### Supplementary file 1. CMO1: Reflecting patient and carer values

#### Studies that evaluate an intervention

<table>
<thead>
<tr>
<th>Author and country</th>
<th>Study design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Supporting evidence</th>
</tr>
</thead>
</table>
| Belanger 2011 (1)  | Systematic review | Palliative care | SDM in palliative care. | - The majority of patients wanted to participate in treatment decisions but in practice they were rarely encouraged to participate in SDM. Options were not discussed and consent was implicit.  
- Evidence on family members participating in decision-making is limited.  
- Barriers to SDM in palliative care included unmet information needs, unrealistic expectations, framing of options in consultations and delaying decisions due to predetermined care patterns.  
- “Patient preferences have proven difficult to identify and explain, so that approaches to decision-making should be assessed on a case-by-case basis”. discussion  
- Research should follow patients over time throughout the decision-making process |
| Blom 2016 (2)      | RCT          | Older people with 3 or more comorbidities | Proactive care planning and goal orientated integrated care. **Patient & Carer preferences & goals** | - Small change in patient satisfaction levels.  
- No significant improvement in QoL or functional status at 1 yr  
- GPs reported improvement in overview of care records and less unexpected care demands. |
<table>
<thead>
<tr>
<th>Study (Year)</th>
<th>Methodology</th>
<th>Population</th>
<th>Intervention</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Coulter 2015 (3) | Systematic review | Adults with long-term health conditions | Personalised care planning (authors say SDM is considered essential for personalised care planning. Patient & Carer preferences & goals) | - Personalised care planning improves some indicators of physical and psychological health status, and people’s capability to self-manage their condition when compared to usual care.  
- The effects of personalised care planning appear to be greater when the intervention is more comprehensive, intensive, and better integrated into routine care.  
- Achieving PCP in practice authors say ‘it will probably require training for health professionals in how to elicit patients’ goals and priorities, while avoiding the imposition of an overly directive model of care that could undermine patients’ confidence to self-manage their conditions’.
|
| Cramm 2016 The Netherlands (4) | Survey | Primary care intervention aimed at patients with COPD (n=411) | Multicomponent interventions within all six dimensions of the CCM (organizational support, community, self-management, decision support, delivery system design, and information and communications technology). Developing relationships | - For patient’s the perceived quality of chronic care delivery is related significantly to productive interaction/relational coproduction of care (this includes SDM).  
- Highest degree of relational coproduction was with GPs and practice nurses - familiarity with one another and a history of working together leads to higher levels of relational coproduction.
|
| Cramm 2012 Netherlands (5) | Before/after – survey – at start of | Primary care | Implementation of the Chronic Care Model (CCM) by 22 primary care practices. | - Chronic illness care delivery improved to advanced levels (measured by Assessment of Chronic Illness Care short version).  
- Gains were attributed primarily to improved relational coordination—that is, raising the quality of communication and
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Population</th>
<th>Interventions</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Dwamena 2012  | Systematic review (43 RCTs)       | Primary and secondary care. Patients were predominantly adults with general medical problems | Interventions for providers to promote a patient-centred approach in clinical consultations. (in background authors note that SDM has important role in PCC). | • Generally positive effects on consultation processes on a range of measures relating to clarifying patients’ concerns and beliefs; communicating about treatment options; levels of empathy; and patients’ perception of providers’ attentiveness to them and their concerns as well as their diseases. Short training (less than 10 hours) was as successful as longer training.  
• Mixed results on satisfaction, behaviour and health status.  
• Authors say results suggest that the addition of condition-specific educational materials supports further improvement in patient-centred care. |
| Elliot 2016   | Realist synthesis                 | Older adults        | Engaging older adults in health-care decision making.  
**Patient & Carer preferences & goals**  
**Developing relationships** | • Communication is key to developing an open, honest and trusting relationship.  
• Engagement is complex and should be viewed as evolving relationship.  
• Patients/caregivers need to know that they have a right to be engaged in DM.  
• If provider has knowledge on appropriate engagement techniques, this will contribute to respectful communication. |
| Health Foundation 2017 UK (8)(9) | Video describing SDM for deprescribing in care homes | Older adults living in care homes | Structured reviews were carried out by clinical pharmacists. Their findings then discussed at an appointment at care home which involved the resident, the resident’s family, a pharmacist and a nurse from the care home. Where possible, the resident’s GP also attended this meeting. Together, they made decisions with each resident about which medications to stop, change or add. | • "It used to be just the doctor and the pharmacist talking to each other. But actually having everybody round the table, it's just wonderful. It’s a game changer in terms of the decisions you make." Pharmacist  
• "Little changes to medication can make a huge difference to patients’ outcomes. Taking Mr S as a good example of a man who's in pain...By getting his pain control right, we can help him do the stuff he wants to do." Pharmacist  
• One challenge the team faced was getting GPs released from their practices to attend review meetings. They tested a range of ways for GPs to be involved, but found that direct involvement was most valuable. |
|---|---|---|---|
| Holmside Medical Group 2014 UK (10) | Case study | Primary care | The Year of Care - an initiative to give holistic care for people with multimorbidity. Involving all clinical staff and the patient/family in producing, monitoring and updating a care plan which focuses on the QoL for the patient. A lot of cross-disciplinary training. E.g. receptionists trained as | • Patient satisfaction and engagement has increased, there are less unplanned attendances at the practice (not clear how this was measured).  
• "Experience from elsewhere would suggest that it takes two or three years to make a difference to clinical outcomes as habits of both patients and professionals die hard and engagement increases over a number of care planning cycles.  
• QOF figures remained the same. |
<table>
<thead>
<tr>
<th>Researcher/Year</th>
<th>Study Type</th>
<th>Setting</th>
<th>Objectives</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joseph-Williams 2017, UK (11)</td>
<td>Qualitative</td>
<td>Primary and secondary care in UK</td>
<td>Test, and identify the best ways to embed shared decision making into routine primary and secondary care using quality improvement methods.</td>
<td>- Say that SDM not just the responsibility of the Doctor and can be shared between the team. E.g. Dr explain the options and nurse elicit preferences.</td>
</tr>
<tr>
<td>Legare 2014 (12)</td>
<td>Systematic review</td>
<td>Healthcare professionals and patients. Most common clinical conditions: cancer &amp; CVD.</td>
<td>Determine the effectiveness of interventions to improve healthcare professionals' adoption of SDM.</td>
<td>- Among the 39 included studies only 3 targeted more than one type of health professional, but all were positive. - Authors say lack of studies addressing the interprofessional approach is major limitation to understanding the implementation of SDM in clinical practice.</td>
</tr>
<tr>
<td>Mercer 2016 UK (13)</td>
<td>Qualitative</td>
<td>People aged 30-65 with at least 2 long term conditions (excluded those with CI)</td>
<td>Describe the development of a primary care-based complex intervention for patients with multimorbidity in areas of high deprivation. Involved</td>
<td>- Initial appointment required 30 to 50 minutes. - Pts appreciated the time, being able to ask questions, being listened to and having their goals acknowledged. - HCPs felt that training focused on how to engage and motivate patient would be most useful. Pts felt practitioners might benefit from training in listening skills.</td>
</tr>
</tbody>
</table>
1. Establishing and maintaining therapeutic relationships with patients (Connect).
2. Focusing on the ‘whole person’ in assessing health problems in terms of their individual personal and social contexts (Assess).

**Patient & Carer preferences & goals**

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Results</th>
</tr>
</thead>
</table>
| Nunes 2009 (14) | Guideline – based on review of evidence | All age groups and types of patients and any NHS setting | Guideline gives recommendations to clinicians and others on how to involve adults and carers in decisions about prescribed medicine. | • SDM leads to better treatment adherence.  
• Guideline group convinced from evidence that practitioner skills in SDM could be improved and that these could result in increased patient involvement. p69 |
| Sanders 2016 (15) | RCT | GPs Patients with lower back pain - mean age 45 yrs | To determine whether GPs trained in SDM and reinforcing patients’ treatment expectations showed more trained behaviour during their consultations than untrained GPs. | • GPs expressed reluctance in engaging in SDM when the patient’s preferences were not in line with clinical guideline.  
• GPs experienced difficulties in accepting patients personal preferences of having an equal role in selecting treatment |
| Shay 2015(16) | Systematic review | Patient groups not specified | • Review suggests that when pts report they have participated in SDM, they are likely to enjoy better affective cognitive outcomes, such as improved satisfaction and decisions conflict. This highlights the importance of understanding the patient's perspective when measuring SDM.
• Lack of understanding on what leads a patient to report a decision as shared.
• Evidence is lacking for the association between empirical measures of SDM and patient behavioural and health outcomes. |
| Van Summeren 2016 (17) | Mixed methods pilot study | 60 older people with multimorbidity and 17 family practitioners | Pilot study to test an OPT (a conversation tool for outcome prioritisation) for medication review with older people and FPs. **Patient & Carer preferences/goals**

• Increase in satisfaction with medication use from 18% to 68% following the intervention – but authors say tool not suitable for routine medication review at present.
• Some participants found it difficult to rank health outcomes as they were often perceived to be highly interrelated – although half could easily prioritize the 4 health concerns.
• For FPs the tool provided better understanding of their patients (from pt and FP self-administered questionnaires).
• Knowing the individual’s preferences appears to provide a deepening of the patient–doctor relationship.
• A mean consultation duration of 31 minutes indicates that the OPT does not fit into routine medication review in family practice. |
Studies that do not evaluate an intervention (e.g. qualitative, descriptive, observational)

<table>
<thead>
<tr>
<th>Author and country</th>
<th>Study design</th>
<th>Participants</th>
<th>Study focus</th>
<th>Supporting evidence</th>
</tr>
</thead>
</table>
| Belanger 2011 (1)  | Systematic review             | Palliative care            | SDM in palliative care.            | • The majority of patients wanted to participate in treatment decisions but in practice they were rarely encouraged to participate in SDM. Options were not discussed and consent was implicit.  
• Evidence on family members participating in decision-making is limited.  
• Barriers to SDM in palliative care included unmet information needs, unrealistic expectations, framing of options in consultations and delaying decisions due to predetermined care patterns.  
• “Patient preferences have proven difficult to identify and explain, so that approaches to decision-making should be assessed on a case-by-case basis” (from discussion).  
• Research should follow patients over time throughout the decision-making process. |
| Barrett 2016 (18)  | Discussion/opinion            | GPs and pts eligible for statins | Discusses the importance of patient’s needs, views, preferences etc. in SDM/making clinical recommendations. | • Future guidelines should strive to incorporate decision-aids and media tools to help illustrate the risk continuum across treatment choices.  
• Expert panel recommendations should explicitly acknowledge that medical decisions should be based on the preferences |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Methodology</th>
<th>Population</th>
<th>Patient &amp; Carer preferences</th>
<th>Interprofessional working</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bookey-Bassett 2016 (19)</td>
<td>Concept analysis and review</td>
<td>Older adults</td>
<td>Interprofessional collaboration in the context of chronic disease management.</td>
<td>• In order for SDM for older people with multimorbidity under the care of multiple practitioners to take place, optimal IPC is required, in particular effective and frequent communication and trust between team members.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interprofessional working</td>
<td>• Highlights importance of trust between practitioners especially between primary and secondary care.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Patient and carer preferences</td>
<td>• Authors suggest outcomes of IPC – provider job and professional satisfaction, confidence about older adults with chronic diseases and comprehensive care planning and coordination of services</td>
</tr>
<tr>
<td>Bratzke 2015 (20)</td>
<td>Systematic review of qualitative studies</td>
<td>Adults with multimorbidity</td>
<td>Priority setting and/or decision-making in self-management of multimorbidity.</td>
<td>• “Patients with multimorbidity prioritize illnesses. Multiple processes affect choice of a priority or “dominant” chronic illness. For example, the number and inter-relatedness of chronic conditions, their severity and impact on daily life, the symptoms they cause, and their short- and long-term consequences may influence the identification of a dominant illness. The dominant chronic illness shifts over time as conditions and treatments change, and re-prioritization occurs”. p753</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Patient and carer preferences</td>
<td>• Decision making is grounded in the personal and social context of an individual’s life.</td>
</tr>
<tr>
<td>Reference</td>
<td>Study Type</td>
<td>Participants</td>
<td>Objective</td>
<td>Findings</td>
</tr>
<tr>
<td>-----------</td>
<td>------------</td>
<td>--------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
</tbody>
</table>
| Bridges 2015 (21) | Qualitative | HCPs (hospital) | To investigate how cancer treatment decisions are formulated for older people with complex health and social care needs and the factors that shape these processes. | • Building relationships with patients was identified as critical to enabling optimal involvement in decisions.  
• Treatment recommendations were formulated without taking their individual needs and circumstances into account – meaning that treatment not tailored to individuals’ needs and social situations. |
| Chong 2013 (22,23) | Qualitative | HCPs involved in mental health care | To explore healthcare professionals’ perceptions of shared decision-making and current interprofessional collaboration in mental healthcare. | • Medical practitioners advocated a more active participation from consumers in treatment decision-making; whereas other providers (e.g. pharmacists, occupational therapists) focused more toward acknowledging consumers’ needs in decisions, perceiving themselves to be in an advisory role in supporting consumers’ decision-making.  
• Lack of collaboration was thought to lead to inconsistency of information given to consumers leading to possible decision conflict. |
| Couet 2015 (24) | Systematic review | Studies that have used the OPTION assessment tools | Observe the extent to which health-care providers involve patients in decision making across a range of clinical contexts. | • Few health care providers sought to tailor their care to patient’s preferences.  
• ‘The two least-observed behaviours were assessing the patient’s preferred approach (item 3) and eliciting preferred involvement (item 10), which require the health-care provider to enquire about the patient’s preferences’. p556 |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Methodology</th>
<th>Population</th>
<th>Objective</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Cramm 2014 (25) | Mixed methods | Older people with long-term conditions | To identify the influence of quality of care on productive patient–professional interaction. Developing relationships | • ‘health-care providers who consistently listed the options available to their patients did not necessarily also emphasize that the patients could choose any of these options’. p556
• Future interventions aiming to improve the tailoring of care to patient preferences are needed. |
| Dardas 2016 (26) | 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. Developing relationships | • Pts perception of the quality of care was directly related to their perception of the productivity of interactions with HCPs. The latter is moderated by educational level. |
| Elwyn 2012 (27) | Discussion/opinion | NA | Propose a model of how to do shared decision making that is based on choice, option and decision talk. Developing relationships | • Achieving SDM depends on building a good relationship in the clinical encounter
• Individuals often want to discuss options with others and need to allow time for this in effective SDM. |
<p>| Farrelly 2016 (28) | Qualitative (focus groups) | People with mental health problems | Facilitated SDM that | • The usefulness of SDM (JCP) is not always appreciated by HCPs, it may be perceived as more unnecessary work or the 'decisions' may be perceived as impossible to implement. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Research Question</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foot 2014 (29)</td>
<td>Report – draws on research and case studies</td>
<td>Variety of different patient and HCP groups</td>
<td>To explore and clarify how, when, why and how successfully patients are involved in their own care/treatment. The report covers SDM and self-management.</td>
<td>- Do not report patient outcomes.</td>
</tr>
<tr>
<td>Grim 2016 (30)</td>
<td>Qualitative</td>
<td>People with mental health issues (aged 24-62)</td>
<td>To investigate decisional and information needs among users with mental illness.</td>
<td>- Clinicians need skills in decision-support counselling and a curious, supportive consulting style.</td>
</tr>
<tr>
<td>Groen-van de Ven 2016 (31)</td>
<td>Qualitative</td>
<td>People with dementia, their family carers and professionals involved in their care</td>
<td>To describe the challenges of shared decision making in dementia care networks.</td>
<td>- Regardless of the topic discussed, the ability of the provider to create a dialogue characterized by trust, genuine interest, respect, and equality is described as essential.</td>
</tr>
</tbody>
</table>

- **Decision aid**
- **Coaching**
- **Developing relationships**
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Population</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hart 2016 (32)</td>
<td>Qualitative</td>
<td>Patients with tobacco-associated thoracic diseases and their surrogates</td>
<td>To document prevalent themes in patients’ and potential surrogate decision makers’ future-oriented thinking when facing preference-sensitive choices. <em>Patient &amp; Carer preferences Developing relationships</em></td>
<td></td>
</tr>
</tbody>
</table>
|                  |                |                                                 | - Study supports link between continuity and trust  
- Highlights that patients consider impact of treatment decisions on family members when making decisions  
- Tension between hope for the future and true expectations impacts on decision making  
- Participants rely heavily on memories and past experiences when engaging in decision making – may lead to biased decision (because ‘case studies’ overpower data) rather than considering all the available options. **Familiarity bias** |
<p>| Herlitz 2016 (33) | Qualitative – analysis of | Adolescents with Type1 DM | They describe a complementary PCC/SDM approach to ensure that pts are able to execute rational decisions |
|                  |                |                                                 | - ‘little attention was given to patients’ habitual decision-making and actual adherence, whereas a lot of effort and time was spent on gathering information and data’ |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Methodology</th>
<th>Participants</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Korner 2013 (34)</td>
<td>Qualitative</td>
<td>Pts and HCPs</td>
<td>To identify the preferences of patients and HCPs concerning internal and external participation in rehabilitation clinics, in order to develop an interprofessional shared decision-making (SDM) training program for HCPs – describes development of training rather than its impact.</td>
<td>‘More time, more respect from the health care professionals and the desire for more participation in decision-making processes were mentioned most frequently by patients’. p146&lt;br&gt;Authors’ hypothesis– ‘good internal ...communication, coordination and cooperation can help avoid non-integrated processes and lead to the development of more pt-centred treatment plans - leading to enhanced pt involvement and satisfaction and better treatment outcomes’ p147 – but study suggests this is not currently happening.</td>
</tr>
<tr>
<td>Kulski 2013 (35)</td>
<td>Qualitative</td>
<td>Older people with multimorbidity and GPs</td>
<td>Explore types of goals that were important for older persons with multimorbidities from the perspectives of patients, their caregivers and physicians.</td>
<td>Little alignment of goals when looking across pt-caregiver and physician triads. Lack of alignment tended to occur when patients had unstable or declining functional or cognitive health; when safety threats were noted; and when enhanced care services were required.</td>
</tr>
<tr>
<td>Land 2017 (36)</td>
<td>Systematic review</td>
<td>Variety of different patient and HCP groups</td>
<td>Map decision making communication practices relevant to health care outcomes in face-to-face interactions and to examine their function in relation to SDM.</td>
<td><strong>Patient &amp; Carer preferences</strong>&lt;br&gt;‘Eliciting patient perspectives and ensuring that information is genuinely taken into consideration generally result in patients experiencing themselves as involved’. p18</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Legare 2011 Canada (37)</td>
<td>Qualitative</td>
<td>HCPs (n=11)</td>
<td>Reports how an interprofessional and interdisciplinary group developed and achieved consensus on a new interprofessional SDM model.</td>
<td><strong>Interprofessional working</strong>&lt;br&gt;<strong>Patient &amp; Carer preferences</strong>&lt;br&gt;Authors suggest - that the interprofessional team (which includes the patient) analyse the feasibility of the options before determining individual preferences. <strong>Interprofessional working</strong>&lt;br&gt;The IP-SDM model they propose has 3 levels: the individual (micro) level and two healthcare system (meso and macro) levels. At the individual level, patient presents with a health condition that requires decision-making and follows a structured process to make an informed, value-based decisions in concert with a team of healthcare professionals. The model acknowledges (at the meso level) the influence of individual team members’ professional roles including the</td>
</tr>
</tbody>
</table>
decision coach and organizational routines. At the macro level it acknowledges the influence of system level factors (i.e. health policies, professional organisations, and social context) on the meso and individual levels.

- They suggest that use of the model can help health professionals **envision a common goal** and enhance the contribution of different health professionals to SDM.

<table>
<thead>
<tr>
<th>Author</th>
<th>Study Design</th>
<th>Sample</th>
<th>Objectives</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Legare 2011 Canada (38) | Qualitative | HSCPs and managers (n=79) | To develop & validate a model for Interprofessional SDM (model described in previous paper by Legare) | **Interprofessional working**  
- Most often reported barriers were time constraints, insufficient resources and an imbalance of power among health professionals.  
- The most frequently reported facilitators in the context of an IP approach to SDM were mutual knowledge and understanding of disciplinary roles, trust and respect.  
- Decision coach who is trained to support the pts involvement in decision making is seen as central role. |
| Lown 2011 (39) | Describes adaptation of a model | NA | To describe a model which aids the design, implementation & evaluation of training programmes in SDM/collaboration for HCPs. | **Interprofessional working**  
- Interprofessional teams may need to broaden the scope of the decision in order to encourage all stakeholders to contribute to solutions.  
- Important factors include - professionals are familiar with each other’s expertise, roles and responsibilities, have a shared understanding of SDM, and work with systems/tools that facilitate effective and frequent communication between individuals (including different HCPs and patients and carers). |
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Data Collection</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miller 2014 (40)</td>
<td>Literature review (n=36 studies)</td>
<td>Review recent empirical research about the SDM involvement of persons with dementia and their family carers.</td>
<td>Patient &amp; Carer preferences</td>
<td>• Sharing the decision: Trust and respect between team members help professionals ‘envision’ a common goal and enhance the contribution of different health professionals. c) foster continuity. Then patients and their family carers will feel empowered and will understand and value SDM.</td>
</tr>
<tr>
<td>Naik 2016 USA (41)</td>
<td>Observational</td>
<td>Cancer survivors with multimorbidities</td>
<td>To identify a taxonomy of health-related values that frame goals of care of older multimorbid adults</td>
<td>• For multimorbid adults it is more important for HCPs to consider their values which are stable over time rather than</td>
</tr>
<tr>
<td>Study</td>
<td>Methodology</td>
<td>Participants</td>
<td>Research Design</td>
<td>Findings</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Politi 2011 USA  | Development of a model – knowledge synthesis | NA           | To present a communication model to help better understand quality medical decision making, and how patient-centered, collaborative communication enhances the decision-making process. | • ‘use the term ‘collaborative’ decision making rather than ‘shared’ because collaboration connotes a process of mutual participation and co-operation among multiple clinicians, patients, and family members’, p579  
• Strategies such as providing clear explanations, checking for understanding, eliciting the patient’s values, concerns, needs, finding common ground, reaching consensus on a treatment plan, and establishing a mutually acceptable follow-up plan can facilitate collaborative decision making.  
• Communication about complex medical issues often occurs as a series of conversations over time, with multiple clinicians involved.  
• ‘Clinicians must build a partnership with patients, family members, and other clinicians on the treating team’. p583 |
<p>| Robben 2012 The Netherlands (42) | Qualitative | Frail older people (n=11) and informal caregivers with receiving information from HCPs as well as | To explore the experiences of frail older people and informal caregivers with receiving information from HCPs as well as | • Having enough time and a good relationship with professionals involved, were considered of great importance. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Type</th>
<th>Participants</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Ruggiano 2016 | Qualitative     | Older people (n=37, case managers n=9) | Examined perceptions of older adults’ health self-advocacy behaviours and the context under which they self-advocate for their chronic conditions.  
**Patient & Carer preferences**  
- ‘concerns over quality of life is the most common motivator for older adults to engage in health self-advocacy and that self-advocacy involves gathering information to prepare for decision-making and confronting providers about the information gathered’. p401  
- Possibly HCPs can help Pts make decisions by framing choices/outcomes in QoL terms. |
| Shay 2014     | Qualitative     | General population of patients | Develop a conceptual model of patient-defined SDM, and understand what leads patients to label a specific, decision-making process as shared.  
**Developing relationships**  
- Four components of an interactive exchange: Doctor and patient share information, Both are open-minded and respectful, Patient self-advocacy, Personalized physician recommendation  
- Additionally, a long-term trusting relationship helps foster SDM.  
- There's no one-size-fits all process that leads patients to label a decision as shared, the outcome of ‘agreement’ may be more important. |
| Sinnott 2013  | Systematic review of qualitative studies | GPs | Synthesise existing literature on GPs views regarding the management of patients with multimorbidity  
- GPs acknowledged the importance of eliciting patients’ preferences but found it difficult to do this in practice.  
- Discussing risk and outcomes of treatment options in a way that facilitated pt involvement was challenging.  
- Supports importance of continuity of care. |
| Sheaff 2017 UK (45) | Qualitative | 66 general practice patients, mean age 78, with at least two LTCs (had an average of 4) | Analyse the information-sharing difficulties arising from differences between patients' oral narratives and medical sense-making. Look at implications for care coordination and continuity. **Patient & Carer preferences** | • Patients and clinical discourses interpret and frame the patient’s health problems differently.  
• The EPR (electronic paper record) can marginalise aspects of care which lie beyond a biomedical focus or contractual requirements. p3  
• Patients’ narratives differed from the accounts in their medical record.  
• Patients felt pain was not taken seriously – which impacted on trust.  
• Far more pts had mobility problems than apparent from EPR.  
• EPR – little acknowledgment of informal carers, functional impairments or whether a pt lived alone.  
• ‘Parts of patients’ viewpoints were never formally encoded, parts were lost when clinicians de-coded it, parts supplemented, and sometimes the whole narrative was re-framed.’, Abs  
• Except for hospital referrals, EPRs held little explicit information on other services’ involvement.  
• ‘Our findings warn against assuming simplistically that universal adoption of EPRs, at least in their present state, will alone achieve informational continuity and facilitate care coordination between organisations’ p10 |
<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Description</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Tietbohl 2015 US (46) | Qualitative | Primary care clinics                                                       | - A high level of RC within clinical settings may be a key component and facilitator of successful DESI implementation.  
- The high-performing clinic exhibited frequent, timely, and accurate communication and positive working relationships.  
- Suggest that need to explore how a greater focus on the relational dynamics of the entire health care team might better support the process of SDM in routine practice.  
- Building partnership with whole team rather than focusing on clinician-pt relationship may facilitate SDM p10 |
| Wrede-Sach 2013 (47)  | qualitative | Older people                                                               | - Experiences of a good doctor-patient relationship were associated with trust, reliance on the doctor for information and decision making, and adherence.  
- Our older patients showed lower involvement in medical decisions as compared to health-related everyday life decisions.  
- Trust in authority may prevent patient speaking out.                                                                                           |
References


