Assessing health-related quality of life in people with cognitive impairment - a Delphi study protocol.

A. Feißel[1], L. Boyer[2], T. Bratan[3], C. Schlüfter[3], J. Loss[4], C. Apfelbacher[1]

[1] Institute of Social Medicine and Health Systems Research, Faculty of Medicine, Otto von Guericke Universität Magdeburg, Magdeburg, Sachsen-Anhalt, Germany.

[2] Medical Sociology, University of Regensburg, Regensburg, Germany.

[3] Competence Center Emerging Technologies, Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe, Baden-Württemberg, Germany

[4] Department of Epidemiology and Health Monitoring, Robert Koch Institute, Berlin, Germany.

I. Abstract:

There is insufficient knowledge about whether people with cognitive impairment are able to self-report their health-related quality of life (HRQoL), whether it should be reported via proxy by a family member, friend, or caregiver, or whether an outside person should observe it. With this in mind, a Delphi with three online survey rounds and a final consensus conference will be conducted with the aim of reaching consensus to address the research questions a) how the HRQoL of people with cognitive impairment should be assesed and b) what i.e. which domains should be assesed. The Delphi is conducted with two groups of participants: 1) clinical experts in the German-speaking countries as well as scientists with a research focus on patient-reported outcomes and quality of life research or research on dementia/cognitive impairment; 2) affected persons and relatives of people with cognitive impairment. The Delphiquestionnaire was developed with statements from the scientific literature and then pretested and finally optimised. Response options are given along a 7-point agreement scale on the level of agreement from "do not agree at all" (1) to "agree completely" (7). Consensus is reached if at least 75% of the responses are fall into response categories 6 and 7 or 1 and 2 after the third Delphi round. Finally, a consensus conference is held where statements on which no consensus is found in the online survey are discussed. We expect to find the broadest possible consensus on the aforementioned research questions.

This study protocol is structured according to the reporting guidelines for Delphi techniques in health sciences (Spranger et al. 2022).

II. Epistemology:

In this study, the term "cognitive impairment" includes mild cognitive impairment (MCI), as well as severe forms of dementia such as Alzheimer's disease (AD) and other forms of dementia. It is an impairment of memory, attention, and reasoning, usually occurring in older age, without significant limitations in daily life (Petersen 2016). Dementia is defined as a decline and loss of cognitive abilities in the areas of attention, learning and memory, orientation, judgment and planning (executive functions), speech, motor skills, and abilities to interact with others (social cognition) (Deutsche Alzheimer Gesellschaft e.v. Selbsthilfe Demenz 2020). Often, MCI represents the precursor to dementia (Petersen 2016). While MCI is usually not associated with any significant everyday restrictions, dementia impairs everyday activities (Deutsche Alzheimer Gesellschaft e.v. Selbsthilfe Demenz 2020). The most common form of dementia is AD, followed by vascular dementia, Lewy-body dementia and frontotemporal dementia (Stevens et al. 2002).

Up to now, there are no cures for cognitive impairment, so the focus is on increasing the quality of life of those affected. The construct of health-related quality of life (HRQoL) is assessed as the subjective sense of the person concerned (Ayton et al. 2021). This is understood as the consideration of quality of life in the context of health and disease, distinguished from other aspects of quality of life. HRQoL is multidimensional and includes aspects of physical, mental, emotional, and social functioning (Ferrans 2005). To assess HRQoL, we are guided by the WHOQOL User Manual (World Health Organization (WHO) 1998),which describes domains and facets of HRQoL.

There is incomplete knowledge about whether people with cognitive impairment are able to self-report their HRQoL (Heuer und Willer 2020). In addition to self-reported HRQoL, there are two other commonly used methods for measuring HRQoL in people with cognitive impairment. It can also be reported via proxy by a family member, friend, or caregiver by putting themselves in the position of the person with the disease. In addition, it is possible for an outside person to observe and interpret the behavior of the person affected by cognitive impairment and draw conclusions about their quality of life (Heuer und Willer 2020). It is debatable, however, which survey method is the most appropriate, depending on the stage of cognitive impairment (Landeiro et al. 2020). Each of these options has advantages and disadvantages and their use is discussed within the different stages of the disease.

With this in mind, a Delphi will be conducted with the aim of reaching consensus to address the research questions a) how the HRQoL of people with cognitive impairment should be assessed and b) what i.e. which domains should be assessed. We expect to find the broadest possible consensus on the aforementioned research questions.

III. Formal context:

The Delphi is being conducted as part of the Gelang BeLLa accompanying research project (launched by the Federal Ministry of Education and Research; funding code 01GL1905A; project duration 09/01/2021- 07/31/2023, website: www.begleitforschung-bella.de). BeLLa accompanies 174 individual projects and joint projects in 79 German universities and research institutions funded by the programme 'Healthy—for a lifetime' ('GeLang: Gesund – ein Leben lang') and aims to offer

scientific support, to develop standards (e. g. for patient-related outcomes, transfer of research results or participatory approaches) and to establish networks between the projects. Project partners are the University of Regensburg, Medical Sociology; the Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe; the Robert-Koch-Insitute, Berlin and the Otto-von-Guericke-University Magdeburg (OvGU), Institute for Social Medicine and Health Systems Research (ISMG). The Magdeburg site is responsible for the planning and implementation of the Delphi.

IV.   Knowledge base:

The current state of research shows the following results on the three methods as well as existing instruments for assessing HRQoL in people with cognitive impairment:

Self-reporting is affected by deficits in memory, concentration, communication skills, limitations in daily living, and impaired decision making in people with cognitive impairment. Limitations gradually increase across the stages of the disease (Heuer und Willer 2020; Hickey und Bourgeois 2000). Although self-reporting plays an important role in capturing HRQoL, the ability to self-report HRQoL is poorly understood in people with severe cognitive impairment such as dementia (Heuer und Willer 2020). However, (Bourgeois et al. 2016) suggest that people with dementia could successfully self-report their HRQoL even in advanced stages if data was collected via structured interview or if supportive communication strategies were used. The findings of (Ayton et al. 2021) and (Hickey und Bourgeois 2000) also indicate that self-reporting by people with dementia of all severities is possible. Nevertheless, the exclusion of people with severe cognitive impairment remains an unresolved issue (Bowling et al. 2015).

Quality of life is more commonly assessed via proxy or observations in people with advanced cognitive impairment and in longitudinal studies (Heuer und Willer 2020; Landeiro et al. 2020; Bowling et al. 2015). In this context, proxy-reports are influenced by the health status and stress experience of the respondent, as well as the relationship between proxy responder and affected person (Landeiro et al. 2020; Robertson et al. 2017; Hickey und Bourgeois 2000). In addition, HRQoL and psychological well-being are usually underestimated and cognitive abilities overestimated in proxy-reports (Heßmann et al. 2018; Zucchella et al. 2015). There is also a perception that not all relatives or family members are suited to provide assessments of HRQoL of people with cognitive impairments based on their own health status, education level, and ability to understand questions (Heuer und Willer 2020; Hickey und Bourgeois 2000).

Observations can be applied regardless of cognitive abilities, but they are often used in severe stages of cognitive impairment (Missotten et al. 2016). In addition, it is recommended to use them in cognitive-linguistic deficits of affected persons (Dichter et al. 2016). Observations often have the purpose of measuring the impact of interventions, e.g., creative interventions, on HRQoL in people with cognitive impairments (Algar et al. 2016). Algar et al. (2016) argue that the reliability of capturing HRQoL using observational tools is limited because observing behaviors, moods, gestures, and facial expressions is challenging in the advanced stages of the disease. Another limitation is that only objective aspects of HRQoL can be measured instead of subjective ones (Heuer und Willer 2020). For this reason Algar et al. (2016) still recommend self-report or report by proxies in addition to observations to collect all aspacts of HRQoL.

Existing instruments for capturing HRQoL in people with cognitive impairment have often not been sufficiently validated, i.e., studied in terms of their measurement properties (Landeiro et al. 2020; Li

et al. 2018; Bowling et al. 2015; Aspden et al. 2014). Moreover, they are often inadequately validated in terms of language, i.e., the translation of elements of the instruments is not appropriate for use in the target group and is not clearly expressed and understood (Dichter et al. 2016). Even the best-studied instruments lack evidence regarding critical aspects such as sensitivity to change, acceptability, or discriminant validity, or have poor measurement properties (Hughes et al. 2021). In addition, the sample size on which instruments have been tested is often unsatisfactory (Bowling et al. 2015). Literature suggests that a more comprehensive and extensively validated measurement instrument is needed and extensive psychometric research is required (Ayton et al. 2021; Bowling et al. 2015; Li et al. 2018; Yang et al. 2018; Dichter et al. 2016; Aspden et al. 2014).

IV.   Delphi variant and role in research process:

A Delphi is a method for gathering opinions, assessments, and perceptions on issues about which uncertain or incomplete knowledge exists (Häder 2014). The Dephi is used as a method to obtain assessments regarding how HRQoL in people with cognitive impairments should be measured and what should be measured as part of HRQoL. During three online survey rounds, participants are asked to rate statements that are developed based on literature and map uncertain knowledge. After each wave, participants will receive feedback on the results of the previous wave and will be asked to reassess so that they can reconsider and revise their responses if necessary. The online survey rounds are conducted with the software "e-Delphi" (www.edelphi.org). It has been reviewed by OVgU's Information Security and Data Protection. After the three rounds a consensus conference is held on aspects with remaining dissent.

V.   Sample:

The Delphi is conducted with two groups of participants:

1st group: experts

2nd group: affected persons/relatives.

Experts

An interdisciplinary panel of experts is necessary for the Delphi. Therefore, the choice of experts focuses on clinical experts in the German-speaking countries (neurologists, gerontologists, psychologists) as well as scientists from different disciplines with a focus on patient-reported outcomes and quality of life research or research on dementia/cognitive impairment. A contact database with 500 possible participants will be created using Excel. In addition, a flyer and a website for the Delphi will be created to provide information about the Delphi and to motivate participation (https://www.begleitforschung-bella.de/e-delphi-befragung/). The flyer will be distributed at conferences and via a QR-code that leads to the website of the Delphi. Additionally, a Twitter post about the Delphi will be posted. To participate in the Delphi, experts will be able to contact the project staff via e-mail, thereby agreeing to participate and being included in the contact database.

Further experts will be recruited within the Gelang-BeLLa project. Here, all projects will be contacted that deal with dementia research and cognitive impairment in the neuropsychiatric field as well as

research on patient-reported outcomes in older people. These are four individual projects and six collaborative projects.

All contacts will be invited to participate in the online survey via email. The experts receive a cover letter with the background of the study, the aim of the survey, the procedure of the Delphi, information on data protection and specific contact persons. Two weeks after the invitation, a reminder will be sent in order to recruit as many participants as possible. After approval of participation, the experts will be administered in a database. For participation in the consensus conference, the experts will be offered reimbursement of their travel expenses.

Affected persons and relatives

In order to successfully recruit the target group a flyer was created. People with cognitive impairments of all severities and relatives will be recruited via centers for dementia and cognitive impairment, dementia networks, clinics for people with cognitive impairment, self-help groups for people with dementia and their relatives, geriatric and service centers and care services. Furthermore, the flyer will be published on the website of the Dementia Network Magdeburg. In addition, a Twitter post on the Delphi will be posted. The affected persons and relatives are offered an expense allowance of 10 € per survey round and 15 € for the participation in the consensus conference.

Sample size

Literature reports on the optimal number of participants range from a minimum of six, seven or ten people to over 1000 participants or no upper limit for the number of participants (Häder 2014). For the present Delphi, the aim is to invite at least 500 participants consisting of experts and affected persons as well as relatives to the Delphi. We anticipate a participation rate of 20%, resulting in a number of approx. 100 participants for the first round of the survey. The total number will likely decrease with the second and third survey rounds. All participants who will have taken part in at least the first round of the survey will be invited to the consensus conference, as well as other experts in the above-mentioned research fields and affected persons and relatives of people with cognitive impairments. Depending on the number of participants in the survey rounds, 20 to 50 people are expected to attend the consensus conference.
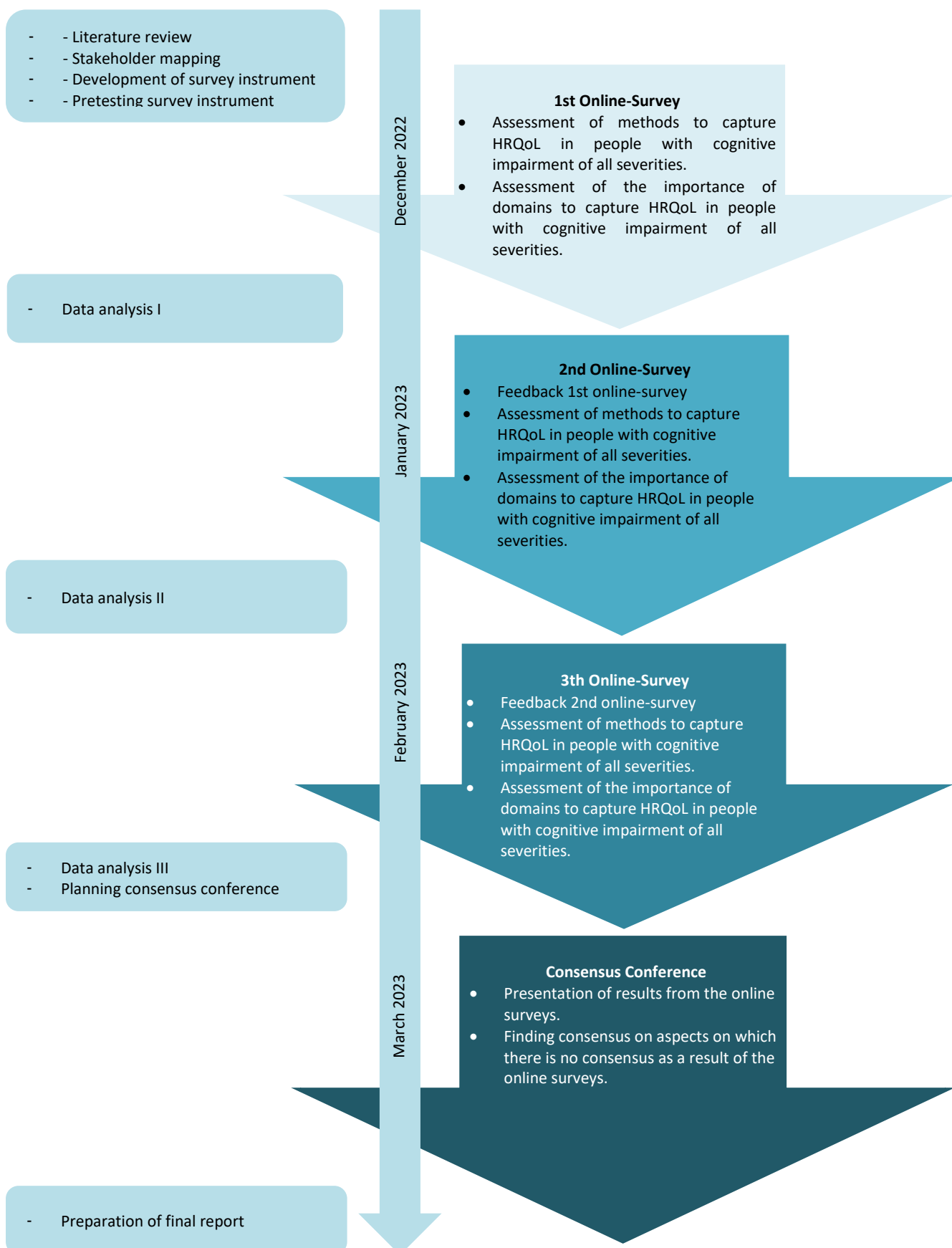
VI.   Survey Instrument

The basis for the questionnaire development was a literature review on capturing HRQoL in people with cognitive impairment (Hughes et al. 2021; Heuer und Willer 2020; Landeiro et al. 2020; Li et al. 2018; Yang et al. 2018; Robertson et al. 2017; Algar et al. 2016; Dichter et al. 2016; Missotten et al. 2016; Bowling et al. 2015; Zucchella et al. 2015). To this end, self-report, proxy-report, and observations and respective instruments were considered as ways to collect data. Furthermore, domains for measuring HRQoL in people with cognitive impairment were researched. Frequently mentioned potentials and limitations of the three measurement methods as well as domains that emerged as relevant from the WHQOL User Manual (World Health Organization (WHO) 1998) were presented as statements, grouped in topics, in the questionnaire (e.g., capturing of health-related quality of life in people with cognitive impairments should always be supported by another person). Response options are given along a 7-point agreement scale on the level of agreement from "do not

agree at all" (1) to "agree completely" (7) (Franzen 2019). In addition, two open fields were integrated into the questionnaire, one for participants to leave comments and suggestions and one for further uncertainties or questions that arise and should be integrated into the Delphi. After completion of the questionnaire (Appendix 1), it was pretested with 14 scientists in October 2022, revised and finalized.

The questionnaire will be used for all three online survey rounds of questioning and be only minimally adapted if the participants indicate further uncertainties or questions in the open fields that should still be integrated into the Delphi.

VII.   Delphi rounds

The Delphi consists of three online survey rounds and a final consensus conference. Figure 1 shows the timeline of the Delphi.

- - Literature review
- - Stakeholder mapping
- - Development of survey instrument
- - Pretesting survey instrument

1st Online-Survey

- Assessment of methods to capture HRQoL in people with cognitive impairment of all severities.
- Assessment of the importance of domains to capture HRQoL in people with cognitive impairment of all severities.

December 2022

- Data analysis I

2nd Online-Survey

- Feedback 1st online-survey
- Assessment of methods to capture HRQoL in people with cognitive impairment of all severities.
- Assessment of the importance of domains to capture HRQoL in people with cognitive impairment of all severities.

January 2023

- Data analysis II

3th Online-Survey

- Feedback 2nd online-survey
- Assessment of methods to capture HRQoL in people with cognitive impairment of all severities.
- Assessment of the importance of domains to capture HRQoL in people with cognitive impairment of all severities.

February 2023

- Data analysis III
- Planning consensus conference

Consensus Conference

- Presentation of results from the online surveys.
- Finding consensus on aspects on which there is no consensus as a result of the online surveys.

March 2023

- Preparation of final report

Fig. 1: Process of the Delphi

Four weeks are allocated to each survey round. The first survey round is scheduled for December 2022, the second survey round for January 2023 and the third survey round for February 2023. After each mailing of the questionnaire, a reminder will be sent by e-mail after two weeks.

Each survey round thematically includes the assessment of methods to capture HRQoL in people with cognitive impairments. In addition, each survey round includes the assessment of the importance of domains.

After each survey round, the results are evaluated. With each new round of questioning, the results are reported back to the participants and they are asked to reassess the items so that they can reconsider and revise their assessments if necessary. After the first Delphi round, participants only receive the results of their own group of participants (the experts receive the results of group 1, the affected persons and relatives the results of group 2); after the second and third round, the results of both groups are shown to all participants.

The consensus conference is planned as a hybrid one day event in Magdeburg on March 28, 2023. Experts as well as patients and relatives are invited to the conference. First, the results of the online surveys will be presented and then a consensus will be reached on aspects on which there is still no consensus as a result of the online surveys.

VIII.   Feedback and Evaluation

The results of the online survey will be processed in a final report and sent to the participants in preparation for the conference including further literature. The evaluation will be anonymous. The response rate is calculated for each online survey round. The quantitative surveys will be analyzed descriptively by SPSS statistical software.

Consensus is reached if at least 75% of the responses fall into response categories 6 (agree) and 7 (fully agree) (positive consensus) or 75% of the responses fall into categories 1 (do not agree at all) and 2 (do not agree) (negative consensus).

IX.   Discussion and limitations of the results

We anticipate the widest possible consensus on the topic of recording HRQoL in people with cognitive impairment. Difficulties may arise with:

a.   The number of participants to be reached in the three online survey rounds and the consensus conference.
b.   The dropout in subsequent survey rounds.
c.   The comprehensibility of the questionnaire or the items.
d.   Questionnaire fatigue.

We can counteract the above difficulties by:

a.   Selecting diverse recruitment methods; reimbursing the travel expenses of the experts for participation in the consensus conference from project funds; limiting the recruitment of patients and relatives to Saxony-Anhalt in order to avoid long journeys; and offering the patients and relatives an expense allowance of 10 € per online survey round and 15 € for the consensus conference,

b. Sending out reminders for participation in the online survey rounds,

c. Pretesting the developed questionnaire,

d. Keeping the questionnaire as short as possible and point out that the questionnaire is identical in all three survey rounds.

X. Dissemination

It is planned to both present the process of Delphi and the results of the Delphi survey at scientific congresses (Annual Conference of the German Society for Social Medicine and Prevention, German Congress for Health Services Research) and to prepare publications.

XI. Data protection and ethics

Ethical approval was obtained from the ethics committee of the Otto-von-Guericke-University Magdeburg (Register-No. 161/22). Participation in the Delphi is voluntary and requires the consent of both target groups, the experts and affected persons and relatives.

The voting of each participant in each survey round is anonymous; the information in the questionnaires cannot be linked to individual participants and the participants do not know who else is taking part in the survey. The evaluation of the first survey round is group-specific (group 1 and group 2), but independent of individuals. The evaluation of the other survey rounds and the consensus conference is completely anonymous and therefore cannot be traced back to individual persons. All data are subject to data protection in accordance with Saxony-Anhalt's state law and are used for scientific purposes only. For all precautions concerning data protection, we adhere to the data security and data protection concept of the Institute of Social Medicine and Health Systems Research (ISMG) version 3.04 of 03/31/2020 as well as to the data protection concept of UMMD.

Informed consent to the privacy policy is given in two ways: On the one hand, the experts are recruited by invitation to the Delphi via e-mail and agree to participation implicitly by responding to the invitation via e-mail. On the other hand, they are informed about the Delphi with a flyer and agree to participate by contacting the project staff member by implied action via e-mail. By doing so, they agree that their contact data may be stored and processed for the purpose of the survey. Consent to the collection, storage, processing and use of the survey data is given in advance of the online survey.

The audio recording of the consensus conference will be announced to the experts in advance of the conference with further conference documents by e-mail. Consent for audio recording will then be obtained at the beginning of the conference by stating that privacy will be protected and no person will be named in the context of the publication of the results. In addition, it is stated that the audio recording of project staff members will be put into written form and stored with special security precautions at the ISMG with a deletion deadline of 07/31/2033. Furthermore, it is pointed out that the written form of the audio recording will only be quoted in excerpts in publications in order to ensure vis-à-vis third parties that the overall context of events arising in the conference with the narratives does not make any person recognizable. A single objection in the run-up to or at the beginning of the conference will result in no audio recording being made. This does not result in any disadvantages for the objector.

Affected persons and relatives agree to participate in the Delphi by signing a data protection consent form for the processing and storage of contact data and for the collection, processing, storage and use of the anonymous data collected from the online surveys and the audio recording of the consensus conference. Participants provide their name and e-mail address on the informed consent form. The

name and e-mail address are needed to contact participants and send the invitation of the Delphi with the link to the online questionnaire. Informed consent forms will be emailed to individuals and family members in advance of the first survey after they have agreed to participate in the Delphi by emailing the project staff member. The consent forms will be stored with special security measures at the ISMG and kept for 10 years, deletion deadline is 07/31/2033. In the consent form for the consensus conference it is also noted that all information will be treated confidentially and will not allow any conclusions to be drawn about individuals.

After agreeing to participate, the experts, affected persons and relatives are administered in an Excel database. For the cover letter and the invitation with link to the online questionnaire, the name and e-mail address are documented. The database will be stored according to the data security and data protection concept of the Institute of Social Medicine and Health Systems Research (ISMG) in version 3.04 of 03/31/2020 (see Appendix 1) on a-drive with special security precautions, so that only the authorized project staff members have access to the data.

Participants have the option to discontinue participation at any time or to refuse to participate in further rounds of the survey or the consensus conference without incurring any disadvantages. In order not to be contacted again, the voluntarily provided data can be revoked at any time. To do so, participants may contact the project staff member and will subsequently be deleted from the contact database. Personal contact data will be deleted when the Gelang-BeLLa project ends on July 31, 2023. The anonymous survey data from the three online surveys as well as the audio recording of the consensus conference will be kept for ten years after the end of the project in accordance with the recommendations of the German Research Foundation (DFG) in a form that ensures reproducibility of the results, but does not allow any conclusions to be drawn about personal data. The deletion deadline is set at 07/31/2033.

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