

Supplementary file 3. CMO3: Preparing for the SDM encounter

Studies that evaluate an intervention

Author and country	Study design	Participants	Intervention	Supporting evidence
Austin 2015 ¹	Systematic review	Adults living with advanced or life-limiting diseases including 2 on older people and 4 on dementia	Decision tools for serious illness – print, video, or web-based tools for advance care planning (ACP) or decision aids for serious illness Most are designed to be used prior to the consultation. Decision aids	<ul style="list-style-type: none"> • DAs increase patient knowledge and preparation for treatment choices including ACP, palliative care and goals for care communication and dementia feeding options. • Clinicians can access and use evidence-based tools to involve patients who are seriously ill in shared decision-making.
Belkora 2008 ²	Qualitative and survey	Pts with breast cancer	Trained facilitators who elicited questions for doctors and audio recorded and summarised doctor-patient consultations. Coaching/facilitation	<ul style="list-style-type: none"> • Consultation Planning was associated with improvements in pre/post measures of decisional self-efficacy, and CPRS in conjunction with the doctor's visit was associated with a reduction in decisional conflict. • But data only collected on 37/278 who took part (convenience sample).
Coylewright 2014 ³	Systematic review (7 studies)		To compare the use of Decision aids vs. usual care in consultations addressing diabetes, chest pain, osteoporosis or myocardial infarction. Decision aids	<ul style="list-style-type: none"> • Knowledge Transfer, Decisional Conflict and engagement with SDM are all improved compared with usual care. • Authors conclude decision aids are effective among a diverse patient population, including the elderly and those with lower educational levels.

Author and country	Study design	Participants	Intervention	Supporting evidence
Durand 2015 ⁴	Review		Review documents concerned with the use of incentives for SDM. Decision aid	<ul style="list-style-type: none"> • There is very little evidence that tools given to patients ahead of clinical encounters lead to changes in communication patterns.
Durand 2014 ⁵	Systematic review	Socially disadvantaged groups	To evaluate the impact of SDM interventions on disadvantaged groups and health inequalities. Decisions aids	<ul style="list-style-type: none"> • ‘simple and concise interventions, written in plain language and specifically tailored to disadvantaged groups’ information and decision support needs appeared most beneficial to underprivileged patients’. p9 • SDM interventions increased; knowledge, informed choice, participation in decision-making, decision self-efficacy and preference for collaborative decision making and reduced decisional conflict among disadvantaged patients. • Interventions – had no significant effect on adherence levels, anxiety and health outcomes. • ‘the potential for SDM interventions to reduce health inequalities and engage disadvantaged patients will essentially be realised if tools and processes are tailored to their needs’ p11. • ‘it is highly likely that in contexts where SDM is not actively promoted and supported by a trained clinician and/or an intervention, disadvantaged patients are most likely to be marginalised, therefore increasing health inequalities’. p11.

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Edwards 2004 ⁶ Elwyn 2004 ⁷	Cluster RCT	20 recently qualified GPs in urban and rural general practices	Training GPs in SDM, and the use of simple risk communication aids in general practice. Training Decision aids (risk communication tools)	<ul style="list-style-type: none"> No statistically significant effects of the risk communication or SDM interventions were seen on the whole range of patient-based outcomes. Authors conclude that patients can be more involved in treatment decisions, and risks and benefits of treatment options can be explained in more detail, without adversely affecting patient-based outcomes.
The Year of Care 2011 ⁸ (Diabetes UK, DH, The Health Foundation)	Case study, questionnaires, data from practice records	People with diabetes	Care planning for DM - DM yearly review replaced by two consultations with blood test results & explanation sent to the patient in advance. The first consultation with e.g. a HCA is to work out what the patient wants to know, and to do the weights & measures. The second, with a GP or specialist nurse, is to discuss the above and look at blood test results and make a plan for DM care and SM.	<ul style="list-style-type: none"> Pts reported improved experience of care and demonstrate changes in self-care behaviour. Practices report better organisation and team work. Biomedical outcomes improve. Possible mechanisms - Pt understanding of DM increases through explanation of biomedical 'goals', feel included in the discussion.

Author and country	Study design	Participants	Intervention	Supporting evidence
Fagerlin 2013 ⁹	Evidence review and expert consensus	46% of included studies focused on treatment decisions (as distinct from prevention or screening)	Examine the theoretical and empirical evidence related to the use of values clarification methods in patient decision aids. VCMs help pts think about the desirability of options or attributes of options. Decision aids	<ul style="list-style-type: none"> • Values clarification methods may improve decision-making processes and potentially more distal outcomes. However, the small number of evaluations of VCMs and, where evaluations exist, the heterogeneity in outcome measures makes it difficult to determine their overall effectiveness or the specific characteristics that increase effectiveness. • The effects of the VCMs were mixed: decision processes were improved in 5 of 8 studies, but other outcomes were not measured frequently enough to reach conclusions about whether the VCMs had mainly positive or mainly neutral effects. • Authors say there is a need to better understand how values clarification relates to SDM.
Foot 2014 ¹⁰	Kings Fund report drawing on research and case studies	All patient groups	To explore and clarify how, when, why and how successfully patients are involved in their own care/treatment. Decision aid	<ul style="list-style-type: none"> • Coaching and counselling can also be provided outside of the consultation in order to help patients prepare for shared decision-making. • Decision aids (such as leaflets and online resources) can supplement the information a clinician gives verbally and help patients think about what different options might mean for them. • When patients use decision aids they: improve their knowledge of the options; feel more informed and clearer about what matters most to them; have more accurate expectations of the possible benefits and harms associated with their options, p23 (From Stacey et al 2011)

Author and country	Study design	Participants	Intervention	Supporting evidence
Glenpark Medical Practice 2016 ¹¹	Report of the introduction, implementation & impact of Care & Support Planning for ppl with multiple LTCs.	Primary care intervention for people with multimorbidity	The Year of Care initiative Practice staff all focused on holistic approach to care for ppl with multimorbidity. Longer appointment times with algorithm for adding extra time.	<ul style="list-style-type: none"> • Pts feel free to ask questions and feel that the HCPs are interested in them as people not just in the condition. “I feel like I can ask the questions rather than just being questioned” “They were interested in how I felt” ... “I got a chance to ask things rather than being asked” ... “I learned a lot”. p3 • ‘Conversations are different now – the agenda setting prompt has given patients permission to talk about things and has led to some more interesting conversations’. p1 • ‘the implementation of the process has valued the development of the staff as much as it has valued the expertise and lived experience of the patients’. p2 • ‘staff are enthusiastic and enjoy working in a different way’. p4 • “patients like the new system”. p4
Hacking 2013 ¹²	Feasibility RCT	People with early stage prostate cancer	Specially and specifically trained navigators, met (face to face or phone) with patients prior to oncology consultations to assist the Pts in formulating the questions, concerns and preferences they wanted to express during the consultation. Coaching/facilitation	<ul style="list-style-type: none"> • The intervention was scored as 'very helpful' by 91.9% of the intervention group. • Compared to control patients, navigated patients were more confident in making decisions about cancer treatment, were more certain they had made the right decision after the consultation and had less regret about their decision 6 months later.

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Jones 2011 ¹³	Questionnaires to assess Pt experiences in the intervention arm of a RCT of SDM	People with CVD	Personal risks for CVD & options for their reduction were presented via the web based decision aid. Decision aid	<ul style="list-style-type: none"> • 32% of Participants liked being presented with a set of options. 31% commented that the options were educational or common sense and/or reinforced their knowledge or current behaviour. • Poor provider uptake.
Joseph-Williams 2014 ¹⁴	Systematic review	All patient groups	Systematically review patient-reported barriers and facilitators to shared decision making (SDM) and develop a taxonomy of patient-reported barriers.	<ul style="list-style-type: none"> • Decision aids are successful at supporting patients in the SDM process, but they fail to address the essential first step of ‘preparing for the SDM encounter’ including perceiving the opportunity and personal ability to be involved. • Patients need knowledge and power to participate in SDM. • Authors argue that need to ‘address the entry level factors to SDM such as changing subjective norms and redefining patients roles, before secondary process factors such as information provision and value clarification.

Author and country	Study design	Participants	Intervention	Supporting evidence
Joseph-Williams 2017 ¹⁵	Narrative report of the learning from the MAGIC programme - to implement SDM in primary and secondary health care settings	Health care professionals and patients of all ages.	Staff were trained in shared decision making skills, situationally relevant decision support tools were available, patient participation was encouraged and there quality improvement support was available.	<ul style="list-style-type: none"> • A key learning point from the MAGIC programme was that ‘skills trump tools, and attitudes trump skills.’, p2 • ‘Developing attitudes and understanding is essential, but then clinicians need to consider their communication skills to engage patients in decision making, drawing on evidence based tools when appropriate. There will never be decision support tools for every decision; nor will every patient find them acceptable or helpful. The skills to have different types of conversations with patients are paramount, with or without an available tool’. • Suggests that short tools to use in the consultation are better (and cheaper and easier to keep updated) than patient information sources for use outside of the consultation. • Experience from MAGIC suggests that in-consultation tools are often better at facilitating discussion between patient and clinician than those used outside the consultation. • However, there risk is that clinicians use brief decision aids to enhance information transfer and talk at patients, rather than improving how they work with patients. • Patients may feel unable rather than unwilling to engage in SDM.

Author and country	Study design	Participants	Intervention	Supporting evidence
Nunes 2009 ¹⁶	Guideline – based on review of evidence	All age groups and types of patients and any NHS settings	Guideline gives recommendations to clinicians and others on how to involve adults and carers in decisions about prescribed medicine.	<ul style="list-style-type: none"> • Cite evidence from 1 review and 4RCTs that decision aids can reduce decisional conflict. • ‘The guideline group considered evidence supporting of structured information in a variety of formats but did not feel it appropriate to make specific recommendations regarding decision aids.’ p119
Schaller 2015 ¹⁷ & Schaller 2016 ¹⁸	Before/after	Caregivers for older people (n=31) & medical practitioners (n=11)	<p>Pilot study to obtain feedback on the eHM-DP (a tailored e-health service) for caregivers of PLWD in the early part of the development process. Informal carers, medical and social professionals have an account (PLWD does not).</p> <p>Coaching/facilitation</p>	<ul style="list-style-type: none"> • Included an element related to preparation for doctor visits. Designed to complement not replace face to face care. • Caregivers indicated a high degree of perceived support from the portal and the decision aid. 89% of caregivers but 54% of MPs indicated they would use it if available. • The most supportive quality of the eHM-DP related to decision making proved to be ‘preparation for doctor visit’ (87 % consent), ‘elaboration of the pros and cons of each option’ (80 % consent) and ‘identification of questions for the doctor’ (76 % consent), Schaller 2015, p4. • Perceived benefits included individualised information, computerised interaction between caregivers and MPs, empowerment in health-related decisions and insight into disease progress.

Author and country	Study design	Participants	Intervention	Supporting evidence
Stacey 2013 ¹⁹	Systematic review	Not specified but appears to be any patient group (no sub group analysis by age or condition)	Coaching or guidance as part of SDM. Decision aid Coaching/facilitation	<ul style="list-style-type: none"> • Authors conclude that the evidence supports the use of coaching or guidance to better support patients in the process of thinking about a decision and in communicating their values/preferences with others. But impact on other outcomes such as participation in decision making or satisfaction with option chosen is more mixed. • Authors suggest that coaching should include non-directive support from a coach - in the process of thinking about a decision and discussing it with others. • Mechanisms inferred from the paper (but not proven) - that if you improve patient's deliberation and communication skills this will lead to empowerment and Pts will feel supported • They conclude 'Although there is theoretical evidence to support inclusion of coaching and guidance with PDAs, there are few RCTs that have evaluated the effectiveness of coaching used alongside PDAs'. p10
Van Summeren 2016 ²⁰	Mixed methods pilot study	60 older people and 17 family practitioners	Pilot study to test an OPT (a conversation tool) for medication review with older people and FPs. Decision aid	<ul style="list-style-type: none"> • Increase in satisfaction with medication use from 18% to 68% following the intervention. • Some participants found it difficult to rank health outcomes as they were often perceived to be highly interrelated.

Author and country	Study design	Participants	Intervention	Supporting evidence
Van Weert 2016 ²¹	Systematic review of RCTs	Included 22 papers	Decision aids for older adults (many of the studies focus on single issues e.g. AF, diabetes). Decision aid	<ul style="list-style-type: none"> • Found that decision tools/aids improve patient engagement with SDM (but didn't define SDM). • Decision aids have the potential to increase older adults' risk perception, improve knowledge, decrease decisional conflict, and improve patient participation in decision making by decreasing practitioner-controlled decision making. • No difference in concordance with chosen treatment between intervention & control groups in most included studies. • Potential mechanisms – feelings of being informed, clarity of values, decrease in practitioner controlled decision making

Studies that do not evaluate an intervention

Author and country	Study design	Participants	Focus	Supporting evidence
Bugge 2006 ²²	Qualitative	Pts HCPs	Qualitative investigation of instances in which information that was potentially relevant to decision-making was not exchanged in consultations.	<ul style="list-style-type: none"> • HCPs often omit relevant information and Pts often omit relevant context or preferences during consultations. • If either HCPs or patients refrain from full discussion of beliefs and concerns they may not reach a shared understanding of the issues that need to be addressed. • Identify number of reasons for non-disclosure including environment not conducive to information exchange or HCP behaviour off-putting.
Bynum 2014 ²³	Qualitative	Older people aged 80 and over	Experience of older adults in healthcare decision making.	<ul style="list-style-type: none"> • Participants described interactions in which they felt unable to make their needs heard and interactions in which communication felt rushed or closed them down. “It’s so hard to get them to pay any attention to you. They don’t listen to what you’re saying. ‘You’re an old lady and, tada, tada, tada’ -- you know?” p6 • A mechanism was whether people perceived that there was a choice. • The authors discuss how people may assert a choice after a consultation – e.g. choosing not to take a medication. • ‘The Ottawa Decision Support Framework is a commonly used model to design shared decision-making interventions. The first step in this model is to clarify the options available for consideration. Yet for the very old, we suggest that, even before clarifying the aspects of a decision, the patient and clinician need to state explicitly that there is a decision at hand’. p7

Author and country	Study design	Participants	Focus	Supporting evidence
Dardas 2016 ²⁴	Survey	Older adults	To determine the preferred decision-making role among older adult patients regarding elective hand surgery and whether it varied according to demographics, health literacy or diagnosis type.	<ul style="list-style-type: none"> • 62% wanted more information before the appointment.
Durand 2015 ⁴	Document review		Review documents concerned with the use of incentives for SDM – includes use of PDAs	<ul style="list-style-type: none"> • ‘One of the most striking themes that we identified was the implicit assumption that the provision of patient decision aids automatically leads to shared decision making.’, p99 • Authors argue that PDAs may improve patient knowledge but on their own do not influence the pt/HCP interaction.
Eaton 2015 ²⁵	Narrative review of the Year of Care initiative	People with long term conditions	Discussion of the need for systematic change within the NHS to facilitate coordinated person-centred care.	<ul style="list-style-type: none"> • People with...poor health literacy, and difficult social circumstances need specific and tailored support but have the most to gain (from coordinated holistic approaches).

Author and country	Study design	Participants	Focus	Supporting evidence
Edwards 2009 ²⁶	Systematic review of qualitative studies	No particular patient grp specified	To identify external influences on information exchange and SDM in healthcare consultations and conceptualise how information is used both outside and within a consultation.	<ul style="list-style-type: none"> • ‘Being informed enhances patients power and control over treatment decision-making by enabling them to weigh up risks and benefits of treatments.’ p48 • Health literacy is an important external influence on doctor-patient communication. • Some patients choose not to act as an empowered patient. • Health literacy is an important external influence on doctor-patient communication. • The receptiveness of healthcare practitioners to informed patients is also crucial to information exchange and empowerment.
Gleason 2016 ²⁷ USA	Questionnaire survey	Older people with multiple co-morbidities (average of 4 LTC)	To determine whether patient activation is associated with depression, chronic conditions, family support, difficulties with activities of daily living and instrumental activities of daily living (ADLs) (IADLs), hospitalisations, education and financial strain.	<ul style="list-style-type: none"> • Patient activation was significantly positively associated with family support and self-rated overall health and significantly negatively associated with depressive symptoms and difficulties with ADLs and IADLs. • The authors concluded that older age, depressive symptoms and difficulties with ADLs and IADLs were associated with decreased patient activation – suggest that need to address issues like depression before people can participate in SDM. • Developing interventions tailored to older adults' level of patient activation has the potential to improve outcomes for this population.

Author and country	Study design	Participants	Focus	Supporting evidence
Gorin 2017 ²⁸	Discussion	Not specified – but relates to clinicians	Commentary on the use of ‘clinical nudges’ and whether they are compatible with SDM.	<ul style="list-style-type: none"> • Minor features of how choices are presented can substantially influence the decisions people make. For example, framing risk in survival rather than mortality terms increases the probability that patients will consent to the intervention. ²⁹ • Authors suggest that not all pts will have authentic preferences, even after engaging in SDM - in such instances clinicians are justified in using nudges in accordance with the best interest standard (BIS).
Grim 2016 ³⁰	Qualitative	22 People with mental health issues (aged 24-62)	To investigate decisional and information needs among users with mental illness. Decision aids	<ul style="list-style-type: none"> • Suggest that the Elwyn model (2013) should be expanded to include a preparation phase – ‘in order to give the user a chance to consider the need for and nature of the decision to be made’. This ‘might serve to promote user involvement from the very onset’. p4 • “There was a belief among the respondents that they as users possess experimental knowledge, which is crucial for the decision-making process and which must be a factor that contributes to the frame for the decision to be discussed, even prior to the onset of the actual decision-making process’. p4 • ‘Being offered the opportunity to prepare for the meeting is described as an indicator of mutuality, a factor that many respondents described as a prerequisite for a participatory decision-making process’. p4 • ‘concrete aids for considering and contributing to the preparation of the decision-making occasion, might reduce power differentials’. p4

				<ul style="list-style-type: none"> • Suggest Elwyn model expanded to include follow-up phase – because care is complex, multifaceted and long-term and will call for continuous evaluating and adapting p6 – ‘which clearly defines the ongoing nature of the decision making process and includes concrete options for reviewing or reconsidering the current decision’. p7
Herlitz 2016 ³¹	Qualitative – analysis of video recordings	Adolescents with Type1 DM and professionals	They describe a complementary PCC/SDM approach to ensure that pts are able to execute rational decisions taken jointly with care professionals when performing self-care.	<ul style="list-style-type: none"> • “the conversational logic of a shared rational problem-solving à la standard PCC/SDM threatens to create a repeated pattern of fear of failure, increasing lack of self-confidence and resulting disempowerment.” p9 • Positive feedback may emotionally empower pts.
Ladin 2016 ³² USA	Qualitative	Older people receiving dialysis	To examine patient perspectives of the decision to start dialysis and the relationship between patient engagement and treatment satisfaction.	<ul style="list-style-type: none"> • Older people not engaged in decision making resulting in poor satisfaction – unaware that dialysis initiation was voluntary and held mistaken beliefs about their prognosis. • Patients who described active decision making appeared more confident and satisfied with their decisions than those who felt pressured to make a choice. • Patients perceived that for SDM to operate active participation and having people to talk to when engaging in the decision were important.
Land 2017 ³³	Systematic review	Variety of different patient and HCP groups	Maps decision making communication practices relevant to health care outcomes in face-to-face interactions and examines their function in relation to SDM.	<ul style="list-style-type: none"> • ‘Exploring patients’ reasons for resistance—even when protocol means there is no alternative—validates patients’ participation. Even where the patient eventually agrees to the original recommendation, where reasons are explored, they will have still participated in the decision making process.’ pp18-19

				<ul style="list-style-type: none">• 'Pursuing agreement without engaging with patients' reasoning for withholding is less encouraging of patients' participation and may be treated as coercive.' p19• 'However, as patients/companions become increasingly proactive in their health-care, HCPs balance the encouragement of participation with the importance of need to not being pressured to give inappropriate treatment.' (this is from a study on prescribing of antibiotics for children) p19
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