

Terms of Reference

Rights Based Review: Paediatric Waiting Times in Northern Ireland

Background

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).

NICCY is aware of the significant numbers of children and young people waiting to access health services in Northern Ireland. The most recent hospital waiting time statistics show that at 31 March 2020, 15,540 children were on paediatric waiting lists, with 3,394 waiting for over a year. This was a substantial increase from the same period the year before when 12,998 were on the waiting list (Table 1). Furthermore, the percentage of children waiting for over a year has increased from 17.9% at 31 March 2019 to 21.8% at 31 March 2020 (Table 2). More recent quarterly waiting time figures for paediatrics are showing persistent upward trends in the numbers waiting, including the proportion of those waiting over a year to be seen.

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

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

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

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

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%

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

The hospital waiting time reports published by the Department of Health, are useful with respect to understanding the extent of paediatric waiting times.¹ However, the statistics in these bulletins and appended CSV forms are not disaggregated by paediatric sub specialities and the categorisation of waiting times is limited to the parameters of the Ministerial target i.e. >52 weeks, and does not report on the average or maximum waiting times. Furthermore, the diagnostic waiting time figures do not subcategorise by paediatric and adult patients, making it impossible to determine waiting times for children.

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 and quality of life outcomes 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 under 16 and 17 year olds and did not include under 16s.²

NICCY's legal team has had representations from parents with children on waiting lists who are distressed and concerned about the impact that waiting times are having on their child's physical and mental health, both in the immediate and long term. Parents and children are very conscious of the time critical nature of treatment and are understandably extremely anxious that treatment will come too late.

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. Lastly, and most importantly, there is a need to enable children and young people (and

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

² <https://patientclientcouncil.hscni.net/the-reality-of-life-on-a-waiting-list/>

their parents / carers) to share their views and experiences on how services can make their wait as easy as possible, and to share the impact that waiting is having on their health and quality of life. This paper set out the details of a rights based review that will be carried out on paediatric waiting times in Northern Ireland.³

The review will be conducted in accordance with NICCY's functions under Articles 7 (2) and (3) of the Commissioner for Children and Young People (NI) Order 2003 which 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.'

In carry out this review, the following duties 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 the rights and best interests.

Children's Rights

The UK State Party and Northern Ireland as a devolved administration, ratified all articles of the UNCRC in 1991, and it subsequently came into force in 1992. 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 are of 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 health care.

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

³ NICCY Business Plan 2020-2021, Objective 2.9.

rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

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).

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 outcome', 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 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 outcome and in access to health services;

(c) Addressing underlying social determinants of health.

In advance of the next examination by the Committee in 2021, the four UK Children's Commissioners produced a joint mid-term report in November 2019 which reflected on their assessment of progress since the last examination. Within this report the Commissioners highlighted the excessive waiting times for children to access healthcare, particularly in Northern Ireland, and a call was made for urgent action to address these.⁴

Context

It is important to reflect on the context within which this review of paediatric waiting times will be conducted. Northern Ireland has some of the longest health waiting times of all regions in the UK.⁵ The newly formed NI Executive has reasserted its commitment to addressing the unacceptably long waiting times for health treatment within the 'New Decade, New Approach' Agreement. The Health Minister has acknowledged that building capacity within the system and addressing the backlog will require 'sustained investment', and progress in reform of the health and social care system, as recommended by a number of significant reviews published between 2011 and 2016⁶. The overarching conclusion from each of these reviews is that 'root and branch' reform of our system is required to address under-performance in services, wherein waiting times is one of the clearest indicators of a system under immense strain and unable to meet need.

Within the 'New Decade, New Approach' Agreement, the Executive has committed to developing a waiting list action plan, and to "consider the scope for how waiting times are measured to reflect the entire patient journey, from referral to treatment, with appropriate targets".⁷ It is the case that out-patient waiting times only show part of the picture in terms of the journey that children and young people face when accessing healthcare. Before being referred to these paediatric specialists, children / young people and their Parents/Carers are likely to have had appointments with other health professionals, at

⁴ UK Children's Commissioners UNCRC Mid Term Report (2019), <https://www.niccy.org/about-us/childrens-rights/un-reporting/>

⁵ Pivotal (2020) Priorities for recovery: A briefing paper for the Northern Ireland Executive's return from recess, Public Policy Forum NI https://www.pivotalppf.org/cmsfiles/Pivotal_Priorities-for-Recovery-Paper.pdf p12

⁶ Transforming Your Care, the Donaldson Report, 'Delivering Together', informed by the expert panel lead by Professor Bengoa which focused on "systems, not structures"

⁷ New Decade, New Approach Agreement https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/856998/2020-01-08_a_new_decade_a_new_approach.pdf p6

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 time young people's physical and mental health and quality of life are impacted.

The range of factors exacerbating health waiting lists are well known. A lack of certainty about access to long term sustainable funding to invest in new service models remains a fundamental concern.⁸ Workforce shortages are also a major challenge faced by the healthcare system in Northern Ireland. In general, gaps in paediatric staffing are higher in Northern Ireland than in any other part of the UK.⁹

The current COVID-19 pandemic will have exacerbated waiting lists even further; we do not yet have up-to-date data on this. On the other hand, new innovations due to be piloted / implemented as part of modernising the healthcare system, are being expedited due to changes required in service delivery as a response to the pandemic; these are expected to reduce waiting times and improve quality of services. For example, the development of regional elective day care centres includes five paediatric surgical specialties, which account for 87% of all paediatric day case practice.¹⁰

Whilst undertaking this review, children's fundamental rights to timely access to healthcare (Article 24), best interests (Article 3), non-discrimination (Article 2) and their right to be heard and have views given due weight (Article 12) will be used as guiding principles. The information gathered will be used to develop a set of rights based recommendations for those responsible for commissioning, planning and delivering paediatric health services.

As addressing waiting times is a priority for the NI Executive and the Department of Health, we are confident that our advice will offer a helpful and timely contribution.

Aims and Objectives

The aims of this Review are to:

⁸ <https://www.health-ni.gov.uk/sites/default/files/publications/health/daycase-elective-care-procedures.PDF> p.8

⁹ <https://www.rcpch.ac.uk/work-we-do/workforce-service-design/workforce-census-2017>.

¹⁰ <https://www.health-ni.gov.uk/sites/default/files/publications/health/daycase-elective-care-procedures.PDF>

- Examine the length of time children and young people are waiting to access appointments at three points: first consultant outpatient; diagnosis; and treatment;
- Review waiting time reporting systems to ensure adequate visibility of children's services;
- Better understand the patient care pathway, and impact that delayed care has on outcomes / health & wellbeing of children; and
- Explore factors contributing to paediatric waiting times in Northern Ireland.

Methodology

There are three-strands to the review with specific objectives and deliverable associated with each stage.

Strand 1: Request waiting time data from each Health and Social Care Trust,

The data request focuses on three points on a child's journey through the health system:

First consultant led outpatient appointment: the number of children on waiting lists across paediatric sub-specialities, and the length of time young people are waiting, to include proportion of referrals that exceed waiting time targets.

Diagnostic Services: the number of children and young people waiting, and length of time waiting for diagnosis at Health and Social Care Trusts in Northern Ireland. To include the type of diagnostic service or condition to which the waiting times relates.

Treatment: the number of children and young people waiting, and length of time waiting, for treatment to begin at Health and Social Care Trusts in Northern Ireland. To include the type of treatment or condition waiting times relates to.

Strand 2: Gather the views and experiences of professionals / practitioners working in paediatric services; to include:

- factors causing / contributing to 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.

Strand 3: Consult children and young people and their families who have experience of being on a waiting list for a paediatric service. This will include:

- the patient journey through the system; and
- the impact of waiting times on the outcomes / health and wellbeing of children.

A NICCY report will be published which will draw on all of the information gathered as part of the Review. NICCY will monitor progress of the report recommendations on an annual basis, which will include a review of paediatric waiting time data.

Timeframe:

Indicative Timeframes for key stages of the Review are set out below:

- Strand 1: September 2020 - February 2021
- Strand 2: January – April 2021
- Strand 3: January – April 2021
- Report launch: September 2021

For further information on this review please contact our office via christine@niccy.org.