



ANNUAL REPORT 2020
University of Gothenburg Centre for
Person-Centred Care – GPCC

www.gpcc.gu.se

Approval of the report

This annual report was prepared by the Centre Director and approved by the GPCC Steering Committee.

Brief background of the GPCC

The University of Gothenburg Centre for Person-Centred Care (GPCC) was established in 2010 when GU received financing from the Swedish government's strategic investment in the strategic area health and care research. Since then, around 100 national and international researchers, with varying disciplinary backgrounds, have collaborated in forming the GPCC as a national centre of excellence in person-centred care.

The vision for the centre remains; *sustainable health through sustainable health care – to prevent and decrease suffering and to strengthen the efficiency in health care through person-centred care.*

The strength and external recognition of the centre's contributions have been:

- Concretizing practical interprofessional approaches to person-centred care with starting points in ethics and philosophy of the person, and evaluating this in comprehensive research designs including effect and process evaluations.
- Doing so in high quality research designs.
- The context focuses on long-term illness.
- A special feature since the beginning has been to develop and apply successful strategies that support synergies between research, education, innovation and dissemination.
- User involvement throughout the research process as a key feature, and a Person Council to validate GPCCs' activities and research from a patient and/or family carer perspective .

As a strategic research area, the GPCC was evaluated by the Swedish Research Council (VR) in 2015. In 2016 the application for a renewed six-year period as a university centre was approved, and a half-time evaluation of the centre was completed in 2019.

Added academic value

The year 2020 was marked by the coronavirus pandemic, especially by the restrictions for clinical research during a major part of the year. Still, several projects have managed to complete data collections, utilized registry data or worked around the restrictions in other ways.

During 2020 there were 26 projects in progress with researchers from Sahlgrenska Academy, School of Business Economics and Law, Faculty of Humanities, IT Faculty, Faculty of Fine Applied and Performing Arts, Faculty of Social Sciences and Faculty of Education. New projects (decided at the end of 2019) further contributed with new partnerships between disciplines and research areas. In addition, external national and international co-investigators and other collaborators were supported by the Centre organization. This includes five PhD students involved in programmes for double degrees with KU Leuven in Belgium. The research collaboration continues to result in added academic value with increased exchange between disciplines and research areas. In terms of research output there were 69 original articles published and three PhD students graduated.

Special achievements for the centre during 2020 include publishing two key publications. First, an overview of completed research from the first ten years with a special focus on a comprehensive mapping of the first 27 intervention studies (Gyllensten et al, 2020, in *Health Expectations* 23, 1362-75), and secondly a comprehensive summary of 15 trials focusing on practical insights to inform future redesigning of healthcare in partnership with patients to achieve better clinical outcomes

(Britten et al, 2020, in *BMJ* 370, m2738). These two publications will be of importance to further proliferate our knowledge dissemination. In addition, the European collaboration Cost Care contributed with a theory driven and evidence based comprehensive plan for the evaluation of Exploratory Health Laboratories (Lloyd et al, 2020, *Int. J. Environ. Res. Public Health* 17, 3050).

Special developments are related to the centre's half time evaluation in 2019 as well as the RED 19 evaluation. Increased collaboration between research projects related to implementation of person-centred care and organization, leadership and governance of person-centred care were implemented as a result of merging these areas into one research domain. Research in the field of learning and education of person-centred care was organized into a new research domain. All junior researchers involved at the centre were offered a mentor, in addition to their post-doc supervisors.

A special context for the research at the Centre is the changing healthcare landscape striving for a structure of healthcare closer to the people in need and all citizens, and the increasing integration of person-centred approaches in Swedish healthcare policy. The knowledge generated at the Centre clearly contributes to this change, and is increasingly visible in reports and clinical guidelines published during the year.

New areas of focus were identified in strategic discussions at the Centre during the year, and planning was initiated for research into these areas: i) collaboration with patient and family carer representatives in healthcare authorities, organizations and research, ii) further facilitating implementation of person-centred care in relation to recent policy change including the usefulness and feasibility of the European standard about minimum requirements for person-centred care, and iii) sustainability of person-centred care systems in critical events such as societal stress and disaster.

Research seminars (i.e. webinars) continued as a core activity for colleagues across research groups as well as with external people, leads of the research domains and the centre's philosophical adviser Professor Bengt Kristensson Uggla. The networks for junior researchers and doctoral students respectively also continued as well as the research amanuensis programme. All these structures important to support interdisciplinary exchange and collaboration.

Collaborations

A milestone for the Centre's knowledge utilization and dissemination, and a direct result of its strategies, was the approval of a European standard for person-centred care; specifically the CEN-standard EN 17398:2020 "Patient involvement in health care – Minimum requirements for person-centred care". This is a result of several years collaboration with leading researchers from the Centre on the EU level. Research evidence from GPCC is explicitly referenced as a foundation for this standard and thus utilizing knowledge from the centre internationally. On behalf of the Centre and GU, Professor Karl Swedberg chaired the Swedish committee and Dr Axel Wolf chaired the European committee. The standard can be accessed for reading on-line in Swedish through the Swedish Institute for Standards (<https://www.sis.se/standarder/kpenstandard/forkopta-standarder/personcentrerad-vard/>).

National and international collaboration, as well as collaboration within GU continues to be strengthened and researchers from the Centre are involved in a number of different national and international collaborations, inside academia and with the larger society. A few important examples can be mentioned:

- The European collaboration *CostCares – person-centred care for sustainable health systems* – led by former centre director Professor Inger Ekman continue to provide special resources and networks of importance for many researchers and junior faculty.
- The Centre's involvement in the *South Africa Sweden University Forum (SASUF)* collaboration continued for the development of person-centred paediatric care practices. Seminars and workshops have continued online with valuable outputs. The vast majority of the projects include both national and international collaboration that has been facilitated by the centre organization.

- In addition, the *Person Council* for patients and family carers continued to provide important knowledge utilization to patient organizations, networks and healthcare services. To facilitate knowledge utilization of users in health care, text materials about person-centred care were produced to specifically target patient organizations, and webinars were organized collaboratively with users, researchers and media profiles.

GPCCs 10th Anniversary conference was held in February with 350 participants to manifest the knowledge and practice development regarding person-centred care from the Centre's first ten years. Participants were significant healthcare stakeholders from across Sweden, and key note speakers included international scientists and collaborators. The event was a success especially as dialogue and partnership in health care were elaborated on and demonstrated with impact building on the interdisciplinary nature of the Centre, foundation in philosophy and ethics, practice applications, performance measurement, interdisciplinary professional teams, digital tools, amongst other aspects.

Representatives from the GPCC were invited to and participated in public events, debate and commenting on governmental inquiries. These include *God & nära vård i praktiken*, and *What Matters to You-day* highlighting person-centred care, organised by Swedish Association of Local Authorities and Regions (SALAR). The centre participated at the 20th International Conference for Integrated Care as knowledge partner and a virtual exhibition stand with the aim of marketing our digital education tools, as well as initiating and hosting successful webinars, with the ability to reach a geographically wider range of audiences.

GPCC Steering Committee and affiliated partners have responded to for example publicly with comments on person-centred care in journals, and on the final report of the Governmental inquiry *Good quality, local health care* (God och nära vård) and to the new initiative from SALAR for person-centred integrated care paths guidelines (as related to specific medical diagnoses). The *Good quality, local health care* inquiry, which has person-centredness as its core, is set to have a major influence on Swedish health care for decades to come. Major governmental reforms and proposals have already emanated from it.

Organization

In 2020 the Centre continued with the Institute for Health and Care Sciences at the Sahlgrenska Academy as the host institution, and Professor Joakim Öhlén as Centre Director. The Steering Committee has held 14 meetings during the year and its members are listed in the appendix. A major focus for the Steering Committee was planning for the strategic development of the Centre with the goal of developing a plan for the Centre following the ongoing period as a GU Centre, to facilitate the continuation from July 2022 onwards. In addition, a handful of research seminars primarily focused on the four research domains in terms of the desired future horizon for the centre. As a result of the strategy work, planning for new research was initiated. The close collaboration of the Grants and Innovation Office, with Dr Tina Verolin as a member of the Steering Committee is advantageous, and has during the year resulted in, amongst other things, safeguarding agreements as related to utilization of knowledge products stemming from research at the Centre.

The research programme of four closely interrelated domains (as updated in 2019) was kept to contribute with knowledge about person-centred care as related to a) theoretical and practical development, b) evaluation and measuring, c) implementation organization leadership and governance and d) learning and education. To this, the Person Council for patients and carers, with 10 members, further contributed strategically from a patient and family carer perspective. Because of the pandemic, almost all research support with activities across projects were performed online.

GPCC in numbers

Year of establishment	2010
Researchers (including PhD students, assistants)	107
Faculties represented (Researchers from UG)	7
Institutes at Sahlgrenska Academy represented	5
External universities represented; Principal investigators	3
Annual PhD course in philosophy and ethics of the person	Since 2011
A Person Council; user involvement of patients and carers	Since 2016
Research projects (total)	
- on-going projects	26
- completed projects	44
- of which testing interventions	25
Original articles published in scientific journals	
- in total; since 2010	606
- during 2018	64
- during 2019	74
- during 2020	69

External evaluations

2015 Swedish Research Council	Performance: Good Strategy: Excellent Added Value: Excellent/Good
2019 External half-time evaluation of the centre	High quality achievements; the multidisciplinary combinations extend what is recognized nationally in health care research
2020 RED 19 (University of Gothenburg)	High-quality research with larger complex interventional studies, implementation and utilisation studies, and the usage of outcome measures that facilitate comparison with other research

Financial report

For the financial year 2020, the Centre for person-centred care received SEK 22.3 million in grants directly via the government approval document to University of Gothenburg. In addition, the principal co-financed the centre with SEK 4.3 million, which gave a total allocation of SEK 26.6 million. In addition to this budget, the projects utilized external funding handled by the principal investigators' primary affiliations, and these are not included here.

In the budget process, it was also decided to use part of the balanced capital before 2020. The budget for 2020 was therefore set at costs of SEK 27.7 million.

The budget was distributed according to the following items:

	SEK thousand
Ongoing projects	15 651
Doctoral students	1 732
Postdoctoral researchers	1 911
Assistants	224
Overall business	6 158
Incentives	1 174
Buffer	900
Total:	27 750

The amount for the ongoing projects was divided between twenty-six different projects. The project *Person-centred patient public private partnership* received SEK 1.9 million. *National and regional governance of person-centred care* received SEK 1.3 million. Subsequently, three projects were financed to an amount of SEK 1 million each; Support for a person-centred toolbox, *Effects of an opioid free person-centred care pathway for patients undergoing obesity surgery*, and *Person-centred care as an evolving field of research; a mixed-methods systematic review*. Five projects received funding between SEK 700,000 - SEK 1 million. The remaining projects financing was below SEK 700,000.

The centre ended the year with a surplus of SEK 900,000, which is to be compared with a budgeted deficit of SEK 1.7 million. The operating costs were lower than the budget. The reason for the surplus is several. The costs of the anniversary conference were lower than budgeted. Some recruitment has taken longer than expected and decisions regarding new so-called incentive projects have been postponed to the future after the steering group did not grant any project funds in the spring application round.

On January the 1th 2020, the balanced capital of the centre amounted to SEK 2.1 million. Balanced capital at the end of 2020 amounted to SEK 3 million. The difference of SEK 900,000 thus corresponded to the positive result for the year.

Members of the GPCC Steering Committee in 2020

Chair, Joakim Öhlén, Professor in Nursing, PhD in Health Care Pedagogics, RN, the GPCC Centre Director.

Representative of the host Institute, Karin Ahlberg, Associate Professor, Institute of Health and Care Sciences, Sahlgrenska Academy.

Eric Carlström, Professor in Health Care Sciences specialized in Management, Sahlgrenska Academy, PhD in Public Administration.

Representative of junior researchers, Birgit Heckemann, postdoc, , Sahlgrenska Academy.

Patient representative, Håkan Hedman, chair of the National Kidney Association, Honorary Doctor and member of the Council for Research Ethics at the Sahlgrenska Academy, chair of the GPCC Person Council for patients and carers.

Lead of the research domain theoretical and practical development of person-centred care, Eva Jakobsson Ung, Professor in Nursing, Institute of Health and Care Sciences, Sahlgrenska Academy.

Lead of the research domain pedagogics and education in person-centred care, Mari Lundberg, Professor in Physiotherapy, Institute of Neuroscience and Physiology, Sahlgrenska Academy.

Lead of the research domain measurement and evaluation of person-centred care, Philip Moons, Professor in Nursing, Institute of Health and Care Sciences, Sahlgrenska Academy, and Professor of Healthcare and Nursing Science at the Department of Public Health and Primary Care of the KU Leuven – University of Leuven, Belgium. He completed his assignment in December 31 and will continue as a scientific adviser.

Research advisor, Karl Swedberg, Senior Professor in Cardiology and Health Care Sciences at the Sahlgrenska Academy, and Professor in Cardiology at the Imperial College, London, UK. He completed his assignment in December 31 and will continue as a scientific adviser.

Charles Taft, Associate Professor in Psychology at the Sahlgrenska Academy; completed his assignment in December 31.

Lead of the research domain implementation, organization, leadership and governance of person-centred care, Lars Wallin, Visiting Professor at the Sahlgrenska Academy, and Professor in Nursing and Centre Director at the Centre for Knowledge Implementation and Patient Safety at Dalarna University, and Director of Research in Region Dalarna. He completed his assignment in December 31 and will continue as a scientific adviser.

Lead of utilization and innovation, Tina Verolin, Innovation Advisor, Grants and Innovation Office at the University of Gothenburg.