

User participation

Overview document about existing practices in 9 inspectorates



Contents

Introduction

A. Existing practices general description per country

B. Questions about existing practices

1. Flanders-Belgium
2. England
3. Finland
4. Northern Ireland
5. Sweden
6. The Netherlands Healthcare Inspection
7. The Netherlands: Youth Inspectorate
8. Portugal
9. Wales

Introduction

This document gives an overview of the answers to the EPSO questionnaire on user participation given by the members of the EPSO user participation working group from the various EPSO countries that practice user participation in a variety of forms.

The interviews were done by telephone by the EPSO secretariat (Jooske Vos) or in one case (Belgium) by using written information in combination with additional information by phone.

The questionnaire was based on earlier work done by Theresa Nixon and Claire Henry from Northern Ireland using information from the EPSO working group (outcomes of the workshop at the Utrecht- Conference), questions raised during user participation try-outs in Flanders and experiences and practices from Sweden, Portugal, Northern Ireland, Wales, England, Flanders and the Netherlands (Youth and IGZ inspectorate).

In this questionnaire and in the preliminary discussion's was never exactly formulated what was meant with "user participation". A definition was not given as we thought that the meaning of the term 'user participation' was completely clear and a definition was not necessary. This was proven to be wrong. Some countries and regions gave a different interpretation or asked for explanation of the term. Especially the difference between a. complaints in the sense of negative feedback about things that –in the opinion of the complainant - went wrong in healthcare and b. user participation as a way of actively being asked to give positive, negative or neutral feedback about amongst other things experiences and results of healthcare.

Therefore we give a kind of definition and description of the term "user participation" that was used when we worked on this questionnaire.

User participation is usually part of a policy that actively involves people who use the health institutions as they need to go there, to include their opinions in the policy of the supervisory organisation. The information from User participation is information from people who use the healthcare institution themselves (patients, clients) or their direct relations (relatives , helpers). So user information is not primarily information from the institution, or the healthcare staff or from intermediate organisations as far as these organisations do not have direct information from the patients/clients. Nevertheless healthcare workers (doctors, nurses staff) and intermediates organisations can be involved in getting user information and can also be very useful sources for policy information about healthcare, but they are not the main target as they are not users.

The user participation feedback differs from the complaints feedback in the sense that it is mostly not intended to provide an answer or solution to an individual case or problem. Users give primarily information to get informed about effects and opinions in healthcare institutions. This is often a more general approach to the institution, primarily meant to learn from.

The definition of user participation does not involve the opinion of the staff and the doctors. Of course this can also be very interesting and maybe even more interesting information but this was not primarily meant with user information in this questionnaire and this working group.

The aim of this questionnaire was to get more detailed information on how to improve the existing processes of user participation in the various EPSO Member States and to get at the end of the process the following information:

- A. Existing practices
- B. Attention points from own experience? Lessons learned.
- C. Difficulties in the implementation of the process of user participation? How to overcome the difficulties?
- D. Best practices;
- E. Results: does it help to use the opinion of service users?
- F. Useful information, documents and legal information
- G. What questions should be answered in advance when organising user participation?

The working group started with this Questionnaire about the existing practices in the various EPSO countries.

Questions were sent in advance to the interviewees. Answers were given in the context of the phone conversation and 'translated' by EPSO.

These answers have been realized with the co-operation of and Interviews given by (per country in alphabetical order):

1. **Flanders- Belgium** Gerda Schotte, Sabine Jakiela and Krist Debruyne;
2. **England** Clare Delap and Ellen Fernandez;
3. **Finland** Ritta Aeismelaesus and Katia Käyhkö;
4. **Northern Ireland** Theresa Nixon and Claire Henry;
5. **Sweden** Anita Bashar Aréen;
6. **The Netherlands Healthcare Inspection** Paul Robben and Corry Ketelaars;
7. **The Netherlands Youth Inspectorate** Kees Reedijk, Jeugdzorg;
8. **Portugal** César Dos Santos Carneiro;
9. **Wales** Mandy Collins.

A. Existing practices general description per country

Existing practice / policy on User Engagement in supervisory organisations in the various EPSO countries / regions

1. **Flanders** ; Flanders has no history of user participation in hospitals and health institutions ; Recently (in 2012) a successful try-out has been carried out in in state youth institutions. The results are positive. The Flemish inspectorate is convinced of the usefulness of the outcome and Plans follow up activities not only in youth institutions but also in the other sectors such as: in the care for the elderly, the general welfare, the child welfare, in hospitals, in kindergartens and with people with mental physical or mental disability.
2. **England**; CQC has a nationwide commitment of involving people and this runs across all of its work. The CQC programme is to make sure that the system of user participation works and to find out how well – or not well- it works out in the various health institutions. CQC has a dedicated team who offer advice and link with local service user networks. This team helps set policy, engage with key stakeholders internally and externally and ensure that service user voice is embedded in the work of teams and programmes of work across the Commission. They also manage a number of initiatives that promote the use of user voice and experiences in our work.
3. **Finland**; In Finland all fields of health care and social care are inspected by five senior medical officers and four senior inspectors (all specialist in health care, physicians or nurses). In addition, several inspectors for social welfare are steering and inspecting different kind of and types of apartments for old people, day care centres and kindergartens, housing services for the disabled etc.
User Information in Finland is mainly coming from complaints. The supervisory organisation in Finland (Valvira) has no active user participation programme in the sense that people are asked to give feedback to Valvira about their experiences in health care institutions. The supervisory organisation is asking health institutions and doctors to organise self-monitoring by themselves. They do not systematically control the results of the self-monitoring except by handling complaints
4. **Northern Ireland**; The relevant director and HOP take responsibility for involving service users in RQIA. The MHLTD team has taken the lead in inspections of hospitals when people are admitted compulsorily or as voluntary patients for treatment who have either a mental health or learning disability or have dementia requiring long term hospital care.
5. **Sweden**; Sweden has just started with an active user participation policy (about 1 year). The Department of Supervision has developed a policy document that outlines when, why and how to engage with service users/user organisations. The document also stipulates follow-up activities. The document is in the Swedish language. It does not answer the questions of this questionnaire but gives quite some general information.
6. **Netherlands IGZ**
The IGZ has no history of user participation and also complaints are not a standard task for the inspection. As a result of some recent problems the national ombudsman has

been involved in some cases and in some press comments have been quite intense and powerful. Two external reports have made the topic of complaints handling to a sensible and politically hot topic. User participation in the broader sense has not yet been discussed widely. The inspection plans to actively use information of complaints in her policy in the near future. The overall policy will not change; complaints are handled by service providers themselves. The inspectorate will oversee if this system works well.

7. **The Netherlands (Youth inspectorate/ Inspectie Jeugdzorg)** ; The policy of the Youth Inspectorate in the Netherlands (Inspectie Jeugdzorg) is to involve and give voice to the children and the parents that are involved with de institutions which we are supervising. However, their involvement is restricted to the role they have during the investigations. They are not involved for instance in the choice of topics or the design of our investigation. Nor do they have an involvement during the reporting phase. We focus on three items: using the information of users, engaging patients in the inspection process and making our inspection results available for citizens.
8. **Portugal**; the involvement of service users through the Advisory Board is a responsibility of the Board of Managers, whereas the contact with complainant service users is done directly by the staff members who conduct the complaints' handling process.
9. **Wales** ; active practice of user participation by health inspectorate.

B. Questions about existing practices:



1. Is the above mentioned **(existing practices)** information correct and complete?
2. **How often** are users involved?
3. **How many** users are involved in user participation and being asked to give an opinion? Are all users of health care involved?
4. How does the involvement of service users **work out in practice**;
5. How is the service **user's voice embedded**? directly / indirectly? all service users systematically?
6. How do you **recruit service users** e.g. internal information or external sources and how is this done?
7. How is the **selection between users** being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?
8. Is the participation of users **systematically prepared** (questions prepared in advance) or ad random (free style and open questions)
9. **How are the users being asked** for their opinion: in groups or individual ; oral or written;
10. Is information **kept secret** or used to improve services? kept secret to whom, how long, when and under what conditions?

11. **When** are the users they being asked? Do they know in advance, after having experienced care ;
12. Are **interviewer's being trained** in advance? how?
What type of induction is offered to (professional or lay) service users reviewers/ interviewers? Are interviewer's being trained in advance? how?
What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?
13. What **type of challenges do you face in offering training** to lay reviewers e.g. communication methods, payment?
14. what are **best practices of user participation**?
15. How are the **results reported**?
16. How is **feedback organised** to the institution? And to the supervisory organisation ? And to the public?
17. Is there an inspection and **control mechanism on the process** of user participation?
18. How is **follow up** organised? best practices?
19. Is there a **link with the complaints** system and legal complaints? How is that organised? Why not?
20. **Does it help** to use the opinion of service users and to have a policy requirement to engage with services users?
What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?

Overview of given answers per country/ region



1. Flanders-Belgium Gerda Schotte, Sabine Jakiela and Krist Debruyn;

Questions about existing practices Flanders :		Answers from Flanders (from written text and short additional interview)
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	Flanders has no history of user participation in health or social care institutions. In 2012 a try out was done in 5 institutions (youth detention centres with open and also with closed regimes) No difference was made between open and closed regimes
2. How often	How often are users involved?	The experiment was done in 5 different institutions .
3. How many	How many users are involved in user participation and being asked to give an opinion? Are all users of health care	In every institution 8 users (of 2 different age groups) were asked about their experiences in a one to one setting. Later a group setting was tried out in an institution for children during weekend and holidays. The total number of users per institution is different (about 40-120); All users were involved(informed about inspection) but not all users were selected for interviews

	involved?	
4. In practice	How does the involvement of service users work out in practice ;	The users were selected by the institution (selection based on language proficiency, IQ) The questioning/ discussion was done in a selected area (a pleasant surrounding with good vibes and some food / drinks)
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	The questions were asked directly with the users in a one to one setting Afterwards conclusions from discussions with the users were checked with the staff from the institution of the same age group 2 inspectors and 2 staff..
6. Recruitment of users	How do you recruit service users? e.g. internal information or external sources and how is this done?	The service users were selected based on internal information. No external information (complaints information from other sources) was used.
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	Users were selected by the institution based on intelligence, verbal talent, free will to talk)
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	The participation was carefully prepared ;the users were informed about aim and procedure of the questioning. Guarantee of anonymous conversation was given. Openness' was promoted. No promises of improvement were made. A list of questions was prepared to prevent different questions to the users (all the same setting and all the same questions)
9. How being asked	How are the users being asked for their	The questioning was one to one and later in the second experiment in small groups 3-4 and 2 inspectors.

	opinion: in groups or individual ; oral or written;	All interviews were oral No closed envelopes or complaints forms were used. The group conversation
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Privacy was respected and reports were anonymized. No special measures were taken to prevent that the individual stories were recognized. The stories were reported if 3 -4 youngsters confirmed the story
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	Users were being asked during their stay. Conversations were held instead of normal activities (school/ sport etc).
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	4 inspectors (Interviewers) were trained in communication skills and got focus points for a better conversation
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	Alternatives for the classical conversation; Interviews during walking around or during games Interviews of youngsters backed by a young person.
14. Best practices	What are best practices of user participation?	User participation in groups group was after all seen as a best practice Group discussion in a as a good and efficient way to get user information. Experience in a group were seen as best

		<p>practice:</p> <ul style="list-style-type: none"> - more group dynamics but possible to handle in small groups; - more guarantee for completeness and objectivity - more perspectives visible - less intimidating for children. <p>Ad random selection is better than selection by the institution</p>
15. Report	How are the results reported ?	In a report to the institution
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	The report is sent to the institution and is available for the users who participated (openly available)
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	Yes there is a follow up aiming at
18. Follow up	How is follow up organised ? best practices?	
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	No link with complaints
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with	Yes Flanders plans to do user participation interviews in the near future in all sectors of health care and social care (older children/ young children/ general hospitals/ care for the elderly/ social care / special youth care / care for psychological and mentally ill patients and for physically handicapped)

	<p>services users?</p> <p>What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?</p>	<p>Not aware of doubtful results.</p>
--	--	---------------------------------------



2. England Clare Delap and Ellen Fernandez;

Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	Additional points are added by Clare (see above)
2. How often	How often are users involved?	Every single inspection users are involved; a. every time when an inspector is visiting a local service provider service users are involved.

		<p>b. The institutions do have to involve service users by themselves</p> <p>c. The organisations of service users are involved on a national level.</p>
3. How many	<p>How many users are involved in user participation and being asked to give an opinion?</p> <p>Are all users of health care involved?</p>	<p>Exact numbers are not known. The numbers depend on the different models for involvement of service users in the different types of services. There are no quota or special selection criteria or involvement of users. All users are invited to come forward with opinions and remarks.</p>
4. In practice	<p>How does the involvement of service users work out in practice ;</p>	<p>In practice there are various ways of involvement of service users. When inspections are planned signs are put up to inform the users and ask service users to react and give opinions. Sometimes people are called (telephone interview), sometimes interviews are face to face.</p> <p>CQC has given priority to build up on-going relations with local groups of service users, local user organisations, local health watch in the various communities (groups representing people with various illnesses, mostly chronicle illnesses).</p> <p>The CQC website has an open forum</p>
5. How voices are embedded	<p>How is the service user's voice embedded directly or indirectly? all service users systematically?</p>	<p>The inspections are usually unannounced and do not have a special preparation in advance (no special guidelines or questionnaires sent to service user)</p>
6. Recruitment of users	<p>How do you recruit service users? e.g. internal information or external sources and how is this done?</p>	<p>Recruitment of users depends on the type of service.</p> <p>Sometimes lay people, or experts by experience are used to interview the service users. The interviewees are often happier to speak to lay people than to speak to inspectors. They feel more comfortable when the lay people come from their own group.</p>
7. Selection of users	<p>How is the selection</p>	<p>Selection of users is mostly ad random (unannounced inspections).</p>

	between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	In domestically care a phone list is used for selected patients / clients. Analysing complaints or making use of existing complaints is not used to select patients. Other selection criteria are also not used.
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	Questions are mostly free style and open (not prepared in advance). Standards for good care are being checked. The standards for good care are on the website.
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	Mostly individual; and in a one to one setting
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Privacy is always kept. Reports are anonymized. Nevertheless the problems to keep the identity of the user secret can create barriers for people to talk, as in many cases it is quite obvious who has said what. This is a problem that should be looked at better in the future.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	While being in care; except the regular contacts with user organisations and the experts by experience who are usually not anymore in the institution.
12. Training interviewers	Are interviewer's being trained in advance? how?	Yes the interviewers have a different background and different skills. Some have natural skills but others do not. Therefore they are trained in general interview techniques.

	What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	A challenge is conducting difficult conversations e.g. in case of dementia and patients with difficult behaviour). There is not enough time to train and not enough guidance about what to the interviewers should be doing (do's and don'ts for interviewers.
14. Best practices	What are best practices of user participation ?	We are very proud on our lay inspector programme. This is really very helpful as it adds a lot of information to the process and it shows to people in the service thatr we try to improve healthcare in the service. The other good practice is that we balance the work with the local groups. We find that it is important and it is our duty to work with the special local groups (such as local health watch and volunteers) and to get them involved in the work of the health inspectorate.
15. Report	How are the results reported ?	Each inspection report has a special paragraph about what people told us.
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	The report is sent to reported back to the institution, published on our website and published locally. No special feedback to the users that gave information
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	A control mechanism afterwards is at stake. CQC organises control of the process of user participation. How well are the institutions doing this

18. Follow up	How is follow up organised? best practices?	Follow up is organised by CQC about concern realised during the inspection. Usually this is only done by writing (paperwork). Only in serious cases other instruments are used for follow up (sanctions) The best
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	NO link with complaints is organised. No analyses of complaints is given back to the user participation process.
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	Yes it helps but it is really hard to say how much it improves the actual process and the outcomes of the healthcare. How do we know whether collection of user information improves the performance of the institutions? It would be a good idea to seek anecdotic evidence for this. Very important is that the user information is systematically analysed by the supervisory organisation, that the outcomes are systematically discussed This can lead to more systematic feedback about the tools of user participation and way they are used now.



3. Finland Ritta Aejmelaesus and Katia Käyhkö;

Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	<p>One also has to take into account that Finland is a small country with a rather long tradition of health and social care supervision based on proper health law.</p> <p>Valvira is very well informed about both experiences and opinions of the public's concerning health and social care in Finland as it is using other method of information than user information (especially the deferent kind</p>

		<p>of complaints from various groups)</p> <p>Valvira supervises social and health care organizations as well as individual professionals at all levels. Our answers in this questionnaire refer mainly to health care. Finland is systematically collecting information that is given to them by other means than user information such as direct complaints, phone calls, letters as well as evaluation requests of complaints sent to the police, Parliament ombudsman etc.</p> <p>Finland uses this information to decide about supervisory activities depending on the issues concerned.</p> <p>Complaints in which patients complain about their own care are dealt with in Regional government offices (5) with which Valvira has close collaboration. Valvira has the duty by law to supervise the offices in harmonizing their judgements about complaints.</p> <p>As user participation is understood as more or less actively and more or less widely collecting information from the patients and their direct relations or family who make use of the health care institutions, Finland is not doing that. Supervisory organisation Valvira is not systematically -directly or indirectly- collecting information from users and is usually not visiting hospitals and health institutions. There is no list of users or intermediate organisations to ask about the actual experiences of users. Valvira is actively collecting and handling complaints.</p>
2. How often	How often are users involved?	<p>Health care units do use a self-monitoring system to get information from the clients and patients. Valvira is not checking the self-evaluation done by the health institutions. No information is available no information is available about whether, when and how often the information is requested to healthcare users.</p>
3. How many	How many users	No information is available about how many

	are involved in user participation and being asked to give an opinion? Are all users of health care involved?	users are involved. Not all users of health and social care are involved
4. In practice	How does the involvement of service users work out in practice ;	The health care institutions involve service users more or less according to their own approach and their own plan. The results and outcomes are not systematically checked by Valvira. There is no follow up except in case of complaints by patients or clients
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	The self-monitoring systems should have a permanent and direct participation of users but if this is in fact the case or not is not known as there is no follow up by the supervisory organisation. All users can launch a complaints with Valvira. The complaints are the spearhead of the monitoring organisation. This leads to an indirect form of involvement of users.
6. Recruitment of users	How do you recruit service users ? e.g. internal information or external sources and how is this done?	Service users are not actively recruited by Valvira. Forms for complaints are on the Valvira website. The forms are not actively distributed, not closed anonymized envelopes.
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	Users are selected by the healthcare institutions. How this is done is not known.
8. Systematically prepared	Is the participation systematically	The questions are not systematically prepared by Valvira. This might be the case by the healthcare institutions but it is not

	prepared (questions prepared in advance) or ad random (free style and open questions)	systematically reported to Valvira.
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	Healthcare institutions can tell people that they can launch a complaint, but this is not controlled by Valvira. The questions for healthcare institutions (how to ask users about the service) are not on the website of Valvira. The forms for complaints are on the website
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Information from patients and clients is not kept secret. The report from Valvira is anonymized and openly available
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	This is up to the healthcare institutions. There is no control mechanism.
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	There is no special training for interviewers. No information is actively collected.
13. Challenges for Training	What type of challenges do you face in offering training	No challenges

	to lay reviewers e.g. communication methods, payment?	
14. Best practices	What are best practices of user participation ?	The active link with complaints can be a helpful and useful instrument to find information from users but this is not enough to get a full perspective of the user experiences
15. Report	How are the results reported ?	The results are yearly published in the overall yearly supervisory report
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	No feedback to Valvira about user information. No feedback from Valvira to the healthcare institutions
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	The Control is done on paper
18. Follow up	How is follow up organised ? best practices?	-Follow up is usually on paper. Only in serious cases follow up is done by visits to the institution or taking measures.
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	There is an active link with the complaints system as this system is the spearhead of the monitoring organisation. This leads to an indirect form of involvement of users who launch a complaint. Other users are not involved.
20. Effect	does it help to use the opinion of service users and to have a policy requirement to	Information from users seems very important; it seems to have a usefully effect on the quality of healthcare, but in Finland complaints is very actively used but other direct involvement of users is still insufficient in practice and not yet systematically part of the process.

	engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	
--	---	--



4. Northern Ireland Theresa Nixon and Claire Henry;

1. Questions about existing practices:		Answers Theresa for Northern Ireland
Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	Yes, information is correct but not complete Theresa will add short info about sectors of health and social care that make use of user information who is responsible <ul style="list-style-type: none"> a. MHLA b. Hospitals c. foster care d. users at their own home e. Other institutions
2. How often	How often are users involved?	In every single inspection / supervisory activity users are involved.
3. How many	How many users are involved in user participation and being asked to give an opinion? Are all users of health care involved?	Exact number of users is not known. Not all users are involved. All users can give their opinion.
4. In practice	How does the involvement of	In practice there are a great number of different ways to ask people about their

	service users work out in practice ;	experiences (loads of different questionnaires for different groups of users: mentally handicapped, disabled children, grown up etc.). Questionnaires are on website. The interviews are sometimes done by more interviewers and sometimes by one interviewer (more interviewers has some advantages over one interviewer)
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	Yes both directly and indirectly Indirectly: trust is being asked to give information and staff is being interviewed and being asked in advance about opinion of users
6. Recruitment of users	How do you recruit service users? e.g. internal information or external sources and how is this done?	The regulator invites people to come and give their opinion by: <ul style="list-style-type: none"> • advertisement in local newspapers • pamphlets • notices • road shows All users can react. The wards are asked in advance to involve users
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	There is no systematic selection but mostly an ad random selection. Mostly a group of carers (20) is asked about their opinion.
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	Yes mostly questionnaires are used. Loads of different questionnaires for different groups and situations (children, mentally handicapped, grownups, different social and intellectual background). Sometimes ad hoc or free style interviews Questionnaires are on website
9. How being asked	How are the	Both individual or in groups

	users being asked for their opinion: in groups or individual ; oral or written;	Oral and sometimes written
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	The information is reported openly without reserve but without names and without referring to individuals unless the person approves that his or her specific case is being mentioned. Lay people report back separately their own findings.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	Usually after while having or having received care and usually informed in advance but sometimes ad hoc.
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	Yes the 'lay' people (volunteers) who do interviews are being trained/ the inspectors are not being trained? In the training is important to train the role model (what do you ask/ why and how)
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	Lay people get no payment but expense allowances such as transport, costs of childcare etc.
14. Best practices	What are best practices of user participation?	Best practices: - send questionnaire 6 weeks in advance ;

		<ul style="list-style-type: none"> - if there is a special reason to check: check afterwards as follow up ; - use stamped envelope that people can use to give anonyms information about the service they have used. (return rate is not very high but the instrument is useful)
15. Report	How are the results reported?	Results are publicly reported on the website and as feedback to the services
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	Feedback is given to the organisation and is immediately published on the website (also when it is not good and before time for improvement has been given) Comments were made (by the institutions) that the institution should have time to react and to improve before the (negative) report is published. As public trust and safety is at stake this is not done. Public publication is a strong and effective instrument for improvement of the quality and safety of healthcare. If there are serious risks other measures can be taken
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	Yes user participation is obligatory by law and has to be inspected by supervisory organisations
18. Follow up	How is follow up organised? best practices?	Follow up is done by reporting. The challenge is to coordinate the follow up, and to learn from experience and to implement the findings Another challenge is to promote that the results and findings contribute to improvement at regional and national level
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	No formal real link with complaint system. Users are being told that they can also launch a formal complaint.

20. Effect	<p>does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?</p>	<p>Yes it does help</p> <p>Results are remarkable</p> <p>The challenge is to organise outcome's and results better and to engage politics and services more in the process of implementing improvement</p>
------------	---	--



5. Sweden Anita Bashar Aréen;

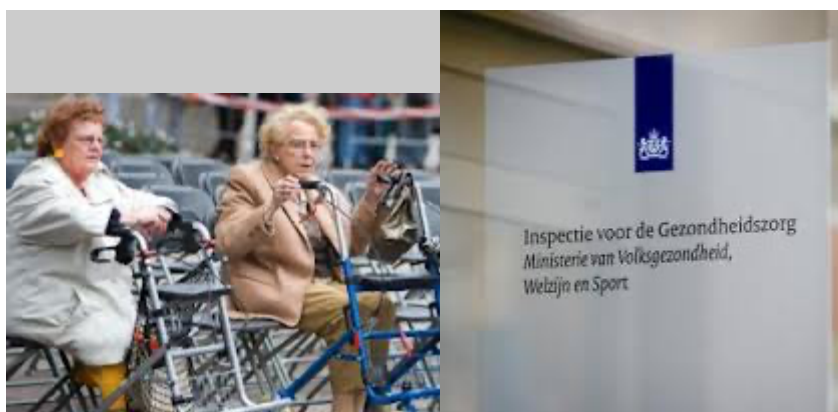
Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	In Sweden practice of user participation exists for about 1 year; practice is not fully implemented yet; the existing policy document is a document on headlines (general guideline). It needs more elaboration for the application in practice. This will be done after the start of the new supervisory authority (the 1 st of June 2013).
2. How often	How often are users involved?	The inspectorate tries to involve users as much as possible (in all inspections and supervisory activities). User participation is more common regarding supervision of social welfare compared to healthcare.
3. How many	How many users are involved in user participation and being asked to give an opinion? Are all users of health care involved?	In principle, we try to involve all users in the inspection process, but that is not possible as not all people can give their opinion. The opinion is always optional, not obliged. If people cannot give their opinion (dementia or some children) their representatives are being asked). Depending on the type of users these are different numbers. (3500 children in residential homes), a few hundred disabled people, a few hundred elderly
4. In practice	How does the involvement of service users	For example supervision regarding residential care for children we use announced/ unannounced inspections.

	work out in practice ;	<p>Announced inspection: the municipalities who have a general responsibility for the health and social care institutions are informed about the inspection and are being asked to organise a number of users to be interviewed. (the supervisory authority informs the municipality in advance and asks for participation of users)</p> <p>Unannounced inspections: users are being asked directly if they like to participate in the inspection and give their opinion. Most of the time the inspections are announced and most of the interviews are semi structured without questionnaires sent in advance. The preparation of the interviews is semi structured with also possibility to pose open questions. Questionnaires are sometimes being used for people who cannot do an interview. These questions are being sent in advance to the representatives of those people who cannot do an interview</p>
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	The inspectors do the interviews themselves (no lay people). Questions are being posed directly to users. In principle all service users are involved.
6. Recruitment of users	How do you recruit service users? e.g. internal information or external sources and how is this done?	The recruitment of service users is done by the service providers as the inspection has no knowledge of the users.
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active	The supervisory organisation in Sweden has no influence on this selection and how it is done. They ask to involve users without preference for certain types of users.

	in intermediary organisations)?	
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	The interviews are systematically prepared (semi structured- no formalised questionnaires)
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	The interviews are usually done in small groups 2-3 users. Oral not written except for people who cannot do an oral interview.
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Yes we keep it secret, we publish an anonymized version without names and not revealing identity of users.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	Users are being asked during the care.
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users	The interviews are being done by the normal inspectors; no special training is provided from occasional training in interviews/conversations with children and youngsters in residential care.

	/reviewers/ interviewers?	
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	No training so no challenges
14. Best practices	What are best practices of user participation?	A best practice is the conversations with children in residential care. This is very successful. It is done twice a year. A first inspection and a second follow up inspection. We see a certain value of that and the children also see the value. The children express that living conditions are very much improved as a result of the interviews. The children feel much better informed about their rights and feel more listened to. The conversations with the children gives information which can be hard to find otherwise.
15. Report	How are the results reported?	The inspection report is presented every year to the government . Directly to the municipalities and service providers and formally in paper. It contains details about evaluation of the services and the user information (anonymized). The report is not actively published but the information is passively disclosed (made public if people ask for it).
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	The report is sent to the municipality and they are being asked to inform the involved patients / users.
17. Control mechanism	Is there an inspection and	Yes. The results are sent and a term of about 2 month is given to follow up the

	control mechanism on the process of user participation?	advice to improve the service. The follow up procedure can use sanctions or re-inspection if measures are not taken to improve deficiencies.
18. Follow up	How is follow up organised? best practices?	Follow up visits are used to inform service providers about the results of the latest inspection.
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	<p>All patients are entitled to make a complaint (written not oral).</p> <p>There is no formal link with the complaints system. The complaints are handled by professionals with different backgrounds and this is a different approach/ perspective from the healthcare and social welfare approach/ perspective of the inspectors who do the interviews of users.</p> <p>All serious injuries according to 'Lex Maria' and 'Lex Sarah' have to be reported to the inspectorate. Sometimes complaints and injuries handle the same cases.</p>
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	<p>Yes it helps : the effect is positive and also for the future more attention will be paid to further improvement of the procedure of user information.</p> <p>The positive effects of the conversations with children is that it influences important issues to emphasize in new inspections. (info from evaluation report). No negative effects of user participation are being seen or reported;</p> <p>The practice of user participation is promoted by the new Swedish inspector-general. The new inspector general has expressed the values of user participation in the inspection process but this has yet to be developed and implemented in the new authority.</p>



6. The Netherlands Healthcare Inspection Answers: Paul Robben and Corry Ketelaars;

Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	Since some serious incidents (Jelmer case, report National Ombudsman, high level advisory group vd Steenhoven, Sorghdrager and) the perspective of the citizen in health and social care is an important issue in the policy of IGZ. The attention is strongly focused on the handling and dealing with complaints and the involvement of plaintiffs. User participation as such (actively inviting of users and their relations to give positive, negative or neutral feedback) is not explicitly mentioned in the policy papers
2. How often	How often are users involved?	-In thematic supervision sometimes patients are involved (depending on the subject of the supervisory activity); - in inspection visits in hospitals always some patients are involved ; - in long-term care (mental diseases, care for the elderly and care homes for vulnerable patients) inspections involvement of patients is a regular part of the inspection process (involvement of the board of patients, and sometimes ad hoc discussions with patients) - lots of user organisations are on a national level connected to the inspection and give their opinion about all kind of topics.
3. How many	How many users are involved in	The exact number of patients / clients involved is not known. Not all patients/ clients are

	<p>user participation and being asked to give an opinion?</p> <p>Are all users of health care involved?</p>	<p>involved or are invited to get involved in the inspection process. A few patients are directly -ad hoc -involved when the inspection is done by walking around in a health or care institution</p>
4. In practice	<p>How does the involvement of service users work out in practice ;</p>	<p>Patients are asked ad hoc. If something obvious is at stake (special behaviour of patients / clients such as shouting or confused patients) the inspector can ask for the file and the way of treatment. There is no special reporting instrument of the discussions with users. The outcome of the conversations will be part of the general report (not mentioned separately – no separate paragraph for user participation in the inspection report).</p>
5. How voices are embedded	<p>How is the service user's voice embedded directly or indirectly? all service users systematically?</p>	<p>The voices of users are to be taken into account in the inspection report. Individual voices are anonymized but not individually reported. They can influence the findings of the inspector and can as such be part of the general inspection report.</p>
6. Recruitment of users	<p>How do you recruit service users? e.g. internal information or external sources and how is this done?</p>	<p>Users are not selected / recruited in a systematic way. No special procedure of external information (complaints or other internal information) or internal information is used to recruit the patients /. clients</p>
7. Selection of users	<p>How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?</p>	<p>The users are randomly picked except for the patient board which is an existing body within the institution. No special selection is made between users. There is also no special selection of specific types of patients</p>
8. Systematically	<p>Is the</p>	<p>The involvement of patients board (in long</p>

prepared	participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	term care) is obliged (inspection policy) and systematically planned in advance. The questions (attention points) are prepared in advance but not sent to or known by the members of the patients board. There is no list of questions on the website. The involvement of patients/ clients during an inspection visit is not planned in advance..
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	Most ad hoc discussions with patients are oral, one to one, and without written account or feed back to the patient. The discussion with the patients board are in a group and also oral without specific written report, afterwards the remarks of the members of the board are anonymized presented as integrated part of the inspection report (not separately mentioned but incorporated in the impressions of the inspection visit)
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	All information is anonymized and. incorporated into the overall assessment of the institution. No information is kept secret. Reports are openly published after about 6 weeks. If asked patients can see the reports. The report goes to the board of the institution.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	Patients/ clients are being asked while being patient or client.
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or	There is no specific training except general communication training for inspectors. No lay people involved No review of the inspection report by third parties.




	lay) service users /reviewers/ interviewers?	
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	No challenges for improvement of training
14. Best practices	What are best practices of user participation ?	The regular meetings with patient- and client- organisations (national intermediate organisations such as NPCF) give a lot of useful information. The link to individual patient information and complaints is not yet overall effective but can become a future good practice.
15. Report	How are the results reported ?	The results of the inspection visits are reported to the minister in the inspection report and the judgement of the inspector(s) visiting the health institution.
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	The opinion of the users is used as feedback to the health institutions and the inspectorate. It is not systematically used as feedback to others (patients and patients organisations and complaints handling). Not reported in detail as feed back to the public.
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	An inspection control mechanism that monitors the progress of the findings of the inspection is in place. The findings are usually not directly related to user information.
18. Follow up	How is follow up organised ? best practices?	Follow up can be: revisit and control or sanctions such as in the most serious cases closing of the institution.
19. Link to complaints	Is there a link with the complaints	Complaints handling is formally not a task of the organization, but people do send lots of complaints to IGZ. The inspectorate can make

	system and legal complaints? How is that organised? Why not?	a selection of the most serious complaints and can decide to intervene in serious cases. The interventions are if necessary reported in inspection reports and can be the subject of further investigation and complaints handling.
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	Yes the effect of user participation as far as used until now seems to help quite a lot for a proper assessment of health institutions, but user information is also sometimes confusing as in some cases was found that the institution was very positively assessed by the patients but the quality of the health care was seen as quite inferior by the inspection. This can lead to a double standard for inspection visits. User information should be developed more in detail in the future: why and for what to use it and how to analyse the information.

7. The Netherlands: Youth Inspectorate

Answers Kees Reedijk

Questions about existing practices In the Youth Inspectorate Netherlands

		
<p>1. Existing practices of user participation</p>	<p>Short description of existing practice of the youth inspectorate In the Netherlands</p>	<p>Our policy is to involve and give voice to the children and the parents that are involved with de institutions we are supervising. However there involvement is restricted to the role they have during the investigations. They are not involved for instance in the choice of topics or the design of our investigation nor do they have an involvement during the reporting phase.</p>
<p>2. How often</p>	<p>How often are users involved?</p>	<p>Basically always unless there are contraindications. All inspections will use the instrument of user participation. Contra indicators can be the context of the child (sexual abuse or other circumstances that make that an interview cannot be basically always unless there are contraindications that make that an interview cannot take place in a situation that is safe for the child or the family.</p>

3. How many	How many users are involved in user participation and being asked to give an opinion? Are all users of health care involved?	All users are involved but not all are selected to be interviewed. The groups of residential care children are usually 7-12 children in a group. Usually for every group of residential care 3-5 children are selected for interviews.
4. In practice	How does the involvement of service users work out in practice ;	The selection is done by the youth inspectorate. In the past this was often done by the youth institution but this did not work out well as the impression was that only positive or more positive children were selected by the institution. The critical ones were at that time usually not involved in the selection to be interviewed. Most inspections are unannounced.
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	There is a large variety of instruments: Interviews oral Electronical and mobile voting instruments used in a group Separate questionnaires per theme and per situation Walking in the institution and doing the daily practice together with the children Ad random interviews The instruments are not made public to the institutions and to the users. The instruments are available for the colleagues in the youth inspectorate All are done by direct contact with the children (no indirect contact by intermediate persons or organisations).
6. Recruitment of users	How do you recruit service users ? e.g. internal information or external sources and how is this done?	The recruitment is done by the inspector
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	The users are ad random selected Usually groups. There is no use of intermediary organizations.
8. Systematically prepared	Is the participation systematically prepared	Yes All inspections are systematically prepared. For instance the guidelines for

	(questions prepared in advance) or ad random (free style and open questions)	interviewing children or the questionnaires that are being used for these interviews are constantly reviewed methodological prior to use and afterwards.
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	Usually the interviews are all done in small groups (3-5 children per group). In exceptional cases one to one interviews are used (small children, unsafe situations).
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	The reports are made public but anonymous and not traceable to a person. In exceptionable circumstances the report will be kept secret (if traceability is not. preventable such as in high profile cases) The report is always sent back to the institution for comment (adversarial process). The institution can correct facts (not opinions). The institution is given time to correct findings that are proven by them to be incorrect before the report will be openly published.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	Always during care situation
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	Yes, the inspectors were especially trained for Difficult conversations with mistreated people or sexually abused children For customized conversations (tailor made); To analyse facts Actors were used and the inspectors were sent to a special in home course.
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	Problem is to find the right mix of general training and specific on the job training focused on the special groups involved. It is not easy to find out What to train? Who to train?

		<p>How to train? And what to train for?.</p> <p>The main problem is that you have to find out what effect / result is reached by the training. What was effective in relation to time and costs and what was really necessary.</p>
14. Best practices	What are best practices of user participation ?	<p>The Best practice of the Youth inspectorate in the Netherlands is: “Inspection by walking along with the youngsters”. This is done by staying on the group as inspectors for a longer period for instance a whole day or even sometimes for a whole weekend. The effect is that the inspector can without giving the impression of an interview nevertheless ask and observe. This way of inspection is much more natural for the users.</p>
15. Report	How are the results reported ?	<p>The results are in a Public report on the website of the inspectorate (anonymized).</p>
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	<p>The report is sent to the institution. The institution gets time to the observations and to improve if necessary.(3 -4 weeks) 3 or 4 weeks after the inspection the report will be published publicly on the website.</p>
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	<p>Yes, inspection and control mechanism is in place.</p>
18. Follow up	How is follow up organised ? best practices?	<p>The inspection shall verify if the comments are followed up by the institution and the necessary improvements are achieved. Sanctions can be given.</p>
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	<p>There is a structural link to the complaints mechanism. The Youth inspectorate uses a risk mechanism (broad inspection vs thematic inspection ; administrative vs functional / operational inspection. The risk perspective is feed by external and internal information and also by policy of the inspectorate. One of the</p>

		topics that feeds the risk profile is the information from complaints from clients or professional care workers about the specific institutions.
20. Effect	<p>does it help to use the opinion of service users and to have a policy requirement to engage with services users?</p> <p>What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?</p>	<p>Yes it helps very much for the quality of the inspection.</p> <p>The effect is not really measured but sometimes user information is missing and especially in these cases there is quite often doubt about the quality of the inspection report as the user information is a kind of safeguard for having seen the right things and having made the right observations.</p> <p>An approach that does not work is or at least is less successful is the user information from closed institutions with children that are obliged to be there. These kids might try to mislead the inspection and often or at least sometimes it is difficult to check the real facts. The outcome might sometimes be doubtful but nevertheless it is also in these cases worthwhile to try to get the right information and disclose facts from fantasy.</p>

8. Portugal

Answers: César Dos Santos Carneiro;



Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	The in the overview mentioned existing practice is complemented by Cesar dos Santos Carneiro
2. How often	How often are users involved?	No direct user participation
3. How many	How many users are involved in user participation and being asked to give an opinion? Are all users of health care involved?	No users invited or asked for their opinion
4. In practice	How does the involvement of service users work out in	No direct user participation except

	practice ;	complaints and advisory board participation in inspection policy
5. How voices are embedded	How is the service user's voice embedded directly or indirectly? all service users systematically?	Via complaints and advisory board
6. Recruitment of users	How do you recruit service users? e.g. internal information or external sources and how is this done?	No recruitment system of service users. The 5 patients - advisory board stakeholders are selected in a way that that the members of the Advisory Board represent a substantial part of the complainants
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	No active selection of users
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	No
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	No individuals or groups asked for their opinion except the stakeholders in the Advisory board.
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Complaints are handled and analysed The main issues are in general presented to Advisory board and presented as priorities for the next year. No privacy issues arise from that working method.
11. When	When are the users they being asked? Do they know in advance, after having experienced care;	During complaint handling process.
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	The training of the staff is a general training to talk to of the complainants
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g.	-

	communication methods, payment?	
14. Best practices	What are best practices of user participation ?	The analyses of complaints handling is one of the best practices of Portugal
15. Report	How are the results reported ?	Twice a year reports are published and presented to the Advisory board analysing the serious changes in the complaints that occurred in the past 6 month
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	Publication on the website and small publication to providers
17. Control mechanism	Is there an inspection and control mechanism on the process of user participation?	Advisory board and complaints are the control mechanism to see whether the right issues are tackled by the inspectorate
18. Follow up	How is follow up organised ? best practices?	No specific follow up on user feed except in very serious cases
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	The complaints handling is the link to the users of health services.
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	The effect of this system is limited but effective in the way that signal from society are monitored, the system supports priorities and organises some feedback. The system misses the direct one to one information form service users almost completely. But as far as known now there is no evidence that additional user information will bring improvement for the users of the system and regarding the quality of the healthcare. Nevertheless a try-out might be interesting to see what difference this makes for the users.



DRIVING
IMPROVEMENT
THROUGH
INDEPENDENT AND
OBJECTIVE REVIEW

9. Wales

Answers: Mandy Collins

Questions about existing practices:		Answers
1. Existing practices of user participation	Is the above mentioned (existing practices) information correct and complete?	Yes, Mandy Collins has added some information
2. How often	How often are users involved?	Always; all reviews have a a component dedicated to user participation. Not only patients but also relatives and cares are involved in the inspection process.

		<p>The involvement of relatives and carers can be done also afterwards to verify or complement the information from patients / clients.</p> <p>In practice relatives are often more open and informative about the institution.</p> <p>Patients are usually less likely to complain about the health institution; they have often apologetically comments about the institution and the healthcare staff.</p>
3. How many	<p>How many users are involved in user participation and being asked to give an opinion?</p> <p>Are all users of health care involved?</p>	<p>Everyone is invited to speak to the inspectorate, but if there are only a few coming forward, the inspectorate will at least speak to 6 patients on each ward (healthcare institution).</p>
4. In practice	<p>How does the involvement of service users work out in practice ;</p>	<p>Inspections are sometimes announced but mostly unannounced. In both cases signs are set up in the area that the inspectorate is taking place or will take place that day and or the next days.</p> <p>In case of announced inspections the users are alerted to the inspection:</p> <ul style="list-style-type: none"> by posters, by telephone, by naming the website <p>sending prepared questionnaires</p>
5. How voices are embedded	<p>How is the service user's voice embedded directly or indirectly? all service users systematically?</p>	<p>The users are always being asked about their experience:</p> <ul style="list-style-type: none"> Mostly directly, one to one conversation; Sometimes in groups such as patients focus groups; Sometimes using network organisations ; Sometimes using peer and lay reviews; Sometime indirectly by using the patients organisation, but if an organisation is used there is also always direct contact with patients;
6. Recruitment of users	<p>How do you recruit service users?</p> <p>e.g. internal information or external sources and how is this</p>	<p>The users are recruited:</p> <ul style="list-style-type: none"> By advertisement in the local newspaper (did not give a true representation of the patients) By invitation (phone/posters) Using risk management; Link with complaints; By involving third sector charities and local patient

	done?	support groups The recruitment of users could be improved by better representation of the users. More research on a better representation of the various groups of patients.
7. Selection of users	How is the selection between users being made (between groups ; ad random, intellectual capacity, active in intermediary organisations)?	The selection is not ad random but always risk based.
8. Systematically prepared	Is the participation systematically prepared (questions prepared in advance) or ad random (free style and open questions)	The questions are always systematically prepared and in addition free style and open questions
9. How being asked	How are the users being asked for their opinion: in groups or individual ; oral or written;	mostly oral.
10. Privacy	Is information kept secret or used to improve services? kept secret to whom, how long, when and under what conditions?	Privacy is no problem. The inspection reports are as much as possible kept on a system level. If individual cases are mentioned the names are anonymized. If individual cases are mentioned things are usually escalated previously and privacy is therefore not anymore a problem as the institution knows that there is discussion about inadequate care.
11. When	When are the users they being asked? Do they know in advance, after	Mostly when they are in the institution. In the past sometimes people were asked afterward to tell about their case but there was not a lot of response on this. Therefore it was stopped.

	having experienced care;	
12. Training interviewers	Are interviewer's being trained in advance? how? What type of induction is offered to (professional or lay) service users /reviewers/ interviewers?	Yes all interviewers are trained: Peer interviewers / lay people/ inspectors The training is on different levels. The idea is to have a personal approach in training
13. Challenges for Training	What type of challenges do you face in offering training to lay reviewers e.g. communication methods, payment?	Challenges for better training are: Develop a plan and find the gaps in the training ; Better approach to vulnerable people (learn how to interview vulnerable people and special groups).
14. Best practices	What are best practices of user participation ?	A best practice is the way we work with children and people with learning disabilities in user participation. We completely changed the earlier approach. Send much more time to talk to individuals, use indirect questions instead of direct questions (what do you enjoy here and what do you enjoy less, instead of are you well treated and are you satisfied with the care.
15. Report	How are the results reported ?	The results are publicly reported Every inspection has a separate report. There are also reports made in an easy to read for special groups ; the reporting is preferably adapted to the group it is meant for.
16. Feed back	How is feedback organised to the institution? And to the supervisory organisation ? And to the public?	Feedback is organised by sending the report to the institution (and by putting the report on the website) There is no feedback to individual people except for particular issues. The reports are sent to the institution for factual accuracy before putting them on the website
17. Control mechanism	Is there an inspection and	The control mechanism is done by NHS (structural follow up) except when significant errors are being

	control mechanism on the process of user participation?	found. In that last case the inspectorate is doing the follow up. The institution has to produce a plan to improve within about 6 weeks
18. Follow up	How is follow up organised? best practices?	A best practice of follow up was as it was done in the past. NHS has had a structural change.
19. Link to complaints	Is there a link with the complaints system and legal complaints? How is that organised? Why not?	There is a link to complaints in the risk approach that is used to select users and institutions.
20. Effect	does it help to use the opinion of service users and to have a policy requirement to engage with services users? What kind of results are reported? What kind of approach gives best results? What kind of approach gives doubtful or poor results?	Yes it absolutely help a lot in improvement of the functioning of healthcare institutions and improving the care. It is difficult to measure improvement of care by using user participation instruments but signals all are pointing in this direction. If you ask people for examples of improvement this is probably easier to find in long term care but also in independent hospitals improvement of care as a result of better communication with patients can easily be found. No indication of poor results except for: Asking people afterwards to react. About the care they received. This gave not a high response Asking in newspapers for response. This gave a not representative response.