




Inspektionen för vård och omsorg

Welcome!



Agenda

- Follow up from the meeting in London
 - Introduction on how we can engage with patient and users on different structural level in our supervisory organizations.
 - Input from
Denmark, England (CQC), Finland, Sweden, Norway (report)
 - In-depth discussion on participation with patient and user organizations
 - Discussion on how we in a structured way can continue to share experiences and knowledge between organizations
 - Commitments and agenda setting for the next working group meeting planned for 11 April 2018.
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The aim for the working group

Sharing knowledge and experiences among the members

To inspire to and support the development and improvement of supervisory practices



First step in the working group

- Introduction to the theme in Stockholm 2016
- First working group London april 2017
- An inventory of ongoing work in the member states
- What the main areas of interest in this topic where



A first inventory on patient and user perspective, October 2016

- ④ Every organisation have it in their policies
- ④ Many used information from users and patients in risk analysis
- ④ Less had experience from involving patient and users in the supervisory activities

Inventory of ongoing work

Iceland	<ul style="list-style-type: none"> ▪ National Patient Survey 		England CQC	<ul style="list-style-type: none"> ▪ Organization of service users – training programme how to report ▪ Expert by experience at inspections ▪ SOFI ▪ General information, social media ▪ Strengthen outcome of information/data from service users to drive change ▪ Feedback of results
Norway	<ul style="list-style-type: none"> ▪ Interviews children and users in welfare services and persons with drugrelated problems ▪ Expert by experience-pilots ▪ Advisory board ▪ Research to identify cultural and organizational barriers for pat/user involvement 		Wales	<ul style="list-style-type: none"> • Advisory board • Laymen reviews • Ask for Patient experience at inspections • SOFI
Finland	<ul style="list-style-type: none"> ▪ Hearings with Patient /user organizations – focus for supervision ▪ Experts by experience 		Latvia	<ul style="list-style-type: none"> • Complaints as basis for supervision
Denmark	<p>Social services</p> <ul style="list-style-type: none"> ▪ User involvement Project 2017- Methods to strengthen user perspective ▪ Experts of experience ▪ Eg. Terminology, use of data, reliable methods to gather user experiences <p>Patient safety</p> <ul style="list-style-type: none"> ▪ A new strategy for citizen involvement 		Estonia	<ul style="list-style-type: none"> • Complaints as basis for supervision • Patient user organizations- meetings
Sweden	<ul style="list-style-type: none"> ▪ Patientdata – focus of supervision ▪ Methods to involve patients-pilots ▪ Patient/user organizations - pilots 		Netherlands IGZ	<ul style="list-style-type: none"> • Zorgkaart and • National hotline on complaints • Consumer panel <ul style="list-style-type: none"> • Experts by experience – pilot • SOFI - pilot

Expectations from the members of the working group

Methods	Best practice	Handling of data	Evaluation of methods	Other
Inventory of methods	Find patient/users to address	Use of data in decision and analysis	Common protocol for evaluation of methods	Training of inspectors
Share experience and knowledge	Pat/user no voice of their own	Develop valid and meaningful data	Pat/user experience and result from supervision compared to assessed quality	Influence of social media
	Advantages and potential risks			Complaints, taxonomy
	Experts by experience/laymen			Connect research to this topic
	Patient/user organizations			

User perspective and interaction on different levels in our organisations

Macro level – management level
e.g. Advisory boards

Meso level
e.g. using data sources in riskanalysis, planning of supervision

Micro level
e.g. collecting experience from patient and users during supervision, as a source of information during inspection



Presentations from the group



Sweden

Macro level

Advisory board, members assigned by the government

10 members - one representative is from a patient organisation

Forum For Dialogue

Open fora for patient and user organisations

- ✓ 90 organisations signed up to participate
- ✓ Mutual planning group IVO and 3-4 organisations
- ✓ Information about IVO and IVO business
- ✓ Seminars on different topics
- ✓ Held once a year

Meso level

Planning of riskanalysis – data from Patient Advisory Committees, adverse events reported to IVO, patient complaints etc.

Contact with patient/user organisations in planning of specific supervisions



Micro level - today

During supervision

Some pilots - interviews and cooperation with organisations


Questionnaires, questionnaires, questionnaires



Micro level –next year

Committee of Inquiry *Patient Complaints*

From January 2018

- ✓ A limited obligation for IVO to investigate patients complaints
 - ✓ Conduct more risk-based supervision
 - ✓ A strengthened patient and user perspective in supervision
 - ✓ IVO ***must ensure*** that patients and users are heard at all inspections.
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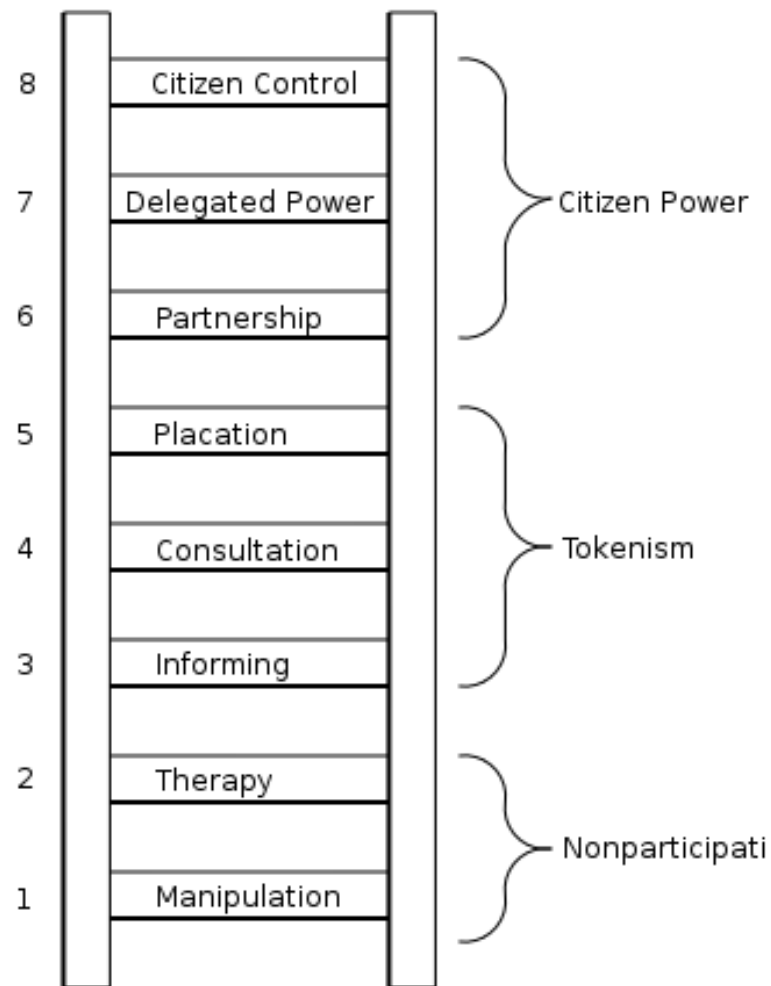
Presentations

Henrik Frostholt, Socialstyrelsen, Denmark

Hanna Ahonen, Valvira, Finland



Arnstiens ladder of citizen participation



Arnstein, Sherry R. "A Ladder of Citizen Participation," *JAIP*, Vol. 35, No. 4, July 1969, pp. 216-224

CONTROL

- *USERS CONTROL DECISIONS*

SHARED DECISION MAKING

- *SHARING POWER AND RESPONSIBILITY*
- *Influence outcome*
- *Partnership*

PARTICIPATION

- *EXCHANGE OF IDEAS*
- *Dialogue, suggestions,*
- *Can influence decisions*

CONSULTATION

- *QUESTIONNAIRES, FOCUS GROUPS*
- *Users asked what they think but have little influence*

INFORMATION

- *ONE WAY COMMUNICATION*
- *Users are passive consumers, knows what is happening but have no influence*

CONTROL

• *USERS CONTROL DECISIONS?*

SHARED DECISION
MAKING

• Advisory boards, co-design

PARTICIPATION

• *Reference groups, workshops*

CONSULTATION

• *Interviews, surveys, focus groups*

INFORMATION

• *Leaflets, webb,*

Discussion

- What is the main purpose for cooperation with patient and user organisations?
- How far have we come in patient/user participation?



- What are the advantages?
- Are there risks?

- How can we maximize the advantages and minimize the risks?

- Do we need to use additional methods?
 - What are these?



Next step – the continued work in the working group

Documentation from this working group - add/correct information

On the EPSO web-site



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Topic for next meeting, April 2018

Committements