Shared decision making

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AbbVie	General	General	Abbvie note that the criteria for members of the shared decision making guideline committee does not include representatives from patient groups or industry. Patient groups / representatives would provide a crucial perspective on 'the other side' of shared decision making. A committee consisting of only specialists and professionals could be perceived as contrary to the principle of shared decision making. Industry partners could also provide expertise on shared decision making, based on projects and partnership working in the health system. Examples of Abbvie's work in this area are included in comment three. NICE should consider expanding the criteria for committee members and extended the deadline for applications.	Thank you for your comment. Please be reassured that there will be lay member (people using services, family members and carers, and members of the public, community or voluntary sector with relevant experience); representation on the committee. These roles have already been recruited to during earlier recruitment, and as such they are not listed in the online invite to join the committee. In addition, experts may be invited to attend a committee meeting to provide evidence from their experience and specific expertise, in the form of expert testimony, which is published on the NICE website when the guideline is published. **Registered stakeholders can also provide their perspective by commenting on the draft version of the guideline during the consultation phase.**
AbbVie	3	14	NICE should consider clarifying the definition 'everybody who delivers healthcare services'. The term might be perceived as too broad for some professions to identify with. For example, does this include those who prescribe, dispense or review medicines?	Thank you for your comment. This term has been used to include everyone who delivers healthcare so as not to exclude any groups.
AbbVie	6	11	NICE should consider the draft question – 'what are the most effective approaches and activities to support shared decision making', and ensure that, as this is developed to guide the literature review, it will be inclusive of relevant literature from Industry. For example, the report on the 'Perfect Patient Information Journey', developed by the Patient Information Forum in partnership with Abbvie. This sets out the points in the pathway	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in

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			where patients will be most receptive to information, and what information they need at which point. Information is a key component of shared decision making as only a well-informed patient can take an active part in decision making. The report can be accessed here: https://www.pifonline.org.uk/launching-today-perfect-patient-information-journey-final-report/ Abbvie also worked with the Fit For Work Coalition and a university partner to develop a shared decision making tool. This tool supports patients to have effective conversation with HCPs about returning to work, and managing their long-term condition. The tool can be accessed here: http://www.fitforworkuk.com/projects/ The evidence on the impact can be accessed here: https://www.abbvie.co.uk/responsibility/improving-health-outcomes/sh_pilots/shared-decision-making-tool.html	the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
AbbVie	7	4-17	NICE should consider expanding the 'main outcomes' they plan to consider when searching for and accessing the evidence. These should include the impact shared decision making has on a patients final decision, for example, to take a treatment or to undergo and operation. As an example, Berkshire West ICS moved to a shared decision making pathway for their osteoarthritis (of the hip and/or knee) services. Initial modelling suggested that 20% less people would opt to not have knee or hip replacement as a consequence. However data showed that 80% of patients are now choosing not to have surgery. This saved over £2.6 million over two years. Examples like this demonstrate the significant impact shared decision making can have on a patient's life-changing choices about their treatment and care.	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review protocols. The guideline committee will consider your comment when developing the evidence review protocols. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols

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			This case study is available in the Royal College of Anaesthetist's report 'A teachable moment' which can be accessed at: https://www.rcoa.ac.uk/document-store/delivering-pom-integrated-care-systems. It could also be used as an example of a cost saving intervention / innovative approach to be included in the guideline.	developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
AF Association	1	18	Using reliable, honest, unbiased resources that are in plain English without medical jargon, provided by professional patient organisations, allowing the patient to make an informed choice.	Thank you for your comment. The scope sets out the areas the guideline will cover. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
AF Association	7	10	This would enable full compliance with any treatments prescribed, the patient needs to be aware of how to follow specific instructions. Often, patients are told "take this medication twice a day" (for example). Some medications require specific instructions – eg to be taken 12 hours apart on an empty stomach.	Thank you for your comment.
Association for Family Therapy and Systemic Practice	3	12	It is important to acknowledge that there may often be differences in perspective between different family members. In order to support collaborative decision-making it may be important to allow sufficient time for discussion and exploration. In complex situations with high levels of difference it would be helpful to be able to refer to a professional with expertise in helping families to negotiate difficult decisions in complex situations where there may be high levels of conflict, such as a family therapist, who can facilitate exploration of all points of view to enable collaboration on the decision. The risk in these more complex situations is that some perspectives may be effectively silenced by a system that has historically only sought consent (i.e. agreement).	Thank you for your comment. Related to your comment, the guideline will consider the evidence for the barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for

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				each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
Association for Family Therapy and Systemic Practice	6	18	A likely barrier for healthcare professionals would be skills in facilitating collaborative discussions, in contrast to explaining information and requesting consent. It would be useful for healthcare providers to have access to high quality training, advice and consultation regarding how to facilitate collaborative discussions and how to help people to give voice to concerns, hopes and ambivalences. A likely barrier could also be time since true collaborative discussions take up more time than didactic information-sharing. Having access to an independent or impartial person with skills in facilitation who can spend time with the individual or family exploring options could be helpful.	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published

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				evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Association for Family Therapy and Systemic Practice	6	19-20	To effectively use collaboration as a model of shared decision-making, ways of addressing the power imbalance between healthcare professionals and people using healthcare need to be found. One cannot effectively collaborate from a 'one-down' position, and one cannot effectively discern true collaboration from compliance from a 'one-up' position. We would encourage the use of patient feedback about the extent to which the person's views felt heard, understood and respected during the decision-making; whether there are remaining concerns that have not been addressed properly; whether they felt they were emotionally in the right place to make the decision and if not, what would have helped. If some routine feedback was used then this could help shape shared decision-making to be more effective. In psychotherapy the Session Rating Scale (SRS) (Miller, Duncan and Johnson 2002) is a helpful method of session-by-session feedback on effective engagement from the client's point of view which also provides opportunities to improve the therapeutic relationship by discussing areas of feedback which are slightly less positive. A similar feedback measure could be developed to monitor the level of collaboration in shared decision-making. The SRS measure is described on Child Outcomes Research Consortium website: https://www.corc.uk.net/outcome-experience-measures/session-rating-scale/ References: Campbell A., & Hemsley S., (2009). Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures. Clinical Psychologist, 12, 1–9.	Thank you for your comment. The scope sets out the areas the guideline will consider. Please note that the scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for

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			Duncan B. L., Miller S. D., Sparks J., Claud D., Reynolds L., Brown J., Johnson L., (2003). The Session Rating Scale: Preliminary psychometric properties of a "working" alliance measure. Journal of Brief Therapy, 3 (1), 3–12.	each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Birth Trauma Association	General	General	Access to some forms of treatment, for example, in-vitro fertilisation, may be subject to the priorities of Clinical Commissioning Group (CCG). Maternity, however, is a special case. Only women give birth and they are a protected group for the purpose of discrimination legislation. Pregnancy is a condition that affects most women and complications of pregnancy can lead to severe long term health consequences for more than one generation. Anyone has an absolute right to refuse any treatment. Women, however, must be able to make an informed choice about how and where to give birth, what pain relief to have and what interventions to accept or refuse since women, not health care professionals, will live with the consequences of these decisions. All modes of birth – both planned vaginal and planned caesarean, have different risks and benefits; further complicated by the different risk factors that individual women may present. The Montgomery judgement makes it clear that it is not the clinician but the woman's view of what is important that should hold sway. Lady Hale particularly emphasised that doctors must not promote birth options that they regard as 'morally superior'.	**Thank you for your comment. The terminology used in the scope, shared decision-making, links in with national policy and initiatives, including the recently published NHS Long Term Plan and NHS England's Personalised Care Group's shared decision making programme. We feel it is important to keep the terminology consistent across national strategies and plans. We have, however, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.**

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			'Shared decision making' is therefore an unhelpful term; misleading for health care professionals and service users alike. Would suggest 'Understanding and supporting informed patient choice'.	
Birth Trauma Association	1	23	Maternity is one of the few services where previously healthy women may face needing to provide consent in an emergency for a potentially life threatening condition. How informed decision making is achieved and the stage at which information is exchanged needs clarifying and improving. This consultation needs to focus on the timing and quality of information giving and receiving.	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The guideline will consider the evidence for effective approaches and activities to normalise shared decision making in the healthcare system. Evidence permitting, the issues you raise will be captured in this review. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.
Birth Trauma Association	4	8	Maternity should not be excluded from this section as complication are extremely common and therefore not 'unexpected'.	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link

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				between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.
Birth Trauma Association	6	General	There is a major problem with the quality, timing and nature of information given to patients/women. Population health outcomes do not take account of patient values, patient experience and patient preferences. Moreover population outcomes are often not helpful in determining the best option for an individual. The most challenging element of the Montgomery judgement is that doctors must now investigate what matters to the patient as an individual and informing them about the kind of experience they may face with different treatment options. Population based data is not necessarily helpful in shaping decisions as it does not look at individual circumstances or what an individual considers is important. There needs to be a separate section (3.3?) entitled 'supporting informed choice' that looks at the complexity of these issues. In particularly, encouraging doctors to understand that supporting choices is as much about listening as information giving; an 'information exchange' rather than 'providing information'. Montgomery has 'changed the game' and it is not clear, without having a special section, that this radical shift will be sufficiently and urgently highlighted.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue

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				you have raised when developing the guideline.
Birthrights	General	General	We have significant concerns about the term "Shared decision making" as we do not believe this reflects either the legal position following the judgements in Montgomery v Lanarkshire and related case law, or the professional regulatory position on patient consent taken by the General Medical Council. We contend that: "Supporting Patient decision making" as described in the latest draft GMC guidance on decision-making and consent (see link below) or another similar term be used which clearly indicates that decision making is not "shared". Whilst medical professionals have an essential part to play in providing relevant information, and in fully discussing all reasonable options, and being able to give the benefit of their experience and expertise – in law there is only one decision maker and that is the patient. We would like this to be made clear throughout the document.	Thank you for your comment. The terminology used in the scope, shared decision-making, links in with national policy and initiatives, including the recently published NHS Long Term Plan and NHS England's Personalised Care Group's shared decision making programme. We feel it is important to keep the terminology consistent across national strategies and plans. We have, however, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
Birthrights	General	General	In light of Montgomery v Lanarkshire and other common law precedent in the UK it is worth stating that a woman retains all the same rights as any other patient when pregnant including the right to make her own informed decisions about her pregnancy and birth even if healthcare professionals believe those decisions may be harmful to herself or her baby. The special nature of maternity, and therefore the particular importance of supporting women's decision making in this context, would also be worth exploring in this guidance. In particular, we emphasise that under most circumstances a pregnant woman is not unwell, and that choice and control in maternity care are recognised as being of central importance to positive birth experiences (Downe et al 2018; Cook and Loomis 2012), ongoing psychological health (Harris and Ayers 2012; Reed et al 2017) and to mother-infant relationships (Birthrights 2013).	**Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.**

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Birthrights	General	General	In relation to question 1 – Birthrights has worked with NHS England to develop an intrapartum consent tool called IDECIDE which helps healthcare professionals and women to discuss reasonable options to enable the woman to make an informed decision under the challenging conditions of labour. The process of user testing with women and midwives/doctors has just been completed and a national rollout led by RCM and RCOG is planned – we would be delighted to provide further details.	**Thank you for providing this information, the team developing the guideline may be in contact regarding this tool in due course.**
Birthrights	1	14	This should be changed to "Supporting patient decision making is about helping the patient to reach a position where they are able to make the decision that is right for them based on the best available information, in the absence of pressure to make any specific choice."	Thank you for your comment. We have, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
Birthrights	1	15	As above healthcare professionals and patients do not work together to choose – the patient chooses.	Thank you for your comment. We have amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
Birthrights	2	3	Again people should be more than "involved" in their care. Legally patients are the decision-maker, as per comment 1 above.	Thank you for your comment. We have amended the scope to clarify that shared decision making is a collaborative process through which a clinician supports a people to reach a decision about their treatment.
Birthrights	2	19	The Montgomery v Lanarkshire judgement makes no mention of a "shared" decision – in our opinion part of the significance of the judgement is that it clearly puts decision making in the hands of the patient. This should be reworded to say "be gained when patients have reached a decision"	Thank you for your comment. We have, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
Birthrights	3	6	The latest GMC guidance is titled "Decision making and consent" and talks about supporting patient decision making not "shared" decisions – this wording should be replaced. https://www.gmc-uk.org/-/media/ethical-guidance/related-pdf-items/consent-draft-guidance/consent-draft-guidance.pdf?la=en&hash=920B435518160455840473FA316D7BEEBDFBB332	Thank you for your comment. The terminology used in the scope, shared decision-making, links in with national policy and initiatives, including the recently published NHS Long Term Plan and NHS

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				England's Personalised Care Group's shared decision making programme. We feel it is important to keep the terminology consistent across national strategies and plans. We have, however, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
British Society of Rheumatology	General	General	We are keen to support shared deTision making and value its importance especially in patients with long term conditions. We are also keen to maintain the emphasis for patients as well as professionals that professionals cannot be forced to provide treatments that they do not professionally consider to be suitable. It is also important to highlight the dilemmas that arise when patients' preferences do not align with guidelines that apply.	**Thank you for your comment. As noted in section 1 of the draft scope, shared decision making is applicable whenever there is more than one NHS care or treatment or management option available (options include doing nothing). Shared decision making enables patients to align their preferences to treatment options that are clinically valid. It does not mean that people can choose treatments that are judged not to be clinically or cost-effective.**
British Society of Rheumatology	2	4	Suggest switching the emphasis in this line to 'greater satisfaction with decisions' rather than 'fewer regrets about decisions' to make the statement more positive	Thank you for your comment, the scope has been amended accordingly.
British Society of Rheumatology	2	9	Suggest altering the wording to 'better concordance with agreed treatment plans' rather than the more paternalistic 'better adherence to an agreed treatment plan'	Thank you for your comment, the scope has been amended accordingly.
British Society of Rheumatology	3	17	Given the integration of health and social care, particularly in some regions (e.g. Greater Manchester), suggest considering moving social care professionals from the 'maybe relevant' category to the 'for' category	Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners,

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				especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
British Society of Rheumatology	4	10	Footnote 2 regarding referral to the NICE guideline on decision-making and mental capacity is noted. However, it could be argued that people who lack mental capacity should be given the opportunity for SDM to occur by proxy through their advocates. Line 5 may intend this to be the case but currently the wording could be interpreted either way.	Thank you for your comment. This population is covered by NICE guideline NG108, Decision-making and mental capacity, which is referenced in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
British Society of Rheumatology	4	15	Consider listing social care residences specifically, especially if including social care professionals explicitly (comment 3).	Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems,

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				and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
British Society of Rheumatology	7	17	In addition to the outcomes listed, please consider the following suggestions, made with reference to the potential benefits outlined on page 2: • effect on communication between patients and healthcare professionals • effect on concordance with treatment • effect on reducing unwarranted variation	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review protocols. The guideline committee will consider your comment when developing the evidence review protocols.
Caesarean Birth	General	General	Could the guideline title, '*Shared decision making*' be changed to remove the term shared? For example, 'Informed decision making'. My organisation has serious concerns about how the term 'shared' will be perceived and implemented, particularly in light of the issues raised about *NHS RightCare* in #8 above. It is evident from the experiences of women who contact *Caesarean Birth* after their caesarean request has been refused that planning a vaginal birth is considered the 'right care' (the opposite being true for caesarean birth). On first glance, a shared decision model appears practical and fair, as outlined in this paper: Elwyn G et al. Shared Decision Making: A Model for Clinical Practice. J Gen Intern Med. 2012 Oct; 27(10): 1361–1367. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445676/ "*…we propose a model of how to do shared decision making that is based on* choice, option *and* decision talk. *The model has three steps: a)* ***introducing choice****, b)* ***describing options****, often by integrating the use of patient decision support, and c) helping* ***patients***	Thank you for your comment. The terminology used in the scope, shared decision-making, links in with national policy and initiatives, including the recently published NHS Long Term Plan and NHS England's Personalised Care Group's shared decision making programme. We feel it is important to keep the terminology consistent across national strategies and plans. We have, however, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.

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			***explore preferences and make decisions**. This model rests on supporting a process of deliberation, and on understanding that decisions should be influenced by exploring and respecting "what matters most" to patients as individuals, and that this exploration in turn depends on them developing informed preferences."* However, in maternity care, this model frequently fails on all three steps (highlighted in bold) above. Choice is introduced in the context of birth place only, options described do not consistently include planned caesarean birth (even when a woman has risk factors such as advanced maternal age, short stature, suspected macrosomia, previous birth trauma, family history of obstetric complications), and preferences can be ignored or downplayed. It would be much clearer, and better, if the language used by NICE reflected the legal position on patient decision making, and removed any room for confusion. Information can be shared, but the decision (which might be to decline making a decision, and defer to the health professional's advice) should rest with the patient.	
Caesarean Birth	General	General	These are some comments from women who have had experience in maternity care, and their views on what this guideline needs to include. All are published here with permission: 1) The guideline should make clear that in normal circumstances it is unacceptable to withhold information about risk from a patient because the healthcare provider thinks it is in their best interest not to know or, as in Montgomery 2015, because the provider does not want that information to influence the patient's decision. The argument that women shouldn't be told of the risks of vaginal birth as it will scare them is completely unacceptable and would never be made in other areas of medicine. 2) The law is clear for any other area of medicine. When recommending a particular treatment, material risks need to be communicated to patients and alternative treatments explained. The material risks of attempt at vaginal delivery are not explained to first time mums unless they are classed as high risk. I believe the same bias operates when second time mums are offered VBAC. The material risks of attempt at vaginal delivery after CS aren't	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The guideline will have the opportunity to cross-refer to related NICE guidance as needed, including the caesarean section guideline (CG132), which states women's right to request and be offered a planned caesarean section. We have amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care. The scope also now references the link

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			given. This is not informed consent. It's a system treating women like children. 3) As a women who would love to be a mom, one of my greatest fears, and one of the reasons why at 39 I'm still not a mother is that I won't be listened to or be given honest, unbiased, evidence based information about everything to do with pregnancy and birth. I am an intelligent women who wants to know the pros and cons before making a decision. I have gone to great lengths to inform myself about the process of pregnancy and birth because the information available seems to me to be very limited, and biased, often with little evidence to back it up. I had to FOI my local trust to get data on birth (1,2,3,4th degree tears, induction levels, instrumental, c-section broken into emergency/planned etc.) so I could decide in my age group how I would like to give birth should the situation arise. I found that in my age group, just 7% of women give birth naturally without intervention of any kind and with no injury. I didn't find this information put clearly anywhere else, and for me this is very important. Some women may be willing to risk tearing or instrumental delivery in order to avoid a c-section, but for me I'd much prefer the controlled manner of a section, even with the longer recovery time and the possible complications for me and my child. When it comes to things they don't want you to do - planned c-section for instance, there's BUCKETS of information about why it's bad, and the dangers of it - but very little balance to say actually for some women it can be absolutely the right choice. There's also very little clear information about the possible long term effects of vaginal and c-section births (prolapse, incontinence etc.) - it seems to all be about the event itself - not the potentially long term and life changing consequences which I feel women should have access to information on. I find the same with breastfeeding data - lots of people saying breast is best - but when you look for the actual hard evidence most of the time its weak, and it seems it's considered best because it's 'natural' in most people's opinion. I want to be able to make informed choices based on good evidence, not the personal belief of my health care professionals. 4) It is extremely frustrating that post Montgomery v Lanarkshire we are still seeing many Trusts refusing to offer caesarean birth to women, which is clearly a reasonable and available NHS treatment option. Having read the judgement I don't think there is any possible reasonable interpretation other than that women should be offered this choice; it seems	between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.

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			Trusts are simply choosing to ignore the law. The quality of the information given to women by Trusts is dreadful, it is contradictory between Trusts, often inaccurate and totally unbalanced, with the risk of vaginal birth significantly under-emphasised or left out altogether. I think the guideline should be clear that written patient consent is required for planned vaginal birth and for induction of labour, with caesarean birth offered as an alternative. I think the argument that it is natural or doesn't involve intervention is invalid for two reasons; firstly it involves acceptance of levels of risk which if associated with a surgical procedure would absolutely require consent, and secondly there is a high likelihood that the planned course of action will result in a situation requiring medical interventions that do require consent, but women are sometimes unaware that they are in effect accepting those risks from the beginning. I think the guideline must also make clear that accurate, balanced information must be given about the risks and benefits of all reasonable treatments. Also, the guideline ought to make it clear that ultimately the decision is the patient's. The healthcare provider can recommend a course of action but ultimately the patient has the right to choose. As I understand it, that is the position in law; you cannot be forced to accept treatment even if everyone else disagrees, if you have capacity. It would be good if the guideline made it clear that this applies to reasonable care options in maternity care (e.g. vaginal birth or c-section).	
Caesarean Birth	General	General	Below are some examples of statements contained within CQC maternity care inspection reports over the past five years. I include them here because they emphasise the current problem with 'shared decision making' in many areas of maternity care. Information and discussion is too often focused on talking women out of having a caesarean birth, encouraging them to have a vaginal birth, and improving the 'rate performance' of the hospital. Five Years of Care Quality Commission (CQC) Maternity Inspections (2013-2018) Part 1: Target Rates – Caesarean Birth and Promoting Normality September 2018 https://caesareanbirth.org/2018/09/07/the-cqc-will-no-longer-inspect-against-targets-and-says-trusts-should-not-be-encouraged-to-reduce-caesarean-rates/	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.

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			"*2014: There was no pathway in place for maternal request caesarean section, which meant* ***there was no mechanism for questioning the decision***." "*2015: Antenatal women who had concerns about their impending labour and delivery could be referred to the Talking about Birth midwifery-led clinic. The* ***aims of the clinic*** *were to: reduce patient anxiety levels and* ***also to reduce elective caesarean rates (where not clinically indicated)***" "*2016: The total caesarean section rate was… higher (worse) than the national average… Staff told us they thought* ***their performance*** *was due to the number of women choosing a caesarean section.*" "*2016: The trust wide caesarean section rate was… generally lower (better) than the national average…* ***performance was due to the success of the birthing clinic*** *which supported women with their fear of childbirth, and* ***helped reduce the number of women choosing caesarean section***." This example of CQC criticism stood out as being different, and was not the norm: "*2013: Respecting and involving people who use services: The provider was not meeting this standard. Reasons for our judgement: …****mother told us she would have preferred a caesarean section, but she felt she was not listened to and that staff involved were "pushing [her] into a natural delivery****"*."	
Caesarean Birth	General	General	Thank you for this opportunity to comment.	Thank you for your comments.
Caesarean Birth	1	17-21	"*…based on evidence and the person's personal informed preferences and values. This involves making sure the person has a good understanding of the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make a decision about the treatment and care that is right for them at that time*" Given that the 2015 Montgomery ruling specifically cited in this guidance is related to maternity care, coupled with the fact that maternity litigation costs have reached unprecedented (and unaffordable) levels, this statement is absolutely key for obstetrics and	Thank you for your comment. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are

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			maternity care. It would be very helpful if this was explicitly mentioned in the guideline. Currently, there is bias in the information that is communicated to women during their antenatal care, and an absence of many risk and benefit facts that might influence their decision making. One of the biggest issues is the focus on PLACE of birth, ignoring MODE of birth, as well as a focus on short-term intrapartum outcomes, often ignoring longer term repercussions. This impedes "*a good understanding of the risks, benefits and possible consequences of different options*". I have commented about this issue in numerous other NICE guideline drafts, and this decision making guideline could be an important first step in establishing and broadening the scope of information that women receive in maternity care. Perhaps It could be included as an example case here?	able to exercise choice about the kind of services they receive.
Caesarean Birth	1	22-25	"*Shared decision making is applicable in all healthcare settings (acute, chronic, palliative and preventative care) whenever there is more than one NHS treatment or management option available (options include doing nothing).*" Suggest adding 'maternity' to this list. Also see comment re: 'shared decision making' in #13 below. Thank you.	Thank you for your comment, the scope is applicable to all healthcare settings where publicly funded healthcare services are commissioned and provided, including maternity healthcare settings.
Caesarean Birth	2	14-15	"*A landmark ruling was made in 2015 by the UK Supreme Court following 15 the Montgomery v Lanarkshire case.*" Excellent to see this formally included in this guideline. However, suggest contextualising the reference and referring to maternity care here.	Thank you for your comment. Section 1 of the scope is a summary of current practice; therefore, we are unable to include a comprehensive outline of why the guideline is needed.
Caesarean Birth	2	27-29	"*As set out in the NHS Constitution for England, people have the right to be involved in planning and making decisions about their health and care, and to be given information and support to enable this.*" See comments in #13 below re: guideline title '*Shared decision making*'. This constitution	Thank you for your comment. The terminology used in the scope, shared decision-making, links in with national policy and initiatives, including the recently published NHS Long Term Plan and NHS England's Personalised Care Group's

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			statement does not refer to a shared decision.	shared decision making programme. We feel it is important to keep the terminology consistent across national strategies and plans. We have, however, amended the scope to clarify that while the process of reaching a decision is shared, ultimately this is to support the person to reach a decision about their care.
Caesarean Birth	2	3	"*The benefits of involving people in decisions about their care may include:*" Suggest adding to this list: - reducing litigation, which can be an additional burden on patients already coping with healthcare issues The suggestion above could be reworded but it is important to acknowledge that reducing litigation is not necessarily just a financial goal; it can optimise patient outcomes and experiences too. Patients often find the pursuit of litigation a very stressful, consuming and lengthy process, and this could be reduced if points 4-11 were more consistently achieved.	Thank you for your comment. Section 1 of the scope is a summary of current practice; therefore, we are unable to include a comprehensive outline of why the guideline is needed.
Caesarean Birth	2 3	29-31 1-2	"*In line with this, the Health and Social Care Act 2012 makes clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice.*" Could/should this include information on Trust websites (as part of CCGs enabling patient choice)? I ask because despite CG132 NICE guidance and QS32 quality standards on caesarean birth (published in 2011 and 2013 respectively), there is a dearth of information about maternal request on NHS hospital websites.	Thank you for your comment. The focus of this guideline will be on the most appropriate ways to undertake shared decision making. Related to your comment, the guideline will consider the evidence for the barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers.

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Caesarean Birth	3	2-4	"*The Department of Health and Social Care's NHS Choice Framework sets out the choices that people can expect to be offered, and information to support these choices.*" I have copied and pasted some of the text from this government framework here, and highlighted problems in **bold (with notes below)** in relation to how information on birth choices is communicated to women: https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs#section-2-maternity "*The NHS Choices pregnancy and baby pages will provide you with all the necessary information you require particularly the **options on where to give birth**.* *In addition, there are a number of **charitable and voluntary organisations** that can also help you decide what to do. These include:* • *National Childcare Trust (NCT) or call their Helpline: 0300 330 0700* • *Which? Birth Choice* • *Association for Improvements in the Maternity Services (AIMS) or email helpline@aims.org.uk or call the Helpline: 0300 365 0663 for advice from volunteers* ***6. Choosing maternity services*** ***What choices do I have?*** ***You can expect a range of choices in maternity services, informed by what is best for you and your baby.*** ***When you find out that you are pregnant you should expect to be able to choose which midwifery service you attend from a range of options. To access this service you can:*** ***- go directly to your chosen midwifery service: you can use NHS Choices to find out more about the different services that are available and then self-refer*** ***- go to your GP and ask to be referred to your chosen midwifery service: your GP should provide you with information about the different services that are available***	Thank you for your comment. The scope has been amended, with reference to the Choice framework removed to avoid confusion. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.

			While you are pregnant you should be able to choose to receive antenatal care from: ***- a midwife*** ***- a team of maternity health care professionals, including midwives and obstetricians. This will be the safer option for some women and their babies*** ***When you give birth you should be able to choose to do so:*** ***- at home, with the support of a midwife*** ***- in a midwife-led facility (for example, a local midwife-led unit in a hospital or birth centre), with the support of a midwife*** ***- in hospital with the support of a maternity team. This type of care will be the safest option for some women and their babies*"** ***"options on where to give birth"*** **– Focus is on place of birth, not mentioning mode.** ***"charitable and voluntary organisations"*** **– The two charities listed are long time campaigners for 'normal birth' and the *Which tool* has been criticised for focusing on place of birth. This list should be broader.** *"informed by what is best for you and your baby"* – This is a problem when the choices and information provided are based on an assumption that planned vaginal birth is better than planned caesarean birth unless the pregnancy is high risk. *"choose which midwifery service you attend"* – This assumes a decision from the outset. What about women who want obstetrician led care? *"go directly to your chosen midwifery service"* – As above *"your chosen midwifery service"* – As above	

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Caesarean Birth	3	7-9	"*NHS England is supporting the implementation of shared decision making across care pathways at national and local level through its NHS RightCare shared decision making programme.*" I have copied and pasted some of the text from this NHS programme here, and highlighted problems in **bold (with notes below)** in relation to how information on birth choices is communicated to women in maternity care: https://www.england.nhs.uk/rightcare/useful-links/shared-decision-making/ "*Evidence shows that where people are more involved in their health care decisions their experience of care is improved. In addition, **more informed people tend to choose less treatment which can result in less waste and harm, as well as better use of resources**.*" *Shared decision making is an integral part of NHS RightCare. Its **function** is to improve outcomes for individuals by **focusing on**:* - ***Value*** ***- Addressing overuse and underuse*** ***- Recognising that informed individuals choose less interventions*** ***- Tackling unwarranted variation*** *- Improving outcomes for individuals* *"more informed people tend to choose less treatment which can result in less waste and harm, as well as better use of resources."* – This statement is hugely problematic in maternity care, where the decision is often between doing nothing or medical intervention (e.g. scans in late term pregnancy, epidurals for pain relief, planned caesarean birth versus awaiting spontaneous vaginal birth). A woman is no less informed if she chooses more treatment, it is not a 'waste' or 'harm', and it is not a poor use of resources. *"function… focusing on… Value… Addressing overuse and underuse… Recognising that informed individuals choose less interventions"*	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive.

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			– Four out of five in this list are already proven to have failed in the context of maternity care safety, both in terms of patient satisfaction and litigation costs. The CQC promised improvements in September 2018 (https://caesareanbirth.org/2018/09/07/the-cqc-will-no-longer-inspect-against-targets-and-says-trusts-should-not-be-encouraged-to-reduce-caesarean-rates/), but there remains an issue with the perception of caesarean rates in maternity care, what they indicate in the context of safety, and what action needs to be taken. The above issues contradict the statement that comes next in the RightCare programme, and as such, illustrate how easy it is to talk about and offer '*shared decision making*' when in reality, there are focuses, biases and assumptions, already firmly in place, that threaten to thwart genuine implementation in maternity care unless this NICE guidance is abundantly clear on the issue: *"NHS RightCare is working in collaboration with NHS England's Personalised Care team to ensure shared decision making is embedded into practice and people are empowered to make informed decisions about their health and care thereby better meeting their individual care and treatment needs and preferences."* This empowerment must include balanced information on the risks of both planned vaginal and planned caesarean birth, and not only for those women who are requesting a caesarean. This cannot be achieved through the focus outlined above in the *NHS RightCare* programme.	
Caesarean Birth	7	2-3	"*The key issues and draft questions will be used to develop more detailed 3 review questions, which guide the systematic review of the literature*" Can you please confirm whether maternity care or obstetrics will be included in the literature review?	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. Accordingly, maternity care will be included in the review protocol.
College of Mental Health Pharmacy	General	General	We welcome this guideline which is much needed in the current healthcare system, particularly in mental health.	Thank you for your comment.

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College of Mental Health Pharmacy	1	14-21	We agree that shared decision making is a collaborative process but the description in lines 14-21 suggests information sharing in one direction: from healthcare professional to patient. True shared decision making involves a two-way conversation in which not only does the healthcare professional impart clinical, evidence-based information but also actively seeks to obtain information from the patient about their own experiential knowledge, values and perspectives (Makoul, G. and Clayman, M., 2006). Patients are often strongly influenced by stories from fellow patients or relatives, online blogs and other online resources, some of which may not have a strong evidence base. It is this knowledge about that individual that the healthcare professional should embrace in supporting that patient with a decision about their own care. We feel that it is essential for this information-sharing to happen in an open, 'safe' environment whereby patients feel confident to be honest about their views to encourage shared decision making (Azra Sumar, 2016). Refs: • Makoul, G. and Clayman, M. (2006) 'An integrative model of shared decision making in medical encounters', Patient Education And Counselling, 60(3), 301-312. Azra Sumar, Masters dissertation: Refinement and evaluative study of a shared decision making tool for psychotropic medication: a mixed-methods study, 2016, University of Nottingham, IRAS project ID 203767)	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Any evidence relating to effective communication and collaboration will be captured in this review. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
College of Mental Health Pharmacy	1	22	We feel that NICE should make it clear at this outset that 'all healthcare settings' includes both physical and mental health.	Thank you for your comment, the scope is applicable to all healthcare settings where publicly funded healthcare services are

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				commissioned and provided, for both physical and mental health.
College of Mental Health Pharmacy	1	28	We agree with this statement: shared decision making is not yet routinely practised. Furthermore, shared decision making has been less evaluated in mental health than physical health (Duncan et al 2010). Ref: Duncan, E., Best, C. and Hagen, S. (2010) 'Shared decision making interventions for people with mental health conditions', The Cochrane database of systematic reviews, (1), CD007297.	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
College of Mental Health Pharmacy	2	1	Agree with this statement. Includes patients with mental health conditions.	Thank you for your comment.
College of Mental Health Pharmacy	2	10	Agree. Please add "***being heard***", a feeling that is really important when receiving care and particularly so in mental health.	Thank you for your comment, the scope has been amended accordingly.
College of Mental Health Pharmacy	2	16	Consent to treatment: NICE may like to include a statement for patients detained under Section 2 and 3 of the Mental Health Act 1983, where consent is not needed for the first 3 months. During this time, patient can receive treatments against their will. After the first 3 months, consent is sought.	Thank you for your comment. Decision-making in people who lack mental capacity to make specific decisions is outside of the remit of this guideline but it is covered by the NICE Guideline 'Decision-making and mental capacity' (NG108).
College of Mental Health Pharmacy	2	9	Agree. Where the treatment plan involves medication, there is improved concordance. In the case of psychotropic medication, a reduced rate of relapse.	Thank you for your comment.

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College of Mental Health Pharmacy	3	7-9	Really pleased to see the amalgamation of knowledge in this area by NHS England. From this programme it is evident that there is little previous work on promoting shared decision making in psychiatry. There are only four decision tools for use in mental health on their website; all four are about depression and take the reader to a Canadian website. We are concerned that Canadian guidelines are not always transferrable to UK guidelines. For example the shared decision making tool entitled "Should I stop taking my antidepressant" states that the prescriber "*may be able to prescribe an antidepressant that costs less*". This is not relevant in the UK because of the pre-set NHS prescription cost for patients. Furthermore, the shared decision making tool entitled "Depression: should I take an antidepressant" is based on just two 2 references, one of which refers to Canadian guidelines which may not be transferable to the UK, and the second one is a single study (n=104), based in Canada that compares medication to cognitive behavioural therapy in moderate to severe depression.	Thank you for your comments.
College of Mental Health Pharmacy	4	10	NICE may like to include a statement for patients detained under Section 2 and 3 of the Mental Health Act 1983, where consent is not needed for the first 3 months. During this time, patient can receive treatments against their will. After the first 3 months, consent is sought. Furthermore, in mental health, patients may have drawn an "advance statement" or "relapse signature" to guide care providers about their preferences regarding medication during a relapse. In situations where capacity is not attainable, healthcare professionals may find it helpful to refer to these documents held by patients and their carers and in their medical notes to promote shared decision making.	Thank you for your comment. This population is covered by NICE guideline NG108, Decision-making and mental capacity, which is referenced in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
College of Mental Health Pharmacy	5	21-25	Agree with these related NICE guidelines	Thank you for your comment.
College of Mental Health Pharmacy	6	10-26	We feel that there is a need for a subdivision for special considerations in mental health because this process is more complex and multifactorial than physical health conditions (Azra Sumar 2016, Azra Sumar, current). Subsequently, it is more difficult to predict possible outcomes for individuals. (Refs:	Thank you for your comment. The scope sets out the areas the guideline will consider. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions

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			- Azra Sumar, Masters dissertation: Refinement and evaluative study of a shared decision making tool for psychotropic medication: a mixed-methods study, 2016, University of Nottingham, IRAS project ID 203767) Quality Improvement project: PINMED (Patient Involvement in Medication Decisions), Leicestershire Partnership NHS Trust, led by Azra Sumar. PINMED is a tool that proposes to encourage shared decision making during discussions about psychotropic medication, currently being piloted, results to follow.	described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
College of Mental Health Pharmacy	8	4-5	Strongly agree that links to NICE "Decision making capacity" and "Service user experience in adult mental health services" are relevant.	Thank you for your comment.
Community Health and Learning Foundation	General	General	The draft scope does not acknowledge the importance of patient health literacy in shared decision-making. It needs to acknowledge that without health literacy, or the health literacy needs of the patient (or client) being taken into account, true shared decision-making cannot take place. Without taking steps to assure that the patient has information or resources / support that they need to access, understand, appraise and use information in making decisions, then shared decision-making cannot truly take place. If this is not made explicit in this scope, there is a risk that encouraging shared decision making without acknowledging health literacy could exacerbate already existing, and worsening, health inequities	Thank you for your comment. The importance of health literacy is noted in the equality impact assessment. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular

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				group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Community Health and Learning Foundation	General	General	Guidance developed must build on existing research, evidence and interventions to maximise impact and make effective use of existing progress. There are multiple tested interventions that can support health literate Shared Decision making for professionals from Teach back and Chunk and Check to guidance on writing written information including a tool developed for NHSE (NHS England) by CHLF (Community health and learning Foundation CIC) and PIF(Patient Information Forum).There is also a suite of national evidence based resources which have recently been updated ;Skilled for Health which embeds health and LLN skills (Language Literacy and Numeracy)which supports individuals to improve their health literacy and has been used to help people with Type 2 Diabetes to improve self-management of their condition in a national demonstrator site. The old version is available via the CHLF website the updated version will be available shortly.	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
Compassion in Dying	General	General	With the NHS Long Term Plan focusing on personalisation and the launch of the Universal Personalised Care, a NICE guideline on shared decision-making is welcome. To ensure effective implementation of these principles, it is vital that the NICE guidelines refer to and build on these policy documents. For shared decision-making to become a reality, the culture change that is required – i.e a move from paternalistic medicine to person-centred care – must be acknowledged and we hope that the detailed guidance places special emphasis on this. For example, the fact that healthcare professionals must respect a person's decision even if they disagree with it and	Thank you for your comment. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. The guideline will consider the evidence relating to approaches and activities for supporting healthcare providers to engage

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			the referral responsibilities in relation to conscientious objection must be included within the guidance if it is to genuinely support shared decision-making.	with shared decision-making as well as evidence relating to barriers and facilitators. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Compassion in Dying	General	General	**Barrier 2** Another barrier worth discussing in the guidelines is the paternalism that unfortunately still exists within the medical profession. People have told us that healthcare professionals made them aware of decisions that needed to be made about their care but did not necessarily involve them in the decision making process. For example, one caller said - *"My first treatment drug produced terrible side effects that put me in hospital for three weeks and took six months to recover from. I wish I had known enough to put my foot down and insist that my then oncologist either reduced the dose or changed the medication. At the time I was new to all of it and could have done with a source of informed support in achieving this."*	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers.

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			On the other hand there are good practices around honest conversations and shared decision making which ought to be replicated. As one caller said – *"The oncologist was really sweet and kind and I liked her a lot. What she said was the drugs I could give you at this stage would actually make you more ill than you are now. This was great. It was frank and honest. Direct."* As such, the principles of shared decision-making and person centred care are relevant to both advance care planning and current decision-making and we hope this will be clearly reflected in the guidance. More information on what people want from healthcare professionals can be found in our report, *I wish I had known…reflections from supporting 25,000 people plan for the end of life (2018) https://compassionindying.org.uk/library/i-wish-i-had-known/*	The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. **The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.**
Compassion in Dying	3	5	Compassion in Dying recommends that NICE liaise closely with the GMC team working on the Decision making and consent guidance to be published later in 2019 as it promises to include progressive and practical support to healthcare professionals on shared decision-making.	Thank you for your comment. We have amended the scope to explicitly refer to the GMC's guidance on good consent practice.
Compassion in Dying	6	14	Much has been written about the importance of healthcare professionals asking "what matters to you?" and we urge the NICE team to review these documents when developing the full guidance • Health Improvement Scotland - http://www.whatmatterstoyou.scot/ • Alf Collins et al - https://blogs.bmj.com/bmj/2018/06/06/anya-de-iongh-and-alf-collins-what-matters-to-you-is-at-the-heart-of-person-centred-care/?utm_campaign=shareaholic&utm_medium=twitter&utm_source=socialnetwork	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as

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				healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. We will keep in mind the issue you have raised when developing the guideline.
Compassion in Dying	6	18	Compassion in Dying has supported over 25,000 people to consider and record their treatment preferences and we have learned about some of the barriers that exist to person-centred care. **Barrier 1** Data gathered from our service-users highlights that and one of the biggest barriers people face when seeking to plan their care, is healthcare professionals not knowing how people can plan ahead in a meaningful and legally relevant way – i.e. using Advance Statements, Advance Decisions and Lasting Powers of Attorney. We therefore recommend that when detailing the facilitators of shared decision-making, focus is placed on the importance of healthcare professionals knowing the various options available to a patient and, in the event of uncertainty, having the confidence and skill to signpost patients to other healthcare professionals and/or external organisations such as dedicated charities and disease specific organisations.	Thank you for your comment. The scope sets out the areas the guideline will consider; section 1 now notes the inclusion of advance care planning within the shared decision making process. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in

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			More information on the impact of this particular issue can be found in our recent report - *Advance care planning in general practice – does policy match reality?* (2018). We were prompted to conduct a Freedom of Information request to all CCGs in England about their policies on advance care planning after receiving frequent enquiries to our free information line about the role of GPs in planning ahead. Callers reported doctors being hesitant, not confident or even unwilling to discuss or record their advance care plans, including Advance Decisions to Refuse Treatment, Do Not Attempt Cardiopulmonary Resuscitation forms, and/or a Lasting Power of Attorney (LPA) for Health and Welfare. We received a 100% response rate from the CCGs and the report highlights that, contrary to the official policies of many CCGs, in practice there is often a lack of quality information and training for GPs on advance care planning; there are failures to fully implement the Mental Capacity Act; and no formal and universally applied systems for recording advance care plans on patients' records. See more here - https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/.	Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Concentric	6	10	I would support a subdivided question here regarding the role of technology in supporting shared decision making - given a significant expected shift in this space in the coming years towards precision/personalised medicine.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in

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				the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
CSF Leak Association	General	General	The CSF Leak Association welcomes the draft scope and would like to see the guidelines cover situations where shared decision making is desired but there is not much in the way of evidence base to advise clinicians and patients of the risks, potential complications and benefits of one treatment option over another.	Thank you for your comment. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Department of Health and Social Care	General	General	We would encourage NICE to think about making these guidelines more applicable to social care settings. As is the case in healthcare settings, there can be multiple options available to an individual when they need social care. Shared and supported decision making is therefore vital to make sure someone receives the right package of care– e.g. which care home will best meet their needs, whether there is an option to receive care at home, whether a personal budget is appropriate, whether they can adapt parts of their home to facilitate independent living etc.	**Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that**

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				shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
Department of Health and Social Care	General	General	Funded Nursing Care and Continuing Healthcare are also publicly funded healthcare services, however are most often delivered in the social care setting. We would encourage NICE to think about addressing this area in the guidelines.	Thank you for your comment. The guideline will cover all settings, including people's own homes, where publicly funded healthcare services are commissioned and provided.
Department of Health and Social Care	General	General	Were NICE to decide it is not appropriate to bring social care into the remit of these guidelines, we would strongly support the development of additional guidelines on shared and supported decision making specifically for social care.	**Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the**

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				referral and development of a separate guideline.
Department of Health and Social Care	6	7-30	Could the scope of the new guideline on Shared Decision Making include a consideration of shared decision making specifically in maternity services. Most women using maternity services are healthy and not considered to be 'patients'. They often have time to think about their choices and plan their care with their midwives. Their circumstances, however, can change rapidly at any stage of the maternity pathway and become life threatening. Currently, midwives and women tend to plan care expecting good outcomes and little thought or discussion goes into 'what if things go wrong' scenarios. Midwives often say that the don't want to scare women, but when women end up needing interventions that aren't expected, then many feel that they have 'failed' in some way. They feel they have been 'done unto', and they wished they had known more in order to give truly informed consent and participate in shared decision making even during labour. One question to consider is what tools to clinicians need to communicate rapidly with women/patient/their partners, when decisions need to be made within minutes, in a way that the women/patient/their partners feel that they have participated in shared decision making and given truly informed consent. Birthrights has been doing work to consider these questions. More information can be found here: http://www.birthrights.org.uk/wordpress/wp-content/uploads/2018/04/Transforming-Consent-Report-Cobranded-Final-April18.pdf	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided, this includes maternity healthcare settings. The scope now references the link between shared decision making and the personalised care objective detailed in the NHS Long Term Plan. A range of actions are set out in the NHS Long Term Plan concerning the quality and safety of maternity services, including aims to ensure more women are able to exercise choice about the kind of services they receive. Related to your comment, the guideline will consider the evidence for the questions listed under supporting shared decision making. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline

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				committee during development. We will keep in mind the issue you have raised when developing the guideline.
Festival of Life and Death	General	General	There is huge potential for more radical innovative creative thinking, as to how we define 'Shared Decision Making' and also for questionaing (radically broadening and deepening) what we understand about the ways to communicate and conceptualise and facilitate and design 'activities' etc., and other fundamental assumptions of terminology and meaning within the documentation, and thereby, the entire Shared Decision Making opportunity, which is incredible vast and fertile, under-estimated, and unexplored, and under-developed.	Thank you for your comment.
Festival of Life and Death	General	General	The processes and methods and language (in the broadest senses) that are implicit within this project, by their nature (e.g., evidence-dependent/driven, and administratively/left-side-brain biased), exclude to serious degrees most of what is required and powerful in innovation. In other words, the styling and philosophical framework for the consultation is inherently self-limiting, because it is designed from an (understandably) clinical and administrative standpoint. We must embed creativity and unlimited possibility, and particularly creativity, flair, imagination, boldness, and absolute accessibility into the consultation, so as to include the greatest possible number of brilliant creative minds and ideas.	Thank you for your comment. The scope sets out what a NICE guideline will and will not cover. For some guidelines, including this one, registered stakeholders are invited to a scoping workshop to talk about the key issues in the scope, and discuss any other aspects as needed. The scoping workshop, if held, is in addition to the formal consultation on the draft scope. Stakeholder organisations with representatives attending the scoping workshop are also encouraged to submit comments in writing as part of the scope consultation.
Festival of Life and Death	General	General	There is huge opportunity/need to establish and refer (often) to an **inspirational vision**. We unleash he potential (and crucially remove self-limiting and assumptions/conditioned barriers that blocking such potential at the outset) of any venture, especially when we seek innovative transformation, and especially in situations where decades (and actually centuries/millennia) of conditioning thinking has prevailed and governed/limited innovation. This is normal, and nobody's fault – it's a feature of vast systems, that the means of change become suffocated by legacy management and culture, language, etc. And so we must think and create radically, and open possibilities and dreams (yes dreams) at the very outset, and at the	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published

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			deepest heart of what and how we facilitate creative change. This is especially so for anything relating to mental health, which basically is everything physical and environmental too. So I am making a very fundamental point, and plea, in this comment.	evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
Festival of Life and Death	General	General	Extending the above point – we have vast opportunity/need to alter bias of philosophy/methods much more towards radical creativity, and reposition the very vital aspects of evidential and administrative rigour to that of a being required rightly for safety, checking, measurement, implementation (to a degree, not wholly), and ongoing improvement. Humanity and all that humanity creates, exists within is organic, and with powerful uncertain universal connections and influences. The design, leadership and facilitation of transformation must respond to and be sympathetic to this organic nature of life and planet.	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
General Medical Council	General	General	We are pleased that NICE is developing a guideline on shared decision making. As you're aware we are currently reviewing our own guidance on *Consent: patient and doctors making decisions together*. Our public consultation, which NICE very helpfully responded to, has just closed. We are aiming to publish the revised guidance ready for publication towards the end of 2019. We look forward to discussing your guideline further with you as it develops, and to working with you to raise awareness of shared decision making, and developing resources to help people implement the principles into their every day practice.	Thank you for your comment and providing this information. We have amended the scope to explicitly refer to the GMC's guidance on good consent practice.

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General Medical Council	General	General	We note that you have not used the term 'consent' in your draft scope. While we would fully support the aim of widening shared decision making from those relatively narrow circumstances where consent to treatment is formally being sought, we feel it's important to state that the guideline covers these circumstances as well as others. It's important that, in seeking a patient's consent to treatment, a healthcare worker is guided by the principles of shared decision making so that the decision made is informed, and not simply, e.g., a signature on a form.	Thank you for your comment. Section 1 of the scope outlines NICE's definition of shared decision making for the purpose of the development of this guideline. It is our understanding that 'consent' is captured under the existing text: 'empowers people to make a decision about the treatment and care that is right for them at that time.' **Furthermore, Section 1, refers to the Montgomery v Lanarkshire ruling: 'A new legal standard set out that adults 'of sound mind' are entitled to make informed decisions when giving or withholding consent to treatment. Consent 'must be obtained before treatment interfering with bodily integrity is undertaken', and it should only be gained when patients have shared a decision informed by what is known about the risks, benefits and consequences of all reasonable NHS treatment options.' We have, however, amended the scope to explicitly refer to the GMC's guidance on good consent practice. We will also keep in mind the issue you have raised when developing the guideline.**
General Medical Council	2	4	We note the listed benefits of involving people in decisions about their care. You may also wish to consider one of the aims of the CMO for Scotland's Realistic Medicine initiative: reducing harmful and wasteful care. While we recognise NICE's remit only extends to	Thank you for your comment. Section 1 of the scope is a summary of why the guideline is needed. The development of the guideline will follow the processes and

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			England, the principles of Realistic Medicine read across to both Consent and Shared decision making.	methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
General Medical Council	3	8	You say that the guideline won't be covering *whether* shared decision making is required. We may have misunderstood, but surely a healthcare worker accessing the guideline will need to know whether or not it applies to them and to the circumstances they are currently facing?	Thank you for your comment. This guideline starts from the principle that shared decision making should be used and that it applies in all healthcare settings.
General Medical Council	4	7	The scope states that the new guideline will not cover the circumstances of "unexpected life-threatening emergency needing immediate life-saving care". We received feedback from doctors during our consultation that they wanted more information about consent in emergency situations, particularly in obstetric cases. You may want to consider signposting to advice about emergency situations if you already have some, or including it as part of the new guideline.	Thank you for your comment. This guideline will consider shared decision making. Consent is outside NICE's remit and will therefore not be included within the guideline. We have amended the scope to explicitly refer to the GMC's guidance on good consent practice.
General Medical Council	5	4	We note that the scope of your shared decision making guidelines also excludes decision-making and mental capacity. We assume that the new guideline will clearly signpost and link to your decision-making and mental capacity guideline.	Thank you for your comment. The scope references NCE guideline NG108, Decision-making and mental capacity, in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
Health Literacy UK	General	General	The draft scope does not acknowledge the importance of patient health literacy in shared decision-making. It needs to acknowledge that without health literacy, or the health literacy needs of the patient (or client) being taken into account, shared decision-making cannot take place.	Thank you for your comment, the equality impact assessment document, linked to section 2 of the scope, details the issue of

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			Without taking steps to assure that the patient has information or resources / support that they need to access, understand, appraise and use information in making decisions, then shared decision-making cannot truly take place. In addition to understanding and appraising the information transmitted to them, low health literacy affects people's ability to transmit and communicate their preferences to their healthcare professionals, which is vital for effective shared decision-making. Reference should be made to interventions designed to improve health literacy, such as 'Teach Back' and 'Skilled for Health' training. If health literacy is not made explicit in this scope, there is a risk that encouraging shared decision making without acknowledging health literacy could exacerbate already existing, and worsening, health inequities.	health literacy. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention to specific groups). In addition, the guideline will also consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers.
Healthwatch UK	4	10	It is not clear why NICE plans to exclude "situations in which people lack mental capacity to make their own decisions about healthcare". Such people may well need to be covered by a different guideline for shared decision-making from that used in connection with patients who have full capacity. In particular, there is an issue with such people about the way in which	Thank you for your comment. This population is covered by NICE guideline NG108, Decision-making and mental capacity, which is referenced in the related

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			information is offered to the patient and also about the stability of their decision. Suppose, for example, that a person with Down syndrome is being considered for surgery on a congenital heart lesion. The person may give consent to surgery on a certain day but then, when the trolley arrives three days later to take him/her to theatre, may refuse consent, even though he/she is judged to have capacity on both occasions. The patient might then change his/her mind again a few days later after a further conversation with relatives, medical staff, etc. Of course, such changes could occur in someone who has full mental capacity but experience suggests that it is more common in someone whose capacity is impaired.	NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
Healthwatch UK	6	11-18	These questions should be expanded to say something like: "What, specifically, are the most effective ways of ensuring that patients with limited 'health literacy', i.e. a modest knowledge of human biology and of disease and its treatment, are in possession of the information that they need, and of the relative importance of different facts or descriptions, when they come to the point of making a decision?"	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The equality impact assessment document, linked to section 2 of the scope, details the issue of health literacy. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully)

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				• any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention to specific groups).
Healthwatch Worcestershire	General	General	As stated in the Guideline shared decision making is a collaborative process. Therefore, it needs to be centred around the patient/service user/carer in a way that is appropriate to their needs. For example, some people may need support to help them understand clinical terminology to enable them to make an informed decision. For shared decision making to take place the advice and information given by professionals must not be based upon their own opinion/preferences and/or skill set. For example, a new mother reported to us she felt pressured to breastfeed her baby and was told bottle feeding was not the 'right way'. Another example was given when someone had received robotic surgery but told by a different consultant the type of surgery makes no difference to the outcome of the operation. Whilst Healthwatch Worcestershire welcomes NICE work around Shared Decision Making we would recommend this is not a Guideline but made Mandatory for commissioners and providers. Given the feedback we regularly receive from patients, services users and carers it is evident providers and commissioners often do not act upon NICE Guidelines because they are not required to. How will NICE know if organisations are following this if it is not made Mandatory?	Thank you for your comment. When making recommendations the committee will consider the implementation of the recommendations as described in Developing NICE guidelines: the manual. In terms of how NICE measures the use of its guidance, impact reports look at how the health and care system uses our recommendations to improve outcomes in priority areas. The reports are based on data showing the uptake of our guidance and quality statement measures from: • national audits • reports • surveys • indicator frameworks.

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				While not mandatory, organisations commissioning and delivering services are expected to take the recommendations contained within NICE clinical guidelines into account when planning and delivering services.
Kidney Cancer Support Network	General	General	We were disappointed to note the current committee vacancies do not include any positions for expert patients, advocates or lay people. It is vitally important that lay people, patients, families and advocates are adequately represented on the committee.	Thank you for your comment. Please be reassured that there will be lay member (people using services, family members and carers, and members of the public, community or voluntary sector with relevant experience) representation on the committee. These roles have already been recruited to during earlier recruitment, and as such they are not listed in the online invite to join the committee.
Kidney Cancer Support Network	General	General	It should be made clear that patients/persons undertake the shared decision-making process voluntarily. There is no requirement for them to be part of the process if they do not wish to.	Thank you for your comment. The scope has been amended accordingly, and now notes, in section 1, that 'Some people prefer not to take an active role in making decisions with their healthcare professionals, but they should always be given the opportunity to choose to what degree they want to engage in decision making'.
Kidney Cancer Support Network	1	13	Reference is made to 'people' using the services. The 'patient' is not mentioned in this opening paragraph setting the context for the use of the shared decision-making guideline. It should be	Thank you for your comment. The scope states that groups that will be covered are 'adults (aged 18 years and over) using healthcare services, and their families,

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			made clear throughout the guideline that shared decision-making is a process involving the patient (and close family and/or friends) and the clinician.	carers and advocates if they choose to involve them.' The use of the word 'person' rather than 'patient' takes into account that not all users of healthcare services will be considered, nor consider themselves, patients.
Kidney Cancer Support Network	1	17	The term "person's personal informed preferences" requires a subjective opinion being made about the validity or value of the patient's personal preferences. It infers that a "person" can't have instinctive or spiritual personal preferences that do not need to be informed by evidence. Who is to judge whether the person is "informed" enough? And who will decide whether the healthcare professional is "informed" about the personal preferences of their patients?	Thank you for your comment. We have amended the scope so that it now references a person's health beliefs, in addition to their personal informed preferences and values.
Kidney Cancer Support Network	1	17-20	"This involves making sure the person has a good understanding." This statement should include the healthcare professional who also requires a good understanding of the risks, benefits, and possible consequences of different treatment options through discussion and information sharing. This is a shared process in which both parties can learn from each other. It should not be one sided.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for: barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this

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				will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
Kidney Cancer Support Network	1	20-21	"This joint process empowers people…" This joint process should be seen to empower both parties; the patient/person and the healthcare professional. Everyone involved needs to make the right decision, not just the patient!	Thank you for your comment. We have amended the scope to clarify that shared decision making is a collaborative process through which a clinician supports a person to reach a decision about their treatment.
Kidney Cancer Support Network	1	24-25	The option of "doing nothing" is not only a management option, it may be a personal preference of the patient.	Thank you for your comment, the scope has been amended accordingly.
Kidney Cancer Support Network	2	12	"Reducing unwarranted variation in clinical practice." We do not feel the shared decision making process should be a surrogate for changing medical practice. If a patient's individual situation warrants a personalised individual approach, then trying to reduce variation seems to run contrary to what is right for that individual? We would like to see a form of words that allows clinicians and patients reach a decision, which is right for that patient at that time, unhindered by what the normal or historical clinical practice dictates. Some clinical practice guidelines are over 15 years old.	Thank you for your comment. The list given in section 1, concerning the benefits of involving people in decisions about their care, is intended to be illustrative rather than exhaustive. We have removed 'Reducing unwarranted variation in clinical practice' from the list.
Kidney Cancer Support Network	2	17	The practise of obtaining consent immediately before surgery, for example, is not the same as a patient giving informed consent. Is it possible to propose within this guideline a minimum time period before an intervention when it can be considered that consent is truly informed, and not simply a *fait accompli*?	Thank you for your comment. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue

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				you have raised when developing the guideline.
Kidney Cancer Support Network	2	27-29	"……people have the right to be involved in planning and making decisions about their health and care, and to be given information and support to enable this." Currently many NHS providers are interpreting the recent GDPR regulations so strictly that patients are being refused access to medical notes and pathology reports unless they pay for them, and also go through the lengthy procedure of legally requesting access. Shared decision making cannot take place unless the patient has access to the information they need to play a meaningful part in the discussions. Patients are not able to do that if the NHS will not allow them access to their own medical notes, scans, etc. in sufficient time to make a decision. This scope should include advice to ensure patients can have timely access to the information they need.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Kidney Cancer Support Network	3	4	"….choices that people can expect to be offered, and information to support these choices." See point 10 above. (*pg 2, 27-29*)	Thank you for your comment. As noted in section 1 of the draft scope, shared decision making is applicable

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				whenever there is more than one NHS care or treatment or management option available (options include doing nothing). Shared decision making enables alignment of patient preferences to available clinically valid treatment options.
Macmillan Cancer Support	1	22	All healthcare settings – this is confusing as it does not list all healthcare settings (including primary care, community). Later in the document it refers to primary and community settings. Would suggest to have a more comprehensive list or leave simply as 'all healthcare systems'	Thank you for your comment the scope is applicable to all healthcare settings where publicly funded healthcare services are commissioned and provided.
Macmillan Cancer Support	1	27	Is there scope to expand on 'increasingly recognised' comment. There is research coming out now that supports the benefits (as listed in page 2) and would be good to bring together more of this evidence when writing the complete guideline	Thank you for your comment. Section 1 of the scope is a summary of why the guideline is needed. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
Macmillan Cancer Support	2	12 - onward	Would suggest inclusion of another line 'better understanding of the needs of diverse communities'	Thank you for your comment. Understanding the needs of diverse communities is captured in the equality impact assessment. The committee will consider whether: • the evidence review has addressed areas identified in the scope as

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				needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Macmillan Cancer Support	3	17	Will shared decision making be rolled out in a way that there is greater integration between the health and social care systems? The current division between the two means that patients/carers often must navigate a lot of bureaucratic structures, and shared decision making can become redundant when it is so difficult to navigate systems in the first place. This is especially true for socioeconomically deprived people who will need greater access to social care throughout the care pathway. In the CPES 2017 survey, 28.4% of people from the most deprived quintile said they were not offered information about how to get financial support/benefits but would have liked to receive it, compared to just 17.3% from the least deprived quintile. Additionally, 12.9% of people from the most deprived quintile said they were not offered information about support or self-help groups for people with cancer but would have liked to receive it, compared to 9.7% from the least deprived quintile.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee

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				will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
Macmillan Cancer Support	6	11	Addressing 1.1, a suggestion for the guidance development: possible approach could be putting people in touch with organisations that support the condition e.g. cancer, diabetes, heart etc. the ideal approach would be peer support from volunteers with lived experience. These volunteers could help support people using services and healthcare providers by acting as 'honest brokers' explaining to patients the process and supporting their involvement	Thank you for your comment. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee

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				will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	6	15	Addressing 1.2, an important barrier is having the conversation at the right time so that treatment and care can be influenced. Too often patients are involved too late to have influence over their treatment and care. Patients find key decisions have already been taken at early stages. We would recommend including consideration and inclusion of timelines within the guidance	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. It will also consider the evidence for the most effective approaches and activities to normalise shared decision making in the healthcare system. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the

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				guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	6	17	A lack of patient confidence and self-efficacy to advocate for themselves constitutes a major barrier to shared decision making. This is especially true for socioeconomically deprived people for may have poor health literacy and lack the means to research further options for their care. Considering this, shared decision making will have to be implemented in way where the healthcare professionals encourage the patients to engage, rather than vice versa. When asked in the CPES 2017 survey '[W]ere you involved as much as you wanted to be in decisions about your care and treatment' people from the most deprived quintile scored 2.4% lower than those from the least deprived quintile.	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide

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				what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	6	18	Shared decision making works well in theory but how will it take place with an already overstretched, overburdened work force who may not have time to engage with patients as much as they would like to?	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.

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Macmillan Cancer Support	6	23	Immediate scoping of a patient's socioeconomic status as well as personal factors should be done to ensure that a care plan is in line with their circumstances and values. For example, those from deprived backgrounds should immediately be put in touch with systems that can offer financial assistance/transport and fuel support/emotional support.	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for the barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	7	11	What will be done to inspire confidence in patients/carers/families to advocate for shared decision making in the event that they do not feel their healthcare professional is facilitating it? Similarly, what will be done to hold healthcare professionals accountable if they are not engaging in shared decision making?	Thank you for your comment. Approaches to measuring shared decision making are currently being tested by NHS England, with a view to developing future guidance. The intention is for this guidance to outline tools and approaches that can be used

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				when measuring shared decisions, thereby supporting providers and commissioners to develop localised approaches to implementing shared decision making.
Macmillan Cancer Support	8	6	Use of the word 'engage' in table and in context of shared decision making: Although engaging is a step forward, there is also something about the information and support people have access to in order to feel confident to engage and feel they are enabled to fully participate and not just be "part" of a conversation which on the face of it looks like shared decision making but actually is just people being in the room.	Thank you for your comment. The current pathway outline is based on the draft scope. It will be adapted, and more detail added as the recommendations are written during guideline development. Links will be added to relevant NICE Pathways, for example decision-making and mental capacity, patient experience in adult NHS services, and service user experience in adult mental health services. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	8	6	Use of the word 'engage' in table and in context of shared decision making: Although engaging is a step forward, there is also something about the information and support people have access to in order to feel confident to engage and feel they are enabled to fully participate and not just be "part" of a conversation which on the face of it looks like shared decision making but actually is just people being in the room.	Thank you for your comment. The current pathway outline is based on the draft scope. It will be adapted, and more detail added as the recommendations are written during guideline development. Links will be added to relevant NICE Pathways, for example decision-making and mental capacity, patient experience in adult NHS services, and service user experience in adult mental health services. We will keep in mind the issue you have raised when developing the guideline.
Macmillan Cancer Support	Equality Impact Assessment	General	It is crucial to recognise ethnicity as a potential equality issue – this was notably absent from the document. Evidence shows that many BAME people have worse health indicators and worse health outcomes. In the CPES 2017 survey, when asked 'Did you understand the	Thank you for your comment, we have amended the equality impact assessment

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			explanation of what was wrong with you?' white patients scored 73.5%, compared to just 62.3% of black patients, 65.5% of mixed patients and 67.4% of Asian patients. This gap, especially between white and black patients, is substantial, and must be addressed. Similarly, when asked 'Before your cancer treatment started, were your treatment options explained to you?', white patients scored 5.3% higher than black patients.	document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Macmillan Cancer Support	Equality Impact Assessment	General	LGBT+ people also need due consideration in the equality impact assessment. In a 2017 Cancer Research study *('A study looking at the experiences and care of lesbian, gay, bisexual and transgender (trans) people facing advanced illness')* looking at the experiences and care of lesbian, gay, bisexual and transgender (trans) people facing advanced illness (including cancer), some participants identified a barrier to services as negative treatment from healthcare professionals, including assuming they were heterosexual, ignoring their partners during discussions, using incorrect pronouns, and a lack of awareness of LGBT friendly support services.	Thank you for your comment, we have amended the equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example,

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				through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Macmillan Cancer Support	Equality Impact Assessment	General	The equality impact assessment makes reference to people at risk of self-neglect, people with lower socioeconomic status, people with lower literacy (digital and health), vulnerable people and people who experience barriers to accessing healthcare. Within these groups, how are healthcare professionals going to be trained to recognise and address these levels of deprivation/barriers? They are not necessarily immediately obvious so this is something that training guidelines must take into consideration. Staff will need training on improving patient activation and empowering self-management, as well as training in identifying both clinical and non-clinical needs of their full population	Thank you for your comment. The guideline will consider the evidence for the barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates, as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. In addition, experts may be invited to attend a committee meeting to provide evidence from their experience and specific expertise, in the form of expert testimony,

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				which is published on the NICE website when the guideline is published. When making recommendations the committee will consider the implementation of the recommendations as described in Developing NICE guidelines: the manual. We will keep in mind the issue you have raised when developing the guideline.
NHS England	General	General	It would be helpful to reference the '**Local action on health inequalities: Improving health literacy to reduce health inequalities**' IHE/PHE (2015) report which showed that between 43/61% of working age English adults do not understand health information. This means that optimal SDM can only occur if this is recognised and conversations in a clinical context are modified accordingly. In addition, people with lower levels of health literacy are more likely to experience health inequalities. Without this modification in practice being explicitly recognised there is a danger that those people will also not benefit from SDM and certainly won't have "a good understanding of the risks, benefits and possible consequences of different options through discussion and information sharing" as set out in the draft scope.	Thank you for your comment and for providing the IHE/PHE 2015 reference. The equality impact assessment document, linked to section 2 of the scope, details the issue of health literacy. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain

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				groups, or by tailoring the intervention to specific groups).
NHS England	General	General	There is a reference to "less uncertainty in making a choice" as a benefit of SDM. This could be misleading as many choices will still be uncertain in terms of risks, benefits etc. Would it be better phrased as "greater clarity about the risks and benefits of the available options"?	Thank you for your comment. The scope has been amended accordingly.
NHS England	General	General	There are a number of references to Choice, including the Choice framework. This is an important but very distinct area from SDM. Is there a danger of confusing the system by linking the two together in this way	Thank you for your comment. The scope has been amended accordingly, with reference to the Choice framework removed to avoid confusion.
NHS England	General	General	In addition the document states that "NHS England is supporting the implementation of shared decision making across care pathways at national and local level through its NHS RightCare shared decision making programme" It would be more accurate to state that "NHS England is supporting the implementation of shared decision making across care pathways at national and local level through its Personalised Care Group's shared decision making programme"	Thank you for your comment. The scope has been amended accordingly.
NHS England	General	General	A specific standard around Equality and Health Inequalities should be included in the actual framework to ensure those implementing the standard give due consideration when planning the delivery of SDM. This would ensure that; • Quality of SDM provision does not vary due to characteristics such as gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status as well as poor socio economic groups. • Commissioners/Providers take additional/necessary steps to ensure equitable access based on the makeup of their local population especially at Primary Care Network Level. • Specific focus is required around language barrier and cultural understanding of healthcare system and professionals, where patients and their carers might never see themselves as equal partners in decision making. • Alongside patients, carers role is extremely important and needs due consideration and involvement especially for certain groups such as young people, Older people, patients with limited English and people with mental health issues (despite with	Thank you for your comment, the equality impact assessment document, linked to section 2 of the scope, details equality issues identified during the scoping of this guideline. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully)

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			capacity in legal terms they often need enormous support from their carers in decision making).	• any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention to specific groups). We will keep in mind the issue you have raised when developing the guideline.
Northern, Eastern and Western Devon CCG	4	10	It would be helpful to clarify further the difference (if there is one) between shared decision-making and supported decision making as discussed in the guidance on decision-making and mental capacity. Since the shared decision-making guidance only excludes people who lack capacity to make the relevant decision at the time, it may include people who have capacity to make their own decisions with support. Without clear guidance, there is a risk of creating a 2-tier system where supported decision making applies to those who may lack capacity and shared decision-making is used only for those for whom there is no reason to doubt capacity. A section on how these two concepts overlap and work together would be useful to clarify that where a person has capacity to make the relevant decision with support (despite cognitive impairment), the shared decision-making guidance would apply.	Thank you for your comment. This population is covered by NICE guideline NG108, Decision-making and mental capacity, which is referenced in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
Parkinson's UK	General	General	We believe that this draft scope should place an emphasis on advance care planning. As this is a key time where shared decision making must be utilised to ensure a person has discussions about care planning and ensure they have their end of life stage clearly set out and understood both by the clinician, patient and their family. In a survey response from 2781 people living with Parkinson's and their family members only 23% had been offered any sort of care plan to support care. We believe there is a need for greater training with health professionals to support them to discuss advance care planning, and to feel comfortable doing so.	Thank you for your comment. The scope has been amended, with section 1 now noting the inclusion of advance care planning within the shared decision making process. Related to your comment, the guideline will consider the evidence for the questions listed under supporting shared decision making.

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				The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.
Parkinson's UK	General	General	The importance of shared decision making to improve medicines adherence and optimisation should be a key area that the scope of the guideline focuses on. A clear medication plan is vital for people with Parkinson's and we believe the effectiveness of this plan can be impacted by the level of shared decision making utilised in its conception. This is particularly true as often people living with Parkinson's will be the experts in their medication and particularly the implications of not receiving it on time. It is vital that health professionals and patients collaborate on how a medication schedule is working, or not working to lead to better patient outcomes. This is featured in Parkinson's UK's medicines optimisation statement.	Thank you for your comment. **The scope references, in the related NICE guidance section, NICE guideline NG5, Medicines optimisation, and NICE guideline CG76, Medicines adherence. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.**
Parkinson's UK	General	General	This guideline should consider how to ensure effective communication and collaboration between health professionals from different disciplines to ensure an individual's choices and decisions made about their care can be enacted. The All-Party Parliamentary Group on Parkinson's 2018 report 'Mental health matters too' - Improving mental health services for people with Parkinson's who experience anxiety and depression' demonstrated people with Parkinson's mental health needs are not being addressed in part due to poor communication and collaboration between mental and physical health professionals.	Thank you for your comment. The guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as **healthcare providers. Evidence permitting, effective communication and collaboration will be captured in this review. We will keep in mind the issue you have raised when developing the guideline.**

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Parkinson's UK	2	General	Parkinson's UK recommends that the draft scope list of benefits should add an explicit mention of the better health outcomes that can be achieved via shared decision making. This is a consensus that is accepted by NHS England and should therefore be the focus of this guideline. In a recent survey of 2775 people living with Parkinson's and their family members, only 57.6% said they were involved in decisions about their care. This demonstrates the importance of utilising shared decision making to improve care particularly for people living with long term conditions.	Thank you for your comment. Section 1 of the scope is a summary of current practice; therefore, we are unable to include a comprehensive outline of why the guideline is needed.
Parkinson's UK	6	27	We believe the scope should include an addition of a question to point 2.3 - "What are the most effective care settings to enable shared decision making." This additional question will allow the guideline to focus on the best care settings and professionals to utilise shared decision making, not just the process of how it is utilised.	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided and shared decision making along the entirety of the care pathway. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to

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				practitioners, commissioners of services and others.
Parkinson's UK	Specific question response	Specific question response	**Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?** An innovative approach that has been taken to improve patient experience and enhance shared decision making is the creation of the Parkinson's Advanced Symptoms Unit. The unit is a pilot scheme based at Redcar Primary Care Hospital. The unit provides the following: • Appointments within 7 days • The option for patients to self-refer • A one-stop shop for patients to see all relevant health professionals • Close-monitoring of patients during condition flair-ups where they can be seen ongoing for several weeks at a time This innovative approach has enabled the hospital to offer 10 additional appointments per a month, which has driven down waiting times. The unit also saved the NHS £560 per a patient if the full multi-disciplinary team is needed in a normal hospital setting. This model encourages greater shared decision making as all relevant health professionals hear from the patient at the same time, taking on their views and circumstances before deciding on potential interventions as a team.	Thank you for providing this information.
Psoriasis and Psoriatic Arthritis Alliance	1	15	Further in the document there is use of the terms "families and carer", should this be added to the context?	Thank you for your comment. We have amended the scope based on your comment.
Psoriasis and Psoriatic Arthritis Alliance	1	17	Perhaps add 'health beliefs and values'. To actually understand someone's health beliefs, is as important as those attributed to other beliefs that people may hold. So instead of a broad 'this is what people believe about health in general', to 'this is what the health beliefs are of the patient in front of me', so a more personalised approach, as shared decision must be	Thank you for your comment. We have amended the scope so that it now references a person's health beliefs, in

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			seen as part of the personalised medicine agenda.	addition to their personal informed preferences and values.
Psoriasis and Psoriatic Arthritis Alliance	1	19	There is no mention of available options. Discussion, surely needs to be about what is available within the NHS, as opposed to what a patient may think is available or read about in the media or via the internet and of course includes licensed indication.	Thank you for your comment. The scope sets out the areas the guideline will cover. Section 1 of the scope includes about choice being for when there is one or more option available from the NHS.
Psoriasis and Psoriatic Arthritis Alliance	2	3	No mentions of being able take responsibility of shared decisions too.	Thank you for your comment. The list given in section 1, concerning the benefits of involving people in decisions about their care, is intended to be illustrative rather than exhaustive.
Psoriasis and Psoriatic Arthritis Alliance	2	9	Dislike the term adherence, still feels like an instruction to abide by, and not a choice.	Thank you for your comment, the scope has been amended to 'better concordance with agreed treatment plans'
Psoriasis and Psoriatic Arthritis Alliance	4	12	I'm assuming home setting applies to visits from a healthcare professional, I wonder whether this could/should also include digital/telephone consultation health processes, where there may be less opportunity to make a shared decision when not face-to-face with a healthcare provider.	Thank you for your comment. The guideline will cover all settings, including people's own home, whether this be a healthcare professional visiting in person or contacting a person via other means.
Resuscitation Council UK	1 6 8	15 13-17 5	'…people who use services…' and '…people using services…' It may not be clear to many people what these phrases mean. We suggest substituting either '…**patients**…' or – if you prefer – '…people who use **health** services…' and '…people using **health** services…'.	Thank you for your comment. The scope has been amended, the questions now refer to healthcare services.
Resuscitation Council UK	1 2	24 20	'Shared decision making is applicable … whenever there is more than one *NHS* treatment or management option available…' and '…informed by what is known about the risks, benefits and consequences of all reasonable *NHS* treatment options.'	Thank you for your comment. The provision of health and care that is privately funded is outside of NICE's remit.

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			This should not be limited to NHS care and treatment. Full shared decision making can only be achieved if the person is fully informed of **all** options for their care and treatment, which sometimes will require discussion of non-NHS treatment or care options (e.g. hospice services, services from independent providers). We suggest **omitting 'NHS'** from these sentences.	
Resuscitation Council UK	1	24	'Shared decision making is applicable … whenever there is more than one NHS treatment or management option available…' The term 'management' could be seen as paternalistic – i.e. the healthcare professional is 'managing' the patient. This detracts from the principle of shared decision making. We suggest substituting '…whenever there is more than one **care or treatment** option available…'.	Thank you for your comment, the scope has been amended accordingly.
Resuscitation Council UK	2	1	The draft scope asserts that *'people'* want to be more involved in decisions about their care. However, the percentages quoted suggest that this should read '**some people**' or '**many people**'. When offering people the chance to engage in shared decision making, it is important to recognise that some of them will wish to hand decision making over to their healthcare professionals or be involved only passively (i.e. agree to decisions, rather than actively take part in making them).	Thank you for your comment, the scope has been amended accordingly.
Resuscitation Council UK	2	21-25	The draft scope states in line 21, in relation to consent: 'It is the doctor's duty…'. Line 25 also refers to '…the doctor...'. However, many healthcare professionals are involved in making decisions with patients, discussing different treatment options and taking consent. These are not all doctors. The guideline applies to 'everyone who delivers healthcare'. We suggest replacing 'doctor' with '**clinician**' or '**healthcare professional**'.	Thank you for your comment. The scope has been amended and now refers to 'health care professionals'.

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Resuscitation Council UK	3 4 4	12 4 5	Where people under 18 are referred to as 'young people and children', **babies** should also be specifically included. While babies cannot be involved in shared decision making, their parents or carers can. We suggest that each line is worded: 'Adults, young people, children **and babies…'**	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021.
Resuscitation Council UK	3	1–9	Whilst the scope acknowledges well that shared decision making is appropriate in many wide-ranging situations, of which end-of-life care is just one, please consider referring in this portion of the scope to 'Choice in end of life care: Government response to the independent review of choice in end of life care: https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response.	Thank you for your comment. Section 1 of the scope is a summary of current practice; therefore, we are unable to include a comprehensive outline of why the guideline is needed. Please note, however, the guideline will consider shared decision making along the entirety of the care pathway.
Resuscitation Council UK	4	14-15	Shared decision making should be equally applicable to the provision of health and care that is not **publicly** funded. We suggest deletion of the words 'publicly funded'.	Thank you for your comment. The provision of health and care that is privately funded is outside of NICE's remit.
Resuscitation Council UK	4	8-11	The draft scope states that an 'Unexpected life-threatening emergency needing immediate life-saving care' and 'Situations in which people lack mental capacity to make their own decisions about healthcare at that time' will not be covered. While patients cannot engage in shared decision making at the time of an extreme life-threatening emergency such as cardiac arrest, or when they lack mental capacity for the decision needed, anticipatory care plans can help clinicians ensure that an individual's previously stated wishes can be respected when these events occur. Patients and their doctors are increasingly being encouraged to plan ahead for the care and treatment to be	Thank you for your comment. The scope has been amended, with section 1 now noting the inclusion of advance care planning within the shared decision making process. Related to your comment, the guideline will consider the evidence for the questions

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			given in a future life-threatening emergency and shared decision-making is an important part of such planning. We feel strongly that anticipatory care planning should be included in the scope and outcomes as it is a topic that has led to complaints and litigation where there have been failures of shared decision making, many of which would now be unlawful. Please see: • Decisions relating to Cardiopulmonary Resuscitation (3rd edition - 1st revision). 2016. Guidance from the British Medical Association, the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the "Joint Statement"). https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/ • The ReSPECT process: www.respectprocess.org.uk • End of Life Care. House of Commons Health Committee. Fifth Report of Session 2014–15. https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf • Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr04110#/abstract.	listed under supporting shared decision making The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.
Resuscitation Council UK	6	26	'…patient culture'. We suggest that this should be **'…public culture**' - to encompass all those who are not yet patients but may become patients, and all those who care about or may speak for patients – their families, friends, carers and other advocates.	Thank you for your comment. Following stakeholder comments we have amended this wording.
Resuscitation Council UK	7	5-17	It is important also to include as an outcome the harms and unwanted outcomes that can arise when healthcare professionals and/or health service users and/or their families and advocates fail to engage in shared decision making.	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review

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				protocols. The guideline committee will consider your comment when developing the evidence review protocols.
Resuscitation Council UK	Specific question response	Specific question response	**Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?** The ReSPECT process: www.respectprocess.org.uk has been adopted in a good many health and care communities and its adoption is continuing in others. It promotes and supports shared decision making as an integral part of anticipatory care planning for a future emergency (please see comment 8 above).	Thank you for providing this information.
Roche Products Ltd.	General	General	Roche is fully supportive of shared decision making, we believe it is a crucial element of patient care. We believe the dialogue between healthcare professionals (HCPs) and patients are a critical consideration when assessing patient care in respect to shared decision making.	Thank you for your comment.
Roche Products Ltd.	General	General	We believe it is important that patients are fully informed about treatment options. The potential benefits and potential side effects of medicines should be clearly communicated and patients should have visibility of clinical trial options.	Thank you for your comment. The scope sets out the areas the guideline will consider. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Roche Products Ltd.	General	General	Patients should have the option to be more informed about the benefits of new technologies which allow the sharing of their data to inform the development of future innovation. There is evidence to show that there is a willingness to share health data to improve patient outcomes, for example to increase access to personalised medicines and enable advances in preventative medicine (1). While it is true that privacy concerns remain a barrier for some	Thank you for your comment. The scope sets out the areas the guideline will consider. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations

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			people, understanding these concerns and addressing appropriately will be an important consideration to address in order for innovation to continue (1).	can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Anaesthetists	General	General	No direct specific comments as the scope is so broad it could or could not feasibly involve ICM when it's written. In general however, It reads as potentially involving elective surgery which is high risk for ICU admission-an area where there does need to be some more work as there isn't much specific guidance on best practice in relation to shared decision making. Discussion from the Intensive Care Society Meeting (December 2018) was that most pre-op/periop services are being woolly at best about what a critical care stay after elective surgery involves. It's may be disingenuous to then claim when a life threatening complication occurs that it is 'unexpected' and not falling under the guidance, as the information about an ICU admission may materially affect some people's decisions about what they would and would not want to embark on. The other area not discussed here is in relation to shared decision making with people with life limiting conditions. The ideal would be to get intensive care treatment discussed with them as part of that planning of care.	Thank you for your comment. The scope has been amended and now makes clear that 'Shared decision making is a collaborative process through which a healthcare professional supports a person to reach a decision about their care, now or in the future (for example, through advance care planning).' The scope is applicable to all healthcare settings where publicly funded healthcare services are commissioned and provided, including ICU and elective surgery settings. Related to your comment, the guideline will consider the evidence for the questions listed under supporting shared decision making. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols

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				developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.
Royal College of General Practitioners	General	General	The RCGP has developed a Person-Centered Care Toolkit, which includes a section on Shared Decision Making https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/person-centred-care-toolkit.aspx	Thank you for providing this information.
Royal College of General Practitioners	General	General	The committee should ensure that recommendations acknowledge the difference between the process of reaching a decision, and a patient giving assent or consent. The process of decision making will depend on capability and wishes of individual and seriousness of decision, and we welcome guidance in this area.	Thank you for your comment. Section 1 of the scope outlines NICE's definition of shared decision making for the purpose of the development of this guideline. It is our understanding that 'consent' is captured under the existing text: 'empowers people to make a decision about the treatment and care that is right for them at that time.' Furthermore, Section 1, refers to the Montgomery v Lanarkshire ruling: 'A new legal standard set out that adults 'of sound mind' are entitled to make informed decisions when giving or withholding consent to treatment. Consent 'must be obtained before treatment interfering with bodily integrity is undertaken', and it should only be gained when patients have shared a decision informed by what is known about the risks, benefits and consequences of all reasonable NHS treatment options.' We have, however, amended the scope to explicitly refer to the GMC's guidance on

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				good consent practice. We will also keep in mind the issue you have raised when developing the guideline.
Royal College of General Practitioners	General	General	The committee should ensure that the guideline does not make recommendations which could imply that practitioners are obliged to provide treatments that patients want. Practitioners and patients should only be expected to discuss options that are available and clinically appropriate and practitioners are not obliged to provide treatment that are not appropriate (for example opiates in chronic pain or major surgery if likely to cause death or other serious consequences).	**Thank you for your comment. As noted in section 1 of the draft scope, shared decision making is applicable whenever there is more than one NHS care or treatment or management option available (options include doing nothing). Shared decision making enables patients to align their preferences to treatment options that are clinically valid. It does not mean that people can choose treatments that are judged not to be clinically or cost-effective.**
Royal College of General Practitioners	General	General	It is important that the guideline focuses on the systems to support decision making rather than becomes a checklist that practitioners must do and to prove has been done through coding or checklist completion in order to demonstrate that guidelines have been followed. This guideline should focus on supporting patient centered care when implementing other guidelines, and give practitioners a framework to justify the decision they make with their patients, even if this deviates from other clinical guidance.	Thank you for your comment. The scope sets out the areas the guideline will cover. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of General Practitioners	General	General	Shared decision making is taught as part of the RCGP curriculum and GP trainees are assessed on their ability in this area. GPs are highly suitable to provide expertise in this area. RCGP curriculum https://www.rcgp.org.uk/training-exams/training/gp-curriculum-overview.aspx	Thank you for providing this information.

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Royal College of General Practitioners	General	General	The committee should be aware that patient choice can lead to conflict in some areas. For example, requests for treatment not generally available or recommended by NICE or subject to local or national guidelines often related to cost. The guidance needs to be carefully worded and make it clear that a person is not able to choose any treatment but is instead able to choose one of a range of treatment options that presented by the practitioner and informed by local and national guidelines, and costs.	Thank you for your comment. As noted in section 1 of the draft scope, shared decision making is applicable whenever there is more than one NHS care or treatment or management option available (options include doing nothing). Shared decision making enables patients to align their preferences to treatment options that are clinically valid. It does not mean that people can choose treatments that are judged not to be clinically or cost-effective. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.
Royal College of General Practitioners	General	General	The developers and committee should be aware that when a person has decided to refuse treatment clinicians often come under pressure from family members or others involved to override the patient's wishes. The guidance needs to be clear that, whilst the patient retains	**Thank you for your comment. When making recommendations the committee will consider the implementation of the**

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			capacity, the patient's wishes override others even when they are unwise from a clinical point of view. Often these issues involve people who are frail and near the edges of capacity, so this judgement to support patient decision making can be difficult and not always clear cut.	**recommendations as described in Developing NICE guidelines: the manual. We will keep in mind the issue you have raised when developing the guideline.**
Royal College of General Practitioners	4	13	Secure and detained settings should be included under 'Settings that will be covered'	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided.
Royal College of General Practitioners	4	3	People within secure and detained settings should be included under 'Groups that will be covered' as a specific patient group. The committee should consider making specific recommendations for this group due to the additional ethical and legal issues relating to shared decision making within these settings. In particular, there are issues relating to the Mental Capacity and Mental Health Act which could be considered within this guidance. Here is a list of things to consider (this list is not exhaustive): - How this guidance might be utilised when someone has placed in the segregation unit in the prison setting, where they are locked up for 23 hours of the day. - Advanced decisions are already very challenging in the secure setting and this guidance could provide helpful advice on how to better manage such shared-decisions. - Young people and children in secure settings are a particularly challenging group. - Assessment of capacity is also very difficult in these settings with considerable emphasis placed on GPs (not necessarily psychiatric services) to make challenging decisions about a person's healthcare when there are a number of differences when compared to services available in the wider community (including social services). - There are a higher proportion of mental health, substance misuse and learning difficulties (often in conjunction with one another) making shared-decision difficult whilst there is a shared duty of care between the legal custodian (e.g. prison authority) and health care provider(s)	Thank you for your comment. This group are included in the populations described in the scope. However, the scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021. Related to the issues you raise, the equality impact assessment document, linked to section 2 of the scope, lists people who experience barriers to accessing healthcare. We will keep in mind the issue you have raised when developing the review protocols and considering any specific populations which should be considered

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Royal College of General Practitioners	6	15	The RCGP welcomes a review of the evidence to identifying the barriers and facilitators to shared decision making. The committee should consider a wider range of barriers to shared decision making such as lack of staff, lack of time, poor continuity, poor relationships between clinicians and patients, lack of clinician support and structural barriers within the NHS. Additionally, developers should be prepared consider NICE's role as a potential barrier/facilitator to shared decision making in the way that NICE clinical guidance is produced and presented. The guidance should include recommendations on the systems, process and resources required to support shared decision making in practice. There is a risk that the recommendations from this guideline will focus too much on practitioners and the standards set will be unattainable without due consideration being given to the systems in which they work. Unless there are systems, process and resources in place to support shared decision making in practice, practitioners will be held to a standard that they are not supported to achieve, which could be adversely affect the morale of practitioners.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop NICE guidance on Shared Decision Making.	Thank you for your comments.
Royal College of Nursing	General	General	Shared decision making is beneficial in that it facilitates trust between the practitioner and the patient as the patient would believe that they have been listened to and have contributed to a discussion about their correct care/treatment.	Thank you for your comment. Section 1 of the scope is a summary of why the guideline is needed. Following your comment we have amended this section of

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			We feel that this important factor has not really been examined in this draft document and suggest that it is included in the scope.	the scope to include the area you have raised.
Royal College of Nursing	General	General	The RCN have some policy guidance on shared decision making on its website: RCN principles to inform decision making - What do I need to know? Making it work - Shared decision-making and people with learning disabilities	Thank you for providing this information.
Royal College of Nursing	General	General	We would also ask that if the guidance is to be read by members of the public, it should be written in a lay friendly format that would be accessible to them.	Thank you. The guideline will be edited before being published, to ensure it meets NICE style. Using clear, consistent wording is an important part of NICE's approach to presenting guidelines and other products, and is in line with gov.uk style.
Royal College of Nursing	General	General	Great to see this document, shared decision making is something we support and have published guidance on (see previous comment). NICE need to ensure that they consider all professionals involved in gaining consent and implementing decisions not just medical staff.	Thank you for your comment. The guideline will be for everybody who delivers healthcare services. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
Royal College of Nursing	General	General	NICE should consider the potential safeguarding implication in taking consent and shared decision making.	Thank you for your comment. When making recommendations the committee will consider the implementation of the recommendations as described in Developing NICE guidelines: the manual. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Occupational Therapists	General	General	A new report from the Royal College of Occupational Therapists, (RCOT), has identified three key factors to enable personalised care:	Thank you for providing this information.

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			1. Focusing on a person's strengths and balancing choice and risk 2. Enabling people to take part in daily activities that are important to them 3. Ensuring people stay connected to family, friends and communities 'Making personalised care a reality' report: http://cotimprovinglives.com/making-personalised-care-a-reality-the-role-of-occupational-therapy/ Please see the Respiratory Service, case example 'Living, not existing' report: http://3clw1r2j0esn1tg2ng3xziww.wpengine.netdna-cdn.com/wp-content/uploads/2017/07/ILSM-Phase-II-England-16pp.pdf Also available upon request: 'Living, not existing' flyer which discusses: 1. Prevention or delaying the need for care and support 2. Helping older people to remain in their communities 3. Ensuring equality of access to occupational therapy Also includes an example concerning a shared decision approach. Also available upon request: How Occupational Therapy meets the aims of the NHS Long Term Plan.	
Royal College of Occupational Therapists	1	22	Shared decision making is also applicable in both primary care and social care	Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a

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				greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
Royal College of Occupational Therapists	2	20	Consideration should be given to integrated services (NHS and Social Care together)	Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services. While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
Royal College of Occupational Therapists	3	14	Including primary care	Thank you for your comment, the scope is applicable to all healthcare settings where publicly funded healthcare services are commissioned and provided, including primary care settings.
Royal College of Occupational Therapists	3	17	It is relevant for social care professionals	Thank you for your comment. This guideline will consider shared decision making in healthcare and public health services.

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				While we acknowledge the guideline may be of interest to social care practitioners, especially given the integrated care agenda and devolved budgets, we have not explicitly included social care in the scope of this guideline. Our understanding is that shared decision making is already embedded in social care systems to a greater extent than in health care systems, and therefore the need for guidance is greater in the latter. For this reason, we feel shared decision making in social care systems requires the referral and development of a separate guideline.
Royal College of Occupational Therapists	6	18	Implications of training staff - time and resources	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols

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				developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Occupational Therapists	6	26	The term 'people who use services' rather than 'patient' should be used	Thank you for your comment. Following stakeholder comments we have amended this wording.
Royal College of Ophthalmologists	General	General	We support the outline in the equality impact assessment that consideration must be given to various groups who might have difficulties of varying degrees in any shared decision making. We would particularly for ophthalmology care wish to see consideration of groups such as those with learning disability, impaired mental capacity and dementia, and visual impairment.	Thank you for your comment. Those with learning disabilities and those with visual impairment are captured in the equality impact assessment. The scope references NICE guideline NG108, Decision-making and mental capacity, in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
Royal College of Ophthalmologists	General	General	It's a shame NICE excluded whether shared decision making is required and are concentrating on the best way to do it. Information on evidence that is works, in what circumstances or for what conditions and groups of patients, and that is adds benefit, is enormously important before consideration is given in detail to how to do it well.	Thank you for your comment. As set out in the NHS Constitution for England, people have the right to be involved in planning and making decisions about their health and care, and to be given information and support to enable this. In line with this, the Health and Social Care Act 2012 makes

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				clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice. Given this it was felt the focus of the guideline should be the on the most appropriate was to do shared decision making rather than if shared decision making is required.
Royal College of Paediatrics and Child Health	General	General	The aims and steps in the Scope are agreed to be relevant and necessary.	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021.
Royal College of Paediatrics and Child Health	General	General	The outcome needs to be succinct and accessible for all patients and carers as well as clinical staff – ideally in a practical set of prompts for both groups in the clinical settings	Thank you for your comment. When making recommendations the committee will consider the implementation of the recommendations as described in Developing NICE guidelines: the manual. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Paediatrics and Child Health	General	General	It's an important topic which needs a focus and a guideline to be made as most of the time a decision should be taken jointly. The important thing which needs to be considered while making a guideline is the age of the child and whether a parent (single or both of them) can make a decision on child's behalf and what to do if the parents opinion differs.	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant,

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				children and young people's experience of healthcare', due to publish in 2021.
Royal College of Physicians	General	General	The RCP is grateful for the opportunity to respond to the above consultation. We fully support the development of Shared decision making NICE guideline, our experts believe that the scope seems entirely appropriate, It is a major factor in person centred care, which is a key goal for RCP and RCPs approach to quality. We have liaised with our Patient Safety Committee and would like to make the following comments.	Thank you for your comments.
Royal College of Physicians	4	5	It is unclear whether this sets out to cover the same ground as the GMC and in particular, decision-making in the context of consent. It would be helpful to include a section on consent as a specific area.	Thank you for your comment. This guideline will consider shared decision making. Consent is outside NICE's remit and will therefore not be included within the guideline. We have amended the scope to explicitly refer to the GMC's guidance on good consent practice.
Royal College of Physicians	6	11	Our experts question whether this will this include the most effective ways of presenting statistical information and risks and whether this should this also relate to research activities as well as standard NHS.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published

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				evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. For selected areas in which there are uncertainties or in which robust evidence is lacking, the guideline committee may write research recommendations. The committee can select up to 5 key recommendations for research that are likely to inform future decision-making. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Physicians	6	22	Our experts question: • How evidence of shared decision-making will be captured in health records in the simplest and most meaningful way • What the implications for evidence of consent will be. • What training would be required at undergraduate and post graduate levels	Thank you for your comment. Approaches to measuring shared decision making are currently being tested by NHS England, with a view to developing future guidance. The intention is for this guidance to outline tools and approaches that can be used when measuring shared decisions, thereby supporting providers and commissioners to develop localised approaches to implementing shared decision making. Consent and specific training courses are outside of NICE's remit.

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Royal College of Physicians	6	25	Our experts question what the best prompts are for patients to ask questions/know what to ask	Thank you for your comment. The scope sets out the areas the guideline will consider. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Physicians	7	14	Consider use of 'decision regret' methodology	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review protocols. The guideline

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				committee will consider your comment when developing the evidence review protocols.
Royal College of Physicians	**7**	17	Impact on cancer p28/62 pathways- less and less time to decide; increased anxiety	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review protocols. The guideline committee will consider your comment when developing the evidence review protocols.
Royal College of Physicians	7	22	Cannot be in isolation from principles of good communication, and purpose e.g. consent, research	Thank you for your comment. Related to your comment, the guideline will consider the evidence for the following review question: What are the core components of effective shared decision making approaches and activities? The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what

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				recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Psychiatrists	General	General	There is an implied suggestion that shared decision making is towards the end of an assessment. Whilst true in many medical and psychiatric encounters, collaborative and co-produced care that includes shared decision making starts right from the beginning of any clinical encounter. Ideas and possible decisions have already been weighed in the balance by patients as they start an assessment. Taking a values-based approach to an assessment naturally leads to shared decision making. General Practice training tends to take this view, and thus it trains its GP trainees to use an SDM consultation process. This type of training is not usually found in Child Psychiatry and thus will not be found usually in the attitudes and clinical behaviour of child psychiatry trainees. As a result, in child psychiatry shared decision making is often left to the end of an assessment, and often time to do shared decision making is not built into the process. This will be covered in the NICE guideline development as a possible barrier to SDM. Again if SDM is at the forefront of a clinicians mind right from the start (using a values-based approach to assessment, then time to do SDM is seamlessly woven into the clinical encounter). Please see the Report of the Values-Based Child and Adolescent Mental Health System Commission.	Thank you for your comment. The guideline will consider shared decision making along the entirety of the care pathway. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021.
Royal College of Speech and Language Therapists	General	General	The RCSLT is concerned at the lack of attention to supporting communication throughout this draft guideline scope. Health and social care professionals need advice and information on how to achieve good communication. We recommend consideration of the following:	Thank you for your comment. The guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both

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			• Professionals should be trained in awareness of speech, language and communication needs and how to support decision-making. • All people would benefit from written information in an accessible format, time to process verbal information and the use of plain language avoiding technical vocabulary or jargon. • If a person has a specific communication need then they may require access to a communication aid or referral to a speech and language therapist. All of these would support high quality conversations and enable patients to make fully-informed choices about their health care.	people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, communication needs will be captured in this review. We have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Royal College of Speech and Language Therapists	General	General	The RCSLT is disappointed at the lack of reference to communication needs throughout the draft scope for this guideline. Communication is central to shared decision making. Acknowledging and supporting communication would maximise patient participation in decision-making. Communication should be acknowledged from the outset.	Thank you for your comment. The guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both

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			Shared decision making involves a conversation between a health professional and a user and the ability to understand and process information is essential. Many shared decision making conversations will involve a discussion of risks verses benefits of a treatment, test or technique and understanding this information is so fundamental especially for preference sensitive decisions.	people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, communication needs will be captured in this review. We have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Royal College of Speech and Language Therapists	General	General	We would encourage NICE to look at some of the given evidence around communication disorders and shared decision making, and the importance of communication in shared decision making when consulting on the guideline development:	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant,

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			Franklon, A. & Sloper, P. (2008). Supporting the Participation of Disabled Children and Young People in Decision-making. Children & Society, 23 (1), 3-15. Kasper et al. (2011). Turning signals into meaning –'Shared decision making' meets communication theory. Health Expectations, 15 (1), 3-11. Levy et al. (2016). Shared Decision Making and Treatment Decisions for Young Children With Autism Spectrum Disorder. Academic Pediatrics, 16 (6), 571-578. Lipstein, E et al. (2016). Shared Decision Making in the Care of Children with Developmental and Behavioral Disorders. Maternal and Child Health Journal, 20 (3), 665-673. Politi, M. C. & Street, R.L. (2010). The importance of communication in collaborative decision making: facilitating shared mind and the management of uncertainty. Journal of Evaluation in Clinical Practice, 17 (4), 579-584. Simmons-Mackie et al. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. Aphasiology, 21 (1), 39-66. Stein, J. & Brady Wagner, L. C. (2006). Is Informed Consent a "Yes or No" Response? Enhancing the Shared Decision-Making Process for Persons with Aphasia. Topics in Stroke rehabilitation, 13 (4), 42-46.	children and young people's experience of healthcare', due to publish in 2021. The guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, communication needs will be captured in this review. We have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development.
Royal College of Speech and Language Therapists	2	17	Acknowledging and addressing communication problems would ensure that decision making is truly a shared process and that consent is achieved.	Thank you for your comment, we have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise.

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				The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Royal College of Speech and Language Therapists	3	21-25	The RCSLT is disappointed at the lack of reference to communication needs in the equality impact assessment. It is essential that communication issues are acknowledged. Communication is absolutely central to shared decision making, and underpins the ability to understand and express one's wishes. This reduces the risk of people having decisions made for them. Disabilities affecting communication are given as an example of a physical impairment in the equality impact assessment (page 1). It is crucial that '**people with communication difficulties' is listed as a potential equality issue in its own right** because not all (in fact, probably considerably few) communication difficulties are due to physical impairments or cognitive impairments. For example someone may have a developmental language disorder, aphasia or a social communication disorder all of which would have a substantial impact on someone's	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, communication needs will be captured in this review. We have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether:

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			accessibility to 'mainstream' information and engagement in discussions around shared decision making. Such individuals would not necessarily have any co-morbid physical impairments or cognitive impairments. Therefore since communication is vital to shared decision making, the equality impact assessment must distinctively highlight this collection of difficulties. Additionally, we would be pleased to see NICE acknowledge autism as something other than an example of a 'learning disability' as we do not feel this belongs to this categorisation.	• the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Royal College of Speech and Language Therapists	3	21-25	Whilst we are pleased to see the reference to supporting children and young people in the equality impact assessment, we are disappointed at the lack of reference to supporting communication needs. Children have a lower level of understanding of complex and technical medical vocabulary. Decision making depends on understanding and as such communication issues need to be acknowledged.	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021.
Royal College of Speech and Language Therapists	3	21-25	The RCSLT welcomes the inclusion of people with lower health literacy in the equality impact assessment.	Thank you for your comment.
Royal College of Speech and Language Therapists	4	14-15	The RCSLT would welcome information from NICE on how this will be measured in people's own homes.	Thank you for your comment. Approaches to measuring shared decision making are currently being tested by NHS England, with a view to developing future guidance.

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			We would also encourage inclusion of educational settings as an example as often this is a key place for healthcare services to be provided (e.g. therapies in schools), however frequently falls under the radar in scoping activities.	The intention is for this guidance to outline tools and approaches that can be used when measuring shared decisions, thereby supporting providers and commissioners to develop localised approaches to implementing shared decision making. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided.
Royal College of Speech and Language Therapists	6	22-26	In the area of "shared decision making in the healthcare system" we believe there are some further gaps in the consideration of the key issues. We would recommend consideration of the following questions and issues? • What are the skills that professionals need to have to be able to engage with shared decision making? When is it appropriate to involve professionals in communication (e.g. Speech and Language Therapists) in discussions about shared decision making?	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. The guideline committee will consider your comment when developing the evidence review protocols. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to

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				practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal College of Speech and Language Therapists	6	7-20	In the area of "supporting and promoting shared decision making" we were very surprised to see no consideration of different approaches to supporting engaging and facilitating communication with people using services, their families and carers or advocates. We would encourage careful distinction between effective approaches for individuals with specific sets of needs to do this to be within the scope of the guideline. The RCSLT believe that there are a number of gaps in the consideration of the key issues. We would recommend consideration of the following questions and issues: • What are the most effective approaches to ensuring that people with communication needs are able to participate in shared decision making? • What are the barriers to shared decision making for people with communication needs? What support and reasonable adjustments are needed to better accommodate speech and communication needs during shared decision making?	Thank you for your comment. The guideline will consider the evidence for supporting and promoting shared decision making in healthcare. It will also consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, communication needs will be captured in this review. We have amended the Equality impact assessment document, linked to section 2 of the scope, to reflect the issue you raise. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully)

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				• any groups of people might find it impossible or unreasonably difficult to receive or access an intervention • recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention.
Royal College of Speech and Language Therapists	7	27-28	The RCSLT would welcome further information on the NICE Pathway on shared decision making that this currently in development.	Thank you for your comment. The current pathway outline is based on the draft scope. It will be adapted, and more detail added as the recommendations are written during guideline development. Links will be added to relevant NICE Pathways, for example decision-making and mental capacity, patient experience in adult NHS services, and service user experience in adult mental health services.
Royal College of Speech and Language Therapists	7	4-17	The RCSLT recommends adding the following outcomes • Involvement in shared decision making • Adding user feedback as part of satisfaction recording • Better understanding of the test, treatment, technique or service Awareness and feeling of autonomy in people managing their healthcare decisions.	Thank you for your comment. The scope includes a list of the main outcomes that the guideline may consider. The guideline committee will define the outcomes that will be considered in the evidence reviews through development of the review protocols. The guideline committee will consider your comment when developing the evidence review protocols.
Royal National Institute of Blind People	General	General	Unfortunately RNIB will not be responding to the consultation at this stage.	Thank you for informing us.

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Royal Pharmaceutical Society	General	General	The scope should also take into account the recently published Comprehensive Model for Personalised Care and the associated implementation plan	Thank you for your comment, the scope has been amended accordingly.
Royal Pharmaceutical Society	General	General	The scope should take health literacy into account	Thank you for your comment. The guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Evidence permitting, health literacy will be captured in this review. The equality impact assessment document, linked to section 2 of the scope, details the issue of health literacy. The committee will consider whether: • the evidence review has addressed areas identified in the scope as needing specific attention with regard to equality issues • criteria for access to an intervention might be discriminatory (for example, through membership of a particular group, or by using an assessment tool that might discriminate unlawfully) • any groups of people might find it impossible or unreasonably difficult to receive or access an intervention

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				• recommendations can be formulated to advance equality (for example, by making access more likely for certain groups, or by tailoring the intervention to specific groups).
Royal Pharmaceutical Society	General	General	The scope should include exploring the benefits of using multidisciplinary teams (MDT). As Primary Care Networks and Integrated Care Systems develop there will be more multidisciplinary working and the effect of this on shared decision making should be explored. With treatment using medicines being the most common intervention in the NHS the MDT must include a pharmacist as they are experts in medicines and their use.	Thank you for your comment. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Royal Pharmaceutical Society	General	General	The scope should also include the use of technology to ensure information about the person and the decisions they have made in relation to their health and wellbeing is shared amongst all those caring for them.	Thank you for your comment. The guideline committee will consider your comment when developing the evidence review protocols.
Society and College of Radiographers	2	3-12	The benefits of involving people in decisions about their care…. The Society and College of Radiographers suggests adding: • Educating the workforce. The Society and College of Radiographers believes patient and public engagement begins with education. • Shifting the traditional balance of power away from the clinician to focus on what matters to the patient • Embedding patient involvement in health research Please see https://www.sor.org/sites/default/files/document-versions/guiding_principles_final_proofed_1.pdf	Thank you for your comment. Section 1 of the scope is a summary of why the guideline is needed. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered

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				by the guideline committee during development.
Society and College of Radiographers	3	11-15	The Society and College of Radiographers suggest adding Educators and Researchers to 'Who is the guideline for '	Thank you for your comment. As NICE guidelines are for the NHS we have not included educators and researchers in this list although we acknowledge the guideline may be of interest to them. Please note that as the guideline committee look at the evidence and formulate recommendations the guideline audience will be further defined in the final guideline.
Society and College of Radiographers	3	14	The Society and College of Radiographers suggest 'Everybody who **design and** delivers healthcare services '	Thank you for your comment, the scope includes commissioners of health and public health services which includes the group you have highlighted.
Society and College of Radiographers	6	13-14	The Society and College of Radiographers suggest again include educators and researchers here	Thank you for your comment. NICE guidelines are for the NHS we have not included educators and researchers in this list although we acknowledge the guideline may be of interest to them. Please note that as the guideline committee look at the evidence and formulate recommendations the guideline audience will be further defined in the final guideline.
Society and College of Radiographers	6	17-18	The Society and College of Radiographers suggest again include educators and researchers here	Thank you for your comment. NICE guidelines are for the NHS we have not included educators and researchers in this list although we acknowledge the guideline may be of interest to them.

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Society and College of Radiographers	6	25-26	The Society and College of Radiographers considers this wording to be reductive and perpetuates the notion that one size fits all. There is no one 'patient culture' rather common expectations across society. Person-centred approaches point toward valuing the unique values and preferences that individuals have within a particular culture.	Thank you for your comment. Following stakeholder comments this section has been amended.
Thrombosis UK	General	General	We would like to seek clarification whether this guideline will include SDM when considering referral or is it restricted to SDM related to treatment decision making only. For example, would this guideline inform shared decision making when seeking referral for a mental health review?	Thank you for your comment. The guideline will consider shared decision making along the entirety of the care pathway.
Thrombosis UK	General	General	It is often difficult to recall all of the information shared during a health consultation, and to then confidently and comprehensively share this with a carer / other healthcare professional or review to recall. Thrombosis UK suggests the scope should include consideration on the formats and media appropriate for sharing information and decision making taken during a shared decision-making process. We believe it is important to recognise 'verbal alone', is not acceptable.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for effective approaches and activities to support engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The guideline will also consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. **The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of**

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				the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.
Thrombosis UK	General	General	Thrombosis UK welcomes NICE scope for a Shared Decision Making (SDM) guideline, however this is a very diverse area and the scope needs to reflect the possible multiple specialities and ways in which a person may enter the health system as well as have access to resources that will help inform and support shared decision making. For health providers, training is also needed to consider how SDM can be provided to really bring benefit to the health and well-being of the person.	Thank you for your comment. The committee is made up of a diverse range of members including people who use health care services and experts in healthcare. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.
Thrombosis UK	3	11-13	We think this statement could be clarified and suggest it be amended to: *Any member of the general public using healthcare services including but not limited or restricted to: Adults (Persons over 18), Children and young people (persons under 18), families of, carers of and advocates of.*	Thank you for your comment. The scope has been amended to include adults aged 18 years and above only. Shared decision making in persons under 18 years will be captured in the NICE guidance on 'Infant, children and young people's experience of healthcare', due to publish in 2021.
Thrombosis UK	3	16	We suggest this guideline would be relevant to *anybody involved in facilitating the process of making healthcare decisions including but not limited to social care workers*. We suggest this sentence should be extended to reflect this. This is important because if shared decision making is not promoted at the outset of any decision it can fail. As example, a school teacher may identify a child with mental health needs and hence would be involved in the initiation for referral for medical treatment for somebody in their care The decision at the outset to refer should be shared not shared once the referral is made.	Thank you for your comment. The scope included carers and advocates which includes the group you have highlighted.

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Thrombosis UK	4	10	Acknowledgement for what guideline will apply to those not included in this scope – eg people who lack mental capacity, should be referenced throughout.	Thank you for your comment. The scope references NCE guideline NG108, Decision-making and mental capacity, in the related NICE guidance section. The guideline will have the opportunity to cross-refer to related NICE guidance as needed.
Thrombosis UK	6	10	This needs to include facilitators: The people who may initiate a healthcare referral need to be included in the process so that valuable information and support is not overlooked/missed. Shared decision making needs to be embedded from the very start.	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Any evidence relating to effective communication and collaboration will be captured in this review. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others.

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University of Warwick Medical School	4	8	We believe that the scope should include anticipatory decisions for unexpected life-threatening emergency needing immediate life-saving care. We conducted research, funded by the National Institute for Research, exploring emergency care and resuscitation decisions across NHS organisations.[1] The context for the research is that 90% of the 285,000 patients who die in hospital do so with a do not attempt resuscitation (DNACPR) decision in place. Dissatisfaction, complaints and litigation[2] about resuscitation and emergency treatment decisions are relatively common and often evolve around lack of patient involvement in decisions as identified in our report[1] and the Parliamentary select committee report[3] An emergency treatment and resuscitation decision is usually made if (i) the patient is dying (ii) through a shared decision which has considered the benefits and burdens of treatment (iii) patient refusal. The field has progressed such that resuscitation decisions are now included as part of overall recommendations for emergency care and treatment plans (RESPECT).[4] Our research showed that there is variation in approach around the degree of patient involvement in such decisions. Clinicians lack confidence about how best to tackle these conversations with patients. Patients do not feel that their voices are heard – many are concerned they will receive treatment against their wishes. The context for anticipatory decisions for emergency treatment seems well aligned with the overall strategy for this NICE proposal. To exclude emergency decisions from shared decision making model will be a retrograde step for patients, clinicians and the NHS. References: [1] https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr04110/#/full-report [2] https://www.judiciary.uk/wp-content/uploads/2014/06/tracey-approved.pdf	Thank you for your comment. The scope has been amended, with section 1 now noting the inclusion of advance care planning within the shared decision making process. Related to your comment, the guideline will consider the evidence for the questions listed under supporting shared decision making. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. We will keep in mind the issue you have raised when developing the guideline.

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			[3] https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf [4] https://respectprocess.org.uk	
Versus Arthritis	General	General	Versus Arthritis is the charity formed by Arthritis Research UK and Arthritis Care joining together. We work alongside volunteers, healthcare professionals, researchers and friends to do everything we can to push back against arthritis. Together, we develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit convers all musculoskeletal conditions which affect the joints, bones and muscles including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis.[i]	Thank you for this information.
Versus Arthritis	General	General	Arthritis and musculoskeletal conditions affect 17.8 million people in the UK and are the single biggest cause of pain and disability in the UK. Cumulatively, the healthcare costs of osteoarthritis and rheumatoid arthritis will reach £118.6 billion over the next decade.ii Musculoskeletal conditions account for a fifth of all sickness absence and result in the loss of around 30.8 million working days to the UK economy each year.[iii]	Thank you for this information.
Versus Arthritis	General	General	We are delighted to have this opportunity to make comments on the draft scope of the proposed NICE Guideline. Shared decision making is an important component of personalised care for people with arthritis that supports decisions about their medical care such as treatment and surgery, as well as decisions affecting quality of life like when to return to employment.	Thank you for your comments.
Versus Arthritis	General	General	Versus Arthritis currently delivers personalised support and information services that support shared decision making through the *Living Well with Arthritis* programme that operates across England. This is delivered either over the phone or face to face by people with arthritis.[iv]	Thank you for this information.
Versus Arthritis	General	General	In 2017, Versus Arthritis held a meeting with stakeholders from NHS England, NICE, NHS Trusts and patient representatives to build shared understanding about shared decision making for people with musculoskeletal conditions. The findings of this meeting provide the background to many of our comments in response to this draft scope.	Thank you for your comments.
Versus Arthritis	General	General	Our response focuses on two separate parts of the draft scope: how to support shared decision making through monitoring outcomes and providing patients with high quality	Thank you for your comments.

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			information; and access to community services to support shared decision making in the healthcare system.	
Versus Arthritis	6	10-20	In addition to these questions focusing on engagement with shared decision making, it is important that the scope includes a question about monitoring the outcomes of shared decision-making conversations. Developing the evidence base about the delivery of actions and activities recorded in conversations that have taken place is crucial to providing the NHS with a clear picture of services that patients may be signposted to, both provided by the NHS and third-party providers.	Thank you for your comment. Approaches to measuring shared decision making are currently being tested by NHS England, with a view to developing future guidance. The intention is for this guidance to outline tools and effective approaches that can be used when measuring shared decisions, thereby supporting providers and commissioners to develop localised approaches to implementing shared decision making.
Versus Arthritis	6	10-20	To establish good practice on capturing actions in shared decision making conversations and their outcomes, we would suggest a question in the scope such as : *"What data needs to be captured in shared decision making conversations and what is the most effective way to monitor the outcomes from those conversations?"*	Thank you for your comment. Related to your comment, the guideline will consider the evidence for the following review questions: • What are the core components of effective shared decision making approaches and activities? The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what

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				recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Versus Arthritis	6	10-20	In addition, the quality of patient information related to different conditions is important to ensure the effectiveness of shared decision making, both before and during consultations. A further question for the scope could be: *"What information do people using services (and their families, carers and advocates) need to support shared decision making, and in what form?"*	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. Any evidence relating to effective communication and collaboration will be captured in this review. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue

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				you have raised when developing the guideline.
Versus Arthritis	6	22-26	Whilst it is important to focus on approaches to embed shared decision making into the healthcare system, support in community settings is a crucial component for those decisions to be implemented in practice and effectively meet patient needs.	Thank you for your comment. The guideline will cover all settings where publicly funded healthcare services are commissioned and provided. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. If the evidence you refer to meets the review protocol, this will be considered by the guideline committee during development. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.

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Versus Arthritis	6	22-26	Therefore, Versus Arthritis recommends that a question is added to this section that reflects the need for this support to be in place for shared decision making to be effective, such as: *"What community systems, resources and support are needed beyond health services to ensure people are able to exercise the full range of choices about their health?"*	Thank you for your comment. Related to your comment, the guideline will consider the evidence for barriers to, and facilitators for, engagement with shared decision making by both people using services, and their families, carers and advocates as well as healthcare providers. The development of the guideline will follow the processes and methods described in Developing NICE guidelines: the manual. Evidence reviews will be conducted for each of the review questions described in the scope which will include all published evidence which meet the review protocols developed for the guideline. The committee will use its judgement to decide what the evidence means in the context of the guideline referral and decide what recommendations can be made to practitioners, commissioners of services and others. We will keep in mind the issue you have raised when developing the guideline.
Versus Arthritis	6	22-26	There is also an issue about which stage of the patient pathway shared decision making should be instigated for people with arthritis, and the healthcare professional/s who should be involved in leading this work. The workshop that we ran in 2017 provided some consensus that shared decision making was best instigated with a second line practitioner in primary care, such as a physiotherapist or extended scope practitioner.	Thank you for your comment. The guideline will consider shared decision making along the entirety of the care pathway. We will keep in mind the issue you have raised when developing the guideline.

Registered stakeholders

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[i] https://www.versusarthritis.org/about-us/

[ii] York Health Economics (2017). The Cost of Arthritis: Calculation conducted on behalf of Arthritis Research UK.

[iii] Office for National Statistics (2016). Sickness Absence Report 2016.

[iv] https://www.arthritiscare.org.uk/our-services-and-support/events/filter:Living%20Well%20with%20Arthritis