One Year Post Publication Monitoring Report
'More Than A Number'- A Rights Based Review of Child Health Waiting Lists

27 October 2022

"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 moulded into a human who will then live life; he is a human who is living life."

Professor T. Ripaldi

1.0 Background

NICCY was established under the Commissioner for Children and Young People (NI) Order 2003. The principal aim of the Commissioner is to safeguard and promote the rights and best interests of children and young people in NI. In exercising these functions, the Commissioner must also have regard to all provisions of the United Nations Convention on the Rights of the Child (UNCRC). *More Than a Number* was conducted in accordance with the powers and functions set out in the Order. In particular, in line with statutory duties to 'keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities, to advise Government and relevant authorities, and encourage children and young people and their parents / carers to communicate with the Commissioner and for their views to be sought.

2.0 More Than A Number

NICCY published *More Than a Number: A Rights Based Review of Child Health Waiting Lists* on 19 October 2021. The aim of the Review was to inform and advise ongoing and future workplans to address the problem of growing paediatric health waiting lists, to ensure children are visible as part of this process and that their rights are considered at all stages.

The Review presented official waiting list data for children's health services not published as part of the Department of Health (DoH) statistical bulletins. It included the voices of children and their families on the impact that waiting was having on their health and quality

of life and outlined their views on what needs to change about the system. NICCY also engaged with professionals and practitioners working in and for child health services.

NICCY's Review made 17 recommendations under four thematic areas which aim to improve the visibility of children across hospital and community child health services, as well as strengthen accountability in decision making, performance reporting and budget allocation processes.

Following publication of the Review, NICCY requested a written response to the recommendations from DoH. The Commissioner also committed to reporting on progress one year after its publication.

This Monitoring Report sets out NICCY's assessment of progress towards implementing the Review recommendations one year after they were made and provides further advice and commentary on what further steps should be taken. It is informed by updated waiting time statistics and feedback from DoH. The original Review provides a lot of background information, i.e. references, methodology and definitions which will not be repeated in this report and therefore it should be read in conjunction with this progress update.[1]

3.0 Context

While the problems with the Health and Social Care (HSC) system's ability to meet healthcare needs have been widely acknowledged, and the numbers of people on waiting lists regularly discussed, prior to this Review, consideration of these issues from the perspective of children's health services had not.

NICCY's Review, published in October 2021, followed commitments made in January 2020 by a restored NI Executive under the 'New Decade, New Approach' Agreement (NDNA). These commitments included addressing the waiting list problem, which covered 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'. NDNA also reasserted the Executive's commitment to 'transform the health system by providing long term funding' and implementation of the 'reform agenda outlined in Bengoa, Delivering Together, and Power

[1] https://www.niccy.org/waitinglists

to People Report'.[2]

Tragically, the pandemic and a further period without an Assembly or Executive has followed, an already struggling HSC system has been pushed to breaking point and some would argue that it has now broken. Restrictions on access and availability of public health services during the pandemic has inevitably increased the number of people on waiting lists. However, a lack of progress on HSC reform before the pandemic and periods without an Assembly or Executive means that the leadership and decision-making mechanisms required to rebuild, and reform has not progressed at the pace they need to. The NI Fiscal Council report, published in September 2022, is the most recent addition to the growing bank of independent and expert-led reports and reviews reaffirming that our HSC system is unsustainable in its current form and that waiting times for health care in NI are consistently higher than in England, Scotland and Wales.[3]

4.0 Child Heath Waiting Time Lists - Updated data for April 2022

The waiting time statistics provided in *More Than a Number* brought into sharp focus the numbers of children waiting for different types of healthcare treatment and lengths of time they were waiting. It showed year on year increases in the number of children waiting for a first consultant led outpatient or inpatient / day case appointment between 2017 and 2021. It also showed a considerable spike in numbers waiting for these services between 2020 and 2021 which was the period impacted by pandemic restrictions. The data gathered as part of the Review for community health services was limited to a small range of services, due to a lack of regional standardised collation or reporting, but the information available also indicated large numbers of children waiting for community child health services.

Updated data for April 2022 continues to present a stark and concerning picture on child health waiting times. Waiting times have continued to increase, with many more children waiting over a year for a first consultant led outpatient or inpatient / day case appointment. In fact, an increasing number of children are waiting years for a first appointment with some services. A summary of the key statistics are outlined below and fuller detail is available in Appendix 1.

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[2] New Decade, New Approach Agreement **2020-01-08_a_new_decade__a_new_approach.pdf (publishing.service.gov.uk)** p6

[3] NI Fiscal Council Sustainability Report 2022: special focus – Health, available from Sustainability Report 2022: special focus - Health | NI Fiscal Council

Outpatient or Inpatient Day Case Appointments

- At April 2022, 38,628 children were waiting for a first consultant led outpatient appointment. This represents a 9% increase or 3,344 more children waiting at April 2022 compared to April 2021.

- At April 2022, 10,371 were waiting for a first consultant led inpatient / day case appointment. This represents a 9% increase or 891 more children waiting at April 2022 compared to April 2021.

- At April 2022, 41% (15,727) of those waiting for first consultant led outpatient appointment have been waiting > 52 weeks.

- At April 2022, 53% (5,462) of those waiting for first consultant led inpatient / day case appointment have been waiting > 52 weeks.

- Between 2021 and 2022, there have been large increases in numbers of children waiting 2 years or over for a consultant led appointment across all HSCTs. This includes 3,213 more children waiting 104-208 weeks (2-4 years) and 939 more children waiting more than 208 weeks (over 4 years) for a first consultant led outpatient appointment; and 1,618 more children waiting >104-208 weeks (2-4 years) and 414 more children waiting over 4 years for a consultant led inpatient / day case appointment.

- The proportion of outpatient waits across priority types, i.e. red flag, urgent and routine has remained consistent between April 2021 and 2022. However, there has been an overall decrease by 2,405 in the number of red flag or urgent referrals waiting to be seen.

- The proportion of Inpatient / Daycase referrals classified as urgent increased from 24% in 2021 to 32% in 2022.

Community Child Health Services

- Between 2021 and 2022 there has been an overall increase of 28% in the number of children waiting for an appointment with one of the community child health services on the Primary Targeting Lists. This equates to 7,460 more children.

- A small number of services have seen a decrease in waiting times between April 2021

and 20211, however, in most cases waiting lists have increased. This is particularly noticeable for Child Health Psychology which has seen a 185% increase, Speech and Language Therapy which has seen an 87% increase followed by CAMHS with a 52% increase and increases of between 30-39% for Autism Assessments, Orthoptics and Nutrition and Dietetics.

- Between 2021 and 2022 there has been an 8% decrease (35) in the number of children waiting for an autism intervention, but a 33% increase (1,690) in the number of children waiting for an autism assessment.

- All HSCTs apart from the SHSCT have seen an increase in the number of children waiting for a first appointment for Step 3 CAMHS. The number of children waiting in the NHSCT has more than doubled (from 359 to 739) and in the WHSCT numbers have increased by 75% (301 to 526).

More Than a Number included the voices of children on waiting lists and their parents / carers, and it was clear from their experiences that delays in access to healthcare has a considerable impact on children's physical 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 and siblings. The updated waiting time statistics for April 2022 are showing a deteriorating picture in terms of numbers of children on health waiting lists, with many more waiting excessively long lengths of time - which extend beyond 2 years for some services. This is clearly having significant adverse impacts on many children and families.

5.0 NICCY Assessment of Progress

The remainder of this report sets out NICCY's assessment of progress on implementation of the recommendations set out in *More Than a Number*.[4] Appendix 2 provides the response from DoH to each of the 17 recommendations made in the Review.

NICCY's recommendations can be grouped under four thematic areas, and these have

[4] Further detail and background information, including definitions and methodology for collecting data are available from the original report which is available from NICCYs website.

been used to structure this progress update and each of the recommendations are listed under the relevant theme:

1. Achieving a Child Rights Based Health and Social Care System;
2. Enabling Processes and Structures;
3. Performance Management; and
4. Waiting Time Measures, Quarterly Reporting and Targets.

5.1 Achieving a Child Rights Based Health and Social Care System (Theme 1)

Recommendation 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.

5.1.1 Why this recommendation is important

More Than a Number acknowledged that worsening waiting times is a symptom of a system under strain and that reform and redesign of services will be the change required to make the most significant difference to waiting times. It also emphasised that the HSC reform process must fully consider children's hospital and community-based health services and how they intersect with primary care, social services and education for children and young people. It described these are vital components of an integrated and rights-based HSC system.

Furthermore, NICCY's Review also advised that 'Think Child Rights' should be central to all decision-making processes on the design and reform of the Northern Ireland healthcare system. It argued that embedding Child Rights Impact Assessments (CRIA) into all Government planning processes would be a practical tool for achieving this. The application of a CRIA should be an essential element of a child rights-based health care system and this 'child rights proofing process' is directly inter-linked with the other key recommendations made in *More Than a Number* which relate to the importance of transparent budgeting, disaggregated data, children's participation and specific children's service standards.

5.1.2 What progress has been made?

NICCY understands from DoH's response to the recommendations in *More Than a Number* that their assessment is that a practical and immediate improvement to child health waiting lists can be gained from providing a renewed focus on the Strategy for Paediatric Hospital and Community Care 2016-2026. In the current climate, NICCY understands DoH's view that building on existing work and structures is the best way forward, however, NICCY's Review drew attention to the lack of investment or prioritisation given to the Strategy for Paediatric Hospital and Community Care since it was published six years ago. More recently, NICCY's Covid Monitoring report - *'A New and Better Normal'* could not find substantial evidence that children have been at the forefront of decision making with regards to Covid-19 rebuild across departments, including in health where a 'Paediatric Rebuild Plan' is still in draft.[5] Further details on how DoH plans to address the historical lack of focus given to children's health services is essential.

It is also important to draw attention to the scope of the Strategy for Paediatric Hospital and Community Care. While it included objectives for improving both hospital and community health services, community health services were given less focus. For this reason, while we acknowledge the Department's position that a full review of children's health services may not be possible at this time, they must proceed with a focused regional review of community services.

NICCY also understand from the DoH response that the Child Health Partnership will provide the vehicle for driving forward the programme of work that was identified within the Paediatric Strategies, as well as the additional challenges of pandemic rebuilding. DoH has stated its intention to ensure that the 'paediatric network is reinvigorated and supported to take on this role.' It is critical that there are robust governance and operational structures to support the delivery of the Paediatric Strategies and the broader reform of the child health system. The structures driving this programme of work forward must be adequately resourced and given responsibility to directly inform, or make key decisions on, commissioning and planning. The need for great visibility and accountability

[5] NICCYs Assessment of Government Response to recommendations in 'A New and Better Normal Report' https://www.niccy.org/about-us/our-current-work/covid-19-niccys-work/

for children's health care is essential and is the focus of recommendation 3 from *More Than a Number*.

NICCY welcome DoH's interest in better understanding the value and use of CRIAs in informing Government decision making.[6] NICCY has already delivered introductory sessions with DoH Officials and is in the process of finalising training modules to be made available on the 'LInKS' NI Civil Service training platform. Developing an understanding of CRIAs also by its nature brings an appreciation and understanding of the reason why child rights budgeting, disaggregated data, children's participation, and specific children's service standards are important. Collectively they have a very powerful and practical use in ensuring that children's welfare, rights and best interests are 'central to all relevant policy decision making.' NICCY welcomes DoH's recent use of a CRIA in the development of the Cancer Strategy. NICCY is willing to provide advice and support to DoH as it goes through a process of learning in how to apply child rights proofing exercises to its policy planning work.

5.2 Enabling Processes and Structures (Theme 2)

Recommendation 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.

Recommendation 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.

Recommendation 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

[6] https://www.niccy.org/about-us/childrens-rights/child-rights-impact-assessment-cria/

sustainability.

Recommendation 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.

5.2.1 Why these recommendations are important

More Than a Number identified a number of strategies relevant to children's health services in addition to the Paediatric Strategies, this included the urgent and emergency service review, disability framework, the review of general surgery, elective care frameworks, regional day case elective care surgeries, amongst others. In some cases, it was unclear what their relevance or focus was to children's services or how they related to the bigger picture in terms of a system wide review.

In order to bring more coherence and co-ordination to the range of reform processes already happening across the system, including identifying gaps, *More Than a Number* recommended that a full review of the child health system should be undertaken to ensure that HSC reform is based on an up-to-date understanding of need across the system and takes account of existing plans and strategies.

NICCY also called for improvements in the visibility of, and accountability for, children's health within key departments and agencies with the introduction of high-level dedicated posts to oversee commissioning, policy and service delivery, to include a Deputy Chief Medical Officer for Child Health. These dedicated posts could then address a wide range of issues such as improving co-ordination and integration across different services which would be particularly beneficial to those children and young people with complex or long-term health conditions.

The ability of any government to demonstrate how much public money is being invested on children is at the core of a child rights-based health care system, without which it is impossible to measure or demonstrate effectiveness, efficiency, equity, transparency or sustainability. NICCY's report also acknowledged the existing collaborative cross-jurisdictional work on child health delivery and encouraged further strengthening of this where it offered benefits in terms of reducing waiting times or improving quality of care.

5.2.2 What progress has been made?

NICCY accepts that DoH does not believe a full review of children's health services is possible or prudent at this time, however, as stated under Theme 1, it is urged that DoH consider proceeding with a focused regional review of community child health services and bring forward a 'Paediatric Services Rebuild and Recovery Plan' without delay. In the medium to long term, a more comprehensive review of the child health system remains a requirement to inform the HSC Reform process. This must take account of the important work already underway to reform different parts of the children's health system, which includes but is not limited to the delivery of paediatric surgery and the development of service delivery frameworks such as the 'Emotional Health and Wellbeing Framework' and 'Children with Disability Services Framework'.

NICCY welcomes the fact that a process is in place to appoint a senior medical officer with responsibility for child health. A senior level public health lead solely focused on children's health services will be extremely valuable in the child health reform process going forward.

It is noted that DoH does not accept the recommendation to have a dedicated departmental policy lead for child health. NICCY remains of the view that a dedicated policy lead for child health would be the most effective way of addressing fragmentation at policy and commissioning level, which can lead to weak lines of accountability and decision making. It is imperative that procedural arrangements are reviewed to strengthen co-ordination and joint working across the different parts of DoH where decisions impacting on children's health care are made. NICCY would argue that applying a CRIA process to decision making, which by its nature requires a 'whole child' approach, would encourage co-operation across Departmental policy boundaries.

NICCY acknowledges the challenges faced by DoH in extrapolating spend on children's services using the current system. However, 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.[7] NICCY strongly recommends that DoH considers solutions to this problem starting with those services in which it is easier to extrapolate spend on children's health services. As noted in DoH's

[7] Children's Budgeting in NI - An Exploratory Study (niccy.org); 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/

response, the move to a new Integrated Care System for planning health and social care services provides an opportunity to do things differently, which should include having clear and transparent budgeting lines for public spending on children's health services.

5.3 Performance Management (Theme 3)

Recommendation 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.

Recommendation 7: Develop a data management process that applies the principles of visibility, vulnerability and voice as recommended by the Office for Statistics Regulation (OSR).

Recommendation 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.

Recommendation 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.

5.3.1 Why these recommendations are important

Structural change of the HSC system is critical but running alongside this is the need for robust accountability, performance management and monitoring systems that support this change process and allows everyone to better understand how change is impacting the patient journey. Good quality and comprehensive data is required to inform robust decision making, service planning and commissioning, that includes waiting times, clear and specific service standards, and a focus on patient outcomes. In all these areas, NICCY's Review found that improvements were needed.

In recognition of the fact that children and families are struggling now, and that it will take time to reduce waiting times and reform the system, NICCY's Review also made a specific recommendation for the establishment of an interim regional waiting list management process to better monitor children who are currently on hospital and community health

service waiting lists - to include enhanced clinical triage, targets for review appointments and support for parents / carers.

5.3.2 What progress has been made?

As part of the establishment of the Waiting List Management Unit (WLMU), NICCY welcome DoH's work to establish dashboards to better monitor children on hospital waiting lists and to maximise the efficient use of clinical time. NICCY also welcomes the WLMU working with the HSCTs and the Patient and Client Council to agree how standardised waiting time information can be made accessible to both GPs and patients. DoH's engagement with an ongoing investigation by the Northern Ireland Public Service Ombudsman into communication with patients on healthcare waiting lists is also positive. However, as documented in NICCY's Review, the stress and challenges faced by parents of children on health waiting lists and by children themselves can be significant. It important that the WLMU, or some other more suitable mechanism also addresses the need for support for parents / carers on waiting lists to include advice on how to manage their child's condition while waiting, how to identify when their condition has deteriorated and for families to have a key contact point for advice or support.

NICCY recognises existing mechanisms involving Public Health Agency, Patient and Client Council and HSCTs to capture service user feedback and are encouraged by the range of developments that appear to be happening to encourage children and young people to engage in these initiatives. Patient engagement strategies for children and young people must be tailored and age-appropriate, and robust system-wide mechanism(s) should be in place to ensure that service user feedback directly shapes services. It is also important that there is a 360-feedback loop so that patients are made aware of how their views have informed service delivery.

NICCY welcomes the fact that DoH recognises the current gap in service standards for child health services and that it 'will consider how standards and quality monitoring systems for child health services may be incorporated into the new Integrated Care System which is currently under development'. Clear and specific child health service standards lead to more tailored and age-specific understanding of care and treatment for children. This is valuable to the patients, parents and carers, and the professionals involved in service delivery, policy and commissioning.

5.4 Waiting Time Measures, Quarterly Reporting and Targets (Theme 4)

Recommendation 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.

Recommendation 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.

Recommendation 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.

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

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

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

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

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

5.4.1 Why these recommendations are important

Setting waiting time standards and measuring services against these are important for monitoring and improving health service performance and providing accountability to patients and the public.[8] The Executive, in 'NDNA' recognised the need to improve waiting

[8] NHS waiting times: our position | The King's Fund (kingsfund.org.uk)

time measurement as part of tackling delays in access to healthcare, and committed to reviewing how waiting times were measured to more accurately reflect the full patient journey.

NICCY's Review offered an insight into what and how statistics were collected across the child health services. It found that, generally, the information in DoH Waiting time statistical bulletins were limited with respect to first consultant led outpatient and inpatient / day case services. However, a reasonable level of disaggregated data that included sub-specialities and waiting time bands longer than 52 weeks, was available on request from the Health and Social Care Board (now the Strategic Planning and Performance Group). It also found a complete absence of regional monitoring or reporting of waiting times for the community child health system.

NICCY recommended that comprehensive waiting time data on hospital and community child health services should be developed as part of a broader performance management system. NICCY also advised that a range of data users should be involved in determining the information collected by the system and that this more detailed data should be reported on as part of DoH statistical reporting schedule. Furthermore, NICCY advised that consideration should be given to establishing specific waiting time targets for child health services. These recommendations were aimed at ensuring that all child health services across the system have equitable standards in terms of level and quality of data available and reported on.

5.4.2 What progress has been made?

NICCY welcomes DoH's response acknowledging the need for improvement in how child health data is collected, analysed and used. NICCY also welcomes the development of the waiting time dashboards for some elective and social care services, the planning work being done with colleagues working on Digital Health and Care NI system, and the DOH's commitment to consider how a greater amount of disaggregated data could be published on paediatric sub-specialty and non-consultant led activity.[9]

NICCY also notes that DoH statisticians are engaging with the Strategic Planning and Performance Group to establish what CAMHS information currently available would meet

[9] Official waiting time data for consultant led outpatient apts is provided by 'paediatric specialty, however there are approximately 50 subspecialties that fall under this. Available from More Than A Number: A Rights Based Review of Health Waiting Lists in Northern Ireland (niccy.org) p.30

official statistics standards and could potentially be disseminated under that framework. NICCY has been monitoring CAMHS statistics as part of the monitoring of 'Still Waiting' since 2018 and has made a specific recommendation for official statistics on CAMHS data to be published in line with other health statistical reporting.[10]

It has been very disappointing that NICCY had to carry out a discrete piece of work again this year to gather basic waiting time information on community child health services, because a regional system is not in place.[11] NICCY notes DoH's intention to address this gap as part of the Encompass software programme. However, NICCY is concerned that this will take some time to complete. This gap in information needs to be filled urgently to inform decision making now, and the broader data development agenda for these services going forward.

Overall, there is clearly a significant amount of work required to bring the child health information management system to an adequate standard. It is vital these issues are given a clear focus in the development of the new Integrated Care System and as part of the Encompass software programme. A range of data users must be involved in this process so that one central source can be used for multiple needs or outputs whether that be at the clinical level, or for commissioning, policy, or performance management purposes.

6.0 Conclusion

NICCY has carefully considered the Department's assessment of our Review recommendations and what can be achieved in the short, medium and longer term. While recognising that the political and financial context DoH is working in remains extremely challenging, there are actions that can be taken, and planning work progressed, while we await the return of a fully functioning Assembly. The DoH response to our Review recommendations has shown that this is possible as they are progressing the appointment of a senior medical officer with responsibility for child health. The WLMU has been actively trying to improve the management of patients through the system, the Department has been applying child rights proofing to strategic plans and active steps have been taken to strengthen HSC mechanisms for gathering the views of patients and public aged under 18 years old. NICCY also understand that the Department is drafting a Paediatric Services

[10] NICCY Still Waiting Monitoring Reports, available from https://www.niccy.org/about-us/our-current-work/mental-health-review-still-waiting/

[11] Each HSCT collates waiting time data for some community child health services which are known as Primary Targeting Lists (PTL), these are historic lists, with no particular criteria set for which services become part of the monitoring list. More Than A Number: A Rights Based Review of Health Waiting Lists in Northern Ireland (niccy.org)

Rebuild and Recovery Plan.[12] NICCY also notes the planning work being undertaken to ensure that standards and quality monitoring systems for child health services are a core focus of the new Integrated Care System. However, the timeframes for these actions are less clear.

NICCY understands the Department is committed to seeking ways to progress work while we await the formation of a Government and agreement of a multi-year budget, and on that basis, this Office urge the Department to consider finding a way to go further in terms of delivery of the recommendations from *More Than a Number*. This includes:

- Continuing to build on DoH Officials' practical knowledge of CRIAs by completing the LInKS training module and using the 'tool' to inform and assess policy plans against child right standards (Recommendation 1: Embed a Child Rights Approach);

- Proceed with a focused regional review of community child health services and bring forward a 'Paediatric Services Rebuild and Recovery Plan' (Recommendation 2: A full review of the child health system to ensure HSC reform is based on an up-to-date understanding of need across the system);

- Strengthen all governance, operational and commissioning structures to ensure strong leadership and delivery of children's healthcare reform which includes implementation of the Paediatric Strategies (Recommendation 3: Improve the visibility and accountability for children's health within departments or agencies);

- Take practical steps at HSC service delivery level to improve Information, Communication and Support with child patients and their parents and carers, on diagnosis and whilst waiting for care / treatment (Recommendation 6: Establish an interim regional waiting list management process); and

- Establish an *interim* regional waiting time monitoring system for all community child health services (Recommendation 13: Community child health waiting times reporting should be established).

In conclusion, NICCY recognises that change in the child health system will take investment and human and technical resource, however, we expect to see steady

[12] NICCY Monitoring Report of Government Implementation of 'A New and Better Normal'- https://www.niccy.org/about-us/our-current-work/covid-19-niccys-work/

incremental progress, and for NICCY's Rights-Based Review and the 17 recommendations contained within it to provide a focus and contribution to the planning work for children's health services going forward.

7.0 Appendix 1 - Waiting Time Statistics

7.1 Waiting Times

First Consultant led Outpatient (Elective) and Inpatient and Day case Appointments

NICCY's *More Than a Number* Review published in October 2021 included figures on the number and length of time under 18 year olds are waiting for first consultant led outpatient and inpatient / day case services between April 2017 and April 2021. It also presented a more detailed range of data related to waiting times at a point in time, i.e. April 2021. This included waiting times by sub-specialty, 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.

This updated data report follows the same format as the original Review and includes health waiting lists data at April 2022, which will provide another point in time series data to show the overall trend in relation to the number and length of time under 18s are waiting for outpatient and inpatient / day case services.

Community Child Health Services

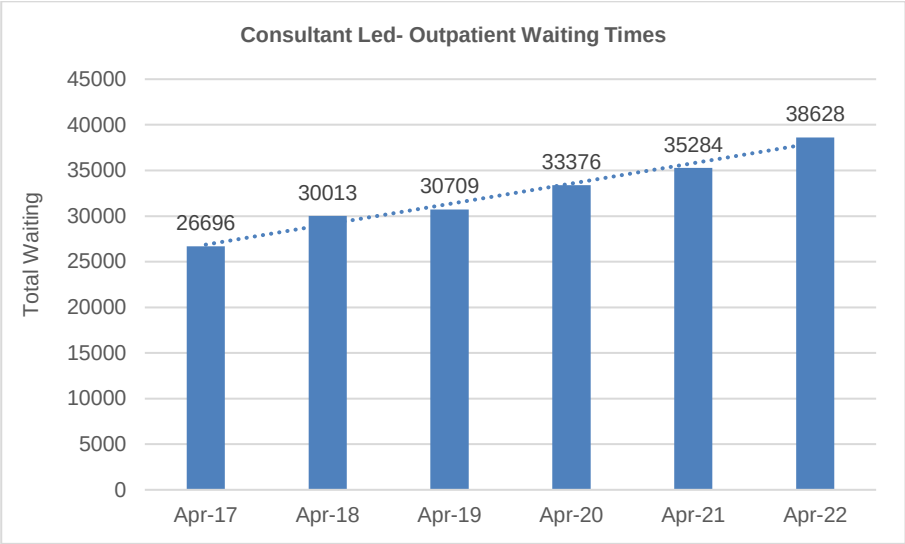
There is no regional data collection or reporting on waiting times for community child health services, therefore the same methodology used for NICCY's original Review was applied to this progress update. A fuller description of the data collection methodology for hospital and community health service data is available in the original Review.[13] Data sources and explanatory notes are available under each figure. The health waiting list data contained in this report has been used to inform NICCY's assessment of progress and for this reason a particular focus has been given to the change in waiting time information between 2021-2022.[14]

[13] https://www.niccy.org/waitinglists, p27-29

[14] when describing the statistics, we are referring to 'number of children waiting' as is done in DoH waiting time statistical bulletins, however, 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.

Overall Waiting Lists between 2017-2022

Figure 1: Waiting lists for first consultant led outpatient appts: period April 2017- April 2022

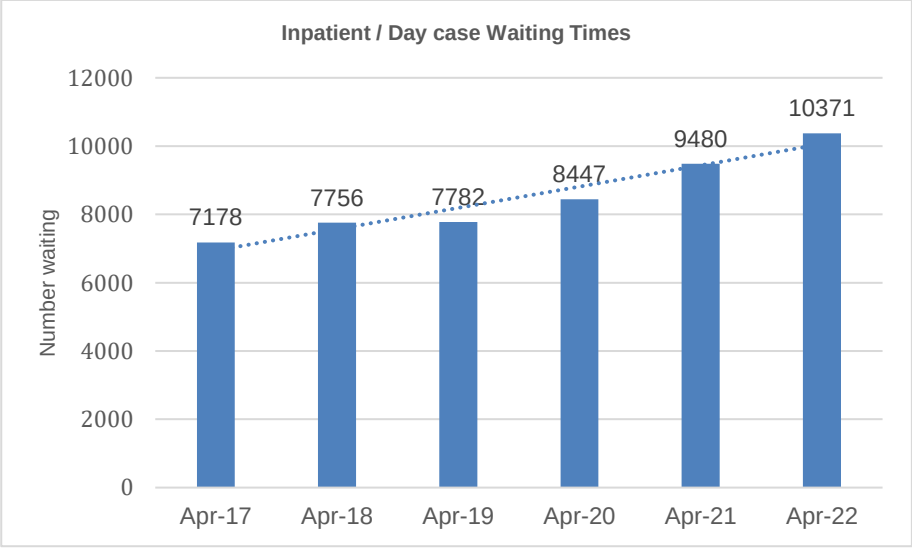


At April 2022, **38,628** children were waiting for a first consultant led outpatient appointment.

This represents a **9%** increase or **3,344** more children waiting between April 2021 and 2022.

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once.

Figure 2: Waiting lists for inpatient / day case appts: period April 2017- April 2022



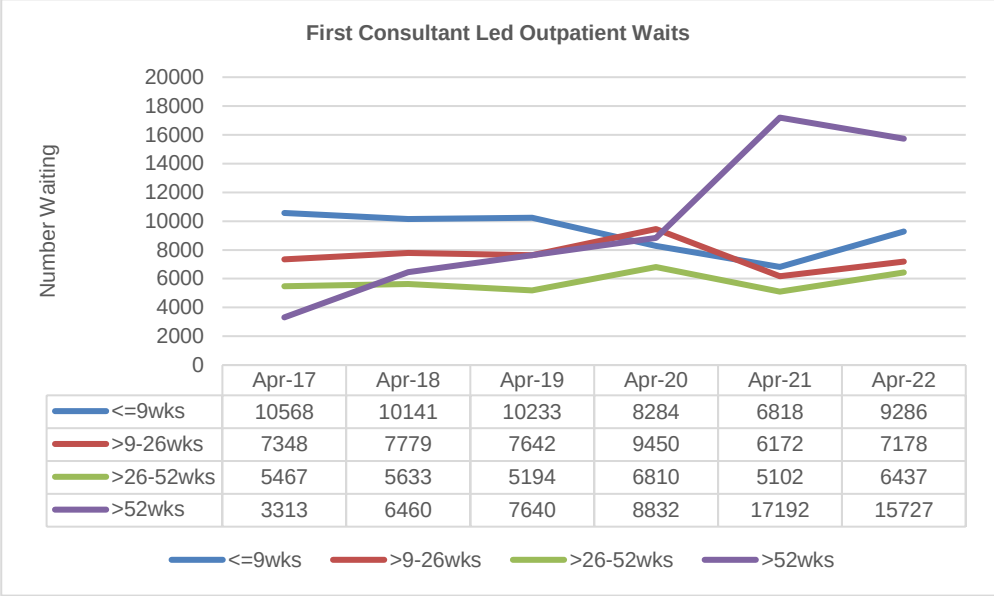
At April 2022, **10,371** were waiting for a first consultant led inpatient / day case appointment.

This represents a **9%** increase or **891** more children waiting between April 2021 and 2022.

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

Length of Time Waiting for First Consultant Led Outpatient or Inpatient / Day case

Figure 3: First consultant led outpatient waiting list by length of time waiting: period April 2017- April 2022



	Apr-17	Apr-18	Apr-19	Apr-20	Apr-21	Apr-22
<=9wks	10568	10141	10233	8284	6818	9286
>9-26wks	7348	7779	7642	9450	6172	7178
>26-52wks	5467	5633	5194	6810	5102	6437
>52wks	3313	6460	7640	8832	17192	15727

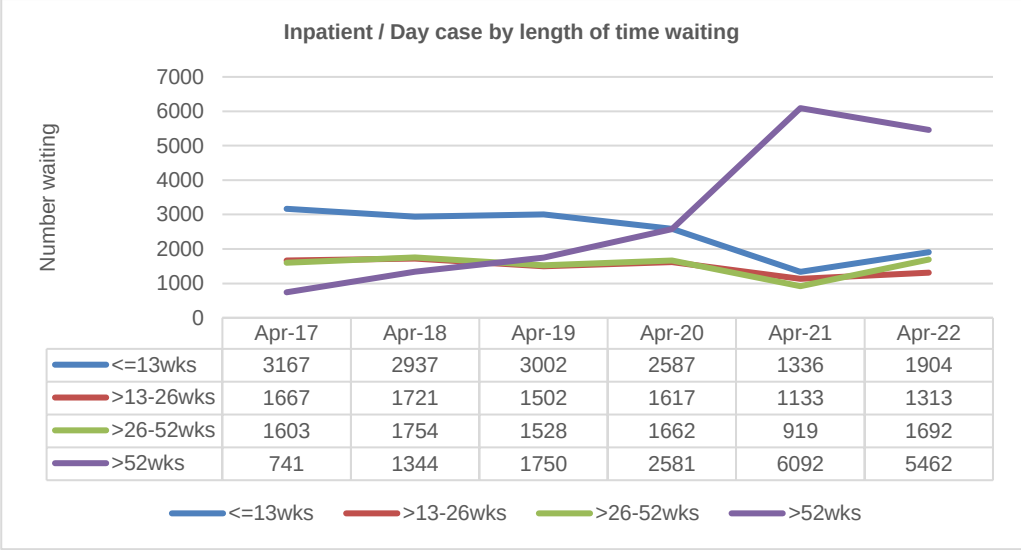
Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

At April 2022, the number of children waiting over a year for a first consultant led outpatient appointment is **4.5 times** higher than number waiting at April 2017.

At April 2022, **41%** of those waiting for first consultant led outpatient apt have been waiting **> 52 wks**.

9% decrease in children waiting over 52 wks between April 2021 and 2022. Equating to **1,465** less children.

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



	Apr-17	Apr-18	Apr-19	Apr-20	Apr-21	Apr-22
<=13wks	3167	2937	3002	2587	1336	1904
>13-26wks	1667	1721	1502	1617	1133	1313
>26-52wks	1603	1754	1528	1662	919	1692
>52wks	741	1344	1750	2581	6092	5462

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

At April 2022, the number of children waiting over a year for a first consultant inpatient / day case appointment is **7 times higher** than number waiting at April 2017.

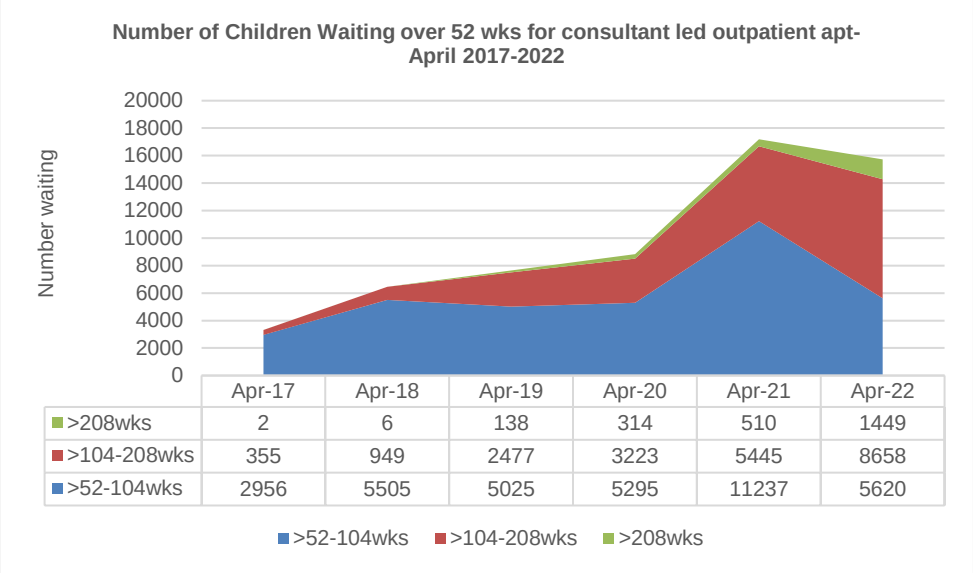
At April 2022, **53%** of those waiting for first consultant led inpatient / day case apt have been waiting **> 52 wks**.

10% decrease in children waiting over 52 wks between April 2021 and 2022. Equating to **630** children.

Maximum Waiting Times

Whilst monitoring is usually carried out under the defined time bands as illustrated in the graphs 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.[15] In both cases an increasing and significant number of those waiting fall within the greater than 52 week waiting category.

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



	Apr-17	Apr-18	Apr-19	Apr-20	Apr-21	Apr-22
>208wks	2	6	138	314	510	1449
>104-208wks	355	949	2477	3223	5445	8658
>52-104wks	2956	5505	5025	5295	11237	5620

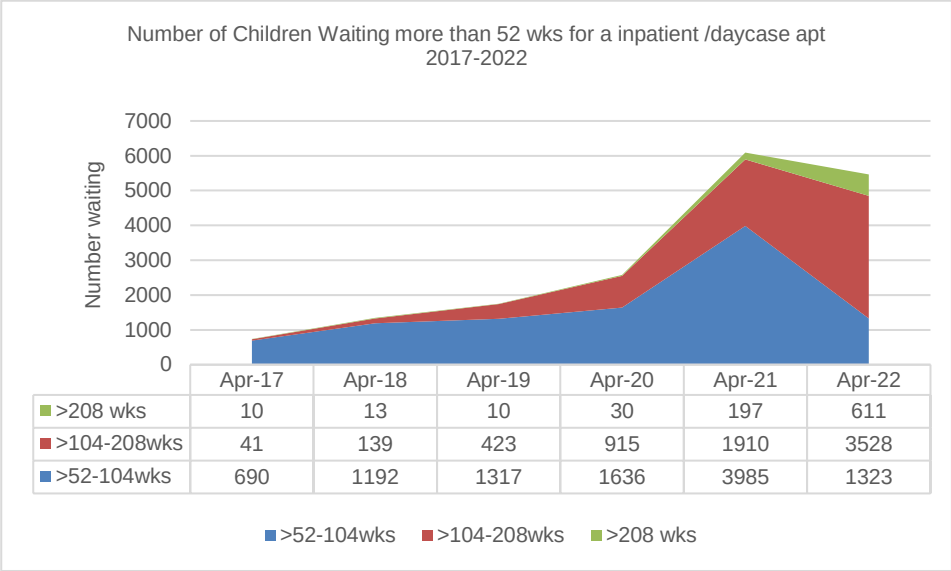
Between 2021 and 2022, there have been an increase of **59%** or **3,213** more children waiting between >104-208 wks for a first consultant led outpatient appointment.

And a **184%** increase or **939** more children waiting more than 208 wks (4 yrs).

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

[15] It should be noted that patients overall length of waiting time can be impacted by a number of factors. Patients may have been offered dates for surgery but declined for various reasons, or the patient may have requested they are suspended from a waiting list.

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



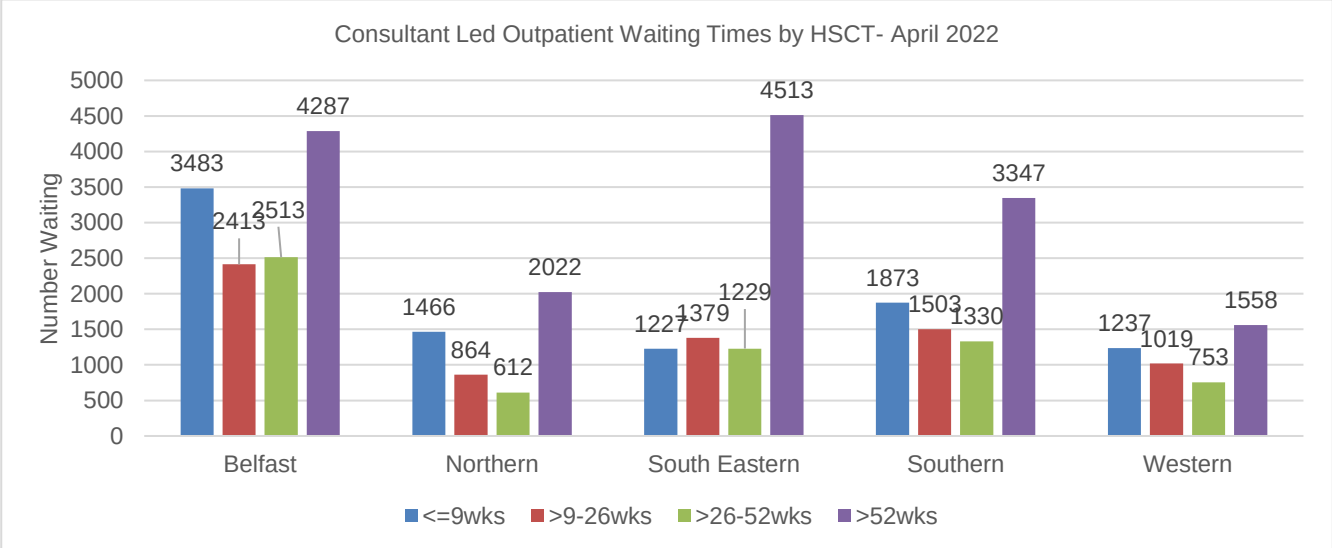
	Apr-17	Apr-18	Apr-19	Apr-20	Apr-21	Apr-22
>208 wks	10	13	10	30	197	611
>104-208wks	41	139	423	915	1910	3528
>52-104wks	690	1192	1317	1636	3985	1323

Between April 2021 and 2022, there has been a **85%** increase in number of children waiting >104-208 wks for a consultant led inpatient / day case apt. This equates to **1,618** more children.

There is also **414** more children waiting more than 4 yrs. Equating to a 210% increase.

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

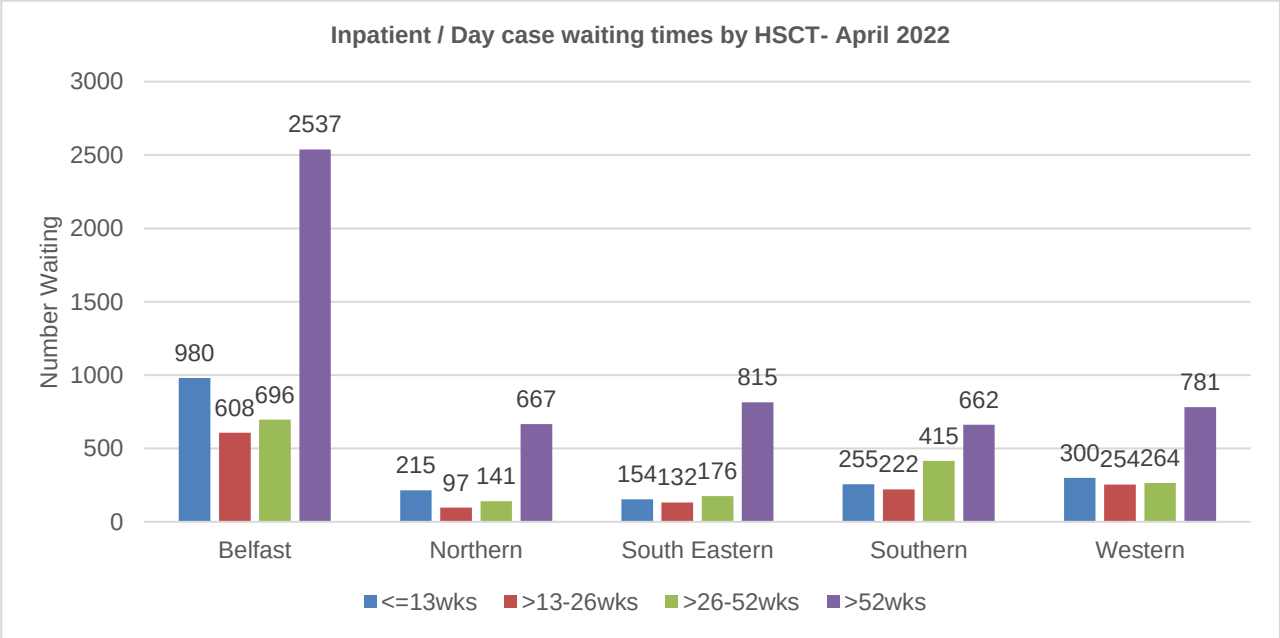
Figure 7: Consultant led outpatient waiting times by HSCT- April 2022



Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Duplication possible where a patient is recorded more than once

At April 2022, every HSCT had substantially more children waiting in the > 52 wk category than for any other time band for a first consultant led outpatient appointment.

Figure 8: Inpatient / Day case waiting times by HSCT- April 2022



Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Note: Total no. of patients waiting may vary depending on the source. Duplication possible where a patient is recorded more than once

At April 2022, every HSCT had more children waiting in the > 52 wk category than for any other time band for a first consultant led inpatient or day case appointment. All HSCTs have a similar proportion of children waiting across each time band, apart from BHSCT which has 2.5 times more children waiting >52 wks compared to <=13 wks.

Table 1: Sub-specialties with largest waiting lists for any outpatient appointment

Specialty Description (R)	2021	2022
PAEDIATRICS	8744	9910
ENT	8853	9616
DERMATOLOGY	3778	4510
TRAUMA AND ORTHOPAEDICS	1825	1917
GENERAL SURGERY	1183	1659
OPHTHALMOLOGY	1236	1345
PAEDIATRIC SURGERY	1099	1336
ORAL SURGERY	1359	1242
CARDIOLOGY	919	739
OTHER*	6288	6354
Total	**35,284**	**38,628**

Table 2: Sub-specialties with the largest waiting lists for inpatient / day case

Specialty Description (R)	2021	2022
ENT	3985	4253
GENERAL PRACTICE (NON-MATERNITY)	1020	1147
PAEDIATRIC SURGERY	882	1017
PAEDIATRICS	776	858
OTHER*	2817	3096
Total	**9,480**	**10,371**

Table 1 & 2 indicates that across outpatient and inpatient / day case the same range of subspecialties have the largest waiting lists.

Total number waiting by priority level

Table 3: Total number of outpatients waiting by clinical priority- April 2022

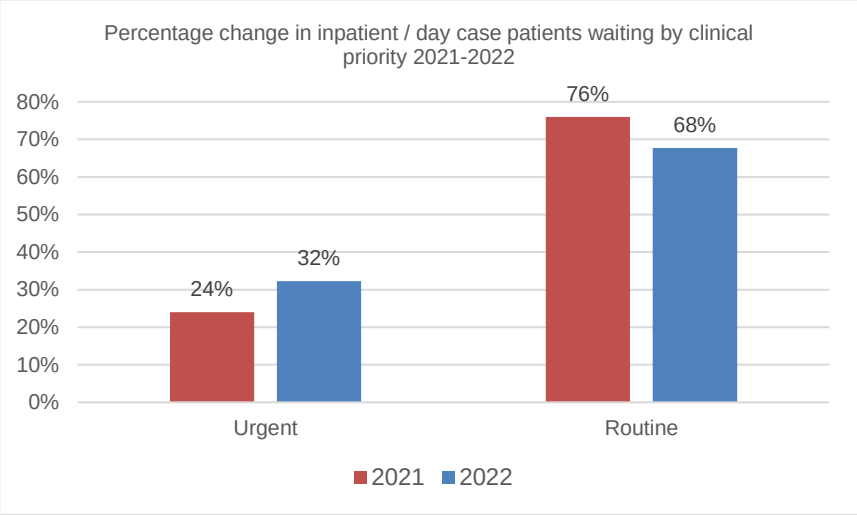
Priority after Triage	<=9wks	>9-26wks	>26-52wks	>52wks	Total Waiting	2022 % total waiting
Red Flag after Triage	79	7*			86	0.2%
Urgent	3158	1510	778	929	6375	17%
Routine	6049	5661	5659	14798	32167	83%
Region	**9286**	**7178**	**6437**	**15727**	**38628**	

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
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.
* Trust has confirmed that patients waiting over 9 wks have been subsequently seen, assessed and discharged with no Cancer Diagnosis

The **proportion of waits** across priority types has remained **consistent** between April 2021 and 2022. However, there has been an **overall decrease by 2,405** in numbers of **red flag or urgent** referrals waiting to be seen.

No red flag cases waiting >26 wks at April 2022 which is an improving picture from 2021 when 45 children were waiting over 26 wks.

Figure 11: Total number of inpatient and day case patients waiting by clinical priority



Between 2021 and 2022 there has been an **increase** in the proportion of inpatient / day case referrals waiting that are classified as **'urgent'** from **24%** in 2021 to **32%** in 2022.

Source: OP Weekly Waits Universe on Business Objects as of 2/4/22
Base No's 2021-n=9640; 2022- n=10371

Community Child Health Waiting Time Statistics

Table 4: Regional waiting time figures for community child health services

Name of service	Regional Total 2021	Regional Total 2022	Freq change b/t 2021 and 2022	% change b/t 2021-2022
LEARNING DISABILITY THERAPEUTIC SERVICE	524	511	-13	-2%
CHILDRENS OCCUPATIONAL THERAPY	2442	2231	-211	-9%
COMMUNITY PAEDIATRIC MEDICAL SERVICE	7066	8014	948	13%
NUTRITION & DIETETIC PAEDIATRIC SERVICE	1887	2526	639	34%
ORTHOPTICS SERVICE	2224	3086	862	39%
PAEDIATRIC PHYSIOTHERAPY SERVICE	1635	1830	195	12%
PODIATRY SERVICE	1370	1549	179	13%
SPEECH AND LANGUAGE THERAPY^	2444	4574	2130	87%
CHILD HEALTH PSYCHOLOGY	169	482	313	185%
AUTISM ASSESSMENT	5155	6845	1690	33%
AUTISM INTERVENTION	442	407	-35	-8%
CAMHS	1460	2223	763	52%
Grand Total	**26818**	**34278**	**7460**	**28%**

Source: community child health service data provided by HSCTs except for Autism and CAMHS Waiting Times provided by SPPG
Note: The community services listed are those which HSCTs collate info on as part of their Primary Targeting Lists. These do not necessarily equate to all community services provided by HSCTs.
^BHSCT Note: this would not include RISE and auditory implant, children's disability services, or children's waiting for MD assessment which would include SLT.

Between 2021 and 2022 there has been an **overall increase of 28%** in the number of children waiting for an appointment with one of the community child health services listed. This equates to **7,460 more** children. A small number of services have seen a decrease in waiting times, however, in most cases waiting lists have increased, this is particularly noticeable for **Child Health Psychology** which has seen a 185% increase, **Speech and Language Therapy** which has seen a 87% increase followed by **CAMHS** with a 52% increase and a 30-39% increase for **Autism Assessments, Orthoptics and Nutrition and Dietetics.**

Table 5: Number of children waiting for an autism assessment

Month End	0 to 13 Weeks	>13 to 26 Weeks	>26 to 52 Weeks	>52 Weeks	Total Waiting
Apr-21	1,098	712	1,150	2,195	5,155
Apr-22	1,489	906	1,719	2,731	6,845
Freq. Change	**391**	**194**	**569**	**536**	**1,690**
% Change	**36%**	**27%**	**49%**	**24%**	**33%**

Source: Monthly Children's Autism Waiting Times returns from Trusts

Between 2021 and 2022 there has been a **33% increase** in the number of children waiting for an autism assessment. This equates to **1690 more** children.

Table 6: Number of children waiting for an autism intervention

Month End	0 to 13 Weeks	>13 to 26 Weeks	>26 to 52 Weeks	>52 Weeks	Total Waiting
Apr-21	376	26	1	39	442
Apr-22	381	23	1	2	407
Freq. Change	**5**	**-3**	**0**	**-37**	**-35**
% Change	**1%**	**-12%**	**0%**	**-95%**	**-8%**

Source: Monthly Children's Autism Waiting Times returns from Trusts

Between 2021 and 2022 there has been an **8% decrease** in the number of children waiting for an autism intervention. This equates to **35 less** children.

Table 7: Number of children waiting for Step 3 CAMHS by HSCTs as at 30 April 2021 and 2022

	2021	2022	Freq. change	% change
Belfast	431	671	240	56%
Northern	359	739	380	106%
Southern	369	287	-82	-22%
Western	301	526	225	75%

Source: Monthly Mental Health Outpatient Waiting Times returns from Trusts
CAMHS delivered in Belfast for both Belfast and SET

All HSCTs apart from the SHSCT have seen an increase in the number of children waiting for a first appointment for Step 3 CAMHS. The number of children waiting in the **NHSCT** has **doubled** and in the **WHSCT** numbers have **increased** by **75%.**

Table 8: CAMHS waiting times as at 30th April 2021 / 2022

Month End	0-9 Weeks (0-63 days)	> 9 to 26 weeks (64 -182 days)	>26 to 52 weeks (183-364 days)	>52 weeks (+365 days)	Total Waiting
Apr-21	1071	354	35	0	1460
Apr-22	1,115	827	229	52	2,223
Freq. Change	**44**	**473**	**194**	**52**	**763**
% Change	**4%**	**134%**	**554%**		**52%**

Source: Monthly Mental Health Outpatient Waiting Times returns from Trusts
CAMHS delivered in Belfast for both Belfast and SET
Al those waiting over 52 wks are within WHSCT

No child was waiting over a year for a first apt with Step 3 CAMHS at April 2021 but at **April 2022 there were 52 children waiting over 1 year.**
The data shows that between 2021 and 2022 there has been a **5.5-fold increase** in the number of children **waiting more than 26 wks to 52 wks**.

Appendix 2 – Departmental Response to NICCY's Recommendations

https://www.niccy.org/morethananumberdohresponse