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PATIENT INVOLVEMENT IN QUALITY IMPROVEMENT IN PRIMARY HEALTH CARE

Claire van Deventer

A Thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

December 2015

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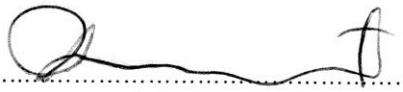
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Declaration

I, Claire van Deventer, declare that this research report is my own work. It is being submitted for the degree of PhD in Family Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at this or any other university.

Signature:



C van Deventer.....

Signed on: 8/12/2015

I Claire van Deventer hereby declare the following:

For the research study, the publication route was followed. Chapter 1 is the introductory chapter in which the overall theme is explained as well as the different research approaches and the results that emerged. Chapter 2 is a published systematic review which commenced after the protocol had been approved and systematic review training had been undergone. This article was published in JBI Review, an internationally accredited Australian journal dedicated to systematic reviews. Chapter 3 was published in the Journal of South African Family Practice (SAFP) as it was based on recent changes and policies in the South African health system that may have had less value for international readers. Chapter 4 was submitted to BMC as the method that was used originated in the UK and the training undergone for this was presented by the Point of Care Foundation in the UK.

Inasmuch as all the work is participatory and many people including health care workers and patients were involved (and acknowledged), I conceived of all the ideas, planned and executed them and wrote the articles based on the research. For the Systematic review, it is imperative to have a second reviewer validating the decisions made on the systematic review software programme and a third reviewer to consolidate and validate the final selection of articles. These 2 people have been acknowledged as authors in the published article.

With the third chapter, many people were involved in the research as co-participants and acknowledged but the article was written in the main by me and my academic supervisor contributed significant comments. for which she was acknowledged in the article.

The 4th chapter was conceived of by me and the process carried out with the help of a core team of three other people who are acknowledged. The article was shared with a POC member who is considered to be an expert and contributed significantly to the article and therefore is a co-author together with my academic supervisor.

The above co-authors confirm that the above is correct:

Dr Anne Wright .....

Prof P McInerney .....

Dr Richard Cooke .....

Prof Glenn Robert .....

Dedication

I dedicate this work to my husband and family (past, present and future) without whom this would not have been possible.

Ecclesiastes 4:12 A cord of three strands is not quickly broken

John Donne: No man is an island

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The following are acknowledged for their academic support as well as their on-going encouragement

My Supervisor: Dr Anne Wright

Co-supervisors: Prof Patrician McInerney, Prof Sam Fehrsen

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All the participants in the projects are acknowledged for being willing to collaborate on new ideas.

The district management team and colleagues who allow me to try out unfamiliar initiatives in the interest of all the patients who are served in the district.

ABSTRACT

Introduction

There has been little published in South Africa regarding quality improvement in health and in particular the involvement of patients in this intervention. There is evidence globally that both quality improvement efforts and particularly the engagement of the users adds value to health services.

Three projects were conceived around this core concept as explained below.

1. Systematic review. Patients' involvement in improvement initiatives: a qualitative systematic review

   After a search was done of databases, 5121 papers were found to be potentially relevant. After screening and critical appraisal for eligibility, it was found that 31 articles qualified for analysis. These were then assessed using JBI software and 5 categories and 2 metasynthesised findings were documented. In summary, there were enablers and barriers to involving patients. The five categories which lead to these 2 findings were the following: (1) although patient participation in QI is acknowledged and encouraged by many policies and documents globally, it is difficult to implement; (2) there are differing views between patients and providers as to the process; (3) on the positive side, different levels of involvement of patients in QI were demonstrated; 4) practical, appropriate and innovative results emerged; (5) individual or group support and incremental development through skills and enablement contributed towards success

2. The Integration of Non Communicable Chronic Diseases (NCDs) and HIV/Aids and mental health care through the involvement of chronically ill patients using Empowerment Evaluation (EE).

   At 9 primary care clinics, the process of EE was followed with chronically ill stable patients and appropriate healthcare workers. This was an additional intervention in an ongoing QI cycle on the integration of all chronic illnesses into one model, based on Lean principles.

   Steps followed were ''taking stock'' ie assessing patients' and HCWs' impressions of the services at the clinic in a measured way, creating a vision and using this as a yardstick for the project and then problems and solutions being co-managed by the collaborative team. A total of 37 interventions were discussed and 23 implemented in the time frame. Innovative solutions were implemented and teams were empowered by the potential they experienced.

3. An exploration of childhood nutrition and wellness in a subdistrict by patient inclusivity in QI using experience based codesign (EBCD) with mothers/caregivers of malnourished children .

Following the steps of EBCD, staff and patients exposed to health services regarding ill children, were interviewed, feedback was given of the findings separately and then in a combined meeting and co-design teams were created to work with the prioritised quality improvement interventions. Touch points in the system were examined through emotional mapping, video interviews and observations. Within the 10 month period of the project, 38 interventions were identified and 25 accepted and implemented at different levels.

Conclusion
The methodologies were chosen to fit with the qualitative aspect of the research. There were concrete appropriate improvement outcomes due to the engagement of service users in both the primary care clinics serving chronically ill patients and the paediatric system in one subdistrict eg the flow of patients improved, logistical improvements like direct admissions for very ill children, school and library opportunities for admitted ill children etc occurred. Subjective gains like the acknowledgement of their power role by patients and a flattening of the healthcare worker hierarchy were also experienced in the research. Other findings were that unexpected roleplayers were identified, the timeframe of such QI cycles needs to be considered especially regarding the resilience of patients and resources were not an importatn limitation. However some modifications would have to be considered to make these research approaches common practice.

The particular research methodologies have not been published in a South African context before and have also not been used for paediatric or integrated chronic illness research and therefore contribute both content and process information to health systems research in South Africa.

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Abbreviations

ART:	Antretroviral Treatment
DHIS:	District Health Information Systems
DKK:	Dr Kenneth Kaunda District
ICDM:	Integrated Chronic Disease Management
MDGs :	Millenium Development Goals
NCDs:	Non Communicable Diseases
NHI:	National Health Insurance (SA)
NHS:	National Health Service (UK)
PAR:	Participatory Action research
PDSA cycles:	Plan-Do-Study-Act cycles
PHC:	Primary Health Care
QI:	Quality Improvement

CHAPTER 1

Patients' involvement in improvement initiatives: an overview

Chapter 1

1.1 Introduction

Quality improvement (QI) in health care is defined as: “The best health outcomes that are possible given available resources and that are consistent with patient values and preferences” .[1] Literature predominantly reflects on QI in developed countries. [2,3,4,5] The process of QI is varied but includes any activities or processes that are designed to improve the acceptability, efficiency and effectiveness of service delivery and contribute to better health outcomes as an ongoing and continuous process.[6]

In South Africa, there has been little published **academically** on QI in healthcare in general and in primary care in particular [7,8] **in contrast to the vast availability of literature on QI in health across the world**. Terms like translational research or implementation research are similar academic approaches to the improvement cycle but even these are not found related to South Africa or even sub-Saharan Africa studies. The involvement of patients in **quality improvement** in health is also a fledgling topic in this context. Where the concept of client or user involvement is found globally it usually refers to individual consultations or at the other extreme, to community involvement on public health issues.[9,10,11,12,13,14] There is much less evidence of patients taking pro-active decisions in improving primary care services, which might lead to more efficient and more acceptable care being provided.[15] There have been initiatives like the expert patient programme in the UK [16,17] and the Voice of the Customer (VOC) which is reported in Canada to have superseded the concept of customer satisfaction[18]. These to a large extent, together with the ‘’shared decision making’’ emphasis of the Chronic Care model[19,20,21,22,23] focus on individual choice within a client -provider relationship and not on client involvement in systems improvement.

“Lean methods’’ [24,25,26,27,28] in QI have become incorporated in health QI projects and QI research in the last decade. Coming from the motor industry, Lean thinking was initiated by the Toyota car manufacturing company in Japan in the 1950’s. The client gained eminence and the tools eg value stream mapping, the 7 wastes, kaizen and kanban were amongst many created to improve the service to clients. Much of this approach has been adopted in health settings and made significant differences in emergency departments,[28,29,30,] radiology,[31] orthopaedics,[32] PHC [33] and others. The National Department of Health’s Chronic Illness directorate used some of these methods in the research district as a pilot

project attempting to integrate all communicable and non-communicable chronic illnesses within an efficient client pathway.[34] This approach was acknowledged and incorporated in the chronic illness project undertaken by the researcher.

In spite of attempts to improve health issues, standards of health care often remain poor in the public service in South Africa, as in the case of mother and child health and chronic illnesses where the Millennium Development goals[35] (MDGs) were not attainable by 2015 and the National Core standard[36] evaluations fall far short of their targets. QI appears to be an approach to be considered in these examples of faltering health care provision. The researcher's exploration of QI and patient involvement will be discussed further in this chapter.

1.2 Scientific value of proposed research. According to Greenhalgh: ''Quality improvement research—that is, applied research aimed at informing change that improves policy and practice—has emerged as a tradition in its own right, embracing a broad range of methods'.' [37p443] **However, as QI has been generally considered a managerial tool, rather than a research strategy, it has long been viewed as inferior to traditional research. This is due to the fact that rigorous analytical methods are often not applied. Greenhalgh et al[37] defend the use of qualitative narrative methods in QI research and emphasise the use of rigorous methods as does Alexander. [38] Baker[39] reflects that ''Quality improvement efforts use evidence to identify changes and focus on *implementing* effective practices, not assessing whether they are effective..''[39p151] Together with Campbell[40], he proposes that QI should be part of the development of research strategies for complex interventions. He also recognises that a strength of QI is that it is adaptable to different sites and situations and that therefore innovations can be specific and appropriate rather than transferable.**

Kring[41] however sees research and QI as two clearly separate processes. The discussion in this paper limits the comparison to that between QI and quantitative research and the opposing philosophical views of logical positivism with what she describes in QI as pragmatism. The fact that other valid research approaches eg qualitative interpretative or critical emancipative are not considered at all, weaken this argument

Other criticisms of QI as a research method have included the duration of the research being too short to indicate sustainability, the lack of generalisability and the complexity of QI as

well as the disregard often for ethical principles being applied [42,43,44] Campbell et al [40] have proposed a sequential approach to developing valid QI research namely developing a theoretical basis, the definition of the components of the intervention, exploratory studies to develop these components and then a definitive quantitative study. However Eccles [45] motivates for the following: '' Whatever design is chosen, it is important to minimise bias and maximise generalisability. Quantitative designs should be used within a sequence of evaluation building as appropriate on preceding theoretical, qualitative, and modelling work.''

The intention of this researcher was to explore qualitative methods that could stand up to academic criticism regarding QI as research and to propose these methods as part of a developmental process for complex health systems interventions. The specific methodologies have not been used in QI methods in South Africa in particular and therefore this is a foray into new territory for the researcher.

1.3 Conceptual framework.

As is described above, QI as a rigorous research approach has been debated by a number of authors. [38,39,41,43,44] There are a plethora of quantitative and qualitative methods used in the literature for the process of QI implementation. The current research has concentrated on the phase of ''preceding qualitative work'' described by Campbell [40] which may be inserted into a QI and become a part of the development of a later quantitative model.

Both of the qualitative research projects discussed in chapters 3 and 4 served as interventions in a current ongoing QI. The QI in each case had followed a traditional service improvement process with a team setting standards, evaluating the situation through audits or other means and planning and implementing certain interventions. However, patients had not been involved in any of these projects and this was the additional theoretical emphasis in this research. See Fig 1 and 2

Figure 1 Integrated chronic illness

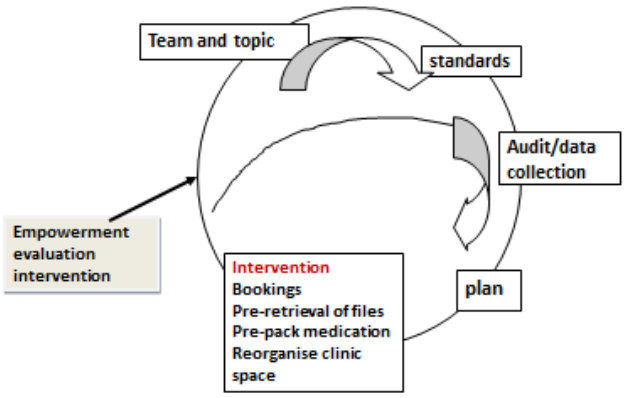
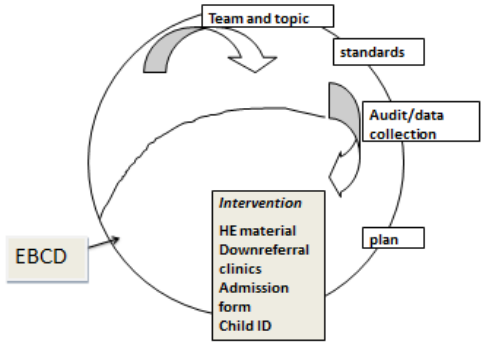


Figure 2 Malnutrition and illness in children



In Figure one, with the original integrated chronic illness QI which is more fully described in Chapter 3, standards were set, baseline audits were done and subsequent interventions implemented and monitored eg a chronic illness patient form, appropriate equipment, training, patient bookings, pre-retrieval of files, reorganisation of clinic space. However, patients were never included in these plans and in the envisaged research this was an added intervention in the already existing cycle, with Empowerment evaluation as the method. This method will be discussed in more detail later in this chapter.

Figure 2 demonstrates what is discussed in detail in Chapter 4, namely how a QI was started relating to malnutrition and HIV in children where health education material including a ‘‘child ID” was created and disseminated, a strong downreferral system established, a package of PHC clinic services consolidated for these patients etc. As above, patients had never been collaborators in this project and so Experience Based Co-design (EBCD) was an added intervention in the cycle to try and enrich the outcomes for these patients. EBCD will be briefly explained later in this chapter and in detail in Chapter 4.

1.4 Problem statement.

In view of paragraphs 1.1 to 1.3 the problem statement of this research is therefore that in primary care in a developing country, the exclusion of patients from QI initiatives in health is a possible barrier to improved quality of patient care. Patient empowerment in other contexts has led to increased patient responsibility and better health outcomes.[46,47,48,49,50]

Primary care in a developing health system was the context of interest of this study, as opposed to hospital based care or developed countries' QI approaches and outcomes. The use of **two** different research methodologies was deliberate in an attempt to compare, explore and crystallize simple approaches, appropriate for use in PHC. **The first**, Empowerment evaluation[51] is used by researchers together with the users of the service to assess where the strengths and weaknesses lie and to attend to these as a group (socialised enquiry) without individuals being criticised. Capacity building and ''coaching'' towards empowerment and self determination are key aspects of this method. The **collaborative** measurement of improvement is core to Empowerment evaluation. T**he second method**, Experience based co-design[52] emanating from client focused industries, is a structured approach with collaborative client/provider teams called ''co-design teams'' identifying experiential problems in the system and working together for improvement.

1.5 In order to address the above mentioned problem statement, the overall aim and objectives for all three studies are the following.

Aim: **The overall aim of the research was to explore patient-inclusive interventions while implementing QI in primary care.**

Objectives:

1. **To identify, through a systematic review, the barriers and enablers to patients' involvement in QI efforts directed towards their own health care**
2. **To explore through empowerment evaluation, the enabling of** patients with chronic illnesses in taking control of their own health care in a QI on the integration of non-communicable chronic illnesses (NCDs) and chronic communicable diseases in a district in the North West province
3. To enhance patients'/caregivers' experiences of care by patient inclusivity in QI using experience based co-design with mothers/caregivers of malnourished and ill children in a subdistrict in the North West Province, as a qualitative intervention

1.6 General structure of thesis.

Chapter one is the introduction, providing the social and scientific focus of the study as well as the theoretical framework. The overall aim and objectives and a short summary of the research methods and results are also dealt with in this chapter. Each of three research projects were embarked upon, published and each comprise a chapter of the thesis.

Chapter 2 is a systematic review to identify enablers and barriers to patients being involved in QI in health. The researcher focused on studies using **predominantly** qualitative methodology in the systematic review, such as Participatory action research (PAR), ethnography, qualitative focus groups and experience based co-design (EBCD) .[52] Chapter 3 reports on research involving chronically ill patients using the qualitative approach of Empowerment evaluation[51] and Chapter 4 is the research on involvement of mothers/caregivers of malnourished or chronically ill children and their experiences of the health system, using EBCD[52]. Both of the latter 2 projects were an intervention in a current primary care QI project in a particular health district. Although quantitative data on client involvement was also found in the literature [53,54,55,56], the congruency of qualitative methods fit more with the participative, subjective ethos of the research statement.

A literature review was not included as a separate chapter for a few reasons. The evidence from many publications has been reflected in Chapter one under the introduction, scientific value and conceptual framework sections. Chapter 2 as a systematic review elicits many of the arguments and debates found in the literature, relating to the core research interest namely patient involvement in QI. Chapters 3 and 4 also reflect a robust body of supporting literature.

Chapter five consists of conclusions based on the critical reflection of different parts of the process, as well as recommendations.

1.7 Contextual environment: The setting for the different research projects and QI's, is in a district in the North West province, in the public sector. This includes 5 hospitals and 39 fixed clinics (inclusive of 9 health centres). The district health system (DHS) divides each of the 9 provinces in South Africa into districts which are in turn usually made up of 4-5 subdistricts with decentralised management. In the research district, there are four widely differing subdistricts in terms of urban/rural, size and patient profile.

The district is sparsely populated with an average density of 53 individuals per square km, which is a characteristic of a rural District[57]. The major causes of deaths in adults in the last 2-3 years have been HIV, TB, cancer and cardiac conditions. Children's mortality has been mainly caused by septiciaemia, pneumonia and gastroentereitis with most of these children having underlying HIV or malnutrition[57.]

Mining and agriculture are the main income generating activities in the district. Consequently there is an unstable, migratory population which makes continuity of health care problematic. Despite improvements in access to piped water and electricity, a very large part of the population lives in informal and non-serviced settlements and average household income in the North West remains below the national average. While social grants have provided a safety net for the desperately poor, and for vulnerable groups such as the elderly, inequality has remained very high and large portions of the population still live in poverty. 33,8% of the North West population, or roughly 1,22 million people, were living in poverty in 2013.[58]

A core PHC problem where systems are not functioning well in North West province currently is malnutrition in children and the initiation of children on Antiretroviral Therapy (ART). Another area of concern is that HIV management has been at the forefront of political health strategies in the last two years and has left other NCDs in the shadow. The integration of systems for all chronic illnesses needs serious attention in order to deliver quality care for chronic patients with single or multiple illnesses. These were therefore the two areas chosen to attempt patient engagement in health care.

South African health policy has influenced the current research on patient involvement in the district, at different stages. PHC reengineering[59] has concentrated on establishing outreach teams to households, strengthening school health and implementing district clinical specialist teams with a focus on mother and child care. The outreach teams played an important role in the chronic illness project, as a valuable voice for both staff and patients. The NHI chose this same district as a pilot district to test certain innovations. PHC clinic doctors were employed under this project and this also had an impact on the chronic illness research.

This research study attempted to contribute towards the above mentioned challenges and context through the research projects discussed next.

1.8 Methods and results

1.8.1 In Chapter two, the systematic review (using the Joanna Briggs Institute software[60]) based on qualitative papers and ‘text and opinion’’ publications is discussed. In order to place the research within a valid international scientific framework, a systematic review was done in order to confront the question “What are the enablers and barriers to patients involvement in QI efforts directed towards their own health care?

From the 5121 originally identified potential papers for this review, after a rigorous

process, 31 were critically appraised and included in the systematic review, none of which included South African or similar countries. This may reflect on the dearth of published research within this particular focus of QI in South Africa. The search led to 5 categories and 2 metasynthesised findings being documented. In summary, there were enablers and barriers to involving patients. The five categories which supported the synthesized findings, were created through the meta-aggregative process. These were applicable to both the qualitative and text and opinion papers, and in summary were the following: (1) although patient participation in QI is acknowledged and encouraged by many policies and documents globally, it is difficult to implement; (2) there are differing views between patients and providers as to the process; (3) on the positive side, different levels of involvement of patients in QI were demonstrated; 4) practical, appropriate and innovative results emerged; (5) individual or group support and incremental development through skills and enablement contributed towards success. Thirty seven findings from the identified articles informed the complete syntheses. These are discussed in more detail in Chapter 2. The implications for practice and research were clarified and guided the two projects which followed.

1.8.2. Chapter 3 intended to explore, through empowerment evaluation, the enabling of patients with chronic illnesses in taking control of their own health care in a QI on the integration of NCDs and chronic communicable diseases

Fetterman[51] uses empowerment research to promote close involvement between the evaluator and the program he or she is evaluating, because doing so is thought to produce more meaningful and useful evaluation results. Thus, in an empowerment evaluation model, the relationship between the evaluator and the evaluation consumers is characterized as a collaborative partnership. Fetterman says...''it is designed to help people help themselves and improve their programmes using a form of self evaluation and reflection. Programme participants conduct their own evaluations and typically act as facilitators; an outside evaluator often serves as a coach or additional facilitator..''.[51 p5]

Empowerment evaluation, [61,62,63,64] has been used across a wide spectrum of services. It has been positively regarded [61,66] : "The participants gain ownership of the evaluation and its results, achieving liberating self-efficacy over their program"[66p388] and has been used for mental health, youth programmes and others. It has also been criticised for being too close to other forms of participatory research and implementation research and not philosophically

well defined enough to warrant acknowledgement.[64,66,67,68] However, the value concept as explained by Fetterman, seemed to fit the patient-inclusivity model the researcher was interested in and it was decided to attempt this methodology .

Using empowerment research, 9 research clinics in the district, other than the 9 ICDM pilot clinics chosen for the national project were selected.. Six meetings were held at each clinic where the initial steps of empowerment research were practised. These were ‘’taking stock’’ ie discussion of the current situation and the development of a chronic patient vision by using validated tools and methods. The next step was a visit to confirm and further discuss decisions and the third step was feedback to the staff. The next 3 meetings at each clinic served to consolidate methods of implementing and measuring improvement.

The individual elements of each vision became the measurable objectives for the project and the thread throughout the process. “’Taking stock”’ of the current situation was assessed using a matrix in terms of interest and satisfaction with certain services.. Once the 4 most common services had been identified by the group, each of these was given a score between one and ten in terms of participants’ perceptions of their value or effectiveness. This set the scene for the group to understand the importance of measurement in improvement projects. These results were then discussed with the group. The chronic services at all the clinics scored on average 7-8 out of 10 which reflects a measure of satisfaction.

A variety of problems and solutions were scrutinised over the meetings, with some of them being particular to a specific facility. At each meeting evaluation methods were discussed or explained. A number of innovative suggestions were made by the teams.

As was found in the systematic review [69] where there was support and incremental development of skills, innovation took place to facilitate the integration of chronic care at all the clinics. A number of relevant patient posters were designed and disseminated, queue marshals identified with marked aprons, support groups started or strengthened and a process of delivery of medication to homes initiated. In total, 37 interventions were suggested by the different groups and 23 implemented in the time frame of the research. The processes and results at all the clinics using empowerment evaluation, are discussed in more detail in Chapter 3.

1.8.3 In Chapter 4, the topic exploring patient involvement in QI is: To enhance patients'/caregivers' experiences of care by patient inclusivity in QI using experience based co-design with mothers/caregivers of malnourished and ill children in a subdistrict in the North West province, as a qualitative intervention

A QI was initiated in a subdistrict in the North West province in 2011, due to the findings by routine data collection for the DHIS[70] (District Health Information System) that 14 % of children admitted to the hospital in October to December 2010 were severely malnourished and only 50% of under one year old's that were HIV positive were initiated on ART, in contravention of the 2010 National HIV guidelines.[71]

EBCD was chosen as an extra intervention, due to the fact that there had been been no previous patient involvement in the QI and as already discussed in the introduction, this focus has had positive outcomes for healthcare in many countries. EBCD is a structured qualitative process based on the design sciences. Emerging from interviews with patients and staff as well as individual and combined staff-patient meetings, priorities are chosen and co-design QI groups work together to seek and implement solutions. More than 50 projects globally have been completed using EBCD or are in process [72,73,74,75,76,77] and have included paediatrics, palliative care, care for the elderly, mental health and others.

The emphasis in EBCD is on the aesthetics of experience namely the feelings of patients and staff about their illness and the services they experience or offer. This is done by following a number of steps. A core team is created and the managers of the health services are well informed of the process. Then observations are done at ''touch points'' within the service. These are where staff and patients meet for any reason. Staff audio interviews and patient video interviews are the next step. A short edited and themed patient film is made from the interviews. Subsequently the two groups meet, first separately to prioritise improvement issues and then they meet together to share their perceptions, form co-design teams and work on core issues. At each of the meetings the short patient film is shown to elicit the body language and authentic experiences of patients who have been exposed to the health pathway. At the patients meeting emotional mapping[77] is done to find which words describe their experiences at different points.

This project involved 9 mothers and 14 staff members in the initial interviews. Themes from staff and patients included logistical problems like excessive waiting times, emotions, communication and attitudes of both staff and patients, continuity of staff and others. Three

co-design groups were formed to work on problem areas and out of 38 suggested interventions 25 were partially or completely implemented in the time frame of the research. Patients expressed greater understanding of staff's challenges and staff indicated they had not realised the pressures patients were experiencing, There were therefore empowerment moments for staff and patients as well as many practical improvements in the service itself.

The process and the results of the interviews, meetings and task teams are described in more detail in Chapter 4.

1.9 Conclusion

Quality and safety in health care have become an important focus over the last 20 years. Many developments have been recorded where QI has become entrenched in management styles and health cultures across the globe. Together with this, consumerism, patient's rights movements and a changing role for clients of health services, have determined a shift in the hierarchies of power in health. This needs to be both recognised and harnessed in the South African public health sector in both a pragmatic and academically accepted way.

The systematic review, using qualitative research and reports, discovered a huge body of literature where patients are being engaged. There is however little evidence of authentic and sustained patient involvement in health, especially in systems improvement.

The two projects undertaken to try and include patients in QI, both reflected the possibilities and difficulties inherent in this paradigm. Although they were time consuming and there were many practical barriers, new information emerged which was very valuable for quality; a sense of possibility was unleashed and real change occurred at all the points of influence.

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CHAPTER 2

PATIENTS INVOLVEMENT IN IMPROVEMENT INITIATIVES: A QUALITATIVE SYSTEMATIC REVIEW

Patients' involvement in improvement initiatives: a qualitative systematic review

Claire van Deventer[1,2]
Patricia McInerney[2,3]
Richard Cooke[2,4]

[1]Department of Family Medicine, University of the Witwatersrand, Johannesburg, South Africa
[2]The Witwatersrand Centre for Evidence Based Practice: an Affiliate Centre of the Joanna Briggs Institute

, [3].Centre for Health Science education Faculty of health Science Education University of the Witwatersrand.

[4] Centre for Rural Health, University of the Witwatersrand, Johannesburg, South Africa

Corresponding author
Claire van Deventer
cvandeventer@nwpg.gov.za

Executive summary

Background

Over the last 20 years, quality improvement in health has become an important strategy in health services in many countries. With the emphasis on quality health care, there has been a shift in social paradigms towards including service users in their own health on different levels. There is growing evidence in literature on the positive impact on health outcomes where patients are active participants in their personal care. There is however less information available on the broader influence of users on improvement in systems.

Objectives

The objective of this review was to identify the barriers and enablers to patients being involved in quality improvement efforts directed towards their own health care.

Inclusion criteria

Types of participants

This review considered studies that included adults and children of any age experiencing any health problem.

Phenomena of interest

The review considered studies that explored patient or user participation in quality improvement and the factors enabling and hindering this process

Types of studies

The qualitative component of this review considered studies that focused on qualitative data, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Other texts such as opinion papers and reports were also considered.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. The searches using all identified keywords and index terms included the databases PubMed, PsycINFO, Medline, Scopus, EBSCOhost and CINAHL.
Qualitative, text and opinion papers were considered for inclusion in this review.
Closely related concepts like community involvement, family involvement, patients' involvement in their own care (for example, in the case of shared decision making), and patient centeredness in the context of a consultation were excluded.

Methodological quality

Qualitative and textual papers selected for retrieval were assessed by two independent reviewers for appropriate rigor according to the Joanna Briggs Institute prescripts prior to inclusion in the review using the standardized critical appraisal instruments from the Joanna Briggs Institute.

Data extraction

Qualitative and textual data were extracted from papers included in the review using the standardized data extraction tool from the Joanna Briggs Institute.

Data synthesis

The above findings were pooled and through the identification of categories, a final metasynthesis was formulated.

Results

Two synthesized findings were created from the included papers. Firstly, there are barriers to patients' participation in quality improvement in health and in spite of policy support for user involvement in quality improvement, it is a difficult strategy to implement. The second synthesized finding was that there are enablers to patients' involvement in quality improvement : When patients are involved in quality improvement efforts in health care, there are innovative, often unexpected, outcomes at different levels of the process, and sustaining these efforts is possible with ongoing individual or group support.

Five categories which supported the synthesized findings were created through the meta-aggregative process.

Conclusions

There are enablers and barriers to involving patients in quality improvement in health care that need

to be considered when planning such interventions.

Implications for practice

Relationships and roles will need to be very clear from the outset. A developmental approach needs to be considered where support and training is part of the project. Where patients are truly engaged in service improvement, unexpected innovation occurs.

Implications for research

There are many more reports and opinion papers published regarding this topic than there are rigorous research studies. This leaves the field open to the development of good methodological studies related to quality improvement and in particular to the participation of patients.

Keywords

Quality improvement in health, patient participation, enablers, barriers

Introduction

Background

The quality improvement (QI) movement in health started in the early 1990s, although other industries had already been using many of the concepts earlier.[1-5] Patient-centeredness was a term coined in the 1960s, pre-dating the QI movement in health. For this reason, reports from 1990 onwards are the focus of this review. Quality improvement is an important movement in many sectors, including health. Patients' involvement in service improvement has only recently been acknowledged as adding value to healthcare. This has a parallel in the value of patient-centred individual consultations with better clinical outcomes, improved costs and other positive outcomes.[6] It is argued that where patients are excluded from QI efforts, there may be missed opportunities relating to patient experience, values, satisfaction and other outcomes of quality care. Where patient involvement and feedback has been used, there is evidence of improved quality of care, for example, in services provided to the aged[7], obstetric health[8], mental health[9], chronic illness[10], physiotherapy[11], health informatics[12], development of clinical guidelines, cancer and many more.[13]

Traditional QI includes cycles of assessment and interventions for change and the teams involved are usually professionals. However, globally the involvement of the patient in such initiatives is being recognized more and more as leading to an increased level of excellence in service provision.[14-17] As a result, there has been improved patient understanding and enablement as well as better patient outcomes.[18-20] The philosophical background leading to this shared decision making is one of consumerism and has been embraced as policy by the British National Health Service (NHS), Sweden, Australia, New Zealand and other developed countries.[21,22]

Service improvement initiatives involving patients are evident in literature across clinical disciplines, for example pediatrics[23,24], respiratory illnesses [25], mental health[9,26], rehabilitation[11], primary health care[27,28], dermatology [29], orthopedics and others.[30] This would indicate that despite a range of differing circumstances, generally the process has been seen to be of value. A peripheral area of patient engagement in QI is where patients have been involved in modifying or developing patient outcome instruments and patient satisfaction scales as part of QI.[31,32,33,34] There has not been full participation, but perceptions and ideas from patients have been sought and incorporated. More inclusive projects however have also been published and it is from these that the reviewer extracted information related to the phenomenon of interest.

An overlapping but tenuous relationship with the current topic involves the global movement on collaborative decision making in chronic illness, where there are numerous reports and research studies with structured quality interventions leading to improved clinical outcomes.[35,36,37,38] Many of these are based on the chronic care model (CCM).[39,40] The concepts and structure of the earlier reports do not reflect QI vocabulary, but implicit in the papers is the QI element, i.e. development of strategies towards health improvements based on different forms of initial baseline assessments. However, the role of the patient or family in the development of these strategies is lacking in all of these reports. Another related term, patient-centredness, has traditionally focussed on individual patient- provider relationships but is being used more and more in a system's context and therefore needs to be taken into consideration for this review.[41]

The literature on the QI movement is predominantly reflective of the healthcare system in developed countries.[42-45] In South Africa, a developing country, the above-mentioned cycles of assessment and interventions for change in health have been utilized on a limited scale and very little, if any, has been published regarding QI innovations in health, particularly regarding the involvement of the patient or client in such improvement projects. What has been published are studies on community (as opposed to the individual or family) involvement in health initiatives.[46,47] However, community development and health is not the focus of this review. There is therefore a fertile area for research in the context of patient and client engagement in health system improvement and change in South Africa.

While the value of this intervention is acknowledged in many studies on this topic, the lack of high quality evidence related to the success as well as the absence of a well-informed strategy to recognize and deal with potential barriers in the planning phases is evident. This is therefore an incentive to search for the most current enablers for future projects as well as a pragmatic acceptance of the potential barriers towards the intervention.

Based on the background briefly described, the exclusion of patients from QI initiatives in health seems to be a factor hindering improvements in the quality of health care provided. The context of

interest for this review is primary care. Primary care is the largest service area for health provision and affects the most patients. Within this sphere, there is a great opportunity for communities and patients to have a direct impact on their care through interest groups or individuals becoming involved in improvement projects. Regarding the engagement of users, there appear to be fewer studies in primary care than in the more technical and high care hospital settings. This is also the context within which the reviewer is working.

The significance of the findings would lie in the clarification of barriers and enablers in this particular field for further well-informed projects. In this review, primary care is understood as first line patient care and includes health provision at community, clinic and general practitioner levels. Patient empowerment in other settings beyond primary care, for example, highly technical intensive care units, has led to increased patient responsibility and better health outcomes.[15,20,44] Papers that have explored the review topic include project reports, editorials, government documents as well as qualitative and quantitative research. However, the focus of this review was on research papers that used qualitative methodologies, and text and opinion reports. This was for the purpose of understanding the underlying reasons for successes and limitations, and for exploring influences on the process of QI and the inclusion or not of patients in these processes.

A preliminary search of the Cochrane Database of Systematic Reviews, Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, Medline, CINAHL, PsycINFO and SCOPUS indicated that systematic reviews that were the most similar to the proposed topic evaluated the effect of clinical care pathways, provider centeredness or contextual influences on QI (where the individual patient was not considered), QI research methods and engaging patients in shared decision making in chronic illnesses; no qualitative or quantitative systematic reviews on patient involvement in QI were found.

Objective

The objective of this review was to identify the barriers and enablers to patients involved in QI efforts directed towards their own health care.

The review question is: What are the barriers and enablers to patients' involvement in QI efforts directed towards their own health care?

Inclusion criteria

Types of participants

This review considered studies that included adults and children of any age experiencing any health problem.

Phenomena of interest

The review considered studies that explored patient or user participation in QI and the factors enabling and hindering this process.

Context

The area of interest was the primary care context.

Exclusion criteria

Closely related concepts like community involvement, family involvement, patients' involvement in their own care (for example, in the case of shared decision making, especially in chronic care), and patient centredness in the context of a consultation were excluded from the review. Patient satisfaction and perceptions of their care were also issues peripheral to the research question and hence studies focussing on these were excluded.

Types of studies

The qualitative component of this review considered studies that focused on qualitative data, including but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Other texts such as opinion papers and reports were also considered. Literature reviews and other systematic reviews were excluded, although their references were searched for relevant articles.

Search strategy and study selection

Firstly, a rapid assessment was undertaken to assess whether there were systematic reviews on the proposed topic. The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of Medline, CINAHL, PsycINFO and PubMed was undertaken, followed by an analysis of the text words contained in the title and abstract and of the index terms used to describe relevant articles. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. The search was limited to studies published in the English language between 1990 and end 2012, as it was during this period that the adoption of QI concepts earlier used in industry and finance began in health care.[1-5] The databases searched included: PubMed, CINAHL, PsycINFO, SCOPUS and Medline. For grey literature, EAGLE and Ethos were searched, as well as conference papers from the International Forum on Quality and Safety in Health. The search strategy is presented in Appendix I. The searches took place between November 2012 and May 2013.

Where there was mention of patient participation, collaboration, empowerment, engagement, satisfaction, involvement or shared decision making in the title or in the abstract, these articles or reports were identified as potential papers in line with the inclusion criteria of the review. This was

followed by the retrieval of the full texts for assessment based on the inclusion criteria. Subsequently through the data synthesis process, the qualitative and text and opinion results were pooled and comprehensive synthesized findings were formulated.

Methodological quality of papers for inclusion in review

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological quality prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II). Any disagreements that arose between the reviewers were resolved through discussion.

Textual papers selected for retrieval were assessed by two independent reviewers for adherence to JBI standards prior to inclusion in the review using the standardized critical appraisal instruments from the Joanna Briggs Institute Narrative, Opinion and Text Assessment and Review Instrument (JBI-NOTARI) (Appendix III). The plan was to use a third reviewer had disagreements occurred. However the few discrepancies that arose between the reviewers were resolved through discussion.

Data collection

Qualitative data were extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix IV). The data extracted included specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. Findings, based on each author's conclusions or key themes in the paper, were accompanied by illustrations supporting each finding. The findings were assigned a level of credibility, namely, unequivocal (evidence beyond reasonable doubt), credible (logical but open to challenge) and unsupported (see Table 2 and Figure 3).

Textual data were extracted from papers included in the review using the standardized data extraction tool from JBI-NOTARI (Appendix V). The data extracted included specific details about the interventions, populations, conclusions and outcomes of significance to the review question and specific objectives. Publication details are similar to the findings discussed above and the conclusions and supporting arguments were extracted and are summarized in Table 4.

Data synthesis

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single

comprehensive set of synthesized findings that may be used as a basis for evidence-based practice.

Textual papers were pooled using JBI-NOTARI. This involved the aggregation or synthesis of conclusions to generate a set of statements that represented that aggregation through assembling and categorizing these conclusions on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

The syntheses of qualitative and textual papers are presented separately. Themes common to both types of evidence are identified and reported in “Discussion”.

Results

During the process of study selection and screening of studies it became clear that there were many articles peripherally related to the research topic; however they did not directly describe the phenomenon of interest of this review. As many articles had words similar to the review search terms, but with different meanings, the selection of appropriate articles was made complicated. For example, “involvement” may mean involvement in one’s own chronic illness with shared decision making about individual health choices; it may also mean involvement in health systems or families or communities.

During the selection process for eligible papers, it was found that patients’ involvement and participation in their individual health is the largest focus area in the literature. This is closely related to the focus of this review; however the difference is that QI involves patients’ participation in system change as opposed to their individual health decisions. Patient-centeredness is another overlapping concept, where collaboration and partnership are linked to positive outcomes. Many of these articles emerged during the search. However as they focussed on individuals’ health behaviours and not on broader quality systems issues, they were excluded. Family and community involvement were also excluded as these are part of a very different dynamic with its own separate paradigm. Community involvement in health and patient advisory groups in the United Kingdom’s (UK) National Health System (NHS), Canada and USA are closer to QI system interventions than the individual focus discussed above, and it informs policy as well as changes systems on the ground. These related areas formed part of the exclusion criteria for selection and the papers were hence not considered for the review.

The terminology “QI” was seldom encountered and alternative terms like “organizational” or “systems improvement” were more commonly used in the literature. Patients’ perceptions of their care and patient satisfaction surveys were not included, as these were not considered to be active factors in changing organizations and systems.

Amongst the qualitative methodologies, participatory action research (PAR) as a research method lent itself to being included in many instances because the QI cycle and the action-reflection cycle of

PAR are very similar. Lesser known methodologies like empowerment evaluation and experience-based design appeared very appropriate to the question and yielded useful papers for inclusion in the review,

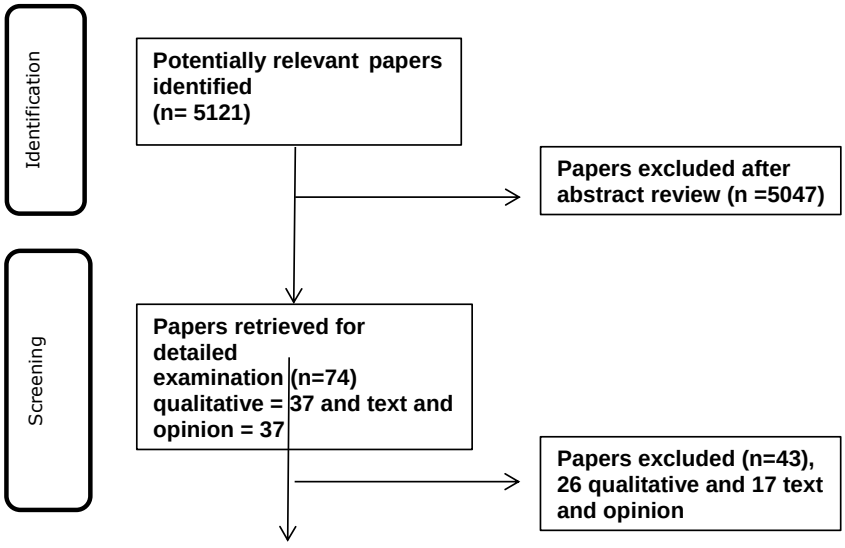
Description of studies

The search of relevant sources and databases identified 5121 citations. Of these, 4613 were excluded when it was clarified that they did not meet the eligibility criteria of the review or were duplicates. There were then 508 citations left which were assessed by two reviewers reading the abstracts. There was agreement that 434 of these studies were not appropriate for retrieval and further evaluation. The main reason for exclusion was that the studies did not relate directly to the phenomenon of interest. See Figure 1 for the study selection process.

A further common reason for exclusion was the apparent involvement of patients in improvements, but in a very peripheral way. Patients were generally involved in satisfaction surveys, or shared perceptions of care or ideas about services, but healthcare workers took the responsibility in decision-making and implementation of changes, without active participation from the patient group.

Thirty-seven full text qualitative articles were retrieved and 26 were excluded after review of the full text as they did not meet the inclusion criteria (see Figure 1 and Appendix VIII). Eventually 11 qualitative studies were critically appraised and 11 were included.

Considering the 37 retrieved text and opinion pieces, 17 of these discussed QI in health with only patients' perceptions or feedback, as opposed to actual commitment to activities for change being considered and, as with the qualitative studies, these were excluded. This left 20 text and opinion papers which were critically appraised, all of which were included for further data analysis (see Figure 1 and Appendix VIII).



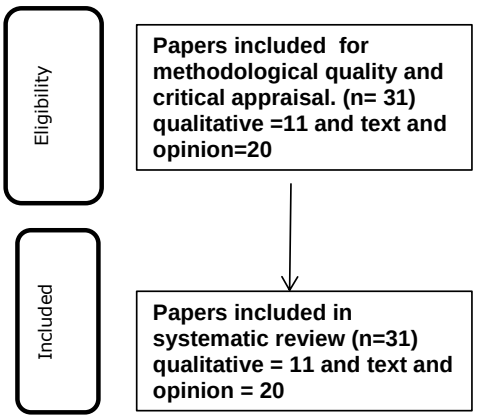


Figure 1: Study selection flow chart

Settings and clinical focus of included papers

The clinical areas most often represented in the included articles encompassed a fairly limited range, as shown in Figure 2. Public health was the area most represented, followed by cancer and other chronic conditions, for example, mental health and non-communicable diseases. Text and opinion papers contributed most to the public health category, and included policy documents, editorials and others.

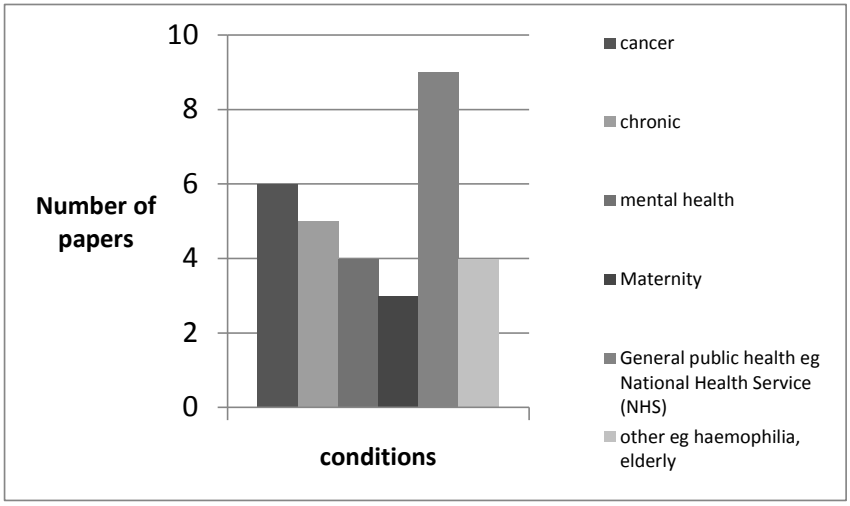


Figure 2: Clinical areas most often represented (n=33 articles)

Of the 31 included papers, 24 related to primary care, and seven were a combination of primary and hospital care. The current review was particularly interested in primary care as a vehicle for patient

participation in QI; however this was not always a well-defined context. The majority of the material was from the United Kingdom (66%). Other countries represented were the USA, Australia and the Republic of Ireland.

The included studies represent different methodologies, including the emancipatory-critical paradigm with four PAR studies[48,49,50,51] , as well as the interpretative qualitative paradigm represented by one empowerment evaluation [52], two quality improvement research studies (although one was called operational research) [53,54], one ethnographic study[55], one case study[12], and two papers with mixed qualitative methodologies[37,56],. The mixed methodologies included data collection methods such as focus groups, observation and document review. (See Appendix VII.)

The text and opinion papers included policy guidelines[57,58,59,62,69], editorials[67,72], opinion pieces[8, 18,61, 60,64,65,66,68, 73, 74,75], and reports.[63,71] The Welsh national leadership and innovation agency for healthcare developed a number of documents relating to collaboration in health care.[57,58,59] These cover general practitioner guidelines, mental health policies and many other areas of health. The patient element is captured in the texts included in this review. Other reports included described attempts to involve patients in their own care and discussion of models of care that had been developed, e.g. for maternity, chronic care and cancer services.[8,37,49,60] The concepts of patient advisory groups or patient councils were discussed by Ponte[18] and Angstman [61] as methods of patient involvement.

~~The fact that most of the papers reflect mental health and palliative care may be because of the advanced emphasis on patient advocacy in these spheres, especially in the United Kingdom.~~

Methodological quality of qualitative studies

Eleven qualitative studies were critically appraised using the assessment tool in QARI.

Table 1: Number of qualitative studies included and excluded

Number of studies included	Number of studies excluded
11	26

Table 2: Final assessment table for qualitative studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Arsand E, Demiris G, 2008[12]	Y	Y	Y	Y	N	Y	N	N	Y	Y
Forbat L, Cayliss S, Knighting K, Cornwell J, Kearney N, 2009[53]	Y	Y	Y	Y	Y	Y	N	Y	N	Y

Fudge N, Wolfe CDA, McKevitt C, 2007[54]	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Gold SKT, Abelson J, Charles CA, 2005[55]	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Sullins CD, 2003[51]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Walsh H, Hostick T, 2005[52]	Y	Y	Y	U	U	Y	Y	N	U	Y
Grogan a, Coughlan M, O'Mahoney B, McKee G, 2012[49]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jones SP, Auton MF, Burton CR, Watkins CL, 2008[48]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Richardson A, Sitzia J,Cotterell P, 2010[37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Zeitz K,Kitson A, Gibb H, Bagley E, Chester M, Davy C, Frankham J, Guthrie S, Roney F, Shanks A., 2010[56]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Truman C, Raine P, 2002[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Q1 to Q10 are the 10 statements used in the first step of the JBI software and are the following:

Q1. There is congruity between the stated philosophical perspective and the research methodology

Q2. There is congruity between the research methodology and the research question or objectives

Q3.There is congruity between the research methodology and the methods used to collect data.

Q4. There is congruity between the research methodology and the representation and analysis of data

Q5 There is congruity between the research methodology and the interpretation of results

Q6. There is a statement locating the researcher culturally or theoretically

Q7 The influence of the researcher on the research and vice- versa is addressed

Q8 Participants, and their voices, are adequately represented

Q9 The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body.

Q10 Conclusions drawn in the research report do appear to flow from the analysis, or interpretation of the data.

Overall the quality of the evidence was high, with most studies sustaining congruency between philosophy, methodology and data collection as well as analysis and interpretation. For the 11 included studies, criteria 1, 2, 6 and 10 were all fulfilled (see Table 2 and Appendix II for the

assessment criteria). These indicated that there was congruity in all the studies between the philosophical perspective and the methodology as well as between the methodology and the research question or objectives. The conclusions were all found to flow from the analysis of the research. In all of the studies the researcher could be located contextually.

For criteria 3, 4 and 5 there were a few uncertainties (see Appendix II for the assessment criteria). These questions relate to the collection and analysis of data and the interpretation of the results. Walsh's[52] community operational research resonates with QI research, but it is unclear whether the choices that were made are based on congruency in method and interpretation.

Question 9 considers ethical approval or ethical approaches. Where there was not implicit or explicit mention of ethics, they were marked as unclear or not present. It was felt by the reviewers that in the papers by Forbat[53] and Gold[55], although there was congruency and good methodology, there was a lack of clear evidence of how the ethical route had been followed. Forbat's[53] methodology followed a QI type of cycle using PDSA (Plan, Do, Study, Act). There has been a great deal of debate about whether QI needs the same ethical rigor as mainstream research. The lack of information regarding ethics in this study may reflect that debate.

Quality of text and opinion articles

Twenty text and opinion papers were critically appraised using the assessment tool in NOTARI (see Table 3).

Table 3: Number of publications included and excluded for text and opinion papers

Number of publications included	Number of publications excluded
20	17

The quality of the evidence for text and opinion was generally high. Included papers were assessed by two reviewers and the findings are summarized in Table 4. The first question which asks whether the source of the data has been clearly identified received negative responses in two documents, namely, a document from the Health Foundation[62] where no authors were indicated, and a report by Small.[63] The Health Foundation is a non-governmental organization based in the UK which, amongst other roles, develops teaching materials; contributors are however not identified in this document. Small's paper is an NHS based palliative care report which does not indicate his credentials.

Table 4: Final assessment for text and opinion papers

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7
Donaldson L, 2000[71]	Y	Y	Y	Y	Y	Y	Y
Airey R, Farrar D, Wilkinson K, Walker J, Tuffnell D, 2009[8]	Y	Y	Y	Y	Y	Y	Y

Bate P, Robert G, 2006[75]	Y	Y	Y	Y	Y	Y	Y
Angstman KB, RO Bender, SM Bruce, 2012[61]	Y	Y	Y	Y	Y	Y	Y
Beresford P, 2006[66]	Y	Y	Y	Y	Y	Y	Y
Jacques H, 2012[67]	Y	Y	Y	Y	Y	Y	Y
Millet A, Devlin J, Adams P, Gill B, 1999[73]	Y	Y	Y	Y	Y	Y	Y
Newman L, Hood J, 2009[60]	Y	Y	Y	Y	Y	Y	Y
Ponte PR, Nies J, Conlin G, Shulman L, Conway JB, Branowicki P et al, 2003[18]	Y	Y	Y	Y	Y	Y	Y
Sang B, 2002[65]	Y	Y	Y	Y	U	Y	U
Staniskewska S, West E, 2004[72]	Y	Y	N/A	Y	Y	Y	N/A
Vincent CA, Coulter A, 2002[68]	Y	Y	Y	Y	Y	Y	Y
Taylor C, Richens Y, Shaw F, Evans P, 2006[74]	Y	Y	Y	Y	Y	U	Y
Health foundation, 2005[62]	N	Y	Y	Y	U	Y	Y
Small N, 2006[63]	N	Y	Y	Y	Y	Y	Y
Gibbons, 2005[59]	Y	Y	Y	Y	Y	Y	Y
Chick P, 2006[69]	Y	Y	Y	Y	N	Y	Y
Williams P, 2007[58]	Y	Y	Y	Y	N	Y	Y
Williams P, Sullivan H, 2007[57]	Y	Y	Y	Y	Y	Y	Y
Matthews R, 2010[64]	Y	Y	Y	Y	N	Y	Y

In NOTARI, the following are the questions:

Q1 Is the source of the opinion clearly identified?

Q2 Does the source of the opinion have standing in the field of expertise?

Q3 Are the interests of patients/clients the central focus of the opinion?

Q4 Is the opinion's basis in logic/experience clearly argued?

Q5 Is the argument developed analytically?

Q6 Is there reference to the extant literature/evidence and any incongruency with it logically defended?

Q7 Is the opinion supported by peers?

The question which had the most uncertain or negative responses was Question 5, which queries the analytical development of the argument. Many of the papers were editorials or policy documents and might not be expected to necessarily have a well-developed argument. Matthews[64], for example, wrote an article on the experiences of two teams who were trying to improve care of and with chronically ill patients based on research evidence. There was no argument or critical discussion. This is simply a report of insights gained and a process which occurred.

Question 7 explores whether the author is supported in his opinion by his peers. It was unclear in Sang's[65] paper whether he, as a patient facilitator and patient advocate, was supported by his peers. One would assume that this was the case as he alleged many years of involvement. However the conclusion remained uncertain.

Results of the meta-synthesis of qualitative research findings

Included qualitative studies and text and opinion pieces were analysed separately. Meta-synthesis of qualitative studies generated two synthesized findings. The first was that barriers to patients' participation in QI in health were: difficulty in implementation in spite of policy support for user involvement in QI, and differing views between users and providers. The second synthesized finding encompassed enablers of the process. When patients were involved in QI efforts in health care, there were innovative, often unexpected outcomes at different levels of the process and sustaining these efforts was possible with ongoing individual or group support.

These synthesized findings were derived from 18 study findings extracted directly from the included qualitative studies that were subsequently aggregated into five categories, described in more detail below. The study characteristics, e.g. the methods, participants and outcomes in each paper, are listed in Appendix VII and a summary of synthesized results from the qualitative studies can be found in Figure 3.

Categories

Policy to practice

This category reflects the difficulties encountered in translating policy and commitment into practice. Despite recognition at the highest levels of the importance of patient participation in improvement in quality health care, there is little evidence of successful implementation. The findings informing this category come from different health settings and countries. The words "policy" and "government commitment" reflect the intention to involve patients but in the findings there is evidence that there has been a failure to meet these expectations (see Figure 3).

The reasons for the discrepancy between the will to transform systems and to engage patients and

the poor outcomes documented, seem to be in relation to the complexity of implementing change as well as inadequate planning for engagement. Additionally, in the less successful projects, the patient's experience of the system has not been considered. See Figure 3 and Appendix IX for more detailed information.

Differing provider/patient perspectives

The second category regarding different patient and provider opinions about their roles is informed by a number of findings. It is clear from these findings that differing viewpoints and beliefs between providers and patients have consequences for the involvement of patients in health projects. Fudge and coworkers[54] discussed different perspectives in an ethnographic study with stroke survivors. Professionals had a variety of views of what involvement entailed, linked to their own background and career history.

Fudge et al [54] reported that healthcare providers generally determined the agenda and that the gains for patients leaned towards personal experiences rather than measurable clinical outcomes. In the light of this and the resource requirements for such interventions, the authors called for more evidence supporting the benefits of patient involvement.

Other professionals saw involvement as an NHS requirement, tending to involve service users at the end of the process to get approval for a product or service, and considered patients to be inarticulate and apathetic.[54] Forbat's[53] research with cancer patients revealed an awareness of power inequalities in spite of efforts to involve patients. Staff, on the other hand, articulated concerns about their professional roles being compromised and were also unsure about the commitment expected from them in terms of energy and time. There was a sense in these papers of the perception of an inadequacy of patients' potential to take on certain roles and a resultant reluctance from health care workers to take responsibility for including them in quality issues. The different perspectives on the roles of providers and patients, if not clarified, were a barrier to effective implementation of user engagement, although this negative impact was not spelt out in the findings.

Whereas in a study by Fudge[54], providers considered patients inadequate to be involved in certain activities, Forbat[53] found that cancer patients themselves did not trust their capabilities. Forbat illustrates this with the following: "As a patient you are far down the pecking order and the type of cancer may preclude active involvement."[53(p87)] In the same study, it became clear that staff were under the impression that they were involving patients through patient satisfaction surveys and in a day-to-day manner. They supported these so-called short interventions rather than formal collaborative QI projects, which they perceived as being too time consuming.

Where deliberate domination by healthcare workers was experienced by patients, much of the lack of success in adequate outcomes related to poor planning and lack of clear thinking before including patients, as mentioned above.[50,55] See Figure 3 and Appendix IX for more details.

Different levels of involvement

In the third category, which was captured as the following: “patients may be instigators of change through prioritizing areas of need or contributing directly towards change”, the different levels of influence that were found are reflected. All the findings report patient involvement, albeit to lesser or greater intensities. These findings mention diversity of interventions, teamwork and partnerships and patient experience as part of change management and all suggest positive results from the involvement.

Forbat[53] argued for involving patients at every stage, from identifying problems to planning, implementing and monitoring change as did Jones.[48] Arsand[12] found positive outcomes for the co-design of self-help tools like blood glucose monitors through direct patient participation. Co-design reflected a pathway of comprehensive involvement at different levels of change.

Sullins[51] described the involvement of mentally ill patients at a “drop-in” centre in an inclusive process of improvement. However, the patients were unable to progress beyond sharing ideas and solutions towards action. This paper then reflects a lesser intensity of participation than the co-design examples referred to above. In stroke patients there was also more indirect and passive involvement related to patient satisfaction surveys, opinions and inputs into teaching materials.[42]

There is therefore a different focus from the different researchers towards the involvement of patients in their care. These range from full engagement to a sequential, developmental approach as well as the more superficial, indirect engagement through the use of information and ideas from patients.[51]

Innovation

Innovation may be interpreted as something out of the ordinary and yet even simple, patient-centered changes were reported in some of the articles. User-centric efforts at QI in health often lead to relevant and sometimes unexpected interventions. This is the fourth category which was identified. There were diverse examples of innovations as reported from the different authors. The findings indicate that both concrete innovations occurred as well as the development of tools and frameworks that were co-designed by patients and providers which lead to further changes. See Figure 3 and Appendix IX for examples from these qualitative studies.

Support and development

The fifth category identified that where there is ongoing individual or group support and collaboration and incremental development through skills and enablement there are better outcomes. A number of findings here relate to the ongoing support within a project, of a team leader and of the development of skills in the group. The importance of continuity of the groups is implied in these findings.

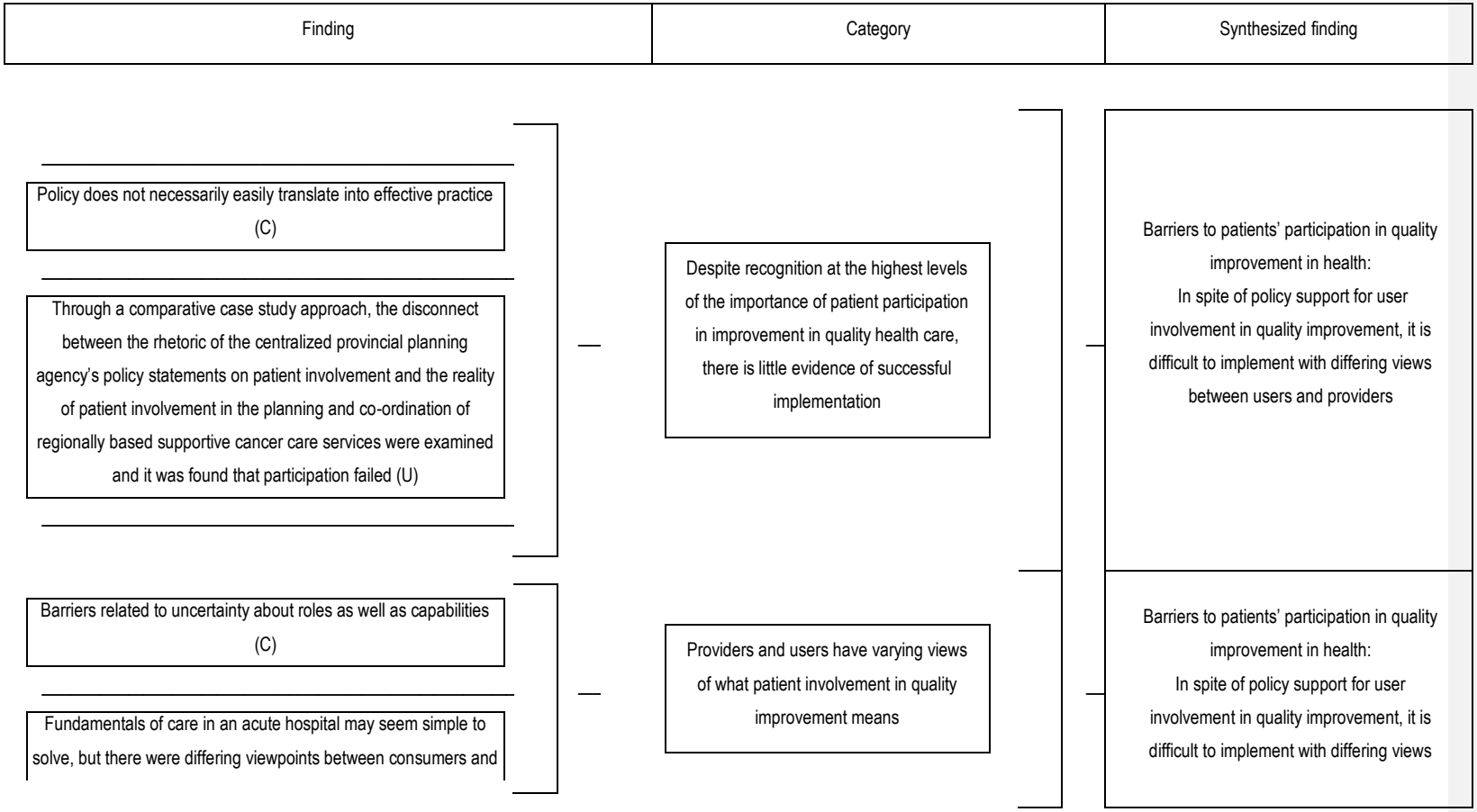
Richardson[37] described cancer groups which evolved in the complexity of tasks and outputs over time, supported by change management training. Forbat et al.[53] reported on a change project where two groups of cancer patients were used as intervention groups and three as controls. Researcher

support, through PDSA cycles, led to seven interventions, including patient advice leaflets and handheld records in the intervention groups. In the qualitative interviews held after the intervention, it was clear that the control group only considered engagement at an informal day-to-day level and did not consider the more intense involvement experienced by the intervention group. The support and ongoing training and exposure in the intervention group appeared to have been the decisive issue. Grogan's[49] evolving haemophilia improvement group was based on a supported patient partnership model which sustained action over a number of years and used participatory action methods to continue with the action and reflection regarding services. The support mentioned above varied from regular meetings with experts, planned training sessions, assistance with technical skills and others.

What was particularly successful were instances where there was some element of developmental support for the patients. Forbat[53] found with supported collaboration, both healthcare providers', patients' and carers' perceptions of their roles changed. In the study, after focus groups and open discussions about barriers and enablers, the intervention group had developed and changed their ideas regarding patient involvement, whereas the control group was still entrenched in the difficulties inherent in such a collaboration.

Categorization and synthesis of qualitative research findings

The final synthesized findings of the qualitative research papers are informed by five categories and 18 findings, as illustrated in Figure 3 below.



providers (C)

The intervention and non-intervention groups differed in their understanding and engagement with involvement and the related barriers and opportunities (C)

Users and providers had a wide range of differing views on involvement of patients (C)

between users and providers

Four work groups were created which dealt with four different aspects relating to stroke care (U)

Intervention groups consisting of mixed providers and users in a lung cancer setting designed improvements using PDSA cycles (U)

Patient involvement evolved into patient partnership and resulted in the implementation of quality initiatives that improved hemophilia

Patients may be instigators of change through prioritizing areas of need or contributing directly towards change

Enablers to patients involvement in quality improvement:
When patients are involved in quality improvement efforts in health care, there are innovative, often unexpected outcomes at different levels of the process and sustaining these efforts is possible with ongoing individual or group support

patient care both directly within the hemophilia service and within the greater health service (C)

The CPP (cancer partnership program) model, in contrast to the PPI (patient and public involvement) model which was more 'scrutinizing', allowed participants to influence policy and change in a real way (C)

The experiences of patients and carers throughout their stroke journeys generated a range of issues for service development (U)

Empowerment evaluation as an engagement and empowerment tool for mental health users was continually adapted to accommodate the reality of a 'drop-in' center (C)

In two different projects, complex theory was shared and built into meaningful user involvement, with positive outcomes (U)

The development of a framework on patient involvement in the design process of self-help tools in health was presented and the

User-centric efforts at quality improvement in health often lead to relevant and sometimes unexpected interventions

Enablers to patients involvement in quality improvement:
When patients are involved in quality improvement efforts in health care, there are innovative, often unexpected outcomes at different levels of the process and sustaining these efforts is possible with ongoing individual or group support

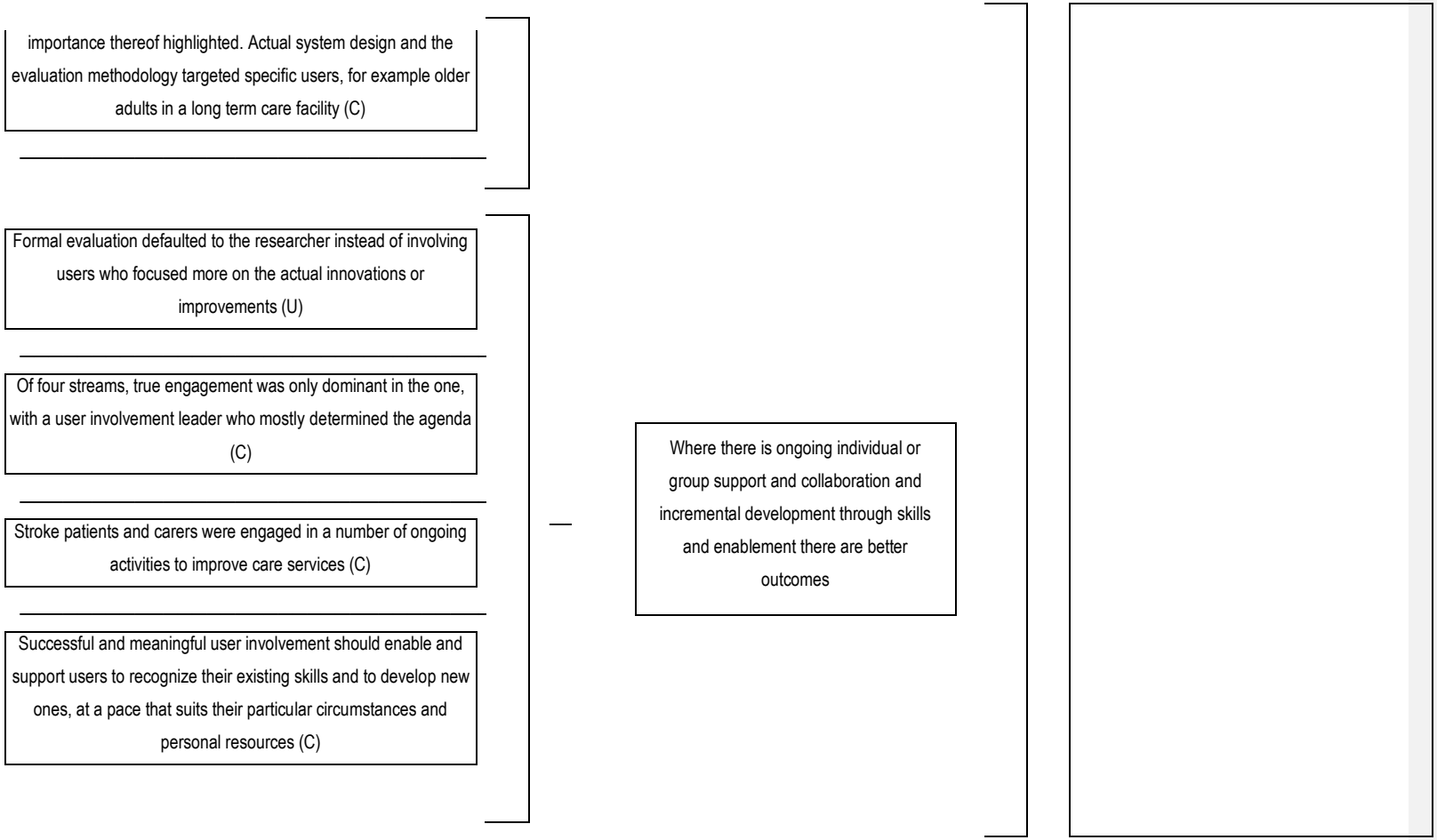


Figure 3: Meta-synthesis of patients' participation in quality improvement

In summary of the above synthesized findings and categories, the key findings from the included studies were that there were clear barriers and enablers to involving patients in a concrete way in improvements in health related systems improvement. In spite of the barriers identified, the enablers revealed potential for positive change. A key finding of the included research was that where patients were involved, unexpected or appropriate innovations were reported. The other enablers were being able to involve patients either through their prioritization of areas for improvement, or by their direct involvement in projects.

Results of meta-synthesis of textual data based on opinion

Meta-synthesis of 20 text and opinion pieces included in this review generated two synthesized findings (see Figure 4). These synthesized findings were derived from 24 publication conclusions that were subsequently aggregated into five categories. The two synthesized findings were congruent with those found for the included qualitative papers. The barriers were represented by the difficulties regarding policy and practice as well as a disconnect in viewpoints between health care workers and patients. The enablers identified in the text and opinion papers were also related to innovation and unexpected outcomes as well as the sustainability of improvement with involvement at different levels. As in the qualitative publications, the five categories included the issues of policy to practice, service provider and patient perspectives, varying levels of involvement, innovation and sustainability. These are addressed in more detail below. The publication conclusions are listed in Appendix VII and the NOTARI view detailing the relationships between publication conclusions, categories and synthesized findings is shown in Figure 4.

Policy to practice

In this first category in NOTARI, as in the qualitative syntheses (see Figure 4), the challenges in engaging patients in spite of organizational commitment to such a process are highlighted by a number of articles. Beresford[66] found that service users were able to offer a complex and sophisticated model of what outcome measures might look like if the users were centrally involved in their definition, but found that in spite of the emphasis on engaging customers, this had not yet reached its full potential. Barriers identified by patients in this case study included inadequate funding, bureaucracy and inflexibility.

The findings informing this category mentioned terms such as challenges and obstacles to implementation of patient involvement. Difficulties inherent in engaging users is more prominently identified in the text and opinion papers than in the previous qualitative findings discussed. Difficulties raised by Jacques[67] in an editorial concerning the different levels of patient involvement in QI were traditional health hierarchies which were seldom challenged by patients, as well as the inability by patients to realize the extent of adverse events needing change management. Vincent [68]supported the lack of insight by patients into safety issues in health which translated into less urgency for users

to be involved in changing systems. Power hierarchies were also mentioned by Williams.[57] He found that this led to user frustration as well as the inability to involve marginalized groups, e.g. youth or ethnic minorities.

Small[63] looked critically at the disparity in the British NHS in the late 1990s, where "choice" was the buzz word for consumers, but in practice, lack of alternatives, information and transparency led to patient disempowerment. Another cogent point made by this author is: "perhaps paradoxically it (patient involvement) can be used to help perpetuate existing power structures. If we can claim that users are involved, we can profess a legitimacy for what is in place that inhibits opposition."[63(p17)] A key strength users identified was networking, and barriers to this were identified by Beresford[66] as being a lack of mobility of users (rural areas) and the effort needed to be involved. From these sources, the difficulties in engaging service users in spite of policy were confirmed. However, a sample of national documents strongly advised inclusion of patients for better outcomes of quality projects.[57-59,69]

There is therefore congruence between both qualitative studies and opinion pieces regarding the difficulties in translating policy into practice. However, amongst the included text and opinion papers, the debate is much broader and incorporated a number of clearly articulated reasons, such as inflexible health hierarchies and lack of patient insight. Other impediments to partnerships and engagement of both users and providers of health care include financial constraints and the effort to be involved, and in some cases political and social challenges and technical challenges which are perceived as being too complicated for patients to understand.

Differing provider/patient perspectives

In the second category, both the importance of recognizing different perceptions about patient and provider roles and the importance of team work emerge from the findings. Beresford[66] highlighted the tensions between consumers and providers in relation to their views on quality, with users demonstrating a narrower understanding of quality in health. The power imbalance between users and health organizations repeatedly emerges. "Service users feel that their knowledge is generally not valued or taken seriously by professionals and services. Trying to impart their knowledge is also frequently a disempowering experience.''[66(p438)]

There is evidence from evaluation research done by Barnes[71] that patients find themselves marginalized when important decisions need to be made as providers hold financial and technical power. There seem to be two arguments in the text and opinion papers regarding client and provider understanding of roles. Patients are unsure of their capabilities and this is worsened by provider paternalism. Resources are skewed to deflect users from optimal involvement.

Different levels of involvement

The third category confirms that patients are involved through patient advisory groups[56], patient councils[18], focus groups[64] and other types of partnerships.[57] More indirect involvement is described in Airey's[8] report on a maternity initiative where users were involved primarily through identifying priorities which led to real and appropriate changes, e.g. gender identification of babies through ultrasound. Angstman's[61] group met regularly as patients with depression and reviewed and made recommendations on acute care, internet access for patients and other initiatives which were primarily enacted by health professionals. These are examples of more peripheral involvement as opposed to the direct, active engagement experiences in Grogan's[49] qualitative article.

There is evidence therefore in the findings of user participation at many levels: however the more intense involvement is reflected by words like co-design, patient advisory group and the repetition of "at all levels". These findings which strongly embrace empowerment and user involvement may be more uniform in their acceptance of patients' roles due to the fact that many are policy documents or opinion pieces. This support for the concept has been found in category one in both the qualitative and text and opinion papers. However, in all the papers it was found that the translation of theory to practice was not easily accomplished.

Not all the included papers acknowledge the variety of levels of involvement that are possible with service users. However, Jacques[67] discussed these, as did Williams[57] who mentioned that patients should be involved in the design and delivery of services. Sang[65] described a looser taxonomy of participation, mentioning so called "expert patients" (chronic patients who assist in service development and improvement), independent lay advocates who promote marginalized patient voices, and social and civic entrepreneurs who are change agents within the system.

Expert patients described by Donaldson[71] were primarily empowered to manage their own illnesses, so shared decision making is core to this paper, but there is some mention of extending the roles to include patient advocates and advisers in each hospital, as well as patient involvement through fora and panels. Gibbons'[59] paper on mental health in Wales proposed involvement of patients in the planning, design, delivery, monitoring and evaluation of improvement projects. Staniskewska[72] almost echoed these exact words in an editorial. She saw healthcare workers as the key to successfully implementing patient partnerships, but questioned the realism of this approach, with the limitations of an aging workforce and shortage of health staff. There is acknowledgement in all of the above of the value of some kind of patient engagement. A working in collaboration series from Wales consistently encouraged user involvement at different levels of health[57,58], as did the mental health protocol from Wales entitled: 'Raising the standard'.[59] All these however are theoretical, in contrast to the qualitative papers where the success of the concept of patient involvement was based on studies.

Innovation

Despite the barriers to implementing patient participation in QI, there is evidence of success. Many practical and innovative interventions are demonstrated (see Figure 4 and Appendix VIII). Generally the innovations discussed in NOTARI tend to be less direct than those in QARI. However there are examples of concrete and practical changes. There was the publication of a council newsletter (called Side by Side) by a cancer patient advisory group.[18] Another one of these cancer patient groups became involved in patient rounds and there was the development of a new telephone triage centre for patients with depression amongst others by Angstman's[61] depression group.

Support and development

Sustainability of patient involvement in QI, through skills training or individual or group support was reflected by a number of projects, e.g. "Shaping our Lives"[66], and the Measures project.[73] This then is the fifth category in NOTARI. Task teams and partnerships are mentioned in the findings and these appear to be the vehicles for mentoring and development, which are crucial to the sustainability of patient involvement in QI. See more detail in Figure 4.

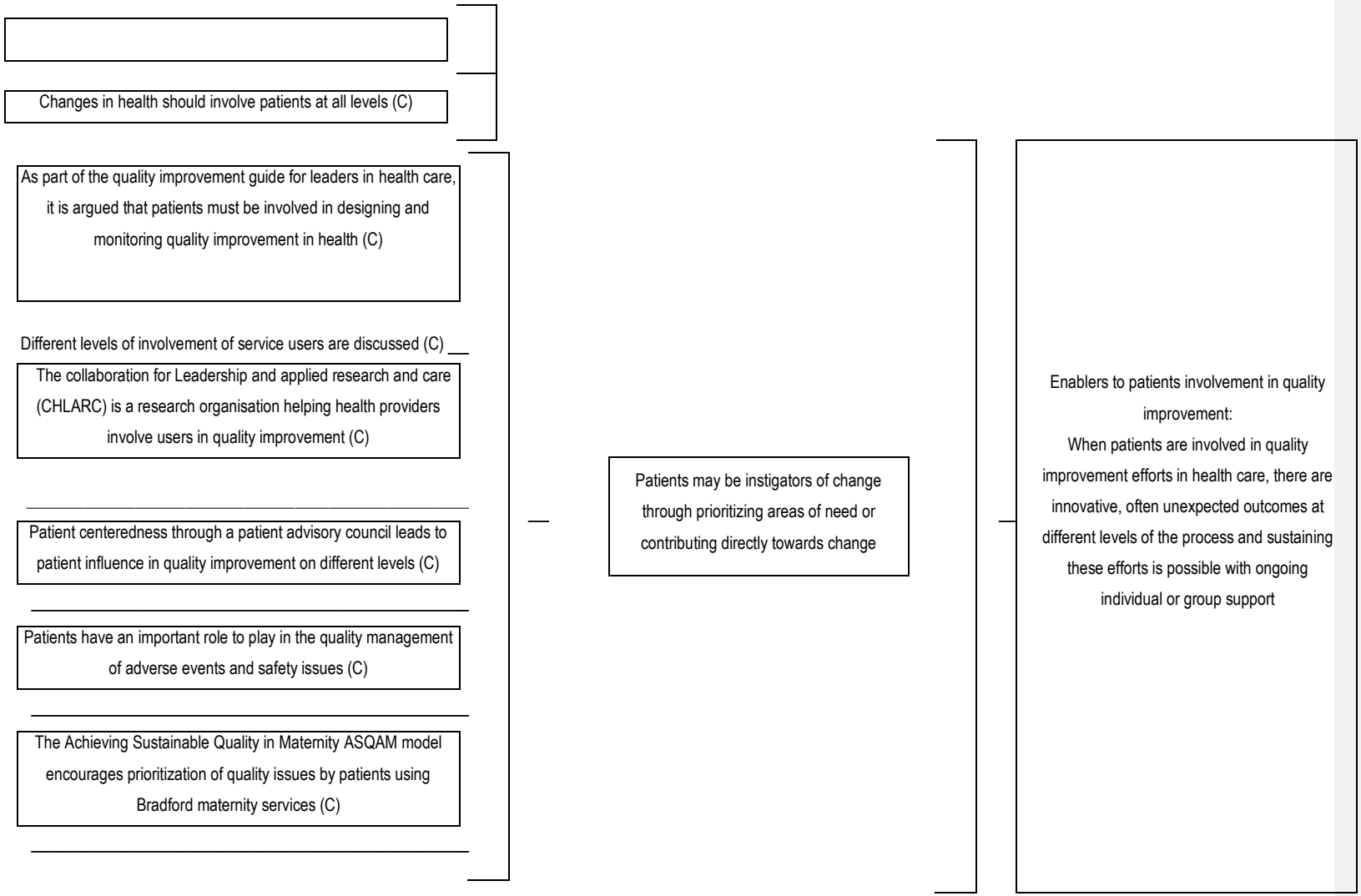
Categorization and synthesis of textual data based on opinion research findings

The final synthesized findings of the text and opinion papers are informed by five categories and 24 publication conclusions as illustrated in Figure 4 below

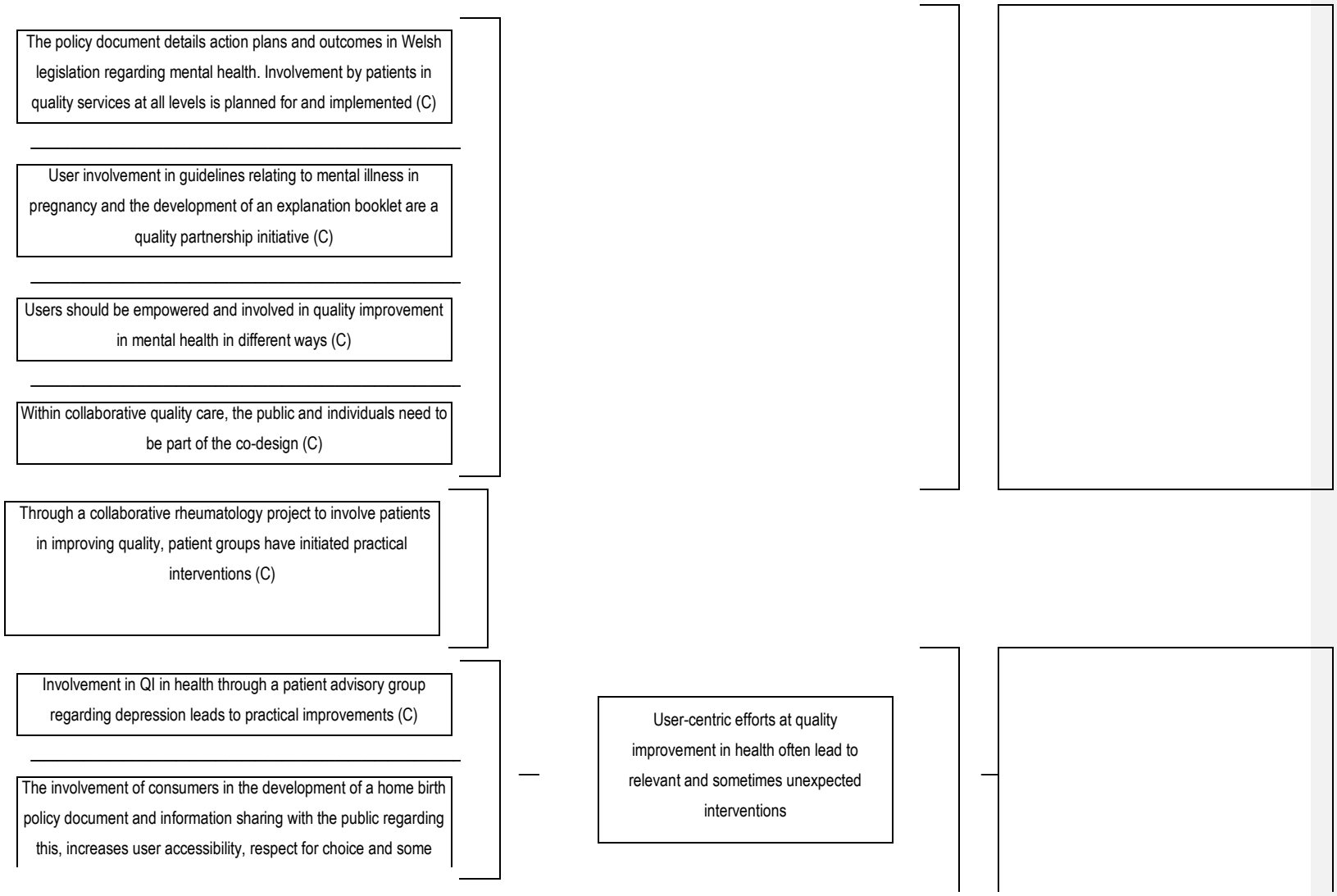
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Conclusion	Category	Synthesized finding
Palliative care offers particular challenges in user involvement at all levels of quality care (C) Users find many obstacles to becoming involved in quality health issues (C)	Despite recognition at the highest levels of the importance of patient participation in improvement in quality health care, there is little evidence of successful implementation	Barriers to patients' participation in quality improvement in health: In spite of policy support for user involvement in quality improvement, it is difficult to implement with differing views between users and providers
Partnership is essential in improvement of health care services (C) Patients and providers need to understand and embrace the new social paradigm of choice and involvement in care (C) There are different definitions and roles of public and citizen involvement in care (C)	Providers and users have varying views of what patient involvement in quality improvement means	

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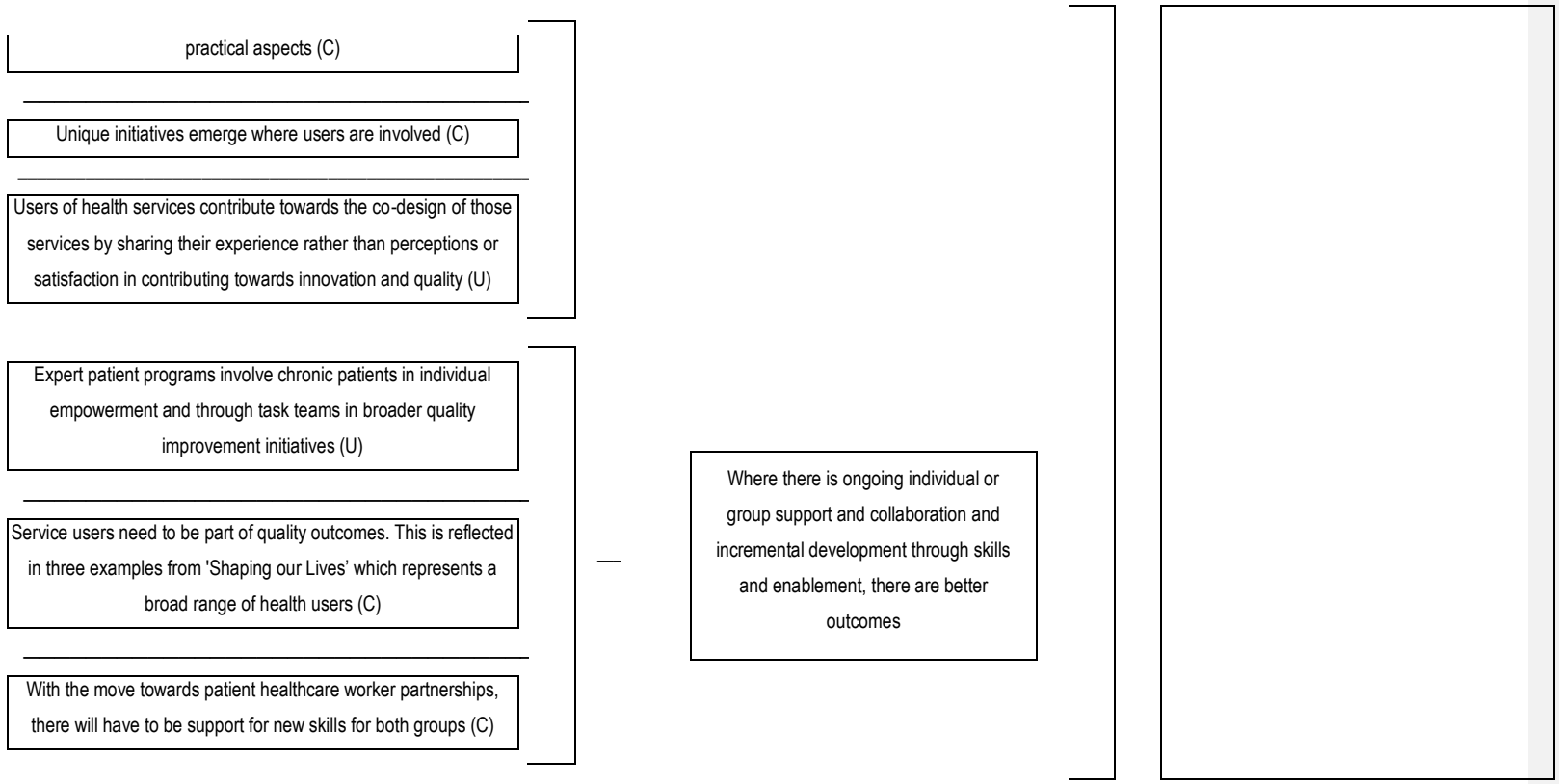


Figure 4: Meta-synthesis of patients' participation in quality improvement

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In summary, the findings synthesized in NOTARI appear congruent with those from QARI and confirm very similar barriers and enablers from the perspective of text and opinion papers. A barrier to successful inclusion of patients repetitively emerges, namely, differing viewpoints regarding the roles and choices of such participants.[57,66] On the positive side, many papers affirm the continued commitment to the patient engagement route.[18,61,73] There are also examples of assistance by patients in applying QI ideas and concrete changes and innovations that have resulted from persevering. These examples range from peripheral involvement to experiential, co-design of services.[3,73,75] Though not common throughout the included studies, some authors report on patients and providers' need for support and on-going training [84,85]

Discussion

The understanding of the term participation is broad. Tritter[76] differentiates between direct and indirect involvement, individual and collective patient participation and reactive or proactive involvement. By using these categories, he essentially makes a value statement about the relevance and genuineness of the level of involvement. Grogan[49] categorizes hierarchies of involvement with the concept of patient involvement being at the lowest level, then patient participation and finally patient partnership representing the height of the hierarchy.

Apart from the levels of involvement identified in the reviewed literature, the excluded literature reflects some of the many overlapping terms found at the beginning of the search process, which had to be recognized in order to be extracted from this systematic review, such as patient-centeredness in the consultation, family or community involvement, patient collaboration in the chronic model and a patient's involvement in his/her own care.

Arnsteins' ladder is quoted in four articles.[48,52,55,70,77] This author describes citizen participation as developing from information sharing and then consultation, through "placation" (choosing apparent patient representatives), partnerships on boards, delegated power and eventually citizen control. Although this is an old reference, it lays theoretical foundations for the development of patient-centered thinking and action. The concept of person-centered care has recently evolved to include systems and patients' roles in the co-design of health services as well as their individual partnerships regarding their illness.[41] This may influence the vocabulary of patient engagement in the future.

Many publications over the last decade have acknowledged the disconnect between the rhetoric and the reality regarding patient partnerships in service improvement in health.[78-85] In spite of these difficulties, there is an on-going commitment to this paradigm shift. It is important then to understand the processes that may impede or support the success of this endeavor.

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The two sets of synthesized findings from this research indicate in essence that there are enablers and barriers to involving patients in QI efforts in health.

Enablers

Where there has been planning for involvement, where there is a developmental process coupled with training and mentoring, and often where there have been adequate resources, projects have been successful and sustained. Positive outcomes have been both "soft" and "hard". The so-called 'soft' outcomes include patient satisfaction with services, feelings of being respected and acknowledged and developing insight into health problems. Mental health patients felt there was de-stigmatization, feelings of safety and a sense of being in control.[51] Petersen's[86] findings of improved adherence, dignity and a sense of security with mental health users were similar to experiences cited by Sullins[51] and Truman.[50] The more concrete outcomes included not only innovations like changed discharge processes and dietary innovations for the elderly, a newspaper for cancer patients and carers, improved after-hours services and co-design of an outpatient department, but also collaboration based on experience and in experience-based design.[12,18,37 ,75]

The other main positive outcome identified in the review indicates that patients can successfully be incorporated into projects with surprising and appropriate results. This occurs at many different points in the QI cycle. There also needs to be on-going support for this to be sustained. Experience-based design stands out as a structured yet flexible vehicle through which true patient involvement may be achieved. Beresford's[66] "Shaping our Lives" group also identified the importance of values and the more subjective user-based measures for projects as they considered quality and quality measures to be essentially subjective in nature. Where there has been success, there is a trend towards "layering" of experience and complexity over time. Part of this developmental aspect is where skills training on communication, QI and team work are incorporated into the project.

Barriers

It is difficult to translate policy into practice due to many complexities such as budgetary constraints, poor communication of the strategy, tokenism and others.[41, 78-85] There has been international support for patient centeredness and different levels of patient participation. However this seems to be very difficult to translate into practice. Beresford's[66] group reported a strong perception from users that not all organizations claiming to be user-controlled in fact are. Other barriers were the emphasis on task orientated care, overprotection of patients by healthcare workers and mistrust of the system by patients.

It is clear from many of the papers included in this review that hierarchical health structures make the involvement of patients in QI difficult. An antidote to this is expressed and reported by a number of authors, i.e. these relationships have been acknowledged and managed. Healthcare workers who

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have been exposed to partnerships with patients collaborate better than those who have not had this opportunity. However, there needs to be a pro-active strategy to develop user-provider teams.

In most cases, the philosophical paradigm of provider-power has been difficult to break from both the healthcare professionals' point of view as well as that of the patients. Patients also have differing interpretations of their role, for example, there are patients who would prefer to abdicate all responsibility for their care to health care providers and others who embrace empowerment on an individual and a systems level.[72] This is supported as well by Langton and coworkers'[87] comment that not all patients would wish to be equally involved in care. Policy makers may assume that in a consumer society there is consensus about active engagement across all categories of patients, whereas Forbat[53] indicated that cancer patients felt incapacitated. Patients with chronic obstructive airways disease were interested but felt they had physical and other limitations and many mental health projects had to overcome user uncertainty.[51,86]

Even with mentoring and support, there are differing outcomes. The haemophilia group that evolved, with support, from a focus group to a fairly independent patient panel and a group of marginalized patients who formed partnerships and shared valuable insights into networking and involvement resulting in concrete changes in health are examples of direct and collaborative engagement.[49,72] Angstmans'[61] patient advisory groups assisting in the development of best practice in depression were supported by the Mayo clinics but were still reliant on a professional person acting as a facilitator in their meetings.

Donaldson[71] found that paradoxically where patients were involved, this was seen as a stabilizing influence on the status quo. There may be a hidden element of disempowerment in the very philosophy of engagement. Where there have been effective projects, these have paradoxically often involved the most disempowered groups of patients, e.g. mental health service users, the elderly and those with cancer.[30,62,63] A lack of planning and strategizing to include patients in care has been identified directly and indirectly by a number of authors as a potentially serious omission. Where there had not been well planned strategies at the outset for the inclusion of patients or patient advocates, the program was less successful.[70] Practical constraints are mentioned by some authors as impediments to sustained outcomes. These include transport, finances, rural participants and others.[56,70]

Context

The initial research question focused on patient involvement with a particular interest in primary care. All of the 31 papers analyzed occurred at least partly in a primary care setting. This means that there is some possibility of transferability of knowledge. The fact that many of the projects were sponsored or had allocated budgets may be an important factor to recognize when embarking on a similar

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process in a resource-restricted environment. Tempfer[88] attributed the importance of logistics, finance and communication to the success of such an endeavor. None of the articles discussed barriers such as culture, language or education (illiteracy), all of which could be relevant in the South African context.

***Cautions from the literature**:*

In spite of the huge emphasis in developed countries on service user involvement at many tiers of care, there are cautionary voices. Beresford's[66] patient group identified the fact that too much emphasis was placed on outcome measures and that these were often separated from the equally important processes leading to them. The patients insisted that there should be a seamless transition from process to outcome.

Particular categories of patients seem to have peculiar issues related to their engagement. In the case of Fudge's[54] stroke patients, the difficulties in integrating patients into active service improvement stem from their not coming from an activist background, as was the case in HIV patients, for example. Small[63] highlighted a number of tensions related to patient involvement, particularly in palliative care. Local autonomy and top down policy decisions need to be balanced. So does the conflict between consumerism and evidence-based care, and the conflict between immediate access to a general practitioner and continuity of care. "Perhaps paradoxically it (patient participation) can be helped to perpetuate existing power structures. If we can claim that users are involved we can profess a legitimacy for what is in place that inhibits opposition."[63(p17)] A concern arising from Forbat's[53] cancer patient study was that patients may be inhibited by offers to train them and that this would then limit collaboration. This contradicts the finding that ongoing support and training are important elements for success.

Models/tools

Models based on the design sciences such as architecture and computer sciences seem to respond best to the rhetoric of patient involvement and reflect holistic engagement of service users. Two examples are taken from Arsand[12] and Bates' work.[75] Arsand[12] developed a framework to include users early in the process of new e-health devices. A prototype was produced and patients could interact with this through storytelling, paper prototyping, thinking aloud or drawing. This became an iterative process of adaptation and implementation.

Experience-based design is a model which incorporates performance (efficiency of service), engineering (safety) and aesthetics (experience/interactivity).[75] This model has a very clear process and, similarly to Arsand, uses narratives, patient journeys and touch points to understand the system and build a prototype. Providers and users are considered equally important in the process. Walsh[52] assisted mental health users to develop a measurement tool in the Impact project, based on the

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conceptual model of Ulrich's critical heuristics.[89] Another initiative from Walsh[52] was the "Trailblazer" project, engaging mental health patients in developing a model for mental health services. Both of these sophisticated projects challenge the perception that patients are incapable of significantly influencing QI initiatives.

Limitations of the review

Terminology regarding QI is varied and patient participation is expressed in a plethora of different ways.[48] For example, operational research is very similar to QI, but this was only discovered later in the search and subsequently incorporated..[52] Exclusion criteria determined that outliers like family participation, community participation, shared decision making etc were recognised and not included in the review.

The decision to concentrate on emancipatory-critical and interpretive- qualitative paradigms would have excluded a large field of literature. However due to different software options from JBI for quantitative, qualitative, economic and text and opinion papers, a practical decision had to be made in order to be both as congruent with the topic as possible and for the sake of effective use of time.

The time delay in undertaking such a review has also excluded the most recent rapidly growing library of literature on this topic.

Conclusion

It is clear from the evidence presented in this systematic review that there is little proof of sustained successful patient involvement in QI in health care. Within the text and opinion papers there is strong support for this approach. These publications however are largely theoretical documents and therefore discuss and support the intention towards patient involvement in systems improvement. The qualitative studies elaborate upon successes and struggles to put into practice what is theorised about. They however are, in the greater pool of literature relatively scarce.

Where successes with patient involvement in QI were apparent in the literature, these related to support from individuals or groups, financial resources and incremental processes which accommodated skills and human development. The barriers or less successful involvement of patients was more apparent where strong policy dictated that patients should be involved, but where there was not clarification of processes and roles. Where a developmental process over a period of time was embraced there was more success than where more immediate results were expected.

The resource constraints in the primary care settings in developing countries need to be seriously considered as well as the period planned for interventions to be successful. However, based on the

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success of a number of the interim outcomes, there does seem to be value in exploring this approach and measuring endpoint as well as interim outcomes.

Implications for practice

The following factors should be considered in practice:

It is difficult to implement patient involvement in QI, often due to insufficient clarity about roles. Relationships and roles will need to be very clear from the outset of any such project. (Level M2 evidence)

Involvement by patients in QI has been demonstrated at different levels of complexity, for example in some cases users' opinions are simply sought regarding systems change on a superficial level but there is also evidence of patients being involved in actual improvement projects through partnerships and as co-designers. A developmental approach needs to be considered where support and training is part of the project in order to obtain the maximum benefit. (Level M2 evidence)

Where patients are truly engaged in service improvement, unexpected innovation is found and interventions are relevant. Flexibility is required to allow innovation from the side of patients when they are involved. (Level M2 evidence)

Implications for research

There is more opinion and text, namely project reports, national guidelines and editorials published regarding this topic than there is rigorous research. There is a need for QI research to be recognized as a competitive research option, not just a managerial tool. This leaves the field open to the development of good methodological studies related to QI and in particular to the participation of patients in QI in health.

Conflicts of interest

None

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Appendix I: Search strategy and results

The following search string was used:

(Quality improvement OR systems improvement OR quality cycles OR quality assurance OR PDSA) AND (patient involvement OR patient empowerment OR shared decision making OR family involvement OR citizen involvement) AND (primary care OR PHC OR first contact care OR general practice)

The searches were conducted between November 2012 and March 2013.

Results of article search process

Complete details are provided for CINAHL. An equivalent strategy was applied to the other databases and the results are summarized.

1.EBSCOhost CINAHL Plus = 1824 articles found. An advanced search was used with full search terms as above and the following limits: full text and abstract; English language; human; references available; 1990–2013; academic journals and major headings (consumer participation, patient satisfaction, patient decision making, quality of health care, patient centred care, primary health care, empowerment, clinical decision making, quality of nursing, health services accessibility).

98 articles were retrieved; 36 were duplicated in other searches.

2. PsycINFO= 2221 articles found. 281 retrieved, 68 duplicated in other searches

3. PubMed = 466 .articles found. 91 retrieved, 11 duplicated

4. Scopus =126 articles found. 24 retrieved. 8 duplicated.

5. MEDLINE =35 articles found. 14 retrieved, no duplicates

6. ETHOS 331articles found. None retrieved

7. EAGLE 118 articles found. None retrieved.

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Appendix II: Appraisal instruments

QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

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Appendix III: Appraisal instruments

NOTARI appraisal instrument

JBI Critical Appraisal Checklist for Narrative, Expert opinion & text

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is the source of the opinion clearly identified?	☐	☐	☐	☐
2. Does the source of the opinion have standing in the field of expertise?	☐	☐	☐	☐
3. Are the interests of patients/clients the central focus of the opinion?	☐	☐	☐	☐
4. Is the opinion's basis in logic/ experience clearly argued?	☐	☐	☐	☐
5. Is the argument developed analytical?	☐	☐	☐	☐
6. Is there reference to the extant literature/evidence and any incongruency with it logically defended?	☐	☐	☐	☐
7. Is the opinion supported by peers?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

_____

_____

_____

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Appendix IV: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

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Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐

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Appendix V: Data extraction instruments

NOTARI data extraction instrument

JBI Data Extraction for Narrative, Expert opinion & text

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

Study Description

Type of Text:

Those Represented:

Stated Allegiance/ Position:

Setting

Geographical

Cultural

Logic of Argument

Data analysis

Authors Conclusions

Reviewers Comments

Data Extraction Complete Yes ☐ No ☐

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Conclusions	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Include Yes ☐ No ☐

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Appendix VII: Included studies

QARI

Study	Methods	Participants	Intervention	Outcomes	Notes
Arsand E, Demiris G, 2008[12]	1. semi-structured individual interviews and prototyping 2.focus groups, paper prototyping &sketching. 3 Focus groups, interviews and observation	1. Fifteen paediatric (9 - 15 years) type 1 diabetics and their parents 2. unknown number of adult diabetics (possibly about 30) and 3. unknown number of older adults in a retirement community	The design of patient-centric self-help tools	It is advocated that the focus on HCI (Human computer interaction) methods and standards within e-health studies should be increased	Useful patient-centred design methods discussed, methodological information incomplete
Forbat L, Cayliss S, Knighting K, Cornwell J, Kearney N, 2009[53]	Collaborative QI working groups (intervention and non intervention). Focus groups and individual interviews	Multidisciplinary health professionals working with cancer, People with cancer and their families,	Through PDSA's, involvement barriers and enablers identified and patient empowerment experienced	It demonstrates that through a process of collaborative working it is possible to influence the actions, beliefs and approaches to engagement among key stakeholders	Supported collaboration leads to change and engagement of patients
, Fudge N, Wolfe CDA, McKevitt C, 2007[54]	participant observation, semi-structured interviews, and collection of documentary evidence	Service users, National Health Service managers, and clinicians	A wide range of activities from patient satisfaction surveys to patient information brochures, patient held records, DVDs of experiences for health providers	Professionals determine how service users will be involved in service development and this may limit change that can be achieved Small numbers of service users were involved, with personal gains for them Service users experiential knowledge is valued because it seems to provide information that will improve delivery of care	Power patterns are very hard to change and policy does not easily translate into practice re involvement of service users
Gold SKT, Abelson J, Charles CA, 2005[55]	In-depth, semi-structured interviews and document analysis were complemented by observations of provincial meetings, regional council and	patients and regional council representatives, provincial agency reps	The development of cancer networks with patient partnerships	Efforts to involve patients faltered as the meaning, intent, and methods for their involvement were not thought out nor were they clearly	Difficulties involving patients in a meaningful way are highlighted

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	network meetings			supported.	
Grogan a, Coughlan M, O'Mahoney B, McKee G, 2012[49]	Focus groups with escalating action from participants	Men between 45-58 with haemophilia, later group also included adolescents and women, patients with other thrombotic and bleeding disorders, a member of the Irish Haemophilia society, managers (nurse, admin and quality assurance) and haematologist	Patients assisted in addressing outstanding issues such as ID alert card content and the algorithm of care for emergency services. Finally, a patient panel was developed	This was an evolution of a model of patient involvement to patient partnership.	The research developed from a qualitative opinion-based study towards real involvement
Jones SP, Auton MF, Burton CR, Watkins CL, 2008[48]	Semi-structured interviews and focus groups	Stroke patients (having had stroke in last 2 years) and carers, health care professionals,, members of voluntary and charity organisations	Information provision, preparation for transfer of care and the integration of social and leisure activities appear to be priorities for the development of stroke services from the perspective of patients and carers. These findings informed the work of four collaborative workgroups to lead developments in the stroke pathway	Useful insights gained by this process which inform the content and delivery of stroke services	Relevant change strategies developed due to patient and carer involvement
Richardson A, Sitzia J,Cotterell P, 2010[37]	Telephonic interviews for mapping + documents, face-face interviews	Representatives of partnership groups (patients, carers, health professionals, group facilitators), NHS staff not involved in cancer networks	Five common activities and achievements were identified: establishment of the group itself; acting as a reference group for consultation; networking and representation of other groups; patient information and communication and proactive influencing. Activities progressed in scale and complexity as groups evolved.	The cancer partnership project seems superior to the PPI project envisioned by the NHS as the latter tends towards 'scrutiny' rather than empowerment	Although the article investigates the function of the CCP rather than doing the QI itself, there are valuable findings regarding patients' involvement in QI
Sullins CD, 2003[51]	Case example	staff and consumers	Attempt to facilitate an empowerment evaluation in	Continuously adapting Fettermans (1996)	The development of an adapted method through a

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			which the consumers would be guided in assessing the drop-in center's progress towards its goals	empowerment model to the structure of the programme and the needs of the stakeholders helped create an effective and empowering evaluation	quality involvement process was empowering and contained the possibility for real change
Truman C, Raine P, 2002[50]	focus groups and individual interviews	gym users(mental health patients) and gym staff	development of a user evaluation tool, a newsletter and a voluntary programme at a gym for mental health users - all by patients	active involvement in mental health services may draw people who may have felt excluded, into community life	There was participation in skills development and other activities as a result of the project
Walsh H, Hostick T, 2005[52]	Meetings using layers of enquiry, Delphi type postal questionnaires	Mental health patients, researchers	Two projects were initiated: IMPACT and Trailblazers. The Impact team originally intended producing a way (tool) of gathering and evaluating evidence to feed into planning and problem solving. Trailblazers used a Delphi technique with GPs to identify areas for improvement in mental health	Both projects demonstrate how COR facilitation can enable service user teams to customize and take ownership of relatively sophisticated tools to begin facilitating improvements in local health services	Multi faceted approaches lead to on-going involvement and a measure of growth was clearly demonstrated
Zeitz K,Kitson A, Gibb H, Bagley E, Chester M, Davy C, Frankham J, Guthrie S, Roney F, Shanks A., 2010 [56]	Workshops with notes and posters	clinicians and older people	reconceptualising 'simple' patient centred inputs eg accessible packaging of food introduced, more sensitive discharge policies	The disconnect between what the consumers viewed as simple aspects of systemic behaviour to change and what professionals experienced as complex, frustrating processes led the whole group to propose a new way of conceptualizing attempts to improve the fundamental aspects of care.	Unexpected and important information gained by a well structured and innovative action research method

NOTARI

Study	Methods	Participants	Intervention	Outcomes	Notes

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Angstman KB, RO Bender, SM Bruce, 2012[61]	A review report on patient advisory groups	Patient advisory groups	Patient advisory groups potentially have an impact on quality improvement in health	Patient advisory groups can be a viable component in the effective management of a primary care practice	A case study of an effective PAG
Airey R, Farrar D, Wilkinson K, Walker J, Tuffnell D, 2009[8]	Clear argument with successes and challenges discussed	Service users of maternity services and their families	Involvement of service providers and service users through ASQUAM fora with discussion and voting for priority changes in maternal services	The ASQUAM model is viewed as positive by service users, the general public and health professionals. It is a step on the path towards successful user involvement in maternity service development and improvement in Bradford	There is development over time of larger user involvement regarding prioritising of quality issues
Bate P, Robert G, 2006 [75]	Experience based design around performance, engineering and the aesthetic experience	Patients and staff involved in co-design of health services	The experience (as opposed to the attitudes or knowledge) of patients is used for redesigning health services effectively	The task for experience design is to gain access to that knowledge (patient experience) and use it in the service of a better design and a better experience for the user.	Clear explanation of the move from patient satisfaction or perception, to the use of patient experience to co-design services
Beresford P, 2006 [66]	Concerns, knowledge and development of appropriate outcomes of Shaping our Lives clearly discussed in a report	A wide group under 'shaping our Lives' - elderly, mental health patients, patients with disabilities	The conceptualisation and measurement of quality in health are significantly influenced by users of these services	This paper describes the findings of three projects undertaken by Shaping Our Lives. These studies confirmed that service-user concepts of outcomes and quality may differ significantly from those currently employed; moreover, service users are able to offer a complex and sophisticated model of what outcome measures might look like if they were centrally involved in their definition and application	Involvement of marginalized patients in appropriate quality issues adds value to outcomes
Chick P, 2006[69]	Guide for improvement for mental health users	mental health care users	quality improvement in mental health has a number of different emphases including	Service users have a unique body of knowledge of mental health services and should be	Amongst other means of producing quality care, users need to be involved in a real

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			involvement of users	involved at all levels of the improvement process. This includes having a genuine influence over planning, development and delivery	way
Donaldson L, 2000[71]	Report on challenges and impact regarding government policy	Chronically ill 'expert' patients	Expert patients taking control of their own illnesses leads to a number of improvements	Research and practical experience in North America and Britain are showing that today's patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process.	This proposal is based on successful programmes in other countries and includes not only shared decision making but also advocacy and systems change
Gibbons, 2005[59]	A broad well-presented action plan	Welsh mental health users	Generally, empowerment and involvement of mental health users in their service	Our focus is on developing a mental health service that is determined by the needs of those using the service, and one that treats patients and carers with dignity and respect	Emphasis is on improvement of quality care, empowerment and user involvement - p 13
Health foundation, 2005[62]	There is a background, principles and practical advice and tools in a well developed guide	All levels of health care but specifically health boards	patients and carers should be involved in co-design, and monitoring of quality health services	Amongst many other issues, the importance of co-design and assessment of outcomes by patients, carers and the broader public is mentioned	page 26 and 27 deal with importance of involvement of patients in QI
Jacques H, 2012[67]	Editorial on levels of involvement by patients	All patients	Personal shared decision making and broader policy etc involvement in health care by patients is discussed	The government is rightly keen to harness the power of patients to improve the quality of care	Patients individual and public involvement in quality issues in health are acknowledged
Matthews R, 2010 [64]	learning points from involvement of chronically ill patients shared through case studies	chronically ill patients	The research group CLAHRC offers patients and the wider community opportunities to influence its programme, and the research and improvement projects it supports, to ensure that its outcomes reflect patients? needs and	Patient and public involvement should be linked to organisational goals and supported by executive managers to maximise impact.	A research initiative to practically improve patient outcomes by involving them on different levels

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			preferences.		
Millet A, Devlin J, Adams P, Gill B, 1999 [73]	Review on Measures project	Patients with rheumatoid arthritis	Practical involvement by rheumatology patients in improvement strategies adds value	The continuing emphasis on proactive patient participation as part of the Measures Project has and will continue to add immense value to the implementation and outcomes.	Presentations by patients to healthcare providers and involvement in hand held patient booklet are 2 practical QI interventions
Newman L, Hood J, 2009[60]	Patient assisted development of home birth policy	Pregnant women having home births	Truly women centred care occurs with involvement of patients in home birth policy and improvements	Inclusion of consumers widely and actively during development and reform of maternity care is essential if real consumer participation is to occur and contribute to care that is truly woman-centered	Authors as users indicated value of patient participation
Ponte PR, Nies J, Conlin G, Shulman L, Conway JB, Branowicki P et al, 2003[18]	redesigning chronic care through patient and family advisory councils	Cancer patients and families	The integration of oncology patients and their families in all care in order to ensure patient centred care	adult and child cancer patient involvement in systems and individual consultations leads to patient centred care	There is evidence of empowerment in patients
Sang B, 2002[65]	4 strands of action and thought summarised	All patients	The emergent trends regarding choice and involvement from patients assist in sustaining quality health, albeit with some resistance form providers	Self-management, advocacy, and ordinary wisdom together demonstrate that individuals can engage with the risks of sustaining health and healing at every level	There is a shift in power regarding health choices with some resistance from the health sector
Small N, 2006 [63]	Report on pros and cons of involvement	palliative care patients	There are advantages and challenges to involving patients in their own health in palliative care	The philosophy which has changed in health to include patients, has both relevant positive influences and tensions	Balanced view of strengths and tensions in NHI philosophy, specifically related to palliative care
Staniskewska S, West E, 2004 [72]	Editorial on patient empowerment and involvement at all levels	Empowered patients in the NHS	In addition to self-management, patients and the public are increasingly seen as having a role in the planning, delivery and evaluation of services to ensure that	Partnerships are needed at all levels and need skills development	Shared decision making, patient centredness and broader patient partnerships are necessary and skills regarding these need to be developed

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			services are designed for users		
Taylor C, Richens Y, Shaw F, Evans P, 2006[74]	A report on patient and public involvement	Pregnant patients (antenatal and postnatal) with mental problems	Patients add value when involved in clinical guidelines	The patient members knew from their own experience how important it was that health professionals treated women as individual human beings, rather than as a bundle of symptoms and that they were listened to	Patients add personal value to clinical guidelines
Vincent CA, Coulter A, 2002[68]	A consumers view on active patient participation in safety issues	patients involved in issues regarding safety e.g. medical errors	Patients have a key role to play in ensuring the safety of medical care.	It is incumbent on providers and policy makers to take active steps to involve patients in efforts to improve the safety of medical care.	Patients are acknowledged in different ways as playing a role in quality improvement in health safety issues
Williams P, 2007[57]	Guide regarding collaboration in health	Health care providers and other collaborators in health	Different elements of collaboration in health are discussed in the report eg leadership, governance	Engaging the public is part of the guide	Most of the guide refers to professionals involved in health care with one section on public and citizen involvement
Williams P, Sullivan H, 2007[58]	Government report on partnerships and collaboration	All involved in public health	Partnerships and collaboration are key to quality in health	Approaches to citizen involvement in collaborative settings requires the resolution of a number of key issues, including who to involve, at what level should involvement take place, what role should community leaders play in the process, what capacity do citizens have to be meaningfully engaged, what influence does the different power relationships between key stakeholders have on the process, and how should marginalized and disenfranchised groups be	Realistic difficulties towards partnership are discussed

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				engaged.	

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Appendix VIII: Excluded studies

All the excluded studies were excluded on the basis of inadequacy in addressing the phenomenon of interest rather than poor methodological quality. All the qualitative studies were of an acceptable quality in terms of research standards.

Qualitative studiesAbma T, Patient participation in health research: research with and for people with spinal cord injuries[15]

Reason for exclusion: More about empowerment than involvement

[2] Alexander IM, Emancipatory actions displayed by multi-ethnic women: "Regaining control of My Health Care"

Reason for exclusion: Research focusses on women's perceptions only – lack of engagement in action

[3] Andrews JA, Manthorpe J, Watson R, Involving older people in intermediate care

Reason for exclusion: Generally not applicable as it is a literature review

[4] Barlow JH, Bancroft GV, Turner AP, Self-management training for people with chronic disease: a shared learning experience

Reason for exclusion: Good qualitative research but does not apply to research question

[5] Bate P, Robert G. Toward more user-centric OD: Lessons from the field of experience-based design and a case study. J Appl Behavioural Sci. 2007; 43(1): 41-66.

Reason for exclusion: Hospital based versus primary care

[6] Beal G, Chan A, Chapman S, Edgar J, McCinnis-Perry EJ, Osborne M et al, Consumer input into standards revision: changing practice

Reason for exclusion: pinions of patients on changes in guidelines, not action

[7] Brown I, Organisational values in general practice and public involvement: case studies in an urban district

Reason for exclusion: Relates more to perceptions than actual involvement

[8] Dancet EAF, Empel IWVF, Rober P, Nelen WLDM, Kremer JAM, D'Hooghe TM, Patient -centred infertility care: a qualitative study to listen to the patient's voice

Reason for exclusion: No action participation by patients

[9 Evans S, Tritter J, Barley V, Daykin N, McNeill J, Palmer N, Rimmer J, Sanidas M, Turton P, User involvement in UK cancer services: bridging the policy gap[85]

Reason for exclusion: Elicits perceptions, not involvement in change

[10] Firth J, Newton R, Anwar JS, Patients as teachers. A new approach to patient involvement

Reason for exclusion: Quality improvement based on patient information but patients not involved in change

[11] Gagliardi AR, Limieux-Charles L, Brown AD, Sullivan T, Goel V,, Barriers to patient involvement

in health service planning and evaluation: an exploratory study

Reason for exclusion: Opinions about participation, not actual participation

[12] Haidet P, Krol TL, Sharf BF, The complexity of patient participation. Lessons learned from patients' illness narratives

Reason for exclusion: Research on individual decision sharing rather than involvement in QI by patients

[13] Litva A, Coast J,Donovan J, Eyles J, Shephed M, Tacchi J et al, 'The public is too subjective': public involvement at different levels of health care decision making[84]

Reason for exclusion: Conclusions are opinions not actions

[14] Long L, Pearson A, Page T, Jordan Z, Engaging consumers in safety and quality at Royal Adelaide hospital

Reason for exclusion: Opinions rather than actual involvement

[15] Marshall SL, Oades LG, Crowe TP, Australian Mental Health Consumers' contributions to the evaluation and Improvement of recovery orientated service provision

Reason for exclusion: Involvement more regarding opinions than action

[165] Messner ER, Quality of care and patient satisfaction The improvement efforts of one emergency department

Reason for exclusion: Patients not involved

[17] Mitchell P, Koch T, An attempt to give nursing home residents a voice in the quality improvement process: the challenge of frailty

Reason for exclusion: Although frail care is a very difficult group to engage, opinions were heard and used but patients/carers were not directly involved in change

[18] Moujmid N, Morelle N, Carrere M, Bachelot T, Mignotte H, Bremond A, Elaborating patient information with patients themselves: lessons from a cancer treatment focus group

Reason for exclusion: Research on assistance with improved guidelines, not fully on a project

[19] O'Grady A, Simmons D, Tupe S, Hewlett G, effectiveness of changes in the delivery of diabetes care in a rural community

Reason for exclusion: More a report on support groups than research on a full QI involvement of patients

[20] Parker L, Pillis ED, Altschuler A, Rubenstein L, Meredith L, Balancing participation and expertise: a comparison of locally and centrally managed health care quality improvement within primary care practices

Reason for exclusion:No patient involvement

[21] Roberts K., Exploring participation: older people on discharge from hospital

Reason for exclusion: Patient Views and experiences not involvement

[22] Stegenga K, Ward-Smith P, The adolescent perspective on participation in treatment decision

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making: a pilot study

Reason for exclusion: Patient perceptions and ideas not direct involvement

[23] Sykes C, Goodwin W, Assessing patient, carer and public involvement in health care

Reason for exclusion: Only patient perceptions, no action

[24 Tveiten S, Knutsen IR, Empowering dialogues-the patient's perspective

Reason for exclusion: Only Patient opinions, not QI

[25] Waterworth S, Luker K, Reluctant collaborators: do patients want to be involved in decisions concerning care?

Reason for exclusion: No patient participation in change

26. Wiig S, Storm M, Aasel K, Gjestsen MT, Solheim M, Harthug S, Robert G, Fulop N. Investigating the use of patient involvement and patient experience in quality improvement in Norway. Rhetoric or reality?.[45]

Reason for exclusion: Hospital based

Text and opinion papers

[1] Baker R, Patient involvement in national clinical guidelines: the NICE guidelines on referral for suspected cancer

Reason for exclusion: Consultation rather than innovative involvement in QI

[2] Barnes C, Mercer G, Din I, Research review on user involvement in promoting change and enhancing the quality of social care services for disabled people

Reason for exclusion: Not on health

[3] Barrie J, Patient empowerment and choice in chronic pain management

Reason for exclusion: Personal empowerment rather than for system change

[4] Blennerhassett M, Challenges for primary care in the age of the autonomous patient

Reason for exclusion: Relates to individual patient engagement within a consultation and not involvement in quality improvement

[5] Borg M, B Karlsson, HS Kim, User involvement in community mental health services- principles and practices

Reason for exclusion: Theoretical

[6] Bridges J, Gray W, Box G, Machin S, Discovery interviews: a mechanism for user involvement

Reason for exclusion: Stories contributing towards QIP but not active patient involvement in QIP

[7] Coleman A, Checkland K, McDermott I, Harrison S, Patient and public involvement in the restructured NHS

Reason for exclusion: Future plans, mostly deals with policy with no direct user involvement discussed

[8] DOHSA, Fast track to quality. The six most critical areas for patient-centred care

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Reason for exclusion: Policy only, no patient involvement

[9] Dixon A, Robertson R Appleby J,Burge P, Devlin, Magee N, Patient choice

Reason for exclusion: Choice rather than involvement

[10] Glasby J, Bringing down the Berlin wall: partnership working and the health and social care divide - guest editorial

Reason for exclusion: Inappropriate to review question

[11] Hunter R, Cameron R, Patient involvement in health care will improve quality (letter to editor)

Reason for exclusion: More shared decision making on an individual level

[12] Mort EA, Patient-centred decision making

Reason for exclusion: Not direct involvement in QIP

[13] Siriwardena AN, Editorial. why quality improvement initiatives succeed or fail: the MUSIQ of quality improvement

Reason for exclusion: No emphasis on patient involvement

[14] Trummer UF, Nowak P, Pelikan JM, Effects of patient empowerment on health outcome and patient satisfaction among surgery patients

Reason for exclusion: Poster

15] Weinstock M, Improving patient engagement

Reason for exclusion: Inappropriate to review question

[16] Worthington B, Engaging Clinicians in a quality agenda

Reason for exclusion: No patient involvement

[17] Worthington B, Clinical Engagement. Primary care leading by design

Reason for exclusion: No patient involvement

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Appendix IX: List of study findings/conclusions

Patient-centric tools are co-designed by diabetic patients and the elderly, making them appropriate for the target population [12]

Finding1	The development of a framework on patient involvement in the design process of self-help tools in health is presented and the importance thereof highlighted. Actual system design and the evaluation methodology targeted specific users, for example older adults in a long term care facility. '
Illustration	'There was a large variation in user preferences for the design of the tool, something that strengthens the argument for user-tailored, and preferably self-adaptable design.' p 161 As a result, the final set of sensors and interfaces were most appropriate for this target audience, but may not be desirable for other populations. p 163

The engagement of cancer patients overcame barriers in their care and in their perceptions of their responsibilities and roles in improving such care [53]

Finding1	The intervention and non-intervention groups differed in their understanding and engagement with involvement and the related barriers and opportunities
Illustration	Important barriers had been challenged and tested by the intervention and found to be easily overcome by those who were involved. Those in non-intervention teams however continued to reiterate concerns about whether patient involvement is really possible. p 89
Finding2	Intervention groups consisting of mixed providers and users in a lung cancer setting, designed improvements using PDSA cycles
Illustration	The finding that active and supported collaborations result in shifts in attitudes and actions related to involvement must surely act as a positive marker for progressing service improvement by involving people in service improvements. p 89

Difficulties in sustained involvement of stroke patients and their carers in service improvement are related to different perceptions from patients and providers [54]

Finding1	Stroke patients and carers were engaged in a number of ongoing activities to improve care of services
Illustration	When asked about how their involvement had improved services, few service users could directly answer the question. p 4
Finding2	Out of four streams, true engagement was only dominant in the one with a user involvement leader who mostly determined the agenda
Illustration	Although all work streams were required to involve service users, in practice the appointment of a user involvement lead and establishing a specific group for user involvement meant that user involvement became a distinct project and was harder to embed throughout the program. p 4
Finding3	Users and providers had a wide range of differing views on involvement of patients
Illustration	Service users gave a range of reasons for participating in the programme, which suggests that involvement was not understood solely as an opportunity to be involved in service development. Motivation to participate included the right forpatients to have asay about the services they use, the chance to meet

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	others in a similar situation, finding out about developments in stroke medicine, accessing health or social care services, and attending as part of the process of recovery from stroke. p 5 Evidence suggests that professionals believed service users would not be capable of participating in some aspects of the programme because they lacked the necessary technical knowledge. p 5
Finding4	Policy does not necessarily easily translate into effective practice
Illustration	As a result of the multiple meanings, philosophies, and outcomes of involvement, user involvement will not necessarily be able to generate radical change to health services as the policy might suggest. p 7

Rhetoric about involving patients in cancer services improvement does not translate easily into practice [55]

Finding1	Through a comparative case study approach the disconnect between the rhetoric of the centralized provincial planning agency's policy statements on patient involvement and the reality of patient involvement in the planning and co-ordination of regionally based supportive cancer care services were examined and it was found that participation failed
Illustration	Network planning in three Ontario regions failed to engage the public and patients more because they and the strategies to engage them were almost completely neglected p 207 The network development processes in these three regions suggests that if there is little commitment to the notion of public and patient involvement, the rhetoric of such involvement should be avoided. p 207

A Haemophilia quality improvement programme involving patients developed through stages towards a patient partnership panel [49]

Finding1	Patient involvement evolved into patient partnership and resulted in the implementation of quality initiatives that improved haemophilia patient care both directly within the haemophilia service and within the greater health service
Illustration	The relationship moved from simple exploration of needs, to directly negotiating and collaborating with the haemophilia team. The team developed a patient partnership panel to comprise of a combination of both health care professionals and patients. p 878

Service users in the development of stroke services implemented appropriate interventions, including education and social activities [48]

Finding1	The experiences of patients and carers throughout their stroke journeys generated a range of issues for service development
Illustration	Prevention. .'But I'm assuming the cigarettes, giving those up would maybe stop the high blood pressure. p 1274 Immediate care.. Even after contacting a GP, some patients and carers were still unsure as to what course of action they should take. p 1274 Immediate rehabilitation '' ;How to get up if I fall. Very useful, hold onto this chair and pull myself if I can''. p 1274 Transfer of care and long term support. p 1275
Finding2	Four work groups were created which dealt with 4 different aspects relating to stroke care
Illustration	Stroke Prevention and Immediate care priorities were merged into one

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	workgroup. Their action plan focused on increasing public awareness of stroke symptoms and risk factors. A key priority identified within the workgroup was to ensure rapid access to the stroke service by encouraging people to use emergency rather than Primary Care services. The group developed information to inform the general public about stroke symptoms and action that should be taken. p 1276 (Another).. workgroup discussed the contents of a new programme of rehabilitation and social activities. These activities have now been made available to patients and include, for example, group discussions, gardening and cooking activities. p 1276 As information giving was a cross-cutting issue, representatives of each workgroup formed an information sub-group. p 1276

Cancer patients involved in a partnership, improved services by appropriate activities which evolved over time [37]

Finding1	The CPP (cancer partnership programme)model in contrast to the PPI (patient and public involvement) model which is more 'scrutinising' allows participants to influence policy and change in a real way
Illustration	Service users often made a significant commitment to the group in terms of time and energy: they carried out activities for the group in between meetings, they worked within subgroups or 'working parties' to take forward specific projects, and they read and considered documents p213

Empowerment evaluation was used to engage mental health users in improvements and innovations in a ''drop-in'' centre [51]

Finding1	Empowerment evaluation as an engagement and empowerment tool for mental health users was continually adapted to accommodate the reality of a 'drop-in' centre
Illustration	Continuously adapting the Fetterman's (1996) empowerment evaluation model to the structure of the program and the needs of the stakeholders helped create an effective and empowering evaluation in this setting. p 396
Finding2	Formal evaluation defaulted to the researcher instead of involving users who focused more on the actual innovations or improvements
Illustration	However, it was also difficult to engage the participants in further evaluative steps that were directly related to assessing the merit and worth of their program. Therefore, I conducted most of the formal evaluation steps myself, incorporating consumer input and feedback at every step of the way. p 390

Mental health patients were involved in a partially successful intervention [50]

Finding1	Barriers related to uncertainty about roles as well as capabilities
Illustration	They [staff] treat you like one of them, but you're not sort of thing; you're still a user. It was a bit confusing really. p 140
Finding2	Successful and meaningful user involvement should enable and support users to recognise their existing skills, and to develop new ones, at a pace that suits their particular circumstances and personal resources.
Illustration	Alongside the structured approach of the volunteer scheme, more flexible forms of user participation requiring varying degrees of responsibility have also been developed. p 142

Two projects, involving patients, developed through different stages with some innovation [52]

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Finding1	In two different projects, complex theory was shared and built into meaningful user involvement, with positive outcomes
Illustration	Trailblazers have successfully produced and piloted key stages in an innovatory approach to consultation.p199 The Impact team originally intended producing a way of gathering and evaluating evidence to feed into planning and problem solving. However, arguably, they produced an embryonic problem-structuring tool with a starting point (the level 1 aspiration questions),an enrichment phase (levels 2, 3 and 4), an action planning phase (level 5) and an evaluation phase (level 6). p197

Older people need to be involved in improvements as providers do not always understand the practical issues [56]

Finding1	Fundamentals of care in an acute hospital may seem simple to solve but there are differing viewpoints between consumers and providers
Illustration	the first was the packaging itself, which older patients could not open easily; the second was the lack of accountability amongst food delivery or clinical staff for ensuring that patient could access and eat their food without the need for assistance.P46 On discharge: No home to go to. p 49

Patient advisory groups involved in practice improvement lead to practical improvements[61]

Finding1	Involvement in QI in health through a patient advisory group regarding depression, lead to practical improvements
Illustration	Our PAG has successfully helped with several projects during the past 5 years. With this experience, they have definite suggestions for the best practices of this type of group and have made recommendations for the possible initiation of a new PAG for all of primary care at Mayo Clinic Rochester. p 331

Patients are involved in improving the quality of maternity service provisions [8]

Finding1	The Achieving Sustainable Quality in Maternity (ASQAM) model encourages prioritisation of quality issues by patients using Bradford maternity services
Illustration	Overall the implementation of the ASQUAM model is viewed as positive by service users, the general public and health professionals. It is a step on the path towards successful user involvement in maternity service development and improvement in Bradford. p 184

Experience -based design uses touch points to understand and incorporate patient experiences[75]

Finding1	Users of health services contribute towards the co-design of those services by sharing their experience rather than perceptions or satisfaction in contributing towards innovation and quality.
Illustration	By identifying the key moments and places (moments of truth or touch points) where people come into contact with the service and where their subjective experience is shaped, and therefore where the desired emotional and sensory connection needs to be established and working with the front-line people who bring alive those various touch points in the journey it is possible to begin designing experiences rather than processes. p 308 The focus of experience design is not so much on user views, attitudes, needs and perceptions (although all comeinto it) as user experiences creating not just a service but a whole experience that appeals and works on a cognitive and emotional level. p

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A case study on different groups of users in service improvement[66]

Finding1	Service users need to be part of quality outcomes. This is reflected in three examples from 'Shaping our Lives''; which represents a broad range of health users
Illustration	While different groups of service users, like people with learning difficulties and older people, may each have their own specific issues, history, culture and so on, there are also common issues and themes, many relating to quality, which make it helpful to work across user groups p439The Shaping Our Lives outcome project made it possible for service users to develop their own ideas and discussions about quality measures. p 439
Finding2	Users find many obstacles to becoming involved in quality health issues
Illustration	The study reveals numerous major barriers which service users see as obstructing user networking at both the individual and collective levels. They identify a range of obstacles in the way of networking as individual service users. These include: problems of mobility in rural areas; the fragility of user-controlled organisations; and the effort of being actively involved ...etc. p 441

A policy guideline which includes patient involvement in improving services[69]

Finding1	Users should be empowered and involved in quality improvement in mental health in different ways
Illustration	Empowerment should be embodied within all policies, protocols and processes, assisting individuals towards a more meaningful and fulfilling life, encouraging well-being and allowing the voice of the service user to be heard to influence and facilitate the improvement of mental health services across Wales. p 14

An editorial on the necessity of patients being placed at the centre of quality[67]

Finding1	Different levels of involvement of service users are discussed
Illustration	But patients can also have a broader role in improving care. They are increasingly getting stuck in with quality improvement on a are increasingly getting stuck in with quality improvementdesign p2

Chronic patient task teams improvement efforts are reported[71]

Finding1	Expert patient programmes involve chronic patients in individual empowerment and through task teams in broader quality improvement initiatives
Illustration	Patient organisations have a vital role to play in partnership with the NHS and the Government in developing national Expert Patients Programmes. This is because: many have already shown innovation in developing programmes themselves; they have a good understanding of, and commitment to, assuring quality and consistency in programmes; through them there is access to a large pool of potential lay tutors. p 32

Patient participation through the Measures project is described[73]

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Finding1	Through a collaborative rheumatology project to involve patients in improving quality, patient groups have initiated practical interventions
Illustration	The meetings have been highly successful and productive, generating highly useful consumer feedback, and re-enforcing the patient-provider partnership context.p282

The Welsh mental health action plan includes a section on engaging patients in all aspects of their care.[59]

Finding1	The policy document details action plans and outcomes in Welsh legislation regarding mental health. Involvement by patients in quality services at all levels is planned for and implemented
Illustration	The Welsh Assembly Government has produced guidance called, ‘’Stronger in Partnership’’ to support implementation of the SAFF target. This sets out to provide advice and information on how to effectively involve people who use mental health services and their carers in the design, planning, delivery and evaluation of those services. It re-affirmed the Assembly Government’s view that service user and carer involvement should not be seen as a one-off intervention or a discrete piece of work, but a broader and more empowering way of working that should be integral to all aspects of mental health design, commissioning and provision. p 37

A guide on quality improvement for managers includes the public as partners[62]

Finding1	As part of the quality improvement guide for leaders in health care, it is argued that patients must be involved in designing and monitoring quality improvement in health
Illustration	Patients, carers and the wider public have a significant role to play: not only in designing improvements, but in monitoring whether they have the desired impact not least because they are the only people who really experience the patient pathway from start to finish. p 27

Chronic obstructive pulmonary disease patients are involved in different initiatives[64]

Finding1	The collaboration for leadership and applied research and care (CHLARC) is a research organisation helping health providers involve users in quality improvement
Illustration	A member of the Breathe Easy group was invited to become a patient adviser. He had been a delegate at the First World Conference of COPD patients, in Rome last June, and was able to report experiences of other patients and care professionals. He challenged the team about the slow progress in implementing the care bundle. In addition, his advice about how to access pulmonary rehabilitation influenced the safe discharge checklist. p 18

Consumers are part of a home birth policy project[60]

Finding1	The involvement of consumers in the development of a home birth policy document and information sharing with the public regarding this, increased user accessibility, respect for choice and some practical aspects
Illustration	Our involvement in the policy’s writing and development was beneficial for the process, since it allowed us to understand and explain the policy’s rationale and content to the maternity consumer groups p 80 Another major influence

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	that we had in improving the policy, in addition to making the wording respectful of women as consumers, was in relation to some of the practical aspects. p 80

Patient councils act as organisational partners in service improvement[18]

Finding1	Patient centredness through a patient advisory council, leads to patient influence in quality improvement on different levels
Illustration	We currently have two councils: one for adult care and one for paediatric. By working through the councils, the voices of patients and families are blended with those of clinicians, administrators, and other staff as the processes and systems of care are designed and delivered. p 82 Patient- and family-centred models need to move beyond the one-dimensional approach, and instead provide opportunities for on-going and direct patient input into the workings of the organization. p 84
Finding2	Unique initiatives emerge where users are involved
Illustration	One of the most exciting aspects of our new relationship with patients and families is being able to facilitate and witness patient-generated initiatives that are designed to improve care p 86Study of unplanned admissions for neutropenic patients Study of emergency room visits by pediatric patients Study of wait time in outpatient clinics Patient rounds Educational program for first year oncology fellows. p 86

A discussion on patient choice and involvement at different levels of care.[65]

Finding1	Partnership is essential in improvement of health care services
Illustration	Partnership is now central for the successful development of health systems and organizations. p 188
Finding2	Patients and providers need to understand and embrace the new social paradigm of choice and involvement in care
Illustration	We need to learn to facilitate dialogue at every level in every process thereby shedding the labels and stereotypes we share about one another p 188 We need to learn to manage our own lives and health journeys p 188 we need to be aware that cooperation within user and carer groups, and across traditional service boundaries, makes a positive difference. p 188

Palliative care users have particular challenges in becoming engaged in service improvements[63]

Finding1	Palliative care offers particular challenges in user involvement at all levels of quality care
Illustration	Perhaps paradoxically it can be used to help perpetuate existing power structures p17 There is danger that using 'user' as a concept imposes too much uniformity. p 17

An editorial on the difficulties in involving patients in partnerships[72]

Finding1	With the move towards patient healthcare worker partnerships, there will have to be support for new skills for both groups
Illustration	The importance and difficulty of developing or enhancing partnership skills should not be underestimated, and will require time, knowledge, motivation and support p4 Being patient centred involves much more than a way of

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	thinking and behaving, where doctors and patients work together as true partners. p 4
Finding2	Changes in health should involve patients at all levels
Illustration	Many of the recommendations from the Bristol Inquiry focused on changing the culture of the UK National Health Service to make it more open and accountable by ensuring that patients and the public were involved at every level. Patients must be at the centre of the NHS, and thus the patient's perspective must be included in the policies, planning and delivery of services at every level. p 3

The contribution of patients and the public to the NICE guideline[74]

Finding1	Users involvement in guidelines relating to mental illness in pregnancy and the development of an explanation booklet are a quality partnership initiative
Illustration	The importance of patient experience has influenced the approach taken by NICE when developing guidelines, with patients and the public contributing in a number of ways. p 390

Patients' involvement in safety issues are explored[68]

Finding1	Patients have an important role to play in the quality management of adverse events and safety issues
Illustration	While we stand by the argument that there is much to gain from actively involving patients in patient safety, it must be acknowledged that this is a relatively unexplored area, that many problems both practical and ethical will undoubtedly emerge, and that there is an urgent need for research in this area. There is preliminary evidence that these approaches are likely to be productive, but the degree to which patients can be involved will vary considerably from specialty to specialty and will depend on the nature and complexity of the treatment and the degree of technical knowledge required to understand the treatment process. p 79

A discussion on patient collaboration[58]

Finding1	Within collaborative quality care, the public and individuals need to be part of the co-design
Illustration	Collaborative public management is increasingly grounded in strategies that seek to place citizens and clients at the centre of the design and delivery of public services p 27 A client-focus ensures that the needs of service users are paramount in the design and delivery of public services. p 27

Different levels of patient engagement are discussed[57]

Finding1	There are different definitions and roles of public and citizen involvement in care
Illustration	One analysis identifies six key purposes for the promotion of public participation at the local level (Sullivan, Barnes and Matka, 2002): citizen participation for governance: citizen involvement in the development and implementation processes of partnerships community development as a method of working user involvement in the planning, delivery and practice of decision making about public services. p 56

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Chapter 3

Integration of non-communicable diseases (NCDs) and HIV/AIDS and mental health care through the involvement of chronically ill patients using empowerment evaluation.

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Integration of Non Communicable Chronic Diseases (NCDs) and HIV/Aids and mental health care through the involvement of chronically ill patients using empowerment evaluation

Abstract

Background. The emphasis in health care in South Africa is gradually shifting to acknowledge the different roles patients have regarding their own care. There is however, very little evidence of this practice and of related practical outcomes. Method. In the North West province, empowerment evaluation was used as the vehicle for patient engagement in integrating and improving services for chronically ill patients, namely those with non-communicable diseases (NCDs), HIV and mental illnesses at Primary Health Care (PHC) clinics. This research was designed as an additional intervention in an ongoing quality improvement (QI) cycle which had started in 2007. Empowerment evaluation shares many participatory action research qualities with an emphasis on collaboration, emancipation and the creation of new knowledge but with the additional aspect of evaluating and monitoring the processes which have been co-developed. Results. After 62 visits to 9 facilities over a year and after capturing 332 patient and health worker opinions and ideas, many interventions were implemented leading to improved flow at clinics, a heightened awareness of good services, interesting performance measuring tools and patient/staff teams that acknowledged their symbiotic strength. Objective measurements comparing clinics that had been exposed to the Integrated Chronic Disease Model (ICDM-which is explained in the article) and those with the collaborative patient/staff groups showed no significant difference in clinical outcomes or waiting times. However waiting time had improved across one subdistrict. This may be because the ICDM clinics have been functioning for 4 years and the research clinics for only 1 year. There have also been many external influences on the project, such as a number of new doctors appointed at clinics, under the National Health Insurance pilot project, a high turnover of staff, a new chronic drug policy, stable patients being able to access their medication at external "pick up points" and others. .
Conclusion. It was found that the potential of patients and patient-staff collaboration are being under-utilsed in a resource-strained sector where the harnessing of this potential might contribute positively towards QI in health.

Key words: Patient involvement, health systems improvement, chronic illness, empowerment evaluation

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Introduction

In a global move towards patient centredness and a focus on the recipients of services, there is much discussion on both the value of this client participative paradigm in terms of patient outcomes[1,2] and the use of different research methods to evaluate it.[3,4,5,6] Publications have shown improved patient outcomes relating to many medical conditions including chronic illness where there has been some measure of engagement of patients.[7,8,9,10] Most of the patient involvement however has been at a superficial level where perceptions or measures of satisfaction alone have been used.[11.12.13.14] There has been some exploration of the more authentic customer or client involvement in health systems for example where patients have developed partnerships [15,16,17] or collaborated closely with professionals on health matters like the design of a cancer hospital,[18] the improvement of meals to the elderly[19], patient led newspapers and brochures [20,21], a mental health service focused completely on the needs of the recipients[22].These all led to unexpected outcomes that had not been foreseen by professionals and had added value to patient experience.

A systematic review including only qualitative studies[23] indicated that the barriers to patient engagement in systems improvement were health staff hierarchies, different perceptions of their roles by patients and providers and an apparent political and managerial will but an inability to put this into practice. The enablers were that where there was ongoing support and mentoring, this approach worked very well. In the papers analysed, there were many opportunities for patient involvement at different levels of complexity and unexpected innovation often occurred when patients were part of the improvement process.

South Africa is attempting through National Core Standards[24] and PHC Reengineering[25] to include patients more in their own care. However this is still in its infancy and very little enquiry has been made regarding the influence of policy on practice. The key interventions of PHC Re-engineering are the establishment of community health worker (CHW) teams that support health at household level, district based specialist medical teams concentrating on mother and child health and strengthening of school health. A great deal of political pressure is being exerted to have this initiative fully implemented as soon as possible. In the same period in which the above was started, the Chronic Illness Directorate at the National Department of Health chose the research district being studied in this paper, as one of three districts[26] in South Africa to brainstorm ideas regarding the integration of services to patients with combinations of NCDs and HIV as well as mental illness.

The primary purpose of this research was therefore to introduce the patient involvement factor into a process of integrating chronic care at clinics. In 2011, 9 pilot clinics in the district had been involved, with the National Department of Health, in changing their systems to offer a more efficient service to patients by following certain Lean principles. These included

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pre-booking patients and ensuring that the expected patient load would be evenly spread across the week in order to plan staff availability on any given day. Files were also re-organised according to patients' date of birth for ease of extraction. It was intended that all the booked patients' files should be pre-retrieved the day before to prevent a bottleneck at the beginning of the day. The pre-packing of each booked patient's medication was also initially part of the pilot process. Each of the pilot clinics had to physically re-plan their patient flow for chronic disease patients, identifying a dedicated waiting space, vital signs area and one or more consulting rooms specifically for chronic disease patients. This was to separate them from the very busy mother and child services and the large number of patients presenting with acute illnesses. All these interventions were intended to decrease the unacceptably long waiting times for patients with chronic disease. The intervention was called the Integration of Chronic Disease management (ICDM) and involved all categories of chronically ill patients. The above plans were attempted with greater or lesser success at the 9 pilot clinics, but there was no effort to involve staff in thinking creatively and no engagement with patients

The serendipity of these important movements dovetailing was an opportunity to explore different patient empowering methods being used globally to maximise patient, family and community involvement.

Fetterman[27] developed empowerment evaluation as a method of client engagement ''to foster improvement and self-determination'' [27p89]. ''He drew on diverse influences….., to craft a vision of the evaluator as an agent of social change.'' [28p273] The intention was to offer disempowered clients control by involving them in decision and monitoring processes where they would previously have been excluded. This method has in particular been used in many situations to encourage reflection and awareness of the importance of evidence within client provider collaborations[,28,29,30,31,32] Thus, in an empowerment evaluation model, the relationship between the evaluator and the evaluation consumers, or the recipients of the service, is characterized as a collaborative partnership. The methodology shares the emancipatory paradigm of Participatory Action Research (PAR) but has a differently structured approach including a strong assessment component. It was designed with marginalised people in mind and a few key characteristics are that these clients are involved in the initial problem identification, the measurement thereof and the ongoing QI process. The detail of this approach will be discussed in the methods section.

The context for this research project was a district in the North West province, in the public sector. This district includes 5 hospitals and 39 fixed clinics (inclusive of 9 health centres). Chronic illness (including HIV and mental health) were the most common reason for patients to present at a clinic. These patients were therefore the focus of the research.

Aim: The aim of this research was to assess the value of patients with chronic illnesses taking control of their own health care in a QI on the integration of non-

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communicable chronic illnesses (NCDs) and chronic communicable diseases in the DKK district, through empowerment evaluation as a qualitative intervention.

Objectives of the empowerment evaluation research:
To describe the processes of the QI where patients and staff are co workers
To demonstrate empowerment evaluation as a method

Methods
Study design: Empowerment evaluation in communities of stable chronically ill patients in a district in the North West province

Site of study. The research district initiated a QI regarding non communicable diseases (NCDs) eg diabetes mellitus, asthma, epilepsy and hypertension in 2007 due to poor outcomes for NCDs in the district.[33] Part of the QI was to investigate the possibility of integrating care for all patients with chronic illnesses, including HIV, mental illness and NCDs as these had been managed separately which led to many different service points and duplicated systems for one patient with compound chronic conditions. The National Department of Health (NDOH) subsequently chose this district as a pilot site in the investigation into the integration of chronic care services (ICDM). The process from the National department was a pre-planned situational analysis for each of the 9 pilot clinics in the district, a patient satisfaction tool, a tool to audit chronic NCD files and a waiting time survey. These steps were completed and analyzed. Solutions were subsequently suggested, implemented and monitored by the department. In this process, there was no patient involvement at all and little allowance for staff inputs or innovation.

Nine other clinics in the district were selected by the researcher by convenience sampling to include clinics in each subdistrict, to participate in the empowerment evaluation. The clinic staff were requested to identify active chronically ill patients who would be willing to be part of a patient/staff group as well as appropriate staff members .

Study Population The study population was patients with chronic illnesses in the district being managed at primary care level and this included both NCDs as in diabetes and asthma and communicable illnesses eg HIV/Aids as well as stable mentally ill patients. Staff, including the CHW teams working in these clinics were also part of the research population.
Sampling: At each of the clinics, through the clinic staff, a cohort of patients was approached to form a team, with the researcher as a Socratic “’coach’’.(this concept will be explained under methodology). The team was generally a manageable size ranging from 5-12 people.

Inclusion criteria were that patients were able to communicate in English or Afrikaans, have a stable chronic illness ie a patient with hypertension, diabetes,

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epilepsy, HIV accessing chronic services from the particular study clinic, a mentally ill patient able to communicate well; a staff member working with chronically ill patients at the study clinic, any members of the PHC Re-engineering outreach teams namely team leaders (nurses) and CHWs attached to that clinic.

Exclusion criteria: Unstable or very ill patients with chronic illnesses

Data collection: Quantitative data were gathered at the outset for a few reasons. It was intended to use this information when meeting with the staff and patients, to establish the importance of measurement. It was also initially the intention to measure clinical outcomes pre- and post-intervention as a consolidation of the additional empowerment evaluation intervention in the QI cycle. Quantitative indicators from the 18 clinics were assessed by doing file audits (using the 27 clinical items captured on each chronic illness form) in 2014 and again in 2015. Waiting times and patient satisfaction surveys, measured at these clinics as a routine were intended to be analysed at the beginning of the research and repeated 12 months later. These are not reported in this article.

Qualitative data: Audio and video recordings of the group meetings were supplemented by minutes of each meeting, physical artifacts [34]eg photos and the material that was created by the groups, eg posters, letters and registers.

Empowerment research which is discussed below, was an intervention inserted into the already existing chronic illness QI see Figure 1.

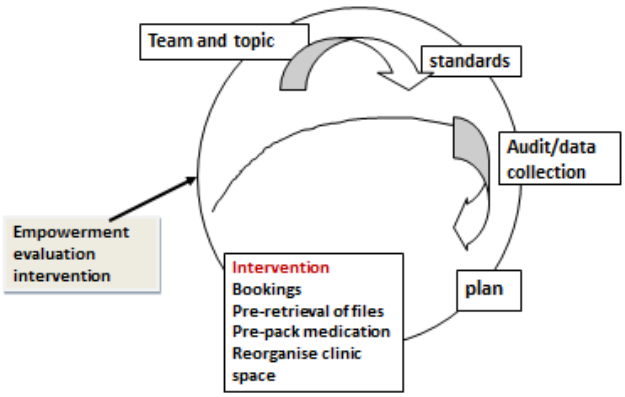


Figure 1. Empowerment evaluation project as intervention in the chronic illness QI in DKK

Empowerment research. This includes developing an open and trusting relationship with the collaborators (patients and staff) beginning with the first step of taking stock, (understanding the situation from the patients' perspectives). When taking stock or creating a baseline for the study, according to Fetterman[27], ''One tool used

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to minimize the time associated with prioritizing activities involves voting with dots. The empowerment evaluator gives each participant five dot stickers and asks the participants to place them by the activity on which the participant wants to focus. The participant can distribute them across five different activities or place all five on one activity. Counting the dots easily identifies the top 10 activities''. Here the most important clinical activities perceived at each clinic, were identified, prioritised and scored by each participant, using a 1 -10 scale.. A matrix was created and reflection on the scores was done as part of the empowerment exercise in creating a baseline measurement.

Step 2 is asking the question where are you and where you want to end up. This is al so seen as the vision of the group. This was co-created at each of the 9 facilities by t he group at the first meeting. From this vision, action plans and strategies need to be encouraged and developed. Clear goals need to be documented. This is an iterative process, and re-interpretation and reflection needs to be done. All the above, including a feedback session to each facility's staff occurred and were documented and used as feedback at the meetings.

An important element is the ongoing collaborative creation of an assessment to document progress. This was encouraged form the second visit at each clinic and was discussed at each subsequent meeting with assessment suggestions being implemented and discussed in an ongoing way. Innovations were shared amongst all the involved clinics.

Ethics. Ethical clearance was sought from the University of the Witwatersrand as well as from the relevant managers and the provincial research committee.. Each participant was requested to sign a letter of consent, having been informed that there would be no identifying characteristics indicated in the research or in the feedback to any other QI task team. It was made clear that there would be no repercussions on clinical care should participants refuse to be part of the research or wish to withdraw at any time. Regular reports were given to the various managers as well as to the appropriate QI groups as to the development of the project. All copies of video or audiotapes were secured and will be kept for 5 years after the research has been completed.

Limitations: Patients were expected to find it intimidating to talk freely about reasons for the problems they encounter. Language limited the most vulnerable from being included. Even when people are quite articulate in a second language, the depth of narrative might have been compromised if not expressed in the first language.

The research methodology is time consuming, relying heavily on the facilitation of processes with as little researcher influence as possible. The perceived power relationship between patients and researcher was recognised as a possible liability. Patients within the system might have been hesitant to criticize the health processes on which they were dependent. Practical difficulties had been foreseen like the lack of continuity of patients and unforeseen changes in staff rotations and

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availability, external influences eg the unpredictability of donors, the lack of resources and financial instability in the province.

Results

Nine clinics were involved in the research to match the 9 clinics that had been part of the ICDM pilot study referred to earlier. They were selected by a convenience sample from the four subdistricts. Six meetings were held at each clinic with a number of smaller follow up visits for action. In total 62 visits were done over the year. The whole process took place between March 2014 and June 2015.

This research was exploring empowerment of patients but was also curious about quantitative outcomes. The quantitative data will not be reported on in detail in this paper but will be briefly mentioned. 3065 files were audited and the chronic form in each file used as the basis of the audit tool. Clinical measures such as blood pressure, blood sugar, viral load and CD4 count were the indicators assessed. Waiting time and patient satisfaction data were also compared between 2014 and 2015 to try and gauge any influence the QI intervention may have had, comparing the ICDM pilot clinics and the research clinics. There was no significant difference between the improvement of clinical indicators at the ICDM pilot clinics and the research clinics. Waiting times had improved considerably in one subdistrict across all the clinics, but had remained stable at all the other clinics with no differences between ICDM pilot clinics and research clinics.

Empowerment evaluation process

Vision and taking stock

Over a period of a year, 331 people contributed towards the ideas and solutions of the improvement project; 179 were patients, 72 were staff and 80 community health workers. The staff members were health promotors, data capturers, Outreach team leaders (the professional nurses heading the PHV re-engineering outreach teams) rather than nurses. Nurses were generally too busy to commit themselves to the somewhat time consuming process of this project.

When taking stock of the services at the clinic all the participants prioritised and discussed chronic care as one of the important services, using blue stickers to develop the matrix (see figure 2 as example from one of the clinics). Each participant was given 5 stickers which they could distribute amongst the services on the list, according to the importance the particular service held for them. Once the four most important services had been identified for each group, each participant would choose a score out of 10 for each of the 4 services which would indicate their perception of its value and excellence for them, and write it down privately in order not to be influenced by others. These scores were then shared and anonymously filled in on the poster. Five facilities scored their experience of chronic care on

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average more than 8 out of 10. 4 facilities scored their experience of care as chronically ill patients between 7 and 8. The clinic perceived by health care workers to be providing excellent clinical care with dedicated attention to detail, scored the lowest from patients' perspectives.

Figure 2. Example of a matrix done at one of the facilities with the blue dots indicating the priorities of the group and the totals of the four priorities indicating the satisfaction with the 4 most relevant services to the group.

services		1	2	3	4	5	6	7	total
Papsmear and HPV (cancer prevention)		6	5	6	5	3	9	4	38/70 54.2%
Preventative services eg flu vaccine									
Tuberculosis		8	10	8	1	1	1	2	31/70 44.2%
Antenatal care		7	9	5	4	4	1	5	35/70 50%
Chronic care		9	6	7	10	8	9	8	57/70 81%
Family Planning									
Dietician									
Social worker									
psychologist									
Emergencies									
Laboratory									
Child care									

At the final visit each group was requested to repeat the matrix exercise based on the original vision which had been co-created at that facility. This will be discussed more fully at the final step of the process.

Vision.

The vision that was co-created at the first visit at all the clinics was remarkably similar with the most common needs of patients being a short waiting time, professional and friendly staff and available and correct medication. There were different focuses at some facilities. Unfairness was a significant discourse at one clinic. People felt the unfairness as well regarding their access to the doctor. Another major issue raised at a neighbouring clinic was the dirtiness of the surroundings. This was affecting the creation of a food garden and staff's willingness to be involved in a support group initiative. The groundsperson was not taking responsibility and was in the process of being disciplined. Cleanliness was also mentioned at another clinic where it seemed to be a favourite theme; plastic toilet seats versus other kinds were debated at length as well as the presence of dirty broken urine glasses and the toilet being used to store the spades and rakes for the garden. It was also

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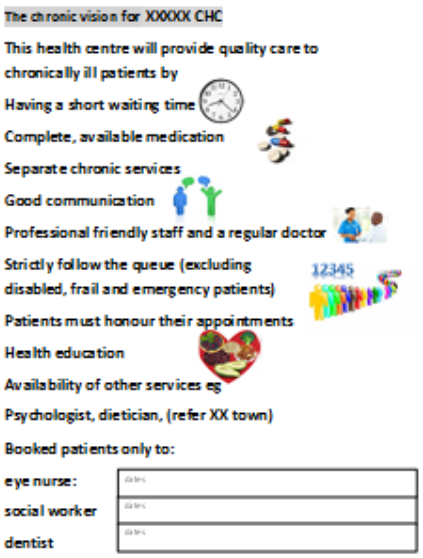
accepted by all the patients that toilet paper could not be left in the toilets because they would be used to ‘’roll zolls (cigarettes)’’ The reception became the central place for people to fetch toilet paper and hand towels.

A very positive theme at one clinic was the presence of a strong chronic support group who cleaned the clinic surroundings weekly, maintained a vegetable garden, started an exercise group and a knitting project. The irony at this clinic was as the group became more articulate about reasons for patient waiting times (for example tardy staff), the more they were victimized by young staff members.

Another clinic had ‘’staff attitudes’’ presented as a reason for patients to default on their planned visit dates. This lead to a snowball effect of clerks not pre retrieving files because patients did not arrive on correct dates. When discussing this, a nurse indicated that they all felt like victims because specific staff members were not named. Patients were allegedly too scared to complain but passively aggressively came on wrong days. Non adherence to booked dates was the main discourse at another facility as well. Here many reasons were given by patients eg social reasons like funerals out if town, babysitting and forgetting. So although waiting time was a recurrent theme, issues emerged which were particular to and impacting on different clinics.

All the groups agreed to their vision being displayed in their clinic and assisted in translating it into local languages. Patients were involved in doing the translation at four clinics and CHWs or health promoters at the others. See Figure 5 as example of a chronic vision poster.

Figure 3.. The English translation of one facility’s vision.



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Setting objectives and generating problem statements and initial solutions.
This happened over three or more meetings at each facility. Each group discussed in detail possible solutions and options based on the vision that had been created. The assessment of progress which will be discussed in more detail later, and is integral to empowerment evaluation, was part of every discussion and was seen as innovation as well as a number of measurement options that were suggested and tested. Table 1 summarises in particular the innovations at each facility which emerged from the collaborative groups as well as the measuring tools or assessment options which emerged.

Commonalities that needed to be attended to at most of the clinics were waiting time, queue marshals, pre-retrieving of files on the previous day, medication being delivered at home, improved attitudes of staff, separation of chronic services, a daily doctor and support groups.

Table 1.A Summary of Innovations

Innovation	Clinics implementing
Queue management eg Queue marshals and other queue interventions eg numbers at the door	9
Appointments in different forms	7
Other eg team building for staff, allied staff visit dates displayed, anonymous staff complaints	5
Support groups with different functions eg food gardens, exercises	5
Availability of equipment/medications at home	3
Improved patient flow for example by separation of different categories of patients in different ways in the waiting room etc	2

In total, 37 different interventions were suggested by the collaborative groups and 23 were implemented. A number of the 23 interventions were duplicated at all 9 clinics like the queue marshals and the pill posters. Where unusual or different thoughts emerged, ongoing sharing between groups was practised but it was relatively seldom that an idea was accepted by all. The queue marshal as an oral source of information was generally preferred to written notices, posters or boards. To this end aprons and sashes were made to identify the queue marshal. Different role players were identified to take on this task eg a clinic committee member at 4 clinics and a patient at one clinic, the others were counsellors, health promoters and a peer educator. A further refinement of this role was made at a health centre where the group crafted a daily speech including information about nurse availability, the complaints procedure and a hearty welcome as well as a signposting function.

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Figure 4. Queue marshal (patient) with identifying apron

Other innovations that were co-developed and shared were a poster with practical tips on how to remember your follow up clinic date, a poster with photos of boxes and pills explaining the changes happening nationally with changed tenders and different pills (causing a great deal of unhappiness amongst patients). Three new support groups were started as the importance of patient interaction was acknowledged. A few suggestions were not attempted eg staff team building and pictorial data for illiterate patients.

External unexpected outcomes, which were direct results from the patient advocacy within the chronic groups, were the renovation of an almost impassable clinic access road, seeds and agricultural expertise being made available for gardens at 4 clinics, a park home which was erected to extend the space of a small facility but with no electricity or water, eventually being connected with these amenities. The local university also became involved with biokinetic exercises for two support groups, 50 glucometres, were donated to patients who belonged to support groups and some support group activities were devolved to ‘’warrooms’’ (shared venues at local wards) where patients could be involved without having to move far distances.

Simultaneous changes which were happening and which impacted on the project, were the chronic medication National Health Insurance (NHI) project ie making drugs available at so-called ‘’pick-up points’’, a number of new doctors being appointed under the NHI grant and training for the CHWs on chronic care.

Iterative feedback A formal feedback session was held at all the clinics to give feedback to staff. The responses were generally neutral or positive. At each of the 6 visits, feedback was given to the collaborative group, regarding objectives that had been reached.

Table 2. Objectives related to the chronic vision, implemented at each clinic

clinic	Vision displayed	Chronic disease patients well separated	Queue marshal	Pre retrieval of files	Daily doctor	Support group	other
B	Yes	Yes - 5 areas	yes	yes	yes	yes	Road improved

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LDS	Yes	partly	yes	no	yes	no	Patient satisfaction stickers
Kh	Yes	yes	yes	no	yes	no	Add chronic room
TC	Yes	yes	yes	partly	yes	yes	Staff debriefing
L	Yes	yes	partly	yes	yes	yes	Many activities and garden
P	no	partly	yes	yes	yes	partly	Warrooms Accessible medication
M	yes	yes	yes	yes	yes	no	-
JBM	yes	yes	yes	yes	yes	no	Complaints mechanism for staff attitudes
K	yes	partly	yes	no	yes	yes	Parkhome water and electricity connected

The overall flow of patients, based on Lean principles,[35,36,37] which had been prescribed for the initial ICDM pilot clinics by the NDOH had to a large extent unknowingly been replicated by patient and staff involvement in the research clinics. The vision was displayed in 8 of 9 clinics, queue marshals were identified at all clinics to help with the flow, files were pre retrieved at 5 of the 9 sites. CHWs were being utilised at most clinics to prepack medication while patients awaited the consultation or CHWs were being incorporated to take medication to homes. All clinics had separated their chronic disease patients' space in different ways eg by blue stickers on a few rows of chairs for chronic disease patients, by positioning chairs in different directions, by laminated words stuck to chairs or by indelible ink in different colours on chairs.. All chronic disease patient rooms were clearly demarcated and in 6 clinics there were designated screening areas for patients with chronic illnesses. This organizational flow took a lot of perseverance to implement because stickers were removed from chairs, posters thrown away by cleaners and then the staff would simply say it didn't work. The booking book was eventually functioning in all clinics but none managed to identify the attendance of patients on their correct appointment days.

Measurement. From the first meeting the concept of ongoing evaluation of a system's improvement was discussed. Methods suggested and tried by different groups are summarised in table 2. The most common suggestion was waiting time surveys and patient satisfaction surveys which are being done occasionally and superficially by facilities as part of the National Core Standards. On at least 3 of the 5 contact sessions at each group meeting, these routine data were shared with patients as an empowerment exercise. A suggestion from one facility was that a pictorial version of data should be created for the illiterate.

Other measurement attempts were a red, yellow and green sticker opinion sheet offered to patients in the waiting room, a short questionnaire for latecomers to elicit their reasons for non-adherence to dates, monitoring non adherent appointments by analysing the booking book and by getting qualitative feedback from patients.

The final measurement based on the objectives identified at each clinic at the first visit and displayed as the ''chronic vision'', was done at the last visit, using the matrix. This time each point (ie objective) of the vision was scored out of 10 by each participant. An additional point

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was added asking what each person thought the contribution from the collaborative group had been to improve services at their clinic.

	Team members	A	B	C	D	E	F	G	H	I		
1	Identified space for chronic patients	5	4	4	6	9	10	9	8	8	63	70%
2	Waiting time	4	3	3	5	6	8	6	7	9	51	56.6%
3	Communication	2	4	6	10	10	10	7	9	10	68	75.5%
4	Patients supplied with own equipment	10	10	10	10	10	10	-	10	6	76/80	95%
5	Support group/garden	10	10	10	10	10	10	10	8	10	88	97.7%
6	Available medication	10	10	10	8	9	8	9	10	5	79	87.7%
7	Staff - professional, efficient	7	5	8	7	10	10	9	8	7	71	78.8%
8	Equipment available at clinic	10	10	10	10	10	10	9	8	6	83	92.2%
9	Dentist availability	0	0	0	0	0	0	0	0	5	5	5.5%
10	Dietician availability	3	3	2	0	0	0	-	2	-	10	11%
11	Psychologist availability	0	0	0	0	0	0	0	0	0	0	
12	Daily doctor	10	10	10	0	10	9	9	7	-	65/80	81.2%
13	Eye nurse	0	0	0	0	0	0	0	0	0	0	
14	cleanliness	10	10	10	10	8	10	10	10	10	88	97.7%
15	Health education	10	10	10	10	10	10	10	10	10	90	100%
16	Own contribution	10	10	20	10	10	10	10	10	10	100	112% !

Figure 5. An example of the final assessment of their vision/objectives by one clinic

In this case, points 1 to 15 were items from the original vision that the group from this particular clinic had wanted to be implemented or improved. There was still dissatisfaction with waiting time and the availability of some allied services. Point 16 was added to assess on which scale participants perceived their involvement to have assisted in improvements. It is clear that all of these participants felt that their contributions had improved chronic services at their clinic. At this clinic all those who participated in this final exercise were patients. Generally, all the other 8 facilities scored their own impact extremely positively. The range of scores was 60%,63% ,68%,72.5%, 74.5%,76%, 82.5%,87.5% Waiting time, medication availability and support by allied health workers were the common problems still identified at all the clinics with problems regarding filing or insufficient equipment being noted at a few others. Satisfaction with staff was rated low in only one clinic.

Discussion

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In Europe and the USA successful collaborations between staff and clients were formed focusing on common areas of interest [16,38,39,]. The differences in these papers was that most of them were funded and their innovations were not limited by money or other resources. It was made clear in the current research to all the groups that there would be no money in the project unless local donors could be accessed .It was encouraging to see how most ideas could be implemented with few extra resources. At the outset of this research it was also not

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entirely clear who should be involved. The large number of patient contributions as well as the proxy voices of the CHWS (who often speak very closely to the feelings and expectations of their patients and therefore could be considered proxies for community members' views) which were recorded and used, indicate that it is possible to involve patients in PHC. The relevance of doing so and the actual positive outcomes are further areas of interest.

Empowerment evaluation. This method has been both acclaimed and criticized.[40,41,42,43] The methodology encourages active participation in problem identification and collaborative solutions as in PAR and but adds the challenge of alerting the groups to the importance of data and monitoring processes. In a review of the method[28], Miller studied 47 case examples of empowerment evaluation and found that it depended on the researchers approach whether the principles of empowerment evaluation were successfully adhered to or not. He identified the ''Socratic'', structured guidance and participatory approaches which will not be discussed at length here. The Socratic approach however showed evidence of adherence to 7 out of the 10 participatory principles on average. These principles[44] relate to community ownership, inclusion, democratic participation, community knowledge, evidence based information and accountability and outcomes that would be expected are improvement, changing organisational culture, fair allocation of resources (social justice) and capacity building regarding data use. In the current research, democratic participation, community knowledge, inclusion, improvement and capacity building were strong elements at all the facilities. The others were partly accommodated ie evidence based decisions were made based on Lean principles but these were not necessarily spelt out to the participants. Resource allocation is usually an external process which was however in some cases influenced by group advocacy, for example, the case of the road being fixed and the parkhome being completed.

Relevance and added value. Patients and staff in collaboration discovered things that neither had known about. Information was shared about the drug policy on pickup points for chronically ill clients, that encouraged a number of patients to ask to be registered. On the other hand staff got honest opinions about how colleagues were speaking on cell phones during consultations or were ignoring patients' greetings. At one clinic the clinic committee member stood on the corner and monitored all latecomers which led to internal problems with staff, that have been subsequently dealt with. A tardy grounds person was disciplined and left the service. These are a mixture of practical and experiential outcomes.

Empowerment of clients is an outcome which is difficult to measure but where there has been much anecdotal evidence of value, in a wide range of settings eg cancer care, dermatology, women's groups, general practice and others.,[45,46,47,48,49] The final point in the matrix was an attempt to assess self -perceived involvement and the effect the collaborative groups had had, as a proxy for empowerment. The clinic with the strongest patient group, which has made a difference by their involvement in the support group, cleaning the surroundings, keeping the staff on their toes etc, scored their contribution as an average of 100%. The two clinics with the poorest continuity and patient involvement scored averages of 63.3% and 60%. This suggests that even though this may be a very subjective, experiential measure of empowerment and involvement, there is some congruency with the reality.

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There was innovation and energy which kept the momentum for change going in all the groups. This was developmental and collaborative as one person would begin with a fairly rough idea which would be refined by others in the group. Thus the innovations emerged from the interactions between staff and patients. This supports what was found in a systematic review about patient engagement in QI that where patients are involved, and with support and mentoring, unexpected solutions emerge.[23] It has also been found by a study that ‘’The(ir) empirical data revealed that the users produced more original ideas than the company’s professional service developers “’ [50p55] The newly created and contextual knowledge is also known as ‘’emergent’’ [51]knowledge which not only empowers the group but addresses the real underlying concerns and needs more accurately.

The ‘’Chronic Vision” as unifying /measuring device

As the project developed, it became clear that the initial exercise of creating a vision at each point, had also been a useful way of developing an objective, measurable thread including baseline objectives which could be measured at the end of the process. The vision was a visual reminder at each meeting of what the ideal situation would be for chronically ill patients at clinics. It also reflects quite closely a sophisticated principle being used in the UK to address quality improvement and safety issues, namely the ‘’Almost Always’’[52] principle where validated tools are used to construct and measure the things that matter most to patients in certain contexts. Waiting time and access, friendly staff and medication form a strong core to this approach, as did the ‘’chronic vision’’ in the research clinics.

Clarification of roles. It is evident that professional nurses cannot be involved directly in service change due to their high clinical workload. In all the groups, specific people emerged as champions and leaders. These ranged from categories of staff like health promotors and counsellors in the clinics, to strong support from the PHC re-engineering teams as well as patients. This alerts one to the unseen potential within the health system. Nonprofessionals were generally very keen to assist and the willingness and openness to take on new challenges was inspiring.

Looking at the quantitative clinical outcomes, there were no significant differences between the ICDM pilot clinics and the research clinics. One could argue that the research clinics had implemented the ICDM process by patient-staff collaboration within one year with comparable results to the original ICDM pilot clinics which had had ongoing National support from the inception of the pilot in 2011, over a number of years to arrive at their outcomes. It has been found in QI research that indicators for objective change are very difficult to measure as these projects are usually complex.[53] In an insightful discussion on the importance of clinical outcomes in chronically ill patients and what determines these, Hershberger[54] says:’’Because so many variables beyond physician control (health system control) affect patient outcomes, relying solely on outcome data (or proxies for outcomes) to determine physician (health system) effectiveness may be both inaccurate and unjustified.’’ In contrast, Alexander [53] decries the lack of consistent data to bolster claims of success in QI which leaves one with a dilemma.

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Conclusion

The way in which current QI is practised in primary care in developing countries, is not well documented and it is therefore difficult to know whether an inclusive approach is

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acknowledged and practised, whereby the patient is an integral part of the process. One of the dilemmas of QI research is the quantitative measurability of outcomes within a very complex cycle of change.

It was found in this study that the empowerment of collaborative patient- provider teams may not make a significant difference in quantifiable terms but in terms of innovative measures to improve the “experience” of being a patient at the clinic and in change management there is evidence of innovation and improvement.

The enormous untapped potential of patients passively entering and leaving health facilities on a daily basis needs to be recognized as a resource. Using a structured method like empowerment evaluation which has its roots in emancipation and self-development, is a potential practical intervention in any QI process in a PHC setting.

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CHAPTER 4

Improving childhood nutrition and wellness in South Africa: involving mothers/caregivers of malnourished or HIV positive children and health care workers as co-designers to enhance a local quality improvement intervention

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Improving childhood nutrition and wellness in South Africa: involving mothers/caregivers of malnourished or HIV positive children and health care workers as co-designers to enhance a local quality improvement intervention

Claire van Deventer*

MBCHB (Stell), FCFP (CMSA), MFamMed(Med), BA(UNISA)

Adjunct Professor

Department of Family Medicine and Rural Health

University of the Witwatersrand

Phillip Tobias Building

York Road,

Parktown,

Johannesburg, South Africa

email: cvandeventer@nwpg.gov.za

Glenn Robert

BA, MSc, PhD

Chair in Health Care Quality & Innovation

Florence Nightingale Faculty of Nursing & Midwifery

King's College London

James Clerk Maxwell Building

57 Waterloo Road

London SE1 8WA

email: glenn.robert@kcl.ac.uk

Anne Wright

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PhD

Family Medicine

University of the Witwatersrand

Phillip Tobias Building

York Road

Parktown, Johannesburg,

South Africa

Email: Anne.Wright@wits.ac.za

* corresponding author

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Abstract (352 words)

Background: a significant proportion of children admitted to a hospital in a South African sub-district in 2010 were severely malnourished and - when concurrently HIV positive - were not correctly initiated on antiretroviral therapy. Audit data over a subsequent four year period revealed that 60% of malnourished children admitted to the hospital were HIV positive. To supplement an ongoing local quality improvement (QI) intervention addressing poor nutritional outcomes in children in this setting, Experience-based Co-design (EBCD) was used to enhance previously low levels of mother, carer and staff engagement.

Methods: EBCD was implemented over an 8 month period. Non-participant observation was conducted comprising a total of 10 hours in 5 different clinical locations. Semi-structured interviews were undertaken with 14 purposively selected staff members as well as 10 mothers/caregivers. The staff interviews were audio-taped whilst the mothers/caregiver interviews were filmed; both sets of experiences were analysed for key 'touchpoints'. Mothers and staff participated in separate feedback events and then came together to identify their shared priorities for improving the service. Participants worked together in 3 smaller co-design teams to implement improvements.

Results: there was overlap in staff and mother/carer views as to their priorities for QI. However, whilst staff typically highlighted pragmatic issues mothers/caregivers were more likely to identify experiential and relational issues. A total of 38 QI interventions were proposed after the priorities had been discussed and delegated to the 3 co-design teams; 25 of these changes had been implemented or were being planned for by the end of the study period. Examples included: a point of care blood machine being bought to shorten the time

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in the emergency department whilst waiting for laboratory results; a play area being organised for children attending the HIV clinic; the development of three standard operating procedures to improve clinical handover and waiting times; and privacy screens installed to improve privacy in reception.

Conclusions: the impact of EBCD was noted both in practical improvements focused on a better experience for caregivers, mothers and children within the system and in reflections from stakeholders as to the value added to the ongoing QI intervention by the co-design process.

Key words Experience-based Co-design, chronically ill children, quality improvement, child nutrition, co-design, HIV

Word count: 3950

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Background

Concerns about the wellbeing of children have increased over the last few decades and these are reflected in United Nations Children's Fund (UNICEF)[1] and World Health Organisation (WHO)[2] guidelines as well as the Millenium Development Goals (MDGs)[3] where Goal 4 was specific to the reduction of child mortality. A large contributor towards child morbidity and mortality, especially in developing countries, is malnutrition. Coupled with HIV/Aids this has become a crippling burden to these populations. South Africa has been unable to attain the MDG goals set for 2015, regarding child health indicators.

Routine health data in a district in the North West province, South Africa, indicated that it was performing relatively poorly in 2010 in relation to severe malnutrition admissions for children [4]. The district comprises four sub-districts with the research subdistrict containing 9 primary health care (PHC) clinics (plus two mobile clinics for farms and outlying areas), all of which refer patients to a secondary hospital in this subdistrict. The hospital is in a large university town comprised of suburbs and surrounding townships. Most of the children admitted to the hospital come from an adjoining township which comprises formal and informal housing. In the hospital there is a general paediatric ward and a general paediatric outpatient clinic. In addition to the general outpatient clinic, there is a special Human Immunodeficiency Virus (HIV) clinic serving adults and children who are HIV positive. All the PHC clinics also manage malnourished and HIV positive children.

In the period October to December 2010, 14 % of children under 5 years old admitted to the hospital were severely malnourished. In the district as a whole 6/1000 children were diagnosed with severe malnutrition (compared to a national average of 4.8/1000 children [4]), placing the district in the bottom quartile of all districts in South Africa. Additionally only 50% of HIV positive under one year olds admitted to the hospital were initiated on Antiretroviral therapy (ART), contravening National ART guidelines [5].

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In response, a multi-disciplinary quality improvement (QI) project involving a ‘QI task team’ was initiated in 2011 by the district family physician. To begin, a range of audits were conducted to provide a baseline relating to various points in the service where children were seen; for example, the paediatric ward, the children’s HIV clinic and the PHCs within the sub-district. The audits involved collating and analysing information from hospital files and handheld child booklets; nutrition students from a local university also examined breastfeeding practises and costed the different milk alternatives available to mothers/carers.

One ongoing audit - based on the admission register of the paediatric ward - was designed to monitor any changing patterns of malnutrition in the period from the start of the QI intervention in 2011 until June 2015. Common reasons for admission were bronchopneumonia (BPN), gastroenteritis (GE) and HIV related illnesses. There was however a large number of children admitted for malnutrition only. For example, in 2011 60% of the children in the audit were admitted with a sole diagnosis of malnutrition although this had decreased by 2014 to 45% with the remainder of the admitted children having co-morbidities. Although BPN, GE and malnutrition alone had increased over the 4 year period as reasons for admission, HIV and TB had slightly decreased (figure 1).

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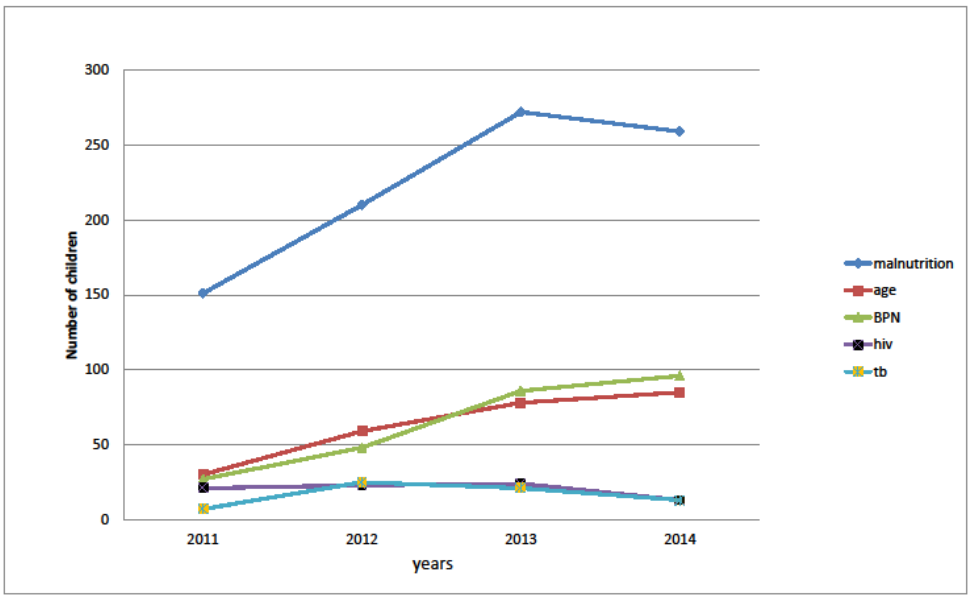


Figure 1. Trends in the most common admission diagnoses associated with malnutrition (2011-14)

A further concern raised by this audit was that in this period, 30% of children with malnutrition had been admitted for a surgical procedure and in 50% of these cases the diagnosis of malnutrition was not made and managed by the clinical team but only identified retrospectively from the ward register by the researcher conducting the audit.

The audit of the ward register also revealed that from 2011 to 2014 60% of all malnourished children admitted had HIV/Aids (although not all were admitted for reasons relating to this). There has been a significant decrease in the numbers of children diagnosed with HIV in South Africa over recent years - reflecting the nation-wide success of the Eradication of Mother to Child Transmission (EMTCT) programme. For example, of the 105 children still being seen at the HIV clinic at the study hospital in January 2015, 49 were in the 10-14 year old group, 25 were in the 5-9 year old group, 27 comprised the 1-4 year old group and only 4

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were under one. It was perhaps initially surprising to find that there was a high level of malnutrition (in different forms) in the older groups of children with HIV, up to the age of 14 years. However, older children are often not cared for by their mothers (most of who have died) and are known to frequently default their medication. Blood results at the hospital indicate that more than half these children (of all ages) are not virologically suppressed (although they have good CD4 counts). Unsatisfactory levels of suppressed viral loads were found for all except the under one year olds, who seem to have benefited the most from PMTCT.. This small cohort of children have remained at the hospital HIV clinic and not been referred to PHC clinics, due to either complications or poor patterns of adherence and are thus the most vulnerable group.

A majority of the malnourished children were from a relatively small area in an adjoining township; knowing this was useful in targeting, firstly, support to the relevant PHC clinics and, secondly, community information sharing. The work of the QI task team from 2011 included health information material being created and distributed widely to PHCs and incorporated the concept of a child identity document (the ‘Road-to-Health’ card) which was intended to accompany parents wherever they went (see figure 2).

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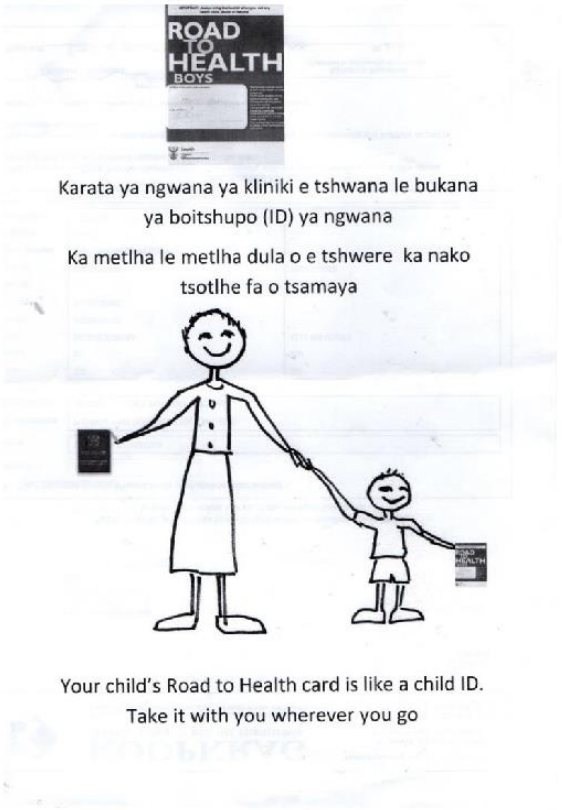


Figure 2. Poster encouraging parents to carry their child's health booklet with them

A hospital-community discharge link was created enabling patients to be identified and followed at the PHCs by dieticians; this new pathway included support for patients with identity documents and food parcels. A patient tracing system was also initiated. On the paediatric ward, HIV counsellors joined ward rounds to ensure that all HIV positive children were initiated on treatment as soon as possible; this led very rapidly to 100% of HIV positive children being started on ART.

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However, ongoing audit results showed that 881 children whose weight was unsatisfactory had been admitted between 2011 (when the QI intervention began) and 2014; the year-on-year results showed that 14.4% of all admitted children in 2011 were malnourished, in 2012 this figure was 11.6%, in 2013 16.1% and in 2014 15.1% suggesting no overall improvement in malnutrition rates during the first 4 years of the QI intervention. And so in spite of the efforts described above, including hospital, clinic and community interventions, there seemed to be no decrease in admissions of malnourished children to the paediatric ward. There was also no decrease in readmissions of children with malnutrition (7 readmissions in 2011 and 9 in 2014). On reviewing these results in late 2014 there was a concern by the QI team that parents of children had never been directly involved in the QI work; it was felt that they might be a useful additional resource in improving childhood malnutrition rates in the sub-district.

There is an increasing evidence base that greater patient engagement leads to improved outcomes. [6,7,8,9,10] A systematic review of the evidence by the author found:

‘’There are barriers to patients’ participation in QI in health and in spite of policy support for user involvement in QI, it is a difficult strategy to implement … there are enablers to patients’ involvement in QI: when patients are involved in QI efforts in health care, there are innovative, often unexpected outcomes at different levels of the process and sustaining these efforts is possible with ongoing individual or group support.’’ [11]

One of the most authentic approaches to client engagement appeared, based on the systematic review, to be Experience-based Co-design (EBCD) where quality improvements are co-created - and jointly implemented - by staff and their patients. [12,13,14,15,16,17,18] The EBCD approach - based on a combination of Participatory Action Research, user

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centred design, narrative approaches and learning theory [18] - explicitly recognises that the experience and feelings of patients regarding their interactions with health care services and staff is an important - but often neglected - component of health care quality. For example, a letter written in the local newspaper in the research sub-district by a mother in June 2015 reads (translated from Afrikaans) as follows:

''I went to the emergency department (with a sick 5 year old) ... I was chased out by a female doctor. I went to open a file and the person who helped me was also not the friendliest, didn't greet me, was just plain rude ... The doctor told my child to vomit in a medical waste holder. There was no silver container for him. While the child waited for test results he started vomiting again and one (nurse) shouted to the doctor, 'doctor the child is throwing up again'. The doctor simply said: 'There is nothing wrong with him, give him the medicine'. They just sat there while my child had to throw up in a dustbin''. [19]

This child survived and was not at risk at any time. Nonetheless, according to the mother this was, unsurprisingly, '' a very traumatic experience for us'', succinctly illustrating the impact of the lack of an aesthetic element in healthcare interactions that needs to be recognised and incorporated into QI activities.

Whilst it is acknowledged that - in the short term - EBCD largely brings about incremental QI changes rather than transformational or dramatic improvements, '' ... the individual and collaborative work underpinning these small changes lies at the root of deeper changes in attitudes and behaviours as well as other valuable legacies from EBCD projects''. [13] The approach has been used in healthcare QI work since 2005 and more than 50 projects have been identified internationally. [20,21,22,23,24,25] Having read extensively about patient involvement in healthcare and in QI in particular and having completed a systematic review on this topic, EBCD therefore appeared to the researcher to be an appropriate method for increasing the involvement of mothers/caregivers in the ongoing QI work and so the

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approach began to be implemented in January 2015 alongside the ongoing local QI intervention (figure 3).

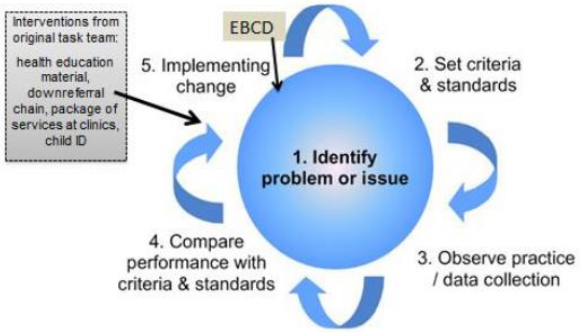


Figure 3 The inclusion of EBCD in the ongoing QI intervention

As illustrated above, a quality cycle usually includes the identification of a problem; the setting of standards; collection of baseline data; a comparison of actual practice with these standards and then planning and implementing change in order to meet the standards that were set. The original QIP had utilised this model and interventions have been briefly discussed above. EBCD was seen as a second round of interventions to add value to the first cycle.

The aim therefore of incorporating EBCD into the QI intervention in this way was ~~to enhance childhood nutrition and wellness in the sub-district by increasing patient inclusivity in the ongoing improvement work which had begun in 2011~~, to evaluate the effectiveness and

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feasibility of EBCD as an approach to improving patient invovlement in quality improvement for the managemetn of childhood nurition''. The objectives towards this aim included exploring the:

- understanding and perceptions of mothers/caregivers of their experiences of health care services for their children;
- providers' experiences with the care they provide towards mothers/carers with children with malnutrition and/or HIV;
- the collaborative planning and implementation of solutions by mothers/caregivers and staff.

The methods to achieve these objectives are described in detail in the following section.

Methods

The implementation of the EBCD approach was undertaken with a group of mothers/caregivers from the paediatric ward and the child HIV/wellness clinic sited in the most vulnerable geographic areas as identified in the audit data, as well as with staff from all of the relevant service provision areas. There were hospital matrons and professional nurses, medical officers, paediatricians, dieticians , social workers, an HIV counsellor and a clinical associate involved and the project leader was a family physician. Most of these personnel members had been part of the original QI. However, in terms strategic involvement, other roleplayers eg the screening nurse at the reception area, were purposively included as well. A core team of 4 health professionals co-ordinated and facilitated all stages of the EBCD process including the feedback and co-design meetings. The core team comprised a nutritionist, a paediatric nurse, a family physician and a paediatric doctor. Regular written reports were submitted to the hospital management on the progress of the project.

Mothers/caregivers and staff members were invited to participate in the EBCD process

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through purposive sampling. Participating staff including a range of professionals involved with caring for the children, as described above. Mothers were recruited through both the HIV wellness clinic and the paediatric ward. The inclusion criteria were all mothers/caregivers with a child either (a) having being diagnosed with malnutrition and/or any other relevant condition - for example, gastroenteritis, pneumonia or HIV - from the township or (b) with children from the same area who were HIV positive and were being managed at the HIV clinic. All participants had to be able communicate in English or Afrikaans. Written consent was obtained from all participants.

Process of EBCD [16]

The core project team oversaw the EBCD process after formal agreement was granted from the hospital management. Ethics approval for the study had also been granted from the University of the Witwatersrand and the provincial research committee. Non-participant observations were undertaken by the researcher along the patient journey and included 5 key service areas where the patients come into contact with the health system in order to provide initial insights into the subtleties of patient experiences. [12,13] The areas chosen for observation were the reception area, two rooms within the children's ward, the HIV clinic on the paediatric outpatient day and the general paediatric clinic. Field notes were taken using a template from the EBCD workbook and kept as narrative evidence.

The next step was to interview staff and gain an understanding of their perception of the service in which they worked and their views on how it could be improved. The interviews were audio-taped. They were then analysed by transcribing the information and colour coding the different themes which emerged. This was fed back to a meeting with staff where facilitated discussion about all the issues led to a set of priorities for improvement being identified and documented.

Concurrently, videotaped semi-structured interviews were conducted with

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mothers/caregivers. The mothers responded to open-ended questions relating to their experiences while their child was ill and being cared for by the health system. Questions were asked regarding the mother's experience at each contact point in her journey as well as her ideas in relation to possible improvements that should be made. The interview concentrated on surfacing ideas and emotions and not on set, closed questions. The mothers were shown the sections of her own interview that had been edited into a shortened compilation film which was structured around the common themes which had emerged in the interviews; this was in order both to validate what was to be shared and to allow each woman the choice to remove any material with which she felt uncomfortable. The mothers/caregivers were then invited to a feedback meeting where the film was shown and attendees shared their positive and negative experiences. A facilitated emotional mapping exercise [26,27,28] (see figures 4 and 5 in results section below) was used as part of the reflective group process to enable the participants to develop their own set of improvement priorities. Emotional mapping involved the mothers/caregivers applying emotion words (positive or negative) to the key points in their experience of interacting with any part of the health care system.

A combined staff-patient event was the forum where the emerging improvement priorities from the staff and patient feedback events described above were shared and 3 mixed patient-staff co-design groups were then formed to work on specific improvement priorities as part of the QI process. These groups then sought to identify and implement practical solutions for change over a period of two and a half months.

Finally, a 'celebration' event was held to which all staff and mothers/caregivers were invited to showcase the changes and assess what further work needed to be done.

Results

Observational fieldwork

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The pathway a mother with an ill child entering the hospital was expected to take, was observed at five points (total observation time was 10 hours across the 5 areas) and the findings were incorporated into the report that was fed back at the staff meeting (see below). A number of disturbing practices were noted as well as other very good processes and high quality care.

For example, in the reception area a mother was informed by the screening nurse - in a patronising way - that the fact that her child had a fever had nothing to do with the child's epilepsy medication (the mother's illness narrative) but rather because the child was overdressed. In the same observation period, an adult patient was asked why she had come to hospital and - with twenty or more fellow patients watching - said she had a chest pain and started pulling up her shirt to indicate the area. She was immediately stopped and severely reprimanded by the same nurse, to the general astonishment of everyone in the waiting room. A common complaint in the patient interviews (see below) was that of extended waiting times and this was confirmed during an observation at the HIV clinic where patients waited for many hours for a doctor to arrive. Children were irritable and running around in the clinic, as there was no activity area available for them.

In contrast to these negative experiences, in the children's ward a nurse entering the 6-bedded ward early in the morning made a point of introducing himself to each mother individually, greeted them with a handshake and cheerfully asked about their children. On this same ward, there were bright pictures on the walls and all the staff members gave attention to the mothers, including the cleaners and clerks. However, two safety issues were noted: a baby was observed crawling in the corridor whilst the polisher with a long electric cord was being used on the floors and a lumbar puncture on a child - who had been admitted the previous night in a stuporose condition - had not yet been performed due to poor handover procedures.

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Staff interviews and feedback event

The staff cohort purposively chosen for interviews encompassed a range of professionals involved with caring for the children: four doctors (including medical officers and paediatricians), two paediatric nurses, two dieticians, one social worker, a clinical associate, a counsellor, two matrons and a triage nurse at reception. These 14 professionals participated in open-ended, audio taped interviews lasting between 20 and 60 minutes. Analysis of the staff interviews was reflected back at the staff meeting and focused on 7 themes:

- emotion
- logistics (waiting; triage; space; clinical protocols)
- patient factors
- staff attitudes
- communication
- teamwork
- continuity of care

An unanticipated theme was that of ‘emotion’; it was evident that all the interviewees had been significantly affected at some point by either anger, sorrow, guilt, memories of patients, enthusiasm etc. Many of these responses were very self-reflective and sometimes painfully honest. The themes are summarised in Table 1 with illustrative excerpts from the interviews for each.

Theme	Illustrative excerpts from relevant quotations
Positive or negative ~~E~~emotions experienced within the working environment	‘To work with children is wonderful ... you can play and pull your face. It is so satisfying’ ‘We get emotional because we care’ ‘I get so angry ...’ ‘I have to say this thing (malnutrition) kills... It is heart wrenching’ ‘It makes me so sad’

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The influence of ~~L~~logistics (waiting; triage; space; clinical protocols)	‘It takes hours waiting for files ... It is ridiculous ... They are so tired when they get to us’ ‘Unnecessary referrals from PHC’ ‘Triage is done by students with no insight’ ‘The new Paediatric outpatient department POPD is very nice’ ‘We need a sound proof room for counselling’ ‘Mothers sleep on the floor’ ‘The 10 steps (WHO training on malnutrition)has helped such a lot’
Patient factors ie cultural and social issues influencing parenting	‘They really don't know... 80% don't know babies can eat protein’ ‘Rooibos (tea). It comes from the grannies ... They see it as medicine’ ‘Mothers are hungry for information. They want to do the right thing and be better parents’ ‘The mothers hide this (that they have given muti(traditional medicine)’ ‘Some of the grants go for alcohol’ ‘Sometimes she cannot read so she misses the appointment’ ‘Their hair is done, they are wearing nice clothes. You don't see suffering on the side of mothers... how did it come to this?’ ‘It is their culture ...The ‘raad’ (traditional medicine)’ ‘Sometimes the mother was alone, there was no food, the father had left and she tried to get money ... when they tell you their story their challenges ... ’
Positive and negative ~~A~~attitudes of staff towards partients	‘I have seen mothers in tears who don't want to talk ... she was told she isn't a good mother’ ‘Patients feel judged’ ‘Guilt and blame is projected by us’ ‘We should move away from the blame and listen to the reasons why certain things happen’ ‘I don't shout at them ... I try and compose myself’ ‘The staff at ward.X ... are very warm, very kind, very welcoming. That kind of atmosphere ... there is a culture’

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Positive and negatibve experiences of ~~C~~communication between staff and patients	'The mother gets some relief where someone is listening'
	'If you remain calm and explain they become receptive and say they will try. If you attack them they shut off... they don't even look at you when you come in the room'
	'After the news was broken that was the difficult moment'
	'We were discussing a child and they (the doctors) started laughing. The mother started crying because she thought we were laughing at her child. The interns don't always realise the parents are listening'
Teamwork	'It's important that the social worker sees them; she gets the true background and the mother gets some relief'
	'The safety net (of the clinic nurses) is not so strong. There is a lack of clinical sharpness/attention to detail'
	'With each and every visit they must go to the counsellor and social worker'
	'When you call a doctor 4-5 times and he doesn't pick up ... those who get into trouble are the nurses'
	'The staff is like minded. The dietician, doctors and nurses: children are important for them'
The importance of ~~Continuity~~continuity of care in chronically ill children	'The paediatricians are very focussed and there is some continuity'
	'Some of them have been there for years and years'
	'She (HIV positive young woman) has a baby who is negative. I have known her for 10 years'
	'They know the children and recognise the story is going on. This affects the way they are managed. I have already treated this child. This is the third time ... this is now serious'

Table 1 Staff themes

At the staff feedback meeting where 24 members attended, 9 areas for improvement were identified. These were practical interventions that could be dealt with immediately, such as buying mobile screens for the reception area in order to increase privacy and budgeting for a

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point of care blood machine to reduce laboratory waiting time for sick children in the emergency department.

Mother and caregiver interviews and feedback event

Twenty five mothers or caregivers were contacted and invited to be part of the research. Two declined outright and thirteen others did not respond to the request. However the 10 mothers/caregivers who agreed to be interviewed were willing to be transparent about both strengths and weaknesses in the health care system as they perceived them. All of the mothers except one were relatively fluent in either English or Afrikaans. A video recording was made of each mother during the open ended interview format. One interview was excluded due to the poor quality of communication, resulting in 9 videotaped interviews. These videos were then watched a number of times by the researcher (CvD) and key themes from each recording identified. Clips from each video illustrating the themes were then tagged and organising according to each theme. The total video time of 208 minutes was reduced to 40 minutes and presented as a short film which could be played back to patients and staff.

Overall, the mothers' stories contained positive and negative elements. A common positive phrase in respect of the OPD, HIV clinic and ward was 'they took me good', meaning they 'treated me well'. A number of individual staff were cited by name as being particularly helpful or supportive. For example, one doctor was praised for calling a child 'her chocolate baby' and giving the child a chocolate every time they visited her; another staff member for encouraging a mother that her child would get better. Whilst 3 of the mothers - despite the rough conditions - found the inpatient experience tolerable, other mothers referred to it as hell, and the staff as 'rude, really rude'. A number of mothers said they were persevering with the service for the lives of their children and seemed not to mind the sacrifice of their personal discomfort. Other mothers said health workers should leave their personal issues at home as it seemed as if they brought them to work with them. There were also allegations of

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rough handling of children and a lack of assistance with feeding of younger, helpless patients. It was clear that some mothers expected much more from the service than they had received.

Generally - with two exceptions - there was heavy criticism of the clinics: ‘they drag their feet’, ’they tell us just go and sit there we will call you’. A repetitive refrain was: ‘We sit!’ This was the representation of the waiting experience which emerged in every discussion with both staff and mothers/caregivers (in both the individual interviews and the feedback meetings).The three QI priority areas that were identified at the mothers’ meeting were logistics, attitude and communication (see table 2).

Theme	Illustrative excerpts from quotations
Logistics related to patient care, both positive and negative	‘Honestly, it was hell being woken at 4 in the morning and waiting till the doctor came at 9’ ‘We had to sleep on 2 blankets on the floor’ ‘I waited from 4 in the morning and the queue went round the clinic’ ‘It needs a play area for the kids’ ‘you have to sit for those pills!’ ‘when I got there, the queue was up to the road’’ ‘’I cannot ask for a day off work every now and then’’ ‘’If they know I am coming and could just leave my things one side, I can get them and go...’’ ‘’You can come at 9 in casualty, maybe they can admit you at 3 o’clock’’ ‘’they will tell you there are no beds’’ ’Surprisingly we waited for doctors... 4 doctors were at paeds.. only 2 were working, one was using a phone. I told the other mothers... 2 doctors are chatting .. a mother went. What she told them I don’t know but when she came back, they came with her’’ ’We went straight to the doctor’’ ’’ I didn’t know where to go and to whom I should speak’’ ’ I slept well, got up the next morning, there was no problem’’ ’We who slept with the children had to phone our mothers to bring food’’ ’To stay there watching her every day, every night, suffering , couldn’t talk, yeah, it was painful’’ ’ Four o çlock .You are getting cold, there is not tea for you..’’ ’They shaved the child’s hair and put the drip up fast’’ ’I am at the clinic for her today and I am supposed to be at G clinic for myself tomorrow’’

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	’The doctor gave her a dosage which was too strong for her’’
Positive and negative attitudes of staff towards patients	‘They shouted me. They said it was my fault (that the child was so ill) and that I had no shame’ ‘She was so naughty, Sister ... (laughing) always making jokes’ ‘It is not all of them, we mustn’t take the negative and put it on top of all the positive, about 10% are like that ... the rest really try hard’ ‘They turned me away (when she came late from work) and told me I would have to make a plan - I said I made a plan ... I am here now!’ ‘I was so angry I was just ready for the fighting ...’ ‘They were really good to me’ ‘’They take me good, and the child’’ ‘’The clinic that I attend.. they work with the people nice..’’ ‘’They try by all means to help’’ ‘’The (clinic) staff sits long and chats and takes a long time to help you’’ ‘’The sister fought with me and said I don’t care for the child’’ ‘’I am a person who is not scared of being shouted at’’ ‘’At the end of the day you will give me the answer that I want’’ ‘’You (as a parent) must check your childs dates and if you have to go to the social worker you should not run away from this’’ ‘’I feel safe here’’ ‘’They don’t speak well with patients’’ ‘’They were very nice.. they were exceptionally nice..’’ ‘’They were rude, very much rude’’ ‘’When they have problems they come with their problems at work’’ ‘’She (nurse) is like.. ‘’parents hold your kids to yourselves, this is not a pre-school’’!
Communication: Both positive and negative between staff and patients	‘I tried to explain and he (doctor) didn’t listen ... he said my question was too difficult’ ‘I can talk to her about all my problems and she will always listen’ ‘’They didn’t tell me why she was swelling’ ‘I know I have to give her mince and maize and bananas’ ‘’They ask you while you are amongst other people ‘’What is your (HIV) status’’’ ‘’In the morning at 4 when they come to wake you up, they scream.. and children are also sleeping’’ ‘’The doctor explained to the others, this is an emergency she must be seen first’ ‘’They didn’t even know how to approach a person’’ ‘’She don’t listen what you say, she just shout’’

Table 2 Mothers’ priorities

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The mothers/caregivers feedback meeting was attended by 5 mothers, 2 of their children and the core team members. Mothers had agreed that the hospital was the most central venue and the meeting was held there, with refreshments and toys for the children. The meeting took two hours, with the film being presented and then the emotional mapping exercise being done. Everyone was asked to write down their thoughts while the film was being played, which they did. In the emotional mapping exercise (see figures 4 and 5) the service area which appeared to raise the most concern was the children's ward with words like 'stressed', 'rude', 'disrespected' and 'powerless' being used; this contrasted strongly with staff members mostly positive impression of the same ward. Other services like the OPD, dietician, social worker and X-rays were mostly perceived by mothers as positive experiences with words like 'confident', 'hopeful' and 'valued' being chosen to describe their experiences at these points.

Thereafter in the meeting, from these two exercises, a prioritised list was drawn up for discussion at the combined patient/staff meeting which included attitudes of staff, waiting time and communication.

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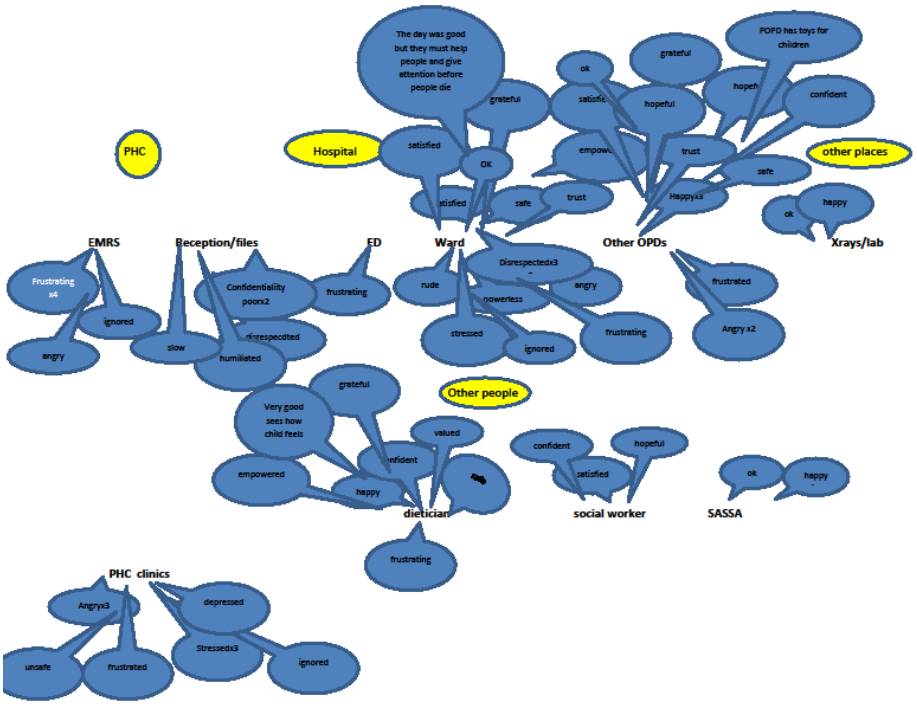


Figure 4 Emotional mapping done with mothers of chronically ill children

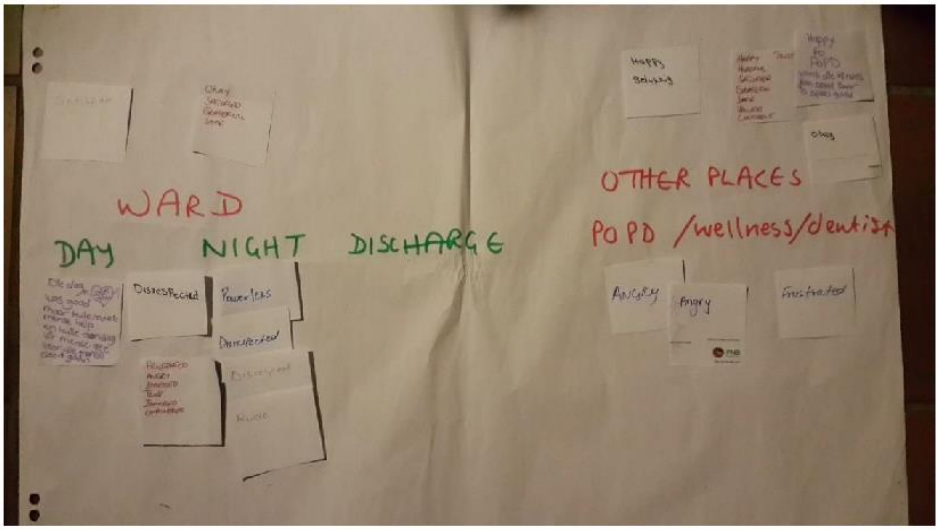


Figure 5. Part of the emotional mapping pathway done by mothers

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The joint feedback event

A third, combined feedback meeting with staff and mothers was held where the 40 minute compilation film was presented, as well as the synopsis of the staff and mothers' QI priorities. The core team together with 16 staff members and 5 mothers (with 3 children) attended this event. After discussion of all the issues which had already emerged, three mixed co-design groups were formed which brainstormed the most important combined priorities resulting in 3 thematic areas:

- attitudes and communication
- waiting
- practical issues.

Everyone was then allocated to a co-design team with at least one mother in each of the teams.

There was a positive energy in this meeting with a patient saying that the value of this process was that, 'we will all understand each other's feelings, behaviours, and attitudes, and another indicating, 'I was very happy to be contributing in the meeting'. Staff, likewise reported it was helpful to hear 'their concerns rather than thinking you know what they are' and from a patient who complained that 'doctors have very bad attitude'. Each individual attendee at the meeting articulated what they had experienced, contributing to a tapestry of 'aesthetics'.

Co-design teams

After 2 further meetings of each of the 3 co-design teams that were formed at the joint feed back meeting, a total of 38 concrete, practical QI interventions were suggested (see table 3 which is based on a format devised by Locock et al [29]). Of these, 25 were implemented in the research study timeframe (January to August 2015) and 5 others were being discussed or were temporarily put aside due to financial constraints eg reorganising the filing registry

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department to have a paediatric component and colour coding paediatric files.. The remainder were considered to be inappropriate for the time being due to lack of management support. These included moving the paediatric ward from the 3rd floor to the ground floor in order for the children to have an outside play area and integrating the general paediatric outpatients department with the HIV children's clinic.

Improvement activity: already implemented or planned for	Small scale	Process design within team	Process design between services	Process design between organisations
Small screen for privacy at reception	x			
Triage by senior staff at ED	x			
Lazyboys (reclining chairs) for long term mothers - donations sourced		x		
Mattresses for mothers in the ward	x			
All referred patients through clinic doctors			x	
Tracing of children through CHWs			x	
Tea for mothers in morning	x			
Debriefing of paediatrics staff by university psychology department				x
Schooling				x
Library				x
Organisation of child files at clinics			x	
Ill children straight to ward	x			

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from ED without waiting for results (with Standard Operating Procedure SOP)					
Downreferral criteria in POPD	x				
Departmentalisation		x			
Prescription pathway at clinics- plan/SOP			x		
Ward orientation tool for admitted patients	x				
Soundproof area in POPD (moved to doctors room)	x				
Urns for Paediatric ward	x				
Psychological support for mothers					x
Play area at wellness		x			
Q marshals at clinics			x		
Q marshals at hospital reception	x				
Positive attitude workshops by subdistrict psychologist planned			x		
Time appointments at POPD		x			
Point of care blood test machine in ED – on priority equipment list		x			

Table 3. Interventions suggested and implemented by co-design teams[29]

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A final celebration event was held in September 2015 to give feedback on progress - the achievements and difficulties encountered in the project - to the managers of the services, staff and mothers. This was attended by 16 people. Based on this combined group's input, a small task team including healthcare workers from primary care and the hospital was chosen to continue with the work and to keep the importance of remaining aware of patient experience alive in the ongoing wider QI work. Whilst EBCD became part of the still ongoing QI project – placing it within a stable, improvement milieu with some continuity - it is not possible to predict to what extent change will continue. The most recent malnutrition death rate at this hospital has been 0 over the last 3 months. One would hope that the QI project incorporating EBCD has made some contribution towards this,. A separate but related ongoing QI project on child antiretroviral therapy (ART) in primary care commenced in 2014, as most of the children from the hospital HIV clinic have been down referred to primary care clinics. This was initiated as a standard QIP but may be considered for an EBCD intervention, with the experience gained in the current research.

Discussion

EBCD is a clearly defined process which allows patient perceptions and emotions to emerge as part of a planned change or improvement process. The approach also acknowledges the importance of staff contributions and - crucially - the important contribution that co-design (staff and patients working together as partners) can make to QI 'work'. In longer term evaluations of the approach it has been reported that EBCD engendered positive working relationships whilst acknowledging issues like the locus of control and the challenge of implementing change processes in complex environments (including the discrepancy between patients' expectations of the speed of improvement and the reality) [17]. As with the project described here, other implementations of EBCD have acknowledged that conflict and/or disagreements between staff and patients cannot be completely removed.[23]

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Emotions and motives for working in healthcare services were unexpected findings amongst the staff. It was interesting that passion characterised many of the staff stories as well as awareness of feelings of guilt and blame; often private family stories were shared as reasons for working with HIV patients or children. The level of engagement from staff in discussing improvement was similarly unpredicted and humbling. Whereas the health care workers contributed more to the pragmatic solutions, patients made more emotive judgments based on their personal experiences. Such experiences were both positive and negative and were captured both in the emotional mapping and also at all the feedback meetings. There were similarities in the themes from staff and patients and solutions were sought, often being generated in the collaborative discussions.

Limitations: The process of recruiting patients and retaining them proved challenging. Studies using EBCD in Emergency Departments in Australia also found the recruitment and retention of patient participants to be difficult [22],[24]. Language was a problem in some cases as English was not the first language for most of the staff and parents. The emotional value of the films is acknowledged but at the same this may act as a constraint for future projects; duplicating this method in the future would be time consuming and costly. It may be necessary to emulate the route followed in the United Kingdom, where previously filmed patient interviews could be used as ‘trigger’ films in improvement work. [29,30] The lack of financial resources to implement some structural suggestions was acknowledged; these were not discarded entirely and were either ‘parked’ as future possibilities or donors were sought. In spite of the barriers, the attitude of co-operation from most of the hospital management was humbling, as was the enthusiasm of the patients that remained involved.

The wealth of usable information that was generated from the EBCD co-design teams is a new and potentially fruitful addition to quality improvement approaches in the public arena of health in South Africa. This study has highlighted the value of emphasising the experiential side of both staff and patients’ perceptions about the care they are involved in. These

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experiences cut to the chase of where things often go wrong and therefore cannot be salved with superficial improvements. This is a shift therefore from the current response to complaints, adverse events and patient dissatisfaction, which is normally dealt with in either a legal and disciplinary way or by staff-led systems' changes which are not always appropriate.

Conclusion

In line with discourses of 'customer/client care' in other industries, the importance of engaging patients to improve the quality of the healthcare services provided to them has proven to be valuable and productive. In this research project, the integration of mothers/caregivers and staff into co-design teams has lead to concrete practical improvements in a paediatric service, and also spanning the boundaries of hospital and primary health clinic care.

As QI practices have not yet become routine in healthcare organisations in South Africa, staff members were almost as much of an untapped source of ideas and perceptions as patients. The energy generated between the two groups, based largely on feelings about being 'together' as part of the same service, lead to 38 possible solutions, all based on discomfort or negative feelings about certain aspects of care.

Possible recommendations form this study would be to embark on a similar EBCD process with the QI referred to which is assessing and intervening in the child ART programme at PHC clinics. As the filming is very intensive and resource constrained, the current film may be used for other projects in lieu of creating a film for each project. This visual material is to a great extent, an emotional trigger which reflects much more than that of standard verbal responses. An alternative would be for a champion of the EBCD method to learn to edit the videotaping into a short film each time the method. is used.

The ongoing QI task team would need to engage mothers in a following cycle in order to effectively evaluate the overall loutcome of all the interventions (includeing the aesthetic

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elements) over a longer period.

This method is a cohesive whole, dependent on the emotional experiences at touchpoints as well as the validation by observations and audiotaped interviews with staff. There is therefore no shortcut or portion that can be used as a simpler, faster QI method. It would therefore maybe make sense for South African practitioners in the public service or elsewhere, to reserve this method for a longer term, more intensive QI where reasons for underlying systems failures have been difficult to identify.

Abbreviations used

ART: Antiretroviral therapy

BPN: Bronchopneumonia

EMTCT: Eradication of Mother to child transmission

GE: Gastroenteritis

OPD: Outpatients department

PHC: Primary Health Care

QI: Quality Improvement

UNICEF: United Nations Children's Fund

WHO: World Health Organisation

Competing interests

The Point of Care Foundation in London provides training in the Experience-based Co-design approach; GR contributes to this training.

Author contributions

CvD The bulk of the research. The first draft of the article and edited versions.

GR

AW Supervisor of researcher's overall PhD study.

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Author information

CvD is a Family physician in Dr Kenneth Kaunda district, North West province. Involved in many quality improvement projects as part of clinical governance within the district.

GR is one of the original developers of EBCD and has been involved in the evolution and adaptation of the approach since the initial pilot project in 2005 which was funded by the NHS Institute for Innovation and Improvement.

AW

Medical anthropologist and lecturer Family Medicine, University of the Witwatersrand, Johannesburg

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All the mothers/caregivers and staff involved in the project.

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Chapter 5

Conclusions and recommendations

5.1 Conclusion

The following chapter will deal with the conclusions from Chapters two to four as well as consolidated recommendations from all the studies. This is however not simply a summary but a critical reflection on a variety of aspects of this study.

The aim of this study was to explore patient-inclusive interventions while implementing QI in primary care. In order to achieve this, a systematic review was firstly undertaken to understand the global situation regarding patient involvement in quality improvement. Thereafter, two different qualitative research methods were used to encourage patient engagement and to document the processes that emerged. These research methods both emerged from the identified literature for the systematic review and attracted the researcher because of their evidence of successful engagement and empowerment of patients.

The systematic review confirmed the researcher's subjective opinion that clients in the healthcare system are not optimally utilised in health systems solutions. There were many examples in the accessed literature of patient-centred consultations, community involvement in projects, and individual empowerment efforts especially regarding chronic illnesses. However, a concerted effort to allow patients to become part of a QI process was lacking and no academic literature from South Africa was found on this topic. The fact that JBI follows a rigorous system with the title, abstract and key words being the focus of the initial search, may have excluded articles with different terminologies for QI and patient participation. As the research progressed, words like implementation research, organisational and translational research were found for approaches congruent with QI.

Similarly, there were many more publications on quantitative than qualitative research on this topic which may have led to additional insights being missed. However, the JBI software is divided into quantitative, qualitative, cost, technology and utilisation assessment packages etc which focus on different philosophical approaches. The decision by the researcher to concentrate on qualitative papers would have excluded a large body of literature but doing this was a pragmatic decision regarding logistics as well as the choice of a methodology which was considered to be more suitable for the paradigm on patient involvement.

The conclusions from the systematic review were that there are barriers and enablers to including patients in QI. Unexpected and patient-centred innovations emanating from

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collaborative QI groups and the improved experiences of care for patients were offset by difficulties in initiating and maintaining this involvement. Further barriers related to hierarchical power structures within health and resource limitations. In view of the fact that South Africa is committed to involving patients in health care improvement through the National core standards and the Ideal clinics, in this research it was important to recognise if this is being achieved or not.

The systematic review had also identified the lack of planning for patient involvement as a significant barrier. The researcher had specifically concentrated on a recruitment process to involve patients and healthcare workers, by requesting staff of the involved facilities to assist with this. In spite of the planning and recruitment, there was a relatively high attrition rate from patients and a very clear time limitation for active engagement. An ongoing replacement mechanism may solve this problem, whereby new participants are constantly sought and included to replace those leaving. This would affect the continuity of the process but may also broaden the culture of involvement.

The difficulties regarding resources eg time and financial needs/constraints were similar to those highlighted by the systematic review as was the amount of effort needed to implement and sustain the projects. Whereas the EBCD project may be limiting for short term projects due to the costs involved regarding the filming, previous films could act as triggers for experiences and emotions as indicated in chapter 4. EBCD could also be a specific intervention for the more entrenched health problems where PDSA cycles or other quick QI tools do not work. Resources for the Empowerment evaluation project however were not necessarily a limitation as much had to do with re-organisation of operational space, basic information posters, measurement of waiting times etc. This need therefore not be the limitation it appears to be.

The differing views of staff and patients was a very real experience in both projects. The so-called lower categories of staff (health promotors, counsellors, community health workers) embraced their roles as enablers and champions. This finding can be used in planning for patient engagement in future projects. In the systematic review it was found by some researchers that the reason for not involving patients in more intense interventions was that healthcare workers felt that patients are inarticulate or lack insight. A similar staff attitude in the research district emerged especially during the EBCD study where patients were blamed for taking traditional medical decisions or not following dietary advice. Patients in turn mentioned issues like the lack of listening skills and judgmentalism from staff. Some members of staff were shocked to experience criticisms from the patient based film.

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However within the feedback meetings and co-design teams, respect grew between the two groups.

Apart from the barriers, the systematic review also pointed out the enablers in patient involvement. This was clear in the Empowerment evaluation project where innovation and a diversity of interventions were implemented. Innovations were suggested from both staff and patents in a collaborative way and this strengthened the process and validity and led to concrete improvements occurring. It was interesting to see that the strength in both the Empowerment evaluation and EBCD projects seemed to lie within the partnership between staff and patients rather than just the clients alone.

The systematic review also recognised that where there was developmental support or coaching, projects were more successful. The Empowerment evaluation and EBCD projects were both supported by either the researcher or a team over a period of 6 months to a year. Nevertheless, there was a limitation to the self-sustained commitment to the projects, in particular regarding the patients.

In the Empowerment evaluation project, a research method was utilised which was based on a structured approach including the collaborative development of a vision, assessment of the perceived experience of healthcare by patients and healthcare workers, and an ongoing process of improvement. Many practical interventions were implemented and the original vision was used as a point of reference and measurement of improvement and empowerment.

The EBCD project reflected views of patients and staff in a paediatric environment, on their experience of healthcare. These ideas and thoughts were then used by co-design teams which then achieved a number of practical, patient-centred QI outcomes as well as a changed vision regarding experiences and emotions of patients and staff in the paediatric system under scrutiny. Examples of concrete outcomes were discussed in detail in chapter 4 and included reclining chairs being ordered for long-term mother-lodgers, an orientation to the ward developed for all new admissions, a library service and schooling for children remaining for long periods etc.

The researcher experienced the process as an intense and emotional journey with many unexpected discoveries along the way. It was humbling to have enthusiastic support from staff, (most of whom were under great work related pressure) as well as from patients. The frustration of limited financial resources was offset by the inventiveness and willingness of participants to think laterally. The untapped and underutilised potential of people who fill the waiting rooms of the health institutions every day was showcased by this research.

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In summary, the newly co-created knowledge which may be of use in particular to Dr Kenneth Kaunda District, North West province, includes the following.

The less professional categories of health workers are very valuable potential members of QIs and have been excluded to a large extent in the past.

Involving patients needs concrete planning in the early stages of a QI project. However, continuing patient involvement has an attrition rate which needs to be considered for optimal involvement of patients in long term projects.

QI outcomes need not be limited by resource constraints, as much can be done with human resources and re-organisation of spaces, time and available administrative resources eg booking systems, basic information materials etc.

Quantitative clinical outcomes related to the interventions, were not included in the articles and report, as had been originally intended. This was due mainly to the fact that there were not standardised data collection methods in the district, as had been assumed and also because the complexity of systems change in a district disallows direct attribution of improvements or changes to one intervention. This is an area which should be carefully planned for future QI cycles in order to allow quantitative and qualitative findings to intersect for optimal outcomes.

It is acknowledged that sustainability remains a challenge and that specific methods need to become part of the culture of change within a quality improvement movement. The novelty and intensity of the two methods chosen may mitigate against their becoming everyday processes, However, where underlying resistance to change is encountered or difficulties in achieving change are found whilst using traditional QI methods, these would be recommended as possible alternatives to solving the problems.

5.2 Recommendations

5.2.1 Roleplayers. In both projects, the staff members involved appeared to be as empowered as the patients and the strength of the teams lay in the collaboration between the different rolepayers. HCWs who are traditionally not accorded much power, demonstrated a great deal of potential for positive involvement in complex change initiatives.. An example is in the way that health promotors and lay counsellors took a strong lead in the ICDM project. Innovation and responsibility was experienced beyond what would normally be expected from these categories of HCW. Insightful contributions were made in the EBCD group by a counsellor and by ward nurses. In any future patient involvement QIs, it would be essential to engage the counsellors, health promotors and clerks as well as more

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junior categories of nurses at an early stage. They are also proving to be the sustaining force in new interventions.

Clinic committees were surprising allies in the improvement of services. Traditionally they have been figure heads and have not involved themselves much in the practical issues of the clinics they serve. However, in the ICDM project, in all the clinics there was at least one clinic committee member who was willing to be a regular queue marshal or assist with ongoing measurement of improvement.

Another rolepayer who has been overburdened with responsibilities but remains at the coalface of health with the PHC re-engineering programme is the team of outreach team leaders (nurses) together with their community health care worker cadres. In many of the clinics, these people were proxies for patients as well as being willing to implement initiatives decided upon by the collaborative teams.

5.2.2 *Lifecycle*. From the 2 original research projects, it is clear that the ‘‘lifecycle’’ of patient involvement is fairly brief and must be optimally utilised. At the first meetings or interviews held in both projects, there was enthusiasm and much vocal contribution. However, to sustain this level of involvement over 6-12 months was very difficult. Patients came and went and it was clear with the ICDM project that 4-6 visits were the most to be expected. In the EBCD project, the interviews, the playback of the film individually, the 2 meetings and 2 co-design meetings were also in total about 6-7 contact sessions and there was attrition in spite of efforts by the researchers to remind and encourage people to attend. Practically this may mean that until a critical mass of patients have become used to being involved in projects in health, planning should take this time frame for patient commitment into account.

5.2.3 Resources. It was evident that much can be accomplished with few financial resources. This needs to be clarified at the outset of QI initiatives where patient/HCW groups collaborate. It is the mind power of groups that are energised and inspired by one another that leads to innovation. Intersectoral collaboration is generally under-used and it was found that when agricultural technical advisers were approached, there was the opportunity to obtain seeds as well as advice. The local University was prepared to invest biokinetic students in a chronic illness support group to assist with exercise groups etc.

In contrast to the above, an important part however of EBCD is the film which is a final construct of a number of experiential stories. The interviews and the analysis do not cost much except the time of the researcher or core team. However, the development of a film from a number of interviewed videos is costly and is not foreseen as a sustainable intervention. In the UK an alternative that is being used is that already existing films are used

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over and over in different projects as triggers for EBCD related QI projects. This may be an option to explore. Another alternative would be to invest in one or two people in the district who could learn basic film editing and who would then be utilised whenever this method was followed.

Finally, the research has shown that there are enablers and barriers to the involvement of patients in QI in primary care. This knowledge makes it possible to consider pragmatically how to overcome the difficulties inherent in the process. It is also an encouragement to actively strive towards a culture of inclusivity in healthcare in a number of ways but in particular where QI is used to address problems within the system.

ADDENDUM 1 ETHICS CLEARANCE

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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Prof Claire van Deventer

CLEARANCE CERTIFICATE	**M120701**
PROJECT	Patient Involvement in Quality Improvement in Primary Care
INVESTIGATORS	Prof Claire van Deventer.
DEPARTMENT	Department of Family Medicine
DATE CONSIDERED	27/07/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09/10/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Anne Wright

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

ADDENDUM 2 TOOLKIT EBCD

1. Is experience-based co-design for you?

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Experience-based co-design (EBCD) can improve services in a way that really makes a difference to patients and service users. It captures the experiences of patients, carers and staff through discussion, observation and filmed interviews.

It then brings staff and patients together to explore the findings and to work in small groups to identify and tackle areas for service improvement. It was designed for and within the NHS to develop simple solutions that offer patients a better experience of treatment and care.

1 EBCD: Is experience-based co-design for you?

Gathering information about patients' experience is not new – but it is usually done through audits or surveys, which can be unsophisticated tools for discovering what really matters to patients. By enabling patients and service users to tell the stories of their experiences from their point of view, EBCD often reveals unexpected areas for improvement that can be surprisingly simple to overcome.

In this approach, patients and staff work alongside each other to identify problems that can be practically overcome and to develop implementable solutions that benefit everyone. The result can be long-lasting change that genuinely makes a difference to patients' experience, along with many wider benefits that result from participating in a revealing, challenging and inspiring collaboration.

Throughout this resource we refer to 'patients', but this also applies to any service user of health and social care.

Key points

- EBCD is a very straightforward and flexible approach that can lead directly to action and genuine improvement.
- EBCD offers an opportunity for dialogue that provides rich insights into the nuance and meaning of patient feedback and can complement other feedback methods, such as surveys and audits.
- EBCD can help organisations meet strategic objectives within the quality agenda, including improving patients' experience and involving patients, and engaging large numbers of staff in service improvement.
- There is a substantial body of evidence to show the effectiveness of EBCD as an approach to improve patient experience. (See our evidence for experience-based co-design for literature surrounding the evidence for the approach).
- Ensuring genuine patient involvement can be a challenge in the face of competing demands. This approach brings the patient voice to the heart of service development in a way that helps staff feel inspired and motivated to make and sustain the changes.
- EBCD is a fresh approach that moves service improvement discussions away from the usual topics, to reveal the often hidden factors shaping patient experiences – for example, it might identify that the most frustrating aspect of long waiting times relates to poor communication rather than the wait itself.
- The approach focuses on solutions that patients and staff develop together, to produce realistic goals that will benefit staff and patients alike.

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- Patients provide both positive and negative feedback through a constructive, collaborative process that participants often describe as motivating and inspiring. This reduces the challenges of receiving feedback that may be critical.
- The two-way process develops connections across staff teams and between staff and patients, and can boost confidence and motivation levels.
- Because patients are involved throughout the development process, EBCD offers the opportunity to check back with patients to make sure that the changes made succeed in improving patients' experience.
- It is the only approach that involves patients and staff working together to design and make improvements to their services.
- The approach can easily be adapted to encompass the views of carers too.

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2. What is experience-based co-design?

Experience-based co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. The approach is different to other service improvement techniques.

2 EBCD: What is experience-based co-design?

EBCD involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions; identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings. A short edited film is created from the patient interviews. This is shown to staff, conveying in an impactful way how patients experience the service. Staff and patients together identify areas for redesign, and work together to make improvements to the service and to the pathway of care.

The approach was developed within and for the NHS, although similar 'user-centric design' techniques have been used by leading global companies for years.

Stages in experience-based co-design

stages-experience-based-co-design.jpg



(click to view in a larger format)

The project steering group should meet at the following critical stages:

- before the project begins

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- before feedback events
- after first co-design group
- after celebration event.

Key points

- EBCD focuses on patient and staff experience and emotions rather than attitudes or opinions.
- The approach uses storytelling to identify opportunities for improvement and focuses on the usability of the service for patients and staff.
- It empowers staff and patients to make changes

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3. Making the case to staff

This stage involves getting sign-up from senior colleagues who are interested in making improvements to services based on patients' experience.

3 EBCD: Making the case for experience-based co-design to staff

For the project to be successful, you need to effectively promote the idea to staff at a number of levels. It is essential to get senior staff involved, including a budget-holder, who will need to lead from the top and open doors for you to work with staff teams. Talk to them about organisational aspirations around patient involvement, patient experience and multidisciplinary working, as this project will deliver across these agendas. Work with the senior leaders to identify the areas of focus. Try to pick an area in which staff members already recognise that change is needed, but that is not in such disarray that the challenges will be impossible to overcome. (For more guidance on how to approach this, see example presentation to senior staff)

Approach the staff within the service by talking to individuals to find out what motivates them, remembering that a team is not always a cohesive unit. Focus on 'what's in it for them'. If they see the project as threatening or time-consuming, this is the time to tackle these issues head on. They may worry about being criticised or exposed, or feel that patient demands could be unrealistic. Explain to staff that this positive approach can reveal a surprising level of commonality between staff and patients. Tap into their aspirations, their desire to be patient-centred and their need for inspiration.

Key points

- You may wish to find a catchy project title and publicise your project by displaying posters, sending out invitations, giving presentations and meeting individuals, as well as identifying influential team players who will enthuse their colleagues.
- Use the sample presentations in the NHS Institute for Innovation and Improvement's EBD Approach material along with information and case studies from other projects, to show how similar services have benefited from the approach.
- Emphasise that experience-based co-design (EBCD) is a cutting-edge approach to addressing the quality agenda that will enhance both individual professionalism and departmental reputation.
- Demonstrate that EBCD is an innovative and cost-effective approach and generates patient stories that can be used extensively in service improvement, training and external communications.
- Explain that because this approach is qualitative, not quantitative, it provides rich insights into the experience of patients. By filming the stories of people's experiences, and then bringing staff and patients together to prioritise areas for improvement and define key actions, it becomes extremely focused and leads to clearly demonstrable results. There is a body of evidence to prove the effectiveness of the approach (see our evidence for experience-based co-design).

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- Keep objectives broad, such as 'to improve the quality and experience of services', as the specific focus will arise only during the course of the project.
- Make it clear that although this is a positive experience, teams must be prepared to accept the challenge of constructive criticism and rethink existing ways of working.
- EBCD does not have to be a stand-alone project: in fact, it is better if it is integrated with other work within the organisation – for example, as part of a wider strategy of quality improvement or patient involvement
- Allow people to choose whether or not to join up. If individuals are forced to take part, they will not have the enthusiasm you need for the project to work. Not everybody involved in the service has to take part, but as some of the areas for change may relate to areas for which senior managers are responsible, it is extremely valuable to have them on boar

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4. Developing your project plan

At this point, you need to develop a detailed plan to take you through the project step by step.

4 EBCD: Developing your project plan for experience-based co-design

As the project facilitator, your job is to set the timeline and make sure everything runs on track. You need to make sure clinical staff and others are involved at the right level, so that individuals do not get too bogged down in the detail. You might be a project worker, or this project might form one element of your day job. Either way, you will need protected time to oversee and direct the filming and editing of staff and patient interviews. For more information about time required, see the sample project timeline. It is important that in your usual role or day job you do not work directly alongside staff taking part in the project, as you need to be objective – particularly when it comes to interviewing and observation.

An important task is to clarify the roles of those involved in the project. You need a key senior person who is really enthusiastic and influential to agree to lead and be accountable for this piece of work. You may need to turn to them when improvement ideas touch on areas outside the responsibility of the staff who are participating in the project. You must also develop a project working group, which will involve key members of staff from the service and their management team, so that you do not overload clinical staff with details of project organisation.

Key points

- Follow good project management principles – particularly in engaging stakeholders. For detailed advice on how to run a project, see the NHS Institute project management guide.
- When working out the project timescales, think about how well the patients are. If you're working with patients who are likely to be unwell, you may need a shorter timeline. To give you an idea of a realistic timeline for a project, see the example project timeline. For more flexible approaches, and other ways of managing the project, see section 15: Adapting the approach to your budget.
- For any staff event, agree dates well in advance, at a time when people tend to be able to meet. For the staff feedback event, allow at least two hours, and for the joint patient-staff event, at least three hours.
- In our experience, the ideal amount of notice to give patients was two weeks. Any less might mean that fewer people are able to attend – but any more can also lead to reduced attendance, as other plans take precedence.
- Book the venues well in advance. Make sure you have thought through arrangements for food, accessibility, transport and clear signposting. Try to achieve an atmosphere that is not too formal or clinical but that is sufficiently professional for staff to take it seriously.
- Offer travel expenses, refreshments and a small payment to thank the patient for their time and effort.
- Plan the co-design groups at a regular time, so people can plan around them.

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- Because experience-based co-design is a service-improvement approach, you do not need to seek research ethics approval. However, it is advisable to notify your local research ethics committee and follow your organisation's clinical governance and information governance procedures particularly regarding patient confidentiality and informed consent. (For more information, see the Department of Health Confidentiality Code of Practice and the Royal College of Nursing's informed consent in health and social care research).
- If you are involving external people in undertaking some of the work with you – for example, the interviews – you may need to meet internal policies in the NHS, such as setting up honorary contracts through local R&D departments. These are likely to require Criminal Records Bureau (CRB) checks, which can take 6-12 weeks. Make sure you have enough time for these to be processed.

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5. Carrying out observations

Once you receive the go-ahead for the project, your first activity is likely to be observation. This involves spending time within the service watching how the teams and systems operate on the ground.

5 EBCD: Carrying out observations in experience-based co-design

This stage involves noting what you see and thinking about how you respond to it, focusing on anything that seems impressive, unusual, surprising, confusing or worrying. Try to imagine you are a patient, or are seeing the service through fresh eyes as a visitor to that area. For example, in one clinic observers noted that patients who arrived early in the morning had to sit in the dark until the receptionists arrived and turned the lights on. Patients will often not mention this sort of detail, even though it may have a major effect on their experience of care. It is helpful for this stage to be carried out by the project facilitator and other colleagues, if possible. Outside observers can play a helpful role in exploring patients' experience.

Observation provides valuable insights into how the service works and what patient and staff perspectives might be. These can be especially helpful in suggesting prompts for the later interview stage. It is also a valuable way of building up trust with the staff team, as it demonstrates your commitment to and interest in the service. It is an important stage, but very flexible. Depending on resources, you may spend three hours observing one clinic or service, or several days visiting different activities at a range of sites. You will report your findings back to staff at the staff event.

Key points

- Pick particular aspects of the service that are practical to observe. For example, it will be easier to access a clinic waiting area than a one-to-one consultation.
- When you arrive, introduce yourself to the person in charge – you will hopefully have met them while you were making the case to staff. You should also bring along documentation showing that you have permission to observe, in case staff on the day are unaware of the project. (See consent form for observation template).
- Do not feel you need to be invisible – explain to people why you are there, and consider bringing along leaflets or business cards to distribute. It is important to reassure staff that you are not there to judge, but to understand the service. Clearly explain the purpose of the observation, and make sure everyone feels comfortable.
- Be friendly and open, ask questions, look at verbal and non-verbal communication, notice the way people use space, look at the way in which the services change depending on the stage of the patient pathway. Try to notice anything that seems curious or that seems to make people feel uncomfortable, and question it.
- Plan the timing around what is feasible. Is there anything happening on particular days? Try to cause minimal disruption – for example, do not observe during a ward round.
- Before you begin your observation, go to the areas you plan to observe and familiarise yourself with the service. Find out where people do which things, where you can sit,

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and so on. It is helpful if staff can show you round the area so you can understand the patient pathway.

- Use the opportunity to talk to patients, to approach staff who have been hard to contact, and even to recruit staff or patients into the project. However, approach this sensitively, and run any names past the clinical lead before confirming.
- If you are observing consultations, seek consent from everyone involved. (See consent form for observation template).
- If you are working alongside a colleague, do not discuss anything you see in your observations until you are away from the area. Remember to respect staff and patient confidentiality. Ideally, try to report information back anonymously, although this can be challenging with small groups of people.
- If the interviews raise additional issues that you would like to see working in practice, consider carrying out more observations later in the project.
- This is a very flexible part of the project. For example, if you have only half a day available, choose busy times when you are most likely to see points of interest relating to patients' experience. If you have longer, you could spend much more time observing, but do not overstretch yourself, as you will need to write up all your notes so you can refer back to them later in the process.
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- If the interviews raise additional issues that you would like to see working in practice, consider carrying out more observations later in the project.
- This is a very flexible part of the project. For example, if you have only half a day available, choose busy times when you are most likely to see points of interest relating to patients' experience. If you have longer, you could spend much more time observing, but do not overstretch yourself, as you will need to write up all your notes so you can refer back to them later in the process.
- Further tips on how to carry out observations can be found in The Point of Care – Hospital Pathways Programme: Observation Guide.

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6. Engaging and interviewing staff

Encouraging staff to get involved is all about winning hearts and minds by presenting compelling arguments, identifying influential colleagues, and carrying out sensitive interviewing.

6 EBCD: Engaging and interviewing staff in experience-based co-design

Once you have buy-in from senior leaders, the next task is to get everyone in the clinical team engaged. People may be suspicious about the agenda, uncomfortable about criticising their workplace or worried about receiving criticism from patients. You need to address these fears and build up trust. You then need to present the project clearly to the entire group, explaining what the project is for, how it will benefit staff and patients, and what sort of commitment is required, to allay any fears. (See example presentation to staff).

The staff you interview may work in various teams across the patient pathway, rather than within one particular team. Ask your key contact for insights into who to interview (in other words, those staff best able to give an informed view of different aspects of the service), and to provide introductions, in order to 'open doors'. Make sure the interviewees are drawn from roles across the entire patient pathway, giving a diversity of views and roles. Once you have selected people, you may need to contact potential participants several times to finalise appointments. People often feel more able to be completely honest and open in one-to-one interviews – preferably face-to-face, but otherwise by phone. Informal, impromptu interviews can be useful for catching key people who are particularly busy.

Key points

- Enlist key support from an influential member of the team (not necessarily the most senior) and from those who commissioned the work in the first place, to explain the reasons for undertaking the project.
- Make sure the project is genuinely participative, and not something that is being 'done to' the staff.
- Make sure everyone has all the information they need, so that no one can claim not to have known about it.
- Explain that the process does not imply anything negative about the service – but that there is always room for improvement. The approach ensures that staff members genuinely get a say in how their service should be improved.
- Staff often find it easier if interviews take place after the researchers have observed the workplace and gained initial insights. Some need encouragement to explore their own needs as well as those of the patients.
- When staff are pressed for time, help them focus on what they feel are the most important issues. Sending through the interview questions in advance will give them time to prepare. (See example script and interview schedule for staff interviews).

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- In our project, even those who were reluctant to be interviewed felt that it had been a valuable use of their time, and often described it as cathartic. People fed back that it was very good to feel listened to, and to think that things might change as a result.

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7. Recruiting patients

This stage involves identifying suitable patients to contact, and inviting them to participate. This process is extremely important, as patient involvement is an essential ingredient in ensuring successful change.

7 EBCD: Recruiting patients for experience-based co-design

The first step is to find one or more key staff members who will work with their colleagues to identify about 5-15 patients. The staff member should have an overview of the range of steps within the clinical pathway – for example, a clinical nurse specialist, a case manager or someone with a pathway coordination role. They will need to find individuals who have a story to tell and who are likely to identify both positive and negative experiences. If the patients offer only positive feedback, they will not be able to contribute to the key aim: to improve services (although positive experiences can provide useful insights too). They will also need to know if the patient is well enough to participate and if there are any clinical reasons why someone should not be invited to take part.

Having identified the potential participants, the project facilitator or a staff member will phone the patients, explain the project, and draw up a list of those who are interested in taking part, before sending through follow-up information and consent forms (see invitation to take part template and consent form for filming of patients template). All participants must agree to being interviewed. Most are filmed, although this is optional. They will also be invited to join in the events and the co-design groups. We found that about two-thirds of our patient participants came to the events. About half of those interviewed eventually became involved in the working groups. All patients should receive project updates at key stages throughout the project.

Key points

- Identify patients who have been through different aspects of the service, and who are beyond the critical point of their treatment, so that they can reflect on their experience.
- Try to include a range of people – not only determined by age, gender and ethnicity, but also in terms of the treatment types and services experienced. Make sure participants' experience of the service has been quite recent, so that the aspects of the service that they report are still current.
- Try to avoid going to 'the usual suspects', as this is a valuable opportunity to gather some fresh thoughts. If you recruit patients involved in patient support groups, explain carefully that in this project they will need to focus on aspects of service delivery that could lead to improvements.
- Do not worry about finding the 'perfect patient sample'. This is a qualitative approach, focusing on the views of only a small number of people, so it is not intended to represent every detail about the service.

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- The project facilitator may need to assertively support the staff who are identifying patients, as this is not necessarily a task that reaches the top of the to-do list for busy clinical staff.
- Begin recruitment early on, as it can take some time.
- Other ways of recruiting patients include sending invitations to randomly selected patients, putting up posters and leaflets so that patients can find out about the project, or contacting local patient groups or voluntary agencies who might help you find people with relevant experience.
- If patients within your service are likely to be unwell, you may experience high drop-out rates during the project, as the interviews and subsequent participation may be too demanding. You may need to recruit more participants later in the process.

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8. Interviewing and filming patients

This stage involves creating a comfortable environment for patients to share their stories of services, and capturing those stories effectively, to provide rich information that will guide improvement.

8 EBCD - Interviewing and filming patients for experience-based co-design

The interviews take place within a couple of weeks of the recruitment process, in a location where the patient feels comfortable. This may be at a hospital, community centre or in their home. Beforehand, send out notes to help them prepare (see example patient interview schedule. When they arrive, welcome them, help them feel comfortable, and take time to develop a rapport. Make sure there are comfy seats, refreshments, tissues, and plenty of privacy. Patients will be asked to consent to the clips that will go into the final version, so encourage them to be completely open at this stage.

The interview itself usually takes between one and two hours. Each individual film is then edited down for the final compilation film, which is half an hour long, divided between 11-12 interviewees. Try to let people tell their story in their own way, but prepare a list of questions for any interviewees who need more structure. While you're listening, make a note of comments that require clarification or more detail. The interview also forms the start of the editing process, as the interviewer may also be involved in editing the film. So, as the patient is talking, listen out for key points and 'touch points' – themes that particularly resonate, and that may have also arisen in interviews with other people.

Key points

- Realistically, you can conduct only two, or at most three, interviews in a day. Bear in mind that patients may have to cancel at short notice – for example, due to sickness. Be aware that it can be emotionally draining for the interviewer as well as the interviewee. Always check on the day of the interview that the agreed time is still convenient for the patient.
- Let the patient decide where the interview will take place. This is very important as the aim is to make the patient as comfortable as possible. Factor in the time that the interviewer will need to take to travel to and set up each interview. If you are travelling to a patient's house, inform a colleague of your planned movements. (For more guidance on personal safety issues see the Suzy Lamplugh Trust website).
- If people are travelling to the venue, offer to pay their travel expenses, and make sure they are clear about directions and travel arrangements. You may also decide to give people vouchers or payment for their time.
- As the video is single-shot footage, showing only the person's head, it may be possible for only one team member to film while interviewing using a tripod. If the interviewer is not confident with the technology this could be a distraction, so make sure they spend some time practising and preparing. If a separate cameraperson is involved in the process, ask them to stand some distance from the interview so that it is less intrusive.

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- It is a good idea for the person doing the filming to have training in filming skills so that they can get the angle, framing and lighting right. (For more information see the guide to filming interviews).
- The interviewer does not need formal training, but must be empathetic, sensitive, non-judgemental, and able to inspire trust. They also need good knowledge of the patient pathway so they can re-order events into the correct chronological order where necessary when editing.
- Throughout the interview, remember that the patient is being filmed, so do not interrupt them. The more the interviewer speaks, the harder it is to edit a clear message from the patient, so try not to make encouraging noises, and remember to turn off all phones. If there are animals or children in the room or some other noise interruption, you may need to ask the patient to repeat themselves.
- Respect patient and staff privacy and confidentiality, and ask patients to try not to use names of staff when describing services. Anything that slips through will be anonymised through the editing process.
- Patients may be nervous before the interview and distressed afterwards. Invite them to bring along a friend, family member or carer for moral support, and schedule in time beforehand and afterwards for a supportive debrief.
- Arrange psychosocial support from within the clinical team or from outside services in case issues are raised that require the patient to have some support. Examples might include a patient-support phone line or staff within the clinical team. The interviewer should also have adequate support too – for example, the opportunity to debrief with a colleague.
- For more information on interviewing patients, see the interview guide.

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9. Editing the film

By this stage you should have a wealth of information, but in order to communicate the salient points you need to reduce it to a manageable length and highlight the key issues.

9 EBCD: Editing the experience-based co-design film

This step involves watching all 11-12 unedited films of the patient interviews – either with another person or alone – to get an overview of what has been said. You then need to pick out the key 'touch points' – themes that particularly resonate, and that may have also arisen in a number of interviews – within each interview and edit each film down to a length of about 10 minutes. The next step is to identify key themes (such as 'getting your diagnosis' or 'moving through the service') and divide up clips into those themes, interweaving the various patients' quotes with each other. The final video will show a title screen for each theme, such as 'Outpatients', followed by views from a number of different patients on that topic.

You will need professional editing equipment and software to carry this out. You will benefit from involving a professional editing team, but you may want to involve them only after you have reduced the footage to 10 minutes per speaker, to keep costs down. The final stage involves reducing the 10 minutes per speaker to a final 30-minute video. A professional editor can help you make sure the footage flows and moves seamlessly from one speaker to the next, grouped by theme.

Key points

- This is the most labour-intensive part of the process – especially if you are unfamiliar with the software. Editing down an interview into a ten-minute video could take a whole day, though you are likely to speed up over time.
- The final video will usually present experiences following the clinical pathway chronologically, so themes might include: outpatients, surgery, follow-up appointments.
- If you are doing the editing yourself, transfer each interview to a DVD with a counter, so that you can accurately edit the films. Then break down the films into themes. Examples of themes you might want to use include: receiving the diagnosis; moving through the service; being an inpatient; receiving treatment (eg, chemotherapy); understanding what's happening; and receiving support. Go through the film frame by frame, noting down times to stop and reduce the film (see the video log sheet template for how to do this). You may need to be quite bold about editing the video down substantially at this stage.
- Your in-house photography department might have the skills to do the editing, or your communications department might be able to advise you of companies they have used before. There are lots of freelancers and companies that specialise in this type of work and it should be straightforward to find someone who can help you.
- Brief the editors clearly to balance out negative comments with positive ones. They also need to focus on stories that constructively explain things that need improving at clearly identifiable stages of the patient pathway.
- Your priority must be to include high-quality material, and it is important to include some quotes from everyone who was interviewed.

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- As with the patients and interviewers, offer psychosocial support to the editors, as they may be affected by the footage they will be working on.
- Give patients the final veto on what is included in the edited film. Ideally, send them a DVD with all their quotes that you would like to include. Do not send them the edited film, as this would betray the confidentiality of other patients. Alternatively, send them the unedited film of themselves, ask if there are any sections they would prefer not included, and make sure these are not used. Allow time for patients to receive and comment on these materials well before the patient feedback event.

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10. Running the staff feedback event

This event aims to enable staff to highlight their priorities for improvements within their service. It is also a key opportunity to show staff that the project seeks to form a genuine partnership between staff and patients.

10 EBCD: Running a staff feedback event in experience-based co-design

The staff feedback event is a facilitated meeting that brings members of the service team together to discuss and share their views about the service. The meeting, which usually lasts between two and three hours, follows a clear agenda. (See staff feedback event agenda template?. The project facilitator opens by explaining the purpose of the meeting. Then, findings of the interviews and observations are fed back to the group (including lots of direct quotes from staff), and the facilitator seeks staff feedback and discussion about these views.

Following the discussions, the facilitator supports the group to identify issues needing service improvement and then to narrow this long list down to four or five key areas that could be taken forward through the experience-based co-design groups. These are then added to the priorities highlighted in the patient feedback event to produce the final list, which will be discussed at the joint patient-staff event.

Key points

- Encourage as many people as possible to attend, however much or little contact they have had with the project to date. Arrange it at a time and place that makes it easy for people to attend – probably a venue within the service. Provide lunch or refreshments and make sure they are invited by an influential member of the team.
- Help people to interact by seating them at one large, or several smaller, tables or circles (depending on the numbers) and starting the event with an icebreaker (for examples of icebreakers see the**Mind Tools website**). Facilitate sensitively to ensure that the more senior or confident members do not dominate the discussions.
- The findings must be fed back by someone who works in and leads the service, to demonstrate ownership of the project. The speaker must be well briefed, familiar with the content, and adept at inspiring commitment and discussion among the audience. (See example staff feedback presentation).
- Pick a method for helping staff select the service they wish to prioritise for improvement. Staff could vote by raising their hand, or you could try writing each issue on a piece of paper, stick them on the wall, and ask staff to physically move the pieces of paper around into their preferred order. (More information on voting techniques is available on the **Creating Minds website**).
- Help staff to identify those issues that could be worked on effectively alongside patients. For example, a review of the skill mix of staff would be less appropriate than work to speed up the process by which patients receive results.
- When seeking interview feedback from staff, ask for their views on the positive and negative perceptions of working in the service/experiencing the service as a patient. Ask what they think are the priorities for improving staff and patients' experience of the service. Take observational notes and quotes during the feedback session.

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- There may be some issues that are not suitable for the staff–patient group but that the team may want to address as a separate process – for example, complaints about how the management team communicates with the staff team. These will need to be addressed or parked, to ensure that discussion moves on to other issues.
- To learn what went well and what could be improved in this event seek feedback from the attendees. (See example staff feedback form).

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11. Running the patient feedback event

This event marks the point at which patient participants come together for the first time. They watch the edited film and discuss what they think are the key priorities for service improvement.

11 EBCD: Running a patient feedback event in experience-based co-design

The patient feedback event is a facilitated meeting that invites patients who have already been interviewed as part of the project to develop their collective feedback about the service. (See invitation to take part template). Bringing the patients together as a group builds their confidence about speaking in a meeting environment before they meet with the staff, and helps them see that they are not just speaking for themselves but for a wider group of patients. The project facilitator introduces the event and explains the project as a whole, setting out the agenda for the day. (See patient feedback event agenda template).

After the patient film is shown, the facilitator gently encourages the patients to talk about their response to the footage and then runs an emotional mapping exercise to help participants highlight key points of the patient journey that they feel could have been managed better (see guide to facilitating the Emotional Mapping exercise). Examples have included 'having day surgery', broken into the specific elements of 'being separated from friends and family' and 'waiting for the operation'. The feedback is then narrowed down to a shortlist of potential areas for service improvement, which will be raised at the joint patient–staff event. If you have time at the end, ask patients in small groups to use the design template to start thinking about what the ideal solutions might look like. (See design template).

Key points

- Many patients are apprehensive about this event, so it is important that they are welcomed by a familiar face and are invited to bring a friend, family member or carer for support if they wish. A relaxed environment, with food and refreshments, is critical. The whole event needs to be very relaxed, with an atmosphere of trust, respect and privilege in hearing people's stories.
- Everyone who was interviewed is invited to the event. Not all will attend, but you need at least four or five participants to get a sense of collective feedback.
- The structured nature of the event can help patients distance themselves from distressing personal experiences, by shifting their focus from their personal experience to finding practical solutions.
- Make sure you have contact details to hand in case patients have questions about aspects of their clinical care or need to access psychological services as a result of participating in the project. Members of the clinical services team would not usually be present at the event. This is to encourage patients to comfortably discuss their honest thoughts about the service between themselves.
- Some participants will be nervous about talking in groups. Use an icebreaker that encourages everyone – including the facilitator – to share information with the group. (For examples of icebreakers see the **Mind Tools website**). Manage dominant group members with care. For example, if someone is dominating the discussion, take them to

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one side at a break and gently ask them to help ensure that other quieter members of the group have a chance to contribute.

- The event requires co-ordination in three areas – logistics, such as refreshments and timekeeping; ensuring that the day's aims are met; and supporting the participants. If possible put in place several different facilitators with clear areas of focus and responsibility.
- Remember that some patient participants might not be able to read or write. The most important thing is that their voices are heard, so use creative approaches to sharing information and ideas, such as asking facilitators to read things out and write down what participants are saying.
- Choose a convenient venue where people feel comfortable. If there is a suitable room in the hospital (with a big enough wall for the emotional mapping exercise) this may feel more relaxed than a smart conference venue. Wherever you choose, the key is to create a warm, welcoming environment that is easily accessible for the participants.
- Again, provide patient participants with travel expenses and a contribution for their time. And find out how the event went by asking participants for feedback. (See example patient feed

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12. Running the joint patient-staff event

This event brings together the patients and staff to hear each others' perspectives on the service and identify the key priorities to tackle together to make improvements.

12 EBCD: Running the joint patient-staff event

This event follows on from the separate feedback events for staff and patients. The proceedings open with a welcome, followed by an overview of the process so far and an explanation of the structure of the event. (See joint patient-staff event agenda template and example joint patient-staff event presentation).

The whole group then watches the patient film, and the group spends 10 minutes discussing the footage. The staff and patient priorities that were agreed at the separate events are shared so that all participants can see the priorities discussed.

After a break, the facilitator ensures that participants are evenly spread into groups of eight or so per table, with a good mix of staff and at least two patients at each table. The participants introduce themselves to the others around the table. There are then 40-50 minutes of unstructured discussion to analyse the long list of issues highlighted at the previous meetings, and to highlight priority areas for work.

After this, the facilitator brings the whole group back together to share those priorities and to jointly narrow the choice down to three or four key target areas for service improvement. Finally, participants are invited to join the co-design group that will focus on the area of most interest to them.

Key points

- The event lasts between two and three hours, and can work well in the afternoon, with lunch provided beforehand to encourage people to arrive on time.
- Patients may be quite nervous about attending, so it is very important that you welcome them attentively. Giving everybody a sticker or badge showing their first name can help patients and staff at all levels to feel more equal.
- Check and double-check your audio-visual equipment. The success of the event depends on the film running smoothly.
- If you can encourage a patient to introduce the film, this will give it much more impact, but do offer support and reassurance when they are planning what to say.
- Where possible, arrange for someone to facilitate each small-group discussion. They can help ensure that everyone has a say.
- The discussion at each table is likely to focus on responses to the film. Allow enough time for people to do this meaningfully, and then make sure that the discussion is brought back to prioritising areas for improvement.
- Although it can be tough for staff to watch frank feedback about their service, viewing the film together and then discussing it is often a moving, powerful and very positive part of the process. If the film raises some very sensitive issues about individual staff members or service performance, you may want to show it to certain staff beforehand.

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- As soon as participants have selected their co-design groups, discuss what time of the week it would suit everyone to meet, plan a date for the first meeting, and gather contact details. Ask staff if any other colleagues should be involved.
- Make sure you get the groups going quickly, and keep in touch with people, so that the momentum does not fizzle out.
- Once word gets out about the patient film, many people will want to see it. Make sure you have robust processes for enabling people to see the film in appropriate contexts that those involved in the service are in agreement with and in line with what was agreed with patients through the consent process.
- It is again valuable for your own reflection and learning to get feedback on this event from the people who attended. (See example joint patient-staff feedback form).

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13. Running the co-design groups

Co-design groups are small working groups of patients and staff designing and implementing solutions to the priority issues highlighted at the joint patient-staff event.

13 EBCD: Running the co-design groups

By now you will have several groups in place made up of patients and staff – usually, one group for each priority area for service improvement. Each group needs to meet sufficiently often to maintain the momentum, but with enough time for outcomes to be achieved in between (for example, fortnightly, moving to monthly, for about six months). The meetings are very practical. An agenda can provide structure – first, identifying a realistic and achievable focus, then asking what needs doing, by whom and by when. (See co-design group meeting agenda template)

Someone must be identified to facilitate and organise each group. This person needs to be present to encourage discussion, help the group develop ideas into concrete actions, and ensure that those actions are followed up. In experience-based co-design, this role goes beyond usual service improvement facilitation. This is because neither patients nor staff are accustomed to working alongside each other, so they may need particular help to overcome barriers, such as brief training in service-improvement techniques. This means the facilitator may need to encourage particularly dominant participants to listen, and enable others (often patients) to speak up.

Key points

- If numbers are low by this stage, you might need to recruit some new participants. These could include staff and patients who were unable to attend the joint patient-staff event, and key staff who are able and committed to taking actions to improve the service. If you need to, you can also recruit patients from existing patient groups.
- If the group gets 'stuck' on criticising the existing system, try using visual aids or other creativity tools to encourage them to reframe those thoughts into positive solutions. (More information about creativity tools is available on the **NHS Institute for Innovation and Improvement website**)
- Meeting notes in the form of ‘next steps’ can make it clear who is going to do what. (See co-design group notes template)
- To make the most of the unique features of experience-based co-design, you need to keep involving the patients throughout the process and asking ‘Is this what you had in mind? Does this work in the way you envisaged?’ and then fine-tuning the solutions accordingly.
- Be aware of areas of sensitivity – for example, a patient may have had a negative experience of a particular staff member, or may associate a part of the hospital or a process with a traumatic life event.
- Some patients may not be familiar with the conventions of workplace meetings, so set out expectations clearly – for example, if they need to bring any documents with them. Make it clear what refreshments will be provided and that travel expenses will be reimbursed.

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- Encourage involvement from everyone through the meetings, so that everybody has space to contribute. Make sure as many patients can attend as possible, so that you get a range of views.
- Make sure you talk to facilitators of other groups in between meetings, in case there is any overlap.
- For examples of the discussions and actions from our co-design groups see examples of what co-design groups achieved.

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14. Reporting, evaluating and celebrating success

The process of experience-based co-design (EBCD) is exciting and inspiring, but it is important not to lose sight of its key objective: to improve services. This stage involves gathering data and communicating outcomes to others, to demonstrate the value of the project.

14 EBCD: Reporting, evaluating and celebrating success

During the course of the project, you will often be asked the question 'What has the project achieved so far?' Every time you discuss the project, it is important to highlight the 'return on investment' – what the project has accomplished to date. You can measure your achievements against two sets of goals: the delivery of the objectives set by the co-design groups, which will focus on the service changes; and project objectives, such as how many people have turned up regularly.

Because EBCD draws on qualitative data, the types of service improvements that result may not be measurable through typical approaches such as audit, but they are still measurable. One type of evaluation is simply to list all the improvements suggested by patients and staff, and to detail which of these have been achieved to date. Many of the improvements will be simple, small-scale adjustments that may not seem much to others, but patients have identified these as making a big difference to their experience of the service. So when considering which elements to measure, think about what participants have highlighted as being important, and focus on those.

Finally you need to celebrate the successes that have been achieved through the project. EBCD requires emotional investment from staff and patients alike. Holding a celebratory event for everyone involved six to nine months after the joint patient–staff event is a simple but important way of thanking participants, reporting back on what has been achieved, and providing a clear ending point to this part of the project. This may also act as a catalyst for future projects.

Key points

- Every time you talk to the person who commissioned the project or your colleagues or project participants, offer them clear facts about how the project is progressing and what it has achieved so far.
- Have a handy presentation or document ready that you can adapt for different purposes, including a couple of strong stories with ‘before-and-after’ evidence of improvements. (See example co-design achievements presentation).
- Keep track of all the service improvements and achievements throughout the course of the project, generating a list of the actions that resulted directly from co-design groups.
- Also mention the links with any other service improvement projects that were already in progress at the start of the EBCD project and were touched on during project discussions. However, make sure you do not appear to take credit for these.

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- Try to demonstrate the wider impacts of being involved in the experience and watching the film. This is easiest to do through qualitative feedback. For example, regularly ask for comments on feedback forms and include quotes in your presentations and literature.
- Where possible, highlight any tangible, measurable changes, citing before-and-after figures. If any changes have a secondary benefit of cutting costs (for example, streamlining processes to avoid duplication of tasks), include those costs where possible.
- Accept any opportunities to talk about the project within wider forums – for example, at internal meetings, or wider networking events or seminars – again providing clear evidence of outcomes.
- Work with your communications department and relevant service-user forums to publicise the project in key groups, newsletters or other media (internal and external). EBCD can also be powerful when bidding for new tenders, so make sure your business development teams are aware of your work.
- If you show film clips, be careful not to break confidentiality. If the film clip shows negative feedback, make sure you balance this out by explaining what has been done to resolve the situation.
- Make the celebration event as informal as possible. Ask someone to give a short talk to summarise the project and to thank everyone involved, remembering that some participants may have been involved at intermittent points during the project. Use this opportunity to collate everything that has been achieved into one document. (See example celebration event presentation).
- At the celebration event, make sure everyone feels comfortable. Assign people the role of facilitating informal chats, to help less confident guests circulate. Putting up posters showing project achievements provides a useful focal point to help guests break the ice.
- In some cases patient groups have remained involved in improvements, so the project has sparked off an ongoing process.

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15. Adapting the approach to your budget

If you are keen to carry out experience-based co-design (EBCD) but are concerned about the resources required, this section explains which components are essential and which could be adapted.

15 EBCD: Adapting the approach to your budget

EBCD is not an approach that you need to stick to rigidly, so do not feel constrained by the methodology. However, it is valuable to adhere to the central elements of the approach – the patient interviews and interaction between the patients and staff – as these are the elements that identify problems and develop the solutions. Even so, it is possible to work around these either to create a pared-down version of EBCD, or to run a separate process that does not claim to be EBCD but that draws on elements of the approach.

The most resource-intensive stages of the process are interviewing and filming the patients and then editing the interviews. However, these form the crux of the approach: without the edited film of patient interviews, the approach could not be considered true experience-based co-design. The film is a very powerful tool that establishes priorities, motivates staff, and gives patients a voice. It enables patients to be their own messengers rather than having others talk on their behalf. On film, patients often talk more honestly than they might otherwise.

Key points

- The costs of your project will depend on which of the elements you include. For example, a recent project that used in-house editors, borrowed videoing equipment and was resourced entirely by existing staff only had to pay for the editor's time, refreshments and expenses for patients. Meanwhile, another project that used experienced researchers from another organisation cost substantially more. The value of the potential benefits should always be weighed against any costs.
- The observation stage adds value to the project, but is not essential. However, it is a cost-effective way of adding valuable insights, and can provide a useful opportunity for recruiting participants.
- You could save money by avoiding using external consultants in the interviewing and filming stages. Perhaps someone within your organisation has these skills, or is keen to learn.
- It is important that staff voices are heard, but this does not have to be through one-to-one interviews. For example, it could be done through a staff focus group event instead.
- The co-design groups form a crucial, and relatively cost-effective, part of the EBCD process. The cost is moderate, and avoids making changes that do not quite 'hit the mark'. However, if you wanted a pared-down approach and had already identified one issue, you could set up just one co-design group to focus on that particular topic.
- If it is difficult to run several parallel co-design groups, you might choose to have one patient reference group that meets regularly, with whom staff could regularly consult on progress. Make sure the patient voice is not lost in the process.
- The key to getting a return on your investment is to make sure you have buy-in from staff early on in the process, so the changes that participants identify will actually be

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driven forward. This means that however much money, time and emotional effort is invested, it will result in positive change.

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The following guide for a successful patient and/or carer interview draws on 'best practice' guidelines from a number of sources:

- NHS Modernisation Agency (2004). *Learning From Patients and Carer Experience: A guide for using discovery interviews to improve care*. Leicester: NHS Modernisation Agency.
- Bate, SP and Robert G (2007). *Bringing User Experience to Health Care Improvement: The concepts, methods and practices of experience-based design*. Oxford: Radcliffe Publishing.
- Heyl B (2001). 'Ethnographic interviewing' in Atkinson P, Coffey A, Delamont S, Lofland J, Lofland LH (eds), *Handbook of Ethnography*. London: Sage.
- Chantler P and Stewart P (2003). 'How to win friends and interview people' in *Basic Radio Journalism*. Oxford: Focal Press.

Further, more detailed, advice and guidance can be found in these publications.

Before you start

Preparations

The initial approach to a patient or carer inviting them to participate is best made by face-to-face contact. Ideally, the invitation should be made by a member of staff who is known to the patient or carer, and involved with the wider project so that they can answer any immediate questions or queries that may arise.

A follow-up letter should be sent to the patient or carer soon after this invitation enclosing a detailed information sheet describing the purpose of the interview as well as the project of which the interviews are a part.

Interviewing can take place anywhere the patient or carer requests – the workplace, the home, the place where the experience is taking or has taken place – the best guide being to take the project out to wherever people are using or contemplating using the service. If the interview is being tape-recorded or filmed then consideration will need to be given to the environment (for example, likely noise, interruptions, lighting) in which the interview will take place.

It should be made clear that partners or carers of patients are very welcome to be present at – and participate in – the interview, if the patient would like them to do so.2

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Briefing patients/carers

Before starting, the purpose of the interview should be reiterated to the interviewee (based on the written information previously provided).

Confirming consent

Explain to the interviewee they can withdraw, either before, or during the interview, if they wish. They also need to know there is no compunction to answer any questions they feel uncomfortable with. Make sure that you have obtained a signed consent form before the interview begins.

Recording the interviews

Make sure the recorder is positioned in the best place to record the interviewee's voice even if it appears to be prominent. Its presence is quite quickly forgotten as the patient or carer tells their story. Check again that the recorder is working before beginning to record the actual interview. Always carry spare batteries and tapes.

The interview itself

Interviews are first and foremost interaction; a conversation between the researcher and the interviewee in which they explore the experiences of the patient/carer. It is important to remember that the aim of a patient/carer interview is to hear the patient or carer's own story in their own words. This means asking as few questions as possible and making sure those that are asked are open-ended and designed to encourage the patient or carer to keep telling their story. Asking too many questions puts the interviewer in control and reduces the opportunity to hear about what is really important to the person telling the story.

The following general tips should help.

- Develop a real interest in your interviewee; make them feel important and show interest and curiosity about their ideas and opinions.
- Have a chat or a conversation with them; try to think 'story' (chronology) rather than a more formal 'interview' (questions).
- Listen well and respectfully.
- Use open-ended prompts that keep the flow going; think of your task as being to help the patient/carer reconstruct the story of their personal experience.
- Do not keep jumping from one subject to another.
- Encourage the patient/carer with eye contact.
- Use nods of the head to show that you are listening and understanding.

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– Do not say 'yes...' or 'I see...' and other audible means of encouragement we typically use in conversation. Your words will be a real nuisance when the film is played back.

Introductions

Interviewers should introduce themselves and make it clear that they are not part of the clinical team that directly provides or provided the patient's care. The introduction should focus on their role as an interviewer rather than being a representative of the services. The way the interviewer introduces themselves sets the context for the interview and will influence what the patient or carer feels comfortable saying.

Questions

The best and most effective way of eliciting information is to use open-ended questions, such as:

- What do you remember about what happened?
- Can you tell us your story from the beginning?
- Tell me what you know about ...

One opening statement and question that has worked well in previous projects is to say: 'We would prefer you to tell us your story in your own words with as few interruptions from us as possible, but we have some prompts if you would prefer that… So… let's begin at the beginning. Tell us your story in your own words ...'

Responding to feelings and distress that may arise

The well-being of the person being interviewed should always take precedence over the interview itself. Telling their story may arouse feelings that need to be acknowledged and responded to sensitively. When this has happened in the past, interviewees have been happy to carry on with the interview after a short break and have declined the offer of additional help. If the patient or carer becomes too distressed, it may be necessary to finish the interview. The interviewer must be able to provide appropriate contact names and telephone numbers so that the patient or carer can seek further support if they wish.

Ending the interview

When the interviewee has finished telling their story or the agreed duration of the interview has been reached, the interviewer should provide one further opportunity for the interviewee to add anything before thanking them for their time and sharing their experience. It is important that the interviewee is clear about what will happen following the interview and how their story will be used to improve services. As well as informing the patient of these plans at the end of the interview it is good practice to also send a letter detailing how the material will be used and 4

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giving them the opportunity to add to – or correct – the transcript of the interview.
In summary, some key aspects of a successful interview are to:
– describe the purpose of the interview and confirm consent
– refer to the suggested interview prompts (if necessary) but keep questions to a minimum
– use open questions that encourage the interviewee to expand their story when appropriate
– use active listening skills to encourage the interviewee to continue their story
– remain neutral and avoid implying value judgments about what you are hearing
– consider your use of body language and that of the interviewee
– allow silences
– close the interview positively, leaving behind any contact details that the interviewee may need in order to follow up any issues.

[Adapted from NHS Modernisation Agency, 2004

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Script and interview schedule for staff interviews

Thank you for agreeing to take part in this project. The aim is to improve the experiences of both those providing and receiving cancer services within our hospitals. The project is part of a wider programme of work, the goal of which is to enhance the way in which care is delivered. We are using an approach called experience-based co-design (EBCD). This approach provides a unique opportunity for staff and patients to work together in redesigning services in order to improve patient and staff experiences. Today, we wish to understand your experience of delivering the service to patients in order to develop services. With your consent, we would like to tape record the interview but the data gained from the interview will be made anonymous and you will also have the opportunity to review your interview transcript if you wish.

1 Introduction

So let us start with your background and how you came into your role.

- Tell me what your role is
- Which hospital/trust do your patients come from?

2 Staff experiences

- Can you tell me what is it like working in this service?
- What's good about working here?
- Can you give me an example of a positive experience you have had?
- What's not so good about working here?
- Can you give me an example of a negative experience?
- Can you describe a typical day's work in this service?
- What do you think are the main problems with this service from the point of view of staff?
- How does working in this service compare to other places you have worked or are working?
- (*For consultants and clinical nursing specialists working in more than one hospital*) What are the differences between the two hospitals?
- (*If staff talk about politics within the service*) How does this issue impact on the patient experience?

*[Interviewer to summarise list of positive aspects and problems]*2

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3. Perceptions of patient experience

• What do you think it is like being a patient in this service?
• What are your perceptions of the service you are providing to patients?
• Which patient needs are met? Not met?
• What do you think are the major problems faced by patients?
• What could be improved for patients in this service?
• (*For staff seeing patients from more than one hospital*) Do you notice differences in the experiences of patients coming from different hospitals?
• In your opinion, what are the major 'touch points' or critical moments in the patient journey (the things or events that really shaped their overall experience)?
• Overall do you think that you provide the care you would like for yourself and your family?
• Would you be happy if a member of your family was going to be treated here?
• What aspects of the service would you be happy or unhappy with?

4. Improving the service

• What do you see are the main priorities for improving the service from the staff point of view?
• How should things develop?
• What other things do you feel would help to improve your experience and the experience of other staff in this service?
• What do you think patients would identify as things that would help to improve patient experiences?
• In your opinion, where might we begin to improve the patient experience around this service?

[Interviewer to summarise list of priorities]
THANK YOU

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