

Teenage & Young Adult 16-18 Diagnostic Pathway

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Executive Summary

The Wessex-wide TYA service that crosses established paediatric and adult service age boundaries has delivered improvements to the age-appropriate treatment, care and supported transition for young people aged 16 and over. One continuing challenge in Wessex and elsewhere is the diagnostic pathway for 16-18 year olds between secondary care providers of paediatric and adult care. The development of a bespoke pathway supported by a TYA 16-18 diagnostic support hub, staffed by TYA cancer specialist nurses seeks to improve clarity and consistency of approach and a single point of contact for advice and support to clinicians and young people/ their parents or carers.

1 Scope and Purpose

Rationale

Currently diagnostic pathways are delivered on a site-specific basis by whichever local (paediatric or adult) team receives the referral. There can be lack of clarity, consistency, and age-appropriate support during this stressful time, and delays due to local teams' unfamiliarity with the TYA service pathway from this small age group cohort (Average new cancers 16-18 year olds 2018-2020 =16 per year) require additional resource and new ways of working to provide clinical advice and coordination.

1. This SOP is written to provide procedural and clinical governance support for a nurse- led 16-18 diagnostic support hub for hospitals that refer to the Wessex TYA cancer MDT hosted by UHS. In addition to clinical details and decisions being recorded in clinical notes, outreach nurses will be linked in with patients if applicable. Any Adverse Events (or near miss) occurring will be reported via the usual route.

The 16-18 diagnostic pathway service aims to deliver the following outcomes:

- To provide a Wessex hub for co-ordination of 16-18 diagnostic pathways.
- Reduction of delay and complexity of diagnostic/investigation pathways.
- Ensure diagnostic pathways are delivered at the right place at the right time.
- To provide support, clinical advice and link up clinical teams.
- To offer support to teenagers and their parents/carers on a cancer diagnostic pathway.
- Ensure patients who do not have cancer are referred onwards for care/support as required.
- To facilitate clinical communication between paediatric and adult site-specific teams.
- To facilitate clinical communication between referring teams and the UHS TYA PTC.

2 Definitions

Standard Operating Procedure (SOP):

A SOP is a set of instructions to be followed in carrying out a given operation, or in a given situation, which lend themselves to a definite or standardized procedure without loss of effectiveness.

3 Details of Procedure to be followed

The hub will provide a first point of contact for paediatric and adult clinicians in secondary care who are managing a cancer diagnostic pathway for teenagers between their 16th and 18th birthdays.

The hub will provide tailored information and guidance to clinical teams. The hub will provide a point of contact with TYA services for teenagers and their parents/ carers, providing personalised information, reassurance, and timeline details during the diagnostic pathway. A summary flowchart is provided (appendix 1)

Staffing

1. Monday – Friday 9-5 the hub will be staffed by a Snr TYA cancer Speciality Nurse (band 7 UHS CNS or Lead Nurse) with access to clinical advice from named paediatric and adult oncology/haematology consultants and administrative support. The hub nurse will have clinical and age-appropriate care competencies and advanced communication skills required to expand their role to provide diagnostic hub clinical advice and support. An ESP to underpin this practice is not required as it is a minor change within current scope of role to provide advice to local services. The medical oncology consultant on Call will provide cover out of hours.

The hub will provide a single point of contact across Wessex TYA hospitals, Monday-Friday 9-5. This will be the hub mobile 07920 261332. Out of hours contact switchboard on 02380 777222 and ask for on call oncology consultant.

A handover between TYA hub Nurse and consultant on call will take place to provide out of hours information as required about any patients on the pathway and decisions or actions required. Should the referral relate to a haematology patient the oncology consultants will seek advice from the on-call haematology consultant.

Procedure

1. Hub is contacted by secondary care clinician who has 16-18 year old in their care with suspected cancer. They will explain the TYA service/ process to the patient/ family and offer an information leaflet.
2. 16-18 Hub Nurse gathers clinical details, family/social information and preliminary investigation plan and any specific concerns from notifying clinician.
3. This is recorded on 16-18 hub notification details record.
4. Patient is registered at UHS.
5. Notification record updated and saved on Edocs.
6. CNS acknowledges notification, advises they will liaise with appropriate consultant, and will call back same day.
7. Patient will be added to live tracker where the CNS will update diagnostic procedures
8. TYA hub nurse triages patient based on clinical and other details, with advice and support, if necessary, from consultant colleague. Outreach nurse to be linked in if applicable.
9. An action plan based on triage outcome will be agreed by consultant and communicated to patient's local clinician. This will be recorded on UHS record which will be sent securely to the patient's local clinician.
10. TYA CNS will contact patient/ parent to discuss support hub function, provide point of contact.
11. Following triage TYA nurse decisions and actions will be recorded in a separate Edocs memo (document will remain in Edocs draft format and continue to be edited until diagnosis confirmed, at which point the CNS will finalise and publish).
12. The triage outcome will assign patients to one of the three agreed pathways (see appendix A).
A- If urgent the patient will be transferred to UHS for continued investigation/ treatment.
B- Patient referred to site specific team OPA at UHS

C- Patient's diagnosis to be managed with current adults/ paed team at patients' hospital with TYA advice and support.

13. In all cases a 16-18 hub nurse will liaise directly between the investigating team and the TYA MDT to agree and support the onward pathway.

14. A hub nurse will maintain contact with investigating team and patient/ parent throughout the diagnostic pathway and facilitate communication between adult and paediatric services/ clinicians at the patient's hospital. They will expedite investigations as required to avoid pathway delays and ensure the patient/ family are updated and supported.

15. An update on all patients on an active 16-18 diagnostic pathway will be presented to the hub clinical team by a hub nurse each Friday afternoon following the TYA MDT and ward round to review progress and initiate changes in plan as required. This will be communicated to the investigating team and / or family as clinically appropriate to avoid and delay in diagnostic pathway or patient support.

16. If clinical circumstances or patient clinical condition or other circumstances change, a more urgent discussion can take place at any time during the diagnostic pathway. The TYA hub nurse will coordinate this and seek clinical advice as required to support decision making.

17. At the end of the diagnostic pathway, patients who are confirmed to have cancer will be discussed at TYA MDT invited to clinic either face to face or via attend anywhere and offered TYA cancer services standard of care. The 16-18 pathway monitoring ends when the patient is registered with TYA MDT with a confirmed site-specific MDT diagnosis

18. Patient attends clinic post diagnostic investigation for non-cancer diagnosis outcome and is signposted to appropriate services. CNS to review to ensure check in call actioned by team patient care handed over to.

4 Roles and Responsibilities

This SOP applies to TYA cancer team staff employed or contracted by University Hospital Southampton (UHS) Foundation Trust who provide care to Teenage and Young Adults aged 16-24 and have been identified as having the specific skill set required to give advice. The hub nurses will be supported by TYA team administrator and UHS Oncology consultants will provide advice out of hours. All staff who work with TYA cancer patients have a responsibility to ensure that they are aware of this SOP and its contents. They should clearly document their rationale if they have not complied with the recommendations detailed in this SOP. It is the responsibility of department managers, consultants, team leaders and education leaders to ensure appropriate staff are aware of this SOP.

5 Related Trust Policies

None

6 Implementation

The SOP will be displayed on the Staffnet and sent to the relevant Care Group clinical teams. The ward leaders will be expected to cascade to all relevant staff. All medical and nursing staff caring for Teenagers and Young Adults should have knowledge that this support is provided following completion of treatment and the contents of the guideline. The working party will ensure this is shared with other hospitals across the network and Gp's will be made aware of this process via training and seminars to raise awareness.

7 Process for Monitoring Compliance/Effectiveness

The purpose of monitoring is to provide assurance that the agreed approach is being followed – this ensures we get things right for patients, use resources well and protect our reputation. Our monitoring will therefore be proportionate, achievable and deal with specifics that can be assessed or measured.

Key aspects of the procedural document that will be monitored:

What aspects of compliance with the document will be monitored	What will be reviewed to evidence this		How and how often will this be done	Detail sample size (if applicable)	Who will co-ordinate and report findings (1)	Which group or report will receive findings
100 % of patients aged 16-18 to be referred to hub whilst awaiting diagnosis.	Edocs to determine if patients identified within this age range were appropriately signposted to hub		Annually by Audit	All patients age 16-18 within set period	TYA Wessex Administrator	Core members of TYA MDT

8 Arrangements for Review of the Policy

The SOP will be reviewed after three years or sooner as a result of audit findings or as any changes to practice occurs.

9 References

Appendices

Appendix A- Process flow chart (CANC007)

Document Monitoring Information

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