

ANNUAL REPORT 2023

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 of Health and Care Research. Every year since then, 100-200 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 further strengthen our position to be a leading European hub for research, education, innovation and utilization for the transitioning of health care to person-centred care. Within four 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 implementing a range of strategies for user involvement with a *Person Council* providing advice from patient and family carer perspectives for the GPCC's strategies, research and knowledge utilisation. During 2023, three new strategic research initiatives were launched.

Added academic value

All the research collaboration continues to result in added academic value, with increased exchange between disciplines and research areas. During 2023 there were 29 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.

Following the new period as a centre, the multidisciplinary research is organized in three interrelated strategic focus areas aiming at: (i) developing, adapting and evaluating person-centred care, (ii) enabling the transition to person-centred health care and (iii) developing partnerships between patient representatives/the general public and healthcare organizations. Central dimensions in all three areas are the concretisation of ethics of the person, the promotion of health, diversity, equity and inclusion perspectives, collaborative governance, learning and digitalisation. The primary target group in the population consists of people of all ages 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. To further strengthening the research programme, strategic discussions with support from international scientific advisers to the centre resulted in launching new plans towards renewed strategic initiatives to reach the vision for developing collaboration within the EU and the WHO, including person centred governance, medical technology in a digital transition and precision health.

In terms of research output, four PhD students graduated, and 55 original articles were published. During 2023, researchers and research groups had ongoing external funding from VR, Forte, AFA, UN, ALF etc with over 11 million SEK. The patient, public, private partnership platform for personcentred policy labs and test beds (the PCP4) has increased and deepened both the partnerships and collaboration with Denmark, and successfully launched a <u>Nordic collaborative project including</u> <u>Norway, Sweden and Denmark within the area of home dialysis funded with over 30 million sek for the period 2023 to 2025 by the Interregional EU</u>.

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.

During the year, we published 10 newsletters and held over 5 seminars, 3 general centre meetings, and 6 Patient Advisory Council meetings. Some events highlights were:

PCV Research Coffee Sessions: 600 people from across the country participated in the digital seminar series on person-centered care hosted by Region Dalarna and Dalarna University. <u>Watch the popular seminar series on the implementation of person-centered care retrospectively | University of Gothenburg (gu.se)</u>

Almedalen 2023: 1 seminar, 1 workshop, 1 roundtable discussion, and 1 article in Dagens Medicin. GPCC in Almedalen 2023: Broad collaboration and good examples are needed to increase person-centration and patient participation | University of Gothenburg (gu.se).

Perceptions of PCC: 6 illustrations. <u>Perceptions of person-centered care are challenged with humor</u> and evidence in dialogue materials | University of Gothenburg (gu.se)

All these activities became important in supporting interdisciplinary exchange and collaboration.

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 GPCC initiative to arrange the first *Global Conference on Person-Centred Care* (GCPCC) in May 2024 involved intensified conference planning during the year (www.gcpcc.org). The GCPCC will take place as a separate conference in close collaboration with the Nordic e-health event *Vitalis*, and GPCC faculty members and staff also collaborate with the conference organiser bureau Meetx and the Swedish Exhibition & Congress Centre in Gothenburg.

To facilitate the implementation of person-centred care as related to the European standard "Patient involvement in health care – Minimum requirements for person-centred care", which builds on the GPCC approach to person-centred care, a collaborative project between the GPCC and the *Swedish Research Institute* has successfully completed. The next step is to plan for a certification process based on the standard in 2024.

A dialogue was also initiated with the new research school SHIFT CARE, focusing on person-centred integrated care, to collaboratively develop synergy effects between the GPCC and SHIFT CARE.

Additional international collaboration includes continuation of the centre's participation in the project collaboration within South Africa–Sweden University Forum (SASUF) as well as the International Community of Practice for Person-centred Practice (ICoP PCP), and the latter will lead a pre-conference workshop in the next years GCPCC.

In the past year, our collaborative efforts have been geared towards bridging the gap between academic research at our center and the practical integration of person-centered approaches within Sweden's healthcare policies and its evolving landscape, with a particular focus on ensuring access to local healthcare services for all citizens, as embodied in the concept of Nära vård. In pursuit of these objectives, our researchers and patient partners have actively engaged in national seminars, shedding light on these pivotal changes. This includes working closely with the Swedish Association of Local Authorities and Regions (SALAR) (Sveriges Kommuner och Regioner), where GPCC representatives not only participated in various public forums organized by entities such as SALAR and the National Board of Health and Welfare but also offered insights on governmental inquiries.

Notably, GPCC researchers have spearheaded highly acclaimed seminars on healthcare governance during the Almedalen week, specifically addressing the challenges associated with the enforcement of patient laws in Sweden. These seminars were complemented by a workshop dedicated to person-centered communication and a roundtable discussion during the Almedalen week. Furthermore, in collaboration with SALAR, we launched a utilization project aimed at developing tangible tools to facilitate person-centered interactions.

Our partnership with The Swedish Health and Social Care Inspectorate has been another cornerstone of our efforts, focusing on creating an observation method to evaluate person-centered practices, which will serve as a vital tool in their regulatory functions and development of national indicators. Additionally, we have continued our collaboration with Funktionsrätt Sverige as part of the EUPATI program, a European initiative designed to enhance patient involvement in the research and development of pharmaceuticals, medical technologies, and clinical trials. Within this framework, a GPCC-funded PhD project is also making significant contributions.

An additional person responsible for education and dissemination of research has been employed on 10% in 2023 and will be increased up to 20% during the upcoming year.

The utilization project aiming to create concrete support for person-centred interaction/conversations, which was initiated in 2022 as a partnership between GPCC and SALAR, has continued during 2023 and processed during a workshop in Almedalen in June. A collaboration with teachers and students at HDK-Valand - Academy of Art and Design has been initiated as a branch from this project in which design students within a course of embedded design will work on person centred conversations as a case.

A compilation of GPCCs research publications in a shareable database in the software EPPI-reviewer was initiated and worked on during the end of the year and will be piloted in the upcoming year.

Organization

In 2023, the Centre continued with the Institute of Health and Care Sciences at the Sahlgrenska Academy as the host institution. To facilitate a generational shift in the leadership, a new centre director was recruited in the first part of the year. Professor Joakim Öhlén was Centre Director from January to August, and Professor Axel Wolf was appointed new Centre Director in August. He has a strong research expertise in person-centred care as well as in innovation and knowledge utilisation.

The Steering Committee has held 11 meetings during the year and its members are listed in the appendix. Meetings continued to take place in a hybrid format. As related to members of the Steering Committee, Professor Eva Jakobsson Ung sadly and suddenly died in June. At the end of the year three members completed their appointments; Ida Björkman completed her two-year junior researcher appointment, Mari Lundberg to release time for research leadership, and Hanna Gyllensten left the steering committee due to strategic commitments within the GPCC. Two new members were recruited to commence their appointments in 2024: doctoral student representative Stina Mannheimer, specialist dr and PhD student and junior researcher representative Matilda Cederberg, psychologist and PhD. 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 strategic initiatives to further the 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. The planning for the Global Conference on Person-Centred Care that will be organised by the GPCC in spring 2024 continued and intensified during the year.

The Person Council, with 10 members representing patient and family carer partners, met six times during the year, and 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. Members of the Person council continued to contribute 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 2023	
- ongoing projects	30
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- completed projects	6
- new projects initiated	-
Original articles published in scientific journals	
- in total, since 2010	794
- during 2018	64
- during 2019	74
- during 2020	69
- during 2021	83
- during 2022	86
during 2023	55
Internal and external communication and events 2023	
 Whole centre meetings 	3
– Seminars	5
– Newsletters	10

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 2023, the GPCC received SEK 23.2 million in grants directly via the government approval document to University of Gothenburg. In addition, the vice-chancellor co-financed the centre with SEK 4.5 million, which gave a total allocation of SEK 27.7 million. The grant increased by SEK 372,000 compared to the previous year.

In the budget process, it was also decided to use part of the balanced capital before 2023. The budget for 2023 was therefore set at costs of SEK 30.7 million, which gave a c a deficit of SEK 3 million.

(SEK thousand):	
Ongoing projects	14 562
Doctoral students	844
Assistants	0
Overall business	9 619
New projects	5 648
Total:	30 673

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

The amount for the ongoing projects was distributed between twenty different projects. The project that received the largest allocation was PCP4, which received SEK 3 million. Review and MinKod received a grant of SEK 1.3 million each. IHOPe and PicPecc received about SEK 1.2 million each. Five projects received funding between SEK 700,000 and SEK 1 million. The remaining project's funding was below SEK 500,000.

The new projects which started in spring 2022, four doctoral projects and six research projects, turnover close to SEK 5.7 million.

The centre ended the year with a surplus of SEK 1.1 million, which is to be compared with a budgeted deficit of SEK 3 million. Surpluses are mainly within a few ongoing projects. The project support and the funds set aside for two new doctoral students and a new professorship have also not been consumed.

On 1st January 2023, the balanced capital of the GPCC amounted to SEK 7.55 million. Balanced capital at the end of 2023 amounted to SEK 8.64 million. The difference of SEK 1.1 million thus corresponded with the positive result for the year.

Appendix

Members of the GPCC Steering Committee in 2023

Chair person January-July: Joakim Öhlén, Professor in Nursing, PhD in Health Care Pedagogics, RN.

Chair person August-December: 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.

Representative of the host Institute, Karin Ahlberg, 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 (January-June).

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.