

## Standing Commission on Carers

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### Response from the Standing Commission on Carers to the Consultation on the NHS Draft Mandate

#### Introduction to the Standing Commission on Carers

The Department of Health established the Standing Commission on Carers in December 2007, to act as an independent advisory body, providing expert advice to Ministers and the Carers' Strategy Cross-Government Programme Board on progress in delivering the National Carers Strategy (a ten year Strategy published in 2008 and 'refreshed in 2010) and on a broad range of other policy issues relating to carers and support for their roles.

The contribution of carers is vital to the delivery of both high quality health and social care and to the wider economy. Therefore, the Standing Commission on Carers is particularly concerned that their role (and their own health and well being) should be fully acknowledged within the current debate about quality of care and the active engagement of patients as key partners in improving health and well-being and achieving the good outcomes expected of a 'world class' NHS.

The last Census (2001) reported that there were approximately 6 million carers in Great Britain (around 5.2 million carers in England and Wales and almost 500,000 in Scotland). 58% of carers were women, 42% men. 68% of carers care for up to 19 hours a week, 11% for 11-49 hours and 21% for 50 or more hours. Over-65s account for a third of all those carers providing more than 50 hours a week. 58% of carers are obliged to give up employment because of caring

responsibilities, with a corresponding number reporting a range of health problems relating to their caring roles. With changing demography and family structures, there is an increase in the number of families with multi-generational (and sometimes distance) caring roles.

## 1. Our response to the Draft NHS Mandate

**1(i)** The **Standing Commission on Carers** warmly welcomes the opportunity to contribute to the consultation on the Draft NHS Mandate. We recognise that over time the Mandate is intended to become a key mechanism through which the public can hold Government, the NHS Commissioning Board and ultimately the Clinical Commissioning Groups to account for performance, value for money and quality in the health service. We also welcome the intention to set out in one key document the main objectives for the NHS for which politicians and commissioners can be held to account.

**1(ii)** However whilst endorsing the principle of a strong and principled agenda for the NHS, as proposed within the draft NHS Mandate, we have a number of points to make about the current proposals and set these out below.

## 2. The presentation of the Draft NHS Mandate

**2(i)** We feel that the content, language and presentation of the Draft Mandate could be made more accessible. In particular, we would welcome a stronger initial message about the *purpose* of the Mandate, with an indication of the intended audience.

- a)** We endorse the widespread views that it would be helpful to have a core set of principles more clearly articulated in the introduction. However, we consider that at present the Draft NHS Mandate is overly focused on hospital based services and insufficiently proactive in endorsing the Government's commitment to more preventive services that promote well-being and reduce the risk of crisis care in acute health settings.
- b)** Because the Mandate is intended to be high level and visionary and to set out the key ambitions of the Government for the future of the NHS, we also consider that a communication strategy will be needed to ensure that it is widely known and understood by the public.
- c)** Any communication strategy should also take account of the broad support for the welcome emphasis on *integration* within the Draft Mandate. We feel that it would be

helpful to clarify the relationship between the objectives, the NHS Outcomes Framework, the Constitution and of course the specialised commissioning for which the NHS Commissioning Board will be responsible. Additionally, in recognition of the Government's wish to encourage preventive earlier intervention and the promotion of general health and well-being, we would like to see stronger referencing to the roles of Public Health, the Health and Well-Being Boards and the Health and Well-Being Strategy.

- d) We would also welcome a stronger reflection of the inter-dependence of the NHS with social care and support and other public services.
- e) We also suggest that it would be helpful to provide a diagram (ie a visual representation) showing the relationship of the Draft Mandate to the wider and changing architecture of the NHS *and its relevant partners in social care and elsewhere*.

### 3. Prioritising Objectives - Objective 15: Recognising the role of carers

**3(i)** The Standing Commission on Carers agrees with other commentators that the NHS Mandate should prioritise and should not be over-crowded with multiple objectives. However, we regard some of the Objectives as key to good outcomes and in particular we warmly welcome Objective 15 and its acknowledgement of the critical role played by carers within a new outcome-focused NHS.

**3(ii)** We strongly recommend that this Objective should be retained in recognition of the role of carers as crucial to the achievement of good health outcomes for a wide range of citizens and in effect as equal and expert partners in care. In particular, we warmly support the aims of **Objective 15**, namely to improve the recognition and support that carers themselves receive from the NHS through:

- a) **Early identification of a greater proportion of carers, with signposting to information and sources of advice and support and:**
- b) **Working collaboratively with local authorities and carers' organisations to enable provision of a range of support, including respite care.**

Whilst accepting that the Draft Mandate should focus on a limited number of key objectives, we are very concerned that this objective should be retained. As noted elsewhere in our response, there is worrying evidence of the impact of unsupported caring on the carer's own

health and well-being. The Royal College of General Practitioners (2012)<sup>1</sup> in its guide on carers for GPs notes that:

- a) **40% of carers have significant distress and depression levels**<sup>23</sup>
- b) **Carers providing more than 20 hours of care a week over extended periods have twice the risk of experiencing psychological distress over a two year period than non carers.**<sup>4</sup>
- c) **One survey found that 20% reported back injury because of heavy physical caring.**

Other studies have found that:

- a) **Higher levels of care are associated with a 23% higher risk of stroke.**<sup>5</sup>
- b) **Older carers who report 'strain' have a 63% higher likelihood of death in a four year period than non-carers or carers not reporting strain.**<sup>6</sup>

**3(iii)** The Royal College of General Practitioners also notes self-neglect by carers who may miss routine healthcare appointments because of their caring responsibilities. A carer's neglected and poor health will ultimately impact on the support that they can offer their relative and in turn incur additional cost to the NHS.

**3(iv)** A survey from the **Princes Royal Trust for Carers**<sup>7</sup> found that 65% of older carers polled said that they had significant health problems or a disability *in their own right*. Only 50% felt capable of providing the care their relative really needed (eg lifting, going out, and managing complex medical procedures) without additional support. Their relative was therefore at much greater risk of multiple admissions to acute NHS care without a coherent and integrated care plan from community and acute NHS services and the local authority.

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<sup>1</sup> RCGP and Princess Royal Trust for Carers(2012), Supporting Carers: a Guide for GPs

<sup>2</sup> Pinquart M, Sorensen S, Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis, *Psychology and Ageing* (2003), 18(2)

<sup>3</sup> Hirst, M(2005), Carer distress: a prospective population based study, *Social Science and Medicine*, 61

<sup>4</sup> Hirst, op cit

<sup>5</sup> Schulz R and Beach S, (1999) Care-giving as a risk of mortality, *Journal of American Medical Association*.282 (23)

<sup>6</sup> Haley, W, Roth DL (2010), Care-giving strain and estimated risk for stroke and coronary heart disease amongst spouse caregivers, *Stroke*, pp331-6

<sup>7</sup> PRTC (2011), Supporting Carers: the Case for Change, Princess Royal Trust for Carers and Cross Roads Care

In this context, we note key messages from the **National Carers Demonstration Sites**<sup>8</sup> with regard to the benefits of recognising the improved health outcomes from prioritizing carers' own health and well-being and encouraging the take up of health-checks by carers in their own right as well as supporting the health and well-being of their relatives. The demonstrator sites clearly showed the importance of offering health checks and related services at locations which are seen as '*carer-friendly*' and where carers can discuss any anxieties about their own health issues and receive practical and relevant advice to improve their own health and well-being.

**3(v) We welcome the key principle of well-being in both health and social care (we also note that well-being is a also key principle within the Draft Care and Support Bill).** Both the Draft NHS Mandate and the NHS Constitution emphasise a major shift in our concept of health care from '*treatment*' for acute conditions to a more preventive and holistic focus on '*well-being*'. However, '*well-being*' at a population level (together with a policy shift of health care delivered in hospitals to healthcare largely delivered in community and family settings) cannot be achieved without support for family *carers*. It is in all our interests to maximise the ability of families to support (and sometimes to co-deliver) treatment and care in the family home rather than in NHS or residential settings.

**3(vi)** By retaining **Objective 15**, we can ensure that carers are seen and supported as expert partners within the reformed NHS infrastructure. Indeed we cannot envisage the **QIPP** agenda being delivered effectively without well supported and informed carers working as expert partners and the links between primary, secondary and tertiary care for people with long term conditions or disabilities.

**3(vii) In the context of the above, we welcome the focus on prevention and reablement as part of planned recovery for the growing number of patients who survive, strokes, trauma and other conditions for whom structured rehabilitation will be vital.** An Australian study (**Drose and Rees, 2006**)<sup>9</sup> found that 3-5 sessions of personal care training to carers (each lasting around 30-45 minutes) resulted in a higher proportion of stroke patients achieving independence at an earlier stage and reduced the need for physiotherapy and occupational therapy. Importantly the study found that the numbers of hospital readmissions were substantially reduced with carers reporting that they now felt '*confident, valued and understood the short, medium and long-term outcomes of the reablement programme and the*

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<sup>8</sup> Centre for International Research on Care Labour and Equalities, University of Leeds and DH (2011), New Approaches to Supporting Carers' health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme

<sup>9</sup> Droses, R et al (2006), University of Sydney, reported in 2012 SCIE review of research on outcomes in reablement, SCIE

*family's role within it.* In many cases community and hospital nursing services worked together to ensure that such training was available and was utilised following discharge.

**3(ix)** We also note that the right to a *family* life is a key right set out within the **International Convention on Human Rights**. *Delivering Dignity*<sup>10</sup> notes that '***working with families on behalf of patients is not always easy but is essential in order to achieve the best possible outcomes***', but rightly acknowledges the stresses that illness, dementia and anxiety about rapid changes in circumstances can put upon them and their relationships. We hope that the Forum *can* help to break down some of the often artificial barriers between carers and patients/users and recognise that support for the *family* as a unit will often be the most effective way of maximising quality of life for the older person.

**3(x)** In this context we see the **National Carers Strategy** (refreshed in 2010)<sup>11</sup> as setting out similar ambitions about choice, control and maximum independence for carers, whilst recognising that the best support for carers will always be the best possible personalised support for their family member or friend. In effect improving the well-being and achieving better outcomes for patients must mean addressing the well-being of the family as key partners in a healthier society.

#### 4. Objective 16: A health service for all ages and all sections of the community

**4(i) Objective 16 (contributing to the work of other public services where there is a role for the NHS to play in delivering improved outcomes)** lists a number of priority areas for both the NHS and social care, including:

- a) **Contributing to multi-agency family support**
- b) **Upholding the Government's obligations under the Armed Forces Covenant and**
- c) **Improving safeguarding practice in the NHS;**
- d) **Reducing violence in particular information sharing around violent assaults and**
- e) **Developing better integrated healthcare services for offenders.**

**4(ii)** We do not feel that this section is helpful as currently drafted. Not only do many of the above suggestions for prioritisation relate to wider NHS objectives. They are also not specifically

<sup>10</sup> Report of Commission on Dignity in Care (2012)

<sup>11</sup> Recognised, Valued and Supported: Next Steps for the Carers' Strategy (2010), HM Government,

related to the Outcomes Frameworks which will form the basis for assessing quality. We would welcome

- a) **The setting of some high level (but specific) objectives such as Objective 15 around carers. These objectives can be related back to the Outcomes Frameworks.**
- b) **Clarity about what an objective is within the context of the Draft Mandate. For example, we see culture change as a principle, but not an objective.**
- c) **We would welcome a stronger emphasis across the Draft Mandate on the interface between the Outcomes Frameworks for Public Health and Social Care. Both will have particular relevance to Objective 16.**

**4(iii)** We are also concerned there is currently very limited reference to maternity services and, most importantly, to services for children and young people. They are tomorrow's citizens and we are well aware that their health and well-being is crucial. We note the report from the Children's and Young People's Health Outcomes Forum<sup>12</sup> and the statement that:

***“Although the NHS has responsibilities for people from conception to death, the reality is that the health system has been largely designed by adults for adults of children and young people.....the benefit of adopting a child friendly health care approach will be to maximize the opportunities for improving outcomes. Looking through a child friendly lens will promote and create alignment and synergy between all the various stakeholders involved in providing services.”***

**4(iv)** In particular, whilst we warmly welcome the Outcomes-based approach throughout the Draft Mandate, we would welcome greater clarification of the measures for success for some of the objectives (in particular around integration). We also note that the success of the NHS Outcomes Framework will to a considerable extent depend on successful outcomes as set out in the Public Health and Social Care Outcomes Frameworks. Reference is made in the Draft Framework to these three Frameworks, but we would also welcome a reference to the forthcoming NHS Children and Young People's Outcomes Framework. The NHS Mandate should be seen as an inter-generational key agenda for action for all our population across the age ranges.

**4(v)** We endorse the proposal in section 3.6 (*Developing our NHS Care Objectives*) that it is the Government's intention to *'set the Board a stretching ambition to improve against each of the five domains as a whole, based on an aggregate measure of performance for each domain.'*

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<sup>12</sup> Report of the Children and Young People's Health Outcomes Forum, July 2012

**4(vi)** We also endorse the recommendation in section 3.7 (Developing our NHS Care Objectives) that the Mandate should *'take a holistic approach that looks at quality of life and quality of care as a whole, rather than focusing primarily on the treatment of individual clinical conditions.'* However, we have some concerns about the statement in the same section with regard to the proposed *'balanced scorecard'* which will give commissioners freedom to decide how to improve quality and outcomes in ways that are most important for their local populations. Given the concerns about meeting the challenge of a rapid rise in the number of people living with long-term conditions (often with complex needs), we would like to see a recognition of the importance of cooperation and joint commissioning between health and social care.

**4(vi)** In this context, we would welcome a reference in section 3.5 (Developing our NHS Care Objectives) to the duty already set out within the NHS and Social Care Act, requiring the NHS to cooperate with the local authority and others and the corresponding duties to cooperate as drafted within the Draft Children and Families and Care and Support Bills. We consider that a specific reference to cooperation and joint commissioning within the Mandate would give a powerful message to the public sector as a whole to work holistically and to thereby improve quality of life for both patients and carers.

## 5. The Accountability Framework

**5(i)** We warmly welcome the emphasis on transparency and accountability and endorse the intention to produce annual reports to Parliament on progress in achieving the objectives set out in the annual NHS Mandate. However, we are concerned that it is not as yet clear how some objectives will be measured. Whilst progress against the indicators in the NHS Outcomes Framework (and other Outcomes Frameworks in the context of integration) is helpful in any performance assessment, we do not currently have robust measures for assessing the quality of the patient (and carer) experience outside a hospital setting. Nor are there currently strong indicators for measuring progress against the ambitions of the QIPP challenge (particularly important in terms of the management of long term conditions).

**5(ii)** We have concerns that the focus on top level health outcomes might obscure the real variation in performance across the NHS and could make it difficult for both Government and the public to accurately assess how different commissioning groups are performing. We are aware that the NHS Commissioning Board must produce an annual business plan, setting out how it will achieve the objectives specified by the Mandate to Parliament. We welcome this requirement but also hope that performance measurement should take into account the



annual business plans of the CCGs and Health and Well-Being Boards to ensure quality across the country and to avoid any possibility of a 'healthcare lottery' emerging.

**5(iii) We also note that:**

- a) **We have particular concerns about the model of accountability and consider that a wider scrutiny than that between the Secretary of State and the NHS Commissioning Board is highly desirable.** If we are describing the NHS as belonging 'to the people', then accountability needs to be as transparent and independent as possible.
- b) **With further reference to accountability, we also note that whereas the NHS Mandate is designed to set out the activities for which the Secretary of State intends to hold the NHS Commissioners to account, many patients receive care from providers such as hospitals and general practices, which are regulated by Monitor and the Care Quality Commission.** We would welcome clarification as to how the NHS Mandate will inter-relate with these two regulatory bodies.
- c) **The Draft NHS Mandate acknowledges the importance of greater integration between health and social care. Therefore, we would like a stronger cross-reference to performance in the social care sector (which in turn will mean clarification of the role of CQC and standards set by NICE and others to ensure quality).** For example, we note that the Health and Social Care Act's duty to cooperate will be replicated within the Draft Care and Support Bill. However such co-operation will necessitate consideration being given to standards and measures of accountability in social care and other settings. We have noted above the fact that CQC and Monitor will also be assessing performance in some cases and compatibility between different regulatory systems will be vital.

**5(iv) We support the Government's vision of an NHS which promotes health and well-being in their widest sense, which is genuinely centred on patients and carers, which is evidence based and innovative and which focuses on quality and outcomes rather than short term interventions.** However, in order to achieve this vision, we need to ensure that accountability to patients, carers and communities and users is seen as a priority and to develop ways of engaging them as critical friends and partners in maximising successful outcomes and ensuring that the NHS Mandate is seen as 'their' vision and agenda for the NHS.

**5(v) The NHS Outcomes Framework** includes 60 outcome indicators across five domains, all of which pose challenges in coordinating care more effectively around the needs of both patients *and carers* and the joining up of health and social care and a range of other public services to ensure that services are seamless.

**5(vi)** The Draft Mandate acknowledges the importance of carers as active partners in achieving good outcomes and we hope that the NHS Commissioning Board will further develop and endorse the concept of ‘*expert carers*’ in the same way that NHS reforms are directed towards the creation of ‘*expert patients*’. Both should be seen as active partners, with reciprocal roles, rights, responsibilities and skills, but we are concerned that the contribution of carers is often neither fully respected nor recognized. In effect, where the Draft mandate refers to ‘*patients*’, we would like to see a parallel ‘*and carers*’.

**6. Objective 4: Increasing the proportion of NHS patients who rate their care as good: Improving quality of care across the patient’s journey across both hospital and community health services**

**6(i)** We agree that it is critical that the NHS takes greater notice of the views of both patients and carers as to the *quality of care that they receive*. In this context, we note that there are over 15 million people in England living with at least one long term condition. This number will increase to around 18 million by 2025/30. 70% of NHS and social care is spent on caring for people with long-term conditions, but many patients and families do not consider that they are able to enjoy a quality of life which is commensurate with that of their peers. More care is rightly delivered in the family home and community and, as the **NHS Confederation** commented (August 2012), we need to shape services very differently for the patients of today and tomorrow. In effect, we must strengthen and expand the role of a wider range of NHS nursing and other services in the community, with families and carers as key partners and move beyond the ‘*friends and family test*’.

**6(ii)** As Opinion Polls indicate<sup>13</sup>, the public tend to exercise choice and rate quality on the basis of very broad criteria such as cleanliness, safety and convenience. These may be adequate in some cases, but we are now looking at a wider range of health services and we need better *qualitative* measures for capturing patient and carer experience across the care pathway.

**6(iii)** Whilst we warmly welcome the proposals within the Draft Mandate, we note that there is a strong *hospital focus*. In practice, many patients living with long-term conditions or disabilities will receive the majority of their care in the community. We suggest that a stronger message should be given about the future role of Health and Well-Being Boards, Healthwatch and the Health and Well-Being Strategies. **We would also welcome a greater emphasis on the patient (and carer) experience of prevention (ie the avoidance of unnecessary or premature**

<sup>13</sup> Ipsos Mori/DH National Patient Choice Survey, Waves 17 and 18

admissions or readmissions to residential or NHS settings because the carer or family are unable to cope at home).

**6(iv) We agree that we need to go much further with the ‘friends and family’ test and that the views of staff themselves are also vital in driving up quality and continuous improvement.**

However, we are also aware that the experience of individual patients and their carers can vary widely. As the Commission on Dignity in Care (2012) noted, we need to create infrastructures which permit staff to delivery high quality care and, importantly, to treat and work with patients (and their carers) with dignity and respect and as expert partners in the achievement of good health outcomes.

**6(v) We welcomed the emphasis in the Draft NHS Mandate on ascertaining the views and wishes of patients themselves and of the family and friends who care for them. We particularly welcome the vision expressed in section 3.1 of ‘an NHS that puts patients, carers and the public first, where shared decision-making – ‘no decision about me without me’ as the norm.**

**6(vi) However, as noted above, we have endorsed the statement in Chapter 3 of the Draft Mandate that the NHS is still at a very early stage of maximising patient and care involvement in decision-making and in review processes. In Chapter 2, we welcome the intention that the NHS Outcomes Framework should be further developed so that it ‘better captures the experience of those who use the health service’, but we also acknowledge that much progress is needed in order to achieve this goal.**

**6(vii) The past months have seen big debates about the future of both health and social care, with much emphasis upon accessible information and active participation in decision-making by those using services and those supporting them. However, as the Joseph Rowntree Foundation notes in a recent study<sup>14</sup>, the experiences and views of older people with high physical or mental health support needs (and their carers) have often been neglected because:**

- a) There has often been an undue focus on specific health and care needs at the expense of wider quality of life issues.**
- b) Assumptions are often made about older and other vulnerable people that ignore their social roles, their individuality and their ability to make choices.**
- c) Stereotypical views of certain groups of people can lead to disrespect and a disinclination to try and improve quality of care.**

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<sup>14</sup> Joseph Rowntree Foundation (2011), A Better Life – What older people with high support needs value, JRF

- d) **Family carers are not necessarily respected nor is their unique knowledge of the patient utilised in maximising good health outcomes.**

**6(viii)** The **Joseph Rowntree Foundation** concluded that quality care should embrace three key (and often over-lapping) areas of life, namely:

- a) **Physical needs and well-being**
- b) **Social well-being and relationships**
- c) **Psychological well-being (including maximum self determination).**

**6(ix)** We strongly advocate the development of the role of key worker, navigator or designated health professional (as touched on in the Draft Mandate) for patients with long term conditions or disabilities *and* their families. We note that many patients and their carers are unsure about how to raise issues of quality or safeguarding with both NHS and social care providers and the relevant regulators. They may fear victimisation or assume that they will not be believed. Whilst formal complaints procedures are important, we would wish the Mandate to encourage a culture of openness where early concerns could be dealt with at an early state and in many cases thereby avoid the crises in care that frequently lead to emergency NHS admission or family breakdown.

**6(x) The ambitions of the new NHS are for the achievement of world-class health outcomes.** We have warmly welcomed the emphasis on patient experience and the assumption that their experience should further inform improvement in NHS services. However, we are concerned that '*patient experience*' as defined in the Draft Mandate appears to be focused on *hospital* care. As noted elsewhere, it also appears to disregard the importance of carers in achieving good outcomes (particularly for those patients with long-term conditions or for older people). They will have complex patient journeys which move across primary, secondary and tertiary care. They also involve a wide range of health and other professionals and community services. Therefore the experience of health care before and after hospital admission should be key in any assessment of quality. In this context (referring back to **Objective 15**) we think it vital that the *family's* perspective of the quality of care should be given parity of esteem with that of the patient.

## **7. Objective 12: Enabling shared decision making and extending choice and control for NHS patients**

**7(i) We welcome the emphasis on patient participation and the ability of patients to have much greater choice in when and how they receive their healthcare. As noted above in our**

comments on Objective 15, we also hope that any discussion about choice will embrace the concept of both informed patients *and* informed carers.

**7(ii)** However, we are concerned that ‘*choice*’ may be neither effective, nor even desired, unless patients and their carers have the support to make *informed* decisions about their healthcare. We agree with **Section 3.8** of the **Draft Mandate**, where it is stated that ‘*many people want greater clarity over when and how they can make choices about the services they use.*’ We note the **Draft Choice Framework** for health services which is published as an annex to the Draft Mandate. However, we do not see the equivalent in the **Draft Choice Framework** to the new duty being proposed for local authorities in the **Draft Care and Support Bill** with reference to the local provision of information and advice services to support informed decision making.

**7(iii)** Whilst we fully endorse the move towards Personal Budgets for both health and social care (**Section 3.9**), we do not envisage these achieving the goal of extended choice and empowerment unless there is an infrastructure to support their use. Indeed we note that there is currently much anxiety and mistrust amongst many users and carers about the implications of more personalised services and the possibility of additional tasks in order to manage greater autonomy and the relevant audit trails. Conversely we are aware of high levels of satisfaction amongst users when they feel adequately informed and supported to make good decisions about their care and support. Therefore, we suggest that a good communication strategy and in particular information, advice and if necessary advocacy and brokerage are key ingredients in taking informed decision-making and genuine choice and control forward.

**7(iv)** In the context of the above comments:

- a) We endorse the Draft Mandate’s statement (**Section 3.3**) that healthcare systems are still in their infancy in terms of putting the experience of the user first. We welcome the reference to care plans which integrate health, social care and any other needs specific to the patient or carer (including the availability of a named professional) but hope that there will be specific proposals within the NHS Commissioning Board’s first Business Plan for achieving this goal.
- b) We refer to proposals for a single integrated plan for disabled children and young people within the Draft Children and Families Bill. This proposal is accompanied by a requirement that key workers will be made available to help young people and families make the best choices about the education, health and care and support. We would warmly welcome a similar proposal within the Draft Mandate. Reference is made to a ‘designated health professional’ but a named health professional is not necessarily the equivalent of a key worker when navigation through a number of often complex

decisions is required. We note the effectiveness of OTs, community nurses and sometimes specially trained home care workers in ensuring good outcomes from reablement schemes, where personal navigation and support is a vital ingredient in good outcomes for both patient and carer – and for the NHS.

- c) With regard to **Chapter 3** of the Draft Mandate, we are pleased to see a reminder to the fact that the **NHS and Social Care Act 2012** requires the NHS Board and CCGs of their responsibility for promoting the involvement of patients *and carers* in decisions about their treatment and care. We consider that this legal requirement is a further endorsement of the need to retain **Objective 15** within the final Mandate.
- d) **As noted elsewhere in this response, we refer to the general responsibility in the Draft Care and Support Bill for local authorities to ensure the provision of information and advice to their local communities in order to help people understand the care and support system, access services and plan for the future.** If the Choice Framework is to achieve its desired objectives, then the Draft Mandate should also highlight the importance of information and advice systems to support informed choice and control.

We fully endorse the **NHS Future Forum's** January 2012 report on public health, which sets out a clear case for changing the culture of the NHS so that healthcare professionals take every opportunity to talk to both patients *and* their carers about how best to improve their health and ***'to make every contact count.'***

## 8. Section 3.11 onwards and Objective 13– Integrated Commissioning and Integrating care around patients

**8(i)** Improved integration and continuity of care are key ambitions within the Government's ambitions for reforming both the NHS and social care. We welcome both as important for all groups of patients and for all citizens needing care and support in any aspect of their lives.

**8(ii)** We endorse Sections 3.11-3.12, and the acknowledgement that: ***'We need a health and care system that is truly responsive to the needs of patients, carers and their families and delivers services designed around individuals, not organisations.'***

**8(iii)** Section 3.12 also states that: ***'Greater integration involves recognising that healthcare outcomes are frequently interdependent...'*** We would welcome clarification in the final text of the Mandate that a health and care system should offer an amalgam of health care options (for some patients including primary, secondary and tertiary care) and social care and support (for many patients with long-term conditions). The 21st century challenge for the NHS is that of

relocating healthcare where possible within a wider range of community support services promoting well-being and ‘wellness’ as well as treating acute conditions. In this context we particularly welcome the reference to carers, who will be key partners within the new system.

**8(iv)** We note that continuity of care (ie managing care across transitions and changing needs) should be a key beneficiary of better integration of health care and its social care counterparts. As **Freeman and Hughes** (2010)<sup>15</sup> have noted:

***‘Continuity of care becomes increasingly important for patients as they age, develop multiple morbidities and complex problems or become socially or psychologically vulnerable.’***

Such continuity is particularly important for older people *and* their carers because not only are they are likely to have multiple problems but negative assumptions may be made about older people’s expectations and abilities and in turn these may have a negative impact on the support offered. We share the **Commission on Dignity in Care’s** emphasis on the need to change attitudes and language towards older people, who are too often seen as ‘bed blockers’ or ‘burdens’ rather than people who have made significant contributions to families and community and who in many cases can continue to make a contribution if properly supported.

**8(v)** We also note that the **King’s Fund** (2012)<sup>16</sup> found the lack of integration between community and hospital (and health and local authority) frequently led to multiple admissions and discharges and poor outcomes for patients ( was a significant factor in admission to long-term care). This lack of continuity of care had particularly challenging implications for carers, many of whom felt ill-informed and unable to provide high levels of support at home without further advice and training. We note and welcome the Government’s ambitions within NHS reform to transfer patient care from hospital to home and community settings. However, this new emphasis is unlikely to be successful unless support for carers is seen as a high priority, with community nursing services both highly valued and often critical to managing discharge and reablement programmes.

**9. Objective 14: Improving the quality and availability of information about NHS services, with the goal of having comprehensive, transparent and integrated information and IT to drive improved care and better healthcare outcomes.**

<sup>15</sup> Freeman G and Hughes, J (2010), Continuity of care and the patient experience, Kings Fund, London

<sup>16</sup> Cornwell, J et al (2012), Continuity of care for older hospital patients: a call for action, Kings Fund, London

**9(i) We strongly endorse the need for better information collection and for the need for such information to be presented in ways which are relevant to patients, carers, communities as well as the relevant professionals and commissioners. In particular, we note that :**

- a) The need for better and sharper information systems ran through the Integration and other work streams within the **NHS Future Forum Phase 2** and also within the work streams within '*Caring for our Future*'. We hope that we will see the development of national and local information strategies which avoid the current duplication of information and knowledge gaps which characterise many services. We envisage the possibility of a new culture of transparency and public engagement through innovative approaches to information and communication. Information for users/patients and carers is an integral part of good care. Without such information strategies, it is difficult to envisage how the NHS can better integrate either within itself or with a wider range of partners in the community.
- b) ***The Operating Framework for the NHS in England 2012/13*** identifies the urgent need to give patients better access to their records and to support integrated care through enabling the appropriate sharing of information between organisations. We hope that improvements in technology will resolve the current challenges around incompatibility between data sets and ensure that patients/users and carers do feel genuinely empowered in managing their own care and support.
- c) **We welcome the RCGP's current work on digital information and electronic records**, both to inform individual patients and carers and also to provide reliable data to be used at a population level for integrated commissioning within the locality.
- d) **Reliable information systems are vital, given the new plurality of providers, the use of personal budgets and the complexity of some conditions necessitating different approaches.** Good information should be built in at every stage of the patient/user/carer journey. We also note the importance of developing systems which not only provide initial information but can also monitor progress. Therefore we welcome the reference to the potential of technology in **Section 17**. We note that **Telecare** and **Telehealth** are part of the digital revolution and can provide personalised and safe oversight for a wide range of people.
- e) Similarly we note the development of improved digital information sharing around care pathways (eg the **Tyze Programme**<sup>17</sup>), and the different partners involved in delivering

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<sup>17</sup> Tyze is an electronic programme developed in Canada to enable users/patients, carers (paid and unpaid) and community members to plan care and support, manage crises and share relevant data and information. Further information on [www.tyze.org](http://www.tyze.org)



care and support offers new opportunities to avoid the current data ‘silos’ that can so often develop because of ambivalence about confidentiality and incompatible software.

**9(ii) Objective 13 recognises the importance of new commissioning systems to promote and support integration of care, particularly for people with dementia or complex long-term needs.** In this context, we note that With increased life expectancy and demographic change, we will increasingly depend on family carers as older people will present with a range of interlocking conditions and challenges. Supporting integration of care between the NHS and the local authority is now a key priority, with the NHS Confederation<sup>18</sup> noting that elderly people who are unnecessarily occupying in-patient beds (because of lack of support in the community) are now costing the NHS £500,000 a day.

**9(iii)** Two studies (**Hoogerduijn, 2007<sup>19</sup>, Lafont, 2011<sup>20</sup>**) suggest that older people not only spend longer in hospital because of their age, but are also more likely to be readmitted within a short time of discharge. In both the above studies, it was noted that there was limited interchange of knowledge and expertise between commissioners in different sectors and with family carers who were unsure about support in the family home. **Both studies noted the importance of shared information systems to inform joint commissioning (and planning) between health and social care and very importantly with families themselves in order to prevent unnecessary or premature admission to hospital or residential care.**

## 10. Objectives 7 and 8: Reducing inequalities – an advocacy role for the NHS

**10(i) We endorse the focus on reducing health inequalities in Objectives 7 and 8. We note that the NHS Commissioning Board’s and the CCG’s legal duties to work towards reducing health inequalities build on the duties of all public bodies in relation to promoting equality.** In particular we welcome the requirement of the NHS *as a whole* to comply with the Equality Act duties on age discrimination in services, which come into force in October 2012. Both the **NHS Constitution** and the **Draft NHS Mandate** acknowledge that there are large sections of the community which have been historically under-served by the health service – for example those

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<sup>18</sup> NHS Confederation (September 2012), Papering over the Cracks

<sup>19</sup> Hoogerduijn, et al (2007), A systematic review of predictors and screening instruments to identify older hospitalized patients at risk of functional decline, Journal of Clinical Nursing, Vol 16, No 1, pp46-57

<sup>20</sup> Lafont, et al (2011), Reducing ‘iatrogenic disability’ in the hospitalized frail elderly, Journal of Nutrition, Health and Aging, Vol 15, No 8, pp645-60

with learning disabilities, mental health problems, dementia, the homeless and older people. Hence the equalization of quality and access across the NHS should be seen as a key priority.

**10(ii) The Equality Act 2010 identifies specific duties for the public sector in terms of placing equality at the heart of health and social care.** This general duty requires public authorities to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relationships across all characteristics protected by the Equality Act 2010. These now include protection from discrimination on grounds of age as well as on grounds of race, disability, gender, age, sexual orientation and religion or belief. Additionally, carers are now protected on grounds of *associative discrimination* because of their engagement with a person who is in the six protected categories. The public sector is expected to consider *and analyse* the impact of any services or developments in terms of the equalities agenda.

**10(ii) With reference to inequalities, we note that the Equality Act 2010 duties with regard to protecting older people from discrimination and less favourable treatment come into force next month.** In the light of a range of reports (for example the report in the *British Journal of Cancer, September 2012*<sup>21</sup> about less favourable treatment of older people, and the likely public anger and anxiety at the conclusions of the **Francis Review**), we hope that the Mandate can be strengthened with regard to equality issues and parity of esteem for older people and other groups of citizens who have not necessarily been given the priority they deserve in accessing public services.

**10(iii) We envisage Health and Well-being Boards having an important role in engaging with minority groups in local communities and identifying strategies to engage them in the development and delivery of appropriate services and support.** Therefore, we would also welcome a stronger recognition of the importance of *public* health in the context of prevention and earlier intervention. In many cases we envisage the Health and Well-Being Boards, with their broad representation, as having a unique perspective on the circumstances of minority groups in the community and hope that their views will be fed into the joint strategic needs assessments and related planning and commissioning arrangements.

**10(iv) As the Equality and Human Rights Commission (2011)**<sup>22</sup> noted in its review of human rights and home care,

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<sup>21</sup> British Journal of Cancer (September 2012), report from National Cancer Intelligence Network on late diagnosis and treatment of cancer in UK

<sup>22</sup> Equality and Human Rights Commission (2011), *Close to Home: An Inquiry into Older People and Human Rights in Home Care*, EHRC, London

*'It appears that commissioning [for older and disabled people] is not being consistently used across all sectors in order to protect human rights effectively. Indeed some commissioning practices make the bad experience that older and disabled people describe more likely to happen. Although practices vary a great deal, very few seem to be consistently underpinned by public services' awareness of their duties under the Human Rights Act.....There is a clear need for supportive senior leadership on the central importance of quality, including respect for human rights principles such as dignity and personal autonomy in the services commissioned.'*

**10(v)** We envisage the NHS and its partners in social care as having an important role in delivering the '**supportive leadership**' identified above and in supporting and acting as advocates for potentially vulnerable people (and their carers) to ensure that they have high expectations and are indeed supported as active and expert partners in care.

## 11. In conclusion

**11(i)** We welcome the NHS Mandate's positive approach and the focus on the outcomes that matters to patients, carers and local communities. We also welcome the emphasis on positive and transparent strategic partnerships between the people who use services and those who design and commission them. The infrastructure of both health and social care are undergoing radical change and transformation and we hope that the NHS Mandate will continue to be ambitious, encourage innovation and integration and maintain a 'citizen first approach' which maximises health and well-being, encourages investment in prevention and maximises good recovery when acute healthcare is needed.

**11(ii)** As noted earlier, we warmly welcome the recognition of the role of carers within the Draft NHS Mandate. This recognition of carers as vital partners in the new NHS should have a profound impact on the quality of care and health and well-being experienced by both patients and carers. Their implementation will be challenging, as commissioners, staff and providers and providers across the public, independent and voluntary sectors will need to accept a new culture of respect and an equalities-based approach to resource allocation and recognition of the right of both patients and carers to high quality care and support.

**11(ii)** As stated above, we feel that a robust and holistic approach to prevention is needed, with appropriate early identification and intervention so that as far as possible people can remain in family and community and carers are adequately respected and supported. We hope that carers – relatives and friends – are reflected in the Forum's future work and respected for their unique commitment and advocacy on behalf of the people for whom they care. As one carer told us:

***'We have a unique knowledge of our relative's strengths, his or her weaknesses and any special care needs. We will be at home caring when the hospital or sometimes the care home decides they have had enough. Carers, like the older people they support, are sometimes seen as a nuisance, unreasonable, even greedy. But in the end families matter. We know what dignity looks like and if we can be true partners in care, then we will achieve services and support fit for the future. At least we are now talking about dignity – it's what makes most people's lives feel worth living!'<sup>23</sup>***

**Note: Further information and additional references on any of the above points can be obtained from:**

**Dame Philipa Russell,**

**Chair,**

**Standing Commission on Carers,**

**e-mail: [prussell@ncb.org.uk](mailto:prussell@ncb.org.uk)**

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<sup>23</sup> Carers' quotations come from a workshop organised by a local carers' group to ask carers for their views on care and support and, in particular, hospital discharge.