Education Provision for Teenagers with Cancer in Wales: Education Practitioners' Perspectives
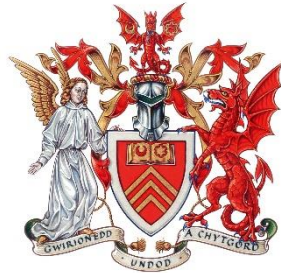
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This is submitted for the degree of

Doctor of Education

January 2025

Abstract

Cancer incidence rates in young people in the United Kingdom have increased over the last two decades, yet there has been a decline in cancer mortality. In recent years, a greater emphasis has been placed on enabling young people with cancer to focus on their life beyond successful treatment, including pursuing educational opportunities. However, there is little research examining the provision of education for young people who have a cancer diagnosis. Drawing primarily upon eight interviews with educators based in Wales (UK) and a secondary analysis of relevant policies, reports and guidelines, I explore how education is delivered for young people with cancer from diagnosis to reintegration. This includes consideration of the extent to which young people living with cancer are enabled and empowered to have access to the same educational opportunities as their peers. The analyses show that participants recognised the importance of implementing adaptable, personalised educational approaches, though this often occurred alongside resource-related challenges. Educators also referenced the pivotal role that collaboration plays in educating young people with cancer, highlighting the benefits and challenges of clear communication strategies and proactive professional cooperation towards shared expertise and best practices. I continue by analysing how educational practice is governed and reveal a disconnect between policy and practice, as well as deficiencies that impact educators' abilities to offer a consistent level of provision across Wales. To conclude, I comment on the need for greater leadership for overcoming the challenges posed by inadequate policy and interprofessional collaboration, and consider the opportunities that flexible technology-based learning pathways could bring to improve the education experiences of young people with a cancer diagnosis.

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Acknowledgements

List of abbreviations

ALN   Additional learning needs

ALNCo   Additional learning needs coordinator

ALNET(W)   Additional learning needs and education tribunal (Wales)

APPG   All party parliamentary group

CAMHS   Child and adolescent mental health services

CDG   Centre determined grades

CRM   Crew resource management

CT   Computerised tomography

COVID-19   Corona virus disease 2019

DCF   Digital competence framework

DECLO   Designated education clinical lead officer

DfES   Department for education and skills

EOTAS   Education otherwise than at school

IEP   Individual education plan

GCSE   General certificate of secondary education

LSA   Learning support assistant

MRI   Magnetic resonance imaging

NAEL   National academy for educational leadership

NCSL   National college of school leadership

NICE   National institute of health and care excellence

PISA   Programme for international student assessment

RCN   Royal college of nursing

TA   Teaching assistant

TCT   Teenage cancer trust

TLS   Transport layer security

UHW   University hospital Wales

WJEC   Welsh joint education committee

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Chapter One: Introduction

This thesis explores the educational provision for young people in Wales with cancer, from the perspectives of those involved in this provision. It aims to understand how educational support is delivered to these young people during their illness. By examining the experiences and insights of educators, this research fills a clear research gap. It identifies the challenges educators face in meeting the educational needs of young people with cancer, the strategies they employ, and the resources required to optimise the educational experience. Ultimately, this research aims to contribute to improving educational outcomes for this vulnerable group by identifying best practice as well as gaps in current educational support systems.

This chapter begins by providing a background on the rising incidence of cancer among young people in the UK and the advances in diagnostics and treatments that have significantly improved survival rates. It highlights the complex challenges these young people face during a critical stage of their personal development, emphasising the importance of addressing their educational needs alongside their medical care. I then summarise key literature, noting that much existing research either overlooks the perspectives of educators on education, or focuses on less life-threatening conditions. A clear gap in understanding educators' knowledge and perceptions of cancer is identified, particularly in the context of providing appropriate educational support for young people undergoing treatment. I then outline my research, which addresses these gaps by focusing specifically on the perspectives of educators and other stakeholders in supporting the educational needs of young people with cancer in Wales. I evaluate current practices, identify areas of best practice, and suggest improvements to ensure equitable and effective education provision for this vulnerable group. The chapter concludes by outlining the structure of the thesis.

Background

Statistics from Cancer Research UK show that there has been a 22% increase in cancer incidence rates in young people in the United Kingdom over the last two decades, with over 2,300 new cases every year (Cancer Research UK, 2024). In Wales,

the numbers equate to one young person being diagnosed with cancer approximately every three days (Public Health England, 2021). The last 20-30 years has seen incidence increases, but also a decline in cancer mortality due to diagnostic improvements as well as evolutions in treatment (Armstrong et al., 1999). Whilst the development of diagnostic technologies, such as CT (Computerised Tomography) scans and MRI (Magnetic Resonance Imaging), has resulted in earlier detection of the disease, the greatest impact on cancer survival has been improved treatment regimens such as intensive chemotherapy (Cann, 2024). As a result, 87% of young people diagnosed with cancer survive for five years and 83% for ten or more years (Cancer Research UK, 2024).

Coping with a cancer diagnosis alongside the usual challenges of a significant developmental stage of a young person's life is recognised by Lombard et al. (2013) as a 'double penalty'. Taylor et al. (2008) further note that this distinct experience requires specific attention, whilst Forsey et al. (2013) specify that professionals must consider the needs and developmental stage of young people with cancer. Generally, the potential personal and psychosocial challenges that are typically faced by this age group should not be underestimated as they make the transition to adulthood. Multiple challenges have been documented, such as peer group issues (Tillery et al., 2017), family difficulties (Hughes et al., 2024), or difficulties with education and work (Altherr et al., 2023). In recent times, a greater emphasis has been placed on preparing these young people to live with the effects of cancer and to enable them to focus on their life beyond successful treatment (Woodgate, 2005). The National Institute for Health and Care Excellence (NICE) guidelines, 'Cancer services for children and young people' (2014), address some elements of the psychosocial needs of these young people, yet no major organisation has done the same to address educational needs. Education during this time has a long-term impact on economic well-being and health (Bonnie et al., 2015). It is a key focus of all young people's lives, no less so for those diagnosed with cancer.

Young people facing these health challenges deserve to have every opportunity to pursue and complete a satisfactory education. It is also important to foster conditions

that promote positive learner identities and develop motivated and engaged attitudes (Carr et al., 2008). For young people with cancer, this entails tailored support mechanisms that safeguard their participation and progression in education despite their challenges. As they navigate the difficulties posed by their medical condition, it is essential to consider how their educational needs can be supported to ensure they have access to the same opportunities as their peers. In Wales, learners with significant health issues, such as cancer, are entitled to tailored educational provision within their schools or through alternative means. In school settings, this support is often formalised through Individual Education Plans (IEPs), which should specify adjustments and learning goals to address the student's needs. For those unable to attend school, Education Otherwise Than at School (EOTAS) services may be provided by local authorities, offering alternative education through home tuition or flexible arrangements. During prolonged stays in major treatment centres, education is delivered by hospital teaching services. Additionally, key workers, often employed by charities, play a central role in liaising with educational institutions to coordinate provision and support reintegration. However, as this research will demonstrate, learners often face limited access to a broad and balanced curriculum, the number of hours offered can be as little as two per day, and opportunities to gain qualifications that match their needs and potential are frequently restricted. Shiu (2001) declares that the challenge for educators is to enable and empower these students, as not doing so will effectively burden them with a double jeopardy.

There is also clear scope to undertake research which considers the relationship between the creation of higher-level policy and local enactment. Davies (2015) argues that the transfer from late teenage years to the emergent stage of adulthood involves some key aspects of personal, social and educational development which demand proper consideration to identify this group's distinct needs. Although cancer is relatively uncommon in teenagers and young adults, incidence data is now presented specifically for this age group to reflect these distinctions. It could be argued, therefore, that young people also warrant specific attention in terms of targeted research and subsequent policy. For the purposes of this research, the focus is specifically on teenagers navigating critical stages of education in the UK system, namely those preparing for

General Certificate of Secondary Education (GCSE) examinations (typically aged 14–16) and Advanced Level (A-level) qualifications (typically aged 16-18). This focus is justified because educational disruption during these examination stages has particularly high stakes for future academic and career opportunities. The transitional nature of these years, coupled with the pressure of national examinations, makes tailored educational support especially crucial for young people with a cancer diagnosis during this period. Recent guidance outlines the requirement to understand the needs of this age group, with an emphasis primarily on recognising that their uniqueness requires support which is tailored to their specific needs (Kelly and Gibson, 2008).

Previous research

The existing literature on education for young people with cancer primarily examines the impact of continuing education on their overall well-being and psychosocial needs. It predominantly incorporates the perspectives of young people, their families and healthcare staff. Educators' perspectives are lacking and are typically derived from studies on more common, less life-threatening chronic conditions, such as asthma, diabetes, and epilepsy. There remains a significant gap in research addressing teachers' knowledge and perceptions. Further, the literature spans various countries, but it is unclear how these align with local contexts and educational policies. A closer examination of the educational context in Wales is needed to develop a more comprehensive understanding.

Whilst the voices of young people with cancer are critical and have been well-documented in existing research, less attention has been given to education practitioners who are instrumental in shaping young people's educational experiences. Understanding their professional perspectives is of great importance as they are the ones who provide day-to-day educational support and who must navigate policy and translate it into practice. Focusing on the providers of education allows for an examination of systemic and practical barriers that young people may not be fully aware of, thus complementing existing youth-centred research and addressing an essential, underexplored aspect of provision.

The literature highlights feelings of isolation experienced by young cancer patients (Hildenbrand et al., 2011) and their strong desire to continue their education (Tsangaris et al., 2014). Access to education is essential to maintain academic continuity and to support a sense of normalcy (Zebrack, 2011). However, provision and support remain inconsistent (Pini, 2014) or are often deemed unsuitable for the specific needs of these students (Gibson et al., 2010), with students with such chronic illnesses tending to underperform academically, largely due to prolonged school absences (Weitzman, 1986).

The literature around education provision highlights few universally applicable characteristics identified for effective teaching (Creemers and Kyriakides, 2008) and no comprehensive guide detailing what teachers need to know to teach successfully (Kennedy, 2016). Effective teaching is seen as being shaped by teachers' perceptions of their students' experiences and learning needs (Schön, 1983) and by the specific content being taught (Gericke et al., 2018). Timperley et al. (2007) consider these factors in conjunction with students' needs and local context, with new learning pathways created by transformative teaching practices (Merzel, 2023).

Policy and guidance literature includes recommendations from the UK Government (2020) for all young cancer patients to have access to hospital tutors, home tuition, and school liaison services. The 'National Standards for Children and Young People with Cancer' (Welsh Government, 2012a), advocates for approaches tailored to the unique needs of this age group. The Teenage Cancer Trust also published 'A Blueprint of Care for Teenagers and Young Adults with Cancer', which focuses on the needs of individuals aged 16–24. This guidance, alongside research that addresses gaps in the literature, can offer advice for professionals that can drive meaningful change. Investigating the provision of education for these individuals may yield valuable insights that enhance both their academic achievement and their broader health and education experiences.

Positionality

Reflecting on my journey as a researcher, I recognise that my years of professional experience in teaching and school leadership in the UK and internationally, has endowed me with a practical understanding of educational systems. This has also deepened my awareness of pedagogical approaches and the complexity of addressing diverse student needs across varying social and cultural contexts. These experiences have shaped my critical view of educational frameworks, policies and practices. My research is also deeply informed by a profoundly personal experience of caring for my daughter throughout her nearly two-and-a-half years of continuous cancer treatment following her Leukaemia diagnosis at the age of fourteen. This experience has significantly shaped my understanding of the unique challenges faced by young people with cancer as they attempt to navigate educational spaces. Balancing intensive medical care with educational demands highlighted the unique needs of students with significant health issues. Rather than this experience being a problem that clouds clarity, it is a tool that I have reflected on and engaged with.

This dual perspective has enriched my research, offering nuanced insights into the intersections of healthcare and education. However, I have been acutely aware of the potential for personal bias, recognising that my experiences, while invaluable, may colour interpretation and analysis. As a researcher, I have continuously committed to a conscious reflection of how my experiences might shape this research process. Such a reflexive approach not only strengthens the rigour of my research, but also recognises the complexity of the experiences of others.

Participants were all very willing to talk openly and extensively, possibly influenced by their perception of my positionality which brought an empathy and understanding of their lived experiences (Berger, 2015; Bourke, 2014). This shared background helped facilitate rapport, and fostered an environment where participants possibly felt more understood and thus more inclined to disclose sensitive information or nuanced insights (Blythe et al., 2013). My dual role as an educator and a parent of a child who has undergone intensive medical treatment may have helped participants feel that I had a genuine appreciation for the complex balance between health and education, potentially

encouraging richer, more detailed responses. That said, I strived to remain impartial throughout to ensure participants did not feel influenced in any way when they responded to interview questions. This was facilitated indirectly with the use of remote interviews which makes it more difficult for the respondent to pick up on any possible unintentional body language cues.

Without these shared experiences, participants might have perceived me as an outsider, potentially leading to a more guarded or generalised level of response, as they may have assumed that I lacked a true understanding of their challenges. Holmes (2020) suggests that participants can sometimes withhold or simplify information if they feel the researcher may not fully grasp the context. Thus, while my personal experiences likely enriched rapport and the depth of insight in this study, they also necessitated a careful approach to balance empathy with objectivity in analysis. Building on these reflections, my research acknowledges that, whilst a dual perspective offers valuable insights, it also presents the potential for researcher bias; such personal involvement brings a need to consciously reflect on any subjective influence. The aim is to employ rigorous academic analysis ensuring that the research remains objective and solely grounded on the research evidence.

My research

Whilst the lived experiences of young people with cancer are invaluable, my research aims to explore the perceptions of those professionals responsible for delivering and adapting education for this vulnerable group. By focusing on education providers, this study seeks to explore perceptions, practice, and policy implementation that may affect effective educational support.

My research employs a qualitative methodology, utilising a case study design that primarily incorporates individual semi-structured interviews. A brief questionnaire was used to identify what participants saw as the key issues in educational provision for teenage students diagnosed with cancer. The questionnaire received responses from 15 participants which served to inform the focus of, and help refine, interview questions. Of these respondents, eight were available for follow-up interviews which were conducted remotely. These interviews provided deeper insights into the participants'

perspectives. A thematic analysis was then conducted, enabling the identification and reporting of key patterns within the interview data. A document analysis of relevant policies, guidelines and reports was conducted alongside this, offering an additional perspective on current practices.

The United Kingdom government state that every local authority has a legal responsibility to arrange education for any child they are responsible for whose illness prevents them from attending school (UK Government, 2023). It recommends that such provision should be on a full-time basis unless the local authority deems part-time schooling to be a more realistic alternative when considering the student's well-being and best interests. This education can be provided by any means under section 19 of the Education Act 1996 when that decision has been reasoned by a medical practitioner (UK Government, 2022). Despite this, research into the effective provision of education for young people diagnosed with cancer is limited, particularly when reflecting the standpoint of those who deliver and support such provision. Some of the more relevant research has drawn attention to the complex issues involved in the provision of educational services for students with chronic illnesses (Shiu, 2001) or has uncovered a lack of clarity amongst education staff about what support should be offered and when it is appropriate to give that support (Moore et al., 2009). Further, Pini (2014) highlights the need for research focused particularly on young cancer patients' engagement with education, and Lewallen et al. (2015) declare the need for more holistic approaches for students with such chronic illnesses.

My study aims to fill part of this research gap by building on these previous investigations. It will follow up on the recommendations to garner the perspectives of other stakeholders (in this case, those that provide and support education provision) to provide a broader account of the matter. It gathers new perspectives of current education practice and policy in relation to young people with cancer diagnoses, evaluate its effectiveness and aim to discover areas of best practice. Based on the aims of this research and a review of the relevant literature, my research addresses the following research questions regarding education provision for young people with cancer:

1) How do educators perceive education provision for young people in Wales with a cancer diagnosis?

2) What do educators perceive is needed to improve provision?

Thesis outline

In this first chapter, the context of the study has been introduced. It notes that young people with cancer receive inconsistent education requiring educators to take account of added complexities through tailored interventions, enhanced collaboration and informed policy. It highlights the limited research around the voice of the educator and the effective provision of education in this context. It outlines the research focus and states an intention to gather new perspectives of practice and policy in order to fill this research gap.

The second chapter reviews existing literature. It reveals how the diagnosis and treatment of cancer can substantially impact young people's educational and social outcomes. Much of the existing research focuses on less life-threatening conditions, with relatively little attention given to teachers' knowledge of cancer. The review shows that literature consistently highlights the critical role of effective communication and collaboration among stakeholders, as well as there being a lack of training and resources. The literature predominantly emphasises the perspectives of students, parents, and key health professionals, neglecting the views of those essential to the educational experience of young cancer patients – the educators themselves.

In Chapter Three, the methodological choices are introduced. Specifically, the adoption of a qualitative, research approach will be justified. The data collection approach, through an initial questionnaire leading to individual semi-structured interviews, will be explained and my analytic method will be defined. I discuss the use of purposive sampling and the limitations of the research. All ethical considerations are discussed, with a particular focus on anonymisation and the sensitive nature of discussions in this area. Finally, I consider my own positionality in this research as someone with a professional and personal commitment to this topic.

The first findings chapter examines the challenges educators face in providing education for young cancer patients, emphasising the need for flexible, personalised pathways that align with each student's health challenges and treatment plans. It looks at effective tutor support, reduced timetables and curricula and reintegration, while stressing the importance of maintaining social connections. Understaffing is identified as hindering effective communication and teamwork, with participants emphasising the need for skilled staff and targeted training. It notes a pragmatic approach to curriculum access, with educators advocating for a focus on core subjects while accommodating individual interests. The chapter also highlights the transformative potential of technology, especially after the COVID-19 pandemic, in enabling blended and remote learning for these students.

The second findings chapter explores the significance of collaboration. It looks at the nature of communication when aiming to align educational activities with students' capabilities. It suggests that enhanced communication, proactive engagement, and clear collaborative channels are critical for building strong professional partnerships. Collaborative meetings are seen to facilitate knowledge sharing and capacity building, helping educators address the academic, emotional, and social needs of students. Several challenges are identified, including poor professional relationships, unclear communication, and logistical barriers. The importance of open communication with students' families as primary stakeholders is emphasised, while highlighting the importance of social interaction and peer connection towards student resilience and engagement.

The final findings chapter looks at governance, particularly around policy and oversight. It examines interview data alongside relevant policies, guidelines, and reports to uncover governance deficiencies that hinder educators' ability to provide consistent educational support across Wales. The findings highlight significant gaps in educators' knowledge, understanding, and application of educational policies resulting in a reliance on individual judgment rather than systematic adherence to formal guidelines. This inconsistent approach is shown to contribute to unequal educational opportunities for students with cancer. The disconnect between policy and practice emphasises the need

for clearer, more authoritative frameworks to guide educators effectively. The findings point towards the need for clear, consistent and coherent guidance.

Finally, the discussion chapter reflects critically on the research findings, explores the implications of the results, and suggests areas for future research. It critically comments on the need for effective leadership in ensuring that Wales can adapt and provide high-quality education for young people with cancer. It also remarks upon the negative impact of poor collaborative efforts, stressing the benefits of strategies such as relevant training, interdisciplinary meetings, and sharing best practice. The integration of online learning is presented as an opportunity to innovate Welsh education, with appropriate consideration to challenges such as the digital divide and the creation of cogent policies. The chapter ends with recommendations around tailored training, policy creation and implementation, and routes towards best practice.

Chapter Two: Literature Review

Introduction

In the previous chapter, I outlined that, by examining the experiences and insights of educators, this thesis explores the provision of education for young people in Wales with a cancer diagnosis. In this chapter, I review the literature around the multifaceted aspects that a cancer diagnosis brings to young people. The review begins by describing the search process and criteria used before outlining the four broad themes. These themes include the impact of cancer diagnosis and treatment on young people, the essential role of communication and collaboration among families, educators, and healthcare providers in supporting these students, resources and practices in teacher training, and the challenges associated with school reintegration.

The review reveals that much existing literature around cancer and education emphasises the perspectives of students, parents, and key health professionals, neglecting the views of those essential to the educational experience of young cancer patients – the educators themselves. Previous research also predominantly focuses on less life-threatening conditions, with relatively little attention given to teachers' knowledge of cancer. This review ultimately identifies research gaps and the need for further research to inform more inclusive, effective educational strategies.

Review Process

A systematic approach was used, drawing from Cardiff University's library resources and digital search tools, as well as other online academic search engines. The initial search strategy used the terms 'education' or 'school', 'teenagers', 'teachers' or 'educators', and 'cancer', and focused on UK-based studies, reflecting the primary focus of this research. Initial searches returned a host of irrelevant material which then needed to be filtered out. This produced a limited return of relevant literature, and a particular lack of focus on educators' voices. To address this limitation, the search parameters were broadened. The geographic scope was extended beyond the UK, while the demographic focus widened to include all young people rather than teenagers alone. These expansions strengthened the review by addressing the lack of specificity

in existing studies and supporting a more informed exploration of the topic. Studies exploring education for those with other serious or long-term health conditions were also incorporated, recognising the possibility of important parallels in the challenges faced. From this broader list, references and citations were then examined to identify any further pertinent studies.

A structured database of the literature was then created, cataloguing key information such as author(s), title, publication date, a brief summary of the relevant content, and a hyperlink to the original resource. This database allowed the literature to be sorted by date, author, or theme to support effective analysis. For example, all older publications that had been superseded by newer editions or more comprehensive studies were able to be readily identified and excluded. This review process remained ongoing in order to take account of emerging literature. Notably, studies published in light of new models of education provision during the COVID-19 epidemic were introduced. This responsive and critical approach ensured that the literature review provided an appropriate overview of the field, while identifying clear gaps and opportunities for further research.

The impact of diagnosis and treatment

Such a life-threatening illness at a key developmental stage of life can have a distinct and considerable impact on the futures of young people with cancer, including on their education (Grinyer, 2007). Aldiss et al. (2009) report on the scant amount of research that has been undertaken to explore the significance of a cancer diagnosis for young people and provide an understanding of this from the young person's perspective. They note the challenging nature of the experience and feelings of isolation and restriction as well as the importance of support and communication. Studies that looked at markers of distress and their effects following diagnosis showed that children who received more information about their illness were found to be considerably less anxious (Last and van Veldhuizen, 1996). There is a need, therefore, to provide specialist social support to young people with cancer to support their specific needs including educational and employment needs (NICE, 2014). A distinct and focused approach for this age group will support their return to normality after treatment. Using a Foucauldian discourse analysis, Cable and Kelly (2019) studied the development of young people's cancer

care as a specialist area and considered how knowledge and awareness has grown through collaborative contributions. They explain how a combination of perspectives leads to new practices in healthcare. However, research has been more limited regarding the effect of new practices, such as education, in areas impacting on young people's lives. Whilst the perspectives of healthcare professionals and young people themselves have been considered, the perspectives of educators have been considered far less so.

A significant issue for young people diagnosed with cancer is the effect that various treatments, such as irradiation, intensive chemotherapy and intrathecal chemotherapy, may have on their cognition and physical well-being. As well as the physical side effects that intensive treatments can have, Montour-Proulx et al. (2005) describe how the development of leukoencephalopathy (cerebral subcortical calcifications) or neurotoxicity, as a result of treatment using methotrexate, has been linked with cognitive difficulties and learning disabilities. Although longer term effects on the intellectual development and academic functioning of young people are contested, some studies argue that chemotherapy treatments do have detrimental cognitive effects (Guran et al., 2022). It has been reported that intrathecal chemotherapy treatment alone brings with it a risk of developing non-verbal learning difficulties, difficulty maintaining focus, and a loss of social skills. Other studies have shown that cognitive function may be impaired leading to difficulties with areas such as verbal memory and geometric design recall (Armstrong et al., 1999) as well as treatment related attention deficit (Buizer et al., 2005). Reeves et al. (2007) further note the frequency of 'slow cognitive tempo' which includes attention deficit, lethargy and disorganised behaviour. According to Butler and Haser (2006) these cognitive hindrances are sufficiently similar to those associated with conditions such as attention deficit hyperactivity disorder or traumatic brain injury. These conditions often require specific additional learning interventions (Armstrong et al., 1999). This being the case, young cancer survivors are more likely to need additional learning support, and a greater understanding of their needs is crucial for the development of appropriate and effective educational interventions (Gurney et al., 2009).

The literature highlights many difficulties that young people with cancer endure with their learning, including an inability to concentrate or maintain a single focus for any length of time, a need to repetitively practice and review basic skills, difficulties with memory, sequencing, organising and learning new material, and forgetfulness, all of which lead to poor achievement under stress (Peckham, 1991). Ferguson and Walker (2012) gathered the experiences and perceptions of young people with cancer and the challenges they face. Despite painting a complex picture, one overarching aspect was the young person's need to feel as normal as possible. This included a recognition of the importance of education despite being disconnected from it. However, Sharma and Brunet (2024) found that young people who had completed their cancer treatment may be more vulnerable to cancer related cognitive impairment. Similarly, Vance and Eiser (2002) reported that young people with cancer felt more isolated than their peers who did not have cancer.

Lahteenmaki et al. (2002) note school phobia amongst a number of prominent problems found in young people after a cancer diagnosis and treatment. Young people with cancer are absent from school frequently, according to Ishibashi (2001), who suggests that further qualitative research is necessary to find a solution to these problems. Treatments such as chemotherapy also change the young person's appearance, self-esteem and overall well-being, which can lead to social withdrawal and school absence (Talla, 2017). Decreased motivation is an inherent effect of low self-esteem and can increase anxiety and may accentuate the young person's worries (Langeveld et al., 2004). Due to prolonged or multiple absences from school and the risk of treatment-induced cognitive issues, the hundreds of young people surviving cancer each year may require additional learning support and discrete education intervention programmes. Without this focus on education, such cognitive issues can lead to further psychological, psychosocial and emotional difficulties which in themselves may lead to intellectual decline and unfulfilled academic potential. Indeed, young people with a cancer diagnosis deserve and are entitled to an education that does not put them at a disadvantage to their peers. Greater insight into the effectiveness of current educational provision and how practice and policy alleviate these issues could support young people to achieve their academic potential and live as normal a life as possible.

Hinton and Kirk (2015) wrote of teachers' concerns about the risk and level of students' disengagement from education and from interacting with their peers following diagnosis of a long-term health condition. Shiu (2004) includes findings from various surveys, including a survey of over one hundred teachers in Spain that showed similar concerns around the possibility of these students becoming marginalised, as well as an Australian survey which found that teachers were troubled by the risk that their students who had been diagnosed with a long-term health condition could become isolated from their peers. Kakaki and Theleritis (2007) reported that these young people may become involved in higher risk activities involving cigarettes, alcohol and drugs, and suggest an association between the severity of the young person's medical experience and amplified risk. Several studies around educational and psychological support for young cancer survivors highlight the importance of identifying any disfunction and providing intervention at the earliest opportunity (Schultz et al., 2007). Whilst the above studies provide a valuable insight into teachers' concerns and student risk, they cover a wide range of age and year groups, and evidence is limited on the best way to meet the young person's needs at this time. The literature also fails to demonstrate any possible relationship between these issues and the stage of the young person's education journey. To find out whether these same concerns are present and/or significant at key progression stages in the students' education (i.e. at the end of Key Stages four and five), and what teacher actions are effective to overcome these concerns, further research is called for.

Communication and collaboration

An overarching theme across much of the literature is that of communication and collaboration in supporting the needs of young people with health conditions. Robinson and Summers (2012) contend that reliance on informal communication pathways to accurately communicate the needs of the young person can bring particular difficulties for some teachers who feel a sense of inadequacy when dealing with such complex needs. Hinton and Kirk (2015) conducted a review and found that teachers received little formal training and had insufficient knowledge of students' long-term health conditions. Generally, communication between the young person's school, healthcare

staff, social care services, charities and families seems to be an obstruction to the provision of effective support (Bruzzese et al., 2010). Eyong et al. (2012) suggest that garnering information from less authoritative sources increases misunderstandings and ensures inaccurate perspectives remain unchallenged. Teachers then rely on their personal experiences, general information from the internet, and discussions with parents to find out about the general nature of the young person's medical condition and how to support them (Bishop and Boag 2006).

A study of over one hundred teachers found that over half thought that young people with long-term healthcare needs did not have the same capacity for intelligence as their peers (Eyong et al., 2012). Cunningham and Wodrich (2006) revealed that teachers' understanding and abilities to effectively support the education of students with complex health needs was improved with clear authoritative information about the student's condition. Whilst teachers often depend on information provided by parents (Robinson and Summers 2012), Shiu (2004) reveals that teachers prefer receiving medical information directly from healthcare staff. Logan et al. (2007) also found that teachers' responses were directly influenced by their access to medical documentation and communication with medical staff.

Teachers' attitudes towards the return of students with long-term health conditions is mixed. Some studies indicate a positive approach around their return to mainstream schooling yet also highlight teachers' concerns about time and resource demands, and the additional monitoring and support these students need (Olson et al., 2004). Other studies found that teachers felt unprepared to support these students (Clay et al., 2004). Whilst these teacher concerns are aptly recorded, they relate to a wide variety of student health issues. None, in this regard, relate to life threatening issues such as cancer. Investigating this area is important to determine if teacher attitudes are similarly mixed and to assess their impact on open communication and the effectiveness of collaborative support for these students' education.

Schools recognise families as central to this experience, serving as key sources of informal information and facilitators of communication with other parties. Teachers expect parents to provide timely information about the student's well-being and help

ensure the young person practices necessary classroom skills (Moore et al., 2009). That said, receiving relevant detailed information directly from medical staff is deemed important (Selwood et al., 2013). Many teachers are willing to accept advice from healthcare staff and place great value on multi-disciplinary meetings where key information is shared (Moore et al., 2009). Such meetings demonstrate the importance of continuous communication between all parties and should be initiated at the earliest opportunity (Mohr and Bullock 2005).

Positive communication experiences are those that involve regular and frank interactions (Roscigno et al., 2015). McLoone et al. (2013) note that positive, open relationships enable early detection of learning needs and adaptation of learning programmes. These may include the provision of extra educational support staff, extra time to complete schoolwork and exams, and tutoring outside of school hours (Bruce et al., 2008). Discussions around planning and preparation also bring about a more productive re-entry into school and yield greater longer-term benefits (Sullivan et al., 2001).

Contrary to more productive efforts, less favourable experiences when communicating with schools have also been reported (Cheung et al., 2014). Interactions can be infrequent and haphazard, leading some parents to adopt a more defensive stance to ensure the provision of appropriate support (Roscigno et al., 2015). Communication is then operated through other professionals to ensure the needs of the young person are understood and acted upon (Kirk et al., 2015). This may indicate that effective collaboration may be hindered because of a lack of understanding or a lack of confidence in being able to manage such a complex situation. It is clear that communication between all parties needs to be formalised and multidirectional rather than relying on indirect and ad-hoc communication through parents.

An in-depth qualitative case study by Wilkie (2012) showed that teachers are not always focused on maintaining communication with students during extended periods of absence. Teachers reported being unclear about whose responsibility it is to provide education as well as contacting students during these times. Moreover, teachers expressed their disquiet and unease about young people maintaining an educational

focus whilst coping with a serious and even life-threatening illness, expecting them to exclusively concentrate on their medical condition. To realise the best outcomes for these young people, continuous effective communication between healthcare and educational staff is required, whilst addressing issues such as the sharing of appropriate medical details between all relevant parties (Mukherjee et al., 2002). Further research is required to gain a comprehensive understanding of teachers' perspectives of effective communication with students who are absent with longer term health conditions. This will help ensure teachers are supported in the provision of ongoing education and eventual school reintegration.

School staff often view their interactions with parents and healthcare staff as inadequate (Canto et al., 2014). They assert that they do not get timely notification of a young person's condition and initial contact between key professionals is often delayed which leads to a sense of limited understanding of their student's circumstances. School staff also consider the information imparted by healthcare staff to be open to interpretation. Not only are these communications deficient, but interactions between different members of staff within schools can also be lacking (Selwood et al., 2013). Poor communication within schools is borne from competing demands interrupting information exchanges (Hawley et al., 2004) as well as a lack of training and disagreements about divisions of responsibility. A key area where a lack of communication within schools can take place is during transition such as moving from year group to year group, or due to staff changes. The literature reveals that school staff view communications far more positively when they have access to relevant formal information, and they are involved in the support process. There are few studies which investigate teachers' perceptions for health conditions in general, and for young people with cancer in particular, which shows a clear need for further research aimed at understanding teachers' concerns about communication with, support for, and eventual reintegration of these young people.

Training and resources

Much of the literature reveals that teachers seem to have scant relevant formal training and assistance to help them support the education and health needs of young people

with cancer diagnoses (Robinson and Summers, 2012). A survey by Bishop (2005) revealed that only 14% of teachers had taken part in training to support specific long-term health needs of their students and a study by Lucas et al. (2012) showed that eighty five percent of teachers had not received any training at all in this regard.

The literature suggests a link between length of service as a teacher and depth of knowledge of appropriate support for students with long-term health conditions (Bishop and Slevin, 2004). Findings from a USA survey of over five hundred teachers shows that they may not be as knowledgeable about less common illnesses compared with more commonplace conditions such as asthma and diabetes (Bishop and Boag, 2006). A later survey of over two hundred teachers further suggested that, despite teachers with special educational needs expertise being more knowledgeable of supporting students with long-term health conditions, they still had an equally low level of confidence in their abilities to meet the academic needs of such students (Nabors et al., 2008). Beyond this, there has been little investigation into the links between teaching experience, training, knowledge and confidence when teaching pupils with long-term conditions, let alone life-threatening conditions such as cancer. Hearing from those who directly teach or support the teaching of these students would give a clearer insight into this area.

A review of the training that teachers did receive to reintegrate students with health issues was undertaken by Canter and Roberts (2012). It suggested that school reintegration can be facilitated, and positive attitudes achieved, through effective training which enhances teachers' knowledge of the specific illness. Teacher training programmes have demonstrated that they are effective in improving teachers' knowledge and confidence in managing long-term health needs in support of effective education (Aydin and Yildiz, 2007; Duggan et al., 2004; Fernandes et al., 2007; King et al., 2005; Smith et al., 2012). A number of these training programmes have been created with the involvement of healthcare professionals and aim to help teachers build sufficient knowledge and confidence. The results of a study by St Leger and Campbell (2008) suggest that teachers viewed the training and information provided by medical professionals to be beneficial. Sapien et al. (2004) reported that teachers' knowledge

was significantly enhanced after a one-hour training session on a specific health issue. It strengthened their understanding of the need to continue to provide educational support to students undergoing treatment. That said, the demand on teachers' time and the additional workload was seen to be considerable.

The literature indicates that there are opportunities for healthcare professionals to assist with the development and/or delivery of educational programmes for students with long-term conditions (Brown et al., 2011). Teachers welcome such assistance (Shiu, 2004) and there is scope to provide this remotely, quickly and cost-effectively (Dubowy et al., 2006), although further research is needed. Sapien et al. (2004) also noted that viewing relevant videos had a greater effect than instruction alone. Two further investigations suggest that there is potential to use current technological resources to provide training remotely (Brown et al., 2011; Dubowy et al., 2006). Both of these investigations proposed that the use of technology-based training, developed in collaboration with healthcare staff, would be user friendly and would improve teachers' knowledge of childhood cancer. It should be noted that these studies involved only a small sample of teachers; research involving a larger sample would further validate these findings.

The literature indicates that there is a significant need and opportunity to improve the education and training of teachers (Tolbert, 2009). Where there is an absence of ongoing professional training which supports teachers in the provision of education and their knowledge in managing health issues, there is also the risk of an adverse impact on the student's safety (RCN and UNISON, 2013). The highest priority for this training would be to ensure teachers can appropriately and quickly respond to any medical emergency; any hindrance here could result in significant harm to the student. Teachers need to be able to deal with possible medical scenarios and be confident in their abilities. This will ensure that students with cancer and other long-term conditions are not unnecessarily limited in their involvement in school activities due to concerns about health risks (Boden et al., 2012). Studies conducted by Duggan et al. (2004) and Canter and Roberts (2012) contend that a positive change in teachers' attitudes towards long-term health conditions is not an automatic consequence of improved knowledge. There are multiple reasons why teachers may consider this a challenging prospect, but further

research would help establish whether relevant teacher training could alter any negative attitudes, negate unsafe environments and improve learning experiences for the student.

The literature highlights the need for targeted professional training to address the educational needs of students with long-term health conditions. Shaw and McCabe (2008) argue that such training equips teachers to make appropriate adjustments to learning activities, enabling these students to participate fully in education. Maslow et al. (2012) emphasise the importance of addressing these needs to ensure students with health conditions achieve their academic potential and are not further disadvantaged. Several charity organisations have provided guidance and information for teachers around long-term health conditions (Diabetes UK, no date; Health Conditions in Schools Alliance, no date). Only relatively recently have similar resources been made available to download in relation to cancers (Children's cancer and leukaemia group, 2023), yet this is not an equitable substitute for direct training. Evidence suggests that healthcare professionals are well-positioned to support teachers in understanding and addressing students' specific needs (RCN and UNISON, 2013). However, a lack of formal processes linking training, communication, and policy presents a critical gap in educational provision for students with health conditions. Further research is necessary to examine how effective training and improved collaboration between healthcare and education staff can address this gap.

Reintegration

With increases in cancer survival rates for children and young people, and the effects of its treatment, comes a need for specialist and personalised educational support. In the past, school reintegration for young people with cancer has not been comprehensively supported by the full range of integrated services required. Harris (2009) declares that school reintegration for this group is most successful when actions between home, school and hospital are coordinated, yet it is difficult to find clear models which detail such focused reintegration. School support services can lack the extensive approach to care that is so important to the treatment of long-term health conditions such as cancer (Gregory et al., 1994). School reintegration often involves a focus on returning the

young person to their usual educational setting and following mainstream educational programmes. However, the fact that they may have disease and treatment related cognitive deficits to some degree is often neglected and can lead to a cycle of failure, frustration, depression and regression resulting in the need for further educational support (Peckham, 1991).

Communication issues described above are particularly relevant during reintegration, and knowledge of the young person's medical situation is crucial for school staff following a return to school. However, they often bemoan a lack of information, an issue which is also declared by healthcare staff and parents (Selwood et al., 2013). School staff may gain some medical and health related information, but they may still feel that they are insufficiently aware of the possible impact of the diagnosis on the young person's education. To confound this, health-related information sourced by the teachers themselves may be flawed (Donnan et al., 2015; Moore et al., 2009). School staff declare that knowledge about the young person's medical condition should be shaped in a way that informs the educational context so that they may provide adequate support in that regard (Mohr and Bullock, 2005; Selwood et al., 2013). Further, the usefulness of just-in-time information around the time that the young person will be reintegrated into school life is highlighted by school staff and parents alike (Aukema et al., 2011; Moore et al., 2009). Initially, parents can provide some basic information about changes in their child's educational motivation and needs. Healthcare providers are then best positioned to follow this up with more detailed responses. However, as has already been outlined, school reintegration can be hampered by poor communication and a lack of training around dealing with young people with healthcare needs (Selwood et al., 2013).

The literature reveals that teachers believe that students with long-term health conditions bring added risk to their role because of the additional responsibilities that their healthcare needs demand (Olson et al., 2004). Boden et al. (2012)'s study in England involved twenty-two teachers who indicated a degree of apprehension about the care that young people with long-term health conditions required and the possibility that their actions would be incorrectly judged and criticised. They also found that the

teachers were concerned about the young person's ability to manage their own condition as well as being afraid that their own lack of understanding and experience could lead to the provision of improper care. A similar study in the USA highlighted similar concerns about teachers' abilities to properly manage students' healthcare (Boyle et al., 2004). Boden et al. (2012) suggest that teachers are keen to support their students but are wary of their need to safeguard their own personal and professional position. These studies show a consistent theme which has considerable implications upon the effective reintegration of these young people back into school following their diagnosis and (during) treatment. Further investigation, which builds upon the valuable research already undertaken, could further explore how best to overcome teacher anxieties, and possible incompetence and lack of confidence, when dealing with students who have cancer.

Some studies indicate a positive approach by teachers towards the reintegration of students with long-term health conditions back into mainstream schooling (Rodehorst, 2003). Conversely, Clay (2004) reports that teachers believe themselves to be inadequately prepared to support such reintegration. Other literature reveals a similar less positive picture with teachers concerned about the demands on their time and resources resulting from the necessary additional monitoring and support that these young people require (Olson et al., 2004). Whilst these teacher concerns are aptly recorded, they relate to a wide variety of health issues. None, in this regard, relate to life threatening issues such as cancer. An investigation in this particular area is worthy of attention not only to see if teacher attitudes are equally as mixed, but also to find out what effect their attitudes have on the success of reintegration and the effectiveness of the education provided to these young people.

For parents, the main areas to work together on with key professionals during their child's period of school reintegration are the provision of an appropriate education and adequate support for their condition. At this time, parents look for advice and direction on how reintegration can be best designed to facilitate effective learning and support well-being (Mitchell et al., 2006; Selwood et al., 2013). Some research shows that health-related advice from healthcare can be of great importance at this time (Gagnon

et al., 2008; Selwood et al., 2013). Parents also value communication from school staff about their child's ongoing readjustment in these areas. More research into the effectiveness of communication between teachers, parents and healthcare staff in support of school reintegration could shed further light on any barriers to the provision of an effective education for these young people. Further, the notion of an appropriate education needs to be explored further to consider whether teachers have a different view from other stakeholders and whether that view is somewhat skewed by the backdrop of the young person's life-threatening diagnosis.

Vanclooster et al. (2018) remark on the insufficient research into the association between communication and students' school reintegration. Healthcare staff report of informal and poorly established cooperative and consultative practices between themselves and school staff (Eilertsen et al., 2004). Ball and Howe (2013) state that specific information about individual students is not always available to all those who need it. Further, Moore et al. (2009) report the lack of clear divisions of responsibilities between healthcare and school staff and poor initial communication when the young person returns to school. Despite most professionals valuing the exchange of information in support of the young person, meetings and consultations are not standard practice (Eilertsen et al., 2004). Healthcare professionals declare that the education of school staff could lead to better levels of support as the young person returns to school and carries out their educational activities. They feel that education, healthcare and family needs can be better integrated with a more flexible and pragmatic approach from teaching staff (Moore et al., 2009; Pini et al., 2013). The literature uncovers these deficiencies and highlights the need for improvement, yet it rarely fully considers the barriers to effective practice. More research is therefore required to consider the obstacles and how best to overcome them in support of an effective reintegration programme that meets the needs of these young people.

The importance of effective collaboration following the completion of the young person's treatment is recognised by healthcare staff (Ball and Howe, 2013; Pini et al., 2013). They note the requirement for more information around education policies and services (Ball and Howe, 2013; Moore et al. 2009; Pini et al. 2013) to help parents successfully

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support their child's return to the educational system. Some of the literature identifies a desire by professional staff and parents alike to appoint a school liaison who could act as a link between all stakeholders and oversee the young person's successful return to school (Donnan et al., 2015; Mitchell et al., 2006; Pini et al., 2013; Selwood et al., 2013.). This could ensure that pertinent information and available training is able to be accessed by relevant stakeholders following the young person's return to school (Ball and Howe, 2013; Mohr and Bullock, 2005). It is suggested that their remit could also include direct supervision of the reintegration process, including the coordination of additional educational services (Mitchell et al., 2006; Sharp et al., 2006). The liaison would not only be generally knowledgeable of the young person's condition and long-term health needs but would also be able to support specific individual circumstances (Donnan et al., 2015; Mitchell et al., 2006; Pini et al., 2013).

COVID-19 lessons

The COVID-19 pandemic significantly disrupted education systems worldwide. Developments reshaped educational delivery during the pandemic while highlighting obstacles faced by vulnerable students. In a multi-cohort study in Wales, almost half of respondents said the pandemic had affected their learning a lot, with over one third not being able to access learning materials at home (Foster et al., 2022). Such obstacles are commonplace for students with cancer, who experience prolonged absences. Addressing these is critical to ensuring that students with long-term health conditions can access education equitably (Parker et al., 2020).

Edirisingha (2022) documents the global shift to online learning from kindergarten to university, with a widespread adoption of digital platforms like Zoom and Google Classroom. Online learning offers opportunities for educational continuity despite physical absences from school (Maity et al., 2021). Sato et al. (2024) highlight how such models accommodate diverse learning needs by enabling students to access education in ways that align with their medical circumstances. Spencer et al. (2024) demonstrate the value of flexible pathways for students with long-term physical health conditions, with participants reporting that online resources introduced during the pandemic enhanced accessibility and engagement, allowing them to continue learning even when

confined to their homes. However, as schools returned to predominantly in-person instruction, it was noted that these supports diminished, raising concerns about the sustainability of online and hybrid models. Bozkurt et al. (2022) highlight the need for enhanced digital readiness and ongoing investment to strengthen technological resilience and continuity. Overall, this adaptability represents a promising development for students with cancer. However, while hybrid approaches could benefit such students, the lack of institutional commitment to maintaining these learning pathways risks excluding them from consistent educational access.

The rapid transition to online education created both opportunities and challenges. Glietenberg et al. (2022) document how scepticism regarding the effectiveness of online learning evolved into recognition of its potential long-term value. Kaden (2020) notes that online learning provided increased flexibility and reduced social pressures, which benefited students managing long-term health conditions. However, challenges persisted, including insufficient support systems, reinforcing the need for comprehensive, long-term strategies to address these gaps. Significant barriers, including unequal access to digital tools and reliable internet connections add to those challenges (Parker et al., 2020; Katz et al., 2021). Winter et al. (2021) further discuss how technology's role in education was both transformative and unequal, disproportionately disadvantaging those without sufficient resources. For students with cancer, access to consistent technology and emotional support, in addition to academic adjustments, remains essential to sustaining engagement in learning. Technology alone cannot meet their needs; these students, already dealing with the physical and emotional challenges of their condition, require holistic support systems.

In a dialogue with Sally Power, Afonso et al. (2018) report on the importance of inclusive education policies, sufficient funding, and tailored accommodations, such as examination adjustments, specialised learning resources, and assistive technologies. The systemic inequalities exacerbated by the pandemic (Couper-Kenney and Riddell, 2021) further reveal the need for such policy interventions to support marginalised groups, including students with chronic illnesses. Such measures are crucial for fostering equitable access to education for students managing long-term health

challenges. Julius and Sims (2020) suggest that digital provision for vulnerable students is lacking and emphasise the importance of equitable access, not only to address barriers faced by disadvantaged students, but also to prevent further inequalities. Further, Czerniewicz et al. (2020) call for emergency action plans and communication protocols to ensure learning continuity during periods of disruption. The successful implementation of effective policies, plans and protocols are essential to sustaining academic engagement during extended absences, and depends on collaboration between educators, healthcare professionals and policymakers. Ensuring these students receive consistent and meaningful support requires an approach that moves beyond short-term fixes to provide lasting solutions that integrates their educational and medical needs.

Thie transition to online learning, whilst transformative, required rapid adaptation by educators. They faced challenges due to a lack of professional training in online instructional methods, which impacted the quality and consistency of teaching (Czerniewicz et al., 2020). The pandemic also highlighted the critical role of teacher preparedness in maintaining student engagement. An et al. (2021) explored the experiences of teachers during the early stages of the pandemic, identifying key challenges such as low student participation, limited parental support, and the need for rapid adaptation to digital tools. Teachers play a crucial role in maintaining students' academic progress, but without proper training, they may struggle to provide the necessary support, highlighting the importance of professional development programmes that equip them with the necessary skills. Roman et al. (2022) also emphasise the importance of trauma-informed teaching practices. Their work highlights how educators adapt their instructional approaches to address students' emotional and cognitive needs, which is particularly relevant for students with chronic illnesses who may experience times of heightened strain due to their medical conditions and treatment regimen. Trauma-informed strategies promote a supportive and empathetic learning environment, however, their widespread adoption requires targeted professional development and institutional commitment.

The lessons learned from the pandemic highlight the importance of building resilient and inclusive education systems. Investments in teacher training, flexible learning plans, and digital infrastructure are essential for addressing educational disruptions and ensuring continuity for all learners. Bozkurt et al. (2022) highlight the need for preparedness through the integration of innovative tools and teaching strategies that promote equitable access to education. For teenage students with cancer, these measures are not just helpful but necessary to bridge the gap between their medical realities and educational aspirations. By addressing these challenges, education systems can ensure that all students, regardless of health status, have the opportunity to thrive academically.

Conclusion

This review has identified a number of gaps in the literature. Many of the studies focus on more common and less life-threatening long-term conditions such as asthma, diabetes and epilepsy. Comparatively, there is very little research around teachers' knowledge and perceptions of other conditions, including cancer. Focused research in this particular area could uncover additional concerns that are specific to this disease and are thus not discussed elsewhere. Whilst a large-scale survey of teachers may be advantageous, even a small-scale investigation involving any professional in support of education could usefully identify relevant training needs. The literature also spans many different countries and, although similar findings are published, it is not clear how they relate to different sociocultural contexts, let alone local educational policies. There is clear scope to undertake research which considers the relationship between the creation of higher-level policy and local enactment. A consideration of the country-specific landscape could provide more detail and yield a more nuanced picture.

Finally, the literature reviewed predominantly focuses on the student, the parent, or key health professionals. The perspectives of other staff working in support of education provision are equally important in order to provide a complete picture of the educational experience of young people with cancer. Whilst this review has called attention to the training needs of teachers, it is important to acknowledge that they are not the only ones responsible for providing and supporting the education of a young person with a long-

term health condition. Others could include teaching assistants, charity support workers, hospital play specialists and people at local authority level with responsibility for governance and oversight. Identifying those with key responsibilities for supporting these students is important. Exploration of current training opportunities taken up by all supporting personnel to ensure they are adequately prepared to provide an equitable education is also called for in order to provide a comprehensive picture.

Chapter 3: Methods

Introduction

This chapter provides an overview of the methodological approach and the methods used to complete this research. The pertinent conceptual frameworks are introduced and consideration given to the strengths and weaknesses of such methodologies. The research design and data gathering processes are described, including the geographical scope, recruitment procedures, and issues arising as a result of the COVID-19 pandemic. I then outline the use of an online qualitative questionnaire and the use of semi-structured remote interviews which looked to elaborate on the answers provided within the questionnaire. This is followed by a section outlining the process of analysis, applying a thematic analysis to the interview data, supported by a document analysis of relevant policies, guidelines and reports, which was used in combination with, rather than as an alternative to, other data sources used. I conclude with a brief examination of the relevant ethical issues and positionality.

Research design

Holloway and Todres (2003) state that it is essential that researchers be clear about the assumptions that underpin their research. The following sections, therefore, outline the ontological and epistemological positions that underscore the research paradigm and the rationale for adopting the chosen methodologies and methods. Silverman (2013) notes the importance of adopting a methodology based on the research questions. The research questions herein are aimed at examining perceptions of education provision and the quality thereof across Wales. This is compatible with a qualitative approach which concerns itself with meaning and understanding of how the world is experienced and made sense of (Willig, 2013). Further, Elliot (2005) states that the aim of qualitative research is to understand people's experiences of, and actions within lived situations.

Ontology and epistemology

My research adopts a pragmatist ontological position, which views reality not simply as subjective construction, but as something that emerges through human action, context and practical consequence (Robson and McCartan, 2016). From a pragmatist

perspective, knowledge and understanding are developed through experiences and interactions within specific situations, where meaning is constructed through practical engagement with the world (Dewey, 1938). The pragmatist stance of my research, as an active process of discovery, reflection and action, will aim to explore education practitioners' contextual practices and understandings, contributing to a more action-orientated and responsive analysis of education provision for young people with cancer in Wales.

With an emphasis on the participants' experiences and perceptions, my research will focus on understanding the subjective insights of participants and will therefore take a subjectivist epistemological position with knowledge being viewed as an ongoing construct resulting from interactions between people. This tradition maintains that it is considered impossible for knowledge to be unaffected by personal interpretations and perceptions; meaning is created in numerous ways by various people who interpret the world differently (Gray, 2014). My intention is to develop an understanding of educators' beliefs and behaviours; to be aware of their experiences and recognise that they have different views, and different experiences, of the same or similar situations. From this position, each participant's understanding of reality is equally valid and is there to be understood (Punch, 2005).

Together, this pragmatist ontology and subjectivist epistemology supports my qualitative research by placing a high value on participants' unique viewpoints and experiences within the given context. It recognises that participants' interpretations are central to understanding and that their voices shape both insights and practical responses. This philosophical alignment enables the exploration of complex, context-dependent understandings, allowing for a more flexible and adaptive approach to inquiry. This qualitative research, guided by these principles, can capture a rich set of data, delving into the subtleties of individual perspectives and uncovering layers of meaning that might otherwise be overlooked. This makes it possible to build a nuanced understanding that reflects the diversity and complexity of the educators' experiences within their contexts.

Research paradigm

This pragmatist ontology and a subjectivist epistemology is the basis for an interpretivist approach to my research, recognising that experiences are subjective and vary across individuals. According to Kivunja and Kuyini (2017), a key feature of interpretivism is that the social world cannot be fully understood from a single perspective because realities are multiple and context dependent. This study brings together multiple perspectives from educators to construct a more comprehensive narrative, accepting that each participant may interpret knowledge uniquely (Smith et al., 2009). By adopting an interpretive paradigm this research will focus on comprehending participants' experiences and actions (Fossey et al, 2002). Denzin and Lincoln (2005) explain that interpretivist research is guided by the researcher's own worldview and interpretation of how reality should be understood. A recognised limitation of this approach is its inherent subjectivity, which can introduce bias into the research process (Creswell and Poth, 2018). Additionally, interpretivist research may lack reliability and generalisability, as findings are often context-specific and shaped by the personal values and perspectives of both the researcher and participants (Merriam and Tisdell, 2016). However, this approach enables in-depth exploration of complex qualitative areas, such as the diverse factors influencing organisational practices, providing rich, nuanced insights. As a result, the primary data obtained through interpretivist research often exhibits high validity, reflecting participants' authentic experiences and perceptions (Lincoln and Guba, 1985).

Methodology

Considering the above positions, I determined that a qualitative approach was most suitable for my research, as these methods are widely recognised as effective for exploring how individuals make sense of the world, focusing on the richness and depth of their experiences (Holland et al., 2008). My approach centres on exploring how different educators perceive educational provision, enabling the identification of both shared and divergent perspectives and thereby deepening the understanding of the issue (Sbaraini et al., 2011). Qualitative studies have proven valuable in capturing in-depth perspectives within real-life contexts, as demonstrated in Grossman's (1992)

work with student teachers and Clandinin's (1986) studies on experienced teachers' professional development.

Through the collection of data from various participants, utilising individual semi-structured remote interviews, my research highlights commonalities across interviews (Tellis, 1997) as well as unique perspectives, enriching the analysis and understanding of the topic (Patton, 1999). This qualitative approach allowed me to gain a nuanced understanding of participants' perspectives, capturing the complexity of their experiences and the meanings they attribute to them. This methodological choice ensured that my research not only provided detailed, context-specific insights but also contributed to a deeper understanding of the relevant issues, grounded in participants' lived experiences, ultimately gathering rich, descriptive data (Lichtman, 2014).

Data collection

Recruitment

My research investigated the education provision for young people with a cancer diagnosis specifically within Wales. In order to keep the parameters of the research as narrow as possible, it was initially planned for this research to cover South, West and Mid Wales only. The aim was to ensure that all participants were not only guided by the same overarching (Welsh) education policies, but moreover that health provision was of a uniform nature. Cancer treatment within these regions is coordinated by the University Hospital Wales (UHW), whereas the treatment for young people from North Wales may be provided across the national border by Alder Hey Children's Hospital, Liverpool or The Princess Royal Hospital, Shropshire. Thus, the aim was to ensure that the research backdrop was consistent from both an education and health perspective. By narrowly defining the geographical scope, it was hoped that the educators' voices would stand out clearly without the noise of differing education policy approaches or differing medical treatment regimen. With such a small group of professionals to call upon, and because of the COVID-19 pandemic, recruitment proved to be slow. It was eventually decided to broaden the scope to include North Wales. This did not detract from maintaining a narrow backdrop as it meant that overarching education policy remained the same and,

it was discovered, treatment regimens do not differ as greatly by region as it does by cancer type and individual needs.

The COVID-19 pandemic posed significant challenges to my recruitment endeavours. During the pandemic, professionals from healthcare, educational, and government sectors experienced increased workloads, staff shortages, and high levels of stress, often limiting their availability and willingness to engage in non-essential activities like research participation (Johnson et al., 2021). Social distancing, remote work mandates, and the shift to virtual communication further complicated recruitment efforts, as traditional in-person approaches became unavailable. This problem was widespread with researchers also facing ethical considerations, needing to balance recruitment efforts with sensitivity to participants' heightened stress and potential exposure risks, which at times made them hesitant to engage (Corbin and Strauss, 2021). Consequently, COVID-19's impact led to decreased response rates to research requests and higher dropout rates, as many potential participants prioritised urgent professional responsibilities over participation in such academic studies (Rogers-Brown and Kreuter, 2021).

All twenty-two local authorities across Wales were contacted, with the invite directed towards those professionals with recent experience of providing education to young people in Wales with a diagnosis of cancer. A combined consent form and research information sheet (Appendix A) was provided which detailed the nature and purpose of the research. It was hoped that this could alleviate any perceived disconnect between higher education research and the priorities of local authorities, which often makes it challenging for them to justify allocating limited resources (Power et al., 2009). The local authorities were also asked to identify any schools that could be approached and to pass on the research information sheet and a request to participate. They were contacted initially by email which elicited a very poor response, which was followed up with further email requests and telephone calls. Following this poor uptake through the local authority route, it was decided to contact all secondary schools in Wales directly. The schools were emailed initially with the relevant research information and a request to participate. I received no responses, so a final attempt was made through personal

local contacts. All major hospitals that provided and/or coordinated cancer treatment for young people were also contacted. This not only included Welsh hospitals but also those across the border in England that treated patients from Wales. These were then narrowed down to those that provided on-site education, whether this be through a dedicated teaching unit, through visiting tutors or through education support staff.

Of the twenty-two local authorities, almost two hundred schools, and all major hospitals, and following an eighteen-month recruitment campaign, only fifteen completed questionnaires were received and eight participants proceeded to the interview stage. Their roles spanned schools, hospitals, local authorities, and the third sector. Three worked for separate local authorities in different areas of Wales. Two secondary school teachers from separate local authorities were also recruited - one was an experienced classroom teacher, the other with middle-management responsibilities. The final three participants were based in three separate hospitals. One was overall in charge of hospital-based education whilst the other two – one of whom was employed by the hospital and the other by a charity - worked in support of the provision of education. Participants were predominantly but not exclusively female, ages ranged from their thirties to their fifties, and the majority had over ten years' experience. Overall, North, West and South Wales were represented. Further to this summary of participant characteristics, a tabulated breakdown of the eight interview participants is provided in Chapter 4, Table 4.1 to support contextual understanding of the findings.

Recruiting a diverse range of stakeholders across institutions, roles, and demographics provided a broad spectrum of perspectives that enriched the data (Creswell and Poth, 2018) and supported a more holistic understanding (McGregor et al., 2024). Research suggests that smaller samples can be effective in qualitative studies. Guest et al. (2017) suggests that qualitative interviews often reach a point where new information or themes from additional participants diminish rapidly, and saturation point is reached at around 12 participants. In this research, data saturation was achieved, with no new themes emerging.

Questionnaire

Participants who provided consent through the research information sheet and consent form were then sent an electronic link to an online questionnaire (Appendix B) which utilised the Qualtrics software programme. Qualtrics was chosen because it is widely used throughout academic and business arenas and, crucially, maintains security through high-end firewall systems and Transport Layer Security (TLS) encryption for all data. The front page of the questionnaire provided participants with an overview of the research and its aims and invited them to take part. It included a clear statement that participation was voluntary, and they could refrain from answering any questions or stop participating at any point. To ensure confidentiality, prospective participants were assured of anonymity (as far as possible) and that any personal data would be used for research purposes only and would be kept completely confidential and secure. They were signposted to relevant information sources before again requesting consent in order to continue.

Although the questionnaire was not formally piloted, it underwent quality checks, generating useful feedback for refinement. This feedback was aligned with the research aims, leading to adjustments that enhanced its focus and usability. The eventual questionnaire was organised into two sections. The first utilised closed and multiple-choice questions to gather information on participants' professional backgrounds, such as roles, responsibilities and experience. This was designed to get an understanding of the professional demographics and to act as a (unused) filter for the interview stage if necessary. It was considered important to create this concrete backdrop against which further responses could be considered and compared, allowing their accounts to be located within their individual contexts if necessary. The second stage took a far more qualitative approach with a range of open questions aimed at eliciting the participants' feelings, understanding, thoughts, experiences and perceptions. These questions centred around professional effectiveness, challenge, support and fulfilment. This was supported by further multiple-choice (including a free-text option) questions to help inform the interview framework and establish a foundation for the interview questions. As such, the questionnaire did not gather statistical data to be analysed using statistical

software. It did provide an overview of participant demographics and allowed them to share insights and express their views on key issues. On completing the questionnaire, participants were required to confirm if they were still willing to take part in a follow-up interview. They were informed that the interview would take place remotely at a mutually convenient time.

Interviews

The second stage involved interviews based on insights from the literature review, and educators' experiences outlined in the initial questionnaire. They comprised a single meeting aimed at encouraging open-ended discussions focused around the main research questions. These semi-structured interviews provided a uniform framework (Appendix C) but importantly allowed for deeper investigation into emerging issues and themes. It supported the rich exploration of participants' subjective knowledge, attitudes, and perceptions on this specific issue. Additionally, the flexibility of these semi-structured interviews made it possible to pursue novel insights and investigate unique perspectives as they arose (Ruslin et al., 2022).

Piloting

Prior to formal release, the interview questions underwent formal piloting which provided relevant feedback for improvement. This was considered in line with the research questions and interview questions were altered accordingly. This was a useful course of action which helped refine processes as well as being a tool to reflect upon aspects of data collection, validity and ethics (Sampson, 2004). It created the scope to practise interview technique as well as testing out the interview framework so that its feasibility could be assessed (Robson, 2002). Due to the very small pool of professionals available for this research in the first place, it was deemed necessary to conduct the pilot using an educational professional without experience of delivering education to young people with cancer. They were, however, able to draw on their broad and lengthy experience to provide answers with experiences of a similar, but not identical, nature. Feedback from this pilot study led to confirmation of the practicability of the framework in terms of the question selection and composition, its ability to elicit rich responses, and the timescales required.

Location

All interviews were conducted remotely, in line with COVID-19 restrictions and practices, with each participant selecting their own setting. Practically, such remote interviews proved easy to arrange as they did not require the participant to be present at a specific location, thus causing minimal disruption to their daily routines. All took place in professional surroundings familiar to each participant but, crucially, in a private space where they wouldn't be overheard and where the risk of distractions and interruptions was minimised. This offered convenience for the participants, created an additional feeling of privacy compared to face-to-face discussion (Vogl, 2013) and provided a perceived level of anonymity (Oltmann, 2016). Further, because of the possibility of emotional triggers resulting from sensitive discussions, the remoteness of the conversation allowed the interaction to be more comfortable (Opdenakker 2006). That said, a criticism of qualitative remote interviews is that non-verbal cues such as general body language can be missed (Oltmann, 2016). Greater attention was paid to what the participants were saying in order to assess their understanding of the questions asked (Trier-Bieniek, 2012).

Interview conduct and framework

At the beginning of each interview, I took the opportunity to provide information on my professional and related personal background to foster a connection and help establish rapport (Kvale and Brinkman, 2009). The level of rapport is said by Jorgenson (1992) to affect the quantity and quality of interview responses and encourage participants to speak candidly. Further, Vogl (2013) suggests that remote (telephone) interviews can allow for a more balanced power distribution between researcher and participant, thus encouraging a more open discussion of sensitive topics. The initial interview question, 'Tell me about your role', was answered easily and fully by participants. It gathered extensive current professional information and context and also elicited responses that shed light on their professional, and sometimes personal, journey. This opener achieved its intention of helping ease the participants into the process and further building rapport before moving on to questions more focused on the topic at hand (Brown and Danaher, 2017).

The interview questions proceeded to explore participants' perceptions, knowledge, relationships, experiences and ideas relevant to the research topic. Follow-up questions were asked when appropriate, allowing participants an opportunity to provide extensive responses. This created a richer, conversational narrative from the interviewees, providing the possibility for a greater understanding of their perceptions (Priede et al, 2014). The ease with which participants responded to the interview questions and their enthusiasm for sharing professional knowledge were positive indicators that participants found questions accessible and meaningful. This reflected an alignment between the interview topics and participants' areas of expertise, as well as an investment in the discussion (Patton, 2015). This level of engagement supports the quality and validity of the research findings, as participants are more likely to articulate nuanced insights within their field (Merriam and Tisdell, 2016). Participants' enthusiasm for sharing their knowledge enhanced the data collected through detailed, thoughtful responses, allowing for a deeper understanding of the issues under investigation (Seidman, 2006).

A closing question asked if participants would like to share any other thoughts or suggest recommendations for improvement. This open-ended closing question, a valuable strategy in qualitative research (Kvale and Brinkmann, 2009), intended to provide participants with an unrestricted opportunity to share additional insights or recommendations they may not have addressed earlier. Most participants simply reiterated key points rather than introduce new information (Guest, MacQueen, and Namey, 2012). This reinforcement of core points was still valuable, as it highlighted areas of consensus and underscored the main issues discussed, offering insights into participants' priorities and validating the main findings of the study (Seidman, 2006).

Recording and transcribing

As a result of the COVID-19 pandemic, as with many other qualitative researchers, I used a video-call app (Zoom or Microsoft Teams) to undertake interviews. All interviews lasted between forty-five and sixty minutes, and audio was recorded using a handheld digital voice recorder. Where Zoom was used, the inbuilt audio and video recording feature was also activated. This offered a practical and accessible means of collecting data while maintaining safe social distancing practices. However, this also presented

the potential for technological issues. All devices were thus pretested, aligning with best practices in qualitative research and ensuring reliability in the data capture (Salmons, 2015).

Each interview transcription took several hours and were anonymised and transcribed as soon as was practicable within a short period following the interviews to avoid memory degradation or interpretative bias that could accrue over time. When transcribed into standard written English, the participants' speech sometimes seemed a little inarticulate as a result of repetitions, interruptions, restarts and the use of filler words. In line with the subjectivist epistemological position of this research, and its aim to fully understand the subjective perceptions of participants, all interviews were originally transcribed in a denaturalised, full-verbatim manner (Bucholtz, 2000) and included all errors, repetitions and utterances. Given that transcription itself is an interpretative act (Bird, 2005), I had to determine the degree of contextual detail to include (Butler, 2015). Therefore, as suggested by Tilley (2003), extraneous aspects were omitted for quotes used in the final thesis to avoid cluttering the text, thereby recording closer to what was intended, whilst still reflecting the original nature of what was said (Braun and Clarke, 2006). Transcription accuracy was ensured by crosschecking the finished results with the audio recordings.

Analysis

Interview analysis

I chose to utilise a thematic analysis (TA) method to identify, analyse and report patterns (Boyatzis, 1998) across the datasets. The flexibility of TA allows researchers to explore how different themes interact with one another and how they may reflect broader societal, cultural, or personal issues, thus providing a nuanced and multi-layered account of the data (Braun & Clarke, 2013). This flexible approach helped provide a detailed account of the data and enabled deeper insights into the meaning behind these themes (Braun and Clarke, 2019). Of importance is that such analysis could inform policy development (Braun and Clarke, 2006), which is an aspiration of this research project. The first step involved close observation of the interview data through repeated and concentrated listening during the transcription process. I approached this

as a journey of discovery, engaging deeply with each interview by repeatedly listening to the recordings during transcription. This process fostered familiarity with the content and nuances, such as tone and pauses, enabling an awareness of previously unforeseen meanings (Pope et al., 2000).

Following the six stages of TA (Braun and Clarke, 2006) (Appendix D), the dataset was analysed systematically, and initial codes generated by identifying similarities across the entire data set. Data extracts were coded multiple times to capture as many relevant patterns as possible across different areas of interest. Whilst codes were attached to different size units of data, they always represented a complete notion. Earlier coded data was periodically reviewed to ensure consistency with data addressed later in the analysis. The coding scheme was deemed complete when further patterns ceased to emerge. Coded data was grouped into initial themes based on similar meanings, each given a concise name reflecting its relevance to the research questions. Significant data points were organised into primary themes and sub-themes, with relationships between codes and themes identified. Incompatible codes were labelled as miscellaneous and set aside for further review.

The identified themes were examined for cohesion and reviewed to determine if they should be refined, combined, retained, or discarded. Unattributed codes were reanalysed and reassigned where appropriate, or new themes were created as needed. Themes with insufficient data were discarded, and similar or interrelated themes were amalgamated. The entire dataset was re-read, and coded extracts were checked against the themes to ensure a coherent pattern. Links between main themes and sub-themes were refined to ensure they were clear and well developed. The coding process ended when the thematic map accurately reflected the key features of the data, providing a detailed description and highlighting similarities and differences.

Document analysis

Document analysis, used here to supplement interview data, is often used in qualitative research in combination with other methods as a means of triangulation, since information derived from them can be valuable additions to a knowledge base. The documents sought were those that contained, or assumed to contain, valuable sources

of information to guide education providers in Wales. In my research, these documentary sources were not used as alternatives to other data sources, but in addition to them, as an understanding of day-to-day operation within any organisation cannot be learned through records alone (Atkinson and Coffey, 2004). Apart from providing data on the context within which research participants operate and a policy backdrop to their actions, a key advantage of compiling such documents is that it can provide a large amount of reliable relevant information. Their use was also aimed at identifying the intentions of the communicator, unveiling cultural patterns and revealing the focus of institutional attention (Weber, 1990). By drawing upon both sources of evidence – interviews and documents – this research aims to explore any corroboration or convergence. This triangulation of the data provides a collection of evidence, further enhancing credibility (Eisner, 1991).

The documentary analysis involved several practical steps to ensure meaningful insights were extracted. First, clear objectives were set to define the information sought from the documents - primarily, to identify the specific and the more general guidance available to support educators working with young people who have cancer. Document collection started at an early point in this research and continued until evidence at all levels from local to national level were obtained. All documents gathered were either public records or publicly available records. As such, they were readily accessible and could be obtained directly from the respective public body or organisation, either online or otherwise. An initial internet search was conducted using relevant search criteria which produced several higher-level policies and reports from the likes of Welsh Government and Estyn, the Welsh inspectorate. A further detailed and expansive search was undertaken which targeted specific organisations such as local authorities, relevant charities, hospitals and schools which uncovered more localised documentation. Finally, where a shortage of information existed, organisations were contacted directly by email and a request made for any relevant records.

The documents obtained were non-technical in nature and a source of information within the context of the participants' professional practice. The documents were mainly policy documents, guidelines and organisational reports but also included other types

that could help 'uncover meaning, develop understanding and discover insights relevant to the research problem' (Merriam, 1998, p.118). They ranged from national level documents such as Government guidance around additional learning needs, Children's Commissioner for Wales reports on hospital-based education, and Estyn reports on effective support, to relevant local policies and cancer charities' information brochures. Once gathered, the content of each document was examined, and all relevant extracts were catalogued. These extracts were then read alongside the interview data to provide background and to contextualise participants' accounts of their experiences, thus building a richer picture of the various participants' realities.

Ethical considerations

Procedural ethics

This research was conducted in accordance with Cardiff University's research integrity and governance code of practice, as well as adhering to the School of Social Sciences' Professional Doctorate student handbook. Ethical approval (Appendix E) was granted from the School's Research Ethics Committee prior to commencing the study and the relevant ethical, legal and professional standards were complied with to ensure safe and responsible conduct at all stages. As such, the University's expectations to observe the highest standards of research integrity were met in order to facilitate high quality research.

All potential participants were provided with an information sheet when first invited to take part in the research process. This included details of my professional and personal background, and an outline of the purposes and procedures of the research, amongst other things. Attached to this information sheet was a consent form which participants were asked to sign to verify that they had read and understood the research process and agreed to take part. My university contact details were further provided for additional information if required. Prior to completing the initial online questionnaire, a brief overview of the research and contact details were again provided, and participants were required to confirm that they had read the information and agreed to take part before being able to proceed. Finally, the information sheet accompanied the interview invite and was summarised in person prior to each interview.

The research information sheet and questionnaire introduction informed participants that they were under no obligation to engage in any part of the research. Participants could skip questionnaire questions, decline interview answers, or withdraw from the study at any time. If they did withdraw, they could request the removal of any data collected up to the point of its analysis. Unless they stated otherwise, all information collected continued to be used for the purposes of this research. They were made aware that all data that reached the point of analysis would form part of the research project results.

As outlined previously, given the remote nature of interviews, participants were asked to participate in private locations where they couldn't be overheard. Participants were given the option of turning video off. The meetings were recorded initially on a digital voice recorder and a password protected laptop, with firewalls and anti-virus software adding a further layer of secure technical protection. Once transcribed, all recordings were subsequently transferred to Cardiff University's secure electronic storage network where access is limited.

To alleviate concerns around participant identification and the attribution of any disclosed sensitive information, all questionnaires and interview transcriptions were fully anonymised. Anonymisation was seen as crucial due to the potential for sensitive information being discussed. This protects participants' identities and promotes an openness in their responses (Saunders et al., 2015). Tolich (2004) suggests that participants are more likely to engage honestly and deeply when assured of their anonymity, as this protection fosters a sense of trust and reduces fears of personal or professional repercussions. During transcription, all identifying information, including participants' names, staff names, school identifiers, local areas, or other contextual details, was removed or masked to ensure complete confidentiality and to avoid any possibility of deductive disclosure.

To maintain coherence and accuracy in presenting participants' perspectives, each individual was assigned a pseudonym. This approach is widely supported in academic literature (Kaiser, 2009; Bruckman, 2002). Pseudonyms served to protect participants' identity and contributed to meaningful and authentic representations in the presentation

of findings. From a practical perspective, the pseudonyms ensured that each participant's narrative was accurately linked to supporting quotes and insights without compromising their privacy (Wiles et al., 2008). Further, pseudonymisation contributes to maintaining ethical standards, ensuring compliance with data protection and ethical guidelines. All information and data were used exclusively for this research and held in strict confidence through each stage of the research process, from recruitment and data collection to analysis, publication, and beyond.

Ethics in practice

During my research, questioning educators on their knowledge was a critical component, but it also presented potential ethical challenges, particularly given my professional background as an educator and my personal experience with cancer. As Guillemin and Gillam (2004) note, researchers must be aware of the power dynamics that can influence the interview process, especially when their personal and professional backgrounds may be perceived as authoritative or evaluative. In this case, my dual role as both a researcher and someone with lived experience had the potential to make participants feel judged or self-conscious, possibly influencing the openness and honesty of their responses. Such researcher influence could have made participants tailor their responses to meet perceived expectations or biases (Bloor, 2001). In my case, educators may have felt compelled to provide responses that they believed I, as an insider in both the educational and cancer contexts, would view as acceptable or knowledgeable. Conversely, my background could have fostered a sense of trust, making participants feel more comfortable and understood, thus encouraging more open, authentic responses. This aligns with the work of Tracy (2010), who emphasises that researcher characteristics, such as shared experiences with the participant group, can foster rapport and deepen the richness of data collection. To this end, I remained reflexive and aware of the potential for both positive and negative influences on the data. I actively ensured that my questioning remained predominantly open-ended and non-judgmental, avoiding language that could be perceived as critical. I also took care to frame my questions in a way that allowed for diverse viewpoints and did not suggest that there was a right or wrong answer, especially given the complex,

multifaceted nature of the issues being discussed. By doing so, I aimed to minimise the risk of inadvertently influencing participants' responses, striving instead to create an environment in which their true perspectives could emerge, free from any perceived judgment (Kvale, 1996).

Due to the sensitivities of discussing young people with a life-threatening illness, it was possible that some participants could consider some discussions to be stressful or upsetting. Any concerns in this regard were offered to be discussed at an early stage and would then inform the construction of that particular participant's interview. If participants were to become upset or distressed as a result of their participation in the research project, they had the option to avoid questions, take breaks or withdraw at any time. They were also informed that details of support groups could also be provided should this be required.

In conducting this research, I encountered several ethical decisions that required real-time, context-specific responses. Guillemin and Gillam (2004) highlight that unforeseen ethical dilemmas often arise during fieldwork, demanding flexible and thoughtful approaches to ensure participant well-being. One such instance occurred when a participant became emotional while recounting a story about a student with cancer who attended the school ball, supported in a compassionate way by another student typically seen as challenging in school. At an appropriate point, I made the decision to ask if they would like to pause the interview. This reflexive response was intended to respect the participant's emotional state and ensure they felt safe and supported, having recognised that this sensitive topic had evoked a strong reaction. My approach aligned with Tracy's (2010) emphasis on the importance of dynamic, reflexive ethical practices that honour participants' needs as they arise. When the participant expressed that her tears were happy ones and they were comfortable continuing, I respected her choice, though I remained attentive to any further signs of distress throughout the session. This experience highlighted the importance of adapting to each participant's cues and remaining responsive to well-being when navigating such sensitive topics. This flexible approach allowed me to uphold ethical standards while fostering a supportive environment.

As a father with first-hand experience in this arena, conducting these interviews was personal and somewhat emotionally challenging. This made me particularly sensitive to the emotional responses of the participants. I was mindful of how easily the discussion could become overwhelming for either party. This awareness led me to consider ethical principles of respect, beneficence, and non-maleficence throughout the research process. I had to navigate the delicate balance between my professional role as a researcher and my personal experiences, ensuring that I remained emotionally present, but not so much that it affected the interview process in any way. Throughout the interviews, I found myself constantly reflecting on the complex intersection between my role as a researcher and my personal experiences. I understood the importance of creating a safe, supportive space where participants felt comfortable sharing their stories, knowing how vulnerable and intimate such conversations could be. This required careful attention to ethical considerations such as emotional safety. As someone who has faced cancer in my own life, I was uniquely positioned to understand and feel the emotions involved, but it also meant that I had to be careful not to project my own experiences and emotions onto others. I had to maintain an ethical boundary and remain focused on their voices and perspectives throughout the process.

Conclusion

This chapter has established its alignment with a relativist ontology and subjectivist epistemology. This foundation supported a qualitative design that employed semi-structured remote interviews, thus valuing participants' unique perspectives. Recruitment challenges during the COVID-19 pandemic were outlined and the small sample justified. The approach to data collection and analysis has also been described, and ethical considerations central to the research process, informed by both theoretical and practical insights, were discussed.

The following findings chapters will explore the three key themes of provision, collaboration and governance. The first uncovers the importance of adaptable, personalised approaches, balancing curriculum priorities with resource limitations. The second chapter delves into cooperation and communication, highlighting the critical role of cohesive partnerships among educators and with external professionals. Finally, the

third findings chapter addresses governance and considers deficiencies in policy and its enactment.

Chapter Four: Findings 1 - Perceptions of Provision

Introduction

This chapter focuses on the major theme of provision. It discusses educators' perceptions of the delivery of a suitable education to young people with cancer. In each area covered, a brief outline of current issue-specific literature will be touched upon. It reflects on educators' comments, which primarily centre around the perceived need for a pragmatic approach that adapts to the evolving needs and capabilities of the individual, as well as practical issues surrounding the supply of appropriate resources. The chapter considers the importance and impact of personalised learning (Pane et al., 2015), recognising that each young person's journey with cancer is unique, and reflecting educators' perceptions of the need for tailored educational approaches. It then discusses the challenges faced by educators when the young person transitions from treatment back to regular school life and their crucial role in supporting this reintegration process. It shows how educators emphasise the importance of maintaining continuity in learning and the need to prioritise a core curriculum. Ultimately, the chapter underscores educators' commitment to ensuring that no young person with cancer falls through the educational net.

I also highlight the multitude of resource-related challenges faced by education providers. The challenges inherent in resourcing education for this specific group are shown to be multifaceted and interconnected, encompassing staffing, curriculum coverage, and the integration of appropriate technologies. Participants reveal a diverse staffing strategy driven by the need to meet demands effectively. They also highlight curriculum coverage that aims to prioritise essential knowledge and skills while accommodating individual preferences to motivate and engage students effectively. Finally, technology is discussed as a crucial resource, particularly in the face of the COVID-19 pandemic. This includes educators' perceptions of the importance of technology in providing students with accessible and adaptable learning experiences.

In what follows, the issues and challenges outlined above are explored along with the solutions employed by education providers to overcome them. Through the experiences

and perceptions of the participants, this research offers a greater understanding of the complex landscape of providing an education for young people with cancer. To support these findings, Table 1 provides a summary of the eight participants interviewed. The table outlines their organisational contexts, professional experience, and roles. These details provide important interpretive context for understanding the perspectives and experiences explored throughout this chapter.

Table 1: Participant characteristics

Pseudonym	Age range	Experience of education provision	Current organisation	Role focus	Time in current role	Support frequency
Alex	30-34	0-2 years	Third sector/ Hospital	Education support	>10 years	Daily
Blake	50-54	>10 years	Hospital	Education support	>10 years	When required
Carey	40-44	3-6 years	Local authority	Oversight and coordination	3-6 years	Weekly
Chris	35-39	>10 years	School	Teacher/ leadership	>10 years	Daily
Danny	45-49	>10 years	Local authority	Oversight and coordination	7-10 years	Daily
Kelly	45-49	>10 years	Local authority	Oversight and coordination	0-2 years	When required
Lee	35-39	>10 years	School	Teacher	3-6years	Daily
Tyler	55-59	>10 years	Hospital	Tutor/ coordination	>10 years	Weekly

Flexible provision

In recognition of the challenges that cancer diagnoses present for young people, participants emphasised the need for flexible education approaches. They demonstrated an understanding of the specific difficulties involved in delivering education for this group of students. They displayed a keen awareness of the unique challenges associated with providing education to such students. They emphasised the importance of adaptability in accommodating fluctuating health conditions, employing strategies like online learning through platforms such as Google Classroom to ensure continuity of education during treatment absences. Personalised learning pathways were crafted through collaborative meetings, tailoring educational support to each student's individual circumstances and preferences. During reintegration into school, educators discussed adopting a phased approach, focusing on core subjects and providing emotional support to facilitate a smooth transition. Overall, their responses demonstrated a commitment to flexibility, responsiveness and compassion in meeting the educational needs of young people with cancer.

Adaptive teaching

During interviews, educators' responses often reflected an acute realisation of the unique challenges associated with providing education to young people with cancer. Unlike the routine support provided to students in a standard educational setting, supporting those with a cancer diagnosis was seen to demand greater adaptability based on a deeper understanding of the physical, emotional, and psychological needs of the student, as well as those of their families. There were honest and transparent acknowledgements of a lack of experience in dealing with such complex and sensitive issues, but also intimations of a willingness to reflect on their limitations and areas for growth:

> I've never been in a situation where I've had to work with people with cancer and work with their families and support their families. I think it's a big difference from supporting pupils day in-day out to supporting somebody who's going through something like this where you don't know what the prognosis is going to be. (Lee)

Comments such as Lee's recognise a significant difference in the level and type of support required in these situations; the challenge of working with individuals whose prognosis is uncertain is clearly expressed. This adds a layer of complexity to the educator's role as they provide for the educational needs of the student while also being sensitive to the unpredictable nature of the student's health condition. Participants expressed the view that it requires flexibility and responsiveness to ever-changing circumstances.

Such comments also recognise the integral role that families play in the educational journey and suggests a need for educators to consider an approach that encompasses the broader support network of the young person. To do so, educators in this field clearly concern themselves with factors that are outside of the profession's usual sphere of practice. They look beyond the standard learning pathway and consider what provision can meet the young person's immediate needs having taken into consideration specific health and well-being factors. Their limited experience here would indicate the need for professional guidance in this regard, yet their actions demonstrate that this is not always pursued. The data shows that educators often adapt by taking direction directly from the parents or the student, and external professional counsel may not be sought at all. Chris commented:

> I've only really had students with, one student regarding this in my teaching and I've taught at [school] for twenty years. My thoughts on it, and it's the first sentence that I say to any parent, is the child's health has got to come first and I'm prepared to take their kind of ... what they want to do, they're the leaders in this.

Educators may often be justified in receiving relevant information primarily from parents; they are often seen as being best placed to inform of the young person's readiness to engage in education. Educators recognise that this readiness fluctuates depending on their daily experiences and health status. They are aware of the need for individualised attention and adapt their provision to address the young person's ability to access education on any given day. Kelly explicitly recognised this when stating:

If you were exhausted and physically exhausted and emotionally a bit fried as well, then one hour of intense English on a computer screen or face-to-face is exhausting. Its tiring, so not the time. We actually have learners that say 'no' when they can't do more than that at the moment. ... So, we try to be flexible. We try to be responsive, and we try to be understanding of the pupils' needs.

This recognises that the physical and emotional toll of cancer treatment may limit a young person's ability to engage fully in education as well as having a significant effect on their overall welfare. The need for support to remain adaptable was important for addressing evolving physical, emotional, and educational requirements throughout the treatment process. Carey commented:

And what the young person can actually deal with as well, if they are going through treatment, they're not always going to be in the best place either to want to access that education. It's about being flexible really and it's offering as much support as we can.

The importance of adopting a flexible attitude, rather than being constrained by a set approach when dealing with the ongoing uncertainty of a young person's physiological and psychological response to their illness and their treatment, was frequently emphasised. Interviewees highlighted an ongoing requirement to provide opportunities for successful educational outcomes whilst observing that the needs of young people with cancer can change rapidly throughout their treatment journey. Educators know that they need to constantly adapt to reflect such changes and fulfil the requirement for education progression. In acknowledging this, Danny observed:

But it's about flexibility. There's lots and lots of things really that kind of make it tick. It's about ultimately meeting what the need of the child is at that specific moment in time. That can be, at the outset, educationally, right what is it that you're going to succeed at? But then also recognising that the needs of that child can change at any given moment on that journey.

Educators emphasised the need for immediate adaptability, to be attuned to the physical and emotional state of the young person, to make a valued appraisal of their

current needs. A continuously adaptable approach was seen to be essential to accommodate the students' varying capacity to participate. Tyler stated:

> As you walk into that room, you've got to make assessments there and then. What's going on for them today? Where are we going to begin? ... Things need to be quite reactive. And I think they need to be quite flexible to the fact that these kids are different from day to day.

Educators clearly reflected the importance of remaining responsive and adaptable and offering flexible and adjustable education options that are tailored to the young person's physical and emotional states whilst remaining relevant and effective. Carey underscores the central importance of adaptability in the educational approach for young people with cancer:

> Again, it comes back to being flexible. And it is difficult to look at every young person and say this is what we provide because you have got to take them on an individual basis and see what support that young person needs.

By acknowledging the difficulty in providing a standardised approach, educators display an understanding of the complexity of each student's individual situation. They suggest that adapting to such multifaceted needs requires a high level of understanding and a sensitive response. Educators engaged in ongoing evaluations of a dynamic situation to determine the appropriate level of support required. Overall, educators' responses reflect a willingness to adapt practices to ensure young people with cancer have ample opportunity to thrive academically despite their health challenges.

Personalised learning

Individual education plans (IEPs) have become a cornerstone of education for students with various additional needs; they can help tailor educational support to each young person's unique medical and academic situation. In my research, the need to focus on IEPs for young people with cancer was considered an essential practical need. Participants highlighted the need to assess and adapt to each young person's abilities and changing requirements.

Kelly's statement below emphasises the importance of supporting personalised learning through collaborative meetings involving several interested parties. By considering the resources that can be accessed as well as the mode of delivery, the educational approach is tailored to the specific needs and circumstances of the young person. This reflects a proactive approach to addressing challenges such as irregular attendance due to medical treatments. Further, the possible provision of flexible learning options within the school environment demonstrates an understanding of the importance to accommodate health needs while still providing opportunities for learning and social interaction. In noting such approaches, Kelly makes it clear that learning experiences are adapted to the young person's personal needs:

> We would have a meeting with the school, with parent and learner, and whether it's online or face-to-face saying what can be accessed and what can't be accessed. Because, for example, the child might not be able to go to school every day ... They might be able to go to the learning and well-being centre within the school or they might be able to go and have check-ins for an hour a day in a medically clinically, less exposed [environment].

Alex similarly spoke of utilising effective skills of communication and problem-solving within meetings to provide effective support, and emphasised the importance of catering to the unique needs of each young individual:

> The support is tailored to each individual young person anyway. So, the majority of the time, it is about having a conversation with them and knowing where to signpost, knowing what your local resources are, knowing who to go to for help if you can't find the answer.

This example shows that, by engaging in conversations with students and knowing how to access local resources, educators ensure that support is customised to meet the needs of each student. The emphasis on knowing where to seek help if needed implies a proactive approach to addressing challenges and ensuring that students receive the support to succeed academically and ensure their emotional well-being.

In hospital settings, educators also recognised the need to tailor educational activities around medical procedures. They demonstrated an understanding of this bigger picture, recognising that students may have medical matters to attend to during planned learning time. They also considered the weight of more minor medical matters against the young person's need for learning. They dealt with this by communicating with medical staff to minimise disruption to the students' education. In the example below, Blake noted a proactive effort to prioritise education whilst acknowledging the demands of medical care:

> So, say you have to do the revision in this, this and this today, or if they come in ... and they say, I'm doing my GCSEs at the minute, so can I do this? But, we do try then to say to the medical staff can you not do your, I mean, they do the ward round at the same time every day, but if there's other things that need to be done, whether be x-rays, blood tests et cetera, that they don't do it within their lesson time, if they've got specific online sessions that they'd be doing.

It was further recognised that each student responds differently to their diagnosis, with some prioritising their learning as a means of feeling normal, while others may feel overwhelmed initially and require time before engaging in educational activities. Tyler highlighted the importance of assessing each young person's readiness and preferences before initiating educational support. The approach is responsive to personal circumstances, allowing for variations in student readiness and ensuring that support is provided at a pace that is comfortable for the individual student:

> It's really, really individual. Generally, when they start off, I'd say I don't push education initially because I think the shock of the diagnosis to everybody concerned is completely overwhelming. But if they want, if different people are, I find that different children are so different. Some of them would actually, to them, doing their schooling is actually important and they think it makes them feel more normal so we would launch straight into education. But a lot, they're so overwhelmed we don't do a lot to start with. (Tyler)

Educators emphasised the goal of creating a sense of normality for young people undergoing cancer treatment while remaining open to feedback and input from the

students themselves, their parents, and other professionals involved in their care. This approach reflects a commitment to meet the needs of each individual, a responsiveness in educational provision, a supportive attitude. Danny exemplifies this:

> Everyone's an individual … It's about trying to create some kind of normality for young people. If that doesn't fit with what they currently need at that point, well obviously, we'll take that on board, whether that be from the child themselves, from parents, from professionals.

Kelly also spoke of personalising the support, but as a basic minimum requirement:

> So that offer would probably be for five hours plus three hours in general, it depends on each child. That is the starting point and then we would make it bespoke.

Again, this response acknowledges that this is not a one-size-fits-all solution. The individuality of each student's situation is recognised. Kelly talks of a foundation upon which customised education can be provided, tailored to the unique circumstances, learning preferences, and abilities of each student. This underlines a commitment and adaptability in educational provision, ensuring that students receive the support they need to continue their learning journey effectively. Such commitment is set against an ever-changing landscape. Lee talked of having to be ready to adapt with little notice:

> Some days, [child's] mum would ring in the morning and say, "he's really well today, can he come in for three lessons?" Yeah, no problem. Or she'd ring and be like, "look, we've had a really bad night. He's not going to make it in today".

This illustrates a dynamic backdrop, requiring timely responses to changes in the student's health status. Decisions around learning capacity are thus made in response to daily assessments of well-being. Whilst this approach necessarily prioritises the young person's health and well-being, during periods of better health, educators would consider individual learning pathways and the most effective means of delivery. When students were able to undertake learning activities but unable to come to school, educators spoke of utilising existing technologies. Lee commented:

I asked staff to put work on Google Classroom. If [student] is well enough, [student] can complete it and at that point I think, because [student] had six weeks at home and had finished his first set of chemo. And we were really lucky that [student] wanted to learn. [student] didn't want to slip behind. So, we provided work on Google Classroom.

This recognises the student's medical condition yet provides them with an opportunity to continue learning at their own pace and convenience, even during periods of treatment or recovery at home. It accommodates the student's desire to learn and helps to prevent them from falling behind. It also ensures the mode of educational delivery aligns with the student's personal capabilities and circumstances. This personalised approach is then adapted as the student's treatment cycle and health status develops. Kelly said:

So, from a cancer point of view, it might be that it had to be online to begin with, but then as their treatment cycle is in different periods they are more able to do face-to-face, we do it at home.

Whilst online learning may be necessary initially due to the unpredictability of the student's treatment cycle and the potential challenges associated with attending face-to-face classes, as the student's treatment progresses and their health condition allows, this shifts towards face-to-face instruction, including classes in the home. Although young people may still not be able to attend school, this transition offers somewhat of a more traditional learning experience. Educators thus continue to show a sensitivity to the student's individual circumstances, providing opportunities for in-person interaction when feasible..

The findings discussed so far demonstrate educators' attitudes towards personalising each young person's learning journey; unique strategies are adopted to meet specific needs and preferences. This becomes more focused as the young person approaches their GCSEs and A levels (or equivalent). Danny clearly illustrated this focus when stating:

Primarily, we are educators and the primary drive for education really should be educational outcomes, not necessarily qualifications but providing education input and having individual outcomes.

Danny implies flexible learning pathways are created to ensure educational outcomes are achieved which align with the student's personal capabilities. Customising education provision that aligns with the circumstances and skills of the young person ensures that their learning journey remains appropriate and allows them the best chance of success at that stage of their educational journey. For students wishing to further their learning journey, educators spoke of providing a narrow, focused approach. Chris noted that their role in this context was to:

Get them the best kind of qualification that works for them. So, it could be kind of working through a reduced timetable. Because, obviously, they need five GCSEs to kind of move on to the next stage in their education process.

Yet, for students who show little appetite for learning, educators remain flexible and compassionate, as can be seen from Alex's comment:

If they're not keen to stay engaged with education, it's just about respecting that, or trying to come up with some ideas of OK, well, if you can't stay engaged 100%, is there anything you do want to do or is there some sort of training course you want to do. Or there's this thing on Eventbrite that's a really good workshop that might be interesting, why don't we sign you up for that? So, it's just finding alternative things that can keep them focused on something, or keep the learning fresh in their minds that isn't learning about cancer.

These responses reflect the emphasis on aligning education with the unique capabilities and needs of each young cancer patient, which involves being selective with qualifications to suit individual circumstances and preferences. Flexibility, adaptability, and a strong focus on personalised learning programmes were seen as key factors in providing effective education while considering their health challenges and treatment journeys.

Reintegration

Aiding the successful return to the routine of formal school-based education was seen by participants to be just as demanding as other phases of provision. Alex's comments demonstrate an awareness of the difficulties young cancer patients face when transitioning from treatment back to 'normal' life:

> Sometimes the expectation is that they finish treatment and everything's going to go back to the way it was and that doesn't happen ... Keeping them going in a time where their routine of hospital has gone, and they may sometimes feel a little bit lost.

Educators saw that the loss of routine, unrealistic expectations, and the need to adjust to a new reality all contributed to yet another difficult period for the young person. The misconception that completing treatment would immediately restore normality had to be overcome. The loss of routine and potential feelings of disorientation emphasised the importance of providing ongoing support to help students navigate this period of readjustment.

Prior to reintegration, and being aware of these upcoming difficulties, educators spoke of their efforts to maintain communication and continuity in learning. The importance of ongoing support during school absences was emphasised. This aimed to prevent students from feeling isolated or disconnected from their school and social communities: 'Keeping that contact is really important because it can be so long that they're not in school' (Tyler).

Educators clearly understood that maintaining contact and continuity throughout a student's absence from school is crucial for their eventual return. Kelly and Chris's comments below exemplify the proactive, yet unforced approach taken by educators to do this. They align learning during absences with the curriculum covered at school, often by utilising available technologies and resources:

> Find(ing) out what school are covering that week, then try to incorporate what they are doing. (Kelly)

Just make sure that the google classroom is up to date, [student] will dip in if and when [they] want to, we don't put any pressure on any missed work. (Chris)

By staying informed about the topics and activities being covered at school, educators tailor their remote learning resources and activities to complement and reinforce what is being taught in the classroom. This ensures that students remain connected to their peers and the ongoing learning process despite their physical absence from school. It reflects a commitment to maintaining educational continuity, supporting students' academic progress and subsequent reintegration. This continuity was further reinforced with the employment of home tutors, as demonstrated by Carey:

The tutor would liaise with a key member of staff within the school, so the school would provide the work the tutor would complete that work with the young person and then return it to school to be marked, et cetera. With a view really that there is that continuity for the work that is being completed in school and at home. So, when they do return eventually, there isn't a massive gap in learning.

Such approaches aim to minimise any gaps in the student's learning and facilitate a smooth transition when they eventually return to school. It underlines the importance of communication between various educators in supporting the educational needs of teenage cancer patients. Educators were thus clearly aware of, and motivated towards, the need to foster a positive reintegration mindset early on to help minimise disruptions to the young person's education.

To facilitate a smooth return when the time was right, participants talked of adopting a phased reintegration, focusing on core subjects like mathematics and English, allowing students to transition more comfortably back into the school environment. Tyler spoke of essential planning activities conducted between hospital and school educators to help realise a smooth transition from hospital to school:

We would be holding reintegration meetings, timetable planning, that type of thing. I'm in contact with school all the time; we'll have Teams meetings and we'll say, "This term, looking at his timetable, what are we going to, this is what

we're hoping that he'll be able to attend". Then working towards the reintegration, once treatment finishes, back into school.

For some students, their reintegration would see them provided with a reduced timetable, coupled with the assistance of a tutor for additional learning support. For others, their physical presence in school could be daunting. As such, tutors may accompany the young person into school, even attending classes with them, aiming to facilitate a smooth transition by re-establishing connections and rebuilding relationships. During this phase, Carey talked of providing a varied approach depending on the individual's needs:

> Some young people want to go back full-time, and some will go back on a reduced timetable, and we'll still have the tutor there then as a support on the other days. Or maybe a couple, two or three afternoons, they'll give an hour session. Some have actually physically gone into school with them just for that initial transition, just for that emotional support because, it's quite a big step once you been out of education for a significant period of time. So, again, it all depends on the individual, what their need is and what support is needed for them to make it a successful transition back into school.

The impact of social interactions on mental and emotional well-being was also considered important. Flexible approaches to education, where the young person has some contact with their school and their peers, allows some degree of normality thus impacting their overall quality of life. Educators in my research spoke of the practical steps put in place to effect this. For example, when considering the social and emotional impact of reintegration on the young person's overall well-being, Lee explained:

> The plan was put in place then to get [student] in for an hour a day well-being. [Student] has spent the time in our well-being hub. Just with different groups of friends so they could all speak to [student], ask questions and know that [student] was OK. ... We just picked up some of those (social and emotional needs) games and they just played those games. But we also encouraged them to ask [student] questions about treatment and how [student] was feeling. And what [student] would do then is just get back into the swing of things.

Throughout this process, incremental steps were taken, progressing from virtual to face-to-face learning, from one-on-one instruction to group settings, and ultimately integrating into the school's mainstream. Periodic reviews may introduce specialist support if necessary but ultimately, the level of support provided is tailored to the individual needs of each student, ensuring a successful reintegration into school life.

Resources

Providing education for young people with a cancer diagnosis is seen by participants as a complex endeavour that requires a comprehensive approach to address several resource-related challenges. They revealed that such challenges span a number of areas of educational provision including staffing, curriculum coverage and the integration of appropriate technologies. The difficulties in resourcing education for this specific group often arise from the limitations, unique needs and vulnerabilities of the students undergoing cancer treatment and recovery. This section uncovers the resource challenges faced when attempting to provide effective education.

Staffing

Ensuring educators have expertise and experience working with young people with chronic illnesses like cancer can be a challenge. Participants' comments make it clear that staffing provision is not uniform across Wales, with varying staffing strategies being applied. Carey spoke of a hybrid approach within one local authority, with both permanent staff and supplementary tutors contributing to meet the students' needs:

> We've got one permanent position now, one HLTA tutor support, and then we have two or three tutors that we utilise on a regular basis who are part of the local authority supply list. (Carey)

The use of a supply list could indicate flexibility in staffing arrangements to accommodate fluctuations in demand. Carey also emphasises the rationale behind employing permanent tutors, particularly recognising the importance of consistent support for students who are unable to attend school regularly due to illness or treatment:

We have actually employed this academic recently, a tutor full-time because previously we would utilise members of staff who are on our supply list but have always done tuition for us. I think it's making sure that we have enough tutors as well for the amount of young people that need that provision.

By employing permanent tutors, the need for stability and continuity in the provision of educational services is acknowledged. This reflects a strategic approach to resource allocation, recognising that students requiring support may have ongoing needs that cannot be adequately addressed by temporary or *ad-hoc* arrangements. Such an investment in regular staff can contribute to the overall quality and effectiveness of the educational support provided to students.

In other areas, educators spoke of the challenges and limitations imposed by understaffing. This can lead to fewer opportunities for collaboration, potentially hindering effective communication and teamwork. Any barriers to collaborative practice could also lead to inefficiencies as there may be fewer opportunities to share insights, resources, and best practices. Working outside of a school setting, Blake explicitly pointed out the limited time for staff collaboration:

We only work together then perhaps once or twice a week, and obviously if there's leave or study time, then obviously work together less.

The reduced frequency of collaborative work due to understaffing could have implications for student support and learning outcomes. This means less time building trust and effective relationships with parents, students, and the school – relationships which facilitate the sharing of information and feedback, enabling timely adjustments to educational provision. With less frequent interaction among staff members, there may be delays in identifying and addressing student needs, leading to potential gaps in support and intervention. Further, the absence of regular collaboration may hinder the implementation of cohesive and coordinated educational strategies.

Despite staffing difficulties, participants were keen to emphasise their readiness to be flexible and adaptable in addressing students' needs. Educators demonstrated a proactive attitude towards ensuring effective and continuous educational support. Whilst

they aim to be adaptable, however, educators acknowledged their limitations. For example, Tyler stated:

> You can't be a specialist in all, everything. It took me a while when I first started doing it to realise that I couldn't. It would be wonderful for these children to have specialist teachers coming in and teaching them.

Tyler conveys an understanding that comprehensive expertise may not always be feasible. By focusing on areas where they can make the greatest impact, educators can enhance the effectiveness of their support. Tyler also implies the importance of teamwork among educators, including the involvement of specialists when necessary. The value that specialised educators can bring in addressing the unique requirements of students, particularly those with complex or specific additional learning needs, is recognised.

An element of professional humility and self-awareness (that all educators in this research portrayed) was also clear in this discussion. The reality that no single educator can be an expert in every area of education or student support is acknowledged. Educators with this mindset recognise their knowledge and skills in certain areas, and their need for support or training in others. Accepting one's limitations as an educator promotes a spirit of authenticity and encourages educators to be transparent with students, parents, and colleagues about areas where they may need additional support or resources. Such openness fosters trust and credibility and implies a genuine commitment to student success.

Danny also talked of staff resources in terms of subject specialists versus permanent generalists. The strategic approach taken by educators to provide personalised support to young people was highlighted:

> We try and get subject specialists in with young people depending on the needs of the child. But quite often what we find is this takes a lot of timetable manipulation. What we tend to find, although they're not subject specialists. It's better to have one member of staff supporting that young person. Because what

happens is they get a relationship going with the family generally and the young person a lot more easily than if there were multiple people coming back and fore.

While the ideal scenario involves subject specialists working with students, logistical and financial challenges often arise, requiring creative solutions. Significantly, having one dedicated staff member supporting the young person could foster stronger relationships. Thus, continuity and consistency play a crucial role in building rapport and trust with both the young person and their family. Minimising the number of educators involved in supporting individual students, streamlines communication, establishes deeper connections, and provides more personalised assistance. There was a sense overall that this was more important in this context than having several subject specialist tutors. It acknowledges the importance of relationships in education, recognising that trust and rapport are essential components of effective learning environments, ultimately enhancing overall educational experiences.

A significant challenge faced by educators when supporting students with cancer was a lack of formal training or preparation for such situations. Lee acknowledges the personal struggle of understanding and coping with a situation they have not experienced before:

> The greatest difficulty for me was I think personally understanding, because I've never gone through anything like this with my own family members. So, staying strong for him when you don't really know what to say. It's not a subject that you ever have training in. It's not a subject that's ever brought up in teacher training or anything like that. You just pick up the phone and deal with it.

Lee notes the emotional burden and pressure placed on educators when navigating such sensitive topics without adequate training or guidance. My research has found that there is an absence of specific training or education within the standard teacher training curriculum to address the complexities of supporting students with any serious illnesses, including cancer. This gap leaves educators feeling somewhat ill-equipped and unprepared to handle the emotional and psychological aspects of such situations effectively. As a result, educators often rely on their instincts and personal experiences, which may not always be sufficient.

Kelly also spoke of the need for skilled staff and noted the importance of training in fostering flexibility and adaptability among educators, particularly in the context of supporting students with diverse needs:

> Being flexible and having a flexible resource that is skilled in a range of areas, that understands multi-agency working, is able to respond to changing levels of need.

Kelly suggests that versatility allows educators to adapt to a variety of circumstances. It follows that staff training should focus on developing skills such as problem-solving and resourcefulness, enabling educators to adjust their approaches and strategies based on the unique needs of individual students. Such training should emphasise the value of teamwork and effective collaboration in order to develop solutions and strategies for addressing distinct challenges in a timely manner. This would ensure that educators are better equipped to meet the diverse needs of students facing complex health challenges. By addressing this gap in training, educators can more effectively support young people with cancer to thrive academically and emotionally despite their health challenges. This value will be discussed more later.

Curriculum

The curriculum is a fundamental resource that outlines the content, learning objectives, and educational activities that students are expected to engage with. The Curriculum for Wales 2022 reflects a holistic vision of education that shapes the personal development and academic learning experiences of young students. This curriculum will likely demand additional resources within schools and at home. Without sufficient resources outside of school, progress could be hindered, resulting in a curriculum experience that differs significantly from the original vision (Power et al., 2020). All young people should have equal access to such a broad and balanced curriculum, but educators in this research demonstrated a wholly pragmatic approach to such access for young people with cancer. Their goal is to ensure that these students have appropriate and equitable access to educational opportunities while considering their health challenges, yet students would not always have the time, energy, or focus to utilise such access.

Participants' comments provide insights into the varying levels of access to the curriculum for students with a cancer diagnosis, and shed light on the nuanced considerations involved. When looking at time allocation, Carey noted the importance of flexibility in curriculum provision, with efforts made to increase access hours based on students' needs. The significance of year 11 (ages 15 to 16), a critical academic year in which school-leaving qualifications are normally obtained, was also stated and support tailored accordingly:

> Usually it's five hours a week, but if we are able to offer more, we try to offer 10 hours a week. then one-to-one for those who are in Year 11. (Carey)

This flexibility was reiterated by Danny:

> The number of hours that people get varies, so if they are in group provision they have access to full time provision, if they have home tuition, they have access to ten hours in individual one-to-one home tuition or community-based tuition. And you get ten hours in key stage four.

Here, access hours are variable based on the type of provision. Danny highlights the diverse provision types available to students, including group provision and home tuition. It acknowledges the need for tailored support to meet students' unique circumstances and further underlines the importance of personalised approaches to curriculum access.

The balance between the quantity and quality of curriculum access was also considered. While acknowledging that 5 to 10 hours may not seem like a substantial amount for a broad education, educators emphasised the intensity of one-to-one learning. This suggests an awareness of the need to prioritise the quality of learning experiences over quantity, ensuring that students receive effective and impactful education provision despite the limited time available. This was reflected in Carey's further comments:

> If you're looking at a broad education, then I guess 5 to 10 hours isn't a massive amount. However, it's also recognising that that one-to-one learning is a lot more

intense ... Ideally, again, you'd give more hours, but it's being realistic of what we can offer and what the young person can actually deal with.

In light of the limited hours provided, educators spoke of the need to make choices about curriculum breadth. The ability of the students to handle intensive learning was also considered, setting realistic expectations. Considering students' capacity to engage effectively reflects a pragmatic approach. Educators sought to optimise curriculum provision within the constraints of the students' health needs, ensuring that support remained feasible. Their comments reflected perspectives that lean towards a narrower curriculum that prioritises depth over breadth. For example, Danny rhetorically questioned:

Should it be supporting young people to achieve what they need - not all the extras - to be able to move forward, you know, post-16 and so on? Which I suppose ultimately is core subjects and one or two others.

Danny's further comment implies a drive towards a depth of understanding within key subjects as opposed to exposure to a broader range of subjects: "You'd expect every single person to be doing their GCSE English, GCSE maths/numeracy or entry level equivalents". The clear emphasis on a limited curriculum offer suggests that the core subjects should receive primary attention. It highlights the prioritisation of fundamental knowledge and skills necessary for a successful transition to the next stage of the young person's journey.

There's a suggestion here that streamlining the curriculum leads to more effective outcomes. The initial statement does, however, acknowledge the importance of including 'one or two other' subjects, which indicates a recognition of the need for some degree of breadth in the curriculum. In light of such recognition, educators acknowledged that if a young person had a particular interest in a subject that they intend to pursue, then provision should be made to accommodate those interests. Educators thus recognise the value of nurturing individual preferences which can serve to aid motivation as well as providing further opportunities for success. This approach aligns with the goal of making education engaging and relevant to the students. The educators' comments reflect a pragmatic educational philosophy that seeks to focus on

equipping young people with essential skills while also considering their specific interests and needs, ultimately providing the best possible well-rounded and engaging educational experience.

The analysis of educators' perspectives on curriculum access for young people with cancer reveals a nuanced and pragmatic approach aimed at promoting their academic success and overall well-being. Educators prioritise assessing individual student needs and providing flexible access to the curriculum, tailoring support based on varying circumstances. While acknowledging the limited time available, they emphasise the intensity and quality of one-to-one learning experiences, ensuring effective education provision within constraints. Educators advocate for a focused curriculum that prioritises core subjects while still accommodating individual interests, thereby nurturing motivation and facilitating success. This pragmatic outlook reflects a commitment towards key skills while fostering engagement and relevance in their educational journey. Thus, educators strive to provide an appropriate learning experience despite challenging circumstances.

Technologies

A technologically driven curriculum for Wales can create particularly acute challenges where there is limited capacity, as disparities in resource availability could exacerbate existing inequalities. All educators in this research shed light on evolving education provision strategies, mainly due to their experiences during the COVID-19 pandemic. They were aware of the resource challenges yet aimed for learning continuity by using technologies as a means of extending educational reach. Carey explained one local authority's actions:

> We are currently looking into young people who may have medical needs and are at home to actually live-streaming lessons. Having lessons with the actual teachers that teach that subject. Then we would be able to offer a broader. It's like the virtual learning that they've done at home. But it would be live-streaming into the actual lesson ... to keep that connection with the school that they're from as well.

Live-streaming lessons with the subject teachers aims to provide a more comprehensive virtual learning experience. This seeks to ensure continuity in education and allow a sense of connection to be fostered between the young person and their school. By leveraging technology to live-stream lessons, educators can bridge the gap between students at home and their peers in the classroom. This initiative reflects a commitment to inclusive education and highlights the importance of adapting teaching methods to accommodate the needs of these students.

Whilst this approach acknowledges the significance of continued access to education and the maintenance of pupil-school links, there is limited availability of appropriate technological devices in some settings. This poses a barrier and highlights the need for additional resources and support to effect equitable access. Blake expressed frustration around this:

> A major thing, I don't know if it's just me, is technology or the provision, or being able to support them if they don't come in with a laptop or their iPad. We have perhaps six iPads and a few tablets ... We don't have ... all the resources to be able to provide them with what they need.

Despite a lack of resources, Kelly spoke of the necessary shift to using online platforms (Google Classroom/Microsoft Teams) because of the impact of the COVID-19 pandemic on education:

> COVID has helped us in two regards; it's made it easier to deliver remote learning. It has made it more expected for schools to have the capacity to have remote or provisional access and tech and all that kind of thing.

The pandemic accelerated the adoption of remote learning practices, making it more commonplace and increasing the expectation for schools to have the necessary infrastructure and technology. It prompted educators and education settings to adapt quickly to ensure continuity of learning in times of need. It led to the creation of online resources, promoting flexibility in learning pathways. Carey reflected on the benefits and challenges of this mode of delivery:

There is a more accessible way of uploading work which they already would have as part of their lesson plans et cetera. and work that they would provide normally ... At the moment, the provision is mainly virtual just because of COVID. And, if I'm honest, we have been able to support a lot more young people virtually as well ... I think the children, young people and the tutors would rather have face-to-face but ... some young people don't like showing their faces on camera, I don't think it's ideal, but it has been a way of making sure that they have some access.

While limitations were identified, these were not insurmountable. Online delivery methods have provided a more accessible route to education for those unable to attend formal education settings. Despite a preference towards more interpersonal connection and engagement that comes with face-to-face learning experiences, virtual provision has allowed for broader support. It has served as a necessary means of ensuring continued access to education during challenging times, albeit with its limitations.

The overall feeling about online learning was positive. They suggested that future practices in education generally, and for young people with cancer specifically, now have the capacity to include this degree of flexibility and adaptability. It was seen to allow young people to feel more connected to their schools and access lessons on their terms. Tyler gave one example of a positive experience where students felt included and part of the school community during remote learning:

That was wonderful because they felt like they were like everybody else. And they didn't necessarily have to participate, they didn't have to have the camera on. But they could be just listening in. And they would just dip in for half an hour when they felt like it. And I just think that they really feel part of school and umm they knew what was going on.

In this context, there is an emphasis on the importance of inclusivity and accessibility in remote learning environments. This approach acknowledges and respects the diverse preferences and needs of students, empowering them to engage with the material in a way that feels comfortable and conducive to their learning. Thus, students could be more likely to continue to feel like valued members of the school community, enhancing

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their overall sense of belonging and connection to their peers and educators. This inclusive approach to remote learning promotes a positive and supportive educational environment where all students can thrive.

Despite this, there have been moves towards stopping online work due to the challenges of maintaining both traditional as well as online education. Tyler commented:

> The school said, "oh, we've closed all that down now, all that online work". It used to be absolutely fabulous, because there was banks of things we could just dip into it was so easy. And I understand why they've done that because it's very difficult for teachers to keep two things going. But it was a real blessing ... The way the things operated under COVID just showed that we could make these big changes. And I know things are really stretched in school, but it was amazing what could be done in a very short space of time. And what I find difficult to accept is that there are all these lessons that were there and now they're just all gone.

This suggests that the transition to remote learning during the COVID-19 pandemic was seen as a temporary measure to ensure continuity of education while schools were closed. With the return to traditional models of schooling, resources were again focused on face-to-face instruction. Participants highlighted the challenges faced in managing both modes of provision simultaneously. It requires considerable time, effort, and resources, which can strain their capacity. Closing online provision could be a pragmatic decision aimed at reducing workload, but issues around digital access could have contributed to this decision. Principally, this likely reflects a balancing act between the benefits and challenges associated with remote learning, as well as the practical considerations and constraints faced by educators and schools.

A broader conversation within Welsh government and education circles around the use of technologies and the future of education was alluded to. Kelly spoke of ongoing discussions regarding blended and remote learning, highlighting possible direct implications on education provision for this group of students:

A big debate going on with Welsh government now around blended learning, about remote learning, about the nature of education. ... For a lot of children working from home, they have been happier. And they have been looking at sort of bullying and mental health and I've heard generally for a lot of children, they've preferred not going to school, they like the remote learning. So, we as educationalists have got to consider what's right or what's not right. What are the key takes from going to school, what are the key benefits?

This demonstrates a willingness to consider alternative modes of education provision. It acknowledges the value of remote learning in light of the experiences during the COVID-19 pandemic. It suggests the importance of considering the well-being and preferences of students. In the bigger picture, such a debate raises questions about the essential components of the educational experience. Participants implied that, through such questions and conversations, educational practices can become more responsive to the evolving needs and realities of students overall and those with a cancer diagnosis in particular.

Overall, educators reflected on the adaptability and resilience of the education system in response to the COVID-19 pandemic, emphasising the utility of technological resources and remote learning. They demonstrated an acute awareness of the pivotal role of technology as a resource to enhance education provision and produce greater educational opportunities.

Conclusion

This chapter has revealed that educating young people with cancer is a complex and multifaceted challenge for educators. It speaks of the critical importance of adaptable, personalised educational approaches and hinges on effectively addressing a range of resource-related challenges. The insights from educators have shown that they believe that flexible education provision can effectively bridge the gaps that emerge due to extended health-enforced absence from school. This chapter has shown that such is the dynamic nature of a young person's cancer journey that it demands that educators adopt a holistic and adaptable approach to education, where they assess immediate needs, provide personalised programmes of learning and respond to the fluctuating

readiness of individuals to engage with that learning. Educators must also balance the need for curriculum breadth with the practical constraints of limited hours, emphasising core aspects of the curriculum while accommodating individual interests and capabilities. This tailored approach not only addresses the academic aspects but can also positively influence psychological well-being, offering a sense of normalcy and purpose during challenging periods. Beyond treatment, educators acknowledge that reintegration into formal school-based education is another crucial phase in the young person's life. They expressed the view that gradual reintegration that continues to focus on personalised support will ensure a successful return to the school environment. The flexible and incremental steps necessary during this process reflect the commitment to support and empower these young individuals.

The insights from educators demonstrate that flexible educational approaches are essential for addressing the unique needs and challenges faced by young people with cancer. They emphasised that the future of education for these students holds promise, with discussions on blended and remote learning gaining prominence. Educators' adaptability and resilience, as demonstrated during the COVID-19 pandemic, particularly highlight the transformative potential of technology as a resource to enhance educational opportunities. Participants expressed the view that future practices in education must continue to emphasise the importance of personalised support where technologies are integrated and resources adapted to meet evolving needs. They indicated that this would empower these young people in their pursuit of education and ensure that they are given the opportunity to access high-quality education that aligns with their health challenges, treatment journeys and future aspirations. In the next chapter I will explore collaborative efforts by examining communication, teamwork practices, and barriers to professional partnerships that impact the well-being and educational success of students with cancer.

Chapter Five: Findings 2 - Collaboration

Introduction

The previous findings chapter focused primarily on the provision of education for young people with cancer. The importance of collaboration was noted, where it was identified as an integral component in facilitating flexible education provision and effective personalised learning. This chapter examines the pursuit of collaboration in detail, including the characteristics of regular communication and cooperation, and the barriers to professional partnerships.

Examples of educators' encounters and perspectives will be used to shed light on the challenges, strategies, and potential outcomes associated with fostering robust communication channels and collaborative practices. It will start by looking at the perceived significance of effective communications that seek to bridge the gap between education and healthcare systems whilst simultaneously proactively engaging families. Regular channels of communication and personalised support will be identified, alongside a call for a single point of contact to streamline services and enhance coherence. Further, it will examine educators' views on the pivotal role of peer communication and support towards fostering psychosocial well-being among students facing cancer. Transparent communication, empowerment through narrative sharing, and efforts to reduce isolation are highlighted as required components of such initiatives.

The discussion of the data also looks at the importance of internal and external collaboration. This was considered by participants to be crucial for providing comprehensive support and continuity in education. They emphasised the sharing of expertise between educators and external professionals, including healthcare workers, social workers and psychologists in order to provide holistic support to students. There was also an emphasis on the experienced benefits of knowledge-sharing and shared decision-making before discussing the complexity of collaboration in professional environments, as well as various perceived barriers such as poor relationships and logistical challenges. Through this discussion, this chapter demonstrates the

participants' belief that proactive measures, ongoing communication and clear sources of guidance are important factors in maximising the potential of collaboration to support students' well-being and learning needs effectively.

By examining these key areas, this chapter aims to provide insights into the critical roles of communication and collaboration towards effective teamworking. In this context, communication is simply considered as the conveying or exchange of information, whereas collaboration is set to mean cooperating or working together where each participant contributes their particular skills to optimally achieve a common objective. The chapter highlights the importance of fostering cohesive and supportive environments to promote the well-being and educational success of students dealing with a cancer diagnosis and its treatment.

Communication

The data highlights the central role of effective communication in providing holistic support. Improved communication is seen to foster collaboration, understanding, and support among educators, students, and families. Participants emphasised collaborative practice based on strong communication as being essential for promoting students' well-being and academic success. Further, educators noted that effective communication enhances resilience, social connectedness, and positive adjustment, contributing to a supportive school environment for students with cancer.

Professional Communication

Participants highlighted the importance of seeking guidance from experienced colleagues in unfamiliar situations. They recognised the difference between routine support and that needed when providing education for young people with cancer. Despite having significant experience working in a general school environment and managing its various challenges, Lee emphasised their lack of experience in dealing with students with a life-threatening diagnosis and spoke of their need to seek relevant counsel to navigate the challenges effectively:

> I spoke to the head of pastoral first of all, because I've never been in a situation
> where I've had to work with people with cancer and work with their families and

support their families. I think it's a big difference from supporting the pupils day-in-day-out to supporting somebody who's going through something like this where you don't know what the prognosis is going to be. ... I went to the head of pastoral because I knew that [they] had dealt with a pupil before and just supported the parents throughout the summer holidays. ... It was really hard, a really hard time to know what to do because we didn't have that guidance and we didn't source it at all.

This reflects the challenges educators face and highlights a need for sensitive communication. Consulting with colleagues demonstrates proactive engagement with support networks. However, Lee also points to the importance of guidance that meets educators' needs. Participants reinforced the importance of regular communication between professionals to address needs. Structured approaches such as periodic meetings ensure support remains responsive and tailored to the student's needs. Alex highlighted the benefit of consistent meetings with different stakeholders:

Monthly check-ins and three weekly check-ins with regional managers, so there's always somebody there. It's usually kind of a recap on what I've been up to, whether I've got any difficulties or anything complex going on, things I'd like to be planning in for the next month, any training I want to do. ... I think between us we've kind of got it down to a fine art. We'll have our weekly meetings where we'll discuss young people, constant check-ins through the week. It's just about staying in touch and dropping an email if something comes up.

Lee also spoke of daily communication and support from team members. Such strong support networks, adaptability, and ongoing communication were seen as key to overcoming complex challenges. This readiness to communicate was seen to ensure access to expertise and guidance and promote a supportive environment conducive to students' overall well-being and success. Lee said:

We've got a really strong pastoral team and we speak daily. We have meetings daily, we speak daily. Even through the holidays, we're on the phone to each other. And the [Headteacher] as well was extremely supportive in ringing me. You know he'd ring me and say, "Have you spoken to Mam?" If I'd say yes, he'd

be on the phone: "How are you? OK, what did she say to you? Did you have any feedback? Do you want to speak about anything? Do you want any help? Do you want me to find anything for you?" So, the Head was really good, and our pastoral team. But I just think there's nothing out there that prepares you for this ... If you haven't got a good support network in school, it must be one of the most difficult situations to deal with.

These comments reflect the crucial role of communication in coordinating educational support for a young person undergoing intense medical treatment. Effective and ongoing communication strategies are clearly seen as essential in ensuring successful provision and reintegration into the school environment following treatment, as noted by Tyler:

I've got a young person at the moment having medical home tuition, so I will be in contact with his school all the time. We'll have Teams meetings and we'll say, right, this term looking at his timetable what are we going to, this is what we're hoping that he'll be able to attend. And then working towards the reintegration, once treatment finishes, back into school.

Participants emphasise the use of familiar technologies and demonstrate a proactive approach to ensuring continuity in the young person's education despite their absence from school. Further, the mention of working towards the student's return to school after treatment speaks of the importance of developing lines of communication between healthcare professionals and educators to facilitate an appropriate transition and provide continued support for the student's educational journey:

We have paediatric oncology outreach nurses, so they cover across Wales and they're probably the ones who go into the schools and have conversations with the schools. (Alex)

The role of such communication in facilitating collaboration between healthcare and educational professionals was seen as indispensable. Outreach nurses were discussed as serving an essential source of assistance to educators; they are pivotal communicators, liaising between healthcare providers and schools to ensure a cohesive

approach to the young person's care and education. By initiating dialogue with schools, these nurses bridge the gap between medical and educational contexts, facilitating understanding and support. Seeking this medical guidance enables educators to tailor educational support to the child's specific medical needs and limitations, as noted by Carey:

> We would usually ask for medical guidance ... it is linking in with the medical professionals around what is realistic for this young person, what they can access, what they can't access.

This communicative approach ensures that decisions are appropriately informed, leading to educational activities which align with the young person's capabilities. Such communication channels, thus, allow for the exchange of information, coordination of care and implementation of tailored support strategies. Lee talked of the pivotal role nurses play in guiding the actions of teachers in these circumstances; their expertise and guidance are often instrumental in addressing educators' uncertainties regarding the student's condition and educational needs:

> We had a meeting then with [student's] nurse, who came in to speak to me and the [Headteacher] because we had a lot of questions. We didn't know a lot about the form of cancer that [student] had. We didn't know how much work to be giving [student]. Were we to provide five lessons a day? Because the only thing that we had at that time was mum saying, "Yeah, yeah, give us some work for [student]". And the nurse gave us the all-clear for [student] to do that. She gave us guidelines.

Healthcare professionals can provide crucial information about the students' form of cancer and offer clear guidance on the appropriate amount of schoolwork to provide. By communicating with nurses, teachers can make informed decisions that promote the well-being and educational success of these students. Yet this is often experienced as difficult. The comments below unveil inter-professional communication challenges:

I didn't get contacted by anybody who was in education within the health board. ... it obviously does exist within the health setting but, again, I don't think it exists for all conditions and all problems. (Chris)

I'd say there's clear divide. I think the only time we really have conversation with them [medical staff] is when we need guidance around what can and can't be done ... Better communication, I guess, it's what it all comes down to ... to get the viewpoint of medical professionals in relation to the education. (Carey)

We tried to build links with the hospital once, so it was with [hospital] to try and identify a key person and it just didn't work. You could never get through to the person you were trying to get hold of. (Danny)

Participants clearly pointed out the significant lack of integration between education and healthcare systems. Despite the existence of outreach nurses or hospital-based educators, the findings uncover an inconsistent association. This discrepancy highlights a systemic gap in communication between these sectors.

The findings suggest that interactions between educators and medical staff are primarily reactive, focusing on immediate needs rather than proactive planning. Attempts to link with hospitals were hampered by logistical challenges and staff availability. These obstacles hinder the development of cohesive support systems for students. Further, bureaucratic constraints within the healthcare system, such as strict communication formats, further exacerbate communication challenges and impede the fluid exchange of information between educators and medical professionals.

Despite these challenges, there were instances discussed by participants where collaborative efforts are successful, as mentioned by Kelly. However, such successes are often reliant on individual persistence and perseverance rather than systematic facilitation of communication and collaboration:

It can be quite tricky to get hold of [healthcare professional] and because the NHS have sort of quite strict rules about the format they can use and whether they can email or not email, or use Teams and that sort of thing, it can be tricky. But I had one the other week where the clinical psychologist was in part of the

PSP meeting on Teams online and was a really key participant in it. I think it's just the same in any kind of aspect of multi-agency working. It's being persistent.

Kelly's extract sheds light on the critical need for improvement in communication between educators and medical professionals to better address the educational needs of young people with cancer. This need is summarised clearly by Carey who emphasises the demand for clear and authentic communication among all stakeholders involved in the student's education:

It's making sure that everybody knows what's happening really. But I think also making sure that we hear the voice of that young person. ... It is just making sure that those lines of communication between the educators, the tutor, the school tutor and parent and young person is open and honest.

Enhanced communication strategies, proactive engagement, and the establishment of clear channels for collaboration are seen to be essential in fostering more effective partnerships between education and healthcare professionals. Ultimately, prioritising better communication practices can lead to more holistic support for students facing such complex challenges.

Family communications

Educators emphasised the importance of initiating contact with students' families and establishing communication channels. This initial step serves as a gateway to communication, allowing for the exchange of information and the establishment of rapport between the educator and the family. Lee commented:

I said, "When you ready here's my e-mail address. We can have a chat". ... we were emailing back and forth then all the way through ... Communication with mum was outstanding. ... in a situation like this, communication is absolute key.

Such exchanges recognise parents' active involvement as primary stakeholders and reflect a growing relationship characterised by trust and collaboration. By maintaining regular contact, a commitment to understanding the family's needs and concerns is demonstrated which seeks to promote a unified sense of purpose. Danny also reflects

on his positive relationships with parents in order to gain valuable insights into the student's needs and circumstances, allowing for more targeted support and intervention through regular reviews:

> Generally, I have very good relationships with parents, so communication is strong. ... I'm in communication with them a lot but what we do have as well, we have a termly reviewing process ... I'm quite an affable person, I'm quite approachable, people quite like me, it's a personality thing, you know. People come to me for advice. (Danny)

Educators' observations highlight the critical role of parents in their children's education, even when facing challenges. They often relied on the family's insights to ensure appropriate provision, recognising parents as crucial partners in their children's education. Carey highlighted the proactive role many parents play, whilst Chris added the importance of parents taking the lead in guiding priorities, as they best understand their child's circumstances:

> My experiences have been that parents have also chased to make sure that it's in place and, so we haven't had many experiences with parents who have been negative about it or have had a negative outlook around education. (Carey)

> I think the lead really needs to come from the parents and the child who know what they're going through and know whether they have that capacity. (Chris)

However, educators also acknowledged the complexities of maintaining consistent communication, as health concerns often take precedence. Sporadic engagement from parents during such periods was seen as an understandable reality, reflecting the primacy of health over educational matters. This recognition highlights the need for flexibility and empathy within these collaborative efforts. Danny's comment offers a nuanced understanding of non-engagement by parents, challenging assumptions surrounding parental involvement:

> I quite often get calls ... schools quite often ring me quite frustrated saying that the parents ... they're not engaging. So, I'm like well yes, take a deep breath because it's not that they don't want to engage. It's that for whatever reason they

can't engage at the moment. There are very few people in the world that don't want to engage even when they very much look like they do. ... there's a reason for non-engagement; you've got to unpick what that reason is.

By reframing non-engagement as a potential indicator of underlying challenges, educators advocate a compassionate and supportive approach that seeks to understand the root causes of parental disengagement. This emphasises the importance of empathy and patience and reflects an understanding of the need for adaptability in order to accommodate the varying priorities and circumstances of these families. Thus, educators can better support parents and students facing challenges that may impede their ability to communicate effectively.

That said, whilst being responsive to the key role of families in the communication process, Chris mirrored many other educators' comments when also acknowledging the need for more proactive communication strategies to offer support and ensure regular contact is maintained:

> But I also do send them emails semi-regularly just because there's going to be a time whether they've had good news after some treatment, there might be a time when they think "Where are we going with this, what do we need?". So, I would, for example, with that student I sent an email saying ... "I know this is probably the last thing on your mind but exams are coming up, would you like me to enter for just maths and English, would you like to actually do the exams at home?".

This approach ensures families feel supported throughout the process. It speaks of the importance of holistic support that encompasses both academic and emotional aspects of the young person's experience. By maintaining open lines of communication this comprehensive approach recognised the overlap of academic, emotional, and medical factors in shaping appropriate education provision.

To further aid effective communication, educators highlighted the benefit of having a single point of contact. By enabling direct communication between parents and a named educator, potential delays or miscommunication can be minimised, ensuring timely access to necessary resources or services. This approach not only focuses the

communication process, but it also makes it easier for parents to advocate for their child's needs and facilitates prompt responses from educators. For example, Kelly spoke of ease of access and parental empowerment:

> Parents could email me or ring me up if they've got concern or a complaint about something ... sometimes the parent starts the process by ringing up straight away and saying that my child is going to be needing this, can I help?

Carey also pointed out that a designated educator as a central point of contact ensures that essential tasks, such as managing schoolwork, coordinating educational support, and facilitating communication, can be handled more efficiently and effectively. In this case, by serving as a liaison between various stakeholders, the tutor plays a crucial role in maintaining continuity and providing coherent support, thereby contributing to the optimisation of the educational experience for the student. Carey said:

> Between the school and parents, they [tutor] are the ones that make sure that everything keeps running and that they've got the work they needed, what work is completed, and making sure there's more work coming, and getting any information that that means. And then they feedback to myself.

This also helps minimise the need for parents to repeatedly convey the same information to multiple parties. Having a designated point of contact supports the effective sharing of pertinent information, such as hospital treatment plans and educational needs, among relevant stakeholders. This integrated approach promotes coherence and consistency in support efforts, ultimately enhancing the overall experience for the family and fostering a sense of holistic support, as indicated by Blake:

> It's that the parents and the child don't have to constantly keep on saying the same information to people, because they already know. They know that that's their hospital treatment plan. They know that the hospital know that's the education plan. It's all, it can all just interweave a little bit more, and it's more about supporting the family then as a whole. And everybody has that one person that they can go to.

The benefits of establishing a single point of contact to coordinate support for students facing health challenges was made clear. By creating a central focus for communication and support services, educators can potentially streamline processes, minimise duplication of efforts, and provide more holistic and responsive support to students and their families.

Ultimately, educators' views mark the central role of communication in fostering collaboration, understanding and support among professionals, students, and their families. They emphasise the need for collaborative, holistic approaches that see communication as the cornerstone of effective education provision, thereby contributing to the well-being and academic success of young people with a cancer diagnosis.

Student-peer communication

The value and significance of maintaining communication between the young person and their friends during cancer treatment was understood on some level by educators, who recognised the crucial role that peer relationships play in the psychosocial well-being of young people facing cancer:

> I think the other thing that's really important as a pastoral lead is that you keep them in communication with their friends and you keep the socialisation of school because that's just as important for me as leaving with maths and English. (Chris)

The importance of effective communication in mitigating the psychosocial impact of cancer diagnosis and treatment on young patients was also highlighted by Lee. By facilitating the sharing of the student's story, Lee empowered the student to have agency and control over the narrative surrounding their illness. This proactive approach allows the student to assert their identity beyond the confines of their diagnosis:

> The news provided us with a story that we could read to the year group, because [student] wanted the year group to know what was happening. [Student] said, "I don't want rumours, I don't want people thinking of this and this, I want people to know exactly what's happened". (Lee)

Open communication was seen by educators to reduce the students' feelings of isolation whilst also enhancing peer support and resilience. Further, by ensuring that potential misinformation is addressed, educators engender a culture of empathy and compassion within the school community. Educators recognise the importance of accurate information and supportive environments in promoting positive psychosocial outcomes and facilitating successful adjustment for these young people.

Alex spoke of prioritising the mental health of young people facing cancer and acknowledged the complex interplay between a student's emotional well-being and their ability to engage. This perspective reflects the importance of addressing the psychosocial impact of cancer alongside the young person's education needs:

> Top of the list for me is young person's mental health. Or how they're feeling at that point in time and where they're able to cope with or take on schooling or education or work or whatever it is, whether they're in the right headspace, to be doing that. (Alex)

Chris noted the vital role of consistent communication in supporting a student undergoing chemotherapy, highlighting its importance in fostering a sense of community. Despite the young person's extended absence, efforts to maintain consistent communications helped them feel connected to the school community. This reflects educators' views that the support they provide, encompasses both academic and social dimensions:

> Because we've kept that communication with [student] as a school, [student] felt part of the community ... and [student] came to the Prom and [student] has been undergoing chemotherapy. At the time everybody was over the moon to see [student], so I mean education is not just about the qualifications, it's about the community. (Chris)

Communication was seen as key to easing students' return to school after extended cancer treatment. Educators claimed effective communication between a school and students during periods of extended absence facilitated a more comfortable transition back to school and made it easier for the young person to readjust to the academic

environment. Tyler highlighted their belief in the transformative power of communication in easing anxieties around school reintegration, emphasising how peer dynamics and school reintegration significantly influence the emotional and social well-being of students with cancer:

> Keeping that contact is really important because it can be so long that they're not in school and then going back to school can become a massive issue. And if you keep that communication going all along and the pupils felt like they're part of the school and they're going to be welcomed back then they're much more - that's going to be much easier for them to go back. (Tyler)

Alex and Lee provided further insight into the high level of awareness educators have of the profound impact of communication on the social and emotional well-being of young people undergoing cancer treatment. Alex emphasises that maintaining contact with friends during this challenging time can help preserve a sense of normalcy, reduce distress, and foster resilience. This perspective highlights how social interaction and support mitigate the emotional and psychological toll of treatment, even as young people contend with profound changes in their appearance and self-esteem. Similarly, Lee illustrates how open dialogue and peer support within a school setting can alleviate fears of returning to school. By encouraging peers to engage with the student's experiences, Lee fosters an inclusive atmosphere that promotes belonging and mutual understanding. Together, these accounts illustrate how communication can serve as an important tool for building emotional resilience and bridging the social divide that can emerge during treatment:

> I think this is why we try and encourage young people to stay in contact with their friends through treatment. You do get some young people who just want to shut off from the world and everything has changed for them, their appearance has changed, self-esteem, they're not in school anymore so they find it really difficult to find things in common with their friends when they go through that time. We try and encourage them to just keep in touch … something that isn't about having questions of your cancer, just something normal, I guess, whatever normal is. (Alex)

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When we spoke to [student] and we were on about coming back to school, obviously [student] said they were really worried about their friends seeing the difference in them ... We encouraged them to ask him questions about treatment and how [student] was feeling and what they would do then is just to get back into the swing of things. (Lee)

By facilitating ongoing and open communication, encouraging social interaction, and addressing concerns about reintegration, educators create supportive environments that promote resilience, social connectedness, and positive adjustment during and after cancer treatment.

The above analysis highlights the pivotal role of peer communication in supporting young people facing cancer. Educators demonstrated a deep understanding of the psychosocial impact of cancer diagnosis and treatment on students, emphasising the importance of maintaining connections with the school community. They acknowledged the significance and positive impact of peer communication in maintaining a sense of social normalcy. Proactively empowering students to communicate comfortably with peers was seen to help foster a supportive environment and reduce isolation:

Making sure it's communicating regularly with the school and making sure that the school is communicating regularly with the pupil. The smallest thing can make a massive difference to that pupil ... where they've been sent something like a video or a card ... I think it's making them feel included and that it's still their school and they're still expected to be there and they are going to go back there. I think, even when a child's prognosis is really poor and they're probably not going to make it back into school, still having those options if they want to go and visit the school - that's really important. (Tyler)

Tyler's recognition of the transformative power of ongoing communication in facilitating students' return to school demonstrates its role in easing reintegration and promoting a sense of belonging. By highlighting the significance of even small gestures, such as sending videos or cards, Tyler points out the emotional support and sense of belonging these actions can provide to students during difficult times. This approach reflects a commitment to inclusivity and support, aiming to uphold students' sense of identity and

belonging within the school environment. Collectively, educators' insights emphasise the critical role of communication in fostering resilience, social connectedness and positive adjustment among young people facing cancer as well as promoting ongoing support and understanding within the school community.

Cooperation

Education is a transformative journey, yet the disruption caused by a cancer diagnosis affects the student's health and their educational trajectory, demanding tailored support and understanding from educators across various contexts. Here, I discuss the pivotal role of internal collaboration among educators in ensuring such support and continuity for students facing cancer.

Cooperation was seen to be the cornerstone of effective support, allowing educators to pool expertise and devise IEPs that accommodate the diverse needs arising from treatment schedules, physical limitations, and emotional well-being. By sharing insights, strategies, and best practices, educators could create supportive environments that enhance the educational experience and outcomes for these young individuals. Further, internal cooperation can foster a culture of empathy and solidarity within educational institutions, empowering educators to offer holistic support beyond academic realms.

From the grassroots level of pastoral teams within schools to multidisciplinary teamwork involving external professionals, this section examines how cooperative efforts enrich support structures for students. It will also highlight challenges and obstacles encountered in such endeavours, shedding light on the importance of proactive measures to overcome barriers and foster a culture of effective collaboration. Ultimately, this section will underscore the vital role of cooperation in nurturing environments where students with cancer can thrive academically, emotionally, and socially, despite their health challenges.

Internal cooperation

Internal cooperation among educators is key to ensuring comprehensive support and continuity in education for students fighting cancer. Such a diagnosis disrupts not only a student's health but also their educational journey, often requiring tailored provision and

understanding from educators across various settings. By collaborating with other educators, expertise can be shared in order to devise IEPs that accommodate treatment schedules, physical limitations and emotional well-being. The data shows that collaborative efforts can foster supportive environments where educators share insights, strategies and best practices, ultimately enhancing the educational experience and outcomes for these young people.

The importance of close-knit teams and collaborative efforts within educational institutions, particularly in the context of providing support to students facing challenges was clearly recognised by educators, not only for the benefit of the student but also to ensure they were enabled to carry out their professional function most appropriately. In the extract below, Lee emphasises the strength of a pastoral team within a school and the benefits of frequent communication and collaboration among team members. By speaking daily and maintaining open lines of communication, the team can effectively coordinate support for students, ensuring that their needs are met consistently and comprehensively:

> We are really, really lucky in this school that we've got a really strong pastoral team. ... We speak daily, even through the holidays we're on the phone to each other. And the [Headteacher] as well was extremely supportive. (Lee)

Further, the mention of support from the Headteacher reflects a top-down approach to fostering collaboration, where leadership plays a crucial role in promoting a culture of teamwork and support. Such a top-down approach involves leaders actively encouraging and supporting teamwork among staff members. In the context of Lee's comment, leadership support for collaboration within the school's pastoral team is evident. It is implied that this support sets the tone for organisational culture, signalling that compassionate collaboration is valued and encouraged. Ultimately, leadership involvement in promoting collaboration helps to create a positive school environment whose key focus is supporting the needs of students.

Danny expands on the idea of collaborative support by highlighting the various mechanisms and links in place to support students. Close links with schools, professionals and regular panel meetings demonstrate a multi-dimensional approach to

supporting students, where different stakeholders come together to provide holistic support and oversight. This multidisciplinary approach ensures that students receive support from various angles, addressing their needs comprehensively and proactively:

> We have all the support mechanisms in place, we've got very close links with the schools, very close links with professionals, we've got regular panel meetings. So, there's eyes on these young people from various angles at all times. (Danny)

Both Lee and Danny's quotes underscore the benefits of close-working teams for collaborative efforts in supporting students. By maintaining strong links with stakeholders and implementing structures of support, educators show that they create supportive ecosystems that promote the well-being and academic success of all students. These insights emphasise the importance of teamwork and collaboration in educational settings, where collective efforts can make a difference in supporting students through challenges and ensuring their success.

The role of tutors as central facilitators of collaborative efforts between educators at different levels was highlighted. Educators noted the importance of constant communication between external tutors and schools to ensure alignment of teaching methods, content coverage and support strategies. Regular reviews were seen to facilitate feedback, allowing for adjustments based on responses from parents as well as the effectiveness of interventions. The tutor is seen to serve as a crucial link between home and school, ensuring continuity in learning experiences and minimising disruptions caused by absences due to illness. This collaborative nature of the relationship between tutors and schools, with both parties working together to support the student's educational journey seamlessly, was exemplified by Carey:

> There is always that constant communication between the tutor and the school and then there are regular reviews then to ensure that people are happy. If there's anything that parents are unhappy with, what's working well, what's not working well and what needs to happen basically. ... It is the Tutor and the school that are the link there, and making sure that if something is missed then this is what needs, for the tutor, needs to complete then ... There is that continuity for

the work that is being completed in school and at home. So, when they do return eventually, there isn't a massive gap in learning.

Similarly, Kelly emphasised the collaborative approach taken by external tutors in tailoring well-being and engagement provision to meet the student's needs:

Our tutor provision, they tailor well-being and engagement provision with LSAs usually leading that. They link into the school, they find out what school are covering that week, they have that each week. They then try to incorporate what they're doing either remotely if the risk assessment/the health assessment requires them to be remote and they try to build that in so that there's that sense of community.

The involvement of LSAs (Learning Support Assistants) indicates a multidisciplinary approach to supporting students' holistic development. By actively engaging with the school curriculum, tutors incorporate relevant topics into their sessions to enhance continuity and relevance for the student. Their efforts were seen to build a sense of community highlighting the importance of connections and belonging for students receiving external support. This collaborative approach ensures that tutors are not operating in isolation but rather working in tandem with schools. This collaborative approach has the potential to enhance the effectiveness of interventions and promote holistic development, ultimately benefiting the student's overall educational experience.

Educators also talked of collaborative practices at higher levels, particularly within the context of a regional and national framework, and considered the benefits of sharing best practices among different local authorities. Regular meetings take place which serve as a platform for discussing various aspects falling under the inclusion umbrella, indicating a focus on addressing diverse needs and promoting inclusive practices:

We do also meet regularly; fortnightly with all Wales managers ... we discuss anything really that comes under the inclusion umbrella ... and there is a representative from Welsh Government who are there, so if we have any queries then we would ask for their guidance as well. ... It's also good to hear the experiences of other local authorities and sometimes you think, OK, that could

work for us, and sometimes you recognise that what works in a city may not work in a rural area. ... So, they are effective, you do get some valuable information from there sometimes. (Tyler)

The collaborative nature of these meetings is evident in the exchange of information, guidance-seeking behaviour and mutual learning opportunities among educators. By meeting regularly and engaging in discussions, managers can share experiences, challenges, and solutions related to inclusion practices. This has the potential to identify effective strategies that may be applicable across different contexts, as well as recognising contextual factors that may influence the implementation of certain practices. Further, the presence of a representative from the Welsh government adds an additional layer of collaboration and support, providing access to expertise and guidance at policy level. This indicates a collaborative partnership between educators in local authorities and higher-level governmental entities, with the capacity to facilitate the alignment of practices with broader policies and initiatives. Overall, these collaborative meetings contribute to knowledge sharing, capacity building and the dissemination of best practices. By leveraging collective expertise and experiences, participants are better equipped to address challenges, implement effective strategies, and promote inclusive practices.

External cooperation

Cooperation between educators and external professionals is believed by participants to be crucial for providing comprehensive support to students in educational settings. This section looks at the diverse range of professionals, including healthcare workers, social workers, psychologists and others, who contribute to educators' actions towards effectively addressing students' particular needs. It will look at how, by working closely together, educators and external professionals develop holistic approaches to support students, ensuring that they receive the necessary resources and assistance to thrive academically, emotionally, and socially. In this context, collaboration is seen to foster continuous learning and professional development for educators as they benefit from the specialised knowledge and training provided by external professionals.

Educators who work closely with healthcare professionals talked positively of the benefits of collaboration, knowledge-sharing, and access to support services. Such professional benefits were portrayed as essential for providing comprehensive support to students. Alex describes the strength of their teamwork and working in a professionally multifaceted team, where collaborative approaches allow for close working relationships:

> I work in an incredible team, so that's nursing staff, healthcarers, lead nurses, social workers. So, I work really closely with them, especially for the young people who aren't treated in our unit. So, we have a really close working relationship. ...That's the really good thing about working as part of a team and that's something we're really brilliant at I think. It's that if you don't know the answer or you haven't faced this particular challenge before, there will be somebody that has or somebody who knows where to signpost or knows what to do. I don't think I'm ever working alone in that aspect.

Lee also provided examples of positive collaborations between school and healthcare staff where they were able to address questions and concerns regarding a student's cancer diagnosis. The meeting that they describe exemplifies the benefits of close working relationships that can occur between educators and healthcare professionals. Working together to develop a care plan ensured appropriate support for the student within the school environment:

> We had a meeting then with [student's] nurse, who came in to speak to me and the Head because we had a lot of questions. We didn't know a lot about the form of cancer that [student] had. We didn't know how much work to be giving ... We had a meeting onsite with myself, the nurse, the Head, head of pastoral just for us to ask her questions ... she came in and done a risk assessment for us and a care plan ... and then she just kept in touch. (Lee)

This collaboration goes beyond mere coordination; it signifies a shared responsibility and collective effort to address the unique needs of the student. Through open communication, mutual understanding, and shared decision-making, educators and healthcare professionals can leverage their respective expertise to tailor support

services that cater to the student's specific requirements. Such collaboration can promote a seamless integration of healthcare and educational interventions, ensuring continuity of care and academic progress for the student. It can foster a supportive environment within the school community, where students feel understood, valued, and empowered to navigate their health challenges while pursuing their educational goals. Ultimately, this would not only benefit the individual student, but also set a precedent for effective interdisciplinary teamwork within educational settings.

The practicalities of multi-disciplinary teamworking among educators was also widely discussed. Educators often emphasised a commitment to providing professional support with regular meetings and check-ins, allowing them to stay updated on student progress and any barriers they may need to help overcome. They spoke of the involvement of a plethora of healthcare professionals who participated in team meetings. The importance of integrating external professionals into the educational support network to engender a holistic approach to education provision and student well-being was implied. By working closely with other professionals, educators could access a wide range of expertise and resources to help address individual students' needs more effectively. This collaborative approach reflects a recognition of the interconnected nature of students' lives and the importance of addressing social, emotional, and psychological factors alongside academic concerns:

> Check-ins through the week with social workers just to update each other on what we're doing, and whether a young person or a family is having a problem. ... We have paediatric oncology outreach nurses, so they cover across Wales and they're probably the ones who go into the schools and have conversations with the schools and try and make sure that things are running as they should - they're involved in our team meetings (Alex)

> The link with the psychology team, which we have quite a good link here. You know, there are other problems that children face and it's just to make it more holistic I suppose. (Blake)

Amongst these external professionals, Kelly spoke of the critical role of the Designated Education Clinical Lead Officer (DECLO) in advocating for students' educational needs within the healthcare system:

> If there were delays in treatment or the treatment wasn't being given or something, and that was impacting the education, you could call on the DECLO to sort of advocate from a health point of view to bring those services in to enable the child to get better education ... their job is to be like an advocate or a champion for education, linked to, they are part of the NHS, but they're advocating for the needs of children with any additional learning need provision. (Kelly)

Effectively, the DECLO serves as a champion for education within the healthcare system, bridging the gap between health and education sectors to prioritise the educational well-being of students with healthcare needs. Kelly talked of being able to call on the DECLO when necessary to ensure appropriate services are provided to support the student's educational progress. This theoretical example sheds light on the intricate intersection between healthcare and education systems. Having a liaison between healthcare providers and educators has the potential for improved communication, coordination, and collaboration. It recognises education as a fundamental aspect of a student's holistic development and recovery process, creating a more comprehensive and integrated support network for students with healthcare needs. Fundamentally, this aligns with broader educational principles that emphasise the importance of addressing the diverse needs of students and providing inclusive and equitable educational opportunities for all.

Another benefit of multi-disciplinary collaborations, according to participants, is that it can broaden educators' professional expertise through training and ongoing support. By collaborating with these external professionals, educators gain access to specialised knowledge, skills, and resources that enhance their ability to address the needs of students. Tyler spoke of training provided by CAMHS and educational psychologists:

> CAMHS will come in and provide training for us, educational psychology come in and train the staff. They obviously provide advice to me on a regular basis, so

you know we've got that kind of a relationship going where some days, I suppose in a sense it's on the job training; you have a query, you want to find something out, they come in and they'll deliver and provide advice and information. (Tyler)

Such advice and training allow educators to acquire new insights and strategies for supporting students. By receiving training directly from experts in the field, educators can deepen their understanding of particular health issues and improve their capacity to provide effective support to students who may be in need. Further, the ongoing advice and support provided by external professionals serve as a valuable resource for educators facing specific challenges or seeking guidance on complex issues; they can turn to these professionals for expert assistance. This collaborative relationship was seen to foster a culture of continuous learning and professional development among educators where they can benefit from real-world expertise and practical strategies that can be immediately applied in their education environment. This experiential learning could equip educators with the skills and confidence to navigate complex situations. By leveraging the knowledge and resources of external professionals, educators could enhance their ability to create inclusive, supportive, and effective learning environments that promote the well-being and success of all students.

Cooperation constraints

In professional environments, collaboration is often regarded as indispensable for achieving common goals and delivering effective outcomes. However, factors such as inaction, poor relationships, and unclear signposting can significantly impede collaborative efforts. This section delves into several examples provided by educators of poor practice and the detrimental impact of these factors on professional collaboration, emphasising the importance of proactive measures to mitigate these challenges and foster a positive culture of effective collaboration.

Despite there being many examples of positive collaborative practices, there were also a significant number of examples provided of barriers to effective teamworking. Carey highlighted a disconnect between healthcare staff and educators, implying that their interactions are primarily transactional rather than collaborative. Seeking guidance from healthcare professionals only when necessary indicates a limited scope of engagement

beyond specific singular queries. This lack of ongoing communication and collaboration may hinder the development of shared goals and strategies for supporting students' well-being and learning needs. Further, the concern raised about pushing students too hard without considering their fatigue or readiness to learn stresses the importance of collaborative practices in aligning approaches to student care and education:

> I'd say there's a clear divide (between healthcare staff and educators). I think the only time we really have conversation with them is when we need guidance around what can and can't be done. You don't want to be pushing the young person too much to the point where they're over-tired and not really in a place to learn. ... There probably is a way that we can improve. (Carey)

This example from Carey accentuates the need for improved communication, mutual understanding, and collaborative efforts between healthcare staff and educators to ensure appropriate support for the young person. Challenges were also encountered by Danny when attempting to establish collaborative links with healthcare professionals. Despite efforts to build connections with the hospital, logistical barriers impeded progress. Frustration was expressed with the lack of responsiveness from the hospital, leading to a sense of discouragement and disengagement from further pursuit of collaboration. This highlights the need for active engagement and commitment from all parties involved. When attempts to establish collaborative links are met with such obstacles, it could lead to a sense of disillusionment and reluctance to continue investing time and effort in collaborative efforts. This may reflect a broader issue of professional inertia, however, it is crucial to recognise that collaboration is not always straightforward and requires ongoing effort and adaptability. Fostering a culture of openness and mutual accountability could encourage greater responsiveness and cooperation from all stakeholders involved. Ultimately, while encountering challenges in collaborative efforts is inevitable, it is essential to view setbacks as opportunities for learning and growth rather than insurmountable obstacles. By addressing such issues, professionals can overcome barriers to collaboration and realise the potential of collective action in achieving better outcomes for the young person.

The following extracts collectively demonstrate the intricacies of collaboration between external professionals and schools, shedding light on both the challenges and potential opportunities within these relationships. They show the importance of considering various factors that influence collaboration, such as individual relationships, organisational constraints and external circumstances. They paint a nuanced picture of collaborative dynamics involving interpersonal connections and proactive communication. By considering these factors, healthcare professionals and schools could enhance their collaborative efforts and better support the needs of students:

> Some schools are amazingly supportive and some need a lot more nudging. ... I think that they're very busy. Sometimes I think it can be down to the individual person that you're dealing with and often I find that if you can get the right person who has already got a relationship with that child, then it's much more positive (Tyler)

> I guess from my point of view, maybe the key workers aren't always there or aren't in contact as much as you would hope they would be, but they've got school to run, COVID is happening, everything else is happening, so I do understand why that happens. (Alex)

> Sometimes, not attitudes, but maybe sometimes not having the work that we need from schools, that's easily fixed. Just having conversations. I think we're quite lucky really in [location] that we do know our schools very well and we do have good relationships with them ... I think sometimes it is difficult, I think it's been worse over the COVID period, just getting that work from school; there's more chasing. (Carey)

In discussing the varying levels of support from schools, Tyler hints at the significance of personal connections in fostering effective collaboration. Their observation suggests that successful collaboration often hinges on identifying key individuals within schools who already have established relationships with the students. This shows how important it is to use approaches that are tailored to the situation when trying to work together. Alex's perspective adds depth by acknowledging the various challenges faced by schools, particularly amidst external pressures like the COVID-19 pandemic. By

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expressing empathy towards schools' constraints and competing priorities, Alex highlights the need for external professionals to understand and accommodate the broader context in which schools operate. The importance of flexibility and adaptability in collaborative endeavours is implied here, as well as the necessity of aligning expectations with schools' realities. Carey notes the significance of open communication and proactive engagement in overcoming barriers to collaboration. Their emphasis on maintaining strong relationships with schools points towards the value of ongoing dialogue and partnership in fostering effective collaboration.

A lack of clear signposting and visible policy regarding support mechanisms for educators was also seen as an obstacle when working with students facing health challenges. Educators talked of a need for greater dissemination of information with regard to the source of additional support. Lee expressed uncertainty about where to turn for further guidance and suggests that without clear guidance, professionals may not proactively seek additional support due to time constraints and competing priorities within the school environment. This suggests a potential gap in policy implementation or communication within educational settings, hindering effective collaboration and support provision:

> I didn't go looking for any other support. But I wouldn't know where to go if it wasn't successful. I think it needs to be publicised more within schools about where to go if, as a professional, where do you get help after you've supported the child and the family ... I think there needs to be something written down in black and white saying this is where you go. Because I think if you've got to go and see for yourself, you're not going to do it. We're so busy in school, looking for things that are not in front of us, sometimes you won't do it. (Lee)

Similarly, Blake reflects on the diminishing levels of information sharing and the lack of visibility regarding health and education links:

> There's not as much information sharing as there used to be and I don't know if that's more to do with confidentiality than it is to do with not sharing. ... The major thing is just having the health and education link which, my bad, it might be the

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fact that there is one out there somewhere, but I don't know ... I wouldn't know the name of the educational officer for every borough now.

The participants acknowledge their uncertainty about the existence and accessibility of sources of support, indicating either a potential lack of awareness or clarity. This highlights the importance of transparent and accessible channels of communication between the various professionals in order to facilitate collaboration. Further, the mention of confidentiality concerns suggests potential barriers to information sharing that may add an extra obstacle to collaborative efforts. In essence, these examples demonstrate the importance of clear signposting, visible policy frameworks and effective communication channels in facilitating collaboration and support provision for professionals working with students with critical health needs. Participants implied that addressing these gaps is central to ensuring that they are equipped with the necessary information and resources to effectively support students and navigate the complexities of health and education partnerships.

Conclusion

The examination of teamworking, communication, and collaboration within the context of supporting students facing cancer diagnoses reveals multifaceted dynamics seen to be crucial in fostering holistic support systems for the provision of education to young people with a cancer diagnosis. Amidst the complexities of providing educational continuity for these students, internal collaboration among educators emerges as a cornerstone for ensuring tailored support and seamless transitions. This internal collaboration not only highlights the importance of cohesive teamwork, but also emphasises the significance of shared expertise and best practices. Through shared knowledge and clear lines of communication, educators can develop IEPs that accommodate students' treatment schedules, physical limitations and emotional needs, thus enhancing the overall educational experience and outcomes for these students. Further, internal collaboration fosters empathetic environments where students feel understood and supported, promoting resilience and inclusivity within their educational setting.

Effective internal collaboration among educators highlights the significance of cohesive teamwork in providing tailored support and ensuring continuity in education amidst health challenges. Further, educators point out the pivotal role of collaboration between educators and external professionals, such as healthcare workers and social workers, in delivering comprehensive support services. Through open communication and shared decision-making, educators and external professionals synergise their efforts to address students' academic, social, and emotional needs, thereby promoting holistic approaches to student support.

That said, despite the recognition of collaboration's importance, challenges such as poor relationships, unclear communication, and logistical barriers were seen to impede collaborative efforts. To mitigate these challenges, participants implied that proactive measures such as ongoing communication, mutual understanding, and transparent policy frameworks are essential. Effective collaboration is seen by educators as not merely a goal but a continuous process requiring dedication, adaptability and a commitment to fostering inclusive and supportive environments for students facing cancer diagnoses. By addressing barriers and nurturing collaborative relationships, professionals can maximise their collective potential in promoting the well-being and academic success of these students.

Chapter 6: Findings 3 - Governance

Introduction

The previous findings chapters considered educators' perceptions of the provision of education for young people with cancer as well as collaborative efforts to achieve that provision. This chapter now examines elements of governance including policy and related practice, the monitoring and review of that policy and practice, and any guidance and support provided beyond that.

The findings presented here are derived from analyses of two data sources: documentary evidence and interview data. The data from both sources are discussed in combination throughout the chapter. This dual approach provides a more nuanced understanding of governance by combining information from reports, policies and guidelines with firsthand accounts and perspectives gathered through interviews. The documentary analysis provides a deeper examination of the critical landscape of educational policies and practices, revealing inconsistencies and inequities that hinder the provision of consistent support. The lack of standardised frameworks is articulated and points towards the need for more authoritative and comprehensive national guidance to bridge the gap between the intent and effectiveness of current policy and guidance and implementation realities. Educators' knowledge and understanding in this context is also explored and the effectiveness of their application considered, with disparities resulting in unequal educational opportunities for students across different local authorities. The analysis of educators' perspectives shows the fragmented nature of provision nationally, suggesting a need for standardised policies aligned with best practices towards more uniform education provision. Monitoring and review mechanisms are also explored and, using relevant documentary evidence, the impact of unsatisfactory oversight on educational quality is examined, particularly for students with complex needs like those with cancer.

Fundamentally, this chapter explores the challenges and opportunities within educational policies and practices that support students with cancer diagnoses. The findings inform recommendations for a more standardised, robust framework that aligns

definitive national policies with local strategies, and advocates for continuous evaluation and accountability to ensure equitable educational opportunities. It aims to address these issues and foster inclusive educational provision conducive to the success and well-being of students with cancer.

Policy

Educators play a crucial role in shaping the educational experiences of students with a cancer diagnosis, yet interviews reveal a significant gap in their knowledge and understanding of relevant educational policies and guidance. This section examines this deficiency and how it impacts the effective implementation and adherence to such policies and guidance. The findings demonstrate a pervasive uncertainty regarding the existence and specifics of educational policies, including confusion between medical guidelines and educational directives. A systemic issue is revealed where educators often neglect to engage with policies critical to their practice, resulting in inconsistent policy application and compromised educational provision for these vulnerable students, particularly when facing prolonged hospital stays due to their healthcare needs. The data herein points to the need for systemic improvements to ensure that educators are adequately informed and equipped to navigate policy landscapes effectively, thereby enhancing educational equity and quality for all students.

Policy effectiveness

A number of educators remarked on inadequate and outdated policies, and the absence of a standardised system which helps them support students with healthcare needs. For example, Chris talked of inconsistent practices and inequities across schools and highlighted the *ad-hoc* nature of current approaches, calling for a more authoritative and equitable framework:

> There's certainly lacking a system which kicks in for every student so that there's equality. It just needs to be something more official. Because what I'm doing, I'm kind of out on a limb maybe, I'm just doing what I think is right. ... I don't think there's anything out there so it's not fair because if I'm doing that here, there's, is there someone doing that in every school? I don't know. (Chris)

The lack of comprehensive national policies is further evidenced in the documentary analysis which identified the Welsh Government's response to Estyn's recommendation that guidance for local authorities and schools in this area be strengthened (Estyn, 2016, p.11). Crafting effective policy is inherently complex, as national frameworks must provide cohesion while allowing for local flexibility to accommodate diverse needs. The subsequent Welsh Government's response was nonetheless non-committal, stating they would "consider how these recommendations can be incorporated into the development of our 'framework for action' for EOTAS " (Welsh Government, 2016a, p.2). This response, while reflecting the challenges of implementing a one-size-fits-all solution, appears to indicate a reluctance to establish firm national guidelines. Further illustrating this, The Welsh Government's 2019 framework for action deemed EOTAS to be a local matter, noting "there is little available evidence regarding what policies and procedures are likely to improve accountability and learner outcomes when introduced on an all-Wales basis" (Welsh Government, 2019, p.5). While this cautious stance acknowledges the difficulties of crafting universally effective policies, it has nevertheless left a significant policy vacuum at the national level.

Compounding these issues, the Additional Learning Needs (ALN) Code for Wales 2021 (Welsh Government, 2021) does not adequately address the needs of young people with healthcare challenges. Although the document is meant to be a comprehensive guide, it does not cover students with ALN resulting from long-term health issues, such as cancer, despite creating a list of different categories of children and young people in specific circumstances. The closest it comes is "other circumstances in which children receive education other than at a maintained school", yet there is no mention of, or specific provision for this group. This omission highlights a notable gap in policy formulation, further supporting educators' concerns about the lack of official, inclusive policies for students with healthcare needs. Without such policies, educators talked of having to navigate these challenges on their own, leading to inconsistent practices and potential inequities in the Welsh education system.

Other educators expressed the belief that educational policies are inherently imperfect and in constant need of refinement. This perspective is articulated by Kelly, who

considers the task of policy improvement to be a perpetual process, yet explicitly points to a commitment towards continuous improvement:

> It's never-ending. It's like painting the Forth Bridge[1], it's never done, is it? ...I mean we'll never get to the point where we think it's perfect. It's a continuous improvement. That's what we try to do on a good day. Our goal is to continuously improve. (Kelly)

Supporting this viewpoint, several reports from the documentary analysis highlight specific shortcomings and ambiguities in EOTAS policies for learners with healthcare needs. For instance, Estyn's thematic review on EOTAS reveals significant gaps and a lack of clarity, which points to a limited understanding (Estyn, 2016). Estyn's comment implies that the effective implementation of support services is being hindered:

> Overall, local authorities' referral processes for learners to gain access to EOTAS are unclear and not well understood (Estyn, 2016, p.10).

The Welsh Government's response, below, acknowledged the need for improvement and accepted the recommendations "in principle", which may reflect the complexity of fully implementing changes. The expectation that local authorities and schools adhere to further updated guidance also adds another hurdle towards achieving clear and actionable policies:

> We accept these recommendations in principle. In responding to them we expect local authorities and schools to have due regard to the updated Welsh Government guidance 'Inclusion and Pupil Support'. (Welsh Government, 2016a, p.5).

Building on this, 2017 Welsh Government guidance further places the onus on local policies rather than consistent national ones:

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[1] This expression is used to describe any job or task that feels endless or repetitive. It originated from the idea that painting the Forth Bridge in Scotland, due to its immense size, was such a huge task that as soon as workers finished painting one end, they would need to start again at the other.

The local authority should have a written policy regarding EOTAS for learners with healthcare needs. Policies should include arrangements for the service ... and a named person who parents, hospital teachers and others should contact. (Welsh Government, 2017a, p.20).

This stresses the importance of structured policies that provide clarity and designated points of contact, essential for supporting learners with healthcare needs effectively. However, the execution of these policies often falls short or leads to the inconsistent practices noted at the beginning of this section and indicated in the earlier reports from 2016. Whilst this analysis highlights the dynamic and iterative nature of policymaking in education, emphasising the need for ongoing adaptation and responsiveness, it also points to the need for consistency which could be borne from a national policy.

This need for updated guidance has very recently been reported on by the Children's Commissioner for Wales. Their recommendation states the need for policy revisions to accommodate new legislative entitlements and ensure comprehensive educational access for all learners, regardless of their circumstances. The recognition of these needs by high-level authorities underscores the gap between current policies and the actual landscape:

I recommend that guidance is updated to ensure that all children and young people under the age of 18 can access educational provision when they are an in-patient in a healthcare setting.... I recommend that guidance is updated to reflect new entitlements under the ALNE[T(W)] Act for learners to receive support with their education, wherever it is being delivered. (Children's Commissioner for Wales, 2024, p.7).

In the interviews, educators were acutely aware of the limitations posed by outdated policies and also acknowledged the obsolescence of existing policies and the imperative for updates. Danny points out:

Policy has been in place now since it was last reviewed in 2018, so it's about to have a major overhaul, so I've just submitted a draft to the Head of Access and

Inclusion last week. Because obviously there've been a lot of ALN reforms in Wales recently.

This may reflect a proactive approach to drafting new policy which considers the dynamic nature of educational needs and the importance of aligning policies with recent reforms, particularly those related to ALN. This effort also implies an understanding that outdated policies can hinder effective educational provision and the need for continuous adaptation. Similarly, Tyler highlights the makeshift nature of current local policies and the pressing need for updates, an admission that reveals a reliance on temporary measures that may not be sufficiently adequate to meet current needs:

> We do have an interim tuition support policy which probably needs updating if I'm honest. And so that's what we abide by really, it's the policy that we have within the County Council. (Tyler)

These insights from the Children's Commissioner for Wales' report and the experiences of educators like Danny and Tyler illustrate a lack of timely action in updating educational policies. Despite the clear recognition of the need for revised guidance and the pressing demand for policies that reflect recent legislative changes and evolving educational requirements, educators felt that there has been insufficient progress in this area. The reliance on outdated or interim policies hampers the ability of educators to provide adequate support, suggesting a critical gap between policy and practice that will be spotlighted later in this chapter. This analysis underlines the urgent need for more proactive and responsive policy updates to ensure that educators can provide consistent and appropriate educational support.

Knowledge of policy

Interview data revealed a significant gap in educators' knowledge and understanding of educational policies. This section draws on draws on that data alongside extracts from relevant documents to highlight the widespread issue of a lack of policy awareness and its impact on educational practice. Participants showed a clear lack of knowledge about policies intended to support educational activities. For example, Blake reveals a fundamental uncertainty around the location of education policies and further

demonstrates confusion around the separation between medical and educational guidelines for young people in hospital. This confusion extended beyond documents like the NICE guidelines towards general global guidelines on children's rights:

> I'm sure there would be something on the NICE guidelines to say that, you know, what is best practice. ... I haven't looked at the NICE guidelines for things like that. …the NICE guidelines are more about medical practice. I don't know if there are education guidelines. … The United Nations says they have the right to education, but then how many people know about the Convention of the Rights of the Child? (Blake)

A similar sentiment of unfamiliarity with existing policies was echoed by Carey, despite being regionally responsible for these:

> It's been such a long time since I've read them. I'm sure there's something in the EOTAS is there? Education other than at school? And there's probably the Welsh Government attendance and behaviour, or it's, I can't remember what it's called, it's on here somewhere. It's been such a long time since I read some of them ... and I know they haven't been updated for, since about 2005. (Carey)

Carey's admission highlights a dual problem: the infrequent examination of policies by educators and the fact that many policies are outdated. This could account for the inconsistent practices evidenced within the interview data. Without a solid understanding of relevant policies, educators face challenges in maintaining educational continuity. Further, adherence to outdated educational policies could negatively impact learning outcomes, and compromise educational consistency and quality.

When asked the same question around available policies that support educators in this particular area, Danny expressed frustration with the ignorance among many educators:

> It's interesting how, for seven years, the schools, they are the ones really, they don't read the policy. ... And they're like "where does it say that in the policy?". The same place it said in the policy last year ... you need to refer to the policy under which you've referred to EOTAS because, you know it is covered there. So before referring into EOTAS, you should read the policy.

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Danny's annoyance points to a systemic issue where educators fail to engage with the policies that directly inform their practice. Neglecting to consult policy documents could lead to divergence from established local or national procedures. This disconnect could result in a fragmented educational experience for students, where the quality and type of support they receive varies depending on individual educators' knowledge of, and engagement with, policy. Further, this lack of engagement can undermine efforts to ensure equity and regulation in education; policies are typically designed to provide a robust yet flexible framework that ensures all students, regardless of their circumstances, receive an equitable level of support and opportunity. Danny's response aims to prevent discrepancies in the delivery of educational services.

This frustration is indicative of a broader need for improved policy communication and training. It suggests that there should be more robust systems in place to ensure that educators are not only aware of the policies that affect their work, but are also provided with the necessary support to implement these policies effectively. Without this the gap between policy and practice will persist. Lee suggests a practical solution to this pervasive problem:

> I think there should be some sort of guidance for staff. And basically a handbook of where to go if this happens, where to go if that happens ... if you are concerned about this, this is the number to ring. If you need some support professionally, this is where you go. If you need to find out where this is, this is what you can do. I think that would be extremely helpful ... just having that information.

An analysis of local authority EOTAS panels also highlighted a significant gap in the establishment of written terms of reference. The report noted that:

> Less than 10% of LAs had written 'terms of reference' for professionals attending panels, while others were in the process of developing 'terms of reference'. A small number of LAs reported that they '…must have them somewhere…'; but that professionals involved in the EOTAS referral panel knew the process. (Kitchener et al., 2018, p.18).

This lack of formal documentation can lead to inconsistent practices and a lack of accountability, undermining the effectiveness of referral processes. The interview data also uncovered a lack of clear signposting for relevant support. Lee implied a need for better communication and dissemination of information around available support systems within schools. They suggest that, without clear guidance, educators may struggle to find and utilise the resources necessary to support their students effectively:

> I didn't go looking for any other support. But I wouldn't know where to go if it wasn't successful. I think it needs to be publicised more within schools about where to go. (Lee)

Training around policies and procedures is provided in some cases, but adherence is often poor. This can result in significant inconsistencies in policy implementation. For instance, one Additional Learning Needs Coordinator (ALNCo), recognised for their diligence, was highlighted as an exception. They received thorough training and consistently applied that knowledge, setting a standard that many of their peers did not follow. This brings to light a broader issue: whilst training may be available, it is frequently not utilised. This gap between training and practice undermines the effectiveness of any policies that are meant to support students, particularly those with additional learning needs and those in more vulnerable situations such as prolonged hospital stays because of their cancer diagnosis:

> [School] are very, very good. [Name] knows the policy. [Name] has had training from me and [name] is one of the few people that actually carries out the training [they have] received, whereas a lot of other schools have the training so I go in, I show them what's needed and then they'll do it for half a term, term, a year and after that they revert back to kind of not, you know, not following policy, not following procedure. (Danny)

This is corroborated by Chris' response when asked about policies and guidelines and whether they were aware of anything that could help support them in this area:

> No, I don't think I am. (I use) my own kind of ethics and compassion and my own safeguarding training and my own understanding of young people.

These responses illustrate that, while training is sometimes provided, it is not always sustained. Educators often revert to personal methods rather than adhering to formal policies, leading to varied implementation and potentially compromising the support provided to students. The poor understanding and adherence to policies is further evidenced by misconceptions about where responsibilities to provide education in these circumstances lie. Kelly stated that "if they're in hospital, then obviously the hospital make provision", an assumption that is not accurate. For learners in hospital, national guidance clearly states:

> The local authority should provide as many lessons as the learner's condition allows, and as is beneficial, taking into account what is suitable for the learner. It may be necessary to give particular consideration to a learner who is on a course leading to qualifications. (Welsh Government, 2017a, p.20)

Such confusion around responsibilities is also reflected in some local authorities' written policies around EOTAS, one of which, under the heading 'Pupils who are not medically fit to attend school' instructed schools to be "responsible for monitoring the quality of the provision for the individual learner e.g. through regular reviewing". ([local authority], 2021, p.9). This highlights a critical misunderstanding of the policies governing educational provision for young people with cancer whilst they undergo hospital-based treatment. In reality, it is the local authority's responsibility to ensure the provision and quality of education for these students when they are not medically fit to attend school. This misalignment between policy and practice can lead to inadequate support and a lack of oversight.

Overall, the interview data reveals a critical lack of awareness of policies among educators. The absence of clear terms of reference, inadequate signposting, inconsistent training and adherence to that training, and misunderstandings about policy responsibilities all contribute to this issue. To address these challenges, there is a need for better communication, comprehensive training, and regular updates to policies to ensure that educators are well-informed and capable of implementing guidelines effectively.

Enactment of policy

The documentary analysis highlighted national issues in EOTAS provision around systemic inconsistencies and a lack of robust frameworks. The Welsh Government's EOTAS framework for action report (2019, p.6) identifies "A commonly held concern across the EOTAS sector is that the referral process for accessing EOTAS provision is not robust enough and inconsistent practice exists across Wales." This makes it clear that processes are not uniformly applied, leading to variability in how educational support is accessed and delivered. This variability could undermine the efficacy of the EOTAS framework and result in unequal educational opportunities for students across different regions. Further, the difficulty in establishing which systems were being used across different authorities, as highlighted in another EOTAS report produced for the Welsh Government, also illustrates the fragmented nature of EOTAS provision across Wales. That report noted that "There were two clear systems currently used across Wales. However, establishing an exact figure of which 'system' is used in each authority was difficult" (Kitchener et al., 2018, p.19). Such ambiguity indicates a lack of standardisation and coherence nationally which could contribute to inconsistent educational provision for those students requiring alternative provision as a result of their illness.

In the interview data, Kelly's comment supports the importance of aligning local plans with Welsh Government guidance:

> In the local authority, you'd have a team plan, you have a directorate plan, you have a strategic plan. So, all of that has to filter through. It has to be in line with Welsh Government guidance.

This highlights a top-down flow of policy implementation, where national guidelines should inform local strategies to ensure uniformity and compliance. However, the Review of Education Otherwise Than at School and Action Plan (Welsh Government, 2012b, p.3) reveals that historically, while there is very good provision in some areas, this is not uniform: "Although some excellent alternative curriculum and out-of-school provision exists, this too tends to vary from authority to authority." Kelly, who is party to shared EOTAS information across all of Wales' local authorities, also acknowledged this

in their interview: "There is a difference between local authorities in terms of what the provision is." This insight demonstrates that, while there may be frameworks in place, the execution varies significantly, potentially leading to inequities in the educational experiences of students.

Danny provided a further perspective on this issue, noting the tendency of schools to navigate their own way through rather than following established policies:

> They just don't follow, they always kind of forget that there's a process. ... [Schools] try and navigate their way through rather than following the policy. I adhere to the policy, I very rarely go off-piste because it's just easier because you've got people constantly, constantly, constantly trying to bend the system.

Such deviation from policy suggests a need for more rigorous enforcement and support to ensure compliance in order to enhance the consistency and quality of EOTAS provision. Danny voiced the importance of adhering to established processes to prevent such prevalent non-compliance. Their statement illustrates a drive towards conformity as a fundamental aspect of maintaining consistency and accountability. It reinforces the idea that policies are in place to ensure that all students receive equal opportunities and support. They were keen to provide support by rigorously reinforcing the integrity and effectiveness of the system.

Tyler also questions the consistency of adherence to policies, but goes further by suggesting that policies represent only the minimum expected standard:

> We've got our own policies that we review every year, and I mean we've got the national guidelines and national policies that I have, obviously, access to. ... it depends how the schools implement them doesn't it. You can do things that just about do it but don't go above that. So, you're just about meeting what you should but it's not that bit extra that makes all the difference. (Tyler)

Tyler suggests that, while policies are available and accessible, their implementation can differ significantly between schools. Possibly of greater note is that policies are often seen as the minimum expected standard. This perspective implies that, while schools may be meeting the basic requirements of the policies, they are left to their own

devices when driving towards excellence, going beyond the minimum to provide additional support, and enhancing educational provision. However, policy development and implementation must strike a balance between national consistency and local flexibility, ensuring broad guidelines allow for adaptation to diverse educational contexts. Adhering strictly to general policies which outline minimum standards may not fully address the diverse and complex needs of students who require additional support when facing significant challenges. Basic and generalised policies that simply outline baseline requirements can result in a variety of actions to improve educational experiences and outcomes for these students.

Kitchener et al. (2018, p.4) analysis of EOTAS practice in Wales points out that local authorities' approaches are often driven by the professional experiences and knowledge of those in charge, leading to a variety of practices: "In general each local authority's approach is unique and reflects the professional experiences and knowledge of those leading the EOTAS decision making". This reliance on individual professional judgment can lead to the inconsistencies in support provided by local authorities that is evidenced in the interview data. Possibly because of this, or maybe as well as this, educators at the very local level also often rely on personal experience and *ad-hoc* solutions. Lee demonstrates this reliance on personal initiative rather than policy when asked if they sought support from outside the school: "No. ... I don't think, I didn't need to at that point because I was having the support in school." Lee's further comment illustrates reliance on improvised procedures rather than systematic policy:

> I talked to the head of pastoral and the Head and said, you know, this has happened today, what is our procedures? What do we do? And because we've only gone through, I think only once we've gone through it in the last, apart from this time, in the last five or six years, we've only gone through once.

This example indicates a lack of familiarity with established procedures due to infrequent use. This significant issue, where educators do not seek external support or adhere to established guidelines, relying instead on personal judgment and existing in-school support, may not always align with best or expected practice.

This examination of EOTAS practice across Wales has uncovered significant systemic issues, such as inconsistencies and a lack of robust frameworks that can lead to unequal educational opportunities for students across different local authorities. Indeed, the data points to nationally fragmented EOTAS provision. This lack of standardisation and coherence at a national level may contribute to inconsistent educational outcomes for students requiring alternative provision. Excellent provision has been reported in some areas, but this is not uniform. Aligning contextualised local strategies with robust national guidance could ensure more equitable provision of education. Further, the importance of following such established policies to prevent inequality of opportunity requires the rigorous enforcement and support that one educator extolled. Current policies were seen to represent only the baseline requirements, leaving educators to act independently and rely on individual professional judgment. Overall, these findings underscore the urgent need for a more standardised and robust framework for EOTAS provision. Ensuring consistency in the application of policies, providing clear guidance, and supporting educators are crucial steps toward achieving equitable educational opportunities for young people with a cancer diagnosis. The data shows a reliance on individual experiences and ad-hoc solutions, implying that educators would welcome more well-defined and better-communicated policies to enhance the consistency and quality of EOTAS provision. Such reforms would address the diverse and complex needs of these students requiring such alternative educational support, ensuring they receive the high-quality education that they are legally entitled to.

Oversight

The documentary analysis found that a UK government all-party parliamentary group (APPG) on Children, Teenagers and Young Adults with Cancer reported that cancer in children, teenagers, and young adults can impact profoundly and have significant, lifelong consequences (APPG, 2018) and the effects could influence their educational experiences and functionality within school. In the interviews, educators called for comprehensive and adaptive support systems within educational frameworks to ensure that they can provide an effective education to these young people. The written commitment of the Welsh Government to developing inclusive policies clearly signals

the importance of enabling all pupils to reach their potential, recognising that success in learning is intrinsically linked to health, social and emotional well-being, and broader economic success (Welsh Government, 2016b). However, the effective implementation and subsequent enactment of such policies relies in part on robust oversight; ineffective governance can lead to deficits in support and guidance, ultimately hindering the ability of students with cancer to meet their educational needs and achieve their potential.

Monitoring and review

The monitoring and review of EOTAS is a critical aspect of educational provision, yet it is often scrutinised to a lesser degree than mainstream education. Most local authorities fail to monitor EOTAS and alternative provision with sufficient robustness (Estyn, 2016). Estyn report that, whilst many LAs collect data on attendance, behaviour and qualifications attained by students receiving EOTAS, there is a notable deficiency in recording students' specific learning needs and their progress against learning targets. This lack of data collection and oversight risks compromising the education of students with cancer, who need tailored support. Their medical treatments and side-effects often affect cognition, physical abilities, attendance, and overall learning, creating complex educational challenges. Without robust monitoring and detailed records of learning needs and progress, it could become difficult to adjust educational plans to meet their evolving requirements effectively. Rigorous monitoring and review mechanisms of EOTAS is essential to provide these students with a supportive and adaptive learning environment that promotes their educational continuity and success amidst their health challenges.

According to the Welsh Government's (2016b) report on inclusion and pupil support, it is essential that all students undergo reviews of their progress and the appropriateness of their educational arrangements at least every six weeks. The outcomes of these reviews should be communicated to all key stakeholders involved in the young person's education. This structured and consistent review process would ensure that any necessary adjustments to educational provision can be made promptly. Further, the need for clear guidance on such progress monitoring processes was highlighted in the Welsh Government framework for action on EOTAS (2019). Such guidance would

provide a cohesive framework for educators, facilitating a more consistent approach to the monitoring and support of young people with cancer receiving EOTAS provision.

As of 2021, a significant concern remained regarding the clarity of roles and responsibilities in the monitoring process. A consultation report (Miller et al., 2021) explicitly stated a need for greater clarity on the divisions of responsibility around monitoring the quality of EOTAS provision. This ambiguity could lead to gaps in oversight and inconsistencies in the quality of education provision. To address these challenges, clear, detailed guidelines on the roles and responsibilities of all parties involved in the monitoring process could be established. Through systematic reviews, transparent communication of review outcomes, and a well-defined accountability framework, a robust and responsive educational system that can adapt to the unique needs of each young person could be created.

Despite these challenges, participants reported several practices which demonstrate a commitment to improving the quality and responsiveness of EOTAS provision. The positive approaches to regular communication and team collaboration discussed in the previous chapter form part of these practices. Further, Carey spoke of an approach that fosters a collaborative environment where feedback is actively sought and acted upon. Regular reviews and meetings ensured all parties involved, including parents, are satisfied and that necessary adjustments are made to address any concerns and enhance provision:

> There are regular reviews then to ensure that people are happy, if there's anything that parents are unhappy with, what's work, you know, what's working well, what's not working well and what needs to happen basically. (Carey)

In theory, by fostering such direct communication and collaboration, guidance and support can be provided promptly, ensuring emerging challenges are managed effectively and the needs of students are promptly met. This has the potential to bridge any gaps where policy may be lacking. This proactive approach could help maintain educational continuity and overcome national issues such as exam attendance and obtaining qualifications, as covered later in this section.

The establishment of dedicated panels within local authorities to review education provision demonstrates a strong commitment to continuous improvement. These panels offer a more structured and focused approach, allowing for a nuanced understanding of each young person's unique circumstances and needs. Danny explains:

> Since I've been involved in the education other than at school, I had a dedicated panel which looked at new cases and looked at reviewing existing EOTAS cases. There was kind of that one-panel focus, now because of the ALN reforms anything in [local authority] that has an ALN base to it is dealt with by a dedicated ALN panel. So, all our work now comes from the ALN panel, but the EOTAS panel does still exist and continues to review cases.

This shift to specialised panels allows local authorities to address the complex educational and health-related challenges faced by students with additional learning needs, such as those with cancer. By creating separate panels for EOTAS and ALN, a systematic and rigorous framework is established, improving oversight and ensuring consistent monitoring. These panels promote personalised interventions, providing tailored support that aligns with a young person's health, psycho-social, and learning needs. Further, they foster greater accountability and consistency in the review process, ensuring that students with significant health challenges receive a high-quality education.

A long-term or strategic approach was also reported on, aimed at ensuring comprehensive and effective education provision. Tyler provided an example of structured and consistent review processes at the local level, where regular meetings and annual development plans are a fundamental aspect:

> I have meetings with my head-of-service each half-term. We have a face-to-face each half term where we feed back. I do a hospital development plan every year which we then review together and work on together. (Tyler)

This approach focuses on the short and longer-term aspects of provision. It clearly demonstrates ongoing evaluation and refinement of educational strategies. This iterative process allows for continuous improvement and alignment with an evolving

educational landscape in Wales as well as the needs of students receiving education in a hospital setting. At the systemic level, a Welsh Government report on inclusion and pupil support makes explicit the importance of maintaining detailed records. Comprehensive data collection enables local authorities to strategically plan EOTAS provisions effectively. It allows for accurate assessment of the level of resources required:

> It is vital that local authorities keep records of all pupils being educated otherwise than at school, on a part-time or full-time basis. Without this information, local authorities would not be able to establish that they are fulfilling their duty to provide suitable and appropriate education to all young people of compulsory school age. Having comprehensive information is also essential to strategically plan EOTAS provision, including the level of resources required. (Welsh Government, 2016b, p.159)

Strategically, the combination of detailed individual planning and comprehensive systemic data collection allows for the creation of a robust framework. Regular review meetings and development plans ensure that educational provision is tailored to individual needs and is continually improved based on feedback and outcomes. Simultaneously, comprehensive record-keeping enables the efficient allocation of resources, the planning for future needs, and compliance with statutory responsibilities. It ensures that education provision for these students is not only reactive but also proactive, anticipating future challenges and adapting to the changing educational landscape. Finally, when providing guidance on inclusion and pupil support, the Welsh Government made clear their expectation of a commitment to continuous improvement and accountability in educational provision:

> Local authorities will be expected to monitor and evaluate the impact of any support being provided to young people. This will enable them to evaluate, make adjustments and hold the providers of support to account by monitoring the impact of their work. (Welsh Government, 2016b, p.160)

By systematically assessing the effectiveness of interventions as outlined in the report, local authorities are effectively directed to make informed adjustments to educational

strategies, ensuring that they are responsive to the evolving needs of students. This approach not only enhances the quality of education, but also holds those responsible for the provision of education accountable for their contributions, fostering a culture of transparency and excellence. Further, focusing on impact measurement enables a dynamic and evidence-based allocation of resources. This rigorous process of evaluation and adjustment, as recommended by the Welsh Government, is crucial for maintaining high standards and achieving long-term educational success.

Guidance and support

In Estyn's (2016) thematic review on EOTAS, they recommend close communication with local authorities who should be provided with comprehensive, timely information. This emphasises the need for collaboration, structured communication and shared responsibilities. In contrast, Danny illustrates a more independent approach to learning and information gathering:

> Noone ever kind of directs me to go and find out about this – it's more my inquisitive brain probably. Lots of words get thrown up in panel about various illnesses, mental health and medications and quite often I'm quite interested in what these long words are, and I will find out a bit about it.

Danny's proactive attitude drives them to seek out information independently, without external guidance. This self-reliant approach contrasts sharply with the collaborative and structured framework recommended in Estyn's report. The juxtaposition of these perspectives demonstrates a tension between structured cooperation and individual initiative. The advantages of collaborative working are detailed clearly in the previous findings chapter. In this context, it would ensure the provision of well-informed guidance, whereas more independent working could lead to inconsistencies in support, as individuals are left to navigate complex information on their own.

A report on local authority EOTAS practices (Kitchener et al., 2018) makes clear the significant disparity in the practices of different local authorities. While some have not updated their EOTAS referral practices for many years, others have actively reviewed and improved their methods. The report also notes that some educators face challenges

in engaging key stakeholders to agree on necessary changes that would enhance practices. This reinforces the importance of sharing effective strategies across Wales. The 2019 Welsh Government's EOTAS framework for action explicitly recommends the collection and dissemination of examples of successful strategies. This sharing of best practices is a cornerstone of continuous improvement; well-informed support arises somewhat from the ability of educators to learn from one another and implement strategies that have been proven effective elsewhere in Wales. By leveraging the knowledge and successes of proactive local authorities and addressing the barriers faced by others, it is possible to create a more equitable and effective education system.

Carey's advice highlights this need to be well informed; by placing the primary onus of educational provision for young people with cancer directly on the school, they may not be wholly fulfilling their remit to provide effective education guidance and support:

> We do very much put responsibility on the school to remember that that child is a child of their school. ... we would go to senior management within the school then and remind them again of what their responsibility is. (Carey)

Schools undoubtedly play a central role in the education and welfare of these young people, but shifting responsibility in this context is incorrect and can lead to inequalities in education provision. Educators within schools who must navigate this multifaceted issue need to be supported rather than simply held accountable. The direction given in this instance overlooks the complexities of such situations which require active engagement and shared responsibility. However, this advice is not wholly surprising, given the limitations of policy, as noted earlier in this chapter. Policies are essential for effective educational governance, ensuring that educators responsible for providing guidance and support are properly equipped to fulfil their roles.

Lee's comment, below, exemplifies the flexibility and practical support that educators at local authority level can offer, but also demonstrates that poorly informed advice does not consider best practice or even demonstrate adherence to policy:

We spoke to our LA advisor and said, "Look, we've got a situation where we've got this young boy, can we reduce timetables?" ... They were very supportive and they said, "Yeah, if you provide work for them online, that's fine". (Lee)

The suggestion to simply provide online work lacks depth in terms of ensuring that the solution aligns with best practices and adheres to established educational policies. Effective support should not only be flexible, but also well-informed and comprehensive, considering the long-term nature of the young person's educational journey during treatment for cancer. The guidance given is clearly not part of a broader strategy that should involve the local authority's responsibility to provide EOTAS. The advisor's agreement, while supportive, indicates a lack of thorough consideration that fails to adhere to best practices and policies, potentially leading to an incomplete or suboptimal support strategy. A nuanced understanding of educational policies and the ability to apply them in a way that is both supportive and rigorous is required, thus ensuring that support strategies effectively promote the long-term educational success and well-being of these young people. Danny's statement supports this point:

The policy supports me in a sense that I pretty much know it inside out; obviously it's my job. So, I could just go and say, "It says that in the policy, it says that in the policy". Where it helps me out is that - and it's happened very, very regularly - schools will come back with challenges about what they think should happen. That's perfectly fine in some situations; if it's not covered in the policy, we could negotiate that.

Such a deep familiarity with policy allows challenges from schools to be confidently addressed, using the policy as a foundation to support decisions. Further, Danny's openness to negotiation when policies do not explicitly cover specific situations is important. It illustrates a balanced approach where policy provides a framework, but professional judgment and flexibility allow for tailored solutions to materialise through dialogue. This then leads to the emergence of best practice which can subsequently be shared across Wales.

The National Model for Regional Working, as outlined in the 2019 EOTAS framework for action, points to a significant limitation in the provision of guidance and support within

the EOTAS arena. The framework talks of the need to explore the inclusion of the wider EOTAS provisions within regional consortia's domain:

> The current National Model for Regional Working does not provide for consortia involvement in 'wider' EOTAS provision i.e. non-PRU provision. To ensure a consistent approach within the EOTAS sector, the EOTAS Delivery Group will work with the Welsh Government to explore the inclusion of wider EOTAS provision within the remit of the National Model for Regional Working. (Welsh Government, 2019, p.10).

This aims to ensure a consistent and cohesive approach to EOTAS across Wales, potentially improving the quality and uniformity of support provided to all EOTAS learners. Further, the report makes an explicit recommendation to increase resources to promote effective consortia collaboration. By sharing strategies, regional consortia could play a crucial role in facilitating best practices. However, a 2024 Welsh Government policy strategy document around the review of roles and responsibilities of education partners in Wales reveals a significant disconnect between the 2019 aspirations and the current realities experienced by school leaders and local authorities:

> School leaders expressed serious concerns about the value-added by the Regional Consortia ... Given the consistency of the messages we have heard across Wales in both the face-to-face sessions and the responses to the survey, the direction of travel that school leaders and a majority of LAs want to see is clear ... partnerships between more than one LA with a move away from a wider regional (consortia) model of support. (Welsh Gov, 2024a)

This indicates a widespread perception that the consortia model is neither providing effective guidance and support nor significantly contributing to educational improvement. The divergence between the 2019 recommendations and the 2024 feedback could be attributed to several factors. Interview comments around guidance and support suggest that school and local authority level educators may not have been sufficiently engaged in the suggested improvement processes. Overall, the role of regional consortia in providing guidance and support within the EOTAS sector is as evolving as the general education landscape in Wales. The initial vision of a cohesive,

resource-enhanced model has not fully materialised, highlighting the need to look again at this issue to ensure guidance and support to educators dealing with the complex issue of education provision to young people with cancer is relevant, appropriate and adaptable to the changing educational environment in Wales.

Addressing disparities

In their thematic review on EOTAS (Estyn, 2016), Estyn found that "Pupils receiving EOTAS do not usually have access to a broad and balanced curriculum that enables them to gain qualifications that meet their needs and potential". The limited curriculum offer for young people with cancer, as examined in chapter four, highlights systemic barriers that hinder academic potential. This is particularly concerning given that they are already facing substantial challenges. The lack of a comprehensive curriculum can exacerbate these students' educational disadvantages, limiting their future opportunities. Limited access to a broad curriculum means these students miss essential academic and vocational qualifications, affecting their future education and employment prospects. This lack of opportunity can lower motivation, increase anxiety about reintegration, and have long-term effects on their socio-economic mobility and personal development.

Estyn's recommendations relating to these educational disparities and future opportunity constraints were accepted by the Welsh Government in principle and, in their 'Education in Wales: Our National Mission' document (2017b, p.2), they made it clear that:

> We are committed to the success and well-being of every learner, regardless of background or personal circumstance. Equity and excellence go hand-in-hand and we cannot have one at the expense of the other. Geography, deprivation or childhood experiences should not prevent learners from reaching their potential.

This policy statement reflects an aspirational vision of inclusivity. It acknowledges the importance of equity, emphasising that true educational success can only be achieved when students, irrespective of their circumstances, are provided with the opportunities and support necessary to realise their potential. The commitment to overcoming

experiential barriers is key here. However, when it comes to exams and qualifications, educators point out that there is a disconnect, with policy and procedures often failing to support this inclusive vision effectively. Education advisors, who play a crucial role in guiding and supporting students, sometimes inadvertently perpetuate these limitations by not thoroughly exploring all available alternatives. This is illustrated by Danny's comment:

> I've had a query this morning about examinations and my answers had to be to them, 'well we've done this now for the last seven years, if you come back with the same query every year, you'll get the same answer every year'.

This remark reveals a strict adherence to established procedures, stifling flexibility. It prioritises procedural consistency, which is an important factor in many circumstances, over responsive, student-centred solutions. Other educators showed some flexibility, but there was still an acceptance of a certain level of student disadvantage. Kelly's perspective demonstrated partial flexibility and, while potentially accommodating, still operates under the assumption that some degree of compromise is inevitable for these young people:

> If the child had not got the right grade or something and then there was a clear reason for it because of what they've been going through in year 10/11, I'd be very surprised if there's the sixth form part of the school who weren't accommodating and say "Try and do it at this point and then do fewer A levels whilst you catch up on these or something". I would expect that to be the norm. I don't, I can't guarantee it is.

This points to a need for a more proactive approach to ensure these students are afforded equal opportunities to succeed without having to negotiate their circumstances or settle for mitigated outcomes. Whilst the Welsh Government's policy articulates a strong commitment to equity and excellence, the practical implementation of these principles remains unfulfilled. Inflexible examination practices and limited curriculum access unveils a disparity between aspirational policy and educational reality. Addressing these discrepancies requires a concerted effort to reform current practices, ensuring all students, regardless of their circumstances, can access qualifications and

fulfil their potential. Tyler saw a solution to this problem, following recent events that forced educators to think of different ways of working:

> One really big thing I'd say is GCSEs. The fact that we have pupils with medical conditions who can't access an exam and they don't get given a grade, they get given a certificate of recognition ... Whereas the precedent has been set now, a lot in COVID times, we did give grades with teacher assessments, so why can't we give these children with medical conditions their GCSEs because they can't sit exams.

The COVID-19 pandemic demonstrated that alternative assessment methods, such as CDGs based on portfolios of evidence, can be effectively implemented. This questions the justification for requiring young people with cancer to sit exams later in their educational journey. By recognising the legitimacy of alternative routes to qualifications during extraordinary circumstances, educators believe there is a compelling argument to extend these exceptions to students with chronic health conditions such as cancer.

In the same year that the pandemic broke out, Estyn reported that 'The Welsh Government aims to ensure that all pupils in Wales have access to a broad and balanced curriculum and to learning support services that will help them overcome barriers to their learning' (Estyn, 2020, p.2). Despite this pledge, educators spoke of the practical implementation falling short. Chris's example below illustrates an initial resistance from the Welsh Joint Education Committee (WJEC) to accommodate the needs of a student who had been diagnosed with cancer during their critical exam years. This reflected the broader issue of inflexibility within the assessment system:

> The WJEC were not particularly helpful to start with regarding grading [student] who had cancer this year ... if we can award CDGs for people during COVID times - where the teacher has actually made an assessment based on actual evidence of work in the classroom - if we can give Centre Determined Grades for that during lockdown, because everybody is at home, surely we can give Centre Determined Grades for the one student who unfortunately wasn't here for Year 11 but has been here working very, very hard, a very intelligent girl, throughout all of the rest of her schooling here. (Chris)

Chris went on to describe how that student's academic potential was eventually recognised and fairly assessed as a result of collaborative efforts and the involvement of higher-level authorities. The committed effort not only secured the student's academic success, resulting in commendable grades, but also highlighted the need for policy changes at the national level to prevent similar occurrences in the future:

> The WJEC had told me that that was it and so there was no way that they could grade [student]. So, I went back to mum with that, and then there was that kind of I suppose spark that triggered her to go to [Senedd Member], Children's Commissioner ... the reason [student] ended up leaving us with very, very good qualifications, mostly Bs and Cs in everything, was because the Children's Commissioner and the [Senedd Member] got involved with the WJEC ... So, I think that's where it needs to change; it needs to change with education ministers. There needs to be something in a policy somewhere. (Chris)

This example illustrates a broader issue within the educational system where procedural limitations have unnecessarily impeded students' academic progress. It exemplifies the importance of policy reform to ensure equality of opportunity. Before that reform comes to fruition a flexible, objective approach, as seen in Chris's account, can lead to desired outcomes.

Finally, a recent spotlight report into educational provision for children and young people in healthcare settings in Wales by the Children's Commissioner for Wales poignantly noted that opportunities to learn in such settings were still not widespread. They asserted that:

> Children who need extended periods of in-patient care, frequent day care or need to stay at home due to their healthcare needs also need every opportunity to develop and learn. In these circumstances, children need extra support, not less! (Children's Commissioner for Wales, 2024, p.2)

This is a strong message to those responsible for the oversight of educational activities to re-evaluate and strengthen the educational frameworks in place for this vulnerable group. The report's emphasis on providing extra support for children with healthcare

needs is a necessary directive. It calls for a systemic overhaul to ensure educational equity and continuity, reinforcing the principle that every child, regardless of health status, deserves full access to educational opportunities. This commitment to educational inclusivity not only supports the immediate academic needs of young people with a cancer diagnosis, but also their longer-term potential is able to be fulfilled.

Conclusion

The interview data, coupled with the documentary analysis, reveals deficiencies in governance, impacting educators' abilities to offer consistent provision across Wales. The data also uncovers significant gaps in educators' knowledge, understanding and implementation of educational policies. A subsequent reliance on individual judgment, whilst well-founded and sometimes successful, rather than systematic adherence to well-defined policies, has shown to have the potential to contribute to unequal educational opportunities. Ineffective guidance and a disconnect between policy and practice is evident, with educators' responses highlighting the *ad-hoc* nature of current approaches and the need for more authoritative frameworks. The Welsh Government's responses have contributed to a policy vacuum exacerbating these issues. This reflects the broader challenge of policy development, where national frameworks must balance consistency with local adaptability to remain effective in varied educational contexts. Despite the aspirational commitments in documents like the ALN Code for Wales 2021, current practices are haphazard when supporting these vulnerable students. Reports from Estyn and the Children's Commissioner for Wales emphasise the need for updated comprehensive national guidance. Aligning local strategies with best practice informed national standards is essential to mitigate disparities and uphold the educational rights of young people with cancer. Thus, a more standardised, robust framework, along with adequate implementation training, could ensure coherent guidance and adequate support for educators. Such reforms are crucial to provide high-quality, equitable educational opportunities for young people with cancer, thereby supporting their short-term education need and enabling the fulfilment of their long-term potential.

Chapter 7: Discussion

Introduction

This chapter will reflect critically on the findings in the previous three chapters. They will be viewed as a whole and in connection with the broader academic literature, aiming to facilitate a deeper understanding of their significance. In particular, the chapter will consider the roles that leadership and inter-professional collaboration play across all three findings areas before then assessing the role of technologies towards improved provision that can better support young people with a cancer diagnosis. By considering the implications, relevance, and potential impact of this research, this discussion will offer insights that can contribute to practical applications, theoretical advancement and future research directions.

Summary of findings

Perceptions of provision

The first findings chapter explored the distinctive challenges that significantly impact the provision of education for young people with cancer. Educators' interview responses reflected a lack of experience but noted a willingness to learn and adapt. Recognising such challenges and limitations, flexible educational approaches were seen by educators to be essential in order to ensure students are given appropriate opportunities to maintain their educational progress despite disruptions. The benefits of adaptable, IEPs were emphasised, as were online learning platforms which could accommodate fluctuating health conditions.

Significant resource-related issues were also presented, particularly around curriculum delivery, staffing, and technology integration. Whilst curriculum provision aimed for balancing depth and breadth, given the limited hours for one-to-one education, educators focused on ensuring high-quality learning experiences which prioritised core subjects. Consistent tutor support was voiced as an important factor in building strong relationships and achieving such quality. However, understaffing was seen to hinder optimum educational support, necessitating a more pragmatic approach which reflected the realistic expectations of staff availability and workload. Educators highlighted the

need to adapt continuously to ensure the best possible outcomes within these constraints.

The use of technological resources was raised, with examples cited of educators' experiences during the COVID-19 pandemic. During this time, online learning platforms accelerated the adoption of remote learning. Despite challenges in resource availability, educators recognised the potential of these tools to maintain educational engagement and connection with the school community. They spoke of opportunities to enable continuity, allowing young people with cancer to participate according to their capacity, thereby aiding the successful return to formal school-based education.

Overall, educators voiced the need for adaptable, personalised educational provision which addresses unique challenges and resource-related constraints. Educators' insights highlighted the potential of flexible education through the use of technologies and their integration into IEPs, reflecting an important shift towards more adaptive educational practices. There was a strong call for future educational practices to continue to prioritise personalised support and adaptable resources, empowering these students to access high-quality education that aligns with their abilities and aspirations.

Collaboration

The essential role of effective collaboration in supporting students with cancer was elucidated in the second findings chapter. The data highlighted the need for communication and cooperation among educators, students, families, and healthcare professionals in order to ensure appropriate education support. Proactive approaches were seen to foster trust and support personal connections. Parents were seen to play a significant role in this process, offering valuable social- and health-related insights and advocating for their children's needs. Educators also noted that regular communication between key stakeholders facilitated an improved holistic response to students' needs, with examples of collaboration between healthcare and educational professionals used to illustrate the bridging of gaps between different professional contexts.

Educators emphasised the importance of students maintaining peer connections to combat isolation, foster social connectedness and promote resilience. Inclusive

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communication practices were seen to help maintain students' identity and agency during treatment, reinforcing the importance of social connections for positive psychosocial outcomes. Educators identified such ongoing communication as aiding positive adjustment towards effective school reintegration and favourable educational outcomes.

Internal and external leadership support, as well as regular communication among teachers and tutors, was deemed critical for aligning support strategies and minimising the inevitable educational disruption. Collaboration at regional and national levels had the capacity to promote the sharing of best practices. However, obstacles such as inaction, underdeveloped relationships, and unclear signposting hindered effective collaboration. A disconnect between healthcare staff and educators, logistical issues, and lack of clear policies were viewed as significant barriers.

The findings highlight the critical role of effective collaboration among educators, students, families, and healthcare professionals in supporting students with cancer. However, they also identified barriers such as inadequate relationships and logistical issues which impede effective regional and national collaboration, suggesting a need for clearer policies and improved coordination. Open communication was seen to enhance relationships and better facilitate tailored support, whilst the preservation of peer connections was thought to aid student resilience. Coordinated efforts and leadership were identified as vital for overcoming barriers, minimising educational disruption and promoting holistic support towards favourable outcomes.

Governance

The final findings chapter focused on governance and brought to light critical gaps in policy and guidance supporting students with healthcare needs such as cancer. The Welsh Government's national policies inadequately address the needs of students with long-term health issues like cancer, and their direction to devolve policy guidance to the local level amplifies the issue. Educators revealed that such deficiencies have led to inconsistent practices and potential inequities within the Welsh education system. The evidence from educators pointed to the need for a standardised and equitable framework of practice within the national education system to support such students.

The lack of authoritative guidance was a significant concern among educators, although the data suggested that this was in part due to educators' lack of awareness or pursuit of such guidance. The absence of a standardised system and the resulting gaps in educators' knowledge of policy has led to reliance on individual judgment which further exacerbates inconsistencies. A disconnect between policy and practice in supporting students with healthcare needs was also obvious, as inconsistent practices and inequities prevail across education settings.

The Welsh Government's non-committal responses to recommendations for stronger guidance highlight the inadequacies of the current approach, leaving educators with a national policy vacuum resulting in potentially inequitable educational support. Further, educators openly admitted to working with outdated policies and a reliance on temporary measures. Such a policy gap, compounded by outdated local policies and temporary measures, has led to inconsistencies and inequities, and highlights the urgent need for clear, authoritative guidance and standardised procedures. Several educators advocated for comprehensive, easy-to-reference guides with clear instructions and contact information. They suggested that this would facilitate quick access to necessary resources and enhance the educational support provided to students.

Contribution

This research addresses a critical gap in the existing literature by documenting the voice of those responsible for education provision to young people with a cancer diagnosis. While the perspectives of young people themselves and healthcare professionals have been well-documented, the specific perceptions, experiences, and practices of education practitioners have remained largely unexplored. By bringing these perspectives to the fore, this thesis provides the missing piece of the jigsaw in the understanding of how education provision is considered and delivered. This educator-focused lens balances existing narratives and ensures that future policies and practices are informed not only by healthcare imperatives but also by the realities within the sphere of education. It recognises the vital role that education practitioners play in

supporting immediate and longer-term well-being by providing opportunities to improve educational outcomes for these young people.

In what follows, this chapter will highlight three major takeaway points from this research. First, I contend that there are significant weaknesses in existing leadership practices and policies in Wales and call for stronger leadership which is directly linked to better school effectiveness, more inclusive environments, and improved educational outcomes, particularly for students with additional needs like cancer. Second, I argue that poor collaboration between educators and healthcare professionals can deepen the academic challenges of young people with cancer. Using insights from other professional sectors, I demonstrate that continuous and early collaboration leads to better outcomes and suggest strategies to improve this. Third, I highlight the significant move from traditional education practices during the COVID-19 pandemic and its benefits for vulnerable students. I suggest that this presents opportunities for innovation in education provision as well as a need to reevaluate traditional assessment methods.

Leadership

The educational landscape in Wales is evolving, with the phased introduction of a new curriculum from 2023 (Welsh Government, 2024b) and a new approach to additional learning needs in place by September 2025 (Welsh Government, 2024c). To match this evolution, there is a requirement for dynamic and effective leadership to ensure that all education settings meet the challenges and opportunities of these ongoing changes. Strong leadership is particularly essential in the education of young people with a cancer diagnosis to address their complex and fluctuating needs, ensuring high-quality teaching and improved student outcomes. Yet, this research has brought to light weaknesses in policy and practice in this area. Effective leaders advocate for necessary resources, provide professional development for educators, and implement policies that support inclusive and continuous education (Bush, 2007). They collaborate with other professionals, engender a culture of positivity, foster supportive environments, and apply strategies to meet a variety of needs (Greany and Earley, 2021). Additionally, strong leaders manage smooth reintegration post-treatment by coordinating efforts towards a supportive and normalised school environment (Helms et al., 2016). This

research implies that, in Wales, much of this remains underdeveloped. Policies are non-existent, deficient or outdated, professional development has shown limited effectiveness, and cooperation with health professionals is inconsistent.

Even prior to the current evolution in Welsh education, as noted above, the Welsh education system was experiencing a significant vacuum in terms of institutional leadership, which impacted the effectiveness of educational reforms and teacher training (Furlong, 2015). Furlong's report asserted that strong leadership is essential to develop a robust teacher education sector in Wales, which could produce competent and motivated educators. Harris et al. (2001), in their study on subject leader training in England and Wales, emphasise that the National College for School Leadership (NCSL) must play a pivotal role in leadership development. They argue that the future of school organisation will rely on strong leadership skills at all levels. The same can be said of the National Academy for Educational Leadership (NAEL) Wales. The limitations in leadership training and support in Wales can hinder the development of specialised educational strategies for students with cancer. Addressing these leadership gaps is essential to foster an environment that can accommodate the complexities of educating young people undergoing cancer treatment, ensuring that their academic and personal development is not compromised.

Effective leadership, characterised by strategic vision and decisiveness, directly correlates with improved outcomes (Dinham, 2005). Dinham explores the relationship between principal leadership and educational outcomes in Australian schools, drawing parallels that can be applied to Wales. Their work implies that Welsh schools could benefit similarly from strong strategic leadership practices. Applying those insights to the context of young cancer patients in Wales, strong strategic leadership could produce clear and effective policies that facilitate seamless coordination between educators and healthcare providers, prioritise professional development, and provide for necessary resources that could significantly enhance the educational continuity and overall well-being of young people with cancer. Thus, strong leadership practices are crucial for fostering an inclusive and supportive educational environment that promotes

the academic success and personal growth of young people with cancer (Dinham, 2005).

The need for robust and collaborative leadership to address the specific educational needs of young people in Wales is supported by Egan (2017). They discuss the concept of school effectiveness and the role of leadership in driving school improvement. They note that strong leadership is crucial for addressing the issues highlighted by PISA (Programme for International Student Assessment) results, which have been, and still are, a concern for Welsh education authorities. Egan advocates for collaborative leadership models that can foster evidence-based school improvement and enhance educational outcomes across Wales. Such models can also facilitate effective coordination among educators, healthcare providers, and families, ensuring a cohesive support system towards better education provision and outcomes. Further, improved leadership could subsequently lead to better overall school effectiveness, more inclusive environments that better serve all students, and enhanced educational outcomes (Egan, 2012).

Educational leadership in Wales, from national to regional levels, can be enhanced in order to address the challenges outlined in this research. The National Academy for Educational Leadership (NAEL) (2024) highlights the importance of collaboration, with its System Leadership framework facilitating the development of leaders who engage in effective cooperation across all levels. Fostering collaborative leadership cultures can drive improvement within education settings. Encouraging a culture of collaboration would help leaders share best practices, address common challenges, and work towards the same goals. Further, studies by Bush and Glover (2012) suggest that distributed leadership could enhance collaboration and shared responsibility. Implementing such models in Welsh schools can create a more inclusive and effective leadership culture.

The NAEL (2024) points to the importance of supporting and developing practices that ensure leaders are well prepared to perform effectively in diverse settings. Cowie and Crawford (2007) also state a need for robust training programmes that equip aspiring leaders with the skills and knowledge required to lead effectively. The further

development of comprehensive training programmes should focus on both theoretical and practical aspects of leadership and be backed by appropriate resources to inform leadership actions in uncommon but significant situations, such as providing for students with cancer. Once trained appropriately, support systems should be enhanced; providing ongoing support and professional development opportunities for school leaders is crucial. This includes mentorship programs and leadership networks which improve communication, enable the sharing of best practice, and promote inter-professional collaboration. Access to shared resources that are relevant, current and comprehensive can also help leaders stay informed and proficient. These actions could serve as a roadmap for policymakers, educational authorities, and school leaders to strengthen leadership in Welsh education.

By prioritising strong and effective leadership, Wales can ensure that its educational institutions are well-equipped, dynamic and adaptable in order to provide high-quality education to all students, and particularly those with additional needs including young people with cancer. This research has found a need for effective leadership practices that improve education provision and enhance student outcomes. By developing comprehensive training programs, promoting distributed leadership models, and fostering a collaborative leadership culture, Welsh education can build a strong foundation for the future success of young people with cancer.

Inter-professional collaboration

This research has shown that poor inter-professional collaboration between educators and healthcare professionals can exacerbate the unique academic challenges faced by students with cancer. The provision of effective education for such students requires a deeper understanding of their physical, emotional, and psychological needs, necessitating a more responsive and dynamic educational approach (Hopkins and Waller, 2020). Effective collaboration is crucial for developing flexible and responsive educational strategies. Engelke et al. (2017) highlight that the failure to adapt educational provisions in response to a student's changing health status can lead to significant academic setbacks. They emphasise the importance of ongoing

communication between healthcare providers and educators to ensure that educational plans are continually adjusted to reflect the student's current health and capabilities.

The development of flexible learning pathways is essential to align educational expectations with the student's personal capabilities. Studies by Hopkins and Waller (2020) show that these pathways allow students to engage with academic content at a pace that is compatible with their health, reducing the risk of academic failure due to absences or periods of low energy. Moreover, a phased approach to reintegration into the school environment, after periods of absence due to treatment, has been shown to facilitate smoother transitions and prevent students from becoming overwhelmed (Shaw et al., 2015). However, educators in this research note that the effectiveness of such strategies is often undermined by persistent communication challenges and a lack of organised collaboration. Successful support for these students frequently depends on the individual commitment of educators and healthcare professionals rather than on institutional support (Hopkins and Waller, 2020). This research supports that finding and shows that a reliance on personal initiative, rather than seeking effective collaboration, often leads to inconsistencies in the support provided.

The challenges of poor inter-professional collaboration between education and healthcare professionals can be better understood by examining similar issues in other sectors where interdisciplinary collaboration is critical. Insights from these sectors can inform strategies to improve collaboration in supporting students with a cancer diagnosis. The urban planning sector, for example, can offer valuable lessons. Effective urban planning requires collaboration across disciplines to create environments that meet the needs of diverse communities. A study by Wondimu et al. (2020) in the area of project management shows that when professionals from different fields collaborate early and continuously throughout the planning process, the resulting projects are more sustainable and better suited to community needs. Similarly, in education and healthcare, continuous and early collaboration between educators and healthcare providers can lead to more effective support plans that address the full range of a student's needs.

Another compelling example can be drawn from the aviation industry where effective communication and teamwork are critical to safety and success. Crew Resource Management (CRM) is a set of training procedures designed to improve teamwork, communication, and decision-making (Helmreich et al., 1999). CRM emphasises the importance of each crew member's role and the need for clear and open communication in order to follow protocol and prevent errors. In the context of education and healthcare collaboration, adopting a CRM-like approach could involve training both educators and healthcare professionals in communication skills, role clarity, and teamwork to ensure that all parties are effectively contributing to the student's well-being. This can then be taken to a more strategic level, as in the military arena, where joint operations involve different branches of the armed forces working together to achieve a strategic objective. These operations require extensive planning, clear communication, and a deep understanding of each branch's strengths and capabilities (Miller and Moss, 2013). The success of joint operations depends on the integration of these diverse elements into a cohesive strategy. Similarly, in supporting students with chronic health issues, educators and healthcare professionals need to develop a unified strategy that integrates educational goals with healthcare needs, ensuring that both are addressed effectively.

This aligns with the principles of co-production within the NHS, where collaborative efforts with various stakeholders aim to be both relevant and meaningful. The approach seeks to dismantle traditional power dynamics, fostering more equal partnerships. While there is evidence that co-production is taking place within the NHS, the evidence regarding its impact remains somewhat unclear; in this research, there is little indication of its impact. Oliver (2019) states that the complexity of relationships makes it challenging to apply co-production in a consistent manner as the variety of stakeholders have differing interpretations of what co-production should look like. This research has shown that the transactional nature of interactions between healthcare staff and educators often limits the depth of collaboration. Research by Forhan et al. (2020) in the context of rehabilitation services highlights how moving beyond transactional interactions to develop deeper, ongoing relationships between professionals can lead to more holistic and integrated care. Fostering these deeper relationships and learning

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lessons from other professional arenas educators and healthcare providers can establish a more unified and comprehensive approach. This would ensure that students not only receive consistent and personalised educational provision but could also promote a support system that is responsive to their changing health needs, ultimately leading to better academic and health outcomes.

To address the challenges posed by poor inter-professional collaboration, several strategies can be implemented to improve communication and coordination between educators and healthcare professionals. One effective strategy is the establishment of a single point of educational contact to ensure continuity, consistency, and ease of communication. Pini et al. (2016) suggest that schools should nominate a staff member with an established positive relationship with the young person and their family in order to overcome miscommunication. Such a role can also be critical in bridging the gap between education and healthcare as it provides a central figure responsible for coordinating support (Willgerodt et al., 2019). This role could help reduce the inclination to rely on individual experiences and ensure a less *ad-hoc* approach to collaboration, as identified within this research.

Providing professional development and training is another strategy to ensure educators are equipped with the necessary skills and knowledge to effectively collaborate with healthcare professionals in these circumstances. Effective training programmes should be comprehensive, addressing not only the specific medical, social and psychological needs of students with specific healthcare needs, but also making imperative the importance of inter-professional collaboration. According to Hopkins and Waller (2020), such training enables educators to understand the complexities of these students' conditions and how they intersect with educational demands. Additionally, training should provide practical strategies for implementing flexible learning pathways, which are critical for accommodating fluctuating health statuses and ensuring that students can engage with academic content at their own pace. Beyond external collaboration, the importance of intra-professional collaboration among educators at all levels cannot be overstated. Building a cohesive support network within and between schools and local authorities can enhance consistency and continuity, ensuring all educators are aligned

in their approach, ultimately leading to more consistent and effective support for students.

Finally, it is noteworthy in my research that monthly EOTAS meetings are held between local authorities, albeit with no obvious effect on education provision. Similar higher-level collaboration through regular meetings involving healthcare professionals, but with structured and meaningful information exchanges, would be an essential strategy for enhancing the support provided to students with long-term health conditions. Regular interdisciplinary meetings not only facilitate the sharing of best practices, but also create a platform for educators to seek guidance from healthcare professionals and build capacity within their establishments. Reeves et al. (2017) point out that such collaborative practices are critical in ensuring that all professionals involved are aligned in their efforts, thereby reducing the risk of fragmented approaches and inconsistent support. Further, the establishment of appropriate policies that mandate regular interdisciplinary collaboration and the integration of shared best practices would be helpful. These policies should ensure that collaboration is not left to individual initiative, but is embedded within the institutional framework, promoting a culture of continuous improvement and professional development. By regulating these practices, educators can create a more cohesive and responsive support system that is better equipped to address the complex needs of students with chronic health conditions such as cancer.

The impacts of poor inter-professional collaboration between educators and healthcare professionals on students can be significant. By integrating insights from other professional sectors and implementing strategies such as establishing a single point of contact, creating comprehensive training programmes and having regular interdisciplinary meetings, collaboration can be improved. Addressing the systemic barriers to collaboration identified within this research and fostering a more integrated approach will allow educators and healthcare professionals to work together more effectively in supporting young people with cancer.

Online learning futures

The adoption of recent practices in online learning in Wales, as a result of the COVID-19 pandemic, presents a transformative opportunity to radically rethink traditional

models of education provision. This section examines the trajectory of online education in Wales, considering the lessons learned from the COVID-19 pandemic and the ongoing efforts to integrate digital learning into mainstream education. The discussion is informed by relevant literature that highlights the challenges, opportunities, and policy directions influencing the future of online learning in Wales, as well as specific issues identified in this research.

The COVID-19 pandemic acted as a catalyst for the rapid adoption of online learning in Wales, as it did globally. Chapman et al. (2020) found that the pandemic forced educational institutions to shift to blended and distance learning models, significantly altering the landscape of education in Wales. The need to adapt quickly led to an accelerated implementation of digital platforms, such as Google Classroom, which became integral to the educational experience of many students. This research also found that educators recognised the benefits of remote learning, particularly for vulnerable students, such as those with long-term health issues like cancer. They spoke of remote learning helping students reduce feelings of isolation, enhancing their resilience and psychosocial well-being, and allowing them to continue learning at their own pace. Although educators acknowledged their limited experience in teaching these students, they expressed a willingness to reflect on their limitations and develop further. Developing and adopting online learning further can help in this development. However, maintaining both traditional and online provision posed significant challenges, leading schools to discontinue their online learning provision post-pandemic due to additional teacher workload and constraints on curriculum coverage.

Despite this, Wales has been somewhat proactive in developing policies that support the integration of digital learning into the education system. The 'Well-being of Future Generations (Wales) Act 2015' serves as a foundational framework for educational policies, promoting sustainability and inclusivity in education (Clark et al., 2023). This legislative framework stresses the importance of preparing students for the future, including equipping them with digital literacy and the skills needed to thrive in an increasingly digital world. The 'Digital Competence Framework' (DCF) introduced as part of the new Curriculum for Wales was designed to support students across a wide

range of activities and scenarios, and points to the importance of the creative and critical use of technologies to embed digital skills in all areas of learning. However, insights into the early enactment of this digital policy by Jimenez (2023) imply a divergence between local enactment of the DCF and policymakers' expectations. This research has also found that there are significant gaps in the national policy framework. The EOTAS Framework for Action (2019) and the 2021 ALN Code fail to adequately address the needs of students with long-term health issues. Further, the Welsh Government's guidance often places the policy onus on local authorities rather than consistent national ones, leading to inconsistencies and outdated practices that may not meet the current needs of students and educators. Whilst there is positive movement in some areas of national policy, the lack of a cohesive set of National policies will still leave educators to navigate challenges on their own, resulting in inconsistent practices and unequal educational opportunities.

Notwithstanding that progress, other challenges still need to be addressed before fully realising the potential of online learning in Wales. A primary concern in Wales is the digital divide (Coleman, 2021) which refers to the gap between those who have access to digital technologies and those who do not. Their review highlights the disparities in access to digital resources, which can hinder the effectiveness of online learning initiatives and the need to take measures to minimise digital exclusion. For students with cancer, the digital divide can significantly exacerbate the challenges they already face in accessing education. Without essential resources, they may be unable to participate fully in online learning, preventing them from benefiting from the psychosocial advantages such as reduced feelings of isolation and enhanced resilience, as highlighted in this research. If students with cancer are unable to access the necessary technology, they may also miss out on tailored, flexible learning pathways that could accommodate their changing health status and personal capacities. Addressing the digital divide for students with cancer requires targeted actions to ensure they have equal opportunity to participate in online learning and help maintain continuity in their education. Without such interventions, the digital divide risks further marginalising these vulnerable students, exacerbating educational inequalities, and hindering their overall well-being.

While challenges clearly exist, the future of online learning in Wales also has opportunities for innovation and growth. The flexibility offered by online learning can make education more accessible. The ability to access educational content at any time and from any location can help learners overcome the barriers that traditional, school-based education might present (Billings, 2023). For students with a cancer diagnosis, the flexibility offered by online learning is particularly beneficial. This flexibility allows them to access educational content at any time and from any location, which is crucial given the unpredictable nature of their health and treatment schedules. Online learning can be adapted to fit around medical appointments, hospital admissions, and periods of rest when the young person may have a limited capacity to learn. This approach means that students with cancer can continue their education, learning at their own pace and accommodating both their physical capabilities and their cognitive energy levels. Such flexibility could ensure that students with cancer remain engaged with their education and prevent them from falling behind their peers, which is critical for their longer-term academic success. Fundamentally, the flexibility of online learning empowers students with cancer to have their education managed alongside their health needs, ensuring that their diagnosis does not prevent them from pursuing their academic ambitions or fulfilling their academic potential.

The advent of digital technology also presents new opportunities for transforming the examination process. One of the primary criticisms of the current examination process is that it often fails to consider the impact of external factors. Research by Trask and Petersen (2016) emphasises the importance of acknowledging the broader context in which students are learning; without considering these elements, examinations risk perpetuating existing inequalities within the education system. Its impact on the well-being of students with cancer is one such element. Research by Matías-García et al. (2024) on student identity and resilience indicates that the pressure of exams can exacerbate feelings of inadequacy and disengagement, particularly among students who face additional challenges.

Neubauer and Neubauer (2024) call for the inclusion of more flexible, multidisciplinary approaches to assessment as the rigid structure of traditional examinations often fails to

accommodate diverse needs. Alternative assessment methods, such as the model of Centre-determined grades used during the COVID-19 pandemic, have been shown to be viable alternatives to traditional exams. This could allow for an extended view of a student's abilities, and even yield a more holistic evaluation considering a broader range of skills and competencies. If traditional exams are preferred, then online assessments could offer greater flexibility, allowing for more personalised and adaptive testing environments. This does not ignore the challenges around integrity, disparities in digital literacy, and system reliability, which would need to be addressed to maintain the credibility of online assessments (Idika et al., 2024). Nonetheless, these issues are not insurmountable. Robust policies and guidelines that govern the use of digital assessments could ensure that they are implemented fairly and consistently across different environments. Ultimately, the future of the examination process in compulsory education will depend on the ability of educators, exam bodies and policymakers to collaborate and innovate, creating an assessment system that is equitable, inclusive, and supportive of all students.

The integration of online learning in Wales offers a transformative opportunity to rethink traditional educational models, particularly in the context of lessons learned during the COVID-19 pandemic. While the shift to digital platforms has brought significant benefits, especially for vulnerable students, challenges such as the digital divide and inconsistent policy frameworks remain obstacles to fully realising its potential. Addressing these issues through targeted interventions and policy reforms is crucial for ensuring that online learning becomes a permanent, equitable, and flexible component of education in Wales. Moreover, the evolving landscape of digital education could pave the way for more inclusive and adaptable examination practices, which are vital for accommodating the diverse needs of all students, including those with significant health challenges. As Wales continues to embrace innovation in online learning, the focus must be on creating an education system that is resilient, equitable, and capable of supporting every student's academic journey.

Recommendations

The findings of this research, while providing valuable insights into educators' perspectives on the provision of education for young people in Wales with a cancer diagnosis, identify several areas where further research is necessary to enhance the effectiveness of educational practices and policies. The following section will address the limitations of this research and explore new avenues for future research such as the development of comprehensive training programs, the use of practical experiences to inform policy, and the investigation of collaborative practices within educational settings. By pursuing these research directions, future studies can build upon the foundation laid by this research, offering even more detailed and actionable insights that could lead to significant improvements in educational policy and practice in Wales.

Study limitations

The primary limitation of this research was the small sample size. The limited number of participants was largely influenced by two key factors: the constrained pool of potential recruits and the reduced response rate, impacted in particular by the COVID-19 pandemic. The restricted pool was a direct consequence of the narrow focus of the study population, which inherently limited the number of eligible participants. Further, the ongoing pandemic introduced unprecedented challenges in participant recruitment as potential respondents faced greater stresses on their key priorities, thus leading to lower engagement with research activities. As such, the small sample size impacts the broader utility of the findings, limiting the extent to which the findings can be applied to a wider population. While the study provides valuable insights from educators into the specifics of providing an appropriate education for young people with a cancer diagnosis, the conclusions drawn will inevitably need to be interpreted cautiously.

To overcome the limitations associated with such a small sample size, future research should consider a number of strategies. Firstly, targeted engagement strategies that continue to clearly communicate the importance and impact of the research, without the competing pressures of pandemic-style working conditions, should be applied. Whilst the pandemic provided potential participants with a valid reason to turn down an invitation to participate, in reality, the majority of people approached failed to respond to

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several requests in different formats. Future efforts could further demonstrate to these educators, particularly those in positions of leadership, that the aims of the research align with their responsibility to provide an equal and accessible education for all.

Next, implementing a longitudinal study could counter the effects of a small sample size by offering an approach that emphasises depth over breadth. In such a study design, data could be collected from the same small pool of participants over an extended period, allowing for the observation of developments over time. Repeated data collection, while not increasing the number of participants, can provide a richer and more detailed dataset. The continuous tracking of participants' responses could enable future researchers to identify stronger themes that might not be otherwise apparent. This depth of analysis could compensate for the smaller sample size by yielding more nuanced and comprehensive findings towards a deeper understanding of the research questions and more robust conclusions (Patton, 2015).

Using other methods such as in-depth case studies that incorporate ethnographic and observational methods could also offer a range of benefits. Being immersed in the professional environment would allow the collection of contextualised data as well as gaining a nuanced understanding of professional dynamics and cultural norms. Ethnographic and observational methods also uncover tacit knowledge that participants may not explicitly articulate in interviews, as well as capturing nonverbal cues. This type of data enhances the validity of the research, especially when triangulated with other sources, such as interviews or documents, to cross-check findings and ensure alignment between what people say and what they do. (Fusch and Ness, 2017)

Finally, to combat the challenges of in-person data collection, as highlighted during the COVID-19 pandemic, the use of online data collection platforms alone could be explored. The type of initial online survey used in this research could be followed up with further, and more targeted, in-depth surveys designed to delve deeper into specific themes or patterns that are identified in the preliminary data. This tiered approach to data collection could allow for the refinement of future research questions as the research progresses, possibly enhancing the overall depth and quality of the findings. This method would also make it easier for potential participants to engage with the

research process in their own time and at their own pace. This flexibility could lead to higher response rates and possibly more thoughtful, reflective responses.

While the small sample size used in this research presents a notable limitation, future research can address this challenge through the strategies outlined herein. By adopting these approaches, future studies can build on this research, contributing more comprehensively to the understanding of educational provision for young people with cancer diagnoses.

Implications and recommendations

This research could be utilised to develop and evaluate comprehensive training programmes for educators and educational leaders who support students with serious illnesses such as cancer. Such training is essential, particularly given the strategic role that leaders play in shaping education policies and practices. Leaders often face the challenge of ensuring that their institutions are equipped to address the complex needs of these students, including their physical, emotional, and psychological well-being. Thus, tailored training programmes for leaders are crucial to enable them to create effective policy, guide staff effectively, and foster a culture of collaborative practice. Such training programmes could also provide a focus for future research which could investigate what the most effective components of training programs are for educators that will equip them with the necessary skills and knowledge in this arena. Evaluating the effectiveness of these programmes could involve observing leaders' abilities to implement inclusive policies, their impact on professional working practices, and how these impact the overall well-being and academic outcomes of students with serious illnesses. Ultimately, this research could act as the foundation for the establishment of effective training programmes that work alongside standardised policy frameworks, thus promoting consistency and excellence in the educational support provided to students with a cancer diagnosis or other serious illnesses.

A further application of this research involves using the practical experiences and insights of educators, as voiced and analysed herein, to inform and shape policy at both national and local levels. These insights can serve as a foundation for developing more effective, evidence-based policies that address the unique needs of students with

cancer. At the national level, integrating educators' experiences into policy development could lead to the creation of standardised guidelines that develop greater consistency in educational provision across Wales. Such policies would reflect the realities of inter-professional dynamics and the challenges of adaptive teaching towards more comprehensive educational frameworks. At the local level, this research could be used to tailor strategies, ensuring that policies are not only theoretically sound, but also practically applicable in all educational settings. This application promotes a bottom-up policy development process, where the voices of practicing educators are central to the conversation. This can lead to more sustainable and actionable policies as they are grounded in practical realities. Consequently, this research not only has the potential to inform policy changes, but also to bridge the gap between policy and practice, ensuring that national and local policies are truly responsive to the needs of all students. Future research could then investigate how effectively current policies are implemented at local level, with a focus on consistency and impact. Such policy creation and further research would provide a full circle exploration of the relationship between policy and practice.

The issues surrounding collaborative practice identified in this research also call for further exploration as they are critical in ensuring consistent and effective support for students. Future research into these issues could be approached from multiple angles, each offering unique insights. Firstly, this research could explore the barriers that impede effective collaboration, identifying the underlying causes of these failures. A thorough analysis would allow the research to propose targeted interventions aimed at overcoming these obstacles. Another avenue for research could involve identifying existing models of successful collaboration within the education sector, evaluating their effectiveness and determining their impact on student outcomes. The scalability of such models could be explored as well as the factors that influence their successful implementation across different schools or authorities. Finally, research could consider examining successful collaborative practices outside the education sector where inter-professional collaboration is more established. It could explore how such models can be adapted to the educational context, identifying the necessary adjustments and potential benefits of their implementation. Pursuing any one of these three research avenues

would provide further valuable insight towards a more cohesive understanding of how to foster effective collaboration in education for the overall benefit of students.

Conclusion

The provision of education for young people in Wales with a cancer diagnosis is a complex area, requiring a nuanced understanding of the multifaceted challenges that these students face. This thesis explored the perspectives of educators on current practices, their effectiveness, and the pathways to best practice. The findings highlighted several areas that require attention: the need for consistent educational responses, the role of flexible technology-based learning pathways, and the challenges posed by inadequate policy and interprofessional collaboration.

Educators recognised their own limitations yet the success of educational provision for students with cancer often relied on the commitment of individual educators rather than systemic facilitation. A lack of consistent integration between the education and healthcare systems was a further barrier resulting in variable communications and fragmented collaboration. *Ad-hoc* approaches created inconsistencies in support, particularly in the absence of clear national guidelines or comprehensive local policies. These gaps contribute to inconsistencies in educational provision. To achieve best practice, it is essential to establish a more integrated and collaborative approach. This could involve the establishment of a single point of educational contact who could foster a culture of shared learning and mutual support between all stakeholders.

There is an urgent need for stronger national leadership to drive policy reform at both the national and local levels. National guidelines should be developed to provide clear and consistent standards, informed by the insights of educators and healthcare professionals to ensure that they are both practical and responsive to the needs of students. Additionally, local policies must be regularly updated and aligned with national standards, with mechanisms in place to monitor their implementation and effectiveness. Greater leadership is also needed to further discussions around online and blended learning futures. The future of education for young people with cancer must include integrated online learning and alternative assessment methods, ensuring that all

students have access to a broad and balanced curriculum and have their learning appropriately assessed, regardless of their health status.

This thesis has shed light on the complex and multifaceted challenges involved in providing education to young people in Wales with a cancer diagnosis. While educators are committed to supporting these students, they are often hampered by a lack of specific experience, inadequate policies, and systemic barriers to collaboration. By addressing an under-explored area, my research offers a missing piece in understanding how educational practices can better support these learners. To move towards best practice, it is essential to address these challenges through comprehensive policy reform, enhanced professional development, and the integration of flexible and dynamic learning pathways that utilise appropriate technologies. By fostering a more collaborative and supportive educational environment, all students with cancer can receive the education that they are entitled to.

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Appendix A: Research information sheet and consent form

PARTICIPANT INFORMATION SHEET

<u>Education Provision for Teenagers with Cancer in Wales:</u>
<u>Education Practitioners' Perspectives</u>

I would like to invite you to take part in my research. It is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please contact me at the email address at the bottom of this information sheet.

What is the purpose of the research?
My research aims to investigate the perspectives of education practitioners as they strive to deliver appropriate education for teenagers in Wales following a diagnosis of cancer. Most research in this area is primarily focused on the impact that continuing education has on the students' overall wellbeing. Some research has been dedicated specifically to the views of patients/students, health professionals, families and partners. This research aims to build on previous investigations and provide a voice explicitly for educators.

Who am I?
I have a professional background in education, having led schools in the UK and overseas, providing education for students from Foundation Stage to Year 13. I also have direct family experience of teenage cancer and the provision of services within England. I am currently undertaking this research as part of a Professional Doctorate at Cardiff University.

Why have you been invited?
You have been invited to take part in this research because you are part of a small group of education professionals who are, or have been, involved in the provision of education for teenagers with cancer in Wales. As such, you are able to provide valuable information to inform this research at Cardiff University.

I am hoping to involve at least twelve participants in this research. Each of you may have worked in schools, for Local Authorities, within hospitals, for specific charities or within private settings delivering and supporting education for these teenagers.

Do you have to take part?
Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw at any stage.

What happens if you decide to take part?
You will be contacted in the immediate future and asked to complete a simple questionnaire which will inform a single follow-up interview. The interview will aim to take place within one month of your

completed questionnaire, at a mutually convenient time; it will be conducted remotely using MS Teams or Zoom and will last about one hour. All participants will be asked the same core questions but discussions will be developed as a result of answers provided. All data will then be analysed and used to inform my research which is due to be completed by 2025.

What are the possible benefits of taking part?
It is hoped that this research will inform future policy and have a positive influence on professional practice organisations involved in the provision of education. There is no guarantee that you will receive any benefits from this research personally, however, it is aimed at helping educators like you improve your students' academic and life opportunities beyond successful treatment.

What risks should you consider?
You may feel that some areas being explored are stressful or upsetting. Any concerns you may have will be discussed at an early stage and will inform the construction of your interview. If you do not wish to answer a question, or if you become upset or distressed as a result of your participation in the research project, you will have the option to avoid questions, take breaks or withdraw at any time. Details of support groups can also be provided.

You may also have concerns around disclosing sensitive information or being able to be identified. All information you provide will be collected in a safe manner and in a secure environment. The Teams/Zoom meeting will take place in a private area free from interruption and the ability to be overheard, and you should aim to do the same. Your questionnaires and interview responses will be wholly anonymised to ensure confidentiality.

What will happen to your data?
All information collected will be used for research only and will be kept completely confidential during all stages of this research from your recruitment through to publication and subsequent data storage. Teams/Zoom meetings will be recorded but you will be given the option of turning video off. If you choose a Zoom meeting, your video can and will be deleted.

Electronic material will initially be recorded on an encrypted laptop with firewalls and anti-virus software adding a further layer of technical protection. This will then be transferred to Cardiff University's secure electronic storage network where access will be limited. It will be stored for no less than five years or two years post-publication. Further information can be found at [Research participants data protection notice - Public information - Cardiff University](#)

What will happen if you don't want to continue as a volunteer?
Participation is voluntary and you have a right to withdraw at any time. If you do decide to withdraw you will have the choice to request the removal of any data collected up to the point of its analysis. Unless you state otherwise, all information collected will continue to be used for the purposes of this research. You should be aware that data that has reached the point of analysis will form part of the research project results.

What will happen at the end of the research?

This research will contribute to the fulfilment of my Doctoral thesis. On completion, it will be published in the public domain. It may also be presented at conferences. It will include verbatim quotes from interviews but these will be fully anonymised. You will not be identifiable from any report or publication. Should you wish to read the final publication, you can contact me and I will provide you with the relevant online link.

Who is funding and reviewing this research?

This research is part of a self-funded Professional Doctorate supervised by Cardiff University. No financial compensation is being obtained from any source. This research has been reviewed and given approval by the School of Social Sciences' Research Ethics Committee (SREC\4183).

What if you have a complaint?

Cardiff University expects all those involved in research activities to observe the highest standards of professional behaviour, rigour and integrity. Any complaints should be submitted in writing to the Chair of the Ethics Committee at socsi-ethics@cardiff.ac.uk

Further information

Please contact Mitchell Jones at jonesm146@cardiff.ac.uk for any further information.

Mitchell Jones

CONSENT FORM

Education Provision for Teenagers with Cancer in Wales:

Education Practitioners' Perspectives

SREC/4183

Name of Principal Investigator: Mitchell Jones

	initial box
I confirm that I have read and understood the participant information sheet for the above research project. I have had the opportunity to ask questions and that these have been answered satisfactorily.	
I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason. I understand that if I withdraw, information about me that has already been obtained may be kept by Cardiff University.	
I understand that data collected during the research project may be looked at by individuals from Cardiff University. I give permission for these individuals to have access to my data.	
I consent to the processing of my personal information and I understand that it will be held in accordance with all applicable data protection legislation and in strict confidence, unless disclosure is required by law or professional obligation.	
I understand who will have access to personal information provided, how the data will be stored and what will happen to the data at the end of the research project.	
I understand that after the research project, anonymised data may be seen and used by other researchers, for ethically approved research projects, on the understanding that confidentiality will be maintained.	
I consent to being audio / video recorded for the purposes of the research project and I understand how it will be used in the research.	
I understand that anonymised excerpts and/or verbatim quotes from my interview and questionnaire may be used as part of the research publication.	
I understand that the findings and results of the research project will be written up and published.	
I agree to take part in this research project.	

Participant:

Signature: Date:

Person taking consent:

Signature: Date:

THANK YOU FOR PARTICIPATING IN MY RESEARCH
PLEASE RETURN THIS COMPLETED FORM TO jonesm146@cardiff.ac.uk
YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Appendix B: Initial online questionnaire

Introduction Thank you for taking part in my research which explores the perspectives of education practitioners as they deliver education to teenagers in Wales after a diagnosis of cancer. It aims to build on previous research and provide a voice for educators on this topic.

You are being invited to take part in this research because you are part of a small group who are, directly or indirectly, involved in the provision of education for teenagers with cancer in Wales. As such, you are able to provide valuable information to inform my Professional Doctorate research at Cardiff University.

This questionnaire should take approximately 15-20 minutes to complete. Participation is voluntary; if you do not wish to answer a question you can skip questions or stop participating at any time by simply closing your browser. Any responses provided are automatically saved.

All information you provide will be collected in a safe and secure manner. To ensure confidentiality your name will be replaced with an anonymous ID and will only be used to link your questionnaire responses with any subsequent interview. When reporting the findings your name will not be included, nor any other identifying information. The data will be used for research only and will be kept completely confidential. Your questionnaire will be stored on Cardiff University's secure electronic storage network where access will be limited. Further information can be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection/research-participants-data-protection-notice

If you would like more information or have any questions, please email me at jonesm146@cardiff.ac.uk

Thank you again for your time and participation.

Mitchell Jones

I HAVE READ THE ABOVE INFORMATION AND AGREE TO TAKE PART.
(If you do not wish to take part, please close this webpage and do not proceed any further)
 Yes (1)

Q2 Name:

_____

Q3 Gender identity:

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Other/self identification (please specify) (4)

_____

○ Prefer not to answer (5)

Q4 Preferred pronoun:

○ He (1)

○ She (2)

○ They (3)

○ Prefer not to answer (4)

Q5 Age:

○ 19-24 (1)

○ 25-29 (2)

○ 30-34 (3)

○ 35-39 (4)

○ 40-44 (5)

○ 45-49 (6)

○ 50-54 (7)

○ 55-59 (8)

○ 60-65 (9)

○ 65+ (10)

○ Prefer not to answer (11)

Q6 Ethnicity:

○ White (1)

○ Black (2)

○ Asian (3)

○ Mixed (4)

○ Multiple ethnic groups (5)

○ Other/self-identification (please specify) (6)

_____

○ Prefer not to answer (7)

Q7 Which of these best describes your role?

○ Government Officer (1)

○ Local Authority Officer (2)

○ Local Authority Tutor (3)

○ School Teacher (4)

○ School Support Worker (5)

○ Hospital Teacher (6)

○ Hospital Support Worker (7)

○ Charity Support Worker (8)

○ Private Tutor (9)

○ Other (Please specify) (10)

_____

Q8 Which of these best describe your main responsibilities? (select all that apply)

☐   Writing policy (1)

☐   Inspecting education provision (2)

☐   Monitoring education provision (3)

☐   Writing curricula/schemes of work (4)

☐   Creating lesson plans (5)

☐   Delivering whole-class lessons (6)

☐   One-to-one tuition (7)

☐   Study support (8)

☐   Writing assessments (9)

☐   Marking and feedback (10)

☐   Other (please specify) (11)

_____

Q9 How many years experience do you have in education provision?

○ 0-2 (1)

○ 3-6 (2)

○ 7-10 (3)

○ >10 (4)

Q10 How long have you been in your current role?

○ 0-2 (1)

○ 3-6 (2)

○ 7-10 (3)

○ >10 (4)

Q11 How often are you involved in providing education for teenagers with cancer?

○ Every day (1)

○ Most days (2)

○ Weekly (3)

○ Fortnightly (4)

○ Monthly (5)

○ Other (please specify) (6)

_____

Q12 Who do you regularly communicate with to support you in this role? (select all that apply)

☐ Local Authority (1)

☐ School (2)

☐ Parents (3)

☐ Medical staff (4)

☐ Charities (5)

☐ Personal tutors (6)

☐ Other (please specify) (7)

_____

End of Block: Default Question Block

Q13 What do you find most fulfilling about your role?

_____

Q14 What do you find most challenging in your role?

_____

Q15 What element of your practice do you consider most effective in terms of educational outcomes, and why?

_____

Q16 What 'best practice' are you made aware of, or specialist training have you received to help you to do your job?

_____

Q17 Are current policies and guidelines for education provision available to you? If so, are they effective?

_____

Q18 How is education provision for teenagers with cancer locally evaluated?

_____

Q19 In your experience, what are the key characteristics of students that successfully engage with their education? (select all that apply)

- [ ] High attainment prior to diagnosis (1)

- [ ] Maintaining and education focus from an early stage in their diagnosis (2)

- [ ] Maintaining continuous links with their peers (3)

- [ ] Strong parental input (4)

- [ ] Less complex medical needs (5)

- [ ] Maintaining a positive attitude (6)

- [ ] Taking responsibility for their own learning (7)

- [ ] Other (please specify) (8) _____

Q20 What barriers do you experience when providing education for teenagers with cancer? (select all that apply)

☐   Health concerns (1)

☐   Absence (2)

☐   Lack of personalised learning materials (3)

☐   Lack of appropriate resources (4)

☐   Location disruption (5)

☐   Setting unable to meet students' needs (6)

☐   Disorganised systems of provision (7)

☐   Unclear division of responsibilities (8)

☐   Parental intervention (9)

☐   Ineffective communication (10)

☐   Lack of professional training (11)

☐   Other (please specify) (12)

_____

- -

Q21 Are there any other key issues or comments that you would like to make note of at this point?

_____

Q22 Thank you for completing this questionnaire.
Can you now confirm that you are still willing to take part in a follow-up interview. This will aim to take place within one month of this completed questionnaire, at a mutually convenient time. It will be conducted remotely using MS Teams or Zoom and will last about one hour.

○ Yes (1)

○ No (2)

Appendix C: Interview framework

1. RQs:

How do educators perceive education provision for young people in Wales with a cancer diagnosis?

What do educators perceive is needed to improve provision?

2. Literature review themes:

Health/psychosocial/education/cognitive impact

Collaboration and communication

School reintegration

Resources/training

3. Themes arising from the questionnaires:

Communication

Resources/training/logistics

Policy

Health/education concerns for reintegration

4. Interview questions guide:

	Key questions		Supplementary

a.	Tell me about you and your role.	
b.	What are your thoughts on the importance of education for this particular group of students?	
		- How do you feel about working with this particular group? - How do and can you support their engagement? - How do student/parent/healthcare views inform your views?
c.	What kind of education provision is available, in your view, to students with a cancer diagnosis?	
		- In your area - From other areas
d.	What stands out to you as the defining characteristics of being able to support education well for this group?	
		- Time - Resources - Information/communication - Consistency/continuity - What hampers this?

e.	Tell me about all the things that might support *you* in your work.	
		- Training - policy - professional guidance/support - Do you feel sufficiently prepared to support the education of these children with such complex long-term conditions?
f.	What challenges/difficulties do you face/have you experienced in your role supporting education provision for this group?	
		- Communication - training - Logistics/resources - Personal/emotional
g.	Tell me about the relationships you have to sustain to be effective in your role.	

		- Student
		- Parents
		- Other educators
		- School
		  -- Do the school share student data/curriculum overviews/short term lesson plans?
		  -- does this continue when student returns to school?
		- Healthcare staff
		  -- Are you informed of the disease impact?
		  -- Are you informed of the impact of medical interventions?
		  -- Does the hospital share relevant medical/care plans?
		- Charities
		  -- Are you aware of their input/role?

h.	What is your experience of the attitudes of these groups to the significance of education at this time?	
		- How does your professional approach differ in relation to different attitudes? - Is your motivation affected by others' attitudes?
i.	What can be done to support school reintegration?	

		- medical
		- emotional
		- information sharing
		  - peers
		  - staff
		- liaison
		- personalised learning programmes

j.	What policies, guidelines and guidance have been/are helpful?	
		- Local/regional/national - Are they effective? - Give examples
k.	What recommendations do you have for improving practice in the future?	
l.	Are there any other thoughts or opinions you would like to share?	

Appendix D: The six stages of thematic analysis

Stage 1	Familiarising yourself with your data:	Transcribing data, reading and re-reading the data, noting down initial ideas
Stage 2	Generating initial codes:	Coding interesting features in the data in a systematic fashion across the entire data set, collating data relevant to each code
Stage 3	Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme
Stage 4	Reviewing themes:	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic map of the analysis
Stage 5	Defining and naming themes:	Ongoing analysis to refine the specific of each theme, and the overall story the analysis tells, generate clear definitions and names for each theme
Stage 6	Producing the report:	Final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report on the analysis

Appendix E: Ethical approval

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20 May 2021

Our ref: SREC/4183

Mitchell Jones
Professional Doctorate Programme
SOCSI

Dear Mitchell,

Your project entitled *'Education Provision for Teenagers with Cancer in Wales: Education Practitioners' Perspectives.'* has now been approved by the School of Social Sciences Research Ethics Committee of Cardiff University and you can now commence the project should all necessary forms of approval been received.

If you make any substantial changes with ethical implications to the project as it progresses you need to inform the SREC about the nature of these changes. Such changes could be: 1) changes in the type of participants recruited (e.g. inclusion of a group of potentially vulnerable participants), 2) changes to questionnaires, interview guides etc. (e.g. including new questions on sensitive issues), 3) changes to the way data are handled (e.g. sharing of non-anonymised data with other researchers).

In addition, if anything occurs in your project from which you think the SREC might usefully learn, then please do share this information with us.

All ongoing projects will be monitored and you will be obliged periodically to complete and return a SREC monitoring form.

Please inform the SREC when the project has ended.

Please use the SREC's project reference number above in any future correspondence.

Yours sincerely

Dr Kirsty Hudson
Chair of School of Social Sciences Research Ethics Committee

cc: Gareth Thomas, Jemma Hawkins