

## Department of General Practice and Primary Care

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## Declaration of consent – copy for the study participant

I have been informed in detail by a study staff member about the nature and objectives of the study and agree with the procedure described in the patient information leaflet. My questions were answered satisfactorily. I have had sufficient time to decide whether to participate and I know that participation is voluntary and not associated with any immediate benefits or disadvantages for me. I know that I can withdraw this consent at any time without giving reasons and without any disadvantages for me.

## I was informed of the following details in particular:

- 1. A study staff member of General Practice and Primary Care of the University Medical Center Hamburg-Eppendorf (UKE) will contact me and interview me in person at the beginning of the study, as well as four further times in writing and by telephone (at the beginning of the study, after 6, 12, 24 and 48 weeks). For this purpose, I will provide my contact information (name, address, telephone number) on a separate data sheet. In the questionnaire and telephone surveys, information about my person, my life situation, my mood, my general state of health and chronic illnesses, as well as the use of the health care system (incl. prescription of drug or non-drug therapies) will be collected, documented and evaluated. All survey data will be pseudonymized, i.e., stored under a personal code.
- 2. I will receive an additional care offer and will be visited by an outpatient nurse specialized in the treatment of symptoms (SHPC nurse) for a 30-minute conversation about my health and psychosocial situation. For this purpose, I give permission for my data (surname, first name, full address, name of my family doctor, my current medication schedule, date of birth) to be sent via fax to the responsible SHPC team by an employee of the Center for Psychosocial Medicine and Institute of General Medicine.
- 3. The SHPC team will store my personal data (see 2) in accordance with the current data protection guidelines.
- 4. Within the framework of the additional care offer, my general practitioner, an SHPC doctor and the SHPC nurse will discuss my health and psychosocial situation as well as my care once by telephone. An employee of the Department of General Practice and Primary Care, UKE will listen in on the case conference and will record it in writing in pseudonymized form. After this telephone call, I will receive regular care.
- 5. All persons involved in the study are bound to confidentiality according to § 203 StGB.
- 6. My data from the written or telephone interviews, carried out by the study staff, will not be passed on to third parties not even to my general practitioner.
- 7. I have the right to be informed about my data. For this purpose, I contact the persons named as contact persons in the study information in the section on the General Data Protection Regulation (DSGVO).
- 8. If I terminate my participation in the study prematurely, the data collected from me up to this point may continue to be used in the study in anonymized form, i.e. without naming or the possibility of attribution to my name.
- 9. The pseudonymized data (using a personal code) collected in the course of the study will be stored electronically in the Department for biostatistics and data management of the University Medical Center Goettingen (UMG) and forwarded to the Department of General Practice and Primary Care (UKE) for data backup after completion of the surveys. In addition, the data from the personal initial survey will be archived in paper form at the Department of General Practice and Primary Care (UKE) in pseudonymized form for a period of 10 years.

- 10. The pseudonymized data (using a personal code) collected during the study will be evaluated by the Department of General Practice and Primary Care (UKE) and the following cooperation partners and used exclusively for research purposes: Institute for General Practice and Palliative Care, Hannover Medical School (MHH), Department of General Practice, University, UMG, Division of General Practice, Carl von Ossietzky University of Oldenburg, Department of Medical Statistics, UMG, and Department of Health Economics and Health Care Research, UKE. Scientific publications are made exclusively in anonymized form and do not allow any conclusions to be drawn about my person.
- 11. **Medical confidentiality**: My general practitioner will be asked about my current care situation as well as my health and psychosocial situation as part of the study. For the purposes of the study, I release my general practitioner from the duty of confidentiality towards the study staff of the Center for Psychosocial Medicine and Institute of General Medicine (UKE). In addition, I release my general practitioner from the obligation of confidentiality towards the SPHC team (SPHC physician and SPHC nurse), for the one-time telephone conference and for possible further contacts for study purposes.
- 12. **Professional confidentiality SPHC team:** The SPHC team will participate in a one-time telephone conference with my primary care physician about my current care situation and my health and psychosocial situation as part of the study. For the purposes of the study, I release the SPHC team from the duty of confidentiality towards my general practitioner and the study staff of the Department of General Practice and Primary Care, UKE.
- 13. **Legal data protection:** The study staff of the Department of General Practice and Primary Care will not pass on information from the surveys to my general practitioner.
- 14. As soon as the purpose of the study allows, my data will be completely anonymized, i.e. names, addresses and telephone numbers will be destroyed. After the retention period of 10 years has expired, all remaining data collected will be destroyed.
- 15. I understand and agree that I may be contacted again at the end of the study to be invited for a personal interview about my experiences during the study.
- 16. If necessary, I agree, that a relative named by me, may also be interviewed about his/her experiences in a group discussion.

I have read and understood the information on the legal basis and the data protection passage on pseudonymization (encryption) and agree to the procedure described. The information collected in the course of the study may be used in pseudonymized form for research purposes by all research centers participating in the study. I was able to clarify any open questions with the study staff.

I am aware that if I have any further questions, I can contact my general practitioner or a member of study staff at the Department of General Practice and Family Medicine directly at any time.

I have received the written information about the study and a copy of this consent.

By signing this form, I declare that I agree with the procedure described above.

My participation in the study is voluntary. I know that I can revoke this consent at any time and without giving reasons. This will not result in any disadvantage for my further medical treatment.

Place, Date	First and surname Participant	Signature participant	
Ort, Datum	First and surname study staff	Signature study staff	_