

WAITING LISTS WAITING LISTS WAITING LISTS

MORE THAN A NUMBER:

A Rights Based Review of Child Health Waiting Lists in Northern Ireland

Acknowledgments

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Foreword

Foreword

“When we adults think of children, there is a simple truth which we ignore: childhood is not preparation for life; childhood is life. A child isn’t getting ready to live; a child is living. ...we have forgotten, if indeed we ever knew, that a child is an active participating and contributing member of society from the time she is born. Childhood isn’t a time when he is molded into a human who will then live life; he is a human who is living life.”

Professor T. Ripaldi

It is well established that Northern Ireland has the longest waiting times for healthcare of any jurisdiction on these islands. The Minister of Health has apologised to us all for how long we have to wait for some aspects of healthcare and it is clearly something that his department has been working on. There has been a lot written about it and a multitude of recommendations as to the way forward. Yet here we are.

Every age group in our population is affected by this issue and this report is not suggesting that children should be prioritised over others. However, we are saying that equity of health and wellbeing should be at the heart of government policy and planning, the myriad of reports, action plans and media stories rarely discuss the long waiting times that thousands of children experience every year, or for the number of children who are waiting years to receive healthcare that will improve their lives. This report is intended to remedy that omission. By examining the data, entitlements and the experiences of children and their families, this report outlines the irrefutable fact that waiting for healthcare adversely impacts a child’s educational, emotional and physical well-being.

The report outlines the experience of the impact on children’s education of not receiving a diagnosis. NICCY has undertaken extensive work on special educational needs, and it is important we are reminded that children should not have to wait for a medical diagnosis to have their educational needs assessed and for supports to be put in place. Once a diagnosis is completed, the educational needs assessment can be reviewed, and amended as necessary.

Children are human beings not human becomings, they are not adults in waiting they have rights as children. We must challenge the notion that children have time to wait for their healthcare because of their age. A year in a child’s life can be unfathomably long particularly if they are in pain or discomfort. Not only does it adversely impact their health

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and education but also their relationship with their peers and as a social being. Every day, week, month and year is a new experience for a child and one that marks a milestone in their life. Those milestones are often reached together with friends and family, and being prevented from doing so due to ill-health that could be addressed, is a clear violation of their rights, which may have long term consequences- making them wait is inexcusable.

Too often in healthcare we overlook children when discussing population wide issues. We must ‘think child’ in all relevant healthcare services and the recommendations are intended to provide the framework to do that. This is not about “reinventing the wheel” but actually getting the wheel to turn more smoothly by implementing accepted children’s rights and best practice standards.

I want to thank the NICCY team for progressing this work during the pandemic and adapting the plan accordingly.

It is a privilege that children and their families allowed us some insight into their experiences and we are very grateful to them. Time to get them off that conveyor belt.

Koulla Yiasouma

Northern Ireland Commissioner for Children and Young People

Executive Summary and Recommendations

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This report is a culmination of a rights-based review of health waiting lists for under 18's carried out by the Northern Ireland Commissioner for Children and Young People, in accordance with its statutory functions as set out under Article 7(2) and 7(3) of The Commissioner for Children and Young People (Northern Ireland) Order 2003.

Northern Ireland has some of the longest health waiting times of all regions in the UK, with approximately 1 in 4 people on a waiting list to see a consultant for the first time or for surgery (based on a population of 1.9 million). There are 1000s of children waiting to access health services in Northern Ireland and these delays and lack of visibility of children in health data are in direct contravention of children and young people's rights.

Over the last decade a number of broad ranging reviews have concluded that significant reform of the system is required to improve the capacity and performance of services. Waiting times is one of the clearest indicators of a system under immense strain and unable to meet the needs of its population. The current Northern Ireland Executive has made a number of commitments to addressing the waiting list problem in Northern Ireland.

Much greater transparency and focus is required on the extent of waiting lists across child health services, and clarity on the steps being taken to address this growing problem. There is a need to engage with professionals and practitioners that work in the services affected and enable children and young people (and their parents / carers) to talk about the impact that waiting is having on their health and quality of life. It is also important that they get the opportunity to share their views on what needs to change about the system, to ensure adequate supports are put in place.

Hospital waiting time statistics published by the Department of Health are useful with respect to understanding the extent of paediatric waiting times for first consultant led out-patient and inpatient and day-case appointment, however they are not disaggregated by subspecialty, and the categorisation of waiting times is limited to set time bands in line with ministerial targets. Hospital waiting times do not include community child health services, a different part of the healthcare system which we know from 'issue specific' reports and reviews has significant and growing waiting times for children. Furthermore, whilst waiting times are an important indicator of ease of access to services, statistics cannot tell us what impact waiting times are having on the health outcomes and the quality of life of children

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and young people while they wait for healthcare.

The aims of the Review were to

- (1.) examine the length of time children and young people (0-18 yr old) are waiting to access appointments, to include first consultant outpatient; diagnosis; and treatment;
- (2.) review waiting time reporting systems to ensure adequate visibility of child health services;
- (3.) better understand the patient care pathway, and impact that delayed care has on health outcomes & wellbeing of children; and
- (4.) explore factors contributing to paediatric waiting times in Northern Ireland.

Outpatient and Inpatient / Day Case Waiting List Statistics

For this review exercise, a reasonable level of disaggregated data was available on request for outpatient and inpatient / day case hospital services. This included a breakdown of waiting lists by subspeciality (including whether this was an adult or paediatric speciality), longest waiting times, and the priority level of appointments. Outpatient waiting time statistics were available for professionals other than consultant and for first and review appointments.

Summary of Key Statistics

First consultant led outpatient waiting times have increased year on year between 2017 and 2021, with 35,292 children waiting for a first appointment at April 2021 (Figure 1). When one considers 'review' as well as 'first appointment' with a consultant, waits increase quite considerably. At August 2021, 89,018 children were waiting for an appointment with a consultant- of which almost two thirds (63%; n=56,921) were waiting for a review appointment.

Inpatient and day case waiting times have increased year on year between 2017 and 2021, with 9,481 children waiting for a first appointment at April 2021. The largest annual increase in children waiting was between 2020 and 2021 when the total number waiting rose from 8,447 to 9,481 (an increase of 1,034).

For both first consultant led outpatient and inpatient / day case appointments an increasing and substantial number of those waiting fall within the greater than 52 wk waiting category- with a considerable spike evident during the covid period (April 2020-2021).

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Community Child Health Services Waiting List Statistics

For this review exercise, the data available for community child health services were extremely limited. Inconsistencies in the presentation of data provided by HSCTs added to the difficulty of presenting a regional overview and this is reflected in the limited amount of information available for this report.

Summary of Key Statistics

Overall, 26,818 under 18s are waiting for access to one of the community child health services listed.

There are considerable differences in the number of children waiting for specific types of community child health services- community paediatric medical service (n=7066) and autism diagnosis (n=5,155) account for 46% of the overall number waiting for the services listed.

Overall, the number waiting to access community child health services (excluding autism and CAMHS) is much higher in the BHSCT (n=7,096) compared to any other HSCT, representing 36% of the overall waits across these services. The fact that BHSCT provides regional wide services may be a factor.

Between 2016-2021 the number of children waiting for an assessment for autism increased by 250% (2,079 to 5,155), with a 750% increase in the number waiting more than 52 weeks for an assessment (279 to 2,195).

In 2019, 311 children (up to 18 years) were diagnosed with scoliosis in Northern Ireland.

At June 2020, 31 children were waiting for fusion surgery with an average wait of 36 wks for an urgent referral and 43 wks for a routine referral.

Overall, with respect to waiting time data, this review has concluded that there are improvements that can be made to hospital outpatient and inpatient / day case statistical reporting and there is a good foundation to work with. However, there is no regional

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monitoring or reporting system for waiting times across the community child health system. It is also the case that the remit of the new waiting list management unit, in place since August 2021, does not extend beyond elective care services and therefore, at least initially, will not cover community child health services.

Impact of Waiting for Healthcare

Recording and reporting on waiting time targets is essential for monitoring the accessibility of health and social care services. However, it is only by speaking directly to children and their families that the full impact on their health and wellbeing can be understood. For the purposes of this review, families affected by delays in access to care or treatment for suspected or diagnosed autism and scoliosis outlined the impact that delays in accessing hospital and community-based healthcare has on them. There was a considerable amount of commonality in the feedback on the impact of being on a health waiting list and the types of improvements they would like to see in the system. This included the impact on their child's physical, social and emotional development. Poor health and lack of intervention also had a considerable impact on the child's education, the well-being of their parents / carers and their wider family circle which includes siblings.

Achieving a Child Rights Based Health and Social Care System

Clearly worsening waiting times is a symptom of a system under strain and therefore the reform and redesign of services will be the change that makes the most significant difference to waiting times. However, a robust monitoring system that supports this process and allows everyone to better understand how change is impacting on the patient journey is important.

Steps should be taken to improve the visibility of, and accountability for, children's health within key departments and agencies and with respect to health data and budgeting. This would also clearly demonstrate the Northern Ireland Executive's commitment to children, on realising their rights and delivering on their Programme for Government draft outcome 1: commitment of 'Our children and young people have the best start in life'.

The families to whom we spoke for this review had experience of both hospital based and community child health services. Their experiences in both highlighted the far-reaching impact of delays to healthcare, extending far beyond the primary medical condition itself. It

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is vital that any performance management process takes account of whether the system is meeting the holistic needs of child patients. The broader health and social care reform process must fully consider both hospital and community-based health services and how they intersect with primary care, social services and education. These are vital components of an integrated and rights-based health and social care system.

Improvement in data management is critical to improving the quantity and quality of services and patient level data. We welcome the commitments given by the current Health Minister to improving performance management and reviewing how waiting times are measured, including the establishment of a waiting list management unit within the HSCB. It is important that the scope of the work of this unit is broad enough to include community child health services.

Performance management processes should ensure that the information captured is at a level of detail that is useful for policy, clinical and administrative purposes and therefore it is vital that a range of data users are involved in deciding what information should be collected by the system. There is also a need for a common set of standards against which the child health system can benchmark themselves and that outcomes and impact become a central focus. Also, the collection, analysis and dissemination of service level statistics must be conducted in a way that brings visibility to how effectively services are being delivered to children.

We must strive to get to a point where all children and young people can get access to the right care, at the right time and in the right place and that no child is left waiting months or years in a queue to access services. Children have a right to receive high quality care without any unnecessary delay. NICCY commits to monitoring the implementation of the recommendations in this review and will publish a progress update report in Autumn 2022.

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Recommendations

Rights Based Approach to delivery of Health and Social Care System

1. Embed a rights-based approach to the delivery of child health and social care services in Northern Ireland. This should include the application of a child rights assessment framework in the development or review of plans and proposals to ensure that children's rights are fully considered in all decision-making processes.

Enabling Processes and Structures

2. A full review of the child health system should be undertaken to ensure that health and social care reform is based on an up-to-date understanding of need across the system. This process should take account of existing implementation plans relevant to the reform and redesign of children's health services and care pathways, and address gaps in knowledge about individual child health services.
3. Improve the visibility of and accountability for children's health within key departments or agencies by:
 - a. Considering the appointment of a Deputy Chief Medical Officer for Child Health;
 - b. Considering the appointment of a policy lead for child health at the Department of Health;
 - c. Establishing a single point of entry system across all HSCTs for all child health services; and
 - d. Strengthening co-ordination between the Departments of Health, Education and Communities for children with complex and long-term health conditions.
4. Establish a transparent budgeting process that shows clear budgeting lines for public spending on children's health services which meets the five child rights principles for public budgeting i.e. effectiveness, efficiency, equity, transparency and sustainability.
5. Explore the potential for further strengthening collaboration with neighbouring jurisdictions in the delivery of health services for children that could help reduce waiting times, improve quality of care and patient outcomes.

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6. Establish an interim regional waiting list management process to better monitor and review children on hospital and community health service waiting lists - to include enhanced clinical triage, targets for review appointments and support for parents / carers.

Performance Management

7. Develop a data management process that applies the principles of visibility, vulnerability and voice as recommended by the Office for Statistics Regulation (OSR).
8. Collect and monitor a greater depth of information regarding patient experiences and outcomes, including outcomes identified by children, young people and their families. Mechanisms to ensure that service user feedback is reflected in service improvements should be strengthened.
9. Establish an agreed set of minimum service standards which can be used as a benchmark by the health and social care system. Improvement plans should be put in place for those services requiring support to meet these standards.
10. All parts of the system should use the same source data for analysing and interpreting service performance and waiting time information. The system codes used across primary, secondary and tertiary services should be harmonised to include specific codes for individual child health services and be integrated with electronic patient health records to ensure no duplication of waiters / referrals are included in waiting time statistics.

Waiting Time Measures

11. Comprehensive waiting time data on hospital and community child health services should be developed as part of a broader performance management system. A range of data users should be involved in determining the information collected by the system; the data collected should include the following:
 - a. Breakdown by specific child health services;

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- b. Number waiting, length of time waiting;
- c. Maximum full patient journey times from referral to treatment;
- d. Number of referrals and % accepted and not accepted;
- e. Referral types i.e. routine/ urgent / red flag referrals;
- f. Waiting times between referral and first appointment;
- g. Waiting times between first and follow-up appointment with professionals;
- h. Waiting time between referral and diagnosis and diagnosis and treatment;
- i. Measuring and reporting on waiting times for health professionals other than first appointment with consultant, to include Allied Health Professionals, Technicians or Nurses;
- j. Waiting times for transition / transfer from paediatric to adult services;
- k. Breakdowns (disaggregated data) by demographic characteristics and geographic area i.e deprivation and HSCT; and
- l. Monitoring and reporting on HSC patients treated by the independent sector and out of jurisdiction i.e. number, conditions, cost.

Quarterly Waiting Time Reporting Process

12. Hospital Waiting Time reporting should always be disaggregated by specific child health services alongside type of treatment i.e. outpatient, inpatient, day case, diagnostics, treatment / surgical waiting times.

13. Community Child Health Waiting Times reporting should be established in line with scheduled publishing for hospital waiting times.

Waiting Time Targets

14. Consideration should be given to whether child specific waiting time targets should be developed for elective hospital services.

15. Establish regional waiting time targets for community child health services.

16. Set waiting time targets for review appointments for both hospital (elective) and community child health services.

17. Consider ways to strengthen accountability for breaches of waiting time targets, such as a regional performance dashboards.

Introduction

1.0 Introduction

The Commissioner for Children and Young People (NICCY) was established in accordance with 'The Commissioner for Children and Young People (Northern Ireland) Order' (2003) to safeguard and promote the rights and best interests of children and young people in Northern Ireland. In carrying out these functions, paramount consideration must be given to the rights of the child or young person, having particular regard to their wishes and feelings and to all relevant provisions of the United Nations Convention on the Rights of the Child (UNCRC). The remit of the Office includes children and young people up to 18 years, or 21 years if the young person has a disability or has been/is in the care of social services.

NICCY is aware that significant numbers of children and young people are waiting to access health services in Northern Ireland. The statistics published by the Department of Health (DoH) on paediatric hospital services (first consultant led out-patient and inpatient and day-case appointment) have shown a persistent upward trend in numbers waiting, including the proportion of those waiting over a year to be seen (see Appendix 2 for further detail). The hospital waiting time statistics are useful with respect to understanding the extent of paediatric waiting times for first consultant led out-patient and inpatient and day-case appointment,¹ however it does not disaggregate by paediatric subspecialties, and the categorisation of waiting times is limited to set time bands in line with ministerial targets i.e. 9wks, 13 wks and >52 weeks therefore does not report on the average or maximum waiting times. The diagnostic waiting time figures do not subcategorise by paediatric and adult patients, making it impossible to determine diagnostic waiting times for children.

The current waiting time statistics do not take account of the full patient journey, for example, before being referred to paediatric specialists, children/young people are likely to have had appointments with other health professionals, at primary and secondary care level and with this comes the likelihood of further waiting times. There are also likely waiting times for diagnosis and/or for treatment which further extends the length of time children are within the healthcare system. The DoH plans to change how elective (planned) care service waiting times are measured to ensure that waiting times are a true reflection of the actual time patients spend with the healthcare system for treatment /

¹ <https://www.health-ni.gov.uk/topics/dhssps-statistics-and-research/hospital-waiting-times-statistics>

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care.²

Hospital waiting times do not include community child health services - a different part of the healthcare system - which we know from 'issue specific' reports and reviews, have significant and growing waiting times for children. This includes unacceptable waiting times for autism assessment, CAMHS and ADHD, however there are many other community child health services where children are waiting for appointments which are not as visible.

Whilst waiting times are an important indicator of ease of access to services, statistics cannot tell us what impact waiting times are having on the health outcomes and the quality of life of children and young people while they wait for healthcare. The Patient and Client Council carried out important research on the impact of waiting for healthcare in 2018; it highlighted the consequences of waiting for medical treatment which included, a deterioration in patients' physical and mental health, living with increasing amounts of pain and becoming increasingly socially isolated. Unfortunately, this report engaged with a very small number of 16- and 17-year-olds, and no-one under 16.³

The scoping exercise for this review identified a need for much greater transparency and focus on the extent of waiting lists across child health services, and clarity on the steps being taken to address this growing problem. It also recognised a need to gather the perspective of professionals working in child health services and to enable children and young people (and their parents / carers) to talk about the impact that waiting has on their health and quality of life.

The review was conducted in accordance with NICCY's statutory remit as set out under the Commissioner for Children and Young People (NI) Order 2003, this includes a duty to 'keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities.' (Articles 7 (2) and (3)). For the purposes of the legislation, children and young people are defined as anyone aged up to 18yrs old or up to 21yrs old where they have a disability or are care experienced (Article 3). The decision was taken that this review would consider services for those up to the age of 18 as this is the legal definition for children and young people in NI⁴ and is the

² [2020-01-08 a new decade a new approach.pdf \(publishing.service.gov.uk\)](#); [Microsoft Word - HE1 21 377360 Elective Care Framework - Final Version Updated 29 June 2021 to reflect change to Nursing Action \(health-ni.gov.uk\)](#)

³ <https://patientclientcouncil.hscni.net/the-reality-of-life-on-a-waiting-list/>

⁴ <https://www.legislation.gov.uk/nisi/1995/755/article/2>

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framework for the planning and delivery of paediatric health services.⁵ However, in practice there remains considerable variability in the age limits for paediatric services, although some of this is 'necessitated by the clinical condition', shortages in workforce and physical clinical space are significant factors. For example, children requiring scoliosis surgery are seen by adult services from the age of 14 due to a lack of theatre space at RBHSC.⁶

In carrying out this review, the following duties as set out in the legislation will also be engaged:

Article 7 (5) (b) & (d) to encourage children and young people to communicate with the Commissioner, and for the views of children and young people, and their parents, to be sought whilst carrying out her functions.

Article 7 (4) (b) to advise relevant authorities and or Executive Committee of the Assembly on issues concerning rights and best interests.

The aims of this Review were to:

1. examine the length of time children and young people (0-18 yr old) are waiting to access appointments, to include first consultant outpatient; diagnosis; and treatment;
2. review waiting time reporting systems to ensure adequate visibility of child health services;
3. better understand the patient care pathway, and impact that delayed care has on health outcomes & wellbeing of children; and
4. explore factors contributing to paediatric waiting times in Northern Ireland.

⁵ <https://www.health-ni.gov.uk/sites/default/files/publications/health/paediatric-strategy-hospital-andcommunity.pdf>

⁶ <https://www.health-ni.gov.uk/sites/default/files/publications/health/paediatric-strategy-hospital-andcommunity.pdf>

Background

1.1. Background

Waiting Times and Health & Social Care Reform

Northern Ireland has some of the longest health waiting times of all regions in the UK, with approximately 1 in 4 people on a waiting list to see a consultant for the first time or for surgery (based on a population of 1.9 million).⁷ Addressing the lack of capacity to deliver the required levels of healthcare has been the most pressing challenge facing the Health and Social Care (HSC) System in Northern Ireland, it also recognised that this challenge has been significantly worsened by the pandemic and that it will take many years to fully address.⁸

Under the 'New Decade New Approach' (NDNA) agreement published in January 2020, the restored NI Executive made a clear commitment to addressing the waiting list problem in Northern Ireland. This included the development of a 'new action plan on waiting times' to include consideration of 'the scope for changing how waiting times are measured, to reflect the entire patient journey, from referral to treatment, with appropriate targets.' It also reasserted the Executive's commitment to 'transforming the health system by providing long term funding' and implementing the 'reform agenda outlined in Bengoa, Delivering Together and Power to People Report'.⁹

Setting waiting time standards and measuring services against these is an important process for monitoring and improving health service performance and providing accountability to patients and the public.¹⁰ A recent study which reviewed health service waiting time monitoring systems across Europe found considerable variation in how countries measure waiting times. Canada and England were identified as examples of best practice because they had national guidelines around the measurement and reporting of waiting lists and waiting times.¹¹ Another European study found that 'children are unacceptably invisible in health data and policy in Europe' and that there is 'inadequate

⁷ [Surgeons outline 10-step plan to tackle backlog as half of patients wait over a year for planned surgery — Royal College of Surgeons \(rcseng.ac.uk\)](https://www.rcseng.ac.uk/news/2020/01/08/a-new-decade-a-new-approach)

⁸ https://www.health-ni.gov.uk/sites/default/files/publications/health/day_case-elective-care-procedures.PDF p6

⁹ [2020-01-08 a new decade a new approach.pdf \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/84842/a-new-decade-a-new-approach.pdf) p6

¹⁰ [NHS waiting times: our position | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/publications/nhs-waiting-times-our-position)

¹¹ [Common patterns in the public reporting of waiting time and waiting list information: Findings from a sample of OECD jurisdictions - ScienceDirect](https://www.sciencedirect.com/science/article/pii/S0926641019300000)

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public health, primary care and inter-sectoral collaboration on child health and development concerns.¹²

It is impossible to consider how waiting time measurement and reporting could be improved without considering the broader system to which the waiting times relate. Several broad reviews have been carried out on the health and social care system over the last decade, the overarching conclusion from each is that significant reform of the system is required to improve the capacity and performance of services, wherein waiting times is one of the clearest indicators of a system under immense strain and unable to meet the needs of its population.¹³

While recognising the importance of addressing waiting times, Nuffield have cautioned against making this the primary focus, rather than the strategic changes required to make the health system work more effectively.

“There is a risk that growing waiting times, which are a symptom of bigger systemic issues becomes the focus rather than seeing the bigger picture and working on the bigger strategic issues that are required for long term improvements in service delivery and patient outcomes.”¹⁴

As a relatively small region, it has been argued that Northern Ireland is spreading its health resources too thinly across multiple sites, and that moving towards a regional approach to health service delivery is the only solution. Whilst movement towards this type of restructure has been painfully slow, the phased introduction of regional day procedure centres is an example of remodelling the existing system to better meet the needs of the population. The plans for regional elective day care centres include five paediatric surgical specialties i.e. ENT, Paediatric / General surgery, Orthopaedics, Oral Surgery and Ophthalmology which account for approximately 87% of all paediatric day case practice.¹⁵ There have been delays in operationalising some of this work due to COVID-19 pressures, alongside longstanding issues with the recruitment of paediatric staff and a need for

¹² [MOCHA-final-report-summary.pdf](#)

¹³ Transforming Your Care, the Donaldson Report, 'Delivering Together', informed by the expert panel lead by Professor Bengoa which focused on “systems, not structures”

¹⁴ [nuffield-trust-change-or-collapse-web-final.pdf](#)

¹⁵ https://www.health-ni.gov.uk/sites/default/files/publications/health/day_case-elective-care-procedures.PDF, section 5.5; p14

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improvements or upgrades in physical theatre spaces.¹⁶

Workforce pressures in the Northern Ireland health sector have been a longstanding problem contributing to the chronic inefficiencies in the system and costs that are higher than would be the case if staffing levels matched demand. There are three times more paediatric posts vacant for over 3 months in Northern Ireland compared to England, with workforce provision in rural areas a particular problem.¹⁷ It has also been reported that even with intense efforts to recruit into paediatrics, lead in graduate training time and the relatively small number of medical trainees that elect to specialise in paediatrics, makes it unlikely that workforce needs will be met solely through recruitment drives.¹⁸ Paediatric and child health experts have argued for improvements in planning around the child health workforce which focus on recruitment, training and retention of paediatricians. This includes an expansion of the non-medical workforce and paediatric training in the primary care workforce.

In 2016, the Department of Health (DoH) published a 'Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community in Northern Ireland 2016-2026' to provide a framework to support the development of future service models.¹⁹ Since the Strategy was launched, there has been no official progress update report published on the Department of Health website, however, information sought by NICCY for the purposes of this Review found that some limited transformation funding to progress parts of the Strategy was not made available until 2019, three years after the Strategy was first published.²⁰ Whilst initiatives that have been able to progress are welcome, the lack of planned and sustainable funding to deliver regional transformation against the strategy's objectives significantly hampers progress.

The current Health Minister has acknowledged that building capacity within the system and addressing the waiting list backlog will require 'sustained investment' and progress in reform of the health and social care system. The pandemic has exacerbated a situation that was already reaching a critical point, exposing problems linked to a fragmented health and social care system which causes inefficiencies that result in preventable delays in diagnosis and

¹⁶ <https://www.rqia.org.uk/ROIA/files/41/416f3113-627c-47f9-9007-6d8f38ff8662.pdf>

¹⁷ [Workforce census: Focus on Northern Ireland \(2019\) | RCPCH](#)

¹⁸ [ibid](#)

¹⁹ [A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community \(2016 - 2026\) | Department of Health \(health-ni.gov.uk\)](#)

²⁰ Progress update Report compiled for NICCY by HSCB on A Strategy for Paediatric Healthcare Services Provided in Hospital and Community Health- September 2021

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treatment, and widening inequalities in access to services across the region.²¹ NICCY published a comprehensive review of the impact of COVID-19 on children and young people's rights in September 2021, and within this report a specific recommendation was made to the Department of Health to ensure its 'response to the health waiting list crisis include specific planning and resourcing to address health waiting lists for under 18's'.²² This review and its recommendations intend to provide further advice on actions the Government should take to reduce waiting lists and address the impact of delays on health outcomes and quality of life.

A finite health and social care budget must meet the needs of the whole population and therefore an increasing demand for services in one area has a knock-on effect regarding available budget in another. Whilst waiting lists have increased between 2013/2014 and 2019/20, the amount of money spent on waiting lists above 'core healthcare funded services' has fallen by 62% over the period, from £97m in 2013-14 to £37m in 2019-20.²³

Whilst some 'one-off' monies have been secured to address waiting lists through COVID-19 rebuilding funding,²⁴ it has been estimated that £750 million to £1 billion per year is required over a 10-year period to address the backlog and build capacity in the system to maintain waiting lists at an acceptable level.²⁵ There is currently no indication that this type of multi-year budgeting and investment, required for long term planning, will be achievable and the NI draft budget for 2021-2022 has been described as effectively 'a standstill of the previous year's budget'.²⁶

During the pandemic the DoH has published a range of HSC rebuilding plans, including a 5-year plan for reforming elective care and addressing elective care waiting lists.²⁷ This plan contains a number of commitments which relate to improving the way waiting times are measured and tracked. These are scheduled as 'long-term actions' aligned to the introduction of the electronic patient information system (Encompass), and the move to

²¹ Health Minister Response to AWQ- [AQW 16384/17-22](#)

²² NICCY (2021) Impact of Covid on Children and Yong People's Rights [NICCY Publications](#)

²³ [NI waiting lists: How could the health service get more funding? - BBC News](#)

²⁴ [AQO 2066/17-22](#) £40m of Covid rebuilding funding to fund Waiting List Initiatives and other Elective developments including orthopedics.

²⁵ NI Assembly Health Committee Session- 11 March 2021 [committee-25663.pdf \(niassembly.gov.uk\)](#)

²⁶ <https://www.nhsconfed.org/-/media/Confederation/Files/Public-Affairs/HSC-Chairs-Response-Draft-Budget-Feb-21.pdf>

²⁷ [Microsoft Word - HE1 21 345889 Elective Care Framework - Final Version Cleared by Minister 14 June 2021 \(health-ni.gov.uk\)](#)

Background

regional service delivery, with a projected completion date of 2023 onwards. The rationale is that the introduction of a new way of measuring waiting times i.e. Referral to Treatment (RTT) would be *‘challenging while the backlog of patients waiting for diagnosis and treatment remains so extensive’*.

The primary objective of an RTT target is to measure and ultimately help reduce patient waiting times over the whole journey of care and not just for discrete stages of treatment.

“The HSCB will work to introduce the Referral to Treatment (RTT) waiting times which better reflect the entire patient journey, from GP referral up to the point where the patient is actually treated.”²⁸

The plan also includes specific actions led by the HSCB to bring a-

“renewed focus to performance, quality and productivity, both in the HSC and in the independent sector. This will include an assessment of gaps in existing management information, consideration of new approaches to performance management, and the establishment of new, realistic performance targets until we are in a position to meet the current ministerial standards.”

This acknowledgment that elective care statistics do not represent the full patient journey and needs to be reformed is a positive development, however the timeframe of 2023 for achieving this goal is far off. The establishment of a new Waiting List Management Unit within the HSCB since August 2021 is welcomed, as its purpose will be on producing annual elective care delivery plans which focus on current performance, targets and demand/capacity.²⁹ However, the focus of the unit, at least initially, appears to be elective care services only.

²⁸ *Ibid*, p53.

²⁹ [Microsoft Word - HE1 21 377360 Elective Care Framework - Final Version Updated 29 June 2021 to reflect change to Nursing Action \(health-ni.gov.uk\)](#) p.53

Child Rights Context

1.2 Child Rights Context

“In a region the size of Northern Ireland, it is not acceptable that people should have such widely different experiences of accessing healthcare based purely on where they live.”³⁰

The UK State Party ratified the UNCRC in 1991, and it subsequently came into force in 1992. This applies to Northern Ireland as a devolved administration of the UK. As a binding International Treaty, it places obligations and responsibilities on State Parties and their Institutions to uphold and realise the rights of children and young people.

The following Articles of the UNCRC have particular relevance to this review:

Article 24 sets out the right of every child to the highest attainable standard of health, facilities for treatment and rehabilitation, and to ensure that no child is deprived of access to healthcare,

24 (1) “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services. “

A rights-based healthcare system must also take account of the health and wellbeing of the child’s main carer. Article 18 of the UNCRC states that;

“parents and / or legal guardians, have the primary responsibility for the upbringing and development of the child, and for the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.” (Article 18 (2))

This responsibility of States Parties is further established in Article 23 in relation to children

³⁰ https://www.health-ni.gov.uk/sites/default/files/publications/health/day_case-elective-care-procedures.PDF section 8.10, p.22

Child Rights Context

with disabilities and sets out the need for special care and assistance to these children as well as their main carers.³¹ These duties are articulated further in United National Convention on the Rights of People with Disabilities (UNCRPD).³²

Furthermore, the Committee on the Rights of the Child reminds all State Parties that when developing and implementing policy, practice and services that affect the lives of children and young people, a number of overarching general principles need to be applied.

These General Principles are:

- to protect the rights of all children not to be discriminated against (Article 2);
- to have their best interests upheld (Article 3);
- to be supported to develop to their maximum potential (Article 6); and
- to be enabled to meaningfully participate in all aspects of their lives (Article 12).

Article 4 of the UNCRC states that Governments have a responsibility to take all available measures to make sure children's rights are respected, protected and fulfilled.

“States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the maximum extent of their available resources and, where needed, within the framework of international co-operation.”

The Committee on the Rights of Child also produce advice papers to support State Parties in their understanding and implementation of rights. General Comment 5 outlines States Parties’ obligations to develop and implement “general measures of implementation”. This General Comment is very helpful in setting out the administrative and other measures required for effective implementation of the Convention, this includes making children visible in budgets through data collection, analysis, and indicators.

In terms of data collection and analysis, General Comment No 5 (V1.F) stresses that the *“collection of sufficient and reliable data on children, disaggregated to*

³¹ [UN Convention on the Rights of the Child \(UNCRC\) - UNICEF UK](#)

³² <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Child Rights Context

enable identification of discrimination and/or disparities in the realisation of rights, is an essential part of implementation.”

The Committee reminds States parties that,

*“data collection needs to extend over the whole period of childhood, up to the age of 18 years. It also needs to be coordinated throughout the jurisdiction, ensuring nationally applicable indicators. States should collaborate with appropriate research institutes and aim to build up a complete picture of progress towards implementation, with qualitative as well as quantitative studies. The reporting guidelines for periodic reports call for detailed disaggregated statistical and other information covering all areas of the Convention. It is essential not merely to establish effective systems for data collection, but to ensure that the data collected are evaluated and used to assess progress in implementation, to identify problems and to inform all policy development for children. Evaluation requires the development of indicators related to all rights guaranteed by the Convention.”*³³

The Committee also makes important points in relation to making children visible in budgets, General Comment No 5 (V1.G) asserts that,

“No State can tell whether it is fulfilling children’s economic, social and cultural rights “to the maximum extent of (..) available resources”, as it is required to do under article 4, unless it can identify the proportion of national and other budgets allocated to (..) to children, both directly and indirectly.”

The importance of transparency and accountability in budgeting is further outlined in General Comment 19 which sets out five principles of public budgeting for children’s rights. These are effectiveness, efficiency, equity, transparency and sustainability:³⁴

Effectiveness – governments should plan and implement budgets and services in such a way that they deliver measurably improved outcomes for children and young people.

Efficiency – public resources should be dedicated to programmes for children in a way

³³ [Treaty bodies Download \(ohchr.org\)](#)

³⁴ *Ibid*

Child Rights Context

that delivers value for money through sound financial management. This includes making efforts to overcome institutional barriers that impede efficient spending.

Equity – public resources should be spent fairly in order to promote equality. This does not necessarily mean spending an equal amount on each child but targeting resources to promote substantive equality among children.

Transparency – state financial systems and practices must be open to public scrutiny, contributing both to efficiency and enabling meaningful participation of civil society, including children, in the budget process.

Sustainability – governments should prioritise the best interests of current and future generations of children in all budget decisions, allocating resources to ensure the progressive realisation of children’s rights.

The General Comment also provides guidance and recommendations on the four stages of the public budgeting process: planning; enacting; executing; and following up, and emphasises the importance of effective cross-sectoral, inter-ministerial, inter-departmental and inter-agency coordination and cooperation throughout the budgeting process to fully realise children’s rights.

Committee on Rights of the Child Monitoring Process

Every 6-8 years the UK and devolved Governments’ progress in realising children’s rights as set down in the UN Convention on the Rights of the Child, is examined by the UN Committee on the Rights of the Child (‘the Committee’).

In its most recent ‘Concluding Observations’ in 2016, the Committee raised concerns ‘at the inequality in access to health services and health outcomes’, and made a series of recommendations which reflected on the need for investment, robust monitoring systems, a focus on health outcomes and access to health services:

59. With reference to its general comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health, the Committee recommends that the State party, the governments of the devolved administrations, overseas territories and Crown dependencies develop

Child Rights Context

comprehensive and multi-sectoral strategies on child health:

(a) With the allocation to the maximum extent of available resources and a robust monitoring mechanism;

(b) With a strong focus on eliminating inequalities in health outcomes and in access to health services;

(c) Addressing underlying social determinants of health.

The Committee is currently in the process of the periodic examination of the UK State Party. To inform this examination the four UK Children's Commissioners jointly published two reports which raise the most pressing issues facing children's rights with the Committee, one of which is the excessive waiting times to access healthcare. In these reports the Children's Commissioners advise the Committee to seek answers from the UK Government and devolved Administrations on what actions they are taking to reduce waiting lists and address the impact of delays on health outcomes and quality of life.³⁵

³⁵ UK Children's Commissioners UNCRC Mid Term Report (2019), <https://www.niccy.org/about-us/childrens-rights/un-reporting/> Report by UK Children's Commissioners: 6th and 7th Periodic Reports (2020) [uncrc loipr report uk-childrens-commissioners final.pdf \(niccy.org\)](https://www.niccy.org/uncrc-loipr-report-uk-childrens-commissioners-final.pdf)

Methodology

1.3 Methodology

The practical steps taken to meet the three strands of the review are outlined in detail below.

Strand 1: Request waiting time statistics from each Health and Social Care Trust.

The original plan was to request disaggregated data in line with existing waiting time reports published by the Department of Health for first consultant led outpatient, diagnostic and treatment. However, subsequent conversations involving HSCB and HSCT information management personnel concluded that it would be best for all data requests to be directed to the HSCB, who would liaise with the HSCTs for data not centrally held by them. Acute hospital information was sourced by the HSCB through the Regional Data Warehouse and on account of the timeframe for data collection the decision was made to focus on first consultant led outpatient and inpatient / day case data and exclude diagnostics. There is no regional data collection system for community child health services (apart from CAMHS and Autism), therefore a discrete piece of work was required to gain waiting time data broken down by HSCTs. The HSCB co-ordinated a process of developing a template and seeking data returns from HSCTs. The community health services selected for this report are those for which the Trusts monitor and collect data on through their LCID system using Primary Targeting Lists (PLTs). There is no particular criteria set for which services become a PLT, the PLTs has been established for many years and are used to determine which community health service waiting times are monitored. For example, ADHD Behavioural Assessment Service is not on a PTL, even though the HSCTs will provide this service. Furthermore, in some cases, community health service waiting times are monitored on different HSCT systems which are managed and reported on separately i.e. LCID and PARIS.

Throughout the report, waiting list statistics are interpreted as the 'number of children waiting', as is done in the DoH quarterly waiting time statistical bulletins. However, please note that a validation exercise to remove duplicate referrals was not carried out on the statistics included in the report, and it is possible that one child can be on a waiting list for a number of services at one time.

Strand 2: Gather the views and experiences of professionals and practitioners working in paediatric services on waiting lists. Topics included: factors causing or contributing to

Methodology

waiting times; the impact of waiting lists on service delivery (ability to meet service standards); and the impact on the quality of life and health outcomes for children and young people affected.

Desk based research was used to identify key reports and reviews on healthcare system which addressed underlying issues causing or contributing to the waiting list problem in Northern Ireland. Meetings were held with the Child Health Partnership and the Royal College of Paediatrics and Child Health (RCPCH) to inform the review and discuss emerging findings and recommendations.

Strand 3: Consult children and young people with experience of being on a waiting list for a health service, and their families. To include the patient journey through the system; and the impact of waiting times on the health and wellbeing outcomes of children.

During June-July 2021 NICCY staff held a series of online discussion groups with parents/carers of children impacted by delays in access to healthcare.

Autism NI facilitated NICCYs engagement with 22 parents/carers of children with suspected or diagnosed Autism through their parent support groups. Three online discussion groups were held in June 2021 with groups based in SHSCT, WHSCT and BHSCT. For ease of reference the term Autism will be used in this report as shorthand for autism spectrum disorder (ASD) more broadly.

Megan's Wish Charity and the Belfast Scoliosis Support Group facilitated NICCY staff engagement with parents/carers of children with scoliosis. An online discussion was held with seven parents, three of whom had travelled to Turkey with their child to get surgery due to being unable to access the surgery through the healthcare system in Northern Ireland. One online discussion group was held with 5 young people with scoliosis (aged 14-19 yrs old).

Ethics

The methodology for the Review went through an internal ethical approval process. This process involved considering how consent would be sought, identifying perceived risks associated with the research and steps to be taken to minimise these, addressing issues of confidentiality, anonymity, and data protection, and managing the potential disclosure of information.

Waiting Time Information and Reporting

2.0 Waiting Time Information and Reporting

Hospital Elective Care Waiting Time Statistics & Reporting

In Northern Ireland, quarterly waiting time statistics are published by the Department of Health (DoH) for separate stages of the planned / elective care patient pathway. These report on the length of time people are waiting for (1) first consultant led outpatient appointments, (2) diagnostic appointments, and (3) inpatient and day case appointments.

The published statistics on waiting times are based around waiting time targets for planned elective care and are set by the Minister of Health. However, the significance of waiting time targets is questionable in that outpatient and inpatient targets have rarely been met since 2009.³⁶ As waiting times and waiting lists have grown over the years, the targets have become less stringent.³⁷ Targets set between March 2019-2021 expected a certain % of patients to be seen within 9 weeks (first consultant outpatient or diagnostics) or 13 weeks (inpatient or day case). (Appendix 1: Waiting Time Targets).

The current waiting time target was set by the Minister of Health in June 2021 as part of the Elective Care Framework for Northern Ireland, and states that:

“By March 2026, no patient will be waiting more than 52 weeks for a first outpatient appointment or inpatient/day case treatment; or 26 weeks for a diagnostics appointment.”

Even by its own standards this is by far the least ambitious target to date and has been set in acknowledgement of the distance the system has to travel to be able to achieve what could be described as a ‘normal’ target.³⁸

The quarterly waiting time statistics published by the DoH on first consultant led outpatient appointments, breaks down waiting time figures by ‘paediatrics specialty’.³⁹ This is a broad category which indicates a hospital service for under 18s (Table 1 illustrates how

³⁶ [RAISE Report-waiting lists Jan 2020.pdf](#)

³⁷ *Ibid*

³⁸ [Microsoft Word - HE1 21 377360 Elective Care Framework - Final Version Updated 29 June 2021 to reflect change to Nursing Action \(health-ni.gov.uk\)](#)

³⁹ A specialty is a particular branch of medicine or surgery. Each consultant is assigned a main specialty from a list recognised by the Royal Colleges and Faculties. Information is recorded against the specialty of the treating consultant.

Waiting Time Information and Reporting

this is presented in the DoH statistical bulletins). However, across paediatrics there can be up to 50 different sub-specialties under which children are treated. Inpatient / day case waiting times are assigned to 'paediatrics' or 'paediatric surgery' which provides slightly more detail but is still very broad. The waiting times for diagnostic services do not include a paediatric category, making it impossible to determine waiting times for children.

Table 1. DoH Quarterly Outpatient Waiting Times Report

Table 3a: Number of patients waiting for a first consultant-led outpatient appointment by weeks waiting and specialty – 31st March 2021¹

Specialty	Patients waiting for a first consultant-led outpatient appointment, by weeks waiting							Total Waiting
	0 - 6	>6 - 9	>9 - 12	>12 - 15	>15 - 18	>18 - 52	>52	
ENT	3,390	1,050	895	608	874	6,536	30,386	43,739
General Surgery	6,575	1,578	1,222	866	1,416	9,106	20,866	41,629
Dermatology	3,284	660	582	382	604	5,222	16,154	26,888
Gynaecology	4,271	1,321	1,144	824	1,138	7,751	9,460	25,909
T & O Surgery	2,602	740	682	501	766	5,796	13,997	25,084
Neurology	1,316	393	350	290	413	2,895	15,383	21,040
Ophthalmology	2,333	711	596	424	614	3,267	12,510	20,455
Rheumatology	1,259	441	362	247	351	2,676	11,613	16,949
Gastroenterology	2,380	671	483	337	470	3,162	7,677	15,180
Paediatrics	2,799	894	673	435	597	3,377	6,206	14,981
Oral Surgery	711	261	202	151	213	1,383	9,639	12,560
General Medicine	1,428	400	301	233	342	2,107	6,613	11,424
Thoracic Medicine	1,096	367	322	253	317	2,250	6,413	11,018
Urology	1,612	336	252	143	217	1,618	6,024	10,202
Cardiology	2,156	564	463	282	344	2,704	3,396	9,909
Pain Management	625	224	194	140	224	1,387	5,608	8,402
Plastic Surgery	580	142	98	71	97	823	3,080	4,891
Geriatric Medicine	567	113	123	131	75	321	552	1,882
Endocrinology	488	150	140	100	99	541	197	1,715
Other	2,773	641	492	318	402	2,580	3,979	11,185
All Specialties	42,245	11,657	9,576	6,736	9,573	65,502	189,753	335,042

Source: DoH Outpatient Waiting Times Dataset

¹Refer to Explanatory Notes 1–10 & 13-14

Official reporting records maximum waits as 'greater than 52 weeks' (>52 weeks), which does not show the actual length of time children are waiting beyond 52 weeks. The statistics provided by the HSCB for this report has confirmed maximum waits of over 4 yrs (>208 wks).

Waiting Time Information and Reporting

The waiting time statistics published by the system only provides a snapshot of the much longer journey that many children and families have from first referral to treatment. Those working in the system refer to the 'hidden waiting list' of people who have not yet come forward or who have not made it on to a hospital referral list.⁴⁰

There are also the 'internal waiting times', which relate to those who have been successfully referred but are then waiting at different points within the system. The system does not track how long patients spend at or between each stage i.e. outpatients, assessment / diagnostics, review and treatment. Waiting times between first and review appointment can be significant, and this was reiterated when speaking to families as part of this review.

Waiting times alone are not sufficient to fully understand the performance of the system, other critical indicators include overall referrals (accepted and not accepted); resources available, the number of patients seen by independent sector; the quality of care and treatment outcomes.

There is no accountability mechanism or sanction in place in NI if Ministerial targets are breached which raises questions about the purpose of targets.⁴¹ In England, Health Trusts are subject to financial penalties when they fail to meet targets. As a result, it is normal practice for them to send patients to other hospitals when an appointment cannot be offered within a set time-period.

Community Child Health Waiting Time Statistics & Reporting

While hospital care statistical reporting in relation to waiting lists may be limited, there is a complete absence of regional monitoring or reporting of waiting times across the community child health system. While quarterly statistics are published for autism services with respect to the number and percentage of 'referrals accepted' and the 'number and percentage of children diagnosed by HSCT', official published statistics do not show 'numbers waiting' or 'waiting times for diagnosis or intervention'. Comprehensive minimum datasets for monitoring purposes have been developed for Autism and CAMHS, however full data from these datasets is not published. The HSCTs' administrative systems are not

⁴⁰ [RCS England Northern Ireland Action Plan \(1\).pdf](#) p.3

⁴¹ [RAISE Report-waiting lists Jan 2020.pdf](#)

Waiting Time Information and Reporting

able to collate all the information needed to provide regionally based, standardised reports on community child health services.

Some limited information on breaches of the 9-week waiting time target for CAMHS is published – included as part of the HSCB Board meeting papers (performance reports). NICCY has called for the publication of more comprehensive CAMHS data reports in line with other health statistical reporting as part of its 2018 review of mental health services and support for children and young people.⁴²

For the purposes of this Review, the HSCB facilitated a discrete piece of work with the HSCTs to provide NICCY with some basic data for community child health services. The information provided by the 4 HSCTs was limited and related to one point in time (April 2021) with no time series data to better understand the pattern in waiting times over time, like has been possible with hospital care statistics.

It was apparent from the outset of this review that a whole monitoring and reporting system needs to be established around community child health service statistics to provide transparency and completeness with respect to the full patient care pathway.

Outpatient and Inpatient and Day Case Waiting Times

This section of the report will set out the overall trend in relation to the number and length of time under 18s are waiting for out-patient and inpatient / day case services between April 2017 and April 2021. It will also present a more detailed range of data related to waiting times at a point in time i.e. April 2021. This will include waiting times by subspecialty, priority level, longest waiting times, waiting times for professionals other than consultant, numbers waiting for review as well as first outpatient appointment and numbers seen within paediatric or adult specialty.⁴³

⁴² ['Still Waiting' - A Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland \(niccy.org\)](#), Recommendation 47

⁴³ All figures in relation to Outpatients / Inpatients / Day cases recorded in Acute Care are as recorded on the hospitals Patient Administration System (PAS). Figures may vary for services across graphs / tables. This is due to variations in inclusion and exclusion criteria across source data.

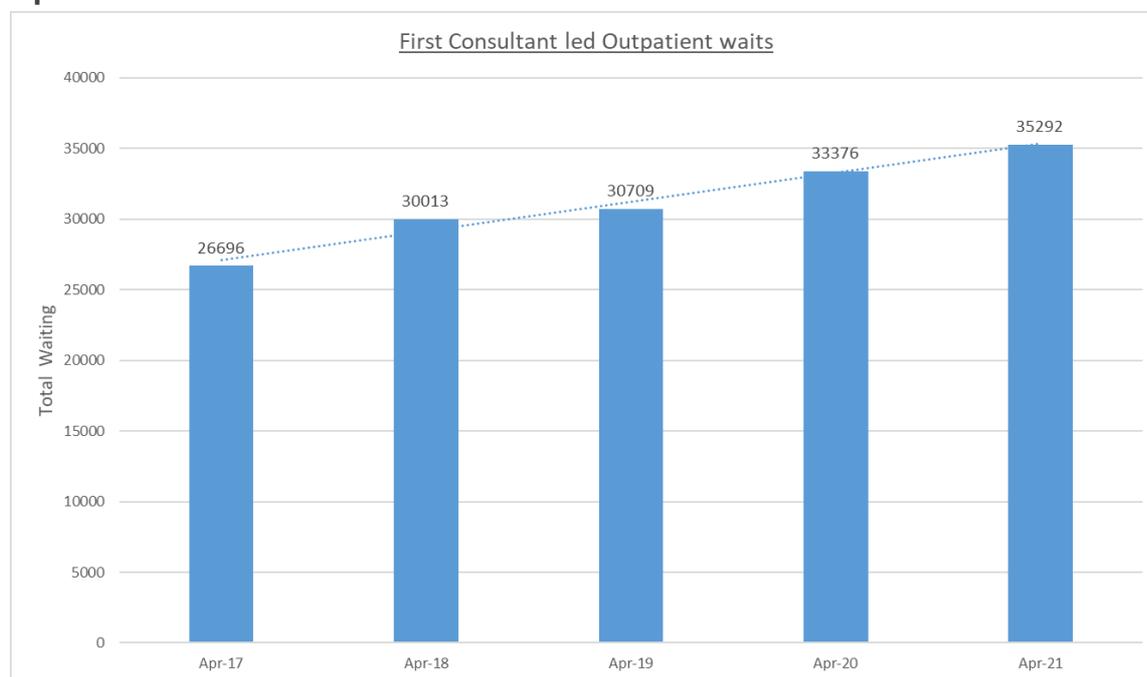
Waiting Time Information and Reporting

Please note: when describing the statistics we are referring to ‘number of children waiting’ as is done in DoH waiting time statistical bulletins, however, please note some duplication is possible if a child is on the system more than once through error or because they are on a waiting list across more than one service. See methodology for further explanation.

Overall Waiting Lists between 2017-2021

Figures 1 and 2 below illustrate total waiting times for first consultant led outpatient appointments and Inpatient and day case appointments across the region for the period April 2017 – April 2021. Figure 1 shows that first consultant led outpatient waiting times have increased year on year between 2017 and 2021, with 35,292 children waiting for a first appointment at April 2021.

Figure 1: Waiting lists for first consultant led outpatient appts: period April 2017- April 2021



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

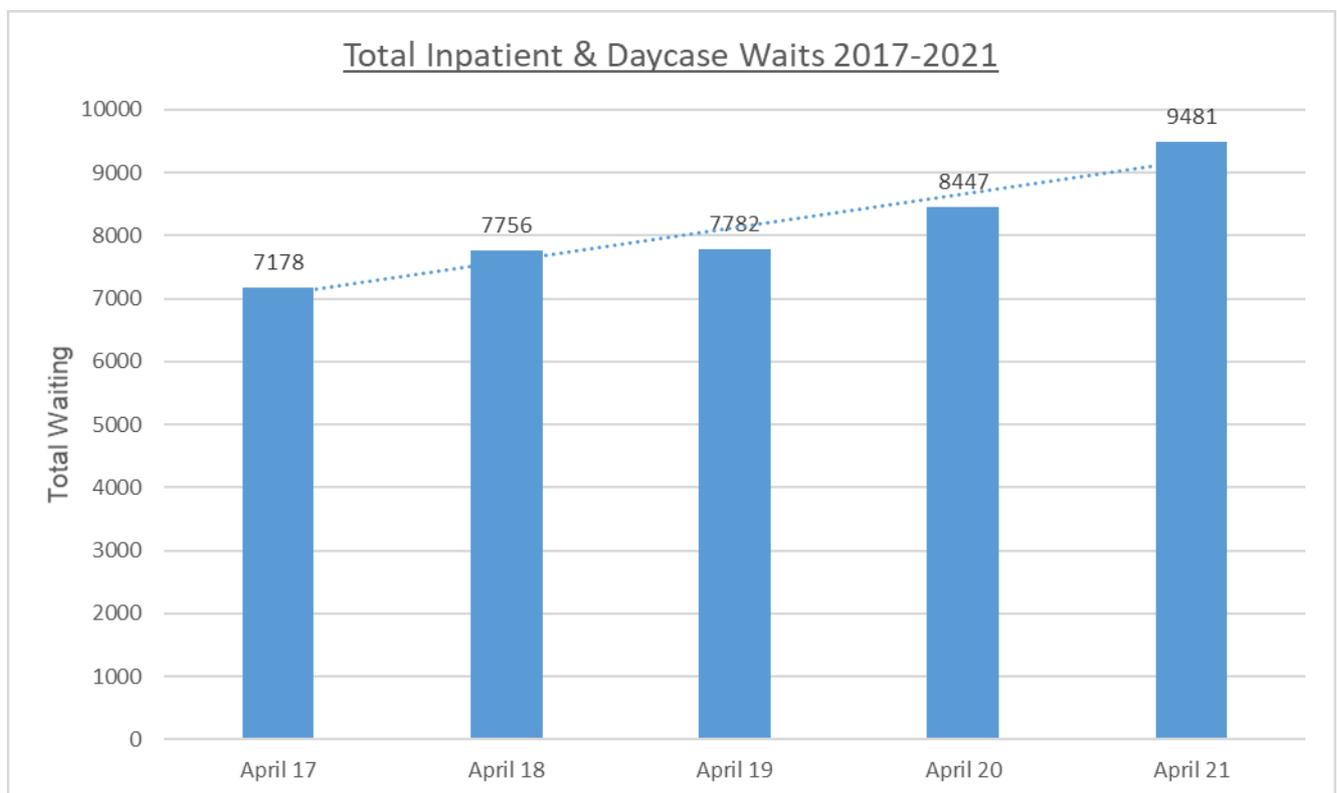
Note: The total number of patients waiting may vary depending on the sources used. Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

Figure 2 shows that inpatient and day case waiting times have increased year on year between 2017 and 2021, with 9,481 children waiting for a first appointment at April 2021.

It also shows that the largest annual increase in children waiting was between 2020 and 2021 when the total number waiting rose from 8,447 to 9,481 (an increase of 1,034).

Figure 2: Waiting lists for inpatient / day case appts: period April 2017- April 2021



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

Note: The total number of patients waiting may vary depending on the sources used. Duplication possible where a patient is recorded more than once.

Length of Time Waiting for First Consultant Led Outpatient or In-patient / Day case

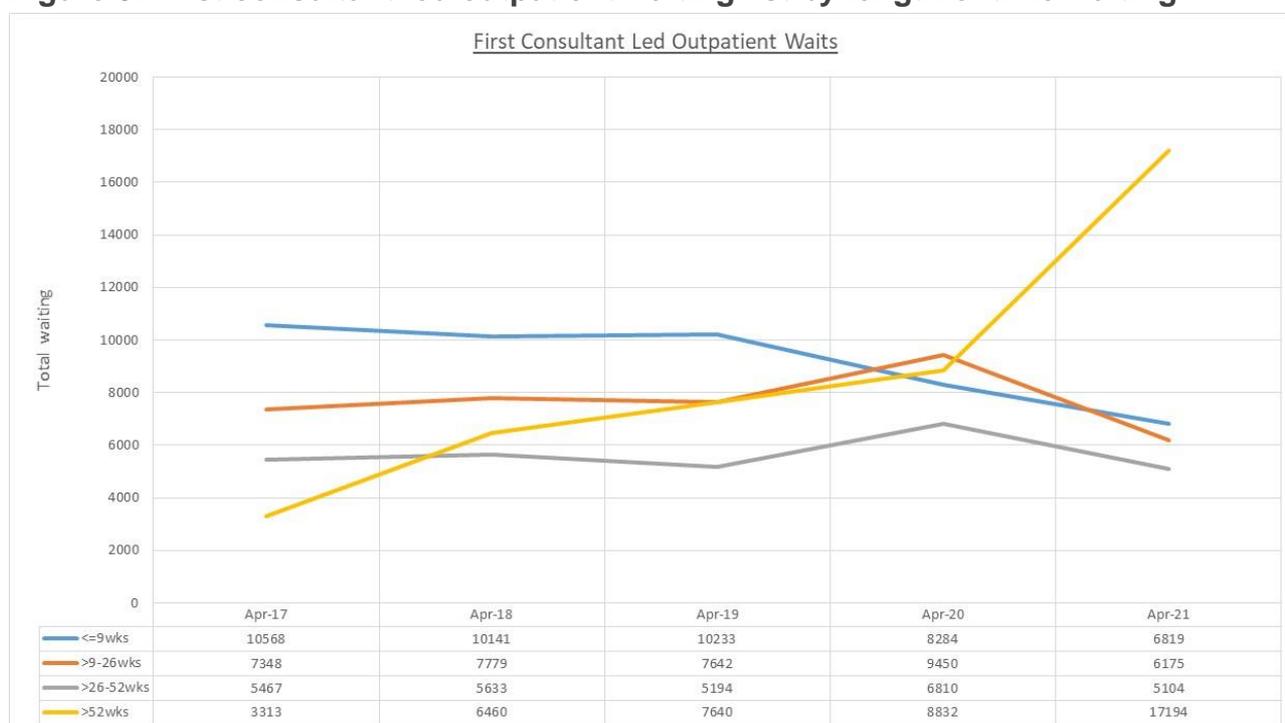
Official waiting time statistics are generally grouped within specified time bands for analysis and reporting purposes. These are referred to as ‘waiting time bands’ and align with statutory waiting time targets set by the Department of Health (see appendix 1 for update on current statutory targets). Data shows that between April 2017 and April 2021 there has been a substantial increase in the number of children and young people waiting

Waiting Time Information and Reporting

over 52 weeks on both outpatient (OP) waiting lists) and inpatient / day case (IP / DC).

Figure 3 shows the number of children waiting for a first consultant led outpatient appointment between 2017 and 2021 by the length of time they are waiting. The graph shows very clearly that between 2017 and 2020, the number of children waiting over 52 weeks had been increasing steadily, however between April 2020 and April 2021, which covers the pandemic period, there was a significant spike in numbers waiting over 52 weeks - from 8,832 to 17,194, equating to a 95% increase.

Figure 3: First consultant led outpatient waiting list by length of time waiting



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

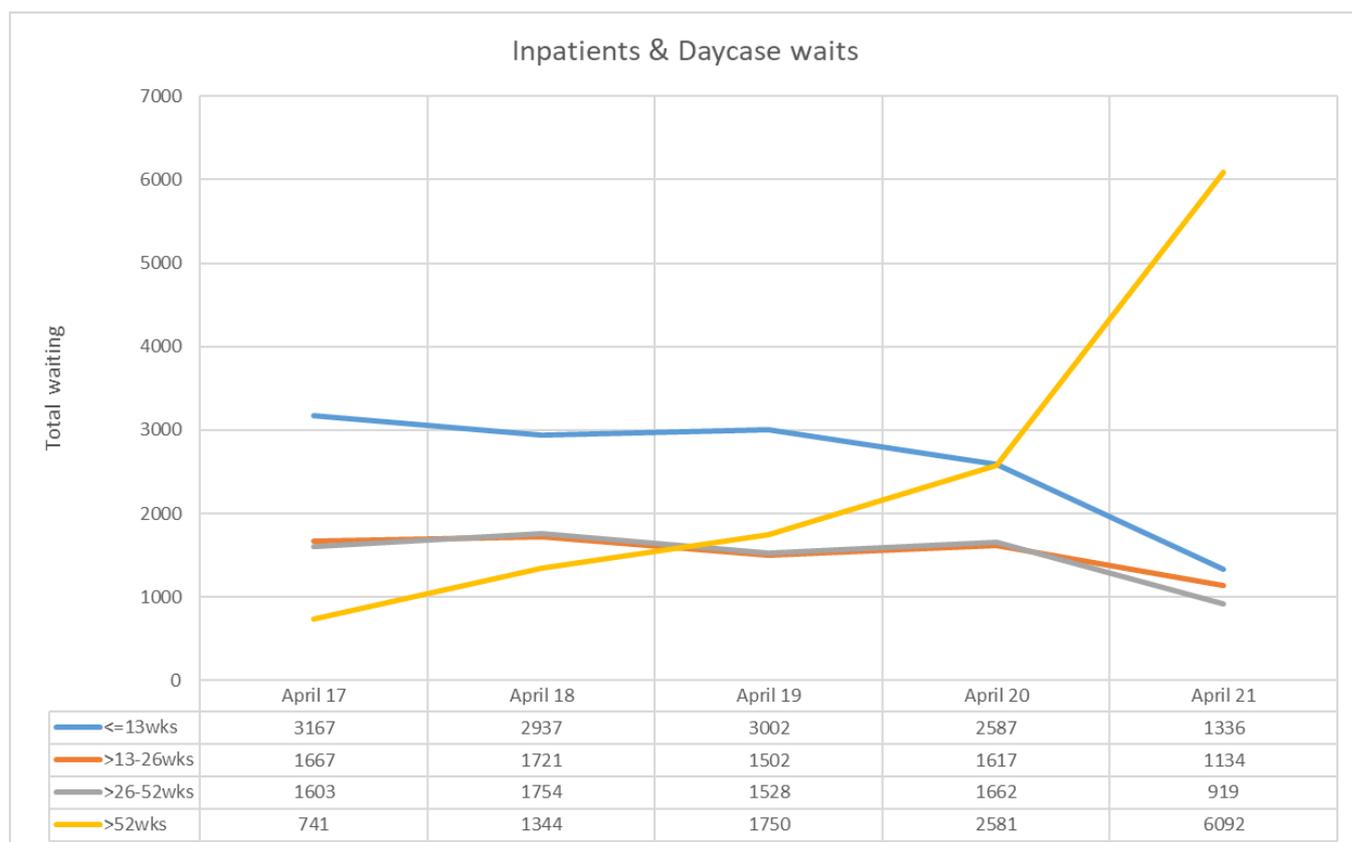
Note: Figure extracted from performance reports- inclusion and exclusion criteria may vary from other data outputs. Duplication possible where a patient is recorded more than once.

Figure 4 below outlining the number of children waiting for inpatient or day case appointments between 2017 and 2021 by the length of time they are waiting shows a very similar pattern. Between April 2017 and April 2020, the number of children waiting over 52 weeks had been increasing steadily. Similarly, to the waiting times for first consultant led outpatient appointments, between April 2020 and April 2021 there was a significant spike in numbers waiting - from 2,581 to 6,092, equating to a 136% increase. The impact on

Waiting Time Information and Reporting

services due to the pandemic is clearly visible here.

Figure 4: Inpatient / day case waiting list by length of time waiting



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

Note: Figure extracted from performance reports- inclusion and exclusion criteria may vary from other data outputs. Duplication possible where a patient is recorded more than once.

Maximum Waiting Times

Whilst monitoring is usually carried out under the defined time bands above, delays in access to healthcare can be more fully understood by reviewing the maximum length of time people are waiting for a first consultant led outpatient appointment or an inpatient or day case appointment.⁴⁴ In both cases an increasing and significant number of those

⁴⁴ It should be noted that patients overall length of waiting time can be impacted by a number of factors. Patients may

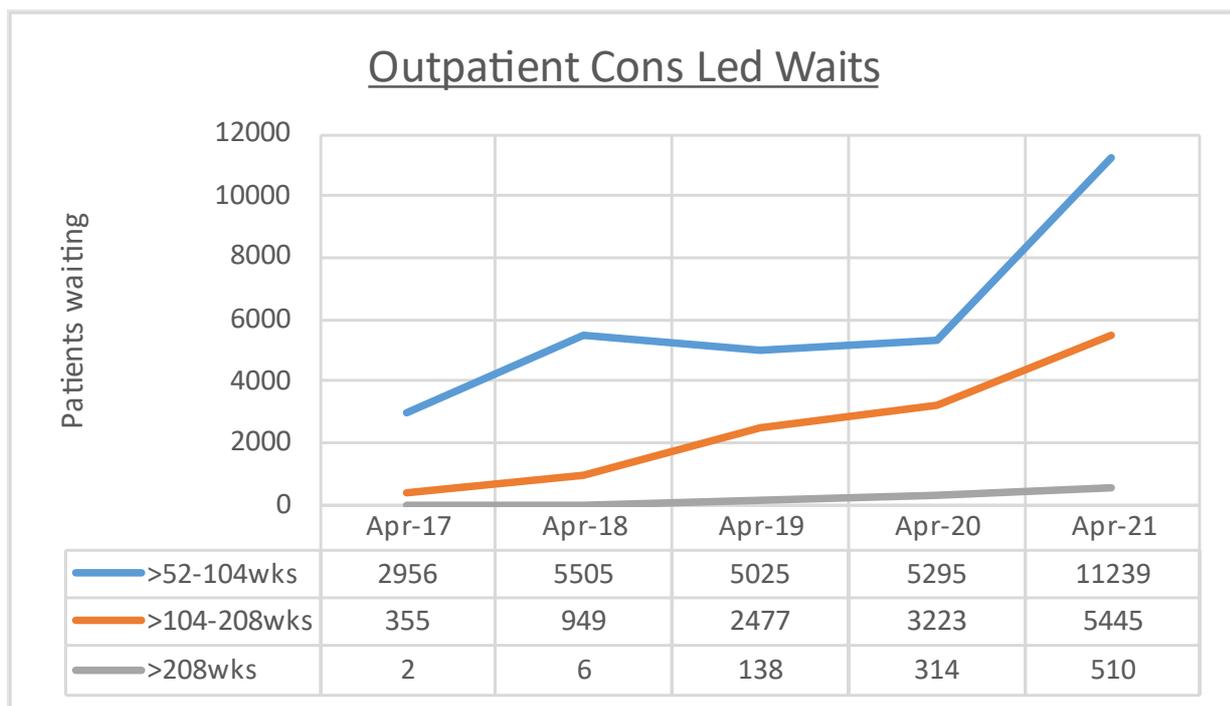
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waiting fall within the greater than 52 wk waiting category.

Figures 5 and 6 below provides a breakdown of the number of under 18 yr old patients waiting over 52 – 104 wks (more than 1 yr - 2 yrs); over 104 – 208 wks (more than 2 yrs - 4 yrs); and over 208 wks (more than 4 yrs); for a first consultant led outpatient appointment or an inpatient or day case appointment.

Figure 5 below shows that of the 17,194 patients waiting over 52 weeks for a first consultant led outpatient appointment at April 2021, 11,239 had been waiting between 1-2 yrs, 5,445 between 2- 4 years and 510 over 4 years.

Figure 5: First consultant led outpatient waiting list by longest waits



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

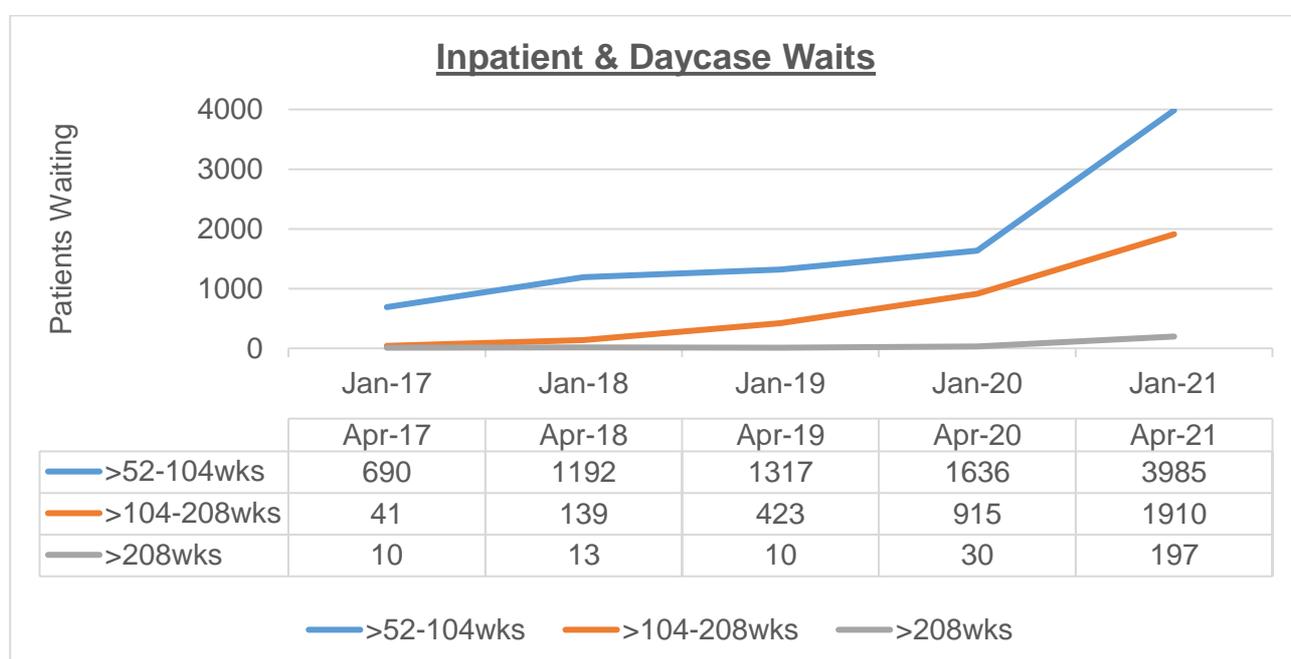
Note: The total number of patients waiting may vary depending on the sources used and length of wait has various contributing factors. Duplication possible where a patient is recorded more than once.

have been offered dates for surgery but declined for various reasons, or the patient may have requested they are suspended from a waiting list.

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Figure 6 below indicates a similar trend to that for outpatients in which there is an increasing number of children waiting a significant length of time and shows that of the 6,092 patients waiting for an inpatient or day case appointment over 52 weeks at April 2021, 3,985 had been waiting between 1-2 years, 1,910 between 2- 4 years and 197 over 4 years.

Figure 6: Inpatient / day case waiting list by longest waits



Source HSCB: Consultant-Led Waits *recorded on PAS*; sourced via Business Objects DWH

Note: The total number of patients waiting may vary depending on the sources used and length of wait has various contributing factors. Duplication possible where a patient is recorded more than once.

Number Waiting for All Outpatient Appointments

Monitoring and official reporting of out-patient waiting lists tend to focus on the first consultant led outpatient appointment. However, it is only by looking beyond these standard ways of measuring outpatient waiting times that the full extent of the number of under 18s waiting for outpatient appointments across the region becomes clear.

When one includes appointments for professionals other than consultant, and for review as well as first appointment, waits for under 18s increase quite considerably. As illustrated

Waiting Time Information and Reporting

in Table 2, whilst consultant led out-patient appointments account for 78% of the overall out-patient waiting list, approximately a fifth (22%) is accounted for by waiting times for access to other professionals which include allied health professionals (n=4,793), technician led (n=3,330) and nurse led (n=2,795) appointments.

Table 2: Number waiting for all outpatient appointments at April 2021

Activity Type	Grand Total
Allied Health Professional	4,793
Consultant-Led	42,363
Diagnostic	47
General Practitioner-Led	14
ICATS-Led	725
Midwife-Led	202
Multi-Disciplinary Team	54
Nurse-Led	2,795
Pharmacy	<5
Student	<5
Technician-Led	3,330
Grand Total	54,328

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

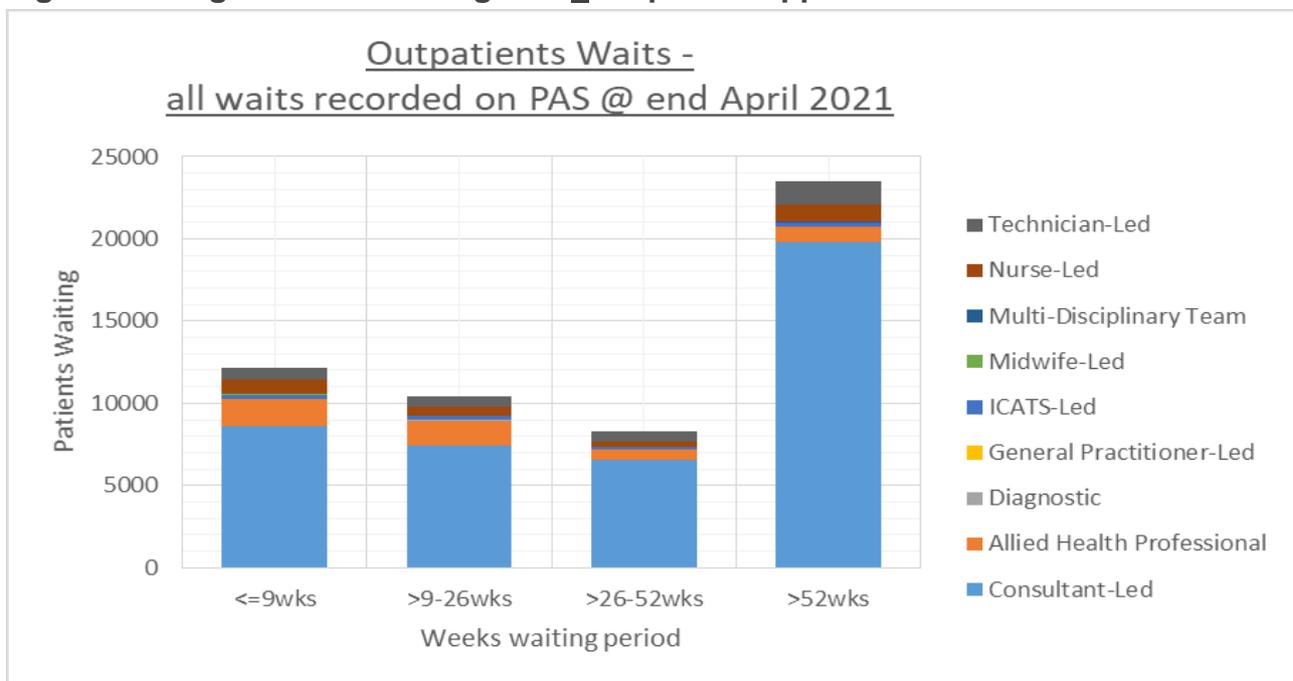
Note: Consultant Led figure includes all waiting lists including some of these initially excluded from performance reports. Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

Length of Time Waiting for All Outpatient Appointments

When one considers the waiting times for those waiting for a first outpatient appointment it is apparent that 43% have been waiting for over 52 weeks (n=23,520) (Figure 7). It is also the case that the waiting times are longest for consultants who also have the biggest overall waiting lists.

Figure 7: Length of time waiting for all outpatient appointments



Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Notes:

Waits include those recorded on the Regional Patient Administration System (PAS) and do not include other systems or manual records. Duplication possible where a patient is recorded more than once.

In the main, the ‘point in time’ statistics provided in this report relate to April 2021, however, Table 3 below provides information on the number of waiters for first and review appointments. As this information cannot be captured retrospectively from the system, the table below is for August 2021.

Waiting Time Information and Reporting

Table 3 shows that at August 2021, 89,018 children were waiting for either a first or review outpatient appointment with a consultant. It also shows that almost two thirds (63%; n=56,921) were waiting for a review appointment, and just over a third (37%; n=32,727) were waiting for a first appointment

Table 3: Number waiting for consultant outpatient first and review appts at Aug2021

First Outpatient appts	Review Outpatient appts	Overall Total waiting for first or review apt
32,727	56,291	89,018

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at August 2021

Note: Duplication possible where a patient is recorded more than once.

Total Number Waiting by Subspecialty

The statistics published on a periodic basis by the Department of Health provide an outline of the number waiting by regional (kroner) specialty i.e. paediatrics in the case of first consultant led outpatients or paediatrics or paediatric surgery in the case of inpatients or day case.⁴⁵ Whilst helpful, this does not provide a clear sense of the types of treatment / conditions for which young people are waiting to be treated. The figures and tables below provide a more detailed breakdown of the number of patients waiting for an appointment by specific subspecialty.

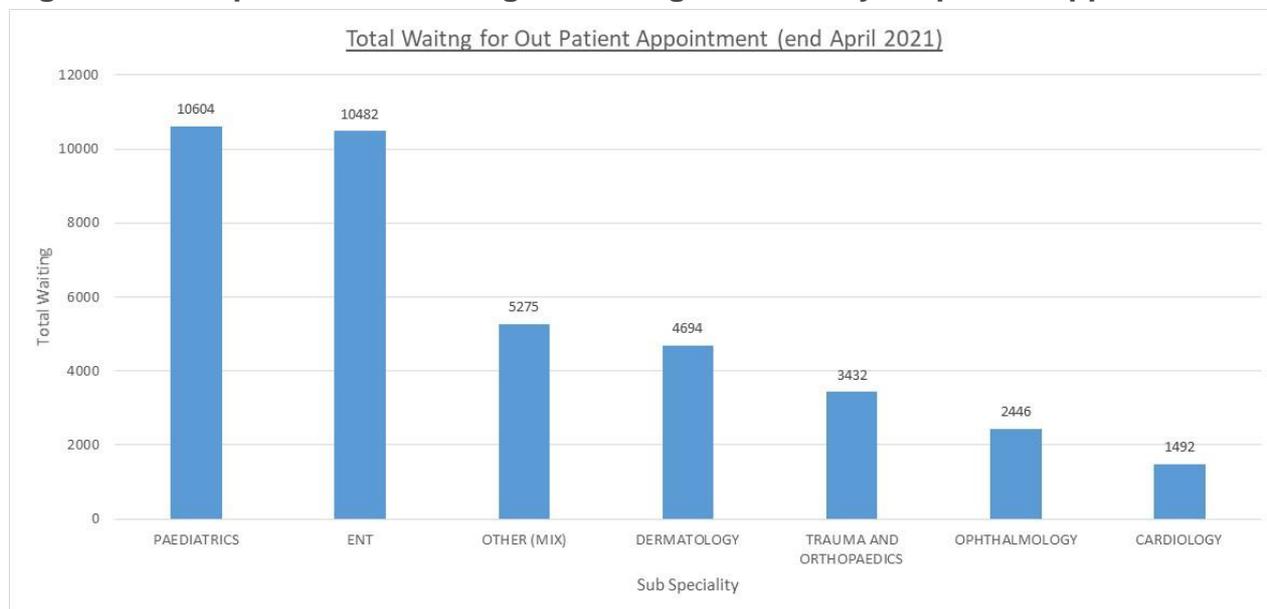
Any Outpatient Appointment

At April 2021, 54,328 under 18s were on a waiting list for any out-patient appointment across 51 different subspecialties. However, 71% (n=38,425) were waiting for an appointment across one of seven sub-specialties which were Paediatrics (n=10,604), ENT (n=10,482), Other (mix) (n=5,275), Dermatology (n=4694), Trauma and Orthopaedics (n=3,432), Ophthalmology (n=2,446) and Cardiology (n=1,492) (Figure 8).

⁴⁵ For the purposes of DoH statistical bulletins, a specialty is a particular branch of medicine or surgery. Each consultant is assigned a main specialty from a list recognised by the Royal Colleges and Faculties. Information is recorded against the specialty of the treating consultant. https://www.health-ni.gov.uk/sites/default/files/publications/health/hs-niwts-outpatient-waiting-times-documentation_1.pdf

Waiting Time Information and Reporting

Figure 8: Subspecialties with largest waiting lists for any outpatient appointment



Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

When looking at the length of time under 18s are waiting for an outpatients appointment, it is apparent that 4 in 10 children are waiting over 52 weeks (Table 4).

Table 4: Length of time waiting for any outpatient appointment by subspecialty

	<=9wks	>9-26wks	>26-52wks	>52wks	Grand Total
Paediatrics	3,165	2,274	1,616	3,549	10,604
ENT	1,171	1,338	1,645	6,328	10,482
Other (mix)	1,535	1,481	619	1,640	5,275
Dermatology	807	717	702	2,468	4,694
Trauma and orthopaedics	1,363	676	608	785	3,432
Ophthalmology	638	634	317	857	2,446
Cardiology	359	365	332	436	1,492
% of Total Waiting	24	19	15	42	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

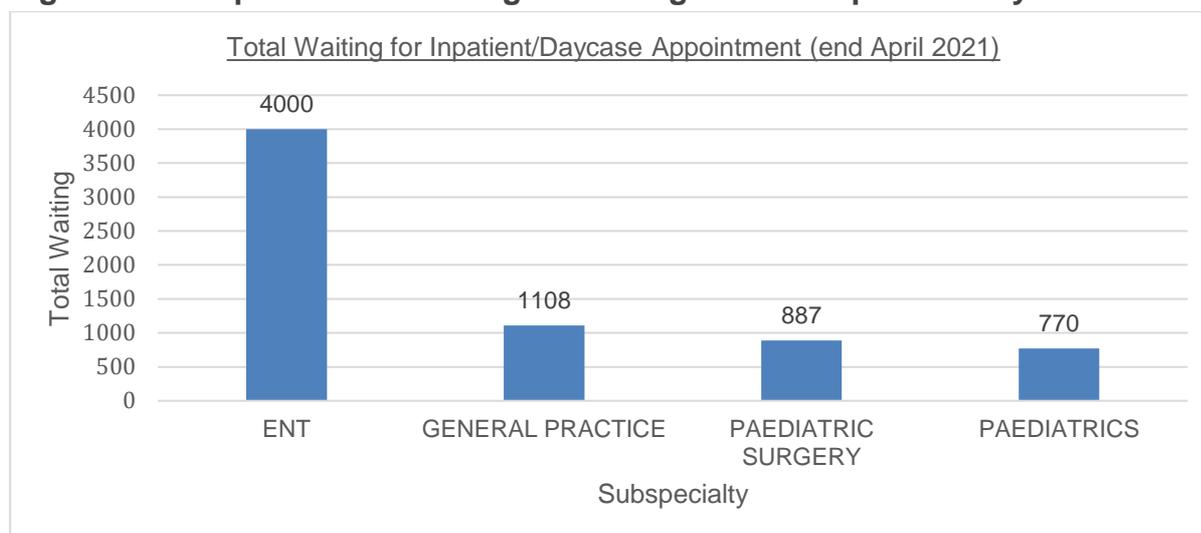
Note: Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

In-patient or day case appointments

At April 2021, 9,640 under 18s were on a waiting list for inpatient / day case appointment across 22 different sub specialities. However, 70% (n=6,765) were waiting for an appointment across one of four subspecialties which were ENT, General Practice, Paediatric Surgery and Paediatrics (Figure 9).

Figure 9: Subspecialties with largest waiting lists for inpatient/ day case



Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Worryingly, Table 5 below shows that more than two in three (69%) of those waiting for an inpatient or day case appointment had been waiting over a year (n=4,671) and again this was disproportionately due to delays in ENT appointments.

Table 5: Length of time waiting for inpatient/ day case by subspecialty

Regional (Kroner) Specialty	<=13wks	>13-26wks	>26-52wks	>52wks	Grand Total
ENT	168	194	390	3,248	4,000
General Practice	349	279	145	335	1,108
Paediatric Surgery	168	116	123	480	887
Paediatrics	63	55	44	608	770
Grand Total	748	644	702	4,671	6,765
% of Total Waiting	11	10	10	69	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

Table 6 shows that across all 'time bands' the waits for day case treatment equates to nearly 75% (n=7,161) of the overall waits, with a quarter waiting for inpatient care (26%; n=2,479). It also shows that it is most common for children to be waiting over a year for treatment (62%).

Table 6: Summary inpatient / day case by length of time waiting

Inpatient / Day Case Waits	<=13wks	>13-26wks	>26-52wks	>52wks	Grand Total	% of total waiting
Day Case	1,140	865	814	4,342	7,161	74%
Inpatient	271	242	291	1,675	2,479	26%
Grand Total	1,411	1,107	1,105	6,017	9,640	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Total Number waiting by priority level

When a patient is referred to hospital for either an out-patient appointment or added to an inpatient / Daycase treatment list, the referral is categorised under 3 main priority types: Urgent referrals are those requiring urgent attention (appointment, surgery or tests). Routine referrals are those that require advice or review for conditions which are deemed non-urgent. Red Flag referrals are those in which cancers are suspect or confirmed.

Table 7 shows that, at April 2021, 54,328 children and young people waiting for any outpatient appointment, of these 45,462 (84%) were classified as routine; 8698 (16%) urgent; and 168 red flag (0.3%). Red flag referrals are those in which cancers are suspected or confirmed.

Table 7: Total number of outpatients waiting by clinical priority

Priority Level	<=9wks	>9-26wks	>26-52wks	>52wks	Grand Total	% of total waiting
Red Flag	97	26	21	24	168	0.3%
Urgent	3,528	2,006	1,297	1,867	8,698	16%
Routine	8,519	8,351	6,963	21,629	45,462	84%
Grand Total	12,144	10,383	8,281	23,520	54,328	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Once referrals have been initially assessed (triaged) by a clinician, the priority type may be re-classified (or re-graded).

Waiting Time Information and Reporting

Duplication possible where a patient is recorded more than once.

As Table 8 shows with respect to inpatient and day case referrals, at April 2021, 7335 (76%) were classified as routine and 2305 (24%) as urgent.

Table 8: Total number of inpatient & day case patients waiting by clinical priority

Inpatient / Day case Waits	<=13wks	>13-26wks	>26-52wks	>52wks	Grand Total	% of total waiting
Routine	836	767	823	4,909	7,335	76%
Urgent	575	340	282	1,108	2,305	24%
Grand Total	1,411	1,107	1,105	6,017	9,640	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Once referrals have been initially assessed (triaged) by a clinician, the priority type may be re-classified (or re-graded).

Duplication possible where a patient is recorded more than once.

As Table 9 shows statistics for both urgent and routine waiting lists, close to half of the waits were for services offered in the BHSC (45.4%), with waiting times for the remaining Trusts ranging between 11-16%. The fact that the BHSC offers specialised regional services unavailable in other HSCTs, which includes the regional specialist children's hospital (RBHSC), is likely to be a contributing factor for the higher proportion of waiting times falling to that Trust.

Table 9: Percentage of inpatient/ day case waits by HSCT

Inpatient / Day case Waits	Grand Total
Belfast	45%
Northern	11%
South Eastern	14%
Southern	13%
Western	16%

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

Adult Versus Paediatric specialty

There is not a specified paediatric service for every condition affecting under 18s, this means that a proportion of children will be treated within an adult service. Table 10 and 11 show that for every 10 patients, 6 are seen by adult services and 4 are seen with paediatric services. This is similar to day case or Inpatient care.

Children seen within adult services will be seen by those with the best clinical expertise for their condition. Clinics may be age specific - separating adults and children, however the environment may not always be child friendly or age appropriate.

Table 10: Total number waiting for outpatient by service type

Outpatient waits	totals	% split of total
Adult	32,477	60%
Paediatric	21,851	40%
Grand Total	54,328	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Table 11: Total number waiting as inpatient / day case by service type

Inpatient / Day case Waits	Totals	% split of total
Adult	6,037	63%
Paediatric	3,603	37%
Grand Total	9,640	

Source HSCB: All Waits recorded on PAS; sourced via Business Objects DWH – Patients Waiting at end April 2021

Note: Duplication possible where a patient is recorded more than once.

Waiting Time Information and Reporting

Community Child Health Service Waiting Time Statistics

The following tables and graphs show waiting times for community child health services that are monitored by the HSCTs. Waiting time data for community child health services are not routinely monitored or reported on at a regional level.

The HSCB facilitated a discrete piece of work to collate waiting time data for community child health services, this involved liaising with each of the 5 HSCTs to gather data on waiting times for community child health services. Table 12 outlines the list of services included as part of the waiting time statistic, these services are included on the LCID system and are based on the HSCT Primary Targeting Lists (PTL), which is a historic list, with no particular criteria set for which services become part of the monitoring list. Further details of the data collection process for community child health service waiting lists are included in the methodology section.

Table 12: Community child health services included in waiting time statistics

Name of Service	
Community Paediatric Medical Service Speech and Language Therapy Occupational Therapy Services Orthoptics Service Nutrition and Dietetics Service Physiotherapy Services Podiatry Learning Disability Therapeutic Service Clinical Health Psychology Service	Grouped Community Child Health Service
CAMHs Autism Diagnosis Autism Intervention	

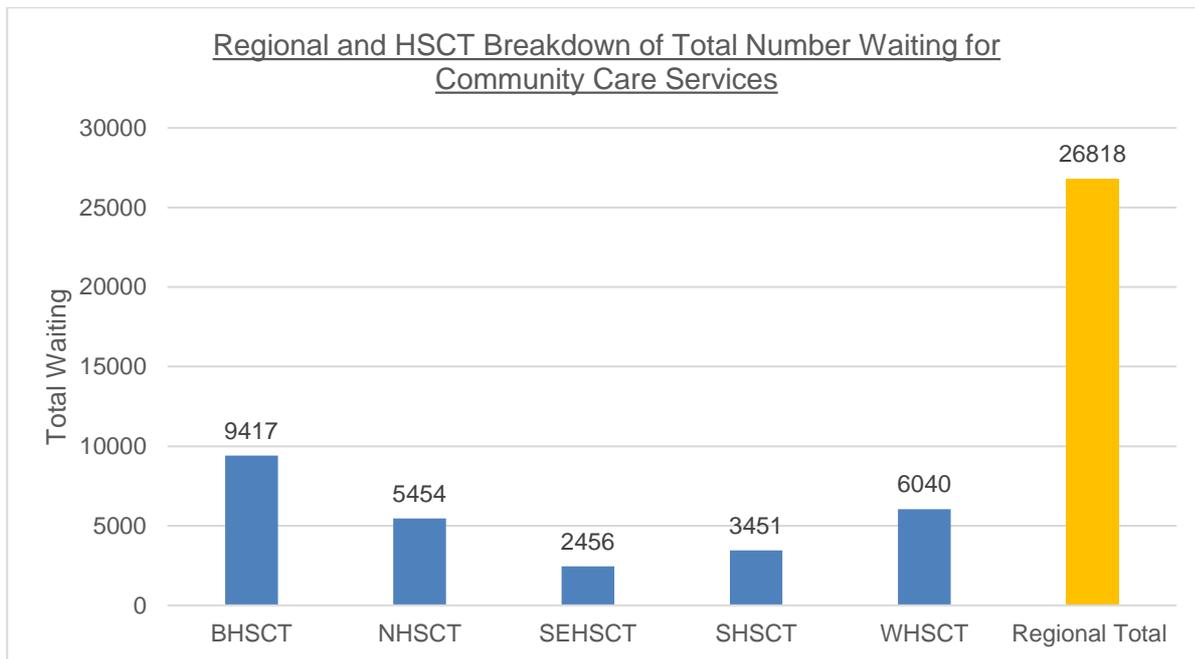
Notes:

Service titles vary across HSCTs. Table 12 has grouped services to give an idea of the regional wait for service areas. A young person could be on a waiting list for several services at the same time.

Waiting Time Information and Reporting

Figure 10 below shows the total number waiting for access to community child health services across the five Health and Social Care Trusts, and shows that overall, 26,818 referrals have been made to one of the services listed in Table 12.

Figure 10: Regional and HSCT breakdown of total number waiting for community child health services



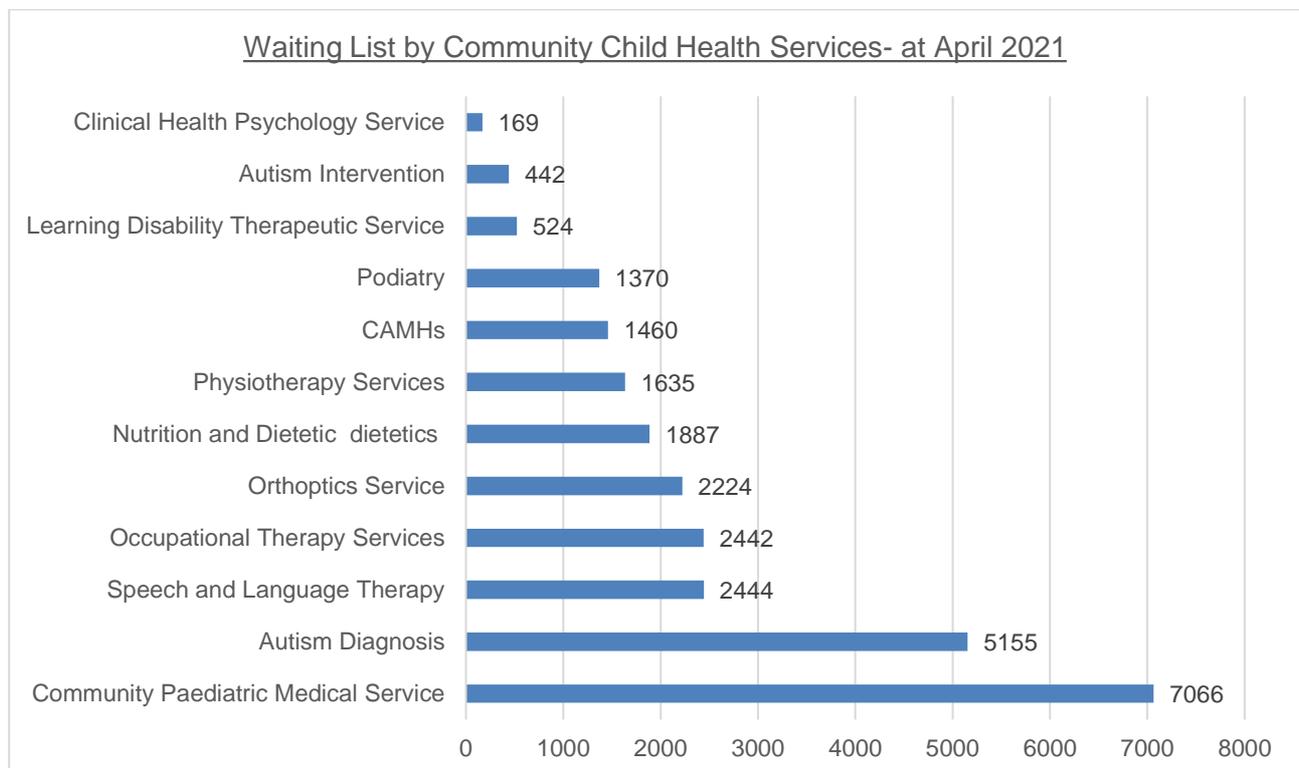
Sources: Grouped community child health service data was provided by each HSCT & Monthly Children’s Autism and CAMHS Waiting Times provided by HSCB.

Notes: Duplication possible where a patient is recorded more than once.

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Figure 11 also shows considerable differences in the number waiting for specific types of community child health services. Community Paediatric Medical Service (n=7,066) and Autism Diagnosis (n=5,155) account for 46% of the overall waiting list for the community child health services included in Table 12.

Figure 11: Total number waiting for community child health services- at April 2021



Sources: Grouped community child health service data was provided by each HSCT & Monthly Children's Autism and CAMHS Waiting Times provided by HSCB.

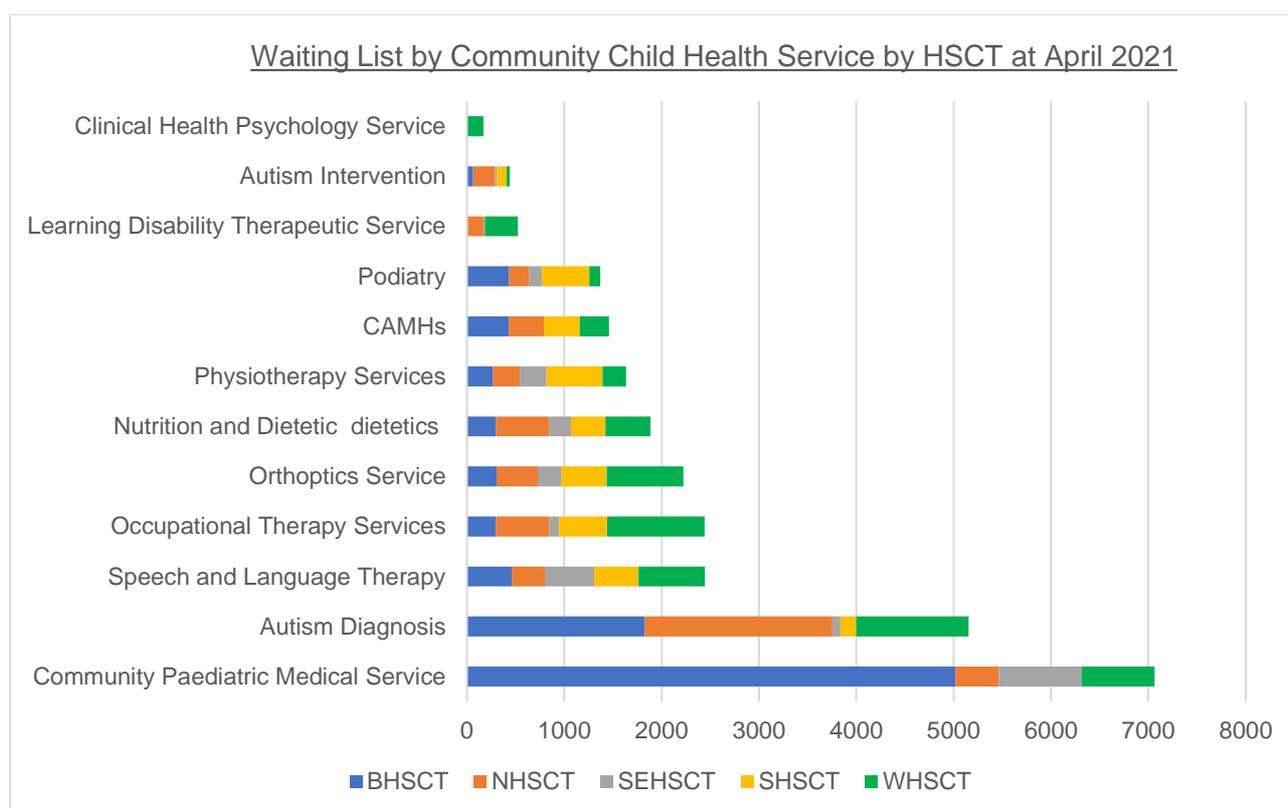
Notes: Duplication possible where a patient is recorded more than once.

Figure 12 provides a breakdown of waiting times for community child health services by HSCT. It shows that there can be significant variation in the length of time children are waiting for the same services across HSCTs. The number waiting for community paediatric medical services is much larger in BHSCT than in any other HSCT, however, the fact that BHSCT provides regional wide services, may be a contributing factor. Waiting lists for autism diagnosis are also much larger in BHSCT and NHSCT, however along with

Waiting Time Information and Reporting

WHST they are also the HSCTs which tend to receive the most referrals.⁴⁶

Figure 12: Total number waiting for community child health services by HSCT- at April 2021



Sources: Grouped community child health service data was provided by each HSCT & Monthly Children's Autism and CAMHS Waiting Times provided by HSCB.

Notes:

CAMHS delivered in Belfast for both BHSCT and SEHSCT

Duplication possible where a patient is recorded more than once.

The following tables provide a HSCT breakdown of the length of time patients are waiting for the identified community child health services. Due to a lack of standardisation in the data provided, waiting times could not be extrapolated for each specific service using standard time bands (i.e. < 9 wks - >52 wks), however it has been possible to provide

⁴⁶ [Autism statistics | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/autism-statistics)

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waiting time bands for services where they are grouped together. Table 12 above provides a list of the community child health services that waiting time statistics are available for. Services where specific waiting times are not possible as described as 'grouped community child health services'.

Table 13 shows that at April 2021, regionally 19,761 under 18s were waiting for an appointment with one of the 'grouped community child health services'. Most of those waiting had been doing so for 26 weeks or less, however a significant number had been waiting longer than that with close to 5,000 waiting over a year. Waits of over one year are more frequent for patients in the BHSCT and WHSCT. It also shows the number waiting to access community child health services is much higher in the BHSCT (n=7,096) compared to any other HSCT, representing 36% of the overall waits across these services.

Table 13: Waiting by length of time waiting - at April 2021- Grouped Community Child Health Services

HSCT	<=26 wks	> 26-52 wks	>52wks	Regional Total
BHSCT	3,063	1,048	2,985	7,096
NHSCT	2,514	342	86	2,942
SEHSCT	2,027	229	96	2,352
SHSCT	2,022	447	355	2,824
WHSCT	2,508	674	1,365	4,547
Regional Total	12,134	2,740	4,887	19,761

Source: Grouped community child health service data was provided by each HSCT

Notes:

*Grouped community services are all services included in Table 12 apart from Autism and CAMHS.

Duplication possible where a patient is recorded more than once.

Table 14 provides a breakdown of the length of time children were waiting for an autism assessment at April 2021. It shows quite significant differences in the total number waiting across HSCTs, with much larger waiting lists in BHSCT and WHSCT compared to the SHSCT and SEHSCT.

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Table 14: Total number waiting by length of time waiting- at April 2021- Autism Assessment

HSCT	0 to 13 Weeks	>13 to 26 Weeks	>26 to 52 Weeks	>52 Weeks	Total Waiting
BHSCT	264	209	330	1,022	1,825
NHSCT	423	344	597	565	1,929
SEHSCT	83	0	0	0	83
SHSCT	162	0	0	0	162
WHSCT	166	159	223	608	1,156
	1,098	712	1,150	2,195	5,155

Source: Monthly Children's Autism Waiting Times returns from Trusts- @30 April 2021

Note: Duplication possible where a patient is recorded more than once.

Table 15 shows that the overall numbers waiting, and length of time young people wait for intervention is relatively small compared to waits for assessment. At April 2021, 442 children were waiting for intervention and half of those waiting were within the NHSCT (N=224; 51%).

Table 15: Total number waiting by length of time waiting- at April 2021- Autism Intervention

HSCT	0 to 13 Weeks	>13 to 26 Weeks	>26 to 52 Weeks	>52 Weeks	Total Waiting
BHSCT	65	0	0	0	65
NHSCT	158	26	1	39	224
SEHSCT	21	0	0	0	21
SHSCT	96	0	0	0	96
WHSCT	36	0	0	0	36
	376	26	1	39	442

Source: Monthly Children's Autism and CAMHS Waiting Times provided by HSCB

Table 16 shows that at April 2021, 1,460 under 18s were waiting for an appointment for a CAMHS appointment. It also shows that the vast majority had been waiting between 0-9 or >9-26 weeks. In the main, those waiting over 26-52 wks were in the WHSCT (31 of 35 waiting).

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Table 16: Total number waiting by length of time waiting- at April 2021- CAMHS

HSCCT	0-9 Weeks	> 9 to 26 weeks	> 26-52 wks	>52wks	Regional Total
BHSCCT	314	113	4	0	431
NHSCCT	258	101	0	0	359
SHSCCT	339	30	0	0	369
WHSCCT	160	110	31	0	301
	1071	354	35	0	1,460

Source: Monthly Children's Autism and CAMHS Waiting Times provided by HSCB

Notes:

CAMHS delivered in Belfast for both Belfast and SET

Impact of Waiting on Healthcare

3.0 The Impact of Waiting for Healthcare

Recording and reporting on waiting time targets is essential for monitoring the accessibility of health and social care services. With respect to children and young people it also allows for greater accountability as to whether their right to the highest attainable standard of health and access to healthcare is being met.⁴⁷ Delays in access to healthcare can have a considerable impact on children's health outcomes, emotional and mental wellbeing, educational attainment, relationships with family and friends and quality of life more broadly. The stress of waiting for healthcare treatment or services can also have an adverse impact on the health and wellbeing of their family, particularly parents/carers but also their siblings.

In this section of the report two conditions, namely autism and scoliosis, are used to illustrate the impact that delays in accessing healthcare can have on children and their families.

Autism is a developmental disability that influences a person's ability to communicate and relate to other people, as well as affecting how they make sense of the world. It is a spectrum condition, meaning that while all people with autism will have similar problems, overall their condition will impact them in different ways.⁴⁸

Scoliosis is a physical health condition in which the spine curves or twists as the child grows. There are three main types of childhood scoliosis- 'congenital scoliosis' which appears at birth, 'early onset scoliosis' in young children and 'adolescent idiopathic scoliosis' in older children and teenagers. There are a number of treatment options for scoliosis depending on its severity, these include bracing and surgery.⁴⁹

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Autism and scoliosis are very different conditions, treated by different parts of the healthcare system: autism is treated under community child health services and scoliosis

⁴⁷ Article 24- [OHCHR | Convention on the Rights of the Child](#)

⁴⁸ <https://www.health-ni.gov.uk/sites/default/files/publications/health/asd-children-ni-2020.pdf>

⁴⁹ [Scoliosis Treatment - Scoliosis Association \(sauk.org.uk\)](#)

Impact of Waiting on Healthcare

under hospital care services. While waiting lists for autism services were reported in the previous section, scoliosis falls under the trauma and orthopaedic subspecialty of children's hospital services, therefore it is not reported on routinely under the PAS system without a specific request. The data presented below is based on a Freedom of Information request made by Megan's Wish Charity which supports children with scoliosis and their families.

Waiting times for children with scoliosis

In 2019, 311 children (up to 18 years) were diagnosed with scoliosis in Northern Ireland.⁵⁰

Waiting Times at June 2020

Waiting time from GP referral to First Outpatient Consultant Apt ⁵¹

Urgent referrals-33 weeks

Routine referral- 50 weeks

The number of children waiting for fusion surgery

Total= 31 (21 on RVH and 10 on RBHSC)

The length of time to wait once on surgery list

RVH – urgent 37 weeks/routine 43 weeks;

RBHSC –urgent 35 weeks/routine 43 weeks

Waiting times for autism assessment

Information on autism waiting times at April 2021 was provided as part of the community child health service data provided by the HSCB for this review and is presented in section 2 of this report.

It is also important to reflect on the pattern of change in waiting times for autism ascertained from other reports.

Between 2016-2021 the number of children waiting for an assessment for autism

⁵⁰ FOI to BHSC by Megan's Wish Charity- June 2020

⁵¹ Ibid

Impact of Waiting on Healthcare

increased by 250% (2079 to 5155), with a 750% increase in the number waiting more than 52 weeks for an assessment (279 to 2195).⁵²

In 2020/21 13,401 children were diagnosed with autism which equates as 4.5% of the compulsory school age population (4-15 yr old).⁵³

Of considerable note is the dramatic increase in the prevalence rates for autism in the compulsory school age population between 2008/2009 (1.8%) and 2020/21 (4.5%).⁵⁴

The following section reports on discussions held with families directly impacted by delays in access to healthcare. This provides an insight into the impact of waiting for healthcare services and on what needs to change about the system to ensure adequate supports are put in place to help children and their families while they wait for treatment / care.

The impact on children's physical health and development

For children with scoliosis the physical health impacts of not having treatment or surgery early enough is significant. Parents talked about scoliosis not being a life-threatening condition but how it can become one due to delays in treatment. The child's growth can be unnecessarily stunted because they are at an age where their body is still developing, and if the spine is not growing in the right position, it presses down on organs such as stomach, lungs, bladder and heart.

In addition to waiting on autism diagnoses and services, parents of children with autism described having problems with getting their child's broader health needs addressed. Children with autism can have a range of co-occurring health condition such as ADHD, anxiety, learning disability or speech and language difficulties (SLT). Parents talked about only being able to make one referral at a time, leading to years of waiting to get the holistic needs of their child met. One parent described it as being on a "*constant conveyor belt of waiting lists.*"

⁵² [Autism NI Broken Promises report 2016](#) p.13 and HSCB Data return for this report.

⁵³ [The Prevalence of Autism \(including Asperger's Syndrome\) in School Age Children in Northern Ireland 2021 \(health-ni.gov.uk\)](#)

⁵⁴ *ibid*

Impact of Waiting on Healthcare

The impact on children's social and emotional wellbeing

A strong theme from the engagement with families was that the social and emotional wellbeing of children waiting for healthcare needs to be given much greater priority.

Some children with scoliosis experience constant pain and discomfort which can have a knock-on effect on their emotional wellbeing and mental health. The young people with scoliosis talked about feeling scared and upset about having to wait for treatment or surgery and not knowing what to expect. Others talked about having mood swings, struggling with their body image and isolating themselves from their peers.

“I was in unbearable pain, in my shoulder blades, hips and stomach. I had to take days off school- I lost a lot of school time. I was always on pain killers for the pain. I struggled with mood swings and my body image; I was very thin at that time. That was the worst part of the journey.” (Young Person- Scoliosis)

Children can also face bullying at school because of how they look or behave. Both groups of parents talked passionately about the lack of holistic care provided to their children and how much they rely on support groups and other families that have had similar experiences for support. They felt that there was not enough counselling or therapeutic support for families.

Many parents of children with autism raised the issue of ‘diagnostic over-shadowing’, a phenomenon in which health professionals mistakenly put a child’s problems down to autism without exploring other possible causes. Mental ill-health was commonly identified as ‘put down to autism’. Many families had to refer and re-refer to CAMHS in the hope that a referral would be accepted.

One parent said,

“My child has been suicidal for months and she’s not happy, we are not happy.”
(Parent of child with Autism)

Another parent talked about her child doing well with CAMHS but was discharged from it after she was assessed as having a developmental and learning disability-

Impact of Waiting on Healthcare

“her IQ score was below a certain level so she couldn’t continue having sessions even though she was really engaging and benefiting from the support.” (Parent of child with Autism) ⁵⁵

The impact on children’s education

Anxiety about how their child’s education would be affected was a huge concern for families. This anxiety was partly driven by a lack of certainty about what support would be offered to their child and for how long.

The review found a mixed picture in terms of the response from schools to children’s needs. Based on the feedback from parents/carers of children with suspected or diagnosed autism, some schools were described as very proactive in identifying signs and adapting to the needs of the child, whilst others were unwilling or unable to provide adequate support for their child.

“It really knocks a child’s confidence when the support isn’t there. They feel worthless and not valued and this can affect a child throughout their childhood and beyond.” (Parent of child with Autism)

Parents of children with scoliosis referred to ‘a lack of acknowledgment’ by schools that their child’s health condition was affecting their school life or the difficulties they have in trying to catch up on missed schoolwork after having time off.

“It is hard for children (with scoliosis) to sit from 9am-3pm. Uniforms don’t fit properly which makes a young person feel really self-conscious. Children are still expected to do PE and to take their (body) brace off, which shouldn’t be taken off. My child stopped trying in school, they were just left to the wayside.” (Parent of child with Scoliosis)

Young people with scoliosis talked about the difficulties of carrying heavy bags around the school, finding it hard to sit in a school chair for long periods and difficulties with concentration due to pain, side effects of medication, poor sleep, and during post-surgery recovery. They talked about the ways that teachers and schools had helped them to manage their school day and adapt around their needs. They also felt that this should not

⁵⁵ determining eligibility of access to specialist mental health services (CAMHS) solely or mainly on the basis of IQ solely or mainly on the basis of IQ was raised in NICCY Still Waiting Report (2018) and a recommendation made for DoH to take all necessary measures to ensure that access to services is always on the basis of need.

Impact of Waiting on Healthcare

be left to young people to raise with teachers, the clinical teams involved in a child's care should talk to school about each child's needs.

“I had to tell the teachers myself, the NHS didn't contact the teachers.” (Young Person- Scoliosis)

The impact on parents/carers

Waiting for assessment(s) and treatment and being the conduit between their child and the health professionals involved in their child's care is an immense stress for parents / carers. This is compounded when families are not clear about what to expect and are having to spend hours “*making phone call after phone call- fighting for appointments.*”

Parents / carers of children with autism said it was particularly hard when professionals said there was ‘nothing wrong’ or ‘your child doesn't have autism’ because this comes at a time when as a parent and main carer, they are struggling to understand how to meet their child's needs.

One parent of a child with autism said,

“I experienced four years of waiting for help, it had a massive impact on family life. I can't remember the first two years of my second child's life because I was so focused on (child with autism). It's really sad to say that. I had to leave work- it impacts on siblings and puts huge strain on your marriage.” (Parent of child with Autism)

Parents with children on scoliosis waiting lists or awaiting decisions about treatment referred to the waiting being “*torturous*”. Parents and children are very conscious of the time-critical nature of treatment for severe or progressive scoliosis and are understandably extremely anxious that treatment will come too late. It is estimated that in the last three years, ten children and young people have travelled to Turkey to undergo privately funded surgery because treatment within Northern Ireland would come too late.⁵⁶

This pressure has had an understandable impact on the emotional wellbeing and mental health of parents / carers. During the discussion groups, one mother described becoming

⁵⁶ Statement made by Belfast scoliosis support group-28.04.2021

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so low that she required medication for depression, and another talked about her partner being diagnosed with post-traumatic stress disorder (PTSD) due to the stress of the situation.

What could be done differently?

Families and children waiting for treatment for scoliosis and families of children at different stages of assessment or treatment for autism were asked to give their views on what needs to change about the system to ensure adequate supports are put in place to help them while they are waiting.

Reduce Waiting Times and Two-Tier System of Care

The most obvious and pressing call from parents, carers and young people was to address the waiting time problem. Parents described the stress and anxiety around waiting for decisions to be made regarding whether their child should be referred and then the length of time between referral and appointments with different professionals.

One young person with scoliosis said,

“I have been put on a waiting list for surgery (in NHS) but told it will take two years- I don’t think waiting lists should exist.” (Young person- scoliosis)

Many parents / carers also raised concerns about a two-tier healthcare system developing in Northern Ireland where children get easier access to clinical appointments, assessments and interventions through the private healthcare system, if parents could pay for them.

“It was so strange to see the same Doctors doing clinical appointments in private hospitals as the ones I was waiting on for an NHS appointment.” (Parent of a child with Scoliosis)

“I went privately for an autism assessment in the hope that the HSCT would accept it, you also need to pay privately to get any sort of therapies.” (Parent of child with Autism)

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Information and Communication

The need for improvements in information and communication between families and services was a key issue. In general, families didn't feel they had been given clear information about diagnosis and treatment, their child's care pathway, the key staff or the information they needed to provide to support clinical decision making.

One parent of a child with scoliosis described the range of questions she had when her child was first diagnosed:

“what does it all mean?, what to look out for?, if ‘monitoring required’ what does that involve?.” “We need information, information, information, otherwise we will go to social media and sometimes all you get is misinformation there.” (Parent of child with Scoliosis)

“We need an information pack on what professionals need to know to make an assessment.” (Parent of child with Autism)

Young people with scoliosis also emphasised the need for medical information to be provided in a way that children and young people can understand:

“The doctors were using all these medical terms that I didn't understand.” (Young person- Scoliosis)

Co-ordination within and between, Health and Education

Parents talked about the need for greater co-ordination between different parts of the health system and between education and health. The need for more integrated working between disciplines and sectors was notable from the sessions with both groups of parents.

Parents felt that primary healthcare providers, especially GPs needed to be better trained and knowledgeable about child health issues. Families felt this was very important.

“GPs need to be better educated as they are often the first port of call when you notice something is wrong.” (Parent of child with Scoliosis)

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“He (GP) didn’t understand autism, so wasn’t able to help with my child’s health needs. I asked for referral for ADHD and he said why do you want that for he’s already got Autism.” (Parent of a child with Autism)

Recent statistics show that 8 out of 10 children diagnosed with autism have special educational needs⁵⁷

“There needs to be a more cohesive process that makes it more bearable for families.” (Parent of child with Autism)

Another parent said,

“It’s really frustrating when you are told the service doesn’t have the capacity to deal with your referral for assessment, even though you are being told your child has the ‘classic signs’, you are being told you have to wait another 16 months. And in the meantime, you’re trying to muddle through with practical things, but worrying that the statementing process for school could be jeopardised.” (Parent- Autism)

Parents of children with scoliosis also thought improvements needed to be made in how education and health work together for individual children’s needs:

“(My child’s) mobility is bad now due to the scoliosis- I tried to get support from EA regarding help with school transport but I gave up- I didn’t have the mental energy to fight it- we relied on private taxis and the kindness of neighbours.” (Parent of child with Scoliosis)

Multidisciplinary working across Health Professionals

Parents felt that there needed to be more person-centred care at all points along the journey from first raising issues with health professionals, to referral and assessment and treatment or intervention. Many parents / carers referred to spending a lot of time ‘chasing appointments’ or ringing around different people to get updates or information. A disjointed and uncoordinated health and social care system prevents children’s needs being met in a holistic way and can lead to families feeling like they were on a constant waiting list.

⁵⁷ <https://www.health-ni.gov.uk/sites/default/files/publications/health/asd-children-ni-2020.pdf>

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One parent of a child with autism reflected on the problems she faced when trying to get access to support for their child's needs,

“I spent all day making up to 10 phone calls to different services from paediatrics, ASD helpline, GP, ASD Social Worker and Clinical Psychologist. Finally, the Clinical psychologist was able to help.” (Parent of child with Autism)

Occupational therapy to support children with scoliosis in schools was highlighted as important but needed to become easier to access, and parents also felt strongly that a range of counselling or therapeutic interventions should be available for parents and children.

Quality of Care

Alongside delays in access to healthcare, families also wished to raise issues about the quality of care their child had received in the Health and Social Care system in Northern Ireland. Families of children with scoliosis that had accessed private care in Northern Ireland and abroad referred to the much better service they received abroad. For example, the body braces used within the Northern Ireland health service were described as extremely rigid and difficult to get on and off without help which can create problems for children when they are outside of the home. The health service in Turkey reportedly uses much more advanced technology to make the braces.

Another parent talked about the information provided by the clinicians in Turkey being much clearer and comprehensive:

“In NHS we felt fobbed off, told that certain health issues weren't due to the scoliosis.” (Parent of child with Scoliosis)

For children with scoliosis the waiting times for surgery or bracing are time critical. Parents talked about the long gaps between clinical appointments and clinics that were only held once a month which led to long waits for updates or reviews.

Parents felt that the clinical appointments, when they did occur were very short, not providing enough time to process the information they were hearing or to ask questions:

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One parent said,

“you feel like you have been left in a vacuum while you are waiting for an appointment.” (Parent of child with Scoliosis)

For too many families of children with autism, the situation got to crisis point before an assessment was provided. For many families the transition into education or between schools was a trigger for challenging behaviour, anxiety and developmental regression. Several families referred to having assessments rushed through to address escalating issues with their child’s behaviour, impact on education etc.

Due to the lack of regular monitoring of their child’s health whilst they were waiting, families were not confident that the triaging process to identify children at highest clinical priority was working effectively. In fact, the families of children with scoliosis we interviewed, did not feel there was any meaningful triaging process in place.

Support for Parents and Families

Both groups of parents / carers felt very strongly that they should be able to access support from statutory services more easily, and that they should not have to rely on parent support groups for information. Although support groups were described as a lifeline, it was stressed that families should not be reliant on the good will and information shared between parents. Across all discussion groups, a consistent message was that the statutory health system needed to be much better at communicating and providing information to families and providing better emotional and practical support for parents / carers who are dealing with their child’s needs whilst they wait for health service treatment or interventions.

The need for improvement in training and support for parents of children with autism was a major issue. The current training workshops were described as ‘useful basic tools’ but that much more child-centred and family focussed programmes or services were required to support families in the longer term as issues arise. Families also raised concerns about a lack of support or interventions to meet children’s needs while they waited for a diagnosis or during the ‘watchful waiting’ period.

“When I was told my child was showing autistic traits, I didn’t know what to do, support at that point would have been good.” (Parent of child with Autism)

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There is a need for easily identified, timely and effective support for families / carers as another mother said,

“when you are in a good place (as a parent), you are better able to help your child.”

Deep-rooted problems

It is important to acknowledge that doctors, nurses, other health professionals and managers make every effort to ensure that any negative impact on patients is kept to a minimum. However, it must also be recognised that failures by the system to ensure patients get access to care and treatment has led to a lack of confidence and trust in it by patients and families. Whilst autism and scoliosis are very different conditions, requiring access to different parts of the healthcare system, there was a considerable amount of commonality in the feedback received from families on the impact of being on a health waiting list and the types of improvements they would like to see in the system.

4.0 Discussion & Conclusion

This Review aims to inform and advise ongoing and future work plans to address the problems of growing health waiting lists, to ensure children are visible as part of this process and that their rights are considered at all stages.

Clearly worsening waiting times is a symptom of a system under strain and therefore reform and redesign of services will be the change required to make the most significant difference to waiting times. A robust monitoring system that supports this process and allows everyone to better understand how change is impacting on the patient journey is also vitally important.

Hospital-based services and social care provision for older people tends to get most attention with respect to health and social care reform, however, community child health services provide essential health and developmental support for children and are inextricably linked to the hospital and broader social care system. A root and branch reform of the system must fully consider hospital and community-based health services and how they intersect with primary care, social services and education for children and young people. These are vital components of an integrated and right based health and social care system.

Achieving a Child Rights Based Health and Social Care System

The Department of Health has acknowledged that there is a lack of equity in access to healthcare and that a lack of regional planning in resource allocation and service delivery is contributing to this problem.⁵⁸ There is a judicial review ongoing in Northern Ireland centring on arguments that the Department of Health and HSCTs have a statutory obligation to provide effective healthcare within a reasonable timeframe. Part of the argument is that patients' human rights are being breached through excessive delays in care / treatment. The applicant is not specifying what they see as an 'acceptable waiting time' but highlighting the disparity between waiting times in NI compared to the rest of the UK.⁵⁹

⁵⁸ https://www.health-ni.gov.uk/sites/default/files/publications/health/day_case-elective-care-procedures.PDF

⁵⁹ <https://www.bbc.co.uk/news/uk-northern-ireland-55651118>

Application of a child rights impact assessment (CRIA) framework in the review of plans and proposals is required to ensure that children's rights are fully considered in all decision-making processes. It is apparent in the feedback from families that a delay in access to healthcare has a profound impact on all aspects of a child's life and the wider family circle. A central pillar of a right based healthcare system is one which takes account of the holistic needs of the child which includes their right to health (Article 24), access to play and leisure (Article 31) and education (Articles 28 and 29).

There have been a range of plans and strategies developed for children that are relevant to the health and social care reform process and it is essential that these inform the changes happening in the system. It is also important to identify parts of the system which require a fuller review and where there are existing gaps in understanding about what changes are needed and the level of resources required for their implementation. Community child health services is a clear example of where greater attention is needed. It is of grave concern that there is no regional comprehensive waiting list monitoring or reporting process in place for community child health services. This lack of visibility of children within this part of the system makes it impossible to adequately measure performance which is required to inform decision-making in relation to these services, and to ensure accountability in this respect.

Steps should be taken to improve the visibility of and accountability for children's health within key departments and agencies. This would also demonstrate commitment by the NI Executive to valuing children, realising their rights and delivering on their programme for government commitment of 'giving every child the best start in life'.⁶⁰

There are a number of ways this could be done which includes appointing a Deputy Chief Medical Officer for Child Health, which remains an outstanding recommendation from the 2018 report of the Inquiry into Hyponatremia related deaths in NI.⁶¹ Other actions could include appointing a policy lead for child health at the Department of Health to oversee the planning and delivery of child health services across the health and social care system and establishing a single point of entry process across all HSCTs for all child health services. It is preferable that those employed in these posts have operational experience in child health. Whilst there has been a general commitment to simplifying pathways for

⁶⁰ <https://www.education-ni.gov.uk/publications/children-and-young-peoples-strategy-2020-2030>

⁶¹ [Vol3-09-Recommendations.pdf \(ihrdni.org\)](#)

patients, with some progress already achieved in some HSCTs, i.e. SEHSCT and BHSCT, and within specific services, e.g. CAMHS, this model is yet to be fully regionalised for all child health services.

Establishing a transparent budgeting process which shows clear budgeting lines for public spending on children's health services, and which meets the five principles of public budgeting for children's rights is essential i.e. effectiveness, efficiency, equity, transparency and sustainability. Over the last 15 years NICCY has published a number of reports which have analysed Government spending on services for children and young people and has offered a range of advice on how a more transparent budgeting process, with a focus on budgeting for children could be achieved.⁶²

UK and Ireland Collaboration with Health Service Delivery

Northern Ireland already has experience of collaborating with other health systems in terms of commissioning healthcare services. There is an established commissioning process between Northern Ireland and other parts of the UK in the delivery of a range of health services, for example the use of Stanmore Hospital for orthopaedic surgery. There are also longstanding inter-governmental agreements between Northern Ireland and the Republic of Ireland, which include the All-Island Congenital Heart Disease Network and the North-West Cancer Centre at Altnagelvin.

It has been argued that considerable benefits could come from further collaboration, including building economies of scale, value for money, developing and sharing clinical specialisms, sharing data and better outcomes for patients.⁶³ It could also be argued that co-operation with neighbouring healthcare systems could mitigate against the establishment of a Two-Tier healthcare system in Northern Ireland where patients get access to clinical appointments if they pay privately. It may also help to ensure that people get access to care as close to home as possible. As outlined in section 3 of this report some families are travelling internationally to access time-critical health treatment for their children which cannot be provided by the Northern Ireland health system. It is critical that there is an improvement in waiting times, for children to be treated as close to home as

⁶² [Children's Budgeting in NI - An Exploratory Study \(niccy.org\)](https://www.niccy.org/publications/2014/march/31/childrens-budgeting-in-ni/); [Fund Mapping: the investment of public resources in the wellbeing of children and young people \(niccy.org\)](https://www.niccy.org/publications/2014/march/31/childrens-budgeting-in-ni/); <https://www.niccy.org/publications/2014/march/31/childrens-budgeting-in-ni/>

⁶³ [heenan_arins.pdf \(ria.ie\)](https://www.ria.ie/heenan_arins.pdf)

possible, and to prevent a two-tier system of healthcare developing in Northern Ireland.

Interim Waiting List Management Process

It is clear from the engagement with children and their parents/ carers that improvements in basic support and services such as communication in the form of 'state of play' updates and more regular reviews of their child's condition while waiting for appointments, would reduce much of the stress and anxiety. Information, communication, and coordination are important basic minimum standards for services, and these are particularly important when waiting times for treatment and interventions are as bad as they are. Parents also identified a need for clearer triaging processes across the system to flag and prioritise the most urgent cases, with regular reviews and monitoring of conditions. The stress and pressure on parents and carers as the main advocates for their child experiencing delays in access to healthcare is immense. A clear message from parents / carers was that emotional and practical support available to them is currently inadequate and needs to be improved. Good patient information management systems also support HSC to manage patient care; this is discussed further below.

Data Management Structures

Improvement in data management is critical to improving the quantity and quality of service and patient level data. Child health professionals NICCY engaged with as part of this review described *"a direct but invisible link between commissioning, service level performance data and patient satisfaction and health outcomes."* They also talked about how *"commissioning of funding for a service is difficult or impossible when the issue it is trying to address is invisible, poorly understood, and with weak lines of accountability."* The DoH has indicated that the new regional Encompass programme will have the capacity to record and report on health waiting times in a much more complete and detailed way.⁶⁴ This digital health record system has the potential to make outcomes and patient care a central focus, particularly if service providers and clinicians are involved in its design and roll-out, and the required resources are provided to ensure that it is fully harmonised across the system, utilised and maintained.

⁶⁴ [RAISE Report-waiting lists Jan 2020.pdf](#)

At a HSCT service level, ‘waiting times’ as a process target, remains the main performance measure. The limited system-wide attention given to performance beyond waiting times is perhaps understandable when one considers the pressure HSCTs are under to deliver core services, the limited information management resources available to them and the historical focus given to Ministerial waiting times targets. The commitments given by the current Health Minister to improve performance management and reporting, and to review how waiting times are measured, alongside the establishment of a waiting list management unit within the HSCB are very welcome. It is important that the scope of the work of this unit is broad enough to cover all child health services.

The Office for Statistics Regulation (OSR) has also recognised the need to improve the range and depth of official statistics produced on children and young people. They have published a framework which is aligned to the principles of child rights and proposes that producers of statistics consider children and young people through three lenses, also described as the ‘3V’s’ i.e. *visibility* (statistics are available on children and young people), *vulnerability* (the experiences of vulnerable children can be analysed separately), and *voice* (statistics reflect the views of children and young people and can be used by them).⁶⁵

Waiting Time Targets

Waiting time standards are an important tool for measuring and improving the performance of the health and social care system and providing accountability to patients and the public, however, they also inevitably lead to a focus on a limited number of services and measures, as generally, “*you value what you measure...*”.

The lack of departmental performance targets in community child health services means that waiting lists and therefore the impact on patient care is much less visible than those being treated in the hospital system as an outpatient or inpatient.⁶⁶ There is also an argument that there should be no waiting lists at all, particularly for certain treatments. As one young person waiting two years for urgent surgery for scoliosis said, “*I don’t think waiting lists should exist*”.

⁶⁵ <https://osr.statisticsauthority.gov.uk/think-of-the-children/>

⁶⁶ [NHS waiting times: our position | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/our-position-nhs-waiting-times)

The families spoken to for this review had experience of both hospital-based and community child health services and highlighted the far-reaching impact of delays to healthcare. They discussed the impact of waiting on their child's condition or disability, as well as their child's physical health and development, their social and emotional wellbeing, and education. It is vital that any performance management process takes account of whether the system is meeting the holistic needs of child patients. To date this level of information is only available by reviewing individual case files or care plans and is highly time intensive to aggregate up for broader system wide performance management purposes.

Quality of Care

In addition to introducing a Referral to Treatment (RTT) based waiting time monitoring measure, the Elective Care Framework set out a commitment to “*renew the focus on performance, quality and productivity...*” Quality of care is a vital component of the work needed to fully understand the system and to inform change.

There is currently no regional standardised quality framework for child health services. A consultation process for a service framework was carried out in 2014 by the Department of Health titled ‘Young People Health Services Standards Framework for Northern Ireland’ but it has never been published.⁶⁷ NICE are considering the development of a child health quality standard for improving services which reflect infant, child and young people's experience of healthcare, but to date nothing has been scheduled into the work programme.⁶⁸ There is a considerable gap in standards that the child health system can benchmark against and this must be addressed as a priority; benchmarking is fundamental to any performance management system.

This review does not propose to make recommendations on service delivery as it goes beyond its remit, however, it is important to note that parents /carers and children interviewed for this review highlighted a number of issues with services, many of which have been addressed in a range of other reports and reviews such as The Paediatric Strategies which outlines improvement plans for the whole system,⁶⁹ or Strategies or

⁶⁷ [Service framework for children and young people consultation | Department of Health \(health-ni.gov.uk\)](#)

⁶⁸ [Project information | Infant, children and young people's experience of healthcare | Quality standards | NICE](#)

⁶⁹ [A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community \(2016 - 2026\) | Department of Health \(health-ni.gov.uk\)](#)

reviews conducted by specialist charities and health professional bodies that focus on to different divisions of hospital or community child health services.⁷⁰ It also includes relevant advice and recommendations made by NICCY in recent reviews of mental health services and special educational need in which the need for improved co-ordination and communication between services and sectors was raised as a critical issue.⁷¹ The Children's Services Co-operation Act (Northern Ireland) 2015 which aims to improve co-operation amongst Departments and Agencies, places a duty on Children's Authorities, as defined by the Act, to co-operate where appropriate as they deliver services aimed at improving the well-being of children and young people.⁷²

Performance Management

The over-riding issues raised by families related to the need for improvement in information, communication, and co-ordination within and across services and the need for improvements in quality of care. Whilst some of these issues can be addressed through setting targets around patient reviews and updates, it also speaks to the bigger picture which considers service user satisfaction, outcomes and service standards. The value and importance of an outcomes / impact focused approach is recognised by Government and is the framework used to develop the current Programme for Government in NI. In line with this high-level strategic direction, a greater depth of information regarding patient experiences and outcomes should be collected and monitored as part of a broader performance management process, to include outcomes defined by, and important to children, young people and their families. Mechanisms to ensure that service user feedback is reflected in service improvement plans should also be strengthened.

The process of sourcing information on waiting times across key child health services has highlighted inconsistencies in the information used or gathered by different parts of the system. Hospital statistical information can be reported in various ways. This can be dependent on who is analysing / requesting information and what specifically the focus is

⁷⁰ [Autism strategy and action plan | Department of Health \(health-ni.gov.uk\)](#);
[Autism+NI+Broken+Promises+Report+\(1\).pdf \(squarespace.com\)](#);
https://10000morevoices.hscni.net/download/CAMHS-and-Autism-Regional-Report-Jan-2017_0.pdf;
<https://www.rqia.org.uk/RQIA/files/41/416f3113-627c-47f9-9007-6d8f38ff8662.pdf>;
[COVID-19 Urgent and Emergency Care Action Plan – 'No More Silos' | Department of Health \(health-ni.gov.uk\)](#);
[RCS England Northern Ireland Action Plan \(1\).pdf](#); [Surgeons outline 10-step plan to tackle backlog as half of patients wait over a year for planned surgery — Royal College of Surgeons \(rcseng.ac.uk\)](#)

⁷¹ *Op Cit- Still Waiting 2018; Too Little Too Late 2020*

⁷² <https://www.legislation.gov.uk/nia/2015/10>

for the user. For this piece of work, the information reported from HSCB to NICCY in relation to Outpatient & Inpatient/Daycase statistics, has been sourced via the Data Warehouse using Business Objects to extract relevant data recorded on the hospital PAS system. These do not include manual returns received from the Trusts, which are included in the DOH reported statistics.

Furthermore, the information collected on hospital services is much more detailed and standardised than that collected for community child health services. As outlined previously, there is no comprehensive regional standardised collation and reporting on waiting times for community child health services except for some limited information on CAMHS and Autism assessment and diagnosis.

From the outset of this review, it was clear that presenting waiting time data by 'paediatric specialty' did not provide a level of detail required to understand waiting times for children's health services. While a further breakdown to subspecialty level is a considerable improvement, in some instances several individual services are grouped into one subspecialty level. For example, within elective hospital services, 'scoliosis' as a specific child health service is grouped under the subspecialty 'trauma and orthopaedics' which contains a range of conditions. In community child health services similar issues are apparent with the grouping several services under one code for administrative purposes.

More broadly, to take a holistic approach to child's health, which is fundamental to a child rights-based healthcare system, key staff across various parts of the HSC system must be able to track children and young people's pathways. This will require primary, secondary and tertiary healthcare services having fully integrated information systems and NICCY has made recommendations regarding the need for improvements in collation of data in both its review of mental health services and special education need provision in mainstream schools.⁷³ Performance management processes should ensure that the information captured is at a level of detail that is useful for policy, clinical and administrative purposes and therefore it is vital that a range of data users are involved in identifying the information that should be collected by the system.

⁷³ [niccy-still-waiting-report-sept-18-web.pdf](#); [Too Little Too Late Reports \(niccy.org\)](#)

Conclusion

Children's rights, including the right to health, right to be heard, right to have their best interests as a paramount consideration, and to be treated without discrimination, must be at the forefront of decision-making and action to reduce waiting times. Indeed, this must be a lens through which health and social care reform is undertaken.

We must strive to get to the stage where all children and young people have access to the right care or treatment, at the right time and in the right place, and that no child is left waiting months or years in a queue to access services. Children have a right to receive high quality healthcare without any unnecessary delay. NICCY commits to monitoring the implementation of the recommendations in this review and will publish a progress update report in Autumn 2022.

5.0 Recommendations

Rights Based Approach to delivery of Health and Social Care System

1. Embed a rights-based approach to the delivery of child health and social care services in Northern Ireland. This should include the application of a child rights assessment framework in the development or review of plans and proposals to ensure that children's rights are fully considered in all decision-making processes.

Enabling Processes and Structures

2. A full review of the child health system should be undertaken to ensure that health and social care reform is based on an up-to-date understanding of need across the system. This process should take account of existing implementation plans relevant to the reform and redesign of children's health services and care pathways, and address gaps in knowledge about individual child health services.
3. Improve the visibility of and accountability for children's health within key departments or agencies by:
 - a. Considering the appointment of a Deputy Chief Medical Officer for Child Health;
 - b. Considering the appointment of a policy lead for child health at the Department of Health;
 - c. Establishing a single point of entry system across all HSCTs for all child health services; and
 - d. Strengthening co-ordination between the Departments of Health, Education and Communities for children with complex and long-term health conditions.
4. Establish a transparent budgeting process that shows clear budgeting lines for public spending on children's health services which meets the five child rights principles for public budgeting i.e. effectiveness, efficiency, equity, transparency and sustainability.
5. Explore the potential for further strengthening collaboration with neighbouring jurisdictions in the delivery of health services for children that could help reduce waiting times, improve quality of care and patient outcomes.

6. Establish an interim regional waiting list management process to better monitor and review children on hospital and community health service waiting lists - to include enhanced clinical triage, targets for review appointments and support for parents / carers.

Performance Management

7. Develop a data management process that applies the principles of visibility, vulnerability and voice as recommended by the Office for Statistics Regulation (OSR).
8. Collect and monitor a greater depth of information regarding patient experiences and outcomes, including outcomes identified by children, young people and their families. Mechanisms to ensure that service user feedback is reflected in service improvements should be strengthened.
9. Establish an agreed set of minimum service standards which can be used as a benchmark by the health and social care system. Improvement plans should be put in place for those services requiring support to meet these standards.
10. All parts of the system should use the same source data for analysing and interpreting service performance and waiting time information. The system codes used across primary, secondary and tertiary services should be harmonised to include specific codes for individual child health services and be integrated with electronic patient health records to ensure no duplication of waiters / referrals are included in waiting time statistics.

Waiting Time Measures

11. Comprehensive waiting time data on hospital and community child health services should be developed as part of a broader performance management system. A range of data users should be involved in determining the information collected by the system; the data collected should include the following:
 - a. Breakdown by specific child health services;
 - b. Number waiting, length of time waiting;

- c. Maximum full patient journey times from referral to treatment;
- d. Number of referrals and % accepted and not accepted;
- e. Referral types i.e. routine/ urgent / red flag referrals;
- f. Waiting times between referral and first appointment;
- g. Waiting times between first and follow-up appointment with professionals;
- h. Waiting time between referral and diagnosis and diagnosis and treatment;
- i. Measuring and reporting on waiting times for health professionals other than first appointment with consultant, to include Allied Health Professionals, Technicians or Nurses;
- j. Waiting times for transition / transfer from paediatric to adult services;
- k. Breakdowns (disaggregated data) by demographic characteristics and geographic area i.e deprivation and HSCT; and
- l. Monitoring and reporting on HSC patients treated by the independent sector and out of jurisdiction i.e. number, conditions, cost.

Quarterly Waiting Time Reporting Process

- 12. Hospital Waiting Time reporting should always be disaggregated by specific child health services alongside type of treatment i.e. outpatient, inpatient, day case, diagnostics, treatment / surgical waiting times.
- 13. Community Child Health Waiting Times reporting should be established in line with scheduled publishing for hospital waiting times.

Waiting Time Targets

- 14. Consideration should be given to whether child specific waiting time targets should be developed for elective hospital services.
- 15. Establish regional waiting time targets for community child health services.
- 16. Set waiting time targets for review appointments for both hospital (elective) and community child health services.
- 17. Consider ways to strengthen accountability for breaches of waiting time targets, such as a regional performance dashboard.

6.0 Appendices

Appendix 1

Waiting Time Targets

Elective Care Framework for Northern Ireland (June 2021)

The current waiting time target was set by the Minister of Health in June 2021 as part of the Elective Care Framework for Northern Ireland, and states that:

“By March 2026, no patient will be waiting more than 52 weeks for a first outpatient appointment or inpatient/day case treatment; or 26 weeks for a diagnostics appointment.”

NDNA Agreement (January 2020) (superseded by Elective Care Framework)

No-one waiting over a year at 30 September 2019 for outpatient or inpatient assessment / treatment will still be on a waiting list by March 2021.⁷⁴

March 2019- January 2020 (superseded by NDNA)

The ministerial target for outpatient waiting times:

*By March 2019/ 2020/ 2021, at least 50% of patients should **wait no longer than nine weeks for a first outpatient appointment**, with no patient waiting **longer than 52 weeks**.*

The ministerial target for diagnostic waiting times is as follows:

*By March 2019/ 2020/ 2021, 75% of patients should **wait no longer than nine weeks for a diagnostic test**, with no patient waiting **longer than 26 weeks**.*

The ministerial target for inpatient and day case waiting times:

*By March 2019/ 2020/ 2021, 55% of patients should **wait no longer than 13 weeks for inpatient or day case treatment**, with no patient waiting **longer than 52 weeks**.*

⁷⁴ [2020-01-08_a_new_decade_a_new_approach.pdf \(publishing.service.gov.uk\)](#)

Appendix 2

DoH Hospital Waiting Time Bulletins

The following tables include extrapolated waiting time data for paediatrics from the waiting time reports published by the Department of Health.

The information presented in DoH reports are derived from the Departmental Outpatient Waiting Times Dataset, CH3 Return (for data not on the Patient Administration System-PAS), Quarterly Outpatient Activity Return (QOAR), Regional Quarterly Outpatient Activity Return (R-QOAR) and IS1 Part 1 Return. These are provided by HSC Trusts and the HSC Board on a quarterly basis.⁷⁵

FIRST CONSULTANT LED OUTPATIENT APTS

Table 1: Number of patients waiting for a first consultant-led outpatient appointment within a paediatric specialty by weeks waiting at 31 March 2019, 2020 and 2021

At 31 March	0-6	>6-<9	>9-<12	>12-<15	>15-<18	>18-52	>52	Total waiting
2019	3,695	1,447	1,113	589	738	3,086	2,330	12,998
2020	2,950	1,709	1,373	638	946	4,530	3,394	15,540
2021	2,799	894	673	435	597	3,377	6,206	14,981

Source: Department of Health website, Publications, out-patient statistics Q4 2018/19 (Table 3a, p10); Q4, 2019-20 (Table 3a, p.11); Q4 2020-21 (Table 3a, p11)

Table 2: Percentage of patients waiting for a first consultant-led outpatient appointment within a paediatric specialty by weeks waiting at 31 March 2019, 2020 and 2021

At 31 March	0-6	>6-<9	>9-<12	>12-<15	>15-<18	>18-52	>52
2019	28.4%	11.1%	8.6%	4.5%	5.7%	23.7%	17.9%
2020	19.0%	11.0%	8.8%	4.1%	6.1%	29.2%	21.8%
2021	18.7%	6.0%	4.5%	2.9%	4.0%	22.5%	41.4%

Source: Department of Health website, Publications, out-patient statistics Q4 2018/19 (Table 3b, p11); Q4, 2019-20 (Table 3b, p.12); Q4 2020-21 (Table 3a, p12)

⁷⁵ The DOH guidance explains how they record and report figures – [Inpatient and Day Case Waiting Times - Supporting Documentation \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/inpatient-and-day-case-waiting-times-supporting-documentation)
[Outpatient waiting times - supporting documentation | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/outpatient-waiting-times-supporting-documentation)

INPATIENT / DAY CASE APTS (paediatrics and paediatric surgery)

Table 3: Number of patients waiting for a inpatient /day case appointment under paediatric specialty by weeks waiting at 31 March 2019, 2020 and 2021

At 31 March	0-6	>6-<13	>13-<21	>21-<26	>26-<52	>52	Total waiting
2019	73	71	67	29	120	88	448
2020	54	90	49	38	153	255	639
2021	30	29	34	15	44	342	494

Source: Department of Health website, Publications, in-patient/ day case statistics Q4 2018/19 (Table 3a, p10); Q4, 2019-20 (Table 3a, p.10); Q4 2020-21 (Table 3a, p10)

Table 4: Percentage of patients waiting for an inpatient/day case appointment for under paediatric specialty by weeks waiting at 31 March 2019, 2020 and 2021

At 31 March	0-6	>6-<13	>13-<21	>21-<26	>26-<52	>52
2019	16.3%	15.8%	15.0%	6.5%	26.8%	19.6%
2020	8.5%	14.1%	7.7%	5.9%	23.9%	39.9%
2021	6.1%	5.9%	6.9%	3.0%	8.9%	69.2%

Source: Department of Health website, Publications, in-patient/ day case statistics Q4 2018/19 (Table 3b, p11); Q4, 2019-20 (Table 3b, p.11); Q4 2020-21 (Table 3b, p11)

Table 5: Number of patients waiting for a inpatient /day case appointment under paediatric surgery specialty by weeks waiting at 31 March 2019 2020 and 2021

At 31 March	0-6	>6-<13	>13-<21	>21-<26	>26-<52	>52	Total waiting
2019	143	131	105	53	172	166	770
2020	90	125	112	58	205	174	764
2021	81	93	79	50	89	487	879

Source: Department of Health website, Publications, in-patient/ day case statistics Q4 2018/19 (Table 3a, p10); Q4, 2019-20 (Table 3a, p.10); Q4 2020-21 (Table 3a, p10)

Table 6: Percentage of patients waiting for a inpatient /day case appointment under paediatric surgery specialty by weeks waiting at 31 March 2019 2020 and 2021

At 31 March	0-6	>6- <13	>13- <21	>21- <26	>26- <52	>52
2019	18.6%	17.0%	13.6%	6.9%	22.3%	21.6%
2020	11.8%	16.4%	14.7%	7.6%	26.8%	22.8%
2021	9.2%	10.6%	9.0%	5.7%	10.1%	55.4%

Source: Department of Health website, Publications, in-patient/ day case statistics
Q4 2018/19 (Table 3b, p11); Q4, 2019-20 (Table 3b, p.11); Q4 2020-21 (Table 3b, p11)

Appendix 3

Definitions

The following definitions are provided for a number of technical terms that will be used within the report.

Acute Care

Acute care is a branch of secondary healthcare where a patient receives active but short-term treatment for a severe injury or episode of illness, an urgent medical condition, or during recovery from surgery.

Day Case / Inpatient Care (DC / IP)

When a patient requires treatment they will be added to a waiting list. If it is expected that the patient will not require an overnight stay they are added to a Day Case waiting list. If it is expected that the patient will likely require a minimum 1 overnight stay, then they are added as an Inpatient Waiting List.

CAMHS

Child and Adolescent Mental Health Services (CAMHS) is the overarching service which encompasses a number of teams- these are Primary Mental Health Teams, Step 3 / Core CAMHS, Eating Disorder service, Crisis Response Home Treatment and Drug and Alcohol Mental Health Service.

Elective Care

Elective care is care that is planned, it involves specialist clinical care or surgery, generally following a referral from a GP or community health professional.

First Consultant Led Outpatient Appointment (OP)

Outpatients can be assessed at consultant or nurse-led clinics. For reporting and general service budget agreements, the figures are usually reported against those patients awaiting their first appointment with a consultant.

Hospital Waiting Lists

Waiting lists fall under the grouping of assessment (Outpatient), treatment (Inpatient / Day case), and Diagnosis. These can be monitored & reported in various ways depending on the audience / requester e.g. for budgeting / staffing / capacity / patients waiting for specific consultant or specialties.

Paediatric Specialty

Paediatrics is the branch of medicine that involves the medical care of infants, children, and adolescents. Some Trusts will have specified Paediatric Specialities – most commonly found for instance within The Royal Belfast Hospital for Sick Children (RBHSC).

Priority Levels of Referrals

RED FLAG = suspect / confirmed cancers

URGENT = requiring urgent attention (appointment or surgery or tests)

ROUTINE = condition requiring advice / review but non-urgent

Regional (Korner) Specialty

This refers to the overall regional title of agreed specialty e.g. General Surgery / General Medicine.

Review Outpatient Appointment / Nurse Led / Pre-Assessment / Technician Led

Once a patient has had their initial first appointment they can be added to a review waiting list, discharged back to referrer or added to a diagnostic or treatment waiting list.

RTT

Referral to Treatment (RTT) waiting times reflect the entire patient journey, from GP referral up to the point where the patient receives treatment.

Subspecialty

The sub-specialty or local speciality within the main regional (kroner) specialty e.g. General Surgery can be split by Vascular / Breast / Paediatric and General Surgery.

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