



ANNUAL REPORT 2021
**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, annually 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 target group in the population is people with long-term conditions.
- 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 is a key feature, and a *Person Council* provides advice and validates GPCCs' activities and research from patient and family carer perspectives.

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. A half-time evaluation of the centre was performed in 2019.

Added academic value

All the research collaboration continues to result in added academic value with increased exchange between disciplines and research areas. During 2021 there were 22 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. External national and international co-investigators and other collaborators were supported by the Centre organization. In January 2021, new projects were initiated based on strategic discussions in 2020. Two projects are triggered by the ongoing pandemic; one will connect macro, meso and micro levels to develop healthcare systems for sustainable person-centred care and another will investigate person-centred care in time critical situations such as pandemic or other societally challenging situations. A third new project launches a research line into partnership with patient and family representatives in healthcare organisations and decision-making. As a result, a mapping of the literature about patient engagement and participation in healthcare organisations and decision-making is ongoing. An initiative for collaboration with new projects within GU that became affiliated to the GPCC was initiated and this includes for example a national implementation of a patient-reported quality of life system to minimize burden on patients while increasing accuracy in the measurement.

The research domain of learning and education of person-centred care (initiated in 2019 following the centre's half time evaluation as well as the RED 19 evaluation) became further established. Another recently initiated field with important progress is a project with an analysis of prerequisites for person-centred care in Swedish healthcare legislation. It is led by a researcher from the Department of Law.

Further, there are ongoing PhD projects involved in programmes for double degrees with KU Leuven in Belgium.

In terms of research output 83 original articles were published. Three key publications from 2021 can be mentioned. First, a model for how to test cost containment of person-centred initiatives developed within the European collaboration *CostCare* (Swedberg et al, 2021, *Health Science Reports*, 4, e309), and secondly a multi-centre evaluation of person-centred care provided through a platform combining digital and telephone support for people with cardiac failure and COPD, which contributes to the effects of operationalizing ethics to a person-centred care intervention (Ali et al, 2021, *Journal of Medical Internet Research*, 23, e26794). Thirdly, the field of person-centred communication in paediatric care was elaborated in a position paper to influence future clinical development and research (Thunberg et al, 2021, *Nursing Inquiry*, e12426).

Other publications are related to cost-effectiveness evaluation of person-centred care interventions, and informal care and peer support for old people. Adaptation of person-centred care for children were related to the context of school nursing and children with long-term conditions transitioning from paediatric to adult healthcare services. Further, adaptation of person-centred care approaches for specific professional groups focused on physiotherapists and pharmacists. Additionally, some publications contribute to prerequisites for the implementation of person-centred care, including outsourcing and back-sourcing healthcare services in the public sector. Study protocols for clinical intervention studies are increasingly published in international journals.

As related to the Covid-19 pandemic there were both national and international studies published into children's and adolescents' perspectives of vaccination against and mitigating the spread of Covid-19 as well as their health literacy related. A review investigated healthcare professionals' nudging to improve treatment of patients with Covid-19.

Research seminars (i.e. webinars) continued as a core activity for colleagues across research groups as well as with external participants, leads of the research domains and the centre's philosophical adviser Professor Bengt Kristensson Ugglå. The networks of junior researchers and doctoral students respectively also continued as well as the research amanuensis programme. All these activities became important to support interdisciplinary exchange and collaboration. Impact from the coronavirus pandemic continued in year 2021, although mild restrictions for clinical research during the summer and autumn. Clinical feasibility was restricted for some projects, while the majority of the projects could follow set plans (that sometimes already were adapted to the pandemic in year 2020).

Collaborations

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. To further facilitate the implementation of person-centred care a new project was initiated in collaboration with the *Swedish Institute for Standards* to explore feasibility of the European standard "Patient involvement in health care – Minimum requirements for person-centred care", which was initiated in 2020 and led by representatives from the GPCC both on the national and European level. Additional collaboration was initiated with *Research Institutes of Sweden (RISE)*; also with the purpose of disseminating the standard.

We have continued linking the knowledge development at the centre to the integration of person-centred approaches in Swedish healthcare policy and the changing healthcare landscape striving for local healthcare to all citizens (in Swedish *Nära vård*). Researchers and patient partners have participated in national seminars to this change, including collaboration with Swedish Association of Local Authorities and Regions (SALAR) (*Sveriges Kommuner och Regioner*). Representatives from the GPCC were invited to and participated in public events (organised by e.g. SALAR and National Board of Health and Welfare) and commenting on governmental inquiries. Researchers from the

GPCC led a webinar as part of the Almedalen week on circumstances for the transitioning to person-centred care in Sweden and Europe.

Collaboration with the *Swedish Disability Rights Federation* (an umbrella organisation for patient organisations) resulted in a collaboratively performed series of seminars for patient representatives about person-centred care, which became successful to increase research-based knowledge and awareness in Swedish patient associations. Patient partners, educators and researchers from GPCC developed and performed the seminars, which became successful and appreciated by the participants.

European collaboration continued in several ways. The *CostCare* network, initiated and chaired by the GPCC through an EU funded COST Action involving 28 European countries peaked with several publications on how to design and evaluate person-centred care in different European countries with varying healthcare systems. The network continued to generate knowledge how future healthcare could be developed to deliver high quality care and at the same time be affordable for both individuals and the society at large. The patient, public, private partnership platform for person-centered policy labs and test beds (the PCP4) has increased and deepened the partnerships included and has ongoing supportive projects. Their activities included planning for reorganizing the previous non-profit company *GPCC Implement to PCP4 SVB*; rules and instructions are to be completed with the owner *GU Venture*. Further, the scope of PCP4 that started as a Swedish collaboration, was broadened by means of collaboration with Denmark and a plan for a collaborative interregional application next year.

Additional international collaboration pertains to the centre's participation in the international Community of Practice for Person-centred practice (ICoP PCP; hosted by Queen Margaret University, Edinburgh) for academics and practitioners became alive with digital meetings (after being put on hold due to the pandemic in 2020). Further, a GPCC project group continued collaboration within South Africa–Sweden University Forum (SASUF). The centre was represented by keynote speakers: at the 24th International Philosophy of Nursing Conference hosted by University of Gothenburg two keynote speakers (Drs Inger Ekman and Bengt Kristensson Ugglå), and at the annual conference of the International Society for Quality of Life organized in Calgary, Canada as well as in the 3rd International Colloquium on the Philosophy of Caring – Person-centered care, Coimbra, Portugal one keynote speaker respectively (Joakim Öhlén).

Special activities during the year were focused on the final evaluation of the GPCC for the ongoing period as a university centre. For this purpose, series of seminars were arranged internally, but also with participation of external collaborators who also were represented for the final evaluation. For the final evaluation two external evaluators were recruited: Professor Stuart Logan from University of Exeter in UK and Professor Gerd Ahlström from Lund University. All these activities became important for team building as well as reconciliation and critical reflection upon achievements and needs for further development.

Organization

In 2021 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 13 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 for a new period as a centre starting in 2022, to facilitate the continuation from July 2022 onwards. An important part of this work was the planning for the final evaluation by two external reviewers, compiling the centre's self-report and renewal of the research programme and centre strategies related. Additionally, this involved planning for composition of the GPCC Steering Committee members and scientific advisors for the coming six years period. Further, the Person Council with 10 members representing patient and family carer partners, also contributed strategically from patient and family carer

perspectives. As a result of restrictions related to the pandemic, almost all research support for projects as well as administrative and leadership meetings were performed online.

The research programme of four closely interrelated domains (as updated in 2019) guided the research 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. However, strategies were also developed in order to plan for an additionally coming six-years period as a centre, which meant considerations for initiatives to facilitate future goals for the centre.

The close collaboration of the Grants and Innovation Office, with Dr Tina Verolin as a member of the Steering Committee was terminated by the end of the year. This was due to limited resources at the Grants and Innovation Office. To compensate for this change, the Steering Committee already have two members with expertise in knowledge utilization; Ulf Petrusson from the School of Business, Economics and Law and Axel Wolf from the Sahlgrenska Academy. The junior researcher representative Birgit Heckemann completed her period as a steering committee member and a new junior researcher to start in year 2022 was recruited.

GPCC in numbers

Year of establishment	2010
Researchers (including PhD students, assistants)	c. 150
Faculties represented (Researchers from UG)	7
Institutes at Sahlgrenska Academy represented	5
External universities represented; Principal investigators	4
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	22
- completed projects	48
- of which testing interventions	27
Original articles published in scientific journals	
- in total; since 2010	677
- during 2018	64
- during 2019	74
- during 2020	69
- during 2021	83

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
2021 External final evaluation of the centre	Excellent record of achievement.

Financial report

For the financial year 2021, the GPCC received SEK 22.7 million in grants directly via the government approval document to University of Gothenburg. In addition, the vice chancellor co-financed the centre with SEK 4.4 million, which gave a total allocation of SEK 27.06 million. The grant increased by SEK 458,000 compared with 2020. 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 2021. The budget for 2021 was therefore set at costs of SEK 28.9 million.

The budget was distributed according to the following items:

	SEK thousand
Ongoing projects	15 904
Doctoral students	2 195
Assistants	330
Overall business	6 358
New projects	4 100
Total:	28 887

The amount for the ongoing projects was divided between twenty-two different projects. The project *Person-centred patient public private partnership* received SEK 2.4 million. The projects *IHOPE*, *Review of person-centred care* and *Support for a person-centred toolbox* received a grant of just over SEK 1 million each. Subsequently, two projects were financed to an amount of SEK 1 million each; *Effects of an opioid free person-centred care pathway for patients undergoing obesity surgery*, and *Medicine taking*. Seven projects received funding between SEK 500,000 - SEK 800,000. The remaining projects financing were below SEK 500,000.

Provisions for new projects were distributed during the year to five different projects;

- Dissemination of the CEN standard
- Facilitating the transition to person-centered care
- Collaboration with patient and family caregiver representatives in authorities, health care and research
- Sustainability of person-centred care systems in critical events such as societal stress and disasters
- Connecting the macro-, meso- and micro levels to develop systems for sustainable person-centred care

The centre ended the year with a surplus of SEK 3 million which is to be compared with a budgeted deficit of SEK 1.65 million. Surpluses are found primarily in the new major projects that were started up during the latter part of the year and which also will run during 2022. Funds set aside for project support have not been consumed either. These effects are primarily related to consequences of the pandemic. The costs for the ongoing projects, on the other hand, are in principle according to budget.

On the 1st of January 2021, the balanced capital of the centre amounted to SEK 2.8 million. Balanced capital at the end of 2021 amounted to SEK 5.8 million. The difference of SEK 3 million 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.

Hanna Gyllensten, Associate Professor in Health Care Sciences, Institute of Health and Care Sciences, Sahlgrenska Academy; initiated her assignment on January 1.

Representative of junior researchers, Birgit Heckemann, postdoc, Sahlgrenska Academy; completed her assignment in December 31.

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 learning and education in person-centred care, Mari Lundberg, Visiting Professor, Institute of Health and Care Sciences, Sahlgrenska Academy, and Sophiahemmet University, Stockholm.

Lead of utilization and innovation, Tina Verolin, Innovation Advisor, Grants and Innovation Office at the University of Gothenburg; completed her assignment in December 31.

Axel Wolf, Associate Professor in Nursing, Institute of Health and Care Sciences, Sahlgrenska Academy; initiated his assignment on January 1.