

# BMJ Open What do patients expect? Assessing patient-centredness from the patients' perspective: an interview study

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## ABSTRACT

**Objective** Although there has been much conceptual work on patient-centredness (PC), patients' perspectives on PC were neglected. In a previous study, participating patients rated the relevance of 16 dimensions of an integrative model of PC as high to very high. However, it remained unclear which specific behaviours described in the dimensions were considered most relevant. Thus, the aim of the current study was to further explore which of the specific behaviours described in the model are especially relevant for the high ratings in the previous study.

**Methods and design** We conducted semistructured interviews with 20 patients with chronic diseases (16 females, 4 males, mean age: 52 years). Patients answered questions regarding their experiences in the German healthcare system and how optimal healthcare would look like from their perspective. Furthermore, patients were asked to reflect on the most important aspects which they had mentioned in the interview before. Data were analysed via content analysis.

**Results** Participants addressed many different aspects of PC, but mostly focused on three major themes: (1) time appropriate access to care, (2) competence, empathy and being taken seriously by HCPs, (3) HCPs' individual consideration of each patient's situation (eg, wishes and needs). Minor themes were: (1) taking a holistic perspective of the patient, (2) patient-centred communication, (3) integration of multidisciplinary treatment elements, (4) transparency regarding waiting time and (5) reduction of unequal access to care.

**Conclusion** This study enriches the construct of PC by depicting essential aspects of PC from the patients' perspective. The results allow prioritising strategies to implement patient-centred care. Thus, this study helps to pursue the ultimate goal of fostering patient-centred healthcare delivery in Germany.

## INTRODUCTION

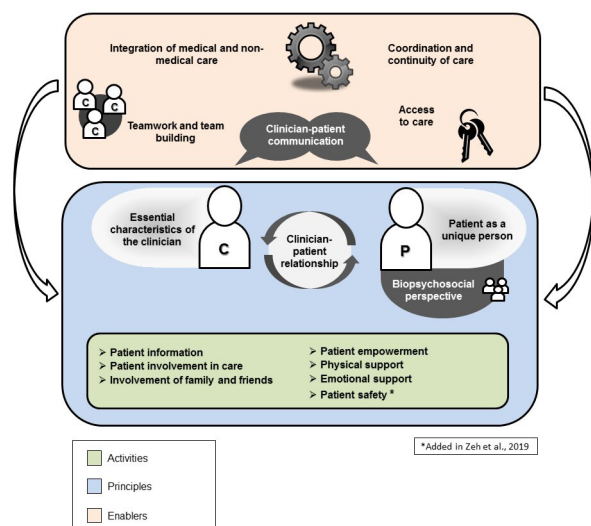
Patient-centredness (PC) has been widely discussed over the last decades and its relevance in health policy, research and healthcare practice has been growing constantly.<sup>1–3</sup> Different studies showed positive associations of PC with patient satisfaction, well-being, adherence,<sup>4</sup> health behaviour,<sup>5</sup> knowledge about the medical condition and recovery rate.<sup>6</sup> However, the term PC was lacking

## Strengths and limitations of this study

- Qualitative interviews enable an in-depth understanding of the patients' perspective.
- Interviews empower participants to freely talk about their experiences.
- Semistructured guidelines allow further probing for interesting and relevant insight.
- Differentiating between major and minor themes enables prioritisation of strategies to foster patient-centred care.
- Only few male participants and possible self-selection bias could make it harder generalising results.

conceptual clarity for a long time.<sup>7–12</sup> Therefore, Scholl and colleagues<sup>8</sup> developed an integrative generic model derived from literature. The model included 15 dimensions of PC and provides a comprehensive definition of PC (see figure 1). 'Here, patient-centred care is characterised by adequate access to continuous, and coordinated care and by competent, empathetic and respectful healthcare providers (HCPs). They work in interdisciplinary teams to integrate medical and non-medical care as needed, take a biopsychosocial perspective to understand the patient as a unique person and build a partnership with the patient through collaboration. Furthermore, they communicate clearly and communicate health information in an individualised manner, involve the patient and, where appropriate, the patient's family in health decisions. Finally, they encourage patients to take actions to improve their health and help patients to strengthen their physical and emotional well-being'.

This model was validated by assessing the views of different healthcare stakeholders on its relevance and clarity.<sup>13</sup> While some representatives of patient organisations participated in this assessment, the perspective of individual patients was not included.



**Figure 1** Integrative model of patient-centredness (Scholl *et al* 2014<sup>8</sup>; Zeh *et al* 2019<sup>19</sup>).

Consequently, the conceptualisation of PC was still missing its most crucial aspect: the assessment and evaluation of PC in healthcare from the view of patients.<sup>14–16</sup>

Until now, there are only few international studies (eg, Maassen *et al*<sup>17</sup>) and even fewer German studies investigating patients' views on PC (eg, Zill *et al*<sup>13</sup> or Vennedey *et al*<sup>18</sup>). However, it is decisive to assess relevance and current implementation of elements of PC in order to identify and prioritise strategies to foster its implementation.<sup>19</sup> In this recent Delphi study, we asked patients to rate the aforementioned 15 dimensions regarding relevance. We found that every dimension was rated as (highly) relevant but also not well implemented from the patients' perspective.<sup>19</sup> Additionally, 'patient safety' was added as a 16th dimension since it was missing so far from the patients' perspective. In general, this Delphi study yielded almost no variance between the different dimensions of PC in terms of relevance. Therefore, it was difficult to prioritise steps to foster implementation. Furthermore, it used a deductive approach by asking participants to rate dimensions derived from the literature<sup>19</sup> (figure 1) instead of specific behaviours which could be grasped more easily by patients. Therefore, the results were generated at a relatively high level of abstraction. Consequently, it would be interesting to know which specific aspects of patient-centred care patients mention without giving out restricting dimensions. For example, it could compliment the results of the Delphi study if patients were to mention respect and empathy on their own without researchers prompting them in this study. By doing so, results more in depth on the level of specific aspects instead of broad dimensions could help prioritising and implementing the most relevant topics of patient-centred care.

This study therefore aims at further exploring the patients' perspective on PC using qualitative interviews in order to better interpret the results of the Delphi study and to prioritise implementation strategies.

## METHODS

### Study design

We conducted a qualitative study using semistructured interviews, guided by Consolidated criteria for Reporting Qualitative research (COREQ statement<sup>20</sup>). The COREQ checklist can be found in the online supplemental appendix A1. This study was conducted within an explanatory sequential study design<sup>21</sup> as follow-up to the Delphi study with patients.<sup>19</sup>

### Sampling, recruitment and data collection

Participants were invited to participate via convenience sampling. Participants were eligible if they were at least 18 years of age and belonged to one of four chronic disease groups (cancer, mental disorders, cardiovascular diseases and musculoskeletal disorders). In March 2019, we approached 32 individuals who were recruited via community-based strategies and had already participated in a focus group on patient-centred care in the past.<sup>22</sup> In those focus groups, participants were asked to provide insight into examples of behaviour of healthcare practitioners they had experienced in the past (eg, how they communicated with participants). After the focus group, we asked the participants if they were also interested in participating in an individual interview as part of a separate study. All participants of the focus groups were eligible for this study because, during discussions, no apparent differences in responding behaviour was shown by the participants (eg, major formal thought disorders). Thirty-two patients indicated interest and 20 of them participated. Ten patients never responded to our invitation and two did not appear to the scheduled interview. All interviews were conducted in rooms of the Department of Medical Psychology. The interviews were conducted in German by SZ, a male psychologist and doctoral researcher with experience in the method and professional interest in understanding the patients' perspectives on PC. After the interview, participants received a financial compensation of 20€.

The interview guide (see online supplemental appendix A2) was piloted with a student assistant prior to the first interview.

After greeting the participant and explaining the procedure, participants were first asked about relevant positive and negative experiences in the healthcare system. After exploring experiences, their own idea of an optimal healthcare system was further discussed. Participants were able to express their thoughts, SZ only intervened if necessary or if the provided answer indicated that more content could be drawn out of it. At the end of the interview, participants were asked what they associate with the term 'patient-centredness'. By asking these questions, we wanted to examine what about healthcare is relevant to patients on a more detailed level compared with the Delphi study.<sup>19</sup> For example, participants were able to explain which specific behaviours healthcare practitioners showed in their appointments that made the participants feel satisfied or comfortable in this specific

situation or over the period of treatment. If participants were not able to understand the questions in the intended way, the interviewer (SZ) rephrased the question and asked in a different way to ensure understanding.

We assessed demographic and clinical characteristics of participants using a short written patient-reported survey at the end of the interview. Interviews were audio-recorded and field notes were made during the interview facilitating probing questions.

Regarding data saturation and based on other studies, we first estimated that 8–12 interviews could suffice.<sup>23</sup> However, because of the known variance of the topic we decided to schedule 20 interviews to make sure that we would not miss important content. After 16 interviews, the first author who conducted the interviews (SZ) had the impression that theoretical saturation was achieved but continued with the interviews that were already scheduled with participants in order to ensure that no relevant novel themes would emerge from further interviews.

### Data analysis

Recordings were transcribed verbatim and imported to MAXQDA<sup>24</sup> for content analysis. We used a deductive and inductive approach based on prior studies<sup>8 19 22</sup> and new emerging themes so that we could use pre-existing dimensions as well as possibly new emerging aspects. Transcripts and results of data analysis were not returned to participants for feedback. SZ was the main coder, EC discussed critical sections with SZ. An exhaustive description of the coding tree can be found as a supplementary file (online supplemental appendix A3). Every aspect was a subcode of 1 of the 16 dimensions of the integrative model.<sup>8</sup> Additionally, every aspect mentioned by participants was coded and analysed thematically in regard to patient-centred care as well as how much space the topic was given by individual participants. Furthermore, we analysed, how often specific aspects were mentioned over all interviews in order to determine major and minor themes. For qualitative data analysis, we used MAXQDA, descriptive statistics of demographic and clinical data were calculated using SPSS V.23.<sup>25</sup> Furthermore, the results were split by the first author (SZ) into major and minor themes and not into single categories (according to the definitions of Vaismoradi *et al.*<sup>26</sup>) for easier interpretation. Major and minor themes thus represent coherent aspects of patient-centred care describing a specific aspect in general. Major themes are aspects, which were reported by the majority of participants and which a lot of time was allocated to by the participants, whereas minor themes were also mentioned frequently and described in detail, but not as extensively as major themes.

### Patient and public involvement

We did not involve patients in the development of the research questions. However, we obtained collaboration agreements with several federal and regional patient organisations during the development of the research proposal and prior to submission to the funding

agency in order to secure field access and feasibility. We approached patient organisations for that purpose. All gave us positive feedback on the study aims, acknowledging that more research is needed on patients' experiences related to PC care. Thus, patient organisations supported recruitment of study participants by disseminating advertisement for study participation. No individual patient was involved in recruitment and conduct of the study. All study participants and every interested person in the public have the possibility to read and download regular project updates and study results on the project website (<http://www.ham-net.de/de/projekte/projekt-aspired.html>).

## RESULTS

### Description of sample

All 20 participants provided demographic and clinical data. Mean age was 52 (range: 30–79 years) and the sample was predominantly female (85%). A detailed description can be found in [table 1](#).

### Major and minor themes

An overview of all major and minor themes can be found in [box 1](#). Interviews lasted 30 min on average (range: 24–35 min).

### Major themes

#### Competence, empathy and taking patients seriously

The characteristics of HCPs are one of the three major themes that occurred frequently and extensively. Hereby, a set of distinctive traits were commonly used by participants to describe how HCPs should act towards patients. First, patients should be treated by competent HCPs that are skillful and knowledgeable. One participant stated '(...) *I want to be treated by the doctor and I have trust that he [or she] correctly and competently treats me. Otherwise, I could consult Google, you know*' (Interview 9). Furthermore, participants wanted HCPs to take them seriously and not disregard their distress or symptoms. Many felt that their own perception and experience with their disease was disregarded instead of considering them as experts for their own body. This could be helpful for the correct diagnosis and treatment. The following quote illustrates this experience well:

And then, they [the staff] looked at it [a rash the patient had shown to her physician several times before] and she [the physician] said: 'Oh yes, indeed, an allergic reaction'. And I was thinking, great, what did I just say? Do they really think patients are that dumb?' (Interview 18).

Lastly, participants wanted HCPs to show empathy towards them: '*So, I am missing humanity, empathy, this is what I had wished more*' (Interview 18).



**Table 1** Demographic and clinical characteristics of the sample (N=20).

Characteristics	Frequency
Age (in years)	M=52.05 (SD=15.05)
Sex	
Female	17 (85%)
Male	3 (15%)
First language	
German	19 (95%)
Other	1 (5%)
Chronic disease group (multiple answers possible)	
Mental disorder	15 (75%)
Musculoskeletal disorder	9 (45%)
Cardiovascular disease	7 (35%)
Cancer	3 (15%)
Other*	14 (70%)
Relationship status	
Single	12 (60%)
Married	4 (20%)
Divorced	4 (20%)
Education	
Without diploma	1 (5%)
Middle-school diploma	9 (45%)
High-school diploma	5 (25%)
University/college diploma	5 (25%)
Employment status	
Employed	3 (15%)
Non-working	3 (15%)
Retired†	8 (40%)
Others‡	6 (30%)

\*Other diseases include (but are not limited to) Hashimoto's thyroiditis, Infection with HIV, migraine, psoriasis or irritable bowel syndrome. These diseases were written on the questionnaire by participants prompted by an open answer category.

†Retired includes all types of retirement (eg, early retirement or retirement due to sickness).

‡Other employment statuses include for example being off sick or volunteer work.

### Time appropriate access to care

Another major theme emerged from the fact that time is a very limited resource in healthcare, which can result in negative experiences for patients. Participants frequently told us that they had to wait a long time for an urgent appointment: *'I think it is inappropriate, if someone is in deep pain or had an accident; it just can't be that you'll get an appointment in six weeks'* (Interview 7). Additionally, participants wished for longer consultations. They understand that time is an essential and limited resource in healthcare. Still, they felt that conversations with less time pressure could provide a better exchange of information for both the physician and the patient: *'So, there aren't any*

### Box 1 Overview of major and minor themes

#### Major themes

Competence, empathy and taking patients seriously  
Time appropriate access to care  
Acknowledgement of the patient's individual situation

#### Minor themes

Taking a holistic perspective of the patient  
Patient-centred communication  
Integration of multidisciplinary treatment elements  
Transparency regarding waiting time  
Reduction of unequal access to care

*long conversations. (...) everything is short and concise, and I understand, but this has to be changed urgently in my opinion, so that there will be more time for conversations with patients'* (Interview 12).

### Acknowledgement of the patients' individual situation

The last major theme revolves around being treated as a human being with fears, worries, wishes and needs. Patients reported being in a highly vulnerable state of illness, so it should be important for HCPs to understand that it is a stressful and exceptional situation for patients. They wanted to be met with respect and appreciation for their individual situation. Two quotes demonstrate the core of this theme. One participant described how it should be: *'So I was there – and I felt like I was seen as a human being and not like a random number'* (Interview 11). The second quote illustrates a negative experience:

The nurses, they always babbled, always: 'You need to do it like this, everybody knows this'. One nurse hissed at me. And every time, I said: 'Excuse me, but this is my first time in the hospital and this is my first child I delivered'. (Interview 7)

### Minor themes

#### Taking a holistic perspective of the patient

The first minor theme was that participants wished that HCPs would take a biopsychosocial perspective on their health condition and acknowledge the connection between body and mind. One quote demonstrates this well:

I once was in the psychiatric hospital for a longer stay and was (...) referred to further specialists in an outpatient setting. They did not only look at my psychiatric disorders but also on every other aspect, it was holistic and they also focused on my body. (Interview 9)

### Patient-centred communication

Participants wanted to receive information on their condition. They also wanted to be listened to when they are presenting their own information to the HCPs. Therefore, participants wanted HCPs to use terms easy to understand, to listen attentively and to focus on the patient instead of the computer:

The HCPs always (...) look up something in the computer. They won't even look at you. (...) I want them to look me in the eyes and in those five min, I don't want them to play with the computer, I want them to be directed towards me and to listen to me and to treat me friendly. (Interview 7)

### Integration of multidisciplinary treatment elements

Another minor theme was the wish of participants to not only focus on conventional medicine but to also be able to explore or to integrate complementary or additional treatments. Participants wished that their HCPs were more open to talk about and to integrate multidisciplinary treatment elements, for example, possible massages, physiotherapy, support groups, complementary medicine or herbal medicine. One participant got further additional elements for her own treatment and profited a lot, as she said:

So you'll get massages, you can talk to them, physiotherapy, and yes, exercise therapy. All together and also psychosomatic conversations and help for eating disorders. It is evident that a physician is not able to provide everything on his own and it is important to integrate those things nevertheless. (Interview 3)

### Transparency regarding waiting time

A further minor theme was that participants, as seen above, understand that time is very limited in medical encounters and that delays in scheduled appointments can occur due to emergencies for example. Nevertheless, participants wished to be better informed about the time they will have to wait. The best option would be to reduce the waiting time in general. However, if that is not possible, participants wanted at least to receive transparent information about the reasons for delay and about the estimated remaining waiting time. Here are few examples on the perspectives of participants: *'Not knowing, what the physician does next. I want to be part of it. I want to get explanations'* (Interview 6) and *'What I want to say, after having waited two and a half hours (...) I still needed to wait and that was okay, because I knew, it could get longer'* (Interview 12).

### Reduction of unequal access to care

The final minor theme is related to the fact that universal health coverage in Germany is delivered in a public (statutory) and private health insurance. Participants with public health insurance described that they experienced unequal access to care, compared with patients with private health insurance, that is, they experienced longer waiting times for an appointment. This results in a feeling of being a second-class patient as one participant describes very vividly:

I called the physician twice and disguised myself as someone else for the second call so that I would know if I really have to wait 7 weeks for an appointment.

**Table 2** Mapping of aspects to dimensions of patient-centred care

Dimension of the integrative model	Theme mentioned by patients in the interviews
Essential characteristics of the clinician	Competence, empathy and taking patients seriously (major theme)
Patient as a unique person	Acknowledgement of the patient's individual situation (major theme)
Biopsychosocial perspective	Taking a holistic perspective of the patient (minor theme)
Access to care	<ul style="list-style-type: none"> <li>► Time appropriate access to care (major theme)</li> <li>► Reduction of unequal access to care (minor theme)</li> </ul>
Integration of medical and non-medical care	Integration of multidisciplinary treatment elements (minor theme)
Clinician–patient communication	<ul style="list-style-type: none"> <li>► Patient-centred communication (minor theme)</li> <li>► Transparency regarding waiting time (minor theme)</li> </ul>

Nope, I could have come next Tuesday if I was privately insured. (Interview 12)

### Summary of results

For an illustration, see [table 2](#) for an overview mapping all major/minor themes to the 16 dimensions of the aforementioned model.<sup>8 19</sup>

### DISCUSSION

This study adds the patients' perspective on specific aspects of PC and broadens therefore the knowledge about what patients consider relevant about PC. The study yielded three major themes: (1) competence, empathy and taking patients seriously; (2) time appropriate access to care; (3) acknowledgement of the patients' individual situation. Furthermore, the following minor themes emerged: (1) taking a holistic perspective; (2) patient-centred communication; (3) integration of multidisciplinary treatment elements; (4) transparency regarding waiting time; (5) reduction of unequal access to care. Notably, next to empathy and respect the aspect of 'being taken seriously by HCPs' which was missing in previous work on PC<sup>8 13 19</sup> was highlighted within the interviews.

This is not the first qualitative study to explore patients' experiences and needs regarding patient-centred health-care (eg, Dierks and Bitzer<sup>27</sup> or Maassen *et al*<sup>17</sup>). In 1999, Dierks and Bitzer<sup>27</sup> found among other things that patients in Germany expect to be seen as individuals and from a holistic perspective, which is comparable to our results. Maassen and colleagues<sup>17</sup> recently found that psychiatric patients mostly wanted HCPs to listen without

judgements. Also in line with existing literature,<sup>28</sup> some participants with a statutory health insurance reported unequal access to care compared with privately insured patients.

This study broadens the research on the patients' perspective on PC which has been underrepresented and complements the already existing literature well. As written above, PC was explored on the level of specific aspects instead of dimensions. Thus, it is now more distinct which dimensions<sup>19</sup> and, especially, which specific aspects patients consider relevant since we clearly mapped the mentioned aspects to our existing dimensions (see table 2). For example, if an organisation wanted to focus on fostering patient-centred care because they already knew that this dimension is highly relevant for patients,<sup>19</sup> they now also know which aspects to possibly focus on the most. In their implementation (eg, via trainings/workshops), they could focus on HCPs listening more attentively, using simpler words and training HCPs and practice teams to communicate waiting times transparently. This helps in prioritising implementation strategies. However, that does not mean that other aspects like treating patients with respect are irrelevant to patients. It should always be seen as an addition. Therefore, individual HCPs and healthcare delivery organisations that want to foster PC can now see which dimensions are highly relevant to patients and what specific aspects within these dimensions are relevant to patients. Consequently, this study provides implications on how to provide more patient-centred healthcare (eg, if an intervention is planned but the organisation only wants to focus on the most relevant aspects).

### Strengths and limitations

This study provides an explanation to the broader results of the Delphi study,<sup>19</sup> further strengthens the evidence for the results and gathers more insights for more concise interpretations due to using a different method as well as a different population. A further advantage of this study was the approach to let patients freely talk about their own experiences and vision of an optimal healthcare system without restricting them with preselected dimensions to talk about. This provided a chance for patients to express their own perception authentically and allowed them to talk about problematic structures in the German healthcare system without a social desirability bias. However, this study also has limitations. One possible flaw is the self-selecting bias which could be accounted for the fact that many participants reported mostly negative aspects. This could limit variance in reporting different aspects by participants. Another limitation to our study is the predominantly female proportion in our sample and an over-representation of patients with mental disorders. Although it seems like male participants or participants with mental disorders did not show major discrepancies of reported aspects of PC, it still needs to be accounted as a possible restriction. Consequently, generalisation is only

possible to a limited extent (as generalizability is often not primarily expected in qualitative studies like this one).<sup>29</sup>

### Future studies

Regarding the limitations, this study provides several possibilities for further research. Since our study was conducted with a convenience sample, it could be interesting to know if similar results occurred with a second, independent sample (eg, purposive sampling or with different diseases compared with this study). This way, results of this study could be consolidated. Furthermore, this study yielded results related to the German healthcare system and are therefore not generalisable beyond this level. It would be interesting to know which aspects patients from other countries would depict. Additionally, a similar study with more male participants or different chronic disease groups could provide knowledge on the question how or if different aspects of patient-centred care need to be accounted for (eg, if specific aspects are more common in a subgroup). Finally, results could differ for patients in different settings, for example for patients receiving care for the first time (or for the first encounter) or in emergency situations.

### CONCLUSION

In summary, our study provides an enrichment of the patients' perspective on PC. We showed which aspects of patient-centred healthcare seem to be most important to patients: being taken seriously, being treated competently and with empathy, being recognised as individuals in exceptional situations, having enough time during encounters and timely access to care. These results can be used to prioritise specific strategies to foster implementation of patient-centred care.

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**Contributors** IS is the responsible principle investigator of the study. IS, EC, JMZ, MH and AB were involved in planning and preparation of the study. SZ recruited participants and collected data, and SZ analysed the data with help of EC. All authors interpreted the results. SZ wrote the first draft of the manuscript. IS, EC, JMZ, MH and AB critically revised the manuscript for important intellectual content. All authors gave final approval of the version to be published and agreed to be accountable for the work.

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**Ethics approval** The study was carried out according to the latest version of the Helsinki Declaration of the World Medical Association. Principles of good scientific practice were respected. The study had been approved by the Ethics Committee of the Medical Association Hamburg (study ID: PV5724). Study participation was voluntary and no foreseeable risks for participants resulted from the participation in this study. Participants were fully informed about the aims of the study, data collection and the use of collected data. Written informed consent was obtained



prior to participation (see online supplemental appendix A4). Preserving principles of data sensitivity, data protection and confidentiality requirements were met.

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## 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

2 Table A: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist <sup>1</sup>

Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	See page 4
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD	M.Sc. in Psychology, doctoral researcher
3.	Occupation	What was their occupation at the time of the study?	Research Associate/Psychologist
4.	Gender	Was the researcher male or female?	See page 4
5.	Experience and training	What experience or training did the researcher have?	See page 4 f.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	A relationship for research purposes was established prior to the interview
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All reasons were disclaimed (doctoral and project related interests)
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	See page 5
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	See page 5
Participant selection			
10.	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	See page 4
11.	Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	See page 4
12.	Sample size	How many participants were in the study?	See page 4
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	See page 4, reasons for non-participation were not disclosed to SZ



Setting			
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	See page 4
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Besides the interviewer and the participant, there were no other people present
16.	Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	See page 7
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See page 5 and interview guide A2
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Interviews were not repeated
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	See page 5
20.	Field note	Were field notes made during and/or after the interview or focus group?	See page 5
21.	Duration	What was the duration of the interviews or focus group?	See page 8
22.	Data saturation	Was data saturation discussed?	See page 5
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	See page 5
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	See page 5
25.	Description of the coding tree	Did authors provide a description of the coding tree?	See page 5
26.	Derivation of theme	Were themes identified in advance or derived from the data?	See page 5
27.	Software	What software, if applicable, was used to manage the data?	See page 5
28.	Participant checking	Did participants provide feedback on the finding?	Participants did not provide feedback on the findings
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Each quote was identified with interview number (no further data due to anonymity)
30.	Data and findings consistent	Is there consistency between the data presented and the findings?	See pages 8 to 11

31.	Clarity of major themes	Were major themes clearly presented in the findings?	See page 8 to 9
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	See page 9 to 11

3

4 **REFERENCES**

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7

## Guideline for semi-structured interviews

Introduction	<p>Thank you for participating at this interview. Here, I want to talk with you about your experiences in the health care system and how to improve it. You can refer to every single aspect of health care, for example the treatment itself, conversations or examinations. I am interested in, for example, how your needs and wishes were integrated. Furthermore, you can refer to every health care practitioner and their respective characteristics (e.g. Physicians, Psychologists, Nurses and so on). When talking about the health care system, I want you to think about as many of those domains as possible. Do you have any questions?</p> <p><i>If more information is needed:</i> Health care system means more than only the treatment itself (e.g. which information I received during the consultation and if my needs and wishes were met). It also refers to the characteristics of the HCPs, e.g. if they seem to be trustworthy. Furthermore, you can refer to the system itself (e.g. the organization of hospitals or the health insurance system).</p>
Subject	Probing questions
Introduction (sharing own experiences)	<p>1. To start, I would like you to tell me about your experiences in health care. <i>Please tell me about a positive experience, what was especially good about it?</i> → Exploration of positive aspects (Focus on description of situation)</p> <p>2. You talked about a positive experience. <i>Have you also had negative experiences? If so, would you please tell me about it? What was especially bad about it?</i> → Exploration of negative aspects (Focus on description of situation)</p>
Leading over to patient-centeredness	<p>3. You told me about positive and negative experiences. I am also interested in why you were able to remember these experiences. <i>Can you tell me what was exceptionally important to you in these situations?</i> → Exploration of important aspects and reasoning</p>
Exploration of patient-centeredness	<p>4.1 Now, I would like to know what your image of an „optimal“ health care system would be. Imagine you woke up one day and the system has changed overnight in the way that it fits all your wishes. <i>How would it be? What is different, how do health care practitioners behave?</i> → Exploration of central aspects of optimal health care (= wishes)</p> <p>4.2 You just said, it would be optimal for you if XXX was implemented. Why is that important to you? → Exploration of reasons for importance</p>
Leading over to the end of the interview	<p>5. You told me about good and bad things and explained why those things were important to you. It is easy to summarize them as “patient-centeredness”. Hearing this term, what are you thinking about patient-centeredness? → Exploration of association with patient-centeredness</p>

Ending of the interview	<p>At the end, I would like to ask you two more questions.</p> <p>6. You mentioned during the interview many things important to you (naming examples). <i>Are all equally important to you? Which ones are especially important?</i></p> <p>➔ Prioritizing of important aspects</p> <p>7. I am further interested in your opinion on <i>why treatment isn't always optimal. Why is that so, what do you think?</i></p> <p>➔ Perspective of patients on treatment/the system in general</p> <p>Finally, I would like to know if there are still things missing that matter to you. Do you have any comments on that?</p>
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Notes:



Color of the coding	Description of the dimension\Aspect of the respective dimension (in German)
●	Einzigartigkeit\Allgemein
●	Einzigartigkeit\Bedürfnisse
●	Einzigartigkeit\Wünsche
●	Einzigartigkeit\Sorgen
●	Einzigartigkeit\Erwartungen
●	Einzigartigkeit\Anerkennung Einzigartigkeit
●	Einzigartigkeit\Nicht näher bezeichnet
●	Einzigartigkeit\Anerkennung Ausnahmesituation
●	Empowerment
●	Empowerment\Allgemein
●	Empowerment\Kompetenzen des Pat.
●	Empowerment\Anforderungen im Alltag
●	Empowerment\Aktiv im Gespräch
●	Empowerment\Aktiv in der Behandlungsumsetzung
●	Empowerment\Navigation Gesundheitswesen
●	Empowerment\Verbesserung Situation
●	Empowerment\Zugriff eigene Daten
●	Empowerment\Nicht näher bezeichnet
●	Empowerment\Selbstständige Informationsbeschaffung
●	Ergänzende Angebote
●	Ergänzende Angebote\Allgemein
●	Ergänzende Angebote\Information durch Behandelnde
●	Ergänzende Angebote\Einbezug auf Wunsch
●	Ergänzende Angebote\Fort-/Weiterbildungen
●	Ergänzende Angebote\Selbsthilfegruppen
●	Ergänzende Angebote\Alternativmedizin
●	Ergänzende Angebote\Spirituell/Seelsorge
●	Ergänzende Angebote\Nicht näher bezeichnet
●	Ergänzende Angebote\Internet/E-Healthangebote
●	Ergänzende Angebote\Aktiver Austausch bzgl. Angebot
●	Gesamt Nicht näher bezeichnet
●	Gesamt Nicht näher bezeichnet\Zufriedenheit
●	Gesamt Nicht näher bezeichnet\Systemvariable
●	Gesamt Nicht näher bezeichnet\Einrichtungsbeschreibung
●	Gesamt Nicht näher bezeichnet\Organisationskultur
●	Gute Planung
●	Gute Planung\Allgemein
●	Gute Planung\Kontinuität Behandlung
●	Gute Planung\Absprache aufeinanderfolgende Behandlungen
●	Gute Planung\Termine Vor-/Nachsorge
●	Gute Planung\Übergabe/Entlassung

●	Gute Planung\Absprache zwischen Behandlern
●	Gute Planung\Absprachen mit Patient
●	Gute Planung\Fester Ansprechpartner
●	Gute Planung\Nicht näher bezeichnet
●	Gute Planung\Transparente Wartezeiten
●	Gute Planung\Zielvereinbarungen
●	Gute Planung\Tagesablauf
●	Gute Planung\Schnelle Hilfe
●	Körperliche Unterstützung
●	Körperliche Unterstützung\Allgemein
●	Körperliche Unterstützung\Schmerzbehandlung
●	Körperliche Unterstützung\Ernährung
●	Körperliche Unterstützung\Unterstützung Alltag (Pflegedienst)
●	Körperliche Unterstützung\Unterstützung Alltag (Hilfsmittel)
●	Körperliche Unterstützung\Nicht näher bezeichnet
●	Pat.orientierte Merkmale
●	Pat.orientierte Merkmale\Allgemein
●	Pat.orientierte Merkmale\Einfühlsamkeit
●	Pat.orientierte Merkmale\Ehrlichkeit
●	Pat.orientierte Merkmale\Wertschätzung
●	Pat.orientierte Merkmale\Respekt
●	Pat.orientierte Merkmale\Vertrauenswürdig
●	Pat.orientierte Merkmale\Offenheit
●	Pat.orientierte Merkmale\Ernst nehmen
●	Pat.orientierte Merkmale\Selbstreflektion
●	Pat.orientierte Merkmale\Kompetenz
●	Pat.orientierte Merkmale\Nicht näher bezeichnet
●	Pat.orientierte Merkmale\Engagement
●	Pat.orientierte Merkmale\Sich vorstellen
●	Patientensicherheit
●	Patientensicherheit\Allgemein
●	Patientensicherheit\Hygiene
●	Patientensicherheit\Evidenzbasiert
●	Patientensicherheit\Wechselwirkung Medikamente
●	Patientensicherheit\Aufzeichnung Behandlungsverlauf
●	Patientensicherheit\Fehlermanagement
●	Patientensicherheit\Nebenwirkungen
●	Patientensicherheit\Patientenrechte
●	Patientensicherheit\Nicht näher bezeichnet
●	Patientensicherheit\Sicherheitskultur
●	Patientensicherheit\Datenschutz
●	Patientensicherheit\Strukturierte Prozesse
●	Patientensicherheit\Kontraindikationen

●	Patientensicherheit\Einverständniserklärung
●	Persönlich angepasste Informationen
●	Persönlich angepasste Informationen\Allgemein
●	Persönlich angepasste Informationen\Information Vorsorge
●	Persönlich angepasste Informationen\Information Erkrankung
●	Persönlich angepasste Informationen\Information Behandlungen
●	Persönlich angepasste Informationen\Angepasst
●	Persönlich angepasste Informationen\Vor- und Nachteile
●	Persönlich angepasste Informationen\Kosten
●	Persönlich angepasste Informationen\Patienten können Wissen teilen
●	Persönlich angepasste Informationen\Raum für Fragen
●	Persönlich angepasste Informationen\Medikamentenplan
●	Persönlich angepasste Informationen\Nicht näher bezeichnet
●	Persönlich angepasste Informationen\Einsatz von Hilfsmittel
●	Persönlich angepasste Informationen\Information Nachsorge
●	Psychische Unterstützung
●	Psychische Unterstützung\Allgemein
●	Psychische Unterstützung\Ansprechen Gefühlslage
●	Psychische Unterstützung\Psychologische Angebote
●	Psychische Unterstützung\Ressourcenaktivierung
●	Psychische Unterstützung\Unterstützung im Alltag
●	Psychische Unterstützung\Nicht näher bezeichnet
●	Gemeinsame Entscheidungsfindung
●	Gemeinsame Entscheidungsfindung\Allgemein
●	Gemeinsame Entscheidungsfindung\Gleichberechtigung
●	Gemeinsame Entscheidungsfindung\Gemeinsame Entscheidung
●	Gemeinsame Entscheidungsfindung\Entscheidungspräferenz
●	Gemeinsame Entscheidungsfindung\Aktive Rolle Patient
●	Gemeinsame Entscheidungsfindung\Nicht näher bezeichnet
●	Gemeinsame Entscheidungsfindung\Einladung zu Gemeinsame Entscheidungsfindung
●	Gemeinsame Entscheidungsfindung\Gemeinsames Problemverständnis
●	Vertrauensvolles Miteinander
●	Vertrauensvolles Miteinander\Allgemein
●	Vertrauensvolles Miteinander\Gleichbleibende Ansprechpartner
●	Vertrauensvolles Miteinander\Behandler informiert sich
●	Vertrauensvolles Miteinander\Ansprechen von Beschwerden/Befinden
●	Vertrauensvolles Miteinander\Nicht näher bezeichnet
●	Vertrauensvolles Miteinander\Beziehungsgestaltung
●	Vertrauensvolles Miteinander\Verlässlichkeit
●	Vertrauensvolles Miteinander\Erreichbarkeit
●	Vertrauensvolles Miteinander\Partnerschaftliches Verhältnis
●	Zugang Behandlung
●	Zugang Behandlung\Allgemein

●	Zugang Behandlung\Wohnortnähe
●	Zugang Behandlung\Barrierefrei (Behinderung)
●	Zugang Behandlung\Barrierefrei (Sprache)
●	Zugang Behandlung\Barrierefrei (Anderes)
●	Zugang Behandlung\Geringe Zuzahlungen
●	Zugang Behandlung\Terminvergabe rechtzeitig
●	Zugang Behandlung\Wartezeit
●	Zugang Behandlung\Terminvergabe flexibel
●	Zugang Behandlung\Ausreichend Länge Termin
●	Zugang Behandlung\Zwei-Klassen-Medizin
●	Zugang Behandlung\Notfall Behandlung
●	Zugang Behandlung\Information Spezialisierungen/Leistungen
●	Zugang Behandlung\Nicht näher bezeichnet
●	Zugang Behandlung\Eindeutige Wegweisung
●	Zugang Behandlung\Barrierefrei (Gesundheitskompetenz)
●	Zugang Behandlung\Bewertungen von Behandelnden
●	Zugang Behandlung\Bevorzugter Zugang durch Kontakte
●	Zugang Behandlung\Freie Behandelndewahl
●	Zugang Behandlung\Ablauf der Aufnahme
●	Zugang Behandlung\Zugang zu Hilfsmitteln/Werkzeug
●	Zusammenarbeit Behandler
●	Zusammenarbeit Behandler\Allgemein
●	Zusammenarbeit Behandler\Wichtigkeit Zusammenarbeit
●	Zusammenarbeit Behandler\Interdisziplinarität
●	Zusammenarbeit Behandler\Gute Absprachen
●	Zusammenarbeit Behandler\Respekt
●	Zusammenarbeit Behandler\Vertrauen
●	Zusammenarbeit Behandler\Gemeinsame Verantwortung
●	Zusammenarbeit Behandler\Förderung durch Leitungsebene
●	Zusammenarbeit Behandler\Nicht näher bezeichnet
●	Zusammenarbeit Behandler\Gemeinsame Sprache
●	Zusammenarbeit Behandler\Teamzusammenhalt
●	Zusammenarbeit Behandler\Super-/Intervision
●	Zusammenarbeit Behandler\Verantwortungstragende Person





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Patienteninformation und Einwilligungserklärung zur Teilnahme an  
einem Interview (Semistrukturiertes Interview)

## Projekt „Patientenerfahrungen im Gesundheitswesen“

Hamburg, 17.05.2021  
Seite 1/3

Sehr geehrte Patientin, sehr geehrter Patient,

das Projekt „Patientenerfahrungen im Gesundheitswesen“ wird am Institut für Medizinische Psychologie am Universitätsklinikum Hamburg-Eppendorf (UKE) durchgeführt.

Ziel dieses Projektes ist es, die Patientenorientierung in der Gesundheitsversorgung zu fördern, indem ein Fragebogen erstellt wird, der Patientenorientierung aus Sicht der Patientinnen und Patienten misst.

Um Fragen zu erstellen, die für Patientinnen und Patienten relevant sind, führen wir Interviews (sog. Semistrukturierte Interviews) mit Ihnen durch. Mit Ihrer Teilnahme an einem Interview können Sie einen wichtigen Beitrag zu diesem Projekt leisten. Während des Interviews möchten wir über Ihre persönlichen Erfahrungen im Gesundheitssystem sprechen. Dabei möchten wir herausfinden, was für Sie besonders wichtig ist und wie Fragen für einen Fragebogen formuliert werden könnten. Im Rahmen der Interviews werden Sie zusätzlich gebeten einen einseitigen, anonymen Fragebogen mit Angaben zu Ihrer Person (z.B. Alter, Geschlecht) und gesundheitlichem Status auszufüllen.

Das Interview wird von unseren Studienmitarbeiter/innen durchgeführt, dauert etwa 30 bis 45 Minuten und wird per Tonbandaufnahme aufgezeichnet. Im Anschluss an das Interview wird diese Tonbandaufnahme verschriftlicht (sogenannte Transkription). Hierbei werden Namen und andere Identifikationsmerkmale (z.B. Namen von Ärzten, Namen von Orten, usw.) nicht aufgeschrieben, sodass die schriftlichen Daten den Studienteilnehmerinnen und Studienteilnehmern nicht mehr zugeordnet werden können. Nach Abschluss der Transkription werden die Tonbandaufnahmen gelöscht. Dies geschieht spätestens 3 Monate nach dem Interview. Für die weitere Auswertung werden lediglich die anonymisierten Verschriftlichungen genutzt.

Für die Teilnahme an einem Interview erhalten Sie eine Aufwandsentschädigung in Höhe von 20 Euro.

Ihre Teilnahme an dieser Studie ist freiwillig. Ihre Daten werden nur verwendet, wenn Sie die Einwilligungserklärung unterschrieben haben. Sowohl aus der Teilnahme als auch aus einer Nichtteilnahme entstehen keine Nachteile für Sie. Sie können bis zum Abschluss des Interviews jederzeit und ohne Angabe von Gründen entscheiden nicht mehr teilnehmen zu wollen, also auch wenn Sie bereits Ihre Einwilligung erteilt haben.

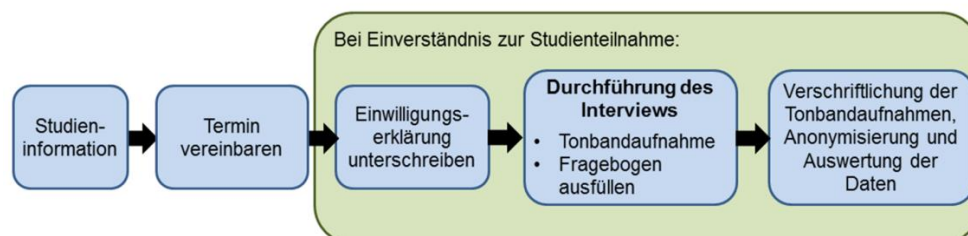
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Prof. Dr. Dr. Uwe Koch-Gromus | Joachim Prölß | Marya Verdel



Folgende Abbildung bietet einen Überblick über die Studienteilnahme:



### Datenschutz

Die im Rahmen der Studie nach Einwilligungserklärung des Studienteilnehmers erhobenen persönlichen Daten unterliegen der Schweigepflicht und den datenschutzgesetzlichen Bestimmungen.

Sie werden als anonymisierte Verschriftlichungen in Papierform und auf Datenträgern für die Dauer von zehn Jahren am Institut für Medizinische Psychologie gespeichert. Bei der Anonymisierung<sup>1</sup> werden der Name und andere Identifikationsmerkmale (z.B. Teile des Geburtsdatums) nicht gespeichert und die Daten können dem Studienteilnehmer nicht mehr zugeordnet werden. Nach 10 Jahren werden alle Datendatenschutzkonform vernichtet. Unter Umständen werden Daten in anonymisierter elektronischer Form am Institut und Poliklinik des UKE darüber hinaus gespeichert. Die Einwilligungserklärungen werden nach Abschluss der Studie umgehend datenschutzkonform vernichtet.

Die Auswertung, Nutzung, Weitergabe und Veröffentlichung der Daten durch den Studienleiter und seine Mitarbeiter erfolgt ausschließlich in anonymer Form. Datenschutzrechtlich verantwortlich ist das Universitätsklinikum Hamburg-Eppendorf, Körperschaft des öffentlichen Rechts, Martinistraße 52, 20246 Hamburg.

Die Daten können aufgrund der Anonymisierung durch die Studienteilnehmer nicht eingesehen und diese über anfallende personenbezogene Ergebnisse der Studie auch nicht informiert werden, da eine Zuordnung zu einzelnen Personen nicht mehr möglich ist. Diese Studie ist durch die zuständige Ethik-Kommission beraten worden. Der zuständigen Landesbehörde kann ggf. Einsichtnahme in die anonymisierten Studienunterlagen gewährt werden. Zur Überprüfbarkeit von Forschungsergebnissen können zudem vollständig anonymisierte Datensätze, die ebenfalls keinerlei Rückschlüsse auf die Person zulassen (Löschung von Ausfülldatum und Freitextantworten), in wissenschaftlichen Veröffentlichungen zugänglich gemacht werden.

Ein Widerruf der Studienteilnahme ist aufgrund der Anonymisierung nach Abschluss der Fokusgruppe nicht möglich.

### Rechtsgrundlage: Europäische Datenschutz-Grundverordnung<sup>2</sup>

Die Informationen zum Datenschutz und Ihren Rechten sind in Einklang mit der Europäischen Datenschutz-Grundverordnung (DSGVO). Die Rechtsgrundlage zur Verarbeitung der Sie betreffenden Daten bildet bei wissenschaftlichen Studien Ihre freiwillige schriftliche Einwilligung gemäß Art. 6 Abs. 1 lit. a), 9 Abs. 2 lit. a) DSGVO. Wir beachten weiter die Deklaration von Helsinki (Erklärung des Weltärztebundes zu den ethischen Grundsätzen für die medizinische Forschung am Menschen) und die Leitlinie für Gute Klinische Praxis.

### Beschwerdemöglichkeit

Sie haben das Recht, Beschwerde bei der/den Aufsichtsbehörde/n einzulegen, wenn Sie der Ansicht sind, dass die Verarbeitung der Sie betreffenden personenbezogenen Daten gegen die DSGVO verstößt:

Datenschutz: Kontaktdaten der Aufsicht der Studienleitung

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<sup>1</sup>Anonymisieren ist das Verändern personenbezogener Daten derart, dass die Einzelangaben über persönliche oder sachliche Verhältnisse nicht mehr oder nur mit einem unverhältnismäßig großen Aufwand an Zeit, Kosten und Arbeitskraft einer bestimmten oder bestimmbarer natürlichen Person zugeordnet werden können (§ 3 Abs. 6 Bundesdatenschutzgesetz)

<sup>2</sup>Verordnung (EU) 2016/679 des Europäischen Parlaments und des Rates vom 27. April 2016 zum Schutz natürlicher Personen bei der Verarbeitung personenbezogener Daten, zum freien Datenverkehr und zur Aufhebung der Richtlinie 95/46/EG (Datenschutz-Grundverordnung)



Institut und Poliklinik für  
Medizinische Psychologie

Projekt „Patientenerfahrungen im Gesundheitswesen“ Seite 3/3

#### Informationen zur Identifikation der Teilnehmer

Um die Personen identifizieren zu können, die bereit sind an den Interviews teilzunehmen, benötigt die Projektgruppe (Projektleitung: Dr. Isabelle Scholl) am Institut und Poliklinik für Medizinische Psychologie des Universitätsklinikums Hamburg-Eppendorf Ihren vollständigen Namen auf der Einwilligungserklärung.

Die persönlichen Daten (Name) dienen ausschließlich der Identifikation der teilnehmenden Personen und werden getrennt von den Fragebogendaten und der Verschriftlichung der Interviews aufbewahrt. Die Einwilligungserklärung wird in Papierform am Institut für Medizinische Psychologie des Universitätsklinikums Hamburg-Eppendorf verwahrt und nach Abschluss des Projekts umgehend vernichtet. Die Projektdauer beträgt 36 Monate. Danach liegen der Projektgruppe ausschließlich anonymisierte Daten vor.

Wenn Sie die Informationen zur Studie und zum Datenschutz gelesen und verstanden haben und Sie an dem Interview teilnehmen möchten, bitten wir Sie, die untenstehende Einwilligungserklärung zu unterschreiben. Eine Ausfertigung dieses Schreibens behalten Sie, damit Sie jederzeit nachlesen können, in was Sie eingewilligt haben. Sollten Sie nicht teilnehmen wollen, müssen Sie nichts unternehmen.

Sollten Sie noch Fragen zum Projekt haben, wenden Sie sich bitte an die Projektmitarbeiterin Frau Eva Christalle (Email: e.christalle@uke.de, Tel.: 040-7410-57723) und Stefan Zeh (Email: s.zeh@uke.de, Tel.: 040-7410-52001) oder die Projektleiterin Frau Dr. Isabelle Scholl (Email: i.scholl@uke.de, Tel.: 040-7410-57135).

Mit freundlichen Grüßen

Dr. Isabelle Scholl  
(Projektleitung)

Eva Christalle  
(Projektmitarbeiterin)

Stefan Zeh  
(Projektmitarbeiter)

#### Einwilligungserklärung

Unter den oben genannten Voraussetzungen willige ich in die Teilnahme an oben beschriebenem Forschungsvorhabens ein und willige ein, dass das Gespräch auf einem Tonträger aufgenommen werden darf und meine Angaben und Daten entsprechend den vorstehenden Hinweisen verarbeitet und genutzt werden dürfen.

Name, Vorname: \_\_\_\_\_

\_\_\_\_\_  
Ort, Datum

\_\_\_\_\_  
Unterschrift des Teilnehmers

\_\_\_\_\_  
Unterschrift des aufklärenden Projektmitarbeiters



Patientenerfahrungen  
im Gesundheitswesen