

## **Application for a new operating period as a center 2022 - 2028 for The University of Gothenburg Center for person-centred care - GPCC**

The University of Gothenburg Center for person-centred care (GPCC) has since 2010 been successfully established as a national center with an international reputation. GPCC has conducted successful research and innovation, which has been of crucial importance for utilization regarding the development, evaluation and implementation of person-centred care in Swedish health care. During the next center period, GPCC intends to become a leading European hub in line with the University of Gothenburg's (GU) aim to be an international university that takes responsibility for societal development and contributes to a sustainable world. GPCC strives for sustainable health (Goal 3 in Agenda 2030) through person-centred care and the application includes sustainable innovative education programmes and innovations to achieve this goal. These will focus on clinical interventions for person-centred care, enabling the transition to person-centred health care and care in society, and the development of partnerships between patient representatives / the general public and health care organizations. The planned activities will be of great importance to society as their potential knowledge development has been stated as central to the national and international transition of health care towards a care closer to the citizens, which in Sweden is referred to as a "Local care" (SoU 2020:19) and internationally, by for example WHO, is referred to as People-centred care and Integrated care.

### **1. Background**

GPCC was formed in 2010 when GU received funding from the Swedish government's strategic investment in the strategic research area (SFO area) of healthcare research. Through national and international collaboration, more than 100 researchers have collaborated in a multi-disciplinary manner each year, which has established GPCC as Sweden's leading research center for person-centred care. This knowledge development focuses on methods for more efficient use of healthcare resources and patients' ability to handle health challenges. For eleven years, GPCC has successfully contributed to establishing person-centred care as a central concept in health care, which has started a national transition to person-centred care in Sweden. This has received tremendous support from both patient and professional organizations. The fact that person-centred care is regarded as a desired outcome within the Horizon Europe framework programme underlines how extensive the impact has been. In the ongoing national transition work to "Local care" in Sweden, person-centred care serves as a foundation. GPCC has played a central role by contributing knowledge basis for the ongoing transition. Although GPCC has a strong international foothold, an even stronger position internationally will be established in the coming center period, which is in line with GU's vision for *A University for the World*.

GPCC was evaluated in 2015 as an SFO area within healthcare research by the Swedish Research Council. This led to the government's continued SFO funding, which was further strengthened through co-financing by the Vice-Chancellor at GU and external research funds. The current six-year period as a center at GU was approved in 2016. Apart from annual reports, according to rules for centers at GU, a half-time evaluation in 2019 and a final evaluation this summer (evaluators' report, see appendix) were carried out (both by external independent experts).

#### ***Academic added value***

GPCC's international position can be explained by its research that, based on action ethics, develops applicable person-centred practice in multi-professional teams and conducts complex studies that include both effect and process evaluations. The research has so far generated 662 original articles as well as a number of books, book chapters and popular science publications in combination with several digital tools (health portals and educational programmes for patients, staff and family carers) as well as tools that facilitate the implementation and evaluation of person-centred care. A total of

28 doctoral students have completed dissertation projects within the GPCC and the activities have each year attracted a number of national and international postdocs and junior researchers.

### ***Multidisciplinarity***

GPCC has involved researchers affiliated with seven of GU's eight faculties as well as several national and international universities. At present, more than a hundred researchers from various disciplines and fields of science participate. They are active in 35 ongoing projects regarding development, evaluation, implementation and training. The multidisciplinary profile of the research has gradually been updated in order to develop knowledge that contributes to developments in health care, care and society.

### ***Openness***

The Centre activities are characterized by openness to promote multidisciplinary research, innovative forms of collaboration and conditions for utilization. GPCC strives for transparency in decision-making processes. Research leaders, advisors and junior researchers collaborate with representatives of patient organizations, the general public and healthcare professionals and leaders, and increasingly, companies and industry. An inclusive approach has contributed to the success of GPCC's overall operations. In the seminar activities (conducted as hybrid seminars for increased accessibility), researchers from various subject areas, patient and user organizations together with employees mainly active in health care participate. Together with the popular science summaries of projects on GPCC's websites, and other utilization strategies, these activities reflect the activities' efforts to create meetings between different forms of knowledge and actors that represent different perspectives on person-centred care.

### ***Utilization***

GPCC is characterized by having developed evidence-based strategies based on synergies between research, education, innovation and utilization. Projects and activities have contributed to the development of collaboration forms that support person-centred care in health and medical care, education but also society in a broader sense. This has contributed to authorities turning to the GPCC for advice on the development and evaluation of person-centred care. In this way, the GPCC has contributed to the development of policy and priorities on a national level. In 2016, GPCC initiated and led the development of a European standard for person-centred care, a standard that in 2020 was adopted in Europe - *Patient participation in health care - minimum requirements for person-centred care* (SS-EN 17398: 2020). The standard emphasizes the GPCC's international position and influence.

### ***Collaboration***

GPCC has established well-functioning forms of local, regional, national and international collaboration. In these contexts, nationally and internationally leading researchers have been recruited as advisors. We intend to further strengthen our international collaboration and multidisciplinary profile. GPCC runs an extensive patient / user and citizen collaboration that characterizes both research and utilization with an active Person council (the largest of its kind in Sweden) closely involved in the development and validation of the Centre activities. This ensures that patient and family carer perspectives are maintained. GPCC participates in international research networks and has, through the coordination of EU funds, initiated the European network *CostCares for person-centred care*. Other activities include participation in the South Africa – Sweden University Forum (SASUF) for the development of person-centred care for children, adolescents and young adults. In each research project that the GPCC supports, researchers from several different disciplines and patient representatives participate.

## ***Innovative***

The distinctly multidisciplinary profile of research at GPCC is unique in healthcare research in Sweden. GPCC covers, for example, law, humanities, fine arts, applied IT, medicine and care sciences. In 2020, an overview of GPCC's intervention research on person-centred care was published in the journal BMJ (impact factor 39.9), which can be seen as an expression of the strong position that GPCC's research has in the international research community. The research has contributed to the development of innovative and applicable practice approaches and tools for health care as well as knowledge bases for the new European standard (see above, SS-EN 17398: 2020).

## **2. Description of planned activity**

With the following programme, GPCC applies for a new operating period for six years as a center at GU.

### ***Vision***

To become the internationally leading platform for collaboration-based research and utilization regarding person-centred health care.

**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 within the EU and the WHO regarding person-centred care.

### ***Academic added value and multidisciplinary***

During the period 2022-2024 (ie the first part of a new period of activity as a center), multidisciplinary research will be organized in three related strategic focus areas aimed 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.

In all three areas, the concretisation of the ethics of the person, the promotion of health, equality and diversity perspectives, collaboration, learning and digitalisation are central dimensions. The primary target group in the population consists of people with long-term illnesses and failing health and their family carers. Focus areas may be re-evaluated based on the mid-term evaluation for the remaining three years of the new center period.

#### ***I. Development, adaptation and evaluation of person-centred care***

We intend to carry out empirical studies and syntheses of international research on person-centred care of significance for regional, national, international care, treatment and care guidelines. These will include explanatory models for the extent to which person-centred care is generic and can be applied to promote health and reduce ill health, as well as how they can be adapted to specific health and medical care situations and living circumstances (such as ages - children and adolescents and the elderly). Specifically, we intend to contribute with the adaptation of person-centred care to improve continuity in the care chain. We will also have a special initiative to strengthen the ability for person-centering through digitization, such as person-centred med-tech and studies focusing on how AI/Big Data can be utilized. Through this research, the implementation of person-centred care will range from physical meetings between patients and staff to digital practice and tools for person-centred care, both entirely digital care solutions and hybrid practice that combine digital tools with personal care meetings. The implementation will also include collaboration between formal care providers and informal care and care within the family, networks and civil society.

#### ***II. Enable transitioning to person-centred health care and care***

We intend to contribute with knowledge about design, implementation, impact and effects in terms of strategies for implementation of and learning about person-centred care in the health care and

care establishments as well as in professional education. This research ranges from specific measures for health promotion and inclusive health care and care, to studies of the transition to person-centred care at micro, meso and macro levels. The intention is that the research will thus contribute to national, Nordic and European transition to person-centred care in both care in commonly occurring societal situations and in stressful situations (time-critical events, increased work load and deployment of reinforcement resources in for example pandemics and other extensive societal challenges).

### *III. Development of partnerships between patient representatives, the general public and healthcare organizations and decision-making systems*

This part of the research programme is intended to provide explanations for forms of partnership with patients and the general public within healthcare organizations and what can be seen as optimal for favorable decision-making in relation to organizations' assignments. We intend to shed light on the significance that inclusion of patients' and family carers' perspectives, in addition to research-based evidence, can have for decision-making in health care. GPCC has a unique ability to implement this as we have established well-functioning forms of collaboration with national patient organizations and in that we systematically include patient and user participation in the projects.

### **Utilization**

Utilization will involve several target groups. Nationally, the general public, patient representatives, decision-makers, management and employees in health and care, researchers, authorities, companies and national organizations are involved. Internationally, researchers, leaders and those responsible for health care and care, policy makers and patient organizations are involved.

GPCC will host international conferences every two years. These, like the research, will have collaboration as a trade mark, to enable that several knowledge perspectives and actors meet. The research results that will be presented will include an account of and questions about what the results can mean for both the transition to person-centred care and partnerships with patients and the general public within the healthcare organizations. Meetings between persons with different competencies will thereby be promoted for dialogues that can lead to innovation and practical development.

We also intend to attempt to establish an international scientific journal in collaboration with an international publisher with a specific focus on the development and evaluation of person-centred care, with the possibility of parallel publication in several European languages, primarily the EU standard languages English, German, French and Spanish, which today does not exist. Here we also intend to test the possibility of including popular science summaries, in text or as short video presentations.

### **Collaboration**

We intend to further develop forms of collaboration that support person-centred care, between actors that include researchers and universities, patients and the general public, public and private care providers as well as industry and representatives from civil society. This applies to collaboration that supports the implementation of person-centred care, but also development and research as well as platforms and networks that support this.

The analysis tool for identifying both organizational and cultural barriers and factors that enable person-centred care, developed within the *CostCares* project, is a special resource for constructive collaboration development. To achieve the long-term goal of changing health care and care to person-centred practice, we will combine test beds for operation change and a policy lab for system change. These are mainly implemented within GPCC's partner-initiated projects (within the framework of the PCP4 project, ie Person-centred Patient-Public-Private Partnership), which is

supported by the interregional EU-for-project, Nordic Cost Care, which is implemented in collaboration with Aarhus University .

Starting in 2022, GPCC will build a graduate school on person-centred care (application for the upcoming announcement of graduate schools aimed at teachers in health and medical education; Research Bill 2020/21: 60) and apply for the establishment of an excellence center (Research Bill 2020/21 : 60). We intend to develop these initiatives in collaboration with other universities, regions and within existing international networks, as well as in-depth international collaborations. We will here, in particular, use opportunities for collaboration and collaboration support within the university alliance EUTOPIA, which we believe provides special opportunities for international collaboration in the establishment of the planned graduate school (especially based on established collaborations with universities that are part of EUTOPIA). We will also further develop already established educational activities, which for example include a public education dimension through web-based education for patient representatives (collaboration with The Swedish Disability Rights federation, an umbrella organization for patient associations).

GPCC will continue to develop the natural collaboration with the host department, the Department of Health and Care Sciences. This will (in addition to seminars and research, education and utilization activities, which is open to all participating researchers and departments) focus on strategies for research funding and the implementation of faculty positions that strengthen long-term infrastructure in terms of both research and education.

### ***Openness***

Through additional complementary strategies, GPCC will aim to significantly increase its capacity to reach out externally. We already have established strategies for social media as well as seminar and conference activities. In particular, we intend to continue the free access to knowledge such as open data, open access publishing, online training modules ([www.mutualmeeting.org](http://www.mutualmeeting.org)), apps, etc. We plan to strengthen the capacity for communication using digital resources for increased interaction with civil society, business, public sector as well as academia. For example, all our seminars will be hybrid seminars and research results will continue to be available in various forms (including podcasts, digital presentations, etc.). We will also continue to translate our digital resources such as the online education Mutual Meetings ([mutualmeetings.org](http://mutualmeetings.org)) into several languages (in addition to English that already exist) e.g. Spanish and German.

### ***Innovative***

GPCC's researchers, as well as patient and user representatives have shown great creativity and willingness to push boundaries in research, education and collaboration. For example over the years, GPCC, in collaboration with the Röhsska Museum of Design and Crafts, has initiated a vision for the care department of the future (the Ubuntu exhibition, [link](#)), created national reference wards within a Vinnova (Sweden's innovation agency) project, developed the first European standard for patient involvement in person-centred care, created one of Europe's largest academic networks for person-centred care and health ([CostCares](#)) through an EU-funded project, completed postgraduate courses as well as training for patient organizations in person-centred care and established a unique Person Council. We will continue to strengthen the above areas through increased focus on digitalisation in health care, academic education, research and utilization. A special effort will also be made to establish the concept of person-centred medical technology, such as AI, Big Data, mobile applications and various forms of welfare technology.

## **3. The organization of the Center**

### ***Location and organization***

GPCC is located at the Institute of Health and Care Sciences at the Sahlgrenska Academy.

### **Centre Director**

Joakim Öhlén, Professor of Nursing at the Institute of Health and Care Sciences, GU.

### **GPCC's organization**

A steering committee is responsible for strategic leadership. Advisors consist of: i) a *Person Council* with representatives of patients and family carers, together with ii) external and senior scientific advisors. The three strategic focus areas for research are led by researchers, together with the advisors. GPCC has specialized administrative support. To support utilization, there is the non-profit company *PCP4 AB*, which through the university's holding company the *GU Venture* is wholly owned by the university.

### **Steering Committee**

Strategic leadership takes place within GPCC's steering committee, which meets approximately ten times annually. The Center Director is chair of the Steering Committee. The composition of the Steering Committee is characterized by diversity and representation of the many parts of the Center operations. Co-opted members of the Steering Committee are the GPCC's Administrator, Communications Office and Finance Officer. A Drafting Committee supports the Steering Committee with the operational management of the GPCC and prepares matters for the Steering Committee. The Drafting Committee meets approximately 20 times a year and consists of the Centre Director, two researchers who are also members of the Steering Committee and GPCC's Administrator, Communications Officer, Finance Officer and Project Manager for utilization. The Centre Director is the chair. Based on current issues, additional experts are co-opted to the Steering Committee and the Drafting Committee.

A GPCC Junior Research Representative is appointed for two-year periods by the Steering Committee.

#### *Steering Committee members:*

Chair Joakim Öhlén, Professor of Nursing at the Institute of Health and Care Sciences, GU.

Karin Ahlberg, Professor of Nursing and Head of the Institute of Health and Care Sciences, GU, Representative of the host department's leadership.

Jana Bergholtz, PhD in Geoscience, active at the Rare Diseases Sweden and researcher at GPCC, GU, Patient Representative.

Eric Carlström, Professor of Care Sciences with a focus on Leadership and Healthcare Organization at the Institute of Health and Care Sciences, GU.

Inger Gjertsson, Professor of Internal Medicine and Rheumatology at the Department of Medicine, GU.

Hanna Gyllensten, Certified Pharmacist, Doctor of Medicine, Associate Professor of Care Sciences at the Institute of Health and Care Sciences, GU.

Håkan Hedman, Chairman of the Swedish Kidney Association, Honorary Doctor at the Sahlgrenska Academy, GU, patient representative.

Eva Jakobsson Ung, Professor of Nursing at the Institute of Health and Care Sciences, GU.

Thomas Lindroth, Assistant Professor at the Department of Applied Information Technology, GU

Mari Lundberg, Visiting Professor of Care Sciences with a focus on Person-centred Care, GU, and Professor at Sophiahemmet University in Stockholm and Guest Professor of Physiotherapy at Vrije Universiteit, Brussels, Belgium.

Ulf Petrusson, Professor of law at the Department of Law, GU, and Affiliated Professor at Chalmers University of Technology and Director of the Institute for Innovation and Societal Change, School of Business, GU.

Axel Wolf, Associate Professor of Nursing at the Institute of Health and Care Sciences, GU.

The composition of the Steering Committee includes possibilities for future generational change in terms of GPCC's leadership as it includes researchers in varying career stages. If the need arises, the potential exists to recruit new members to the Steering Committee and also to the post of Director. The advisory group includes the former Director and Steering Committee members (see below).

### ***Person Council***

Based on the direction of the organisation, GPCC has a *Person council* with the task of developing and validating GPCC's research and activities from a patient and family carer perspective. The council consists of eleven people with extensive personal experience of health care, as patients and/or family carers. Their combined experience covers a wide range of healthcare specializations. The majority of the members have positions of trust at national level within patient organizations. The council meets about ten times annually, and the members also participate in various activities within the GPCC.

The Chair of the Person council is Håkan Hedman, Chair of the Swedish Kidney Association, Honorary Doctor at the Sahlgrenska Academy, GU. Vice Chair is Eva Jakobsson Ung, Professor of Nursing, GU.

### ***Advisors***

GPCC's operations and strategic management are supported by expertise from external scientific advisors:

David Edvardsson, Professor of Nursing, La Trobe University in Melbourne, Australia. Expert in person-centred care and development and testing of interventions (H-Index = 41; Web of Science).

Maria Santana, Associate Professor of Public Health, University of Calgary, Canada. Expert in patient participation in research and quality of care regarding person-centred care (H-Index = 27).

Bengt Kristensson Uggla, professor i filosofi, kultur och företagsledning vid Åbo Akademi, Finland. Expert inom personfilosofi och etik.

Philip Moons, Professor i omvårdnad vid KU Leuven, Leuven i Belgien samt professor i omvårdnad, GU. Expert inom mätning och utvärdering av kliniska interventioner (H-Index 45).

Bengt Kristensson Uggla, Professor of Philosophy, Culture and Management at Åbo Akademi University, Finland. Expert in Philosophy of the person and ethics.

Philip Moons, Professor of Nursing at KU Leuven, Leuven in Belgium and Professor of Nursing, GU. Expert in measuring and evaluating clinical interventions (H-Index 45).

Richard Sawatzky, Professor of Nursing and Canada Research Chair in Person-centred Outcomes at Trinity Western University in British Columbia, Canada and affiliated with the Institute of Health and Care Sciences, GU. Expert in measuring person-centred care.

### ***Senior Advisors:***

Håkan Billig, Professor, Department of Physiology, GU. Extensive experience of strategic development regarding research, utilization and collaboration nationally (such as VR and SBU) and internationally (H-Index = 45).

Inger Ekman, Senior Professor of Care Sciences at the Institute of Health and Care Sciences, GU. Former Centre Director of the GPCC and internationally recognized expert in person-centred care (H-Index = 37).

Karl Swedberg, Senior Professor of Cardiology and Care Sciences at GU. Expert in research design for evaluation of clinical interventions (H-Index = 120).

Lars Wallin, Professor of Nursing at Dalarna University in Falun. Expert in implementation research in health care (H-Index = 28).

During the coming center period, we intend to attach additional internationally strong advisers to the GPCC.

As utilization is central to the business, we have created a network of advisers in the healthcare system, which includes SALAR, professional associations and patient associations. Internationally, the network includes representatives of, for example, the Universities of Exeter, Plymouth, Dublin, Skopje, Vilnius, Lod, Haifa and others. (28 countries represented through the CostCare network) and from the UN Population Fund.

### ***Management of the three strategic focus areas***

Each focus area is led by a researcher who is a member of the GPCC's Steering Committee together with an additional researcher and one or more of the advisers (see description above). Additional researchers associated with the management of the focus areas are recruited from researchers active within the GPCC.

<b><i>Strategic research focus</i></b>	<b><i>Leader</i></b>	<b><i>Advisor</i></b>
Development, adaptation and evaluation of person-centred care	Hanna Gyllensten Thomas Lindroth	Philip Moons Richard Sawatzky
Enable transitioning to person-centred health care and care	Mari Lundberg Ulf Petrusson	Lars Wallin David Edvardsson
Development of partnerships between patient representatives, the general public and healthcare organizations and decision-making systems	Axel Wolf Jana Bergholtz	Maria Santana

Inger Ekman contributes with overall advice and when needed to all three focus areas in terms of strategic development and evaluation of person-centred care, Bengt Kristensson Uggla in terms of ethics and philosophy of the person, Håkan Billig in terms of strategic research collaboration and Karl Swedberg in terms of research design.

### ***Networks for doctoral students and junior researchers***

GPCC invests in the future of research in person-centred care by promoting career development for junior researchers and providing support for their career development. For this operational period, GPCC, as part of the planned doctoral school, will further develop existing networks for doctoral students and junior researchers.

## **4.GPCC's planned communication**

GPCC has an established website: [gu.se/gpcc](http://gu.se/gpcc)

### ***Internal communication***

The purpose and goal of the internal communication is that everyone involved in the Centre should feel included in a Centre partnership and should have access to the necessary information to be able



to work in a unified direction to achieve GPCC's vision. Furthermore, the purpose is for employees at GU to be aware of the GPCC's focus and activities. Employees at Sahlgrenska Academy should be able to turn to the GPCC with queries regarding person-centred care and patients' and the public's participation in research.

### **External communication**

The purpose of the external communication is to create an interest in and an awareness of GPCC, its activities and research and GPCC's knowledge development about person-centred care. The goal of the external communication is that GPCC should be seen as a hub for research and current development regarding person-centred care and to promote increased collaboration with health care, care, patient organizations, industry, civil society, other researchers and other stakeholders. Furthermore, the goal is to attract successful researchers and funders to take part in GPCC's research.

### **Target groups**

Internal: Researchers and all staff affiliated with the GPCC, employees at the host department and the Sahlgrenska Academy, other employees and students at GU, as well as GU's and SA's management.

External national: Research community, health care and care (staff, managers, decision-makers, administrators), patients and family carers and the general public, politicians, authorities, industry, financiers and the media.

External internationally: The research community, healthcare and care (staff, managers, decision-makers, administrators), patient and related organizations, the general public, politicians, policy makers, industry, financiers and the media.

Communication channels: GPCC's website, Facebook, Twitter, internal and external seminars, news letters, workshops and conferences, meetings, press and media (especially industry magazines), printed matter, advertisements, publications, professional and social networks and GU's and SA's various channels .

## **5. GPCC funding**

The budget below shows forecast revenues and expenses for the next three years. The income is based on an annual government research grant, which derives from previous SFO grants for healthcare research (application 2009). Co-financing by the Vice-Chancellor is based on a resource allocation decision for 2022, with a forecast for 2023-2024. In addition, there are approved external grants from VR and FORTE. We will continue apply for external research grants.

<b>Account structure</b>	<b>Budget 2023</b>	<b>Budget 2024</b>	<b>Budget 2025</b>
Government research grant	23 178	23 424	23 672
Co-financing by the Vice-Chancellor	4 454	4 501	
<b>Total income</b>	<b>27 632</b>	<b>27 925</b>	<b>23 672</b>
Wage costs, of which	-13 787	-12 328	-8 937
<i>Develop, adapt, evaluate PCC</i>	<i>-4 136</i>	<i>-3 698</i>	<i>-2 681</i>

<i>Enable transitioning to PCC</i>	-4 136	-3 698	-2 681
<i>Partnership development</i>	-2 757	-2 466	-1 787
<i>Strategic collaboration development</i>	-1 379	-1 233	-894
<i>Utilization</i>	-1 379	-1 233	-894
Change in holiday debt			
Other staff costs	-451	-459	-467
Doctoral students	-4 009	-5 767	-6 029
Other operating expenses, of which	-2 040	-2 076	-2 114
<i>Develop, adapt, evaluate PCC</i>	-612	-623	-634
<i>Enable transitioning to PCC</i>	-612	-623	-634
<i>Partnership development</i>	-408	-415	-423
<i>Strategic collaboration development</i>	-204	-208	-211
<i>Utilization</i>	-204	-208	-211
Indirect costs	-6 492	-6 602	-5 615
Local costs	-853	-692	-511
<b>Total costs</b>	<b>-27 632</b>	<b>-27 924</b>	<b>-23 672</b>
<b>Total RESULTS</b>	<b>0</b>	<b>0</b>	<b>0</b>

Co-financing from the Vice-Chancellor for 2024 would also mean that salary costs for the three strategic focus areas as well as collaboration development and utilization could continue at the same level as for the first two years.

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