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To cite this article: Morris Gordon, Simon Gupta, Debra Thornton, Michael Reid, Ernie Mallen & Angela Melling (2019): Patient/service user involvement in medical education: A best evidence medical education (BEME) systematic review: BEME Guide No. 58, Medical Teacher, DOI: [10.1080/0142159X.2019.1652731](https://doi.org/10.1080/0142159X.2019.1652731)

To link to this article: <https://doi.org/10.1080/0142159X.2019.1652731>

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## Patient/service user involvement in medical education: A best evidence medical education (BEME) systematic review: BEME Guide No. 58

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### ABSTRACT

**Background:** The extent to which patients and service users are involved in medical education varies widely. There is a need for an up to date systematic review of the literature that examines what involvement (description), the potential outcome of such involvement (justification) and 'why' such involvement impacts students (clarification).

**Methods:** Systematic searches of four databases were undertaken. Citations were screened and consensus reached for inclusion/exclusion of studies. Quality of study design and interventional presentation were assessed.

**Results:** Of the 39 studies included in the review, 4 studies were encounter based, 17 sharing experiences, 16 with patients involved in teaching, 2 studies describing consumers as tutors, and none with involvement at the institutional level. Outcomes in terms of benefits to learners included increased empathy and understanding of illness as experienced by patients, improved communication with patients and a greater understanding of patient-center care. Educational quality assessment showed specific weaknesses in theoretical underpinning, curriculum outcomes, content or pedagogy.

**Conclusions:** Patients can enrich medical education by allowing learners to explore patient-centered perspectives in holistic care. For educators this review highlights the lack of an underpinning conceptual basis for which to translate theory into practice.

### Background

'To study the phenomenon of disease without books is to sail an uncharted sea, while to study books without patients is not to go to sea at all.'

Sir William Osler

Patients and service users have always been vital to medical education, but in the past this role has been a learning resource or 'clinical material' (Flexner 1910), illustrating conditions, pathologies or signs for examination. Since the 1980s, the notion of the 'expert patient' (Tuckett 1985) has led to a recognition that patients should be more actively involved in their own care and a partnership between healthcare professionals and patients should be encouraged. This idea has gained increasing prominence in the United Kingdom (UK) government policy with a requirement that 'patient and public involvement should be part of everyday practice in the National Health Service (NHS) and must lead to action for improvement' (Department of Health 2007). The Health and Social care Act of 2012 built on the previous 2006 Act to ensure the voice of patients is heard throughout the healthcare system and all statutory bodies in the UK relating to health now have duties with regards to the involvement of patients, carers, and the public.

Clearly, this has an impact on postgraduate and undergraduate education and in 2009 recommendations were written into Graduate Medical Council (GMC) guidance for the involvement of patients in undergraduate medical education (UME) as they 'can contribute unique and invaluable expertise to teaching, feedback and assessment of medical students' (General Medical Council 2009). They further

### Practice points

- Most studies involved patients sharing their personal experiences with students (17), 16 with patients involved in teaching and/or evaluating students and none with involvement at the institutional level.
- Patient involvement led to increased empathy and understanding of illness and improved communication with patients.
- Educational quality assessment of studies showed specific weaknesses in theoretical underpinning, curriculum outcomes, content or pedagogy.

recommended that the development of medical school curricula must be informed by medical students, doctors in training, educators, employers, other health and social care professionals and patients, families and carers (General Medical Council 2016).

In other countries, too, there is a call for increased involvement of consumers – patients and the public – in healthcare and healthcare education. A World Health Organization report in 1995 called for medical schools to adopt a new paradigm of social accountability in meeting the needs of their communities – the priorities for these needs being identified jointly by governments, healthcare organizations, healthcare providers and the public (Boelen and Heck 1995).

There is wide variation in the extent and manner of patient involvement in health professional education and

these have been examined by the use of a number of conceptual frameworks. The Cambridge framework developed by Spencer et al. (2000) describes the classification of the setting of involvement:

- Who: the individual background, culture, and experience of each patient, their family, and carers.
- How: including, patient role (passive or active), nature of the encounter, length of contact, and degree of supervision.
- What: the content of the education including the type of problem (general versus specific) and the knowledge, skills, and values to be learned.
- Where: location of interaction (for example, community, hospital ward, clinic).

This framework provides an overview of the possibilities of how active a role patients/service users may play in the patient/learner encounter.

Tew and Foster (2004) describe a framework for classifying the extent of involvement. Their 'Ladder of Involvement' included five steps: little involvement; emerging involvement; growing involvement; collaboration; partnership. This has been used in many studies and discourses on user involvement and was heavily influenced by Arnstein's 'Ladder of Citizen Participation' (Arnstein 1969). Other frameworks exist which measure patient engagement in healthcare, but the framework devised by Towle et al. (2010) integrated the Cambridge framework and Tew's Ladder of Involvement to produce a taxonomy with elements of both these models (Table 1), specifically designed to measure the depth and impact of involvement in education rather than in healthcare in general. The Towle framework was selected as a pragmatic, comprehensive framework that enables us to highlight the significant diversity of service-user involvement within medical education.

Previous reviews (Morgan and Jones 2009; Spencer et al. 2011) primarily sought to characterize the concept of 'what' involvement is taking place and whether such works are effective at enhancing learning encounters. However, both these reviews were not systematic and attempted no synthesis of evidence using a scholarly secondary research approach. More importantly, given the advent of more recent strategic guidance after these reviews were published that has likely led to contemporaneous research reports, there is a need for an up to date systematic review of the literature. This review must address three different aspects through a synthesis of the evidence base. These are those aspects described within Cook et al's (2008) framework of medical education research and led to three distinct research questions:

- What service user involvement is taking place in medical education (description)?
- To what extent this involvement impacts the student's education (justification)?
- How and why such learning may be impacted by service user involvement (Clarification)?

This final question is one that has not been previously addressed and indicated as an area of work needed (Spencer et al. 2011).

## Methods

No single research paradigm underpins this review. We planned to embrace both positivism (through alignment to a systematic, transparent and reproducible model for evidence collection and consideration of our justification and descriptive outcomes) and constructivism (through consideration of underpinning theoretical frameworks that inform interventions and synthesis of content and outcomes to address our clarification questions).

The study protocol was peer-reviewed and published by BEME on the 13th January 2016 (Gordon et al. 2016). Due to changes in roles of the main authors and delays in securing agreed funding for the project, there were several delays and the review was placed on hold and officially started again on 1st July 2017. Funding was sought from Blackpool Teaching Hospitals' 'Blue Skies' charity which supports numerous projects, including research. The funding provided one researcher's salary (0.2 WTE) for 10 months.

We have reported our findings in alignment with the STORIES (Structured approach to the reporting in health-care education of evidence synthesis) statement (Gordon and Gibbs 2014), as well as by using the BEME review checklist (Hammick et al. 2010).

## Search strategy

We conducted our search on 1st September 2017. We used a standardized search strategy (Supplementary Appendix 1) following a recognized methodology (Jenkins 2004) to the following databases: MEDLINE, EMBASE, CINAHL, PsychINFO). Additionally, we reviewed articles listed as references in included studies, and we contacted experts in the field of service user involvement identified as authors of key opinion pieces and cited works from this review. In addition to online searching of the databases, abstracts from the last 5 years of the Association for Medical Education Europe (AMEE) annual meeting proceedings (2013–2017 inclusive) were hand searched. Where published studies were not available, authors of abstracts were contacted by email. Authors who did not respond were contacted a second time before being excluded. We included studies undertaken in any country and published in English. No limitation on the search dates was imposed. Whilst the authors were aware the field has changed substantially over the decades, we did not believe the addition of older studies would in any way negatively impact findings.

It is important to note that the search strategy was particularly challenging for this review. This was because the terms 'patient/service user' is so generic and ubiquitous in their use that thousands of irrelevant articles were retrieved. Additionally, the lack of an agreed, uniform nomenclature used for patient/service user involvement complicated the search. We encountered patient instructor/educator, mentor, patient partner, service user, teaching associate, patient volunteer, patient moderator, community educator, lay health mentor amongst the terms used in the literature. Interestingly, the search strategy from a previously published review of the topic (Morgan and Jones 2009) was used as a starting point for scoping and despite

**Table 1.** Towle's taxonomy of the spectrum of patient involvement in medical education (Towle et al. 2010).

A	B	C	D	E	F
Degree to which the patient is actively involved in the learning encounter	Duration of contact with the learner	Patient autonomy during the encounter	Training for the Patient	Patient involvement in planning the encounter and curriculum	Institutional commitment to patient involvement in education
1. <i>Paper-based or electronic case or scenario.</i> Patient is focus of a paper-based, electronic or web-based case or scenario.	None	N/A	N/A	None	Low
2. <i>Standardized or volunteer patient in a clinical setting</i> Patient encounter with student is scripted and serves as an example to illustrate or reinforce learning (e.g. teacher asks patient to provide student with history or student practices a clinical examination)	Encounter-based	None	None	None	Low
3. <i>Patient shares his or her experience within a faculty-directed curriculum</i> Patient is invited to share experience, faculty members plan the encounter but patient determines personal comfort and level of participation	Encounter-based	None-Low	Brief, simple	None	Low
4. <i>Patient-teacher(s) are involved in teaching or evaluating students</i> Patient is given preparation for a specific teaching role, may actively question students, may be involved in giving feedback and evaluating students' performance	Variable	Moderate	Structured, extensive	Low-Moderate	Low-Moderate
5. <i>Patient-teacher(s) as equal partners in student education, evaluation and curriculum development</i> Patients are involved in many aspects of educational delivery, development and evaluation beyond specific courses to the curriculum as a whole; this is a true partnership in which patients make meaningful and valued contributions to decision making	Moderate-extensive	High	Extensive	Moderate-extensive	Moderate
6. <i>Patient(s) involved at the institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development for students.</i> As (5) above but with additional institutional policies that ensure involvement in decision-making bodies within undergraduate, graduate and continuing health professional education.	Extensive	High	Extensive	High	High

N/A = not applicable.

**Table 2.** Inclusion/exclusion criteria.

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>Interventional study designs;</li> <li>Studies had to describe the employment of patients/service users in any fashion that could be categorized using Towle's Taxonomy (Towle et al. 2010).</li> <li>Our target population comprised primarily groups of medics, including medical students, postgraduate trainees, residents and attending physicians. This can be with other professionals, such as nursing students, nurses, nurse practitioners, physician assistants or midwives, but must include medics in the learner groups.</li> <li>Studies that assessed the intervention at any level of Kirkpatrick's Hierarchy of learner outcomes (Yardley and Dornan 2012) and using any primary methodology (comparative, before and after and non-comparative studies).</li> </ul>	<ul style="list-style-type: none"> <li>Surveys, audits, commentaries, and review articles.</li> <li>Studies without any form of assessment of the interventional design</li> <li>Studies that mentioned involvement of service users in a cursory fashion, with no detail given to judge the nature of the involvement.</li> <li>Studies that described an educational intervention, program or curriculum that involved patient / service users as a minor component of a larger package.</li> <li>Papers that described the employment of people who take on a simulated role, including simulated patients or actors.</li> <li>Studies involving other health professional learners as the primary learner group</li> </ul>

limiting to similar dates and following the strategy verbatim, a very different set of results was achieved, raising the further question of this work. We worked closely with our librarian author to refine the search and the final terms are displayed clearly in [Supplementary Appendix 1](#), but differ from the published protocol (Gordon et al. 2016). The limitation of some key terms in describing users was necessary to ensure a viable search, but scoping ensured that no key papers were lost and that this was a valid approach.

### Screening

A pilot screening phase involving the first 500 hundred citations was conducted to ensure closer inter-rater agreement and discussions addressed key areas of lack of clarity. This led to the quality assessment tool being amended slightly so that section three, instead of reading 'no' (mention or details of underpinning, pedagogy, content, etc.) read 'no or extremely limited.' Full screening then took place, with one author (SG) screening the full list of 6155 citations and two authors (MG and DT) independently screening half each. Inter-rater agreement using Cohen's kappa showed fair agreement at 0.401. Conflicts between raters were resolved by discussion before proceeding to full-text evaluation.

### Inclusion/exclusion criteria

The inclusion and exclusion criteria are shown in [Table 2](#). Studies had to discuss the service user involvement in more than a cursory fashion as scoping searches found several studies that simply made a single statement about including service users and no further details. This was independently judged by two authors performing the searches. Studies also had to describe some form of assessment of the intervention in practice to confirm its actual deployment for learners, but any method could be used. The inclusion of medical learners was an arbitrary decision and may lead to the need for future reviews in other settings.

### Data extraction and synthesis

A data extraction form ([Supplementary Appendix 2](#)), based on BEME guidance (Hammick et al. 2010) was used to assess the content of the studies and collected data on the interventions, study types, outcomes and results, as well as Towle criteria relating to user involvement and Kirkpatrick

levels of learner outcomes (Kirkpatrick and Kirkpatrick 2006). This data was then assessed by all three authors to generate themes. In the case of key missing data, authors of studies were contacted to supply this information.

The Towle Taxonomy was selected as a pragmatic, comprehensive framework that enables us to highlight the significant diversity of service user involvement within medical education.

In considering the Towle taxonomy and its use in conceptualizing patient involvement in education, the authors encountered some initial difficulty. The authors initially believed that the implication within the taxonomy is that a given study could be assessed on a single level and that level would dissect the six dimensions A–F. However, it was very clearly apparent that specific interventions were more complex, with rating possible on different levels for each of the six domains. The underpinning assumption is rough alignment across dimensions, but clearly, this is not always the case. As such, it was decided to rate each study individually for each domain and as such receive 6 elements of categorization. Whilst more complex, the authors believe this more accurately synthesizes the evidence for readers. In the case of dimensions where several items were the same (for example, for domain F the first 3 levels are ratings of 'Low'), the lower or higher levels were ignored and the rating set at the most extreme level where the descriptor was appropriate. So in the case of domain F, this would be level 3 at the low end or in the case of domain C, level 5 at the high end. This amendment to the use of the Towle taxonomy is shown in [Supplementary Appendix 3](#).

Kirkpatrick's four levels of learning evaluation, adapted for interventions in medical education research and adopted by the BEME collaboration as part of the systematic review process (Yardley and Dornan 2012), were used to classify outcome measures used by each study. These four levels are:

- Level 1: Reaction – what was the reaction of the learners to the intervention?
- Level 2: Learning – the extent to which participants changed their attitude (Level 2a) or improved their knowledge or skill (Level 2b) following the intervention.
- Level 3: Behavior – change in behavior or practice due to the intervention.
- Level 4: Results – changes in organizational practice (Level 4a) or benefit to patients/clients (Level 4b) due to the intervention.

Studies may describe outcomes that reflect more than one level on the hierarchy.

### Synthesis of evidence

A descriptive synthesis took place which summarizes the data from the studies, focusing on study type, educational intervention, collaboration details and outcomes of the primary study. Key method, content and outcome items to be extracted from the studies were discussed and agreed by the authors. Additionally, content related to the quality assessment indices was extracted, including where relevant any additional content or appendices. The inclusion of key details that focus on the educational intervention being described and assessed by the included studies was a unique addition not addressed in previous reviews of the patient/service user literature. As stated below in *quality assessment*, this equated higher levels of reporting in key areas of educational interest as higher quality, as this was of implicit utility to primary readers and therefore readers of this review. This information is offered within a tabulated form to allow readers to gain utility from considering such content. Additionally, the presentation of the RAG (red, amber, green) ratings of such interventional reporting should support readers in making decisions on the use of such information. The data is also summarized within the context of the results.

If suitably homogeneous outcome data were present, meta-analysis – to explain Justification – was planned as per our published protocol. However, as such data was not available in any of the studies, details are not reported.

Meta-ethnography – to describe Clarification – is a qualitative synthesis technique which involves the synthesis of the findings of qualitative studies (Dixon-Woods et al. 2005). As mentioned before, it was planned to address our third research question with this method, but as there was a paucity of such data, these methods are not reported in full and no such analysis was completed.

### Quality assessment of included studies

Whilst there have been many different methods employed to assess quality within the context of health education systematic review, no consensus method exists. There are two key elements to consider: Firstly, the methodological quality of any study and secondly, the quality of any educational interventions presented. This distinction is important as a report may be methodologically sound with high-quality reporting of investigative process, but if the education that was the intervention itself is not reported in detail, not underpinned theoretically, not described from a resource or cost perspective and materials not available, it is hard to suggest this as a high-quality piece of educational writing.

A visual RAG ranking system, previously used in an earlier systematic review (Gordon et al. 2011), was employed to judge the quality or extent of the *reporting* of information in each of six areas relating to the educational intervention:

- Theoretical underpinning
- Curriculum or syllabus design

- Setting (educational context and learner characteristics)
- Pedagogy
- Content
- Strength of conclusion

Items were judged to be of high quality (green), unclear quality (amber), low quality (red) in terms of comprehensiveness in each of the above reporting areas, rather than the merit of what was reported.

### Patient/service user involvement

Due to the topic of this systematic review, we felt it pertinent to involve service users from the start. We contacted the COMENSUS (Community Engagement and Service User Support) group at UCLan for interested users and two from this group volunteered to review the manuscript and add a user perspective to the discussion.

### Results

The literature search produced an initial 11,093 citations, with a further 47 identified from reference lists and AMEE conference abstracts. No further unique studies were received from contacting four experts in the field. After removing duplicates, the resulting 6155 citations were available for screening.

All three authors then screened the abstracts of 96 full-text articles to determine eligibility for inclusion, using the inclusion/exclusion checklist described above. Disagreements were resolved by discussion and a final total of 39 articles were deemed to meet the inclusion criteria, with study flow shown in [Figure 1](#).

### Excluded studies

The list of excluded studies can be found in [Supplementary Appendix 4](#), but of the 57 excluded studies, the most common reason was lack of any form of evaluation of the intervention (46 studies). A further 11 studies involved other health professionals as the primary learner group, i.e. not medics.

### Overview of included studies

Relevant details of the 39 included studies are shown in [Supplementary Appendix 3](#). Further comprehensive data can be found in [Supplementary Appendix 5](#).

### Level of involvement of patients/service users

[Figure 2](#) shows the categorization of the individual studies according to Towle's framework, mapping to the six domains and ranging across the six levels of this taxonomy, thus demonstrating how the current literature reflects the range of the depth and impact of patient/service user involvement in medical education. Our exclusion criteria specifically removed all level 1 studies and so none were included.

The majority of studies involved patients at Level 3 or Level 4 of Towle's Taxonomy (see [Supplementary Appendix](#)

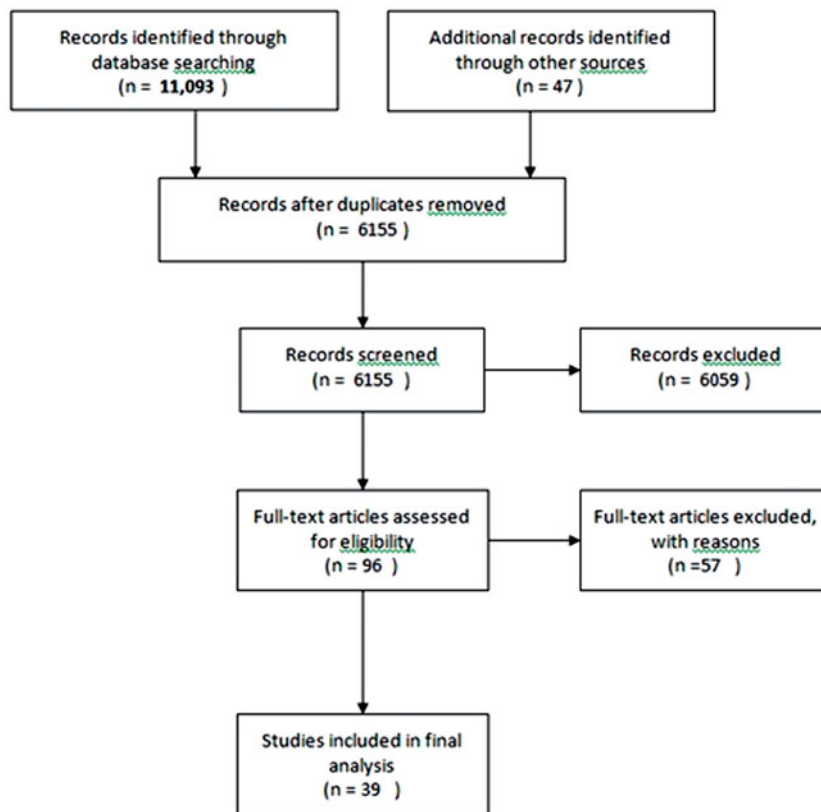


Figure 1. Study flow diagram.

4 and Figure 2), which indicates the feasibility of involving patients as facilitators, teachers or assessors.

#### Encounter-based studies

The encounter is planned by faculty; the patient is invited to share their experience; personal comfort and level of participation is determined by the patient. Of the 17 studies in this category, 16 used descriptive techniques in a qualitative methodology and suggested benefits to learners of increased empathy and understanding of illness as experienced by patients; improved communication with patients and a greater understanding of holistic and patient-centered care. The benefits to patients, where reported, included improved communication by ‘breaking down barriers’ (Cooper and Spencer-Dawe 2006), a belief that their personal stories will help to improve treatment effectiveness (Salerno-Kennedy et al. 2009; Graham et al. 2014), and enjoyment of the session (Jha et al. 2013; Lenton and Storr 2015; Makker 2017).

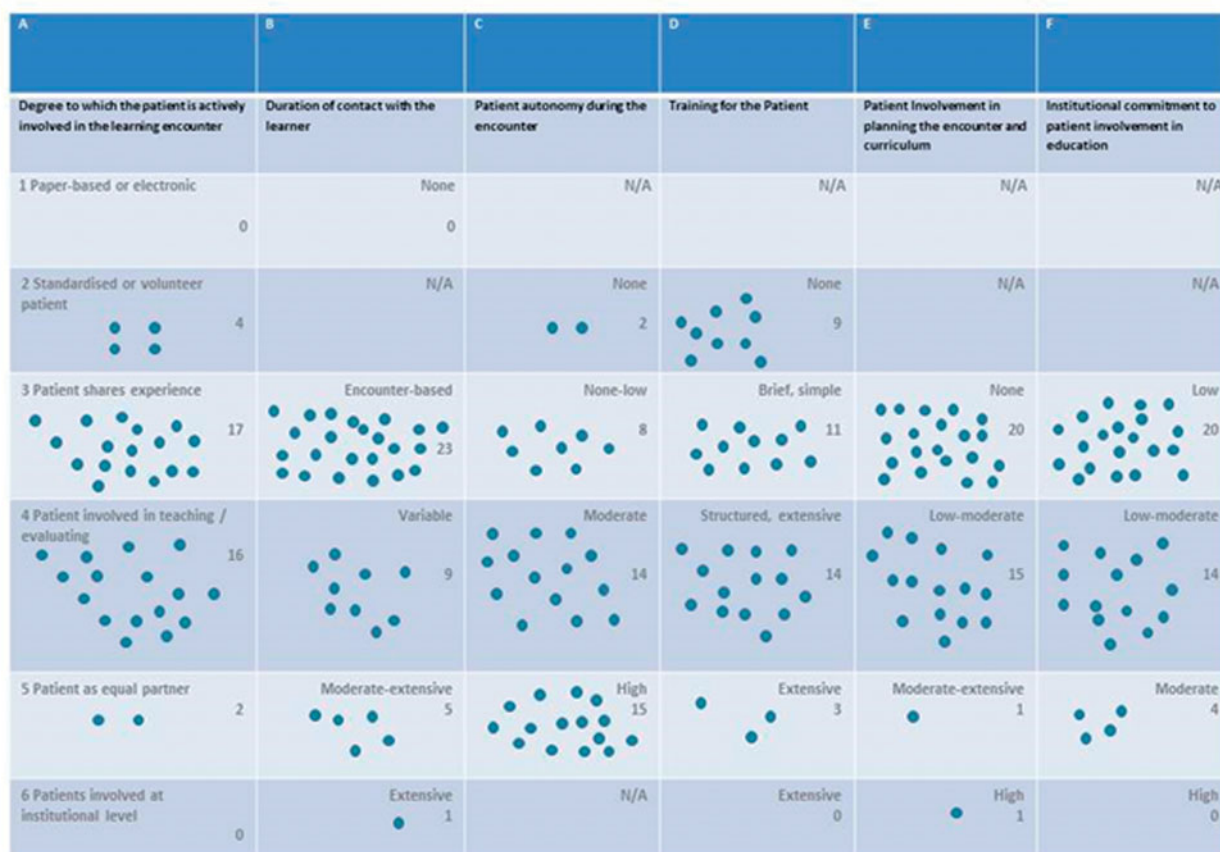
Examples of interventions at this level include Arenson and colleagues’ study (Arenson et al. 2015) which utilized ‘Health Mentors’ to facilitate learning between health professionals. The 4 module encounter with patients, who had at least one disability or chronic health condition, provided an opportunity for teamwork between teams of medical students and students from allied professions. This was a moderately well-reported study according to our quality criteria and the results showed a benefit in developing collaboration within student teams. Only one study in this category (Jha et al. 2015) provided ‘justification’ by means of comparison with standard teaching, as well as attempting ‘clarification’ by using Kumagai’s transformative learning framework of empathy and moral development, by which they explained how the patient narratives helped

‘communicate meaning’ by evoking an emotional response among the participants. This randomized control trial (RCT), in which patients shared their experiences of medical errors or harm to enhance safety training amongst doctors, showed no difference between the intervention and control groups in its primary aim – to change attitudes towards patient safety.

Only one other study in this category reported a theoretical underpinning for their study (Cooper and Spencer-Dawe 2006). In this qualitative study, trained service users co-facilitated inter-professional workshops to enable students from different professional groups to ‘learn with and from each other with a view to raising awareness about collaborative practice and its link to improving the effectiveness of care delivery.’ The underpinning complexity theory of self-organization, connectivity, emergence, the edge of chaos drew out the themes of linearity, unpredictability, self-organization, connectivity, and emergence. Students’ experience of hearing about users’ personal experiences and their involvement with services (their ‘stories’) enhanced inter-professional integration, partnership working and teamwork through a heightened patient-centered perspective in providing holistic care and a better understanding of the theoretical concepts underpinning teamwork.

#### Patients as teachers/assessors

The patient is given preparation for a specific teaching role and may give feedback or evaluate student performance. All but one of the 16 studies we assessed at Towle Level 4 were interventions which taught practical clinical examination or assessment techniques and, as such, were often able to compare outcomes with a control group or intervention (justification). Outcomes of the comparison studies



**Figure 2.** Studies mapped to each of the six domains and six levels of the Towle Taxonomy of involvement. ● represents one study. This indicates the range of the depth of involvement of the patient/service user, from a passive participant sharing their experiences in a faculty-led encounter to a fully integrated member of the curriculum-planning faculty, with autonomy for planning and delivery.

in this category demonstrated that teaching by patients/service users is at least as effective (Anderson and Meyer 1978; Kleinman et al. 1996; Hendry et al. 1999; Schrieber et al. 2000; Smith et al. 2000; Duffy et al. 2016) as teaching by faculty and, in some studies, was shown to be more effective (Branch et al. 1999; Haq et al. 2006; Livingstone et al. 1980). Of the studies which used a pre- and post-test outcome measure, these also showed an increase in skill/knowledge attainment. For example, Bideau and colleagues (Bideau et al. 2006) employed extensively-trained 'Patient Instructors' (PIs) who planned and taught sessions on examination of the knee and hand. This study comprehensively reported the curriculum and content of the sessions, enabling reproduction of this study for future research. It noted a marked improvement in students' ability to grasp the psychological, emotional, social, professional and family aspects of the disease and suggested this may be due to the direct contact with real patients. Henriksen and Ringsted's study (Henriksen and Ringsted 2014) used a qualitative methodology using a theoretical model devised by themselves in a previous study to assess teaching delivered by rheumatologists compared with PIs. They found that, in terms of power relations, the PI-student relationship differs from those between faculty teachers and students, and students and patients in the clinic. This balanced power relationship legitimizes the students' taking on the role of learners and daring to ask questions they perceive to be inappropriate to the clinical setting. This study clarified and confirmed the sensitizing concepts of content matter, pedagogical format and power relationship which had emerged from their earlier theory but also

introduced a new concept of negotiations about knowledge – experiential or scientific biomedical knowledge.

Results of the studies in this category suggest that utilizing patients as teachers and assessors work best when it is possible to construct standardized assessment checklists and scoring criteria. This finding was more or less consistent across all of the Level 4 studies, with a further finding that, when tested, the improvements were not sustained at objective structured clinical examination (OSCE) or follow up (Livingstone et al. 1980; Gruppen et al. 1996; Smith et al. 2000; Duffy et al. 2016).

#### *Patients as equal partners*

Patient tutors are involved in many aspects of educational delivery, development, and evaluation. Only 2 studies (Owen and Reay 2004; Towle and Godolphin 2013), which described consumers as tutors, were categorized as Level 5 on Towle's Taxonomy – patient teachers as equal partners. In Owen and Reay's (2004) study, consumer tutors were involved in all aspects of planning, development, implementation, and evaluation as part of a steering committee that authored the student curriculum. This study gave a clear description of patient-teachers being involved as equal partners in the delivery of a curriculum for 4th-year medical students in effective approaches to interviewing and making a meaningful and valued contribution to medical education. Towle and Godolphin's (2013) study describe Consumer Educators and their unique role in designing, delivering and evaluating inter-professional educational workshops on living with and managing chronic



conditions. The workshops were designed by the Consumer Educators, with input from faculty as part of an Advisory Group, but faculty did not mediate or control the teaching. Only Towle's study in this category utilized a theoretical basis on which to base the outcomes. They used a patient-centeredness framework, where the patient is the teacher, to study a program of interprofessional education using patients as educators, specifically to clarify how the experience and expertise of patients reduce the power imbalance and enhances learning.

We did not find evidence of Level 6 within the 39 studies, whereby patient partners are involved at the institutional level with the support of institutional policies.

### **Benefits for learners (using Kirkpatrick's levels of training evaluation)**

Nine of the studies were assessed as reporting Kirkpatrick level 1 only (learner reactions to the quality or acceptability of the intervention), and not attempting to assess any other aspect of the outcome of the educational intervention. These were generally feasibility studies which assessed the practicalities and benefits of involving patients in medical education and usually concluded that involving patients was both feasible and practical in attempting to enhance trainees' perceptions of patient-centered care. In total, 29 studies reported outcomes at level 1, but many also reported further outcomes as described in the following text.

16 studies reported Kirkpatrick Level 2a (modification of attitudes or perceptions following the intervention). These employ different research methodologies (RCT, observational, qualitative and pre/post-test). Five of these studies also reached Towle's taxonomy of 4 or above (Gruppen et al. 1996; Farber et al. 2003; Owen and Reay 2004; Towle and Godolphin 2013; Henriksen and Ringsted 2014) indicating that the patient was deeply involved in the educational intervention as teacher and, often, as assessor. Farber's study involved cancer patients using their own case histories to teach 'breaking bad news' concepts to internal medicine residents. This pre- and post-test study used a four-point Likert scale questionnaire to gather responses to 11 items on giving bad news to patients. The results indicated that the participants gained enhanced empathy towards patients in three areas: ensuring they convey hope to the patient; ascertaining the patient's initial understanding of their condition and encouraging the expression of feelings. In Owen and Reay's (2004) study consumers were involved in all aspects of the planning, delivery, and evaluation of the curriculum. The main outcome of the study was that it raised the profile amongst participants of consumers as legitimate teachers of interviewing skills in medical education.

Of the 15 studies that reported outcomes at Kirkpatrick level 2b (increased knowledge or skills) the majority (14 studies) measured participants' approaches to the clinical or physical examination skills using traditional quantitative data capture methodologies – RCTs, pre-and post-test designs or comparison groups. Duffy et al's (2016) RCT involved trained Gynecology Teaching Associates (GTAs) delivering gynecological examination skills sessions to medical students which demonstrated improvements in

students' knowledge, comfort, and confidence, with no significant difference in summative OSCE scores between the intervention and control groups. The remaining study (Graham et al. 2014) used a qualitative approach to study interviewing or history taking skills amongst patients with Tourette Syndrome and reported an improvement in participants' knowledge of the syndrome, along with an increase in empathy and humanistic approach to these patients.

No studies reported outcomes at levels 3 or 4 of Kirkpatrick's hierarchy of patient or user involvement – transfer of skills into practice or leading to a change in practice across an organization. Some studies attempted to follow up the participants after the intervention (Anderson and Meyer 1978; Gruppen et al. 1996; Duffy et al. 2016), but only assessed the outcomes relating to the participants – they did not assess the benefit of the intervention on organizational attitudes to patient involvement in medical education or the benefit to patients that resulted from the study.

### **Study methodology**

The majority of studies used a qualitative methodology – focus groups or interviews. Whilst these do not allow for quantitative analysis of the impact of the interventions they are an extremely rich source of experiential data which will allow future studies to build on the findings and create a clearer perspective on patient involvement in medical education. These studies demonstrated how issues of professionalism, communication, attitude towards health and illness, interviewing skills and competencies, patient-centredness and holistic care could effectively be taught using patient or service users in the educational intervention.

Pre-and post-test studies collected several baseline measures and were then able to draw conclusions on whether the training had led to an impact on any aspect of learning. However, they do not determine which aspect of the intervention led to the change. The seven studies which used a control group design enabled comparisons to be made between the teaching involving patients and the standard teaching methods normally employed. In all of these, except Jha et al. (2013), the studies concluded that involving patients was at least as effective as standard teaching practices.

Only four studies classified themselves as RCTs, although the method of randomization was not stated. Of these, two (Hendry et al. 1999; Duffy et al. 2016) concluded that patient-led teaching had a moderate effect on learning outcomes, Jha et al. (2015) concluded that patient-led teaching was no more effective than faculty-led teaching and Humphrey-Murto et al. (2004) found that faculty-led teaching was more effective in MSK examination than patient-led teaching.

### **Learner type and context**

A high proportion (77%) of the included studies involved solely undergraduate medical students as the learner group. Of these, 11 were in their pre-clinical years and 19 were in their clinical years.

Only six studies focused on the continuing professional education of postgraduates, with two studies including both undergraduate and postgraduate trainees.

### **Clinical speciality**

The studies could be grouped into 6 major clinical specialities: musculoskeletal (11 studies), long-term/chronic health conditions (10 studies), mental health (3 studies), gynecology (3 studies), cancer (2 studies), other or not specified (11 studies).

In the musculoskeletal and gynecology studies the intervention generally consisted of applied techniques, i.e. the teaching of a specific joint examination technique, with the patient being involved to a greater or lesser extent in the teaching, assessment, and feedback. 5 of the 14 studies (Gruppen et al. 1996; Kleinman et al. 1996; Bideau et al. 2006; Haq et al. 2006; Duffy et al. 2016) specifically sought to explore elements other than simply joint examination teaching: for example, history taking with a special emphasis on the psychological and functional impact of the disease or incorporating patient-centred empathy and increasing student comfort and confidence. The conclusion in 10 of these studies was that skills teaching by trained patients were at least as effective as training by faculty whereas just one study had a different finding and concluded that rheumatology faculty were more effective teachers of the MSK physical examination than patient partners (Humphrey-Murto et al. 2004).

Patient involvement in teaching related to long term health conditions was the subject of 10 studies, the purpose of which was to allow the students/trainees to explore patients' lived experiences of managing a long-term condition, gain a greater understanding of the doctor-patient relationship, or explore interdisciplinary approaches to patient care.

In the remaining studies, the health conditions included mental health, cardiovascular disease, diabetes, kidney conditions, or simply were not stated as the studies concentrated on the personal experiences of healthcare users and their authentic role in helping trainees gain skills in interviewing techniques, empathy, and attitudes towards patient-centered care.

### **Methodological quality of included studies**

The quality assessment method incorporated a visual RAG ranking system to judge the quality of the reported education in question (see methods section).

In terms of theoretical underpinning, only four studies achieved a ranking of green (high quality) for the reporting of these criteria (Cooper and Spencer-Dawe 2006; Towle and Godolphin 2013; Henriksen and Ringsted 2014; Jha et al. 2015). Cooper and Spencer-Dawe chose complexity theory as their underpinning theory and the four principles of self-organization, connectivity, emergence, edge of chaos were used to guide the development of the project, which they then went on to discuss using five areas of a-linearity, unpredictability, self-organization, connectivity, and emergence (Cooper and Spencer-Dawe 2006). Henriksen and Ringsted based their study on constructionist theory and drew sensitizing concepts from a prior

model which explored the power balance between patient-teachers and students (Henriksen and Ringsted 2014). Jha and colleagues used the conceptual framework of transformative learning suggested by Kumagai to deliberately use emotional stories from patients to enhance the learning experience of trainees and to provide the learners with a greater understanding of safety from the patient's perspective (Jha et al. 2015). Towle and Godolphin used the Bleakley and Bligh framework of patient-centredness to study a program of interprofessional education using patients as educators, specifically to determine how the experience and expertise of patients reduce the power imbalance and enhances learning (Towle and Godolphin 2013).

Description of the curriculum was sufficiently described in six studies (Owen and Reay 2004; Bideau et al. 2006; Towle and Godolphin 2013; Arenson et al. 2015; Jha et al. 2015; Duffy et al. 2016), but in the remaining studies we felt the description of the curriculum or syllabus lacked the depth or level of detail required for accurate replication of the study in future research. Similarly, not all studies included sufficient details of the pedagogy, setting, and content of the intervention. Only Cahill et al. (2015), Duffy et al. (2016), Jha et al. (2015), Owen and Reay (2004), and Towle and Godolphin (2013) achieved close to an optimum description of the above criteria. These studies describe fairly comprehensively the requirements for each of their interventions so that the study could be replicated with learners in a similar or different context to test their theories and further develop their conceptual frameworks.

### **Discussion**

Since the publication of a previous review of the literature around patient involvement in medical education (Morgan and Jones 2009), there have been at least 18 new studies identified in this review.

With regard to the level of involvement of patients/service users in education, our review shows that a high number of studies are demonstrating the feasibility of users contributing to teaching, assessing and evaluating (Towle level 4 – 16 studies) and also in sharing their experiences directly with students (Towle Level 3 – 17 studies). Future research should address the involvement of patients/service users at a higher level i.e. as equal partners in developing, delivering and assessing educational curricula, as the studies by Towle and Godolphin (2013) and Owen and Reay (2004) have shown that this is possible and can be successful.

Morgan and Jones's review found the majority of studies to evaluate outcomes at Kirkpatrick Level 2 – immediate impact on learner knowledge, skills, and attitudes. Our review found similar, with the higher number of studies in our current review which evaluate outcomes at Level 2 (impact on learning) demonstrating that medical educators are attempting to evaluate the impact of user involvement on student attitudes and skills but are still not finding ways to embed this learning, i.e. demonstrate an impact on behavior in practice, and thus make a difference to patient care.

Most of the studies were of undergraduates. These findings perhaps reflect the problems in redesigning

postgraduate training programs to incorporate research, due to increasingly overburdened curricula in postgraduate education, which need to balance service delivery and multi-faceted professional, managerial and leadership development. Additionally, as patient involvement may be seen as implicit for postgraduates working with patients, such studies may not be pursued.

The overall quality of the actual primary study reporting of interventions was poor. With 39 studies published, half in the last 10 years, the fact that less than a fifth of studies presented sufficient content to allow their actual intervention to be understood or disseminated is extremely disappointing. When it comes to theory, just four studies were judged as high quality, providing underpinning that allows understanding of how or why interventions were deployed in a particular manner. This is, unfortunately, a pervasive problem in the field that BEME reviews often identify, but this is simply not an excuse for publishing studies that leave readers asking 'so what.' This, of course, raises the question as to why studies do not report such key outcomes. There are three possibilities in answering the question. Firstly, the authors simply may have chosen not to publish some data, a problem well reported (Hoffman et al. 2013). Secondly, the lack of publishing may be because such considerations have not been made, with either theory not considered or content not produced in any meaningful way, suggesting low-quality education. The third option could be elements of both, with perhaps some more work available than published, but not at a sufficient standard that the authors felt able to publish. Unfortunately, when considering the evidence base as a whole, we can only consider what is available and therefore this significantly limits the utility of the evidence in this area for future teaching and research works.

Within the contexts of Cook et al's (2008) classification, there is limited work to answer our initial 'what,' 'how,' and 'why' questions. Considering these in turn, description of the curriculum (what) was sufficiently described in just 6 studies and pedagogy, setting and content of the intervention described in just 5 studies in this review (see RAG ratings in Table 3). Without these simple, but crucial attributes of interventions, it is impossible to readers of the primary literature and in turn readers of this review to have any insight into the nature of the interventions reported. This is a paradoxical, but unfortunately common finding within the education literature (Gordon 2016). But this is a more important barrier to utility in the context of this topic, which is not established fully throughout the field and is evolving.

Our review also shows that very few studies have attempted to answer the question 'how' or 'why' a particular intervention work. Of the 39 studies included only 4 of them described an underpinning theory or framework with which to present their findings. Such studies are required to advance our understanding of medical education by mapping outcomes to learning theories and explain why an intervention works. The theories used in the studies we evaluated were complexity theory (Cooper and Spencer-Dawe 2006), constructionist theory (Henriksen and Ringsted 2014), transformative learning (Jha et al. 2015), socio-cultural learning theory (Towle et al. 2014). These studies demonstrated how learning theories can translate into

pedagogical programs to create a power balance between trainee and patient, empowering patients to take on a teaching role and the trainee to be able to question patients without needing to be in the role of responsible competent professional. Additionally, learning theories help to explain the concepts of empathy and patient-centredness and demonstrate how a humanistic approach to an educational intervention involving patients can lead to an enhanced understanding of the meaning of medicine and the emotional response to medical intervention and, ultimately, allow learners to better identify with the patient.

There is clear evidence of an increased range of service user involvement in medical education. What is encouraging to note is that several institutions in these studies have established formal user engagement groups to ensure patient or service user involvement in medical education. The University of Wisconsin (Arenson et al. 2015) has been incorporating the Health Mentors Program into their teaching since 2007, the Launceston Clinical School in Tasmania (Barr et al. 2014) has established a Patient Partner program for over 8 years, the University of Liverpool has a Forum of Carers and Users of Services (FOCUS) group which plays a key role in user involvement in healthcare education (Cooper and Spencer-Dawe 2006). Other institutions which have similar formal groups to promote patient or user involvement are the University of Copenhagen (Henriksen and Ringsted 2014), the University of Nebraska (Hinners and Potter 2006), North Carolina Medical School (Kleinman et al. 1996), University of Queensland, Australia (Lane et al. 2015), University of Arizona (Mohler et al. 2010), University of Sydney (Owen and Reay 2004), University of British Columbia (Towle and Godolphin 2013; Towle et al. 2014).

Reflecting the findings of previous publications (Department of Health 2007; Morgan and Jones 2009; Spencer et al. 2011) we have found that involving patients in the teaching and assessing of students and trainees has several benefits: for learners their understanding of patient-centered care and the humanistic aspect of the impact of illness on everyday life is enhanced, they report greater confidence in their own knowledge of examination and history taking skills and they enjoy sessions where patients/service users are involved. The benefits for patients include satisfaction from using their personal experiences in medical education and greater confidence in their knowledge of their own health or illness.

There are, obviously, difficulties in designing research studies in this field. Apart from the practicalities of identifying, recruiting, training and maintaining patient educators, there can often be a lack of clarity on outcome measures, the multitude of variables which need to be considered in concluding any kind of impact, the strength of conclusions when studies are based on participants' perceptions rather than observed behavior and the possible reluctance of faculty in relinquishing their role of expert.

Our service user authors were integral in the synthesis and interpretation of this data and were involved in several discussions about the content, findings, and format of the final manuscript. There were several key points that came from these discussions that are relevant. Funding is an important issue and is mentioned in only a few of the studies. Payments for time, or for incurred expenses are offered by some medical education institutions and, due to

the limited amount of budget available, can sometimes curtail the amount of involvement realistically achievable. Additionally, if service users are paid at the market rate, should they not be classed as a 'professional service user and patient?' Nonpayment can also have both positive and negative outcomes. The positive being that numbers of patient/service user representatives within the universities may increase. Enabling patients with diverse conditions and backgrounds can ensure their unique voice, ideas and opinions are heard, whilst they are considered to be independent. Negative aspects, such as capricious funding arrangements in medical schools may mean 'patients/service users are informed at short notice, that they are not required to attend meetings.' This leads to questions around authenticity and will impact on the opportunity for learning for the students. Another important aspect is the impact of funding on patients' state benefits, with some central government sources viewing such income negatively and in turn creating a negative pressure that would penalize involvement. This must be considered in the local context of each university.

Due to existing and long-standing practices within medical schools, there can often appear to be a tokenistic approach to patient/service user involvement in education. The focus of Towle outcomes in what is the synthesized sum of published literature does little to dispel this subjective view. The experiences of our user authors are that involvement at levels 2 or 3 of Towle's Taxonomy can leave such volunteers feeling like 'a live body to be poked and prodded' rather than an authentic partner in the learning experience. Patients have a wealth of knowledge about their own conditions and experiences of services which can give a unique perspective – offering a holistic and humanistic approach to medical education. Building a framework to work in partnership and gain from this authenticity is something the literature clearly still does not guide, leaving those with the vision to increase the use of such methods still left asking how to do this.

Training is also an important aspect of patient/service user involvement – it gives patients a better understanding of what is required of them and it can highlight any strengths or weaknesses which can then be addressed. However, in the studies included it is the faculty members who mostly made the decisions regarding the content, timing, and funding of training. This clearly has an impact on the ultimate end working relationship and should be considered for those looking to achieve higher levels of involvement.

### Limitations of the review

This systematic review has several limitations: the search was restricted to the English language only articles due to a lack of availability of translation services. A frustrating constraint was the lack of consistency over the terminology used to describe patients/service users involvement in patient-centered care and medical education. As is always required in any synthesis, pragmatic judgments had to be made, as well as a measurement of the author's level of agreements within the review. However, it is possible that certain papers were not included that may be relevant. Related to this, a pragmatic decision was made to not

include paper-based or electronic scenarios within this review (Level 1 of Towle's Taxonomy). The review is also limited by the methodological quality of the included studies pertaining to the lack of detail in reporting – particularly around theoretical concepts, pedagogy, and curricula. This precluded any form of synthesis of the outcomes of the studies.

### Implications for teaching

This review has shown, through 'justification' studies, that teaching by patients/service users can be at least as effective as teaching by faculty. In addition, patients and consumers of healthcare services have a rich knowledge of their own illnesses which can greatly enhance learners' attitudes, knowledge, and empathy but the extent to which this expertise could best be employed in educational programs is yet to be discovered. What is clear is that patient-led teaching opportunities can cover a diverse range of topics, including physical examination skills, consultation and history-taking, inter-professional education, the experience of living with an illness, the effect on partners and families, and the changing dynamic of patient/professional relationships (patient empowerment). The large body of evidence has clearly identified there are no real contextual or learner factors that prevent the involvement of users at any level of Towle's Taxonomy. This is a key finding and from the perspective of the author team and specifically the user authors on this review, they felt it as a takeaway message that must be considered by readers.

However, it should also be apparent to readers that the evidence base is limited in all ways it can be synthesized. We were not able to determine an optimum level of patient involvement to demonstrate benefits of this method of teaching and the lack of detail of content, pedagogy, and curricula preclude many of these studies being replicated accurately. Similarly, we were unable to identify which aspects of the interventions worked most effectively, for whom, in what circumstances and in particular how to optimize the type of involvement from the user perspective to ensure an optimal relationship. We cannot give extensive evidence of content or theory, however, would suggest clinical teachers consider the relevant sections of the results that do report the limited high-quality evidence in this area and use this as a starting point for local production of resources.

### Implications for further research

This systematic review has highlighted a lack of educationally robust studies which are needed to advance our understanding of user involvement in medical education by exploring context and learning processes which would then map outcomes to learning theory concepts and explain why an intervention works. This is a key area for future focus, with studies specifically describing what they have done in the context of a framework, such as Towle's, as well as why these choices were made. This is not hinged on the methodology of investigation of studies, which while poor, is not integral to meeting this concern. Instead, authors simply need to present their education in a manner that fully presents 'what' teaching they have done. It is

not costly or difficult to present learning objectives, content produced, curriculum maps and even the theoretical or conceptual elements employed to support production. Such reporting may then start to form an evidential agreement as to how patients are best employed within medical education. Studies also adopting learning theories would enable a clearer picture of the value of the different aspects of patient/user involvement – whether this is to elicit patient-centered care by sharing their experiences, to improve communication and history-taking skills by giving immediate feedback on learners' interpersonal skills, or by using their knowledge of their own condition to give expert instruction in place of faculty educators. Measuring outcomes from the perspective of the user is also needed, such as how they perceive their role and what they gain from involvement. Finally, the value must always be considered and reporting on the resources directly or indirectly needed to facilitate such involvement is vital. It is worth noting that none of these elements should massively encumber writers of future papers and could hugely impact the evidence base.

## Conclusions

Despite a recent increase in the number of publications exploring patient involvement in medical education, these reports fail to move the scholarly or teaching field forward. The studies explore a wide range of methods of involvement and demonstrate the feasibility of involving patients or service users in educational interventions. They show that patient involvement can effectively deliver practical clinical skills, history taking and interview skills, enhanced perceptions of communication and empathy, and can enrich medical education by allowing learners to explore patient-centered perspectives in holistic care. However, the extent to which patients are involved at an institutional level or, indeed, at the level of designing educational curricula, has not improved. Nor has the outcomes of these interventions progressed. We need to see evidence of patient involvement benefitting learners not just in an educational context, but in professional practice. There is also a lack of reporting of pedagogy, content, curricula or any other key elements that facilitate dissemination or replication of research methods to involve patients and service users. Future studies must be underpinned by clear and relevant theory, implemented with appropriate pedagogy and reported in a fashion that supports evidence-based replication and dissemination of patient and service users in medical education.

## Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

## Funding

The present study was financially supported by Blue skies charity.

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