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**Patient/service user involvement in medical education: A Best Evidence Medical Education (BEME) systematic review**

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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 was undertaken. Citations were screened and consensus reached for inclusion / exclusion of studies. Quality of study design and interventional presentation were assessed. Synthesis was planned at three levels – descriptive, meta-analysis and meta-ethnography, where sufficient data was available.

**Results:** A total of 11,140 articles were initially identified, with 39 included in the review. Using the Towle Taxonomy for patient involvement in medical education we identified 4 studies that were encounter based, 17 with patients sharing their personal experiences with students, 16 with patients involved in teaching and/or evaluating students, 2 studies describing consumers as tutors and none with involvement at the institutional level. The majority (29) of studies employed outcomes at level 1 or level 2 of Kirkpatrick’s hierarchy (learner reactions and modification of attitudes or skills).

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-centre care. Educational quality assessment showed specific weaknesses in theoretical underpinning, curriculum outcomes, content or pedagogy.

## **Conclusions:**

Patients can offer learning opportunities that are at least as effective as faculty trainers in imparting practical clinical skills and can enrich medical education by allowing learners to explore patient-

centred perspectives in holistic care. For educators this review highlights the lack of an underpinning conceptual basis for which to translate theory into practice. Despite a recent increase in the number of publications exploring patient involvement in medical education, there is a lack of reporting of learning outcomes, content, training or other key elements that facilitate dissemination or replication of 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.

## 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 largely as 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 professional and patients should be encouraged. This idea has gained increasing prominence in 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 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' (GMC 2009). They further 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 (GMC 2016).

In other countries, too, there is a call for more involvement of consumers – patients and the public – to be involved 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 organisations, 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 encounter, length of contact, degree of supervision.
- What: the content of the education including 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 et al (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. (Towle 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

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>Standardised 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 practises 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 1 – Towle’s taxonomy of the spectrum of patient involvement in medical education (Towle et. al. 2010)**

Previous reviews (Morgan 2009, Spencer 2011) primarily sought to characterise 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 synthesis of the evidence base. These are those aspects described within Cook's (2009) 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 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 13<sup>th</sup> 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 1<sup>st</sup> 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 healthcare education of Evidence Synthesis) statement (Gordon 2014), as well as by using the BEME review checklist (Hammick 2010)

## **Search strategy**

We conducted our search on 1<sup>st</sup> September 2017. We used a standardized search strategy (**Supplementary Appendix 1**) following a recognised 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 were 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' are 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 previous published review of the topic (Morgan 2009) was used as a starting point for scoping and despite limiting to similar dates and following the strategy verbatim, a very different set of results was achieved, raising further question of this work. We worked closely with our librarian author to refine the search and the final terms are displayed clearly in Appendix 1, but differ from the published protocol (Gordon 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.

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 categorised using Towle's Taxonomy (Towle 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 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, programme 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>

**Table 2: Inclusion /exclusion criteria**

### **Data extraction and synthesis**

A data extraction form (**Supplementary Appendix 2**), based on BEME guidance (Hammick 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. 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 conceptualising 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 6 dimensions A to F. However, it was very clearly apparent that specific interventions were more complex, with rating possible on different levels for each of the 6 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 categorisation. Whilst more complex, the authors believe this more accurately synthesises 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 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: Behaviour – change in behaviour 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 summarises 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 summarised within the text 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 synthesis of the findings of qualitative studies (Dixon-Woods 2005). As above, 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 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 very hard to suggest this is a high quality piece of educational writing.

A visual RAG ranking system, previously used in an earlier systematic review (Gordon 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.

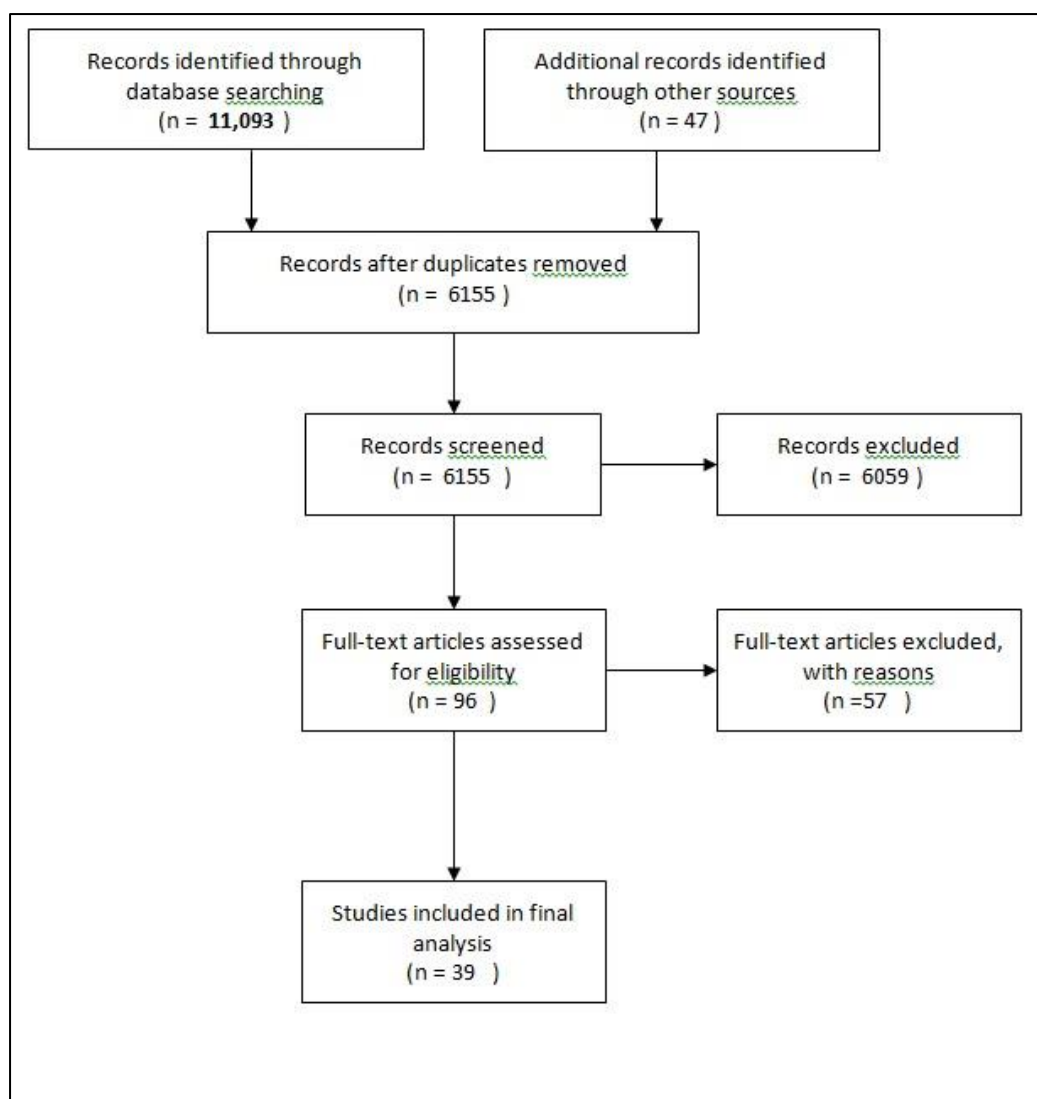
### **Patient / service user involvement**

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 of 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.



**Figure 1 Study flow diagram**

**E**

### **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 below in Table 3. Further comprehensive data can be found in **Supplementary Appendix 5**.

## Included studies

	AUTHOR	Study Type	INTERVENTION	CONCLUSION	QUALITY INDICES*						LEVEL OF OUTCOME	
					U	C u	S	P	Con t	Conc	Kirkpatrick	Towle
1	ANDERSON 1978	Comparison group	Instructor Patients (IP) teach physical examination skills of neurological, MSK, respiratory and cardiovascular systems	IP taught students have comparable technical skills to M.D. faculty taught students, when assessed 5 – 8 weeks after the teaching session.							1, 2b	4
2	ARENSON 2015	Pre- and post-test	Lay Health Mentors educate multidisciplinary teams of students in history taking, wellness planning, patient safety and drug management.	Two different attitude scales were used – one showed significant difference in attitude to teamwork, the other showed no difference in attitude towards interdisciplinary education. Students of all professions valued the health mentor as teacher.							1, 2a	3
3	BARR 2014	Qualitative	Students practice history taking and examination skills with a Patient Partner	Develops insights into patient experiences and the doctor-patient relationship							1	3
4	BIDEAU 2006	Pre- and post-test	Highly trained Patient Instructors (PI) conduct a clinic style consultation consisting of history taking, hand and knee examination and training / correction followed by feedback on performance and attitude.	Total scores for the 38 expected answers were 39% in the pre-test and 47% in the post-test ( $p < 0.001$ ). Students showed improved knowledge of the psychological, emotional, social, and family aspects of the disease.							1, 2b	4
5	BRANCH 1999	Pre- and post-test	Intervention group: MSK examination skills were assessed using clinic experience and AE (Arthritis Educator) as trainer / subject. Control group received clinic experience only.	Residents who had the arthritis educator intervention plus clinic training improved their skills significantly more than the residents who received the clinic training alone.							2b	4
6	CAHILL 2015	Qualitative	2 hour communication workshop to practice interviewing skills with adolescent patients providing feedback.	Implications drawn into the use of patients to assist in training doctors							1	2
7	COLBERT 2009	Qualitative	Quarterly patient conferences allow trainees to reflect on relevant issues of professionalism, communication and system issues.	Qualitative results suggest trainees assimilated the patient feedback to develop their knowledge and competence							1, 2a	3
8	COOPER 2006	Qualitative	Trained service users, selected from FOCUS user group, co-facilitated inter-professional student group workshops designed to enhance inter-professional integration, partnership working and teamwork.	Contact with service users appeared to be associated with an increased awareness of patient centred care, through interconnection of theory and practice – hearing users' real stories							1, 2a	3

9	DUFFY 2016	RCT	Both groups received standard (control) training – lectures/examinations on manikin by gynaecologist. Intervention group received additional teaching: 2 Gynaecology Teaching Associates (laywomen) guided each group of 4 students through Gynae consultation, bimanual and speculum exam, smear test. Each student practised and received feedback. Comparison of scores between groups at end of year OSCE.	Intervention had Moderate Effect on Knowledge and Participant Confidence, Large Effect on Participant Comfort compared to Control at end of clinical rotation. At end of year OSCE 5 months later, overall the intervention had no impact on skills compared with the Control Group.							2b	4	
10	FARBER 2003	Pre- and post-test	Cancer patients facilitated ‘breaking bad news’ scenario and discussion with feedback. Learned concepts were later assessed in a second session.	Two particular aspects showed a change in participants’ attitude following the workshops – conveying hope and assessing patient understanding.								2a	4
11	GALL 1984	Observational	MSK performance and content checklists were devised so that the Patient Instructors could assess if the participants were carrying out the examination correctly and the participants knew the content of the examination. These were then used in 281 examinations during the study period	Performance and content scores showed positive change across repeated encounters with the PI								2b	4
12	GRAHAM 2014	Qualitative	Teenage patient educators (PE) present their medical history and experience of Tourette’s Syndrome. Followed by 20 min Q&A.	Results showed a significant increase in participants self-rated attitude towards empathy following the patient-led presentations								1, 2b	3
13	GRUPPEN 1996	Pre- and post-test	Arthritis Educator (AE) taught basic anatomy, clinical presentation and joint examination of rheumatoid arthritis. Panel discussion with AE explored psychosocial impact of disease.	Improvements in students’ confidence & knowledge of RA and its features, ability to perform joint examination, awareness of the psychosocial aspects of its chronicity. Significant improvement sustained at 12 month follow up.								1,2a, 2b	4
14	HAQ 2006	Comparison group	Patient Partners (PP) interactively taught clinical examination, history taking skills and non-drug treatments for back pain.	OSCE scores were higher overall but non-significant for the back pain station. Students gave a high rating for the usefulness of the course and teaching method.								1, 2b	4
15	HENDRY 1999	RCT	Students randomised into 8 groups for teaching. 4 groups taught MSK exam skills by Patient Partner. 4 groups taught by consultant rheumatologist with an untrained patient.	Both groups showed gains in mean scores of self-rated levels of confidence. PP Group rated themselves significantly higher for one skill only (knee examination) No significant difference between the groups in OSCE performance. Students valued the Partner tutorials highly and								1, 2b	4



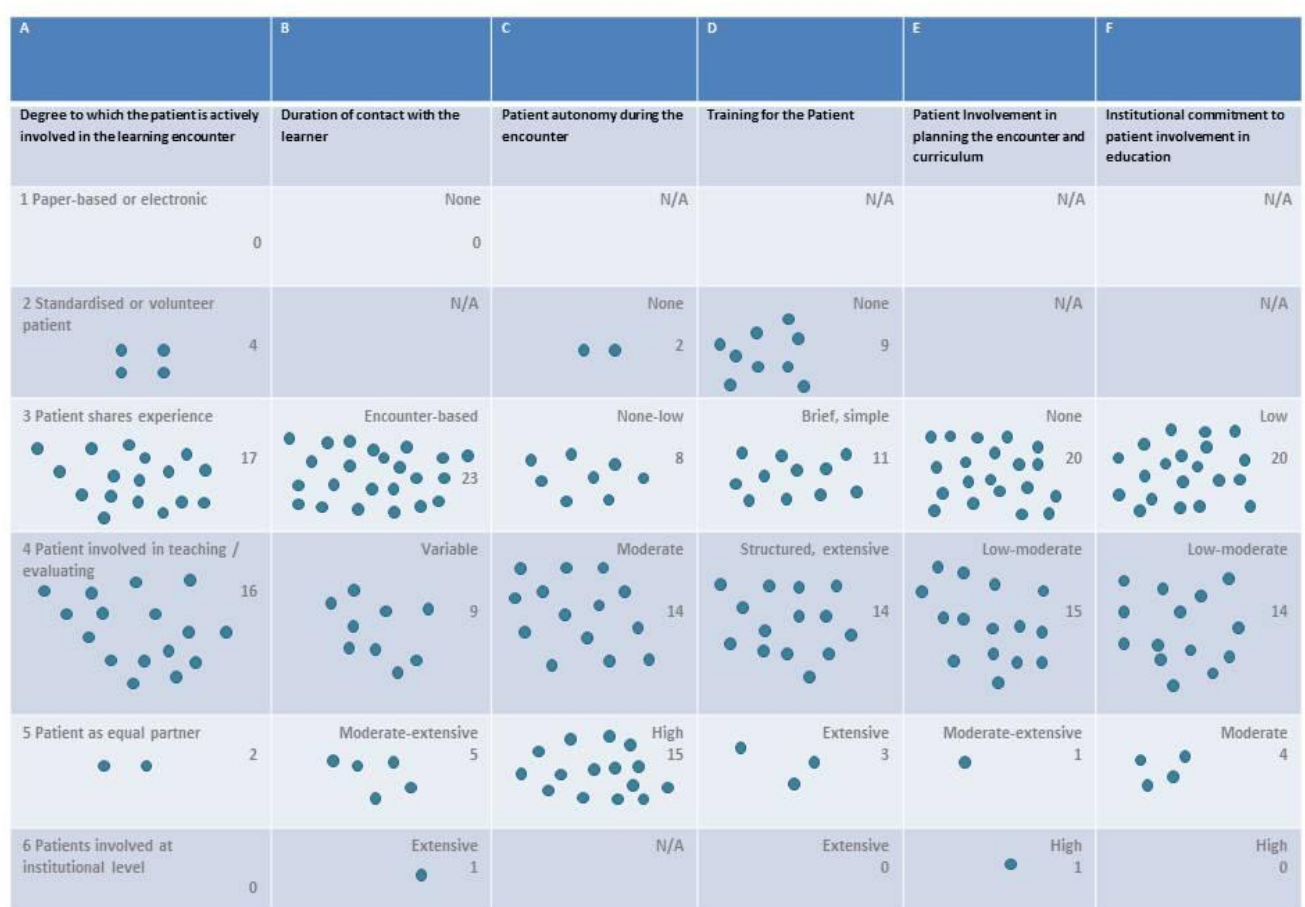
24	LENTON 2015	Qualitative	Patients gave their experiences of living with long term conditions and led a Q&A session, following which the students created a poster on one of three topics relating to the patient experience	Students agreed that the session was useful and informative on the biopsychosocial aspects of long term conditions and the importance of communication								1	3
25	LIVINGSTONE 1980	Comparison group	Intervention group received teaching on pelvic exam by professional-patient instructors (PPIs). Control group taught by gynaecologist with clinic patients	Both pelvic examination and abdominal examination scores were higher in the intervention group								2b	4
26	MAKKER 2017	Qualitative	Patient Health Mentors met 6 times to lead a discussion with a total of 5 students as part of a self-selected component. Each meeting had a theme to explore patient's perspective and journey of living with a long-term health condition. Students kept reflective journal.	The study indicated that there is value in implementing a PHM programme during medical education as a means of broadening student understanding into long-term illness								1, 2a	3
27	MOHLER 2010	Qualitative	Students designed and practised physical activity and social engagement counselling sessions with input from Healthy Aging Mentors.	Mentors assessed the effectiveness of the intervention as good (30%) or excellent (67%) Students rated their attitude towards aging as more positive								1, 2a	2
28	OWEN 2004	Observational	Trained Mental Health consumers designed, delivered and assessed a programme to teach interview skills in mental health consultations	All students passed the assessment for interview skills. On a four point Likert scale students rated the tutorials as fair or above (mean score 2.8)								1, 2a	5
29	PLYMALE 1999	Qualitative	Cancer survivors participated in Structured Clinical Instruction Modules, giving their experiences of their cancer, and provided feedback to students about their performance	Students agreed that the participation of cancer survivors had been beneficial (mean score 4.5 on a 5 point Likert scale)								1	2
30	SALERNO-KENNEDY 2009	Qualitative	1. Lecture: Patient with chronic illness (diabetes/hypertension) delivers presentation + Q&A 2. Small Group: Facilitator interviews patient about impact of disease on life (RA/Osteoporosis/Asthma/Renal Failure)	Small group creates affords relaxed atmosphere/one-to-one interaction. Patient encounters early in UG training can motivate learning, empathy and developing a holistic approach.								1, 2a	3
31	SCHREIBER 2000	Comparison group	25 Students taught hand and wrist exam by Patient Partner. 12 Students taught by non-specialist doctor with an untrained patient.	Patient partners are either equal or superior to doctors in the teaching of musculoskeletal examination techniques and communication skills.								2b	4
32	SHAPIRO 2009	Qualitative	Students visit patients in their homes to document on film their experience of living with chronic illness	Students indicated that they gained a greater understanding of the impact of a long term illness on patients and their families and a greater understanding of patient centred care								1, 2a	3
33	SMITH 2000	Comparison group	Students were taught MSK examination skills by either a Patient Partner or a rheumatology fellow	OSCE results were comparable in both the rheumatologist-trained group and the Patient Partner group								2b	4

3 4	SOLOMON 2011	Qualitative	Patients living with a chronic illness were interviewed by groups of students from different professions as part of an Inter-Professional Education programme	Students felt that it was a positive learning experience – both from the perspective of IPE and of the patient experience								1	3
3 5	STILLMAN 1980	Pre- and post-test	Patient Instructors assessed students' cardiovascular and pulmonary examination skills using a performance checklist to evaluate thoroughness of the examination and provided further feedback and instruction where necessary	Performance scores increased from initial examination to repeat examination following PI instruction. Students rated the training as effective								1, 2b	4
3 6	TOWLE 2013	Qualitative	Community Educators participated in Inter-Professional Education workshops designed to raise student's awareness of living with chronic illness (epilepsy, arthritis, HIV/AIDS and mental illness). Used the 'power dynamic' concept of Bleakley and Bligh's conceptual theory of patient-centredness.	Students rated the experience highly, with 96% stating the highlight was the exposure to the lived experience of the patient								1, 2a	5
3 7	TOWLE 2014	Qualitative	Patient mentors with a chronic condition met with small groups of students, following a pre-planned session outline. Students kept a reflective journal and shared their learning with other groups.	Students and mentors rated the programme highly – 4.1 out of 5 on a Likert scale								1, 2a	3
3 8	VAIL 1996	Qualitative	4x half-day sessions included didactic and experiential components. Students paired 1-to-1 with HIV / AIDS patients to hear their stories and practice clinical skills	Students discussed aspects of the impact of the disease and the importance of the doctor patient relationship in the care of patients with HIV/AIDS.								1, 2a	3
3 9	WEISSER 1985	Qualitative	Patient/relative recounts their experience of a number of clinical issues, ranging from sexual assault to SIDS, with emphasis on psychosocial and communication problems experienced.	Students valued the interaction with the patients in which they felt stimulated to consider broader aspects of patient problems								1	3

**Table 3. Included studies** (\*Quality indices [from BEME guidance] indicate the quality of reporting of the following criteria: U = Underpinning educational theory; Cu = Curriculum details explained fully ; S = Setting reported in adequate detail; P = Pedagogy described adequately; Cont = details of content of the intervention; Concl = Conclusion [does the conclusion match the findings of the study]).

### Level of involvement of patients / service users:

Figure 2 shows the categorisation of the individual studies according to Towle's framework, mapping to the six domains and ranging across the 6 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.



**Figure 2:** Studies mapped to each of the six domains and six levels of the Towle Taxonomy of involvement. ● = 1 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.

The majority of studies involved patients at Level 3 or Level 4 of Towle's Taxonomy (see table 3 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-centred care. The benefits to patients, where reported, included improved communication by 'breaking down barriers' (Cooper 2006), a belief that their personal stories will help to improve treatment effectiveness (Graham 2014, Salerno-Kennedy 2009), and enjoyment of the session (Jha 2013, Lenton 2015, Makker 2017)

Examples of interventions at this level include Arenson and colleagues' study (Arenson 2015) which utilised "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 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 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, edge of chaos drew out the themes of a-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-centred perspective in providing holistic care and a better understanding of the theoretical concepts underpinning teamwork.

Patients as teachers / assessors. (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 in this category demonstrated that teaching by patients / service users is at least as effective (Anderson 1978, Duffy 2016, Hendry 1999, Kleinman 1996, Schreiber 2000, Smith 2000) as teaching by faculty and, in some studies, was shown to be more effective (Branch 1999, Haq 2006, Livingstone 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 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 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 legitimises 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 utilising patients as teachers and assessors works best when it is possible to construct standardised 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 weren’t sustained at Objective Structured Clinical Examination (OSCE) or follow up (Duffy 2016, Gruppen 1996, Livingstone 1980, Smith 2000).

Patients as equal partners. (Patient tutors are involved in many aspects of educational delivery, development and evaluation). Only 2 studies, (Owen 2004, Towle 2013) which described consumers as tutors, were categorised as Level 5 on Towle's Taxonomy – patient teachers as equal partners. In Owens' 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'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 utilised a theoretical basis on which to base the outcomes. They used a patient-centredness 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 reduces 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 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-centred care. In total, 29 studies reported outcomes at level 1, but many also reported further outcomes as described below.

16 studies reported Kirkpatrick Level 2a (modification of attitudes or perceptions following the intervention). These employed different research methodologies (RCT, observational, qualitative and pre/post-test). Five of these studies also reached Towle's taxonomy of 4 or above (Farber 2003, Gruppen 1996, Henriksen 2014, Owen 2004, Towle 2013,) 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 expression of feelings. In Owen'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) measured participants approaches to clinical or physical examination skills using traditional quantitative data capture methodologies – RCTs, pre-and post-test designs or comparison groups. Duffy's 2016 RCT involved trained Gynaecology Teaching Associates (GTAs) delivering gynaecological 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 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 – transferal of skills into practice or leading to a change in practice across an organization. Some studies attempted to follow up the participants sometime after the intervention (Anderson 1978, Duffy 2016, Gruppen 1996), but still 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 2013, the studies concluded that involving patients was at least as effective as standard teaching practices.

Only four studies classed themselves RCTs, although the method of randomisation was not stated. Of these, two (Duffy 2016 and Hendry 1999) concluded that patient led teaching had a moderate effect on learning outcomes, Jha (2015) concluded that patient-led teaching was no more effective than faculty-led teaching and Humphrey-Murto (2014) 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 6 studies (focused on the continuing professional education of postgraduates, with two studies including both undergraduate and postgraduate trainees).

### **Clinical Specialty**

The studies could be grouped into 6 major clinical specialties: 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 gynaecology 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. Five of the 14 studies (Bideau 2006, Duffy 2016, Gruppen 1996, Haq 2006, Kleinman 1996) 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 ten of these

studies was that skills teaching by trained patients was 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 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 inter-disciplinary 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-centred 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 4 studies achieved a ranking of green (high quality) for the reporting of this criteria (Cooper 2006, Henriksen 2014, Jha 2015, Towle 2013). Cooper and Spencer-Dawe chose Complexity Theory as their underpinning theory and the four principles of self-organisation, 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 2006) . Henriksen and Ringsted based their study on constructionist theory and drew sensitising concepts from a prior model which explored the power balance between patient- teachers and students (Henriksen 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 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 reduces the power imbalance and enhances learning (Towle 2013).

Description of the curriculum was sufficiently described in 6 studies (Arenson 2015, Bideau 2006, Duffy 2016, Jha 2015, Owen 2004, Towle 2013), 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 also included sufficient details of the pedagogy, setting and content of the intervention. Only Cahill 2015, Duffy 2016, Jha 2015, Owen 2014 and Towle 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 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 (2013) and Owen (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 behaviour 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 4 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 don't 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 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's classification (2009), 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 2016a). 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 2006), constructionist theory (Henriksen 2014), transformative learning (Jha 2015), socio-cultural learning theory (Towle 2015). These studies demonstrated how learning theories can translate into pedagogical programmes 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 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 clearly 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 2015) has been incorporating the Health Mentors Program into their teaching since 2007, the Launceston Clinical School in Tasmania (Barr 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 2006). Other institutions which have similar formal groups to promote patient or user involvement are the University of Copenhagen (Henriksen 2014), the University of Nebraska (Hinnens 2006), North Carolina Medical School (Kleinman 1996), University of Queensland, Australia (Lane 2015), University of Arizona (Mohler 2010), University of Sydney (Owen 2004), University of British Columbia (Towle 2013, 2015)

Reflecting the findings of previous publications (Dept of Health 2007, Morgan 2009, Spencer 2010) we have found that involving patients in the teaching and assessing of students and trainees has several benefits: for learners their understanding of patient-centred 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 behaviour 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"? Non-payment 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 penalise 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 synthesised sum of published literature does little to dispel this subjective view. The experiences of our user authors is 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 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-centred care and medical education. As is always required in any synthesis, pragmatic judgements 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 is a take away 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 synthesised. 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 optimise 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-centred 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, 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.

## **Conclusion**

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-centred 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.

## **References:**

- AKOBENG, A. E., M GORDON, M 2016. Glutamine for induction of remission in Crohn's disease. *Cochrane Database of Systematic Reviews*.
- AKOBENG, A. Z., D GORDON, M MACDONALD, JK 2016. Oral 5-aminosalicylic acid for maintenance of medically-induced remission in Crohn's disease. *Cochrane Database of Systematic Reviews*.
- ANDERSON, K. K. & MEYER, T. C. 1978. The use of instructor-patients to teach physical examination techniques. *Journal of medical education*, 53, 831-836.
- ARENSON, C., UMLAND, E., COLLINS, L., KERN, S. B., HEWSTON, L. A., JERPBAK, C., ANTONY, R., ROSE, M. & LYONS, K. 2015. The health mentors program: three years experience with longitudinal, patient-centered interprofessional education. *Journal of interprofessional care*, 29, 138-143.
- ARNSTEIN, S. 1969 A Ladder of Citizen Participation *Journal of the American Planning Association*, 35, 216-224.
- BARR, J., OGDEN, K. & ROONEY, K. 2014. Committing to patient-centred medical education. *The clinical teacher*, 11, 503-506.
- BIDEAU, M., GUERNE, P. A., BIANCHI, M. P. & HUBER, P. 2006. Benefits of a programme taking advantage of patient-instructors to teach and assess musculoskeletal skills in medical students. *Annals of the rheumatic diseases*, 65, 1626-1630.
- BOELEN C, HECK JE. 1995 Defining and measuring the social accountability of medical schools. Geneva, Switzerland: World Health Organization;
- BRANCH, V. K., GRAVES, G., HANCZYC, M. & LIPSKY, P. E. 1999. The utility of trained arthritis patient educators in the evaluation and improvement of musculoskeletal examination skills of physicians in training. *Arthritis care and research : the official journal of the Arthritis Health Professions Association*, 12, 61-69.
- CAHILL, H., COFFEY, J. & SANCI, L. 2015. 'I wouldn't get that feedback from anywhere else': learning partnerships and the use of high school students as simulated patients to enhance medical students' communication skills. *BMC medical education*, 15, 35.
- COLBERT, C. Y., MIRKES, C., CABLE, C. T., SIBBITT, S. J. B., VANZYL, G. O. & OGDEN, P. E. 2009. The patient panel conference experience: what patients can teach our residents about competency issues. *Academic medicine : journal of the Association of American Medical Colleges*, 84, 1833-1839.
- COOK, D. A. B., G. SCHMIDT, H. G. 2008 Description, justification and clarification: a framework for classifying the purposes of research in medical education *Medical Education*, 42, 128-133.
- COOPER, H. & SPENCER-DAWE, E. 2006. Involving service users in interprofessional education narrowing the gap between theory and practice. *Journal of interprofessional care*, 20, 603-617.

DIXON-WOODS, M. A., S. JONES, D. YOUNG, B. SUTTON, A. 2005. Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy* 10, 45-53.

DUFFY, J. M. N., CHEQUER, S., BRADDY, A., MYLAN, S., ROYUELA, A., ZAMORA, J., IP, J., HAYDEN, S., SHOWELL, M., KINNERSLEY, P., CHENOY, R., WESTWOOD, O. M., KHAN, K. S. & CUSHING, A. 2016. Educational effectiveness of gynaecological teaching associates: a multi-centre randomised controlled trial. *BJOG : an international journal of obstetrics and gynaecology*, 123, 1005-1010.

FARBER, N. J., FRIEDLAND, A., ABOFF, B. M., EHRENTAL, D. B. & BIANCHETTA, T. 2003. Using patients with cancer to educate residents about giving bad news. *Journal of palliative care*, 19, 54-57.

FLEXNER, A 1910. Medical Education in the United States and Canada: A Report to the Carnegie Foundation for the Advancement of Teaching (PDF), *Bulletin No. 4., New York City: The Carnegie Foundation for the Advancement of Teaching*

GALL, E. P., MEREDITH, K. E., STILLMAN, P. L., RUTALA, P. J., GOODEN, M. A., BOYER, J. T. & RIGGS, G. E. 1984. The use of trained patient instructors for teaching and assessing rheumatologic care. *Arthritis and rheumatism*, 27, 557-563.

GANAIE, M. M., M GORDON, M LIM, HF EVANS, DJW 2016. Patient- and parent-initiated oral steroids for asthma exacerbations. *Cochrane Database of Systematic Reviews*.

GENERAL MEDICAL COUNCIL 2009. Patient and public involvement in undergraduate medical education. London, GMC

GENERAL MEDICAL COUNCIL 2016. Promoting Excellence: standards for medical education and training. London, GMC

GORDON, M. 2016a. Are we talking the same paradigm? Considering methodological choices in health education systematic review. *Medical Teacher*, 38, 746-750.

GORDON, M. 2016b. Patient/service user involvement in medical education: A Best Evidence Medical Education (BEME) systematic review. *BEME Collaboration*.

GORDON M, BAKER P 2012. Non-technical skills training to enhance patient safety: a systematic review. *Medical Education*, 46, 1042-1054.

GORDON M, Findley, R. 2011. Educational interventions to improve handover in health care: a systematic review. *Medical Education*, 45, 1081-1089.

GORDON, M. G., T. 2014. STORIES statement: publication standards for healthcare education evidence synthesis. *BMC medicine*, 12, 143.

GORDON, M. M., JK PARKER, CE AKOBENG, AK THOMAS, AG 2016. Osmotic and stimulant laxatives for the management of childhood constipation. *Cochrane Database of Systematic Reviews*.

GORDON, M. N., K THOMAS, AG AKOBENG, AK 2011. Oral 5-aminosalicylic acid for maintenance of surgically-induced remission in Crohn's disease. *Cochrane Database of Systematic Reviews*.

GRAHAM, K. L., GREEN, S., KURLAN, R. & PELOSI, J. S. 2014. A patient-led educational program on Tourette Syndrome: impact and implications for patient-centered medical education. *Teaching and learning in medicine*, 26, 34-39.

GRUPPEN, L. D., BRANCH, V. K. & LAING, T. J. 1996. The use of trained patient educators with rheumatoid arthritis to teach medical students. *Arthritis care and research : the official journal of the Arthritis Health Professions Association*, 9, 302-308.

HAMMICK, M., DORNAN, T. & STEINERT, Y. 2010. Conducting a best evidence systematic review. Part 1: From idea to data coding. BEME Guide No. 13. *Medical teacher*, 32, 3-15.

HAQ, I., FULLER, J. & DACRE, J. 2006. The use of patient partners with back pain to teach undergraduate medical students. *Rheumatology (Oxford, England)*, 45, 430-434.

HEALTH, D. O. 2005. Creating a patient-led NHS. London: Department of Health.

HEALTH, D. O. 2007. Patient and public involvement in the NHS.

HENDRY, G. D., SCHRIEBER, L. & BRYCE, D. 1999. Patients teach students: partners in arthritis education. *Medical education*, 33, 674-677.

HENRIKSEN, A.-H. & RINGSTED, C. 2014. Medical students' learning from patient-led teaching: experiential versus biomedical knowledge. *Advances in health sciences education : theory and practice*, 19, 7-17.

HINNERS, C. & POTTER, J. 2006. A partnership between the University of Nebraska College of Medicine and the community. *Gerontology & geriatrics education*, 27, 83-91.

HOFFMANN, TC. ERUETI, C. & GLASZIOU, PP. 2013. Poor description of non-pharmacological interventions: analysis of consecutive sample of randomised trials British Medical Journal, 347 :f3755

HUMPHREY-MURTO, S., SMITH, C. D., TOUCHIE, C. & WOOD, T. C. 2004. Teaching the musculoskeletal examination: are patient educators as effective as rheumatology faculty? *Teaching and learning in medicine*, 16, 175-180.

ISSENBERG SB, M. W., PETRUSA ER, LEE GORDON D, SCALESE RJ 2005. Features and uses of high-fidelity medical simulations that lead to effective learning: a BEME systematic review. *Medical Teacher*, 27, 10-28.

JENKINS, M 2004. Evaluation of methodological search filters—a review. *Health Information & Libraries Journal*, 21, 148-163.

JHA, V., BUCKLEY, H., GABE, R., KANAAN, M., LAWTON, R., MELVILLE, C., QUINTON, N., SYMONS, J., THOMPSON, Z., WATT, I. & WRIGHT, J. 2015. Patients as teachers: a randomised controlled trial on

the use of personal stories of harm to raise awareness of patient safety for doctors in training. *BMJ quality & safety*, 24, 21-30.

JHA, V., WINTERBOTTOM, A., SYMONS, J., THOMPSON, Z., QUINTON, N., CORRADO, O. J., MELVILLE, C., WATT, I., TORGERSON, D. & WRIGHT, J. 2013. Patient-led training on patient safety: a pilot study to test the feasibility and acceptability of an educational intervention. *Medical teacher*, 35, e1464.

KENT, G. G., CLARKE, P. & DALRYMPLE-SMITH, D. 1981. The patient is the expert: a technique for teaching interviewing skills. *Medical education*, 15, 38-42.

KEW, K. C., R DONOVAN, T GORDON, M 2017. Asthma education for school staff. *Cochrane Database of Systematic Reviews*, 4.

KLEINMAN, D. E., HAGE, M. L., HOOLE, A. J. & KOWLOWITZ, V. 1996. Pelvic examination instruction and experience: a comparison of laywoman-trained and physician-trained students. *Academic medicine : journal of the Association of American Medical Colleges*, 71, 1239-1243.

L, K. D. 2006. *Evaluating training programs: the four levels*, San Francisco, Berrett-Koehler.

LANE, M. A. M., G.K. TOWERS, P.A. WONG, W.Y. 2015. Teaching clinical skills by utilising community patient volunteers – a program evaluation FOCUS ON HEALTH PROFESSIONAL EDUCATION: A MULTI-DISCIPLINARY JOURNAL. *FOCUS ON HEALTH PROFESSIONAL EDUCATION: A MULTI-DISCIPLINARY JOURNAL*, 16, 45-56.

LENTON, C. & STORR, E. 2015. Patients as teachers for undergraduates: real-life experiences of long-term conditions. *Education for primary care : an official publication of the Association of Course Organisers, National Association of GP Tutors, World Organisation of Family Doctors*, 26, 109-112.

LIM, W. S. T., K.M. ADZAHAR, F. B. NEO, H. Y. WONG, W. C. RINGSTED, C. 2017. Determinants of clarification research purpose in medical education research: A systematic review. *The Asia Pacific Scholar*, 2, online only.

LIVINGSTONE, R. A., MOODIE, P. F. & OSTROW, D. N. 1980. A follow-up study of patient-instructors who teach the pelvic examination. *Journal of medical education*, 55, 715-717.

MAKKER, T. R. 2017. The effect of patient health mentoring on students' long term understanding of chronic illness. *Dissertation - Barts and The London School of Medicine*.

MOHLER, M. J., D'HUYVETTER, K., TOMASA, L., O'NEILL, L. & FAIN, M. J. 2010. Healthy aging rounds: using healthy-aging mentors to teach medical students about physical activity and social support assessment, interviewing, and prescription. *Journal of the American Geriatrics Society*, 58, 2407-2411.

MORGAN, A. & JONES, D. 2009. Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: a literature review. *Medical teacher*, 31, 82-95.

OWEN, C. & REAY, R. E. 2004. Consumers as tutors - legitimate teachers? *BMC medical education*, 4, 14.

PLYMALE, M. A., WITZKE, D. B., SLOAN, P. A., BLUE, A. V. & SLOAN, D. A. 1999. Cancer survivors as standardized patients: an innovative program integrating cancer survivors into structured clinical teaching. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 14, 67-71.

SALERNO-KENNEDY, R. H., P. O'FLYNN, S. 2009. Patients with chronic diseases as partners in medical education. *The Clinical Teacher*, 6, 155-159.

SCHMIDT, H. G. 2005. The influence of research on practices in medical education: the case of problem based learning. *Annual Meeting of the Association for Medical Education in Europe*. Amsterdam, Netherlands.

SCHRIEBER, L., HENDRY, G. D. & HUNTER, D. 2000. Musculoskeletal examination teaching in rheumatoid arthritis education: trained patient educators compared to nonspecialist doctors. *The Journal of rheumatology*, 27, 1531-1532.

SHAPIRO, D., TOMASA, L. & KOFF, N. A. 2009. Patients as teachers, medical students as filmmakers: the video slam, a pilot study. *Academic medicine : journal of the Association of American Medical Colleges*, 84, 1235-1243.

SHARMA, R. G., M DHARAMSI, S GIBBS, T 2015. Systematic reviews in medical education: A practical approach. AMEE guide 94. *Medical Teacher*, 37, 108-124.

SMITH, M. D., HENRY-EDWARDS, S., SHANAHAN, E. M. & AHERN, M. J. 2000. Evaluation of patient partners in the teaching of the musculoskeletal examination. *The Journal of rheumatology*, 27, 1533-1537.

SOLOMON, P. 2011. Student perspectives on patient educators as facilitators of interprofessional education. *Medical teacher*, 33, 851-853.

SPENCER, J., BLACKMORE, D., HEARD, S., MCCRORIE, P., MCHAFFIE, D., SCHERPBIER, A., GUPTA, T. S., SINGH, K. & SOUTHGATE, L. 2000. Patient-oriented learning: a review of the role of the patient in the education of medical students. *Medical education*, 34, 851-857.

SPENCER, J. G., W. KARPENKO, N. TOWLE, A. 2011. Can patients be teachers? Involving patients and service users in healthcare professionals' education. London: The Health Foundation.

STILLMAN, P. L., RUGGILL, J. S., RUTALA, P. J. & SABERS, D. L. 1980. Patient instructors as teachers and evaluators. *Journal of medical education*, 55, 186-193.

TEW, J. G., C. FOSTER, S. 2004. Learning from experience: involving service users and carers in mental health education and training. Nottingham: Higher Education Academy/NIMHE/Trent Workforce Development Confederation.

TODRES, M. STEPHENSON, A. JONES, R. 2007. Medical education research remains the poor relation. *BMJ* 335, 333–335.

TOWLE, A., BAINBRIDGE, L., GODOLPHIN, W., KATZ, A., KLINE, C., LOWN, B., MADULARU, I., SOLOMON, P. & THISTLETHWAITE, J. 2010. Active patient involvement in the education of health professionals. *Medical education*, 44, 64-74.

TOWLE, A., BROWN, H., HOFLEY, C., KERSTON, R. P., LYONS, H. & WALSH, C. 2014. The expert patient as teacher: an interprofessional Health Mentors programme. *The clinical teacher*, 11, 301-306.

TOWLE, A. & GODOLPHIN, W. 2013. Patients as educators: interprofessional learning for patient-centred care. *Medical teacher*, 35, 219-225.

TUCKETT, D. 1985 Meetings between experts: An approach to sharing ideas in medical consultations. London: Tavistock Publications, 1985.

VAIL, R., MAHON-SALAZAR, C., MORRISON, A. & KALET, A. 1996. Patients as teachers: an integrated approach to teaching medical students about the ambulatory care of HIV infected patients. *Patient education and counseling*, 27, 95-101.

WEISSER, R. J. & MEDIO, F. J. 1985. The patient as teacher. *Journal of medical education*, 60, 63-65.

YARDLEY, S. & DORNAN, T. 2012. Kirkpatrick's levels and education 'evidence'. *Medical education*, 46, 97-106.