



Patient Information Forum

For everyone involved in health information and support

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NHS England Health Literate Shared-Decision Making Framework

The objective is to produce:

“A framework to enable information producers to produce health literate decision support resources, which will assist clinicians and patients to have better Shared Decision Making (SDM) conversations.”



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Definitions

Health literacy - World Health Organization (WHO):

“The personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.”

Shared decision-making (SDM) - Nice SDM collaborative

“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.

It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences.”



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What's happening in practice

- 61% of working age adults find it difficult to understand health information.
- Only 56% of hospital in-patients felt involved in decisions about their treatment.
- We can't change literacy and numeracy but we can change the complexity of info provided.

"As an outsider it is interesting - you really speak a different language."

Jonathan Dimbleby, commenting on a session on the Great Manchester Health Partnership, at last week's ABPI conference.

Rowlands et al 2015

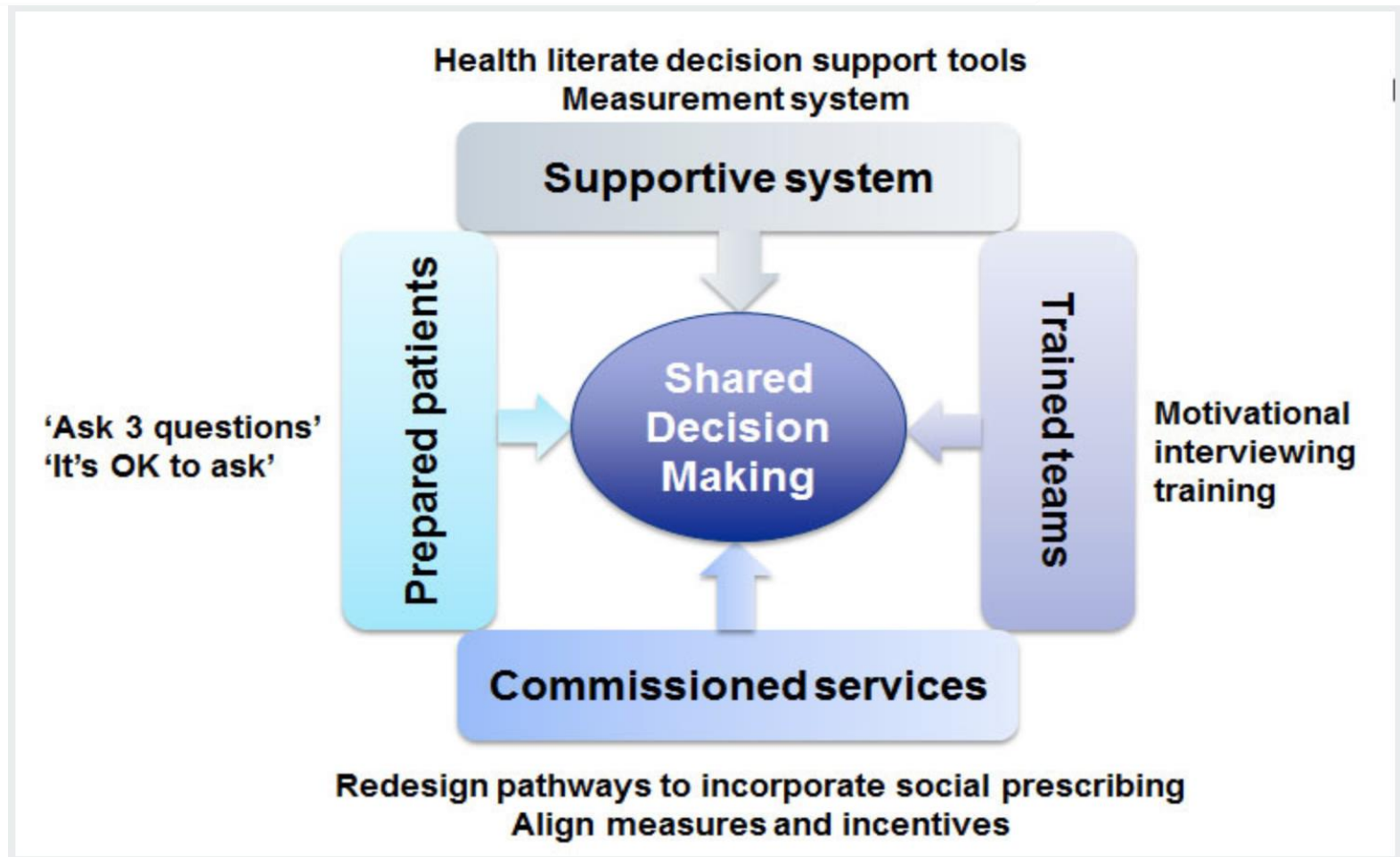
Care Quality Commission in-patient survey, 2016; NHS England.



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The process:

Joint project between PIF and the Community Health and Learning Foundation. Started in March.

- *Carried out a literature review*
- *Asked members of our networks what they needed from a framework, what it should 'look like' and to identify barriers to developing health literate decision support resources*
- *Invited network members to submit examples of health literate DSRs.*
- *Consulted with patients within both networks*
- *Ran consultation sessions with anaesthetists (PIF) orthopaedic surgeons (CHLF)*



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Outcome of consultation 1

Materials /advocacy groups

Very little literature on health-literate DSRs, consensus appears to be that more research is needed.

Very few examples of health-literate DSRs, where these exist the barriers to their creation and use are:

- resources (seen as an add on rather than core patient information)
- organisational resistance/buy-in to 'dumbing down' of resources
- the complexity of some of the decisions that need to be made.

Most of the examples came from national advocacy groups. They ranged from complex treatment comparison websites – money supermarket style – to single page decision aids to support consultations.



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Outcome of consultation 2

Healthcare professionals

Information on important outcomes for people to make a decision about treatment. *'No one opts for surgery based on the prospect of being alive 30 days later.'* Hand function in MS , a priority for patients only just been introduced as an outcome measure in clinical trials.

Timing of information/decision – embed early in the care pathway to give people time to consider a decision. Practical resources that fit within time constraints of 15 minute appointment.

Risk communication: Guidance on communicating risk in simple terms while maintaining accuracy.



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Outcome of consultation 3

Patients

Very few patients felt involved in decisions about their treatment, they did not feel their views were taken into account during consultations.

One person with MS had switched hospitals and found a consultant who was willing to listen to her desire for a less aggressive therapy.

Patient response focused more on consultation skills and continuity of care and less on DSRs. Consultation skills are out of scope of this framework but some DSRs are designed to be used in consultation.

Patients expressed a desire to have time to consider a decision and for continuity of care through the decision making process.

Very clear the DSRs need to support not replace consultations



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What will the framework look like?

5 pages plus checklist – to meet the needs of the system

- Provides definitions and the legal basis for SDM
- Identifies types of decision resource and examples of good practice
- Draws on broad principles for the creation of DSRs
- Provides a process checklist (maps to IPDAS criteria)
- Signposts toolkits and other frameworks – for example the National Health Literacy Toolkit
- Provides case studies



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Guiding principles 1

Produce health-literate information – *embed health literate approaches throughout the process from 1st contact with patients to final evaluation. Use plain English and drop the jargon*

Be patient-centred - *understand your patients and co-produce with them throughout, work with voluntary sector to ID patients find out what matters to them*

Involve HCPs - *secure buy-in and ensure the DSR is embedded at an appropriate point in the care pathway*



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Guiding principles 2

Provide evidence-based information – *be clear about the strength of evidence*

Communicate risk and benefit clearly – *signpost tried and tested words and pictures*
description of risk

User test with clinicians and patients – *adapt in response to feedback*

Train staff to use the DSR – *this is vital and may also need to cover consultation skills*

Evaluate and measure impact



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Next steps

- Feedback from within the working group
- Wider consultation with information producers and people who contributed to the first round
- Delivery of framework to NHS England – end of June 2018.
- Pilot of framework and evaluation.

Please get involved!

There are Post-it pads on your tables. If you have any comments or feedback or would like to be involved in the consultation, please stick your comments and contact details on our feedback wall.