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Supporting disclosure to support empowerment -- Poland

What was the problem?

One of the biggest challenges uncovered in the Stigma Index report on Poland was people's fear of disclosing their HIV positive status. Only 8% of the respondents were unafraid to tell anyone about their status. Many people had not even informed their close family or medical staff.

Why was change needed?

This lack of disclosure is likely to lead to less effective health seeking behaviours and reduces people's ability to live well with HIV. It has also been shown to be psychologically damaging and socially isolating to completely hide a diagnosis.

How could matters be improved?

This demonstration project took a group of people with HIV currently afraid of disclosing their status. It offered workshops and interventions to inform them about their rights, help to build confidence and evaluate attitudinal change. PLHIV in key populations were prioritised.

What were the barriers to change?

In Poland HIV-infected persons rarely talk about their serological status, even to their closest friends or immediate family. At the same time infected individuals have great reservations about sharing this information with healthcare professionals. HIV status concealment stems from the fear of discrimination and stigma.

How long did change take and who was involved?

The workshop was held in summer 2016 and work resulting from it is ongoing.

How was change made?

A three day residential workshop was held for 20 key PLHIV from across Poland with five trainers on "Barriers to Disclosure". The form and content of the workshop were developed in conjunction with GNP+ and focussed on the benefits to be gained from sharing information about a diagnosis appropriately. The sessions covered medical, sexual and psychological aspects of disclosure. The workshop identified and quantified challenges to people accessing testing and treatment services and explored possible strategies (personal, changes to policy and practice, regulations and legislation etc.) that would help to overcome or mitigate these barriers. This formed the basis for an ongoing work programme in which examples of good practice were identified and documented. This includes dissemination workshops which increase the number of PLHIV able to learn from

the initial findings and further explore the stigma barriers they face in seeking healthcare. One of them, at the national PLHIV conference, attracted around 100 people. Many of the initial group of 20 have become leaders in exploring the issues and forming strategies to fight stigma.

During the workshop key aspects of patient and doctor relationship were drawn up:

1. The patient decides whether to share their information and in what form
2. The patient knows his or her rights
3. The patient knows the possibilities of intervention
4. The patient has the right to use support (NGO presence)
5. The patient has a right to expect reliable knowledge of HIV therapies or adequate consultation with an infectious diseases specialist
6. The patient has a right to receive a list of reliable health care units applying proper standards (lawyer, medical procedures)
7. The patient has a right to privacy and information provided with respect to human dignity

Are there any ongoing issues?

All of the participants agreed that in recent years and with good treatment, disclosing infection holds a different importance than previously. The greatly decreased risk of infection in sexual contacts should also help disclosure, but is not widely understood as yet. While HIV should not be perceived as a problem for a society, the Polish community needs more time to stop applying stereotypes and cliches in the perception of HIV as a fatal disease.

What lessons have been learnt?

The decision to disclose HIV status must be an individual, personal decision. All patients have a right to privacy and information must be provided to them with respect for their human dignity. But also, PLHIV need greater support from NGOs in order to understand their rights and be empowered to defend themselves and others if anybody should attempt to discriminate against them because of their HIV status. It is a new challenge to find a solution which communicates the importance of human rights for this group. We need more workshops with PLHIV and their friends and relatives to stop people from being afraid to stand up for their human rights.