Response ID ANON-9K5H-J83K-1

Submitted to **Your views: building a strong, integrated care system across England**
Submitted on **2021-01-07 11:15:30**

Integrated Care System (ICS) legislation

1 What is your name?

Name:
Elinor Jayne

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::
Sue Ryder

Email::
elinor.jayne@sueryder.org

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?

Disagree

If you have any specific comments or additional information to provide, please provide it in the text box below::
If a restructure is to take place, we should aim for fundamental reform. We are not convinced that the current proposals go far enough and instead simply risk restructure fatigue amongst an already exhausted workforce.

Of course, health and social care providers should collaborate - with people who use those services - to shape and deliver services. However, an enormous amount of preparatory work is needed to make this work effectively. This is even more true in light of the coronavirus pandemic, with huge backlogs in the health and social care system and massive strains across every element of the system. The incentive mechanisms currently in place, coupled with political pressures prevent genuine long-term planning and collaboration and we do not think the proposed reforms address this in any way.

There needs to be a large-scale restructure of CCGs and other health and social care groups across the NHS. It is vital that the voluntary sector is part of these new structures - this is not made clear enough in the proposals as they currently stand. For instance, as specialist providers of palliative care and of neurological care, it is paramount we are involved in decisions on governance structures and decision-making processes, in order to influence and input to patient service redesigns.

The timescale for the fundamental change needed would be several years. An ambition for everything to be in place by April 2022 is unrealistic.

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::
The degree of collaboration will depend on membership of ICSs and relationships within them and with other stakeholders. There is a risk of dominance by the larger providers, which would result in a loss of community and/or population responsiveness currently met by smaller providers and providers from the voluntary sector.

For systems to successfully work together as a collaborative entity, data sharing and interoperability need to first be enabled. Without shared access to patient information and NHS data and processes, it will not be successful. The question of who will pay for this data sharing transformation remains unclear.

Whatever model is taken forward, it needs to be genuinely outcomes-based and accountable. England would not be the first country to make reforms aimed at integrating services in this way and experiences from elsewhere should shape the NHSE plans. For instance, Scotland used legislation to integrate health and social care services and the structural changes have not made much impact on the experiences of patients. Two years on from the new structures being up and running, Audit Scotland found “financial planning is not integrated, long term or focused on providing the best outcomes for the people who need support”(https://www.audit-scotland.gov.uk/uploads/docs/report/2018/nr_181115_health_socialcare_update.pdf). Along with lack of collaborative leadership, inability to share data and lack of engagement with staff, communities and politicians, the question needed to be asked why such disruptive reforms had taken place with little discernible benefit, at that point.

This makes the point that time and relationships are key to improving services, rather than the structures themselves. This requires clear, collaborative leadership.

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?

Neutral

If you have any specific comments or additional information to provide, please provide it in the text box below::
Option 2 offers a model that does not go far enough to address population health as a whole (as opposed to a medical model of ill health). There needs to be detailed work in each locality to understand population needs - not just now, but for the future. This work needs to then shape the membership of the new systems to ensure those local population needs are addressed.

Whilst there has to be some flexibility for the structures of the ICS and other governing committees based on local priorities, there should be a national standard to ensure that all areas of health, social care and voluntary groups are represented, reflecting the needs of the local population they serve. Attention is needed to ensure ICSs are representative of all providers, including from the voluntary sector, particularly those supporting under-represented patient groups.

A focus on tackling bureaucracy and involving the voluntary sector in governance is positive. However, allowing systems to shape their own governance arrangements will result in regional variation i.e. how the voluntary sector will be involved will vary from locality to locality. This can be positive so long as health outcomes are achieved and people do not feel they are subject to a postcode lottery of services. That is why early and ongoing meaningful engagement with local communities is key.

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?

Agree

If you have any specific comments or additional information to provide, please provide it in the text box below::
Regional and system leadership with greater knowledge of local populations should have the commissioning powers to meet local need. Again, this should be communicated clearly with local communities to avoid confusion about what it would mean in practice for people who rely on these services. Not only that, questions about funding would need to be addressed at the same time: services cannot be transferred without the required resourcing being put in place.

This is on top of a more urgent need to address questions on how funding for existing services will be allocated in order to meet population needs. Smaller providers such as ours cannot wait for reforms to take place before decisions on funding allocations are made: we need immediate clarity on our funding position or our services will be at risk, impacting on the wider health and care system and on people’s care and lives.