Patient declaration of consent for participation in the NEOCYST registry

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Patient declaration of consent for participation in the NEOCYST registry

I, _____, date of birth _____, give my consent to participate in the NEOCYST study, as long as is am agreeing to do so. I am aware that the participation is voluntary. I am aware that I am free to withdraw my data privacy laws consent at any point in time, without cause and without any consequences for my treatment by contacting the person in charge listed on the patient information. I have been made aware, and I agree that data and samples are being collected, saved and stored anonymized. My name will not be registered in the study or mentioned in any publications. I received a copy of the patient information and the patient declaration of consent. I had adequate time to think the participation in the study over. I was able to ask further questions and discuss concerns with the attending doctor. All questions have been answered in a detailed and understandable way.

Consent for data privacy protection:

1. I agree that the following information about me is being recorded for study purposes: health conditions, history of disease, gender, age, weight, height, ethnic background.
   The data will be anonymized and forwarded to the following authorities:
   a) The study initiator (for scientific analyses)
   b) The surveillance authority (to survey correct study execution).
2. I agree that the study initiators or the surveillance authority appoint a representative to access my personal data for surveillance purposes. The authorized representative is obliged to confidentiality.

I agree that anonymized data regarding me, collected within the context of the NEOCYST registry will be recorded, saved, analyzed and published.

□ Yes □ No

I agree to provide the following biological samples for study purposes within the context of the NEOCYST registry.

□ Urine □ Blood □ Nasal swabs

I agree that my anonymized biological samples are being stored in the Biobank. I agree that my anonymized biological samples are being used for future cystic kidney disease research.

□ Yes □ No

I restrict the use of my biological samples in the following way:

_____

I agree that my anonymized samples are being used to examine genetic changes relevant to cystic kidney diseases.

□ Yes □ No

I agree that retrieved samples from my kidney or any other biopsy are being sent to and stored at the biobank in Hannover. Any samples will strictly be retrieved if a biopsy or operation is being ordered for medical purposes. No interventions are being ordered for research purposes only:

□ Yes □ No

I agree that the attending doctor will be informed by the study coordinator in case any relevant medical findings will arise from analyzing my data and samples:

□ Yes □ No

In case of participation in any other nephrological study (please specify here :_____): I agree that already reported data from this study are being transferred to the NEOCYST study anonymized:

□ Yes □ No □ Not applicable

_____

Patient: Last name, first name (to be filled in by the patient / legal representative)

_____ _____

1. Attending physician: Last name, first name *Place, Date, Signature*