Personalised Care

NHS

Shared Decision Making
Summary guide

Shared decision making

NHS England and NHS Improvement

Contents

SDM Mini Guide v4

Introduction

Shared decision making is part of the NHS Long Term Plan's commitment to make personalised care business as usual across the health and care system.

Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths and needs. This happens within a system that makes the most of the expertise, capacity and potential of people, families and communities in delivering better outcomes and experiences. Personalised care takes a whole-system approach, integrating services around the person. It is an all-age model, from maternity and childhood through to end of life, encompassing both mental and physical health support.

This represents a new relationship between people, professionals and the health and care system. It provides a positive shift in power and decision making that enables people to feel informed, have a voice, to be heard and be connected to each other and their communities.
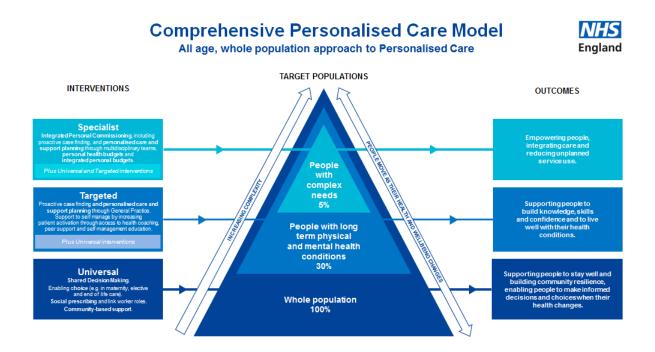
Personalised care is implemented through the Comprehensive Model for Personalised Care (see Figure 1). The model has been co-produced with a wide range of stakeholders and brings together six evidence-based and inter-linked components, each defined by a standard, replicable delivery model. These components are:

1. Shared decision making
2. Personalised care and support planning
3. Enabling choice, including legal rights to choice
4. Social prescribing and community-based support
5. Supported self-management
6. Personal health budgets and integrated personal budgets.

The deployment of these six components will deliver:

- whole-population approaches, supporting people of all ages and their carers to manage their physical and mental health and wellbeing, build community resilience, and make informed decisions and choices when their health changes

- a proactive and universal offer of support to people with long term physical and mental health conditions to build knowledge, skills and confidence to live well with their health condition

- intensive and integrated approaches to empower people with more complex needs, including those living with multi-morbidity, to experience co-ordinated care and support that supports them to live well, helps reduce the risk of becoming frail, and minimises the burden of treatment.

Figure 1: Comprehensive Model for Personalised Care

Comprehensive Personalised Care Model
All age, whole population approach to Personalised Care

More information about the Comprehensive Model for Personalised Care, and supporting summary guides for its successful implementation, are available on the personalised care pages of the NHS England website.[1]

[1] https://www.england.nhs.uk/personalised-health-and-care/

Who is this document for?

This summary guide is aimed at people leading local implementation of shared decision making (SDM). It enables:

- increased understanding of what good SDM looks like and how it ensures that we commission and provide systems and services that informed individuals want
- commissioning of local SDM initiatives and embedding them in care pathways
- providers to have better conversations with people using services, thereby supporting them to make more informed choices based on their personal values and preferences and what is known of the risks, benefits and consequences of the options available to them.

The [implementation checklist attached to this guidance](2) is a practical tool to help you start or continue conversations to understand where you are locally on SDM and to support local improvements.

This guide provides best practice advice, not statutory guidance.

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[2] https://www.england.nhs.uk/publication/shared-decision-making-summary-guide/

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What is shared decision making?

People want to be more involved in decisions about their health and care.[3] SDM ensures that people are supported to be as involved in the decision making process as they would wish.

SDM means people are supported to:

- understand the care, treatment and support options available and the risks, benefits and consequences of those options
- make a decision about a preferred course of action, based on evidence-based, good quality information and their personal preferences.

It is, therefore, a process in which clinicians and individuals work together to select tests, treatments, management or support packages, based on evidence and the individual's informed preferences.[4]

SDM is relevant in any non-life threatening situation when a health or care decision needs to be made and a range of options (including doing nothing) is available.

SDM ensures that individuals are supported to make decisions based on their personal preferences and are, therefore, more likely to adhere to evidence based treatment regimes, more likely to have improved outcomes and less likely to regret the decisions that are made.[5]

By paying attention to individuals' informed preferences we can support people to achieve outcomes that matter to them. Aggregating the decisions of informed individuals to a population level means we can commission and provide services that informed people want and therefore allocate resources more efficiently.

A systematic review found that SDM interventions significantly improve outcomes for disadvantaged people.[6] By addressing people's level of health literacy when sharing decisions we can also reduce health inequalities. Staff should use health-

[3] Care Quality Commission (2017), Better care in my hands: a review of how people are involved in their care. Available online: https://www.cqc.org.uk/publications/themed-work/better-care-my-hands-review-how-people-are-involved-their-care (accessed 23 October 2018)

[4] NICE / NHS England (2016), Shared Decision Making: a consensus statement. Available online: https://www.nice.org.uk/Media/Default/About/what-we-do/SDM-consensus-statement.pdf (accessed 23 October 2018)

[5] Stacey, D. et al. (2014), Decision aids for people facing health treatment or screening decisions, Cochrane Database Syst. Review (1): CD001431

[6] Durand, M.A., Carpenter, L., Dolan, H., et al. (2014), Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. PLoS One 9(4):e94670

literate decision support materials (when such materials are available) and tailor their conversations to take account of low health literacy by using specific techniques, building on the health literacy toolkit.[7]

SDM is driven by the duties for NHS England set out in the NHS Act 2006 as amended by the Health and Social Care Act 2012 to: promote individual participation in decisions about care, treatment, tests, and prevention of illness; promote patient choice; and exercise its functions with a view to securing continuous improvement in the quality of services.

SDM can also support the health and care system to respond to the judicial ruling, which has UK-wide applicability, in Montgomery v. Lanarkshire Health Board (2015),[8] in which a health board was found vicariously negligent when a person was not presented with all possible options in a transparent way.

Health and care professionals have a professional duty set out in their codes of conduct to listen to people and respond to their preferences and concerns:

General Medical Council (2013)[9]

Nursing and Midwifery Council (2018)[10]

Health and Care Professions Council (2016)[11]

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[7] https://www.hee.nhs.uk/our-work/health-literacy
[8] https://www.supremecourt.uk/decided-cases/docs/UKSC_2013_0136_Judgment.pdf
[9] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice
[10] https://www.nmc.org.uk/standards/code/
[11] https://www.hcpc-uk.org/publications/standards/index.asp?id=38

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What good shared decision making looks like – for people

- SDM supports people to be as involved as they would wish in a decision about which course of action to take when their health status changes.

- The process supports people to understand the diagnosis they have and the options they face (including doing nothing) alongside what is known of the risks, benefits and consequences of pursuing those options. In a process of deliberation, they are then supported to talk about 'what matters to me' in terms of their attitude to risk, the trade-offs they are willing to make and the outcomes that are important to them. Finally, a decision is made in partnership with their professional team.

- The process can be supported by the use of evidence-based decision support tools that are tailored to support people (especially those with low levels of health literacy) to understand their options and what is known of the benefits, harms, consequences and burdens of those options.

- The system should ensure that people are prepared to have a shared decision making conversation by:

  o putting in place a campaign that encourages people to 'ask 3 questions'[12], to ask 4 questions, such as BRAN[13], or equivalent

  o having access to relevant information and decision support materials before, during and after an appointment with a healthcare professional.

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[12] http://personcentredcare.health.org.uk/resources/ask-3-questions-materials

[13] http://www.choosingwisely.co.uk/resources/

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What good shared decision making looks like – for the system

Figure 1: **NHS England shared decision making Implementation Framework**

- Ask 3 questions
- It's ok to ask

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Supportive systems and processes

- Leadership at every level, including clinical
- Health-literate decision support tools
- Measurement and monitoring

Shared Decision Making

- Redesign pathways to incorporate SDM
- Align measures and incentives SDM in local delivery plans and operational models

Commissioned services

Trained teams

- Accredited training
- SDM champions
- Mixed learning methods
- Mixed levels of learning

1.   Commissioned services

SDM should be built into points along a care pathway when a decision needs to be made. This is particularly relevant when people face 'high value' decisions where the choice can have a significant impact (positive or negative) on their lives. At these decision points, options should include medical treatments, doing nothing and (where relevant) the option of psychosocial/community support.

2.   Trained teams

Most health and care staff will need to receive accredited training to confidently take part in SDM conversations. The skills required involve training in motivational/health coaching approaches, alongside specific training in risk communication and in working with people at low levels of health literacy. A barrier to the uptake of training is 'unconscious incompetence'- in other words many clinicians do not understand that they might benefit from training. Local clinical leaders who appreciate the value of training in SDM and can act as champions can be particularly helpful in encouraging uptake of training opportunities.

3.   Prepared public

Individuals should be supported to play as active a role as they wish in decisions about their care. As outlined above, there is a number of ways in which local health systems can ensure that people are prepared to share decisions.

4.   Supportive systems and processes

The implementation of SDM is a complex intervention.

Implementation should be clinically-led and all improvement efforts should be co-produced with people with lived experience. Senior organisational leaders (executive, clinical, voluntary and community sector, and lived experience) should visibly signal that SDM is an important organisational priority to drive improvement.

Care pathways should be mapped to identify decision points and consideration given to embedding health literate decision support resources at these points; these tools should be readily available to clinical teams. NICE guidelines should be the primary resource for decision support tools as NICE routinely incorporates them into its guidance.

Validated measurement and monitoring of SDM should be used to ensure that it is taking place to a high standard. Measures that can be used include:

- GP patient survey item 28[14]
- Three-item CollaboRATE[15]
- SDM Q9[16]

Commissioners should also measure the *impact* of implementing SDM on service utilisation. Implementing this feedback loop will ensure that over time, commissioners and providers design and deliver services that informed individuals want.

Shared decision making self-assessment checklist

A useful SDM self-assessment checklist[17] is available as part of this guide. It can be used to ascertain where you are locally in terms of SDM and help you put in place the key elements of a successful change programme.

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[14] https://gp-patient.co.uk/Files/Questionnaire2018.pdf
[15] http://www.glynelwyn.com/collaborate.html
[16] http://www.patient-als-partner.de/index.php?article_id=20&clang=2/
[17] https://www.england.nhs.uk/publication/shared-decision-making-summary-guide/

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How shared decision making fits with other personalised care components

SDM is the gateway to personalised care for people when their health status changes. At the point of diagnosis, most people are not aware of the care, treatment and support options that are available to them nor what is known of the benefits and harms of pursuing those options. SDM is about taking a personalised approach that routinely recognises and takes account of people's health, wellbeing, social circumstances, preferences and values and helps them understand the evidence based options available to them.

Personalised care and support planning (PCSP) and SDM both enable people to make informed decisions based on what matters to them, and to decide on a plan of care. However, PCSP is a proactive, future-focused conversation that supports people living with long term conditions (who might also have care and support needs) to live well, whereas SDM is a present-orientated conversation to decide on a course of action when a person's health status changes.

Understanding a person's level of knowledge, skills and confidence (their "activation") is integral to engaging in SDM conversations. By understanding and engaging with peoples' confidence to become involved in healthcare decisions, it can increase the likelihood of mutually useful SDM conversations between people and health care professionals.

Social prescribing enables all local agencies to refer people to link workers, who give people time and focus on what matters to the person as identified through shared decision making or personalised care and support planning. They connect people to community groups and agencies for practical and emotional support. It may be an appropriate single option arising from a SDM conversation in some cases, or could be pursued alongside a medical treatment.

What guidance and resources are available?

Below is a summary of key resources that can support implementation.

Supportive system

Decision support resources: a range of decision support resources are available through NICE

- https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making

SDM Measurement guidance: explaining why you should measure SDM, the challenges and some things to consider, including a description of three measurement tools

- GP patient survey item 28
  The GP Patient Survey assesses patients' experience of healthcare services provided by GP practices and experience of NHS dental services.
  https://www.gov.uk/government/statistics/gp-patient-survey-2018

- CollaboRATE: A patient reported measure with three brief questions completed after a consultation.
  http://www.glynelwyn.com/collaborate-measure.html

- SDM Q-9 / SDM-Q-DOC: A nine item questionnaire completed by the individual and health care professional following a consultation.
  http://www.patient-als-partner.de/index.php?article_id=20&clang=2/

Trained teams

Skills for Health, Skills for Care and Health Education England: E-learning introduction to person centered approaches.

https://www.skillsplatform.org/courses/5192-person-centred-approaches

Association of Medical Royal Colleges and University of Cambridge risk communication toolkit: e-learning course designed for health care professionals to help them develop skills for communicating effectively about the potential harms and benefits of treatment options.

- Communicating potential harms and benefits
  https://moodle.wintoncentre.uk/

Prepared public

Ask 3 questions: resources to help increase individuals' awareness of shared decision making; increase their expectations for a shared decision

making consultation; and provide them with a way of taking part in shared decision making.

https://www.aquanw.nhs.uk/resources/shared-decision-making/Ask%203%20Questions%20Poster.pdf
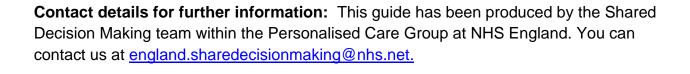
BRAN: Choosing Wisely UK and Association of Medical Royal Colleges campaign to encourage individuals to ask four questions of the doctor or nurse to make better decisions together.

http://www.choosingwisely.co.uk/resources/shared-decision-making-resources/

Specific health literacy resources

Simplified communication techniques: multiple resources are available to help clear communication between a health and care professional and the person they are caring for. These can all be found in the national health literacy toolkit, hosted on behalf of the system in England, by Health Education England.

https://www.hee.nhs.uk/our-work/health-literacy

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact england.personalisedcare@nhs.net