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su···re
from data to action

Using data from SURE

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Background

The following data analysis framework defines the rules and processes for handling SURE-data – from formulating the research question to utilising the results.

About the tool
SURE (Surveillance Response) is a **digital counselling and data management tool** developed by the Swiss AIDS Federation (AHS) to support HIV and STI testing services. It enables testing centres, community organisations, clinics and private practices to simplify and standardise counselling processes and to systematically record voluntary counselling and testing (VCT).
The tool structures counselling processes and helps ensure that relevant and important questions are consistently addressed. By organising workflows, SURE can reduce administrative burden and supports standardised service delivery. SURE also serves as a national platform for test surveillance, collecting anonymised data across multiple sites. SURE thus contributes to better health outcomes and greater health equity through data. Overall, **SURE combines operational support with public health surveillance in one integrated system**.

About the data
The available data is covering three areas: **metadata on the consultation** such as date, location or version of questionnaire; **client-related information** through client and consultant questionnaires, including sociodemographic and sexual health-related items, as well as standardised questionnaires such as PHQ-4; and **testing data** on performed tests and recorded results.
This data must be analysed to generate insights on HIV and STI testing patterns, in particular, health equity for key populations. The **evidence informs decisions** on services, particularly in the areas of prevention and care for affected populations in Switzerland.

About the stakeholders
The **Swiss AIDS Federation** acts as the system owner and provider, operating SURE as a digital infrastructure, maintaining and further developing the platform, and defining its scope of services.
Tenants (testing centres, community organisations, clinics and private practices) are key user stakeholders. They use SURE to document VCT. From a contractual perspective, these service providers enter into a usage agreement with the Swiss AIDS Federation, which grants them a non-exclusive, non-transferable right to use SURE during the contract period while committing them to the agreed conditions of use, which, in particular, grants the right to analyse data.
Indirect stakeholders include **clients as group(s) under study**, whose data is recorded. Their interests must be considered in all analyses, so as not to reinforce stigmas or assumptions through the negligent presentation or interpretation of data. Their interests must be adequately represented in the process and publications. As studies may produce controversial or sensitive results, it is necessary to clarify to what extent publications are reviewed prior to publication.

Process

There is a defined process for every analysis of the data, from which one should not deviate except in justified exceptional cases (e.g. an outbreak of disease). The process applies to external partners just as much as it does to AHS itself. **Tenants are advised to follow this process as well when dealing with own data.**

Step		Stakeholders	Key Tasks
1	**Define interest**	**Researchers** in dialogue with AHS	– Formulate research interest based on observations, scientific or practical questions, or emerging subjects. – Figure out whether SURE data is suitable for contributing to interest. – Check whether the necessary resources are available for a project. – Assess the risks associated with the impact of any findings on the populations under study or the tenants.
2	**Present interest**	**Researchers** consult Advisory Boards	– Present the research interest to all applicable Advisory Boards as defined below. The final decision as to who is to be consulted is taken by AHS. – Gather insights, feedback and ideas to adjust the research design.
3	**Design the research**	**Researchers** develop and propose to AHS	– Develop a research design in accordance with the criteria set out below. – Submit the final version to AHS.
4	**Get approval**	**AHS** requests tenants' agreement and provides data to researchers	– If AHS considers the research project suitable of support, AHS will request permission to use anonymized data from all tenants (in accordance with the contractual agreements). The tenants' consent is mandatory in order to be able to use the data. – Data from all tenants who give their consent will be made available by AHS to researchers in form of a CSV file. A data use agreement will be signed for this purpose.
5	**Conduct research**	**Researchers**	– Stick to your study design – good luck! – Delete data permanently upon completion (no later than 12 months after publication of the results)

Advisory Boards

Advisory Boards are defined as existing bodies within AHS, as well as relevant partners who represent the interests of a group under study. **AHS may define further consultative bodies or point persons based on the research interest.**

When planning research on →, it is necessary to consult ↓	anything	a key population	surveillance, services, etc.
Roundtable SURE	X		
Scientific Advisory Board	X		
Strategy Commission			X
Expert Commission on MSM		if under study	
Expert Commission on FSW		if under study	
Expert Commission on TM		if under study	
Expert Commission on MHIV		if under study	
Positive Life Advisory Board		if under study	
ProCoRe Switzerland		if under study	

Design

The anonymised data from SURE can, in principle, be analysed by all stakeholders. Community-based, action-oriented research is particularly encouraged. For this reason, research designs do not need to meet a long list of formal requirements. Instead, the focus is on answering the following questions: Why is it worth carrying out a study, what insights can be gained from it, and how will these impact the work for public health? Why is the SURE data suitable for this and which data do we want to analyse, and using which epidemiological or other methods?

The study should **identify the extent of a public health issue, affected groups, their use of services, and inform about setting priorities**. It is recommended to choose simple, clear research hypotheses and questions, to carry out a goal-oriented study.

The data in SURE enables both cohort (based on returning clients) and cross-sectional studies (based on consultations). It is necessary to describe which groups are being compared, which items are being analysed, which stratifications are being carried out, and so on. The key principles of any study are **relevance, consistency, validity and traceability**. Scientific publications should be methodologically rigorous, reproducible, and ethically sound. Researchers should openly discuss limitations, uncertainties, potential biases, and alternative interpretations while ensuring that conclusions remain proportional to the data and evidence presented.

The quality of the individual data records varies considerably, but there is a large volume of consultations all over Switzerland. SURE is a civil society initiative that does not have the same resources as, for example, university cohort studies. Data cleaning, for example, is therefore the responsibility of researchers.

As studies might also produce controversial or sensitive results, particularly on an issue that is often exploited for political ends, it is necessary to clarify to what extent publications can be reviewed by AHS before they are published. The SURE consortium is usually represented through appropriate co-authorship.

As the data is only available thanks to the commitment of the groups under study and the tenants, it is essential that every research design specifies how the research findings will be made available to these two stakeholder groups in an appropriate form. AHS provides support in this regard. The aspect of **science communication** is particularly indispensable when drawing up a budget for a study. Results can be presented in all sorts of ways: as a report, a presentation, a visual representation or a scientific journal article.

It is important to be able to demonstrate how the data is stored securely, how access is regulated and how it is irrevocably destroyed once the research is complete. A contract must be signed with AHS setting out the **compliant use and storing of the data**.