

**Recommendations from the South-West Clinical Senate Council on how we might ensure that children and young people waiting for paediatric specialties and/or within all-age (medical and surgical) and community pathways are appropriately prioritized and receive safe, high-quality, and timely care, whilst taking into consideration the impact on their development, future health, education, and health inequalities.**

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## 1.0 Background

*'How the South West might ensure that children and young people waiting for care are appropriately risk stratified and prioritised to ensure that they receive safe, high quality and timely care'* emerged as a deliberative topic for the Senate Council, from conversations with Dr. Vinay Takwale, Medical Director NHS England – South West who is responsible for coordinating elective care recovery in the South West region, and supported by conversations with colleagues from NHS Devon ICB, who were also aware of potential inequities in the application to children's pathways, of tools intended for the prioritisation of adults.

Clinical colleagues in Devon ICB had explored a couple risk stratification tools, and it was felt that there would be a benefit in seeking the perspective of a wider clinical audience. The South West Clinical Senate was asked to consider what risk stratification and prioritisation process could be introduced across the South West region, to support children and young people (CYP) waiting for care, to ensure equitable access to care is provided within four groupings - Surgery, Paediatric specialities, All-age specialities, and Diagnostic Imaging.

### 1.1 National context

In 2023, several of the national press have carried headlines<sup>123</sup> that paint a challenging picture of elective recovery of NHS services with an excessively high number of people on waiting lists, post-pandemic.

An article by *Healthcare and Protection* stated that at the end of March 2023, *"7,331,974 people were waiting to access care and treatment, and of this number, 359,798 patients had been waiting more than a year, 10,737 patients more than 18 months, and 559 patients were waiting more than two years"*<sup>4</sup> (published 11 May 2023).

The Royal College of Paediatrics and Child Health (RCPCH)<sup>5</sup> stated that 403,955 children were on a waiting list for consultant-led care, with 17,991 waiting for essential treatments, and that whilst progress has been made in reducing the adult backlog, the waiting list for children and young people continues to grow (published on their website dated 11 May 2023).

In a joint press release, the Royal College of Surgeons of England, Royal College of Paediatrics and Child Health, British Association of Paediatric Surgeons, and the Association of Paediatric Anaesthetists of Great Britain and Ireland, stated that *"Whilst*

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<sup>1</sup> <https://www.theguardian.com/society/2023/sep/17/sick-children-health-worsening-record-numbers-wait-for-nhs-care-in-england>

<sup>2</sup> <https://www.independent.co.uk/news/health/nhs-children-surgery-waiting-list-b2333261.html>

<sup>3</sup> : <https://www.independent.co.uk/news/health/nhs-children-waiting-list-england-b2432337.html>

<sup>4</sup> [NHS waiting lists hit 7.3m with record children's wait times a 'national scandal' - Health & Protection \(healthcareandprotection.com\)](https://www.healthcareandprotection.com)

<sup>5</sup> [Record high: Over 400,000 children waiting for treatment amidst child health crisis | RCPCH](https://www.rcpch.ac.uk/news-and-views/record-high-over-400-000-children-waiting-for-treatment-amidst-child-health-crisis)

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*much of the initial focus around elective recovery has been on reducing the adult surgical waiting list, we are concerned that children's waiting lists are now **increasing at double the rate of adult lists** while surgical activity lags behind adult activity. For children, there can be potential life-long consequences of lengthy delays for surgery. We would urge all Trusts, supported by their regional Operational Delivery Networks, to review the current situation so that children's surgery is fully considered within the whole scope of elective recovery."*<sup>6</sup> (published 24 July 2023)

To support systems, address the recovery of elective paediatric services, NHS England's Getting It Right First Time (GIRFT) team produced a list of actions entitled '*Closing the gap: Actions to reduce waiting times for children and young people*'<sup>7</sup>. This document complements NHS England's *Children and Young People Elective Recovery Toolkit*<sup>8</sup>.

### 1.2 Regional perspective

National headlines point to a growing rise in health inequalities faced by children and young people in the aftermath of the COVID-19 pandemic. The South West as a region has not been exempt from this, and the section below shows a snapshot of a few services and the impact that these factors have had in the South West region, in terms of reducing elective care capacity for paediatric services which has resulted in children waiting longer for care:

#### I. The impact of the COVID-19 pandemic

Whilst children were generally less impacted by COVID as a disease than adults, the measures taken to limit the spread of the virus had a far more profound and sustained impact on children. It is important to note that the indirect impacts of the COVID-19 pandemic were felt most in children who already had pre-existing inequalities due to their wider determinants of health or the groups to which they belong.

The contributors are reduced access to time critical interventions for debilitating conditions, changes to the delivery of education and reduced opportunities for socialisation due to lockdown restrictions. This has further compounded a pre pandemic increase in demand for children's mental health services, an increased prevalence of overweight or obese primary-age children, and a rising number of children living in poverty.

#### Children's surgical services

The National Anaesthetic Audit NAP 7 (Nov 2023),<sup>9</sup> shows that in the period (2021/22), the most impacted service was children's surgery in terms of reduction, as compared with the previous year's activity. This was also less than a third of activity when compared with

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<sup>6</sup> [Ref. Courtman, S. 2023. *A surgical perspective*, SW Clinical Senate Council meeting, 23 November 2023, Online]

<sup>7</sup> [Closing-the-gap-Actions-to-reduce-waiting-times-for-children-and-young-people-FINAL-V2-September-2023.pdf \(gettingitrightfirsttime.co.uk\)](#)

<sup>8</sup> [NHS England » Children and young people's elective recovery toolkit](#)

<sup>9</sup> [NAP7 Report | The Royal College of Anaesthetists \(rcoa.ac.uk\)](#).

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adults’ surgical services. In the South West region, children’s surgical services were reduced to 28% of the previous year. This is a significant reduction in capacity which adds to the delays in children waiting to access care.



Figure 1: UK and regional variations in the average percentage of paediatric surgery activity at R1 (blue) (October 2020), R2 (purple) (December 2020) and R3 (green) (January 2021) compared with the corresponding previous year’s activity’ taken from National Anaesthetic Audit Report (NAP7) November 2023.pp 55. (Ref. Courtman, S. 2023 *A surgical perspective*. SW Clinical Senate Council meeting, 23 November 2023, Online)

## Children's Access to Dental Services

In the South West region, there is continuing pressure for access to dental services. As the chart below indicates, services have not caught up, since the pandemic.

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov
Plymouth	Green	Green	Red	Red	Red	Green	Green	Green	Green	Green	Green
Exeter	Green	Green	Red	Red	Red	Red	Red	Green	Green	Green	Green
Torbay	Green	Green	Red	Red	Red	Red	Red	Green	Green	Green	Green
North Devon	Green	Green	Red	Red	Red	Red	Red	Green	Green	Green	Green
Truro	Green	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red
Bath	Green	Red	Red	Red	Red	Red	Red	Red	Red	Red	Red
Gloucester	Green	Green	Red	Red	Red	Red	Red	Green	Green	Green	Green
Swindon	Green	Green	Red	Red	Red	Red	Red	Red	Green	Green	Green
Bristol	Green	Green	Red	Red	Red	Red	Green	Green	Green	Green	Green
Taunton	Green	Green	Red	Red	Red	Red	Red	Red	Green	Green	Green
Yeovil	Green	Green	Red	Red	Red	Red	Red	Red	Red	Red	Red

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Figure 2. South West Surgery in Children Operational Delivery Network – Dental extractions in Children, 2021. This graph indicates delivery of dental extractions in children under anaesthesia, red indicating when the service had ceased, and green when it had restarted. It highlights how slow areas have been to restart these services leading to significant buildup of the dental waiting list. (Ref. Courtman, S. 2023 *A surgical perspective*. SW Clinical Senate Council meeting, 23 November 2023, Online)

### II. The impact of the post pandemic elective recovery

The NHS England Elective Recovery Plan<sup>10</sup> sets out the ambition to eliminate waits of more than 65 weeks by March 2024, and waits of longer than a year by March 2025, and so doing, reduce the number of patients waiting in all clinical areas. This 'targets-based approach' has determined which patients are prioritised, and this has favoured the high-volume adult waiting lists over the smaller paediatric waiting lists.

In addition, most hospitals have diverted most of their resources to address adult elective surgical activity, with paediatric surgical activity lagging behind due to lack of prioritisation. Apart from the impact on the backlog number of children waiting for care and treatment, this has led to a reduction in confidence and competence in the clinical workforce in dealing with paediatric cases, which has resulted in a reduction in willingness to operate on children – particularly the younger age ranges. The consequence has been an increase in referrals to specialist centres of non-specialist surgical cases.

### III. The impact of waiting for care

Outside of specialist children's hospitals, children waiting for surgical and medical services are often on all-age lists (mixed with adults). Although there are a smaller number of children waiting for care, established prioritisation tools are not sensitive enough to pick up the future harm resulting from delays in interventions that address barriers to development (e.g., hearing or mobility).

#### A look at Paediatric Audiology Services

There are more than 45,000 deaf children in England – half of which were born deaf whilst the other half develop deafness in childhood. For these children, it is important that they are identified as soon as possible, and during a 'window of opportunity' when exposure to sound and language enables the brain to build the neural connections that allow the development of early language and cognitive pathways in a baby's first year. If these pathways are not used in this crucial period, they will not develop, and the child is likely to face ongoing challenges. With high-quality early years support, the impacts from the deafness can be overcome and the child can go on to live a fulfilling life.

However, paediatric audiology services, in the South West region and nationally, are facing difficult challenges in the post-pandemic recovery with services under significant pressure with increasing demand, long waiting lists, staffing issues, barriers to gaining Improving Quality in Physiological Services (IQIP) accreditation and other resource or funding issues.<sup>11</sup> This has meant, there is an increasing number of delayed or missed

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<sup>10</sup> [C1466-delivery-plan-for-tackling-the-covid-19-backlog-of-elective-care.pdf \(england.nhs.uk\)](#)

<sup>11</sup> [Internal report \(ndcs.org.uk\)](#)

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diagnoses – both of which have significant consequences for a child’s development and could have a lifelong impact on the child’s ability to fulfil their potential.

### 1.3 A growing rise in health inequality

Health inequalities are “unfair, avoidable differences in health across the population and between different groups within society which include life expectancy, the health conditions that they may experience and the care that is available to them.”<sup>12</sup> There are different kinds of health inequality:

- Health status, for example, life expectancy
- Access to care, for example, availability of given services
- Quality and experience of care, for example, levels of patient satisfaction
- Behavioural risks to health, for example, smoking rates
- wider determinants of health, for example, quality of housing
- This means that when we talk about ‘health inequality’, it is useful to be clear on which measure is unequally distributed, and between which people.

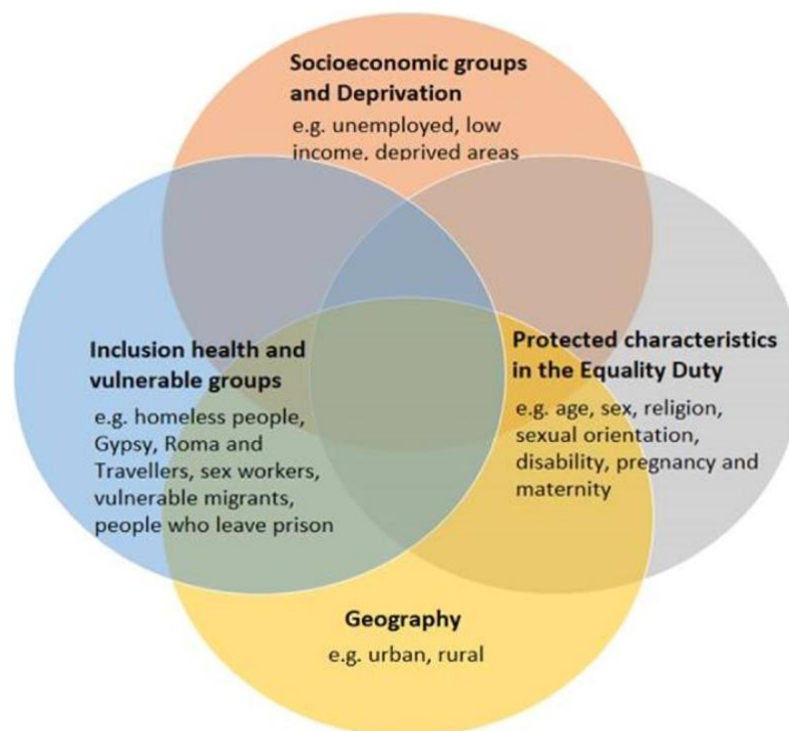


Figure: 3 The Overlapping dimensions of health inequalities (Ref. (Ref. Hooper, C. 2023 *Why are Health Inequalities important when we consider prioritisation of children on waiting lists?* SW Clinical Senate Council meeting, 23 November 2023, Online)

The NHS England’s Children and Young People’s Elective Recovery Toolkit recognises that long waits before accessing planned care can have lifelong consequences on the

<sup>12</sup> [NHS England » What are healthcare inequalities?](#)

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development of children and young people. The Toolkit also encourages that Systems need to embed measure to improve health and reduce CYP health inequalities. It is recognised that for children and young people from population groups with pre-existing health inequalities, the negative impacts of the waiting for care may be more greatly felt.

The example shown in Figure 4 (see below) shows the impact of inequalities and the stark difference in outcomes for two children of the same age, waiting for the same treatment, and added to the waiting list at the same time.

### Consider 2 children of same age added to same waiting list at same time

Child A	Child B
<ul style="list-style-type: none"><li>▪ IMD 6</li><li>▪ Dual parent family</li><li>▪ School attendance over past 6 months 85%, 98% prior to current illness</li><li>▪ Own room</li><li>▪ Both parents in good health</li><li>▪ During pandemic good access to online learning and parents have paid for some catch up tutoring</li></ul>	<ul style="list-style-type: none"><li>▪ IMD 2</li><li>▪ Single parent family</li><li>▪ School attendance over past 6 months 85%, 90% prior to current illness</li><li>▪ Has free school meals</li><li>▪ Shares room with 2 younger siblings.</li><li>▪ Carer for mother who has mental health issues and can miss school due to caring responsibilities</li><li>▪ During pandemic, struggled to access online learning due to limitations of internet, lack of quiet study space and need to help with younger children</li></ul>

One  Devon

Figure: 4 This case study shows the potential negative impacts of health inequalities on outcomes for children on waiting lists (Ref. (Ref. Hooper, C. 2023 *Why are Health Inequalities important when we consider prioritisation of children on waiting lists?* SW Clinical Senate Council meeting, 23 November 2023, Online)

Education is a significant contributory factor to children and young people fulfilling their potential and for social mobility. However, there are population groups where children and young people are at greater risk of poorer educational outcomes – young carers, young Gypsy, Roma and Traveller (GRT) people [with only 34% of GRT children meeting expected standards in Maths in Year 2 compared to 76% of children in general population (GOV UK, April 2020)], Care leavers, and children with special educational needs and disabilities.

Long waits for these children will only further exacerbate and increase their health inequalities as they are unlikely to have access to resources or support, to enable them overcome impacts caused by the delay in treatment – particularly in terms of their education.



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## 1.4 Current approaches to risk stratification

The consequence and potential lifelong harm of delayed access to care for children and young people have created an urgency for the stratification and prioritisation of children and young people on waiting lists, to be addressed. Current risk stratification tools capture risks to mortality and morbidity but do not take into consideration other risks such as social, educational, health inequalities, as well as the impact of delay on a child's development and future health. In addition, these tools do not take into consideration that the negative impacts will be greater for children with pre-existing inequalities which may impact on their life chances and social mobility in later life.

Two tools currently available are:

- **The Children's Hospitals Alliance (CHA) Risk Tool**<sup>13</sup>, developed by The Children's Hospitals Alliance. This tool captures a holistic measure of risk to children on surgical waiting lists. It does not capture health inequalities and is not suitable for children on medical and community waiting lists.
- **The Health Equity and Referral-To-Treatment (HEARTT)**<sup>14</sup> tool, developed by the University Hospitals Coventry and Warwickshire NHS Trust, uses clinical, social, and demographic information alongside waiting times to prioritise patients based on needs. However, there is a cost associated with procuring this tool which is a disincentive to some local providers.

It is important to note that both the NHS England's *Children and Young People Elective Recovery Toolkit* and the GIRFT '*Closing the gap: Actions to reduce waiting times for children and young people*' advocate the use of more holistic tools to ensure children are more appropriately prioritised for surgery. However, no tools with this capability have been introduced within the South West region, at the time of writing this report.

Similarly, there are no such tools available to risk stratify or appropriately prioritise those children who are waiting on paediatrics and community waiting lists for treatment.

This report will focus primarily on identifying risk stratification and prioritisation approaches to supporting children and young people waiting for care in the various pathways (surgical, medical, and community) to ensure equitability of care given in the South West region, setting out recommendations for systems and commissioners.

## 2.0 The Question

The South West Clinical Senate were posed the following question:

- How do we ensure that children and young people waiting for paediatric specialties and/or within all-age pathways (medical and surgical) and community pathways

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<sup>13</sup> [The Children's Hospitals Alliance Risk Tool \(CHART\) - Children's Hospital Alliance \(childrenshospitalalliance.co.uk\)](https://www.childrenshospitalalliance.co.uk/)

<sup>14</sup> [What matters when waiting? – involving the public in NHS waiting list prioritisation | The Strategy Unit \(strategyunitwm.nhs.uk\)](https://www.strategyunitwm.nhs.uk/what-matters-when-waiting/)

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are appropriately prioritised and receive safe, high quality, and timely care, whilst taking into consideration the impact on their development, future health, education, , and health inequalities?

During the meeting, the Senate Council considered the following questions:

- How do we stratify risk in a way that identifies children who need to be seen as a priority?
- Is there a tool that can be used/ developed to support the risk stratification of children and young people (CYP) so that they are appropriately prioritised?
- How do we ensure that health inequalities are not increased whilst CYP wait for care?
- How do we manage the transition to adult services for CYP waiting for care?

### 3.0 Observations

#### 3.1 Risk Stratification

- The current situation of the long lists of children waiting for care across multiple pathways is unsatisfactory and requires urgent action to be taken.
- Failure to address the impact of long wait times for time critical interventions in children will increase the burden on health and social care in the future.
- Current risk stratification tools do not take a longitudinal view of a child's health outcomes but focus primarily on the numbers and the status and progress of the waiting lists.
- The current risk stratification tool used for all surgery, the p coding system, does not capture or consider the underlying issues as to the need for surgery in children, nor the longitudinal consequences of missing key windows for correction, both physically and mentally, which may result in lifelong impacts.
- There are risk stratification tools that can be used to prioritise waiting lists, for example: Children's Hospitals Alliances Risk Tool (CHART)<sup>15</sup>, and the Health Equity and Referral to Treatment Tool (HEARTT)<sup>16</sup>. Systems should agree the consistent application of a tool which considers the impact of delay on development and the widening of inequalities.
- A Paediatric Surgical Prioritisation Tool, developed by Dr. Sarah Wimlett, Dr. Hannah Wright, and Dr. Simon Courtman, combines elements from the Children's Hospitals Alliance Risk Tool (CHART)<sup>17</sup> tool as well as assessing Health Inequalities (by looking at the deprivation index, additional needs, and neurodiversity). This tool is in its development and has not yet been validated however, it is reported to be simple and well-received during a recent pilot study involving a cohort of 75 patients.

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<sup>15</sup> [The Children's Hospitals Alliance Risk Tool \(CHART\) - Children's Hospital Alliance \(childrenshospitalalliance.co.uk\)](https://childrenshospitalalliance.co.uk)

<sup>16</sup> [What matters when waiting? – involving the public in NHS waiting list prioritisation | The Strategy Unit \(strategyunitwm.nhs.uk\)](https://strategyunitwm.nhs.uk)

<sup>17</sup> [The Children's Hospitals Alliance Risk Tool \(CHART\) - Children's Hospital Alliance \(childrenshospitalalliance.co.uk\)](https://childrenshospitalalliance.co.uk)

### 3.2 Impact of deprivation

- There is evidence that the implementation of post-covid recovery programmes is further widening existing inequalities for children. Any prioritisation tool should be cognisant of this. The design of recovery pathways should seek to mitigate challenges of access from rural communities or those with limited digital access.

### 3.3 Waiting Well

- Where waiting is inevitable there should be equitable access to support to mitigate the harm from delays to treatment. This may require support to be targeted to those families with less resources (both financial and capacity and capability).

### 3.4 Follow-up Lists

- Most recovery programmes target those individuals who are waiting to be assessed or listed for an intervention, which means those waiting a 'follow-up' are delayed. Many children are on "follow-up lists" as they have known conditions that need monitoring and interventions in future. These lists are typically less visible, but any risk stratification tool chosen would need to be regularly applied to children on these lists too.

### 3.5 Resource Allocation

- The National Policy approach to elective recovery is focused on the adult population where the numbers are greater. This results in resource allocation decisions which not only fail to prioritise children but may reduce existing resources for children's services. Paediatric surgery is often competing for resources, where they are shared with adult services such as, theatre capacity and workforce. During the pandemic, some hospitals decided to repurpose the clinical spaces that would have been used by paediatric outpatient services, to allow for the provision of additional adult beds. In many cases, these physical spaces have not been returned to the paediatric services for normal clinical practice resulting in a loss of clinical capacity.
- Over the last year national policy has placed an increasing focus on elective recovery in CYP services which affords the opportunity to provide equity and explicit understanding of the differences and impact on CYP waiting for clinical interventions.

### 3.6 Lack of skilled and specialist workforce

- The Senate Council observed that the centralisation of paediatric surgical services does have the capacity to deskill the local services. This has been exacerbated by the reduced paediatric surgical activity both during the pandemic and in the recovery.
- The development of the specialist workforce to respond to the needs of children has resulted in a reduction in paediatric training for more generalist roles. This is a significant contributory factor to the level of capacity and confidence within local services to tackle the children's cases in the elective care backlog .

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### 3.7 Access to Data

Children may be on waiting lists within hospitals in paediatrics, or on all-age waiting lists amongst adults waiting to see specialists for medical or surgical conditions. They may also be on community provider waiting lists for other professionals such as speech and language therapists, occupational therapists or CAMHS as examples. Data on hospital waiting lists is more easily accessible than those on community provider waiting lists, but it is still challenging to identify children on all-age waiting lists or where their episode of care has not been read-coded correctly. Community waiting lists are somewhat more challenging and children may need to see several professionals as part of their pathway of care before a diagnosis can be made or treatment started. Systems do not have well enough developed information systems to give visibility of the entire experience for the child and their families.

### 3.8 Governance and Accountability

Whilst there are children and young people programmes (with a limited scope) at a regional, and an ICS level, the lines of accountability are disparate, and level of priority given to these programmes is not well defined and varies across. ICSs.

## 4.0 Recommendations

The South West Clinical Senate makes the following recommendations which are loosely grouped into two themes:

- navigating the challenges around prioritisation in the existing system
- a fundamental shift in the system to afford greater priority to healthcare services to children and young people.

### Theme: Navigating the challenges around prioritisation in the existing system

#### A. Risk Stratification

1. The Senate Council **recommends** that the South West region commits to the introduction of a risk stratification tool that is capable of taking into account the impact of waiting (in terms of consequences, likelihoods, and outcomes). This tool needs to be simple, replicable, and universally applied across surgical, medical, and community pathways. The Paediatric Surgical Development Tool developed in Devon could be a good starting point.
2. Resources should be allocated to support further development and evaluation of a tool. The tool must be validated to ensure sensitivity and specificity. The Health Innovation Networks could help assist with the validation process.
3. Children and their families should be involved in the development of the risk stratification tool.

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4. The risk stratification tool should take a holistic needs-based approach for children and their families. It should be a multi-dimensional assessment tool and assess against an agreed set of parameters namely:

- **Clinical**

- **age:** i.e., the 'under-fives' age group because of the impact on a child's development, as the first years of a child's life have a significant role in determining their chances in later life and is a crucial period when the gap in outcomes between children from different socio-economic backgrounds first takes hold. In addition, in relation to 'periods before milestone exams' such as GCSE, A levels, etc.
  - **stage of development:** there is recognition that some types of treatment will have more impact on a child's development e.g., mobility issues in a very young child who requires orthopaedic surgery will have a greater impact on their development than an older child of 9 or 10 years.
- **Broader determinants including Social, Wellbeing, Educational, Employment, Economic, Psychological factors (SWEEEP).** These will capture the child and their family's circumstances and any factors that increase the risk of experiencing health inequalities. It is important to understand the negative impacts of waiting for care, and any indirect consequences in terms of their education, will be felt greatest by those children who have pre-existing inequalities. For example, if a child on a waiting list, is young carer – not only is there a risk of a negative impact on their education, but they may also be unable to continue providing carer support in the family, due to their medical condition/illness. This could have a significant impact on the family.

This may lead to prioritisation decisions that differentially favour children at certain ages or certain socio-economic groups.

### B. Waiting List Management

5. The Senate Council **recommends** that there is a mechanism to highlight children on all-age waiting lists.
6. The Senate Council **recommends** that there are regular reviews of all children on waiting lists, considering any changes in circumstances. A 'curator' role should be introduced, who would keep in regular contact with the child on the waiting list and their family, and other professionals involved in their care (health visitors, school nurses etc.) so that they receive updates on any changes in circumstances which could result in a change in priority.

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### C. Waiting Well

7. The Senate Council is not aware of the provision of waiting well services for children and young people in the South West region. The Council **recommends** that work is undertaken to determine what a Waiting Well service for CYP in the South West, should look like.

### D. The Role of the Integrated Care Boards [ICBs]

8. The Senate Council **recommends** that targets relating to the elective recovery for children and young people should be set nationally for each ICB relating to reducing the harm to children and young people whilst waiting for an intervention. This will help to reduce local variance and ensure equity.
9. The Senate Council **recommends** that there should be greater access and timely provision of data to the ICBs to create visibility of CYP on waiting lists for all children services.

### E. Managing Transitions

10. If a young person has been waiting for a year on a paediatrics waiting list, the length of time they have waited needs to be considered to ensure they are not disadvantaged or discriminated against when moved onto an adult waiting lists, having turned 18. The Senate Council **recommends** that there should be mechanisms in place to ensure that children are not disadvantaged when transitioning to adult waiting lists.

## Theme: Making a fundamental shift in system to afford greater priority to children

### A. Target setting

1. The NHS England's *Delivery Plan for tackling the COVID backlog of elective care* has at its heart the ambition is to reduce elective care waiting lists to 65 weeks by March 2024, and 52 weeks by March 2025. Funding is assigned within the Plan against the delivery of Referral-To-Treatment (RTT) targets which prioritises individuals that have been waiting the longest. Typically, the adults who make up the larger proportion of those on waiting lists fall within this patient cohort and are prioritised to receive care. So, systems focus on meeting the RTT targets, but could still have many children and young people on their waiting lists, as children may not have 'waited long enough' to fall within the patient cohort, prioritised to receive care. However, this masks the reason why the child is on the waiting list, in the first place. If it is to address a developmental problem, it is crucial that the care intervention is carried out within a time 'window'. If the care or treatment is delayed beyond this 'window', it could result in harm and lifelong health issues for the child.

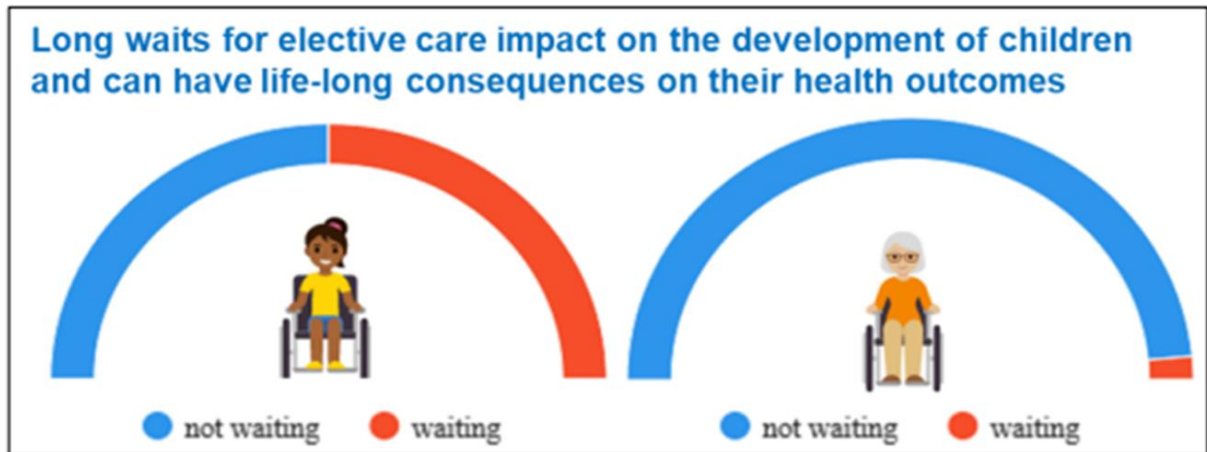


Figure 5: Ref. NHS England, 2022

2. The Senate Council **recommends** that timely data is made available, so that the impact of waiting for care, by children and young people, can be clearly understood and that specific NHS England 'CYP- related' targets be set to capture activity for children and young people or the allocation of resources to child health activities.
3. The Senate Council **recommends** that resourcing decisions at ICB, Regional, and National levels are reviewed to understand the resources that are allocated to benefit children.
4. Whilst the clinical rationale for the centralization of children's services is understood, more consideration should be given to the development of network models that help to maintain capability, capacity and confidence at a local level.
5. The South West region is a Marmot region which creates an opportunity to create linkages with the work of the regional Marmot project team. The Marmot team is looking at health inequalities in children and young people, with a special focus on the return on investment, on investing in children and young people. The Marmot Team should give prominence to the prioritisation of tackling the paediatric waiting lists as part of this work.

These recommendations will be shared with the NHS England Children and Young People Transformation/ Elective Recovery Team, CYP Elective Recovery Steering Group, South West Surgery in Children Operational Delivery Network, the South West Region's ICBs (Devon, Dorset, Somerset, Gloucestershire, Plymouth, Bristol, North Somerset and South Gloucestershire [BNSSG], Cornwall and the Isles of Scilly), NHS England – South West Medical Directors, NHS England South West Region Healthcare Scientist, and Devon Elective Care Board Senior Leaders (provider organisations). It will also be published on the website of the South West Clinical Senate.

## Appendices

### Appendix 1: Links to speaker presentations

Speaker presentations are available to download on the South West Clinical Senate website. Please follow link to the website: [Home - South West Senate \(swsenate.nhs.uk\)](http://swsenate.nhs.uk)

Title	Speaker	Link
Scene setting		
A surgical perspective	<b>Dr. Simon Courtman</b> , Care Group Director Women's and Children's Services at University Hospitals Plymouth, Clinical Director SW Surgery in Children Operational Delivery Network	
A medical and community perspective	<b>Dr. Rowan Kerr-Liddell</b> , Consultant Paediatrician with Expertise in Cardiology, Torquay, Torbay General District Hospital	
Health inequalities	<b>Dr Claire Hooper</b> , Deputy Strategic Clinical Advisor Planned Care, NHS Devon	
A Case Example: The Impact & Harm for CYP of waiting and delays in Paediatric Audiology	<b>Sarah Cooper</b> , Regional Lead Healthcare Scientist - South West, NHS England, Chief Clinical Cardiac Scientist Training and Development Lead, Royal Cornwall Hospital NHS Trust  <b>Stuart Harris</b> , Paediatric Audiologist, University Hospitals Plymouth	
Reflections from the Citizens Assembly: A patient and public perspective	<b>Debbie Rigby</b> , Chair of Citizens Assembly	



## Appendix 2: Further reading and useful resources

www.england.nhs.uk. (May 2021). *NHS England» Good communication with patients waiting for care.* [online] Available at: <https://www.england.nhs.uk/publication/good-communication-with-patients-waiting-for-care/>. [Accessed 29 November 2023]

www.england.nhs.uk. (February 2022). *NHS England» NHS launches online platform to empower patients as they wait for care.* [online] Available at: <https://www.england.nhs.uk/2022/02/nhs-launches-online-platform-to-empower-patients-as-they-wait-for-care/>. [Accessed 29 November 2023]

www.england.nhs.uk. (May 2023). *NHS England» Children and young people’s elective recovery toolkit.* [online] Available at: <https://www.england.nhs.uk/long-read/children-and-young-peoples-elective-recovery-toolkit/>. [Accessed 29 November 2023]

www.cqc.org.uk. (n.d.). *State of Care 2022/23 - Care Quality Commission.* [online] Available at: <https://www.cqc.org.uk/publications/major-report/state-care/2022-2023>. [Accessed 29 November 2023]

Transition & Patient Empowerment Innovation, Education and Research (TIER)Network. (n.d.). *TIER Homepage.* [online] Available at: <https://www.readysteadygo.net/>. [Accessed 29 November 2023]

Campbell, D., and editor, D.C.H. policy (2023). Sick children’s health worsening as record numbers wait for NHS care in England. *The Guardian.* [online] 17 Sep. Available at: <https://www.theguardian.com/society/2023/sep/17/sick-children-health-worsening-record-numbers-wait-for-nhs-care-in-england> [Accessed 29 November 2023].

Simons, G. (2023). *NHS waiting lists hit 7.3m with record children’s wait times a ‘national scandal.’* [online] Health & Protection. Available at: <https://healthcareandprotection.com/nhs-waiting-lists-hit-7-3m-with-record-childrens-wait-times-a-national-scandal/> [Accessed 30 Nov. 2023]

The Independent. (2023). *NHS failing to tackle children’s surgery waiting lists as backlog hits record levels.* [online] Available at: <https://www.independent.co.uk/news/health/nhs-children-surgery-waiting-list-b2333261.html> [Accessed 30 Nov. 2023].

The Independent. (2023). *Children waiting years for community care as NHS chiefs slam government inaction.* [online] Available at: <https://www.independent.co.uk/news/health/nhs-children-waiting-list-england-b2432337.html> [Accessed 30 Nov. 2023].

Closing the gap: Actions to reduce waiting times for children and young people. (2023). [online] *Getting it Right First time*, NHS England, p.1-6. Available at: <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2023/09/Closing-the-gap-Actions-to-reduce-waiting-times-for-children-and-young-people-FINAL-V2-September-2023.pdf> [Accessed 30 Nov. 2023].

From the pond into the sea: Children’s transition to adult health services. (2014). [online] *Care Quality Commission*, England: Care Quality Commission, p.1 -72. Available at: [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf) [Accessed 30 Nov. 2023].

Listening to Young People about health and social care in York! (2020). [online] Healthwatch York, pp.1–34. Available at: <https://www.healthwatchyork.co.uk/wp-content/uploads/2020/03/Healthwatch-York-CAYP-report-A4-Final-Version33101.pdf> [Accessed 30 Nov. 2023].

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NICE guidance on Health Inequalities includes mapping to frameworks such as Marmot and Labonte, and Core20PLUS5 children and young people priority areas for improvement (which includes the oral health clinical area). <https://www.nice.org.uk/about/what-we-do/nice-and-health-inequalities>

NICE guidance [Transition from children's to adults' services for young people using health or social care services \[NG43\]](#). This covers the period before, during and after a young person moves from children's to adults services.

NICE guidance: [Transition from children's to adults' services \[QS140\]](#) covers the period before, during and after a young person (aged up to 25) using children's health and social care services who are due to make the transition to adults' services.

CQC is incorporating Transition from Childrens to Adult Services within Single Assessment Framework underpinned by NICE guideline and quality standard on transition. [Safe systems, pathways and transitions - Care Quality Commission \(cqc.org.uk\)](#)

### Appendix 3: Senate Council membership

The table below shows the Senate Council membership (at the time of writing this report) with those that attended the meeting highlighted in blue.

Membership type	Name	Job Title	Organisation	Attendance at meeting
Standing Member	Dr Sally Pearson	Chair of South West Clinical Senate	South West Clinical Senate	Yes
Standing Member	Prof David Halpin	Consultant Physician and Honorary Professor & Vice Chair of Clinical Senate	Royal Devon and Exeter Hospital, South West Clinical Senate	Yes
Standing Member	Debbie Rigby	Chair of Citizens' Assembly	Citizens Assembly (Patient & Public Partner)	Yes
Standing Member	Debi Reilly	Regional Director South West	NHS England South West	No
Standing Member	Mark Juniper	Medical Director for the WEAHSN	West of England Academic Health Science Network	No
Standing Member	Dan Lys	Deputy CEO of the SW AHSN.	SWAHSN	No
Standing Member	Rebecca Whitting	Interim Portfolio Director - Implementation	SWAHSN	No
Standing Member	Prof Maggie Rae	President of the RSM Epidemiology and Public Health Section, Deputy Director – Regional Public Health Programmes, NHS England – South West	NHS England SW	Yes
Core member	Dr Steve Jones	Consultant Paediatrician and Neonatologist	Royal United Hospitals Bath NHS FT	No
Core member	Prof Parag Singhal	Consultant General Medicine, Diabetes and Endocrinology	UHBW Foundation Trust	No
Core member	Dr Christine Spray	Consultant in Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN)	United Hospital Bristol Healthcare Trust	Yes
Core member	Dr Giorgio Gentile	Consultant Nephrologist	Royal Cornwall Hospitals NHS Trust	Yes
Core member	Dr Nick Kennedy	Consultant Anaesthetist and Intensivist	Taunton and Somerset NHS Trust	Yes
Core member	Prof Minesh Khashu	Clinical Lead for Poole Hospital	University Hospital Dorset	No
Core member	Dr Anne Frampton	Consultant in Paediatric Emergency Medicine	UHBW Foundation Trust	No
Core member	Dr Katie Cross	Consultant General Surgeon	Northern Devon Healthcare Trust	No
Core member	Dr Ann Lyons	Consultant Colorectal Surgeon	North Bristol NHS Trust	No
Core member	Dr Neil Hopper	Consultant Vascular Surgeon	Royal Cornwall Hospitals Trust	No
Core member	Rebecca Reynolds	Director of Public Health	BATHNES Council	Yes

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Core member	Dom Williamson	Consultant Emergency Medicine	North Bristol NHS Trust	Yes
Core member	Dr Paul Winterbottom	Consultant Psychiatrist	2gether NHS Foundation Trust	Yes
Core member	Dr Anita Pearson	Specialist in gender health care	Devon Partnership Trust	No
Core member	Dr Tom Hilliard	Consultant Respiratory Paediatrician	University Hospitals Bristol & Weston NHS Foundation Trust	Yes
Core member	Peter Davis	Consultant Paediatric Intensivist	University Hospitals Bristol NHS Foundation Trust	Yes
Core member	Miles Wagstaff	Consultant Paediatrician, Neonatologist	Gloucestershire Hospitals NHS Foundation Trust	No
Core member	Will Mongare	Clinical Nursing and Quality Manager / CAMHS Case Manager	NHSE/I	No
Core member	Carol Stonham	Respiratory Nurse Specialist Primary Care	Gloucestershire ICB	No
Core member	Dr Clare Barlow	Consultant Medical Oncologist	Musgrove Park Hospital	Yes
Core member	Dr Marion Andrews-Evans	Executive Nurse	Gloucestershire ICB	Yes
Core member	Joanne Meacham	Head of Nursing Adult Community Services		Yes
Core member	Dr Peter Wright	Director of Healthcare Science and Technology	University Hospitals Plymouth NHS Trust	No
Core member	Dr Sara Evans	Consultant Geriatrician, Lead for Medical Education research and development, and medical workforce	Royal United Hospital Bath	No
Core member	Dr Rachel Bradley	Consultant Geriatrician	Bristol Royal Infirmary University Hospitals Bristol & Weston Trust [Care of Older People]	Yes
Core member	Mark Stone	Pharmacist Consultant/Devon LPC Project Lead, Vice Chair of the East Cornwall Primary Care Network	Devon Local Pharmaceutical Committee and Tamar Valley Health Practices	No
Core member	Bruce Daniel	Head of Pathology, South West region	NHS England – South West	Yes
Core member	Alex Sharp	Head of Clinical Development	SWASFT	No
Core member	Alyson O'Donnell	Medical Director	Royal Bournemouth and Christchurch Hospital NHS Trust	No
Core member	Dr Mary Backhouse	GP	North Somerset CCG	No
Core member	Dr Amelia Randle	Clinical Lead SWAG Cancer Alliance and GP	Somerset CCG	No
Core member	Richard Walters	Physiotherapy	University Hospitals Plymouth NHS Trust	No
Core member	Ros Wade	Head of Therapy Services	Royal Devon & Exeter NHS Foundation Trust	Yes

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Core member	Dr Emma Jones	Consultant Healthcare Scientist in GI Physiology	University Hospital Southampton	Yes
Co-opted member	Dr Geeta Iyer	Chief Medical Officer	BNSSG ICB	Yes
Co-opted member	Dr Amanda Webb	Chief Medical Officer	BANES ICB	No
Co-opted member	Dr Andrew Seymour	Chief Medical Officer	Gloucestershire ICB	No
Co-opted member	Dr Nigel Acheson	Chief Medical Officer	Devon ICB	No
Co-opted member	Dr Bernie Marden	Chief Medical Officer	Somerset ICB	Yes
Co-opted member	Dr Helen Skinner	Chief Medical Officer	Cornwall ICB	No
Co-opted member	Dr Paul Johnson	Chief Medical Officer	Dorset ICB	No
Non-Voting member	Jane Jacobi	Implementation Facilitator, NICE Field Team	National Institute for Health and Care Excellence	Yes
Non-Voting member (professional in training)	Dr Matthew Boissard-Cooke	Neurosurgery Specialist Registrar	University of Hospitals Plymouth NHS Trust	Yes
Non-Voting member (professional in training)	Dr Hannah Lyons	Medical Oncology Registrar	Bristol Haematology Oncology Centre	No

**Appendix 4: Other attendees at the meeting**

**Citizens' Assembly representatives**

Citizens Assembly representatives	Nick Pennell	Member	Citizens Assembly	Yes
Citizens Assembly representative	Joanna Parker	Member	Citizens Assembly	Yes

**Senate Assembly representative**

Senate Assembly representative (as observer)	Dr Tom Fontaine	Consultant Paediatrician	Royal Cornwall Hospitals	Yes
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