Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

SPECIALISED HEALTHCARE ALLIANCE RESPONSE TO NHS ENGLAND'S CONSULTATION ON PROPOSED REVISIONS TO CLINICAL REFERENCE GROUPS (CRGs) IN SPECIALISED COMMISSIONING

The Specialised Healthcare Alliance (SHCA) is a coalition of 118 patient organisations, supported by 15 corporate members, which campaigns on behalf of people with rare and complex conditions requiring specialised care. All members and financial contributions are listed on the Alliance's website www.shca.info.

The SHCA was established in 2003 and focuses exclusively on the overarching policies and structures of specialised care, without involvement in individual therapy areas.

General comments

The Alliance has been a longstanding supporter of the CRG model and continues to see these groups as vital in providing service-specific advice to NHS England's specialised commissioners.

If these reforms set CRGs on a stronger footing for the future, professionalising their work and clarifying their role, the Alliance will be a strong advocate for the new model. However, a large number of SHCA members have serious concerns about how their service areas will be affected by these changes.

The Alliance would therefore see it as vital that NHS England provides clear details of the future operating model for CRGs, and particularly how subgroups will ensure that service-specific clinical and patient expertise is retained.

Question: Do you have any comments on the proposed revisions set out in section 2 of the engagement guide around the resourcing of CRGs, the remuneration of members or the number of members in each CRG?

Resourcing of CRGs

The Alliance strongly welcomes NHS England's proposal to provide administrative resource to CRGs.

Since their establishment, CRGs have provided highly valuable clinical and patient insight to the planning and management of specialised services.

However, despite the excellent work undertaken by CRGs, their lack of financial or administrative resource has meant that output quality has been highly variable, based on the dedication and goodwill of members.

In order to assess whether the additional resource being pledged by NHS England will be sufficient NHS England needs to set out the level of financial or secretarial support being pledged to CRGs. In particular, it would be helpful if NHS England clarified how resource will be broken down by programme of care, CRG and CRG sub-group, including funding for patient representation.

Furthermore, if there is notable variation in resource granted between therapy areas, NHS England should explain to relevant stakeholders how these calculations have been made.

Remuneration of CRG Chairs

The Alliance recognises that CRG Chairs play an important and time-intensive role and that it is reasonable for NHS England to remunerate Chairs for their time. However, NHS England will also need to provide clear, public assurances on the independence of Chairs.

Indeed, this requirement is given greater urgency in the context of the new policy development process, which gives greater powers to CRG Chairs to take chair's action in lieu of consultation with the CRG as a whole.

Do you have any comments on the proposed revisions set out in sections 3 – 8 of the engagement guide relating to the numbers and remit of the CRGs within each National Programme of Care?

Remit of CRGs

First and foremost, the Alliance strongly welcomes the retention of CRGs as service-specific groups with an explicit focus on national specialised commissioning. While it will be important to consider how specialised and non-specialised commissioned services interact, the role of CRGs in providing advice on gaining the highest quality specialised care is vital.

CRGs play an important role in the commissioning system for specialised services, which is based on the premise that the sophisticated expertise required to commission complex specialised care should be brought together at national level. As the vehicles for this expertise, the retention of CRGs focusing on specialised commissioning is crucial.

Number of CRGs and role of sub-groups

The reduction in the number of CRGs has caused serious concerns for many Alliance members.

While there are clear arguments in favour of merging some CRGs, particularly to ensure that the new resource being given to CRGs is used effectively, there are many legitimate concerns from individual patient groups on the impact of the proposed changes.

In particular, members have flagged some concern that clinically inappropriate mergers are being proposed, and that broader CRGs might lose sight of the requirements of rarer and more complex services. This would of course be an unacceptable outcome of any CRG reforms.

NHS England must therefore engage with each of the services which have raised

concerns on this score and set out clear mitigations. As set out below, the Alliance is concerned that the post-consultation timelines will not allow for meaningful engagement of this kind to take place.

Furthermore, and most importantly, NHS England can mitigate stakeholder concern and can substantially improve the operation of the new CRGs by encouraging and facilitating the use of CRG subgroups, as mentioned in the consultation document. At present, the Alliance is concerned that insufficient clarity has been provided by NHS England on the standardised function of subgroups. NHS England must demonstrate that subgroups will not simply replicate the problems of variation currently seen at CRG level. With this in mind, NHS England should, in response to this consultation, set out clearly its expectations for CRG subgroups, with particular reference to:

- When subgroups will be convened;
- How frequently they will meet;
- Whether subgroups will have patient and public members; if so, whether these will be in equal proportion to CRGs;
- Whether subgroups will be granted administrative resource and at what level;
- How registered stakeholders can engage with the work of CRG subgroups?

The Alliance considers that the development of well-run, properly resourced CRG subgroups is vital to the success of the new CRG model. Without these, it is difficult for the Alliance to support the new approach being proposed.

Consultation timeframe

The Alliance is concerned about the timeline for this consultation. With the consultation closing on Thursday 10th March and the new arrangements being decided in April 2016, there will clearly be insufficient time to respond meaningfully to consultation feedback.

Alongside concerns that consultation feedback will not be seriously considered and acted upon, there are also fears that the subsequent recruitment to CRGs will risk being rushed. In order to deliver the benefits of the CRG model in future, time should be taken to appoint the right members for the job.

Are there any other changes or revisions that NHS England should consider to the role, function or membership of CRGs?

Maintaining patient and public voices in CRGs

While the number of patient and public voice members on CRGs has been reduced, the Alliance recognises that this remains proportional given the accompanying reduction in clinical membership. However, for many services this will mean that patients and patient organisations representing important subspecialties within a CRG's scope are not part of the group's membership.

This adds particular urgency to the need for NHS England to clarify its plans in respect of CRG subgroups. Further, there should be clear and regular mechanisms for patients, the

public and others to feed in to CRG deliberations as a matter of course, whether in membership or not. This would be greatly aided by improved transparency on the part of CRGs, including publication of meeting papers for comment in advance.

Registered stakeholders

The Alliance also notes NHS England's intention to refresh CRG registered stakeholder lists. To date, stakeholder lists have been managed on an *ad hoc* basis, with little clarity on what stakeholders can expect from their registration.

Therefore, the Alliance sees it as vital that the following points are articulated to potential stakeholders:

- How to sign up to stakeholder lists;
- How often updates can be expected from CRGs;
- What the nature and content of circulated materials will likely be;
- What opportunities and avenues exist for engagement with CRGs.

By providing greater clarity on stakeholder lists, NHS England will again be able to reassure patients and members of the public that their voice has not been stifled as part of these reforms. These matters should be an integral part of the operating model for CRGs.

Managing CRG membership

A number of Alliance members have raised the importance of maintaining CRG member goodwill and morale, given the commitment made by those in membership. These changes may impact a number of individual members directly and, when reforms are implemented, future members are likely to expect to be assured that their advice is heeded by NHS England.

An important first step in this process is to provide clarity on what will happen to projects already initiated by current CRGs when the new arrangements come into force. Future consideration will also need to be given to how discussion and joint working between CRGs can be facilitated in future, given that some conditions will continue to fall into multiple groups.

SHCA
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