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# **ANNUAL REPORT 2022**

## **University of Gothenburg Centre for Person-Centred Care – GPCC**

[www.gpcc.gu.se](http://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 of Health and Care Research. Every year since then, 100-150 national and international researchers from various disciplinary backgrounds have collaborated in forming the GPCC as a national centre of excellence in person-centred care. As a governmentally funded strategic research area, the GPCC was evaluated by the Swedish Research Council (VR) in 2015. In 2016 and 2021, the application for renewed six-year periods as a university centre was approved by the vice-chancellor. This means a new period was initiated in July 2022 with a renewed research programme.

Building on the initial *vision* of sustainable health through sustainable health care – to prevent and decrease suffering and to strengthen the efficiency of health care through person-centred care, the vision for the new period is *to become the internationally leading platform for collaboration-based research and utilization regarding person-centred health care*. Followingly, the goal is to become a European hub for research, education, innovation and utilization for the transitioning of health care to person-centred care. Within five years, the GPCC intends to be the natural interlocutor for person-centred care within the EU and the WHO. Special features include developing and applying successful strategies that support synergies between research, education, innovation and dissemination, and implementing a range of strategies for user involvement with a *Person Council* providing advice from patient and family carer perspectives for the GPCC's activities and research.

## Added academic value

All the research collaboration continues to result in added academic value, with increased exchange between disciplines and research areas. During 2022 there were 37 projects in progress, of which four short-term focused utilisation projects, 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.

Following the new period as a centre, the multidisciplinary research is organized in three related strategic focus areas aiming at: (i) developing, adapting and evaluating person-centred care, (ii) enabling the transition to person-centred health care and care and (iii) developing partnerships between patient representatives/the general public and healthcare organizations. Central dimensions in all three areas are the concretisation of the ethics of the person, the promotion of health, equality and diversity perspectives, collaboration, learning and digitalisation. The primary target group in the population consists of people with long-term illnesses and failing health and their family carers. This renewed research programme is both a continuation and renewal of the previous research programme, aimed at strengthening its impact. However, the third strategic research area is completely new for the centre: developing partnerships between patient representatives/the general public and healthcare organizations.

New research projects have been initiated: six new research projects and seven doctoral student projects, all of which are primarily related to one of the three strategic focus areas. Additional new research projects also became affiliated to the centre. In this way, the research continues to concretize practical interprofessional approaches to person-centred care with starting points in ethics and philosophy of the person, and evaluates this in comprehensive high quality research designs, including

effect and process evaluations. For future strategic development, a forward view project was initiated regarding the prospects for future development of health care in relation to person-centred care. Here, views from different stakeholders were obtained in a series of workshops.

In terms of research output, four PhD students graduated, and 86 original articles were published. These publications are related to the structure of the domains in the previous research programme, and most concern the theoretical and practical development of person-centred care (a total 46 articles). Two articles were highlighted by the journals respectively: ‘Epistemic injustices in clinical communication: the example of narrative elicitation in person-centred care’ (2021 in *Sociology of Health and Illness*, 43, 186-200 by Öncel Naldemirci and colleagues) and ‘Being heard–Supporting person-centred communication in paediatric care using augmentative and alternative communication as universal design: A position paper’ (2022 in *Nursing inquiry*, 29(2), e12426) by Gunilla Thunberg and colleagues. Both of these exemplified the GPCC’s research efforts for the theoretical and practical development of person-centred care to counteract inequity in health care, as well as for tailoring such practices to children and young people. An effect evaluation (RCT design) of a person-centred eHealth intervention for people on sick leave due to mental disorders showed a significant difference in favour of the intervention group, largely due to increased self-efficacy (Cederberg et al. “Effects of a Person-Centred eHealth Intervention for Patients on Sick Leave Due to Common Mental Disorders, PROMISE Study: Open Randomized Controlled Trial” *JMIR Mental Health* 2022;9.3: e30966). In addition to other evaluation and measurement studies, there were six process evaluations of interventions and four person-centred care implementation research articles, illustrating the breadth of the research, including real world practices of person-centred care (Fridberg et al “Tracking, naming, specifying, and comparing implementation strategies for person-centred care in a real-world setting: a case study with seven embedded units” *BMC Health Services Research* 2022;22:1-18). Further, five articles contributed by examining the impact of the COVID-19 pandemic on people’s everyday lives and its social restrictions for both adults and children. This is an example of researchers’ agility in responding to societal events.

Research seminars (hybrid format to facilitate easy access) 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 Uggla. Both networks of junior researchers and doctoral students also continued, as did the research amanuensis programme. All these activities became important in supporting interdisciplinary exchange and collaboration. The impact of the coronavirus pandemic lessened in 2022, only restricting clinical feasibility in exceptional cases.

## 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 projects within academia and society at large in Sweden, Europe and further afield. The implementation of person-centred care as related to the European standard “Patient involvement in health care – Minimum requirements for person-centred care” was included in the priorities, as it builds on the GPCC approach to person-centred care and colleagues from the centre led the committees that contributed to it being agreed upon at EU level. Previous collaboration with the *Swedish Research Institute* has continued, with additional collaboration initiated with *Research Institutes of Sweden* (RISE) to further facilitate the development and piloting of a certification process based on this European standard.

A clinical training programme in person-centred care, building on the GPCC learning and education programme *Mutual Meetings*, was initiated by GPCC researchers in the Democratic Republic of the Congo. The course participants came from a variety of professions, such as midwives, nurses and physicians. The researchers can report the course was very positively received, with great commitment, and has the potential for great future impact. Moreover, it contributes to the *Mutual Meetings* with additional learning modules about adapting person-centred care for people who have experienced sexual violence.

Additional international collaboration includes the centre's participation in the international Community of Practice for Person-centred practice (ICoP PCP; hosted by Queen Margaret University, Edinburgh), as well as the project collaboration within South Africa–Sweden University Forum (SASUF). The patient, public, private partnership platform for person-centred policy labs and test beds (the PCP4) has increased and deepened both the partnerships and collaboration with Denmark, and includes a proposal for Interregional EU funding for a Nordic project including Norway, Sweden and Denmark within the area of home dialysis.

Collaborations have also aimed at linking 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 concerning this change, including collaboration with the 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 the National Board of Health and Welfare) and commented on governmental inquiries. Researchers from the GPCC led seminars as part of the Almedalen week, which looked at the development of health care in relation to person-centred care. A utilisation project aiming to create concrete support for person-centred interaction/conversations was initiated in a partnership between GPCC and SALAR. Additional collaboration with The Swedish Health and Social Care Inspectorate focused on their development of an observation method for person-centred practice to be used in their exercise of authority. The centre also started up collaboration with Funktionsrätt Sverige within their EUPATI programme, a European initiated programme for increased patient participation in research and development of medicines, medical technology and clinical studies. A GPCC funded PhD project is also involved.

Further, the GPCC's web pages on research results and tools were updated, as was the Centre brochure. In addition, a short animated film about Person-centred care was developed by researchers and members of the Person Council at the GPCC, along with faculty members of the host department, the Institute of Health and Care Sciences.

## Organization

In 2022, the Centre continued with the Institute of Health and Care Sciences at the Sahlgrenska Academy as the host institution, with Professor Joakim Öhlén as Centre Director. The Steering Committee has held 12 meetings during the year and its members are listed in the appendix. Ida Björkman became the new junior researcher representative, and Jana Bergholtz, researcher at the Institute of Health and Care Sciences and patient representative, Inger Gjertsson from the Institute for Medicine, and Tomas Lindroth from the Department of Applied Information Technology also became new members. Philip Moons, professor KU Leuven in Belgium, and Lars Wallin, professor at Dalarna University in Sweden continued as scientific advisors, while Bengt Kristensson Uggla, professor at Åbo Akademi in Finland continued as philosophy advisor. Previous centre director Inger Ekman continued together with Karl Swedberg and Håkan Billig as internal scientific advisors; all professors at the University of Gothenburg. David Edvardsson, professor at La Trobe University in Australia, Maria Santana, Associate Professor at University of Alberta in Canada, and Richard Sawatzky, professor at Trinity Western University in British Columbia, Canada all became new advisers. Anneka Knutsson, former Chief for Sexual and reproductive health at the United Nations Population Fund in New York, USA became Global health and health care advisor. All these new members of the GPCC Steering Committee and the advisors were introduced for the new six-year period. Research support for projects, as well as administrative and leadership meetings, gradually switched from online only to a hybrid format.

Knowledge utilization continued as a strategy and feature. A major focus for the Steering Committee was planning for the strategic development, as related to a new period as a centre. An important part of

this work was launching the renewed research programme and related centre strategies, and this included a major focus on the annual centre retreat. Priorities were given to the strategic leadership of the strategic focus areas. A new initiative was planning for an international conference: the Global Conference on Person-Centred Care will be organised by the GPCC in spring 2024. Detailed planning to follow.

The Person Council, with 10 members representing patient and family carer partners, continued to contribute strategically from patient and family carer perspectives. Strategic work focused on optimising the Person Council's collaboration within the centre and its meeting structure. The work of the Person council was, for example, presented at *VA: Public & Science's* 20<sup>th</sup> Anniversary celebrations in Stockholm. Members of the Person council also contributed to various research and utilization projects at the centre in a number of ways.

## GPCC in numbers

Year of establishment	2010
Researchers (including PhD students, assistants)	appr. 150
Faculties represented (Researchers from UG)	7
Institutes at Sahlgrenska Academy represented	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) in 2022	
- ongoing projects	23
- completed projects	8
- new projects initiated	11
Original articles published in scientific journals	
- in total, since 2010	763
- during 2018	64
- during 2019	74
- during 2020	69
- during 2021	83
- during 2022	86

## 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 2022, the GPCC received SEK 22.9 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 27.3 million. The grant increased by SEK 286,000 compared to the previous year.

In the budget process, it was also decided to use part of the balanced capital before 2022. The budget for 2022 was therefore set at costs of SEK 29.4 million. In the spring there was an invitation for new projects, and additional project funds of SEK 2.9 million were allocated, which gave a costs forecast for 2022 of SEK 32.3 million or a deficit of SEK 5 million.

The budget/forecast was distributed according to the following items (SEK thousand):

Ongoing projects	21 236
Doctoral students	502
Assistants	235
Overall business	7 437
New projects	2 946
<b>Total:</b>	<b>32 356</b>

The amount for the ongoing projects was distributed between 23 different projects. PCP4 received SEK 2.6 million. The Review and IHOP projects were financed with SEK 1.4 million each. Subsequently, seven projects were financed to an amount of approximately SEK 1 million each. Six projects received funding between SEK 500,000 and SEK 800,000. The remaining projects were financed below SEK 500,000. As a result of the invitation for new projects, four doctoral projects, six research projects and four utilisation projects were initiated. The doctoral and research projects will also run in 2023. The utilisation projects, on the other hand, were completed in 2022.

The centre ended the year with a surplus of SEK 1.7 million, which is to be compared with a budgeted deficit of SEK 5 million. Surpluses can be found in both ongoing and new projects. The project support and the funds set aside for a new doctoral student were also not consumed.

On 1<sup>st</sup> January 2022, the balanced capital of the GPCC amounted to SEK 5.85 million. Balanced capital at the end of 2022 amounted to SEK 7.55 million. The difference of SEK 1.7 million thus corresponded with 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.

Jana Bergholtz, PhD, Researcher and Patient Representative, Institute of Health and Care Sciences, Sahlgrenska Academy. Lead for the strategic focus area developing partnerships between patient representatives/the general public and healthcare organizations.

Representative of junior researchers, Ida Björkman, Assistant 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.

Inger Gjertsson, Professor in Rheumatology, Institute for Medicine, Sahlgrenska Academy.

Hanna Gyllensten, Associate Professor in Health Care Sciences, Institute of Health and Care Sciences, Sahlgrenska Academy. Lead for the strategic focus area developing, adapting and evaluating person-centred care.

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.

Tomas Lindroth, Associate Professor in Applied Information Technology, Department for Applied Information Technology, Information Technology Faculty. Lead for the strategic focus area developing, adapting and evaluating person-centred care.

Eva Jakobsson Ung, Professor in Nursing, Institute of Health and Care Sciences, Sahlgrenska Academy, vice chair of the GPCC Person Council for patients and carers.

Mari Lundberg, Visiting Professor, Institute of Health and Care Sciences, Sahlgrenska Academy, and Professor at Sophiahemmet University, Stockholm. Lead for the strategic focus area enabling the transition to person-centred health care and care.

Ulf Petrusson, Professor, Department of Law, School of Business, Economics and Law. Lead for the strategic focus area enabling the transition to person-centred health care and care.

Axel Wolf, Professor in Nursing, Institute of Health and Care Sciences, Sahlgrenska Academy. Lead for the strategic focus area developing partnerships between patient representatives/the general public and healthcare organizations.