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Notes from the working group for patient and user involvement in supervision

Reykjavik 27 September 2017

Participants:

Lena Weilandt, IVO, Sweden, chair and notes
Laura Scheving- Thorsteinsson , Iceland
Hanna Ahonen, Finland
Henrik Frostholt, Denmark
Alvaro de Moreira da Silva, Portugal
Cheew Bin tee, Singapore
Carmen Buttigieg, Malta
Jooske Vos, EPSO

1. Lena Weilandt, chairperson, extended a warm welcome to the participants of the working group and gave a background to previous work done on this topic in EPSO.
2. Lena presented the result of the short questionnaire done before the earlier meetings. The result showed that many of the participating organizations have patient and user involvement stated in their policies, 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. Lena presented also the over view of existing practices within the organisations in EPSO. The group made some additions to the table.
3. Lena presented the ongoing work in Sweden and the change in legislation from 2018 that will increase the expectations on IVO to have clear patient and user perspective and systematically collect data on patient and users experiences of services during supervision. She also shared a report from Bente Smedbraten,

Helsetillsynet, Norway and their very positive experience of an advisory board of patient/user organisations.

4. Laura told the group of the experiences from the pilot of using a national survey of patients experiences in Iceland and Alvaro presented some of their experiences on the same topic.
5. Henrik told the group of their work to strengthen the user perspective in supervision of social services. The project involves three areas of further development
 - ✓ New methods to support different user groups with different needs
 - ✓ Involving the next of kin (ethical, legal and methodology topics)
 - ✓ Introducing Experts by experience (cooperation with Norway, CQC, Wales and The Netherlands)
6. Hanna told the group about the workshop they organize where all patient and user organisations are invited to discuss, among other topics - what is most important in health and social care? What should supervision focus on?
7. Be Tin described the system in Singapore with strong patient advocacy groups. Carmen and Alvaro shared their experience from Malta and Portugal.
8. Lena introduced the model for participation based on Arnstein ladder of participation and the EU Code for good practice of Civil Participation in the decision making Process. Each country discussed how far they have come based on the different steps. All countries shared the experience that there could be further improvement in involving patient/users and in their impact on the decision making in the supervisory organizations.
9. The next meeting will be held in Copenhagen the 16th April 2018. The group suggested to continue to focus on one topic at the time – in Copenhagen the main topic for the working group will be on the method *Experts by Experience*. Lena, Henrik, Laura will have a pre-planning meeting ahead of next time.