## Contribution on data collection and management to the UN Independent Expert on SOGI

The answers to these questions are based on the situation in Sweden, and cannot be generalized to other countries, where the situation is different.

* What are the current efforts by States to increase their knowledge of the LGBTQ population?  Specifically, are questions about sexual orientation and gender identity included in government surveys (e.g. the census, national health surveys, income and living condition surveys, or other surveys funded or mandated by the State), administrative records (e.g. birth certificates/birth registries, identity Cards, school records, professional licenses, social security and public benefit records, and other government documents)?

The Swedish state tries in different ways to follow health and other aspects of LGBTQ-people’s lives. A few examples are listed below.

**Public health survey**

The Swedish public health survey by the Public Health Agency (PHA) done every second year with about 10 000 respondents, giving a statistically representative selection of the Swedish population.

From 2005 a question on sexual identity has been included and specific reports and research about the health of homosexual and bisexual men and women have been published.

The question is:

How do you define your sexual identity?

- Heterosexual

- Bisexual

- Homosexual

- Other (open answer)

- I don’t know

For the first time 2018 two questions on gender identity and trans experience have also been included, the data is not yet published.

The questions are:

How do you define your gender identity?  
- Woman

- Man

- Other

- I don’t know

Are you, or have you been, a trans person? (Trans people is an umbrella term that usually describe individuals whose gender identity and/or gender expression always or sometimes break the norm for the gender assigned to them at birth)

- Yes

- No

- I don’t know

The Public Health Agency also get legal gender from registry data.

RFSL embraces the development to include gender identity and sexual orientation in the survey.

**Data on trans health**

In 2014 the Public Health Agency made a large survey about health among trans people in Sweden, with a very close co-operation with RFSL and RFSL Youth throughout the whole process. It was a success. 800 trans people answered the survey and a report from the PHA and several research articles using the data. This led to an increased knowledge on trans people’s health and living conditions in Sweden.

**Administrative records**

In administrative records there is data about who has changed their legal gender and who is in a same-sex-marriage, but not about who identifies as LGBTQ. The records can be used (anonymously) to compare with data about different health concerns and diagnoses etc. There is a very useful report by the Swedish Social board for health and welfare about the health of people in same-sex marriages compared with people in different sex marriages, for example.

Information on identity is not gathered in administrative data. In some ways this leads to a lack of data, but in other ways it protects the integrity of people.

**Lack of data about medical interventions on intersex kids**

There are no administrative or medical records where it is possible to gather data about how many kids are subjected to early surgery and other medical interventions on the account of intersex variation. Therefore, it is impossible to know, even for the state itself, how often this human rights violation occurs in Sweden, which is a big problem. There is a need for a database where data about all care for people with all different intersex variations is gathered. Such a database exists both within gender affirming health care and HIV care, making it possible to follow the quality of the care and get statistics.

* What kinds of data can be collected by government to understand the nature and extent of violence (e.g. through statistics on LGBTQ-phobic hate crimes and hate speech), discrimination, and disparities in health, education, labour, civic participation, and other important areas?

Sweden has a register of LGBTQ phobic attacks and violence. However, it’s up to the policeperson who meets a victim to tick a specific box in the data system to high-light that the act might be LGBTQ phobic, resulting in that not all hate crimes are registered. The trust in the police among LGBTQ people in Sweden, and trans people specifically, is low, also resulting in people not reporting crime they are subjected to to the police, leading to a probably significant gap in the data. There is a government body collecting data about crimes, including hate crimes, in Sweden.

There is a great need for self-reported data, surveying the LGBTQ population specifically. Self-reporting is to date the only way to get data based on identity in Sweden. The best way to do this is to co-operate with LGBTQ-organizations to reach targets groups and to make surveys relevant to the target group.

There are still surveys made by the state, or financed by the state, that do not ask about LGBTQ-identity, and that is a big problem. For example, a large survey targeting school children about alcohol and drug use, where we miss important data due to the lack of two or three important questions on gender identity and sexual orientation. Also, the public health survey for school kids lack these questions. Even though the Public Health Agency make other, inclusive, questionnaires, they do not included questions on gender identity and sexual orientation in this study.

* When States engage in data gathering activity, to what extent is civil society able to meaningfully participate in the design and implementation of these programs?  This question includes the following:

a. Do states have policies that guide the process of civil society participation national statistical programs and other State efforts to increase knowledge about LGBT populations?

b.     Does civil society have the capacity, in terms of expertise and technical knowledge, to meaningfully participate in State efforts to gather data?

c.     What constitutes meaningful participation in this area?

There is no policy in Sweden (to RFSL’s knowledge) saying that civil society should be a part of data collection and reporting. The different government bodies handle this differently. Some are very good at including RFSL, for example, in their surveys and questionnaires, while others do not invite us to the table.

Meaningful participation means being involved in the process from the beginning to the end. Influencing every step of the way. Being financially compensated for our time and effort. RFSL and RFSL Youth certainly have enough skills and expertise to participate, but of course it is hard to generalize to all civil society organizations.