The HOUSE Journal

The newsletter for the Year of Care Community of Practice

Issue 22
Shared decision making

Welcome to The HOUSE Journal

Dr Nick Lewis-Barned – Co-chair and Clinical Lead

In this edition of The House Journal, we explore shared decision making (SDM) as a specific standalone activity and consider its fit within a personalised care and support planning approach (PCSP).

Person centred care puts emphasis on the agency of individuals in formulating and putting in place plans for their health in the context of their values, priorities and circumstances, supported by professionals [1].

SDM is often defined as "a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences" [2].

However, as Rachel Johnson's article highlights, in general practice decisions are often made in complex personal and clinical settings and across several contacts with different practitioners. This lends itself to PCSP with a cycle of proactive conversations around sometimes complex health and social issues by people with long term conditions.

SDM is a key component of the Universal Model of Personalised Care. It is the subject of NICE guidance, professional standards and the law and is not going away.

1 Lhussier M, Eaton S et al. 2015 Care planning for long-term conditions – a concept mapping - PubMed (nih.gov)
2 Coulter A, Collins A Making shared decision-making a reality, The King's Fund publication, July 2011 (kingsfund.org.uk)

Montgomery, the law and consent – what does it mean for SDM?

Nadine Montgomery had type 1 diabetes and in 1999, towards the end of her pregnancy, had concerns that were either not taken seriously enough by the team providing her care, or were met with reassurances. Also, her options including to have a caesarean were not discussed with her. Her son Sam was born with birth trauma causing serious disability and in 2014, after twice being rejected in court, her claim was upheld by the Supreme Court in London. This established a new precedent in law[3] emphasising:

- Unless a person lacks capacity, practitioners are obliged to ensure that a person "*is aware of any material risks involved in any recommended treatment and of any reasonable alternative*".
- It is the duty of the practitioner (not the person) to ensure that the person has understood these.
- The person must give consent freely and without coercion.

This shifts the emphasis of decision making in health from one where a practitioner *"acted in accordance with a practice accepted as proper by a body of responsible and skilled medical opinion"* (known as the Bolam Test) to insistence that where *"there are choices to be made, arguments for and against each of the options to be considered, and sufficient information must be given (to the person) so that this can be done."*

In other words, where there are options, any decisions must now be made with or by the person rather than for them.

In November 2020 the General Medical Council (GMC) clarified its guidance on decision making and consent[4] and set out principles that must be followed including documentation of decisions. Every day in practice people make decisions with practitioners to act (or to not act), and the change in law applies to all of these.

This means that simply giving information is not enough. People can expect to have support, including the opportunity to be prepared for decisions and, where possible, have time to weigh up options. It is a huge stimulus to organisations and practitioners that the key principles of SDM are now enshrined in law and good clinical practice.

For a link to a video of Nadine's Story and its implications for consent visit:
Nadine's story - consent (part two) - NHS Resolution

3 Montgomery v Lanarkshire Health Board [2015] UKSC 11 (11 March 2015) (bailii.org)
4 Decision making and consent - GMC (gmc-uk.org)

GMC guidance: *"Shared Decision Making and consent are fundamental to good medical practice"*

Year of Care – Shared Decision Making training

Year of Care have developed a new training programme to support groups of clinicians who work together to consider how they can introduce SDM for service improvement in line with national policy and guidance.

The training is delivered over 2 half day sessions and can be augmented by a service facilitation session which supports the team with detailed mapping of the SDM points in patient journeys.

The training includes discussion, demonstration, practice and planning around the following areas:

- Philosophy, benefits and components of SDM
- Identifying the key SDM moments across a patient pathway
- Observation, practice and reflection of the consultation skills involved in SDM
- The use of language and discussion of risk
- Making plans to put in place practical changes to embed SDM into care pathways and patient journeys

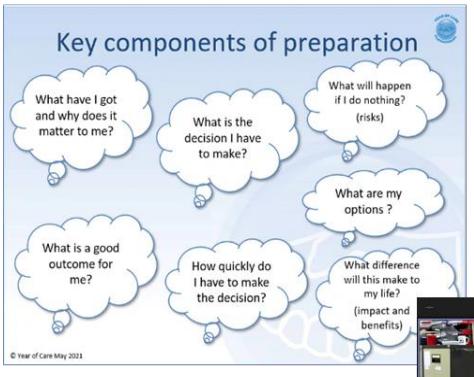
Please contact Year of Care if you are interested in this training.

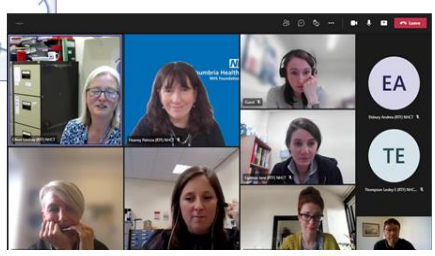
Taking a Shared Decision Making Approach in Speech and Language Therapy (SLT)

We are lucky to have been working with Year of Care Partnerships since last January, when we were introduced to SDM in a taster session. We explored how we could use SDM to support the principles of 'Realistic Medicine' in acute and community speech and language therapy.

As SLTs we are often involved in difficult decision making both on the wards and in community, alongside the wider MDT. For example, we support people making non-oral feeding decisions. We are skilled at using resources to assist communication if this is also affected, and we are closely involved with people with MND, helping them to decide whether to 'bank' their voice, and exploring options for their end of life care.

What ignited our interest in SDM right from the start was the focus on enhancing the experience of the person, reducing decisional regret and increasing the person's ability to understand their options and communicate their views and preferences. As SLTs we are extremely well placed to advocate for people within the MDT, and feel that SDM can enhance this even further.





A follow up face to face Year of Care training session in June got us brainstorming the myriad of ways in which we could implement service improvement within our pathways.

Because we are involved in peoples' decisions about whether to undergo a particular assessment or treatment in the first place, we decided that a good place to start to embed SDM would be around referral for videofluroscopy (VF) examination (an X-ray assessment of swallowing).

This has resulted in reworking our information leaflets in collaboration with the radiology team, to include sections such as 'What are the benefits?', 'What are the risks?', 'Are there any alternatives?' and 'What difference could this test make?'.

As well as providing the person with clearer and unbiased information, we are looking at allocating patients more time to think through their options and what they might lead to, instead of routinely referring for VF.

Enthused and brimming with ideas about how this could work in our whole team, momentum for testing this out has been good, and whilst COVID and winter pressures have delayed a couple of planning sessions, we have a meeting scheduled to create a final draft our new VF information leaflet.

Next, we are going to trial this with patients and get valuable feedback.

Laura Burtle
Specialist Speech and Language Therapist
Northumbria Healthcare NHS Foundation Trust

Personalised Care and Support Planning and Shared Decision Making

Shared decision making (SDM) shares the same core value set as personalised care and support planning (PCSP) but with an emphasis on specific decisions, actions or interventions at a point in a person's health journey where there are clear options.

SDM is often a component of a wider PCSP conversation. It's often also fairly easy to identify specific SDM moments in specialist pathways where there are options, and where the consequences of a decision can be anticipated.

SDM will be more successfully implemented when people are clear there is a decision for them to make and where attention is given to helping people to prepare for these key conversations, much like PCSP.

Also like PCSP, this will require that systems and tools are developed to support people to understand their health, and navigate their choices and the health system.

Professionals also need the values, knowledge and skills to support people. The ability to elicit people's priorities skilfully is as important to SDM as PCSP, and the ability to discuss risk clearly and without bias is even more critical.

In summary, while the context differs both SDM and PCSP share much in common in terms of principles, approaches, and skills. To be delivered well they require system change with careful attention to helping people be informed and prepared. Both require organisational sign up, consultation skills, teamworking and leadership from clinical teams.

Shared Decision Making – how it's working in general practice and what we can do

Shared decision making (SDM) was first suggested in relation to well defined one-off decisions with a clear evidence base (e.g. whether to have a particular surgical treatment). In general practice however, where such decisions are relatively rare and people often bring multiple problems arising from different health conditions, functional difficulties and social circumstances to each appointment, the mantra of 'no decision about me without me' can seem daunting. While it's routine to formulate problems and think through options these seldom map to a neat evidence base and may take place over several contacts, sometimes supported by several practitioners.

In my PhD I observed consultations between different healthcare professionals and people with either heart failure or hypertension. It was clear that there were lots of decisions being made, by the person in deciding what to raise in the consultation, and by the practitioner thinking through the diagnosis and possible next steps. Practitioners often used their understanding of the person, perhaps built up over time, to inform the decision making.

Yet it was rare for practitioners to share their thinking, there was little explicit discussion of the choices that were being weighed up, and few opportunities for the patient to either develop their understanding of the choices, or to contribute their experience, understanding and values. Despite these, primary care teams do have the skills to support SDM and recognise that it fits with the holistic, person-centred care that most practitioners value.

Glyn Elwyn describes three stages of SDM - choice talk (acknowledging that there is a choice to be made), option talk (discussing the options in detail) and decision talk (supporting the person to come to a decision). Underpinning all of these is the need to support people to understand their health and their options. We must recognise the expertise that people bring, check the assumptions that we are making, seek to establish what is most important to the person and what they want to achieve and be explicit when we are weighing up decisions. If we can do this people and practitioners can reach a shared understanding of the choices being made, and people can be confident that the decisions reached reflect their values and preferences.

Dr Rachel Johnson
NIHR Clinical Lecturer in General Practice, Uni of Bristol
General Practitioner, The Old School Surgery, Bristol

The NICE Shared Decision-Making Guideline (NG 197) - June 2021

The NICE Guideline Development Committee reflected key stakeholders being comprised of patients, lay people, researchers, surgeons, physicians, psychiatrist, dentists, GPs, medical ethicists, philosophers and chaired by a former NHS Trust CEO. From the start there was clear agreement that that shared decision making (SDM) was a "good thing", but also that studies and projects looking at SDM, whilst useful, did not fit with the usual NICE process for reviewing and grading evidence and meta-analysis was not feasible. As a result we were not being asked to review the evidence for SDM, but rather, how to implement it as 'the norm' within healthcare systems.

The Committee came up with key recommendations in 4 areas:

1. Embedding shared decision making at an organisational level
   Although enthusiasm on the ground is necessary from practitioners and people experiencing healthcare, without high level leadership and support within an organisation, it is very difficult to implement SDM. This means looking at the systems and processes people experience and how SDM principles can be embedded at each stage as part of quality improvement.

2. Putting shared decision making into practice
   Practitioners need support and training to develop the skills to facilitate shared decisions, ensuring that a person has all the information they need, and the decision reflects their preferences. One model for supporting SDM conversations, the 'Three-talk Model[5]', was suggested but other models can be used.

3. Use of Patient Decision Aids (PDAs)
   These should be relevant to the specific situation, supported by healthcare organisations, and locally available. Critically they need to be quality assured (both for accuracy and usability). NICE recommended development of a library of PDAs to support these discussions.

4. Communicating risks, benefits and consequences
   This can be challenging and requires a good deal of skill. Many staff are either not confident in explaining risk in terms a patient can understand, or lack the available evidence to support this. Developing skills and high-quality PDAs is seen as key to achieving this.

Making SDM more likely

When developing pathways, clinicians and organisations are advised to consider how to optimise SDM before, during and after a consultation.

Adapted from NICE SDM Guideline 2021

It may take time to embed SDM systematically throughout healthcare, so it's a positive step to have NICE Guidelines to support this.

Dr Helen Morgan
Consultant in Palliative Medicine, Northumbria Healthcare NHS Foundation Trust
NICE Guideline Development Committee Member for Shared Decision Making

5 Elwyn, G. et al (2017) A three-talk model for shared decision making: multistage consultation process. BMJ 2017;359:j4891.