

September 2023

Dear PCC NET members and interested individuals,

Today it's my pleasure to introduce to you two projects which aim to promote patient-centered care in routine care. Meet with me Eva Christalle and Rieka von der Warth, both are members of the PCC NET, introducing what they are working on!

Kind regards,

Nadine (on behalf of the PCC NET core team)

Through the patients' eyes – measuring patient-centeredness with the 'Experienced Patient-Centeredness Questionnaire' (EPAT)

Dear PCC-Net members,

my name is Eva Christalle. During the last 6 years, I had the pleasure to work with Prof. Isabelle Scholl, Dr. Stefan Zeh, Clara Haufschild, Hannah Führes, Alica Schellhorn, Dr. Pola Hahlweg, Dr. Jördis Zill, Prof. Levente Kriston and Prof. Martin Härter in the ASPIRED project. Within this project we have developed and tested a patient-reported experience measure to assess patient-centeredness (PC; [Christalle et al., 2018](#)) in German. Until now, there has been no measure that comprehensively assesses PC in all its dimensions. However, measuring PC is a prerequisite for assessing the status quo, testing the effectiveness of interventions and thus promoting PC.

Many of you are familiar with the integrative model of PC ([Scholl et al., 2014](#)). This was the starting point for our project. As we wanted to focus on the patients' perspective, we have converted the model into lay language and used a Delphi study to discuss the relevance of the different dimensions with patients ([Zeh et al., 2019](#)). We have then developed a questionnaire based on the model with input from focus groups with n=40 patients, n=10 key informant interviews with experts and a literature review ([Christalle et al., 2022](#)). We tested the questionnaire on a sample of n=2025 patients. The final questionnaire showed good psychometric properties (Christalle et al., in prep). There is a short version with 16 items, which allows a quick overview assessment of PC. In addition, three more items can be added to each dimension of PC, resulting in 64 items to cover all dimensions. However, the assessment of specific dimensions is also possible. This allows a flexible adaptation according to the interests and resources of the users.

As a final step, we tested the feasibility of the EPAT questionnaire in routine care and presented the results at an expert work-shop on 13 July 2023. This allowed us to discuss the future use of the EPAT with 26 participants from a wide range of backgrounds – a truly motivating experience that gave us many ideas for the further distribution of the EPAT and future research! We are currently working on a translation of the EPAT questionnaire into English.

We would like to thank all participants, cooperation partners and colleagues who have supported us during the last six years and beyond!

You want to know more? You can contact me via e.christalle@uke.de.



Communication preferences of transgender and/or gender-diverse individuals – the CommTrans Project

Transgender and/or gender-diverse individuals face a great deal of stigma, discrimination and violence compared to cis-gender individuals. This is also prevalent within the health care system, with clinicians to be known to have negative attitudes towards the community. As a result, transgender and/or gender-diverse individuals tend to avoid health care services, with individuals fearing mistreatment and harassment during consultations. Following the minority stress model, this non-acceptance of gender identity leads to worse mental health and overall life satisfaction. In fact, transgender and/or gender-diverse individuals have an increased prevalence of depression and anxiety disorders, as well as physical illnesses.



Accordingly, several research describes that transgender and/or gender-diverse individuals expect an overall respectful communication style. Often mentioned topics are describing gender-related communication, such as pronoun usage, deadnaming and overall acceptance of gender by clinicians. There is also some evidence, that transgender and gender-diverse individuals have similar communication preferences as other patient groups, inter alia, active listening and showing empathy.

Following the concept of person-centred care, clinician-patient communication should be adapted to the respective sample and individual. However, to date, too little is known about communication preferences in transgender and/or gender-diverse individuals and most clinicians lack the knowledge to provide patient-centred care.

Therefore, the CommTrans project aims to expand the knowledge on communication preferences in transgender and/or gender diverse individuals. For this, a sequential mixed-methods study was conducted. Firstly, communication preferences were exploratory assessed using semi-structured interviews. Results included general communication aspects (e.g. active listening), the role of gender in health care (e.g. how to address gender appropriately), and gender-neutral language (e.g. current experiences). Furthermore, the interviews showed the importance of the patients' communication style within clinician-patient communication. In addition, other contextual factors such as communication of all team member were reported as important. The results of this study were recently published ([von der Warth et al., 2023](#)).

Based on the interviews, a new questionnaire was developed in order to systematically assess communication preferences. The questionnaire was tested using an online survey. Using the same survey, possible factors that are associated with the communication preferences were tested. As a result, we found, that individuals identifying with a non-binary gender had different needs compared to their binary-gendered counterparts. Furthermore, not identifying with a minority was associated, underlying the concept of intersectionality. Currently, two papers describing the results of the questionnaire development as well the investigation of associated factors are submitted.

Lastly, the new knowledge about communication preferences in transgender and/or gender-diverse individuals was provided to clinicians using a mixed-methods survey, asking them if they could meet the preferences in their daily practice. The results are currently analysed.

The results of this study could be used to develop educational programs for clinicians, providing them with the needed knowledge for person-centered care for transgender and/or gender-diverse individuals. Furthermore, the questionnaire might also be applied in clinical practice to help clinicians adapt their behavior to the single patient.

If you like to get in contact with Rieka about the topic or the project, here are her contact details:

Rieka von der Warth (she/her)
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Section of Health Services Research and Rehabilitation Research
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Recent publications

Communication preferences of trans and gender diverse individuals (*see also above*)

This study aimed at assessing communication preferences using semi-structured interviews. Results included general communication aspects (e.g. active listening), the role of gender in health care (e.g. how to address gender appropriately), and gender-neutral language (e.g. current experiences). Also, this study revealed the importance of the patients' communication style within clinician-patient communication.

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0284959>

Short notes

Save the date!

Dr. Natalie Joseph-Williams from the Cardiff University is an international re-known expert in shared decision-making research. Her research has informed national training programs, NHS healthcare policy, and international guidelines. In our next online seminar, Dr. Joseph-Williams will present **Achieving shared decision-making in routine practice: Tools, challenges and solutions.**

When? **28 September at 16:00-17:30 (Germany), 11am-12:30pm (Chile)**
Simultaneous translation to Spanish will be provided.

Newsletter

If you want to share anything of your work with the PCC Net members, you are very much welcome to put this information into a future newsletter. We are very much looking forward to your input!

We thank Eva Christalle and Rieka von der Warth for their contribution to this newsletter! Also, if you like to participate in our online events, please email info@pcc-network.org. We are looking forward to seeing you at our next event!

Kind regards,

Dr. Nadine Lages, Prof. Dr. Paulina Bravo, Ivo Engert, Prof. Dr. Dr. Martin Härter,
Constanza Quezada, Prof. Dr. Isabelle Scholl