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**Supplementary response from Denmark concerning data collection in the health care sector to OHCHR questionnaire: Independent expert on protection against violence and discrimination based on sexual orientation and gender identity**

*Question 1: What are the current efforts by States to increase their knowledge of the LGBT population?*

Answer:

The National Health Profile (Sundhedsprofilen) does not include questions on sexual orientation or gender identity, nor at national or regional level. The National Health and Morbidity Survey (SUSY) in 2013 and 2017 included questions on sexual orientation, allowing for investigation into the correlation between health, health behavior, risk factors and sexual orientation.

A number of scientific studies has included questions on sexuality and gender identity since 2009, which is the primary knowledge base regarding the life and health of LGBT persons in Denmark.

The most recent is the SEXUS study. Project SEXUS constitutes a research collaboration between Statens Serum Institut (Department of Epidemiological Research) and Aalborg University (Center for Sexology Research). Project SEXUS aims to shed light on the sexual attitudes, preferences, experiences, and behaviours of the Danish population and to provide novel knowledge about the interplay between sexuality, lifestyle, and health. Project SEXUS invites approximately 200,000 Danes aged 15-89 years to participate. Respondents were randomly selected from the Danish population. The study collects data using a digital questionnaire with a broad range of items on health, lifestyle, and sexuality. It is a prospective cohort study where participants will be re-invited regularly. The researchers behind Project SEXUS expect that approximately 75.000 respondents will answer the questionnaire and take part in the study. Results from Project SEXUS will be published in a main report and in international scientific journals. In addition, results will be discussed on the project's website (www.pro-jektsexus.dk) and/or in independent press releases. No results have yet been published.

After initial data validation and reporting, pseudonymized raw data will be made available to other institution-related researchers with an interest in sexological health research after specific application and permission from The Danish Data Protection Agency and the Project SEXUS 'steering group.

In the Danish Governments Action plan to promote the rights and well-being of LGBT people, two initiatives in particular, include the gathering of knowledge on disparities in health and health conditions of LGBT people. Discrimination is mostly covered in one of the projects and primarily in the sense of differences in access to health care services.

As part of the initiative ‘Strengthened health efforts in general practice targeted at LGBTI people’ (initiative 11) The Danish Health Authority has undertaken a literature review investigating the current knowledge of the health inequalities between LGBTI persons and the background population. The review includes both Danish and international literature as well as interviews with LGBT persons and health care professionals highlighting experiences with barriers towards accessing health care services including experiences with discrimination.

Furthermore, the action plan contains an initiative to support research and the dissemination of knowledge in the field of healthcare for transgender people: ‘Establishment of a centre of knowledge concerning gender identity’ (initiative 7). In addition to support research the centre of knowledge can arrange courses for healthcare professionals and conferences, etc. In connection with the initiative it is also considered to establish a national clinical quality database. It should be noted however, that no decision has yet been made on which research areas and information activities should be allocated funds as part of the overall initiative.

*Question 2: What kinds of data can be collected by government to understand the nature and extent of violence (e.g. through statistics on LGBT-phobic hate crimes and hate speech), discrimination, and disparities in health, education, labour, civic participation, and other important areas?*

Answer:

As mentioned above the primary source of knowledge on life and health of LGBT persons is scientific studies of varying size and strength and the National Health and Morbidity Surveys from 2013 and 2017. The literature review commissioned by National Health Authority in 2019 gathers the newest information from across Denmark and Western Europe.

With the newly establish SEXUS cohort there will be better possibilities for monitoring LGBT health in the future.

Some NGO’s monitors experiences with discrimination and violence based on sexual orientation and gender identity. Some of these receive public funding.

*Question 6: 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?*

Answer:

The Danish Health Authority has a strong tradition in terms of inviting civil society (patient and user organizations) and professional experts to participate in relevant forums, networks and working groups as well as in the development of our projects and products. The collaboration and participation of civil society is not limited to only data gathering activities. Also almost all new legislation, national clinical guidelines and similar products are subjects to public hearings where civil society actors, health care professionals and local governments can comment on the specific products and thereby make their voices heard.

In 2013, the Danish Health Authority published ‘Policy on user involvement’. The publication aims to make sure that:

* Users are directly involved as active parties in the activities of the National Health Authority and thus have influence on the development of health activities
* Knowledge about user preferences and other relationships of importance for the users is illuminated through other forms of representation and research-based knowledge than by directly involving the users

The policy distinguishes between participation on three levels: the systemic/administrative level, the health care activity level and the individual level.

All though the Danish Health Authority has a broad selection of users other than patients and citizens (authorities, companies, employees and administrators in the health service), the term ‘user’ in this publication specifically is used only as a term for the perspective of citizens, patients and relatives.

Even though the 2013 publication was our first formal policy on the involvement of users, it should be noted that the invitation of civil society to participate in our work has taken place for much longer than the last 6 years. At the time of writing this, we are in the process of pre-paring a new policy for user involvement that will replace the policy from 2013. The new policy is expected to be released later this year.

In addition to our overarching policy, the involvement of users is guided by the demand to make sure that especially health care professionals are impartial, legally competent and without personal and/or financial interests in the project at hand. Also, we do our best to ensure equal geographical and organizational representation.

In general, the Danish civil society organizations have the capacity, in terms of expertise and technical knowledge, to meaningfully participate in State efforts to gather data and knowledge and to participate in relevant forums, networks and working groups and so forth. However, the capacity to participate of the civil society organizations may vary due to size, economic capacity and degree of professionalism of the specific organization.

The Danish Health Authority does not have a definition as to what constitutes meaningful participation. However as mentioned above we try to make sure that users are directly involved and that their knowledge and preferences are taken into consideration in both the development of our specific products and in our strategic work with healthcare planning.

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