

Response to the consultation on proposed changes to clinical reference groups

Background

Clinical Reference Groups (CRGs) are made up of experts (for example clinicians, commissioners and patients) and advise on service specifications and commissioning policies for their respective disease area. For more information on CRGs: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/>. There is currently a Brain and CNS Tumours CRG. NHS England has proposed changes to the structure and organisation of CRGs for specialised services which will see the merger of the Brain and CNS Tumours CRG with 8 other cancer site specific CRGs e.g. Sarcoma. The Brain Tumour Charity outlined our concerns in response to an NHS England consultation.

In summary

We are wholly against the merger of the current site specific cancer CRG's into one surgical CRG for the following reasons:

- We represent a highly complex and specialised disease area (Brain Tumours).
- We are a cancer of unmet need (10 year survival rate of less than 15%).
- We are always disadvantaged by a 'whole cancer' approach.
- The new model will mean we may be left with no specialist representation in this new cancer surgery CRG.
- Inevitably our voice will be greatly reduced or removed altogether.
- The reduction in patient representatives is contrary to all NHS rhetoric about the needs of patients being foremost and will only reinforce the view of our community that the NHS does not give brain tumours the attention they deserve.

Full response

One: Do you [The Brain Tumour Charity] 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?

Whilst we have no comment on the remuneration plans for CRG members, we do have significant concerns about the proposed numbers of participants. We are wholly against the merger of the current site specific cancer CRG's into one surgical CRG.

Our disease cohort (brain tumours) is a highly specialised and complex cohort. We represent a rare cancer group which already suffers a lag behind the big four cancer types (Breast, Prostate, Lung and Bowel) on all fronts; awareness, diagnosis, treatment and survival. The current Cancer Strategy ([ACHIEVING WORLD-CLASS CANCER OUTCOMES A STRATEGY FOR ENGLAND 2015-2020](#)) whilst containing many goals which we are keen to see reached, is necessarily a 'whole cancer' approach which leaves cancers of unmet need like ours us at risk of being left behind with this lag being masked by progress in other cancer types. To

be explicit in survival rates for example whilst huge progress has been made in the last 5 years in many cancer types e.g. breast and prostate, virtually no progress has been made in brain tumours:

40% of people diagnosed with a high grade brain tumour will die within one year and just 19% of people will survive for five years or more.¹

Brain tumours are one of four cancers with a ten-year survival rate of less than 15%.²

Whilst survival has doubled across all cancers, changes in survival rates for adults with a brain tumour have improved little compared with other cancers in over 40 years. Since 1971 there has been an overall increase in survival of less than 10% for people with a high grade brain tumour, one of the poorest improvements across all cancers.³

In the current Cancer Strategy states 'Cancer survival in England has improved significantly over the last 15 years. More than half of people receiving a cancer diagnosis will now live ten years or more.' (Page 4 **ACHIEVING WORLD-CLASS CANCER OUTCOMES A STRATEGY FOR ENGLAND 2015-2020**) When survival data is approached as 'whole cancer' data rather than disease specific data this inequality is masked by overall cancer survival rates going up.

Additionally:

- 53% of high grade brain tumours were diagnosed as an emergency in 2013 - more than any other cancer and survival for patients diagnosed with a high grade brain tumour through emergency presentation is significantly worse than for patients presenting through all other routes. Only 28% of people diagnosed through this route are still alive one year following diagnosis, compared to 38% diagnosed through an urgent '2 week wait' GP referral.⁴
- Brain tumours reduce life expectancy by, on average, 20 years - the highest of any cancer.⁵
- Brain tumour patients and their carers repeatedly report some of the worst experiences amongst all cancer patients. (Quality Health. The English National Cancer Patient Experience Survey [Internet].⁶
- 40% of adults with a brain tumour do not feel that the healthcare professionals they talk to understand brain tumours.⁷
- 91% of adults said that their brain tumour affects their emotional and mental health.⁸
- 89% of people with a brain tumour experience ongoing symptoms including personality changes, memory problems and cognitive problems.⁹
- There are over 130 different types of brain and CNS tumours - it is not one disease.¹⁰

In this context it is vital that rare cancers like ours have a highly specialised CRG. The current site specific CRG includes 15 clinical specialists (including the Chair) and 4 patient representatives. We fear that in a 'Cancer Surgery CRG' our voice will be completely removed. The current proposal is effectively a merger of 6 CRG's - thoracic surgery, upper gastro-intestinal surgery CRG, sarcoma CRG, central nervous system

¹ Cancer Research UK. Brain, other CNS and intracranial tumours survival statistics [Internet]. 2015 [cited 2015 May 19]. Available from: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain/survival>

² Cancer Research UK. Cancer Survival [Internet]. 2014. Available from: http://publications.cancerresearchuk.org/downloads/Product/CS_REPORT_SURVIVAL.pdf

³ (as above)

⁴ NCIN. Routes to Diagnosis 2006-2013 workbook [Internet]. 2015. Available from: <http://www.ncin.org.uk/view?rid=3053>

⁵ Burnet NG, Jeffries SJ, Benson RJ, Hunt DP, Treasure FP. Years of life lost (YLL) from cancer is an important measure of population burden--and should be considered when allocating research funds. Br J Cancer. 2005 Jan 31;92(2):241-5

⁶ NHS England; 2014. Available from: [https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey-national-reports](https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports)

⁷ The Brain Tumour Charity. Losing Myself: The reality of life with a Brain Tumour [Internet]. 2015. Available from: <https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/>

⁸ (as above)

⁹ (as above)

¹⁰ Cancer Research UK. Brain, other CNS and intracranial tumours Key Stats [Internet]. 2014. Available from: <http://publications.cancerresearchuk.org/publicationformat/formatfactsheet/keyfactsbrain.html>

tumours CRG, specialised urology CRG, and complex head and neck surgery CRG. Which will in its entirety will have 4 places for specialist clinician representatives and 2 patient representatives. It is inevitable that in the proposed Cancer Surgery CRG at least 2 of the 6 Cancer groups will not be represented at all. The severe reduction of patient representatives in this new group is contrary to NHS rhetoric that it is vital the system is patient centred and reflects the needs of the public it serves.

Whilst we understand the need to reduce bureaucracy and inefficiencies our understanding is that this proposal will not alter the bureaucratic processes that CRG's need to follow to ensure that specific commissioning policies are brought about, these highly complex processes are due to the inner mechanics of NHS England and not due to the numbers or membership of the current CRG's this proposal does not address these. In reality, if these changes are enacted, rare disease areas like ours will to all intents and purposes end up being unrepresented in this new landscape particularly as we will be competing for places with representatives of more prevalent cancers such as Prostate Cancer who arguably have greater clout by virtue of their cohort numbers.

Two: 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?

We strongly oppose the merger of the Central Nervous System Tumours CRG (CNST CRG) into a Cancer Surgery CRG. The output of the CNST CRG in recent years has been vital. For example the CRG has adopted and/or revised a number of service specifications for Brain Cancer and Central Nervous System Tumours for example Complex Neurofibromatosis Type 1 and Neurofibromatosis, utilising the specialist clinical expertise of the Group's membership.

The clinical expertise represented in the membership of the CNST CRG includes oncologists, neurosurgeons and radiographers, providing a depth of knowledge about treatment areas across the care pathway for CNS Tumours. Additionally, there are a number of professional bodies involved in the Group, such as the Royal College of Radiologists.

By disbanding the site-specific CRGs this clinical expertise would be diluted within a CRG that would allow only limited (if any) representation for each tumour type.

Site-specific CRGs also provide the opportunity to patients and carers who are personally affected by a disease area to help shape commissioning policies and service specifications for cancer at a national level. The proposals to reduce the number of patient and public voice (PPV) representatives from 24 (4 for each of the site specific CRG's) down to 2 across all 6 areas will inevitably silence patients and prevent these 'experts by experience' from contributing to the commissioning of specialist cancer services in England.

This is particularly troublesome for the reasons already outlined in question 5 above. In addition our own research as reported in '[Finding Myself In your Hands – The reality of Brain Tumour Treatment and Care](#)' (hereafter 'Finding Myself in Your Hands') demonstrates that people affected by brain tumour do not think the NHS gives brain tumours the attention they deserve:

- Nearly 90% of people with brain tumours in this study have received, or are receiving, treatment and of these just over half (52%) of brain tumour patients do not feel that the NHS gives brain tumours the attention they deserve.

This move to reduce specialist representation in commissioning procedures will only exacerbate this perception within our community.

One of the up -coming work streams of the current CRG (should they remain unchanged) would be around access to neuro-rehabilitation which we know despite forming a key recommendation of the NICE Improving Outcomes Guidance (Page 112 [National Institute for Health and Clinical Excellence – Guidance on Cancer Services, Improving Outcomes for People with Brain and CNS Tumours: The Manual](#)) is not routinely offered to patients with a brain tumour despite this condition having a massive impact on cognition, personality, mobility and the senses¹¹:

- 1 in 4 experience cognitive problems.
- 1 in 3 experience personality changes.
- 1 in 3 have poor mobility.
- 1 in 3 have visual problems.

In 'Finding Myself in Your Hands' 43% of respondents reported having no access to support services (defined here as Allied Health Care –Psychologists, speech and language therapists, physiotherapists etc.) This down scaling of site specific CRG's and consequent de-skilling will only hamper the NHS ability to deliver specific specialised commissioning policies which could improve patient experience.

We urge the NHS to re-think this re-structure which will inevitably leave those affected by this dreadful disease without a voice in this highly specialised and vital commissioning work stream.

On another point we are greatly concerned about the lack of consultation prior to this proposal, despite the assertion in the engagement guide that there have been various discussions with patient groups etc. in the last year as we were not aware of this proposed change until the consultation was published. We would be interested to know who has been consulted and when/how.

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

As outlined extensively above in questions 5 & 6 we do not seek any changes to the current role, numbers of CRG's or the membership of the same but we do urge NHS England to review its' bureaucratic processes which we believe are greatly impeding the work of the current CNST CRG and are not addressed in any way by these proposals.

Four: Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed revisions that we have described?

Our response to questions 5 & 6 above outline the health inequalities which if these changes are enacted will occur. Our disease group will be greatly disadvantaged by these changes and is consistently disadvantaged by a 'whole cancer' approach as proposed here.

Contact

If you would like us to provide any verbal evidence on any of the above or for further information on any of the specific suggestions please contact Rebecca Shortt, Policy & Advocacy Manager at rebecca.shortt@thebraintumourcharity.org

¹¹ The Brain Tumour Charity. Losing Myself: The reality of life with a Brain Tumour [Internet]. 2015. Available from: <https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/>