Patients participating as co-researchers in health research:

A systematic review of outcomes and experiences

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Abstract

Objectives: To map out the scope and type of health research studies conducted with patients involved as co-researchers throughout the research process and to explore outcomes and experiences of such research.

Methods and data sources: We conducted a narrative review searching systematically in selected databases. 1 451 hits were identified and screened. 17 primary studies were included and categorized regarding type of health problem, design, publication sources and modes of presentation. We conducted an inductive and iterative analysis of outcomes and experiences of patient involvement.

Results: We identified two types of impact from patients participating as co-researchers: 1) *patient involvement as primary focus* where seven articles largely reported and reflected upon the shared experiences, and 2) *patient involvement as strategy* where ten articles presented results from empirical studies of specific health problems, with patient involvement as a strategy to expand understanding. The former group of studies reported collaborative processes and resource investments, while the latter addressed specific health problems with a special view due to patient involvement. Several studies in both groups repeated or confirmed positive values of user involvement rather than adding original findings. In both groups, methodological standards were often downgraded to provide access for the co-researchers.

Conclusions: These articles, where the co-researcher model represents the contemporary superior level of patient involvement, may indicate that the mere collaboration efforts are prioritized at the expense of knowledge outcomes and scientific quality. Other collaboration formats than participation as co-researchers may be necessary for patient involvement in medical research to deliver surplus knowledge.

Keywords: Patient involvement; Health research; Co-researcher; Systematic review

Rationale

Consumer involvement in health care and other public services has been recognized and endorsed since the 1970s [1], aiming to strengthen democratic rights and public accountability and to improve health care services and medical knowledge [2]. In Norway, consumer involvement in health care has been a commitment since 2000 with rights for patients and service users as the regulatory legal framework [3]. The legislation regulates rights concerning waiting time, choice of hospital or service providers, including involvement in clinical decision making. Equal access to high quality services, confidence in the relation between service provider and patient, and respect for the patient's life, integrity and dignity are core values [4].

Within health care, a *consumer* is defined as a receiver or a potential receiver of health care, with different terms such as patient, service user, user, lay person or client [5]. 'Consumer' and 'user' are often used as interchangeable concepts. The term *end user* specifies patients or clients and their relatives [6]. Health care professionals and policy makers are also sometimes called consumers, in their capacity as clinicians or decision makers, consuming research knowledge.

Consumer involvement emerged as attempts to modernize the public sector [7], offering new positions for patients or service users [8]. What started as a strategy to democratize healthcare and learn from patients' experiences some decades ago, has developed into various practices. Replacing the patient role with the consumer role may indicate increased marketization of public services. In health care, consumer involvement typically concerns *patient involvement*, occurring on an *individual* level in the clinic through shared decision making [9] or on a *structural* level in boards and agencies with plans and decisions about services and policy. The different patient involvement practices imply various foundations, aims, tasks and roles.

Discussing available choices for surveillance of blood glucose for a particular patient with diabetes entangles for example other challenges than discussing the design of care services for children with mental health problems. When consumer involvement is on the agenda, it is therefore crucial to specify whom we are talking about and why so.

Since the 2000s patient involvement has also been incorporated in *health research*, incited by legislation, regulations and funding agencies [2, 5, 10-13]. Patient involvement in health research has a dual rationale: firstly, patients and relatives are affected by implementation of research knowledge in health care and therefore have a right to influence, and secondly their experiences and insights complement those of the researchers, contributing to potentially more adequate knowledge [10]. The amendments of the Norwegian legislation of patient involvement demonstrate substantial changes analogous with international progress and expands the impact area for participation from clinical practice to also include research [3].

Depending on the type and degree of participation, consumer involvement in health research is classified as 1) consultation, 2) collaboration or 3) consumer control [5]. According to Boote, *consultation* implies that consumers are asked about their views to influence decision-making regarding research, typically as members of a reference group. With *collaboration*, an ongoing partnership between researchers and consumers takes place in the research project, including planning, design, data collection, analysis or reporting, or - most extensively – all of these steps. In *consumer controlled* research, consumers design, undertake and disseminate the results of a research project, with researchers involved only at the request of the consumers themselves. In 1994, Smith coined the term *co-researcher* in a collaborative research design, with participants fully included as peer members of the research team, beyond the capacity of informants or advisors [14].

In 2014, the Norwegian government introduced patient involvement as a mandatory element of medical research funded by the regional health trusts [15], specified in their guidelines for Ph.D project applications [16]. Since 2016, patient involvement has also been mandatory in health projects funded by the Research Council of Norway (RCN). In an RCN conference in 2016 launching two health research programs (BEDREHELSE and BEHANDLING), a substantial proportion of the conference program addressed patient participation in research [17]. Ambitious ideals for extensive involvement were announced, applauding projects with patients or next of kin as co-researchers participating as peers with academic researchers. Discussions dealt, however, mainly with infrastructure related to training and funding of co-researchers, while ethical and epistemological matters were not considered.

We had previously explored evidence-based methodology, to understand relations between ideals and practices for developing knowledge for policy and practice [18]. Our attention was then drawn towards another field with strong ideals for new research practices, specifically as research with consumers extensively involved in the research process.

In 2002, Boote et al addressed 1) how can consumer involvement in health research be further conceptualized, 2) how and why does consumer involvement influence health research, 3) how can the influence of consumers in health research be measured and evaluated, and 4) what factors are associated with ‘succesful’ consumer involvement in health research? [19]. Almost two decades later, this kind of research is still far from customary. We therefore found that experiences and outcomes from the field deserved closer attention.

Objectives

We therefore set up a study to map out the scope and type of existing health research studies with patient participation organized as extensive end user involvement (co-researchers - CR) all through the research process, and to explore outcomes and experiences of research projects with patients involved as CRs.

Methods

Based on a protocol, we conducted a *systematic review* [20] of health research studies where patients or relatives involved as *co-researchers* (CRs) were participating in priorities, planning, design, data collection, analysis and reporting as peers collaborating with academic researchers [5]. We tried to register the study in Prospero but concluded that standard questions did not fit our study and did therefore not allow complete registration.

Search strategy and information sources

An experienced research librarian helped us conduct a systematic search of the following databases in October 2016: MEDLINE (1946 to present), EMBASE (1974 to present), AMED (1985 to present), CINAHL (1981 to present). Identifying appropriate search terms was a challenge, as hardly any available standard key words incorporated the phenomena we wanted to explore. Several unproductive test searches provided enormous numbers of hits, but no relevant publications. Finally, we composed a search based on terms appearing as recurrent text words in a few exemplary articles of the kind we were looking for. The strategy was adjusted after some test searches and finally included the following text words:

> *co-researcher; peer-research; expert-by-experience; research involvement OR collaboration with consumer OR user; collaborative inquiry*

entered individually and in combination, spelled in full and in short forms using an asterisk.

We applied no search filters limiting study categories, patient groups, types of health problems, study design or publication language.

Eligibility criteria

After organizing the hits from the search and removing duplicates, we screened the remaining unique references for relevance according to our aim by title and abstract (and in a few cases – the full text), and subsequently for methodological quality. Screening was accomplished independently by both authors, negotiating discrepancies towards agreement.

Publications from empirical studies were included for assessment if they documented a process where patient(s) or relative(s) were involved as CR(s) covering all steps of the research process. Studies about patient involvement in practice or policy without this extent of research involvement were excluded. We also excluded community studies where healthy lay CRs participated without being patients themselves and studies where patients or relatives were involved merely in the capacity of informants. Publications where the academic researcher reflected upon experiences from CR collaboration without involving the co-researcher in reflections and presentation as well as theoretical papers, book-chapters, reviews, comments, editorials or dissertations were also excluded.

Empirical data and analysis

The common feature of the included primary studies was related to *process* (patient involvement with CR), not to theme or content of research. Meta-synthesis or meta-analysis were therefore not adequate approaches. Considering our aim, we decided to summarize the included primary studies as a *narrative review* [21] with broad descriptions of scope, type, outcomes and experiences from health research studies accomplished with patients involved as CRs. Exploring the sample, we had a special attention to documentation reflecting contextual preconditions and resources required for this mode of health research. Analysis was jointly negotiated by both authors.

Results

Database searching and study selection

The initial database search identified totally 2 432 records (presented as flowsheet in Figure 1).

<Please insert Figure 1 about here>

Duplicates were removed automatically (n = 797) and manually (n = 184), leaving 1 451 unique references to be independently screened for relevance by the two authors. Discrepancies regarding assessment of respectively inclusion or exclusion were few and easily negotiated to consensus.

From the screening process we identified 35 *candidate articles* to be assessed in full text for relevance and quality. Of these, 24 articles were excluded due to deficient relevance and compliance to our inclusion criteria. Some of the initially selected articles turned out to lack presentation about an underlying empirical study. Although they were also excluded, they contained information we could use for *back-chaining* with subsequent assessment and inclusion of seven studies.

The eligible 18 articles were independently assessed for methodological quality by the two authors, guided by the Critical Appraisal Skills Programme checklist (CASP) for qualitative studies [22]. CASP includes ten issues about aim, appropriate qualitative methodology, design, recruitment strategy, data collection, researcher/participant relationship, ethical issues, analysis, statement of findings and the value of the research. One article was excluded due to methodological shortcomings, leading to a final sample of 17 primary studies of acceptable relevance and methodological quality.

Study characteristics

Our sample of 17 primary studies [23-39] provided the empirical material for our analysis. The common denominator across the sample of primary studies was a high level of involvement with patients or relatives in a CR position all through the research process, leading to a published article. An overview of the sample is presented in Table 1.

<Please insert Table 1 about here>

The included studies, all published in English language, had been conducted 1997-2016 in four different countries (UK: 6, Canada: 4, Norway: 4, Australia: 3). The authors' academic affiliations were mostly with different universities, but also from various kinds of clinics. The studies represented patient groups with different health problems (mental health problems, learning disabilities, occupational injuries, cancer, osteoarthritis). Although not decided in advance, the sample consisted of qualitative studies only (individual interviews, focus group studies, participatory action research, single case study, nominal study), mostly with rather limited theoretical or philosophical commitment concerning analysis.

Two of the articles had been published in Qualitative Health Research and two in British Journal of Learning Disabilities, with the remaining 13 in journals for psychiatry, learning disabilities, cancer, occupational medicine, reproductive medicine and other subject areas. The range of printed pages in the included articles was 4-19 (median 11). Some of the articles contained illustrations beyond figures and tables, most often joint outcomes from research workshops. In eight of the studies, one or more CRs were co-authors. For the remaining nine, the methods section reported explicitly that CR involvement had been accomplished also during reporting, though without leading to co-authorship.

Analysis of the role and outcomes of patient involvement

After the descriptive summary presented above, we conducted an inductive and iterative analysis targeting the role and substantial outcomes of patient involvement in the studies included in our sample [40]. Both authors reread all the 17 articles in depth, attending particularly to how patient involvement had been staged in aim, results and conclusions of the articles. At this step, we noticed that some authors primarily addressed patient involvement as such, while others addressed substance matters related to specific health problems. We then decided upon an analytic approach where we first explored the balance between study aim and outcomes for each article in these two groups and then compared and discussed our interpretations.

We started analysis by categorizing the primary studies in two different groups: one in which patient involvement itself was the primary focus, and another where patient involvement was used as a strategy to study substantial issues related to specific health problems. In the first category - *patient involvement as primary focus* - we included seven articles where co-researchers and academic researchers largely reported and reflected upon their shared experiences [24, 25, 29, 33, 36, 37, 41]. In the second category – *patient involvement as strategy* - we included ten articles where results from empirical studies of specific health problems were reported, with patient involvement as a strategy to expand understanding [23, 26-28, 30-32, 34, 38, 39]. We used the abstracts (some of them structured, some not) from each article in both categories to explore the relationship between study aim or purpose and results/conclusions, in some cases supplemented from the article text. Below, we present and summarize these findings. This analysis lead to comparison and discussion of outcome and experiences from health research with extensive participation from patients or relatives, as demonstrated in studies including a CR position all through the research process.

1. *Patient involvement as primary focus – reflections upon preconditions and experiences*

Seven of the included 17 primary studies presented aims, results and conclusions referring predominantly or entirely to the issue of patients participating in research as CRs [24, 25, 29, 33, 35, 36, 42]. In this group, patients or relatives of patients with mental health problems [24, 25, 35, 42] or learning disabilities [29, 33, 36, 37] had participated. Most of these articles are short, some of them very vividly written, presenting participatory action designs, often reported as case studies of individuals or supportive environments. Some of them took specific experiences from everyday life, treatment or welfare settings for the particular patient group as their point of departure. Table 2 presents the aims and results/conclusions of these articles.

<Please insert Table 2 about here>

These articles mainly offer accounts and knowledge about preconditions for or experiences from extensive patient involvement in research, elaborated and presented jointly by academic researchers and CRs. Empowerment appears to be an important purpose in all these studies. Most of these articles also comments upon the research impact of the actual collaboration process, arguing that enhanced insight has evolved and has been shared. Considering these articles as reflexive accounts, we have assessed the scientific quality of most of them as acceptable. Yet, transferability, strength of impact and relevance of findings were often not extensively discussed. Preconceptions and founding values frequently seemed to be confirmed, reappearing as results without substantial methodological reflection.

A critical reader might question the surplus information value of findings from this category of articles, also when approving their focus on process and collaboration. Most useful we find the authors' descriptions of extensive resources invested in supporting, training and conducting this kind of collaborative efforts, emphasizing fundamental issues of power, dignity, trust and respect. Two of the articles describe in neat details how individuals with limited literate abilities can be supported to analyze and communicate such processes [33, 37], while two articles emphasize interactions and support within the research group [24, 25]. To facilitate these efforts, extensive resources are described. One of the studies reported a collaboration process lasting four years including 33 structured meetings of 2-3 hours in length [35].

2. *Patient involvement as strategy - a resource for understanding health problems*

Ten of the included primary studies presented aims, results and conclusions about health problems, beyond the issue of including patients or relatives as CRs [23, 26, 28, 30-32, 34, 38, 39].

These studies dealt with work-related injuries [23], cancer research priorities [26], mental health problems [28, 30-32, 38, 39] and osteoarthritis [34].

Table 3 presents the aims and results/conclusions of these articles.

<Please insert Table 3 about here>

Compared to the primary studies in the previous category, most of these articles were presented in more traditional research designs, such as interview studies, often organized in the IMRAD format, with results emphasized more than process. Qualitative analysis was generally conducted according to methodological standards, although several authors remarked that a simplified approach had been chosen for analysis. Scientific quality for most of these articles was assessed by us as acceptable. Still, with some exeptions, several of these articles suffer from somehow vague aims, modest designs with methodological and analytic compromises and limited relevance of findings. We find it hard to recognize findings of surplus information value, not known from previous theory or empirical research, associated with the reported patient involvement.

A study about cancer research priorities [26] stands out by asking other questions and arriving at outcomes clearly influenced by the patient involvement, although perhaps not so surprising findings. Others deserve attention by offering relevant, specific and trustworthy knowledge about therapeutic interaction in different contexts with convincing footprints from consumer positions [38, 39].

Discussion

Summary of evidence

Our analysis demonstrated that some health research studies with patients or relatives extensively involved as co-researchers presented reflexive accounts with patient involvement itself as the primary focus. Other studies used patient involvement as a strategy to study substantial issues related to specific health problems. The former group of studies reported experiences from collaborative processes, while the latter group addressed specific health problems with a special view due to patient involvement. Yet several studies in both groups seemed to predominantly repeat or confirm positive values related to user involvement rather than adding original findings, even when we fully acknowledged the aims of the former group. Below, we discuss the impact of these interpretations and the strengths and limitations of our study.

What is known from before – what does our study add?

We are not the first to review the research literature about consumer involvement in health care. A Cochrane review (2006) summarized studies about the effects of consumer involvement on information material, informed consent document consumers and participation as interviewers and concluded that the impact seemed to be limited and evidence had low or very low quality [2].. Exploring outcomes of patient involvement in health research with a different methodological approach, our study furthermore suggests that patient involvement does not necessarily lead to more advanced knowledge. Our analysis indicates that involving patients or relatives as co-researchers as peers with academic researchers will not guarantee the assumed research deliveries.

Surplus information value from analysis with consumer involvement was not always recognizable in our sample, even in studies assessed to hold acceptable methodological quality. For both study categories, a logical consequence of the reported mode of patient involvement is that academic teammembers step aside from their researcher roles to create space for the co-researcher. Some of the studies from the first category portray a collaborative style where the researcher's task mainly is to accomodate the co-researchers in a safe and responsible way rather than fostering the research itself. Under such circumstances, the ethical and responsible use of human and economic resources as consequences of such ambitious policies for patient involvement may be questioned.

Boote et al presented consensus derived principles about successful consumer involvement in health research, commenting that these are normative judgements addressing mainly the process, as opposed to outcome issues in research [11]. Our study demonstrates some of the outcomes of similar attitudes. The reflexive accounts from the first category of studies in our sample expose researchers who are sincerely devoted to offer comprehensive training and follow up to incorporate lay people with experience-based knowledge. Nevertheless, presentations of methods and results in our sample, also from the second category of studies, revealed numerous compromises made to involve individuals without academic training in data collection and analysis. Similar issues concerning attitudes to academic rigor were raised in a recent scoping review of end user involvement in disability research [43].

True patient involvement in health research must inevitably entail new positions and relationships, for their voices to challenge or complement the preconceptions and habitual approaches of the academic researcher to be empowered. When such new positions oppose the use of advanced methodology or impiy that the curiosity of the academic researcher should be kept on a tight leash, the prospects of developing new knowledge from patient experiences will unfortunately suffer. Although involvement may be perceived as rewarding, research requires specific skills and experiences. Reviewing research literature to identify existing knowledge holding scientific quality is, for example, not an easily accessible competence. Our analysis does not convince us that that advanced investments for participation with co-researchers, as illustrated by our sample, will generally lead to development of more relevant knowledge in health care.

Analysis also drew our attention to attitudes to academic competence underlying some of the studies in our sample. While Ph.D.-programs are organized with years of fulltime training for regular academic students [44], co-researchers are offered comparably tiny training, even with the reported great investments [45] They are, nevertheless, expected to participate fully in the research team, who subsequently downgrade theoretical and methodological competence to offer the lay co-researchers access. Our analysis indicates that academic research qualifications are not always prioritized in data collection and analysis when co-researchers are included.

Such interpretations triggered our ethical concerns that patient involvement can become tokenism in the name of democracy [6], although we do not attribute such challenges to specific studies in our sample. Still, we fear that research conducted with good intentions may cause a boomerang effect striking co-researchers as well as the idea of patient involvement, when the research outcome is scarce. In this way, misleading and unfortunate contradictions between research and democracy may emerge.

We strongly support the ideas that involvement of patients and relatives can encourage democratic rights and improve medical knowledge. Yet, our analyses have generated some questions about strategies concerning the model of fully involved co-researchers as the utmost standard for how patient involvement is best accomplished. Looking at the types of health problems and medical disciplines represented in our sample, it is understandable that this specific model is not suited to encompass all kinds of medical research. We expect patients or relatives fully involved as co-researchers neither in sophisticated technical research projects, such as molecular medicine, nor in research on specific surgical procedures, such as glaucoma or hip replacement. Priorities or other vital choices for health research or specific projects with consequences for the end user, however, are certainly domains for tailored and relevant patient involvement strategies.

The voices of end users may therefore be better accommodated if patients and relatives are given more powerful positions in reference groups for research programs and projects. Patient experiences may even be better attended to and developed from informants in well crafted research projects, with skilled researchers dedicated to transform voices from vulnerable positions to medical knowledge that can make a difference for the affected groups.

Study strengths and limitations

With an extensive literature search and review Shippee et al aimed for an evidence-based framework for patient involvement in health research but concluded that such efforts are limited by the non-standard and non-empirical nature of much of this literature [13]. We recognized similar patterns in our search and final sample, even though we confined our search specifically to empirical studies where the published article documented that co-researchers had been involved in every step of the process.

We have rigorously conducted our review with standard procedures for systematic and transparent literature search and screening [20], not by cherry picking [46] of data that do not conform to preconceptions or policy. Still, primary studies conforming to our inclusion criteria will remain undentified by our search. The insufficiency of indexing for qualitative studies and for marginal research themes due to standardized key words is well known [47]. We do not believe that our sample of included primary studies is a complete one, thereby limiting the external validity of our findings. We therefore present our discussion and conclusions with due caution, referring to our data as appropriate examples for relevant discussions and our interpretations as contestable.

Comparing aims and purposes with results and conclusions for each of the included primary studies was not always easy. Only some of the articles had structured abstracts, and the presentation of results in many articles was not very comprehensive or clear. Although our data for analysis contained much more information, our best idea to demonstrate transparency for this step was to present the comparison in tables mainly based on abstracts.

Some of the references for the primary studies appeared to be inconsistent concerning publication year, with different years appearing in different versions. Reviewing all the material over again, we presume the discrepancy to be due to time lags between epub and and final publication, without representing any substantial analytic problem.

Conclusions

Our systematic review has demonstrated several major challenges of co-researcher strategies as patient involvement in health research. Our exploration of process and experiences from this type of patient involvement in research did not demonstrate a large domain of health research with co-researchers participating, and a limited number of studies are available where such ambitions have been accomplished to the finish line of publication. Reviewing these articles and considering them against the regulations that authorize and recommend the co-researcher model for patient involvement, we are concerned that the mere collaboration efforts are prioritized at the expense of academic skills, scientific quality and knowledge outcome. Other collaboration models may be necessary for patient involvement in medical research to deliver surplus research knowledge. We conclude that it is time to revisit the established ideals and strategies for patient involvement in health research.

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Figure 1 – Search strategy and outcome

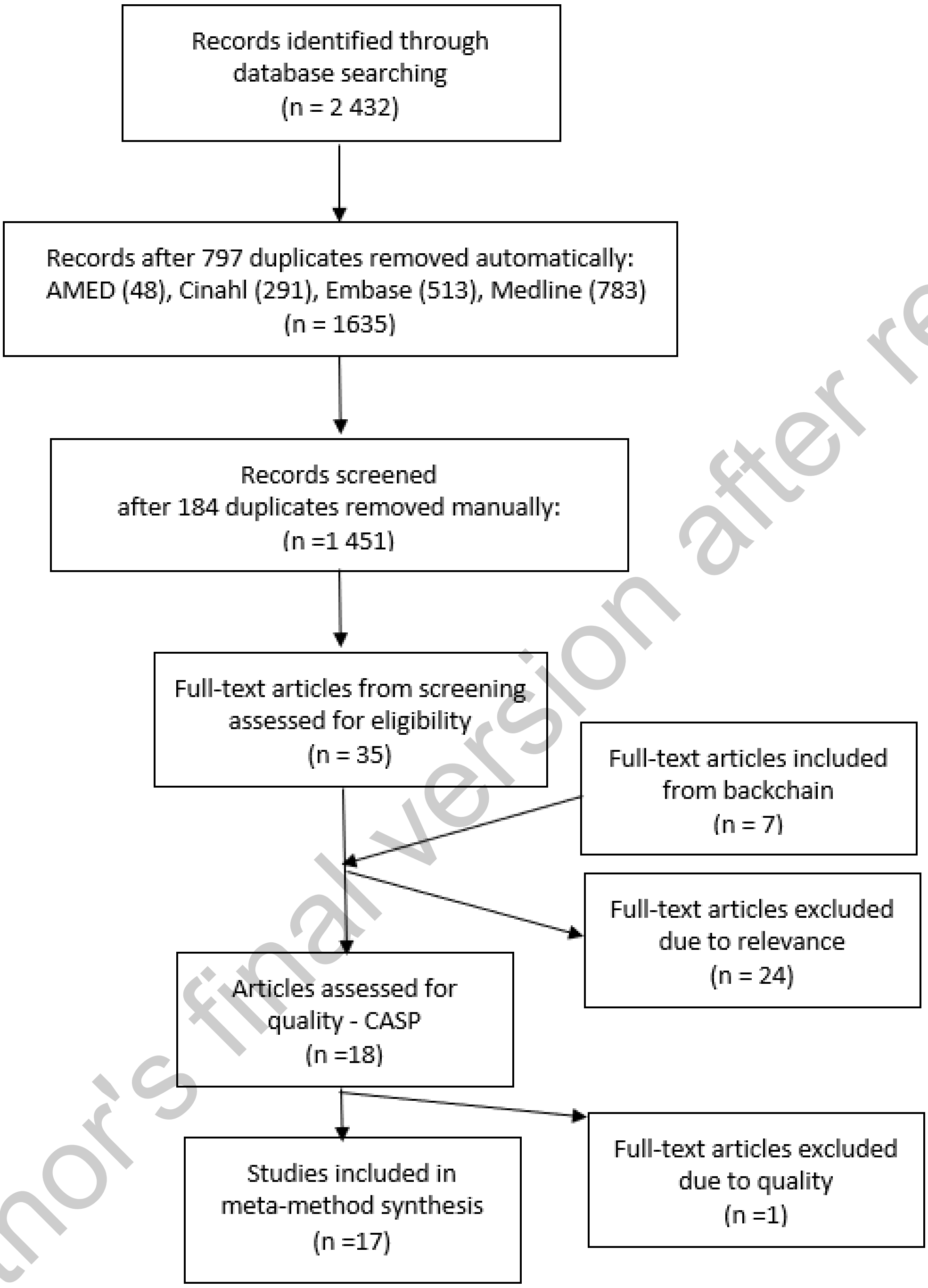

Table 1 – Included primary studies

FIRST AUTHOR	COUNTRY	GROUP OF PATIENTS	DEALING WITH	STUDY DESIGN	JOURNAL
Beardwood 2005	Canada	Injured workers	Injured workers	Semistructured individual interviews	Qualitative Health Research
Byas 2003	Australia	Child/adolescent mental health	Client experiences of therapy	Focus group study	Families, Systems & Health
Clements 2012	Canada	Mental health	Recovery and clubhouse membership	Participatory action research with Photovoice	J Psychiatr Ment Health Nursing
Corner 2007	UK	Cancer	Cancer research priorities	Participatory action research focus groups and nominal	Br J Cancer
Crain 2009	Canada	Mental health	Individual Placement and Support employment program	Case study, semistruct indiv interviews	Work
Eriksen 2012	Norway	Mental health	Service users' encounters with other people	Semistructured individual interviews	Nursing Ethics
Flood 2013	UK	Learning disabilities	Co-researcher with learning disabilities studying abuse	Participatory action research (not explicitely stated)	Br J Learning Disabilities
Franks 2016	UK	Mental health in pregnancy	Mental health threats in pregnancy	Individual and group interviews	Women and Birth
Gillard 2015	UK	Mental health	Recovery with personality disorders	Individual interviews	BMC Psychiatry
Heron 2012	UK	Mental health postpartum	Recovery among women with postpart psychosis	Semistructured individual interviews	Arch Womens Ment Health
March 1997	UK	Learning disabilities	Co-cresearchers studying self-advocacy and families	Participatory action research, Case study	Br J Learning Disabilities
Miller 2016	Canada	Osteoarthritis	Gaps between support and needs, quality care	Focus groups, telephone individualinterviews	Patient
Mjosund 2016	Norway	Mental health	Contributions of user involvement to research quality	Case study	Journal of Advanced Nursing
Stevenson 2014	Australia	Learning disabilities	Data analysis with co-researchers with Down's syndrom	Participatory action research, case study, indiv interviews	J Applied Res Intellectual Disab
Tuffrey-Wijne 2010	UK	Learning disabilities	The contribution of co-researcherss with learning disability in analysis	Case study, reflection	Health Expectations
Veseth 2016	Norway	Mental health	Therapists view of recovery in patients with bipolar disorder	Semistructured individual interviews	J Psychotherapy Integration
Veseth 2012	Norway	Mental health	Processes of recovery in bipolar disorder	Semistructured individual interviews	Qualitative Health Research

Table 2 – Articles with patient involvement as primary focus - Aims and results/conclusions

AUTHOR	AIM/PURPOSE	RESULTS/CONCLUSIONS
Byas 2003	To describe the Collaborative Outcomes Research Project where consumers and mental health professionals worked together in designing, conducting, analyzing and writing up a project on client experiences of therapy.	Tthe richness that collaboration with consumers can bring to the exploration of therapy outcomes and satisfaction with mental health services. Phase 1: developing the methodology, generating research questions, and recruiting participants to become co-researchers. Phase 2: application of the outcomes of Phase 1 to explore a further group of consumers' experiences of therapy.
Clements 2012	The Our Photos Our Voices project uses participatory action research and photovoice to effectively access, explore, document and share personal, local knowledge about recovery grounded in the personal experience of the Clubhouse researchers.	The project demonstrates how participatory action research and photovoice are well suited for collaborative research in mental health which honours principles underlying consumer empowerment and recovery. The foundation of empowerment is the power to act on one's behalf; participatory action research and photovoice support the full participation of concerned individuals in all aspects of research with the ultimate goal of action to solve problems or to meet goals identified by those individuals. The project uses participatory action research and photovoice to effectively access, explore, document and share personal, local knowledge about recovery grounded in the personal experience of the Clubhouse researchers.
Flood 2013	What does it means to be a researcher using the words, views and experiences of three people with learning disabilities working as co-researchers.	People with learning disabilities are increasingly taking on the role of researcher within participatory research projects. The article talks about what they found helpful, and what they found challenging, comparing their experiences to those of other people and highlights the importance of support. It has been a positive experience which helped them to learn a great deal and they provide advice that they hope will help others thinking about taking on such a role.
March 1997	This article is written by three people with learning difficulties. It is about their experience of doing research.	The article describes why they decided to get involved, their feelings about doing research and what they did. It explains the help they had to take part. Researchers have been talking about disabled people doing research for quite some time, but involving people with learning difficulties as researchers is only just beginning. This article is one of the very few times that people with learning difficulties have written about carrying out research.
Mjosund 2016	To xamine how service user involvement can contribute to the development of interpretative phenomenological analysis methodology and enhance research quality.	The advisory team became 'the researcher's helping hand'. Multiple perspectives influenced the qualitative analysis, which gave more insightful interpretations of nuances, complexity, richness or ambiguity in the interviewed participants' accounts. The outcome of the service user involvement was increased breadth and depth in findings. They conclude that sService user involvement improved the research quality in a nursing research project on mental health promotion. The interpretative element of interpretative phenomenological analysis was enhanced by the emergence of multiple perspectives in the qualitative analysis of the empirical data. Service user involvement and interpretative phenomenological analysis methodology can mutually reinforce each other and strengthen qualitative methodology.
Stevenson 2014	To illustrate the process of data analysis in a project located within the Emancipatory Disability Research paradigm.	The participation of the co-researchers is demonstrated and a global theme, deduced from the collaborative analysis, is described. They conclude that authentic participation of co-researchers in the data analysis stage of the research process is an example of 'inclusive research' and assures adherence to the principles of Emancipatory Disability Research in informing the theory and practice of social inclusion for young adults with an intellectual disability.

Tuffrey-Wijne 2009	To examine the potential contribution of people with learning disabilities to data analysis in qualitative research.	The researcher with learning disabilities coped well with the emotive content of the data and with the additional support provided, he was able to extract themes that added validity to the overall analysis. His contribution complemented those of the other members of the research team. There were unexpected benefitsin terms of a more reciprocal and supportive relationship between the two researchers. They conclude that it is possible and valuable to extend involvement to data analysis, but to avoid tokenism and maintain academic rigour, there must be a clear rationale for such involvement. Extra support, time and costs must be planned for.

Table 3 – Articles with patient involvement as tool - Aims and results/conclusions

AUTHOR	AIM/PURPOSE	RESULTS/CONCLUSIONS
Beardwood 2005	To describe experiences of workers who sustained an injury attributable to the workplace, who consider that they are receiving inadequate compensations and who are unable to return to satisfactory employment.	The process victimizes participants and renders them powerless and dependent on others. Health professionals and bureaucrats impede their rehabilitation. Injured workers should be included in the decision-making process of rehabilitation and rebuilding their lives.
Corner 2007	To present the findings of the first consultation to be conducted with UK cancer patients concerning research priorities.	Fifteen areas for research were identified. Top priority areas included the impact cancer has on life, how to live with cancer and related support issues; risk factors and causes of cancer; early detection and prevention. Although biological and treatment related aspects of science were identified as important, patients rated the management of practical, social and emotional issues as a higher priority. There is a mismatch between the research priorities identified by participants and the current UK research portfolio. Current research activity should be broadened to reflect the priorities of people affected by the disease.
Crain 2009	Individual Placement and Support) - a case study presenting a 42-year-old-man who has schizophrenia and who attends a community mental health team in a Canadian urban centre.	The enduring and individual support of Individual Placement and Support is credited with being central to the study subject's successful acquisition and maintenance of paid employment. His involvement in paid work is also associated with improved health outcomes, including a significant reduction in the frequency of medical appointments to monitor his mental health. Improved social skills and self-efficacy are also reported. They conclude that provision of Individual Placement and Support services within a multidisciplinary mental health team can promote the acquisition of durable employment for individuals in recovery from serious mental illness. Clinicians are reminded to check their assumptions regarding which individuals could benefit from Individual Placement and Support and are encouraged to take their lead from clients in determining whether to commence or continue employment services.
Eriksen 2012	To explore how users of services describe and make sense of their meetings with other people.	Results confirm that reciprocity is fundamental for relationships, and that recognizing the individual entails personal involvement. The participants describe a struggle and recognizing this struggle may help the professional to achieve a deeper understanding of the individual.
Franks 2016	Tto explore mothers' and professionals' perspectives on the factors that influence pregnant women's mental health.	Significant areas of commonality were identified between mothers' and professionals' perspectives on factors that undermine women's mental health during pregnancy and what is needed to support women's mental health. Analysis of data is provided with particular reference to contexts of relational, systemic and ecological conditions in women's lives. They conclude that women's mental health is predominantly undermined or supported by relational, experiential and material factors. The local context of socio-economic deprivation is a significant influence on women's mental health and service requirements.

Gillard 2015	To explore understandings of recovery from the perspectives of people with lived experience of personality disorders.	*R*ecovery cannot be conceptualised separately from an understanding of the lived experience of personality disorders. This experience was characterised by a complexity of ambiguous, interrelating and conflicting feelings, thoughts and actions as individuals tried to cope with tensions between internally and externally experienced worlds. The analysis suggested a process of recovering or, for some, discovering a sense of self that can safely coexist in both worldsThey conclude that key facilitators of recovery - positive personal relationships and wider social interaction - are also where the core vulnerabilities of individuals with lived experience of personaility disorders can lie. Personality disorders services should provide a safe space in which to develop positive relationships. Through discursive practice within the research team understandings of recovery were co-produced that responded to the lived experience of personality disorders and were of applied relevance to practitioners.
Heron 2012	To gain an understanding of the difficulties faced by women recovering from postpartum psychosis and to inform the planning of post-discharge information and support services.	Postpartum psychosis is a life-changing experience that challenges women's sense of personal and social identity. Recovery themes are organised around ruminating and rationalising, rebuilding social confidence, gaining appropriate health service support, the facilitation of family functioning, obtaining appropriate information, and understanding that recovery will take time. Women suffering from postpartum psychosis must be adequately supported following discharge from psychiatric hospital if we are to address maternal suicide rates. A successful collaboration between academics and service users exploring the needs of women and their families is described.
Miller 2016	To address the perspectives of patients with osteoarthritis about the gap between available support and their needs, with a focus on patient experience and what is important to them.	An overarching theme of "supporting us in managing a meaningful life with osteoarthritis " was underpinned by three components of quality care: (1) right knowledge-specific and detailed knowledge and information; (2) right professional support-ongoing access to health professionals with osteoarthritis expertise; and (3) right professional relationship-a partnership with health professionals who help them develop and revise personal self-management plans. Peer-to-peer research informed and challenged the research team and stakeholders to consider the need for upstream support for osteoarthritis patients. Results are helping to transform arthritis care, shifting the health system from an acute episodic model to one that meets the needs of the growing number of patients with chronic diseases.
Veseth 2016	To explore how experienced therapists view recovery in bipolar disorders. In what ways do professionals conceptualize and give meaning to processes of healing and growth? How do they experience working with their patients toward recovery?	The participants' descriptions of recovery in bipolar disorders are summarized according to three themes, outlining important aspects of their patients' struggles and efforts: (a) "a puzzling given," (b) "the protagonist of the recovery process," and (c) "the heroic fighter does not always win." The themes' relations to established theory, research, and practice, along with the limitations and strengths of the study, are discussed.
Veseth 2012	To discuss processes of recovery in bipolar disorder.	Four core themes were drawn from the analysis: (a) handling ambivalence about letting go of manic states; (b) finding something to hang on to when the world is spinning around; (c) becoming aware of signals from self and others; and (d) finding ways of caring for oneself. Interrelationships between the four themes, along with limitations, strengths, and implications of the study are discussed.