

Patient Pathways for Teenagers and Young Adults (TYA)

University Hospitals Bristol NHS Foundation Trust (working in partnership with North Bristol NHS Trust) has been the designated Principal Treatment Centre (PTC) for Teenagers and Young Adults (TYA) with cancer in the South West (SW) of England, a population of almost 5 million, since 2011. The PTC oversees the delivery of specialist malignant haematology and oncology care along with the provision of emotional, social and practical support to young people diagnosed with cancer, low grade brain tumours and non-malignant conditions requiring 'cancer-type' therapies such as Haemopoietic Stem Cell Transplantation (HSCT) aged between 16 and 24 years.

The NHS England Standard Contract for TYA with cancer (B17/S/a) reflects previously published national guidance (NICE IOG 2005) and states that young people aged 16-18 years (i.e. to 19th birthday) should be referred to a TYA PTC for treatment in age appropriate facilities and that young adults aged between 19 and 24 (i.e. before 25th birthday) should be offered the opportunity to receive treatment at a PTC in age appropriate facilities. However, when the TYA service was first commissioned in the SW, a devolved network model of care was agreed with the Specialised Commissioners.

For geographical reasons, and in line with a long standing and well-established regional 'shared care' network in childhood cancer in the same region, it was agreed that a regional network for TYA care would be established linking the PTC in Bristol with 6 designated hospitals offering TYA services across the SW. They are:

1. Gloucestershire NHS Foundation NHS Trust
2. Royal United Hospitals Bath NHS Foundation Trust
3. Taunton & Somerset NHS Foundation Trust
4. Royal Devon & Exeter NHS Foundation Trust
5. Plymouth Hospitals NHS Trust
6. Royal Cornwall Hospitals NHS Trust

The rationale for this decision was to ensure that all young people were able, whenever possible and appropriate, to access treatment locally.

Diagnosis and age criteria for referral

TYA cancer is rare, accounting for less than 1% of cancer in all ages. The spectrum of cancer types in this age group is also distinct from those seen in both children and adults. However, tumour types more commonly seen in young children or older adults

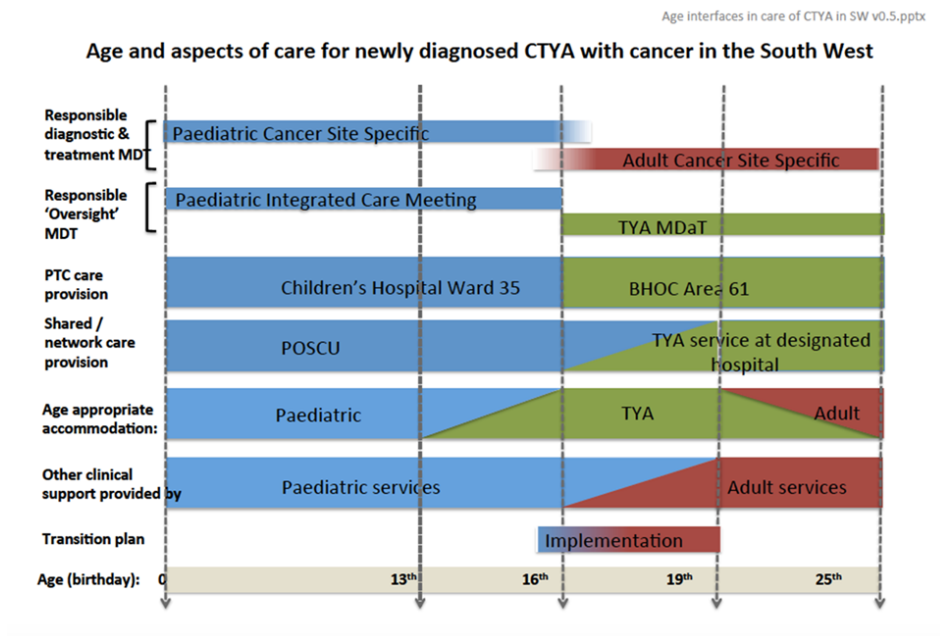
may occasionally also be seen in the TYA population. The most common tumour types in TYA patients are:

- Lymphomas;
- Germ cell tumours;
- Central nervous system tumours;
- Malignant melanomas;
- Acute leukaemias; and
- Sarcomas.

The service can also support TYAs diagnosed with low-grade brain tumours or non-malignant conditions requiring 'cancer-type' therapies such as Haemopoietic Stem Cell Transplantation (HSCT).

A review of the lower age threshold for referral to the TYA service was conducted in collaboration with the childhood cancer service in 2016. This considered the complexity of the age interface in relation to: MDT discussion; provision of in-patient care at the PTC; provision of paediatric shared care and TYA designation across the region; the availability of age appropriate accommodation; and the provision of support from either paediatric or adult services. Variability exists in the policies about the upper age limits for paediatric care across hospitals involved in the network.

This is illustrated below:



The implications of this decision for the service has been that

- all young people newly diagnosed with cancer from the 16th birthday to before the 25th birthday must be referred to the TYA MDaT (Multi-disciplinary advisory Team) whether or not they are under paediatric or adult site specific cancer care.
- all children and young people newly diagnosed with cancer before the 16th birthday should be referred to the paediatric oncology/haematology service.
- young people newly diagnosed with cancer from the 16th birthday and before 18th birthday may be referred either to paediatric or adult cancer services. Referral to paediatric services at this age may still be appropriate in relation to the nature of the diagnosis, the preference of the young person and his/her family; and his/her developmental status. Before making this decision, however, due consideration should be given to how shared care can be delivered, the need for a transition plan, and the possibility of requiring subsequent transfer to adult services.
- young people newly diagnosed with cancer from the 18th birthday should be referred to adult site specific cancer services.
- all children and young people who were originally diagnosed with cancer prior to the 16th birthday but who transit their 16th birthday whilst still on treatment, should be referred to the TYA MDaT whether or not they remain under paediatric care.

Facilities

There are two areas for the care of young people with cancer in the Principal Treatment Centre at UH Bristol: Ward 35, in the Bristol Royal Hospital for Children, and Area 61, a newly built TYA Unit for young people in the Bristol Haematology and Oncology Centre (BHOC).

Ward 35, cares for young people aged 11-16, with four beds specifically supporting young people with cancer. There is active collaboration between Ward 35 and Area 61.

Area 61 was funded and developed in partnership with the Teenage Cancer Trust. The Unit opened in 2014 and provides care, treatment and consultation for young people with cancer aged from 16 to 24. It is built over two floors with one floor dedicated to in-patients featuring five en-suite rooms; a social area equipped with gaming and entertainment equipment and a kitchen and dining space; quiet room; treatment room; and a more recently planned wellbeing room. The other floor is for day patients featuring three treatment 'pods'; three consulting rooms; a procedure room; social space; waiting area and a staff office.

Age specific facilities have been/are being established in many of the designated network hospitals, with Teenage Cancer Trust support.

The TYA Multi-disciplinary advisory Team (MDaT) meeting

National policy (NICE Improving Outcomes Guidance 2005 and the national service specification for TYA cancer) require that all TYA patients (aged 16-24 years) are discussed both at a relevant site-specific diagnosis and treatment MDT and by the regional TYA MDT. This forms part of TYA Cancer Peer Review Measures/Quality Surveillance. The services provided by the TYA team differ from those provided by site specific groups. The site specific team (SiSp) has primary responsibility for the investigation and diagnosis of cancer and for the delivery of treatment and every young person will be formally discussed at the SiSp diagnostic MDT.

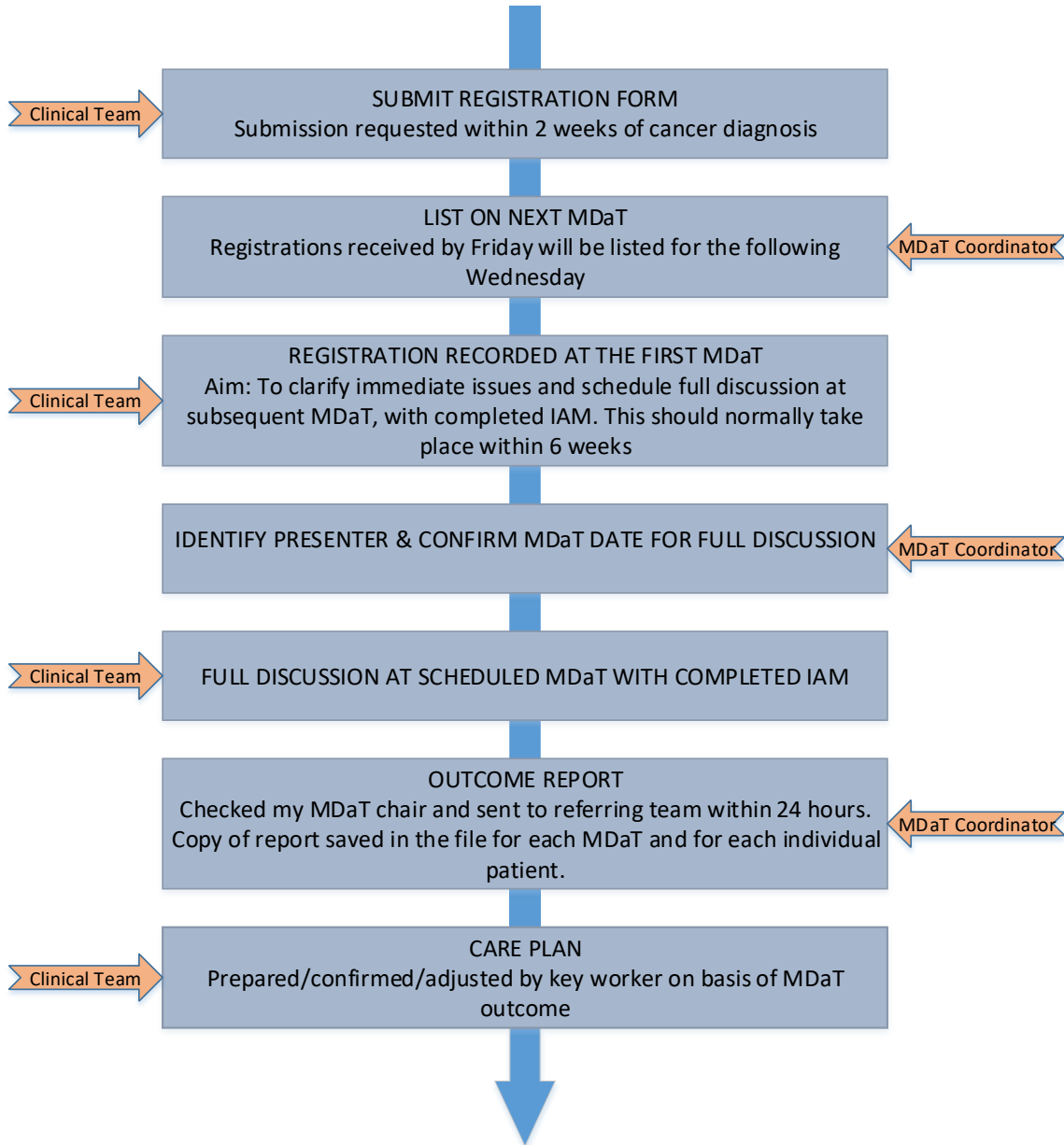
We call the TYA MDT the 'MDaT' both to avoid confusion between the two MDTs involved and to emphasise its role as an advisory body. The focus of the discussion at the MDaT is to ensure that each young person's needs are discussed holistically and that the advice and resources of the TYA service are offered to add value to the care each young person receives

MDaT Process

The TYA SW MDaT takes place as an online WebEx meeting and is held weekly on Wednesdays from 12:30-14:00. The referral of new patients is managed as a two-step process:

1. First, we ask that patients are registered using the SWIMMS (South West Integrated MDaT Management System) system using this link: www.swimms.co.uk for online registration or via a registration form by contacting the MDaT Coordinator at tyamdat@UH Bristol.nhs.uk or by calling 0117 342 7654. A logon, password and brief user guide for SWIMMS can be obtained via the Teenage Cancer Trust Regional Coordinator by contacting rob.spate@uhbristol.nhs.uk or Phone: 0117 342 7592.
2. We log each new registration to be included at the next available MDaT so that the wider team is aware of the patient at an early stage and will suggest a date for a full discussion, usually within 4-6 weeks. The second step is undertaken by the MDaT coordinator who will liaise with you to obtain further information about the patient and confirm the best date and time for them to join the MDaT (on line or in person) for a full discussion.

Summary of TYA MDaT Process for new patients from 6th April 2016





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Please note that, in order to comply with information governance requirements, all patients must be provided with information about how their personal data are handled and by whom these are to be discussed. This is achieved by issuing every patient with the TYA SW Service Offer Leaflet that includes a section explaining this. A copy of the service offer leaflet can be obtained from our website <http://www.uhbristol.nhs.uk/tya>. Registration via SWIMMS requires that the referrer confirms this has taken place, and without such confirmation, the system will not allow the registration to proceed.

At the full discussion, the chair of the MDaT (usually the TYA Lead Clinician or TYA Lead Nurse) facilitates a short presentation from the referring team around the patient's diagnosis, prognosis and treatment plan and will ask about recruitment to any available clinical trial and whether or not fertility preservation was necessary, possible or implemented. The patient's holistic needs are then discussed, using the IAM (Integrated Assessment Map) submitted prior to the meeting to structure the conversation. If the young person has not submitted their own IAM, or one done in partnership with a healthcare professional, the key worker is asked to submit a professionally led IAM before the MDaT discussion.

The outcomes and actions from the meeting should be used to inform the patient's care plan and are emailed (via nhs.net) to the referring team by the MDaT coordinator as a pdf document which can be downloaded to electronic medical records and/or printed and filed in the patient's notes. This includes a date for review at a future TYA MDaT if this has been agreed to be appropriate. All patients are routinely reviewed at/around the end of treatment.

For more information on the referral process and support offered by the TYA Cancer service please visit our website via [SW TYA Cancer Service information for professionals](#)

NOTE: There are occasions where a young person will decline support from the TYA Team. However for auditing purposes they will be registered on SWIMMS to account for our service offer.



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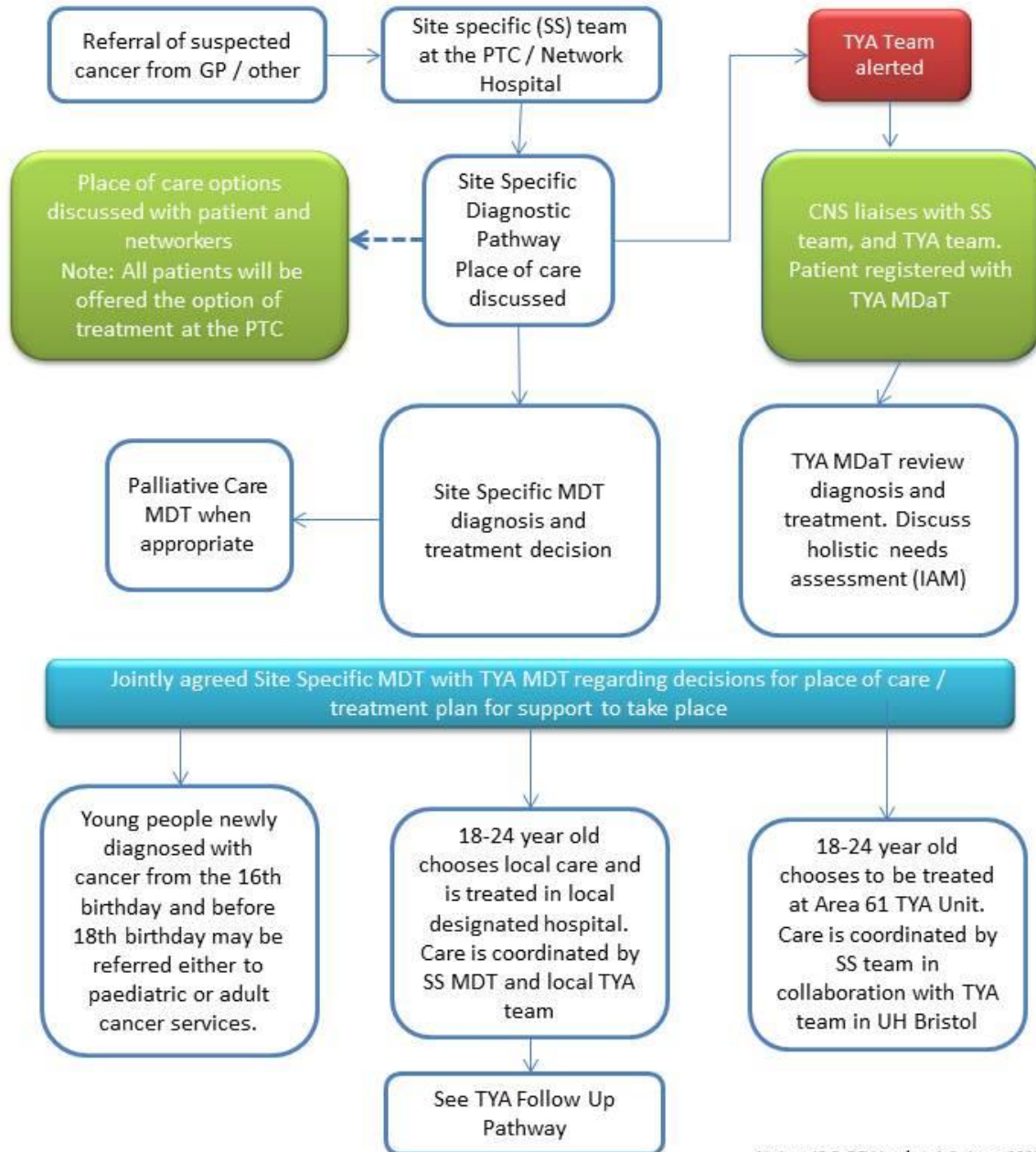
After treatment

After completion of the initial definitive treatment, the ongoing disease surveillance and follow up of the patient is the responsibility of each Site Specific MDT; the TYA service collaborates with the Site Specific MDT to ensure that an individualised long term care plan is in place. All patients will be offered 2 years of peer and social support from the TYA team, alongside access to specific wellbeing support identified through assessment of their wider holistic needs as the transition to supported self-management.

Patients treated by a paediatric team will transition to the SW Aftercare service for long term follow up who will liaise with specialists in endocrine, cardiac, neurology as required.

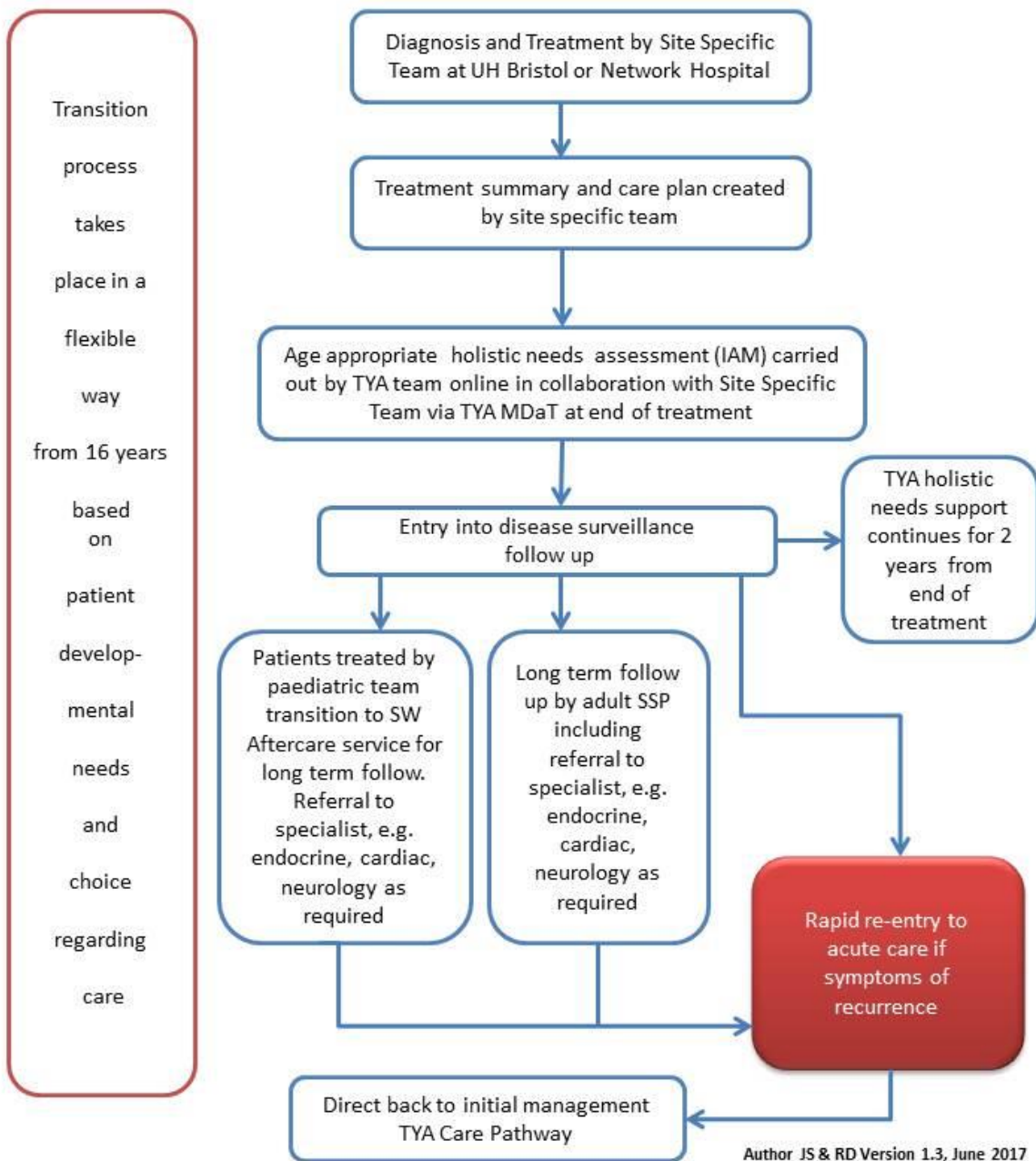
Patient pathways designed specifically for teenagers and young adults between the ages of 16 to 24 years are as shown on the following page.

South West Teenage and Young Adult (16-24) Patient Pathway for Initial Management of Cancer



Author JS & RD Version 1.3, June 2017

The TYA Pathway for Follow Up on Completion of First Line Treatment





South West Clinical Network
Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services

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VERSION HISTORY

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3 rd May 2019	0.1	First Draft	RS
8 th May 2019	0.2	MDaT Process	RS
8 th May 2019	0.3	Referral details to account for SWIMMS	JC

APPROVALS

Date	Document Version	Approver Name and Title	Approver Signature