GPCC Self-evaluation 2021

This self-evaluation has the structure of a SWOT analysis, the scope of which is the centre's activities since it was launched in 2010, with a clear emphasis on the current period as a centre since 2016. We also refer to the SWOT performed in 2019 in relation to the centre's mid-term evaluation, hereby trying to avoid obvious repetitions. Additionally, we refer to the most recent annual reports (i.e., internal evaluations) and external evaluations: the centre's mid-term evaluation in 2019 and the university's research evaluation RED19, in which the evaluation of the Inst. of Health and Care Sciences included the contribution of the GPCC.

Moreover, this self-evaluation is related to the centre's research programme and how it has evolved since 2010 with emphasis on the on-going six-year period (please see separate document #6 "Overview of the GPCC research programme since 2010"). The current research domains are:

- Theoretical and practical development of person-centred care
- Evaluation and measurement of person-centred care
- Implementation, organization, leadership and governance of person-centred care
- Learning and education in person-centred care

The structure of the self-evaluation below is: research, knowledge utilization and education, and stakeholder collaborations.

1. Research

1.1. Strengths

- Evaluations of clinical interventions based on operationalized ethics of the person
- Furthering the research focus on micro level research to a broad scope of micro, meso and macro levels of person-centred care
- Synthesizing research into a *Gothenburg framework for person-centred care*
- Activities and research initiated, developed and validated from patient and/or family perspectives
- Recruiting national and international scientific advisers and researchers

The success of the centre is based on its unique approach; an operationalization of ethics and philosophy of the person into practical clinical healthcare interventions that have been evaluated in high quality research designs. This has been implemented and evaluated in numerous clinical settings for people with long-term conditions. The results advance person-centred care as well as healthcare in relation to specific settings and patient populations. Today there is ongoing research related to micro, meso and macro levels of healthcare. In addition to implementation and organization research, the broader scope comprises education and learning research, which provides an important foundation for the contribution of knowledge to support the transformation to person-centred care in healthcare. To this adds the combination of effect and process evaluations in supporting understanding of how to implement person-centred care. All these types of evaluations have predominantly shown positive results (e.g., articles #2-4, 6 in the 10 most significant original articles) and had an impact on furthering healthcare practice, as well as evaluation research.

The initiative to research and synthesize the intervention studies as "Translating person-centred care from theory into practice" (e.g., article #5 in the 10 most significant original articles) became important to underpin the development of the research and provides the foundation for the influential *Gothenburg framework for person-centred care* (article #9 in

the 10 most significant original articles). The publications from this external synthesis are of special significance to following-up the visionary position paper from 2011 (article #1 in the 10 most significant original articles) with overview of major research results from the centre. The framework has proliferated into generic and specific interventions, the latter including contextualized focuses e.g., physiotherapy.

Patient participation in the projects is actively promoted and the overall development of the centre is supported by the *Person Council.* In this way, activities and research from patient and/or family carer perspectives is validated, and ideas and activities for further development of the programme co-created. All new project decisions are based on reviews by scientific advisors and patient partners external to the Steering Committee. Further, the cross-disciplinary research in collaboration between several faculty areas within and outside University of Gothenburg (GU) is a major facilitator, as is the involvement of strong researchers from a range of disciplines and faculty areas, which has been the case since 2010. Most recently, collaboration with the Department of Law and expanded collaboration with the Department of Applied Information Technology (GU) can be mentioned.

The recruitment of research leaders nationally and internationally has, in combination with the long-lasting strategies since 2010, facilitated career development for PhD students (28 graduated since 2010), post-doctoral researchers and for promotion to associate and full professors, making strong research possible. Moreover, the host institute has employed person-centred care researchers with various disciplinary and professional backgrounds as faculty members, (including visiting professors Nicky Britten, Bengt Kristensson Uggla, Philip Moons, Lars Wallin) which especially supports long-term infrastructure development.

The interests of doctoral students and junior researchers are safeguarded in their two respective informal networks to secure activities of relevance to both. Activities have included a series of seminars to support high quality proposals in person-centred care research for junior researchers, supported by senior faculty members. The external funding of centre projects has increased, with current project funders including the Swedish Research Council, FORTE, Vinnova (Sweden's Innovation Agency), the Swedish Childhood Cancer Fund, the Diabetes Association, and the Childhood Diabetes Fund and also EU level funding.

The development and maintenance of high-quality research is clearly facilitated by the recruitment of expert researchers, such as PIs, national and international scientific advisors. Including centre advisor(s) related to ethics and philosophy of the person right from the launch of the centre has been an important contribution to this.

The research is structured into four research domains, with all projects primarily linked to one of these, facilitating interproject exchange and collaboration. Regular research seminars facilitated by a scientific adviser provide an important forum for critical discussions, furthering shared knowledge and supporting a sense of community. Moreover, contributions to the international research agenda for person-centred care are achieved through the two European projects: firstly *We-Care* and more recently, *COSTCARES* – both coordinated by the GPCC. A number of publications have been produced from the COSTCARE network, including a recent development of a previously proposed framework (article #10 in the 10 most significant original articles).

A range of practical tools aimed at practising person-centred care have been developed (see document #19 *Tools ...*) and used in both intervention studies, as well as in practice developmental work in healthcare services. These are promising and contribute to health professionals' learning, education and practice of person-centred care in ways that support interprofessional teamwork.

1.2 Weaknesses

- The *Gothenburg framework for person-centred care* is not sufficiently developed
- Not always clear how selection of endpoints for evaluations reflect patients' priorities
- Lack of critical analysis as related to philosophy and ethics of the person to support theoretical and practical development
- Insufficient internal communication of how the research is strategically developed
- Low levels of external funding by PIs
- The one-year budget process can hamper long-term initiatives
- Project delay due to the ongoing Covid-19 pandemic

The *Gothenburg framework for person-centred care* is still not sufficiently explicated. This particularly challenges how it may be applied in new settings and contexts, and especially in healthcare systems outside Sweden. Some patterns related to spreading person-centred care have been identified but such results indicate a need to contextually adapt person-centred care. Further, the results show challenges related to health professionals' understanding and reproduction of practices related to operationalized ethics (e.g., articles #5 and #7 in the 10 most significant original articles). Moreover, various person-oriented developments in health care may require critical analysis pertaining to premises in relation to person-centred care.

The research domains have been increasingly debated within the centre in respect to the risk of silo effects. Nevertheless, one or another aspect of the research programme structure is still considered necessary, and being aware of the risk is an advantage. This can be related to the challenge of concerted efforts for a large volume of projects with the involvement of around a hundred researchers to strive in a collaborative direction. This has been clearly emphasized during the pandemic, with virtual meetings the only option. For these reasons, a structured research programme will be kept, but updated according to the achievements gained.

Previous development of new projects was primarily bottom-up driven (and focused on the micro level, mainly in hospital settings), with challenges for the development of a dense and cohesive research programme. This has recently been complemented by strategic initiation of new research areas from the micro to the macro levels of healthcare, and an invitation for new projects in specifically defined research areas. However, too few proposals have been submitted, which could be related to communication challenges within the centre and researchers assuming continuation of a bottom-up driven research agenda.

The relevance of the centre's projects for high societal priorities could be even more strongly validated. For this purpose, the *Person Council* and its partnership with a range of stakeholders are proving beneficial, although renewed consideration of how to more clearly build on known knowledge gaps and development of the research agenda in partnerships would be useful.

One observation is that typical mainstream research design and methods have predominantly been applied – with some exceptions. This consequently leaves room to consider more innovative research designs and methods (e.g. netnography, photo-voice, modern perspectives on measurement validation, and data driven research including AI and natural language processing) and if and how alternative designs and methods could help strengthen the research and/or study of new areas and topics.

Although several projects have been competitive in obtaining external funding, there are also projects only supported financially by the centre. Increasing external funding is necessary.

Due to the pandemic clinical projects have been delayed, with healthcare services prioritizing patient care and treatments over a longer period, and only allowing clinical staff to be involved in research as exceptions. Fortunately, this has not on all ongoing projects.

Although the centre has already provided examples of smooth and wise career transitions, there are a number of researchers and leaders who will reach retirement age during the next six-year period, re-emphasizing a need for career planning and transitioning. There is a need to recruit experienced expert person-centred care researchers, as well as doctoral students and post-doctoral researchers. During the latter part of the ongoing six-year period, the funding of PhD students has been hampered by a one-year budget process at the university. Although governmental research funding has been continuous, the time limit as a centre has been regarded as an argument for not initiating commitments beyond the six-year period.

Being guided by ethics of the person is a core feature and argument at the centre. However, the named Gothenburg framework of person-centred care (article #9 in the 10 most significant original articles) is – though increasingly known and referred to – less theoretically explicated, elaborated or analysed. Methodologically too, there is a need for additional elaboration or synthesis on the evidence for how to design and evaluate interventions building on the framework.

Even if several project plans include healthcare economic evaluation components, not all of these have been performed.

The use of too many different endpoints and several measures of each end point hamper explanation of its evidence, which in turn influences practice. Further, to what extent the end-points for the evaluation of person-centred care reflect patients' concerns and priorities are not sufficiently implemented in the research designs. This might reflect the importance of undertaking meta-analyses and meta-syntheses, as well as including patient (family carer or public) representatives in the research teams, but also of ensuring that broader variations in patients' perspectives and preferences are taken into account.

1.3 Opportunities

- For the coming six-year period further develop the research programme based on the achievements reached, with a focus on:
  1. *Creating, adapting and evaluating person-centred care*
  2. *Enabling transformation to person-centred care practice*
  3. *Partnerships between actors in the healthcare organization/decision-making system and patients and the general public*
- Utilize the collaborative partnerships to further develop the research and activities – including upcoming calls for research schools and centres of excellence
- Further develop the *Gothenburg framework for person-centred care*
- Further and implement additional strategies to increase external funding
- Increase internal collaboration that support quality and a sense of community

Future development of the research programme will build upon the experience and results achieved over the years. New initiatives may be even stronger selected for potential to further the unique development of research guided by ethics. As a result of an extensive strategic discussion between scientific advisors and the Steering committee new projects focus on meso- and macro levels person-centred care research (initiated in January 2021). In two of these projects literature reviews are currently ongoing, and the results from these will guide further development of how to design empirical studies. This strategy was combined with an invitation for external projects to be affiliated to the centre. Further, the national collaboration platform PCP4 'Person-centred Patient Public Private Partnership' provides significant potential for stakeholder collaborative initiatives to the further development of the research programme, as it involves partnership in a testbed environment with healthcare regions, services, private companies in the healthcare and medical industry and patient organizations.

The collaborative discussions amongst various stakeholders and activities serve to identify relevant needs for knowledge development about person-centred care.

We identified the need to further advance knowledge about the micro, meso, macro levels of person-centred care and our current research strategy is reflective of this need. To further develop the research programme for the coming six-year period, the centre will:

- Contribute to national, Nordic and European development in terms of transforming to person-centred care
- Critically examine the enabling of and transforming to person-centred care and its consequences
- Continue the move from research focusing on the implementation and effects of person-centred care at the micro level to focusing on synergies and integration of its micro, meso and macro levels
- Focusing on person-centred care for broader groups of medical conditions and population groups, and examining how person-centred care can be somewhat generic and how it needs to be contextualized and adapted to specific situations and living circumstances.

The following areas have been identified to focus on for the coming six-year period:

1. *Creating, adapting and evaluating person-centred care*. What are the generic aspects of person-centred care and what kind of contextualization are needed when and how? How can person-centred care be adapted for especially fragile life situations, such as childhood, transitions in healthcare and people in old age? How can digital solutions support person-centred care where the patient and family carers are located? How can digital literacy in person-centred care be supported? What unintended consequences follows from digital person-centred care? How can the *Gothenburg framework for person-centred care* be further developed to contribute to equity in healthcare and explain how person-centred care is contextualized and influenced?
2. *Enabling transformation to person-centred care practice*. How can the transformation of healthcare to person-centred care be enabled? What are the legal and other formal enablers? What are the informal enablers? What are the most useful (combinations of) implementation strategies? What factors influence the change process? What healthcare and educational organization, leadership and governance enable person-centred care? What learning modalities enable person-centred education, practice and leadership? How can patients' narratives and person-centred related aspects be utilized (e.g., in healthcare quality registers and through the use of machine learning) to inform solutions for healthcare decision making? How can sustainability of transformations to person-centred care in ordinary everyday healthcare practice be created?
3. *Partnerships between actors in the healthcare organization/decision-making system and patients and the general public*. What forms of partnership for patient and public involvement can optimize healthcare decision-making? What is the impact of patients' and family carers' perspectives, as related to research evidence in the development of health care?

Funding. In the long-term perspective, there is a clear need to obtain strategic centre funding as well as increase external funding in each supported project. Two governmental initiatives mentioned in the 2020 government budget bill of special strategic importance are plans for research schools in healthcare and centres of excellence. Plans to propose for these calls have already been initiated. Further, strategic long-term budget planning will be developed.

We have planned several initiatives to increase external funding. A series of seminars first held in 2020 will be repeated. We will also continue to work with representatives from the

Grants and Innovation Office at GU. The office provides valuable support including strategic advice on proposal writing and information of future funding opportunities before calls are published.

As a concrete measure, a proposal submitted this spring to an innovation agency has a patient partner as PI (for the investigation of patient perspectives involvement in the national initiation of new treatments; hence highly relevant for being led by a patient representative). This could be a source of inspiration to further consider in the development of new projects.

Finally, in collaboration with the Inst. of Health and Care Sciences we are exploring possibilities to approach philanthropist funders, especially to fund guest long-term employment initiatives such as professors and PhD students.

Future directions for research and its dissemination. The ongoing review project of international person-centred care research together with the completed overviews of GPCC intervention studies provide special opportunities for the further development of a Gothenburg framework for Person-Centred Care. Here, international developments provide special resources, such as the EU COSTCARE network[2] and the person-centred quality indicators[1] (to which we became invited through established Canadian collaboration). Additional resources for the theoretical and practical development include the views of person-centred care in the public[2] (through the SOM-questionnaire), reports thereof in the media[3] and the ongoing study into its legal enablers. These will potentially be useful in the further contextualisation of person-centred care in the Swedish arena.

Further building upon the long established and well-attended GPCC research seminars relating to the knowledge development to ethics of the person is needed. Such seminars were previously mainly held in person on campus, but during the pandemic have been online only. Following the pandemic restrictions, there is a need to renew these seminars and gather project members in retreats in order to further develop internal networks across projects and increase a sense of community within the centre. At the same time, the advantage of virtual meetings also needs to be included and balanced with campus activities, in particular to facilitate participation for researchers and partners outside Gothenburg.

Internal monitoring and support. The tertiary follow-ups of all the centre's research projects were recently revised, but might be further strengthened making them more useful in terms of providing support and advice to the projects, and to enable the centre to review progress.

1.4 Threats

- Absence of societal support for the theoretical foundation of person-centred care

The major threat is that need for concrete evaluation strategies in healthcare and society at large might not admit time for further theoretical and methodological development of person-centred care. Further synthesis is needed in order to both understand and explain how person-centred care is practised and contextualised in various settings and health/illness circumstances; how its implementation is facilitated and how it is evaluated.

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[1] Santana et al. (2020). Improving the quality of person-centred healthcare from the patient perspective: development of person-centred quality indicators. *BMJ Open*, *10*(10), e037323.

[2] Wallström et al (2017). The Swedes' view of person-centeredness in healthcare (in Swe). In: Andersson et al. *The SOM-survey 2016*. University of Gothenburg, the SOM Institute.

[3] Magnusson (2018) Person-centred care on the media's agenda (in Swe). Soc Med Tidskr, 95 (1), 53-61.

2. Knowledge utilization and education

2.1 Strengths

- Knowledge utilization on the European level through an agreed standard
- European and national collaborative projects supporting utilization
- Person-centred care implemented in 1st, 2nd and 3rd cycles of higher education
- Patient partners enable utilization in patient organizations and civil society

Strategies building on the knowledge triangle have been used throughout the centre periods, which refers back to the interaction between research, education and innovation as key drivers to a knowledge-based society. In addition to the dissemination of research results, a number of pedagogical tools, learning materials and initiatives are developed and distributed (e.g., study circles, academic courses, videos; see document #16 *Tools …*).

The major knowledge utilization achievement is the development and agreement of a *European Standard for Minimal patient involvement in person-centred care* (CEN/TC 450), which was initiated and chaired by representatives of the GPCC. This explicitly builds on research performed at the GPCC and relates to participation in person-centred care on the individual level (e.g., care plans), the operative level (e.g. pathways) and the strategic level (e.g., development and evaluation of policy documents). The GPCC sponsored the Swedish version to be freely available and is still involved in its implementation and evaluation. The standard has potential to be used in several ways, including quality improvement developments, benchmarking, out-sourcing and back-sourcing, as well as for the development and description of innovations in person-centred care research.

In addition to customary research publications, international knowledge utilization has been especially supported by two European collaborative EU funded projects: *We-Care* and *COST CARES*, with 28 participating countries utilizing GPCC research outputs. Although the primary purpose of the PCP4 is to initiate collaborative projects and facilitate test-beds for person-centred care, the project also reaches out through all partners and facilitates knowledge utilization through its partnerships, seminars, workshops and related activities. A more recent participation in the International Community of Practice for Person-centred Practice provides an additional arena for collaboration and knowledge utilization, although this has so far been hampered by the ongoing pandemic.

As part of contributing to social innovation, two special digital tools supporting knowledge utilization through person-centred learning modalities are in place: *the PCC game* and *Mutal Meetings*; both translated to English and available for free (see document #16 *Tools…*). Research is ongoing to further evaluate and disseminate these.

A number of the doctoral students, post-doc researchers, as well as research amanuenses (students in first or second cycle of higher education) and research staff are employed in other healthcare organizations and are spreading the knowledge of person-centred care. In addition, the higher education health profession programmes that include person-centred care learning modules are significant actors for the diffusion of person-centred knowledge and practice.

A portfolio of elective courses clearly related to person-centred care research within the doctoral education programmes at the Sahlgrenska Academy (see document #20 *syllabuses* and #17 *publications*) provides an important educational structure for knowledge utilization. The course on person philosophy and ethics is the most long-standing and has been provided each year since the centre commenced activities, as have the courses on qualitative methods and patient-reported measures. More recently, courses in complex interventions, implementation in healthcare, validation of latent variables and theory of science have been

made available; al courses of importance for person-centred care research. 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.

There are several education programmes for health professions at GU that include person-centred care in the local programme goals. An elective interprofessional course (7.5 credits) at Master's level, designed on the Gothenburg framework for person-centred care has been offered and is the clearest and strongest utilization of the centre in the higher education of health professionals. This course involved researchers from different fields and patient partners.

The *Person Council* has members in various leading positions in different patient organizations, some also acting as patient representatives in healthcare organizations or authorities. Thus, all members, including the alumni, are important in supporting the utilization of person-centred knowledge and practice in both civil society and within healthcare. Members of the council have co-produced a leaflet about person-centred care and are currently in collaboration with the major umbrella organisation *The Swedish Disability Rights Federation*, co-arranging an educational programme for patient organizations on person-centred care. Both members of the council and researchers from the centre will take part in the programme. This programme has special potential to reach out in Swedish society, with further impact on the country's healthcare.

2.2 Weaknesses

- Delays in renewal of the knowledge utilization strategy
- Reduced activities due to the pandemic
- Too few press releases to support communication of results to the public

At the beginning of the current six-year period, education and implementation support lines were well established and new strategies were needed. A significant step was the formation of *GPCC Implement*, a non-profit company owned by the holding company *GU Venture*. About three years ago, the requests for educational and/or implementation support from healthcare services and authorities exceeded our capacity and staff recourses. In response, we revised the centre's utilization strategy. We initiated a network among health professionals for dialoguing about utilizing person-centred care. However, the power of these initiatives is weaker today.

While the educational and knowledge utilization tools have not been sufficiently documented and evaluated, it is clear that future development can be more easily supported through established research on learning and education. Although digital solutions for knowledge utilization have been implemented at the centre, the pandemic has hampered activities.

Patient partners (such as members of the Person Council) are seldom involved in higher education.

There are few press releases highlighting achievements and publications to the media and for further dissemination to the public.

2.3 Opportunities

- Initiate national and international conferences, workshops and similar events
- Lobby for the inclusion of "person-centred care" as a Mesh-term in PubMed
- Strengthen the communication of person-centred practice tools

The GPCC Jubilee conference held in 2020 was a truly successful event for knowledge utilization and to increase the interest in person-centred care. Recently, several researchers at the centre participated in an international conference hosted by the Inst. of Health and Care

Sciences with the theme “Personhood: philosophies, applications and critique in healthcare”. Such events indicate the capacity of the centre to facilitate knowledge utilization through the initiation and organization of national and international conferences, workshops and similar events.

To counteract the challenges related to difficulties in performing feasible systematic searches of person-centred care, research literature special measures should be explored to influence search terms in major databases.

Today, external requests for utilization, educational and implementation support have decreased and the centre is able to respond to the vast majority of requests. A recent survey to map specific competencies related to person-centred care among researchers and staff gives opportunity to more easily match external requests to competencies among colleagues. Workshops/seminars for larger groups of health professionals on specific aspects of person-centred care are in the pipeline. Another recently initiated project to facilitate knowledge utilization is the mapping of practice tools developed at the centre and supporting person-centred care practice. The outcome of this mapping will be used to further develop the communication of practice tools on the GPCC web, possibly in a user-friendly report and also to provide part of the foundation of an implementation strategy for a new project under development about the facilitation of healthcare services transformation to person-centred care.

2.4 Threats

- Literature searches obstructed by the lack of specific index terms in major databases
- Risk of person-centred care publications not being read and incomplete reviews because of the lack of specific index terms in international databases
- Blurred and vague understandings of person-centred care
- Inconclusive implementation of person-centred care in the education of health professions threatens interprofessional person-centred care team work

Variations in conceptualization of person-centred care sometimes makes for blurred understanding among stakeholders, which can weaken recommendations and processes for implementation. While the majority of healthcare regions have the implementation of person-centred care on their agendas, there is an obvious risk that the notion of person-centred care becomes unclear and even diluted. Having the practice operationalized in terms of ethics and philosophy implies a risk to be regarded as too complicated, especially since this practice goes beyond the use of checklists. Here, the European standard, together with strategic work from SALAR (the Swedish Association of Local Authorities and Regions; in Swedish SKR), the healthcare regions and others are and will be of importance. Nevertheless, the question remains as to how to make person-centred care explicit enough for health professionals to work with. Moreover, it is not articulated to what extent this might be the case among all colleagues involved at the centre. For the future, we need to come to a well-established and substantiated understanding that is more tangible and includes the implications of person-centred care being co-created while avoiding relativism.

The lack of specific index terms for relevant databases in healthcare is a major threat to knowledge utilization. For example, in Pub Med, the most closely related Mesh-term is patient-centred care but this does not capture the breadth in the field of person-centred care, since it is categorized under primary healthcare and includes two sub-headings: narrative medicine and patient navigation. Internationally, the terms used for person-centred care differ and the term ‘person-centred’ care might refer to other concepts. To provide a comprehensive database search several search terms need to be combined. However, this may result in about

190 000 citations (before limiting to specific diagnosis or fields of healthcare). In this way, there is a risk that relevant person-centred care publications may not be retrieved either internally or externally.

As a result of these challenges, integrative review and summaries of person-centred research tend to be inconclusive. One example is a recent European edited volume about person-centred health systems aimed at reviewing research evidence, which only refers to the GPCC position paper and not to any research results. This might also be related to the challenge of reaching with knowledge development guided by ethics and taking a starting point at micro level instead of macro level development.

At the beginning of the current six-year period, the Västra Götaland Region implemented strategic person-centred care facilitators across healthcare services, which functioned as champions supporting the practice of person-centred care. However, these facilitators are now integrated in ordinary improvement work and development, which challenges the support of person-centred care, with the risk of regarding it as a minor aspect among several additional quality aspects.

The varied inclusion of person-centred care in higher education programmes for health professions is a threat that might increase the gap between theory and practice. Moreover, if it is included only in a few programmes, it especially threatens collaborative person-centred team work, which is essential to its practice. In all higher education programmes for health professions there is competition around topics and components to be included to avoid curriculum overload. This might be especially challenging for a new field such as person-centred care, which is also interdisciplinary and interprofessional.

3. Stakeholder collaborations

3.1 Strengths

- Interdisciplinary research and patient partner collaboration
- Established research collaboration with the healthcare industry
- The reputation of Gothenburg's healthcare research is supported by the centre

The GPCC *Person Council* was established in 2016 and significantly supports the infrastructure of the centre. Each of the members has extensive experience of a wide range of conditions and types of healthcare services; as patients and/or family carers. Representatives of the council participate in various centre activities, including the Steering Committee, seminars, retreats, strategy discussions, publications, lecturing, internal development of working processes, as well as review of new projects. The council started by meeting three times a year, but now has about ten meetings a year, streamlined in relation to the Steering Committee meetings to facilitate exchange and collaboration. As collaboration with major patient organizations is increasingly facilitated through members of the council, this meets the aim of validating centre activities and knowledge development from patient and family carer perspectives, as well as co-creating ideas and activities.

Research collaboration with the healthcare industry is well established. Several projects have been and are performed with the Sahlgrenska University Hospital in Gothenburg and other services across the Västra Götaland Region, as well as with other national services including multi-centre studies. The collaboration with Dalarna University and Region is a good partnership example.

The above-mentioned EU projects *We-Care* and the ongoing EU *COSTCARES* also focus on a system change in healthcare with cost containment while improving quality of care through

person-centred and health promoting approaches. This has also resulted in a European network including important arenas for GPCC junior faculty members.

The development achieved in the EU collaboration projects are already used in the above mentioned PCP4 project. This involves collaboration between the Västra Götaland Region, Region Blekinge and Region Dalarna, SALAR, three universities, three patient organizations and additional incoming partners including elderly care.

The centre's tradition to collaborate in partnership with the surrounding society is long-standing (in addition to the above mentioned e.g., Patient associations, Swedish Association of Health Professionals), which has enabled the societal relevance of person-centred care. Additional significant stakeholders come from different healthcare industry areas and extend to universities, healthcare services and patient organizations. Collaborating partners include companies such as Essity, Dimh/IUS Innovation and Doberman, big pharma companies such as Novartis and AbbVie, and the Swedish Institute for Standards. Collaboration also includes the trade unions Swedish Associations of Health Professionals, Physiotherapists, and Occupational Therapists.

Since the establishment of GPCC, the centre's host at GU, the Inst. of Health and Care Sciences, has implemented person-centred care as a profile for education, research and collaboration. Nationally, faculty members from the institute are regarded as representatives of the GPCC, irrespective of whether they are affiliated to the centre or not, which may reflect the strong reputation of the centre. Further, the centre's attractiveness to researchers is supported by the reputation of the Sahlgrenska University Hospital, especially in regard to profiling their evidence-based approach beyond medical care through a career track programme for all health professions with a PhD.

3.2 Weaknesses

- Too few partnerships with primary care, municipality care and care for old people
- Vague initiatives responding to the societal digital development

There are too few projects that involve collaboration with primary care and municipality care, such as home care services and care services for old people. However, the already ongoing projects in these settings provide opportunities to build on. Such collaboration is especially important to develop to meet societal needs for healthcare closer to citizens' living situation. The centre has only a few collaborations with private healthcare services and only few ongoing collaborative projects with pharmacy companies or medical equipment design and manufacturing companies. There is a need for new digital solutions to have input on the significance for person-centred care, and we have learned that companies are actively seeking collaboration to reach this type of input (e.g. Essity, AbbVie). There is a need to more clearly recognize that digital development goes beyond simple eHealth tools and how person-centred approaches may utilize – and influence the use of – artificial intelligence.

Optimal forms of collaboration and working between the Person Council and the Steering Committee and other patient partners and the centre at large are still to be developed.

Challenges exist in including representatives of the interprofessional healthcare team professions. Even if collaboration includes individual physicians, there is a need for strategic collaboration with physicians, higher education programmes for physicians, and medical and physician organizations. Needs for strategic collaboration with additional professions should be identified and considered.

3.3 Opportunities

- Strengthen collaborative partnerships, regionally, nationally and internationally
- Formalize academic collaborative partnerships, e.g. PhD double degrees

Discussions with the GU holding company opens for restarting the GPCC Implement (non-profit company) for knowledge utilization as part of the Patient Public Private Partnerships as related to the collaboration in the PCP4 project. To further this project, a special opportunity is the Interreg North Sea application "Inter-Care-Labs" (England / Scotland / Netherlands / Denmark / Sweden) on the development of test beds for person-centred care related innovations. Another opportunity is the WHO:s emphasis on people-centred care, and an going discussion towards some kind of agreement of collaboration; however, this could not be completed because of the pandemic.

To supplement the formal centre organizational structure and ongoing collaborations, considerations include the development of advisory groups with students and health professionals, similar to the Person Council. This would secure building on significant stakeholders' perspectives and experience-based knowledges.

The double degree in the doctoral education between Sahlgrenska Academy and, for example, the University of Leuven in Belgium provides a successful model for academic collaboration that could be implemented in additional collaborations.

Despite restrictions during the pandemic, external requests for collaboration and advice have been posed to the centre, including the SALAR for the development of a platform to support implementation of person-centred care in the healthcare regions.

3.4 Threats

- Insufficient funding programmes for healthcare practice-oriented research
- Organizational fashion trends
- Patient decision-making driven by check-lists and flow-charts

Even if there is broad support for the transformation of healthcare to person-centred care, a lack of financial support for research and development projects exists.

Successful development of healthcare practice and systems are interdependent on a range of actors and factors, such as government, authorities, the SALAR, and professional organizations. The message from top level organizations might differ from views among health professionals and staff at the micro level, as well as managers and leaders. Thus, there are several actors influencing person-centred knowledge development and utilization and from different angles.

Organizational changes are at a high risk of being influenced by organizational fashion trends. An emphasis on check-lists and flow-charts driving decision-making close to the patient risks coming into conflict with enablers of person-centred care, and from this follows a need to clarify this as different from decision-making supported and supplemented by decision-making tools and person-centred care tools.

In Sweden, strong legislation governs independence for regions and municipalities in terms of how to organize welfare services; the only requirement is to provide. Since person-centredness is primarily related to how to do healthcare, there is a risk of this independence hampering the transformation of healthcare to person-centred care.

GPCC 2019 SWOT ANALYSIS

Research

GPCCs research is divided into four research domains. Each domain has one or two Line Managers (senior researchers), whose work is supported by one or two junior researchers.

These research domains are:

- Theoretical and practical development of person-centred care
- Evaluation and measurement of person-centred care
- Implementation of person-centred care
- Organisation, leadership and governance of person-centred care

Strengths

Recruitment: Swedish professors in implementation research and policy research and international guest professors from Belgium, England and US as well as junior international affiliates have been recruited. These efforts have been fruitful and are planned to continue in collaboration with the Institute of Health and Care Sciences.

Young investigators: Over the years GPCC have financed 40 PhD candidates who are now able to, both in their respective clinical day to day practice as well as in research, bring the theoretical and practical development and implementation of person-centred care further. Five post-docs are at present financed by GPCC including Nursing, Physiotherapy, Occupational therapy and Speech therapy. Their projects include for example the work-related health among staff in settings implementing person-centred care and the practical and theoretical development of documentation of person-centred care.

Many controlled studies on PCC have been performed but also descriptive and explorative studies aiming at creating knowledge on how to further develop a care based on ethics/philosophy of the person. A synthesis and critical review of the research performed by GPCC has been led by a team of researchers in England. They concluded that the research provides an evidence base, in a range of clinical areas, using an ethically yet practical framework for PCC. The interventional studies were all initially financed by GPCC but several of the projects have been awarded substantial funding from other funding agencies during and after the project period ended.

Implementation and organisational research is led by two professors nationally and internationally well established in these two areas of research. Several projects have been carried through and new ones have recently started up. As part of studies in health care, economic evaluations on the structural level of PCC have been performed. These studies are mostly conducted as cost and utility analyses, however one transaction cost analysis on PCC versus usual care in hospitals has been performed. In several projects, including a completed PhD project, the willingness/reluctance to change towards PCC has been evaluated and described. These studies paved the way for an improved understanding of the basis of organizational and financial effect of PCC.

The implementation research projects are well anchored in theory and international agenda on implementation research shaped in a creative and constructive collaboration between research teams at Gothenburg University and Dalarna University.

Collaborative funding of research: The ongoing projects in implementation research are performed through a co-design approach and funding for two PhD students has been provided by Region Dalarna. An increased general interest from stakeholders in how to implement and organize person-centred care has strengthened the incentive to continue and broaden the research within implementation/organisation stream.

International collaboration: In 2013, GPCC coordinated a European Support Action (supported by the EU FP7-program) to develop a European R&D Roadmap towards "Healthcare Cost Containment while improving the Quality of Care (WE-CARE)" with GPCC as the driving force. This Action lead to an EU-R&D Roadmap presented in 2016 developed by "EU-Key players", representing stakeholders in the EU healthcare sector [1]. In parallel with coordinating the development of the EU-R&D-Roadmap, GPCC was also successful in gaining EU support to maintain the network of EU-Key players by an EU-COST-Action (www.COSTCARES.eu) with 28 participating countries.

Development of research methods: GPCC has since the start emphasized the importance of developing research methods to be used in health care and PCC research and implementation. A direct observational tool for assessing health professionals' skills in delivering PCC is under development. Two additional questionnaires, from patient- respectively staff perspectives to be used in PCC evaluations are being developed and tested. Traditional PROMs are recognized to be limited with respect to their efficiency, comprehensiveness, interpretability and relevance for use in research and clinical practice. An ongoing international research project led by GPCC directly addresses and potentially overcomes many of these limitations by combining item banking with modern psychometric techniques (Rasch) and computer adaptive testing (CAT). To date, a Rasch-calibrated item bank for assessing fatigue and a CAT program for item bank administration have been developed. The overall aim of this research program is to develop a new generation of measurement tools for individualized, efficient and real-time assessment of patients' functioning, symptoms and wellbeing and to evaluate their feasibility, usefulness, propriety and effectiveness for use in clinical practice and research. The research group has recently initiated collaboration with the University of Exeter, UK and recruited two joint doctoral students. A current focus is on developing item banks for use in assessing person-centred care.

Patient involvement/participation/engagement in research: The GPCC person council consists of 10 persons with long personal experiences of Swedish health care, either as patients or significant others/informal carers. The width of their collective experience covers a wide spectrum of various health care environments; hospital care, primary care, elderly care and child health care etc. And they have experienced an equally wide variety of specialist care, for example diabetes, heart conditions, psychiatric, stroke, aphasia, and irritable bowel disease. Emanating from their own personal stories many work dedicatedly

[1] Ekman I, Busse R, van Ginneken E, Van Hoof C, van Ittersum L, Klink A, Kremer JA, Miraldo M, Olauson A, De Raedt W, Rosen-Zvi M, Strammiello V, Tornell J, Swedberg K. Health-care improvements in a financially constrained environment. Lancet 2016;**387**(10019):646-7.

through a variety of means, co-creating events with GPCC or on their own initiative; lecturing, writing books, being active in social media, sitting on national and regional health care patient panels and so on.

The aim of this council is to validate GPCCs activities and research from a patient and significant other/informal carer perspective, as well as receive the council members input, and also to co-create ideas, content and activities related to person-centred care. The council normally meets three times per year, and members participate regularly in various GPCC activities like workshops and events.

Weakness

End-points formulated together with patients: Research evaluating PCC should to a higher degree use outcome measures which reflect and are formulated together with patients about priorities, to enhance its relevance for patients and relatives. A research agenda on PCC, in which patients are involved is lacking to date.

Bottom up projects: Many projects to date have been bottom-up driven, defined largely by PIs individual interests and accessibility to for example infra-structure. The studies have been performed on a micro-level (relations between health professionals and patients) and very few involving links from micro level to a meso- (e.g culture) and macro- (policy) level. All of the studies have been performed in Sweden. More knowledge on person-centred care in different care system is needed.

Research based in the ethics/philosophy of the person: There are not sufficient number of projects starting up explorative research taking the point of departure from the ethics and philosophy in relation to care practices. Further, there is only few theoretical studies performed that has linked philosophical underpinnings to empirical work and practical applications, or that has analysed significant or influential premises for person-centred care practices.

The GPCC framework for person-centred care. The centre is known for having developed a framework for person-centred care that is supported by strong empirical results. However the details of is this framework is less explicated and analysed.

Lack community care projects: Too few projects have been performed in community/municipality care, the hospital setting dominate although the whole care chain has been included in one project.

Too little collaboration with social science and humanities: Collaboration with disciplines from social science and humanities has been emphasized from the start but such further involvement has not increased as much as should have been expected. Collaborations between nursing, health sciences and clinical medicine dominates.

No structured programmes for doctoral students and post-docs: Structured career planning programs for juniors and post-docs needs to be developed. Doctoral students are eligible for an elective course in person-centred philosophy, however there is no structure to support

PhD students (or supervisors) over time to become future faculty and investigators in the furthering of person-centred care.

Too little external funding: Several of the PIs supported by GPCC have no other external funding, which must increase for improved research.

Opportunities

An increase in collaboration in research within care sciences/nursing in Sweden would probably be fruitful for all parties since the mean age all over Sweden is high and there is a need to better share scarce youth resources.

International collaboration in method development: In a Swedish-British-Canadian collaboration, a new initiative for further methodological development was recently decided. Collaboration is established with (i) Drs McCormack and McCance in UK who have developed the Person-Centred Practice Inventory (PCPI) for use of patients and/or their families, professional providers and students, and (ii) Dr Richard Sawatzky who holds a Canada Research Chair (CRC) in Person-Centred Outcomes, which provides access to resources to support modern perspectives of measurement analyses. The plan includes translation and cultural adaptation of the PCPI into Swedish, and a psychometric evaluation thereof based on pooled data through the international collaboration. Further, the Canadian person-centred care indicators under development by Santana, Sawatzky and co-workers in Canada will be tentatively translated and adapted to Swedish. These indicators are related to a person-centred care framework, which in year 2019 could be considered for potential to translation and adaptation into Swedish. The indicators are aimed for health care organizations to monitor and improve quality of care.

Living labs: There is a need to put PCC research within wider endeavours – to identify what has been done, what questions are not or inadequately answered, etc. In order to be able to explore this further, GPCC has initiated a programme (*Person-centred, patient-, public-, private partnership – PCP4*) to test and research the process and impact of PCC in health care. The programme will start with three different regions and counties in Sweden (Region Blekinge, Region Dalarna and Western Region), changes will be explored starting 2019, to identify the optimal combination to facilitate the implementation of PCC. Since organisations aspects in health care are in focus in this program, researchers from social science such as for example law and policy have been recruited. This will be done in partnership with the health care organisation, the private sector (e.g Essity), academia, patient organisations and informal carers. Researchers from other universities will be invited to participate and also other regions will be invited as soon as the structures of the programme have been consolidated. An opportunity is also to expand the programme into an international level since the EU-funded COST Cares Action including partners from 28 countries on how to implement PCC in different settings in Europe, the PCP4 project will be one of five test-beds in this project.

Interest from stakeholders: The fact that GPCC is well recognized in Sweden and has an extensive network gives the opportunity to scale up the findings from research.
In order to develop complex interventions which are more likely to be effective, sustainable and scalable, evaluators need to understand not just whether, but how and why an intervention has a particular effect and which parts of a complex intervention have the greatest impact on outcomes. The evaluation studies therefore are now designed including

process evaluation which may make important contributions in this area. The interest from stakeholders has also paved the way for an ongoing collaboration with a team at the Swedish Association of Local Authorities and Regions regarding development of a patient survey on experiences of person-centred care which might be included as part of the National Patient Survey.

European standard: An important project initiated by GPCC, is the development of a European (CEN) standard for *Minimal patient involvement in person-centred care*. The work is co-ordinated by Swedish Standard Institute (SIS). The text will be presented for a final Ballot in the fall of 2019 and a standard will be available early 2020. Such a development will simplify research applications as the methodology will be more clear. It will also help to define a PCC-standard on a meso-and macro-level which will clarify PCC better for organizations and politicians.

Systematic review: A project recently initiated on a systematic review of PCC research. This initiative will hopefully contribute to the theoretical foundations of PCC by a systematic review, critical analysis and integration of results related to international PCC research. This is motivated by PCC research being a growing field of healthcare practice and research with sparse knowledge of aggregated knowledge building on previous research.

Open seminars: A series of seminars established around the philosophical underpinnings of person-centred care; creative and well-attended will probably stimulate to research-questions based in person-centred ethics.

Threats

PCC diluted: GPCC has described how the philosophical assumptions of the person and personhood can be operationalized as PCC, which has been disseminated mainly nationally but also internationally through publications, books and activities such as seminars, talks, social media etc. This is now widely spread in Sweden and more than half of all counties/Regions state that they have decided to implement PCC. It is an obvious risk that PCC develops to be just a label for all sorts of health care changes and the core meaning and foundation in relational ethics risk being diluted. This threat will probably be attenuated once the CEN-standard is in place.
In addition GPCC has supported the implementation in a number of places but GPCC has no longer the resources to facilitate cross-national implementation in person.

Need of instruments for evaluation of PCC: Other threats are the need of additional validated scales for assessing PCC and the problems with RCT and need for acceptance of less traditional designs such as qualitative and mixed methods designs.

Need of researchers: Many researchers in GPCC are from care sciences and nursing and most of them are also lecturers and the assignments for teaching make it difficult for them to devote the time needed for high quality research. Further, researchers from other areas such as clinical medicine, social science and the humanities are more limited and should increase.

Too few young PIs: Principal investigators with deep knowledge about the philosophical assumptions have been aligned with governance of the centre. The age of the senior researchers are rather high and recruitment of junior researchers are urgently needed. Since

the financing of the centre was not clear after 2016, very few new PhD students have been recruited during recent years.

Lacking a PCC researcher community. There are only few meeting points/venues for PCC/GPCC researchers and groups across projects to meet, discuss, critique and share experiences, and no shared forum/seminars for discussion of manuscripts and research.

Education and implementation

Strengths

Tools: GPCC has developed various educational tools (workshops, conferences, digital tools, books and seminar activities). These tools have been used in various training- and implementation initiatives and in different health-, medical- and social care businesses around Sweden. Further, these tools have been used by patients, students and professionals in clinical practices.

Digitalization: Several of the education tools have been digitized (the PCC-game, the Online Education named Medmänniska) in order to increase the businesses own responsibility for the implementation of person-centred care.

Social innovation: An additional way to drive for implementation has been the development of the company "GPCC Implement", a SvB company within the University of Gothenburg. The company has served as a social innovation, a kind of test lab for the implementation of person-centred care.

Academic courses: GPCC has developed national courses at advanced and postgraduate level in person philosophy and person-centred care.

Project review and assessments: Projects in the centre are reviewed on a quarterly basis to determine relevant educational materials they generate or can contribute to, and to determine if this material can be packaged into executive, academic, or general public education with additional support.

Weaknesses

Not evaluated enough: The educational tools are insufficiently evaluated, both scientifically and in everyday practices.
Shortage of staff: GPCC has had a shortage of researchers / lecturers who can translate knowledge and support application of person-centred care in practice.

Opportunities

Courses and conferences: To create joint courses and national conferences for all professional groups in healthcare, medical and social care practices.

To support changes in practice: To contribute to the businesses taking greater responsibility for converting to person centred care through online education, games, movies, books and workshops.

Packages: To tailor education packages to the health, medical and social practices.

Research: Pedagogical research on knowledge translation and implementation of person-centred care.

Threats

Absence of educational initiatives: Lack of initiatives to integrate person-centred care in formal educational programmes risks increasing the gap between theory and practice. If the dissemination of knowledge is reduced, for example due to a lack of resources, GPCC risks losing important and relevant research issues from practices.

Lack of competence: The demand for pedagogical competence is greater than the supply of teachers who can teach both theory and practice with a person-centred approach.
As PCC is a new field and an interdisciplinary approach, there is a risk (already experienced) that traditional educational programs will be resistant to the introduction of PCC such as the physician program. If this cannot be overcome, education in PCC will be limited to fewer groups of health professional's e.g. registered nurse and occupational therapy programs.

Stakeholders

Strengths:
Care sector collaboration: Working directly with the care sector, both primary and secondary care, provides GPCC with direct input into the needs and main issues facing its key stakeholder. The collaboration with hospital care at Sahlgrenska University Hospital is particularly strong, with GPCC having offices located within the hospital, and many researchers holding dual employments, experiencing the challenges of the care sector in practice. Collaboration with and support from, amongst others, national bodies like the Swedish Association of Health Professionals and The Swedish Society of Nursing and Swedish Society of Medicine organisations with great influence on the care sector and national politics, help drive the call for PCC, which they see as important topics of their agendas for national health care improvement.

Patient representation: Patients are among the most directly affected stakeholders in PCC. GPCC always ensures that patient needs are understood and addressed, by directly researching the patient perspective, by involving patients as partners in research project design and execution, and through collaboration with patient representative organisations, for example as part of the GPCC executive board. In addition, GPCC has established a Person Council for patients and informal carers (see above) who are a great resource for GPCC in communication and information about PCC.

Project review and assessments: Projects in GPCC are reviewed on a quarterly basis to determine which societal and/or business needs they address, and to determine if they can target those needs more effectively with additional support.

Industry support: The centre initiated a European project in 2013, supported by the European Commission under Framework Programme 7, entitled WE-CARE, which was a network of leading European actors headed by GPCC to set the research and development agenda for future cost containment in care [1]. This project became a foundation for future international networking and expansion activities. It resulted in the ongoing COST CARES as discussed above. The collaboration with service design companies such as Doberman has increased over the years but also big pharma such as Novartis.

Public opinion: Although increasingly embraced by healthcare administrators and professionals, government agencies and patient organizations, little is known about how the general population views PCC. GPCC therefore has collaborated with the Society, Opinion and Media Institute (SOM Institute) in their annual national surveys to gauge public attitudes to and experiences of PCC. Results from the first survey showed that although the general public has overwhelmingly favourable attitudes to PCC such as being a partner in care, a disproportionate number felt they were not given opportunities to participate in their care planning and were not provided adequate information to make informed decisions about their care.[2] GPCC intends to monitor potential changes in public attitudes and experiences as PCC implementation efforts intensify in the coming years.

Communication: GPCC has, through a variety of activities, some by invitation and others organised by GPCC, endeavoured to establish PCC as a self-evident care in Sweden and GPCC as the "go-to place" for information about PCC. These activities include meetings, seminars, lectures and stands at major national and international conferences, networking events etc. The GPCC website had 21000 users and 33000 sessions during 2018. Our Facebook page and Twitter have c. 1000 followers each. Bi-annual newsletters go out to our Swedish network contacts (1300+), and printed information materials have also been developed and distributed to thousands of relevant people at relevant events.

Weaknesses:

Communication: GPCC could achieve more if communication activities were better planned long-term and more strategically. At present GPCC has one person working 50% with communication (although researchers and Person Council members also communicate), therefore a lot depends on which individuals (both researchers and patient representatives) are able and willing to give their time and commitment at any given time.

Industry engagement: While there is general support for the centre from relevant industry actors, it has been difficult to promote and sustain active engagement, barring a few notable exceptions. Industry actors often lack necessary interfaces for relating effectively to the care context, and find it challenging to identify incentives for close involvement.

Policy networks: While the research at GPCC has resulted in strong interest from both politicians and civil servant policy makers, the centre lacks strong, ongoing policy collaborations and networks (except for the COST CARES). This hampers the ability to reach key decision makers and build new national or international collaborations.

Academic collaborations: While the centre has initiated some collaborations with other academic organizations outside the university, these have not been as deep and formalized as could be hoped for (e.g. personnel exchange, joint research agendas, etc). Collaboration with international institutions has started with Exeter University, University of Plymouth and Duke University and is ongoing through the contracted visiting professors.

[2] Wallström S, Ekman I, Taft C Svenskarnas syn på personcentrering i vården. SOM-rapport, Göteborg, SOM-institutet, 2017

Opportunities:
Communication: A communication strategy and plan was updated and expanded in 2018. It includes many good ideas and plans for further work.
Many other organisations, including Vårdförbundet, Riksförbundet Hjärt/Lung and SALAR (SKL) create their own information material, often based on/referring to GPCCs definitions and research, and work pro-actively with spreading this.

Challenge roadmap: By drawing on stakeholder input and developing a roadmap of key challenges for the future of person-centred care, GPCC has the opportunity to create a governance framework for utilization activities that directly corresponds with evolving stakeholder needs.

Challenge reference group: By establishing a dedicated reference group of stakeholder representatives for formulating challenges, directly assessing the centre's capacity to address those challenges, and making challenge-driven recommendations, GPCC has the opportunity to improve its relevance to societal and business needs, and to address them.

Personalized (Precision) medicine: Personalized medicine is gaining prominence as an area for future breakthroughs in individually tailored diagnostics and treatment, yet it is unclear how compatible these advances are with the involvement of the patient in the care process, and with the goal of cost containment. GPCC has studied the links between PCC and personalized medicine, and has the opportunity to support the development of complementary solutions that would address the need for person-centred and cost effective personalized medicine.

Demand for implementation: The success of the GPCC Development program, the centre has experienced very high demand for implementation support and training in PCC. However, as discussed above, GPCC has decided to focus on research and thus participates in implementation by performing implementation research.

Threats:
Communication: The concept of person-centred care risk being distorted and/or hi-jacked if GPCC researchers do not take the time to comprehend and understand the philosophical underpinnings of PCC, or have the time or willingness to prioritize dissemination of PCC.

Disinformation: The internet and public debate arenas are great for spreading information, but there are also risks to doing this, as it can be taken out of context, twisted and distorted for the use of others, for example.

Innovation system anchoring: If GPCC is not able to clearly anchor its implementation activities in both the innovation ecosystem of the university, and the Swedish care context, there is a risk that innovation and utilization activities will lack the necessary authority and legitimacy for widespread impact. If this is not possible to maintain, the centre risks facing obstacles when working with anything other than research, as its role will not be clear.

Maintaining momentum: The primary challenges addressed by research at the centre are large and well known. If the centre cannot maintain its momentum and its visibility, there is a risk that national initiatives addressing these challenges will bypass GPCC and opt for competing, non-PCC solutions.

This analysis has been performed in collaboration by the GCC steering committee.

2019-02-07
Inger Ekman Director GPCC

Evaluation of Strategic Research Areas

FRÅGA 1

Evaluation of Strategic Research Areas (Toward Person-Centered Care in Long-term Illness) Self-evaluation

The self-evaluation is part of the background information for the evaluators in their assessment of the increased support to strategic research areas and the included research environments. The self-evaluation is distributed to each one of the 43 research environments included in the government's investment in strategic research areas.

The focus of this self-evaluation is
Research Output
Strategic value for society and the business sector
Collaborations
Research and Education Integration

The following should be considered when you are carrying out the questionnaire:
The self-evaluation should be answered in consultation with co-applicant(s).
When answering the questions, the original grant application and the previously reported information provided in the annual follow-up studies should be considered.
There is limited space for your answers, use it to give as detailed and to-the-point information as possible.

Last response date for the survey is May 19, 2014

FRÅGA 2

OUT: Research output

FRÅGA 3

OUT 1a) Please fill out the proportions of different kinds of publications from the strategic research environment (numbers should correspond to the number of publications reported in the 2010-2013 follow-up studies)

	Number of outputs 2010	Number of outputs 2011	Number of outputs 2012	Number of outputs 2013
Books	1	0	5	9
Book Chapters	6	5	7	12
Journal Articles	14	162	211	387
Conference Publications	16	25	71	38
Other	2	0	15	3

FRÅGA 4

OUT 1b) Please comment on the publication profile and its development over time (Out 1a) (1600 characters)

The publication profile of the centre reflects the diversity of expertise which contributes to the centre's make-up. Since the centre was formed, the number of publications has more than tripled (excluding the first, formative year). This increase reflects both an increased output from individuals as well as an increase in persons tied to GPCC. Early publications were few but indispensable for defining the concept of person-centered care (PCC) from GPCC and present this in an international environment.

An example is the publication Person-centred Care – Ready for Prime Time? (Ekman et al 2011). This publication was the result of a two day conference with GPCC researchers and affiliates. It has been downloaded about 2500 times and is extensively used in education.

GPCC has focused on publications (and studies) where the relationship between signs and symptoms are evaluated in order to better understand symptom development. Publications related to irritable bowel syndrome (IBS) can illustrate this relationship strategy with 18 papers (e.g. Ringstrom et al 2013). There are now a number of such studies from GPCC researchers in cardiology, rheumatology, physiotherapy, and orthopedic surgery, reporting on the disconnection between experienced symptoms and organ dysfunction.

Another priority has been to initiate controlled studies. Even if PCC has become a common key-word in literature there are only seven published controlled studies, two of them from GPCC researchers. GPCC has been a forerunner for controlled studies in PCC. As an example we designed, carried out and published a controlled study in patients with chronic heart failure on hospital care for worsening heart failure (Ekman et al 2012). This study was published in the leading European cardiovascular journal (IF 14) accompanied by an Editorial.

FRÅGA 5

OUT 2) What research results from the strategic research environment have had the most significant academic impact? Describe briefly the development and standing of the research compared to the research performed internationally. (1600 characters)

There had previously been very few controlled studies in the field of person-centred care, and few researchers had been able to show what effects it could have. GPCC has been a forerunner and now dominates the controlled studies in this field. As GPCC continues to support controlled studies, our academic impact can be expected to become even more visible when study results become available in the near future.

As we have been able to publish results from two controlled studies, uptake is still limited. However, the results of these studies have had a major impact on the academic discussion as well as health care directors and policy makers in Sweden. They are also gaining international impact, e.g. the British charity for Health Care improvement “The Health Foundation” refers to many GPCC studies and results in their recent report “Helping measure Person-centred care”.

The three most important academic areas for GPCC are:

1. Controlled studies of PCC

As we have shown in a published review, there are only seven controlled studies published on the effects of person-centred care and two of those are from our own studies in Gothenburg. Thus, we dominate the controlled studies in this field.

2. Symptoms and connection to organ dysfunction

The observational studies from GPCC on symptoms and signs have reported findings from cardiovascular and gastro-intestinal areas. They have received limited number of citations in the short time frame. Our research on the efficacy of person-centred care and symptoms and signs are on the international front-line.

3. International frontline research on efficacy of PCC in a clinical setting

Our research on organization and implementation is small but growing. The paper by Carlström, Ekman (2012) was the second most downloaded from JHOM in 2013. These studies will grow in importance when ongoing studies on the effects of PCC are published.

FRÅGA 6

STR: Strategic value for society and the business sector

Compare to question B6 in the follow-up focusing on the industrial and/or societal problems and needs that have been addressed in the research.

FRÅGA 7

STR 3) Elaborate on your strategic research environment's capacity and capability to transfer research results for utilisation in society or the business sector. (1600 characters)

To enable research transfer to society and the business sector, GPCC has integrated research directly into utilisation and education. Three key elements have been integral:

- Integrating research transfer in organization and processes
- Collaborating with key stakeholders in society and the business sector
- Establishing dedicated research transfer initiatives

Integrating research transfer into GPCC organization and processes has included:

- Establishing a dedicated utilisation function in centre management
- Utilisation-oriented research project design:

Promoting intervention research
Requiring active involvement of stakeholders (e.g. care providers and patients)
Mandatory code of conduct with clear utilisation and collaboration ambition

- Tailoring research projects to societal / industry challenges, and evaluating their progress on a quarterly basis
- Hands-on support in research transfer (attracting collaboration partners, contractual support, etc.)

Collaboration initiatives include:

- Close collaboration with care sector, particularly Sahlgrenska University Hospital (SUH) / Region Västra Götaland:

GPCC offices established at SUH/ Östra
Joint research projects and applications
Part-time dual employment of many researchers at the hospital

- Transfer-oriented collaboration initiatives, for example:

Collaboration with SCA to evaluate potential person-centred care in China
Collaboration with AstraZeneca and life science partners in the Beyond the Pill initiative
Role as scientific advisor for the implementation project Forum för välfärd (http://forumforvalfard.se/)

Dedicated initiatives to transfer results into practice include

- Person-centred Care in Practice: an implementation and change management program for sustainable transitions to person-centred care in practice
- Person-centred reference wards at SUH (see also COL 12)

FRÅGA 8

STR 4) Elaborate on the impact of your research to society. (1600 characters)

GPCC aims to drive society's transition to research-based, person-centred care. This takes aim at several urgent needs:

- Growing demands on healthcare providers,

- Increasing healthcare costs, and

- A lack of evidence-based methods for including the patient as a partner, despite this being a political goal and legal requirement on healthcare.

Inability to care for the growing number of persons with chronic illnesses risks lowered quality of care, increased pressure on care providers, and overall increased costs for society.

Person-centred care enables an interdisciplinary approach utilizing the range of expertise of care professionals; a partnership between patient and care provider(s), taking into account the capacity of the patient and her context, and integrating the entire care chain, including self-care and health promotion. We develop tools to support new practice and organizational change, training and educating people who will carry responsibility for the change, and providing a platform for changing opinion and policy to better support person-centred care.

Examples of societal impact include:

- Studies involving the implementation of person-centred care in hospital care have demonstrated 30-50% shorter hospital stay, reducing cost of care by 40%, while also enhancing quality of care (increasing patient satisfaction and reducing readmission rates). These examples demonstrate direct relevance for some of society's most urgent care challenges.

- The Person-centred Care in Practice program has been provided to over 60 care professionals supporting the transition to PCC at 3 hospital wards, reaching over 350 practitioners. It is being expanded to also reach community care (70 practitioners currently participating) and developed as a national sustainable infrastructure for enabling person-centred care implementation.

FRÅGA 9

STR 5) Elaborate on the impact of your research to the business sector. (1600 characters)

For large and multinational companies (MNCs), many traditional business models are losing ground to global competition and a changing healthcare landscape. The pharmaceutical and medical technology industries are facing cost containment requirements, and risk failing to:

- Effectively retain loyalty against brand-generic competition (pharma),
- Integrate efficiently with public care processes (medtech) or
- Foster sufficient adoption to reach critical mass (healthcare ICT).

Research on PCC addresses these issues through innovative care processes with new roles for both private and public actors, particularly stressing the involvement of the patient, and by enabling a closer, more equal relationship with patients, which allows businesses to develop customized and personal services and value propositions. Working together with MNCs such as AstraZeneca, IBM, and SCA, GPCC has helped facilitate the involvement of MNCs in healthcare.

For small and medium sized enterprises (SMEs), a primary obstacle to competitiveness in the healthcare sector is the difficulty of collaborating directly with potential customers and working in the clinical context. Innovative SME's are dependent on their understanding of patient needs, care provider experiences, and the care system as a whole. An increased focus on short term efficiency, as well as procurement rules, make it difficult for SMEs to access these key resources. Research on PCC gives insight into actual end-user needs and desires, and innovative intervention projects allow SMEs to design new products or services in direct connection with clinical practice. Working with SMEs such as Doberman, Circadian, and industry networks, GPCC has helped facilitate SME involvement in healthcare.

Finally, for the private care sector, GPCC can supply best practice models aligned with the values described in STR 4.

FRÅGA 10

STR 6) Exemplify how industrial and societal needs have been identified and how it has influenced the choice of research problems addressed. (1600 characters)

GPCC continuously identifies societal needs through close integration of care providers and patients as partners in research project design, to more concretely specify these stakeholders' current practical needs. The progress of research projects toward meeting these needs are reviewed quarterly, and is supported continuously through innovation facilitation.

GPCC management actively monitors national and global trends and policy developments through a sustained interaction with and presence on various relevant national and international societal arenas, including invitations to participate directly in government initiatives.

The PCC summits initiated and hosted by GPCC with international experts coming together to identify global trends and needs in health and healthcare.

The needs of the business sector are identified in collaborative projects involving industry as co-designers (see e.g. COL 12), as well as more visionary initiatives to discover future needs, such as the Beyond the Pill Initiative. Outcomes from these initiatives feed into project design, evaluations, and new funding applications.

The primary societal needs addressed by our research are the challenges and opportunities facing the care sector.

Among the challenges are:

-A growing aging population

-Inadequate involvement of patients in their own care

-Increasing rates of chronic and multi-illnesses

-Growing costs of healthcare

Among the opportunities are:

-Improved ICT solutions for shared care and self-care

-A more active and informed population living with long-term conditions

-New solutions for personalized and tailored healthcare

These societal challenges also present challenges for businesses needing to adapt their business models - the single largest factor underlying rising health care costs is advances in medical technology and pharmaceuticals.

FRÅGA 11

COL: Collaborations

Collaboration with co-applicant(s) universities/research institutes

FRÅGA 12

COL 7) What is the long term plan for the collaboration between host-university and co-applicant(s) regarding the strategic research environment? (1600 characters)

We have no co-applicants.

FRÅGA 13

COL 8) What has been the major challenges in the collaboration between host-university and co-applicant(s) regarding the strategic research environment? (1600 characters)

We have no co-applicants.

FRÅGA 14

Collaboration with other strategic research environments

FRÅGA 15

COL 9) To what extent have you collaborated with other research environments included in the strategic research areas? (500 characters)

Our specific area of research has attracted researchers from several Swedish regions, as well as representatives from the strategic research environments at Karolinska Institute and Umeå University. These partners have also contributed with two chapters in our text book with 11 chapters describing the theoretical point of departure in person-centred care as well as how results can be applied in the whole care chain.

Two major research groups from GPCC and Uppsala strategic research area have discussed forming a common research group since their field of interest overlap with ours.

FRÅGA 16

Strategies and support regarding collaborations

FRÅGA 17

COL 10) Describe the purpose of different kinds of collaborations to reach the intentions of your strategic research? (Please make use of Table B3 in the annual follow-up studies) (1600 characters)

In order to reach our aim of building infrastructure in the area of person-centred care research, innovation and education, our focus has been on creating collaborations with strategic and high quality contacts from different disciplines, industries, and public sectors. Examples include:

- Top researchers from other universities were recruited in order to complement core research groups (e.g. Karolinska Institute, Duke University, Imperial College).

- Stakeholders were needed to help develop research questions and utilise research findings. Hospitals such as for example Sahlgrenska University Hospital (SUH), primary and community care organisations, patient representative organisations (the Swedish Kidney Association president is a member of the GPCC Executive Board), industry, (IBM, Astra Zeneca, SCA) and policy makers.

GPCC has also worked to build specific platforms for collaboration, for example in the test bed for person-centred care established at SUH, where industry, academia, and the public sector collaborated around implementation of person-centred care as well as spin-off studies on patient-reported outcomes (headed by AstraZeneca).

Within the Person-centred Care in Practice program, GPCC has collaborated with SCA (a global hygiene and forest products company) to develop and pilot an expansion program for person-centred municipal primary care. Financed by SCA, the expansion program is being implemented at Angereds kommunala äldreomsorg (municipal elderly care), directly involving over 70 care practitioners. The pilot combines person-centred care research with SCA's expertise in care for the elderly and persons living with incontinence.

FRÅGA 18

COL 11) Describe the development, since the start of the funding, of your international collaborations with partners in and outside academia (including the EU Framework programme). (1600 characters)

During the development of GPCC as a Strategic Research Area, the number and level of international collaborations has been steadily increasing, toward the goal of becoming a European core research centre. Individual academic collaborations on a project level have increasingly been supplemented with larger, policy- and implementation-directed collaborations.

One key example of international collaboration is the WE-CARE initiative (www.we-do-care.eu), an EU funded initiative where GPCC is coordinating the development of a new R&D Strategy plan and R&D Roadmap for Horizon 2020. The project addresses cost containment in healthcare with maintained or even improved quality of care, and involves several international partners such as the European patient forum, IBM, former and present public ministers in Europe, IMEC (technical industry), Imperial college (health economy), Technical University Berlin (health policy). During the process of formulating a strategy and a roadmap, these collaborations have been intensified and expanded into additional EU proposals relating to person-centred care.

Other important collaborations include Duke University (US), who supported our initial application with an endorsement letter and have during the years been an important research and development partner; international post-doc exchange programs, proposals to a NIH call on patient reported outcomes (PICORI), clinical research etc. In recent years important collaborators within the field of person-centered care has also been identified such as Australia (Griffith University), UK (Health Foundation) and the Netherlands (Radboud University, Nijmegen). GPCC is also currently collaborating with Fudan University of Shanghai in the field of person-centred care.

FRÅGA 19

Collaboration Case Study

We have chosen a case study format. This to create the possibility for you to focus on one successful ("best practice") project that includes collaboration as an example of when it has served the purpose of conducting research of high international quality with relevance for society or the business sector.

You can describe your case in a separate document to be uploaded below.

FRÅGA 20

COL 12) Choose one of your research projects that include collaboration with one or several non-academic organizations or companies to illustrate how collaboration a) has improved the research quality and b) has improved the prerequisites for society and the business sector to utilise the research.

Please enter the name of the chosen project and the project period in the table. Also give a short description of the procject (500 characters).

	Name of project	Project period	Short descritption (500 characters)
	National reference wards implementing person-centred care (NATREF)	Oct 2012 – Dec 2013	The NATREF project was a VINNOVA-supported collaboration initiative to implement person-centred care (PCC) in practice at an internal medicine ward at Sahlgrenska University Hospital. The project involved industry, public sector and academia, aiming to drive innovation, establish best practice, and conduct research. The project was a significant success, and key success factors included collaboration across stakeholder boundaries, a dedicated change management program for sustainable change, and evidence-based tools for standardized practice.

FRÅGA 21

Please enter collaboration partners (maximum 2) and verfied contact information.

	Name of organisation	Name of contact person	Verfied contact information, including e-mail
Partner 1	Sahlgrenska University Hospital	Putte Abrahamsson, Head of Department of Medicine, Geriatrics and Emergency Ward	Putte.abrahamsson@vgregion.se
Partner 2	IBM	Torbjörn Hägglöf, Client executive, life sciences area	Torbjorn.hagglof@se.ibm.com

FRÅGA 22

When describing your case we would like you to consider the following aspects:

A description of how the collaboration has been organised (contracts; division of labour; meetings; financial or in-kind contributions etc.).

If and in what way the research collaboration has led to advances or alterations in higher education programs associated with the strategic research at the university

If and in what way the research collaboration has led to an improved international status of the strategic research environment.

The major challenges in this research project with regard to its collaborative aspects.

In total you have 6000 characters at disposal for your case study.

Please upload the case study as a pdf or word-file here:

Antal bifogade filer: 1. Filen/filerna kan ses i resultatöversikten (webb).

FRÅGA 23

INT: Research and Education integration

FRÅGA 24

INT 13) Exemplify how research within the strategic research environment is integrated with different levels of education (1600 characters)

Integration of research into education has been a key mission for the centre from the start. Since 2010, our researchers have been including person-centred care in their teaching whenever appropriate at different levels and programs at the University of Gothenburg and in the undergraduate program for nursing at LaTrobe University, Australia. Since 2011 we have more systematically started to offer academic courses on person-centred care.

The first course (7.5 credits) was at PhD-level. Since then, we have offered similar PhD-level courses once a year, targeting multidisciplinary classes.

To reach other levels within academic education, we integrate research based knowledge on person-centred care in all programs for specialist nursing (postgraduate level). All students in half-time pace programs (surgical, medical, oncological, psychiatric, elderly care) and full-time pace program (anesthesia, pediatric, adolescent, intensive, surgical, district) develop knowledge of person-centered care.

To reach undergraduate level, we will pilot a course of person centred care in four programs (nursing, medicine, occupational therapy, physiotherapy). This course starts in October 2014, and the students will earn 7.5 credits. The intention is that this course will be implemented in all programs at Sahlgrenska Academy by 2016.

Finally, an enhanced executive education and implementation program (Person-Centred Care in Practice) was designed and launched in 2012 (see also COL 6). In 2014, the program was further expanded, to also cater to professionals in municipal elderly care (see also COL 10). The core program is complemented by ongoing seminars and workshops held on-demand for teachers, multidisciplinary researchers and care professionals in various organisations throughout Sweden. Demand is currently very high.

FRÅGA 25

INT 14) Explore to what extent the educational programs associated with the strategic research environment provide the industry and society with qualified personnel and research based knowledge. (1600 characters)

Through our tailor-made enhanced executive education Person-centred Care in Practice, we have reached app. 300 professionals at hospitals (nurses, assistant nurses, physicians, care managers) and 150 professionals (nurses, assistant nurses, occupation and physio-therapist, care managers) in municipal elderly care, providing them with knowledge and practical skills in person-centred care.

Through our unique pilot scheme started this year GPCC will provide different care settings with graduates (physicians, nurses, occupational therapist, physiotherapists) who will have a thorough knowledge and understanding of person-centred care. In 2016, they will start working in their new professions. If proving successful, this scheme will be rolled out across all undergraduate programmes at Sahlgrenska Academy.

Person-centred care research has been implemented in master's level educations for nursing students at Sahlgrenska Academy, who are now beginning careers in their respective specialties. This means that our research environment has provided wards of surgical, medical, oncology, elderly and psychiatric care with 42 new specialist nurses who are capable of carrying out person-centred care tailored to their professional contexts.

In 2015, we will further educate 134 new specialist nurses in the fields of anesthesia-, pediatric and adolescent-, intensive-, surgical, midwifery and district nurse care.

At present 6 persons have completed PhD degrees, 3 persons licentiate degrees and 5 persons have begun their post doctorate process in the field of person-centred care within the centre. They will all continue spreading person-centred care in their clinical work or in our higher education system here in Sweden and abroad. All 32 current PhD students linked to the centre take part in a regular person-centred care programme.

FRÅGA 26

INT 15) Explain to what extent you use international recruitment of students (including research training of PhD students and post-docs) to achieve the goals for the strategic research environment? (1600 characters)

International recruitment of students has not been a prioritized strategy to reach the goals of the centre, but has been encouraged and facilitated where appropriate. Recruitment has primarily focused on the needed range of competences for specific research goals, which at times has placed heavy emphasis on familiarity with the Swedish care setting and its practice, and in other projects has been entirely separated from the specific Swedish context.

The 32 Ph. D. students fully or partly financed by the centre are thus primarily Swedish, and receive support from the centre to build international networks, collaborate outside of Sweden, and participate in conferences and exchange programs. We do, however, have some international PhD students; one from Portugal, one from Vietnam and one from Saudi Arabia, as well as two Postdoctorate scholars from the U.K..

GPCC is expanding its international network and presence, and will continue to support international recruitment wherever most suitable for the specific research needs.

FRÅGA 27

OTHER

FRÅGA 28

OTH16) What are the major changes made in the research program since 2009? Please describe and motivate (1600 characters)

Two significant changes have been made:

First, we reorganized both on a management and project level, to minimize the risk of disciplinary silos forming. The reorganization removed the domain-based management system for centre research (symptoms and signs, patient education and learning, clinical methods and organizational research), and established a more active cross-project organisation. Although the domains remained as thematic boundaries for the program as a whole, projects were allowed and encouraged to cross domain boundaries.

Second, we reorganized to integrate innovation and education with research at all stages – not research first, then education and innovation. A further effect of these changes has been an increasingly challenge-driven focus reflecting the expectations set by GPCC's vision to drive the transition to person-centred care, which has been widely internalized among GPCC's researchers.

On a governance level, these changes resulted in the formation of an executive committee with one coordinator each for research, education and innovation meeting weekly to jointly evaluate, manage and plan for all projects. In addition a meeting has been held on average bi-monthly with PI's of core projects with a standardized reporting and discussion format. This structure has helped build a sense of joint identity, a common basis for theoretical development, cross-disciplinary links, broader awareness of challenge areas and research questions, and better alignment to build necessary critical mass for societal impact. Concretely, several core research groups have developed into joint programs while weaker groups have been integrated with others.

FRÅGA 29

OTH 17) Describe your long-term strategy for the supply of competence to the research environment, both in terms of research capacity and leadership. How are succession, equality and diversity dimensions incorporated in this? (3200 characters)

In order to ensure the sustainability and continued evolution of the centre, we have developed and implemented:

- A short term strategy to directly enhance the centre by recruiting top senior researchers in relevant fields, and

- A long-term strategy to develop competences, leadership and loyalty in students and junior researchers.

This strategy also includes international collaboration with other environments within the area of person-centred care (The Netherlands, Great Britain, Belgium, the United States, etc.), exchanging post doctorate students and visiting researchers and professors. This activity has developed over the years and is now growing both in terms of international as well as national collaborations. Representatives and collaboration with stakeholders, such as patient organizations, hospitals, primary - and community care and policy makers as well as industry within the area has been a strategy from the start (e.g. several endorsement letters added to our application) and has rapidly developed over time.

In all strategic decisions the centre maintains an awareness of and desire to promote equality and gender balance in a traditionally female-dominated field. The Centre management group represents a diversity of educational backgrounds, ages, and genders, and annual reviews of research projects indicate a near equal gender balance. Further, GPCC adheres to the University of Gothenburg policies and guidelines on equal opportunities, equality and diversity.

SHORT TERM STRATEGY:
Students from both basic and advanced levels, spanning a range of disciplines at the University of Gothenburg (psychology, philosophy, occupational therapy, medicine, nursing among others) have applied to GPCC for curator positions, i.e. spending a portion of their time during their education within a research group following the research process and working with different tasks in the group such as collecting data etc. After concluding their basic education and exams, several of these have continued as PhD students within GPCC, indicating the attractiveness of the research and the environment.

At present we have 32 PhD students who, through the courses and seminars provided in the centre, will comprehend the theoretical framework, strategy and methodology in depth. Many of them will have post-doc periods at our international collaborators, and we will receive post-docs from these environments.

The executive board including only seven persons; the director, a patient representative, one each from research, education, innovation, economy and administrative support, meet every week and closely follow activities in the center through short follow up reports submitted every second month by the researchers. The researchers are also guided by the members of the executive board in methodology, education and utiliation issues, as well as economy, in regularly meetings including discussions on project progress, barriers and possibilities for progress.

LONG TERM STRATEGY:

Ten Principal Investigators from the centre’s core research groups, together with three junior researchers and the executive board, are participating in a long-term program on leadership and strategy on research, innovation and education. This group is the cadre in GPCC and forms the leadership board for the centre. The majority of the participants is comprised of senior researchers in GPCC, but junior and younger representatives are also involved to enable succession to run smoothly and stepwise.

FRÅGA 30

OTH 18) Have you applied for, and/or received EU-funding within the scope of the research environment? Please list the number of applications and received grants respectively. (500 characters)

Within FP7, GPCC was granted funding under “Preparing the future for health research and innovation”. GPCC coordinates this project (WE-CARE), which addresses coordination efforts between the key European players in health and health care policy and practice. Academia, industry, national programmes and other relevant organisations, come together to develop a strategy plan for further development of targeted health research areas with high impact on competitiveness,healthcare systems and benefit for Horizon 2020. The R&D roadmap will be presented and submitted in 2015.

FRÅGA 31

OTH 19) Elaborate on how your research environment ensures that also future industrial and societal needs are identified and incorporated in the research (1600 characters)

In addition to maintaining the activities outlined in STR 6, three elements are expected to ensure the continued relevance of GPCC projects for future industrial and societal needs:

1. A dynamic roadmap of key challenges for healthcare

In order to identify and meet future needs, GPCC will develop a proactive roadmap of challenges outlining the most significant trends and potential obstacles facing the care sector and society. Known trends like our aging population and changing life science business models must be translated into concrete needs. This roadmap will be used to evaluate research projects, scout for needed competences, and design new research projects with innovation potential. A dedicated stakeholder group representing the care sector, industry, and policy makers will support the development and evolution of the roadmap, as well as its application to research projects.

2. The continued transfer of implementation results back to the centre

The transfer of research results to industry and society will continue to be a two-way process, feeding knowledge about stakeholder needs back to the centre. This will verify assumptions about stakeholder capacity and needs (for an example, see COL12). Expanding the Person-Centred Care in Practice program will continue to bring in new knowledge about challenges / possibilities for implementation and evolution in practice. Other research projects will be monitored for contributions to our understanding of needs.

3. Continued development of person-centred care theory

The continued evolution of an interdisciplinary, practice-oriented theory of person-centred care is also expected to ensure the relevance of centre research, by complementing our awareness of future challenges with the discovery of new opportunities and areas for development, and transferring this awareness to stakeholder partners.

FRÅGA 32

OTH 20) What has the specific funding from the strategic research grant meant to your research environment? (1000 characters)

The strategic research grant has allowed the formation of core research centre driving the shift toward evidence-based person-centred care. Its primary impacts have been:

- An interdisciplinary research centre spanning all faculties at the University of Gothenburg, with over 40 current or completed coordinated research projects addressing person-centred care.

- A research environment with clear governance and management organization to develop and drive the vision of evidence-based person-centre care in research, education, and innovation.

- A platform for disseminating research results and raising awareness nationally and internationally about person-centred care, allowing for the development of strong national and international networks.

- The necessary resources and cohesiveness to establish dedicated initiatives for designing, testing and implementing person-centred care in practice together with industry and the public care sector.

FRÅGA 33

Thanks for your answers! Go to next page to send in your report!

Name of the strategic research environment: Toward Person-Centered Care in Long-Term Illness: A Research Core Center

Acronym: VårdGu

Host university: University of Gothenburg

Co-applicant(s): none

Rapporteur: Pam Fredman, Vice-Chancellor

UM 1) Are there differences in how the University supports the SFO-environment compared to other priority research areas of the University that have not received external strategic funding? If there are differences, can you give examples?

The University of Gothenburg hosts one strategic research area, GPCC, but is also co-applicant on six strategic research areas (BioCare, MultiPark, MERGE and BECC with Lund University; Transport, and Materials with Chalmers). The participation in these strategic research areas is considered to be very important for the university, since this allows us to influence the development of several strategic research areas within Sweden. It allows close interaction with our partners, and enables our own researchers to participate in research at highest international standards. For the University of Gothenburg, the strategic research area for which we are the host university – Care research – is of special value and we are dedicated to support this effort to be an international leading center within this area of research. The university allocates additional funds corresponding to 50% of the amount awarded by the government to all of the SFO-environments at the University of Gothenburg, irrespective of whether they are main applicant och co-applicants.

One important purpose of our own strategic investment is to further stimulate interaction between both other parts of the university and external collaborators with the SFO environments. Thus, we aim to achieve "added value" by using the additional resources to encourage cooperation with GPCC in order to take advantage of this investment to initiate research related to, but not within the core of GPCC activities. For example, these additional resources have been used to initiate research in health economics at School of Business, Economics and Law at the Center of Health Economics. This has enabled us to recruit leading scientists in health economics to the university, which in turns adds value to research activities at GPCC. Another example is the incentive to develop research collaborations with other universities and health care providers. Thus, an agreement of cooperation in the research area Care research was signed by all local university colleges, Chalmers University of Technology, The University of Linköping, The University of Jönköping, The University of Halmstad, Region Västra Götaland and the Göteborg Region Association of Local Authorities (GR). This agreement aims to increase research collaboration and further develop focus areas within Care research in close collaboration with the health care sector. Another example, from the SFO BioCARE, is that these additional resources have been instrumental for the establishment of our Cancer Research Center, which in turn is important for the success of the collaboration with Lund University in the strategic research area "cancer".

There are other strategic investments in research environments at the University of Gothenburg. Many of these have been successful in receiving external funding. For example, we have two programs within the Linnaeus grants awarded by the Swedish Research Council (VR). Both of these environments have recently been evaluated and found to be very successful resulting in increased funding by VR. The way we support our strong research areas thus seems to be successful. Also these environments are supported by the university with an additional basic funding to allow them to take initiatives beyond the core of their applications, obviously resulting in "added value".

Five years ago the university decided to invest in "areas of strength" to focus on a limited number of research areas. This was a process in which the deans of the faculties together with the vice-chancellor identified areas believed to have potential to develop into leading international research environments taking advantage of the full-scale university. The areas were "globalization", "learning", "opinion and democracy", "cultural heritage" and "language technology". The investment will be evaluated by an international advisory board this fall, but it seems that some of these internal investments have been very successful and now can rely on national and internal competitiveness for research funding. In principle, similar strategies have been used to promote and stimulate research within strong and strategically important research areas although the magnitude of central support may vary. Definitively, the support to the SFOs is one of the major priorities of our university.

UM 2) What is the inspiration and the benchmark for the university's Higher Education and Research Management, and why, in regard of

a) **Maintaining or reaching research quality of the highest international standard and to reach an international leading position within their field of research.**

The University of Gothenburg is a full-scale university with 37 000 students and 8 faculties including all natural sciences and health sciences, as well as creative arts, humanities and social sciences; only engineering is not represented, this being covered by Chalmers. The university has a strong history of outstanding research in several areas, not least within medical and health care sciences. One example of this strength would be the awarding of the Nobel Prize in medicine and physiology to Professor Arvid Carlsson in 2000. The University of Gothenburg has strong local and regional ties at the same time as its research, education and cooperation are characterized by strong global engagement. The distinct sense of social responsibility and the openness to the rest of the world are important for providing inspiration.

In 2010 the university performed an evaluation of its research from an international perspective. It is the single most important benchmarking effort comprising the entire university and resulted in the report *Research evaluation for development of research 2010 (RED10)* (https://gupea.ub.gu.se/handle/2077/24885). This evaluation was performed by 122 international evaluators forming 18 panels. The overall assessment was that there were many excellent and enviable elements, including a unique position in life sciences, medical sciences and several areas in social sciences, humanities and arts. However, concerns were raised and suggestions were made to improve overall research quality at the university.

RED10 served as an important source and inspiration in the process of developing the university Vision 2020. Vision 2020 lays down the long-term aims to achieve continued successful development in the period 2013-2020. It is the result of numerous seminars and work-shops with about 1000 employees participating in the various activities. Vision 2020 in turn, is the basis for yearly Action and Operational plans that are developed at all levels within the university (http://medarbetarportalen.gu.se/vision_2020/action_and_operational_plans/). This provides concretization and adaptation of Vision 2020 to benefit all levels. The plans have included focus on external recruitment of highly qualified researchers, clarification of career possibilities, strategic co-funding of younger investigators who are competitive with respect to highly prestigious grants, co-funding of international grants (EU and NIH) and highly competitive larger national grants (Knut and Alice Wallenberg Foundation, KAW, and others). Several of the faculties have created various incentives to strengthen research, for example by encouraging international publication, stimulating international cooperation etc. The plans also serve as basis for follow-up at all levels.

Inspiration and benchmarking is sought at all levels within the university. For instance the Vice-Chancellor draws inspiration from chairing The Association of Swedish Higher Education (SUHF) and from the European University Association (EUA), including being a member of EUAs Research Policy Working Group, and the university leadership has exchanges with e.g. the University of Aarhus, Denmark and Stellenbosch University, South Africa. Also the University draws on the insight and expert input of our International Advisors – Professors Krista Varantola, former Vice-Chancellor of Tampere University, Arild Underdahl, Chancellor of Oslo University and Iain Robinson from MRC, London. These advisors have been an invaluable help in developing research and education strategies.

b) **Linking the strategic research areas with the needs of societal organization and the business sector?**

In Vision 2020 it is stated that "Our aim is for the University of Gothenburg to by 2020 be characterized by responsible and engaged cooperation efforts. This will have a ripple effect that will

facilitate dissemination of knowledge to the surrounding world, research being put to practical use as well as inflow of new ideas and knowledge. It will also make the university an attractive cooperation partner". There is, of course, a political pressure on universities all over the world, not least Europe and Sweden, to increase their efforts into dissemination and translation of research results into society. The SFOs and Horizon 2020 are clear examples of such inspiration, apart from an internal driver obvious from the Vision 2020 process.

Therefore, the university has invested resources in an Institute of Innovation and Social Change (www.iis.gu.se) and in scaling up the support functions in the Grants and Innovation Office (FIK). These resources, in combination with our holding company, GU Holding (GUH), form a basis for linking the research areas with the needs of societal organizations and the business sector.

In fact, GPCC is an inspiration as such in the university's efforts to engage with and address societal needs – that is, packaging research results through providing some type of consulting or other service that goes beyond education and research, without transferring research and control over results into a privately owned commercial product. GPCC was one of the first to take an action in this area. This raises again the need to identify a permanent solution for these types of constructions – not only for GPCC, but also for a number of other environments that have a need to engage in similar actives.

Because it is characterized by a breadth and diversity of research areas, the university recognizes that there are, accordingly, a variety of ways to create value from research outcomes. While commercialization-oriented innovation is a well-established and recognizable means of creating value, there are also opportunities for other types of impact – for example, in the form of process development in the public sector or by means of promoting equality, sustainability and social justice.

As a result, the Grants and Innovation Office offers research environments across all disciplines integrated support in relation to a broad range of needs, stemming from:

- securing external research funding,
- collaborating with industry and other public research organizations,
- negotiating contracts with external parties, as well as
- managing a broad range of utilization and innovation activities.

In addition, this integrated approach is used to support research environments in a proactive manner. This means that instead of waiting for researchers themselves to identify potentially valuable ideas and seek out support, the Grants and Innovation Office works proactively to identify and analyze potentially valuable knowledge assets generated from research along with relevant utilization opportunities. This enables these research environments to assess paths for creating value and impact from research using a more holistic approach to utilization which encompasses social innovation, collaboration with regional or governmental actors, education and training of professionals, consulting opportunities or generating new products or services for public and private sectors, among others.

The goal of this integrated approach is to put researchers, research leaders and management in the best possible position to make informed and strategic decisions to most effectively generate value and societal impact from research. The support activities offered by the Grants and Innovation Office help strengthen the university's ability as an organization to take responsibility for the results generated by research and education activities. By enabling informed decisions and a holistic approach that go beyond only commercialization, strategic research environments are able to more effectively work towards contributing to the university's vision to take greater social responsibility.

As a result of these needs, both GUH and FIK have begun to work with these types of issues. GPCC represents an opportunity for GUH and FIK to work together in identifying, developing and evaluating

an appropriate model for how the university can actively work with environments that have these specific needs – namely, non-commercial offerings that have the ability to generate substantial societal impact but which also need to be economically sustainable.

c) Cultivating collaborations with other universities and non-academic organizations?

The university Vision 2020 sets ambitious goals for collaboration and societal impact for the whole university and has served as an inspiration also for processes related to collaborations with other universities and non-academic organizations. The integrated strategy for cooperation, academic and non-academic, is implemented through yearly planning and follow-up processes where cooperation as part of the scientific and organisational development is always considered closely. Cooperation with non-academic bodies is considered top priority for all university research centres and projects. The Annual Report of the university brings out examples of cooperation and the explicit results in terms of innovation and quality, and the annual university award for excellent cooperation projects brings special attention to the implementation of our goals.

The implementation of Vision 2020 relies on prioritizing the development of international academic contacts. The bulk of these collaborations are planned and developed on department or faculty level and the goal is invariably to press on for higher quality and international standing in all fields. At management level the university strives for a limited number of high quality cooperation projects such as the SFOs. Other long-term exchange agreements are kept with institutions and university cities and regions such as Tokyo, Shanghai, Bombay, East Africa, Massachusetts, California etc. All agreements are prepared and evaluated by the central International Office and supported by the Grants and Innovation Office. The international contacts and cooperations are followed up on the educational side with a large number of international Masters Programs and European exchange students. The university's newly launched program for Global Challenges (UGOT Challenges) is set up to support international cooperation for cross-faculty projects.

d) Strengthening the link between the research and education?

One of the most important outcomes of Vision 2020 was the strong emphasis on the link between research and education resulting in the terminology "complete academic environments". The inspiration for the strategies of the university is thus a result of numerous work-shops and seminars during the Vision 2020 process and visits to other universities, such as Imperial College, London, University of Manchester and Aarhus University and by scrutinizing and analyzing documents from 6 other universities, among these University of Amsterdam, University of Wisconsin and University of Leeds. During this process speakers and participants from other national and international universities were invited.

Again, the GPCC experience can illustrate the importance of the Vision 2020 and action plans for strengthening the link between research and education. In the Action plan for year 2013, the Sahlgrenska Academy decided to focus on inter-professional learning with a strong research base. The Vice-Dean for Education initiated a project in which the program coordinator together with teachers/researchers and students from each of the professional education programs (medicine, physiotherapy, occupational therapy and nursing) together with researchers/teachers from GPCC develop the educational programs with respect to content and design based on research outcomes in GPCC.

UM 3) What is the nature of support (for example recruitment strategies, management training, collaborations, infrastructures) from the host-university when it comes to development and management of the strategic research environment in regard of

a) Maintaining or reaching research quality of the highest international standard and to reach an international leading position within their field of research.

As part of its Vision 2020, the University of Gothenburg works actively to establish complete academic environments, capable of supporting cross-border interdisciplinary collaboration within research and education, and first-rate research. The university has enabled and encourages the formation of academic centres to host these environments, as platforms which support interdisciplinary collaboration and infrastructure development, as well as a launching point for national and international awareness-raising.

The university has funded and supported the formation of GPCC as one of 30 academic centres at the university, allowing it to tie together research across almost all faculties at the university, and facilitating collaboration within research, education and innovation. This has been a necessary building block for GPCC, allowing it to reach across faculties and disciplines, and providing it with autonomy to drive the development of its core concept (Person-Centred Care, PCC). As the PCC concept ties together care sciences, medicine, economics, social sciences, pedagogy, and many other disciplines, the ability to span all faculties at the university and also allocate funding independently across faculties has been and will continue to be crucial for the quality of research at GPCC.

The university promotes active recruitment to foster strong research environments, support the development of young researchers, and attract nationally and international talent. The GPCC recruitment strategy is coordinated with this strategy, and aligned in close collaboration with the head of the Institute of care sciences. Personnel at GPCC are employed at their respective institutions within the university, including dedicated administrative support as well as economic management support. This has provided GPCC with the capacity to directly interface with research projects on a running basis, and enabled it to fine-tune research financing and project agreements to the overarching goals of GPCC.

The Strategic Research Area has been one of the university's most ambitious research centre initiatives, and has evolved beyond expectation, both as regards the breadth of interdisciplinary research, and the continuous dissemination and integration of results into education and innovation has proven beneficial to challenge-driven, practice-oriented care science of the highest quality. The initiative has also proven a solid foundation for international outreach, and GPCC is now a leading European platform for person-centred care research and implementation. The university will continue to support GPCC as a complete academic environment after its period as a Strategic Research Area, to ensure that it has the capacity to maintain or strengthen its established links to all the faculties at the university, and to allow it to continue to tailor interdisciplinary projects that drive the development of PCC nationally and internationally. The university will also specifically support and facilitate the interaction and collaboration between GPCC and the Centre for Health Economics at the university, as well as Chalmers University of Technology, to complement competences within GPCC. GPCC will be expected to pave the way for future strong academic environments at the university, and will be encouraged to also develop collaborations and close integration with these where appropriate.

b) Linking the strategic research areas with the needs of societal organization and the business sector

The university aims to promote research that addresses and over time solves regional and global problems through collaboration and innovation. It has funded GPCC to promote collaboration and challenge-driven research and innovation. It has also initiated a social innovation program, for identifying and driving social innovations with the potential to address key societal or business needs. This program will provide a structural platform for the development, implementation and education initiative "GPCC Development", anchoring the initiative in the university innovation system and giving it structural stability and legitimacy. The university will continue to support this program, to allow GPCC to meet the high demands currently experienced for implementation and education

facilitating a transition to PCC in practice. By offering the GPCC Development programs to stakeholders across the country, GPCC is able to directly learn from the needs of caregiver organizations (including decision makers, professionals, and patients). This requires an integrated platform with the capacity and legitimacy to work professionally to provide evidence-based implementation, which will be the focus of the social innovation program.

The University of Gothenburg also promotes challenge-driven research that addresses global issues that can be understood, addressed, and/or resolved through the application of research. The university is launching the UGOT Challenges initiative to finance and support research that tackles global societal challenges, and this initiative will be open to GPCC. Within this program it will be possible to establish flagship initiatives that deal with specific, pressing challenges, which are not on the same scale as GPCC, but which will benefit from targeted research and support. The university will also support the further development of challenge-driven governance at GPCC, enabling it to develop a clearer definition and road map of the challenges facing society and the care sector.

c) Cultivating collaborations with other universities and non-academic organizations?

Meeting global challenges requires collaborative research across stakeholder boundaries, and the need for collaboration grows as the complexity and scope of the challenges becomes increasingly obvious. The university supports and promotes collaboration between on the one hand academic research and education, and on the other hand society and the commercial sector. The interdisciplinary collaborative projects in GPCC are an example of internal collaboration promoted in the university across disciplines and faculties.

In terms of external collaboration, the university has supported GPCC in initiating collaborative projects with both the care sector and with private actors, and will continue to support these initiatives. A key component in this has been GPCC's ability to initiate, support and drive close collaboration with the health and care sector, and to compensate some of the costs incurred by public organizations in setting up innovative interventions and implementation projects, which the university will continue to support. GPCC has also received operative support in identifying public-private project calls, and organizing applications for these calls from the dedicated university innovation support function, as well as in managing procurement. In the event that GPCC chooses to engage in large scale national or international collaborations such as a Knowledge and Innovation Community in health, the university will ensure that GPCC has the resources to commit fully to such an initiative.

Finally, to promote new collaboration opportunities, awareness raising and outreach, the university has supported GPCC in ongoing communications activities, conference participation, and targeted events for reaching stakeholders, policy makers, etc. This has included providing rooms and locales, hosting events, and financing participation in public dissemination events. The outcome of this has been highly valuable, as GPCC has grown to be recognized as a key player both nationally and internationally. In this way GPCC promotes and contributes to the development of the university brand, and has built up excellent channels for continued research, collaborations, as well as thought leadership within the field of person-centred care.

d) Strengthening the link between the research and education

The link between education and research and the dialogue between researchers and students is vital for the university's long-term knowledge accumulation, and all education at both undergraduate (first) and advanced (second) level must have a clear link to research, just as all research must have a link to education. The university has supported GPCC in fostering this link, and enabled it to establish several academic educations in PCC on various levels. It has also supported the delivery of executive education programs in PCC, initially through the GU School of Executive Education and in the future

through the GPCC Development platform at GU Holding. The university will continue to support GPCC's integration of PCC research into academic education and to overcome potential resistance to introducing PCC in the curriculum of traditional educations.

UM 4) Please explore the Strengths, Weaknesses, Opportunities and Threats to the Strategic Research Area hosted by your university, in regards of:

a) **Maintaining or reaching research quality of the highest international standard and to reach an international leading position within their field of research.**

Summary: The Strategic Research Area has developed into a complete academic environment with interdisciplinary projects representing almost all faculties at the university. It has defined and promoted its core concepts nationally and internationally, and initiated several research projects with high potential. A strong grounding in clinical care practice provides it with a foundation for new and ongoing research of high practical relevance. There is a relative lack of international collaborations and prominence, and need to continue to focus on complementary research and the interdisciplinary perspective.

Strengths

Core concept: GPCC has defined its underlying concept (Person-Centred Care, PCC), and its core pillars, both nationally and internationally through publications and awareness-raising dissemination activities. This has established a foundation for further theoretical development of high quality, and has clearly defined the centre as a leader within its field.

Interdisciplinary projects: GPCC has initiated several interdisciplinary projects with relevance for person-centred care, which bring together researchers from almost all faculties at the university, and which are generating new results and publications continuously. As an independent centre within the university, it has been possible to design projects and allocate funding across faculties at the university.

Cadre function: GPCC has established a research cadre function comprised of thought leaders and principal investigators, and aligned these with governance of the centre. This function will more directly align research activities across projects with the core concept of the centre, and allow for streamlined governance of project activities.

Ph.D. students: In order to build future scientific prominence, the centre has recruited 40 doctoral students and trained these individuals in the PCC concept. These students represent a diversity of scientific disciplines and a strong commitment to developing the scientific excellence of the centre under the PCC umbrella.

Weaknesses

International test beds: Research at the centre benefits greatly from access to care practice as test beds and arenas for conducting projects in connection with practice. However, due to a lack of access to international care organizations with similar capacity, the research at the centre often has limited impact on international practice.

International collaborations: While some international collaborations have been initiated on a central level, many of the projects in GPCC lack international partners, academic or otherwise, which could boost the scientific quality and international position of research further, as well as open up future collaboration opportunities.

Health economics: Obtaining expertise in health economics has been identified as a key means of expanding the relevance and quality of research at the centre, but with the exception of the university investment in a Centre for Health Economics (see UM1), which has led to positive results, it has been difficult to complement existing research with strong health economics competences.

PCC Recognition: As PCC is an interdisciplinary concept, it has been and will be more difficult to obtain scientific recognition and impact within this specific field. Many of the projects in the centre have obtained recognition within traditional fields, but not necessarily for the person-centred focus of the projects.

Opportunities

GPCC Development: GPCC has launched an ambitious development program for evolving and implementing PCC in practice, combining knowledge transfer, executive education, and change management to work directly with partners and stakeholders to enable a transition to PCC. This platform continually feeds back knowledge to the centre, providing new practice cases for research and new project design.

PCC theory: After establishing the core PCC concept and its philosophical and ethical foundation, there is an opportunity to further explore the links and overlaps between PCC and relevant theories, as well as explore the possibility of a dedicated PCC theoretical framework. Internationally there is a call for defining the theoretical basis and key concepts of PCC, and since GPCC already has done a lot of work in this area, others have shown great interest.

PCC Summit: GPCC has on two occasions hosted a summit of internationally leading participants from industry, academia and policy makers, on topics of relevance for PCC. This has already opened up access to valuable networks and project ideas, and is an opportunity for further establishing the international leadership of the centre.

Threats

Development focus: Developing PCC from a concept to a robust theoretical framework will require dedicated activities and resources. If GPCC is not able to maintain a unifying environment, and dedicate support for focusing on PCC development, there is a risk that the current understanding and application of PCC will fragment.

Interdisciplinarity: Interdisciplinary research is a cornerstone of PCC research but requires support and specific activities, such as joint meetings or conferences across disciplinary borders, as well as incentives to maintain links across disciplines. If GPCC is not able to continue as a centre formation in the university spanning all faculties, and is relegated to a single faculty or discipline, it will not be possible to maintain its interdisciplinary connections.

Project governance: Successfully driving the development of PCC as a research area has required freedom to assess, govern, and support projects according to non-traditional criteria such as person-centredness. If GPCC loses the freedom or the resources to effectively make such governance decisions, it will be unable to effectively align projects with the PCC research vision

Loss of leadership: While GPCC has positioned itself as a leader in defining PCC, there are several other organisations exploring similar concepts and research areas. If the centre loses momentum or development focus, there is a risk that others will overtake GPCC and either co-opt or dilute the PCC concept. This could mean losing the strict, evidence-based focus of PCC to other organizations using the concept primarily as a brand.

b) Linking the strategic research areas with the needs of societal organisation and the business sector?

Summary: GPCC has developed a strong practice of integrating the needs of stakeholders in its research, primarily through collaboration. The care sector has been the primary targeted stakeholder, but also industry. Practice-oriented research and direct implementation programs have allowed for direct feedback on stakeholder needs. GPCC lacks strong ICT competences and has relatively few actively engaged industry partners. Several opportunities exist for improving the link to societal and business needs, including a more challenge-driven governance and direction of the centre. Key threats involve the continued momentum of GPCC and anchoring in both the university and care setting, to provide support and legitimacy.

Strengths:

Care sector collaboration: Working directly with the care sector, both primary and secondary care, provides GPCC with direct input into the needs and main issues facing its key stakeholder. The collaboration with hospital care at Sahlgrenska University Hospital is particularly strong, with GPCC having offices located within the hospital, and many researchers holding dual employment, experiencing the challenges of the care sector in practice. Collaboration with and support from, amongst others, national bodies like the Swedish Association of Health Professionals and The Swedish Society of Nursing, both organisations with great influence on the care sector and national politics, help drive the call for PCC, which they see as top of their agendas for national health care improvement.

Patient representation: Patients, while not a societal organisation, are among the most directly affected stakeholders in PCC. GPCC always ensures that patient needs are understood and addressed, by directly researching the patient perspective, by involving patients as partners in research project design and execution, and through collaboration with patient representative organisations, for example as part of the GPCC executive board.

Project review and assessments: Projects in GPCC are reviewed on a quarterly basis to determine which societal and/or business needs they address, and to determine if they can target those needs more effectively with additional support.

Industry support: From the foundation of GPCC, industry actors have strongly supported its formation as a platform for PCC research, with the potential to benefit the pharmaceutical sector, the medical technology sector, consumables and services, and private care providers.

GPCC Development: The ongoing evolution of the GPCC Development function enables it to identify new stakeholder needs and branch out in relevant needs-driven directions. An example is the recent development of a new implementation program directed specifically at municipal elderly care, currently ongoing.

Weaknesses:

Needs-driven governance: Projects in GPCC are currently reviewed and given support to address stakeholder needs, but the centre does not have a function for governing and directing projects in this regard, meaning that addressing needs is still a voluntary effort, compared to research milestones and goals.

ICT competences: Experience at GPCC shows a pervasive ICT-component (information and communication technology) to almost all stakeholder needs – while PCC can be implemented without developing or adapting specific ICT solutions, the working practices of most stakeholders mean that many needs can be more efficiently and directly addressed if complementary ICT solutions are included. Currently GPCC lacks these competences in-house.

Industry engagement: While there is general support for the centre from relevant industry actors, it has been difficult to promote and sustain active engagement, barring a few notable exceptions. Industry actors often lack necessary interfaces for relating effectively to the care context, and find it challenging to identify incentives for close involvement.

Opportunities:

Challenge roadmap: By drawing on stakeholder input and developing a roadmap of key challenges for the future of person-centred care, GPCC has the opportunity to create a governance framework for utilization activities that directly corresponds with evolving stakeholder needs.

Challenge reference group: By establishing a dedicated reference group of stakeholder representatives for formulating challenges, directly assessing the centre's capacity to address those challenges, and making challenge-driven recommendations, GPCC has the opportunity improve its relevance to societal and business needs, and to address them.

Personalized medicine: Personalized medicine is gaining prominence as an area for future breakthroughs in individually tailored diagnostics and treatment, yet it is unclear how compatible these advances are with the involvement of the patient in the care process, and with the goal of cost containment. GPCC has studied the links between PCC and personalized medicine, and has the opportunity to support the development of complementary solutions that would address the need for person-centred and cost effective personalized medicine.

Demand for implementation: As a result of GPCC's efforts to establish national reference wards in PCC, and the success of the GPCC Development program, the centre is experiencing very high demand for implementation support and training in PCC (currently discussing implementation in 12 different Swedish organisations and regions, with new requests coming in with high frequeny). This is an opportunity to connect with new stakeholders and gain insight into challenges and specific needs.

UGOT Challenges: The university is currently launching a program for supporting challenge-driven research on the theme "Global societal challenges." Participating in this initiative will be an opportunity for GPCC to enhance its ability to address pressing challenges and societal needs in its research.

Threats:

Involving industry: If GPCC is unable to more closely involve industry partners, there is a risk that the needs identified in the centre will not be possible to link to solutions, as the centre will lack the capacity to satisfy demand.

Innovation system anchoring: If GPCC is not able to clearly anchor its implementation activities in both the innovation ecosystem of the university, and the West Swedish care context, there is a risk that innovation and utilization activities will lack the necessary authority and legitimacy for widespread impact. If this is not possible to maintain, the centre risks facing obstacles when working with anything other than research, as its role will not be clear.

Maintaining momentum: The primary challenges addressed by research at the centre are large and well known, and are beginning to engender national responses. If the centre cannot maintain its momentum and its visibility, there is a risk that national initiatives addressing these challenges will bypass GPCC and opt for competing, non-PCC solutions.

c) Cultivating collaborations with other universities and non-academic organisations?

Summary: GPCC has worked closely with the care sector and with selected industry partners. Collaborations have often been built around implementation of PCC. International contacts have been initiated, including EU-funded research agenda development. More active industry collaborations, as well as with other universities, would strengthen the centre, as well as closer links to policy networks. Several collaboration opportunities exist, both in the high demand for implementation support, and national and European collaboration initiatives. This demand risks overwhelming the centre's resources however, which is a distinct threat to future collaboration.

Strengths:

Care sector collaboration: GPCC has built up a strong collaboration and close relationship with the care sector, including both primary and secondary care organizations, which allows for knowledge transfer, access to patients and care infrastructure for intervention-based research.

WE-CARE network: The centre has initiated a European project, supported by the European Commission under Framework Programme 7, entitled WE-CARE, which is a network of leading European actors headed by GPCC to set the research and development agenda for future cost containment in care. This project is a foundation for future international networking and expansion activities.

GPCC Development: In addition to acting as a springboard for collaboration with additional care sectors, the GPCC Development program also functions as a platform for collaborative development and delivery of implementation services relating to PCC. One such example is the ongoing collaboration between the centre and SCA to develop a branch focusing in implementing PCC hygiene and continence care for the elderly in the municipal care setting.

Collaboration support: GPCC offers all research projects access to targeted collaboration support, including partner matching, contract drafting, and development of joint projects and proposals, to overcome barriers to collaboration.

Weaknesses:

Industry collaborations: While some notable industry collaborations exist, the collaborations in the centre primarily focus on involving the care sector, meaning that collaborations tend to be primarily driven by research or care sector needs, rather than industry challenges.

Policy networks: While the research at GPCC has resulted in strong interest from both politicians and civil servant policy makers, the centre lacks strong, ongoing policy collaborations and networks (except for the WE-CARE network). This hampers the ability to reach key decision makers and build new national or international collaborations.

Academic collaborations: While the centre has initiated some collaborations with other academic organizations outside the university, these have not been as deep and formalized as could be hoped for (e.g. personnel exchange, joint research agendas, etc). Collaboration with Chalmers University has not yet progressed beyond initial discussions.

Opportunities

Health KIC 2016: The centre has been in discussions with the Swedish consortium working toward a Knowledge and Innovation Community (KIC) in healthy and active aging. Participating in a Health KIC would position GPCC as an expert knowledge provider within a larger platform and network, tackling significant European challenges and driving extensive collaboration.

WE-CARE continuation: Follow-up projects from the fruitful collaboration in the WE-CARE project can provide GPCC with an expanded network and stronger international integration.

H2020 Health projects: The Horizon 2020 programme contains several calls with relevant themes for person-centred care, which could be pursued by GPCC. Examples include several projects under H2020-PHC-2015-one-stage and H2020-PHC-2015-two-stage: "PERSONALISING HEALTH AND CARE".

National initiatives: Person-centred care is gaining recognition among national actors and decision makers. By participating in national initiatives to develop and implement PCC, e.g. Forum för välfärd, GPCC can expand its collaboration and position itself nationally as a competence centre driving the transition to person-centred care.

Demand for implementation: The experienced high demand for implementation support and change programs for PCC in practice indicates several opportunities for future collaborations for the centre.

Threats

Inadequate resources: If GPCC does not have the necessary resources (people, funding) to design and drive collaborations, it will be necessary to turn down requests for collaboration, meaning opportunities will be lost and existing collaborations will be likely to lose momentum.

d) Strengthening the link between the research and education?

Summary: GPCC has worked over the last five years to integrate research results into new educations and pedagogic materials, targeting all levels at the university as well as executive education. It has a process for reviewing and promoting these activities in research projects and on the Executive Board. Through its GPCC Development platform it has the opportunity to develop and deliver additional executive education, and it has initiated discussions with patient organisations to provide additional education. Key threats are a lack of resources to pursue the opportunities and maintain the strong link to research, as well as a resistance to the introduction of PCC in traditional academic educations.

Strengths

Ongoing academic educations: GPCC has worked to ensure that research results are integrated into academic educations at the university, both in educational material and course curricula. GPCC offers education in PCC at graduate and PhD levels across medical and care disciplines. An innovative pilot to incorporate PCC in the curriculum of the major undergraduate programmes has started and, if successful, will see PCC as a key concept taught across Sahlgrenska Academy and provide opportunity for cross-professional team working between the different undergraduate programmes.

Executive education capacity: As part of the GPCC Development initiative, the centre has successfully offered executive education to care professionals in PCC, reaching over 450 participants to date.

Care setting training: As several of the research projects at the centre are intervention-based and practice-oriented, the majority of projects involve training and education of care provider personnel. This has led and is leading to the continuous development of pedagogic materials and information, which have been possible to translate into more formal education components.

Project review and assessments: Projects in the centre are reviewed on a quarterly basis to determine relevant educational materials they generate or can contribute to, and to determine if this material can be packaged into executive, academic, or general public education with additional support.

Weaknesses

Academic collaborations: A lack of close academic collaborations has meant that it has not been possible to offer academic educations at other universities (with the exception of LaTrobe University, Australia) or to develop joint education programmes with other actors that can provide complementary capacity.

Opportunities

Patient organisations: GPCC is currently in discussions with patient representative organisations to develop and offer course in PCC from the patient perspective. This presents the centre with an opportunity to reach new stakeholders and develop educational materials that support patients in being active partners in their own care.

GPCC Development: Anchoring the implementation platform GPCC Development with the university holding company GU Holding and developing new implementation branches will also enable the development and delivery of new executive education programs.

Threats

Inadequate resources: If GPCC does not have the necessary resources (people, funding) to continue to support the development and delivery of research-based educations, there is a strong risk that it will be impossible to deliver on the experienced demand for executive education, and that academic educations will not be updated with the most up-to-date research.

Resistance to PCC: As PCC is a new field and an interdisciplinary approach, there is a risk (already experienced) that traditional educational programmes will be resistant to the introduction of PCC. If this cannot be overcome, education in PCC will be limited to only a few of the affected professions.

UM 5) What is your plan for the long-term partnership and collaboration with the co-applicant organisation(s) for the strategic research area? Please include considerations regarding the distribution of funding between the universities.

Not applicable.

COL 12) Choose *one* of your research projects that include collaboration with one or several non-academic organizations or companies to illustrate how collaboration a) has improved the research quality and b) has improved the prerequisites for society and the business sector to utilise the research.

Please enter the name of the chosen project and the project period in the table. Also give a short description of the project.

Name: National reference wards implementing person-centred care (NATREF)	Period: Oct 2012 – Dec. 2013
The NATREF project was a VINNOVA-supported collaboration initiative to implement person-centred care (PCC) in practice at an internal medicine ward at Sahlgrenska University Hospital. The project involved industry, public sector and academia, aiming to drive innovation, establish best practice, and conduct research. The project was a significant success, and key success factors included collaboration across stakeholder boundaries, a dedicated change management program for sustainable change, and evidence-based tools for standardized practice.	

Col 12b) Please enter collaboration partners (maximum 2) and verified contact information

Partner	Contact person	Contact information
Sahlgrenska University Hospital	Putte Abrahamsson, Verksamhetschef	Putte.abrahamsson@vgregion.se
IBM	Torbjörn Hägglöf, Client executive, life sciences area	Torbjorn.hagglof@se.ibm.com

Background

The NATREF project was initiated as an innovation project to demonstrate the effectiveness and feasibility of implementing person-centred care (PCC) in a hospital setting. Previous studies (see STR 4) had indicated that the structured introduction of PCC would lead to direct benefits in these settings, including shorter hospital stay, fewer re-admissions, improved patient self-efficacy and satisfaction, and improved workplace satisfaction and professional pride.

The NATREF project was initiated with the goals of:

- adapting the PCC process to the requirements of the selected ward,
- establishing a sustainable organization at the hospital to maintain and evolve the person-centred practice,
- providing tools and training to care professionals, and
- establishing a national reference example of the feasibility and effects of PCC practice.

In addition to these goals, the project aimed to establish a test bed for care innovation, in collaboration with the Swedish innovation agency VINNOVA. The test bed would design, implement, and evaluate new care innovations in a practical setting.

Process

The following partners were involved in the NATREF project:

- GPCC
- Sahlgrenska University Hospital (SUH)
- AstraZeneca (AZ)
- IBM
- Doberman
- The IT University at GU / Chalmers
- Gro Consulting

Together with GPCC, SUH was responsible for establishing the initial reference ward, including the selection of personnel and the organizational mandate to implement the project. The ward, 352a, was selected to be as representative as possible, treating patients with a variety of conditions but specializing in chronic conditions such as diabetes, chronic heart failure, gastrointestinal disorders, etc. In order to avoid factors that would lessen the representative effect, the implementation was carried out in a ward that operated under real life requirements and pressures (during the project, demand at the hospital lead to the expansion of the project to include an additional ward, 352b).

The PCC process in the hospital setting has been described in other parts (see STR 4), but fundamentally rests on a genuine partnership between patient and care provider, which includes:

- Interdisciplinary teams of care professionals, ensuring continuity in the care process
- A PCC-plan, built on the ability, desires and needs of the patient, communicated to and agreed to by the patient, and updated throughout the care process
- A care process taking into account the resources and capacity of the patient
- Structured documentation of the above, aligned with the medical expertise of the care providers.

The above pillars cannot be established ad hoc, requiring GPCC and SU to develop and implement:

- Tools for working according to PCC principles
    - Protocols for person-centred patient interviews, including interpretation guides
    - PCC-plan templates
- Training in the PCC perspective, and the use of PCC tools
- Education in PCC philosophy and related theory
- Change management support, to facilitate the adaptation of the PCC processes to routines at the ward
- Structural support, to anchor the new working process in the organization and with management

The above components were brought together in the Person-centred Care in Practice (PCP) program, which key personnel at all levels at the reference ward underwent. The PCP program has also been implemented at other care organizations and generated significant demand within Sweden.

Partners and organization

The NATREF Project established two steering groups for the practical governance of the project: one steering group within SUH, responsible for governance of the reference ward, and one steering group consisting of the full partner group, responsible for overall project governance. The partners collaborated under a consortium agreement, outlining the general obligations and rights of the partners, as well as expectations on the joint project. The total budget of the project exceeded 23 MSEK, but this included the cost of operating the reference ward at normal capacity. The innovation and implementation work had a total budget of 6 MSEK, with VINNOVA financing 3 MSEK.

AstraZeneca participated to learn how an active partnership with the patient can enable more individualized product offers and an in-depth relationship with the patient that would build better customer loyalty, as well as how to measure the qualitative effects of changes in care practice.

IBM participated to learn how the patient's need for and use of care information changed in a PCC process, and to what extent the current ICT platform of public care providers could accommodate this approach to sharing access to information. During the project, IBM studied the limitations of existing information management systems, in relation to the needs and potential of the patient as an active partner.

Doberman participated to map the patient journey in a PCC process, and to understand the various information and decision sharing points in this journey. During the project, Doberman developed a visualization of the patient journey, as well as a journal to help document patient experiences.

Outcomes

- Two reference wards (expanded from the original scope due to demand at SUH) working entirely according to PCC principles, implementing the tools and processes developed at GPCC.
- Significant attention and demand for PCC within the hospital, the region and in Sweden as a whole. In SUH alone it contributed to an initiative to evaluate the implementation of PCC in the entire hospital.
- A successful pilot for the PCP program, subsequently generated significant demand for future implementation projects with other organisations.
    - Based on the pilot outcome PCP was integrated in the Gothenburg University infrastructure for social innovation and executive education
- A demonstration of the value of PCC, and the feasibility of implementing PCC.
- Insight for industry partners into the PCC process, as well as a test arena to assess new business opportunities servicing the care sector, and concrete opportunities to develop relevant tools expanding their service capacity.
- Person-centred care for patients at the reference wards, and sustainable implementation of the PCC process.
- A PCC Forum for management at SUH, anchoring PCC principles throughout the hospital.

Challenges

A key collaborative challenge in the project was the involvement of public authorities. As some inertia in this area was expected, the project contacted the necessary authorities (Region Västra Götaland) at a very early phase to involve them in the project. It was feared that a lack of alignment with the IT agenda and strategy of the region could otherwise risk leading to obstacles at a later point, and potentially wasted effort. Unfortunately it became clear in the project that the lack of flexible and person-centred IT tools was viewed as a tangible obstacle to the person-centred care process, as this meant that the personnel at the reference wards had difficulties in integrating the PCC process in the existing information systems.