

# “positive stimmen” - the PLHIV Stigma Index in Germany

## Highlighted results of the community initiative on HIV-related stigmatization and discrimination

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### Background

Stigmatization and discrimination are two of the main barriers for a successful HIV-Prevention. In 2009 UNAIDS stated: “Stigmatization and Discrimination act as impediments to uptake of HIV testing, treatment and care and to adherence to treatment<sup>4</sup>.” A step of an updated and systematic debate on this is the international PLHIV Stigma Index, initiated by GNP+, ICW, IPPF and UNAIDS. The aim of the project is to display the current stigmatization-related situation and to empower PLHIV communities during that process.

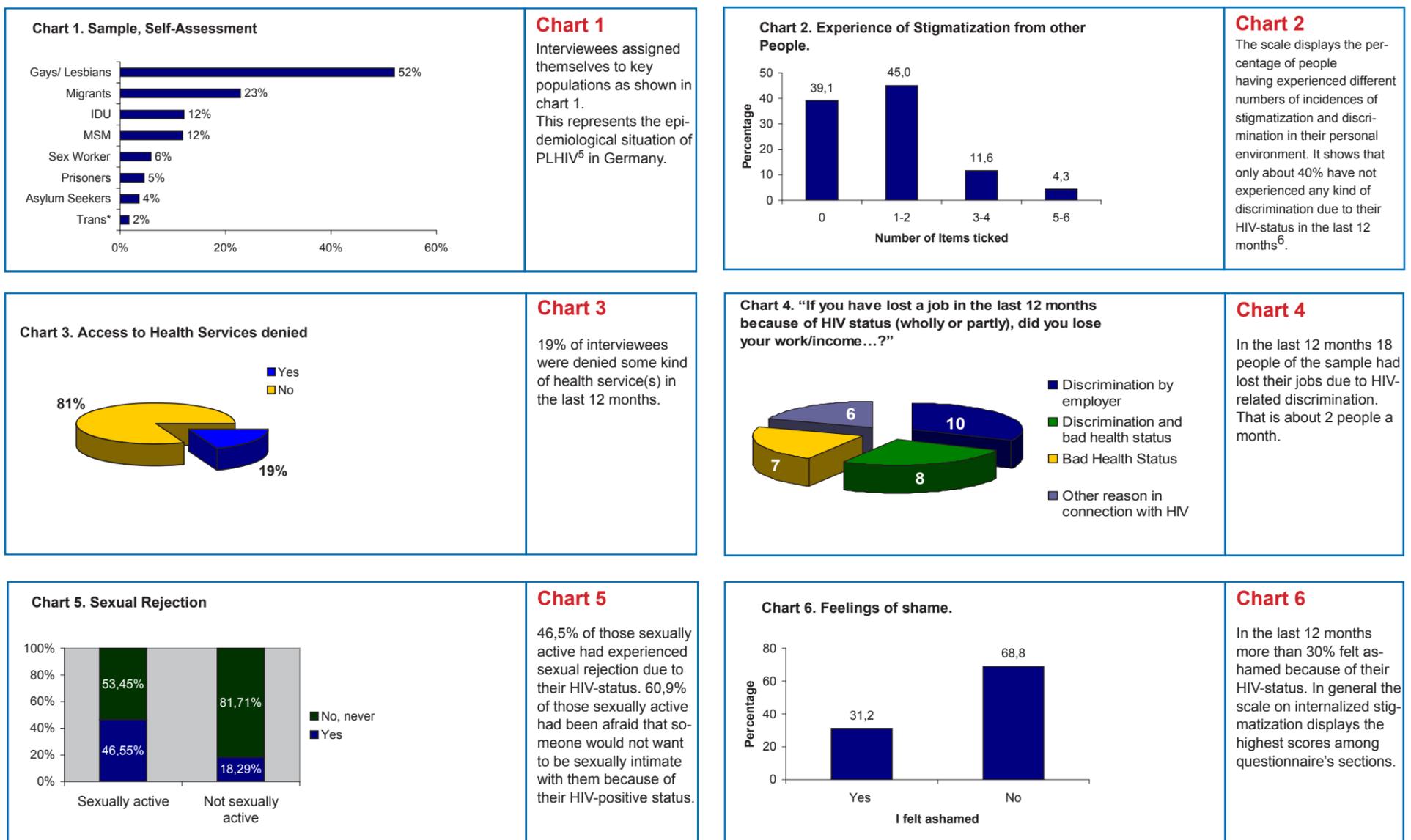


### Approach

The innovation of the approach lies in its combination of HIV-stigmatization-related research with the ownership and empowerment of PLHIV communities. 40 PLHIV were trained as peer researcher. In side-by-side interviews with other PLHIV they documented experienced stigmatization and discrimination. The interviews were conducted via an internationally standardized questionnaire that captures the areas: personal relations, workplace/ educational and health sector, disclosure/ confidentiality and internalized stigmatization. Furthermore information on resources, counselling and self-organisation initiatives were provided during the interviews. Quantitative Data was analyzed by statistical software SPSS.

### Results

Within six months 1148 interviews were conducted. This represents 1,6% of all people living with HIV in Germany. One third of the interviews took longer than two hours – indicating a big interest in exchange on the topic. 96,4% of all interviewers described their average interview experiences as “positive” or “very positive”.



### Conclusion:

The project succeeded in initiating an updated discussion and reflection on HIV-related stigmatization and discrimination in many parts of PLHIV communities. A permanent working group of PLHIV will team up to support an ongoing debate in the communities. The study supports existing research saying that discrimination in the health sector and in personal surrounding is still prevalent – more education among medical staff and support for PLHIV in dealing with negative experiences in private settings is required. With (at least) two people a month losing their job due to HIV-related discrimination the topic of HIV at workplace remains an area where cooperation with e.g. employers, companies and trade unions is necessary to improve working opportunities and conditions for PLHIV. Many cases of experienced sexual rejection in times of non-infectiousness under effective ART underline the necessity to enforce communication efforts towards the general public and sub-communities. Analyzed data indicates the necessity to further pay attention to the consequences of internalized stigmatization, e.g. by providing time and place for reflection.

*At the heart of the roll-out in Germany stood 40 overwhelmingly motivated interviewers who have accomplished to spread the word of the project in PLHIV communities and who succeeded in conducting more than 1100 interviews. A big thank you also to all 1148 people who took the time for the interviews and decided to be part of this fantastic worldwide initiative!*

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4 UNAIDS (2009). HIV-related stigmatization and discrimination: A summary of recent literature.  
5 Robert Koch Institut, HIV/AIDS in Deutschland – Eckdaten der Schätzung; Epidemiologische Kurzinformation des Robert Koch-Instituts Stand: Ende 2011  
6 Six questions are captured by the scale: Exclusion from social gatherings and family activities, awareness of being gossiped about, verbal and physical harassment, physical assault.

