Department of Health consultation – No decision about me, without me

1. I write with regard to the Department of Health consultation on – No decision about me, without me.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 44,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient–centred generalist clinical care. Through our General Practice Foundation, established by the RCGP in 2009, we maintain close links with other professionals working in General Practice, such as practice managers, nurses and physician assistants.

3. The College welcomes the opportunity to respond to this consultation. As you will be aware, we responded in some detail to the previous consultation ‘Liberating the NHS: Greater Choice and Control’ and most of what we said at that time remains pertinent. We would remind you that, despite the emphasis here on choice of healthcare provider, the great majority of patient interactions happen in primary care,

and the majority of conditions are resolved in primary care settings. The overwhelming experience of our members, particularly those living outside of London, is that patients are anxious to ensure that they have access to good, safe local facilities, and that the choice of an alternative to a good local provider is rarely desired or exercised. The efforts to attract a greater range of providers to the healthcare ‘marketplace’ is, in many cases, a diversion from developing local services that are effective and integrated.

4. We note that the present consultation paper reflects some of the criticisms made by ourselves and other organisations, and welcome this. In particular, the acceptance that patient choice should be based on shared decision making, and from treatment options that are clinically appropriate and affordable, is an encouraging change of tone. The greater note of caution in extending choice of mental health services, and the change in tack on urgent and emergency services are also encouraging developments, and reflect our concerns that the extension of ‘any qualified provider’ in all areas would be destabilising.

5. This said, there are still a number of major difficulties with the approach outlined in this paper, areas of inappropriate emphasis and glaring omissions. In particular, we are concerned that the paper, in its subtitle and elsewhere, takes a definition of shared decision-making that makes it synonymous with patient choice, including choice of provider, and goes on to discuss provider choice extensively as a constituent part of shared decision-making. This is misleading. As articulated by Angela Coulter for the Kings Fund\(^2\), shared decision-making is:-

> ‘a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and patients’ informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients’ treatment preferences.’

6. It is our view that the policy emphasis on provider choice is predicated on a largely episodic notion of the nature of healthcare, whereas in reality we know that in the

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\(^2\) Coulter A, Blog – Please stop muddling shared decision-making and provider choice (1\(^{st}\) June 2012) - http://www.kingsfund.org.uk/blog/decisionmaking.html
future the key challenge is going to be the provision of care to the growing number of people with long term and multiple conditions.

7. The RCGP supports shared decision-making, it is embedded in the GP curriculum and a great many of our members already put into practice shared decision-making approaches to the GP-patient consultation. The potential benefits of SDM include better consultations, clearer risk communication, improved health literacy, more appropriate decisions, fewer unwanted treatments, healthier lifestyles, improved confidence and self-efficacy, safer care, greater compliance with ethical standards, reduced costs and better health outcomes. Shared decision making is also important for commissioners because it can reduce unwarranted variation in clinical practice.

8. Effective SDM is not yet the norm and we recognise that many patients want more information and involvement in decisions about treatment, care or support than they currently experience. Embedding SDM into systems, processes and workforce attitudes, skills and behaviours will be a considerable challenge for us and for our patients.

9. For patients to make an informed choice they will need a high degree of health literacy – to understand the nature of their problem, its causes and the probable implications, what if anything can be done about it and the degree of uncertainty, risk and probability that surround such issues. The commitment to improving and universalising access to healthcare information is encouraging, but these are very complex areas, which even doctors, with their training and knowledge of relative risk may struggle with.

10. If difficulties such as these are to be overcome or at least mitigated, and shared decision-making is to be as effective as envisaged, we will need more GPs, with more time in the consultation and longer training. Clinicians need to be confident that they are able to deliver the right information, in the right way to patients in the limited time they have for each consultation, including to patients with limited health (or indeed general) literacy. They will need additional training in facilitating shared decision-making. How should clinicians respond when a patient makes a choice that is clearly not in their best interests, such as choosing herbal medicine over evidence-based treatments? How should they explain when a patient’s choice cannot be accommodated for budgetary reasons? Such circumstances require significant communication and negotiation skill, which requires training. Without this, and if doctors trained in evidence-based medicine feel compelled to ignore their clinical judgement in favour of principles of consumer-choice, the risk is that they will
emotionally withdraw from their patients’ care, and the health service’s capacity to deliver improved outcomes for its patients will be much the poorer for it.

11. Lastly, the emphasis on choices and decisions should not mask the fact that a great deal of clinical time, for GPs in particular, is not spent in making decisions about treatment or referral at all – but in activities such as supporting, witnessing, certifying and diagnosing. To reduce clinical care to a series of choices is to imply that general practice is algorithmic; it isn’t – it’s far more complex than that.

12. We have addressed the specific consultation questions below:-

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

Choice of GP Practice

We have rehearsed our concerns about the prospect of practice boundaries being abolished and patients being given a completely unrestricted choice of GP practice on several previous occasions. In summary:-

i. The potential dislocation of patients from local practices will pose serious difficulties for commissioners who are tasked to commission services for the whole of their local population. Patients will effectively be able to ‘shop-around’ for their commissioners, driving a postcode lottery effect for healthcare commissioning and increasing health inequalities.

ii. The likelihood of multiple registrations, and the diminution of local registration, will weaken the excellent basis for research currently provided by the practice-boundary system.

iii. Practice boundaries are a vital tool to allow GPs to see their patients in their homes, keep track of vulnerable patients and control demand.

iv. A geographically defined GP practice area is also relevant in relation to working with other specialised health services (such as mental health, midwifery/health visitor/district nurse) and local authorities (social care and public health).

v. It is likely that those registered at a practice at a distance from their home will access more costly hospital care directly when they become ill. There will be
additional costs of added staffing and the bureaucratic and financial consequences of new registration arrangements.

vi. Patients will be at greater risk with the lack of prior knowledge to inform emergency decision-making. Currently, IT systems do not allow for the safe and secure sharing of relevant data.

vii. Removing practice boundaries will threaten the viability of local, especially rural, practices that provide a vital service to those residents who are less mobile and potentially more vulnerable. It may also mean that practices in city centre locations are unable to provide the level of care they are presently able to offer due to an increased number of patients on their lists.

We are aware that pilots are ongoing, and urge that the outcomes of these pilots are very carefully evaluated before any definitive approach is implemented.

Choice of Provider for Community Services

We support the approach taken to choice of provider for community services as outlined in paragraph 3.10 – crucially, any decision regarding the roll-out of ‘any qualified provider’ into new areas should be for clinical commissioning groups to decide, on the basis of whether they believe this will add value and be in the best interests of patients. We are reassured that the Department of Health appears to agree with this emphasis.

b) before a diagnosis

Choice of diagnostic test provider

As in our response to the consultation on ‘Greater choice and control’, we would argue that in the majority of cases it would be preferable for the line of investigation for a patient in a given condition to be followed through within a single provider or federation of providers – primarily this is to ensure continuity and consistency of accountability. Until we have foolproof and efficient information sharing between providers the risk of costly and potentially harmful misunderstandings seems likely to outweigh any benefit from free choice of test provider.

In particular, we are concerned that applying an any qualified provider approach in this area will lead to a huge upsurge in unnecessary testing, with concomitant false positives, false negatives, significant patient harm and increased costs to the NHS. It is likely that
tests will be directly marketed at patients by providers incentivised to increase numbers of tests, with or without the clinical judgement of patients’ GPs.

Indeed, this is the risk in most areas where any qualified provider is applied in conjunction with a per-activity payment model – this combination seems certain to drive demand and undermine the capacity of primary care to match supply of treatment to genuine need, with a dangerous impact on increasingly scarce resources.

c) at referral

Choice of provider

We have expressed previously our doubts at the proposal to guarantee a free choice of provider to all patients. In our view this is likely to increase both costs and health inequalities, make local commissioning of services more difficult and lead to disappointment for patients in many cases. As already stated, in our members’ experience what patients generally want is to have some choice, in consultation with their doctor, over types of treatment, and rarely a choice of where that treatment should take place – the preference is almost always for a high quality, local provider.

Choosing who provides your mental health services

We would take issue with paragraph 5.18 – the statement that patients who had a choice of therapy were more content than those who wanted a choice but did not receive it is so obvious as to not need stating. Further, they were more content with their therapy – but what were the clinical outcomes? And what of patients with complex psychological problems, such as Chronic Fatigue Syndrome, where a choice of treatment might do more harm than good?

But is this not more a question of the availability of provision – particularly, in the case of mental health services, provision of talking therapies? If enough high quality services are not developed and funded, to talk of choice is beside the point. As argued in our response to ‘Greater Choice and Control’, it is desirable to identify the needs of mental health service users and to offer a choice of treatment options – but if the chosen option is then not available, or only at the end of very long wait, this is likely, for some patients, to be more frustrating and damaging than having no choice at all.

Furthermore, in all services, but particularly for mental health services, it is vital that they are able to provide localised community care and have good relationships with local
community teams. We are concerned that this may be damaged if services are split up and de-localised under any qualified provider.

Choice of self-referral

We are very sceptical of the benefits of extending self-referral – the primary/secondary care split, and the use of general practice as a gatekeeper to secondary care services makes the NHS more cost effective than many other health systems, and ensures that patients see the most appropriate specialist services. In our view there are few circumstances in which self-referral would not lead to greater costs, more clinically inappropriate treatments and greater health inequalities.

d) after a diagnosis

Personal Health Budgets

On the issue of personal health budgets (p31), the RCGP has issued a detailed position statement3, which in summary states:-

The RCGP believes strongly in the importance of personalised care and shared decision making to deliver better patient outcomes. Personal health budgets are one of a variety of tools that may have the potential, under the right circumstances, to help realise these benefits for some patients. In particular, personal health budgets may provide patients with the opportunity to access different services that are better suited to their needs, and act as a stimulus for shared decision making and an increased focus on care planning.

At the same time, the implementation of personal health budgets poses a number of challenges that the government in England, to date, has yet adequately to address. Key issues include:

- achieving the appropriate balance of responsibilities for ensuring the clinical effectiveness and quality of services purchased
- managing the impact of the introduction of personal health budgets on Clinical Commissioning Group (CCG) costs and on the financial sustainability of existing NHS services
- setting appropriate budgets in line with the principle of the provision of

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comprehensive health services on the basis of clinical need, free at the point of use

- ensuring that personal health budgets do not give rise to new health inequalities.

Before proceeding with the roll-out of personal health budgets in England, the government should allow the opportunity for the outcomes from the pilot sites to be fully evaluated and discussed, and for conclusions concerning the implications for future policy to be drawn. More detail is also needed of the policy framework that the government intends to put in place for personal health budgets – how will it be designed to maximise the benefits to patients, while mitigating the main areas of risk? There are many variables for patients and their personal and professional carers to consider, and the College would wish to see these fully explored in further proposals. We would also like to be involved in the further development of the policy and its formal and systematic evaluation.

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

The proposals may well be realistic and achievable. We would question whether, in many case, they are desirable. The emphasis on provider choice risks distracting from the core business of the NHS, the great majority of which takes place in primary care, in one-to-one consultations between patients and members of the general practice team.

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

As above – the emphasis is on provider choice rather than all the other things that will do much more to improve the experience and outcomes for patients. We do think that shared decision-making, as defined earlier in this response rather than as a synonym for provider choice, has the capacity to improve quality and outcomes for patients. To make shared decision-making universal and maximally effective requires more GPs, with more training and more time in consultation with patients.

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?

Please see earlier comments. With regards to specific proposals:-

The Mandate
We will be responding shortly to the Department of Health’s consultation on the draft Mandate to the NHS Commissioning Board.

**Choose and Book**

As you will be aware, the Choose and Book system is unpopular with many GPs, who regard it as cumbersome; there are also concerns that the way in which information is presented may obscure details such as follow-up waiting times, giving a misleading impression. We agree that the proposals to modify the standard contract would be helpful in this regard. The proposal (p35) to publish uptake statistics fails to tackle the root cause of low levels of participation in Choose and Book in some places – what is needed are radical improvements to the speed and reliability of the system to make it work for patients and doctors alike. Certainly, as it stands Choose and Book utilisation will not be the best metric by which to judge the success of shared decision making.

Further, we would be very cautious at the proposal to make Choose and Book an information and booking system for patients – for the reasons above and also because, as already stated, anything that threatens the gatekeeper role of general practice in the NHS is likely to generate extra costs and unnecessary, possibly harmful procedures.

**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?**

As will already be clear, in our view they go too far, in many cases in the wrong direction. We have concerns at the speed of change too. Where proposals are being trialled, as with the proposals on choice of GP and personal health budgets, it is vital that these trials are fully evaluated, with a genuine willingness to change direction should the outcomes not be as expected.

Overall, the proposals take too mechanistic an approach to shared decision-making, where what is needed is a cultural change to make it the norm for both patients and doctors – to this end, we will be glad to support the proposal in paragraph 7.16 ‘to work with the Royal Colleges and other organisations to explore the potential and opportunities to ensure education reinforces shared decision-making as the norm.’

We gratefully acknowledge the contributions of members of the RCGP Council, and our Centre for Commissioning in formulating this response.

Yours sincerely
Professor Amanda Howe MA Med MD FRCGP

Honorary Secretary of Council