

## **NATIONAL OPTIMAL PATHWAYS FOR CHILDREN'S CANCERS**

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### **Point of Suspicion to First Definitive Treatment in Children (under 16)**

<b>Date of Issue: March 2022</b>
<b>Date of Review: March 2024</b>
<b>Owner: Children's Cancer Site Group</b>

## Background

The aim of the **Suspected (Single) Cancer Pathway (SCP)** programme is to improve access to timely and effective diagnostic tests and treatments, ensure patients are supported through the pathway and allow improvement of upstream factors that will improve earlier detection of cancer.

The SCP is a Welsh Government target for diagnosing cancer and starting treatment more quickly. The performance target for the SCP is that:

At least 75% of patients start their first definitive treatment (FDT) within 62 days of the point of suspicion (POS).

The NHS Wales National Optimal Pathways (NOPs) have been developed to support the SCP programme of work. The Wales Cancer Network (WCN) has worked with health professionals, third sector organisations, and the Welsh Government to develop these cancer specific NOPs. The pathways are owned and reviewed by the relevant Cancer Site Group (CSG). They describe good practice diagnostic and treatment pathways for site specific cancers to support a shortened time to diagnosis.

## Aim

The NOPs aim to:

- standardise care, reduce unwarranted variation and drive improvement
- increase quality across each of the cancer pathways
- support the service to meet the SCP cancer waiting time of 62 days for patients presenting with a suspicion of cancer,
- improve cancer patient experience,
- improve cancer patient outcomes throughout Wales to that comparable with the best outcomes in Europe
- reduce the percentage of patients diagnosed having presented as an emergency

The NOPs are designed to support the following services:

- Cancer service providers and their commissioners
  - Outlining the basic structure of an effective and efficient cancer pathway
  - Detailing each stage of the pathway, including communication with patients
  - Consistency across pathways, assisting with standardised data collection and evaluation
  - Enable demand and capacity planning, making the case for expansion of workforce, facilities and equipment
- Primary and non-specialist secondary care teams
  - Providing clarity and consistency around the referral process into secondary care
  - Improve detection rates

## General principles

Some general principles have been applied when developing the NOPs. These include the following:

- Patients diagnosed with cancer should start their treatment within 62 days of POS. This is a standard target, but treatment would be expected to start significantly earlier in a child or young person.
- The diagnostic (and staging) pathway should be completed within 28 days from POS<sup>1</sup>
- First definitive treatment should be commenced within 21 days from date of decision to treat (DTT). The DTT is the date that the consultation between the patient and the clinician took place and a Planned

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<sup>1</sup> The diagnostic and staging pathway for tertiary services is currently being reviewed and may be 38 days for some tertiary services to allow for the complexity of the pathway

Cancer Treatment was agreed. The definition for FDT and other reported waiting time definitions are incorporated in the Welsh Government's Guidelines for Managing Patients on the Suspected Cancer Pathway (see reference below)

- Patients should be managed with the aim of starting treatment at the earliest clinically appropriate time rather than against any performance measure. All patients should wait the shortest possible time for diagnosis and treatment.
- The pathways are an expression of good practice based on the best available evidence for each respective cancer tumour site. Typically, the authoritative source will be NICE or professional guidelines which are referenced below. Where this is absent, clinical consensus among the appropriate clinical community has been channelled through the CSGs
- Children and young people can be referred for investigations ahead of a referral to General Paediatrics, but if the young person warrants urgent review, appropriate investigation will follow rapidly within the hospital setting.
- Patients should receive consistent information and support, tailored to meet their needs. The NOPs are heavily influenced by the person centred care strategy outlined at appendix one.

## Children's Cancer Pathways

- The Children's cancer pathways apply to children from the age of 0-15 (up to the 16<sup>th</sup> birthday) suspected of having any cancer diagnosis. For diagnosis and management of young people diagnosed with cancer aged 16-24 please refer to adult services and liaise with the teenage and young adult services.
- Cancer in children is rare, with about one in 600 children developing a cancer by age 15 years.
- There are approximately 1400 new cases of cancer among children 0-15 years in the UK each year: suggesting an annual incidence in Wales of approximately 70 children per year.
- Children's needs differ according to their developmental stage (emotional, social, psychological and physical) and the need to consider the impact on the wider family of a cancer diagnosis.
- In children, the most common malignancy is leukaemia, followed by tumours of the central nervous system. Around 40% of all cancers diagnosed in children in the UK are leukaemias and lymphomas and 25% are brain tumours, with the remaining conditions comprising a wide range of solid tumours.
- Diagnosis, treatment and care for children's cancers are guided by national frameworks based on guidelines and research.
- Diagnosis and management of children diagnosed with cancer in Wales should adhere to the National Standards for Children with Cancer aged 0 to 15 years (see references below).
- Services for Children with Cancer in Wales should comply with the Welsh Health Specialised Services Committee: Service specification for children with cancer (see references below).
- Children with suspected cancer are usually referred to a local General Paediatrician then on to the Paediatric Oncology team as soon as possible.
- Some children require referral to Paediatric Oncology due to their diagnosis and treatment even though the diagnosis may not be classed as malignant, e.g. Craniopharyngioma and Langerhans Cell Histiocytosis
- Paediatric cancer services are delivered by area:
  - In North Wales, care is provided by Alder Hey Children's Hospital (Principal Treatment Centre; PTC). Closer to home, care is shared with three satellite Paediatric Oncology Shared Care Units (POSCU) within the Betsi Cadwaladr University Local Health Board. The PTC provides tertiary care for children with leukaemia and solid tumours. The Cheshire and Merseyside Cancer Alliance coordinates the care of all children and young people in the North West Region of England and North Wales.
  - In South Wales, care is provided by the Children's Hospital for Wales (PTC), within the Cardiff & Vale University Health Board. Where care can be delivered closer to home, this is provided by two POSCUs, based at Glangwili General Hospital, in the Hywel Dda University Health Board, and Morriston Hospital, in the Swansea Bay University Health Board.

- In Powys, care may be provided by Birmingham's Children's Hospital NHS Foundation Trust (PTC), or through the North or South Wales pathway, depending on geographical location.
- For teenagers over 14 and young adults (TYA), the TYA MDT should be informed of the diagnosis and treatment plan in order to better support those in this age group. There is good support within Children's services, but needs change with transition into the TYA age group. Changes may include where in-patient care is delivered, as well as psychosocial, symptom control and palliative support.

## Further guidance and references

[Children's Cancer and Leukaemia Group \(cclg.org.uk\)](http://cclg.org.uk)

Department of Health: Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies (2008).

Healthcare Commission: Improving Services for Children in Hospital (2007)

National Service Framework: Children, Young People and Maternity Services (2004).

NICE: Children and Young People with Cancer, (2014)

NICE: Guidance on Cancer Services: Improving Outcomes in Children and young People with Cancer (2005).

Welsh Government: National Standards for Children with Cancer aged 0-15 (2011).

Welsh Government: Together for Health: Cancer Delivery Plan – A Delivery Plan up to 2016 for NHS Wales and its Partners.

Welsh Health Specialised Services Committee (February 2015) Specialised Services Service Specification: Services for Children with Cancer (CP86)

[CP86 Services for Children with Cancer Service Specification v1.01.pdf \(wales.nhs.uk\)](#)

NICE NG12: Suspected cancer: recognition and referral (2015, Updated 2021)

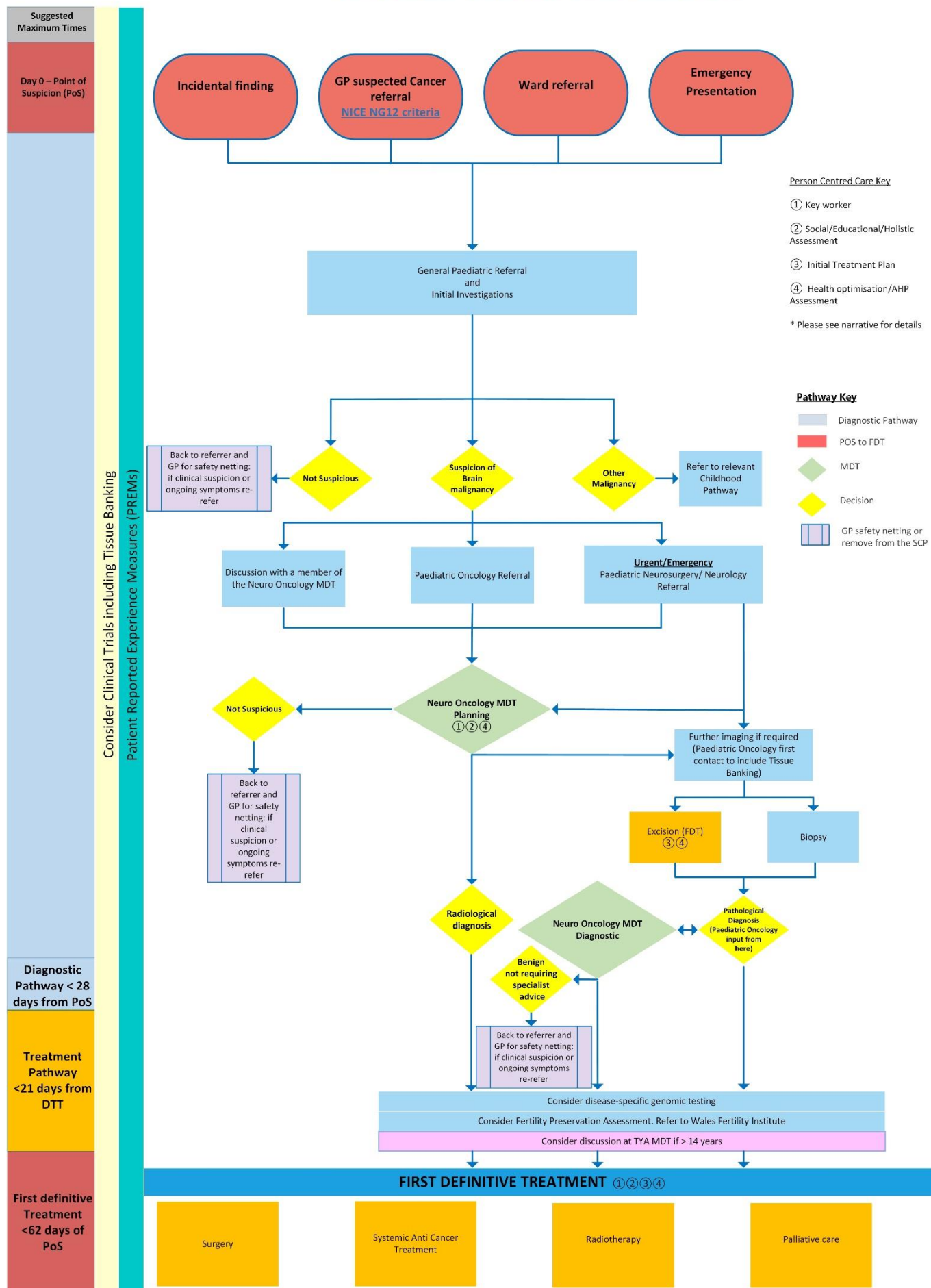
## Pathway development and approval

The pathway development work has been led by Consultant Paediatric Oncologists Cathy Morley-Jacob and Meriel Jenney.

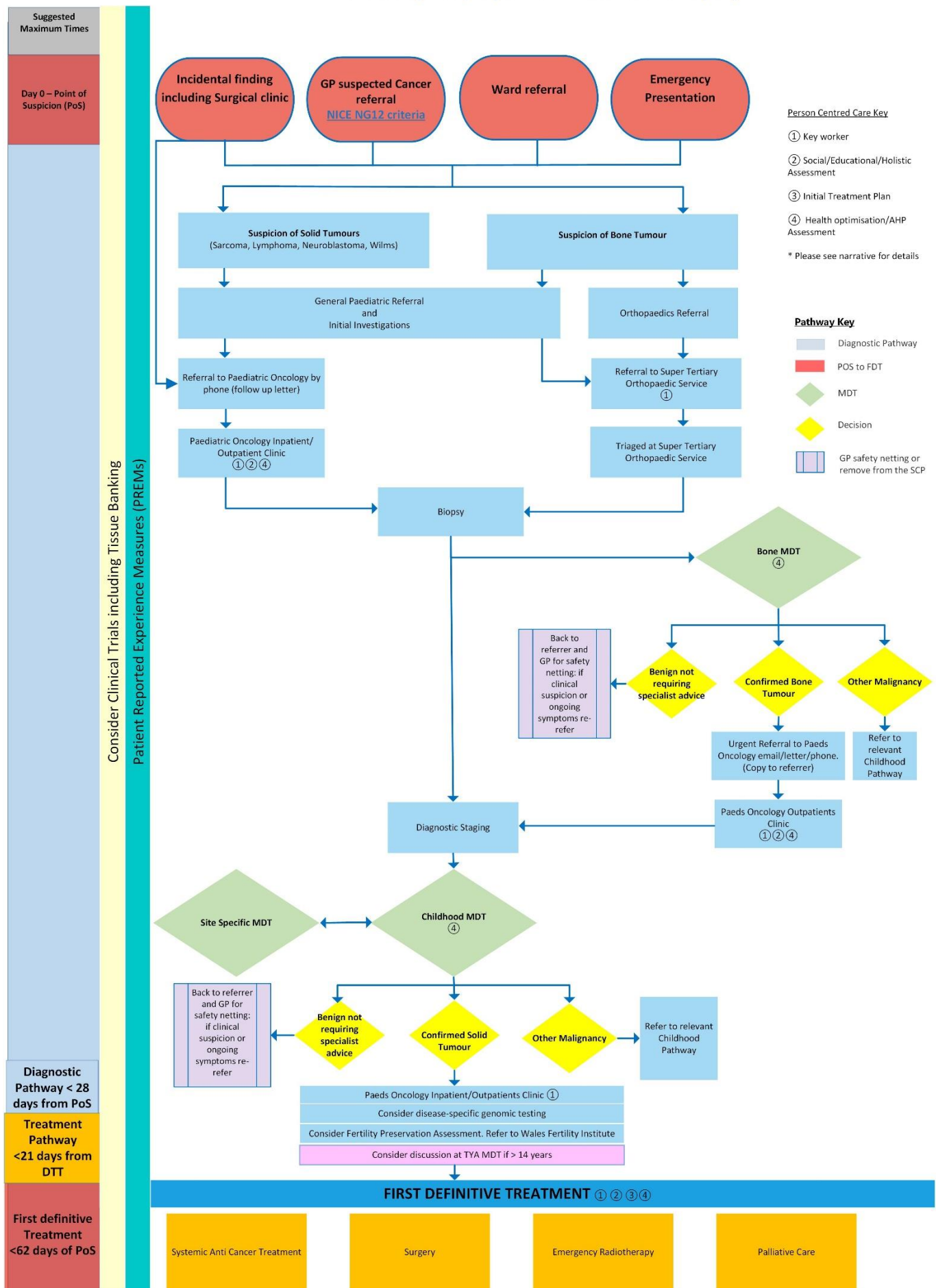
Approved by:

(to be completed post consultation)

## National Optimal Cancer Pathway for suspected and confirmed Children's Brain and Spinal Cancer : Point of Suspicion (PoS) to First Definitive Treatment (FDT)

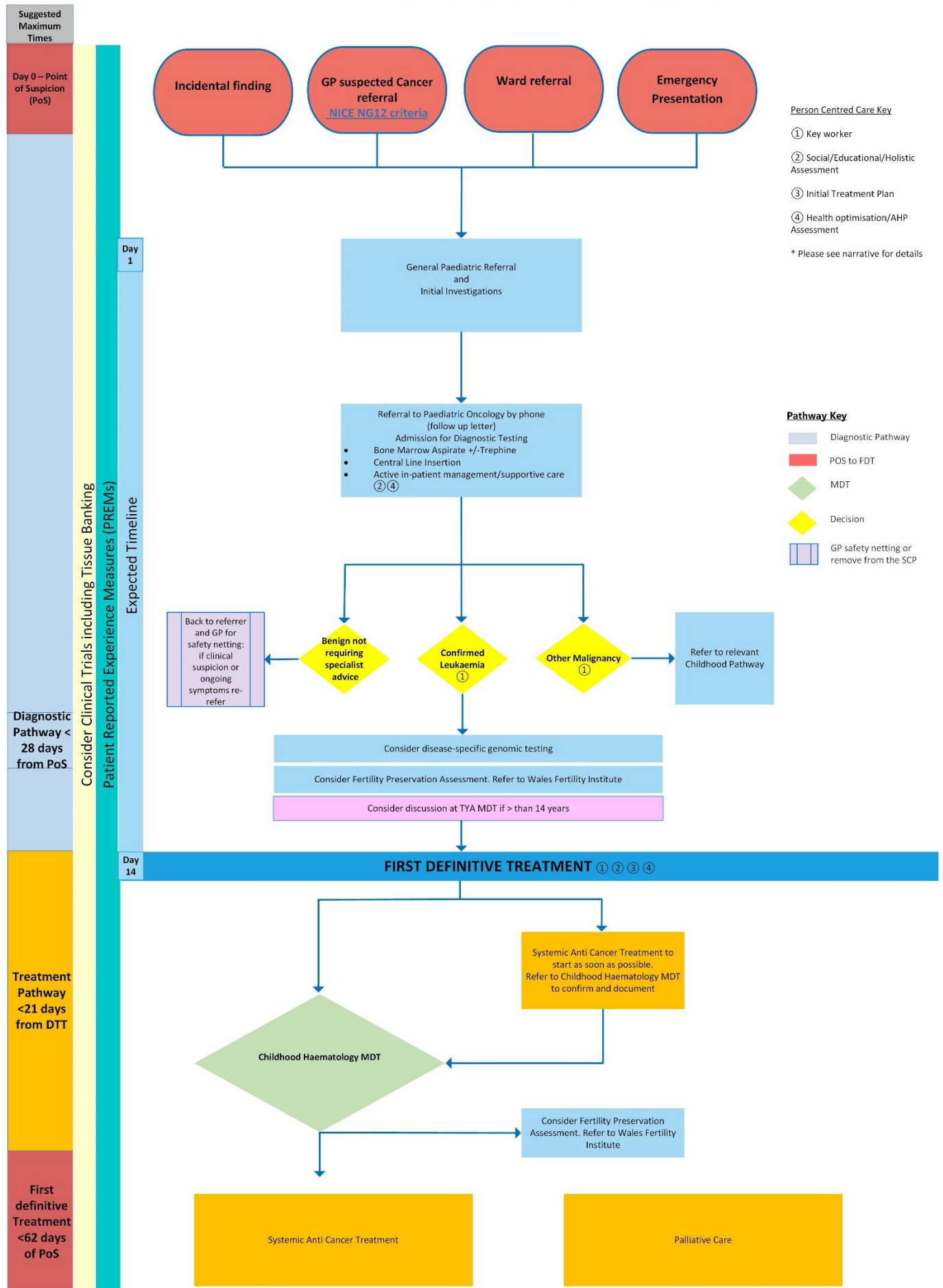


## National Optimal Cancer Pathway for suspected and confirmed Children's Bone and Solid Tumours : Point of Suspicion (PoS) to First Definitive Treatment (FDT)





## National Optimal Cancer Pathway for suspected and confirmed Children's Leukaemia : Point of Suspicion (PoS) to First Definitive Treatment (FDT)



# Appendix one - PERSON CENTRED CARE

<b>Key Worker</b>	<p>A cancer key worker is <i>“a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice”</i>.</p> <ol style="list-style-type: none"> <li>1. All cancer patients must have an allocated key worker</li> <li>2. Allocation / Review of key worker to take place at key time points including: <ol style="list-style-type: none"> <li>a. Around the time of diagnosis <i>*please note: allocation of key worker <b>may</b> occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy.</i></li> <li>b. Commencement of treatment</li> </ol> </li> <li>3. When not under active management by the cancer MDT, the Key worker would be a member of the primary care team. This involvement is critical as many patients living with cancer also live with 2 or more other chronic conditions.</li> </ol> <p><a href="#">Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES</a>  <a href="#">Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</a></p>
<b>Social/ Educational/ Holistic Assessment</b>	<p>Assessment and discussion of the patient and family’s needs for physical, psychological, social, spiritual, education and financial support should be undertaken at key points including:</p> <ul style="list-style-type: none"> <li>• Around diagnosis <i>*please note: undertaking a Holistic Needs Assessment <b>may</b> occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy; and it is supported by professional judgement.</i></li> <li>• At commencement, during, and at the end of treatment;</li> </ul>
<b>Health Optimisation / AHP Assessment</b>	<p>Health Optimisation refers to a proactive approach to supporting children who present to NHS services with concurrent health conditions (e.g. hemiplegia, anaemia, diabetes), or health risk behaviours (e.g. diet, physical inactivity).</p> <p><a href="#">Welsh Government (2018) A Healthier Wales.</a>  <a href="#">Welsh Government (2015) Wellbeing of Future Generations Act.</a></p> <p>Making Every Contact Count (MECC), is a behaviour change approach that helps health and social care professionals to help people to improve their health and wellbeing through prevention and early intervention. <a href="#">Public Health Wales Strategic Plan 2018-2021</a></p>