

External evaluation 2021 of the activities of the Centre for Person-Centred Care at the University of Gothenburg, GPCC

Executive summary

Introduction

The external review covers the period from the Centre's establishment in 2010 to June 2021 and is based on the provision of extensive documentation and virtual interviews with both staff, associated researchers, doctoral students and with external collaborators.

The overall goal for the GPCC centre be an international leader in research, innovation and the use of person-centred care. The underlying vision is Sustainable health through sustainable care: Preventing and reducing suffering and strengthening the efficiency in health care through person-centred care.

GPCC is primarily funded by Swedish government's strategic grants with co-financing from the University of Gothenburg, the Sahlgrenska University Hospital and regional stakeholders and is hosted by the Institute for Health and Care Sciences at the Sahlgrenska Academy.

Multidisciplinary, Academic added value, and Cooperation and collaboration.

Overall, the Centre has been extremely successful in meeting these aims for a centre at the university.

GPCC researchers include health care scientists, education and pedagogical scientists, medical scientists, health economists, organisational researchers, and humanists. Current Centre projects engage 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 and numerous regional, national and international collaborators.

The substantial academic outputs from the Centre, involving a huge range of disciplines and methodological approaches point to significant added value.

The Centre has an exemplary record in involving public collaborators, including through the Person Council who have a strong voice in the strategic management of the Centre. They have also established effective links with healthcare providers in both the acute and community sectors and with trades unions representing healthcare workers.

Quality of the research and outputs

Centre-affiliated staff produce high-quality research, published in respected international journals and widely cited. Staff are successful in achieving external grant funding although the Centre recognizes the need to further strengthen this in future years.

The focus on seeking impact on services has led to significant influence on service providers, particularly in the local acute and community healthcare organisations but with wider influence in Sweden. The research and innovative tools produced by GPCC have also had a clear influence on the field in other parts of the world. The evaluators were particularly impressed by the wide range of methods used by the Centre to facilitate the use of person-centred care in multiple contexts.

Not only does the contribution of the Centre to education have a value in itself, the courses provided are an important component of trying to improve services for patients and public. The GPCC contributes to boundary-crossing collaborations in education and knowledge utilization, where cooperation with both public and private actors in society is one of the major features.

The evaluators were also impressed by the clear commitment and carefully structured approach to capacity building amongst staff, students and external collaborators.

Overall assessment

The Centre has an excellent record of academic achievement and of impact on services and health. This is built on a real commitment to multidisciplinary working and collaboration across disciplines and institutions and with members of the public and those who provide services. They have a clear vision for the future and provide evidence of a questioning culture which will help them to remain academically successful and widely influential.

1. Introduction

This external evaluation of the GPCC centre covers the period from the Centre's establishment in 2010 to June 2021, focusing on the last six-period. The external reviewers have thoroughly read a comprehensive package of documents, consisting of policy and strategy plans, applications for strategic research grant and to become a centre at the University of Gothenburg, the programme of the GPCC, research publications, self-evaluations, previous external evaluations (Appendix), and the homepage. Furthermore, the site visits consisted of online meetings with a wide range of people at nine different meetings. The reviewers met leaders from the Sahlgrenska Academy; representatives for the GPCC Steering Committee; the Person Council; principal investigators (PI) for research projects; junior researchers and doctoral students; education and knowledge utilization representatives; centre advisors; collaborating partners; and leaders for regional or national associations.

2. The GPCC centre

The overall goal for the GPCC centre is to work for Swedish healthcare to switch to person-centred care and become an international leader in research, innovation and the use of person-centred care. The underlying vision is *Sustainable health through sustainable care: Preventing and reducing suffering and strengthening the efficiency in health care through person-centred care*.

The financing of the GPCC since 2010 is dominated by the Swedish government's strategic grants (ordinarily 20 million SEK each year) with co-financing from the University of Gothenburg, the Sahlgrenska University Hospital and regional stakeholders. In addition, researchers employed outside the host institution receive external grants for separate projects, and external grants are therefore not exclusively managed by the centre.

The GPCC centre has been evaluated by Swedish Research Council 2015 and by external reviewers in a mid-point evaluation (2019) as well as being included in the review of the research at the University of Gothenburg 2020 (RED 2020). Each of these assessments has rated the research as high-quality. The research programme was updated as a result of the mid-point evaluation into four research domains; 1) *Theoretical and practical development of person-centred care*; 2) *Evaluation and measurement of person-centred care*; 3) *Implementation, organisation, leadership and governance of person-centred care*; and 4) *Learning and education in person-centred care*.

The centre organisational and administrative infrastructure follows the policy for centres at the University of Gothenburg. The host department is the Institute for Health and Care Sciences at the Sahlgrenska Academy.

2:a Multidisciplinarity

Collaboration with researchers from different disciplines has been the primary strategy for supporting and conducting unique and high-quality research on person-centred care and evaluating its implementation in practice. The 100 researchers working and collaborating with the GPCC centre represent varying fields including health care scientists, education and pedagogical scientists, medical scientists, health economists, organisational researchers, and humanists. The 24 ongoing projects engage 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. In addition, the research involves several stakeholders on regional, national and international levels, and emphasis has been given to strategies that support synergies between research, education, innovation and dissemination. The multidisciplinary research context of the GPCC facilitates the realisation of both applied, theoretical, and measurement research.

2:b Academic added value

Since 2010, somewhat more than 600 articles have been published in international peer-reviewed scientific journals and 28 dissertations about person-centred care. This comprehensive knowledge production has been reported in two systematics reviews. An additional value for the area is an increased focus in the last two years on the implementation research of person-centred care in practice.

The dissemination of the multi-disciplinary research has been through open conferences for researchers in Sweden and internationally and for stakeholders and professionals in healthcare. Additional communication strategies used include seminars, workshops and social media. As a result, the GPCC has developed into a regional, national, and internationally well-known and highly respected centre at the University of Gothenburg. In addition, the knowledge translation is effectively promoted through a stable collaboration between research and education facilitated by the host department. Besides integrating person-centred care in the relevant teaching, two specific courses of 7.5 ECTS credits are provided each year, one on master- and one on research-level for doctoral students on person-centred care.

2:c Cooperation and collaboration (local, regional, national and international)

The Person Council was established in 2016 and can be seen as a unique model for other research centres, locally, nationally and internationally. The GPCC's Person Council consists of 10 people with long personal experience in Swedish healthcare, either as a patient or relative. Together with the researchers at the GPCC centre, the council co-creates the meaning of the activities from a patient (i.e. person) perspective and provide comments on designing new research projects.

The GPCC centre has several strategic collaborative projects. CostCares is a European collaborative project with key players participating from 28 EU countries. This project builds upon the previous We-Care project, EU funded and coordinated by the GPCC. Secondly, the International Community of Practice for Person-centred Practice (PcP ICoP) is an international community, mainly of academics interested in advancing knowledge of person-centred practice in care, education, research, management, and policy.

The Swedish platform, the Person-centred Patient Public Private Partnership (PCP4), for research, education and implementation of test-beds is organised in collaboration between universities, patients, healthcare decision-makers, staff and the business community.

The collaboration with experienced advisors on regional, national and international level include a wide range of relevant expertise on designs and methodological issues, EU cooperation and applications, philosophical aspect of person-centredness, strategic and policy issues.

3. Quality of the research and outputs

Overall context

GPCC staff and external collaborators include a number of highly successful academics. A key question for the evaluation is whether being part of the Centre facilitates their production of high-quality work, in other words, does its existence add academic value?

What stands out is the extent to which GPCC has successfully brought together researchers from a wide range academic groups and disciplinary backgrounds, far beyond the traditional disciplines working in healthcare research. This interdisciplinary approach (with academics clearly wanting to move beyond their own disciplinary boundaries) and the widespread links between the researchers and those providing and managing health services, significantly contributes to the breadth of work and its potential impact. We were impressed to see the extent to which this way of working has become the norm for those within and allied to the Centre.

This same ethos is reflected in the extent to which we saw close collaboration between GPCC academics and people from other faculties in the University of Gothenburg, from other Universities and beyond academia. For instance, we were impressed to see collaborations with the Departments of Law and Applied information Technology in addition to the more obvious collaborations with other groups related to healthcare. In our evaluation, we were able to discuss with a wide range of collaborators, including clinicians, health service managers and

senior people from professional organisations, who were overwhelmingly positive about the degree of collaboration and the influence GPCC has had on their work.

A particularly strong component of the organisation and work of the Centre is the degree to which public collaborators are involved throughout. The “Person Council” brings together an impressive group of individuals, many of whom hold leadership positions in national patient organisations. They contribute to the development of strategy, selection of the work programme (through membership of the Steering Committee) and to the management of the organisation. Of note, potential proposals are reviewed by both scientific advisors and patient partners outside of the Steering Committee. In addition, it was clear from conversations with researchers that individual projects routinely recruited patients and members of the public to assist in the design and conduct of research projects.

3:a Research (theoretical and applied research)

Overall, the quality of the research in the Centre is high. A number of explicit strategies are employed to maintain research standards. Since its inception the Centre has recruited visiting professors with methodological expertise who contribute to the design of studies and to the develop of the skills of junior faculty. The seminar programme includes opportunities to explore methodological questions with experts within and from external to the Centre and has been maintained virtually during the pandemic. Potential projects are evaluated by both scientific and patient partners before decisions are made by the Steering Committee.

There are some limitations identified by the Centre with regard to existing research which they plan to address in the future. They identify the need to need to further develop the theoretical framework for PCC and to seek to test its effects at a more macro level, much of the previous research on effectiveness relating to circumscribed populations or services. In addition, they discuss a need to clarify the approach to selection of outcome measures for studies of effectiveness to ensure that these reflect patient needs.

The Centre self-evaluation also points to a desire to employ a wider range of methodological approaches, recognising the challenges posed by evaluating complex and highly context-specific interventions such as PCC. These challenges are illustrated in the systematic review by Gyllensten et al (Health Expect 2020;23(5):1362-1375) of intervention studies that evaluated this approach to PCC. They include 27 intervention studies (of which 12 were RCTs) but most are relatively small and a wide variety of outcomes measures makes it difficult to synthesise results. It is important to say that published papers do already employ an impressively wide variety of methodological approaches including experimental studies evaluating the effectiveness of PCC, qualitative research and theoretical exploration. The inclusion amongst Centre collaborators of academics from diverse backgrounds including ethics and law as well as

traditional healthcare sciences strengths the opportunity to build on this breadth of methodological approaches. One of the strengths of the Centre highlighted within our discussions with external collaborators was the extent to which the Centre's insistence on collaboration across disciplines has influenced researchers from more traditional healthcare research backgrounds to change their approach, including by more explicitly working with patient partners.

The quality of the research is illustrated by the list of publications which documents an impressive volume and quality of outputs. It is important to point to the limitations of citation indices as reflections of quality and indeed many funders and universities have signed the DORA declaration (<https://sfdora.org/>) rejecting their use. Accepting these limitations, the field-weighted citation index associated with these publications does suggest that they are widely read within the field. Reviewing the text of the "10 most significant original articles" we found a pattern of high-quality research, published in internationally recognized journals and reflecting a breadth of scholarship. PCC is an idea which is gaining traction in many countries, but both the conceptual framework and methods for practical use remain contested. It is clear that GPCC research is forming an important component of this debate.

Attracting external grant funding to supplement the core support received for the Centre is essential to produce high-quality research. GPCC reports current research funding from sources including the Swedish Research Council, FORTE, Vinnova (Sweden's Innovation Agency), the Swedish Childhood Cancer Fund, the Diabetes Association, the Childhood Diabetes Fund and EU funding. We note that the total grant funding has increased in recent years. However, the self-evaluation points to a need to further increase the capture of external research grants and this is a central strategic objective for GPCC in the future.

3:b Education and knowledge utilization

The GPCC centre is an multidisciplinary centre contributing to boundary-crossing collaborations in education and knowledge utilization, where cooperation with both public and private actors in society is one of the major features. An academy-wide course at advanced level in person-centred care has been developed and implemented jointly by occupational therapists, physiotherapists, medical and nursing education programmes together with researchers from the Educational Development and Learning and the GPCC.

An elective course on person-centred care on the research level at the Sahlgrenska Academy provides an essential educational structure for knowledge utilization among doctoral students from different disciplines. This course on person philosophy and ethics is the longest standing and has been provided each year. More recently, courses in complex interventions, implementation in healthcare, validation of latent variables and theory of science have been

arranged. All these courses have had participants affiliated to the GPCC but also from other research hubs at GU and several other universities, including international exchange students. In addition, the doctoral students at the GPCC meet regularly in thematic seminars and the themes for the seminars are decided by the network and facilitated by the doctoral students themselves.

Developing and researching pedagogical methods based on the same basic assumptions of person-centredness changes the current teaching methods and places for teaching. Mapping of educational tools has facilitated better knowledge dissemination and aids the work with a study guide for how to practice person-centred care. This mapping is related to the evaluation project of two digital educational strategies, *Mutal Meetings and the Person-centred care game for educations to health professions*. Another project is the mapping of how person-centred care is implemented in Swedish higher education.

The around 100 national and international researchers from different disciplines affiliated with the GPCC function as ambassadors, disseminating the research on person-centred care from the centre in their teaching internal and external. One of the knowledge utilization strategies is to facilitate learning about person-centred care and empower patient organizations through seminars during fall 2021 in collaboration with The Swedish Disabilities Rights Federation.

The academic added value by the GPCC centre is the unique positive knowledge resulting from intervention studies, which provides an outstanding foundation for implementing person-centred care into healthcare and higher education.

An additional academic value to Gothenburg University is expected when the Centre plans to launch a research school in person-centred care research. The GPCC centre is waiting for the announcement of the call mentioned in the governmental research proposition from December 2020. This would strengthen the need for high-quality competence among faculty members involved in teaching person-centred care in the health professionals' education programmes. In the proposition from the Government, a centre of excellence is also mentioned, which is another opportunity for the GPCC to apply.

From the documents and site visits, we see an increased strategic investment during the last two years, when education and knowledge utilization has become a specific research area with a distinct leadership. This research area *Learning and education in person-centred care* supports knowledge development related to health professionals. Facilitating the transition to person-centred care and knowledge utilization is strengthened in terms of staff from the centre participating in development projects in healthcare. In addition, the doctoral students, post-

docs and researchers in other healthcare organisations spread the knowledge of person-centred care and are significant actors of the diffusion of person-centred expertise and practice.

The GPCC centre is an open meeting place for cooperation and collaboration where external parties, as well as members of faculties, are given the opportunity to enter into dialogue and collaboration within the centre's activities. The activities in the non-profit company GPCC Implement (owned by the holding company GU Venture) aim to promote knowledge utilization as part of the project Patient Public Private Partnerships (PCP4). This activity is supported by an Interreg North Sea application, "Inter-Care-Labs" (England / Scotland / Netherlands / Denmark / Sweden), on the development of testbeds and innovations for person-centred care.

The partnership with the Person Council results in an open platform for mutual learning between the patients, family carers and researchers. The current council included persons with extensive experience who lead major national patient organizations and have experience of working directly with government. The result of the open platform is illustrated by an application with a patient partner as PI, for an external grant from a national innovation funder and through recruiting a researcher who is an active member in a patient organization at the national level.

The cooperation with a particular focus on interprofessional education has been supported by a distinct responsible teacher/researcher employed at the host department and this person is also a member of the steering group. In recent years this member represents both the research domain pedagogics and education in person-centred care.

The GPCC collaborates with major national stakeholders through the SALAR organization (in Swedish SKR) in the development of a platform to support person-centred practice in municipality care and the healthcare regions.

All post-docs (partly or fully) financed by the centre were in 2019/2020 offered a mentor, usually a senior researcher within the centre. In addition, the director of the centre has had a yearly meeting with the postdocs/junior researchers and doctoral students, encouraged them to arrange informal network meetings.

International knowledge utilization is promoted through established networks created through the European We-Care and Cost-Care projects and the network for developing the EU standard for patient involvement and minimum requirements for person-centred care. The GPCC has

during this year become connected to the International Community of Practice for Personcentred Practice (ICoP) chaired by Prof Brendan McCormack, UK. GPCC has also initiated work with the WHO and UN regarding developmental issues for person-centred care.

3:c. Impact

Translating person-centred care from theory into practice in a way which benefits patients is an explicit objective of GPCC. It underpins both the development and evaluation of the approach to PCC and the attempt to work with services and those who deliver them to promote its adoption. The challenges associated with implementation, particularly of complex interventions such as PCC, is widely recognised. We appraise that in this area GPCC has achieved considerable success, based on senior staff from Sahlgrenska University Hospital reporting widespread attempts in their service to use this approach. We were also told that there was significant penetration into community-based services in the local region and to some extent in others. However, GPCC staff say that progress has been more limited in other parts of the country although officials from unions representing some healthcare staff did suggest that the GPCC approach was influential in the practice of significant proportions of their members.

The Centre has approached this aim of impact from a number of complementary directions.

i) Education

Education is discussed more fully elsewhere but this is clearly important in the dissemination of this approach to the new generation.

ii) Developing Tools to support and evaluate PCC

We were provided with a useful resource which summarised the multiple tools that have either been developed by the Centre or adapted from research conducted elsewhere.

Many of the tools are designed to facilitate PCC in specific patient groups and particular circumstances while others aim to help clinicians conduct person-centred conversations across patient groups or provide opportunities for providers to learn more about this approach. The other group of tools aim to enable the evaluation of the degree to which services are person-centred. The tools are available in different formats including a number which are digital.

During interviews, it was suggested to us that these tools are important in enabling clinicians and services to develop this approach. The work to develop and evaluate these tools continues, including as part of the PCP4 project involves collaboration between the Västra Götaland Region, Region Blekinge and Region Dalarna, the SALAR (Swedish Association of Local Authorities and Regions), 3 universities, and 3 patient organisations.

iii) Involving clinicians and professional organisations

The Centre has a clear policy of seeking to engage the involvement of clinicians from a variety of backgrounds, partly through educational activities, and through the developed of research projects relevant to specific patient groups. This has led to multiple studies of PCC-based approaches conducted in different patients groups.

We were also impressed by the extent of the involvement of the Centre with staff from trade unions such as Swedish Associations of Health Professionals, Physiotherapists, and Occupational Therapists.

iv) Involving Patient organisations

Current and previous members of the Person Council include individuals in leading positions in different patient organizations, some also acting as patient representatives in healthcare organizations or authorities. These individuals have been able to influence their organisations and members to support the utilization of person-centred knowledge and practice in both civil society and within healthcare.

v) Involving Private sector organisations

GPCC has also sought to involve private sector organisations in this work and has established collaborations with companies including Essity, Dimh/IUS Innovation and Doberman, and pharma companies Novartis and AbbVie, as well as the Swedish Institute for Standards. Of particular note was the involvement with the Chalmers School of Entrepreneurship with regard to bringing person-centredness to innovation with both the public and private sectors.

Overall our sense was that the Centre has had significant influence in promoting this approach to services – more strongly locally than nationally or internationally (though the research is influential internationally within the debate about how best to achieve person-centred care) but with significant penetration amongst clinicians.

3.d Capacity building

Interviews with junior research staff and collaborators from other institutions and organisations revealed an impressive commitment of the Centre to capacity building. As discussed in a previous section there is an active educational programme providing opportunities which cross Faculties. The Centre has an active PhD programme and we were struck by the enthusiasm expressed by past doctoral students now based in other Institutions for maintaining links with GPCC. For junior researchers, we were told that not only was there an active programme of seminars and other opportunities for learning, but a culture of openness which encouraged

them to seek advice and help from senior staff including methodological expertise from those allied to the Centre from other Faculties. In addition to the normal structure of supervisors for PhD students, they and post-doctoral researchers are offered the opportunity to have mentors though not all took up the offer.

Interviewees with health services and the leadership of professional organisations also stressed the willingness of GPCC staff to contribute advice and education to their organisations which was seen as a useful channel for spreading this approach into the broader culture and into service delivery.

4. Recommendations for the GPCC

Our key conclusion is that the Centre has an excellent record of achievement. The suggestions below reflect areas that we believe may be worth further consideration.

1. Further strengthen the national and international collaboration with formal agreements with a few universities and stakeholders in order to increase the impact of evidence-based education and a broader area for knowledge utilisation of person-centredness and person-centred care.
2. An increased focus on gender and equality perspective in person-centredness and person-centred care.
3. An increased focus on research issues related to person-centred care in digital health care.
4. Increase the investment in research on the pedagogic focus of person-centred care and knowledge translation to health care and higher education using digital approaches.
5. Further increase the capture of external research grants which is a central strategic objective for GPCC in the future.
6. We understand the complexities of funding but suggest considering the establishment of a multidisciplinary postgraduate school where doctoral students and postdocs from large and small universities exchange experiences for future knowledge development. This might be based on a model where each higher education institution finances the affiliated doctoral students' salaries and project costs, while the graduate school finances doctoral students and postdoctoral researchers through courses, workshops, network meetings, conferences, and pedagogical assignments for postdoctoral fellows.
7. Plan for the generation change of leadership for the centre at all levels of the organisation.

September 23, 2021



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Appendix



UNIVERSITY OF GOTHENBURG CENTRE FOR PERSON-CENTRED CARE – GPCC

List of Documents for GPCC Final Evaluation 2021

All documents for the final centre evaluation are listed below. The documents are grouped according to the headlines.

The current view of centre activities and achievements may primarily be reflected in the overview of the research programme (document #6), in the centre self-evaluation (document #8a), in the output of research publications (document #7) and in the tools supporting person-centred care practice and education (document #16).

Policy Documents

1. Policy for Centres at The University of Gothenburg (GU)
2. Rules for Centres at GU
3. Administrative procedures for the establishment of centres at GU

Centre Applications

4. Application for a centre at GU in 2016
5. Application for a strategic research centre in 2009

Research

6. Overview of the research programme
7. Research publications

Reports

8. Centre self-evaluations
 - a. 2021 Self-evaluation
 - b. 2019 Self-evaluation (for the centre's mid-term evaluation)
 - c. 2014 Self-evaluation (for the governmental *Strategic Research Areas*)
 9. Annual Reports
 - a. GPCC Annual Report 2020
 - b. GPCC Annual Report 2019
 - c. GPCC reports for 2010-2014
 - d. GPCC in the University of Gothenburg's annual reports 2010-2020
 10. External evaluations
 - a. Mid-term evaluation in 2019
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- b. The University of Gothenburg's *Research for Evaluation* 2019(RED19) in which the GPCC was included in the host institute
 - c. Evaluation of GPCC as a Strategic Research Area in 2015
11. Internal project follow-ups (reports 3 times annually); exemplified with two projects since 2019: the HOPE project, and the PROTECT project (*remains*)

Strategy plans

- 12. Strategy aims and action plan 2017-2022
- 13. Updated action plan from 2019
- 14. Communication strategy plan 2018-2022
- 15. Person Council Handbook

Public, healthcare and higher education knowledge utilization

- 16. Tools supporting person-centred care practice and education
- 17. Education and outreach publications
- 18. European standard *Patient involvement in healthcare - Minimum requirements for person-centred care*
- 19. GPCC Communication and events
- 20. Higher education knowledge utilization

Additional document

- 1. Strategic actions at the GPCC from 2019 to 2022 – supplement to the GPCC Action plan from July 2019 to 2020