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Cystic fibrosis (CF) care through the patients' eyes – A nationwide survey on experience and satisfaction with services using a disease-specific questionnaire[☆]

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Summary

The patients' perspective is an important aspect of quality management. A newly developed disease-specific questionnaire was used to assess the patients' experiences with care provided in specialised cystic fibrosis (CF) care centres.

Methods: 90 CF centres in Germany were invited to participate. Centre staff collected patient consent forms and sent the patients' addresses to the study centre. The questionnaires for adults and parents had 100 and 104 items respectively, with 3–6 response categories each. Items were dichotomised into "problem scores" (PS), indicating the presence or absence (PS 0%) of a reported problem.

[☆] Part of this work was presented at the 26th North American Cystic Fibrosis Conference 2012 and at the 36th European Cystic Fibrosis Conference in 2013.

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Results: 56 CF centres took part in the survey and recruited 1642 adults with CF and 1205 parents. The response rates were 74% in each group, with 1221 completed questionnaires from adults and 891 from parents. Participants reported good experiences with care. Factor analysis revealed 10 factors covering 70 items. Participants reported the best results for the factors "Physiotherapists" (PS 6%) and "Physician–Patient Relationship" (PS 9%). Factors with the highest problem scores were inpatient and outpatient "Facilities, Hygiene and Services". CF centres received reports of their own results and mean problem scores of all participating institutions. The problem scores differed considerably between CF centres.

Conclusions: The nation-wide CF-specific patient experience survey identified specific shortcomings which were mainly related to communication, centre organisation, and facilities. Centre staff can use the results to improve the quality of care. We suggest that patients' views should become an integral component of efforts to promote patient-centred care.

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Introduction

In 2005, the European Cystic Fibrosis Society published standards to ensure high quality medical care for patients with cystic fibrosis and their families [1]. Experts recommended to treat patients at specialised CF centres, and they defined the kind and number of multi-professional staff and resources needed to provide good care. Further aspects contributing to good treatment are guidelines, standardised procedures and processes, and patient databases.

National and international patient registries reveal the medical situation of patients with cystic fibrosis, and differences between countries and centres have been identified [2,3]. However, there is a lack of information on how patients and parents assess the services and treatments they receive at the CF centre. The patients' perspective is an important aspect of total quality management. Moreover, good services increase the proportion of satisfied patients, and satisfied patients will adhere better to treatment [4]. Good treatment adherence is particularly important in a life-long chronic disease such as cystic fibrosis which requires daily treatment at home. Thus, CF centres should provide care that is focused on their patients' needs.

The board of the physicians working group (AGAM) in the German CF association (Mukoviszidose e.V.) started an initiative in 2007 to develop a CF-specific patient experience of care questionnaire. A project group was established with the Picker Institute Germany as a major partner. The Picker Institute Germany is a not-for-profit organisation and a subsidiary of Picker Institute Europe. It has more than 30 years experience in conducting patient satisfaction/experience surveys. In the present study the Picker Institute also served as the study centre.

After a successful pilot study in four centres, the draft questionnaire was revised [5], and the final version was used for a nationwide survey which started in 2011. The present article describes how a cohort of more than 2000 patients and parents assessed the quality of multi-professional care in German CF centres.

Methods

Development of a CF-specific patient experience of care questionnaire

For generating the questionnaire, we combined newly developed items covering specific aspects of CF care with widely-used, reliable generic items from the Picker Institute which are relevant to patients with all kinds of medical problems [6]. Importantly, the Picker method implies that participants report on their care experiences, rather than rating their satisfaction [6], since the latter type is prone to positive bias [7]. An example of a reporting style question is "Are you told about medication side effects to watch for? Yes, always – Yes, frequently – Sometimes – Nearly never/never". A detailed description of the methods is presented elsewhere [5]. In brief, we first interviewed experts from multi-professional CF teams on the specific medical needs of patients with cystic fibrosis. In the next step we conducted focus groups of adult CF patients and parents of minors (below 18 years of age) with CF. The results from these discussions were used to draft the first questionnaire, which was tested in a pilot study at four CF centres (Hamburg, Berlin, Innsbruck, Köln) in 2009. Feedback from the pilot study was used to create the final questionnaire. Two slightly different versions were constructed, one for adult patients with cystic fibrosis and one for parents of minors with CF. The parent and the adult versions comprised 104 and 100 closed-ended questions, respectively, including 14 items on demographic and clinical parameters (since the survey was anonymous) and 3 open ended questions. Responses to open questions such as "If you had a wish and you could change anything in the CF centre, what would it be?" were included in the report to the individual CF centre, but are not part of the present study. The CF-specific topics in the questionnaire were related to hygiene, staff of the multi-professional team, CF treatment and care, services and facilities at the centre, accessibility, and inpatient treatment on the ward. Parents with more than one child with CF replied by referring to their oldest child.

Table 1 Patient characteristics as reported by respondents.^a

	Parents/children ^b	Adult patients
Recruited (N)	1205	1642
Responded (N, % of recruited)	891 (73.9%)	1221 (74.4%)
Male: female ratio, patients (%)	49:51	48:52
Male: female ratio, parents (%)	15:85	
FEV ₁ (%)		
>80% predicted	59.8	27.4
50–80% predicted	13.9	36.4
< 50% predicted	2.1	28.5
I don't know	21.1 ^c	5.8
No response	3.1	2.5
<i>P. aeruginosa</i> isolated (%)		
Never	38.2	8.9
Yes, sometimes	43.1	24.7
Yes, repeatedly	14.5	61.5
I don't know	2.0	2.9
No response	2.0	2.0
Subjective health status (%)		
Good	64.0	38.7
Not the best	29.0	39.4
Poor/very poor	5.0	19.5
No response	2.0	2.4

^a To assure that the survey was anonymous, there was no link between the questionnaires and medical records.

^b Clinical data are from minors with CF.

^c Children below 6 years of age had no lung function tests.

In addition to adults and parents, adolescents aged 12–17 years were surveyed using a different questionnaire which focussed on the health care preferences of chronically ill adolescents [8]. This instrument was amended to ask not only for preferences, but also for the respondents' health care experiences [9]. The results of this part will be presented elsewhere. However, parents of adolescents replied using the parents' questionnaire, so that their views were also included in this study.

Recruiting centres

The nationwide survey was conducted in Germany in 2011. Ninety CF centres known to the Mukoviszidose e.V., the German CF association, were invited to take part in the project. It was emphasised that participation was voluntary. Participating centres agreed to use their results for quality improvement measures and to discuss them with patient representatives.

Recruiting and surveying participants

Patients were recruited according to established procedures [10]. Clinic staff informed each patient or parent in person about the project. During the outpatient visit, an information leaflet was handed out, and patients were asked to provide written consent for transmitting their home address to the study centre at the Picker Institute Germany. Subjects who signed the consent form will hereafter be referred to as "recruited". Once a week, centre staff faxed the patient addresses to the study centre. A recruitment sheet was also transmitted, listing

the approached patients plus the reasons why persons had declined to take part.

Each participant received the questionnaire plus a response postcard by mail. Patients filled in the anonymous questionnaire and sent it back in a pre-paid envelope. In addition, participants mailed the separate postcard to the study centre to indicate that no reminder is necessary. Staff at the study centre monitored the responses and sent out reminders after two and four weeks to subjects who had not returned the postcard in due time. After survey termination, the list' of participants' addresses were destroyed.

Analysing data

In order to easily identify suboptimal care, the answers of each item were dichotomised into two categories, indicating either optimum care or a "problem". For example, the item "Does your doctor listen to what you have to say?" has the desirable response "Yes, very carefully", while both "To some extent" and "No" would present a problem. For each item the percentage of respondents reporting a problem was calculated, thus displaying the problem score (PS) with a score of zero percent being ideal. Respondents who did not answer the question were not included in the calculation of the problem scores.

To provide summary scores for the different aspects of care factor analysis was performed to group the questionnaire items into factors. The factor problem score was calculated as a weighted mean of the problem scores of the respective items.

Table 2 Items with the best results (mean problem score $\leq 3\%$ in any group).

Item	Mean problem scores (%)	
	Parents	Adult patients
How would you rate the courtesy of the physiotherapists?	1	1
How would you rate the courtesy of the dieticians?	1	4
How would you rate the courtesy of your doctor?	2	2
When you have questions to ask your doctor, do you get answers that you can understand?	2	3
How would you rate how well department staff work together?	2	6
How do you assess the way the nurses deal with you child?	2	na
How would you rate the courtesy of the nurses?	3	4
Would you recommend the CF department to your family and friends?	3	6
Are you under the impression that the department staff do everything they can to make sure you get the best possible treatment?	3	7
How would you rate the courtesy of the psychosocial staff? ^a	4	0
Do the physiotherapists take enough time with you?	4	3
Do you get enough time with your doctor ?	4	3
When you have questions to ask the psychosocial staff, do you get answers that you can understand?	6	3

na: not applicable.

^a $N = 341$ (38.3%) parents and $N = 213$ (17.4%) adults reported contacts with psychosocial staff during the last 12 months.

Online reports

The survey results of each centre were provided online. Centre staff used a code to access their results on the online platform. Each centre received three different reports. The first contained the frequency tables showing for each item how many respondents from the CF centre had chosen each of the alternative answers. The second report compared the centres' results with the aggregated results of all participating centres in form of a bar chart. In order to facilitate the interpretation of this external comparison, means and standard deviation of the aggregated results were provided. The third report, a priority matrix, displayed the factors in relation to overall importance and performance. Centre staff had no access to individual data from other institutions.

Statistics

Descriptive results are expressed as means, with standard deviations of the mean in brackets. Statistics were calculated using Graph Pad Prism for Windows version 6.02 (March 2013). Comparisons between groups were made with two-tailed *t*-tests.

Results

Patient characteristics

Of the ninety CF centres which were invited to participate, 56 took part in the survey. The participating centres cared for 4265 patients, which was equivalent to about 85% of patients documented in the German cystic fibrosis registry in 2009. Centre staff recruited 1642 adult CF patients and 1205 parents of minors (Table 1). In parallel, 513

adolescents were recruited to report their experiences using another questionnaire (results will be published elsewhere).

The response rates were 74% in both adults and parents. The two reminders that had been sent out to unresponsive patients increased the response rates by more than one third. Patient characteristics are displayed in Table 1, as reported from participants. Respondents covered the whole spectrum of cystic fibrosis lung disease, although most were mildly to moderately affected.

General experience with care

In general, participants reported favourable experiences with CF centre care. Twenty-three items had very good problem score between 1 and 5%, while 31 questions had problem scores of over 20%. Table 2 summarises the items with the lowest problem scores. Both parents and adults met friendly staff who spent enough time with patients and gave understandable answers to their questions.

When asked about their overall experience, most respondents rated the care as excellent or very good and stated that they would recommend the CF department to friends or family (Table 3). Responses of adult patients and parents were very similar.

CF specific experiences

Fig. 1 shows that the best experiences with the lowest problem scores were related to the factors "Physiotherapists" and "Physician–Patient Interaction". On the other end of the spectrum, both inpatient and outpatient "Facilities, Hygiene and Service" had higher median problem scores of around 30%. The factors "Inpatient Care on the Ward", "Nurse–Patient Interaction", and "Information and Training" had problem scores over 15%.

Table 3 Items addressing the general impression of patient care.

	Frequency (%)	
	Parents	Adult patients
Overall, how would you rate the care you receive in the CF department? (<i>Item 75</i>)		
Excellent	32.7	24.9
Very good	46.1	44.5
Good	17.5	24.3
Fair	3.1	4.8
Poor	0.6	1.4
(No response)	(5.0)	(2.1)
Would you recommend the CF department to your family and friends? (<i>Item 76</i>)		
Yes, definitely	71.4	56.8
Yes, probably	26.1	37.0
Not really	1.1	4.1
No	1.4	2.1
(No response)	(5.6)	(2.2)

In spite of favourable overall experience, there were several issues where centre staff did not meet the requirements of the majority of respondents. Table 4 shows the items with the highest problem scores. Half of the respondents could not discuss their anxieties and fears with nurses in an appropriate way, although 70% of participants stated they wished to do so. There were also problems with respect to informing patients about possible adverse drug reactions, informing about new medical research on CF, and prompt notification of test results.

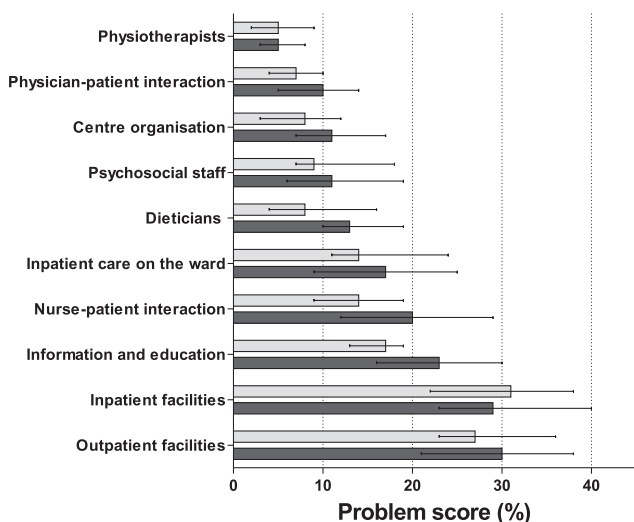


Figure 1 Problem scores of factors in the participating centres. Problem scores of the ten factors in the 56 participating centres. The boxes contain the median values (50th percentile), and the error bars stretch from the 25th to the 75th percentiles. Light bars reflect the results from parents and dark bars those from adult patients with CF. The names of the factors have been abbreviated due to space constraints on the graph.

Several of the 32 items that were not covered by one of the ten factors also showed suboptimal care. Examples are “If you have urgent medical questions and the contact you want is not available immediately, how long does it usually take for someone to get back to you?”, where 48.9% of parents and 32.2% of adults stated they had to wait more than 2 h for a response. Another example is “Do you know whom to contact outside CF department hours?” with 30.7% of parents and 34.2% of adults answering with “no”.

As shown in Fig. 1, adults had higher problem scores than parents in eight of the ten factors. Answers from adult patients were generally more discerning regarding most of the items, too.

Comparisons with other centres and online reports

Fig. 1 shows the median problem scores of the ten factors across centres. As reflected by the 25th and 75th percentiles, considerable variation was found between the 56 participating institutions. For “Inpatient Care on the Ward” of adult patients, for example, the 14 centres with the best results (lower quartile) had problem scores $\leq 9\%$, while the 14 centres of the upper quartile had problem scores of $\geq 25\%$.

All participating centres had online access to the survey results of their clinic. Centre data were related to means and standard deviations from all participating institutions, and staff could judge their performance in comparison to that of direct peers. An example is shown in Fig. 2.

Making use of survey results

All centres had given written consent to evaluate the findings of the survey and to use them for quality improvement efforts. Since this was the first patient experience survey in German CF centres, no instructions were given beforehand on how centres should make use of their results. A survey in the participating centres was carried out in 2013. Results showed that 35 (87.5%) of the 40 responding centres had initiated changes based on the survey results. Staff regarded the efforts for recruiting patients as adequate (85%) or low (8%). The majority (75%) assessed the online reports displaying the survey results as comprehensible. Discussions with patient representatives had taken place in 30 (75%) centres, and 24 (60%) centres reported positive experiences. Most centres were interested to participate in a follow-up survey which should preferably be performed in 2015.

Discussion

This nationwide survey explored the patients’ and parents’ views on the care and services provided at German CF centres. Respondents reported mostly positive experiences with centre staff, and their overall experience was very positive. However, the newly developed, disease-specific questionnaires also revealed a number of shortcomings. Major issues were related to communication, information and education, as well as to facilities and services in the outpatient clinic and on the ward.

Table 4 Items with the highest problem scores grouped by factors.

Factor	Item	Mean problem scores (%)	
		Parents	Adult patients
Nurse–patient interaction	If you have anxieties or fears about your condition or treatment, does/do the nurse(s) discuss them with you?	47	56
	Do you feel you are well looked-after by nursing staff in terms of expertise?	25	37
	Do you have confidence and trust in the nurse(s)?	25	27
Information and training	Are you told about medication side effects to watch for?	45	48
	Are you under the impression that the CF department is doing everything possible to inform you about test results quickly?	41	46
	Are you kept informed about new medical developments in the treatment of cystic fibrosis?	40	39
Facilities, Hygiene and Service (CF centre)	Are the toilets and wash-basins as clean as you would expect?	40	46
	In the CF department I think toys for children are ... (excellent – ... – poor)	39	39
	In the CF department I think the medical information brochures are ... (excellent – ... – poor)	39	38
Facilities, Hygiene and Service (hospital ward) ^a	On the ward I find the food is ... (excellent – ... – poor)	33	45
	On the ward I find the personal atmosphere ... (excellent – ... – poor)	35	33
	On the ward I find the toilets ... (excellent – ... – poor)	28	27
Physician-Patient-Interaction	If you have anxieties or fears about your condition or treatment, does your doctor discuss them with you?	16	22
	Do you have confidence and trust in your doctor?	15	20
	Do you feel you are well looked-after by your doctor in terms of expertise?	8	17
Organisation and Access	Is it easy to get an appointment quickly outside routine visits?	14	21
	Is the CF department always easy to contact by phone or e-mail if you have a question?	15	20
	After your child is discharged, is the key information about the hospital stay quickly available in the CF department?	7	11

^a $N = 540$ (60.6%) parents and $N = 886$ (72.6%) adult patients responded to these items.

To our knowledge, this is the first report on a nationwide patient experience survey using a CF specific questionnaire. Two slightly different versions of the instrument were generated for adult patients with cystic fibrosis and for parents of minors with CF. The items addressed important areas of health services, communication, and education, and they also displayed the performance of the different professional groups involved in CF care. The only other CF-specific experience of care questionnaire we are aware of was developed in the United States [11]. It contains 50 questions covering dimensions such as access to care, health team care, and self-care. Many topics are common to both the US and the German questionnaires. Only the US instrument addresses self-care and self-confidence of patients, while the German questionnaire differentiates between the groups of professional caregivers.

We achieved very good response rates: even though the questionnaire contained more than 100 items, 74% of both adult patients and parents took their time to respond. These rates compare favourably with other patient surveys, for example the 37% response rate in 51,129 chronically ill patients in the U.S. [12] or the 58.5% response rate from patients in 24 Swiss hospitals [13]. In addition, we regard the investigated sample as representative for the whole patient cohort,

since the 56 participating centres cared for about 85% of patients documented in the German CF patient registry.

In the US survey, the response rates were much lower, only between 3% and 23% [11]. Subjects responded either via a web-based survey or by using a toll-free phone-line. In the present study, staff at the CF centre stressed the importance of getting feedback from their patients. Participants received an information leaflet and were requested to sign a consent form. A signature represents a much stronger commitment to participate than getting an invitation by e-mail [14]. The survey was completely anonymous, and the study centre had neither access to clinical data of individual patients nor to the German CF patient registry. We also used further methods which are known to significantly increase the response to postal surveys [15], namely, an interesting questionnaire topic, assurance of confidentiality, use of stamped return envelopes, and sending out two reminders.

Factor analysis revealed ten factors which covered the majority of items and accounted for about 50% of the total variance [5]. Patients reported different experiences with respect to these themes. Only very few problems with physiotherapists and physicians were reported, while there were several issues regarding facilities in the outpatient

Do you feel involved in the ongoing planning of your care?

Yes, always - Yes, frequently - *Sometimes* - *Almost never* / *never* - I don't want to be involved

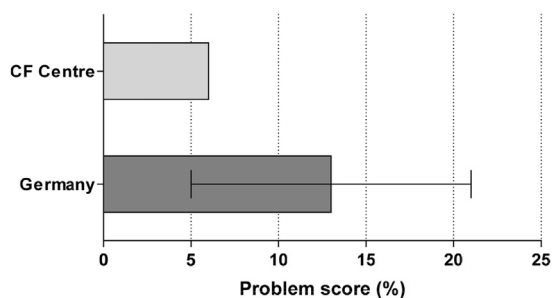


Figure 2 Online report: comparison of centre results with those of all participating centres (means and standard deviations). Example of survey results as displayed in the online reports. Problematic answers to the question are written in bold italics. The upper box shows the problem frequency in the CF centre, the lower box is the mean problem frequency of all 56 participating centres, and the error bars reflect the standard deviations of the mean. This way of presenting the data allows centre staff to compare their results with those of other German CF centres.

clinic and “hotel services” on the ward. In the US pilot study, patients had generally positive opinions regarding the health care team [11]. Interestingly, only about 50% gave positive responses to the item “Wish you knew more about meds”. Likewise, in our study a high proportion of respondents complained that they did not receive sufficient information on medication side effects.

The online reports allowed comparisons between centre results and the aggregated results of all 56 participating institutions. The relatively large variances suggest that considerable differences between centres were present. In the United States, the 25 item HCAHPS questionnaire (Hospital Consumer Assessment of Healthcare Providers and Systems) is used to assess general medical care in almost 4000 hospitals. Comparison charts are regularly published on the internet, grouped by hospital region, location, bed size, teaching status, and ownership and control [16]. The data of April 2013 were generated from nearly 3 million patient surveys. Compared with a project of that size, our CF specific nationwide survey included only small numbers of participating institutions and patients. The potential for external quality management with meaningful centre comparisons was therefore limited. In the 27 largest institutions, however, we compared the problem scores of the factor “Organisation and Access”, and observed that three centres had significantly better results than the others. Thus, the new instrument can be used for statistical comparisons between larger centres. Nevertheless, we think that the simple display of centre results compared with means and standard deviations of others will already serve as an important tool for quality management. For national comparisons, it would be worthwhile to use translated and adapted versions of this instrument in other countries.

The project group has developed disease-specific questionnaires for two other chronic diseases of childhood, namely juvenile rheumatoid arthritis [17] and type 1

diabetes mellitus. While nationwide surveys have not been performed so far using these instruments, the concept has the potential to delineate strengths and weaknesses of care across different chronic diseases.

The project had some limitations. First, although 90 CF centres were approached, only 56 joined in. The participating centres however treated about 85% of all patients with cystic fibrosis documented in the German CF registry that year. Because participation was optional and was not associated with financial compensation, we had estimated at the outset that about 30 centres would agree to participate. In retrospect, it seemed important that the Physicians Working Group AGAM had promoted the project from the very beginning. Second, not all patients treated at the centres were recruited, and not all recruited patients returned the questionnaire. We cannot exclude that the remaining patients had different views. Not all patients visited the centre during the recruitment period. Some patients were not invited because of inadequate German language skills, so there is no systematic feedback from this subgroup. Ethnic and socio-economic aspects may influence the patients’ views, as has been observed in the United Kingdom [18]. Third, due to financial and organisational restraints we did not create a questionnaire version specifically for children and adolescents. Patients aged 12–17 years were nevertheless surveyed in parallel using a modified and translated version of an established questionnaire on health care preferences and priorities of adolescents [8]. Preliminary results of the adolescents’ pilot survey have been presented in poster form [9].

In conclusion, the newly developed, CF specific questionnaire was used to explore the participants’ perspective of the care they receive in CF centres. In general, patients’ and parents’ care experience was positive. In spite of this, the instrument showed specific shortcomings related to communication, centre organisation, and facilities. The comparison with aggregated results from all participating centres helped to identify which topics were of major importance for quality improvement in each centre. In the future, translating the instrument into other languages and adapting it to the conditions of other health care systems would allow international comparisons. We suggest that the patients’ views should become an integral component of quality management efforts to promote patient-centred care.

Conflict of interest statement

GS, HE, EH, SvK, WB, and CS declare no conflict of interest.

KS is director of research and product development at the study centre, Picker Institute Germany gGmbH. MB is project coordinator at the Picker Institute.

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List of participating centres

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 Universitätskinderklinik Dresden CF-Ambulanz
 Universitätsklinikum Essen Mukoviszidose Zentrum
 Mukoviszidose-Ambulanz Oldenburg
 Carl-Thiem-Klinikums Cottbus Mukoviszidose Ambulanz
 CF-Ambulanz Worms
 Klinik Schillerhöhe CF-Ambulanz für Erwachsene
 Mukoviszidose-Ambulanz Wesel
 Nachsorgeklinik Tannheim
 CF-Ambulanz Wangen
 CF-Ambulanz Dr. Niethammer
 Klinikum Solingen Mukoviszidoseambulanz
 Luisenhospital Mukoviszidose Ambulanz
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 Mukoviszidose-Ambulanz Potsdam
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