

*The below responses were submitted via an online proforma to the Independent Commission on Whole Person Care, 23/8/13.*

*Questions 1-4 asked for respondents' details (name, organisation, etc.).*

**5. What Government policies can ensure that patients, service users and carers have more control over their care, ensuring it meets their individual needs?**

Care planning must become routine in health and social care, and must be done collaboratively with service users, taking account of the outcomes they wish to achieve. Too often it is a box-ticking exercise, with care plans devised solely by health and social care professionals, and sometimes not shared with each other or even with the service user.

With care effectively planned, it must also be co-ordinated, both within the NHS and with other services. A care plan must bring with it a named professional responsible for co-ordinating care. Embedding care planning and co-ordination across the NHS will require a substantial and sustained policy drive over many years.

Effective care planning will also include anticipatory assessment: for people with rapidly progressive conditions, it is not acceptable to wait until a predictable need has arisen, and then face a delay in putting the necessary support in place; care planning must take future need into account.

Personalised delivery options such as personal budgets can have a transformative effect in supporting people with long term conditions. Their deployment must be judicious, and not done as a blanket, one-size-fits-all approach: some people, perhaps those with rapidly progressive terminal conditions, perhaps those with little experience of budgeting or aptitude for it, would find the imposition of responsibility for procuring their own care an unwelcome burden.

We also recommend that the terminal nature of diagnoses such as motor neurone disease, and their often rapid progression, are fully recognised by the system: too often, fast-track processes are hard to access for many people because the criteria that determine access are based on the characteristics of terminal cancer and do not take account of other disease types.

**6. What Governmental policies might ensure that people who are not able to take full charge of decisions, receive care focussed on the whole person?**

Care planning and co-ordination, including full consultation with both service users and their carers, and anticipatory assessment of need, can still allow people who are not able to take full charge of decisions to receive high quality care that meets their needs. There may also be a role for advocacy in securing the most appropriate services for people in this position.

**7. What are the barriers that exist within the current system and processes of health and social care that prevent a more co-ordinated working, AND which if removed would facilitate such working?**

One barrier is a lack of national guidance on some highly demanding conditions, not least MND. This is currently being remedied, with NICE due to produce a full guideline by 2016, which should make best practice much clearer to the wide range of professionals involved in the care of a person with MND.

There are more substantial structural barriers beyond this, related to the financing and commissioning of care. Care co-ordination activity does not generate revenue under the tariff. Some providers therefore officially discourage or even forbid it.

Any activity carrying an up-front cost, irrespective of the potential longer term savings, is also likely to be subject to cost-shunting, either between the NHS and social care or within the NHS, for instance between CCGs and specialised commissioners. This is particularly acute in respect of social care due to the current crisis of funding it faces, but is becoming ever-more problematic in the NHS too, in response to tightening budgets and the need for new institutions to establish their responsibilities. A shift to a funding mechanism based on outcomes or a year of care might eliminate the problem of intra-NHS cost shunting and of providers actively declining to undertake co-ordinating work.

The emerging model of CCGs engaging prime contractors for large bundles of services is also of concern. It appears to present a serious risk of smaller, more specialised and often voluntary sector providers being squeezed out, and engaged either as a sub-contracted afterthought or not at all, leaving smaller, more challenging and more specialised patient groups with only general support. This contracting model has had exactly this effect when used by DWP in the Work Programme, and appears to be operating similarly in the NHS. Co-ordinated care requires an understanding of what care needs to be co-ordinated; shutting out smaller providers with expertise in smaller and more complex patient groups is likely to hinder this.

**8. What further actions by Government (as opposed to local mechanisms) do you feel would provide an environment that would facilitate co-ordinated care?**

Empowered national leadership could improve the consistency with which health and social care services are co-ordinated. A regime for national clinical leadership currently exists: it could perhaps be better resourced, and an expansion of its remit to cover social care might also be beneficial, but we would not necessarily advocate abandoning it and starting again.

Recent experience of national clinical leadership and policy direction shows its effectiveness: the National Service Frameworks in areas such as heart disease drove major improvements in outcomes in the NHS; NSFs that lacked

national leadership and funding for implementation, such as the NSF on long-term neurological conditions, proved ineffective in driving change. This conclusion was supported by an audit of neurology services by the National Audit Office in 2011.

Another possible area for national leadership is timeliness: again, a consistent drive for this across the country is the only likely way to achieve substantial progress. For rapidly progressive conditions, there is always a danger of unacceptably long waits for assessment, equipment or new care provision; these waits can mean that the person's condition changes, and by the time provision is eventually made provided it is no longer appropriate, or the person has died.

**9. What system measures would you put in place to give confidence that co-ordinated care is producing good outcomes for people?**

Outcomes can be difficult to assess for a condition such as motor neurone disease, in which the ultimate outcome is invariably the death of the person with MND. Even developing a care plan with achievable outcomes in it can be hard: the disease is so relentless and so devastating that the parameters of what can be achieved are very narrow. We would however suggest that outcomes could be measured against a well-judged care plan, and this approach should be considered.

We also recommend that non-elective admissions and critical bed days should be monitored. While MND is a highly challenging illness to manage, this is usually best done in the home: an unplanned admission or long stay in an intensive care unit or high dependency unit will often suggest a failure, perhaps in respiratory support or in the provision of equipment leading to a fall.

**10. Within existing global resources, what changes to financial flows and incentives across the system would best assist in achieving co-ordinated care?**

As a representative organisation for patients and service users, we cannot allow the assumption that the totality of resources available will not, or should not, be increased to go unchallenged. Currently resources are undergoing significant cuts: social care finance is at crisis levels, while the NHS's nominal real-terms increases in budget are calculated with reference to consumer inflation, which is irrelevant – healthcare inflation is significantly higher. Additionally, with money siphoned off from the NHS to plug gaps in social care, and research due to take a larger portion of the NHS's budget, the overall picture for the NHS is one of substantial real terms cuts at a time of rising demand. We would not expect any future government to continue this situation after the general election without making a positive case for decreasing care resources over the long term – a case which would be unlikely to secure widespread public support.

Leaving the issue of resource levels aside, it is right to identify financial flows and incentives as a very substantial factor in the successful provision (or not) of co-ordinated care. The logic of planning NHS services by commissioning is that all the key activities necessary for care must generate revenue for the provider. Yet in practice it is very hard to align monetary rewards with clinical need exactly, particularly for complex conditions such as MND, where well over a dozen, sometimes close to two dozen professionals will be involved in a person's care at any one time, not all of them from the NHS. The result can be a failure to provide vital support, not least work to co-ordinate services. Switching to a remunerative mechanism other than the tariff, such as a year of care funding model, may avoid this need to align financial drivers with care needs so precisely, and therefore avoid negative consequences when this is done imperfectly.

More generally, we would observe that there is broad consensus about the appropriate policy approach for planning NHS services over the coming years: community services need to be strengthened, to reduce undesirable and expensive inpatient stays and ultimately to de-commission some hospital capacity if possible. Unfortunately this service redesign requires up-front investment, sometimes by organisations other than the NHS; equally, the eventual savings of this investment might not always be picked up by the service that made it. Strong direction, incentives to redesign services and sufficient cash to make this work feasible are therefore all needed.

### **11. Who should be the commissioner of more co-ordinated care, and why?**

If care is to be co-ordinated, it will often be provided by multiple institutions: either the NHS plus other statutory services, or multiple parts of the NHS. It is not feasible for all of this care to be commissioned by the same part of the system. Rather, the commissioning of dedicated co-ordinating services must be undertaken. Who commissions these will again depend on the nature of the service: for MND, it may be that the co-ordinator will be most usefully attached to a specialised MND clinic, in which case they should be commissioned on a specialised basis. At other times however, the professional with the key co-ordinating role will be based in the community, and therefore most likely commissioned by a CCG.

We note that the question assumes the continuation of commissioning within the NHS in England. While this is no doubt very likely, this is an assumption that the review might wish to question in light of the different approaches taken by the NHS elsewhere in the United Kingdom.

### **12. What workforce changes and development would help to ensure more co-ordinated care across organisational boundaries?**

Care for people with MND involves a wide range of health and social care professionals, including occupational therapists, dieticians, physiotherapists and speech and language therapists. We strongly recommend that all

therapists and allied health professionals, and ideally social workers, involved in the care of people with MND have some knowledge in depth of neurological conditions. We have been concerned to see a drift towards generalism in recent years, which makes it less likely that assessment and planning will be anticipatory, or provision sufficiently timely. Professionals who understand the highly complex and demanding nature of MND are also more likely to understand the importance of co-ordinated care.

We also recommend that the NHS commissions dedicated care co-ordinators. Currently these roles exist largely in MND Association care centres, funded largely by the MND Association. The NHS should not be reliant on a subsidy from the voluntary sector for this vital role.

It is also the case that the UK has fewer neurologists per head of population than comparable European countries. This in turn means that there is a relatively small pool of neurologists who specialise in MND, although where they exist they are often highly influential in enhancing the provision of multi-disciplinary care. Specialists of this kind are often clinician-researchers who drive our world-leading research effort into MND; this group of clinicians must be supported and expanded.

**13. What are the information quality and flow issues arising from creating whole person care (including access by the public), and how would you deal with them?**

Data covering neurological conditions is in a problematic state. A neurology dataset has been promised by the Government, but has yet to emerge. The current health, public health and social care outcome frameworks contain very few indicators specifically relevant to neurology, partly because relatively little data is currently gathered that can be used to measure outcomes. Coding problems relating to neurology have hindered the development of a service specification for specialised neurology commissioning.

NHS providers, commissioners and strategic clinical networks are also failing to make best use of available data. Some have asked neurological charities to make Hospital Episode Statistics data available to them without charge, even though the charities have to pay a fee to access it.

**14. If you know of good examples of co-ordinated whole person please detail below, indicating what data exists to demonstrate a difference has been made to people. Please supply any contacts, if known.**

The MND Association's care centres and networks provide effective care co-ordination for people with MND, across the multiple agencies and disciplines involved in supporting them. We are currently commissioning a study to provide an up-to-date evaluation of this model; it may not be ready in time for submission to this review, but we will be happy to make it available to NHS England, the Government, political parties and other stakeholders when

published. Academic papers published to date suggest this model of care increases longevity, and reduces unplanned admissions.