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The role of outreach workers in care coordination for teenagers and young adults with cancer: The BRIGHTLIGHT_2021 programme

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ABSTRACT

Purpose: Teenagers and young adults (TYA) with cancer have distinct developmental, psychosocial, and clinical needs that require age-appropriate care. Healthcare policy in the United Kingdom advocates care in centralised specialist age-appropriate TYA Principal Treatment Centres (PTCs). The responsibility of coordination and delivery of 'joint care' is reliant on outreach workers who bridge the gap between the PTC and hospitals and support young people closer to home. We aimed to explore outreach workers' experiences of their role in coordinating TYA cancer care.

Method: Semi-structured qualitative interviews were conducted with 10 outreach workers and care coordination staff working across PTCs and designated hospitals in the United Kingdom. Data were analysed thematically using framework analysis informed by rapid assessment procedure (RREAL RAP) sheets.

Results: Outreach workers described their role as providing coordinated care and liaison across multidisciplinary teams, addressing TYA needs and filling a perceived gap in services. Participants reported that their role contributed to continuity of care and facilitated equitable access to age-appropriate care closer to home. Potential barriers included isolation due to large geographic coverage and travel time and limited staff understanding outreach roles, alongside inconsistent referral routes. Outreach workers emphasised the need for skills such as communication, relationship-building and strong clinical knowledge.

Conclusions: Outreach workers described their role as highly skilled, complex and varied. Incorporating the identified facilitators and barriers into outreach strategies, including integration into healthcare settings, increased resourcing, and staff awareness may help inform future TYA care coordination, workforce planning and integration of outreach workers into routine TYA cancer healthcare settings.

1. Introduction

In the United Kingdom (UK), although it is uncommon, there are approximately 2378 new cases of cancer each year among teenagers and young adults (TYA) who are aged between 15 and 24 years (Bautista-Gonzalez et al., 2025a). Young people with cancer have specialist needs such as psychosocial and clinical requirements that differ from children and older adult populations (Carr et al., 2013).

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Young people are likely to experience rapid physical, social and emotional development, which can cause uncertainty and lower quality of life compared to other age groups with cancer (Carr et al., 2013). It is now widely recognised that young people require flexible and ongoing support. Care needs must address age-appropriate transitions, with a holistic approach to treatment focusing on factors such as developmental transitions (e.g. employment, education, family and peer relationships) (Pannier et al., 2019) and equity of care for underrepresented groups (Dixit et al., 2021). Since 2005, National Institute of Clinical Excellence (NICE) guidance has recommended age-appropriate support being provided for young people aged 16-24 delivered through Principal Treatment Centres (PTC) and Designated Hospitals (DH) in England (National Institute for Health and Care Excellence, 2005; National Institute for Health and Care Excellence, 2014) as a means of reducing disruptions and the emotional impact that illness and treatment bring (Department of Health, 2011). The NICE guidance was superseded in 2023 by service specifications specific for PTCs and DHs, which outlined an expectation for the development of joint care across the TYA multidisciplinary team (MDT) in the PTC and the DH (England, 2023). In England, care is now organised in Operational Delivery Networks (ODN) who are responsible for coordinating care between the TYA-PTC and DHs within a specified geographical area. These networks organise care complying with NHS policies which emphasise the importance of personalised care, survivorship, psychosocial support and equitable access. However, implementation varies geographically and is subject to local trust and governance processes, therefore young people's care coordination is often a complex component of cancer services. There is a need to refine current models of care to ensure a seamless delivery of care to TYAs irrespective of whether they receive care within a PTC or a designated TYA centre. At the forefront of this is outreach workers' roles in the delivery of care, who support communication and care delivery across multiple settings (Furness et al., 2017).

Over the last two decades, the UK has seen the development of TYA cancer centres across the UK, providing a spectrum of treatments. While treatment and services vary depending on geographical location, level of care and local resource availability, the specialist age-appropriate units are staffed by teams with wide ranging expertise in both the medical and psychosocial management of young people and form the TYA multidisciplinary Team (MDT). The MDT is convened virtually, and provides holistic care, considering the individual nature of treatments as well as providing age-appropriate expertise (e.g. education, career and peer support) during critical periods of young people's lives. Specialised care for cancer patients is not a new phenomenon, since the 1960s there has been a momentum to create a 'web of care' across primary, secondary care and tertiary care (Hunt, 1995). Furthermore, within this system, care spans across three domains: informational, management and relational, and TYA pathways often overlap multiple sites, making effective coordination essential (Ljungholm et al., 2022). However, while the importance of coordination is well established, less is known about how these functions are operationalised in practice across specialist and non-specialist settings for young people with cancer. Effective coordination across these domains depends on workforce roles that can operate across organisational and geographical boundaries, yet little is known about the experiences of staff responsible for delivering this support.

Although patient navigation and specialist nursing roles have been explored within paediatric and oncology services, there is limited research on the role of outreach workers and their experiences of providing support for TYAs with cancer, particularly on the experiences of staff working in clinical roles and within major cancer centres or PTCs (LaRosa et al., 2019).Existing studies have largely focused on patient navigators, specialist nurses or care delivered within major cancer centres. Patient navigator roles primarily focus on supporting access and navigation of healthcare systems, whereas the specialist nurse's role is typically centred on advanced clinical symptom management. In contrast, outreach workers combine care coordination, psychosocial support, advocacy and practical assistance with more specific focus on community, home-based support, employability and broader integration into daily life for teenagers and young adults (Martins et al., 2016). Furthermore, they often operate across organisational boundaries, bridging specialist and non-specialist services. Despite their importance, relatively little is known about how outreach workers experience and deliver care coordination across different healthcare settings, creating an important gap in understanding service delivery.

In this study, we use the term 'outreach workers' to refer to staff who coordinate and deliver age-appropriate support for young people treated at DHs. These workers support teenagers and young adult patients by coordinating clinical care, mental health support, and social or financial assistance both in hospital and at home. The NHS, Teenage Cancer Trust and Young Lives vs Cancer, provide specialist Teenage and Young Adult (TYA) outreach teams. Outreach workers are sometimes referred to as 'navigation' workers (LaRosa et al., 2019) with the goal of reducing barriers during cancer care, however their role extends beyond navigation alone. They provide a link between patients, families, and MDTs, and help facilitate and provide information, psychosocial support (e.g. addressing risk behaviours) and advocate for practical adjustments such as overnight carers, school, university and employer liaison (Pannier et al., 2019). Advocacy aims to ensure that care, support and treatment is tuned to individual needs and is truly person-centred and promotes recovery (Machin et al., 2016). The role of outreach workers incorporates elements of navigation but, within UK TYA cancer services, this extends beyond navigation alone. There is no 'one-size fits all' approach to the role, with challenges reported in lack of communication with cancer centres and the need to fulfil multiple roles and responsibilities, particularly due to the unique barriers faced by young people and the importance of ensuring they do not fall through the cracks (LaRosa et al., 2019).

Although we have seen widespread improvements in care services for young people, there is still variation in treatment and care. Thirteen TYA PTCs provide care across England; however, they differ in staffing, facilities and co-located services. These differences may create challenges in delivering consistent age-appropriate care and contribute to variation in pathways and patient experience across geographical regions. Young people not treated in a TYA-PTC are often treated in children's or adult cancer units, depending on local age thresholds, with some treated in children and others in adult services. Treatment for young people is therefore reliant on the coordination and networks of care, which require enhanced communication and interprofessional approaches. For example, for young people unable to travel to the PTC, support may be offered closer to home, reducing travel and financial burden for the young person and family. However, this can increase coordination workload for healthcare teams across sites, such as scheduling, information flow and role clarity (Warner et al., 2018). These co-ordination processes are subject to variation in governance, leadership and agreement on the division of responsibilities between organisations, which can affect whether the needs of young people are met in a timely manner. Existing evidence suggests that young people value direct communication and a responsive single point of contact from outreach workers which can improve understanding, reduce anxiety and support navigation across multiple sites (Aldiss et al., 2023; Critoph et al., 2024). These findings demonstrate the importance of care coordination and supportive relationships. However, existing studies have primarily focused on patient experiences, and little is known about the barriers and facilitators that may impact the delivery of age-appropriate care.

Outreach workers operate across settings, often working alone, which may impact access and outcomes for young people. These insights are important to inform adaptive changes in provision to address needs that arise in response to policy describing how to provide specialist care outside the TYA-PTC. Despite the increasing emphasis on care closer to home, there remains limited evidence on how outreach workers

experience and deliver coordination. Outreach workers often experience issues in role clarity, buy-in and support and lack of engagement from wider teams. This study aimed to explore outreach workers' experiences of their role in coordinating TYA cancer care, the challenges they faced, and their views on strengthening future models of care coordination. This study forms part of the wider BRIGHTLIGHT (2021) study (https://fundingawards.nihr.ac.uk/award/NIHR201438). The BRIGHTLIGHT(2021) study aimed to explore TYA outcomes to specialist care, with input from young people (Bautista-Gonzalez et al., 2025a; Fern et al., 2025).

2. Methods

This qualitative interview study, conducted as part of the BRIGHTLIGHT (2021) study (Bautista-Gonzalez et al., 2025b) explored the role of outreach staff in coordinating care for young people with cancer. A qualitative rapid appraisal design was used to collect and analyse data in a targeted way within limited timeframes to explore specific processes of care delivery (Beebe, 2014). Rapid qualitative approaches are increasingly used in applied health services research to generate timely insights into service delivery, understanding workforce experiences and organisational processes while maintaining methodological rigour (Vindrola-Padros, 2021). The study was informed by a pragmatic qualitative approach, focusing on understanding participants' experiences of care coordination within different geographical healthcare settings (Horwood et al., 2022).

2.1. Participants and recruitment

We recruited ten participants from services within Teenage and Young Adult ODNs in UK through the cancer charity Teenage Cancer Trust's funded staff networks (Teenage Cancer Trust, 2026). Participants included staff in a nursing outreach role (n = 10) in the sense that they were involved in the coordination of care for young people with cancer across different settings. Staff were recruited across England, Scotland and Wales within 10 different NHS Trusts. Time in role ranged from 1 to 11 years. Purposive sampling was employed to include a range of stakeholders working as or working closely with outreach staff from different geographic regions, NHS Trusts and service contexts. This ensured we captured a range of experiences of delivering outreach support and care coordination.

Local BRIGHTLIGHT Principal Investigators sent potential participants and the wider team an electronic copy of the participant information sheet containing study details and to ask if they would be happy for a member of the University College London (UCL) research team to contact them with more information about the study. Participants were eligible if they were aged 18 years or older, currently employed by or affiliated with Teenage Cancer Trust or BRIGHTLIGHT-linked investigators, and had direct experience of outreach and/or coordination for TYA cancer care. Participation was voluntary, and staff who wished to be interviewed were contacted by the UCL research team directly and sent the information sheet. This ensured that personal details were not passed on without consent and reduced the possibility of participants feeling pressurised to take part. All participants provided written informed consent prior to the interview. Recruitment continued until sufficient information power was achieved to address the study aims and generate in-depth insights into outreach workers' experiences. The sample size was informed by the concept of information power (Malterud et al., 2016) whereby smaller samples may be sufficient when participants possess highly relevant experience and the study aims are focused. Participants represented a range of outreach experiences across service settings within the UK.

2.2. Data collection

A semi-structured interview schedule (see Appendix 1) was developed by the UCL research team in consultation with the BRIGHTLIGHT research team and stakeholders (including outreach staff) to ensure the language and terminology used was appropriate and the questions were relevant. Questions were designed to elicit staff perspectives on the role of outreach staff in TYA cancer services, including their responsibilities, impact on care coordination, and challenges faced in service delivery. The guide was structured yet flexible, allowing participants to elaborate on areas of particular relevance to their role and experience.

Interviews were conducted between April and June 2025, via Microsoft Teams or by telephone, depending on participants' preference. Interviews lasted between 30 and 40 min and were audio-recorded with notes taken. Audio recordings were transcribed verbatim by members of the research team. All identifiable details were removed during transcription, and they were anonymised before analysis.

2.3. Data analysis

We used a rapid qualitative data analysis approach (Vindrola-Padros, 2021). RREAL Rapid Assessment Procedure (RAP) sheets were completed after each interview to summarise data against key domains as data collection was ongoing. RREAL RAP sheets served as a dynamic tool throughout data collection and analysis, to synthesize the information, identify initial codes and themes across the entire dataset and guide in-depth analysis (Vindrola-Padros et al., 2022) .

Key themes were then synthesised using Framework Analysis (Gale et al., 2013), a form of thematic analysis involving a case by theme approach. This involved a systematic approach that facilitated comparison across cases while retaining contextual detail. The team met weekly to discuss and agree on codes, index codes, and reach consensus on the development of themes, which facilitated critical reflection and minimised individual bias. Initial coding and RAP sheet development were undertaken by members of the research team following each interview. Codes were compared and discussed during weekly team meetings before being organised into higher-order categories and themes. Themes were refined iteratively through discussion, review of supporting quotations and comparison across participants. The themes were then reviewed and refined by the BRIGHTLIGHT research advisory team, adding an additional layer of rigour and ensuring that the analytical process was both robust and relevant to the context of TYA cancer care. The iterative nature of data collection and analysis, alongside team-based research enabled critical discussions of the emerging interpretations. This reduced the chance for interpretive bias, limiting human error and greater insight into the data (Vindrola-Padros et al., 2022).

2.4. Reflexivity

The research team had experience in qualitative health services research and TYA cancer research. Throughout data collection and analysis, regular team discussions were used to question emerging interpretations and consider how researchers' backgrounds and prior knowledge may have influenced data interpretation. Reflective dialogue was central to the analytical process to ensure the transparency, credibility and ethical conduct in the research process.

2.5. Ethics

Ethical approval for this study was granted from the UCL Research Ethics Committee (REC) (Ref:0608) on 26 March 2025. In this paper, we report only on findings relevant to the experiences of outreach staff working in care services. Findings related to other components of BRIGHTLIGHT_2021 are reported elsewhere (Fern et al., 2025; Bautista-Gonzalez et al., 2025b).

3. Results

Three main themes were created: (1) The role and value of outreach

in coordinating TYA cancer care, (2) Barriers and facilitators to effective outreach provision and (3) Strengthening future models of care coordination (see Table 1).

3.1. Theme 1: the role and value of outreach in coordinating TYA cancer care

Participants described their role as outreach workers as supporting patients and their families throughout their experience with cancer. Their role extended beyond signposting or appointment coordination. This included providing TYA specific expertise, psychosocial support, advocating for the patient and their needs, helping patients access additional services and support, connecting different care teams and specialists with each other and acting as a link between young people and their families and the care teams.

3.1.1. Coordination, navigation & liaison across services

Outreach workers described coordinating care across multiple teams and settings, they were key in helping young people navigate complicated care systems, acting as a link between young people, their families and different treatment teams to coordinate care and support. This included referring young people to additional services and understanding treatment pathways. This was particularly important when communication was delayed or fragmented, they helped young people as a point of contact for questions about treatment plans or upcoming appointments, such as assisting them in rescheduling appointment times, and following up results on their behalf.

> *"I would sort of describe myself as a bit of PA [personal assistant]. So, you know, someone that understands the pathway, knows what's going on, knows where they need to be when, can follow up on blood tests and scans, get results to them" [OW_009]*

Participants described actively managing gaps in communication, rather than passing information between services. Young people often wanted answers quickly, outreach workers described their role as providing an outlet for young people to ask clinical questions due to their capacity to be more responsive than their clinical teams.

> *"Young people really appreciate quick answers essentially. And there are some clinical teams that aren't that accessible for whatever reason, that's not good enough for young people. So, I think the fact that we can be more responsive is really valuable." [OW_007]*

Outreach workers also liaised with schools/universities and employers to ensure they were aware of the young persons' situation and providing them with appropriate support or accommodations. This involved connecting specialist teams, designated hospitals, GPs, schools, universities, employers and voluntary sector services.

Table 1
Main themes and sub-themes.

Theme	Sub-Theme
The role and value of outreach in coordinating TYA cancer care	Coordination, navigation & liaison across services
	TYA specific expertise and advocacy
	Supporting psychosocial care to patients and families beyond hospital
Barriers and facilitators to effective outreach provision	Isolation within designated hospitals
	Geographic coverage and travel time
	Limited staff awareness and referrals
	Communication and relationship building
	Organisation, time management & boundaries
	Clinical knowledge and credibility
Strengthening future models of care coordination	Facilitators for successful outreach intervention
	Barriers and recommendations for strengthening outreach work

> *"I link them in with charities, making sure they've got all the support they need from social work. Making sure that their university, colleges, work understand what's going on, writing supportive letters. Just generally being on the end of the phone for whatever they want, really whatever they need." [OW_009]*

Outreach workers identified their role as helping to communicate age-appropriate information and often served as a conduit between families and young people. If they were unclear about aspects of their care plan, outreach workers shared this information with patients and their families to make sure they were properly informed.

> *"So, I'm on the phone to parents going 'this is what's going on, stop asking the questions of your young person because they don't want to talk about it anymore, but you can come to me to ask those questions, and you can come to me to share your worries'." [OW_007]*

3.1.2. Provide TYA specific expertise

Participants described outreach workers as 'in-house' experts on TYA cancer care for the designated hospitals and care teams, as these providers may be less familiar with working with young people. This involved both advocating for TYA specific needs and providing training and education to other care teams on how to provide age-appropriate care for young people.

> *"It is just making sure that the extra things that teenage young adults need and that everyone needs to be aware of, that that is at the forefront of people's mind. I do lot of teaching and training. I think I did like over 20 different teaching sessions last year for different teams" [OW_009]*

Participants described supporting individual patients and also contributing to the wider capacity of designated hospitals to provide age-appropriate care. Participants described advocating for practical adjustments of their clinical care such as organising fertility preservation before treatment began, as well as more emotional considerations such as being given a single occupancy room and ensuring that parents, carers and supporters were allowed to stay overnight with them.

> *"I've just had a new patient. So, I coordinated their care; I've sent them for sperm banking and make sure that was all done before they went into clinic and make sure they knew where they had to go." [OW_004]*

Outreach workers felt that their TYA cancer expertise added value by being able to provide specialist age-appropriate support closer to home at designated hospitals. This enabled young people to stay close to their community and support systems even when not treated at a PTC.

> *"I think it's trying to replicate that [PTC] support as much as possible in designated hospitals. So, you know, it's kind of ensuring that those young people that opt to have their treatment locally to home … that's not detrimental to their support." [OW_006]*

Outreach workers experienced their role as not only supporting individual patients but also added value for the staff they worked with, as care teams that did not have much experience working with young people were often apprehensive and unsure how best to communicate with them or meet any age-specific needs they had.

> *"A lot of the time you get nurses and you get staff on the wards at the same age as these [young people]. And you know, they're coming in in the poorly or the palliative or their end of life. So, we support those teams as well." [OW_010]*

Outreach workers mentioned that they were more easily able to build rapport with young people than other clinical staff were, as they were easier to access and could see the patients more than the clinical teams could. This made young people more likely to confide in outreach workers and disclose additional needs or concerns with them. This was valuable for clinical staff as outreach workers were able to provide them with additional insight into patient specific circumstances that might

affect their care and allowed the care teams to make more informed clinical decisions.

"I have a young girl who really struggled with a radiotherapy. So, I worked really closely with [the] radiotherapy [team] for like distraction techniques. So, she [had] about 8 weeks [of radiotherapy] and I think for the first few of them I sat and read Harry Potter down the microphone to her. And then gradually, we got the students and the other members of radiotherapy to get involved." [OW_003]

3.1.3. Supporting psychosocial care to patients and families beyond hospital

Outreach workers also described their role as extending beyond hospital-based care into young people's everyday lives. This support often involved attending outpatient appointments to offer emotional support, helping young people feel less out of place, and being with them if they were admitted to hospital and visiting them on the ward ensuring their needs were met. They were available to speak with patients via text or over the phone to help answer questions and also met with patients outside of the clinical settings, such as at coffee shops or at the patient's home.

"Offering face to face or virtual support, both within the hospital and could be in the community as well. So, I could do home visits potentially. Or potentially meet people at other appointments and things like I've been over to different hospitals, for example. I could potentially see people in hospices and things like that as well." [OW_006]

Most outreach workers believed they helped integrate young people back into their community after a long in-patient stay, which could lead to difficulties such as isolation and adjusting back to everyday life priorities. Outreach workers also felt that the support they provided to the families and loved ones had value for the families and the young people themselves.

"I think the fact that we can support the entire family [is valuable]. And we aim, you know, we aim for families to feel better supported. I think that is valuable to young people as well." [OW_007]

Participants highlighted psychosocial support as supporting clinical staff to focus on providing clinical care improving the efficiency of the service. They felt that, given their high caseloads, clinical staff did not typically have the capacity to provide psychosocial support to young people. In this way, outreach workers viewed their role as bridging a gap between medical care and the broader psychosocial needs of young people and their families.

"They understand the value and the additional support that young people get through our service … And it, you know, allows them the time to do what they need to do but move on to the next, given their limited time constraint." [OW_001]

3.2. Theme 2. barriers and facilitators to effective outreach provision

Outreach workers described several barriers and facilitators that influenced their ability to deliver effective support. These extended beyond practical challenges and reflected the complexity of working across organisational, geographical and professional boundaries. Participants highlighted that successful outreach provision depended not only on service structures, but also on their ability to establish credibility, build relationships and maintain visibility within systems where TYA care was not always prioritised.

3.2.1. Isolation within designated hospitals

Several outreach workers cited the isolated nature of the role as a challenge they faced. They worked independently within the designated hospitals and often felt unsupported when embedded in designated hospitals without established TYA structures.

"There is nobody else you can sit and have a you know, 'what do you think?', 'How do you think we should go about this?' … but you are essentially isolated in these designated hospitals on working for TYA. You are the only TYA professional in those designated hospitals. There is no other TYA service." [OW_001]

Being the sole TYA professional within designated hospitals often meant limited opportunities for peer support, reflective discussion and shared decision-making. This placed additional responsibility on outreach workers to independently navigate complex situations while maintaining continuity of care.

3.2.2. Geographical coverage and travel time

Geographical coverage was identified as a factor creating tensions between accessibility and capacity. Many outreach workers covered large geographical areas and worked across multiple hospitals. Therefore, they spent a significant amount of time travelling between different locations, which limited the time they could spend with patients. Extensive travel requirements could restrict opportunities for face-to-face engagement and reduce flexibility in responding to emerging needs.

"We cover a vast area as well. So, I'm always saying like we need notice like we can't just drop everything and be at a hospital which is an hour and a half away if we've got stuff on". [OW_010]

Participants described tensions between the desire to provide responsive, person-centred care and the practical constraints associated with delivering outreach services across different geographical regions.

3.2.3. Limited staff awareness and referrals

Some designated hospital staff did not fully understand or appreciate the purpose of the outreach role, which could lead to reluctance to proactively involve them in young people's care.

"I think it causes more work for people or causes questions about what gets done. So, I feel like sometimes people aren't the most friendliest at the thought [of an outreach worker being involved with their TYA patient]." [OW_003]

Participants described role awareness as a prerequisite for effective outreach provision. If providers were not aware of the role of outreach it could lead to reluctance to involve outreach workers. Limited understanding of the outreach role could delay involvement until treatment had started, or at times even finished, which created barriers in building up relationships with young people. In some cases, this contributed to young people sometimes declining to work with an outreach worker altogether.

"If teams are interested and they found the TYA service beneficial, I think they like are more likely to reach out and kind of ask for help and support. But some of them, if they've not really, if they don't really understand what we do, for example, or they don't see the value in it, then I think it's quite hard to kind of rely on them to refer patients." [OW_006]

Outreach workers believed that the effectiveness of their role was shaped not only by their own skills and expertise, but also by organisational understanding and acceptance of their function.

3.2.4. Communication and relationship building

Nearly all participants viewed communication skills as critical to the role, as outreach workers needed to be adept at having complex conversations with young people and had to effectively liaise with a variety of clinical teams, including advocating for patients with clinical teams when necessary.

"Sadly, we are having really complex conversations with young people, often, all the time … For me, I think it's really important to have a high level of skill in regards to your communication in an outreach role." [OW_002]

The ability to build relationships and rapport with both young people and clinical staff was underscored as fundamental to maintaining continuity across multiple care settings. Communication was a mechanism through which outreach workers coordinated care, negotiated support and advocated for young people across organisational boundaries.

"You absolutely have to be mindful about liaising with different teams … as many different teams are involved and every clinical team will have different ways of engaging. So, I think you've you've got to be willing to do a lot of legwork to find these young people and to engage with the clinical teams as well." [OW_007]

3.2.5. Organisation, time management and professional boundaries

Participants suggested that outreach work required a high degree of autonomy as they coordinated their own visits and had to cover large geographical areas. Due to the isolated nature of many posts, organisation and time management skills were considered essential.

"You're kind of managing your own diary a lot of the time and it kind of does require a level of being organised." [OW_006]

In the case of one outreach worker, she cautioned against not overbooking her day and ensuring she still had enough time with each patient, while taking into consideration the travel time between patients. The role also required a certain amount of flexibility as no two days were the same and outreach workers needed to be responsive to unexpected issues.

Managing competing demands across multiple sites required strong organisational and time management skills. Some outreach workers also spoke about the importance of having strong professional boundaries, resilience and access to a good support network for sustaining emotionally demanding work with young people and families. One outreach worker reflected on the importance of self-care, making sure that she had an established network that she could turn to when she needed emotional support. Other outreach workers reflected on the emotional burden of the role, particularly when the patient outcome was not positive.

" It's important for outreach workers to have] clear professional boundaries. These are young people with quite emotive issues and it's [about] being aware of your own boundaries and also making sure that you, you know, have that support for you because it there, you know, it is highly emotive, so it's making sure that you have a clear kind of support network around you." [OW_001]

3.2.6. Clinical knowledge and credibility

Participants highlighted the importance of having a strong clinical knowledge base, as young people would often reach out to outreach workers for detailed information about their diagnosis, treatment and future care. Clinical expertise was also recognised as important for influencing decisions and advocating in multidisciplinary teams, despite outreach workers not holding direct responsibility for treatment decisions.

" They're asking me quite complex clinical questions about their treatment, about their tumor, about what's next. And if I didn't have the clinical background I've got, that would be impossible." [OW_009]

Some participants stated that a level of seniority or experience enhanced their credibility within multidisciplinary teams, making it easier to advocate for young people's needs. However, participants also emphasised that, while it may have been necessary to have a level of seniority or clinical expertise, staff of any level should have the confidence to advocate for patients to raise concerns and represent young people's needs within wider care teams.

" I think some people like hierarchy and some people when you approach them, I think there's a kind of element of hierarchy … but I think ultimately anyone can advocate for a patient. I don't think it matters what level you are." [OW_003]

3.3. Theme 3. strengthening future models of care coordination

Outreach workers identified several factors that they believed were important for strengthening future models of TYA care coordination. Their recommendations focused on increasing integration of outreach services within designated hospitals, improving awareness of the outreach role and developing workforce capacity to support sustainable delivery of age-appropriate care.

3.3.1. Facilitators for successful outreach intervention

Outreach workers highlighted the importance of the outreach role to young people, they felt it was crucial that the role continued to be a feature of future models of TYA cancer care.

"I hope they keep the outreach post. Because I think they are really valued by young people." [OW_004]

Outreach roles embedded in designated hospitals were identified as a key facilitator for ensuring that young people who chose not to be treated at a PTC were still able to be treated closer to home while still having all their age-appropriate needs met. Participants believed that embedded outreach is helping to reduce variation in access to support and maintain continuity between specialist and local services.

"For those [TYA patients] that are under this designated hospital and don't access the PTC at all, I worry they would miss out if there wasn't someone based here [at the designated hospital] making sure that their needs as a young person were addressed. So, I can't think of any other way of doing it to make sure that, you know, everyone gets the optimum treatment." [OW_009]

Attending regular MDT meetings with other providers such as meetings for TYA MDTs, psychosocial MDTs, and clinical nurse specialist teams was viewed as ensuring that the care teams were aware of the needs of the young people they were treating. These were important facilitator for information sharing and collective decision-making. These meetings provided opportunities to discuss complex cases, share experiences and coordinate support across services.

"Everyone's invited to share a patient, patient names that they've had kind of contact with or issues with or concerns about. And that's brought into the meeting and then everyone is aware of what's happening with those particular patients, especially ones that are very challenging or, you know, palliative and things like that … And then they bring ideas of what can help support that patient more, which is really helpful. Yeah, it's a really good supportive network as well as functional purpose." [OW_004]

3.3.2. Barriers and recommendations for strengthening outreach work

Participants identified several areas for improvement within future models of care coordination. A key recommendation was improving awareness of the outreach role among designated hospitals to support earlier and more consistent referral pathways, such as including outreach information in new-starter orientation. Outreach workers also recommended early involvement with young people and raised concerns that this should become standard practice from the beginning of their care, rather than crisis-driven referrals or reliance on teams with limited TYA exposure.

"There's clinical teams that are excellent, will always refer [young people to outreach workers], but there's actually clinical teams that that kind of don't. Or [they'll refer young people] in a crisis moment that or [if they have] a really, really, really complex person that they think is needing a lot support." [OW_002]

Outreach workers also highlighted the need for greater education

and awareness of TYA-specific needs among designated hospital staff. A commonly mentioned barrier was staff capacity and to ensure all staff had a base level understanding of young people.

> *"[Outreach workers] need the time to help educate the designated hospital staff in TYA care: having those link workers within each specific areas and getting them involved. But they, often their clinical demands don't allow it." [OW_001]*

To address the challenge of lone-working and capacity constraints, outreach workers shared several suggestions, such as including increased support in their work with young people by adding additional outreach workers in their region or collaborating with youth support workers.

> *"I could do with a friend, like a buddy, to buddy up with. Because I feel like sometimes you try and go out and see all these different people and outreach, but naturally I still have people that are in hospital or in clinic. And so, it's about sometimes it's about balancing time to decide. And I think that's something that naturally, could be improved." [OW_003]*

Outreach workers also proposed increased support structures within designated hospitals, for example, introducing TYA leads or support coordinators to enhance integration of age-appropriate care.

> *"It would be nice to have additional staff out in the designated hospitals … I mean, it would be great if we had youth support coordinators." [OW_001]*

4. Discussion

This study explored outreach workers' experiences of their role in coordinating TYA cancer care, the challenges associated with delivering outreach support, and opportunities for strengthening future models of care coordination. The findings suggest that outreach workers identified themselves as supporting the continuity of age-appropriate care across organisational boundaries through care coordination, psychosocial support, advocacy and liaising with multidisciplinary teams. Participants believed that outreach workers provide additional support in addressing the needs of young people with cancer. Specifically, as shown in other studies, coordinated care pathways helped alleviate patient worries and ensured treatment completion (Clarke et al., 2003). Research also shows that established outreach provision that advocates and champions young people's needs can help with the disruption that illness brings (Harden et al., 2012). Outreach workers roles were seen as beneficial to clinical staff, including releasing their time to deal with clinical concerns. Participants highlighted that the role is particularly valuable for young people living in rural areas at a greater distance from specialist centres, as it was seen as useful in increasing rural patients' access to advice and additional support. Further to this, other components of the BRIGHTLIGHT 2021 study demonstrated similar patient reported outcomes for TYA regardless of location of care (Fern et al., 2025). One possible explanation was effective communication and coordination between the PTCs and DHs (Bautista-Gonzalez et al., 2025b). Further investigations revealed that there was no difference in where young people were treated and the support they received from key members of the TYA MDT team such as the TYA CNS, most likely due to the mechanism of recruitment to the study where eligible patients were identified through the TYA-MDT and they could then mobilise outreach age-appropriate services. This study provides insight into complexities and challenges associated with coordinating age-appropriate care across multiple settings.

TYA outreach workers' roles mirror other long-standing specialities, such as paediatric oncology outreach nurse specialist models (Hollis, 2005) that provide coordinated, family-centred care across home, school and hospital, and act as key workers within multidisciplinary pathways (Hunt, 1995). Paediatric oncology has an established evidence base for outreach specialist nurse roles, often NHS employed and embedded in services (Martins et al., 2016). By contrast, many TYA outreach posts have been charity funded (e.g. via the Teenage Cancer Trust) within NHS settings, which can create vulnerabilities in funding cycles despite participants perceiving the role as valuable (Fern et al., 2025). These findings highlight the importance of considering how TYA outreach roles are funded, integrated and supported within services, particularly where provision varies across geographical areas.

Outreach workers provide psychosocial support to young people throughout their cancer journey, but the extent to which the outreach worker is involved can vary between patients as they are led by the young person in how much support they want, determining the intensity and modality of support (Teenage Cancer Trust, 2025). Through building relationships with young people and providing them with emotional support, outreach workers are able to gain additional insights into the individual needs and circumstances of the TYA patients they worked with. Outreach workers viewed this as valuable for patients as it allowed them to advocate for young peoples' specific needs. Participants described relationship-building as an important component of effective advocacy. Information shared with outreach workers allowed teams to tailor treatment, rather than duplicate clinical roles. For example, staff reported supporting treatment adherence by facilitating practical adjustments during radiotherapy, illustrating the functionality and how the role shapes care decisions.

However, delivery of outreach was challenging due to the nature of lone work and covering large geographical areas. Participants described a potential trade-off between bringing outreach closer to home which lessens the burden on young people and families, but without adequate capacity and integration, it can increase fragmentation of coordination between sites and teams. Participants identified several factors that may support the delivery of outreach services, including manageable geographical coverage, clear referral pathways, defined MDT responsibilities and opportunities for supervision. Examples discussed within the wider literature include smaller geographical coverage, standardised referral processes, clearly defined MDT responsibilities and opportunities for supervision (Scodari et al., 2024). These approaches align with the challenges identified by participants regarding lone working, referral dependency and geographical coverage (Tsipa, 2022). Although the provision of outreach work has undergone transformation, outreach workers may still take on additional duties and responsibilities to meet local need, clear role descriptors and pathways can retain local responsiveness while reducing confusion.

Participants suggested that earlier introduction of outreach workers may help reduce reliance on crisis-driven referrals and support continuity of care. Participants highlighted referral pathways and staff awareness as important influences on whether outreach workers became involved early in the care pathway (Aldiss et al., 2023). Similarly, outreach workers were concerned that role variation by region could contribute to confusion about the role. Participants suggested clear, short role descriptors, referral criteria and handovers to other professionals (e.g. psychologists, social work and youth workers) may help clarify responsibilities across organisations. Participants also highlighted the importance of recruiting staff with an appropriate combination of clinical knowledge, communication skills and experience of working with young people in relation to the current recruitment guidelines, which may restrict capacity to train in and deliver outreach in addition to existing duties (House of Commons Public Accounts Committee, 2009). Participants consistently emphasised the importance of clinical literacy, strong communication and advocacy, and experience of working with young people when delivering outreach support. While some participants saw seniority as helpful for influence

in lone-working settings, others emphasised confidence plus clear organisational backing. The findings suggest that future workforce development may benefit from recognising the combination of clinical knowledge, communication skills and advocacy described by participants. Participants also highlighted the potential value of training, supervision and progression routes to support the distinct function of TYA outreach workers (Hunt, 1995).

Previous research has found buddying and peer mentoring as helpful to outreach workers (Simoni et al., 2011), this may include additional posts in high-volume geographies, and hybrid models incorporating virtual check-ins. Participants viewed reflective supervision and peer support as potentially valuable for managing emotional demands and maintaining professional boundaries. Participants viewed greater integration of outreach workers within designated hospitals as a potential mechanism for improving liaison, role visibility and collaborative working. Similar approaches have been used in large geographical patient-navigation programmes (e.g., US mountain-west states) (Warner et al., 2018), where navigators combine contact with scheduled site visits and clear escalation protocols to reduce travel burden whilst remaining responsive to patients and integrated into healthcare settings. Participants suggested that clearer models of working between outreach services and MDTs may facilitate joint working arrangements.

4.1. Strengths and limitations of the study

Key strengths to this study include the inclusion of outreach workers from multiple NHS Trusts across England, Scotland and Wales, providing insight into a range of TYA cancer service contexts. The study offers a focused exploration of outreach workers' experiences of coordinating care across specialist and non-specialist settings, an area that has received relatively limited attention within the TYA cancer literature. The use of RREAL RAP sheets combined with Framework Analysis enabled timely, contextual insights into how outreach is organised and practiced across sites.

Several limitations should be acknowledged. First the sample size was small (n = 10) and participants were recruited through established TYA networks, which may have introduced potential selection bias toward services with established outreach workers. Second, the study focused exclusively on outreach workers' perspectives, this study did not examine patient outcomes or service level performance to determine the effectiveness of outreach workers. As data was collected from outreach workers, the findings may reflect positive experiences of their role and outreach provision. The study would have been strengthened by the inclusion of diverse perspectives, including young people with cancer and their families to understand their perspectives on the implementation of outreach workers. Furthermore, the findings should be interpreted as participants' experiences of the role rather than evidence of service impact. Finally, the study was conducted within the UK healthcare system and a specific commissioning context. While the findings may be transferable to settings with similar models of coordinated TYA care, their applicability to healthcare systems with different governance, commissioning and workforce structures remains uncertain.

5. Conclusion

This study provides insight into outreach workers' experiences of their role in coordinating age-appropriate TYA cancer care across different locations of care. This model of care closer to home has been reflected in healthcare policy for young people with cancer for a number of years and is further supported by the new English NHS 10-year plan of moving care and services *'from hospital to community'*. Participants described outreach work as encompassing care coordination, psychosocial support, advocacy and liaison across multidisciplinary teams, while also highlighting challenges associated with lone working, geographical coverage, role visibility and referral pathways. The findings suggest that outreach workers identified several factors that may influence the delivery of outreach services, including organisational support, role clarity, workforce capacity and integration within multidisciplinary care pathways.

However, despite the desired outcome of increasing access to care for the teenage and young people cancer population, outreach workers described a number of barriers and challenges in establishing and delivering these roles in what is predominantly organised around adult cancer services, such as availability of adequate resource to conduct and supervise outreach work. Further research incorporating patients, families, healthcare professionals and service-level outcomes is needed to better understand the implementation and perceived impact of outreach provision. Such work would help inform future service development and the organisation of age-appropriate care for teenagers and young adults with cancer.

CRediT authorship contribution statement

Syka Iqbal: Writing – original draft, Formal analysis, Data curation. **Ailey McLeod:** Writing – original draft, Formal analysis, Data curation. **Rachel M. Taylor:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Lorna A. Fern:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Julie A. Barber:** Writing – review & editing, Funding acquisition, Conceptualization. **Jamie Cargill:** Writing – review & editing, Funding acquisition, Conceptualization. **Richard G. Feltbower:** Writing – review & editing, Funding acquisition, Conceptualization. **Laura Haddad:** Writing – review & editing, Funding acquisition, Conceptualization. **Maria Lawal:** Writing – review & editing, Funding acquisition, Conceptualization. **Martin G. McCabe:** Writing – review & editing, Funding acquisition, Conceptualization. **Louise Soanes:** Writing – review & editing, Funding acquisition, Conceptualization. **Dan P. Stark:** Writing – review & editing, Funding acquisition, Conceptualization. **Cecilia Vindrola-Padros:** Writing – original draft, Supervision, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Informed consent statement

Informed consent was obtained from all subjects involved in the study. Written informed consent was obtained for the use of anonymised quotations.

Institutional review board statement

The study was conducted in accordance with the Declaration of Helsinki and approved by the UCL Research Ethics Committee (protocol code 0608, approval date 26 March 2025).

Data availability statement

The data are not publicly available due to ethical and privacy restrictions arising from the terms of UCL Research Ethics Committee approval (protocol 0608) and participant consent. De-identified excerpted quotations are included in the article. Further de-identified materials may be available on reasonable request to the corresponding author, subject to data-sharing agreements and additional approvals.

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Declaration of competing interest

LS is employed by Teenage Cancer Trust, who fund much of the infrastructure for TYA cancer care. She was not involved in data acquisition or analysis. The remaining authors declare no conflict of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2026.103353.

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