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Mr Mark Loughridge
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Dear Mr Loughridge

Re: Specialised Services Commission - Call for Evidence

We are pleased to submit this response to the Specialised Services Commission – Call for Evidence which covers the areas of specific interest highlighted by the Commission.

1. SAFETY, QUALITY AND MONEY

The definition of a highly specialised service in ophthalmology has been agreed and is one of the areas that work well.

For ophthalmology this includes:-

- Ocular oncology service (adults)
- Ophthalmic pathology service (adults and children)
- Osteo-odonto-keratoprosthesis service for corneal blindness (adults)
- Retinoblastoma
- Stickler's Disease

The general principle that diseases that are less common are provided in highly specialised centres on the whole works well. This allows centres to maintain and improve the standard of care by seeing sufficient cases. The focused national funding also promotes stability to the centres. However, the true definition of specialised ophthalmology services is still being debated.

There are specifications which have been written by the Clinical Reference Group with input from the Royal College of Ophthalmologists but there have been issues with interpretation, funding and implementation.

One reason for this is that as most ophthalmologists are trained as general consultants but with a subspecialty interest. This means that smaller eye departments now have the ability to deliver what would have been traditionally specialised work which used to be in the domain of larger

regional centres. Specialised Ophthalmology has for many years worked as a network. However, the new commissioning arrangements have not always supported these patient pathways. This has led in turn to issues with funding of services when local commissioners and NHS England cannot decide who should pay for the service. This has caused inequity of access for patients e.g. Corneal cross-linking and the provision of Serum Eye Drops where some clinical commissioning groups will fund whilst others will not as it is deemed specialised. This can lead to inequity of access such that some patients have their treatment delayed having their treatment or have to travel unnecessarily. Equally some patients are not able to access treatment at all.

Clearly the simple use of the incidence of eye conditions as a marker for what should be specialised does not work on its own. The CRG developed the concept of delivery networks in order for local areas to work together to determine how they wish specialised services should work locally. This means that smaller centres which may not be able to fulfil all of the criteria for specialised designation would work with other centres in order to comply.

The idea was that one centre would act as the central hub with many spokes. This would encourage closer working relationships and allow patients to be treated closer to home yet have similar high standards of care. The hub would also be the centre where the coding was done and this avoids the need for different commissioning pathways. In each centre the patient would be assigned a lead consultant responsible for their care, ensuring patients were not "lost" to follow-up.

The growth in funding for specialised services is likely to grow faster than that of general services as a per patient expenditure. This is because new treatments and technologies are likely to cost more e.g. new biologic drugs for inflammation. However, as specialised conditions are usually less common the overall expenditure may not grow as much as for non-specialised services.

Both clinicians and patients should be involved at all stages of planning for specialised services. It is clear that patients would be prepared to travel if they knew the service they would get is of a higher standard than what is available locally. This does mean that there must be flexibility of funding to "follow the patient". Some patients may choose to go to another centre where they have relatives to support them during their care for example.

The NICE HSTA is the current 'gold standard' as it comes with a statutory obligation for NHSE to fund technology which is judged to be cost-effective. Policies that are developed by NHSE may be cost-effective, but will not be funded unless there is money available (which there isn't at the moment). Therefore, currently the limited capacity of the NICE HSTA gives the few technologies that they do consider a huge advantage in the competition for limited funds. NICE examines each case in isolation whilst NHSE has to look at the totality of proposals and make prioritisation decisions. In a shrinking health economy, this two speed system is inequitable, and there is a clear risk that large amounts of resource are used on funding NICE approved technologies when other services and interventions which have not had the opportunity to go through NICE would actually be more cost-effective. A single process which makes equitable cost-effectiveness decisions is required. This applies to all levels of commissioning.

There should be use of regular audits to provide clinical outcome data as well as the development of PROMS and PREMS to evaluate the quality of services from the patients'

perspective. The CQC should be inspect centres offering specialised services on a regular basis to ensure quality care is being delivered.

2. PROVISION AND INTEGRATION

The providers of the service play a key role in delivering specialised services. They therefore need to be involved in the planning of specialised services. Care pathways need to be developed with clear protocols to follow.

Providers need to ensure the quality of their care but where necessary work with each other, playing their part in each of the steps of the patient pathway. However one needs to avoid creating a competitive environment between the providers and encourage an integrated approach.

It is clear that the providers need to be able to code for the services properly, distinguishing which part of the care provided is specialised and which is not. Providers also need to be honest and clear about which services they cannot provide and which network they belong to in order to ensure patients get the care they need.

The new models of care programme fits well with the view of the profession that clear patient pathways within networks of care will provide the best quality care for patients and the most efficient and effective use of resources by the NHS. Ophthalmology is one of the surgical specialities included in the Getting it Right First Time programme, led by Professor Tim Briggs. This programme will enable data to be collected for both specialised and non-specialised services to be collected and informed decisions made as to how services can be improved.

One of the biggest challenges faced by providers is coding. At present the diagnostic codes and the procedure codes cannot always distinguish specialised from non specialised services. This can then lead to inadequate funding and a disincentive for centres to provide the service locally. Work needs to be done with HSCIC and Monitor to ensure that the diagnostic and procedure codes work well.

Needless to state but it is also important that the tariff for providing specialised care reflect the true costs. At present in ophthalmology, the increased cost of corneal transplant material means that each procedure incurs a loss (cost of £1600 vs tariff of under £800).

3. ACCOUNTABILTY AND ENGAGEMENT

There should be regular inspection of service providers. The CQC will no doubt have a role and they should work with Royal Colleges and NICE to set the parameters of inspections. There should also be a system of shared learning to promote standards of care.

Within networks and between networks there should be the opportunity to learn from each other.

COMMISSIONING THROUGH EVALUATION (CTE) AND THE ROLE OF RESEARCH

The interaction between commissioning and research is crucial to ensure that where the UK has a strong research interest and ability this can be maximised so that 1) patients receive effective,

timely treatment and 2) the UK can advance its knowledge and experience of medical technology and research in specific areas (e.g. the ARGUS II retinal implant, which is being considered as part of the CtE process, has no timeframe and, as a result of the lack of a commissioning decision, the centres in England can no longer advance their experience in this technology and have lost their position as a leader in this field). The current commissioning strategy, which does not take this into account means patients are being provided with a poor service due to the inability to provide timely high quality commissioning.

GENERAL RECOMMENDATIONS

Common coding processes are developed in all areas- making it simple to distinguish specialised form non-specialised care for audit and charging purposes.

Patient pathways and Processes are defined, transparent, consistent and agreed in advance – with a recognised methodology across the board, with an awareness that all technologies may not have had the opportunity to be evaluated through NICE processes and this should not be disadvantageous.

Commissioning groups should work more closely with researchers in the UK and Internationally. Evidence and advice are taken from a broad group of parties – and not confined to enthusiastic, vocal groups. This should be integrated.

Early and continued communication is established between NHSE and the clinical and patient groups that have significant knowledge and input into the running of services.

Better liaison is developed between highly specialised commissioning, specialised commissioning and local commissioning. As patient care can involve all these services, there must be a process that identifies where they are and the care received is integrated and seamless.

In view of the nature of evidence for rare diseases, NHS England should for each disease -

- define a robust search methodology
- define in advance what the required evidence should be admissible
- horizon scan and consider experience and evidence from expert groups, but not be dependent on NICE processes to which access is not equitable and, when underway, can lead to long unnecessary delays

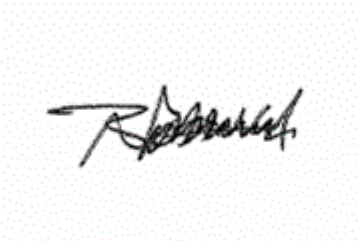
Decisions need to be clearly documented against these pre-determined specifications and processes.

Tighter control via managed access plans with clearly defined entry and exit criteria with mandatory data collection and analysis deserve consideration where relevant.

When services are not commissioned – despite being in active use in specialised units – plans must be clearly iterated for patients who are currently being provided with affected treatments. Funds and funding flows are clearly identified and earmarked.

The Royal College of Ophthalmologists and the Clinical Reference Group for specialised services in ophthalmology stand ready to work with the commission and NHS England going forward.

Yours sincerely



Mr Bernard Chang FRCOphth
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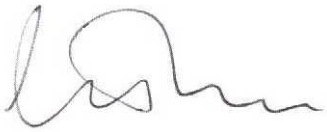

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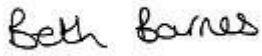

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Specialised Ophthalmology CRG Chair