Changing Societies*, this book presents all abstract contributions presented by invited expert keynote speakers, workshops, panels/symposia as well as oral and poster presentations. Together, the book presents almost 250 abstracts. The theme reflects the relevance of various types of knowledge to further person-centred care and contributions include empirical, theoretical, literature reviews, practice-based examples, as well as art, performance and media. In this way the GCPCC signals the importance of reaching out to and fostering collaborations and partnerships globally among the various actors in the field of person-centred care.

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# Welcome to the first Global Conference on Person-Centred Care

Axel Wolf and Joakim Öhlén

The University of Gothenburg Centre for Person-Centred Care (GPCC) is pleased to have organised and welcomes you to the first *Global Conference on Person-Centred Care* (GCPCC), taking place in Gothenburg, Sweden, from 13<sup>th</sup>–16<sup>th</sup> May, 2024. The Conference has been organised in collaboration with the Nordic region's largest conference and exhibition focused on eHealth: *Vitalis*, and all GCPCC conference participants have full access to the large *Vitalis* exhibition.

GPCC was established in 2010 with the vision of promoting sustainable health through sustainable care; to prevent and decrease suffering and to strengthen the efficacy of healthcare through person-centred care, all with the support of the Swedish Government's strategic investment in research. Interdisciplinary research and knowledge utilization is accomplished through local, regional, national and international collaboration with different interest groups and experts.

The aim of the GCPCC is to provide an arena for diverse people with an interest in furthering person-centred care practice, innovations, perspectives, and knowledge(s). The conference provides an arena for explorations and accounts of person-centred care, as related to several interdisciplinary and interprofessional fields. These include integrated care, comprehensive care, and personalised health founded on partnerships, transcending healthcare practices and organisations, as well as policy and structural levels. We hope to create opportunities for networking in a person-centred community that will flourish beyond the conference.

The conference is therefore of interest to health professionals from across the globe, encompassing patient- and family carer representatives, researchers and students from various disciplines, leaders and decisions-makers in healthcare and health policy, as well as the healthcare industry. We proudly anticipate 28 different countries to be represented among the conference participants. As might be expected, the Nordic countries are well represented, along with other European countries with extensive research and development in person-centred care, such as the Netherlands, United Kingdom, Switzerland. Several countries from other

continents in both the southern and northern hemisphere are also represented, including South Africa, Brazil, Japan, Philippines, Singapore and Canada.

All conference presenters are presenting in person, with condensed versions of the presentations being available online. Different abstracts have been submitted, such as empirical and theoretical papers, literature reviews and practice-based examples, as well as art, performance and media. The presentation formats include poster, oral, symposia/panel, or workshop; the latter with interactive components. Inclusion of abstracts was decided by an international panel of expert reviewers conducting blinded peer review assessments.

We are especially proud of being able to invite a number of prominent, internationally well-known scholars to contribute with keynote presentations. These reflect the breadth of person-centred care scholarship, from healthcare practice development (Professor Brendan McCormack) to informal care (Professor Elizabeth Hanson), with underpinnings of 'being a person' spanning from Ingenious Sámi people (Dr. Petter Stoor), Continental European philosophy (Professor Inger Ekman) and Sub-Saharan African philosophies (Dr. Elvis Imafidon). Further, the keynote presentations reflect various practices, including integrated care (Dr. Viktoria Stein), patient-reported outcome measures as related to power in patient-professional relationships (Professor Joanne Greenhalgh), and the need for a paradigm shift to enable the patient's pathway to health (Anders Olausson).

The conference starts on 13<sup>th</sup> May with pre-conference workshops and an opening session arranged in partnership between the GCPCC and Vitalis. This is followed by a welcome reception sponsored by Västra Götaland Region and Gothenburg Municipality. Pre-conference workshops continue through the morning of 14<sup>th</sup> May. The formal GCPCC welcome and first keynote session take place after lunch, followed by parallel sessions. Keynote presentations and parallel sessions then continue through 15<sup>th</sup> May and into the morning of the 16<sup>th</sup>. Thematic parallel sessions are being held throughout the three main conference days, and these include a special theme *Towards the State of Science in Person-Centred Care*. The final keynotes, awards and closing session conclude the conference at lunch time on 17<sup>th</sup> May. In addition to the conference schedule, the GCPCC is offering social events, including "dine around" in Gothenburg (dinner at restaurants in the city in smaller groups with a local host), a reception and visit at the Museum of World Culture, and a conference dinner.

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We warmly welcome you to the first Global Conference on Person-Centred Care, which we hope will be a great opportunity to share, learn, network and collaborate in expanded and new flourishing constellations to promote person-centred care.

Axel Wolf and Joakim Öhlén

Co-Chairs for the GCPCC

Director and former Director for the University of Gothenburg Centre for Person-Centred Care

# Scientific committees for the GCPCC 2024

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# Conference programme

GCPCC 2024 programme overview.

May 13 <sup>th</sup>					
3 – 5 pm	<b>Opening keynotes</b> <b>Making dreams reality: Accelerating foundations for people-centred integrated health</b> Eric Sutherland. Organisation for Economic Co-operation and Development, OECD  <b>Perfect timing to attend a conference on person-centred care!</b> Inger Ekman. University of Gothenburg, Sweden  <b>Moderators</b> Axel Wolf & Erica Bonns				
May 14 <sup>th</sup>					
1 – 2:30 pm	<b>Welcome and keynotes</b> <b>A whole-systems approach to the development of person-centred services</b> Brendan Mc Cormack. The University of Sydney, Australia  <b>Integrated care, population health management and person-centredness: reflections and experiences from around the world</b> Viktoria Stein. Leiden University Medical Centre, The Netherlands  <b>Moderators</b> Axel Wolf & Joakim Öhlén				
2:45 - 3:45 pm Parallell sessions	<b>Workshop Learning and education</b>	<b>Art/Media/Performance</b>  <b>Moderator</b> Pamela Lindgren	<b>Orals Children and youth</b>  <b>Moderator</b> Ewa-Lena Bratt	<b>Panel Precision health</b>	<b>Orals Comprehensive Care</b>  <b>Moderator</b> Lilas Ali
Poster session					
<b>Moderators</b> Birgit Heckeman & Stefan Nilsson, Sepideh Olausson & Sara Wallström					
4:30-5:30 pm Parallell sessions	<b>Workshop: Equity</b>	<b>Orals Learning and education</b>  <b>Moderator</b> Maria Lindström	<b>Mini orals Digitalisation an e-health</b>  <b>Moderator</b> Filipa Ventura	<b>Panel Children and youth</b>	<b>Orals People of old age</b>  <b>Moderator</b> Anna-Karin Edberg
May 15 <sup>th</sup>					
8:30-9 am	<b>Keynotes</b> <b>Fluidity, Relationality and Personhood in African Understanding of Health and Wellbeing</b> Elvis Imafidon. SOAS University of London, UK  <b>Equity for Sámi Patients Too: Unraveling Paradoxes within a Universal Healthcare System</b> Jon Petter A Stoor. Umeå University, Sweden  <b>Moderator</b> Lisen Dellenborg				
9:45-10:45 am Parallell sessions	<b>Workshop Equity</b>	<b>Orals Implementation</b>  <b>Moderator</b> Qarin Lood	<b>Orals Practice-based implementation &amp; knowledge translation</b>  <b>Moderator</b> Erna Haraldsdottir	<b>Panel Mental health</b>	<b>Orals Global &amp; Local perspectives</b>  <b>Moderator</b> Karen van Zijl

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11:15 – 12:15 am Parallell sessions	<b>Workshop</b> Comprehensive/Integrated care	<b>Orals Theoretical perspectives on person-centred care</b> Moderator: Inger Ekman	<b>Person-centred tools and assessment</b> Moderator Andreas Fors	<b>Panel</b> Health economics	<b>Orals Life-limiting conditions</b> Moderator Cecilia Larsdotter
<b>Break</b>					
1:30-2:30 pm Parallell sessions	<b>Workshop</b> People of old age	<b>Orals Informal care and support</b> Moderator Cornelia Van Diepen	<b>Panel</b> Towards state of science Moderator: Joakim Öhlén	<b>Panel</b> People of old age	<b>Orals</b> Equity Moderator Helen Lloyd
<b>Poster session</b>					
<b>Moderators</b> Tomas Lindroth & John Chaplin, Ewa Carlsson Lallo & Lars Wallin					
3:15-4:15 pm Parallell sessions	<b>Orals</b> Towards State of Science Moderator Joakim Öhlén	<b>Orals</b> Digitalisation and e-health Moderator Vasiliki Mylonopoulou	<b>Brief Orals</b> Co-creation Moderator Emmelie Barenfeldt	<b>Panel</b> Communication	<b>Workshop</b> People of old age
4:30-5:30 pm	<b>Workshop</b> Towards State of Science Moderator Joakim Öhlén			<b>Seminar</b> Theoretical perspectives	
<b>May 16<sup>th</sup></b>					
8:30-9 am	<b>Keynotes</b>  <b>Patient Reported Outcome Measures (PROMs) and patient centred care: It aint what you do, it's the way that you do it</b> Joanne Greenhalgh. School of Sociology and Social Policy, University of Leeds, UK  <b>Advancing Person Centered Models of Care in a Value-Based System: What Will It Take?</b> Bradi B Granger. Duke-Margolis Health Policy Center, USA  <b>Moderator</b> Hanna Gyllensten				
9:45-10:45 am Parallell session	<b>Panel</b> Equity	<b>Panel</b> Digitalisation/ eHealth	<b>Workshop</b> Pharmacy	<b>Art / Media / Performance</b> Moderator Emma Forsgren	<b>Workshop</b> Design
11:15-12:45	<b>Keynotes</b>  <b>Informal carers as partners within person-centred long-term care</b> Elizabeth Hanson. Linnaeus University, Sweden  <b>The patient's pathway – necessitates a shift of paradigms</b> Anders Olausson. European Patients' Forum  <b>Moderator</b> Axel Wolf				

# Introduction to the conference theme

Hanna Gyllensten, Axel Wolf, Joakim Öhlen, Håkan Hedman, Eric Carlström

This abstract book contains the contributions to the first *Global conference on Person-Centred Care* (GCPCC) in Gothenburg, taking place 13<sup>th</sup>–16<sup>th</sup> May, 2024. The conference has been organized by the University of Gothenburg's Centre for Person-Centred Care (GPCC) and aims to become a recurring international platform for research and development in person-centred health, care, and social care. GPCC has been conducting research and supporting knowledge utilisation on person-centred care as a strategic government-funded research area since the centre was inaugurated in 2010. Since then, GPCC has brought together more than 200 national and international researchers along with healthcare professionals, leading patient- and public representatives, and other interest groups from various social spheres and research fields to increase the evidence-based knowledge.

## Key Reasons for Hosting a Global Conference on Person-Centred Care

The conference signals the importance of reaching out to and fostering collaborations and partnerships among national and international actors in the field of person-centred care. The conference theme, *Knowledge(s) and Innovation for Health in Changing Societies*, alludes to the rapid evolution of healthcare observed in many parts of the world, as well as the increasing expectations and demands for participation and influence from populations, particularly from patients and their families. This evolution manifests both at the point of care for individual patients and their families and at structural levels, such as organizational development, policy development, and laws and regulations. While the opportunities to diagnose, treat, and cure continue to improve, healthcare is becoming increasingly fragmented across areas of expertise in ways that risk neglecting who is cared for, also highlighting the need to consider how and when to provide specific actions. At the same time, increasing numbers of people are living with long-term conditions over time, especially – but not limited to – the older population. Decision-makers, policy-makers, legislators, practitioners, patients, and people at large are struggling to understand and navigate the changing landscape of both healthcare and informal care, as issues once believed to belong to the future are already manifesting.

Precision health/medicine and digital infrastructure, with an increased focus on AI, create a growing need for collaboration on priorities, privacy, security, ethics, equity, and equality. Evolving governance models with increasing centralisation require attention to the issues of participation and how decisions are implemented and evaluated. Healthcare systems' sensitivity to financial fluctuations, lack of trained personnel, overcrowded hospitals, insufficient primary and home care, along with unsatisfactory attention to and support for informal care, also demand capacity expansion with the ability to prioritize when there is an imbalance in the system. The evolving healthcare landscape, changing health and care needs, demographic shifts and social care structures are all being impacted by both formal and informal healthcare systems. Globally, there is a rising demand for healthcare services, along with inequity and disparities in access to healthcare as related to geographical location, socioeconomic status, systemic and structural racism and personal resources and capabilities. Healthcare systems face increasing costs, and the need to find sustainable financing and reimbursement models challenges traditional models of tax- and insurance-funded healthcare.

With all these challenges, but also new opportunities (such as precision health and digitalization) the patient's self-care and their family members' informal care have become increasingly important co-actors in healthcare. The interest in person-centred care is spreading, and various perspectives on how to strengthen the patient's role are being discussed, ranging from holistic perspectives and the individual's unique position and right to demand respect and autonomy. Today, patient-reported experiences and patient-reported outcomes of healthcare are crucial for shaping guidelines for both decision-makers and healthcare services.

Although healthcare has its origins in professional bureaucracies and logics that have excluded patients from influence, knowledge, and mutual decision-making, the pressure on healthcare services now is to adapt in harmony with increasing demands for socio-political justice, including equity and civic rights. More and more countries are adjusting their legislation and implementing increased patient participation and person-centred care to strengthen patients' rights, autonomy, and access to various healthcare services. This necessitates partnerships between representatives of the public and other interest groups, so that more perspectives can be highlighted and applied to tailor healthcare to those who need it the most.

The Global Conference on Person-Centred Care 2024 promotes the exchange of knowledge on successful practices for person-centred healthcare, as well as research and innovations in the field. Participation from around the world contributes with a diversity of perspectives to enrich the discussion on how

healthcare can be improved. Thus, different forms of knowledge and modes of inquiry are reflected in the various contributions to this abstract book, such as design, performance, art, and various forms of empirical and theoretical inquiries.

Another purpose of the conference is to bring experts and stakeholders together from different countries to promote collaboration and networking. This will contribute to knowledge dissemination and utilisation, as well to developing standards and guidelines for person-centred care. It also fosters collaborative projects that can benefit both patients and healthcare professionals around the world. By highlighting successful examples and best practices, others can be inspired to implement similar methods and approaches in their own healthcare settings. Ultimately, this may facilitate empathetic, respectful and effective care cultures.

## GPCC patient partners' reflections on the conference theme

As patient representatives, we are delighted to welcome all readers of this abstract book, which captures a variety of pioneering scientific presentations, as well as art and performances featured in the first *Global Conference on Person-Centred Care* in Gothenburg, 13<sup>th</sup>–16<sup>th</sup> May 2024. For almost 15 years, The GPCC has contributed both in Sweden and internationally to disseminating knowledge about person-centred care and the benefits for healthcare, society and individual patients and family carers when they are seen as partners. Since fostering collaborations and gathering a variety of perspectives is important in order to move the field forward, it was a natural next step for the GPCC to host this global conference, including a special session entitled, *Towards the State of the Science*. We are pleased that the GPCC's person council was consulted, and that two patient representatives actively participated in the conference organising committee.

While human society is facing serious challenges worldwide, such as increasing demographic imbalances, widening inequalities and a diversification of threats, there is also much hope rising amongst us patients as we follow the latest research on person-centred care. In fact, we are delighted to see keynote speakers addressing matters such as whole-system approaches, equity for disadvantaged populations, and how to partner with patients and carers to improve healthcare systems worldwide.

Healthcare is constantly changing as research creates new opportunities to cure and treat patients. The development of digital tools has enabled better conditions for communication between patients and healthcare, meaning great opportunities today for good patient participation and partnerships, which creates person-centred care.

Attitudes to various issues in society have changed over time. Younger generations are being brought up to have a more questioning and critical attitude than older generations. Such changes therefore place new demands on the healthcare system because patients can sometimes have a head start on and more information about their illnesses than the healthcare professional.

Everyone's knowledge and experiences are different, which combined is very valuable in healthcare and research. Unfortunately, these resources are rarely exploited. Researchers are happy to initiate projects within their own areas of

interest and that can develop their academic careers. The involvement of patient representatives in research still needs to be improved. In order for the research to be conducted effectively, projects must be based on the demands of patients and users, and the latter must also be included as partners in these projects.

Sixteen different workshops and panels/symposia are being offered at the conference to foster dialogue and interaction on important topics, such as communication, transitions, mental health and also ethics, collaboration and representativeness. We deeply appreciate the high number of abstracts submitted for oral and poster sessions on children and youths, the elderly, co-creation, implementation of person-centred care and tools to measure and assess experiences and outcomes.

Healthcare is currently in a difficult financial situation, which also means limited opportunities to develop person-centred care and patient involvement. The big challenge for the future is to make the concept and meaning of person-centred care known to the general public, healthcare professionals and decision-makers. Increased person-centeredness results in satisfied patients and safer care. We would like to thank everyone who has contributed and submitted abstracts to GCPCC. We hope that this abstract book serves as a catalyst for further dialogue, collaboration and innovation in the field of person-centred care, both now and in the future.

Håkan Hedman, Chair, Swedish Kidney Association  
Margareta Haag, Chair, Swedish Network Against Cancer  
Jana Bergholtz, Patient Co-Researcher, GPCC



# Reflections on the conference theme from an international research perspective

We are delighted to have the opportunity to learn from all of you and build collaborations across disciplines and countries with the final objective of creating the international network to promote, support and propel Person-Centred Care globally.

As we know the world is facing multiple challenges that affect health and healthcare, including levels of poverty increasing, displacement of people from their countries, budget cuts affecting resource allocation to healthcare and many more. All in all, challenging a healthcare that is person-centred. Care that is unique to people as persons, to their own experiences, values, priorities, and preferences; care that recognizes the dignity, autonomy, contextuality and humanity in personal people. The theme Knowledges and Innovations for health in changing societies is of utmost importance in our rapidly changing world, where knowledge and innovation can lead the way through increasing global financial, geopolitical, social and psychological uncertainty.

The *Global Person-centred Care Conference* is the first to bring together a multi-disciplinary cross-sectorial audience across the world. We are privileged to come together as a passionate community of clinicians, researchers, healthcare policy makers, patients, caregivers, and members of our societies sharing a common vision, championing the principles of person-centred care.

We look forward to exchange knowledge, and transformative ideas, learn from each other best practices, it is then when collectively we can propel change, improve outcomes that are important to people and transform healthcare.

Thank you all for your active participation and let's share our commitment to Person-centred Care as a more compassionate and equitable healthcare system. It is therefore a great pleasure to welcome all of you, speakers, and participants who come from all corners of the globe to this transformative conference.

Welcome to Gothenburg!

Maria J. Santana, MPharm, PhD, Cumming School of Medicine,  
University of Calgary, Canada

David Edvardsson, RN, MNurs, MBAC, PhD, School of Nursing & Midwifery  
La Trobe University Australia

Rick Sawatzky, RN, PhD, School of Nursing,  
Trinity Western University, British Columbia, Canada

## Keynote Speaker Contributions

The order of the abstracts for keynotes is according to the order of presentation in the programme.

### Perfect timing to attend a conference on person-centred care!

*Inger Ekman, RN, PhD, Senior professor, FESC, FAAN, University of Gothenburg Centre for Person-Centred Care, and Institute of Health and Care Sciences, University of Gothenburg, Sweden*

The application of person-centred care in clinical trials has yielded positive results, including improved quality of care and reduced costs. As a result, politicians and managers are increasingly promoting the adoption of this approach. However, evidence shows that many patients express lower satisfaction levels with their care. These divergent results prompt professionals to contemplate the fundamental aspects of person-centred care and its optimal execution. The establishment of a collaborative and respectful alliance, rather than a display of authority is essential, but remains difficult due to the prevailing culture within the health care field. The relationship between patients and professionals is one of partnership and collaboration, as they work together to plan and deliver care in a person-centred manner. To ensure improvement of care quality, it is crucial to allocate resources towards patients, enabling them to acquire knowledge and confidence to actively participate as co-producers in care. The implementation of person-centred care also requires stakeholders and managers to empower and motivate health care personnel to acquire knowledge in practicing the ethics of person-centred care. The focus of the debate must shift from the need to implement person-centred care to discussing delivery methods and the components to be included in the package.

*Dr. Inger Ekman is the former director and founder of the University of Gothenburg Centre for Person-Centred Care (GPCC, [www.gpcc.gu.se](http://www.gpcc.gu.se)). Over eight years, she held the position of head of the Institute of Health and Care Sciences. Additionally, she has served as vice dean at the Sahlgrenska Academy, University of Gothenburg. Between 2013 and 2015, she coordinated a 7th FP EU project, resulting in a roadmap for future health care in Europe. From 2016 – 2020, she was the coordinator for COSTCARES, a European initiative focused on evaluating person-centred care, with 28 partner countries. Inger holds the title of Fellow of the American Academy of Nursing (FAAN), in addition to being the recipient of the Sigma Teta Tau*

*European Nursing Recognition Award and the Carl-Axel Palm Research Award. The primary focus of her research has been on controlled studies evaluating interventions for person-centred care. She has approximately 170 publications in scientific journals. Currently, she is the primary investigator in a randomized controlled trial that assesses remote person-centred care in frail elderly.*

## Integrated care, population health management and person-centredness: reflections and experiences from around the world

*Viktoria Stein, Assistant Professor, Department for Public Health and Primary Care at Leiden University Medical Centre, Leiden, the Netherlands*

From the very beginning, integrated care set out to transform care systems and shift the focus from organisations and structures to patients and communities. The IOM (2001) defined patient-centredness as one of the six elements of high quality health care, and the WHO has emphasised the importance of responsiveness, person- and people-centredness and community involvement in several reports over the last 2 decades, starting with the World Health Report 2000. Population health management (PHM) has also been around for some time, but it has garnered new interest in recent years with the rise of big data and predictive modelling. One core principle of PHM is to look at a population as a whole, taking into account how the social determinants of health play out in a specific neighbourhood or area. As such, it is hailed to be inherently person-centred. But when putting theory into practice, the inclusion of people and communities on all levels and in all aspects of care is still far from the norm and often an afterthought. The prevailing culture is still that we do care TO people and not WITH them. This presentation reflects on the reasons why and the failure inherent in our current systems, and wants to provoke the audience into action to finally make person-centredness happen at scale.

*Dr. Viktoria Stein is Assistant Professor at the Department for Public Health and Primary Care at Leiden University Medical Centre and joint editor-in-chief of the International Journal of Integrated Care. She is also the president of the Austrian Public Health Association and core group member of Women in Global Health Austria. Viktoria's recognition as a leading expert in integrated care policy, design and implementation has led to her extensive work as a consultant and expert for international agencies like the World Health Organisation, World Bank, the European Commission, or Accreditation Canada. A special focus throughout her career has been the creation of learning opportunities and environments, which foster knowledge generation and exchange. To this end, Viktoria has promoted the involvement of people, families and communities in every phase of design and implementation of integrated care, as well as on every level of decision making.*

## A whole-systems approach to the development of person-centered services

*Brendan McCormack, D.Phil (Oxon.), BSc (Hons.), FRCN, FEANS, FRCSI, PGCEA, RMN, RGN, FAAN, MAE, Faculty of Medicine and Health, University of Sydney, Australia*

Person-centred care continues to be a dominant focus as the hallmark of a high quality healthcare service. However, despite more than 20 years of developments in person-centred care, including concept and theory development, intervention implementation and evaluation and advances in patient-reported outcomes, it seems that most health systems do not have person-centred systems to sustain person-centred care. Research and development in person-centredness continues to primarily focus on patient experience as a discrete event of care and much of the outcome measurement tends to focus at this level also. A person-centred service goes beyond such narrow perspectives of service delivery and quality systems, and instead aims to understand what it means to have a person-centred service that is person-centred for all persons. Adopting a whole-systems approach to the development of person-centred services Is crucial should we ever achieve the ideal goal of person-centredness for all persons. These issues will be explored in this presentation and a whole-systems methodology proposed for considering the systematic development of person-centredness at all levels of the healthcare system.

*Dr. Brendan McCormack's research focuses on person-centredness with a particular focus on the development of person-centred cultures, practices and processes. He has engaged in this work at all levels from theory development to implementation science and through to instrument design, testing and evaluation. He is methodologically diverse, but is most at home in participatory/ action research. Whilst he has a particular expertise in gerontology and dementia practices, his work has spanned all specialities and is multi-professional. He also has a particular focus on the use of arts and creativity in healthcare research and development. Brendan has more than 600 published outputs, including >300 peer-reviewed publications in international journals and 12 books. Brendan is a Fellow of The European Academy of Nursing Science, Fellow of the Royal College of Nursing, Fellow of the Royal College of Surgeons in Ireland and Fellow of the American Academy of Nursing. In 2014 he was awarded the 'International Nurse Researcher Hall of Fame' by Sigma Theta Tau International. In 2022 Brendan was selected as a member of The Academia Europaea.*

## Fluidity, Relationality and Personhood in African Understanding of Health and Wellbeing

*Elvis Imafidon, PhD, Director of the Centre for Global and Comparative Philosophies, SOAS University of London*

The shift from body-centred to person-centred healthcare discourse acknowledges the importance of personhood in health and wellbeing. But who is a person or what constitutes personhood? Sub-Saharan African philosophies of personhood emphasise the fluid and relational natures of the self in the attainment and sustenance of personhood and wellbeing. Concerning fluidity, personhood and wellbeing are not fixed or static states of being. There is always room for being-better. The fluidity and dynamism depend largely on relationality. Concerning relationality, personhood and wellbeing are co-created and collaboratively achieved by agents in an active and lively community of beings, including humans and non-humans. In this talk, I explore these features of African Philosophies of Personhood and their importance in thinking about person-centred healthcare. The fluidity of the self indicates the fluid realities of health and wellbeing, the non-stable nature of being-healthy. The relationality of the self shows the importance for co-creating wellbeing and health at all levels of engagement as well as the need for a holistic approach to a person's health and wellbeing. I show that these features of African philosophies of personhood are significant for rethinking healthcare services at individual, community and global levels including planetary health.

*Dr. Elvis Imafidon (PhD) lectures in the Department of Religions and Philosophies at the School of Oriental and African Studies (SOAS), University of London. He is also the Director of the Centre for Global and Comparative Philosophies at the same institution and a Research Associate at the African Centre for Epistemology and the Philosophy of Science (ACEPS), University of Johannesburg, South Africa. His background is in the philosophy of difference, philosophy of corporeality, philosophy of healthcare, philosophy of disability, comparative philosophy, ethics, and ontology, primarily from African philosophical perspectives. He has published many articles and essays in reputed journals such as Theoretical Medicine and Bioethics, Nursing Philosophy, Polylog, International Journal of Critical Diversity Studies, Foundations of Science, and the Journal of Human Rights Practice. He is the author and editor of several books including Ontologized Ethics: New Essays in African Meta-ethics (Lexington Books 2014), The Ethics of Subjectivity: Perspectives since the Dawn of Modernity (Palgrave Macmillan 2015), African Philosophy and the Otherness of Albinism: White Skin, Black Race (Routledge 2019), Handbook of African Philosophy of Difference (Springer 2020), Cultural Representations of Albinism in Africa: Narratives of Change (Peter Lang 2022), and Handbook of African Philosophy (Springer 2023).*

## Equity for Sámi Patients Too: Unraveling Paradoxes within a Universal Healthcare System

*Jon Petter A Stoor, PhD, Department of Epidemiology and Global Health, Umeå University, Sweden, and Centre for Sámi Health Research, UiT The Arctic University of Norway, Tromsø, Norway*

Person-centred healthcare systems necessitate an understanding of how Indigenous worldviews and socio-cultural realities influence the health experiences of Indigenous people. The majority of the Indigenous Sámi reside in their traditional northern homelands in Fenno-Scandinavia – Sápmi, and thus grapple with health challenges associated with long distances, inadequate infrastructure, and rurality. While some of these issues can be addressed with sufficient funding and political will, I argue that other challenges are deeply rooted in national norms, practices, and legislation. This will be exemplified from the situation in Sweden. Why are Indigenous Sámi patients still not entitled to healthcare in Sámi language(s), and can we genuinely claim the existence of person-centred care in such a scenario? Furthermore, could the adaptation of care to meet Sámi needs be perceived as conflicting with the principle of equity, foundational to any universal healthcare system? Drawing from experiences, knowledge, and research, I try to highlight the challenges to, and the pathways towards, achieving equitable services, realising person-centred care for Indigenous Sámi, too.

*Stoor (Pikke-Nilsa Ánde Biehtar) is a clinical psychologist turned suicide prevention worker turned public health researcher. He initiated and coordinates the Lávvuo research group, Sweden's first university-based health research milieu focusing on Sámi health, at Umeå University. On behalf of the Sámi parliament in Sweden, and in collaboration with the Agency for Public Health in Sweden, Lávvuo implemented the first nationwide population-based health study among Sámi in Sweden, in spring 2021. Supported by this key resource, Lávvuo strives to reach the aim of supporting Sámi health in Sweden through research and education activities, maintaining a community-driven “nothing for us – without us” principle. Ongoing projects focus on impacts of discrimination on Sámi health, impacts of the Covid-19-pandemic on Indigenous communities, traditional food for healthy aging (with Slow food Sápmi), work-related health in reindeer husbandry (with Sámiid Riikasearvi), support-systems for Sámi women exposed to violence (with Niejda) and Global Indigenous youth health (with Sáminuorra). Still a junior researcher (PhD 2020), Stoor is fortunate to take part in the Lancet commissions on suicide and self-harm, and Arctic health.*

## Patient Reported Outcome Measures (PROMs) and patient centred care: It aint what you do, it's the way that you do it

*Joanne Greenhalgh, PhD, Professor, School of Sociology and Social Policy, University of Leeds, United Kingdom*

In this talk I will examine the relationship between the feedback of Patient Reported Outcome Measures (PROMs) to clinicians and patients and patient centred care. I will briefly review what we understand by 'patient centred care', though this concept probably needs little introduction to the audience of this conference. I'll then introduce PROMs, for those who may be unfamiliar with them. I will outline the ideas and assumptions about how the feedback of PROMs to clinicians and patients are intended to realise patient centred care. I'll also consider some of counter ideas and concerns about these claims and briefly consider sociological literature on power in the clinician-patient relationship. I'll examine the empirical evidence on whether and how PROMs feedback can support patient centred care and situate the findings in the critical data studies literature and the ethics and philosophy of measurement. The moral of this presentation is that it is not whether but how PROMs are implemented and used that shapes whether and how they support patient centred care. As the saying goes, it aint (just) what you do, its (also) the way that you do it.

*Dr. Joanne Greenhalgh is a Professor of Applied Social Research Methodology at the School of Sociology and Social Policy and President [or Past President from October 2023] of the International Society for Quality of Life Research. Her research has focused on exploring how the routine collection of patient reported outcome measures (PROMs) improves patient care. Joanne also has expertise in realist methods and was part of the RAMESES team that developed quality and reporting standards and resources and training materials for realist evaluation.*

## Advancing Person Centered Models of Care in a Value-Based System: What Will It Take?

*Bradi B. Granger, Professor, Duke University School of Nursing, Margolis Institute for Health Policy, Duke University, USA*

Person-centered models of care are defined broadly as the ways in which health services are delivered for individuals and populations experiencing various stages of health and illness. Ideally, care models focus on patients' needs and incorporate the social, environmental, spiritual, and financial resources that a person brings into care planning. The goal being to ensure that people receive "the right care, at the right time, by the right team and in the right place." In US healthcare, a major challenge underpinning person-centered care delivery is the current payment system, which remains largely fee-for-service rather than value-based

reimbursement. These payment models fail to reimburse health care systems or clinicians for longitudinal care, leading to uncoordinated, fragmented, and low-quality care. This session presents a practical framework demonstrating evidence that health care organizations can accomplish person-centered care delivery across diverse settings. This framework was developed in collaboration with the American Heart Association and the Margolis Institute for Health Policy at Duke University. We highlight barriers to implementing measurable, person-centered components of care into clinical practice and provide strategies to overcome those barriers, focusing on strategies that can be implemented across settings, especially low-resource and community-based practices representing broad social, economic, and geographic diversity.

*Dr. Bradi Granger is Director of the Duke Heart Center Nursing Research Program. Her research is focused on health system and health policy support for cardiovascular person-centered care. Specific foci of research include health equity, health behaviors and self-management, medication use in chronic illness, and strategies to facilitate safe care transitions across settings of care, from hospital to home and community-based settings. Dr. Granger has published and lectured extensively, both nationally and internationally, on methods and interventions for person-centered medication management in complex chronic illness. As a mentor to clinicians and students, she has led a number of team-based studies in the field of cardiovascular care resulting in publications and featured work in Journal of the American Medical Association, the American Heart Journal, the Journal of Advanced Nursing, Patient Education and Counseling, the Lancet, the European Journal of Cardiovascular Nursing, and others.*

## The patient's pathway – necessitates a shift of paradigms

*Anders Olauson, Honorary president, European Patients' Forum, the Ågrenska Centre, Sweden*

Having a chronic diagnosis provides the person with a unique perspective and knowledge about the true impact the condition has on your life. Your diagnosis affects all aspects of your life. This perspective is your own, and your involvement is paramount in your rehabilitation, cure and care. We now understand that when a patient can participate in their own health and treatment, it leads to much better outcomes. A holistic view is necessary, which is why all involved partners in the patient's journey through life must cooperate. This means that healthcare, social care, school, insurance, and adult life need to be involved. It is not because healthcare professionals are not trained or skilled enough; it is simply because "it takes one to know one". You, as a patient, possess a unique perspective! Even though we have known this for many years, we still do not apply it in ordinary healthcare. Why? The reason is said to be multiple, but even so, it has to stop now.



*Anders Olauson has extensive and longstanding experience in establishing international and national organization for patient organisations and advocates. He has served as president and board member for the EURORDIS, a non-profit international alliance for rare disease patient organisations and has also served as president for European Patients' Forum (EPF) from 2005 until 2016 when he was appointed Honorary President for EPF. His significant contributions include his participation in the establishment of The Committee for Orphan Medicinal Products at the European Medicine Agency. In Sweden, he was instrumental in the establishment of the Ågrenska Centre, a national centre for rare health conditions, for which he has served as its director and is presently chairman. One of his notable achievements is the founding of The Ågrenska Virtual International Academy, a research centre dedicated to rare conditions. Anders Olauson has received numerous honours, including being appointed a member of ECOSOC within the United Nations in 2005, and the EURORDIS Lifetime Achievement Award. The Swedish government recognized Anders' dedication by appointing him as a member of the Advisory Council at The National Board and Welfare from 2008 to 2014. His commitment was further acknowledged when he received HM The King of Sweden's Medal.*

## Informal carers as partners within person-centred long-term care

*Elizabeth Hanson, PhD, Professor, Research Director, Department of Health and Caring Sciences, Linæus University, Kalmar, and the Swedish Family Care Competence Centre, Sweden*

Globally, informal (family) carers provide most of the care to persons with long-term care (LTC) needs. It is estimated that in the European Union alone, more than 52 million people – 14.4% of the adult population aged 18-74 – provide informal care on a weekly basis, with women providing two thirds of all informal care. The estimated economic value of informal care ranges between €320 and €368 billion per year. The COVID-19 pandemic shed a spotlight on carers' invaluable role, so it would seem self-evident that they are a key partner within person-centred services and systems, alongside the person living with long-term, chronic conditions. Yet, to what extent are carers routinely identified, included, and valued as partners within person-centred policy, research, and practice? I will illustrate a growing research base of partnership working with families and outline how health and LTC policies increasingly recognize the role played by informal carers, referring to the European Care Strategy. However, I will also explain the existing gap between carer friendly research and policy and their implementation within everyday person-centred care practices. I will conclude by arguing for the need to work at multiple levels to nurture care partnerships and to effectively reach out, support and empower carers.

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*Dr. Elizabeth Hanson leads the 'Informal Carers, Care and Caring' research group at Linnaeus University which acts as the research arm of the Swedish Family Care Competence Centre (Nka). Nka is a national centre of excellence on informal (family) care funded by the Swedish Ministry of Health and Social Affairs. Elizabeth acts as expert advisor to the National Board of Health and Welfare Sweden on carers issues. She has a long-standing interest in informal care and over the last twenty-five years Elizabeth has led a variety of national and international projects in partnership with informal carers, patients/service users, health and social care practitioners, decision makers, policy makers and NGOs. The goal being to strengthen the knowledge base and stimulate evidence-based policies and practices for and with carers across the life course. Elizabeth is a board member and prior president of Eurocarers, the European association working for informal carers. She established the Eurocarers Research Working Group whose aim is to feed into the definition of evidence-based policy making on the role and added value of informal carers.*

# Reflections on the abstract contributions

Axel Wolf, Eric Carlström, Hanna Gyllensten, Joakim Öhlén

The concept of Person-Centred Care (PCC) stands in contrast to traditional healthcare models by prioritising co-creation, integrated practice, and the development of both digital and physical infrastructures to help elicit the patient's narrative and support meaningful life. Evaluation of interventions is emphasised in order to tailor care to the capabilities, needs, and values of patients. This paradigm champions a healthcare model that is not only efficient but also upholds ethical standards, with emphasis on respect, autonomy, and dignity within various care contexts and service models. Moreover, PCC has been developed to be applicable from micro to meso and macro levels. All these aspects are reflected in the abstracts for keynotes, workshops, panels/symposia, oral and poster presentations at the GCPCC.

All the contributions published here are of high quality and have been selected through competition. They provide insightful analyses, creativity, innovative thinking, important knowledge, and reveal people's views of living with health, illness and suffering, as well as giving practice views, critical remarks, and a look into the future, and/or utility. The contributions offer a broad overview of current knowledge development regarding person-centred care, its challenges, opportunities, obstacles, applications, and effects in diverse contexts such as health, informal care, healthcare, and societies, both globally and locally.

In line with the conference theme, *Knowledge(s) and Innovations for Health in Changing Societies*, abstracts are related to different types of knowledge and modes of inquiry, including empirical, theoretical, literature-based, practice-based, and art, performance and media work. These types and modes are mostly included in the various topics and for all presentation forms.

In this chapter we comment on and provide brief reflections as related to selected abstract contributions. Please note, these comments are not meant to be comprehensive, but rather exemplify the breadth of the contributions.

All keynote speaker presentations and their respective abstracts are freestanding and found in the previous chapter.

## Workshops, Panel/Symposia and oral presentations

Several of the overarching topics covered in the keynotes and in the oral and poster presentations are also reflected in the workshop and panel/symposia topics. Narrativity in relation to PCC is a focal point in several of the workshops. PCC as a fundamental organisational value in higher education to illuminate learning relationships and culture is explored by a team from the Netherlands. Another

workshop focuses on the practical aspects of using pictorial support in PCC for children and adolescents with communication difficulties, drawing on examples from South Africa and Sweden. Using a framework for non-representation in research, a team from the Picker Institute Europe in the UK facilitates discussions on the impact of underrepresentation in research, addressing barriers and strategies for improvement in representation. The utilization of Open Dialogues to establish a climate of trustworthy conversation is demonstrated and carried out by a non-profit healthcare association, with a focus on elderly individuals.

The panels also cover a variety of topics and contexts crucial to PCC. The first panel showcases research projects that explore how to integrate PCC with information-driven care through advanced data analysis. Additionally, the development, outcomes, applications, and implementation of a novel PCC program designed to assist adolescents with long-term conditions in transitioning from paediatric to adult healthcare services is presented.

Drawing on examples in dementia research, another panel aims to raise awareness about how health literacy can enhance PCC, including the development of a health professional competence profile. Furthermore, insights into communication as it relates to shared decision-making, patient involvement, and partnership in PCC are discussed, based on a series of studies conducted by a team from the Netherlands and Sweden. Health professionals, researchers, and a patient association collaborate to develop strategies, such as the assignment of specially trained nurses, education for healthcare professionals, a rehabilitation process for those with incomplete recovery, and the organisation of care in a more structured manner to meet the needs of patients. These efforts have culminated in the launch of a new national disease-specific guideline, with examples from the healthcare of patients with hyperthyroidism. Additionally, one panel delves into discussions around electronic health models, measurements, and ethics for healthcare innovation in the context of the European Standard for Patient Involvement in Health Care (CEN-EN 17398:2020), and aims to address the challenges of implementing digital health tools within a PCC framework.

Although PCC is a well-known concept adopted by the international community of healthcare providers, implementing it remains a challenge. In an oral session, Hølge-Hazelton and colleagues emphasize the importance of management. Under the heading “How person-centred research supports leadership practice” they raise concerns about the difficulty of transitioning from ‘person-centred moments’ to ‘person-centred cultures’. They propose strategies such as participation in journal clubs, action learning, and the organization of national conferences focusing on person-centred care for ward managers to promote PCC. The authors argue that person-centred values are currently facing challenges and pressure within today’s healthcare systems, making it essential to continue efforts in the PCC process. Nevertheless, there are various national initiatives underway aimed at transforming the healthcare sector towards PCC. Gervind and colleagues present a national initiative in Sweden that introduces diagnosis-specific and person-centred care processes. These processes are being

developed by national groups of medical experts and patient representatives, based on a compilation of medical evidence and patient experiences. Additionally, Elise et al. discuss how the Australian residential aged care sector is currently redesigning its entire system, highlighting the need for a clear and explicit definition of PCC within aged care governing bodies. One valuable tool mentioned is the European standard “Patient involvement in health care – Minimum requirements for person-centred care” (CEN-EN 17398:2020). Waldo et al. demonstrate how the European standard can be effectively utilized to enhance both practice and management towards PCC.

The presentations propose various strategies for implementing PCC in clinics. In the section entitled “Supporting the implementation of person-centred care in healthcare through facilitation: Evaluation of a facilitation training program – acceptability, appropriateness, and feasibility” Lalloo and colleagues advocate for facilitating the transition through a training program designed for healthcare personnel. Initial analysis indicates variations in the acceptability, appropriateness, and feasibility across different healthcare units, while emphasising the critical role of supportive leadership.

The appropriateness of PCC nevertheless varies with the specific care context. For example, contributions addressing informal care and support focus to a high degree on care for elderly relatives or those with dementia. Topics include how the user themselves needs to balance between being capable and passing the ball, how informal carers are positioned in the current healthcare and research narrative, the everyday experiences and support needs of informal caregivers and what support is provided for such caregivers. Support initiatives highlighted include adaptation of tools, insights into the use of online support tools, and a review of tools to mitigate negative health effects among informal caregivers.

Addressing international contexts and global perspectives, Phiri et al. report that health policies in Sub-Saharan Africa are often not effectively implemented, resulting in a policy-implementation gap. Moreover, in a study entitled “How could clinical services respond to the person-centred care needs of adults living with heart failure? – A qualitative cross-sectional study with patients, caregivers, and healthcare professionals in Thailand” Giusti and colleagues stress that although Person-Centred Care (PCC) has grown in high-income countries, there is a lack of comprehensive data exploring this concept in low and middle-income countries.

Another type of challenging healthcare context is clinics dealing with time critical events and emergency care. This part of the healthcare sector is, in contrast to elderly care, psychiatry and family care, less adaptable to PCC. Pavedahl and colleagues report under the heading “Person-centred fundamental care in the emergency room: insights from patient experiences” that such healthcare is characterized by a biomedical focus and reinforces medical-technical and task-oriented aspects. However, they did find that despite being life-threateningly ill, patients were still able to describe their unique needs. Timely and personalized information, and existential needs were identified as essential fundamental care needs which were not or only partly met. Similarly, Tikkanen and colleagues

demonstrate that ambulance care is focused on medical care, whereas interpersonal interaction between patients and ambulance clinicians appeared less prioritized.

Several contributions also examine the development, adaptation, or use of different tools and assessment using more traditional methods from health science research, for example, in assessing patient-reported outcomes and person-centred care. Abstracts included those evaluating tools for either staff or patient perspectives on such services, those focusing on the development or cultural adaptation of measurements, including an observational tool for person-centred care and an item bank of relevant measures, those using PROMs to evaluate health services, and a systematic review of commonly used PROMs in such evaluations.

As can be expected from its role as a social determinant of health and part of the sustainable development goals, health equity is a topic of interest for PCC. Contributions cover how to account for different stakeholder perspectives in healthcare governance, empowering patient involvement for diverse population groups, including children, immigrants and people with life-limiting conditions, supporting staff in incorporating the patient voice in practice, and examining how social determinants of health and equity are represented in current knowledge about person-centred care cost-effectiveness.

It is clear from the contributions on equity, that care for children and youths poses some additional issues. In addition to empowering their equitable participation regardless of language, culture, and disabilities, several contributions also focus on adapting measures and needs assessments to children, along with issues related to informed consent. Immigrant children and marginalised groups are specific groups highlighted within the child group. To address the specific needs of children and youths, several interventions are also proposed, adapted, or evaluated, such as tactile massage, online support, cognitive orientation, a school intervention, and transition programmes from paediatric to adult care. While much focus is on the child or adolescent themselves, several contributions also focus on how to incorporate both child- and parent-perspectives, including several systematic reviews about family-centred care from different perspectives.

Clement et al. and Ventura et al. delve into the integration of PCC in the digital age, focusing on digital counselling services and ethical considerations in digital health interventions. Their insights reveal how digital technologies can augment PCC while also spotlighting the challenges in preserving personal connections and ethical norms within digital healthcare services. As digital health gains traction globally, the maturity of digital health and telemedicine in different countries becomes pivotal. A study by Waiswa et al. from Uganda underscores the essential role of policymakers in endorsing telemedicine nationwide as a foundational element of quality digital healthcare. This effort aims to enhance health equity and ensure continuous healthcare delivery, particularly in response to potential future pandemics.

Leonardsen et al. and Forsgren et al. contribute to the expanding knowledge on person-centredness within digital primary healthcare services and the broader concept of centredness in healthcare research. These studies stress the evolving

comprehension and implementation of PCC in healthcare research, underlining the necessity for further exploration and theoretical refinement.

Emmesjö and colleagues examine the challenges of implementing an integrated mobile home healthcare physician model across divided organisations (regional and municipal). They highlight the need for governance that supports seamless care coordination and caters to patients' unique home-based needs. Transitioning from home to hospital settings, Rabes and Sivanathan explore the journey towards a person-centred workplace culture within a department at a Swiss University Hospital. They illustrate how integrated practice is nurtured through shared leadership and ongoing dialogue, showcasing the importance of collaborative leadership in prioritizing patient needs.

O'Sullivan and colleagues investigate healthcare professionals' experiences of PCC in allogeneic hematopoietic stem cell transplantation settings, emphasizing the significance of PCC education in improving care quality. This aligns with the principle of incorporating patient-reported outcome and experience measures in evaluating interventions, a notion echoed in the context of neonatal care by Wilson et al. Their work underscores the collaborative development of evaluation tools for parents' experiences in the Neonatal Intensive Care Unit, highlighting the impact of incorporating diverse perspectives to enhance tool relevance and effectiveness.

Despite recognising the importance of Patient and Public Involvement (PPI) in healthcare, practices often verge on tokenism, with minimal and merely symbolic patient involvement. Bergholtz and colleagues critique this superficial engagement, advocating for the GPCC model's ethical framework to embed PPI meaningfully at both point of care and organisational levels. This model strives for authentic participation, valuing patients' and family carers' insights through transparent decision-making processes, thereby reducing tokenism in patient and public involvement.

A number of additional abstracts are included that all collectively advance our understanding of PCC, showcasing its diverse applications across global healthcare sectors and providing significant critical remarks. We invite you to explore all these valuable contributions. Please note that the GCPCC conference digital programme includes short video presentations of most of the abstracts included in this volume (<https://gcpcc.org>; choose "programme" in the menu at the top and then "Detailed programme").

### Towards the State of the Science in Person-Centred Care

The knowledge field of person-centred care is extensive and proliferating, and marked by a combination of empirically grounded knowledge and major theoretical frameworks.

With key scholars in the field of person-centred care meeting at the GCPCC, this creates opportunities for taking steps toward summarising the state of science in the knowledge field of person-centred care. The goal is to provide an overview of current knowledge of 'person-centred care in a generic sense' that critically picturises its theoretical and empirically informed advancement so far. The overall

purpose of the initiative is to provide a benchmark to further scientific progress. The theme *Towards the State of Science in Person-Centred Care* spans three conference sessions. The steps formulated at the GCPCC are to be regarded as the first steps, which will undoubtedly need following up, for example, in synthesising knowledge and identifying knowledge gaps.

This theme is framed by broader societal movements with impact on people's health, healthcare and informal care. Brief presentations of influential frameworks of person-centred care provide the starting point:

- Person-centred care with a foundation in ethics, by Professor Inger Ekman from the GPCC, University of Gothenburg, Sweden
- Person-centred practice, by Professor Brendan McCormack, the University of Sydney, Australia
- Person-centred care, by Professor Maria J Santana, University of Calgary, Canada
- Integrated person-centred care, by Assistant Professor Viktoria Stein, Leiden University Medical Centre, the Netherlands

This is complemented by five literature reviews with different foci as related to PCC. Finally, group discussions aim to sum up, analyse and critique the state of PCC pertaining to core theoretical foundations, and modes and strategies for translating PCC into practice. Based on the discussions in these special sessions, a report will later on be published.



## Workshops & Panels/Symposia

The order of the abstracts is according to the order of presentation in the programme, which means that abstracts for workshops and panels/symposia are mixed.

### Person-centred care and information driven care: finding common ground. ID 152

*Elin Siira, Halmstad University; Jens Nygren, Halmstad University; Petra Svedberg, Halmstad University; Axel Wolf, University of Gothenburg*

Person-centred care (PCC) encompasses the holistic consideration of each patient as an unique individual, accounting for their unique abilities, needs, and social and cultural backgrounds in all parts of the care process (1-4). Widely regarded as the pinnacle of care provision, PCC is deemed essential to be incorporated into all facets of healthcare (5). Information-driven care (IDC) signifies an approach to healthcare wherein decisions, workflow, and organizational processes related to patient care are significantly influenced by the application of information derived from advanced data analysis. IDC integrates artificial intelligence (AI) and systematic data collection and utilization to inform and enhance healthcare service delivery (6). At times, the pursuit of PCC and IDC may appear incompatible or even at odds in their nature, presenting challenges for their harmonious integration within contemporary healthcare systems (7). For instance, AI has been suggested to challenge the trust in the doctor-patient relationship (8, 9), which is crucial to PCC. However, research also suggests that AI can enhance aspects of PCC, such as personalization and shared decision making, thereby supporting PCC (7). To date, the integration of PCC and IDC in healthcare is still in its early stages, leaving numerous unresolved queries on how to do so effectively. The aim of this symposium is to promote interdisciplinary knowledge sharing among researchers from two specialised Swedish research centres focusing on PCC and IDC. Specifically, the Centre for Person-centred Care (GPCC) at the University of Gothenburg and the Information driven care research program at Halmstad University. Representatives from both centres will showcase research projects, offering the audience an in-depth insight into the latest developments in PCC and IDC and explore potential avenues for seamlessly integrating these two approaches within the healthcare sector.

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Let us tell you a story and invite you to refurbish our  
home: Improving person-centred educational practice ID  
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*Cis Lijten, Fontys University of Applied Sciences; Amy Otto, Fontys University of Applied Sciences; Esther van den Hende-Wijnands, Fontys University of Applied Sciences*

Background: Developing person-centered healthcare should be a whole system endeavour including all (care, educational and collegial) relationships, structures and processes (Cook et al., 2022). At Fontys University of Applied Sciences we aim to educate self-aware and entrepreneurial professionals with and for healthcare organisations in Southern Netherlands through the generation, sharing and application of high-quality knowledge. We view the context of care and well-being as being highly complex and continuously changing and feel that future professionals need to be prepared to interact flexibly and proactively with these contexts. Person-centredness has been a core organisational value for some time, although its application has primarily been limited to person-centred care. As a partner in the development of the person-centered curriculum (PCC) framework we are undergoing an enlightenment journey into how person-centredness also ‘colours’ the way we educate future practitioners (Van Aalst et al., z.d.). The extensive and holistic view of a curriculum is particularly relevant for the Ba Nursing programme where students spend 50% of their time learning within practice. Working with the framework is starting to help educators within university and practice settings explore the meaning of person-centredness for their learning relationships and culture. Aim: For this workshop, we collected various stakeholders' experiences and perceptions of person-centeredness within our Bachelor of Nursing curriculum. The data was used to construct a multi-stakeholder narrative reflecting student, educator and leader perspectives within the university and the practice settings. Inviting participants to use the narrative

content to formulate improvement actions and map them onto the PCC framework, we hope to enable active and meaningful engagement with a theoretical framework. Our intended audience are healthcare professionals, educators, students and leaders. Workshop outline: 1. A theatrical presentation of the current narrative. 2. ‘Refurbishing the Fontys house’: gathering improvement insights and suggestions. 3. Sum-up: mapping improvement onto the PCC-7S-model.

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## Improving Transition and Transfer: Person-Centered Care for Adolescents with Long-Term Conditions – The Stepstones Project Experience. ID 057

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Young people with long-term conditions represent a growing group of the population due to recent decades advancements in treatment of life-threatening conditions. Nevertheless, the integration between pediatric and adult care has been deficient, creating the potential for adverse events that can compromise the well-being of young people. Transition programs have been proposed to prevent these adverse events and improve quality of care and patients experience of care. However, the implementation of person-centered transitional care remains, on a broad scale, scarce. The aim of this symposium is to describe the development, outcome, application, and implementation of a person-centered transitional care program for adolescents with long-term conditions. The symposium will include: Theme 1 Closing the Healthcare Gap for Adolescents with Long-Term Conditions: Transforming Transitional Care – the Stepstones project. This theme will give a background to the healthcare problem from adolescents, care providers, and stakeholders perspectives. We will present how the Stepstones transition program was developed using patient and stakeholder involvement, and share a summary of results from the Stepstones project. Theme 2 Practical applications of the Stepstones transition program? The second theme will highlight practical

applications to promote person-centered care in encounters with adolescents following the experiences from the Stepstones project. Different strategies, tools and outcomes reflecting the cornerstones in person-centered care will be presented. Theme 3 Evolution and Expansion: Implementing the Stepstones Transition Program for Enhanced Transitional Care across Diverse Settings. The final theme will discuss the remaining challenges and opportunities to implement transition programs as well as introducing the program to other target groups and adaptation to a digital delivery. The symposium will end with a 10-minute panel discussion where we will invite patient representatives, researchers and clinicians, and the audience to participate.

### Pictorial support as a tool to enable participation and person-centered care for children and adolescents with communication difficulties ID 120

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Many children and adolescents have difficulties to understand and/or express themselves during health care situations, most often caused by problems with language and culture, cognitive maturity and different types of disabilities or the medical or psychological conditions hindering communication. This means that person-centered care, building on the patient's own story and the communication between the child and the caregiver is challenged. Research and practical experiences show that most often health care professionals tend to turn to the parents expecting them to act as interpreters (Thunberg et al., 2015). Sometimes this is necessary, but the research and practical experience from our work with different types of supportive strategies, mainly based on pictures, show that these can enable the voices of children, sometimes with severe communication problems, to be heard (Thunberg et al., 2015; 2022). During this mainly practically oriented workshop we will show videoclips and examples from research and practice in Sweden and South Africa, and then enable participants to design a pictorial support of their own using their phone and the free web tool [www.bildstod.se](http://www.bildstod.se).

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## Person-Centered Mental Healthcare: Exploring the present state, looking forward. ID 059

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Person-centered care has revolutionized healthcare, yielding significant results in various medical fields. While these principles align well with mental health needs, research in this area has been limited in comparison to other fields. In recent years, there has been progress in narrowing the gap - a shift welcomed by NGOs which have long advocated for a person-centered approach that prioritizes what matters most to the individual and focuses less on organizational aspects. This symposium offers an up-to-date overview of mental health research and practice in Sweden, showcasing person-centered approaches from diverse disciplines. The panel includes representatives from NGOs, GPCC's Person Council, healthcare professionals, and researchers, and aims to discuss co-creating person-centered mental healthcare across multiple contexts. Examples of topics: What research has been conducted in this field? What sets person-centered mental healthcare apart, if anything? What key considerations are there when constructing person-centered mental healthcare? Are there specific areas within mental health where person-centered care might be less appropriate or effective? How does GPCC's research progress compare to international research and achievements? What lies ahead for the future of person-centered mental healthcare?

## Person centred care for all: understanding and improving the representativeness of health services and research ID 122

*Chris Graham, Picker Institute Europe; Jenny King, Picker Institute Europe; Amy Tallett, Picker Institute Europe*

This workshop will provide attendees with a framework for improving the representativeness of person centred care research. Person centred care research frequently involves the collection of patient and public views. This may be quantitative (eg patient experience surveys) or qualitative (eg ethnography). Typically the focus is on understanding the needs, preferences, and experiences of

people who use health and care. There is a growing focus on issues of equality, diversity, and inclusion. Despite this, person centred research often addresses only limited barriers to representativeness, which can lead to a superficial interpretation of representation, undermining efforts to understand equality and equity. We propose a framework of non-representation in research that identifies five causes for users to address: Non-access - groups are excluded because of their inability or unwillingness to access care services. Non-invitation - groups are excluded in selection, often for practical reasons. Non-response - groups are systematically less likely to respond to requests to participate. Non-identification - research fails to identify people from different communities. Non-review - data is not analysed according to available diversity markers, or issues important to certain communities are not considered. Workshop content: CG to explain the framework, with clear examples and discussion of the impact of underrepresentation - 20 minutes. CG, JK and AT to facilitate group discussions of two case study projects - one quantitative and one qualitative - to analyse barriers to representation and identify improvements - 30 minutes. We will use paper templates, pens, and post-its to record the discussion. Reconvene to one group providing feedback in a plenary discussion led by CG - 10 minutes. For inclusivity and to support participation, plain English will be used throughout. Following the event we will - with consent - e-mail participants the workshop content including presentation, case studies and analysis conducted in the groups.

## What is the cost-effectiveness of person-centred care? ID 192

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Issue: In the symposium we will focus on how to evaluate the cost-effectiveness of person-centred care (PCC). An ongoing systematic review explored the current evidence, and research groups from GPCC have conducted a sizeable proportion of all such studies. Although most studies have shown PCC to be cost-effective, we also identify several limitations in the current knowledge, potentially limiting its usefulness for decision-making. An example is the lack of process evaluations exploring studies where PCC interventions were found to be dominated by care as usual, and the lack of clarity on how the intervention differed from its comparator. Aim: That the audience become familiar with the current state of the evidence for cost-effectiveness of PCC and can assess the role for future such economic evaluations in decision-making. The discussion will explore opportunities and pitfalls in conducting such studies. Outline: Short introduction to priorities in

healthcare and the role of health economics in decision-making. A 5-minute presentations from each participant will be followed by a moderator-led discussion about how to develop future high quality economic evaluations of PCC. This will explore the most pressing issues for decision-makers, where the audience will have the opportunity to pose questions. Participants: Moderator and patient-representative: JB. SP: set the GPCC literature in perspective to the international literature. LP: presenting the evidence from the early GPCC-projects single study economic evaluations. HG: presenting the evidence from studies exploring implementation cost for PCC. BH: presenting an overview of (core) outcomes for economic evaluation of PCC. JJ: provide perspective on economic evaluations of healthcare programmes and health economics. Materials: Audience should bring phones or laptops to be able to post questions to the moderator.

### Open Dialogues - a case study ID 113

*Inger Blennox, Eldrekraft; Lars Engkvist, Eldrekraft; Christina Bäckblom Fahlén, Eldrekraft; Birgitta Schill, Eldrekraft; Yvonne Wallberg Andersson, Eldrekraft*

In Open Dialogues, one actively tries to create a climate of conversation where time is given for everyone to express what is important to them, while others listen without evaluating what they heard. If the reflections then take their point of departure from what has been said, the participants will perceive that they are respected and taken seriously. The possibilities of creating new and useful sentences increase when several perspectives are allowed to emerge. In this type of open conversation, there are a number of considerations regarding ethical stance, who can be invited, introduction, interview and reflection patterns, evaluation and organizational conditions. Inspiration has been taken from the following sources: Andersen (2007), Seikkula (2011), White (2007). In a workshop, we will present how Open Dialogues can be used. A former patient will be interviewed and the different steps of the method will be demonstrated. Participants will be invited to participate in an outsider-witness-group (White, 2007). Maximum number of participants 40 people.

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Health literacy a factor to consider in person-centered care for older people: the Skills 4 Health Literacy competency profile and training regarding health literacy for care and social care personnel who work with people with or at risk of dementia. ID 110

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Health literacy (HL) is an important factor to consider in health promotion, disease prevention, and health care to be able to work in a person-centered way. Personal HL is about individuals' abilities to access, understand, appraise, and apply health information in ways that maintain or improve quality of life. Organizational HL is the enabling work of health organizations and providers make sure that people can find, understand, and use health information and services to manage decisions and manage health for themselves and others. The overall aim of the symposium is to increase awareness of how HL strengthens people-centered care. Results will be presented from the dementia-related Skills 4 Health Literacy project supported by ERASMUS+. This project aims to increase the health literacy capacity of health and social care professionals working with people with dementia and their families. The symposium will consist of four sections: 1) An overview of HL, and its importance, on both individual and organizational levels, and how HL links to person-centered care. 2) A presentation of results from a mapping of knowledge and competence related to HL among health- and social care professionals working with people at risk of dementia. Moreover, a competency profile for health and social care professionals focusing on HL and people living with risk of dementia, based on the results from the mapping, will be presented. 3) Presentation of three different forms of trainings (classroom, online and open online) targeting HL and dementia for health- and social care professionals working with people at risk of dementia. All trainings are based on the competency profile and have been pilot-tested in Nordic countries (Sweden, Denmark, and Finland). 4) An open dialogue between the presenters and the audience about the link between health literacy and person-centered care.



Implementing Person Centred Care for people with Long Term Conditions (LTCs) across health systems and cultures: Learning from experience with Personalised Care and Support Planning (PCSP) in the UK and Singapore. ID 049

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Theme: Supporting people with Long Term Conditions (LTCs) not only to manage their health, but to live their best lives is a huge global health challenge. Context: Personalised Care and Support Planning (PCSP) is the principle clinical method for delivering person-centred care for LTCs the UK. It is part of the Realistic Medicine programme in Scotland (2016)<sup>1</sup> and Personalised Care in England (2019)<sup>2</sup>. Year of Care Partnerships (YoCP) have developed and delivered PCSP training and implementation in health communities in England and Scotland since 2011<sup>3</sup>. Around 1:6 general practices in Scotland use this approach for people living with single and multiple LTCs. The National University Health Systems Cluster in Singapore have adapted and adopted PCSP for specialist clinics (2018) and polyclinics (2019) for people with diabetes. Impact: The YoCP approach to PCSP is robust and effective in diverse cultures within and across all three nations. It delivers person-centred care, promotes system changes that enable more equal partnerships between people with LTCs and healthcare professionals, provides greater enablement and self-efficacy, and improves health outcomes. Workshop: Participants will: Explore the values-base, clinical, economic and whole system benefits of PCSP, and case studies of impact. Engage in exercises derived from personal experience to understand the rationale for PCSP, explore the underpinning philosophical approaches and be able to relate these to clinical practice. Be introduced to the YoCP consultation model for PCSP. Reflect upon the core system components and skills of successful PCSP. Have the opportunity to test how these approaches can be applied in their own health setting.

## More than words – Communication and person-centred care ID 140

*Annelie J Sundler, University of Borås; Sandra van Dulmen, Nivel (Netherlands institute for health services research) & Radboud university medical center, the Netherlands, University of Borås, Sweden; Lena Hedén, University of Borås; Ida Kleye, University of Borås; Tanja Gustafsson, University of Borås; Elin Blanck, University of Gothenburg, Centre for Person-Centred Care (GPCC) & University of Borås*

Person-centred care places the person in the centre. To treat patients as persons is a complex and ongoing process that requires communication efforts to acknowledge patients' experiences and involvement in healthcare. Given that the notions of person-centeredness and patient involvement are pivotal to respond to the needs and preferences of patients, the overall aim of this symposium is to give in-depth insights from our research on communication and person-centred care for patients in different ages and healthcare practices. We will further discuss the contribution and importance of communication to person-centred care, shared decision-making, and patient involvement. Mind your words (van Dulmen). Communication behaviors can have both positive effects on patient outcomes and be perceived as harmful. As shown in several studies, strengthening beneficial and preventing adverse effects of communication requires a person-centered and tailored approach. Child involvement and emotional communication during needle procedures (Kleye). The way in which nurses communicate with children during needle procedures can really make a difference. Our observational study shows that when children's own preferences and strategies is taken into account, fear and pain can be handled in a better way. Empathic opportunities when caring for older persons (Gustavsson). Our research shows that communication with older patients about their emotional distress depends on seizing empathic opportunities. This asks for caution and attention by professionals to emotional cues and concerns. Partnership and accountability (Blanck). Partnership as observed in patient-nurse interactions will be discussed in terms of social, cognitive, and moral accountability, and its impact on the formation of partnership as a joint interactional achievement.

## Narrative matter? The role of narrative and relational communication in person-centred care for older persons living with frailty. ID 214

*Staffan Josephsson, Karolinska Institutet; Linda Timm, Karolinska Institutet; Joakim Öhlén, Göteborgs Universitet; Maria Lindström, Umeå Universitet*

The aim of this workshop is to identify core concepts and reasoning on the potentials of narrative and relational communication in person-centred practice for older persons living with frailty. Particular focus will be on emotional and

relational resources of older persons in this matter. Rationale: Narrative and relational communication is a cornerstone in person-centred practices. Further these forms of communication have been identified as central in supporting influence and everyday democracy involving the older person with frailty. However how narrative modes of communication function as resources for person-centredness in practices involving older persons living with frailty remains inadequately known. Therefore, there is a need to gather and synthesize experiences from scientists and practitioners and other stakeholders in this matter. Potential outcomes for participants: Participants will have opportunity to discuss and problematize current discourses within person-centered care. Particularly role and functioning of narrative and relational communication in achieving central values such as wellbeing, individual and social agency, and everyday democracy will be discussed. Further participants will discuss how emotional and relational resources of older persons living with frailty can be an asset in caring practices. Relevance to conference theme: This workshop has ambition to challenge practices on narrative and relational communication within health and social care for older persons living with frailty and discuss ways these modes of communication can stay relevant in meeting future challenges and needs within person-centered care.

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## Workshop about Person-Centred Care and Pharmaceutical Care ID 195

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Subject: Health systems in many countries are currently undergoing an evolution towards more person-centred care. However, there is little or no guidance available on how to apply person-centred care to pharmaceutical care and clinical pharmacy practice. In this workshop we will describe how pharmaceutical care can become more person-centred and explore how this can be used in the clinical work settings of outpatient and inpatient pharmacists. Outline: First, a presentation about

person-centredness and the current evidence on its use in pharmaceutical care, including findings from a systematic review (10 min). Thereafter, participants will be divided in groups based on their clinical settings or interests. Groups will discuss the following questions (40 min), based on their own experiences from clinical practice: How can pharmacists put person-centered care into practice? What do pharmacists need to practice person-centered pharmaceutical care, in particular for initiating, working, and safeguarding the partnership with the patient? As appropriate, how can pharmacists change their practice? Time for summarising and discussion between groups will be offered at the end of the workshop (10 min). Output: The intent is to incorporate findings (anonymised) from this workshop in a publication (opinion paper or popular science format), all participants will be asked about their interest to collaborate on that during the workshop. Materials: Participants will work on the questions above in small groups and publish their ideas on an interactive tool like Padlet®. Hence, participants are required to bring a computer, tablet, or smartphone with them.

Collaboration between patients, patient organisations and healthcare professionals achieve more for the care of patients with thyroid disease than each of them can achieve on their own ID 193

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Background: Views on health care differ from the perspective of health professionals, patients, and patient organisations. The overall vision of the organisations is common, but in practice they operate in different realities. A mutual understanding of the narrative context will improve collaboration and benefit patient care. Seminar outline: The Swedish Knowledge Organisation aims to harmonise care by national guidelines, where patients' perspective is included.

Within the area of hyperthyroidism this work resulted in a national guideline where 4 of 5 news were non-medical, but created from the patients' needs. HFN highlights the process that patient involvement brought to the national guidelines. CL presents the patients' perspective. In addition to updated medical procedures, we judge that what would improve care outcomes the most was a thyroid nurse, education of health care professionals, a rehabilitation process for those with incomplete recovery, and organising care in a clearer tiered structure so that patients with different levels of disease complexity meet the right expertise. Working with some patients became a catalyst for working with the patient organisation. They created a council of healthcare professionals, and we included them in the university training programme for future thyroid nurses. Together, we held a seminar for the Swedish Parliament to raise awareness of the unmet needs of thyroid patients in our country, where healthcare is mostly tax-funded. KN features the work of the patient organisation and bilateral benefits, and AB discusses rights and opportunities for patients with disabilities. AL leads the discussion to highlight how cooperation can be implemented as effectively as possible; what needs cooperation and what requires us to act as separate entities to achieve the greatest mutual benefit. Conclusions: Together, we can go beyond what each of us can do. This includes new values in healthcare aimed at personcentred care based on patients' needs.

### Person-centered care in the digital era: models, measurements, and ethics ID 201

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Electronic health (eHealth) solutions have become a critical area of focus in healthcare innovation, with their relevance depending on the contribution to improving health outcomes, while being respectful of the person's values and preferences, trustworthy for both clinicians and the person, and sustainable to the healthcare system. Departing from the ethics of person-centred care, the symposium will entail five presentations covering use-cases of digitalisation in healthcare, including Artificial Intelligence (AI), and discuss them in relation to the European Standard for Patient Involvement in Health Care (CEN/TC450). Stefan Nilsson will present PicPecc, which is a collaborative initiative that provides a user-

friendly digital toolkit for paediatric symptom management. Sabine Valenta will focus her presentation on the implementation and evaluation of eHealth supported integrated care models (eICMs) with a focus on stakeholder engagement and user-centred design approach. John Chaplin will describe the PROMIS ® Patient-Reported Outcomes Measurement Information System and its potential use to increase person centred care. With clinical decision-making being supported by AI tools, Carina Dantas will discuss the need for holistic models to analyse ethical challenges and address them iteratively as they emerge, ensuring inclusion, equality in access and ethical AI. Although most digital health projects claim to be person-centred, not all are designed and implemented in close collaboration with patients. Souzi Makri will give voice to the patient experience with digital health interventions, and to the importance of public and patient involvement as early in the co-design process as possible. The symposium will take 60 minutes (i.e., 10 minutes for each presenter, plus 10 minutes discussion). The discussion will seek to unravel the challenges of implementing digital health tools in a person-centred care pathway, including trust, transparency and user engagement with digital tools, and their contribution to shared goal-setting and decision-making aiming at the persons' good life.

### How can design foster conversations on person-centred care? ID 216

*Ulises Navarro Aguiar, HDK-Valand Academy of Art and Design, University of Gothenburg; Samantha Hookway, HDK-Valand Academy of Art and Design, University of Gothenburg*

Person-centred care (PCC) is a perspective that aims to re-humanise care within healthcare systems that have progressively been burdened by institutional complexities, political demands, and weakened public financing. Human-centred design (HCD), with its range of methods and practices, has emerged as an important generative tool in the implementation of PCC, prompting in recent years a rapprochement between design and healthcare disciplines. HCD promises to mobilise designerly empathy and imagination to articulate and address human needs. However, HCD is no panacea, and its application must be undergirded by a participatory ethos that rejects tokenistic or lazy uses of empathy that reduce people being cared for to a list of needs. In the field of design, HCD has been criticised for its overemphasis on problem solving and shallow conceptualisation of empathy. What if, rather than problem solving, design is used to open conversations? What if, rather than taking them for granted, notions of “care” and “need” are jointly defined in conversation by all parties concerned? How can design help such conversations? This workshop aims to cut through HCD hype and engage participants in an exploration that elicits the heart of PCC, communication between the cared for and the cared by. The subject matter of the workshop will be “conversation starting” and the interactive component will

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consist of a hands-on activity in which participants will be tasked with making “conversation pieces” from a playful and designerly point of view. That is, this activity will depart from the tendency within design to provoke conversations using the production of materialisations, artefacts, and experiences – often for exhibition purposes. Participants will have the opportunity to collaboratively explore formgiving with run-of-the-mill materials (paper, pens, markers, sticks, tape, and other supplies) to evoke conversations together and coproduce “conversation pieces” ready for display. The workshop will end with a small-scale participant exhibition. The workshop will be structured as follows: introductory presentation (10 min), guided hands-on activity (35 min), mini-exhibition (15 min). Both workshop organisers will play the roles of presenters and facilitators.

## Oral Sessions

The order of the abstracts for oral sessions is organised into topics.

### Children and Youth

#### Understanding and improving person-centred care for children and young people ID 251

*Amy Tallett, Picker Institute Europe*

Background: Person-centred care is vital to delivering high quality care that focuses on the recipient's needs and preferences. Person-centred care measurement is needed to understand improvement priorities. There are perceived challenges with understanding person-centred care in children and young people relating to ethics, variations in development and communication abilities, in addition to challenges regarding any symptoms and treatment. Approach: When seeking feedback about children's healthcare, it is important to consider the views of both the patient/child and their parents/carers. Evidence suggest views may differ, so it is important to gather both perspectives<sup>1</sup>. Surveys are widely used to gather feedback from patients. Those for children and young people should be developed in collaboration with them to ensure they are appropriate in terms of: Design – materials should be engaging. Wording and terminology – language should be comprehensible to a younger audience. Topic – we should ask about things that matter to them. Cognitive testing<sup>2</sup> of surveys ensures people interpret questions as intended, and a pilot can trial the data collection methods. Examples: We have developed several survey programmes in England to gather feedback from children and their parents/carers on care experiences, including: The Under 16 Cancer Patient Experience Survey on behalf of NHS England. The Children and Young People's Patient Experience Survey on behalf of the Care Quality Commission – focussing on hospital inpatient and day care. Insight from these surveys is used by care providers and commissioners to understand and improve person-centred care.

#### Person-centredness in paediatric nursing – The parents' perspective ID 146

*Christine Siller, Paracelsus Medical University, University Hospital Salzburg*

Background: In the literature on person-centred care, it is explicitly emphasized that it is not only about the person directly receiving care, but also about his or her environment and that relationships between all persons involved in the care



process are of great importance. However, it remains unclear what constitutes a person-centred view on relatives and in which concrete principles this manifests itself. Since parents play a central role in the care of children, this is particularly evident in this field. Objective: The aim was to identify aspects of the role of parents of hospitalized children and to gain insights into what it means for them to feel perceived as a person in this situation in order to derive principles of person-centred care in the sense of a holistic view on the parent-child dyad. Method: A qualitative study was conducted. Parents of hospitalised children in an Austrian Hospital were interviewed, single or with their partner. Data were analysed qualitative content analysis. Results: Parents have to balance everyday life within and outside the hospital by taking on various roles. Inside they focus on their child as coordinators, experts and advocates for their child and try to keep on being a family in the hospital. They also maintain family life at home and keep on their own professional role. Parents want also to be perceived as persons with individual needs, values and relationships. They want to live a self-determined life in hospital and value appropriate information and communication. Conclusion: From the results, first principles for person-centred care with focus on parents as part of the care arrangement were derived. Although these should be elaborated by further studies, they can inform nursing trainings, guidelines for person-centredness in paediatric care and instruments to evaluate the perception of person-centred care from a parents' perspective.

### What Matters Most to Young Immigrants Living with Mental Health Concerns: A Community Priority Setting in Alberta, Canada ID 224

*Farva Naqvi, University Of Calgary; Maria Jose Santana, University Of Calgary*

Introduction/background: Frequent studies have indicated that numerous mental health (MH) issues develop during an early age, and they can evolve into mental disorders. These disorders affect about 1 in 4 Canadian youth. Youth make up 19.2% of the Canadian population. Even more so according to Stats Canada (2016), 37.5% of these Canadian youth belong to immigrant families. With an immigrant identity, the experience of displacement, trauma, stigma, and racism can be rampant within this community. Methods: A qualitative patient-oriented research project that identifies priorities of immigrant youth living with MH concerns in Alberta, Canada. Young Immigrants aged 15 to 25 years old were recruited. We collected questions related to what matters to their MH. Then, these questions were thematically combined and then posed via focus groups to garner their MH priorities. EDI: The youth self-identified as immigrants. We had a diversity in age group, racial/ ethnic background, language, and mental health experiences. This entire study was conducted based on the notion to be inclusive to immigrant youth voices, garner mental health experiences with diverse participants, and have an equitable platform to reach out to this underserved

cohort. Results and analysis: Thirteen focus groups with urban and rural Albertans as well as after conducting a Nominal Group Technique, the most chosen questions ranked by the youth included: how MH can be improved, how MH affects education and job opportunities, stigma and how to deal with worsening MH challenges were prioritized. Conclusions: The outcome of this study will be beneficial for policy makers and health decision makers to understand what the MH needs are of immigrant youth. The results of this study can also foster more education on cultural competency and create specified mental health supports for immigrant youth.

### Children with long-term health conditions: preferences for digital and in persons support and involvement in their own care ID 010

*Stefan Nilsson, Institute of Health and Care Sciences, and Centre for Person-Centred Care, University of Gothenburg, Sweden, and The Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Sweden; Diana Swolin-Eide, Department of Paediatrics, Institute for Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden, The Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Sweden; Malin Berghammer, The Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Sweden*

A long-term health condition (LTHC) affects everyday life for most children and can lead to negative effects on these children's perception of life and on their health and well-being. When healthcare professionals use a person-centered approach, it makes it easier for them to support children with their individual needs. This can be applied in digital and in person support in health care, but knowledge is scarce about what type of support children would prefer. The aim of this study was first to describe how children with a LTHC experienced digital and in person support as part of their care, second, what type of information they needed and to what extent they considered themselves to be participants in their own care. Twelve children between 10 and 17 years old participated in the study. A qualitative descriptive method was used, with children interviewed either individually or together with a caregiver, with qualitative manifest content analysis. Two categories emerged from the analysis, "Support and involvement in one's own health care" and "Receiving information in different ways". Children with a LTHC need information and support that focuses on their own needs. This type of support must be based on both professional and peer-to-peer support.

Help Overcoming Pain Early (HOPE), a brief person-centred intervention in a school setting for adolescents, may improve symptoms of insomnia ID 171

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**Introduction and Objectives:** Insomnia symptoms are prevalent among adolescents experiencing chronic pain, underscoring the critical need for early intervention. This study aimed to evaluate the secondary effects of the Help Overcoming Pain Early (HOPE) intervention on insomnia symptoms and self-rated health. **Methods:** This study utilized aggregated data from a prior randomized controlled trial, including both the active and control groups, where the control group later received the HOPE intervention. Symptoms of insomnia were evaluated using the Minimal Insomnia Symptom Scale, while self-rated health was assessed with a single item at three time points: at the outset of the intervention, post-intervention, and at a six-month follow-up. Baseline variables encompassed age, gender, pain location, pain's impact, school attendance, and symptoms of depression (measured via the Center for Epidemiological Studies Depression Scale for Children). Linear Mixed Models (LMM) were employed for inferential analysis, and Cohen's *d* was calculated to gauge effect sizes. **Results:** Statistically significant enhancements in insomnia symptoms emerged at the six-month follow-up, along with significant improvements in self-rated health both at the intervention's conclusion and the six-month follow-up. Despite statistical significance, effect sizes remained small for all outcomes and assessment points. **Discussion and Conclusion:** This study demonstrated modest yet statistically significant improvements in insomnia symptoms and self-rated health among adolescents grappling with chronic pain after undergoing the HOPE intervention. While the need for cautious interpretation of these findings persists, they underscore the potential value of a concise, easily accessible early intervention within a school-based context.

## Comprehensive and Integrated Care

Quality of care in nursing homes from the resident's perspective: How Connecting Conversations went from theory to practice ID 245

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Introduction: Person- and relationship centered care acknowledge the important of residents, relatives, and professional caregivers' voices, regarding how they experience quality of care in nursing homes. Narrative methods provide a good foundation for this, as they allow respondents to tell their own stories, which provide rich information for quality improvements. We present the impact that the narrative method, Connecting Conversations, has achieved since 2017. Methods: Connecting Conversations is a narrative method that assesses experienced quality of care in nursing homes from the resident's perspective by having separate conversations with a resident, relative and professional caregiver. It has been developed in co-creation with residents, relatives, care professionals and policy makers. Connecting Conversations is founded on four theoretical pillars: INDEXQUAL (experienced quality of care), relationship-centered care, appreciative inquiry and collaborative learning. It consists of two trainings: one for interviewers to perform the conversations and one for coordinators to implement and facilitate the process of using the method. Results: To date, six studies have been completed on the development, feasibility, validity and implementation of Connecting Conversations. More than 70 interviewers have been certified and hundreds of conversations have been performed in 14 long-term care organizations. The method has been shown to be feasible, valid and valuable. Five key conditions for implementation are coordination, ownership, communication, flexibility and external support. Connecting Conversations has contributed to changes in quality assessments and policy in Dutch nursing homes and it has helped to improve experienced quality of care for residents. Conclusion: Stories from multiple perspectives provide valuable information for quality improvement as they facilitate a rich understanding, reflection, and learning. Yet, in order to use methods such as Connecting Conversations to their full potential, care

organizations need to be supported in how to implement them into their organizational structures and how to use stories for quality improvements.

## Person-centred care and the work-related health and job satisfaction of healthcare professionals: A continuation of the PCC@work project ID 062

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Background: The interplay of ethical stress, heavy workloads, and job dissatisfaction can hinder the recruitment and retention of healthcare professionals (HCPs). Person-Centred Care (PCC), rooted in ethical principles, involves collaborative care and is associated with the challenges. Prior research in the PCC@work project on the impact of PCC on HCPs' work-related health and job satisfaction has yielded mixed results<sup>1</sup>. Our cross-sectional study found significant associations<sup>2</sup> and our qualitative study review suggest improved job satisfaction and role changes<sup>3</sup>. Neither provide tangible solutions to recruitment and retention challenges. Understanding how the application of PCC influences HCPs across different settings requires further exploration through rigorous methodology. Aim: The overall aim of PCC@Work is to follow, describe and assess the impact of applying PCC in hospital, municipality and regional primary care on work-related health and job satisfaction among HCPs, and to explore HCPs' experiences of their work-related health and job satisfaction while applying PCC. Methods: The study design is a prospective, longitudinal cohort study combined with qualitative focus group study. A web-based questionnaire will be distributed at intervals to HCPs in hospital wards, municipality and regional primary care centres in The Västra Götaland Region, Sweden. In addition, focus groups will be conducted with HCPs from different healthcare settings. Discussion: Optimising HCPs' work environment is vital to retain the workforce and safeguard the quality of care. PCC can form a critical component for effective change in the work environment of HCPs. PCC@Work will highlight some of the knowledge gaps on the effects of PCC on work conditions of HCPs by including diverse professions and underrepresented healthcare settings. The uniqueness of the PCC@work project lies in the all-encompassing longitudinal approach, blending quantitative and qualitative methods, involving various professions and settings, to explore HCPs' work-related health and job satisfaction under PCC.

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## Effects of a person-centered care intervention on the social dimension of people with chronic heart failure (SHARE Study): A study protocol of a randomized controlled trial ID 169

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**Background:** People with chronic heart failure live in a complex situation that significantly affects both their social well-being and other health outcomes due to symptomatic burden and psychosocial factors. Interventions on social life dimensions should be offered to support maintained engagement in social life and roles and having relationships beyond the family. Adopting a person-centered care (PCC) approach implies moving toward a care model in which health plans are centered on patients' wishes, and they take an active role in their care and decision-making. **Aims:** To evaluate the effectiveness of a PCC intervention on the social dimension of people with CHF. **Setting:** Three Outpatient Heart Failure Units in Spain. **Design:** A multicenter randomized controlled trial following the new MRC framework for complex intervention using a program theory and logic model, and co-created together with patients and clinicians. The effect of a three-month intervention of a person-centered face-to-face and telephone intervention, in addition to standard care, versus usual care alone, will be evaluated in a sample of 340 people with CHF. **Methods:** The intervention will be developed by a multidisciplinary team of registered nurses, physicians, social workers, and psychologists from each hospital. The intervention's effect on patients' ability to participate in social roles and activities, level of perceived social isolation, and perception of social support will be measured, as the perception of self-efficacy, level of self-care, anxiety, and depression, and their overall health experience, as well as the rates of hospitalization, decompensation, emergency room visits, and death. The multidisciplinary team led by registered nurses will create a partnership with each patient, allowing them to express their goals, wishes, and resources regarding their health situation in a narrative. Both will jointly develop a person-centered health plan that will reflect short- and long-term goals, identify the resources available to the person and how they want to receive support from healthcare professionals. Subsequently, a monthly telephone follow-up will be maintained for three months to update the personal health plan. Tentative results will be presented at the conference.

Leading care close to the patient in community home care -  
A person-centered approach with ethical dimensions ID  
069

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**Aim:** The aim is to develop knowledge about the phenomenon of leading care close to the patient in community home care from the perspectives of older person's (aged 65 years and older), next of kin and registered nurses. **Background:** When the home becomes the context for caring, it can be both a place for rest and worry. Demands are placed on the registered nurse, as responsible for leading a person-centred care guided by the older person's expectations. However, research is limited on the phenomenon of leading care close to older persons in community home care. **Methods:** Results from four studies were further interpreted into a comprehensive understanding. The overall research process was guided by a qualitative descriptive and interpretative approach grounded in reflective lifeworld research. **Findings:** The comprehensive understanding illuminates that leading care close to the patient in community home care was found to consist of an ethical demand that came with the responsibility to lead the care through others in a space between closeness and distance. Leading care in a space between closeness and distance can be understood as leading between health and illness, between biology and existence and attuning to the older person's autonomy and integrity, allowing the other to surrender to care with trust. Leading care can then mean maintaining an ethical approach in the meeting with the patient to preserve dignified care for older persons in need of care at home. **Conclusions:** The result from the comprehensive understanding highlights ethics, relations, responsibility, trust and confidence as essential structures for a leadership that is person centered. The knowledge gained can help us better understand the prerequisites for leading person-centered care in community home care and can contribute to improving the care for patients in an existentially vulnerable life situation.

Who gets preference-based patient participation in primary healthcare when living with hypertension? - An evaluation from the PERson-centredness in Hypertension treatment using Information Technology trial (PERHIT) ID 104

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Introduction: A significant aspect of person-centred care is the potential for patients to participate in their own health and healthcare in correspondence with their needs and resources, getting preference-based patient participation. A person living with hypertension is expected to partake in both self-care and prescribed treatment management. Yet, little is known what facilitates such engagement. This study illustrates their preference-based patient participation, evaluating the effects of a web-based support system via mobile phone. Methods: A randomised controlled trial in which 949 patients across 31 primary healthcare centres completed the Patient Preferences for Patient Participation tool, the 4Ps, at three time points: baseline, following an 8-weeks intervention, and at 12 months. Results: At baseline, approximately half of the participants had a match between their preferences for and experiences of their participation in health and healthcare. Consequently, almost every second patient either had less provision for their engagement than favoured or had experiences of participation exceeding their conditions. Most prominently sex, age and education were associated with different preferences for and experiences of participation, and the level of concordance thereof. The support system did not affect the preference-based patient participation long term, but the match between preferences and experiences seemed to improve regarding managing prescribed treatment and knowing what was done after 8-weeks in the intervention group. Conclusion: With roughly half of the persons with hypertension not having had preference-based opportunities for participation there is a remaining need to facilitate healthcare professionals' identification of patients' preferences for participation in their care, and to let them serve as a guide in how communication, medical treatments and lifestyle modifications are planned and conducted. Further studies are planned on how more person-centred dialogues can be achieved in encounters in primary healthcare.



## Learning and Education

Understanding person centred care (PCC) in the context of higher education ID 185

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Background: Implementing person-centred care (PCC) into higher education is ongoing in many parts of the world including Sweden. In a recent study we found that inclusion of PCC in steering documents was fragmented in national study programs for medicine, occupational therapy, physiotherapy, and nursing in Sweden. A subsequent interview study with program-directors revealed an ongoing but ambiguous process of incorporating PCC into the study programs. As a step towards facilitating implementation of PCC within higher education; we aimed to identify discourses of teaching and learning PCC. Methods We conducted a discourse analysis on interviews with program-directors from the national study programs (n=19) in Sweden. Discourse refers to the idea that our access to reality is through language, and that knowledge is created by our way of categorizing the world. The notion of subject position for the teacher and the student guided our analysis on how discourses designate positions for people to occupy; both create and limit possibilities for action. Results Preliminary results show four dominating discourses, grouped in two antagonistic pairs. Teaching and learning PCC is on the one hand discussed as part of a change in shifting power-relations but also expressed as something ruled out by scarcity and rigidity. Within the second antagonistic discourse pair, PCC is spoken of as an opening for interprofessionality, something bridging communication between professional groups, but was also described in connection to the need of guarding professional boundaries. The interpreted subject position within the discourses points out these contradictions. For example within the first discourses mentioned the student is positioned as being responsible and acting for change or as someone in need of

protection when facing the prevailing reality. These results will contribute towards creating educational resources for teaching and learning PCC.

Translation, validation, and cultural adaptation of a person-centred care course into a maternal and new-born healthcare context in Democratic Republic of Congo ID 026

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Background: Effective healthcare depends on person-centred care (PCC), encompassing patient needs and capacities. This approach is especially critical for improving maternal and new-born health, a challenge in the Democratic Republic of Congo (DRC). To facilitate the PCC integration, the Swedish “Mutual Meetings” online course was developed, based on the ethical routines- partnership, patient narrative, and documentation. This study presents the process of translating the course into French, its validation, and cultural adaptation within DRC’s maternal and new-born healthcare context. Method: The PCC course was translated into French and tested in a workshop with 31 healthcare providers, all involved in maternal and new-born healthcare in the eastern DRC. The participants and the two course facilitators evaluated the PCC course in group interviews (n=4) and individual interviews (n=2). The interview texts were analysed deductively using a process evaluation framework with the key components fidelity, dose, reach, acceptability, and adaptation. Results: The course content matched and even exceeded the participants’ expectations. Its pedagogic structure, using a reflective approach, was found to be innovative and it mediated a sense of comfort. It also enabled the participants to use a person-centred approach with each other. The course was found to be applicable in both teaching

and clinical care, although with some suggested contextual modifications. Conclusion: The French version of the PCC course “Mutual Meetings” was feasible, acceptable, and well received by the participants, who identified a need of minor revisions. The findings can serve as a model for future validation studies. The study demonstrates the importance of contextual adaptation of complex interventions in new settings, such as a course, while keeping the core elements in place.

### The implementation of learning into person-centred practice: evidence from a community nursing preparation programme ID 128

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Background: This study aimed to explore the implementation of learning into person-centred practice of post-registration student and qualified nurses (community and public health) who had undertaken, a professional and educational qualification within a person-centred curriculum framework. This program of study at a university in Scotland is philosophically and theoretically embedded in the theory of McCormack and McCance (2017) and specifically their Person-centred Practice Framework. It recognises and celebrates learners and facilitators’ continued state of being and becoming, with the aim to promote healthfulness, through the adoption of person-centred cultures and processes. Materials and Methods: Sixty-seven community and public health nurse graduates as well as current part-time and full-time students undertaking the programme, completed a survey. A quantitative research design was used to explore what learning has been implemented into practice, specifically regarding developing person-centred culture and practice using PCPI-S (Slater et al 2017). We also offered space for open comments which invited in-depth qualitative responses. Quantitative data were organised and analysed using a Bayesian one-way analysis of variance (ANOVA) approach. Results: Pre-requisites domain showed statistically supported differences. Other domains of the PCP framework (Care environment and Care processes) did not show statistically supported differences. Post-hoc comparisons across specialisations for Pre-requisites revealed statistically supported differences between qualified health visitors and student district nurses (qualified scoring higher) as well as between qualified district nurses and student district nurses (qualified scoring higher). Qualitative data supported these results. Conclusion: This study adds empirical evidence around the development of Pre-requisite concepts such as Knowing self, Clarity of values and beliefs and Developed interpersonal skills. Educators therefore need to continue to emphasise these in programme content. Importantly, practice educators and leaders need to provide more supportive environments where students and

qualified community and public health nurses feel able to be person-centred and promote person-centred ways of working.

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## Developing a concept for person-centred workplace learning ID 046

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A few years ago, the Nursing Development Unit of the Municipal Hospital Zurich, a Swiss tertiary hospital, developed a concept for person-centred workplace learning based on the Clinical Nurse Specialists' (CNS) shared values and principles of personcentredness. The concept was widely used for ongoing workplace learning with Registered Nurses (RN). However, since its development, a lot has changed. Challenges like the pandemic, hospital fusion with another municipal hospital and organisational restructuring contributed to a high level of nurse turnover and a shortage of registered nurses. Yet, promoting a person-centred learning culture where everyone can flourish has a high priority for the Nursing Development Unit. Further, a good introduction programme helps retaining nurses, especially newly graduates (Schmitt & Schiffman 2019). Therefore, the members of the Nursing Development Unit revised the concept in an inclusive, collaborative and participatory way. First, person-centred practice development literature was revisited and compared to a model of workplace facilitation- the critical allies framework (Hardiman & Dewing 2019). In a critical dialogue, the team members explored what is missing in the concept and negotiated what should be added. Second, the concept was tested in practice. Feedback from both CNS and RN using it in sequences of workplace learning was obtained and, where applicable, included in the concept. In this presentation, we are going to share our experiences with revising the concept in a person-centred way. Further, we talk about enabling factors and barriers when using it in practice and give voice to registered nurses who experienced workplace learning using this concept.

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Patient and Community Engagement Research (PaCER)  
program: teaching person-centred, qualitative peer-to-peer  
research in Canada ID 307

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Person-centred health research evidence is essential to person-centred health care. This oral presentation will introduce the Patient and Community Engagement Research (PaCER) program, an innovative program at the University of Calgary in Canada that teaches participatory health research methodology to sponsored teams of diverse learners with the aim of integrating the patient and community voice, experience, and perspective into health research projects from conception to completion. PaCER students represent diverse cultural, academic, professional, and geographical backgrounds as well as unique health and healthcare experiences. Through the 1-year, online, experiential based program students learn participatory health research methodology and skills, then design, develop, and carry out a qualitative, peer-to-peer research project about a health topic or concern that matters to them and their sponsor. PaCER projects often inform larger research projects and programs, as well as publications, academic conference and community and patient organization presentations. Presenters will include Ingrid Nielssen, PaCER instructor, and Marcia Bruce, PaCER alumni, team support and now program manager for a maternal health research program at the University of Calgary. They will discuss the PaCER approach and program delivery, the role of learners and team sponsors, some past and current PaCER projects, and possibilities for students and projects post-PaCER. It is also hoped to allow some time for audience questions.

## Digitalisation and eHealth

Developing a person-centred approach to staff wellbeing  
using digital storytelling ID 270

*Caroline Dickson, Queen Margaret University; Kathleen MacDonald, ListenUpStorytelling CiC*

Person-centredness in health and social care settings is fundamental to all persons within that context, and the outcome of person-centred (PC) practices is the

development of person-centred cultures. There is increasing evidence to support that person-centred cultures promote PC care, for care givers as well as those experiencing care. [1]. This presentation introduces a leadership strategy to develop person-centred cultures through the development of a digital co-created resource: CAKE: produced as an outcome of creative work undertaken with community nurses during the Covid 19 pandemic. CAKE stands for Caring for each other Attending to what's important, Keeping connected and Engaging and Empowering [2]. CAKE comprises 8 slices that build a process of developing PC workplace cultures in teams: The process involves: creating a shared safe space, connecting through storytelling and reflection, and action planning and evaluation. This process is supported by facilitation. This presentation will give an overview of the resource and give insight into the animations and videos that demonstrate the process of developing PC practices through the slices of CAKE. This is achieved through interaction with the resource on delegates' mobile phones in real time. We will use creative resources such as auditory prompts and story cards. We will highlight the impact of CAKE as evidenced by teams testing the resource in practice. Given the very real issues facing staff in this post-pandemic world of work: stress, burnout, poor recruitment and retention [3], we believe CAKE is a fundamental part of the recipe that supports healthful, person-centred workplace cultures. Join us for a taste of CAKE

Innovate together – and the result will be so much better!  
inspiring insights from Co-creating a digital Alzheimer's  
guide together with recently diagnosed patients. ID 231

*Maria Cavalli, Alzheimerguiden /Nadio*

In response to the challenges faced by those diagnosed with Alzheimer's and their families, our collaborative effort in Sweden initiated a transformative project. Teaming up with patients, caregivers, healthcare experts, and researchers, we embarked on co-creating an innovative digital solution: the Alzheimer's Guide. We're thrilled to share the process of our collaborative effort, showcasing how patient involvement significantly enhanced our platform's intelligence. The journey involved gathering needs and determining content through surveys, patient-focused focus groups, engagement with family members, healthcare professionals, and ongoing collaboration with patients in a dedicated working group. Over 400 participants contributed to our collaborative workshops, shaping the content creation process. Our focus was on crafting a holistic platform rooted in patient needs and emphasizing personalization. Patient insights were fundamental in shaping the digital guide's content, addressing not only disease-specific information but also broader aspects of life. The platform aims to holistically support patients beyond medical aspects. The platform's intelligence is credited to our patient working group, resulting in a universally designed and customizable platform. Personalized information became paramount, especially

for individuals with cognitive decline. Filtering and emphasizing relevant information were crucial, considering diverse needs—such as those of a mother in her 50s with teenagers and an 80-year-old widower—distinctly different in their requirements. Launched in November 2022, the Alzheimer's Guide has garnered over 2000 users in Sweden, owing its success to our partnership with patients. The guide stands as a user-friendly platform with unique features. We invite you to join us, learning more about the needs and our collaborative process. Listen to the voices of our patient representatives discussing their involvement in creating supportive resources for those impacted by Alzheimer's disease!

### Co-creation of a Digital Platform for Peer Support Between Adolescent and Young Adult Cancer Patients ID 007

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Background: AYAs diagnosed with cancer report psychological challenges and social isolation due to their situation. Peer support has been shown to be a valuable resource for coping with these experiences. Aim: The aim of this study is to map the needs for emotional peer support among AYA cancer patients in Sweden; and building on these results to develop and test a prototype of a digital tool for peer support between AYA cancer patients. Method: The study was conducted in close collaboration in a research team consisting of AYA cancer survivors, researchers, and a health tech company in Sweden. Through interviews the needs for emotional support among was investigated. Based on this information, a prototype of a digital platform was co-created by the research team. The platform was tested by AYAs and evaluated through an online survey and follow-up interviews as part of the iterative development process. Results: The AYAs described feeling lonely and having a need for processing their cancer experiences with peers. A combination of support through interaction with peers in both digital and physical meetings was preferred. A prerequisite for being a valuable resource, the digital platform had to have a high degree of security. Piloting the prototype, 87% reported feeling secure, all participants found it valuable to interact with peers on the platform. In the follow-up interviews the AYAs reported the log-in procedure to be difficult and the need to make this easier, while still maintaining high security. Conclusion: A secure digital platform for peer support can be a valuable and easily accessible a complement to other forms of support. The presence of moderators was found to enhance security and perceived usefulness of the platform. Co-creating tools for support with AYAs ensures relevance and usability. Acknowledgement: We thank all AYA cancer patients for participating in this study.

Using participatory design in the development of a virtual reality calm room in a psychiatric inpatient care setting to strive for a more person-centred intervention: a mixed-method study ID 227

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Background: Person-centred care (PCC) is based on ethical principles by which a contractual agreement is formed involving the patient as an active partner in the care and decision-making process [1]. As we strived to attain a high usability of this project, we used a participatory design (PD), which gave a possibility to empower the users by involving them in the design and artefacts (Spinuzzi, 2005). The method draws on the users 'tacit knowledge' - i.e. their implicit or unarticulated knowledge learned and transmitted through experience and apprenticeship e.g. by taking part in this project. Research investigating Virtual Reality (VR) calm rooms in psychiatric settings present that VR environments have shown potential to induce well-being and is a self-management tool for several mental health conditions[2-4]. VR technology is appreciated by users [5] and has become increasingly widespread in psychiatric care [6]. This study therefore aims to elucidate patients' experience and evaluate a VR calm room that was developed using a PD involving patient representatives in the developing process. Method: This study is part of a research project aimed to explore the effect of a VR and physical calm room in psychiatric inpatient care in Sweden. Data consisting of 30 individual interviews and n=59 evaluations questionnaire. The development of the VR intervention took place in 2019 and the collection of data has been ongoing



since 2022. Results: Final results of patients' experiences will be presented at the conference. Conclusion: To meet today's demands on accessible and efficient care it is important to develop new methods to facilitate the feeling of participation. There is also a relation between people's expectations, their opinion about the process of the intervention and the outcome, therefore it is of importance to include users in the design process. For the interpretation of the results of an intervention, the users' expectations and experiences of the intervention needs to be elucidated and investigated. PCC using VR calm rooms designed with user involvement could be one way to meet the demand and provide support for people with mental illness.

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## Patients' and staff's use of a remote person-centred intervention: A process-evaluation with a health economic perspective ID 084

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Background: The person-centred remote intervention PROTECT (based on the cornerstones described by Ekman et al) has shown to be meaningful and to impact

short term self-efficacy (3 month-follow up). However, at the 6 month-follow the effect was no longer significant. To better understand program outcomes and bridging the knowledge gap on intervention use in remote person-centred interventions the aim was to describe to what extent activities in the PROTECT intervention was used over time and to explore the association between intervention use and program outcome(s). Methods: An explorative study was performed as part of the process evaluation of a randomized controlled trial. Intervention-group participants (n=110) and staff (n=5) were included. Data on program outcomes were collected at baseline, and at the 3- and 6-months follow ups. Moreover, data on intervention use and time using the intervention were collected. Imputations were performed for missing data to avoid underestimation of time use. Analysis is ongoing. Descriptive statistics and regression analysis will be performed. Results: Preliminary findings show that most patients interacted with staff throughout the 6-month intervention, with a peak in contacts during the first intervention month. The association between intervention use and program outcome(s) as well as time using/performing the intervention will be presented. Conclusion: Patients' and staff's time use are requested but seldom reported in detail in process-evaluations. To our knowledge, this is the first study to report on remote person-centred intervention activities and time spent on remote person-centred care. The mapping of resource use among both patients and professionals contributes a unique perspective which provides insights for future health economic evaluations of remote interventions. Moreover, the result is expected to contribute to the discussion of how much interaction is needed to reach the intended intervention effect.

### Integrating Health promotion with and for Older People – ehealth (IHOPe): a randomised controlled trial ID 050

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Background: Healthcare systems worldwide are not equipped to accommodate for the growing population of older people. People in this age group often have an increased risk for developing frailty, multi-morbidity and functional impairments. Given that 40 % of all patients seeking care at the emergency department are frail older people, there is a need to identify ways to initiate preventative actions to frail

old people. Aim: To describe and evaluate a person-centred remote intervention via telephone and a digital platform for community-dwelling frail older people, above 75 years who seek acute hospital care but are not hospitalised. Methods. Design: The IHOPe study is a randomised, controlled, trial with two parallel groups and a primary endpoint 3 months after inclusion (1). Frail older people aged 75 years or older, living in ordinary housing and not hospitalised, will be screened for frailty at the Emergency department and randomised to intervention or control. Intervention: The intervention comprises person-centred phone-calls (stimulating narration) and co-creation of care through a digital platform for up to 6 months. The older person (sometimes with significant others) together with the health care professional will formulate a person-centred health plan, which is then uploaded to the IHOPe platform. The health plan focuses the older persons' goals, resources and needs. The health plan is the point of departure for the forthcoming dialogues. Primary endpoint: The primary endpoint is a composite of changes in general self-efficacy and need for hospital care. Results: At present 160 participants have been included. Considering the long period of time between last date for submission of abstracts and the conference (six months), we will have included the planned study population and be able to present tentative findings from analyses of data in IHOPe, at the conference in May 2024.

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iWheld into practice: Understanding the factors influencing widespread implementation in the UK of an online person-centred care staff development programme for supporting people living with dementia in care homes. ID 295

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The iWHELD programme is an on-line programme based on WHELD (Improving Wellbeing and Health for People Living with Dementia), an evidence-based person-centred care programme aimed at improving the well-being of care home residents through staff development (Ballard 2018, Fossey 2019). Clinical trials demonstrated that WHELD improved quality of life and reduced agitation and aggression in people living with dementia. The online resource combining digital resources, interactive tools, and social sharing for care staff working in care homes and live online coaching for care home staff during the COVID pandemic

demonstrated an improvement in quality of life and a reduced use of antipsychotic medication (McDermid 2023). This study reports on an implementation project using the Consolidated Framework for Implementation Research (Damschroder et al. 2009) aimed at understanding which factors are important in homes adopting this programme and factors that influence how person centred care home staff development can be rolled out more widely across the UK. Interviews were analysed using a framework analysis approach (Ritchie 2014) to identify key themes emerging from 27 interviews with care home managers and staff who worked in participating homes across six regions of the UK, in order to understand iWheld specific factors. Additionally interviews were conducted with 16 people who had some current role associated with care home education or commissioning in any of four of the six regions in which the iWheld implementation took place, in order to understand the broader context of psychosocial support and staff development that could impact wider roll-out. The emerging themes will be discussed highlighting the facilitators and barriers to adoption of iwheld and psychosocial training in care homes more generally, the value of evidence base and of staff development, influence of local networks and the policy and commissioning framework.

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## People of Old Age

Receiving physical assistance as a dependent older person –  
the meanings of experiences ID 144

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When a person gets old, frail and dependent, physical assistance is usually needed with daily life activities. Assisting older patients physically can be seen as the fundamental nursing care. For nurses, it is important to understand what physical assistance moments mean to older patients to be able to offer Person-Centred Care. The aim of the study is to describe and understand older patients' perspective of receiving physical assistance with their daily life activities. The research question of the present study is: What are the meanings of older patients' experiences about physical assistance moments? A cross-sectional qualitative study design was used with a targeted selection of older patients who were in rehabilitative hospital care. Face to face semi structured interviews were conducted with 16 older patients in southern Finland. They were 67-96 years old and needed various degrees of physical assistance. The interviews were recorded and transcribed verbatim. The narratives describing physical assistance moments were selected from the interviews and after that the narratives were analysed inductively with means of narrative analysis. Five different meanings of experiences were found in the participants' narratives about physical assistance moments: Trust in the care one is exposed to, Being at the mercy of others, Receiving nurturing care and Feeling desolated. Older patients seemed to find a sense of contentment mainly from the provision of tailored and timely physical assistance and by the respect afforded to them by their nurses. How nurses encounter and communicate while performing physical assistance is therefore utterly important. Physical assistance that nurses give to older patients is not only a physical deed, but need to be founded in a deeper understanding and contemplating about older patients' life worlds, nurses' own behaviour, ethical issues and what creates trust and hope for dependent older patients.

Exploring results from national patient experience surveys  
in the UK to understand the care experiences of older  
people with frailty ID 116

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Background: People are living longer and by 2030, 1 in 6 people in the world will be aged 60 years or over (World Health Organization, 2022). Frailty is an important and growing challenge that comes with population aging. We know that older people with frailty are disproportionate users of care services. This impacts health services, but also means that people have substantial and complex experiences of health and care which need to be understood. Methods: Through analysis of quantitative data from national patient experience surveys in the UK, such as the Adult Inpatient Survey (Care Quality Commission, 2022) and the Urgent and Emergency Care Survey (Care Quality Commission, 2022), we explored the patient experiences of older people with frailty. Results: We found that older people with frailty or multiple long-term conditions often reported poorer experiences and more problems with hospital care. And that those with more than one long-term condition reported worse experiences than those with a single limiting condition. This was the case across many different elements of person centred care, from quality of communication and information, involvement in care, to respect, dignity and privacy. But we also found that measuring the quality of person centred care of people who are frail is practically difficult. Limitations are explored including whether experience measures in the UK focus on what really matters to older people and whether the right mechanisms are place to support the involvement of older people in person centred care research. Implications: This analysis demonstrates the role that patient experience surveys have in helping understand the differences in the quality of person centred care experienced by older people with frailty. It highlights the importance of understanding what matters most to older people and designing health services that work for all.

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Staff members experiences with video bikes and Virtual Reality-glasses (VR-glasses) activities in nursing homes ID 136

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Introduction/Background: People in nursing homes frequently live their lives inactive and with little social contact. Consequently, the nursing home residents loose opportunity to live their lives to the fullest. Person-centred practice require

good relationship between residents and staff, power sharing and a supportive organisation. At three nursing homes video bikes and VR-glasses were used to increase engagement and social activity in order to contribute to person-centred practice and yield person-centred outcomes. Aim: The aims of the study were to explore how staff members experience activity with video bike and VR-glasses and how the activity contributed to person-centred practice. Method: The study has an explorative design with a qualitative approach. The sampling of informants was purposeful. We conducted nine individual interviews with staff and volunteers who had experience from leading the activity. Data was analysed with systematic text condensation. The study is conducted in compliance with research ethics principles. Result: Analysis of data yielded four categories: K1 The activity promoted engagement and well being. K2 The activity promoted a sense of community. K3 The activity contributed to person-centred practice by being proactive and adaptive to the resident's preferences and needs. K4 The activity was promoted and hindered by several factors. Conclusion with implication for practice (educational and/or clinical): Staff members and volunteers experienced that the activity with video bike and VR promoted moments of engagement, well being and a sense of community between the resident and the staff. Thus, it seems reasonable to assert that the activity resembles person-centred processes which yielded person-centred outcomes. Though, there are need for available personnel resources and dedicated persons with responsibility for the activity to succeed in creating person-centred practice.

### Going the extra mile- exploring person-centred leadership in residential care for older people ID 082

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Aim: Exploring person-centred leadership in residential care based on first-line managers descriptions. Background: Previous studies have shown that leadership is crucial for promoting and leading person-centred care. Despite that person-centred care is the leading care model, existing knowledge on person-centred leadership in residential care facilities for older people is scarce.

Methods: Data was collected from October 2021 to March 2022. The design was exploratory using digitally focus groups and individual interviews. A total of 21 first-line managers in residential care facilities (RCF) for older persons in five municipalities in Sweden participated in the study. Conventional content analysis was used to analyse the data. Findings: Person-centred leadership consists of two parts that together form a whole; being person-centred as a leader by having the relationship with the personnel in focus and, simultaneously; leading person-centred care by focusing on the older person. Going the extra mile for the

personnel and the older person, meant that the first-line managers were person-centred themselves. They emphasised that this orientation must be grounded in their own beliefs in order to communicate this to the personnel and to the older person. Going the extra mile also involved having the courage to “go outside the box” when necessary. Conclusions: This study contributes with empirical knowledge about person-centred leadership in RCF, i.e., being and doing person-centredness as a leader. Being person-centred as a leader involves acknowledging the personhood of personnel in words and actions which has the potential to promote person-centred practices. Person-centred leadership entails promoting personnel to meet the older people’s changing needs, having operational, financial and personnel responsibilities, while simultaneously trying to meet the needs of personnel.

### Exploring the impact of Person-centered care: A five-year comparison on nursing home residents’ health and QoL ID 119

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Background: The global aging poses nursing care challenges, with an increasing demand for complex care among older individuals. In Sweden, the 80+ age group is projected to grow by 50% from 2020 to 2030, necessitating a comprehensive examination of factors influencing nursing home residents' health and quality of life (HRQoL). Within this landscape, person-centred care (PCC) has demonstrated its central role in elevating the health and HRQoL of nursing home residents. Aim: To investigate relationships between leadership, person-centred care (PCC), resident health (cognitive impairment, neuropsychiatric symptoms, daily living activities), and resident quality of life (QoL) and changes over five years. Design: This study employs a repeated cross-sectional design with data from staff, residents and managers. Data collection occurred in 2014 and 2019, using reliable scales to assess health-related quality of life (HRQoL), cognitive impairment, neuropsychiatric symptoms, PCC and leadership. Methods: Data collection included 4,831 residents at baseline 2014 and 3,894 residents at follow-up in 2019. Additionally, 3,665 staff (baseline) and 2,985 staff (follow-up) participated in 2014. Organizational data covered 172 nursing homes at baseline and 202 at follow-up. Robust statistical analyses, including descriptive statistics and regression modelling, explored relationships between person-centred care, leadership and residents' health and quality of life.

Results: No association was found between leadership and resident health or HRQoL. Significant correlations emerged between person-centred care and resident HRQoL and other health outcomes. This underscores the role of PCC



for nursing home residents. Conclusion: This study reveals the interplay between leadership, PCC, resident health, and QoL in nursing homes. While leadership may not directly impact resident outcomes, person-centred care seems to beneficially impact HRQoL and other health outcomes. Prioritizing PCC practices in nursing homes may increase residents' quality of life. Further research is warranted to explore specific PCC elements contributing to improved QoL among nursing home residents.

## Implementation

### How person-centred research supports leadership practice across a large organization ID 093

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Background: At Zealand University Hospital, Denmark (ZUH), it is a strategic goal for nursing and allied health professionals (AH), that the treatment and care is person-centred. If such an ambition is to succeed, leaders at all levels must act as genuine role models. However, if the leaders themselves don't experience connectivity (1), have confidence and knowledge about person-centred practice, moving from 'person-centred moments' to 'person-centred cultures' it is not likely to happen.(2) Aims and method: Over a period of 10 years, leaders across the leadership span, have been offered targeted facilitation processes from a person-centred research perspective, facilitated by academically trained staff (3). This included: Participation in journal clubs and continuing action-learning sets for chief nurses/AH (4); facilitating practice development in the ward-managers network; conducting research focusing on how person-centred nursing leadership may be strengthened (5); facilitating a pilot-course in practice development for leaders; initiating person-centred national conferences for ward managers; facilitating leadership writing processes and participation in international collaboration evaluating programs aimed at developing leaders in person-centred practice. Results: Many leaders have become inspired by the idea of person-centredness, but the person-centred vision is not solidly embedded throughout the hospital yet. However, the number of 'person-centred moments' led by leaders at ZUH is raising. One important example of this is the publication of the book "Leaders with determination and courage" (6), where leaders across the leadership span described their own experiences with supporting practice development. Conclusion: Culture change is a difficult, dynamic and continuous process and person-centred values are challenged and under pressure in today's health care systems. The person-centred research regarding leadership roles at ZUH demonstrates that there is still a need for a shift in focus from strengthening

individual leadership resilience to the establishment of healthful and resilient cultures in accordance with person-centred leadership (7).

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## Implementation of person-centered care in primary health care - when theoretical and empirical evidence meets reality in primary health care practice ID 072

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Background: There is a national initiative in Sweden aiming for equal, evidence based, person-centered and integrated care. Diagnose specific care processes, based on compilations of medical evidence and patient experiences by national groups of medical experts and patient representatives, are a central part of this initiative. All 21 Swedish administrative regions, involving both inpatient and primary health care, are to implement these care processes. The presenters work with implementation of person-centered and integrated care processes in primary health care, in the Region of Västra Götaland, Sweden. Aim: 1) Picturing specific challenges and opportunities working person-centeredly in primary health care. 2) Addressing these challenges and opportunities when implementing person-centered and integrated care processes in primary health care in the Västra Götaland region in Sweden. Method: Oral presentation of different perspectives of the topic. There will be room for both preregistration of questions and questions from the audience. Program content will be tailored to answer pre-registered questions. Expected outcome Increased understanding of what characterizes person-centered primary health care, and measures necessary to enable implementing such care in a way that benefits patients. We hope to bring

about the audience's willingness to contribute to person-centered primary health care from their respective positions, whenever given the opportunity.

### Person-centred care in residential aged care: A scoping review ID 051

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The concept of person-centred care has emerged in Australia alongside many different descriptions in the literature without consensus on a global definition. The Australian residential aged care sector is currently redesigning its entire system. Person-centred care remains a broad and heterogeneous topic in healthcare. A clear and explicit definition of person-centred care could not be found in Australian aged care governing bodies. Examining which descriptions of person-centred care exist in residential aged care nursing practice literature can provide information to inform practice and policy. Therefore, a scoping review of published work and grey literature is being conducted guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA –SCR) and Chapter 11 of the Joanna Briggs Institute (JBI) Reviewer's 3 Manual. The aim of the scoping review is to synthesise the descriptions of person-centred care in residential aged care nursing practice. A population, concept, and context (PCC) framework has been used to develop the research question and define inclusion and exclusion criteria. The scoping review is being conducted to answer the question: What is the definition of person-centred care in residential aged care nursing practice? Evidence is being sourced from CINAHL, PubMed, Scopus, and Web of Science databases, and references from all included articles. Data will be extracted based on congruency with the eligibility and inclusion criteria, research question, and objectives of this scoping review. The PRISMA flowchart will be used to show the source selection process. Data will be mapped with a descriptive format that aligns with the PCC framework, research questions, and objectives of the review. A synopsis of descriptions will be presented. This evidence could help move person-centred care from an emerging concept to an established nursing practice in Australian residential aged care.

### 'Guiding Lights for Effective Workplace Cultures' ID 137

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The centrality of person-centredness as a core value linked to action that enables authentic partnerships, practice and workplace cultural transformation to occur is becoming widely recognised. Four Guiding Lights for Effective Workplace

Cultures (GL for EWC) were developed through a collaborative inquiry based on the principles of appreciative inquiry and realist evaluation:

1. Collective Leadership. 2. Living shared values. 3. Safe, critical, creative, learning environments. 4. Change for good that makes a difference. The GL for EWC describe what good workplace cultures are; and the intermediate and ultimate outcomes that result for the person providing and/or experiencing care/services (Cardiff et al., 2020; Sanders et al., 2021; Webster et al., 2022). A GL for EWC programme was commissioned by NHS England/Improvement. It focused on applying the four GL for EWC to the community (nursing and/or interdisciplinary) team setting across the 7 regions of England. 21 participants joined the programme from a range of different community settings. Evaluation of the programme identified that participants used the GL for EWC with their teams as an opportunity to learn about workplace culture as it provided a structure for both evaluation of and action planning to enhance their workplace setting. The end of the programme was not perceived as closure, rather the start of ongoing development (Webster and Sanders, 2022). The programme facilitators recognise the centrality of the ‘person’ to effective workplace cultures and the resonance with the need to create ‘healthful cultures’ (McCormack and McCance, 2021) that support learning, development and transformation. Following the success of the national programme, the former Norfolk and Waveney (N&W) Clinical Commissioning Group (now N&W Integrated Care Board) have commissioned the delivery of the programme across the N&W Care System (September 2023 – March 2024). The presentation will blend learning from both the national and N&W programmes.

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## Patient centered care in interprofessional collaborative practice: users’ opinion. ID 180

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In accordance with guidelines from the World Health Organization and following national guidelines for health courses in Brazil, the Faculdade Pernambucana de Saúde (located in the Northeast of Brazil) created in 2022 the Center for Interprofessional Health Care and Learning (CAAIS) with the aim of developing interprofessional practical activities centered on the person, and involving teachers and students from eight health courses, i.e. physical education, nursing, pharmacy, physiotherapy, medicine, nutrition, dentistry, and psychology. This is an experience report with the opinion of users from the Tijolos community about the activities carried out centered on the person through a word cloud. The community of Tijolos is located around the health school and does not have a basic health unit. At CAAIS, care is offered to children, adolescents, adults and the elderly with the main aim of restoring, maintaining and promoting health. An opinion survey was carried out during a week of service. The most used and highlighted words in the word cloud were: Satisfaction, Good, Great, Joy, Attention, Care, Concern, Relief, Outburst, Great service, Excellent, Great opportunity, Looking eye to eye. The degree of satisfaction of users of person-centered care is consistent with the literature. However, in informal discourse the most frequent feedback is “being heard and welcomed”, reflected in several cases in which problem solving with dialogue and guidance, even before diagnostic and therapeutic intervention itself. These results indicate that we are on the right path in terms of the type of health care, with emphasis on this practice occurring even during the graduation of courses.

### Enhancing Person-Centred Care: Implementation of a Tool for Organisational Learning and Measurement ID 143

*Åsa Waldo, Region Skåne; Stine Thorsted, Region Skåne*

Swedish healthcare aims to provide person-centred care based on patients' needs, preferences and resources. In 2021, the Swedish Agency for Health and Care Services Analysis pointed out that the goals for patient involvement in healthcare have not yet been fully achieved by Swedish health care providers. To successfully implement person-centred care, healthcare organisations require tools for continuous learning and systematic monitoring at both individual and group levels. The Swedish standard ‘Patient involvement in health care – Minimum requirements for person-centred care’ (SS-EN 17398:2020) outlines key aspects of a practice-based approach to person-centred healthcare. The aim of this presentation is to introduce a tool based on the minimum requirements defined in the standard. This tool has been developed to facilitate organisational learning and measurement of person-centred care. It comprises both the organisational level, where administrative managers and management teams can learn how to improve conditions for person-centred care, and the point-of-care level, where clinicians

can develop person-centred care for patients. It includes sets of questions designed for discussion and reflection within teams, occupational groups, and management teams, as well as rating scales to enable self-assessment for estimating the extent of performed person-centred care. The tool has been developed and tested in collaboration with managers, clinicians, organisational development specialists, and patient peer supports within Office for Psychiatry, Habilitation and Technical Aids in Region Skåne. Currently, it is being implemented in three distinct departments: Sight, hearing and deafness, Forensic psychiatry, and Habilitation. Preliminary results indicate that the tool effectively enhances the identification of improvement opportunities for both practice and management towards more person-centred care. Examples include changed routines, strengthened child focus, improved competence in communication methodology, real-time documentation, and establishment of patient expert councils. Potential improvements in person-centred care need to be verified and supplemented with feedback and data from the patients themselves.

### Certification opportunities of standard for patient participation in healthcare. Minimum requirements for person centered care (SS-EN 17398-2020) ID 039

*Hanna Svensson och Jenny Wetterling, RISE och Region Skåne*

The purpose of this collaborative project between “Center for person-centered care” and RISE was to develop an audit that form the basis of a certification process and to analyse organisational prerequisites and obstacles for a certification process. As a support to organizations, the standard “Patient participation in healthcare – minimum requirements for person-centered care” has been developed. It aims to facilitate cooperation between patients and healthcare professionals in the design, execution of care, implementation, and evaluation of healthcare services. In the standard, participation is both about the individual's participation in their own care, and about patient participation at the organizational level. The Standard can be used as an aid for planning, management, implementation, and systematic evaluation of daily activities, and enabling patients to manage their daily lives and empower them in the care process. In addition, it can be used to support patient participation at the system level and thus ensure that the patient perspective is included in the development, implementation and evaluation of services, research, and policies in healthcare. A certification based on the standard gives service providers the opportunity to increase its efficiency and quality regarding the person-centred care that patients receive. A certificate of patient participation in healthcare shows that a healthcare organization has implemented the working methods according to SS-EN 17398 and that it has been reviewed and approved by a certification body.

What did we learn? How can we use the standard in implementation of the participating aspect of person-centred care?

## From modernist to post-modernist worldview: nine theoretical perspectives for mental healthcare ID 124

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Within the ongoing discussion on what is and how to deliver best care (Anjum, 2016), discussions about what type of knowledge is needed, and how it is ontologically and epistemologically rooted are often lacking. Majority of interventions are still dominated by knowledge stemming from the biomedical model, pharmacology, and cognitive-behavioural psychotherapy, all approaches representing a post-positivist worldview. This is especially true for inpatient mental healthcare, where new approaches like e.g., occupation and participation, have both difficulties to be implemented as intervention and gain serious conceptual recognition by the established mental health systems and institutions. This presentation refers to elements of a configurative review aiming to synthesize, analyze, and interpret how programs focusing on occupation and participation are theoretically grounded. A systematic search integrating methodological elements of both a structured matrix-method and inductive thematic (Xiao & Watson, 2017) analysis was applied, resulting in the identification of nine theoretical perspectives that currently guide mental healthcare. In aiming to contribute to the field's discussions e.g., on how the biomedical model and person-centered care are linked in terms of science philosophy, these nine theoretical perspectives have been situated in an ontological and epistemological continuum ranging from modernist-biomedical to postmodernist-holistic theoretical underpinning (Moon & Blackman, 2014). While in this continuum person-centered care seems to have found its place as part of the post-modernist worldview, the role of both participation and occupation remains unclear. The authors' intention is to provide an example of newly generated knowledge that contributes to the call for more ontological and epistemological diversity in mental healthcare theories. However, more research is needed to strengthen theoretical perspectives beyond biomedical approaches, and support integration of patients' perspectives in terms of occupation and participation, within programs for people affected by severe mental illness.

## Celebrating Patient Journeys within a Learning Disabilities Assessment and Treatment Ward ID 179

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Assessment and Treatment Wards (ATW) support individuals with learning disabilities where the required clinical response goes beyond that possible in the community. Individuals can find the transition into an ATW challenging, partly due to their complex and rapidly changing dynamics. Staff's focus on person-centred practice, and health care environments as places of growth and healing, can also be undermined by circumstances out-with their control, such as delayed discharge. Gaining fresh perspective on these issues can be difficult for staff. For these reasons, a collaboration with the Glasgow School of Art (GSA) Innovation School was developed, to explore new approaches to the relational transitions which characterise admissions. Two GSA Innovation School interns from the Product Design Undergraduate course were recruited to work with staff and patients of the Ayrshire ATW over 5 weeks. Using co-design approaches they captured participants' insights, and used them to shape practical responses to the issues, opportunities and restrictions of care within a clinical environment. The interns delivered 2 key resources: a booklet celebrating existing and potential activity within Ward 7A; and a Journey Journal. The first was intended as a vehicle for communicating and recognising existing good practice within the ward, while the second was provided as a practical resource for patients to record their experiences throughout their admission, and provide them with something to reflect back on following discharge. Both are finding practical use within the ward, and are attracting interest from other professionals and services. This is the second internship the North Ayrshire Learning Disability Service has developed with GSA. As with the previous one, it demonstrates the value in novel perspectives on complex issues; the relevance of design-thinking and practice in clinical settings, particularly as a means of enabling innovation; and the importance of spaces for creation and celebration within high pressure environments.

## Healthcare Professionals' Perspective of Person-Centred Wound Treatment: A Qualitative Study ID 041

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Chronic wounds present a major challenge to healthcare systems globally as the population ages (1, 2). To improve wound treatment outcomes, person-centred care (PCC) has been suggested, but there is limited research on its application in wound treatment (3). Implementing PCC in wound treatment can be challenging



due to, for example, poor communication between healthcare professionals and patients regarding painful and malodorous wounds (4). Therefore, it is crucial to gain a better understanding of healthcare professionals' perspectives on PCC in wound treatment, and potential challenges with its implementation. This understanding can support the application of PCC and improve the quality of care, similar to other patient groups (5, 6). In this study, we interviewed 22 Swedish healthcare professionals in primary care who work with wound treatment to understand their perspective on PCC. Using qualitative content analysis with an abductive approach (7, 8), we employed Ekman et al.'s framework (9) to define PCC. The findings illustrate the healthcare professionals' perspectives on initiating, implementing and safeguarding PCC in wound treatment. Initiating PCC involved seeing the whole person and the underlying causes of the wound, using the patient's goals and preferences to establish, and motivating the patient to accept, treatment. Implementing PCC involved building a relationship of trust with the patient, tailoring the treatment to the patient's goals and preferences, and supporting the patient in managing day-to-day life. Safeguarding PCC involved documenting, updating and keeping up to date with the patient's treatment records, and communicating about these between healthcare professionals. The healthcare professionals recognized the value of PCC in wound treatment, but also challenges with its application such difficulties in building a partnership with the patient, lack of continuity in the patient's care and issues of information-sharing between healthcare institutions. The findings provide valuable insights for the implementation of PCC in wound treatment.

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An analysis on personnel costs and working time for implementing a more person-centred care approach: A case study with embedded units in a Swedish region ID 086

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Background/aim: Legislators and health care organisations in Sweden have put person-centred care (PCC) high on the development agenda. However, the knowledge about costs associated with introducing a more PCC is limited and scattered. Overlooking such costs, however, implies that the time added for this implementation is minimal and can be ignored. This study aimed to describe the time and costs used during the implementation of a more PCC approach as part of ordinary practice. Methods: A case study with embedded units was conducted in Region Dalarna, Sweden. Participants included the Department for Development (DD) staff who provided a central support function in the implementation and six healthcare units: nephrology, two geriatric care and rehabilitation units, two psychiatry units, and primary care. Logbooks were used to identify time spent for implementation strategies, service delivery, and research/development costs. Administrative data and mean salaries were used to estimate costs for these activities. Results: The health care units logged on average 5.5 working days per staff member. In the healthcare units, 6-57% of the time reported was used for implementation strategies, 40-90% for service delivery, and 2-12% for research/development. Of the time reported by the DD, 88% was assigned to implementation strategies. Costs associated with reported time indicated 23% of costs for this implementation occurred in the DD. Using the budgeted cost, this proportion increased to 48%. The budget for the DD corresponded to SEK 2.30 per citizen per year and 0.009 % of the total health care budget of the region. Conclusions: The study found that a large part of resources used for this implementation of more PCC occurred in the DD, although at least half of the costs occurred in the healthcare units. Moreover, the cost of the central support function corresponds to a tiny proportion of the total health budget.

## Global and Local Perspectives

Person-centred nursing research? A historical case study on the establishment of nursing science in the Netherlands ID 269

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The world increasingly relies on nurse scientists in order to safeguard person-centred quality of care and healthcare transformation. Opinions on what entails nursing science however, vary widely. Consequences of these discussions include a lack of defined career trajectories for academically-prepared nurses and a heightened resource competition within nursing and the broader medical field (see: Martini et al., 2023; van Oostveen et al., 2017). Research on the socio-historical context of nursing science reveals insights into the origins of these debates. Focusing on the establishment of the first Dutch nursing science faculty in the 1980s, our case study unravels the strategies that nurse scientists pursued to gain legitimacy among both nurses and academic peers. Applying the feminist concept of ‘caring power’ (Drenth & Haan, 1999), we observe that the challenges faced by these scientists were intricately tied to their efforts to professionalize a traditionally perceived feminine professional field (nursing), within male-dominated domains (i.e. medicine and academia). Early nurse theorists defined person-centered care as nursing’s defining element, endorsing qualitative research methods closely aligned to the behavioral sciences. Influential nurse leaders however, concerned about legitimacy amongst other healthcare academics, advocated for an empirical biomedical model (with perceived higher status). The eventual trajectory of the nursing science program in the Netherlands was unique. Students did not need nursing backgrounds for enrollment, and graduates could not register as nurses, resulting in a detachment from its person-centred origins. In this study we 1) show the continuous influence of gendered assumptions of nurses and nursing work on the establishment of nursing science as an academic discipline and 2) argue that defining nursing science is complex and requires an understanding on its national socio-historic roots. By doing so, we advance our understanding of the gendered mechanisms behind the establishment of a science of person-centred care. Consequently, we contribute to the reassessment of person-centered care’s significance within the field of nursing science.

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## Global perspectives on implementing person-centered care: lessons from Ethiopia, Ghana, Nepal, and Zambia ID 238

*Jessica Posner, JSI; Nicole Castle, JSI*

Health outcomes are influenced by our health care, social, governmental, economic, and environmental systems — all dimensions of the Sustainable Development Goals. Achieving these goals requires a broadened application of person-centered care across health systems. Indeed, person-centered care plays a fundamental role in shaping people's trust and confidence in the health system and affects health outcomes across the life course. In this session, we will provide an overview of JSI's person-centered care framework, which is theoretically based in the socioecological model and includes five principles and six domains derived from literature and practice. We will discuss how the framework can be used to improve the design, management, delivery, and measurement of global health programs that are shaped by and responsive to the needs of individuals and communities. Using country examples across contexts (Ethiopia, Zambia, Ghana, and Nepal) and health areas (maternal health, immunization, and HIV/AIDS), we will discuss how we have applied person-centered care more broadly across health systems and communities. We will use the person-centered care framework as the guide for our discussion. We will hold time for facilitated discussion with the audience to learn more about the application of person-centered care globally and to gather feedback on JSI's framework. We will close with a call to action for how we can collectively advance person-centered care and other relevant approaches in order to achieve global goals of health and well-being for all.

Person-centred patchwork with a common thread: 12 years of targeted work with building up, developing and consolidating a person-centred practice culture in a Danish University Hospital Department ID 278

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Introduction: Both internationally and nationally person-centred practice is a priority within healthcare systems. In 2011 Department of Hematology at Zealand University Hospital (ZUH), initiated a targeted nursing research- and development process with the aim of developing a person-centred practice/-culture in the Department using a person-centred framework described by McCormack and McCance (1). The clinical nursing-focus for research and development in the Department was and still is: “Quality, continuity and coherence in individually tailored hematologic patient trajectories” (= the common thread). Method: The research-/ development processes are grounded in a participatory approach, where dialogue and reflection both individually and collectively are key concepts. Most of the research- and development projects at the Department are conducted as small-scale projects with the purpose/aim of developing our Department by producing new, useful and meaningful local knowledge in cooperation with healthcare staff, patients and their families (2). Results and Conclusion: From 2011-2023 we have conducted more than 40 projects/ development processes, originated in practice and with a person-centred approach, and they all have involved an organizational, health professional and family-oriented level (the patchwork). We have evaluated all our projects/ development-processes and the results show that we have developed our practice for the benefit of both patients and their families and for staff also. We have been moving forward from moments of person-centredness to patterns of person-centredness – but the results also show, that there are different barriers/hindering factors in the way of developing and act person-centred in clinical practice = having a person-centred practice culture. Perspectives: Continuous development and consolidation of a person-centred practice/culture is an ongoing process, which demands both active and positive engagement from all healthcare staff, especially leaders, and a supportive context.

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Aktionsforskning i sundhedsvæsenet: Ideer til kommunikative og innovative forandringer i en sundhedsfaglig praksis (pp.174-197). Aalborg Universitetsforlag.

## Perspectives on the Person-Centered Practice of Healthcare Professionals at an Inpatient Hospital Department: A Descriptive Study ID 066

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The characteristics of health professionals and their understanding of person-centeredness may have important implications for the development of person-centered practice in specific care settings. In this study, we characterized the perceptions of the person-centered practice of a multidisciplinary team of health professionals working in the internal medicine inpatient unit of a Portuguese hospital. Data were collected using a brief sociodemographic and professional questionnaire and the person-centered practice inventory-staff (PCPI-S), and the effect of different sociodemographic and professional variables on each PCPI-S domain was determined using an analysis of variance (ANOVA). The results showed that a person-centered practice was positively perceived in the major constructs of prerequisites ( $M=4.12$ ;  $SD=.36$ ), the practice environment ( $M=3.50$ ;  $SD=.48$ ), and person-centered process ( $M=4.08$ ;  $SD=.62$ ) domains. The highest scored construct was developed interpersonal skills ( $M=4.35$ ;  $SD=.47$ ), and the lowest was supportive organization systems ( $M=3.08$ ;  $SD=.80$ ). Gender was found to influence the perceptions of knowing self ( $F(2,75)=3.67$ ,  $p=.03$ , partial  $\eta^2=.089$ ) and the physical environment ( $F(2,75)=3.63$ ,  $p=.03$ , partial  $\eta^2=.088$ ), as was profession on shared decision-making systems ( $F(2,75)=5.38$ ,  $p<.01$ , partial  $\eta^2=.125$ ) and commitment to the job ( $F(2,75)=5.27$ ,  $p<.01$ , partial  $\eta^2=.123$ ), and the educational level on being professionally competent ( $F(1,75)=4.99$ ,  $p=.03$ , partial  $\eta^2=.062$ ) and having commitment to the job ( $F(2,75)=4.49$ ,  $p=.04$ , partial  $\eta^2=.056$ ). In addition, the PCPI-S proved to be a reliable instrument for characterizing healthcare professionals' perceptions of the person-centeredness of care in this context. Identifying personal and professional variables that influence these perceptions could provide a starting point for defining strategies to move practice toward person-centeredness and for monitoring changes in healthcare practice.

How could clinical services respond to the person-centred care needs of adults living with heart failure? A qualitative cross-sectional study with patients, caregivers and healthcare professionals in Thailand ID 268

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Introduction: Heart failure is a leading cause of serious health-related suffering in low- and middle-income countries (LMICs), and is associated with high symptom burden, clinical uncertainty, and unplanned, prolonged hospital admissions. Person-centred care (PCC), a critical component of high-quality healthcare, is particularly vital in the context of a serious illness such as heart failure. However, PCC evolved in a few high-income countries and there are limited data exploring this concept in this population in LMICs. The aim of this study was to generate evidence-based recommendations for relevant PCC for individuals with heart failure in Thailand, with potential for adaptation in other settings. Methods: Cross-sectional qualitative study. In depth, semi-structured interviews were conducted in Thailand with heart failure patients (n=14), their caregivers (n=10) and HCPs (n=12). Framework analysis was conducted with deductive coding to populate an a priori coding frame based on an existing model of PCC, with further inductive coding of novel findings to expand the frame. Results: The study findings reveal specific practice actions that deliver PCC for persons living with heart failure in Thailand. Such actions include proactive responses to physical, psychological, social, relational and information needs of patients and caregivers, engaging patients and families in symptom management, providing opportunities for patients to be cared for in the community and at home, and considering and responding to the social determinants of health and healthcare access. Conclusion: Person-centred policy and healthcare must aim to address the social determinants of health and illness, and person-centred interventions for heart failure patients must be tailored to correct for prevalent negative social determinants. To enable PCC, health systems should bolster local, decentralised levels of healthcare service provision, placing focus on community- and home-based care. Heart failure patients and caregivers must be supported to self-care and self-manage, including how to recognise symptoms, take appropriate action, and using home therapeutic equipment.

## Theoretical Perspectives

### Relational Ethics in Medical Technologies and Digital Health – a Person-Centred Analysis. ID 322

*David Edvardsson, La Trobe University, Goteborgs universitet; Riitta Subonen, University of Turku; Minna Stolt, University of Turku*

Health care organisations globally are developing and implementing digital health services in a systemic shift towards medical technologies and digital care. Digital health has been defined as any application of information and communication technologies to improve healthcare and health outcomes, and the current emergence of medical technologies moves rapidly and broadly across clinical specialties. The concept and application of ethics and person-centredness in such digital medical technology is surprisingly absent from scholarly and clinical debate. For example, Martin Buber suggests relational ethics in terms of I-it relationships or I-thou relationships. Firstly, I-it relationships refers to objectifying, distant and instrumental ways of relating to others, and indicates partial, pragmatic or partial interactions where “it” remains the object for I. Secondly, I-thou denotes a more person-centred and relational ethics where oneself and the other have encounters that are mutual, reciprocal, equivalent and dialogical where the I engage personally with the thou. Such relational ethics also emerges in the GPCC theoretical framework where the patient’s story, forming a partnership and using narratives for documentation are key. I-thou relationships can develop when we conceptualize, describe and act towards others in terms of who they are rather than what they are, when encounters are close and personal instead of distant and professional. As medical technology and digital health services influence relationships in particular ways, there is a need to further analyse, highlight and critically discuss the ethics and person-centredness in such applications, particularly for older adults. This paper will contribute with such a critical analysis of relational ethics and person-centredness in the context of medical technologies and digital health.

### Reframing the gap: methodological reflections on linking theory and practice using an example from the field of person-centred care ID 053

*Martin Wallner, Karl Landsteiner University of Health Sciences; Hanna Mayer, Karl Landsteiner University of Health Sciences*

The relationship between theory and practice in nursing is often characterised as tense and has been metaphorically described as a gap that needs to be bridged or levelled. Both areas, theory, and practice, are based on different logics of action



and sources of knowledge. Using this tension constructively is a challenge that must be faced on both sides. Person-centred care exemplifies this issue, where theoretical frameworks often encounter obstacles in practical application. Using an example of theory development from the field of person-centredness in long-term care, we aim to demonstrate how such a balancing act between theory and practice can be achieved. In this case, mutual understanding between theory (researchers) and practice (practitioners) was facilitated through a collaborative, dialogical approach that served both theory development as well as practice development. The metaphorical gap was thus, in a sense, reframed as its opposite: it was not a separating but a connecting element between theory and practice; a collaborative and discursive space in which actors from both fields met as equals and existing tensions were channelled into constructive paths through dialogue. We will conclude by discussing lessons learned and perspectives for future inquiry.

### Facilitating patient-centred care, satisfaction, and engagement using the 6 aims of nursing ID 123

*Margaret Erickson, American Holistic Nurses Credentialing Corporation*

Nurses today are challenged with high nurse-patient ratios; clients with complex healthcare challenges; and emotional-laden work environments. In addition, they are often taught within a biomedical paradigm, focusing on curing versus caring-healing. The result is many nurses experience a disconnect between their desire and need to practice person-centered care and the reality experienced in their work setting. Consequently, they may suffer from compassion-fatigue, burnout, and emotional exhaustion. This results in less than optimal patient care, decreased patient satisfaction and wellbeing; diminished nurse satisfaction and resiliency; and a focus on tasks versus patient-centered care. One way to help decrease nurse stress and improve quality of patient care is by facilitating holistic theory-based-nursing practice. When nurses are able to clearly articulate what they know, why and how they are intervening, and effect desired outcomes they are able to communicate their value and decisions with their consumers, colleagues, and other stakeholders. Furthermore, they are able to positively, intentionally, and purposefully guide their nursing practice and engage in person-centered care. The Six Aims of Nursing Interactions, based on the theory of Modeling and Role-Modeling provides a theoretical framework that can help nurses practice from a holistic framework, while increasing their productivity, decreasing their stress, increasing their feelings of satisfaction and professional accomplishments; and most importantly increase their clients' state of wellbeing. This presentation will offer nurses a framework that can be used with any population, in any setting. Through the creation of a safe, trusting, and sacred space, nurses engage with their clients to facilitate a sense of hope, control, affirmation, and empowerment to establish mutual goals that will initiate greater states of eudaemonistic health and wellbeing. Following the presentation, participants will be able to apply the major

content presented into their practice, engaging and empowering their patients; essential to implementing Patient-centered care.

## The Lesson of Sleeping Beauty: Person-centred Practice in the face of Levinas' Radical Alterity ID 111

*Theresa Clement, Karl Landsteiner Privatuniversität für Gesundheitswissenschaften; Hanna Mayer, Karl Landsteiner Privatuniversität für Gesundheitswissenschaften; Brendan McCormack, The University of Sydney*

The development of a person-centred care practice is inextricably linked with the debate about being a person and personhood. This debate takes on a particular relevance when certain prerequisites, which are often used as defining characteristics, can no longer be fulfilled by our counterparts. This is the case, for example, with intensive care patients who are often (temporarily) impaired in their responsiveness and consciousness due to their critical state of health. Due to sedation, severity of illness and loss of voice, delivery of person-centred care in the intensive care setting is described as challenging (Cederwall et al. 2018). Despite far reaching implications on the therapeutic, ethical, and legal handling of this patient clientele, a definition of personhood at the stage of briefly diminished (by anesthetic measures), limited, or absent consciousness and ability to communicate has so far been discussed only superficially. In order to meet this challenge and to develop an understanding of person-centred practice suitable for the context of intensive care, Emmanuel Levinas' relational ethics and his understanding of radical alterity will be discussed. We uncover the implications of Levinas Ethics of Radical Alterity on the care for the unconscious and unresponsive patient in the ICU setting and further on the person-centred approach to practice. This provides an opportunity for the ontological embedding of the person-centred care approach, which makes it possible to meet and care for these patients in a person-centred manner.

### References

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## The Power and Challenges of Photovoice in Nursing Research ID 206

*Sepideh Olausson, Institution of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg*

This presentation will share the experiences derived from using the photovoice methodology to research the lived experiences of place and space in ICUs where voiceless and critically ill patients and their families are cared for (Olausson &

Lindahl, 2022). Photovoice, conceptualized by Wang and Burris (1997) is rooted in feminist theory, Freire's educational methods, and documentary photography. At its core, photovoice aims to amplify awareness and actively involve individuals in decision-making processes concerning their community. Whereas traditional research methodologies often adopt a stance of "research on people," photovoice distinguishes itself by transitioning towards "research with people." This participatory approach primarily serves as a tool to empower participants, giving people a voice and platform to share their experiences. In this project photovoice methodology was modified and contextualized specifically for the ICU context to capture the critically ill patients' lived experiences. However, undertaking photography within the ICU poses its challenges, primarily due to ethical considerations and the presence of patients who may be unable to express their concerns. Yet, this method offers valuable insights into tangible experiences, underscoring the importance of place and space in delivering patient care. This presentation will focus on the theoretical and methodological considerations that arise when employing photovoice within the realm of nursing research and offers practical examples.

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## Tools and Assessments

Prioritizing Patient Reported Outcome Measures (PROMs) to use in the clinical care of youth living with mental health concerns. A Nominal Group Technique Study ID 255

*Kalpna Thapa Bajgain, University of Calgary; Justino Mendoza, General Psychology, Capella University; Fariba Aghajafari, Department of medicine, University of Calgary; Karen Tang, Department of medicine, University of Calgary; Jeniffer Zwicker, Faculty of Kinesiology, University of Calgary; Maria Santana, Department of Pediatrics, University of Calgary*

Background: In the past few decades, particularly in the mental health setting, there has been growing interest in using Patient Reported Outcome Measures (PROMs) to assess the efficacy of the treatments in healthcare systems. Despite recent initiatives for global harmonization, there remains a lack of consensus on which PROMs are best practice and appropriate. Engagement of the service users, such as patients and family members/caregivers, is vital at this stage to ensure the selected PROMs are feasible, relevant, and acceptable to them. This study aimed to prioritize PROMs by youth and family/caregiver based on feasibility, relevance,

and overall importance to be used in the clinical care of youth living with anxiety and/ or depression. Methods: Ten validated and widely used PROMs were presented to the patient and family/caregivers. Nominal group techniques were employed to prioritize the PROMs based on feasibility, relevance, and overall importance. Results: For patients and families/caregivers, the PROMs, Revised Child Anxiety and Depression Scale (RCAD 25), and The Young Person's Core (YP-CORE) were the highest priorities. Both felt that RCAD 25 was comprehensive, short, easy, and quick to complete, whereas regarding YP-CORE, patients and family/caregivers thought it was also short and relevant. Due to some specific concerns, the Strength and Difficulties Questionnaire and Child Health Questionnaire were the lowest prioritized by patients and family/caregivers. Conclusion: It is of utmost importance that patient's and family/caregivers' voices or opinions are considered while selecting and implementing PROMs in mental health settings. Our study provides practical recommendations around measures best suited to achieve this.

## Exploring patient preferences for monitoring nutritional intake ID 157

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Background: The nutritional status of hospitalized patients has a great impact on their morbidity and mortality. Nutritional monitoring of food and fluid intake gives insight into the nutritional status of a patient and is used as a method for nutritional follow up. Traditionally, monitoring is done manually by hospital staff which usually excludes patient inclusion, participation and collaboration. Negotiating patient, or significant other, inclusion and participation in the monitoring process would enhance a personcentred approach to care. To do this, we need to understand what patients value and how they perceive the role of others and their own (potential) role in manually or technologically monitoring their nutritional intake. Such an approach is conducive to the values of respecting unicity and selfdetermination, as well as mutual respect and understanding between service users and healthcare professionals (McCormack et al., 2021). This research aims to explore patient values, needs, beliefs and abilities with regards to monitoring nutritional intake within a hospital setting. Findings will be used to construct patient preference profiles for monitoring nutritional intake. Methods: This cross-sectional study used a quantitative survey among consenting, hospitalized patients, in an urban hospital, between May and November 2023. Outcome measures included demographic features, the validated short form Patient Activation Measure' (PAM-13), the validated 'Dutch Health Literacy Questionnaire' (HLQ), as well as digital skills and statements regarding patients' values, needs and beliefs.

Logistical regression will be performed to explore associations between patient characteristics (demographic features, activation, health literacy, digital skills) and their preferences for monitoring. Results: Patient preference profiles for monitoring nutritional intake, based on statistical analyses exploring associations between patient characteristics and monitoring preferences, will be presented at the conference.

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## Experiences from using Patient-Reported Outcome Measures (PROMs) for person-centred care in a Swiss sarcoma center ID 071

*Mayuri Sivanathan, University Hospital Basel*

**Background:** Sarcoma is a rare but life-threatening disease. During the course of the disease, many patients experience physical and psychological burden and therefore a reduced quality of life. To address such patients' needs from diagnosis until follow-up care an Advanced Practice Nursing (APN) service was implemented in January 2020 at a Swiss university hospital sarcoma center. In this sarcoma center, patient-reported outcome measures (PROMs) were introduced following a multi-center longitudinal feasibility study<sup>1</sup>. The APN service includes planning and coordinating person-centred care using PROMs. Experiences from using PROMs in the APN service are presented. **Methods:** The following PROMs were collected from October 2021 to July 2023: EQ-5D-5L-CH (quality of life), Pearlman Mayo Survey of Needs (needs and burden), Distress-Thermometer (distress) and TESS-Toronto Extremity Salvage Score (physical functionality). After primary diagnosis, PROMs were issued as online questionnaires when a treatment included a surgical therapy. PROMs were provided at five time points during patient pathway: after diagnosis, 6 weeks postoperatively, 3-, 6- and 12-months postoperatively. **Results:** By using PROMs for patients (n=45) within the APN service, their needs could be addressed individually. PROMs allowed to plan nursing consultations, monitor symptoms and to communicate person-centred considering patients' values and beliefs. The APN responded on priority needs, evaluated initiated interventions and planned new interventions together with patients. **Conclusions:** There is potential in collecting PROMs systematically to coordinate individual patient care. PROMs enhance person-centred care as patients' needs are addressed in a timely and effective manner. Also shared decision making is facilitated. Moreover, PROMs enable improving support in patients' self-management, which encourages patients' autonomy and in turn supports a trustful APN-patient relationship.

References

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## Operationalizing a Culturally Competent Patient Satisfaction Assessment Tool for the Philippines using a Co-production Model between Providers, Patients and Families ID 150

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Ensuring good patient experience is an integral component of providing high-quality care. Patient satisfaction (PX) surveys have evolved globally since the early 1990's, using standardized questionnaires. The aim of this initiative is to develop a standardized culturally competent patient satisfaction survey for Filipinos, that is co-produced by healthcare providers and patients. Methods: The interdisciplinary team from the Institute for Advancing Care Transformation (i-ACT) of Great Valley Medical Center in the Philippines, reviewed the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), the Picker Patient Experience Questionnaire, the UK National Health Service inpatient survey and existing local tools. Select questions were modified to be culturally competent. Questions about hospital efficiency, security and access to parking were added as these were deemed important to local environment and processes of care. The initial survey incorporated a total of 24 questions. We administered the Survey to a diverse cohort from the Philippines' National Capital Region (NCR) with a multi-modal approach using digital and paper forms. Questions to assess generalizability, clarity and relevance of the tool were included. We conducted focused interviews for feedback to implement rapid cycle improvement. Results: 98% (N=55/56) concurred that the goal of the survey, instructions and questions were clear and relevant to patient experience. Qualitative feedback suggested the inclusion of preferred language/dialect to patient demographics and revision of question related to inclusion of next of kin. Discussion: Co-production models between providers and patients help us gain unique perspective to help develop a culturally competent tool to assess patient satisfaction. We were able to incorporate elements unique to the local settings of care. Culturally, Filipinos rely heavily on next of kin

## Author Index

for decision making. The inclusion of next of kin as respondent, is vital for quality improvement to drive family and patient-centered care. Next step will include beta-testing and spread.

SURVEY TOOL			
	Digital	26	46%
	Forms	30	54%
	TOTAL	56	100%

WITH RECENT HOSPITAL EXPERIENCE (N=42)			
	Private	33	79%
	Public	9	21%

GENDER			
	Female	30	54%
	Male	26	46%

AGE			
	18-24 y/o	8	14%
	25-34 y/o	18	32%
	35-44y/o	11	20%
	45-64 y/o	13	23%
	≥65 y/o	6	11%

IDENTIFICATION			
	Patient	31	55%
	Next of Kin	11	20%
	N/A	14	25%

BETA TEST	Achieved % (N)	Partially Achieved % (N)	Not Achieved % (N)
1. The goal of the survey was clearly stated.	62% (35)	38% (21)	
2. The instructions were easy to follow.	62% (35)	36% (20)	2% (1)
3. The survey questions were presented in a way you can easily understand. (Please state the question(s) that needs improvement.)	68% (38)	30% (17)	2% (1)
4. The questions included in the survey were relevant to your patient experience.	61% (34)	39% (22)	

## Insights from the process of translation and cultural adaptation of the Person-centred Practice Inventory Staff (PCPI-S) in German Language ID 241

*Christoph von Dach, Bern University of Applied Science / Solothurner Spitäler AG, Switzerland; Nanja Schlup, University Hospital of Psychiatry, Bern, Switzerland; Stefan Gschwenter, Karl Landsteiner University of Health Science, Krems, Austria; Brendan McCormack, Sydney Nursing School, The University of Sydney, Sydney, Australia*

Background: The Person-centred Practice Framework (1) represents a cornerstone for practice development in healthcare and gets increasingly common. To measure the effect the Person-Centred Practice Inventory—Staff (PCPI-S) is used. It measures clinicians' experience of a person-centred culture in English language (2). Method: A cross-sectional observational study followed the guidelines of good practice for the translation and cross-cultural adaptation (3). First step involved the translation and cultural adaptation to the acute care setting. For the second step, psychometric retesting and statistical analysis based on a quantitative cross-sectional survey were undertaken. To evaluate the construct validity, a confirmatory factor analysis was implemented. Cronbach's alpha was used to determine the internal consistency. Further a consensus conference took place with experts in the field from Austria, Germany, and Switzerland, to culturally adapt the person-centered practice framework and related models and concepts into German language. Results: A sample of 711 nurses in a Swiss acute care setting participated in the study. Confirmatory factor analysis indicated a good overall model fit, validating the strong theoretical framework, which underpins the PCPI-S aG Swiss. The results the harmonized translations are crucial for the further development of person-centered practice in German spoken countries. Conclusion: The chosen procedure ensured cultural adaptation to the German-speaking part of Switzerland. The psychometric results were good to excellent and comparable

with other translations of the instrument. Discussion: As a result, the importance of the use of language and words in fostering a common understanding has been showed. In this presentation the procedure for translating and the culturally adapting the PCPI-S will be presented. Furthermore, it will illustrate how to organize a process to achieve a harmonized translation. The experiences of these three nations can serve as a role model for other countries facing with similar challenges.

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## Development of an item bank to measure patient-reported experience of person-centred care ID 314

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Background: Reorienting healthcare towards a more person-centred approach requires new approaches to evaluate whether care is perceived as person-centred from the patients' perspective. The overall aim of this project was to develop a Rasch-analysed item bank to describe and measure patient experiences of person-centred care for people with chronic or long-term conditions. Methods: From a previous review of extant patient-reported experience measures for Person-centred care, items that best probed the University of Gothenburg Centre for Person-Centred Care and the Person-Centred Coordinated Care conceptual models was selected. The candidate items were translated into Swedish before a qualitative item analyse with two validation rounds using questionnaires, a focus group, and individual interviews with different stakeholders. Resulting items (n = 57) were handed out to 140 adults with various cancer diseases in Sweden and to 501 adults with different types of long-term conditions in the United Kingdom. Rasch analyse was used to examine psychometric properties of the candidate items. Results: Out of 855 items, 155 item was translated to Swedish and 111 items was selected for the qualitative analysis. The language used in many of the extant questionnaires was outdated and even inappropriate for the core principles of



PCC. The qualitative item analysis resulted in 57 items, rewritten as statements and to position patients as actively partnering in their care. For the initial analysis there were several indicators of misfit such as signs of local dependency. Local dependency could be accommodated for with superitems and/or by removal of items that did not fit the Rasch measurement model. Conclusion: The results support a hierarchical model of patient perceived person-centred care, from items regarding rapport and communication to higher levels with items representing the partnership, shared decisions, and goals. This item set can be used for development of a future item bank.

### Facilitating Positive Patient and Staff Experiences of Care and Improving Patient Outcomes, Using a developed Model of Person-Centred Lean Six Sigma. ID 325

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1.Problem / Background: Failure to understand the differences and relationship between person-centredness, person-centred care and person-centred cultures can result in improvement initiatives that rely exclusively on measurement, hard evidence and tangible outcomes, and fail to take account of authentic patient and staff experiences of care. Developing this understanding therefore has implications for improvement theory, research, education, policy, and practice. 2.Goals/Objective: To research, develop, pilot and deploy a user friendly model of Person-centred Lean Six Sigma (PCLSS), to guide practitioners in carrying out improvement initiatives, and facilitate positive patient and staff experiences of care, and improved patient outcomes. 3. Methodology: · A full systematic review of the relevant literature · A realist review of the relevant literature · A realist evaluation with a purposive sample of qualified Lean Six Sigma healthcare practitioners · Testing of the developed model within acute hospital study sites · Model refinement and wider deployment. 4.Findings: Since development, the model has been used and has been shown to be effective in designing and redesigning care pathways in single-study sites in public hospitals (Connolly et al., 2020; Teeling et al., 2020; 2021), private hospitals (Daly et al., 2021, 2022; Ward et al., 2022) and community health (Donegan et al., 2021) settings in Ireland, and more recently in a multi-site (n=10) hospital and community health context (Teeling, Keown et al., 2023). 5.Key Learnings: The study has demonstrated that use of a PCCLSS model to guide improvement work facilitates better health for all, by promoting a deep understanding of the values, beliefs, habits and routines of staff supporting them in their improvement work, acknowledging the work they

do, showing respect for them and their work, and not approaching improvement as a decontextualised toolkit. This facilitates the delivery of excellent, quality patient care. Better health for all.

## Life-limiting Conditions

Nonverbal communication about life-threatening disease -  
A qualitative study of experiences expressed by patients  
and significant others ID 188

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Background: Communication about life-threatening disease is essential but mainly studied with caregiver's perspective included, focused on verbal components. How patients communicate about disease in relation to significant others, we know less about. Despite the fundamentality of nonverbal communication, its dimensions in communication about disease, has not been extensively examined. This study aimed to understand and characterize patients' experiences of nonverbal communication about disease, in relation to significant others. Method: A secondary qualitative content analysis was applied on 23 in-depth interviews with patients (15) in specialized palliative care at home in Sweden and their significant others (8). Results: Patients express experiences of nonverbal communication in the form of cues, conveying meaning about disease and its consequences, often beyond their control. These dimensions of nonverbal communication are characterized as: body talk, extension talk and action talk. Both patients and significant others find these cues important and actively related to how bodily appearance, aids, and acts, serve communicative functions. Patients choose whether to verbally comment on the nonverbal communication due to their intentions, considering individual needs, care for others as well as an evaluation of the relationship. Significant others acknowledge the presence of nonverbal cues and stress their efforts to interpret their meaning, often without verbally commenting on this to the patient. Conclusion: This study contributes to a knowledge base on the dimensions and complexities of nonverbal communicative aspects in the context of disease. Professionals should be aware that dimensions of care, such as prescribed aids, from patients' perspective can be perceived as nonverbal cues that might "speak of" disease progression. Inconsistencies between

nonverbal and verbal communication about disease can be understood as in line with patients' intentions rather than a problem professionals need to solve.

## Feelings safe: Person-centred End-of-Life Care at Home

ID 064

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Background: Person-centred end-of-life care was set up by a Hospice in Scotland to enhance care in the community and support more people to be cared for and die at home. The underpinning theory for the model of care and the service was based on the Person-Centred Practice Framework developed by McCormack and McCance. Aim: To set up and evaluate a person-centred end-of-life care service at home through understanding both the key constructs that underpinned the service model as well as the outcomes for those who received the care. Method: A shared vision was developed for the service amongst stakeholders with jointly developing and agreeing on the necessary infrastructure that would underpin the service. Pluralist approach with the aim of understanding both what was happening and how it happened as the service was developed and delivered. To provide a deep and realistic illustration of the components and structure (mechanism) as well as outcome of the service through a detailed process information and understanding as to what happens and why. Findings: This study has brought to light the essential elements of the service and how and why these worked. Providing an in-depth understanding of a person-centred model of care that enables people with non-medical palliative care needs to be cared for and die at home. Thematic analysis highlighted three main constructs of the model; flexibility and responsiveness within the service, relationship-based care and enablement and empowerment. Conclusion: It was evident that the underpinning model of care provided a sense of safety at home which enabled people to stay and being cared for at home. This need to feel safe at home was fundamental to enable people to stay at home and die at home for those who participated in the study.

Patient perspectives on conversations with healthcare professionals about life in the context of serious illness and palliative care ID 164

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Background: A challenge for palliative care is the general perception that palliative care is equivalent to end-of-life care. This can make healthcare professionals hesitant to initiate conversations about early palliative care and life in the context of serious illness. There is therefore a risk that health care professionals postpone the introduction of palliative care to the very end of life. Aim: To describe and interpret patients' experiences and preferences for conversations with healthcare professionals about life in the context of serious illness and palliative care. Design and method: Qualitative design. Participants were recruited at a specialized palliative care unit and a hematology unit at a university hospital in Sweden. So far, nineteen people (55-84 years) have given their consent to participate and the interviews were conducted in the participants' homes. The transcribed audio recordings have been preliminarily analyzed qualitatively descriptively. After complete data collection, a more comprehensive phenomenological hermeneutic analysis will be conducted. Preliminary results: According to the patients, conversations about severe illness with healthcare professionals were mainly about disease-specific medical treatments. Conversations about the future, symptom relief, family support and places of care were only exemplified in conversations with palliative care specialists. Trust in the person the patient talks to about such issues is emphasized as more important than the person's profession. The concept of palliative care was perceived by several participants as a loaded word and something that did not yet apply to them. Rather, they said that palliative care will apply later when they need hospice care. Many participants wanted more knowledge about available support when disease-specific treatment is no longer possible. Discussion: There is a particular need for professionals to invite the patient to talk about uncertainties, the future, preferred places of care and what is particularly important to them.

Everyday life is governed by institutional cultures:  
Exploring everyday life concerns and priorities in  
residential care facilities through photo-elicitation  
interviews ID 018

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Background: There is currently a lack of literature on everyday life concerns and priorities in residential care facilities and how it affects the experience of the facility as a home in a Swedish context. This study hopes to contribute to closing the gap in knowledge through a participatory research approach. Aim: This study aimed to identify concerns and priorities in everyday life, as experienced by older persons living in residential care facilities. Methods: Thirteen frail older persons living in residential care facilities were involved in this study that applied photo elicitation interviews. This meant that the older persons were asked to take photos of their home in everyday life, and the photos were then followed up with individual interviews. The interviews and photos were analysed using reflexive thematic analysis. Preliminary results: The findings of this study are divided into core themes with the overarching theme: Everyday life is governed by institutional cultures, which meant that the residential care facility functioned as an institution with rules, norms, and routines that influenced both what the older persons did and how they experienced their everyday lives. This is further described in the core themes: The importance of dialogue and A game of power between older persons and staff, both with subthemes. Preliminary conclusions: The main conclusion is that the experience of the home as being governed by institutional cultures, and that the cultures were permeated by the scarcity of meaningful dialogue and a game of power. Power, dialogue, and culture are interdependent of each other. Person-centred climate was not always achieved and the result reveals areas where more research needs to be done, such as the prerequisites for residential care facilities of facilitating person centred care.

Caregiver singing and music activities in dementia care.  
Professional caregivers experiences of its similar and  
different benefits in the care of persons with dementia – A  
qualitative study ID 015

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Background: Caregiver singing is an intervention aiming to facilitate care situations and is defined as when caregivers sing for or together with persons with dementia during care activities. In the literature, it is commonly addressed as a music activity rather than a care intervention. The aim was to describe caregivers' experiences when using Caregiver singing and music in the care of persons with dementia. Method: Data were three focus group interviews with 12 professional caregivers for persons with dementia from three different residential settings. All caregivers had been taking training of the use of music and Caregiver singing and how to practice it in a person centered spirit. The focus groups were analysed using qualitative content analysis. Results: the analysis resulted in two themes: 1) Caregiver singing ease the moment, increase interaction, and build companionship and were preferable to use during care activities where commonly responsive behaviours occurs, such as during toilet visits od showering. Caregiver singing were described as an intervention to increase cooperation, communication and increase moods. 2) Music activities as reminiscence reflects the person's self which were used to increase socialization, increase energy and to increase moods and were more commonly used together with other residents such as during sing along activities, but also as background music during e.g. mealtimes. Regardless Caregiver singing or the use of music, the caregivers stressed the importance of person centeredness in choosing songs and music, as otherwise responsive behaviours may increase. Conclusion: Both Caregiver singing and music have positive influences and the results are sometimes intertwined. However, Caregiver singing are shown favourable to facilitate problematic caring situations and should be seen as a tool to increase cooperation and moods and decrease responsive behaviours such as resistance and aggression.

## Informal Care and Support

The meaning of support in persons living with chronic pain and its possible connection to person-centred care -  
Balancing between being the MVP and passing the ball ID  
022

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Background: Around 20% of the population live with chronic pain. Chronic pain negatively affects both the individuals, their family, friends and society. Support from social networks and health care is important in pain management. Understanding the meaning of support could contribute to improved tailoring of supportive interventions for persons living with chronic pain. Objective: To elucidate the meaning of lived experiences of support in persons with chronic pain and its connection to person-centred care. Methods: Ten participants (seven women, two men and one non-binary person) living with chronic pain were recruited from patient organisations in Sweden. Interview data from participants were analysed using a phenomenological hermeneutics approach. Findings: The meaning of support in persons with chronic pain is balancing between being a capable person and accepting support, which could be interpreted as balancing between being the most valuable player (MVP) and passing the ball. Conclusion: Support when living with chronic pain means balancing between being capable (the MVP) and accepting support (passing the ball). The findings confirms that persons living with chronic pain want to take the lead in their lives and pain management. This aligns with person-centred care, in which the patient being an expert and active partner is central. The findings also indicate that accepting support can enhance one's capability, which is pivotal in person-centred care.

## Carers of people with mental illness: results from a national survey ID 098

*Ingrid Lindholm, Swedish Family Care Competence Centre (SFCC) Nationellt kompetenscenter anhöriga (Nka)*

A national survey was conducted in the Autumn 2018-January 2019 by the Swedish Family Care Competence Centre (SFCC) and Linnaeus University. This presentation refers to a sub-study of the national survey with the aim of describing the situation of carers who regularly provide care, help and support to a significant other with mental illness. The survey study intended to provide answers to questions about how much care and support carers provide to their family member/s or friend/s, what support carers receive themselves and how their life situation can be affected by providing care and support. This study is an important contribution to the work being done to develop evidence-based support for carers of people with mental illness in Sweden. The results highlighted that a clear majority of carers of people with mental illness provided care and support on a daily or weekly basis and felt that it was demanding to some extent. Only a small proportion of carers of people with mental illness were offered support from the municipality, and more than half did not know who they could contact if needed. Results indicate the need for more information about where support is available and what type of support can be offered. Support that was widely requested was information and counselling, education, supportive conversations, health screening and health counselling and financial benefits/support. The study results will be discussed in relation to goals in the 1) Swedish National Carers Strategy, namely welfare efforts, a family perspective in health and social care, and support in one's role as a carer. Also, in relation to aspects of 2) Person-centred care; namely the themes of Listen and Together, which can be of significance to carers themselves and in their support to their significant other.

## The role of informal carers in person centred care - insights from a study on welfare technology for older people and their informal carers. ID 060

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The concept of person centred care is increasingly popular within healthcare in Sweden (1), and the ongoing reform “Good Quality, Local Healthcare “ (2) has been central in that development (3). Even though informal carers are included in the ongoing reform, position papers concerning person centred care primarily focus on partnership between the patient/service user and health and social care



staff (4). In contrast, the recent Swedish National Carer Strategy (5) recognizes the need for recognition of informal carers, and the internationally adopted concept of integrated, people-centred care also highlights informal carers as partners alongside the patient and formal health and care professionals (6) to ensure sustainable long-term care systems within Europe (7, 8). This presentation explores this divergence of views regarding the role of informal carers within person centred care with reference to recent PhD thesis findings regarding society's views of formal and informal care for older people within a Swedish context (9). The PhD studies illuminate the welfare technology solution discourse, that is, arguments in policy for the implementation and use of welfare technology to meet the challenges of an ageing population, finite financial resources and staff shortages, from the angle of international research, Swedish local policy, local politicians and older adults represented by pensioners' organisations. The presentation will focus on the findings concerning informal carers, which revealed how they were positioned as part of the older person's social sphere. This position ignores the help, support and/or care they provide to their older family member or friend on a regular basis. The pensioners' organisations viewed the discourse with concern and positioned informal carers as crucial for the older person's security and wellbeing. The presentation will conclude by inviting delegates to consider informal carers' role within person centred health and care services operating in their respective countries.

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## Caring for a partner with dementia during the Covid-19 pandemic: Lived experiences of spouse carers ID 154

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Background: While the challenges faced by healthcare professionals on the front lines of the COVID-19 pandemic are well-documented, less is known about its impact on informal carers. This study aims to describe the experiences of spouses of persons with dementia (PWD) living with and caring for their partners during the COVID-19 pandemic. Method: A phenomenological approach based on 24 phone interviews with spouses of community-dwelling persons with dementia. Result: The overarching patterns of the phenomenon revealed diverse experiences of fear related to COVID-19 and recommendations on social distancing. There was a difference between those perceiving their lives as relatively unchanged and those experiencing considerable change. Among those who experienced less change due to the pandemic, some were already in relative isolation because of their partner's dementia, while others were able to adapt to social distancing recommendations. While there was a distinction between those fearing COVID-19 and those who didn't, the capacity to adapt to the situation varied. Those caring for partners with extensive care needs and relying on home care were disproportionately affected by the lack of services. The experience of health and well-being also varied when the opportunity for recuperation diminished. Nonetheless, there are numerous accounts of health maintenance. This was attributed to increased access to rehabilitative measures for those who weren't afraid of COVID-19 and thus didn't hesitate to seek assistance. Following constituents emerged: Contrasting experiences of health, Living in fear, Healthcare as a vector of infection, Consequences of insufficient support, Existential distress of carer burden, Balancing loneliness with COVID-safe socialization. Conclusion: These findings emphasize the complexity of the pandemic's impact on persons with dementia (PWD) and their spouse carers. They underscore the necessity of understanding: resilience and adaptation, service accessibility, health and well-being maintenance, and the overall importance of tailored support and person-centered interventions.

### Social support, engagement and social identity in online support groups for family carers. ID 261

*Rosemary Daynes-Kearney, University of Limerick; Stephen Gallagher, University of Limerick*

Objectives: The study sought to explore the relationship between social support, engagement and health in online support groups (OSG) for family carers. Using the social identity approach it was anticipated that social identity was a key factor driving any association between social support, engagement and perceived stress. We hypothesised, first that those engaging with OSG would report lower levels of social support in real life compared to those who did not engage with OSG. Second, that those who engaged with OSG would report higher social support from their OSG members, and this would be correlated with a higher social identity with OSG members and together these would be associated with lower perceived stress in OSG members. Design: Data was collected using an online

survey. The survey was distributed through representative family caregiver support services nationally and internationally and made generally available online. Participants self-selected by following the link to the survey. Methods: 137 respondents completed the survey, of those 93% (n=127) were female and 69% (n=96) were white. The age range was 19-72 years old. 62% (n=91) of respondents used OSG, and of this group 25% engaged at least once a day. Results: There was no statistical difference between family caregivers who were or weren't in OSG from each other in terms of social support in real life,  $t(134) = -1.25, p > 0.05$  and perceived stress (134) = 0.16,  $p > 0.05$ . Within our OSG group, social identity was a positive predictor of social support,  $r = 0.64, p < 0.001$ . Unexpectedly, neither social identity nor social support were associated with perceived stress in this sample. Further analysis will be conducted to explore these results. Conclusions: The findings from this study will contribute to a list of recommendations being developed for use by practitioners, funders and policy makers.

## Online Support Groups for Family Caregivers: A Scoping Review ID 262

*Rosemary Daynes-Kearney, University of Limerick; Gallagher Stephen, University of Limerick*

Background: Caregiving can affect people of all ages and can have significant negative health impacts on family caregivers. Research has shown that social support acts as a buffer against many negative health impacts. A common source of social support is online support groups (OSG). Over the last decade the number of OSGs increased exponentially, however there is not consensus on what factors or characteristics of OSG contribute to the development of social support within these groups or what types of OSG are available to family caregivers. Objective: The purpose of this present study was to conduct a scoping review to contribute to the understanding of the types and characteristics of online support groups (OSGs) for family caregivers. Methods: Following the Prisma-ScR guidelines, the CINAHL, PsychInfo, Psych Articles, Social Sciences, Communication Source, Medline, and Web of Science databases were searched using inclusion and exclusion criteria. 19 studies were included in the review. The analysis process explored (1) what type of the social support groups are online for adult family caregivers (2) what are the communication medium and characteristics of these OSGs and (3) what psychosocial or other factors that made OSG successful or unsuccessful for participants? Results: We found that the majority of OSG took place on public text-based forums, were illness-specific and the most common communication medium found was text-based communication. Results for Q3 developed two overarching categories of safe communication and engagement. These described successful groups as having similar others with common life experiences sharing in non-judgmental space, overseen by trained peer or professional facilitators. Conclusions: There are several key considerations for OSG to be successful for family caregivers. A general recommendation for

practitioners is the importance of building active moderation and multi-faceted structures of support to meet different levels of caregiver needs and ability to engage.

## Health Equity

Identifying social determinants of health and quality of life measures for an Indigenous digital health ecosystem. ID 198

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Person-centred healthcare empowers individuals to have a more active role in their personal, social, and community health. This is particularly important for Indigenous communities, who have experienced historical and ongoing colonization and research atrocities. Indigenous ways of being align with a whole-person approach and extend to a nation-based, whole-community approach that respects Indigenous sovereignties. The purpose of this study is to explore and describe social determinants of health (SDOH) and quality of life (QOL) domains and indicators relevant for health and social services in Indigenous communities in Canada. We are critically examining the experiences, priorities, and concerns of Indigenous peoples regarding their SDOH/QOL by conducting: (a) a hermeneutic review of academic and grey literature, (b) an interpretive descriptive qualitative study involving Learning Alliance Table focus groups, storytelling, interviews, and (c) a Delphi study with Indigenous knowledge keepers and service providers. We gathered information from 98 academic articles and via 7 Learning Alliance focus groups, and 2 interviews. Data analysis (currently in progress) involves sensitized reading of the data to Indigenous worldviews. Initial results suggest that SDOH and QOL domains are not mutually exclusive and are grounded in underlying principles of interconnectedness and culture. Participants in the qualitative study shared Indigenous wellness stories describing intricate relationships across SDOH/QOL domains and highlighted the need of a holistic, strength-based framework that is adaptable within each community based on their unique circumstances. Our analysis identifies a gap in knowledge about how to integrate and use SDOH/QOL measures in digital health systems, and emphasizes privileging Indigenous voices for the use of their own data. A next phase of our research is to inform development of an SDOH/QOL measurement framework for integration into a person-centred, nation-based, community driven, and

culturally appropriate Indigenous digital health ecosystem for health and social services in Indigenous communities in Canada.

### Nudging Child Participation in Care through Norm-creative Technology ID 237

*Britta Teleman, Halmstad University; Anna Isaksson, Halmstad University*

**Background:** This study aims to fill the existing knowledge gap concerning the potential of support tools to amplify child perspectives and foster a more person-centred approach to children's care. Digital tools have been posited as advantageous in facilitating children's participation, and norm-critical design perspectives hold promise in enhancing inclusiveness within such support tools. This involves counteracting adult-centric and biomedical norms. Such perspectives also entail a shift in emphasis from solely addressing individual barriers to critically examining prevailing structures and contextual norms. **Methods:** Acknowledging the influential role and power position of care professionals, our paper explores 11 professionals' perceptions of how one digital support tool affected child participation in paediatric and social care meetings. Professionals' narratives were analysed from a socio-technical perspective. **Results:** We found that different aspects of the tool's design and materiality were perceived to improve the participatory conditions for some children but not all. In cases where professionals experienced that the tool facilitated participation, it was described how redistribution of control affected conversation topics, meeting dynamics, and involvement from guardians. Based on these experiences, professionals identified shortcomings in current approaches and practices. They expressed an increased openness toward new tools and proposed ideas for alternative ways of working. **Implications:** The results strengthen arguments about the importance of offering children different means of participation. We discuss what properties of the tool were perceived to facilitate instant participation, and also what implications such experiences may have for norm transformation in care contexts over time. The insights can help designers and care professionals aiming to nudge participation for children in care contexts.

### An Equity, Diversity and Inclusion-driven Approach to Designing a Person-Centred, Accessible Educational Intervention for Vaccination in Pregnancy Conversations in Canada ID 303

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One in four Canadians is foreign-born, and 78% of new Canadians belong to a visible minority. Ethnically diverse communities in Canada face disparities in vaccination uptake. Our team conducted a scoping review of resources available to support person-provider vaccine communication during pregnancy and revealed that only 2% of resources addressed ethnically diverse populations. Using an implementation science approach informed by behavioural sciences, we co-designed a more inclusive intervention to improve vaccine conversations between pregnant persons and their healthcare through a co-designed, multimodal, skill-based course for healthcare providers and a public-facing digital hub. Collaborating with patient and community partners from diverse newcomer communities, equity, diversity, and inclusion (EDI) consultants and adult learning specialists, the intervention content, language choices and mode of delivery were iteratively and rigorously developed employing an EDI lens. Co-design included working with 1) a diverse person council, 2) an expert panel of healthcare providers (doctors, midwives, doulas, nurses and pharmacists), 3) data from interviews and focus groups with pregnant persons and healthcare providers, 4) heuristics/functionality testing and 5) usability testing with diverse populations. We prioritized EDI principles along with the co-design of our educational intervention to ensure culturally safe care and communication, especially for newcomers and the broader ethnically diverse community in Canada. The intervention is person-centred and employs a combination of videos, text, and graphics designed to cater to different learning styles while ensuring that complex scientific information is accessible. Images were carefully selected to reflect our diverse patient population. Using EDI principles to develop interventions is a much-needed approach to healthcare intervention design in Canada. This initiative presents a model for developing person-centred healthcare resources that resonate with Canada's diverse population.

### Inclusive Knowledge Translation ID 277

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Inclusive Knowledge Translation (IKT) is an evolving approach that prioritizes diverse perspectives and collaborative processes to ensure that research findings are accessible, meaningful, and applicable across varied populations. Person-centred care, with its emphasis on tailoring healthcare to individual needs and preferences, demands a paradigm shift in knowledge translation. Traditional methods may inadvertently exclude certain demographics, hindering the universal applicability of research outcomes. In this context, IKT emerges as a crucial strategy to bridge these gaps and foster a healthcare landscape that truly serves all

stakeholders. This presentation will highlight principles of IKT, emphasizing the importance of engaging diverse stakeholders, including patients, families, and community members, throughout the research-to-practice continuum. By actively involving these voices, IKT strives to co-create knowledge that is relevant, culturally sensitive, and responsive to the unique needs of various populations. Furthermore, the session will showcase real IKT examples that were co-developed with patient, family, and community research partners, including the Patient Engagement Podcast (PEP Talks), the Patient Engagement Journal Club, Digital Storytelling, Patient-led co-created conference posters, etc. Attendees will gain insight into how IKT can help research findings reach a broader audience, and enhance communication, trust, and collaboration between academics and people with lived experiences.

### Predictors of preparedness for recovery following colorectal cancer surgery: A latent class trajectory analysis ID 196

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With an interest in providing knowledge for person-centred care, our overall goal is to contribute a greater understanding of diversity among patients in terms of their preparedness before and up to six months after colorectal cancer surgery. Our aim was to describe and provide a tentative explanation for differences in preparedness trajectory profiles. The study was explorative and used prospective longitudinal data from a previously published intervention study evaluating person-centred information and communication. The project was conducted at three hospitals in Sweden. Patient-reported outcomes measures, including the Longitudinal Preparedness for Colorectal Cancer Surgery Questionnaire, were collected before surgery, at discharge, and four to six weeks, three months, and six months after surgery. Clinical data were retrospectively obtained from patients' medical records. We used latent class growth models to identify latent classes that distinguish subgroups of patients who represent different preparedness trajectory profiles. To determine the most plausible number of latent classes, we considered statistical information about model fit and clinical practice relevance. We used multivariable regression models to identify variables that explain the latent classes. The sample (N = 488), comprising 56% women and 44% men, had a mean age of 68 years (SD = 11). Of the total sample, 60% had colon cancer and 40% rectal

cancer. The latent class growth models identified six latent classes with different preparedness for surgery and recovery trajectories. The latent classes were predominantly explained by differences in age, sex, physical classification based on comorbidities, treatment hospital, global health status, distress, and sense of coherence (i.e. comprehensibility and meaningfulness). Contrary to the received view that emphasizes standardized care practices, our results point to the need for adding person-centred and tailored approaches that consider individual differences in how patients are prepared before and during the recovery period related to colorectal cancer surgery.

## Co-creation

EUPATI Sweden – a practice-based description of the co-creation of a new training to increase patient partnership in research and development ID 248

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This abstract presents the co-creation of a Swedish patient training programme by patients, academia, industry, and the public sector to increase patient partnership in Research and Development (R&D) of medicines and medtech. It is a description of a practise-based innovation process in which over 20 organisations collaborated. Oral presentation will be made by second and third co-author. Background: The European Patients' Academy on Therapeutic Innovation (EUPATI)<sup>1</sup> is a multi-stakeholder public-private partnership with a mission to provide education that empowers patients to effectively partner in the R&D of medicines and medical devices. EUPATI Sweden<sup>2</sup>, the official Swedish national platform for EUPATI, was initiated by the Swedish Disability Rights Federation with support from a three-year project grant from the Swedish Inheritance Fund (Allmänna arvsfonden) from September 2021- 2024.<sup>3</sup> The aim of EUPATI Sweden is to increase patient participation in research by educating patients and representatives in Sweden. Co-creation of the EUPATI Sweden platform: EUPATI Sweden's platform development followed the British Design Council's Double Diamond design process, with four different phases. 1. Discover (Sep 2021 - Jan 2022): Engaged over 300 representatives from patient organizations, industry, 1 <https://eupati.eu/> 2 <https://eupati.se> 3 <https://www.government.se/government-agencies/swedish-inheritance-fundarvsfondsdelegationen/> academia, and public sector to identify needs and expectations. 2. Define (Feb - Aug 2022): Analyzed insights from the discovery phase, emphasizing a sustainable solution, demands on availability and



accessibility, and a content for training curriculum. 3. Develop (Sep - Mar 2022): Co-created 14 lectures with representatives from patient organizations, industry, academia, and the public sector to ensure accessibility, availability, and quality. 4. Deliver (Feb - Oct 2023): Piloted with 24 patients and representatives, analyzed and prioritized feedback until July 2023, and implemented selected improvements in Sep-Oct 2023. Results: The education platform was launched in November 2023. The training is freely available on-line. Matchmaking to connect patients and stakeholders is underway, and EUPATI Sweden is in the process of becoming an association

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1 <https://eupati.eu/>

2 <https://eupati.se>

3 <https://www.government.se/government-agencies/swedish-inheritance-fundarvsfondsdelegationen/>

## Co-developing patient and family engagement indicators for health system improvement with healthcare system stakeholders: A consensus study ID 253

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Background: Increasingly patients have been involved in health research and system transformation to inform priorities, care delivery and outcomes. While efforts to advance patient engagement in health research and system transformation exist; currently there are no system level indicators to measure meaningful patient engagement. Objective: The objective of this work is to develop a set of patient and family engagement indicators (PFE-Is) for measuring engagement in health system improvement for a Canadian provincial health delivery system. Methods: The three-phase project included: (1) review of the literature on measures of patient and family engagement. The Public and Patient Engagement Evaluation Tool (PPEET) was selected after consultations with a provincial advisory council; (2) surveys and one-on-one semi structured interviews with patient and family advisors, and staff members of the Alberta Health Services' Strategic Clinical Networks™ (SCNs) were conducted to capture the experiences of participants working together within their SCNs; (3) Delphi consensus process to identify and refine a core set of PFE-Is. Results: Specifically, 33 PFE-Is were developed through the survey results and themes identified from the interviews with stakeholders. These 33 drafted indicators were presented to the Delphi panel for prioritization. The consensus process yielded 18 final PFE-Is after 3 rounds of voting. These included indicators related to communication, comfort to contribute, supports needed for engagement, impact and influence of the engagement initiative, diversity of perspectives, respectful engagement, and working together. The indicators align with the core principles highlighted in the

Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework: Inclusiveness, Support, Mutual Respect, and Co-Build. Conclusion: This group of final PFE-Is can be used to measure and evaluate meaningful engagement in health research and system transformation. The use of these metrics can help to improve the quality of patient and family engagement to drive health research and system transformation.

### Co-developing research with parents, researchers, and healthcare professionals: Creating a measure of parent experience with family-centered care in the Neonatal Intensive Care Unit ID 293

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Background: The hospitalization of an infant within the complex environment of the Neonatal Intensive Care Unit (NICU) is incredibly stressful for families. Family-centered care (FCC) principles that integrate families into their parental role by forming relationships, sharing information, and supporting knowledge and skills are integral to NICU infant and parental health outcomes. Parents from a maternal-child health Parent Advisory Group in Alberta, Canada identified the need to evaluate parents' experiences with FCC in the NICU. However, reliable tools developed with contribution from stakeholders to evaluate parent experiences are lacking, despite the importance of FCC in NICUs. Objective: This in-progress research responds to the parents' call-to-action, with the objective to co-develop and validate an instrument to evaluate parents' experiences with FCC in the NICU. The Neonatal Intensive Care Experience Reporting (NICER) Instrument is being co-developed by a team of five parents, three researchers, and three healthcare professionals. Methods: The NICER Instrument co-development includes four phases. Phase 1 (complete): defining NICU-specific FCC principles to underpin instrument co-development. Phase 2 (in-progress): selecting items and validating content with parent, researcher, and healthcare professional advisory groups. Phase 3: pilot-testing the instrument amongst 30 NICU parents. Phase 4: assessing instrument reliability and validity across 300 NICU parents. Results and Implications: This co-developed research highlights how healthcare system gaps can be identified by patients and families, and how solutions can be addressed by collaborative teams of knowledge users embedded within a healthcare system. Throughout this research, the co-development team has gained practical knowledge to share related to (1) stakeholder engagement and network development; (2) working effectively with diverse knowledge users; and (3) the impact of patient and family input. Our takeaways from the co-development process highlight the importance of combining parent's experience, researcher's

expertise, and healthcare professional's knowledge to strengthen the content and relevance of FCC evaluation.

## Designing a Person-Centered Intervention to Improve Vaccine Confidence: A Patient-Led Study to Understand Parental Communication Preferences ID 301

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Background: Maternal immunization is underutilized as an approach to prevent maternal and neonatal mortality and morbidity from infectious diseases. The COVID-19 pandemic highlighted how important person-centered vaccine information and communication is to help address vaccine confidence in pregnancy. Understanding parental preferences regarding vaccination conversations with their healthcare providers is key to designing a person-centered intervention to improve vaccine confidence and uptake to protect moms and babies from vaccine-preventable infectious diseases. Methods: Two patient partners trained in Patient and Community Engagement Research (PaCER) recruited fourteen participants for online focus groups (n=4) and in-depth individual interviews (n=4) to understand parental preferences regarding vaccine conversations in pregnancy. Participants were from Canada and self-identified as either preparing for pregnancy, pregnant, postpartum, or breastfeeding. Data was analyzed deductively using thematic analysis. Results: Four themes were identified: 1. Communication Approach: Participants preferred a participatory communication approach during vaccine conversation in pregnancy reassuring their autonomy while receiving guidance to facilitate decision making. 2. Provider Relationship: Trust in their health care provider was more important to participants than the providers' profession. 3. Conversation Timing: Participants emphasized the importance of discussing vaccines early and often, allowing them time to reflect and discuss options with their partners before making decisions. 4. General Vaccine Conversation Experiences: Participants stressed mutual respect and the absence of coercion as crucial. They asked for empathetic consideration of their circumstances, concerns and values as well as information overload. Participants pointed out that what might feel like a routine discussion for a healthcare provider can be overwhelming to a parent, especially to a first-time parent. Conclusion: Pregnancy is a unique experience and even individuals who self-identify as vaccine-confident can experience decisional conflict when pregnant. Understanding the preferences of parents regarding vaccine conversations during pregnancy is indispensable in co-designing person-centred interventions to improve care and save lives.

## Patient-Centered Co-Creation: Exploring Methods and Experiences in Research and Innovation for Young Adult Cancer Care ID 178

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The purpose of this study is to critically discuss aspects of and methods for genuine co-creation (Hardyman et al., 2015) and partnership between patients and researchers. As a case and point of departure, we base the discussion on the experiences we have drawn from working in close collaboration in a research- and innovation project developing tools and services to care for and support young adult cancer patients. The foundation of the project was a person-centered approach placing the patient at the center, to ensure relevance and usability. Moreover, the team (consisting of adolescent and young adult (AYA) cancer survivors, an interdisciplinary group of researchers, and a health tech company in Sweden) strove to work together as equal partners to shape and influence the entire research and innovation process. The person-centered approach in the project is related to both to the goal of developing a digital platform for peer-support and to the methods and processes employed in developing it (i.e. engaging and involving patients in partnership as co-researchers and co-designers throughout the whole process). However, working with approaches and methods to achieve genuine co-creation necessitates an approach by which the patient consistently is placed at the core, and requires an ethical approach which entails “being knowledgeable and prepared; present and aware; adaptive and context sensitive; and honest and mindful” (Markham, 2006; Markham et al., 2018).

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## Experiences of patient participation in the governance and management of health care ID 319

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Developing a person-centred healthcare system does not occur in individual patient encounters; patients need to be involved at all levels. However, there is

limited knowledge about patient participation at the system level in a Swedish context. This study contributes by gathering the experiences of almost 500 patient representatives and regional and organizational representatives, such as politicians and government officials, who are involved in patient participation in healthcare governance. Our main data collection method has been a questionnaire sent to people identified as members of, for example patient councils. To our knowledge, this is the first survey of this magnitude in this field. We draw three forward-looking conclusions: 1. The regions need clear governance and systematic working methods for patient participation to create value. The majority of respondents believe that patient representatives offer valuable perspectives and should play a significant role in healthcare development. However, there are differing views on how patients should be involved. To maximize its potential, it is important to determine early on why the patient perspective is needed and the level of influence of the patient participants. 2. The patient organisations need to strive to continue to be relevant collaborative partners. Membership numbers in patient organisations are decreasing, particularly among younger people. The organisations, therefore, need to work actively with expanded recruitment and knowledge acquisition in order to represent broad patient groups. 3. Patient participation needs to be coordinated nationally to a greater degree than today. There is a growing tendency to emphasize the patient's perspective, also at the system level. The regions have handled this in different ways, resulting in a fragmented system. A government strategy could enhance coordination across regions, providing more equal conditions for patient representatives. Additionally, we see a need for a national platform that includes best practices and supports recruitment.

### A bold proposal to reduce tokenistic practices in patient and public involvement (PPI) initiatives on meso- and macro-level: Striving for “person-centred PPI” ID 337

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The Gothenburg person-centred care (GPCC) model (1–4) promotes genuine patient involvement in direct care settings through three routine steps: 1. Active listening and narrative elicitation (initiating the partnership), 2. Shared decision-

making and co-creation of a plan (safeguarding the partnership), 3. Documentation and continuity (implementing the partnership).

The GPCC model is based on Ricœur's ethical standpoint that guides our practical actions (4,5) and one intellectual strength of this model is its universality as it allows the three routine steps to be transferred to organisational levels and multilevel governance. This is especially interesting in the context of requests for increased patient and public involvement (PPI) initiatives in operative and strategic levels of healthcare systems (6). In such settings, patients or family carers can be involved by either representing themselves (as member of the public) or by representing an interest group (e.g., non-profit patient organisation). There is a plethora of frameworks for PPI (7–13), however, as Arnstein (13) pointed out in 1969, tokenistic practices are common, i.e. making only a symbolic effort to include citizens to give the appearance of valuing their perspectives. This is still commonly observed in PPI initiatives (14,15). Genuine PPI, however, aims for an honest recognition and integration of patients' and family carers' unique expertise and knowledge, as well as full transparency in decision-making. Here, we propose that through a person-centred approach, tokenism could be reduced if not eliminated by guiding our practical actions. We suggest following the three routine steps of the GPCC model (mentioned above) and striving for person-centredness in PPI initiatives. In practice, this is characterized by actively listening to each other's perspectives, developing a shared narrative, striving for shared and transparent decision-making, co-creation and documentation of plans to follow up continuously. In our presentation, we will elaborate on practical examples and best practices.

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## State of Science

### Mapping the concept of centeredness in health care research: A scoping review ID 155

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Various terms are used to describe centredness, there are no consensus definitions and various terms and concepts are often used interchangeably. This fact hinders focused database searches and thus hampers an overview of the research field. The objective of this scoping review was to map and categorise the extent, range, and nature of international literature on centeredness. The databases PubMed, Scopus, PsychINFO, CINAHL and Web of Science was searched using adapted search strings. Language restriction was English, and no time restriction. A combined manual and computer-assisted screening was used to identify relevant citations. The citations needed to explore, discuss, or elaborate on the construct of centredness in health care, i.e., care in which the patient is treated as a person encompassing a unique expertise in own health condition, where the patient is part of the healthcare team together with professionals and/or significant others. Data relevant to the aim were extracted and a uniform charting approach was used. The preliminary results were based on 1423 citations. A total of 57 countries were

represented in the sample but most publications were from the USA, the UK, Australia, Canada and Sweden. Citations from year 1973 up to today were represented showing an increase in publication rate in the beginning of the 21st century. A clear reduction in citations was seen in 2020-2021 which could be connected to the global pandemic. The terms most often used were patient-, person- and family-centeredness/centred care. The term 'patient' dominated up until 2018 where the term 'person' took over. Empirical studies were in majority, followed by theoretical studies and reviews. In the empirical studies, hospital care was the most common setting while home care was least common. The results provide an overview of current knowledge, which is of significance for further theoretical development as related to person-centred care.

### Costs and Associated Health Outcomes of Person-Centered Interventions: A Systematic Review ID 090

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Background: Person-Centered Care (PCC) has been associated with greater patient empowerment and economic benefits. However, results from individual cost-effectiveness studies regarding PCC are inconclusive, partially due to non-standardization in defining PCC along with only certain age groups or ailments being reported. Objective: To explore the current evidence on the costs and associated health outcomes of PCC, by populations studied and settings of care. Method: PubMed, Scopus, CINAHL, and grey literature were systematically searched using free text and MeSH terms related to PCC, cost, and benefit. Only papers defining PCC as partnership were included, and the degree of deviation from the University of Gothenburg center for person-centered care (GPCC) model was analyzed. Selection of studies and extraction of data were conducted by two independent reviewers. Data was then synthesized and categorized as PCC being either i) cost-effective, ii) cost-saving with negative health outcomes, iii) more costly but effective, or iv) more costly and less effective than usual care. Results: Of the 2,766 papers identified, only 32 met the inclusion criteria. All included studies reflected populations from developed countries and were predominantly random control trials or quasi-experimental designs. Majority of these studies (63%) had time horizons of one year or less and reported interventions for individuals over the age of 60 with long term and chronic conditions. Most studies found PCC to be more cost-effective, cost-saving, or potentially cost-saving (78%, n=25) than care as usual. Conclusion: This is the first study to systematically explore and analyze costs and benefits of PCC compared



to usual care or other models of PCC using a well-established definition of PCC. This study not only confirms that PCC is cost-effective overall, it also identifies potential areas of bias in both the population explored and the items being reported. Prospero Registration #: CRD42022313047

## State of science in Cardiovascular Person-centred Practice: A systematic review ID 167

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Background: Cardiovascular Person-centred Practice (cv-PCP) has increasingly changed the way care is provided to patients with cardiovascular conditions (Rossi et al, 2023). However, person-centeredness is often poorly defined in research and inconsistently implemented in practice. There is a need to systematically synthesize current evidence to identify avenues for development. In this study, we use theoretical concepts from the Person-centered Practice Framework to define and review cv-PCP (McCormack and McCance, 2017). Objective: This study aims to describe the current state of knowledge in cv-PCP and identify limitations, challenges, and potential opportunities for advancement. Method: A systematic review is currently underway. Terms related to cardiovascular care, person-centred practice, person-centredness, and patient-centred practice were systematically searched in Medline, Embase, Scopus, Cochrane Library, and CINAHL databases with support from a health sciences librarian. Journal publications, literature reviews and commentaries published since 2013 in English were included to capture contemporary practice. Studies were screened by two independent reviewers and cross-verified and merged by a third independent reviewer. All the reviewers have extensive experience in cardiovascular care and person-centred practice theory and measurement. Publications that met the inclusion criteria were critically appraised using CASP checklist (2018). PRISMA checklist was used for rigour and reporting. Data will be synthesized and categorized on the following criteria (i) definition of cv-PCP, (ii) measurement of cv-PCP, (iii) population of interest and (iv) cultural and global context. Results: At the time of submission, the review is underway and progressing as planned. Results will be available at the time of the conference, and we will use this opportunity to present our findings for the first time. Conclusion: This review will be the first to present the current state of science in cv-PCP using a globally accepted PCP framework and will provide recommendations to ensure the use of theory-based frameworks in guiding the implementation of person-centred cardiovascular care.

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## Key components in implementation of person-centred care for older people in out-of-hospital settings- A systematic review ID 036

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**Background:** This systematic review has previously been published in *Geriatric Nursing* [1]. As the global population ages, the demand for healthcare services for older people outside of hospital has grown significantly. This study is contemporary in the time of an ongoing reform to an integrated and person-centred care in Sweden. It provides a holistic overview of the current state of person-centred care interventions for older people in out-of-hospital settings. The review encompasses various healthcare settings, including primary care, home care, long-term care, and community-based services. **Objective:** The aim of this systematic review was to explore the content and essential components of implemented person-centered care in the out-of-hospital context for people aged 65 and older. **Method:** A systematic review was conducted, searching for published research in several electronic databases between 2017 and 2019. Original studies with both qualitative and quantitative methods were included and assessed according to the quality assessment tools EPHPP and CASP. **Results:** The results underscored four interconnected themes crucial to the implementation of person-centered care: 1. Recognizing and validating the patient as a whole person. 2. Co-creating a tailored health plan. 3. Engaging in teamwork across various healthcare professionals and fostering cooperation with both the older persons and their relatives. 4. Establishing a person-centred base with focus on preventive and health-promoting actions. **Conclusion:** Practicing a person-centred ethic, approaching an interpersonal and inter-professional teamwork is a crucial prerequisite to co-create integrated and person-centred care practice with and for older people and their relatives in their unique context. The importance of

preventive and health-promoting actions is emphasized in teamwork and consultation. It underscores the need for continued research, policy development, and practice innovation, to promote the adoption of person-centred care as a standard approach to caring for older adults in diverse healthcare settings.

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## The interplay of leadership dynamics and person-centred practice in nursing homes ID 106

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Background: A person-centred approach to healthcare in nursing homes can boost patient satisfaction and perception of care quality and contribute to higher job satisfaction among healthcare staff. Leaders hold a significant role in shaping the culture within nursing homes, crucial for the successful implementation and maintenance of a person-centred practice. While there exists some empirical evidence, a more comprehensive understanding is needed of how leaders foster and maintain person-centred practice in this setting. Aim: To identify the underlying leadership dynamics that facilitate the adoption and maintenance of a person-centred practice in nursing homes, informed by both leadership and staff insights. Methods: A systematic review was conducted using the Joanna Briggs Institute Methodology. Relevant articles were selected based on predefined criteria. Rayyan software was utilized for article screening and selection. Results: Ten studies, comprising five qualitative and five quantitative, were included in the review. The analysis yielded three core themes. First, leadership defined by a collectively endorsed vision for person-centred practice emerged as a central dynamic. Second, the importance of a consistent and systematic approach to realizing person-centred outcomes was underscored. Lastly, it was revealed that leaders play a pivotal role in leading by example, embodying person-centred values through their actions. Conclusions: The significance of leadership in facilitating the adoption and maintenance of a person-centred practice in nursing homes is confirmed by this systematic review. The leadership dynamics hinge on a collective vision, methodical pursuit of person-centred outcomes, and role-model behaviours. The role of leaders in setting and exemplifying person-centred values in nursing homes is paramount. These findings synthesize the existing body of knowledge, offering key findings that enhance our understanding and provide valuable insights for nursing home leaders and policymakers seeking to enhance person-centred practice in healthcare.

## Digitalisation and eHealth

Facilitating co-design processes: Researchers' reflective insights on person-centredness in co-design workshops ID 210

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Background: Co-design holds the potential to facilitate authentic and equitable collaboration between stakeholders and can be regarded as both a philosophy and a method that aligns with the values of person-centred care, which stresses equality and partnership. However, reflection on the role of the researchers and power relationships is necessary to ensure genuine and equal stakeholder participation in the design process. Currently, we lack creative solutions on how to include such reflections in the design process. As researchers leading a co-design project, we interrogated our interactions with stakeholders in consecutive reflective interviews and dialogues that accompanied a series of co-design workshops in interviews and dialogues. This study aimed to provide insight into how co-design workshops can be best facilitated to ensure a well-balanced, equal and collaborative group dynamic. Design: a qualitative descriptive study. Sample and setting: two researchers (nursing and human interaction) leading a co-design project. The project aims to develop person-centred tools that facilitate person-centred communication and enable people living with chronic pain to manage their lives better. It includes stakeholders such as healthcare professionals and patients. Data collection and analysis: A thematic analysis of ten consecutive individual semi-structured interviews and five dialogues recorded between September 2023 and January 2024, 24 hours after workshops with stakeholders. Results: Preliminary results show that co-design workshops require careful management to achieve a balance and dynamic that honours the participants' illness and life narratives yet enables tapping into the creative energies necessary for co-design and creating new, empowering narratives. For the researchers, it can be a challenge to navigate this process. Including patient representatives as moderators and a flexible project design play an important role in managing group dynamics. Conclusion: Reflection is essential for researchers to become aware of power relationships and equality to ensure person-centred, balanced, productive group dynamics in co-design.

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## In the field of tension between Technology and Person-centredness - A Caring Encounter in digital Space ID 156

*Theresa Clement, Karl Landsteiner University of Health Sciences; Katharina Gabl, Karl Landsteiner University of Health Sciences; Hanna Mayer, Karl Landsteiner University of Health Sciences*

Background: Supporting family caregivers has been identified as a high-priority health goal worldwide. Alles Clara (AC) is a novel social service in Austria that connects family caregivers with professional counselors from the fields of care and psychology via an app, thus offering flexible, low-threshold and yet personal counseling. As part of a larger-scale realist evaluation study we investigated how family caregivers experience the counseling in digital space and how counselors in AC carry out the consultation and experience their work. Method: We conducted eight narrative interviews with family caregivers who use the app and two focus group interviews with counselors in AC (n=5). Data were analyzed thematically and according to prior hypothesis generated in an initial program theory on how the digital counseling in AC is supposed to work. Findings: Findings suggest that aspects of anonymity, flexibility, and low-thresholdness, that characterize a digital tool like AC, have positive effects on family caregivers and counselors. However, we recognized that the key to successful counseling lies in the establishment of a trusting relationship, putting family caregivers at the center. In the counseling room, family caregivers remain anonymous, while they present their personal concerns, worries, and wishes. Counselors emphasize and see the achievements and abilities of family caregivers. As an elementary component and essential prerequisite of a relationship in the sense of professional nursing, the encounter plays a fundamental role. Both parties encounter each other in a way in which they allow themselves and the other to be the person they are. Conclusion: Person-centeredness and technology are often seen as incompatible because 'human closeness' would conflict with distanced technology. Our findings suggest that establishing relationships in a person-centred manner is possible also in digital space. However, the aspect of the caring encounter in the digital context needs to be further examined.

## Technology in healthcare innovations – moving beyond staring at the technology to working with the persons involved ID 272

*Christi Nierse, Fontys University of Applied Sciences, School of People and Health Studies; Teatske van der Zijpp, Fontys University of Applied Sciences, School of People and Health Studies; Shaun Cardiff, Fontys University of Applied Sciences, School of People and Health Studies; Camielle Noordam, Fontys University of Applied Sciences, School of People and Health Studies*

In an era of rapid technological advancement it's undeniable that many innovations have the potential to transform patient care. However, the current landscape often leans toward supply-driven adoption of healthcare technology, thereby overshadowing the critical aspect of its integration into healthcare practices, alongside a pressing need for person-centered care (Van Der Zijpp et al., 2022). We argue that a purely technological rational approach to integrating healthcare technology into practice threatens continued involvement of those patients and healthcare practitioners grappling with the impact of technology on person-centred care. An inclusive and dialogical approach fosters reciprocity, relational empowerment and mutual learning (Abma et al., 2009) as issues arising from the implementation into practice are predicted, described and resolved. In our project Living Longer @Home we used the principles of inclusivity and dialogue to guide the construction and analysis of multi-perspective/multi-stakeholder case narratives about the use of technology in community care. In this presentation we firstly reflect on the process of collecting and working with case narratives to facilitate dialogue on a person-centred approach to using healthcare technology. Bachelor student nurses were trained and supervised in the construction of multiple perspective narratives which they consequently fed back to teams for critical dialogue: exchanging of perspectives and collaborative action planning on the further use of health care technology within the team. Secondly, we will focus on the main themes deduced from a meta-analysis of those narratives collected by the nursing students. The themes illustrate affirming and competing values, needs and expectations of stakeholders, offering us learning about a person-centred approach to integrating health care technology into health care practice.

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## Empowering Pediatric Patients: Evaluating Patient Engagement Strategies in Co-creating Surgical Consent Videos ID 300

*Marina Rosa Filezjo, University of Calgary; Nishan Sharma, University of Calgary; Jennifer Thull-Freedman, University of Calgary; Fabio Ferri-de-Barros, University of Calgary; Maria Santana, University of Calgary*

Informed consent prior to any surgical procedure is a mandatory step in medical practice. According to the Canadian Medical Protective Association, the consent must be voluntary, and the patient or guardian must have capacity to

consent and be properly informed prior to consenting<sup>(1,2)</sup>. The literature shows that the traditional method (verbal) of informing patients and guardians may not provide enough understanding of all risk, benefits and expectations associated with the surgical procedure for treating scoliosis in pediatric patients. Health centers and research institutes are exploring innovative approaches to improve the comprehensibility of the informed consent process, including the use of multimedia sources (such as video tools)<sup>(3,4)</sup>. In this study, we collaborated with six patient partners to co-develop a video tool aiming to improve guardians' comprehension and understanding of the pre-operative surgical discussion preceding spinal surgery for pediatric scoliosis patients. This paper outlines the patient engagement strategy employed during the development of the educational video tool, providing a comprehensive description of this process. Both quantitative and qualitative data was collected from the public and patient engagement evaluation tool (PPEET)<sup>(5,6)</sup> to look into the effectiveness of the patient engagement strategy implemented in the co-creation of the educational video. Findings from the PPEET display positive results reinforcing the study's efforts to ensure inclusiveness, support, mutual respect, and co-building during the co-creation of the educational video.

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Cost-effectiveness of a Person-centered eHealth intervention to people with common mental disorders: A randomized controlled trial in western Sweden ID 199

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Background and aims: Effective and cost-efficient interventions are essential to reduce the impact of common mental disorders and facilitate work participation. The PROMISE project applied person-centered eHealth intervention as an add-on to the usual care to improve the health of patients with common mental disorders. Thus, the aim of this economic analysis was to evaluate the cost utility of this intervention compared to the usual care alone. Methods: An open randomized controlled trial was conducted from February 2018 to June 2020 in western Sweden with the sample size of 110 in the intervention and control groups, each. In the intervention group, individuals received person-centered eHealth services through telephone and a web-based digital platform in addition to the usual care. Meanwhile, the control group received only the usual care. Data were collected using questionnaires and by extracting from national and regional databases and registers, including follow-up records. The incremental cost-effectiveness ratio (ICER) was determined using Quality-Adjusted Life Years (QALYs) as the measure of health outcomes. This evaluation was conducted from a societal perspective, and the analysis followed the intention-to-treat principle. The study had a one-year time horizon. Results: The add-on person-centered eHealth intervention to the usual care resulted in an ICER value of -3776895, which was based on an average incremental cost of SEK -20296 and an average incremental gain in QALYs of 0.0054. This approach exhibits a 76.3% probability of being cost-effective. Conclusion: The add-on person-centered eHealth interventions to the usual care dominated the usual care alone in reducing the impact of common mental disorders, such as depression and anxiety, for patients taking sick leave



## Art, Media, and Performance

### Domstolen

*Tilda Karlsson; Interview with Anders Westgerd, CEO GIL*

We have interviewed Anders Westgerd, the CEO of GIL, who will be exhibiting the artwork “Domstolen” during the GCPCC in May 2024. GIL, which stands for Göteborg Cooperative for Independent Living, coordinates personal assistance. An important aspect of their work involves educating the public, increasing accessibility and changing attitudes towards individuals with disabilities. In Swedish, “Domstolen” is a play on words as the word means ‘court’ but also, translated literally, ‘chair of judgement’. Among other things, “Domstolen” serves as a discussion opener created to challenge people's attitudes and prejudices.

*You have a solid background in activism and spreading knowledge about functionality, would you like to tell us about your previous projects?* “Wow, we have done so many, I think we have done 33 projects since 2012. The starting point was the ‘CP doll GIL’. The ‘CP doll GIL’ is a doll that we created with a clear disability. Not all people have preconceived ideas, but there are many people who have an open need to coddle disabled people as if they were children or less knowledgeable, it is quite tiring. We developed a ‘CP doll’ for people who have that need. Coddle and behave badly with the doll but be nice in real life.”

*Anders tells us how the doll made it to the news overnight.* “Our doll was probably in every newspaper and got a lot of TV and radio exposure. It was also widely distributed internationally. In the beginning, we didn't know what would happen to the doll; no one really knew how big it would become. But somewhere along the line we knew that it would be provocative. We work a lot with humor and provocation. Humor is important to overcome the grimness, misery and tragedy that lies over our issues. Then humor is disarming and liberating. Provocation is good because people often become defensive, which provides an opportunity to meet these people in a discussion and hopefully change their attitude towards what we want to discuss. It is good if there is at least one nay-sayer because then the discussion lives longer.”

*In addition, GIL has also made a beer.* “The following year, we made ‘an ordinary CP beer’. Not because disabled people are bad at drinking alcohol, but because there has been a paradigm shift in the last 10-15 years where pubs and restaurants have become a living room, regardless of whether you drink alcohol or not. It is a meeting place. Pubs and restaurants are usually quite inaccessible if you have a disability, especially if you are in a wheelchair. Of course, we want to be able to

take part in it too, but there are high thresholds, stairs, heavy doors, crowded, high bar counters and quite often poor toilets. Then there are some people who think that "you with a disability should not drink alcohol". No - I have the right to decide for myself.”

*The beer was then launched at the largest health and social care fair in the Nordic region.* “We thought there was a lot of focus on diagnoses and aids, but not so much focus on living life. [...] When the fair was over, the beer had been drunk up. The media wrote a lot about the beer and then pubs and restaurants started contacting us. They had read about ‘An ordinary CP beer’, liked the message and the beer, and wanted to be a pub or restaurant that is accessible to everyone. They wanted to sell our beer, which we were not prepared for. [...] The requirement we set for a restaurant to be able to sell the beer was that people had to be able to get in and out by themselves, get a decent treatment and a toilet that worked. [...] For many people, beer is a de-dramatized way to start talking about these issues. [...] We work on a broad front, not only with campaigns, we have contact with politicians, the City of Gothenburg, write debate articles and are active in social media. It's about changing and transforming an inaccessible society and people's attitudes. At the same time, we do this because historically, lasting social change has not come from being nice and compliant. Of course, we also discuss these issues in a civilized manner, but we do not believe that this is the only way forward. Historically, people have been rather uninterested in our issues. Even the media has been uninterested in writing about our issues, there is no public interest or news value. I think most people living in Sweden believe that Sweden is the best in the world when it comes to accessibility. We are of course better than many countries but if you look at the countries in Western Europe, Sweden is one of the worst countries when it comes to accessibility. Then if you look at taxes and welfare, many people think that you get what you need, but that's not the case. We want to convey this myth to people. We also want to convey that we are ordinary people, even if we have disabilities. We are not UFOs or tricky things that are infected. We have dreams and ambitions about life like everyone else, just that we are not given the same opportunities to realise them. We also want to erase the idea that people should feel sorry for us. There are many people who feel sorry for people with disabilities, and if you feel sorry for a person you meet, the meeting will not be equal. We want people to understand that we are ordinary people by appearing in forums where people do not expect us to appear, reaching new target groups, educating people and normalising our issues. The ‘CP doll’, the ‘CP beer’ and *Domstolen* are good examples of how we spread our message.”

*You mentioned Domstolen which you will be exhibiting at GCPCC in May, can you tell us a bit about that?* “The work is about connecting to the widespread perception in society that life in a wheelchair is not worth living. *Domstolen* is coffin shaped like a wheelchair. We created it together with a famous furniture designer called Staffan Holm, he has won both national and international awards for his furniture work. Then we had an opening at the Röhsska Museum in May 2023, and now it's coming to you. The work challenges the myth that a disability equals an undignified and bad life. This is absolutely not the case, but a society that is not accessible and maintains differences between people based on function reinforces the public's sense that life with a disability is equal to death, and that death is preferable. *Domstolen* then becomes a manifestation of society's attitudes towards people with disabilities, it shows society's view of us with disabilities and how we are placed in a box that we ourselves do not recognize.”

*What thoughts do you hope the artwork evokes in those who see it at the GCPCC?* “That the artwork touches people and that you can live a good life even if you have a disability. We are full members of society with the same rights and obligations. Right now, we do not have the same rights and obligations as the rest of society. I can't move around freely in the streets, I can't enter premises freely, I can't use public transport freely, and sometimes I encounter biased attitudes. This is something we want to change through our various campaigns, including *Domstolen* to change and improve the world for individuals with disabilities. An accessible society is a society that is better for everyone, there are no contradictions. Everyone benefits from accessibility, but it is usually said that it is vital for maybe 10% of the population but convenient for 100%. But to get there, you have to make people understand and realise that disabled people are ordinary people who want to move in society just like ordinary people.”

*Where does your interest in activism come from?* “I think it's because I've lived in both worlds. You see how unfair and unequal society is. Somewhere it's probably my previous prejudices that are also some kind of catalyst. No one goes around planning to become disabled. It's just something that happens to others or something you happen to read about. Then suddenly it happened to me. I thought I was a tough and brave person before I got injured, then all of a sudden I became one of them - the disabled who are often portrayed as either superheroes or victims. It was very difficult for me to place myself in either of those categories. My journey of coming to terms with my situation and accepting it took maybe two and a half years. Before that it wasn't a straight line, it was darkness, isolation and suicidal thoughts. It was a dark journey until it turned around. Somehow that is

also what drives you forward in this work. To show that you can highlight these issues in a different way and make them more attractive - because they are very unattractive. The solidarity around our issues is very limited. They almost only concern those who invest in our issues, those who have a relative or work with them. Apart from that, there is not much involvement in our issues. From my perspective, this is also what drives my commitment, the desire to change and improve. But if you had asked me that before I got injured, I would probably have just shaken my head. Initially, when I was injured, there were no thoughts of activism either, it felt mostly bad that you couldn't move around like you used to, there was a lot you had to opt out of. The more I encountered it, the more critical I became. My disability is what it is, but how you create societies and people's attitudes - that's where you can actually make a difference. I changed my focus and felt that I wanted to do something but I didn't know how, who should I turn to? Can my little voice make a difference? [...] I've been at GIL since 2008, so that's 16 fun years. Then you can think it's fun to make 'CP dolls', 'CP beer' and *Domstolen*, but you don't really want to do that, you want to have progressed further in society. Somehow it feels like we're not the ones who should be pushing these issues, but politicians, municipalities and government agencies have a great responsibility to create accessible and inclusive societies. In that sense, it is quite tragic that we have to work in the way we do. Progress is slow and sometimes it even goes backwards, so it can be comfortless at times. Then you have to show perseverance and not give up.”





### Through the Nurses' Lens ID 088

*Rubina Rana, Trinity Western University; Nicole Kozak, Douglas College; Agnes Black, Providence Health care*




Person-centredness can focus on either those being care for or the care givers. This study and exhibit focus on the care givers. Photovoice is community-based, participatory action research that focuses on social justice, giving voice to those whose voices are not always heard. Nurses working in patient care during the COVID-19 pandemic from hospitals in British Columbia, Canada participated in this photovoice study, providing a local perspective and insight into nursing during the COVID-19 pandemic. This study used nurses' narratives and photographs to better understand the experience of caring for patients with the COVID-19 virus and encouraged change by nurses and health care leadership and understanding from the public. Participants noted that having a collective voice was therapeutic, allowing group discussions and expressions of shared stressors and celebration of collective progress. 12 nurses participated in this research study, submitting a total

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of 55 photos and narratives, as well as participating in focus groups. Data was analyzed using an inductive content analysis approach. Five main themes were identified from this rich data: “The Work of Nursing”, “Miscommunication”, “Fatigue”, “Resilience” and “Hope for the Future”. This exhibition is an opportunity to amplify the voices of nurses who felt challenged to keep patients at the center of their care and reflect on the first two years of the COVID-19 pandemic compared to where we are now. The exhibition will showcase the participants’ images submitted throughout this project, alongside their quotes. In this study, we were able to magnify the experiences of frontline nurses and give them a voice to make recommendations to leadership and policymakers. Nurses are positioned to ensure the perspectives of the patients are in the center of all care provided and their perspectives need to be considered and integrated into health care to support meaningful change and prepare for future pandemics. Image List:

<b>Image # (for printing )</b>	<b>Size</b>	<b>Title</b>	<b>Image Thumbnail</b>	<b>Medium</b>	<b>Year</b>
01	20" x 24"	Diligent Health Care Providers		Digital Photograph	2020
02	20" x 26"	Emotional Labor		Digital Photograph	2020
03	20" x 26"	A Peaceful-Looking Battlefield		Digital Photograph	2020
04	32" x 42"	These Tracks On My Face Tell A Story		Digital Photograph	2021






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05	20" x 26"	Ever Changing PPE requirements		Digital Photograph	2021
06	20" x 26"	Broken-Hearted		Digital Photograph	2020
07	20" x 34"	I Miss Hugs		Digital Photograph	2020
08	10" x 13"	Staying Calm		Digital Photograph	2021
09	26" x 20"	Chaos		Digital Photograph	2020
10	20" x 34"	Overwhelming Anxiety and Fear		Digital Photograph	2021

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11	20" x 26"	Five Stages of Grief		Digital Photograph	2020
12	20" x 26"	Light at the end of the tunnel		Digital Photograph	2020
13	24" x 38"	Vaccination		Digital Photograph	2021
14	20" x 26"	Resilience		Digital Photograph	2020
15	20" x 26"	The positive energy that keeps me going		Digital Photograph	2020
16	26" x 20"	Forest through the trees		Digital Photograph	2021
17	26" x 20"	Helping in Nunavut		Digital Photograph	2021

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18	26" x 20"	Gratitude Garden		Digital Photograph	2021
19	20" x 26"	Beauty and Sacrifice		Digital Photograph	2020
20	10" x 13"	Treasured time with family		Digital Photograph	2021
21	17" x 10"	Respite by the Ocean		Digital Photograph	2021
22	20" x 26"	Stand in my Shoes		Digital Photograph	2020

Please note, nurses participating in the photovoice study submitted images using pseudonyms, so we have not noted individual names of photographers below. Permission and photo releases were provided to share these photos.

Playing oneself as if another - Acting and directing strategies as practical approaches in person-centred health and care ID 134

*Victoria Brattström, University of Gothenburg Academy of music and drama*

The theatre has developed techniques for establishing partnership and handling interaction in collaborative work on the stage. Interplay in a practical theatrical context builds on the actors ability to make themselves receptive to their fellow actors onstage. The actor needs to understand how they are affected by the onstage action, as well as how they are affecting the onstage action, when acting within the framework of the scripted role and/or the dramatic situation. (Brattström 2015). The PhD study, performed as a collaborative project between the Academy of



Music and Drama and University of Gothenburg Centre for Person-centred Care, explores how particular techniques of acting and directing can contribute to person-centred health and care practice focusing the process of partnership-creation between patients and healthcare professionals in clinical healthcare encounters. The PhD study develops a method of analysis highlighting co-creative and analytical aspect of the acting and directing professions. Central to the study are the concepts of the magic 'I' and 'Given Circumstances' part of the system of acting techniques developed by actor and theatre director Konstantin Stanislavsky [1863–1938]. In the study transcribed audiorecordings from clinical healthcare encounters are explored through different steps of analysis including: (1) Interpretation of the transcripts as if they were scenes in a play, based on a director's way of analysing a playscript in the context of theatrical production. (2) Exploring the process of partnership-creation through interactive workshops with focusgroups. (3) "Rehearsal laboratories". The transcribed dialogues, transformed into the format of playscripts, are explored both from the point of view of the patient and professional role together with actors in a co-creative and analytical process similar to a theatrical rehearsal. The study reveals insights into the complex interplay between role- and personal identities in the process of partnership-creation and in the context of clinical healthcare encounters.

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It is as it is ID 217

*Maria Johansson Josephsson, Musikhögskolan Örebro Universitet; Tove Sahlin, Shake it Collaborations/ Kungliga dramaten*

It is as it is A song cycle-A dance macabre Through sincere musings, danced incantations and newly written music for one - and sometimes two voices - we encounter possible transactions, possible and impossible passages in time and space, the unmentionable but also the lust for life, the joy of being and a large measure of humor while dying - is cleaned out. It's a performance with two actors, they use their voices and bodies to make visible change in the different stages of life. The work has been created in a collaboration between Maria Johansson Josephsson, singer, actor and composer and Tove Sahlin choreographer and dancer. "It is as it is" is inspired by various theories and thoughts about change, transformation, care, decay and man's opportunity to find comfort in and believe in the power of music, dance and art. The theme that runs as a, perhaps somewhat blurred but still highly present, line through the entire work is the most central and yet among the most unmentionable themes in our lives: Life and death. The performance had its premiere in Stockholm in 2017 and has since then, among other things, played at festivals in Sweden and Germany and toured in Sweden for

the Riksteatern. "It is as it is" is an attempt at a post in a discussion about who we are and become in the cycles of change that meet humans throughout life, both the natural movements through the years but also the worrying injuries, diseases, caring person-centered practices and the worrying end of earthly life. Through the performative art and music, the actors are not looking for answers but something that can be compared to comfort, and it is also something comforting that they want to express through their song cycle and dance macabre- "It is as it is". For more information: <http://www.shakeitlab.com/it-is-as-it-is/>

## Digital Storytelling (DST) in Health Research: Amplifying Patient Voices to Improve Person-Centred Care ID 275

*Sandra Zelinsky, University of Calgary, Alberta SPOR SUPPORT Unit, Patient Engagement Team; Sadia Ahmed, University of Calgary, Alberta SPOR SUPPORT Unit, Patient Engagement Team; Maria Santana, University of Calgary, Alberta SPOR SUPPORT Unit, Patient Engagement Team; Paul Fairie, University of Calgary, Alberta SPOR SUPPORT Unit, Patient Engagement Team*

Stories and storytelling are powerful tools, helping us to make sense of our thoughts, feelings, and experiences, providing a deeper understanding of our environment, interactions, and values. This presentation explores the use of Digital Storytelling (DST) in health research, positioning it as an innovative Community-Based Participatory Research (CBPR) method that significantly enhances the involvement of individuals with lived experiences. As a CBPR method, DST serves as an innovative method to amplify the voices of underrepresented populations and people with lived experiences in healthcare, providing meaningful engagement with those who value storytelling as a way of knowing and understanding. Digital stories are short (3-5 minutes), first person video narratives created with the combination of images, video, narration, and music, offering a compelling and accessible medium for expression. The adoption of DST by academics across disciplines, including health research, over the past two decades underscores its versatility and impact. This presentation introduces the audience to the 7-step methodology (owning your insights, owning your emotions, finding the moment, seeing your story, hearing your story, assembling your story, and sharing your story) developed by Story Center, US (Lambert, J., 2020, *Digital Storytelling: Story Work for Urgent Time*, Berkeley, CA.: Digital Diner Press) and the inherent benefits and challenges of DST in the context of health research. Moreover, the presentation showcases healthcare-themed DST workshops and patient digital stories, illustrating how DSTs can serve as a powerful knowledge translation tool to enhance person-centred care. By offering tangible examples and insights, we aim to demonstrate the potential of DST in bridging the gap between research findings and meaningful, patient-centric outcomes, ultimately contributing to the advancement of person-centred care.

## Can product design influence the outcome of person-centred care? ID 226

*Pamela Lindgren, member of the Person Council for patients and carers at the University of Gothenburg Centre for Person-Centred Care (GPCC), Gothenburg University, PhD at Chalmers University of Technology, Design & Human Factors, Department of Industrial and Materials Science*

Assistive Technology (AT) is not only used by people with impairments or disability needs ('primary' users) but also by people assisting them such as home care and hospital personnel ('professional' users) and informal carers like relatives. However, there are few studies comparing different AT user needs for aids they commonly use. This synopsis presents findings from two qualitative user studies included in a design project aiming to map user needs for an individual AT transfer aid. Four AT user categories were interviewed: primary users, relatives of elderly, hospital and home service personnel. The project was used as a case study within a Research through Design (RtD1) approach for analyzing and comparing different user categories' needs, product experience and preconditions for AT acceptance. Findings show that users in different categories describe similar needs for functionality, usability, accessibility, and safety. However, the implications linked to these needs differed between users in the same user category as well as between user categories. In addition, the AT product design was understood to convey different meanings depending on the user's role, situation, and user environment. 'Professional' users perceived the design as rational and suited to optimizing and streamlining work tasks, thus communicating efficiency. 'Primary' users perceived the same design not only as conveying functional aspects but also aesthetics. They saw it as a carrier of users' individual characteristics, and as communicating and exposing vulnerability. The interpretation ascribed to AT influenced the needs described and expectations of how needs could be met to make acceptance possible. From a person-centred care perspective, the findings imply that AT product experience can influence how care is experienced by users in different situations and environments. It is important to know this when striving to strengthen the efficacy of healthcare through person-centred care.

## “Sketch and Talk” —Getting Closer To Patients' Lived experiences Of Their Care Environment In Institutions For Care and Incarceration ID 204

*Franz James, Campus Steneby, HDK-Valand Academy of Art and Design, University of Gothenburg*

This presentation will primarily focus on the development and application of the method “Sketch and Talk” in which ethnographic and visual methods are used to get closer to patients' and clients' lived experience of their care environment.

“Sketch and Talk” uses sketching and talking when meeting a participant in their cell or room as a way of creating a space for mutual observation and understanding of the interior (James, 2017). The method has been developed in research in institutions of care and incarceration (ICI), that is, prisons, special residential youth homes and forensic psychiatric hospitals. In these closed environments there are limitations to which research methods and tools that can be used. An awareness and respect for vulnerable groups as well as security is key to determine how the researcher can learn how personal stories of the dialectic relationship design, materiality, functionality and people’s experience of space, body, time and relations. ICIs are understood as an existential and ethical dichotomy with well-being on the one hand and the losses that incarceration brings on the other. The tension between punishment and (re)habilitation manifests through materiality, design, and high-security measures. However, the question for design in these environments is not whether it is possible to hinder the pain and losses that come with incarceration but how design can mitigate these losses, alleviate pain, foster well-being, and assist staff through a safe and supportive work environment (James, 2023). The findings suggest that future research can contribute with more knowledge on how an interior can promote well-being through design for autonomy, dwelling, and movement and as a result can open up new horizons of change and hope.

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# Poster sessions

## Children and Youth

### 1. Concept analyses of "Family Centered Care": A review ID 290

*Mohammad Al-Motlaq, The Hashemite University; Mandie Foster; Maggie Zgambo; Sarah Neill*

**Aim:** to assess the level of maturity of the concept of Family Centered Care based on previously published concept analysis studies. **Background:** Concept analysis has been used extensively in nursing to clarify concepts. Examples include studying the concept of FCC where ambiguities still exist among outcomes. Clear definition can help improve patient outcomes. **Methods:** Formal databases were used to search for previously published concept analysis studies on the concept of FCC. We used the Morse concept maturity evaluation approach to appraise these studies and conclude the level of maturity of the FCC concept. **Outcomes and conclusion:** The review included a list of reviewed articles that met the inclusion criteria, main approaches used, and outcomes of each study. The review included those studies which provided clarification and operationalisation of the concept of FCC which reflect the level of maturity of the concept. The study showed a reason for the shift towards new models such as Child and Family Centered Care (CFCC), and Child Centered Care (CCC).

**Key words:** Concept analysis, Family Centred Care, Children, Family, Literature review, concept maturity

### 2. Mental Health in Youth-friendly Health Services: a scoping review. ID 339

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**Introduction:** There has been an increase globally in mental health problems amongst young people in the past decades. However, young people have also been shown to underutilize available healthcare resources. This led the World Health Organisation (WHO) to formulate guidelines in 2012 for youth-friendly health

services (YFHSs) in order to cater to the needs of young people and increase youth participation in healthcare. There now exist numerous youth-friendly initiatives around the world, starting both before and after the publication of the WHO guidelines, offering treatment to young people with different types of mental health needs. It is important to further study if YFHSs can create person-centred treatment options for young people and if YFHSs manage to reach the underserved youth, where mental health concerns could be identified at an early stage and adequately treated, leading to positive health outcomes. Aim: To conduct a scoping review of research on YFHSs, as well as mental health status of adolescents and young adults attending these services, with the particular aim of identifying knowledge gaps and future directions of research. Methods: A scoping review of available research will be conducted with the help of information specialists. Databases such as PubMed, PsycINFO and Web of Science, as well as other sources of published articles and grey literature, will be searched. A study protocol with clearly defined research questions, population, concept and context (PCC)-statements as well as inclusion and exclusion criteria will be established a priori, and abstracts will be screened independently by collaborators in the project in order to achieve an unbiased synthesis of available research. Conclusions: The present scoping review will create an overview of the available research concerning YFHSs and the mental health of youth using these services. Such a review may give valuable directions for future research into person-centred youth services.

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### 3. A new digital self-assessment scale for pain in children

ID 077

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Pain in children need to be recognized early and their self-report should be the primary source of information. Due to age and cognitive development, there may be challenging for children to communicate their symptoms. Previous studies have shown that children prefer digital tools for non-verbal communication regarding symptom management. The electronic Faces Thermometer Scale (eFTS) is a newly developed assessment scale, accessible through the mobile application Pictorial Support in Person-Centred Care for Children (PicPecc). The eFTS feature a universal design and uses colours, faces-emojis and numbers to display pain on an 11 graded scale. The aim of the study was to determine how children use eFTS when assessing hypothetical pain. Methods: A mixed methods design was used. The study was conducted at a university hospital in Sweden. Children between 8-17 years of age who visited the outpatient clinics were invited and 102 out of 124 children were included. Children were introduced to 17 pictures displaying different levels of pain and were asked to assess their hypothetical pain in each picture using eFTS. Analyses were made with descriptive, comparative statistics and content analyses. Results: There were a total of 1,734 assessments on hypothetical pain using eFTS. Analysis showed that the children used the entire scale when rating their hypothetical pain from no pain to high pain. Assessments were made using numbers, colours and faces-emojis. Each child chose their preference for assessment for each picture. The eFTS can differentiate between no pain and high pain. However, the younger children had difficulties to differentiate between low and moderate pain. Conclusion: The eFTS, an assessment scale accessible through a mobile application, shows potential to be used in pain assessments for children. As a part of PicPecc, eFTS may facilitate communication about different symptoms including pain, thus enabling person-centred care.

#### 4. Educational programmes for paediatric healthcare professionals in patient- and family-centred care. A scoping review ID 220

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Introduction: Patient- and family-centred care is of increasing interest in paediatrics, which comprises a complex and unique triadic relationship involving the paediatric patient, family members and healthcare professionals. Little is known about what educational programmes are available to train paediatric healthcare professionals in this approach. The aim of the study was to identify and describe educational programmes in patient- and family-centred care for paediatric healthcare professionals. Methods: This scoping review was conducted and reported according to the JBI Manual for Evidence Synthesis and the PRISMA guideline. The databases searched included MEDLINE (PubMed), PsycINFO, CINAHL, Scopus, Cochrane, and Embase. Inclusion criteria were experimental, observational and qualitative studies about educational programmes on patient- and family-centred care for paediatric healthcare professionals. Exclusion criteria were reviews and non-peer-reviewed literature. Two reviewers independently screened and extracted the data using Covidence. Results: Of the 13922 records identified, 49 articles met the inclusion criteria. There was a large variety of educational programmes, half of which were interdisciplinary, that mainly targeted nurses and doctors. The median number of participants was 51 (range 7 to 1411). The predominant target population was children with chronic disabilities and neonatal intensive care units, and only one programme specifically targeted adolescents. The median duration was one day (range 5 minutes to 3.5 years). Development of competencies was the most common objective. We identified 12 different educational content areas. Content mainly focused on communication and relational competencies, including partnership, which involved shared decision-making, mutual agenda setting, and negotiation of a plan. Many kinds of educational strategies were found but experiential learning through simulation and roleplay was used most. Conclusion: A large variety of educational programmes in paediatric patient- and family-centred care exist. Educational content mainly focused on communication and relational competencies. Experiential learning including roleplay and simulation was the most used educational strategy.



## 5. Cultural adaptation of a paediatric person-centred programme for implementation in a South African private hospital ID 323

*Ensa Johnson, University of South Africa; Emma Forsgren, University of Gothenburg; Angelica Höök, University of Gothenburg; Ariné Kuyler, University of South Africa; Mary Clasquin-Johnson, University of South Africa; Stefan Nilsson, University of Gothenburg*

There is a need to improve the implementation of interventions for comfort and support in conjunction with medical interventions in paediatric care and to give all children, regardless of their communication skills, the opportunity to make decisions about their care whenever possible (Nilsson et al., 2015). Person-centred care (PCC) places a central focus on the patient in partnerships and is regarded as the gold standard of care (Thunberg et al., 2022). PCC interventions positively affect children's participation in their care. Furthermore, children's preferred choice for non-verbal communication concerning symptom management motivates the use of digital tools (Thunberg et al., 2022). The University of Gothenburg's PCC framework includes three simplified care procedures: (i) Initiating a partnership between the patient and the provider through the elicitation of the patient's story/narrative; (ii) Sustaining a working partnership with shared decision-making and (iii) Co-creation of healthcare and safeguarding the partnership by documenting the patient's story/narrative, preferences, and participation (Britten et al., 2020). As such, a study is conducted in South Africa to implement PCC in a paediatric setting. This study involves the exploration of the implementation of PCC in a paediatric setting using i) an online education (Mutual Meetings), ii) pictorial support schedules and iii) a digital toolkit (Pictorial Support in Person-Centred Care for Children [PicPecc]) (Wiljén et al., 2022). The focus of the poster will be on sharing insights of the pilot study of the adaptation of the paediatric PCC programme for children, parents, and healthcare professionals. Next, the cultural adaptation to meet the unique needs of children, parents and healthcare professionals in a South African private hospital will be provided. The adaptation of the paediatric PCC programme is co-designed by participants of the programme to ensure a feasible implementation in a hospital. Suggestions for adaptations and practical implementations of the paediatric PCC programme will be presented.

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## 6. Tactile massage – a complementary treatment for adolescents diagnosed with Attention Deficit/Hyperactivity Disorder ID 019

*Anna-Carin Robertz, NU Hospital Group; Stefan Nilsson, Gothenburg University, Institute of Health and Care Sciences, Sahlgrenska Academy; Viola Nyman, NU Hospital Group, Region Västra Götaland; Carl-Johan Törnåge, Skaraborg Hospital; Anne-Katrin Kantzer, NU Hospital Group, Region Västra Götaland*

Background: Attention deficit hyperactivity disorder (ADHD) in adolescents has a prevalence rate of 5% and affects their level of functioning and quality of life. Linked to ADHD is a heightened pain sensitivity compared to the general population. The aim of this study was to investigate tactile massage as a complementary treatment for adolescents diagnosed with ADHD. The data presented here is part of a pilot study within a larger investigation. Materials and Methods: Fourteen adolescents, aged 15-17, enrolled at the Child and Adolescent Psychiatric Clinic in NU Healthcare Region in Västra Götaland County, were offered 10 sessions of tactile massage once a week. Inclusion criteria were a diagnosis of ADHD according to ICD-10, either unmedicated or treated with central stimulants or Atomoxetine. Presented here is data recorded six weeks before (T0) and immediately after the last massage treatment (T3). PROMIS (Patient Reported Outcomes Measurement Information System) pain impact has a median value for the T score at 50 (reference range 34-78), where values above 50 indicate pain impact. SDQ (Strengths and Difficulties Questionnaire), hyperactivity domain, has a cutoff value of 7 (reference range 0-10), where values > 7 indicate hyperactivity. Results: PROMIS: At T0, the median value was 43.5 (min 34, n=5, and max 60.6), and at T3, it was 34 (min 34, n=7, and max 59.5). SDQ hyperactivity domain: The frequency of symptoms (above the cutoff) for hyperactivity was 6/14 adolescents (42.9%) at T0 and 3/12 (25%) at T3. Symptoms of hyperactivity have decreased, and pain impact was reduced in the group. Conclusion: Tactile massage appears to have a positive effect on hyperactivity and pain impact. The results need confirmation through a study involving a larger, comparable population.

## 7. Enhancing Informed Consent through Multimedia Tools in Pediatric Spinal Surgery: A Comprehensive Review ID 299

*Marina Rosa Filezio, University of Calgary; Nishan Sharma, University of Calgary; Jennifer Thull-Freedman, University of Calgary; Fabio Ferri-de-Barros, University of Calgary; Maria Santana, University of Calgary*

This comprehensive mini review explores the critical significance of valid informed consent prior to pediatric spinal surgery, emphasizing the need for

effective comprehension and understanding in this specific context. An evaluation of the health sciences literature was performed to explore understanding of surgical informed consent by patients and their guardians, focusing on the use of multimedia tools as a possible process facilitator. The evidence discussed throughout this review, based on legal and ethical perspectives, reveals challenges faced by patients and guardians in achieving comprehension and understanding during this process, especially when facing stressful medical situations. In this context, the introduction of multimedia tools emerges as a patient-centered strategy to help improve comprehension and decrease pre-operative anxiety. Moreover, this review presents a tailored approach in obtaining informed consent for pediatric patients and explores the potential impact of shared decision making in standardizing the surgical discussion process, while improving patient autonomy and experience.

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## 8. Tools and Norm Critical Aspects in Participatory Health Research and Design involving Marginalized Youth: A Scoping Review ID 232

*Britta Teleman, Halmstad University; Petra Svedberg, Halmstad University; Anna Isaksson, Halmstad University; Jens Nygren, Halmstad University*

**Background:** To enhance person-centered approaches for youths within care contexts, developments must engage individuals with lived experience. There is a risk that the perceived intricacies of engaging vulnerable youths deter researchers from including them. Despite the expanding body of health-related research involving young individuals, the utilization of pathogenic methodologies and traditional research methods risk excluding marginalised youth and preserving biases in knowledge production. Among these youth, some face multiple marginalization and without norm-critical perspectives their involvement could lead to tokenism and disempowerment. Hence, there is a need for inclusive, adaptable research tools. **Objective:** To assist researchers in making methodological decisions, this study pull together method contributions from recent health-related research and design projects that involved marginalized or vulnerable youth in a range of fields. We explore participation levels and norm-critical aspects and maps the rationales, outcomes, and tools. **Methods:** An interpretive scoping review was conducted. 508 studies were identified by searching six databases, and 38 were included for analysis. An analytical framework was created based on Hart's Ladder of Participation and literature in critical participatory and health-related research. **Results:** The studies represented 18

different disciplines. 11 to 15-year-olds were most likely to be involved. A great variation in tools and materials was observed, where visual material was used in 20 out of 38 studies (of which 13 used Photovoice). Participation levels were not directly related to tool types. Rather, high levels of participation were often found where norm-critical aspects were largely reflected. Studies that developed tools, interventions or services reached lower scores for participation levels and norm-critical aspects compared to studies that aimed for a general understanding of target group perspectives. While many studies stressed their method contribution, few compared or critically reflected on their choice of tools. Furthermore, studies differed in their acknowledgement of participants' expertise and contributions.

9. Being able to talk about one's own health - digital support to enable participation and person-centred care for children and young people with communication disabilities  
ID 118

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Background: There is currently a lack of literature on everyday life concerns and priorities in residential care facilities and how it affects the experience of the facility as a home in a Swedish context. This study hopes to contribute to closing the gap in knowledge through a participatory research approach. Aim: This study aimed to identify concerns and priorities in everyday life, as experienced by older persons living in residential care facilities. Methods: Thirteen frail older persons living in residential care facilities were involved in this study that applied photo elicitation interviews. This meant that the older persons were asked to take photos of their home in everyday life, and the photos were then followed up with individual interviews. The interviews and photos were analysed using reflexive thematic analysis. Preliminary results: The findings of this study are divided into core themes with the overarching theme: Everyday life is governed by institutional cultures, which meant that the residential care facility functioned as an institution with rules, norms, and routines that influenced both what the older persons did and how they experienced their everyday lives. This is further described in the core themes: The importance of dialogue and A game of power between older persons and staff, both with subthemes. Preliminary conclusions: The main conclusion is that the experience of the home as being governed by institutional cultures, and that the cultures were permeated by the scarcity of meaningful dialogue and a game of power. Power, dialogue, and culture are interdependent of each other. Person-centred climate was not always achieved and the result reveals areas where more

research needs to be done, such as the prerequisites for residential care facilities of facilitating person centred care.

10. Validity and reliability of a patient-reported experience measure of healthcare professionals' empathy levels in the care of Swedish children with cancer or long-term illnesses  
ID 016

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Background: Children with long-term illnesses (e.g. cancer) regularly meets with healthcare professionals and requires hospital care. Research shows that these children value participating in empathic and respectful discussions and that most want to be involved in medical consultations. Empathy enables a holistic view of the patient which can improve patient's compliance and treatment efficiency. Patient-reported experience measures allows children to express their experiences with the care received. Previous studies have shown validated patient-reported experience measures are used inconsistently in Swedish paediatric care with only half of the departments surveying children directly. The Visual CARE Measure also called the Paediatric CARE Measure, is a short questionnaire that gives children and parents the opportunity to express how a meeting with a healthcare professional was experienced. Aim: The aim of this study was to translate and validate a patient-reported experience measure of the levels of empathy demonstrated by healthcare professionals' as perceived by children during procedures in general pediatric care. Method: The translation and cultural adaptation of this measure followed the professional society for health economics and outcomes' research principles of good practice. Construct validity, inter-rater reliability and internal consistency were calculated. Results: A total of 290 children 0-17 years and their parents answered the questionnaire. The preliminary results indicated that children and their parents perceived similar levels of empathy from healthcare professionals' during a needle procedure or nasal tube insertion. Between a third and a quarter of the respondents reported the maximum score, indicating that respondents used the entire Likert scale. Most participants answered all items, indicating high acceptability for the Swedish version of the measure. Conclusion: The child-friendly patient reported Visual CARE measure can be used in a general paediatric setting for children with cancer to evaluate their perceived levels of empathy displayed by healthcare professionals'.

## Global and Local Perspectives

### 11. GAHN: Supporting Creativity in Patient Centered Care ID 141

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Health care providers are clearly providing care in a time of change with holistic nursing at the center of that change. Emerging from the COVID pandemic, health care now recognizes the contributions holistic nursing brings to health care with our focus on caring-healing and the concepts of authenticity, presence, compassion, knowing participation, cultural humility, reflection and self-care practices, all elements that intersect with the philosophy of patient-centered care. As holistic nurses we have emerged stronger from both the personal and professional crises and challenges that COVID created. Holistic nurses have emerged, valuing the importance of patient-centered care, relational based care and reflexive nursing practice. Multiple opportunities are emerging in health care creating opportunities for holistic nurses to enhance the ways we provide care for patients, and address the diverse needs of the populations; particularly addressing ways to eradicate health disparities and promotion of safe healthy communities. GAHN is a global community of scholars committed to the advancement of the philosophies, theories and praxes of holistic health and healthcare transformation. Embracing the interacting values of trustworthiness, social justice, caring, healing and scholarship, GAHN seeks to cultivate a network of holistic scholars committed to expanding creative transcultural, integrative caring healing practices that promoting well becoming; realizing the changing patterns and manifestations of wholeness and healing; and providing the leadership and wisdom to promote and sustain healthcare transformation. This presentation will share how the philosophy and scholarship of patient centered care addresses the challenges of today's healthcare. Clinical exemplars will be provided that will explicate how reflexive praxis; thoughtful reflection, caring, actions informed by a theory and research-driven practice inform the way nurses provide patient centered care. This presentation will illustrate how the scholars of GAHN are working to integrate the philosophy and scholarship necessary to provide patient centered care needed today.

### 12. Enhancing 'muchness' (or subjective experiences of well-being) through reflection and action (praxis): sharing the findings of a participatory inquiry with nurses ID 138

*Kate Sanders, Foundation of Nursing Studies*

Introduction: I discovered the concept of muchness when reading a blog that considered quotes from Alice in Wonderland to identify what meaning they could offer healthcare. One of these quotes was: ‘You used to be much more “muchier”. You’ve lost your muchness’, said the Mad Hatter. Reflecting on my experiences of working with nurses who reported feeling overworked, undervalued and undermined, I questioned whether some nursing staff had lost their muchness - their subjective experience of well-being. Aim: The aim of the presentation is to consider how reflection and action (praxis) can facilitate muchness (or subjective experiences of well-being). Methods: An innovative research method was developed – Virtual Picture Voice, enabling nurses internationally to create and share ‘stories of muchness’ to generate understanding about muchness; and to participate in analysing and synthesising the stories contributing to the creation of the Muchness Model Version 1. This model was further refined through a metasynthesis process drawing upon wider philosophical and theoretical understandings, resulting in the development of the Muchness Model Version 2. Outcomes/findings: Situated within virtue ethics, the findings of this research, as represented in the Muchness Model V2, advocate for a ‘full-life’ understanding of well-being, that is a balance between the pursuit of feeling fulfilled and feeling good. Critical reflection on self, our relationships and the contexts within which we work can generate knowledge to inform actions towards experiencing muchness and flourishing in the workplace. Conclusions: A holistic approach to the facilitation of well-being should be used, that includes individuals and organisations, working at micro, meso and macro levels, to enable nurses to identify what is important/matters to them both personally and professionally. This knowledge can be used to inform actions relating to their nursing work, their relationships and their workplace context to enhance their muchness or subjective experience of well-being.

### 13. Mapping person-centered practice in the Portuguese healthcare services: An ongoing scoping review 108

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Recognizing the international advancements on person-centered practice (PCP) with positive implementation outcomes at the varied levels of healthcare systems, this scoping review examines the evidence on PCP in Portuguese healthcare services. The JBI guidance for scoping reviews is being followed. The Population (P) Concept (C) Context (C) mnemonic scaffolded the research questions, the inclusion and exclusion criteria, and the searching strategy. Literature reporting on



person-centeredness domains at the macro-, meso-, and micro levels applied to Portuguese healthcare services in Portuguese and English were considered for inclusion. Accordingly, MEDLINE, CINAHL, SCOPUS, LILACS, SCIELO, Open Access Scientific Repository of Portugal (RCAAP) were searched. The literature was screened for eligibility by two independent reviewers, first by title and abstract and currently by full text. A data extraction matrix designed to answer the research questions will be used for the included literature. The charted data will be thematically analyzed and presented graphically, with a narrative description of the literature characteristics. Data will map the Portuguese legislation and regulatory standards related to PCC, best practices and their philosophical underpinning, PCC processes and their effectiveness, as well as instruments being used to assess it. The results are expected to inform healthcare stakeholders at varying levels about the PCP domains where further improvements might be required in order to raise the quality of care to the international gold standards.

## Informal Care and Support

### 14. Online support groups for family caregivers: A scoping review 262

*Rosemary Daynes-Kearney, SASH-Lab, University of Limerick; Stephen Gallagher, SASH-Lab, University of Limerick*

Background: Caregiving can affect people of all ages and can have significant negative health impacts on family caregivers. Research has shown that social support acts as a buffer against many negative health impacts. A common source of social support is online support groups (OSG). Over the last decade the number of OSGs increased exponentially, however there is not consensus on what factors or characteristics of OSG contribute to the development of social support within these groups or what types of OSG are available to family caregivers. Objective: The purpose of this present study was to conduct a scoping review to contribute to the understanding of the types and characteristics of online support groups (OSGs) for family caregivers. Methods: Following the Prisma-ScR guidelines, the CINAHL, PsychInfo, Psych Articles, Social Sciences, Communication Source, Medline, and Web of Science databases were searched using inclusion and exclusion criteria. 19 studies were included in the review. The analysis process explored (1) what type of the social support groups are online for adult family caregivers (2) what are the communication medium and characteristics of these OSGs and (3) what psychosocial or other factors that made OSG successful or unsuccessful for participants? Results: We found that the majority of OSG took place on public text-based forums, were illness-specific and the most common communication medium found was text-based communication. Results for Q3 developed two overarching categories of safe communication and engagement.

These described successful groups as having similar others with common life experiences sharing in non-judgmental space, overseen by trained peer or professional facilitators. Conclusions: There are several key considerations for OSG to be successful for family caregivers. A general recommendation for practitioners is the importance of building active moderation and multi-faceted structures of support to meet different levels of caregiver needs and ability to engage.

## 15. Adaptation of iSupport, a digital intervention for carers of people with Parkinson's and cognitive impairment ID 313

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The problem: Most care needs of people with Parkinson's with cognitive impairment (PwPCI) are met by informal carers. This role is often associated with reduced quality of life, and impaired physical and mental well-being. Despite their important role, there is a lack of support for carers of PwPCI. The aim of this project is to adapt a globally available digital intervention for dementia carers (iSupport) to meet the specific needs of carers of people with PwPCI (iSupport-PD). Approach/methodology: We used the Person-Based Approach (PBA) to intervention development to maximise user engagement with iSupport-PD. Insights from a rapid scoping review, preliminary interviews with carers of PwPCI (n=9), and PPI and stakeholder consultation were tabulated to identify the needs of carers of PwPCI. Key findings: Generally, carers felt that the topics of the original iSupport were relevant to them. They valued its focus on carers' own needs, not just on how to better manage symptoms. However, new content needs to be added to address the complexities of CI in Parkinson's (e.g., causes, interacting symptoms). Some aspects of iSupport were deemed patronising and have been swapped for more empathetic design features (e.g., stories). Carers requested that terminology used promotes inclusivity, recognises 'partnership', and avoids suggesting that the person with Parkinson's is 'impaired'. Implications: Findings informed provisional guiding principles to outline how the specific needs of carers of PwPCI will be addressed in iSupport-PD. Qualitative think-aloud interviews will iteratively optimise iSupport-PD content. This study demonstrates how the PBA can be applied to intervention adaptation.

16. Experiences of everyday life and the new normality as a spouse and carer of a person with dementia; the support they receive and the support that they need 061

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Health and social care providers should aim to include family carers in the planning and delivery of care of persons with dementia, following a person-centered approach. However, caring for a person with dementia may impact the carer, and spouse carers have been found to be especially vulnerable to negative outcomes of caring and in need of support. Yet, support is often generic, and uptake is low. The aim of the present study is to explore how persons who care for a cohabitant spouse with dementia experience everyday life, how they manage difficulties and how they are supported. The study employs an explorative qualitative design with semi-structured interviews with spouse carers aged 65 years old or older (n= 24), using the six-stage approach to reflexive thematic analysis with descriptive and interpretive coding. The thematic analysis generated three integrated themes: Finding a new normality in everyday life, Being together an apart from my partner and Finding support while needing more. Study findings indicate that spouse carers experience a disruption of ageing together as a couple when their partner receives a dementia diagnosis, that requires them to re-evaluate their everyday life and their relationship and to form a new normality with dementia. They also express how transitioning into caring may be indicative of losing the role as spouse and becoming a carer. While being offered support, it often lacked person-centeredness, as support often focused more on their partners' dementia rather than their individual needs. Our findings suggest that health and social care providers need to focus on early interventions for spouse carers to ameliorate the disruption caused by dementia. Support should focus on maintaining the spouse carers' personhood, as they often lose themselves into caregiving, while also strengthening the couple by offering support to both the carer and the person with dementia.

17. Effectiveness of interventions to address the negative health outcomes of informal caregiving to older adults: an umbrella review 029

*Mariam Kirvalidze, Aging Research Center, Karolinska Institutet; Amaia Calderón-Larrañaga, Aging Research Center, Karolinska Institutet*

Background: Providing informal care can exert a considerable strain on caregivers' health. How to best support the complex needs of informal caregivers remains largely debated. This umbrella review (overview of reviews) aims to evaluate (1) whether effective interventions can mitigate the negative health outcomes of informal caregiving, (2) whether certain types of interventions are more effective than others, (3) whether effectiveness of interventions depends on caregiver, care receiver, context or implementation characteristics and (4) how these interventions are perceived by caregivers in terms of their implementation outcomes, such as acceptability. Methods: We synthesised systematic reviews of primary studies focusing on the effectiveness of interventions aimed at reducing the impact of caregiving on caregivers' physical or mental health. This includes quantitative and qualitative syntheses of implementation studies. The literature search was completed in Medline, CINAHL, PsycINFO and Web of Science. Quality appraisal was conducted using the AMSTAR-2 checklist for quantitative reviews and with an ad hoc checklist for qualitative research syntheses. Primary study overlap was assessed using Corrected Covered Area. Narrative and tabular summaries of extracted data were produced, and mega-aggregation framework synthesis was employed for weaving together evidence from quantitative effectiveness studies with findings on implementation from qualitative studies. Results: The synthesis of 47 reviews revealed that, for objective physical and mental health outcomes, evidence of effectiveness is inconclusive. Heterogeneity among caregivers is often overlooked. There are important issues related to quality of reviews, as well as overproduction of similar reviews close in time. While qualitative reviews tend to show some subjective benefits, quantitative reviews are largely equivocal. Conclusions: Despite the abundance of systematic reviews regarding support interventions for informal caregivers, evidence for improved physical and/or mental health is lacking. Further intervention studies should account for heterogeneity among caregivers and should measure objective health outcomes more comprehensively.

## 18. How can we help the helper? – informal caregivers' psychosocial health and needs ID 244

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Background: The proportion of elderly people in the world is increasing and this means an increased strain and burden on the healthcare system. More people will

need to be involved in informal care in the future. Current figures show that informal care accounts for about 3.5% of the total GDP (Gross domestic product) in Europe and this is expected to increase as the number of hospital beds in health and social care is expected to decrease. Aim: To map the psychosocial health and the need for information and support among informal caregivers in Sweden. Furthermore, to find out how they feel about receiving the support via the internet. Method: The design is a closed-ended survey including background questions as well as four instruments to map the informal caregiver's psychosocial health and needs for information and support. The instruments used are the caregiver burden scale (CBS), the depression, anxiety, and stress scale (DASS-21), the caregiver competence scale (CCS) and the rewards of caregiving scale (RCS). The study is advertised via the Swedish Family Care Competence Centre, different patient associations and social media. The survey is administered digitally using our platform [iterapi.se](#), which is a secure platform, using procedures like those used by internet banking, and with a plan to include 200 informal caregivers in Sweden. The data will be analyzed with descriptive statistics. The importance of the study: Data collection will continue until the end of January 2024 and therefore there are no results to present yet. The results of the study will provide important information about the psychosocial health of informal caregivers, as well as their need for information and support. This information is planned to be used to develop and evaluate an internet-based support program for informal caregivers.

## Learning and Education

19. From sowing seeds to flourishing: how a person-centred community of practice can support learning, being and becoming on the doctoral journey ID 075

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Life as a doctoral candidate can be lonely. Having a supporting network of fellow candidates can have a big impact on learning, motivation and wellbeing. A Community of Practice can not only be part of this network, but also support learning and wellbeing. It is defined by Wegner et al. (2002, p. 4) as: “a group of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis”. The Student International Community of Practice (SICoP) is a network of doctoral candidates; a subgroup of the The Person-centred Practice International Community of Practice CIC (PCP-ICoP). It was founded in 2010 by a group of doctoral candidates dedicated to person-centred research. The aim of

SICoP is to offer a safe space for connection and reconnection, reflection and learning. The overarching unifying topic is person-centred research. The community shares a virtual platform, meets twice a year and uses social media for informal contacts. In 2015, SICoP members critically reflected their experiences of being a SICoP member (Lynch & Frost 2015). Four years later, using creative hermeneutics, another group of subsequent SICoP members reflected and shared their experiences (Sanders et al. 2020). In this presentation, we share how doctoral candidates experience being a member of SICoP, how we meet challenges like keeping SICoP sustainable and maintaining connections, and how candidates benefit from this community of practice.

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## 20. Effects of an age suit simulation on nursing students' perspectives on providing care to older persons - an education intervention study ID 182

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Background: Nursing students are important future health care providers to the growing number of older persons in society. However, two barriers preventing a person-centred approach are ageist attitudes and their lack of interest in geriatric care. This is a concern in light of the global demand for more nurses. “Walking in the shoes” of an older person in age suit simulation is a safe pedagogical tool for nursing students to gain an understanding of age-related health problems and functional limitations. Method: This study investigated the effects of ageing simulation with an age suit as a part of experiential learning in a nursing programme. The simulation allowed the students to experience specific and common health problems from the patient’s point of view in a controlled environment and a relevant context of care provision for future nurses: a home with welfare technology and other aids. The learning process involves a continuous cycle of doing and reflecting resulting in knowledge that also becomes “ingrained” in the body of the learner. Data were collected using a quasi-experimental pretest–posttest design with a control group. Results: The results showed that the intervention had a positive effect on various aspects of nursing students’

perspectives on caring for older persons. Work experience was associated with more positive attitudes. The control group was more negative towards geriatrics as a career choice than the intervention group. Conclusion: Age suit simulation can be an innovative intervention in nurse education as it raises awareness and understanding of aging and the health challenges of older persons, which are important in combatting ageism among future nurses which is crucial for the provision of person centred care.

## 21. A person-centred framework for undergraduate nursing education to foster the development of person-centred practitioners in German-speaking countries ID 279

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Background: In order to achieve person-centred outcomes, it requires nurses to possess attributes outlined in the Person-Centred Practice Framework prerequisite construct. To ensure that they attain these attributes, it is needed to address them during basic education. At this academic level, it is unclear which competencies are necessary to meet these attributes, how they can be developed as part of basic nursing education, and how educators can promote them and develop a person-centred teaching and learning culture. Aim: This project aims to develop a framework for undergraduate nursing education to foster the development of person-centred practitioners in German-speaking countries. Objectives are: 1) Identify person-centred competencies and how they can be developed and evaluated in undergraduate programmes; 2) Investigate the required attitudes, pedagogical skills, and knowledge of teaching staff; 3) Describe what is needed for the development of a person-centred teaching and learning culture; 4) Derive recommendations for nursing curricula and practice development in teaching. Methods: A multi-perspective approach is planned: I) Informing the framework: a) Collecting person-centred moments from students and teachers in nursing and teaching practice, b) Conducting focus groups with both parties, c) Identifying further relevant theoretical approaches. II) Developing the framework: a) data analysis and integration to draft a first version of the framework; b) Validation of findings through workshops with different stakeholders and finalization in a consensus-conference. III) Translating the framework for undergraduate degree programmes: a) Transformation of the findings for nursing curricula; b)

Development of strategies for person-centred learning and teaching culture. IV) Enabling evaluation: a) Development of a measurement to assess students' person-centred competencies; b) Deriving recommendations for a multi-faceted approach to evaluate person-centred teaching and learning culture. Current state: The project is in its initial development phase. The presentation will focus on the discussion of the theoretical background and methodological approach.

## 22. Person-centred practice for nurse leaders. Learnings from a pilot course 094

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Development of person-centred practices and cultures within healthcare has increased focus both national and international. At Zealand University Hospital in Denmark (ZUH), we are working strategically with developing person-centred practice (PCP) from the theoretical framework developed by Brendan McCormack and Tanja McCance (1). If PCP are to become culturally embedded in an organization, leaders have a pivotal role to play in order to legitimize and secure conditions that are aiming to support a healthful culture for all. However, this role is demanding and assumes a solid level of knowledge regarding PCP. On this background, a pilot course in PCP- development for nursing leaders in a Department at ZUH was established. Description of the course: As no internationally agreed generic PCP course for leaders exist, the course was developed based on action learning and to the PCP-framework, described by McCormack and McCance (1). Participants were seven nurse leaders at different levels, employed at the same Department. The course consisted of three half days with a one-month intervals, and with individual assignment between the course-days. Results, conclusion, perspective: The participants evaluated the course positively: they stated they had gained insight in/ useful knowledge and tools according to PCP, PCP-leadership and themselves as leaders. But they also stated they felt a need for more support, both at an organizational and relational level before they felt, they could change their actual leadership practice. Even though ZUH since 2015 have worked with implementing PCP and a PCP-culture at different levels and in different ways we must acknowledge, that changing an actual practice/culture is a highly complex process, which is consistent with implementation literature. Person-centred leadership is both a complex, contextualized, relational and dynamic practice, therefore a three-days course is not enough for changing actual practice, but it can be a starting point.

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### 23. Pros and cons of training person-centred leadership in a digital context: experiences of feasibility of a leadership programme ID 085

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Background: The Swedish Association of Health Professionals and the University of Gothenburg Centre for Person-Centred Care have developed a leadership programme with focus on person-centred ethics. The training programme is based on person-centred learning principles and has been running since 2015. Since 2022 the programme has been performed in a blended learning format where most of the workshops have been performed digitally. Due to a high demand from healthcare leaders to attend the programme, and the COVID-19 pandemic, the programme was revised to be provided digitally. Aim: To explore programme managers' and healthcare leaders' experiences on feasibility when realising a person-centred leadership programme in a digital context. Methods: The programme include leaders across a large variety of healthcare settings in Sweden. It relies on a blended learning format and consists of six learning modules, out of which one is performed face-to-face and five in a digital setting. Each module consists of individual preparatory work (digital lectures, reading, and practical home assignments and diary-writing), followed up by workshops. For this abstract we have merged findings from a focus group study with programme managers (n=2) and individual interviews with leaders (n=13) participating in the programme performed in 2022. Preliminary results: Performing the program digitally had both pros and cons. We will present and reflect upon facilitators and challenges of performing the programme digitally and report on changes made to the programme design year 2023 to increase feasibility. Conclusion and implications: Providing the programme digitally increased the geographical reach, but it did not result in a higher rate of leaders completing the programme. Although some parts of the programme were feasible to perform digitally, the digital context was experienced as a barrier for person-centred learning in some

modules. Our conclusion is therefore that at least two face-to-face meetings should be provided.

#### 24. How can we integrate healthcare leadership and person-centred ethics? Experiences of developing and realising a leadership programme in Sweden ID 035

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Background: Ensuring the application of person-centred ethics to healthcare practice has been shown to be a complex process, dependent upon individual, group, and organisational factors. Healthcare leaders are argued to have a pivotal role in the culture change needed for such an application, but there is little guidance on how to support healthcare leaders in facilitating a person-centred practice. The Swedish Association of Health Professionals and the University of Gothenburg Centre for Person-Centred Care have therefore developed a leadership programme with focus on person-centred ethics. This study is part of the scientific exploration and evaluation of this programme. Aim: To explore experiences of the development and realisation of a leadership programme to facilitate the implementation of person-centred care. Methods: Applying a social constructivist research design, focus group discussions with 12 programme management members were conducted digitally and analysed according to the structured method described by Krueger and Casey (2015). This meant that there was a clear focus on the co-creation of knowledge through interaction between participants. Results: Preliminary findings visualise the dynamic nature of programme development and realization as a collaborative journey towards integrating leadership and person-centred ethics. The metaphor of a journey depicts how the programme was described as a joint and ongoing expedition that does not end with the programme. Leadership was carefully integrated with person-centred ethics throughout the programme, in both pedagogical approach and content, to provide leaders with practical tools to use on a day-to-day basis. Conclusion and implications: Based on our analysis, we draw the conclusion that incorporating person-centred ethics is essential in both the teaching methods and curriculum of leadership programmes to facilitate the implementation of person-centred care. Furthermore, our findings underscore the importance of leadership programmes continuously supporting the merging of leadership principles and person-centred ethics in practice.

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25. Assessing the Efficiency of Data Science Programs in Enhancing Big Data Analysis Skills among Health Libraries and Information Scientists. ID 252

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Introduction: The healthcare sector has shifted towards data analysis due to technological advancements. Data Science programs are enhancing professionals in health libraries and Information Science to manage and analyze large datasets, known as Big Data. However, there is a research gap in assessing the effectiveness of these programs in equipping Health Libraries and Information Scientists with the necessary skills for proficient Big Data analysis. This study aims to bridge this gap and contribute to knowledge advancement in this evolving field. Aim: The study evaluates the efficacy of Data Science programs in enhancing the skills and knowledge of professionals in health libraries and Information Science, specifically in handling and analyzing Big Data in healthcare. Method: The study used a quantitative approach to gather data from 150 participants in health libraries and Information Science fields who completed Data Science programs in Tanzania. The survey evaluated their perceptions, skill sets, and confidence in executing Big Data analysis post-program completion. Statistical tools like descriptive statistics were used to analyze the collected data, providing insights into the effectiveness of Data Science programs in enhancing Big Data analysis skills. Results: The study found that 82% of 150 professionals who completed a Data Science program saw a significant improvement in their skills in Big Data analysis. 75% of participants expressed increased confidence in applying advanced analytical techniques. 90% of respondents were satisfied with the program's content and structure, indicating its effectiveness in teaching practical skills for handling Big Data in healthcare and Information Science fields. Conclusion: Data Science programs enhance professional skills in Big Data analysis, boosting competence and confidence. This has implications for health libraries and Information Science, fostering an agile workforce capable of advanced data analysis techniques for informed healthcare decision-making.

26. Patient centered care in interprofessional collaborative practice: undergraduate students' opinion. ID 205

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In accordance with guidelines from the World Health Organization and following national guidelines for health courses in Brazil, the Faculdade Pernambucana de

Saúde (located in the Northeast of Brazil) created in 2022 the Center for Interprofessional Health Care and Learning (CAAIS) with the aim of developing interprofessional practical activities centered on the person, and involving teachers and students from eight health courses, i.e. physical education, nursing, pharmacy, physiotherapy, medicine, nutrition, dentistry, and psychology. This is an experience report with the opinion of undergraduate students from the Tijolos community about the activities carried out centered on the person through a word cloud. The community of Tijolos is located around the FPS and does not have a basic health unit. At CAAIS, care is offered to children, adolescents, adults and the elderly with the main aim of restoring, maintaining and promoting health. An opinion survey was carried out during a week of service. Ninety-five students participated in practical activity at CAAIS and in the opinion survey, with an average age of 22.5 (SD =/- 3.6) years, of which 55 (57.9%) were female and 40 (42.1%) were male. In relation to the undergraduate course, 61 (64.2%) were from the medicine course, 15 (15.8%) from the nutrition course, 8 (8.4%) from the nursing and dentistry course respectively, and 3 (3.2%) from the physiotherapy course. In relation to having had previous practical activity centered on the person, 39 (41.1%) reported never had any. The most used and highlighted words in the word cloud were: welcoming, humanization, integrality, interprofessionality/interprofessionalism, health, care and challenges. The experience suggests that students understood the person/patient-centered care strategy and reinforced its importance.

## 27. Patient centered care in interprofessional collaborative practice: teachers opinion. ID 207

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In accordance with guidelines from the World Health Organization and following national guidelines for health courses in Brazil, the Faculdade Pernambucana de Saúde (located in the Northeast of Brazil) created in 2022 the Center for Interprofessional Health Care and Learning (CAAIS) with the aim of developing interprofessional practical activities centered on the person, and involving teachers and students from eight health courses, i.e. physical education, nursing, pharmacy, physiotherapy, medicine, nutrition, dentistry, and psychology. This is an experience report with the opinion of teachers from CAAIS about the activities carried out centered on the person through a word cloud. The community of Tijolos is located around the FPS and does not have a basic health unit. At CAAIS, care is offered to children, adolescents, adults and the elderly with the main aim of restoring, maintaining and promoting health. An opinion survey was carried out during a week of service. Nineteen CAAIS teachers with an average age of 41.9

(SD= $\pm$  14.4) years old participated in the opinion survey, of which 12 (63.2%) were female and 7 (36.8%) were male. Regarding degrees, 3 (15.8%) had specialization, 8 (42.1%) master's and doctorate respectively. Regarding the undergraduate course, 4 (21.1%) were from the physical education medicine course respectively, 3 (15.7%) were from the dentistry and nursing courses respectively, 2 (10.5%) were from the nutrition and pharmacy courses respectively, and 1 (5.25) was from the psychology course. The average length of professional practice was 14.5 (SD= $\pm$  14.5) years. Regarding having previous experience with patient/person-centered care, 9 (47.4%) reported yes. The most used and highlighted words in the word cloud were: care. Welcoming, Empathy, Learning, Individuality and Humanization. This experience suggests that teachers understood the person/patient-centered care strategy and its importance and commitment.

## Life-limiting conditions

### 28. Improving person-centred care through reflective writing for health care assistants providing palliative and EoL care ID 151

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**Background:** Developing a reflective practice allows one to explore emotions, experiences, actions, and responses so that individuals can identify personal and professional strengths and identify their professional development needs (Gravier, Burney & Radermacher, 2019). A scan of the literature reveals that reflection is encouraged amongst many health care professionals including psychologists and medical practitioners working with clients receiving palliative or EoL care, citing significant improvements to patient centred care. However, findings specific to health care assistants and their development of reflective practice was limited to identifying what it is, why it is important or a vague statement of how to become a reflective care provider. Yet, healthcare assistants working in long-term care settings are often the ones who work with clients who are dying. To effectively provide person centred care and meet the physical, spiritual, mental, and emotional needs of dying people, one must first identify personal values and beliefs about death and dying (Murray, 2020). **Objective:** The objective of this study is to explore if reflective writing about death and dying adequately prepares health care assistant students working in long-term care settings to provide holistic patient centered care. **Methodology:** The study will provide guided opportunities for health care assistant students in one cohort at a Canadian college to reflect on personal values, beliefs and experiences about death and dying prior to initiating a clinical experience with clients who may be receiving end-of-life care. Upon completion of the clinical experience, students will be interviewed using a Likert-type scale to

assess the impact, if any, reflective writing had on them providing patient centered care. Results: Results of the study will help inform the development of person-centred curriculum on death and dying and supplement an already established EoL simulation in the health care assistant program at the college. Key words: person-centred care, palliative care, reflective writing, long-term care, health care assistant

## 29. The existential dimension of care as perceived by professionals caring for people approaching death ID 190

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### Background:

Existential/spiritual questions often arise when a person suffers from a serious and/or life-threatening illness. 'Existential' can be seen as a broad inclusive term for issues surrounding people's experience and way of thinking about life. This broad definition enables us to investigate and work with the existential dimension in a country like Sweden, which is regarded as highly secular. To be able to meet patients' existential needs, knowledge is needed about what the existential dimension includes. Aim: To investigate how professionals caring for people with life-threatening disease perceive the existential dimension of care. Methods: Health care professionals in specialized palliative care, an oncology clinic and municipal elderly care have been asked in a survey how they perceive existential questions, - needs and - care. Results: According to the 77 responding professionals: Existential questions encompassed a broad spectrum. Most prominent were the meaning of life, thoughts about life and death, and life after death. Existential needs were centred around the possibility to communicate, to share your thoughts and experiences; to be seen and heard. Existential care was most often connected to communication, sharing moments in the present without doing anything and sometimes described as an ordinary care intervention, performed by all professionals. The professionals regarded the existential dimension as important. Conclusions: Identifying existential needs and performing existential care is considered a possible task for any professional as it is a matter of attitude and responsiveness. In this sense, many considered existential care imbedded in all care. Even though Sweden is considered a secular country, the existential dimension is expressed to be important by the majority of the participants in this study.

### 30. “From Thread to Cloak” - Enhancing Palliative Care in Swedish Nursing Homes Through Education and Consultation ID 274

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Background: Access to palliative care is a human right and should be offered in all healthcare settings but the distribution of palliative care in Sweden is unequal<sup>1</sup>. Patients in specialized palliative care receive better care than those in general palliative care. Younger patients receive better care than older, and individuals with cancer receive better care than those with dementia<sup>2</sup>. In Sweden, approximately 90,000 people die annually<sup>2</sup>, of which about 40% die in a nursing home (SÄBO)<sup>2,3</sup>. Almost 30% of individuals entering SÄBO in Stockholm dies within six months and more than 50% within two years<sup>4</sup>. Objective: To enhance quality of care and integrate an early palliative approach in SÄBO through palliative rounds and educational programs targeting the entire care team: Physicians, nurses, nursing assistants, physiotherapists, and occupational therapists. Project Description: A palliative consult team visits five SÄBO facilities every second week over 12 months for workshops and palliative rounds. A one-hour workshop is conducted with participants from the entire care team. Various aspects of palliative care are discussed in six modules: "Introduction to Palliative Care," "Symptom Relief," "Communication and Relationships," "Support for Next of Kin," "Teamwork," and "End of Life Care." The palliative rounds address patients, both in the early palliative stage and those approaching the end of life. The rounds follow a palliative checklist, closely linked to the Swedish person-centered and cohesive care pathway in palliative care. Results: The ongoing project will be evaluated by Marie Cederschiöld University. A baseline survey showed participants' self-assessed palliative care knowledge surprisingly high, averaging 7.32 out of 10. Comfort levels in discussing death with residents and relatives were 6.75 and 6.45, respectively. Several areas for improvement have been identified: The need for a specific forum for palliative issues, a language to discuss death, and a clear structure for the palliative rounds.

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### 31. Towards a Nuanced Understanding of Grief in Contemporary Sweden ID 131

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The purpose of this study was to examine the individual variations of grief in contemporary Sweden and to identify both existing and sought-after support measures for individuals experiencing grief. A survey was distributed that dealt with feelings, support, experiences of grief. The survey was answered by 255 people (181 = women; 74 = men). Some respondents experienced the loss as expected and some experienced it as unexpected. The results of the survey point to differences as well as similarities in terms of feelings, forms of support, strategies for dealing with grief and need for support, depending on how the death occurred. Research in person-centered care has observed that individual uniqueness and active listening constitute fundamental components. This insight also holds significance within the framework of support interventions for individuals experiencing grief. Despite criticism in academia for the lack of evidence for its effectiveness, normative models for grief stubbornly persist both in popular imagination and among health care professionals. Such assumptions have contributed to medicalizing and pathologizing what research has shown to be natural responses to loss for the vast majority of bereaved individuals. For person-centered care to effectively function as a strategy for promoting human well-being, on both an individual and a societal level, it is imperative that we develop an understanding of well-being in the terms articulated and expressed by individuals. Everyone, sooner or later, encounters losses and lives with grief. However, particularly within the healthcare domain, grief frequently remains concealed and inadequately addressed and may be misconstrued as ill-health and disease, potentially resulting in medical intervention. Therefore, it is of utmost importance that healthcare professionals possess a comprehensive understanding of natural grief.



32. Trends in place of death in Sweden and potential associations with palliative care policy and regional infrastructures. Implications for person-centred palliative care ID 266

*Cecilia Larsdotter, Sophiahemmet university; Joakim Öblén, Gothenburg university; Stina Nyblom, Sahlgrenska university hospital and Gothenburg university; Carl-Johan Furst, Lund university; Anneli Ozanne, Gothenburg university; Hanna Gyllensten, Gothenburg university*

Background and aim: Equal access to palliative care for all in need thereof, regardless of care place, is stressed as a major public health concern by WHO. Over the past decades dying in the preferred place is recognized for its' impact on wellbeing and has accordingly evolved into a quality indicator for palliative care. Understanding where people die is vital to support health policies, resource allocation, organisation, and provision of person-centred palliative care. National Swedish clinical guidelines and guidance for palliative care were launched in 2012. We aimed to; follow up the impact of those policies by investigating trends in the place of death within the Swedish population 2013 – 2019; analyse how palliative care is articulated in national disease specific policy documents and guidelines; investigate regional stakeholders' perspective on the status of palliative and end-of-life care for disease populations in Sweden. Design and methods: We used population-level longitudinal data including all deceased individuals >18 years old with a registered place of death (n=599 137), from public and patient data registers and the national register for palliative care. Trends and associations between place of death and co-variables were investigated on total and subgroup level, by logistic regression- and interaction analyses. For the second part we used a mixed-methods design with document analyses and qualitative focus groups component targeting regional cancer care stakeholders' perspectives. Results: The results from the register study show a trend towards a decrease in hospital deaths within the total population and on group-level, but with large diagnosis-related and crossregional variations. Analyses of documents and interviews are currently ongoing and will be presented.

33. Articulations and conceptualisations of palliative care in Swedish national policy documents for care of severe chronic illness and cancer: lack of conditions for person-centred palliative care ID 292

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Background: The inclusion of palliative care in policy has been encouraged internationally, and gradually implemented in Sweden. To achieve person-centred care relevant for people in the general population with palliative care needs is policy foundational. Objectives: The objective of this study was to examine articulations and conceptualisations about palliative care as displayed in Swedish national disease-specific policy and guideline documents to illuminate prevailing ideas and assumptions regarding palliative care. Methods: A document analysis of Swedish policy and guideline documents for care of different disease-specific groups (severe chronic conditions; cancer and non-cancer) was performed. In total 140 documents were analysed for articulations and conceptualisations referring to palliative care. Results: The inclusion of palliative care in the documents varied (in both cancer and non-cancer policies); from no inclusion at all to substantial chapters dedicated to palliative care. In the documents articulations of palliative care varied from mentioning the term without explications to elaborations of palliative care. Further variations of palliative care articulations were disease-specific palliative treatments (e.g. anti-tumoral treatments), care of the dying, referring to established definitions (e.g. WHO:s definition), an integrated care approach, and family support. Conclusion: There are great variations in articulations and conceptualisations of palliative care in Swedish national disease-specific policy and guideline documents. The conceptualisations of palliative care are limited to disease-specific palliative treatments and care of the dying person, which delimits its scope in ways that are contrary to current evidence for early integrated and person-centred palliative care. A lack of palliative care recommendations adapted for each specific diagnosis may signal a lack of knowledge and that palliative care is not prioritised. The current conceptualisations of palliative care in national policy documents needs to be further investigated with regard to the intended use and expected impact of policy documents for equitable palliative care.

### 34. Preferences for place of care and death among bereaved people – a cross sectional survey study ID 079

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Background: Home is often described as the ideal place for care at the end of life and death. To be cared for and die in one's preferred place can be considered an essential part of person-centred care at the end of life. Aims: To investigate preferred place for care at the end of life and death for people who had recently lost a family member, and possible associations between preferences, individual characteristics and health related quality of life, as well as associations with quality of care that their family member had received, their family members' preferred place of death, and involvement in decision-making about care. Methods: A cross-sectional survey with people who had recently lost a family member with advanced illness who died in hospital. Descriptive statistics and multivariable multinomial logistic regression models were employed. Results: Of the 485 participants 70.7 % were women and 36.1% >70 years, 34.5% were partners and 51.8% children of the deceased. The most preferred place for care at the end of life and of death was home. Higher likelihood of preferring in-patient palliative care unit was associated with being female and having a higher education, whereas lower likelihood of preferring nursing home for place of care and of death was associated with having a higher-secondary or a higher education. The relationship of being a partner was associated with a higher likelihood of preferring hospital for place of care and nursing home for place of death. Conclusions: Home was the most preferred place for care at the end of life and death. Bereaved peoples' experiences of care at the end of life may impact their preferences, especially a close relationship as partner, with higher preference for nursing home and hospital care. Person-centred conversations about preferences for place of care and death considering previous experience are encouraged.

35. Boundary situations - a window of opportunity for person-centred care for patients with lung cancer undergoing immunotherapy. ID 317

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Background: Lung cancer is by many perceived as prognosis pessima, entailing severe existential consequences and suffering related to symptoms and disease. Immunotherapy is recommended as adjuvant treatment in unresectable stage III non-small cell lung cancer, extending total treatment period by up to twelve months. Research regarding the experiences of people undergoing immunotherapy is lacking. Experiences relating to existential concerns are especially poorly understood making it difficult for healthcare personnel to support patients and their relatives. Aims: To describe the existential concerns during adjuvant treatment with immunotherapy for locally advanced lung cancer and at what points in time support is needed the most. Method: This qualitative study performed within an abductive reasoning includes interviews with patients undergoing adjuvant treatment with immunotherapy for locally advanced lung cancer and their relatives (n=30). Irvin Yalom's concepts describing existential fundamentals serves as the framework of the deductive analysis to identify existential concerns and boundary situations where existential concerns actualize and intensify. An inductive analysis will be performed to further understand need of support and what personal and external resources are used during treatment. Results: So far 17 interviews have been performed. Current analysis shows that the interviewees express several existential concerns and categories are identified for each of the main existential concerns described by Yalom. The various existential concerns intersect and are interconnected, with crossings shedding light on the different resources that patients and their relatives use. Recognizing the intertwined existential concerns pinpoint specific boundary situations in which support can be needed. Discussion: The intersections among the existential concerns understood as boundary situations is a new way of understanding the experience of undergoing an immunotherapy treatment period for lung cancer. By identifying the boundary situations in every person's treatment, healthcare personnel can accurately and efficiently intervene, strengthening the resources of each affected person.

### 36. Person-centred palliative home care from patient- and carer-perspectives – a scoping review ID 260

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Patients approaching end of life often express a desire to spend their last months – and even die – at home, if given appropriate support. Thus they may benefit from palliative care at home. The aim of this study was to summarize and synthesize the literature regarding patients’ and carers’ perspectives of palliative care at home through the analytic lens of the 6S-model for person-centred palliative care. A scoping review was performed with PubMed, CINAHL, and Scopus (2008- June 2019) including twenty-four studies illustrating the perspectives of the patient (1), patients and carers (4) and solely carers (19). A qualitative deductive analysis was applied using the 6S model: Self-image, Self-determination, Symptom relief, Social relationships, Synthesis and Strategies.

Palliative home care enabled patients and carers to maintain daily life, which strengthened their self-image. However, if carers’ expectations of the healthcare system were unmet, it could be perceived as a threat. Adequate symptom relief was sometimes described as a prerequisite for palliative home care, as severe symptoms caused uncertainty and distress. Fulfilling the patient’s wish to be cared for at home contributed to the experience of maintaining control: self- determination. Continuity and familiarity (including having family and friends around) was preferred when establishing relations with professionals. Social relationships were thus crucial to the patients and contributed to their wellbeing. Synthesis and strategies involved finding meaning in their situation and being able to share life stories. For carers, support from healthcare professionals was crucial, as they provided information about the patient’s condition and the unfolding of the dying process. Our results demonstrate that the dimensions in the 6S model are relevant for both patients and family caregivers when palliative care occurs at home. Database searches from more recent years are ongoing, which might modify the results.

## Living with health, illness, suffering

### 37. Towards a person-centred rehabilitation practice for people with aphasia ID 298

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Introduction: Communication is a key component of person-centred practice. In meetings between healthcare professionals and people with aphasia, communication is often described as complicated due to problems deriving from the acquired language impairment. Still, communication difficulties are also a result of the inability of healthcare professionals to adapt their conversation techniques to the person in front of them. To enable a functioning dialogue where people with aphasia can express their lived experiences and their individual needs and wishes, healthcare professionals must use strategies to facilitate conversation. If not, there is a risk that people with aphasia are denied access to person-centred rehabilitation. In this presentation, we would like to highlight a fruitful example of how an intervention was adapted to support healthcare professionals in meeting the needs of people with aphasia. Method: We adapted a group intervention called the “re-orientation group” which is part of an outpatient rehabilitation program for people with acquired brain injury and has the purpose of supporting orientation towards the new life situation. Speech-language pathologists and neuropsychologists worked together to adjust materials used during the intervention to better suit people with aphasia. The group is led by a neuropsychologist with a speech-language pathologist attending each session to further facilitate communication. Participants are also supported by speech-language pathologists in doing the homework assignments between sessions. Result: The group was successfully adapted and as a result, people with aphasia now have access to a group where they can explore and discuss life after brain injury together with peers. Discussion: This clinical example highlights that it is possible to include people with aphasia in person-centred rehabilitation. However, a prerequisite is interdisciplinary teamwork where the speech-language pathologist can share knowledge on supportive communication techniques as well as time to adapt materials.

### 38. Symptom cluster management in patients with lung cancer ID 212

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Background: Despite advances in oncological treatments, patients with lung cancer continues to experience many co-occurring symptoms negatively affecting their

quality of life. Several symptom clusters, mainly encompassing fatigue, depression, appetite loss, pain, dyspnea and cough, have been identified in this population (Karlsson et al., 2023), and they have more supportive care needs, worse physical functioning and more symptom distress compared to other major cancer sites (Sanders et al., 2010). Improved symptom management strategies are therefore vital to improve the level of symptom distress and quality of life (Sung et al., 2017). Health care professionals must provide more adequate support and interventions to meet the patients' unmet needs and improve quality of care. Objective: The aim of this study was to explore symptom cluster management process in patients with lung cancer, from time of diagnosis and during oncological treatment. Methods: By using a constructivist grounded theory approach (Charmaz, 2014), semi-structured individual interviews were conducted with 15 patients with lung cancer receiving curative oncological treatment. Data were analyzed by the constant comparative method for coding and category development. (Results, Conclusions and Implications for Practice are in progress, manuscript to be finalized and submitted in November -23) Results: The categories 'Changing relationships and Coherence', 'Vulnerability', 'Hope and Determination' describe the outcome of living with symptom clusters, 'Acceptance, Normalization and Taking one day at a time', 'Reevaluating life and Setting limitations' and 'Support and Guidance' focus on the symptom management strategies, and factors - 'The Body (physical), the Self (psychological) and the Situational (social interactions) - influencing the symptom cluster experience and management were identified. Conclusions: Patients are often left to their own device dealing with symptoms, feeling like many symptom are "normal" and not asking for support, or support is not being offered. Primarily, debilitating fatigue is affecting their everyday lives. Implications for practice: Timely and continuous symptom assessment and management including patient education is required. The professional knowledge amongst health care personnel and the patients' own resources must be considered in further development of patient-centered care for this population.

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### 39. Person-centred care and preferred outcomes in early rheumatoid arthritis — the patients' perspective ID 312

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Background and aim: Rheumatoid arthritis (RA) is a chronic, systemic, inflammatory joint disease affecting all aspects of life (1). Rheumatology care strives to achieve optimal health based on person-centred care (PCC). A compilation of four papers in a doctoral thesis was performed to explore patients' perspectives on PCC and preferred outcomes in the early stages of RA (2). This exploration aimed to encompass patients' perceptions of PCC (3), their perspective on health (4), and preferred treatment outcomes, considering both Swedish (5) and European (6) contexts. Methods: This qualitative, longitudinal, multi-center study, including both individual (early in the disease course) (3, 4) and focus group interviews (one-year follow-up), was conducted in Sweden at two time points, comprising 31 and 22 patients, respectively (5). Then, a meta-synthesis was performed based on three independent longitudinal qualitative studies from Sweden, the Netherlands, and Belgium (6, 7). Results: For patients with early RA, PCC included meeting professional competence, having access to care, support, and involvement in care, being satisfied with the care, and achieving optimal health (3). Health was understood as belonging, happiness, freedom, and empowerment (4). The preferred treatment outcomes from a Swedish perspective were to "master a new life situation" through disease control, autonomy, regained identity, and joy (5). From a European perspective, it was to "live a normal life" through disease control, physical performance, self-accomplishment, and well-being (6). Conclusions: PCC in early RA includes meeting supportive, dedicated, and professional healthcare professionals, having easy access to care, and the ability to be involved in decision-making. Three key aspects highlighted preferred outcomes: independence; implies a meaningful life and a sense of freedom, empowerment; reflects patients' ability to engage in self-management, and well-being; encompasses the broader spectrum of physical, mental, and social health; which ultimately captures the holistic benefits of a person-centred approach.



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#### 40. Treating the Disease and Meeting the Person with the Illness - Patient Perspectives of Needs During Infective Endocarditis – A Qualitative Study ID 315

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Background: Infective endocarditis (IE) is a rare but severe infectious disease. Patients with IE are treated for weeks in the hospital and have profound impairments on health. New treatment modalities increase the options for outpatient care. Little is known of how patients perceive their health on hospitalization. We aimed to explore the needs of patients with IE during hospitalization and the first months after discharge. Methods: In this qualitative study, 20 patients (45-86 years of age) hospitalized due to IE in Swedish hospitals were interviewed at a median of 112 (67-221) days after hospitalization. Data were analysed with qualitative content analysis identifying eight subcategories, two categories and an overall theme. Results: The overall theme illuminated a spectrum of needs between treating the disease and meeting the person with the illness. The categories expressed: 1) the need for medical excellence explored by the needs for diagnosis and attention to complications; treatment and follow-up; soon home-coming; and reliable healthcare. Patients with IE needed care in specialized units, longed to go home and feared shortcomings of healthcare. Symptoms of fatigue, wasting, cognitive and mental distress were often neglected. 2) The need for person-centred care were explored by the needs for knowledge;

reorientation; health restoration and to be seen as unique. Personalized information led to knowledge of the disease and started reorientation towards recovery. Conclusions: This explorative study shows the needs in a spectrum between medical excellence and person-centred care. Care in specialized units secure the quality, early discharge is requested, and the outpatient care needs to develop with preserved safety, medical excellence and person-centred care. The disease trajectory after discharge show slow progress and the possibility of impinging this is still unclear. Identification of delayed recovery and rehabilitation are important fields for future studies.

#### 41. Pain and everyday challenges of hypermobility in people with Hypermobility Spectrum Disorder (HSD) or hypermobility Ehlers Danlos Syndrome (hEDS) ID 265

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The overall aim of this thesis is to shed light on the everyday life challenges of people with the hypermobility syndromes Hypermobility Spectrum Disorders (HSD) or hypermobility Ehlers Danlos Syndrome (hEDS). Hypermobility is common and the prevalence is estimated to be around 10-15% of the population. It is hereditary, congenital and occurs naturally in children and is more common in women than in men (1). Characteristics of these syndromes are local or general hypermobility, which can lead to joint instability and musculoskeletal problems, and pain is present in more than 90%. Other common symptoms and comorbidities that can contribute to a more complex problem and limitations in everyday life are palpitations, dizziness, fatigue, sleep disturbances, headache as well as mental illness such as anxiety and depression (2). Everyday life and its routines are about how we tend to think and to act. Everyday life is something that we often take for granted, but in case of illness it can become a challenge to cope and to be independent. Currently, we do not know much about how pain affects everyday life or the activities that we want to perform in everyday life, for people with hypermobility syndrome. With an increased knowledge about the person's everyday life and with a focus on person-centred care and co-product, it can contribute to robust support to designing a tailored intervention that promotes commitment to living a sustainable and an active life, based on their conditions. In addition, the hypermobility syndromes often debuts at a young age and with the need for repeated interventions from healthcare. In part one, the characteristics of pain in people with hypermobility syndrome are presented and how they affect the

activities of everyday life, which are contrasted with other pain syndromes, collected from the Swedish Quality Register for Pain Rehabilitation (SQRP).

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## 42. Patients' experience of facing Graves' disease- how healthcare can address their needs ID 135

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Background: Graves' disease (GD), the most common form of hyperthyroidism in Sweden affecting 2100 patients annually, primarily impacts working-age women who present with symptoms such as anxiety, nervousness, lack of patience and concentration, and memory loss. Research exploring the patient's perspective on the care they receive is scarce. The aim of this study was to describe how patients with GD perceive the support provided by healthcare professionals in the first three months of treatment. This study seeks to offer valuable insights on how to optimise care for patients with GD and improve outcomes. Method: A qualitative study including 15 patients (12 women and 3 men, with a mean age of 47,3) who were interviewed within three months of receiving their diagnosis. The interviews were analysed using qualitative content analysis. Findings: The results highlighted the challenges faced by patients with GD in recognizing and understanding their symptoms, managing their daily lives, and seeking appropriate support. Four categories were formulated: facing illness; interaction with healthcare; consequences in daily life; and moving forward/reorientation. The participants emphasised their concerns over not being able to recognise themselves and the uncertainty about whether the condition was transient or not. They also stressed the importance of receiving a more customised support and follow-up according to individual needs and resources. Conclusion: Patients with GD request tailored support and healthcare professionals need to be aware of the challenges met by

patients with GD. A person-centred care (PCC) approach, which emphasizes collaboration and support, may be a suitable approach. Consequently, we are in the process of planning a randomised controlled trial to evaluate if a PCC intervention can improve health outcomes and contribute to the patients' recovery process.

### 43. Suffering out of sight but not out of mind – interpreting experiences of sick leave due to chronic pain: a qualitative study ID 017

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Background: Chronic pain is a complex health problem affecting about one-fifth of the European population. It is a leading cause of years lived with disability worldwide, with serious personal, relational and socioeconomic consequences. Chronic pain and sick leave adversely affect health and quality of life. Thus, understanding this phenomenon is essential for reducing suffering, understanding the need for support and promoting a rapid return to work and quality of life. Objective: This study aimed to describe and interpret persons' experiences of being on sick leave due to chronic pain. Design: A qualitative study with semi-structured interviews analyzed using a phenomenological hermeneutic approach. Setting: Participants were recruited from a community setting in Sweden. Participants: Fourteen participants (12 women) with experiences of part-time or full-time sick leave from work due to chronic pain were included in the study. Results: Suffering out of sight but not out of mind was the main theme of the qualitative analysis. This theme implies that the participants' suffering was constantly present yet invisible to others, causing them to feel they were not being justly treated in society. Feeling overlooked led to a continuous struggle for recognition. Moreover, the participants' identities and their trust in themselves and their bodies were challenged. However, our study also revealed a nuanced understanding of the experiences of sick leave as a consequence of chronic pain,

where the participants learnt important lessons, including coping strategies and re-evaluated priorities. Conclusions: Being on sick leave due to chronic pain threatens a person's integrity and leads to substantial suffering. This study highlights the importance of feeling acknowledged and being met with justice in encounters with others. We believe the central aspects of person-centred care; listening to the person's narrative and establishing a partnership, can be an important part of the puzzle towards achieving this.

#### 44. Foreign movement in one's own body: Patients' experiences of being awake while treated with catheter ablation-a phenomenological study ID 197

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**Introduction:** To address the consequences of living with supraventricular tachycardia (SVT) and to improve the quality of treatment, by opening to person-centred care, there is a need to highlight patient experiences of treatment with catheter ablation. SVT is an unpredictable occurrence of tachycardia with a complex impact to the persons daily life (Nordblom, Broström & Fridlund, 2017; Withers et al., 2015; Wood, Wiener & Kayser-Jones, 2007). Catheter ablation involves a physical intervention, with the intention to localize abnormal activity, which leads to the determination of a diagnosis and decide further treatment during the same procedure (Brugada et al., 2020). Therefore, the aim was to describe the phenomenon of catheter ablation, as it is experienced by patients being treated awake. **Methods:** A descriptive design was applied based on a reflective lifeworld research (Dahlberg, Dahlberg & Nyström, 2008) founded on phenomenological epistemology. Interviews were conducted between December 2021 and Mars 2022 with seven women and five men, three to twelve months after they underwent catheter ablation. **Results:** Patients undergoing catheter ablation while awake during treatment, which includes experiences of relying on others expertise, being actively passive, and striving to be cured. It entails experiences of having a foreign object moving in one's body and heart and can be endured through strategies of mainly shifted one's mental focus. **Discussion:** The main findings are characterized by reliance on expertise and being actively passive in striving to be cured. It also pinpoints vulnerable situations in which the patient perspective is lacking through the experience of being or feeling unprepared, mainly expressed as need of support before the planned elective ablation, but also during and after treatment. The effort of undergoing a catheter ablation is worthwhile as the confirmation of a physical curable condition that opens a future with possibilities instead of the obstacle in daily life that tachycardia entails. For the patients, an informative and caring conversation was needed that would have provided the support they lacked before and during the ablation.

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## 45. Navigating Life with Gout: Unmet Needs of Individualized Care Shapes a Process of Adaptation ID 186

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**Aim:** To explore how people with gout experience the health care and everyday life with gout. **Method:** A constructivist grounded theory approach employing simultaneous data collection and analysis were conducted. Eight men and four women with gout from three regions in the middle of Sweden who had lived with gout between 1-35 years and were between 40 to 87 years of age participated in semi-structured individual interviews. **Results:** The navigation of life with gout was represented by the two categories “a mismatch between person’s needs and provision of care” and “a process of adaptation”. The mismatch consisted of unmet needs for pain relief, a sense of insignificance as a person with an often-overlooked disease and lack of individualized and relevant care. The process of adaptation included searching for explanations, developing personal strategies for managing life with gout and habituating to pain and other impairments. **Conclusion:** The study highlights a critical need for healthcare to adopt a more person-centered approach that aligns with the unique needs and expectations of persons with gout. Health care personnel can provide sufficient care by adhering to person-centered care principles and evidence-based treatment recommendations; reduce the burden of unnecessary pain and thereby decreasing the need for adaptation. **Key words:** Gout, patient experience, disease impact, grounded theory, health care experience.

46. Disclosing mental health struggles in a highly competitive work environment: An interdisciplinary literature review and research agenda for advancing mental health and well-being in academia ID 208

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Academia is a fast-paced, highly competitive work environment. Particularly in the last decade, academic staff had to juggle the increasing demands of attracting external funding with job insecurity and higher teaching loads. These changes affect both physical and mental health. A number of studies indicate that academic staff are more likely to suffer from depression and anxiety than the general population. Studies on how academic staff cope with mental health struggles are sparse. The small body of research is concentrated on early-career scholars and higher academic institutions in North America and the United Kingdom. Moreover, research points to a reluctance to disclose mental health struggles. The extent to which academic staff meets expectations „set by themselves, colleagues, or the system as a whole“ affects „their sense of identity as an academic, and thus their sense of belonging to the academic community“ (Nicholls et al., 2022, p. 15). Decisions to not disclose mental health conditions serve as a means of self-preservation and identity management (Brown & Leigh, 2018, based on Goffman, 1990). However, without an open discourse on mental health and well-being, an image of the academic as infallible is perpetuated. A reliance on individual coping strategies limits the development of better structures and tools of support for staff members. This presentation concentrates on an interdisciplinary literature review as a basis for developing a research agenda on mental health and well-being in academia on all levels of seniority - with a particular focus on the Nordic countries. To address questions of mental health and well-being holistically, empirical research and practical recommendations need to focus on both preventive and curative care. Moreover, they need to take the individual characteristics of a diverse workforce into consideration. Person-centred care provides a well-suited approach to advancing (research on) mental health in academia.

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47. Young adults using online health information for unknown symptoms: the need for health-care knowledge, critical thinking, and interpretive skills in decision making  
ID 222

*Lisa Viktorsson, Region Östergötland; Pia Yngman-Uhlin, Region Östergötland; Magnus Falk, Linköpings universitet; Eva Törnwall, Region Östergötland*

Young adults experiencing unfamiliar symptoms commonly seek health information online. This study's aim was to explore how health information websites express and communicate health information and guide young adult readers in regard to health, illness, and care. Symptoms commonly searched for by young adults were used as search terms. The resulting data comprised material from 24 web pages and was analyzed using content analysis. The foremost purpose of online health information is to try to narrow down the user's symptoms and then advise the user on what actions to take. This is done by first forming a foundation of knowledge through descriptions and explanations, then specifying the symptom's time, duration, and location, and finally giving advice on whether to self-manage symptoms or seek additional information about them. However, the uncertainty of the diagnosis may rule out self-care. For those who are young and inexperienced with health care, forming a decisive conclusion about diffuse symptoms on the sole basis of online health information is demonstrated to be challenging. The necessity of health-care knowledge, critical thinking, and interpretation skills is highlighted. We demonstrate that, in the future, health advice given online should be required to conform with health-care access.

48. The impact of post-stroke fatigue on work and other everyday life activities ID 286

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Each year, about 21,000 persons suffer a stroke in Sweden, with one in six between 20 and 64 years of age. Post-stroke fatigue (PSF) is a life-limiting condition, identified as one of the most challenging impairments to manage in everyday life. When planning rehabilitation to promote health after a stroke, it is crucial to acknowledge the person as an expert in their everyday life. However, few studies have focused on the role of work as an integral part of everyday life post-stroke and there is a need to expand the existing knowledge base on PSF and everyday



life using larger sample sizes. This study investigated PSF, its development over time, and its impact on return to work and other everyday life activities. In addition, whether PSF could predict functioning in everyday life activities one year post-stroke was investigated. This prospective registry-based study included 2850 patients between 18 to 63 years of age registered in the Swedish Stroke Register during 2017 and 2018. Data were analyzed at 3- and 12-month post-stroke. Three months post-stroke, 43% self-reported fatigue, at 12-months the proportion increased to 48%. Dependence in complex activities one year post-stroke was significantly associated with fatigue. The absence of fatigue one year after stroke was a predictor for positive functioning in everyday activities, increasing the chance of returning to work (OR = 3.7) and to pre-stroke life everyday activities (OR = 5.7). Post-stroke fatigue is a crucial determinant of functioning in complex activities in everyday life. Since PSF persists or increases during the first year post-stroke, it is important for rehabilitation professionals to regularly assess PSF and functioning in everyday life after discharge and allow for the initiation or resumption of rehabilitation measures. Further, interventions addressing PSF are needed to increase the chance of returning to everyday life, including work.

#### 49. Unraveling the path to a sustainable everyday life with post-stroke mental fatigue ID 287

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Mental fatigue is a common life-limiting condition after stroke with a negative impact on the ability to return to work and maintain employment. People of working age typically participate in complex activities, such as work, family responsibilities, childcare, and transportation, requiring them to employ planning, multitasking, and problem-solving skills. Today there is limited research that has regarded work as an integral part of everyday life. The aim was to investigate how people of working age with mental fatigue after stroke experience their work potential in relation to a sustainable everyday life. A qualitative and descriptive design, involving 37 telephone interviews (age 38 – 62, 76% women) using the Worker Role Interview (WRI) complemented with a survey including the Mental Fatigue Scale, the Work Ability Index, and the Hospital Anxiety and Depression Scale was conducted. Written notes from the WRI assessment were analyzed through manifest content analysis. Statistical analyses were performed on WRI and survey data. Results revealed the persons' motivation as a strong prerequisite towards rediscovering work ability in everyday life, and to act and make

occupational choices to manage mental fatigue. Negotiating roles and navigate daily routines by simplifying everyday life and incorporate rest were prerequisites for maintaining employment. Moreover, an essential need was to have supportive environments, both within and outside of the workplace. This study emphasizes the vital need to consider everyday life and work as a cohesive whole. Recognizing mental fatigue having a negative impact on performance of activities and on meeting pre-stroke role expectations. Work training provided insights into challenges related to integrating work into everyday life. A person-centred approach is crucial to providing proactive, health-promoting interventions in order to support a sustainable return to work and life-situation over time.

### 50. Person-centered care: Needs and preferences of adult patients with chronic cardiovascular diseases - A Scoping Review ID 228

*Magdalena Walter, Nursing Science*

**Background:** Cardiovascular diseases (CVDs) are classified as chronic diseases with an increasing number of death rates worldwide. The number of rehospitalizations of patients with CVDs is constantly increasing and represents an immense burden for the individual patient. Person-centered care (PCC) aims to consider individual patients in order to provide holistic care, but little is known about its core components in nursing care. The aim of this master thesis is to identify the needs and preferences of adult patients with chronic CVDs during hospitalization. **Method:** Guided by the Joanna Briggs Institute (JBI) manual, a scoping review was conducted. Studies reporting on the needs and preferences of adult patients with chronic CVDs were examined. A systematic search was performed across four medical databases. Additionally, Google Scholar was used. Inclusion criteria were based on population, concept, and context characteristics. A total of 25 studies were included and subjected to a critical quality assessment using the JBI checklists. **Results:** The scoping review shows that patients with chronic CVDs regard information and learning needs as important aspects during their hospitalization. Patients' needs are related to discharge information and learning how to manage their condition. Preferences such as educator preferences or the patients' preferred role in medical decision-making during hospitalization were specified. Patients' desire for active participation in medical-decision making decreased with age, and differences in terms of education and gender were identified. Moreover, needs expressed by patients often differed from those perceived by nurses. **Conclusion:** This thesis demonstrates the extent of the existing literature on patients' needs and preferences in the hospital setting. The results indicate that nurses and discharge management play an essential role in terms of needs and preferences of adult patients with chronic CVDs. A conceptual clarification of PCC as well as further investigation in nursing research and practice is therefore needed.

## 51. Patients' expectations and experiences of consultations with registered nurses in primary care ID 316

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Background: For many patients, registered nurses in primary care are the first point of contact with healthcare services. Registered nurse-patient consultations are increasingly taken place as an alternative to doctor-patient consultation when such are not urgently needed. For primary care to be effective, it should be tailored to meet patients' health needs and expectations. Interpersonal aspects of healthcare consultations have been found to contribute substantially to a patient's perception of the quality of primary care delivery. A poor experience can result in mistrust and heightened anxiety, even when healthcare decisions or treatment have been beneficial. Still, patients' preferences regarding expectations and experiences with registered nurse consultations are unknown and so does the extent to which nurses meet patients' preferences. Aim: To explore patients' expectations and experiences in primary care consultations with registered nurses. Methods: To assess to what extent registered nurses met patients' preferences regarding nurse-patient consultations, the Quality of care through the patients' eyes (QUOTE-COMM) questionnaire was given to a total of 150 patients to answer before the consultation (I), directly after the consultation (II), and at two weeks follow-up (III). These data were gathered between September 2023 and February 2024. Results: Overall, patients had high pre-consultation expectations, both instrumental, problem-solving aspects of the consultations and of the affective, emotion-focused aspects. At post-consultation, patients rated their experiences equally high. To a large extent nurse visits were found to meet patients' preferences. Conclusion: This study contributes to research into the evaluation of nurse-led primary care services, needed for guidance of first point of contact. The findings indicate that nurse-patient consultations meet patients' needs and preferences of communication and interaction.

## Pandemic preparedness and responses

### 52. Patient-Reported Experiences and Outcomes of Virtual Care During COVID-19: A Systematic Review ID 250

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**Introduction:** The onset of COVID-19 has caused an international upheaval of traditional in-person approaches to care delivery. Rapid system-level transitions to virtual care provision restrict the ability of healthcare professionals to evaluate care quality from the patient's perspective. This poses challenges to ensuring that patient-centered care is upheld within virtual environments. The study aimed to review how virtual care has impacted patient experiences and outcomes during COVID-19, using patient-reported experience and outcome measures (PREMs and PROMs). **Methods:** A systematic review was conducted in accordance with the PRISMA checklist to evaluate patient responsiveness to virtual care during COVID-19. The search strategy was run in MEDLINE, CINAHL, EMBASE, and PsychInfo databases between January 2020 and 2022. Based on a prior set of inclusion/exclusion criteria, two reviewers independently reviewed the Title, abstracts, and full texts for eligibility. Data were abstracted using a standardized form. A patient partner was consulted throughout the study and co-conducted the review. **Results:** Of the 7187 evidence sources identified, 644 were reviewed in full text, and 102 studies were included in this study. The included studies were predominantly cross-sectional and reported on virtual care delivery in specialized adult outpatient settings. This review identified 29 validated PREMs and 43 PROMs. Several advantages to virtual care were identified, with patients citing greater convenience (saving travel time and cost, less waiting experienced to see care providers) and increased protection from viral spread. Studies also reported challenges patients and caregivers faced with virtual care, including feeling rushed during the virtual care appointment, lack of physical contact or examination presenting barriers, difficulty communicating symptoms, and technology issues. **Conclusion:** This review provides a comprehensive overview of virtual care experiences from patient and caregiver perspectives during the pandemic. Further research into healthcare professionals' perspectives would offer a supportive lens toward a strong person-centered healthcare system.

53. Patient Voices: How Hearing from Someone “Like Me” Builds Confidence and Trust and Facilitates Shared-Decision Making Regarding Vaccination in Pregnancy ID 302

*Marcia Bruce, University of Calgary; Maria Castellon Pardo, University of Calgary; Monica Surti, University of Calgary; Medea Myers-Stewart, University of Calgary; Quentin Collier, University of Calgary; Eliana Castillo, University of Calgary*

During the Delta wave of the COVID-19 pandemic, our team in Alberta, Canada engaged with pregnant and nursing persons from intimate group discussions to large public events. We intended to create safe spaces for pregnant persons and their families to ask questions and seek answers to their health concerns regarding COVID-19 infection during pregnancy, and preventative measures like vaccination, masking, social distancing and hygiene. Pregnant persons experience decisional conflict regarding many aspects of their health during pregnancy, like vaccines or medications, even if aware of safety or efficacy. During one of our sessions, a pregnant person, shared with us how torn and scared she felt from either falling sick from COVID-19 infection or vaccination. She asked if we had seen anyone “like me” get the COVID-19 vaccine and deliver a healthy baby. The desire to hear from someone “like me” is a theme that continues to come up in our work. Patient narratives are critical for informing and delivering more person-centred care to support complex decision making. Our patient partners have generously shared their testimonials about their lived-experience making vaccination in pregnancy decisions. These powerful testimonials are part of a multimodal intervention designed to support pregnant individuals and their families in their vaccine decision-making journey and healthcare provider training to improve vaccine communication during pregnancy, with the ultimate goal to improve maternal, fetal and infant health outcomes. We will present the voices of our patients through a series of videos and written testimonials. Although testimonials center on making vaccination decisions, their insights are applicable to other complex health decision-making and are important for providers to hear and internalize.

54. Person-Centred Research and Pandemic Preparedness and Response ID 304

*Eliana Castillo, University of Calgary; Marcia Bruce, University of Calgary; Maria Castellon Pardo, University of Calgary; Ingrid Nielsen, University of Calgary; Maria Santana, University of Calgary*

The recent COVID-19 pandemic reminded us that pregnant persons and their offspring are at increased risk of infectious diseases-related morbidity and mortality. The recent pandemic also reminded us that vaccinations rather than

vaccines save lives. The scientific prowess behind designing, testing and manufacturing vaccines is defeated if persons do not get vaccinated. “Vaccination, after water sanitation, proved the most effective intervention to reduce the morbidity and mortality associated with infectious diseases, and has been shown to be more effective than antibiotics” (Stanley Plotkin 2008). Trust is at the core of vaccine confidence and acceptance: person-centred care builds and maintains trust between persons, communities, providers and health systems. Seeking to support pregnant persons and their providers making health decisions during the COVID-19 pandemic in the face of evolving knowledge, our reproductive infectious disease research team at the University of Calgary, Canada partnered with the Alberta SPOR SUPPORT Unit, Patient Engagement Team to embed trained patient research partners with lived-experience on our research team and to recruit a patient council to inform research priorities and processes. The trained patient research partners and patient council have been instrumental to understand vaccine communication and vaccine decision making in pregnancy and to co-design interventions to improve vaccine communication during pregnancy. The patient research partners and our patient council have highlighted and addressed linguistic and cultural nuances in data collection, analysis and dissemination. Peer-to-peer data collection has made it possible to mitigate power differentials, collect richer data and foster researcher-participant trust. We will share our experience as a research team where members are patients with lived-experience and are formally trained in patient-oriented research. Our learnings provide proof-of-concept for person-centred research role to improve pandemic preparedness and response.

#### 55. Perspectives on work in the continuing care sector during and after the COVID-19 pandemic: A Pilot Study of Nursing Students ID 221

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Background: Improving the recruitment and retention of healthcare workers in the continuing care sector is critical to ensuring adequate care for older adults, particularly following the COVID-19 pandemic. Purpose: The purpose of this study was to understand the perceptions prospective registered nurses have about working in the continuing care sector and identify workplace attributes that attract prospective nurses to the sector. Methods: A partially mixed and sequential mixed methods study was conducted with nursing students at Ontario Tech University. Focus groups (n=14) asked students to comment on views about working in the continuing care sector, and job attributes that may attract them to the sector. Focus group data was analysed using thematic analysis. A cross-sectional survey asked students to respond to elicited choice job scenarios that varied job attributes

informed by the focus group interviews. The survey data (n=139) was analysed using least absolute deviations estimator. Willingness-to-pay (WTP) values of wages gained or forgone were generated for each job attribute. Results: Focus group interviews suggested fair compensation, optimal client-to-staff ratios, unionized work environments, comprehensive benefits packages, and flexible work arrangements were important job attributes. In survey results, 18.0% expressed interest in working in continuing care sector compared to 75.5% in acute care. Regression analysis suggested that higher amounts of paid vacation (WTP: -5.983; 95% CI: -13.749, -0.037) and higher risk of injury (WTP: 0.684; 95% CI: 0.124, 1.208) were associated with work in the continuing care sector. Impact: Continuing care workplaces can attract nurses by offering flexible options like part-time positions and paid vacation, and by actions that reduce the risk of workplace injury, violence, and abuse. Nursing students should be shown the positive aspects of working with older adults and dispel negative perceptions about the continuing care sector. Further research is needed to understand risk perceptions among nursing staff.

## 56. Person-centred care and ethical challenges in residential care during the pandemic - leaders' experiences ID 129

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**Aim:** The aim was to explore first-line managers and registered nurses' experiences of ethical challenges during the Covid-19 pandemic in residential care facilities, with focus on person-centred care. **Background:** The Covid-19 pandemic challenged the health- and social care in Sweden as in the rest of the world. Older persons were highlighted as a vulnerable group, being at high risk of seriously illness and death. The care of older persons should embrace person-centredness, a care founded on ethical values. Previous studies have shown that ethical challenges in the care older persons emerged due to all the pandemic measures. However, knowledge of ethical challenges with focus on person-centred care in residential care facilities from the leaders' perspectives still needs to be highlighted. **Methods:** An exploratory design with individual interviews with 12 registered nurses and 14 first-line managers were conducted between February 2022 to Mars 2023. All participants worked in residential care facilities in the southern or northern part of Sweden. The data were analyzed with conventional content analysis. **Findings:** The overall findings showed that the leaders had to disregard the individual needs of the person in order to protect the group and the society. Providing person-centred care was difficult as all older persons had to be treated and cared for in the same way. **Conclusion:** This study highlights that instead of promoting person-centredness, the leaders had to focus on the entire residential care facility instead of the individual persons' needs and preferences during the

pandemic. The findings also highlight several pandemic measures that clashed with the leaders' own beliefs of providing good care for older persons.

### 57. Being forced into an unsustainable and unethical working situation while caring for older people during the COVID-19 pandemic in Sweden ID 005

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**Bakgrund:** Worldwide, older people were more severely affected during the COVID-19 pandemic than others. In Sweden, those living in residential care facilities had the highest mortality rate, followed by those receiving home care services. The Swedish and international literature on the working environment for auxiliary nurses and nursing aides during the pandemic shows an increase in stress, anxiety, depression and post-traumatic stress syndromes. Care organisations were badly prepared to prevent the virus from spreading and to protect the staff from stress. Therefore, this study aims to describe the residential care and home care service staff's physical and psychosocial working experiences during and after the COVID-19 pandemic. **Methodology:** The data was collected through four focus groups interviews with 19 participants and analysed using qualitative content analysis. **Results:** The result shows that the staff were forced into an unsustainable and unethical working situation by being portrayed as scapegoats by the older people's relatives and the news media. In addition, they did not feel valued by people in general or by their own managers. The worsening working conditions that the pandemic contributed to resulted in a high degree of stress and risk of burnout, with staff members both wanting to and actually leaving their employment. Not only did the staff become innocent scapegoats in terms of the spread of the virus, after the pandemic they felt forgotten again and left to cope in an even worse situation than before. **Conclusions:** According to the participants, the pandemic brought them, their working conditions and this part of the caring system to a tipping point, which the government and the media should no longer ignore. The pandemic revealed even more unsustainable and unethical working conditions for the staff in HCR and RCS than before the pandemic, including the vulnerability of the older people in their care.

### 58. Personcentredness – the missing piece during the pandemic? ID 229

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Person-centred care is one of the core competencies for registered nurses in Sweden. Florence Nightingale's way of working is seen as an example of person-centred care. However, the amount of stress, workload, and mass casualty that Florence had to endure as a nurse during the Crimea war caused depression, and symptoms reminiscent of burnout. Stress researchers state that long periods of high workload can lead to a permanent hypersensitivity to stress. In general, nurses' own work situation and work environment form basic prerequisites for their opportunity for good occupational health, and to be able to do a good work. Therefore, to perform a person-centred care the nurses need to experience personcentredness in their own work situation influenced by the work culture of the organization. Our current research, where we analyze data from survey and in-depth semi-structured interviews with nurses that worked during the pandemic, has shown work caused mental illness in nurses working under high workload during the Covid-19 pandemic. Additionally, some nurses were not familiar with the term person-centred care and that some have heard of the term but are unfamiliar with what it implies. A majority of the informants stated that they did not work according to person-centred care during the pandemic. Something that could be considered a missed opportunity since there were restrictions in place during the pandemic meaning that relatives of patients were not in attendance. The nurses did not have the opportunity to provide the care and attention that both themselves and the authorities imposed on them, which could increase the risk of suffering from work-related mental illness. Therefore, it is of immense importance to develop new knowledge to understand if and how the organization enables personcenteredness in the nurses' work situation to reinforce good and sustainable work experiences and retain nurses in the profession.

59. What are the barriers and supports to a return to health from long COVID? – A qualitative Canadian study designed, developed, and conducted by individuals with lived experience of long COVID. ID 306

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Long COVID is now recognized as a persistent and debilitating condition that affects individuals in multiple ways that can also change over the course of the illness. Because of the significant physical, emotional, and economic impacts long COVID holds on individuals, their families and society more broadly, it is imperative that a multi-faceted approach is taken to the long COVID research that aims to improve outcomes for those affected by this phenomenon. The Patient

and Community Engagement Research (PaCER) program is an experiential-based learning program offered through the University of Calgary, Canada. A PaCER team of 7 student researchers, all with lived experience of long COVID co-designed and conducted a peer-to-peer research study to understand barriers and supports to a return to health for those living with long COVID. Patient experience and perspective data was collected through online focus groups and semi-structured interviews. The team used a collective and iterative thematic analysis approach to analyze the focus group data and narrative analysis to identify and contrast stories within the interview data. Six themes emerged and were defined as: (1) medical; (2) mental well-being; (3) money matters; (4) energy capacity; (5) resources and supports; and (6) disregard. Twenty-one subthemes emerged that aligned with these themes. This patient-directed study also yielded 6 essential recommendations to supporting a return to health for those living with long COVID and to enable them to re-engage with their previous social, family, employment, and other relational activities. In addition to demonstrating inclusive and effective patient engagement approaches integrating the long COVID patient voice and perspective into long COVID research, the study results can inform more appropriate person-centred, compassionate health care, health planning and policy management for those living with, and for those who will be living with, long COVID going forward.

## Patient and Public Involvement

### 60. Patient representatives' contribution during pharmaceutical research ID 145

*Elin Bruto Winberg, GPCC University of Gothenburg; Kiana Kiani, GPCC University of Gothenburg*

Introduction: Previous research indicates that the structure of patient participation in research and the competence possessed by patient representatives influence their experience being involved in research. The role and possibilities of patient representatives has not been explored extensively and specifically in relation to pharmaceutical research and is therefore an area where further exploration is needed. Aim: The aim of the study was to explore the possibilities for patient representatives to contribute during pharmaceutical research through non-clinical patient participation, what resources are necessary for participation and how the subjective knowledge of patient representatives is valued. The study was motivated by the ambition to further evolve patient participation within pharmaceutical research and explore the possibilities of patient representatives. Methods: Semi-structured qualitative research interviews were conducted with six patient representatives from different patient organisations. After the interviews were transcribed, a qualitative content analysis was performed where codes, categories

and themes were identified. A theoretical framework was applied during the analysis of the data collected through the interviews. One of the main theories used was Pierre Bourdieu's theory on capital and this concept was related to resources necessary for patient participation. Results and conclusion: Patient representatives find it difficult to access scientific knowledge and this prevents them from contributing to pharmaceutical research. Economic, social and specifically scientific capital are the forms of capital, and therefore resources, most necessary for non-clinical patient participation. To promote patient participation, it's essential to determine the requisite level of resources that patient representatives should ideally possess. The subjective knowledge of patient representatives is perceived, by the representatives themselves, as highly valued by researchers. It should however be specified when the knowledge is relevant for effective contribution to pharmaceutical research. In conclusion, the role of patient representatives could be further specified to increase their possibilities of contributing to pharmaceutical research.

## 61. Patients With Unresectable Esophageal Cancer and Their Caregivers: Unmet Needs In Developed Countries ID 342

*Shirin Khalili, Independent Patient Advocate*

Due to a lack of widely available noninvasive screening programs, patients who are diagnosed with esophageal cancer often present at an advanced stage of disease. With a 5-year survival rate of <20%, it is among the least survivable cancers. Ironically, esophageal cancer patient advocacy is often dominated by hope and survivorship, which leaves the majority of these patients and their caregivers under-represented, and their unmet needs thereby under-reported. This review aims to explore the variability in treatment modalities, health systems, and cultural attitudes in North American, European, and East Asian countries as they pertain to these patients and their caregivers.

## 62. Patient involvement in health research and development- a pilot study ID 105

*Kiana Kiani, University of Gothenburg*

Patient representatives are crucial to ensuring that patients are involved in health research and development, thereby improving health services. However, the role of patient representatives and collaboration between stakeholders, levels of trust as well and experienced barriers are poorly understood. This pilot survey is part of a larger project that aims to explore patient and public involvement in health research and development using the launch of EUPATI (European Patients Academy on Therapeutic Innovation) Sweden as a case. Aim: To explore patient

representatives' views on their role in health research and development. Methods and Materials: 30 patient representatives were recruited through EUPATI. Participants were asked to rate statements on their role in health research, collaboration between different stakeholders, general understanding of the role of patient in collaboration with other stakeholders in health research and development and trust between different stakeholders and barriers to patient involvement on a scale of 1-5 (1=not important and 5=extremely important). Result and conclusion: The majority of participants were over 40 years old and predominantly female (70%). Most participants possessed post-secondary education qualifications (83%) and had affiliations with patient organizations (82%). They highly valued involvement in roles such as educating healthcare professionals (90%), advising within the healthcare system and research (89%), and advising regulatory agencies and decision-makers (86%). Patient representatives played vital roles in organizations and research and clinical trials (89%). They often collaborated with other patient groups (97%) and healthcare professionals (90%), but interactions with health sector procurement officers/purchaser were infrequent (6%). Participants were most positive about working with researchers (60%) and healthcare professionals (55%) and had high trust levels in them (90% and 70%, respectively). Areas needing more knowledge included drug and medical technology development, regulations, ethical guidelines for patient participation, and collaboration. Further studies will be carried out in autumn to better understand other stakeholders' views on patient involvement including barriers and facilitators.

## People of old age

### 63. Quality of care and the importance of digital tools from the perspective of persons with dementia living in nursing home ID 092

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Background: Healthcare supported by technology may be experienced as simultaneously supportive and contributing to an increased distance between persons. What is important for persons living in a nursing home, how do they experience using technology and how do they experience healthcare quality, are

questions seldom asked persons with dementia. Aim: To explore the person with dementia's experiences of care quality and use of technology in a nursing home and what is of importance for the person with dementia when living in a nursing home. Method: A cross sectional study was conducted in one Norwegian nursing home for persons with dementia using the questionnaire Quality from the patient's perspective (QPP), including six items on technology. Persons who could give their informed consent, understood and were able to express themselves verbally and that their mental and physical health made it ethically justifiable, were invited to participate. In all 33 persons with dementia participated (RR 37,5%). Descriptive statistics (frequency, percent, mean, standard deviation) and chi-square tests were run using IBM SPSS 27. Results: The respondents' mean age was 85 years (range: 72-96 years) and 68% were women. A total of 61% of the respondents experienced that the quality of care they received in the nursing home was satisfying. Having a computer, an Ipad, or internet connection in the person's room had statistically significant low importance. Having a mobile phone was neither important nor unimportant. On the other hand, having their own remote tv-controller and safety alarm were of high significant importance. Conclusion: Persons with dementia can answer questions about what is of importance for them and how they experience care quality when living in nursing homes. Their answers can be used in quality improvement work so that a higher number of persons can experience living in nursing homes based on their individual terms.

#### 64. Moving between being and doing- Illuminating meanings of person-centredness in residential care ID 114

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Background: Despite a vast amount of research on various person-centred frameworks, interventions, processes, and outcomes in nursing homes, with convincing evidence that older persons and staff benefit from person-centred initiatives, meanings of person-centredness have still not been fully elucidated in the international literature. Aim: To illuminate meanings of person-centredness as narrated by nursing home managers in nursing homes. Method: Twelve nursing home managers in 11 highly person-centred nursing homes in 7 municipalities in Sweden were interviewed. The data were analysed by using phenomenological-hermeneutic analysis. The naive understanding revealed that person-centeredness involved both doing person-centredness and being person-centred. Additional elements of person-centredness such as; knowing, giving, sharing, and sensing emerged during the structural analyses. The comprehensive understanding highlights that person-centredness supports both dimensions of the self, Idem and Ipse, in Ricoeur's hermeneutics of the self. Findings: Meanings of person-

centredness could be understood as moving between doing and being through knowing, sensing, sharing, and giving for person-centredness. Moving between doing and being connects ‘what’ with ‘who’ in person-centred practices, by moving between “with and for” the older person and integrating the task ‘doing for’ with the relational aspects of ‘being with’. Conclusion: The findings indicate that moving between doing and being through the elements of knowing, sensing, sharing and giving for person-centredness has the potential to preserve, acknowledge and support the person’s identity. Also, embracing Knowing-, Sensing-, Sharing- and Giving for person-centredness may contribute with sense-making, preserve dignity, and promote self-esteem when aiming to provide a good life for older persons in nursing homes, within an ever-present ethical stance.

## 65. Person-centredness when arranging group exercise for community-dwelling older persons ID 294

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Background: Health promotion interventions such as physical activity are important for healthy ageing. Therefore, stakeholders arrange group exercise for community-dwelling older persons via meeting places in municipalities. As the older target group is heterogeneous, person-centredness is relevant (1) to motivate and retain older persons in exercise activities. Person-centredness is also important when prerequisites change e.g. during a pandemic. Therefore, the aim was to explore person-centredness in group exercises arranged by stakeholders for older persons via meeting places in municipalities prior to and throughout the Covid-19 pandemic. Methods: Six online focus group interviews were conducted with 25 stakeholders, such as decision-makers and representatives from the non-profit sector, from seven municipalities in Sweden. The stakeholders shared experiences about arranging group exercise via the meeting places before and during the Covid-19 pandemic. Data were analysed using focus group methodology (2). Findings: The stakeholders highlighted strategies in which person-centredness emerged. First, person-centredness emerged in the strategies concerning the older persons. These strategies included strengthening them as persons by being listened to, feeling a sense of belonging, adapting to their wishes, and facilitating leadership and shared decision-making. During the pandemic the importance of shared decision-making and shared ownership with the older persons was highlighted. Also, new solutions with smaller exercising groups during the pandemic made it possible to see each older person and person-centred encounters were thereby facilitated. Second, person-centredness emerged in the strategies concerning organisational structures. These strategies included strengthening of financial and personnel resources, competence development, strengthening relationships and collaboration within the organisation. During the pandemic, lack of

communication and collaboration impacted the possibilities of a person-centred environment. Conclusions: When arranging health-promoting interventions, person-centredness can advantageously be used both in terms of the organisational structure and in the encounters with the older persons.

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## 66. Older adults' experiences of being discharged from in-patient care to home ID 331

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**Background:** The growing number of older adults worldwide coupled with chronic disease challenges already strained healthcare systems. Healthcare and social care is obliged to coordinate care and support upon discharge. In addition, individuals have a legal right and willingness to participate in the planning for support. Despite efforts to make healthcare person-centered and improve the interaction between different healthcare providers in clinical practice, previous research indicates that healthcare systems remain fragmented, having poor coordination when delivering care. **Aim:** To describe older adults' experiences of being discharged from in-patient care to home. **Methods:** This study had a qualitative descriptive design, enabling straight descriptions of older adults' experiences of being discharged from in-patient care to home. Individual semi-structured interviews were conducted with 17 older adults (aged 65 years, or older) living in the south of Sweden, with chronic diseases and in need of coordinated care transitions. Data were analyzed using inductive qualitative content analysis. **Results:** The analysis yielded four generic categories and the main category "Being the main character but not always involved in one's own care transition". This indicates that older adults are not always involved in the planning and decision-making regarding their care transition leading to a mismatch between actual needs and the expectations of planned support after discharge. **Conclusions:** The study reveals a notable disparity between the assumed central role of older adults in care transitions and their insight and involvement in planning and decision-making. The findings are significant in the context of person-centered care, which emphasizes the importance of tailoring healthcare services to the individual's unique needs and preferences.

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### 67. ”Everything is in the home environment” – experiences from older adults receiving home rehabilitation in Sweden ID 249

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Introduction: Rehabilitation in home has become a strategy to meet the needs of an increasing aging population. Home rehabilitation aims to promote independence and to enable older adults to remain in ordinary homes for as long as possible [1], in line with many older adults wishes [2, 3]. The home is often associated with a sense of at-homeness and identity [4-6] where the home and neighbourhood become more important during aging. The home rehabilitation strategy is in accordance with the Swedish transition to Good quality, local health care, with a focus on developing person-centred working methods. However, although home rehabilitation interventions often are characterised as person-centred, all participants may not experience them as such [7], and there is a lack of scientific knowledge from user perspective to inform home rehabilitation initiatives. The purpose of this study was to explore valuable aspects of home rehabilitation experienced by older adults [8]. Method: Nine older adults and five spouses were interviewed about their experiences of receiving a municipal home rehabilitation intervention in their homes. Nine de-identified interviews were analysed as secondary data through qualitative content analysis. Findings: A familiar home environment with inclusive collaborations and the mastery of everyday life were valuable aspects for older adults in home rehabilitation. The creation of a tailored rehabilitation together with competent professionals through mutual trust gave a feeling of security in the home which was also considered valuable. The result indicate that the professionals had the ability to build



partnerships based on each older adult's unique situation. Conclusions: The home as context for rehabilitation seems to have potential to create conditions for a person-centred practice. When rehabilitation professionals have the competence and skills to use the home as an arena for inclusive collaboration, a person-centred process with person-centred outcomes will be able to take place.

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## 68. Trust and easy access to home care staff are associated with older adults' sense of security: A Swedish national longitudinal study ID 058

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**Aim:** Older adults are increasingly encouraged to continue living in ordinary housing with support from home care services (HCS). However, few studies have focused on older adults' safety in home care. This study explored associations between sense of security and factors related to demographic characteristics and HCS. **Methods:** The mixed longitudinal design was based on a retrospective national survey. The study population consisted of individuals in Sweden (age 65+) granted HCS at any time between 2016 and 2020 (n = 82,834–94,714). Multiple ordinal logistic regression models were fitted using the generalised estimation

equation method to assess the strength of relationship between the dependent (sense of security) and independent variables (demographics, health and care-related factors). Results: The sense of security tended to increase between 2016 and 2020 and was significantly associated with being a woman, living outside big cities, being granted more HCS hours or being diagnosed/treated for depression (COR 2–9% higher). Anxiety, bad health and living alone were most strongly associated with insecurity (COR 17–64% lower). Aside from overall satisfaction with HCS, accessibility and confidence in staff influenced sense of security most. Conclusion: We stress the need to promote older adults' sense of security for safe ageing in place, as mandated by Swedish law. HCS profoundly influences older adults' sense of security. Therefore, it is vital to prioritise continuity in care, establish trust and build relationships with older adults which is prerequisite for person-centred, and high-quality care. Future research needs to focus on sustainable approaches of implementing person-centred care considering the complexity of an increased older population in need of advanced care in their homes, and at the same time an increased shortage of staff and lack of appropriate competence.

69. Older adults needs and wishes in contact with outdoor environments at residential care facilities –conditions and take-home messages for person-centred care outdoors ID 038

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There is increased awareness of the importance of providing health-promoting indoor and outdoor everyday environments for persons with special needs. To understand older adults' needs and wishes in contact with the outdoor environments at residential care facilities (RCFs) it is important to explore and include the residents' own experiences. Therefore, the present qualitative study aims to illuminate needs and wishes of older adults living at RCFs regarding their contact with the outdoors. To gain a comprehensive understanding of the potential of the outdoor environment as a resource for person-centered care, the study covered four different zones of the physical environment, in which contact with the outdoors can occur. Twelve older adults from three RCFs participated in individual walking interviews in indoor and outdoor environments. Through qualitative content analysis three categories were identified that exemplify how the needs and wishes of older adults can serve as a resource for developing supportive everyday environments at RCFs. The first category describes several aspects of normality linked to outdoor stays at RCFs for older adults. The second category describes aspects of attractiveness; it relates to the longing for outdoor stays,

appreciated features and well-kept outdoor environments. The third category describes accessibility in the environments at RCFs, access to personal support for outdoor stays and experiences with uncertainty. The results from the study can be used to develop outdoor environments at RCFs, possible to use for person-centred care. The results are intended to facilitate practical knowledge that is useful to staff and managers at RCFs and to decision makers, property developers, architects and planners. The study is at the intersection of caring science, architecture and landscape architecture.

## 70. Experiences of patients receiving Home Care and living with polypharmacy: a qualitative interview study ID 099

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**Background:** In Sweden, patients receiving Home Care (HC) are older people with frailty and multimorbidity, and are often treated with many medicines. Their perspectives on polypharmacy have been sparsely explored. **Aim:** To investigate HC patients' experiences and perceptions regarding polypharmacy. **Design & setting:** Semi-structured interviews with 17 patients with HC in Stockholm, Sweden. **Method:** The interview questions were open and aimed to encourage participants to speak freely about their personal experiences of living with polypharmacy. Data was analysed using inductive thematic analysis. **Results:** The participants' median age was 83.5 years (range 74-97 years) and the median number of prescribed medicines was 11 (range 5-30). The following two themes were identified: (1) experiences from daily life with polypharmacy; and (2) dependency on the relationship to healthcare professionals. The first theme contains the main finding, which was the diversity in how older people experienced polypharmacy and how they coped with polypharmacy in everyday life. While some were satisfied despite having multiple medicines, others experienced such psychological unease owing to polypharmacy that it led to reduced quality of life. The second theme reflects the importance of the relationship between the older person and healthcare professionals for medicine-related ideas and attitudes. **Conclusion:** The individual variation in experiences regarding polypharmacy points to the value of interprofessional teamwork with the patient as an active partner. Therefore, healthcare professionals need to adapt a more person-centred approach where the

patient's perspectives are respected and considered in medicine-related decision-making.

71. The clarity and adaptability of instructions preventing the spread of the Covid-19 virus. Perceptions of staff in care of older people in Sweden and their association with individual factors and organisational factors regarding the psychosocial work environment. A cross-sectional study.  
ID 014

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Background: Older people in residential care had the highest mortality rates, followed by those who received home care during the COVID-19 pandemic in Sweden. Staff working in the care of older persons assumed responsibility for preventing the spread of the virus in spite of lacking the prerequisites and training to do so. This study aimed to investigate how staff in the care of older people described their psychosocial work environment during the COVID-19 pandemic; it also aimed to examine the perceived clarity of the instructions and the staff's ability to follow the instructions to prevent the spread of the virus and its association with individual factors and organisational factors regarding the psychosocial work environment. Methods: A cross-sectional web survey was conducted for the data collection. The staff's perceptions of their psychosocial environment were analysed using descriptive statistics. The association between organisational and individual factors, as well as the degree of clarity of the instructions and the staff's ability to follow them, were assessed using multivariate (ordinal) regression analysis. Results: The main findings were that perceptions of the clarity and adaptability of the instructions were primarily correlated with organisational factors, as higher responses (positive) for the subscales focusing on positive challenges, role clarity, control, support and encouragement in leadership at work were associated with the belief that the instructions were clear. Similarly, those indicating high job demands and high individual learning demands were less likely to report that the instructions were clear. Conclusions: High job demands and individual learning demands were demonstrated to decrease the staffs understanding and adoption of instructions. These findings are significant on an organisational level, since the work environment must be prepared for potential

future pandemics to promote quality improvement and to generally increase patient safety as well as the health of staff enabling practice person centered care.

72. Documentation of Person-centered Care in a Long Term Care setting Implementing Age Friendly Health Systems/4Ms Framework: A Quasi-Experimental Study ID 223

*Karen Moore, Hebrew Senior Life*

The Age Friendly Health Systems movement is a person-centered approach to care that follows an essential set of evidence-based practices, causes no harm, and aligns with “What Matters” to the older adult, their family and other caregivers using the 4Ms framework of “What Matters”, Medication, Mentation, and Mobility (IHI, Age Friendly Health system Guide, 2020). The 4Ms are considered together to determine goals of care and treatment planning. The Age Friendly Health Systems/4Ms (AFHS/4Ms) framework is rapidly disseminating across health settings in the U.S. and other countries (Fulmer & Pelton, 2022, IHI, News, 2022) yet, barriers to documentation threaten its sustainability (Adler-Milstein et al, 2020, Burke et al., 2022). Most electronic health records are designed to collect symptom reporting rather than personal information and goals (Broderick & Coffey, 2014, Jakobsson et al 2019, Jakobsson et al, 2022, Nagykaldi et al, 2018, Heckemann et al , 2020). Gaps in documentation of person-centered care need to be addressed through informed redesign of the EHR. A senior health system in the northeastern United States initiated a strategic commitment to implementing person-centered care and a plan to implement the AFHS/4Ms framework beginning with a pilot on two long-term care units. Using the “Protocol for Reviewing Person-Centered Content in Medical Records” (Jakobsson et al., 2019) documentation will be reviewed before and after clinicians complete an education program on person-centered care. Clinicians will also be surveyed on confidence with assessing PCC and ability to document PCC in the medical record. The quantitative, quasi-experimental study aims to evaluate if there is an increase in documentation in the EHR of elements of person-centered care (PCC)/” What Matters” on long-term care units where clinicians have completed an education program on the AFHS/4Ms framework. This project is being conducted in partial fulfillment of the requirements for a Doctor of Nursing Practice degree by the investigator at Regis College in Weston, Massachusetts, U.S.A. Data collection is planned for the Fall of 2023.

73. Key findings and implications of a qualitative study of older people's experiences of person-centred care (PCC) in an integrated care context (PCIC) in Ireland utilising the Person-Centred Practice Framework. ID 021

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While most evaluations of integrated care often focus on systemic or clinical outputs, theoretically informed research emphasising the values, preferences and voice of older persons relating to experiential dimensions PCIC is less prominent. This paper presents the findings of a multiple qualitative case study exploring older persons' experiences of PCIC in an integrated care programme in Ireland, NICPOP. The conceptual underpinnings of this study stem from a review undertaken of the PCC literature and use McCormack and McCance's Person-Centred Practice Framework (PCPF) as a sensitising framework to interpret data generated in 23 interviews with individuals and caregivers across three heterogenous NICPOP sites. Key findings evidence the centrality of PCPF care processes, including relational processes: working with patient's beliefs and values; being sympathetically present; engaging authentically; sharing decision-making and providing holistic care. Findings indicate ways in which positive patient/service provider interactions lead to PCPF person-centred outcomes including a good care experience and wellbeing. Findings attest to the importance of the care context on experiences of care. Specifically, they suggest that a home-based, as compared with clinical hub based, model of care enables relationship building, which provides for a greater insight into the social contexts of the older person, revealing their vulnerabilities, priorities and needs, and facilitates more tailored holistic care. The findings illustrate the importance of holistic care and a healthful culture where decision-making is shared (PCP), often experienced differently by older people with varying biographies and related health and social care needs. Recommendations include more emphasis on the psychosocial contexts of the patient and their caregivers within care planning and delivery; further development and prioritisation of case management approaches and longer-term intensive supports for complex situations; and more interprofessional collaboration to improve transitions across care settings and systems, enhancing felt experiences of continuity and coordination arising from PCIC.

74. Activity-guide – social support efforts aimed at reducing the involuntary loneliness of elderly persons ID 296

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The function of an activity-guide is an innovative municipal collaborative support effort that fits well into the strategies for healthy ageing and person-centred care. The activity-guide mission is to be a support, a personal contact, for elderly who experience involuntary loneliness in daring to recommence or find new social contexts, such as physical, cultural or creative activities. Today we know that experienced involuntary loneliness over longer period of time not only affects the psychological well-being but also the physical health. Put into perspective, involuntary loneliness is refereed to be as strongly associated with premature death as smoking fifteen cigarettes a day. Simultaneously, we know that involuntary loneliness can be difficult to break by yourself, as perceived loneliness is often surrounded by feelings of shame. Fortunately, today there are good initiatives of collaborative support efforts to break the involuntary loneliness of elderly. One of these good initiatives is this collaborative project between Skövde Municipality and the University of Skövde where the aim is to contribute in development of the activity-guide function and collect data to evaluate the users' perception and usefulness of the activity-guide function. The project is collecting both qualitative and quantitate data from elderly who have contact with the activity-guide. Preliminary data collected from individual-in-depth interviews with the elderly, shows that the activity-guide have a significant role in resuming or finding new social contexts. Concurrently, the preliminary results show that the elderly want more understanding and knowledge from healthcare providers about how involuntary loneliness affects their health and well-being. In the project, it is planned for focus-group interviews with the persons who are activity-guides in the municipalities that offer their residents this function. This projects knowledge can be used for a deeper understanding of what enables and prevents elderly person from daring to recommence or find new social contexts.

#### 75. Healthcare personnel's experiences with person-centredness and advanced care planning among nursing home residents with dementia. ID 091

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Background: Advanced care planning (ACP) is a formal and planned conversation between the patient, next of kin, and healthcare personnel, about the patient's wishes for their end of life, but patients seldom participate. Aim: The aim was to explore how healthcare personnel in nursing homes experienced participating in ACP as a person-centered intervention. Method: Data was obtained through individual interviews with seven healthcare personnel at a nursing home for

persons with dementia in Norway. Results: The participants experienced patients with dementia seldom participated in the formal ACP. However, topics from ACP were communicated in everyday conversations in moments when the patient's cognitive function appeared temporarily improved. These conversations were not scheduled, and neither the physician nor the next of kin were present, as they would be in formal ACP. However, some of the healthcare personnel talked about these conversations as ACP. In this way, the patients conveyed their wishes for the end of life directly and not through their next of kin or the healthcare personnel. Conclusion: Healthcare personnel experienced that patients with dementia were able to express their wishes for the end of life but did seldom participate in the formal ACP. Results of this study indicates that informal conversations during a patients' period of transient cognitive enhancement in everyday life can add important information about the patients' wishes for the end of life. The end-of-life care for the patient is presumed to be more person-centred when the wishes come directly from the patient, rather than through potential interpretations by others.

#### 76. Improving and evaluating relationship-centered care during meetings with the resident-family-caregiver triad in nursing homes ID 247

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Introduction: In long-term care, the provision and improvement of relationship-centered care have become increasingly important. The narrative method Connecting Conversations offers the opportunity to evaluate experienced quality of care (1). These narrative stories contain useful information to reflect on, learn from and improve relationship-centered care (2). The aim of this study is to explore how narrative data collected with Connecting Conversations is used in evaluation meetings with the care triad (residents, family members, care professionals) to improve relationship-centered care. Methods: A qualitative approach was used, consisting of structured observations. Participants were care professionals, residents and family members from two nursing home wards. Participating wards organized evaluation meetings to discuss experienced quality of care based on narrative data collected with Connecting Conversations. An independent researcher observed the process of organization of these meetings and the content discussed during the meetings. Detailed notes were taken and data were analyzed thematically by using conventional content analysis.



Results: In total four evaluation meetings were organized of which three meetings took place. The first ward organized a meeting for care professionals and a second meeting for care professionals, residents and family members. A follow-up meeting was organized but cancelled by the family members. The second ward organized a meeting for care professionals and decided beforehand not to invite residents and family members. When compared to the collected narrative data, topics regarding experienced quality of care were only superficially discussed during the evaluation meetings. Conclusion: When using narrative quality data for quality improvement, the richness of the data is not used to its full potential. Furthermore, the collaboration with care professionals, family members and residents remains challenging when reflecting on relationship-centered care.

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## 77. Older persons' perspectives on constrained participation in health care: A framework synthesis ID 340

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Patient participation is a considered an ideal in current health care. Yet, some studies suggest that the enactment of patient participation is not always ideal but constrained. Aim: To analyse critically the concept of 'constrained patient participation' in health care, from the perspectives of older persons, through a systematic review of qualitative research findings. Methods: Data in the form of qualitative studies published from 2012- 2023 were retrieved from five bases, with 45 studies eventually included in the review. Diverse attributes of constrained participation in health care were identified and contrasted with person-centred participation and analysed through a framework synthesis, drawing upon prior conceptual frameworks. Results: Constrained participation in health care from older persons' perspectives was found to be characterised by patients experiencing less or more participation than preferred, which most often involved communication struggles between them and health-care professionals. In these instances, the latter either did not allow patients the desired kind/extent of participation or forced them into unwanted participation. Constrained patient participation manifested itself via two constructs: 'fought-for participation', or experiencing less participation than preferred, and 'forced-to participation'. Those were further divided into 3-4 themes respectively. Example of one of the theme in which the former construct was divided into was 'experiencing a lack of, or fighting for receiving appropriate information' while example of a theme of which the latter

construct was comprised was 'forced to make decision or influence care'  
Conclusion: The results challenge earlier concept analyses of patient participation, where these constructs do not appear.

## 78. Sensor-based screening of fall risk in preventive home visits for older persons ID 172

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Introduction: Fall injuries are important causes of disability, suffering, and death globally. Between 26-35% of all persons aged 65 and over fall each year, the number increases by age and most falls in independent older community-dwelling persons occur in their homes. Aim: The aim of this PhD-project is to contribute to person-centred fall prevention by investigate self-rated and objective measures association and prediction to fall risk and explore older persons and home visitors' experiences of sensor-based screening of fall. Research questions: 1. How is the agreement between subjective and objective measures of fall risk? 2. Can objective fall risk screening predict future falls? 3. How do seniors experience objective fall risk screening? 4. How do home visitors experience objective fall risk screening? Design: Cross sectional design with longitudinal follow-up and qualitative design will be used. Method: Two-hundred and fifty persons between 77 and 82 years will be recruited consecutively in connection with invitations to Preventive home visits (Pre-H). The older persons will use a sensor (Snubblometer®) for one week before Pre-H. A digital questionnaire about the older persons life situation will be filled in during the home visit. A fall journal followed up for one year. One year after the Pre-H visit data will be extracted from a register regarding falls and fractures. Data will be analysed statistical. Of the participants using the Snubblometer, 20 persons will be interviewed after the home visit. Twelve home visitors will be interviewed and observed during the home visits. The qualitative data will be analysed with content analysis.

## 79. Person-Centered Practice in Hospitalized Older Adults with Chronic Illness: Clinical Study Protocol ID 065

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The aging trend, high hospitalization rates, multiple chronic illnesses, and increased vulnerability of hospitalized older people require a person-centered

approach to healthcare, an approach that values a person's participation in the healthcare relationship, supports shared decision-making and mutual understanding, and respects a person's values, preferences, and beliefs. However, its implementation and development are still challenging for various health systems and professionals worldwide. The implementation strategy must be based on each country's health system organization, practice contexts, and professionals involved. This work aims to provide guidelines to understand the state of development of person-centered practice (PCP) in the daily care of hospitalized older adults with chronic illnesses within an internal medicine department of a Portuguese hospital. We focus on characterizing the perceptions of a multidisciplinary team working at an inpatient hospital department of PCP; the perceptions of hospitalized older adults with chronic illnesses about PCP; the work culture of an inpatient hospital department with a high prevalence of older adults with chronic illnesses; the PCP Framework at the organizational and structural levels of the healthcare system, and the elements that influence the implementation of PCP at this context. Therefore, a mixed-methods analysis with a convergent design was planned, and data will be collected in parallel and independently from distinct samples of health professionals and older inpatient adults within this department. Furthermore, health policies and strategic plans will be analyzed to identify guidelines for PCP. Studying the clinical practice dimensions in this healthcare context following the PCP Framework can allow us to understand the extent of its development in terms of prerequisites, care environment, care processes, and the macro-context healthcare system. Thus, we might identify and characterize the dimensions achieved and those requiring improvement and establish a starting point for defining strategies to advance practice toward person-centeredness and monitor changes in practice.

#### 80. The use of indicators from the quality registry SveDem to measure and improve person-centred dementia care in nursing homes ID 063

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Background: The Swedish registry for cognitive/dementia disorders, SveDem ([www.svedem.se](http://www.svedem.se)), is the world's largest quality registry of dementia diseases. The aim of the register is to improve quality of diagnostics, treatment, and care for persons with dementia in Sweden. Since 2012, nursing homes can register in SveDem's nursing home module and follow-up quality indicators to improve care and support provided. Methods: Persons with dementia are registered in the SveDem's nursing home module at an annual follow-up. The registrations are based on variables measuring nursing practice such as person-centred care, activity

level, restraints, risk assessments, drug treatment and quality of life. Nursing homes affiliated to SveDem receive online reports with descriptive statistics based on their registrations. The online reports are based on quality indicators, of which four measure person-centred care; life story used as a foundation of care, interaction strategies, individual physical environment adjustments documented and person-centered activities. Results: Between 2016-2022 a total of 7 862 persons with dementia were registered in the nursing home module. The proportion of all four quality indicators for person-centered care had increased between 2016 and 2022; life story used as a foundation of care from 66% to 78%, interaction strategies from 67% to 84%, individual environment adjustments from 57% to 78% and person-centred activities from 78% to 86%. Improvements in person-centered care were also seen at the local level for units who use their reports in SveDem. Conclusion: SveDem contributes to important knowledge and quality development in care provided for persons with dementia in a nursing home setting. The quality indicators for person-centred care are an important tool for improving quality of dementia care in nursing homes. Data from SveDem is also a good source for epidemiological research with the aim of studying the relationship between how person-centred care affect care and treatment.

## Time-critical events

### 81. Person-centred fundamental care in the emergency room: insights from patient experiences ID 068

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Background: Life-threateningly ill or injured persons are cared for in hospitals' emergency rooms. In these rooms the time-critical event and biomedical focus may reinforce a culture that value the medical-technical aspect of nursing. To meet patients fundamental care needs, such as respect, information and toileting in a person-centred way seems challenging. Little is known about how person-centred care is visible and valued by vulnerable and exposed patients in emergency rooms. Methods: Individual interviews with 15 patients who had been life-threateningly ill and cared for in an emergency room at a university hospital in Sweden. The transcribed interviews were analyzed with deductive content analysis based on The Fundamentals of Care Framework, which is constituted of three interrelated

dimensions: relationship, integration of care, and context of care. Results: Despite being life-threateningly ill, patients were still able to describe their unique needs—and these were not only related to medical care. Relationship, timely and personalized information, and existential needs were identified as essential fundamental care needs, which were not, or only partly met. Patients preferred personalized care but described the nursing care as task-oriented. Despite being life-threateningly ill, patients adapted to the patient role to avoid burdening the registered nurses. Conclusion: Patients described experiences related to the three dimensions of fundamental care – relationship, integration of care and context of care. Fundamental care needs were not always met, which might lead to complications and suffering. Such needs should be met in a person-centred way and be supported by nursing leadership and guidelines. The finding highlights the need to prioritize fundamental care also for life-threateningly ill or injured patients, which in turn calls for focus on organizational prerequisites to enable person-centred care. This knowledge can be used in emergency care settings to facilitate person-centred fundamental care, avoiding missed nursing care.

## 82. Care relationship and interaction between patients and ambulance clinicians: A qualitative meta-synthesis from a person-centred perspective ID 259

*Viivi Tikkanen, Mälardalen University; Kay Sundberg, Karolinska Institute*

Ambulance care is characterised by disaster medicine, traumatology and care for acute illnesses and accidents. The focus of ambulance care is clearly on medical care, whereas interpersonal interaction between patients and ambulance clinicians appears less prioritised. A patient within ambulance care needs to be listened to, be taken seriously, be treated with empathy and be seen as a unique person. These are fundamental to delivering Person-centred care. The aim is to describe how the care relationship and interaction between patients and ambulance clinicians in prehospital emergency care are described in the literature and how they can be interpreted from a Person-centred perspective. A qualitative meta-synthesis was used. Data collection was carried out with PubMed, CINAHL Plus and Web of Science in September–October 2022 and in August–September 2023. The first article searching applied a timeline 1990–2022 and the second 2022–2023. A total of 13 studies employing a qualitative approach were evaluated and included in the interpretive analysis. Three themes were identified: A good care relationship, Decision-making and Hindrances to practising person-centred care in ambulance care. Trust, good communication and respect for patients' dignity were the most important parts of the good care relationship between patients and ambulance clinicians. Decision-making regarding the examination of patients, medical treatment and transport to the receiving care unit was one of the tasks that ambulance clinicians do independently but in cooperation with patients and family members. Person-centred care within ambulance care may be hindered due to

environmental factors, attitudes and behaviour of ambulance clinicians and patient-related factors. Many ambulance clinicians have already adopted Person-centred care, but several factors can hinder Person-centred care in interactions with patients. Although the results build on a limited number of studies, they indicate that Person-centred care needs to be further developed and studied for high-quality ambulance care.

83. Patients' expectations and experiences of emergency care video meetings with geographically dispersed staff in primary care - A qualitative interview study in rural Sweden  
ID 168

*Lina Ärlebrant, Umeå University, Region Västerbotten; Hanna Dubois, Karolinska Institutet; Johan Creutzfeldt, Karolinska Institutet; Anette Edin-Liljegren, Umeå University*

*Background: Digital meetings such as video consultations in healthcare are increasing rapidly after the COVID -19 pandemic when it became an immediate necessity (1). In rural areas recruiting and retaining health care professionals is a severe challenge and long distances between health care facilities sometimes limit access and possibility for equal care. Video consultations offer both opportunities including less traveling and more accessible healthcare, but also challenges such as inequality in digital access and competence (2) and a risk of inferior quality in digital health care (3). Understanding patients' perspectives is crucial to develop person-centred health service delivery but little is known about emergency care video visits with geographically dispersed staff in a rural context. The aim of this study was to explore patients' expectations and experiences of emergency care video meetings with geographically dispersed healthcare staff in rural cottage hospitals. Methods: This is a qualitative study with inductive approach. Semi- structured in-depth interviews with questions inspired by person- centred care were carried out with twelve patients aged 18 -89 recruited using purposive sampling. The patients had experience of an emergency care meeting with a general practitioner on video screen and a nurse present with the patient in the emergency room. The interviews were conducted between October 2021 and Mars 2023 at seven primary care cottage hospitals in Västerbotten, Sweden. Interviews were audio-recorded, transcribed, and analysed with content analysis as described by Graneheim and Lundman (4) using MAXQDA software. Preliminary results: The analysis has so far revealed areas of importance to patients experiences and expectations e.g. an effective care-process, being noticed as equal despite the screen, limitations of healthcare technology, the desire of dedicated time and the right help, and patient contribution to the care meeting. Final results will be presented at the conference.*

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## Digitalisation and eHealth

### 84. The use of artificial intelligence in mental health to support decision making - Scoping review ID 333

*Hassan Auf, Dentsply*

Artificial intelligence (AI) has been used to support decision-making in mental health domain for both healthcare professionals and patients on different levels in the healthcare systems and self-care services. AI has been included in several health applications such as predicting mental health problems, diagnostics, treatment plans, workflows, and other duties that require decision-support. Understanding the use of AI tools and how it is applied for support decision-making in the mental health would contribute in improving the design, development and implementation in practice. Further knowledge will also help benefit shaping person-centered care approaches when using AI tools by understanding the dynamics used nowadays in support decision-making and how to include patients in the development of future processes and tools, with assurance for shared decision-making capacity. It is unclear what types of decisions that AI tools most commonly participate in supporting in mental health, how these tools are applied, and whether its implementation is engaging patients in the process of decision-making or not, this unclarity may contribute in shifting the decision-making process toward more technology polarization and far from patient centeredness. Therefore, a scoping review is conducted to map the characteristics of research done on AI tools for supporting decision-making in the mental health field to contribute in the body of knowledge regarding how decisions are supported. In the proposed poster we will present our findings regarding the use of AI in mental health and reflections on support decision-making.

85. Insights on meaningful and non-meaningful use of the remote intervention PROTECT: reflections on implications for practice ID 083

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Background: Remote interventions are needed in promoting health among people with chronic conditions. If and how remote person-centred interventions contribute to meaningful use in promotion of health are unexplored areas. Therefore, the aim was to explore patients' experiences of the person-centred intervention PROTECT (provided via telephone and a digital platform) and to identify predictors for meaningful use. Method: The PROTECT study, a randomised controlled trial was developed together with people diagnosed with chronic obstructive pulmonary disease (COPD) or chronic heart failure (CHF). During the 6-month intervention period, the participants created a personal health plan together with an occupational therapist, physiotherapist or registered nurse. Mixed methods were used in data collection and analysis. Demographic data, ratings and written comments on meaningful and non-meaningful use were collected from 86 participants, of whom 12 were also interviewed. Each data source was analysed separately by descriptive statistics, logistic regression, or content analysis, and thereafter synthesised during the interpretation phase. Results: The results of this study which is published (1) showed that participants mostly rated the intervention as meaningful to use, particularly the telephone support. Two categories: Benefits in everyday life and A personal boost explained meaningful use whereas the categories Not in need and Communication deficiency provided insight on non-meaningful use. The findings also identified predictors of meaningful use of intervention functions such as direct messaging, access to professional support, and symptom ratings in relation to participant demographics. Conclusion: Most participants experienced the intervention as meaningful to use, while it tended to be more meaningful to those diagnosed with COPD. When used by participants, the intervention was appreciated and deemed easily applicable to



supporting health promoting actions in a person-centred manner. Shortcomings in the digital platform's implementation negatively influenced experiences of meaningful use.

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## 86. A qualitative study of older persons' experiences of getting individual support with digital needs in the context of home ID 281

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Background: Digitalization is seen as a necessity to manage the increasing burden on the health care system and is accordingly considered an important tool in the transformation to integrated care (Swedish Nära vård). However, when health care is digitalized older persons are at increased risk of being marginalized and dependent on others due to their generally lower digital competence. To address this, several Swedish municipalities offer individual support to older persons in their own home, a service called Digital Coach (DC). As this service is new, the aim is to describe older persons' experiences of getting individual support with digital needs in the context of home. Method: Semi-structured interviews (n=14) were conducted with older persons who have had DC support in their home. The focus was on older persons' experiences of the support. Data was analyzed with qualitative content analysis. Results, preliminary: The overall theme, to be a valued person in the digital society, represents a feeling of being taken seriously and worth investing resources in to gain access to society. Three categories emerged: (1) The need to keep up with the times which means to understand and navigate the new digital landscape with the opportunity for independence and participation, (2) Support and respect in the learning situation, is crucial for feeling comfortable to expose insufficient knowledge, and (3) Increased digital competence empowers autonomy and is manifested as the ability to handle the digital tools and services by your own creates a feeling of joy and satisfaction and increases the opportunity to participate in both social and community activities. Conclusion: The result shows that individual support with digital needs in the context of home increase digital competence in older persons and create feelings of being valued and included in the digital society, which can extend to integrated person-centered care.

87. What are the goals of patients on sick leave with common mental disorders? An exploration of health plans in a person-centred eHealth intervention. ID 326

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Sick leave attributed to common mental disorders (CMDs, e.g., depression, anxiety, and stress-related mental illnesses) is a growing concern in many countries including Sweden. Sick leave episodes can be caused by illness or by social or work-related factors, but often multiple factors play in. This contributes to a complex situation and the need for individually tailored interventions with a holistic focus. Person-centred care focuses beyond functional or disease-related goals towards that which is meaningful to the patient. The aim of this study was to explore the content of personal health plans derived in person-centred phone conversations between health care professionals and patients on sick leave with CMDs. More specifically, we wanted to identify what type of goals the plans contained. We performed a qualitative content analysis of health plans documented in a randomised controlled trial evaluating effects of a remote person-centred intervention for patients on sick leave with CMDs, in which a total of 102 patients received the intervention. Among these, n=99 had at least one personal health plan, and these plans constituted data for the present study. Findings are tentative, but primary analysis has resulted in three overarching types of goals, reflecting both a focus on illness (e.g., receiving treatment), functionality (e.g., return to work) or other areas of life (e.g., relationships or personal interests): 1. Change-oriented goals, 2. Getting back to how things were, and 3. Maintaining status quo. In the first theme, goals expressed a desire for internal changes in one's attitude or feelings, or external changes in circumstances or priorities. In the second theme, goals expressed a desire to regain something the patient felt lost, such as certain abilities, connections, or a sense of identity. In the third theme, patients' goals oriented towards maintaining a change process already initiated, or a focus on enduring certain circumstances.

## 88. Frail older people's experience of a person-centred remote intervention – IHOPe ID 037

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**Background:** In response to the growing demand for integrated and person-centered care for frail older people, this study explores frail older people's experiences of a remote person-centered care intervention. Person-centered care is a fundamental ethic that involves collaboration between the patient and health care professionals through active listening to patients' narratives and jointly formulating tailored health plans. Integrating such care via digital health tools remains a challenge. **Objective:** The aim of this study was to explore frail older people's experiences of a remote person-centred e-health and telephone intervention. **Methods:** A total of 14 participants who had participated in the intervention in the IHOPe study [1] were selected through a purposive sampling strategy. The participants were people aged 75 or above, who had sought hospital care and been screened as frail. The intervention was a remote person-centred intervention via telephone calls and a digital platform. Individual qualitative telephone interviews were conducted, and data was analyzed through inductive content analysis. **Results:** The findings highlight that frail older people preferred telephone conversations over digital platform. These conversations were perceived as a professional and friendly contact and stimulated a sense of security. The accessibility and user-friendliness of the digital platform posed challenges. **Discussion:** The findings emphasize the importance of person-centred communication and contact through interactions via telephone while pointing out difficulties associated with the digital platforms. Person-centered care via telephone has the potential to be further developed and tested.

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## 89. Person-Centred Care with Remote Treatment (ePCC)

ID 187

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**Background:** Access to health care for an aging population with growing needs presents major challenges in northern Sweden's sparsely populated regions, SPR [1]. Few people, the lack of professionals, and long distances make it difficult to provide health care on equitable terms according to the Swedish legislation. Remote treatment (RT) using information and communication technology has been suggested to overcome these difficulties, and person-centered care (PCC) is a desired philosophy [2] to improve the quality of health care. However, there is scarce knowledge about how patients experience RT meetings. **Objective:** This study aimed to describe the experiences of patients with cardiovascular disease revisiting specialist physicians via RT guided by a PCC perspective, in northern Sweden's SPR. **Methods:** A qualitative study was conducted based on interviews with 8 patients with cardiovascular disease revisiting their physician through RT, from a digital health room to a health care center or from a health care center to a hospital. The interviews were recorded, transcribed verbatim, and analyzed using inductive content analysis [3]. The results are discussed from a PCC perspective [4]. **Results:** The analysis resulted in 6 categories: good accessibility, safety with good relationships, proximity and distance with technology, habit and quality of the technology facilitating the meeting, cherishing personal integrity, and participation in own care. These categories were interpreted as the theme, participation and relationships are important for good and close care via RT. **Conclusions:** The study shows that PCC can be applied to improve the quality of RT meetings but needs to be extended to the digital domain—electronic PCC (ePCC), especially the communication component, as it is the most salient difference from a face-to-face meeting. Important factors that should be considered before, during, and after the RT meeting have been identified [5].

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## 90. Understanding the Patient Journey to improve Person-Centered Wound Care. ID 318

*Oskar Gustafsson, Mölnlycke Healthcare; Jens Lundström, Halmstad University; Mattias Ohlsson, Halmstad University; Daniel Tsang, Mölnlycke Healthcare; Ernst Ahlberg, Mölnlycke Healthcare*

Wound care in the healthcare system is associated with a growing financial burden. Hard-to-heal wounds cause pain, suffering and reduce quality of life of patients. It is estimated that around 1-3% of the healthcare budget in developed countries is spent on wound care [1]. While wound care is crucial, it has not been established as an independent specialty among medical professionals in Sweden. Consequently, the standard of care differs significantly across regions. Complications due to lack of knowledge, inefficiency and poor compliance with guidelines contribute to wound care costs [2]. To provide person-centered wound care [3] clinicians must understand the patient journey and the impact of decisions and documentation made across the care continuum. In this study, we analyzed a cohort of patient data from electronic health records (EHR) in Region Halland (n=38970) in collaboration with clinicians from the region. The cohort included patients with wounds in Region Halland between 2008 and 2021 and the aim was to improve the understanding of their pathways and journeys through the healthcare system. The analysis included sub-groups, such as patients with different types of wounds, and how the patient journeys differed across the sub-groups. The analysis utilized AI and process mining to improve the understanding of the care pathways from data. The work has highlighted the importance of local hands-on clinical expertise when interpreting patterns found in EHR-data.

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## 91. A pilot study focusing on registered nurses' experiences of person-centered care and competence in digital care ID 148

*Malin Holmström Rising, Mittuniversitetet*

Background: Health care's rapid transition from in-person visits to more digital care meetings has challenged nurses to find new, sustainable ways of using digital

technology. Methods: The aim was to describe registered nurses' (RN) experiences with person-centred care (PCC) and competence after participating in a course in Digital Competence in Care (DCC). A qualitative descriptive design was used, and 16 individual interviews were carried out with RNs. Data were analysed using qualitative content analysis and the COREQ checklist was used in this study. Results: The results were presented in four categories: being open to change and new ways of working with patients; struggling to handle requirements; developing new ways of working and focusing on patients despite the distance. Conclusions: The DCC course helped develop RNs' skills and practice of PCC in digital care meetings. Training in digital care theory increased RNs' competence and facilitated the creation of new knowledge. The RNs' professional role was strengthened and developed by participating in the changing of work routines. Digital care meetings were shown to be distance bridging and complementary to physical care meetings contributing to PCC. The increased availability of health care via digital means has affected the consumption of care and tailored education needs for RNs must be met by nursing education programs. Digital care is accessible, efficient and enables care regardless of geographical conditions, its innovative development needs to be based on science and experience and RNs are key personnel in this process.

92. “Stroke health” - a user-friendly, digitally provided pre-visit tool that captures concerns and specific health issues after a stroke: findings from a web-based survey ID 047

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Background: Structured follow-up visits to a stroke team professional should be offered after a stroke. These should involve a person-centered approach enabling shared decision-making. To support this process, the 11- item Post Stroke Checklist was created to be used by healthcare professionals during the visit. Based on subsequent evaluations, a pre-visit tool (“Stroke health”) was developed in a co-design process to ensure people with stroke can prepare well in advance.

Objective: To explore people with strokes' views and opinions on the pre-visit tool, identifying its benefits, practicality, and effectiveness in capturing stroke related health issues before the follow-up visit. Methods: Built on the Technological Acceptance Model, a self-administered online survey with 18 items was developed, incorporating demographics and items related to experiences of using the pre-visit tool. Responses used a Likert scale, along with four open-text fields. Recently discharged people with stroke who had received and used the pre-visit tool before a follow-up visit were invited to participate. Results: The cohort

included 80 participants (45 men), living independently, median age 67 (range 32-91). Stroke severity was mild with a median of 1 (0-13) according to the NIH stroke scale. Mood-related health problems were reported by 48%, life after stroke concerns by 46%, and cognitive issues by 34%. Of 58 respondents, 96.6% were satisfied or very satisfied with the pre-visit tool's ability to capture their health-related issues. Qualitative analysis of open-text yielded four themes: 1) Structure that ensures that issues will be lifted; 2) Usefulness and user-friendliness; 3) Digital approach as means of communication; and 4) Answer experiences. Conclusion: The digital pre-visit tool captured health issues and was perceived as user-friendly, among people with stroke living in their own home.

### 93. Person-centredness in the context of mobile phone support for rehabilitation after stroke ID 288

*Kajsa Söderhielm, Karolinska institutet; Susanne Guidetti, Karolinska institutet; Malin Tistad, Dalarna University; Charlotte Ytterberg, Karolinska institutet*

Person-centredness is described as essential in stroke rehabilitation, where the complexity of the condition can result in diverse effects on everyday life. The F@ce-intervention aims to support home-based stroke rehabilitation through person-centred goal setting. To identify goals related to personally relevant activities of everyday life, the Canadian Occupational Performance Measure is used, and strategies for goal achievement and problem-solving are discussed with the team. The intervention also utilises information- and communication technology (ICT) in the form of SMSs to support goal achievement. However, there is a lack of research on how ICT support can be devised to be compatible with a person-centred practice. Method: Twelve participants (7 men, and 5 women) were included and interviewed individually 1-2 weeks after the end of the intervention and again at 6 months after inclusion. A reflexive thematic analysis was used. Result: Three themes were developed; Setting personally relevant goals requires a trusting relationship, To be supportive, SMSs need to be integrated into the rehabilitation process and Support from the team is essential for recapturing daily activities after stroke. Discussion: When listening to the participants, it became clear that building a trusting relationship with the team was essential for the intervention to be person-centred. The interviews did however highlight a potential tension in person-centred goal setting between building on the lived experience of people with stroke and meeting their desire to be guided by experts. Participants also expressed that the team sometimes needed to be present during rehabilitation and could not be replaced with mobile phone support. In conclusion, the results indicate that when ICT support is based on person-centred goal setting it can be used as a complement in stroke rehabilitation to support goal achievement.

## Health Equity

### 94. Building the bridges between worldviews: Honoring our differences ID 147

*Margaret Erickson, American Holistic Nurses Credentialing Corporation*

Healthcare providers are challenged today by a world full of turmoil, conflict, and dissenting opinions. Differences in worldviews affect the care we are able to give our patients. It has become a world of “us versus them.” Financial, social, physical and environmental resources are limited. Systemic social inequities and disparities, racism, and bias are present and the associated consequences are progressing at an accelerated rate. Anxiety, fear, anger, and grief create difficult situations, and the underserved and marginalized populations are at most risk. Challenges abound as we try to find common ground with each other and those whom we serve. All of these factors negatively affect our ability to provide optimal patient-centered care. Before we are able to accept and honor other cultural and world-views we must first be able to connect with who we are; what we value, feel and believe, as these influence the words we use, actions we take, and how we practice as healthcare providers. Next, we must take steps to better understand the worldviews of those we serve. This requires seeing the world through their eyes. Only through this understanding can we then provide individualized, person-centered care that incorporates values, culture, attitudes and beliefs that may differ from our own. Participants will learn how to step into others’ worldviews using a practice-based conceptual framework and case examples, which will help them better understand the people they serve. This “Model” in turn provides the foundation that is fundamental to creating plans of care that are efficient, effective, and support peoples’ needs, values, and cultural belief system. Through this process, healthcare providers can take the first step towards building bridges, breaking down barriers, and creating a space where our diversity and differences are honored; and used to create greater health and wellbeing at a global level.

### 95. Designing the Roadmap for Change: An Alberta Framework for an Integrated People-centred Healthcare System ID 338

*Jessica Gish, Health Quality Council of Alberta; Melissa Rolfe, Health Quality Council of Alberta; Mollie Cole, Health Quality Council of Alberta; Markus Lahtinen, Health Quality Council of Alberta; Jeanette Jackson, Health Quality Council of Alberta; Alta Magee, Health Quality Council of Alberta*



High-performing healthcare systems require well-designed, evidence-based visions and principles, as well as the strategies and structural elements that facilitate improvement. These are often presented in frameworks that create the roadmap for change. The Framework for an Integrated People-centred Healthcare System presents a common vision of public healthcare in Alberta, Canada that provides equitable services responsive to the needs of individuals, families, communities, and the population. The Alberta framework synthesizes leading thinking from established and respected organizations within and beyond Canada, input from engagement with our system partners over the past two years, and government policy and funding priorities. Our jurisdictional review analyzed a variety of frameworks – at regional, national, and international levels – and found they are consistently influenced by common definitions and strategies identified by healthcare organizations and peer-reviewed journals. These frameworks are oriented around a common vision (i.e., integrated, people-centred care), show consensus about what quality health services should be, and include a wide range of performance dimensions and conceptual perspectives. Patients and providers were interviewed about the dimensions of quality presented in the Alberta Quality Matrix for Health adopted in 2005: acceptability, accessibility, appropriateness, effectiveness, efficiency, and safety. Interviews and the jurisdictional review confirmed that language and perspectives on quality have evolved to include equity, provider experience, and partnership/engagement. The Alberta framework aligns with government priorities to strengthen access to primary care, and the prevailing concepts of access, integration, partnership and inclusion, and cultural responsiveness. This framework brings these inputs together, into an Alberta context, to rally people and optimize systems to effect positive change and deliver better person-centred care and health outcomes for Albertans. This poster will present this framework, outline its inputs and rationale, and how it can help to facilitate a roadmap to improvement in Alberta.

## 96. Health equity in economic analyses of person-centred care: a systematic review ID 174

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Background: Person-centred care (PCC) interventions have been associated with economic benefits. However, the paradigm shift towards PCC places greater emphasis on healthcare systems to recognise key social determinants of health (SDoH) to ensure equitable healthcare, whilst acknowledging the importance of the demographic distributional aspects of the global population. Objective: To

explore to what extent the current evidence about the costs and associated health outcomes of PCC reflects sub-groups of the population by the social determinants of health. Method: A systematic review was conducted with retrieved literature from PubMed, Scopus, CINAHL, and grey literature using free-text and MeSH terms related to PCC, costs, and benefits. Papers that defined PCC as a partnership were included. Study selection and data extraction according to a standardised extraction sheet was conducted by two independent reviewers. A narrative synthesis was used for demographic characteristics and exclusion/inclusion criteria to understand how SDoH were taken into consideration, using deductive analysis to the rainbow model by Dahlgren and Whitehead. Results: A total of 2,766 papers were initially identified, of which, only 32 met the inclusion criteria. All studies included populations from developed countries and were predominantly randomised controlled trials or quasi-experimental designs. Of the 32 studies, 28 reported their inclusion/exclusion criteria. Disease and related symptoms were reported in all the studies when enrolling patients. Disabilities, language, ethnicity, and life expectancy were defined in the exclusion criteria of 19 studies. Age and gender were the most frequent SDoH amongst other reported determinants: ethnicity, income, and education. Only 2 studies performed sub-group analyses. Conclusion: The findings indicate that the evidence on the cost-effectiveness of PCC does not account for many of the SDoH. There is a risk that the underrepresentation of vulnerable population groups and their specific needs could lead to imbalances in evaluating and implementing PCC interventions. Prospero Registration #: CRD42022313047.

97. Re-valuing Nursing Expertise. Nursing Directors' Tactics to (Re)work Knowledge and Power in Hospital Governance towards a Person-Centred Perspective. ID 273

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Shared governance in hospitals promotes the inclusion of nurses' expertise, knowledge and skills in organisational processes. Although, historically, nurses have been structurally excluded from power hierarchies, governance structures, and decision-making venues, they increasingly fulfil (hierarchical) organisational positions in hospitals<sup>1</sup>. This is partly due to a growing consensus that a person-centred approach - in which, among others, providing holistic care, engagement and shared decision-making are key- is necessary to face the burdens that healthcare systems face<sup>2</sup>. Theoretically, shared governance increases nurses' influence in shaping policy and practice. However, incorporating nursing expertise in governance structures might be complicated, as these structures are largely based on managerial and biomedical expertise as the dominant modes of

knowing<sup>3,4</sup>. Drawing on a Foucauldian perspective on knowledge and power<sup>5</sup>, intertwined and embedded in everyday practices and interactions, we study what happens when ten newly appointed nursing directors in a large university medical centre challenge dominant modes of knowing by emphasizing person-centredness as crucial nursing expertise. We conducted a (historical) document analysis to gain insight into how the history of nursing director roles relates to how (s) in which nursing expertise is/might be valued presently in healthcare organisations. Furthermore, following the so-called learning history method, we gathered qualitative data (coming from multiple sources) to explore nursing directors' practical tactics to become part of new 'knowledge-power knots' that support person-centredness. Data analysis shows three main tactics: 1) profiling, 2) positioning and 3) powering. By 1) becoming visible, 2) being taken seriously, and 3) exerting influence, nursing directors try to embed themselves and their expertise in hospital governance. This study contributes to a socially embedded everyday understanding of power and empowerment in nursing and provides academic and practical starting points for strengthening person-centred nursing in hospital governance.

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## 98. Patient and Family Experiences of Adverse Events in Pregnancy in Canada from a Multicultural Perspective ID 305

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Using a patient-led, peer-to-peer approach, this study aimed to understand patient and family member experiences and perspectives of maternal morbidity in Canada from a multicultural perspective. The Patient and Community Engagement Research (PaCER) program is an experiential-based learning program offered through the University of Calgary, Canada. Seven PaCER student researchers representing multiple cultural and professional backgrounds, as well as lived experiences of pregnancy, co-designed and carried out this study. Focus groups and individual semi-structured interviews were used to understand the perspectives and experiences of diverse patient and community members who self-identified as having experienced an adverse event(s) in pregnancy. Data was collectively and iteratively analyzed using thematic and narrative analysis. Five key themes emerged and were defined as: (1) access to appropriate, timely, coordinated care and follow up; (2) lack of transparent communication from healthcare providers and the ways power differentials and need for urgent action affected shared decision making; (3) cultural differences between participants' traditions, and Canadian pregnancy care practices; (4) mental health impacts as participants struggled to access diagnosis for conditions that "didn't feel right" and to understand "why" adverse events happened (5) supports and resources participants felt were missing that would have been most helpful to managing the morbidity. Our team also identified five person-centred, actionable recommendations for dissemination and implementation of study findings. This peer-to-peer study demonstrates innovative and inclusive engagement approaches to effectively integrate essential, often missing patient and community voices into health research evidence. Our results can inform more patient-focused future maternal morbidity research priorities, as well as offer unique patient and community insights into designing best practices for more person-centred maternal health policy and clinical care.

#### 99. The cross-cultural person-centred care for migrants: A narrative literature review ID 218

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According to the World Migration Report, the number of international migrants has been on the rise in the past 50 years. In 2020, over 281 million people resided outside their country of origin, which is more than double the number in 1990 and accounts for 3.6% of the global population (International Migration Organization, 2021). This has led to increasing demand for healthcare that is tailored to immigrants and refugees. However, healthcare systems still show gaps in accommodating diverse cultural backgrounds. Though person-centred care (PCC)

is increasingly integrated in health care, there is still a lack of understanding of how to provide PCC to foreign-born migrant people. Therefore, this review aims to explore the intersection of PCC and cultural perspectives in care for immigrants and refugees. There were 1330 articles, included in the large scoping review of international literature on PCC by Forsgren et al., (2023) at the University of Gothenburg Centre for Person-Centered Care (GPCC), of which 9 articles met the inclusion criteria for this review. Nearly all of the 9 articles pertained to studies conducted in North America, whereas only one was conducted in Israel. The selected articles were reviewed and the following three key themes were identified: a) migrants' shared power and decision-making, b) the provision of individualized care with cultural empathy and c) the promotion of culturally sensitive interactions. These themes highlighted the significance of respecting diverse cultural beliefs about shared decision-making and understanding how PCC is perceived in different cultural contexts. There is a need for educational programs that equip healthcare providers with culturally relevant communication skills and knowledge to provide culturally sensitive care and manage any existing cultural differences between healthcare providers and migrants. Overall, the three key themes of PCC for migrants can serve as a guide to foster healthcare that values and respects cultural diversity.

## 100. LIVE-Until We Die ID 329

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With an increasingly large group of elderly people in our society, the suffering that comes with being at the end of life affects not only the dying person, close relatives, and the care staff, but also society in general. The lack of contact with the outdoors can lead to an increase in burnout among healthcare staff, more suffering for the sick, and memories of confinement that remain with the relatives for a long time. Palliative care should be about autonomy and person-centred care, but in many cases, the possibility of deciding if you want to be outside is rarely an option. Access to outdoor environments for people in the last stages of life is sparsely explored, despite the knowledge about the positive effects on health and well-being that nature brings. The LIVE - Until We Die project aims to emphasize the importance of the outdoor environment, which should be equal across the nation, through accessibility and design. The end-of-life care environment has to be based on the evidence regarding what environmental psychology says about design and what the environment should contain. This is to promote mental health and well-being and thereby raise the quality of life for the sick person, close relatives, and the staff. The starting point is a systematic literature review and quantitative analysis of policy options. Furthermore, qualitative interviews follow to validate findings along the progress of the project, to ensure that the policy proposals are of societal benefit and lead to increased quality of life and better public health. The project will develop the concept of care environment to also include the outdoor

environment and thus enable all the positive health effects that nature can contribute. Palliative care must be equal and person-centred, and with that, the offer to get out must be self-evident.

## Evaluation of Interventions

### 101. An Economic Evaluation of a Hospital-wide Bundle Intervention to Reduce Hospital-Acquired Infections and Adverse Events among Hip Fracture Patients in Sweden ID 161

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Background: Preventing adverse events in healthcare, including hospital-acquired infections, is crucial and requires effective evidence-based care. To address this challenge, a strategy directed to implement improved hand hygiene and aseptic techniques in the care process of hip fracture patients was adopted, building on person-centred ethics. Through co-creation, leaders and staff developed a bundle intervention including two different sub-interventions; Safe Hands and Safe Bladder, focusing on reducing urinary catheter-associated urinary tract infection (UC-UTI) and bladder distension (BD), respectively. This study aimed to estimate the cost-effectiveness of this implementation program (including the bundle intervention) compared to standard care in this patient group. Method: A before/after study included patients undergoing hip fracture surgery in a Swedish hospital during 2015 (before) to 2020 (after). A decision tree model was used to estimate implementation costs and cost-effectiveness of the bundle, adopting a healthcare perspective. Health outcomes were frequency of adverse events, i.e., UC-UTI and BD. Analyses included calculating the incremental cost-effectiveness ratio (ICER) indicating the additional cost per percentage reduction in infection, and sensitivity analyses to test its robustness. Results: The bundle intervention increased the likelihood of not getting infected from 50% to 87%. The discounted implementation cost was SEK 890,389. However, the implementation was offset by costs for prolonged hospital stay due to adverse events, resulting in cost savings of SEK -7,333.64 per patient in 2020 compared to before the project was conducted. The intervention was thus cost-effective, resulting in both cost savings and reduced adverse events frequency. Conclusion: The implementation program (including the bundle intervention) was cost-effective among hip fracture patients

in this hospital. Although further research should explore if the findings are generalizable to other settings, it offers decision-makers insights that implementation programs with co-creation processes can result in effective use of resources. Trial registration ID: NCT029831336 and ID: ISRCTN 17022695.

102. Effects of a person-centred eHealth intervention on fatigue in patients with common mental disorders: secondary outcome analysis of a randomised controlled trial ID 309

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Background: Common mental disorders (CMDs), such as depression, anxiety, and stress-related disorders, pose a public health challenge in several countries, including Sweden. Patients seeking care for CMDs often describe severe symptoms, with fatigue being a common issue. Despite the proven benefits of person-centred care (PCC), there is a scarcity of studies assessing the impact of PCC via eHealth on patients with CMDs. Aim: The aim of this study was to evaluate the effects of a PCC eHealth intervention on self-reported fatigue in patients on sick leave for CMDs. Method: A secondary outcome analysis of a randomised controlled trial. Patients (n=209) on sick leave due to CMDs were recruited from primary care and allocated to either a control group (n=107) receiving usual care or an intervention group (n=102) receiving usual care and PCC in the form of telephone support and an interactive digital platform. Self-reported symptoms of fatigue were assessed using the Multidimensional Fatigue Inventory Scale (MFI-20) at baseline and at 3 and 6 months. Results: At the 3- and 6-month follow-ups self-reported fatigue, as measured by MFI-20, reduced significantly more in the intervention group, than in the control group. This reduction was observed in the total summary score (Global fatigue) and in three of the five underlying dimensions (Physical fatigue, Reduced activity, Mental fatigue). In addition, the General fatigue dimension at six months and the Reduced motivation dimension at three months showed significant improvement in the intervention group compared with the usual care group. Conclusion: A person-centred eHealth intervention combining telephone support and an interactive platform holds potential for reducing symptoms of fatigue in patients on sick leave due to CMDs.

### 103. Person-centredness in Hypertension Management using Information Technology (PERHIT): a Randomized Controlled Trial in Primary Care ID 045

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**Background:** Despite the availability of effective hypertension treatments, fewer than half of the patients with hypertension in primary care reach target blood pressure (BP). With health care based on a person-centred approach, where the patient's knowledge, capabilities and resources are recognized, more patients may find insight and motivation to adhere to treatment. IT-solutions has the potential to support patients' self-management of chronic conditions, such as hypertension. **Methods:** We conducted the PERson-centredness in Hypertension management using Information Technology (PERHIT) randomized controlled trial across four Swedish primary care regions, enrolling over 900 patients with hypertension [1]. The intervention group received a home BP monitor and used an interactive web-based support system for eight weeks. They self-reported daily, via their own mobile phone; BP and pulse, and rated their wellbeing, physical activities, symptoms and side effects during the day. Patients had access to graphical feedback through a secure web portal and were offered to receive motivational messages. Follow-up consultations with the patient's nurse or physician occurred after eight weeks and after twelve months. **Results:** Significantly more patients in the intervention group achieved BP < 140/90 mmHg after eight weeks compared to the control group, though the long-term effects remained uncertain [2]. Both patients and professionals found the system valuable for communication about BP and lifestyle. The patients became more actively engaged in their treatment and both patients and professionals described a more personalized and equal consultation based in the patient's experiences and insights [3].

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104. Health-related quality of life outcomes at an integrated, person-centered clinic for patients with combined cardiovascular disease, diabetes mellitus and chronic kidney disease; a randomized trial ID 165

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**INTRODUCTION:** Patients with cardiovascular disease, diabetes mellitus, and chronic kidney disease often require extensive healthcare, but coordination among specialists and providers is lacking, potentially contributing to reduced quality of life (QoL). We aimed to assess whether multidisciplinary and person-centered care at an integrated clinic (HND-centrum) improve self-reported health-related QoL. **METHOD:** Patients in the Care-HND trial (ClinicalTrials.gov Identifier: NCT03362983) completed RAND-36, EQ-5D-3L and a Patient Reported Experience Measures (PREM) questionnaire at baseline, 6, and 12 months. Chi-square, t-tests, and ANOVA repeated measurements with Tukey's post hoc test were used to assess changes over time and between groups. **RESULTS:** Of 128 patients, 71 were randomized to HND and 57 to traditional care (control). The response rates were 86%, 81% and 69% at baseline, 6 and 12 months. Using RAND-36, HND patients improved in Role Physical (RP), Social Function (SF), and General Health (GH) over time, significantly outperforming controls in RP and SF ( $p=0.021$ ;  $p=0.019$ ). Using EQ-5D-3L, HND patients showed improvement in Pain and Anxiety over time but not significantly compared to controls. For the visual analog scale (VAS), the HND group improved over time ( $p=0.007$ ) and outperformed controls ( $p=0.011$ ). Using PREM questions, HND patients reported higher satisfaction with given verbal information and staff accessibility. **CONCLUSIONS:** Patients at the HND clinic reported improved general health over time, while controls experienced more pain and anxiety. HND patients were more satisfied with staff accessibility and verbal information quality.

105. Economic evaluation of person-centred care using a digital platform and structure telephone support for people with chronic heart failure and/or chronic obstructive pulmonary disease ID 334

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**BACKGROUND:** Person-centred care (PCC) is an ethical approach, whereby a patient is regarded as an equal ‘partner’ in the design and implementation of their own care. Optimising care through PCC interventions can improve disease-specific management whilst addressing the needs of people living with long-term conditions like chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD). **AIM:** The aim of the study was to evaluate the cost-effectiveness of a remote PCC add-on intervention compared with usual care alone for people with CHF and / or COPD. This intervention has previously been reported to improve self-efficacy. **METHODS:** Patients from 9 primary care centres were randomised into either the intervention group (IG, n=110) or control group (CG, n=112). The IG participated in a PCC add-on through a digital platform and telephone support, both groups received care as usual. Used resources were identified over a 2-year time horizon. Health system costs included directed healthcare costs and costs for drug use, calculated using national statistics and analysed descriptively by cost components. Societal costs accounted for productivity loss using labour market costs, patient co-payments and time spent participating the trial. **RESULTS:** The IG had lower costs for inpatient care, specialised outpatient care, drug use, and absenteeism due to sick leave. However, polyclinical care was significantly higher in the IG due to a single surgical procedure. The preliminary results of this cost-effectiveness analysis show incremental effects of 0.11 quality-adjusted life years and incremental costs of -95 088 SEK (Swedish crowns). The PCC alternative was both more effective and resulted in lower healthcare costs compared with care as usual. i.e. PCC was dominant. **CONCLUSIONS:** Based on the preliminary results a remote PCC add-on intervention for people with COPD and / or CHF had lower healthcare costs and higher health-related quality of life than individuals receiving usual care.

## 106. A Core Outcome Set for the Evaluation of New Healthcare Programs in Sweden ID 158

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**OBJECTIVES:** Evaluating healthcare programmes that focus on shared decision-making and participation, e.g., person-centred care (PCC), regularly report beneficial results regarding symptom burden and self-efficacy. However, traditional outcomes used within economic evaluations are less sensitive to these changes, thereby limiting the availability of information for decision making and prioritisation. The aim of this study is to develop a core outcome set (COS) for the evaluation of such programmes, including economic evaluations. **METHODS:** This study included participants representing 4 stakeholder groups; patients, healthcare workers, researchers, and managers/leaders. A questionnaire was developed based on outcomes from a systematic review on the cost-effectiveness of PCC, complemented with pilot interviews with stakeholder representatives. A Delphi study was conducted in 2 rounds, where outcomes were scored from 1-9 based on their perceived importance for the decision-making process of each stakeholder group. Participants could suggest new outcomes during the 1<sup>st</sup> round that were included in round 2. After 2 rounds, an outcome was deemed critical to the core outcome set if scored between 7-9 by at least 70% of the participants. After an opportunity for all stakeholder representatives to provide feedback, a consensus meeting will be held with 2 patient representatives (Autumn 2023) to determine the final COS. **RESULTS:** Outcomes were grouped into; health and quality of life, capabilities and prerequisites, process measures related to care implementation or digitalization, and health economics. In round 1, 58 participants (patients n=14; healthcare workers n=16; researchers n=17; managers/leaders n=10) scored 52 outcomes and recommended a further 13 for inclusion in round 2. In round 2, 46 participants had re-scored the outcomes (missing n=12), with scores being changed between scoring thresholds on 168 separate occasions. **CONCLUSIONS:** The preliminary COS at the completion of round 2 highlights stakeholder preferences towards outcomes corresponding to capabilities and prerequisites, and process measures related to care implementation.

107. Lessons learned from conducting a randomised controlled trial, providing person-centred support through telephone and an e-health platform for persons on sick-leave due to chronic pain ID 023

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Background: Chronic pain is one of the most prevalent reasons for sick leave and people with chronic pain have difficulty returning to work. Person-centred care (PCC) has been suggested as a way of helping them. A randomized controlled trial (RCT) aimed at evaluating if remote PCC increases self-efficacy and return to work. Sixty persons (30 intervention/ 30 control) were recruited. In addition to usual care the intervention group received person-centred support through telephone calls with a health care professional and access to an e-health platform for 6 months. Primary outcome was a composite score consisting of self-efficacy (GSE) and sick-leave ratio (self-reported). Screening was conducted between August 2021 and June 2023. The first patient representative joined the project in June 2021 and the second in May 2022. The intervention will continue until spring 2024 and data analysis will follow its completion. Aim: To describe lessons learned from conducting a RCT focusing on enhancing self-efficacy and return to work among persons on sick-leave with chronic pain. Methods: Synthesis of the research group's experiences, built upon consensus reached in discussions within the group. Results and conclusions: Including patient representatives can mitigate upcoming difficulties when conducting a RCT and preferably the patient representatives participate from early design stage. However, the representatives' opinions might not always cohere to those of the intended target group, as the representatives can be more resilient than the target group. The knowledge from experienced researchers together with the patient representatives will therefore make a good basis for development of the project plan. Persons living with chronic pain tend to struggle with comorbidities and biopsychosocial factors that can hinder their participation in studies. Thus, intervention components and questionnaires could favourably be designed accordingly to avoid missing data and burdening the participants.

108. Early Accessible Person-centred Rehabilitation for Patients with Chronic Pain (EAPER-P) - A randomized controlled trial ID 027

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Background: Chronic pain is a public health issue and a leading cause of years lived with disability worldwide. Chronic pain is defined as pain that persists or recurs for more than three months and is today recognized as a disease in its own right. Both the societal costs and personal consequences of chronic pain is substantial. People on sick leave due to chronic pain often have difficulties returning to work. The effects of person-centred care interventions on a person's self-efficacy as well as level of sick leave has been investigated in previous research on different populations and diagnoses. However, little is known regarding the effects of person-centred care interventions for persons being on sick leave from work due to chronic pain. Objective: To evaluate if an early person-centred rehabilitation intervention, consisting of a combined e-health platform and telephone support, increases self-efficacy and return to work in persons on sick leave due to chronic pain. Methods: A randomized controlled trial with two arms. The control group receives usual care, whereas the intervention group receives usual care with the addition of a person-centred intervention comprising access to an e-health platform and person-centred telephone calls with a health care professional during a 6-month period. The primary outcome is a composite score of changes in general self-efficacy (GSE) and level of sick leave at the 6-month follow-up. Status: 60 participants on sick leave due to chronic pain has been recruited from 11 primary health care centers across Gothenburg, Sweden. Participants were allocated to

either a control group (n=30) or an intervention group (n=30). Screening was stopped in June 2023; the intervention will continue for the succeeding 6 months. Statistical analyses will be carried out on the collected data during fall 2023. Preliminary results are expected in early spring 2024.

109. Healthcare professionals' and managers' experiences of person-centred care (PCC) in the context of allogeneic hematopoietic stem cell transplantation (allo-HSCT) ID 080

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**Background** This study is part of a research project aiming to implement and evaluate the effects of a model for PCC in allo-HSCT, a web-based PCC education is a part of the model. Level of PCC in allo-HSCT has not previously been investigated and is important for the implementation of PCC. **Objectives** The aim was to investigate healthcare professionals' level of person-centredness in care provided, and associations with individual characteristics, workplace and PCC education. **Methods** In total, 85 healthcare professionals and managers, at two allo-HSCT centres in Sweden answered the Person-centred Care Assessment Tool (P-CAT), containing 13 statements. Descriptive and analytical statistics were employed. A total scale (min 13 – max 65), and two subscales were calculated: 1. Extent of personalizing care (min 8 - max 40) and 2. Amount of organizational and environmental support (for PCC) (min 5 – max 25), higher numbers indicating higher level of PCC. **Results** Total scale mean was 45.31 (SD: 7.88, range 28-62), subscale one 28.41 (SD: 5.32, range 16-39) and subscale two 16.90 (SD: 4.73, range 8-24). Items rated highest were: daily assessment of patients' needs (74.5%, mean 4.0), Often discuss how to give PCC (67.4 %, mean 3.96) and Formal team meetings to discuss patients' care (70.6%, mean 3.84). Items rated lower were: Do not have time to provide PCC (31.4 %); the environment is chaotic (39.2 %); Get the work done before worrying about a homelike environment (25.5% ); the organization prevents providing PCC (25.5%). Higher age (B: 4.44; CI: 1.53- 7.35; p=0.00) and PCC education (B: 3.65; CI: 0.50-6.79; p=0.02) was associated with higher ratings of PCC. **Conclusion** The level of PCC in allo-HSCT is high regarding discussing and assessing patients' needs, but there is room for

improvement of organisational and environmental aspects. Further, PCC education increases the level of PCC.

### 110. Following a standardised pathway: Healthcare professionals' perspectives on person-centred care within ERAS for patients with colorectal cancer ID 242

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Background: Enhanced Recovery After Surgery (ERAS) is used within the care of colorectal cancer to optimize recovery and participation (1). Despite this, the healthcare professionals describe a discrepancy between following standardized processes and achieving person-centred care (2, 3). Previous research has mainly focused on the clinical benefits of ERAS and person-centred care (4,5), while studies exploring health care professional's perceptions of person-centeredness in standardized colorectal cancer care are sparse. Aim: To describe healthcare professionals' perceptions of person-centred care for patients with colorectal cancer, within the standardized pathway of ERAS. Design: Qualitative descriptive design was used. Methods: The study was conducted in a hospital, south of Sweden from January to February 2020. Data were collected by using focus groups interviews, four focus groups interviews were held including 22 health care professionals. Data were analysed using deductive content analysis according to Hsieh and Shannon (6). Results: The findings, presented in three themes, Framework in the healthcare system, Facing differences in participation and Interacting with the person beyond the illness. The themes reflect the healthcare professionals' perceptions of conditions for person-centred care within ERAS. The main findings were related to the interactions between healthcare professionals and patients, and the impact of a traditional hierarchical culture. Conclusion: A mismatch was found between ERAS and the fundamentals of nursing practice. The healthcare professionals strived to create an interprofessional environment with conditions for person-centred care, despite obstacles such as the structure of care and absence of organizational support. To achieve person-centred care, the relationship between healthcare professionals' and patient should be balanced, and the different perspectives must be respected and treated as equal. ERAS and person-centred care can be combined but cannot be seen as a straight path of clinical intentions, but rather as a multidimensional network leading to a mutual goal.

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## 111. Individualized and person-centred physical activity for patients with non-functioning pituitary adenoma: study protocol for a randomized controlled trial ID 283

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Introduction: Patients with pituitary adenoma have reduced self-reported quality of life (QoL) and well-being (1,2), and an increased risk of developing cardiovascular diseases (3). Person-centred care focuses on preserving health and wellbeing by acknowledging patients' resources, motivations and strengths, and strives to engage the patient in health-related decision-making (4). Physiotherapy outlined within a person-centred approach is effective for a broad range of disorders (5). The effect of increased physical activity in patients with pituitary adenoma is, however, yet unexplored. Aim: To study the effects of person-centred physical activity on QoL, cardiorespiratory fitness, fatigue, self-efficacy, and cardiovascular risk profile in surgically treated patients with non-functioning pituitary adenoma. The main hypothesis is that increased physical activity



improves QoL. Methods: This is a prospective, randomized, controlled trial where patients with non-functioning pituitary adenoma, treated with pituitary surgery during the last ten years at the Sahlgrenska University Hospital in Gothenburg, Sweden, will be screened for eligibility. 120 participants will be randomly assigned to either intervention or standard care (Figure 1). The intervention group will receive an individualized and person-centred prescription of physical activity and exercise, described in figure 2. Intervention follow-up visits (in-person or digitally) will be scheduled at 4, 8 and 12 weeks by a physiotherapist. The study outcome measures are presented in Table 1 and will be assessed at baseline, six and twelve months by a blinded evaluator. This study is approved by the Swedish Ethical Review Authority (Dnr: 2023-02770-01). Potential clinical benefits: If our hypothesis is correct, QoL in patients with non-functioning pituitary adenoma can be improved by individualized and person-centred physical activity and this, in turn, strengthens the patient’s confidence in managing self-care. Authors declare that no corporate sponsors, shareholdings, patents, or other commercial interests are linked to the project.

Endpoint	Assessment objective	Specific test or questionnaire
<b>Primary endpoint</b>	Health-related quality of life	SF-36
<b>Secondary endpoints</b>	Health status	EQ5D
	Physical activity	SGPALS, GIH-Sed and with an accelerometer
	Physical fitness	RPE-scale
	Cardiorespiratory fitness	Submaximal EKBLOM-BAK test
	Muscle strength	Grip strength will be measured with JAMAR and muscle strength of the lower extremities with the chair stand test
	Self-reported fatigue	MFI-20
	Self-reported self-efficacy	Self-Efficacy to Manage Chronic Disease Scale
	Cardiovascular risk profile	Weight and waist circumference, Body composition, blood pressure, Lipids, Glucose metabolism and hs-CRP
	Patients’ perceptions of person-centred care	GPCCQ

Between-group differences will be calculated and analysed from baseline to 6 and 12 months. SF-36; short form 36, EQ5D; EuroQol-5D, SGPALS; Saltin-Grimby Physical Activity Level Scale, GIH-Sed; Single-Item Question for Assessment of Sedentary Behaviour, RPE-scale; Rating of Perceived Exertion Scale, MFI-20; Multidimensional Fatigue Inventory-20, GPCCQ; Generic Patient Perceptions of Person-centred Care Questionnaire.



Figure 1. Study flow chart. 1 All participants will receive standard care, including recommendations on physical activity (6) and meetings with an endocrinologist at baseline and after 6 and 12 months. Health related issues and perceived symptoms are reviewed and, when needed, doses of hormonal replacement are adjusted during the visits. 2 Individualized and person-centred physical activity and exercise.

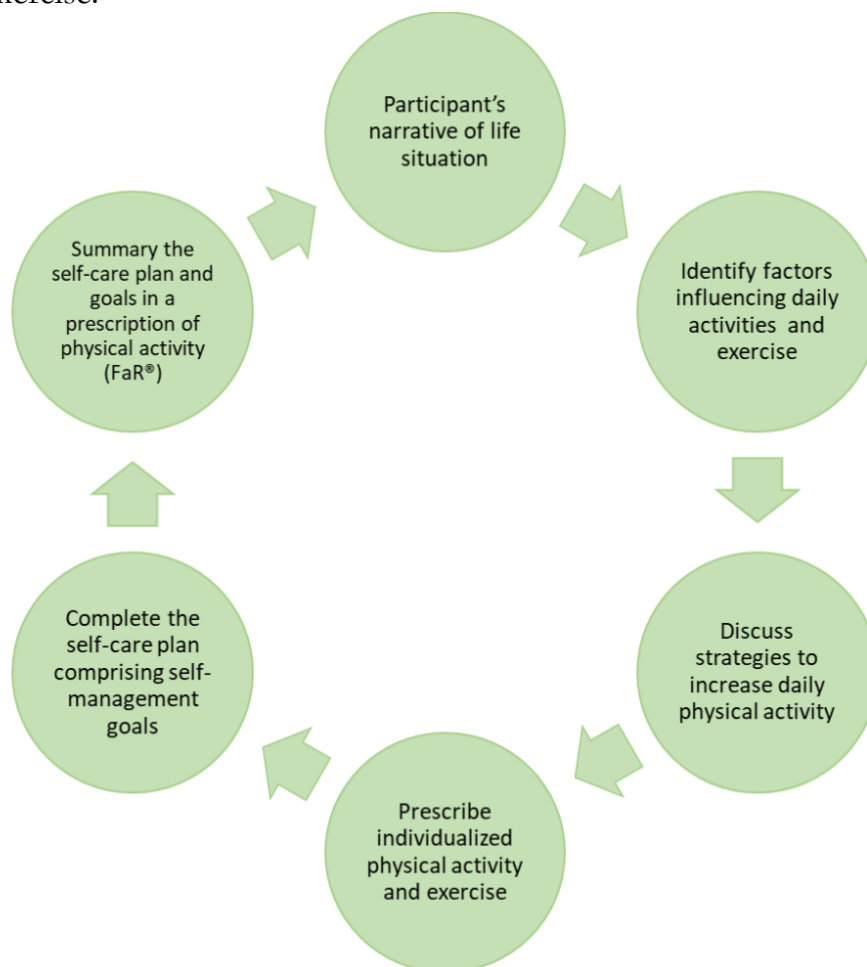


Figure 2. Description of the study intervention with examples of the interactive parts of the baseline meeting between patient, physiotherapist, and nurse.

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## 112. Experiences of Person-Centred Nurse-Led Care for Patients with Gout in Primary Care: Self-Measurement and Dose Escalation of Urate-Lowering Treatment. ID 189

*Helene Sedelius, Dalarna University; Malin Tistad, Dalarna University; Anna Svärd, Uppsala University*

**Aim:** This study aims to evaluate the feasibility, as perceived by both healthcare personnel and patients, of a person-centred nurse led procedure involving patients' self-measurement of urate and dose escalation of urate lowering treatment (allopurinol). **Method:** Participants from three primary care units in Sweden were recruited; patients with gout and urate >405 µmol/L, nurses and physicians. Patients received nurse-led education on gout and of how to use a urate meter for self-measurement at home. Monthly follow-up and support was planned together by the nurse and patient and continued until the target for urate level was achieved, through dose escalation of allopurinol. Data collection involved the use of questionnaires and semi-structured interviews with all participants. **Results:** Of the 29 eligible patients, 12 agreed to participate. Common reasons for not participating included absence of gout-related problems, side effects from allopurinol, and comorbidities. Notably, all included patients completed the procedure and reached their target urate levels. Both patients and personnel found the procedure to be straightforward and simple regarding performance. Patients reported feeling more engaged in their treatment and gaining awareness and knowledge for managing their gout. Nurses described the procedure as manageable and professional, noting that it was time-consuming initially but not during follow-up. **Conclusion:** The self-measurement procedure appears to be a suitable first choice before resorting to regular lab tests when implementing person-centred nurse-led gout care in primary care settings. Patient involvement in self-measurement and home-based urate monitoring increases their sense of participation in care and treatment. **Key words:** primary care, gout, experience, feasibility, task shifting, nurse-led care, self-measurement, person-centred care.

113. Adapting a person-centred care intervention to enhance self-efficacy after a myocardial infarction to a Portuguese healthcare context through co-creation. ID 175

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**Objectives:** Cardiovascular diseases remain a leading cause of death worldwide and recovering from myocardial infarction (MI) is challenging because the symptoms and emotional reactions are not due to physical conditions alone. The enhancement of self-efficacy through the implementation of person-centred care (PCC) in healthcare can promote the person's recovery from MI. To guarantee that a complex intervention, such as PCC, will be successful when transferred to a new context, it must be aligned with the stakeholders' needs and priorities. This study aims to adapt an existing PCC intervention to a Portuguese healthcare context to enhance self-efficacy of the person who suffered a myocardial infarction. **Methods:** A PCC intervention successfully implemented and evaluated in a Swedish healthcare context will be adapted through co-creation with stakeholders alongside with researchers. Stakeholders (i.e. nurses, physicians and people who suffered a MI), will be recruited from a cardiology unit from a tertiary hospital, including both inpatient and outpatient departments. Their personal narratives about the PCC intervention's acceptability, appropriateness, and feasibility, will be accessed by semi-structured focus group interviews with start in September 2023. Data analysis will be conducted using content analysis following a deductive approach to further inform the adaptations needed to be made for the Portuguese healthcare context. **Results:** Preliminary results from the study will be presented. **Conclusion:** A co-creation approach will enable the early involvement of providers and users as partners with a voice in the decision-making process for adaptation. Also, the implementation of PCC is expected to improve the recovery process of people suffering of MI, by allowing a greater understanding of the person's perception and role.

114. DigiSTRENGTH, a person-centered support to increase participation, activities, meaning and joy in life and support diminished involuntary and existential loneliness in older persons living in special housing ID 308

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Background: Involuntary and existential loneliness is a widespread societal problem with serious impact on healthy aging and wellbeing. Over half of those older persons living in special housing express sense of loneliness. DigiSTRENGTH; Reflective STRENGTH-giving dialogues with the digital platform Digitala Samtal, address this problem and will be evaluated in this project. Aim: To describe how loneliness in older persons living in special housing is experienced and influenced by DigiSTRENGTH. Methods: A qualitative and quantitative design. Participants are care providers and residents in special housing. Results: Pre-analysis of interviews analyzed with a phenomenological approach shows that the participants find the dialogues to be of value for sense of health and wellbeing. The dialogues are conducted in a new way compared to ordinary conversations; have a direction, a goal and a meaning.

Conclusions and Implications: The pre-analysis address the need of extended individual and holistic guidance and support to diminish involuntary and existential loneliness in older persons lives. Dissemination of innovative strategies in local health care, as DigiSTRENGTH, could contribute to advance quality of care and improve meaning in life for older persons in special housing.

## Implementation and Knowledge Translation

115. Supporting implementation of person-centred care in healthcare by facilitation: evaluation of a facilitation training program's acceptability, appropriateness and feasibility ID 052

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Objectives: Swedish healthcare is transitioning towards more person-centred care (PCC). To support this transition, a training program targeting healthcare personnel focusing on facilitation and PCC was developed and implemented: Facilitating Implementation of Person-Centred Care-training program (FLIP). The FLIP-training program introduces facilitation skills, such as tools for supporting behavior change processes, combined with person-centred care. This study evaluated the training package's acceptability, appropriateness, and feasibility. Methods: Five healthcare units were recruited: four from a hospital and one from the primary health care. Two healthcare personnel from each unit were selected to participate in the training program between October 2022-February 2023 in seven online workshops and two individual supervisions. Data was collected before and three months after the training program by targeting all healthcare personnel at the five units using the short version of the questionnaire Person-centred Practice Inventory – Staff (PCPI-S). Moreover, group and individual interviews were held with facilitators, managers, healthcare personnel, and FLIP-training package/program leaders at these two time points and directly after completing the training program. The transcribed interview data were analysed deductively according to qualitative content analysis. Results: In total, 63 individuals were interviewed, and 184 questionnaires were answered. The attendance at the FLIP-training program varied due to the high workload and sick leave. Preliminary analysis shows that the acceptability, appropriateness and feasibility differed between the healthcare units and that supportive leadership is key. The acceptability of PCC seemed high at all units, while the appropriateness varied depending on the care context. The questionnaires have not yet been analysed. Conclusion: The findings suggest a potential of using facilitation as a

strategy to support the implementation of PCC. However, what components of a training program that are most important for learning and implementing PCC need further investigation.

116. Training as implementation strategy for goal-oriented care: identifying training needs of primary care providers using interpretive description ID 076

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Background: The increasing demand for care and support for people with complex and long-term care needs has prompted shifts towards integrated health and social care delivery models, rather than disease or problem oriented approaches. Goal-oriented care (GOC) – a strategy that starts from the patient’s personal goals – is believed to reduce fragmented care and to optimize integrated care. In Flanders, the Dutch speaking part of Belgium, a training initiative on GOC for primary care providers (PCP) was organized as part of the regions aim of improving integration of health and social care services. Aim: This study aimed to better identify the training needs of PCPs regarding the implementation of GOC in daily practice, to help improve future training programs. Method: We applied a multi-method approach to address the research question: “What are training needs of PCPs who want to adopt GOC in practice?”. Fifty-one Flemish PCPs participated in an interprofessional pilot training on GOC. The 20-item Normalization Measure Development-Survey (NoMAD) was administered post-training to assess how GOC could become part of the PCPs’ practice. In addition, 26 participants contributed to four focus groups, discussing efforts to implement training knowledge into practice. Interpretive description guided data analysis. Findings: The results show participants’ enthusiasm for integrating GOC into their practice. The training had facilitated reflexivity regarding GOC’s current presence in participants’ work, revealing to them opportunities for further adoption of GOC. Training also highlighted the importance of organizational allies for effective implementation of GOC to maximize the impact of training efforts. Furthermore, interprofessional peer consultation addressing complex care scenarios was identified as an influential learning context to implement GOC.

## 117. Exploring normalization of person-centred ambulance care in Sweden - a qualitative study ID 230

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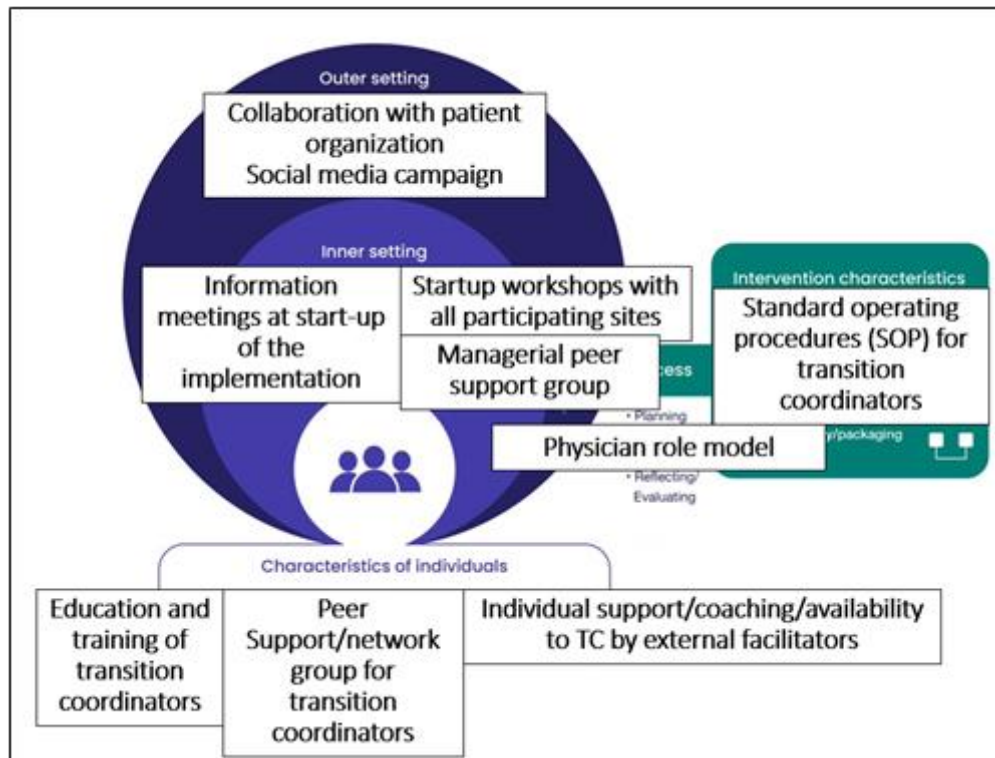
**Introduction:** Person-centered care (PCC) is one of the core competences in nursing and part of the nurse's ethical guidelines. However, in the medical- and task-oriented ambulance service PCC has not yet been formally introduced. PCC involves a change in behavior and behavioral change is challenging, and support needed. Therefore, the aim of this study was to explore an attempt to normalize PCC as a new work approach in the ambulance service personnels daily work, using trained facilitators as implementation strategy. **Participants:** One county in mid-Sweden was involved in a research lead implementation project. An intervention to train and support facilitators to implement more person-centeredness in ambulance care was carried out. Four stations with a total of about 100 eligible ambulance personnel were chosen. Forty-one ambulance personnel agreed to participate. **Methods:** The Normalization Process Theory (NPT) was used as theoretical framework in the data collection and analysis process. Semi-structured interviews in group, pair and individual were conducted at two occasions, 6-12 months and 18-22 months after the start of the intervention. Data was transcribed verbatim and analyzed deductively. **Results:** The normalization of PCC in ambulance care can be described using the four NPT constructs (Coherence Building, Cognitive Participation, Collective Action and Reflexive monitoring) and explained in detail using the 16 sub-constructs of the theory. PCC was considered challenging to grasp, and as having the fortitude to see beyond the patient's medical needs. Facilitators and managers initially engaged the personnel in PCC, however, summer and Covid-19 effected engagement. To enact PCC, ambulance personnel discussed the use of their tablet, treating each other as valuable colleagues, considering the way the stretcher was handled and how the ambulance was driven as actions that PCC requires. The value of PCC was considered difficult to assess and deemed to be something the patient should assess.



118. Prerequisites for implementing a person-centered transition program for adolescents with long-term conditions: a framework-driven stakeholder analysis of the STEPSTONES-Implement project ID 233

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Background and aim: Transition programs for adolescents with long-term conditions have been evaluated through randomized controlled trials and proven effective in improving patient-reported outcomes as well as clinical and administrative outcomes. However, implementation in healthcare remains scarce. The aim of this study was to (1) evaluate the prerequisites for implementation of an evidence-based transition program for adolescents with long-term conditions in a Swedish context, and (2) identify strategies to promote uptake and maintenance of the program. Methods: A qualitative design, using the Consolidated Framework for Implementation Research (CFIR) was used to identify determinants of implementation. Semi-structured interviews (n=21) were carried out with healthcare providers working at outpatient clinics at six university hospitals providing care for adolescents with long-term conditions (specifically heart disease), managers, and representatives from patient organizations. Data were analyzed deductively with content analysis in Nvivo v.15 using the CFIR as coding framework. Results: Most determinants for implementation (i.e., barriers and facilitators) pertained to the CFIR domains Individuals involved and Inner setting. The innovation (i.e. transition program) was perceived as credible but in some settings similar to current practices, although more comprehensive than usual care. Strategies to promote the uptake and maintenance of the innovation were categorized according to each domain of the CFIR network and are presented in Figure 1. Conclusion: Implementation of person-centered care for adolescents with long-term conditions is according to these findings dependent on the individuals involved and local context. An innovation that is tailored to the populations needs is crucial in ensuring credibility to implementers. Based on these determinants, strategies to facilitate the uptake and maintenance of the innovation has been identified. The use of CFIR in this study proved effective and can inform future studies aiming to implement person-centered care for people with long-term conditions. **Figure 1.** Strategies identified pertaining to each domain of the CFIR framework.



119. Cultural adaptation and validation of the Portuguese version of a Person-Centred Care educational course - “Mutual Meetings” ID 170

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Objective: Person-centred care(PCC) aims to ensure healthy lives and well-being through mutual respect and co- creation of healthcare, enabling individuals to achieve their full potential. Yet, the concept is not always well defined and operationalized into practice, challenging its implementation. The University of Gothenburg Centre for Person-centred care(GPCC) has developed an on-line course to provide training in PCC and to support healthcare units implementing it in daily practice. This study aims to culturally adapt and validate the course for Portuguese healthcare personnel in hospital services. Methods: The forward translation of the PCC course to the Portuguese language was conducted, followed by a translatability assessment performed by two Portuguese reviewers with knowledge on healthcare context and competence on PCC. To provide evidence supporting the acceptability, appropriateness and feasibility, the PCC course will

first be delivered to two groups of healthcare professionals (i.e. nurses and/or physicians) in a cardiology and oncology unit of Portuguese hospitals with start in September 2023. Secondly, the participants' perception on the structure and content of the PCC course will be assessed in focus group interviews, using a semi-structured interview guide, followed by a content analysis of the qualitative data. To explore the outcomes of the PCC educational intervention, a before-after design will be used, assessing the perspectives on person-centered practice using a self-reported measure (Person-centred Practice Inventory–Staff, PCPI-S). Results: Preliminary results will be presented. Conclusion: The validation of this course will contribute to the systematic practice of PCC in Portuguese healthcare contexts. Furthermore, Portuguese is the official language in 10 countries, representing more than 304 million of people worldwide. The translation of the course to Portuguese will therefore make it accessible in other Portuguese-speaking countries, where further validation efforts might be pursued. Hence, this study will also contribute to the global implementation of person-centeredness towards sustainable healthcare systems.

## Integrated Practice Development

### 120. Person-centred Culture in a Swiss Cancer Outpatient Clinic: a Participatory Inquiry ID 031

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Background: Depending on the stage of the disease and therapy regimen, persons diagnosed with cancer spend a lot of their time in cancer outpatient clinics. It is critically important that not only their needs are met, but also, they feel welcomed and safe. Over the last ten years, numbers of service users treated by the same number of healthcare professionals (nurses and oncologists) at the cancer outpatient clinic of the Zurich Municipal Hospital, site Triemli, were continuously rising. This work pressure results in a rather treatment focused practice which leads to unsatisfying conditions. It is argued by McCance et al. (2013) and Manley (2017) that person-centred care is dependent on a thriving person-centred culture. In the cancer outpatient clinic a culture change towards a person-centred practice is crucial, in which all facets of a person are valued, patients and professionals alike. Aims: The aims of my PhD research are to assess the current workplace culture in relation to person-centred practice at the cancer outpatient clinic, to develop a shared understanding of person-centred culture, and to identify areas of practice in order to further develop and to enhance a person-centred culture. Methods: The research contains several stages of co-creation. The main focus will be on methods to access persons' experiences of care and on methods that help the healthcare

team in getting a better understanding of their culture. As a part of this process, participants are invited to participate in data collection and analysis. Results and discussion: As fieldwork is ongoing, I will be sharing how I developed my methodological principles of this person-centred participatory research that guides the co-creation of this research. Further, I am discussing ethical challenges I have faced so far, and share how I encountered them in respect to principles of person-centredness.

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## 121. New Nursing Professional Practice Model in a Multisite Hospital: a mixed-method study in Switzerland, with an explanatory sequential design ID 264

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Introduction: Nursing Professional Practice Models (NPPMs) illustrate how nurses practice, collaborate, and develop professionally, ensuring quality care, professional satisfaction, and healthcare professionals' engagement. Objective: This study aimed to define NPPM elements in a multisite hospital, emphasizing active involvement of nurses and midwives from the study's outset. Methods: The sample included nurses and midwives (Clinical/Leadership). Employing a mixed-method study, with an explanatory sequential design, the study encompassed four meetings, an online survey, two Workshops, a World Café with nursing leaders, and a Focus Group. The study's phases used descriptive methods of quantitative data and a thematic analysis of qualitative investigations analysed by Braun & Clarke thematic analysis using NVivo®. Results: The investigations allowed describing current hospital realities. The survey (N=1312 RR=65%) identified six elements of the model, confirmed by Workshops/Focus Groups: LEADERSHIP: Focused on enhancing individual strengths, capabilities, goal-sharing. A leader uses communication skills to act as a role model, motivate others, and positively influence practice. WORK CLIMATE/ENVIRONMENT: Emphasizing

dialogue, listening, and respect. A healthy work environment promotes good practices and effective nurse-patient relationships. AUTONOMY/COLLABORATION: Professionals are autonomous and accountable in relation to their competencies. Communication facilitated the collaboration. RESEARCH/INNOVATION: Promoting problem-solving and quality care through the dissemination of research and evidence-based practice. DEVELOPMENT/RECOGNITION: Emphasis on individuality, role recognition, and professional development. CARE OUTCOMES: Nurse-patient (or family) interaction increases safety and quality at the organizational level. Conclusions: Person-centered cultures are pivotal for developing good practices through collaboration. Elements of our NPPM lay the groundwork for culture dissemination. Developing such cultures is complex, especially in a multisite context. A bottom-up approach, with active involvement of the staff from the early stages, has proven successful. Next steps: developing a new nursing care model aligned with the NPPM. Implications for Practice/Research: Developing and valuing nurses can enhance satisfaction, reduce abandonment rates, and improve patient outcomes, aligning with the evolving nursing care model.

## 122. Organizational prerequisites for contact nurses in Swedish cancer care – a vital component of person centered care ID 100

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Contact nurses in Swedish cancer care are meant to function as enablers of availability, continuity, safety, and patient participation. The goal is that everyone diagnosed with cancer should be offered the services of a contact nurse. The assignment includes assessment of care needs, supporting, informing, monitoring lead times, and assuring active care transitions. They are seen as facilitators of person-centered care and function as patient's assigned health care professional. Previous research indicates that contact nurses' organizational prerequisites to provide high quality care differ significantly. Their scope of, and prerequisites for work differ across settings. Departing from the notion that high quality outcomes for patients are dependent on high quality structures, the QOPCoN research group (Quality and Organizational Prerequisites of contact nurses) aims to investigate organizational prerequisites of contact nurses and their bearing on quality of care. The theoretical underpinnings are based on the Donabedian (2005) quality evaluation framework and the McCormac and McCane (2006) person-centered nursing framework. These scholars acknowledge that the care environment, the structure, has significant impact on quality of care, and the operationalization of person-centered nursing. In our session, we want to give an overview and

background to contact nursing in Swedish cancer care from a person-centered care perspective. Furthermore, we want to demonstrate a newly developed indicator instrument that measures structural prerequisites for contact nurses. In a comprehensive and visually appealing manner, the tool can provide insights and guidance for leaders and practitioners alike. It can serve as a springboard for quality improvement efforts and enables comparison across cancer care settings and over time. Person-centered care is not achievable if health care professionals are not supported by suitable organizational and structural prerequisites. Our goal is to make this realm tangible and comprehensible in relation to the important role of contact nurses in Swedish cancer care.

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### 123. Pathway to a person-centred workplace culture in a department at a Swiss University Hospital ID 070

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Background: Since May 2021 a Swiss university hospital is organized with a new management structure focusing stronger on nursing. There are six medical departments, which are headed by a department medical officer (DMO), a department financial officer (DFO) and a department nursing officer (DNO). The implementation of a DNO as one of the trio is new and innovative for a university hospital in Switzerland. The DNO has a shared leadership role with a department clinical nurse leader (DCNL). Here the DNO and the DCNL describe the pathway to a person-centred workplace culture with the nursing ward leadership teams within their department after the implementation of the new management structure. Methods: At first the DNO and the DCNL analysed critically their understanding of shared leadership as well as person-centred workplace culture by clarifying their beliefs and values and by building up a shared vision for person-centred leadership. Following, several workshops with the nursing ward leadership teams we clarified beliefs and values on person-centred workplace culture. We also used several practice development methods on building up a vision about person-centred nursing within the department. Results: A flourishing person-centred workplace culture is enabled through the DNO and the DCNL by living a shared leadership, being authentic as leaders, being close to the teams and being facilitators by using enabling questions. Thus, the DNO and the DNCL set an example of living person-centredness as role model for their nursing ward leadership teams. Conclusions: Based on our experience to date, constant dialogue and relational connectedness between nursing ward leadership teams are required to have a shared understanding and to enable a person-centred workplace culture.

Shared values and beliefs have been shown to be crucial for a successful teamwork and an effective workplace culture.

#### 124. When aiming for a good life - Person centered integrated care in a home health care context ID 087

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Background: The rapidly increasing older population with extensive care needs has shifted health care from institutions to the older person's home. A cross-organisational integrated care model was created by health care authorities to meet these challenges, the Mobile integrated care model (MICM). The MICM with a home health care physician is a collaboration between regional and municipal health care, working in the patients home. Methods: Semi-structured interviews with patients, next of kin and health care professionals. Results: The home was described by all as the best place to provide health care to these patients, creating safety and increasing autonomy for the patients. The health care professionals found trust in working together as a team, but struggled because of the divided organizations. Patients and next of kin found MICM to be hierarchic, where the structure at times improved participation, and at other times prevented it. Conclusion: More time for health care professionals were the main development which all participant groups described. Furthermore, the patients and next of kin longed for a personal contact and being able to form a relationship with the health care personnel. The health care professionals found being employed by separate organizations as a challenge, where divided documentation systems and lack of equipment hindered the work.

#### 125. The concept of partnership in care/person-centred care: a scoping review ID 183

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Background: Today no clear consensus exists regarding definitions or conceptualizations of partnership. The current literature and in clinical practice imply a variety of describing the concept partnership. There seems to be little consensus and clarity about the definition and what partnership consist of, but there is a general agreement that it is conceived as a collaborative process between patients and health professionals. Aim: The aim is to identify and describe the concept of partnership in care/person-centred care. Method: Electronic literature searches were conducted in PubMed, PsycINFO and CINAHL for English-

language articles describing the concept partnership published from 2000 until 2022. Three authors independently assessed the records for eligibility. All duplicates were removed and articles were excluded that were irrelevant based on abstract. All remaining articles will be read in full text. The articles will be analysed based on Ricoeur's ethics where partnership is a strive for health and wellbeing with and for others. Thereby underscoring mutual respect and collaboration between the health professional and the patient. Results and conclusion: At present we are including articles in full-text, analyses will be made during 2023 and May 2024 we will be able to present tentative findings at the conference.

## 126. Bridging Boundaries for Integrated Care: Constructing Interprofessional Collaboration Pathways for Complex Care Needs ID 310

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**Background:** Amid the increasing prevalence of chronic diseases and multimorbidity globally, the quest for integrated care models has intensified. However, empirical evidence on their implementation remains limited. Understanding the intricacies of effective interprofessional collaboration is crucial for achieving seamless integration of care. **Aim:** This study seeks to construct a grounded theory elucidating the dynamics of interprofessional collaboration across care providers to support integrated care for persons with complex needs. **Design:** A constructivist grounded theory approach guided the research. **Methods:** Observational and interview data were collected and analyzed using constant comparative methods to reach theoretical saturation. The sample consisted of 86 participants from diverse professional backgrounds within health and social care sectors, including hospital, ambulance services, primary care, and community care settings. **Results:** The theory titled “Negotiating Care in Organizational Borderlands” conceptualizes interprofessional collaboration as a complex and layered process. The process encompasses three distinct levels, influenced by how effectively organizational and professional boundaries are navigated. At the fragmentation level, care is disjointed, leading to a lack of cohesion among providers. The dependence level sees professionals relying on each other yet struggling with boundary issues. Ultimately, integration is possible when care providers collaboratively transcend organizational divides, leveraging their collective expertise while maintaining clearly defined accountability lines. **Conclusion:** Establishing clear pathways for robust collaboration is pivotal for care integration. However, care integration from the patient's perspective does not prevent healthcare professionals from encountering fragmented roles. This underscores the importance of clearly defined accountability lines to support shared responsibility and to bridge gaps across professional and organizational boundaries. **Relevance to Clinical Practice:** This research emphasizes the need for adaptive collaboration to support integrated care for persons with complex needs.



It underscores the importance of clear accountability and communication pathways in organizational borderlands to provide person-centered care and meet individual patient needs.

127. Using the Workplace Cultural Critical Analysis Tool  
Revised in two German speaking hospitals:  
recommendations for practice ID 285

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Introduction: The participative observation tool, Workplace Culture Critical Analysis Tool Revised, (WCCAT<sup>®</sup>), is based on the theoretical framework of person-centred practice. Utilising a participatory process, the tool is used to support transformations towards a person-centred workplace culture. The WCCAT<sup>®</sup> was translated and culturally adapted into German by a Swiss research group. Additionally, it was further adapted by experts from Austria, Germany and Switzerland. To date, the adapted tool has not yet been used in practice. Aim: A research group from nursing departments in two German-speaking hospitals planned to integrate the observation tool into their practice development activities. The goal of the project was to systematically and critically reflect on experiences regarding the application of the WCCAT<sup>®</sup>, while taking the contextual circumstances into consideration. Also, recommendations for use of the WCCAT<sup>®</sup> for German-speaking practitioners were formulated. Methods: In the development of the recommendations, our approach was based upon action research and practice development methodology. During the observations and communication with the observed teams, we followed the instructions of the authors of the WCCAT<sup>®</sup>. The observers' observational experience was written down using Gibbs reflection model and reflected upon in the research group. Conceptual Mapping method was used to analyse data and develop recommendations for action. Results: Four observations were conducted at the two hospitals, using one research member per hospital. Our results show how important it is to be well prepared as an observer, but also to be in dialogue with the teams to be observed. Recommendations for this and further additions to the existing recommendations were formulated. The main challenge is to enable the observed practitioners to participate to the entire process.

128. Development of a Swiss Advanced Facilitation School: adding a piece to the jigsaw of person-centred practice ID 006

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More than ever, current healthcare practice demands for facilitators who foster the development of person-centred healthcare cultures and who accompany transformative processes. Since 2015, the Swiss Practice Development Network offers a Foundation Practice Development School (PD School) based on the curriculum of the International Practice Development Collaborative (IPDC). The aim of the PD School is to enable and support healthcare professionals to initiate, foster and evaluate person-centred practice development in their field of practice. One finding in the thorough evaluation of the Swiss Foundation Practice Development School was the need of external learning conditions and networks to renew and deepen knowledge. Over the last few years, there was a growing demand for a subsequent programme like an advanced facilitation school, however held in German, also in Switzerland. Internationally seen, to our knowledge, advanced facilitation schools have been offered in Australia, the UK and the Netherlands. Therefore, the Swiss Practice Development Network decided to develop a Swiss Advanced Facilitation School (AF School) considering language, culture and contextual factors. With this AF School, we aim adding another piece of the jigsaw to foster person-centred practice. Methodologically, the development of the Swiss AF School was guided by three elements: “Listening and learning from others” through conversational interviews and reviewing the literature, “designing” using the Appreciative Inquiry method, and “living participation” through the inclusion of various stakeholders. In this session, we present the results on two levels. On one hand, we will present the curriculum development and the curriculum itself. On the other hand, we talk about the crucial efforts and experiences that have allowed us to incorporate cultural realities and person-centredness in a participatory way.

129. Utilizing cartoons to enhance research communication on Person-Centred Care ID 176

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This abstract reports from an innovative approach to facilitating discussions when communicating research on person-centered care (PCC). The initiative involves a collaboration between researchers, communicators, and a patient representative who is also an artist. In the realm of healthcare, diverse understandings of PCC exist among healthcare professionals, students, patients, and the general public, which may pose challenges to its effective implementation. These understandings were identified through a review of sources, including published research literature as well as through focus groups with various stakeholders. Six distinct conceptions of PCC were identified: 1. PCC only works in specific healthcare contexts. 2. PCC equates to patients making all the decisions. 3. Many patients think that PCC is too demanding for them. 4. The term "patient" may no longer be used. 5. Healthcare services are already person-centered. 6. There are insufficient time and resources for PCC. To facilitate understanding and discussion of these conceptions, cartoon-style illustrations were developed for each concept. One such illustration, representing the idea that "PCC equates to patients making all the decisions" is included above. Subsequently, pedagogical materials were created to delve into these conceptions, with relevant research citations provided for each conception. The creation process for the cartoons and accompanying texts involved group meetings characterized by lively discussions focusing on inclusion, diversity, and differing perspectives within various care contexts. After each meeting, the artist adjusted the cartoons based on the group's discussions, while researchers and communicators revised the accompanying text. The overarching goal of this initiative is to offer materials that can support and stimulate reflections, thoughts, and discussions about person-centered care.

130. Understanding nursing effectiveness: a person-centred perspective on the nurse's role ID 054

*Hanna Mayer, Karl Landsteiner University of Health Sciences; Martin Wallner, Karl Landsteiner University of Health Sciences*

Professional nursing is social action in complex systems. The effect and effectiveness of nursing action can therefore not be explained by considering isolated technical and functional procedures. Rather, they emerge as a process, both through intentional action and through relational interaction. From a methodological point of view, this leads to a conundrum: while there is a pressing need to demonstrate the effectiveness of person-centred interventions, traditional approaches to effectiveness research repeatedly face limitations. The aim of the talk is to elucidate the role of the nurse as a person in intervention research from the perspective of person-centred care theory and to derive methodological implications for intervention research. Generative mechanisms and cause-effect relationships theorised in selected nursing programme theories from various fields, including dementia care, palliative care, and family counselling, serve as an empirical basis. For the 'production' of effective nursing, person-centredness, as reflected in the nurse's attitude, is the prerequisite. It forms the basis for a hermeneutic process in which different forms of knowledge are integrated and lead to actions tailored to the individual situation. Traditional approaches to knowledge production need to be reconsidered with regard to the role of the nurse in the effectiveness of nursing action, not least through the approach of person-centred theory. Concepts such as determinism, replicability, or standardisation conflict with this view, in which the nurse is considered a central factor, rather than a potential source of bias or confounding. Intervention research may benefit from exploring alternative methodologies such as theory-based evaluations, which acknowledge the embeddedness and social nature of interventions. This could be one way of overcoming the apparent mismatch between person-centred practice and traditional designs of effectiveness research at the methodological level.

131. Patient-centered care: no decision about me, without me ID 330

*Evanthia (Evi) Orfanou, Cancer & Rare Diseases Association Evros (Greece) "Together for Life"*

Being a good doctor does not only require thorough specialization and constant updating of scientific knowledge; it also means listening to your patients' needs. The concept of a patient-centered care is constantly gaining ground. The key element of the patient-centered care is patient being involved in the decision-making. There is often a confusion in understanding the difference between shared decision-making, self-management, and an individualized treatment plan. These

topics are becoming even more confusing or difficult to manage in some specific areas like rare diseases where many times the patient is the expert himself. Patients with chronic health problems and with limited or no access to the healthcare system, spend a lot of personal time self-managing their symptoms. The failure to recognize and satisfy these needs, decreases health care resources and lead to poor outcomes, because these individuals will have a longer and more financially demanding patient journey with increase private spending and poor healthcare outcomes. What is known in rare diseases as the patients notify, is the odyssey-journey to the final diagnosis. EVERY PATIENT IS UNIQUE! Every patient needs his own time (personalization). The answers the patient needs are to be adapted to his level of knowledge, cognitive and social background to personal care issues. Self-care and participatory decision-making, in a patient-centered care context, are mutually supportive practices that can maximize the results of a therapeutic intervention. Positive effects on disease outcomes can be improved when health professionals give the patient an active role in their health care. In conclusion, the term “Patient-centered care” is used to equity and the democratize the access to care. The concept remains far away from the daily clinical practice. Therefore, the state, doctors, and patients alike should work to make this concept implemented and included in everyday healthcare.

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### 132. It's about addressing Confidence, Satisfaction, Emotions, and Knowledge – Person-centeredness in Diabetes Care ID 162

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Introduction: Current diabetes practice guidelines advocate for person-centered care, including individualized treatment, and strength-based communication, with the aim of supporting improved quality of care and better outcomes. However, implementation in routine care is challenged by tensions with established workflows, limited resources and time, as well as uncertainties around the concept of person-centeredness. We sought to explore what makes diabetes management person-centered according to people with diabetes and healthcare providers to

develop a practice-oriented definition of person-centeredness that can be easily implemented. Methods: We conducted focus groups with people with diabetes and healthcare providers. Participants were recruited through purposive snowball sampling and interviews were conducted using a semi-structured interview guide. We used codebook thematic analysis. Initial coding was guided by a common definition of person-centeredness, i.e., a focus on individual wishes, needs and barriers to a meaningful life, as well as diabetes-relevant PRO categories from the literature. Codes were organized into overarching themes and subthemes based on shared statements or meanings. Results: We identified six main themes relating to emotions and actions associated with living with and/or managing diabetes. They illustrate how people with diabetes and healthcare providers imagine person-centered care, reflecting the issues that need to be addressed during consultations: “Being able to cope in daily life”, “Not feeling restricted and receiving support”, “Having a healthy body”, “Experiencing and managing emotions”, “Feeling well and having a good quality of life”, and “Being knowledgeable about diabetes”. Conclusion: Based on our interviews, we formulated six strategies for achieving person-centered diabetes care: considering patients’ coping abilities and self-management; recording symptoms and treatment satisfaction; monitoring physical health and diabetes status, emotional well-being, and key drivers of quality of life; and being aware of individual diabetes literacy. Following these strategies can support practitioners in implementing person-centeredness and helping people with diabetes achieve meaningful health outcomes.

### 133. The researchers’ dilemmas when examining their own practice – Developing person-centred practice and culture using an Action research approach ID 177

*Elizabeth Rosted, Zealand University Hospital and University of Southern Denmark; Mette Kjerholt, Zealand University Hospital*

Introduction: Person-centred practice is a priority within healthcare systems internationally and at Zealand University Hospital in Denmark. To develop practice two departments at Zealand University Hospital initiated a three-year action research study with the purpose of developing clinical practice and the culture towards a more person-centred approach. Purpose: The purpose of this presentation is to describe the researchers’ dilemmas when doing action research within their own practice. Method: The study was an action research study with a participatory approach. We used dialogues and reflections both individually and collectively to open for perspectives in relation to person-centred practice, which otherwise may not have emerged. The two nursing research leaders from the participating departments were responsible for structuring the development of a more person-centred care and culture, for data collection in relation to the action research process and for the compliance with the ethics of action research. Data was collected using questionnaires, interviews, field studies and logbook records.

Results and Conclusion: Results from the data collection represented value and cooperation conflicts, power relations and lack of psychological safety to speak critically about practice, thus the action researchers experienced several dilemmas. As action researchers, they have responsibility to uncover and present results from the data collection, also if they included problems associated to the existing practice culture. However, if the results uncovered are not acknowledged by the participants, there is a risk that results will not be considered and necessary change of the existing culture may not be implemented. The relation between the action researchers and participants may be compromised and thus complicate the cooperation. Perspectives: Being an action researcher has a “flip side of the coin”, that one must be aware of when performing action research in one’s own department.

### Scratching the surface – person-centred knowledge morally and professionally commits nurses ID 181

*Elizabeth Rosted, Zealand University Hospital and University of Southern Denmark; Mette Linnet Olesen, Copenhagen University Hospital, Rigshospitalet*

Background: Regardless of the tight schedule in outpatient settings caring should be based on patients believes of what is important in relation to maintain everyday life. Within the person-centred framework, Guided self-determination is a method that supports reflection, collaboration, personal decision-making and problem solving. The purpose of the study was to examine clinical nurses’ experience of facilitating Guided self-determination during radiation or outpatient chemotherapy treatment and the ward managers’ motivation for implementing Guided self-determination in their departments and their expectations of impact. Method: Qualitative Interview study using a phenomenological hermeneutic approach. Five nurses, who had completed a Guided self-determination certification course and their leaders’ were interviewed using individual semi structured- and focus group interviews. Analyses were conducted using thematic analysis according to Braun and Clarke’s six-phases. Findings: Two overall themes were generated ”GSD is meaningful to both clinical nurses, ward managers and patients” and ”GSD creates an extraordinary room for counselling incompatible with clinical practice in a short-term contact but causing moral distress”. Conclusion: All nurses experienced the Guided self-determination intervention to be meaningful, person-centred and of value but difficult to implement in a busy technical field. To the clinical nurses this created a dilemma in everyday practice when they had to treat their Guided self-determination patients with the risk of causing moral distress. The nurses used different strategies to cope with this. The ward managers emphasized the importance of GSD in this setting where information and accelerated treatment is in focus. By supporting the patients during treatment, they would potentially be better prepared to live with cancer.

The ward managers also expected the GSD conversations to develop the nurses' professional competencies.

### 134. Person-Centred Practice in the stroke patient trajectory- A Scoping Review. ID 280

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**Introduction:** Person-centred practice is receiving more attention in healthcare practice and research. Nevertheless, more knowledge is needed to understand person-centred practice in stroke care (Bally et al., 2023; Elvén et al., 2023; Lobo et al., 2021). The aim of this scoping review is therefore to characterise the roles, needs, and perspectives of patients, carers, and healthcare staff regarding person-centred practice throughout the stroke patient trajectory. **Methods:** A scoping review was conducted following the nine steps of the Joanna Briggs Institute methodology (Peters et al., 2015). The review identified literature published in English between 2013 and 2023 using three electronic databases (Medline, CINAHL, and EMBASE). Key search terms (“patient-centred care”, “client-centred care”, “person-centred care”, “patient involvement”, “family-centred care” and “stroke”) and inclusion and exclusion criteria were used as strategies to identify relevant articles. **Results:** Twenty-eight empirical studies met the inclusion criteria. These studies were from 14 countries and involved patients, carers, and healthcare staff, and both quantitative, qualitative, and mixed methods were used. Eighteen studies were in the non acute phase, mostly within rehabilitation, six covered multiple stages, and four covered acute stroke care. The characteristics of person-centred practice depend on the phase of the stroke trajectory. While person-centred practice is seen as a challenge and barrier in the acute phase, it is well explored and necessary in rehabilitation. The role of patients and carers shifts from being predominantly passive in the acute phase to becoming partners in the rehabilitation phase. Furthermore, patient and carer needs in the acute phase are focused on communication and resourcing, while in the rehabilitation phase, other aspects are also present, such as decision-making and working with patients' values. **Conclusions:** In this scoping review, the findings document the variability of person-centred practice throughout the stroke patient trajectory. Further research is needed in the acute setting to better identify its characteristics.



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135. Monitoring of Person Centred Care in the context of Missed Nursing Care and Moral Distress in Nursing ID 289

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**Aim:** This study aims to evaluate the feasibility, as perceived by both healthcare personnel and patients, of a person-centred nurse led procedure involving patients' self-measurement of urate and dose escalation of urate lowering treatment (allopurinol). **Method:** Participants from three primary care units in Sweden were recruited; patients with gout and urate >405 µmol/L, nurses and physicians. Patients received nurse-led education on gout and of how to use a urate meter for self-measurement at home. Monthly follow-up and support was planned together by the nurse and patient and continued until the target for urate level was achieved, through dose escalation of allopurinol. **Data collection** involved the use of questionnaires and semi-structured interviews with all participants. **Results:** Of the 29 eligible patients, 12 agreed to participate. Common reasons for not participating included absence of gout-related problems, side effects from allopurinol, and comorbidities. Notably, all included patients completed the procedure and reached their target urate levels. Both patients and personnel found the procedure to be straightforward and simple regarding performance. Patients reported feeling more engaged in their treatment and gaining awareness and knowledge for managing their gout. Nurses described the procedure as manageable and professional, noting that it was time-consuming initially but not during follow-up. **Conclusion:** The self-measurement procedure appears to be a suitable first choice before resorting to regular lab tests when implementing person-centred nurse-led gout care in primary care settings. Patient involvement in self-measurement and home-based urate monitoring increases their sense of participation in care and treatment. **Key words:** primary care, gout, experience, feasibility, task shifting, nurse-led care, self-measurement, person-centred care

136. Development of a nursing care model guided by J. Fawcett's' metaparadigm (FM) through nurse and patient engagement ID 282

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Background: Nursing students are important future health care providers to the growing number of older persons in society. However, two barriers preventing a person-centred approach are ageist attitudes and their lack of interest in geriatric care. This is a concern in light of the global demand for more nurses. "Walking in the shoes" of an older person in age suit simulation is a safe pedagogical tool for nursing students to gain an understanding of age-related health problems and functional limitations. Method: This study investigated the effects of ageing simulation with an age suit as a part of experiential learning in a nursing programme. The simulation allowed the students to experience specific and common health problems from the patient's point of view in a controlled environment and a relevant context of care provision for future nurses: a home with welfare technology and other aids. The learning process involves a continuous cycle of doing and reflecting resulting in knowledge that also becomes "ingrained" in the body of the learner. Data were collected using a quasi-experimental pretest–posttest design with a control group. Results: The results showed that the intervention had a positive effect on various aspects of nursing students' perspectives on caring for older persons. Work experience was associated with more positive attitudes. The control group was more negative towards geriatrics as a career choice than the intervention group. Conclusion: Age suit simulation can be an innovative intervention in nurse education as it raises awareness and understanding of aging and the health challenges of older persons, which are important in combatting ageism among future nurses which is crucial for the provision of person centred care

137. Healthcare communication and decision-making in nurse-patient consultations in primary care: A systematic integrative review ID 153

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Background: Person-centred communication is needed to acknowledge patients' experiences and enhance their involvement in healthcare. For many people, primary care is the first point of contact with healthcare services. For first line decision-making processes to best meet patients' and public's health needs, it is important to identify communication strategies that support person-centred care and take into account patients' level of health literacy. Aim: To review empirical research and identify knowledge gaps on patient-nurse communication and decision-making within primary care consultations. Methods: A review of published empirical studies which include observations of real-life patient-nurse communication in primary care. A systematic literature search in four data bases was conducted. A total of 7211 articles was screened, which resulted in the inclusion of 19 articles. Results: The number of studies on real-time patient-nurse communication and decision-making in primary care is limited. This points to a scarcity of insights in the field of communication and decision-making in patient-nurse consultations within primary care. Further results will be presented at the conference. Conclusion: There is a need for research to gain a deeper understanding of nurses' communication strategies and the way they involve patients in decision-making. Such insight is needed to enhance person-centred care within nursing encounters being patients' first point of contact within Swedish primary care.

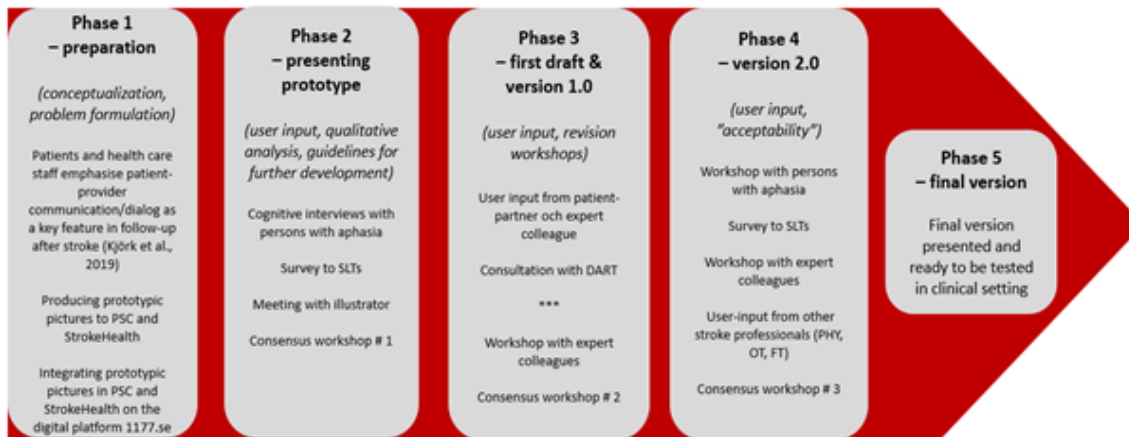
## Tools and Assessments

138. The development of pictographic support to the Post-stroke checklist and the pre-visit tool Stroke Health – a co-design study ID 044

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Background Effective clinician-patient communication is key to enable person-centered care [1, 2]. However, communication difficulties after stroke is common and may cause barriers in delivering health care [3, 4]. Consequently, there is an increased risk for adverse events due to mistreatments [5, 6]. The Post-stroke checklist (PSC) [7] is a tool to support follow-up and is endorsed by the World-Stroke Organization. Stroke Health [8] is a newly developed pre-visit tool based on the PSC. To date, there is no adaptation of these tools to support communication between health care professionals and persons with communication disorders. Co-design has been suggested in development and implementation of person-centered care [2]. Aims/purpose This study aims to describe the process of developing a pictographic support using a co-design approach, and what stakeholders stress as important in such an adaptation. Methods: Methods of data collection and user input involved interviews, workshops and surveys (see Figure 1). Stakeholders include persons living with aphasia (n=6) recruited from patient organizations, a patient-partner (n=1), speech language therapists (n=14), and other stroke professionals (physician, occupational therapist, physiotherapist). Prototypic pictures were used in cognitive interviews with persons with aphasia and in surveys and workshops with stroke professionals. All decisions, concerning revisions based on user-input, were made in consensus workshops with a patient-partner with stroke, before being relayed to an illustrator. Results: The user input from stakeholders guided the development process. Stakeholders requested a variety in disability, gender, age and culture. Participants with aphasia preferred pictures of individuals engaging in activities as a way to display context. Conclusion: The use of prototypes in the development process facilitated discussions, enabled persons with aphasia to fully contribute and allowed for all participants to give suggestions to improve the pictures. Planned studies will evaluate if the co-designed pictographic version facilitates clinician-

patient communication in a clinical setting. Figure 1. The co-design process of developing a pictographic support.



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### 139. How are patient-reported outcome measures being used to improve meaningful and timely patient involvement in the choice of medical implants? ID 321

*John Chaplin, University of Gothenburg*

**Aims:** The use of patient-reported outcome measures (PROMS) in medical research is widespread but there is little understanding of how PROMS could be used to improve patient choice and participation in treatment decisions. A recent study of PROMS related to high-risk medical implants conducted by the European CORE-MD (Coordinating Research and Evidence for Medical Devices) group allows us to examine how PROMS are currently being used and how they could be used to promote greater person-centred care. **Methods:** A systematic literature review of MEDLINE, CINAHL, the Cochrane trials databases (January 2000–June 2022) was conducted for PROMs used in orthopedic, cardiovascular and diabetes medical implant research. English-language articles reporting randomized

or observational trials of implant surgeries with at least three months follow-up were retrieved. In addition, an online Delphi study and focus group was carried out together with the European Patient Forum, as the patient partner organization, of users of high-risk medical devices across Europe. Results: 410 articles were identified (Orthopedics = 205; Cardiovascular = 169; Diabetes = 236). A full-text review was conducted by four independent researchers, resulting in 117 papers for full-text analysis (Orthopedics = 44, Cardiovascular = 38, Diabetes = 35). The most frequently used PROMs were the generic measures of EQ-5D and SF-12 or SF36. Satisfaction or experience measures were almost exclusively presented in the form of a visual analogue scale. None of the studies reported having consulted the patient in the choice of PROM instrument and discussion of results. Conclusion: PROMS have the potential to act as a method of clinical communication between the patient and the health professional but also as feedback to manufacturers of medical devices. The issue of satisfaction with treatment emerged as an important domain from the patient perspective but lacked adequate definition and standardization of measurement.

140. A new direct observation tool for assessing person-centred care: Evaluation of content and usability using think aloud and probing techniques. ID 133

*Nina Ekman, University of Gothenburg; Andreas Fors, University of Gothenburg; Philip Moons, KU Leuven; Eva Boström, University of Umeå; Charles Taft, University of Gothenburg*

Objective: To evaluate the content and usability of a new direct observation tool for assessing competency in delivering person-centred care (PCC) based on the Gothenburg Centre for Person-Centred Care framework (gPCC). Design: A qualitative study using think aloud techniques and retrospective probing interviews. Setting: Sessions were conducted remotely via Zoom with participants in their homes or offices. Participants: Eleven participants with lengthy experience of receiving, delivering and/or implementing gPCC were recruited using purposeful sampling and selected to represent a broad variety of stakeholders and potential end-users. Results: Participants generally considered the content of the four main domains of the tool, i.e., PCC activities, Clinician manner, Clinician skills and PCC goals, to be comprehensive and relevant for assessing PCC in general and gPCC in particular. Some participants pointed to the need to expand PCC activities to better reflect the emphasis on eliciting patient resources/ capabilities and psychosocial needs in the gPCC framework. Think aloud analyses revealed some usability issues primarily regarding difficulties or uncertainties in understanding several words and in using the rating scale. Probing interviews indicated that these problems could be mitigated by improving written instructions regarding response options and by replacing some words with more common synonyms. Participants generally were satisfied with the layout and structure of the tool, but some suggested enlarging font size and text spacing to improve

readability. Conclusion: The tool appears to satisfactorily cover major PCC activities outlined in the gPCC framework. The inclusion of content concerning clinician manner and skills was seen as a relevant embellishment of the framework and as contributing to a more comprehensive assessment of clinician performance in the delivery of PCC. A revised version addressing observed content and usability issues will be tested for inter- and intra-rater reliability and for feasibility of use in healthcare education and quality improvement efforts.

#### 141. Navigating towards a meaningful life after intensive care – from the perspective of older persons ID 117

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Background: The median age of patients admitted to the intensive care unit is above 65 years in many countries. Intensive care contributes to prolonging life for critically ill older persons, but research underscores challenges to acceptable Health-Related Quality of Life (HRQoL), recovery and well-being after receiving intensive care. Aims: The aim was to determine how HRQoL, recovery and well-being are followed up and characterised in persons  $\geq 65$  years of age who were being cared for in an intensive care unit. Design: A scoping review. Methods: CINAHL, MEDLINE (Ovid) and PsycINFO databases were searched in. 20 studies met the inclusion criteria. Results: Results are presented under five subheadings: Study characteristics, Type of studies, Methods for follow-up, health-related quality of life, and Recovery. Patients'  $\geq 80$  years old admitted to the ICU have a one-year mortality rate of around 60%. However, time seems to be an important factor regarding HRQoL among older patients, with most elderly survivors perceiving their HRQoL, recovery and well-being as acceptable after 1 year. Studies showed patients' willingness to be readmitted to the intensive care unit if necessary, indicating that life is worth fighting for. Conclusion: This scoping review illustrates how findings in HRQoL, recovery and well-being for older persons being cared for in an intensive care unit include a variety of quantitative data. In addition, the studies applied different tools for measurement, which made it difficult to evaluate and compare the results from the included studies. The diversity in study designs impacts the synthesis of findings and the possibility of gaining a greater understanding of how the transition towards a meaningful life is experienced for older persons after being cared for in an ICU. To apply a more person-centred care older persons perspectives needs to be evaluated through self-reported data and through qualitative in-depth interview studies.



142. Instruments used in the evaluation of person-centered care from a healthcare staff perspective: a scoping review  
ID 107

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Introduction: Person-centered care (PCC) is a globally recognized approach to healthcare that prioritizes the needs and values of the person receiving care while also considering the structure of the healthcare interaction. However, the systematic implementation of PCC in practice remains limited. Aim: A scoping review was undertaken to map the current knowledge of instruments used to evaluate PCC from a healthcare staff perspective. Methods: Following the PRISMA guidelines and the framework by Arksey and O'Malley, a comprehensive search was conducted in MEDLINE, EMBASE, and CINAHL. In addition, two grey literature databases were explored. The inclusion criteria were: 1) measurement of PCC or a specific subcomponent, 2) a focus on the use of or validation of an instrument, and 3) the instrument is answered by healthcare staff or students. Results: The search yielded 1612 records, with 147 studies meeting the inclusion criteria after the first review round describing 141 instruments. Studies were carried out across the globe; 41 countries were identified. The majority of the studies were conducted in Europe (44%). By country, the highest number of studies were conducted in the USA (21), Australia (12), and Sweden (10). The most commonly occurring instruments with a frequency of four or more in the included studies were ICS-Nurse (4), PDC (4), ICI (5), RIAS (5), PCPI-S (8), PCQ-S (12), PPOS (12), and P-CAT (26). None of the instruments fully followed the internationally recognized framework for PCC best practice. In addition, most studies implementing the instruments were one-off research projects with limited generalizability of the findings. Conclusions: Many instruments are available for evaluating PCC from a staff perspective. However, these instruments have not been integrated into routine healthcare quality assessment. To inform the implementation of PCC, future studies should examine instruments' psychometric properties and ways to implement them effectively in different contexts.

143. Attending to the health-related pleasure of patients:  
the development of a novel scale ID 240

*Preston Long Medical University of Vienna; Tanja Stamm; Medical University of Vienna*

Pleasure is a cornerstone of human behavior. Its exclusion from the medical sciences has been to the detriment of society. The process to include pleasure as a patient-reported outcome has multiple beginnings. A pleasure scale must be developed for clinical purposes and original research must be conducted to

establish the added value of measuring pleasure. Treatment comparisons, prediction models for recovery, side-effect investigations, and more may benefit from the collection of patient-reported pleasure. Furthermore, simply inquiring about a patient's pleasure may serve as a positive intervention by giving them permission to discuss the positives in their life, offering a more complete picture of the patient. Reporting on pleasure can also benefit patients by reallocating their attention towards the positive, rather than the often consistent redirection towards the negative as seen in most patient questionnaires. This presentation will review a novel piloted health-related pleasure scale and explore its potential in healthcare.

#### 144. Translation, cultural adaptation, and validation of Quality of Trauma Acute Care Experience Measure to a Swedish context ID 209

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**Aim:** To validate a Swedish version of Quality of Trauma Care Patient Experience Short Form Measure (SF QTAC PREM - Acute). **Method:** Patients are recruited from a single site Trauma 1 centre during 2023-2024. The translation process was carried out according to international guidelines. Confirmatory factor analysis will identify dimensions and reliability and construct validity. Cohen's  $\kappa$  coefficient and Cronbach's  $\alpha$  will be used to analyse construct validity. **Preliminary results:** Forward and back translation, advice from expert groups and patient interviews were used to translate and culturally adapt the survey to Swedish which resulted in the removal of one demographic question. A working version of the measure has been created in Swedish for use in the test-retest phase. Around fifty patients have been recruited to the study to date, with half of the test-retest data collected (n=20) with recruitment ongoing. Reliability will be investigated using 40 test-retest responses. After reliability is determined and relevant adjustments made, data collection will continue for the whole study (n= 190). Analysis of the test retest and preliminary analysis of the data collection for psychometric data collections will be presented. **Clinical application:** The validation of the Swedish version of SF QTAC-PREM will support systematic collection of trauma specific patient experiences of care, which is currently unavailable in Sweden. Data from the PREM will inform the development of interventions and predictive models which aim to improve short- and long-term outcomes for trauma patients.

## 145. Enhancing Patient-Centric Care: The Role of PROMs Utilizing SRS-30 in Scoliosis Management ID 297

*Marina Rosa Filezjo, University of Calgary; Ramyn Jooma, University of British Columbia; Maria Santana, University of Calgary*

Scoliosis, the most common spinal disorder in pediatric patients, is defined by a curvature of the spine greater than 10 degrees. The most common type of scoliosis is called Adolescent Idiopathic Scoliosis (AIS) and is found in individuals between 11 to 18 years of age. AIS corresponds to 90% of the cases of scoliosis in the pediatric population, with an overall prevalence of 0.47- 5.2%, affecting girls more than boys <sup>(3:1)</sup> <sup>(1,2)</sup>. There are different treatment options for scoliosis, depending mainly on the curvature size and skeletal maturity (Maruyama et al. 2003; Bunnell, 1986). Surgery is reserved for patients with curves greater than 45 degrees while still growing or greater than 50 degrees for skeletally mature patients <sup>(3,4)</sup>. As the healthcare continues to evolve, there is a growing recognition of the need to prioritize patient-reported outcomes (PROMs) for a comprehensive understanding of the impact of scoliosis on individuals' lives <sup>(5)</sup>. This abstract explores the importance of PROMs, specifically the Scoliosis Research Society-30 questionnaire, in assessing and improving the quality of care for scoliosis patients that were submitted to surgical intervention.

PROMs data were collected from 88 AIS patients at the Alberta Children's Hospital undergoing surgical intervention. Comprehensive assessments were conducted at distinct time points, including preoperative baseline measurements and postoperative evaluations at 3, 6, and 12 months. The evaluation encompassed five key domains, including: function, pain, self-image, mental health, and satisfaction/dissatisfaction with management, as well as possible changes in the results before and after surgery. This project highlights the pivotal role of PROMs, with a specific focus on the SRS-30 questionnaire results, in creating a more holistic and patient-centered approach to scoliosis management.

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146. Development and usefulness of the person-centred assessment tool Hermes: Qualitative synthesis ID 341

*Kristin Thorarinsdottir, University of Akureyri*

The person-centred assessment tool Hermes which is phenomenological derived is mainly used in rehabilitation nursing. Its development and use has been explored in four separate qualitative research. Aim: To explore the development and usefulness of Hermes and in what ways the tool facilitates person-centred care. Method: Four qualitative research on Hermes were qualitatively synthesised. Data was analysed with thematic analysis. Participants in the studies were 37 health care users, 26 nurses and 27 other health care professionals. Results: The first theme centred on the structure and the assessment method. The main part of the tool includes 27-32 issues that focuses on the disturbing impact of illness which are structured according to Functional health patterns of Gordon. Through Hermes users can identify and discuss with nurses health issues that are of disturbance in daily life, assess the severity of the disturbances, and importance to attend to them. The assessment interview takes 30-45 minutes and is based on narrative and interpretative dialogue. The second theme entailed how the tool facilitated the appearance of the users' perspectives from holistic approach, while the third one centred on the development of connection and realisation of useful interview technique. Enhanced understanding of the health situation, possibilities provided for adjusting for health issues of concern, variance in the use in teamwork and need for education and training were addressed in the other themes. Conclusion: The synthesis which contributed to knowledge development on Hermes supports that its use facilitates person-centred care. Further studies are needed on the tool. Key words: Person-centred, assessment tool, phenomenology, qualitative synthesis.

147. Development and psychometric testing of a short form of the Person-centred practice inventory – staff version ID 127

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Background: The Staff version of the Person-centred Practice Inventory (PCPI-S) has been translated and adopted globally as a leading measure of person-centred practice (Slater et al, 2017). This 56-item questionnaire is theoretically based on the Person-centred Practice Framework by McCormack and McCance (2017) and has been tested and translated in German, French, Norwegian, Spanish, Malaysian,

Swedish, Portuguese and Chinese (PCPI-ICoP, 2023). Given the vitality of this instrument in evaluating the development of person-centred practice cultures, there is a growing need to create a short form of the questionnaire. This study aims to develop and psychometrically test the PCPI-S short form, a shorter version of the more comprehensive PCPI-S. There are several advantages – (i) shorter form is time efficient, (ii) it provides a balance between cognitive fatigue and a need to capture all the relevant constructs and domains of the PCP framework, (iii) it also expands on the original PCPI-S by addressing the order effect and by expanding the current rating scale from a 5-point scale to a 7-point scale. Materials and Methods: Completely anonymised secondary data will be obtained from authors of published studies using PCPI-S. A collective global dataset will be collected and organised in clusters of languages and psychometric testing will be performed on this dataset. Through a recursive statistical and expert knowledge exchange process, items are reduced to obtain the short form of the PCPI-S. Results: It is expected in the present study that several items will demonstrate statistical expendability and will be likely candidates for removal. It is also expected that data clusters from other languages will highlight similar items. At the time of submitting this abstract, the study was commencing as planned. It will be complete by the time of the conference, and we will use this opportunity to present a final short form for the first time.

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## 148. The European standard for patient involvement in health care: development of an assessment tool ID 311

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Introduction: Person-centred care (PCC) faces difficulties in definition and implementation amongst healthcare professionals. The European Committee for Standardization has provided a standard (SS-EN 17398:2020) for patient involvement in health care, minimum requirements for person-centred care, which is directed at healthcare professionals. The standard consists of three domains: Patient's narrative and experience of illness; Partnership; and Documentation, care plan and information sharing. The standard is not regulated by an authority but it is recommended as a standard for the Swedish health care system. Aim: The aim of this study was to explore Swedish healthcare professionals' understanding of PCC and their perspectives on the ability of SS-EN 17398:2020 to assess PCC. Methods: A mixed method approach was used to develop and test an online questionnaire based on the Standard. Semi-structured interviews with healthcare

professionals were conducted to examine how the Standard matched perception's of PCC. The psychometric qualities of the instrument including internal consistency and concept matching via exploratory factor analysis (EFA) was tested via a national survey. Results: Healthcare professional's understanding of PCC is largely consistent with the core domains of Patient narrative and Partnership. The instrument demonstrated high reliability on all three domains (Cronbach's alpha 0,803; 0,892; 0,830). The factor structure was largely confirmed with a four-factor solution EFA. However, the study identified a strong effect of occupation on reporting PCC. The qualitative interviews identified some confusion on terms and concepts. Healthcare professionals reported a lack of management ambitions, time and lack of PCC education, as limitations to fulfilling person-centeredness. Conclusion: The standard provides a strong framework for the description of PCC in healthcare and the instrument has largely fulfilled the need for measurement. However, further research is needed to understand and adequately incorporate the occupational effects on measurement and to ensure increased clarity and generalizability of the concepts used.

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