Patient involvement in Patient Safety: A literature review about European primary care

Helle Max Martin

Jessica Larsen

The Danish Institute for Health Services Research

The Danish Institute for Health Services Research (DSI) is an independent not-for-profit research organisation established by the State, the Danish Regions and the Association of Municipalities in 1975.

DSI aims to provide an improved knowledge base for the work and decisions of the Danish health authorities at local, regional, and national levels. The institute pursues this objective by collecting, examining and disseminating information, conducting research and providing theoretical and practical consulting. The main areas of work include hospitals, primary health care, community health services and the pharmaceutical sector.

Content

Summary

Objective and background

The objective of this review is to identify best practice of patient involvement in patient safety in European primary care. The review is based on indexed literature about Europe, but it also draws on grey literature from significant patient safety institutions in the Western world.

The review questions are:

♦ Which safety risks in primary care can be minimised through patient involvement according to health professionals, patients and their relatives?

♦ Which methods of patient involvement are used for this purpose?

♦ What are the potentials and weaknesses of these methods in relation to patient involvement?

♦ What are the potentials and weaknesses of the methods in relation to patient safety?

The review is part of the activities of the LINNEAUS EURO-PC project. This project aims to increase and strengthen the activities related to patient safety in European primary care and the primary care/secondary care interface. Eight research institutions and patient safety organisations from six European countries participate. The Danish Society for Patient Safety coordinates the work on patient involvement.

Methodology

The indexed literature was generated from a systematic electronic search including scholarly articles in the English and the Nordic languages published in the period from 2006 to 2011. The search for grey literature was carried out on the websites, i.e. publication lists, bibliographies and databases, of large international organisations concerned with patient safety. A free text search was carried out in Google, and reference lists of all included articles were hand-searched.

The selection process was carried out in three stages by the librarian and the authors. We included publications with a specific focus on patient involvement in patient safety in European primary care (the inclusion of grey literature was not region-specific). A total of 13 articles and 9 reports were included.

Description of the included literature

The literature is very heterogeneous and comprises different types of studies with varying objectives and methodological approaches. In sum, there are six literature reviews, three discussion papers, two background papers, two qualitative studies, one survey, one secondary analysis, one mixed methods study, one tip sheet, one reference guide and four reports on various projects and policy processes. Most of the publications are from Europe (primarily the UK), but four of the reports are from Australia and Canada. 10 publications focus specifically on primary care, the remaining 12 also include secondary care. Eight articles had the specific objective of studying patient involvement as a means of improving patient safety. The literature has a focus on general practice and other sites of primary care are poorly represented.

A status of patient involvement in patient safety in European primary care

Safety risks

The articles list a range of safety risks that occur in primary care within the following areas: 1) medication, 2) diagnosis, 3) communication, 4) treatment and care, 5) technology and equipment, 6) organization and administration, and 7) environment.

The above mentioned risks are often interrelated and further compounded by the characteristics of primary care, i.e. interaction across health care disciplines and health care sites and the diversity of the patients. Several patient groups are mentioned as particularly vulnerable, the elderly being the most significant one. Patients with various communications barriers are also mentioned. The knowledge and skills of health care providers can be a compounding factor.

Patient involvement methods

The included literature does not provide information on interventions in which patient involvement methods have been systematically implemented with the purpose of improving patient safety. A number of potential strategies for patient involvement are mentioned. In general, most of these strategies are about 'speaking up' in the case of safety concerns, awareness and knowledge of safety risks, close observation of medication and treatment, coordination of care, contributing to hygienic practices, self-management and compliance.

Although general practitioners may have a positive view of patient involvement, applying patient involvement methods to improve patient safety seem to have less support.

Implications for patient involvement

Little research is done about patients' willingness and ability to adopt patient safety promoting behaviours. The literature in this review points to several factors that determine the extent and character of patient involvement: 1) patient demographics, 2) type of illness and comorbidity, 3) health care professional's attitude and abilities, 4) health care setting, 5) the nature of involvement/health care task, 6) stakes of the proposed outcome, 7) acceptance of new patient role, 8) level of health literacy, 9) level of confidence in own capacities, and 10) type of decision making required.

Specific barriers are old age, lack of education, non-Western background, professional's training and specialisation. Health workers' attitudes are emphasised as crucial for patients' willingness to be involved and to speak up if they have safety concerns.

Implications for patient safety

It is a general observation in several studies that there is only weak evidence on the effectiveness of patient involvement in patient safety in primary care.

Evidence of some effect on patient safety is found in self-management of medication (oral anticoagulants), in simplifying dosing regimens and educating health care workers in patient involvement. Several studies mention patient involvement in the hand hygiene practices but the evidence of its effect on safety is unclear.

Discussion and conclusion

Judging by the number and character of publications included in this search, patient involvement in patient safety in European primary care is quite an understudied topic. Therefore we cannot provide conclusive answers about the strengths and weaknesses of particular patient involvement methods in relation to patient safety in European primary care, neither can we identify a set of best practices.

The literature points to a great need for further interventions and research with a focus on testing the potentials and weaknesses of patient involvement strategies and methods to improve patient safety. The following topics also call for attention: 1) the patient perspective including their ability to translate safety concerns into a willingness to engage in safety and contribute to patient safety in a timely and effective manner, 2) trust and the effect of patient involvement on the patient-provider relationship, 3) the diversity of patients in primary care and their capabilities in relation to patient involvement in safety, and 4) the challenges to a patient safety culture in primary care which encompasses multiple sites, health professions, geographical environments etc.

Not until a solid knowledge base about concrete interventions and topics like the above is available can we discern best practices of patient involvement in patient safety in European primary care.

Introduction

The delivery of health care is known to involve potential safety risks for the patients who are supposed to benefit from medical treatment and care. Since seminal studies from Australia, the US and Europe (1-6) published around the turn of the century reported on the magnitude and extent of harm caused to patients from adverse events, patient safety has received increasing attention among policy makers, health care professionals, and in the research communities.

Patient safety may be defined as "freedom for a patient from unnecessary harm or potential harm associated with healthcare." (7) The work on patient safety has focused on mapping the nature and extent of risk, errors and adverse events and on developing strategies to prevent and handle harm and potential harm. These strategies have mainly aimed at changing and improving work routines for clinical personnel or making organisational change to encourage reporting and learning from adverse events, and has the overall purpose of creating a patient safety culture that forefronts patient safety on the institutional agenda at all times and in all professional settings.

For the most part studies on patient safety and strategies to prevent adverse events in health care have focused on hospitals and the risks of inpatient-care. Gradually, this focus has broadened and today there is an increasing interest in the safety of primary care. For instance, in 2008 WHO argued for a stronger emphasis on primary care in patient safety research because the majority of health care is delivered in primary care facilities rather than in hospitals (8).

Over that last decade the patient has gradually come to play a part in patient safety work and research. This may partly be due to a more general focus on patient centred care but is also a realisation that all actors in health care are needed to contribute to the improvement of patient safety. Patients are keen observers of their own health, treatment and care and are present in all stages of treatment and care. Therefore, their insights and experiences are assumed to be of value for patient safety.

The LINNEAUS-PC collaboration (Learning from InterNational Networks About Errors And Understanding Safety in Primary Care) is an international network of health professionals and researchers that in 1999 identified the need to focus on improving patient safety in primary care. This review is part of the activities that LINNEAUS-PC undertakes in the European Union.

Objective

The objective of this literature review is to identify 'best practice' of patient involvement in patient safety in European primary care. For this purpose the review seeks to answer the following four questions on the basis of the included literature:

♦ Which safety risks in primary care can be minimised through patient involvement according to health professionals, patients and their relatives?

♦ Which methods of patient involvement are used for this purpose?

♦ What are the potentials and weaknesses of these methods in relation to patient involvement?

♦ What are the potentials and weaknesses of the methods in relation to patient safety?

Thus, the review aims to create an overview of the patient involvement interventions and methods that have been applied to a European primary care setting with the purpose of improving patient safety, as well as analyses that may contribute to developing patient involvement in this field.

Background

Serving as background information to the review, this section gives a brief introduction to patient safety in primary health care, patient involvement in patient safety and a description of the activities in the LINNEAUS EURO-PC project.

Patient safety in primary care

Primary care refers to basic medical treatment and care. The professionals in primary care would most often be general practitioners or family physicians, and general practice serves as a first point of consultation for most citizens experiencing a health problem. Services ancillary to medicine, such as dental care, pharmacies, home nursing and elder care are also part of primary care, and patients may opt to see another health care professional first, such as a pharmacist, or in some localities (such as the UK), a nurse. The patients and clients in primary care span all ages and all socioeconomic and geographic origins, and all manner of acute and chronic physical, mental and social health issues, including multiple chronic diseases.

Primary care plays a key role in diagnosing and treating acute illness, and taking care of on-going treatment and management of chronic disease as well as general health promotion and disease prevention, referring patients to relevant secondary or specialist care and thereby integrating their care with the rest of the health system. In the UK alone a literature review estimates that one million people visit a general practitioner and 1.5 million prescriptions are dispensed every day (9). The same study estimates the rate of adverse events at 5 to 80 per 100,000 primary care consultations. Despite this relatively low number, the volume of total contacts and the diversity of services call for serious and systematic attention to safety risks.

As mentioned above, so far most patient safety work has focused on hospital care where treatment is more sophisticated and complex and thereby potentially more dangerous to the patient if something goes wrong. The LINNEAUS EURO-PC project (10) points to four reasons why primary care has received less attention in relation to patient safety:

1. Primary care is perceived to be a low technology environment where safety is not a problem.

2. Primary care is carried out in multiple sites making a coordinated effort to map risks and improve patient safety more difficult.

3. Thirdly, the interfaces between primary and specialist care vary widely between European countries, making the study of patient safety in the interface problematic.

4. Finally, consultation and interpersonal skills are critical to the delivery of primary care and exploring issues related to patient safety in this area raises challenges.

A WHO literature review on the methods and measures used in primary care patient safety research globally (11) makes the point that "primary care providers often have less control over care management and delivery than in the more continuously monitored hospital admissions, and more than one site is often required for an episode of care". Furthermore, primary care episodes often extend over long periods of time – sometimes years, and involve patients with undifferentiated problems, uncertain diagnoses and multiple co- morbidities (11).

As of late there has been an increased awareness that some of the safety risks identified in secondary care also apply to primary care, that there are risks that are unique to primary care (12), and that many adverse events in hospitals actually originate in the diverse sites of primary care (11). Supporting this line of thinking, Thomas and Petersen (13) emphasise that any individual error or adverse event is usually the result of numerous latent errors, including system defects. This draws attention to the complexities and process-related nature of patient safety risks and is highly pertinent for primary care, where the factors contributing to an actual adverse event may be even more diverse and diffuse than in secondary care.

Patient involvement in patient safety

Over the last decades the idea of patient involvement as one of the ways in which the quality and effectiveness of health care services may be addressed has gained momentum. Strategies and methods have been developed to make patients active partners in their own treatment and care, or to include them in the development of the organisation and service design of health care and the political processes related to it. The basic idea is that patients are the focal point of health care services and that their experiences can provide crucial information about both their own specific patient journey and the overall functioning of health services.

Ten years ago Vincent and Coulter (14) proposed that patients can contribute to the prevention of adverse events and organisational learning for safety. They argued that patients have a central role to play in relation to the diagnostic process, decisions regarding treatment, administering of medicines etc. Yet recent studies maintain that so far little is known about the feasibility and effectiveness of such involvement strategies (15,16). Vincent (17) points out that in practice patients are considered to be passive victims of error and safety failures, rather than the key source of experience and expertise needed to ensure the fail free flow of treatment and care. Certainly, in the context of primary care patient involvement in patient safety also deserves more attention, and the LINNEAUS EURO-PC project has taken up that challenge.

The LINNEAUS EURO-PC project

The international LINNEAUS-PC collaboration has obtained the EU Framework 7 grant and as a result of that has extended and developed the collaboration at the European Level. Recognising the deficit in attention to patient safety in primary care The LINNEAUS Euro-PC project aims to increase and strengthen the activities related to patient safety in primary care and the primary care/secondary care interface. As of December 2011 eight research institutions and patient safety organisations from six different European countries participate in the project: UK, Germany, Austria, Netherlands, Poland, and Denmark. By facilitating the establishment of a European research and patient safety network the LINNEAUS Euro-PC project will ensure that current knowledge and experience on patient safety in primary care can be exchanged between the member states, thereby paving the way for future collaboration on patient safety activities in primary care. The project is organised into nine Work Packages, each led by one of the project participants:

Work package 1:   Project management and coordination activities

Work package 2:   Developing a taxonomy of errors for primary care

Work package 3:   Medication errors in primary care

Work package 4:   Diagnostic errors in primary care

Work package 5:   Safety culture and performance

Work package 6:   Learning for patient safety

Work package 7:   Developing interventions for patient safety in nascent organisations

Work package 8:   Patient involvement

Work package 9:   Dissemination

The Danish Society for Patient Safety coordinates work package 8 on patient involvement. The purpose of this work package is to explore how patient perspectives may become an integral part of error identification and the improvement of safety. This literature review is part of work undertaken in work package 8 and will contribute to the development of recommendations for patient involvement in patient safety that have Pan-European applicability and may contribute to a general enhancement of patient safety throughout the European region.

The literature search

Search methodology

For the purpose of this literature review we aimed to identify scholarly articles focusing on Europe that describe 1) interventions with the purpose of testing patient involvement methods in the context of patient safety, and 2) analyses of how patient involvement methods may contribute to the improvement of patient safety. Grey literature from large organisations central to the field of patient safety was included as well. The grey literature does not have an exclusive focus on Europe but is included to provide inspiration for the way patient involvement methods may be used to improve patient safety in primary care in general.

Electronic searches for scholarly articles were carried out in the following literature databases:

- Medline
- Cochrane Library
- Cinahl
- Embase
- CRD-databases (DARE, NHS EED and HTA)
- SveMed
- Pharmakon

Searches for grey literature were carried out on the web sites, i.e. publication lists, bibliographies and databases, of the following organisations:

- Institute for Healthcare Improvement
- Canadian Patient Safety Institute
- Agency for Healthcare Research and Policy
- The King's Fund
- NHS National Patient Safety Agency
- Pharmakon
- Planetree
- Picker Institute Europe
- Linnaeus EURO-PC
- The Australian Commission on Safety and Quality in Health Care
- WHO
- Helsebiblioteket (Norway)
- Socialstyrelsen (Sweden)

A free text search was carried out in Google using different combinations of the search terms described below to elicit both articles and grey literature. Finally, the reference lists of all included articles were hand-searched to generate items that were not included in the electronic search.

The databases and web sites were identified in collaboration with the Danish Society for Patient Safety. Librarian Anne Nørgaard-Pedersen at the Danish Institute of Health Services Research carried out the search.

Search design

The time limit of all searches was material published in 2006-2011. The languages included were English, Danish, Swedish and Norwegian.

Different databases may employ slightly different search terms for similar topics. Below we have described the electronic search in Medline as an example. The full search can be reviewed in appendix A.

Medline-search

1. Patient Participation OR Consumer Participation

2. Medical Errors OR Safety OR Safety Management OR Risk Management

3. Primary Health Care OR Community Health Services OR General Practice OR Family Practice OR General Practitioners OR Physicians, Primary Care

4. Pharmaceutical Services OR Community Pharmacy Services

5. Nursing Homes OR Intermediate Care Facilities

6. Dental Care

7. (1 AND 2) AND 3

8. (1 AND 2) AND 4

9. (1 AND 2) AND 5

10. (1 AND 2) AND 6

11. (1 AND (3 OR 4 OR 5 OR 6) AND Quality Assurance, Health Care

12. (2 AND (3 OR 4 OR 5 OR 6) AND "Patient-Centered Care

In the PubMed search 1,137 items/studies were found. The whole search in all databases and web pages, and free text search, generated a total number of 1,630 findings/studies.

Selection process

The abstracts of the identified articles were reviewed and selected on the basis of four thematic criteria of relevance: The articles had to be relevant for *patient involvement* in *patient safety* in *primary care* in *Europe.* The grey literature included reports from organisations from all Western countries.

The selection process was carried out in three stages by three different people and involved a progressively close reading of the studies. Finally the number was narrowed down to a total number of 13 articles and 9 reports.

Given the very limited number of relevant publications we did not make any methodological selection. We simply included all the publications that fulfilled the four thematic criteria mentioned above in or-

der to get an overview of the work done in Europe in this field. That means that we also included editorials, discussion papers, commentaries etc.

Topics which are related to patient involvement and/or patient safety, i.e. clinical decision making, health literacy, communication, medication adherence, self-management of disease etc., are only included in this review if they have a stated focus on patient involvement as a method for improving patient safety.

Finally, although the search was comprehensive, it is nevertheless possible that some publications have been missed. The publications that appeared in our search were indexed under the MESH-term 'primary care' (as well as the three other criteria). Nevertheless, in some of the publications primary care turned out to play a minor role. Depending on index systematics, we may have missed publications that also mention primary care, but have not been indexed as such.

In the discussion we will also draw on literature which is not included in the selected publications. This literature will appear in the reference list, but is not included in Appendix B.

Description of the included literature

13 articles and 9 reports are included in this review (see Appendix B for a thorough description of each publication). The publications are very heterogeneous and include different types of publication from different countries and with varying methodological approaches and objects of study.

Type of study

The articles include four literature reviews, three discussion papers, two qualitative studies, one survey, one mixed methods study, one secondary analysis, and one tip sheet. The grey literature includes two literature studies, two background papers, four reports on various projects and policy processes, and one reference guide.

Origin

Of the 13 articles, nine are from the UK, two from the Netherlands, and one is from Switzerland. The origin of tip sheet is not specified. The grey publications include one from Europe, one from Denmark, two from the UK, two from Canada, and three from Australia.

Health care setting

In five of the 13 articles included in this review the setting is exclusively primary care (9,18-21). In terms of grey literature it is five out of nine (22-26). The rest of the publications consider both primary and secondary care (2,8,12,16,27-35). To underscore this tendency, a number of authors point out the fact that research mainly covers hospital settings and rarely primary care (20,32,34). Furthermore, within studies of primary care very little mention was made of patient involvement in settings other than general practice, such as pharmacies, home nursing (24), elder care and dental care. Mental health, which cuts across both sectors, is represented by a single publication and this topic will not be treated exclusively here, unless the issue in question can be said to refer only to mental health.

Objectives

Eight articles and one report had the explicit objective of studying patient participation as a means of improving patient safety (16,27,29-32,36,37). One report had the objective of developing practice level indicators for safety and quality in primary care and mentions patient involvement as an overall dimension (22). In the remaining publications, patient participation was but one aspect of efforts to

improve patient safety or patient involvement was discussed but not necessarily in a patient safety context alone.

Methodology

The studies employ both quantitative and qualitative research methods, but not all offer details on their methodology. This impairs the ability to compare results. Several of the included authors also point to the wanting methodological standards of the field (16,28,30,37). In the studies that review interventions a description of study population demographics was lacking. The duration of follow-up was non-existent or not mentioned, leaving out the measurement of possible long-term effects or lack thereof.

Apart from wanting methodological descriptions, the publications – their purpose (e.g. to compile literature reviews, evaluate interventions, present commentaries etc.), their object of study (e.g. patient participation in patient safety, patient safety in patient participation, patient safety in quality improvement, mixed or primary health care settings), their point of departure (e.g. patient's perspective, professional's perspectives, patient safety intervention or theoretical approach) further complicate comparison.

Status of patient involvement in patient safety in European primary care

In the following we provide answers to the four research questions listed in the introduction. Together they constitute a status of patient involvement in patient safety in European primary care.

Unless there are issues that are only relevant in a European setting we do not distinguish between indexed literature (with a European focus) and grey literature (all Western countries) in the following. Because of the overlaps in the descriptions of primary care risks across continents it would not make sense to make separate accounts. For this reason, any method or strategy of patient involvement would be equally relevant in Holland or Denmark as it is in Australia and therefore we have made no distinction there either.

In the following we define a patient involvement *strategy* as an overall, non-specific approach to achieve a particular goal, e.g. improving patient safety. We define a patient involvement *method* as a systematic recipe for implementing a strategy. We define an *intervention* as an implementation of patient involvement methods in a particular clinical setting.

Safety risks

Research question: *Which safety risks in primary care can be minimised through patient involvement according to health professionals, patients and their relatives?*

For the most part, the description of safety risks in the included literature is not directly related to the potential of patient involvement methods of preventing any adverse events that may arise from these risks. Neither is there any description of who defines the risks, i.e. the researchers, health professionals, patients or patients' relatives. Therefore the literature does not provide a full answer to the above question.

The following description of risks therefore does not represent a particular perspective and is not related to any assumed or proven effectiveness of patient involvement methods. Below we describe the risks that are mentioned in the literature either pertaining specifically to primary care or to both primary and secondary health care. Since none of the publications have the purpose of identifying primary care safety risks this may not be an exhaustive nor prioritised list. It represents only the risks that are mentioned in the included literature and thereby also the themes and objectives of the included publications. Furthermore, we only mention the risks that specifically pertain to primary care and thereby not all the risks mentioned in the articles are necessarily included (e.g. risks related to surgery etc.). Finally, in most of the publications medication risks are simply mentioned or indirectly referred to but not further described. The below lists are a summary of the risks that are mentioned, but not all the listed publications mention all listed risks or use the same terms for these risks.

Medication

Risks in relation to medication management was mentioned in 11 of the included publications (9,19,23-25,28-30,32,36,37) and Sandars et al. state that medications errors account for 13% to 51% of reported adverse events in primary care (9). The overall risks are considered to be related to:

♦ Prescription

♦ Dispensing of medicine

♦ Administration of medicine

♦ Adverse drug reactions

♦ Polypharmacy

Additional information may be found in the report from the Municipality of Copenhagen (24) and Pearson (25) (see below). Coulter and Ellins (37) and Sandars (9) also provide limited additional information.

By far the most detailed list of medication risks is found in the pilot study in nursing care in the Municipality of Copenhagen, Denmark (24). The report lists the following risks:

♦ Lack of medication harmonisation

♦ Lack of clear professional responsibility for medication harmonisation

♦ Lack of information about new drugs in the patients home

♦ Discrepancies between physician's prescriptions and medicine lists

♦ Lack of information about medication after ambulatory treatment

♦ Lack of information to physician and home nursing unit about medication alteration after discharge

♦ Omissions and errors in documentation of medication on medicine lists in home nurse documentation system

Pearson et al. (25) add further details to this list:

♦ Failure to review and manage polypharmacy in older people

♦ Prescribing errors during dispensing and transcription stage

♦ Errors due to high medication volumes

♦ Pharmacist fatigue and overwork

♦ Interruptions to dispensing

♦ Drug names

♦ Lack of systematic dispensing and regulatory guideline

♦ Patient's misunderstanding of label instruction

♦ Insufficient formatting and readability of medication information

A pilot survey among general care physicians in Poland showed that 82% of primary care physicians expect patients to prepare a list of their medicines but rarely ask to see it. It further showed that 76% of the physicians had never reported an adverse drug event (ADR) despite the fact that they are obliged to do so by Polish legislation. Finally, the pilot survey showed that only 30% of patients knew the names and dosages of their medicine.

While a lot of the risks mentioned above are relevant primarily for health professionals and pharmacists there are interesting insights to be gained in relation to patients. Several studies refer to elderly patients as particularly vulnerable in relation to medication safety – either as victims of adverse events or as a risk factor in themselves (lack of compliance, little knowledge of own medicine) (9,24,25).

Considering the complexity, volume, and combinations of medication given to elderly patients this is a group that poses a particular challenge in relation to medication safety.

Diagnosis

Safety risks related to the diagnostic process are mentioned by 7 of the included studies (9,23,25,28,29,31,32). According to Sandars (9) delayed diagnosis constitute 54% of malpractice claims in primary care. The main risks are considered to be:

♦ Missed diagnoses

♦ Inaccurate or wrong diagnosis

♦ Delayed diagnoses

Several of the included studies mention the experience, knowledge and skills of primary care health professionals as central to ensuring accurate diagnoses and appropriate treatment (16,23,25,33). Blennerhasset (18) who regards patient safety in primary care from a patient perspective exemplifies the risk related to diagnosis and provider knowledge with the case of cancer. Patients with cancer experience either delayed referrals or too many urgent referrals due to the GP's lack of familiarity with symptoms of cancer.

Kingston-Riechers et al. (23) also point to the importance to patient safety of assessing the quality of information available to providers, its ease of use and the ways in which new information is integrated in practice. Furthermore, because primary care patients often see several providers, exchange and integration of information between providers is important. See also Pearson (25) for more information.

Communication

Eight publications mention communication as a risk factor (9,20,23,25,29,31,33,37). In general practice, the trusting relationship between patient and general practitioner is emphasised as important to communication and the exchange of information deemed necessary to patient safety. Communication risks include:

♦ Omissions in communication

♦ Mistakes and misunderstandings in communication

♦ Poor communication leading to breakdown in patient-clinician relationships

♦ Poor communication and information flow between health care settings

In relation to communication non-questioning patients and patients with communication challenges were seen as most exposed to safety problems (23). Language barriers are also mentioned as a compounding factor (25). Communication problems during handover between primary care and secondary care are mentioned in relation to mental health care (33). See also Pearson (25) for more information.

Treatment & care

Risks related to treatment and care (other than medication) are mentioned by five of the included publications (16,23,25,28,29). The following risks are mentioned:

♦ Care of patients with yet unclear diagnosis

♦ Unacknowledged deterioration of condition

♦ Delays in referral and treatment

- Errors in technical testing and treatment procedures

- Treatment complications

- Poor technique

- Mistimed procedures

The above risks related to treatment and care processes may lead to diagnosis or treatment delay and potentially impact on treatment outcomes and the recovery of the individual patient. Kingston-Riechers (23) and Pearson (25) may offer additional information on this topic.

Technology and equipment

Risks posed by technology and equipment appear in three publications (16,25,37):

- Technological failure

- Equipment failure

- Poor quality of equipment

- Failure to maintain equipment

Technology and equipment failure may lead to safety errors related to diagnostics, coordination with patients and with other providers or health care facilities etc. Kingston-Riechers (23) and Pearson (25) may offer additional information on this topic.

Organisation and administration

The somewhat less distinct field of organisation and administration as a risk to patient safety is mentioned in seven of the included (16,23,25,28,31,33,34). The following risks are listed:

- Inaccurate medical records

- Errors in organisational systems

- Deficient processes

- Deficient management

- Inappropriate policies

Organisation and administration risks contribute to the system conditions that give rise to lapses in care and safety standards. Some of these risks appear rather vague but are not further specified in the literature. See Coulter and Ellins (37) and Pearson (25) for additional information.

Environment

The final risk factor of the environment is mentioned in three studies (16,23,33). There is agreement that at least the part of primary care that takes place in other sites than designated clinical areas, such as private homes, is less patient safe.

The above mentioned risks are to a large extent interrelated and further compounded by the characteristics of primary care, i.e. interaction across health care disciplines and health care sites (31) and the diversity of the patients. Several patient groups are mentioned as particularly vulnerable, the elderly being the most significant one. Women, however, are also mentioned as a vulnerable patient

group in one study; as are patients who fail to actively take part in communication with their provider or who are unable to do so because of a language barrier (23).

Strategies and methods of patient involvement

Research question: *Which methods of patient involvement are used for this purpose (i.e. to minimise risks)?*

The publications in this review do not yield much detailed information about concrete methods for patient involvement, i.e. what is to be done, by whom, and with what means. Indeed, no studies report on results from specific interventions in which patient involvement methods have been systematically tested and evaluated in terms of their impact on patient involvement and patient safety. Two literature reviews (28,30) endeavour to review the effectiveness of interventions using patient involvement methods to improve patient safety, but both point to the lack of research and the incomplete methodological accounts of the individual studies. Supporting their observations Longtin et al. (16) point out that despite of an increasing amount of literature, patient involvement in safety is still poorly defined and can relate to rather diverse types of activity. What we may extract from our material is a comprehensive list of primarily patient involvement strategies, i.e. overall plans of action aimed at making patients active partners in the effort to improve patient safety. The best ways that these strategies may be realised will have to be determined and documented in future studies.

On the basis of the included studies (12,18,26,28,30,31,37) the following patient involvement strategies with an assumed impact on error reduction and error containment and hence a potential effect on patient safety include:

♦ Patient rights sensitisation and educational campaigns (31)

♦ Information to help choose safe providers (28,31,37)

♦ Patient skill development ('speaking up', making wishes known) (31)

♦ Helping to reach an accurate diagnosis (26,37)

♦ Informed consent (31)

♦ Sharing decisions about treatments and procedures (26,37)

♦ Contributing to safe use of medications (30,37)

♦ Participating in infection control (28,37)

♦ Confronting poor communication (31)

♦ Checking the accuracy of medical records (37)

♦ Observing and checking care and treatment processes (26,28,37)

♦ Detecting underperformance/deviation from standards (28,31)

♦ Identifying and reporting treatment complications and adverse events (28,31,37)

♦ Treatment monitoring (28,30)

♦ Practising effective self-management (37)

♦ Patient involvement in post-event activities (31)

♦ Involvement in shaping the design and improvement of services (30,37)

♦ Involvement of patients in writing patient information (18)

Because of the focus on medication management as the most important risk factor in primary care and the vulnerability of elderly patients, a tip sheet by Blaney-Koen (27) with the purpose of giving advice to this patient group about medication safety deserves special mention. The following actions are recommended in the tip sheet:

♦ Coordinate care/medication reconciliation

♦ Get the facts about prescribed medication and report side effects to physician

♦ Ask questions

♦ Tell and repeat everything to physician about current medication

♦ Remind physician about medication allergies and reactions

♦ Talk about costs if medication is expensive

♦ Use one pharmacy to avoid drug interactions

♦ Have a yearly check-up

♦ Take caution if medication makes you dizzy

♦ Schedule medication into your daily life

♦ Take medication as directed

Hall et al. note that patient tip-sheets are the most common patient involvement method used by health care providers to improve patient safety. Finally, several of the studies mention that encouraging patient to ask clinicians if they had washed their hands is one of the most common ways of involving patients in patient safety (16,28-30,36,37). In their literature review Longtin et al. (16) provides a list of medical errors and the ways in which patients may contribute to the prevention of these errors. The list does not focus specifically on primary care.

Only two studies from Holland shed light on the primary care physicians' view of patient involvement as a way of improving patient safety (19,20). The first study (20) assesses the relation between general practice characteristics in 10 countries (9 European) and patient safety management, and finds that in terms of patient involvement larger practices were more likely to have organised patient feedback items, such as a suggestion box, complaints procedure, or leaflet with practice information. The second study (19) identifies the most important patient safety strategies from the perspective of primary care physicians. In this study a web-based survey was completed by 58 respondents (convenience sample) from 8 Western countries. 46 of the respondents were practicing GPs, 8 had other medical training or a social science background, and the remaining four did not mention their profession. The respondents were asked to estimate the current use and potential of 38 patient safety strategies. Of the 38 patient safety strategies, the ones that involved patient participation considered whether there were:

♦ Campaigns to increase patients' and public's awareness of patient safety in general practice. 39.6% deemed this "very much important for patient safety" (3.8% deemed it > 50% present in country)

♦ Surveys and other types of consultations of patients regarding safety incidents. This received 0% of importance (3.8% deemed it > 50% present in (the) country)

♦ Patient held medical records, which scored 49.1% in relation to importance (13.2% deemed it > 50% present in country). Under the option to note other strategies, respondents did not include

patient involvement. Overall, the GPs in this study are not very optimistic about the potential of patient involvement for improving patient safety.

The limited potential assigned to patient involvement methods by primary care health providers is also reflected indirectly in the report from Canada (23) where patient safety experts were asked to recommend strategies to improve patient safety and made no mention of patient involvement. In a UK study (21) aimed at developing a theoretical framework for a patient safety culture in primary care primary care, clinicians argued that patient involvement was a feature of all safety dimensions, but requires a relatively mature safety culture.

Implications for patient involvement

Research question: *What are the potentials and weaknesses of these methods in relation to patient involvement?*

Several studies point out that little is known about patients' willingness and ability to adopt patient safety promoting behaviours (30,31,36,37). Considering that information about concrete methods in primary care is scarce, providing a definite answer to the above question is not possible. Nevertheless, a number of factors that are assumed to determine the extent and character of patient involvement in patient safety are identified in the publications.

Davis (36) and Longtin (16) argue that patient involvement relies on factors related to:

♦ Patient demographics: the patient may participate if s/he feels vulnerable to safety issues, is generally younger, female and educated

♦ Type of illness and comorbidity: both severely and less severely ill patients tend to take on participation, but it is intensified by prior experience of illness or safety incidents and inhibited by impact of illness/symptoms

♦ Health care professionals' approach and abilities: professionals' attitudes to participation and the nature of interaction with patient

♦ Health care setting: patients experience more difficulty participating in hospitals than with a GP

♦ The nature of involvement/health care task: participation is easier for patients in tasks that do not require medical knowledge and do not confront professionals

♦ Stakes of the proposed outcome

♦ Acceptance of new patient role

♦ Level of health literacy

♦ Level of confidence in own capacities

♦ Type of decision making required

Age, especially old age, is also mentioned as a factor in the patients' willingness to engage in patient safety. The pilot project from the Municipality of Copenhagen that focused exclusively on elderly patients confirms this (24). The report concludes that the patients did not wish to be involved in their own treatment. This was assumed to be due to the range of different and changing medication taken daily as well as their state of illness (confusion, pain, tiredness, forgetfulness, lack of energy).

Age is also mentioned in the studies by Longtin (16) and Howe (31) along with personality, low health literacy, little education, non-Western culture, lack of assertiveness in consultation. The same studies

argue that there are specific barriers to involvement that relate to both patient and health care professional, i.e. time, attitudes, power relationships, cultural backgrounds and different worldviews.

Longtin (16) list the barriers to participation on the part of the professional as a desire to maintain control; type of illness; personal beliefs; professional specialisation; ethnicity; training. More specifically, barriers were seen in health care workers' attitudes, withholding information or exercising paternalistic power over patients. Longtin argues that primary physicians are more willing to accept patient involvement than specialists, which point in a different direction than the data in Gaals study from Holland, where primary care physicians did not prioritise patient involvement as a viable method to improve patient safety (19).

Speaking up

As described in the previous sections communication is considered to be a potential source of misunderstandings, misinformation, and conflict, as well as a key to patient involvement in patient safety. This is evident from the list of involvement strategies above.

Sandars (9) mentions the 'Please Ask Campaign' launched by the National Patient Safety Agency as an example. This campaign highlights the active role of patients in safe care and encourages patient to offer information on side-effects, to question treatment and to report on safety concerns. A UK study by Entwistle et al. (29) also points out that one of the most common ways of encouraging patients to play an active role in patient safety is asking them to 'speak up' if they have concerns about their own safety. However, according to the authors little is known about patients' experiences of this recommended behaviour.

Two studies concern patients' perspectives on voicing safety concerns to health providers (29,32). Speaking up was generally considered difficult by the patients included in the study and influenced by how professionals behave and relate to the patients. In the study by Entwistle the following reasons for speaking up or not were defined:

♦ The patient's situational assessment: the severity of threat, emotional/psychological/physical problem, how grave the potential for harm, how serious the shortfalls in care standards, how important compared to other patients, staff workload, staff receptiveness

♦ The patient's personal ability to assess problems: how familiar is the patient with condition and intervention, the amount of information offered by staff, prior experiences with like events, self-confidence

♦ The patient's judgement about responsibilities: health care professionals have the primary responsibility, but patients acknowledge importance of their own role, e.g. informing of current medications and allergies. However, patients emphasised the importance of a good quality patient-professional relationship for this to work

♦ The patient's judgement of consequences of speaking up: positive response facilitates further speaking up, concern that challenging professionals might result in substandard care

What Entwistle points out in this study is that it cannot be assumed that an encouragement to 'speak up' will produce the desired sharing of information and dialogue on errors in all cases. Contextual factors such as health condition, knowledge, and the patient-provider relationship also determines patients' communication practices.

In the UK study by Ocloo (32) 2.5 years of participatory action research was conducted among medically harmed patients. A common denominator in the patients' experiences was that of professional resentment when they addressed their concern, by both individual doctors and health care organisa-

tions. The participants had the impression that professionals routinely covered up medical harm and treated the patient as the problem; external organisations failed to provide independent investigations. The patients did not feel included in patient safety reforms; were met with a culture of denial when tackling safety issues; and that the regulatory bodies failed them after the adverse event. The group wanted to share their personal stories and recommended recognition of "lay perspectives" but does not specify how this is to be done.

Ocloo concludes that the patient-professional relationship and health professionals' attitudes shape patients' confidence in speaking up and raising concerns and thus whether some patient safety issues are ignored or go undetected. Concurrently with speaking up campaigns, listening up campaigns for health care workers is suggested.

Implications for patient safety

Research question: *What are the potentials and weaknesses of these methods in relation to patient safety?*

It is a general observation in several studies that there is only weak evidence on the effectiveness of patient involvement in patient safety (16,30,37), although a few exceptions are mentioned.

Hall et al. (30) conclude that the only evidence of effectiveness regarding patient participation in patient safety in their review was found in self-management of medication (oral anti-coagulants).

Coulter and Ellins (37) find that patient involvement in infection campaigns have proved effective. Of other strategies, the most effective is simplifying dosing regimens. Educational interventions seem unlikely to be effective on their own.

The literature review by Longtin et al. (16) mentions one follow-up detail in one reviewed intervention, namely that educating health care workers in patient participation showed benefits up to 10 years later.

Several studies mention patient involvement in the hand hygiene practices but the evidence of its effect on safety is unclear (16,28,30,36).

The pilot project on home care in the Municipality of Copenhagen showed that medication errors were significantly reduced by the systematic account during home visits, but could not confirm that it motivated the patient to acquire knowledge about treatment and use of medication, nor could it be measured whether health care workers in other units acquired knowledge about the patient's health status, as a systematic review of this was not possible (24).

In the literature review by Pearson (25) the provision of leaflets encourage patients to raise queries concerning treatment, but despite a patient satisfaction outcome, no patient safety improvement was measured. Likewise, little impact was found in encouraging patients to monitor treatment and report incidents, unless combined with a national scheme.

Howe (31) finds that one of the greatest benefits of patient involvement in safety is the potential to increase professionals' awareness that their actions have consequences. This can moderate professionals' risk-taking behaviour and may lead to error-prevention, development of a stronger organisational safety culture, professional behaviour change, enhanced adherence to advice and improved self-management. Interventions will be most effective, the author believes, if they include patients and all professional disciplines and aim to change professional attitudes and behaviours.

Coulter and Ellins (28) note that patient safety can only be improved through patient involvement if patient involvement is valued and supported. Likewise Davis et al. (36) conclude that patient involvement requires a positive safety culture.

In sum, evidence on the effectiveness of patient involvement in patient safety in primary care is scarce and inconclusive and a clear answer to the above research question would demand more systematic research on how patient involvement methods work in practice.

Discussion & conclusion

Judging by the number and character of publications included in this search, patient involvement in patient safety in European primary care is quite an understudied topic. In the included literature, no intervention were systematically tested and evaluated in terms of impact on patient involvement and patient safety. Therefore we cannot provide conclusive answers about the strengths and weaknesses of particular patient involvement methods in relation to patient safety in European primary care, neither can we identify a set of best practices.

Despite the lack of strong evidence and the acknowledgement of various barriers, the majority of the publications are generally positive about the overall idea of applying patient involvement to patient safety. The study from the Municipality of Copenhagen is the one exception (24). Almost all of the publications (except the more operational ones) point to the need for more research, particularly on the effectiveness of interventions and patients ability and willingness. Indeed, the paucity of research leave behind a list of topics and unanswered questions that need to be explored, before a full overview of potentials and weaknesses of patient involvement in patient safety is within reach.

First of all, the patient is a central actor in patient involvement and yet only two of the included studies represent a patient perspective. In a WHO literature review from 2008 on the methods and measures used in primary care patient safety research globally (11) the authors conclude that the patient perspective is poorly represented. Nevertheless, there seems to be a general concern with the ability and willingness of patients to handle being involved in patient safety, several of the included studies call for further research about patients' acceptance of such a new role (2,29-32,36,37).

In an analysis of the patient role in safety work Scwappach (15) points out that while patients who are sick and under treatment will always be concerned about the risks related to treatment and care "it is not naturally given that such concerns for safety translate into willingness to engage for safety." (page 120). He also argues that we must not take for granted that the ability to identify errors enables patients to act in a timely and effective way to intercept these errors. He points out that although patient involvement in patient safety seems a logical and promising next step there is so far no substantial volume of scientific knowledge that have explored systematically and in detail to what extent and with what means patients may contribute to improving patient safety and how this will change the patient role.

A review of patient engagement in primary care by the King's Fund (38) point out several challenges related to patients' taking an active role in the consultation:

♦ GPs and their patient may have specific ideas about their roles in the consultation and may be concerned about compromising their relationship if these roles change

♦ Patients and GPs may lack confidence in increasing the level of patient engagement in the consultation

♦ Patients may feel they lack the necessary information and support to become involved in the consultation

♦ GPs may feel that lack of time, information and resources stand in the way of patient involvement

♦ Some patients may feel uncomfortable with involvement because of the GP's status as expert

This study from the King's Fund makes two central points. Firstly, both the patient and the general practitioner may feel uncertain about what precisely is expected and demanded of them when patients are supposed to play a more active part in the consultation. This is certainly an issue to take into account when applying patient involvement methods not only in general practice, but in other primary care sites where the encounter between patient and health provider may be less clearly defined as a GP consultation.

Secondly, both doctor and patient may feel that patient involvement is a potential threat to the doctor-patient relationship. Even though the study by the King's Fund was not concerned with patient safety, we may also apply this point to our study. The consultation may well be a situation that is particular to general practice, but other professionals in primary care, e.g. elder care and home nursing, may also experience long-term relationships with patients.

Indeed, several of the included studies (16,23,28,29,31) mention the importance of the doctor-patient relationship but without providing any details about how patient involvement in patient safety may have an impact on it. The attitude of health care providers is mentioned as having an impact on the way the patients experience involvement or view the potential for involvement as two studies in this review have shown (29,32). However, several other studies have discussed the impact on the trust between patient and health care provider if safety issues are openly voiced and patient vigilance encouraged. Some of these studies point out that both patients and health care providers may see patient involvement in safety work as a threat to the professional authority and identity of the provider. On the same note, Scwappach (15) argues that patient involvement methods could erode trust. On the other hand, Entwistle (39)states that patients are well aware that health care also implies risk and that openness about this is trustworthy in itself. Thus, rather than assuming – as much of the grey literature in this review does – that patient involvement is positive per se, it is vital that patient perspectives are further explored. Certainly, the lack of insights into the implications of patient involvement in patient safety for the patient-provider relationship needs calls for further studies because this may have an impact on the effectiveness of involvement methods.

This is even more pertinent when the diversity of primary care patients is taken into account. Several vulnerable groups have already been mentioned – the elderly, women and people with poor communication skills. The study from the Municipality of Copenhagen (24) made the point that the elderly patients who were visited by a home nurse were neither able nor willing to become involved in their own care and treatment. Thus, given the diversity of the patients and health care sites in primary care we may assume that this creates both limitations and opportunities for patient involvement in safety. It might be fruitful to consider the possibilities of a more individualised approach to the concretisation of involvement strategies and the testing and implementation of involvement methods. One size does not necessarily fit all.

A final topic, which is closely related to the above, concerns the patient safety culture, which is mentioned in several of the included publications as crucial to patient involvement and patient safety (9,26,31,32,36) and which is promoted by influential institutions such as the Institute for Health Care Improvement (IHI). Only the reference guide from Australia provides information about what this implies in practice and defines it as a culture where individuals in organisations and teams have "a constant and active awareness of the potential for things to go wrong" (26). In organisations with a safety culture it is assumed that health staff would not display negative attitudes to patients voicing their concern, but would rather be supportive and encouraging (31) – something that the included publications agree to be vital for patient involvement to develop and contribute to the improvement of safety. If we once more consider the character of primary care and diversity of sites that are part of it, it becomes obvious that creating a culture of safety across these sites and the health professions rep-

resented in them presents a significant challenge. It may well be possible to identify particular primary care dimensions of a safety culture (21), but what does it take to create a sustainable safety culture in the diverse sites of a rural general practice, an urban nursing home, or a dental clinic with only two employees? Primary care facilities are often different in terms of size, location and organisation. There is a dire need to determine to what extent the range of institutions in primary care are prepared to adequately respond to patients' activities in relation to patient safety, and the kinds of institutional adaption that are necessary for patient involvement to work (15).

In sum, if patient involvement is to play its part in patient safety in European primary care in the future, there is a need for interventions and research to test and evaluate the potentials, weaknesses and general viability of involvement methods, to assess the perspective of professionals and patients on the implications of patient involvement in practice, and to assess the basic organisational requirements in the various primary care sites. Only then may we be able to identify best practice.

References

(1) Baker GR, Norton PG, Flintoft V, Blais R, Brown A, Cox J, et al. The Canadian Adverse Events Study: the incidence of adverse events among hospital patients in Canada. CMAJ 2004 May 25;170(11):1678-1686.

(2) Davis P, Lay-Yee R, Briant R, Schug S, Scott,A.,Johnson,S., Bingley W. Adverse Events in New Zealand Public Hospitals: Principal Findings from a National Survey (Occasional Paper No.3). Wellington: Ministry of Health; 2001.

(3) Department of Health. An Organisation with a Memory. Report of an Expert Group on Learning from Adverse Events in the NHS. London: The Stationary Office; 2000.

(4) Kohn LT, Corrigan JM, Donaldson MS. To Err is Human. Building a Safer Health System. Washington, D. C.: National Academies Press; 2000.

(5) Schioler T, Lipczak H, Pedersen BL, Mogensen TS, Bech KB, Stockmarr A, et al. Incidence of adverse events in hospitals. A retrospective study of medical records (in Danish). Ugeskr Laeger 2001 Sep 24;163(39):5370-5378.

(6) Wilson RM, Runciman WB, Gibberd RW, Harrison BT, Newby L, Hamilton JD. The Quality in Australian Health Care Study. Med J Aust 1995 Nov 6;163(9):458-471.

(7) Health EU, The Public Health Portal of the European Union. Patient Safety. Links to EU activities. Available at: http://ec.europa.eu/health-eu/care_for_me/patient_safety/index_en.htm. Accessed 12/7, 2011.

(8) World Health Organization. Patient safety. Available at: http://www.euro.who.int/en/what-we-do/health-topics/Health-systems/patient-safety. Accessed 12/7, 2011.

(9) Sandars J. Recent developments in patient safety in primary care. Qual Prim Care 2007;15(3):165-167.

(10) LINNEAUS EURO-PC. Learning from International Networks about Errors and Understanding Safety in Primary Care. Available at: http://www.linneaus-pc.eu/index.html. Accessed 12/8, 2011.

(11) Makeham M, Dovery S, Runciman W, Larizgoitia I. Methods and Measures used in Primary Care Patient Safety Research. Results of a Literature Review. [S.l.]: World Health Organization, Patient Safety; 2008.

(12) Proposed National Safety and Quality Framework. Consultation Report. : Australian Commission on Safety and Quality in Healthcare; 2010.

(13) Thomas EJ, Petersen LA. Measuring errors and adverse events in health care. J Gen Intern Med 2003 Jan;18(1):61-67.

(14) Vincent CA, Coulter A. Patient safety: what about the patient? Qual Saf Health Care 2002 Mar;11(1):76-80.

(15) Schwappach DL. Review: engaging patients as vigilant partners in safety: a systematic review. Med Care Res Rev 2010 Apr;67(2):119-148.

(16) Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. Mayo Clin Proc 2010 Jan;85(1):53-62.

(17) Vincent C. Patient Safety. Edinburgh: Elsevier; 2006.

(18) Blennerhassett M. Challenges for primary care in the age of the autonomous patient. Qual Prim Care 2007(15):201-206.

(19) Gaal S, Verstappen W, Wensing M. What do primary care physicians and researchers consider the most important patient safety imrprovement strategies? BMC Health Services Research 2011;11(102).

(20) Gaal S, van den Hombergh P, Verstappen W, Wensing M. Patient safety features are more present in larger primary care practices. Health Policy 2010 Sep;97(1):87-91.

(21) Kirk S, Parker D, Claridge T, Esmail A, Marshall M. Patient safety culture in primary care: developing a theoretical framework for practical use. Qual Saf Health Care 2007 Aug;16(4):313-320.

(22) Practice-level Indicators of Safety and Quality for Primary Health Care. Consultation Paper. Sydney: Australian Commission on Safety and Quality i Healthcare; 2011.

(23) Kingston-Riechers J, Ospina M, Jonsson E, Childs P, McLeod L, Maxted J. Patient Safety in Primary Care. Edmonton, Alberta: Canadian Patient Safety Institute & BC Patient Safety and Quality Council; 2009.

(24) Københavns Kommune, (Municipality of Copenhagen). Sygeplejefaglig indsats over for hjemmeboende borgere, som anvender flere lægemidler samtidigt. En rapport om resultater og udfordringer til medicinhåndtering i hjemmesygeplejen. København: Københavns Kommunes Sundheds- og Omsorgsforvaltning; 2010.

(25) Pearson A, Aromataris E. Patient Safety in Primary Healthcare: A Review of the Literature. Adelaide: Australian Commission on Safety and Quality in Health Care; 2009.

(26) Woodward S. Seven Steps to Patient Safety for Primary Care. The Full Reference Guide. [London]: National Patient Safety Agency; 2006.

(27) Blaney-Koen L. Medication Safety for Seniors. J Patient Saf 2009;5(1):53.

(28) Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ 2007 Jul 7;335(7609):24-27.

(29) Entwistle VA, McCaughan D, Watt IS, Birks Y, Hall J, Peat M, et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. Qual Saf Health Care 2010 Dec;19(6):e33.

(30) Hall J, Peat M, Birks Y, Golder S, PIPS Group, Entwistle V, et al. Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review. Qual Saf Health Care 2010 Oct;19(5):e10.

(31) Howe A. Can the patient be on our team? An operational approach to patient involvement in interprofessional approaches to safe care. J Interprof Care 2006 Oct;20(5):527-534.

(32) Ocloo JE. Harmed patients gaining voice: challenging dominant perspectives in the construction of medical harm and patient safety reforms. Soc Sci Med 2010 Aug;71(3):510-516.

(33) Brickell TA, Nicholls TL, Procyshyn RM, McLean C, Dempster RJ, Lavoie JAA. Patient Safety in Mental Health. Edmonton, Alberta: Canadian Patient Safety Institute & Ontario Hospital Association; 2009.

(34) Coulter A. Patient safety: what role can patients play? Health Expect 2006 Sep;9(3):205-206.

(35) Tarasenko N, Virone MG. Patient Engagement in Reducing Safety Risks in Health Care. Report of the Meeting on Patient Safety and Rights, Copenhagen, 31 August 2011. Copenhagen: World Health Organization; 2011.

(36) Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? Health Expect 2007 Sep;10(3):259-267.

(37) Coulter A, Ellins J. Patient-focused Interventions: a Review of the Evidence. London: Picker Institute Europe & The Health Foundation; 2006.

(38) Parsons S, Winterbottom A, Cross P, Redding D. The quality of patient engagement and involvement in primary care. London: The King's Fund; 2010.

(39) Entwistle V, Quick O. Trust in the context of patient safety problems. Journal of Health Organization and Management 2006;20(5):397-416.

Appendix A: Literature search

Search period: 2006-2011. Languages: English, Danish, Norwegian, Swedish.

Medline

#1 "Patient Participation"[Mesh] OR "Consumer Participation"[Mesh]

#2 "Medical Errors"[Mesh] OR "Safety"[Mesh] OR "Safety Management"[Mesh] OR "Risk Management" [Mesh]

#3 "Primary Health Care"[Mesh] OR "Community Health Services"[Mesh] OR "General Practice"[Mesh] OR "Family Practice"[Mesh] OR "General Practitioners"[Mesh] OR "Physicians, Primary Care"[Mesh]

#4 ("Pharmaceutical Services"[Mesh] OR "Community Pharmacy Services"[Mesh])

#5 ("Nursing Homes"[Mesh] OR "Intermediate Care Facilities"[Mesh])

#6 "Dental Care"[Mesh]

#7 ((#1 AND #2) AND #3)), limits = only items with abstracts: 364 articles

#8 ((#1 AND #2) AND #4): 9 articles

#9 ((#1 AND #2) AND #5): 1 article

#10 ((#1 AND #2) AND #6): 1 article

#11 ((#1 AND (#3 OR #4 OR #5 OR #6) AND "Quality Assurance, Health Care"[Mesh])), limits = only items with abstracts: 244 articles

#12 ((#2 AND (#3 OR #4 OR #5 OR #6) AND "Patient-Centered Care"[Mesh])), limits = only items with abstracts: 165 articles

Related articles for article:

A Howe. Can the patient be on our team? An operational approach to patient involvement in interprofessional approaches to safe care. Journal of Interprofessional Care 2006 Oct; 20 (5):527-34

353 articles

Cochrane

#1 "Patient Participation"[Mesh] OR "Consumer Participation"[Mesh]

#2 "Primary Health Care"[Mesh] OR "Community Health Services"[Mesh] OR "General Practice"[Mesh] OR "Family Practice"[Mesh] OR "General Practitioners"[Mesh] OR "Physicians, Primary Care"[Mesh]

#3 "Medical Errors"[Mesh] OR "Safety"[Mesh] OR "Safety Management"[Mesh] OR "Risk Management "[Mesh]

#4 ((#1 AND #2) AND #3): 19 articles

#5 (#1 AND #2): 371 articles

#6 ((#1 AND #3) AND ("Pharmaceutical Services"[Mesh] OR "Community Pharmacy Services"[Mesh] OR "Dental Care"[Mesh])): 0 articles

Cinahl

#1 "Safety"[Mesh] OR "Patient Safety"[Mesh] OR "Treatment Errors"[Mesh] OR "Risk Management" [Mesh]

#2 "Family practice" [Mesh] OR "Primary health care" [Mesh] OR "Pharmacy Service"[Mesh] OR "Dentistry"[Mesh])

#3 "Consumer participation" [Mesh] OR "Patient-Centered Care"[Mesh]

#4 ((#1 AND #2) AND #3): 20 articles

#4 "Patient involvement" [Title] AND Safety [Title]: 7 articles

Embase

#1 Patient safety [Mesh] OR Safety [Mesh] OR Medication error [Mesh]

#2 Primary health care [Mesh] OR General practice [Mesh] OR Pharmaceutical care [Mesh] OR Pharmacy[Mesh] OR Dental care[Mesh]

#3 ((#1 AND #2) AND Patient participation [Mesh]): 12 articles

CRD-databases

#1 "Patient Participation"[Mesh] OR "Consumer Participation"[Mesh]

#2 "Primary Health Care"[Mesh] OR "Family Practice"[Mesh]

#3 "Medical Errors"[Mesh] OR "Safety Management"[Mesh] OR "Risk Management" [Mesh]

#4 ((#1 AND #2) AND #3): 0 articles

#5 (#2 AND #3): 7 articles

#5 ((#1 AND #3) AND "Dental Care"[Mesh]): 0 articles

#6 ((#1 AND #3) AND ("Pharmaceutical Services"[Mesh] OR "Community Pharmacy Services"[Mesh])): 0 fund

SveMed

#1 "Patient Participation"[Mesh] OR "Consumer Participation"[Mesh] OR "Patient-Centered Care"[Mesh]

 #2 "Family Practice"[Mesh] OR "Physicians, Family"[Mesh] OR "Primary Health Care"[Mesh] OR "Community Health Services"[Mesh]

#3 "Medical Errors"[Mesh] OR "Safety"[Mesh] OR "Safety Management"[Mesh] OR "Risk Management"[Mesh]

#4 ((#1 AND #2) AND #3): 7 articles

#5 Fritekst: Patientsäkerhet$: 33 articles

Websites:

Search words used at the websites' search function, if available: Different forms of "Safety", "Patient involvement" and "Primary health care".

 http://www.ihi.org/Pages/default.aspx Institute for Healthcare Improvement: 1 report

http://www.patientsafetyinstitute.ca/English/research/Pages/default.aspx Canadian Patient Safety Institute: 1 report

 http://www.ahrq.gov/qual/patientsafetyix.htm   Agency for Healthcare Research and Policy: 1 report

http://www.kingsfund.org.uk/ The King's Fund: 1 report

http://www.npsa.nhs.uk/ NHS National Patient Safety Agency: 1 report

http://pharmakon.onconfluence.com/display/doku/Apotekernes+Dokumentationsdatabase Pharmakon, Apotekernes Dokumentationsbase: 1 report

 http://www.planetree.org/   Planetree: 0 reports

http://www.pickereurope.org/   Picker Institute Europe: 2 reports

http://www.linneaus-pc.eu/aboutus.html Linnaeus EURO-PC, bibliografi om patientsikkerhed: 2 articles/reports

http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/PatientSafety-PHC The Australian Commission on Safety and Quality in Health Care: 4 reports

http://www.who.int/patientsafety/en/   WHO Patient safety: 0 reports

http://www.helsebiblioteket.no/Kvalitetsforbedring/Pasientsikkerhet Helsebiblioteket (Norway): 0 reports

http://www.socialstyrelsen.se/patientsakerhet Socialstyrelsen (Sweden): 0 reports

Google

A search combing different variations and combinations of the following terms: "Patient involvement", "Patient safety", "Primary care", "Patient partnering": 3 additional publications.

Appendix B: Literature overview

The literature is divided into the general headings of *scholarly articles* and *grey literature*. Under each of these headings every publication is described by the following subcategories: *Type of study*, *reference information*, *contribution*, *method*, *safety issues*, *patient involvement*, *improvement of patient safety* and *other*. These aspects are described as fully as allowed by the publications' level of detail. *Other* may be both the authors' comments and our comments and is not included in all descriptions. Because of the very different character of the publications, the categories do not necessarily follow in the same order.

A note should be made on the contribution of the individual studies, which is summarised in one sentence for each text box. The contribution of the publications is most often broader in scope than our description, as the purpose here is to focus specifically on the aspects concerning patient involvement in patient safety. These aspects are not always the direct or only aim of the publications.

The publications span the period 2006-2011 and are arranged by name of the author.

Scholarly articles

1. Tip sheet	
Paper	Patient Education: Medication Safety for Seniors *Journal of Patient Safety*'s Patient Education Page
Year	2009
Author	Lisa Blaney-Koen
Country	N/A
Sector	Primary and secondary sector

Contribution
Lists tips for seniors on how to prevent medication-related problems.
Method
The publication is a tip sheet.
Safety risks
N/A
Patient involvement
The tip sheet aims at enabling seniors to contribute to the management of adverse medication events. To help prevent medication errors, the following steps are recommended: 1) coordinate care/medication reconciliation, 2) get the facts about prescribed medication and report side effects to physician, 3) ask questions, 4) tell and repeat everything to physician about current medication, 5) remind physician about medication allergies and reactions, 6) talk about costs if medication is expensive, 7) use one pharmacy to avoid drug interactions, 8) have a yearly check-up, 9) take caution if medication makes you dizzy, 10) schedule medication into your daily life, 11) take medication as directed.
Improvement of patient safety
The premise of the tip sheet is that the above points may contribute to avoiding adverse medication events.

2. Discussion paper (patient perspective)	
Paper	Challenges for primary care in the age of the autonomous patient *Quality in Primary Care, 15, 201-6*
Year	2007
Author	Mitzi Blennerhassett
Country	UK
Sector	Primary sector

Contribution
Presents a patient's perspective on the challenges to primary care clinicians by patient autonomy, and their implications for training.
Method
Essay
Safety risks
Delayed referrals or too many urgent referrals due to GP's lack of familiarity with cancer.
Patient involvement
Today patients are knowledgeable and want to be involved in care pathway from the outset.
Improvement of patient safety
Risk training of GPs, including openly sharing mistakes. Should include feedback from significant event meetings to affected patients. A partnership between patient and GP is recommended.
Other
Recommends communication skills training to clinical staff and involvement of patients in writing patient information

3. Literature review	
Paper	Effectiveness of strategies for informing, educating and involving patients *British Medical Journal*, pp. 24-27
Year	2007
Author	Angela Coulter & Jo Ellins
Country	UK
Sector	All health care settings

Contribution
Collates existing evidence on the effect of patient involvement in safe health care.
Method
Systematic literature search in electronic databases, specialist websites and patient organisations, and a reference scan for key papers. 129 systematic reviews and numerous studies were found. The studies both were qualitative and quantitative. The authors note that lack of standardisation in research hampered comparison of results.
Safety issues/risks
Risks are not defined indirectly in the article. The following list is extracted by assessing the suggested focus for patient involvement:
Inaccurate diagnosis, medication management, infections, inaccurate medical records, care processes, treatment complications and adverse events.
Patient involvement
The patient-focused quality studies reviewed, 18 in total, covered interventions to improve health literacy; improve clinical decision making; improve self-care; improve patient safety.
Relevant outcomes of the studies reviewed are listed in the article as the interventions' impact on the patient's knowledge and understanding of their condition; on the patient's experience of illness and treatment; on the use of services and costs; and on the patient's health behaviour and health status.
10 reviews on patient decision aids showed improvement in the patient's knowledge and understanding of their condition, of treatment and improved agreement between patient preferences and treatment decisions and were cost-effective. Barriers, however, include lack of awareness, knowledge and skills, concerns about time and resource pressures, and professional fear that patient involvement could undermine professional-patient relationships.

Improvement of patient safety
Patient focused interventions with an potential impact on patient safety include: information to help choose safe providers; helping to reach an accurate diagnosis; contributing to safe use of medications; participating in infection control; checking the accuracy of medical records; observing and checking care processes; identifying and reporting treatment complications and adverse events; practising effective self-management and treatment monitoring.
Most research was found to focus on safer use of medicines and infection control such as hand washing. Most effective was simplifying regimens, whereas other interventions were less conclusive. Still, the authors believe there is evidence that supports patient participation's efficacy. They note that patient safety can only be improved if patient involvement is valued and supported as well as if health literacy is addressed.
Other
Research in patient participation in patient safety is noted as being in its infancy.

4. Literature review	
Paper	Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expectations* 10, pp. 259-267
Year	2007
Author	Rachel E. Davis et al.
Country:	UK
Sector	Primary and secondary care

Contribution
Delineates factors that may affect patient participation in quality and safety issues.
Method
Literature review of patient involvement in health care, both direct evidence from safety contexts, and indirect evidence from patient participation in treatment decision-making. Further, a conceptual framework is developed that illustrates known and putative factors that could affect participation and practical implications of patient involvement in safety is discussed.
Safety risk
The authors mention medication errors and adverse events as safety issues.
Patient involvement
A conceptual framework is put forth by the authors. Patient involvement relies on factors related to:
1) Patient demographics: the patient may participate if s/he feels vulnerable to safety issues, is generally younger, female and educated
2) Type of illness: both severely and less severely ill patients tend to take on participation, but it is intensified by prior experience of illness or safety incidents and inhibited by impact of illness/symptoms
3) Health care professionals' approach and abilities: professionals' attitudes to participation and the nature of interaction with patient
4) Health care setting: patients experience more difficulty participating at hospitals than with GP
5) The nature of involvement/health care task: participation is easier for patients in tasks that do not require medical knowledge and do not confront professionals.
The authors note that interventions should be multi-modal and target specific patient groups.
Improvement of patient safety
Safety is considered dependent on the interplay of above factors, and likewise, patient involvement requires a positive safety culture. Medication errors and hand washing proved effective participation interventions. The potential for engaging patients in safety is considerable, but further research is needed. The authors also stress that patient involvement is but a small part of safety and that patients should not carry the responsibility of their own health care, but only function as a safety buffer, so that not participating does not result in sub-standard treatment.
Other
The authors note that patients' perspectives on their own involvement in patient safety remain unknown. Further research on the impact of the above-mentioned factors on patient participation and the interaction between them is deemed a pressing need.

5. Qualitative study	
Paper	Speaking up about safety concerns: multi-setting qualitative study of patient's views and experiences *Quality and Safety in Health Care* 19, pp. **1-7**
Year	2010
Author	Vikki A. Entwistle et al.
Country	UK
Sector	Primary and secondary care

Contribution

Explores patients' and family members' experiences of and views on speaking up about safety issues in health care.

Method

Qualitative study using 71 individual interviews and 12 focus group discussions with:

a) Patients (of childhood asthma, diabetes, breast cancer, elective joint replacement and severe and enduring mental health problems) with experiences of safety issues

b) People who have lodged concerns with health care providers.

Safety risks

128 findings of safety risks were uncovered, including unacknowledged deterioration of condition; missed diagnoses; delays in referral and treatment; errors in prescription; dispensation and administering of medicine; errors in technical testing and treatment procedures; omissions or mistakes in communication; shortfalls in hospital accommodation and cleanliness; exposure to threats from other patients; and deficiencies in inpatient nursing. It is noted that some concerns raised by patients do not pose substantial threats. Findings were strikingly consistent across patient groups.

Patient involvement

Speaking up was generally considered difficult and influenced by how professionals behave and relate to the patients. The following reasons for speaking up or not were defined:

1) The patient's situational assessment: the severity of threat, emotional/psychological/physical problem, how grave the potential for harm, how serious the shortfalls in care standards, how important compared to other patients, staff workload, staff receptiveness

2) The patient's personal ability: how familiar is the patient with condition and intervention, the amount of information offered by staff, prior experiences with like events, self-confidence

3) The patient's judgement about responsibilities: health care professionals have primary responsibility, but patients acknowledge importance of own role, e.g. informing of current medications and allergies. However, patients emphasised the importance of a good quality patient-professional relationship for this to work

4) The patient's judgement of consequences of speaking up: positive response facilitates further speaking up, concern that challenging professionals might result in substandard care

Improvement of patient safety

It is concluded that the patient-professional relationship and health professionals' attitudes shape patients' confidence in speaking up and raising concerns and thus whether some patient safety issues are ignored or go undetected. Apart from a potential adverse event not being addressed, this can also lead to significant emotional harm of the patient. Concurrently with speaking up campaigns, listening up campaigns for health care workers is suggested.

Other

Most research has thus far focused on patients to ask clinicians if they washed hands and to speak up. Research is needed on professionals' attitudes to these strategies.

6. Survey	
Paper	What do primary physicians and researchers consider the most important patient safety improvement strategies? *BMC Health Services Research* 11(102), pp. 1-6
Year	2011
Author	Sander Gaal et al.
Country	Netherlands
Sector	Primary care

Contribution

Identifies the most effective patient safety strategies as considered by an international panel of primary care physicians.

Method

Web-based surveys undertaken by 58 individual physicians and researchers (convenience sample) from eight primarily European countries with a strong primary care system (Austria, Denmark, France, Germany, the Netherlands, New Zealand, Slovenia, UK). The questionnaire considered 38 patient safety strategies based on previous studies (among them Gaal et al. 2010, see below) and telephone interviews with five international experts. The guide was subsequently reviewed by three experts. It considered current use and potential of the 38 patient safety strategies as estimated by respondents. 46/58 respondents were practising GPs.

Safety risks

N/A

Improvement of patient safety

According to the authors, many definitions of patient safety exist, the shortest being to do no harm to patients. Among health care staff, patient safety is broadly perceived. The survey considered five themes: practice facilities, patient safety management, communication and collaboration, generic conditions for patient safety and education on patient safety.

Of the 38 strategies the respondents ranked an up-to-date electronic medical record and good telephone access to the practice as most important and considered these strategies widely present. Accordingly ranked on importance (but not current use) were standards for record keeping, learning culture, vocational training on patient safety for GPs and availability of patient safety guidelines.

Patient involvement

Of the 38 patient safety strategies, the ones that involved patient participation considered whether there were:

1) Campaigns to increase patients' and public's awareness of patient safety in general practice. 39.6% deemed this "very much important for patient safety" (3.8% deemed it > 50% present in country)

2) Surveys and other types of consultations of patients regarding safety incidents. This received 0% of importance (3.8% deemed it > 50% present in country)

3) Patient held medical records, which scored 49.1% (13.2% deemed it > 50% present in country)

Under the possibility to note other strategies, respondents did not include patient involvement. Overall, the GPs in this study are not very optimistic about the potential of patient involvement for improving patient safety.

Other

The authors conclude that the most promising approach to improving patient safety seems to be through education for health professionals. They point to the need to develop tools such as practice risk analysis, guidelines and attention to patient safety in vocational training.

7. Secondary analysis of observational and questionnaire data	
Paper	Patient safety features are more present in larger primary care practices *Health Policy* 97, pp. 87-91
Year	2010
Author	Sander Gaal et al.
Country	Netherlands
Sector	Primary care

Contribution

Explores whether specific characteristics of general practice influence patient safety management.

Method

Secondary analysis of data from a European Practice Assessment study consisting of questionnaires from 271 single, dual or group primary care practices (convenience sampling) in 10 European countries (Austria, Belgium, England, France, Germany, Israel, the Netherlands, Slovenia, Switzerland, Wales) and practice visits. The study team selected 45 items related to patient safety management, divided into 10 domains (see below). Practices were divided into rural/urban and categorised after working conditions, team climate, responsibility given and experienced work pressure as perceived by staff. The authors note that the EPA instrument is used in several other studies and is thus validated.

Bias is noted as the fact that the present study's defined outcomes were developed post hoc, i.e. taken from the EPA instrument.

Safety risks

N/A

Improvement of patient safety

From the questionnaires 10 measures of patient safety were defined: 1) practice building safety, 2) telephonic accessibility and triage, 3) medication safety, 4) incident reporting, 5) medical record keeping, 6) professional competence, 7) hygiene, 8) organised patient feedback, 9) quality improvement, 10) organised secondary prevention programmes. As mentioned, these were selected from the original EPA study.

In general, 8 out of 10 outcome measures (safety issues 1, 3-9) scored higher in large practices (>2 GPs). Practice size thus has the strongest impact on patient safety management. In practices with positive perceptions of physical working conditions, issue 1) also scored higher. Better safety management is explicitly expected by the authors to provide better patient safety, e.g. through systematic quality improvement programmes. The authors suggest that patient safety could benefit from larger practice size, although no causal relationships could be determined in the study between patient safety features and primary health outcomes.

Patient involvement

Among the included patient safety measures, issue 8) involves the patient, defined as whether the practice has a visible suggestion box, a complaint procedure and leaflets with practice information in the waiting room. Organised patient feedback scored higher in larger practices (> 2 GPs).

Other

The authors note, that research and development of patient safety has mostly focused on hospital care and encourage further research on the effect of practice size in patient safety management.

---

8. Literature review	
Paper	Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review *Quality and Safety in Health Care* 19, pp. **1-7**
Year	2010
Author	Jill Hall et al.
Country	UK
Sector	All health care settings

Contribution

Systematically compiles interventions involving patients in patient safety.

Method

A systematic literature search was conducted up to August 2008 of databases, report databases, conference proceedings, grey literature, on-going research, patient safety organisations and a hand-search of two journals (not specified). There were no language restrictions. Over 22,000 references were retrieved, but only 14 studies and one systematic review met the criteria; no on-going studies were identified. Of the 14 studies, two emanated from Europe (Belgium and the UK) and three in a GP setting. The review was from the UK. In interventions, participants were primarily English-speaking literate adults and elderly. It is noted that the methodological quality of the included studies was poor.

Safety issues/risks

The safety risks identified in the studies were: death, medication errors, adverse drug events and reactions, close-call (near miss) drug errors and patient reporting of adverse clinical events.

Patient involvement

The review identified 14 intervention types under the following headings:

1) Patients informing management plan with relevant information

2) Self-monitoring and ensuring safe delivery of treatment

3) Patient representation on making systems safer.

The authors note that success of patient participation depends entirely on patients' views and preferences.

Improvement of patient safety

Eight studies and the systematic review regarded intervention type 1); half of them reported improved outcomes. Three studies related to intervention type 1) and 2); two of them reported favourable outcomes. Two studies related to intervention 2); they reported no difference or no safety incident outcomes.

7 of 14 reviewed studies and the systematic review reported at least one outcome related to patient safety incidents, all related to the use of medications. Due to concerns about the methodological quality of the studies, the only evidence of effectiveness regarding patient participation in patient safety was found in self-management of medication (oral anti-coagulants).

Patient tip-sheets are the most common safety intervention used by health care providers. Others are participating in reporting systems. However, there is little evidence on these interventions' efficacy.

Other

The authors note that little is known about patients' willingness and ability to adopt patient safety promoting behaviours and that patients are rarely included in the development of interventions. Future research should focus on areas other than medication safety, consider appropriate research design for the intervention and include qualitative methods.

---

9. Discussion paper	
Paper	Can the patient be on our team? An operational approach to patient involvement in interprofessional approaches to safe care *Journal of Interprofessional Care* 20(5), pp. 527-534
Year	2006
Author	Amanda Howe
Country	UK
Sector	Primary and secondary care

Contribution

Presents a concept of patient safety in the context of risk management in health care.

Method

The article is termed a 'discussion paper'. It conceptualises patient-centered practice in patient safety and focuses on bringing together health care workers across disciplines to facilitate this. Based on a non-systematic literature review, the author lists two types of initiatives that have "already been promoted to address safety issues" (p. 529) by the NHS:

a) error reduction: patient rights sensitisation, advocacy organisations, patient skill development ('speaking up'), educational campaigns, informed consent, making wishes known, patient choice of provider, planned advocacy arrangements for individuals, security-proofed workflows, confronting poor communication

b) error containment and resolution: detecting deviance from policy or standards, detecting errors, reporting concerns or adverse events, patient involvement in post-event explanations, litigation, coroner's inquest

Safety issues

The author finds safety risks in primary care in six main areas: getting access to services; communication leading to breakdown in patient-clinician relationships; diagnostic errors; prescription errors; errors in organisational systems; technological failures. The areas involve interaction across health care disciplines, and a checklist is put forth for working towards the improvement and management of patient safety, which places emphasis on the professionals' approach and organisational facilitation more than patient involvement *per se.*

Patient involvement

Barriers to patient involvement in improved safety are listed as time, attitudes, power relationships and different worldviews. The barriers can be intrapersonal (patient's condition and personality); interpersonal (patient-professional relationship); and regarding cultural background (both that of patient and professional). The author states that in exploring patient safety, only one article found asked the question "Could patients themselves ever be seen as team members?" (p. 528).

Improvement of patient safety

The author finds that one of the greatest benefits of patient participation is the potential to increase professionals' awareness that their actions have consequences. This can moderate professionals' risk-taking behaviour and may lead to error-prevention, development of a stronger organisational safety

culture, professional behaviour change, enhanced adherence to advice and improved self-management. Interventions will be most effective, the author believes, if they include patients and all professional disciplines and aim to change "professional attitudes and behaviours" (p. 532). Patient involvement, however, varies according to patient and professional motivation, ability and expertise.

Other

More research is needed on the willingness of patients to participate in their own care, on the extent to which measures of effective teamwork correlate with patient involvement and positive safety measures.

10. Mixed methods study	
Paper	Patient safety culture in primary care: developing a theoretical framework for practical use *Quality and Safety in Health Care 16*, pp. 313-320
Year	2007
Author	Susan Kirk et al.
Country	UK
Sector	Primary care

Contribution

The study develops and tests a framework for making the concept of safety culture meaningful and accessible to managers and frontline staff.

Method

Phase 1: literature review and postal survey of experts to identify key dimensions of safety culture in primary care. Semi-structured interviews with 30 clinicians and managers from 6 primary care trusts about key dimensions and organisational maturity in relation to patient safety.

Phase 2: 33 interviews and 14 focus groups with participants sampled from phase 1 sites

Safety issues/risks

N/A

Improvement of patient safety

8 dimensions of a patient safety culture in primary care are identified: 1) overall commitment to quality, 2) priority given to patient safety, 3) perceptions of the causes of patient safety incidents and their identification, 4) Investigating patient safety incidents, 5) Organisational learning following a patient safety incident, 6) communication about safety issues, 7) personnel management and safety issues, 8) staff education and training about safety issues, 9) Team working around safety issues.

Organisational descriptions were developed for how these dimensions may be characterised at five levels of organisational maturity. The resulting framework aids clinicians' and managers' understanding of patient safety culture and promotes discussions with teams about their safety culture maturity.

Patient involvement

There was debate about whether patient involvement should be a separate dimension, but most interviewees argued that patient involvement was a component of all the dimensions and would be more evident in organisations with a mature safety culture.

Other

Participants in Phase 2 thought that the concept of safety culture would be unfamiliar to many of the potential users of the framework.

11. Literature review	
Paper	Patient Participation: Current Knowledge and Applicability to Patient Safety *Mayo Clinic Proceedings* 85(1), pp. 53-62
Year	2010
Author	Yves Longtin et al.
Country	Switzerland
Sector	Secondary and primary

Contribution

Reviews the principles of patient participation, its efficacy and barriers.

Method

Literature search from January 1966 to December 2008 in English and French. Keywords: patient participation, patient involvement, patient education, professional-patient relations, decision-making, informed consent, chronic disease, medical errors, infection control, nosocomial infection, cross infection. Reference lists were hand searched. Grey literature was not included. The article is according to the authors a comprehensive summary rather than a systematic review. It is noted that few included studies qualified as high quality of evidence.

Safety risks

The authors mention safety issues to be medical errors and these are seen as due to health care workers' knowledge and attitudes, deficient processes, poor equipment, poor technique, inappropriate environment, deficient management, inappropriate policies and patient behaviour.

Patient involvement

Current trends in patient participation include questioning health care workers, the initiative of WHO's World Alliance for Patient Safety, networks of patients and consumers to promote participation, advocacy and dialogue. The authors identify a shift from a paternalist care model, where the patient was a passive spectator, to the patient being a key player in its own health and in improving the system by demanding quality and lodging complaints. However, despite abundant literature, it is noted that the concept of patient participation is poorly defined and can relate to diverse aspects such as decision making, self-medication and -monitoring, patient education, goal setting and taking part in physical care.

Factors influencing participation are found in the reviewed studies to be acceptance of new patient role; level of health literacy; level of confidence in own capacities; type of decision making required; stakes of the proposed outcome; type of illness and comorbidity; age; sex; socioeconomic level; ethnicity; use of alternative medicine; health care worker professional specialty. Specific obstacles to participation on the part of the patient is thus the patient's refusal; low health literacy; type of decision-making situation; severity of disease; older, male and less educated patients; less interested; non-Western cultures; lack of assertiveness in consultation (e.g. referral and prescriptions).

Obstacles to participation on the part of the professional are a desire to maintain control; time; type of illness; personal beliefs; professional specialty; ethnicity; training in participation. More specifically barriers were seen in health care worker's attitudes; withholding information; exercising paternalistic power over patients; lack of time; primary physicians more willing than specialists; Caucasian more than non-white.

Improvement of patient safety

Efficacy in patient participation interventions in decision-making and treatment of chronic disease suggests that participation could be successfully extended to prevention of medical errors, but considerably less evidence exists. Studies of hand hygiene among health care workers are presented, showing varying results. A model is proposed for patient participation in safety, comprised of giving attention to the above factors regarding patient and professional.

Other

More research is needed, as there is conflicting evidence of the efficacy across all possible factors of patient involvement in patient safety.

12. Qualitative study	
Paper	Harmed patients gaining voice: Challenging dominant perspectives in the construction of medical harm and patient safety reforms *Social Science & Medicine* 71, pp. 510-516
Year	2010
Author	Josephine Enyonam Ocloo
Country	UK
Sector	Primary and secondary care

Contribution

Discussion of how alternative narratives of power and accountability should be considered in patient safety reforms.

Method

2,5 years of Participatory Action Research was conducted among medically harmed members of:
a) Medical Harm Self-Help Network, a campaigning group
b) The Break Through Programme, a two day residential programme in October 2005
Further, data analysis of websites, legal documents and reports, as well as questionnaires (18 received) and ten individual interviews with group members were conducted.

Safety risks
The network members recounted diverse experiences of harm, such as catching hospital infections, being damaged through vaccine injecting, experiencing birth trauma, not being diagnosed with epilepsy or injured by surgical or other treatments. They did not feel included in patient safety reforms; were met with a culture of denial when tackling safety issues; and the regulatory bodies failed patients. The group recommends recognition of "lay perspectives".
Participants in the Break Through Programme experienced misdiagnosis and being prescribed the wrong medication. They noted that professionals routinely covered up medical harm and treated the patient as the problem; external organisations failed to provide independent investigations. The patients wanted to share their personal stories.

Patient involvement
A common denominator in participants' experiences was that of professional resentment when they addressed their concern, by both individual doctors and health care organisations. The author notes that in Denmark, Sweden and the UK policies and no-fault compensations schemes are being developed to manage medical malpractice claims. However, the author points to studies showing that legal action for financial compensation is not the primary motive of raising concern; rather it is to get an adequate explanation.

Improvement of patient safety
The study shows that harmed patients felt that their experiences have served as a catalyst for the patient safety movement in health care, but that the clinical markers still determine reform efforts. It is that the development of a patient safety culture is hindered by a culture of denial in the UK, a lack of openness and transparency and failure of complaint procedures to bring justice. To improve patient safety the perspective of harmed patients is suggested to be included in policy reform.

Other
It is mentioned that research mainly covers hospital settings and rarely primary care.

---

13. Discussion paper	
Paper	Recent developments in patient safety in primary care
	Quality in Primary Care 15, pp. 165-167
Year	2007
Author	John Sandars et al.
Country	UK
Sector	Primary care

Contribution
Presents an overview of the main challenge areas in patient safety in primary care.

Method
Based on a selective review of news items on safer healthcare and the National Patient Safety Agency's websites, and on the author's involvement in patient safety research, an overview of recent advances in patient safety in primary care is put forth.

Safety risks
The main risks are
1) Delayed diagnosis: the most common cause; 54% of malpractice claims
2) Use of medication: 13% - 51% of reported adverse events in primary care
3) Poor communication with patients
4) Lack of a positive safety culture.
However, few issues of harm to patients are known in primary care. The author quotes between five and 80 cases per 100,000 consultations, but methods differ which complicates estimation. Still, the author has registered recent developments in patient safety in primary care, such as increased understanding of threats and new methods to reduce these threats. He lists recent initiatives such as reporting and investigation systems, patient involvement and the appreciation of a safety culture.

Patient involvement

Regarding 3) poor communication with patients, the National Patient Safety Agency has launched the Please Ask campaign, and there seems to be encouragement to offer information on side-effects, to question treatment and to report on safety concerns. In the US and Australia, insurers in the medical malpractice field require specific communication skills training as a condition of being insured.

Improvement of patient safety

The author estimates that 60% - 83% of patient safety issues are preventable.

Other

The above-mentioned interventions need to be developed and assessed further.

Grey literature

14. Consultation Report	
Paper	Practice-level indicators of safety and quality for primary health care. Australian Commission on Safety and Quality in Healthcare
Year	2011
Author	Australian Commission on Safety and Quality in Healthcare
Country	Australia
Sector	Primary care

Contribution

Presents the consultation process in developing voluntary indicators for safety and quality in primary health care.

Method

The University of Tasmania undertook the research, including two focus groups in March 2011 with peak and expert groups and a literature review and environmental scan. Further, the Commission conducted consultations with representatives of stakeholder groups. Neither is further specified.

Safety issues

The seven dimensions of safety and quality are accessibility; appropriateness; acceptability/patient participation; effectiveness; coordination of care; continuity of care; and safety. The candidate indicators in each dimension are suggested for inclusion in the national set of practice-level indicators for safety and quality in primary care.

Patient involvement

The proposed indicators for the dimension of patient participation are self-rated health; patient experience survey; patient experience survey response rate; satisfaction with patient experience; patient complaints response; and informed consent for treatment.

Patient safety

The proposed indicators for the dimension of safety are adverse drug reactions and medication allergies; patient safety incidents investigations; patient safety incidents follow-up; and infection control.

15. Consultation report	
Paper	Proposed National Safety and Quality Framework. Consultation report Australian Commission on Safety and Quality in Healthcare
Year	2010
Author	Australian Commission on Safety and Quality in Healthcare
Country	Australia
Sector	Primary and secondary care

Contribution

Summarises the consultation process leading to a national framework on national safety and quality in health care.

Method

1) 179 written comments submitted from national educational, private, insurance, consumer, government, health services, safety and quality organisations.

2) An online survey completed by 924 consumers, clinicians, health service managers, researchers and

policy makers
3) Consumer workshops in nine cities, one national workshop and one telephone conference
4) 12 peak body focus groups, including GP and patient safety organisations
5) 12 key informant interviews with representatives of stakeholder organisations

Safety issues

N/A

Improvement of patient safety

The framework presents three general strategies for improving patient safety: patient-focused; driven by information; and organised for safety.

Patient involvement

Feedback on the patient-focused strategy acknowledged the importance of involving patients in safety through 10 steps: a) to develop service models which improve access to health care, b) to increase health literacy, c) involve patients in decisions about care and life planning, d) provide care that is culturally safe, e) enhance continuity of care, f) minimise risk at hand-over, g) provide case management for complex care, h) facilitate patient-centred service models, i) promote health care rights and j) inform and support harmed patients.

Other high priority issues were added, that were not in the framework, but many of which pertains to patient involvement: recognition of carers as partners across the continuum of care; support for end of life care planning; improved communication between patients and providers, assistance from patient advocates, improved coordination of services, ensure patients and consumers are involved in health system planning and decision making, education for professionals on patient focused care , communication and health care rights.

Feedback on the key safety strategy 'driven by information' agreed on the framework's suggestion to learn from patients' and carer's experiences, although some surveys saw this as problematic, as it cannot be applied in all settings and patient experiences are too subjective. Feedback on the 'organised for safety' strategy also noted involving consumers in the design of the health system.

16. Background paper	
Paper	Patient safety in mental health
	Canadian Patient Safety Institute and Ontario Hospital Association
Year	2009
Author	Tracey A. Brickell
Country	Canada
Sector	Primary, secondary and tertiary care

Contribution

Outlines current issues in patient safety across mental health settings.

Method

1) A literature review was undertaken on patient safety incidents related to violence and aggression; suicide and self-harm; seclusion and restraint; patient accidents; absconding and missing patients; and adverse medication and diagnostic event. Studies in English published after 1999 included. 66 websites were searched for grey literature.

2) 19 telephone interviews with professional key informants within patient safety and/or mental health.

3) One roundtable discussion event with 72 patient safety and mental health professionals.

Safety issues

The authors delineate factors contributing to safety risks in mental health as pertaining to:

- the patient: behaviour, condition, comorbidity
- the provider: attitude to patients, work demands, communication between professionals and with patient, experience, information flow between health care settings
- the organisation: recruitment, training programmes, work processes and policies, resources, relation to other sectors of care
- the physical environment: design of inpatient units, residences and private homes

The authors urge a systemic approach that takes structural factors into account.

Patient involvement

In the literature review, further research is encouraged, not least on the patient and family's perspective on patient safety in mental health and the emotional harm inflicted following adverse events. During the telephone interviews, no patient involvement was touched upon that is included in the report.

During the roundtable discussion overcoming mental health stigma through attention to the patient's perspective as well as seeking input from patient and family to further safety is mentioned as possible strategies, i.e. patient on review boards, creating patient groups that may contribute to patient safety programs.

Improvement of patient safety

During the interviews, priority issues were mentioned as follows: medication safety, suicide, slips and falls, aggression/violence. Insufficient resources were seen as a barrier to safety improvement. Change in provider attitudes deemed central.

During the roundtable discussion, access to care was identified as a patient safety issue, especially children, elderly and rural residents.

Other

The poor quality of studies on this subject was mentioned, and a need for further research on patient safety in mental health care was identified. The authors also note that the patient's perspective is rarely represented in existing literature.

---

17. Literature review	
Paper	Improving patient safety
	Patient-focused interventions. A review of the evidence. Picker Institute Europe, pp. 143-178
Year	2006
Author	Angela Coulter and Jo Ellins
Country	UK
Sector	Primary and secondary care

Contribution

Maps current initiatives and possible future developments of enhancing patients' role in patient safety.

Method

Electronic search of databases, specialist websites, patient organisations and a reference scan of key English language papers published 1998-2006 on patient-centered interventions. The studies are of varying quality.

Safety issues

Medical errors are listed as related to diagnostic, treatment, prevention, other (i.e. communication, equipment or system failure). The list is not sector specific. Safety concerns are found in health care organisations, as well as in nursing homes, ambulatory care and patient self-management.

Patient involvement

The patient as active partner is understood as making informed choices about providers; helping to reach accurate diagnosis; sharing decisions about treatments and procedures; contributing to safe medication use; participating in infection control initiatives; checking the accuracy of medical records; observing and checking care processes; identifying and reporting treatment complications and adverse events; practicing effective self-management; shaping the design and improvement of services.

Of these, few interventions have been developed and tested (except for patient adherence to medical treatment). The report finds that the following interventions have been evaluated: infection control initiatives (six intervention studies on hand hygiene in hospitals), adherence to treatment (18 systematic reviews on simpler regimens, patient education, home counselling and aids, patient cards, self-reporting, patient motivation), patient reporting of adverse drug events (two intervention studies), equipping patients for safer health care (one systematic review, two intervention studies), wrong surgery prevention (one intervention study). In a UK survey, it was found that only 6% of harmed patients wanted disciplinary action, 11% financial compensation and 34% only an apology or explanation. Doctors, in another study, did not disclose medical errors to patients as often as they felt they ought to (32% versus 70%).

Improvement of patient safety

The report finds Patient involvement in infection campaigns have proved effective. Of other strategies, the most effective is simplifying dosing regimens. Educational interventions seem unlikely to be effective on their own. The rest of the interventions showed mixed results. The long-term impact is not able to be determined on the basis of the included studies and reviews.	
Other	
Further research is needed on ways in which patient safety can be enhanced through patient involvement, including patients' willingness and ability, the efficacy of interventions, barriers to implementation, patient education. Research also needed to establish the incidence of errors and adverse events in primary care and other non-acute settings.	

18. Background paper	
Paper	Patient Safety In Primary Care
	BC Patient Safety & Quality Council and Canadian Patient Safety Institute
Year	2010
Author	Joann Kingston-Riechers et al.
Country	Canada
Sector	Primary care

Contribution

Describes patient safety in primary care including its unique issues and challenges, and interventions aimed at enhancing patient safety.

Method

1) A systematic search of scientific and grey literature was conducted in databases, on the internet as well as through reference lists. Methodological quality was not considered. 1.323 publications were found, of which 46 studies were included in the review.

2) 16 telephone interviews with Canadian and international experts (clinicians and researchers) in patient safety.

3) A round-table event, where literature and interview findings were presented and discussed.

Safety issues

The literature review revealed two primary themes in patient safety, namely missed or delayed diagnosis and medication management. These were affected by aspects of communication, administrative processes and professional's knowledge and skills. Especially women and elderly seem to be at risk.

The interviews showed the following concerns among experts: quality of information available to providers, coordination of information between providers, ease of use and integration of new information in practice, ability of patients to understand and use information, the opportunity to build long-term relations with patient, physical and virtual infrastructure in clinical setting, care of patients with yet unclear diagnosis, information integration between providers. Elderly patients, polypharmacy, First Nations, non-questioning patients and patients with communication challenges were seen as most exposed to safety issues.

The round-table discussion largely substantiated the literature and interview findings, in that diagnosis, medication management and communication were seen as key issues.

Patient involvement

The literature reviewed was not reported by the authors to include patient involvement, except for one patient education intervention which showed favourable results for patient safety outcomes and one electronic safety message system intervention directed at patients regarding their medication, which reduced adverse drug events.

In the interviews, the expert informants stressed the time aspect in communication with patients and the latter's ability to understand and use information as important to patient safety.

The round-table meeting suggested bettering patient-provider communication by creating mutual understanding of their respective perspectives, expectations and responsibilities, but that lack of time and fee-for-service mechanisms challenge this.

In conclusion the report mentions including patients and their families in safety and quality improvement.

Improvement of patient safety

Strategies to improve patient safety are described as documenting and collecting information about adverse events, benchmarking and national guidelines, including patients and families in quality improvement, incorporating patient safety in curricula and bettering inter-professional communication.
Other
The authors state that research on all aspects of patient safety in Canada's primary care is needed.

19. Report of pilot project	
Paper	Sygeplejefaglig indsats over for hjemmeboende borgere, som anvender flere lægemidler samtidigt. En rapport om resultater og udfordringer til medicinhåndtering i hjemmesygeplejen. *(Nursing care for clients living at home and using several pharmaceuticals concurrently. A report about results and challenges in medication management in home nursing)*.
Year	2010
Author	Municipality of Copenhagen
Country	Denmark
Sector	Primary sector

Contribution
Assesses the conditions for medication management in home nursing. Concludes that a systematic account of medication in home care might benefit polypharmacy patient living at home.
Method
Data collection took place through observation of 36 home visits by a home nurse and a health care consultant in 18 homes of polypharmacy patients. Patients were between 68-101 years old; 14 were female. The visits focused on the patient's medicine status. Additional data about the patient's medicine and medical history was extracted from the Municipality's home care database.
Safety issues
The pilot project showed that medication errors were extensive: patients on average consulted 10 physicians concurrently, medication lacked coordination and patients saw several home care workers. The report lists the following challenges: lack of medication harmonisation; no clear responsibility for medication harmonisation; lack of information about new drugs in the home; discrepancies between physician's prescriptions and medicine lists; lack of information about medication after ambulatory treatment; lack of information to physician and home nursing about medication alteration after discharge; omissions and errors in documentation of medication on medicine lists in home nurse documentation system.
The report also points to the lack of knowledge among all stakeholders, including the patient, about indications, effect and side effects etc.
Patient involvement
The pilot project showed that patients did not wish to be involved in their own treatment. This was assumed to be due to the range of different and changing medication taken daily and their state of illness (confusion, pain, tiredness, forgetfulness, lack of energy). Thus offering them training was not found realistic.
Improvement of patient safety
During the pilot project, medication errors were significantly reduced by the systematic account during home visits, but could not confirm that it motivated the patient to acquire knowledge about treatment and use of medication, nor could it be measured whether health care workers in other units acquired knowledge about the patient's health status, as a systematic review of this was not possible.
Other
The full scale of the pilot project is not discussed here; only aspects relating to patient safety and patient involvement.

20. Literature review	
Paper	Patient Safety in Primary Care: a review of the literature Australian Commission on Safety and Quality in Healthcare
Year	2009
Author	Alan Pearson et al.
Country	Australia
Sector	Primary care

Contribution

Defines patient safety risks in primary care, reviews international research hereof and describes research gaps.

Method

Scoping review of English language peer-reviewed and grey literature, reviews, opinions, reports and guidelines published in 1999-2009, conducted in databases of completed and on-going research. 33 papers were included out of approximately 1,800 papers. The review was based on two features:

1) Safety risks in primary care

2) Interventions to minimise risks in primary care

A narrative form was adopted for the review due to the diverse field of the literature.

Safety issues

Evidence points to the following safety risks:

- Process errors: diagnosis, prescribing, communication, policy, administration.
- Therapeutic activity: language barriers, judgment, communication between offices, mistimed procedures, medication errors.
- Specific interventions: Lacks in clinical information, failure to maintain ultrasound equipment, contaminated ultrasound equipment, failure to sterilise instruments and equipment, failure to review and manage polypharmacy in older people, prescribing errors during dispensing and transcription stage, errors due to high medication volumes, pharmacist fatigue and overwork, interruptions to dispensing, drug names, lack of systematic dispensing and regulatory guideline, patient's misunderstanding of label instruction, insufficient formatting and readability of medication information, gaps in US patient medication knowledge, lack of GP training in cardiopulmonary resuscitation techniques.

Taxonomy of errors in GP is put forth on the basis of the literature: process; administration, treatment, communication, payment, knowledge and skills, diagnosis, treatment decision, task execution. The types of harms or consequences reported by health care staff were found to be regarding patients, time/financial cost, delay in care, pain, emotional/psychological, temporary physical, hospitalisation, permanent/very serious, death.

Patient involvement

One paper described the provision of leaflets to encourage patients to raise queries concerning treatment, but despite a patient satisfaction outcome, no patient safety improvement was measured. One paper examined patient-professional tele-communication intervention, but found no long-term improvement to patient safety. Patient involvement through education, self-monitoring, medication cards and medication reviews by/with a pharmacist could improve compliance and reduce risks. Sharing of information deemed central. Less impact was found in encouraging patients to monitor treatment and report incidents, unless combined with a national scheme.

Improvement of patient safety

22 of 51 papers were included showing moderately positive evidence of solutions to enhancing patient safety in primary care regarding the following: event analysis is feasible in the UK, pharmacist led medication review to reduce hospital admissions, in electronic prescribing improves accuracy, IT alerts for prescribing, computerised link of prescribing to lab results, educational interventions in medical students and practitioners, communication between patient and professional via telephone helpline, GP access to radiological experts via technology, computer technology to prevent medication errors. The main challenges seem to be related to organisational change, prescribing, communication and diagnosis and no simple solutions are applicable.

Other

Describing the research gaps, the authors mention involving patients in driving a safety agenda.

21. Reference guide	
Paper	Seven steps to patient safety for primary care. The full reference guide National Patient Safety Agency
Year	2006
Author	Suzette Woodward
Country	UK
Sector	Primary care

Contribution

Presents a best practice guide describing seven key areas of patient safety activity for primary care organisations.

Method

The seven key areas form a toolbox, which is based on a thorough literature review (not further specified) of international patient safety studies and developed in collaboration with patient safety experts and National Health Service staff and organisations.

Safety issues

Patient safety risks are not explicitly defined, but mentioned broadly as unintended or unexpected incident that could have or did lead to harm; it covers adverse events, clinical errors and near misses.

Improvement of patient safety

The seven steps are to: 1) build a safety culture, 2) lead and support your staff, 3) integrate risk management 4) promote reporting, 5) involve and communicate with patients and public, 6) learn and share safety lessons, 7) implement harm-preventive solutions.

The premise of the toolbox, not least based on the reviewed literature, is that patient safety is enhanced through primary health organisations' implementation of the seven steps.

Patient involvement

Patients are described as experts in their own condition and as willing to partner in their own diagnosing, treatment, risk assessment and self-monitoring. Step 5) implies a) involving patients and public in developing safer systems, b) involving patients in self-care, c) being open and encouraging two-way dialogue, d) engaging with patients during investigations, e) providing support for patients.

22. Report	
Paper	Patient Engagement in Reducing Safety Risks in Health Care
Year	2011
Author	World Health Organization
Region	Europe
Sector	Primary and secondary care

Contribution

The project aims to improve patient safety by enhancing patient empowerment and health literacy. The report describes four studies of patient involvement in patient safety undertaken in four different European countries. It is the study on "Increasing patient role in mediation prescribing in and pharmacotherapy safety in Poland" that is relevant for this review.

Method

The study included a review of relevant national legislation, focused pilot survey primary care physicians and patients and a specialist overview.

Safety issues

Doctors are obliged by Polish legislation to report adverse drug reactions (ADR). Patients' rights do not cover medication safety and/or the provision of patient education. The pilot survey showed that only 30% of patient knows names and dosages of their medicine. 82% of primary care physicians expect patients to present a list of their medicines but rarely ask to see it. 76% of physicians have never reported an ADR.

Patient involvement

Patient organisations need to take an active role in providing relevant skills, knowledge, empowerment and encouragement to individuals and organisations related to the prevention of ADR.

Improvement of patient safety

A comprehensive approach to improvement of patient medication safety is suggested, including doctors, pharmacists, patients and other stakeholders.