The King's Fund response to the Department of Health's consultation: *Liberating the NHS: No decision about me, without me*

The King's Fund is a charity that seeks to understand how the health system in England can be improved. Using that insight, we help to shape policy, transform services and bring about behaviour change. Our work includes research, analysis, leadership development and service improvement. We also offer a wide range of resources to help everyone working in health to share knowledge, learning and ideas.

This document forms the response by The King's Fund to the Department of Health's consultation *Liberating the NHS: No decision about me, without me*. The King's Fund is well placed to comment on these proposals, having published two highly relevant pieces of research recently.

- *Making shared decision-making a reality: no decision about me, without me* (Coulter and Collins 2012) produced a clear definition of shared decision-making and outlined what steps need to be taken to implement it.
- *Patients' preferences matter: stop the silent misdiagnosis* (Mulley *et al* 2012) highlighted how 'silent misdiagnosis' arises when doctors fail to consult patients about what care they would actually like. Its implications for both better patient care and better use of NHS resources are significant.

It is disappointing that the Department of Health consultation is more about patient choice of provider than about shared decision-making. Our views on patient choice were set out in our response to the Department of Health's public consultation on choice in January 2011 (The King's Fund 2011) and many of these views remain.

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?

The proposals outlined in this consultation document are concerned with patient choice rather than with shared decision-making and so will not provide more opportunities for patients to make shared decisions about their care in any of these areas. Patient choice is a policy that is popular with the majority of patients, but few exercise it to go to a non local provider (Dixon *et al* 2010). Although quality of care is important to patients, most find it difficult to make sense of the mass of publicly available information even when this is presented in a user friendly format (Boyce *et al* 2010).

Angela Coulter and Alf Collins (2011) defined the principle of shared decision-making in the context of a clinical consultation as a process whereby: a patient is supported to articulate what they hope treatment or support to self manage will achieve; the patient is informed about the benefits and risks of any treatment or support options available; the patient and clinician arrive at a decision based on mutual understanding and the decision made is recorded and then implemented.

In order to realise the benefits of shared decision-making, which include a reduced level of intervention, there needs to be a sense of priority such that providers of NHS care measure and report whether each patient receives the treatment they would choose were they fully informed as a matter of course, just as they measure patient complaints and length of waiting times (Mulley 2012).

Apart from a reference to the Right Care Shared Decision-Making programme (para 7.16) there is little recognition in this consultation document of the extensive training and support that will be needed to embed shared decision-making in every clinical consultation undertaken in the NHS in England. Persuading the clinical community to divert their limited time from medical diagnosis to preferential diagnosis in every consultation they undertake will require a huge shift in culture and will not become a reality without an extensive training programme and very clear clinical leadership. Without such a programme there will be no expansion of opportunities for patients to make shared decisions about their care and treatment.

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

The proposals outlined to make shared decision-making a reality through the standard contract (7.11) pertain to patient choice (eg, the requirement that providers list services eligible for patient choice on Choose and Book). They do not recognise the complexity involved in medical, let alone preferential, diagnosis and will not realistically lead to greater take-up of shared decision-making .

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

Yes, in particular the very specific nature of a consultation involving 'shared decision-making' as defined by Coulter and Collins and the extent of the leadership, training and support that will be required if clinicians are to adopt it throughout the NHS. The consultation document fails to articulate a compelling case for the benefits of shared decision-making – for example, in reducing unwarranted variations in care.

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, the means identified relate to patient choice.

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?

No, see above.

References

Boyce T, Dixon A, Fasolo B, Reutskaja E (2010). *Choosing a high-quality hospital: The role of nudges, scorecard design and information.* London: The King's Fund.

Coulter A, Collins A (2011). *Making shared decision-making a reality: No decision about me, without me*. London: The King's Fund.

Dixon A, Robertson R, Appleby J, Burge P, Devlin N, Magee H (2012). *Patient choice: How patients choose and how providers respond*. London: The King's Fund.

Mulley A, Trimble C, Elwyn G (2012). *Patients' preferences matter: Stop the silent misdiagnosis*. London: The King's Fund.

The King's Fund (2011). 'The King's Fund response to the Department of Health's public consultation on *Greater Choice and Control*'. The King's Fund website. Available at www.kingsfund.org.uk/press/parliamentary_activities/consultations/index.html.