

Same description, different values. How service users and providers define patient and public involvement in health care

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Abstract

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Background Patient and public involvement in health care is important, but the existing definitions of the concept do not integrate the stakeholders' own perceptions.

Objective To investigate and compare service users' and service providers' own definitions of patient and public involvement and their implications.

Design, setting and participants Qualitative study with mainly individual in-depth semi-structured interviews conducted between June 2007 and June 2009. Data were analysed using a grounded theory approach.

Results A total of 20 patients, 13 public representatives and 44 health service providers/managers in both somatic and mental health care were interviewed. A common definition of patient and public involvement emerged: It is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making. Nevertheless, users and providers assigned different values to the core aspects: Respect was imperative for service users and implied for providers, dialogue was a way to gain respect for service users and to achieve good outcome for providers, and both worried that the other party wanted to make sole decisions.

Conclusions Users and providers need to consider that although they have a common definition of involvement in health care, they assign different values to its aspects. Increasing and improving patient and public involvement therefore requires knowledge on and dialogue between the parties about these differences.

Introduction

Patient and public involvement is viewed as a democratic privilege and is highly emphasized in the western world.^{1,2} In the Scandinavian welfare states and in some other countries, patient and public involvement is regulated by laws and guidelines, making it a population's right. These regulations typically encompass involvement both on a system level and on an individual level and instruct health-care providers to implement and maintain patient and public involvement on both levels.

Although there are multiple well-funded definitions of public and patient involvement³⁻⁹, several have argued that there exists no definition of patient and public involvement, which is agreed upon, and that the concept is insufficiently articulated and understood.^{1,10-13} Some have linked user involvement to consumerism,¹⁴ while others have discussed patients' choice and care linked to patients' different roles in society.¹⁵ Involvement has been described as ways for the public to influence the evaluation, development, organization and delivery of health services,³ as public involvement in health service and policy decisions,⁴ as an inclusive dialogue between stakeholders,⁵ as patients drawing on their experience,^{4,12} as the patients' right to be involved in decisions that affect them^{6,7} and as a change of the patients' role from passive recipients to active participants.³

Studies investigating public and patient involvement in practice have found that providers and users hold different perspectives and values regarding public and patient involvement.^{16,17} Some have found that providers and users understand and practice involvement in different ways and that involvement does not necessarily lead to improved quality of services.¹⁸ It would be reasonable to think that discrepancies in understanding could hinder co-operation between users and providers when working with involvement. This could limit efficient communication and collaboration between the different stakeholders, patients, public representatives, health personnel and

management.^{1,7,12,19} A lack of shared understanding of what patient and public involvement is could thus hinder the work towards increasing and improving involvement in health care.

Previous studies have investigated how health personnel perceive and experience patient and public involvement,²⁰⁻²² and some have investigated the patients' view.²³⁻²⁶ Smaller studies have investigated and compared how patients and health personnel experience the involvement process in specific health-care settings,^{16,17} but none have undertaken a more extensive comparison and synthesis of service users' and providers' own perceptions. Such a synthesis would be useful in trying to understand what might hinder co-operation between users and providers in working with involvement, on both the system and individual level. The aim of this study was therefore to investigate and compare service users' and service providers' own definitions of patient and public involvement and its implications.

Methods

This was a qualitative study based on semi-structured in-depth interviews with service users and providers. The recruitment and data collection took place at two different points of time, from June 2007 to September 2008 and from January to June 2009. The regional committee for medical ethics in Central Norway approved of the study and it was registered with the Norwegian Data Inspectorate.

Setting

The first data collection took place at four hospital trusts in Central Norway. Each trust included at least two hospitals with somatic and psychiatric units. The second collection took place at a mental health hospital in Central Norway offering both inpatient and outpatient treatment. In Norway, involvement is at present mandatory in individual treatment and in hospital trusts.

Participants

We recruited patients, public representatives, health personnel and hospital managers. Some had and some had not experience in patient and public involvement. Public representatives were current or former patients or next of kin who participated in operational committees at the hospital. Through the analysis, we placed the participants in two groups: We considered patients and public representatives as service users, and health personnel and hospital managers as service providers. All but one of the participants signed a consent form before taking part in the study as one manager waived signing the consent form arguing it was a part of the job to participate. We decided not to exclude this participant.

Recruitment

The sampling strategy was theoretical, and informants were recruited continuously alongside the analysis to ensure variation. In the first data collection, a letter was sent to all 12 departments in the hospital trusts in the region, asking whether they practised patient and public involvement and requesting contact details for health personnel and managers who had taken an active part in this work. Based on these replies, informants were selected across discipline, department, hospital and type of involvement. We recruited the first public representatives through their associated hospital units. Subsequent representatives were recruited through information from representatives participating in initial interviews.

The second data collection took place in a community mental health hospital. To recruit patients, invitations were mailed to a random sample of 60 patients. Two additional patients recruited themselves by responding to a note posted in the inpatient unit. In addition, public representatives associated with the hospital were recruited. Sampling of patients was carried out to ensure variation in gender, age, diagnosis and whether the patients had experience from in- or outpatient treatment. Health service providers

and managers in leading positions were initially selected by the researcher, and those participating in the interviews suggested subsequent informants. Sampling of health service providers was carried out to ensure variety in gender, age, unit representation, experience and health service provider group.

Data collection

We made interview guides for service users and providers, respectively, before starting to interview and evaluated and slightly modified these during the process. The modification of the interview guides did not influence the material generated in this study. To obtain data on experience, attitudes and expectations towards patient and public involvement, the main question was how the participants understood, perceived and defined patient and public involvement.

The first and second authors carried out the interviews, which were conducted at the hospitals, in the interviewer's office or in the patients' homes. Sixty-three of the interviews were individual, four interviews were with two participants, and two interviews were with three participants. The interviews lasted from 20 to 90 min, and there were no differences between the lengths of the interviews with users compared to providers. All interviews were tape-recorded and transcribed verbatim. We edited the Norwegian dialect into formal written Norwegian and deleted all redundant words and pauses. The first author translated the quotes from the transcripts used in the article, and the second and last authors controlled the translation.

Analysis

We started analysing the interviews from the mental health hospital. A project group consisting of all the authors undertook the analysis using a grounded theory approach.²⁷ Sampling was thus carried out until theoretical saturation; the recruitment was stopped when no new topics emerged in new interviews. The authors

coded the first transcripts by hand, and each author coded some interviews alone and some together with the group. The group discussed and modified the codes until deciding upon a list of basic codes. The first author subsequently coded all interviews using NVivo 8.0 (QSR International, Southport, UK). The project group refined these categories by continuous discussions and confirmed them by the method of constant comparison with the transcripts. This gave a list of preliminary analytic categories from interviews with service users and providers (Table 1).

At this stage of analysis, it became evident that both service users and providers described patient and public involvement as constituted by three core aspects. This formed a common definition of patient and public involvement. In addition, it became clear that service users and providers assigned different values to the core aspects of this definition. The next stage of the analysis was therefore to compare these and to describe similarities and differences. Subsequently, a summary of two perspectives on a

definition of patient and public involvement emerged. To test the validity of the results from the mental health hospital, we subsequently analysed the interviews with the public representatives, health personnel and managers from the four hospital trusts. This part of the analysis was conducted by the first author who coded the transcripts in accordance with the basic code list, compared codes with the transcripts and searched for potential discrepancies between the initial findings and the second set of interviews. The analysis was inspected and approved by all authors. This final step confirmed the emerging results. The quotes used in this article are representative for the material and are chosen to illustrate and complement the description of the findings. The quotes are identified with type of participant (U for user and P for provider), ID number, gender and type of health care.

Results

The first sample consisted of 13 public representatives and 19 health personnel and managers. The second sample consisted of 17 patients, three public representatives and 25 health personnel and managers. A total of 77 service users and providers thus participated: 33 patients and public representatives and 44 health service providers and managers (Table 2). Sixteen of the users had experience being public representatives. The providers worked in somatic or mental health services and had various educations, and 21 of them had managerial responsibility.

The main result from this study was a common definition of patient and public involvement, consisting of three core aspects. The aspects were described by both service users and providers and constitute therefore a common definition based on the participants' own descriptions. However, service users and providers assigned different values to these core aspects with different emphasis, views and concerns. The common definition and the differences between users' and providers' perspectives are described in the following.

Table 1 Analytic categories from interviews

Service users
Being heard and taken seriously
Dialogue
Taking part in the decisions
Not being overruled
Voicing needs and wishes
Human worth and respect
Receiving explanations and information
Contributing to treatment and controlling your own situation
Being exempt from decisions when needed
Being trusted and believed in
Service providers
Providing knowledge and information
A part of the treatment
A given/self-evident/implied
The relationship between health personnel and user
The users decide or do not want to decide
Users' influence on the treatment
The users' rights
Coercion excludes participation
Users have to choose between professionally sound options
Respecting, recognizing and taking the user seriously

Table 2 Participants

Type of participant	Total (<i>N</i> = 77)	Data collection 1 (<i>N</i> = 32)	Data collection 2 (<i>N</i> = 45)	Female (<i>N</i> = 47)	Mental health (<i>N</i> = 58)
Personnel	23	8	15	18	19
Managers	21	11	10	11	14
Patients	17	–	17	11	17
Public representatives	16	13	3	7	8

The core aspects: respect, dialogue and shared decision making

The core aspects of patient and public involvement described by both service users and providers were respect, dialogue and shared decision making.

Respect

The respect aspect was described as fundamental for patient and public involvement and included mutual respect and acknowledgement between service users and providers. This aspect was described as service providers ‘seeing’ and ‘hearing’ the user, viewing the user as a human being and equal party and taking the service user seriously.

Users highlighted the importance of being listened to and taken seriously:

(...) where both parties feel respected and not overruled. Both must be allowed to say what they think and feel and... (...) To walk the road together... Not one person having one opinion and the other something else.

U12 Female, Patient mental health

That was the very first thing I said when I was asked to be a public representative. They have to listen to us. [...] We are supposed to be in an advisory committee for the management and the hospital board. And the day I feel they aren't listening to us I will walk away. [...] I won't be bothered to sit there and talk nonsense and not being listened to.

U21 Male, Representative somatic health

Mental health personnel pointed to the power imbalance between users and providers and underlined the importance of respect because of this imbalance:

It's all about respect... to highlight equality and the values you have. Why do we have public and patient involvement? It is because the power is uneven in a situation which is all about the patients' rights being respected. Completely.

P31 Female, Manager mental health

Dialogue

The second aspect – dialogue – was described as bilateral exchange between different proprietors of knowledge – the service user and provider, respectively.

Users highlighted the importance of expressing both experiences and knowledge about their illness to the therapist, as this user describes:

Like the way we are talking now [*in the interview*] and you are asking me about my experience. What I think and how I feel, and what I need... what I could change.

U11 Male, Patient mental health

The providers underlined the necessity of providing knowledge to the patients about illness and treatment:

When I'm alone with a patient I think about participation as being a part of your own treatment... knowing as much as possible... having as much knowledge as possible about your own disease.

P24 Female, Physician

Providers also described dialogue as an interaction between user and provider directed towards enhancing motivation, reaching shared understanding and establishing treatment goals:

It is an interaction between you and me. And I can't cure you just like that with a pill... it's about shared understanding and motivation and whether you agree with me or not. And whether you want to try what I think we ought to try. So it's a lot of interaction and dialogue that leads somewhere.

P42 Female, Psychologist

The dialogue and exchange of knowledge included information about management of the health service on the system level, i.e. economic and operational aspects, information about diagnosis, treatment options and patients' wishes and needs on the individual level.

Shared decision making

Shared decision making was described as a process where service users and providers made decisions about individual treatment or health-care management together. These decisions were based on reaching a shared understanding of the situation.

Patients described the decision-making process as a joint effort necessary to reach good results:

If patient involvement has as wide a definition as I think it has... it would mean... to have a shared responsibility... and sufficient self-knowledge to be able to reach a goal and a result... that both parties... it's not like the one is working by the oars while the other is sitting in the bow with both feet on the rail looking up in the sky.

U11 Male, Patient mental health

To providers, shared decision making was paramount to achieve good outcomes, as described by this provider:

We can do a lot of great work which we find jolly good, but if it isn't working for the patients it's no good. And it's important that they are being heard and have a chance to influence things... a genuine possibility... not only on paper. I think that's crucial.

P28, Female, Administrative employee mental health

While describing shared decision making as a core aspect of patient and public involvement, both service users and providers considered solitary decisions made by either party as the opposite of involvement. The participants highlighted, nevertheless, the necessity of adjusting the decision-making process to certain limitations, e.g. the characteristics of the decision, economic and organizational bounds, a patient's degree of illness and the patient's wishes. Shared decision making was thus described as a cardinal goal that still had to be handled flexibly according to several factors.

Based on the three core aspects described so far, the common definition of patient and public involvement could be worded like this: Patient and public involvement is founded on mutual respect and is carried out through dialogue aiming to achieve shared decision making.

Different perspectives on the core aspects

While service users and providers described the same core aspects of patient and public involvement, they simultaneously assigned different values to them.

Respect: imperative to service users, implied to providers

There was considerable difference in the emphasis service users and providers put on the aspect of respect. Service users highly emphasized respect and its expressions as an important objective in its own right:

A fundamental thing must be to be heard, seen, and valued. With that done I guess there are a million possible approaches. But that's the essential thing.

U13 Female, Patient mental health

Service providers described on the other hand respect as an implied and self-evident value in all treatment practice and management of health services. Health personnel described respect as an inherent part of their work:

In my opinion the professionalism and the fundamental respect... the attitude... it's in our blood.

P24 Female, Psychiatrist

However, while providers described respect as an inherent part of their work, service users did not consider mutual respect between service users and providers as self-evident, either in previous or prospective interactions. User representatives described how hard they found it to gain genuine influence:

So we have... a recurring question... Why are we present? And it's not easy to grasp. Why aren't we asked directly in discussions... about our opinions? We have to be on the offensive instead. And that's annoying, even though they are nice people.

You have to cling to their backs and say; Listen to me! Listen to me! They don't ask me what I think.

U7 Male, Representative, somatic health

Service users described respect as such a fundamental aspect that it was a prerequisite for all interaction during the involvement process. They also described the possibility of gaining respect through the other two core aspects: through dialogue and shared decision making. Respect was thus a fundament for dialogue and shared decision making, and the latter two were means to increase the feeling of worth and respect.

Dialogue: a way to gain respect for service users and to achieve good outcome for providers

Service users and providers also had different views on the most important gain from dialogue. Users put most emphasis on gaining respect and acknowledgement from being an equal party, as described previously. Patients described the importance of being respected and acknowledged during periods of strong symptoms:

To feel that you have a say in a situation where you aren't quite capable of taking care of yourself is a signal that helps in strengthening the psyche. Nobody is saying; 'Oh, you're so ill, we aren't listening to you.' To be allowed to say tiny things about how you feel and what you need is very important.

U13 Female, Patient mental health

Service providers described on the other hand the dialogue as a means to exchange information and knowledge to make sound decisions, which included the service users' perspective, either on a system level or individually. Providers described thus that dialogue led to sound decisions that, according to this manager, led to better management of the health services:

Well... the medical ward is run to treat the patients as good and cost effective as possible. And every advice and any input on this are positive.

P16 Male, Clinical manager

Health personnel also described that dialogue led to better treatment results:

The dialogue and the motivation itself are in the treatment... or a very big part of the treatment. It's not just about getting a pill... the interaction is a huge part of the treatment...

P42 Female, Psychologist

The main outcome from interaction and dialogue was thus perceived and described differently from users and providers, users gaining a sense of worth and respect from dialogue and providers gaining better outcomes on treatment or management.

Shared decision making: concerned about the other party wanting to make sole decisions

Service users expressed a general concern about being 'overruled' by providers, wondering whether decisions would be made without their consent. They perceived patient and public involvement as a possibility to genuinely influence the decision-making process and thereby avoid being pacified or controlled. This concern was expressed this way by one of the users:

To be able to tell what you want. That your wishes are being heard. That the providers don't make a plan that pacifies you...Pacified... I feel it's to be managed, to be overruled. Some might be happy with that, but I like to participate actively.

U9 Female, Patient mental health

Service providers expressed on the other hand concerns about whether patient and public involvement implied full service user governance and that the users were supposed to make all the decisions. Full user governance was described as leading to derogation of the providers' responsibility in both treatment and management decisions, resulting in poorer outcomes. Providers expressed a need for drawing limits to users' making the decisions:

There is a limit... where we have to avoid turning participation into... it cannot be weakness from the treatment team to not handle the situation. There is a crossing point where you no longer take responsibility for the patient. And if this is a patient who isn't capable to take care of himself, but chooses... and this crossing point varies from patient to patient... and from situation to situation.

P33 Male, Nurse and manager, mental health

These concerns were voiced far less, and even contradicted, by those who had extensive expe-

riences with patient and public involvement. One of the health-care managers had changed opinion about patient and public involvement during his work:

We were worried in the beginning... before we learnt differently... that these representatives should be persons who demanded things... their rights and needs... and wanted everything perfect on behalf of the patients. And that they wouldn't realize the practical problems with running a hospital, maintaining high medical quality, and that this is quite demanding. But we experienced that the public representatives [...] were clever, sensible persons who were able to see the political and economical reality... who were thoughtful and who cared about the ranking of priorities... that we have to say no to some things. And they understood the limits we had to manage within.

P6 Male, Clinical manager, somatic health

Service users and providers thus expressed the same concerns on whether the other party wants to make all the decisions without reaching a shared understanding. Such concerns were less prominent in users and providers who had some experience with involvement, either in individual treatment or on a system level.

Discussion

We found a definition of patient and public involvement that was common for both users and providers. This is founded on mutual respect, carried out through dialogue aiming at achieving shared decision making. Nevertheless, users and providers assigned different priorities to the core aspects. For the former, respect was imperative, and for the latter, dialogue was the way to provide this, and both were concerned about the desire of the other party to make sole decisions.

Strengths and limitations

The size of the sample, with the inclusion of patients, public representatives, health personnel and managers from both mental and somatic health services, is a strength to this study. A possible limitation is the self-recruitment of patients, which might reduce the variation. However, it was ensured that the patients varied

regarding gender, age, diagnosis and treatment experience. Furthermore, they were considered to represent a varied sample based on the clinical experience of the authors. The sample might nevertheless have involved many persons who took an interest in the phenomenon and this might have influenced the results. As it could be expected that those volunteering in such a study might be positive towards patient and public involvement, it was ensured that persons voicing a more critical view on the proposed advantages of participation were recruited.

The interviews were undertaken by two researchers, and the analysis was conducted by a research group. To ensure that different perspectives were present, the author group consisted of persons with different professional backgrounds from psychology, sociology, health sciences and medicine and with different practical experience from research, medicine and mental health care. Furthermore, the fourth author is a public representative who has worked with patient and public involvement for several years. Although the authors have an influence upon the findings, the broad composition of the research group and the thorough analytic process helped ensure the reliability of the findings. Testing the emerging findings constantly during the analysis process strengthened the validity.

A new definition of patient and public involvement

The definition of patient and public involvement found in this study was made up of three core aspects: respect, dialogue and shared decision making. These aspects have been identified individually previously,^{6,24,28,29} but not combined to form a definition of patient and public involvement. Previous studies investigating separately the patients' and health personnel's perceptions of patient and public involvement have described involvement as patients contributing to decision making,²⁴ as collaboration between patients and health service provider,²³ and have highlighted the importance of a mutually respectful and equal relationship.^{20,30,31} A few small studies have compared

both views and have described involvement as partnership between the parties³² and as activating and providing knowledge to patients.¹⁶ We have expanded these fragmentary definitions to include respect as fundamental and dialogue as the necessary instrument to achieve shared decision making.

Another interesting finding was that the definition encompassed both the individual level and the system level. The definition thus goes beyond the usual division of patient and public involvement.

Understating the fundament of respect

The results also highlight important differences in how service users and providers assign values to the core aspects and hence the risk of talking at cross purpose about patient and public involvement. Although some have underlined such differences, the descriptions have been only fragmentary. The service users in this study emphasized respect as fundamental for patient and public involvement, while providers described this as an inherent value. These findings confirm how important the aspect of respect is to patients, its essential role in building a good relationship between patients and providers and respectful communication and interaction being fundamental in user involvement. Nevertheless, this study also showed the existence of power inequalities between users and providers and that patients did not view equality as a given. Possibly, service providers described respect as implied because of a sincere perception that the user was an equal partner; hence, they might possess a respectful attitude without showing it when interacting with users. Thus, providers have to be aware not only of the difference between the views but also the need to demonstrate more clearly their underlying respect for the users. Our results confirm that service users' and providers' attitudes and behaviour influence each other. Patients are known to feel more involved in the decision-making process and are more satisfied when health personnel invite them to discuss reasons for diagnostic examinations.³³ Patients' styles of participation during consul-

tations also influence the extent and type of information physicians provide, and health personnel with a respectful attitude towards patients provide more information and are more positive, thereby improving communication.³⁴

Who is supposed to make the decisions?

Both service users and providers expressed concerns about the decision-making process; the former were worried about being overruled, while the latter worried that users should decide too much. This displays uncertainty and confusion about how patient and public involvement is supposed to affect the process. Users viewed involvement as a possibility of partaking in decisions on their own treatment as patients and on hospital management as user representatives. Nevertheless, users emphasized that making all decisions on their own is contrary to involvement and that decisions have to be made jointly to reach common ground. Service providers warned against any final decision being made by the user but agreed that there should be collaboration with users. Others have emphasized a partnership between patients and health personnel,^{8,35} the importance of adjusting the decision-making process,³⁶ variations in service users' preferred type of involvement³⁷ and have warned against users being the sole decision-maker.³⁸ Service providers were concerned about the possibility of users being responsible for a final decision, but we found that this was contradicted by the users' statements. Such concerns might nevertheless lead to reluctance towards involvement and might explain some of the difficulties in implementing and maintaining patient and public involvement in health care.

Another important aspect of decision making is that providers are unable to leave some decisions solely to the users and are held responsible for the decisions made. Taking into account the providers' professional and legal obligation to make sound decisions, either on patients' treatment or on service priorities, adds additional explanation to providers' expectant and uncertain attitudes towards the decision-making process. The difference between providers unfavourable

miliar with involvement and more experienced providers indicates, however, that experience with patient and public involvement reduces some of the concerns regarding decision making. Addressing the users' and providers' expected responsibilities and roles while working with patient and public involvement will thus be essential.

Conclusion and implication for clinical practice

A common definition of patient and public involvement could be vital when working with patient and public involvement in health care. The different values service users and providers assigned to the core aspects of this definition need, however, to be highlighted. Describing the same definition while assigning different values to its core aspects means that service users and providers are at great risk of talking at cross purposes about patient and public involvement. This could be an important obstacle in implementing patient and public involvement, and hence, discussing the core aspects and different perspectives is essential. We believe that our definition of patient and public involvement and elucidating the different perspectives on it could contribute to highlighting the fundamental topics the stakeholders need to address.

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Conflicts of interest

No conflicts of interest have been declared. HG is a member of the board of one of the hospital trusts where some of the interviews took place.

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