Information Letter

Project description and basis of consent

1. Research project: xxx

2. Project duration: xxx

3. Responsible institution and project management:

| University of Basel          | Name of researcher          |
| xxx                         | University of Basel         |
| xxx                         | Department xxx              |
| Switzerland                 | 40xx Basel                  |
| xxx                         | Switzerland                 |
| xxx.xxx@unibas.ch           | xxx.xxx@unibas.ch           |

4. Interviewer: ___________________________  Date of interview: __________________

5. Description of research project
This research project proposes that xxx serves as a telling example of how a disease came to be constructed as an 'neglected tropical disease' through (re)definition by various external actors xxx. For the purpose of this research, individual oral history interviews with former participants in xxx, xxx will be conducted. Through this research, the understanding and knowledge surrounding the notion of ‘neglected diseases’ is expected to deepen.

6. Voluntary nature of participation and impact on participants
Participation in the interviews is on a purely voluntary. Interviewees have the possibility to end the interview or not answer questions during the interview without having to fear negative consequences in any form. Interviewees do not receive any payment or other benefits for their participation.
The interview is designed in an open way so that interviewees can set their own priorities. In the course of the interview, negative experiences xxx may be discussed. This triggered reflection on one's own health may rise
negative feelings in individual cases. The interviewees have the right at any time not to answer questions that make them uncomfortable if they find them too personal or if they trigger insecurity, discomfort or other negative feelings. The researchers will protect the anonymity of the interviewees and their statements during the interview, throughout the evaluation process and in possible publications and will pseudonymise the interviews and securely store the data obtained. All in all, it is not to be assumed that the interview participants will be endangered or impaired as a result of this study. Even after consent has been given and the interview has been conducted, participants have the right to have individual passages removed from the transcript if they fear any kind of disadvantage from them. These parts can then no longer be used for analysis and publications in the future. They must contact the researchers for this and may receive a transcript of their interview if necessary.

7. **Type of personal data collected and pseudonymisation procedure**

The personal data collected is data that is necessary for the organisation of the research and is recorded in the interview. The personal data collected for the research organisation includes the surname and first name of the interviewees, as well as their contact details (e-mail and/or mobile number). The interview includes questions about the biography of the interviewees, especially their experiences with xxx. The data collection thus also includes special categories of personal data (IDG BS §3 and xxx). The interview as well as parts of the pre- and post-discussion are recorded with a digital audio recorder. The audio recordings are first transcribed and then pseudonymised. This means that names, exact age, exact biographical data and other data that allow conclusions to be drawn about the person are deleted from the transcript or replaced by a pseudonym. Information about xxx are important for the research interest, these are therefore retained or paraphrased (e.g. [Pseudonym] contracted xxx). In the transcription process, the pseudonyms are documented to facilitate the process. Digital photographs or video recordings may be taken with express permission. If pictures or videos are taken, care is taken to ensure that the people on them are not recognisable (e.g. by photographing them from behind and not showing their faces). If faces are recognisable and the people pictured prefer to remain anonymous, the faces will be digitally blurred.

8. **Use of interview data for research and publications**

The transcript will be used in small excerpts in project-related publications, such as the project report. It is also used for further publications, lectures for the presentation of the project or for qualification work (e.g. the dissertation of the principal investigator). The transcript may also be used in small excerpts for teaching, training and research purposes (e.g. methodological research). In each case, all personal data that allows conclusions to be drawn about the person will be deleted or pseudonymised.
9. **Data handling**

The audio recordings of interviews are not transferred automatically to a cloud service and are initially only saved on the recording device. The same applies to photo or video recordings. After each interview, the corresponding audio file is reviewed for quality and completeness (using the open-source software *Audacity*) and then saved in an encrypted form in the project manager's institutional SWITCHdrive cloud account, provided by the University of Basel. The interview recordings are transcribed and pseudonymised after the data collection is completed. Pseudonymisation is carried out by creating an electronically stored pseudonymisation table. The data contained in this table is stored in encrypted form on the server, separate from the raw data and the transcriptions. Access to the data is limited to the project manager (see point 3). Photographs and video recordings are also stored in the encrypted SWITCHdrive account. Where applicable, recognisable faces are anonymised (blurred) using the open-source software *GIMP* or the open-source software *OpenShot*. Handwritten notes by the project manager before, during or after the interviews are typed up and also stored on the SWITCHdrive cloud account.

10. **Storage of data and duration of storage**

For the storage of audio and video recordings, pictures, interview transcripts as well as analysed data of the interviews and the pseudonymisation table, the secure cloud service SWITCHdrive of the University of Basel is used, which is operated by the university's own IT services (for contact details see "Your rights", point 13). The deletion of the audio recordings and pseudonymisation table will take place after completion of the project or completion of the dissertation produced as part of the project. The pseudonymised transcripts are stored electronically for the duration of the project and the associated research work (such as the dissertation). Secure deletion procedures are used to delete electronically stored data; analogue stored data is destroyed properly and securely.

The transfer of data between the end devices used and the central storage system is encrypted. Only the pseudonymised transcripts and analysis data are transmitted between the locations.

The consent forms for the collection and processing of personal data are securely stored separately from the interview transcripts.

11. **Transnational data transfer**

As a transnational research project, the data collected is transferred from xxx to Switzerland. The data are processed on the same basis (IDG BS §10, xxx). Only the pseudonymised transcripts and analyses of the same are affected by the data exchange. Data protection is also guaranteed, as the handling of data is regulated by the Swiss Federal Act on Data Protection (FADP).

12. **Legal basis**

Data processing is carried out on the basis of the Information and Data Protection Act
13. Your rights
You are entitled to the rights set out in IDG BS §25-§28 and xxx. This includes:

- Right to be informed about the nature of the data and its processing (IDG BS §25, xxx)
- Right of access to your own personal data (IDG BS §26, xxx)
- Right to rectification of personal data and, if not possible, its deletion (IDG BS §27, xxx)
- Right to object to your data being processed (IDG BS §28, xxx)

If you wish to exercise any of these rights, please contact the responsible project leader (see point 3). Furthermore, you have the right to file a complaint with the supervisory authority of xxx:

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Furthermore, you also have the option of filing a complaint with the supervisory authorities of the University of Basel:

<table>
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<th>University of Basel Data Protection Officer</th>
<th>Data Protection Officer of the canton of Basel-Stadt:</th>
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<tr>
<td>Danielle Kaufmann, lic. iur. University of Basel General Secretariat Petersgraben 35, Postfach 4001 Basel Phone: +41 61 207 31 22 E-mail: <a href="mailto:danielle.kaufmann@unibas.ch">danielle.kaufmann@unibas.ch</a> Homepage: <a href="https://www.unibas.ch/en/University/Administration-Services/General-Secretariat/Data-Protection.html">https://www.unibas.ch/en/University/Administration-Services/General-Secretariat/Data-Protection.html</a></td>
<td>Henric Petri-Strasse 15 Postfach 205 4010 Basel Phone: +41 61 201 16 40 E-Mail: <a href="mailto:datenschutz@dsb.bs.ch">datenschutz@dsb.bs.ch</a> Homepage: <a href="https://www.dsb.bs.ch/">https://www.dsb.bs.ch/</a></td>
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14. Revocation on the part of the participants
You can revoke your consent at any time. The revocation of consent does not affect the
lawfulness of the data processing from the time of consent until the revocation (revocation with effect for the future). You will not suffer any disadvantages as a result of the revocation. Furthermore, you are entitled to the specified rights according to IDG BS §25-28 and xxx.

I have taken note of this information and have been given a copy of this information letter.

Place, Date                     Signature interview partner
Declaration of consent to participate in the study "xxx"

Consent to the collection & processing of personal data

I hereby give my voluntary consent to participate in the study and to the collection and processing of my personal data within the framework of the research project “Oxxx”. If I specify or have specified special categories of personal data, these are covered by the declaration of consent. I have read the information letter on the study and the consent to the collection and processing of personal data, have been adequately informed and have had the opportunity to ask questions. I have been informed about the consequences of revoking my consent under data protection law.

I have received the written information and consent form.

I agree that the interview conducted with me by ________________________ (name of interviewer) on ________________ (date) may be recorded and transcribed using a digital recording device. The transcribed version may be used for the evaluation within the framework of the research project “xxx”. I have been informed verbally about the contents of the research project before the beginning of the discussion. I also agree that the transcribed interview may be used within the framework of the project, but only in small excerpts. I have been assured that all personal data that could be used to draw conclusions about me will be deleted or completely pseudonymised.

I was informed about the possibility of having passages from the interview subsequently deleted if I expected disadvantages from their analysis and processing. I was given contact details of the researchers for this purpose.

In this context, I also agree that the transcribed interview may be used for further publication purposes (e.g. for dissertations, in lectures for the presentation of the research project) or for the preparation and publication of research work following the project, but only in small excerpts. Here, too, I am assured that all personal data that could be traced back to me will be deleted or pseudonymised.

I also agree that the transcribed interview may be used for training, teaching and research purposes at the University of Basel, but only in small excerpts. Here, too, I am assured that all personal data that could be used to draw conclusions about me will be deleted or pseudonymised.

I agree that my name and telephone number/email address will be kept confidential and secure for the period of the evaluation of the study according to the rules of data protection (in case of clarification of queries during the project period) and will only be deleted after completion of the project.

(Please cross out where not applicable.)

Place, Date        Signature interview partner