

Response ID ANON-9K5H-J8DK-J

Submitted to **Your views: building a strong, integrated care system across England**

Submitted on **2021-01-08 16:25:07**

Integrated Care System (ICS) legislation

1 What is your name?

Name:

Katharine McIntosh

2 In what capacity are you responding?

In what capacity are you responding?:

Charity, patient representative organisation or voluntary organisation

If you have selected 'Other', please specify::

3 Are you responding on behalf of an organisation?

Yes

Organisation name::

The Neurological Alliance

Email::

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4 Do you agree that giving ICSs a statutory footing from 2022, alongside other legislative proposals, provides the right foundation for the NHS over the next decade?

Neutral

If you have any specific comments or additional information to provide, please provide it in the text box below::

The Neurological Alliance is of the view that initiatives that enhance and improve integration are a good thing, so long as such changes filter down to improve patient experience of joined-up service provision. At present, care is all too often experienced as being extremely disjointed; care pathways in neurology are often fragmented, characterised by services that do not work well together. This is particularly problematic given that many people with neurological conditions need to access multiple services – the complexity of living with a neurological condition cuts across traditional service boundaries. For families, this means having to navigate a vast array of services and professionals simply to meet a patient's minimum care needs, adding considerably to distress caused by the symptoms for which the services are needed.

There has been considerable work in recent years to produce integrated frameworks for optimal care in various neurological conditions. This includes work by NHS RightCare to produce optimal pathways in their epilepsy, headache and migraine, and progressive neurological conditions toolkits, in addition to ongoing work under the auspices of the NHS England Transformation programme optimum clinical pathways for people across a wide range of neurological conditions setting out what good treatment, care and support involves.

The intention is for these pathways to support the improvement of services, set out aspirations for good care, and enable good commissioning of neurological services locally and nationally and in an integrated fashion. However, such frameworks are only effective if they are implemented by regional and local decision makers. Integrated Care Systems could be an effective way of utilising these resources to develop more effective and efficient models of care locally.

At present, the NHS's infrastructure does not foster much local engagement with neurology. CCGs seem to be too small to prioritise neurology at a local level, especially in the face of NHS priorities focussing on other clinical areas. And our 2016 audit of STPs found that STPs most commonly engaged with neurology by engaging with stroke/dementia, generally overlooking wider neurology.

The whole systems approach outlined in the consultation document is particularly suited to what is needed in neurology. Putting ICSs on a statutory footing could put weight behind mechanisms to improve integration, as well as improving accountability.

But while what is outlined is likely to lay the foundations for facilitating improved, integrated care in neurology, it is not sufficient.

Firstly, the plans are sorely let down by the apparent lack of patient engagement in pulling them together. As laid out in the Five Year Forward view, and reinforced in the NHS England Patient and Public Participation Policy,

"One of the great strengths of this country is that we have an NHS that – at its best – is 'of the people, by the people and for the people...we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services."

Moreover, NHS England has a legal duty under section 13Q of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012) to properly involve patients and the public in its commissioning processes and decisions.

It is therefore surprising and concerning that patient and public participation in drawing together the plans outlined in the consultation document are not discussed at all. Whether this is because this simply has not happened, or whether it is a communication oversight, is unclear. But what is clear is that in order for voluntary sector organisations such as ourselves to have any faith in the propositions – and in order for the proposals to be as good as they can be – this needs thoughtful and thorough rectification.

Secondly, statutory mechanisms to support patient engagement in the proposed ICS framework, particularly with regard to service improvement and digital transformation are severely lacking. This needs to be addressed as a matter of priority.

More detail is needed on how the plans fit with existing improvement initiatives. Section 4.6 states that support will be made available to systems through regional improvement hubs. This is fine in principle but more detail is needed on how this will work in practice. In neurology there has been a number of improvement initiatives (including the Getting It Right First Time neurology programme, the NHS England and Improvement neuroscience transformation programme, and NHS RightCare toolkits), to leave it to chance about whether learnings will be embedded in practice. Due consideration should be given to such initiatives, and of course similar initiatives in other specialities, moving forward.

Thirdly, we were pleased to see a focus on data and digital in the consultation document, and agree that these have great potential to drive system working and improved outcomes. However, what is lacking is an underpinning understanding that some clinical areas are far more data-rich than others; at present the data playing field is not an even one, potentially cementing existing variation in the experiences of patients with different conditions. Indeed, neurology has long been a data-poor area. Although there has recently been limited investment in neurology data by PHE, this was starting from such a low baseline that we still lack even basic knowledge about some neurological conditions such as accurate prevalence and incidence statistics, as well as more detailed knowledge about service performance and patient outcomes. This has an impact on both the ability of local systems to plan and commission effective care to meet local need, as well as tracking spending on neurological treatment, care and support in its entirety. We would therefore welcome a focus on data improvement on those areas where data is currently of insufficient quality or quantity, including neurology.

Data at a population health level is therefore generally lacking, and even where there is some data, prevalence is often so low as to be overlooked.

In order to remove barriers to collaboration, there are also problems that need thinking through in relation to data sharing – many records are kept at GP level, on a variety of different recording systems which generally have no interface with data records held in secondary care. This could prove a significant barrier to better integration and need to be addressed in conjunction with wider integration plans. Indeed, improvements to data sharing across different systems have been made due to the need for a whole system view in responding to the COVID-19 pandemic – lessons learnt ought to be harnessed and expanded upon.

In conjunction with the points made above, we suggest that concrete mechanisms are needed as part of future accountability frameworks to better incentivise areas to seek to understand their local population of patients with neurological conditions and to implement the findings of improvement initiatives.

Finally, we agree that providing the right foundation for the NHS for the next decade is hugely important. Meaning we need to get the process right from the outset. So in response to the question, yes we agree that statutory footing needed, but we would suggest that the plans are not yet ready. Further work is needed in line with our responses above. We would also suggest that this is a poor time to be consulting on such plans – given the ongoing national health emergency, many voluntary organisations are busy fire fighting and will simply not have the capacity to engage with this at present. Therefore, we believe the timescales outlined should be revised, to allow the necessary time for various aspects of the plans to be developed further, and for essential patient and public engagement to take place in a meaningful way.

5 Do you agree that option 2 offers a model that provides greater incentive for collaboration alongside clarity of accountability across systems, to Parliament and most importantly, to patients?

Neutral

If you have any specific comments or additional information to provide, please provide it in the text box below::

We completely agree that a distracting top-down re-organisation must be avoided – the NHS simply cannot afford this. We also want to see much stronger accountability for patient outcomes. So while we do not have enough close-hand experience to provide much insight on which of the two models is stronger, from the way they are outlined model two does sound to be the better model insofar as it provides for more accountability, but avoids significant re-organisation.

6 Do you agree that, other than mandatory participation of NHS bodies and Local Authorities, membership should be sufficiently permissive to allow systems to shape their own governance arrangements to best suit their populations needs?

Disagree

If you have any specific comments or additional information to provide, please provide it in the text box below::

We disagree that membership should be permissive beyond the participation of NHS bodies and Local Authorities, on the basis that membership must include voluntary sector/patient and public voice representation, and that governance arrangements should not be entirely permissive.

While understandings of the importance of patient and public voice in planning service provision has been increasing within the NHS in recent years, we are still very far from a place where this is universally well understood and implemented. All too often, it is misunderstood or overlooked, or lip service is paid. We therefore are very concerned that if the proposals do not include a mandatory seat at the table for patient organisations/representatives, we will continue to see very patchy involvement across the country, resulting in weaker plans in some areas. Similarly, unless some manner of blueprint for governance arrangements is put in place which mandates proper, thorough arrangement with the full diversity of patients and the public (going over and above engagement with the local HealthWatches, some of which are much stronger than others), the likelihood is that governance will not suit population needs in some areas. We would therefore like to see minimum expectations of governance arrangements clearly laid out.

7 Do you agree, subject to appropriate safeguards and where appropriate, that services currently commissioned by NHSE should be either transferred or delegated to ICS bodies?

Neutral

If you have any specific comments or additional information to provide, please provide it in the text box below::

Care for people with neurological conditions is all too often extremely disjointed, reflecting the fragmentation and confusion over the division of commissioning responsibilities. Unfortunately there have been situations in which patients fall through the commissioning cracks where neither the CCG nor NHS England have seen it as their responsibility to provide services. As such, longer-term strategic planning on a regional level covering all commissioned services could potentially offer a step forward for neurology services. However, the delegation/transfer of services currently commissioned by NHS England down to ICS bodies is not without significant risk, meaning robust safeguards must be in place for this to go ahead – we would therefore welcome further consideration of this.

In line with our points already made above around patient and public involvement, we strongly advocate for such robust safeguards to include mechanisms for patient involvement.

In the consultation document at 2.72, Principle Four states that funding of specialised services will shift from provider-based allocations to population-based budgets. This seems to be based on a key underlying assumption that a proper assessment has been made of the relevant population. But as outlined above neurology is a data poor area, and there has historically been little prioritisation given to neurology by CCGs and STPs due to a lack of proper assessment of population needs, and a lack of incentivisation mechanisms (e.g. in the CCGOIS).

Given both the poor track record of areas in making an appropriate assessment of their neurology populations, and the relatively poor data of the prevalence and incidence of neurological conditions, it very much remains to be seen whether this could unintentionally do a disservice to neurology service provision. We are therefore concerned that unless it is very clear what must be provided at a local level, disinvestment in some existing services, and/or lack of investment in much needed but currently lacking services, could result. We would therefore like to see accountability frameworks with in-built mechanisms to better incentivise areas to properly understand their local population of patients with neurological conditions, so that they can commission services accordingly. We welcome the continued role of national guidance and specifications for specialised services. Coupled with NICE guidance and Quality Standards, and other relevant service improvement resources, this will help to mitigate against the potential for further unwarranted variation in treatment, care and support.

We also note that decisions about what to commission for particular groups of patients involve a detailed understanding of patient needs. As an example, decisions about commissioning neurorehabilitation would require a person who is skilled and experienced in neurorehabilitation service provision, delivery or commissioning to be involved in decision making, in partnership with other stakeholders.

We're pleased to note that the consultation document notes that in some cases ICSs will need to group together to commission services – as commissioning for some rare conditions is not realistic even at ICS level. However, the proposals on this lack detail. It is particularly important that these proposals are well-thought out given existing service infrastructure – such as the neurology regions established in Getting It Right First Time neurology methodology report. Secure mechanisms for multi-ICS commissioning are needed to ensure that treatment for rare neurological conditions does not become a post code lottery, especially if disagreement occurs. These mechanisms should be established before giving the go-ahead, in order to ensure a smooth transition and avoid commissioning chaos.