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CONSUMER and COMMUNITY ENGAGEMENT:

A review of the literature



ACI NSW Agency
for Clinical
Innovation



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ABBREVIATIONS

ACI	Agency for Clinical Innovation
ACSQHC	Australian commission on Safety and Quality in Health Care
AIHI	Australian Institute of Health Innovation
ARC	Australian Research Council
BCNA	Breast Cancer Network Australia
CERP	Community Engagement Research Project
ePHRs	Electronic personal health records
HTA	Health Technology Assessment
NHHRC	National Health and Hospital Reform Commission
NHMRC	National Health and Medical research Council
NICE	The National Institute for Health and Clinical Excellence
PPIP	The Patient and Public Involvement Programme
SDM	Shared Decision Making
SIGN	The Scottish Intercollegiate Guidelines Network

DEFINITIONS

The table below illustrates the varied definitions encountered in systematic reviews of the literature evaluated as part of this meta-review. The variations and the lack of precision in terminology used to define “consumer and community engagement” are further explored in section 1.2 of this report. This lack of definition and conceptual clarity is a major finding of the literature review. One of the outcomes of the CERP study could be achieving a consensus on key definitions, in consultation with stakeholders.

TERM	DEFINITION
Community (1)	<i>Living in the same geographical area and sharing the same problems and resources.... know one another and have a feeling of togetherness’ However, geographical proximity does not always equate to social cohesiveness and shared interests, particularly where there are imbalances in resource availability, cultural heterogeneity, ethnic tensions, itinerant populations or governance systems that promote individualism (Atkinson et al, 2011:3)</i>
Community (2)	The first issue in evaluating community engagement strategy is to understand what ‘community’ is. This is not straightforward, since ‘communities’ may consist of individual citizens or of groups of citizens organised to represent a community’s shared interests. In developing definitions of community, most scholars have generally agreed that communities can be characterised by three factors: geography, interaction and identity. Communities primarily characterised by geography represent people residing within the same geographic region, but with no reference to the interaction among them. Communities primarily identified by regular interaction represent a set of social relationships that may or may not be place based. Communities characterized primarily by identity represent a group who share a sense of belonging, generally built upon a shared set of beliefs, values or experiences; however, the individuals need not live within the same physical locality. Given these different conceptions of community, it can be difficult to identify a community to engage with. Furthermore, different communities may interact with each other , or it may be unclear who in the community has formal or informal authority or the resources to engage in particular processes (Bowen et al 2010: 6)
Community (3)	<i>Community is a fluid concept; individuals may belong to multiple communities at any one time. We use the following definition: a group of people united by at least one but perhaps more than one common characteristic, including geography, ethnicity, shared interests, values, experience, or traditions. (Brenner et al, 2011: 87)</i>
Community	<i>... the process of working collaboratively with and through groups of</i>

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TERM	DEFINITION
engagement	<i>people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioural changes that will improve the health of the community and its members. It often involves partnerships and coalitions among partners, and serves as a catalyst for changing policies, programs, and practices. (CDC, 2011: 7)</i>
Community participation	<i>We defined 'community participation' in Chagas disease vector surveillance as simply the involvement of local residents in reporting the presence of suspect bugs in their households. This narrow definition is justified by the need to use some measure of effect size that is (at least qualitatively) comparable across studies (Abad-Franch, 2011: e1207)</i>
Engagement	<i>We developed a working definition of engagement as "actions individuals must take to obtain the greatest benefit from the health care services available to them." This definition emphasizes the role of the individual independent of changes aimed at improving the effectiveness of the health care system. (Gruman et al, 2010: 351)</i>
Health information	<i>Health information was defined broadly, to include conventional medical information as well as information about health conditions, treatments, complementary and alternative medicines, and physical or emotional well-being. This broad definition was used because in practice consumers do not make distinctions between these different types of health information (Car, 2011: 9)</i>
Participation	<i>Unfortunately, we do not have a standard definition of participation or of any of these other partly overlapping concepts. That is no problem in itself—there probably is limited consensus on many other concepts that are commonly used in rehabilitation. However, the problem is more significant with respect to participation than in relation to other terms that are key to rehabilitation. In addition, participation appears to be a part of the social model of disability, not the medical model, and issues such as the proper relationship of individual to society, biological and social standards for normality, and so forth, play a role in defining and operationalizing the concept. Participation at first blush appears to be a simple concept to measure, but each attempt to construct an instrument needs to address issues in conceptualization and operationalization that get at the core of science epistemology and methodology (e.g., value-free measurement) and of metrologic theory and practice (e.g., CTT vs. clinimetrics). (Dijkers, 2010: 5)</i>
Person-centred planning	<i>There is no universal definition of person centered planning. ... the researchers described person-centered planning in general terms of a person-centered planning process ... investigators specified the described planning processes as a personal career plan ..., innovative and culturally responsive person-centered practice..., and later-life planningthe authors defined the person-centered planning process as Whole Life Planning... and Personal Futures Planning (Claes et al, 2010: 433)</i>
Public	<i>In the UK, the term 'public' is said to include: patients and potential patients; people who use health and social services; informal carers; parents/guardians; disabled people; members of the public who are</i>

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TERM	DEFINITION
	<i>potential recipients of health promotion programmes, public health programmes and social service interventions; and organisations that represent people who use services (Boote et al, 2010: 12)</i>
Public involvement in research	<i>Public involvement in research has been defined as doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public.... Three main levels of public involvement have been identified ...: these are (1) consultation (where researchers seek the views of patients and members of the public on key aspects of the research); (2) collaboration (an on-going partnership between researchers and the public throughout the research process); (3) ‘user-control’ (where the public designs and undertakes the research and where researchers are only invited to participate at the invitation of the public) (Boote et al, 2010: 12)</i>
Shared Decision making (SDM) (1)	<i>In SDM, the intention is that patients and health professionals share both the process of decision making and ownership of the decision made. Shared information about values and likely treatment outcomes is an essential prerequisite, but the process also depends on a commitment from both parties to engage in the decision-making process. The clinician has to be prepared to acknowledge the legitimacy of the patient’s preferences and the patient has to accept shared responsibility for the treatment decision (Abreu et al, 2011: 242)</i>
Shared Decision making (SDM) (2)	<i>The concept of SDM has suffered from being variably and loosely defined in the literature ... Despite the conceptual work ..., they found that inconsistency of definition and in many cases no reference to preceding work ... proposed an integrative model of SDM that built upon the most widely used definitions. For a decision to be a ‘shared’ decision it has to have certain characteristics. It must involve at least two participants, and the sharing of information. The decision (which may be to do nothing) must be made and agreed upon by all parties ... identified that the suitability of a decision for SDM depends upon the clinical context, patient preferences, and practitioner responsibilities. ... was necessary to add another component to the model: ‘ongoing partnership between the clinical team (not just the clinician) and the patient’ (Duncan et al, 2010: 3)</i>

EXECUTIVE SUMMARY

This review of the literature on consumer and community engagement examines the evidence for consumer and community engagement, maps out the field as it currently stands, and identifies the gaps in what is currently known about the best way to engage consumers and communities in healthcare services and research. The review, a meta-analysis of existing systematic reviews, was conducted in 2012.

We used a list of 47 phrases and 11 MeSH terms to undertake a comprehensive search of relevant databases, including Pub Med, EMBase, EBM Reviews, CINAHL, APAPsycNET, and Scopus. The aim of the review was to identify the most systematic English language reviews, which addressed the issue of community engagement in health care.

From the original identification of 10078 initial findings, 117 systematic reviews were included in this review. An overview of the included reviews indicated that there is an ambiguity and perplexity in the relevant terminology and taxonomy. On the one hand, different phrases were used to refer to similar concepts; and on the other hand, some phrases were used to refer to different topics. Other authors have also observed this confusion and have referred to the problems caused by the situation.

By ‘community engagement’, the authors referred to different activities that were described on a continuum. Evaluation of case studies of consumer and community engagement in different countries and various health conditions revealed that shared decision making is generally valued among consumers and health care professionals; however, there are many prerequisites that are yet to be developed before routine implementation of consumer and community engagement is possible. Barriers such as cost, time, literacy (both health and general) are commonly noted. Education of both health professionals and consumers is a commonly advised strategy, but is not, on its own, sufficient to ensure the effective implementation of consumer and community engagement strategies. A scarcity of evidence on the impact or value of consumer and community engagement strategies was noted in several key areas. Considering a wide range of identified factors that are involved in consumer and community engagement implementation of such approaches seems to be a long term process that requires a systematic approach and built in evaluation.

This review has mapped out and identified the gaps, concepts, facilitators, and barriers related to community engagement in health care. As a result a model is proposed that

identifies eight different areas that need to be explored to facilitate implementation of consumer and community engagement in healthcare.

1. INTRODUCTION

This section provides a brief background on a research project of the Agency for Clinical Innovation (ACI) and the Australian Institute of Health Innovation (AIHI) of the University of New South Wales. It outlines the key definitions used within the field, provides a schema of consumer and community engagement in healthcare, and furnishes a snapshot of the range and type of engagement directed at consumers and communities. This section is based upon a review of the consumer/community engagement literature which was undertaken to ascertain the breadth of the field, key search terms, and potential search limits.

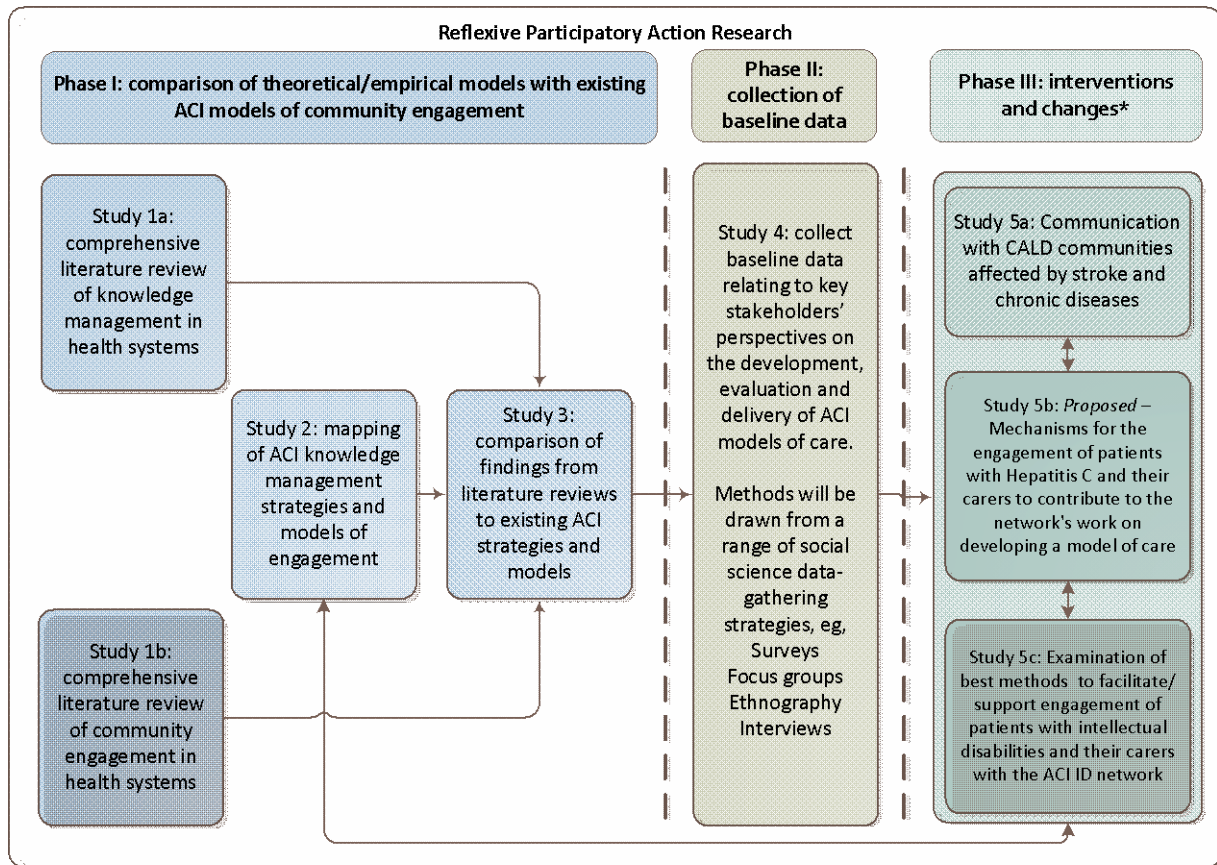
1.1 BACKGROUND

The ACI and the AIHI established a research partnership in 2011, with the aim of examining and advancing ACI's work on consumer and community engagement. The *Community Engagement Research Project* (CERP) brings together ACI staff, network members, clinicians, consumers, carers and members of the wider public in this endeavour.

CERP will inform the development of ACI's models of care and knowledge management strategies aimed at the wider community. The project has four objectives. These are to: capture and evaluate existing consumer and community engagement knowledge, models and practices across the ACI networks; evaluate the impact of the consumer and community engagement process; develop model(s) to extend consumer and community engagement to vulnerable groups; and test these models in a number of select groups. A three phase, five study project methodology (Figure 1, next page) was developed in order to meet these aims and objectives.

The work of the ACI is closely aligned to broader policy and service delivery trends in both the government sectors and non-government sectors (McCaffery et al., 2011). Community engagement is supported by the Australian Health Ministers (Australian Charter of Health care rights), the Australian Commission on Safety and Quality in Health Care (ACSQHC), and the National Health and Hospital Reform Commission (NHHRC) (McCaffery et al., 2011). The Australian Health Ministers have recently approved the Australian Charter of Healthcare Rights, which implies good health outcomes are dependent on consumers' participation in decisions about their care and health (ACSQHC, 2008).

Figure 1: CERP project methodology



The NHMRC has supported implementation of community participation via their 'Statement on Consumer and Community Participation in Health and Medical Research' and 'Model Framework for Consumer and Community Participation in Health and Medical Research' (McCaffery et al., 2011, NHMRC and CHF, 2002, NHMRC and CHF, 2005). In 2010 the NHMRC and Australian Research Council (ARC) funded three grants which were related to community engagement (McCaffery et al., 2011).

1.2 COMPLEXITY OF DEFINITIONS

Consumer and community engagement is one of the most complex areas of health care practice and research, and it is challenging to define accurately. This is because both terms – 'community' and 'engagement' are ill-defined, and have many synonyms (Baggott and Forster, 2008, Contandriopoulos, 2004). For community, the literature

can refer to: patient, patients, consumers, citizens, clients, service users and carers (in relation to patients) amongst many other terms. Engagement terms vary from the principles, including for example patient or consumer participation or choice to the practice, including examples such as patient or consumer surveys, patient networks, complaints mechanisms, consumer councils or boards, or citizen's juries.

The phrases 'community engagement' or 'public involvement', the words 'community' and 'public' could refer to different overlapping groups of people: patients and service users, carers, taxpayers, and representatives (Menon and Stafinski, 2011). Overlapping terms of engagement, participation, empowerment, or involvement could be also variously defined (Evans, 2010, Goss et al., 2011). Attree et al have suggested that 'community engagement' is an umbrella term that could refer to various approaches, with different aims (Attree et al., 2011). Arguably the best known model of consumer and community engagement, Arnstein's ladder of citizen participation, describes a hierarchy of engagement, from non-participation (which allows for the public to be educated and influenced by those who are in power), to co-operation, and delegation of full power and control to the citizens, which in turn enables the public to influence decision making and be in effective control of the systems they are seeking to influence (Menon and Stafinski, 2011, Attree et al., 2011). Another example of a particular definition and classification is provided by Brenner et al, who refer to a continuum model for community engagement that starts from 'community consultation, to community participation, and ends to community consent' (Brenner and Manice, 2011).

This variation and different use of concepts could be problematic. Eyssen et al (Eyssen et al., 2011) Levasseur et al (2010), Cook and Oliver (2011) and Dijkers (Dijkers, 2010) all concluded that variation in the definition of participation is particularly problematic. Moore and Kirk specifically reviewed children and adolescents' participation in decisions related to health care and reported that participation is defined and interpreted in different ways by different groups (Moore and Kirk, 2010). Differences in definition are geographic and locational, as well as conceptual. Legare et al reported that only in Canada is shared decision making linked with 'knowledge translation'. This, they argue, implies application of research evidence to enhance people's health and health services (Legare et al., 2011b). Chung et al reported that differences in definitions of participation both within and across service types, including community-based rehabilitation, and commented that this has led to many controversies (Chung et al., 2011).

The need for clear definitions is supported by Gruman et al (2010). They argue that a clear definition of the concept of community engagement is important for two reasons. The first is that such a definition is essential if healthcare providers and researchers are to be able to assess the size of the challenge of the engagement process for both the health care system and consumers. The second is that such a definition is required in order for services to be able to focus and tailor their engagement strategies and interventions (Gruman et al., 2010).

1.3 RATIONALE FOR CONSUMER AND COMMUNITY ENGAGEMENT IN HEALTH CARE

For almost fifty years there has been a recognition of the need for a more active role for consumers in health care, what Mold (2010) refers to as the inclusion of patient 'choices' and patient 'voices', with the aim of improving service delivery, patient experiences, and patient outcomes (Crawford et al., 2002). The impetus behind consumer involvement in health care has continued to grow and to change over the decades. Although a number of patient/consumer organisations have been active since the 1950s, momentum built in the 1960s and 1970s with the emergence of the patient rights' movement (van der Zeijden, 2000) as part of large scale citizenship and social rights movements (Harrison et al., 2002). These movements include both a general focus on the role of patients and consumers, and more specialised foci on specific advocacy areas, including for example HIV-AIDS (Roy and Cain, 2001).

The patient-consumer rights movement came about at the same time as an increased questioning of professional power and medical beneficence (the right of the professional to withhold information from patients) (Will, 2011). This movement was also linked to gained increased media and public scrutiny in the aftermath of major patient safety inquiries (Stanley and Manthorpe, 2004). This, coupled with a growing revelations that patients have been involved in medical research without their knowledge (Bloche, 2001) raised broader issues of consent, and active consumer involvement in and autonomy from medical decision making (Will, 2011).

In more recent years three additional factors have opened up the space for the more active engagement of consumers. The first of these is changing nature of patient profiles (Wilson et al., 2005), in particular the increasing number of individuals living with chronic and complex conditions. The second are the large scale reform agendas which have swept most developed countries, including Australia (Fulop et al., 2002, Braithwaite, 2005). The third is the involvement of patients in the patient safety movement, that is in monitoring and developing strategies for responding to medical errors and adverse events (Ward et al., 2011).

1.4 GAPS AND BARRIERS TO CONSUMER AND COMMUNITY ENGAGEMENT IN AUSTRALIA

In 2006, NHMRC reported that there was a lack of evidence for consumer and community engagement in relation to health information (NHMRC, 2006). It suggested that barriers to effective consumer and community participation included (NHMRC, 2006):

- Lack of infrastructure support of organisations
- Lack of skill and confidence in organisations
- Lack of skills in consumers
- Insufficient opportunity for vulnerable groups for input
- Weak links between providers of health information and recipients
- Disseminating information without consumer inputs

A series of specific challenges to community engagement, including stigma, language and cultural differences were also identified (NHMRC, 2006). The NHMRC's conclusions are supported by other international and Australian studies. These studies found similar barriers to engagement of consumers and communities in health system planning, provision, reform and research (Fudge et al., 2011, Happell and Roper, 2007, Oliver et al., 2004, Woodall et al., 2010). Time factors and geographic distance are commonly identified as adding to the difficulties in engaging consumers (McCaffery et al., 2011, Bajramovic et al., 2004). Consumer literacy – both health and general, further complicates the process (ABS, 2006). At least one study identified physical and psychological exhaustion of involvement as a barrier to the engagement of some people with disabilities (Attree et al., 2011).

Structural issues, such as the division of Australian health care into national and state/territory governments presents particular challenges to consumer and community engagement. Australia lacks a national strategy for implementation of consumer and community engagement, along with adequate resources to implement such strategies (McCaffery et al., 2011).

Consumer engagement also requires new perspectives and approaches both on the part of the consumer and the professional. Hibbard et al have suggested that advocating community engagement might be pressing clients to adopt new roles (Hibbard, 2009). It is important to note that different perspectives on what consumer and community engagement is, or should be, can operate within and across

organisations, and between different consumers and staff members and between members of different professions, at any one time (Fudge et al., 2011, Daykin et al., 2004). A more centralised approach to support research and implementation of consumer and community engagement has been suggested (McCaffery et al., 2011).

1.5 LEVELS OF CONSUMER AND COMMUNITY ENGAGEMENT

Three levels of consumer and community engagement were identified by Travaglia and Robertson (Travaglia and Robertson, 2011). These include:

Micro: consumer to clinician, direct where consumers are seen as experts/equal partners in the delivery of care; where consumers have an active role in assessing and directing the quality and safety of their own or their family member's care; and or where consumers directly participate in research (Wright-Berryman et al., 2011, Maslin-Prothero, 2003, Tattersall, 2002, Hall et al., 2010a).

Meso: consumer and community engagement in service and information planning and delivery; in designing, directing or governing research including through ethics committees; in evaluating the effectiveness of services; and or in developing or directing information about health care issues (Webster, 1996, Boote et al., 2010, Simpson and House, 2002).

Macro: consumers are engaged as part of health system consumer councils; in state or country wide ethics committees and review mechanisms; in patient safety inquiries; on professional boards and bodies; in setting professional and service standards; accreditation boards; and or in agencies like ACI (Crawford and Rutter, 2004).

Studies have explored community engagement from various perspectives: at an individual level, consumer and community engagement can refer to the active participation of consumers in consumer-clinician communication, risk communication, the acknowledgement and incorporation of consumer and patient preferences, and evidenced based patient choice (McCaffery et al., 2011). The concept is referred to with different terminologies that have overlaps and differences, such as 'shared decision-making (SDM)', 'patient participation', and 'consumer and community participation'.

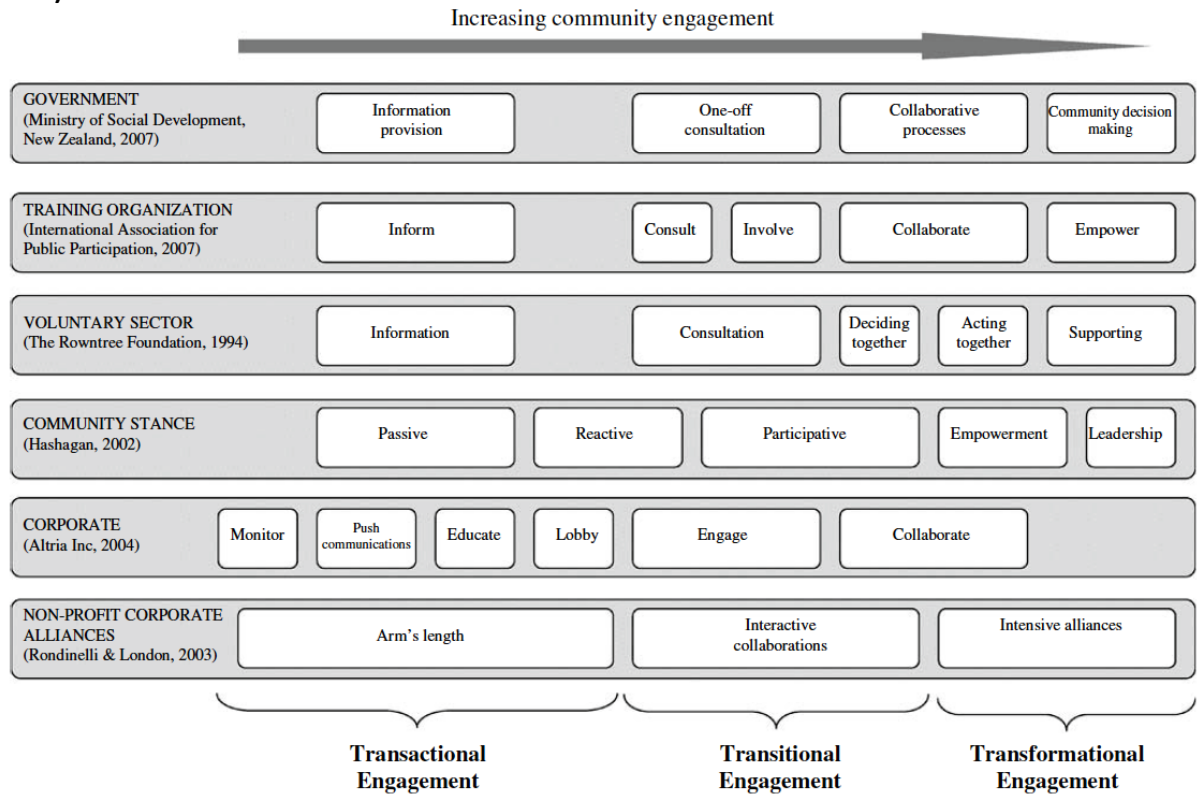
Community engagement occurs in different fields, in different ways and for various purposes. In some instances its focus is the clients who are receiving services, for

example strategies to involve clients in the development of consent documents (Guarino et al., 2006); or consumers could be involved in health related research or in prioritising health services (Kitzhaber, 1993). Consumers are also involved in activities such as peer support, management and governance of services, units or programs, sitting on ethics committees at a service or state level, developing or reviewing guidelines or consumer information, and direct training of healthcare professionals (Fudge et al., 2011). Various strategies and mechanisms are employed for community engagement. These tools can range from democratic prioritisation (Johanson et al., 2002), discussion and deliberation (Dolan et al., 1999), and co-designing (Iedema et al., 2010).

While the macro, meso, micro analysis of consumer and community engagement is common, other conceptualisations of community engagement are also widely utilised (Bowen et al., 2010). Bowen et al, for example, employ the 'continuum of community engagement'. Engagement strategies within this model fall into three categories, these are: 'transactional, transitional, and transformational engagement', as illustrated in the Figure 2 (Bowen et al., 2010).

In this, the Bowen et al model, in the first stage, the community has a passive role and is receiving information (e.g. charitable donations, employee volunteering, and information sessions). In the second stage, there is a more active role for the community and there is a two way communication, but the community is still more a recipient than an equal participant (e.g. stakeholder dialogues, public consultations, meetings). In the third stage, there is shared decision making, and the community has an equal position (e.g. joint management, joint decision-making, co-ownership) (Bowen et al., 2010). Bowen et al suggested that community engagement will provide long-term benefits, rather than immediate cost-benefits (Bowen et al., 2010).

Figure 2: Community engagement strategies, adopted from Bowen et al 2010 (Bowen et al., 2010)



1.6 WHAT ARE THE KNOWN BENEFITS OF CONSUMER AND COMMUNITY ENGAGEMENT?

It is important to note that while the principles of consumer and community engagement are strong, the evidence for it actually improving patient outcomes is relatively weak if 'gold standard' measures of outcomes are considered (Crawford et al., 2002, Simpson et al., 2009, Nilsen et al., 2006). At best, most evidence is mixed, meaning that the impact of consumer and community engagement is not clear, that it is context dependent or that it requires further study (Wright-Berryman et al., 2011).

One notable exception is the impact of user involvement in the development of patient information, where this input was found to result in information which was more relevant, 'readable' and understandable than that produced by clinicians alone (Nilsen et al., 2006). Consumer perspectives can assist in making health information more balanced and relevant to patients, and increase the chance of meeting the needs of consumers (NHMRC, 2006). There is some evidence for the implementation of organisational change based on community involvement (Crawford et al., 2002).

At an individual level, consumers involved in engagement activities have reported that involvement in engagement activities made them feel as though they were being listened to by professionals, that their ideas were being acted upon, and that their individual experiences as a patient was being used to help others (Fudge et al., 2011, Crawford et al., 2002). Overall, building more effective consumer networks can contribute to improvements in the wider community and in the active citizenship of individuals and groups (Krebs and Holley, 2006).

1.7 TARGET GROUPS AND STRATEGIES

Strategies to engage consumers can be targeted at the public in general, or at particular groups, such as culturally and linguistically diverse communities (Henderson and Kendall, 2011) or Aboriginal and Torres Strait Islander communities (Liaw et al., 2011). Which consumers are involved depends, in the first instance, on the level and type of involvement. Both these factors are discussed later. The question of which consumers are involved depends also on whether the consumer is involved as an individual or as a representative, and in the latter case of what or whom.

Consumers acting as representatives of communities have fallen into three broad categories: those who represent themselves; those who represent specific communities or groups (including patients); and those who are asked to represent consumers or patients in general. In many developed countries formal consumer groups for patients, that is, those ‘representing the patient away from the politics of specific diseases’ have existed since the mid 1950s (Mold, 2010: 506). Just how representative consumers are or are meant to be is a complex and much debated question within this field (Crawford et al., 2003). Recent research reiterates the need to examine whether the involvement of some, and not other consumers, can lead to an increase marginalisation of some groups (Fudge et al., 2011).

The NHMRC emphasises the diversity of consumer perspectives, supporting the need for the utilisation of multiple engagement strategies and approaches, particularly but not only for minority and vulnerable groups (NHMRC, 2006). Underpinning these approaches are the principles of equity, transparency and enhanced communication, along with more pragmatic issues such as clear policies, resources and training for participants. This needs to be supported, they argue, by precisely defined roles and responsibilities and the involvement of consumers in all health information-related steps: planning, development, evaluation, and dissemination (NHMRC, 2006).

Amongst the consumer and community engagement mechanisms and tools suggested by the NHMRC are:

- Consumer representation, e.g. the SIGN Patient Involvement Project
- Consumer and community advocacy, network of consumers with similar conditions; e.g. Breast Cancer Action Network
- Community development (joint work of consumers and workers on health information)
- Consumer and community partnership (involving consumers in key decisions; e.g. indigenous communities)
- Focus groups (could be used to involve smaller or marginalised subgroups)

Consumer groups have recommended a similar range of strategies. These include: enhancing health literacy, encouraging community participation and empowering consumers; and increasing consumer representation (McCaffery et al., 2011, NHHRC, 2009). A full discussion of strategies to strengthen consumer and community engagement is outlined in section 3 of this report.

2. METHODOLOGY

2.1 BACKGROUND

CERP study 1 is essentially a scoping study or review. Scoping studies are useful maps, used to examine the literature on a given topic, identifying the key themes, concepts, approaches and evidence, as well as to identify gaps in the literature. In research projects such as CERP, scoping studies can be useful in establishing the parameters of the research (e.g. not replicating existing research) as well as providing directions for the conceptual and methodological framework (Arksey and O'Malley, 2005).

Unlike systematic reviews (such as Cochrane reviews), scoping studies do not seek to examine the entire evidence base on any given topic – but rather identify and examine the most important references, building on existing reviews. The differences between a systematic review and a scoping study are summarized in Appendix 1.1.

A preliminary review (discussed in the previous section) indicated that the concept of community engagement in health care is wide and diverse and it is necessary to further map out the field. It was also noted that there are vast numbers of systematic reviews already available which address the related topics and sub-topics associated with consumer and community engagement. It was therefore deemed to be both feasible and appropriate to focus the scoping review on an analysis of existing systematic reviews (meta-review).

2.2 AIMS

This review has four aims. These are to: identify existing systematic reviews on consumer and community engagement in health care; to analyse these reviews as a way of identifying the evidence base for consumer and community engagement; to identify the gaps in current knowledge; and finally, to create a map of the field to date.

2.3 DATABASE SEARCH

A range of databases were identified as appropriate to this review. The databases searched included:

- Pub Med Central

- Embase
- EBM reviews (including EBM Reviews - Cochrane Database of Systematic Reviews, EBM Reviews - ACP Journal Club, EBM Reviews - Database of Abstracts of Reviews of Effects)
- CINAHL
- APAPsycNET (including PsycINFO, PsycEXTRA, PsycCRITIQUES, PsycARTICLES)
- Scopus [Health Sciences: covers source titles in: Medicine, Nursing, Veterinary, Dentistry, Health Professions, Multidisciplinary (> 6,800 titles. 100% Medline coverage)]

2.3.1 Search terms

Key phrases, identified in the preliminary search were applied in the final review. Terms were tested and cross checked for alternatives definitions or alternative spellings. The final list of search terms is presented in Tables 1 and 2.

Citations and abstracts were downloaded into Endnote X5, a bibliographic database. The authors also identified and followed up on references within reviewed articles, and conducted a hand search of key journals, utilising the same terms.

Table 1: Search terms relating to community engagement

SEARCH TERMS
user involvement
user led research
user controlled
user representative
user participation
user contribution
user oriented
community collaboration
community participation
community representative
community engagement
community input
community led
community involvement
lay representative
lay perspective
lay perception
lay involvement

SEARCH TERMS
lay voice
lay participation
lay network
lay control
lay member
consumer participation
consumer involvement
consumer groups
consumer network
consumer driven
consumer advocacy
consumer generated
consumer engagement
patient perspective
patient involvement
patient driven
patient led
patient participation
patient representative
patient engagement
citizen participation
citizen involvement
citizen engagement
citizen deliberation
citizen representative
client representative
client involvement
client participation
client engagement

Table 2: Search terms relating to community engagement - Medical Subject Headings

Medical Subject Headings (MeSH)
patient participation
patient involvement
community networks
health information networks
consumer participation
participation: health care decisions
community role
community-institutional relation
consumer participation
patient participation
consumer networks

2.3.2 Inclusion criteria

A number of criteria were established to decide which articles would be reviewed. The articles included were those which were:

- Systematic reviews that directly addressed community engagement in health care (thorough evaluation of the method of engagement)
- Participants: all health care clients
- Target conditions: all health problems
- Search terms: consisted of phrase searches and Medical Subject Headings (MeSH) searches (a per Table 1 and 2 above)

There were no geographical limitations.

2.3.3 Exclusion criteria

A number of criteria were established to decide which articles would be excluded from the review. The documents which were excluded were those which:

- Were opinion pieces, books, chapters, discussions, and letters
- Had no geographical restriction
- Were publications in languages other than English

2.3.4 Additional limits

At first inclusion and exclusion criteria were applied to titles and abstracts. Full texts of the remaining citations were obtained and evaluated for inclusion or exclusion. The first authors' recommendations were reviewed by the second author, and any differences were resolved through discussion.

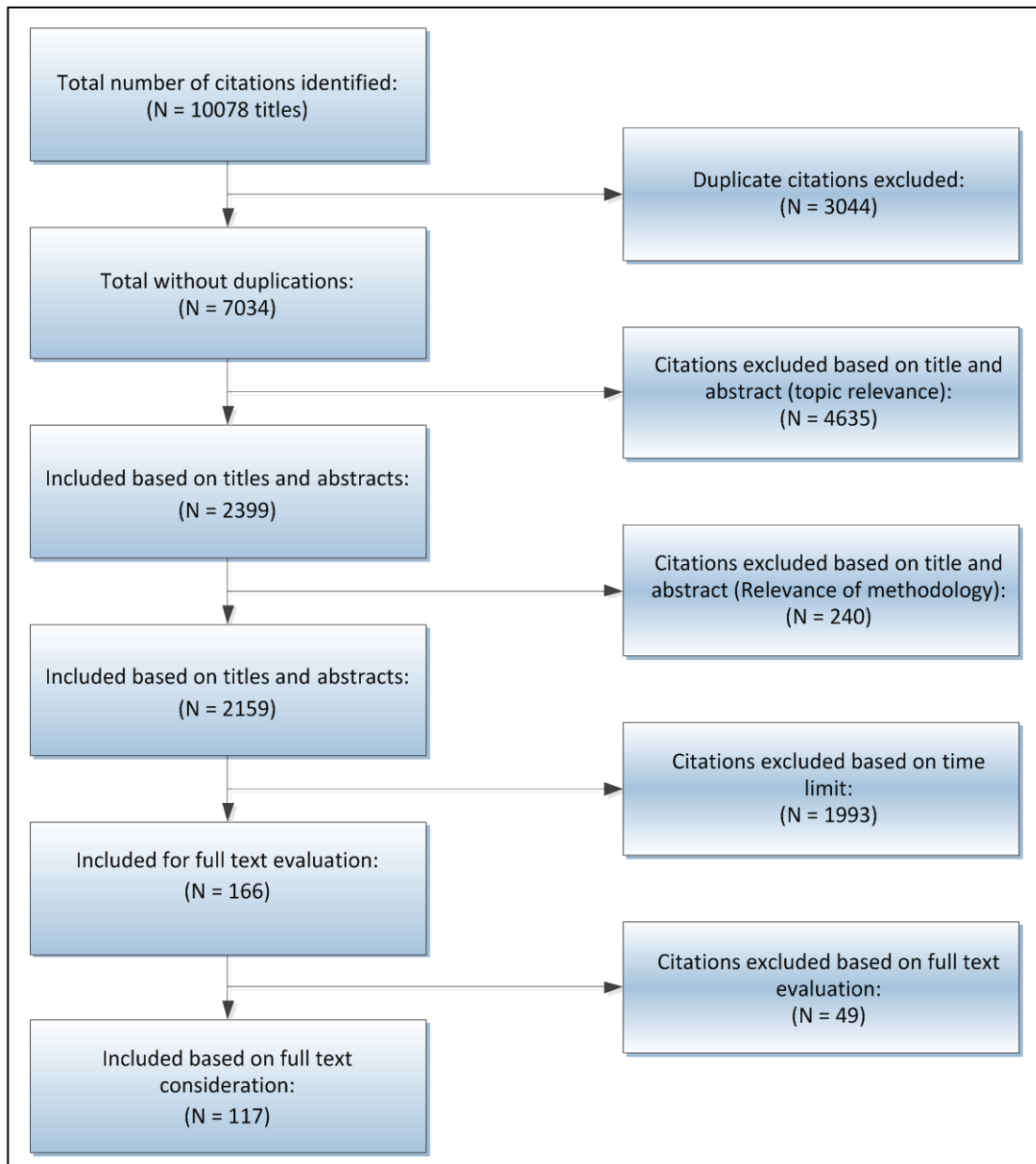
The results of the review are presented in Figure 3. The initial search produced 10078 citations. After excluding duplicates (n=3044), 7034 citations were evaluated by title and abstract. A total of 4635 citations were excluded and 2399 citations included, at this stage.

The full list of citations are listed and classified in Section 8. Classifications are based on the themes that emerged during the review, as discussed in the following sections. It should be noted that although some citations are placed in more than one theme, the majority are allocated to one theme only. This full list has been analysed using data mining techniques. The results of that analysis are presented in a separate report.

Given the size and the scope of the findings, a new exclusion criteria, that of papers produced before 2010 (n=1993) was applied.

This left a total of 166 papers dated 2010 and 2011 to be included for full text consideration. During the final stage 49 papers were excluded after evaluation of the full text considering the topic relevance or methodology and 117 papers were analysed and evaluated. A table of key details of these paper and their abstracts are presented in Appendix 1.2 and 1.3 respectively.

Figure 3: Summary of study inclusion and exclusion process



2.3.5 Data analysis

Analysis of the included papers was conducted based on predetermined themes and also emerging themes. The predetermined themes considered for analysis of papers were concepts, barriers and facilitators. In addition, a thematic approach was used to analyse the result of reviews, informed by grounded theory (Glaser, 2008). Emergent themes were grouped together, leading to the development of broader overarching concepts. The analysis process included:

1. Examination of full text of each included paper for key themes, topics and sub-topics
2. Review of papers under each topic and sub-topic for salience and fit within the topic area
3. Identification of methods, findings and conclusions of each topic
4. Creation and review of a table organised in relation to 1 – 3 above.

3. FINDINGS

3.1 INTRODUCTION

The review identified a complex set of inter-related concepts, strategies and approaches relating to community engagement. A thematic map of consumer and community engagement in health care is presented in Figure 4. The map represents the five major, inter-related themes associated with consumer and community engagement in health care. These are: 1) community engagement; 2) patient centeredness; 3) clinician-consumer communication and interaction; 4) shared decision making; and 5) community based treatment.

Linked to each of these themes are a series of smaller concepts and themes. These include: community based research; research; policy; consumer evaluation of services; electronic systems; virtual consumer held information; informed decision making; decision aids; consumer education; outcome evaluation; management; informal care givers; virtual communities; self management and shared management. Each of the key themes and sub-themes will be addressed in turn.

3.2 CONSUMER AND COMMUNITY ENGAGEMENT

Consumer and community engagement addresses the need to increase citizen's awareness of, and involvement in, in health-related decisions such as the: prioritizing research and allocation of funding (Goss et al., 2011, Cornuz et al., 2011) and the design and delivery of interventions aimed at enhancing public health and reducing health inequality (Attree et al., 2011). The process can involve different aspects or elements, such as "patient involvement, participation, collaboration, education, and empowerment" (Goss et al., 2011: 279).

3.2.1 The case for consumer and community engagement

Numerous reasons have been identified to support the need to actively involve consumers in health care, and many are discussed throughout this document. Primary arguments include: the directive by the World Health Organisation that participation is a right of all people; the claim that consumer and community involvement is a means to the democratization of health care; that the involvement of consumers could reduce the gap between health care professionals and patients; and that it could help increase the acceptance and efficiency of health care (Tempfer and Nowak, 2011); the potential

contribution of consumer participation in the successful implementation of universal protocols (Conrardy et al., 2010); and, at a meso level, amongst many studies, there is the argument that widespread community involvement is among the factors that define successful programs, such as an Indigenous cardiovascular disease program (Huffman and Galloway, 2010).

3.2.2 Elements for successful implementation of consumer and community engagement

A number of factors have been identified as contributing to the success of consumer participation. These include: adequate financial and logistical support; adequate communications; collaboration with consumer organizations; and keeping the project at small scale (Tempfer and Nowak, 2011).

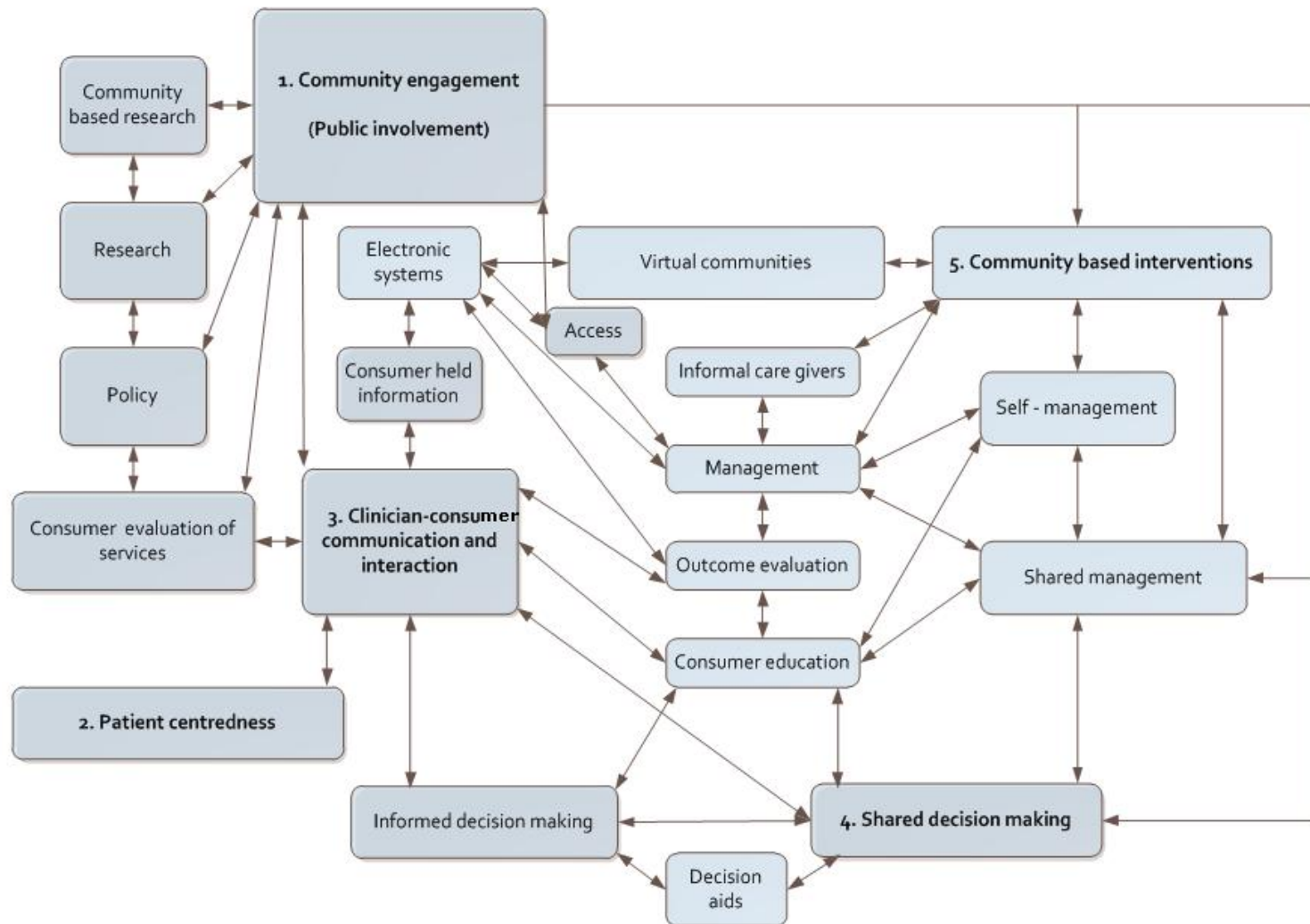
For vulnerable indigenous populations, additional factors such as: widespread community involvement; an explicit focus on the Indigenous population as a whole and high risk individuals in particular; the use of Indigenous health workers; and regular contact with participants were identified as contributing positively to the engagement process (Huffman and Galloway, 2010).

3.2.3 Engagement behaviour framework

One major review explored the subjective experience of consumers who were involved in consumer and community engagement initiatives (Attree et al., 2011). The reviewers found that although the experience of involvement could have positive consequences for the self-esteem and social relationships of consumers, some consumers found these experiences physically and financially demanding and exhausting (Attree et al., 2011).

Gruman et al identified the range of behaviours that consumers should undertake in order to receive the optimum benefit from the health care system, at an individual level (Gruman et al., 2010). The model included a range of interactions including 'preparing, acting, interacting and following up'. Activities identified included strategies such as 'seek and access the appropriate health care setting'.

Figure 4: Thematic map of consumer and community engagement in health care



3.2.4 Consumer and community engagement as an access strategy

Consumer and community engagement has also been used as a strategy to increase public's access to health care, for example via telemedicine (Myers et al., 2011). Here, participation did not necessarily mean active involvement in decision making, but refers rather to the engagement of individuals in existing, 'standard' care. Cooper et al examined differences in use of dementia care by various culturally and linguistically diverse groups and found that these groups have less access to medication and care. Their recommendation was that consumer and community engagement be utilised to address these inequalities (Cooper et al., 2010). Thomas et al came to a similar conclusion, in a review which considered strategies to increase influenza vaccination rates (Thomas et al., 2010).

In this concept the aim is to help patients, who have impairments, such as stroke patients (Graven et al., 2011), to participate in social activities (Levasseur et al., 2010). Here, participation is an index of patients' health and rehabilitation (Eyssen et al., 2011). Alternatively, patient participation could refer to other social activities, for example, Regan et al reviewed the literature on patient participation in public elections (Regan et al., 2011).

3.2.5 Consumer and community engagement for disease prevention and control

A sub-set of the literature specifically addresses the role of consumer and community engagement in the process of disease prevention and control, including chronic diseases. Studies identified included areas such as the role of consumers in: vaccination rates, controlling communicable diseases; increasing screening strategies; and improving physical activity.

Consumer and community engagement is considered an important element in increasing influenza vaccination rates (Thomas et al., 2010). Four types of strategies were identified: 1) interventions aiming to increase community demand (e.g. reminders, education); 2) interventions to increase access (e.g. home visits, free vaccinations); 3) provider based interventions (e.g. physicians reminder or education, incentives for physicians); and 4) society-level interventions (e.g. government policies) (Thomas et al., 2010).

Atkinson et al suggested that consumer and community engagement could have an important role in the control and elimination of communicable diseases. They reviewed 60 years of literature with the aim of providing guidance for malaria elimination campaigns (Atkinson et al., 2011). They could only find four papers that

evaluated community participation in malaria transmission and these papers were incomparable due to their methodological differences (Atkinson et al., 2011). The authors concluded that community participation could have a statistically significant effect in reducing disease incidence, but that community participation has a complex architecture (Atkinson et al., 2011). A similar study explored community participation in Chagas disease vector surveillance and provided examples of the value of community participation in this context, such as insect notification by householders (Abad-Franch et al., 2011).

Along with broad prevention strategies, a number of studies have explored the role of consumer engagement in screening for specific cancers. Bonfill Cosp et al reviewed studies on strategies for enhancing participation in breast cancer screening and concluded that an invitation letters, posting educational materials, telephone calls, and a combination of these approaches could be effective in increasing participation (Bonfill Cosp et al., 2010). However, they reported a lack of evidence as to which method is better (Bonfill Cosp et al., 2010). Spadea et al reviewed interventions aimed at enhancing cancer screening in women in lower socioeconomic groups (Spadea et al., 2010). They concluded that in order to improve access to screening, it is possible to lower the costs (e.g. free tests, reducing geographical barriers), increase involvement of primary-care physicians and modify communication to fit with the needs of different individuals (Spadea et al., 2010).

At an individual level, community participation in physical activity has long been identified as a way to improve health and decrease the risk of some diseases (Baker et al., 2011). Baker et al, however, found that available studies are not of good quality and that there is not enough evidence to determine if current approaches are effective in increasing community participation in physical activities (Baker et al., 2011).

3.2.6 Consumer and community involvement in research

Several studies addressed the involvement of consumers in health and healthcare related research. These ranged from those which considered direct consumer participation in research, to others which considered the involvement of consumers in shared decision making on the whole process of research design and practice. A smaller range of studies focused on the participation in research of vulnerable groups (e.g. children, ethnic groups). Community members have also had an active role in research projects, such as community-engaged studies (Dubois et al., 2011) and community-based participatory research (Chen et al., 2010).

DuBios et al reviewed the evidence on community engaged research (Dubois et al., 2011). They suggested that members of the public and consumers could engage in research in various forms. These include: representation on ethics committees; undertaking attitude research on study populations; involvement on community advisory boards; developing partnerships with community organizations; and undertaking the role of co-investigators (Dubois et al., 2011). The authors also referred to barriers for community-engaged research such as costs and the need for training (Dubois et al., 2011).

A complementary review of public involvement in research design (Boote et al., 2010) reported that group meetings were the most common method of public involvement, and suggested the following list for the contributions that members of public could make in the research design: checking the consent processes and information sheets; outcome recommendations; review of data collection processes; and giving suggestions on timing of study inclusions and follow ups (Boote et al., 2010). The authors also reviewed the evidence on public involvement in the systematic review process and concluded that the public could be involved in the process in different ways such as: defining the scope of the review, recommending and identifying relevant literature, evaluating the literature, interpreting the findings, and writing up (Boote et al., 2011).

Several reviews identified concerns about the representativeness of research participants, and found that because participants might reflect a limited range of backgrounds, the results of studies could become less relevant to other groups. DiClemente et al reviewed barriers to adolescent participation in HIV prevention research and concluded that there are individual, operational and community-level barriers to adolescents' participation in HIV biomedical research (Diclemente et al., 2010). Dhalla and Poole reviewed barriers of enrolment in HIV vaccine trials, and suggested that personal and social risk and costs, and misconceptions were the main barriers to participation (Dhalla and Poole, 2011).

Clavering and McLaughlin reviewed ways to include children's accounts in research. They concluded that although children's perspectives can be included at varying levels, sometimes it is not possible or appropriate (Clavering and McLaughlin, 2010).

In relation to the participation of ethnic groups, Cooper et al suggested that people with minority ethnic background are less likely to access clinical trials (Cooper et al., 2010). In comparison, a review by Sykes of response rates across and ethnic groups, found that different ethnic populations participate in surveys at a similar rate (Sykes et

al., 2010). Shah et al undertook a meta-analysis of qualitative studies on motivation of Indians to participate in clinical trials and suggested that mistrust, concerns, psychological reasons, burden, and languages as barriers to participation in research (Shah et al., 2010). Shah et al also referred to motivating factors for involvement in such research, including personal health benefits, trust, income, and knowledge (Shah et al., 2010). A study of participants in Brazil found that the most important barrier for participation in research was the fear of side effects, while the major motivator was altruism (Zammar et al., 2010).

Several barriers were identified to participation in mental health research. These included transportation problems, distrust of the researchers and the fear of stigma of mental illness (Woodall et al., 2010). The authors recommended using bilingual staff, providing help for transportation, avoiding stigmatising language, and educating potential participants as a way of overcoming these barriers. (Woodall et al., 2010).

Chen et al has introduced community-based participatory research as a method of investigation about complicated health problems that cannot be investigated by outside researchers alone (Chen et al., 2010). They reviewed dissemination of such results to non-scientific audiences, and found that there are challenges to timely and widespread dissemination of such findings. These included a lack of funding for dissemination, and difficulties in translating the results into a simple and culturally appropriate language for a lay audience (Chen et al., 2010).

Gona et al reviewed the literature on participatory rural appraisal and key informants and concluded that these methods could be used for identifying people with disabilities (Gona et al., 2010). Tapp and Dulin recommended the combination of community-based participatory research with practiced-based research networks to: undertake research that is more close to stakeholders' needs; develop a research methodology that is more amenable to participants; enhance recruitment; improve data collection; and aid in the rapid translation of results to the community (Tapp and Dulin, 2010).

Finally, consumer and community involvement in Health Technology Assessment (HTA) has been reviewed by a number of authors, including Menon and Stafinski (Menon and Stafinski, 2011) and Facey et al (Facey et al., 2010). Facey et al reported that because patients' views are often seen as biased and non-scientific, they are not included in HTA. They recommended that strong evidence on patients' views about HTA issues be gathered using social science research (Facey et al., 2010). Avar et al reviewed public involvement in health genomics (Avar et al., 2010) and reported that a considerable

proportion of current evidence does not clearly define what is meant by ‘public’ involvement, does not place the topic into its context, and does not clarify the goals of public engagement (Avard et al., 2010).

3.2.7 Consumer and community engagement in patient safety

Peat et al (Peat et al., 2010), Longtin et al (Longtin et al., 2010), Woodward et al (Woodward et al., 2010), Davis et al (Davis et al., 2011), and Hall et al (Hall et al., 2010b) reviewed evidence on the involvement of consumers in patient safety and reported inadequacy of evidence of the patient involvement on safety outcomes. Longtin et al identified both consumer and clinician related factors that could affect the involvement of consumers in the health care process. For consumers, these factors included the: acceptance of a new role, lack of knowledge and confidence, and sociodemographic parameters (Longtin et al., 2010). For healthcare professionals, the factors included the: desire to maintain control, time limitations, and personal beliefs (Longtin et al., 2010).

Schwappach and Wernli suggested that patients could observe errors in the administration of drugs and so could assist in error prevention (Schwappach and Wernli, 2010). They suggested that it is necessary to train, support and encourage patients to enable them to be cautious partners (Schwappach and Wernli, 2010). Schwappach in another review explored feasibility and effectiveness of patient involvement in error prevention (Schwappach, 2010). Schwappach reported that although patients have a positive attitude to be involved in their own safety, their intentions and behaviours could vary. Schwappach referred to lack of rigorous evidence on educational campaigns and suggested that complex behavioural modification and sensitive implementation is needed (Schwappach, 2010).

3.2.8 Consumer and community engagement of vulnerable groups

Several systematic reviews investigated how to enable patients with limitations and disabilities to return to society and participate in daily life and physical activities. This concept is core to rehabilitation and the aim is to measure health and functioning of recovering patients in different life situations (Eyssen et al., 2011).

Eyssen et al refer to participation as a sign of recovery, health and functioning and explored the instruments that evaluate participation of patients (Eyssen et al., 2011). They suggested that there are problems in the definition of participation, and as a result most of the instruments they found did not explore the whole possible aspects of participation (Eyssen et al., 2011). Dijkers addressed the problems that

conceptualization of participation has caused for its measurement and suggested that disagreements in the concept of participation has interfered with the progress of related services and research (Dijkers, 2010). Other studies and reviews have confirmed this lack of agreement on the definition of consumer participation and have concluded that further research into and clarification of these concepts, and their associated measures and tools, are required (Levasseur et al., 2010, Ziviani et al., 2010, Magasi and Post, 2010). Cook and Oliver referred to lack of agreement in the definition of key concepts in relation to sociability and community participation of children with intellectual disability (Cook and Oliver, 2011). They found that participation is poorly defined (Cook and Oliver, 2011). Studies of interventions aimed at community integration for children with brain injuries reported lack of evidence in this area (Agnihotri et al., 2010)

Some evidence exists for the impact of a range of specific interventions. These include the: efficacy of community-based interventions to increase stroke patients' mobility, activity and involvement in social situations (Graven et al., 2011); positive impact of active participation for people with spinal cord injuries (Reinhardt and Post, 2010); the participation of children with congenital limb deficiencies (Michielsen et al., 2010); the role of health promotion interventions in increasing community participation for people with physical disability and secondary conditions (White et al., 2011); and the participation in persons with impairment who use smart home technology (Brandt et al., 2011).

3.3 PATIENT CENTREDNESS

The concept of 'patient-centeredness' (or consumer centeredness) focuses on the need to consider patients' needs and concerns in the development and delivery of healthcare services. The review identified papers addressing patient centred care in relation to: person-centred planning, patient centred schedules and the application of patient centred care to children's healthcare.

Person-centred planning is an approach which develops individualized collaborative and goal-oriented programs focusing on community presence and participation, positive relationships and competence (Claes et al., 2010). Claes et al reviewed the literature on person-centred planning for patients with intellectual disabilities, and concluded that although this planning has positive outcomes, available evidence is weak and the impact is moderate (Claes et al., 2010). Rosewilliam et al reviewed patient-centred goal setting in relation to stroke rehabilitation and reported lack of rigorous evidence on efficacy of incorporating such methods (Rosewilliam et al., 2011).

Patient centeredness has also been applied to the delivery of services, through the medium of scheduling. An open-access and patient-driven scheduling method is claimed, by one review, to be 'more' patient-centred (Rose et al., 2011). But although the review found that this method could reduce waiting time and no-show rates, there was no clear evidence to support its role in patients' satisfaction and clinical outcomes (Rose et al., 2011).

One study explored the way children might be involved in their own health care (Curtis-Tyler, 2011). The reviewers identified a range of levers to patient-centred care with children. These included engaging with children about their experience of life and their preferences and willingness to engage with children without making any assumptions about children age-based capacities (Curtis-Tyler, 2011). The reviewers suggested that the levers are a change in historical focus of hospitals and therefore present different challenges in healthcare settings (Curtis-Tyler, 2011).

3.4 CLINICIAN-CONSUMER COMMUNICATION AND INTERACTION

Several systematic reviews examined communication between health care professionals and lay people and factors that could affect their relationship. This is an overlapping concept and other relevant reviews are presented in other sections, for example the relationship between e-health and clinician-consumer relationship is discussed in the e-health section.

In order to study the clinician-consumer relationship and the distribution of power within such relationships, different methodologies could be employed. Fine et al reviewed studies that have used direct observation as their research method (Fine et al., 2010). They reported clinicians may avoid emotional encounters and dominate sessions, while consumers are more satisfied with supportive behaviours (Fine et al., 2010). This could represent the importance of shared decision making in increasing consumers' satisfaction and also implies clinicians' culture as a potential barrier for consumer engagement.

3.4.1 Consumer information and education

Bunge et al examined the quality of information provided to consumers. They reported that although the information provided was in general based on good evidence and ethical guidelines, there was still a lack of evidence on quality of many aspects of information provided, including important elements such as the pictures used, narratives employed, language levels and cultural aspects of the information (Bunge et al., 2010).

In this perspective of patient participation, patients are invited to have active roles in educating or providing care and treatment for other patients (Doughty and Tse, 2011, Forbes et al., 2011, Macdonald and Turner, 2011, Lassi et al., 2011). Education of patients could be related to consumer participation, since it is suggested having access to health information will enable people to participate in their health care (Car et al., 2011). Therefore systematic reviews that explored education of patients in relation to community engagement are included in this study and considered in this section. Some of these systematic reviews explore whether patients should hold their medical records, or if they should have access to their medical records. Some other reviews investigated if patients have enough information about their condition or about how to get involved in health care. Gruman et al suggested that community engagement imposes new roles on patients and it is necessary to explore the best ways for delivering information to patients (Gruman et al., 2010).

A meta-review of the interventions used to promote use of advance directives concluded that the best educational method is to combine informative materials with frequent personal conversations (Tamayo-Velazquez et al., 2010). The authors reported that passive informative materials are ineffective, while interactive interventions could make a positive difference (Tamayo-Velazquez et al., 2010). Ryhanen et al concluded from their review of interactive computer-based patient education that there is a positive relationship between interactive computer-based education and the knowledge level of patients (Ryhänen et al., 2010). They also emphasised the need for more research on internet-based patient education (Ryhänen et al., 2010).

A scoping review of diabetes education found, amongst a range of other issues, that incorporating patient's choice, peer educators, health literacy, telecare models, and feedback technologies were all significant strategies in consumer education and engagement (Forbes et al., 2011). Other reviews of peer-led interventions, which examined their role in decreasing risk of HIV in youth, concluded that peer leaders could be a successful mean for education and changing knowledge and norms amongst young people (Maticka-Tyndale and Barnett, 2010).

Stephan et al reviewed the evidence aiming to enhance clinical trials education, and concluded that it is a complex issue involving multiple variables (Stepan et al., 2011). They recommended the development of decision aids, video/print resources, and age-specific booklets to support involvement in clinical trials, along with the provision of adequate time and clear, concise information to the consumers and the education of staff (Stepan et al., 2011).

Some of the systematic reviews reported the inadequacy of evidence to support evaluated educational interventions. Gagnon and Sandall found, in relation to antenatal education, a lack of high-quality evidence which means that the effects of antenatal education remain unknown (Gagnon and Sandall, 2011). Ryan et al considered the use of audiovisual education for people who attend clinical trials, finding only four papers. They concluded that uncertainty around the effectiveness of this type of education remains (Ryan et al., 2010). An analysis of the evidence for increasing online health literacy of consumers could only find two studies suitable for inclusion in the review and concluded that there is only low quality evidence to support the efficacy of that type of intervention (Car et al., 2011).

Consumers are also actively engaged in teaching and educating health care professionals. Jha et al considered the role of patients in intimate examination teaching. They found that such education could have positive short term effects, but that the long term effects and effects on the patients still need exploring (Jha et al., 2010). Towle et al came to a similar conclusion about the active patient involvement in the education of health care professionals, concluding that there is not enough rigorous research and that confusing terms are used (Towle et al., 2010).

3.4.2 The role of electronic information in consumer and community engagement

Changes in communication media and methods have increased the opportunity for the engagement of individuals and communities across the range of health care service delivery. In this section we consider how telepsychiatry, electronic personal health records, and the World Wide Web have affected consumer and community engagement.

Telepsychiatry (telemental health) is currently being utilised as one way to more actively engage underserved populations, including children and adolescents with mental health problems (Myers et al., 2011). One review study concluded telemental health could be a feasible and acceptable mode of health service delivery, but noted that the evidence for efficacy of such methods is still inadequate (Myers et al., 2011).

Ennis et al reviewed electronic personal health records (ePHRs) as a way of ensuring consumers are actively engaged in their healthcare. They found difficulties in access to information technology, recognizing appropriate people, dealing with sensitive information (Ennis et al., 2011) as barriers to the use of ePHRs. Ammenwerth found that while electronic health record portals may help consumers have more information about their conditions, having more information did not result in healthier individuals

and more evidence is needed to explore the impact of such tools (Ammenwerth et al., 2011).

This lack of evidence was echoed in other reviews. A review examining the impact of patient-held medical records concluded that there was an obvious advantage in implementing these records, but at the same time suggested that more high quality studies are needed in this regard (Ko et al., 2010). A examination of user-held personalised information for care of people with severe mental illness could not identify any suitable studies for inclusion in their review (Henderson and Laugharne, 2011).

While electronic health records have been discussed for some time, the impact of the World Wide Web on consumer and community engagement is still relatively new. Samoocha et al considered the effectiveness of web-based interventions on patient empowerment, measured empowerment with the diabetes empowerment scale, disease-specific self-efficacy scales and Pearlin Mastery scale (Samoocha et al., 2010). While they reported positive effects for web-based interventions, they could access only low quality evidence and found that the significant effect that they found was small (Samoocha et al., 2010). In comparison, Ryhanen et al concluded from their review of interactive computer-based patient education that there is a positive relationship between interactive computer-based education and the knowledge level of patients (Ryhänen et al., 2010). They also emphasized the need for more research on internet-based patient education (Ryhänen et al., 2010).

Application of web 2.0 technologies in health care has created terms like ‘health 2.0’ or ‘medicine 2.0’ (Van De Belt et al., 2010). However, a review of the literature aiming to identify a unique definition of Health 2.0 or medicine 2.0 concluded that there is no consensus in this regards (Van De Belt et al., 2010).

3.5 SHARED DECISION MAKING

The concept and strategy of shared decision making (SDM) relates to each of the levels of engagement, from micro to macro. As an underlying principle of consumer engagement, SDM speaks to the re-distribution and a recalibration of power between clinicians and consumers. It is widely reported in the literature both in Australia and around the world.

Some systematic reviews considered the general theme of shared decision-making (SDM), is very close to the concept of community engagement. SDM refers to the style

of communication and tools that will place patients' preferences and values beside clinical information (Curtis et al., 2010). SDM is said to make the communication between physician and patient more satisfying and to assist in the selection of better treatment options (Curtis et al., 2010). SDM is directly promoting consumer involvement in health related decisions (Curtis et al., 2010).

3.5.1 Shared decision making in Australia

SDM in Australia is linked directly to explicit commitments to the concept of community engagement made by the Australian Health Ministers (Australian Charter of Health Care Rights), the Australian Commission on Safety and Quality in Health Care (ACSQHC), and the Australian National Health and Hospital Reform Commission (NHHRC) (McCaffery et al., 2011). The NHMRC has advocated implementation of community participation via their *Statement on Consumer and Community Participation in Health and Medical Research* and *Model Framework for Consumer and Community Participation in Health and Medical Research* (McCaffery et al., 2011, NHMRC and CHF, 2002, NHMRC and CHF, 2005). In 2010 the NHMRC and Australian Research Council (ARC) funded three grants which were related to community engagement (McCaffery et al., 2011). Both the government sectors (e.g. Cancer Australia) and non-government sectors (e.g. Alzheimer's Australia) are actively engaged in community participation (McCaffery et al., 2011). The importance of SDM is widely recognised and it is supported by a number of consumer organisations, guidelines, and policy documents (McCaffery et al., 2011), including the mandatory involvement of members of public in health-related process, for example, research ethics committees (McCaffery et al., 2011).

Despite an overt commitment to SDM, a number of factors, including time and geographic distance, have been identified as challenges to the engagement of consumers (McCaffery et al., 2011). Structural issues, such as the division of Australian health care into national and state/territory governments also presents challenges to consumer and community engagement. As a result of this division, and differences in perspectives and approaches, Australia is said to be lacking a central and dominant policy and strategy for implementation of SDM (McCaffery et al., 2011). This is said to have limited both the resources allocated to SDM and its implementation (McCaffery et al., 2011). Although some state bodies are supporting community engagement such as the Victorian Department of Health (via a policy called 'Doing it with us not for us'), there is no national strategy to implement community engagement in healthcare (McCaffery et al., 2011). A nation-wide approach to support research and implementation of SDM has been suggested (McCaffery et al., 2011).

Consumer groups have also recommended that community engagement should be facilitated via enhancing health literacy, encouraging community participation and empowering consumers; and in particular 'consumer representation' is advocated (NHHRC (National Health and Hospitals Reform Commission), 2009, McCaffery et al., 2011). In order to increase public health literacy and help citizens to know more about medical conditions and things that they could ask their doctors, a web site, Health Direct (<http://www.healthdirect.org.au/>), has been established with the support of the Australian government (McCaffery et al., 2011). There are also tools and materials for clinicians to enhance their knowledge of community engagement <http://www.psych.usyd.edu.au/cemped/> (McCaffery et al., 2011).

3.5.2 International perspectives in shared decision making

Canada, like Australia, has a federated system of government, and shares similar issues in the implementation of SDM, that is significant regional differences in the development and level of SDM (Legare et al., 2011b). Additional barriers include a reported widespread lack of interest of professionals in SDM. However there are a range of initiatives from the use of decision aids at a micro, clinician-patient level, to macro level SDM activities such as sponsoring of SDM research by Canada's main research agency (Legare et al., 2011b).

In the UK, SDM is part of the policy agenda, supported by legislation (Coulter et al., 2011). Patient information and decision aids are widely used. However, there is a need for more training, evidence for effectiveness of tools, and financial and other incentives to make SDM a part of normal care (Coulter et al., 2011). While the importance of consumer participation in public health is well acknowledged in the UK, one review found that there is little evidence to support beneficial social and health outcomes of participatory approaches by UK NHS public health units (Evans, 2010).

In the United States SDM has recently been incorporated in a range of federal and state regulations, which include key provisions to support the SDM process (Frosch et al., 2011). SDM-related research has attracted funding, a range of decision aids for various conditions have been developed (Frosch et al., 2011). SDM is advocated by many professional organizations and different ways of incorporating SDM into routine clinical practice has been tested and evaluated (Frosch et al., 2011). Overall, SDM is an important element in health care policy and debate in the USA (Frosch et al., 2011).

While SDM is not universally present in clinical practice in Brazil (Abreu et al., 2011), Abreu et al argue that the first steps towards SDM have commenced. The issues presented in this case study ranged from the need for changes to medical education to

the resistance of health care professionals to the principle of SDM (Abreu et al., 2011). Bravo et al report growing attention and interest in SDM in Chile as evidenced by its inclusion in government policy (Bravo et al., 2011). Barriers to SDM in Chile include a lack of tools, interventions, and research (Bravo et al., 2011).

SDM in France is framed by a complex clinician-patient relationship (Moumjid et al., 2011). Ten years after enforcement of the Law on Democracy in health care, it is premature to judge the situation, suggested Moumjid et al (Moumjid et al., 2011). In addition, Moumjid et al introduced a plan to establish an 'observatory of shared decision making in French-speaking countries' that aims to bring together different stakeholders to exchange ideas on SDM (Moumjid et al., 2011).

Germany has a range of regulations which underpin the partnership of clinicians and patients in the decision making process, and which ensure the right of patients for informed decisions and appropriate information (Harter et al., 2011). These measures are supported by training programs for health care professionals and research programmes. Limits to this work include the need to implement SDM into routine practice and training (Harter et al., 2011).

According to Miron-Shatz et al, although in Israel there are regulations for informed consent and patients' right for information, formal activities on SDM are minimal (Miron-Shatz et al., 2011). On the one hand, a patients' movement for participation and enhancing medical education has begun. On the other hand, the Israeli Government does not support a program to enhance decision aids, and has limited support for SDM-related research (Miron-Shatz et al., 2011). The lack of funding for SDM related research means SDM is only infrequently applied in clinical practice (Miron-Shatz et al., 2011).

Italian official documents support patient's participation in health care decision making. Patient associations are active but do not have a major role in health debates. There is lack of evaluation tools for SDM, except a couple of tools applicable at the micro-level. There are undergraduate courses to teach medical students how to promote patient participation (Goss et al., 2011).

SDM has received a growing recognition in the Spanish National Health System (NHS), which is funding the development of decision aids (Perestelo-Perez et al., 2011b). Although SDM is supported by law, there is no standardised implementation of the principle, and most patients and professionals are not familiar with patients' rights for information and participation in decisions (Perestelo-Perez et al., 2011b). There are

only a few studies assessing the effectiveness of Spanish decision aids, and a need for more research on Spanish SDM and decision aids has been identified (Perestelo-Perez et al., 2010).

Studies have found that although health care professionals in Switzerland acknowledge the importance of SDM, there is no national programme to promote it (Cornuz et al., 2011). Despite the provision of training for medical students on SDM and a number of patient support programmes, hierarchical asymmetric doctor-patient relationships are still prevalent (Cornuz et al., 2011).

3.5.3 Effects of shared decision making (SDM)

Duncan et al reviewed the effects of increased SDM for mental health patients (Duncan et al., 2010). Only two studies of good quality were included in the review, and as a result the authors suggested that there is not enough evidence to draw a firm conclusion. They did, however argue that those two studies on the one hand reported that SDM could increase patients' satisfaction although there was no effect on clinical outcome (Duncan et al., 2010). A second review of SDM in mental health has concluded that although patients prefer to be involved in their treatment and receive more information, more evidence is needed about the impacts of SDM (Perestelo-Perez et al., 2011a).

3.5.4 Role of consumers

Tariman et al reviewed the literature to explore the degree of match between consumers' preferred role during decision making and actual participation roles (Tariman et al., 2010). They concluded that patients demand more participation than is currently being offered. The authors suggested that there was a need both for more consumer engagement interventions and regular assessment of patients' expectations (Tariman et al., 2010).

These findings have been repeated with different groups. Belanger et al, reviewed shared decision making in palliative care and found that most patients have the desire to participate in decision making, but their real participation is less than desired (Belanger et al., 2011). Belanger et al emphasized that research was inadequate, and more research is needed (Belanger et al., 2011). Moore and Kirk reviewed children and adolescents' participation in decisions related to health care and reported that children and adolescents want to be involved in decision making. They also identified a number of issues regarding the quality of the evidence base: it was not clear for example, to what degree children were involved in participation. Participation may be

interpreted and defined differently in a paediatric setting, and there was scarce evidence of the benefits of participation (Moore and Kirk, 2010). Vis et al also examined child participation in decision making and concluded that although successful participation could have beneficial side effects, there is not enough evidence regarding long term effects and nor about outcomes of the failed attempts at participation (Vis et al., 2011).

Ryan et al undertook a meta-review of strategies to enhance the effective use of medicine, and amongst the effective strategies they identified were self-monitoring and self-management. These authors felt could be combined with education and skills training to support active consumer participation in their own healthcare (Ryan et al., 2011). Minet et al explored the effect of self-care management intervention in diabetes and concluded that it could make improvements in glycaemic control (Minet et al., 2010).

3.5.5 Role of health care professionals

A review of interventions intended to encourage health care professionals to help patients to be involved in the process of SDM (Legare et al., 2011a) identified a number of methods of educating and providing learning materials for health care professionals, including giving the professionals feedback and decision aids (Legare et al., 2011a). Moore and Kirk reviewed children and adolescents' participation in decisions related to health care and suggested that health care professionals need guidance to help children's participation (Moore and Kirk, 2010).

3.5.6 Decision aids (DAs)

Decision aids (DAs) are tools such as pamphlets and videos that provide structured information about health options and help patients to make a decision and participate in their health care (Curtis et al., 2010, O'Connor et al., 2011). They have also been used to promote patients' informed consent (and are occasionally called 'informed consent tools') (Legare et al., 2011b). The design of DAs is a complex procedure and should be done carefully so patients do not come to regret the decisions they have made (Sivell et al., 2011). One recommendation is that DAs be based on the theory of planned behaviour and the 'common sense model of illness' representations (Sivell et al., 2011).

Curtis et al (Curtis et al., 2010) and O'Connor et al (O'Connor et al., 2011) noted that shared decision making and DAs could be useful, if the consumer has more than one option open to them, if there is uncertainty on which option is the best, and when the

outcome is dependent to patient's compliance. O'Connor et al reviewed DAs and suggested that DAs could increase patients' knowledge about options and their risks and benefits, and enhance their participation in the process (O'Connor et al., 2011).

3.5.7 Tools related to shared decision making (SDM)

Scholl et al argue that new instruments are still being developed since SDM is a young field (Scholl et al., 2011). Scholl et al reviewed instruments related to shared decision making and classified them into three groups: 1) tools measuring decision antecedents such as role preference, 2) tools assessing the decision process such as observed and perceived deliberation phase, 3) tools focusing on decision outcomes, such as satisfaction (Scholl et al., 2011). Tools that School et al identified in their review are summarized in Table 3.

Goss et al reported two scales that evaluate patient participation in decision making at a micro-level in Italy: OPTION and the SDM-Q (Goss et al., 2011). Foss and Askautrud reviewed tools that evaluate elderly patients' experience at the time of discharge, and found only one instrument designed to measure patients' level of participation [Patient Participation Preferences Assessment (PPPA)] (Foss and Askautrud, 2010).

Table 3: Published instruments on shared decision making (Scholl et al., 2011)

CLASSIFICATION	PUBLISHED INSTRUMENTS ON SHARED DECISION MAKING
Decision antecedents	Autonomy preference Index
	Control Preference Scale
	Decision Self Efficacy scale
	KOPRA questionnaire
	Krantz Health Opinion Survey
	Patients attitudes and beliefs scale
	Preparation for Decision-Making Scale
	Scale on participation in nursing care
Decision process	Brief decision support analysis tool
	Decision support analysis tool
	Decision analysis system for oncology
	Dyadic OPTION Scale
	Facilitation of Patient Involvement Scale
	9-item Shared Decision-Making Questionnaire
	OPTION Scale

CLASSIFICATION	PUBLISHED INSTRUMENTS ON SHARED DECISION MAKING
	Perceived Involvement in Care Scale
	Rochester Participatory Decision Making Scale
	Scale on Participation in nursing care
	Shared Decision-Making Scale
	The Health Care Empowerment Questionnaire
Decision outcomes	Bereaved family regret scale
	COMRADE scale
	Decision Attitude Scale
	Decision Evaluation Scales
	Decision Regret Scale
	Decisional Conflict Scale
	Provider Decision Process Assessment Instrument
	Satisfaction with Decision Scale
	SURE

3.6 COMMUNITY BASED INTERVENTIONS

A number of studies have investigated how consumers could take an active role in supporting other consumers. Mechanisms included patient delivered care, peer educators, peer support workers, consumer led services, community based interventions and family interventions.

Forbes et al reviewed evidence and undertook research into the organization and delivery of diabetes education. They reported that although their research participants described peer supports to be beneficial, their literature review did not identify any clinical benefits from the use of peer educators (Forbes et al., 2011). They suggested that future research distinguish between the role of peer support in enhancing the experience of care (mediating role) and its role in enhancing clinical outcomes (clinical role) (Forbes et al., 2011). In contrast to this finding, Maticka-Tyndale and Barnett reviewed peer-led interventions for decreasing risk of HIV in youth, and found that peer leaders could be used effectively in the provision of peer education and could successfully change youths' knowledge and norms (Maticka-Tyndale and Barnett, 2010).

Mental health is a common site for peer support work. A study of peer support workers employed in mental health services in the UK were found to enhance recovery

in patients, although the researchers underscored the importance of adequate training, supervision, and management of the process (Repper and Carter, 2011). A review of consumer-led mental health services found that those services could be effective, especially in areas such as reducing hospitalization and enhancing employment and living. The same study found, however, these services were underfunded (Doughty and Tse, 2011). The involvement of a consumer provider could be beneficial for community assertiveness programs, although as with numerous other programs, more research was needed to support this strategy (Wright-Berryman et al., 2011).

A study of community-based interventions aiming to improve maternal and neonatal health concluded that there was encouraging evidence of the value in integrating community-based interventions in maternal and neonatal health (Lassi et al., 2011). Ng et al.'s study of community-based interventions for reducing HIV infection (Ng et al., 2011) could not confirm the efficacy of proposed strategies, although it should be noted that they included only four trials in their review (Ng et al., 2011).

One study of family interventions was identified. Macdonald and Turner suggested that treatment foster care (TFC) could have helpful clinical, social, and educational effects for young people (Macdonald and Turner, 2011). However, Macdonald and Turner only found five studies and therefore their findings have limited generalisability (Macdonald and Turner, 2011).

3.6.1 Community based interventions with vulnerable groups

Several of the systematic reviews address issues relating to the engagement of vulnerable groups. These include children and adolescents, the elderly, people from culturally and linguistically diverse (CALD) and lower socio-economic backgrounds (SEB).

The participation of children and adolescents in different fields such as telemental health (Myers et al., 2011) and HIV research (Diclemente et al., 2010) has been discussed previously. Clavering and McLaughlin maintain that while children's perspectives should be included at varying levels in research, sometimes it is impossible or inappropriate to do so (Clavering and McLaughlin, 2010).

Curtis-Tyler explored literature on the way children might be involved in their own health care and suggested levers to patient-centred care with children: engaging with children about their experience of life and their preferences, and willingness to engage with children without making any assumptions about children's age-based capacities

(Curtis-Tyler, 2011). Moore and Kirk suggested that health care professionals need guidance to help children's participation (Moore and Kirk, 2010) and Vis et al's review of child participation in decision making concluded that although successful participation could have beneficial side effects, there is not enough evidence regarding long term effects and outcome of failed attempts of participation (Vis et al., 2011).

Lyttle and Ryan reviewed factors that affect older patients' participation in health care and reported shortages of research on the topic. They suggested that it should not be assumed that all older patients prefer to participate in health care and this issue should be assessed for each case (Lyttle and Ryan, 2010). The key factor, they argue, is the importance of autonomy and choice of patients and the need for supporting health care professionals to develop necessary skills for enhancing older patients' participation (Lyttle and Ryan, 2010).

Cooper et al undertook a meta-analysis on ethnic differences in use of dementia treatment and research in the USA and Australia and found that people from CALD backgrounds are diagnosed later in life and have less access to medication, research trials and care (Cooper et al., 2010). Chung et al explored community-based rehabilitation (CBR) in Chinese communities and suggested that western CBR concepts cannot be applied to Chinese communities (Chung et al., 2011). Sykes et al, however, undertook a review of CALD response rates and found that ethnicity did not appear to affect research participation, and that different ethnic populations participate in surveys (Sykes et al., 2010).

With regards to people from lower socio-economic backgrounds, Spadea et al reviewed interventions aimed at enhancing cancer screening in women from lower SEB and suggested a range of strategies to improve access to screening these groups. These included the lowering of costs (e.g. free tests, reducing geographical barriers), increased involvement of primary-care physicians, and the modification of communication to fit with the needs of different individuals (Spadea et al., 2010).

3.7 BARRIERS TO CONSUMER AND COMMUNITY ENGAGEMENT

A range of barriers to active consumer and community engagement in health care have been identified in the literature. Some are located within the locus of control (e.g. personal or social) or based on the nature of barrier (e.g. risk or costs) (Dhalla and Poole, 2011).

3.7.1 Cost

Facilitating consumer and community engagement and patients' participation could impose a financial burden on health care systems. While tools such as electronic personal health records are reported to be effective in enhancing patients' participation, their implementation could impose a significant financial burden to health care systems (Ennis et al., 2011). Several reviews have identified budget limitations as a barrier for consumer and community engagement. Doughty and Tse argue that consumer-led services could be effective and useful, but they are still underfunded (Doughty and Tse, 2011). DuBios et al list funding as one of the challenges of community-engaged research (Dubois et al., 2011), while Coulter et al suggest that despite availability of supportive legislations and efforts in UK, there is still a need for financial and other incentives in order to promote shared decision making (Coulter et al., 2011). The financial cost of participation has been raised as a specific barrier (along with physical demands) for people with disabilities (Attree et al., 2011).

3.7.2 Limitations of participation methods

Although philosophical commitment to public participation in health has existed for four decades, the application of practical approaches to engagement still need further investigation (Evans, 2010). Based on a review of grey literature and interviews with key informants, Menon and Stafinski (2011) identified several limitations to common methods for patient participation. These included that: representatives might find it difficult to talk in public that they may need training, and that consumer organisations usually do not have adequate funding to compete with organisations that are supported by industry. In addition to these issues, they identified that: in some engagement processes input is taken from representative organizations rather than individual consumers; some consumers are not aware of possibility of providing inputs; at times the impact or role of consumers may be limited; and that although consumer representatives may be present in committees, they might be not actively involved in the processes (Menon and Stafinski, 2011).

3.7.3 Skills requirement of consumers

Consumer and community engagement in health care will require specific skills and abilities of the individuals involved. Ennis et al suggested that expecting consumers to use an electronic personal health record will require them to have a level of computer literacy, adequate cognitive ability, and access to computers and the internet (Ennis et al., 2011). Such expectations could form significant barriers for specific groups of patients, including people with disabilities. DiClemente et al investigated barriers to

adolescent participation in HIV prevention research, and they found that adolescents might have inadequate understanding and mistrust of research (Diclemente et al., 2010). Health and general literacy are also issues in consumer and community engagement. While regulation in the UK requires clinicians to send relevant letters to consumers, for some consumers the letters may be difficult to understand and can cause distress (Ennis et al., 2011).

3.7.4 Skill requirements of health care professionals

Consumer and community engagement equally requires additional skills from healthcare professionals. DuBios et al identified the need for training of researchers involved in community based research (Dubois et al., 2011). Coulter et al also identified the need for staff training, although in their review it was more generally required as a way to promote shared decision making (Coulter et al., 2011).

Legare et al have reported that in order to encourage health care professionals to help patients involved in the process of shared decision making both training and education and the provision of learning materials is required (Legare et al., 2011a). Other authors have emphasized the need for supporting health care professionals to develop necessary skills for enhancing the participation of older consumers (Lyttle and Ryan, 2010).

3.7.5 Condition-specific limitations

Participation can carry risks. One review found that for some psychiatric patients, access to their own health care information may increase their distress or may contribute to the deterioration of their condition (e.g. re-enforcing a paranoid delusion) (Ennis et al., 2011). The same reviewer found that although this was a real risk, it did not justify depriving those consumers from receiving their health-related information. It would, however, necessitate the development of appropriate communication methods that could efficiently impart the information without causing the consumers any distress (Ennis et al., 2011). Curtis et al also suggested that shared decision making in the mental health field is more complicated than in general medicine. They argue that it is not possible to use decision support materials produced for general medicine in mental health (Curtis et al., 2010). The stigma that is attached to some conditions may equally be a barrier to participation in healthcare. Both DiClemente et al (Diclemente et al., 2010) and Dhalla and Poole (Dhalla and Poole, 2011) found that one of the barriers to participation in HIV research is HIV-related stigma.

3.7.6 Population-specific limitations

Coulter et al found that people's preference for involvement in decision making is dependent on characteristics such as age, educational level, disabilities and ethnic and cultural backgrounds (Curtis et al., 2010). The authors note that an individual's preference for engagement might change over time or be based on changing circumstances (Curtis et al., 2010). Children and adolescents face specific difficulties in consumer engagement. These include issues such as parental consent, as was the case in one study of adolescents' participation in HIV prevention research (Diclemente et al., 2010). Clavering and McLaughlin reviewed ways of including children's accounts in research and concluded that while children's perspectives can be included, this is neither possible nor always appropriate (Clavering and McLaughlin, 2010).

3.7.7 Organizational and clinical culture

Organisational, cultural and contextual factors affect the integration of consumer and community engagement approaches in healthcare services. A review of the introduction of new technologies into the healthcare system found that these can affect clinicians and services users' roles, identity and expectations. For that reason a technology, with a proven success elsewhere, might fail in a new context (Ennis et al., 2011). Modification of initiatives, to ensure a better fit with the individual context and setting are required in the implementation of new initiatives, as are the use of existing networks and social relations, including not only consumers and clinicians, but also many other relevant stakeholders (Ennis et al., 2011).

Some of aspects of current clinical culture could impose limitations in physician-patient communication. Implementing shared decision making by changing long-established communication styles has proven a challenge even for well educated and motivated professionals (Curtis et al., 2010). Fine et al reviewed studies on doctor-patient relationships and observed that while consumers are more satisfied with supporting behaviours, doctors tend to dominate sessions (Fine et al., 2010). Changing current communications styles between doctors and consumers and enhancing consumers' participation requires significant cultural change. Physicians might need to learn to "speak less, listen more" (Fine et al., 2010: 601).

3.7.8 Structural issues

Successful implementation of community engagement requires regulation and organizational support. Cornuz et al found that although health care professionals in Switzerland acknowledged the importance of shared decision making, there was no national programme to promote such an approach (Cornuz et al., 2011). Structural

issues, such as 'fee for service' healthcare delivery have been implicated in resistance to shared decision making which is considered to be more time consuming (Cornuz et al., 2011).

3.8 ADDITIONAL STRATEGIES AND TOOLS TO SUPPORT CONSUMER AND COMMUNITY ENGAGEMENT

A variety of strategies have been used to enhance consumer and community engagement. A major Australian review has suggested a more centralised approach to support research and implementation of shared decision making (McCaffery et al., 2011). Citizen participation at this level could potentially provide a random or purposeful sample of population to represent the general population. This method has been used by UK's NICE (National Institute for Health and Clinical Excellence) and Toronto's Health Policy Citizen Council (Menon and Stafinski, 2011).

Social marketing more recently has been utilised as a tool in the delivery of health care services based on community participation (Aras, 2011). Its success is dependent on a number of factors, primarily relating to sustainability, including technical (selecting the right product, place, strategy for promotion, and price) financial, institutional, and market sustainability (Aras, 2011).

Coulter et al have suggested a list of prerequisites that should be put in place in order to make shared decision making a norm in clinical practice. These included: appropriate policies, regulation and standards; availability of tools and information; tools for monitoring progress; training; clinical and patient champions; evidence of effectiveness; incentives; and implementation plans (Coulter et al., 2011).

Consumer groups themselves have suggested a range of engagement strategies. These include: enhancing health literacy; encouraging community participation; empowering consumers; and advocating for 'consumer representation' (McCaffery et al., 2011, NHHRC, 2009). These suggestions are supported by a review of methods to enhance participation in breast cancer screening and have concluded that invitation letters, posting educational materials, telephone calls, and a combination of these could be effective in increasing participation (Bonfill Cosp et al., 2010). However, they reported lack of evidence on which method is better (Bonfill Cosp et al., 2010).

Menon and Stafinski have identified three mechanisms for considering consumers' perspectives: committee membership; presentation of written or oral testimonials from

patients; and providing opportunities to review reports and draft communication (Menon and Stafinski, 2011).

DuBios et al reviewed papers on community engaged research (Dubois et al., 2011) and have suggested that members of public and patients could engage in research via various forms such as representation on ethics committees, undertaking attitude research on study population, involving community advisory boards, developing partnerships with community organizations and assigning the role of co-investigators to community members (Dubois et al., 2011). Group meetings appear to be the most common method of public involvement at the design stage of research (Boote et al., 2010).

Methods of facilitating engagement have been specifically designed for particular groups of consumers, such as children. Curtis-Tyler explored the literature on the way children might be involved in their own health care and suggested levers to patient-centred care with children: engaging with children about their experience of life and their preferences, and willingness to engage with children without making any assumptions about children's age-based capacities (Curtis-Tyler, 2011).

3.8.1 Electronic and internet-based facilities

Electronic and internet-based tools could be used to increase people's access to health care (Myers et al., 2011). Website blogs and social media could also be investigated to learn about the view of patients and members of public (Menon and Stafinski, 2011). Electronic personal health records are also considered a tool to enhance patients' participation (Ennis et al., 2011). Positive aspects of e-health include: the possibility of sending and receiving information from a distance, providing interactive encounters, the possibility of sending personalized messages, real time accessibility, protecting the anonymity of users, providing a means of communication between users with each other and with health care professionals (Dedding et al., 2011). However, e-health may also provide incorrect information, cause uncertainty and confusion in users, and fear of power and authority loss in health care professionals (Dedding et al., 2011). The effects of e-health on doctor-patient relationships and patient participation is complex and could range from replacement of face-to-face visits, to supplementing normal care, strengthening patient participation, disturbing patient-doctor relations, and more demands for participation (Dedding et al., 2011).

3.8.2 Photovoice

Catalani and Minkler examined the use of photovoice as an innovative type of community-based participatory research (Catalani and Minkler, 2010). In this method, after a brief training in photography, members of a community will take photos of their community's strength or concerns, and then they return the photos and discuss them in groups. This cycle could repeat as long as necessary. In this way, people can identify and represent their community and contribute to enhancing their community. Photovoice has been used in a variety of health and social studies and has involved participants from different ages. Photovoice embraces the core principles of community-based participatory research, such as empowerment, co-learning and balancing research and action. The reviewers concluded that photovoice could contribute in promoting understanding of community strengths and needs (Catalani and Minkler, 2010).

3.9 GAPS IN RESEARCH INTO CONSUMER AND COMMUNITY ENGAGEMENT

A range of gaps within and across the literature on consumer and community engagement have been identified. These are discussed below.

3.9.1 Lack of evidence and research

Although there is a significant body of consumer and community engagement related literature (Evans, 2010), a lack of evidence in relation to their specific topics or settings (Ennis et al., 2011) still hinders the field. Menon and Stafinski reported that their review of public and patient participation in health technology assessment (HTA) could not find any studies on validation or application of different approaches (Menon and Stafinski, 2011), and that limited studies were available which reviewed mechanisms for involving patients and public in HTA area. Their conclusion is that there is insufficient research available to provide insight into the effectiveness and impact of different approaches of involvement of patients and the public.

Evans et al undertook a systematic review and could not find enough evidence to support beneficial social and health outcomes of participatory approaches by UK NHS public health units (Evans, 2010). Ennis et al justified their research by referring to the point that there was general evidence for the positive impact of electronic personal health records in general health, but not in mental health (Ennis et al., 2011).

Curtis et al suggested there was a lack of knowledge on the influence of communication styles on the process of shared decision making (Curtis et al., 2010).

Baker et al found that where studies were available, they were not of good quality and that, therefore, there was not enough evidence to determine if current approaches are effective in increasing community participation in physical activities (Baker et al., 2011).

In a number of countries, for example Italy, while shared decision making studies are growing, they are still limited (Goss et al., 2011). In addition, Legare et al have reviewed interventions to encourage health care professionals to help patients involved in the process of shared decision making, however, they could only identify five papers, and they had methodological limitations (Legare et al., 2011a).

Gagnon and Sandall reviewed studies on antenatal education that aimed to prepare parents for labour-related decision making and reported a lack of high-quality evidence which make the effects of antenatal education unclear (Gagnon and Sandall, 2011). Ryan et al who examined the application of audiovisual education for people who attend clinical trials, found only four papers and concluded that uncertainty clouds this area (Ryan et al., 2010). Car et al came to a similar point in reviewing interventions for increasing online health literacy of consumers. They could only find two studies suitable for inclusion in their review and concluded that there is only low quality evidence to support efficacy of the aforementioned interventions (Car et al., 2011).

Duncan et al reviewed the effects of increased SDM on mental health consumers and could include only two studies in their paper. They suggested that there is not enough evidence to draw a firm conclusion about the involvement of consumers in shared decision making (Duncan et al., 2010). Handerson and Laugharne evaluated studies on the application of user-held personalised information for care of people with severe mental illness, but could not include any studies (Henderson and Laugharne, 2011). Perestelo-Perez et al also reviewed engagement in mental health and found that although consumers prefer to be involved in their treatment and receive more information, more evidence is needed about the impact of shared decision making (Perestelo-Perez et al., 2011a).

Also at a population level, Lyttle and Ryan report deficits in research on older patients' participation in health care (Lyttle and Ryan, 2010). Moore and Kirk reviewed children and adolescents' participation in decisions related to health care and reported it is not clear to what degree children are involved and there is scarce evidence on the benefits of participation (Moore and Kirk, 2010).

There are similar shortfalls in the evidence to support patient involvement on safety outcomes (Peat et al., 2010). This is in line with the findings of another review which found only limited, poor quality evidence (Hall et al., 2010b).

In relation to community involvement in communicable disease campaigns, Atkinson et al reviewed 60 years of literature with the aim of providing a guidance for malaria elimination campaigns, but could only find four papers that evaluate the community participation on disease transmission and concluded that those papers were incomparable due to their methodological differences (Atkinson et al., 2011).

Bunge et al examined studies of the quality of information provided for patients and reported although information was based on good evidence and ethical guidelines, there is lack of evidence on quality of many aspects of such information such as pictures, narratives, language and cultural aspects (Bunge et al., 2010). Preston et al have found similar conceptual gaps and lack of evidence of effect in relation to community participation (Preston et al., 2010).

3.9.2 Lack of clarity and precision in literature

Several areas of conceptual confusion and lack of clarity in relation to community participation have been identified (Preston et al., 2010). Menon and Stafinski reported that the literature related to public involvement is using terms such as ‘public’ and ‘patients’ interchangeably; while patients and the public could have different perspectives, for example, patients may welcome further investment on technologies that facilitate their lives, while the public might object based on costs (Menon and Stafinski, 2011).

Avard et al reviewed studies relating to public involvement in health genomics and reported that a considerable proportion of current evidence does not clearly define what authors mean by ‘public’ in their papers, and they do not place the topic into its context and do not clarify the goals (Avard et al., 2010). For Ennis et al, the discrepancies and imprecision that exists in literature about the term ‘empowerment’ is said to potentially lead to disagreement on the success of a particular plan in providing ‘empowerment’ (Ennis et al., 2011).

Van De Belt et al reviewed the literature aiming to identify a unique definition of Health 2.0 or medicine 2.0, but they concluded that there is no consensus in this regard (Van De Belt et al., 2010). Eyssen et al have suggested that lack of clarity in definition of participation (as an index for rehabilitation) has led to the inadequacy of most instruments for assessment (Eyssen et al., 2011). Dijkers suggested that

disagreements in the concept of participation (as an output of rehabilitation) has interfered in the progress of related services and research (Dijkers, 2010).

3.9.3 Lack of evaluation tools

New evaluation tools for consumer and community engagement are still being developed (Scholl et al., 2011, Goss et al., 2011). Foss and Askautrud reviewed tools that evaluate experience of elderly patients at the time of discharge. They found only one instrument which was designed to measure levels of participation at the time of discharge, and concluded that there is no tool that could measure the full range of participation of elderly patients at the discharge process (Foss and Askautrud, 2010). Both Eyssen et al and Dijkers reviewed literature on instruments for evaluation of patients' participation (i.e. an index for rehabilitation) and both concluded that due to variation in the definition of participation, most instruments do not measure whole aspects of participation (Eyssen et al., 2011, Dijkers, 2010).

4. DISCUSSION

4.1 CONCEPTUAL CLARITY

One of the most striking points uncovered by this review is the need for careful attention to conceptual clarity and used terminologies. As discussed throughout this report, the concept of ‘community engagement’ (involvement or participation) is an overlapping and heterogeneous term (Evans, 2010). Terms such as ‘community engagement’, ‘consumer engagement’, ‘public involvement’ and ‘patient participation’ are variable and ambiguous in meaning. The same applies to core terms such as community, the public, and their various combinations. To add to the confusion, community engagement is not a single action and could refer to a range of activities at different levels.

4.2 IMPLEMENTING CONSUMER AND COMMUNITY ENGAGEMENT

Even after resolving conceptual perplexities, implementing a consumer or community engagement intervention raises numerous challenges. There are challenges in how to gather and synthesise consumers’ viewpoints, there is variation in consumers’ or community views, and there is often not enough evidence to compare different methods of consumer and community engagement in order to adequately judge which approach is most likely to be effective (Menon and Stafinski, 2011).

The importance of carefully evaluating initiatives for consumer and community engagement before starting to implement it is a primary finding of this review. It is useful to estimate and evaluate the costs, benefits, barriers and facilitators of each intervention. Our findings imply the need to undertake a comprehensive approach to assessment, including ‘hidden’ costs such as the need for training of health care professionals and consumers, factoring in the time required in the whole participation process, and not just that allocated for meeting times or presentations. The costs of such interventions have to be compared with the benefits that community engagement could bring for consumers, community and health care system, such as enhancing ownership and empowerment for the involved citizens and making initiatives more accountable (Attree et al., 2011). In order to make sure the analysis is comprehensive and rigorous enough, it is necessary to ensure that the viewpoints of different groups of stakeholders are included in such analysis.

There remain various questions to be addressed before undertaking further studies in this area, such as which community to consider (e.g. particular group of consumers public, carers, etc); what sort of involvement is to be assessed (from nonparticipation to total control); what topics or issues are to be targeted as the focus of the engagement. Table 5 presents some examples for these aspects, observed in this meta-review. In the next section, aspects that need to be evaluated are discussed.

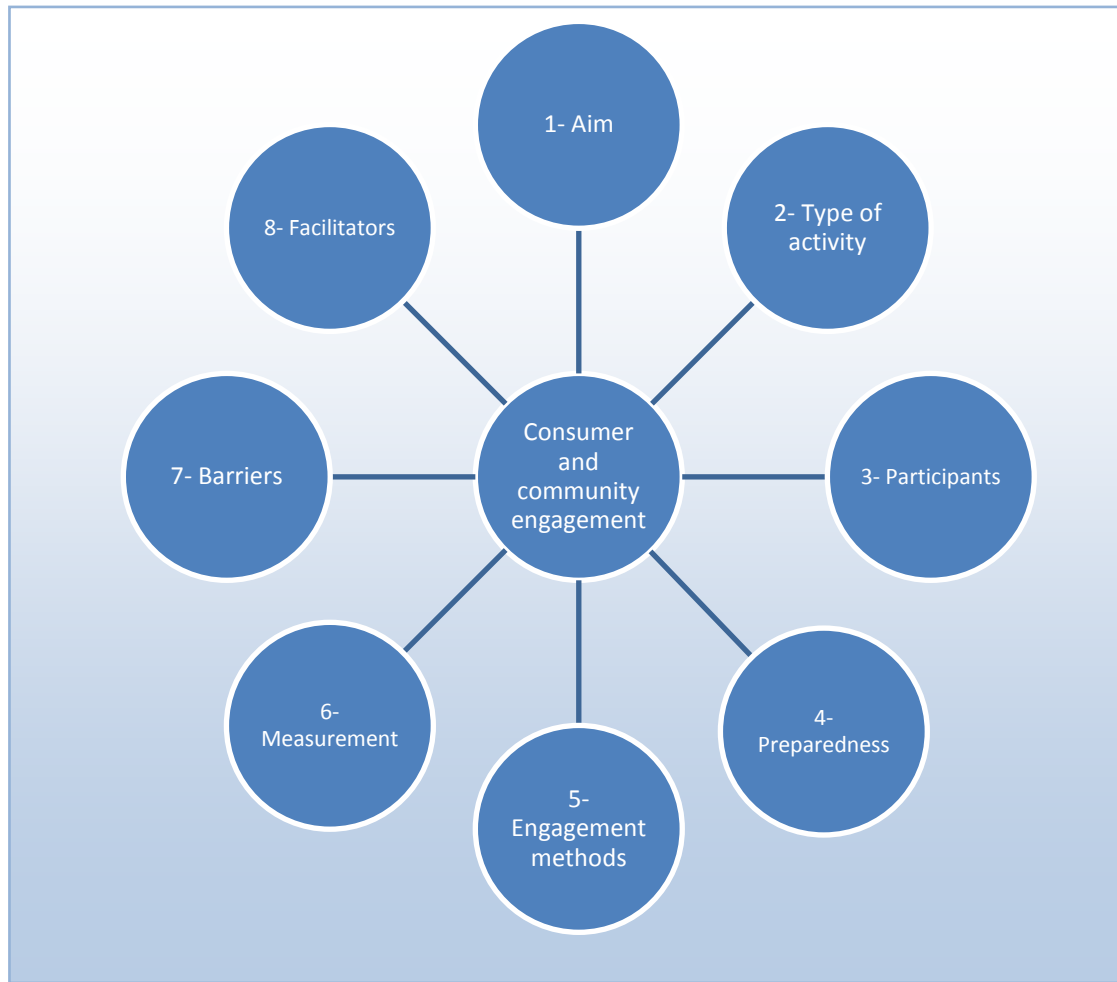
Table 4: Examples of various aspects of consumer and community engagement

COMMUNITY	TYPES OF INVOLVEMENT	TOPIC (AREA)
<ul style="list-style-type: none"> • Consumers • Public • Citizens • Community members • Lay people • Children and adolescents • Elderly patients • Disadvantaged groups • Vulnerable groups • Culturally and linguistically diverse groups • Marginal groups • Hard to reach people • Consumers with specific conditions (e.g. individuals post-stroke) • People with chronic disease • People with disabilities 	<ul style="list-style-type: none"> • Shared decision-making • Alliances • Collaboration • Partnerships • Development; empowerment • Engage; involve; participate • Participating in research • Increasing social activity; rehabilitation 	<ul style="list-style-type: none"> • Mental health care • E-health, telemedicine, telemental health • Community-based rehabilitation • Health technology assessment • Community medicine unit • Department of public health • Health education department • Palliative care • HIV prevention • Discharge

4.3 A MODEL FOR CONSUMER AND COMMUNITY ENGAGEMENT IN SHARED DECISION MAKING

A model identifying the key elements of consumer or community engagement in shared decision was developed from this review. This is presented in Figure 5. Each of the elements are introduced and discussed in the next section of this report.

Figure 5: The eight stage model for implementation of consumer and community engagement



4.3.1 Aim of consumer or community engagement for shared decision making

The first step in the process of shared decision making is deciding the focus of the intervention. As evidence from this review shows, numerous interventions have failed, or have not been able to be effectively evaluated because the purpose, aim and target are not clearly defined.

4.3.2 Type of activity

Once the aim is defined, it is necessary for those involved to identify on which activities the consumer will be engaged. Consumers and communities are engaged in activities including, research, service planning and delivery, policy making, development of informational materials and decision aids and their own treatment regimes. Consumers can and have provided input into each of these activities, including for example:

- Research: design (ethical considerations, sample selection, decisions on methodology), research process and distribution of results of the research
- Policy making: regulations, budget
- Service delivery: location of services, service priorities
- Treatment: treatment options, time of discharge, place of treatment (hospital, home, etc)

4.3.3 Participants

Any combination of individuals, groups or representatives of the population at large can be participants in a consumer and community engagement process. These include, but are not limited to:

- Consumers
- Relatives
- Carers
- Citizens and members of the public
- Members of specific communities
- Health care providers
- Researchers
- Policy-makers

4.3.4 Preparedness to be involved in the process of consumer and community engagement

Education and training in preparation for participation was a common theme of this review. Assessment of available and acceptable forms of education, training and information materials is required. These can include materials such as decision aids. Education could involve members of the public, patients or health professionals.

4.3.5 Engagement methods

Depending on the topic and the individuals involved a range of potential engagement methods can be utilised. These range from strategies which best suit micro-engagement (such as decision aids), through to focus groups or discussions bringing together members of a community or communities, through to public inquiries which can open up the debates on health care to the whole community.

4.3.6 Measurement of shared decision making in consumer and community engagement

Any plan for the evaluation and measurement of the process of consumer and community engagement will require an evaluation of its efficacy. This will include an assessment of the: availability of evaluation tools; measurement of experience of people; and measurement of effectiveness and outcomes.

4.3.7 Barriers to shared decision making in consumer and community engagement

In order to implement consumer and community engagement potential barriers need to be identified and addressed. This review identified several common barriers, including:

- Cultural and linguistic differences and literacy levels
- Regulation, legislation and policies
- Costs and budget
- Structure of health care systems
- Lack of skills in both consumers and health professionals
- Time limitations

4.3.8 Facilitation tools and strategies to enhance shared decision making in consumer and community engagement

In order to implement and enhance consumer and community engagement processes a range of tools and strategies need to be considered. This review identified three pivotal factors in effective consumer and community engagement: education (of both consumers and professionals); regulation and policies supporting the process; and incentives.

5. CONCLUSION

The principle of consumer and community engagement has been acknowledged and applied in healthcare for decades. Despite this long standing commitment and the plethora of approaches, strategies, techniques and tools employed, the evidence base for this field remains diffuse, and hard to synthesise. Available evidence primarily supports local, context-specific interventions.

It is difficult to extrapolate a clear model for engagement which is evidence based. Rather, what emerges from the evidence is an eight stage model for consumer and community engagement incorporating key elements which underpin the principles, the processes and the practices of consumer and community engagement. It is clear that attempts at engagement at each level of the health system, micro, meso and macro, need to take these elements into account to plan, execute, and evaluate consumer and community engagement activities accordingly.

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7. APPENDICES

7.1 APPENDIX 1.1: DIFFERENCES BETWEEN SYSTEMATIC REVIEWS AND SCOPING STUDIES

Table 5 Differences between a systematic review and a scoping study (Arksey and O'Malley, 2005)

	A SYSTEMATIC REVIEW	A SCOPING STUDY
Aim of the study	To address very specific research questions	To deal with broader topics
Type of the included studies	Limited to particular types of studies	Might include different types of studies
Quality appraisal of the included studies	Quality appraisal is done and results are presented based on the weight and quality of evidence	Does not evaluate quality of the included studies
Analysis and reporting the results	Synthesizes evidence and aggregates findings	Undertakes thematic construction and make a narrative to summarise the results
Study selection	Study selection is based on the inclusion and exclusion criteria that are set at the beginning of the study	It has criteria that are developed gradually while familiarity with literature is increased
Comprehensive	It attempts to include all relevant materials	Attempts to be as comprehensive as possible, but also consider cost and time limitation; e.g. there might be a time deadline for inclusion of studies

APPENDIX 1.2: REFINED DATA SET

REFERENCE	AIM	COMMUNITY ENGAGEMENT RELATED THEME	FINDINGS/CONCLUSIONS CITED FROM CORRESPONDING ABSTRACTS IN ENDNOTE LIBRARY UNLESS PAGE NUMBER FROM FULL PAPER INCLUDED
Abad-Franch, F., et al., <i>Community participation in Chagas disease vector surveillance: systematic review</i> . PLoS Neglected Tropical Diseases [electronic resource], 2011. 5(6): p. e1207.	P2 “reviewed published evidence to (i) assess the effectiveness of insecticide-based vector control, gauging the importance of reinfestation; (ii) compare the efficacy of programme-based (with households periodically visited by trained staff) and community-based (with residents reporting suspect vectors found in their homes) surveillance strategies; and (iii) evaluate the performance of alternative vector-detection methods.”	Disease prevention	“Community participation should become a strategic component of <i>Chagas disease</i> surveillance, but only professional insecticide spraying seems consistently effective at eliminating infestation foci. Involvement of stakeholders at all process stages, from planning to evaluation, would probably enhance such Community participation -based strategies.”
Abreu, M.M.d., et al., <i>Shared decision making in Brazil: history and current discussion</i> . Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen, 2011. 105(4): p. 240-4.	P 241: “Aims to present a brief review of SDM development in Brazil.”	Case study	“There is no SDM in clinical practice in Brazil. The first steps have been taken towards research and tool development recently. Likewise, our society is starting to get involved with decision making in health care. This paper aims to offer an overview of the Brazilian health system history, its values, and its influence on SDM. The participative social control concept is introduced as a result of the movement against the dictatorship era. In addition, the influence of social changes on the Medical Ethical Code is delineated. SDM state of the art in Brazil is also discussed and the challenges to implement it on clinical practice are described. Regardless the challenges, it is possible to make a positive assessment of SDM in Brazil.”
Agnihotri, S., et al., <i>Community integration</i>	“To identify and summarize published literature that examined the	Patients back into society	“Additional studies investigating social and community integration interventions are necessary, including those with measures tailored

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REFERENCE	AIM	COMMUNITY ENGAGEMENT RELATED THEME	FINDINGS/CONCLUSIONS CITED FROM CORRESPONDING ABSTRACTS IN ENDNOTE LIBRARY UNLESS PAGE NUMBER FROM FULL PAPER INCLUDED
<i>interventions for youth with acquired brain injuries: A review.</i> Developmental neurorehabilitation, 2010. 13 (5): p. 369-382.	effectiveness of social and community integration interventions for children and adolescents with ABI in order to provide recommendations regarding future research on this topic."		specifically to community integration, larger samples, as are better controls and recruitment of youth with varying severities of brain injuries."
Ammenwerth, E., P. Schnell-Inderst, and A. Hoerbst, <i>Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals.</i> Studies in Health Technology & Informatics, 2011. 165 : p. 63-7.	"To provide a first overview of the state-of-the-art and the impact of patient portals."	Electronic	"Based on a systematic literature search, we identified five evaluation studies on patient portals. These studies demonstrate only little effect of patient portals on patient empowerment."
Aras, R., <i>Social marketing in healthcare.</i> Australasian Medical Journal, 2011. 4 (8): p. 418-424.	"To review the existing literature in order to project the benefits of social marketing in healthcare."	Tools	"The purpose of this literature review was to ascertain the likely effectiveness of social marketing principles and approaches and behaviour change communication towards health promotion. It is important for all healthcare workers to understand and respond to the public's desires and needs and routinely use consumer research to determine how best to help the public to solve problems and realise aspirations. Social marketing can optimise public health by facilitating relationship-building with consumers and making their lives healthier."
Atkinson, J.A., et al., <i>The architecture and effect of participation: A</i>	"Reports the findings of an atypical systematic review of 60 years of literature in order to arrive at a more	Disease control and prevention	"The current global malaria elimination campaign calls for a health systems strengthening approach to provide an enabling environment for programmes in developing countries. In order to realize the benefits

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<i>systematic review of community participation for communicable disease control and elimination. Implications for malaria elimination. Malaria Journal, 2011. 10.</i>	comprehensive awareness of the constructs of participation for communicable disease control and elimination and provide guidance for the current malaria elimination campaign”		of this approach it is vital to provide adequate investment in the ‘people’ component of health systems and understand the multi-level factors that influence their participation. The challenges of strengthening this component of health systems are discussed, as is the importance of ensuring that current global malaria elimination efforts do not derail renewed momentum towards the comprehensive primary health care approach. It is recommended that the application of the results of this systematic review be considered for other diseases of poverty in order to harmonize efforts at building ‘competent communities’ for communicable disease control and optimising health system effectiveness.”
Attree, P., et al., <i>The experience of community engagement for individuals: A rapid review of evidence. Health and Social Care in the Community, 2011. 19(3): p. 250-260.</i>	“Reports on a rapid review of evidence of the effectiveness of initiatives which seek to engage communities in action to address the wider social determinants of health, to explore individuals’ subjective experiences of engagement.”	Community engagement	“the majority of ‘engaged’ individuals perceived benefits for their physical and psychological health, self-confidence, self-esteem, sense of personal empowerment and social relationships. Set against these positive outcomes, however, the evidence suggests that there are unintended negative consequences of community engagement for some individuals, which may pose a risk to well-being. These consequences included exhaustion and stress, as involvement drained participants’ energy levels as well as time and financial resources. The physical demands of engagement were reported as particularly onerous by individuals with disabilities. Consultation fatigue and disappointment were negative consequences for some participants who had experienced successive waves of engagement initiatives. For some individuals, engagement may involve a process of negotiation between gains and losses.”
Avard, D., et al., <i>Public involvement in health genomics: The reality</i>	P 509: “Examines the perspectives of various stakeholders such as governments,	Case studies	“We found that less than a third of the documents defined who the public is, and when mechanisms for public involvement were mentioned, they were rarely placed into a context. Few documents

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REFERENCE	AIM	COMMUNITY ENGAGEMENT RELATED THEME	FINDINGS/CONCLUSIONS CITED FROM CORRESPONDING ABSTRACTS IN ENDNOTE LIBRARY UNLESS PAGE NUMBER FROM FULL PAPER INCLUDED
<i>behind the policies.</i> International Journal of Consumer Studies, 2010. 34 (5): p. 508-524.	health professionals and the public regarding their policies on public involvement in the area of human genomics and genetics."		drew attention to evaluation. It is reassuring to see that there has been an emphasis placed on public involvement in the area of health and genomics. The findings underscore the gaps existing in the actual policy documents/guidelines and the need to clarify the goals, the methods, who is the public, what mechanism are appropriate and the need for evaluation when addressing public involvement in health genomics."
Baker, P.R., et al., <i>Community wide interventions for increasing physical activity.</i> Cochrane Database of Systematic Reviews, 2011(4).	"To evaluate the effects of community wide, multi-strategic interventions upon population levels of physical activity"	Community engagement for disease prevention and control	"Although numerous studies have been undertaken, there is a noticeable inconsistency of the findings of the available studies and this is confounded by serious methodological issues within the included studies. The body of evidence in this review does not support the hypothesis that multi-component community wide interventions effectively increase population levels of physical activity. There is a clear need for well-designed intervention studies and such studies should focus on the quality of the measurement of physical activity, the frequency of measurement and the allocation to intervention and control communities"
Belanger, E., C. Rodriguez, and D. Groleau, <i>Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis.</i> Palliative Medicine, 2011. 25 (3): p. 242-61.	"The aim of this study is to synthesize knowledge about the process of shared decision-making (SDM) in palliative care."	Shared decision making	"Results demonstrate that while a majority of patients want to participate in treatment decisions to some extent, most do not achieve their preferred levels of involvement because decisions are delayed and alternative treatment options are seldom discussed. The literature regarding the process of SDM itself remains scarce in palliative care. Further research is needed in order to better understand the longitudinal, interactive, and interdisciplinary process of decision-making in palliative care."
Bonfill Cosp, X., et al., <i>Strategies for increasing the participation of</i>	"To assess the effectiveness of different strategies for increasing the participation rate of women invited to	Community engagement for disease	"Most active recruitment strategies for breast cancer screening programs examined in this review were more effective than no intervention. Combinations of effective interventions can have an

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REFERENCE	AIM	COMMUNITY ENGAGEMENT RELATED THEME	FINDINGS/CONCLUSIONS CITED FROM CORRESPONDING ABSTRACTS IN ENDNOTE LIBRARY UNLESS PAGE NUMBER FROM FULL PAPER INCLUDED
<i>women in community breast cancer screening [Systematic Review].</i> Cochrane Database of Systematic Reviews, 2010. 11: p. 11.	community (population based) breast cancer screening activities or mammography programs."	prevention and control	important effect. Some costly strategies, as a home visit and a letter of invitation to multiple screening examinations plus educational material, were not effective. Further reviews comparing the effective interventions and studies that include cost-effectiveness, women's satisfaction and equity issues are needed."
Boote, J., W. Baird, and C. Beecroft, <i>Public involvement at the design stage of primary health research: a narrative review of case examples.</i> Health Policy, 2010. 95 (1): p. 10-23.	"To review published examples of public involvement in research design, to synthesise the contributions made by members of the public, as well as the identified barriers, tensions and facilitating strategies."	Community engagement	"The issues raised here should assist researchers in developing research proposals with members of the public. Substantive and methodological directions for further research on the impact of public involvement in research design are set out"
Boote, J., W. Baird, and A. Sutton, <i>Public involvement in the systematic review process in health and social care: A narrative review of case examples.</i> Health Policy, 2011. 102 (2-3): p. 105-116.	"To review the evidence on public involvement in the systematic review process in health and social care; to examine the different methods, levels and stages of involving the public; to synthesise the contributions of the public, as well as the identified tensions, facilitating strategies and recommendations for good practice."	Research	"The public was found to contribute to systematic reviews by: refining the scope of the review; suggesting and locating relevant literature; appraising the literature; interpreting the review findings; writing up the review. Numerous tensions, facilitating strategies and recommendations were identified. Conclusions: The issues raised in this paper should assist researchers in developing and conducting systematic reviews with the involvement of the public."
Bowen, F., A. Newenham-Kahindi, and I. Herremans, <i>When suits meet roots: The antecedents and consequences of</i>	To "examine when, how and why firms benefit from community engagement strategies."	Community engagement	"A foundational concept underlying many studies is the 'continuum of community engagement'. We build on this continuum to develop a typology of three engagement strategies: transactional, transitional and transformational engagement. By identifying the antecedents and outcomes of the three strategies, we find that the payoffs from

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<i>community engagement strategy</i> . Journal of Business Ethics, 2010. 95 (2): p. 297-318.			engagement are largely longer-term enhanced firm legitimacy, rather than immediate cost-benefit improvements. We use our systematic review to draw implications for future research and managerial practice."
Brandt, Å., et al., <i>Activity and participation, quality of life and user satisfaction outcomes of environmental control systems and smart home technology: a systematic review</i> . Disability & Rehabilitation: Assistive Technology, 2011. 6 (3): p. 189-206.	"To examine activity and participation, quality of life, and user satisfaction outcomes of environmental control systems (ECSs) and smart home technology (SHT) interventions for persons with impairments."	Patients back into society	"Due to few and small studies and study diversity, it was not possible to determine whether ECS/SHT have positive outcomes for persons with impairment, even though the technologies seem to be promising. High quality outcomes studies such as randomised controlled trials, when feasible, and large longitudinal multi-centre studies are required."
Bravo, P., et al., <i>Shared decision making in Chile: Supportive policies and research initiatives</i> . Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 254-258.	describe activities, opportunities and barriers of SDM on Chile	Case study	"What about policy regarding SDM? Since 1999, there has been a small but growing interest by academics, the government, and society as a whole in strengthening patients' and professionals' involvement in shared decision making (SDM). Two governmental policy documents that indicate support for SDM are (1) Health Reform in 2003 and (2) Sanitary Objectives 2011-2020, which includes a brief section on client participation and SDM. What about tools – decision support for patients? Research by Chilean academics has highlighted the patients' desire to participate in health decisions and effective approaches for enhancing health professionals' skills in interprofessional SDM; however, little has been done to support this need and the work is centralised in only one academic institution. Decision support tools and coaching interventions are limited to patients considering decisions

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			about managing type 2 diabetes. What about professional interest and implementation? Although there is increasing attention to studying patients' participation and involvement on their healthcare, little has been studied in relation to professionals' interest in SDM. As well, there are significant challenges for implementation of a country-wide SDM policy. What does the future look like? The future looks promising given the new health policies, local Chilean research projects, and international initiatives. Collaboration between health professionals, academics, and government policy makers, with public involvement needs to be strengthened in order to promote concrete strategies to implement SDM in Chile."
Bunge, M., I. Muhlhauser, and A. Steckelberg, <i>What constitutes evidence-based patient information? Overview of discussed criteria</i> . Patient Education & Counseling, 2010. 78 (3): p. 316-28.	"To survey quality criteria for evidence-based patient information (EBPI) and to compile the evidence for the identified criteria"	Patient information	"The results of this review allow specification of EBPI and may help to advance the discourse among related disciplines. Research gaps are highlighted. Practice implications: Findings outline the type and extent of content of EBPI, guide the presentation of information and describe the development process."
Car, J., et al., <i>Interventions for enhancing consumers' online health literacy</i> . Cochrane Database of Systematic Reviews, 2011(6): p. CD007092.	"To evaluate the effects of community wide, multi-strategic interventions upon population levels of physical activity."	Patient information	"Although numerous studies have been undertaken, there is a noticeable inconsistency of the findings of the available studies and this is confounded by serious methodological issues within the included studies. The body of evidence in this review does not support the hypothesis that multi-component community wide interventions effectively increase population levels of physical activity. There is a clear need for well-designed intervention studies and such studies should focus on the quality of the measurement of physical activity, the frequency of measurement and the allocation to intervention and

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			control communities.”
Catalani, C. and M. Minkler, <i>Photovoice: a review of the literature in health and public health</i> . Health Education & Behavior, 2010. 37 (3): p. 424-51.	“Draws on the peer-reviewed literature on photovoice in public health and related disciplines conducted before January 2008 to determine (a) what defines the photovoice process, (b) the outcomes associated with photovoice, and (c) how the level of community participation is related to photovoice processes and outcomes.”	Tools	“Findings reveal no relationship between group size and quality of participation but a direct relationship between the latter and project duration as well as with getting to action. More participatory projects also were associated with long-standing relationships between the community and outside researcher partners and an intensive training component. Although vague descriptions of project evaluation practices and a lack of consistent reporting precluded hard conclusions, 60% of projects reported an action component. Particularly among highly participatory projects, photovoice appears to contribute to an enhanced understanding of community assets and needs and to empowerment.”
Chen, P.G., et al., <i>Dissemination of results in community-based participatory research</i> . American Journal of Preventive Medicine, 2010. 39 (4): p. 372-8.	“In this systematic review, researchers evaluated studies utilizing the CBPR approach to characterize dissemination of research results beyond scientific publication. Specifically, the focus was on dissemination to community participants and the general public.”	Research, tools	“Among research meeting strict criteria for inclusion as CBPR, dissemination beyond scientific publication is largely occurring. However, myriad challenges to timely and widespread dissemination remain, and current dissemination to community participants and the general public is variable.”
Chung, E.Y.-h., T. Packer, and M. Yau, <i>When East meets West: community-based rehabilitation in Chinese communities</i> . Disability & Rehabilitation, 2011. 33 (8): p. 697-705.	“Reviews the development of CBR and describes its practice in Chinese communities in order to discuss current controversies within CBR practice internationally and in the Chinese context.”	Vulnerability	“Shifting ideology and practices mean many different activities are labelled CBR. Variation across contexts has led to many controversies, specifically: the lack of evidence to support practice; ownership of programs; conceptual differences surrounding autonomy and participation and cultural issues. Contemporary Chinese cultural values and Chinese CBR are shaped by traditional peasant culture, traditional Chinese philosophy and socialist ideology. Conclusion. The review indicates that Western CBR concepts and philosophy cannot be directly

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			applied to the Chinese context. An appropriate model or framework is needed to fit the unique Chinese cultural context and to guide practice in Chinese communities.”
Claes, C., et al., <i>Person-centered planning: analysis of research and effectiveness</i> . Intellectual & Developmental Disabilities, 2010. 48 (6): p. 432-53.	“To (a) review the current status of effectiveness research; (b) describe its effectiveness in terms of outcomes or results; and (c) discuss the effectiveness of person-centred planning in relation to evidence based practices.”	Person centred	“This planning has a positive, but moderate, impact on personal outcomes for this population. The body of evidence provided in this review is weak with regard to criteria for evidence-based research.”
Clavering, E.K. and J. McLaughlin, <i>Children's participation in health research: from objects to agents?</i> Child: Care, Health & Development, 2010. 36 (5): p. 603-11.	“Seeks to examine ways in which children have been included in health-related studies to identify strengths and weaknesses.”	Vulnerability	“Inclusion of children’s perspectives can be achieved, at varying levels, in each approach (on, with and by) examined here. Although claims to authority around including children’s perspectives may appear to hold more credence when children have directly participated in the research, there may be times when this is neither possible nor appropriate. Researchers are challenged to be open and reflexive about ways in which children are engaged with, incorporated in and represented across the many stages of research. Whichever approach is taken, ethical issues and notions of equity remain problematic. This point holds particular resonance for ways in which ethics around children may be considered in National Health Service ethics governance processes.”
Conrardy, J.A., B. Brenek, and S. Myers, <i>Determining the state of knowledge for implementing the universal protocol recommendations: an integrative review of the</i>	“The purpose of this study was to determine the current state of knowledge concerning the implementation of the Joint Commission's Universal Protocol.”	Community engagement	“The current state of knowledge varies from facility to facility, and we noted significant trends, gaps, and areas of concern in the implementation process. Successful implementation of the Universal Protocol has the following elements: a multidisciplinary team approach, active staff/patient participation, supportive hospital administration/leadership, and active communication that promotes a

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<i>literature</i> . AORN Journal, 2010. 92 (2): p. 194-207.			healthy work environment.”
Cook, F. and C. Oliver, <i>A review of defining and measuring sociability in children with intellectual disabilities</i> . Res Dev Disabil, 2011. 32 (1): p. 11-24.	“Reviews definitions for four concepts related to the central concept of sociability (social cognition, social competence, social skills and social behaviour).”	Patients back into society	“By reviewing the definitions available in the wider social and cognitive psychology literature and comparing these to definitions provided in research with individuals with intellectual disabilities it is clear that concepts are poorly defined. The current article proposes working definitions which may be used give impetus to future debate in the area. The clinical implications of having implicitly understood concepts rather than definable and measurable traits are considered. The review calls for researchers to provide definitions for the concepts under investigation and their relationship to measures employed in research.”
Cooper, C., et al., <i>A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research</i> . American Journal of Geriatric Psychiatry, 2010. 18 (3): p. 193-203.	“To compare the use of health and social services, treatments for dementia and dementia research between different ethnic groups.”	Vulnerability; Research	“The authors found consistent evidence, mostly from the United States, that ME people accessed diagnostic services later in their illness, and once they received a diagnosis, were less likely to access antidementia medication, research trials, and 24-hour care. Increasing community engagement and specific recruitment strategies for ME groups might help address inequalities, and these need to be evaluated. More research is also needed to evaluate ME access to dementia services outside the United States.”
Cornuz, J., B. Kuenzi, and T. Krones, <i>Shared decision making development in Switzerland: Room for improvement!</i> Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011.	P 297: “We will describe activities, opportunities and barriers of SDM on the nationwide macrolevel, the mesolevel of Swiss cantons and institutions and the local microlevel.”	Case study	“In Switzerland there is a strong movement at a national policy level towards strengthening patient rights and patient involvement in health care decisions. Yet, there is no national programme promoting shared decision making. First decision support tools (prenatal diagnosis and screening) for the counselling process have been developed and implemented. Although Swiss doctors acknowledge that shared decision making is important, hierarchical structures and asymmetric physician-patient relationships are still prevailing. The last years have

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105 (4): p. 296-299.			seen some promising activities regarding the training of medical students and the development of patient support programmes. Swiss direct democracy and the habit of consensual decision making and citizen involvement in general may provide a fertile ground for SDM development in the primary care setting”
Coulter, A., et al., <i>Implementing shared decision making in the UK</i> . Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 300-304.	The current position in the UK in respect of different pre-requisites of shared-decision making is reviewed.	Case study	“What about policy regarding SDM? SDM is on the national policy agenda and has been prioritised as part of the health reform bill currently going through the Houses of Parliament. The NHS Constitution emphasises patients’ right to be involved in decisions and this is reinforced in standards set by professional regulators. What about tools – decision support for patients? The UK governments have invested in patient information and a few decision aids are freely available on public websites. What about professional interest and implementation? There is interest in SDM and in collaborative care planning, but this is not yet the norm in clinical practice and few clinicians have received training in the topic. Several programmes are under way to encourage implementation of SDM. What does the future look like? Future developments will depend on the extent of clinical commitment and on whether there are sufficient funds available to invest in the promotion of SDM at a time when health care resources are tightly constrained.”
Curtis, L.C., et al., <i>Pushing the envelope: shared decision making in mental health</i> . Psychiatric rehabilitation journal, 2010. 34(1): p. 14-22.	“Reviews the literature on shared decision making in health and mental health and discusses tools in general health that are proposed for adaptation and use in mental health.”	Shared decision making	“Structured shared decision making in mental health shows promise in supporting service user involvement in critical decision making and provides a process to open all treatment and service decisions to informed and respectful dialogue.”
Curtis-Tyler, K., <i>Levers and barriers to patient-centred</i>	“Aimed to synthesize findings of children’s experiences of long-term	Vulnerability;	“Findings suggest key ‘levers’ to patient-centred care with children include: (1) engagement with children’s expertise about their own lives:

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<i>care with children: findings from a synthesis of studies of the experiences of children living with type 1 diabetes or asthma.</i> Child: Care, Health & Development, 2011. 37 (4): p. 540-50.	illness and, from this, to identify levers and barriers to patient-centred care with children."	Patient-centred	their personal and social experiences of their care, including how these are affected by their relative lack of power in some settings; (2) exploring children's understandings and preferences in terms of their physical sensations and day-to-day experiences; (3) willingness to find resources to engage with even the youngest children; (4) avoiding age-based assumptions about children's contributions to their care. <i>Discussion and conclusions</i> Action on the above 'levers' may present a range of challenges in healthcare settings not least because it represents a move away from medicine's historical focus on children's developing competencies to engage rather with children's social realities from the earliest ages."
Davis, R.E., C.A. Vincent, and M.F. Murphy, <i>Blood transfusion safety: the potential role of the patient.</i> Transfusion Medicine Reviews, 2011. 25 (1): p. 12-23.	"This article considers the patients' role in ensuring safe care along the transfusion trajectory"	Case study	"The literature on patients' attitudes to, and involvement in, transfusion-related behaviors was systematically reviewed and opportunities for patient involvement were identified. The evidence suggests that although there is considerable potential for patients to be involved in different blood transfusion processes, it is very unclear at present how able and willing patients would be to take on an active role in this aspect of their health care management. Research in this area is paramount in helping to inform the design and implementation of interventions aimed at encouraging patient involvement in this very important but largely under-researched area"
Dedding, C., et al., <i>How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between</i>	"Discuss the consequences of e-health for patient-clinician encounters"	Electronic	"On the basis of an analysis of the literature, we propose an analytical framework, composed of five different themes, regarding the impact of e-health on the relationship between patients and their health professionals. Internet health sites can: be or come to be a replacement for face-to-face consultations; supplement existing forms of care; create favourable circumstances for strengthening patient participation; disturb relations; and/or force or demand more intense patient

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<i>medical professionals and patients</i> . Social Science & Medicine, 2011. 72 (1): p. 49-53.			participation. Though there is as yet insufficient empirical evidence supporting these effects, we believe that distinguishing the proposed themes will help to guide an in-depth discussion and further research. We conclude that in particular the redistribution of tasks and responsibilities to patients in their daily lives requires more attention in future research”
Dhalla, S. and G. Poole, <i>Barriers of enrolment in HIV vaccine trials: A review of HIV vaccine preparedness studies</i> . Vaccine, 2011. 29 (35): p. 5850-5859.	Evaluate “Barriers to participation in an HIV vaccine trial have been examined in many HIV vaccine preparedness studies”	Research	“Barriers to participation in an HIV vaccine trial have been examined in many HIV vaccine preparedness studies (VPS). These barriers can be understood in terms of the locus of the barrier (personal vs. social) and the nature of the barrier (risk vs. cost). Another type of barrier is perceived misconceptions.”
Diclemente, R.J., M.S. Ruiz, and J.M. Sales, <i>Barriers to adolescents' participation in HIV biomedical prevention research</i> . Journal of Acquired Immune Deficiency Syndromes, 2010. 54 (SUPPL. 1): p. S12-S17.	“Identifies and addresses individual, operational, and community-level barriers to adolescents' participation in HIV biomedical prevention research”	Vulnerability, research	“Barriers identified and addressed in the paper include: (1) insufficient understanding of clinic prevention research, (2) self-presentation bias, (3) issues surrounding parental consent, (4) access to clinical trials, (5) mistrust of research, and (6) stigma associated with participation in clinical trials. Examples of programs where adolescents have been successfully engaged in prevention research are highlighted and the lessons learned from these programs indicate that establishing collaborations with key stakeholders in the community are essential for conducting biomedical research with vulnerable populations, including adolescents.”
Dijkers, M.P., <i>Issues in the conceptualization and measurement of participation: an overview</i> . Archives of	“Explores a number of the major issues related to the quantification of participation and makes suggestions for new directions”	Patients back into society	P s13: “This article has sketched a number of significant issues that must be dealt with in the conceptualization, operationalization, and measurement of participation. Defining and operationalizing

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Physical Medicine & Rehabilitation, 2010. 91 (9 Suppl): p. S5-16.			participation requires developers of measures to consider these choices as a package. Given the complexity of participation and its manifestations in various groups defined by age, culture, and accessibility of the physical and sociocultural environment, it will be far from easy to create a measure that is simple yet reflects participation adequately based on the conceptualization of most stakeholders. However, improvements over the currently available instruments are feasible and needed."
Doughty, C. and S. Tse, <i>Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries.</i> Community mental health journal, 2011. 47 (3): p. 252-66.	"Examined the evidence from controlled studies for the effectiveness of consumer-led mental health services."	Peer support	"Overall consumer-led services reported equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment or living arrangements, and in reducing hospitalizations and thus the cost of services. Involving consumers in service delivery appears to provide employment opportunities and be beneficial overall for the consumer-staff members and the service. Despite growing evidence of effectiveness, barriers such as underfunding continue to limit the use and evaluation of consumer-led services."
Dubois, J.M., et al., <i>Ethical issues in mental health research: the case for community engagement.</i> Curr Opin Psychiatry, 2011. 24 (3): p. 208-14.	"To describe community-engaged research (CEnR) and how it may improve the quality of a research study while addressing ethical concerns that communities may have with mental health and substance abuse research"	Community engagement, Research	"Recent findings CEnR represents a broad spectrum of practices, including representation on institutional ethics committees, attitude research with individuals from the study population, engaging community advisory boards, forming research partnerships with community organizations, and including community members as co-investigators. Summary CEnR poses some challenges; for example, it requires funding and training for researchers and community members. However, it offers many benefits to researchers and communities, and some form of CEnR is appropriate and feasible in nearly every study involving human participants."
Duncan, E., C. Best, and S.	"To assess the effects of provider-,	Shared decision	"No firm conclusions can be drawn at present about the effects of

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Hagen, <i>Shared decision making interventions for people with mental health conditions</i> . Cochrane Database of Systematic Reviews, 2010(1): p. CD007297.	consumer- or carer-directed shared decision making interventions for people of all ages with mental health conditions, on a range of outcomes including: patient satisfaction, clinical outcomes, and health service outcomes."	making	shared decision making interventions for people with mental health conditions. There is no evidence of harm, but there is an urgent need for further research in this area."
Ennis, L., et al., <i>Rapid progress or lengthy process? electronic personal health records in mental health</i> . BMC Psychiatry, 2011. 11 .	"To document the specific problems which might occur throughout the implementation of electronic personal health records (ePHRs) in mental health"	Electronic	"Several potential difficulties are highlighted and addressed, including access to information technology, identifying relevant populations and the handling of sensitive information. Special attention is paid to the concept of 'empowerment' and what this means in relation to ePHRs"
Evans, <i>Rhetoric or reality? A systematic review of the impact of participatory approaches by UK public health units on health and social outcomes (Provisional abstract)</i> . J Public Health, 2010. 32 (3): p. 418-426.	P 419: "The key question addressed by this systematic review was: what has been the impact of participatory approaches by UK NHS public health units (including health promotion units) on health and social outcomes?"	Case Study	"This systematic review demonstrates that there is very little evidence in the peer-reviewed literature of participatory approaches by UK public health units or of such approaches having any noteworthy impact on health and social outcomes".
Eyssen, I.C., et al., <i>A Systematic Review of Instruments Assessing Participation: Challenges in Defining Participation</i> . Archives of Physical	"To evaluate: (1) whether instruments which intend to measure participation actually do and (2) how frequently specific aspects and domains of participation are addressed."	Patients back into society	"According to our working definition of participation, most instruments that aim to measure participation do so only to a limited extent. These instruments mainly assess aspects of participation problems and participation accomplishment. The domains of participation covered by these instruments primarily include work/study, social life, general

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Medicine & Rehabilitation, 2011. 92 (6): p. 983-997.			participation, home, leisure, transport, and shopping.”
Facey, K., et al., <i>Patients' perspectives in health technology assessment: A route to robust evidence and fair deliberation</i> . International Journal of Technology Assessment in Health Care, 2010. 26 (3): p. 334-340.	P 335: “This study seeks to dispel myths about the poor quality of evidence associated with patients' perspectives and to assert the patient participation in HTAs should be integral to the assessment processes.”	Case study	“, HTA is still driven by collection of quantitative evidence to determine the clinical and cost effectiveness of a health technology. Patients' perspectives about their illness and the technology are rarely included, perhaps because they are seen as anecdotal, biased views. There are two distinct but complementary ways in which HTAs can be strengthened by: (i) gathering robust evidence about the patients' perspectives, and (ii) ensuring effective engagement of patients in the HTA process from scoping, through evidence gathering, assessment of value, development of recommendations and dissemination of findings. Robust evidence eliciting patients perspectives can be obtained through social science research that is well conducted, critically appraised and carefully reported, either through meta-synthesis of existing studies or new primary research. Engagement with patients can occur at several levels and we propose that HTA should seek to support effective patient participation to create a fair deliberative process. This should allow two-way flow of information, so that the views of patients are obtained in a supportive way and fed into decision-making processes in a transparent manner.”
Fine, E., et al., <i>Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature</i> . Journal of Palliative Medicine,	“To review studies that used direct observation (i.e., videotaping or audiotaping) methods in palliative/end-of-life care communication research. Design: Descriptive thematic analysis”	Patient-doctor relationship	“This study demonstrates that direct observation methods can be feasibly used when studying physician–patient/physician–family communication in palliative/end-of-life care, but few investigations have utilized this approach. This article highlights areas that need improvement, including physicians' ability to address patient/family emotional issues and provide what patients and families find most satisfying (participation and support). A particular focus on older

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2010. 13 (5) : p. 595-603.			patients and patients with end-stage or late-stage chronic (noncancer) illness, the adaptation/application of existing communication measurement tools to capture palliative care communication issues, and development of corresponding outcome measures to assess impact is now needed."
Forbes, A., et al., <i>Organizing and delivering diabetes education and self-care support: findings of scoping project.</i> J Health Serv Res Policy, 2011. 16 Suppl 1 : p. 42-9.	"To provide an overview of current research and development on the organization and delivery of diabetes education and self-care support, incorporating stakeholder perspectives."	Patient information	"The literature review identified themes relating to the organization and delivery of diabetes and selfcare support: structure and flexibility in models of education; accessibility; patient choice; integrating self-care within the overall care system; quality improvement; peer educators; health literacy; efficiency in delivery; telecare models; feedback technologies; care planning; psychological intervention; and self-care outcome measures. This generated four models to provide a framework to help shape the development of diabetes selfcare: a diabetes education pathway; integrating self-care and clinical care; choice as a method of optimizing care; and an integrated framework for delivering diabetes self-care. Conclusion: The clinical benefit of the identified models need to be evaluated."
Foss, C. and M. Askautrud, <i>Measuring the participation of elderly patients in the discharge process from hospital: a critical review of existing instruments.</i> Scandinavian Journal of Caring Sciences, 2010. 24 Suppl 1 : p. 46-55.	"Review of existing survey instruments designed to assess patients' perspectives on the discharge process"	Tools	"The major finding of the review is that none of the existing instruments capture the full range of participation, nor do they cover those areas of the discharge process identified by elderly patients themselves as the most essential."

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Frosch, D.L., et al., <i>Shared decision making in the United States: Policy and implementation activity on multiple fronts.</i> Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 305-312.	P 306: “Describe how shared decision making (SDM) was incorporated in the federal health care reform and other state legislative initiatives. An overview of research funding from public and private sources, and the role of professional societies, patient organizations and social networking communities in advocating for SDM. Describe the broad range of implementation projects being conducted at academic and community-based health care organizations and outline the development of decision support interventions (DESI) for patients by non-profit, for-profit, academic and government organizations Review what has intrigued policy makers about SDM and consider some of the risks and opportunities for the future.”	Case study	“Shared decision making in the United States has become an important element in health policy debates. The recently passed federal health care reform legislation includes several key provisions related to shared decision making (SDM) and patient decision support. Several states have passed or are considering legislation that incorporates SDM as a key component of improved health care provision. Research on SDM is funded by a range of public and private organizations. Non-profit, for-profit, academic and government organizations are developing decision support interventions for numerous conditions. Some interventions are publicly available; others are distributed to patients through health insurance and healthcare providers. A significant number of clinical implementation projects are underway to test and evaluate different ways of incorporating SDM and patient decision support into routine clinical care. Numerous professional organizations are advocating for SDM and social networking efforts are increasing their advocacy as well. Policy makers are intrigued by the potential of SDM to improve health care provision and potentially lower costs. The role of shared decision making in policy and practice will be part of the larger health care reform debate.”
Gagnon, A.J. and J. Sandall, <i>Individual or group antenatal education for childbirth or parenthood, or both [Systematic Review].</i> Cochrane Database of	“To provide an overview of current research and development on the organization and delivery of diabetes education and self-care support, incorporating stakeholder perspectives.”	Patient information	“The effects of general antenatal education for childbirth or parenthood, or both, remain largely unknown. Individualized prenatal education directed toward avoidance of a repeat caesarean birth does not increase the rate of vaginal birth after caesarean section.”

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Systematic Reviews, 2011. 10 : p. 10.			
Gillis and L. Mac, <i>Service learning with vulnerable populations: review of the literature</i> . International Journal of Nursing Education Scholarship, 2010. 7 (1): p. 1p.	"The literature on service learning with vulnerable populations in nursing education is reviewed and synthesized in this article."	Tools	"A description of service learning experiences, identification of knowledge and skills learned, opportunities for critical thinking and reflection, and a discussion of factors that act as enablers and barriers to service learning are explored. Recommendations for successful integration of service learning into educational settings are provided for nurse educators, academic institutions and community partners. As the service learning model spreads across nursing education it is suggested that it offers promise to foster social change and produce graduates who are fully engaged citizens and professionals."
Gona, J.K., et al., <i>Identification of people with disabilities using participatory rural appraisal and key informants: a pragmatic approach with action potential promoting validity and low cost</i> . Disability & Rehabilitation, 2010. 32 (1): p. 79-85.	"To investigate the strengths and weaknesses of PRA and KI approaches in the identification of people with disability in resource-poor countries."	research	"The PRA and KI approaches could be fast and cost-effective methods for identifying people with disabilities as an alternative to surveys. They are especially useful when identification is related to subsequent development of community-based services for persons with disabilities. However, surveys were shown to be more sensitive and therefore more accurate for establishing prevalence rates of impairment."
Goss, C., et al., <i>Participation of patients and citizens in healthcare decisions in Italy</i> . Zeitschrift fur Evidenz Fortbildung und Qualitat	P 278: "To update the current state on SDM in health care in Italy. In the paper we will provide: a) a description of the organization of the Italian National Health Service; b) a description of the	Case study	"What about policy regarding SDM? The Italian National Health Plan and many regional and local health authorities explicitly recognise the importance of patient/citizen participation. These official documents rarely mention the specific concept of SDM, but they use terms such as patient involvement, participation, and empowerment. Patient associations are actively involved in promoting patient/citizen

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im Gesundheitswesen, 2011. 105 (4): p. 277-82.	governmental and institutional initiatives regarding participation; c) examples of initiatives promoting patient/citizen participation; d) a narrative report on research projects on patient participation published on peer-reviewed journals; and e) examples on training activities to promote patient participation”.		participation, but still play a marginal role in the health debate compared to health professionals, clinicians and healthcare managers. What about tools – decision support for patients? There are only a few examples of decision aids designed for patients according to SDM concepts. A critical point is the lack of specific tools for the evaluation of SDM processes. Exceptions include the Italian versions of the OPTION scale and the SDM-Q, used at the micro-level for the evaluation of SDM. What about professional interest and real implementation? Health professionals recognise that doctor-patient communication is an important area. Italian research in SDM has grown and improved. It is very promising, but still limited. Undergraduate and postgraduate courses of some medical schools include specific programs on doctor-patient communication skills, focusing also on promotion of patient participation. What does the future look like? In conclusion, there is room for improving the Italian efforts to implement SDM into practice at both the individual and public level.”
Graven, C., et al., <i>Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke?</i> Disability & Rehabilitation, 2011. 33 (17/18): p. 1501-1520.	“To explore the effectiveness of community-based rehabilitation interventions delivered by allied health professionals and/or nursing staff in reducing depression, facilitating participation and improving health-related quality of life (HRQoL) post-inpatient stroke rehabilitation.”	Patients back into society	“Community-based interventions targeting participation and leisure domains showed moderate evidence for improvement in global participation measures and HRQoL. Comprehensive rehabilitation demonstrated limited evidence for depression and participation, and strong evidence for HRQoL There is limited to moderate evidence supporting some rehabilitation interventions in affecting the outcomes of depression, participation and HRQoL post-stroke. Heterogeneity of the studies made evidence synthesis difficult.”
Gruman, J., et al., <i>From</i>	“Advances in health care require that	Community	“People must make informed choices about insurance and clinicians,

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<i>patient education to patient engagement: implications for the field of patient education.</i> Patient Education & Counseling, 2010. 78 (3): p. 350-6.	individuals participate knowledgeably and actively in their health care to realize its full benefit. Implications of these changes for the behaviour of individuals and for the practice of patient education are described."	engagement, patient education	coordinate communications among providers and manage complex treatments on their own. Not doing so risks preventable illness, suboptimal outcomes and wasted resources."
Hall, J., et al., <i>Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review.</i> Quality & safety in health care, 2010. 19 (5): p. e10.	"Reports a systematic review of evaluations of the effectiveness of interventions that have been used with the explicit intention of promoting patient involvement in patient safety in healthcare."	Case study	"There is limited evidence for the effectiveness of interventions designed to promote patient involvement on patient safety incidents and in general is poor quality. Existing evidence is confined to the promotion of safe self-management of medication, most notably relating to the self-management of oral anticoagulants. "
Harter, M., et al., <i>Patient participation and shared decision making in Germany - History, agents and current transfer to practice.</i> Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 263-270.	"The main focus of the present paper is to describe 1) the healthcare system specific influences on patient participation in medical decision making and 2) the current state of research and implementation of shared decision making (SDM) after ten years of substantial advances in health policy and research in this field."	Case study	"What about policy regarding SDM? The "Medical Patients Rights Act" is to standardise all the rights and responsibilities within the scope of medical treatment. This also comprises the right to informed decisions, comprehensive and comprehensible information for patients, and decisions based on the partnership of clinicians and patients. What about tools - decision support for patients? SDM training programmes for healthcare professionals have been developed and partly implemented. Several decision support interventions - primarily with support from health insurance funds - have been developed and evaluated. What about professional interest and implementation? Against the background of the German health policy's endorsement of patient participation, the German government and other public

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			institutions are currently funding different research programmes in which shared decision making is playing a substantial role. The development and implementation of decision support tools for patients and professionals as well as the implementation of trainings for healthcare professionals require stronger efforts. What does the future look like? With the support of health policy and with the utilisation of scientific evidence, the transfer of shared decision making into practice is considered to be meaningful in the German healthcare system. The translation into routine care will remain an important task for the future."
Hartman, M.A., K. Hosper, and K. Stronks, <i>Targeting physical activity and nutrition interventions towards mothers with young children: A review on components that contribute to attendance and effectiveness</i> . Public Health Nutrition, 2011. 14 (8): p. 1364-1381.	"To gain insight into intervention components targeted specifically to mothers of young children that may contribute to attendance and effectiveness on physical activity and healthy eating."	Disease control and prevention	"The number of experimental intervention studies for promoting physical activity and healthy eating among new mothers is limited. However, useful first recommendations can be set for targeting interventions towards mothers, in particular for promoting attendance and physical activity. More insight is required about the need for targeting health promotion programmes at new mothers, especially of those directed at nutritional behaviour."
Henderson, C. and R. Laugharne, <i>User-held personalised information for routine care of people with severe mental illness [Systematic Review]</i> . Cochrane Database of	"To evaluate the effects of personalised and accessible patient-held clinical information for people with a diagnosis of psychotic illness."	Electronic	"There is a gap in the evidence regarding patient-held, personalised, accessible clinical information for people with psychotic illnesses. It cannot be assumed that patient-held information is beneficial or cost-effective without evidence from well planned, conducted and reported randomised trials."

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Systematic Reviews, 2011. 5 : p. 5			
Hordern, A., et al., <i>Consumer e-health: an overview of research evidence and implications for future policy</i> . Health Information Management Journal, 2011. 40 (2): p. 6-14.	"Assessed the evidence about consumer use of e-health"	Electronic	"Identified five categories that encompass consumer e-health: (i) peer-to-peer online support groups; (ii) self-management/self-monitoring applications; (iii) decision aids; (iv) the personal health record; and (v) Internet use. Our findings reveal that e-health offers consumers many possibilities and potential benefits, although there appears to be apprehension concerning the efficacy of some interventions and barriers relating to the trustworthiness of Internet-acquired information. It is imperative that policy initiatives address these issues to ensure that consumer e-health services can be effectively, efficiently, and safely accessed."
Huffman, M.D. and J.M. Galloway, <i>Cardiovascular health in indigenous communities: successful programs</i> . Heart Lung Circ, 2010. 19 (5-6): p. 351-60.	"Aim to describe some of these programs in order to understand common approaches and links that make them successful. Once this survey is completed, a template for successful CVD programs can be created for the development of future programs."	Community engagement	"Common themes that define successful Indigenous CVD programs include: dedicated focus on the Indigenous population, widespread community involvement within the Indigenous population, often through the use of Indigenous community health workers, a focus on high-risk individuals within the population and regularly scheduled contact between the program and participants. We recommend that these themes are incorporated during development of future CVD programs for Indigenous people."
Jha, V., et al., <i>Patient involvement in teaching and assessing intimate examination skills: a systematic review</i> . Medical Education, 2010. 44 (4): p. 347-57.	"Provides a summary of the evidence for the involvement of real patients (RPs) and simulated patients (SPs) in the training of health care professionals in intimate examination skills."	Patient information	"There is evidence of a short-term positive impact of patient involvement in the teaching and assessment of intimate examination skills; however, evidence of longer-term impact is still limited. The influences of sexuality and anxiety related to such examinations are explored to some extent, but the psychological impact on learners and patients is not well addressed."

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Ko, H., et al., <i>Patient-held medical records for patients with chronic disease: a systematic review</i> . Quality and Safety in Health Care, 2010. 19 (5): p. 1-7.	"To determine whether in patients with chronic disease a patient-held medical record (PHR), compared to usual care, improves clinical care, patient outcomes or satisfaction"	Electronic	"There is no clear benefit of implementing a PHR, and due to medium to high risk of bias these findings should be interpreted with caution. More high quality studies are needed to evaluate properly the effectiveness of PHRs in chronic disease populations."
Lassi, Z.S., B.A. Haider, and Z.A. Bhutta, <i>Community-based intervention packages for reducing maternal and neonatal morbidity and mortality and improving neonatal outcomes [Systematic Review]</i> . Cochrane Database of Systematic Reviews, 2011. 1 : p. 1.	"To assess the effectiveness of community-based intervention packages in reducing maternal and neonatal morbidity and mortality; and improving neonatal outcomes."	Peer support	"Our review offers encouraging evidence of the value of integrating maternal and newborn care in community settings through a range of interventions which can be packaged effectively for delivery through a range of community health workers and health promotion groups. While the importance of skilled delivery and facility-based services for maternal and newborn care cannot be denied, there is sufficient evidence to scale up community-based care through packages which can be delivered by a range of community-based workers."
Legare, F., et al., <i>Moving SDM forward in Canada: Milestones, public involvement, and barriers that remain</i> . Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 245-253.	Evaluating SDM in Canada	Case study	"Canada's approach to shared decision making (SDM) is as disparate as its healthcare system; a conglomerate of 14 public plans at various administrative levels. SDM initiatives are taking place in different pockets of the country and are in different stages of development. The most advanced provincial initiative is occurring in Saskatchewan, where in 2010 the provincial government prepare to introduce patient decision aids into certain surgical specialties. With regard to decision support tools for patients, perhaps the most active entity is the Patient Decision Aids Research Group in Ottawa, Ontario. This group maintains

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			a public inventory of decision aids ranked according to International Patient Decision Aid Standards and has developed the generic Ottawa Personal Decision Guide, as well as a toolkit for integrating decision aids in clinical practice. All of these tools are publicly available free of charge. Professional interest in SDM in Canada is not yet widespread, but Canada's principal health research funding agency is sponsoring several important SDM projects. Researchers from institutions across the country are promoting SDM through continuing professional development programs and other interventions in fields as varied as primary care, dietary medicine and workplace rehabilitation. Still, the future of SDM in Canada remains uncertain. Canada's provincially based structure obliges promoters to work with each province separately, and the recent growth of private healthcare risks dissipating efforts to implement SDM."
Legare, F., et al., <i>Interventions for improving the adoption of shared decision making by healthcare professionals [Systematic Review]</i> . Cochrane Database of Systematic Reviews, 2011. 1: p. 1	"To determine the effectiveness of interventions to improve healthcare professionals' adoption of SDM"	Shared decision making	"The results of this Cochrane review do not allow us to draw firm conclusions about the most effective types of intervention for increasing healthcare professionals' adoption of SDM. Healthcare professional training may be important, as may the implementation of patient mediated interventions such as decision aids. Given the paucity of evidence, however, those motivated by the ethical impetus to increase SDM in clinical practice will need to weigh the costs and potential benefits of interventions. Subsequent research should involve well designed studies with adequate power and procedures to minimise bias so that they may improve estimates of the effects of interventions on healthcare professionals' adoption of SDM. From a measurement perspective, consensus on how to assess professionals' adoption of SDM is desirable to facilitate cross-study comparisons."
Levasseur, M., et al.,	"Provides an inventory and content	Patients back into	"Content analysis showed that social participation definitions (n ¼ 43)

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<i>Inventory and analysis of definitions of social participation found in the aging literature: proposed taxonomy of social activities.</i> Soc Sci Med, 2010. 71 (12): p. 2141-9.	analysis of definitions of social participation in older adults. Based on these results, a taxonomy of social activities is proposed”	society	mostly focused on the person’s involvement in activities providing interactions with others in society or the community. Depending on the main goal of these social activities, six proximal to distal levels of involvement of the individual with others were identified: 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, 5) helping others, and 6) contributing to society. These levels are discussed in a continuum that can help distinguish social participation (levels 3 through 6) from parallel but different concepts such as participation (levels 1 through 6) and social engagement (levels 5 and 6). This taxonomy might be useful in pinpointing the focus of future investigations and clarifying dimensions specific to social participation.”
Longtin, Y., et al., <i>Patient participation: current knowledge and applicability to patient safety.</i> Mayo Clinic Proceedings, 2010. 85 (1): p. 53-62.	“We review the origins of patient participation, discuss the published evidence on its efficacy, and summarize the factors influencing its implementation”	Case studies	“Patient-related factors, such as acceptance of the new patient role, lack of medical knowledge, lack of confidence, comorbidity, and various sociodemographic parameters, all affect willingness to participate in the health care process. Among health care workers, the acceptance and promotion of patient participation are influenced by other issues, including the desire to maintain control, lack of time, personal beliefs, type of illness, and training in patient-caregiver relationships. Social status, specialty, ethnic origin, and the stakes involved also influence patient and health care worker acceptance. The London Declaration, endorsed by the World Health Organization World Alliance for Patient Safety, calls for a greater role for patients to improve the safety of health care worldwide. Patient participation in hand hygiene promotion among staff to prevent health care-associated infection is discussed as an illustrative example. A conceptual model including key factors that influence participation and invite patients to contribute to error prevention is proposed. Further research is essential to establish key

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			determinants for the success of patient participation in reducing medical errors and in improving patient safety.”
Lyttle, D.J. and A. Ryan, <i>Factors influencing older patients' participation in care: a review of the literature</i> . International journal of older people nursing, 2010. 5(4): p. 274-82.	“To review the literature on factors influencing patient participation in care with a particular focus on the perspective of older people.”	Vulnerability	“Although patient participation has received considerable attention in the literature, this review highlights the dearth of research from the perspective of older people. There is a general consensus that preference for participation should be assessed and not assumed, and the review offers a sobering reminder that participation should not be achieved at the expense of patient autonomy and choice.”
Macdonald, G. and W. Turner, <i>Treatment Foster Care for improving outcomes in children and young people [Systematic Review]</i> . Cochrane Database of Systematic Reviews, 2011. 5: p. 5.	“To assess the impact of TFC on psychosocial and behavioural outcomes, delinquency, placement stability, and discharge status for children and adolescents who require out-of-home placement”.	Peer support	“Although the inclusion criteria for this systematic review set a study design threshold higher than that of previous reviews, the results mirror those of earlier reviews but also highlights the tendency of the perceived effectiveness of popular interventions to outstrip their evidence base. Whilst the results of individual studies generally indicate that TFC is a promising intervention for children and youth experiencing mental health problems, behavioural problems or problems of delinquency, the evidence base is less robust than that usually reported.”
Magasi, S. and M.W. Post, <i>A comparative review of contemporary participation measures' psychometric properties and content coverage</i> . Archives of Physical Medicine & Rehabilitation, 2010. 91(9	“To provide a review of contemporary participation measures' conceptual foundations, psychometric properties and linkage to the International Classification of Functioning, Disability and Health (ICF).”	Patients back into Society	“This review provides tools--a detailed review of individual participation measures, a comparative table of the measures' psychometric properties, and ICF linkages--and a set of 3 guiding questions to help users select appropriate participation measures.”

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Suppl): p. S17-28.			
Maticka-Tyndale, E. and J.P. Barnett, <i>Peer-led interventions to reduce HIV risk of youth: a review</i> . Evaluation & Program Planning, 2010. 33 (2): p. 98-112.	“Critically reviews and synthesizes the results and lessons learned from 24 evaluated peer-led programs with an HIV/AIDS risk reduction component that target youth in the communities where they live and are delivered in low- and middle-income countries”	Patient information, Peer support	“Interventions were identified through a comprehensive search of the peer reviewed AIDS-related literature as well as publication lists of major organizations in the UN family that address HIV and AIDS. Our synthesis of study results finds that these programs have demonstrated success in effecting positive change in knowledge and condom use and have demonstrated some success in changing community attitudes and norms. Effects on other sexual behaviors and STI rates were equivocal. We include an overview of characteristics of successful programs, a review of program limitations, and recommendations for the development and implementation of successful community-based peer-led programs in low-income countries.”
McCaffery, K.J., et al., <i>Shared decision making in Australia in 2011</i> . Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 2011.	“Describes the current position of shared decision making (SDM) within the Australian healthcare system”	Case study	“SDM policy in Australia: Support for SDM exists through guidelines and policy documents, and is strongly endorsed by consumer organisations; however, there is no clear overarching policy framework for SDM in Australia. Tools for SDM: There are limited tools available for SDM in clinical practice. Access to tools exists through some Australian health research and consumer organisation websites but the use of tools remains idiosyncratic. Implementation of SDM: Comparatively little has been achieved in the implementation of SDM in Australia. Although there is wide recognition that consumer involvement in health decisions is important, provision of resources and infrastructure to achieve it is limited, and there is no clear strategy to support implementation within the healthcare system. SDM in the future: Current reforms to the healthcare system may enable a more centralised approach to implementation of SDM in the future. A new federally funded consumer health information organisation may assist by providing a central point through which SDM interventions may be made available to the

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			Australian public and the Australian Charter of Rights has the potential to provide a national framework for consumer involvement. However, priority needs to be given to SDM by both federal and state governments with greater investment in SDM research and in activities to support implementation in clinical practice."
Menon, D. and T. Stafinski, <i>Role of patient and public participation in health technology assessment and coverage decisions</i> . Expert Review of Pharmacoeconomics & Outcomes Research, 2011. 11 (1): p. 75-89.	P76: "To examine the roles of patients and the public in health technology assessment (HTA) used to inform coverage and reimbursement decisions on health technologies".	Case study	"Although there appears to be a general view that involvement of patients and the public is highly desirable, research offering insights into the effectiveness of different approaches to accomplish this is scarce. Nonetheless, many of the HTA agents in developed countries have established some mechanism for seeking input from patients or the public in their processes."
Michielsen, A., I. Van Wijk, and M. Ketelaar, <i>Participation and quality of life in children and adolescents with congenital limb deficiencies: A narrative review</i> . Prosthetics & Orthotics International, 2010. 34 (4): p. 351-61.	"A comprehensive review of the literature was conducted on participation, quality of life and psychosocial functioning in children and adolescents with congenital limb deficiencies."	Patients back into society	"The literature to date provides limited knowledge on how children and adolescents with congenital limb deficiencies participate and how they perceive their quality of life. The psychosocial functioning, although described as at risk, appears to be comparable to healthy peers. In conclusion, more research is needed on how children and adolescents with congenital limb deficiencies participate and how they perceive their quality of life. A broader perspective will not only help parents in making the right choices for their children, but can also have implications for health care providers, teachers and agencies funding rehabilitation services."
Minet, L., et al., <i>Mediating the effect of self-care management intervention in type 2 diabetes: A</i>	"To perform a meta-analysis assessing the effects of self-care management interventions in improving glycaemic control in type 2 diabetes by analysing	Self management	"In type 2 diabetes, there are improvements in glycaemic control in people who receive self-care management treatment with a small advantage to intervention with an educational approach. Practice implications Further research on frequency and duration of intervention

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<i>meta-analysis of 47 randomised controlled trials. Patient Education and Counseling, 2010. 80(1): p. 29-41.</i>	the impact of different study characteristics on the effect size."		may provide useful information to identify the most effective regime."
Miron-Shatz, T., et al., <i>The status of shared decision making and citizen participation in Israeli medicine. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 271-276.</i>	Describing situation of shared decision making (SDM) related activities in Israel	Case study	"What about policy regarding SDM? Though informed consent and patients' right to information are regulated by Israeli law, there is a low level of formal activities focused on shared decision making (SDM) in Israel. Further, there are few organized programs to promote SDM among medical professionals or the public, and governmental support of SDM-related research is minimal. What about tools – decision support for patients? The Israeli government does not have a program on development of patient decision aids. What about professional interest and implementation? Nonetheless, patients have begun to influence litigation in both formal and informal capacities, medical schools have begun to incorporate courses for improving physician-patient communication into their curricula, and the largest national health plan has initiated a plan to increase public awareness. Funding for researching and promoting SDM is not centrally allocated, and studies show that despite the positive effects of SDM, such an approach is infrequently applied in actual clinical practice, and initiatives to promote SDM (e.g., decision aids) are in their infancy. What does the future look like? In conclusion, though not actively promoting SDM at present, Israel, with its governmentally regulated universal coverage with good access to high-level services possesses all the requisite elements for rapid, widespread advances in SDM in future years."
Moore, L. and S. Kirk, <i>A literature review of</i>	"To review and critique the research literature on children's and young	Shared decision making	"RESULTS: Children want to be involved in discussions about their care but it is unclear to what extent this happens in practice. The research

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<i>children's and young people's participation in decisions relating to health care.</i> Journal of Clinical Nursing, 2010. 19(15-16): p. 2215-25.	people's participation in health care decision-making, to highlight gaps in the research and to identify implications for nursing practice."		conducted has interpreted participation in different ways. Studies have compared decisions of differing importance in terms of risk and many have a wide age range in their samples, including children who are arguably too young for meaningful participation. However, this heterogeneity is often overlooked in the reporting of studies. Aspects of practice which can help or hinder participation are identified but there is little evidence on the outcome benefits of participation. In addition, there has been an over-reliance on interviews as the method of data collection. CONCLUSIONS: Research using a combination of observation and interviewing would provide more in-depth knowledge about participation in practice. In addition, studies should consider decisions of similar consequence and children at an age when participation is appropriate. RELEVANCE TO CLINICAL PRACTICE: The need for health professionals to ensure children are protected is undisputed but should not prevent children's rights to participate from being enacted. Practitioners, therefore, need further guidance on how to facilitate the participation of children."
Moumjid, N., et al., <i>Shared decision making in the physician-patient encounter in France: a general overview in 2011.</i> Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen, 2011. 105(4): p. 259-62.	P260: "described the bases, the status and the development of shared decision making in the physician-patient encounter in France."	Case study	"What about policy regarding SDM? There is a social demand in France for more healthcare user information and greater patient participation in the decision making process, as reflected by the law of March 4th 2002 pertaining to patients' rights and the quality of the healthcare system known as the Law on Democracy in healthcare. What about tools – decision support for patients? At the micro level, some research projects are being developed, some of them using decision aids. Preliminary results show that patients want to be informed but that the concept of shared decision making needs to be analysed and refined from both the patients' and the physicians' points of views. What about professional interest and implementation? However, the relationship between physicians/healthcare professionals and patients/healthcare

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			users is very complex and progress in this field takes time. Only ten years after enactment of the Law on Democracy in healthcare, it might be premature to try and determine the state of the art of shared medical decision making at the macro and meso levels in France. What does the future look like? There is room in France for further studies on shared decision making in the medical encounter. Researchers, decision makers, healthcare users and healthcare professionals need a place to meet and exchange. An observatory dedicated to shared decision making will be launched in the coming months, both at the national level and in collaboration with several other French-speaking areas like Switzerland and the province of Quebec."
Myers, K.M., N.B. Palmer, and J.R. Geyer, <i>Research in child and adolescent telemental health</i> . Child and Adolescent Psychiatric Clinics of North America, 2011. 20 (1) : p. 155-171.	"To summarize the state of research in child and adolescent telemental health (CATMH)"	Electronic; diversity; tools	Page 168: "The feasibility and acceptability of CATMH has been well demonstrated. However, to bring CATMH into mainstream practice and reimbursement, an evidence base is needed that demonstrates the efficacy of CATMH as a health services delivery model with the ability to provide state-of-the-art treatment to underserved youth."
Ng, B.E., et al., <i>Population-based biomedical sexually transmitted infection control interventions for reducing HIV infection [Systematic Review]</i> . Cochrane Database of Systematic Reviews, 2011. 5 : p. 5.	"To determine the impact of population-based biomedical STI interventions on the incidence of HIV infection"	Peer support	"We failed to confirm the hypothesis that STI control is an effective HIV prevention strategy. Improved STI treatment services were shown in one study to reduce HIV incidence in an environment characterised by an emerging HIV epidemic (low and slowly rising prevalence), where STI treatment services were poor and where STIs were highly prevalent; Incidence was not reduced in two other settings. There is no evidence for substantial benefit from a presumptive treatment intervention for all community members. There are, however, other compelling reasons why STI treatment services should be strengthened, and the available

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			evidence suggests that when an intervention is accepted it can substantially improve quality of services provided."
O'Connor, A., et al., <i>Decision aids for people facing health treatment or screening decisions</i> [Systematic Review]. Cochrane Database of Systematic Reviews, 2011. 10 : p. 10.	"To evaluate the effectiveness of decision aids for people facing treatment or screening decisions."	Shared decision making	"New for this updated review is evidence that: decision aids with explicit values clarification exercises improve informed values-based choices; decision aids appear to have a positive effect on patient-practitioner communication; and decision aids have a variable effect on length of consultation"
Peat, M., et al., <i>Scoping review and approach to appraisal of interventions intended to involve patients in patient safety</i> . Journal of Health Services & Research Policy, 2010. 15 Suppl 1 : p. 17-25.	"To review the literature on the involvement of patients in efforts to promote their own or others' safety while using health care services."	Community engagement	"An approach for appraising interventions intended to promote patient involvement in patient safety should involve: identification of the routes by which interventions assume patients' actions might contribute to their safety; identification of the conditions that would need to be met for patients to behave and contribute as the interventions (implicitly) assume; examination of the extent to which the intervention supports fulfilment of those conditions; and consideration of the potential negative effects of the intervention."
Perestelo-Perez, L., et al., <i>Decision aids for patients facing health treatment decisions in Spain: preliminary results</i> . Patient Education & Counseling, 2010. 80 (3): p. 364-71.	"Reviews on the effectiveness of shared decision making (SDM) interventions (including decision aids (DAs))"	Case studies	"Systematic reviews carried out highlight that there are few studies assessing the effectiveness of DAs for OA, BPH, and depression. The development of DAs and their assessment currently differs for each medical condition. The DAs assessed for OA and BHP are well accepted. In a pilot study with OA patients, the DA produced a significant improvement in the decisional conflict "informed" subscale. CONCLUSION: Research on SDM and DAs for different chronic conditions is at a very early stage in Spain. It is not possible to draw any definite conclusions about the effectiveness of DAs for clinical practice."

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Perestelo-Perez, L., et al., <i>Shared decision making in Spain: Current state and future perspectives.</i> Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4) : p. 289-295.	P 290: “reports the evolution and current situation of shared decision making (SDM) in Spain.”	Case study	“In the last two decades there has been a growing recognition in the Spanish National Health System (NHS) of the importance of considering patients’ values and preferences in clinical decisions. Patient participation in shared decision making (SDM) is gaining importance as a suitable approach to patient-health professional communication and decision making in Spain. In addition, the NHS is funding the development of patients’ decision aids (PtDAs) for shared decision making (SDM) by Health Technology Assessment Agencies. However, the NHS has still not incorporated reforms in law that includes SDM and PtDAs as a key component of health care services and professional curricula, nor is there a standardised implementation of interventions to support decisions in routine care. Most patients are not very familiar with their rights to be kept informed and participate in their own health care decisions. Most professionals are not familiar with or educated about patients’ rights to be kept informed and participate in health care decisions either. The future of SDM in Spain is promising. The next course of action should be to maintain the production and adaptation of high-quality PtDAs while at the same time reinforcing effective dissemination strategies among patients and training programmes for professionals focused on SDM.”
Perestelo-Perez, L., et al., <i>Patient involvement and shared decision-making in mental health care.</i> Current Clinical Pharmacology, 2011. 6(2) : p. 83-90.	To describe patient involvement and shared decision making in mental health care	Shared decision making	“SDM in mental health care can be more complex than in general health care because that several patient characteristics, health care provider, and system level factors may hinder normalization and implementation of this model into clinical practice. To date, in comparison with other health problems, there are few studies which have assessed SDM in this context. In spite of that, evidence points favorably towards the inclusion of SDM in mental health treatment decisions, given that the majority of patients with mental illness prefer to be involved in the process and wish to have information. However, more studies are needed to provide

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			evidence about the impact of SDM on treatment compliance and health care outcomes. In this overview, the authors present the current state and the future perspectives of SDM in mental health."
Preston, R., et al., <i>Community participation in rural primary health care: intervention or approach?</i> Australian Journal of Primary Health, 2010. 16 (1): p. 4-16.	"To disentangle the conceptual gaps in this area, and clarify our common understanding of community participation."	Lack of clarity and evidence	"Although there is some evidence of benefit of community participation in terms of health outcomes, we found only a few studies demonstrating higher levels of evidence. However, it is clear that absence of evidence of effect is not necessarily the same as absence of an effect. We focus on areas of debate and lack of clarity in the literature. Improving our understanding of community participation and its role in rural primary health care service design and delivery will increase the likelihood of genuine community-health sector partnerships and more responsive health services for rural communities."
Regan, P., N. Hudson, and B. McRory, <i>Patient participation in public elections: a literature review</i> . Nursing management (Harrow, London, England : 1994), 2011. 17 (10): p. 32-36.	"Reviews the literature on promoting patients' participation in local and general elections"	Patients back into society	"patients' voting rights should be endorsed by organisations and nurse leaders through policy guidelines and a flexible and proactive nursing approach to participation"
Reinhardt, J.D. and M.W.M. Post, <i>Measurement and evidence of environmental determinants of participation in spinal cord injury: A systematic</i>	"review of measures of environmental influences on participation in spinal cord injury (SCI) and of the current evidence collected with these measures"	Patients back into society	"This review provided only weak and in part conflicting evidence on environmental determinants of participation in SCI."

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<i>review of the literature.</i> Topics in Spinal Cord Injury Rehabilitation, 2010. 15 (4) : p. 26-48.			
Repper, J. and T. Carter, <i>A review of the literature on peer support in mental health services</i> . Journal of Mental Health, 2011. 20(4) : p. 392-411.	"This article aims to review the literature on Peer Support Workers (PSWs) employed in mental health services to provide a description of the development, impact and challenges presented by the employment of PSWs and to inform implementation in the UK."	Peer support	"PSWs have the potential to drive through recovery-focused changes in services. However, many challenges are involved in the development of peer support. Careful training, supervision and management of all involved are required."
Roozen, H.G. and R. de Waart, <i>Community reinforcement and family training: an effective option to engage treatment-resistant substance-abusing individuals in treatment [corrected] [published erratum appears in ADDICTION 2010 Nov;105(11):2040]</i> . Addiction, 2010. 105(10) : p. 1729-1738.	"The objective of this systematic review was to compare Community Reinforcement and Family Training (CRAFT) with the Alcoholics Anonymous/Narcotics Anonymous (Al-Anon/Nar-Anon) model and the Johnson Institute intervention in terms of its ability to engage patients in treatment and improve the functioning of CSOs."	Community engagement for disease prevention and control	"CRAFT has been found to be superior in engaging treatment-resistant substance-abusing individuals compared with the traditional programmes."
Rose, K.D., J.S. Ross, and L.I. Horwitz, <i>Advanced</i>	"To describe patient and physician and/or practice outcomes resulting	Person centred	"Studies of advanced access support benefits to wait time and no-show rate. However, effects on patient satisfaction were mixed, and data

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<i>access scheduling outcomes: A systematic review.</i> Archives of Internal Medicine, 2011. 171 (13): p. 1150-1159.	from implementation of advanced access scheduling in the primary care setting."		about clinical outcomes and loss to follow-up were lacking."
Rosewilliam, S., C.A. Roskell, and A.D. Pandyan, <i>A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation.</i> Clinical rehabilitation, 2011. 25 (6): p. 501-14.	"To map out from the literature the nature, extent and effects of application of patient-centred goal setting in stroke rehabilitation practice. DESIGN: Systematic review."	Person centred	"Patient-centred goal setting is minimally adopted in goal-setting practice due to various barriers. Since the effects of incorporating this concept have not been evaluated rigorously it is suggested that further research is essential to investigate its effect on patient outcomes."
Ryan, R., et al., <i>Audio-visual presentation of information for informed consent for participation in clinical trials [Systematic Review].</i> Cochrane Database of Systematic Reviews, 2010. 11: p. 11	"To assess the effects of providing audio-visual information alone, or in conjunction with standard forms of information provision, to potential clinical trial participants in the informed consent process, in terms of their satisfaction, understanding and recall of information about the study, level of anxiety and their decision whether or not to participate."	Patient information	"The value of audio-visual interventions for people considering participating in clinical trials remains unclear. Evidence is mixed as to whether audio-visual interventions enhance people's knowledge of the trial they are considering entering, and/or the health condition the trial is designed to address; one study showed improved retention of knowledge amongst intervention recipients. The intervention may also have small positive effects on the quality of information disclosed, and may increase willingness to participate in the short term; however the evidence is weak. There were no data for several primary outcomes, including harms. In the absence of clear results, trial lists should continue to explore innovative methods of providing information to potential trial participants. Further research should take the form of

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			high-quality randomised controlled trials, with clear reporting of methods. Studies should conduct content assessment of audio-visual and other innovative interventions for people of differing levels of understanding and education; also for different age and cultural groups. Researchers should assess systematically the effects of different intervention components and delivery characteristics, and should involve consumers in intervention development. Studies should assess additional outcomes relevant to individuals' decisional capacity, using validated tools, including satisfaction; anxiety; and adherence to the subsequent trial protocol."
Ryan, R., et al., <i>Consumer-oriented interventions for evidence-based prescribing and medicines use: an overview of systematic reviews</i> . Cochrane Database of Systematic Reviews, 2011(5): p. CD007768.	"To evaluate the effectiveness of decision aids for people facing treatment or screening decisions"	Self-management	"New for this updated review is evidence that: decision aids with explicit values clarification exercises improve informed values-based choices; decision aids appear to have a positive effect on patient-practitioner communication; and decision aids have a variable effect on length of consultation"
Ryhänen, A.M., et al., <i>The effects of internet or interactive computer-based patient education in the field of breast cancer: A systematic literature review</i> . Patient Education and Counseling, 2010. 79 (1): p. 5-13.	"The aim of this systematic review was to analyze what kind of Internet or interactive computer-based patient education programs have been developed and to analyze the effectiveness of these programs in the field of breast cancer patient education."	Electronic, patient education	"The results suggest a positive relationship between the Internet or computer-based patient education program use and the knowledge level of patients with breast cancer but a diverse relationship between patient's participation and other outcome measures. Practice implications: There is need to develop and research more Internet-based patient education."

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Samoocha, D., et al., <i>Effectiveness of web-based interventions on patient empowerment: a systematic review and meta-analysis</i> . Journal of Medical Internet Research, 2010. 12 (2): p. e23.	"Our objective was to evaluate whether Web-based interventions are effective in increasing patient empowerment compared with usual care or face-to-face interventions."	Electronic, patient centeredness	"Web-based interventions showed positive effects on empowerment measured with the Diabetes Empowerment Scale, disease-specific self-efficacy scales and the Pearlin Mastery Scale. Because of the low quality of evidence we found, the results should be interpreted with caution. The clinical relevance of the findings can be questioned because the significant effects we found were, in general, small."
Scholl, I., et al., <i>Measurement of shared decision making - a review of instruments</i> . Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 313-24.	"To give an update on current developments regarding the measurement in the field of SDM, as well as to give a short overview of published and unpublished instruments."	Tools	"We found eight scales that have been subjected to further psychometric testing, eleven new and psychometrically tested instruments and nine developments that are still in the publishing process. The results show that there is a trend towards measuring SDM processes from a dyadic approach (assessing both the patient's and the clinician's perspective). More and more scales have been developed and tested in languages other than English, which indicates the growing research efforts in various countries. While reliability of most scales is good, they differ in their extent of validation. Further psychometric testing is needed, as well as the development of a theoretical measurement framework in order to improve consistency of measured constructs across research groups."
Schwappach, D.L.B. and M. Wernli, <i>Medication errors in chemotherapy: incidence, types and involvement of patients in prevention. A review of the literature</i> . European	"To review the literature of medication errors in chemotherapy, their incidences and characteristics, and to report on the growing evidence on involvement of patients in error prevention."	Community engagement for disease prevention and control	"Current developments in oncology, namely, increased outpatient treatment at ambulatory infusion units and the diffusion of oral chemotherapy to the outpatient setting, are likely to increase hazards since the process of preparing and administering the drug is often delegated to patients or their caregivers. While professional activities to error incidence reduction are effective and important, it has been increasingly acknowledged that patients often observe errors in the

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Journal of Cancer Care, 2010. 19 (3): p. 285-92.			administration of drugs and can thus be a valuable resource in error prevention. However, patients need appropriate information, motivation and encouragement to act as 'vigilant partners'. Examples of simple strategies to involve patients in their safety are presented. Evidence indicates that high self-efficacy and perceived effectiveness of the specific preventive actions increase likelihood of participation in error prevention. Clinicians play a crucial role in supporting and enabling the chemotherapy patient in approaching errors."
Schwappach, D.L.B., <i>Engaging patients as vigilant partners in safety: A systematic review.</i> Medical Care Research and Review, 2010. 67 (2): p. 119-148.	"A systematic review was conducted on the evidence of patients' attitudes toward engagement in error prevention and the effectiveness of efforts to increase patient participation"	Community engagement for disease prevention and control	"Patients share a positive attitude about engaging in their safety at a general level, but their intentions and actual behaviors vary considerably. Studies applied theories of planned behaviour and indicate that self-efficacy, preventability of incidents, and effectiveness of actions seem to be central to patients' intention to engage in error prevention. Rigorous evaluations of major educational campaigns are lacking. Interventions embedded within clinical settings have been effective to some extent. Evidence suggests that involvement in safety may be successful if interventions promote complex behavioral change and are sensitively implemented in health care settings."
Shah, J.Y., et al., <i>What leads Indians to participate in clinical trials? A meta-analysis of qualitative studies.</i> PLoS One, 2010. 5 (5): p. e10730.	To investigate "what factors affect their willingness to participate in clinical trials."	Research	"We identified factors that facilitated and barriers that have negative implications on trial participation decisions in Indian subjects. Due consideration and weightage should be assigned to these factors while planning future trials in India."
Sivell, S., et al., <i>Understanding surgery choices for breast cancer:</i>	"A systematic review was conducted on the evidence of patients' attitudes toward engagement in error	Shared decision making	"Patients share a positive attitude about engaging in their safety at a general level, but their intentions and actual behaviors vary considerably. Studies applied theories of planned behaviour and

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<i>how might the Theory of Planned Behaviour and the Common Sense Model contribute to decision support interventions?</i> Health Expectations, 2011. 14 : p. 6-19.	prevention and the effectiveness of efforts to increase patient participation."		indicate that self-efficacy, preventability of incidents, and effectiveness of actions seem to be central to patients' intention to engage in error prevention. Rigorous evaluations of major educational campaigns are lacking. Interventions embedded within clinical settings have been effective to some extent. Evidence suggests that involvement in safety may be successful if interventions promote complex behavioral change and are sensitively implemented in health care settings."
Spadea, T., et al., <i>The impact of interventions to improve attendance in female cancer screening among lower socioeconomic groups: A review</i> . Preventive Medicine, 2010. 50 (4) : p. 159-164.	"To review the scientific evidence on the effectiveness of interventions to promote attendance to breast and cervical cancer screening among lower socioeconomic groups."	Community engagement for disease prevention and control, Vulnerability	"Evidence from studies suggests that the attendance of deprived women to cancer screening can be improved with organized screening programs tailored to their needs. The same may apply to the prevention of adverse outcomes of other health conditions, such as hypertension, hypercholesterolemia, and diabetes."
Stepan, K.A., et al., <i>Recommendations for enhancing clinical trials education: a review of the literature</i> . Journal of Cancer Education, 2011. 26(1) : p. 64-71.	"This study aims to apply the evidence-based practice (EBP) process to determine the factors that influence patients' understanding of, participation in, and satisfaction with clinical trials, the informed consent process, and treatment decisions and to make recommendations for improving clinical trials education."	Patient information	"The issues surrounding clinical trial education are complex due to multiple variables interfering with poor patient understanding of, participation in, and satisfaction with clinical trial treatment decisions. On the basis of our findings, we recommend that clinicians involved in educating patients, families, staff, and communities about clinical trials have an awareness of and understanding for very complex issues."
Sykes, L.L., et al., <i>A systematic literature review on response rates</i>	"To conduct a systematic review examining whether minority ethnic populations participate in surveys as	Research, vulnerability	"Response rate varied across studies but was similar across ethnicities. Response rate may be related to many factors, including survey mode, length of questionnaire, survey language and cultural sensitivity to

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<i>across racial and ethnic populations</i> . Canadian journal of public health, 2010. Revue Canadienne de Sante Publique. 101(3): p. 213-9.	actively as the majority ethnic population."		content. Our review indicates that ethnic populations who participate in surveys are as likely to participate in research as Whites. In literature, data validity across ethnicity is still unknown and should be studied in the future."
Tamayo-Velazquez, M.-I., et al., <i>Interventions to promote the use of advance directives: an overview of systematic reviews</i> . Patient Education & Counseling, 2010. 80 (1): p. 10-20.	"To identify, appraise and synthesise the results of systematic reviews of the literature (SRLs) that examines the effectiveness of interventions to increase advance directive (AD) completion rate."	Patient information	"The most effective method of increasing the use of ADs is the combination of informative material and repeated conversations over clinical visits. The use of passive informative material in isolation does not significantly increase AD completion rates. However, when interactive informative interventions are employed, the AD completion rate increases and the majority of the studies identify multiple sessions as the most effective method for direct interaction between patients and health care professionals."
Tapp, H. and M. Dulin, <i>The science of primary health-care improvement: potential and use of community-based participatory research by practice-based research networks for translation of research into practice</i> . Experimental Biology & Medicine, 2010. 235 (3): p. 290-9.	"This review focuses on bringing together the ideals of CBPR and PBRNs in order to tackle intractable problems such as disparities in health-care access and outcomes and translate these results into practice."	Research	"Specifically, the CBPR PBRN approach can: (1) guide the research process so that studies more closely match the needs of all stakeholders (including providers, patients and community members); (2) assist in the development of the research protocol and identification of research methodologies so that the study is more amenable to participants; (3) facilitate recruitment of research participants; (4) enrich the data collection and analysis; and (5) allow rapid translation of results from the study back into clinical practice and the community. Once these mechanisms have been clearly elucidated, their widespread adoption will positively impact overall health at both a local and national level."
Tariman, J.D., et al., <i>Preferred and actual</i>	To explore "evidence on the degree of match between patients' preferred	Shared decision	"These groups of patients wanted a more shared or an active role versus a less passive role. Across all cancer types, patients wanted more

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<i>participation roles during health care decision making in persons with cancer: a systematic review.</i> Annals of Oncology, 2010. 21 (6): p. 1145-51.	and actual participation roles during decision making.”	making	participation than what actually occurred. Research to date documents a pervasive mismatch between patients' preferred and actual roles during decision making. Yet, there is lack of innovative interventions that can potentially increase matching of patients' preferred and actual role during decision making. Role preferences are dynamic and vary greatly during decision making, requiring regular clinical assessment to meet patients' expectations and improve satisfaction with treatment decisions.”
Tempfer, C.B. and P. Nowak, <i>Consumer participation and organizational development in health care: A systematic review.</i> Wiener Klinische Wochenschrift, 2011. 123 (13-14): p. 408-414.	“To provide an overview of published data on user participation in Health Care. Background: Active and passive involvement of consumers into agendas associated with Health Care is still an exception. Data on the success of user participation projects in various areas of Health Care are lacking.”	Community engagement	“Most consumer participation projects were performed in research agenda setting, internal medicine/oncology, and health worker training. Various methods have been used in the projects, the level of consumer participation was low, and the success rate of the investigated projects was moderate. Potential factors associated with project success and future areas of research are discussed.”
Thomas, R.E., M. Russell, and D. Lorenzetti, <i>Interventions to increase influenza vaccination rates of those 60 years and older in the community.</i> Cochrane Database of Systematic Reviews, 2010(9): p. CD005188.	“To assess effects of interventions to increase influenza vaccination rates in those 60 or older.”	Community engagement for disease prevention and control	“Forty-four RCTs were included. All included RCTs studied seniors in the community and in high-income countries. No RCTs of society-level interventions were included. Heterogeneity was marked and meta-analysis was limited. Only five RCTs were graded at low and six at moderate risk of bias. They included three of 13 personalized postcard interventions (all three with the 95% confidence interval (CI) above unity), two of the four home visit interventions (both with 95% CI above unity, but one a small study), three of the four reminder to physicians interventions (none with 95% CI above unity) and three of the four facilitator interventions (one with 95% CI above unity, and one P < 0.01). The other 33 RCTs were at high risk of bias and no

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			recommendations for practice can be drawn.”
Towle, A., et al., <i>Active patient involvement in the education of health professionals</i> . Medical Education, 2010. 44 (1): p. 64-74.	To review and summarise “the literature on active patient involvement in health professional education.”	Patient information	“A synthesis of the literature reveals increasing diversity in the ways in which patients are involved in education, but also the movement's weaknesses. Most initiatives are 'one-off' events and are reported as basic descriptions. There is little rigorous research or theory of practice or investigation of behavioural outcomes. The literature is scattered and uses terms (such as 'patient'!) that are contentious and confusing.”
Van De Belt, T.H., et al., <i>Definition of Health 2.0 and Medicine 2.0: a systematic review</i> . Journal of Medical Internet Research, 2010. 12 (2): p. e18.	“The objective was to identify unique definitions of Health 2.0/Medicine 2.0 and recurrent topics within the definitions.”	electronic	“Health 2.0/Medicine 2.0 are still developing areas. Many articles concerning this subject were found, primarily on the Internet. However, there is still no general consensus regarding the definition of Health 2.0/Medicine 2.0. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate discussion and further research.”
Vis, S.A., et al., <i>Participation and health - a research review of child participation in planning and decision-making</i> . Child & Family Social Work, 2011. 16 (3): p. 325-335.	“The purpose of this study is to review the research evidence for effects, positive or negative, of participation on health outcomes for children in care.”	Shared decision making, vulnerability	“We conclude that when participation is successful, it may have beneficial side effects. Chief among these are that participation may improve children’s safety, increase the success of care arrangements and increase feelings of well-being for children involved. Evidence for long-term effects of successful or failed participation attempts on subsequent health outcomes is however largely absent.”
White, G.W., et al., <i>Secondary analysis of a scoping review of health promotion interventions for persons with</i>	“To further investigate these assumptions, we conducted a review of the literature on health promotion interventions that include physical activity for adults with disabilities to	Patients back into society	“This review demonstrates that research on health promotion interventions containing physical activity lack description about whether such interventions help reduce or prevent secondary conditions. Additionally, the review shows that further work is needed in terms of sustaining health programs effects beyond the initial

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<i>disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation?</i> Disabil Health J, 2011. 4 (2): p. 129-39.	determine whether they have a positive effect on the reduction of secondary conditions and increased community participation."		proximal activity gains, with attention given toward more distal outcomes of increased participant participation in the community."
Woodall, A., et al., <i>Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?</i> BMC psychiatry, 2010. 10 : p. 103.	"The aim of this paper is to a) review the current literature on the nature of barriers to participation in mental health research, with particular reference to gender, age and ethnicity; b) review the evidence on the effectiveness of strategies used to overcome these barriers."	Research	"Mental health researchers should consider including caregivers in recruitment procedures where possible, provide clear descriptions of study aims and describe the representativeness of their sample when reporting study results. Studies that systematically investigate strategies to overcome barriers to recruitment are needed."
Woodward, H.I., et al., <i>What have we learned about interventions to reduce medical errors?</i> Annu Rev Public Health, 2010. 31 : p. 479-97.	"This review provides a broad perspective on major effective, established, or promising strategies to reduce medical errors and harm."	Case study	"Promising interventions include forcing functions, computerized prescriber order entry with decision support, checklists, standardized handoffs and simulation training. Many of the interventions described still lack strong evidence of benefit, but this should not hold back implementation. Rather, it should spur innovation accompanied by evaluation and publication to share the results."
Wright-Berryman, J.L., A.B. McGuire, and M.P. Salyers, <i>A review of consumer-provided services on assertive</i>	To review "the literature examining the outcomes of having consumer providers on case management teams, with attention devoted to randomized	Peer support	"Including a consumer provider on an ACT team could enhance the outreach mechanisms of ACT, using a more recovery-focused approach to bring consumers into services and help engage them over time. More rigorous research is needed to further evaluate integrating consumer

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<i>community treatment and intensive case management teams: implications for future research and practice.</i> Journal of the American Psychiatric Nurses Association, 2011. 17 (1): p. 37-44.	controlled trials (RCTs)."		providers on teams."
Zammar, G., et al., <i>So different, yet so similar: Meta-analysis and policy modeling of willingness to participate in clinical trials among Brazilians and Indians.</i> PLoS ONE, 2010. 5 (12)(e14368).	"To understand of factors that affect the willingness to participate in clinical trials of patients from those countries assumes a central role in the future of health research."	Research	"Our study provides important insights for investigators and sponsors for planning trials in Brazil (and India) in the future. Ignoring these results may lead to unnecessary fund/time spending. More studies are needed to validate our results and for better understanding of this poorly studied theme."
Ziviani, J., et al., <i>Measures of participation outcomes and environmental considerations for children with acquired brain injury: A systematic review.</i> Brain Impairment, 2010. 11 (2): p. 93-112.	"To examine the psychometric properties and application of assessments used to evaluate participation outcomes and environmental factors for children with acquired brain injury (ABI)."	Patients back into society	"The measures were critiqued in relation to content, validity, reliability, clinical utility, responsiveness, and overall strengths/weaknesses. These measures need to be evaluated more extensively with children who have ABI to further determine their psychometric properties and clinical usefulness with this population."

APPENDIX 1.3: ABSTRACTS OF REFINED DATA SET

Abad-Franch, F., et al., *Community participation in Chagas disease vector surveillance: systematic review*. PLoS Neglected Tropical Diseases [electronic resource], 2011. 5(6): p. e1207. Background: Vector control has substantially reduced Chagas disease (ChD) incidence. However, transmission by household-reinfesting triatomines persists, suggesting that entomological surveillance should play a crucial role in the long term interruption of transmission. Yet, infestation foci become smaller and harder to detect as vector control proceeds, and highly sensitive surveillance methods are needed. Community participation (CP) and vector-detection devices (VDDs) are both thought to enhance surveillance, but this remains to be thoroughly assessed. Methodology/Principal Findings: We searched Medline, Web of Knowledge, Scopus, LILACS, SciELO, the bibliographies of retrieved studies, and our own records. Data from studies describing vector control and/or surveillance interventions were extracted by two reviewers. Outcomes of primary interest included changes in infestation rates and the detection of infestation/reinfestation foci. Most results likely depended on study- and site-specific conditions, precluding meta-analysis, but we re-analysed data from studies comparing vector control and detection methods whenever possible. Results confirm that professional, insecticide-based vector control is highly effective, but also show that reinfestation by native triatomines is common and widespread across Latin America. Bug notification by householders (the simplest CP-based strategy) significantly boosts vector detection probabilities; in comparison, both active searches and VDDs perform poorly, although they might in some cases complement each other. Conclusions/Significance: CP should become a strategic component of ChD surveillance, but only professional insecticide spraying seems consistently effective at eliminating infestation foci. Involvement of stakeholders at all process stages, from planning to evaluation, would probably enhance such CP-based strategies.

Abreu, M.M.d., et al., *Shared decision making in Brazil: history and current discussion*. Zeitschrift für Evidenz Fortbildung und Qualität im Gesundheitswesen, 2011. 105(4): p. 240-4. There is no SDM in clinical practice in Brazil. The first steps have been taken towards research and tool development recently. Likewise, our society is starting to get involved with decision making in health care. This paper aims to offer an overview of the Brazilian health system history, its values, and its influence on SDM. The participative social control concept is introduced as a result of the movement against the dictatorship era. In addition, the influence of social changes on the Medical Ethical Code is delineated. SDM state of the art in Brazil is also discussed and the challenges to

implement it on clinical practice are described. Regardless the challenges, it is possible to make a positive assessment of SDM in Brazil.

Agnihotri, S., et al., *Community integration interventions for youth with acquired brain injuries: A review*. Developmental neurorehabilitation, 2010. **13**(5): p. 369-382. Objective: To identify and summarize published literature that examined the effectiveness of social and community integration interventions for children and adolescents with ABI in order to provide recommendations regarding future research on this topic. Methods: A literature review was conducted to identify studies that focused on social and community integration interventions for youth with ABI. Further manual searching of relevant journals with a paediatric rehabilitation focus was also carried out. Results: Currently, limited research has been published evaluating such interventions. The lack of research may stem largely from issues relating to how to measure community integration. Recommendations regarding intervention settings and structure are discussed. Conclusion: Additional studies investigating social and community integration interventions are necessary, including those with measures tailored specifically to community integration, larger samples, as are better controls and recruitment of youth with varying severities of brain injuries.

Ammenwerth, E., P. Schnell-Inderst, and A. Hoerbst, *Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals*. Studies in Health Technology & Informatics, 2011. **165**: p. 63-7. Patient portals provide patients with access to a provide-managed electronic health record (EHR). They may provide an interesting approach to increase patient empowerment. The objective of this paper is to provide a first overview of the state-of-the-art and the impact of patient portals. Based on a systematic literature search, we identified five evaluation studies on patient portals. These studies demonstrate only little effect of patient portals on patient empowerment.

Aras, R., *Social marketing in healthcare*. Australasian Medical Journal, 2011. **4**(8): p. 418-424. Background Social marketing is an important tool in the delivery of healthcare services. For any healthcare programme or project to be successful, community/consumer participation is required. The four principles of social marketing can guide policymakers and healthcare providers to successfully plan and implement health programmes. Aim To review the existing literature in order to project the benefits of social marketing in healthcare. Method A search of periodical literature by the author involving social marketing and marketing concepts in health was carried out. Items were identified initially through healthoriented indexing services such as Medline, Health STAR and Cinahl, using the identifiers "social marketing" and "marketing in health". An extensive search was also carried out on educational database ERIC. Results A literature review of various studies on social marketing indicated that the selection of the right product (according to the community need) at the right place, with the right strategy for promotion and at the right price yields good

results. However, along with technical sustainability (product, price, promotion and place), financial sustainability, institutional sustainability and market sustainability are conducive factors for the success of social marketing. Conclusion The purpose of this literature review was to ascertain the likely effectiveness of social marketing principles and approaches and behaviour change communication towards health promotion. It is important for all healthcare workers to understand and respond to the public's desires and needs and routinely use consumer research to determine how best to help the public to solve problems and realise aspirations. Social marketing can optimise public health by facilitating relationship-building with consumers and making their lives healthier.

Atkinson, J.A., et al., *The architecture and effect of participation: A systematic review of community participation for communicable disease control and elimination. Implications for malaria elimination.* Malaria Journal, 2011. **10**. Background: Community engagement and participation has played a critical role in successful disease control and elimination campaigns in many countries. Despite this, its benefits for malaria control and elimination are yet to be fully realized. This may be due to a limited understanding of the influences on participation in developing countries as well as inadequate investment in infrastructure and resources to support sustainable community participation. This paper reports the findings of an atypical systematic review of 60 years of literature in order to arrive at a more comprehensive awareness of the constructs of participation for communicable disease control and elimination and provide guidance for the current malaria elimination campaign. Methods: Evidence derived from quantitative research was considered both independently and collectively with qualitative research papers and case reports. All papers included in the review were systematically coded using a pre-determined qualitative coding matrix that identified influences on community participation at the individual, household, community and government/civil society levels. Colour coding was also carried out to reflect the key primary health care period in which community participation programmes originated. These processes allowed exhaustive content analysis and synthesis of data in an attempt to realize conceptual development beyond that able to be achieved by individual empirical studies or case reports. Results: Of the 60 papers meeting the selection criteria, only four studies attempted to determine the effect of community participation on disease transmission. Due to inherent differences in their design, interventions and outcome measures, results could not be compared. However, these studies showed statistically significant reductions in disease incidence or prevalence using various forms of community participation. The use of locally selected volunteers provided with adequate training, supervision and resources are common and important elements of the success of the interventions in these studies. In addition, qualitative synthesis of all 60 papers elucidates the complex architecture of community participation for communicable disease control and elimination which is presented herein. Conclusions: The current global malaria elimination campaign calls for a health systems strengthening approach to provide an enabling environment for

programmes in developing countries. In order to realize the benefits of this approach it is vital to provide adequate investment in the 'people' component of health systems and understand the multi-level factors that influence their participation. The challenges of strengthening this component of health systems are discussed, as is the importance of ensuring that current global malaria elimination efforts do not derail renewed momentum towards the comprehensive primary health care approach. It is recommended that the application of the results of this systematic review be considered for other diseases of poverty in order to harmonize efforts at building 'competent communities' for communicable disease control and optimising health system effectiveness.

Attree, P., et al., *The experience of community engagement for individuals: A rapid review of evidence*. Health and Social Care in the Community, 2011. **19**(3): p. 250-260. Community engagement is central to strategies to promote health and well-being and reduce health inequalities in many countries, particularly interventions which focus on improving health in disadvantaged populations. Despite the widespread use of community engagement approaches, however, there have been relatively few attempts to review the evidence on the impact that participation has on the lives of individuals involved. Drawing on a wider review of evidence carried out on behalf of the National Institute for Health and Clinical Excellence (NICE), this article reports on a rapid review of evidence of the effectiveness of initiatives which seek to engage communities in action to address the wider social determinants of health, to explore individuals' subjective experiences of engagement. The rapid review process was guided by NICE's public health methods manual, adapted to suit the diversity of the evidence. A total of 22 studies were identified containing empirical data on subjective experiences of community engagement for individuals. The findings of the rapid review suggest that the majority of 'engaged' individuals perceived benefits for their physical and psychological health, self-confidence, self-esteem, sense of personal empowerment and social relationships. Set against these positive outcomes, however, the evidence suggests that there are unintended negative consequences of community engagement for some individuals, which may pose a risk to well-being. These consequences included exhaustion and stress, as involvement drained participants' energy levels as well as time and financial resources. The physical demands of engagement were reported as particularly onerous by individuals with disabilities. Consultation fatigue and disappointment were negative consequences for some participants who had experienced successive waves of engagement initiatives. For some individuals, engagement may involve a process of negotiation between gains and losses. This complexity needs to be more widely recognised among those who seek to engage communities.

Avard, D., et al., *Public involvement in health genomics: The reality behind the policies*. International Journal of Consumer Studies, 2010. **34**(5): p. 508-524. Public involvement is increasingly becoming the norm as stakeholders recognize the need to inform,

consult and engage the public. However, there is limited understanding about the meaning and implications of public involvement, in particular elements like the levels of public involvement, the goals of the involvement, the type of public to be involved, the methods of involving the public and the need to assess effectiveness. We conducted a systematic review of policy documents/guidelines published between 1998 and 2009, by governments, health professionals and the public regarding public involvement in the area of human genomics. Documents were identified using the HUMGEN database and organizational web sites. A total of 70 documents were retrieved addressing public involvement and human genomics. The review revealed that 22 documents mentioned the active process of partnership and collaboration, whereas 27 mentioned consultation and 29 mentioned education. The most common goals were building trust and respect, followed by education, governance and lastly, understanding risks and benefits. We found that less than a third of the documents defined who the public is, and when mechanisms for public involvement were mentioned, they were rarely placed into a context. Few documents drew attention to evaluation. It is reassuring to see that there has been an emphasis placed on public involvement in the area of health and genomics. The findings underscore the gaps existing in the actual policy documents/guidelines and the need to clarify the goals, the methods, who is the public, what mechanism are appropriate and the need for evaluation when addressing public involvement in health genomics.

Baker, P.R., et al., *Community wide interventions for increasing physical activity*. Cochrane Database of Systematic Reviews, 2011(4). Background Multi-strategic community wide interventions for physical activity are increasingly popular but their ability to achieve population level improvements is unknown. Objectives To evaluate the effects of community wide, multi-strategic interventions upon population levels of physical activity. Search strategy We searched the Cochrane Public Health Group Specialised Register, *The Cochrane Library*, MEDLINE, MEDLINE in Process, EMBASE, CINAHL, LILACS, PsycINFO, ASSIA, The British Nursing Index, Chinese CNKI databases, EPPI Centre (DoPHER, TRoPHI), ERIC, HMIC, Sociological Abstracts, SPORTDiscus, Transport Database and Web of Science (Science Citation Index, Social Sciences Citation Index, Conference Proceedings Citation Index). We also scanned websites of the EU Platform on Diet, Physical Activity and Health; Health-Evidence.ca; the International Union for Health Promotion and Education; the NIHR Coordinating Centre for Health Technology (NCCHTA) and NICE and SIGN guidelines. Reference lists of all relevant systematic reviews, guidelines and primary studies were followed up. We contacted experts in the field from the National Obesity Observatory Oxford, Oxford University; Queensland Health, Queensland University of Technology, the University of Central Queensland; the University of Tennessee and Washington University; and handsearched six relevant journals. The searches were last updated to the end of November 2009 and were not restricted by language or publication status. Selection criteria Cluster randomised controlled trials, randomised controlled trials (RCT), quasi-experimental designs which used a control population for comparison, interrupted

time-series (ITS) studies, and prospective controlled cohort studies (PCCS) were included. Only studies with a minimum six-month follow up from the start of the intervention to measurement of outcomes were included. Community wide interventions had to comprise at least two broad strategies aimed at physical activity for the whole population. Studies which randomised individuals from the same community were excluded. Data collection and analysis At least two review authors independently extracted the data and assessed the risk of bias of each included study. Non-English language papers were reviewed with the assistance of an epidemiologist interpreter. Each study was assessed for the setting, the number of included components and their intensity. Outcome measures were grouped according to whether they were dichotomous (physically active, physically active during leisure time and sedentary or physically inactive) or continuous (leisure time physical activity, walking, energy expenditure). For dichotomous measures we calculated the unadjusted and adjusted risk difference, and the unadjusted and adjusted relative risk. For continuous measures we calculated net percentage change from baseline, unadjusted and adjusted risk difference, and the unadjusted and adjusted relative risk. Main results After the selection process had been completed 25 studies were included in the review. Of the included studies, 19 were set in high income countries, using the World Bank economic classification, and the remaining six were in low income countries. The interventions varied by the number of strategies included and their intensity. Almost all of the interventions included a component of building partnerships with local governments or non-governmental organisations (NGOs) (22 studies). None of the studies provided results by socio-economic disadvantage or other markers of equity consideration. However of those included studies undertaken in high income countries, 11 studies were described by the authors as being provided to deprived, disadvantaged, or low socio-economic communities. Fifteen studies were identified as having a high risk of bias, 10 studies were unclear, and no studies had a low risk of bias. Selection bias was a major concern with these studies, with only one study using randomisation to allocate communities (Simon 2008). No studies were judged as being at low risk of selection bias although 16 studies were considered to have an unclear risk of bias. Eleven studies had a high risk of detection bias, 10 with an unclear risk and four with no risk. Assessment of detection bias included an assessment of the validity of the measurement tools and quality of outcome measures. The effects reported were inconsistent across the studies and the measures. Some of the better designed studies showed no improvement in measures of physical activity. Publication bias was evident. Authors' conclusions Although numerous studies have been undertaken, there is a noticeable inconsistency of the findings of the available studies and this is confounded by serious methodological issues within the included studies. The body of evidence in this review does not support the hypothesis that multi-component community wide interventions effectively increase population levels of physical activity. There is a clear need for well-designed intervention studies and such studies should focus on the quality of the measurement of physical activity, the

frequency of measurement and the allocation to intervention and control communities.

Belanger, E., C. Rodriguez, and D. Groleau, *Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis*. Palliative Medicine, 2011. **25**(3): p. 242-61. The aim of this study is to synthesize knowledge about the process of shared decision-making (SDM) in palliative care. Medline, EMBASE, CINAHL, PsychInfo, Web of Science were searched with core concepts: shared decisions, patient participation in decision-making, and palliative care. Titles and abstracts were screened according to inclusion criteria (original research, adult patients, Western contexts, decision-making, palliative treatment or setting), yielding 37 articles for analysis. A narrative synthesis was created using the methods of thematic analysis, conceptual mapping, and critical reflection on the synthesis process. Results demonstrate that while a majority of patients want to participate in treatment decisions to some extent, most do not achieve their preferred levels of involvement because decisions are delayed and alternative treatment options are seldom discussed. The literature regarding the process of SDM itself remains scarce in palliative care. Further research is needed in order to better understand the longitudinal, interactive, and interdisciplinary process of decision-making in palliative care.

Bonfill Cosp, X., et al., *Strategies for increasing the participation of women in community breast cancer screening [Systematic Review]*. Cochrane Database of Systematic Reviews, 2010. 11: p. 11. Background Strategies for reducing breast cancer mortality in western countries have focused on screening, at least for women aged 50 to 69 years. One of the requirements of any community screening program is to achieve a high participation rate, which is related to methods of invitation. Therefore, it was decided to systematically review the scientific evidence on the different strategies aimed at improving women's participation in breast cancer screening programs and activities. Objectives To assess the effectiveness of different strategies for increasing the participation rate of women invited to community (population based) breast cancer screening activities or mammography programs. Search strategy MEDLINE (1966-2000), CENTRAL (2000), and EMBASE (1998-1999) searches for 1966 to 1999 were supplemented by reports and letters to the European Screening Breast Cancer Programs (Euref Network). Selection criteria Both published and unpublished trials were eligible for inclusion, provided the women had been invited to a community breast screening activity or program and had been randomised to an intervention group or a control group with no active intervention. Data collection and analysis: We identified 151 articles, which were reviewed independently by two people. The discrepancies were resolved by a third reviewer in order to reach consensus. Thirty-four studies were excluded because they lacked a control group; 58 of the other 117 articles were considered as opportunistic and not community-based; 59 articles, which reported 70 community-based randomised controlled trials or clinical controlled trials,

were accepted. In 24 of these, the control group had not been exposed to any active intervention, but 8 of the 24 had to be excluded because the denominator for estimating attendance was unknown. At the end, 16 studies constituted the material for this review, although two studies were further excluded because their groups were not comparable at baseline. Data from all but one study were based on or converted to an intention-to-treat analysis. Attendance in response to the mammogram invitation was the main outcome measure. Main results The evidence favoured five active strategies for inviting women into community breast cancer screening services: letter of invitation (OR 1.66, 95% CI 1.43 to 1.92), mailed educational material (Odds Ratio(OR) 2.81, 95% Confidence Interval (CI) 1.96 to 4.02), letter of invitation plus phone call (OR 2.53, 95% CI 2.02 to 3.18), phone call (OR 1.94, 95% CI 1.70 to 2.23), and training activities plus direct reminders for the women (OR 2.46, 95% CI 1.72 to 3.50). Home visits did not prove to be effective (OR 1.06, 95 % CI 0.80 to 1.40) and letters of invitation to multiple examinations plus educational material favoured the control group (OR 0.62, 95 % CI 0.32 to 1.20). Authors' conclusions: Most active recruitment strategies for breast cancer screening programs examined in this review were more effective than no intervention. Combinations of effective interventions can have an important effect. Some costly strategies, as a home visit and a letter of invitation to multiple screening examinations plus educational material, were not effective. Further reviews comparing the effective interventions and studies that include cost-effectiveness, women's satisfaction and equity issues are needed.

Boote, J., W. Baird, and C. Beecroft, *Public involvement at the design stage of primary health research: a narrative review of case examples*. Health Policy, 2010. **95**(1): p. 10-23. Objective: To review published examples of public involvement in research design, to synthesise the contributions made by members of the public, as well as the identified barriers, tensions and facilitating strategies. Design: Systematic literature search and narrative review. Findings: Seven papers were identified covering the following topics: breast-feeding, antiretroviral and nutrition interventions; paediatric resuscitation; exercise and cognitive behavioural therapy; hormone replacement therapy and breast cancer; stroke; and parents' experiences of having a pre-term baby. Six papers reported public involvement in the development of a clinical trial, while one reported public involvement in the development of a mixed methods study. Group meetings were the most common method of public involvement. Contributions that members of the public made to research design were: review of consent procedures and patient information sheets; outcome suggestions; review of acceptability of data collection procedures; and recommendations on the timing of potential participants into the study and the timing of follow-up. Numerous barriers, tensions and facilitating strategies were identified. Conclusions: The issues raised here should assist researchers in developing research proposals with members of the public. Substantive and methodological directions for further research on the impact of public involvement in research design are set out.

Boote, J., W. Baird, and A. Sutton, *Public involvement in the systematic review process in health and social care: A narrative review of case examples*. Health Policy, 2011. **102**(2-3): p. 105-116. Objectives: To review the evidence on public involvement in the systematic review process in health and social care; to examine the different methods, levels and stages of involving the public; to synthesise the contributions of the public, as well as the identified tensions, facilitating strategies and recommendations for good practice. Method: Systematic literature search and narrative review. Findings: Seven case examples were found covering the following review topics: patients' perspectives on electro-convulsive therapy; user involvement in nursing, midwifery and health visiting research; treatments for degenerative ataxias; teaching, learning and assessment of law in social work education; HIV health promotion for men who have sex with men; the conceptualisation, measurement, impact and outcomes of public involvement in health research; methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. The public was found to contribute to systematic reviews by: refining the scope of the review; suggesting and locating relevant literature; appraising the literature; interpreting the review findings; writing up the review. Numerous tensions, facilitating strategies and recommendations were identified. Conclusions: The issues raised in this paper should assist researchers in developing and conducting systematic reviews with the involvement of the public.

Bowen, F., A. Newenham-Kahindi, and I. Herremans, *When suits meet roots: The antecedents and consequences of community engagement strategy*. Journal of Business Ethics, 2010. **95**(2): p. 297-318. Understanding firms' interfaces with the community has become a familiar strategic concern for both firms and non-profit organizations. However, it is still not clear when different community engagement strategies are appropriate or how such strategies might benefit the firm and community. In this review, we examine when, how and why firms benefit from community engagement strategies through a systematic review of over 200 academic and practitioner knowledge sources on the antecedents and consequences of community engagement strategy. We analytically describe evidence on the rise of the community engagement strategy literature over time, its geographical spread and methodological evolution. A foundational concept underlying many studies is the 'continuum of community engagement'. We build on this continuum to develop a typology of three engagement strategies: transactional, transitional and transformational engagement. By identifying the antecedents and outcomes of the three strategies, we find that the payoffs from engagement are largely longer-term enhanced firm legitimacy, rather than immediate cost-benefit improvements. We use our systematic review to draw implications for future research and managerial practice.

Brandt, Å., et al., *Activity and participation, quality of life and user satisfaction outcomes of environmental control systems and smart home technology: a systematic*

review. Disability & Rehabilitation: Assistive Technology, 2011. 6(3): p. 189-206. Objective. To examine activity and participation, quality of life, and user satisfaction outcomes of environmental control systems (ECSs) and smart home technology (SHT) interventions for persons with impairments. Method. A systematic review. Seventeen databases, three conference proceedings, and two journals were searched without language or study design restrictions covering the period January 1993 - June 2009. Reviewers selected studies, extracted data, and assessed the methodological quality independently. Result. Of 1739 studies identified, five effect studies and six descriptive studies were included. One study was on SHT and the remainder on ECS; functionalities were overlapping. The studies varied in most aspects, and no synthesis could be drawn. However, ECS/SHT tended to increase study participants' independence, instrumental activities of daily living, socialising, and quality of life. Two studies showed high user satisfaction. The level of evidence was regarded as low, mainly due to small study sizes, lacking confounder control, and a majority of descriptive studies. Conclusion. Due to few and small studies and study diversity, it was not possible to determine whether ECS/SHT have positive outcomes for persons with impairment, even though the technologies seem to be promising. High quality outcomes studies such as randomised controlled trials, when feasible, and large longitudinal multi-centre studies are required.

Bravo, P., et al., *Shared decision making in Chile: Supportive policies and research initiatives*. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. 105 (4): p. 254-258. What about policy regarding SDM? Since 1999, there has been a small but growing interest by academics, the government, and society as a whole in strengthening patients' and professionals' involvement in shared decision making (SDM). Two governmental policy documents that indicate support for SDM are (1) Health Reform in 2003 and (2) Sanitary Objectives 2011-2020, which includes a brief section on client participation and SDM. What about tools – decision support for patients? Research by Chilean academics has highlighted the patients' desire to participate in health decisions and effective approaches for enhancing health professionals' skills in interprofessional SDM; however, little has been done to support this need and the work is centralised in only one academic institution. Decision support tools and coaching interventions are limited to patients considering decisions about managing type 2 diabetes. What about professional interest and implementation? Although there is increasing attention to studying patients' participation and involvement on their healthcare, little has been studied in relation to professionals' interest in SDM. As well, there are significant challenges for implementation of a country-wide SDM policy. What does the future look like? The future looks promising given the new health policies, local Chilean research projects, and international initiatives. Collaboration between health professionals, academics, and government policy makers, with public involvement needs to be strengthened in order to promote concrete strategies to implement SDM in Chile.

Bunge, M., I. Muhlhauser, and A. Steckelberg, *What constitutes evidence-based patient information? Overview of discussed criteria*. Patient Education & Counseling, 2010. **78**(3): p. 316-28. Objective: To survey quality criteria for evidence-based patient information (EBPI) and to compile the evidence for the identified criteria. Methods: Databases PubMed, Cochrane Library, PsycINFO, PSYINDEX and Education Research Information Centre (ERIC) were searched to update the pool of criteria for EBPI. A subsequent search aimed to identify evidence for each criterion. Only studies on health issues with cognitive outcome measures were included. Evidence for each criterion is presented using descriptive methods. Results: 3 systematic reviews, 24 randomized-controlled studies and 1 non-systematic review were included. Presentation of numerical data, verbal presentation of risks and diagrams, graphics and charts are based on good evidence. Content of information and meta-information, loss- and gain-framing and patient oriented outcome measures are based on ethical guidelines. There is a lack of studies on quality of evidence, pictures and drawings, patient narratives, cultural aspects, layout, language and development process. Conclusion: The results of this review allow specification of EBPI and may help to advance the discourse among related disciplines. Research gaps are highlighted. Practice implications: Findings outline the type and extent of content of EBPI, guide the presentation of information and describe the development process.

Car, J., et al., *Interventions for enhancing consumers' online health literacy*. Cochrane Database of Systematic Reviews, 2011(6): p. CD007092. Background Access to health information is critical to enable consumers to participate in decisions on health. Increasingly, such information is accessed via the internet, but a number of barriers prevent consumers making effective use of it. These barriers include inadequate skills to search, evaluate and use the information. It has not yet been demonstrated whether training consumers to use the internet for health information can result in positive health outcomes. Objectives To assess the effects of interventions for enhancing consumers' online health literacy (skills to search, evaluate and use online health information). Search strategy We searched: the Cochrane Consumers and Communication Review Group Specialised Register; Cochrane Central Register of Controlled Trials (CENTRAL, *The Cochrane Library*, Issue 1 2008);MEDLINE (Ovid); EMBASE (Ovid); CINAHL (Dialog); ERIC (CSA Illumina); LISA (CSA Illumina); PsycINFO (Ovid); Index to scientific and technical proceedings; SIGLE; ASLIB Index to Theses; ProQuest Dissertation Abstracts; National Research Register/UK CRN Portfolio database; Current Controlled Trials – Meta Register of Controlled Trials. We searched all databases for the period January 1990 to March 2008. Selection criteria Randomised controlled trials (RCTs), cluster RCTs and associated economic evaluations, quasi-RCTs, interrupted time series analyses, and controlled before and after (CBA) studies assessing interventions to enhance consumers' online health literacy, in any language. Data collection and analysis Two review authors independently selected studies for inclusion, assessed their quality and extracted data. We contacted study authors for clarification and to seek missing data. We presented results as a narrative

and tabular summary, and calculated mean differences where appropriate. Main results We included two studies: one randomised controlled trial (RCT) and one controlled before and after (CBA) study with a combined total of 470 participants. The RCT compared internet health information classes with patient education classes for participants with HIV infection. Only the RCT, which we rated as having a moderate risk of bias, reported statistically significant positive effects for primary outcomes related to online health literacy in the intervention group, for the following outcomes: 'Self-efficacy for health information seeking', 'health information evaluation skills' and the 'number of times the patient discussed online information with a health provider'. The CBA, which we rated as having a high risk of bias, compared internet health information classes with a control group receiving no intervention among healthy adults aged 50+. It showed significant positive changes only in a secondary (behavioural) outcome in the intervention group, regarding the readiness to adopt the internet as a tool for preventive health information. No adverse effects were reported. There is low quality evidence that such interventions may improve some outcomes relevant to online health literacy in certain populations. Authors' conclusions Due to the small number of studies and their variable methodological quality, the evidence is too weak to draw any conclusions about implications for the design and delivery of interventions for online health literacy. There is a need for well-designed RCTs to investigate the effects of such interventions. These should involve different participants (in terms of disease status, age, socio-economic group and gender) to analyse the extent to which online health literacy reduces a barrier to using the internet for health information. Trials should be conducted in different settings and should examine interventions to enhance consumers' online health literacy (search, appraisal and use of online health information) like internet training courses, measuring outcomes up to at least one year after the intervention to estimate the sustainability of the intervention effects.

Catalani, C. and M. Minkler, *Photovoice: a review of the literature in health and public health*. Health Education & Behavior, 2010. **37**(3): p. 424-51. Although a growing number of projects have been implemented using the community-based participatory research method known as photovoice, no known systematic review of the literature on this approach has been conducted to date. This review draws on the peer-reviewed literature on photovoice in public health and related disciplines conducted before January 2008 to determine (a) what defines the photovoice process, (b) the outcomes associated with photovoice, and (c) how the level of community participation is related to photovoice processes and outcomes. In all, 37 unduplicated articles were identified and reviewed using a descriptive coding scheme and Viswanathan et al.'s quality of participation tool. Findings reveal no relationship between group size and quality of participation but a direct relationship between the latter and project duration as well as with getting to action. More participatory projects also were associated with long-standing relationships between the community and outside researcher partners and an intensive training component. Although vague descriptions of project evaluation

practices and a lack of consistent reporting precluded hard conclusions, 60% of projects reported an action component. Particularly among highly participatory projects, photovoice appears to contribute to an enhanced understanding of community assets and needs and to empowerment.

Chen, P.G., et al., *Dissemination of results in community-based participatory research*. American Journal of Preventive Medicine, 2010. **39**(4): p. 372-8. Context: Community-based participatory research (CBPR) has been promoted as an approach to understanding complex health problems not amenable to research conducted solely by outside investigators. Although broad dissemination of research results is a key element of the CBPR approach, existing dissemination efforts have not been assessed. Evidence Acquisition: In this systematic review, researchers evaluated studies utilizing the CBPR approach to characterize dissemination of research results beyond scientific publication. Specifically, the focus was on dissemination to community participants and the general public. The literature search encompassed articles published between January 1, 2005, and December 31, 2009. Corresponding authors were also invited to complete a web-based survey. Data were collected and analysed between July 1, 2008, and March 8, 2010. Evidence Synthesis: In all, 101 articles met inclusion criteria. All articles were assessed for the quality of community involvement in research. Scores ranged from 1.4 to 3.0 (on a 3-point scale), with a mean of 2.3. The 21 articles in which an intervention was evaluated were scored for the rigor of research methods. Scores ranged from 2.0 to 2.9 (on a 3-point scale), with a mean of 2.4. Dissemination beyond scientific publication was reported in 48% of publications with varying levels of detail. However, among survey respondents, 98% reported dissemination of results to community participants and 84% reported dissemination to the general public. Conclusions: Among research meeting strict criteria for inclusion as CBPR, dissemination beyond scientific publication is largely occurring. However, myriad challenges to timely and widespread dissemination remain, and current dissemination to community participants and the general public is variable.

Chung, E.Y.-h., T. Packer, and M. Yau, *When East meets West: community-based rehabilitation in Chinese communities*. Disability & Rehabilitation, 2011. **33**(8): p. 697-705. Purpose. Community-based rehabilitation (CBR) has been practiced in mainland China for over three decades. This study reviews the development of CBR and describes its practice in Chinese communities in order to discuss current controversies within CBR practice internationally and in the Chinese context. Method. Review of literature. Development of CBR, its principles and controversies internationally and in the Eastern world is reviewed. CBR practice in Chinese communities is examined. Results. Shifting ideology and practices mean many different activities are labelled CBR. Variation across contexts has led to many controversies, specifically: the lack of evidence to support practice; ownership of programs; conceptual differences surrounding autonomy and participation and cultural issues. Contemporary Chinese cultural values and Chinese CBR are shaped by traditional peasant culture, traditional

Chinese philosophy and socialist ideology. Conclusion. The review indicates that Western CBR concepts and philosophy cannot be directly applied to the Chinese context. An appropriate model or framework is needed to fit the unique Chinese cultural context and to guide practice in Chinese communities.

Claes, C., et al., *Person-centered planning: analysis of research and effectiveness*. Intellectual & Developmental Disabilities, 2010. **48**(6): p. 432-53. Person-centred planning is a well known and widely used approach to individual program planning in the field of intellectual and developmental disabilities. Its purpose is to develop collaborative supports focused on community presence, community participation, positive relationships, respect, and competence. Because there is little research on its effectiveness, our purpose here was to (a) review the current status of effectiveness research; (b) describe its effectiveness in terms of outcomes or results; and (c) discuss the effectiveness of person-centred planning in relation to evidence based practices. Analysed studies suggest that, overall, this planning has a positive, but moderate, impact on personal outcomes for this population. The body of evidence provided in this review is weak with regard to criteria for evidence-based research.

Clavering, E.K. and J. McLaughlin, *Children's participation in health research: from objects to agents?* Child: Care, Health & Development, 2010. **36**(5): p. 603-11. *Background* In the UK, there is a growing recognition of the need to include children's accounts in research on paediatric health care. This paper seeks to examine ways in which children have been included in health-related studies to identify strengths and weaknesses. *Methods* Key empirical based studies were identified via comprehensive searches of academic literature databases to exemplify research practices related to three ways of engaging with children in health-related research. These three approaches are summarized as research *on* children, *with* children and *by* children. *Results* Research *on* children engages with adult 'authorities', such as parents and medical professionals. This approach allows some access to children including those understood as hard-to-reach: for example, pre-speech infants, or children with complex developmental disabilities. Research *with* children includes children as respondents to engage directly with their own understandings. This may be achieved alongside adult representatives, or by focusing only on the children themselves. Research *by* children encourages children to participate in the research process itself. This may occur across any, or indeed, every stage from design to dissemination to enable children to set the agenda themselves. Each of the three approaches has strengths and weaknesses, and involves some form of adult-mediation. *Conclusion* Inclusion of children's perspectives can be achieved, at varying levels, in each approach (on, with and by) examined here. Although claims to authority around including children's perspectives may appear to hold more credence when children have directly participated in the research, there may be times when this is neither possible nor appropriate. Researchers are challenged to be open and reflexive about ways in which children are engaged with, incorporated in and represented across the many stages of

research. Whichever approach is taken, ethical issues and notions of equity remain problematic. This point holds particular resonance for ways in which ethics around children may be considered in National Health Service ethics governance processes.

Conrardy, J.A., B. Brenek, and S. Myers, *Determining the state of knowledge for implementing the universal protocol recommendations: an integrative review of the literature*. AORN Journal, 2010. **92**(2): p. 194-207. The purpose of this study was to determine the current state of knowledge concerning the implementation of the Joint Commission's Universal Protocol. We conducted an integrative review of the literature through a systematic search of the National Library of Medicine (ie, PubMed) database to identify empirical and theoretical documents that discussed the implementation process for the Universal Protocol. The current state of knowledge varies from facility to facility, and we noted significant trends, gaps, and areas of concern in the implementation process. Successful implementation of the Universal Protocol has the following elements: a multidisciplinary team approach, active staff/patient participation, supportive hospital administration/leadership, and active communication that promotes a healthy work environment.

Cook, F. and C. Oliver, *A review of defining and measuring sociability in children with intellectual disabilities*. Res Dev Disabil, 2011. **32**(1): p. 11-24. There is a substantial body of research indicating that compromised social functioning for individuals with intellectual disabilities has far reaching implications for quality of life, community participation and wellbeing. However, an inherent difficulty for research into social functioning is the lack of agreed definition of key concepts in the area. The current paper reviews definitions for four concepts related to the central concept of sociability (social cognition, social competence, social skills and social behaviour). By reviewing the definitions available in the wider social and cognitive psychology literature and comparing these to definitions provided in research with individuals with intellectual disabilities it is clear that concepts are poorly defined. The current article proposes working definitions which may be used give impetus to future debate in the area. The clinical implications of having implicitly understood concepts rather than definable and measurable traits are considered. The review calls for researchers to provide definitions for the concepts under investigation and their relationship to measures employed in research.

Cooper, C., et al., *A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research*. American Journal of Geriatric Psychiatry, 2010. **18** (3): p. 193-203. The number of people with dementia from minority ethnic (ME) groups in western countries is projected to rise dramatically, and they may be less able to access dementia services. To compare the use of health and social services, treatments for dementia and dementia research between different ethnic groups. A systematic review of 33 articles fitting predetermined criteria. Compatible results were pooled in a meta-analysis. ME people with dementia were more cognitively impaired,

and Hispanic people reported a longer duration of memory loss than non-ME people, at the time of referral to diagnostic dementia services in the United States and Australia (pooled weighted mean difference on Mini-Mental State Examination -3.48 [95% confidence interval [CI]: $2.87-4.09$]; $z_{-11.19}$, $p_{0.0001}$; $N_{2,090}$). These differences remained after controlling for premorbid level of education. The use of community social services did not vary between ME and non-ME people with dementia, but African Americans were 30% less likely to be prescribed cholinesterase inhibitors (odds ratio (OR) 0.7 [$0.6-0.9$]; $z_{-3.1}$, $p_{0.002}$; N_{175}), and ME groups were underrepresented in U.S. dementia drug trials. ME people with dementia were 40% less likely to enter 24-hour care (pooled hazard ratio 0.59 [95% CI: $0.52-0.69$]; $z_{-7.15}$, $p_{0.0001}$; $N_{12,053}$). The authors found consistent evidence, mostly from the United States, that ME people accessed diagnostic services later in their illness, and once they received a diagnosis, were less likely to access antidementia medication, research trials, and 24-hour care. Increasing community engagement and specific recruitment strategies for ME groups might help address inequalities, and these need to be evaluated. More research is also needed to evaluate ME access to dementia services outside the United States.

Cornuz, J., B. Kuenzi, and T. Krones, *Shared decision making development in Switzerland: Room for improvement!* Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. **105 (4)**: p. 296-299. In Switzerland there is a strong movement at a national policy level towards strengthening patient rights and patient involvement in health care decisions. Yet, there is no national programme promoting shared decision making. First decision support tools (prenatal diagnosis and screening) for the counselling process have been developed and implemented. Although Swiss doctors acknowledge that shared decision making is important, hierarchical structures and asymmetric physician-patient relationships are still prevailing. The last years have seen some promising activities regarding the training of medical students and the development of patient support programmes. Swiss direct democracy and the habit of consensual decision making and citizen involvement in general may provide a fertile ground for SDM development in the primary care setting.

Coulter, A., et al., *Implementing shared decision making in the UK*. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. **105 (4)**: p. 300-304. What about policy regarding SDM? SDM is on the national policy agenda and has been prioritised as part of the health reform bill currently going through the Houses of Parliament. The NHS Constitution emphasises patients' right to be involved in decisions and this is reinforced in standards set by professional regulators. What about tools – decision support for patients? The UK governments have invested in patient information and a few decision aids are freely available on public websites. What about professional interest and implementation? There is interest in SDM and in collaborative care planning, but this is not yet the norm in clinical practice and few clinicians have received training in the topic. Several programmes are under way to

encourage implementation of SDM. What does the future look like? Future developments will depend on the extent of clinical commitment and on whether there are sufficient funds available to invest in the promotion of SDM at a time when health care resources are tightly constrained.

Curtis, L.C., et al., *Pushing the envelope: shared decision making in mental health*. Psychiatric rehabilitation journal, 2010. **34**(1): p. 14-22. *Topic:* This article reviews the literature on shared decision making in health and mental health and discusses tools in general health that are proposed for adaptation and use in mental health. *Purpose:* To offer findings from literature and a product development process to help inform/guide those who wish to create or implement materials for shared decision making in mental health. *Sources used:* Published literature and research on issues related to shared decision making in health and mental health, focus groups, and product testing. *Conclusions:* Structured shared decision making in mental health shows promise in supporting service user involvement in critical decision making and provides a process to open all treatment and service decisions to informed and respectful dialogue.

Curtis-Tyler, K., *Levers and barriers to patient-centred care with children: findings from a synthesis of studies of the experiences of children living with type 1 diabetes or asthma*. Child: Care, Health & Development, 2011. **37**(4): p. 540-50. *Background* The last 50 years have seen a sea change in approaches to health care with children, from a time when children were routinely separated from parents while in hospital, to current recognition of the importance of placing the experiences of children and their families at the heart of care. Yet, there is a gap in the evidence about how children's involvement might be best achieved. This study aimed to synthesize findings of children's experiences of long-term illness and, from this, to identify levers and barriers to patient-centred care with children. *Methods* A synthesis of studies of the experiences of children living with type 1 diabetes or asthma. *Data sources* Eight health and social care databases, bibliography searches and consultation with field experts and first authors of included studies. *Eligibility criteria* Qualitative studies with children 10 years (mean) and younger on their experiences of living with type 1 diabetes or asthma. *Main results* Findings suggest key 'levers' to patient-centred care with children include: (1) engagement with children's expertise about their own lives: their personal and social experiences of their care, including how these are affected by their relative lack of power in some settings; (2) exploring children's understandings and preferences in terms of their physical sensations and day-to-day experiences; (3) willingness to find resources to engage with even the youngest children; (4) avoiding age-based assumptions about children's contributions to their care. *Discussion and conclusions* Action on the above 'levers' may present a range of challenges in healthcare settings not least because it represents a move away from medicine's historical focus on children's developing competencies to engage rather with children's social realities from the earliest ages.

Davis, R.E., C.A. Vincent, and M.F. Murphy, *Blood transfusion safety: the potential role of the patient*. Transfusion Medicine Reviews, 2011. **25**(1): p. 12-23. UNLABELLED: There are many initiatives to reduce transfusion-related errors. However, one important intervention that remains largely unexplored is that of patient involvement. This article considers the patients' role in ensuring safe care along the transfusion trajectory. STUDY DESIGN AND METHODS: Empirical data on patients' attitudes to, and involvement in, transfusion-related behaviors were systematically reviewed. Opportunities for patient involvement in transfusion processes were identified by extant national guidelines and expert consultation. RESULTS: A number of transfusion-related behaviors in which patients can participate were highlighted, but to date, little is known about patients' preferences for taking on an active role. Many patients have no recollection of consenting to a blood transfusion, and some are not even aware they have been transfused. Information provided to patients about transfusion is often poorly understood. Patients have a number of misconceptions about the safety of blood transfusion, and the way in which information is presented to patients can significantly affect their level of confidence and subsequent acceptance in receiving a blood transfusion. SUMMARY: One important intervention that could help to improve the quality and safety of the blood transfusion process is involvement of the patient themselves. This article considers the patients' role in ensuring safe care at different stages of the transfusion trajectory. The literature on patients' attitudes to, and involvement in, transfusion-related behaviors was systematically reviewed and opportunities for patient involvement were identified. The evidence suggests that although there is considerable potential for patients to be involved in different blood transfusion processes, it is very unclear at present how able and willing patients would be to take on an active role in this aspect of their health care management. Research in this area is paramount in helping to inform the design and implementation of interventions aimed at encouraging patient involvement in this very important but largely under-researched area.

Dedding, C., et al., *How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients*. Social Science & Medicine, 2011. **72**(1): p. 49-53. In this report we discuss the consequences of e-health for patient-clinician encounters. On the basis of an analysis of the literature, we propose an analytical framework, composed of five different themes, regarding the impact of e-health on the relationship between patients and their health professionals. Internet health sites can: be or come to be a replacement for face-to-face consultations; supplement existing forms of care; create favourable circumstances for strengthening patient participation; disturb relations; and/or force or demand more intense patient participation. Though there is as yet insufficient empirical evidence supporting these effects, we believe that distinguishing the proposed themes will help to guide an in-depth discussion and further research. We conclude that in particular the redistribution of tasks and

responsibilities to patients in their daily lives requires more attention in future research.

Dhalla, S. and G. Poole, *Barriers of enrolment in HIV vaccine trials: A review of HIV vaccine preparedness studies*. Vaccine, 2011. **29 (35)**: p. 5850-5859. Barriers to participation in an HIV vaccine trial have been examined in many HIV vaccine preparedness studies (VPS). These barriers can be understood in terms of the locus of the barrier (personal vs. social) and the nature of the barrier (risk vs. cost). Another type of barrier is perceived misconceptions. In this systematic review, we categorize barriers, and compare these barriers between the Organization for Economic Co-operation and Development (OECD) countries and the non-OECD countries. In the OECD countries, we retrieved 25 studies reporting personal risks (PR), 9 studies reporting social risks (SR), 10 studies reporting personal costs (PC), and 16 studies reporting misconceptions. In the non-OECD countries, we retrieved 27 studies reporting PR, 19 studies reporting SR, 18 studies reporting PC, 1 study reporting social costs (SC), and 13 studies reporting misconceptions. Important PR were “adverse effects” and “vaccine-induced seropositivity”, “distrust of institutions”, and “temptation to have unsafe sex” in men who have sex with men (MSM). “Discrimination” was a common SR. “Time commitment” was an important PC, and “family commitments” were a SC in one non-OECD country. “HIV infection from the vaccine” was a common misconception. Both the OECD and the non-OECD countries have similar barriers, and people’s decisions to participate in a clinical trial involve multiple barriers. However, these barriers apply to hypothetical HIV vaccine trials, and barriers for actual vaccine trials need further assessment.

Diclemente, R.J., M.S. Ruiz, and J.M. Sales, *Barriers to adolescents' participation in HIV biomedical prevention research*. Journal of Acquired Immune Deficiency Syndromes, 2010. **54 (SUPPL. 1)**: p. S12-S17. The inclusion of adolescents in HIV prevention clinical research has the potential to improve the current understanding of the safety and efficacy of biomedical prevention technologies in younger populations that are at increasing risk of HIV infection. However, there are significant individual, operational, and community-level barriers to engaging adolescents in clinical prevention trials. This paper identifies and addresses individual, operational, and community-level barriers to adolescents' participation in HIV biomedical prevention research. Barriers identified and addressed in the paper include: (1) insufficient understanding of clinic prevention research, (2) self-presentation bias, (3) issues surrounding parental consent, (4) access to clinical trials, (5) mistrust of research, and (6) stigma associated with participation in clinical trials. Examples of programs where adolescents have been successfully engaged in prevention research are highlighted and the lessons learned from these programs indicate that establishing collaborations with key stakeholders in the community are essential for conducting biomedical research with vulnerable populations, including adolescents. Given the importance of understanding young peoples' reactions to, acceptability, and utilization of new biomedical prevention

technologies it is imperative that researchers acknowledge and address these barriers to enhance adolescents' participation and retention in HIV biomedical prevention research.

Dijkers, M.P., *Issues in the conceptualization and measurement of participation: an overview*. Archives of Physical Medicine & Rehabilitation, 2010. **91**(9 Suppl): p. S5-16. While participation is increasingly defined as the key outcome of rehabilitation, disagreements on and shortcomings in the definition, operationalization, and measurement of this concept abound and interfere with the progress of clinical services and research. This article explores a number of the major issues related to the quantification of participation and makes suggestions for new directions, using the following orienting questions: What is the definition of participation? Where is the border between Participation and Activity? Is there more to participation than performance? What domains should be included in a participation measure? What are the appropriate metrics in quantifying participation? How do we define adequate participation? How should participation be operationalized? What is the proper measurement model for participation instruments? How should we collect data on participation? How do we evaluate the quality of a participation instrument?

Doughty, C. and S. Tse, *Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries*. Community mental health journal, 2011. **47**(3): p. 252-66. This study examined the evidence from controlled studies for the effectiveness of consumer-led mental health services. Following an extensive search of material published in English from 1980, predefined inclusion criteria were systematically applied to research articles that compared a consumer-led mental health service to a traditional mental health service. A total of 29 eligible studies were appraised; all of them were conducted in high-income countries. Overall consumer-led services reported equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment or living arrangements, and in reducing hospitalizations and thus the cost of services. Involving consumers in service delivery appears to provide employment opportunities and be beneficial overall for the consumer-staff members and the service. Despite growing evidence of effectiveness, barriers such as underfunding continue to limit the use and evaluation of consumer-led services. Future studies need to adopt more uniform definitions and prioritize the inclusion of recovery oriented outcome measures.

Dubois, J.M., et al., *Ethical issues in mental health research: the case for community engagement*. Curr Opin Psychiatry, 2011. **24**(3): p. 208-14. Purpose of review To describe community-engaged research (CErR) and how it may improve the quality of a research study while addressing ethical concerns that communities may have with mental health and substance abuse research. This article includes a review of the literature as well as recommendations from an expert panel convened with funding from the US National Institute of Mental Health. Recent findings CErR represents a

broad spectrum of practices, including representation on institutional ethics committees, attitude research with individuals from the study population, engaging community advisory boards, forming research partnerships with community organizations, and including community members as co-investigators. Summary CEnR poses some challenges; for example, it requires funding and training for researchers and community members. However, it offers many benefits to researchers and communities, and some form of CEnR is appropriate and feasible in nearly every study involving human participants.

Duncan, E., C. Best, and S. Hagen, *Shared decision making interventions for people with mental health conditions*. Cochrane Database of Systematic Reviews, 2010(1): p. CD007297. Background One person in every four will suffer from a diagnosable mental health condition during their life course. Such conditions can have a devastating impact on the lives of the individual, their family and society. Increasingly partnership models of mental health care have been advocated and enshrined in international healthcare policy. Shared decision making is one such partnership approach. Shared decision making is a form of patient-provider communication where both parties are acknowledged to bring expertise to the process and work in partnership to make a decision. This is advocated on the basis that patients have a right to self-determination and also in the expectation that it will increase treatment adherence. Objectives To assess the effects of provider-, consumer- or carer-directed shared decision making interventions for people of all ages with mental health conditions, on a range of outcomes including: patient satisfaction, clinical outcomes, and health service outcomes. Search strategy We searched: the Cochrane Central Register of Controlled Trials (CENTRAL, *The Cochrane Library* 2008, Issue 4), MEDLINE (1950 to November 2008), EMBASE (1980 to November 2008), PsycINFO (1967 to November 2008), CINAHL (1982 to November 2008), British Nursing Index and Archive (1985 to November 2008) and SIGLE (1890 to September 2005 (database end date)). We also searched online trial registers and the bibliographies of relevant papers, and contacted authors of included studies. Selection criteria Randomised controlled trials (RCTs), quasi-randomised controlled trials (q-RCTs), controlled before-and-after studies (CBAs); and interrupted time series (ITS) studies of interventions to increase shared decision making in people with mental health conditions (by DSM or ICD-10 criteria). Data collection and analysis Data on recruitment methods, eligibility criteria, sample characteristics, interventions, outcome measures, participant flow and outcome data from each study were extracted by one author and checked by another. Data are presented in a narrative synthesis. Main results We included two separate German studies involving a total of 518 participants. One study was undertaken in the inpatient treatment of schizophrenia and the other in the treatment of people newly diagnosed with depression in primary care. Regarding the primary outcomes, one study reported statistically significant increases in patient satisfaction, the other study did not. There was no evidence of effect on clinical outcomes or hospital readmission rates in either study. Regarding secondary outcomes, there was an indication that interventions to

increase shared decision making increased doctor facilitation of patient involvement in decision making, and did not increase consultation times. Nor did the interventions increase patient compliance with treatment plans. Neither study reported any harms of the intervention. Definite conclusions cannot be drawn, however, on the basis of these two studies. Authors' conclusions No firm conclusions can be drawn at present about the effects of shared decision making interventions for people with mental health conditions. There is no evidence of harm, but there is an urgent need for further research in this area.

Ennis, L., et al., *Rapid progress or lengthy process? electronic personal health records in mental health*. BMC Psychiatry, 2011. **11**. A major objective of many healthcare providers is to increase patients' participation in their own care. The introduction of electronic personal health records (ePHRs) may help to achieve this. An ePHR is an electronic database of an individual's health information, accessible to and maintained by the patient. ePHRs are very much in vogue, with an increasing number of studies reporting their potential utility as well as cost. However, the vast majority of these studies focus on general healthcare. Little attempt has been made to document the specific problems which might occur throughout the implementation of ePHRs in mental health. This review identifies such concerns through an electronic search of the literature. Several potential difficulties are highlighted and addressed, including access to information technology, identifying relevant populations and the handling of sensitive information. Special attention is paid to the concept of 'empowerment' and what this means in relation to ePHRs.

Evans, *Rhetoric or reality? A systematic review of the impact of participatory approaches by UK public health units on health and social outcomes (Provisional abstract)*. J Public Health, 2010. **32**(3): p. 418-426. Background There has been a philosophical commitment to participation in public health since the 1970s. UK policy rhetoric on participation in public health has been particularly marked since 1997. It is less clear that participatory approaches have been pursued by UK public health units in practice. Methods A systematic review was undertaken of all studies using any recognized research methodology from 1974 to 2007 reporting on health and social outcomes of participatory approaches by UK public health units. Seventeen electronic databases were searched and inclusion/exclusion criteria and quality appraisal criteria applied. Results Five thousand and four hundred and fifty-one references were identified, reduced to 2155 once duplicates were removed. Only eight papers covering seven studies were relevant and included in the analysis. Only two studies met more than half of the relevant quality appraisal criteria. The studies fell into two distinct groups: four used qualitative methods to illustrate the complexities of effective community participation; three claimed success for their participative initiative without providing adequate evidence to substantiate such claims. Conclusions This systematic review demonstrates that there is very little evidence in the peer-reviewed

literature of participatory approaches by UK public health units or of such approaches having any noteworthy impact on health and social outcomes.

Eyssen, I.C., et al., *A Systematic Review of Instruments Assessing Participation: Challenges in Defining Participation*. Archives of Physical Medicine & Rehabilitation, 2011. **92**(6): p. 983-997. Objectives: To evaluate: (1) whether instruments which intend to measure participation actually do and (2) how frequently specific aspects and domains of participation are addressed. Data Sources: A systematic search was performed in PubMed. Study Selection: Included were patient-reported instruments that primarily aim to measure participation. Data Extraction: The full-text instruments were extracted from the articles or obtained from the authors. Two reviewers independently rated each item of the included instruments as measuring participation (yes, no, or undetermined). For each item, the specific aspect and domain of participation were categorized. Data Synthesis: Included were 103 instruments (2445 items). Of the included items, 619 items concerned participation and 217 concerned undetermined items. In total, 68 instruments contained at least 1 (sub)scale with 50% or more participation or undetermined items. The participation items referred to the participation aspects: participation problems (53%), participation accomplishment (31%), and satisfaction with participation (9%). The domains of the participation items concerned: work/study (27%), social life (27%), general participation (19%), and home (11%). The undetermined items mainly referred to domains about leisure (43%), transport (26%), and shopping (12%). Conclusions: According to our working definition of participation, most instruments that aim to measure participation do so only to a limited extent. These instruments mainly assess aspects of participation problems and participation accomplishment. The domains of participation covered by these instruments primarily include work/study, social life, general participation, home, leisure, transport, and shopping.

Facey, K., et al., *Patients' perspectives in health technology assessment: A route to robust evidence and fair deliberation*. International Journal of Technology Assessment in Health Care, 2010. **26**(3): p. 334-340. There is increasing emphasis on providing patient-focused health care and ensuring patient involvement in the design of health services. As health technology assessment (HTA) is meant to be a multidisciplinary, wide-ranging policy analysis that informs decision making, it would be expected that patients views should be incorporated into the assessment. However, HTA is still driven by collection of quantitative evidence to determine the clinical and cost effectiveness of a health technology. Patients perspectives about their illness and the technology are rarely included, perhaps because they are seen as anecdotal, biased

views. There are two distinct but complementary ways in which HTAs can be strengthened by: (i) gathering robust evidence about the patients perspectives, and (ii) ensuring effective engagement of patients in the HTA process from scoping, through evidence gathering, assessment of value, development of recommendations and dissemination of findings. Robust evidence eliciting patients perspectives can be obtained through social science research that is well conducted, critically appraised and carefully reported, either through meta-synthesis of existing studies or new primary research. Engagement with patients can occur at several levels and we propose that HTA should seek to support effective patient participation to create a fair deliberative process. This should allow two-way flow of information, so that the views of patients are obtained in a supportive way and fed into decision-making processes in a transparent manner.

Fine, E., et al., *Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature*. Journal of Palliative Medicine, 2010. 13 (5): p. 595-603. Objectives: To review studies that used direct observation (i.e., videotaping or audiotaping) methods in palliative/end-of-life care communication research. Design: Descriptive thematic analysis. Setting: Multinational studies were conducted in both the outpatient and inpatient setting. Measurements: Extensive bibliographic searches (January 1, 1998 to July 31, 2009) of English-language literature involving physician–patient (or physician–family) interactions were conducted and augmented by reviews of reference listings. Three investigators independently abstracted key information from each article. Results: Of the 20 retained articles, most enrolled young-old participants (mean age, 60 years) who were white and had a cancer diagnosis. Patient/family participation rates ranged from 68% to 89% demonstrating feasibility of this approach when studying palliative/end-of-life care communication issues. Four common themes were identified: (1) physicians focus on medical/technical and avoid emotional/quality of life issues; (2) sensitive topics are perceived by physicians to take longer to discuss and often do take longer to discuss; (3) physicians dominate discussions; and (4) patient/family satisfaction is associated with supportive physician behaviors. Conclusions: This study demonstrates that direct observation methods can be feasibly used when studying physician–patient/physician–family communication in palliative/end-of-life care, but few investigations have utilized this approach. This article highlights areas that need improvement, including physicians’ ability to address patient/family emotional issues and provide what patients and families find most satisfying (participation and support). A particular focus on older patients and patients with end-stage or late-stage chronic (noncancer) illness, the adaptation/application of existing communication measurement tools to capture

palliative care communication issues, and development of corresponding outcome measures to assess impact is now needed.

Forbes, A., et al., *Organizing and delivering diabetes education and self-care support: findings of scoping project*. J Health Serv Res Policy, 2011. **16 Suppl 1**: p. 42-9. Objective: To provide an overview of current research and development on the organization and delivery of diabetes education and self-care support, incorporating stakeholder perspectives. Method: Four methods were used: literature review (159 papers and 52 grey literature items); patient participation event (n 5 38); online survey of professionals (n 5 423) and patients (n5 495); and, a conference. Results: The literature review identified themes relating to the organization and delivery of diabetes and selfcare support: structure and flexibility in models of education; accessibility; patient choice; integrating self-care within the overall care system; quality improvement; peer educators; health literacy; efficiency in delivery; tele-care models; feedback technologies; care planning; psychological intervention; and self-care outcome measures. This generated four models to provide a framework to help shape the development of diabetes self-care: a diabetes education pathway; integrating self-care and clinical care; choice as a method of optimizing care; and an integrated framework for delivering diabetes self-care. Conclusion: The clinical benefit of the identified models need to be evaluated.

Foss, C. and M. Askautrud, *Measuring the participation of elderly patients in the discharge process from hospital: a critical review of existing instruments*. Scandinavian Journal of Caring Sciences, 2010. **24 Suppl 1**: p. 46-55. Measuring patients' experiences has been a major task for health care organisations during the past decade. The discharge process is identified as a vulnerable component of health care in need of assessment, especially when it concerns elderly persons. There are no published reviews or systematic assessment of the existing instruments developed to capture patients' perspective on the discharge process. This study gives a review of existing survey instruments designed to assess patients' perspectives on the discharge process. We used systematic searches for potentially relevant instruments in MEDLINE, PubMed, CINAHL, and the Cochrane Database of Systematic Reviews for English language studies published between 1998 and 2009 was considered to evaluate the patients' perspective on the discharge process. Ten studies were included and assessed according to the established criteria, and the studies presented a total of 47 items related to participation. The review identified only one instrument designed specifically to capture participation in the discharge process. The main focus is on the information flow from the professional to the patient and never vice versa. Few of the

instruments studied/analysed to what degree the patients were invited to share their knowledge, and none of the instruments inquired whether, in the patients' experiences, their perspective was taken into account. The major finding of the review is that none of the existing instruments capture the full range of participation, nor do they cover those areas of the discharge process identified by elderly patients themselves as the most essential.

Frosch, D.L., et al., *Shared decision making in the United States: Policy and implementation activity on multiple fronts*. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 2011. 105 (4): p. 305-312. Shared decision making in the United States has become an important element in health policy debates. The recently passed federal health care reform legislation includes several key provisions related to shared decision making (SDM) and patient decision support. Several states have passed or are considering legislation that incorporates SDM as a key component of improved health care provision. Research on SDM is funded by a range of public and private organizations. Non-profit, for-profit, academic and government organizations are developing decision support interventions for numerous conditions. Some interventions are publicly available; others are distributed to patients through health insurance and healthcare providers. A significant number of clinical implementation projects are underway to test and evaluate different ways of incorporating SDM and patient decision support into routine clinical care. Numerous professional organizations are advocating for SDM and social networking efforts are increasing their advocacy as well. Policy makers are intrigued by the potential of SDM to improve health care provision and potentially lower costs. The role of shared decision making in policy and practice will be part of the larger health care reform debate.

Gagnon, A.J. and J. Sandall, *Individual or group antenatal education for childbirth or parenthood, or both [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 10: p. 10. Background Structured antenatal education programs for childbirth or parenthood, or both, are commonly recommended for pregnant women and their partners by healthcare professionals in many parts of the world. Such programs are usually offered to groups but may be offered to individuals. Objectives To assess the effects of this education on knowledge acquisition, anxiety, sense of control, pain, labour and birth support, breastfeeding, infant-care abilities, and psychological and social adjustment. Search strategy We searched the Cochrane Pregnancy and Childbirth Group's Trials Register (April 2006), CINAHL (1982 to April 2006), ERIC (1984 to April 2006), EMBASE (1980 to April 2006) and PsycINFO (1988 to April 2006). We hand-searched the Journal of Psychosomatic Research from 1956 to April 2006 and reviewed

the reference lists of retrieved studies. We updated the search of the Cochrane Pregnancy and Childbirth Group's Trials Register on 7 July 2011 and added the results to the awaiting classification section of the review. Selection criteria Randomized controlled trials of any structured educational program provided during pregnancy by an educator to either parent that included information related to pregnancy, birth or parenthood. The educational interventions could have been provided on an individual or group basis. Educational interventions directed exclusively to either increasing breastfeeding success, knowledge of and coping skills concerning postpartum depression, improving maternal psycho-social health including anxiety, depression and self-esteem or reducing smoking were excluded. Data collection and analysis Both authors assessed trial quality and extracted data from published reports. Main results Nine trials, involving 2284 women, were included. Thirty-seven studies were excluded. Educational interventions were the focus of eight of the studies (combined n = 1009). Details of the randomization procedure, allocation concealment, and/or participant accrual or loss for these trials were not reported. No consistent results were found. Sample sizes were very small to moderate, ranging from 10 to 318. No data were reported concerning anxiety, breastfeeding success, or general social support. Knowledge acquisition, sense of control, factors related to infant-care competencies, and some labour and birth outcomes were measured. The largest of the included studies (n = 1275) examined an educational and social support intervention to increase vaginal birth after caesarean section. This high quality study showed similar rates of vaginal birth after caesarean section in 'verbal' and 'document' groups (relative risk 1.08, 95% confidence interval 0.97 to 1.21). Authors' conclusions The effects of general antenatal education for childbirth or parenthood, or both, remain largely unknown. Individualized prenatal education directed toward avoidance of a repeat caesarean birth does not increase the rate of vaginal birth after caesarean section.

Gillis and L. Mac, *Service learning with vulnerable populations: review of the literature*. International Journal of Nursing Education Scholarship, 2010. 7(1): p. 1p. The service learning model has been touted as a powerful pedagogical approach, a reasonable option for providing care to vulnerable and diverse populations, and a vehicle for educating nursing students to become agents of social change. The literature on service learning with vulnerable populations in nursing education is reviewed and synthesized in this article. A description of service learning experiences, identification of knowledge and skills learned, opportunities for critical thinking and reflection, and a discussion of factors that act as enablers and barriers to service learning are explored.

Recommendations for successful integration of service learning into educational settings are provided for nurse educators, academic institutions and community partners. As the service learning model spreads across nursing education it is suggested that it offers promise to foster social change and produce graduates who are fully engaged citizens and professionals.

Gona, J.K., et al., *Identification of people with disabilities using participatory rural appraisal and key informants: a pragmatic approach with action potential promoting validity and low cost*. Disability & Rehabilitation, 2010. **32**(1): p. 79-85. BACKGROUND: Surveys have been the conventional methods used for identification of people with disabilities; however, they have been observed to be expensive and time-consuming that may not be affordable or practical. As a result, the participatory rural appraisal (PRA) and key informant (KI) approaches have been developed and increasingly used in the resource-poor countries. OBJECTIVE: To investigate the strengths and weaknesses of PRA and KI approaches in the identification of people with disability in resource-poor countries. METHOD: A review of published related papers was performed by searching electronic databases including PubMed, Scirus, Health on the Net (HON), Ovid Medline and SOURCE disability database. RESULTS: A total of 11 relevant papers were identified from the literature that used PRA or KI methods or both. The PRA and KI approaches were not only consistently less expensive than conventional surveys, but also observed to be simple and fast for identifying disabilities according to local perceptions, although they were less sensitive. The evidence showed that PRA and KI processes had the benefit of engaging and developing long-term partnerships with the local communities and so the likelihood of positive long-term impact on the community. CONCLUSIONS: The PRA and KI approaches could be fast and cost-effective methods for identifying people with disabilities as an alternative to surveys. They are especially useful when identification is related to subsequent development of community-based services for persons with disabilities. However, surveys were shown to be more sensitive and therefore more accurate for establishing prevalence rates of impairment.

Goss, C., et al., *Participation of patients and citizens in healthcare decisions in Italy*. Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen, 2011. **105**(4): p. 277-82. What about policy regarding SDM? The Italian National Health Plan and many regional and local health authorities explicitly recognise the importance of patient/citizen participation. These official documents rarely mention the specific concept of SDM, but they use terms such as patient involvement, participation, and empowerment. Patient associations are actively involved in promoting patient/citizen

participation, but still play a marginal role in the health debate compared to health professionals, clinicians and healthcare managers. What about tools – decision support for patients? There are only a few examples of decision aids designed for patients according to SDM concepts. A critical point is the lack of specific tools for the evaluation of SDM processes. Exceptions include the Italian versions of the OPTION scale and the SDM-Q, used at the micro-level for the evaluation of SDM. What about professional interest and real implementation? Health professionals recognise that doctor-patient communication is an important area. Italian research in SDM has grown and improved. It is very promising, but still limited. Undergraduate and postgraduate courses of some medical schools include specific programs on doctor-patient communication skills, focusing also on promotion of patient participation. What does the future look like? In conclusion, there is room for improving the Italian efforts to implement SDM into practice at both the individual and public level.

Graven, C., et al., *Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke?* Disability & Rehabilitation, 2011. **33**(17/18): p. 1501-1520. Purpose. To conduct a systematic review to explore the effectiveness of community-based rehabilitation interventions delivered by allied health professionals and/or nursing staff in reducing depression, facilitating participation and improving health-related quality of life (HRQoL) post-inpatient stroke rehabilitation. Method. A search was conducted in the databases of MEDLINE, PEDro, CINAHL and the Cochrane Library. Publications were classified into categories based on the type of the interventions. Best evidence synthesis and meta-analysis were utilised to determine the level of evidence. Results. Fifty-four studies were included in the review, and divided into nine broad intervention categories. Meta-analysis demonstrated significant reduction in depression with exercise interventions ($n = 137$; effect estimate SMD: -2.03 , 95%CI: -3.22 , -0.85). Community-based interventions targeting participation and leisure domains showed moderate evidence for improvement in global participation measures and HRQoL. Comprehensive rehabilitation demonstrated limited evidence for depression and participation, and strong evidence for HRQoL. Conclusions. There is limited to moderate evidence supporting some rehabilitation interventions in affecting the outcomes of depression, participation and HRQoL post-stroke. Heterogeneity of the studies made evidence synthesis difficult. Further consideration needs to be given to the type and timing of outcome measures selected to represent the domains of participation and HRQoL.

Gruman, J., et al., *From patient education to patient engagement: implications for the field of patient education*. Patient Education & Counseling, 2010. **78**(3): p. 350-6.

OBJECTIVE: Advances in health care require that individuals participate knowledgeably and actively in their health care to realize its full benefit. Implications of these changes for the behavior of individuals and for the practice of patient education are described.

METHODS: An "engagement behavior framework" (EBF) was compiled from literature reviews and key informant interviews. To assess the focus of research and interventions on the identified engagement behaviors, the EBF was used to code scientific sessions in professional conferences relevant to patient education in the US in 2006-2007.

RESULTS: Many specific behaviors constitute engagement. Professional conferences on patient education show only modest attention to the full range of relevant behaviors.

CONCLUSION: People must make informed choices about insurance and clinicians, coordinate communications among providers and manage complex treatments on their own. Not doing so risks preventable illness, suboptimal outcomes and wasted resources.

PRACTICE IMPLICATIONS: Increased responsibilities of individuals, sick and well, to find and actively participate in high quality health care provides an opportunity for patient education researchers and clinicians to improve health outcomes by developing innovative strategies to support all individuals to effectively participate in their care to the extent possible. Copyright 2010 Elsevier Ireland Ltd. All rights reserved.

Hall, J., et al., *Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review*. Quality & safety in health care, 2010. **19**(5): p. e10.

BACKGROUND: There is growing international interest in involving patients in interventions to promote and support them in securing their own safety. This paper reports a systematic review of evaluations of the effectiveness of interventions that have been used with the explicit intention of promoting patient involvement in patient safety in healthcare.

METHODS: The authors searched Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, CENTRAL, CINAHL, EMBASE, HMIC, MEDLINE, MEDLINE in-process, PsycINFO and ASSIA to August 2008. We also searched databases of reports, conference proceedings, grey literature, ongoing research and relevant patient safety organisations, and hand-searched two journals. Meta-analysis of the data was not appropriate; therefore, studies were categorised according to how the interventions encouraged patients' actions to improve safety--informing the management plan, monitoring and ensuring safe delivery of treatment (by health professional and by self), making systems safer--and

were critiqued in a narrative manner. FINDINGS: The authors identified 14 individual experimental and quasiexperimental studies plus one systematic review. The majority of studies fell into the monitoring and ensuring safe delivery of treatment by self category and were all related to enhancing medication safety. Authors reported improved patient safety incident outcomes for the intervention groups compared with controls where the interventions aimed to encourage patient involvement in: (1) monitoring and ensuring safe delivery of treatment by self (self-management of anticoagulation, 'easy' read information leaflet, nurse-led education to promote self-medication in hospital, patient package insert using lay terminology); (2) informing the management plan/monitoring and ensuring safe delivery of treatment by self (individualised teaching plan by nurse, pharmacist counselling). It was not possible to draw any clear conclusions as to the effectiveness of the interventions (with the exception of one specific aspect of self-medication, that is, self-management of anticoagulation) due to concerns about the methodological quality of the studies. CONCLUSIONS: There is limited evidence for the effectiveness of interventions designed to promote patient involvement on patient safety incidents and in general is poor quality. Existing evidence is confined to the promotion of safe self-management of medication, most notably relating to the self-management of oral anticoagulants.

Harter, M., et al., *Patient participation and shared decision making in Germany - History, agents and current transfer to practice*. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. **105 (4)**: p. 263-270. The main focus of the present paper is to describe 1) the healthcare system specific influences on patient participation in medical decision making and 2) the current state of research and implementation of shared decision making (SDM) after ten years of substantial advances in health policy and research in this field. What about policy regarding SDM? The "Medical Patients Rights Act" is to standardise all the rights and responsibilities within the scope of medical treatment. This also comprises the right to informed decisions, comprehensive and comprehensible information for patients, and decisions based on the partnership of clinicians and patients. What about tools - decision support for patients? SDM training programmes for healthcare professionals have been developed and partly implemented. Several decision support interventions - primarily with support from health insurance funds - have been developed and evaluated. What about professional interest and implementation? Against the background of the German health policy's endorsement of patient participation, the German government and other public institutions are currently funding different research programmes in which shared decision making is playing a substantial role. The development and implementation of decision support tools for patients and

professionals as well as the implementation of trainings for healthcare professionals require stronger efforts. What does the future look like? With the support of health policy and with the utilisation of scientific evidence, the transfer of shared decision making into practice is considered to be meaningful in the German healthcare system. The translation into routine care will remain an important task for the future.

Hartman, M.A., K. Hosper, and K. Stronks, *Targeting physical activity and nutrition interventions towards mothers with young children: A review on components that contribute to attendance and effectiveness*. Public Health Nutrition, 2011. **14**(8): p. 1364-1381. Objective To gain insight into intervention components targeted specifically to mothers of young children that may contribute to attendance and effectiveness on physical activity and healthy eating. Design Systematic literature searches were performed using MEDLINE, Embase and cited references. Articles were included if they evaluated the effectiveness of a lifestyle intervention to promote physical activity and/or healthy eating in an experimental design among mothers with young children (age 0-5 years). Data were extracted on study characteristics, intervention components targeted towards mothers with young children, attendance and effectiveness. Extracted data were analysed in a descriptive manner. Results Eleven articles describing twelve interventions met the inclusion criteria. Of the six studies that measured attendance, two reported high attendance. Embedding the intervention within routine visits to child health clinics seems to increase attendance. Three studies found significant effects on physical activity and three on healthy eating. Effective interventions directed at physical activity included components such as counselling on mother-specific barriers or community involvement in intervention development and implementation. One of the three interventions that effectively increased healthy eating had components targeted at mothers (i.e. used targeted motivational appeals). Conclusions The number of experimental intervention studies for promoting physical activity and healthy eating among new mothers is limited. However, useful first recommendations can be set for targeting interventions towards mothers, in particular for promoting attendance and physical activity. More insight is required about the need for targeting health promotion programmes at new mothers, especially of those directed at nutritional behaviour.

Henderson, C. and R. Laugharne, *User-held personalised information for routine care of people with severe mental illness [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 5: p. 5. Background It is important to seek cost-effective methods of improving the care and outcome of those with serious mental illnesses. Patient-held records, where the person with the illness holds all or some personal

information relating to the course and care of their illness, are now the norm in some clinical settings. Their value for those with serious mental illnesses is unknown.

Objectives To evaluate the effects of personalised and accessible patient-held clinical information for people with a diagnosis of psychotic illness.

Search strategy Electronic searches of AMED (1980-1998), Biological Abstracts (1985-1998), British Nursing Index (1994-1998), CAB (1973- 1999), CINAHL (1982-1999), The Cochrane Controlled Trials Register (Issue 1, 1999), EMBASE (1980-1999), HEALTHSTAR (1990-1999), HMIC (King's Fund Database 1979-1998 & HELMIS 1984-1998), MEDLINE (1966-1999), PsycLIT (1887-1999), Royal College of Nursing Database (1985-1996), SIGLE (1990-1998), Sociological Abstracts (1963-1998) and the Internet (<http://www.controlled-trials.com/>) were undertaken. This was supplemented by personal contact with the Executive Board of the European Network for Mental Health Service Evaluation.

Selection criteria The inclusion criteria were that studies should: i. be randomised or quasi-randomised trials; ii. have involved adults with a diagnosis of a psychotic illness; and iii. compare any personalised and accessible clinical information held by the patient beyond standard care to standard information routinely held such as appointment cards and generic information on diagnosis, treatment or services available.

Data collection and analysis Study selection and data extraction was reliability undertaken. Analysis was not possible.

Main results Not one study met the inclusion criteria for the review. One study (Stafford 1997) was found on the use of client held records for people with long term mental illness but the participants had not been randomised. Two important randomised studies (Lester 1999, Papageorgiou 1999) are ongoing.

Authors' conclusions There is a gap in the evidence regarding patient-held, personalised, accessible clinical information for people with psychotic illnesses. It cannot be assumed that patient-held information is beneficial or cost-effective without evidence from well planned, conducted and reported randomised trials.

Hordern, A., et al., *Consumer e-health: an overview of research evidence and implications for future policy*. Health Information Management Journal, 2011. **40**(2): p. 6-14. Consumer e-health is rapidly becoming a fundamental component of healthcare. However, to date only provisional steps have been taken to increase our understanding of how consumers engage with e-health. This study, an interpretive review, assessed the evidence about consumer use of e-health and identified five categories that encompass consumer e-health: (i) peer-to-peer online support groups; (ii) self-management/self-monitoring applications; (iii) decision aids; (iv) the personal health record; and (v) Internet use. Our findings reveal that e-health offers consumers many possibilities and potential benefits, although there appears to be apprehension

concerning the efficacy of some interventions and barriers relating to the trustworthiness of Internet-acquired information. It is imperative that policy initiatives address these issues to ensure that consumer e-health services can be effectively, efficiently, and safely accessed.

Huffman, M.D. and J.M. Galloway, *Cardiovascular health in indigenous communities: successful programs*. Heart Lung Circ, 2010. **19**(5-6): p. 351-60. BACKGROUND: Indigenous people across the globe have generally had suboptimal access to quality medical care and effective prevention programs. The available programs that existed have generally been poorly funded and have primarily focussed on infectious diseases. More recent trends denoting significant rising morbidity and mortality of chronic diseases have brought some limited medical focus on cardiovascular diseases, their risk factors and their prevention. However, there is a growing body of evidence-published and unpublished-of developed and developing successful programs to provide culturally appropriate and sensitive treatment for cardiovascular diseases and prevention. Within this report, we aim to describe some of these programs in order to understand common approaches and links that make them successful. Once this survey is completed, a template for successful CVD programs can be created for the development of future programs. METHODS: We used several methods to gather information about successful Indigenous CVD programs: Pub Med search (keywords: Indigenous, native, First Nation, Aboriginal, cardiovascular, cardiac, etc.), online searches of government-based health programs (World Health Organization, Centers for Disease Control, etc.) and non-government health programs (World Heart Federation, Bill & Melinda Gates Foundation, etc.), and, importantly, personal communication with multiple thought leaders and program directors in the field of international CVD treatment and prevention. RESULTS: Programs can be divided into: (1) epidemiologic programs, which focus on data collection, (2) focussed prevention programs and population approach to CVD prevention, and (3) clinical prevention and intervention programs. DISCUSSION: Common themes that define successful Indigenous CVD programs include: dedicated focus on the Indigenous population, widespread community involvement within the Indigenous population, often through the use of Indigenous community health workers, a focus on high-risk individuals within the population and regularly scheduled contact between the program and participants. We recommend that these themes are incorporated during development of future CVD programs for Indigenous people.

Jha, V., et al., *Patient involvement in teaching and assessing intimate examination skills: a systematic review*. Medical Education, 2010. **44**(4): p. 347-57. OBJECTIVES:

There are recognised difficulties in teaching and assessing intimate examination skills that relate to the sensitive nature of the various examinations and the anxiety faced by novice learners. This systematic review provides a summary of the evidence for the involvement of real patients (RPs) and simulated patients (SPs) in the training of health care professionals in intimate examination skills. METHODS: For the review, 'intimate examinations' included pelvic, breast, testicular and rectal examinations. Major databases were searched from the start of the database to December 2008. The synthesis of findings is integrated by narrative structured to address the main research questions, which sought to establish: the objectives of programmes involving RPs and SPs as teachers of intimate examination skills; reasons why SPs have been involved in this training; the evidence for the effectiveness of such training programmes; the evidence for measures of anxiety in students learning how to perform intimate examinations; how well issues of sexuality are addressed in the literature; any reported negative effects of involvement in teaching on the patients, and suggestions for practical strategies for involving patients in the teaching of intimate examination skills. RESULTS: A total of 65 articles were included in the review. Involving patients in teaching intimate examination skills offers advantages over traditional methods of teaching. Objective evidence for the effectiveness of this method is demonstrated through improved clinical performance, reduced anxiety and positive evaluation of programmes. Practical strategies for implementing such programmes are also reported. CONCLUSIONS: There is evidence of a short-term positive impact of patient involvement in the teaching and assessment of intimate examination skills; however, evidence of longer-term impact is still limited. The influences of sexuality and anxiety related to such examinations are explored to some extent, but the psychological impact on learners and patients is not well addressed.

Ko, H., et al., *Patient-held medical records for patients with chronic disease: a systematic review*. Quality and Safety in Health Care, 2010. **19**(5): p. 1-7. Objectives To determine whether in patients with chronic disease a patient-held medical record (PHR), compared to usual care, improves clinical care, patient outcomes or satisfaction.Design Systematic review.Data sources Databases searched were All EBM (The Cochrane Database of Systematic Reviews, DARE CENTRAL), Medline, CINAHL and EMBASE from 1980 to 16 February 2009.Study selection Two reviewers assessed comparative studies that compared paper-based PHR to usual care for inclusion using a priori study selection criteria.Studies reviewed Four hundred and eighty-one articles were reviewed by title and abstract. Full text was retrieved for 120 articles. Fourteen studies met the inclusion and exclusion criteria and were appraised using a priori criteria for methodological quality.Results Fourteen studies were included in diabetes,

oncology, mental health, rheumatoid arthritis, stroke and palliative care. The studies used a variety of designs of PHR and compared this with usual care. PHR were implemented with varying degrees of patient and staff support and education, mainly for six months or less. Outcomes included attitudes on the usefulness of PHR, the quality of information exchange, process indicators, and clinical and physiological indicators. The effectiveness of PHRs is generally of low or very low quality, with the majority of studies having a high risk of bias. These studies do not demonstrate a significant benefit of introducing PHR. Conclusions There is no clear benefit of implementing a PHR, and due to medium to high risk of bias these findings should be interpreted with caution. More high quality studies are needed to evaluate properly the effectiveness of PHRs in chronic disease populations.

Lassi, Z.S., B.A. Haider, and Z.A. Bhutta, *Community-based intervention packages for reducing maternal and neonatal morbidity and mortality and improving neonatal outcomes [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 1: p. 1. While maternal, infant and under-five child mortality rates in developing countries have declined significantly in the past two to three decades, newborn mortality rates have reduced much more slowly. While it is recognised that almost half of the newborn deaths can be prevented by scaling up evidence-based available interventions such as tetanus toxoid immunisation to mothers; clean and skilled care at delivery; newborn resuscitation; exclusive breastfeeding; clean umbilical cord care; management of infections in newborns, many require facility based and outreach services. It has also been stated that a significant proportion of these mortalities and morbidities could also be potentially addressed by developing community-based packages interventions which should also be supplemented by developing and strengthening linkages with the local health systems. Some of the recent community-based studies of interventions targeting women of reproductive age have shown variable impacts on maternal outcomes and hence it is uncertain if these strategies have consistent benefit across the continuum of maternal and newborn care. Objectives To assess the effectiveness of community-based intervention packages in reducing maternal and neonatal morbidity and mortality; and improving neonatal outcomes. Search strategy We searched The Cochrane Pregnancy and Childbirth Group's Trials Register (January 2010), World Bank's JOLIS (12 January 2010), BLDS at IDS and IDEAS database of unpublished working papers (12 January 2010), Google and Google Scholar (12 January 2010). Selection criteria All prospective randomised and quasi-experimental trials evaluating the effectiveness of community-based intervention packages in reducing maternal and neonatal mortality and morbidities; and improving neonatal outcomes. Data collection and analysis Two review authors

independently assessed trial quality and extracted the data. Main results The review included 18 cluster-randomised/quasi-randomised trials, covering a wide range of interventional packages, including two subsets from one trial. We incorporated data from these trials using generic inverse variance method in which logarithms of risk ratio estimates were used along with the standard error of the logarithms of risk ratio estimates. Our review did not show any reduction in maternal mortality (risk ratio (RR) 0.77; 95% confidence interval (CI) 0.59 to 1.02, random-effects (10 studies, $n = 144,956$), I^2 39%, P value 0.10. However, significant reduction was observed in maternal morbidity (RR 0.75; 95% CI 0.61 to 0.92, random-effects (four studies, $n = 138,290$), I^2 28%; neonatal mortality (RR 0.76; 95% CI 0.68 to 0.84, random-effects (12 studies, $n = 136,425$), I^2 69%, P value < 0.001), stillbirths (RR 0.84; 95% CI 0.74 to 0.97, random-effects (11 studies, $n = 113,821$), I^2 66%, P value 0.001) and perinatal mortality (RR 0.80; 95% CI 0.71 to 0.91, random-effects (10 studies, $n = 110,291$), I^2 82%, P value < 0.001) as a consequence of implementation of community-based interventional care packages. It also increased the referrals to health facility for pregnancy related complication by 40% (RR 1.40; 95% CI 1.19 to 1.65, fixed-effect (two studies, $n = 22,800$), I^2 0%, P value 0.76), and improved the rates of early breastfeeding by 94% (RR 1.94; 95% CI 1.56 to 2.42, random-effects (six studies, $n = 20,627$), I^2 97%, P value < 0.001). We assessed our primary outcomes for publication bias, but observed no such asymmetry on the funnel plot. Authors' conclusions Our review offers encouraging evidence of the value of integrating maternal and newborn care in community settings through a range of interventions which can be packaged effectively for delivery through a range of community health workers and health promotion groups. While the importance of skilled delivery and facility-based services for maternal and newborn care cannot be denied, there is sufficient evidence to scale up community-based care through packages which can be delivered by a range of community-based workers.

Legare, F., et al., *Moving SDM forward in Canada: Milestones, public involvement, and barriers that remain*. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. **105 (4)**: p. 245-253. Canada's approach to shared decision making (SDM) is as disparate as its healthcare system; a conglomerate of 14 public plans at various administrative levels. SDM initiatives are taking place in different pockets of the country and are in different stages of development. The most advanced provincial initiative is occurring in Saskatchewan, where in 2010 the provincial government prepare to introduce patient decision aids into certain surgical specialties. With regard to decision support tools for patients, perhaps the most active entity is the Patient Decision Aids Research Group in Ottawa, Ontario. This group maintains a public inventory of decision aids ranked according to International Patient Decision Aid

Standards and has developed the generic Ottawa Personal Decision Guide, as well as a toolkit for integrating decision aids in clinical practice. All of these tools are publicly available free of charge. Professional interest in SDM in Canada is not yet widespread, but Canada's principal health research funding agency is sponsoring several important SDM projects. Researchers from institutions across the country are promoting SDM through continuing professional development programs and other interventions in fields as varied as primary care, dietary medicine and workplace rehabilitation. Still, the future of SDM in Canada remains uncertain. Canada's provincially based structure obliges promoters to work with each province separately, and the recent growth of private healthcare risks dissipating efforts to implement SDM.

Legare, F., et al., *Interventions for improving the adoption of shared decision making by healthcare professionals [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 1: p. 1. Background Shared decision making (SDM) is a process by which a healthcare choice is made jointly by the practitioner and the patient and is said to be the crux of patient-centred care. Policy makers perceive SDM as desirable because of its potential to a) reduce overuse of options not clearly associated with benefits for all (e.g., prostate cancer screening); b) enhance the use of options clearly associated with benefits for the vast majority (e.g., cardiovascular risk factor management); c) reduce unwarranted healthcare practice variations; d) foster the sustainability of the healthcare system; and e) promote the right of patients to be involved in decisions concerning their health. Despite this potential, SDM has not yet been widely adopted in clinical practice. Objectives: To determine the effectiveness of interventions to improve healthcare professionals' adoption of SDM. Search strategy We searched the following electronic databases up to 18 March 2009: Cochrane Library (1970-), MEDLINE (1966-), EMBASE (1976-), CINAHL (1982-) and PsycINFO (1965-). We found additional studies by reviewing a) the bibliographies of studies and reviews found in the electronic databases; b) the clinicaltrials.gov registry; and c) proceedings of the International Shared Decision Making Conference and the conferences of the Society for Medical Decision Making. We included all languages of publication. Selection criteria We included randomised controlled trials (RCTs) or well-designed quasi-experimental studies (controlled clinical trials, controlled before and after studies and interrupted time series analyses) that evaluated any type of intervention that aimed to improve healthcare professionals' adoption of shared decision making. We defined adoption as the extent to which healthcare professionals intended to or actually engaged in SDM in clinical practice or/and used interventions known to facilitate SDM. We deemed studies eligible if the primary outcomes were evaluated with an objective measure of the adoption of SDM by healthcare professionals (e.g., a third-observer

instrument). Data collection and analysis At least two reviewers independently screened each abstract for inclusion and abstracted data independently using a modified version of the EPOC data collection checklist. We resolved disagreements by discussion. Statistical analysis considered categorical and continuous primary outcomes. We computed the standard effect size for each outcome separately with a 95% confidence interval. We evaluated global effects by calculating the median effect size and the range of effect sizes across studies. Main results The reviewers identified 6764 potentially relevant documents, of which we excluded 6582 by reviewing titles and abstracts. Of the remainder, we retrieved 182 full publications for more detailed screening. From these, we excluded 176 publications based on our inclusion criteria. This left in five studies, all RCTs. All five were conducted in ambulatory care: three in primary clinical care and two in specialised care. Four of the studies targeted physicians only and one targeted nurses only. In only two of the five RCTs was a statistically significant effect size associated with the intervention to have healthcare professionals adopt SDM. The first of these two studies compared a single intervention (a patient-mediated intervention: the Statin Choice decision aid) to another single intervention (also patient-mediated: a standard Mayo patient education pamphlet). In this study, the Statin Choice decision aid group performed better than the standard Mayo patient education pamphlet group (standard effect size = 1.06; 95% CI = 0.62 to 1.50). The other study compared a multifaceted intervention (distribution of educational material, educational meeting and audit and feedback) to usual care (control group) (standard effect size = 2.11; 95% CI = 1.30 to 2.90). This study was the only one to report an assessment of barriers prior to the elaboration of its multifaceted intervention. Authors' conclusions The results of this Cochrane review do not allow us to draw firm conclusions about the most effective types of intervention for increasing healthcare professionals' adoption of SDM. Healthcare professional training may be important, as may the implementation of patient mediated interventions such as decision aids. Given the paucity of evidence, however, those motivated by the ethical impetus to increase SDM in clinical practice will need to weigh the costs and potential benefits of interventions. Subsequent research should involve well designed studies with adequate power and procedures to minimise bias so that they may improve estimates of the effects of interventions on healthcare professionals' adoption of SDM. From a measurement perspective, consensus on how to assess professionals' adoption of SDM is desirable to facilitate cross-study comparisons.

Levasseur, M., et al., *Inventory and analysis of definitions of social participation found in the aging literature: proposed taxonomy of social activities*. Soc Sci Med, 2010.

71(12): p. 2141-9. Social participation is a key determinant of successful and healthy aging and therefore an important emerging intervention goal for health professionals. Despite the interest shown in the concept of social participation over the last decade, there is no agreement on its definition and underlying dimensions. This paper provides an inventory and content analysis of definitions of social participation in older adults. Based on these results, a taxonomy of social activities is proposed. Four databases (Medline, CINAHL, AgeLine and PsycInfo) were searched with relevant keywords (Aging OR Ageing OR Elderly OR Older OR Seniors AND Community involvement/participation OR Social engagement/involvement/ participation) resulting in the identification of 43 definitions. Using content analysis, definitions were deconstructed as a function of who, how, what, where, with whom, when, and why dimensions. Then, using activity analysis, we explored the typical contexts, demands and potential meanings of activities (main dimension). Content analysis showed that social participation definitions (n = 43) mostly focused on the person's involvement in activities providing interactions with others in society or the community. Depending on the main goal of these social activities, six proximal to distal levels of involvement of the individual with others were identified: 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, 5) helping others, and 6) contributing to society. These levels are discussed in a continuum that can help distinguish social participation (levels 3 through 6) from parallel but different concepts such as participation (levels 1 through 6) and social engagement (levels 5 and 6). This taxonomy might be useful in pinpointing the focus of future investigations and clarifying dimensions specific to social participation.

Longtin, Y., et al., *Patient participation: current knowledge and applicability to patient safety*. Mayo Clinic Proceedings, 2010. **85(1):** p. 53-62. Patient participation is increasingly recognized as a key component in the redesign of health care processes and is advocated as a means to improve patient safety. The concept has been successfully applied to various areas of patient care, such as decision making and the management of chronic diseases. We review the origins of patient participation, discuss the published evidence on its efficacy, and summarize the factors influencing its implementation. Patient-related factors, such as acceptance of the new patient role, lack of medical knowledge, lack of confidence, comorbidity, and various sociodemographic parameters, all affect willingness to participate in the health care process. Among health care workers, the acceptance and promotion of patient participation are influenced by other issues, including the desire to maintain control, lack of time, personal beliefs, type of illness, and training in patient-caregiver

relationships. Social status, specialty, ethnic origin, and the stakes involved also influence patient and health care worker acceptance. The London Declaration, endorsed by the World Health Organization World Alliance for Patient Safety, calls for a greater role for patients to improve the safety of health care worldwide. Patient participation in hand hygiene promotion among staff to prevent health care-associated infection is discussed as an illustrative example. A conceptual model including key factors that influence participation and invite patients to contribute to error prevention is proposed. Further research is essential to establish key determinants for the success of patient participation in reducing medical errors and in improving patient safety.

Lyttle, D.J. and A. Ryan, *Factors influencing older patients' participation in care: a review of the literature*. International journal of older people nursing, 2010. 5(4): p. 274-82. BACKGROUND: Over the past 10 years, there has been an increase in the literature promoting patient involvement in health care at all levels of the decision-making process. AIM: To review the literature on factors influencing patient participation in care with a particular focus on the perspective of older people. METHOD: Various search engines were used to conduct the review and articles were identified through the following databases; CINAHL, CSA ILLUMINA, Science Direct, Blackwell Synergy, the Cochrane Library, OVID, SAGE, AHMED, BNI and MEDLINE. Research studies ranging from 2000-2007 were selected for inclusion on the basis that they investigated patient participation and/or older peoples' involvement in health care. FINDINGS: Seven key themes emerged from the literature: the concept of participation, the need for older people to be involved, autonomy and empowerment, patients' expectations, benefits of participation, factors influencing participation and precursors to participation. CONCLUSIONS: Although patient participation has received considerable attention in the literature, this review highlights the dearth of research from the perspective of older people. There is a general consensus that preference for participation should be assessed and not assumed, and the review offers a sobering reminder that participation should not be achieved at the expense of patient autonomy and choice. RELEVANCE TO PRACTICE: Quality care and the most productive use of resources are dependent on the public's engagement with health service providers. However, despite being central to contemporary nursing practice, this review suggests that the reality is not matched by the rhetoric. Future initiatives should focus on supporting nurses and other healthcare professionals to develop the competencies required to facilitate greater participation by older people who wish to become more involved in their care.

Macdonald, G. and W. Turner, *Treatment Foster Care for improving outcomes in children and young people [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 5: p. 5. Background Treatment foster care (TFC) is a foster family-based intervention that aims to provide young people (and, where appropriate, their families) with a tailored programme designed to effect positive changes in their lives. TFC was designed specifically to cater for the needs of children whose difficulties or circumstances place them at risk of multiple placements and/or more restrictive placements such as hospital or secure residential or youth justice settings. Objectives To assess the impact of TFC on psychosocial and behavioural outcomes, delinquency, placement stability, and discharge status for children and adolescents who require out-of-home placement. Search strategy We searched the Cochrane Controlled Trials Register (CENTRAL) 2006 (Issue 4), MEDLINE (1966 to January 2007), CINAHL (1982 to December 2006), PsycINFO (1872 to January 2007), ASSIA (1987 to January 2007), LILACS (1982 to January 2007), ERIC (1966 to January 2007), Sociological Abstracts (1963 to January 2007), and the National Research Register 2006 (Issue 4). Selection criteria Included studies were randomised controlled trials investigating the effectiveness of TFC with children and young people up to the age of 18 who, for reasons of severe medical, social, psychological and behavioural problems, were placed in out of home care in restrictive settings (e.g. secure residential care, psychiatric hospital) or at risk of placement in such settings. Data collection and analysis Titles and abstracts identified in the search were independently assessed for eligibility by the two authors (GM and WT) who also extracted and entered into REVMAN. Data were synthesised on the few occasions where this was possible. Results are presented in tabular, graphical (forest plots) and textual form. Main results Five studies including 390 participants were included in this review. Data suggest that treatment foster care may be a useful intervention for children and young people with complex emotional, psychological and behavioural need, who are at risk of placements in nonfamily settings that restrict their liberty and opportunities for social inclusion. Authors' conclusions Although the inclusion criteria for this systematic review set a study design threshold higher than that of previous reviews, the results mirror those of earlier reviews but also highlights the tendency of the perceived effectiveness of popular interventions to outstrip their evidence base. Whilst the results of individual studies generally indicate that TFC is a promising intervention for children and youth experiencing mental health problems, behavioural problems or problems of delinquency, the evidence base is less robust than that usually reported.

Magasi, S. and M.W. Post, *A comparative review of contemporary participation measures' psychometric properties and content coverage*. Archives of Physical

Medicine & Rehabilitation, 2010. **91**(9 Suppl): p. S17-28. OBJECTIVES: To provide a review of contemporary participation measures' conceptual foundations, psychometric properties and linkage to the International Classification of Functioning, Disability and Health (ICF). DATA SOURCES: Major medical databases, including PubMed, Medline, PsychInfo, and CINAHL. STUDY SELECTION: Articles that described the psychometric properties of generic measures of adult participation published in English between 1998 and 2008 were included. DATA EXTRACTION: Two reviewers independently reviewed each measure using recognized quality criteria for health questionnaires. Individual items were linked to the ICF using established linking rules. DATA SYNTHESIS: Eight measures met the inclusion criteria: Impact on Participation and Autonomy, ICF Measure of Participation and Activities, Keele Assessment of Participation, Assessment of Life Habits, Participation Profile, Participation Survey/Mobility, Participation Scale, and the Participation Measure for Post-Acute Care. The selected measures were based primarily on the ICF and demonstrated moderate to good validity and reliability, but psychometric information was often incomplete. The most commonly addressed ICF domains were mobility; domestic life; social interactions; major life domains; and community, social, and civic life. CONCLUSIONS: This review provides tools--a detailed review of individual participation measures, a comparative table of the measures' psychometric properties, and ICF linkages--and a set of 3 guiding questions to help users select appropriate participation measures.

Maticka-Tyndale, E. and J.P. Barnett, *Peer-led interventions to reduce HIV risk of youth: a review*. Evaluation & Program Planning, 2010. **33**(2): p. 98-112. One approach in HIV prevention programming targeting youth is to use peer leaders in what is referred to as peer education programming. This paper critically reviews and synthesizes the results and lessons learned from 24 evaluated peer-led programs with an HIV/AIDS risk reduction component that target youth in the communities where they live and are delivered in low- and middle-income countries. Interventions were identified through a comprehensive search of the peer reviewed AIDS-related literature as well as publication lists of major organizations in the UN family that address HIV and AIDS. Our synthesis of study results finds that these programs have demonstrated success in effecting positive change in knowledge and condom use and have demonstrated some success in changing community attitudes and norms. Effects on other sexual behaviors and STI rates were equivocal. We include an overview of characteristics of successful programs, a review of program limitations, and recommendations for the development and implementation of successful community-based peer-led programs in low-income countries.

McCaffery, K.J., et al., *Shared decision making in Australia in 2011*. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 2011. The paper describes the current position of shared decision making (SDM) within the Australian healthcare system. SDM policy in Australia: Support for SDM exists through guidelines and policy documents, and is strongly endorsed by consumer organisations; however, there is no clear overarching policy framework for SDM in Australia. Tools for SDM: There are limited tools available for SDM in clinical practice. Access to tools exists through some Australian health research and consumer organisation websites but the use of tools remains idiosyncratic. Implementation of SDM: Comparatively little has been achieved in the implementation of SDM in Australia. Although there is wide recognition that consumer involvement in health decisions is important, provision of resources and infrastructure to achieve it is limited, and there is no clear strategy to support implementation within the healthcare system. SDM in the future: Current reforms to the healthcare system may enable a more centralised approach to implementation of SDM in the future. A new federally funded consumer health information organisation may assist by providing a central point through which SDM interventions may be made available to the Australian public and the Australian Charter of Rights has the potential to provide a national framework for consumer involvement. However, priority needs to be given to SDM by both federal and state governments with greater investment in SDM research and in activities to support implementation in clinical practice.

Menon, D. and T. Stafinski, *Role of patient and public participation in health technology assessment and coverage decisions*. Expert Review of Pharmacoeconomics & Outcomes Research, 2011. **11**(1): p. 75-89. Health technology assessment (HTA) has become an integral part of decision-making on the coverage of new health technologies in most health systems in the developed world. In recent years, pressure to involve patients and members of the public in HTA has grown. In this article, we summarize findings from peer-reviewed and 'gray' literature, and discussions with key informants to determine potential roles for patients and the public in HTA and coverage decision-making. We also summarize existing roles for both groups in jurisdictions. Although there appears to be a general view that involvement of patients and the public is highly desirable, research offering insights into the effectiveness of different approaches to accomplish this is scarce. Nonetheless, many of the HTA agents in developed countries have established some mechanism for seeking input from patients or the public in their processes.

Michielsen, A., I. Van Wijk, and M. Ketelaar, *Participation and quality of life in children and adolescents with congenital limb deficiencies: A narrative review*. Prosthetics &

Orthotics International, 2010. **34**(4): p. 351-61. Children and adolescents with congenital limb deficiencies are visibly and physically different from their peers. They present limitations in activities, depending on the severity of deficiency. Therefore they are at risk for lower participation in social and leisure activities. This might negatively influence the perception on their quality of life. The aim of this narrative review is to describe participation and quality of life in children with congenital limb deficiencies. Participation and quality of life are relatively new concepts. Psychosocial functioning, being closely related to the concept of quality of life, is described as well. A comprehensive review of the literature was conducted on participation, quality of life and psychosocial functioning in children and adolescents with congenital limb deficiencies. The review involved a systematic search using multiple data sources. Fifteen cross-sectional studies were included in this review. The literature to date provides limited knowledge on how children and adolescents with congenital limb deficiencies participate and how they perceive their quality of life. The psychosocial functioning, although described as at risk, appears to be comparable to healthy peers. In conclusion, more research is needed on how children and adolescents with congenital limb deficiencies participate and how they perceive their quality of life. A broader perspective will not only help parents in making the right choices for their children, but can also have implications for health care providers, teachers and agencies funding rehabilitation services.

Minet, L., et al., *Mediating the effect of self-care management intervention in type 2 diabetes: A meta-analysis of 47 randomised controlled trials*. Patient Education and Counseling, 2010. **80**(1): p. 29-41. Objective To perform a meta-analysis assessing the effects of self-care management interventions in improving glycaemic control in type 2 diabetes by analysing the impact of different study characteristics on the effect size. Methods A literature search in eight scientific databases up to November 2007 included original studies of randomised controlled trials involving adult patients diagnosed with type 2 diabetes and evaluating a self-care management intervention. Results The 47 included studies yielded 7677 participants. The analysis showed a 0.36% (95% CI 0.21–0.51) improvement in glycaemic control in people who received self-care management treatment. In the univariate meta-regression sample size (effect size 0.42%, $p=0.007$) and follow-up period (effect size 0.49%, $p=0.017$) were identified to have significant effect on the effect size in favour of small studies and short follow-up. For type of intervention and duration of intervention there was a non-significant effect on effect size in favour of educational techniques and short interventions. Conclusion In type 2 diabetes, there are improvements in glycaemic control in people who receive self-care management

treatment with a small advantage to intervention with an educational approach. Practice implications Further research on frequency and duration of intervention may provide useful information to identify the most effective regime.

Miron-Shatz, T., et al., *The status of shared decision making and citizen participation in Israeli medicine*. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 2011. 105 (4): p. 271-276. What about policy regarding SDM? Though informed consent and patients' right to information are regulated by Israeli law, there is a low level of formal activities focused on shared decision making (SDM) in Israel. Further, there are few organized programs to promote SDM among medical professionals or the public, and governmental support of SDM-related research is minimal. What about tools – decision support for patients? The Israeli government does not have a program on development of patient decision aids. What about professional interest and implementation? Nonetheless, patients have begun to influence litigation in both formal and informal capacities, medical schools have begun to incorporate courses for improving physician-patient communication into their curricula, and the largest national health plan has initiated a plan to increase public awareness. Funding for researching and promoting SDM is not centrally allocated, and studies show that despite the positive effects of SDM, such an approach is infrequently applied in actual clinical practice, and initiatives to promote SDM (e.g., decision aids) are in their infancy. What does the future look like? In conclusion, though not actively promoting SDM at present, Israel, with its governmentally regulated universal coverage with good access to high-level services possesses all the requisite elements for rapid, widespread advances in SDM in future years.

Moore, L. and S. Kirk, *A literature review of children's and young people's participation in decisions relating to health care*. Journal of Clinical Nursing, 2010. 19(15-16): p. 2215-25. AIMS AND OBJECTIVES: To review and critique the research literature on children's and young people's participation in health care decision-making, to highlight gaps in the research and to identify implications for nursing practice. BACKGROUND: Children have a right to participate in decisions about their lives. The recognition of this, along with greater acknowledgement of children's capabilities, has led to an increasing awareness that children's views must be given value in both national policy and individual decisions. Health professionals have also been given explicit direction to ensure that children are actively involved in decision-making. DESIGN: Literature review. METHOD: Search of electronic databases and manual searching of journals and reference lists between 1990-2009. RESULTS: Children want to be involved in discussions about their care but it is unclear to what extent this happens in practice.

The research conducted has interpreted participation in different ways. Studies have compared decisions of differing importance in terms of risk and many have a wide age range in their samples, including children who are arguably too young for meaningful participation. However, this heterogeneity is often overlooked in the reporting of studies. Aspects of practice which can help or hinder participation are identified but there is little evidence on the outcome benefits of participation. In addition, there has been an over-reliance on interviews as the method of data collection. CONCLUSIONS: Research using a combination of observation and interviewing would provide more in-depth knowledge about participation in practice. In addition, studies should consider decisions of similar consequence and children at an age when participation is appropriate. RELEVANCE TO CLINICAL PRACTICE: The need for health professionals to ensure children are protected is undisputed but should not prevent children's rights to participate from being enacted. Practitioners, therefore, need further guidance on how to facilitate the participation of children.

Moumjid, N., et al., *Shared decision making in the physician-patient encounter in France: a general overview in 2011*. Zeitschrift für Evidenz Fortbildung und Qualität im Gesundheitswesen, 2011. 105(4): p. 259-62. What about policy regarding SDM? There is a social demand in France for more healthcare user information and greater patient participation in the decision making process, as reflected by the law of March 4th 2002 pertaining to patients' rights and the quality of the healthcare system known as the Law on Democracy in healthcare. What about tools – decision support for patients? At the micro level, some research projects are being developed, some of them using decision aids. Preliminary results show that patients want to be informed but that the concept of shared decision making needs to be analysed and refined from both the patients' and the physicians' points of views. What about professional interest and implementation? However, the relationship between physicians/healthcare professionals and patients/healthcare users is very complex and progress in this field takes time. Only ten years after enactment of the Law on Democracy in healthcare, it might be premature to try and determine the state of the art of shared medical decision making at the macro and meso levels in France. What does the future look like? There is room in France for further studies on shared decision making in the medical encounter. Researchers, decision makers, healthcare users and healthcare professionals need a place to meet and exchange. An observatory dedicated to shared decision making will be launched in the coming months, both at the national level and in collaboration with several other French-speaking areas like Switzerland and the province of Quebec.

Myers, K.M., N.B. Palmer, and J.R. Geyer, *Research in child and adolescent telemental health*. Child and Adolescent Psychiatric Clinics of North America, 2011. **20 (1)**: p. 155-171. Over the past decade telepsychiatry, and more broadly telemental health (TMH), services with children and adolescents have been implemented with diverse populations in many geographic areas across the United States. The feasibility and acceptability of child and adolescent TMH have been well demonstrated, but little research exists on the efficacy and effectiveness of TMH in improving the mental health care and outcomes for underserved youth. This article summarizes the state of research in child and adolescent telemental health TMH and examines studies in other areas of telemedicine that may inspire and guide child and adolescent telepsychiatrists to collect data on the process and outcomes of their own work. 2011 Elsevier Inc.

Ng, B.E., et al., *Population-based biomedical sexually transmitted infection control interventions for reducing HIV infection [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. 5: p. 5. Background The transmission of sexually transmitted infections (STIs) is closely related to the sexual transmission of human immunodeficiency virus (HIV). Similar risk behaviours, such as frequent unprotected intercourse with different partners, place people at high risk of HIV and STIs, and there is clear evidence that many STIs increase the likelihood of HIV transmission. STI control, especially at the population or community level, may have the potential to contribute substantially to HIV prevention. This is an update of an existing Cochrane review. The review's search methods were updated and its inclusion and exclusion criteria modified so that the focus would be on one well-defined outcome. This review now focuses explicitly on population-based biomedical interventions for STI control, with change in HIV incidence being an outcome necessary for a study's inclusion. Objectives To determine the impact of population-based biomedical STI interventions on the incidence of HIV infection. Search strategy We searched PubMed, EMBASE, the Cochrane Central Register of Controlled Trials (CENTRAL), Web of Science/Social Science, PsycINFO, and Literatura Latino Americana e do Caribe em Ciências da Saúde (LILACS), for the period of 1 January 1980 – 16 August 2010. We initially identified 6003 articles and abstracts. After removing 776 duplicates, one author (TH) removed an additional 3268 citations that were clearly irrelevant. Rigorously applying the inclusion criteria, three authors then independently screened the remaining 1959 citations and abstracts. Forty-six articles were chosen for full-text scrutiny by two authors. Ultimately, four studies were included in the review. We also searched the Aegis database of conference abstracts, which includes the Conference on Retroviruses and Opportunistic Infections (CROI), the International AIDS Conference (IAC), and International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention

(IAS) meetings from their inception dates (1993, 1985 and 2001, respectively) through 2007. We manually searched the web sites of those conferences for more recent abstracts (up to 2010, 2010 and 2009, respectively) In addition to searching the clinical trials registry at the US National Institutes of Health, we also used the metaRegister of Controlled Trials. We checked the reference lists of all studies identified by the above methods. Selection criteria Randomised controlled trials involving one or more biomedical interventions in general populations (as opposed to occupationally or behaviourally defined groups, such as sex workers) in which the unit of randomisation was either a community or a treatment facility and in which the primary outcome was incident HIV infection. The term “community” was interpreted to include a group of villages, an arbitrary geographical division, or the catchment population of a group of health facilities. Data collection and analysis Three authors (BN, LB, TH) independently applied the inclusion criteria to potential studies, with any disagreements resolved by discussion. Trials were examined for completeness of reporting. Data were abstracted independently using a standardised abstraction form. Main results We included four trials. One trial evaluated mass treatment of all individuals in a particular community. The other three trials evaluated various combinations of improved syndromic STI management in clinics, STI counselling, and STI treatment. In the mass treatment trial in rural south western Uganda, after three rounds of treatment of all community members for STIs, the adjusted rate ratio (aRR) of incident HIV infection was 0.97 (95% CI 0.81 - 1.2), indicating no effect of the intervention. The three STI management intervention studies were all conducted in rural parts of Africa. One study, in northern Tanzania, showed that the incidence of HIV infection in the intervention groups (strengthened syndromic management of STIs in primary care clinics) was 1.2% compared with 1.9% in the control groups (aRR = 0.58, 95% CI 0.42 - 0.79), corresponding to a 42% reduction (95% CI 21.0% - 58.0%) in HIV incidence in the intervention group. Another study, conducted in rural south western Uganda, showed that the aRR of behavioural intervention and STI management compared to control on HIV incidence was 1.00 (95% CI 0.63 - 1.58). In the third STI management trial, in eastern Zimbabwe, there was no effect of the intervention on HIV incidence (aRR = 1.3, 95% CI 0.92 - 1.8). These are consistent with data from the mass treatment trial showing no intervention effect. Overall, pooling the data of the four studies showed no significant effect of any intervention (rate ratio [RR] = 0.97, 95% CI 0.78 - 1.2). Combining the mass treatment trial and one of the STI management trials, we find that there is a significant 12.0% reduction in the prevalence of syphilis for those receiving a biomedical STI intervention (RR 0.88, 95% CI 0.80 - 0.96). For gonorrhoea, we find a statistically significant 51.0% reduction in its prevalence in those receiving any of these

interventions (RR 0.49, 95% CI 0.31 - 0.77). Finally, for chlamydia, we found no significant difference between any biomedical intervention and control (RR 1.03, 95% CI 0.77 - 1.4). Authors' conclusions We failed to confirm the hypothesis that STI control is an effective HIV prevention strategy. Improved STI treatment services were shown in one study to reduce HIV incidence in an environment characterised by an emerging HIV epidemic (low and slowly rising prevalence), where STI treatment services were poor and where STIs were highly prevalent; Incidence was not reduced in two other settings. There is no evidence for substantial benefit from a presumptive treatment intervention for all community members. There are, however, other compelling reasons why STI treatment services should be strengthened, and the available evidence suggests that when an intervention is accepted it can substantially improve quality of services provided.

O'Connor, A., et al., *Decision aids for people facing health treatment or screening decisions [Systematic Review]*. Cochrane Database of Systematic Reviews, 2011. **10**: p. 10. Background, Decision aids prepare people to participate in decisions that involve weighing benefits, harms, and scientific uncertainty., Objectives, To evaluate the effectiveness of decision aids for people facing treatment or screening decisions., Search strategy, For this update, we searched from January 2006 to December 2009 in MEDLINE (Ovid); Cochrane Central Register of Controlled Trials (CENTRAL, issue 4 2009); CINAHL (Ovid) (to September 2008 only); EMBASE (Ovid); PsycINFO (Ovid); and grey literature. Cumulatively, we have searched each database since its start date., Selection criteria, We included published randomised controlled trials (RCTs) of decision aids, which are interventions designed to support patients' decision making by providing information about treatment or screening options and their associated outcomes, compared to usual care and/or alternative interventions. We excluded studies in which participants were not making an active treatment or screening decision., Data collection and analysis, Two review authors independently screened abstracts for inclusion, extracted data, and assessed potential risk of bias. The primary outcomes, based on the International Patient Decision Aid Standards, were:, Main results, Of 34,316 unique citations, 86 studies involving 20,209 participants met the eligibility criteria and were included. Thirty-one of these studies are new in this update. Twenty-nine trials are ongoing. There was variability in potential risk of bias across studies. The two criteria that were most problematic were lack of blinding and the potential for selective outcome reporting, given that most of the earlier trials were not registered., Authors' conclusions, New for this updated review is evidence that: decision aids with explicit values clarification exercises improve informed values-based

choices; decision aids appear to have a positive effect on patient-practitioner communication; and decision aids have a variable effect on length of consultation.

Peat, M., et al., *Scoping review and approach to appraisal of interventions intended to involve patients in patient safety*. Journal of Health Services & Research Policy, 2010. **15 Suppl 1**: p. 17-25. Objective: To review the literature on the involvement of patients in efforts to promote their own or others' safety while using health care services. Method: A total of 1933 reports were identified as potentially relevant and 745 of these were included in the review (437 descriptions of interventions, 299 comment or opinion pieces and 42 discussions or studies of patients' willingness and ability to adopt safety-promoting behaviours). Results: The rate of publication on these topics has increased, especially in the USA and UK. However, there is scant evidence of the impact of patient involvement initiatives on safety outcomes and there has been little exploration of patients' willingness and ability to adopt particular safety-oriented behaviours. We identified three broad routes by which patients' actions might contribute to their safety by helping to make sure that: their treatment is appropriate for them (informing the management plan); treatment is given as planned and according to appropriate protocols (monitoring and ensuring safe delivery of treatment); and problems and risks within health care systems are identified and reduced (informing systems improvements). Conclusions: An approach for appraising interventions intended to promote patient involvement in patient safety should involve: identification of the routes by which interventions assume patients' actions might contribute to their safety; identification of the conditions that would need to be met for patients to behave and contribute as the interventions (implicitly) assume; examination of the extent to which the intervention supports fulfilment of those conditions; and consideration of the potential negative effects of the intervention.

Perestelo-Perez, L., et al., *Decision aids for patients facing health treatment decisions in Spain: preliminary results*. Patient Education & Counseling, 2010. **80**(3): p. 364-71. OBJECTIVE: This study presents ongoing research aimed at understanding the suitability and impact of various decision aids (DAs) on patients with different chronic conditions in the Spanish National Health System. METHODS: A three-phase process was employed to develop and evaluate DAs for patients with hip or knee osteoarthritis (OA), benign prostatic hyperplasia (BPH), and depression, including: (1) systematic reviews on the effectiveness of shared decision making (SDM) interventions (including DAs); (2) the development of DAs; (3) a pilot study assessing the DAs. RESULTS: Systematic reviews carried out highlight that there are few studies assessing the effectiveness of DAs for OA, BPH, and depression. The development of DAs and their

assessment currently differs for each medical condition. The DAs assessed for OA and BHP are well accepted. In a pilot study with OA patients, the DA produced a significant improvement in the decisional conflict "informed" subscale. **CONCLUSION:** Research on SDM and DAs for different chronic conditions is at a very early stage in Spain. It is not possible to draw any definite conclusions about the effectiveness of DAs for clinical practice. **PRACTICE IMPLICATIONS:** It is necessary to conduct more high quality studies to evaluate the effects of DAs in the Spanish context.

Perestelo-Perez, L., et al., *Shared decision making in Spain: Current state and future perspectives*. Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 2011. **105 (4)**: p. 289-295. In the last two decades there has been a growing recognition in the Spanish National Health System (NHS) of the importance of considering patients' values and preferences in clinical decisions. Patient participation in shared decision making (SDM) is gaining importance as a suitable approach to patient-health professional communication and decision making in Spain. In addition, the NHS is funding the development of patients' decision aids (PtDAs) for shared decision making (SDM) by Health Technology Assessment Agencies. However, the NHS has still not incorporated reforms in law that includes SDM and PtDAs as a key component of health care services and professional curricula, nor is there a standardised implementation of interventions to support decisions in routine care. Most patients are not very familiar with their rights to be kept informed and participate in their own health care decisions. Most professionals are not familiar with or educated about patients' rights to be kept informed and participate in health care decisions either. The future of SDM in Spain is promising. The next course of action should be to maintain the production and adaptation of high-quality PtDAs while at the same time reinforcing effective dissemination strategies among patients and training programmes for professionals focused on SDM.

Perestelo-Perez, L., et al., *Patient involvement and shared decision-making in mental health care*. Current Clinical Pharmacology, 2011. **6(2)**: p. 83-90. There is growing interest in shared decision-making (SDM) in which the provider and patient go through each phase of the decision-making process together, share treatment preferences, and reach an agreement on treatment choice. Although a majority of the research evaluating SDM has been conducted under "physical" health conditions, patients' participation and SDM for mental health conditions has received increasing interest since the mid 1990s. SDM in mental health care can be more complex than in general health care because that several patient characteristics, health care provider, and system level factors may hinder normalization and implementation of this model into

clinical practice. To date, in comparison with other health problems, there are few studies which have assessed SDM in this context. In spite of that, evidence points favorably towards the inclusion of SDM in mental health treatment decisions, given that the majority of patients with mental illness prefer to be involved in the process and wish to have information. However, more studies are needed to provide evidence about the impact of SDM on treatment compliance and health care outcomes. In this overview, the authors present the current state and the future perspectives of SDM in mental health.

Preston, R., et al., *Community participation in rural primary health care: intervention or approach?* Australian Journal of Primary Health, 2010. **16**(1): p. 4-16. Community participation is considered important in primary health care development and there is some evidence to suggest it results in positive health outcomes. Through a process of synthesising existing evidence for the effectiveness of community participation in terms of health outcomes we identified several conceptual areas of confusion. This paper builds on earlier work to disentangle the conceptual gaps in this area, and clarify our common understanding of community participation. We conducted a research synthesis of 689 empirical studies in the literature linking rural community participation and health outcomes. The 37 final papers were grouped and analysed according to: contextual factors; the conceptual approach to community participation (using a modification of an existing typology); community participation process; level of evidence; and outcomes reported. Although there is some evidence of benefit of community participation in terms of health outcomes, we found only a few studies demonstrating higher levels of evidence. However, it is clear that absence of evidence of effect is not necessarily the same as absence of an effect. We focus on areas of debate and lack of clarity in the literature. Improving our understanding of community participation and its role in rural primary health care service design and delivery will increase the likelihood of genuine community-health sector partnerships and more responsive health services for rural communities.

Regan, P., N. Hudson, and B. McRory, *Patient participation in public elections: a literature review*. Nursing management (Harrow, London, England : 1994), 2011. **17**(10): p. 32-36. Healthcare organisations and nurse leaders have an important role in promoting patients' right to vote, through the development of policy guidelines, integrated networking and innovative practice. Patients' mental capacity to vote is usually assessed by nurses, who must therefore be aware of clients' voting rights and if the right resources are in place to help them do so. Patients' rights, as citizens, are recognised in law and in professional guidelines, but more needs to be done to protect

their voting rights. There should also be better access to transport and family support, and more flexible electoral procedures. This article reviews the literature on promoting patients' participation in local and general elections and suggests that their voting rights should be endorsed by organisations and nurse leaders through policy guidelines and a flexible and proactive nursing approach to participation.

Reinhardt, J.D. and M.W.M. Post, *Measurement and evidence of environmental determinants of participation in spinal cord injury: A systematic review of the literature*. Topics in Spinal Cord Injury Rehabilitation, 2010. **15 (4)**: p. 26-48. A systematic review of measures of environmental influences on participation in spinal cord injury (SCI) and of the current evidence collected with these measures was performed. Psychometric properties were described, and all instruments were linked to the International Classification of Functioning, Disability and Health (ICF). Six generic instruments were identified that had been used in SCI populations or related contexts and had been validated, at least to some extent. None of the instruments considered all environmental categories of the ICF Core Set for SCI. This review provided only weak and in part conflicting evidence on environmental determinants of participation in SCI.

Repper, J. and T. Carter, *A review of the literature on peer support in mental health services*. Journal of Mental Health, 2011. **20(4)**: p. 392-411. Background. Although mutual support and self-help groups based on shared experience play a large part in recovery, the employment of peer support workers (PSWs) in mental health services is a recent development. However, peer support has been implemented outside the UK and is showing great promise in facilitating recovery. Aims. This article aims to review the literature on PSWs employed in mental health services to provide a description of the development, impact and challenges presented by the employment of PSWs and to inform implementation in the UK. Method. An inclusive search of published and grey literature was undertaken to identify all studies of intentional peer support in mental health services. Articles were summarised and findings analysed. Results. The literature demonstrates that PSWs can lead to a reduction in admissions among those with whom they work. Additionally, associated improvements have been reported on numerous issues that can impact on the lives of people with mental health problems. Conclusion. PSWs have the potential to drive through recovery-focused changes in services. However, many challenges are involved in the development of peer support. Careful training, supervision and management of all involved are required.

Roozen, H.G. and R. de Waart, *Community reinforcement and family training: an effective option to engage treatment-resistant substance-abusing individuals in treatment [corrected] [published erratum appears in ADDICTION 2010*

Nov;105(11):2040]. *Addiction*, 2010. **105**(10): p. 1729-1738. **Aims** Many individuals with substance use disorders are opposed to seeking formal treatment, often leading to disruptive relationships with concerned significant others (CSOs). This is disturbing, as untreated individuals are often associated with a variety of other addiction-related problems. Community Reinforcement and Family Training (CRAFT) provides an option to the more traditional treatment and intervention approaches. The objective of this systematic review was to compare CRAFT with the Alcoholics Anonymous/Narcotics Anonymous (Al-Anon/Nar-Anon) model and the Johnson Institute intervention in terms of its ability to engage patients in treatment and improve the functioning of CSOs. **Methods** The electronic databases PubMed, PsycINFO, EMBASE, CINAHL and the Cochrane Library were consulted. Four high-quality randomized controlled trials were identified, with a total sample of 264 CSOs. Data were synthesized to quantify the effect with 95% confidence intervals, using the random effects model. **Results** CRAFT produced three times more patient engagement than Al-Anon/Nar-Anon [relative risk (RR) 3.25, 95% confidence interval (CI) 2.11–5.02, $P < 0.0001$; numbers needed to treat (NNT) = 2] and twice the engagement of the Johnson Institute intervention (RR 2.15, 95% CI 1.28–3.62, $P = 0.004$; NNT = 3). Overall, CRAFT encouraged approximately two-thirds of treatment-resistant patients to attend treatment, typically for four to six CRAFT sessions. CSOs showed marked psychosocial and physical improvements whether they were assigned to CRAFT, Al-Anon/Nar-Anon or the Johnson Institute intervention within the 6-month treatment window. **Conclusion** CRAFT has been found to be superior in engaging treatment-resistant substance-abusing individuals compared with the traditional programmes.

Rose, K.D., J.S. Ross, and L.I. Horwitz, *Advanced access scheduling outcomes: A systematic review*. *Archives of Internal Medicine*, 2011. **171**(13): p. 1150-1159. **Background:** Advanced (“open”) access scheduling, which promotes patient-driven scheduling in lieu of prearranged appointments, has been proposed as a more patient-centered appointment method and has been widely adopted throughout the United Kingdom, within the US Veterans Health Administration, and among US private practices. **Objective:** To describe patient and physician and/or practice outcomes resulting from implementation of advanced access scheduling in the primary care setting. **Data Sources:** Comprehensive search of electronic databases (MEDLINE, Scopus, Web of Science) through August, 2010, supplemented by reference lists and gray literature. **Study Selection:** Studies were assessed in duplicate, and reviewers were blinded to author, journal, and date of publication. Controlled and uncontrolled English language studies of advanced access implementation in primary care were eligible if they specified methods and reported outcomes data. **Data Extraction:** Two

reviewers collaboratively assessed risk for bias by using the Cochrane Effective Practice and Organisation of Care Group Risk of Bias criteria. Data were independently extracted in duplicate. Data Synthesis: Twenty-eight articles describing 24 studies met eligibility criteria. All studies had at least 1 source of potential bias. All 8 studies evaluating time to third-next-available appointment showed reductions (range of decrease, 1.1-32 days), but only 2 achieved a third-next-available appointment in less than 48 hours (25%). No-show rates improved only in practices with baseline no-show rates higher than 15%. Effects on patient satisfaction were variable. Limited data addressed clinical outcomes and loss to follow-up. Conclusions: Studies of advanced access support benefits to wait time and no-show rate. However, effects on patient satisfaction were mixed, and data about clinical outcomes and loss to follow-up were lacking.

Rosewilliam, S., C.A. Roskell, and A.D. Pandyan, *A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation*. Clinical rehabilitation, 2011. **25**(6): p. 501-14. OBJECTIVE: To map out from the literature the nature, extent and effects of application of patient-centred goal setting in stroke rehabilitation practice. DESIGN: Systematic review. DATA SOURCES: A search was conducted in the Cochrane (Wiley), AMED, Medline (EBSCO), Embase, Sports discuss, Medline (Ovid) and CINAHL databases. Secondary search based on references from the preliminary search was undertaken. REVIEW METHODS: Quantitative and qualitative studies that included aspects of patient-centeredness and goal setting in stroke patients from 1980 to June 2010 were collected. Studies were scrutinized for relevance and quality based on published methodology. The findings were synthesized by aggregating the themes from the qualitative studies and relating them to relevant findings from the quantitative studies. RESULTS: Eighteen qualitative and eight quantitative and one mixed method study conducted in stroke rehabilitation services ranging from acute to community rehabilitation were included. Themes that emerged were related to perceptions of patients and professionals regarding patient-centeredness, nominal adoption of this concept, consequences of discrepancies in the perceptions and practice, related ethical conflicts, challenges to application and strategies to improve its application. The effects of following patient-centred goal-setting practice have been studied mostly with weak methodologies and studies show some benefit with psychological outcomes. CONCLUSION: Patient-centred goal setting is minimally adopted in goal-setting practice due to various barriers. Since the effects of incorporating this concept have not been evaluated rigorously it is suggested that further research is essential to investigate its effect on patient outcomes.

Ryan, R., et al., *Audio-visual presentation of information for informed consent for participation in clinical trials [Systematic Review]*. Cochrane Database of Systematic Reviews, 2010. 11: p. 11. Background Informed consent is a critical component of clinical research. Different methods of presenting information to potential participants of clinical trials may improve the informed consent process. Audio-visual interventions (presented for example on the Internet, DVD, or video cassette) are one such method. Objectives To assess the effects of providing audio-visual information alone, or in conjunction with standard forms of information provision, to potential clinical trial participants in the informed consent process, in terms of their satisfaction, understanding and recall of information about the study, level of anxiety and their decision whether or not to participate. Search strategy We searched: the Cochrane Consumers and Communication Review Group Specialised Register (searched 20 June 2006); the Cochrane Central Register of Controlled Trials (CENTRAL), *The Cochrane Library*, issue 2, 2006; MEDLINE (Ovid) (1966 to June week 1 2006); EMBASE (Ovid) (1988 to 2006 week 24); and other databases. We also searched reference lists of included studies and relevant review articles, and contacted study authors and experts. There were no language restrictions. Selection criteria Randomised and quasi-randomised controlled trials comparing audio-visual information alone, or in conjunction with standard forms of information provision (such as written or oral information as usually employed in the particular service setting), with standard forms of information provision alone, in the informed consent process for clinical trials. Trials involved individuals or their guardians asked to participate in a real (not hypothetical) clinical study. Data collection and analysis Two authors independently assessed studies for inclusion and extracted data. Due to heterogeneity no meta-analysis was possible; we present the findings in a narrative review. Main results We included 4 trials involving data from 511 people. Studies were set in the USA and Canada. Three were randomised controlled trials (RCTs) and the fourth a quasi-randomised trial. Their quality was mixed and results should be interpreted with caution. Considerable uncertainty remains about the effects of audio-visual interventions, compared with standard forms of information provision (such as written or oral information normally used in the particular setting), for use in the process of obtaining informed consent for clinical trials. Audio-visual interventions did not consistently increase participants' levels of knowledge/understanding (assessed in four studies), although one study showed better retention of knowledge amongst intervention recipients. An audio-visual intervention may transiently increase people's willingness to participate in trials (one study), but this was not sustained at two to four weeks post intervention. Perceived worth of the trial did not appear to be influenced by an audio-visual

intervention (one study), but another study suggested that the quality of information disclosed may be enhanced by an audio-visual intervention. Many relevant outcomes including harms were not measured. The heterogeneity in results may reflect the differences in intervention design, content and delivery, the populations studied and the diverse methods of outcome assessment in included studies. Authors' conclusions The value of audio-visual interventions for people considering participating in clinical trials remains unclear. Evidence is mixed as to whether audio-visual interventions enhance people's knowledge of the trial they are considering entering, and/or the health condition the trial is designed to address; one study showed improved retention of knowledge amongst intervention recipients. The intervention may also have small positive effects on the quality of information disclosed, and may increase willingness to participate in the short term; however the evidence is weak. There were no data for several primary outcomes, including harms. In the absence of clear results, trial lists should continue to explore innovative methods of providing information to potential trial participants. Further research should take the form of high-quality randomised controlled trials, with clear reporting of methods. Studies should conduct content assessment of audio-visual and other innovative interventions for people of differing levels of understanding and education; also for different age and cultural groups. Researchers should assess systematically the effects of different intervention components and delivery characteristics, and should involve consumers in intervention development. Studies should assess additional outcomes relevant to individuals' decisional capacity, using validated tools, including satisfaction; anxiety; and adherence to the subsequent trial protocol.

Ryan, R., et al., *Consumer-oriented interventions for evidence-based prescribing and medicines use: an overview of systematic reviews*. Cochrane Database of Systematic Reviews, 2011(5): p. CD007768. Background Numerous systematic reviews exist on interventions to improve consumers' medicines use, but this research is distributed across diseases, populations and settings. The scope and focus of reviews on consumers' medicines use also varies widely. Such differences create challenges for decision makers seeking review-level evidence to inform decisions about medicines use. Objectives: To synthesise the evidence from systematic reviews on the effects of interventions which target healthcare consumers to promote evidence-based prescribing for, and medicines use, by consumers. We sought evidence on the effects on health and other outcomes for healthcare consumers, professionals and services. Methods We included systematic reviews published on the Cochrane Database of Systematic Reviews and the Database of Abstracts of Reviews of Effects. We identified relevant reviews by hand searching both databases from start date to Issue 3 2008. We

screened and ranked reviews based on relevance to consumers' medicines use, using criteria developed for this overview. Standardised forms were used to extract data, and reviews were assessed for methodological quality using the AMSTAR instrument. We used standardised language to summarise results within and across reviews; and a further synthesis step was used to give bottom-line statements about intervention effectiveness. Two review authors selected reviews, extracted and analysed data. We used a taxonomy of interventions to categorise reviews. Main results We included 37 reviews (18 Cochrane, 19 non-Cochrane), of varied methodological quality. Reviews assessed interventions with diverse aims including support for behaviour change, risk minimisation, skills acquisition and information provision. No reviews aimed to promote systems-level consumer participation in medicines-related activities. Medicines adherence was the most commonly reported outcome, but others such as clinical (health and wellbeing), service use and knowledge outcomes were also reported. Reviews rarely reported adverse events or harms, and the evidence was sparse for several populations, including children and young people, carers, and people with multimorbidity. Promising interventions to improve adherence and other key medicines use outcomes (eg adverse events, knowledge) included self monitoring and self-management, simplified dosing and interventions directly involving pharmacists. Other strategies showed promise in relation to adherence but their effects were less consistent. These included reminders; education combined with self-management skills training, counselling or support; financial incentives; and lay health worker interventions. No interventions were effective to improve all medicines use outcomes across all diseases, populations or settings. For some interventions, such as information or education provided alone, the evidence suggests ineffectiveness; for many others there is insufficient evidence to determine effects on medicines use outcomes. Authors' conclusions Systematically assembling the evidence across reviews allows identification of effective or promising interventions to improve consumers' medicines use, as well as those for which the evidence indicates ineffectiveness or uncertainty. Decision makers faced with implementing interventions to improve consumers' medicines use can use this overview to inform these decisions and also to consider the range of interventions available; while researchers and funders can use this overview to determine where research is needed. However, the limitations of the literature relating to the lack of evidence for important outcomes and specific populations, such as people with multimorbidity, should also be considered.

Ryhänen, A.M., et al., *The effects of internet or interactive computer-based patient education in the field of breast cancer: A systematic literature review*. Patient Education and Counseling, 2010. **79**(1): p. 5-13. Objective: The aim of this systematic

review was to analyze what kind of Internet or interactive computer-based patient education programs have been developed and to analyze the effectiveness of these programs in the field of breast cancer patient education. Patient education for breast cancer patients is an important intervention to empower the patient. However, we know very little about the effects and potential of Internet-based patient education in the empowerment of breast cancer patients. Methods: Complete databases were searched covering the period from the beginning of each database to November 2008. Studies were included if they concerned patient education for breast cancer patients with Internet or interactive computer programs and were based on randomized controlled, on clinical trials or quasi-experimental studies. Results: We identified 14 articles involving 2374 participants. The design was randomized controlled trial in nine papers, in two papers clinical trial and in three quasi-experimental. Seven of the studies were randomized to experimental and control groups, in two papers participants were grouped by ethnic and racial differences and by mode of Internet use and three studies measured the same group pre- and post-tests after using a computer program. The interventions used were described as interactive computer or multimedia programs and use of the Internet. The methodological solutions of the studies varied. The effects of the studies were diverse except for knowledge-related issues. Internet or interactive computer-based patient education programs in the care of breast cancer patients may have positive effect increasing breast cancer knowledge. Conclusion: The results suggest a positive relationship between the Internet or computer-based patient education program use and the knowledge level of patients with breast cancer but a diverse relationship between patient's participation and other outcome measures. Practice implications: There is need to develop and research more Internet-based patient education.

Samoocha, D., et al., *Effectiveness of web-based interventions on patient empowerment: a systematic review and meta-analysis*. Journal of Medical Internet Research, 2010. **12**(2): p. e23. BACKGROUND: Patient empowerment is growing in popularity and application. Due to the increasing possibilities of the Internet and eHealth, many initiatives that are aimed at empowering patients are delivered online. OBJECTIVE: Our objective was to evaluate whether Web-based interventions are effective in increasing patient empowerment compared with usual care or face-to-face interventions. METHODS: We performed a systematic review by searching the MEDLINE, EMBASE, and PsycINFO databases from January 1985 to January 2009 for relevant citations. From the 7096 unique citations retrieved from the search strategy, we included 14 randomized controlled trials (RCTs) that met all inclusion criteria. Pairs of review authors assessed the methodological quality of the obtained studies using

the Downs and Black checklist. A meta-analysis was performed on studies that measured comparable outcomes. The GRADE approach was used to determine the level of evidence for each outcome. RESULTS: In comparison with usual care or no care, Web-based interventions had a significant positive effect on empowerment measured with the Diabetes Empowerment Scale (2 studies, standardized mean difference [SMD] = 0.61, 95% confidence interval [CI] 0.29 - 0.94), on self-efficacy measured with disease-specific self-efficacy scales (9 studies, SMD = 0.23, 95% CI 0.12 - 0.33), and on mastery measured with the Pearlin Mastery Scale (1 study, mean difference [MD] = 2.95, 95% CI 1.66 - 4.24). No effects were found for self-efficacy measured with general self-efficacy scales (3 studies, SMD = 0.05, 95% CI -0.25 to 0.35) or for self-esteem measured with the Rosenberg Self-Esteem Scale (1 study, MD = -0.38, 95% CI -2.45 to 1.69). Furthermore, when comparing Web-based interventions with face-to-face deliveries of the same interventions, no significant (beneficial or harmful) effects were found for mastery (1 study, MD = 1.20, 95% CI -1.73 to 4.13) and self-esteem (1 study, MD = -0.10, 95% CI -0.45 to 0.25). CONCLUSIONS: Web-based interventions showed positive effects on empowerment measured with the Diabetes Empowerment Scale, disease-specific self-efficacy scales and the Pearlin Mastery Scale. Because of the low quality of evidence we found, the results should be interpreted with caution. The clinical relevance of the findings can be questioned because the significant effects we found were, in general, small.

Scholl, I., et al., *Measurement of shared decision making - a review of instruments*. Zeitschrift für Evidenz Fortbildung und Qualität im Gesundheitswesen, 2011. **105**(4): p. 313-24. The last years have seen a clear move towards shared decision making (SDM) and increased patient involvement in many countries. However, as the field of SDM research is still relatively young, new instruments for the measurement of (shared) decision making (process, outcome and surrounding elements) are constantly being developed. Thus, the aims of this structured review were to give an update on current developments regarding the measurement in the field of SDM, as well as to give a short overview of published and unpublished instruments. We conducted an electronic literature search in PubMed and theWeb of Science database, performed hand searches of relevant journals and contacted key authors in the field. We found eight scales that have been subjected to further psychometric testing, eleven new and psychometrically tested instruments and nine developments that are still in the publishing process. The results show that there is a trend towards measuring SDM processes from a dyadic approach (assessing both the patient's and the clinician's perspective). More and more scales have been developed and tested in languages other than English, which indicates the growing research efforts in various countries.

While reliability of most scales is good, they differ in their extent of validation. Further psychometric testing is needed, as well as the development of a theoretical measurement framework in order to improve consistency of measured constructs across research groups.

Schwappach, D.L.B. and M. Wernli, *Medication errors in chemotherapy: incidence, types and involvement of patients in prevention. A review of the literature*. European Journal of Cancer Care, 2010. **19**(3): p. 285-92. Medication errors in chemotherapy occur frequently and have a high potential to cause considerable harm. The objective of this article is to review the literature of medication errors in chemotherapy, their incidences and characteristics, and to report on the growing evidence on involvement of patients in error prevention. Among all medication errors and adverse drug events, administration errors are common. Current developments in oncology, namely, increased outpatient treatment at ambulatory infusion units and the diffusion of oral chemotherapy to the outpatient setting, are likely to increase hazards since the process of preparing and administering the drug is often delegated to patients or their caregivers. While professional activities to error incidence reduction are effective and important, it has been increasingly acknowledged that patients often observe errors in the administration of drugs and can thus be a valuable resource in error prevention. However, patients need appropriate information, motivation and encouragement to act as 'vigilant partners'. Examples of simple strategies to involve patients in their safety are presented. Evidence indicates that high self-efficacy and perceived effectiveness of the specific preventive actions increase likelihood of participation in error prevention. Clinicians play a crucial role in supporting and enabling the chemotherapy patient in approaching errors.

Schwappach, D.L.B., *Engaging patients as vigilant partners in safety: A systematic review*. Medical Care Research and Review, 2010. **67** (2): p. 119-148. Several initiatives promote patient involvement in error prevention, but little is known about its feasibility and effectiveness. A systematic review was conducted on the evidence of patients' attitudes toward engagement in error prevention and the effectiveness of efforts to increase patient participation. Database searches yielded 3,840 candidate articles, of which 21 studies fulfilled the inclusion criteria. Patients share a positive attitude about engaging in their safety at a general level, but their intentions and actual behaviors vary considerably. Studies applied theories of planned behaviour and indicate that self-efficacy, preventability of incidents, and effectiveness of actions seem to be central to patients' intention to engage in error prevention. Rigorous evaluations of major educational campaigns are lacking. Interventions embedded

within clinical settings have been effective to some extent. Evidence suggests that involvement in safety may be successful if interventions promote complex behavioral change and are sensitively implemented in health care settings.

Shah, J.Y., et al., *What leads Indians to participate in clinical trials? A meta-analysis of qualitative studies*. PLoS One, 2010. **5**(5): p. e10730. BACKGROUND: With the globalization of clinical trials, large developing nations have substantially increased their participation in multi-site studies. This participation has raised ethical concerns, among them the fear that local customs, habits and culture are not respected while asking potential participants to take part in study. This knowledge gap is particularly noticeable among Indian subjects, since despite the large number of participants, little is known regarding what factors affect their willingness to participate in clinical trials. METHODS: We conducted a meta-analysis of all studies evaluating the factors and barriers, from the perspective of potential Indian participants, contributing to their participation in clinical trials. We searched both international as well as Indian-specific bibliographic databases, including Pubmed, Cochrane, Openjgate, MedInd, Scirus and Medknow, also performing hand searches and communicating with authors to obtain additional references. We enrolled studies dealing exclusively with the participation of Indians in clinical trials. Data extraction was conducted by three researchers, with disagreement being resolved by consensus. RESULTS: Six qualitative studies and one survey were found evaluating the main themes affecting the participation of Indian subjects. Themes included Personal health benefits, Altruism, Trust in physicians, Source of extra income, Detailed knowledge, Methods for motivating participants as factors favoring, while Mistrust on trial organizations, Concerns about efficacy and safety of trials, Psychological reasons, Trial burden, Loss of confidentiality, Dependency issues, Language as the barriers. CONCLUSION: We identified factors that facilitated and barriers that have negative implications on trial participation decisions in Indian subjects. Due consideration and weightage should be assigned to these factors while planning future trials in India.

Sivell, S., et al., *Understanding surgery choices for breast cancer: how might the Theory of Planned Behaviour and the Common Sense Model contribute to decision support interventions?* Health Expectations, 2011. **14**: p. 6-19. To describe the evidence about factors influencing breast cancer patients' surgery choices and the implications for designing decision support in reference to an extended Theory of Planned Behaviour (TPB) and the Common Sense Model of Illness Representations (CSM). A wide range of factors are known to influence the surgery choices of women diagnosed with early breast cancer facing the choice of mastectomy or breast conservation surgery with

radiotherapy. However, research does not always reflect the complexities of decision making and is often atheoretical. A theoretical approach, as provided by the CSM and the TPB, could help to identify and tailor support by focusing on patients' representations of their breast cancer and predicting surgery choices. Literature search and narrative synthesis of data. Twenty-six studies reported women's surgery choices to be influenced by perceived clinical outcomes of surgery, appearance and body image, treatment concerns, involvement in decision making and preferences of clinicians. These factors can be mapped onto the key constructs of both the TPB and CSM and used to inform the design and development of decision support interventions to ensure accurate information is provided in areas most important to patients. The TPB and CSM have the potential to inform the design of decision support for breast cancer patients, with accurate and clear information that avoids leading patients to make decisions they may come to regret. Further research is needed examining how the components of the extended TPB and CSM account for patients' surgery choices.

Spadea, T., et al., *The impact of interventions to improve attendance in female cancer screening among lower socioeconomic groups: A review*. Preventive Medicine, 2010. **50 (4)**: p. 159-164. Objective: To review the scientific evidence on the effectiveness of interventions to promote attendance to breast and cervical cancer screening among lower socioeconomic groups. Methods: We performed a computerized literature search looking for relevant papers published between 1997 and 2006. Papers were classified into three groups based on the type of intervention evaluated: (1) implementation of organized population screening programs; (2) different strategies of enhancing attendance within an organized program; (3) local interventions in disadvantaged populations. Results: The available evidence supports the hypothesis that while organized population screening programs are successful in increasing overall participation rates, they may not per se substantially reduce social inequalities. Some strategies were consistently found to enhance access to screening among lower socioeconomic groups, including cost-reducing interventions (e.g. offering free tests and eliminating geographical barriers), a greater involvement of primary-care physicians and individually tailored pro-active communication that addresses barriers to screening. Conclusions: Evidence from studies suggests that the attendance of deprived women to cancer screening can be improved with organized screening programs tailored to their needs. The same may apply to the prevention of adverse outcomes of other health conditions, such as hypertension, hypercholesterolemia, and diabetes.

Stepan, K.A., et al., *Recommendations for enhancing clinical trials education: a review of the literature*. Journal of Cancer Education, 2011. **26**(1): p. 64-71. This study aims to apply the evidence-based practice (EBP) process to determine the factors that influence patients' understanding of, participation in, and satisfaction with clinical trials, the informed consent process, and treatment decisions and to make recommendations for improving clinical trials education. Beginning with evidence retrieval, the authors identified key search terms and searched MEDLINE--Ovid, MEDLINE--PubMed, and the Cumulative Index to Nursing and Allied Health Literature to identify articles published between July 2001 and July 2006 that highlighted clinical trials education. The articles were reviewed for clinical trials patient education information, clinician methods of communicating clinical trial information to patients, and patient satisfaction with the clinical trials process, including the informed consent process. As a result, practice changes were recommended for the patient/family, staff/community, and institution. From the literature review, 81 articles were identified. Recurring themes included decision-making, patient education, staff education, and pediatrics. Most articles focused on methods and strategies aimed at improving education at the patient/family, staff/community, and institutional levels. The issues surrounding clinical trial education are complex due to multiple variables interfering with poor patient understanding of, participation in, and satisfaction with clinical trial treatment decisions. On the basis of our findings, we recommend that clinicians involved in educating patients, families, staff, and communities about clinical trials have an awareness of and understanding for very complex issues.

Sykes, L.L., et al., *A systematic literature review on response rates across racial and ethnic populations*. Canadian journal of public health, 2010. Revue Canadienne de Sante Publique. 101(3): p. 213-9. OBJECTIVE: To conduct a systematic review examining whether minority ethnic populations participate in surveys as actively as the majority ethnic population. METHODS: A literature and grey literature search was conducted using five online databases as well as government databases and reports, including the search terms: survey response rates or non-response rates and racial or ethnic populations (White, African American, Asian, and Hispanic); survey modes or methods (mail, telephone, face to face, e-mail); and response bias (non-response bias, response bias or social desirability). The search was limited to English language and articles published from January 1990 to June 2009. Article exclusions were based on further inclusion and exclusion criteria. SYNTHESIS: Thirty-five articles were identified on ethnicities and response rates to survey modes. Six articles compared survey mode and response rate for multiple ethnic populations. Response rates ranged from 22.0% to 68.8% in Whites, and in other ethnic groups ranged from 15.4% in African

Americans to 70.9% in Latino Americans. Among the 29 articles that presented survey mode and response rate for a specific ethnicity, the highest response rate reported was from African Americans (92.5%) and the lowest was from Cambodian Americans (30.3%). CONCLUSION: Response rate varied across studies but was similar across ethnicities. Response rate may be related to many factors, including survey mode, length of questionnaire, survey language and cultural sensitivity to content. Our review indicates that ethnic populations who participate in surveys are as likely to participate in research as Whites. In literature, data validity across ethnicity is still unknown and should be studied in the future.

Tamayo-Velazquez, M.-I., et al., *Interventions to promote the use of advance directives: an overview of systematic reviews*. Patient Education & Counseling, 2010. **80**(1): p. 10-20. OBJECTIVE: To identify, appraise and synthesise the results of systematic reviews of the literature (SRLs) that examines the effectiveness of interventions to increase advance directive (AD) completion rate. METHODS: Narrative review of the literature- an overview of SRLs focused on interventions to improve patients' AD completion rate. RESULTS: Seven SRLs were located. A wide range of interventions was identified in order to determine their influence on the AD completion rate. CONCLUSION: The most effective method of increasing the use of ADs is the combination of informative material and repeated conversations over clinical visits. The use of passive informative material in isolation does not significantly increase AD completion rates. However, when interactive informative interventions are employed, the AD completion rate increases and the majority of the studies identify multiple sessions as the most effective method for direct interaction between patients and health care professionals. PRACTICE IMPLICATIONS: The progressive ageing of the population and the provision of quality care during the process of ageing and dying, have given rise to the Governments' interest in developing moral autonomy and regulating tools as ADs. In order to put legislation into practice it is necessary to set up successful interventions to expand ADs use.

Tapp, H. and M. Dulin, *The science of primary health-care improvement: potential and use of community-based participatory research by practice-based research networks for translation of research into practice*. Experimental Biology & Medicine, 2010. **235**(3): p. 290-9. There is a need for new approaches to supplement the existing methods of taking research from bench to bedside and from bedside to practice. Community-based participatory research (CBPR) is an emerging model of research that enhances ongoing clinical research by involving key stakeholders, including community

members and patients. A practice-based research network (PBRN) is a group of primary care practices devoted principally not only to the primary care of patients, but also with a mission to investigate questions related to community-based practice and to improve the quality of primary care. Traditionally, PBRN research has not included patients or community members, while CBPR has excluded health providers as key stakeholders. Typical overlap topics of PBRN and CBPR research are health-care disparities, prevention, chronic disease management and mental health. The inclusion of CBPR within a PBRN has been identified as an important next step with the potential to significantly enhance the research process. This review focuses on bringing together the ideals of CBPR and PBRNs in order to tackle intractable problems such as disparities in health-care access and outcomes and translate these results into practice. Specifically, the CBPR PBRN approach can: (1) guide the research process so that studies more closely match the needs of all stakeholders (including providers, patients and community members); (2) assist in the development of the research protocol and identification of research methodologies so that the study is more amenable to participants; (3) facilitate recruitment of research participants; (4) enrich the data collection and analysis; and (5) allow rapid translation of results from the study back into clinical practice and the community. Once these mechanisms have been clearly elucidated, their widespread adoption will positively impact overall health at both a local and national level.

Tariman, J.D., et al., *Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review*. *Annals of Oncology*, 2010. **21**(6): p. 1145-51. The preferred and actual participation roles during decision making have been studied over the past two decades; however, there is a lack of evidence on the degree of match between patients' preferred and actual participation roles during decision making. A systematic review was carried out to identify published studies that examined preferred and actual participation roles and the match between preferred and actual roles in decision making among patients with cancer. PubMed (1966 to January 2009), PsycINFO (1967 to January 2009), and CINAHL (1982 to January 2009) databases were searched to access relevant medical, psychological, and nursing literature. Twenty-two studies involving patients with breast, prostate, colorectal, lung, gynecological, and other cancers showed discrepancies between preferred and actual roles in decision making. These groups of patients wanted a more shared or an active role versus a less passive role. Across all cancer types, patients wanted more participation than what actually occurred. Research to date documents a pervasive mismatch between patients' preferred and actual roles during decision making. Yet, there is lack of innovative interventions that can potentially increase matching of

patients' preferred and actual role during decision making. Role preferences are dynamic and vary greatly during decision making, requiring regular clinical assessment to meet patients' expectations and improve satisfaction with treatment decisions.

Tempfer, C.B. and P. Nowak, *Consumer participation and organizational development in health care: A systematic review*. Wiener Klinische Wochenschrift, 2011. **123**(13-14): p. 408-414. Objective: To provide an overview of published data on user participation in Health Care. Background: Active and passive involvement of consumers into agendas associated with Health Care is still an exception. Data on the success of user participation projects in various areas of Health Care are lacking. DESIGN: Systematic literature review using public databases. Results: We identified 467 studies including five systematic reviews describing various participation projects, among them workshops, citizens' panels, focus groups, citizens' juries, and consultation meetings. A general trend favoring a specific method was not observed. The categorization of evaluable studies according to Health Care area (n = 331) yielded the following results: general medicine/preventive medicine (n = 5), internal medicine/oncology (n = 132), obstetrics and gynecology (n = 2), surgery (n = 1), neurology/psychiatry (n = 2), social medicine (n = 16), health worker training (n = 38), and research agenda setting (n = 135). Predefined qualitative parameters were extracted from 69/467 (15%) studies. Sixty one of 69 studies (88%) were retrospective analyses without control groups and without outcome assessment. Six studies had outcome assessment, three judged the outcome as successful, two as negative, and one multi-project study reported 'very successful' project assessments in 24% of the projects. In 18 studies, the level of consumer participation was described as 'informed' in 2/18, 'advisory' in 14/18, and 'decision-making' in 2/18. The following factors associated with project success were identified: adequate financing, partnerships with well institutionalized consumer organizations, advanced project logistics, small-scale projects, and adequate internal and external communication. Conclusions: Most consumer participation projects were performed in research agenda setting, internal medicine/oncology, and health worker training. Various methods have been used in the projects, the level of consumer participation was low, and the success rate of the investigated projects was moderate. Potential factors associated with project success and future areas of research are discussed.

Thomas, R.E., M. Russell, and D. Lorenzetti, *Interventions to increase influenza vaccination rates of those 60 years and older in the community*. Cochrane Database of Systematic Reviews, 2010(9): p. CD005188. Background Although the evidence to support influenza vaccination is poor, it is promoted by many health authorities. There

is uncertainty about the effectiveness of interventions to increase influenza vaccination rates in those 60 years or older. Objectives To assess effects of interventions to increase influenza vaccination rates in those 60 or older. Search strategy We searched the Cochrane Central Register of Controlled Trials (CENTRAL) (*The Cochrane Library*, 2010, issue 3), containing the Cochrane Acute Respiratory Infections Group's Specialized Register, MEDLINE (January 1950 to July 2010), PubMed (January 1950 to July 2010), EMBASE (1980 to 2010 Week 28), AgeLine (1978 to July 2010), ERIC (1965 to July 2010) and CINAHL (1982 to July 2010). Selection criteria Randomized controlled trials (RCTs) to increase influenza vaccination rates in those aged 60 years and older, recording influenza vaccination status either through clinic records, billing data or local/national vaccination registers. Data collection and analysis Two review authors independently assessed study quality and extracted data. Main results Forty-four RCTs were included. All included RCTs studied seniors in the community and in high-income countries. No RCTs of society-level interventions were included. Heterogeneity was marked and meta-analysis was limited. Only five RCTs were graded at low and six at moderate risk of bias. They included three of 13 personalized postcard interventions (all three with the 95% confidence interval (CI) above unity), two of the four home visit interventions (both with 95% CI above unity, but one a small study), three of the four reminder to physicians interventions (none with 95% CI above unity) and three of the four facilitator interventions (one with 95% CI above unity, and one $P < 0.01$). The other 33 RCTs were at high risk of bias and no recommendations for practice can be drawn.

Towle, A., et al., *Active patient involvement in the education of health professionals*. Medical Education, 2010. **44**(1): p. 64-74. CONTEXT: Patients as educators (teaching intimate physical examination) first appeared in the 1960s. Since then, rationales for the active involvement of patients as educators have been well articulated. There is great potential to promote the learning of patient-centred practice, interprofessional collaboration, community involvement, shared decision making and how to support self-care. METHODS: We reviewed and summarised the literature on active patient involvement in health professional education. RESULTS: A synthesis of the literature reveals increasing diversity in the ways in which patients are involved in education, but also the movement's weaknesses. Most initiatives are 'one-off' events and are reported as basic descriptions. There is little rigorous research or theory of practice or investigation of behavioural outcomes. The literature is scattered and uses terms (such as 'patient!') that are contentious and confusing. CONCLUSIONS: We propose future directions for research and development, including a taxonomy to facilitate dialogue,

an outline of a research strategy and reference to a comprehensive bibliography covering all health and human services.

Van De Belt, T.H., et al., *Definition of Health 2.0 and Medicine 2.0: a systematic review*. Journal of Medical Internet Research, 2010. **12**(2): p. e18. BACKGROUND: During the last decade, the Internet has become increasingly popular and is now an important part of our daily life. When new "Web 2.0" technologies are used in health care, the terms "Health 2.0" or "Medicine 2.0" may be used. OBJECTIVE: The objective was to identify unique definitions of Health 2.0/Medicine 2.0 and recurrent topics within the definitions. METHODS: A systematic literature review of electronic databases (PubMed, Scopus, CINAHL) and gray literature on the Internet using the search engines Google, Bing, and Yahoo was performed to find unique definitions of Health 2.0/Medicine 2.0. We assessed all literature, extracted unique definitions, and selected recurrent topics by using the constant comparison method. RESULTS: We found a total of 1937 articles, 533 in scientific databases and 1404 in the gray literature. We selected 46 unique definitions for further analysis and identified 7 main topics. CONCLUSIONS: Health 2.0/Medicine 2.0 are still developing areas. Many articles concerning this subject were found, primarily on the Internet. However, there is still no general consensus regarding the definition of Health 2.0/Medicine 2.0. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate discussion and further research.

Vis, S.A., et al., *Participation and health - a research review of child participation in planning and decision-making*. Child & Family Social Work, 2011. **16**(3): p. 325-335. Effective child participation in child protection proceedings has proved difficult to achieve in Norway. Although participation is in principle accepted as a human right and something of benefit to children, when children's health is at stake there is a tendency to view participation in decision-making processes by children as potentially disruptive to their well-being. The purpose of this study is to review the research evidence for effects, positive or negative, of participation on health outcomes for children in care. A scoping review of major health and social work research databases was undertaken. Searches in five databases yielded 1830 studies of which 21 were finally included in this review. Studies were included if a relationship between health and participation was evident from the data presented, even if this was not the main objective in the study at hand. We conclude that when participation is successful, it may have beneficial side effects. Chief among these are that participation may improve children's safety, increase the success of care arrangements and increase feelings of

well-being for children involved. Evidence for long-term effects of successful or failed participation attempts on subsequent health outcomes is however largely absent.

White, G.W., et al., *Secondary analysis of a scoping review of health promotion interventions for persons with disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation?* Disabil Health J, 2011. **4**(2): p. 129-39. BACKGROUND: Secondary conditions can have very serious outcomes for people with physical disabilities. Such consequences can range from immobility due to pressure sores to withdrawal and isolation due to depression, decreasing participation in the community. OBJECTIVE/HYPOTHESIS: To further investigate these assumptions, we conducted a review of the literature on health promotion interventions that include physical activity for adults with disabilities to determine whether they have a positive effect on the reduction of secondary conditions and increased community participation. METHODS: We conducted a secondary analysis of the results of a scoping review of health promotion programs containing physical activity for people with mobility impairments (N = 5). This secondary analysis examined the relationship between health promotion containing physical activity and prevention of secondary conditions among people with various physical disabilities. We further examined evidence and effects of independent variables on the outcome of increased community participation for study participants. RESULTS: The outcomes from this investigation are varied, with 2 studies providing evidence of reducing secondary conditions while another shared anecdotal statements referencing a decrease in secondary conditions. Of the remaining 2 studies in this paper, 1 showed no intervention effect on reducing secondary conditions while the remaining study reported an increase in secondary conditions. Regarding increased participation in the community, 2 of 5 studies directly reported on these outcomes, while increased community participation was referenced in another 2 articles, but without any data presented. The final study did not report on any post intervention in the community. CONCLUSIONS: This review demonstrates that research on health promotion interventions containing physical activity lack description about whether such interventions help reduce or prevent secondary conditions. Additionally, the review shows that further work is needed in terms of sustaining health programs effects beyond the initial proximal activity gains, with attention given toward more distal outcomes of increased participant participation in the community.

Woodall, A., et al., *Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?* BMC psychiatry, 2010. **10**: p. 103.

BACKGROUND: It is well established that the incidence, prevalence and presentation of mental disorders differ by gender, ethnicity and age, and there is evidence that there is also differential representation in mental health research by these characteristics. The aim of this paper is to a) review the current literature on the nature of barriers to participation in mental health research, with particular reference to gender, age and ethnicity; b) review the evidence on the effectiveness of strategies used to overcome these barriers. **METHOD:** Studies published up to December 2008 were identified using MEDLINE, PsycINFO and EMBASE using relevant mesh headings and keywords. **RESULTS:** Forty-nine papers were identified. There was evidence of a wide range of barriers including transportation difficulties, distrust and suspicion of researchers, and the stigma attached to mental illness. Strategies to overcome these barriers included the use of bilingual staff, assistance with travel, avoiding the use of stigmatising language in marketing material and a focus on education about the disorder under investigation. There were very few evaluations of such strategies, but there was evidence that ethnically matching recruiters to potential participants did not improve recruitment rates. Educational strategies were helpful and increased recruitment. **CONCLUSION:** Mental health researchers should consider including caregivers in recruitment procedures where possible, provide clear descriptions of study aims and describe the representativeness of their sample when reporting study results. Studies that systematically investigate strategies to overcome barriers to recruitment are needed.

Woodward, H.I., et al., *What have we learned about interventions to reduce medical errors?* Annu Rev Public Health, 2010. **31**: p. 479-97. Medical errors and adverse events are now recognized as major threats to both individual and public health worldwide. This review provides a broad perspective on major effective, established, or promising strategies to reduce medical errors and harm. Initiatives to improve safety can be conceptualized as a "safety onion" with layers of protection, depending on their degree of remove from the patient. Interventions discussed include those applied at the levels of the patient (patient engagement and disclosure), the caregiver (education, teamwork, and checklists), the local workplace (culture and workplace changes), and the system (information technology and incident reporting systems). Promising interventions include forcing functions, computerized prescriber order entry with decision support, checklists, standardized handoffs and simulation training. Many of the interventions described still lack strong evidence of benefit, but this should not hold back implementation. Rather, it should spur innovation accompanied by evaluation and publication to share the results.

Wright-Berryman, J.L., A.B. McGuire, and M.P. Salyers, *A review of consumer-provided services on assertive community treatment and intensive case management teams: implications for future research and practice*. Journal of the American Psychiatric Nurses Association, 2011. **17**(1): p. 37-44. BACKGROUND: Assertive community treatment (ACT) is an evidence-based practice that provides intensive, in vivo services for adults with severe mental illness. Some ACT and intensive case management teams have integrated consumers as team members with varying results. METHODS: The authors reviewed the literature examining the outcomes of having consumer providers on case management teams, with attention devoted to randomized controlled trials (RCTs). RESULTS: Sixteen published studies were identified, including eight RCTs. Findings were mixed, with evidence supporting consumer-provided services for improving engagement and limited support for reduced hospitalizations. However, evidence was lacking for other outcomes areas such as symptom reduction or improved quality of life. CONCLUSION: Including a consumer provider on an ACT team could enhance the outreach mechanisms of ACT, using a more recovery-focused approach to bring consumers into services and help engage them over time. More rigorous research is needed to further evaluate integrating consumer providers on teams.

Zammar, G., et al., *So different, yet so similar: Meta-analysis and policy modeling of willingness to participate in clinical trials among Brazilians and Indians*. PLoS ONE, 2010. **5** (12)(e14368). Background: With the global expansion of clinical trials and the expectations of the rise of the emerging economies known as BRICs (Brazil, Russia, India and China), the understanding of factors that affect the willingness to participate in clinical trials of patients from those countries assumes a central role in the future of health research. Methods: We conducted a systematic review and meta-analysis (SRMA) of willingness to participate in clinical trials among Brazilian patients and then we compared it with Indian patients (with results of another SRMA previously conducted by our group) through a system dynamics model. Results: Five studies were included in the SRMA of Brazilian patients. Our main findings are 1) the major motivation for Brazilian patients to participate in clinical trials is altruism, 2) monetary reimbursement is the least important factor motivating Brazilian patients, 3) the major barrier for Brazilian patients to not participate in clinical trials is the fear of side effects, and 4) Brazilian patients are more likely willing to participate in clinical trials than Indians. Conclusion: Our study provides important insights for investigators and sponsors for planning trials in Brazil (and India) in the future. Ignoring these results may lead to unnecessary fund/time spending. More studies are needed to validate our results and for better understanding of this poorly studied theme.

Ziviani, J., et al., *Measures of participation outcomes and environmental considerations for children with acquired brain injury: A systematic review*. Brain Impairment, 2010. **11 (2)**: p. 93-112. This systematic review examined the psychometric properties and application of assessments used to evaluate participation outcomes and environmental factors for children with acquired brain injury (ABI). An electronic search of eight databases for articles published up to June 2009 revealed reference to 98 outcome measures. According to inclusion criteria based on the International Classification of Functioning, Disability and Health (ICF: Child and Youth version), five were identified as measures of participation (Children's Assessment of Participation and Enjoyment [CAPE], Child and Adolescent Scale of Participation [CASP], Assessment of Life Habits for Children [LIFE-H], Participation Index of the Mayo-Portland Adaptability Index [M2PI], and the Participation Subscale of the School Function Assessment [SFA-PS]). Six were identified as measures of environment (Child and Adolescent Scale of Environment [CASE], Craig Hospital Inventory of Environmental Factors [CHIEF], European Child Environment Questionnaire [ECEQ], Family Inventory of Life Events and Changes [FILE], HOME Inventory, and the Multidimensional Scale of Perceived Social Support Scale [MSPSS]). The measures were critiqued in relation to content, validity, reliability, clinical utility, responsiveness, and overall strengths/weaknesses. These measures need to be evaluated more extensively with children who have ABI to further determine their psychometric properties and clinical usefulness with this population.

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