

Liberating the NHS: No decision about me, without me
Further consultation on proposals to shared decision-making

Royal Pharmaceutical Society response

The Royal Pharmaceutical Society (RPS) is the professional body for every pharmacist in Great Britain. We are the only body that represents all sectors of pharmacy in Great Britain.

The RPS leads and supports the development of the pharmacy profession within the context of the public benefit. This includes the advancement of science, practice, education and knowledge in pharmacy. In addition, it promotes the profession's policies and views to a range of external stakeholders in a number of different forums.

Its functions and services include:

Leadership, representation and advocacy: promoting the status of the pharmacy profession and ensuring that pharmacy's voice is heard by governments, the media and the public.

Professional development, education and support: helping pharmacists to advance their careers through professional advancement, career advice and guidance on good practice.

Professional networking and publications: creating a series of communication channels to enable pharmacists to discuss areas of common interest.

General comments

In general, we do not believe that this consultation is about shared decision-making. The consultation focuses on choice of provider, which whilst equally important, is not the same as shared decision-making. We believe that choice of provider is different to patients making informed choices about the treatment they receive.

Shared decision making is not only about collaboration between healthcare professionals and patients but also between groups of health professionals, especially doctors and pharmacists¹.

The RPS agrees with the principle that patients and the public should have greater choice and control over their care and treatment and choice of any qualified healthcare provider, wherever relevant. We also agree with the concept of shared decision making between professionals and patients and believe this will lead to better outcomes for patients. However, in order to truly make this work patients need to have access to the right information in a way they can understand, the correct support and infrastructure needs to be in place and there needs to be a cultural change within the NHS. The data that constructs the information for people needs to be comparable across all service providers to ensure people can compare like with like.

We would like to emphasise that choice is not just about the provision of information, but also about how that information is interpreted and provided to patients. We would see pharmacists increasing their patient advocacy role as they are an independent resource for patients and can help them make informed choices about medicines. Pharmacists could provide an opportunity for patients to have an in depth discussion about their medicines. We would like to see pharmacists more widely

¹ http://www.rcplondon.ac.uk/sites/default/files/n1_why_people_matter_in_medicines.pdf

utilised to help patients navigate through the information provided to enable them to make informed choices.

It is important that the many professionals involved in a patient's care have access to relevant patient information, including information about their medicines. Patient involvement models rest on the assumption of informed professionals².

Pharmacists already play a significant role in shared decision making when carrying out medication reviews. Pharmacists also assist patients and the public to make decisions about their lifestyle and provide a number of public health services. They have a very important role in the self care agenda, recommending lifestyle changes, responding to patient's symptoms and raising awareness of issues such as early detection of cancer.

Currently around £8.8 billion³ is spent on medicines each year in the NHS and around £300million of medicines is wasted each year⁴. Whilst medicines are clinical interventions they require the active participation of the patient so patients need to be involved in the decision making process around treatments. Pharmacists are the experts in medicines use and the Government have recognised their lead role in medicines optimisation⁵ so we see pharmacy as a major player in helping patients make decisions about their medicines.

Specific Questions:

Q1. Will the proposals provide patients with more opportunities to make shared decisions about their care and treatment in the following areas?

- a) in primary care?**
- b) before a diagnosis?**
- c) at referral?**
- d) after a diagnosis?**

Pharmacists believe that in certain circumstances a pharmacy service could also be an option for initial testing. Many community pharmacies already offer diagnostic services such as NHS Health Checks, anticoagulation services. The benefits of including pharmacy as an option are that they are accessible and open at convenient times. Pharmacies could also provide an option for ongoing monitoring services.

Pharmacists fully support the greater availability of psychological or talking therapies. Most evidence shows that treatments are more likely to be effective if combined with careful optimisation of medicine treatments. As well as improving access to psychological therapies we would welcome greater access to specialist mental health pharmacists to assist in ensuring optimal medicine treatment. If patients are really to understand their choices for medicines then specialist mental health pharmacists are ideally situated to offer this in an independent way and therefore their accessibility should be increased for all people with mental health problems. There is already a framework in place to enable people with mental health problems to have access to personalised care planning and this is via the development of advanced statements. Specialist mental health pharmacists trained in this area should be available to assist patients to complete useful advanced statements.

² <http://www.kcl.ac.uk/sspp/departments/education/news/Involvementandmedicines.pdf>

³ Data taken from the NHS Information Centre

⁴ http://php.york.ac.uk/inst/yhec/web/news/documents/Evaluation_of_NHS_Medicines_Waste_Nov_2010.pdf

⁵ Equity and Excellence: Liberating the NHS paragraph 3.22

Q2. Are the proposals set out in this document realistic and achievable?

We do not think that the proposals set out in this document are entirely realistic and achievable. We do agree with the aspiration that shared decision making should become 'the norm' for all clinician-patient consultations and that exclusions (2.6, 2.12) are appropriate, as well as situations where patients are happy to give the responsibility for a decision back to their clinician. However, the majority of the document needs revision if it is to truly reflect shared decision making.

For all providers to be able to provide an equitable service they all require access to relevant information about the patient. Currently, community pharmacy has no access to a patient's electronic record and in hospital pharmacy access is varied and mainly reliant on having web-based systems in place. This places pharmacists and other healthcare providers at a serious disadvantage when tendering for services as a qualified provider. All qualified providers must have the same access to data and the same level of support to provide services.

Q3. Looking at the proposals collectively, are there any specific areas that we have not recognised appropriately in the consultation document?

We believe that the first part of the document should focus on patient involvement in their clinical choices of treatment from diagnosis onwards, with appropriate discussion of benefits and risk and potential outcomes. If treatment providers offer different clinical care from each other, this needs to be taken into account at the stage of diagnosis as part of the risk / benefit discussion. This would ensure that patients are supported in making their treatment choice according to their needs, integrating what providers can offer them rather than focussing on the choice of where treatment is offered and by which provider (which the consultation document focuses on heavily).

The key issue is that patients should be supported in understanding their diagnosis and treatment options before they choose who provides it. This will require discussion of treatment goals between patients and clinicians in order to agree the best option for them with the clinician. The decision a patient makes is often one about clinical choices and different clinicians will often differ regarding a preferred treatment. The consultation document ignores this and makes the assumption that there is an ideal treatment which may be provided by a range of providers. This means the focus is against the ethos of 'no decision about me without me'.

Another key element is the provision of information and having better information available to patients. Making sure that both patients and professionals are well informed about every aspect of their treatment must be a top priority. This will assist patients in making the choices that are right for them.

Clinicians may need to be supported in use of alternative communication techniques in line with current thinking around long term conditions such as telehealth. In general, the issue of provider choice is likely to come after diagnosis, treatment and care planning discussion, unless providers differ in what they offer. Treatment choice is referred to in the care planning section 3.11. This section would benefit from discussion of how clinicians can be supported to ensure that patients feel empowered to share in decision making, integrated with appropriate provision of patient information. The use of a coaching approach to consultations should be included here.

Once the patient understands their diagnosis and therapeutic choices and they are supported in sharing decisions, they will be in a position to realistically consider what can be provided by the NHS. There is a clear need for transparency here: where the NHS cannot afford a service, the patient must be told in order to make truly informed choices. This needs to be at the heart of the document and

requires clinicians to know how much treatments (including medicines) cost and reasons for NHS provision or lack of it. This should be based on evidence based information provided by NICE. This is alluded to in 6.3 but needs to be strengthened. It is likely to be a contentious and difficult issue for clinicians to address and they may need support in this.

When the patient and clinician address the questions of who (which provider) and where (location of provider), issues such as quality and safety information about that provider's services are required to support patients' decisions. If any qualified provider is offered to patients, there must also be a minimum standard of communication between all providers which occurs irrespective of provider to provide seamless care across interfaces. We believe that there needs to be a cultural shift in the NHS to make shared decision making a reality in all aspects of patient's care. Clinicians need help in making shared decision making part of their daily practice and will require feedback from patients about how well it is working. While 7.16 refers to support for clinicians in shared decision-making, this section needs to be greatly strengthened if we want to make it a reality in all NHS practice. In section 7.17 there is a suggestion that shared decision-making could cause more disagreements between patients and clinicians. If there is evidence to suggest that shared decision-making can harm clinician-patient relationship, clinicians will reject it. Therefore this needs clarification from the existing body of evidence for shared decision-making, to give clinicians and patients the confidence to move forward.

Finally, section 7.18 refers to information access for patients and this is fundamental if shared decision-making is to work. Currently clinicians often have difficulty accessing information from other provider organisations. Perhaps the document should consider direct electronic access for patients to their records via secure web so that they can have meaningful discussions with any provider in any health or social care setting with internet access. This should be accessible directly by the patient rather than the clinician so that the patient owns their records, which also reduces the governance issues for the NHS.

We also believe that the process of transfer has not been recognised in this consultation document. This is an important area of significant risk to patients. The likelihood that an elderly medical patient will be discharged on the same medicines that they were admitted on is less than 10%⁶. Between 28-40% of medicines are discontinued during hospitalisation⁷ and 45% of medicines prescribed at discharge are new medicines⁸. 60% of patients have 3 or more medicines changed during their hospital stay⁹. It is important to discuss medication changes with the patient or their carer, as the discharge letter to GP may take several days leading to a delay in any changes in medicines being noticed and rectified. It would also be beneficial if the patient's community pharmacy received the discharge information so when a follow up prescription is supplied they can check that the appropriate medication changes have been made.

Q4. Have we identified the right means of making sure that patients will have an opportunity to make shared decisions, to be more involved in decisions about their care across the majority of NHS funded services?

No. If SDM is to become part of the NHS culture, it starts with the culture change in the NHS which requires education and support for NHS clinicians. What follows is the patient being given appropriate information by all healthcare professionals and choosing the treatment they want with

⁶ Relationship of in-hospital medication modifications of elderly patients to post discharge medications, adherence and mortality. *Ann Pharmacotherapy* 2008; 42: 783-9

⁷ Health care system vulnerabilities: understanding the root causes of patient harm. *Am J Health Syst Pharm* 2012; 69: 43-5

⁸ What happens to long-term medication when general practice patients are referred to hospital? *Eur J Clin Pharmacol* 1996; 50: 253-7

⁹ Drug changes at the interface between primary and secondary care. *Int J Clin Pharmacol Ther.* 2004; 42:103-9

the support they need to make a decision. The agreed decisions become part of the patients care plan, which has been created through SDM, after which the discussions about providers can happen usefully. This should all be documented in the patient's notes. This consultation document would benefit from refocusing: rather than provider choice, the focus should be on treatment/care plan choice which, from the patient perspective, is the more important of the two.

Q5. Do you feel that these proposals go far enough and fast enough in extending choice and making “no decision about me, without me” a reality?

The title of the document suggests that its focus is on securing shared decision making within the NHS. However, it appears that the detail in the document is around giving patients the choice of provider. While this is important, it is absolutely secondary to patient making informed choices about the treatment they receive, which has much less emphasis in the document. The document would benefit from refocusing on supporting patients in choosing treatments, rather than provider choice.



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