

Please reply:

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A RESPONSE TO FUNDING CHANGES FOR CARE AND TREATMENT REVIEWS FROM EXPERTS BY EXPERIENCE GROUP, NHSE SOUTH

Thursday 17th May 2018

Ref: JC/PAR

The Rt Hon. Jeremy Hunt MP
Secretary of State for Health and Social Care
Department of Health
Richmond House
79 Whitehall
SW1A 2NS

Dear Secretary of State,

Re: Possible changes to funding and support for Care and Treatment Reviews, Transforming Care

In a recent meeting between our group of Experts by Experience with members of NHS England, we learnt that the learning disability Transforming Care programme is due to end in March 2019. As a result, there is uncertainty over what support will remain in place for Care and Treatment Reviews (CTRs) / Care Education and Treatment Reviews (CETRs).

Whilst we are pleased to hear that C(E)TRs will continue, we have grave concerns - about how changes in funding and support will affect patients and potential patients through any loss of regional roles, support from the Commissioning Support Unit, who organise and book the C(E)TRs and the support for Experts by Experience. Our concerns are grouped under headings "Impact on people", "Impact on systems and costs" and "Impact on impartiality" in appendix a).

Currently, it is possible to guarantee that C(E)TRs are carried out by an independent panel of people which importantly includes an Expert by Experience, who is a person with a learning disability or autism or a family carer with lived experience of services.

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Together with the rest of the panel they ask key questions and make recommendations that improve the quality of care received in hospital, encourage progress towards appropriate discharge to sustainable supported provision and often lead to improvements in safety, care and treatment.

Our experience leads us to believe there are serious risks in dismantling the present system and we want to help ensure full consideration is given to these while planning changes. Dangers include:

- People being held in hospitals for longer than needed because some commissioners lack a clinical background and can't make an effective challenge to the responsible clinician without support from the C(E)TR panel
- Loss of the important voice of people with learning disabilities and families in the C(E)TR process- which has been shown to have a positive impact
- Changes to regional structures that would leave a lack of oversight, focus and quality assurance

We believe that any decision to reduce support for this important work goes against the principles of the Transforming Care agenda, which is yet to fully achieve its ambition – making sure people receive the best support, in the best place possible and having opportunities to live the life they deserve. We are also concerned that this decision might be made without hearing from and involving those who would be affected by the change.

We believe that compared to the human and financial cost of people being inappropriately placed in hospitals or discharged without suitable personalised support, the cost of sustaining the present system of C(E)TRs is slight.

We ask for clarity around the changes and would welcome a meeting with you to further discuss our hopes and concerns. We look forward to your response

Yours faithfully,

Jill Corbyn

Jill Corbyn, Learning Disability Development Lead, NDTi

On Behalf of the Experts by Experience group, NHSE South

Cc. Simon Stevens, Chief Executive, NHS England
Ray James, National Learning Disability Director, NHS England

Full list of concerns noted on 23rd April 2018 by the Experts by Experience Group, NHSE South

Supported by Jill Corbyn, Learning Disability Development Lead, NDTi

Impact on people

- Without the stewardship from NHS England, a lack of buy-in from CCGs and local authorities may mean that people are not supported to move back to their communities. Some CCGs are not currently attending C(E)TRs and are disincentivised to do so when specialised commissioning are paying for placements in Assessment and Treatment Units. NHSE interrogates any lack of CCG active engagement reported by the panel.
- C(E)TRs could become Multi-Disciplinary Teams. We have seen this happen, where Experts by Experience are not involved and meetings are re-branded, the patient loses a significant opportunity for expert input from beyond the status quo and there is little expectation of a change in their circumstances. Experts by Experience bring a whole life perspective to the review.
- More people will die in hospital, because they are in hospital for longer.
- Families, who have told us they value having family members as Experts by Experience on the panel, will not have this support and identification if C(E)TRs either don't go ahead or the panel membership changes.
- Safeguarding issues are not identified – this is a particular concern for people who don't have family, or whose family are not able to advocate for them, perhaps because of the long distances people are placed away from home.
- Community C(E)TRs –which greatly reduce the need for hospitalisation - are not done, resulting in more admissions

Impact on systems and cost

- A change to the regional structure would leave a lack of oversight and focus
- It risks duplication of administration by CCGs regionally and nationally
- Loss of intelligence gathering, regional oversight and quality assurance
- More postcode lottery, because of the reduction in regional oversight and coordination
- A lack of accountability
- A reduction in value for money as quality issues are not picked up and people have poorer outcomes
- Loss of economies of scale – organisation, training and recruitment
- We are also concerned that CCGs might struggle to finance and prioritise C(E)TRs, due to competing demands

Impact on impartiality

- CCGs may use Experts by Experience that are known to them, risking the independence, transparency and rigorous challenge – the current system avoids this.
- It might be a challenge for individual CCGs to identify and support Experts by experience.
- Without national and regional support, it is more difficult for people with learning disabilities and autism to be involved in the project.
- It is important that there is regional oversight to challenge poor practice, lack of engagement and to ensure good outcomes for people.

The group feels strongly that the people affected by any decision should be involved in the decision, and it is made in line with the principles and values of the project. We also hope that:

- C(E)TRs continue to be regionally organised, independent of CCGs
- There is a place to raise challenge and concern at a regional level
- CCGs will continue to be held to account – with national and regional and independent oversight, data collection and analysis
- Experts by Experience will continue to be supported – independent recruitment, training and support as well as opportunities to come together and share their experience are vital
- Experts by Experience with learning disabilities and autism will stay involved, as this often allows individuals the support they need to have their say and participate in their own C(E)TR
- Experts by Experience continue to be valued and recognised as part of this process
- C(E)TR data recording is shared with the CQC
- C(E)TRs are added to contracts as a requirement
- There is a record of unmet needs
- There is a cost analysis of what is currently being achieved, and this is considered against a projection of what it would take individual CCGs to set up a new system and deliver change for people who are being held in ATUs
- If a decision is made to change the delivery of C(E)TRs, the budget is ringfenced
- Consideration is given to how to sustain involvement of Clinical Reviewers and Experts by Experience in the ongoing work

Key Facts About CTRs:

- Currently, 80% of preadmission C(E)TRs result in the decision not to admit someone to an Assessment and Treatment Unit.
- C(E)TRs are arranged by the Commissioning Support Unit, who bring together a panel including the Chair (usually the commissioner), an independent Clinical Reviewer, and an independent Expert by Experience. There is currently regional oversight and quality assurance led by NHSE regional team to ensure quality and consistency, and to challenge poor performance and delayed discharges.
- Experts by Experience have a learning disability or autism or are family carers for someone with a learning disability or autism. Experts by Experience in NHSE South region are recruited, trained and supported by NDTi.