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Empowering stakeholders to shape the implementation of the teenage and young adult cancer service specification

Recommendations from researchers, clinicians and young people



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About the project

“Do specialist cancer services for teenagers and young adults add value?”

This research project was funded by the National Institute for Health and Care Research (project reference RP-PG-1209-10013) and ran from 2012 to 2019. It was a programme grant including six studies in three workstreams, evaluating the environment care was delivered, the professionals delivering care, the experiences of young people and their main carer who were accessing cancer services and an evaluation of the cost of care to young people, their families and to the NHS. It analysed survey data, national cancer registration and hospital episode statistics data, observation and interview data.

The study’s findings have been reported in full¹⁻¹³, summarised in the final NIHR report¹⁴.

The views expressed in this report are those of the authors and not necessarily those of the NHS, NIHR or the Department of Health and Social Care.

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Introduction

Teenagers and young adults (TYA) with cancer, those aged 16-24 years at diagnosis, are a unique population with specific needs, which are not fully met by childrens or adults cancer services. This has resulted in poorer improvements in outcomes and lower survival rates than children and older adults in some cancers. This is related to the spectrum of rare cancers occurring in young people, longer times to diagnosis, cancer biology, lower rates of participation in clinical trials and the unique psychosocial consequences of a cancer diagnosis during adolescence and young adulthood. These unique circumstances have driven the development of care models specifically for TYA, often focused on dedicated purpose-designed patient environments supported by a multidisciplinary team (MDT) with specialised expertise. A model of care was first proposed in 2005 by the NICE Improving Outcome Guidance, where care was delivered across England in 13 Principal Treatment Centres.

In 2011, TYA networks of care were established, delivered through 13 Principal Treatment Centres (PTCs) commissioned by NHS England. The PTCs provide treatment expertise across the range of cancers common in young people, supported by a dedicated TYA MDT. These networks of care also included varying numbers of associated “designated hospitals”, which are hospital trusts where individuals could receive some of their care in a more local setting, should they have to travel some distance to the PTC. Those aged 19-24 years could chose to have their care delivered in the PTC or more locally to home but should have ‘unhindered access age appropriate care’.

At the same time as the establishment of these networks, recruitment started to the TYA patient cohort of the National Institute for Health Research-funded BRIGHTLIGHT research programme, a national evaluation of the outcomes and costs associated with TYA care. The study and its findings are described in Box 1.

Box. 1 The BRIGHTLIGHT study

BRIGHTLIGHT was an NIHR-funded evaluation of TYA care delivered in PTCs. It used a mixed-methods design, with a qualitative study exploring the culture of care and quantitative studies investigating the outcomes and costs associated with TYA-PTCs. The cohort was divided into three groups: those who had all their care delivered by a PTC, those who had a mix of care jointly from a PTC and another hospital, and those who did not have any care in a PTC.

Findings showed differences in outcomes depending on where individuals were treated, notably that those receiving joint care had poorer outcomes and care was more expensive for both the NHS and patients and families, as shown in Table 1.

Following completion of the evaluation, a follow-on study – the RELAY_ME project – was established to communicate the findings from BRIGHTLIGHT, with the aim of supporting the implementation of the new service specification. The service specification was developed by NHS England during the time of the BRIGHTLIGHT study and launched in 2023, aiming to improve outcomes for young people aged 16-24.

Table 1: Summary of the BRIGHTLIGHT research findings on different metrics (QoL: Quality of Life)

	No access to TYA-PTC	Some care in TYA-PTC	All care in TYA-PTC
Best	QoL at diagnosis		Rate of improvement in QoL over time
	Illness perception		
	Costs to the NHS	Caregiver support, information and services specific for them	Processes associated with specialist care
	Travel costs		Caregiver support, information and services specific for them
	Out-of-pocket expenses		
Middle		Processes associated with specialist care	Costs to the NHS
		Out-of-pocket expenses	Travel costs
Worst	Rate of improvement in QoL over time	Overall QoL	
	Processes associated with specialist care	Illness perception	Illness perception
		Involvement in decisions	
	Caregiver support, information and services specific for them	Costs to the NHS	Out-of-pocket expenses
		Travel costs	
All similar (including where differences are not significant)		Overall satisfaction with care	
		Depression, anxiety	
		Social support	

NHS England has now launched a new TYA cancer service specification

Prior to the findings of the BRIGHTLIGHT research being available, NHS England began work on developing a TYA cancer service specification that sought to ensure that the TYA-PTC model of care was delivered consistently across England. Three separate documents set out the expected standard of care for PTCs, designated hospitals and TYA Cancer Networks.¹ Central to this specification was that TYA-PTCs and designated hospitals work together to deliver “joint care”.

The specification was based on the evidence available at the time, which was limited in relation to the outcomes of joint care. The subsequent publication of the BRIGHTLIGHT findings (see Box 1), which showed that some outcomes were poorer for those receiving joint care, has created a gap between the service specification and the research’s understanding of what works well – a gap which needs to be explored and bridged as the service specification is rolled out.

Implementation of the new service specification will require the involvement of a range of stakeholders, including local commissioners, the operational management of TYA-PTCs and designated hospitals, the clinical teams that work in delivering cancer services, and the young people undergoing treatment. To coordinate this implementation, Operational Delivery Networks (ODNs) will play a critical role in developing and sustaining the move to consistent delivery of TYA cancer care.

A Policy Lab explored how different stakeholders could be empowered to shape implementation of the service specification

To (i) explore the implications of the BRIGHTLIGHT research for the implementation of the new service specification and (ii) look ahead to the role that different stakeholders could play in ensuring that services work as well as they can to benefit TYA patients, we convened a Policy Lab in November 2022 to address the question:

What is the roadmap for empowering different stakeholders to shape how the TYA service specifications are implemented?

The Policy Lab brought together researchers, professionals from TYA cancer services and ODNs, young people with personal lived experience, commissioners, charities and policymakers. The aim was to think broadly about the issues identified in the BRIGHTLIGHT study – including the gap between the service specification and subsequent evidence around joint care – and their implications for how services are organised and delivered.

¹ Full documents available at: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b05/>

Participants were encouraged to think creatively about possible actions to support the roll-out of the service specification, as well as the practicalities of implementing them at a suitable scale and the roles of different stakeholders in achieving this.

Following the Policy Lab, we ran an online workshop in June 2023 to explore the implementation of some of the recommendations from the original Lab. As part of this we asked participants to discuss their priorities for implementation and potential challenges. Given the practical focus, participants were those involved in the implementation of the service specification and day-to-day running of TYA services, including doctors, nurses, and ODN managers, alongside young people with lived experience of cancer treatment.

This document sets out the ideas and recommendations discussed at the Policy Lab and follow-on workshop. It begins by describing a set of ambitions for implementation of the service specification, before moving on to implementation considerations. In doing so, it also explores potential factors that may have contributed to the poorer outcomes found in BRIGHTLIGHT for some aspects of TYA-PTC care, in the hope that implementation of the service specification might be able to help address these.

Ambitions for the service specification implementation

Policy Lab participants agreed a set of broadly shared ambitions for implementation of the TYA cancer specification.

1. All individuals should receive standardised, high-quality care, regardless of where they live and where they are treated.
2. The delivery of care should be a shared endeavour between designated hospitals and the TYA-PTCs. Designated hospitals should not be seen as a “step down” given that some patients will choose these because of a preference for being treated locally. The result of the specification implementation should be TYA-PTCs and designated hospitals working together as part of a package.
3. TYA patients should “feel like a young person” and care settings and service delivery should be designed with this in mind.
4. Implementation should consider the pathway to diagnosis (e.g. through primary care or via A&E) as a potential cause of significant variation between TYA patients.
5. Implementation should ensure that people do not “fall through the gap” between TYA-PTCs and designated hospitals – e.g. in relation to offering to pay expenses for food, travel and respite care or ensuring access to antibiotics and other necessary support.
6. Implementation should acknowledge that young people with experience of cancer treatment can be valuable mentors for other TYA patients and can help in guiding them through their journey, helping them avoid or mitigate trauma (e.g. by accessing relevant support) and identifying questions to ask at different points in the process.
7. TYA patients and carer networks should have a single point of contact within their local cancer network that they can go to with questions (e.g. to ask what a meeting with clinicians is about, to get help with claiming costs, to ensure their feedback is heard). This is a different – though related – role to a TYA CNS and could be funded to work across the network.
8. The specific value of having a TYA CNS should be promoted. Trusts can be encouraged to work with the third sector to ensure these roles are in place and their funding ringfenced or protected as far as possible.
9. TYA patients should be able to access clinical trials on an equitable geographic basis. This is complex and daunting but is important in addressing health inequalities.



Addressing the potential gaps between the service specification and feedback from the BRIGHTLIGHT research

The BRIGHTLIGHT research showed that, for some metrics, the results were poorer for those receiving care delivered in TYA-PTCs than for those who did not. These measures included:

- Illness perception
- Quality of life (QoL) at diagnosis
- Involvement in decisions
- Travel costs / out-of-pocket expenses
- Costs to the NHS

Operationalising the service specification presents a potential opportunity to address some of the underlying factors that might contribute to these outcomes. Participants at the Policy Lab explored what some of these factors might be and pointed to several things that could be borne in mind as part of implementing the service specification.

Illness perception

Participants offered a range of views on how to interpret illness perception as reported by individuals. In broad terms, though, there was agreement that rather than considering these findings as “good” or “bad”, the study pointed towards there being benefits to TYA patients having exposure to “people like them” within the TYA-PTC setting. This might be in terms of sharing their experiences or acknowledging that “you are allowed to feel ill” or “can feel like a cancer patient”. It was felt that this, in fact, might be helpful with treatment compliance.

The care pathway that brings people to the TYA-PTC (including the process of diagnosis, which was prolonged for some) would also, it was suggested, have an impact on illness perception.

Quality of life (QoL) at diagnosis

TYA patients experience quite different routes to diagnosis, including, for example, whether the initial contacts are within primary care or via A&E departments. Those who took longer to be told (from symptom onset to first cancer consultation/diagnosis) were more likely to be experiencing symptoms of depression and anxiety, and have lower QoL scores.

It was agreed that differences between areas in the use of age cut-offs (at either 16 or 18) caused variations in experience and led to the possibility of people falling through gaps between child, TYA and adult services, both in clinical care and in access to support services (e.g. community nursing).

Involvement in decisions

Caregivers of individuals receiving some of their care at a TYA-PTC reported lower levels of involvement in decisions. This raised a discussion at the Policy Lab about “paralysis at the point of diagnosis” and the need for guidance and support in deciding the best course of action. There was agreement that it is important to periodically establish with patients and their care networks how much support is needed or wanted. This should be the case all the way from initial diagnosis (when it was felt that no-one should be given this alone, to ensure both that they have personal support and that important information is retained) to the transition back to day-to-day life after completion of treatment and the choices needed to make that as successful as possible.

At all stages, it was seen as immensely valuable to have some form of advocate for the patient, as well as the option to contact specific people for practical advice and signposting.

Another suggestion was to explore the use of technology (e.g. QR codes) to enable access to information in an easy and timely way. This might also benefit from input from current or previous TYA patients to develop messaging and prompts that gives honest answers to the range of typical questions/scenarios (e.g. around preserving fertility) that individuals will face as they move through the pathway.

The development of a patient portal for disseminating this information (and ideally also for allowing for the easy accessing and sharing of patient records), either at national level or in the local network, would also be highly desirable.

Travel costs and out-of-pocket expenses

Participants found it unsurprising that the costs of travel were higher to TYA-PTCs, given the additional length of journeys likely to be involved. However, currently the grants provided to TYA patients provide the same amounts to everyone, regardless of the duration of the treatment. For some, this treatment may last years, while others have a one-off intervention at the TYA-PTC.

It was agreed that efforts should be made to make the support for expenses simpler, for example by not making the payments retrospectively and moving away from a cheque-based system. However, it was also noted that some TYA patients don't mind “accruing” costs, if this means that the ultimate value to them of the support received is greater.

The question of costs to the patient raised some debate about the relative value of treatment, summed up by the question “what is worth the travel?”. Most often, patients will need help in evaluating the answer to that question. It was suggested that it should be possible to design shared care so that regular check-ups are done locally, but that more complex or specialist care would justify the time and money spent travelling.

Related to this, it was highlighted that long journeys home (e.g. by train) can be challenging for those who have visited TYA-PTCs for treatment. Again, assessing how people will feel during this time (“thinking about the whole experience”) is an important consideration of deciding where the treatment should be delivered if there are alternatives available. This extends also to considering the impacts of taking time out of work or studies.

Finally, while there may be a willingness to travel, the present cost-of-living pressures may mean people cannot readily afford this. Not easily being able to take up TYA-PTC-based treatment options might cause concerns and stress, as well as raise questions of fairness in access to care.

Costs to the NHS

Concern was raised that without ring-fenced funding, it might be challenging for ODNs to deliver the new specification as intended. This is particularly the case in places where there is significant variation between current provision and the care proposed in the specification. Reducing variation will require investment to ensure that all areas can align fully with the new specification, following on from an initial gap analysis to indicate where changes are required.

All of the issues listed above should be considered when implementing the new service specification. The research from BRIGHTLIGHT demonstrates the risks of attempting a “one size fits all” approach when it comes to implementing new models of care. Implementation should be rolled out in partnership with local stakeholders, considering local and national priorities. The following sections contain a number of potential actions which Lab participants felt could help ensure implementation is successful.

Empowering stakeholders to shape implementation of the service specification

The Policy Lab suggested a set of actions for how ODNs could engage and empower different stakeholders to get their support for and input to implementation of the service specification. Some of these applied at a national level, some needed a local focus and others were important at both these levels of implementation. Some involved immediate “next steps”, while others were for the longer-term.

Four areas stood out as important at both national and local ODN levels:

- Launching the service specification with effective communication
- Monitoring and evaluating patient outcomes and network performance
- Harnessing the ideas of young people
- Building strong relationships with the third sector

These are expanded upon below and are followed by actions specific to national and local levels. The first three points were highlighted as particularly important priorities for ODN participants and were discussed in more detail at the follow-up implementation workshop.

Launching the service specification supported by compelling communication

Communicating the service specification at a national level

All participants at the Policy Lab (which took place prior to the release of the service specification) agreed that it would be good to have the specification launched nationally to raise awareness across all parts of the system. In doing so, effort should be given to educating all the relevant stakeholders, both on the issues they need to be aware of in planning service design but also, crucially, on the rationale for the likely changes. This should emphasise the benefits that adherence to the specification will bring to TYA patients and serve as a motivation for those who need to take action locally.

Participants at the implementation workshop also stressed this need for a strong national voice on TYA care, which could help to ensure TYA issues receive a hearing at a local level. Stories from TYA service users should be championed in order to make clear what needs to change.

Participants also talked about the need to establish that all parts of the system have a stake in the implementation of the service specification. The translation of national-level messaging to the local context of each ODN is crucial so that implications for local services and responsibilities for implementation are clear. National communication may also need to demonstrate the need for extra local resources to support this. It was agreed that ring-fenced resourcing would simplify the process of implementation and allow services to focus on areas which need improvement.

Two specific ideas were suggested in the Policy Lab to support effective national communication. First, an animated infographic could be used to underline the importance of the specification and what it contains. This should cover the “why”, the “what’s new” and the “what if NOT” (i.e. the potential benefits that will be lost, or possible harms that TYA patients might face).

Second, it was felt that a focus on equity would be persuasive in selling the benefits of the specification. This related to all aspects of equity, including approaches to funding, access to types of treatment or trials, removing inequalities because of geography and other similar factors.

Communicating the service specification at a local level

The big initial task facing the ODNs is “selling” the service specification to their local Integrated Care Boards (ICB), cancer networks and NHS provider organisations. This involves distilling and articulating the “value proposition” – what the specification offers patients and the participating organisations.

This will be especially important in ensuring that designated hospitals can see the benefits to TYA patients that justify the inevitable investments and change process that will be required (pathway redesign, staff training, wider awareness raising and education, etc). It was suggested that issues of “patient ownership” may be a particular challenge in getting full buy-in from clinicians who may have some scepticism about the benefits of the new model of care.

The relationship between ODNs and designated hospitals was identified as a key area where good communication could act to improve relationships. Currently designation is done in “good spirit”, which means it can be difficult to hold designated hospitals to account, and the lack of MDT co-ordinators in designated hospitals means that patients can be missed. A validation certificate of some kind for designated hospitals was discussed as a potential tool for quality assurance.

Many of these issues stem from the fact that staff in designated hospitals are working under a significant amount of time pressure and find it difficult to prioritise TYA work. They might see very few TYA cancer patients relative to other areas of care, meaning that many staff are unfamiliar with the service specification and the practicalities of working with TYA-PTCs. This poses problems for implementation, in that awareness around the specification is currently lacking and teams are unlikely to be able to dedicate large amounts of time

to studying the changes within the new specification. ODNs may wish to begin conversations with designated hospitals by laying out what they can offer to support staff in their work.

Within the changing and highly pressurised environment at local system levels, with ICBs still establishing themselves, the role of the ODNs in driving a holistic cross-system approach to implementing the specification will be crucial. As part of this, the ODNs should ensure that their own governance structures fit within the local situations to maximise the chances of bringing about the necessary changes.

A “one size fits all” approach to local communication is unlikely to work given the variety of stakeholders, but this could also be seen as an opportunity. “Service spec days” held at an ODN level could be engaging and helpful, with participants from different backgrounds presenting challenges in their area which the group then might work together to address.

Policy Lab participants expressed concerns that some staff are currently unaware of the dedicated support available for TYA patients. Continued education and raising awareness was identified as a priority for ODNs and commissioners, in order to ensure that staff are aware of the options available. Workshops and TYA champions on wards were two potential examples of initiatives which could help break down barriers. Participants suggested that lead nurses – as well-connected individuals – might also have an important role in raising awareness throughout ODNs, but clearly this work in engaging others must be balanced with their other duties.

Communicating with community and primary care

The ODNs will also need to engage with community and primary care. It was suggested that this could be done through distributing information (e.g. multi-media such as bite-sized videos) and running local conferences and roadshows. It was felt that offering the chance to interact with colleagues with secondary and tertiary level knowledge enriches understanding of what can be done to benefit TYA patients. This does not imply asking those in the community and primary care professionals to “over specialise”; rather there is an opportunity to link delivery of TYA cancer care to the topics they might already be interested in (e.g. youth mental health or fertility issues).

Close cooperation with community and primary care would also help understand where pathways might have broken down (e.g. around the 16-18 age group in accessing psychological support services) and help design ways to take advantage of existing resources (e.g. using occupational health services to help those struggling with career issues because of their cancer treatment).

Monitoring and evaluating patient outcomes and network performance

Two distinct but related actions were proposed in the Policy Lab, both of which are important in supporting good quality care: the evaluation of patient outcomes and experiences, and the establishment of a national dashboard for TYA cancer network performance. A national dashboard will provide a benchmark for service delivery and a means for ODNs to monitor the ongoing implementation of the service specification over time and relative to other networks. Beyond this monitoring of service delivery, the effectiveness of implementation should be assessed by evaluating how this translates into outcomes and experiences of TYA patients, particularly over the longer term. These two aspects were both considered in further detail in the implementation workshop.

Establishing a national dashboard of TYA cancer network performance

As well as having responsibility in launching the new specification, NHS England and its Clinical Reference Group also have responsibility for implementing a set of metrics to collect data on the performance of the TYA cancer networks.

It was agreed by Policy Lab participants that putting this data into a dashboard accessible to ODNs would be very helpful in working with different stakeholders at a system level to identify actions and to follow up on these where needed. Participants felt that metrics should be used in a constructive manner, not as a “stick” to criticise ODNs. It was suggested that any dashboard should be private to start with, with providers granted exclusive access for a period in order to respond to any identified issues.

The implementation workshop attempted to define evaluation in more detail, with questions raised about how best to define quality within TYA services. Participants felt that currently benchmarking between areas is poor. Often the data collected provides no information beyond the surface level, and it was agreed that a new dashboard would need to be based around a clear definition of “quality” and developed in conjunction with patients themselves. It is also important to bear in mind the significant challenge of collecting useful data at scale from a complex TYA population, given the sheer diversity of patients, pathways and tumour types.

A dashboard would need to have a clear route to impact so that those responsible for collecting and submitting data can see how their involvement will lead to positive changes. A commitment to taking action to rectify any problems the dashboard highlights will be important in demonstrating its value and getting buy-in from those involved. Broader questions were raised over whether networks would have the power and resources necessary to actually do this though. Even where the data is clear and a path forward obvious, business cases asking for more resource have no guarantee of success. Quality improvement based around in-depth data analysis needs to be encouraged by national leadership, with financial and analytic support provided to local networks.

Evaluation of TYA patient outcomes and experiences

Evaluation of the experiences and outcomes of care are clearly a vital mechanism for empowering TYA patients to shape service design and delivery over the longer-term. It was strongly recommended in the Policy Lab that future research of individual outcomes and experiences should track impacts for more than the current three years, since there are many aspects (e.g. in relation to effects on fertility) that will only become apparent later in life. It was also acknowledged that this is often not straightforward due to patients aging out of TYA services and moving between areas as they grow older. It was suggested that local experience surveys could be pooled in order to compare services across different areas.

Future research should also seek to develop greater richness in the quality of life assessment, beyond the set of questions used to date. This could involve attempts to assess the impact of the many small interactions, experiences and service design elements that have a marked impact on individuals.

Harnessing the ideas of young people

Utilising young people's lived experience to improve services

It was acknowledged that the direct input of young people to implementation of service design and delivery is invaluable and a number of possible approaches for this could be considered.

At a national level, a TYA cancer service board could be established (possibly linking to the NHS youth forum). This could, for example:

- help with recruitment of young people at a local level to work with individual ODNs
- support the creation of training materials for staff
- act as an initial sounding board if new ideas emerge which could possibly be rolled out across all networks
- provide feedback on the perception of service development.

A variety of technologies could be used in supporting such a board, including using online meetings where travel is hard for some, messaging to involve people at a local level and surveys to reach out to wider groups of TYA patients where there are specific questions to be explored.

Discussion of testing new ideas with young people also led to the suggestion of a national “Dragon’s Den” model, where ODNs could pitch ideas for service improvement. This could be part of the role of a TYA cancer service board or set up as a one-off initiative.

There was strong agreement among participants that all ODNs need to put in place supportive patient engagement arrangements at a local level, for example establishing a local version of the national patient board

in the form of a panel or council. It may also be appropriate to have experts by experience represented within the ODNs themselves or sitting on the local cancer boards to help steer future priorities. TYA patients and carers could help develop a richer picture of the different stages of the patient journey as it is experienced locally. Their input could also be valuable in conducting a gap analysis, for example if there is change required to get more TYA patients into trials or gain access to tumour banking and whole genome sequencing.

Wherever young people are encouraged to get involved, it will be important to give something back to them for the contribution they make – beyond simply having their expenses reimbursed and receiving reasonable payment for their time. This could be in the form of offering generic skills training that might have value for them in a future career (e.g. around project skills or presenting) as well as acknowledgement through participation certificates or nominations for awards.

Participants at the implementation workshop agreed that engagement with TYA service users needs to be expanded and discussions focused on identifying and overcoming some of the current barriers to achieving this. There were questions regarding how best to engage a diverse group of young people, how to cope with time pressures impacting both young people and NHS staff, and how best to reward young people who did give up their time. It was also noted that participation is often time-limited due to the life stage commitments of those involved.

Effective engagement requires dedicated resource in order to succeed, in the form of staff time and funding. This is in part to make it as easy as possible for young people to access opportunities, whether through paying directly for their time, providing other incentives in-kind or coordinating logistics such as travel and accommodation. While resource constraints are clearly an issue, it may be worth exploring potential for sponsorship or working with charities in this area. There may also be scope to work opportunistically with individual patients in the course of their routine engagement with services. Current practice appears to vary between areas – while some ODNs have patient representation already, some do not. It was felt that good practice should be shared between ODNs, and where possible useful learning should be taken from international comparators.

Building strong relationships with the third sector

Working with the third sector at national level

Charities play an enormously valuable role in supporting TYA patients with information, guidance and practical support, and through augmenting the delivery of care (e.g. in the form of funding CNSs). It was pointed out though, that TYA patients and those responsible for commissioning and managing service delivery, often do not fully understand what might be available from the third sector and the boundaries of this. The implementation workshop echoed this in suggesting that some stakeholders mistakenly perceived TYA cancer

as a well-resourced area with significant third sector support, when in fact it represents a relatively small “cog” within a much larger machine.

It was therefore suggested that it would be helpful to coordinate the provision of information to NHS providers about the potential offer from different charities that work in the field of TYA cancer (i.e. what might be on offer, how it works, which age groups are covered, how long the support is likely to last, etc). Commissioners and trusts should, in turn, be encouraged to consider the possible “quid pro quos” for each party (e.g. committing to sustain CNS positions once third sector wedge funding comes to an end).

Working with the third sector at local level

Individual ODNs can assist NHS providers by flagging where support from the third sector may be available, either to develop staff skills, fund particular posts (such as MDT coordinators, social workers, CNSs, etc) or be integrated into the support offered to young people. Any funding, in particular, could be an effective way of addressing some of the new roles and skills that might be needed in implementing the specification.

Above all, it will be important to assess what is available locally, from both NHS providers and the third sector, to ensure that there is no unnecessary duplication of services or support.

Actions at a national level

Assisting staff in accessing national-level treatment provision

It was suggested at the Policy Lab that some local teams are better-placed than others to access national-level treatments that are located in specific centres and/or provided at a national level (such as proton beam therapy, types of immunotherapy, etc). Disseminating information on how these resources can be accessed and training for relevant staff across the networks would help ensure more consistent availability to all TYA patients.

It was also suggested that there was significant scope for more engagement between TYA and adult cancer services at national level, to understand where there were opportunities for shared learning and, in particular, in understanding how the plans for adult services could affect or be used to the advantage of TYA treatment and care.

Learning and sharing across the ODN networks

The formation of the “ODN of ODNs” network has generated some momentum and it was agreed that this should be kept going, since it offers an effective way to bring people together to share learning and provides a forum for matching skills and knowledge to opportunities where they can be applied. It is also at this level that the networks can explore and agree consistent or standardised approaches on specific issues – for example, on the appropriate level of psychological support to make available.

Similarly, to avoid unnecessary duplication, there ideally should be a central repository of information and resources that are common across the ODNs. This could cover a wide variety of things, including staff training packages, pathway protocols, TYA patient communication and feedback from patient and public involvement (PPI).

Learning across networks was explored in more detail during the implementation workshop, where it was mentioned that ODN managers and lead nurse groups were already coming into existence organically. Further support from commissioners would be welcome, but there is no need to “reinvent the wheel” and establish groups where useful forums already exist.

“Buddying” of ODN networks

Individual ODNs are also stakeholders in the success of other ODNs. Consistent progress with implementation across the whole ODN network will create opportunities both for sharing learning and for influencing policy and resource allocation in ways that would be less likely if some ODNs are lagging behind.

It was suggested that ODNs could be paired together as informal partners to work in a “buddying” relationship to try and drive improvement consistently across the country. This is an attractive alternative to more formal “peer review” approaches, enabling ODNs to be open about what they are finding difficult and to focus on learning and helping each other. At the same time, it is often useful to have an external perspective on how things are being done and this can provide valuable evidence and support in making the case for change (e.g., by showing that service delivery metrics have been assessed and verified by a neighbouring ODN).

Actions at an ODN level

Undertaking an initial gap analysis

Policy Lab participants recommended that ODNs should carry out two forms of gap analysis to assess how current provision compared to the service specification. One would be from the point of view of professionals and the other from the perspective of TYA patients. These assessments can then be combined into an overall assessment of the need for change.

This can be used to produce collaboratively an improvement action plan, with the involvement of NHS providers and commissioners, engagement with the third sector and input from young people and their support networks.

It will also be important to revisit the gap analysis from time-to-time, perhaps through recurrent benchmarking across ODNs. With respect to possible treatments, for example, the pace of progress means that new options

are likely to continue to emerge (e.g. based on genomics developments, alternative types of radiotherapy, etc) and it will be important to ensure that equitable access to these is maintained.

Investing in staff skills

A distinct skillset is needed to deliver high-quality TYA care. Competence is required not just in cancer-related care but also in young person-related care. Full implementation of the specification is almost certain to require some element of staff training and development. This relates both to individual professionals and to building an overall culture that is effective in sustaining high-quality TYA cancer care and support.

Participants felt that “knowledge competences” may be relatively easy to put in place and measure (depending on the organisational environment) while “attitude competencies” (e.g. attitudes and patient communication style) will be harder to implement comprehensively and consistently. To support this, it was suggested that learning is shared from teams that have good two-way communication in place.

Optimising MDT and pathway communication

There was strong agreement that successful implementation of the specification will require high quality communication amongst all those involved in the treatment, care and support of TYA patients. This should start with making clear how pathways are to work (with contact details and processes to make MDTs easy to access in both directions) and putting in place the necessary infrastructure to coordinate for all the patients discussed at TYA-MDTs. It was suggested that members of the MDT should be drawn from the designated hospitals as well as the PTC.

For the majority of TYA patients, it is already the case that MDT conversations occur prior to higher-stakes decisions on modality of treatment. It was recommended that these conversations should be held wherever possible. It was also recommended that cases should be discussed at MDTs not just at diagnosis but also at the point of any relapse. To optimise the quality of the MDT deliberations, ODNs might consider putting in place learning feedback loops to understand what works well and spread good practice.



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