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Notes from the working group for patient and user involvement in supervision
Stockholm 28 September 2016

Participants:

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Tove Gemzell, Sweden
Bente Smebråten, Norway
Diana Dumina, Latvia
Birgir Jacobsen, Iceland
Sorien Kleefstra, Netherlands
Sipko Mulder, Netherlands
Paul Robben, Netherlands
Renée Bouwman Netherlands
Hanna Ahonen, Finland
Riitta Aejmelaeus, Finland
Anne Lund Frydensberg Denmark
Henrik Frostholm, Denmark
Hanne Sognstrup Denmark
Charlotte Hjort Denmark
Torsten Larsen, Denmark
Jooske Vos, EPSO
Mari Murel, EPSO

1. Lena Weilandt, chairperson, extended a warm welcome to the participants of the new working group. Nine countries and 11 organizations has expressed interest to participate.
2. Jooske Vos gave a background to previous work done on this topic in EPSO. The topic has been on the agenda since 2008. (see power point)

3. Lena presented the result of the short questionnaire done before the meeting. The result showed that many of the participating organizations have patient and user involvement stated in their policy's, and also use different sources of patient/user experience when planning supervisory activities. The main challenges focused on involving patient/user in the actual supervision. There answering organisations had done pilots but not yet done this in a systematic way. Only one organisation have hade patient/user as a partner in a supervisory team and only one or two have tried including patient organization when meeting organizations to give feedback after a supervision.

4. The group discussed expectations of the coming work in the working group. They where
 - Sharing experiences and knowledge
 - Learn more about how to systematically involve patients in supervision and to discuss possible advantages and disadvantages for example how to identify patient and users during a supervision.
 - Means and methods for recognizing meaningful and valid information and discuss how to use patient/user data together with other information.
 - Discuss best practice – what are effective methods for user participation in supervision what have greatest effect in order to improve the service.
 - Discuss potential risks.
 - Different needs and methods for different groups.

 - Discuss how research could help. Help to gather information to develop recommendations for "best practice" in supervision. Identify research questions for this purpose.

 - Discuss if there are other methods or sources to give the patients a voice in supervision

 - Transparency in communication of results

 - Patients experiences as risk-indicators

The next meeting will be held in London the 24th or 25th of April 2017. Lena will send out an invitation on how to proceed further with the work in between. The group suggest to continue- possibly- in a smaller groups and focus on one topic at the time.

Lena and the EPSO secretariat will discuss the follow up procedure and send a proposal to all.

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