

# Consultation response

## The King's Fund's response to the Department of Health's public consultation on *Greater Choice and Control*

14<sup>th</sup> January 2011

**The King's Fund 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.**

We welcome the opportunity to comment on these proposals. This response is one of two submitted by The King's Fund to the government's consultations: on the information revolution and on greater choice and control. These responses are also available on our website, together with our previous consultation responses on regulation, outcomes, democratic legitimacy and commissioning, and the original response to the White Paper, *Equity and Excellence: Liberating the NHS*.

We have recently published two reports that have significant implications for the government's approach to information and choice, *Choosing a high-quality hospital: the role of nudges, scorecard design and information*, and *Patient choice: how patients choose and how providers respond*. We draw on these in our responses but suggest that policy-makers in these areas may wish to refer to the reports directly.

### Overview

The King's Fund welcomes the commitment by the Department of Health to develop an NHS that offers greater choice and control to patients. However, the consultation lacks clarity about the purposes of introducing greater choice and the types of choices being offered.

### **Objectives of choice**

The consultation talks about choice both as a key lever to promote competition, which will in turn increase quality and responsiveness to patients, and as a means of patients taking greater control over their health care (supporting personalisation and empowerment). It is important that future policy development clearly distinguishes between these two separate goals.

Our work suggests that choice is valued by patients and enables more patients to be treated at the hospital they choose. Even if few patients use their ability to choose to go to a non-local provider, the ability to exit appears to be important to the majority of patients. This suggests that choice may have intrinsic value (Dixon *et al* 2010a).

## **Types of choice**

Patients make many choices and decisions about their health and health care, either alone or in consultation with a professional. Patients may wish to exercise choice about the type of care they receive (what), the type of professional they receive it from or even a particular professional (who), and which provider they access the services from (where). For example, patients with depression may wish to exercise a choice about whether to receive medication or talking therapies; people with joint pain may wish to avoid or delay surgical joint replacement by receiving intensive physiotherapy or pain medication. Some patients may choose to wait longer in order to see their regular GP rather than take the first available appointment. Women may wish to exercise a choice about where they give birth – for example, at home or in a midwife-led unit or birthing centre. A patient needing major surgery might wish to choose to be operated on at a particular hospital where the outcomes are good and the reputation of the clinical team is excellent. Patients also value having some control over the date and time of appointments (when).

In the past, patients did not have a choice about when they were seen. Choose and Book was originally designed to give patients a choice to be seen at a time convenient to them; it was subsequently extended to facilitate choice over where the patient was referred to. Patients may also have preferences about how they are treated – for example, whether carers or family members are present at consultations, what food they are offered as inpatients (and meal times), whether they are on a ward or in a private room, and whether they are seen individually or as part of a group consultation. These aspects of how patients are cared for are important to the overall patient experience.

Not all these choices will be appropriate to every patient at all times. However, if the health system is to be patient centred, it needs to consider how it can involve patients more fully in these decisions and, where clinically appropriate and where resources allow, give patients greater choice and control. Policies to increase choice could usefully highlight which of these types of choices they are seeking to increase.

## **Key issues**

In this section we discuss some key issues that the proposals in this consultation raise. Choice of provider is mainly associated with the first objective of promoting competition. We also discuss choice of commissioner, as this is another way in which health systems internationally use choice to promote competition. We then turn to choices relating to the second objective of personalisation and control. We consider choices about treatments and choices for those with long-term conditions.

### **Choice of provider**

Policy to date in the NHS has largely focused on choice of provider – specifically, choice at the point of referral to specialist care. Patient choice of provider has been introduced to create competition among health service providers and thereby improve their efficiency and quality. While there is some evidence that competition between providers in some areas has increased (Gaynor *et al* 2010), the evidence indicates that choice of provider does not currently act as a strong driver for service improvement (Dixon *et al* 2010a).

Our research found that while the threat of patients choosing a different hospital led some providers to focus on reputation and ensure that patients attending the hospital had a good experience (through collecting and acting on patient feedback), there was little evidence of direct competition for individual patients' custom. There was some

evidence of providers competing for GP referrals, particularly from practices on the periphery of their catchment areas.

Only about half of the patients involved in the study were offered a choice at point of referral, and of those, 29 per cent chose to attend a non-local hospital (compared with 21 per cent among those who were not offered a choice). The main reason for not attending a local hospital was a previous bad experience of that hospital. Choice of provider seems particularly important to enable those who have had a bad experience of a local hospital to exercise choice to go elsewhere. Regardless of its effectiveness as a driver for quality improvement, we therefore conclude that, given its intrinsic value, the NHS should continue to offer patients a choice of hospital.

It will be important in developing an 'any willing provider' (AWP) market to pay attention to lessons learned from implementing the policy of choice at point of referral to secondary care.

The consultation proposes to extend 'free' choice of any willing provider to other sectors. We believe there is some confusion in policy documents about the meaning and intentions of an AWP market in health services. Our interpretation of AWP is that any provider (public or private) that is registered by the Care Quality Commission (CQC) would be able to deliver services, with the expectation that they will be reimbursed by NHS commissioners at an agreed price (usually a nationally set tariff) as long as they deliver care in line with agreed standards (again, these would usually need to be defined in a national contract). It appears that the term AWP is also being used to describe a process of open and competitive tendering for services in which both public and private providers are treated fairly. This needs to be clarified by the Department of Health in future documents.

We set out below the pros and cons of an AWP market compared with a process whereby a commissioner competitively tenders or procures services (selective contracting).

- First, AWP allows new providers to enter the market more easily, reducing barriers to entry and potentially encouraging innovation. However, in an environment in which funding will be tight, these entrants will be taking market share away from incumbent providers, resulting in a greater number of closures, which may prove politically difficult. Given the need to reduce capacity in some sectors, eg, acute care, it may be preferable to enable commissioners (either the NHS Commissioning Board or groups of consortia) to make strategic commissioning decisions about the range of services available (as happened in London with stroke services) through selective contracting of particular providers.
- Second, AWP ensures standardised contracts, thus reducing the burden on providers of having to meet different contractual requirements for different patients (depending on their commissioner). There is a danger otherwise that each GP consortia would try to specify different care pathways. This fragmentation of commissioning would increase transaction costs. To make AWP work effectively, it would be beneficial if the NCB developed standard contracts by service line with associated outcomes, currencies and prices. GP consortia can then buy services from any provider who meets these terms. However, the consequence of AWP is that commissioners will have to passively reimburse care with little scope for specifying different or innovative service models. This would mean that GP consortia would have to buy care on a 'take it or leave it' basis. It must be recognised that AWP reduces the ability to use contracting and tendering to drive changes in services, and weakens the purchasing power of commissioners.

- Third, AWP is not appropriate to all types of care. For example, it might work well in planned surgery, where the episode of care is well defined, the outcomes are easily measured, and patients may have time to consider the options. But the majority of health care is not purchased as a 'spot' purchase by the consumer or the consumer's agent (the GP); rather, it is commissioned via longer-term contractual relationships. Complex services such as those for trauma or cancer need a co-ordinated approach across providers. Quality has been demonstrably improved by focusing care within centres of excellence and creating networks of providers – an approach which necessarily reduces the extent of choice for patients. So, a market that encouraged multiple new entrants to 'dabble' in these services would not be good for patients. Choice between and within integrated networks would be beneficial, but remains largely unexplored (Curry and Ham 2010).

The real question is not whether competition is good or bad for health, but where and how it should be applied. The challenge is to ensure that competition does not lead to fragmentation of services or a reduction in quality. Competition works well in some types of health care markets, but less well in others. Given the benefits of more integrated services, particularly for those with chronic conditions and complex needs, it is important that choice of provider does not result in greater fragmentation of care.

### **Choice of commissioner**

Patient choice of GP, combined with the ability of practices to align to different GP consortia, means the de facto introduction of choice of commissioner. The government needs to be more explicit about this policy intention and address a number of challenges that arise from it:

- Allocating resources to consortia based on the individual characteristics of members rather than by the demographics of electoral wards will require a robust risk capitation formula. We have concerns about the ability of consortia to manage financial and insurance risk, particularly given the accuracy of methods for resource allocation. The NHS Commissioning Board will need to draw on actuarial expertise if it is to act as the insurer of last resort, as simply top-slicing allocations will not be sufficient. Alternatively, if consortia are to take on full financial liabilities, there will need to be a regulated market for re-insurance to ensure that they are sufficiently financially protected (through risk-pooling, stop loss or other arrangements).
- If patients were allowed to change consortia on a regular basis, the incentives for commissioners to invest in individual preventive activities would also be diminished, as the savings would accrue to another commissioner.
- There could be a risk that commissioners would seek to select patients/practices on the basis of their risk profile. This would result in increased marketing costs for consortia associated with retaining membership. There is also a danger that there will be adverse selection by patients based on the treatments/services offered by a particular consortium. For example, a consortium that specialised in commissioning/providing high-quality services for people with mental health problems might find that it had a higher proportion of these people registered.

Choice of insurer has been introduced in a number of countries, including Germany and the Netherlands, with the expectation that it would increase efficiency (not only of the insurers but of providers). However, evidence suggests that without the ability to selectively contract with providers (as opposed to an AWP model), insurers have focused on selection of enrolees rather than on driving changes in the provider market through their purchasing role. The lack of sophistication in the risk adjustment used to allocate a

capitation to the insurers has meant that there have remained incentives for selection of low-risk/low-cost enrolees. Both systems have complex processes for redistributing funding between insurers with different risk profiles (risk equalisation) to ensure that insurers are not penalised for excessive costs resulting from the higher needs of enrolled patients.

### **Shared decision-making**

Research into shared decision-making about treatment decisions, as evidenced by Coulter (see Coulter and Ellins 2006; Coulter 2007), Kasper and Mulley (see Kasper *et al* 1992; Mulley 1995), shows that patients who are actively involved in decisions and informed about the risks and benefits of surgery or alternative options (including watchful waiting) often make different (and more conservative) decisions than their clinicians would have made. Our forthcoming analysis of these kinds of variations highlights the persistence of variations in preference-sensitive treatments in England, suggesting that there is scope for greater use of shared decision-making to help patients choose between clinically appropriate treatments.

While information and decision support tools for patients are important, shared decision-making will require a fundamental shift in clinician–patient interactions.

There is a risk that changes to the dynamic between patients and clinicians will compromise this relationship. When patients and their consultants disagree about the best treatment decision, it is unclear how this disagreement will be mediated and resolved to ensure that relationships between consultants and patients do not break down. Ultimately, this is about preserving patient trust in the health care system.

The King's Fund has commissioned Angela Coulter to write a monograph on shared decision-making, which will be published later this year.

### **Choices for patients with long-term conditions**

There is good evidence in the field of long-term conditions that self-management and greater control in care planning lead to higher outcomes and lower utilisation of services (Rijken *et al* 2008). Policy commitments have already been made that all those with a long-term condition should have a care plan (Department of Health 2008b), but implementation of this commitment has not been achieved. Both patients and clinicians are required to support the achievement of effective care planning and self-management.

Research in the social care field that has highlighted the benefits for patients of direct payments (Department of Health 2008a) has been encouraging. The extension of personal budgets and direct payments to health, while having potential benefits for those with complex health and social care needs, is not a panacea. The results of the pilots and evaluations should be considered carefully before roll-out.

The King's Fund will be doing more work on the management of long-term conditions and would welcome the opportunity to share our findings with the Department.

## **Section 1: Greater Choice and Control**

### **Q1. How should people have greater choice and control over their care? How can we make this as personalised as possible?**

Please see our overview.

## **Q2. Which healthcare services should be our priorities for introducing choice of any willing provider?**

As stated in our overview, AWP is not appropriate to all types of care. For example, it might work well in planned surgery, where the episode of care is well defined, the outcomes are easily measured, and patients may have time to consider the options. The majority of health care is not purchased as a 'spot' purchase by the consumer or the consumer's agent (the GP) but rather, is commissioned via longer term contractual relationships. Complex services such as those for trauma or cancer need a co-ordinated approach across providers. Quality has been demonstrably improved by focusing care within centres of excellence and creating networks of providers - an approach which necessarily reduces the extent of choice for patients. So, a market that encouraged multiple new entrants to 'dabble' in these services would not be good for patients. Choice between and within integrated networks would be beneficial, but remains largely unexplored (Curry and Ham 2010).

## **Q3. How can we offer greater choice of provider in unplanned care?**

Offering greater choice of provider in unplanned care may not be clinically appropriate (see 'Overview'). Too much choice of unplanned care providers may also leave patients feeling confused by the choices they have to make, which could result in greater numbers of people actually accessing A&E, rather than other unplanned care organisations. This could be simplified by the strengthening of unplanned care networks to ensure timely access to an appropriate level of service.

## **Q4. What would help more people to have more choice over where they are referred?**

Our research (*Choosing a high-quality hospital* (Boyce *et al* 2010) and *Patient choice: how patients choose and providers respond* (Dixon *et al* 2010a)) has found that the success of introducing and implementing greater choice of hospital provider rests on the following patient factors.

- **Awareness of choice**

Around half (45 per cent) of the patients surveyed said that they knew before visiting their GP that they had the right to choose a hospital. Older patients and those looking after their family at home were more likely to know about choice, possibly because of their more regular contact with the health service, as were men and those holding a university degree.

- **Offer of choice**

Although GPs maintained that they always offered their patients a choice, we found that just under half (49 per cent) of patients recalled being offered a choice. Very few patients recalled being offered a private sector option and few (19 per cent) were aware, before visiting the GP, that they had a right to this.

GPs appeared to be more willing to let patients choose when the referral was fairly routine, but were more directive when more specialist treatment was required.

GPs also had difficulties in using Choose and Book to help offer choices (for reasons outlined in response to Q37).

- **The ability to exercise choice**

In our study, most patients chose their local provider (69 per cent of those who were offered a choice), and providers and GPs described their patients as loyal to their local trust and reluctant to consider travelling further for treatment. When considering hypothetical situations, almost one in five respondents always chose the local provider, regardless of their characteristics.

Among those who were offered a choice, one of the main reasons for choosing a non-local hospital was a previous bad experience with that hospital. This suggests that the biggest threat to a hospital's market share is providing poor-quality care to individual patients. They are less likely to return, more willing to go to a non-local provider, and may not recommend the hospital to friends and family.

- **The availability of appropriate information to support choice**

Patients reported making little use of available information on the performance of hospitals; just 4 per cent consulted the NHS Choices website and 6 per cent looked at leaflets, both of which provide comparative information on hospital performance. Instead, patients relied heavily on their own experience (41 per cent), that of friends and family (10 per cent), or the advice of their GP (36 per cent). This suggests that there are improvements to be made in the provision of information to support choice.

The research demonstrates the importance of providing information that is accessible, in sensitive formats (including Braille, translated languages and sign language), and ordered and presented in ways that 'nudge' patients to make choices on the basis of quality.

#### **Q5. Which choices would you like to see in maternity services and which are the most important?**

The consultation outlines several choices in maternity services that women value. But women also want 'safe' experiences.

The challenge facing maternity services is balancing the choice of women against the quality/safety of care. Larger maternity units may be necessary, along with more appropriate deployment of staff, given the staffing requirements to deliver safe care (for more information, see The King's Fund's work on 'Safer births: supporting maternity services to improve safety' (The King's Fund 2010a)). Safeguarding maternity services will not necessarily lead to the extension of patient choice.

#### **Q6. Are these the right choices for users of mental health services, and if not why not?**

Choice and shared decision-making are highly important to people who use mental health services, and the government's intention to expand this should be commended. This should not be limited to choice of provider, but should also include choice of treatment and choice of professional, wherever appropriate. For example, the choice between antidepressant medication and/ or psychological therapy is one that should be made jointly, with evidence suggesting that heeding patient preferences increases treatment effectiveness (Lin *et al* 2005).

The use of advance directives or crisis plans, which people can use to outline what care they would wish to be provided with during future episodes of acute illness, is also something that should be encouraged. Properly used, these can empower service users and may also be effective in reducing compulsory hospital admissions (Henderson *et al* 2004).

There is also scope to give increased choice to those with severe mental illnesses such as schizophrenia or bipolar disorder, and to detained patients. Even for the minority of people who are detained for compulsory treatment, research shows that it is both feasible and beneficial to limit disempowerment by granting more choices over certain aspects of care and over practical considerations such as diet and daily routines (Department of Health 2003).

The use of Community Treatment Orders (CTOs) needs to be carefully examined in the light of evidence that they are being used far more widely than expected. The Care Quality Commission has found that CTOs are being used inappropriately in some instances (see Care Quality Commission 2010); in the context of its guiding principle that there should be 'no decision about me without me', it is important that the government ensures that CTOs are used only when necessary and in the best interests of patients.

**Q7. When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken:**

- **At their initial appointment - for example, with a GP, dentist, optometrist or practice nurse?**
- **Following an outpatient appointment with a hospital consultant?**
- **Whilst in hospital receiving treatment?**
- **After being discharged from hospital but whilst still under the care of a hospital consultant?**

While it might be desirable to give greater choice of diagnosis at each stage, offering greater choice should be predicated on high-quality communication between clinicians and patients, and on developing information standards that ensure accuracy in the information relayed from diagnostic providers to NHS clinicians. Currently, there remains a level of distrust of diagnostic results from other providers, and tests are often repeated.

**Q8. Are there any circumstances where choice of where to go for diagnostic testing would not be appropriate, and if so what are they?**

No response written

**Q9. Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?**

Our research found that patients are still not always aware of their right to choose. Dixon *et al* (2010a) found that around half of the patients surveyed said that they knew, before visiting their GP, that they had the right to choose a hospital; they also found that only half of patients recalled actually being offered a choice. In order to address this, there need to be improvements to the accessibility and quality of information to support patient choice. GPs also need to fully understand, accept and perform their role in offering choice to patients.

Evidence on the experience of implementing choice at the point of referral has also shown that the uptake of Choose and Book, designed to support choice at the point of referral, has been slow (Dixon *et al* 2010b). Some of the initial problems encountered can be resolved by improving the electronic referral system itself, in particular its functionality and integration with other information sources. But other aspects of



implementation will rely on changes in the behaviour of GPs, hospital outpatient departments and, ultimately, patients.

**Q10. What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?**

See response to Q4.

**Q11. Is there anything that might discourage you from changing your healthcare provider or named consultant-led team - for example, if you had to repeat tests, wait longer or travel further?**

Our research has shown that loyalty to local hospital provider, and previous positive patient experience, are the dominant 'pull' factors influencing choice of hospital provider. Conversely, mode of transport used for getting to hospital was not a significant factor in predicting whether patients were more likely to choose a non-local provider in practice (when data was weighted).

We also found that providers were quite sceptical about the extent to which patients were acting as informed consumers. Any observed changes in referral patterns were largely seen to be a result of GP decisions rather than the preferences of individual patients. Consequently, providers focused their promotional activities on GPs. Few providers were undertaking market research to understand what preferences influenced the choice of hospital for 'potential' patients, but instead, they were focusing on the experience of 'current' patients (that is, feedback and complaints) and the interests of GPs. Many providers were using this information to drive quality improvement.

Providers saw GPs as a significant barrier to developing patient choice and establishing a competitive market for health care services. They perceived GPs' referral patterns to be fairly stable and giving little attention to quality. Practice-based commissioning (PBC) and the development of community-based services run by GPs were also seen as a potential conflict of interest.

**Q12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?**

Not all people have the confidence and skills to self-manage in all circumstances. For personalised care planning to be most effective in helping those with long-term conditions to have more choice and control over their care, it is essential that it takes place in conjunction with self-management support from professionals (see Rijken *et al* 2008).

Some patients with long-term conditions might not want a care plan, and/or their information shared across providers (ie, some may choose to opt out of personalisation of their health care). They should be allowed the choice to do so.

**Q13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?**

Please see also response to Q14.

The choice consultation makes reference to offering a national choice for patients nearing the end of their life. Considerable progress is already being made across the country in implementing the *End of Life Care Strategy* (Department of Health 2008c) and

in working to meet patient choices regarding their end of life care needs and place of death. The prospect of a national choice offer should not detract from this progress.

**Q14. We need to strengthen and widen the range of end of life care services from which patients and carers can choose. How can we best enable this?**

**Strengthening**

Research by Addicott and Ross (2010) has identified a number of fundamental and inter-related reasons why patient preferences are not being sufficiently met, and solutions to how these issues might be addressed:

<b>Issue</b>	<b>Solution</b>
Poor identification of end of life care needs	Training, multidisciplinary co-ordination of care, and inter-professional access to palliative care records.
Poor communication about prognosis and care planning	Specialist palliative care providers have a role in working with generalist health care providers to alleviate anxieties about initiating conversations about prognosis and care planning and increasing the confidence and competence of all providers.
Poor provision of care during out-of-hours periods	The current level of access to specialist advice and assessment 24 hours a day needs to be qualified; the standard required is that the out-of-hours support should be comparable to that available during traditional office hours. Where services are too small to offer comprehensive support, there may be a need to consider organising care across areas – for example, centralising across a county. Similarly, in care homes, specialist palliative care teams, particularly hospice-based providers, should offer out-of-hours provision. Hospices should be commissioned only if they can provide support to local care homes and admissions 24 hours a day.
Lack of care co-ordination	Advance care planning (and communication of plans within and across providers) can be an effective mechanism for ensuring that patients' care preferences are achieved. Such a whole systems approach to co-ordination of care should also include patients and their carers.
Lack of a whole systems approach	End of life care is provided in a variety of organisational settings by a range of health and social care professionals. Service improvement must therefore be addressed by a whole systems approach, in which attention is given to the entire pathway of care in order to ensure that high-quality care is achieved irrespective of the location, and that patient preferences are better able to be met.

Commissioning appropriate end of life care is complex, and there is a need for greater clarity about the various levels at which it takes place. For example, community nursing and generalist care might be appropriately commissioned by practice-based commissioners or at primary care trust (PCT) level, while specialist care may need to be handled across a wider network. The current model for cancer commissioning may be helpful to apply to end of life care. Whatever models are adopted, they should acknowledge the introduction of personalised care planning and personal budgets, which should provide patients and carers with greater control over the management of their care.

**Widening**

There is an urgent need to stimulate, expand and diversify the market of providers in end of life care, particularly in view of the projected increase in the numbers of people dying (Gomes and Higginson 2008). At the same time, commissioners could use people's rising expectations about the level of care they will receive as a useful lever for change, though it will be important not to undermine confidence and trust by raising expectations that cannot be met.

While there is not – nor should there be – a 'one size fits all' model of joint service provision, whatever is shaped locally should at least have clear objectives, with identified outcomes for the needs of the local population. It should bring together the different professionals with clear, agreed and delineated roles and responsibilities. As well as devising local solutions to deliver these outcomes, commissioners and providers will need to consider how the workforce is deployed and where the greatest needs are. These local solutions should be based on available evidence and informed by examples of best practice.

**Q15. Carers may sometimes feel that they themselves have no choice when the person they care for chooses to die at home. How should the respective needs and wishes of patients and carers be balanced?**

Advance care planning should involve both patients and their carers in open communication about care preferences and needs which are acceptable to both the patient and their carers – as well as realistic within the current context of local care provision. Advance care planning should be a dynamic process (and document) that evolves and is updated as the care preferences and needs of both patients and carers change over time (see also Addicott and Ross 2010).

**Q16. What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self-management, medication or a procedure like surgery.**

No response provided.

**Q17. How can we encourage people to take more responsibility for their health and treatment choices?**

In general, patients are more confident when they are making decisions for themselves or experience something they have encountered before. When they have to make decisions on behalf of others, such as their children, or adults with impaired capacity, they can be less confident and need reassurance. Not surprisingly, then, the use of out-of-hours services is more common by those who are experiencing things for the first time (such as students away from home) and by parents and carers.

Information and how it is used will be key to supporting people to take more responsibility for their health and treatment choices. There will increasingly be an expectation that professionals share information of all kinds and that they work alongside the patient to consider the implications, whether it be in terms of different treatment options, self-management regimes or the performance of the service to which a referral might be made.

There is a reciprocal obligation for patients to engage with and use the information provided, but that should be handled with care. There will be some circumstances where the patient does not wish or feel able to be in control or where they do not want to have certain information – that, too, should remain their right. Individual professionals and those designing services will need to explore different ways of engaging patients to reflect this changing set of relationships.

While encouraging people to take more responsibility for their own health and treatment choices, the NHS and other public services clearly have a responsibility themselves to support people to stay as healthy as possible, and that is likely to require a more proactive approach (Rijken *et al* 2008). If individuals take on more responsibility for their health, this may actually increase contact with the health service as they seek more preventive health services.

## **Section 2: Shared Healthcare Decisions**

### **Q18. How do we make sure that everyone can have a say in their healthcare?**

#### **In service design**

The key to ensuring that patients can have a say in their health care is a change in service culture to one where services are designed around the needs of patients rather than organisations. This means helping clinical staff to design services around patients' needs, and understanding the lived experience of health care. Periodically, staff from ward to board should be exposed to qualitative information on the patient experience: patients' stories, patient shadowing, and observation of staff–patient interactions.

Interventions such as Experience-Based Co-Design, being piloted by The King's Fund, have been shown to be successful in achieving a culture change in services, where the relationship between patients and staff is one of partnership and equality. Patients report feeling that they have influenced the design of services, which are now more responsive to their needs. While this is just one possible methodology, the principle is that the NHS needs to engage with patients in a meaningful way, to understand the lived experience of service users, and to involve them in service design.

#### **For individuals**

The Institute of Medicine (2001) has made it clear that patient-centred care is a key component of quality in health care. In turn, patient-centred care is defined by six different factors, which include the provision of information and the involvement of family and friends in a patient's care. Involving family should be embedded systematically into the whole of the patient journey. We know that the support of their family - for example, in decision-making – is very important to patients.

### **Q19. How can we make sure that people's choices can reflect their different backgrounds - whether ethnic, religious or any other background that could affect their healthcare preferences?**

Enabling choice for different population groups will be predicated on facilitating equal access to services, and providing appropriate and timely support to enable patients to make informed decisions about their care.

### **Q20. How can we make sure that carers and the families of patients and service users can have a say in decisions about the healthcare of the people they support, where appropriate?**

With regard to patients who are nearing the end of their life, and their carers, please refer to Q15.

The Mental Capacity Act (2005) can also be used as a formal tool when ascertaining what is in a person's best interests.

**Q21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?**

Training for health professionals should include discussion about the changing roles of the patient and the professional, and should ensure that they have the skills to support patients to be as healthy as possible, which will include helping them to self-care and self-manage (Dixon 2008).

**Q22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?**

Please see response to Q21.

**Q23. Should healthcare professionals support the choices their patients make, even if they disagree with them?**

If the patient has had access to accredited information, is capable of making decisions (with or without the support of another), and has been able to discuss their choice with the healthcare professional (ie, is in a position to make an informed choice), it is difficult to argue that patient choice should not be supported, even if the professional disagrees.

For decisions taken about how a patient should spend their personal health budget, further consideration will need to be given as to how disagreements will be mediated to prevent sub-optimal spending of these budgets.

**Q24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?**

No response written

**Q25. How can we encourage more people to engage in advance care planning about their preferences for the care and support they receive - for example, when they are approaching the end of their life?**

It is important that consideration is given as to when to broach the subject of end of life care decision-making with patients and carers. All health and social care staff should learn these opportunities for dialogue as part of their training in end of life care.

Training, multidisciplinary co-ordination of care, and inter-professional access to palliative care records could help to overcome some of these issues.

Professional and public attitudes towards death and dying have impeded open conversations about prognosis and care planning for those nearing the end of life. Dying Matters ([www.dyingmatters.org](http://www.dyingmatters.org)) is a national coalition established by the National Council for Palliative Care, with approximately 12,000 members, which aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement. The activities of this coalition should be supported into the future, in order to continue to make progress in encouraging patients and carers to engage in advance care planning.

**Q26. Would you welcome a chance to engage in advance care planning before you become ill – for example, when you go for your mid-life Health Check – rather than after a diagnosis of a life-threatening condition?**

No response written

**Q27. How could training and education make choice and shared decision making a part of healthcare professionals' working practices?**

Please see response to Q21.

**Q28. How can we help people to learn more about how to manage their health?**

There are a plethora of information tools that can be used to support self-management (for a full list, see Rijken *et al* 2008).

Those with complex needs, those with limited resources and those who are not motivated will require different strategies to support them to manage their own care. Self-management systems therefore need to be effectively tailored to meet individual needs and requirements, and to ensure that there is equitable access to all patients requiring these systems.

Patients should be given greater control over routine monitoring to support self-management, but this needs to happen alongside adequate training of medical professionals to support this process.

Further research is required into the effectiveness of self-management support services to understand which components of the programmes improve outcomes for patients; it is vital that programmes are developed using as strong an evidence base as possible to ensure value for money from these interventions.

**Q29. What help should be available to make sure that everyone is able to have a say in their healthcare?**

See response to Q15 and Q18.

The information revolution must ensure a sensible and standardised level of quality in the information provided to support individuals to make choices about their care. A market for the provision of published information should encourage innovation in the content and presentation of information to support informed choice.

Preference documentation tools – such as the Gold Standards Framework (GSF) – provide a valuable resource for assisting health care professionals in initiating conversations with patients and carers, and subsequently documenting and sharing these care preferences with other providers.

The existence of preference documentation tools in themselves will not improve patient care or outcomes, so it is vital that health care professionals act on the information that they are collecting for care planning – both for their individual patients and across their populations.

**Q30. Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?**

Please see response to Q34.

**Q31. How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?**

With regard to patients who are nearing the end of their life, and their carers, please refer to Q15.

**Q32. What information and support do carers, parents, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?**

In relation to end of life care, the types of support that are needed by carers will vary depending on where they are within the patient journey. Our research has highlighted some examples of the importance of information in enabling professionals to help patients and carers. These included assessing the needs of carers, explaining the various aspects of end of life care, and signposting them to alternative or additional services if necessary and appropriate.

Health and social care professionals must recognise the emotional impact that providing end of life care has on carers. It is important that all staff members involved in a patient's care are sufficiently trained in communication skills and can signpost carers to a source of support, such as a carers' group or a member of staff who can provide support. Carers also expressed a need for information relating to the practicalities of the experience – how to access health and social care support, the array of funding systems, and processes and decisions that must be made following the patient's death.

**Q33. What information and support do voluntary sector and patient-led support groups need so that they can continue to help people to make choices about their healthcare?**

No response written

**Q34. How can people be encouraged to be more involved in decisions about their healthcare?**

Please see response to Q18 and Q29.

Patient involvement in care decisions rests critically on the discussions of clinicians and their patients (Coulter 2007). It will not always be the case that patients want to adopt the same role as decision-maker throughout their care pathway, and there will inevitably be variations in patients' desire to engage across domains such as age, educational status and disease severity. Medical professionals must be trained, enabled and incentivised as necessary to engage in active and ongoing dialogue with patients about the role they wish to adopt with regard to decision-making.

**Q35. Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?**

There are many validated decision-making tools to support informed decision-making that are increasingly available on NHS Choices. The issue is ensuring that clinicians provide opportunities to patients to access these tools and support them in using them. This may require repeat appointments to allow patients to go away and consider their options (which will increase the time taken to travel through a patient pathway).

**Section 3: Making It Happen**

**Q36. How should people be told about relevant research and how should their preferences be recorded?**

No response written

**Q37. How can we encourage more healthcare professionals to use Choose and Book when they make a referral?**

Research by Dixon *et al* (2010a) found that GPs had a number of reservations about the way the current choice policy was working in practice. Most of these reservations centred on the Choose and Book system itself. GPs, in particular, conflated patient choice with Choose and Book, in part because it is through this system of booking that the policy of patient choice is 'enacted'.

The financial incentives for GPs to use Choose and Book proved highly influential over their willingness to engage with the system, and we believe that an associated payment system may prove to be an effective method to encourage greater use of Choose and Book. The system must become more timely, accurate, flexible, and able to manage increased demand on booking slots, as well as there being a need to develop Choose and Book support aids and translated information about services available, to facilitate more effective consultant–patient discussions and decision-making.

The research also showed that GPs wanted to be able to refer directly to named consultants, so the introduction of this function as part of the new proposals may serve to encourage greater usage of Choose and Book among health professionals.

**Q38. How can we encourage more healthcare providers to list their services on Choose and Book?**

Please see response to Q37.

**Q39. How else can we make sure that Choose and Book supports the choice commitments in chapter 2?**

Please see response to Q37.

**Q40. Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?**

No response written

**Q41. Do you agree with the proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?**

At a minimum, providers should be registered with the CQC, and abide by both the Information Standard and national standard pricing to avoid the practice of spot purchasing.

**Q42. Should this approach apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?**

No

**Q43. Do you agree that an "any willing provider" directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?**

Yes

**Q44. The White Paper indicates that the Government will explore the potential for introducing a right to a personal health budget in discrete areas. Which conditions or services should be included in this right?**



Personal health budgets pose some challenging questions for the NHS. Their roll-out should be approached carefully for the following reasons (see also Dixon and Ashton 2008).

- Personal health budgets are usually targeted towards those with 'predictable' conditions like long-term conditions, but it is important to note that these patients also experience emergency episodes requiring acute interventions. The risk of ill health cannot be accurately predicted at an individual level. This has both cost and resource implications, and mechanisms for deciding which conditions are covered by the budget will be important.
- There remains a risk that personal health budgets will be spent on sub-optimal care pathways if the parameters for using them are set too widely. Parameters must be clearly set for patients, carers and health care professionals alike, but this will impact on the implementation of AWP. The care co-ordinator becomes a critical factor in how much choice personal health budgets really offer patients.
- It will also need to be decided what will happen if a person exhausts their personal health budget. Will they have to rely on their own means, 'topping up' their own budget? Affordability sits at odds with equity of choice for patients.
- Commissioners will need to stimulate the market so that patients have a choice of where to spend their budget; but this may be compromised under the AWP model (see 'Overview').

#### **Section 4: Safe and Sustainable Choices**

##### **Q45. How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?**

Patients need to be aware of their rights as set out in the NHS Constitution, including the right to complain. People should also be clearly informed about the implications of requesting to break from a chosen care pathway/ provider/ care plan, before they engage in any decision-making process.

##### **Q46. What do you consider to be the main challenges to ensuring that people receive joined-up services whatever choices they make, and how should we tackle these challenges?**

Joining up services through better co-ordination of health and social care services and reducing the fragmentation or duplication of care is essential to improve outcomes for patients. This will be very difficult if the policy drivers of choice and competition produce an increasingly fragmented array of competing public and private providers.

While there are many different approaches to integration, common features include a combined responsibility for commissioning and provision, multi-specialty medical practice, the extensive use of information to improve performance, investment in information technology, and aligned incentives that support a focus on prevention, primary care, care closer to home and the use of acute hospitals only when appropriate. Evidence suggests that much of the innovation in these areas has come from providers, so it will be important to adapt the learning from integrated systems in the next stage of reform and avoid sticking rigidly to a separation of commissioning and provision. This could include supporting GP commissioners to promote integrated forms of provision that overcome barriers between primary and secondary care, between health and social care, and between practices themselves (see The King's Fund 2010b; Curry and Ham 2010).

**Q47. What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?**

No response written

**Q48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?**

No response written

**Q49. Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?**

No response written

**Q50. What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?**

### **Incentives and penalties**

There will need to be incentives to encourage GP consortia to offer choice. Our response to the *NHS outcomes framework* consultation called for a mix of process and outcomes measures, and here lies an example of the need for a process measure in the framework. Choice cannot be incentivised through outcome measures alone.

Offering choice needs to be embedded in a GP's role and there is a need to measure how effectively GPs are offering choice. There would need to be clarity over who holds them to account for this and who assesses their performance – whether this is the consortia or the NHS Commissioning Board.

### **Culture change**

Incentives and penalties alone are unlikely to achieve the changes needed. GPs will need to see the value in offering choice, and this needs to be part of the cultural shift that needs to take place. Many GPs have referred patients to the same hospital/consultant for many years based on established personal relationships. It will take time for this to change.

**Q51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?**

No response written

**Q52. Are the responsibilities of organisations as outlined enough to:**  
**- ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable?**

No response written

**- ensure that no-one is disadvantaged by the way choice is offered or by the choices they make?**

No response written

**Q53. If you do not get a choice you are entitled to, what should you be able to do about it?**

No response written

**Q54. What are the main risks associated with choice and how should we best mitigate these risks?**

Please see the 'Overview' to this consultation.

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