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Service user involvement in mental health care: an evolutionary concept analysis

Samantha L. Millar PhD MSc BSc CPsychol AFBPsS,* Mary Chambers DPhil DN BEd (Hons) RNT† and Melanie Giles PhD BSc CPsychol FHEA‡

*Research Fellow, UKCRC Centre of Excellence for Public Health, Institute of Clinical Sciences, Queen's University Belfast, Royal Victoria Hospital, Belfast, †Professor of Mental Health Nursing, Faculty of Health and Social Care Sciences, St George's University of London and Kingston University, London and ‡Professor of Psychology, Head of School of Psychology, University of Ulster, Coleraine, County Londonderry, UK

Correspondence
Samantha L. Millar PhD MSc BSc CPsychol AFBPsS
Research Fellow
UKCRC Centre of Excellence for Public Health
Institute of Clinical Sciences
Queen's University Belfast
Royal Victoria Hospital
Grosvenor Road
Belfast BT12 6BA
UK
E-mail: s.millar@qub.ac.uk

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Abstract

Background The concept of service user involvement is an evolving concept in the mental health-care literature.

Objective This study sought to explore and analyse the concept of service user involvement as used in within the field of mental health care.

Methodological approach An evolutionary concept analysis was conducted using a literature-based sample extracted from an electronic database search. One hundred and thirty-four papers met the inclusion criteria and were analysed to discover key attributes, antecedents and consequences of service user involvement and to produce a definition of the concept.

Findings Five key attributes of service user involvement within the context of mental health care were identified: a person-centred approach, informed decision making, advocacy, obtaining service user views and feedback and working in partnership.

Discussion and conclusions Clarity of the attributes and definition of the concept of service user involvement aims to promote understanding of the concept among key stakeholders including mental health professionals, service users and community and voluntary organizations. The findings of the research have utility in the areas of theory and policy development, research on service user involvement in mental health care and service user involvement in mental health practice. Directions for further research regarding the concept are identified.

Background

The history of service user involvement in mental health spans at least five decades. Opportunities for service user involvement have been created by three main factors of de-institutionalization, questioning of the legitimacy of biomedical theory and practice of consumerism.[1] The contemporary interest in involving service users in their own care and treatment derives from the philosophical and political critiques of traditional psychiatry that emerged at the end of the 1960s and the beginning of the 1970s in Europe, the USA and Canada.[2,3]

These movements were a response of anger against the biomedical model, psychiatry and institutions. A background of social change and government mental health policy initiatives has provided the setting in which the concept of service user involvement has arisen. Mental health care has undergone some profound changes over the years which have made it possible for the service user involvement agenda to emerge. Service user involvement has now become a key policy action which informs and underpins health and social services.[4]

The term service user involvement has become popular in the mental health field. Considering this, the authors of this study felt that an analysis of the concept using concept analysis methodology would be a useful addition to the existing literature.[5–8] The guiding framework of concept evaluation proposed by Morse, Mitcham, Hupcey and Cerdas[9] was applied during an exploratory literature review to confirm suitability for in-depth concept analysis (see Table 1). According to Morse,[10] before undertaking a concept analysis the researcher should ask 1) Is the concept well-defined? 2) Are the attributes identified? 3) Are the preconditions (antecedents) and outcomes described and demonstrated? 4) Are the conceptual boundaries delineated? If, after applying these criteria, evidence emerges that the concept is immature, then it is recommended that further research is required to clarify the concept. After application of these criteria to the concept of service user involvement in mental health care, it became clear that user involvement while a frequently used concept, did not meet the criteria for maturity. While other authors have provided definitions of the concept, the defining attributes have not been considered in detail.[6,7,11–15] Despite the growing literature, a disparity between service user involvement and associated terms is evident.[16] Given the above, service user involvement was deemed an appropriate term for further analysis using concept analysis methodology. The aim of this study was to describe the findings of an evolutionary concept analysis of the term service user involvement in mental health care.

Table 1 Criteria for concept analysis (adapted from Morse *et al.*[9])

	Indices of concept maturity	
Criteria	Emerging	Mature
1. Concept definition	Lacks clarity Competing definitions	Clear Consensual
2. Attributes	Not identified	Clearly described
3. Antecedents and outcomes	Not identified	Described fully
4. Boundaries	Not known	Delineated

Methodological approach

Concept analysis synthesises information with the aim of clarifying and defining a concept, aiding communication and providing clarity of language. Concept analysis is a rigorous process that enhances the knowledge base of the area under study and promotes descriptive understanding of the concept among colleagues. The evolutionary approach of Rodgers[17–21] was chosen as the most appropriate method for the analysis. The seven steps of concept analysis outlined by Rodgers[17] were followed:

1. Identify the concept of interest and surrogate terms
2. Identify the setting and sample for data collection
3. Collect data to identify the attributes and to identify references, antecedents and consequences
4. Analyse data to identify the attributes and to identify references, antecedents and consequences
5. Conduct interdisciplinary and temporal comparisons.
6. Identify an exemplar of the concept, if appropriate.
7. Identify implications for further development of the concept.

Electronic database search strategy

The electronic databases EBM Reviews (Cochrane Reviews, ACP Journal Club, DARE,

CCTR, HTA, NHSSEED), Ovid Medline, PsycINFO and the British Nursing Index were searched for the term 'service user involvement'. Initially, the term was not mapped to a subject heading; however, this produced too large volume of papers unrelated to service user involvement in mental health care so as a result, the term was mapped to the standard medical subject headings (MeSH) term. Identical searches were used for all databases, and duplicate references were removed. Studies were included if they were published between 1st January 1970 and 4th November 2010; related to adults aged 18–65 years and were published in the English language. Although carer involvement is also an important term in mental health care, it was considered to be a separate term, requiring a separate concept analysis and so was not included in the search strategy.

The initial search strategy yielded 851 citations. This was reduced to 642 citations when duplicates were removed, limited to adults aged 18–65 and papers published in the English language. Abstracts of all 642 papers were examined and the relevance of the paper to mental health care was assessed. The concept of service user involvement is used in many areas throughout health care, and citations were found in cancer care, maternity care, care of people with a learning disability, care of older people and rehabilitation, and technology development, in addition to mental health care. It was immediately clear from reading the titles and abstracts of some articles that they concerned an area outside of mental health care and were therefore not relevant to the aim of the research. Following this assessment, 194 citations were retained. The full text of each of these articles was obtained, and each paper was read once to consider the general subject of the work and its relevance, and as a result some additional papers were excluded from the analysis. Reasons for non-relevance included not being in the specific area of mental health care and having little or no content relating to service user involvement. Papers were included if they discussed service user involvement explicitly and in depth, rather than casually referencing the term.

Data analysis

The content of each paper was read once initially. If the paper was deemed suitable for inclusion in the concept analysis, the details of the paper were entered into a table which contained information on the authors of the paper, date of publication, topic, methodology used, country of origin and discipline. This aided the classification of references and data management and retrieval. Following the initial reading, each paper was assigned a category according to the main area which the paper related to. As categories began to unfold the papers were sorted accordingly. Each paper was then read a second time to identify the attributes, antecedents and consequences. Key information was marked in highlighter pen, and notes were made to describe the subject and utility of the paper. Papers were read numerous times as the researcher often returned to the raw data to gain additional information or depth on a point as the concept analysis progressed. No citation was read less than three times. Notes were made in the margins of each paper which included ideas for attribute names when attributes were identified in the papers. Lists were made of key attributes, antecedents and consequences, and names, labels and descriptions written, developed and clarified as the concept analysis progressed.

Findings and discussion

Disciplinary and temporal contexts

The retained citations (n = 134) were published in a variety of disciplines, a majority (27) originated from nursing (20.1%), but were also from psychiatry (15, 11.2%), written by a service user or a representative of a service user organization (15, 11.2%), social work (15, 11.2%), psychology (13, 9.7%), multidisciplinary (12, 8.9%), sociology (7, 5.2%) and the National Health Service (6, 5.2%). Just under half of the papers (5) with multidisciplinary, authors had service user input. Eighteen papers (13.4%) were categorized as other disciplines,

such as primary care (4), health services studies (4) and health policy (2). The majority of the papers came from the United Kingdom (112, 83.6%), with 6 (5.2%) from the USA and the remainder (17) from other countries. Sixty-five (48.5%) papers were research studies, 49 (36.5%) were discussion papers, 9 (6.7%) were literature reviews, 4 (3%) editorials, 2 (1.5%) books and 5 (3.8%) other types of papers. One paper (0.7%) was published in the 1980s, 25 (18.7%) in the 1990s and 108 (80.6%) from the year 2000 onwards.

The concept of service user involvement was used in policy and strategy, in individual assessment and care management, in service development, planning, delivery and evaluation, in the education, training and recruitment of mental health professionals and at all stages in the conduct of research. The reviewed citations provided a rich picture of the concept of service user involvement in mental health from differing disciplines, perspectives and models. Almost 15% of the papers were written by service users or had service user input into the writing, providing a useful portrayal of the views of service users as well as the views of mental health professionals.

The analysis considered a 40-year time period of data regarding service user involvement in mental health care, demonstrating the growing popularity of the concept of service user involvement. As more than 80% of the retained literature sample was published since the year 2000, this would suggest that the concept of service user involvement in mental health is still an emerging concept and one which is growing in use and popularity. This finding also provides support for the usefulness of further clarification of the concept. No papers were identified which had previously completed a concept analysis of the term service user involvement in mental health care in any discipline.

Key attributes of the concept of service user involvement

The core aim of concept analysis research is to identify the defining attributes of the concept.[22] Five defining attributes of service user involvement within the context of mental health care were extracted from the literature sample retrieved from the electronic database search: a person-centred approach, informed decision making, advocacy, obtaining service user views and feedback and working in partnership.

A person-centred approach

Valued characteristics of person-centred care found in the sample of literature were empathy and respectful listening,[7,23–30] treating service users with dignity and/or respect,[25,31–34] being respected as an individual[7,25,31,33,35] and trust.[36] Building a therapeutic relationship was considered important by Greaves[24] and Borg *et al.*[5] who suggested that this required interest in and awareness of the service user's daily life and difficulties. Fulford and Wallcraft[37] called for a 'person-centred focus that builds on the strengths, resiliencies and aspirations of the individual service user as well as identifying his or her needs and challenges'.(37, p. 55) Furthermore, a non-judgemental approach,[38] acknowledging people's views and experiences[6,38] and considering the reasons behind behaviour rather than making a judgement[38] were also identified. Research by Hodge[25] highlighted the lack of 'professional listening' services and psychological therapies. Both Rush[39] and Kemp[4] found that service user involvement in the classroom provided student mental health nurses with the opportunity to see service users in recovery, rather than only in the in the acute stages of their illness, as would often be the case in placements in practice settings. Students welcomed seeing the service users when they were not experiencing distress and discovering that they were 'no different from us'.

Emphasis is placed on the individual in a person-centred approach. Bhui *et al.*[40] described their experience of adopting a person-centred approach to involving service users in community mental health services: 'Our experience is that we are constantly re-educated by users about their uniqueness'.(40, p. 10) Care planning needs to take into account the personal and social circumstances of the service user in

addition to clinical issues such as medication.[41] The need for person-centred care to extend beyond mental health professionals to everyone involved with the treatment and care of mental health service users, for example, general practitioners[23] or police officers[42] was identified.

Informed decision making

The second derived attribute was termed informed decision making. Areas of informed decision making were identified in assessment and risk assessment, medication and other treatment and in care planning. Considering the sample of literature revealed important ingredients of informed decision making such as appropriate provision of information, adequate shared information and a choice of options on which to base decisions regarding treatment and care. A range of treatment options and active involvement in making the most comfortable and beneficial choice of treatment and service were recommended by Price *et al.*[27] and Weinstein.[41] Milewa[43] felt that informed decision making should extend from the individual to the collective level to involvement in decisions about services.

Service users frequently reported lack of information on both treatment[44] and services[34] and the need to receive such information.[33,38,45] Service users in research by Rudman[38] wished that information would be given to them openly: 'The answer you often get is 'you don't need to know that'. As though you are incapable of understanding about medical information: as though it's a little secret between the professionals'.(38, p. 299) Information about medication options and side-effects was considered vital, and similarly a lack of information about medication and a desire to receive such information was reported.[46–48] Research by Harris *et al.*[49] presented positive results in terms of increased service user perception of involvement in treatment in an evaluation of a medication management training programme for mental health professionals using a cluster randomized controlled trial.

A number of researchers highlighted the need for service users to be given information about and input into their care plan and provided evidence that this was not always the case.[37,50,51] Langan[52] and Gosling[53] highlighted the importance of involving service users in risk assessment. Information about advance directives and statements would allow service users to make provision for future decisions about treatment in case they later become unable to express those views.[48]

Advocacy

The third identified attribute of service user involvement was advocacy. There was an identified need for advocacy for mental health service users in the sample of literature.[1,43,54,55] Evans and McGaha[54] described advocacy as a way for mental health service users to have an impact on policy or decision making. Rudman[55] argued that professional advocacy on behalf of service users can be flawed and stresses the importance of citizen advocacy and self-advocacy as these are independent of service provision and therefore do not have a conflict of interest. Gosling[53] also stressed that the advocate should act in the true interest of the individual and not according to a professional agenda. The importance of independent advocacy was also highlighted in research by Diamond *et al.*[6] People detained under the *Mental Health Act* in England and Wales 2007, those making a complaint about services and those lacking decision-making capacity all have a right to an independent advocate under current government legislation.[42] However, access to advocacy for other service users is patchy and often depends on investment by each statutory body. Advance directives can be used to enable service users to plan the type of treatment and care they would like if a crisis arises.[56]

Lack of power and power imbalance were mentioned by many authors.[53,56] This highlighted the importance of advocacy as an aspect of service user involvement. However, advocacy encompasses more than having access to an independent advocate or making an advance directive in the event of a crisis. Many examples were given where service users advocated for themselves in a variety of other ways

such as writing papers for publication, talking to policymakers or the media,[54] involvement in patient's groups and providing training for mental health professionals.[33,57]

Obtaining service user views and feedback

The fourth attribute of service user involvement identified in the concept analysis was termed obtaining service user views and feedback. A number of papers from the sample highlighted the importance of obtaining service user views. There may be a discrepancy between the views of mental health professionals and the views of service users, as demonstrated in research by Crawford and Rutter,[58] who found the priorities of service users to be very different to those of mental health professionals. Thornicroft and Tansella[59] argued that service users view quality of life more highly as an outcome measure than mental health professionals. Slade[60] called for increased service user involvement in needs of assessment, arguing that many of the needs of assessment instruments assess symptomology rather than needs and are more useful in informing service provision than assessing the needs of a particular service user.

Satisfaction surveys are often used to gain the views of service users, and a number of the papers from the sample reported on satisfaction surveys.[61] Providing feedback to service users is very important[30] as is the evidence that the results have been put into action. Often the results of attempts to seek service users' views in satisfaction surveys are not fed back to service users, and it is unclear whether changes have taken place as a result.[62] Judd[63] provided some useful ideas for feedback methods in the context of clinical audit, proposing ideas relevant to other areas. She suggests that anonymized results can be provided to service users via a number of methods such as notice boards, information leaflets, newsletters and bulletins, presentations to service user groups, reports and publications.[63]

Working in partnership

The fifth attribute was termed working in partnership. Many authors stressed this was important for successful service user involvement.[8,64] Haeney *et al.*[65] found that service user trainers of psychiatric trainees needed to be given an 'equal footing' with the other professionals involved with the course. Russo and Stastny[66] asserted that partnership should be evident in every project or initiative and not just claimed. For partnership working to be achieved, the view of 'patient as expert' or 'expert by experience' was considered important.[5,31,66–70] Service users have a unique perspective on mental health care and are part of the process of care. As such they have a personal knowledge of what it is like to experience and live with a particular mental health difficulty and to be a user of mental health services. 'What really makes these people a unique resource is their background: insight developed through the accumulation of knowledge and experience over many years of contact with services'.(71, p. 134) These authors asserted the value of the paraprofessional service user in the provision of support by example and a model of success, disclosure and sharing, and ability of the service user to relate to a paraprofessional service user.[71] Heffernan[12] introduced the notion of a 'professional service user' where a particular service user gained a job related to her service user status and developed a 'collective identity' and a sense of belonging in this manner. The view of the service user as an expert has the potential for influence in many different areas such as government, parliament, the civil service, professional groups, lobbying, through briefings and reports, in the media, providing evidence and other informal mechanisms. Experiential knowledge needs to be viewed as complementary to rather than competing with empirical knowledge.[72,73]

Antecedents and consequences of service user involvement

Antecedents are 'the events or phenomena that are generally found to precede an instance of the concept'.[17] Citations did not specifically discuss antecedents, and the concept analysis methodology provided few clear

guidelines for exactly how the process of identifying antecedents should be carried out. It was also difficult to pinpoint clear events or incidents that precede the concept of service user involvement in mental health care. The authors from the retrieved literature sample for the concept analysis universally discussed the importance of the policy context and the historical background as an antecedent for service user involvement in mental health care, and there was the assumption of willingness to become involved on the part of the service user.

The outcomes of service user involvement summarized in Table 2 showed that many positive consequences of service user involvement were discussed in the sample.

Negative outcomes were also identified, particularly if the motives for involvement were not right or the service user involvement was at a superficial tokenistic level:

'User involvement is often introduced into policy and practice as something which intrinsically reduces the inequalities between service users and professionals. Yet, if inequalities are not addressed as part of involvement itself this can perpetuate injustice, reinforcing lack of respect, lack of power and lack of resources. It can also isolate service users, instead of providing opportunities for their mutual support and empowerment'.[74, p. 472] For example, there can be frustration that service user involvement did not lead to the expected actions.[75,76] In terms of research, researchers themselves do not have the power to make the changes to practice required from their scientific studies.[76] It has also been suggested that the benefits of service user involvement may be limited to the specific service users who are involved. Results of a thematic analysis of documents from minutes of meetings of a board partnership with the involvement of service users suggested that while there were positive outcomes for the service users involved, their presence may have been largely symbolic.[32]

Surrogate terms

Rodgers and Knafl[22] define surrogate terms as a means to express the concept other than the term used by the researcher. It can be noted that while a few surrogate terms were identified

Table 2 Summary of identified consequences of service user involvement

Service user-centred	Service-centred	Societal
Self-determination & increased autonomy	Evidence-based decision making	Reduced stigma and social inclusion
Increased confidence	Patient satisfaction	Provision of improved mental health services
Personal development	Feedback about services to enable tailoring to needs	Reduced burden of mental health difficulties
Positive experience of care	Improved quality of services	Increased participation of service users in society
Positive view of staff	Meeting policy goals	Increased understanding of mental health difficulties
Decreased feeling of powerlessness and dependency	Improved communication	
Social inclusion	Promotion of best practice	
Improved morale & self-esteem	Raised awareness of service user perspectives	
Knowledge	Increased job satisfaction	
Improved communication	Reduced complaints	
Developed understanding of mental health professionals	Better working relationships	
May be therapeutic & aid recovery	More likelihood of engagement with treatment and care plans	
Empowerment	Changed attitudes of mental health professionals	

from the literature sample, the majority of citations used the concept of service user involvement. This of course reflected the aim of the research and the search strategy adopted and provided evidence that the search strategy retrieved citations relevant to the aim of the research.[17] The term participation was the most frequently occurring surrogate term and 'consumer participation' was used interchangeably with service user involvement by three authors. 'User participation' was used as a surrogate term by eleven authors.

Defining the concept of service user involvement in mental health care

A definition of a concept enables it to be 'referred to, to be communicated, to be identifiable, and to be recognizable to others'.[6, p. 384] Some previous definitions of service user involvement were identified from the literature sample. Hickey and Kipping[16] defined user involvement as 'service users participating in the decision-making process' (p. 84). Storm and Davidson[47] defined service user involvement as 'involve, participate and influence the planning and implantation of their treatment and service' (p. 113). While these authors concurred that service user involvement involves decision making, these are narrow definitions given the breadth of scope of service user involvement. A more comprehensive definition was provided by Lathlean *et al.*[77] as 'an active and equitable collaboration between professionals and service users concerning the planning, implementation and evaluation of services and education' (p. 733). Stringer *et al.*[62] used the definition provided by Tilley *et al.*[78] where user involvement was defined as 'the extent to which the patient is involved in defining problems and setting the targets that constitute the plan of care (p. 679). Storm *et al.*[79] provided two separate definitions of service user involvement: 'at the individual level, service user involvement concerns a person's rights and opportunities to influence and participate in decision making about planning and implementation of treatment and services' and 'a collective term for various methods aimed at involving service users in the development of mental health services in general' (p. 1898). Raptopoulos[80] also recognized the individual and collective levels of service user involvement and provided the following definition 'patients (i.e. clients, service users, consumers, survivors) becoming involved in their own and other's care, at individual or service level' (p. 82).

While these definitions are indeed useful, none fully captures the attributes of service user involvement in mental health care and some authors expressed a need for further definition of the concept.[6,7,11,12] The defining attributes from the concept analysis of service user involvement in mental health care were used to construct an operational definition of the concept. This definition evolved over the course of the concept analysis. This definition of service user involvement in mental health care was proposed as:

> An active partnership between service users and mental health professionals in decision making regarding the planning, implementation and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.

Empirical referents of service user involvement

Service user involvement was described as having positive consequences by many authors, but few studies empirically tested this assumption.[35,44,81] Empirical evidence of change resulting from service user involvement is scarce.[30,82,83] There is a lack of knowledge about which factors contribute to successful service user involvement in mental health care[5,64,69] and few examples of rigorous evaluation of service user involvement initiatives in mental health care. One exception to this was a systematic review of 337 worldwide papers by Crawford *et al.*[84] which was supportive of the finding that the involvement of mental health service users has a positive contribution

to health care. Some authors called for valid and reliable measures of service user involvement.[50,62] There were some identified attempts to use self-report instruments for this purpose; however, these did not capture all the key aspects of service user involvement. No instrument could be identified which measured service user involvement in its entirety.

Looking for an exemplar of the concept

Exemplars or cases are illustrations of the concept in action and provide an everyday example of the attributes of the concept.[22] An ideal exemplar of the concept could not be identified from the sample of literature. Rodgers[20] warns against the temptation to construct a case when an exemplar is not found. She states that the inability to identify an appropriate exemplar should not be seen as a limitation of the research, but instead can be viewed an indicator of the clarity and developmental status of the concept. Therefore the inability to identify a true exemplar of service user involvement in mental health care in action is suggestive that the concept is currently not well clarified.

Conclusions

The findings of this research provide a picture of how the concept of service user involvement has evolved and evidence-based clarity on the meaning and definition of the concept to promote discussion and understanding of the concept among key stakeholders including mental health professionals, service users and community and voluntary organizations. The findings of the research have utility in the areas of theory and policy development, research on service user involvement in mental health care and service user involvement in mental health practice.

It is necessary to acknowledge that there were limitations to the concept analysis. Choosing one search term and four databases placed limitations on the knowledge produced. Other search terms and other databases may have produced relevant material. However, it was necessary to set boundaries to achieve the aims of the research and achieve a sample that could be examined within an appropriate and realistic timescale. Despite this, the search retrieved a manageable sample which was adequate to meet the aims of the research and contained a good range of citations written from different disciplinary perspectives and over a large time period. Temporal and disciplinary comparisons are not a feature of other approaches to concept analysis and are a particular strength of the evolutionary method. The size of the sample met the sampling criteria of Rodgers[21] and a form of saturation was reached as there was little disagreement within the data over the resultant attributes and other identified aspects of service user involvement in mental health care.

Although not a requirement of concept analysis methodology, it would be useful to strengthen the authenticity of results of such research if the iterative process of concept analysis could be conducted by more than one researcher. However, concept analysis is a rigorous and time-consuming method when completed correctly and this would place a high demand on members of a research team. In this case, it was only possible for one researcher to complete the entire analysis process. However, the analysis process was monitored by another researcher to ensure rigour and reduce potential bias. An audit trail was kept in the form of methodological, analytical and personal reflective notes as recommended by Rodgers and Cowles.[85]

Areas of further inquiry and development of the concept

According to the evolutionary approach, concept analysis is a never-ending process, and the end product of concept analysis is never definitive as to what a concept is or is not, but is part of a heuristic cycle of continuing development providing the clarity necessary for further inquiry.[22] In fact, identification of areas of further inquiry is perhaps one of the most significant outcomes of the method.[22] The completed

concept analysis has provided rich data that could be used to produce empirical methods to measure service user involvement and to operationalize the concept of service user involvement. The identified critical attributes of the concept of service user involvement form an evidence base for measurable indicators of the concept. The identified attributes of service user involvement would themselves benefit from further analysis. Consideration needs to be given to both the positive and negative consequences of service user involvement and additional research is needed to determine which outcome measures are most valued by service users.[86]

Attention also needs to be focused on the surrogate terms as interchange of terms has contributed to confusion surrounding the concept of service user involvement. One of the aims of concept analysis is to identify the surrogate terms for the concept of inquiry. As such, surrogate terms were not included in the search strategy for this analysis. However, the identification of the surrogate terms of user participation has opened up an area for further inquiry. Further analysis of surrogate terms such as user participation would help to clarify the differences between the concepts and terms. In addition, it is acknowledged that almost 84% of the papers used in the analysis originated from the United Kingdom. It would be interesting to see if perhaps other terms are more frequently used in other countries to explore the international dimensions of the concept. Finally, identification of exemplars of the concept would help to communicate exactly what service user involvement means in practice and how the concept can be communicated and utilized to its full potential.

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