

Shared decision making – Stakeholder workshop discussion:

Monday 3rd December 2018

Area of scope	Stakeholder views
<p>Scope: overall impression</p> <p>Does the scope make sense?</p> <p>Overall, do we have the right focus?</p>	<p>Stakeholders discussed the importance of a clear definition of what the guideline means by “shared-decision making”, noting overlaps in lexicon with other similar terms. It was raised that while shared decision making is often about decisions made at particular points in time, there are often long-term implications. It was stated that shared decision making is a continuous process and is based around giving patients choice along their care pathway. It was felt that the scope should be explicit in saying shared decision making is continuous process and that decisions can be changed.</p> <p>Stakeholders expressed that the scope should capture that people will be engaging with a range of different healthcare professionals as well as other sources of health advice (including multi-disciplinary teams, google and social contacts) who may give conflicting advice of differing reliability, making shared decision making much more difficult.</p> <p>Stakeholders discussed the issue of advanced care planning, noting that:</p> <ul style="list-style-type: none"> • Making decisions at the time of an emergency is not appropriate. • Where a potential emergency situation can be anticipated, knowing what patient want in advance is key. • Patients will have different views at different times in a sequential healthcare process. • There were concerns around who makes the decision that a patient is incapacitated. • Not all members of multi-disciplinary teams will have the opportunity to engage first hand with patients, as such, it is important shared decision making is undertaken with the patient and advanced care planning decisions are shared with all team members

	<p>The issue of mental capacity and ability to take part in decision making was raised by stakeholders, noting this matter should be covered by the scope of the guideline. Concern was expressed about the potential for people lacking mental capacity to be coerced into decisions.</p> <p>The use of the word ‘adherence’ was queried by stakeholders, noting that it seems at odds with the collaborative nature of shared decision making.</p> <p>Stakeholder discussed the relevance of shared decision making to other NICE guidelines A request was made that the scope emphasise that shared decision making will be adequately covered in related NICE guidelines. Concerns was expressed over the alignment of this guideline with other NICE guidance, noting that there are already recommendations for shared decision making. To aid patients with multi-morbidity to undertake shared decision making, it was suggested that disease-specific NICE technology appraisals need to be combined.</p> <p>Stakeholders expressed that the scope should set out that is for all people involved in healthcare. In addition, it was felt there was a need to clarify what was meant by “providers” and “commissioners”.</p> <p>It was noted by stakeholders that NHSE are undertaking work in this area on personalised care and will be publishing soon; NICE is aware of this programme of work.</p> <p>Stakeholder suggested different formats of the final guidance be made available for people with communication disabilities.</p>
<p>Section 2: Who the guideline is for</p> <p>This guideline is for:</p> <ul style="list-style-type: none"> • Providers and commissioners of health and public health services • People using health services, their families and carers. <p>It may also be relevant for:</p> <ul style="list-style-type: none"> • Social care professionals 	<p>The following were noted by stakeholders:</p> <ul style="list-style-type: none"> • The term “service users” may not capture all people interacting with services. Some patients make decisions to not utilise a service without face to face interaction with a healthcare professional and therefore are not defined as service users. For instance getting a screening letter and choosing not to attend. • The word ‘providers’ needs to be clarified.

<p>Is there anyone else this guideline should be for?</p>	<p>The following amendments were suggested by stakeholders:</p> <ul style="list-style-type: none"> • “their families and carers” may already be covered by “service users”. • Patients should be in the first bullet to need make it clear that the guidance is primarily for service users • This section should include everybody who delivers healthcare and public health services. • The scope should be clear if it means paid or informal carers • Include the general public for advanced care planning shared decision making.
<p>Section 3.1 Who is the focus? The population</p> <ul style="list-style-type: none"> • People using healthcare services <p>Are the inclusions / exclusions from the scope correct?</p> <p>Specific consideration will be given to:</p> <ul style="list-style-type: none"> • children and young people • older people • families and carers • people with communication difficulties • people with complex needs and long-term conditions • people who do not have support from family members, carers or an advocate • people with disabilities <p>Are there any other groups we should give specific consideration to?</p>	<p>Stakeholders suggested that the scope needs to be clearer on what is meant by “people with disabilities”, it was noted disabilities can be temporary and permanent.</p> <p>The following amendments were suggested by stakeholders:</p> <ul style="list-style-type: none"> • The scope should cover the general public because of the need for advanced care planning decisions. • Remove wording “need support from health and social care practitioners to make their own decisions about healthcare” as this is shared decision making. • The scope could include surrogate decisions. • Advocates in mental health and learning disabilities should be included. • Suggested additions and amendments to groups to be given specific consideration: <ul style="list-style-type: none"> ○ Include those <ul style="list-style-type: none"> ▪ with cognitive impairment ▪ anticipating treatment, which often also includes family members

<p>The guideline will not cover:</p> <ul style="list-style-type: none"> • People with a life-threatening emergency needing immediate life-saving care. • People who lack mental capacity and need support from health or social care practitioners to make their own decisions about healthcare <p>Are there any other groups we should exclude?</p>	<ul style="list-style-type: none"> ▪ temporarily not in a mental state to engage with shared decision making, for example after receiving bad news ▪ with low health literacy ▪ with multiple co-morbidities under the care of multiple specialists ▪ receiving end of life care ▪ people in transition between children and adult services, however, it was noted that this is complicated by the different age cut-offs for transition across specialisms. <ul style="list-style-type: none"> ○ Clarify which disabilities are of relevance in terms of shared decision making. <p>Stakeholders suggested the following amendments for excluded groups:</p> <ul style="list-style-type: none"> • A non-subjective definition of emergency is needed with wording such as “no chance of discussion”. • People who lack mental capacity should not be excluded. The wording could be tightened to prevent professionals from refusing to take part in shared decision making. • The mental capacity definition should be aligned with Mental Capacity Act, which says that capacity is decision-specific. • The scope needs to be clear that people covered by the Mental Capacity Act are covered elsewhere and not by this guideline. • Remove the section on groups that should be excluded. It was noted that even in emergency situations there may be opportunities for share decision making with family members or carers. <p>The following were noted by stakeholders:</p> <ul style="list-style-type: none"> • Whether shared decision making is appropriate depends more on the specific circumstances, rather than populations and settings.
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	<ul style="list-style-type: none"> • Patients need to be able to question the decisions. Many patients want information but do still want the professional to make the ultimate decision. It is important that patients can delegate decisions but are informed. • For mental health conditions, informed choice is important because the patient is managing the condition themselves. • Healthcare professionals have a duty of care to save people first and foremost. It was discussed that there is no requirement for shared decision making in situations where there are no alternative treatment options. • It was felt that it would be difficult to draw a boundary between people who lack mental capacity and people with fluctuating mental capacity. It was noted that it is still possible to involve people in decisions about their care, even if they lack full mental capacity. <p>Stakeholders shared these concerns:</p> <ul style="list-style-type: none"> • NICE guidelines that are referred to in this scope may not share the same viewpoint regarding shared decision making. • Omitting people who lack mental capacity is a safeguarding problem because it is easy for clinicians to say someone lacks mental capacity and make decisions without consulting them. • People with mental health conditions are sometimes coerced but the patient needs to be involved in ongoing decisions.
<p>Section 3.2 Settings The guideline will cover all settings where publically funded healthcare services are commissioned and provided.</p> <p>Are there any settings that should be excluded?</p>	<p>Stakeholders expressed that the setting needs to be clear if the guideline is going to be implemented effectively.</p> <p>Stakeholders suggested the following amendments to this section:</p> <ul style="list-style-type: none"> • Dentist surgeries should be included. • Social care should be included. It was noted that healthcare given in social care settings are covered and provided by healthcare professionals.

	<ul style="list-style-type: none"> • This should be extended to include all public and private healthcare settings. • People in the criminal justice system need special consideration. • Some consideration should be given to how the guideline addresses screening. Inviting people to attend screening tests brings ‘well’ people into the healthcare system and requires them to make decisions about their care • Stakeholders expressed concern that people may read this section as being that commissioners will be involved in shared decision making.
<p>Section 3.3 Activities, services or aspects of care and Section 3.5 Key issues and questions.</p> <p>We have drafted the following 5 questions to consider supporting shared decision making</p> <p>1.1 What are the most effective approaches and activities to support people using services to engage with shared decision making?</p> <p>1.2 What are the most effective approaches and activities to support healthcare providers to deliver shared decision making?</p> <p>1.3 What are the barriers to, and facilitators for, engagement with shared decision making by people using services?</p>	<p>Stakeholders were in broad agreement that the questions in this section were appropriate. They agreed that the two key areas are appropriate for shared decision making.</p> <p>It was queried whether it would be appropriate to have separate questions for primary and secondary care. It was highlighted that while in secondary care, decisions about care will often be in the context of offering different treatment options, GPs are sometimes seen as ‘gatekeepers’ to services who may often be advising patients that further onward referral into the healthcare system is not required.</p> <p>Stakeholders expressed that the scope covers the composition of effective decision making aids.</p> <p>Area 1: Supporting shared decision making</p> <p>The following were suggested as amendments to key area 1:</p> <ul style="list-style-type: none"> • The title should be “supporting and promoting shared decision making” to ensure service users are getting more involved in a positive way. • Regarding question 1.2, it was suggested that ‘facilitate’ should replace ‘deliver’.

<p>1.4 What are the barriers to, and facilitators for, delivery of shared decision making by healthcare providers?</p> <p>1.5 What are the core components of effective shared decision making approaches and activities?</p> <p>Are these the correct questions? Any comments?</p> <p>We have drafted the following question to consider shared decision making in the healthcare system 2.1 How should shared decision making be built into the healthcare system?</p> <p>Is this the correct question? Any comments?</p> <p>The NICE guidelines on patient experience in adult NHS services and service user experience in adult mental health contain related recommendations. The guideline will cross-refer to these recommendations as appropriate.</p> <p>These are the areas the guideline will address is there anything else we should consider?</p>	<ul style="list-style-type: none"> • Regarding questions 1.2 and 1.4, "engage" should replace "deliver" since it is important for healthcare providers to engage with shared decision making as well. • Regarding questions 1.1 and 1.2, and 1.3 and 1.4, there needs to be another question, to bring the question pairs together. • The following questions were suggested: <ul style="list-style-type: none"> ○ How should we empower patients to be more engaged? ○ How do we adapt and remove the barriers for these groups? ○ How is shared decision making being evaluated? ○ Has the patient felt involved in the decision-making process? ○ Are clinicians listening to patient values? • Patient decision aids should be included in the questions. <p>Stakeholders noted the following for area 1:</p> <ul style="list-style-type: none"> • Questions appear to be tailored to healthcare professionals and not patients. • Implementation of the guideline will require a culture change. People should expect shared decision making when coming to see all healthcare professionals. • People can feel dissatisfied with consultants by not making a choice for them, people say "how am I supposed to know" and "that's the clinician's job". It's important to ensure people using services understand shared decision making is a positive process. • Not listening to patients will mean the consultation will take longer so identifying people's preferences is key.
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- Some healthcare professionals may think shared decision making will require extra consultation time burden, which may act as a barrier
- Regarding question 1.5, effective shared decision making will include information resources for patients to access before and after their discussion with their healthcare professional to ensure that they are well informed.
- Different areas may have different set-ups for how care is delivered, leading to different models or approaches to shared decision making.
- There are unlikely to be many RCTs looking at different service models and approaches but likely be data available in the grey literature.
- It is important to recognise that shared decision making will continually change as a person moves through their life course.

Area 2: Shared decision making in the healthcare system

The following amendments were suggested by stakeholders for area 2:

- With question 2.1, it was suggested that “should” be changed to “can”.
- Make section 2 more aligned with 1 so questions 1.4 and 1.5 are featured in section 2.
- Social care should be included because patients leave the healthcare system and enter the social care system.
- The question “How much is this imbedded in practice?” should be included.
- A question on timing and review of decisions should be included but this can be captured in any of the questions so may be already covered.
- A question on at what point in the pathway is shared decision making required should be included – primary, secondary or tertiary care.
- A question about how to manage a situation when a patient asks for treatments not offered by the NHS should be included.

	<ul style="list-style-type: none"> • There needs to be a question for people lacking mental capacity, if they are included within scope. • Question 2.1 should include commissioning. • Sections 1 and 2 should feature either “should” or “effectiveness”, not both. <p>For area 2, stakeholders noted:</p> <ul style="list-style-type: none"> • Crisis care planning and advanced decision making could be covered in question 2.1 clarification might be needed around planning crisis care or having conversations about it. • Much shared decision making literature is from the US. Consideration of the NHS care pathway is paramount so that the evidence reviews capture the where/when/who specific to the UK • If social care is not included, its importance should be noted for future updates. • There needs to be a distinction between providers and professionals when answering questions because of their different roles. • Regarding question 2.1, check the systems in NHS Scotland and Wales that are ahead in terms of shared decision making. • Any recommendations will need to take account of the legal framework that exists within this area, particularly with respect to the Mental Health Act.
<p>Section 3.6 Main outcomes The scope has listed the following outcomes, these are broad to allow the committee to consider which outcomes they would like to look at for each question.</p> <ul style="list-style-type: none"> • engagement in shared decision making 	<p>Stakeholders felt that there are no clear metrics for determining what good shared decision making looks like.</p> <p>Stakeholders suggested the following outcomes for inclusion:</p> <ul style="list-style-type: none"> • Respected decisions

- wellbeing and quality of life (related to physical health, mental health and social wellbeing)
- changes in healthcare providers' knowledge, intentions, ability and confidence about undertaking shared decision making and how often they offer it as an option
- changes in knowledge, attitudes and behavioural intentions towards shared decision making in people who use services
- satisfaction, in terms of decision making, of people who use services (including perceptions of how satisfied they are from their carers, family members and advocates)
- unintended consequences

**Are these the right outcomes?
Are there any outcomes you think the committee should specifically consider?**

- How conflict is resolved
- Changes in knowledge
- Engagement in shared decision making should be left open so engagement from patients and professionals are both considered
- Patients offered decision
- Decision of individual conflicts with public health aim
- Delivery of information by professionals
- Improvement indicators such as reduction in cancelled procedures
- Number of complaints and legal cases
- Stress reduction in healthcare professionals
- Continuation of shared decision making through changes in service
- Documenting the decisions made
- Implementation of shared decision making
- Treatment burden
- Communication

Stakeholders suggested the following amendments to this section:

- Outcomes 2-5 could be scrapped because they are about what shared decision making is and not about how it can be achieved.
- Change the word "satisfaction".
- "Medicine adherence" should be broadened to include treatments or health technology.
- "offer it as an option" should be changed because shared decision making is not just an option but a process that should be done.

Stakeholders noted the following:

- Measuring quality of life may not be appropriate as that will often be directly related to the effectiveness of the treatment ultimately received, rather than to the quality of the decision making process that preceded it.
- The evidence being searched for outcome 2 will be huge and it was suggested that the definition for “quality of life” should be more specific.
- Many outcomes in the current scope are about what will happen after a decision is made but outcomes should be about the process and experience of shared decision making.
- It is possible to have an improvement in patient satisfaction but a drop in patient health outcomes. Stakeholders noted that this would depend on what is more important to patients.
- Better communication by professionals is brought up by patients often so outcome 4 is valuable.
- Less regret would be felt by patients who have shared a decision on their health, which would improve the unintended consequences outcome.
- The shared decision making movement is about informing patients. Stakeholders suggested that how NICE presents its evidence can be improved for the public.
- If patients don’t adhere to the guideline it is not the “correct” choice. This happens often in mental health as people living with the condition know more about the condition than the professionals.
- When shared decision making is not done well it can mean handing over all responsibility to patients.
- Patient engagement should be weighed against risk and burden.

	<ul style="list-style-type: none"> • There is an existing Cochrane review in this area looking at the effectiveness of patient decision aids, but that that may not be directly relevant to the questions that are currently being asked in the scope. • It was suggested that metrics used to evaluate the success of screening programmes shouldn't be used as indicators of a positive impact of shared decision making, for instance an increase in uptake of screening doesn't indicate that there has been an increased rate of effective shared decision making. <p>It was queried how shared decision making is recorded as having taken place, who records these instances and how this is evaluated.</p> <p>Stakeholders queried what effectiveness is in shared decision making. They suggested:</p> <ul style="list-style-type: none"> • How well you are • How well you understand • How comfortable you are • Meaningful conversations about shared decision making • Getting the outcome the patient wants • Patient perception • Perception may be deceptive, a healthcare professional may be very nice but not good at giving shared decision making yet the patient is still happy • How informed the patient is
<p>Equalities Potential equality issues to consider during the development of this guideline. The guideline will look at inequalities relating to age, disability, including physical disability, sensory impairments, mental</p>	<p>Stakeholders suggested the following could be considered in the guideline equality impact assessment:</p> <ul style="list-style-type: none"> • People with mental health issues • Cognitive function concerns affecting communication

<p>health problems and learning disability, people from diverse religious and cultural backgrounds and vulnerable people</p> <p>Are these the right equality issues? Please raise any issues that you identify as being relevant to the equalities theme.</p>	<ul style="list-style-type: none"> • People who are less health literate and do not possess health-seeking behaviour • People who are homeless • People with English as a second language. • People with communication impairment • People with autism • People with disabilities present at the time of the decision • Complex needs • Long-term conditions • Health literacy • Digital literacy • Travellers • Frailer people • Care leavers • People from different cultural and social backgrounds. • Sex <p>Stakeholders felt that “vulnerable people” should be clearly defined for this guideline.</p>
<p>Scope in general: Are there any other comments on the scope?</p>	<p>Stakeholders suggested the following amendments:</p> <ul style="list-style-type: none"> • Remove “clinical” from “based on clinical evidence” as too specific. • Stakeholders suggested that “life/lives” should be included with maternity topics. • It was suggested that “Currently available NHS treatment options” should be included instead of reasonable treatment’.

	<ul style="list-style-type: none"> • It was suggested to change “where shared decision making might be key” because shared decision making is key everywhere. <p>The following were noted by stakeholders:</p> <ul style="list-style-type: none"> • The scope needs a very clear definition of what “preference-sensitive” situations are because a clinician could decide a case is not preference sensitive and then no shared decision making would take place. • A study that considered shared decision making in neonatal intensive care was highlighted. It stated that starting a consultation with sympathetic phrases shows a more humane approach, which builds trust and understanding. • Consistency of care, team working and relationship building between service user and provider are needed for good outcomes, especially if the situation is complex. • Shared decision making is about finding personal preferences instead of risk of a procedure and should be highlighted more in the scope. • There should be a consideration for resource impact and health economics, whether it be positive or negative. However, health economics of shared decision making can potentially miss the benefits and implications for wider determinants health. • It was felt that the NICE pathway should have the nodes for healthcare professionals and people on the same level to avoid the implication of a hierarchy.
<p>Guideline committee composition We are recruiting the following members for the committee: Option 1:</p> <ul style="list-style-type: none"> • 2-4 further lay members with a breadth of experience 	<p>Stakeholders were concerned by the constraints around committee numbers because they wanted a committee composition with a breadth of knowledge. They felt that having specialist full committee members would leave gaps so believed that co-opting specialist members and recruiting members with multiple areas of expertise could overcome this problem. Stakeholders questioned whether 2-4 lay members would be sufficient. It was</p>

<ul style="list-style-type: none"> • Second shared decision making academic • Oncologist • Surgeon • GP with commissioning experience • Nurse specialist in chronic disease mgt • Pharmacist with an interest in shared decision making • Care of the elderly medic • Palliative care medic • Mental health prof • Medical ethicist <p>Option 2:</p> <ul style="list-style-type: none"> • 2-4 further lay members with a breadth of experience • Second shared decision making academic • GP with commissioning experience • Pharmacist with an interest in shared decision making • Mental health professional • Medical ethicist • Medic and AHP from primary care • Medic and AHP from secondary care • Medic and AHP from tertiary care. <p>Which of these memberships is more appropriate? Should we recruit anyone else either as a committee member or a co-opted expert?</p>	<p>agreed that it was more important to recruit the right lay members rather than focussing on the number of lay members.</p> <p>Suggestions made for full committee members by stakeholders were as follows:</p> <ul style="list-style-type: none"> • A speech and language therapist • A dentist • A midwife • A health visitor • Representation from AHP/nurse/doctor from primary and secondary or tertiary care • A large number of lay members with a variety of backgrounds, such as experience of shared decision making in primary and secondary care; good and bad experiences of shared decision making; shared decision making and mental capacity; and those who support people to engage in shared decision making • Someone with experience in safeguarding • 2 x medical ethicists with different perspectives • A non-medical-specific ethicist • A lawyer or academic with an interest in ethics • A social care worker • A shared decision making coach • An Independent Mental Capacity Advocate • Someone with experience in the voluntary sector • Someone who is not in favour of shared decision making • A community pharmacist
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- 2 x mental health professional
- A palliative care professional
- An elderly care professional
- A decision scientist
- A dietitian
- A health strategist

It was suggested that a paediatrician could be co-opted and to ensure that some of the lay people on the group are parents or young people.

It was noted that the committee composition would have to be amended if social care were included.