



Liberating the NHS: Greater Choice and Control

General Comments

The **Association of Directors of Adult Social Services (ADASS)** and the **Local Government Group (LG Group)** welcome the opportunity to respond to this consultation which is focussed on greater choice and control in the NHS and the raising of the quality of patient experience. We have significant experience of personalising care through the transforming of adult social care services and increasing service user voice and choice. ADASS and the LG Group support the general direction of travel set out in this document and the drive towards involving service users in every step of their care. We also support shared decision-making and closer integration of health and social care services so that health promotion and prevention of illness are closely linked with acute and community resources.

This is a significant shift in the way in which the NHS operates and this should be recognised and reflected in the timing, resourcing and implementation of the change programme. Whilst the “choice” agenda is not new, progression within the NHS has been slow and uneven. We feel that more consideration and detail is needed on how the significant cultural shifts within the NHS will be communicated, embedded, sustained and identified.

The impact of increased choice in the NHS on adult social care also needs to be recognised. Support and planning is needed for services to be joined up across health and social care. Whilst the responses to the consultation may help to mitigate risks there is a national leadership role for identifying emerging practice and evidencing what helps or hinders. ADASS and the LG Group are keen to discuss with Government how we can build on existing good practice and put in place sector-led improvement and support.

This consultation is about maximising the opportunities arising from new ways of working. As such the Government response should set out in more detail the expected benefits [outcomes] for patients, users and carers and for health professionals, the tax payer and local communities.

In responding to the consultation we have selected various questions from the consultation which cross over health and social care.

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

Increasing choice and control and personalising services occurs at different levels. At an individual level, personal health budgets will give patients increased choice, control and improved outcomes. Personal budgets allow people to have control over resources and to secure their preferred treatment options.

Social care services have extensive experience of offering people personal budgets, enabling them to choose the services that they feel will meet their needs. Enabling people to have greater choice and control requires both a strong partnership between community and acute resources as well as a service market able to meet individual needs.

In designing an NHS which offers personalised care, it will be essential that commissioning decisions are focussed on both acute and non acute support, partnership and integration for health and social care services, prevention and promotion services and the whole care pathway so that individual choices will resonate and remain sustainable.

We fully support personal health budgets and the opportunity to integrate with health in order to meet people's needs.

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

We support the overall approach in terms of giving people with mental health problems greater levels of choice and feel that the principles that underpin personalising care should be applied universally to meet individual needs.

We recognise the importance of offering mental health service users personal budgets so that choice and control can be increased. Mental health service users often receive both health and social care services and offering personal budgets will allow more flexibility in choice of care.

We support the Government's proposals to:

- Allow mental health service users to have a "choice about where, how and what services are provided to them and by whom" (DH, 2010, p:10).
- Have more choice about how to access mental health services
- Choice of any willing provider
- Ensuring choice of different treatments for people with mild to moderate anxiety and depression
- Personal care planning to meet health and social care goals

With regards to people who are detained under the Mental Health Act we agree that it may be necessary to restrict some choices for reasons of safety and urgency. However, the general principles regarding choice and control should apply when it is deemed safe and appropriate. Similarly, this applies to people who are lacking in decision-making capacity under the Mental Capacity Act, 2005. It is important to remember that even when people have

limited mental capacity there will be some elements of their lives about which they can still exert choice and control. This is particularly important for people when they are in hospital. Decisions should be in the best interests of the person and involve carers, family and advocates. Extending choice to carers in these cases may be appropriate.

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?

“Personalisation and community are the key building blocks of a reform agenda, shaping around an individual’s own expertise and resources. When people need ongoing support, this could help them to retain or regain community membership...” (Putting People First, 2010:p1).

Enhancing community capacity is one of the key-stones in helping people to retain choice and control over their health care. Combined personal health and social care budgets will allow for greater integration of services and the opportunity to meet individual needs holistically. It will also allow for preventative and acute services to work together to promote overall health and wellbeing.

We strongly support the statement that

“Having a single assessment and care planning discussion that is led by one professional such as a nurse, doctor or social care worker followed by an agreed joined up care or support plan can really make a difference to the way professionals share information and work together” (DH, 2010:p18). (A more specific reference is required)

This however must be driven by joint commissioning so that holistic care pathways are developed. We believe that commissioning services in relation to particular diseases, such as COPD or stroke services, has the potential to overlook important causal or contributory factors that may be social or environmental. For example, people disabled as a result of a road traffic accident or a stroke may have similar social care needs and have much in common as a result of their experience of disability.

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

We welcome the acknowledgement that many people who would otherwise prefer to die at home, currently die in hospital. We look forward to the proposed establishment of a national choice offer for those who choose to die at home. We also welcome the acknowledgement that carers play a pivotal role in supporting people during the process of their death.

Partnership working between community and acute resources, as well as health and social care integration will promote increased choice for people

who are dying and need both health and social care intervention. We believe that community service provision and good advance care planning for people with complex needs will increase people's ability to choose to die in their own homes.

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?

Often there will be common interests and concerns that can be talked through. End of life care support for people with cancer is probably the most developed. Here there are a range of practice and information materials to enable people to make informed choices and to have support. These can be built upon. In the case of other groups it may be that information and support services are less well developed. Improved awareness of and use of information and advice would be helpful.

A key principle here is "nothing about me without me". Another is the principle of the therapeutic alliance inherent in the "triangle of care" model between professionals, patients and carers. Information and advice are essential and cancer survivorship materials, for example, offer a basis for developing safe, sound and supportive practice. Neither the carer nor the patient should be at risk of feeling of isolated or abandoned. 24-hour access to a key professional is essential.

Carers and the role they play, or may be expected to play, need to be included in discussions at an early stage. Health and social care professionals need to be both patient-centred and carer-aware in a personalised way. There will be practical (e.g. facilities at home), risks and emotional issues to be considered. The willingness of carers to take on such responsibilities should not be assumed. Carers' rights to an assessment needs to be more widely understood throughout the NHS.

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?

All services should allow all 'citizens' fair access. Offering increased choice should extend to people of all backgrounds and we believe that through personalised care planning and support, people will be able to direct their own care and request culturally appropriate services.

There is however a potential issue of how to ensure equal access to choice and control for patients in healthcare settings both now and in the future. This is about those patients who may be very isolated or be without support or otherwise at risk of discrimination in terms of ability to make choices. This area is in need of further exploration if choices for all people are to be offered and sustained.

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?

The underpinning principle “nothing about me without me” applies to patients, carers and families in this context. It is our experience that carers and families of patients want the best possible treatment and outcomes for the patient. Carers should be regarded as expert partners in care by all the professionals in contact with them.

Patient views on the involvement and sharing of information must be kept in mind. There may be some occasions when the interests and wishes of both the patient and the carer may have to be balanced and where expectations may be different.

There is a lot of good practice and evidence that can be built upon. Work in local areas on hospital discharge along with that by the Princess Royal Trust for Carers and the Moffat Project in Scotland identified a range of pointers to effective practice. The Partners in Care programme also developed a range of materials to guide practice and discussion in this area much of which is transferrable. There are three main dimensions to this issue:

- Patient expectations and preferences about care and support are critical and professionals should not make assumptions about willingness or ability of families and carers to do. Patients need to be aware of and assured about what information can be shared without breaching confidence. We need a greater understanding of how this and information from carers may be used in shaping the quality of care experience along their particular care pathway.
- Health and social care professionals need to be carer-oriented and aware. This will help ensure recognition and support as will being aware of carers’ rights and timely and proportionate assessments. Work with General Practitioners by the Princess Royal Trust for Carers points to benefits of effective recognition and support and added value for health professionals arising from this.
- Carers and families need timely and appropriate information and advice. Where appropriate assessment should be offered to assist in making informed decisions about their involvement, risks and support. Access to independent information, advice, advocacy and support may also be helpful for some carers.

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

Organisational cultural change and sensitivity is central to this question. Securing the shifts in behaviours to support the changing relationships involves healthcare professionals and patients, users and carers and will take

time. It will require consistent leadership and ownership by all care professionals.

The essential ingredient to securing change will be whether care pathways and experiences result in improved quality in terms of processes, experience and outcomes for all those involved in the triangle of care we have described.

For patients, families and carers it means raising awareness of respective expectations, options and opportunities and how this translates into a better care experience and outcome. Progress is likely to be faster in some areas than others. Issues for patients, families and carers from socially excluded groups or who are isolated and vulnerable may require special attention.

Question 31: How can we make sure that Carers' views are taken into account when the person they support makes a healthcare choice?

In some ways the response is "it depends on the nature and implications of decisions or choices by the supported person". Both patients and carers have the right and the responsibility to make informed choices about their healthcare and care pathways. Health professionals need to understand the implications for the patient and the carer in exercising that choice and how to support them in arriving at informed choices.

If carers are involved as "partners in care" and if the principle of "nothing about me without me" is applied consistently then inclusion of carers views would become an integral element of all decision making. As such, care choices would be more likely to be arrived at in partnership between the professional, the patient and the family or carer.

An underpinning principle should be that of "best interests" considerations for the patient both at the time and in the future.

Question 32: What information and support do carers, patients, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?

The central issues are patient capacity to make choices and the need for others to assist them in doing so having regard to their "best interests". Existing guidance and practice materials around mental capacity may be relevant.

What is equally important is that health professionals have a clear understanding of legal and professional frameworks for balancing rights and responsibilities around:

- different types of power of attorney that may exist arising from changes in legislation, their scope and potential limitations;
- patient decisions or expectations surrounding current or future care choices;

- the critical importance of “best interests” considerations;
- avoidance of undue pressure on patients and carers around what they feel able to or wish to decide at the time and space to enable them to make choices.

Availability of information, advice and support, including independent advocacy for patients, their families and carers are essential.

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?

There is a risk that services will become fragmented when GP consortia form in different ways across the country. At an individual level GPs will need to be fully engaged with social care services and it is important that they promote personal health care budgets as a way of securing choice and control for people with long term conditions.

Health and Wellbeing Boards will be vital in making overall strategic decisions, pooling budgets and other resources, and encouraging joint commissioning to ensure that services are joined up and focused on achieving improved health and social care outcomes. It is important that Health and Wellbeing Boards are not just expected, but specifically authorised, to hold GP consortia to account. This is in the interests of patients receiving the care they need and making sure GP consortia carry out their public health functions alongside primary care.

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

We acknowledge that there are both financial and non-financial risks in offering increased choice. From our experience, whilst offering personal budgets may increase costs, service users often use the service more efficiently and effectively, thereby balancing out additional costs with improved health and social care outcomes and improving the return on investment.