Care Planning – Mini Topic Review

April 2011

Reader Page

Title	Care Planning Mini Topic Review
Author	Dr Felix Mukoro
Publication Date	April 2011
Target Audience	Commissioners, nephrologists, renal nurses, home dialysis nurses, renal social workers, home dialysis patients, carers, primary care practitioners
Circulation List	Available online at www.evidence.nhs.uk and www.kidneycare.nhs.uk.
Description/purpose	This review examines the evidence relating to the experiences of patients and healthcare professionals in the care planning process, in order to determine factors that influence successful development of a care plan.
Cross Ref	n/a
Superseded Docs	n/a
Action Required	To review and consider in context of local provision for care planning and shared decision making.
Timing	This report supports the government commitment to a patient-led NHS, ensuring that patients have genuine choice over their treatment options.
Contact details	admin@kidneycare.nhs.uk

Contents

Acknowledgments

1. Introduction

1.1 Background

The involvement of patients in health decision-making is now a central theme of national and local policy in the NHS (1)(2). This is underpinned by the conviction that individual involvement and empowerment are critical to improving health outcomes (3-6). The burden of chronic and long term conditions is growing, and this has exposed significant limitations in traditional models of care delivery which are typically reactive, curative and focused on acute, episodic illness (7). Patient involvement improves patients' experience and satisfaction with NHS services, as well as the appropriateness and outcomes of care (7)(1). Research shows that patients feel involved in their care when they are treated as equal partners, listened to, and provided with adequate information (1). Furthermore, patient involvement enables self-management (1)(8).

Since the 1990s the United Kingdom policy has stated a strong commitment to support people to self care. According to Skills for Care (2008) (3), supporting self care is about partnership working between the individual and the care professional in an ongoing process of two-way communication, negotiation and decision making whereby both parties contribute to the care planning process to achieve the best possible outcomes for the individual. In 2006, the White Paper 'Our health, our care, our say' (6) emphasised the government's commitment to supporting self care and developing and delivering services around the needs of the individual and in partnership with them. 'Supporting People with Long Term Conditions to Self Care' (9) restated this commitment and stressed a shift of values towards individuals' empowerment and self care. Support for self care increases the capacity, confidence and efficacy of individuals to take care of their own health and well being (10). The principles of self care are underpinned by a value base which focuses on person-centredness, partnership working and shared decision making (3).

Individuals will need good understanding of their condition as well as access to any additional information they need in order to self-manage effectively and participate in any decision making processes (4). This highlights the importance of user involvement in the development of interventions intended to empower and enable people with long-term conditions (11). Care planning is about the process of negotiation, discussion and decision-making that takes place between the professional and individual (12). The care planning process brings together the concepts and principles of patient involvement, shared decision making, self-care support and patient centred care. Despite a growing recognition of the importance of taking a person-centred and integrated approach to care planning the experience of people accessing services varies significantly (13).

1.2 Aim

To explore the process of care planning/shared decision making and describe the experiences of patients and healthcare professionals in order to determine factors that influence successful development of a care plan.

1.3 Objectives

a. To review the published evidence relating to care planning for long term conditions in order to identify key knowledge areas.
b. To review policy documents to highlight the direction of current policy in relation to care planning for long term conditions.
c. Produce a mini topic review of care planning for long term conditions which present a synopsis of the available evidence by identified themes.

1.4 Review Question

The focus of the review will be on the following question:

For patients with long term conditions, what factors determine success in the care planning process?

1.5 Outline of the Report

This paper falls into seven main sections. The next section is a discussion of the terminology. The third section reviews policy documents relating to care planning. The fourth section outlines the methods used for this review. The fifth section contains the results of the review. Following this section, is a more general descriptive narrative of the findings and their implications, and a discussion of the limitations of this review. The conclusions drawn from this review are provided in Section 7.

2   Terminology

Several terms are found in the literature that link with the concepts of care planning. They include; "nursing plan", "treatment plan", "discharge plan" and "action plan". While these terms refer to aspects of the care planning process, they do not include the concept of patient involvement and shared decision making, which is key to the care planning process. For example, the nursing care plan was defined as 'a written guide to the individual patient's nursing needs, purposefully stated so that appropriate nursing actions are specific or implied' (14) (15).

Often in the literature, there was an assumption that care planning can be understood without definition. However, a consistent concept echoed across a limited number of papers portray care planning as a process of collaborative care and joint working between the patient and the health professional, underpinned by the principles of patient centredness and partnership working (16); (17)(12). This process provides an opportunity for patients with long term conditions and the health professional to share their perspectives and to make joint decisions on actions needed to minimise health risks (16). This results in the development of a plan of action that is envisaged to eventually lead to improved quality of life, improved clinical outcomes and improved patient well-being. The process encourages provision of support to the individual patients, which will enable them to develop confidence and competence in managing the challenges of living with their condition (12).

The care planning approach is inherently holistic and person-centred rather than condition-centred and offers a model of care for people with long term conditions (17). According to Diabetes UK Care Planning Working Group (2006) (17), this approach provides a single comprehensive and patient-centred review for those who have other co-existing health conditions. This is particularly important in situations where patients have multiple chronic conditions necessitating the involvement of more than one health care team, which may compound the number and type of decisions required. For example, some patients with chronic kidney disease may also have diabetes mellitus and/or cardiovascular disease. For Diabetes UK Care Planning Working Group (2006) (17), care planning should enhance and promote coordination of health and social care services at an organisational level, while supporting local commissioning. The care planning approach aims to provide high quality care personalised to meet the needs of the individual patient, taking into consideration all aspects of the person's life (18) (19).

For people with long term conditions, the development of a personalised care plan has been strongly advocated (1,6,9,11,17,20-23) and this is central to empowering the patient to take

control of their health and their life. A care plan records the outcome of the care planning discussion between an individual and their health professional. In addition to documenting choice and preferences as discussed in the care planning consultation, the care plan outlines a specific set of actions, the person(s) responsible for each action, and the timescale for completion of these actions as agreed by parties to the care planning process (17). Depending on the health and social care needs of the individual, the care plan can be a simple or complex document which is either a written or electronic record containing all the information the individual needs in order to effectively manage their own health (11,24,25). The care plan is owned by the individual who should be given a copy if they want one (25). Where the care plan is written in a separate document from the health records, it should be stored in the person's medical record (25), and made available when the person accesses any part of the service (17). Copies should also be accessible to all health and social care professionals involved in the patient's care (25).

3 Review of Policy Documents on personalised Care Planning

For many years now, UK health policy has demonstrated a clear understanding of the complex needs people with long term conditions, showing a strong commitment towards their care. The paper, 'Supporting People with Long term Conditions' (11), proposed an intensive, on-going and personalised case management for people with long term conditions which will help to improve the quality of life and outcomes for these patients. One of the steps to achieving this involves carrying out thorough assessments and development of a care plan to reflect the personal needs and aspirations of the patient and their carer(s). Another paper, 'Self care – A real choice: self care support – a practical option' (10), sets out the position on the Department of Health's policy to support self care, highlighting that with the right support people can be empowered and learn to be active participants in their own care thereby improving health outcomes and quality of life.

There are now many policy documents and guidelines showing clear commitment to personalised care planning for long term conditions. Key policy documents are summarised below; other relevant guideline documents and specific commitments are outlined in Box 1:

The National Service Framework for Renal Services (23)

The National Service Framework for Renal Services, published in 2004, sets five standards and identifies 30 markers of good practice which will help to improve health outcomes and care quality for renal patients. Standard 1 emphasises a patient centred service which encourages patient involvement, with the provision of self care support and individual care plans.

> *All children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.*

The White Paper Our Health, Our Care, Our Say (6)

This 2006 white paper recognised that many people with long term conditions have social care as well as health care needs, and aimed to address the concerns regarding poor coordination of care between health and social services for them. The paper proposed a more integrated approach through the development of Personal Health and Social Care Plans and integrated social and health care records. The paper stated a commitment that:

> *By 2008 we would expect everyone with both long term health and social care needs to have an integrated care plan if they want one. By 2010 we would expect everyone with a long term conditions to be offered a care plan.*

Further, the paper aimed to address the need to do more to empower people with long-term health and social care needs through greater choice and more control over their care. To achieve this, the policy stated a clear commitment to provide support for people with long term conditions to "take better control of their care and condition through a wide range of initiatives", which will include a major new focus on self care and self management. For example, the paper committed to a expanding the capacity of the Expert Patients Programme (EPP) which provides training for people with a chronic condition to develop the skills they need to take effective control of their lives.

High Quality Care for All: NHS Next Stage Review Final Report (20)

The focus of this 2008 review was to encourage people to exercise choice and be partners in decisions about their own care, shaping and directing it with high quality information and support. According to the review, provision of care plans and better patient information underpins true partnerships between people with long-term conditions and the professionals and volunteers that care for them. The review proposed a more personalised and joint approach which extends the original commitment to care plans in the 'Our Health, Our Care, Our Say' White Paper. The review stated a commitment that:

> *Over the next two years, every one of the 15 million people with one or more long term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care.*

Equity and Excellence: Liberating the NHS (26)

The current government white paper published in July 2010 sets out to uphold the principles of "shared decision making" with strong emphasis on patient choice and control. The paper acknowledges the importance of involving patients fully in their own care, and stresses decisions about the individuals care has to be made in partnership with clinicians if good healthcare outcomes are to be achieved.

Box 1: Specific Commitments and Guidelines

Specific Commitments

  a. *The Long Term Conditions PSA Target (2004/05 to 2007/08)* link
     To improve health outcomes for people with long term conditions by offering a personalised care plan for vulnerable people most at risk, and to reduce emergency bed days by 5% by 2008 through improved care in primary care and community settings.

---

b. *The NHS Operating Framework 2009/10* link

   "over the next 2 years, to ensure those living with a long term condition receive a high quality service and help to manage their condition…..everyone with a long term condition should be offered a personalised care plan…"

c. *NHS 2010 - 2015: from good to great. Preventative, people-centred, productive* (published December 2009) link

   Our plans to transform care for patients with long-term conditions will involve people being offered personalised care planning and support for self-care. This will help them to manage their condition and cope with any exacerbation of symptoms. New systems of care and technology will allow them, their carers and their professionals to monitor their care, intervene early to prevent deterioration and avoid hospital admissions.

d. *The Operating Framework for the NHS in England 2010/11* (published December 2009) link

   There is real benefit still to be had by helping people with LTCs make the best use of an approach that is based on personalisation of care and reduced utilisation. The basic building blocks of case management, personalised care planning, supporting people to self-care and making the best use of new emerging assistive technology is based on the best evidence internationally.

e. *The Operating Framework for the NHS in England 2011/12* (published December 2010) link

   "During 2011, choice should be introduced in care for long term conditions as part of personalised care planning."

   "PCTs should develop and implement plans for shared decision making and information giving and should include these areas in contracts."

Guideline Documents

Self Care Guidelines

a. *Supporting People with Long-Term Conditions to Self Care. A Guide To Developing Local Strategies And Good Practice* (published 2006) link

b. *Your Health, Your Way* (published 2008) link

   This guide sets out the support that people with long term conditions should expect to receive locally if they choose to self care and covers five pillars including:

information, skills and knowledge training, tools and self-monitoring devices, healthy lifestyle choices, and support networks.

Care Planning Guidelines

a. *Supporting People With Long Term Conditions: Commissioning Personalised Care Planning - A Guide For Commissioners* (published 2009) link

This guide provides commissioners of health and social care services with the information and support they need to fulfil their obligation to embed personalised care planning in their localities.

b. *Outline Service Specification: Personalised Care Planning For People With Long Term Conditions.* (published 2009) link

This has been developed to help commissioners to put in place appropriate arrangements to ensure people with long term conditions have informed choice of, and access to, services that best enable them to manage their condition.

c. *Partners In Care: A Guide To Implementing A Care Planning Approach To Diabetes Care* (published 2008) link

The Year of Care model, developed by the National Diabetes Support Team, helps people to exercise choice and be partners in decisions about their own care, and supports them to self care effectively. It promotes the care planning approach to facilitate collaboration between clinicians and people with long term conditions, and ensures that local services are identified and made available through commissioning as needed.

d. *Getting To Grips With The Year Of Care: A Practical Guide* (published 2008) link

This guide is designed to help commissioners, clinicians and networks interested in setting up the Year of Care model locally. It concentrates on what needs to be put in place and the key role of commissioning.

e. *Good Care Planning For People With Long-Term Conditions* (published 2005) link

Following the publication of the National Service Framework for People with Long-Term Conditions (NSF), Matrix was commissioned by the NHS Modernisation Agency to identify and report on the key elements of good care planning for people with long-term conditions. The key objective of the project was to produce user-friendly guidance and tools to assist local health and social care service providers to implement evidence-based, person-centred care planning for people with long-term conditions.

Patient Choice

f. *Generic Choice Model For Long Term Conditions* (published 2007) link

This document offers a best practice generic model with associated case studies, for commissioning services for those with long-term conditions to support choice and personalisation of care.

4   Review methods

This is a descriptive review based on a database search of peer reviewed literature from 1990 to 2010. A series of searches were conducted in August 2010 to retrieve literature relevant to care planning for long term conditions. A health sciences librarian assisted in executing the search of relevant bibliographic databases[1]. Some of the key words used in the searches (individual and combined) include:

care planning, * shared decision making, *self care, * self management, *decision making models, * patient centred care, *patient decision aids, *goal setting, *doctor-patient communication, * Long Term Conditions, *patient involvement, *patient choice, *personalised care planning, *electronic care planning, *primary care, *care pathway.

In addition to the bibliographic database searches, a search was conducted for relevant policy documents and grey literature. Google Scholar was also used. Bibliographies of selected articles were also searched for relevant studies.

4.1   Study selection (inclusion and exclusion criteria; methods)

Abstracts were used as the basis for inclusion; relevant full text articles were then obtained and reviewed in full. Included publications reported research with a clearly stated purpose, the primary intent of which was to examine care planning or shared decision making for long term conditions. Original articles that focused on the preferences and perspectives of participants in the care planning process were also included. This review excludes publications that discussed aspects of the care planning process if that was not the original or primary purpose of the study. For the purpose of article selection, this review classified the practitioner-patient interaction as shared decision making when the following conditions are met as proposed by Charles et al. (27): (1) there are at least two participants involved: the practitioner and patient; (2) information is shared between both parties; (3) both parties take steps to build a consensus about the preferred treatment; and (4) both parties agree with the decision made.

Only primary research papers are included in this review. Excluded are studies that focused on clinical management plans, including plans for nursing care on admission, as well as treatment action plans within the hospital, where the patients were neither involved nor their preferences sort in the development of the care plans. Reviews, news items, non-English papers, opinion pieces, symposium summaries, and letters to the editor were excluded. Studies appraised as of limited methodological validity using published guidelines (28) were also excluded (The final review does not include a methodological appraisal of each resource).
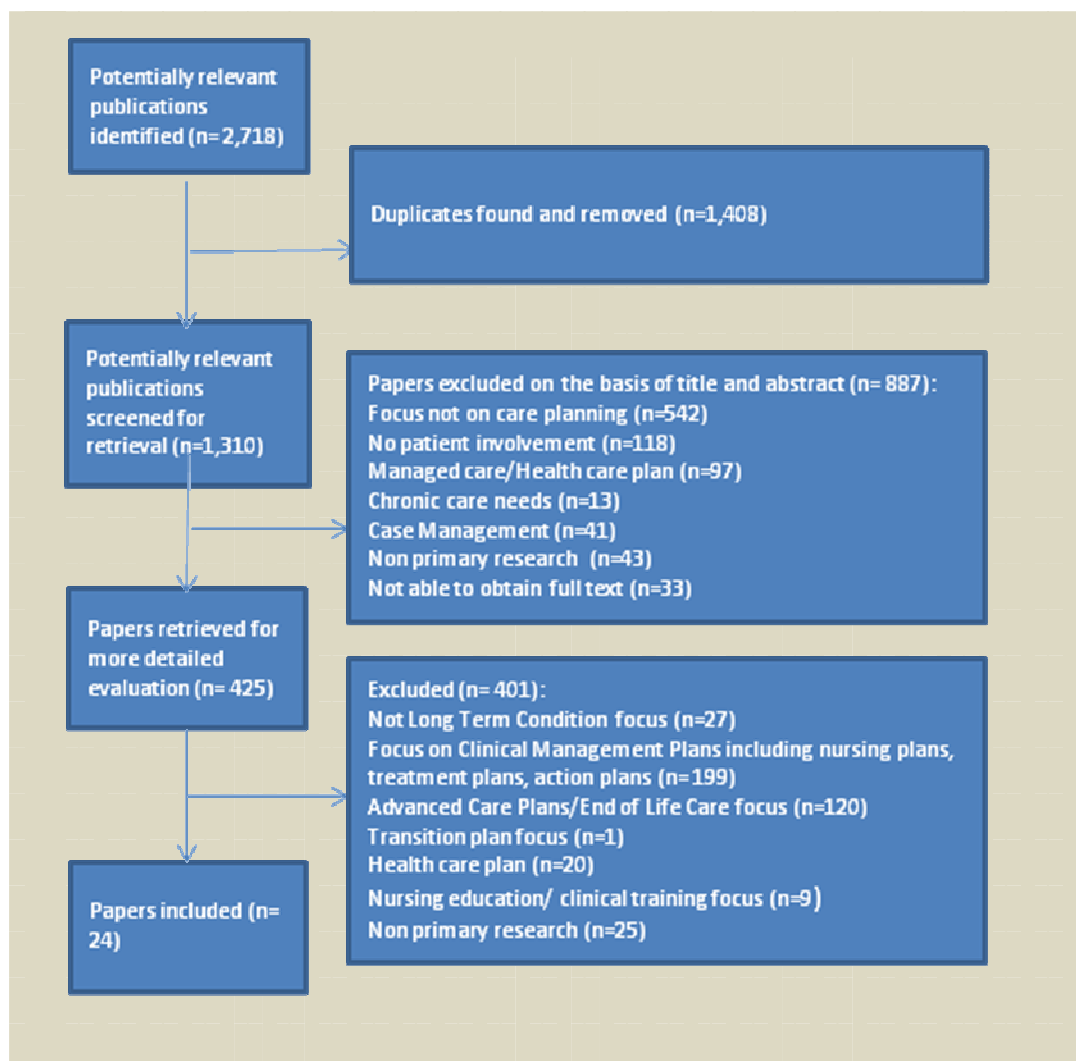
---

[1] Many thanks to staff from the Bodleian Library for their assistance in conducting the database searches.

5   Results of the review

5.1   Study Characteristics

Figure 1 shows details of exclusion and inclusion of studies. Table 1 (Appendix B) shows the characteristics of the included papers.

Fig 1 Flow diagram of Literature Review

The research strategy produced 1310 potentially relevant papers after removal of duplicates. Further analysis resulted in a total of 425 candidate studies. Many of these had to be excluded for reasons of no or unclear patient involvement in development of the care plans. For 119 of the 401 excluded studies, the focus was on advanced directives at the end of life. A total of 24 studies met all the criteria and have been included in the review. The range of topics of primary focus of studies identified in the search was wide and included decision aids, perspectives of patients/carers and healthcare staff, self care, family meetings. However, the studies included in the review did not address all of the questions posed in the review protocol. For example, the search strategy found only 22 relevant studies relating to

chronic kidney disease, all of which were focused on advanced care planning at the end of life.

Of the 24 studies included in the review, twelve were qualitative studies (29-40), four were quasi-experimental studies (41-44), one RCT (45), three surveys (46-48), two comparison studies (49,50), and two longitudinal studies (51,52).

Included studies targeted a range of conditions. Across the 22 studies, there were four different conditions targeted - stroke, diabetes, cancer and dementia. The majority of the studies focused on multiple complex or chronic illnesses. Please see Table 1 (Appendix B) for detailed information of all of the included conditions.

Five of the studies were conducted in the UK (29,37-39,50), four in USA (30,44,47,51), four in Australia (35,36,45,52), three in Canada (34,46,49), three in Norway (41-43), two in Sweden (32,33), two in Finland (40,48) and one in New Zealand (31).

5.2 Findings of the review

5.2.1 Studies that examined patient and clinician perspectives on care planning and share decision making

The perspectives of patients and clinician varied from study to study. While some studies reported the notion that patient involvement is unrealistic and impractical and of no benefit to the patients, others reported the care planning process as useful, providing opportunities for the clinician to engage with the patient. The following is a summary of the findings of five papers located, examining the perspectives of the patients and/or clinicians on the care planning process.

In order to evaluate the impact of a holistic, patient-centred, and pragmatic approach to improve the management of chronic disease in the setting of Canadian family practice, Russell et al. (34) examined the effect of external facilitators in enhancing the delivery of chronic condition care planning in primary care. A qualitative evaluation using semi-structured interviews with a purposive sample of 13 family physicians and 20 patients was conducted. They found that family physicians generally perceived the management of chronic illness from a biomedical perspective. For these physicians, the patient's problem is viewed only in biomedical disease terms without the inclusion of psychological or social issues. While some of the participating physicians welcomed the idea of care planning, the majority felt that it was not their role to complete the care plans and that the strategy was impractical within available resources. For these participants, patients were not capable of engaging in the sorts of decisions essential to collaborative care planning and so, their involvement in care planning was regarded as unrealistic.

In another study in Australia Shortus et al. (2007) (36) reported findings of a qualitative study using grounded theory methodology to explore care planning practice for people with diabetes, with particular focus on the role of collaboration. Purposely selected for this study were 19 General Practitioners (GPs), eight diabetics-related allied health professionals (AHPs), two endocrinologists, and nine adults with type-2 diabetes. The findings reveal that GPs used care plans primarily to organise clinical care or help patients access allied health providers. They also used written plans to educate patients about their care and to motivate change. These GPs viewed the care plans as clinical tools to engage patients in their care. This study also found that GPs rarely collaborated with other healthcare providers when preparing multidisciplinary care plans or use care plans to communicate specific information about patients to other providers.

Sainio et al (2001) (40) used focused group interviews with 25 cancer patients to determine how they perceive patient participation in decision-making and to see which factors in their view promote and hinder participation. The researchers used the method of qualitative content analysis to interpret the data. The results showed that the patient, nurses and physicians are all perceived to have a share in patient participation in decision-making. The results also reveal that there are three ways patients could participate in decision making, including asking questions, obtaining accurate and reliable information and choosing from given alternatives. The participants felt that providing information to patients was crucial to participation in decision-making. The information presented by the nurses or physicians should be clear and easily understandable. Most participants felt their own active involvement in asking questions and information was important in promoting participation. Other identified factors thought to promote participation in decision making include: the presence of a primary nurse/physician who is responsible for their care; the encouragement of nurses and physicians to participate; the treatment of patients as equals; and nurses and physicians having enough time for patients. Obstacles to patient participation identified include patient ignorance about their illness and treatment, the patient's physical condition, and shyness to speak up. Other nurses/physicians related factors perceived to hinder participation include the tendency for them to treat patients as objects, to fall into a routine, problems with information dissemination and lack of time.

Reporting on the patients' perspective, two studies in Australia (Shortus et al. (2005) (35) and Shortus et al. (2007) (36)) reported consistent findings which revealed that most patients did not expect to be involved in decisions about their care. Shortus et al. (2005) (35) reported that most patients did not understand the idea of care planning and felt that the process is not personally beneficial. The patients in both studies preferred to access GPs for

acute problems rather than anticipatory care, and most could not see a need for care planning.

5.2.2   Studies that examined preparing participants for care planning meeting

Two tools to facilitate access to information and prepare participants for the care planning meeting were examined in the reviewed studies, including decision aids and patient or carer held records. The studies reviewed showed that clinicians perceived decision aids to be both useful and appropriate to prepare patients for decision making. However, there were concerns that available time may be insufficient to effectively incorporate the decision aids into the consultation. Decision support systems to elicit and incorporate patient preferences into care plans improved care provision and patient outcomes. While the carer held record was found to increase sense of control, the patient held records seemed to have the opposite effect.

5.2.2.1 Decision Aids and Decision Support Systems

Graham et al. (46) conducted a cross-sectional survey of random samples of 640 Canadian physicians, including respirologists (n=255), family physicians (n=255), and geriatricians (n=130) to elicit physicians' opinions on the characteristics of the decision aid and their willingness to use it. The study aimed to evaluate three purposively selected decision aids representing a range of decisions made in primary and tertiary care and to represent a spectrum of decisions, including lifestyle and end-of-life decisions, faced by both patients and carers. A follow up of physicians who indicated a strong likelihood of using the decision aid was done three months after the study, to find out their actual use of the decision aid. The findings of Graham et al. (46) revealed that more than 85% of the respondents felt the decision aid was well developed and that it provided understandable, balanced, and unbiased information for decision making. The findings also showed that a majority of respondents (>80%) felt that the decision aid was suitable in preparing patients to participate in decision making and to reach a decision. Fewer physicians (<60%) felt the decision aid would improve the quality of patient visits or be easily implemented into practice; and very few (27%) felt that the decision aid would save time. The study also showed that physicians' intentions to use the decision aid were related to their comfort with offering it to patients, the decision aid topic, and the perceived ease of implementing it into practice. While 54% of the surveyed physicians indicated they would use the decision aid, less than a third followed through with this intention.

Burges et al (2008) (39) considered health care practitioners' perceptions and use of patient decision aids in routine clinical practice. Participants from five general practice surgeries in northern England took part in focus group sessions around the themes of patient decision aids, patient and practitioner preferences and shared decision making (SDM). Participants

included general practitioners (n = 19), practice nurses (n = 5) and auxiliary staff (n = 3). The focus group sessions were recorded and transcripts were analysed using the framework approach. The study found that participants in those practices predisposed to a patient-centred approach and SDM were more likely to talk positively about using patient decision aids even when acknowledging the difficulties. In contrast, participants from more practitioner centred practices were less enthusiastic and more ready to explain and justify their lack of use of patient decision aids and other SDM practices. A perception that patient decision aids were not designed with 'real life' consultation pressures in mind was echoed across the practices, with the length of the consultation viewed as too short to effectively incorporate a the decision aid.

Ruland (1999) (41) presented the results of a quasi experimental study to evaluate the use of a paper-based decision support system to support clinicians in eliciting and integrating patient preferences into clinical practice. The sample consisted of 151 participants in a three-group study with one experimental and two control groups. In the experimental group computer-processed information about individual patient's preferences was placed in patients' charts to be used for care planning. The evaluation focused on the effects of knowledge of patient preferences on nurses' care priorities. It was found that knowledge of patients' preferences changed nurses' care priorities to be more consistent with patient preferences and improved patient preference achievement and physical functioning. The study concluded that decision support for eliciting patient preferences and incorporating them in nursing care planning is an effective and feasible strategy for improving nursing care and patient outcomes. The author built on the findings of this paper-based system with the development and evaluation of a computer-based system with similar results (42,43). Ruland (2002) (43) found that the nurses' use of the system made nursing care more consistent with patient preferences ($F=11.4; P<0.001$) and improved patients' preference achievement ($F=4.9; P<0.05$).

Another study (44) tested the effects of providing case managers with tools to assess and respond to client values and preferences on their subsequent knowledge of client's values and their practices in arranging long-term care. Kane et al. (44) adopted a quasi-experimental design involving 301 participants (158 in experimental group and 143 in control group); each group included case managers, clients and care plans. The patients in the experimental group were asked to complete a values assessment instrument designed to elicit patient values and preferences, which was then shared with the case managers in the experimental group. The results show that experimental clients were significantly more likely to report that case managers had asked them about their own preferences, offered them choice about services, and that the care plans would have taken into account their preferences regarding the type, amount and timing of services. The experimental case

managers were slightly more accurate judges of client responses to value questions at three-month follow-up. At follow-up, experimental case managers reported more case activity tailoring plans to client preferences. Furthermore, some case managers indicated that the experiment helped them focus on client preferences as distinct from that of family members, and also helped them to talk about preferences as distinct from needs and to recognise when client preferences and professionally determined needs are in conflict.

5.2.2.2 Patient-Carer Held Records

To evaluate whether a patient-held record (PHR) would result in greater patient satisfaction and better care planning for stroke patients, Ayana et al. (50) carried out a controlled comparison study with a control-intervention-control time series design among London teaching hospital general medical and geriatric medicine inpatient wards. All stroke patients admitted to the wards during the intervention phase received a PHR and were instructed in its use. The paper found that PHR group patients were more satisfied with the recovery they had made (79% vs. 59%, p=0.04), but felt less able to talk to staff about their problems (61% vs. 82%, p=0.02). PHR group patients also reported receiving fewer explanations about their condition (18% vs. 33%, p=0.12) and treatment (26% vs. 45%, p=0.07), and were more afraid of asking doctors questions (21% vs. 4%, p=0.01) than controls. PHR group patients were no better prepared for hospital discharge than control group patients, and both groups were ill-informed about services and benefits that might have helped after discharge from hospital.

In a pilot study (38) 20 carers of patients with dementia were given carer-held records to hold at home for a six-month period with the aim of assessing carers' roles as partners with professionals in care planning via use of the record. Both quantitative and qualitative data were obtained by use of a questionnaire that used quantitative scales of measurement and allowed carers to express views. Reporting the findings of this study, Simpson (38) showed that carers were happy with the system and reported that they felt more empowered and valued by service providers because of use of the documentation. Eight out of 12 respondents indicated that there was a considerable increase in their ability to be assertive about their views on the care planning and evaluation of care plans.

5.2.3   Studies that examined forum for decision making

Several studies examined the process of communication and decision making, focusing on patient-physician communication and goal setting, and family meetings. The studies reviewed here show that inadequate information provision was the most frequent source of patient and carer dissatisfaction. The process of goal setting is full of risks of disagreements and requires effective and open communication of goals of care to ensure adequate care planning. Satisfactory family meetings require adequate provision of information pre-

meeting, clear purpose/agenda, sufficient time for patients and family members to consider options, and adequate follow-up after the meeting.

5.2.3.1 Patient-Physician Communication and Goal Setting

Bradley et al. (30) explored the process of goals setting for medical care in the context of chronic disease with the aim of developing a theory of goal setting that is applicable to clinical medicine. The authors found that the process of goal setting is complex and full of risks for disagreements, particularly where there are conflicting goals or varying weighting of goals between the patient, family and clinician. The findings suggest that the characteristics of the individual, the disease, and the interactions of patients, families, and clinicians are central components in the goal-setting process. Individual characteristics include their degree of risk-taking, perceived self-efficacy, and acceptance of the disease. Disease characteristics include the urgency and irreversibility of the medical condition, and characteristics of the patient-family-clinician interaction include the level of participation, control, and trust among patients, family members, and clinicians. Furthermore, the authors argued that explicit discussion of goals for care may be necessary to promote effective communication between the patient, family and clinician, and also to ensure adequate care planning.

Another study to examine the performance of an expanded menu of goals in a geriatric rehabilitation setting found that patients and families have a broad range of goals that are not always identified by the healthcare team (49). This prospective comparative study involved 19 in-patients and their family members and seven unit team members individually reviewing a standardized menu of medical, functional, psychosocial, spiritual, and future planning goals which were compared with the goals set by the healthcare team. Glazier et al. (49) revealed that agreement between patients, family members, and the healthcare team ranged from 28% to 72%. When chance agreement was taken into account, the level of agreement was poor. For medical, functional, and psychosocial goals, patients were more often in accord with the healthcare team than with family members. The lowest concordance was found for future planning between the family and team members.

5.2.3.2 Family Meetings/Conferences

Griffith et al. (31) explored the opinions and experiences of staff, patients and families in family meetings to determine how to improve the quality of this important rehabilitation tool in a tertiary teaching geriatric rehabilitation hospital. This qualitative study used staff focus groups, written family surveys and individual semi-structured interviews of 16 patients who just completed a family meeting within the previous 48 hours. Emerging themes from the staff focus groups revealed that there were concerns and disagreements regarding how better preparation for the meetings might be achieved, the most appropriate person to

facilitate the meetings, and how to deal with patient and family reactions after the meetings, particularly when these were perceived as negative. Findings from family member's surveys suggested a high level of satisfaction with the information conveyed in the meetings as well as the manner in which the information was conveyed. The patient interviews revealed a worrying lack of adequate informed consent to participate in the family meeting. Six of 16 (37.5%) reported they had not been informed the meeting was taking place; three stated they had not wanted a family meeting. Twelve (75%) reported they had not been asked who they would like to be present. In addition, the patients identified a diversity of aims for the meeting, including; resolving inconsistencies, updating, educating and informing, and/or reviewing care options. For all three groups of participants, an unclear agenda was identified as the underlying reason for unsatisfactory meetings. The findings also revealed that an unfavourable outcome decision (such as placement in institutional care) also influenced patient opinions on the process.

Hansen et al. (47) discussed the complexities of family conferences as a forum for decision making from the perspective of social workers. These meetings where the patient, family members and hospital personnel meet together to exchange information about the patient's condition and to plan for the future, include three phases; preparation, the conference meeting, and follow up. The setting for this exploratory study was an acute rehabilitation teaching hospital where 13 social workers were surveyed. The findings suggest that over all, conferences achieve the desired outcomes for hospital staff. The most commonly identified purposes for the conference were to provide family members with information (92%) and to facilitate collective decision making about the patient's future care (85%). The study reported very high frequency of disagreements between family members and hospital staff (50%) and relatively fewer disagreements between patients and hospital staff (27%). However, some degree of resolution was achieved in more than 60% of the instances of disagreements with some degree of clarification achieved in many cases where resolution was not possible. The one hour duration of the conferences was also perceived to be inadequate to achieve the multiplicity of objectives for the different participants, and for the patient and family to adequately consider the options.

Hedberg et al. (32) reported the findings of an exploratory study to describe how nurses act as moderators of the communication in cooperative care-planning meetings for stroke patients with communicative disabilities. Thirteen purposely and consecutively sampled care-planning meetings were audio-recorded and transcribed with nurses, social workers and stroke survivors as the main participants. The findings reveal that the patient's own perspective of their illness or care planning was not sought by the nurses in the meetings. Also, the nurses mostly suggested opinions or asked the patient to confirm or select an option given by the nurse. The nurses were found to act as the patients' advocates by talking

for or about them and rarely supported the patients' utterances thereby inadvertently excluding the patients from the conversation. This study throws light on the need for professionals involved in care planning meetings to adapt their communication style to a level that can facilitate the patient's participation. The authors argued that assessment of the patient's communicative abilities before the care-planning meetings as well as knowledge about how to invite them can improve the patient's participant status.

Another study which focused on exploring ways to facilitate carers' involvement in decision making (37) revealed that carers perceived the family meetings as formal opportunities for carers and staff to share information about the patient and, for the majority of carers, their only opportunity to discuss current and future care needs with the multidisciplinary team. The carers however felt that in reality, the meetings were dominated by the agenda of the professionals, which often left them feeling disempowered and undervalued. Generally, they felt that decisions had already been made without them, that they could not raise issues they wanted to discuss and that the professionals wanted the meeting over with as quickly as possible. Another issue raised by the carers was the interruption of meetings by pagers and by people leaving to make phone calls, which suggest to carers that professionals' minds are elsewhere. Furthermore, there was no follow-up check made to ensure that the carer felt satisfied with the outcome of the meeting as often, they only thought of what they wanted to say once they had left the room.

5.2.4   Studies that examined experience of participation in decision making

The experiences of patients and carers in participating in care planning decision making was explored by several studies. There was general agreement among the studies that participation in decision making leads to greater satisfaction with care received. Patients and carers feel encouraged to participate when they have good relationship with the staff and feel treated as equals. The findings from seven papers located have been summarised below.

Ramfelt and Lutzen (33) explored the experiences of participation in treatment planning decisions from the perspective of 10 purposely selected patients recently treated for colorectal cancer in their study using grounded theory methodology. The concept of 'compliant participation in serious decisions' emerged from their findings. This was composed of the two variations: complying with participation; and complying without participation. Complying with participation was characterized by feelings of self confidence and self-competence and by open dialogues between the participants, their family, and the physician. Complying without participation was characterized by participants' feelings of uncertainty and distress, and of being rushed into submitting to decisions without having time to reflect on the information provided or the opportunity to influence the treatment and

care process. The study found that participation helped the individuals to preserve self-control.

In order to identify the extent to which cancer patients participate in decision-making, and also to assess the impact of background characteristics, information obtained and relationships with staff on cancer patients' participation in decision-making, Sainio (2003) (48) carried out a survey using a structured questionnaire. A sample of 273 cancer patients at two university hospitals in Finland took part. The findings revealed that the extent to which patients participated in decisions was not as high as they felt the importance of that participation to be. The majority of the respondents (70%) were of the opinion that they had made their decisions at least to some extent, together with the physician. However, almost half (49%) were not even aware that they had different alternatives in treatment, and a further 60% had not been allowed to make any choice between such alternatives. Around 20% of the respondents felt that staff had not encouraged them to take part in decision-making, had not given them the opportunity to express their views and opinions, and had not taken notice of their wishes. The results revealed that the health care staff play a crucial role in patients' participation in decision making as the amount and extent of information received was found to correlate strongly with patient's participation. Relationships with staff were also found to correlate with decision-making. When respondents felt that they had a good relationship with staff members, they participated more in decisions about treatment and nursing care than when they felt the relationship was not so good.

Abbott et al. (29) carried out semi-structured interviews with 99 continuing health care patients and/or their carers to examine patients' and carers' experiences of receiving community health services, and consider the degree of patients' participation in the management of their continuing care. The paper found that only a handful of informants felt able to and willingly took an active role in their own care. Usually, these were either patients who did not suffer from very disabling conditions, or younger adults with severe and long-term disabilities. A few others reported participation in planning their care, or benefiting from ongoing, regular contact with the care professional responsible for the continuing coordination of their care arrangements. The majority of patients did not take an active role in arranging and coordinating their care. These were not satisfied with the care they received, feeling unclear about how their needs had been assessed and how services had been arranged. Some had felt compelled to become proactive in order to ensure that the care provided was adequate. These also reported not having had a copy of a care plan and were unaware of a designated care manager. They were mostly disappointed by the absence of timely and adequate information about their condition and about available services and resources, and by the lack of regular contact with a care manager

Arora et al. (51) reported the findings of a four-year observational study of 2,197 patients with chronic disease to identify the determinants of patient preferences for participation in medical decision making. Multivariate logistic regression models were used to estimate the effects of patients' socio-demographic, clinical, psychosocial, and lifestyle characteristics on their decision-making preferences. The results showed that majority of the patients (69%) preferred to leave their medical decisions to their physicians. The odds for preferring an active role significantly decreased with age and increased with education. Women were more likely to be active than men (odds ratio [OR] = 1.44, $P < 0.001$). Compared with patients who only suffered with un-severe hypertension, those with severe diabetes (OR = 0.62, $P = 0.04$) and un-severe heart disease (OR = 0.45, $P = 0.02$) were less likely to prefer an active role. Patients with clinical depression were more likely to be active (OR = 1.64, $P = 0.01$). Patients pursuing active coping strategies had higher odds for an active role than "passive" copers, while those who placed higher value on their health were less likely to be active than those with low health value (OR = 0.59, $P < 0.001$). The authors concluded that although a majority of patients prefer to delegate decision making to physicians, preferences vary significantly by patient characteristics. Approaches to enhancing patient involvement will need to be flexible and accommodating to individual preferences in order to maximize the benefits of patient participation on health outcomes.

Shortus et al. (2005) (35) reported the findings of a qualitative study of adult patients with chronic illnesses to examine their experiences of chronic illness, their usage of healthcare and difficulties with healthcare. Sixteen patients were interviewed and five participated in focus group. The study found that majority of the patients who understood the idea of care planning did not believe they would personally benefit from it. A follow-on study by the same authors in 2007 (36) reported the findings of a study aiming to understand how multidisciplinary care plans are being used in the management of patients with diabetes using grounded theory interview methodology in a primary care setting in Australia. There were 38 participants included in the study (19 GPs, eight Allied Health Professionals, two endocrinologists and nine patients with type 2 Diabetes). The results of this study, which drew on the perspectives of participants regarding the purpose of care planning as well as collaboration in care planning, indicated that patients do not expect to be involved in decisions about their care plan. One reason noted for this is that the patients perceived the care plan as a document of clinical goals and activities about which they had no expertise.

Another study focused on carer experiences (37). This study adopted a qualitative case study design to explore the extent to which carers are involved in care planning decision making, and to identify practical, realistic ways of facilitating their involvement in decision making. Data were collected in a respite and assessment (23 bedded) ward within the Psychiatric Unit of a hospital specializing in the care of older people. It consisted of

interviews with informal carers (n=20), members of the multidisciplinary team (n=29) and observations of family meetings, multidisciplinary team meetings and ward routines. Field notes from these observations, together with the interview data were analysed using constant comparative method. The findings of this study reveal that majority of carers felt dissatisfied with the level of their involvement in decision making. Two main barriers to carer's involvement identified were the hospital systems and processes, and the relationship between nursing staff and carers. The carers perceived that markers of satisfactory involvement include feeling that: (a) information is shared; (b) they are included in decision making; (c) there is someone they can contact when they need to; and (d) the service is responsive to their needs.

5.2.5 Studies that examined impact of self care support within the care planning process on patient outcomes

A body of literature examining the effectiveness of self management education programmes on patient outcomes have produced mixed findings (53-59). The papers summarised here examine the impact of self care support within the care planning process, showing that this leads to better understanding of illness and improvement in the patients' ability to manage their symptoms.

Harvey et al. (52) reported a longitudinal demonstration project to explore the effect of improved service access in conjunction with self management support for patients with chronic and complex health conditions. The project was conducted in three separate sites in which patients with complex chronic conditions were recruited through the general practitioner-led Enhanced Primary Care (EPC) care planning process. A total of 175 participants were enrolled into an intervention group following assessments with a modified Stanford Health Assessment tool and the Partners in Health (PIH) scale. Patient self reported data and health providers' score for patients were collected at enrolment and at six-month intervals using the same PIH scale, in order to assess changes in health status, service access and levels of self management skill and ability. In their final report of the chronic disease self management study, Harvey et al. (52) concluded that involvement in peer led self management education programs has a positive effect on patient self-management skill, confidence and health-related behaviour. Mean patient self-reported PIH scores and mean health provider PIH scores for patients improved significantly over time indicating that patients' understanding of their condition, as well as their ability to manage and deal with their symptoms, improved.

Battersby et al. (45) tested whether coordinated care would improve health outcomes at the cost of usual care by comparing a generic model of coordinated care with the usual care. 4,603 participants were randomly allocated to intervention group (n = 3115) or control group

(n = 1488). Patients in the intervention group were provided care planning and care coordinators. Outcome measures were assessed in both intervention and control groups using the Self-assessed health status (the SF-36) which was used as a generic measure of self-reported health and well-being; and the Work and Social Adjustment Scale (WSAS), which was used as a measure of disabilities and handicaps. Further, enrolled patients consented to having their service use tracked for the two years before their enrolment and for the duration of the trial. The SF-36 in the intervention group showed significant improvements relative to the control group. The results also revealed that patients who had been hospitalized in the year immediately preceding the trial were the most likely to save on costs. A mid-trial review showed that health benefits from coordinated care depended more on patients' self-management than the severity of their illness. These results led to the development of the Flinders Model of Self- Management Support (45).

6   Discussion

6.1   Statement of principal findings

Shared decision making requires the patient's participation in decision making about their own health and health care. The aim is to make a decision that is informed by the best available scientific evidence and consistent with patients' views on what is most important to them (8). In order to achieve this, staff involved in patients care meet with the patients to discuss the health related reasonable options, benefits and risks, while the patients bring information about what is most important and practical for them in their situation (8). For such discussions to be effective, studies reviewed here showed that open communication between the patient and health care staff is beneficial. Explicit discussions of goals for care are perceived as necessary to promote effective communication and ensure adequate care planning.

Evidence suggests that patients' preference for involvement in the treatment decisions varies (60,61). Some patients feel they lack the knowledge and experience to make the right choice and would therefore not want to be involved in the decision making process. According to Bowling (60), those who do not want to be involved are likely to represent significant subgroups of the population, such as older people and those with fewer educational qualifications who lack the experience of social inclusion and participation. However, the literature reviewed here suggests that most patients want doctors to understand their preferences even if they do not wish to make the final decision. The studies looking at patient involvement in decision making showed that participation of patients in decision making requires self confidence, a perception that dialogue will be open, and not feeling rushed to a decision. The patient's diagnosis and characteristics of the disease were also shown to have some influence on patient's willingness to participate in decision making. This review reports a positive correlation between patient participation in decision making and satisfaction with care received. Other studies have reported that patients who have been involved in decisions about their health and health care are likely to experience increased satisfaction with their decision, increased quality of life, decreased levels of anxiety and depression, increased feelings of control over their illness, and increased self-efficacy (King, 1998, 2000; Marron et al., 2005 reported in (8)).

Family meetings or patient/family conferences provide opportunities for the patient, family or carer and the health care professionals to make decisions about the patient care. These meetings aim to facilitate open discussion between the participants (health care professional, patient, and family members). The studies reviewed here suggest that other participants feel the healthcare professionals benefit most from these meetings. Findings

relating to the satisfaction of family members with the conduct and outcomes of these meetings were mixed; while some studies reported family members' satisfaction with the information provided in the meetings and the way the information was conveyed, other studies found that family members were dissatisfied with the whole process. This review also found that patient dissatisfaction in family meetings can be attributed to poor preparation for the meetings, unclear goals, and a feeling that the healthcare professionals set the agenda, dictate the meetings and make the decisions without necessarily soliciting their opinions/preferences. For these patients, participation in the meetings may not necessarily influence the outcomes. Such patients usually felt undervalued and are therefore less likely to comply with the decisions. The studies reviewed highlighted the risk of patients feeling that they cannot influence the decisions, and/or lack the expertise to make such decisions. From the carer's perspective, satisfactory involvement in care planning decision making will require a strong sense of inclusion in the decision making process, and a perception that information is shared openly. In addition, carers need to feel that there is someone they can contact when they need to, and that the service is responsive to their needs.

Multiple treatment options are often available for the patient with a long term condition, with each having different benefits and risks. Patients may therefore feel uncertain about which option to choose against the backdrop of their goals and values. Findings of this review suggest that patients and family have a broad range of goals which are not always identified by the health care team. Several papers in this review showed that reaching decisions is not always simple as there is risk of disagreements between participants. However, there were consistent findings suggesting that agreements are more likely to be reached between the patients and the healthcare team than between the patients and family or family and healthcare team.

Patients may feel unable to make decisions regarding their care, and may therefore need some help in understanding the right course of action when two or more reasonable options have benefits and harms which they may value differently (8). Decision aids are designed to support patients in the decision making process and ensure the patient gets the care that best fits their preferences and also meet their needs. A greater understanding of patients' preferences for care is central to current models of shared patient-doctor decision making and will potentially enhance the patient's adherence to treatment (60). The intention for using a patient decision aid is to supplement rather than replace patient-practitioner interaction (62) (46). The papers reviewed here showed consensus amongst health professionals that decision aids are useful tools in preparing patients for decision making. The studies also demonstrated that decision support systems that help health care professionals to elicit patient preferences and incorporate them into their care plan helped to improve patient care experience and health outcomes.

This review reported one study which examined the use of patient held records to prepare patients and found it to be detrimental to patient participation in care planning. However, the results of this non-randomised comparison study of stroke patients must be viewed with some caution. Explaining the result, the author suggested the likelihood that the participants may have been too ill to make use of the patient held record. In contrast, another study focusing on carer held records found this to be beneficial as it improved carer satisfaction, preparedness and participation in the care planning meeting. Carers also felt empowered and valued by the system.

Patients often require information to help them make decisions about their lifestyle and how to manage their condition. This review showed that timely and adequate access to information is necessary to helping patients make the right decisions and participate effectively in their own care. According to (8), meeting patients' information needs is an important part of helping patients to plan and manage their self-care. Self care allows patients to take responsibility for their own health and wellbeing, with support from the professionals involved in their care (25). Self care is enhanced by collaborative goal setting which relies upon an understanding of patient's needs and preferences (36). The studies reported in this review showed that involving in care planning improved patients' ability to self care, and also, improved patients' overall health outcome. A literature review (54) reported evidence from controlled trials which suggests that teaching self-management skills is effective in improving clinical outcomes and have been shown to reduce costs for arthritis and for adult asthma patients. Bodenheimer et al. (54) concluded that self-management education for chronic illness may soon become an integral part of high-quality primary care.

6.2 Implications of findings

This review has shown that this is a topic of great interest to policy makers, patients and their family/carers, and healthcare professionals. However, the growing body of knowledge and expertise in the care planning process can now better inform the focus of this interest and future research questions. This review offers an opportunity to gain greater understanding of how the care planning process can be most effective to achieve its desired outcomes for all concerned.

While this review acknowledges the large body of interest in this topic in both the academic and grey literature, it was rather surprising that no relevant primary study on care planning in chronic kidney disease was identified for inclusion. Studies have described some effects of socio-demographic and educational characteristics on patient preferences for participation in health care decision making which may have some implications for care of CKD patients given their age, socio-economic and ethnic distribution. Further work around the preferences

of CKD patients to be active in decision making about their care could be illuminating. More work is also needed to explore the experiences and views of culturally and linguistically diverse people regarding decision making about their treatment. In addition, work is needed to understand what to do if patients don't want to be engaged, and how to address the challenges of individuals who prefer not to get involved in decision making but then don't adhere to decisions made. For instance, will longer term efforts to inverse involvement change participation?

6.3 Limitations of review

This review draws on a range of studies that previously set out to examine the experiences, perspectives and preferences of participants in the care planning process using a number of different methodological approaches. Several limitations have been identified in the conduct of this review. Firstly, it is possible that the literature search is not sufficiently specific to identify relevant literature, even though a comprehensive search strategy was used. It is also possible that inappropriate inclusion or exclusion of a study may have occurred, given the complexity of possible sources, terminology and descriptions of interventions. The fact that only English language publications were considered may have also excluded some potentially relevant studies. Every attempt was made to obtain full text of all the articles identified as relevant; however, it was not possible to obtain a few articles and so, such were inadvertently excluded from this review.

Secondly, article selection and analysis was done by a single researcher; hence the subjective interpretation of narrative data may have being biased by the author's own perceptions. The interventions and outcomes of the included studies in this review are heterogeneous, and therefore the review presents the findings in narrative form only. The number of papers reviewed within the identified themes are, in some cases, too few to provide a body of evidence.

Despite these limitations this review helps in developing an understanding of what factors are important in influencing patients' involvement in the decision making about their health care. This has become particularly important as health professionals try to better understand how the care planning process can be most effective to achieve desired outcomes. Considering that the subject and literature are very heterogeneous, no single review is able to encompass the entire issue and literature. This means that a very different direction and piece has been produced here which should be considered alongside other similar reviews.

7 Conclusions

This review has examined the evidence relating to the experiences of patients and healthcare professionals in the care planning process in order to determine factors that influence successful development of a care plan. This review has established the following conclusions:

- Patients feel involved in their care when they are treated as equal partners, listened to and properly informed. Patients need to be reassured that dialogue will be open. Explicit discussions of goals for care are perceived as necessary to promote effective communication and ensure adequate care planning.

- It is crucial that the opinions/preferences of the patients/carers are solicited before any decisions are made. Patients should not be rushed to a decision. Sufficient time is needed for patients to consider their options.

- The extent to which patients want to take responsibility for decision making varies. Nevertheless, most patients want doctors to understand their preferences even if they do not wish to make the final decision. Decisions should be made with, and not for, the patients.

- Adequate preparation needs to be made for the care planning meetings. The goals of the meeting need to be clear and an agenda should be set in conjunction with the patients and/or carers.

- Patients/carers need to feel that there is someone they can contact when they need to, and that the service is responsive to their needs. Patients feel encouraged to participate when they trust the health care staff.

- Effective communication and information provision are very important in the professional-patient relationship. Everyone who is involved in the patient's care need to take an active role to encourage patient participation.

8   References

(1) Department of Health, Farrell C. Patient and public involvement in health: The evidence for policy implementation. 2004. [Online] Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4082332 Accessed 23 March 2011

(2) Social Care Institute for Excellence. Involving individual older patients and their carers in the discharge process from acute to community care: implications for intermediate care. 2005; [Online] Available at: http://www.scie.org.uk/publications/briefings/briefing12/index.asp. Accessed 23 August, 2010.

(3) Skills for Care. Common core principles to support self care: a guide to support implementation. 2008; [Online] Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_084506.pdf. Accessed August 23, 2010.

(4) Diabetes UK, NHS National Diabetes Support Team, Department of Health, Health Foundation. Getting to grips with the year of care: a practical guide. 2008. [Online] Available at: http://www.diabetes.org.uk/Professionals/Service-improvement/Year-of-Care/The-Year-of-Care-concept/Year-of-Care---care-planning/ Accessed 23 March 2011

(5) National Diabetes Support Team. Partners in Care: A guide to implementing a care planning approach to diabetes care. 2008. [Online] Available at: http://www.diabetes.nhs.uk/document.php?o=75   Accessed 23 March 2011

(6) Department of Health. Our Health, Our Care, Our Say. 2006. [Online] Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127602 Accessed 23 March 2011

(7) Ellins J, Coulter A, Picker Institute Europe. How engaged are people in their health care? Findings of a national telephone survey. 2005. [Online] Available at: http://www.pickereurope.org/Filestore/PIE_reports/project_reports/Patient-Activation-Survey.pdf Accessed 23 March 2011

(8) Registered Nurses' Association of Ontario.
Decision support for adults living with chronic kidney disease , Clinical best practice guideline. 2009. [Online] Available at: http://www.guideline.gov/content.aspx?id=15611 Accessed 23 March 2011

(9) Department of Health. Supporting people with long-term conditions to self care. A guide to developing local strategies and good practice. 2006. [Online] Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_4130868.pdf Accessed 25 March 2011

(10) Department of Health. Self Care – A Real Choice; Self Care Support – A Practical Option. 2005 [Online] Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_4101702.pdf Accessed 25 March 2011

(11) Department of Health. Supporting People with Long term Conditions. 2005. [Online] Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_4122574.pdf Accessed 25 March 2011

(12) Matrix Research and Consultancy. Good Care Planning for People with Long Term Conditions. 2005. [Online]. Available at http://www.matrixknowledge.com/wp-content/uploads/careplanningreportsep05.pdf Accessed 25 March

(13) Department of Health. Impact assessment for implementing personalised care planning for people with long term conditions (including guidance to NHS and Social Care). 2008; Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_098503.pdf. Accessed August 18, 2010.

(14) Lee TT, Chang PC. Standardized care plans: experiences of nurses in Taiwan. J Clin Nurs 2004;13(1):33-40. Pubmed Link

(15) Lee TT. Nurses' perceptions of their documentation experiences in a computerized nursing care planning system. J Clin Nurs 2006;15(11):1376-82. Pubmed Link

(16) Graffy J, Eaton S, Sturt J, Chadwick P. Personalized care planning for diabetes: policy lessons from systematic reviews of consultation and self-management interventions. Primary Health Care Research and Development 2009;10(03):210-222. Link to abstract

(17) Department of Health and Diabetes UK Care Planning Working Group.
Care Planning in Diabetes. 2006. [Online]. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_064572.pdf Accessed 25 March 2011

(18) Department of Health/Long Term Conditions.
Supporting People with Long Term Conditions: Commissioning Personalised Care Planning. 2009. [Online]. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_0 93360.pdf Accessed 25 March 2011

(19) Wood J. Supporting vulnerable adults. Practice Nursing 2009;20(10):511-516. No link available.

(20) Department of Health. High quality care for all: NHS Next Stage Review final report. 2008. [Online]. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_085828.pdf Accessed 25 March 2011

(21) Department of Health. Supporting people with long term conditions: commissioning personalised care planning - a guide for commissioners. 2009. [Online] Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_0 93360.pdf Accessed 25 March 2011

(22) Department of Health. Your health, your way – a guide to long term conditions and self care. 2009. [Online]. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_1 09467.pdf Accessed 25 March 2011

(23) Department of Health. National Service Framework for Renal Services: Part One - Dialysis and transplantation. UK. 2004;34134. [Online] Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digital asset/dh_4137331.pdf Accessed 25 March 2011

(24) Walker M. Adopting year of care planning. Practice Nursing 2009;20(11):571-575. No link available.

(25) Beasley C. Supported self care and care planning for patients with long-term conditions. Br J Community Nurs 2009;14(9):394-7. Pubmed Link

(26) Department of Health. Equity and excellence: Liberating the NHS. . 2010. [Online]. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf Accessed 25 March 2011

(27) Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44:681-692. Pubmed Link

(28) NHS Centre for Reviews and Dissemination.
Undertaking Systematic Reviews of Research on Effectiveness 2001;4. [Online] . Available at http://www.medepi.net/meta/guidelines/Overview_CRD_Guidelines.pdf Accessed 25 March 2011

(29) Abbott S, Johnson L, Lewis H. Participation in arranging continuing health care packages: experiences and aspirations of service users. J Nurs Manag 2001;9(2):79-85. Pubmed Link

(30) Bradley EH, Bogardus S,Jr, Tinetti ME, Inouye SK. Goal-setting in clinical medicine. Soc Sci Med 1999;49(2):267-78. Pubmed Link

(31) Griffith JC, Brosnan M, Lacey K, Keeling S, Wilkinson TJ. Family meetings--a qualitative exploration of improving care planning with older people and their families. Age & Ageing 2004;33(6):577-81. Pubmed Link

(32) Hedberg B, Cederborg AC, Johanson M. Care-planning meetings with stroke survivors: nurses as moderators of the communication. J Nurs Manag 2007;15(2):214-21. Pubmed Link

(33) Ramfelt E, Lutzen K. Patients with cancer: their approaches to participation in treatment plan decisions. Nurs Ethics 2005;12(2):143-55. Pubmed Link

(34) Russell G, Thille P, Hogg W, Lemelin J. Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada. Annals of Family Medicine 2008;6(2):146-53. Pubmed Link

(35) Shortus T, Rose V, Comino E, Zwar N. Patients' views on chronic illness and its care in general practice. Aust Fam Physician 2005;34(5):397-9. Pubmed Link

(36) Shortus T.D., McKenzie S.H., Kemp L.A., Proudfoot J.G., Harris M.F. Multidisciplinary care plans for diabetes: How are they used? Med J Aust 2007;187(2):78-81. Pubmed Link

(37) Walker E., Dewar B.J. How do we facilitate carers' involvement in decision making? J Adv Nurs 2001;34(3):329-337. Pubmed Link

(38) Simpson RG. Carers as equal partners in care planning. Journal of Psychiatric & Mental Health Nursing 1997;4(5):345-54. Pubmed Link

(39) Burges Watson D, Thomson R, Murtagh M. Professional centred shared decision making: Patient decision aids in practice in primary care. BMC Health Services Research 2008;8(1):5. Pubmed Link

(40) Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care. Cancer Nursing 2001;24(3):172-179. Pubmed Link

(41) Ruland CM. Decision support for patient preference-based care planning: effects on nursing care and patient outcomes. Journal of the American Medical Informatics Association 1999;6(4):304-12. Pubmed Link

(42) Ruland CM. Clinicians' use of a palm-top based system to elicit patient preferences at the bedside: a feasible technique to improve patient outcomes. Proceedings / AMIA Annual Symposium 2000:739-43. Pubmed Link

(43) Ruland CM. Handheld technology to improve patient care: evaluating a support system for preference-based care planning at the bedside. Journal of the American Medical Informatics Association 2002;9(2):192-201. Pubmed Link

(44) Kane RA, Degenholtz HB, Kane RL. Adding values: an experiment in systematic attention to values and preferences of community long-term care clients. Journals of Gerontology Series B-Psychological Sciences & Social Sciences 1999;54(2):S109-19. Pubmed Link

(45) Battersby M, Harvey P, Mills PD, Kalucy E, Pols RG, Frith PA, et al. SA HealthPlus: a controlled trial of a statewide application of a generic model of chronic illness care. Milbank Q 2007;85(1):37-67. Pubmed Link

(46) Graham I, Logan J, Bennett C, Presseau J, O'Connor A, Mitchell S, et al. Physicians' intentions and use of three patient decision aids. BMC Medical Informatics and Decision Making 2007;7(1):20. Pubmed Link

(47) Hansen P, Cornish P, Kayser K. Family conferences as forums for decision making in hospital settings. Soc Work Health Care 1998;27(3):57-74. Pubmed Link

(48) Sainio C, Lauri S. Cancer patients' decision-making regarding treatment and nursing care. J Adv Nurs 2003;41(3):250-260. Pubmed Link

(49) Glazier SR, Schuman J, Keltz E, Vally A, Glazier RH. Taking the next steps in goal ascertainment: a prospective study of patient, team, and family perspectives using a comprehensive standardized menu in a geriatric assessment and treatment unit. J Am Geriatr Soc 2004;52(2):284-290. Pubmed Link

(50) Ayana M, Pound P, Lampe F, Ebrahim S. Improving stroke patients' care: a patient held record is not enough. BMC Health Services Research 2001;1(1). Pubmed Link

(51) Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? Med Care 2000;38:335-341. Pubmed Link

(52) Harvey PW, Petkov JN, Misan G, Fuller J, Battersby MW, Cayetano TN, et al. Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes. Australian Health Review 2008;32(2):330-339. Pubmed Link

(53) Barlow JH, Williams B, Wright CC. `Instilling the strength to fight the pain and get on with life': learning to become an arthritis self-manager through an adult education programme. Health Education Research 1999 August 01;14(4):533-544. Pubmed Link

(54) Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient Self-management of Chronic Disease in Primary Care=20. JAMA: The Journal of the American Medical Association=20 2002=20 November 20=20;288=20(19=20):2469=20-2475=20. Pubmed Link

(55) Bailey WC, Kohler CL, Richards JM,Jr, Windsor RA, Brooks CM, Gerald LB, et al. Asthma Self-management: Do Patient Education Programs Always Have an Impact? Arch Intern Med 1999 November 8;159(20):2422-2428. Pubmed Link

(56) Charlton I, Charlton G, Broomfield J, Mullee MA. Evaluation of peak flow and symptoms only self management plans for control of asthma in general practice. British Medical Journal 1990 December 15;301(6765):1355-1359. Pubmed Link

(57) DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. BMJ 2002 October 05;325(7367):746. Pubmed Link

(58) Mullet J. Partnerships for better health: a self care pilot project. Final evaluation report. 2000. [Online] Available at http://www.health.gov.bc.ca/library/publications/year/2000/evalfin.pdf Accessed 23 March 2011

(59) Lorig K, Sobel D, Stewart A, Brown BJ, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Medical Care 1999;37(1):4-14. Pubmed Link

(60) Bowling A, Ebrahim S. Measuring patients' preferences for treatment and perceptions of risk. Quality in Health Care 2001 September 01;10(suppl 1):i2-i8. Pubmed Link

(61) Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Quality in Health Care 2001 September 01;10(suppl 1):i34-i38. Pubmed Link

(62) Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ 2006;333(7565):417-424. Pubmed Link

Appendix A

Study	Country	Condition	Perspective	Total No of participants	Response rate (%)	Data collection	Methodology	Analysis	Principal experiences explored
Abbott, et al. 2001	UK	Complex health and disability problems	Patients, carers	99	Not stated	Interviews	Qualitative research	thematic analysis	Patients' and carers' experiences of receiving community health services, and considers the degree of patients' participation in the management of their continuing care.
Arora & McHorney 2000	USA	Chronic illness	patients	2197		Questionnaires	Longitudinal study	logistic regression models	Patient preferences for participation in medical decision making
Ayana, et al. 2001	UK	Stroke	Patients	119	97%	Questionnaire	Time series control comparison study	Chi-square test, Fischer exact test,	Patient's satisfaction with use of patient-held

								Logistic regression	record (PHR) and its impact on care planning for stroke patients
Battersby,et al. 2007	Australia	Complex medical conditions	Patients, GPs	4603	44% intervention; 46% control	Measuring instruments (SF-36; WSAS)	RCT	Quantitative and qualitative	Comparison of coordinated care with usual care
Bradley, et al. 1999	USA	Dementia	Patients, Carers, Case Managers, Physician	36	Not stated	Interviews	Qualitative research	Constant comparative method	Goal setting in clinical medicine
Burges et al 2008	UK		Healthcare professionals			Focus group sessions	Qualitative	Framework approach	Perspectives of health Care professionals on barriers to SDM, and the implementation of patient decision aids in practice
Glazier,et al 2004	Canada	Complex medical and psychological problems	Patients, family, healthcare team	38	100%	Interviews	Prospective comparative study	Kappa statistics	Performance of an expanded menu of goals in a geriatric setting
Graham, et al 2007	Canada		Physicians			Questionnaires	Cross sectional surveys	Logistic regression models	Physicians' perceptions and intentions to use decision aids

Griffith,et al. 2004	New Zealand	Elderly patients	Patients, family, healthcare team	47	Not stated	Focus groups, questionnaires and interviews	Qualitative exploration	Thematic analysis	Opinion of participants in family meetings
Hansen, et al. 1998	USA		Social workers			Questionnaire	Exploratory survey	Quantitative and qualitative	Social workers' perception of family conferences
Harvey, et al. 2008	Australia	Complex medical conditions	Patients, health providers	175	Not stated	Questionnaire	Longitudinal study	Random coefficient regression analysis	
Hedberg, et al. 2007	Sweden	Stroke	Nurses			Recorded care planning meetings	Qualitative	Thematic analysis	Nurses involvement in care planning meetings
Kane, et al 1999	USA	Elderly patients	Patients, case managers	313	93%	Questionnaire	Quasi-experimental	Chi-square test, T-test, kappa statistics	
Ramfelt & Lutzen, 2005	Sweden	Cancer	Patients	10		Interviews	Qualitative	Constant comparative method	Patients' involvement in decisions about their care
Ruland, 1999	Norway	Elderly patients	Patients, nurses	151		Questionnaire	Quasi-experimental	Quantitative	Effects of decision support systems in eliciting and integrating patient preferences in clinical care

Ruland, 2000	Norway	Elderly patients	Patients, nurses	155		Questionnaire	Quasi-experimental	Quantitative	Effects of decision support systems in eliciting and integrating patient preferences in clinical care
Ruland, 2002	Norway	Elderly patients	Patients, nurses	155		Questionnaire	Three-group sequential design	Quantitative	Effects of decision support systems in eliciting and integrating patient preferences in clinical care
Russell, et al 2008	Canada	Chronic illness	Patients, physicians	20		Interviews	Qualitative	Constant comparative method	Experience of family physicians and patients with a chronic illness management initiative that involved the joint formulation of comprehensive individual patient care plans.
Sainio	Finland	Cancer	Patients	273		Questionnaire	cross	Descriptive	Extent of

2003							sectional surveys	analysis and non-parametric tests	patient participation in decision making
Sainio 2001	Finland	Cancer	Patients	25		Focus group sessions	Qualitative	Qualitative content analysis	Patients perspectives on factors that could promote or hinder participation in decision making
Shortus, et al 2005	Australia	Chronic illness	Patients	16		Focus groups, interviews	Qualitative	Thematic analysis	Patient's attitude towards chronic illness and planned care
Shortus, et al 2007	Australia	Diabetes	Patients, GPs, Allied Health Professionals	9		Interviews	Qualitative	Constant comparative method	Use of multidiciplinary care plans in management of diabetic patients
Simpson, 1997	UK	Dementia	Carers	20		Interviews	Qualitative	Constant comparative method	Use of carer held records
Walker & Dewar 2001	UK	Dementia	Carers	20		Interviews, focus groups, field notes	Qualitative	Constant comparative method	Carers involvement in decision making

Table 1: Characteristics of included studies   * Number of patients and/or carers only