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?

The Cystic Fibrosis Trust has grave concerns as to the sufficient and appropriate representation of the cystic fibrosis community in the proposed CRG model; the allocation of budgets for administrative and logistical support is inconsequential in the light of those concerns. The diminished representation the consultation document proposes, as a result of reduced CRG membership at this tier of NHS England's policy development process in combination with the effective dissolution of the CF CRG, means that whatever extra investment is made in supporting CRGs financially would be rendered irrelevant by the dismantling of a voluntary source of expertise of the highest calibre.

The simplification and clarification of the CRG structure, as proposed in the consultation document, would, in normal course, be welcomed by the Cystic Fibrosis Trust but the "absorption" of the Cystic Fibrosis CRG into the Specialised Respiratory CRG (in reality by disbanding the former) is not only inappropriate (as will be discussed further elsewhere in this response) but means that cystic fibrosis representation would be reduced from the current 14 'senate' clinical members and four PPV members (who include both carers and patients), potentially to nil. In the (by no means guaranteed) scenario that cystic fibrosis is represented by one clinical member on the proposed CRG, it is certain that cystic fibrosis would suffer critical underrepresentation; the consequences of which are discussed in our response to question 2.

NHS England's Five Year Forward View (5YFV) sets out a vision of a positively transformed NHS, set to meet the demands of the coming years, and describes the attributes needed to get there.

5YFV commitments to back diverse solutions (for example, the innovative year-of-care, severity-banded tariff used to reimburse specialist CF centres), to support a modern workforce (the cultivation of an evidence based multi-disciplinary approach to CF care), to exploit the information revolution (the UK CF Registry), and to empower and engage patients (working with PPV representatives, the Cystic Fibrosis Trust and a cultural commitment within the CF clinical community to put the person at the heart of care) have all been encapsulated by the work of the CF CRG.

That the CF CRG has been well-organised, functional and highly effective – an exemplary service in delivering proactive and impactful horizon-scanning, commissioning policy development and prioritisation, Quality Dashboard development and monitoring, and Service Specification development that has benefitted from broad clinical and PPV involvement – would appear to have been disregarded by these proposals.

It is implausible to suggest that this output could be maintained under the suggested revised arrangements. The suggestion that *ad hoc* working groups or even a standing CF working group would suffice is insufficiently described in the consultation papers. Clarification was sought on this subject during the "CRG review - Internal Medicine" webinar on 29/02/2016. However, NHS England representatives were not able to describe to how such working groups would be appointed or function in practice. The impression created in the webinar was that the proposals were being made up on the hoof, whereas the necessary framework forms an essential component of the whole planning process but is absent from the proposals being consulted on. It appears that such working groups would have no status to add meaningfully to the prioritisation of the proposed CRGs work programme or to protect the interests of patients.

If NHS England believe that working groups really are the answer, then it is unclear as to how the new CRGs are anything more than an added layer of bureaucracy in delivering service improvements and better outcomes for the cystic fibrosis community; and the new structures would not protect against underrepresentation – perhaps especially for PPV members representing cystic fibrosis, where NHS Constitution and 5YFV commitments to actively involve the patients, encourage feedback, and utilise their expertise-through-experience to better coordinate and tailor services to their needs and preferences appear to have been ignored or even actively diminished.

The proposed merger undermines the needs and interests of people with cystic fibrosis by marginalising their voice and those of the professional clinical teams responsible for their care. The

Cystic Fibrosis Trust cannot stand back and allow this change to happen in the form proposed unopposed.

Members of the CF CRG have voluntarily given significant amounts of their time in aid of delivering the achievements of the group to date. The role of the chair is particularly time-consuming and it is natural that NHS England is considering remuneration for this important role. However, the Cystic Fibrosis Trust seeks clarification as to how this arrangement would be harmonised with the necessity for the chair to lead impartial, independent guidance on delivering the highest-quality cystic fibrosis services, directed at NHS England.

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?

The subordination of the CF CRG into the Specialised Respiratory CRG is fundamentally inappropriate for a variety of both practical and logical reasons.

The key to these reasons is the nature of the condition: cystic fibrosis is a multi-system, genetic disorder that affects individuals from birth.

41% of people with the condition are less than 16 years old and 44% of patients receive their care in a specialised paediatric setting.

Non-respiratory effects and complications of the disease are numerous and are significant drivers of reduced quality of life in people with the condition: liver disease, cystic fibrosis-related diabetes, infertility, osteoporosis and arthropathy, pancreatic insufficiency, and a multitude of gastro-intestinal complications. Psychological complications are also a common feature of cystic fibrosis, necessitating the presence of specialist CF psychologists within cystic fibrosis multi-disciplinary teams.

Multi-disciplinary cystic fibrosis care has been shown to increase survival in cystic fibrosis and specialist cystic fibrosis teams are made up of physicians, nurses, physiotherapists, psychologists, pharmacists and dietitians with a committed multi-disciplinary approach.

Discrete adult and paediatric specialist teams work in close collaboration to develop a holistic approach to disease management, and share clinical and research interests. Indeed, the CF CRG pioneered a coordinated approach to CF from birth through to adulthood, tackling the challenge of transition head-on. The exceptionally low numbers of patients lost to follow-up is a testament to the success of this approach to a key priority challenge (transition to adult services) to NHS England.

However, the well-used paediatric mantra that children are “not just small adults” must be recognised by NHS England in the expert advice that it seeks on CF care. Indeed, the nature of cystic fibrosis and its management is ultimately different in children and adults. The proposals for an ‘expanded’ Specialised Respiratory CRG will make it necessary that (at best) both sets of expertise are channelled through one representative. It is highly unlikely that the General Medical Council would look favourably on an adult clinician representing the interests and needs of a paediatric population at the national level. This is unsafe. It would be inappropriate for a paediatric clinician to represent an adult population whose needs are distinct from those of paediatric patients.

The Specialised Respiratory CRG’s current work programme has shared few characteristics with the whole-life, chronic multidisciplinary management of cystic fibrosis, and the logistics of coordinating care across a large network of specialist clinics.

The cystic fibrosis population continues to grow year-on-year, as a consequence of stable incidence and improved survivorship, driving service delivery pressures and budgetary pressure on the Specialised Services envelope.

The proposed dissolution of the CF CRG will critically undermine a central focal point for representation of both service delivery and service developments in cystic fibrosis at a time when NHS England will need it most in order to anticipate change, innovate, and plan to meet the enormous and pressing challenges the service faces.

To this end, the *de facto* disbanding of the CF CRG would inevitably limit the specialist information about cystic fibrosis immediately available to commissioners, and leave cystic fibrosis services unfairly vulnerable to prioritisation against services with very different needs. The Five Year Forward View commits NHS England to accelerating useful health innovation and driving efficiency and productive investment; cystic fibrosis is a disease area offering these opportunities but the CRG proposals for cystic fibrosis would undermine the likelihood that such opportunities might be realised.

Given this context, it seems improbable to us that representatives of specialised respiratory conditions covered by the current CRG would welcome proposals that an enlarged specialised respiratory CRG should include a complex multisystem disease which faces fundamental service delivery challenges, and requires discrete paediatric and family/carer representation, and which is also subject to a fast-moving pipeline of service developments and an expanding adult population for which NHS England has made no capacity provision. Further, there is no evidence in the proposals put forward by NHS England that this could lead to anything but the marginalisation and/or fragmented delivery of the non-respiratory aspects of cystic fibrosis.

We reject the consultation document's reassurance that 'working groups' could bridge this gap – primarily because of the lack of information about the establishment, status, accountability, and governance of such groups, or about their authority to identify and raise policy considerations; but also because it would not resolve the problem that (under the overall proposals) responsibility for policy initiation, development and prioritisation would be channelled through an inappropriate overarching group which will lack the necessary specialist knowledge of cystic fibrosis.

However they might be dressed up, the proposals indicate a clear intention to depart from NHS England's commitment to being guided by expert clinical and patient/carer advice and involvement in planning cystic fibrosis services (a commitment enshrined in *"Clinical Reference Groups for Specialised Services – A Guide for Stakeholders"* published in 2013 and which confirmed that the fundamental role of CRGs was to provide service-specific clinical advice to specialised commissioning). That commitment was made in order to ensure that the interests of patients were paramount in decisions about the design and commissioning of services. There is no evidence to suggest that the interests of patients would be preserved or adequately protected by the proposed arrangements, or have received any consideration at all by NHS England when formulating its proposals.

If, as was suggested by Clinical Director of Specialised Services (Mr James Palmer) during the "CRG review - Internal Medicine" webinar on 29/02/2016, that the purpose of the new CRGs would be the same as for the old ones, we cannot see how that suggestion correlates with the specific responsibilities of a CRG as set out at paragraph 18 of the 2013 *"Guide for Stakeholders"*, which would necessitate service-specific expert clinical and patient input for cystic fibrosis.

These responsibilities could not be discharged, with respect to cystic fibrosis, by the proposed CRG for Specialised Respiratory Services. The role and functioning of the proposed new CRGs has been neither thought through nor defined by NHS England and is little more than a blank canvass: both patients and clinicians deserve better.

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

The Cystic Fibrosis Trust believes, in the absence of any rationale, risk or benefit assessment, that the proposal effectively to disband the CF CRG is unworkable and would result in unnecessary detriment to the quality of cystic fibrosis services.

The Trust does not believe that paediatric care, multi-disciplinary care, multi-system care, the patient voice, the parent/partner-caregiver voice, or the expertise of the wider community of researchers and stakeholders within the cystic fibrosis community would be adequately represented or protected under the new arrangements.

The Trust believes that the retention of a discrete CF-specific CRG (containing both adult and paediatric clinicians in sufficient number to be representative, and both carer and patient cystic

fibrosis PPV representation) would be the only way to ensure the preservation of high-quality proactive, specialist cystic fibrosis advice to commissioners. Such a CRG could be organised in accordance with the generic proposals for the size and constitution of future CRGs.

However, in the absence of such a proposal, and given the lack of critical detail in relation to the practical operation of the proposed structure and its impact on cystic fibrosis services, the Cystic Fibrosis Trust unreservedly opposes the proposed restructure of cystic fibrosis representation within Clinical Reference Groups.