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RESEARCH ARTICLE

National advisory panels for childhood cancer in the United Kingdom: An evaluation of current practice and a best practice statement for the future

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Abstract

Background: National advisory panels (NAPs) have been established for the care of children and young people (CYP) with cancer in the United Kingdom since 2011, with an increase in panel number in recent years. Their practice has not previously been reviewed; therefore, we sought to evaluate the role, practice and impact of six selected NAPs offering expertise in ependymoma, histiocytosis, leukaemia, neuroblastoma, renal tumours and sarcoma.

Procedure: This service evaluation used mixed methodology, including review of NAP documentation, semi-structured interviews with the NAP chairs and an analysis of the cases referred for discussion.

Results: Total 1110 referrals were analysed. Results demonstrated the significant scope and amount of work undertaken by the NAPs, largely testament to the commitment of the panel members. Specific roles fulfilled have been highlighted, and NAP recommendations have been shown to influence clinical decision-making and be implemented in the majority of cases. Despite widespread good practice, areas to address have been identified; these include clarity regarding NAP membership, consistency in recommendations, the consideration of holistic information to promote personalised management and the exploration of wider multidisciplinary team roles.

Abbreviations: ALL, acute lymphoblastic leukaemia; EMAG, Ependymoma Multidisciplinary Advisory Group; ES, Ewing's sarcoma; HSCT, haematopoietic stem cell transplant; MDT, multidisciplinary team; usually from a single institution; NAP, national advisory panels; NEMDT, National Ewing's MDT; NHS, National Health Service; NSAP, National Sarcoma Advisory Panel; PBT, proton beam therapy.

Conclusions: In the context of increasing demand and the escalating number of NAPs, it is timely to consider how service improvement can be facilitated. Best practice guidelines have been formulated as a product of this study, to promote a sustainable and effective model for NAPs. Review and benchmarking national panel performance against these guidelines will drive high standards of care going forward and they should be embedded as standard practice.

KEYWORDS
multidisciplinary team, national advisory panel

1 | INTRODUCTION

In recent years, there has been significant improvement in the outcomes of paediatric cancers.[1–3] There is widespread evidence that centralisation of services confers a survival benefit, and this is juxtaposed with multidisciplinary team (MDT) working.[4–7]

Before the 1990s, cancer care in the United Kingdom was predominantly based around a generalist model, whereby clinicians tended to work independently without specific expertise and skills.[8] Patient outcomes in the United Kingdom compared poorly to the rest of Europe; additionally, there appeared to be variation in care across the country. This, coupled with increasing patient complexities, led to the evolvement of MDT, and in 1995, the Calman–Hine report was published, which advocated for restructuring of cancer services, centred around collaborative multidisciplinary working.[9] It proposed that patients should be cared for by specialists, working as part of a team, sharing knowledge and skills, making evidence-based recommendations for diagnosis and management.[10] MDT working is now mandated as part of the National Health Service (NHS) Cancer Plan,[11] with proposed advantages of this model including improved patient outcomes, evidence-based treatment decisions and increased clinical trial recruitment, along with enhanced educational opportunities for MDT members.[8,12,13]

In the United Kingdom, there has been a recent rise in the number of national advisory panels (NAP) for children and young people's cancer (CYP). One of the first of these was established in 2011 for patients with Ewing's sarcoma (ES). The National Ewing's MDT (NEMDT) began following the analysis of the European Intergroup Cooperative Ewing's Sarcoma Study (EICESS) 92 study, which showed higher survival rates for ES patients treated in Germany compared to UK patients.[14] This discrepancy in survival rates appeared to result from differences in local therapy approaches whereby German patients benefitted from more centralised, consistent decision-making processes compared to those in the United Kingdom, which ultimately appeared to lead to better outcomes. Evaluative research into the NEMDT highlighted a number of desirable characteristics of an effective MDT, including a core membership with the required level of expertise and specialisation, discussion of patients only if a clinician who has met them is present, robust web-based technology and timely communication of MDT recommendations.[15]

There are a number of NAPs in the United Kingdom providing expertise for various tumour types and for specific treatment, such as haematopoietic stem cell transplant (HSCT). In addition to the NAPs selected for evaluation under the remit of this project, others have since developed including for germ cell tumours and non-Hodgkin lymphoma.

The NAPs identify themselves as distinct from MDTs. Meetings are held virtually, discussions are undertaken regarding individually referred patients and outcomes are formally disseminated; however, the responsibility for the final treatment decision remains with the referring clinician and local MDT. There are no formal guidelines to benchmark against in terms of defining standards. Any MDT or NAP should regularly assess its own effectiveness and performance[13]; these panels add a further layer to an already complex patient pathway and therefore need to be evaluated robustly. Of note, the UK Leukaemia MDT and the NEMDT use the term MDT to describe their team but they are not single-institution entities.

The NAPs to be evaluated within the remit of this project are:

- Ependymoma Multidisciplinary Advisory Group (EMAG)
- National Neuroblastoma Advisory Panel (NNAP)
- National Renal Advisory Panel (NRAP)
- National Sarcoma Advisory Panel (NSAP)
- UK Leukaemia Multidisciplinary team
- UK Histiocytosis Advisory Panel (UKHAP)

2 | METHODS

The study was undertaken as a service evaluation, defined by the NHS Health Research Authority standards, and therefore did not require research ethics committee approval.[16]

It was undertaken in two phases.

Phase 1 was retrospective; it reviewed the infrastructure, scope and work of the panels, from their respective dates of inception to December 2018. Methodology included face-to-face interviews with the panel chairs, review of the NAP documentation (terms of reference and the referral proformas) and retrospective review of the cases discussed. Each panel dataset had patient identifiers removed by the respective NAP chair and was shared with the study team using secure

mail (nhs.net). The parameters reviewed included meeting frequency, technology and organisation; membership of the panels; number of referrals, age of patients referred, their disease-type and the referral reasons. The individual records were analysed using Microsoft Excel.

Phase 2 was prospective over a 6-month period between December 2019 and June 2020. It utilised specifically modified referral proformas, designed by the study team, to capture information that was missing from phase 1. These proformas were approved by each panel chair and circulated to referrers for use. Each referred case was shared, in real-time, with the study team using secure mail. The individual records were analysed as in phase 1, with additional data reviewed including panel quoracy; dates of referral, panel meeting and outcome circulation; stage of disease process, predefined referral question category; additional roles of the panel; the documentation of evidence base to support recommendations; whether patients are referred for a clinical trial; whether patients are informed of panel referral and whether there are additional family-related factors that may influence decision-making. Each referrer was contacted directly by the study team, via email, 2 months after the case discussion to obtain follow-up information; this included whether panel recommendations were implemented and the reasons for non-implementation as appropriate; whether patients were informed of recommendations was also reviewed.

3 | RESULTS

3.1 | Panel infrastructure and referral process

Each panel is a multidisciplinary group of clinicians with interest and expertise within the particular cancer type. All of the NAPs have an allocated chair. The terms of reference for the NAPs do not formally detail the other individual members of each panel. In most cases, a broad description of the group membership is stated, such as origins from the relevant special interest groups and the relevant clinical trials; for example, EMAG membership is very closely related to the SIOP Ependymoma II trial. The UK leukaemia MDT does not have a formally defined panel; it comprises of the clinicians that call into the meeting each week.

There is no expectation that patients are referred to a NAP; this is at the discretion of the treating clinician. Distinct from this is referral to EMAG, whereby it is recommended that all newly diagnosed patients with ependymoma are referred for central review and trial stratification. Patients are referred by their treating clinician. A specifically designed proforma, comprising details of patient demographics, diagnosis, relevant investigation results and referral question, is emailed to the relevant chair/sub-chair/administrator prior to the panel meeting. The proformas are not standardised; although some information collected is common to all, there is a degree of variation between the data collected. For the solid tumour NAPs, radiology images are prepared in advance of the meeting and clinical data are reviewed in advance of the meeting by the panel chairs.

The meetings take place at a routine specified date and time; members across the country are linked virtually via teleconferencing forums such as ZOOM and Microsoft Teams.

The referring clinician, or a representative from their team, attends the meeting to present their patient, sharing relevant clinical information. For the solid tumour NAPs, radiology is discussed in real-time by the panel radiologists, and surgical decisions are made in real-time by the surgeons. Individualised recommendations are made in real-time and subsequently outcomes are circulated. The panel role is advisory; responsibility for the final decision re-investigation or management of the patient lies with the referring clinician, local MDT and patient/family.

Most of the administrative duties are undertaken by the chair/chairs. The EMAG and National Leukaemia MDT have additional administrative support from existing non-clinical staff members. Panel data are stored on specifically designed databases held on the individual computers of the relevant staff members. The panels do not have a consistent method for data collection and for anonymising data. Some use patient initials, date of birth or an individual number identifier.

3.2 | Phase 1 results: Data from the date of panel initiation to December 2018

Total 920 referrals were reviewed during Phase 1. Table 1 shows the number of meetings and discussions for each panel reviewed during Phase 1.

Since phase 1 data collection, the demand on the panels has increased in terms of referrals; Figure 1 compares the number of referrals received per panel per meeting analysed for phase 1, compared to data from the year 2021.

3.3 | Phase 2 results

A total of 180 referrals were reviewed for Phase 2 between December 2019 and June 2020: 173 of these had recommendations that were evaluated; two cases were withdrawn prior to the panel meeting and hence no recommendations were formulated; four cases were discussed at a meeting chaired by a deputy, the outcomes were not circulated and hence not available for evaluation; one case did not have recommendations made, as the panel deemed there was insufficient information available to allow informed conclusions to be drawn.

The average time from referral to panel discussion was 10 days (range 2–22 days); the average time from meeting to recommendation circulation was 4 days (range 2–7 days).

3.4 | Referral findings

Five out of six panels collected data regarding clinicians attending the NAP meetings to present their own patients; this was undertaken in 123/138 cases (89%).

TABLE 1 Number of meetings and referral numbers from panel initiation to December 2018

Panel and year of initiation	Meeting frequency	Number of meetings	Number of referrals	Average number of referrals per meeting
Ependymoma 2015	Once a week	129	311	2.4
Neuroblastoma 2017	Once a month	19	70	3.7
Renal tumours 2017	Twice a month	30	86	2.9
Sarcoma 2011	Once a month	61	155	2.5
Leukaemia 2016	Alternate weeks	46	234	5.1
Histiocytosis 2013	Twice a month	37	64	1.7
Total	NA	322	920	NA

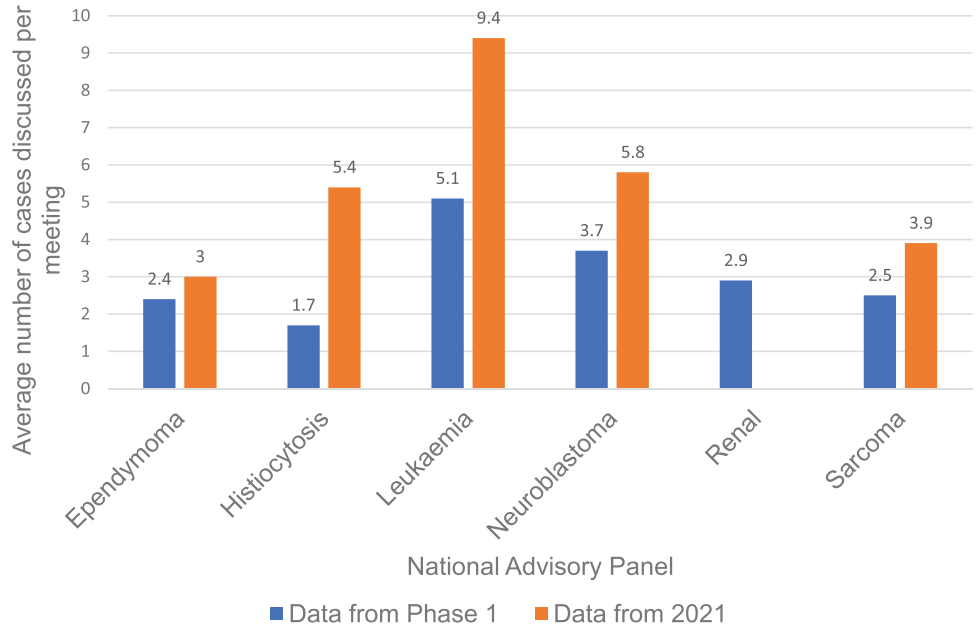

FIGURE 1 The number of referrals received per panel per meeting analysed for phase 1 compared to data from the year 2021

Five out of six panels collected data regarding the stage of disease process for each referred patient. For neuroblastoma, the majority of high-risk cases (80% of 10 cases) were refractory (38%), relapsed, (50%), or progressive (13%); the low/intermediate-risk neuroblastoma cases were mainly undergoing first-line management (86% of seven cases). For the 15 patients with renal tumours, 20% were referred during diagnosis, 27% during first-line management pre-surgery, 27% post-surgery and 26% were refractory or had relapsed disease. Sarcoma patients were mainly referred during first-line treatment (83% of 18 patients), reflecting the panel's role in local therapy decision-making, with the remainder undergoing diagnostic workup (6%) or having relapsed disease (11%). The patients with histiocytosis were referred during diagnosis (25% of 17 cases), staging (10%), first-line management (20%), or had refractory (25%) or reactivated disease (20%); some patients were referred with more than one category. A large proportion of the 67 patients with leukaemia were referred with relapsed (41%) or refractory disease (24%); the remainder were referred during diagnosis (3%) or first-line management (30%).

Phase 2 required referrers to specify their referral questions using categories; the average number per patient referred was 1.8. The breakdown of referrals per category can be seen in Figure 2.

3.5 | Recommendation findings

Figure 3 shows the results of the recommendations findings across all the NAPs.

An example of recommendations changing practice can be seen in the case of EMAG, which provides central review of imaging and histology. In 26% (of 27 cases), locally assigned histological subtype was changed; similarly, 24% (of 25 cases) had local imaging findings modified.

Referral recommendations for specialist treatment or services are additional roles of the NAPs. These include advice on the feasibility of surgery and other treatments, including immunotherapy, mIBG, CAR-T, early-phase studies and opinions regarding

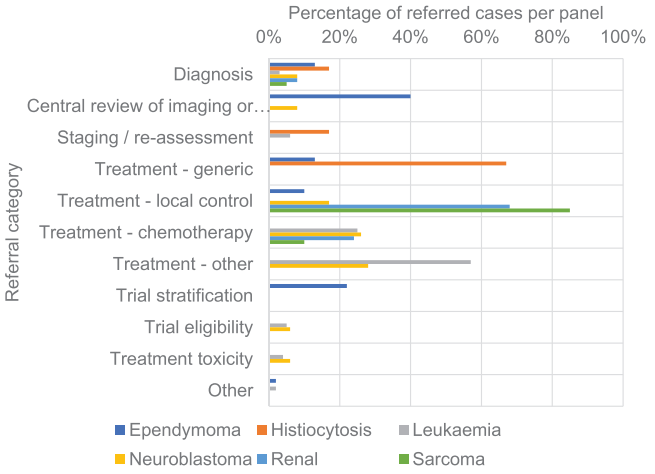

FIGURE 2 The percentage of patients referred to each panel by their referral categories

treatment options available outside the United Kingdom (neuroblastoma); conservative surgery and brachytherapy, referral for consideration of the AMORE protocol (ablative surgery, mould technique brachytherapy and surgical reconstruction) and advice regarding the likelihood of acceptance for proton beam therapy (PBT) (sarcoma); PBT and biobanking (ependymoma); HSCT and CAR-T therapy (leukaemia); specialist nephron-sparing surgery for bilateral renal tumours and biobanking and disease registries for histiocytosis.

Eleven percent of recommendations were not implemented, and the reasons for this were found to be patient choice (47% of 17 cases), change in clinical condition (29%), choice by referring clinician (12%), central review outcome changed advice (6%) and/or impact of the COVID pandemic (6%).

3.6 | Patient and family findings

Phase 2 collected data specifically to include patient and family information. It was found that 85% of the 180 patients referred to the selected panels were informed of the referral and 99% of those with follow-up information (141 cases) were informed of the recommendations. Only 30% of cases had additional patient-related factors recorded; these gave further personal information that may influence decision-making, including psychosocial factors and specific treatment preferences.

4 | DISCUSSION

The MDT approach to cancer care is now widely embedded in practice, yet remains both resource and time consuming. The characteristics of an effective MDT are well known,[13] but it is imperative to examine whether MDT and NAP working is beneficial. Children are surviving longer[1–3]; a recent report showed that the 5-year survival for children under 15 years of age was 81%, and 84% for teenage and young adult patients (15–24 years of age).[17] The success is the sum of increasing clinical knowledge, improved treatments and the centralisation of care delivered from specific centres.[18] Decision-making is becoming more complex, and team-based decisions are increasingly desirable at various time points throughout a patient's journey, not just at diagnosis, but also at treatment response assessments, at times of toxicity or treatment complications and at relapse. Advances in treatment means more options are available, some of which will not necessarily be standard of care. Therefore, expert opinion and experience are increasingly relied upon in the absence of evidence-based practice, and it is becoming increasingly expected that these are presented as a consensus, rather than individual judgements.[19]

The significant amount of work undertaken by the NAPs is clear; the number of referral questions per case gives an indication of the complexity of patients discussed, and the range of stages of disease process that are consulted about, highlights the variety of cases presented. The work to date has largely been achieved through the commitment of the chairs and panel members. The service is currently not commissioned and is outside the remit of agreed job plans, hence it is undertaken during the members' own time. In the future, it will be important to measure this scale of time and effort, to enable accurate job planning and appropriate investment.

Desirable characteristics of NAPs have previously been highlighted.[15] One of these was that a patient should only be discussed if a clinician who has met them is present; our results were encouraging; 89% of case discussions were presented by their referrer. Timely communication of outcomes is another area of recognised good MDT practice.[13,15] The recommendations made at panels are shared in real-time during the meeting discussion; we have shown that the collective average interval between meeting and recommendation circulation was 4 days.

Value can be derived by examining several observations, all highlighting the impact of the panels. When examining clinical decision-making at MDT, research has shown that a significant proportion of patients have their management plans modified. This has mainly been due to having varying specialties and expertise present, for example when interpreting results.[20] Our results mirror these findings; 77% of those referred to NAPs with a local management plan made, had this changed, or at least added to, by the recommendations; thus, highlighting the influence national discussion can have on patient management. Over a third of total cases referred did not document the local MDT plan on the referral form, even though each patient will have been discussed locally. This raises a question regarding an increasing reliance on the panel's recommendations for patient management. This is interesting to consider, particularly with the current position of the national panels as providing informal advice, with no formal responsibility for decision-making.

Another element to review when attempting to establish MDT value and effectiveness is the implementation of MDT recommendation; we found nearly 90% of NAP recommendations were implemented. This supports other research showing similar reassuring results.[21]

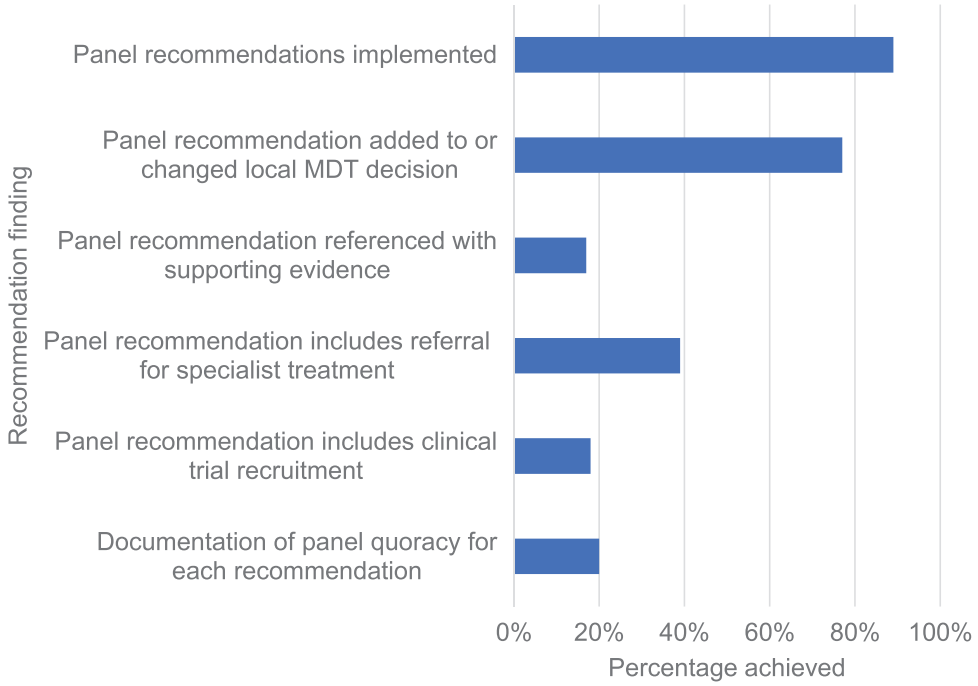

FIGURE 3 The collective results of the recommendations findings across all the national advisory panels (NAPs)

It has been suggested that MDTs can develop and improve by regularly reviewing recommendation implementation, and most importantly the reasons for non-implementation.[22]

With increasing specialisation and the development of supra-regional services in paediatric oncology, such as those for retinoblastoma, PBT or CAR-T, referral to quaternary services is becoming more commonplace. In addition to providing general management advice, the panels also fulfil specific roles, including recommending specialist treatments at quaternary centres. This is a pertinent example of national panel impact.

A characteristic of an effective MDT is membership and attendance; this should be documented for each meeting to ensure relevant specialties/clinicians are present to contribute to discussions. This is based upon the core value that the entire MDT is required for making the most appropriate management recommendations, rather than individual opinion alone.[13] Panel quoracy was therefore identified as an important factor to address in terms of both definition of quoracy and documentation of achievement for each NAP meeting. These data were only available for three of the selected panels; it was achieved in 68% of those recorded. Overall, it was documented in only 20% of discussions, and thus remains an important area to address in the future. Furthermore, it is noted that all the current NAP chairs are from England, so in order to make the panels more UK-wide, it would be important to consider rotating chairs and to ensure more NAP members are included from outside England.

The consistency of panel recommendations is an important factor to address. MDT recommendations should be evidence-based where possible; however, in complex and rare cases, there may be a paucity of available literature to support management plans; in these circumstances, recommendations are founded upon expert opinion. This was often illustrated in the cases reviewed for this study. Data were not available from one panel, and of the remainder, evidence-based recommendations were only seen in 17% of discussions. The panels, by definition, are often faced with cases for which standard-of-care options have been exhausted or for which the optimal treatment is unclear, subsequently the collective consensus of the group directs management. Going forward, it is important to ensure this is explicit in the recommendations, as valuable information for referrers and patients. This promotes open communication, transparency and involvement in decision-making. Where possible, in the absence of evidence-based recommendations, guidelines should be developed to ensure consistency of decision-making and practice.

Robust web-based technology is recognised as a necessity for effective team working[15,23] in order to provide video-conferencing, data transfer and cross-site coordination. The recent COVID pandemic has imposed remote working on healthcare professionals, promoting the rise of online platforms, which provide a forum for information sharing, data storage, conferencing and collaboration. This presents the NAPs with an opportunity to take advantage of such platforms, utilising reliable conferencing technology, but more importantly confidential, secure and dynamic data storage, resulting in a more efficient and confidential process for NAP function and facilitation of practice review and audit.

The NAPs have developed alongside increasing centralisation of cancer services, specialised therapies and enhanced complexities of patient management. The role these panels offer is highly valued, as we have shown, and it seems likely that these specialist advisory groups will continue to develop and increase in number over time. Since this project commenced, similar forums for different cancer types have been launched. These include for germ cell tumours,

haemophagocytic lymphohistiocytosis, central nervous system tumours and non-Hodgkin lymphoma. Additionally, a panel dedicated to patients receiving CAR-T therapy has evolved from the Leukaemia MDT. Moreover, the demand on the existing panels is increasing. Cases discussed at the NSAP have risen from an average of 2.5 per meeting (data from 2011–2018) to 3.9 in 2021. Similarly, histiocytosis cases have gone from an average of 1.7 to 5.4 and neuroblastoma from 3.7 to 5.8. Referrals to panels are becoming increasingly accepted as standard of care. There are numerous examples of recently published national UK guidelines recommending panel referral; these include for soft tissue sarcoma,[24] relapsed acute lymphoblastic leukaemia (ALL),[25] infant ALL,[26] relapsed high-risk neuroblastoma[27] and renal tumours.[28] Furthermore, in the context of increasingly sought second opinions, the demand on the panels is likely to escalate further.

With the increasing number of panels and mounting demand on existing forums, it is pertinent to consider their work going forward and additional components of MDT working that currently, the NAPs do not exploit.[13,29] Education is one such facet. Although the panels currently fulfil informal roles in training, none have a defined position. The panels could utilise their substantial and rich source of interesting and complex cases by offering exposure to these discussions in a formalised role. Audit and data validation are further examples. Some of the panels have started to develop their service by modifying their referral proformas to facilitate specific data collection; for example, EMAG collect information regarding neurosurgical and neurological outcomes of their patients; the leukaemia panel also collects specific follow-up information linked to the aforementioned guidelines for infant ALL and relapsed ALL, thus allowing outcome data to be collected in the absence of a clinical trial. This could be further adopted by the other panels going forward. There are no formal guidelines or standards against which to benchmark the UK NAPs, and no currently established system for review of practice. It is however widely recognised that the regular assessment of performance is paramount in order to share good practice and drive improvement of service.[13,15,30]

Using the findings of this project, coupled with a number of supporting resources and references,[13,15,19,30,31] a best practice statement, terms of reference and operational guideline (Supporting Information) have been formulated to facilitate the implementation of uniform practice, to drive high standards of care and provide a model against which to benchmark the service of the NAPs.

5 | CONCLUSION

National panels for childhood cancer in the United Kingdom clearly fulfil an important role, undertaking a significant amount of work with recognised impact and added value. In the context of spiralling demand on existing panels and an increasing number of newly formed panels, it is timely to consider their practice going forward in order to support their advancement and consolidation. Best practice guidelines are essential to provide a model against which to benchmark the service, promoting higher standards of care. Increasing work pressures mandate this judicious implementation, coupled with appropriate investment to ensure their sustainability.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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