



**National Voices**

People shaping health and social care

## **National Voices' submission to NHS England's 'Proposed revisions to Clinical Reference Groups: guide to 30 day engagement period'**

March 2016

National Voices is the coalition of health and social care charities in England. We work for a strong patient and citizen voice and services built around people. We stand up for voluntary organisations and their vital work for people's health and care.

We have more than 140 charity members and 20 professional and associate members. Our membership covers a diverse range of conditions and communities and connects with the experiences of millions of people.

National Voices is a patient organisation member of the NHS England Specialised Commissioning Patient and Public Voice Assurance Group.

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### **Section 2**

National Voices believes that the involvement of people with lived experience is vital to ensure that a full understanding of the conditions being discussed, how they affect people's lives, and the experience of using treatments is understood. There are wide-ranging benefits to the inclusion of the perspectives of people with lived experience of the conditions and services under discussion. They understand how the condition affects them and their families, what it feels like to use the services on offer. This can strengthen decision making and avoid a situation where services do not meet the real-life needs of those they are designed to help.

National Voices understands that the proposals to reduce the number of lay members on each CRG, when taken with the reduction to the number of clinicians on each CRG, represents an overall increase in the *proportion* of CRG members who are Patient and Public Voice (PPV) members. However, we believe that the plan to reduce the *total* number of PPV places will put this voice at risk.

The survey of PPV members carried out in 2014 highlighted concerns about the lack of integration of patient and carer representation in some CRGs. Reducing the number of these representatives risks making this integration more difficult without additional support to ensure that they can play a full role.

Having a smaller number of people with lived experience (or carers) involved may mean that at some meetings there is in practice at most one PPV member, as fluctuating health or caring responsibilities – the very things that make their contribution so valuable – may mean they are sometimes unable to attend. A higher number of patient representatives would help to mitigate this risk as well as include a more diverse range of voices. Some conditions are quite complex so no patient will experience the same symptoms and treatment may reflect this.

On this point, little is said about how the PPV members will be selected, and we have heard discussion of using less specialist 'lay members' instead of drawing on those with the specific conditions represented, or their patient organisations which bring expertise and knowledge of the experiences of many patients. While National Voices recognises the benefits of lay membership, we believe that the specialist nature of the work that CRGs do, and of the different experience that patients have in accessing treatment compared to those using non-specialised services, means that this would represent a loss of knowledge and expertise that would make it yet harder for the non-clinical members to play an active role.

National Voices believes that the proposed reduction in the number of clinical members also poses a risk to the effectiveness of the CRGs. This will reduce the diversity of expertise available on the CRGs, particularly where there are a wide range of conditions to be overseen. We have also heard concerns from members that the proposal will lead to a regrettable loss of more localised knowledge on the CRGs. It is not yet clear how NHS England plans to ensure that this reduction does not weaken the capacity of the CRGs. It may be through the working groups and sub groups, but as plans for these have not been set out it is difficult to comment fully. We urge NHSE England to ensure that the final proposals are developed in discussion with the existing CRGs and affected patient groups before they are agreed.

We welcome proposals to provide more remuneration to chairs and to PPV members, and to provide more induction to both. However, we have some reservations regarding the detail of these proposals. We believe that all PPV members should be paid for their work on CRGs, and this support should not be left to patient organisations to provide, particularly given that many of the charities working with people who use specialised services will be (by nature) very small and are very often under-resourced: often these volunteers are already providing much help to the beneficiaries of their charity. It is an important principle that the NHS should recognise and demonstrate that they properly value the contributions of patients and the public who give their time, knowledge and expertise.

We are pleased that CRG members will be given an induction. We hope that for the CRG chairs and clinical members this will involve discussion about how to support and work effectively with PPV members. The proposal to provide additional administrative resources to the CRGs is also welcome. However, insufficient information has been provided about this in the engagement documents, which means it is difficult to provide informed feedback. Key questions including the level of

resource available, how this will be allocated to the CRGs and to the working groups, remain unanswered.

### **Sections 3-8**

As an umbrella body working across a wide range of patient groups, National Voices is not in a position to comment in detail on each of the NPOC grouping proposals. A number of our members have raised concerns with us however. These are set out below, and we would endorse each organisation's individual submission which will provide more detail. We hope that representations from patient groups and patients themselves are taken into consideration when developing the final policy.

Our members (Changing Faces and British Society of Rheumatology) have raised concerns about the mergers of the Trauma and the Burns CRGs, and of the Specialised Rheumatology and Specialised Dermatology CRGs. In both cases there is a strong belief that these conflate different needs and very different pathways, and which will lead to a reduction in expertise on the new CCGs. This is of great concern to our members and to the people they represent.

The mergers are particularly concerning in the context of the reduced size of each of the CRGs: in effect the representation for people with approximately 50 Rare or Specialist Rheumatological conditions and with Burns is reduced further still as a result. Whereas, for example, there were patients with experience of the conditions covered by the old CRGs, in the new model, there will be at most one. This is also a concern for the British Kidney Patient Association, as the merger of the renal CRGs means a reduction of PPV from 8 to only 2, despite feeding back on a total of six specifications. This will dramatically reduce the level of knowledge of patient experience of need on the CRGs. For the surgical cancers group, six are being combined into one. The proposed membership will mean it is not possible for all groups to be adequately represented. This is compounded by the reduction in clinical representation for each condition.

We are very disappointed that the relevant patient groups do not appear to have been consulted in developing these proposals, and we hope that the concerns that they set out in their submissions will be fully considered and acted upon. We would call on NHS England to arrange a meeting with patients and patient groups in those areas affected to enable this. This will help ensure a workable solution.

### **Other revisions to consider**

As discussed above, National Voices believes it is essential to retain and develop the constructive involvement of patient organisations in supporting the delivery of effective representation of people's experiences of services.

We also believe that there has been a continuing and unacceptable lack of transparency in the development of the whole of specialised commissioning and would like to see plans for ensuring that the work of the CRGs and their sub groups is clear and transparent, that people external to NHS England can access details of how they are governed, when they meet and what they discuss, and that their decisions are made public.

## **The policy development process**

There were initially some good pieces of engagement carried out as part of this process, in particular the survey and event held at the end of 2014, which are reflected in the proposals to, for example, provide induction to CRG members, and to provide administrative support.

However, it appears that proposals to merge some of the CRGs (for example Trauma and Burns) have not been developed in partnership or discussion either with the clinicians involved or affected, or with patients and their organisations. These groups hold both a huge amount of expertise about areas that are by definition specialist; they also have experience of the CRGs themselves and how these work.

We believe that better coproduction of the proposals, which NHS England had previously committed to, would have led to stronger, (and less contentious) proposals being made, and would have been a more efficient process in the long run. We would urge that any further amendments to CRGs and to Specialised Commissioning structures are developed following engagement with clinicians, patients and the voluntary sector, rather than prior to it. We believe that the current timeline, to report on the final policy in April, is too ambitious and undermines the policy development.

## **The engagement process**

The timescales allowed for this engagement are relatively short, which is a particular concern because of the, often smaller capacity of many of the organisations who work with the patients affected in these rare and specialised areas. This is particularly significant given the number of other specialised commissioning-related consultations on the generic and specific policies that are being held concurrently.

In addition, we believe that the information provided in the engagement process was insufficient to help people understand either the background to the proposals (including the earlier engagement work, and how this has been used) or the impact – what are the benefits to patients with burns, or needing renal services for example? How will the working groups and sub groups function and what will their purpose and membership be? This means that it is difficult to give an informed view on much of what has been presented; it also suggests that this detail will be developed (quickly) by NHS England without engagement with or feedback from those affected, including existing patient and clinician members.

Bringing the proposals to the PPVAG prior to launching the engagement is one way of avoiding these issues. We recognise that in part this did not happen because the team was keen to ensure that there were no unnecessary delays. However, getting the engagement right is fundamental to developing good policy and practice. Ensuring that those affected have the best opportunity possible to share their expertise will strengthen rather than hamper the process.

We also understand that some of these issues remain to be agreed and worked through – doing this after the engagement process with a very short timescale again

weakens the engagement and risks imposing processes onto CRGs that do not benefit those most immediately affected.

We welcome the use of Webinars to engage with those affected, to talk through proposals and to gather feedback. However, we were disappointed that the engagement process was launched before these were put online, making it difficult for people to find out about and take part in these. We understand that there were difficulties for people to actually get access to the webinars, despite phoning in and this caused great frustration to existing PPV members.

We are also concerned that it appears that information about, for example, the proposal to merge specific CRGs was only going to be discussed there, and was not included in the engagement papers, making it more difficult for people unable to participate in these to comment. We hope that these issues will be addressed in future engagement and consultations.