

BORDERS TO CROSS

Title:	<i>What is necessary for structural change?</i>
Name workshop:	Interaction and Responsiveness
Projects presented:	1. Democratic Community of Practice DemCom 2. Patient involvement in federal joint committee
Workshop director(s):	Maurice Galla
Name rapporteur(s):	Gergana Yovova
Date and time of workshop:	30 Oct. 2013, 2:30 – 4:00

Heading:

Both projects involve different groups representing different issues to work towards achieving their joint interests together; problems stem from the possibility for incomplete representation and limited interaction between the groups.

What triggered me:

The peculiar way in which health-care regulations are introduced in Germany without the involvement of the state, and the ultimate problem with actively involving certain groups of patients.

Description and elaboration of observations and reflections of projects and/or things that happened and/or were discussed during the workshop:

The lack of voting power of the patients' committees seemed hard to grasp at first, as well as their ability to influence health-care decisions. It was explained, however, that health-care discussions are open and deliberative, and whenever the patients' views were ignored, the organization makes the issues public through the media, thus exerting additional influence on the decision making. However, as it is up to the patients to get involved, it is usually the well-educated ones that pursue their specific interests. They might, however, have divergent interests – such as the pro-and-cons dispute on breast cancer screening and its hazards. In addition, immigrant minorities might be involved or ignored. Involving the elderly can also be problematic as the interaction with them is limited and their response is different from the other patient groups'. Another issue is the accurate representation of chronically-ill and disabled patients, as well as the lack of desire of patients who have successfully recovered from mental illnesses to address the institutionalization of patients (they would rather forget about the experience as a whole). In this sense, alternative tools for engagements need to be tailored for the specific groups of patients.

DemCom aims at uniting similar projects which, on their own, may not be successful, but because of their shared goals would be stronger together. Capacity building and sharing experience across borders, however, again attracts mainly young people. Two main problems are the difficulty to secure funds, and the inability to secure the mobility of the participants. Still, many of those projects might have been already dropped without the sense of support DemCom provides, and thus the initiative seems to enable innovations on a European level.

Reflection, possibly linking up to the leading questions and threads:

One main issue lies in how formal organizations will influence the system. While the government

might find it easier and be encouraged to deal with such a structure, the organization may also become more rigid and less representative. From the government's perspective, it is also unwise to delegate all decisions to the public. The main question in the end of the workshop, therefore, was how to unify patients in a constructive and representative way, making sure that all health-care problems are accounted for.

In this sense, before policymaking becomes truly inclusive, organizations of patients have to become fully-inclusive, too.