**Patient and Parent Perspectives on Paediatric Cancer Multidisciplinary Team Working and National Advisory Panels in the UK:**

**A Qualitative Research Study**

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**ABSTRACT**

**Objective**

The concept of patient-centred care is central to the role of cancer multi-disciplinary teams (MDTs) and particularly pertinent with the recent rise in number of virtual national advisory panels (NAPs) for childhood cancer in the UK. We sought to explore patient and caregiver views, regarding MDT working and NAPs.

**Methods**

Three focus groups were undertaken between March 2019 and January 2020.

**Results:**

Sixteen participants attended. All regarded MDTs and NAPs highly, whilst highlighting patient involvement in decision-making should not be diluted by this process. The importance of personalised consultations was stressed, acknowledging that information-sharing preferences may change with circumstance and time. Most participants felt they had not been actively involved in decisions, including those made following MDT or NAP discussions. Group suggestions to improve patient-centred care included a clinician knowing them presenting their case, referral proformas to include family-related factors and an advocate attending meetings to represent the patient/family view.

**Conclusion:**

Several changes have been driven forward by this work, including the modification of NAP referral proformas to include additional information. Patient and parent perspectives are now embedded into a best practice model for the NAPs to promote personalised recommendations at national level.

**ARCHIVES OF DISEASE OF CHILDHOOD SPECIFIC INFORMATION**

**What is already known on this topic**

* Multi-disciplinary decision-making is particularly useful for rare diseases, complex decision-making, and instances where recommendations lie outside established treatment pathways; in paediatric oncology, national advisory panels for specific cancer types have evolved to offer individualised expert advice remotely in such circumstances.

**What this study adds**

* Patients and parents, with direct experience of paediatric cancer, deemed national advisory panels well placed to provide consensus second opinions in complex cases.
* They advocated for personalised recommendations to be maintained at national level discussions and provided strategies for how this could be achieved.

**How this study will affect practice and policy**

* National best practice guidelines for paediatric oncology national advisory panels have been formulated to include the patient-specific information elicited during this study. They have since been published and will be implemented nationally via the Children’s Cancer and Leukaemia Group.
* The individual national advisory panel referral proformas have all been modified in line with the recommendations provided by the parents and patients.

**INTRODUCTION**

Multi-disciplinary teams (MDT) are the foundation for paediatric cancer care delivery in the UK. They meet to review case-specific information and formulate consensus management recommendations. It is standard of care for every child with a new oncological diagnosis to be discussed at a Principal Treatment Centre (PTC) MDT. Additional MDT discussions are likely at further decision-making time points, including treatment response assessments, treatment complications and relapse. The PTC MDTs typically comprise healthcare professionals that know the patient well, but the patient voice is not routinely captured.

The UK has seen a rise of national advisory panels (NAPs) for certain types of childhood cancers. These are national multi-disciplinary groups of clinicians offering remote expertise within a particular cancer type for individually referred patients. Currently, there are UK NAPs for embryonal brain tumours, ependymoma, germ cell tumours, histiocytoses, leukaemia, neuroblastoma, renal tumours and sarcoma.

On the background of increasing centralisation of paediatric cancer services and enhanced patient complexities, second opinions are becoming increasingly routine. There is an emerging preference for collaboratively formulated recommendations, rather than the traditionally sought individual’s advice. (Royal College of Paediatrics and Child Health, 2021)

NAPs have evolved to fulfil a specific role addressing complex cases, in which clinical decisions are challenging and robust evidence-base may be lacking. They are deemed distinct from PTC MDTs, namely because they are advisory, rather than decision-making forums; clinical responsibility remains with the treating clinician and PTC MDT.

Across UK healthcare, the expectation is that patient preference should inform clinical decision-making (General Medical Council, 2008); the National Health Service (NHS) strives for a culture of ‘’no decision about me, without me’’. (*No Decision about Me, without Me Liberating the NHS: Government Response*, n.d.) Since the re-structuring of cancer services in the UK following the Calman Hine report in the 1990s, which advocated for a collaborative MDT approach taking account of patient view (Calman & Hine, 1995), work has continued to reflect these core values. It has focussed on the improvement of MDTs, striving for effective and efficient patient-centred practice (National Cancer Intelligence Network, 2010). Shared decision-making between clinical teams and patients / families is fundamental to this (Cancer Research UK, 2015; NHS England & NHS Improvement, 2019) and is recognised as particularly important in cancer care whereby decisions are multifaceted, underlining the need for care to be individualised. (Epstein & Street Jr., 2007) Guidelines recommend specifically that patients view be considered at MDT and subsequently opportunity offered to patients to work in partnership with their clinical team to make treatment choices. (National Cancer Intelligence Network, 2010)

The primary role of the MDT is to determine the most individually appropriate treatment options, hence the information presented should be holistic. Clinical detail coupled with psychosocial aspects, patient preference and values are integral to this process (Hamilton et al., 2016; National Cancer Intelligence Network, 2010; NHS England & NHS Improvement, 2019)

We propose this philosophy is also relevant for NAPs. Despite the clinical outcomes being advisory only, investing time formulating treatment recommendations, which are not aligned with patient / family preference, is potentially ineffectual. It has particular relevance in the climate of escalating time pressures and demands on healthcare staff. Patient / parent input to MDTs and NAPs is even more important.

We anticipate patient engagement and the design of a patient-centred model, will help shape enhanced NAP working, by promoting personalised recommendations. We sought to explore the opinions of patients and parents, with direct experience of childhood cancer, regarding communication throughout their cancer journey with a focus on shared decision-making and involvement in MDTs and NAPs.

**METHODS**

Three face-to-face patient and family focus groups took place at a conference centre on a hospital site, between March 2019 and January 2020.

Patients and parents with experience of childhood cancer were invited via existing patient research groups and in-hospital poster advertising; there were no exclusion criteria. Expressions of interest were invited via email to the researchers, using a secure inbox set up specifically for the research.

Participants were given written information, regarding the researchers’ professional credentials, the background of the research and the expectations during the groups, prior to attending. Contact details were shared and the opportunity to ask questions offered. Consent was subsequently implicit for those who attended.

Each group was conducted according to research governance guidance. Two researchers were in attendance during all groups; SB, a Paediatric Oncology Research Fellow, led each group using the same semi-structured topic guide, devised by SB (see appendix 1). JB, a Consultant Paediatric Oncologist, facilitated. An introduction to the researchers and the research rationale was explained. Written records were contemporaneously documented by a research nurse, independent of the project; responses had patient identifiers removed.

The written transcripts were reviewed using framework analysis; SB familiarised herself with the text and developed data codes. These were then grouped into categories, and the transcripts were reviewed again line by line with each data point assigned and inputted into a specifically designed spreadsheet. The major reported themes were derived from this.

All the participants gave consent for follow-up contact, and the opportunity to debrief, within 3 months of the focus groups. A report of the discussions was shared, and comments invited.

Data saturation was achieved after 3 groups.

Ethics approval was granted by the University of Southampton via the Ethics and Research Governance Online (ERGO) system (ERGO number 71831).

**RESULTS**

The mean duration of the groups was 3 hours; 16 participants attended in total, with representation from 4 principle treatment centres (PTC) from across the UK. 5 participants had a pre-existing professional relationship with the researcher, SB; one such participant attended the first group; 3 attended the second and the fifth attended the final group. The remaining participants were unknown to SB.

Tables 1 to 4 give details of the participant demographics.

The overarching themes from the groups were:

* Communication and shared decision-making
* Awareness of MDTs and NAPs
* Strategies to promote personalised decisions

**Communication and shared decision-making**

All participants acknowledged that patient / parent preferences regarding information-sharing are individual, influenced by several factors and may change over time and circumstance.

The stage of the cancer journey was highlighted as an important factor influencing information preferences. Communication preferences at diagnosis may be different to other stages of the cancer journey, in view of the perceived vulnerability and heightened emotions of families at this time. Group members consistently volunteered the information at diagnosis can feel overwhelming in terms of content and amount, compounded by use of medical terminology and these factors can impact the individual’s ability to contribute meaningfully to discussions. It was acknowledged at other stages, preferences may be different, including when patients are discharged from in-patient care and there is a shift in responsibility from the clinical team to the family. Similarly, at relapse, the group felt that more information may be sought, especially if an optimal treatment pathway is unclear.

The long-term survivors also recognised that preferences for shared decision-making may change based upon who the decision is regarding; they acknowledged their wishes would potentially be different when considering treatment choices for their children, compared to making personal judgements.

There were detailed discussions within all the groups regarding information delivery impacting understanding. Every participant highlighted the importance of trusting the professional responsible forcommunicating key information, stressing they should know the family well, in order to promote personalised consultations.

In terms of experiences of shared decision-making, it was largely reported that adequate information during consultations had been shared, however the individual’s preferred roles in decision-making varied. Five participants agreed clinicians make all the decisions for them ‘I rely fully upon the doctors’ (Table 5: quote 1); the remaining felt it was important to share their opinions to inform decisions. Most had not been actively involved in decision-making, with 2 participants stating ‘my choices never changed care’ and ‘sometimes I feel like I’m not being heard’ (Table 5: quotes 2 and 3). All felt it was important to tailor shared decision-making preferences to the individual, acknowledging that inclinations may change. One parent of a child previously treated for Ewings sarcoma shared ‘I felt different to my husband at the beginning…I wanted all the information so I could be involved but he wanted very little, just the ‘bottom line’. As the shock wore off, he felt able to understand more’ (Table 5: quote 4).

**Views regarding MDTs and NAPs**

Most group members were familiar with the concept of MDT working, however parents whose children had been recently diagnosed were unaware ‘I had no idea that a group of professionals were meeting to discuss my daughter’s care and this is important; I feel more reassured’ (Table 5: quote 5). There was a commonly held perception that MDTs were beneficial by offering collective expertise and opinion ’10 brains are better than 1’ (Table 5: quote 6).

NAPs were generally regarded highly. Affirmation of treatment recommendations through a forum of professionals with specific expertise, was felt to be well placed as a source of reassurance for families.

One participant vocalised a concern that NAPs potentially add another layer of complexity to an already multi-faceted treatment pathway; the rest of the group agreed and therefore advised NAP roles be explicit to both professionals and parents. It was proposed their primary function should be advice for rare cancers, unusual presentations, relapsed or refractory disease and late effects / toxicity of treatment.

It was sensed by the groups that MDT and NAP meetings are primarily focussed on clinical information ‘only medical facts contribute to decisions’ (Table 5: quote 7), yet there was consensus that personal factors should be heard, to make recommendations individually appropriate ‘a panel should have known what was important to my family at that time….we wouldn’t have been able to travel far for treatment’ and ‘we really didn’t want him to have an amputation at first as we are such an active family’ (Table 5: quotes 8 and 9). There was a commonly held concern about the impact NAPs could have on personalised treatment recommendations as panel members wouldn’t necessarily know the patients discussed. Most participants recognised a time-pressured environment could limit the ability of the referring clinician to impart relevant non-clinical information and hence NAP recommendations would likely be affected.

**Recommendations for promoting personalised outcomes at national level**

The participants suggested strategies to promote personalised recommendations. These included always having a clinician who knows the family attending meetings to present their patient and family-related factors being included on the referral proforma, such as psychosocial circumstances, quality of life considerations, or treatment preferences. Additionally, all patients should be made aware of the referral and outcome, comparable to the process of receiving test results, where sufficient time is allocated to share this information. Finally, they proposed a patient advocate could attend meetings to present the family view; a specialist nurse would be well placed for this ‘the nurses got to know us as a family so well; it wasn’t just about the medicine….a nurse could be our voice’ (Table 5: quote 10).

**DISCUSSION**

**Shared decision-making**

It is recommended that efforts to support the process of shared decision-making are integral in cancer-care; clinicians may recommend the medically optimal option, but this should be coupled with the patients personal circumstance and preference. (Cancer Research UK, 2015). The recent Under 16’s cancer experience survey revealed 68% of parents / carers and children felt involved in the child’s care.(*Under 16 Cancer Patient Experience Survey 2021 National Report (Quantitative)*, 2022) Despite this, there is evidence, including in our findings, to demonstrate shared-decision making is not always the reality or perception of practice. It may be complicated by the heightened emotion and sense of uncertainty associated with having an oncological diagnosis (Politi et al., 2012). Our results support this; all the participants recalled the stress and emotion of having a cancer diagnosis, coupled with the complexity of information provided. Most preferred jointly making decisions, or at least informing the clinician of their opinions. However, the collective opinion was that particularly at diagnosis, they felt overwhelmed and unequipped emotionally to contribute to decision-making. Thus, their experience reflected very little active involvement at the beginning; other studies align with this. (R. Brown et al., 2012; Hirpara et al., 2016).

The disparity perhaps reflects the personal nature of shared decision-making preferences, along with potentially different requirements based on who the decision concerns and the stage of treatment. The limited involvement at diagnosis may also reflect treatment being largely protocol driven at this stage, with subsequent lesser need for patient / parent input into decision-making. Parents also grow as ‘experts’ during treatment and particularly at relapse. Within our groups, members reported differing requirements, emphasising the need for personalised communication and consultation. Other research supports this; parental preferences for involvement vary with the weight of the decision being made; clinicians are better placed to carry the burden of responsibility for choices where the outcome is uncertain or unfavourable. (Whitney et al., 2006) A recent study by Pearson et al agreed; the consensus from their parent and patient group was values and preferences, are fluid, affected by current treatment and the clinical condition of the child. (Pearson H et al., 2022) It should also be acknowledged that more recently, with the widespread use of the internet, detailed medical information is extensively and easily accessible; therefore, should additional detail be sought by parents and patients, this can be obtained from resources other than treating medical teams; this may affect preferences for information directly from clinicians and has potential to influence preferences for involvement in decision-making.

The aforementioned RCPCH document was drafted in the context of expert opinion and experience becoming increasingly relied upon when evidence-based practice is lacking. It recognises the value of consensus second opinions rather than individual judgements. (Royal College of Paediatrics and Child Health, 2021) Whilst it should be recognised that complex patients discussed within forums in which a number of consultants contribute, has the potential for multiple conflicting expert opinions, our group members welcomed this collective informed discussion and perceived that a primary role of NAPs was to offer advice in circumstances where a clearly defined treatment pathway is absent. In such situations, treatment decision-making becomes more complex, but parental involvement is more likely (Hinds et al., 1997); it is recognised that shared decision-making is even more crucial to empower patients to make the appropriate judgement, in the face of potentially limited clinical evidence. (Kane et al., 2014) With more than one reasonable treatment option, families, with their deeper appreciation of the child’s character and preferences, should inform decisions, particularly when considering ‘quality of life’ versus ‘prolonging of life’. (Whitney et al., 2006) Pearson et al proposed an intervention to support parental decision-making in poor-prognosis childhood cancers (Pearson H et al., 2022) and, it has been shown, when parents are involved, regret is less evident. (Mack et al., 2016).

**Personalised recommendations at NAPs:**

Despite the existing standards and proposed advantages of patient involvement, a UK nationwide review process of MDT function and performance found that MDTs have insufficient patient-centred information. (Gray et al., 2017) A study in Sweden reported similar findings when evaluating national MDTs for rare tumours, including paediatric cancers; patient-based information was perceived to be minimal compared to clinical detail imparted. (Rosell et al., 2019a) This is also supported by other studies. (Hamilton et al., 2016; Taylor et al., 2014)

Our groups were clear that despite the recognised advantages of NAP working, patient involvement in decision-making should not be diluted by this process. Research has shown that inadequate consideration of patient-related information at MDT can negatively impact implementation (Blazeby et al., 2006; Jalil et al., 2013; Wood et al., 2008). Recommendations rely on the quality of information provided and patient involvement enriches this. (Butow et al., 2007). The RCPCH document advocates for the same principles which underpin routine MDT referrals to apply to external secondary opinions too; our groups shared this view, advising that processes should be embedded to ensure individual family circumstance and preference inform NAP discussions. Multiple suggestions to facilitate this were made, including the patient case being presented by a trusted clinician who knows them This aligns with work by Bate et al and the National Cancer Action Team. (Bate et al., 2018; National Cancer Intelligence Network, 2010) Furthermore, in agreement with previous work (Bate et al., 2018; Kidger et al., 2009) it was deemed important that a patient representative, such as a specialist nurse, attend NAP meetings. Our groups also advocated for referral proformas to include patient factors; this has been recommended previously (Gray et al., 2017; Jalil et al., 2013; NHS England & NHS Improvement, 2019)

Finally, clinicians should ensure sufficient time to share information resulting from NAP discussions.

**Limitations:**

Various factors could introduce potential bias.

By the nature of focus groups, participants self-select; this, coupled with the small numbers in our study, may mean the sample is not representative of the general paediatric oncology patient / parent population. Furthermore, the number and characteristics of people who didn’t volunteer is unknown.

The researcher led the focus groups and analysed the data, hence the potential for leading questions and confirmation bias. This was mitigated for by following the pre-defined topic guide and by SB fulfilling a facilitation role only, managing group dynamics, but not partaking in active discussions. Data was analysed using framework methodology and coding based on the results, rather than using pre-defined criteria.

There was potential for participant bias, especially as a minority knew the researcher. Open questions and free discussions were encouraged to minimise this, with SB maintaining neutrality.

The semi-structured topic guide was not piloted. Multiple focus groups however functioned to address this; the first acted as an exploratory group with the subsequent 2 verifying the guide with the consistency of themes discussed.

CONCLUSION

The strengths of this study are the rich insights into parent perspectives regarding involvement in their child’s care and their recommendations that will inform future paediatric oncology NAP practice in the UK.

This study has yielded several outputs

An article was published in the Contact Magazine, for families of children with cancer, regarding MDTs and NAPs, to raise awareness of their role and function in paediatric oncology care. (S. Brown & Bate, 2020)

A patient and parent information resource regarding MDT and national advisory panels for paediatric oncology has been designed, and the information reviewed by the parent group; this is awaiting dissemination via the Children’s Cancer and Leukaemia Group (CCLG) website.

Changes have been made to NAP referral proformas to now record patient-related information:

* Whether the referring clinician will personally be attending to present the patient
* Whether the patient and family have been informed of NAP referral and outcome
* Whether there are any patient-based factors that require consideration by the NAP
* Whether NAP recommendations are implemented
* In the case of non-implementation, whether patient preference was a factor

A best practice model for NAPs, incorporating patient-centred processes, has been published (S. Brown et al., 2023) with a plan to implement this nationally via the CCLG (https://www.cclg.org.uk/member-area/National-Advisory-Panels). Integrating patient and family view into discussions will help to ensure the formulation of individualised recommendations that are more likely to be implemented based on their acceptability to the patients and parents.

This study is illustrative of the importance of focus groups and collaborative working with patients and parents in shaping future healthcare practice.

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**TABLES**

Table 1 – Patient age at diagnosis

|  |  |
| --- | --- |
| **Patient age at diagnosis (years)** | **Number of patients** |
| 0-4  | 3 |
| 5-9 | 6 |
| 10-14 | 4 |
| 15-19 | 3 |

Table 2 – Participant description

|  |  |
| --- | --- |
| **Participant description** | **Number of participants** |
| Long term survivor | 2 |
| Parents of patients currently receiving treatment | 7 |
| Parents of patients <5 years from end of treatment (EOT) | 3 |
| Parents of patients in long term follow-up | 2 |
| Bereaved parent | 1 |
| Patient <5 years from EOT | 1 |

Table 3 – Cancer type of each patient

|  |  |
| --- | --- |
| **Cancer type** | **Number of participants** |
| Ewing’s sarcomaRelapsed | 41 |
| Osteosarcoma | 2 |
| Relapsed Wilm’s tumour | 1 |
| Langerhans cell histiocytosis | 1 |
| Relapsed anaplastic large cell lymphoma | 1 |
| Acute lymphoblastic leukaemia | 3 |
| Lymphoblastic lymphoma | 3 |

Table 4 – Description of the interval from diagnosis at the time of the focus group attended by each participant

|  |  |
| --- | --- |
| **Description of interval from diagnosis**  | **Number of participants** |
| Newly diagnosed | 1 |
| On active treatment | 6 |
| <5 years from end of treatment (EOT) | 4 |
| >5 years from EOT | 3 |
| >10 years from EOT | 2 |

Table 5

|  |  |  |  |
| --- | --- | --- | --- |
| Reference number | Theme | Quote | Participant |
| 1 | Shared-decision making | ‘I rely fully upon the doctors’ | Parent of patient on active treatment for relapsed ALCL |
| 2 | Shared decision making | ‘my choices never changed care’ | Parent of patient previously treated for ES |
| 3 | Shared decision making | ‘sometimes I feel like I’m not being heard’ | Parent of patient on treatment for relapsed WT |
| 4 | Shared decision making | ‘I felt different to my husband at the beginning…I wanted all the information so I could be involved but he wanted very little, just the ‘bottom line’. As the shock wore off, he felt able to understand more’ | Parent of patient previously treated for ES |
| 5 | MDT / NAPs | ‘I had no idea that a group of professionals were meeting to discuss my daughter’s care and this is important; I feel more reassured’ | Parent of patient recently diagnosed with ALL |
| 6 | MDTs / NAPs | ’10 brains are better than 1’ | Parent of patient on active treatment for LCH |
| 7 | MDTs / NAPs | ‘only medical facts contribute to decisions’ | Patient previously treated for ES |
| 8 | MDTs / NAPs | ‘a panel should have known what was important to my family at that time….we wouldn’t have been able to travel far for treatment’  | Parent of patient previously treated for relapsed ES |
| 9 | MDTs / NAPs | ‘we really didn’t want him to have an amputation at first as we are such an active family’ | Parent of patient previously treated for OS |
| 10 | Strategies | ‘the nurses got to know us as a family so well; it wasn’t just about the medicine….a nurse could be our voice’ | Parent of patient previously treated for ALL |