



NICE clinical guideline 180: Atrial fibrillation

Using the NICE patient decision aid

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Note: this is not an official NICE presentation

What this slide set covers:

- What is shared decision-making?
- Why a patient decision aid (PDA) for anticoagulants in atrial fibrillation?
- How does the PDA fit into the consultation?



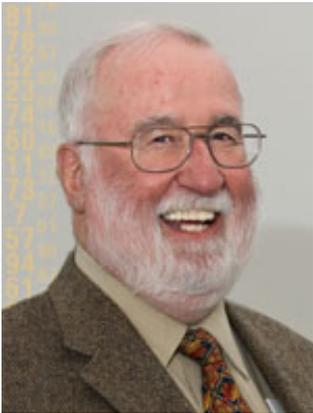
What is shared decision-making?

Elwyn G, et al. *J Gen Intern Med* 2012; 27:1361–7

‘..an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.’

Shared decision-making: a key part of expertise in evidence-based medicine

Sackett D, et al. BMJ 1996;312:71–72



‘The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research.’

‘Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients’ predicaments, rights, and preferences in making clinical decisions about their care.’



Overemphasis on following algorithmic rules?

Greenhalgh T, et al. *BMJ* 2014;348:g3725

‘Well intentioned efforts to automate use of evidence through computerised decision support systems, structured templates, and point of care prompts can crowd out the local, individualised, and patient initiated elements of the clinical consultation...

Inexperienced clinicians may (partly through fear of litigation) engage mechanically and defensively with decision support technologies, stifling the development of a more nuanced clinical expertise that embraces accumulated practical experience, tolerance of uncertainty, and the ability to apply practical and ethical judgment in a unique case...

As the language of EBM becomes ever more embedded in medical practice, and as bureaucratic rules become the accepted way to implement ‘the best’ evidence, its requirements for evidence are quietly attenuated in favour of an emphasis on rules.’



Two sources of expertise

Clinician's expertise	Patient's expertise
Diagnosis	Experience of illness
Disease aetiology	Social circumstances
Prognosis	Attitude to risk
Treatment options	Preferences
Outcome probabilities	Values



Why a patient decision aid for anticoagulants in atrial fibrillation?

- The evidence for the effects of anticoagulants on the risk of ischaemic stroke is strong.
- For the individual person, the decision about whether or not to take an anticoagulant, and if so which one, is ‘preference sensitive’
 - involves trade-offs
 - the right choice for the person will depend on the importance they give to these trade-offs.
- ‘The first task of shared decision-making is to ensure that individuals are not making decisions in the face of avoidable ignorance.’ (Elwyn G, et al 2012)



Does using decision aids help shared decision-making?

Stacey D, et al. *Cochrane Database of Systematic Reviews* 2014 Issue 1. Art No.: CD001431

Compared with usual care, decision aids:

- improve people's knowledge regarding options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values
- stimulate people to take a more active role in decision making
- improve congruence between the chosen option and the patient's values
- have no apparent adverse effects on health outcomes or satisfaction.

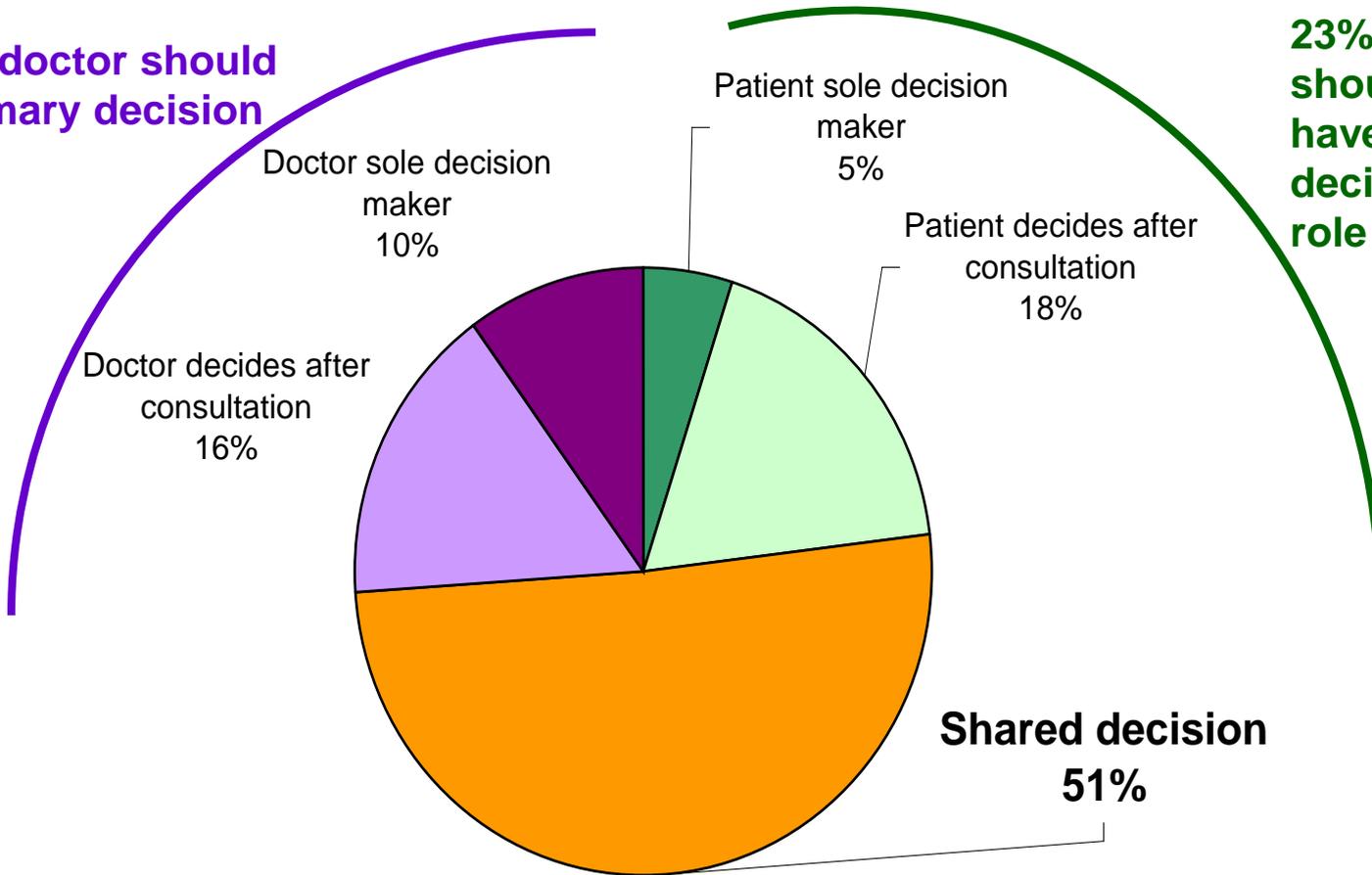
Do patients want to be involved in decisions?

Coulter A, Jenkinson C. Eur J Public Health 2005;15:355–60

Patient expectation about involvement in decisions

26% say doctor should have primary decision role

23% say patient should have primary decision role





Do GPs accurately assess their patients' desire to be involved in decisions?

Cox K, et al *British Journal of General Practice* 2007;57:777–84

- Study in 5 GP practices in inner south London
- Consecutive patients aged over 18 years consulting 5 GPs were invited to take part (n=479)
 - asked before consultation about their preferred level of involvement in decisions about medicines for the main health problem they wanted to discuss with the doctor
 - asked after the consultation about decisions that had been made and their involvement and satisfaction with this
 - GPs also completed a questionnaire after each consultation.



Do GPs accurately assess their patients' desire to be involved in decisions?

Cox K, et al *British Journal of General Practice* 2007;57:777–84

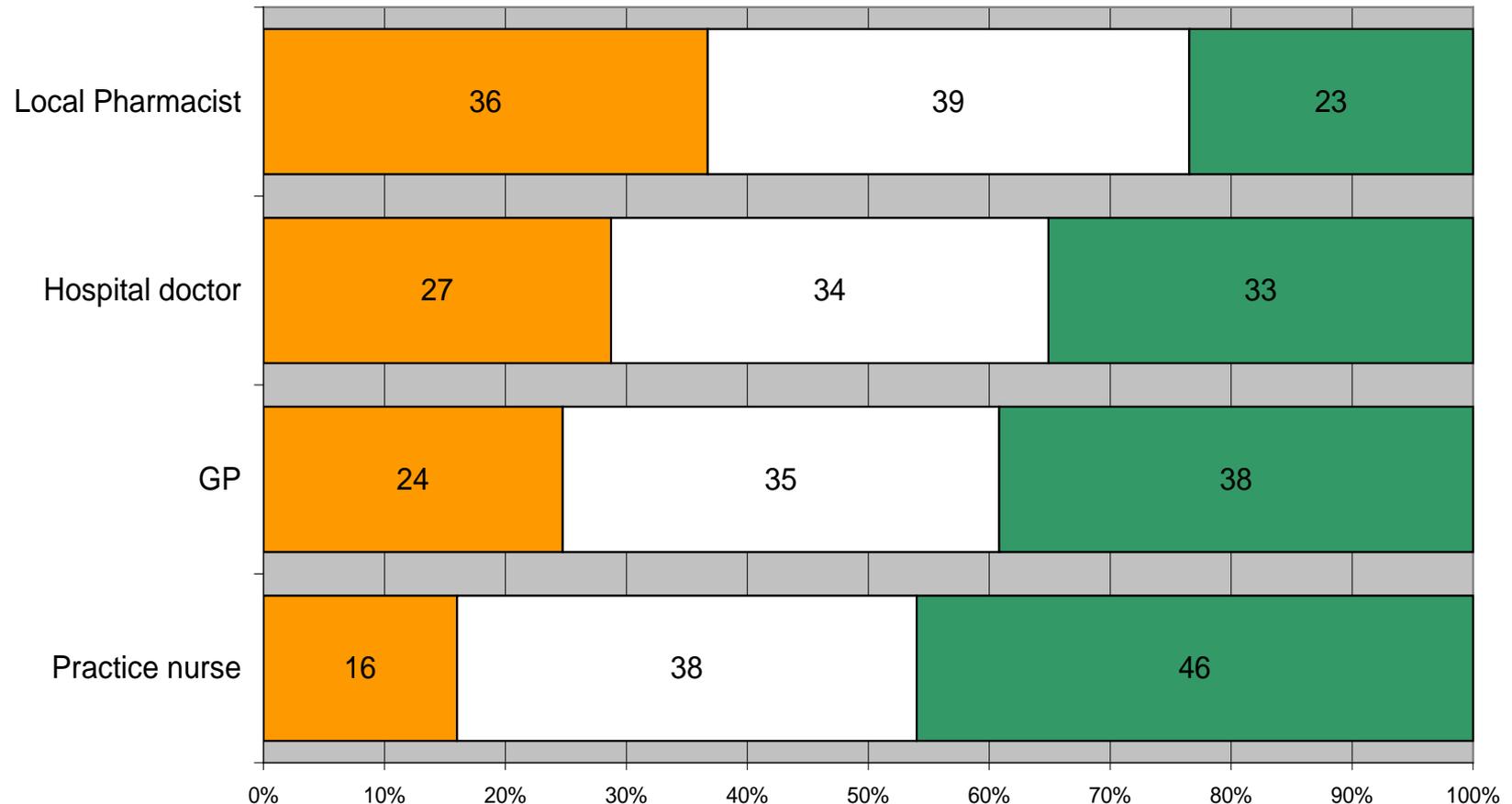
Results

- 39% of patients said they preferred shared decision-making
 - 16% wanted to be the main (14%) or only (2%) decision-maker
 - 45% wanted the GP to be the main (28%) or only (17%) decision-maker.
- GPs correctly estimated their patients' decision-making preferences in 32% of cases
 - Overestimated in 45%, underestimated in 23% ($\kappa = 0.09$)
 - Patients' educational attainment was independently associated with GPs underestimation of preferences.

Patients' perceived involvement in decisions

DH (2009) Self care for people with long term conditions

Were you encouraged to self care or play an more active role in caring for your long-term condition when you approached or looked at.....



Source: Self care for people with long-term conditions, Department of Health, 2009

■ No □ Yes, a bit ■ Yes, a lot



Quality standards for patient experience in adult NHS services

QS15 February 2012

Statements relevant to shared decision-making

- **Statement 1.** Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.
- **Statement 2.** Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
- **Statement 4.** Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.



Quality standard for patient experience in adult NHS services

QS15 February 2012

Statements relevant to shared decision-making (continued)

- **Statement 5.** Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.
- **Statement 6.** Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.



Quality standard for patient experience in adult NHS services

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Statements relevant to shared decision-making (continued)

- **Statement 7.** Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.
- **Statement 9.** Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.



Tasks in shared decision-making

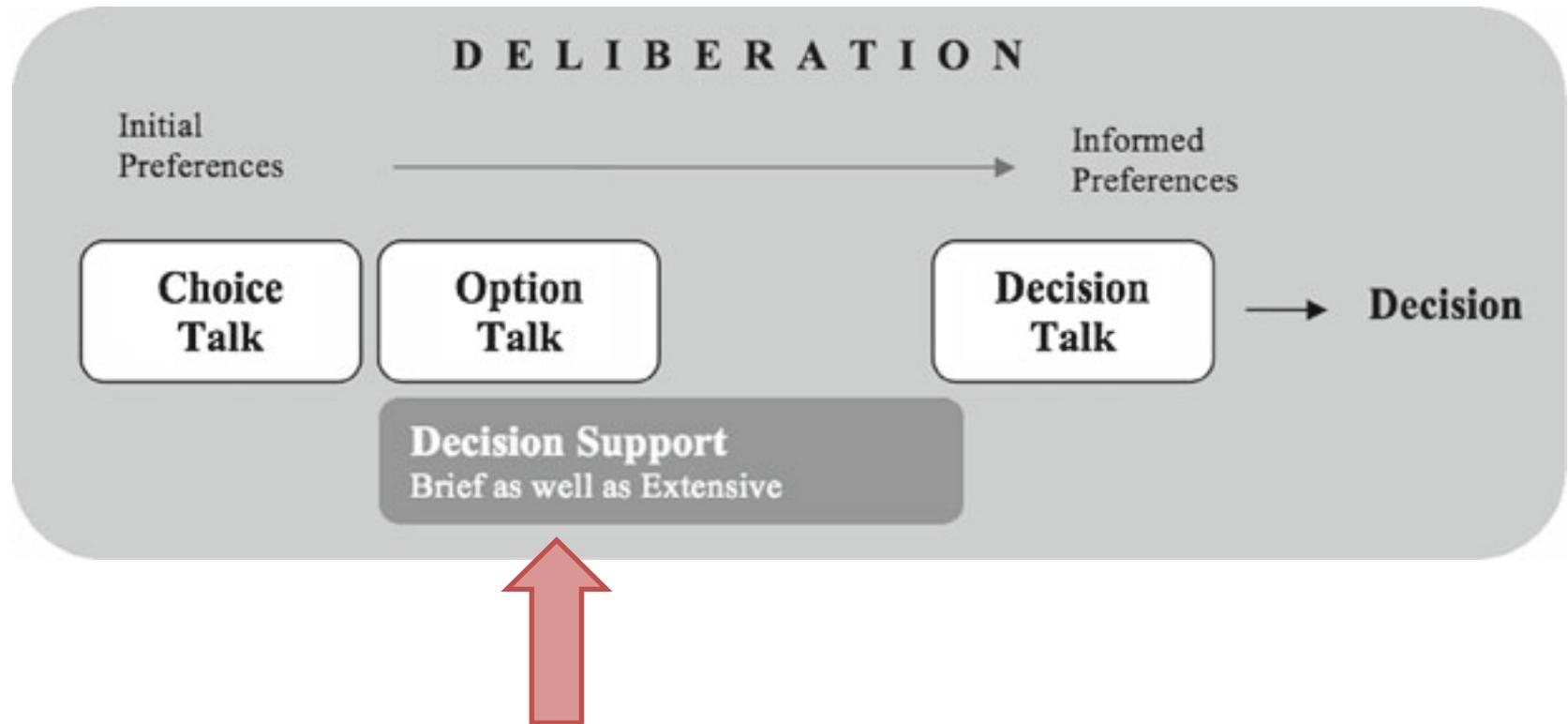
Elwyn G, et al. *J Gen Intern Med* 2012; 27:1361–7

- The first task of shared decision-making is to ensure that individuals are not making decisions in the face of avoidable ignorance.
- The second task is to support people to deliberate about their options by exploring their reactions to information
 - some people feel surprised or unsettled by the offer of options and uncertainty about what might be best
 - if all responsibility for decision making is transferred to patients they may feel abandoned.

- Ideas
- Concerns
- Expectations

How does the PDA fit into the consultation?

Elwyn G et al. J Gen Intern Med 2012; 27:1361–7

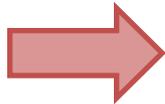




How does the PDA fit into the consultation?

Elwyn G et al. J Gen Intern Med 2012; 27:1361–7

Deliberation	A process where patients become aware of choice, understand their options and have the time and support to consider 'what matters most to them': may require more than one clinical contact not necessarily face-to-face and may include the use of decision support and discussions with others.
Choice talk	Conveys awareness that a choice exists – initiated by either a patient or a clinician. This may occur before the clinical encounter.
Option talk	Patients are informed about treatment options in more detail.
Decision talk	Patients are supported to explore 'what matters most to them', having become informed.
Decision Support	Decision support as designed in two formats: 1) brief enough to be used by clinician and patient together and 2) more extensive, designed to be used by patients either before or after clinical encounters (paper, DVD, web).
Initial Preferences	Awareness of options leads to the development of initial preferences, based on existing knowledge. The goal is to arrive at informed preferences.
Informed Preferences	Personal preferences based on 'what matters most to patients', predicated on an understanding of the most relevant benefits and harms.





Phase 1: choice talk

Elwyn G et al. J Gen Intern Med 2012; 27:1361–7

- Step back:
 - ‘Now we need to decide what to do next.’
- Offer choice
 - ‘There’s good information about how these options differ that I’d like to discuss with you.’
- Justify choice
 - the importance of respecting individual preferences and the uncertainty of outcomes
- Check reaction
 - ‘Shall I tell you about the options?’
- Defer closure
 - if the person reacts by saying ‘just tell me what to do’, reassure them that you are willing to support the decision-making process.



Phase 2: option talk

Elwyn G et al. J Gen Intern Med 2012; 27:1361–7

- Check knowledge:
 - ‘What have you heard or read about anticoagulants?’
- List options
 - providing a list gives a structure to the conversation
- Describe options
 - be clear about the pros and cons of the different options
- Provide decision support
- Summarise
 - assess understanding by asking the person to tell you in their own words what the options entail.



Phase 3: decision talk

Elwyn G et al. J Gen Intern Med 2012; 27:1361–7

- Focus on preferences:
 - ‘What, from your view, matters most to you?’
- Elicit a preference
 - be ready to offer more time or to guide the person if they indicate that is their wish
- Moving to a decision
 - ‘Are you ready to decide? Do you want more time? Do you have any more questions? Is there anything more we need to discuss?’
- Offer review
 - remind the person that decisions can be reviewed.



Patient experience in adult NHS services

CG138 February 2012

Patient views and preferences

- Hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management. Allow adequate time so that discussions do not feel rushed
- Review with the patient at intervals agreed with them:
 - their knowledge, understanding and concerns about their condition and treatments
 - their view of their need for treatment
- Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments



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Patient views and preferences (continued)

- Accept that the patient has the right to decide not to have a treatment, even if you do not agree with their decision, as long as they have the capacity to make an informed decision and have been given and understand the information needed to do this
 - Assess the patient's capacity to make each decision using the principles in the Mental Capacity Act (2005)
- Respect and support the patient in their choice of treatment, or if they decide to decline treatment
- Ensure that the patient knows that they can ask for a second opinion from a different healthcare professional, and if necessary how they would go about this



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Shared decision making

- When discussing decisions about investigations and treatment, do so in a style and manner that enables the patient to express their personal needs and preferences
- Give the patient the opportunity to discuss their diagnosis, prognosis and treatment options



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Shared decision making (continued)

- When offering any investigations or treatments:
 - explain the medical aims of the proposed care to the patient
 - openly discuss and provide information about the risks, benefits and consequences of the investigation or treatment options (taking into account factors such as coexisting conditions and the patient's preferences)
 - clarify what the patient hopes the treatment will achieve and discuss any misconceptions with them
 - set aside adequate time to allow any questions to be answered, and ask the patient if they would like a further consultation



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Shared decision making (continued)

- Accept and acknowledge that patients may vary in their views about the balance of risks, benefits and consequences of treatments.
- Use the following principles when discussing risks and benefits with a patient (next slides)



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Principles for discussing risks and benefits

- personalise risks and benefits as far as possible
- use absolute risk rather than relative risk
 - for example, the risk of an event increases from 1 in 1000 to 2 in 1000, rather than the risk of the event doubles
- use natural frequency rather than a percentage
 - for example, 10 in 100 rather than 10%
- be consistent in the use of data
 - for example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5



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Principles for discussing risks and benefits (continued)

- present a risk over a defined period of time (months or years) if appropriate
 - for example, if 100 people are treated for 1 year, 10 will experience a given side effect
- include both positive and negative framing
 - for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients



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Principles for discussing risks and benefits (continued)

- be aware that different people interpret terms such as rare, unusual and common in different ways, and use numerical data if available
- think about using a mixture of numerical and pictorial formats (for example, numerical rates and pictograms)



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Shared decision making

- Offer support to the patient when they are considering options. Use the principles of shared decision making:
 - ensure that the patient is aware of the options available and explain the risks, benefits and consequences of these
 - check that the patient understands the information
 - encourage the patient to clarify what is important to them, and check that their choice is consistent with this



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Shared decision making

- Be aware of the value and availability of patient decision aids and other forms of decision support such as counselling or coaching. If suitable high-quality decision aids are available, offer them to the patient
- Give the patient (and their family members and/or carers if appropriate) adequate time to make decisions about investigations and treatments



Practice time!

‘..in our experience the best way to learn these skills is to use simulations, either with colleagues or with trained actors’

Elwyn G, et al 2012