Supplementary File 2. Data extracted from included studies

Author Year Country	Types of PE activities[9]	Objective	Research design	Results
Groene 2014 UK [20]	<u>Involvement</u> • Members of quality committees • Members of project teams	To describe the involvement of patients in quality management functions	Survey of 72 hospital quality managers and 16 heads of clinical units for clinical pathways for myocardial infarction, stroke, hip fracture, and deliveries in 7 countries: Czech Republic, France, Germany, Poland, Portugal, Spain and Turkey	Most respondents said that patients were never involved in various quality management functions; this did not differ across clinical pathways: • developing quality criteria (56.7%; p=0.211) • designing/organizing processes of care (60.8%; p=0.217) • quality committees (64.8%; p=0.276) • quality improvement projects (50.0%; p=0.202) • discussion of quality improvement project results (59.4%; p=0.322)
Nathan 2014 Australia [21]	<u>Involvement</u> • Members of hospital management committees • Members of project teams	To explore how community members influenced over hospital health service planning and improvement	Qualitative case study involving interviews with 10 community members and 24 hospital managers and observation of meetings of hospital committees (n=10), community member networks (n=11) and the community member council (n=5) from 8 areas	• Community members said they were deeply committed to making a difference for patients • During committee meetings controlled by hospital staff their input was minimal; even when they did contribute to discussions, their influence on decisions was minimal • In network meetings that were community-controlled community members raised numerous issues for action; hospital representatives attending these meetings appeared open to the ideas but the ideas were not pursued subsequent to meetings • During interviews, staff questioned the representativeness of community members and the relevance of their personal experiences; however, they also identified the value and specific impact of community members on hospital services • Community member influence occurred outside of formal meetings during opportunistic interaction with supportive staff who navigated hospital processes to effect change
Armstrong 2013 UK [22]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services <u>Involvement</u> • Members advisory panels,	To describe patient involvement in quality improvement	Qualitative case study of three projects involving qualitative interviews with 126 patients and providers and observation of meetings across three projects (two based in hospitals, one in primary care)	• Rationale for involving patients varied: externally mandated, perceived value of patient involvement based previous work, lack of any previously collected data on the patient experience, belief among providers that capturing the patient experience was important • Patients were engaged through a virtual network of patients who could be consulted as required, questionnaires, patient representative on the project team throughout the course of the project, participation in regional meetings, and advisory groups that worked with project teams • Facilitators of meaningful involvement were early involvement so that patients could understand the project's aims and shape the work,

	councils or networks • Members of project teams			• debriefing after meetings to provide feedback on how the session had gone, less formal interaction through email and phone calls, explicit value and respect for input from all team members, and formalizing patient roles • Patients exerted influence by persuading clinicians that there was an important problem to be addressed and about how it should be addressed; this was largely achieved by participation in meetings and training events with clinicians; and by acting as knowledge brokers to build links between patients and clinicians
Chan 2013 Canada [23]	Involvement • Members advisory panels, councils or networks Partnership and shared leadership • Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board	To outline how an Ontario hospital initiated an intensive Citizens' Advisory Panel related to budget and service provision decisions	Qualitative case study (surveys and direct observation)	• After each CAP session, members were surveyed. Members were enthusiastic about participating, generally thought the sessions were well organized, and agreed the facilitators were effective. • There was frustration with the public roundtable in terms of its limited attendance, and the event's representativeness and overall merit. • CAP members were also surveyed prior to the board presentation (14 responses, 56% response rate). Although enthusiasm about participation in the panel remained strong, there was also some anxiety because of the magnitude and complexity of the recommendations. • A final questionnaire mailed to CAP members after announcements of hospital service changes (12 responses, 48% response rate) found that members generally had a positive view of their experience, thought the panel had accomplished something important, and had been of benefit to the community and the hospital. • Overall, 75% of the respondents thought the CAP was an effective way to incorporate the community's perspective in decision making. • Some individuals in the public expressed anger about service cuts, although none of the anger was directed at the process or panel members.
Martin 2011 UK [24]	Involvement • Members of project teams	To explore how patients were involved in working with health care professionals to design and improve patient-centred cancer	Qualitative case study including interviews with 32 staff (physicians, nurses, genetic counsellors, managers) from cancer-genetics services and 12 patients, and observation of 21 meetings across 5 sites	• At 4 sites, 1 or 2 patients were invited to planning meetings • Observation found that patients attended but were largely silent • Interviews found that patients felt they were not effectively involved as partners and their suggestions were ignored; staff at these sites agreed • Barriers included lack of guidance on the role of patients and how they should be involved; staff suspicion about the capacity of patients to contribute given lack of criteria for inclusion or a vetting process; infrequent meetings; lack of informal opportunities outside of meetings for interaction to build trust; dysfunction and hierarchies among the health care professionals • At 1 site patients and health care professionals viewed their work as a genuine partnership

		genetic services		• Facilitators included selection of patients based on their personal characteristics and skills; the team met monthly and sometimes more frequently if needed; small team size that was less hierarchical and more easily integrated patients; patients and staff were keen to form close, informal bonds that would support their working together; and conscious effort to involve patients in meetings; patients were granted 'volunteer status' by the hospital, which formalized their roles;
Solbjør 2011 Norway [25]	<u>Involvement</u> • Members advisory panels, councils or networks • Members of project teams • Provide education to other patients	To explore clinician views about the value and involvement of patients in health service improvement	Qualitative interviews with 18 physicians, nurses, other health care professionals and health care managers from 12 regions	• Patients were involved in user committees that regularly met with management, project groups that worked for limited periods of time, as representatives on regional councils and by providing education to other patients • User involvement was viewed as valuable when it provided unique insight on problems that created new possibilities for solutions, and particularly valuable when it aligned with what they viewed as appropriate
Hsu 2010 Taiwan [26]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services	To evaluate a narrative interviewing approach (story-telling) to collect information from older people about how to improve health care services	Qualitative interviews with 20 patients aged 65 or older in a rehabilitation unit at a single hospital	• The study found it unhelpful to use broad questions at the beginning to understand older people's unique meaning attached to health care service; supplemental probe questions offered limited help to understand the narrators' thoughts in relation to their hospital stay experiences • Instead, warm-up questions such as "Tell me how you feel when you stay in the hospital?" could help patients express themselves freely and build rapport with the researcher. They found that it was only when narrators were asked about "feelings" that they provided a more detailed account of what they had experienced from their surroundings. • Ward meetings and rounds were viewed as the best opportunity to identify and recruit patients compared with nursing notes, reviewing patient assessment records or during nurse handovers. • The best time to conduct interviews was immediately after a patient had been notified of their discharge date • The interviews revealed that nursing assessment skills such as listening and probing could be applied to interviewing older people
Nathan 2010 Australia [27]	<u>Involvement</u> • Members of project teams	To examine health care professional views about the value and roles of community	Questionnaire survey of 142 clinicians and managers from one region that had been on a committee with community members	• 94% of staff had been on a committee with community representation; 26 % had been a chair and 19% had been a support person for community members • The most common types of community member influence were strategic planning, priority setting, service redesign, service delivery, and improved signage and patient information • 75% said that community members represented the views of the broader

		members on health service committees		• community • 40% said that community members and health care professionals agreed on the role of community members, and 30% said that they understood the community member role and how to work with them • Most agreed that community members' role was to improve communication between the health service and the community (98%), share their experiences (60% and ask difficult questions (59%) • Fewer agreed that community members actually fulfilled each of these roles
Rutebember wa 2009 Uganda [28]	Consultation • Provide voluntary feedback through mass media or suggestion boxes Involvement • Members of hospital management committees	To explore how hospitals acquired input from community members about hospital services	Qualitative interviews with 8 medical managers and 3 board members, and 8 focus groups with clinicians (n=NR) and 8 focus groups with community members (n=NR) from 8 hospitals in 5 districts	• Community members were involved in hospital management committees, or provided feedback through mass media like radio or suggestion boxes in hospitals • Community members did not see themselves as partners in health care delivery, nor were they recognized as such • Each hospital management committee had at least one community member recruited from religious groupings, political leaders or village opinion leaders; the majority of participants thought that these individuals were not representative of the community • Hospital management committees did not use feedback from communities nor did communities receive any news from hospitals • Community members used FM radio to phone in and share views about hospital services; clinicians and managers thought this was ineffective because the callers complaints were not substantiated and clinicians or managers did not have the opportunity to respond • Managers said that feedback from suggestion boxes represented personal opinions and not those of the community; community members said suggestion boxes were not helpful because the very people they talked about were those who would review suggestion box feedback • Some clinicians thought that the community was very happy with hospital services; other clinicians felt that the community grumbled but never conveyed their complaints to clinicians and some of those grumbling were ungrateful
Brooks 2008 UK [29]	Involvement • Members of advisory panels, councils or networks	To explore the role of patients in a nurse-led advisory council	Qualitative case study involving observation of 14 meetings and interviews with 18 nurses and 17 patients in a single hospital	• Patients were involved in a range of activities including commenting on documents, establishing working groups on specific topics and membership on hospital multidisciplinary groups to conduct service • Initially there were tensions between nurses and patients on councils • Patients had clear ideas about how services could be developed based on their own or their families' experiences, and were frustrated when blocked from offering what they felt was a unique perspective and specialist knowledge

				- Nurses felt they instead needed to address specific demands from senior management - Nurses reacted negatively to what they viewed as patient 'story telling' and 'subjective interruptions' that were irrelevant and hindered the smooth running of meetings - Nurses were defensive and described patients as difficult, intimidating, ungrateful and hostile - Nurses admitted to feeling inexperienced and unprepared to engage with an empowered questioning group of patients - Over time conflict was resolved through ongoing discussions at meetings where patients were increasingly given a voice and nurses developed new ways of interacting with patients

PE= patient engagement; NR=not reported