

National advisory panels for paediatric cancer in the UK as an example of rare cancer multidisciplinary team meetings

Rare Tumors
Volume 13: 1–2
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DOI: 10.1177/20363613211052503
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We recognise the proposed advantages of multidisciplinary team (MDT) working that Rosell et al.¹ describe in their evaluation paper. In the UK, multidisciplinary team (MDT) working is mandated in the National Health Service (NHS) Cancer Plan. Benefits of this model include improved evidence-based treatment decisions, coordination of care and education for MDT members, along with improved patient outcomes and clinical trial recruitment.^{2–5}

Childhood cancer is rare. There are approximately 1900 new cases per year in the UK, with childhood cancer cases comprising less than 1% of all new cancer cases.⁶ All children with suspected cancer in the UK are referred to one of 19 principle treatment centres (PTC) which together comprise a network of tertiary specialist cancer services for diagnosis, treatment and coordination of care for each patient. It is standard of care for every child with a new diagnosis to be discussed at a PTC MDT meeting at which recommendations are formulated for management. In addition to PTC MDT meetings, there has been a recent rise in a number of virtual national advisory panels (NAP) for children's cancer in the UK. These panels have developed alongside increasing centralisation of cancer services and enhanced complexities of patient management. Advice may be sought from these panels for individual patients with specific disease types including sarcoma (panel established in 2011), histiocytosis (2013), ependymoma (2015) leukaemia (2016), neuroblastoma (2017) and renal cancers (2017). As of January 2019, collectively there had been 920 referrals to the NAPs in the UK.

Rosell et al. acknowledge rare cancers and complex cases may benefit from referrals to such forums to gather further clinical expertise, particularly when the evidence base is lacking or treatment pathway is not clearly defined. In contrast to the Swedish model described in Rosell's evaluation, NAP referral is not mandated at either diagnosis or

relapse. Furthermore, NAPs are distinct from PTC MDT meetings, involving national experts for particular cancer types offering an advisory role only ensuring overall responsibility for the patient remains that of the referring team. While the primary role of the NAPs is not to ensure equitable access to treatment, there is a degree of overlap with the UK Experimental Cancer Medicine Network regional meetings (ECMC). These meetings are designed to discuss cases at time of relapse to ensure equitable access to clinical trials, irrespective of geography. In contrast to the NAPs, it is an expectation that all children with relapsed disease in the UK are referred for discussion at an ECMC meeting.

The foundation of each NAP is the personal investment of the chairs and panel members. Mirroring the implementation of the national MDTs in Sweden, their development occurred independently in an ad hoc basis and has not involved formal commissioning or processes. There is currently no allocated time in job plans to prepare cases or to attend the meetings. In terms of panel membership, the NAPs all have allocated chairs and multi-disciplinary input from radiology, surgery, oncology, radiotherapy and pathology. However, similar to that described in the Swedish model, there is currently minimal representation from allied health care professionals in UK NAPs. All of the NAP chairs are paediatric oncologists/haematologists who take on the coordination role in addition to chairing. These chair

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positions are relatively fixed rather than a rotational system as described by Rosell et al. It is key to define and ensure expertise of the panel and multi-disciplinary membership should be a focus for the future model of national MDTs in terms of ensuring relevant participation.

There are no formal guidelines or standards against which to benchmark the UK NAPs and no established system for review of practice. Furthermore, whilst the panels clearly fulfil an important role, their remit and impact on patients has not previously been studied. The patient perspective and psychosocial aspects of each case are not routinely requested or recorded when making recommendations; moreover the current NAP model does not currently have a system in place for follow-up or record of recommendation implementation. These important aspects of MDT working will be the subject of a funded evaluation of NAPs in the UK (<https://www.cclg.org.uk/our-research-projects/c140091b-39b1-4365-8387-74e5dabe01ee>).

Rosell et al. guidelines for establishing and running a national virtual MDT meeting highlight the importance of considering the principles of referral. Our project has recently modified the referral proformas for selected panels to request information regarding patient views and psychosocial aspects that can potentially influence NAP recommendations. The prospective data we collect will now also include whether patients have been informed of the referral and outcome. It is known that having a professional who knows the individual patient and can represent the patient view to inform recommendations is preferable at MDT meetings but is not always possible, particularly in the virtual setting.^{4,7} Patient focus groups are being utilised to further develop tools to improve patient involvement in these national forums. Principles for follow-up and adherence rate of recommendations need to be established and our evaluation plans to record whether recommendations are implemented or not, and in the case of non-adherence, the reasons contributing to this, including patient factors.

Rosell et al. recommends that assessing the performance of national MDTs is a priority and a system needs to be developed to review and improve their function. The childhood cancer NAPs in the UK have similar aims and objectives to the rare tumour MDTs described and our planned evaluation aims to address the potential issues and design a

best practice model against which NAPs and MDTs can be benchmarked and evaluated.

Author contributions

JB and SB designed the work and wrote the manuscript collaboratively.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Children's Cancer and Leukaemia Group (CCLG)

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